



NINR

Bringing Science to Life

NATIONAL INSTITUTE OF NURSING RESEARCH
PHILIP L. CANTELON, PHD

NINR: *Bringing Science To Life*

National Institute of Nursing Research (NINR) with Philip L. Cantelon

National Institute of Nursing Research

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TABLE OF CONTENTS

Preface

The National Institute of Nursing Research at NIH: Celebrating Twenty-five Years of Nursing Science.....	v
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Acknowledgments	ix
------------------------------	----

Chapter One

Origins of the National Institute of Nursing Research	1
---	---

Chapter Two

Launching Nursing Science at NIH	39
--	----

Chapter Three

From Center to Institute: Nursing Research Comes of Age	65
---	----

Chapter Four

From Nursing Research to Nursing Science	113
--	-----

Chapter Five

Speaking the Language of Science.....	163
---------------------------------------	-----

Epilogue

The Transformation of Nursing Science.....	209
--	-----

Appendices

A. Oral History Interviews.....	237
B. Photo Credits	239
C. National Advisory Council for Nursing Research Member List.....	241

Index	247
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Preface

The National Institute of Nursing Research at NIH: Celebrating Twenty-five Years of Nursing Science

At no time has the nursing profession been transformed more dramatically than in the past thirty years. Behind that revolution, literally millions of nurses have constituted a team of committed actors: clinicians, professional nursing organizations, schools of nursing, and the National Institute of Nursing Research (NINR). Their creativity and cooperation, coupled with the strong support of Congress, fashioned a different nursing profession and moved it beyond procedure to promise, beyond implementation to innovation, and into the mainstream science at the National Institutes of Health (NIH).

Nursing research became part of NIH twenty-five years ago. After several years of promising starts and frustrating stops, Congress chartered the National Center for Nursing Research (NCNR) in the fall of 1985. There were sharp divisions about creating such an entity at NIH. The Reagan administration opposed a center as an addition to administrative costs at NIH. Many NIH officials rejected the notion of nursing research, which they viewed as neither disease- nor basic science-oriented, as part of the NIH medical community. Nurses,

too, were divided over a presence at NIH. Several deans of nursing graduate schools feared that there would not be an environment that could understand or support nursing research at America's premier medical research institution. But nurse researchers at the American Nurses Association found vigorous allies in Congressman Edward R. Madigan and Senator Orrin G. Hatch. Recognizing the potential of an institute, the nursing community put aside its differences and seized the opportunity of a supportive Congress for nursing research to take, as Senator Hatch said at the time, "its rightful place in those NIH halls of ivy."

Since 1986, the NINR and its predecessor, the NCNR, have served as the nucleus for the advancement of nursing science, providing the profession with national leadership on the federal level and financial support for research initiatives throughout the country. From the beginning, nursing's national research agenda retained its orientation to patient care. But over the years, nursing science directed at critical health outcomes has grown and developed a sophistication that is enabling our profession to translate scientific research and data into policy that helps shape the nation's health care system.

As this history demonstrates, nursing research at NIH has both provided for and partnered with nurse educators in the recruitment, preparation, nurturing, and continued support of nurse scientists. Twenty-five years ago, only a small number of nurse researchers in the United States could claim advanced degrees in science. Today, there is an entire sector of the nursing profession populated with highly trained, innovative nurse scientists. Their growing body of work, often in tandem with other scientific disciplines, has altered the way Americans approach many health care issues. Three decades ago, we worried about nursing shortages, recognizing the facts without fully understanding the impacts on nurses, patients, and health care costs. Today, because of nursing research, we possess the hard clinical data to understand the physical, psychological, and financial impacts—as well as health outcomes on patients—caused by inadequate nurse staffing.

Similar research over the past two decades has led to parallel advances in community-based health care, which addresses crucial health issues for minorities and other hard-to-reach or underserved groups. NINR-sponsored research has discovered factors to enhance health relationships and has developed community-based intervention programs that changed dangerous behavior patterns for at-risk groups, thereby promoting wellness and mitigating or preventing disease. Other policies, informed and shaped by the research data of nurse scientists, have shortened hospital stays, decreased patient complications, increased patient satisfaction, and eased the transition to home care. Perhaps most significantly, especially in tough economic times and for the future of health care reform, these new policies, by emphasizing prevention and continuity, can save millions—if not hundreds of millions—of dollars annually.

As the current debate over health care reform continues, nursing science, as it has in the past, will be at the forefront of designing programs that promote wellness, prevention, and, not coincidentally, lower health care costs. The story of the NINR recounts the development and use of science to form new constructs of nursing practice—from observation to translation, from nursing care to nursing science, from procedure to practice to policy.

The NINR's accomplishments stand on the foundations laid by those who came before us—from the early nurse scientists to the current growing cadre of talented scientists. Preserving that history and applying its lessons are essential for nurse scientists and health care policy makers, both now and in the future. I am personally gratified to be a part of the success of the NINR, for what it has provided to the nursing science community and to the direction of health care in the United States over the past quarter of a century. Far less would have been accomplished over that short period without the backing and vigorous commitment of elected officials, the biomedical community, nursing educators, and the thousands of talented young women and men who discovered their destinies in nursing science and forever

altered the nursing profession. A tribute goes also to the millions of practicing nurses who support the ideas research entails and incorporate new science into their practices. Nurse scientists will always be a key wellspring of the information required so that evidence-based practice and policy can prevail and ensure the delivery of high-quality health care. I am confident that a continuing flow of fresh ideas and innovative science from nurse investigators will help reform and transform the American health care system in the twenty-first century. I also believe that the NINR is a tribute to the amazing things the nursing profession can accomplish when it unifies behind an idea—may we continue to do so.

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September 1, 2010

Acknowledgments

The preparation of this book was accomplished through the efforts of many individuals. Over the course of researching and writing the history of the National Institute of Nursing Research (NINR), an array of nurse scientists and historians were involved. They all made the work much easier during the course of delving through primary records and conducting a wide range of oral history interviews of those who worked to create the National Center for Nursing Research and advance it to the status of a full institute at the National Institutes of Health (NIH). For more than a quarter of a century, the NINR built steadily upon the fundamental work of the professional nursing organizations, nurse educators, members of Congress, nurse scientists, and NINR administrators. Each group and many individuals played important parts in the conception, development, and growth of the NINR. In supporting research that brings nursing science into the lives of all Americans, the NINR has become the nursing profession's leader and patron.

The oral history interviews with the first acting director, Dr. Doris Merritt, and the Institute's two directors, Dr. Ada Sue Hinshaw and Dr. Patricia A. Grady, were compelling and informative. The success of the NINR was due in large part to their knowledge, commitment, perseverance, and staff selections, which helped shape and expand the Institute. The other interviewees, listed on page 237, were also most helpful, especially those of Dr. Patricia Moritz of the University of Colorado School of Nursing; Dr. Janet Heinrich, now at the Health Resources and Services Administration; Dr. Kathleen Dracup of

the University of California, San Francisco, School of Nursing; Dr. Geraldene Felton, emeritus of the University of Iowa School of Nursing; and Dr. Nancy Fugate Woods of the University of Washington School of Nursing, all of whom helped when the writing became most challenging. The insights, suggestions, and corrections from the members of the NINR History Advisory Committee, all of whom generously donated their time to this endeavor—Drs. Moritz, Dracup, and Felton—were most thoughtful and perceptive. Consultants Ms. Mary Miers, Dr. Patricia O'Brien D'Antonio, and Dr. Victoria Harden provided invaluable expertise and guidance.

Finally, a thank you is extended to Ms. Eileen McGuckian, who read and commented on the manuscript through several drafts and learned the lasting value and great promise of nursing science.

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The National Institutes of Health, Building 1.

1

Chapter 1

Origins of the National Institute of Nursing Research

Just before Christmas 1985, Dr. Doris H. Merritt had a telephone call from the director's secretary. "Doris," she said, "can you get down here? Jim needs to see you." Merritt walked down a flight of stairs and over to the other side of Building 1. National Institutes of Health (NIH) Director James B. Wyngaarden sat alone in his big corner office. "You probably know they passed the Center for Nursing Research over the President's veto," he began. "Yes," Merritt replied. "Well, I want you to make it happen." Wyngaarden was not happy about having nursing research at NIH. Like most scientists around NIH, he believed nursing research was an oxymoron and now "it was going to be foisted on the absolute pinnacle of research in the nation." But the law was the law. If NIH was going to have a Center for Nursing Research, Wyngaarden wanted it done and done right—to NIH standards. Would Merritt get it up and running? Merritt, an experienced senior NIH administrator, said no.¹

It was not an auspicious beginning.

Wyngaarden's meeting with Merritt does not begin to reveal the long and bumpy road that the nursing profession and its allies had traveled so that a nursing research center might reside at the NIH. Nursing science was a relatively new member of the U.S. scientific community, beginning as an occupation in a hospital setting, not as

an academic discipline. For nearly a century, nursing had followed the path of Florence Nightingale, advancing the science of nursing by observation. Teacher's College at Columbia University established the first doctoral program in nursing in the early 1920s, but however large its influence, the numbers of graduates remained small. World War II marked the beginning of a change in the approach to nursing research. The war had demonstrated the necessary nexus between science and nursing care and the growing demands on the profession. The Public Health Service Act of 1944 authorized the Division of Nursing Resources in the Bureau of Medical Services to conduct and support research, but Congress did not appropriate any funds for it. In 1948 Esther Lucille Brown argued in *Nursing for the Future* that to become fully professional, nursing required a knowledge base supported by research. But it was not until 1955 that the division initiated a small program for extramural support, the Nursing Research Grants and Fellowship Program. By that time the curricula of nursing schools had begun to change. The “three years under a hospital roof” education was giving way to associate degree and baccalaureate programs that followed “the pattern of those established for other professions.”²²



Early nurse advocates and educators (from left): Lavinia Dock, Isabel Stewart, Lillian Wald, Annie Goodrich, Mary Adelaide Nutting.

Dr. Faye G. Abdellah, an early advocate of nursing research and the author of *Better Patient Care Through Nursing Research* (1965), developed the first federal nurse specialist training program for the preparation of nurse researchers. In California, the state Board of Regents also recommended the introduction of graduate programs in nursing to prepare clinical specialists, administrators, nursing instructors, and directors of nursing education. The newly formed Council of Baccalaureate and Higher Degree Programs of the National League for Nursing applauded these goals. Over the next fifteen years, graduate studies “focused almost entirely on the role of the nurse, nursing theory, and nursing education,” according to one nurse commentator. “Because few nurses were prepared to do nursing research, much of the funding was channeled into supporting advanced education for nurses.” However, by the mid-1960s, some master’s degree programs had not only expanded but also switched from concentrating on functional skills such as teaching, supervision, and administration, to clinical knowledge and skills in cardio-pulmonary, medical-surgical, maternal-child, psychiatric, and community health nursing.³

By 1960 the Division of Nursing Resources merged with the Division of Public Health Nursing to become the Division of Nursing in the Health Resources Administration (later the Health Resources and Services Administration [HRSA]), but the impact on research was minimal. In 1963 the Surgeon General’s Consultant Group on Nursing reported that nursing research suffered from a lack of funding and argued for more research fellowships and financial support of research projects. The report also advocated additional funds for graduate-level training, with a separate recommendation to give greater emphasis to support for those seeking doctoral degrees. In response to the Surgeon General’s report and to Great Society legislation in the mid-1960s, particularly Medicare and Medicaid, the Division of Nursing sponsored research conferences and boosted funding for the development of research in nursing institutions.⁴

Nursing scholars in the 1960s became increasingly aware of the need for the discipline's knowledge base to be theoretically grounded. Two U.S. Public Health Service initiatives, the Faculty Research Development Grants in 1959 and the Nurse Scientist Training Grants in 1962, "were instrumental in both stimulating nursing faculty research activities and expanding the numbers of doctorally prepared nurse scientists." Nursing research became more theoretical, often using conceptual models drawn from other disciplines including psychology, physiology, and sociology. With the expansion of doctoral programs in the 1960s and 1970s, according to an article in the *Journal of the New York State Nurses Association*, "research mentorship made a profound impact on the development of nurse researchers," who often investigated questions from a qualitative perspective.⁵

Jessie M. Scott, the highly regarded director of the Division of Nursing in HRSA and a two-star admiral in the Commissioned Corps of the U.S. Public Health Service, recognized that nursing was becoming more sophisticated and encouraged nurses to become more involved in the research process. She entered the Public Health Service in 1955 after a first career as an infirmary nurse at the University of Pennsylvania, where she received her bachelor's degree. She taught at



Pioneers of nursing research (from left): Dr. Myrtle Aydelotte, Dr. Virginia Henderson, Dr. Harriet Werley, Jessie M. Scott, Dr. Faye G. Abdellah.

Jefferson Medical College in Philadelphia and became an organization executive with the Pennsylvania Nurses Association. By 1957 she became deputy chief of the service; seven years later Surgeon General Luther Terry appointed her the second director of nursing. Her testimony to Congress on the need for better nursing training led to the passage of the 1964 Nurse Training Act, the first major legislation to provide federal support for nurse education during peacetime. "I'm convinced that nursing is the linchpin in the delivery of health care in this country," she told Congress. With the clout to carry through on her vision of expanding nursing education at the baccalaureate level, she laid the groundwork for more scientific research into nursing care. "As more nurses sought higher education," one observer noted, "the level of interest and expertise in research grew." While the primary focus of the division's funding remained on nursing education, clinical nursing, and ways to alleviate a series of real or anticipated nursing shortages, Scott's basic support of educational growth was fundamental to the future of nursing research. "The money that Jessie Scott and HRSA invested in nursing in the 1970s expanded nursing programs in colleges and universities," said one early nurse researcher. "For those programs to be sustained, their faculty had to do research like all other faculty in academic institutions," thereby laying the foundation for more sophisticated nursing science and gradually moving research designs from being primarily observational to more experimental.⁶

As Scott's government program built a base for future nurse scientists, other funding came from professional nursing groups and private foundations, including Sigma Theta Tau International (STTI), the nursing honorary society; the American Nurses Foundation (ANF); and the Cunningham, Avalon, Russell Sage, Rockefeller, Robert Wood Johnson, and W. K. Kellogg Foundations. Nevertheless, between 1955 and 1968, the Division of Nursing, STTI, and ANF funded a total of only 226 research projects. No one kept count of the grants issued by other private funding bodies, but they were not numerous. Small as the programs were, however, they did begin to have a positive impact

on nursing research, with a growing emphasis on interdisciplinary methods and the application of findings to all practice fields.⁷

In the early 1970s, under the leadership of Virginia Cleland, the American Nurses Association's (ANA) Commission (later Cabinet) on Nursing Research focused its attention on gaining support for nursing research at the federal level in both Congress and the executive branch. "We were discouraged from such activities by those within and outside of ANA, who said that the commission should concern itself with such things as establishing a philosophy and priorities for nursing research and leave the politics to others," recalled one nurse scientist a decade later. The nine members of the commission thought otherwise. They moved the commission's meeting to Washington, D.C., so that the major activity on its agenda would be visiting various federal agencies and members of Congress. They soon realized that to make a significant impact the lobbying effort would need to be expanded. In 1975 they approached the ANA Council of Nurse Researchers for assistance and began to coordinate lobbying activities. They also included political and legislative programs in the council's meetings. As a result of these actions, according to Ada Jacox in *Nursing Outlook*, by the mid-1980s "nurse researchers [became] much more sophisticated in their ability to interpret nursing research to members of Congress and to lobby effectively for support for nursing research."⁸

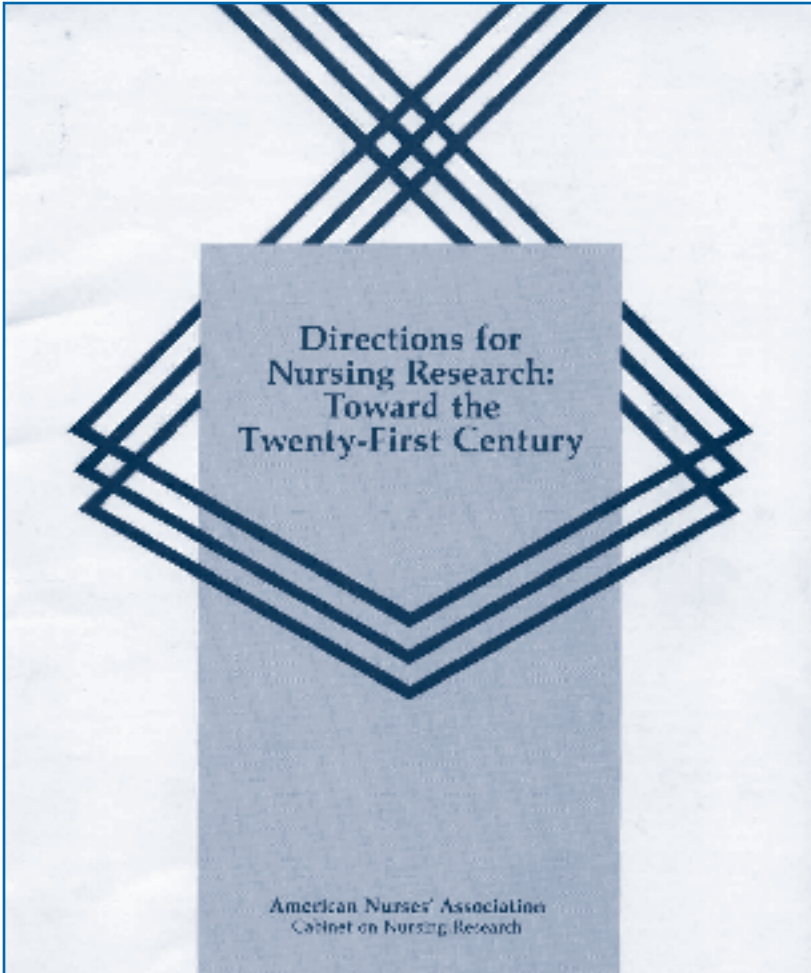
The lack of a vigorous nursing research program, many nurses believed, stemmed from the fact that federal programs were scattered among several agencies. To be successful, nursing leaders advocated centralizing nursing research in one agency that would focus on funding research. Many agreed that the most logical place for such an entity was the organization that had successfully sponsored it in the past: the Division of Nursing at HRSA. Scott had championed the cause that nursing education, research, and practice were interconnected and needed to function together. As a result, the Division of Nursing harbored all of these components. When, in the mid-1970s, the Bureau of Health Resources Development (BHRD) of the Public

Health Service looked at the transfer of nursing research project grants to one federal agency, Scott was prepared. She met with Dr. Gerald Rosenthal, the director of BHRD, and Dr. Kenneth M. Endicott, the administrator of HRSA, to discuss where best to place nurse training and nursing research grants. They agreed that “research directly related to nursing education and the more clinical aspects of nursing research was probably not appropriate for BHRD and that the bureau’s emphasis would be primarily on the manpower aspects of nursing services.” Scott convinced them that the Division of Nursing was the natural location for such grants. The transfer occurred, but Scott was able to effect little change in the political visibility of nursing research or the level of funding received by nurse scientists, many of whom were becoming increasingly disillusioned with the situation.⁹

Nurse scientists believed they had good reason to be frustrated. The growth in nursing research had been painfully slow. Although an NIH task force reported that there were approximately 4,000 nurses with doctoral degrees in 1980 and more than half of them held PhDs, only 6 percent of those reported their primary function as research. The low research figure was understandable. Limited funding was available, schools of nursing did not promote faculty on the basis of their research, and most of the biomedical community—including, most importantly, NIH, the country’s premier research institution and funder—neither understood nor appreciated nursing research.¹⁰

That the nursing community in the 1980s was divided on the definition of nursing research contributed to the biomedical community’s disdain. Nurse investigators struggled to define their work to make it more identifiable as a clinical and basic science. Still, many in the nursing profession viewed research in observational and behavioral terms pertaining to clinical practice. Far fewer in numbers, but more on the cutting edge, were those who began to define nursing research as a part of a larger world of medical research. By the late 1970s, a small group of nurses from the ANA’s Commission on Nursing Research, including Joanne S. Stevenson, Nola J. Pender, Ada Jacox,

Ora Strickland, Ada Sue Hinshaw, Carolyn Williams, and Nancy Fugate Woods, all of whom held doctoral degrees, began a campaign to expand the vision of nursing research. They lobbied within the professional nursing associations, on Capitol Hill, and at NIH for greater recognition of and funding for nursing research.¹¹



A small group of persistent and energetic nurse researchers turned activist in the late 1970s and early 1980s. Their years of engaged effort produced the pivotal publication “Directions for Nursing Research: Toward the Twenty-First Century” and helped guide the creation of the National Center for Nursing Research (NCNR).

Stevenson was a good example of the group of nurse research activists emerging in the 1970s. From 1969 to 1972 she had been a beneficiary of a predoctoral fellowship at NIH sponsored by HRSA. Subsequently, she was elected as fellow of the American Academy of Nursing in 1978 and had been a key participant at a conference sponsored by the Division of Nursing in 1979 called "Future Directions for Nursing Research." Stevenson and Jacox, then president of the ANA, were making regular visits to congressional staffers, stressing the need for more funding for nursing research. At the same time, Stevenson and Woods, a faculty member of the School of Nursing at the University of Washington, carried a similar message to the institute directors at NIH. Every time she and Woods came to Bethesda, they made regular visits to specific directors. "We were trying to learn. We did our homework. We started out looking in the NIH phone book and studying org[anizational] charts to figure out where there might be a match for the kind of research that nurses did and whether there would be places where we could look to find the kind of support we needed." They explained that some nursing research was already occurring in many NIH institutes and that more funding was needed to support the kind of research nurses did, "trying to help them understand...the appropriate focus for nursing research," Woods recalled. The women were careful in conveying their message. There were many in the profession who were very happy with nursing research in the Division of Nursing, and the ANA had taken no formal position on making any changes. However, within the ANA, the Commission, later the Cabinet on Nursing Research, criticized the stagnant status of nursing research, saying that it needed to be more closely allied with other scientists in other disciplines.¹²

A major breakthrough occurred in 1983 with the publication of an Institute of Medicine (IOM) report that recommended that nursing research be placed in the mainstream of scientific investigation by establishing a separate federal entity that would foster nursing research and develop more nurse scientists. The congressionally mandated report,

Nursing and Nursing Education: Public Policies and Private Actions, had been two years in the making and reflected many of the views advanced by the nursing research activists. “Despite the fact that nurses represent the largest single group of professionals in the provision of health services,” it stated, “there is a dearth of research in nursing practice. The lack of adequate funding for research and the resulting scarcity of talented nurse researchers have inhibited the development of nursing investigation. The government’s specific nursing research initiative [approximately \$5 million in grants administered by the Division of Nursing in HRSA] is not at a level of organizational visibility and scientific prestige to encourage professionals to pursue careers in nursing research,” the report said. In addition, nurse investigators suffered from a number of competitive disadvantages in pursuing grants, including a lack of representation on peer review committees and “subject matter that may not be of prime interest to other reviewers.” Greater, more focused federal support for nursing research, the report argued, would better “inform nursing and other health care practice.” The information stemming from such research “could lead to a reduction in the federal health care bill by lessening the length of hospital stay, minimizing the need for additional treatment, and preventing unnecessary or premature institutionalization in long-term care facilities.”¹³

The report stopped short of identifying a specific federal agency to become the organizational base for nursing research, recommending that it should be “at a high level in the federal government to be a focal point for promoting the growth of quality nursing research.” Without directly saying so, the report implied that the current funding organization was lacking in terms of what was required to attack the problem. As committee members were split on the best location for such a federal entity, they hoped that an internal NIH review of its research structure might provide guidance on nursing, as well as biomedical, research. Some committee members favored an institute at NIH, the report acknowledged, while others “question the wisdom of adding new units to NIH. However, all agreed that the goal should

be an entity for nursing research at a level of scientific credibility that would provide impetus toward the initiation, coordination, monitoring, and dissemination of clinical and operational research in academic and other research centers throughout the United States.”¹⁴

The IOM report on nursing dramatically intensified the debate over the nature of funding for nursing research and what government entity should be that funder. As the report stated, not all could agree on an institute at NIH. There were more than a few in the profession who saw these proposed changes not as an elixir for nursing but as a divisive witch’s brew. Opponents believed that the drive for a separate, NIH-based institute would severely damage the Division of Nursing and only achieve a balkanization of the profession. Dr. Geraldene Felton, dean of the University of Iowa School of Nursing, was particularly sensitive to a diminution of the Division of Nursing. Years before, she had received a postdoctoral research grant from the division and had served on a number of its review panels. She warmly remembered the professional importance of that first grant and became a good friend of the division’s head, Jo Eleanor Elliott, who had succeeded Scott. Not surprisingly, she opposed any action that might reduce the division’s importance in the profession.¹⁵

She was not alone. A number of deans within the American Association of Colleges of Nursing (AACN) remained cool to or outright opposed the idea. One questioned the wisdom of creating an institute when there were so few nurse scientists, calling an institute “premature.” Dr. Ruby Wilson, dean of the Duke University School of Nursing, a committee member on the IOM report, and a strong force in the national nursing community, was initially outspoken in her opposition of a separate entity. Her opposition contributed to the report’s vagueness on naming a specific place for nursing research funding.¹⁶

Another who worried about a nursing institute and preached caution in embracing a new entity at NIH was Dr. Rhetaugh Dumas, dean of the University of Michigan’s School of Nursing. One of the foremost African-Americans in the profession, Dumas had worked

at the National Institute of Mental Health, where she served as deputy director of the Alcohol, Drug Abuse, and Mental Health Administration from 1979-1981, the first woman and first nurse to hold that position. Prior to that, she was chief of the Psychiatric Nursing Education Branch of the Division of Manpower and Training Programs. Dumas was investigating the connections among mental health, psychiatry, psychology, and psychosocial issues in nursing care. According to a friend, “she had tried to find ways of integrating that body of research into NIH and had been frustrated by those efforts. From her perspective, she had [experienced] some basic reality on which to base her belief that nursing research, part of which is psychosocial concepts, would not be welcome, that it would not be a good fit at NIH.”¹⁷

Moreover, there was considerable opposition within NIH regarding a nursing institute. Reagan administration and NIH officials opposed the creation of any other new institutes. They viewed nursing as far removed from NIH’s biomedical mission. “Nursing research was not seen as bench science or hard science. It represented a soft science” not appropriate to NIH’s mission, according to one nurse activist. Put another way, NIH believed in “cure research,” one congressman commented, and nursing research was “care research” and therefore not part of NIH’s mission. NIH Director James Wyngaarden expressed his frustration with the possibility of a nursing institute and reflected the attitude of most of his colleagues when he stated that nursing research did not fit into the biomedical research program at NIH. In response to the IOM report and increasing political pressure to create a nursing research institute, Wyngaarden commissioned an internal study of nursing research at NIH. In doing so, he hoped to derail the creation of a new nursing research institute by proving that NIH was already active in this area. Nonetheless, “the fact that nursing research itself is not exactly at the heart of the kind of research NIH feels most comfortable about,” observed *Science*, “only makes matters worse.”¹⁸

Additional opposition came from the medical community,



NIH Director James B. Wyngaarden and President Ronald Reagan at NIH in 1987. The NCNR was created over President Reagan's veto just two years earlier.

particularly the American Medical Association and the Association of American Medical Colleges (AAMC). They vigorously opposed all new institutes, calling the proposed addition of two new institutes—one for Nursing and one for Arthritis and Musculoskeletal and Skin Diseases—a “disease-of-the-month” mentality. The AAMC deplored the increasing congressional role in changing the nature of NIH as “administratively costly and scientifically ineffective.” The organization argued to keep NIH the way it was, taking an “if it ain’t broke, don’t fix it” posture. The editor of the *American Journal of Nursing*

was particularly irked by the attitude that “nursing research *uses* rather than generates information,” a view she laid at the door of the medical organizations.¹⁹

Aside from the opposition to an institute within NIH and the Reagan administration, the central issue, according to *Science*, remained the definition of nursing research. “Just what is nursing research? The short answer is ‘ill-defined.’ It spans a wide range of activities that includes the prevention of bed sores, the education of patients with special dietary needs, and the emotional support of the chronically ill and their families.” Badly needed was a definition that the public and the biomedical community could grasp. The ANA took the lead in the nursing community to provide this definition. The organization suggested an example of cost-effective nursing research with a clearly biomedical side: a study of premature infants to determine criteria for early hospital discharge. Doubters were hardly convinced. Moreover, the issue became a Catch-22 situation: because nursing research lacked a clear definition, it was impossible to categorize within the NIH mainstream; therefore, it was inappropriate to be part of the NIH research world. It was a frustrating dilemma. “If you look at the other institutes,” explained one advocate, “you see that having an institute in itself helps develop research.”²⁰

The ANA launched a campaign to explain and sell nursing research. The network of nurse scientists pulled together a series of examples that would make sense to politicians, government bureaucrats, and the biomedical community. One example that proved exceptionally effective was how nursing research had led to advances to control nausea and vomiting that occurred as side effects of chemotherapy drugs. Another emphasized the effectiveness of informing patients beforehand about a procedure. The result, nursing research had proven, was that prepared patients were far less anxious or distraught about a procedure than those who were not informed, and they recovered more quickly. “We wanted to win people over by giving examples of nursing research that made a difference in practice...and to provide examples that fit nicely

within the concept of NIH,” according to Dr. Jan Heinrich, who helped organize the campaign. The group drafted blueprints for a nursing institute within NIH, drew up a proposed organization chart, and even selected the Cloisters, a former nunnery of the Sisters of Visitation and a prime historical property on the NIH campus, as the location for the new institute.²¹

Staunch supporters, including several members of Congress, seized the report’s recommendation on creating an institute and quickly received the backing of the Tri-Council for Nursing, a group



Representative Edward R. Madigan (R-Illinois) was a vocal supporter and welcome ally of a nursing research institute.

consisting of representatives of the American Nurses Association, which represented registered nurses, the National League for Nursing, which termed itself the “voice for nursing education,” and the American Association of Colleges of Nursing, which promoted baccalaureate and higher degree nursing education programs. The ANA’s considerable lobbying machine went into action. Though based in Kansas City, Missouri, the ANA maintained a staff of about ten people at its governmental affairs office in Washington, D.C., and it tirelessly worked the halls of the Senate and the House to convince members of Congress of the need for a national institute for nursing research.²²

The most enthusiastic supporter of a nursing research institute was Rep. Edward R. Madigan, an Illinois Republican who had just been re-elected to a sixth term from his district in the central part of the state. Madigan hailed from Lincoln, Illinois, a small town whose claim to fame was that it was the only place named for Abraham Lincoln before he became President. While Lincoln had practiced law there in the 1850s, perhaps its most famous native son was the poet Langston Hughes. Ed Madigan was a businessman turned politician. By 1983 he was the ranking minority member of the Subcommittee on Health and the Environment of the House Committee on Energy and Commerce. Leonard E. Heller, a Robert Wood Johnson Fellow assigned to Madigan’s staff, had brought the IOM report to the congressman’s attention about the time Madigan was looking for a legislative hook on which to conduct his next campaign. The wife of his presumptive opponent was a nurse. For Madigan, the idea for greater federal support for nursing research was a delicious irony with which he could stifle his opponent’s attacks. He seized the opportunity. Even in the face of opposition from a Republican White House, Madigan was convinced of the necessity for an institute. With Madigan’s support, the possibility of a nursing institute within NIH took on a fresh life.²³

There was a dose of political sophistry in Madigan’s espousing a nursing institute. He and fellow Republican James T. Broyhill of Virginia had blocked a Democratic reauthorization bill sponsored by Henry A.

Waxman of California, which called for NIH to initiate research into specific items such as diet therapy for kidney failure, spinal cord regeneration, sudden infant death syndrome, and Alzheimer's disease. In demanding these requirements among many others, the Democrats were forcing congressional control over NIH, the Republicans claimed. They said that NIH administrators "are far better qualified than those of us on the House floor to make the determination as to where NIH dollars go." The Republicans wanted to authorize the same funding levels for NIH as the Democrats—they just wanted fewer strings attached. The irony was not lost on *Science*, however, which noted that "although Madigan has become a staunch supporter of the idea that NIH should be relatively unencumbered by congressional mandates," it was worth noting he was sponsoring an amendment for the creation of a new national institute for nursing research.²⁴

As the IOM report had stirred debate in the nursing community regarding a separate entity at NIH, so too did Madigan's proposed amendment. The ANA held a conference call in late June 1983 to review short- and long-range goals relating to the idea of a National Institute of Nursing. In a report to the Tri-Council representatives of the ANA, the conference participants noted that it would be important to push for more "visibility and credibility with the other research communities and with the nursing profession." This could best be accomplished by moving nursing research to the NIH, while at the same time supporting "manpower production" through the Nurse Training Act at HRSA. The position taken by the ANA in the summer of 1983 demonstrated the influence of the association's Cabinet on Nursing Research, which strongly supported the NIH institute.²⁵

Nonetheless, there was wide recognition that the various constituencies of the Tri-Council were not united on a specific policy. Just after Labor Day, the Virginia-Carolinas Doctoral Consortium in Nursing, a group consisting largely of academics and academic administrators, including Drs. Ruby Wilson and Rhetaugh Dumas, met at George Mason University in Fairfax, Virginia. The group made every

attempt to air out all opinions. Dr. Linda Amos, the president-elect of the AACN, Jo Eleanor Elliott, director of the Division of Nursing, Dr. Nola Pender, chair of the ANA's Cabinet on Nursing Research, and Jessie Scott also participated. The meeting was important because the issues and concerns expressed by the participants at that time would remain much the same for the next two years. Was the intent to form a center as the National League for Nursing (NLN) had suggested, or was it an institute as proposed in the amendment? How stable would a new nursing entity be at NIH? Why had there been insufficient time and opportunity for input on the desirability and direction of the amendment? Why was nursing not proactive in developing its own legislation rather than being reactive to Madigan's proposal? Was this the best way to take advantage of the current federal political and administrative interest in nursing? What kind of negotiating power would nurses have under another placement within the federal government? What would be the impact of the amendment on the Division of Nursing?²⁶

While the Tri-Council strongly believed that riding on the tail of the Madigan amendment was the best way to enhance nursing's position in the federal government through an institute at NIH, the larger group preferred a less ambitious strategy. They suggested an agency within the Public Health Service, parallel with NIH, "not within it." The idea was to have something comparable to the Centers for Disease Control or the Food and Drug Administration. Other preferences were for bureau status for nursing within the Division of Nursing or a National Institute of Nursing with the Division of Nursing as the nucleus. The minutes of the meeting reflected both the divisions and the places of agreement among the groups. "An overriding concern across all the suggested options was that immediate efforts be taken to *strengthen the Division of Nursing* [emphasis in original], especially in reference to the Nurse Training Act of 1964. Under no circumstance, the participants agreed, should the research, education, and practice elements of nursing be separated, as each derived strength from the other."²⁷

The idea of separating the three legs of the stool of nursing gnawed at those participants who believed that the Tri-Council had first placed and then pushed nursing research above other aspects of the profession. Jo Eleanor Elliott reminded the group that “two of the three organizations within the Tri-Council favored an Institute for Nursing Research, not an Institute for Nursing, which encompassed research, education, and practice.” Echoing Elliott’s concerns, several others commented that “nursing research had a small constituency and that constituency was not large enough to support legislation for an institute focused on research.” “The Tri-Council,” these participants cautioned, “ought to be aware of other important constituencies within nursing from whom they needed support to successfully pass legislation, namely educators and nurses in practice.”²⁸

Whatever the differences within the group, the participants chose to take the debate to their boards—the ANA, AACN, and NLN—rather than take the divisions public by relaying them to Madigan’s office. The participants agreed to hold additional meetings, listen to the nurse scientists, and continue the discussions of the issues related to placement of nursing within the federal government. The decision to raise concerns to the various boards maintained the idea of a unified nursing community. In reality, the decision was a victory for the institute’s supporters, as the legislation was on track for a vote before most of the boards would meet to express an official opinion.²⁹

In November, H.R. 2350, the Health Research Extension Act of 1983—legislation reauthorizing the appropriations for NIH—made its way through the House. Madigan, as expected, attached a floor amendment to create a National Institute for Nursing Research at NIH. He later recalled that the IOM report convinced him that there was a “remarkable absence of funding for research into nursing practice... which resulted in a critical shortage of nursing leadership in faculties of colleges of nursing and in clinical practice.” To solve the problem, he said, the federal government needed “to establish a more visible research activity for nurses.” The new institute would give nurses

“unprecedented visibility, prestige, and esteem,” he told reporters. Quoting almost directly from the IOM report, Madigan told his colleagues that “this is a straightforward amendment that seeks to put nursing research into the mainstream of scientific investigation.”³⁰

The amendment passed on a voice vote as part of a bipartisan compromise between Waxman, who chaired the subcommittee that had jurisdiction over NIH, and Madigan to get the entire bill enacted. Waxman’s support was crucial because he brought along those undecided representatives inclined to follow the lead of a major subcommittee chair. When the amendment came to a floor vote on November 17, 1983, legislators were reluctant to speak against what many viewed as a “mom and apple pie” issue. The amendment passed overwhelmingly. Moreover, in the meantime Congress had appropriated \$9 million for nursing research for fiscal year 1984, nearly doubling the previous year’s appropriation. The increase indicated the federal government’s growing interest in nursing research. Nursing also responded. The Division of Nursing, which received the funding, reported a dramatic increase in the number of applications for nursing research grants.³¹

Science commented that the nursing institute amendment passed the House with “remarkable alacrity by political standards. Despite the fact that some nursing groups have been pushing for greater status in the federal government for some time,” the journal said, “the institute’s passage took people by surprise.” The Senate, however, took a more cautious approach. “We’re willing to hold hearings, but not to have this thing sail through on the wings of the gender gap,” a Senate staffer told *Science*. But neither Utah Republican Orrin G. Hatch, chair of the Senate’s Labor and Human Resource Committee, nor Massachusetts Senator Edward M. Kennedy, the ranking committee Democrat, “were likely to go along with a nursing institute now,” the journal believed. Nonetheless, *Science* was mightily impressed with what had been accomplished. “Whatever the outcome of this round, thanks to Madigan, nurses have won Congress’s attention as never before.”³²

The corollary was also true: the Madigan amendment energized the nursing community. Over the summer of 1983, before the amendment hit the floor of the House, the big three nursing organizations—the AACN, the ANA, and the NLN—held a series of meetings to discuss the situation. “Many of nursing’s strongest legislative supporters found themselves,” an observer wrote later, “in a very difficult position. While not wanting to oppose a nursing initiative, they were also on record as being against the formation of any new institutes at NIH.” The professional nursing organizations consulted with others who stood on all sides of the issue, including Jessie Scott and Jo Eleanor Elliott from the Division of Nursing, who were cool to the idea, and Drs. Ada Jacox and Nola Pender, who strongly supported greater federal aid outside of HRSA. Those interested in the amendment believed that the happy coincidence of the IOM recommendation and reauthorization of NIH “provided a most expedient method of accomplishing a highly visible organizational entity for nursing research in a fairly simple” and straightforward way. “Input and concerns have been heard, considered, and pondered,” one participant from the AACN wrote. “Clearly not all consultants have favored the amendment to establish an institute within NIH; others have strongly favored the idea.” Not all of the AACN board members favored the idea either, but a majority believed that the “benefits outweighed the risks and there were at least as many risks involved in doing nothing or taking no position.” By mid-July, representatives from the three nursing organizations, working with Heller in Madigan’s office, “hammered out the final wording for the amendment and all voiced their support for it.”³³

The Division of Nursing, understandably fearful of how the Madigan amendment might alter its own future, fought back. In August 1983 Dr. Doris Bloch released a report explaining all that the Division of Nursing had accomplished for nursing research since the inception of federal support programs in 1955. “There has been tremendous growth and development in all aspects of the nursing research effort,” she wrote. “There are more nurses with doctoral degrees, more

nurses engaged in research, and more schools of nursing educating nurse researchers.” She noted the increase in sophistication of nursing research, the growing number of nursing research journals, and the expansion in the dissemination of research findings through refereed journals and professional conferences. Judging from the number of articles cited, the most prevalent source of funding for nursing research in 1981 was the Division of Nursing, she reported. In 1972 Scott wrote that she wanted the Division of Nursing to increase scientific knowledge by “fostering on a nationwide basis, high-quality research of value to nursing.” Scott’s vision, in Bloch’s view, had been reached. The Division of Nursing was doing the best job possible, she believed. There was no reason to make any changes.³⁴

Others in the nursing community agreed. The AACN divided over the idea of an institute. A number of deans feared that changes in the system would upset the current situation, which, while not perfect, was one with which they were comfortable and that worked tolerably well. They envisioned losing control over the use of funds “to a director and an advisory committee not friendly to nursing.” The AACN’s board was suspicious of NIH and believed nursing organizations would lose influence over the type or focus of research in a situation where only biomedical-related research projects would be funded. A major risk, some believed, would be an erosion in the number and amount of grants awarded by the Division of Nursing, a long-time source of funds for nursing schools. An institute at NIH would separate “research from manpower and training programs, making it more likely to remove further functions from the Division and ‘divide and conquer.’”³⁵

The central concern for many nursing deans was the uncertainty that would surely arise in changing the structure of funding for nursing. They raised the same issues that had been discussed at the conference at George Mason University the year before. For those in the academy, the Division of Nursing was an old and trusted friend. It might not have the wherewithal to give you everything you wanted,

but it was reliable and had a track record of support for the profession. Many recalled all that Jessie Scott had done and personally liked her successor, Jo Eleanor Elliott, and they sought to guard the interests of the division. Alarmed that the Tri-Council had backed the Madigan amendment with too little discussion beyond a few officials representing the three nursing organizations, Dumas and Felton published an article outlining their concerns in *Nursing Outlook* in early 1984 before the Senate took action on the House bill. The article “Should There Be a National Institute of Nursing?” stressed the interdependence of nursing education, nursing practice, and nursing research and asked for a “thoughtful examination of the proposed amendment by a wider nursing constituency.” Nursing had embraced the Madigan proposal of a new institute too hastily, they cautioned. The “growing eagerness to implement” the IOM’s recommendation had prompted the Tri-Council to support Madigan’s plan and eschew full discussion of its merits, they wrote. Yet “many prominent nurse leaders believe that it would be unwise at this stage in the development of nursing science to locate support programs for nursing research and those for nursing education and practice in separate agencies,” which the Madigan amendment would do.³⁶

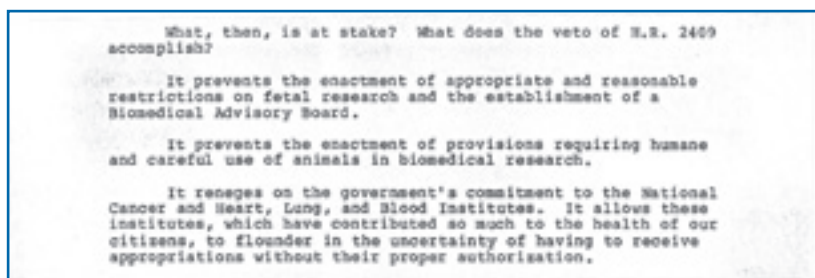
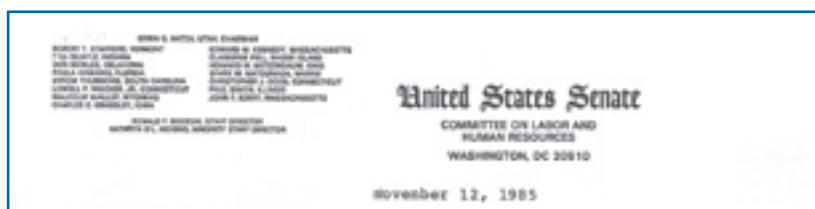
The two deans appealed to the profession to consider other alternatives to an institute. While there was “little disagreement among nurses that an adequately funded organizational entity is needed at a high level in federal government to foster the development of nursing research,” there needed to be further consideration of where it could best be located. Placing it within NIH, the authors feared, would “give other institutes greater influence in the review of nursing research grants, in decisions to approve or disapprove them, and in matters pertaining to their oversight and management.” Dumas and Felton believed it crucial to “maintain linkages among nursing research, education, and practice.” They concluded that placing the new entity within the Division of Nursing—which had long understood, supported, and advanced the needs of the nursing community—was best.

Such placement would give the Division of Nursing more visibility and greater support. “No other organizational unit has had the experience in the affairs of our discipline that the Division of Nursing has had. Furthermore, up to this time, no others have appreciated our actual and potential contributions in health care delivery and scientific inquiry.” Therefore, the nursing community “might have a good deal more to gain and less to lose by establishing the new nursing entity within a stronger, more viable Division of Nursing.”³⁷

However, other deans saw fresh opportunities in an NIH institute of nursing. It would provide a prominent, highly visible entity for nursing research, something that didn’t exist in HRSA. They also anticipated that a new institute would increase credibility and status for nursing research and provide “far greater opportunities for post-doctoral research training and research fellowships.” They stressed that it was only after “painstaking deliberations that the AACN Board decided to support the amendment in order to make it as strong as possible.”³⁸

Over the spring and summer of 1984, House and Senate conferees shaped the legislation with the assistance of a united Tri-Council. Any differences within the Tri-Council were hammered out behind closed doors so the nurses could present a united front in favor of an institute. “This cohesiveness was very important in promoting the bill,” an NLN analyst believed. The key person in the Senate was Orrin Hatch, who chaired the committee that dealt with health matters. Hatch opposed a nursing institute, but did want to pass some legislation that would respond to the recommendations of the IOM report. In May, Hatch proposed promoting nursing research by elevating the Division of Nursing to bureau status, an initiative proposed earlier by the Tri-Council to ensure the continued strength of the existing nursing support agency. However, Hatch proposed creating within the bureau a Center for Nursing Studies and Research, which would coordinate all nursing research sponsored by all of the various federal agencies and eliminate the need for a new institute. The Tri-Council

did not support Hatch's proposed alternative to an institute of nursing, arguing that a center should be considered as a step toward the establishment of an institute, not an excuse to kill it. Nevertheless, with Hatch's opposition to a nursing institute, Senate support appeared lukewarm at best. At that point, Senator Daniel K. Inouye (D-Hawaii) took up the torch for an institute, circulating a "Dear Colleague" letter to drum up support. As a result, several senators came out in support of the institute, including Republicans Paula Hawkins from Florida and Robert T. Stafford of Vermont. Spark M. Matsunaga, Hawaii's junior Democratic senator, also came aboard. Importantly, all three were members of Hatch's committee and took independent positions in opposing him on this issue.³⁹



Congressional support was critical to the NCNR's creation. Pictured is Senator Orrin Hatch's (R-Utah) letter of support for HR 2409.

In addition, one health care issue beyond a nursing institute held up the bill. The legislation also contained a highly controversial section on fetal research, which the Reagan administration vehemently opposed. After several months, House and Senate conferees finally reached agreement, leaving only the nursing institute remaining

on the table. Madigan and Waxman held firm on a nursing institute, and Senator Hatch finally relented. By October 1984 the two houses agreed on the language of the NIH reauthorization bill, now labeled S. 540, which included the provision to establish a National Institute of Nursing. The new bill would “provide a focal point for promoting growth and quality of nursing research, to provide leadership in expanding the pool of researchers, and to promote interaction with other bases of health care research.” The conferees intended that nursing research activities conducted by the Division of Nursing in HRSA would be transferred to a new entity in NIH. Still opposed to a new institute, President Reagan allowed the bill to die through a pocket veto after Congress adjourned in October 1984.⁴⁰

A number of nurses blamed themselves for Reagan’s veto. Some argued that the ANA’s endorsement of Democratic candidates Walter Mondale and Geraldine Ferraro was the reason. Others believed it was the inclusion of the nursing institute. But in retrospect, according to a political analyst for the NLN, there was no “one particular issue that was the final cause. There was a strong likelihood that the bill would have been vetoed regardless of the ANA’s endorsement.” The administration had opposed other provisions of the bill “that specified the degree to which Congress would have jurisdiction over NIH activities,” the same reasoning that Madigan and other Republicans had used to block Democratic initiatives. While emphasizing his support for biomedical research, in his veto message the President said that “creating unnecessary, expensive new organizational entities,” such as the arthritis and nursing institutes, would impede health research. “This reorganization of NIH is premature in light of a study of the NIH organizational structure to be released in a few weeks by the IOM.”⁴¹

Therefore, it surprised no one that the IOM report mentioned in Reagan’s veto message, “Responding to Health Needs and Scientific Opportunity: The Organizational Structure of the National Institutes of Health,” rejected the idea of creating new institutes. The study had two principal objectives in reviewing the organization of NIH. One was to

be responsive to health needs and to capitalize on scientific opportunities. The second was to “promote basic science and maintain standards of scientific excellence.” While nursing research was most pertinent to the first objective, NIH’s traditional attachment to basic science would serve to block a nursing institute altogether. According to the IOM report, “there should be a presumption against any additions at the institute level, because changes would fragment the scientific effort, add to administrative costs, and diminish effective communication between institutes.” But the report did not eliminate every possibility. A new institute could be created if it were “demonstrable that the research area of a new institute or other major organizational entity... is not already receiving adequate or appropriate attention.” That criterion, all of the nursing organizations agreed, could be applied to nursing and “can contribute to the arguments in favor of nursing research at NIH.” In addition, the report recommended that the director of NIH be given more authority and that a new board be established within the Department of Health and Human Services (HHS) to determine oversight for the research organizations of the Public Health Service (PHS). “Nursing’s input to both the director’s office and the board... are [sic] critical,” an NLN analyst wrote. And nursing still had many friends in Congress.⁴²

On the heels of the release of the IOM study, the NIH Task Force on Nursing Research issued its report. Appearing in December 1984, the internal task force reiterated Wyngaarden’s view that no new institute was needed but emphasized the potential for a greater role for nursing research at NIH. This was no accident. Wyngaarden had selected the task force from among those NIH officials who had worked with nurses and better understood the importance of nursing research. The director of the National Institute on Aging, Dr. T. Franklin Williams, chaired the task force, which consisted of directors, deputy directors, and assistant directors from the Office of the Director, the National Cancer Institute, and the Division of Research Grants, among others. Moreover, the ANA suggested a number of people who would be

valuable in helping the task force understand nursing research. These included people who held differing opinions but all of whom wanted more nursing research. Ruby Wilson, Rhetaugh Dumas, Joanne Stevenson, and Edyth H. Schoenrich, a dean at the Johns Hopkins School of Public Health, were among those recommended by the ANA. Before meeting with the task force, the ANA staff invited the women to lunch. “Here is an opportunity to inform all of the institutes at NIH about nursing research,” Heinrich recalled telling them. “Our plea was ‘stick to the issue of what is nursing research and stay away from where it should be housed.’”⁴³

The ANA strategy worked. All focused on nursing research and what it could do for public health. No one mentioned whether something should be located in HRSA or NIH. In a series of three meetings, the group examined the definition of nursing research and the existing nursing research activities within NIH. In its conclusions, the task force recommended ways to expand them within the current administrative structure. The nursing research environment at NIH could be enhanced by “fostering the awareness of nursing research” and by “encouraging more collaborative and interdisciplinary research and training within the extramural and intramural programs,” it stated. Again, the report helped the nursing community define policy priorities as a new Congress returned in 1985. In addition, the nurses’ testimony opened a few eyes at NIH, Heinrich believed. The nurses were “very, very well received,” she recalled. “People began to say, ‘Oh, now I know what to look for in our own research portfolios at NIH.’”⁴⁴

While the Tri-Council continued to support the creation of a national institute of nursing (NIN) at NIH, the larger nursing community was still divided. “Many nursing leaders oppose the NIN and made their view heard in public,” wrote a government affairs analyst for the NLN. “Nursing needs to hold open forums to discuss the institute so that, as much as possible, we iron out these differences among ourselves.” Yet those who believed that an NIN remained the strongest means to promote nursing research needed “to have stronger arguments

for the NIN than merely its ability to project nursing research into the mainstream and increase nursing visibility. Legislators need to hear more about the advantages and cost-effectiveness of nursing research for patients and other voters in their district. We may not reach a consensus,” the NLN analyst concluded, “but the need for greater discussion on the ramifications of a National Institute of Nursing and on the decision-making process for this and other issues confronting nursing is critical.” In any case, the increased attention that nursing research received in the previous two years greatly raised the expectations of the nursing community. And that community was determined to get something accomplished.⁴⁵

The Division of Nursing at HRSA was determined to keep its central role as the “go to” federal agency for nursing research. With the encouragement of Dr. Robert Graham, the director of HRSA, Dr. Edward Brandt, the assistant secretary for health, commissioned Lewin and Associates, Inc., a D.C.-based consulting company, to conduct a study to determine ways to “augment nursing research activities within PHS.” Deliberately timed for release before the NIH Task Force and House-Senate conference reports, the Lewin Report, they believed, would receive administration backing and take the wind out of the sails of Congress’s effort to establish an institute of nursing at NIH. Again, the ANA recommended nurse scientists as resources for the Lewin team. The ANA strategy was to voice its strong support for a federal focus for nursing research, something that HRSA’s Graham also backed. The Lewin Report offered several options, all including a strong federal focus for nursing research. The preferred option was to establish a center for nursing research in the Division of Nursing—something, the report noted, that could be done without passing new legislation and without impact on the Division of Nursing. Thus, the report could respond favorably to the recommendation of the IOM report and mesh with administration policy. With the backing of HHS Secretary Margaret Heckler, HRSA established a center for nursing research within the Division of Nursing in 1985.⁴⁶

**ASSESSMENT OF THE
ORGANIZATIONAL LOCUS OF
THE PUBLIC HEALTH SERVICE
NURSING RESEARCH ACTIVITIES**

By:

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Lewin and Associates, Inc.

September 7, 1984

The "Lewin Report" offered several options for nursing research at the federal level.

Because Congress could not override Reagan's pocket veto in the fall of 1984, the legislation introduced in the next Congress, H.R. 2409, the Health Research Extension Act of 1985, was substantially the same, including the provision for the nursing institute. Again, the House and

Senate conferees agreed on the concept of improving federal support for nursing research. But the bill that finally emerged in October 1985 called for the establishment of a national center for nursing research, similar to the Fogarty International Center on the NIH campus, rather than an institute. While the nursing community viewed the center as a necessary compromise, the ANA and other professional groups worked with Madigan and his supporters to ensure that the center would have the same authorities as an institute. The bill passed unanimously in the Senate and by a 395 to 10 vote in the House. Once again, the White House and Congress were at odds over NIH legislation. On November 8 President Reagan vetoed the bill, saying it imposed congressional “micromanagement” on NIH and was “overloaded with objectionable provisions that seriously undermine and threaten the ability of NIH to manage itself and is therefore unacceptable.” The President also took a direct swipe at nursing research in his veto message. “I do not believe that the establishment of a nursing research center at NIH is appropriate, for a very basic reason—there is a lack of comparability between the mission of such a center and the mission of NIH.” Reagan, following the lead of NIH, believed that nursing research was not sufficiently scientifically oriented to merit an institute. Both House and Senate leaders, who viewed NIH as an organization for promoting health rather than a “National Institute of Diseases,” disagreed and moved quickly to override the veto.⁴⁷

All of the major nursing organizations encouraged their members throughout the country to contact their members of Congress and sent their Washington lobbyists up to Capitol Hill to urge the override. On November 12, the House, as expected, voted 380 to 32 to do just that. About a week later, Senators Hatch, Kennedy, and Connecticut Republican Lowell P. Weicker, Jr., urged their colleagues to follow the House example. Hatch was particularly annoyed with the veto message and the dismissive attitude of NIH toward nursing research. The missions of NIH and a center for nursing research were not incompatible, as Reagan had suggested, he said. According to the

Utah Republican, “the truth lies closer to a comment attributed to an NIH scientist: ‘Nurses are not a disease, and at NIH we do disease research.’” The notion that the \$5 million for nursing research within NIH’s \$5.5 billion budget was “too much,” Hatch said, was “preposterous. A proposal for nursing research to have one one-thousandth of the NIH budget is too much? My fellow Senators, don’t you believe it,” he admonished. “It is high time that nursing research took its rightful place in those NIH halls of ivy.” Most senators agreed. They voted to override the veto, 89 to 7.⁴⁸

Chapter 1 Endnotes

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- 3 Marilyn E. Flood, *Promise on Parnassus: The First Century of the UCSF School of Nursing* (San Francisco, CA: UCSF Nursing Press, 2007), 77-78, 93; "The History of the National Institute of Nursing Research," n.d., NINR Records, Box 5; Gray, "A Brief History of Nursing Research"; *NIH Task Force on Nursing Research: Report to the Director* (Bethesda, MD: National Institutes of Health, 1984), 9. On the application of funds for graduate nursing education in California, see Flood, *Promise on Parnassus*, 90-91.
- 4 *NIH Task Force on Nursing Research*, 9; "Federal Support for Nursing Research," August 18, 1983, NINR Records, Box 11, Folder: Nursing Research: NIH or HRSA?; *NIH Task Force on Nursing Research*, 9.
- 5 Miller, et al., "What Is Nursing Research," 5.
- 6 Obituary for Jessie M. Scott, *The Washington Post*, October 30, 2009. Scott received the Distinguished Service Medal from the Department of Health, Education and Welfare in 1973 and, some years later, the American Academy of Nursing named her a "Living Legend." Patricia Moritz, telephone interview by Philip L. Cantelon, March 13, 2008, 7 (hereafter Moritz Oral History); Linda Aiken, telephone interview by Philip L. Cantelon, June 10, 2008, 11 (hereafter Aiken Oral History); Miller, et al., "What Is Nursing Research," 6.
- 7 Gray, "A Brief History of Nursing Research," 9.
- 8 Ada Jacox, "The Coming Age of Nursing Research," *Nursing Outlook* 34, no. 6 (November/December 1986): 277-78.
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- 10 *NIH Task Force on Nursing Research*, 9.
- 11 Janet Heinrich, telephone interview by Philip L. Cantelon, March 21, 2008, 1-4 (hereafter Heinrich Oral History March 21, 2008).

- 12 Ibid.; Stevenson c.v., <http://www.con.ohio-state.edu/> (accessed July 15, 2008); Nancy Fugate Woods, telephone interview by Philip L. Cantelon, March 24, 2008, 20-21, 1-3 (hereafter Woods Oral History).
- 13 Institute of Medicine, *Nursing and Nursing Education: Public Policies and Private Actions* (Washington, D.C.: National Academy of Sciences, January 1983), 215-17.
- 14 Ibid., 216-17.
- 15 Geraldene Felton, telephone interview by Philip L. Cantelon, June 30, 2008, 6-7, 17.
- 16 Heinrich Oral History March 21, 2008, 6.
- 17 Ibid., 6, 9-11; Barbara J. Culliton, "A Nursing Institute for NIH?" *Science* 222 (December 23, 1983): 1310; biography of Rhetaugh Dumas, www.nursing.umich.edu/dumas/bio.html (accessed July 15, 2008).
- 18 Culliton, "A Nursing Institute for NIH?" 1310-11; see *NIH Task Force on Nursing Research*, 1, 5.
- 19 Barbara J. Culliton, "Study of NIH Gets Under Way," *Science* 222 (October 21, 1983): 306; Mary B. Malison, "A Toast: To Overriding a Presidential Veto," *American Journal of Nursing*, January 1986, 9.
- 20 Culliton, "A Nursing Institute for NIH?" 1310-11.
- 21 Heinrich Oral History March 21, 2008, 12-16; "The History of the National Institute of Nursing Research," n.d., NINR Records, Box 5. The Howard Hughes Medical Institute later purchased the Cloisters.
- 22 Geraldine (Polly) Bednash, telephone interview by Philip L. Cantelon, June 3, 2008 (hereafter Bednash Oral History), 11; Heinrich Oral History March 6, 2008, 7.
- 23 Information on Madigan from his entry in Wikipedia, June 22, 2008; Heinrich Oral History March 21, 2008, 17.
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- 25 Patricia Jones and Rose Boroch to Tri-Council Representatives, Memorandum on National Institute of Nursing, July 15, 1983, ANA Library, Folder: NINR, passim.
- 26 Nola Pender to Eunice Cole, et al., Memorandum, "Report of Proceedings, Work Group Conference to Define the Federal Focus of Nursing," September 11, 1983, 1-2.
- 27 Ibid., 4-5.
- 28 Ibid., 5.

- 29 Ibid., 6.
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- 31 Sally B. Solomon, "The Fate of the National Institute of Nursing," *Legislative Challenges for Nursing in the 80s*, National League for Nursing Publication #19-1981 (New York: National League for Nursing, 1985), 4.
- 32 Culliton, "A Nursing Institute for NIH?" 1312.
- 33 Pat Scarse to Colleagues Interested in the Amendment to Create a National Institute of Nursing, Memorandum, July 21, 1983, ANA Library (hereafter Scarse Memo); Solomon, "The Fate of the National Institute of Nursing," 4.
- 34 Doris Bloch, "Federal Support for Nursing Research," August 18, 1983, NINR Records, Box 11, Folder: Nursing Research: NIH or HRSA?
- 35 Scarse Memo.
- 36 Rhetaugh G. Dumas and Geraldene Felton, "Should There Be a National Institute of Nursing," *Nursing Outlook* 32, no. 1 (January/February, 1984): 16, 18.
- 37 Dumas and Felton, "Should There Be a National Institute of Nursing," 18-20.
- 38 Ibid., 21. Some years later Felton regretted writing this article, listing it under the category of "Famous Miscalls" in a paper titled "History and Development of Nursing as a True Academic Discipline," presented to the 32nd Annual Meeting of the American Association of Nurses in November 2005, presentation in Geraldene Felton Folder, NINR History Files.
- 39 Solomon, "The Fate of the National Institute of Nursing" 4-5.
- 40 Ibid., 6; "Annotated (and simplified) Legislative Chronology," National Center for Nursing Research, December 10, 1985, 1-2, NINR Records.
- 41 Solomon, "The Fate of the National Institute of Nursing," 6. NIH did receive across-the-board funding increases for 1985 of some \$5.1 billion, approved by the Reagan administration. Nursing research received an increase of \$400,000 in 1985, for a total of \$9.4 million (ibid., 7).
- 42 Solomon, "The Fate of the National Institute of Nursing," 7-8.
- 43 *NIH Task Force on Nursing Research*, 3; Heinrich Oral History April 11, 2008.
- 44 Solomon, "The Fate of the National Institute of Nursing," 10; Heinrich Oral History April 11, 2008, 7.
- 45 Heinrich Oral History April 11, 2008, 10. In August 1985, Jo Eleanor Elliott made a final pitch to a group of nursing consultants to place a Center for Nursing Research in the Division of Nursing and HRSA. It was a good planning idea depending on the political winds of the pending legislation. See Donna Diers,

- “Report of an Ad Hoc Advisory Committee: Center for Nursing Research,” September 3, 1985, *passim*, NINR Records, Box 11, Folder: Nursing Research: NIH or HRSA?
- 46 Heinrich Oral History April 11, 2008, 10-13; Lewin and Associates, “Assessment of the Organizational Locus of the Public Health Service Nursing Research Activities,” Contract Number 282-83-0072, September 7, 1984, copy in NINR Records, Box 11, Folder: Nursing Research: NIH or HRSA?
- 47 *Washington Post*, November 9, 1985; Bonnie Bullough, “Public Policy: National The Center for Nursing Research,” *Journal of Professional Nursing*, September-October 1986, 270; Angela Barron McBride, “Nursing Research: Coming of Age,” *Grants Magazine* 11, no. 2 (June 1988): 62-63.
- 48 McBride, “Nursing Research: Coming of Age,” 62-63; *The Washington Post*, December 29, 1985; *Congressional Record*, November 20, 1985. Colman McCarthy wrote in *The Washington Post* that “the nurses lobby had been sophisticated in making the case that a research center was needed.” See *The Washington Post*, December 29, 1985.



The NCNR shared space in Lister Hill Center's basement with NIH's Division of Computer Research and Technology, whose technicians made this punch-paper sign, held by **Doris Merritt** and **Geraldine "Polly" Bednash**, to make the nurses feel welcome.



Chapter 2

Launching Nursing Science at NIH

A legislative mandate, even one passed over a presidential veto, did not translate into a functioning center for nursing research. There were the obvious hurdles to clear—funding, staffing, and space. There were also more subtle barriers to establishing the Center, those lurking in the attitudes of individuals who ran the National Institutes of Health (NIH) and had opposed the creation of any new competitor on the campus, especially one that they believed lacked the credentials of basic science. In addition, there was a built-in gender bias. Nearly all NIH leaders were men. To those at NIH who looked down their noses at women in science—and there were many—the new nursing research center was an interloper in a world run by men. There were numerous bureaucratic potholes available to delay, if not halt, the Center’s progress. By no means could nurse scientists rest assured that their new creation would succeed. There was a good deal of hard swimming ahead before the National Center for Nursing Research (NCNR) could enter the mainstream of the NIH research community.

Creating the NCNR took more than five months, due largely to those bureaucratic potholes. Under the new law, the House and Senate conferees intended for the research and training activities supported by the Health Resources and Services Administration’s (HRSA) Division of

Nursing to be moved to NIH. Until the NCNR was established under the NIH aegis, however, Jo Eleanor Elliott retained those activities in the Center for Nursing Research at the Division of Nursing. While Elliott agreed to provide program supervision, merit reviews, and grants management and to “preserve the status quo for as long as necessary,” she wanted the activities moved to NIH and the NCNR “as soon as possible.” Nonetheless, there were delays stemming from budget battles with the Office of Management and Budget (OMB), which had not requested funds for the new center, and in Congress, which was struggling with the requirements of the Gramm-Rudman-Hollings Balanced Budget Act. With that as a background, it boiled down to how soon Wyngaarden could establish the Center on the NIH campus.¹

For many nurse scientists across the country, the establishment of the NCNR at NIH marked a rite of passage for their profession into the scientific community. In the 1970s, nurses at the Veterans Administration discovered that nursing research was classified in a list of diseases, placed alphabetically between multiple sclerosis and periodontal disease. A list of areas of scientific expertise published by NIH had pages of categories dealing with biological aspects of disease, but nursing was mentioned only under “Health Sciences and Health Services Delivery,” specifically “Nurse/Midwifery” and “Nursing Education and Training.” With such long-held attitudes pushing against the full acceptance of nurse scientists, Dr. Ada Jacox, a leading advocate of nursing research, wondered if it ever would be possible for nurses to “fully contribute their perspective, knowledge, and talent to the development of the science of health.” She noted that nursing’s “emphasis on combining behavioral and biological aspects of health does not reflect the dominant values in the scientific community,” which paid but minimal attention to health promotion, patient education strategies, and the behavioral aspects of health and illness. Jacox was outraged that, for years, NIH had no way to identify nursing research. “Not only have we not been integrated into the scientific community, very often we have not even been acknowledged by it except in superficial and misleading ways.”²

Jacox's frustration stemmed from her lobbying activities on behalf of a National Institute of Nursing Research (NINR). Most people had no idea that nurses did something called nursing research. "We encountered a common assumption that nursing research is concerned only with determining how many of what kinds of nurses are needed in various work settings. The fact that nurses do research on clinical problems still comes as a surprise to many." Added to this was a general skepticism in federal agencies and in the medical community that there was anything "worth researching in nursing" or that "nurses had the capacity to do science." Later, she said, "the surprise and skepticism gave way in some cases to an attitude of paternalism: that is, if you are interested in joining us, let us speak for you." As female professionals coming of age in a period of active feminism, Jacox and her colleagues considered such a position anathema.³

Moreover, nurse scientists faced another barrier to joining the scientific community: money. Scientists at NIH and elsewhere wanted to keep the status quo in both science and research dollars. "Any encroachments," Jacox wrote, "including but not limited to nurses, into what they [scientists] define as their turf, are apt to be met by suspiciousness, hostility, and resistance." She concluded that nurses "must not make the mistake of thinking that, because we have achieved legislation for a national center for nursing research at NIH, we will now be welcomed there." Therefore, she believed that "much work needs to be done to integrate nursing research into the scientific community."⁴

Whatever his previous opinions about creating a new center at NIH, Wyngaarden did not hesitate to get it launched. Soon after Congress approved the law over President Reagan's veto, Doris Merritt received Wyngaarden's call. She believed she had good reason to turn him down, even though Wyngaarden was an old friend of hers and her husband's from their days together at Duke University Medical School, where Wyngaarden chaired the Department of Internal Medicine and her husband was chief resident. Nurse scientists, she realized from her NIH experience, would be strangers in a strange land.⁵

Merritt grew up in New York City and in 1944 graduated from Hunter College, then an all-women's school, where she majored in English literature and philosophy. An only child, she was eager to get out of New York and away from home. Faced with a manpower shortage during World War II, the Navy was recruiting graduates in the upper 10 percent of their class for officers' training school. With approval from her parents, Merritt signed on. Just short of her twenty-first birthday, she received her commission and was stationed in Washington, D.C. For the next two and a half years, she worked in the Code Room in one of the long rows of "temporary" buildings on the Mall, rickety relics from World War I plopped down alongside the Reflecting Pool between the Washington Monument and the Lincoln Memorial. Her job was to take incoming radio transmissions, have a machine decipher them, and distribute them to the right people. As exciting as she found D.C. during the war, the Code Room and the Navy were not part of her future.⁶

When the war ended and the nation demobilized, Merritt knew she wanted neither to teach nor to go into sales. Unmarried and determinedly independent, she decided on a career in medicine. She looked over the catalogs from The George Washington University and was somewhat appalled by the science requirements, since her science in college had been astronomy and photography. She asked the dean of admissions of the medical school if it was really necessary to take all those physics and chemistry classes. "He must have been completely entertained by this naïveté," she later recalled, but "he was very courteous. He told me to go away and take some of the prerequisites and come back in six months. I kept seeing him every six months [until] I was admitted."⁷

After graduation, one of two women in her class, Merritt headed to Duke University for an internship in pediatrics. She married Dr. Donald Merritt, an internist, had a baby, and then moved to Bethesda, Maryland, in the mid-1950s when he took a position as an investigator at NIH. After a month home with the baby, Merritt, who had

held one job or another since she was sixteen, “was climbing the walls.” Because of her medical degree, she landed a job as a senior administrator in the Division of Research Grants, responsible for selecting the group that reviewed applications for support at NIH. Her Navy luck held. At that time the entire extramural program staff for all of NIH was housed in one temporary building. Importantly, the people there formed a tight-knit group consisting of everyone who worked in the review process, including associate directors. As a result, Merritt came to know many of the individuals in the various institutes, something that would become very helpful later.⁸

In 1961 the Merritts left NIH for Indiana University, where she became the director of grants in the dean’s office and the following



Dr. Doris Merritt, the first acting director of the NCNR.

year became an assistant dean. She also had an appointment in pediatrics, building both administrative and academic credentials. When the presidents of Indiana and Purdue created a new school in Indianapolis, Indiana University–Purdue University–Indianapolis (IUPUI), Merritt came in to run the school's grants and contracts office, becoming dean for research and sponsored programs for the entire campus. In the meantime, her husband, Donald Merritt, had started a department of medical genetics at the Medical School at IUPUI, the third such program in the country. In 1978 he had an opportunity to return to NIH as a medical officer of the National Library of Medicine, which was developing a genetics database. For the next seven years, Doris Merritt served first as a special assistant to Dr. Donald Frederickson, the director of NIH, and then as research training officer and research resources officer for NIH.⁹

Then came the call from Wyngaarden's office. Merritt knew the score when she declined Wyngaarden's offer. "These nurses are not going to be happy if you put a physician in charge of them when they have been spending the last thirty years trying to get out from under that yoke," she told him. Further, she fully understood the low level of respect in which most NIH researchers held nursing research. The research scientists and medical doctors had made no secret of their contempt during the debate over a nursing research entity at NIH. Moreover, no new institute or center had been established for more than ten years, since the National Institute on Aging was created in 1974. The new institute authorized in the 1985 legislation, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, had been split off from the existing National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases. The two institutes split their staffs, each experienced in the cultural landscape of NIH. Nurses would not have that luxury. NIH would be alien territory. Furthermore, no one had experience in setting up a new center and there was no template for doing so, Merritt said. But Wyngaarden was insistent. He would give Merritt all the support she requested, whatever she needed, except

for one thing: people. There was a hiring freeze, so she would have to make do with whatever or whomever she could beg or borrow. He told Merritt to get it launched. In spite of his opposition to the Center, “I want you to do a good job of it,” he said. “Just get it done and don’t bother me with it. Do it, please,” he asked. Caught between an appeal and an order, Merritt decided to do it.¹⁰

Whatever Wyngaarden’s animosity toward nursing research or a new entity at NIH, his selection of Merritt to implement the Center was inspired. He was confident of her abilities. An experienced and seasoned manager familiar with the back roads, secret byways, and idiosyncrasies of the NIH bureaucracy, Merritt knew and had earned the respect of the people who could get things done at NIH. While she admitted her ignorance about nursing research and her own prejudice about it, she had a job to do. As a pediatrician, she had often worked with nurses and had learned a good deal from them. “I was generously received by a community that had every reason to resent my being put there to direct them,” she recalled later. She read the Institute of Medicine report on nursing and the legislation creating the Center. She read the discussions held within the nursing community about it. “I was open to learning. I had to be.”¹¹

Once the legislation passed and it was clear that NIH would get the NCNR, the health-related agencies that had previously opposed it now lined up to get it going. Wyngaarden’s appointment of Merritt was an indication of his attitude. In Dr. Jan Heinrich’s view, once the Center was coming to NIH, Wyngaarden decided that “we’re going to be good and we’re going to be smart, and what we put out is going to be up to NIH standards.” The Division of Nursing realized it had lost the political battle and agreed to make the transfer of personnel and funding as smooth as possible. By January 1986 Merritt was hard at work organizing the Center.¹²

Merritt travelled to San Diego in early January to attend a meeting of the Council of Nurse Researchers. The session provided her with an opportunity to discuss nursing research and hear about

different examples of what nurse scientists were doing. Soon after the meeting, Dr. Ada Sue Hinshaw, then the chair of the American Nurses Association (ANA) Cabinet on Nursing Research, wrote Merritt to say how pleased the members of the cabinet were with her selection to establish the Center for Nursing Research and to offer their assistance. Hinshaw suggested that Merritt review the Tri-Council for Nursing's resolution concerning the mission of the NCNR and the cabinet's "latest policy statement outlining the priorities for the profession's scientific endeavors for the coming decade."¹³

Merritt turned to the nursing community for assistance, knowing their participation and "buy-in" would create a group of solid support, something especially important to a non-nurse. In mid-February she reassured Heinrich at the ANA that in spite of President Reagan's rescission of the Center's budget in fiscal year (FY) 1987, all the work and documentation necessary to establish the Center for Nursing Research would continue. Heinrich and her political allies, of course, were already at work to ensure future funding. But Merritt needed more help. Would the professional nursing organizations help her find a permanent director? She wanted the nursing community to have a central role in shaping the guidelines for the individual's qualifications and identifying a pool of "the best possible candidates." The Center would be best served by a highly qualified nurse researcher who could relate to and have the respect of the NIH biomedical community. "We want to be sure we don't miss anything," she told Heinrich.¹⁴

Merritt faced two more pressing problems: personnel and space. Elliott agreed to move nine people to the new Center—six professionals, a grants manager, and two clerks. They would become the core of the Center's staff. But would they be the right people? The grant-making culture at the Division of Nursing was far different from that at NIH. At HRSA, Merritt learned, "the staff sought the grants, advised people how to write them, ran the reviews and then managed them after they were awarded." There was "no separation of church and state," an NIH staffer reported. "Each professional is

lawyer, judge, and jury for her own programs.” That arrangement was diametrically opposite of that at NIH, which separated the review and award functions from the managing of grants. HRSA’s staff had to be brought into the NIH way of doing business. By February 1986 the Division of Research Grants at NIH would review all applications for nursing research. Wyngaarden’s office moved to create a separate advisory council to evaluate them as well. And space was a permanent nightmare. When asked about the physical resources available for the Center, the facilities man for the director of NIH replied, “Pathetic.” He had visited the HRSA offices with Merritt. People were jammed into small spaces partitioned by a maze of file cabinets and old desks. When the office became very busy, case officers had to use the pay phones in the hall. He concluded that “even a windowless suite with adequate elbow room would be an upgrading of their present quarters.” He also suggested using NIH’s discarded office equipment. “It would still be better than what they [the Division of Nursing] have.”¹⁵

Merritt overcame these problems with help from several places. One was the Division of Nursing at HRSA; the other, officials at NIH. To get started, Merritt needed a staff familiar with nursing issues. As promised, Elliott, who had rightfully worried about the impact of the Center on her own agency, arranged to transfer her grants staff to the new Center. They were ready to go within a week of Merritt’s appointment. The NIH people were appalled at the Division of Nursing’s offices in the Parklawn Building, a ten-story office building housing mazes of offices in Rockville, Maryland—a testament to government frugality in leasing office space. Merritt rejected the notion of running a bifurcated office, one part on the NIH campus and the other two miles north up Rockville Pike. She brought down nine people from the Division of Nursing, including Dr. Doris Bloch, Dr. Patricia McCormick, Dr. Deidre Blank, Dr. Adele Woods, and Harriet D. “Bunny” Carroll, to handle grant applications coming into the Center. Crucial to adapting to the NIH culture and grant-making

environment, Bloch, McCormick, Blank, and Woods held doctorates and Carroll had previously worked on the Bethesda campus. The following year, Merritt hired another nurse scientist from HRSA, Dr. Patricia M. Moritz, who had been with the Advanced Nursing Resources Branch of the Division of Nursing.¹⁶

Merritt also received assistance from other parts of NIH. Because of a hiring freeze, she had to beg and borrow from those already on the NIH payroll. "I went around the NIH to directors with whom I was friends and I asked if they could possibly lend me any personnel on a short-term assignment to help me get this off the ground." The director of the Division of Research Resources provided a much-needed executive officer, and the central budget office gave her a legislative assistant. Dr. Ruth Kirschstein, the director of the National Institute of General Medical Sciences, lent Merritt a full-time grants officer who could run the awards process until the Center was fully operational. Wyngaarden, good to his word, approved the space, the temporary assignments, and all the transfers.¹⁷

Cajoling some office space for her new team was Merritt's first miracle. One of the medical world's worst-kept secrets is how fierce the battle can be to capture a location on the NIH campus in Bethesda. So even if Congress mandated a new entity, that organization was destined to get space that others either shunned or abandoned. One of these spaces was a small suite in the basement of the Lister Hill Center, home to the Division of Computer Research and Technology, NIH's information technology operations. Merritt convinced Dr. Donald Lindberg, head of the National Library of Medicine, to let the Center use it. The division tended to the large mainframe computers that churned out miles of Teletype-size sheets of paper. In April they learned that the new NCNR would be joining them. They didn't know what that was exactly, but the information technology staff was excited to have company in their basement. On the day the Center's personnel moved in, the Division hung up a huge banner of perforated computer paper reading, "Welcome Nurses."¹⁸



The Lister Hill Center. The NCNR's first home was in its basement.

On April 18, 1986, Dr. Otis R. Bowen, Secretary of the Department of Health and Human Services, announced the creation of the National Center for Nursing Research under Public Law 99-158 and the appointment of Dr. Doris H. Merritt as acting director. The announcement ended more than two years of efforts by professional groups to achieve a national focus for nursing research. Bowen and the nurses recognized the important efforts of Hatch and Madigan in guiding the legislation authorizing the Center. A week later, on April 28, the NCNR was open for business in its temporary quarters in the basement of the Lister Hill Center (Building 38A) on the NIH campus. At last, nurses were part of NIH.¹⁹

With a staff in place and ready to operate, Merritt received a further jolt—a bureaucratic squabble over funding. The Public Health Service tried to transfer some \$7 million in nursing funds to the NCNR but found it impossible because the new Center had no appropriation symbol or account number. Attempts to solve the problems hit snags in OMB. Then the union, Local 41 of the American Federation of Government Employees, wanted written assurances that the transferred personnel were being treated equitably. OMB, Merritt recalled, was in no hurry to assign an account number “because their tactic was if you don’t have the money, you can’t spend it.” In order to function, the NCNR borrowed funds from HRSA to meet expenses for travel and the installation of computer equipment. An interagency agreement allowed HRSA to continue making awards on continuation grants and to pay personnel. Only when Wyngaarden approved a spending shortcut could the Center purchase supplies that it badly needed. The financial snafus made it very difficult, if not impossible, to use the \$5 million carried over from FY 1985 to establish the Center or to prepare budgets for FY 1987 and FY 1988. In addition, the situation hampered Merritt’s ability to meet current commitments, hire new personnel, procure needed items, track obligations, make new grants, or conduct a search for a permanent director.²⁰

In Merritt’s view, a third group was also crucial to her getting

through these difficulties. Three weeks after Merritt's appointment, a delegation of four nurses representing the ANA, the American Association of Colleges of Nursing, the National League of Nursing, and Sigma Theta Tau International, the nursing honor society, came to see her. "They had really done their homework to find out what I was like," Merritt remembered. "They probably knew what I ate for breakfast." She got straight to the point. Confessing how little she knew about nursing, Merritt asked the delegation to help structure the Center into three branches—one for prevention, one for chronic diseases, and one more loosely defined as nursing services. The delegation offered advice on establishing a national advisory group. "I can't tell you how generous they were with their time and their information, supplying lists of names from around the country that I could appoint as reviewers," Merritt later recalled.²¹

Working with borrowed people on borrowed money in borrowed space, Merritt pushed hard for the Center to become fully operational. HRSA, Merritt said, had told the Division of Nursing that there was no point in reviewing grant applications as they came in because there was no money to fund even those that had been previously approved. "The whole program was stymied," she recalled, "which was one of the reasons that the research nurses were so eager to get out from HRSA." She set her transfer nurses to work reviewing grants. "If we get money," she told them, "we're going to be ready." It was not the first clash between the HRSA and NIH cultures, but Merritt was determined to establish an NIH culture at the Center. "They were not very happy with me. I kept saying, 'But this is the way we do it at NIH,' and they would say, 'But we've never done it that way.'" In addition, NIH based its awards on priority scores, "not on a first come, first served who-was-waiting-the-longest basis," as she described the HRSA system. Again, the Division of Nursing transfers pushed against the change. But Merritt's husband had just been diagnosed with terminal cancer. With additional worries at home, she had little patience or sympathy for any foot-dragging at the office.²²

Merritt fully knew OMB's penchant for releasing appropriated funds that it didn't want spent at the very last minute of the fiscal year "in hope that the system could not react quickly enough to get all the grants awarded." If that happened, she said, the funds went back to the U.S. Treasury and "it's an absolute cardinal sin at NIH to send money back." HRSA, she understood, was not always prepared for OMB's funding process and subsequently lost the funds. Therefore, she made it a high priority to get all the grant applications reviewed and scored and approved by a council borrowed from the Division of Nursing. Three weeks before the end of the fiscal year, all the paper-work was in place. True to form, in mid-September, OMB released the funds, and the Center for Nursing Research made approximately \$6 million worth of awards in two weeks. Both awards were institutional grants continuing work already underway—one was in the Acute and Chronic Illness Branch, the second in the Nursing Systems and Special Projects Branch.²³



Out of necessity, the early NCNR staff learned how to navigate the complex world of the NIH grants process.

The success of grant-making during the Center's initial year was crucial to establishing its reputation within the nation's nursing community and at NIH. It was no coincidence, as Merritt carefully steered

the Center toward the mainstream of NIH research. “I am inclined to treat the RN/PhD investigator population how we treat MD/PhD investigators,” she told the *Cancer Nursing Letter* in June 1986. She wanted the Center to “integrate nursing research activities into ongoing NIH programs while establishing the nurse investigator as a colleague rather than a coordinator working under an NIH investigator.” The goal of the Center was to improve nursing care by expanding the scientific base for nursing practice. NCNR programs, she stressed, would complement other NIH biomedical research programs and seek more collaboration with them.²⁴

The Center’s professional staff initially came from HRSA’s Nursing Research Branch of the Division of Nursing. Doris Bloch led the transfer of nursing research and training programs from the Division of Nursing. A native of Berlin, Germany, Bloch escaped Nazi persecution during World War II by hiding with families in the Dutch countryside. She immigrated to the United States after finishing high school in the Netherlands and graduated from Mount Holyoke College with a BA in zoology. She earned a master’s degree in nursing from Yale University and a doctorate in public health from the University of California, Berkeley. As the leader of the Nursing Research Branch, Bloch “contributed significantly to nursing research by categorizing nursing terminology and clarifying concepts, such as defining goals and objectives for nursing research centers.” As a result of her work over the years, the “quiet and unassuming” Bloch became “a legend” among nurse scientists and a mentor to many of nursing’s future leaders. As interim extramural director and branch chief, she assumed primary responsibility for program planning and evaluation before completing her career as special assistant to the director of the National Institute of Nursing Research (NINR). The Center’s Division of Extramural Programs, initially headed by Bloch, developed three program target areas, two concerning biological and behavioral factors on health and the third, recovery from illness.²⁵

In addition to the Division of Extramural Programs, the NCNR created three other branches, much as Merritt had recommended to the



Dr. Doris Bloch was among Division of Nursing staff members who moved to the Lister Hill Center to assist with the grants process.

professional nursing organizations. The Health Promotion and Disease Prevention Branch was headed by Deidre M. Blank, who had worked in the Nursing Research Branch of the Division of Nursing before moving to the NCNR. Her division funded studies that addressed the general health of the population and were not directed toward any one disease or disability. Studies to promote health might include nutritional requirements adjusted to the various phases of one's life

or the relationship between biomedical and behavioral dimensions of human health. The branch also took interest in studies that enhanced the ability of individuals and families to respond to actual or potential health problems. The Acute and Chronic Illness Branch, headed by Patricia McCormick, who also worked in the Nursing Research Branch, considered technological developments in rehabilitation therapies, epidemiological factors in disease and disability, nursing interventions, and biomedical, cognitive, and perceptual responses to illness or disability. The third branch was the Research Development and Review Branch under Adele Woods. Her responsibility was to ensure an adequate cadre of well-trained nurse investigators to meet the nursing research needs of the future. New research directions for the NCNR included an increasing emphasis on predoctoral and postdoctoral fellowships for research. The branch also launched two career development awards: the Academic Investigator Award, a five-year award for nursing faculty “to establish their research programs and mature into independent investigators,” and the Clinical Investigator Award, a three-year postdoctoral program for nurse investigators working in general clinical support centers. The Division of Research Resources of NIH, which Merritt directed before becoming acting director of the NCNR, funded this program.²⁶

Other key people who came to the NCNR from the Division of Nursing were Gertrude K. “Trudy” McFarland and Bunny Carroll. McFarland had worked in the special projects program in the Division of Nursing and was the first scientific review administrator for nursing research at NIH. She and her staff worked at the NIH Center for Scientific Review to ensure “rigorous and timely processing of nursing research grant applications.” Carroll initially ran the Nursing Systems and Special Programs Branch, which investigated the environment in which nursing management and care were delivered. For example, the branch sponsored studies comparing the outcomes of home care, long-term care, and hospital care to identify the mechanisms responsible for different outcomes and thereby improving nursing care. Patricia

Moritz moved from HRSA to become branch chief of the Nursing Systems Branch in mid-1987.²⁷

By the spring of 1987 Merritt's staff worked out of three separate buildings on the NIH campus. The program and grants management staff occupied some 1,400 square feet in the Lister Hill Center; the administrative, budget, and planning offices were in Building 31; and Merritt and her secretary remained in Building 1. Merritt had already staked out about 2,700 square feet of space in Building 31 so all of the NCNR would be consolidated in one spot. Her schedule was to move everyone into the new area in early 1988.²⁸

Merritt had also assembled an NCNR National Advisory Council by the beginning of 1987. The National Advisory Council met in mid-February of that year to review new program development initiatives and become familiar with the NIH review procedures that the NCNR had adopted. The council consisted of individuals from throughout the country and included nurse scientists and educators, such as Drs. Nola Pender, Ann W. Burgess, and Dyanne D. Affonso, health experts like Dr. Leonard Heller, formerly of Congressman Madigan's staff, and public citizens including Frederick C. Matthaei, Jr., president of ARCO Industries Corporation, and Elaine W. Conway, an interior decorator. That first council expressed a special interest in two areas: the ethics of decision making, in which the nurse played an important role, and the need for research initiatives that focused on the patient's perception of what makes for a healing hospital stay. An additional role of the council was to assist the NCNR staff in developing the Center's long-range plans.²⁹

Most critical to the Center's long-range plans and goals was the development of more nurse scientists. Echoing a refrain often heard in nursing circles, Merritt saw opportunity for nursing in the emerging AIDS epidemic. Testifying to the House Appropriations subcommittee that oversaw the NCNR's funding, Merritt admitted that "the nursing profession does not yet have a cadre of well-trained nurse scientists with sufficient postdoctoral training to become successful independent

investigators.” The Center sought applications for several awards in the area of AIDS, she said, an Academic Investigator Award (KO7), a Clinical Investigator Award (KO8), and an Institutional National Research Service Award (T32). These awards, she said, “should help correct these deficiencies.”³⁰

Just as Merritt integrated the National Advisory Council into the culture of NIH, so did she seek to integrate the NCNR into the NIH community. One ready method of doing this was to collaborate in research projects with other NIH institutes and centers so that they might get a deeper understanding of nurse scientists. The NCNR invested heavily in this approach. Some \$1.5 million, nearly 10 percent of the Center’s entire budget in 1986, was invested in these collaborative efforts. Most important were three projects with the National Institute on Aging, two projects with the National Institute of Child Health and Human Development, and four projects with the National Heart, Lung, and Blood Institute. Other partners included the National Library of Medicine, which co-funded a project for the “Development of New Techniques for the Retrieval and Delivery of Problem-Specific Information,” and the National Institute of Mental Health, whose project of “Social Competence Risk Assessment—Mother–Child Factors” was reassigned to the NCNR.³¹

Collaboration was most cost effective at a time when funding was limited and the Center was trying to establish a basis for its annual budget. But in addition, the Center had to rethink the grant review process. The peer review system for research proposals developed at the Division of Nursing ran by a different set of rules from that at NIH. In the 1970s Jessie Scott had warned the Nursing Research and Education Advisory Committee that it was “being too hard...and that the disapproval rate [75-80 percent] was too high,” though the aim was to fund nearly all the approved proposals. At that time, Ada Jacox recalled, “our response typically was to insist that we were not going to compromise our standards and that nursing research proposals had to be as good as any other proposals.” Nurses learned that the approval

rate in other federal agencies was closer to 80 percent. The review groups at NIH, for example, would know a cut-off point for funding “but made generous use of the approval system for other proposals that will not be funded. The large number of approved but unfunded proposals then is used as an argument for increasing the appropriation for the next year.” The dichotomy between the two approaches led people to cite the high disapproval rate as evidence of the poor quality of nursing research proposals. To merge into the mainstream NIH culture, the NCNR would need to be both alert and adaptive to the nuances of the institution’s traditional practices.³²

Merritt was someone who connected the dots, who could gather disparate facts and link them together. She used this talent to begin the process of integrating nurses into the NIH culture. “By this time I was learning a bit about behavioral sciences and saw how the effects of



Among the NCNR’s accomplishments of the first year was the creation of the Nursing Research Study Section within the Division of Research, which reviewed individual and institutional training grants. (Front row, from left): Marilyn T. Oberst, RN, EdD, FAAN; Kathleen A. O’Connell, RN, PhD; Thelma J. Wells, RN, PhD, FAAN, FRCN; Sister Callista Roy, RN, PhD, FAAN; Geraldene Felton, RN, EdD, FAAN, chairperson; Gertrude K. McFarland, RN, DNSc, FAAN, health scientist administrator; Mi Ja Kim, RN, PhD, FAAN; Joyce Roberts, RN, CNM, PhD, FAAN; Melanie C. Dreher, RN, PhD; Susan L. Jones, RN, PhD; Betty L. Chang, RN, DNSc. (Back row, from left): Sandra G. Funk, PhD; Sharol F. Jacobson, RN, PhD; Linda R. Cronenwett, RN, PhD; Ivo Abraham, RN, PhD; Marie Cowan, RN, PhD, FAAN; Darlene Wood, PhD; Carolyn J. Walker, grants technical assistant.

nursing research could expand or add to the effects of clinical research in cancer.” Patient compliance—whether patients did what they were supposed to do, such as take their drugs or stick to their therapy—applied to a number of institutes. “It just seemed to me that there were so many ways that nurses could...serve on institute committees.” She convinced institutes to incorporate nurses into their programs, believing that both could profit from the experience and exchange of ideas. “The word got around that these people [nurses] were pretty good. A certain amount of collegiality began to form where there was none before, or where they would have been actually ostracized or ignored.” Nurses, Merritt hoped, would eventually fit into NIH.³³

Within a year the Center, under Merritt’s leadership, had chartered a nursing research study section to review individual and institutional training grants, had formed a national advisory council, was making its own grants, was getting its own budget, and was conducting a search for a permanent director. By the end of September 1986, the NCNR had obligated its entire FY 1986 appropriations and made 109 research and 165 training awards. The Search and Screen Committee was beginning its hunt for a director and planned to review candidates for the job within weeks. Notably, Merritt had put the stamp of NIH culture on nursing research. The structure of the Center paralleled that of the various NIH institutes, giving nurses greater access to a range of opportunities at NIH. Within a year of her appointment, Doris Merritt, pediatrician, had been the mother, midwife, and parent to the NCNR.³⁴

The development of a more aggressive approach to nursing research, which led to the creation of the NCNR at NIH, was the result of the investment that Jessie Scott, the Division of Nursing, and, to a lesser extent, private foundations had made in nursing education over the years. That investment stimulated the growth of nursing education and the number of nurse researchers. By the late 1970s, the expansion of undergraduate and graduate education programs in schools of nursing had produced a critical mass of young professionals eager to advance

both their own careers and the discipline of nursing. Impatient with the static funding and slow advances achieved by the Division of Nursing and ever mindful of the expanding dollars going into basic research at NIH, nurse researchers seized leadership of the profession. Operating largely from bases in Washington, D.C., they finally convinced their nursing colleagues and their members of Congress that the time for nursing research to enter the mainstream of medical science had arrived. They had no intention of denigrating the Division of Nursing or what it had achieved in the past; they had every intention of redefining and changing the profession's future. Congressman Madigan provided the legislative vehicle to crash through the old barriers and onto the NIH campus. The establishment of the NCNR was a milestone in the history of nursing research. It raised the standing of the profession and greatly improved its ability to get the funding necessary to conduct significant research.

Any doubts that nursing activists held about NIH biomedical snobbery were dissipated with Wyngaarden's appointment of Doris Merritt. In retrospect, it is hard to imagine a better choice. A skilled administrator and savvy in the ways of NIH, she deftly maneuvered through or around every snarl and snag. Within a year she successfully launched the new Center with a \$16 million budget, more than three times the funding available from HRSA. She stretched those dollars even further by pushing collaborative programs for nurse researchers with other institutes. "The NCNR is expected to thrive as it carries out its mission to augment the nursing science base that underlies effective patient care and the efficient delivery of nursing services, which benefit every individual in the United States at some time in his or her life," Merritt wrote in August 1986. Hers was a virtuoso performance.³⁵

Chapter 2 Endnotes

- 1 “National Center for Nursing Research, Outline Memorandum,” February 4, 1986, NINR Records, Box 11, Folder: NCNR Achieved.
- 2 Ada Jacox, “The Coming of Age of Nursing Research,” *Nursing Outlook* 34, no. 6 (November/December 1986): 277, 276.
- 3 *Ibid.*, 278.
- 4 *Ibid.*, 280-81.
- 5 Doris Merritt, telephone interview by Philip L. Cantelon, April 28, 2008 (hereafter Merritt Oral History), 17-18, 43.
- 6 *Ibid.*, 1-3.
- 7 *Ibid.*, 3-4.
- 8 *Ibid.*, 5-7. Building T-6 had a “temporary” life of some twenty years and was then torn down to become a parking lot for Building 31.
- 9 *Ibid.*, 8-10.
- 10 *Ibid.*, 14, 13.
- 11 *Ibid.*, 13-14.
- 12 Janet Heinrich, telephone interview by Philip L. Cantelon, March 6, 2008 (hereafter Heinrich Oral History March 6, 2008), 12.
- 13 Ada Sue Hinshaw to Doris Merritt, January 14, 1986, copy in ANA Library.
- 14 Doris H. Merritt to Jan Heinrich, February 19, 1986, copy in ANA Library.
- 15 Merritt Oral History, 15-17; National Center for Nursing Research, Staff Memo, February 4, 1986, NINR Records, Box 11, Folder: NCNR Archives; see also Richard Mandel, *A Half Century of Peer Review, 1946-1999* (Bethesda, MD: National Institutes of Health, Division of Research Grants, 1996).
- 16 Merritt Oral History, 17-21.
- 17 *Ibid.*, 20-21. Merritt had co-chaired with Kirschstein a task force studying the status of research into women’s health issues a few years before. Ruth L. Kirschstein, telephone interview by Philip L. Cantelon, January 17, 2008, 2, 8 (hereafter Kirschstein Oral History).
- 18 Geraldine (Polly) Bednash, telephone interview by Philip L. Cantelon, June 3, 2008 (hereafter Bednash Oral History), 17-18; Merritt Oral History, 18.
- 19 *The NIH Record* 28, no. 9, NINR Records, Box 6, Folder: NCNR Archives; *ANA News*, Press Release, April 18, 1986, ANA Library, Folder: NINR.
- 20 National Center for Nursing Research, Fact Sheet, n.d., NINR Records, Box A, Folder: Notebook Prepared by Gerry Pollen; Merritt Oral History, 23; Daniel K.

- Inouye to James B. Wyngaarden, May 14, 1986, copy in ANA Library, Folder: NINR. See also, John H. Kelso and James B. Wyngaarden to Donald Ian McDonald, April 14, 1986, Memorandum, "Establishment of the National Center for Nursing Research, NIH," April 14, 1986, NINR Records, Box A, Folder: Notebook Prepared by Gerry Pollen.
- 21 Merritt Oral History, 15; Heinrich Oral History March 6, 2008, 3.
 - 22 Merritt Oral History, 23-24.
 - 23 *Ibid.*, 26-27; Merritt Testimony, "Hearings," Subcommittee on Appropriations, House of Representatives, March 17, 1987, 710.
 - 24 *The Cancer Nursing Letter*, June 1986, 3-4, copy in ANA Library, Folder: NINR; National Center for Nursing Research in National Institutes of Health Fact Sheet, n.d., NINR Records, Box B, Folder: NIH History (hereafter NCNR Fact Sheet).
 - 25 NCNR Fact Sheet, *passim*; Doris Bloch obituary, *NIH Record*, September 9, 2003; Deidre M. Blank and Patricia Moritz, "Encouraging Service Through Collaboration," *Reflections on Nursing Leadership*, Fourth Quarter 2006, *passim*.
 - 26 NCNR Fact Sheet, *passim*; Blank and Moritz "Encouraging Service Through Collaboration," *passim*.
 - 27 NCNR Fact Sheet, *passim*; Blank and Moritz, "Encouraging Service Through Collaboration," *passim*; Patricia Moritz, resume, NINR files.
 - 28 Merritt Testimony, "Hearings," Subcommittee on Appropriations, House of Representatives, March 17, 1987, 710.
 - 29 *Ibid.*, 711.
 - 30 *Ibid.*, 713.
 - 31 *Ibid.*, 711-12.
 - 32 Jacox, "The Coming of Age of Nursing Research," 279.
 - 33 Merritt Oral History, 41.
 - 34 *Ibid.*; see also, Angela Barron McBride, "Nursing Research: Coming of Age," *Grants Magazine* 11, no. 2 (June 1988): 64; Merritt Testimony, "Hearings," Subcommittee on Appropriations, House of Representatives, March 17, 1987, 679. The central NIH Office of Research Grants reviewed the Center's research applications. Note from Patricia Moritz, August 2008.
 - 35 Doris Merritt, "The National Center for Nursing Research," August 1986, 8, NINR Records, Box A, Folder: Notebook Prepared by Gerry Pollen.



As the leadership changed, **Ada Sue Hinshaw**, right, recognized **Doris Merritt** and her staff for their “remarkable” accomplishments “during the ‘start-up days.’”



Chapter 3

From Center to Institute: Nursing Research Comes of Age

When Doris Merritt agreed to become the acting director of the National Center for Nursing Research (NCNR), her job was to get the new Center solidly organized within the National Institutes of Health (NIH). But she was not a nurse, and there was wide agreement that a nursing professional should direct the Center. The director of NIH, Dr. James B. Wyngaarden, had insisted that Merritt initiate a search for a permanent director. Whatever the derogatory comments about nursing science from the NIH biomedical community, Merritt and the nursing community were determined to bring the new Center fully into the NIH orbit and earn nursing research the respect of other institutes on the Bethesda, Maryland campus. Finding the right person to become director was crucial to the future success of the Center and to the scientific opportunities of the nursing profession.¹

In September 1986 Wyngaarden, with Merritt's assistance, selected a search committee, headed by Dr. T. Franklin Williams, director of the National Institute on Aging. Williams, considered by many to be the father of geriatrics in the United States, had long been interested in the care of the elderly and had publicly recognized nursing's critical role in delivering this care. Over the years he had proved himself a good friend of nursing science and had supported

an institute for nursing within NIH. Consequently, Williams's selection pleased Merritt, the American Nursing Association (ANA), and many others within the nursing community. The committee drafted specifications for the job and began a nationwide search for qualified candidates in the fall of 1986. Merritt, Wyngaarden, and the search committee interviewed the finalists. After those discussions, one candidate emerged, Merritt recalled later, who was "head and shoulders above anybody else." In her mid-March testimony, Merritt told Congress that a nomination had been forwarded to Secretary of Health and Human Services Dr. Otis Bowen. She estimated that the new person might be on board by May. Congressman Carl Pursell (R-MI) wanted to know who it would be. "That is Ada Sue Hinshaw?" he asked. "Yes," Merritt replied, but, understanding the politics of the appointment, quickly added, "she has been nominated by Dr. Wyngaarden along with other candidates for Secretary Bowen's consideration."²

Merritt was overly optimistic by a month. Bowen announced the selection in June, and Wyngaarden swore in Dr. Ada Sue Hinshaw as the first NCNR director in the auditorium of NIH on June 24, 1987.³

Hinshaw possessed all the credentials to head the NCNR. She held a dual appointment as professor and director of research at the University of Arizona College of Nursing. She had received four major research grants from the Division of Nursing and was project director of the Biomedical Research Support Grant awarded to the university's Medical Center. She had Washington experience, including actively lobbying for the establishment of the NCNR. Hinshaw was a member of the ANA Cabinet on Nursing Research from 1980 to 1984 and chaired the cabinet from 1984 to 1986 as the Madigan amendment wound its way through Congress. She was a member of the National Institute of Mental Health Task Force on Nursing Research and the governing council of the American Academy of Nursing, as well as a registered nurse and a Fellow of the American Academy of Nursing. The nursing community held Hinshaw in the highest regard. In December 1985

she received the first Nurse Scientist of the Year Award from the ANA's Council of Nurse Researchers.⁴

Nursing was in her blood. The daughter of a nurse, Hinshaw was born and raised in small towns in southeastern Kansas. Following her mother's example, she went to the University of Kansas in Lawrence for two years and then to the Medical Center in Kansas City to earn a bachelor of science degree in nursing from the University of Kansas. At graduation, she was "capped" with her mother's nurse's cap. As she recalled, "it was always a foregone conclusion that I would do nursing." But unlike her mother, Hinshaw did not go to work in a hospital. Rather, she saw her career in higher education and entered the master's program at Yale University in 1965 because it offered strong clinical programs. At the time it never entered her mind to study nursing research, she said, but at Yale she had the opportunity to study with some of the early nurse researchers in the country, such as Drs. Rhetaugh Dumas and Jane Johnson. She also studied with two sociologists, Robert C. Leonard and Dr. Powhatan J. Wooldridge, who were teaching nurses interdisciplinary research techniques in behavioral science and social practice and applying them to nursing theory. Nursing science was just emerging, and Yale was one of the first in the country to offer nursing research, Hinshaw later recalled. "We were so new at this," she later observed, "we didn't have our own people or our own faculty."⁵

The pioneering program at Yale was, in the beginning, focused on the sociological, psychological, or psychiatric aspects of improving patient care. Leonard and Wooldridge were medical sociologists newly arrived in New Haven. Both were interested in health care delivery and began developing research agendas for nursing. Leonard had co-edited a book, *Social Interaction and Patient Care*, published soon after Hinshaw arrived at Yale. Wooldridge and Leonard would later publish a noted book, *Behavioral Science and Nursing Theory*. Dumas had been a psychiatric nurse for some time and later joined the Yale faculty as a research associate. She had earned "quite a bit of

credibility as a scholar and a scientist in the psychiatric world,” according to Hinshaw, and was doing a study that investigated the impact of preoperative teaching on postoperative stress. Dumas’s research, Hinshaw recalled, was “one of the first experimental studies ever done by nursing.” Hinshaw embraced the research courses and the whole process of entering a world of new scientific discovery.⁶

After finishing her master of science degree in nursing at Yale, Hinshaw returned to teach at the University of Kansas. After a year at her alma mater, she moved west to teach maternal/child nursing at the University of California, San Francisco. She also conducted educational research with Dr. Marlene Kramer, whose work focused on biculturalism and socialization for nursing. Hinshaw considered Kramer one of the strongest nurse research mentors in the country. Inspired by Kramer, Hinshaw realized that she could not rise in the research community without a PhD. In 1971 she moved to the University of Arizona in Tucson, attracted by its nurse scientist programs. Funded by the Division of Nursing at Health Resources and Services Administration (HRSA), the program at Arizona was one of nine in the country established in the early 1970s to train nurse scientists who would be capable of building nursing research programs elsewhere. After graduate school she focused on satisfaction modeling, integrating the processes of theory construction, research methodology, and statistical analysis with medical sociology and their applications to professionals and large organizations. In her dissertation she developed an anticipated turnover study to predict when nurses were going to leave a work environment because of bad circumstances. Working with Dr. Jan Atwood, she studied job stress, job satisfaction, group cohesion, clinical autonomy, and control over nursing practice, interviewing more than 1,000 nurses in urban and rural hospitals throughout Arizona to evaluate the impact of work environments on patient outcomes.⁷

To earn her PhD, Hinshaw changed her field of study to sociology. As an undergraduate she had taken one sociology course. To make up her deficiencies in the field, she enrolled in basic courses

while pursuing a master's degree. Completing an MA in sociology in 1973, Hinshaw was accepted into the PhD program. Her dissertation dealt with professionals in organizations and how they made complex decisions, something she considered a good combination of sociology and nursing and that reinforced the importance of the application of nursing research to nursing practice.⁸

After receiving her PhD in 1975, Hinshaw accepted a joint appointment at the University of Arizona between the College of Nursing and the University Medical Center. She wanted to continue her research, and having an appointment in the Medical Center was critical to its application. Later, she assessed how the dual appointment affected her career. "That was my laboratory. I was director of research for the College of Nursing and associate director for research over in the Medical Center. It was the twelve years that I spent in that dual position that made me think about how to focus and set up programs at the NCNR so that very tight, theory-driven research would have a practical application."⁹

From her base in Tucson, Hinshaw moved to the forefront of the push for more resources for nurse scientists. She worked extensively with the Council of Nurse Researchers and the Western Society of Nursing Research, and then ran successfully for a seat on the Commission on Nursing Research, the ANA's major policy group for nursing research in the country. In that capacity she made frequent trips to D.C. to lobby on behalf of nursing research and was among the leaders who pushed for an institute at NIH. Once the legislation for a national center passed, however, Hinshaw retreated from the national scene to concentrate on heading a large institutional research training grant at the University of Arizona. When she first learned that the National Center for Nursing Research was seeking a permanent director, Hinshaw was not interested. She said she loved her research and "didn't want much to leave it."¹⁰

Initially, Hinshaw did not apply for the opening. Nevertheless, her colleagues convinced her to apply. "They felt like NIH needed to

know the caliber of people that were out there,” she said. She agreed that she would “take a look at it,” but told her friends that “I don’t really want to leave and I don’t really intend to take it, so this is just to increase the pool.” She sent in her application, and the committee invited her to NIH for an interview. That went well, as did a follow-up interview with Doris Merritt. Her interview with Wyngaarden, however, was awkward, “as cool and formal as the furnishings in his corner office,” she remembered. Even though she had lobbied at NIH for a nursing research institute, Hinshaw had never met Wyngaarden. She did, however, have a sense of his research interests. To break the ice, she asked about his work on the biological mechanisms of gout but “received a very sharp answer” as though she should not have asked. Moreover, Hinshaw was nervous about the interview. “I was stilted because I wasn’t sure what I was doing there and didn’t expect to take anything if I was successful,” she recalled. “I went home thinking, well, that’s the end of it.”¹¹

A couple of weeks later, Hinshaw’s phone rang. Wyngaarden was calling to offer the job. She was dumbstruck, recalling her perplexing interview with him. After a long pause, she told the NIH director that “I didn’t expect you to call me and I didn’t think I’d be interested in considering this.” Wyngaarden laughed and told her to think about it and that he would call her back in a couple of days to discuss it. The casual manner of the phone conversation, so different from the interview, trumped the misgivings from the awkward first meeting. She spoke with her children, friends, and colleagues about the job and decided to take it. “It’s probably the biggest risk I’ve ever taken in my career,” she said in retrospect. “We knew we had a lot of people and organizations who really didn’t want us out there [at NIH]. I knew it was going to be a huge amount of work to show what nursing research was, and yet for all the risk it was such an exciting challenge and opportunity. I had so much invested in it, it was worth doing. I finally just couldn’t say no.”¹²

In selecting Hinshaw, Wyngaarden had picked an individual who believed passionately in the idea that nursing science could shape



NIH Director James B. Wyngaarden swore in Ada Sue Hinshaw as the NCNR's first director on June 24, 1987.

regional and national health policy. “Accurate information is basic to the ability to make knowledgeable and effective clinical and administrative decisions,” Hinshaw told an audience at the National Forum on Doctoral Education soon after she had accepted the NCNR directorship. She stressed that nursing research could provide this information through collaborating with clinicians or administrators and presenting these findings to policy makers. Nurse scientists needed “to synthesize research with societal needs and professional imperatives to influence health care policy,” she said. To do this, the profession had to identify “areas of nursing research that could be legitimately funded under the goals and objectives of existing federal programs.” She warned that in one study that examined the proposals submitted by nurse scientists to NIH, only approximately half of these matched the scientific interests of any of the national institutes. Nursing research proposals had to “become part of the current mainstream of health care research,” she said. “Our challenge is to develop strategies based on the growing body of knowledge in health care policy that relates to nursing science

and research.” Now Hinshaw had a “bully pulpit” to inspire a new generation to meet those challenges.¹³

Since the early 1980s, nurse scientists had argued that their research would help shape health care agendas and policy over the coming decade. In 1981 the Commission on Nursing Research of the ANA recognized that “the full potential of nursing’s contribution to health care is contingent on a scientific basis for clinical practice.” Moreover, it noted that “increasing attention is being directed to generating new knowledge through research and to providing mechanisms for ensuring its use in practice.” The Commission observed that “nurses are assuming increased decision-making responsibility for the delivery of health care and they can be expected to continue to assume greater responsibility in the future. Nursing research directed to clinical needs can contribute in a significant way to the development of these solutions.” The Commission emphasized that there was a symbiotic relationship between nursing science and biomedical research. “Biomedical advances,” the position paper argued, had led to greater numbers of those who required nursing care, “such as the frail elderly, the chronically ill, and the terminally ill,” and observed that nursing had to keep pace.¹⁴

Therefore, the Commission argued, nurses should give priority to clinical “nursing research that would generate knowledge to guide practice in promoting health, well-being, and competency for personal care among all age groups.” Nursing science could prevent health problems throughout life, decrease the negative impact on individuals’ ability to cope with health issues, develop appropriate strategies to meet the care requirements of particularly vulnerable groups, and design and develop health care systems that were cost effective in meeting the nursing needs of the population.¹⁵

While it continued to wrestle with an adequate definition for nursing research, the Commission could offer solid examples of research consistent with its priorities. Health care could profit from the “identification of determinants of wellness and health functioning

in individuals and families such as the avoidance of abusive behaviors including alcoholism and drug use, successful adaptation to chronic illness, and coping with the last days of life.” Nursing practice might also be better informed through studies analyzing the impact of anorexia, diarrhea, sleep deprivation, infection, diet, and chemical imbalance on the course of recovery. The Commission cited other areas for nurse scientists such as reducing stress from surgical procedures and intrusive medical examination and monitoring devices, providing more effective care to high-risk populations, especially mothers and infants, and enhanced care of “clients culturally different from the majority,” such as African-Americans, Mexican-Americans, and Native Americans. Other areas ripe for nursing research were those populations with special problems, such as teenagers, prisoners, and the mentally ill, and the underserved, such as the elderly, the poor, and rural residents. Finally, the Commission placed a high priority on the design and assessment of models for delivering nursing care strategies found to be effective in clinical studies.¹⁶

When the Commission on Nursing Research published its report on research priorities in 1981, its vice chair was Ada Sue Hinshaw. Not surprisingly, the new NCNR director’s top priority six years later was to set a national agenda for nursing.

Hinshaw used the occasion of her swearing-in ceremony to explain publicly her goals for the Center and how critical NIH would be in helping nursing accomplish them. Her audience was ideal for outlining her vision for the Center. Timed to coincide with the meeting of the Center’s scientific review panel, the ceremony included not only the entire review panel, but also several directors from other NIH institutes, including supporters Dr. Franklin Williams from aging, Dr. Anthony Fauci from infectious diseases, Dr. Ruth Kirschstein from general medical sciences, and Dr. Murray Goldstein from neurology. Hinshaw explained that the NCNR’s “union with the National Institutes of Health...allows for nursing research to be developed [and] conducted in collaboration with the other scientific disciplines

in a complementary manner. In this environment, nurse investigators will be able to capitalize on NIH's tradition of scientific excellence and numerous alternatives for research support." With adequate collaborative and interdisciplinary support, she said, nurses would "continue to build a solid, high-quality body of nursing science."¹⁷

Hinshaw then turned from NIH to the vital role the nursing community itself would serve in incorporating nursing research into the broader base of health care science. The NCNR's National Advisory Council had recommended several program initiatives, she said. Importantly, the Center's first initiative—the development of a national nursing research agenda—came from those recommendations. With extensive input from the nursing community, the NCNR would assess the major health needs of society and the current state of the discipline and then outline priorities for investigators. From this assessment, the nurse scientists envisioned a five-year plan identifying the programs to be developed and the resources needed for their implementation.¹⁸

A second initiative Hinshaw announced that day involved increasing the research training opportunities "for nurses who are committed to careers as scientists." The NCNR, Hinshaw vowed, "would emphasize funding for postdoctoral and predoctoral fellowships and institutional HRSA awards." The aim, she stated, was eventual growth in the career development award programs.¹⁹

Another major priority, Hinshaw said, would be increased collaboration with the other institutes, divisions, and centers within NIH. Using the speech to clarify the nature and activities of nursing science at NIH, she explained how nurse investigators synthesized knowledge across disciplines. "The scientific networks within the Institutes offer innumerable opportunities for collaboration in research of mutual concern," she stated. Hinshaw cited a successful cooperative program on incontinence that the Center had done with the National Institute on Aging as "an excellent example of inter-institute collaboration involving a major 'care' problem of concern to the elderly in our society." Her comment was both a public appreciation for institute director Franklin

Williams and his longtime support for nursing at NIH and an appeal to other institute directors to bring in nurse scientists and stretch their research program dollars.²⁰

Hinshaw's swearing-in remarks not only outlined for her new NIH colleagues the aspirations of nursing, but also how nursing science was an integral part of the NIH mission. She recognized Doris Merritt and her staff for their "remarkable" accomplishments "during the 'start-up days.'" Merritt's leadership and "commitment to excellence" had already brought the NCNR considerable stature within NIH. "You have my pledge of commitment to facilitate the efforts of our discipline's scientific endeavors," Hinshaw told the gathered NIH leadership and the nursing community, "through the investment of intellectual and leadership capabilities in promoting the continued development of the NCNR...and to realize our profession's vision of bringing nursing science into the mainstream of health care research at NIH."²¹

Hinshaw quickly settled into her new job. She moved into a house on the NIH campus, near her office in Building 31. In one sense, living on campus near others in leadership roles symbolized her intent to integrate nursing science into NIH. It gave her access to this group outside of official duties and, she hoped, would make nursing science more acceptable to the biomedical scientists that had opposed the Center. On her first day she met with Merritt, Doris Bloch, Adele Woods, Patricia Moritz, Harriet Carroll, and others to get a sense of the issues. "It was not a huge day," she recalled, "but I was very excited." Within a few months, she knew she had made the right decision.²²

As she tried to integrate the NCNR more fully into the NIH network, Hinshaw believed it was essential that the Center provide leadership within the nursing community. She discussed this at length with Williams, Merritt, and Kirschstein. They told her they doubted that nursing science could emerge from individual studies by nurse investigators. Hinshaw agreed. Such studies lacked a central purpose,

something nursing science needed to develop if it were to be an integral part of NIH. She queried them about setting agendas to build nursing science. That must be done, they said. In addition, they advised that the Center would eventually need to show Congress what it was achieving. Focusing resources on a few priorities would provide those outcomes. At the time, nurses were “well-educated and prepared, but had relatively little [research] experience,” she recalled. “We needed to focus our endeavors.” As long as nursing research followed the interests of the individual researcher—a “shotgun” approach—the profession could not build science over time. Groups of studies needed to be validated in order to build, one upon the other. What nursing needed, Hinshaw determined, was a national agenda, and the NCNR would provide the vehicle to draft the priorities for that agenda.²³

In the fall of 1987, the NCNR announced its intention of setting a national nursing research agenda. Hinshaw envisioned it as a five-year plan, expanding the numbers of nursing scientists and focusing on nursing research priorities until the end of 1992. Working with Doris Bloch, she mapped out a two-year planning process that would define “initiatives to provide a structure for selecting scientific opportunities and a knowledge base for nursing practice and to give direction and momentum to research within the nursing discipline.” None of this could be accomplished, she believed, without the full involvement of the nursing community, which had to participate fully in setting the agenda. She invited the top sixty research scientists in the nursing profession—“seasoned investigators,” Hinshaw called them—representing as many fields and methodologies as possible, pointedly moving away from those in nurses’ training toward those in nursing education and research training. Early in 1988, the NCNR brought them to Bethesda under the auspices of the first Conference on Nursing Research Priorities and installed them at the Hyatt Hotel with the goal of developing a national nursing research agenda “to provide structure for selecting opportunities and initiatives and to promote depth in developing the knowledge base for nursing practice.”²⁴

Working in conference rooms in the basement of the hotel, the nurse scientists broke into small groups, first according to specialty areas, and then in groups that crossed specialty lines. For two and a half days, the conferees focused on identifying research priorities and, at the same time, defining the direction of nursing science. The Center established three major criteria for setting those priorities. First, the agenda had to focus on a critical public health problem in the country. Second, the nursing research had to be applicable and make a difference. And third, the nursing profession had to have the investigators able to conduct appropriate studies. “We were a little thin in places,” Hinshaw said of that period. “A lot thin in some places.” During the conference, the participants met in groups representing various combinations and permutations of interests to rank research priorities, establish an agenda for nursing that focused on science, and devise programs for beefing up those thin spots.²⁵

According to Hinshaw, in addition to formulating a national nursing research agenda, one other important professional change emerged from these discussions. For years nurses had talked about issues for research but had stalled in debates over whether qualitative or quantitative research was better. As more research funding became available, Hinshaw believed that nursing could ill afford to be mired in this controversy. It had to embrace more quantitative research. She knew that NIH had long advocated Lord Kelvin’s statement that “when you measure something and express it in numbers, you know something about it.” Hinshaw translated this to nurses “have got to focus on science.” She told the group to “get over [the debate] and move on.” She was relieved with the ease in which the nurses accepted her suggestion. “They did it beautifully,” she recalled. Nursing came to embrace a more quantitative approach to research as a result of the meeting. “It was very important for us to focus to both build science and to explain nursing science to NIH. As we began to define areas of research, we told NIH who we were and what nursing research was. So the agenda emerging from the meeting served to educate as well

and, I think, make people at NIH and the Congress feel much more comfortable.” The ultimate value of nursing research, most agreed, was to “create knowledge about the relationships and interactions between persons and their environments, which results in recognizable changes in health status.”²⁶

The broad priorities coming out of the Bethesda conference went to a subcommittee of the National Advisory Council for Nursing Research for further consideration and development. From there, expert panels consisting of scientists from nursing and related disciplines refined and elaborated on the priority areas that might give nursing the greatest impact in improving health care and therefore merited research funding. The National Advisory Council then sent its recommendations to Hinshaw.²⁷

The priority-setting process moved on a very fast track, taking less than five months. The National Nursing Research Agenda identified seven priority areas for nursing science, most cutting across areas of nursing research to integrate behavioral and physiological measures. The NCNR announced its interest in receiving proposals for studies that identified health risk factors, designed educational and intervention strategies to reduce health risks, and determined the efficacy and cost effectiveness of health prevention methodology. The Center urged that proposals focus on the seven priority areas: (1) low birthweight infants and their mothers; (2) HIV positive patients, partners, and families; (3) long-term health care for the elderly; (4) symptom management, such as intervention strategies for pain and other symptoms associated with acute and chronic illness; (5) health promotion to modify behavior for reducing risk factors; (6) family adaptation to chronic illness; and (7) improving the quality of life during chronic illness. The nursing community agreed that all of these areas demanded additional study by nurse scientists. Soon after establishing the research agenda, the NCNR called for proposals in those areas of science, allocating about 35 percent of the Center’s funds to two of the priority areas in the first year. The two target areas recommended by the Center were

the psychological and physiological aspects of care and caregiving for patients with HIV positive conditions and their families and the prevention and care of low birthweight infants.²⁸

Even as the National Nursing Research Agenda evolved over the next year, the NCNR needed to demonstrate to Congress the value of its activities. Budget appropriations were the lifeline that nourished the Center's development, and the appropriators demanded evidence of leadership, progress, and accomplishment to sustain and strengthen its support. The Center's budget request for the following fiscal year (FY) 1989, depended in part on presenting convincing proof of the Center's achievements. For a new entity just initiating funding for multiyear projects, however, it was easier to explain how nursing science was meeting current challenges and working toward specific goals than to outline specific accomplishments.

Hinshaw traveled to Capitol Hill with her staff and Wyngaarden to testify for the first time before Congress in the spring of 1988. The room was packed with proud nurse scientists, "probably the only people in the room," Hinshaw recalled, "because we had everybody else crowded out." Although she faced a very friendly and solicitous subcommittee on health, headed by Democrat William H. Natcher of Kentucky, she recognized the importance of making a strong, positive impression. Natcher's subcommittee was the first line in appropriating funds for NIH and the subcommittee largely viewed its role as an advocate for the institutes, so few of the questions came as a surprise. No one wanted to make the new director's maiden voyage before Congress a rough one.²⁹

Hinshaw thanked the committee for its "vigorous support of nursing research" and outlined current challenges facing the nursing community and how the NCNR planned to tackle them. The Center had started "a strenuous formal and national process of identifying research priorities for nursing science," she said, referring to the National Nursing Research Agenda. In addition, the Center was expanding the cadre of nurse scientists committed to research careers

and developing programs to “increase the physiologic and biomedical content of the research.” To accomplish this, the NCNR publicized its goals and initiatives to the nursing community. She highlighted three promising scientific developments emerging from NCNR-supported research. One was a study of pressure sores, commonly known as bed sores, in hospitals, nursing homes, and the home. The research, she explained, found a significantly higher incidence among elderly residents with lower intakes of protein, calories, iron, zinc, and folic acid. “The long-term significance of this research,” she said, “will be its contribution toward accurately predicting elderly persons at risk for developing pressure sores, and aiding in the development of preventative nursing therapies.”³⁰

The second study involved insomnia and other sleep disorders, which impaired tissue healing and immune function and increased the susceptibility to lesion formation. The incidence of insomnia was as high as 35 percent in adults, Hinshaw explained, and occurred more frequently in women as they grew older. Nurse scientists learned that emotional upheaval, more than hormone changes, may affect sleep patterns in women approaching menopause. This was just one example, Hinshaw said, of the “kind of study that will assist health professionals to identify specific factors responsible for sleep disorders.”³¹

The third focused on urinary incontinence, which health care professionals considered a major problem, especially in nursing homes. Incontinence, normally associated with aging, was the principal cause of nursing home admissions. Incontinent elderly persons tended to withdraw from social activities and increase the burden on those who provided care, Hinshaw told the committee. Moreover, incontinence was one of the most disruptive and costly conditions that affect nursing home patients. The NCNR was supporting research to develop treatment, technologies, and procedures with the potential for reducing the incidence and complications of incontinence, thereby reducing the cost of managing those patients and alleviating the personal and social consequences of the condition. One technology the nurse scientists

were assessing was a noninvasive electronic device to establish a patient's pattern of voiding. "This pattern is then used as a basis for an individual continence training program," she said.³²

Nonetheless, even by 1988, some members of Congress remained confused by the changes nursing science had brought to the profession. They were still unclear about the differences between the programs of the NCNR and the Health Resources and Services Administration (HRSA). Clarification was critical for the new Center to establish its own identity both on Capitol Hill and in the biomedical community. HRSA, Hinshaw carefully explained, funded the education of nurses. The NCNR had responsibility for the conduct, support, and dissemination of research and research training associated with patient care. The Center's programs focused on "health promotion and disease prevention, understanding and mitigating the effects of acute and chronic illnesses and disabilities, and the delivery of nursing services. Nursing research," she continued, "examines the biomedical and behavioral processes that underlie health and the environment in which health care is delivered."³³

The most vocal supporter for nursing on the subcommittee was Carl D. Pursell, who represented Michigan's Second District, which included the Detroit suburbs and Ann Arbor, and was the ranking Republican on the House Labor-Health and Human Services (HHS) appropriations subcommittee. Described as "ruffled, chatty, usually inclined to seek consensus but ready to speak out when aroused," he became a leader of the "Gypsy Moths," a group of moderate Republicans who opposed the Reagan administration's budget cuts for social programs. Pursell had long been an advocate for NIH and, more recently, Madigan's ally in first calling for a National Institute of Nursing Research (NINR) and later in establishing the NCNR. He called the institutes "The Untouchables" when it came to funding from the appropriations subcommittee and emphasized to Wyngaarden how proud he was of the development of the Nursing Center at the University of Michigan. He saw himself as close to the nursing community and understanding of



Ada Sue Hinshaw and Representative Carl Pursell (R-Michigan) amid stacks of grant applications at the NCNR offices.

its needs. Pursell also realized how far a single legislator could push his own agenda through pointed questioning at budget time.³⁴

Indeed, Pursell claimed some ownership or direct paternity for the Center's birth, referring to it when speaking with Hinshaw as "our center." The NCNR represented an area of interest to him, and the nursing groups helped him to prepare for the hearings. He phrased his questions in part to highlight the value of nursing science and in part to anticipate the Center's funding needs to carry out its developing five-year plan. He worried that the Center might not be able to meet the desired number of nursing research trainees in 1988—the National Academy of Sciences recommended 320—and still maintain a high-quality performance. Prepared for the question, Hinshaw explained that the NCNR was, "first of all, committed to funding good science and excellent applicants." As a result, the Center was funding fewer nurse scientists than the National Academy had proposed but

planned to reach the recommended level in 1991, pending available funding. Hinshaw explained that “we are obviously trying to balance the training endeavor in relation to research grant support.” Satisfied with the response, Pursell moved to another, somewhat controversial, topic—intramural research.³⁵

The underpinning of basic science at NIH was its reputation for pioneering intramural research programs within the institutes and centers. Such programs allowed experts to devote full time to their research, unencumbered by teaching or other duties. Intramural research programs defined many institutes’ standings in the biomedical world—the higher the quality of the program, the greater the reputation of the institute, or so it was perceived by many. The NCNR, however, had no intramural program in the years following its creation. Pursell asked Wyngaarden if he would support an intramural program for nursing so that it might be on par with entities at NIH. Wyngaarden demurred, instead praising the Center for its “very soundly planned” extramural program. “I think the center has come along very, very well, both during the period when we had a temporary director, and since Dr. Hinshaw has arrived.” Since the NCNR’s programs placed “a heavy emphasis on developing collaborative work with other institutes,” Wyngaarden said, “I think the extramural program...can grow over the years, resources permitting.” But, he continued, as a result, the “NCNR does not need as large a staff as some of the other centers that have laboratories since much of this is collaborative.” In effect, he told Pursell, any intramural program for nursing was not a priority and would need to wait.³⁶

As Kirschstein, Merritt, and others had warned Hinshaw, she would need to demonstrate to Congress the accomplishments of the Center. FY 1987 was the first year that all new grant proposals were received, reviewed, and awarded under the auspices of the NCNR and NIH, rather than HRSA, though the Center continued to fund awards originally made by HRSA. And though it was premature to identify specific scientific accomplishments made possible by the Center’s

grants, Hinshaw did outline the areas in which the Center was working—areas of research in the nursing community and areas that spoke to the interests of the subcommittee members.³⁷

One research area involved cancer. The medical community had long recognized that a diagnosis of cancer created an immediate crisis for patients and their families. As patients underwent radiation therapy, used in some 50 percent of cancer patients, they experienced side effects, depression, and anxiety, frequently becoming preoccupied with fears of disability and possible death. Nonetheless, little scientific research had been done to see how the problem might be mitigated. Under an NCNR program, researchers developed a three-tape video program that presented information about radiation therapy, common side effects and approaches to management, and hospital and community resources. Nurses ran the first tape prior to treatment, the second during the second week of treatment before the onset of side effects, and the third during the final week. “An assessment of patients’ comprehension has shown a high level of understanding of all these programs and has documented the usefulness of the program as an effective educational intervention,” Hinshaw told the subcommittee. The NCNR, she maintained, was also seeing progress in programs relating to health care for elderly in nursing homes, insomnia in women, and health-compromising behaviors such as early sexual activity, cigarette smoking, drug and alcohol use, and excessive food and caffeine consumption.³⁸

Finally, Hinshaw explained that the NCNR vigorously supported research activities related to HIV/AIDS, a scourge that held wide attention in the late 1980s as a major public health concern. In 1988 the Centers for Disease Control reported some 42,000 AIDS cases in the United States. The number of deaths from this group was almost 25,000, leading to “conservative estimates” that between 2 million and 4 million Americans would be infected with HIV by 1991, she said. Unlike cancer patients, who experienced a steadily declining illness trajectory, the disease trajectory for AIDS patients tended to be up

and down, up and down, throughout its downward trend. Nurses, one expert said in a presentation to nurse researchers in 1988, needed to learn more about how to “help persons cope with the affective stages of AIDS, denial, depression, anxiety, and ultimate death.” With an AIDS epidemic on the minds of many Americans, nursing science was moving to respond. The NCNR encouraged investigator-initiated research that addressed AIDS as it related to nursing and would make its first grant awards for this in FY 1988. The Center also collaborated with the National Institute of Allergy and Infectious Diseases (NIAID) to sponsor a national outreach conference for health care practitioners, including nurses and social workers, to provide “accurate, relevant, and timely information on issues associated with AIDS and the care of AIDS patients and their families.”³⁹

Each of the programs sponsored by the NCNR provided an example of the direction in which nursing science was moving—symptom management. Researchers had studied pain or fatigue or some other area, Hinshaw recalled, “but had not clustered them in the sense of symptom management. That was, essentially, a new kind of cluster of studies that nursing began to evolve. Symptom management was a term that we pretty much coined and worked with, but it was not a well-used term like it is today.” Rather than focusing on cancer or a type of cancer, nursing looked at how one assesses and manages symptoms, such as how patients could better deal with pain, fatigue, hair loss, and the like. The same was true for the care of HIV/AIDS patients. “If you’re talking about care of,” Hinshaw said, “then you’re talking symptom management. That goes across any field.”⁴⁰

Hinshaw requested a budget of \$24,400,000 for the Center’s activities in FY 1989, an increase of \$1,530,000 from the previous year. The fund obligated for nursing research would be \$22,257,000, which would fund forty-five competing and eighty-four noncompeting research project grants, a number of career training awards, nearly 200 research fellows, and institutional training grants for fifty-nine individuals. The balance of the money, about \$2,000,000, a bit less than

10 percent of the amount targeted for research, would go to research management of the extramural programs and additional administrative support, approximately the same percentage as for all of NIH. Funding for AIDS research, a priority area for the NCNR, totaled an additional \$700,000 and was to come out of a general NIH appropriation request for AIDS of \$1.3 billion.⁴¹

Hinshaw was pleased with the Center's accomplishments in its first years and its potential to shape the future of nursing science at NIH. The nursing community had united behind the Center and established a national research agenda. True to predictions, the creation of the NCNR had raised the profile of nursing science, introduced the concept to the biomedical world of NIH, and attracted more funding and underwrote more grants than ever before. The results were a testament to Merritt's administrative savvy, Hinshaw's leadership, and the enthusiastic response of the nursing community to create a focused agenda for nursing science.

Over the next five years the National Nursing Research Agenda set the guidelines for nursing science, and Congress supplied the funds to achieve those goals. At times the NCNR tweaked the agenda to meet the immediate health concerns of a member of Congress, but the agenda was broad enough to accommodate these changes, even if they spread the Center's funding more thinly in other areas. Nevertheless, when it came to the National Agenda, the professional nursing organizations and their congressional allies continued to be effective lobbyists for additional money for scientific studies.

The congressional budget hearings in the spring of 1990 provided an opportunity for the NCNR to demonstrate clearly the impact and effectiveness of the National Nursing Research Agenda and the development of an expanded knowledge base for nursing practice. These hearings were especially important, as the budget for the following year was essentially flat. Hinshaw related the "considerable advances" that the Center had made between 1989 and 1990. In particular, she noted the completion of the reports of the first two priority expert

panels for nursing's national research agenda and the development of research initiatives in both areas. The first major nursing initiative had concentrated on the prevention and care of low birthweight infants, including preconception care, prenatal care, hospital care, and follow-up care of the infant and mother after discharge. The studies were testing the "effectiveness of prenatal and postpartum nurse home visitation services as a means of enhancing the health and well-being of unwed poor women and their first-born children" in urban and rural areas.⁴²

Hinshaw was especially proud of the research that the NCNR had sponsored in the area of very low birthweight infants (VLBWI). The NCNR "probably put more money into low birthweight...in the first several years. That was a major public health problem for the country at that time. We tried to get better programs by which people could prevent low birthweight infancy or care for low birthweight infants." In response to an anticipated change in the federal payment system enacted in 1983 that encouraged early hospital discharges to save health dollars, nurse scientists led by Dr. Dorothy Brooten, then at the University of Pennsylvania, recognized that the early discharge of vulnerable patients, such as VLBWI, posed health risks and the potential for increased health care costs due to complications and readmissions. Brooten and her colleagues developed a transitional care model that demonstrated the cost effectiveness of a comprehensive intervention program that included counseling of parents and home follow-up by nurse specialists, thereby creating a "feasible model of care and a new role for master's-prepared advanced practice nurses." The results were remarkable. The program improved the infant's environment, was safe and effective, and "saved approximately \$18,560 per infant in hospital and physician costs." A later study funded by the NCNR built on Brooten's work. Another researcher, Hinshaw said, "got drastic difference between low birthweight infancy rates for women who had continuous telephone call contact and ones who did not," thereby establishing that patients could go home faster and cheaper from the



Improving the care of low birthweight infants and their mothers was one of seven priority areas identified by the National Nursing Research Agenda in 1988.

hospital “as long as you had advanced practice nurses who made one home visit and then all the rest were phone calls.”⁴³

The second major program initiative was AIDS. In 1988 the Center had established a new collaborative intramural research program on symptom management for AIDS patients with NIAID and the NIH Clinical Center Department of Nursing. This initiative, set up along cooperative lines suggested by Wyngaarden in 1988, marked the first time that the NCNR would test the waters of intramural research at NIH. The AIDS collaboration was ideal for initiating an intramural research program for nurses because many Americans considered the AIDS epidemic as one of the major health challenges facing the country. “We are strongly committed to research on the physical, psychosocial, and ethical problems central to prevention of HIV infection,” she said. Hinshaw explained that the NCNR nurse scientists would “quantify changes in nutritional status and then develop nursing interventions to minimize the nutritional problems such as anorexia, nausea, and weight loss.” As AIDS patients lived

longer, she said, nursing research was critical to “discover ways to decrease the morbidity, and to diminish the economic and personal costs of this infection and to promote an optimal quality of life.” This early intramural program, conducted out of the Office of the Director of NINR, provided the foundation for the Clinical Therapeutics Laboratory.⁴⁴

The NCNR could boast of other accomplishments beyond the major priorities. In 1988 the Center established four centers for nursing research, a program pushed by Pursell. Two were specialized centers for nursing research, each funded at a level of about a half-million dollars; the other two were called exploratory centers, which were funded at a much lower level, a bit more than \$100,000 per year. The first specialized center, established at the University of Washington, supported research with an emphasis on women’s health. The NCNR funded a second specialized center in 1989 at the University of Pennsylvania, which concentrated on behavioral research on patient care. One promising study at Penn that was in the center, Hinshaw told the members of Congress, emphasized the depressive signs and symptoms experienced by stroke patients. The results, she said, “should give nurses the ability, through the development of a new instrument for detecting depression, to make timely referrals for treatment.”⁴⁵

The research centers program attracted considerable attention from the nursing community, and competition for funding was fierce. The NCNR received eleven applications for specialized centers and awarded two; of the thirty-two applications for exploratory centers, the NCNR selected only two—one located at the University of Pittsburgh, which concentrated on critical care nursing, and the second at the University of Minnesota, which specialized in long-term care of the elderly, “particularly factors that influence the autonomy and independent functioning of older persons.” The National Advisory Council on Nursing Research recommended that the number of centers be increased over the next five years to eight specialized centers and eleven exploratory centers.⁴⁶

One central element of the NCNR's research initiatives was training new investigators. Since the idea of a nursing research institute gained traction in the early 1980s, the advocates of scientific nursing research had worried that the profession had too few scientists to be readily accepted by NIH. Rhetaugh Dumas and Geraldene Felton had advanced that argument in opposition to a proposed national institute for nursing research. The nursing community and its allies in Congress saw the NCNR as the leader in developing new investigators in nursing science. The Center emphasized increasing the number of trainees, building postdoctoral programs, and encouraging more minority nurse scientists. In its first year of operation, the NCNR supported 171 trainees. The following year, FY 1988, the Center funded 194 trainees through National Research Service Award fellowships and institutional training grants. In 1989 the Center supported 228 trainees. By 1990, though, the lack of funding forced the Center to cut its research training goal from 270 to 257, still well below the 320 nursing research trainees recommended in 1985 by the National Academy of Sciences. Hinshaw said that the NCNR planned to increase the proportion of postdoctoral trainees under a new Nurse Scientist Program. Similar to the Physician Scientist and Dental Scientist award programs of other NIH institutes, the Center intended to build a "cadre of clinical nurse researchers with a background of rigorous scientific training."⁴⁷

Over its first few years of operation, the bulk of the NCNR's funding went into research on health and behavior, which had always been a strong interest for nurse scientists for whom public health applications had long been an important focus. Forty-seven percent of the Center's extramural funds were targeted for this research. The area held great promise for improving health and preventing disease, since many current public health concerns were the result of lifestyle choices and behaviors. To Hinshaw, nursing science was "very family and community oriented, so from our disciplinary perspective, we roll those two together very easily." The Center supported research studies to prevent and lower the risk of illness and strategies to manage the symptoms of

diseases and their treatment. One major longitudinal study examined risk-taking behaviors relative to overeating, drug use, early sexual activity, and smoking in rural adolescents. Congress had allocated an additional \$600,000 for rural health care the year before, and Hinshaw emphasized the importance of developing and evaluating community-based rural nursing practices for underserved populations. With the more limited funding for these types of projects anticipated for 1991, Hinshaw encouraged the Center to partner with the Division of Nursing in HRSA and the newly created Agency for Healthcare Research and Quality to fund two or three proposals on rural health care.⁴⁸

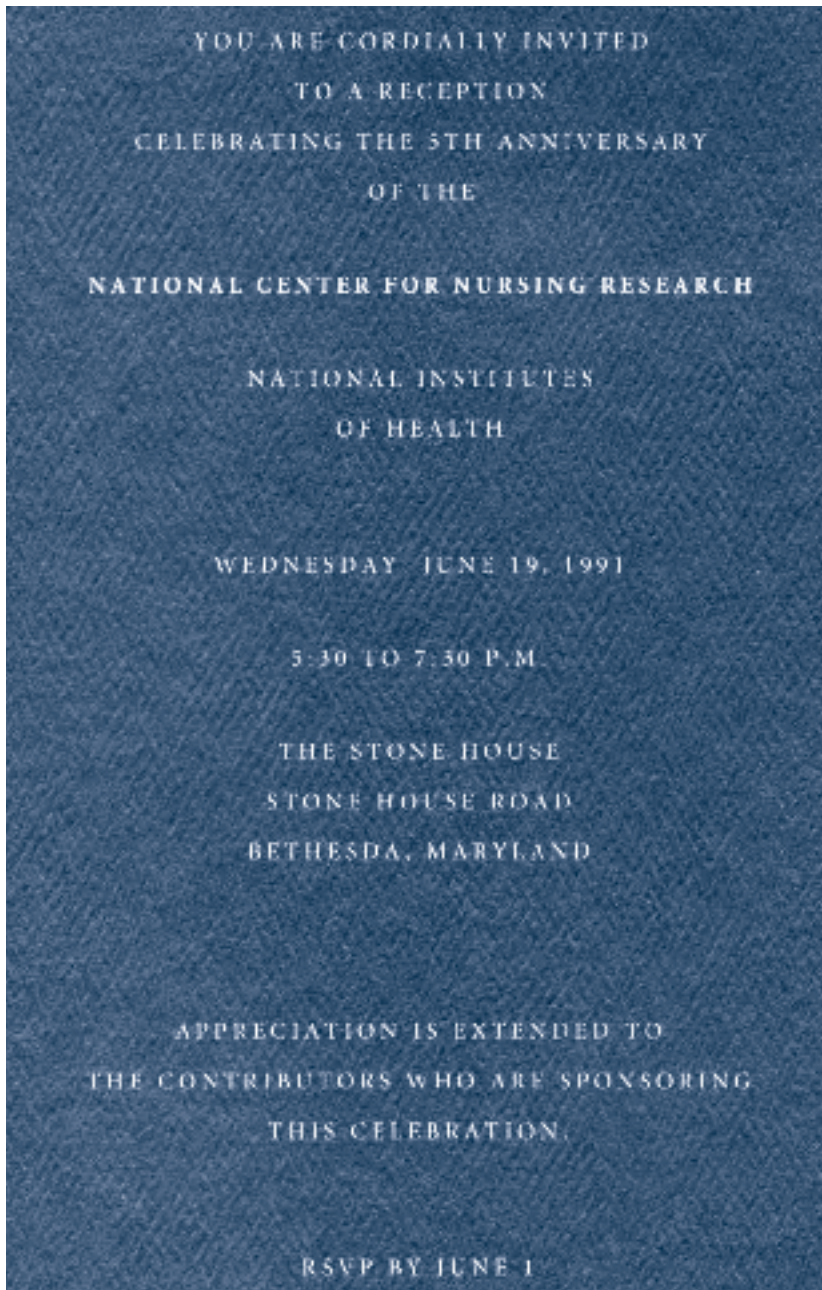
The most notable impact of the flat administration budget was the decline in competing research grants, or newly funded research initiatives. In its first year, 1987, the Center awarded forty-eight such grants. The number increased to fifty-two in 1988 and then dropped to fifty the following year. In 1990 the Center awarded forty-five grants, but in 1991, Hinshaw said, the number would drop by a third, to approximately thirty-three competing grants. The award rate for nursing grants, that is, the number of awards versus the number of applications, was 12 percent, less than half of the award rate for the rest of NIH. To achieve parity with the other institutes, the NCNR would require an additional \$10.3 million over the President's budget request for FY 1991. "Being a young program, we have been supporting a rapidly growing number of outstanding scientists who are now receiving noncompeting continuations," or previously funded multiyear projects, Hinshaw explained, making a case for the importance of new, emerging work. As a result, she noted, "we are using an increasing portion of our research project grant funds to support the noncompeting portion of our portfolio."⁴⁹

If additional funding were available, Hinshaw allowed, the NCNR would increase the number of competing research project grants to match the NIH-wide award rate, add three specialized centers and four exploratory centers, increase the number of trainees and research career awards, initiate a collaborative program with the NIH Clinical

Center for nursing research with HIV-positive patients, and expand the Center's staff to handle the increased administrative responsibilities, which had been kept below authorized staffing levels to offset some of the costs associated with starting the Center. Hinshaw estimated that the NCNR would need to phase in over three years an annual budget of \$132 million to "facilitate the rapid momentum of the nursing research community and to handle the backlog of questions that need to be addressed to improve nursing practice." According to Hinshaw, "this would enable [the NCNR] to attain a funding level close to that of some of the smaller research institutes at NIH."⁵⁰

Hinshaw's comment drew quick attention from Representative Pursell. While all members of the subcommittee supported the programs of the NCNR, Pursell was nursing's constant champion. He embraced the role as the major financial advocate for the NCNR, and his position on the HHS appropriations subcommittee put him in the right place to be effective. In the spring of 1990, Pursell began a campaign to garner above-average annual increases in the NCNR's appropriation to "jump-start" funding for nursing science. He had learned from Rhetaugh Dumas, the dean of the University of Michigan School of Nursing, that "excellent proposals were overwhelming the dollars available." She briefed him on the newly funded projects at the School of Nursing and followed up with a tour to meet the nurse scientists. Pursell mulled over what he had learned. Looking at a ranked order of the various NIH budgets, he noticed that the two organizations ranked above the NCNR were the newly organized Division of Research Resources and the new National Institute of Deafness and Communicative Disorders, both of which were funded at \$122 million per year. The NCNR's budget for FY 1990 was \$33 million. He believed that nursing should have budget parity, or at least closer levels of funding, with those organizations. The question was whether the Center could handle any additional funding.⁵¹

Pursell put this issue to Hinshaw when she appeared before the committee. He was proud of the NCNR's accomplishments and



The NCNR's staff was very proud of the Center's accomplishments in its first five years.

particularly fond of a photograph showing him among high stacks of applications. “What level of funding do you need to be at three years from now...to be brought up-to-par with the more established institutions?” he asked. She said that the NCNR could spend \$50.3 million on quality research in FY 1991. She had learned during the struggle to establish the Center that “when you have an opportunity in Washington, you jump.” Following that principle, Hinshaw told the subcommittee that an estimated \$132 million might be an appropriate funding level for FY 1994.⁵²

Not all nurses agreed with Hinshaw’s optimistic vision of nursing’s research capabilities. While all agreed that the quality of research proposals meriting funding warranted such appropriations, the reality was that the nurses did not have a long-term strategy other than to expand existing programs to absorb such elevated funding. The Council of Nurse Researchers thought that the NCNR could handle an appropriation of a little more than \$41 million, what it termed an “eyebrow raising” increase of 20 percent in comparison with other NIH units. Nonetheless, the Council estimated that even at \$41 million, less than one-fifth of the approved grants would actually be funded.⁵³

Pursell worked hard to guarantee that “his” center would succeed. He pushed Dr. William Raub, then the acting director of NIH, for more research dollars for the NCNR. His staff urged nursing groups throughout the country to convince their representatives to learn more about nursing research, to tour local nursing research projects, and to learn how nursing applied to public policy concerns and the cost savings that would accrue from the research. They asked nurse scientists to use their universities’ public relations staffs to get their research covered in the national media. The Council of Nurse Researchers backed Pursell’s efforts to expand legislative interest in major funding increases for the NCNR with an additional lobbying effort of its own through nursing political action committees in most congressional districts.⁵⁴

While the NCNR could not lobby, it could demonstrate to policy makers and others the value of its sponsored research. As nurse

scientists began to get substantiated findings from their research, the NCNR and the professional nursing organizations began to use those accomplishments in testimony to Congress, rather than tell the members what the next year's plans would be. The Center circulated the results widely in publications and other local and national media outlets. The effort, Hinshaw later said, paid off. The NCNR was able to establish "this area of important education of other colleagues [and the public] as to what nursing research was about."⁵⁵

Never far from Pursell's mind was the future of the Center becoming an NIH institute as Madigan originally planned. Pursell recognized that to maximize resources for nursing science, the Center would need to obtain institute status at NIH. He introduced legislation assuring that institute status was contained in the National Health Revitalization Act of 1991. Although President George H. W. Bush vetoed the bill for reasons unrelated to the NCNR, Pursell's bill rejuvenated the campaign to promote the designation of the Center to an institute, a goal never far from thought for Pursell or the nursing lobby. Hinshaw, too, continued to advocate for a nursing institute. Since the establishment of the NCNR, the budget for nursing research had tripled. She believed that this extensive growth had occurred in large part because nursing science was part of NIH. If nursing could achieve institute status, she thought, nursing's funding potential could increase even more. Writing in the summer of 1992 to Charles A. Meyer, an editor of the *American Journal of Nursing*, she noted that "obtaining institute status will have a significant impact on [funding]." Further, she explained that there were occasions when it was detrimental not to have institute status. "A recent example of the difficulty associated with being designated as a Center occurred when the NIH Director was allowed to request transfer authority of funds appropriated for cancer research and Alzheimer's disease research to those research institutes of the NIH that had meritorious scientific proposals for research in those areas." Although the Center had an approved proposal for Alzheimer's research, she noted, the

“NCNR was unable to receive any of the funds since it was a ‘center’ and not a ‘research institute.’”⁵⁶

Even as nurse scientists chafed at the delays blocking the NCNR from becoming a full-fledged institute at NIH, there was no doubt that nursing research was taking enormous strides. In two decades the number of nurse scientists had grown from 500 to more than 5,000. At the beginning of 1978 there was but one nursing research journal in the United States, *Nursing Research*, which began publication in 1952; by 1992 there were more than seven. This growth in the number of research journals was critical to the profession. They not only published scholarly investigations, but also influenced society via their editorials and essays. For the nursing community, the creation of the NCNR marked public and professional recognition of the utility, diversity, and credibility of nursing science. Since the inception of the NCNR in 1986, funding for nursing research had increased from \$16 million to more than \$48 million, a threefold increase, by 1992. Moreover, the politics surrounding health care in Washington had changed considerably. Congress gave budget increases for the NCNR only grudgingly during the Reagan and Bush administrations. The Clinton administration, which took office in January 1993, gave a new impetus to health care research. Not unimportantly for the nursing profession, whose members were 95 percent female, President Clinton appointed women to the two top health roles in the country: Dr. Donna E. Shalala was confirmed as Secretary of HHS and Dr. Joycelyn Elders, a physician and former nurse’s assistant, was appointed Surgeon General, the first African-American to hold that position.⁵⁷

Internally, the NCNR had moved to more closely align its operations with the NIH institutes in order to demonstrate the quality of its science. While the Center had successfully built an extramural program, funding research projects at institutions throughout the country, it had shied away from developing an intramural program. But in 1991, Hinshaw decided to start an intramural research program within the NCNR. Such a program, she hoped, would demonstrate

that nurse scientists, like other investigators at NIH, could conduct serious quantitative research on the Bethesda campus. The program would also send a strong message to the new generation of nurse scientists coming out of graduate school that nursing research had entered the mainstream of science at NIH. Nonetheless, the decision carried two potential challenges. First, the initiative would pull some of the Center's money out of the extramural budget, where all agreed it was badly needed. Hinshaw feared this move might generate opposition within the nursing community, but she believed that the science at the NCNR was "strong enough to do it and [the Center] had enough money to do both." She proved right on this count, and no nurses protested the intramural program. The second issue, which she did not expect but quickly discovered, concerned the other institutes at NIH. In the early 1990s the scientific directors of the intramural research laboratories at many of the other institutes did not approve of nurse researchers on campus. "For them, nurse researchers were not two words that went together," Hinshaw later recalled. "The whole concept of nurse and researcher just didn't go together." Nonetheless, Hinshaw launched the intramural program with a budget of about \$300,000, bringing in Dr. Carolyn Murdaugh to build the program. Murdaugh was a highly regarded scientist and nurse whose assignment was to plan and conduct a new portion of the Honolulu-Asia Aging Study in Hawaii to examine the impact on the caregivers, usually female family members, of dementia occurring in aging men. The goal of the NCNR study was to improve understanding of the burdens that caregivers experience and the effect of caregiving on the quality of the caregiver's life.⁵⁸

By 1992, the NCNR created the Division of Intramural Research to develop and conduct research programs relevant to nursing practice and health care apart from collaborations with other institutes. Both the Clinical Therapeutics Laboratory and the Laboratory for the Study of Human Responses to Health and Illness ran separate research programs addressing the interaction of biological and behavioral



Nurse scientist Dr. Carolyn Murdaugh came to the NCNR to build its new intramural program.

aspects of health and disease. At the same time, the labs presented research training opportunities to develop nurse scientists while extending the depth of the science in research programs.⁵⁹

President Clinton's victory in the fall of 1992 sparked considerable discussion about health care reform as part of the administration's agenda. During its first months, his administration focused much of its energies on health care reform, but for a variety of reasons—both internal and external—the effort failed. Nevertheless, the concept of health care delivery shifted from a medical model emphasizing individuals and their particular afflictions to a health model that encompassed the patient, the family, and the community. For the nursing profession,

which had long recognized that illness affects families and communities, not just the individual, it was a change that ensured nursing would have an important role to play in whatever health care reform might emerge in the future.⁶⁰

The manifestation of the change in health care delivery for the nursing community came in November 1992, when the NCNR convened the second Conference on Nursing Research Priorities. As it had done almost five years earlier in 1987, the NCNR invited nurse scientists from across the country to meet in Bethesda to develop a new five-year agenda for nursing research priorities. For three days, more than fifty top nurse scientists from across the country met to debate and ultimately select a new list of nursing's most urgent issues. "We voted with little voting machines on the priorities for nursing research," Hinshaw later recalled. The voting resulted in the selection of five research priorities that were phased into the National Nursing Research Agenda and guided a portion of research funding between 1995 and 1999.⁶¹

The five priorities coming out of the second Conference on Nursing Research Priorities reflected the changes being discussed among health care professionals. Nurses now placed an emphasis on developing and testing community-based nursing models for rural and other underserved populations and patients and families living with chronic illness. They also began to move away from behavioral programs to investigate more intensively biobehavioral interventions, that is, interdisciplinary research that examined the interaction of psychological, biological, social, medical, and nursing factors on health care issues. The basic premise was to move the research results to clinical and community applications. Three of the five new priorities focused on biobehavioral nursing interventions in HIV/AIDS, cognitive impairment, and immunocompetence. The program fit well into the health care reform ideas circulating in the Clinton administration and garnered the support of Clinton's HHS secretary, Donna Shalala.⁶²

Neither the nurses nor their allies in Congress had forgotten the



In 1992, nurse scientists from across the country met in Bethesda, Maryland, to establish nursing research priorities. Here, participants use handheld voting machines as part of the process.

disappointment of becoming a center rather than an NIH institute. The professional nursing organizations had worked with Congress to keep the idea alive and found strong bipartisan support from Pursell and Senators Daniel K. Inouye of Hawaii and Tom Harkin of Iowa, then chair of the appropriations subcommittee overseeing health care funding. The Center stressed that a conversion to an institute would require no modification to the existing infrastructure and that the designation was “budget neutral,” as the established programs and administration would be largely unchanged. Dr. Bernadine Healy, then the director of NIH, also favored an institute for nursing. In

the summer of 1992, Pursell resubmitted language to create an NINR in the NIH reauthorization bill of 1993, which would come before a new administration and Congress after the November 1992 elections. Hinshaw met with Healy to let her know what Pursell was doing so she and NIH would not be caught by surprise. Hinshaw, as a federal official in the executive branch, could not endorse the change without approval from any new administration. She told Healy about the congressional effort for redesignation to an institute. "I need to know whether we can support that or not," she asked. Healy replied, "I think that's a good idea. Do you think you're ready for that?" Hinshaw explained that the Center had a good array of programs in place. She thought the staff and the nursing community could do it. Since legislation was not always passed, as had happened to Pursell's redesignation effort two years before, Healy thought that an executive order might work and asked her staff to draw one up.⁶³

Following Hinshaw's conversation with Healy, but before the presidential election in the fall of 1992, HRSA held a reception and dinner for leaders of the health care community. At that event Hinshaw and Healy questioned then-HHS Secretary Louis Sullivan and Assistant Secretary for Health, Dr. James Mason, about the institute. Given the long-term opposition from the medical community to institute status for nursing at NIH, Healy needed to know the position of the Bush administration on the change. Mason asked if the Center was ready. Healy replied, "Absolutely. It's time to go for it." Mason simply said, "Okay," and turned to an aide and said, "Note that down." It was the night the administration said yes. Someone nearby who overheard the exchange said to Hinshaw, "What a coup." The support "neutralized opposition from the medical community so quickly," Hinshaw recalled, "[this time] we never heard from them." Healy instructed her office to file the paperwork to begin the process of redesignation through executive channels. This time, however, the legislation passed, even as the executive redesignation order came to the desk of Shalala, who had replaced Sullivan as the Secretary

of HHS in the new Clinton administration. In June 1993, Shalala signed the papers creating the NINR.⁶⁴

The creation of NINR realized the dreams of many in the nursing



In June 1993, HHS Secretary Donna Shalala and NCNR Director Ada Sue Hinshaw marked the Center's attainment of institute status.

community. For Hinshaw, however, it marked the end of “a really fun adventure.” In 1993 she was named “Health Leader of the Year.” She saw herself as a builder, and the institute was becoming an agency requiring more maintenance than building. She was tired of the bureaucracy. “Now the science had to build, and that’s a job of many, many years. I knew that and didn’t want to stay there for years and years.” She toyed with the idea of returning to a university setting but turned down opportunities to become a vice president for research because she wanted to stay in nursing. A school of nursing deanship, however, especially at a research-intensive university, looked far more attractive. She knew that Rhetaugh Dumas was stepping down as dean at the University of Michigan. Hinshaw had spent a short time in Ann Arbor just before taking over the NCNR. “I liked it a lot. It [was] a strong school, still a lot of growth to be done, a lot of openness, [and] a good faculty.” In the summer of 1994, Hinshaw left the NINR to become dean of the School of Nursing at the University of Michigan.⁶⁵

Looking back at the impact of the creation of a nursing entity at

NIH, Hinshaw emphasized the “excitement of building the science, a science that had both a strong clinical and a strong scholarly orientation.” The NCNR had accomplished this, she believed, by involving the nursing “community in what we did, so we were able to keep the flavor and commitment of nursing to the science. The other piece was the early and consistent involvement of the other disciplines through the other institutes. Our science is much richer for that.” She was very proud of the redesignation to an institute, “because all of us worked



Ada Sue Hinshaw celebrated with the newly named NINR staff. Her work largely complete, Hinshaw left the NINR the following summer.

very hard on that.” By the time she left for Michigan, she recalled, “we no longer had NIH fighting us, but with us, as we moved for something.”⁶⁶

In retrospect, Hinshaw considered the NCNR’s centers program to have had the greatest influence on nursing science because they “grow and raise more scientists at the same time they produce more science. Centers do double duty—they produce very fine scientists and also much research.” When the NCNR began, Hinshaw recalled, nursing had but a handful of postdoctoral students; when she left the institute, there was a “whole cadre of postdocs, people who really do know how to do research and were well underway with research programs. Their mentors, by running these centers and producing [new scientists] at the same time, have really added to the science in many ways.” In particular, Hinshaw cited Dr. Linda Aiken, whose studies to determine adequate nurse staffing and patient outcomes became the basis for establishing policy guidelines for nursing practice. Aiken, working with NINR funding, determined that inadequate staffing increased mortality and morbidity. She argued that facilities needed to carry a staffing ratio of no higher than four- or five-to-one in terms of patients to nurses. Failure to do so, her studies indicated, meant that for every increase in the patient load by one, the death rate for that patient thirty days from discharge increased by 7 percent. The results, published in the *Journal of the American Medical Association*, changed state laws to require staffing levels set by Aiken’s research in California and elsewhere. “So there’s some real impact there that’s made a difference,” Hinshaw concluded, especially for a small and very young agency with money available to fund limited research. “And yet, it began to make some huge policy impacts very quickly.”⁶⁷

After seven years as the director of the NCNR, Hinshaw was proud of the vibrant research program nurse scientists had established. She could point to the advances made in transitional care with low birthweight infants and research breakthroughs in the area of women’s health, including a greater understanding of menopausal symptoms

in midlife women. She noted the success of community-based health prevention studies, such as one in which nurse scientists were able to reduce the prevalence of cardiovascular risk factors in rural children through a specially designed education program taught in the schools. Another source of pride was the development of a pediatric pain tool, the “OUCHER scale”, that used graphic facial expressions to help children communicate how much pain they felt. Originally developed



The “OUCHER scale” uses graphic facial expressions to help measure the location, intensity, and quality of pain in children.

in 1983 by Dr. Judith E. Beyer at the University of Missouri–Kansas City School of Nursing, the scale proved to be reliable in measuring the location, intensity, and quality of pain in children and adolescents. The NINR sponsored additional programs of research in the assessment and treatment of pain for minorities, including studies done by Beyer and by Dr. Mary J. Denyes at the Wayne State University School of Nursing. “We at the NCNR,” Hinshaw told a group of senators in 1993, “believe the intellectual rigor and resulting interventions of nursing research can make an impressive, cost-effective difference. It provides essential scientific substantiation for innovative available, high-quality health care for all Americans.” Although Hinshaw would leave in a year, her comments captured the essence of what she believed the new agency had achieved.⁶⁸

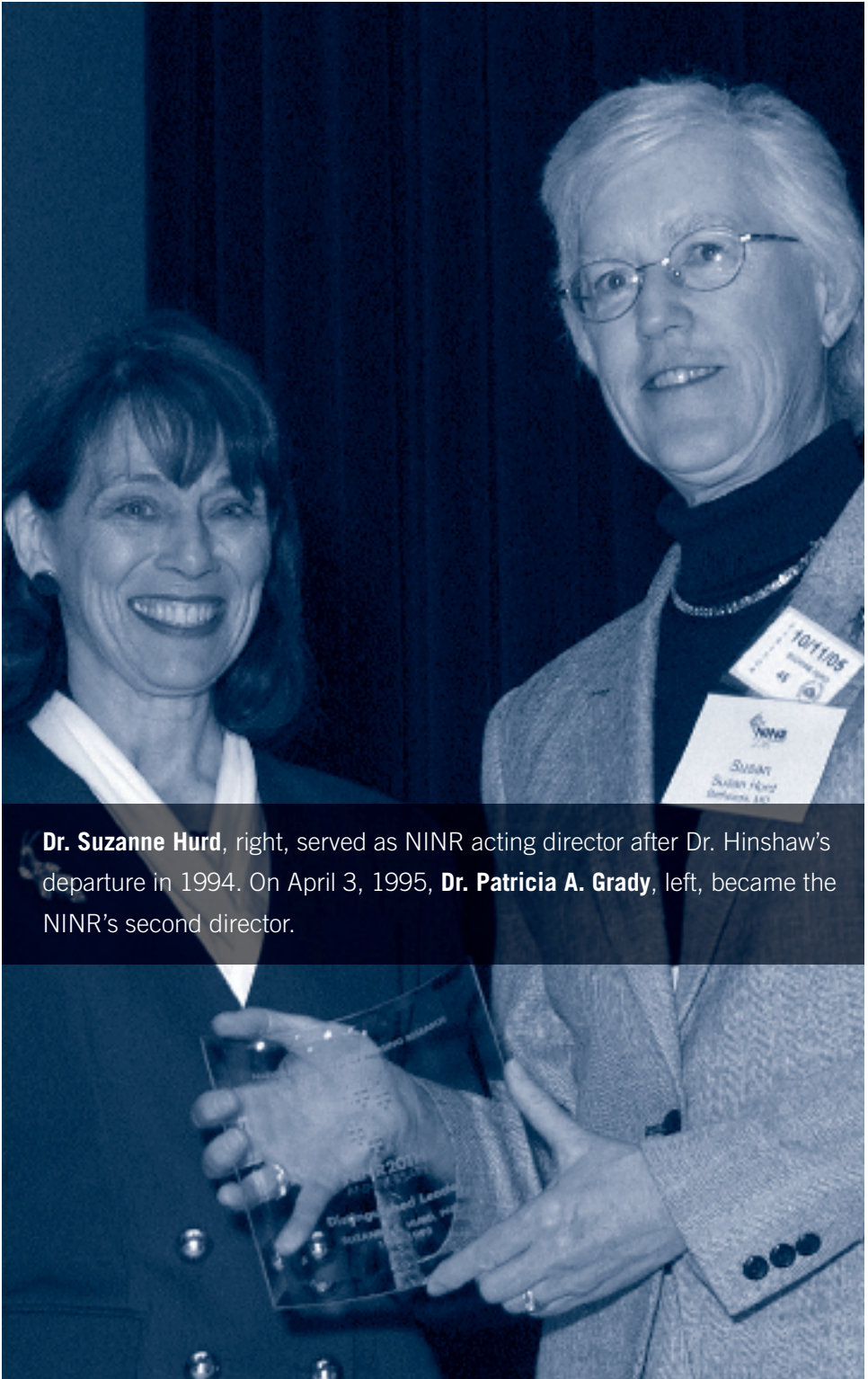
Chapter 3 Endnotes

- 1 Doris Merritt, telephone interview by Philip L. Cantelon, April 28, 2008, 45 (hereafter Merritt Oral History); testimony of Dr. James B. Wyngaarden, March 17, 1987, 694, NINR Records, Box 6, Folder: Legislation for NCNR.
- 2 Merritt Oral History, 45; testimony of Dr. Doris Merritt, March 17, 1987, 679, 690, NINR Records, Box 6, Folder: Legislation for NCNR. The list sent to Bowen contained three names with Hinshaw at the top. Ada Sue Hinshaw, telephone interview by Philip L. Cantelon, August 20, 2008, 44 (hereafter Hinshaw Oral History August 20, 2008).
- 3 “Hinshaw Heads NCNR,” *AACN Newsletter*, July 1987, NINR Records, Box 11, Folder: NCNR Achieved.
- 4 Ada Sue Hinshaw, Resume, Box A, NINR Records; Legislative Network For Nurses, “NCNR Director Nominated,” n.d., NINR Records, Box 11, Folder: NCNR Achieved.
- 5 Hinshaw Oral History August 20, 2008, 2-3. The nursing or nurse’s cap, derived from a nun’s habit and introduced into nursing by Florence Nightingale in the mid-1850s, fell out of favor in the 1980s as more men entered the nursing profession and scrubs were adopted as a unisex uniform for nurses.
- 6 See Powhatan J. Wooldridge, Robert C. Leonard, James K. Skipper, and Madeleine H. Schmitt, *Behavioral Science and Nursing Theory* (St. Louis: Mosby, 1983) and James K. Skipper and Robert C. Leonard, ed., *Social Interaction and Patient Care* (Philadelphia: J. B. Lippincott, 1965); Hinshaw Oral History August 20, 2008, 4-5.
- 7 Hinshaw Oral History August 8, 2008, 6-7; Ada Sue Hinshaw, telephone interview by Philip L. Cantelon, April 22, 2009, 3-5 (hereafter Hinshaw Oral History April 22, 2009). Kramer’s landmark book, *Reality Shock: Why Nurses Leave Nursing*, was published in 1974.
- 8 Hinshaw Oral History August 20, 2008, 8-9.
- 9 *Ibid.*, 9-10.
- 10 *Ibid.*, 11, 16, 42.
- 11 *Ibid.*, 42-43; Hinshaw Oral History August 28, 2008.
- 12 Hinshaw Oral History August 20, 2008, 43, 47.
- 13 Ada Sue Hinshaw, “Using Research to Shape Health Policy,” *Nursing Outlook* 36, no. 1 (January/February 1988): 21-24.
- 14 Commission on Nursing Research, “Research Priorities for the 1980s: Generating a Scientific Basis for Nursing Practice” (Kansas City: American Nurses Association, 1981), *passim*.

- 15 Ibid.
- 16 Ibid.
- 17 "Hinshaw Heads NCNR," *AACN Newsletter* 13, no. 6 (July 1987), NINR Records, Box 11, Folder: NCNR Achieved; Hinshaw Oral History August 28, 2008, 7-8.
- 18 "Hinshaw Heads NCNR."
- 19 Ibid.
- 20 Ibid.
- 21 Ibid.
- 22 Hinshaw Oral History August 20, 2008, 48-49.
- 23 Hinshaw Oral History August 28, 2008, 10-11, 14-15.
- 24 Hinshaw testimony to the House Subcommittee of the Committee on Appropriations, 100th Cong., 2d sess., March 10, 1988, 1017 (hereafter Hinshaw Testimony); Hinshaw Oral History August 28, 2008, 13-14; National Nursing Research Agenda, "Setting Nursing Research Priorities," September 13, 1993, 1, NINR Records, Box 5; Patricia Moritz, telephone interview by Philip L. Cantelon, March 13, 2008, 24, 26 (hereafter Moritz Oral History). The conference was later known as CORP I.
- 25 Hinshaw Oral History August 28, 2008, 13-14; Hinshaw Testimony, 1020.
- 26 Hinshaw Oral History August 28, 2008, 14-16; Georgia K. Miller, et al., "What Is Nursing Research: Evolving Approaches to Methods and Content," *Journal of the New York State Nurses Association* 23, no. 3 (September 1992): 5.
- 27 See Hinshaw Testimony, 1020; National Center for Nursing Research, "National Nursing Research Agenda," March 13, 1992, 1, NINR Records, Box 22.
- 28 Presentation of Dr. Marie Cowan, Task Force on Nursing Research, November 28, 1988, 78-90, NINR Records, Box A, Folder: Excerpts (hereafter Cowan Presentation); Hinshaw Oral History August 28, 2008, 16; Hinshaw Testimony, 1014.
- 29 Hinshaw Oral History August 28, 2008, 56; Hinshaw Testimony, 1011.
- 30 Hinshaw Testimony, 1012-13.
- 31 Ibid.
- 32 Ibid., 1013.
- 33 Ibid., 1044.
- 34 Ibid., 1022; *The Washington Post*, June 13, 2009.
- 35 Hinshaw Testimony, 1022.
- 36 Ibid., 1023.

- 37 Ibid., 1066.
- 38 Ibid., 1067.
- 39 Ibid., 1067-68; Cowan Presentation, 80-81. The downward trajectory was reversed in 1996 with the introduction of Highly Active Anti-Viral Therapy, which kept patients on a steady or upward trajectory. See A. B. Williams, "New Horizons: Antiretroviral Therapy in 1997," *Journal of the Association of Nurses in AIDS Care* 8, no. 4 (July-August 1997): 26-38.
- 40 Hinshaw Oral History April 22, 2009, 10.
- 41 Hinshaw Testimony, 1064-65, 1069, 1078-79.
- 42 Ibid., 791-92.
- 43 Sue K. Donaldson, "Breakthroughs in Scientific Research: The Discipline of Nursing, 1960-1999," *Annual Review of Nursing Research* 18 (2000): 261; Hearings, Senate Subcommittee of the Committee on Appropriations, 101st Cong., 1st sess., May 1, 1989, 1228; Hinshaw Oral History April 22, 2009, 10-11.
- 44 Hinshaw Testimony, 792; NINR, Division of Intramural Research, Annual Report for FY 1995, 8.
- 45 Hinshaw Testimony, 793, 829, 816.
- 46 Ibid., 817.
- 47 Ibid., 817-18.
- 48 Ibid., 819-20; Hinshaw Oral History April 22, 2009, 15.
- 49 Hinshaw Testimony, 821-22.
- 50 Ibid., 832-33, 841-42.
- 51 "Jump-starting Funding for NCNR," *CNR News* 17, no. 3 (1990): 4, NINR Records, Box A, Folder: Publications.
- 52 Ibid.; Hinshaw in "Advancing Health Through Science: Building Knowledge for Patient Care," 15th Anniversary Symposium, October 24, 2001, 14, NINR Records (hereafter 15th Anniversary Symposium); Hinshaw quoted in Charles Meyer, "Nursing on the Political Front," *American Journal of Nursing*, October 1992, 59.
- 53 "Jump-starting Funding for NCNR," 4. NCNR received more than \$43 million in FY 1992, up about 10 percent from the previous year. See William K. Russ to Dr. Peter Reineke, October 28, 1991, NINR Records, Box 11, Folder: From Center to Institute.
- 54 "Jump-starting Funding for NCNR," 4.
- 55 Hinshaw, 15th Anniversary Symposium, 12, 14-15.

- 56 Celebration of Establishment of a National Institute of Nursing, November 17, 1993, 13, NINR Records, Box 5; Hinshaw to Meyer, August 28, 1992, NINR Records, Box 6, Folder: Legislation for NCNR.
- 57 Talking Points for Donna E. Shalala, November 1993, 1, NINR Records, Box 5. For Joycelyn Elders, see http://www.military.com/Careers/Content1?file=trans_joycelyn_elders.htm&area=Content. Other specialty journals also published nursing research in neonatal and critical care, as well as oncology, to name a few fields, but nurse scientists were just emerging as a conceptualized discipline of their own. See Donaldson, "Breakthroughs in Scientific Research," 248. For a listing of nursing research periodicals, see Miller, et al., "What Is Nursing Research," 6.
- 58 Hinshaw Oral History August 28, 2008, 47-49; Hinshaw Oral History April 22, 2009, 2-3, 13-14; Hearings of the Subcommittee of the House Committee on Appropriations, 100th Cong., 2d sess., March 25, 1992, 550.
- 59 NINR, Division of Intramural Research, Annual Report for FY 1995, 8.
- 60 Talking Points for Donna E. Shalala, November 1993, 3, NINR Records, Box 5.
- 61 "Setting Nursing Research Priorities," September 23, 1993, 1, NINR Records, Box 9, Folder: Priority Setting–NINR; Celebration of Establishment of a National Institute of Nursing, November 17, 1993, 15, NINR Records, Box 5.
- 62 "Setting Nursing Research Priorities," September 23, 1993, 2, NINR Records, Box 9, Folder: Priority Setting–NINR; Talking Points for Donna E. Shalala, November 1993, 3-4, NINR Records, Box 5.
- 63 Hinshaw Oral History August 28, 2008, 38; William K. Russ to Peter Reinecke, October 28, 1991, NINR Records, Box 11, Folder: From Center to Institute.
- 64 Hinshaw, 15th Anniversary Symposium, 17, 19; Hinshaw Oral History August 28, 2008, 41-42; Hinshaw Speech, November 13, 1993, NINR Records, Box 5. Days after the establishment of NINR, NIH Director Bernadine Healy, who was so critical to the redesignation, left NIH.
- 65 Hinshaw Oral History August 28, 2008, 45.
- 66 *Ibid.*, 55-56.
- 67 Hinshaw Oral History April 22, 2009, 23-24, 26-28.
- 68 Hearings, Senate Subcommittee of the Committee on Appropriations, 103d Cong., 1st sess., May 26, 1993, 680-82; author's correspondence with Antonia M. Villarruel, March 8, 2010; see also, Judith E. Beyer, Mary J. Denyes, and Antonia M. Villarruel, "The Creation, Validation, and Continuing Development of the OUCHER: A Measure of Pain Intensity in Children," *Journal of Pediatric Nursing* 7, no. 5 (October 1992): 335-46.



Dr. Suzanne Hurd, right, served as NINR acting director after Dr. Hinshaw's departure in 1994. On April 3, 1995, **Dr. Patricia A. Grady**, left, became the NINR's second director.

Chapter 4

From Nursing Research to Nursing Science

When Ada Sue Hinshaw departed for Ann Arbor and the deanship of the University of Michigan School of Nursing in 1994, she left behind a very different nursing entity than she had taken over eight years earlier. The National Center for Nursing Research (NCNR) had gained institute status, funding levels for research were more than three times what they had been in 1986, graduate schools were educating greater numbers of nurse scientists, and, as if to validate the National Institute of Nursing Research's (NINR) acceptance into NIH, nursing had initiated its own intramural program. None of this had been easy or the automatic result of being part of NIH. The staff of the NINR, the professional nursing associations, and nurse scientists throughout the country had planned, justified, prodded, and advocated for the growth and development of nursing science. Despite their successes, however, these were but first steps in the evolution of the NINR. It remained a small institute, still laboring under the perception that nurses did only clinical research, not the more basic science that led to clinical research as in other NIH institutes. While most nurses agreed that Hinshaw had done an "outstanding job to build the research program base for the NINR," they also realized that much remained to be done. To some, the NINR was still a stepchild at NIH.¹

In July 1994, a month after Hinshaw's departure, NIH Director Harold E. Varmus appointed Dr. Suzanne S. Hurd acting director of the NINR, a position she held in addition to her job as the director of the Division of Lung Diseases at the National Heart, Lung, and Blood Institute (NHLBI). A graduate of Bates College in Maine, she earned her advanced degrees at the University of Washington. After post-doctoral studies at the University of California, Berkeley, Hurd came to NIH in 1969. Though she had concentrated her research interests on chronic obstructive pulmonary diseases, she built her career at the NHLBI in health science administration.²

One of Hurd's administrative strengths was building a solid program management infrastructure for the funding of grants for research projects. Although she expected her term at the NINR to be short, she believed that her long experience with program development at NIH could benefit the Institute until a permanent director was found. She began a review of the Institute's budget history to uncover its previous funding patterns, program balance, success rates, plans for future research directions, and mechanisms for program planning in order to provide recommendations for future growth. Hurd concluded that "the future success of the NINR will be tested based on the ability of individual researchers to develop and submit an *increasing* number of innovative, high-quality nursing research proposals related to NIH basic and clinical research goals." In other words, Hurd believed that bringing the NINR more in line with the programs of other NIH institutes during a period of tight resources would pay handsome dividends for nurse scientists.³

Hurd became acting director of the NINR at a time of considerable uncertainty. Off-year elections in November 1994 during President Clinton's first term had brought stunning change to the political landscape in Washington. For the first time since 1954, the Republican Party captured both houses of Congress. Led by Congressman Newt Gingrich of Georgia and his conservative Contract with America, the Republican victory was a reaction—in part—to the failure of Clinton's



In 2001 the NINR celebrated fifteen years of nursing research at NIH.

attempt to reform the nation's health care system. Although there had been substantial support for the NINR from Republicans in the past, the new leadership's position was unclear. Committee and subcommittee chairs would change in the 104th Congress. Familiar ties were weakened, if not broken altogether. With much change came much uncertainty, especially in the level of medical research funding.⁴

The new chair of the appropriations subcommittee was John Edward Porter, who represented the suburban "silk stocking" district north of Chicago on the shore of Lake Michigan. A strong supporter of medical research, Porter nonetheless questioned Hurd closely in budget appropriations hearings about areas in which the NINR could

cut costs. Porter realized that while all institutes had to share in cutting personnel, a small institute like the NINR had less flexibility to downsize its staff. Hurd explained that the NINR was developing management teams and job sharing to achieve workload balances with fewer employees. In addition, NIH was reducing the number of required reports and amount of paperwork and streamlining the grant application process. All of this would result in better efficiency to effectively use the scarce resources, she assured him, and preserve the work of nurse scientists.⁵

If so, Porter asked, why did the NINR have “the dubious distinction of having the lowest projected success rate on campus in 1996 of about 12 percent?” It was a question that referred to the number of funded applications divided by the number of applications received,



U.S. Representative John E. Porter (R-Illinois), chair of the appropriations subcommittee and a strong supporter of medical research.

and one that the subcommittee had pondered earlier with Hinshaw. Since her first day as acting director, Hurd replied, she had wrestled with this question. “Indeed, it would appear overall that the success rate is significantly lower than the other institutes,” she said. “However, if you separate out the applications that are investigator-initiated applications,” she said, “the success rate is similar to the success rates throughout NIH.” The difference, she explained, was the large number of applications that the NINR received in response to the solicitations, i.e., Requests for Applications (RFAs), which modified the success rate. Her solution was to encourage more nurse-initiated applications. The issue needed close attention, she concluded, “but it is not the same magnitude that has been presented in the past.”⁶

Hurd had already begun the process of inviting more innovative proposals. In a series of articles in early 1995, she attempted to put into perspective for nurse scientists the problems facing the NINR. For the near future, Hurd observed, budgets at NIH and the NINR would do well to keep up with inflation. “The likely diminution of future resources,” she wrote, would be “especially hard on a developing institute with a small base, such as the NINR.” Because the Institute had the lowest success rate at NIH, it needed to attract more research proposals, particularly those from individual investigators. However, she noted, “we are receiving fewer applications now, a worrisome trend that must be reversed to preserve and enhance the Institute’s stature and effectiveness.”⁷

Hurd praised the two conferences on research priorities (CORP I in 1988 and CORP II in 1992). This method of identifying areas of high scientific emphasis was “an outstanding means to develop new and innovative approaches to specific areas of interest and to meet federal program objectives,” she wrote. Because the RFA programs were “very broad in scope,” they generated a large number of applications and, therefore, a lower success rate. Of all of the NINR’s extramural funding, more than 80 percent went to these research project grants. In addition, because of the NINR’s small funding base, “the presence or

absence of even small numbers of grant applications can exert considerable influence on the NINR success rate.” The solution, she argued, was to build an increasing number of multidisciplinary “innovative investigator-initiated research projects (R01 and R29 applications), thereby demonstrating the enormous potential of nursing research.”⁸

From her analysis of the NINR over the previous three years, Hurd believed she understood both the strengths and weaknesses of the Institute. Her purpose was to bring the NINR more in line with other NIH institutes and increase the scientific merit of its research. She recommended that the NINR continue to work with the nursing research community—a strength—while “carefully balancing support” for RFAs with the individual investigators for whom she urged greater funding. Based on her experience in the NHLBI, Hurd believed that greater scientific merit could be found in the work of innovative individuals. Moreover, she urged the Institute to evaluate carefully the progress of the RFA programs and to identify and evaluate specific topic areas that could be implemented through special initiatives. Finally, the NINR should “publish the results of nursing research projects in the broad scientific literature to establish the impact of scientific findings.”⁹

Hurd’s review of the NINR carried the message of a friendly, well-meaning, but stern aunt inclined to tell youngsters how to emulate successful adult behavior. Her articles were not quite sermons or lectures, but rather instructions on self improvement, as well as sharp guidelines to improve the NINR’s basic science for Hinshaw’s eventual successor. Her message to the nurses was: You’ve started out on the right path, but you’ll need to advance the quality of the science of your research to become something more than a stepchild institute at NIH. Hurd’s message was important. It was a call to nurses to alter their thinking about research and become more proactive. She encouraged nurse researchers to think of themselves as nurse scientists—to move beyond observation to initiating innovative research programs.

Varmus agreed with Hurd. The co-recipient with J. Michael Bishop of the Nobel Prize in Medicine in 1989 for his research on the cellular

origin of retroviral oncogenes, Varmus, as NIH director, was pushing for more and better research at NIH, urging Congress to increase funding for basic science. His choice of Hurd as interim director reflected his emphasis on basic research and his interest that it should be ramped up at the NINR. After Hinshaw left for Ann Arbor, a rumor circulated among staffers on Capitol Hill that the NINR might be redesignated as a center. No one knew what currency Varmus gave these whispers, if indeed he had heard them. But like Wyngaarden before him, whatever



Dr. Harold E. Varmus, NIH director from 1993 to 1999.

his opinion about an institute of nursing at NIH, he wanted the NINR to represent the very best science. In any case, improving the Institute's scientific reputation would guarantee its survival. To help assure his vision of a refocused NINR, Varmus selected someone with whom he had worked and whom he considered to have the proper credentials, credibility, and capability to implement that vision. He would encourage her to apply for the Institute's directorship. Unfortunately, his candidate, Dr. Patricia A. Grady, had already been proposed as chair of the NINR Director Search Committee.¹⁰

In the spring of 1995, Grady was just completing a stint as the acting director of the National Institute of Neurological Disorders and Stroke (NINDS). An internationally recognized stroke researcher specializing in cerebral blood flow, metabolism, and function, Grady had come to the NINDS in 1988 as a program administrator. Four years later she assumed the responsibilities of assistant director. In 1993 she became the deputy director. Nine months later, when the institute's long-time director, Murray Goldstein, retired, Secretary of Health and Human Services Donna Shalala appointed Grady acting director of the NINDS. After Goldstein's successor was selected, Grady returned to her position as deputy director and agreed to chair the NINR selection committee.¹¹

When Varmus saw Grady's name on the selection committee list, he may have asked why it was there. "Because she's a nurse" would have been the logical reply. It also meant that Grady was not considering the position. She was at a meeting in Dallas when Varmus tracked her down. "You know," he began, "I'd really like to keep you on my team. I wonder if you'd be willing to compete for the [NINR] job. I can't promise it, but I really think you'd be very competitive and do a great job if you were selected and took it." The conversation overturned Grady's plans to chair the committee and return to her old position at the NINDS, where "life would be back to normal."¹²

Grady thought about Varmus's suggestion. She had not planned to take on anything new. She knew she could do the deputy job at the

NINDS. Moreover, staying in her area of science carried additional advantages and comfort. The more she thought about the challenge, however, the more reasons she raised for possibly remaining on Varmus's team and moving to the NINR. Like many at NIH, Grady viewed the NINR as more of an institute on paper than a full-fledged member of the NIH community. She believed the NINR directorship would be a good opportunity to pull together her nursing training, her scientific background, and her NIH administrative experience to benefit the Institute. On the other hand, she realized that she was not as well known in the nursing community as other potential candidates. In addition, Grady was uncertain whether nurses would consider her a viable candidate. "It boiled down to doing something that I really liked doing, which was being the deputy, or taking something on that I really thought I would like and thought maybe I could make a difference and do something new. So I opted for the new challenge."¹³

Grady was raised in Delray Beach, then a small town on Florida's east coast south of Palm Beach. Her parents were from Connecticut, so when Grady graduated from high school, she decided to return north for college. She excelled in science and was interested in health, so like many similarly inclined women at that time, she decided on a career in nursing "because it gave you flexibility and the potential to carry out the profession in any number of settings and variety of lifestyles." She settled on the St. Francis School of Nursing in Hartford, close to a number of her extended family. Nurse training at St. Francis consisted of a three-year diploma program, after which Grady transferred to Georgetown University School of Nursing to complete her bachelor of science degree. Because Georgetown accepted her St. Francis nursing credits, she was able to take many liberal arts and science courses with a few upper-level nursing classes sprinkled into the mix. When she graduated in 1967 with a BS in nursing, she received the equivalent of an undeclared minor in philosophy, a by-product of Georgetown's Jesuit education. After Georgetown, Grady also served as an instructor at the Washington Hospital Center's

School of Nursing, teaching in the newborn division of the Maternal and Child Health Department and supervising the clinical experience for student nurses.¹⁴

The following year Grady moved to Baltimore to pursue a master's degree at the University of Maryland School of Nursing. Completing the degree in 1968, she accepted a job at the university, teaching courses on critical care nursing and leadership and management in the clinical setting. In her second year Grady became the director of the newly created Neurological and Neurosurgical division. There she discovered her special research interest in stroke and related problems. She returned to school full time in 1973, entering the doctoral program at Maryland's School of Medicine. She received her PhD in physiology in 1977 and continued her research while teaching advanced courses to medical and doctoral students. By 1980 Grady held a primary appointment as research assistant professor in the School of Medicine, where she directed a Cerebrovascular Physiology Research Laboratory, and a joint appointment as assistant professor in the School of Nursing. While there, her research proposals won NIH funding for independent projects in stroke.¹⁵ She also received funding from the Office of Naval Research for an interdisciplinary study on brain function.

In the course of her research work, Grady presented her scientific findings in a number of national and international scientific meetings, including symposia at NIH. In 1988 the NINDS recruited her to become an administrator, first in the area of head injury and soon after in the area of stroke. "The only job I would have liked better than the one I took," she recalled later, "was the one that they gave me after I arrived, so it worked out quite nicely." For the next three years, she served as health scientist administrator for the Division of Stroke and Trauma, as well as taking on more NIH-wide duties on behalf of the NINDS. Among these was serving as her institute's liaison to the National Center for Nursing Research (NCNR). She rose quickly through the administrative structure, becoming assistant director of the NINDS in 1992, deputy director the following year, and acting director



The NINR directorship allowed Dr. Patricia A. Grady to employ her nursing training, her scientific background, and her NIH administrative experience.

in 1994. During that time Grady developed NINDS policies, priorities, and program activities. She coordinated all research activities in neurological disorders and stroke, overseeing the institute's budget of about \$700 million and a staff of approximately 1,000. By 1993 she had become the chief advisor to Varmus on neurological research and science policy.¹⁶

By the time Grady decided to apply for the directorship of the NINR, she was somewhat familiar with the workings of the Institute.

While on the University of Maryland faculty, she had worked with Ada Sue Hinshaw when they were both consultants to the doctoral program at the School of Nursing. She dealt with Hinshaw again when the latter was the NINR director. She made another point to speak with her when she was considering the directorship. “I knew about the science, but I talked with her about what the issues were. I came to know pretty much what you would know about your neighbors, what’s going on in the [NINR] neighborhood,” she recalled. She also spoke with Hurd, several longtime veterans of NIH, and institute directors, including Anthony Fauci of the National Institute of Allergy and Infectious Diseases (NIAID), Duane Alexander of the National Institute of Child Health and Human Development, and Claude Lenfant of the NHLBI, who was looking forward to getting Hurd back to her position as director of the Division of Lung Diseases. All encouraged Grady, especially Hurd. “I think you should do this,” Hurd said, in part because her background was similar to Grady’s—a basic scientist—and she had found working at the NINR an enjoyable experience.¹⁷

The selection committee, co-chaired by Dr. Richard J. Hodes, director of the National Institute on Aging (NIA), and Kathy Montgomery, director of the Clinical Center Nursing Department, began its work. Soon Grady’s name circulated as a potential director, and a number of nurses’ organizations, such as the American Nursing Association and the American Academy of Nursing, called her to support her candidacy. “Others didn’t call,” she later joked, “because they didn’t want to encourage me.” Publicly, deans of nursing schools stayed neutral because one or two of them were also candidates for the job. The selection process, which was to be quiet in the sense that no one openly campaigned for it, was rife with rumors. When the search deliberations were over, Varmus called Grady in mid-March to say that the job was hers. Shortly thereafter, on April 3, 1995, Secretary Shalala made the appointment official.¹⁸

In announcing Grady’s appointment to the NIH community, Varmus praised her experience. “The breadth of Dr. Grady’s scientific

and management expertise,” he said, “meshes well with the leadership requirements of an institute that has a broad mandate. Her experience in conducting and managing neurological research makes her the ideal leader to carry out the NINR mission that includes linking biological and behavioral research programs to benefit people’s health.” Grady, whose career began with clinical neurological and neurosurgical nursing, said that she was assuming her position at a time when the nation’s health care system was undergoing a science-based evolution. To meet this challenge, she intended to expand the scientific base for nursing. “Scientific research for nurses,” she stated, “is more crucial than ever before.”¹⁹

Even before becoming director of the NINR, Grady had been a leader at NIH in supporting the advances of women in science. In the spring of 1995, while still deputy director at the NINDS, she demonstrated her enthusiasm for the changes female scientists were bringing to NIH. Writing in the *AWIS Magazine*, the quarterly journal of the Association for Women in Science, Grady noted that in 1985 few women held positions on review boards, study sections, advisory boards, or tenured posts in laboratories at NIH. But a decade later, she said, while women were still not well represented in senior positions, “no clinical trial, review board, or tenured group is complete without them.” The difference, she explained, was that more women had successfully entered professional scientific careers, “despite structural and informal barriers, despite different socialization patterns for boys and girls, despite ‘glass ceilings,’ long hours, editorships, review committees, faculty meetings, motherhood, and ‘old boy networks.’” One in five independent investigators supported by NIH was a woman scientist. In addition, the number of women submitting applications to NIH was rising while the number of men was declining. “The success of women scientists in the NIH system,” she wrote, “suggests they will remain competitive and important contributors to the health of the Nation in the 21st century.” The NINR appointment provided an ideal platform to continue her message.²⁰

From her experience as the acting director of an institute with more than 1,000 employees, Grady recognized that size mattered when it came to slicing up the NIH pie. That there was a pecking order at NIH was an unacknowledged reality. Institutes outranked centers, and big institutes carried more importance than smaller ones. When nursing research was a center, even a freestanding center with all the rights and privileges of an institute, it was recognized that such a situation did not carry the stature of an institute. When competing for pooled funds, centers and small institutes received less than the larger entities. In reviewing the history of the NINR, Grady learned that even as an institute, the NINR struggled for parity. Coming from outside the nursing community, she saw what the nurses were able to accomplish and what, in her opinion, remained to be achieved. The year that Hinshaw had served as an institute director was too short to accomplish parity or improve status within NIH. Hurd, as acting director, was unable to do much more than keep the new institute in a holding pattern. Grady envisioned funding better science and, by doing so, improving the NINR's competitiveness in relation to other institutes, which would garner it more respect within the NIH community. Varmus had praised Grady's credentials as a nurse academician, clinician, and researcher. Her experience at NIH, he said in announcing her appointment, would "be invaluable in building on the NINR's already impressive record of collaborative efforts with other NIH institutes and Public Health Service agencies." While not abandoning collaborative research, Grady's long-term strategic goal was to move the NINR from a campus collaborator to a campus leader.²¹

Varmus's confidence in his new NINR director was not misplaced. Having served as an acting institute director, Grady fully understood the importance of congressional support. She also had the credentials and the self-assurance to explain the NINR's role within NIH as she viewed it. In testimony before the House Appropriations subcommittee, she said that the goals of the NINR were twofold: improving health and reducing costs. She indicated that "while scientific research must

continue to seek cures, it must also find ways to ease the symptoms of disease and modify problems arising from treatment.” Secondary symptoms, such as those associated with cancer or AIDS, she noted, could be as life threatening as the disease itself. “Nursing research findings, once envisioned to affect nursing practice alone,” she said, “are now understood to be relevant to the work of all health care practitioners.”²²

During the mid-1990s, the entire nursing profession was under pressure from congressional efforts to balance the federal budget. To accomplish this, the budget committees of both houses called for deep cuts in social programs, including funding for nursing programs, education, and research. Although appropriations for the NINR were relatively secure because of the assurance of NIH funding, the Tri-Council for Nursing pushed for a \$10 million increase in the NINR’s budget in order to fund a higher percentage of nursing research grants. The Tri-Council prodded nurses to begin a grassroots lobbying campaign to write their members of Congress and explain both the importance of nursing education and nursing research—and the health care savings that research produced.²³

The most prominent examples of the NINR’s ability to save health care dollars came in areas in which it had been working for some years—low birthweight babies and the elderly. Health care costs for a low birthweight baby could be in excess of \$20,000, versus an average just below \$3,000 for children of normal birthweight. While low birthweight infants accounted for only 7 percent of all U.S. births, their care amounted to more than 50 percent of costs for all newborns, according to the NINR. Therefore, prevention of low birthweight could result in significantly reduced neonatal health care costs. In one program with low-income African-American women, NINR-supported investigators had reduced the number of low birthweight deliveries by 36 percent, which made a remarkable contribution toward reducing both short-term and long-term costs to the health care system. “Describe how research funded by [the NINR] has helped nurses

discharge low birthweight babies from hospitals sooner, and therefore less expensively,” the Tri-Council urged. When compared to control groups, according to the NINR, cost savings of 29 percent were achieved with women who had caesarean births and savings of 38 percent were realized for diabetic mothers with newborns. Moreover, women had fewer postnatal rehospitalizations and expressed greater satisfaction with their care. In addition, each nurse should let Congress know how nursing research programs had prevented injuries from falls among the elderly, the Tri-Council suggested, “injuries that account for a significant portion of the expense for caring for the elderly and prevent costly complications in critically ill patients.”²⁴

The campaign had some effect. The idea that scientific research could produce cost savings seemed to be a given by the spring of 1996. Fresh initiatives, especially in the glitzy world of genetics, captured more of this interest. Although Congressman Porter, then in the second year of his chairmanship, changed the format of the subcommittee’s hearings, bringing representatives from several institutes at a time to talk about specific health care themes, such as the role of genetic information, risk factors, or pain, rather than specific institute programs, he remained a staunch supporter of NIH. The purpose of Porter’s panel format was to find ways for the institutes to coordinate research and prevent duplication of effort in order to save money. Each institute had an opportunity to mention its successful programs in each area of Porter’s interest. Grady believed that the approach achieved the goal of showcasing areas of mutual interest, collaboration, and individual perspectives on research problems—and the special missions and priorities of each institute. She explained the NINR’s new clinical ethics program focusing on decision making and participation in genetic studies and clinical trials. She explained the Institute’s concentration “on the aspects of being tested or not being tested.” In collaboration with the Clinical Center, its ethics department, and the Genome Center, the NINR, she said, was “planning to be a part of this long-term process and

to guide patients in these very difficult decisions, as the information unfolds from the genetic discoveries.”²⁵

Nevertheless, one immediate impact of the more conservative and budget-conscious Congress was a change in the process by which the NINR set its research agenda. In times of fiscal constraint, Grady told Porter, the Institute had simplified its planning process. Rather than bring experts for multiday sessions in Bethesda, Maryland, “what we are looking at now,” she said, “is having smaller work groups convene at national meetings, and also using our council more actively.” Two initiatives, she reported, were new workgroups: one studying nursing issues in the environment and the second examining nursing in genetics. Grady’s objective was to keep the level of funding for the NINR as close to the previous year as possible while still continuing successful research projects and allowing additional funds to sponsor new investigations. Her request—in keeping with the President’s budget—for nearly \$52 million was basically flat.²⁶

While all of NIH was concerned with funding after the 1994 elections, health concerns proved to be one of the few common grounds on which both parties could agree. The NINR received its requested appropriation. With the re-election of President Clinton in 1996, the first Democrat to serve two full terms since Franklin Roosevelt sixty years before, the emergence of a federal budget surplus, and the anticipated funds from settlement with the tobacco companies, funding for health research would increase dramatically over the next decade.

In 1996 the NINR celebrated the tenth anniversary of nursing research at NIH. More than 400 nurse scientists, deans of nursing schools, graduate and undergraduate nursing students, and many others filled the Masur Auditorium in Building 10 on the Bethesda campus for a day-long symposium in September in recognition of the Institute’s first decade. Opening the meeting, NIH director Varmus congratulated the NINR on its contributions and praised the “broad and interactive nature of nursing research,” particularly in the areas



In 1996 the NINR celebrated the tenth anniversary of nursing research at NIH with a day-long symposium in Bethesda. (Front row, from left): Nancy Fugate Woods, RN, PhD, FAAN; Loretta Sweet Jemmott, RN, PhD, FAAN; Dr. Patricia Grady, RN, PhD, FAAN; Barbara Therrien, RN, PhD, FAAN; Dorothy Brooten, RN, PhD, FAAN. (Back row, from left): Gayle Page, RN, DNSc; Sue Donaldson, RN, PhD, FAAN; Gary Morrow, PhD; Kathleen Buckwalter, RN, PhD, FAAN; Dyanne Affonso, RN, PhD, FAAN.

of genetic counseling, prevention research, and pain and cognitive research. The symposium, entitled “Advancing Health Through Science: The Human Dimension,” featured presentations by nine distinguished nurse scientists on current research topics from improving pregnancy outcomes to pain and its immunological implications. The keynote presentation by Dr. Sue Donaldson of The Johns Hopkins University School of Nursing on translating basic science into clinical care carried several of the themes—such as the influence of gender or ethnicity on the effectiveness of nursing interventions—underscored in other papers. The final presentation, by Dr. Nancy Fugate Woods of the University of Washington, highlighted some of the issues that would be important to nurse scientists in the near future, including access to data, ethical issues surrounding genetic indicators of disease, and the challenges presented by emerging diseases. The anniversary celebration, which had included a day of poster sessions on Capitol

Hill the day before the symposium, ended with a “Nightingala” reception and banquet honoring distinguished nurse scientists.²⁷

Grady, who had recognized the value of history since her days at Georgetown, continued to use the anniversary to review the Institute’s accomplishments. Her analysis, Grady told the readers of *Image: Journal of Nursing Scholarship*, a publication of international nursing honorary society Sigma Theta Tau, “reinforced the view that we can take pride in so much progress over such a short period.” The budget had increased from \$16 million to more than \$50 million, supporting an intramural program with three laboratories and a growing extramural program that included six research and training centers. “The attainment of institute status in 1993,” she wrote, “enhanced national and international recognition for nursing research. We view this impressive progress as a beginning and eagerly await future opportunities to achieve much more.”²⁸

Grady’s advice to young nurse scholars blended an acknowledgment of past accomplishments with recognition of the changes in nursing science yet to come. She praised the research priority areas established by the nursing community over the previous decade, but as “important as these designated priority areas are,” she said, “from the beginning, the NINR has always given emphasis to the knowledge, creativity, energy, and dedication of its individual scientific investigators. These scientists strive to evaluate the effectiveness of different interventions. They seek the twin goals of health care effectiveness and cost effectiveness. In sum, these scientists form the backbone of the Nation’s nursing research activities.” Grady believed that nurse scientists, among all the researchers in health care, were special. They were changing the landscape of scientific research not only by asking the right questions, but by asking unique ones—questions raised by their interactions with patients and their families. She encouraged young nurse scientists to link basic, clinical, and behavioral research in addressing health problems. “Ten years ago,” she stated, “nursing research was not investigating problems at the molecular level. But

today we can be important contributors to issues surrounding genetic screening and genetic therapy.” She outlined the work to be done in managing symptoms resulting from diseases and medical therapies, increasing awareness of prevention, and the importance of adherence to treatments. Nursing research was more than just bench science. In Grady’s view, the NINR’s research emphasis brought a “consistent, patient-oriented perspective to biomedical research that extends beyond the traditional research continuum.” Nursing’s scientific agenda had a human face, she said, “one that is directly relevant to improving the nation’s health.”²⁹

Grady crusaded for more nurse investigators and, by inference, more grant applications for the NINR to sponsor. She also emphasized the scientific leadership provided by the NINR. The Institute had “taken a lead in a major NIH-wide initiative to explore the biologic and behavioral aspects of pain,” she explained in *Nursing Outlook*. According to Grady, the NINR would “explore neurochemical influences on pain perception; controlling transmission of pain to the brain; and interactions of molecular mechanisms of pain with such variables as gender, genetic differences, and cultural background.” The field of genetics had also pushed its way into the foreground of nursing science in order to develop counseling strategies to help nurses deal with “issues surrounding genetic environments and pinpoint which people should be tested.” Whether nurse investigators would deal with managing chronic wounds, treatment side effects, genetic advances, cognitive impairment in the elderly, or other targeted health problems, Grady stressed that “investigator-initiated research is at the heart of scientific progress.”³⁰

Drawing on her own experiences and using her post at the NINR, Grady became a combination of advocate, teacher, counselor, and cheerleader for nursing science. She believed that nursing’s primary challenge was to translate research findings into clinical practice. She urged nurses to involve themselves in the research process, to understand the culture of research, to “have a healthy sense of curiosity, [to]

ask questions about what's going on around you and be curious about why things are done a certain way." In short, she encouraged young nurses to think like independent investigators, like the next generation of nurse scientists. Grady also stressed the value of student research teams that combined undergraduates and graduates to collect data, which would take some of the mystery and intimidation out of research. The profession needed to "figure out how to excite the imagination of young minds and how to keep these minds excited. When specific research isn't going the way you want," she said, "it's this excitement that sustains you. It is really important to have a passion for research. We need to foster that passion and develop any research interests in our youth." Grady believed that virtually anyone could—and should—play a role in the research process. "We are in a time of great change," she explained, "and times of change often produce uncertainty and anxiety, but they also produce unexpected opportunities."³¹

Grady was correct about change. Nursing research was becoming more active in different areas of science, such as pathophysiology and immunology, and entering into fields that had not existed for nurse investigators a decade earlier. As greater numbers of nurse PhDs trained in the biological sciences emerged from graduate school, nursing's research agenda moved with them. In certain traditional research areas, such as rehabilitation to restore lost function and improve quality of life for the elderly, nursing science blended both the physiological and psychological aspects of rehabilitation. And while many researchers maintained their interest in the Institute's long-time specialties—low birthweight, HIV/AIDS, elder care, women's health, and symptom management—other nurse scientists, pushed by the NINR, moved into emerging areas of scientific investigation. Genetics and Grady's own research area of neuroscience were two fields that marked new directions for nurse investigators. Environmental science was a third. As before, this new critical mass of nurse scientists would build on the foundations of the NINR's earlier programs and policies, such as the centers program and increasing sponsorship of individual nurse investigators.³²

In December 1995 NIH released its “Report and Recommendations of the Panel to Assess the NIH Investment in Research on Gene Therapy.” The document called for more basic genetic research to “understand the pathophysiology of disease and the action of gene transfer vectors.” The panel participants emphasized the need for rapid incorporation of new findings into valid and reliable psychosocial interventions. Nurse scientists recognized that a major gap in genetics research was its lack of integration with behavioral sciences, an area in which nurse scientists were major participants. The NIH panel acknowledged the special position nurses occupied to translate genetic research to patients and families and encouraged the NINR to collaborate with other agencies to discuss how genetic information might be incorporated into behavioral studies to develop improved strategies for health care management and policies.³³

Following the NIH lead, the NINR began to publicize the opportunities for nurse scientists in genetics research in 1996. In mid-April the NINR hosted a workshop covering areas for science research, critical research directions, and training and development opportunities in genetics. The Genetics Research Workgroup consisted of nurse scientists from schools of nursing and research facilities around the nation. “The initiation of studies that blend genetics bench research with the behavioral sciences is critical for the transfer of laboratory findings into clinical practice,” the panel announced. The group identified gaps in genetics research where nurse scientists could make significant contributions, in such areas as gene-environment-behavioral interface, biological, psychosocial, and neuroimmunological markers, and basic research, among others. Obesity and cardiac arrhythmia, for example, offered nurse investigators an opportunity to examine the complex interplay between genetics, behavior, and environment in a patient’s condition. For nurse scientists the goal was to identify and isolate disease markers and risk factors for persons with genetic conditions and in individuals and families at risk of developing genetic conditions. Progress in this area of research, the group believed, would

enable clinicians to tailor prevention strategies for at-risk persons and test interventions for treating persons with genetic illnesses.³⁴

Once again, nurses faced ethical issues associated with genetic health. Nurse scientists had already explored individual attitudes toward genetic testing. Therefore, the NIH panel noted, researchers should continue to “play an important role in describing, characterizing, and explaining the responses of individuals and families to genetic testing and test results.” Nurses needed to perform additional studies to clarify the impact of the timing and the conveying of genetic information, especially as it pertained to children, and to develop models for health care providers to use in presenting to patients the risk of developing a genetic illness. Further research, the panel hoped, would “clarify issues critical to the genetic testing of children, such as the age at which testing is appropriate, informed consent issues in genetic testing, and how understanding the implications of results can be monitored in children.” These same ethical issues carried over to the health care delivery use of any genetic information. “The vast literature developed by nurse researchers on grief and grieving,” the panel suggested, “may also be applicable to understanding the outcomes of genetic testing and counseling.”³⁵

In a series of articles in professional nursing publications, the NINR used the report of the Genetics Workgroup to emphasize new directions for a brave new world of genetics research, which the panel believed related to all areas of nursing science. Nurses who had examined issues of health care delivery using populations and community approaches would need to shift focus from studying health issues across populations to studying specific phenotype, or marker, variations. Nurse scientists would now “need to give special attention to multipurpose intervention studies, development of family models that allow for different definitions of family, and multifactorial studies in which cohorts are followed over a long period of time.” In addition, integrated research, that included “both descriptive and intervention studies, [was] especially needed for groups...at high risk, including

minorities, populations with special care needs, and families currently underserved by the health care system.”³⁶

As a relatively new area of study for nurse investigators, genetics also offered special opportunities to initiate multidisciplinary projects. The workgroup participants urged nurse scientists to stimulate genetics research by “piggybacking” nursing research components onto existing or new studies and sharing expertise on various aspects of genetics research at scientific gatherings. According to the report, “nurse researchers can take leadership roles and contribute to basic genetic studies with their biological, environmental, and behavioral linkages” and were “especially well positioned for fostering the necessary connections between basic and applied studies through the development and implementation of improved strategies for preventing and managing genetic disease.” Nurses, in effect, were ideally placed to guide patients and families in the use of genetic information to make health-related and ethical decisions and guide therapeutic approaches to ensure the safety and efficacy of treatments. Moreover, the NINR, Grady and her staff announced, would invest its extramural funds to advance such research and to develop a cadre of nurse scientists trained in genetics research to translate those findings into clinical practice.³⁷

A notable success of the NINR’s program to develop young scientists was the Summer Genetics Institute (SGI). Conceptualized in 1999, the SGI provided a two-month, full-time research training program on the NIH campus targeted at faculty, graduate students, and advance practice nurses to develop and expand genetic research capacity and to furnish a basis for clinical practice in genetics. Since the program began, more than 80 percent of its graduates have published peer-reviewed papers and presented their research findings at numerous national and international conferences. Moreover, the SGI experience often served as a springboard to additional research training and education.³⁸

The NINR followed a similar path in promoting the incorporation of nursing research into the environmental sciences. In September 1995



The NINR's Summer Genetics Institute provides intensive research training on the NIH campus.

the Institute of Medicine released a report, “Nursing, Health, and the Environment,” that stressed the need to enhance the occupational and environmental health content in the practice of nursing, nursing education, and research training. In the next year, the NINR convened an Environmental Health Sciences Working Group to identify the gaps in the knowledge base of environmental health science, to discuss promising research opportunities for nurse scientists, and to recommend research areas that could be explored through investigator-initiated research. A major attraction of environmental research for nurses lay in its public health aspect—the rich potential to expand from the laboratory into the community and, from there, to clinical studies. As Grady and her staff wrote in *Nursing Outlook*, “a compelling illustration of gaps in scientific knowledge regarding target populations and target research areas is evident in research literature, suggesting certain disadvantaged populations and communities may be at greater risk for environmentally induced diseases or health problems.”³⁹

Moreover, the nature of environmental research meshed perfectly

with the concept of interdisciplinary and multidisciplinary collaboration, ensuring that budget dollars could be stretched further. The NINR stressed that such coordinated efforts would be essential if nursing research were to have an impact on environmental health challenges. Grady and her coauthors pointed to existing partnerships that the NINR had with other parts of NIH in this area. One, with the National Institute of Environmental Health Sciences (NIEHS), sponsored programs for predoctoral and postdoctoral training in environmental health sciences. A second collaboration, with the NIEHS and NIH Office of Behavioral and Social Sciences Research, underwrote programs for community-based prevention intervention research. The NINR viewed this initiative as a model “for collaborating agencies to use in the science base needed by clinicians, target populations, policy makers, bioethicists, and decision makers to address environmental health issues.”⁴⁰

According to the Environmental Health Sciences Working Group, promising areas for the future ran the gamut of community-based nursing research approaches for investigator-initiated clinical studies. Among these were surveillance studies to identify populations at risk from exposure to work-site chemicals and radiation and investigations of the impact of pesticide behavior among migrant and seasonal farm workers. Other recommendations included cohort studies to tie health effects and exposure to environmental hazards, such as investigations to study the impact of pesticide exposure on reproductive functions and the consequent neurological functioning in children. The research examples, Grady and her team noted, “provide a mere starting point because the challenges in environmental health sciences for nurse researchers appear to be unlimited.”⁴¹

The annual increases in the NIH and NINR budgets for research funding during the second half of the 1990s, anticipated from the tobacco settlement and the federal budget surplus, gave some financial underpinning to the opportunities Grady envisioned. The Institute’s highest priority was to fund research project grants, with some 70 percent of

its appropriations targeted to support them, including both competing and noncompeting awards. As the NINR's funding rose, however, the trend in awards changed. In its initial years on the NIH campus, nursing research funded a higher percentage of new grants because there were few continuing projects. Over time, however, nurse investigators became more successful in getting longer-term grants, which committed funds for several years. Moreover, many projects in the NINR portfolio involved clinical research, which was more expensive. Coupled with the increasing average cost of grants, there was less funding available for new competing grants, despite higher appropriations. This situation made the need for collaborative agreements and partnerships with other institutes even more critical to stretch research dollars and maintain a growing pool of nurse scientists.⁴²

During these years the NINR also began to compete successfully for funds from the Office of the NIH Director. Two of these were particularly innovative: Shannon Awards provided discretionary funding to support scientists whose grant applications just missed the cut in any given major grant application cycle, and Academic Research Enhancement Awards supported smaller projects not covered by major NIH research grants. The NINR also competed effectively for funding from the Office of Research on Women's Health and the Office of Research on Minority Health.

With the support of the NIH director, the NINR had taken a leadership role within NIH for research on end-of-life (EOL) care. In the fall of 1997, the NINR co-sponsored a workshop to discuss managing symptoms in terminal illness. As a result, NIH provided the Institute with additional funding to support research in this area. In doing so, Varmus provided the NINR with both a challenge and an opportunity. It was up to nurse investigators to respond. Speaking at a conference of the American Association of Colleges of Nursing, Grady urged the nursing community to submit proposals for EOL care research. A year later Grady termed the response to the EOL research initiative "excellent" and looked forward to the scientific advances that would

emerge from that work. The EOL program was unique also because of its interdisciplinary nature.

By the late 1990s, increased funding allowed the NINR to expand its research and centers programs as well as its professional outreach. The future for nursing science looked bright, according to Grady. She encouraged nurse scientists, especially young professionals, to take advantage of all the possibilities. The NIH campus offered research opportunities for nurse scientists that “would be difficult or impossible elsewhere,” Grady said. “The enormous breadth of expertise across disciplines and diseases, a unique mix of intellectual and physical resources, and the proximity of clinical and basic researchers,” she noted, “create a rich environment for training and mentoring of young investigators.”⁴³

By the end of the twentieth century, the traditional paths of inquiry in nursing science—low birthweight, pain, chronic illness, and care for the elderly—were growing in significance as public health problems, influenced by demographic shifts, scientific and technological advances, and epidemiological trends. The aging of the population, the rise in chronic conditions, and the proliferation of treatment-resistant strains of known pathogens would alter the future of health care, Grady told a gathering at the Joint Center for Nursing Research and the School of Nursing at the Vanderbilt University Medical Center in 1999. So, too, would knowledge about human genetics result in new technologies that would improve the ability to diagnose and treat people. In addition, shifting population patterns would lead to an emerging majority of people of different cultures who were once in the minority. As a result, “health care team roles and functions will become more responsive,” she predicted.⁴⁴

Over the first two decades of the twenty-first century, the population cohort known as the “baby boomers” would enter the time of life when chronic illness was more common. The size of the generation was likely to overwhelm traditional systems, Grady believed. Because chronic conditions were the leading cause of illness, disability,



The NINR works to eliminate health disparities. Here, Dr. Grady poses with (left) Dr. Clifton Poodry, director of the National Institute of General Medical Sciences' Minority Opportunities in Research Programs, (right) Dr. John Ruffin, director of the National Center on Minority Health and Health Disparities and (far right) Dr. Betty Smith Williams, president of the National Coalition of Ethnic Minority Nurse Associations.

and death in the United States, health care costs required to meet this demographic shift would increase dramatically. As nursing research had long focused on efforts to understand and manage the symptoms associated with chronic illness and the prevention of related complications and disability, Grady saw the shift as a rich opportunity for nurse investigators. The same was true for genetic advances. As researchers closed in on completing the mapping of the human genome, scientific knowledge about predisposition to disease would rapidly accelerate. However, as new knowledge about genetics was absorbed into health care practice, people would face hard decisions about being tested for genetic diseases. Grady believed that, because nursing offered a patient-oriented rather than disease-oriented perspective, nurse scientists had an especially important role to play in the genetics of symptom management. As a result, the NINR began offering postdoctoral fellowships that linked training in nursing research and genetics and encouraged currently funded investigators to add a genetic component to their research projects.⁴⁵

The NINR also recognized the importance of the ethnic and cultural changes occurring in the country. Waves of immigration

from Latin America and Asia had a profound impact on the traditional delivery of health care in the country. Nurse investigators recognized that certain community-based health programs had failed to reach immigrant and other vulnerable populations. When they brought greater cultural sensitivity to the programs, including Spanish language assessment questionnaires, and targeted health behaviors that placed ethnic groups at risk, they became much more successful. The NINR began another initiative in self-management strategies for diabetics that included cultural, ethnic, and age-related factors. The Institute also responded by enhancing its outreach activities to underserved groups in collaboration with the National Coalition of Ethnic and Minority Nursing Associations. The NINR was instrumental in forming the coalition whose membership consisted of the major minority nursing organizations. Out of this partnership, the NINR sponsored a major conference, “Minority Health Research Development,” in the summer of 2000 to identify minority research plans and assist career development of minority nurse researchers.⁴⁶

The graying of the United States gave greater impetus to the NINR’s leadership role within NIH for EOL research initiatives. The goal was to establish additional empirical evidence to improve care for those approaching death. In 1996 the National Advisory Council for Nursing Research (NACNR) identified EOL research as a key initiative. NIH appointed the NINR as the lead institute the following year, in large part, due to its extensive research activities in pain management, clinical bioethics, and symptom management, all of which served as a foundation for EOL studies.⁴⁷

Of all the institutes at NIH, the NINR focused most intently on symptom management research. Many patients at the end of life experienced the same symptoms regardless of their underlying medical condition. Pain, difficulty breathing, episodes of confusion and loss of concentration, loss of appetite and muscle wasting, nausea, fatigue, and depression were the most common symptoms, adding significantly to the suffering of patients and the burden on their families. Nurse

scientists demonstrated that in many cases these symptoms could be treated or prevented and health care costs decreased.⁴⁸

For more than half a decade, the NINR had conducted research on symptom management through its Division of Intramural Research. It also funded a number of extramural programs on managing symptoms of AIDS patients and the aged. In the early 1990s, nurse scientists led by Dr. Mary Ropka from the Institute's Clinical Therapeutic Laboratory (CTL), in cooperation with the NIAID and the NIH Clinical Center, initiated the first intramural study at the NINR to develop and test methods of managing HIV symptoms and side effects. In collaboration with the NIA, the CTL also studied incontinence and the prevalence of postoperative complications from hip fractures. The NINR's participation in the Honolulu Heart Program and the Aging Asian Study, in collaboration with the NHLBI, expanded intramural research into the field of aging.⁴⁹

Extramural researchers also studied symptom management for



While the NINR has moved into new research areas over the years, it has remained faithful to its longtime priorities, including HIV/AIDS research, as reported by Dr. Antonia M. Villarruel, PhD, FAAN, at the NINR's twentieth anniversary symposium.

patients at the end of life. Dr. Virginia Tilden of the University of Oregon examined how families reached decisions about withdrawing life support and the effects of the attitudes and behavior of health care professionals on the patient's family. Tilden's work provided clear guidelines for helpful behavior on the part of clinicians, an outcome extremely important for the state of Oregon, which was on the cutting edge of EOL care and death-with-dignity legislation. Other NINR studies revealed the need for more emphasis on advance directives.⁵⁰

NINR extramural researchers also worked on three other critical areas of terminal illnesses—pain management, breathing difficulties (dyspnea), and loss of appetite and muscle wasting (cachexia)—and the results of their research began to have an impact. Nurse scientists at the University of Wisconsin in Madison developed an educational intervention to provide patients with information about analgesic side effects and opioid use to improve patients' appropriate use of pain medication. Dr. Jon D. Levine and Dr. Christine Miaskowski of the University of California, San Francisco, established that gender played a key role in pain relief, with women obtaining satisfactory relief from kappa-opioid drugs, which had fewer side effects than more typically used morphine-like opioids. Another researcher studied rats with cancerous tumors to test treatment interventions for loss of appetite in an effort to see if caloric intake could be improved by increasing the caloric content of the rats' diet. Instead, the results indicated that the rats adjusted their food intake by eating less to maintain a steady caloric balance. A study on dyspnea conducted at the University of California, San Francisco, found that people with chronic obstructive pulmonary disease could differentiate between the distress and anxiety associated with difficult breathing and symptoms associated with other stressors, leading to more specific treatments to manage the symptom.⁵¹

Most nurse investigators acknowledged that there was much research yet to be done on EOL care. At an NINR-sponsored Terminal Illness Workshop, participants recommended collecting better

epidemiological data on the incidence and co-occurrence of symptoms for EOL patients; conducting basic research on the mechanisms and interactions of these symptoms and on pharmacologic interventions, particularly opioid receptors; and increasing clinical research into drug therapies as well as mobilizing psychosocial and spiritual resources to mediate the perception and interpretation of symptoms. Research methods for EOL inquiry needed standardization. “There are pressing needs to better define key concepts, identify and test appropriate measures, and devise methods for complex data analysis,” Grady explained to a group at the Institute of Medicine. “In addition to basic research into the epidemiology and pathophysiology of symptoms and the mechanisms of symptom relief,” she said, “the foundation for improved care at the end of life requires social, behavioral, and health services research.” She also indicated that more needed to be “understood about the emotional, social, cultural, and spiritual experiences of people who are dying and about the attitudinal, organizational, legal, cultural and other factors which influence the care of those persons.” In light of its contributions to the knowledge base underlying the interaction of human biology and behavior, the NINR, Grady assured the meeting, would be an effective leader for the nine institutes, centers, and agencies co-sponsoring EOL research.⁵²

In addition to the challenges provided by changes in demographics, genetics, and environmental issues in the 1990s, some believed—though many disagreed—that nursing research faced a potential threat from the trend to managed care. With its emphasis on price controls, managed care was changing the practice of medicine and influencing the conduct of biomedical research. By the mid-1990s, many health professionals believed that managed care had caused a paradigm shift in health care and its long-range implications for science. At an NIH conference titled “Managed Care: Crisis and Opportunity for Biomedical Research” and coordinated by the NINR and the nursing department at the Clinical Center, Grady noted several concerns with the new developments, especially as they pertained to

clinical trials. She wondered if patients in managed care would be available for clinical trials or if research dollars would become more scarce as managed care organizations (MCOs) sought to reduce or eliminate payments for activities that did not immediately benefit the patient. It was a critical issue for nurses, Grady said, as “the success of clinical research, particularly clinical trials, is often dependent upon nurses.”⁵³

The complexities of the shift in health practices that managed care caused were just beginning to be understood. A study conducted at the Vanderbilt School of Nursing noted some of these changes. According to the school’s dean, Dr. Colleen Conway-Welch, if there were to be a trial including managed care patients, any MCO would want to be part of the planning, not simply presented with an already designed trial. Their databases were designed for business needs, not for research, she explained. Moreover, MCOs were interested in quick answers. An eighteen-month study, for example, would be seriously disrupted by patients leaving the study by switching MCOs at the annual window for changing providers, thereby damaging data designed for a full study and the possibility of follow-up.⁵⁴

Nevertheless, Conway-Welch noted that there were significant mutual interests between MCOs and nursing research. MCOs, she said, “value prevention, patient education, screening, early detection, and comprehensive treatment plans—all of which mesh well with nurses’ values.” Lowering costs was another area of mutual interest, added Dr. Dorothy Brooten of the Frances Payne Bolton School of Nursing at Case Western Reserve University. She presented several examples of how nurse-directed transitional care of women with high-risk pregnancies had fewer rehospitalizations and low birthweight infants, reducing hospital charges by 40 percent. “These sorts of numbers make bookkeepers sit up and take notice,” she said. “Nursing research is one of the best investments managed care can make.” The key, she emphasized, was to get the word out about the value of nursing research to the MCOs. Both women agreed that representatives of

managed health care companies needed to be included in nursing conferences, that nurse researchers needed to write op-ed pieces, and that the profession needed to do a better job of highlighting its successes to Congress and the public. “We should try to get published in *USA Today*,” Conway-Welch suggested. “Nurse investigators who are proactive and tenacious and who aggressively market their studies will be the most likely to thrive.” Grady moved to include MCOs in the NINR’s planning by naming Jean R. Marshall, the corporate vice president of Meridian Health Systems, to the NACNR in 1998.⁵⁵

Near the end of the twentieth century, Grady reflected on the achievements of research in advancing health care. She cited improvements in imaging techniques, molecular biology, and genomic mapping as factors changing the way health care would be delivered in the future. While the NINR had accomplished much as a small and very new institute, Grady believed that few understood those accomplishments. “One of my goals,” she said, “is that within five



In 1998 Dr. Grady welcomed five new members to the National Advisory Council for Nursing Research. Reflecting Dr. Grady’s desire to include current concepts of health care in the NINR’s planning was the appointment of Jean R. Marshall (2nd from left), corporate vice president of Meridian Health Systems. Also pictured (from left): Gene A. Blumenreich, Sarah J. Sanford, Dr. Grady, Dr. Kathleen Buckwalter, and Dr. Curtis L. Patton.



Dr. Loretta Sweet Jemmott, one of the foremost researchers on behavioral interventions for HIV/AIDS, particularly among African-American adolescents and adult women. At right, Dr. Monique Howard, of the New Jersey Women and AIDS Network, looks on.

years, everyone will be able to cite examples of how nursing research is making a difference.” To achieve this, nursing research translated into clinical practice—“from bench to bedside”—needed to be the focus for nurse scientists, she argued. The NINR’s goal in this equation was to encourage and sponsor the science that would “bring life to research and research to life.”⁵⁶

As part of the program to broadcast the accomplishments of NINR-sponsored research, Grady praised the work of selected nurse

investigators whose pioneering work led to new understandings of the impact of nursing research on patient care, the health care environment, and clinical practice. She cited the work of Dr. David Olds, whose studies in Elmira, New York, and elsewhere established that home visits by registered nurses significantly lowered mothers' high blood pressure during pregnancy. He also determined that the visits reduced abuse and neglect of the children. Olds's Nurse-Family Partnership demonstrated that nurse-visited mothers were more likely to enter the workforce and had fewer pregnancies before the first child's second birthday. Children in the program also demonstrated better language and behavior skills than nonparticipants. Another NINR pioneer investigator was Dr. Loretta Sweet Jemmott of the University of Pennsylvania School of Nursing. One of the foremost researchers on behavioral interventions for HIV/AIDS, her development of gender-appropriate, culturally sensitive programs for hard-to-reach, vulnerable populations reduced sexual risk behaviors for HIV, particularly among adolescent male African-Americans. Subsequently, the Centers for Disease Control and Prevention distributed her program, "Be Proud! Be Responsible!" throughout the nation. Along similar lines, the research of Dr. Martha Hill of The Johns Hopkins School of Nursing, using multidisciplinary health teams, successfully developed and tested strategies to improve hypertension control in young, inner city African-American males.⁵⁷

The NINR also targeted health disparities as a major research focus, which required community-based interventions that would teach self-management and other techniques to improve health behaviors. Dr. Kate Lorig, a senior researcher at the Stanford School of Medicine, applied a culturally sensitive self-management program at the community level for Spanish-speaking Hispanics suffering from chronic diseases such as heart disease, arthritis, type-2 diabetes, and lung disease. She found that participants in the program had improved health and energy, required fewer emergency room and physician visits, and were better able to manage their disease and to improve the quality of their lives.⁵⁸



Dr. Kate Lorig found that Spanish-speaking Hispanics with arthritis, diabetes, or lung disease were better able to manage their disease when she applied a culturally sensitive self-management program at the community level.

Of critical interest to nurses nationwide was the impact of staffing levels and working conditions on patient care. In a series of studies funded by the NINR, Dr. Linda Aiken, a professor of nursing and sociology at the University of Pennsylvania, demonstrated that hospital working conditions and the adequacy of nurse staffing per patient could significantly affect patient recovery. In hospitals where nurses had lower patient workloads, she found that patients had substantially lower mortality rates.⁵⁹

Aiken's research, as well as that of others, was applicable to efforts to improve the health care, and consequently lower the health care costs, of the elderly. For example, in 2003 the American Hospital Association estimated that the total direct health care expenditure for elders with heart failure exceeded \$24 billion annually. Since 1989 Dr. Mary Naylor, a professor of gerontology at the University of Pennsylvania School of Nursing, had conducted three NINR-funded clinical trials focusing on discharge planning and follow-up of high-risk elders by advanced practice nurses. Naylor's research aimed at reducing health care costs while improving health outcomes. She learned that customized intervention for the experimental group dropped costs by one-third when compared to routine care and improved outcomes by nearly 15 percent—results that helped change nursing practices for the elderly. Similarly, nursing homes and hospitals nationwide adopted the work of Dr. Nancy Bergstrom of the University of Texas School of Nursing. Bergstrom tested the Braden scale for predicting risk of pressure sores and found it to be quite accurate. As a result of her work, the Agency for Healthcare Research and Quality incorporated the scale into its Clinical Practice Guidelines. Since then, nursing homes and hospitals have used the guidelines to identify patients susceptible to pressure sores.⁶⁰

One of the most complicated issues nurses face is how to care for patients who are chronically critically ill. In a three-year, NINR-supported study at Case Western Reserve University, Dr. Barbara Daly and her team studied an intervention designed to reduce health care



Among other things, Dr. Linda Aiken demonstrated that working conditions and nurse staffing levels could significantly affect patient recovery and mortality rates.

costs and improve outcomes for the chronically critically ill who are released from hospitals. Daly learned that the best way to care for these patients was to treat them in an environment that is designed for long-term care. The most important element for a chronic patient's physical



Dr. Mary Naylor's research focused on reducing costs while improving outcomes for high-risk elders. Below, advanced practice nurses working on Dr. Naylor's NINR-funded heart failure study.



Left to right: JoAnne Konick-McMahan, M. Brian Bixby, Catherine McKenna.

and emotional well-being was continuity of nursing staff support. For these patients, Daly said, “it’s not the therapy, it’s the nurses.”⁶¹

The Center for Research in Chronic Disorders at the University of Pittsburgh School of Nursing is studying another significant element in examining the management and self-management of the treatment of chronic disorders. Headed by the school’s dean, Dr. Jacqueline Dunbar-Jacob, the NINR-funded center has focused on a combination of variables in chronic disorders, including the level of adherence to treatment in both patient and provider, management of treatment regimens, quality of life, functional status, and co-morbid conditions, and the central role that adherence plays in clinical outcomes. In addition to its research, the center provides mentorship and support for new and seasoned investigators and the dissemination of new knowledge about the care and treatment of persons experiencing chronic disorders.⁶²

Through such research initiatives, Grady said, NINR-funded investigators were reducing the impact of illness, improving the quality of life for the chronically ill, reducing health care costs, and changing both the clinical practice of nursing and the delivery of health care. “We are,” she proudly told a gathering of nurse scientists, “making a difference.”⁶³

In 2006, twenty years after the creation of the NCNR at NIH, the NINR developed a new five-year strategic plan “to advance nursing science through research.” A long-standing leader in integrating biological and behavioral science, the NINR believed that the field of biobehavioral research—the study of the interactions among biological, behavioral, and social factors and their effects on outcomes—distinguished nursing science from other NIH institutes. According to the plan, the NINR intended to remain a leader in applying the results of this interdisciplinary research and in expanding and improving nursing science methods. The Institute also planned for nurses to stay at the forefront of new technologies, especially for screening, symptom monitoring, and detection and delivery of interventions,

such as the applications of telehealth. To assure a solid foundation for future research, a critical mission for the NINR was to prepare the next generation of nurse scientists and nursing faculty and to increase the number of them holding PhDs. Moreover, the NINR would not only make research opportunities more available, Grady announced, but also make the activities and events at the Institute, the findings of its investigators, and general information about nursing science more available through the Internet via an updated Web site and podcasts.⁶⁴

The differences in the training of Hinshaw and Grady accentuated the changes that had occurred at the NINR since its inception. Hinshaw, a nurse whose graduate training was in sociology, represented the first steps in advancing nursing science. In contrast, Grady was trained in neurology, a basic “bench” science better understood and, accordingly, accepted than sociology by other scientists at NIH. Grady led the NINR in a harder science direction, something Hinshaw could not have accomplished because, in part, the nursing profession had not yet created enough trained investigators to conduct the research. Nevertheless, the careers of both women reflected the evolution of nursing science, each building on the accomplishments of those nurse scientists who came before them. For years, graduate schools of nursing had encouraged researchers to get clinical experience after their bachelor’s and master’s degrees. As a result, most nurse scientists did not earn their doctorates until they were in their mid-forties, thereby delaying their research careers and limiting the length of time they had to actually do research. The training of younger nurse scientists took time. Both leaders saw the need to create a sufficient cadre of nurse investigators who would build careers around their program of research. The NINR spent more than twice the percent of its overall budget on training as compared to the NIH average for pre-doctoral and postdoctoral students. The policy paid off. Applicants for NINR grants increased more proportionally than those for all other institutes. By the end of the century, graduate schools, through research opportunities largely funded by the NINR, had increased the number

of “fast-track” nurse scientists and thereby steered nursing science into the mainstream of NIH research.⁶⁵

Grady was the embodiment of what many had in mind in the 1980s when they pushed for nursing research to become part of the mainstream of biomedical and behavioral science at NIH. She approached her job the same way a scientist approached a problem, she told *The NIH Record* in late 2000. “Collect the data, analyze it, look for the best possible approaches and solutions, weigh them and then make a decision.” Grady pushed nursing research, while respecting its core, to be more like research at other institutes—both an integral part of and a vital partner to the work done throughout NIH. “Interrelationships of mind and body—between biological and behavioral—are increasingly under study at NIH,” she wrote in a survey of the nursing profession published in 2001, “and nursing research has long been active in this area of inquiry. NIH scientific activities in prevention also benefit from nursing contributions,” she continued, and suggested that “together, NIH and NINR emphases coincide with national health concerns, such as prevention of low birthweight, reduction of cardiovascular disease and cancer, reduction of obesity, and issues surrounding end-of-life and palliative care.” Whatever changes were shaped by scientific breakthroughs, changing economic and demographic trends, or new health care theories, Grady believed that health research, health care, and health choices were increasingly interdependent and insisted that the NINR be fully responsive to those changes in order to meet future health care issues head on. “If nurses think they’re interested in research,” Grady said, “they should just jump in.” And the NINR would provide the support to make it happen.⁶⁶

Chapter 4 Endnotes

- 1 See Patricia Moritz, telephone interview by Philip L. Cantelon, March 13, 2008, 18-19; Suzanne S. Hurd, "The National Institute of Nursing Research of the National Institutes of Health," *Nursing Outlook* 43, no. 2 (March/April 1995): 89.
- 2 Marquis *Who's Who in America*, 2009.
- 3 Suzanne S. Hurd, "RX for a Healthy NINR," *Nursing Research* 44, no. 1 (January-February 1995): 3.
- 4 See Patricia A. Grady, "A Brief History of Nursing Research," September 11, 1996, NINR Records, Grady Folder.
- 5 Hurd testimony to the House Subcommittee of the Committee on Appropriations, 104th Cong., 1st sess., part 4 (March 22, 1995), 982-83.
- 6 *Ibid.*, 983.
- 7 Hurd, "RX for a Healthy NINR," 3.
- 8 Hurd, "The National Institute of Nursing Research," 92; Hurd, "RX for a Healthy NINR," 1, 3. For an explanation of grant activity codes, see http://grants.nih.gov/grants/funding/ac_search_results.htm.
- 9 Hurd, "The National Institute of Nursing Research," 91-92.
- 10 Patricia A. Grady, telephone interview by Philip L. Cantelon, January 26, 2009, 19, 15 (hereafter Grady Oral History).
- 11 Grady curriculum vitae, January 2009; Grady Oral History, 12-14, 16.
- 12 Grady Oral History, 15-17.
- 13 *Ibid.*, 18-19.
- 14 Grady curriculum vitae, January 2009; Grady Oral History, 1-4.
- 15 Grady curriculum vitae, January 2009; Grady Oral History, 9.
- 16 Grady Oral History, 9-10; Grady curriculum vitae, January 2009.
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- 18 *Ibid.*, 22-23, 25-26.
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- 21 *Ibid.*, 28-30; NIH News, n.d., Press Release on Patricia A. Grady Appointment, NINR Records, Box A, Folder: NINR Resources.
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- 24 NINR, "Economic Benefits of Research," September 7, 1995, 1-3, NINR Records, Box 17, Folder: Misc. Clips. This document was written by the Office of Public Affairs and Education in May 1995 and released in the fall. Avery, "Nurse Education Act," 281.
- 25 *Biographical Directory of the United States Congress, 1774-1989* (Washington, D.C.: Government Printing Office, 1989), 1662; Grady Testimony, 1902. The Genome Center became an institute in 1997.
- 26 Grady Testimony, 1898, 1867. It is important to keep in mind that, as a member of the executive branch, the director's request must mirror the request of the President.
- 27 Marianne Glass Duffy, "Hundreds Celebrate NINR's Tenth Anniversary," *The NIH Record* 48, no. 24 (November 19, 1996).
- 28 Patricia A. Grady, "Landmark Anniversary for Nursing Research at the National Institute of Health," *Image: Journal of Nursing Scholarship* 28, no. 1 (Spring 1996): 4.
- 29 *Ibid.*, 5; Patricia A. Grady, "NINR and the Nursing Research Community: The Next 10 Years...The Next Century," *Nursing Outlook* 45, no. 1 (January/February 1997): 43.
- 30 Grady, "NINR and the Nursing Research Community"; see also Grady Testimony, 1866. About this time, leadership in the NIH pain research initiative was shifting from the National Institute of Dental Research (now National Institute of Dental and Craniofacial Research) to the NINR and the National Institute of Neurological Disorders and Stroke. See http://www.history.nih.gov/exhibits/pain/docs/page_13.html.
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- 37 *Ibid.*, 217-19; see also, Hilary D. Sigmon, "Linking Critical Care Nursing and Genetics with Research Funding Opportunities," *AACN Clinical Issues* 9, no. 4 (November 1998): 569-73.

- 38 Patricia A. Grady, "Intramural Research and Training at NINR," *Nursing Outlook* 55, no. 4 (July/August 2007): 209.
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- 41 *Ibid.*, 75.
- 42 NINR Update, March 13, 1998, *passim*, NINR Records, Box H, Folder: Speeches, Vol. 3.
- 43 *Ibid.*
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- 54 *The NIH Record*, March 25, 1997.
- 55 Conway-Welch and Brooten quoted in Grady speech, "NINR: The First 20 Years"; *The NIH Record*, August 11, 1998.

- 56 Patricia A. Grady, "Bringing Research to Life," *Applied Nursing Research* 11, no. 1 (February 1998): 1; Robert Bock, "NINR's Grady Manages Science with Science," *The NIH Record*, November 28, 2000.
- 57 Grady speech, "NINR: The First 20 Years"; Andy Goodman, "The Story of David Olds and the Nurse Home Visiting Program," Robert Wood Johnson Foundation (July 2006), 14. Dr. Martha Hill was the first non-physician to serve as president of the American Heart Association.
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- 60 Ibid.
- 61 Barbara Daly, "Chronic Critically Ill Patients Pose Special Challenges," *AACN News* 18, no. 1 (August 2001).
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- 65 Bock, "NINR's Grady Manages Science with Science"; Megan Flaherty, "Making Its Mark: Institute of Nursing Research Gaining Clout at the NIH," *Nurse Week/Health Week*, May 6, 1999, copy in NINR Records, Box G, Folder: NINR in the News, May 1999.
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The NINR's early support of cost effectiveness research led to a program that saved \$18,560 per infant in hospital and physician costs while improving the neonatal environment.

Speaking the Language of Science

For the past twenty-five years, from its earliest days as the National Center for Nursing Research (NCNR) until today, the National Institute of Nursing Research (NINR) has steadfastly supported both basic and clinical science, the training of nurse scientists, and the development of individual, community, and public health strategies to improve the health of the nation. In the spring of 1987, NCNR acting director Dr. Doris Merritt explained the multidisciplinary nature of nursing. She noted that nursing research broadly encompassed “studies relevant to individual responsibility for wellness and the diagnosis, treatment, and prevention of disease” and included “both the scientific inquiry into fundamental biomedical and behavioral processes relevant to nursing and study of the applications of nursing interventions in patient care.” Merritt also highlighted the NCNR’s efforts to “enrich the research training of top caliber nurse scientists” and “assure that properly prepared nurse investigators will continue to contribute their unique point of view to health care.” Such efforts included emphasis on individual postdoctoral training opportunities in established National Institutes of Health (NIH)-funded research centers, as well as NCNR-initiated career development awards for nurse scientists and NCNR-provided institutional research training opportunities for both

pre- and postdoctoral trainees. It was the NCNR's intention, Merritt emphasized, to ensure "that the nurse scientists of the future will be adequate in number and extremely well qualified." For the first time, nursing science would have the funding and the flexibility to tackle the broad demands of the nation's health care issues.¹

But the challenges for nursing science became far more complex than professional leaders might have imagined. By the 1980s, public officials faced new sets of public health questions on a scale largely unanticipated by previous generations. As America's population aged, officials focused on treating chronic and degenerative diseases such as Alzheimer's disease and dementia, pain management, and end-of-life (EOL) care. The spread of highly infectious and mutating viruses presented fresh challenges to affected communities and caretakers. In each case, questions arose regarding a patient's symptoms and quality of life, the long-term costs of treating the diseases, and the impact on families and communities. New genetic technologies opened previously unimagined research paths. The NCNR/NINR's efforts to fund basic and clinical scientific inquiry and train nurse scientists put it in the vanguard of contemporary public health concerns. The NINR's mission was simple and direct: "To strengthen nursing practice to promote health, prevent disease, and ameliorate the effects of illness and disability through the support and conduct of research, research training, and dissemination of research results." NINR director Dr. Patricia A. Grady emphasized this responsibility, noting the NINR's goal of advancing "nursing science by integrating biological and behavioral science for better health, adopting, adapting, and generating technologies for better health care, improving research methods, and developing nurse scientists for today and tomorrow." Reflecting on NINR's history, Grady characterized the Institute's role in the advancement of nursing research in the United States as "a journey," the result of which "is not only the advancement of nursing science but also the improvement in the health and well-being of millions of Americans and countless numbers worldwide."²

A key factor in the NINR's advancement of nursing science has been its role in developing the National Nursing Research Agenda to establish funding priorities for investigators in the faculties of nursing schools and the nursing community. By the late 1980s, a few important developments made this possible. The Health Resource and Services Administration Division of Nursing had developed an initial cadre of nurse investigators within academic/clinical research positions, but the total number was small and the growth of nursing science frustratingly slow in the opinion of most nurse scientists. Nonetheless, these nurse investigators, products of an earlier focus on the preparation of researchers, provided an important foundation on which the NCNR could build. Only with large-scale federal funding could doctoral programs at schools of nursing prepare more scientists who recognized the importance of research to the profession, who conducted research in their own disciplines, and who possessed the skills to apply the research findings in practice. The establishment of the NCNR in 1987 accelerated this shift in education from focusing primarily on the preparation of nurse scientists to mentoring graduate and postgraduate scientists in the more sophisticated research required to address current societal health care issues. The NCNR's resources, though puny by NIH standards, provided nurse investigators with a stable source of funding and allowed the Center to set national priorities in the field.³

NCNR officials determined that setting nursing research priorities was an important part of establishing excellence in nursing science, reasoning that research programs for nurse investigators that included series of studies in one common area, with one phase built on the results of the prior phase, would develop depth in the area of study and produce better science. As studies expanded knowledge through dialogue and critique among investigators, the logic went, the findings of the multiple studies would provide substantiated results that could be transferred into nursing practice. Setting research priorities as part of strategic planning for the discipline's scientific programs thus

allowed the nursing community to establish specific directions for nursing research.⁴

In early 1988, the NCNR and the National Advisory Council for Nursing Research launched the first of a series of national research agendas. Nurse scientists and policy makers agreed that the research priorities had to address major critical public health problems and contribute to improving clinical practices. The NINR and its advisors ultimately identified a number of research priorities over the next two decades including, to name but a few, symptom management, preventive health measures, health disparities, and the value of nursing care. Nurse investigators later seized on new research opportunities, such as those offered by the emerging field of genetics. These research priorities shaped nursing's research agenda, producing scientific studies that contributed greatly to the development of nursing science and, in the process, produced several landmark studies that would change both nursing practice and people's lives. Nurse investigators not only spoke the language of science, they also translated it into practical use.⁵

Good science demanded good scientists, and the nursing profession had struggled to produce the number of highly trained PhD investigators needed to conduct advanced studies. Therefore, graduate training of nurse scientists was an immediate and critical priority. From the beginning, every director believed that the additional training opportunities offered by the NINR held great promise for the nursing community. Each highlighted the difference between the traditional course of nurse scientists and those involved in the NIH system. Experience with PhDs and MDs in the NIH system suggested that at least two to three years of postdoctoral research and training were necessary to produce a highly sophisticated, very capable, and competitive investigator. One director noted, however, that nurses typically began "their research careers later in life following extensive clinical practice." Even if they went straight through to their terminal degree, nurse scientists traditionally received their PhD, DSN, or DNS and began teaching without engaging first in postdoctoral research



The NINR has a long history of training nurse scientists for today and tomorrow.

training. Moreover, the median age at which nurses completed the PhD work bore out the distinction of delayed terminal degrees. “Of those doctoral students who receive federal training funds, nurses complete[d] the PhD by median age 41 years as compared to age 30 for basic biomedical PhDs, and age 32 for behavioral and social scientists.” The reason was simple. Nurses often pursued research careers only after obtaining advanced practice credentials and several years of clinical experience. Although nurses with advanced clinical backgrounds brought “vital questions and skills to the research arena from their practical experience in clinical and community settings,” when competing according to NIH standards, postdoctoral training was essential. For the first time, the Institute was not only “making it available, [it was] emphasizing it.”⁶

To implement the policy, the NINR intensified efforts “to provide diverse training and career development programs that meet the needs of individuals along a continuum of academic and clinical backgrounds.” Officials believed that increasing the number of rigorously trained nurse scientists was “essential to the continued growth

of nursing research programs.” The length of time needed to train nursing researchers, coupled with the later start of their studies, meant that trained researchers had fewer years to actually conduct research. By 2006, the Institute’s Strategic Plan included its commitment to programs offering not only high-quality training, but also innovative ways to address the disincentives to early and productive research careers. The NINR aimed to increase the pool of investigators and shorten the period from baccalaureate to the doctoral degree.⁷

Over the years, the NINR developed a variety of tools to emphasize training for nurse scientists. By the mid-1990s, the cornerstone of the Institute’s research training program, the National Research Service Award (NRSA)—the authority under which NIH supported preparation of individuals for careers in biomedical and behavioral research through institutional grants and individual fellowships—had surpassed \$4 million annually. NINR-sponsored NRSAAs included individual predoctoral fellowships (F31s), individual postdoctoral fellowships (F32s), senior fellowships (F33s), institutional training awards (T32s), and minority training supplements. The NINR also utilized Academic Investigator Awards (K07) and Clinical Investigator Awards (K08) to provide opportunities for sponsored research beyond the NRSA program. In 1995, the NINR replaced such K07 and K08 awards with the revised K01 mechanism, the Mentored Research Scientist Development Award–Nursing, to provide scientists with a period of sponsored research in which to gain expertise in new research areas or areas that would enhance their careers.⁸

The Institute also took advantage of partnerships with other NIH groups to train nurse scientists. Designed for postdoctoral students, the Nurse Scientist Training Program provided information regarding NIH resources, techniques in “grantsmanship,” and practical skills for building and advancing scientific careers. Early returns on the program proved positive; by the year 2000, 40 percent of the 181 participants submitted applications. The NINR utilized its intramural

program to sponsor interdisciplinary research training to exploit unique opportunities offered by the NIH campus, such as the National Cancer Institute Division of Cancer Epidemiology and Genetics' invitation to postdoctoral nurse scientists to work alongside its intramural investigators. Addressing the gap in postdoctoral research training between medical and nursing scientists, the Institute offered Intramural Research Training Awards to postdoctoral nurse scientists in the early stages of their careers. Likewise, the Institute initiated a Career Transition Award (K22) to provide intramural training experiences to help postdoctoral students embark on research careers. These K22 awards combined support for research training in an NINR or other NIH intramural laboratory, with subsequent resources for independent research in an extramural institution. After completing such training, the NINR expected individuals to obtain a research project grant (R01) to continue their investigations.⁹

Beyond expanding and restructuring its own training programs, the NINR also worked to coordinate and collaborate with underrepresented nursing groups and other governmental agencies concerned with nurse training. The Institute's intensified focus on attracting nurses from underrepresented groups to biomedical and behavioral research careers played a key role in this effort, including work with the National Black Nurses Association and the National Association of Hispanic Nurses to inform their communities about NINR research and research training opportunities. In 2000 the NINR organized the Minority Health Research Development for Nurse Investigators Conference with more than thirty representatives from major ethnic and minority nursing associations. The two-day conference addressed health disparities and career development for nurses and resulted in a partnership between the NINR, the National Coalition of Ethnic Minority Nurse Associations, and the NIH Center on Minority Health and Health Disparities aimed at developing recommendations for the nursing agenda for minority health issues and nurse scientists. Further, the NINR collaborated with the NIH Center on Minority Health on

partnerships between schools of nursing at historically black universities and more research-intensive universities.¹⁰

Since the first National Nursing Research Agenda, the NINR had for most of its history made symptom management a priority. The Institute urged investigators to develop effective assessment measures and intervention strategies for pain and other symptoms associated with acute and chronic illness, with an emphasis on bio-psycho-social parameters. This pain-related research fit well with the NINR's goal of developing basic and clinical research, epidemiological studies, and training, all of which would address individual and community health issues. Early studies, for example, included an examination of the clusters of clues nurses used in assessing pain in children, the type of care they selected, and the evaluation strategies they used to determine the effectiveness of treatment. Center-funded studies also included research regarding the prevention of pressure sores through using an evaluation scale to predict bed sore risk in varied populations and settings and the effectiveness of transcutaneous electrical nerve stimulations—the application of low-voltage electrical current to the skin—in the healing process.¹¹

Characterizing pain as “a costly, critical health concern,” the Institute suggested that beyond the suffering it caused, pain might adversely affect immune function and be related to increased tumor growth. Beyond its traditional focus on managing the symptoms of pain, the NINR affirmed its desire for improved assessment measures and biobehavioral interventions to assist patients. The NINR supported both basic and clinical research on pain in close collaboration with many institutes, including the National Cancer Institute (NCI) and the National Institute of Dental Research. Drs. Jon Levine and Christine Miaskowski of the University of California at San Francisco conducted a study on postoperative pain management following dental surgery. They found that two kappa-opioids, nalbuphine and butorphanol, produced “significantly greater pain relief in women than in men, even though the women reported higher amounts of pain initially.”



Understanding and managing pain is another of the NINR's longtime priorities. Here, nurse scientists aim to gauge a youngster's level of pain using an "OUCHER scale."

The results contradicted previous research indicating that kappa-opioids were not very effective in pain management. Unexpectedly, their findings stimulated advancements in the field of gender-based biology. The study suggested that the discrepancy in findings could be based on the previous studies' recruitment of male subjects rather than women. This methodological bias obscured evidence that kappa-opioids could be a good analgesic choice for treating women's pain, while a low dose actually intensified pain in men. The identification of this discrepancy and such implications underscored the value nursing science could provide in treating individual patients, as well as the science's contributions to medical understanding of public health questions.¹²

By the time Grady became director of the NINR, the Institute had taken the lead in a major research initiative on pain involving nine other NIH institutes. Grady's leadership catalyzed the NINR's interest in the phenomenon of pain at all levels, from the genetic and molecular, to the cell and organ, to the whole person. She noted that the NINR's focus would be "to understand the physical and behavioral

mechanisms that compromise recovery and quality of life.” NINR researchers explored mechanisms for controlling pain, including genetic differences and changes in the brain’s control of hormones and immune response. Investigators examined how to prevent permanent establishment of neural pathways for pain that perpetuate the discomfort after the removal of the pain’s cause. Beyond that, the NINR provided resources for other pain-related research, including a collaboration with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) regarding exercise programs for elderly with arthritis, as well as research suggesting that the use of antianxiety medications, such as Valium, to sedate patients before surgery blocked the effectiveness of the morphine to reduce pain after surgery. In keeping with its broader mission of supporting research to reduce health disparities, the Institute funded research for education, medication, behavioral change, and other protocols in treating sickle cell related pain.¹³

The NINR’s pain research portfolio also included funding to study perioperative pain, or the pain experienced during the patient’s time under anesthesia, during the operation, and in the recovery room. Dr. Gayle Page’s work at Ohio State University and later at Johns Hopkins University examined the impact that painful stress from surgery could have upon immune function and in promoting tumor metastasis. Page used an animal model to assess the specific role of local, peripheral, and central pain mechanisms as well as the role of the brain’s control of hormones as a consequence of surgery. Specifically, Page investigated the impact of pain associated with surgery on natural killer cells, a subset of lymphocytes (a type of white blood cell) and the development of metastasis. She sought to determine whether pain relief would affect surgical suppression of the proliferation of lymphocytes and natural killer cell activity. Page’s research found that “surgery compromised the animal immune system’s ability to resist metastasis” and that providing morphine before and after surgery significantly decreased the “observed metastatic-enhancing effects of surgery.” As

Grady noted, the study demonstrated “that management of pain is a physiologic necessity” requiring further research.¹⁴

HIV and AIDS represented another high-priority research area for nurse investigators, an area where nurses’ clinical experience proved particularly advantageous. By the mid-1980s, health officials characterized HIV/AIDS as an epidemic and Congress prepared to fund a broad array of research projects to combat it. Countless editorials and public health officials pointed out the crucial role that federal health planning and research funding could play in battling the disease. At the time, Merritt emphasized that AIDS research was “an area of major importance to which nursing research can make a major contribution in the essential areas of prevention, education, acute and chronic care, and support of individual families coping with personal disaster.” Recognizing this importance, she noted that the NCNR was “encouraging research that assesses the health effects of various nursing interventions at different stages of the illness and in various settings” and “the cost-effectiveness of these interventions.” In addition, the NCNR invited research proposals that identified predictive factors, ethical issues related to diagnosis and treatment strategies, and public policy questions concerning AIDS and AIDS patients.¹⁵

The NCNR used HIV/AIDS research to implement the Center’s broader goals of expanding programs at university research centers and with other institutes at NIH. A major focus was on the physiological aspects of HIV/AIDS and caregiving for patients with HIV-positive conditions, their partners, and their families. The NCNR budgeted \$510,000 for AIDS research in fiscal year (FY) 1988 and requested \$707,000 for the following year. By the end of 1988, the Center funded four multiyear AIDS-related studies, two at Johns Hopkins University, one at Case Western University, and a fourth at Rush University Medical Center in Chicago. As part of the Center’s effort to educate other NIH institutes about nurse scientists and to familiarize nurse investigators with other disciplines, the NCNR also held technology transfer conferences with the National Institute of Allergy and Infectious Diseases

(NIAID) targeted to nurses and social workers providing services to HIV-infected individuals. In addition, the NCNR worked with the NCI and the NIAID to develop and test protocols for the nursing care of patients with aberrant immune systems. Moreover, the Center contributed to decision making regarding AIDS policy through its participation in the NIH AIDS Executive Committee, the Public Health Service Executive Task Force on AIDS, and the National Institute of Mental Health (NIMH) AIDS Policy Subcommittee.¹⁶

The NCNR underscored its sharpened focus on investigator-initiated research that addressed the multiple dimensions of AIDS relevant to nursing practice. The Center planned an increased research emphasis for educational strategies to prevent and contain AIDS infection, ethical and public policy issues related to nursing and AIDS, and factors relating to nursing care of persons with AIDS and their families or partners. Center director Dr. Ada Sue Hinshaw stressed the importance of direct efforts toward “decreasing morbidity and increasing the individual’s ability to cope with symptoms from the disease in order to maximize the quality of life and diminish both economic and personal cost.” Each of these approaches fit within nurses’ experience in clinical research settings. Using science, they served the dual public health goals of the discipline: treating individual patients and improving health within the community at large.¹⁷

The NCNR continued to stress the importance of AIDS research over the next few years. By the early 1990s, minority health, health disparities, and high-risk behaviors had become important public health issues; consequently, these topics received regular congressional scrutiny. The Center began seeking applications, in conjunction with the Agency for International Development, the National Institute on Aging (NIA), and the National Institute of Child Health and Human Development, for basic research to provide information concerning high-risk behaviors and behavioral changes related to the transmission of HIV throughout a person’s lifetime. The NCNR funded efforts to develop individualized, effective educational programs regarding safe

sexual behavior for adolescents. Further, the Center sponsored extramural studies focusing on culturally sensitive prevention strategies for high-risk populations.¹⁸

Intervention-based research continued throughout the late 1990s and early 2000s. As observed by Dr. June Lunney, an oncology nurse critical in establishing the NINR's HIV/AIDS research program and portfolio, the shifting profile of HIV-infected persons from "a group of highly educated and motivated gay men to a very vulnerable population"—including disproportionate numbers of minorities and increasing numbers of women—required the identification of prevention methods targeted to different populations. By the end of the 1990s, the NINR supported studies identifying or testing interventions to improve adherence to treatment regimens, including a community-based project testing the impact of self-efficacy-based intervention that stressed patients' ability and confidence to control symptoms and disabilities associated with the illness. Another study examined a phone-based intervention testing the benefits of a program of twelve independent sessions designed to improve patients' daily drug-taking habits through the development of self-assessment and problem-solving skills. The NINR also provided resources for symptom management research, including information and communication skills-building programs to improve pain management in AIDS patients, programs to reduce high-risk behaviors, and studies of the effect of exercise on symptoms of HIV infections.¹⁹

Research funding for the NINR's HIV/AIDS portfolio also continued to increase. By FY 1999, NINR support for HIV research increased to \$6.3 million. By FY 2006, the total was \$12.3 million and included studies of risk reduction in vulnerable populations, management of symptoms and complications, treatment adherence, methodologies, ethics and decision making, and EOL care. The NINR continued to sponsor conferences and discussions regarding HIV/AIDS, including the "Cultural Dynamics in HIV/AIDS Biobehavioral Research: Focus on Young People" workshop in September 2005,

which examined how best to understand and integrate cultural dynamics within the context of HIV/AIDS biobehavioral research focused on methodology and intervention development. Stressing the importance that research on culture and the intersection between history and culture could have for the health of population subgroups, workshop attendees emphasized the need for investigators to disseminate and sustain interventions, use methods that achieved cultural sensitivity, develop and test new measurements and interventions in a variety of settings, develop more provider-based interventions for prevention, pay attention to subpopulations, use meta-analysis to find commonalities and patterns among diverse cultural groups, and ensure “community buy-in.”²⁰

This emphasis on targeting interventions to distinct cultures matched the ongoing public health concern for, and congressional interest in, health disparities among ethnic groups. In response to this continuing concern, the Institute funded research focused on developing programs for different populations. The NINR’s support continued to result in significant research findings, including development of programs addressing the behavior patterns of distinct sets of the population. For example, Dr. Nilda Peragallo completed a study she began at the University of Illinois in Chicago examining HIV knowledge and prevention. Her study showed that an intervention provided by bilingual counselors and designed to decrease risky sexual behaviors among low-income Latina women resulted in improved HIV knowledge and communication skills among participants after six months. The NINR’s successful research programs thus demonstrated an ability to replicate and augment previous research findings, build upon the science, and provide real-world treatment for individuals and communities.²¹

In the late 1980s, a growing enthusiasm emerged within the nursing community for basic science research—a response, in part, to participating in the broader research trends at NIH. Acknowledging the need to support more biological and biobehavioral research, the NCNR convened the Biological Sciences Task Force in March 1990.



Dr. Nilda Peragallo, right, demonstrated that bilingual counselors could improve HIV knowledge among Latina women. At Jackson Memorial Hospital, August 10, 2004 (from left to right): Zehra Madhany, Jimmy Heredia, Teresa M. Rodriguez.

The task force reported “an increased need to develop nurse scientists who can use biological theory and measurement as the underpinning of nursing science” and the need “to increase research collaboration among nurse and biological scientists who conduct basic research.”²²

The meeting led to a ten-year plan to increase the use of biological theory and measurement in the conduct of nursing research. A 1991 report indicated that “few of the biological measurements currently in

use in nursing research are state-of-the-science” and highlighted the need for the NCNR to propose “research, training, and career development mechanisms” to facilitate the “use of ‘cutting-edge’ biological techniques by researchers in nursing.” In addition, the report advocated combining biological theory, measurements, and techniques within all priority areas of nursing research. In a 1993 article regarding the training of researchers, Dr. Marie J. Cowan of the University of Washington, along with Dr. Janet Heinrich of the American Academy of Nursing, Dr. Mary Lucas and Dr. Hillary Sigmon at the NINR, and then-director Hinshaw, suggested the need to increase not only the number of biologically based studies, but also the quality of measurements used in these studies. The NCNR expected that application of such skills to nursing would expand the understanding of both the relationship among biological, behavioral, and social factors in the manifestation of symptoms and how to manage those factors during illness and recovery.²³

Against this background, in November 1992 nurse scientists selected another set of research priorities, including cognitive impairment, to guide research funding between 1995 and 1999. These research priorities and the new emphasis on biological research would shape the development of nursing science in coming years. In 1995, NINR acting director Dr. Suzanne Hurd identified the linkage of biological findings from medical research with behavioral application as a major theme of the Institute’s research programs. When Grady assumed the directorship a year later, she pressed the importance of the NINR’s cognitive impairment research, which she characterized as “a national health care problem” accompanying “many disorders, including the dementias, AIDS, and stroke.”²⁴

The call for research to develop and test both biological and behavioral treatments for cognitive impairment fit well with the NINR’s goals of developing science to address individual and community needs. In the context of the country’s aging population, such research reflected the growing public health concern for EOL issues. Beyond its clear

benefits for individual patients and caregivers, research on decreased mental functioning also represented an opportunity to serve the community's need for lower health care costs. Citing an estimate in a 1995 report of the Advisory Panel on Alzheimer's Disease, the NINR noted that the financial burden of dementia, including costs of direct care and lost productivity, was approximately \$100 billion annually. The Institute acknowledged that effective therapies remained elusive and made a case for addressing symptoms in the best way possible. The NINR suggested that until the physical causes of impairment could be treated, the "greatest hope" for delaying or relieving symptoms lay in effectively managing the behavioral, physical, and functional problems associated with cognitive impairment, including wandering, falls, sleep disturbances, and inadequate nutrition. Noting that cognitive failures "rob people of their minds and deplete their material resources," Grady said the NINR's research aimed to prevent or delay such deterioration. She also underlined NINR-sponsored research to find non-pharmacological ways to manage the symptoms that accompanied cognitive



A participant in an NINR-funded study meets "Pearl," a humanoid from the Nursebot Project, in which nurse scientists aimed to learn how older adults would respond to navigational guidance offered by a mobile robot.

impairment as well as methods to help family caregivers deal with these problems.²⁵

The Institute grasped the implications—for patients, caregivers, and the nation—of estimates that more than 6 million individuals in the United States would have Alzheimer’s disease or related dementia (ADRD) by 2040. The NINR emphasized the critical need for interventions to reduce patients’ secondary symptoms and preserve optimal functioning and supported studies focused on behavioral interventions and the environmental context of care. The Institute also funded research into the harmful effects that caring for cognitively impaired individuals had for the caregivers’ immune function, well-being, and productivity. By 1994, the NINR had begun funding a significant number of studies with the NIA that examined symptom management with Alzheimer’s disease patients and aimed at helping families to handle eating and dressing problems, confusion, and wandering behavior. Preliminary investigations into wandering, disturbed sleep, and agitation served to establish a strong scientific base for large-scale clinical trials addressing behavioral, environmental, social, and organizational interventions to deal with ADRD symptoms.²⁶

Building a broad base of cognitive impairment research, the NINR sponsored projects, such as Dr. Mary Ann Matteson’s early 1990s work at The University of Texas Health Science Center in San Antonio, examining the use of behavioral and environmental modifications along with the reduced use of psychotropic medications in nursing home ADRD patients. Moreover, the NINR funded studies regarding decreased sleep disruption in ADRD patients and their caregivers, as well as the effects of a walking and conversational treatment on the communication ability of ADRD patients. Other studies examined the development of effective models for the family caregivers’ role as part of the management team. The NINR research programs examined the relationship between behaviors and the advancing neurological damage that ADRD patients experienced, as well as neurological and motor changes that contributed to important health problems, like urinary incontinence.²⁷



Nurse scientist Dr. Kathleen Buckwalter, second from right, at a Capitol Hill Breakfast Briefing on Women's Health and Chronic Illness in 1997. Also pictured are (left to right): Dr. Joan Shaver, Dr. Patricia A. Grady, Honorable Louis Stokes, and Dr. May Wykle.

Such efforts and research expansion continued throughout the mid-1990s. By FY 1996, the NINR requested \$3,370,000 for research on Alzheimer's disease, approximately 6.7 percent of the Institute's total 1996 budget. The NINR's research on disruptive behaviors accompanying ADRD included Dr. Kathleen Buckwalter's efforts at the University of Iowa to build upon and extend the Progressively Lower Stress Threshold model she developed with Iowa's Dr. Geri Hall. According to Grady, such studies demonstrated that family caregivers could use cognitive stimulation exercises in the home to decrease behavioral problems, improve overall mental functioning, and reduce stress for all concerned. With improvements lasting "up to nine months," patients were able to remain at home longer, with greater patient and caregiver satisfaction. Grady explained that research into the basic biology of Alzheimer's disease—including a "remarkable series of genetic discoveries"—contributed to "major advances" in understanding the disease. Together with the results of epidemiologic studies, such findings led to the identification of risk factors and of potential

protective interventions for Alzheimer's disease. For example, a study of elderly U.S. nuns found that the coexistence of Alzheimer's disease with vascular disease resulted in more severe dementia than expected on the basis of Alzheimer's alone. The study suggested that prevention or treatment of vascular disease could delay or reduce the development of symptoms in many Alzheimer's disease patients.²⁸

In addition, the NINR's focus on cognitive impairment included research involving the role of sleep in neurological functioning, including studies at the University of California, San Francisco, by Dr. Glenna A. Dowling that addressed the management of sleep in Alzheimer's patients and the use of bright light exposure and melatonin to improve outcomes for sleep disorders in patients with Parkinson's disease. In another study, Dr. Kathy Richards, then at the University of Arkansas for Medical Sciences, examined the effects of nonpharmacological interventions such as social activities and exercise to improve sleep patterns and disorders in dementia patients. Her work was soon



Dr. David Dinges points to one of several video monitors showing volunteers in his Sleep and Chronobiology Laboratory in the Hospital of the University of Pennsylvania. The lower monitors show the physiological recordings of the sleeping subjects.

translated into clinical practice in many nursing homes. By FY 1995, the NINR had also begun supporting interdisciplinary research at the University of Pennsylvania in the neurobehavioral effects of chronic sleep deprivation. Dr. David Dinges and colleagues studied the function of the nervous system, hormone profiles, core body temperature, and sleep/waking polysomnography—a diagnostic test recording physical variables—for various times of chronic sleep restriction to assess increased levels of sleep deprivation. The team also looked at the effects of sleep recovery when measurements were made during the day instead of nocturnally. Using both subjective and objective measures to record their findings, the researchers demonstrated a “significant decline” over time in behavioral alertness and memory, with the group with the greatest deprivation showing the greatest declines in performance. Given the important implications of chronic sleep deprivation for certain workers, the team’s researchers acted as experts for a variety of regulatory agencies on the risks of chronic sleep loss, including the Department of Transportation, National Aeronautics and Space Administration, Department of Justice, National Transportation Safety Board, and Association of American Medical Colleges.²⁹

In the new century, the NINR continued to sponsor research regarding symptom management for degenerative diseases. The Institute provided resources for researchers studying the effectiveness of a nighttime alarm system to monitor wandering in Alzheimer’s disease patients as well as the efficacy of individual daytime activities to replace napping and improve sleep at night. The NINR also funded studies to improve functional ability in nursing home residents with dementia, with particular emphasis on dressing and bathing. The Institute supported, in collaboration with the NIA, the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE). In 2008, ACTIVE researchers showed that older adults with pre-existing mild memory impairment benefited from certain forms of cognitive training that did not rely on memorization as much as adults with normal memory function.³⁰

Another focus of NINR-sponsored research was improving experiences for caregivers dealing with degenerative cognitive diseases. By 2001, an NINR-funded intervention study including selected information and behavior management skill training for caregivers of patients with dementia showed reduced caregiver depression scores among those who were initially depressed, fewer negative responses to the patient's disruptive behaviors, and a moderate decrease in perceived caregiver burden. In a related study, caregivers involved in community-training-based programs that focused on reducing the negative effects of stress by developing knowledge, skills, and beliefs regarding the caregiving role showed a 16 percent improvement in depression and feelings of burden and a 28 percent improvement in distress caused by behavior problems. In addition, the study showed a 9 percent increase in the number of study participants expressing a balanced assessment of their caregiving role.³¹

Collaborative research efforts with other institutes have become the hallmark of many NINR projects, stressing the interdisciplinary and cross-cutting science that is becoming the norm for cutting-edge nurse investigators. Such a strategy provides nurse scientists with fresh interdisciplinary perspectives and stretches available funding due to the cost-sharing arrangements between institutes. The NINR and the National Heart, Lung, and Blood Institute teamed to sponsor research seeking to improve self-care behavior and outcomes in rural patients with heart failure. Led by Dr. Kathleen A. Dracup of the University of California, San Francisco, the research scientists, using a controlled multisite clinical trial with 700 patients living in rural areas, are testing the effects of an educational intervention focused on fluid management on hospital readmissions and mortality. The study is being conducted by an interdisciplinary group of researchers from nursing and medicine, disciplines that usually work as a team to care for this population. Investigators also will calculate cost effectiveness based on the net cost per hospitalization averted or year of life saved. If effective, the study will be broadly applicable and lend valuable insight about treatment of heart failure in rural settings.³²

In another collaborative project, the NINR supported the Resources for Enhancing Alzheimer's Caregiver Health initiative with the NIA. This study consisted of six sites across the country and addressed family caregiving for Alzheimer's disease patients, with special emphasis on underrepresented populations. At one site, NINR scientists focused on African-American and Caucasian caregivers' ability to cope with daily stress and to manage the behavioral problems of Alzheimer's patients. Despite differences in psychological distress, physical health, and cultural and socioeconomic conditions, the researchers designed responses to the common needs of both populations. The NINR also sponsored Alzheimer's research by Dr. Louis Burgio of the University of Alabama at Birmingham. Through interviews, Burgio found that African-American caregivers reported more positive aspects to caregiving than did Caucasians, as well as lower levels of anxiety. As a result, these findings suggested that health care professionals should promote such strategies to all family caregivers, regardless of race. Such NINR-funded results highlighted the partnership among nursing science, individuals, and community health. Addressing the biological bases, behavioral problems, and caregiver impact of cognitive impairment, the NINR's research again investigated and mitigated the physical, emotional, and financial impact of such diseases and disorders on individuals and the community at large.³³

By 1996, the NINR had entered the final years of its second National Nursing Research Agenda. The landscape of nursing science had changed in the intervening five years, such that the Institute convened new panels to discuss future research directions. One such panel at the cutting edge of science was the Work Group on Opportunities in Genetics Research. The emerging field of genetics offered fresh opportunities for nursing research, including basic biologic and behavioral investigations as well as clinical and population studies. Nurse scientists, the work group believed, could take leadership roles and contribute to basic genetic studies with their biological, environmental, and behavioral linkages. The work group also emphasized opportunities in

genetic determination of physical responses and applied studies aimed at translating basic science findings into interventions to solve clinical problems.³⁴

Early NINR-supported genetic research, such as the work of Dr. Janet Meininger from the University of Pennsylvania, explored these avenues of inquiry. Meininger examined genetic variation and specific risk factors for cardiovascular disease in identical/fraternal twins, underscoring the implications that genetics could have for individual patient treatment. She argued that understanding the role of genetic factors in hypertension would revolutionize the ability to prevent and effectively manage that widespread problem. Such information, she demonstrated, could lead informed practitioners and clinical researchers to successfully apply the rapidly expanding knowledge of human genetics. At the same time, the NINR began funding research training and career development programs focusing on genetic research, such as a predoctoral award to investigate the interplay between cognition and the Apolipoprotein E genotype in late-onset Alzheimer's disease. The Institute sponsored senior fellowship grants, such as a research grant aimed at developing effective genetic educational interventions for teaching at-risk populations about hereditary cancers. The NINR also funded career development awards for genetics research, including the potential of gene therapy to treat cachexia, which is the loss of weight and muscle mass caused by disease.³⁵

In the spring of 1998, Grady explained to Congress the importance of genetics in the future of nursing research. Anticipating a great deal of activity in that area, she stressed the potential impact of the NINR's study of genetics on disease risk factors and the development of an ethical decision-making model for testing. As its early training awards suggested, the Institute recognized that beyond the clear opportunities genetics held for nursing researchers, the field also presented them with a set of distinct training challenges that would require innovative solutions reaching a larger number of nurse scientists and clinicians. The NINR, she said, needed to build a robust nurse training program

and boost the ranks of nurse scientists and nursing school faculty prepared to incorporate genetics into their studies.³⁶

Genetic research's cornucopia of opportunities—and concomitant training challenges—merged with the NINR's long-standing efforts to provide training for nurse scientists. As Grady noted, scientific breakthroughs like genetics continued to “reshape” the way health care was provided, requiring nurses to “translate new technology into health care at the personal level—to the healthy and ill in communities, hospitals, and residences.” Almost simultaneously, the ability to identify individuals at risk for heritable disease “rapidly outdistanced the ability to counsel them about what to do with that knowledge.” This widening gap created a significant research path for nurse scientists, but it required that they be trained in genetics. By 1999, “a time when the topic was rarely seen in nursing curricula,” according to Dr. Pamela Hinds of the Children's National Medical Center in Washington, D.C., the Institute had begun developing plans for an intensive training course in genetics for nurse scientists, and in 2000 the NINR launched the Summer Genetics Institute (SGI) for extramural researchers. An eight-week training course, the SGI emphasized genetics in clinical practice, in the research laboratory, and in nursing curricula. As the NINR's intramural training director Dr. Mindy Tinkle noted, the program enabled “graduate students and faculty to develop or expand their research capacity” and enabled “advanced practice nurses to develop and expand their clinical practice in genetics.” By 2008, SGI students discussed clinical case studies and attended lectures and seminars focused on a range of ethical, social, legal, and public policy issues. They spent approximately 100 hours in the laboratory, learning basic techniques used in molecular biology to promote their understanding of the technology of genetic testing.³⁷

Building the growing cadre of nurse scientists equipped to conduct genomic-based research, the SGI produced graduates who developed research grant applications and published papers applicable to clinical practice and research. These NINR-supported scientists facilitated the

integration of genetic content into the curricula of nursing schools. In its first ten years, the program graduated 182 people from across the country and produced more than 130 peer-reviewed papers. More than one-third went on to receive federal funding for their research projects. Through 2009, SGI graduates had won twenty-one predoctoral fellowships and eight postdoctoral fellowships, among other awards. As a measure of the program's success, the SGI shaped the careers of former graduates as they continued their education and career development. Many graduates of the SGI and the Graduate Partnerships Program in Biobehavioral Research continued to pursue genetic and hereditary health research questions. Meeting expectations, the SGI proved to be a springboard for nurse scientists to join the ranks of genomic researchers and an important foundation for their careers. Before the SGI, Hinds observed, "nurses at all levels of preparation were not being exposed to genetics, the role of genetics in health, and the role of nursing in genetics. But that has changed at amazing rates since the NINR created the Institute and began funding very important research related to genetics."³⁸


The completion of the Human Genome Project in 2003 and subsequent research efforts led to major changes in the clinical practice of nursing. By focusing on health rather than disease, nurses were central to using information about the function, structure, and interactions of genes with the goal of improved outcomes. In a key article in the *Journal of Nursing Scholarship*, Dr. Jean Jenkins, a senior clinical advisor, Dr. Francis S. Collins, then director of the National Human Genome Research Institute, and Grady emphasized that the science of genomics was "creating important and profound changes in nursing education, practice, policy, and research. The vision of researchers and clinicians in genomic health care contains three themes," they wrote, "genomes to biology, genomes to health, and genomes to society." They encouraged nurses to become literate in the field, to "assimilate and integrate this burgeoning genetic and genomic science." They concluded, "Nurses, with their long tradition of being educators, and with

sensitivity to emotional and psychological issues and advocacy, are ideally suited to address the emerging needs of patients, families, and communities. Through education, research, and clinical applications, nurses can accelerate the pace of integrating genomics into options for care, thereby contributing significantly to reshaping and optimizing health care.” More than ever, nurses needed to speak and translate the language of a new science.³⁹

As the century ended, the NINR increased its collaboration with other institutes and cemented its place within NIH. Grady’s vision for the NINR was to “demonstrate the essential nature of our science in every institute and center across the campus—that we could tie the science more closely to NIH programs.” Noting that nurse scientists were new players on the scientific research campus with the advantage of starting out when the climate was becoming more collaborative, Grady observed that the “days of scientists in their little closet doing an experiment were over.” The nature of research questions, she argued, now required a more collaborative effort in many more cases than earlier eras. The ability to collaborate with other institutes also fit well with the ethos of nursing research, since it was not disease specific, nor was it dedicated to a particular age group or population. Instead, nursing research asked questions that probed “the very core of patients’ and families’ personal encounters with illness or its avoidance, perhaps to a more immediate, intense extent than other disciplines of science.” Given the NINR’s breadth of research, it was critical that the Institute continue to collaborate across the spectrum at NIH, including work with the NIAMS, the NCI, and the NIA, as well as the NIAID. The NINR’s ability to collaborate across age and disease spectra proved essential as the Institute assumed a new and important leadership role within NIH with EOL issues.⁴⁰

A 1997 Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*, found “widespread dissatisfaction with EOL care and many gaps in scientific knowledge about the topic.” Recognizing the need for greater cohesion for EOL research and the

See
 Short clips from the PBS
 series "On Our Own Terms -
 Patients on Their Way"



Tuesday, November 14
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The End of Our Lives

GUIDING
 THE RESEARCH
 AGENDA

Hear Experts
 In the Field

Thomas Insel, MD
 Director and Chair, Division
 of Neurobiology/Neurology
 Medical College of Virginia

Ann Spong, MD, MBA, MS
 Chief, Pall and Palliative
 Care Service
 NCI Clinical Center

Charles Grady, PhD, RN
 Senior Advis, Department
 of Clinical Research
 NCI Clinical Center

Richard Payne, MD
 Chief, Pall and Palliative
 Care Service
 Memorial Sloan-Kettering
 Cancer Center

Discussion Issues

- Technological Interventions
- Palliative Care
- Ethical Concerns
- Ethical and Cultural Factors

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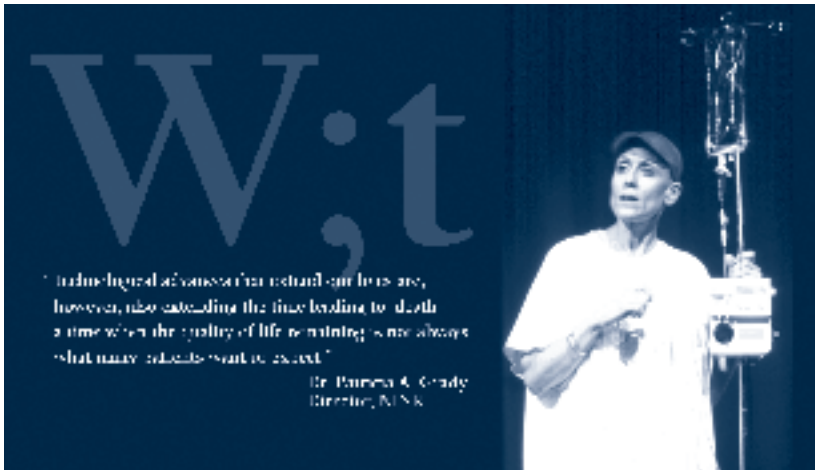
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 Special Interest Group



The NINR is the lead institute at NIH for end-of-life research.

NINR's emphasis on symptom management, NIH director Dr. Harold Varmus designated the NINR as the lead NIH institute for EOL research. Grady also believed the NINR was the logical lead for EOL research, explaining that the Institute's research encompassed "people at all ages, from all populations, and who die from many different causes." After its designation, the NINR helped frame the fundamental issues and spur research in this relatively new area. In 1999, the Institute received more than 100 responses to its request for applications on EOL care. By 2001, the NINR funded twenty-two studies and seven training and career development awards.⁴¹

As the lead institute for EOL research, the NINR's portfolio focused on the physiological and psychosocial components of symptom management, communication, ethics and clinical decision making, caregiver support, care delivery, and quality of life. For example, studies found that only 20 to 30 percent of patients completed advance directives and that families making decisions to halt care of terminally ill patients without the benefit of such directives from the patient experienced a high level of stress that often continued for months after the patient's death. Moreover, in acute care settings, advance directives "significantly" relieved the high level of family stress associated with decision making related to terminal care. Other prominent studies included focus on EOL care ethics, such as nurse scientist Dr. Sharon L. Tennstedt's work at New England Research Institutes, Inc., examining the prevalence, nature, and progression of symptoms in patients with congestive heart failure and chronic obstructive pulmonary disease, as well as the impact such symptoms have on quality of life and their effects on health care costs and utilization. Similarly, Dr. Marie T. Nolan's study at Johns Hopkins University modeled EOL decision making to focus on the preferences of terminally ill patients. Dr. Mark Rubert from the University of Miami examined the use of "Tele-Care" as psychosocial support for elderly caregivers of terminally ill cancer patients, and Dr. Dana Mukamel at the University of Rochester studied the utilization of medical resources and place of death for individuals



In March 2000 the Institute co-sponsored “An Evening of *W;t* and Wisdom: The Science of Care and Compassion at the End of Life.” Actress Judith Light starred in the play *W;t* as a woman with ovarian cancer.

enrolled in a managed care program, including related costs and quality of life and death. Addressing ethics, quality of life, and health care costs, these early studies provided an important base upon which the NINR built its EOL research program.⁴²

The NINR’s efforts to provide scientific leadership for EOL research at NIH included funding for NIH-wide symposia and events to spur discussion of EOL issues. In March 2000, the Institute co-sponsored *An Evening of *W;t* and Wisdom: The Science of Care and Compassion at the End of Life*, which included a performance of this Pulitzer Prize-winning play detailing a patient’s EOL experiences along with a pre-play reception and a post-play question-and-answer forum. Later that year, the NINR also helped form the NIH End-of-Life Special Interest Group to address issues relating to research in this area. That group held a forum entitled “The End of Our Lives: Guiding the Research Agenda” to discuss ethnic and cultural dimensions of EOL issues, the role of palliative care, ethical issues, and the role of technology during the final phase of life.⁴³

To collect a wide array of information and ideas from across other disciplines, the NINR sponsored similar meetings and workshops

regarding EOL issues, including the “Integrative Workshop on End-of-Life Research: Focus on Older Populations” in October 2001; “Ethical Challenges in End-of-Life” in September 2002; “Moving the Research Agenda Forward for Children with Cancer” in August 2003; and “Developing the Capacity for End-of-Life and Palliative Care Research” in August 2004. In addition, the NINR spearheaded the Department of Health and Human Services-wide End-of-Life Scientific Interest Group, which united agencies both internal and external to NIH. The group was the conduit through which the NINR coordinated EOL scientific activities, as well as activities to raise the profile of EOL research, including lectures regarding developments in palliative care and research approaches to meaning and spirituality in EOL care. The NINR also worked with the American Association of Colleges of Nursing and the Association of Academic Health Centers to videotape six one-hour continuing education programs for nurses on end of life that were broadcast to 700 hospitals.⁴⁴

To improve EOL care by “fostering excellence in EOL research and evidence-based practice,” the NINR co-sponsored, with NIH’s Office of Medical Applications of Research, a conference to discuss the state of the science of EOL care. The conference’s panel of experts drafted a statement examining five key issues: the definition of the transition to the end of life; outcome variables that are important indicators of the quality of the EOL experiences of the dying persons and for the surviving loved ones; patient, family, and health care system factors associated with improved or worsened outcomes; processes and interventions associated with improved or worsened outcomes; and future directions for improving EOL care. Reporting that many patients and their family members still struggled with a lack of continuity of care and poor communication between health care practitioners, the panel indicated that ambiguity surrounding the definition of end of life hindered the development of science, delivery of care, and communication between patients and providers.⁴⁵

The panel also called for “rapid development of research

infrastructure” to improve understanding of what approaches were most effective for different groups of patients and recommended enhanced resources to deliver quality care to patients and their families at the end of life. The panel observed that although a growing body of research existed covering a wide range of issues, in many ways, rigorous testing and evaluation of models of care, in terms of patient and family outcomes as well as resource utilization, were still in their “infancy.” Emphasizing the need for research to understand patient, caregiver, and health care system influences on these outcomes, the panel detailed the need for research regarding conceptual models, infrastructure, methodologic issues, ethical issues, treatment, outcomes, and policy.⁴⁶

Beyond the various conferences and symposia that the NINR sponsored to raise the profile of EOL research and discuss its practice and implications, the Institute played an important role in funding ongoing research. Between FY 2001 and FY 2006, the NINR supported fifty-one grants, while an NINR review of EOL scholarship noted fifty-eight peer-reviewed publications between 1997 and 2000. In each case, the data showed an increasing number of funded EOL studies and publications over time, suggesting a growing science. The Institute also issued Program Announcements and Requests for Application in three distinct areas of end of life—quality of life, decision making, and care for dying children—as well as research regarding symptom clusters in cancer and immune disorders. For example, the NINR funded research examining EOL care outcomes of the Program for All-inclusive Care for the Elderly, a community-based managed care program for Medicare recipients aged fifty-five and older, aimed to promote continuity and communication between providers and recipients of care and enhance personal control in care at the end of life. Researchers found that the program helped elders both to develop an advance directive and maintain a continuity of care, thereby “increasing the likelihood” that their wishes would be followed.⁴⁷

More recent studies also began to address the 2004 panel’s observations regarding the breakdown of communication between providers,

patients, and families. Dr. Sharon Kaufman's study at the University of California, San Francisco, regarding inconsistent communication in discussing EOL issues, for example, found that nurses were seen as more available and more willing to share information with family members than doctors. Her study further suggested that most family members wanted doctors and nurses to offer hope, but stick to the truth and help them prepare for the worst. Similarly, Dr. J. Randall Curtis' work at the University of Washington examining communication with families regarding withdrawal of life support found that clinicians in intensive care units often missed opportunities for communication when addressing the concerns of family members while discussing withdrawal of treatment.⁴⁸

The NINR also continued to ensure exposure and funding for EOL issues. Grady reinforced the Institute's leadership for these issues with an August 2005 presentation to the NIH Institute and Center Directors' Meeting entitled "Symptom Management: Chronic Disease and End of Life," which focused on research addressing hard-to-reach populations, successful strategies, quality-of-life issues, and interventions that had been incorporated into practice. NINR planning documents for FY 2007-FY 2011 called for increasing the number of studies and publications and targeted self-management as an area of EOL research. These documents recommended that the Institute issue requests for research for EOL health disparities and for improving AIDS care at the end of life. The NINR's plans also suggested developing biobehavioral studies at the end of life, with research focusing primarily on intervention. The Institute sought to develop and increase EOL research capacity through targeted training opportunities and to collaborate with NIH institutes and centers, including those that had not traditionally collaborated with the NINR on EOL research, like the NIAID.⁴⁹

From its beginnings, the NINR proved an effective champion of the value and necessity of nursing science, an essential bulwark for the nascent but critical discipline, and the leading voice in defining its research priorities and training its future researchers. The NINR's

early agenda-setting work provided a basis for HIV/AIDS research, which fit well with the clinical experience of nurses. This work also developed education and behavior modification programs, interventions, and treatment for symptoms on which the Institute continues to build today. As nurse scientists recognized the need for expanded biological and biobehavioral research, the NINR's emphasis on cognitive impairment provided a hard science base upon which later neuroscience, sleep studies, behavioral management, and caregiver research would build. The Institute's funding for pain management research also built upon its basic science goals and made strides in understanding differences between the way men and women experience pain and in identifying the ways pain could adversely affect an individual's health. With the growing importance of genetic research, the NINR also appreciated the importance of training nurses for the future. The Institute revised training mechanisms and awards, partnered with other nursing agencies to create new training opportunities, and developed the summer genetics program for nurse scientists. After its appointment as NIH's lead institute for EOL issues, the NINR focused its portfolio on symptom management, communication, ethical decision making, and quality-of-life issues. The Institute also led NIH discussions regarding EOL issues in symposia and conferences.

Speaking the language of science since its earliest days, the NINR made possible the long-held, but difficult to implement, vision that nurses need to be scientifically informed, socially experienced, and technically expert. The Institute matched its desire to advance nursing science with the discipline's emphasis on study and preparation. Aligning the nation's nursing agenda and research in support of basic and clinical science, discovering new treatments and creating prevention programs, and producing highly trained nurse scientists for the future all proved key touchstones for evolving science. As the NINR grew, it did so within the context of a rapidly changing public health landscape. Genetic research provided novel opportunities and challenges. At the same time, an aging society became increasingly

concerned with the treatment and costs associated with chronic disease. Throughout its history, the NINR's leadership and the nursing community have responded, staying at the forefront of these emerging public health questions while maintaining nursing's traditional focus on individual and community health concerns.

Chapter 5 Endnotes

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- 16 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 100th Cong., 2d sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 1988), 1014. According to Hinshaw, the Advisory Council also recommended that prevention and care for low birthweight infants be an area initially developed. See also: House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 100th Cong., 2d sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 1988), 1038, 1068; CRISP Database, <http://crisp.cit.nih.gov/>; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 100th Cong., 1st sess., H.R. 2990/H.R. 3566 Part 2 (Washington, D.C.: U.S. Government Printing Office, 1988), 1230.
- 17 *Ibid.*

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- 24 "National Nursing Research Agenda: Setting Nursing Research Priorities," September 23, 1993, NINR Records, Box 9, Folder: Priority Setting—NINR. Other priorities included community-based nursing models, the effectiveness of nursing interventions in HIV/AIDS, living with chronic illness, and biobehavioral factors related to immunocompetence. House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 104th Cong., 1st sess. (Washington, D.C.: U.S. Government Printing Office, 1995), 970; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 104th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1996), 1866.

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- 26 *Biennial Report of the Director, National Institutes of Health, 1995-1996*, 196; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 103rd Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1994), 1907; Senate Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, and Education, and Related Agencies*, 103rd Cong., 2d sess., H.R. 4606, Part 2 (Washington, D.C.: U.S. Government Printing Office, 1994), 402.
- 27 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 103rd Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1994), 1907; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 104th Cong., 1st sess. (Washington, D.C.: U.S. Government Printing Office, 1995), 973.
- 28 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 104th Cong., 1st sess. (Washington, D.C.: U.S. Government Printing Office, 1995), 990; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations*, 105th Cong., 1st sess., H.R. 2264/S. 1061 (Washington, D.C.: U.S. Government Printing Office, 1998), 213-14; CRISP Database, <http://crisp.cit.nih.gov/>. Dr. Buckwalter also participated in the NINR’s 10th anniversary symposium, “Advancing Health Through Science: The Human Dimension,” in which she described “how testing and refining conceptual models of caring for people with dementia has led to developing interventions that benefit not only the patient but also the caregiver.” See Marianne Duffy, “Hundreds Celebrate NINR’s Tenth Anniversary,” *NIH Record* 48, no. 24 (November 19, 1996); Sue K. Donaldson, “Breakthroughs in Scientific Research: The Discipline of Nursing, 1960-1999,” chap. 10 in *Annual Review of Nursing Research*, vol. 19, *Focus on Chronic Illness* (New York: Springer Publishing Company, Inc., 2000), 259.

- 29 National Institutes of Nursing Research, "Making a Difference: Part Two—NINR Research Results," 28-29, NINR Records; Minutes of the National Advisory Council for Nursing Research, May 22-23, 2001, 16-17, <http://www.ninr.nih.gov/aboutninr/NACNR>. On Richards' work, see <http://abramsoncenter.org/pri/staff/richards.htm>. Dowling later continued her research at the Goldman Institute on Aging in San Francisco, California.
- 30 Minutes of the National Advisory Council for Nursing Research, May 22-23, 2001, 14, <http://www.ninr.nih.gov/aboutninr/NACNR>; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 107th Cong., 1st sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 2001), 1057; "Cognitive Training Helps Older Adults Who Have Some Memory Loss," *NIH Record* 60, no. 1 (January 11, 2008).
- 31 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 106th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 2000), 37; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 107th Cong., 2d sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 2002), 992. For additional details regarding skill programs developed for caregivers of people with dementia, see also House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 108th Cong., 1st sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 2003), 381.
- 32 Author's correspondence with Dr. Kathleen A. Dracup, April 7, 2010.
- 33 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 107th Cong., 1st sess., Part 4A (Washington, D.C.: U.S. Government Printing Office, 2001), 236; NINR Focus: An Overview, NINR Records, Box 5; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 107th Cong., 2d sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 2002), 992. According to the NINR's budget justification, researchers found that "spirituality was the major coping mechanism used by African-American caregivers," while "problem solving was the coping method used most often by Caucasian caregivers." In terms of managing behavioral problems in care recipients, the study "identified more similarities than differences between African-American and Caucasian care providers."

- 34 Hilary D. Sigmon, Patricia A. Grady, and Lynn M. Amende, "The National Institute of Nursing Research Explores Opportunities in Genetics Research," *Nursing Outlook*, September/October 1997, 215-19; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 104th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1996), 1898.
- 35 Minutes of the National Advisory Council for Nursing Research, September 14, 1999, 10-11, <http://www.ninr.nih.gov/aboutninr/NACNR>. For Meininger, see http://health.usf.edu/nocms/nursing/ResearchCenters/distinguishedLec_arch.html.
- 36 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 105th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1998), 1694; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 106th Cong., 1st sess. (Washington, D.C.: U.S. Government Printing Office, 1999), 16.
- 37 House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 105th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1998), 1712; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 106th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 2000), 3, 10, 41; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 106th Cong., 1st sess. (Washington, D.C.: U.S. Government Printing Office, 1999), 17; "NINR Summer Program Graduates 18," *NIH Record* 56, no. 18 (August 31, 2004); Ray Bingham, "NINR Completes Ninth Summer Genetics Institute," *NIH Record* 60, no. 20 (October 3, 2008). Dr. Tinkle eventually moved on to become a scientific review officer for NIH.
- 38 Yvette P. Conley and Mindy B. Tinkle, "The Future of Genomic Growth," *Journal of Nursing Scholarship*, First Quarter 2007, 17; Dr. Pamela Hinds, telephone interview by Philip L. Cantelon, August 23, 2009, 6 (hereafter Hinds Oral History); House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 108th Cong., 1st sess. (Washington, D.C.: U.S. Government Printing Office, 2003), 384; Bingham, "NINR Completes Ninth Summer Genetics Institute"; NINR Web site, SGI Graduates Federally Funded Research, <http://www.ninr.nih.gov/Training/>

- TrainingOpportunitiesIntramural/SummerGeneticsInstitute/SGIStudentPage/; Hinds Oral History, 6; Ray Bingham, "NINR Celebrates First Graduates of Graduate Partnerships Program," *NIH Record* 61, no. 4 (February 20, 2009). One of the graduates, Dr. Katy Meilleur, credits SGI with helping to spur her interest in research, observing "I wanted to combine genetics with nursing because I saw the future importance and impact of this combination."
- 39 Jean Jenkins, Patricia A. Grady, and Francis S. Collins, "Nurses and the Genomic Revolution," *Journal of Nursing Scholarship* 32, no. 2 (Second Quarter 2005): 98-99, 101.
- 40 "NINR Celebrates 15th Anniversary," *NIH Record* 54, no. 1 (January 8, 2002); House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 104th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 1996), 1874, 1877, 1882; Senate Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations*, 105th Cong., 2d sess., H.R. 4274/S. 2440 (Washington, D.C.: U.S. Government Printing Office, 1999), 248.
- 41 Harrison Wein, "The Science of End-of-Life Care," *NIH Record* 58, no. 5 (March 10, 2006); "Draft Text for Handout on End-of-Life," NINR Records, Box 16, Folder: Fact Sheets—May 2006; Senate Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations*, 105th Cong., 2d sess., H.R. 4274/S. 2440 (Washington, D.C.: U.S. Government Printing Office, 1999), 249; "Symposium Marks Start of NINR's 20th Anniversary," *NIH Record* 57, no. 23; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 106th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office, 2000), 8; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 107th Cong., 1st sess., Part 4A (Washington, D.C.: U.S. Government Printing Office, 2001), 237.
- 42 Untitled Blue Folder, "National Institute of Nursing Research," n.d., NINR Records, Box B; NINR, "Current Research Perspectives, 1996-2001," September 2001, 17, NINR Records, Box A; House Committee on Appropriations, *Hearings Before a Subcommittee of the Committee on Appropriations, Departments of Labor, Health and Human Services, Education, and Related Agencies*, 107th Cong., 1st sess., Part 4B (Washington, D.C.: U.S. Government Printing Office, 2001), 1057; and CRISP Database, <http://crisp.cit.nih.gov>.

- 43 “Play Raises End-of-Life Issues,” *NIH Record* 52, no. 7 (April 4, 2000); “Forum on End-of-Life Issues,” *NIH Record* 52, no. 22 (October 31, 2000). Members of the group included the NINR, NIA, National Center for Complementary and Alternative Medicine, and NCI. The distinctive spelling of the play’s title references the play’s dialogue about the difference punctuation can make in interpreting poetry.
- 44 Drs. Alexis Bakos and Barbara Smothers, “NINR End-of-Life Portfolio Analysis and Recommendations,” December 2006 Retreat, September 1, 2006, NINR Records, Box 16, Folder: NINR; Grady Speech, 9; see also, “Symposium Explores Dying on One’s Own Terms,” *NIH Record* 53, no. 2 (January 23, 2001).
- 45 “Improving End-of-Life Care,” *NIH Consens State Sci Statements* 21, no. 3 (December 6-8, 2004): 1-28; “NINR Examines Care at the End of Life,” *NIH Record* 57, no. 6 (March 15, 2005). The National Institute for Nursing Research and the Office of Medical Applications of Research were the primary sponsors. In addition, the Centers for Disease Control, Centers for Medicare and Medicaid Services, National Cancer Institute, National Center for Complementary and Alternative Medicine, NIMH, and NIA were also co-sponsors, while the Agency for Health Care Research and Quality supported the conference. See also, “NINR End-of-Life Portfolio Analysis and Recommendations.”
- 46 “Improving End-of-Life Care,” *NIH Consens State Sci Statements* 21, no. 3 (December 6-8, 2004): 1-28.
- 47 Bakos and Smothers, “NINR End-of-Life Portfolio Analysis and Recommendations.”
- 48 Fact Sheets—May 2006, “Draft Text for Handout on End-of-Life,” NINR Records, Box 16, Folder: Minutes of the National Advisory Council for Nursing Research, Sept. 13-14, 2005; “NINR Focus: An Overview,” NINR Records, Box 5; <http://www.ninr.nih.gov/aboutninr/NACNR>.
- 49 Bakos and Smothers, “NINR End-of-Life Portfolio Analysis and Recommendations.”



As a changing public health landscape creates novel opportunities and challenges, NINR has made producing a new generation of highly trained nurse scientists a priority.

The Transformation of Nursing Science

Soon after the end of World War II, in February 1946, the *American Journal of Nursing* held a festive luncheon at the Waldorf-Astoria Hotel in New York City to honor “Tomorrow’s Nurse,” Annie Warburton Goodrich. More than 500 stylishly dressed guests filled the ballroom, including top officials from all of nursing’s professional associations. President Harry S. Truman and New York Governor Thomas E. Dewey sent tributes for the occasion. To be hailed as the nurse of the future by one of the profession’s top journals was all the more remarkable in that Miss Goodrich had just celebrated her eightieth birthday.¹

Indeed, Goodrich’s active days in nursing were largely over, but her work during more than fifty years in the profession was the stuff of nursing legend. In 1906 she was elected president of the National League of Nursing Education. She had been instrumental in the founding of the U.S. Army School of Nursing during World War I and had served as director of the Henry Street Visiting Nurse Service, a pioneer in community-based health. She was president of the American Nurses Association from 1915 to 1918. By 1923 she had founded the Yale School of Nursing and become its first dean. She was the first president of the Association of Collegiate Schools of Nursing. Goodrich, according to her close friend and colleague Adelaide Nutting, was a “resolute



Annie Warburton Goodrich was active in nursing affairs at every level. Among many other things, she developed and, in 1924, became dean of the first nursing program at Yale University. She was responsible for developing the program into the Yale School of Nursing ten years later.

and adventurous [nursing] pioneer. She has no fear of treading any new path.” Nurses, Goodrich often emphasized, should be “scientifically informed, socially experienced, and technically expert.” But most of all, she declared, they must be “prepared to speak the language of science and put the findings fully to use.” In 1929 she did something no other dean had done—she set aside funds in the school’s budget specifically for nursing research. Annie Goodrich was nursing’s visionary for much of the twentieth century.²

Nevertheless, after her death in 1954, the fulfillment of Goodrich’s vision came slowly. One speaker at the Waldorf-Astoria luncheon noted that more than twenty-five years after the first funding of nursing research at Yale in 1929, “the full attainment of this ideal awaits larger resources than those now available.” Not for another three decades, when nursing research became part of the National Institutes of Health (NIH) in 1986 and significantly more resources for nurse investigators became available, did nursing science become more integrated into the broader scientific community and begin to speak the language of science. Throughout the development of nursing science, leading practitioners, theorists, educators, and policy makers undertook critical studies, educated high-quality nurses, and developed new methods to provide the scientific support for the distinct and crucial role nurses play in the health of individuals and their communities. They blazed new paths in nursing research. They are the heirs of Annie Goodrich’s vision.³

The celebration of the National Institute of Nursing Research’s twenty-fifth anniversary in 2011 commemorates the creation and growth of the Institute, its impact on nursing science, and its effect on health. In twenty-five years, the NINR has brought nursing science into the mainstream of research at NIH. During that time, the NINR has fundamentally altered the nature of nursing research by providing funding for increasingly more sophisticated and complex research projects to match the increased complexities of health care needs in America. Although it takes decades to build a strong base for further

research, the NINR can boast of any number of innovations and achievements over its brief history. But as for any twenty-five year old, there remains much to learn and accomplish. The challenge, of course, is how effectively the succeeding generation of nurse scientists will tackle nursing's next research agenda.

Future scientists will benefit from the vision of pioneering nurse scientists who advocated for a place for nursing research at NIH, helped it take root, pushed for its broader acceptance in the NIH community, and pressed their students and protégés to do innovative research. Mostly in their forties when the movement to establish nursing research at NIH caught traction in the early 1980s, this first generation of activists, educators, and scientists is reaching retirement age. Marking the transition of this legacy of nursing research and science, the torch is being passed to the new generation of nurse scientists they have trained. Throughout its history, the NINR has funded talented and dedicated nurse investigators who provided the functional knowledge for clinical practice for the largest professional group in the nation's health care delivery system. The measure of success for nursing research over the next twenty-five years will be how well this new generation meets the challenges of a world in which health care will be defined not solely by finding cures for disease, but increasingly by promoting the health of the nation—the central focus of nursing. Nursing science in the future will investigate patient, family, and community health requirements, utilizing interdisciplinary techniques drawn from ever more complex technologies. This is the direction in which the NINR has channeled its resources and science over the past quarter-century. With a solid base of nurse investigators, the future looks bright for nursing science.

Since nursing research became part of NIH nearly twenty-five years ago, the nation's health care system has changed dramatically. The population has grown, aged, and diversified. Diseases that were once acute and life threatening, such as heart disease, diabetes, and HIV, are now treatable, long-term chronic conditions. At the same

time, the world has become smaller. In an increasingly interconnected and mobile world, global health threats such as tuberculosis, SARS, Ebola, and influenza, among others, can spread at the speed of a jet plane. The World Health Organization (WHO) reports that emerging public health risks “will require enhanced international cooperation and transparency.” Factoring all these changes into data-based effective health care systems will be a part of the NINR’s long-range planning for the second decade of the twenty-first century.⁴

From an initial annual budget in 1986 of \$16 million, the NINR’s appropriation has grown to more than \$145 million, nearly three-quarters of which goes to research project grants and another approximately 20 percent to other research and training initiatives. Institute director Dr. Patricia A. Grady believes the country “is experiencing a convergence of factors that offer nursing research the chance to expand the already substantial impact it has had on the health of the public.” She notes that as the population ages, it increases the need to manage the normal aging process as well as the long-term impact of chronic illness. In addition, the nation’s increasing diversity requires health care professionals to have greater multicultural knowledge and sensitivity. Of significant importance is the shift from patient cure to patient care—the shift from acute illness to chronic conditions and from disease treatment to disease prevention. For the past decade, there has been an increased reliance on technology in health care delivery and a renewed call to translate successful nursing research into clinical practice. To continue to confront and overcome these challenges, Grady believes that the NINR must expand new research opportunities while providing for the future development of nurses, nursing faculty, and scientists.⁵

In the future, nursing science may integrate the knowledge of complex systems into personalized self-management in order to maximize and improve overall health. As in any brave new world, the future brings new challenges that nurse investigators, in partnership with other health care professionals, must be willing and prepared to tackle.⁶



Dr. Pamela Hinds, director of nursing research at Children's National Medical Center in Washington, D.C.

In 2006 the NINR developed a strategic plan that outlined four areas in which the Institute and nurse investigators aimed to elevate nursing science's contributions to clinical research over the following five years. The plan sought to "further the integration of the biological and behavioral sciences, promote the design and use of new patient care technologies, improve nursing science methods, and commit to the ongoing development of new nurse investigators." To accomplish this blueprint for action, the NINR focused its research priorities on health promotion and disease prevention, improving the quality of life through symptom management and caregiving, eliminating health disparities, and leading end-of-life (EOL)-research. In formulating the strategic plan, the NINR sought to apply its resources to the areas of public health that had the greatest need and in which nursing science could have the greatest impact.⁷

At regular five-year intervals, the NINR has reflected on its past achievements to measure the success of its strategies and their effectiveness. In anticipation of its twenty-fifth anniversary celebration, the Institute queried grantees on their assessment of its impact on nursing research. In the past, the NINR marked its accomplishments by the results of the research projects and centers it funded. The importance of these achievements cannot be overestimated. But the broader outlook of more than two decades provided an opportunity to look at the NINR with a fresh perspective, according to Dr. Pamela Hinds, the director of nursing research at Children's National Medical Center in Washington, D.C. Hinds believed that the NINR changed the attitude and the altitude of nurse investigators. As to attitude, the NINR, as the leader in nursing science, has "been inspirational, and that inspiration and the financial support that came with it has led to a huge incremental increase in the number of nurses prepared to do research. The NINR has improved the sophistication of the research [nurses] conducted, such as more interventional and multisite trials, and more interdisciplinary studies. This occurred as a result of the expansive viewpoint of the NINR with its priorities, its collaborative nature on the NIH campus, and its resources distributed to investigators." As to altitude, or raising the level of nursing research, Hinds asserted that the NINR, as an integral part of NIH, gave nursing science legitimacy. Many nursing professions agree that the NINR has worked hard to become a positive force for health care and health care research, not just on the NIH campus, but across the nation. And that, in itself, has been no small accomplishment.⁸

Others applauded the catalytic role that the NINR assumed over the years. Dr. Kathleen A. Dracup, dean of the University of California, San Francisco, School of Nursing, whose work has centered on cardiology, disease management, and EOL issues, believed that the NINR "contributed more than any other institute to clarify these issues for the medical system." She remarked that nursing research lacked a strong scientific base twenty-five years ago. "It didn't have a lot of doctorally

prepared scientists within its ranks, and it was hard to encourage people to conduct research because funding was difficult to obtain from other institutes.” Now the NINR “is the catalyst for predoctoral training, postdoctoral training, new investigator funding, thereby opening the way for an academic career. The NINR has made a huge difference in people’s lives in terms of research and academic success.”⁹

Nearly all nurse scientists agreed on one particular achievement: the importance of locating the NINR at NIH. Dr. Elaine L. Larson, a professor and associate dean of research at the Columbia University School of Nursing, said that just being on the NIH campus brought nursing research to the larger scientific table. Before 1986, “there was essentially no presence at NIH of nurse scientists. Nursing was pretty invisible, and it wasn’t because anybody was trying to hide anything. It was because the other institutes didn’t consider nursing to have a body of research.” The NINR changed much of that, though not always to the extent that many nurses hoped.¹⁰

Nursing research at NIH turned out to be a two-way street. Not only did other scientists learn about the value of nursing’s behavioral research, but at the same time, nurse investigators integrated more biological and basic science methodologies into their own studies, creating new interdisciplinary programs of research. The NIH Roadmap in 2004 provided opportunities for scientists to go beyond the tried and true, “to color outside the lines.” The Roadmap was the way for “off-road” vehicles to escape the well-traveled paths of traditional research and support innovative, high-risk science. One area ripe for such an approach emerging from the advances in science over the previous decade was genetics. By merging the study of human biology with behavior, the Roadmap sought to detour around the traditional highways of health research and follow paths leading to more creative interdisciplinary inquiry. Investigators assembled teams of scientists to build bridges across the biological, behavioral, and social sciences while training scientists to cultivate and integrate interdisciplinary approaches to complex health problems. The effect of the



The NIH Roadmap for Medical Research was launched in September 2004 to address roadblocks to research and to transform the way biomedical research is conducted. NIH director Dr. Elias Zerhouni (right) spoke at the kickoff event.

Roadmap, in which the NINR took a leadership role, was to increase the number of nurse scientists working with peers from another discipline. “The NINR has been very actively involved and supportive of the whole idea of translational and interdisciplinary research,” Larson said. The formula was simple and it has been successful, she asserted. “You do better research when you have different perspectives.”¹¹

The trend toward more interdisciplinary research allowed nursing research to “be more scaled up and become more mainstream,” according to Dr. Linda H. Aiken, a noted investigator and the director of the Center for Health Outcomes and Policy Research at the University of Pennsylvania School of Nursing. Because of the NINR’s support, she said, “nursing research is being published in interdisciplinary journals and adding to the cumulative interdisciplinary knowledge base on a number of issues. I think we are going to see more scientists viewing clinical problems through the lens of nursing and more nurse scientists leading interdisciplinary research teams to solve these problems,” she concluded.¹²

Dr. Lauren S. Aaronson, a leading nurse scientist and former senior advisor to the director of the NINR, agreed but argued that nursing should be considered a pioneer in melding the work of several research fields. “There was no one discipline that has all that is needed to address the complexities of today’s health problems,” she said. Aaronson, a professor at the University of Kansas School of Nursing, was particularly impressed with the idea of scientists working collaboratively and across disciplines to the point of developing “additional sciences that are a blending of the work coming from different disciplines.”¹³

In a twist of fate, or at least one of the unintended consequences of the paucity of nursing research three decades ago, it was this lack of doctoral programs that created one of the profession’s strengths, Aaronson reflected. “When we first started this research enterprise,” she said, “there were very few doctoral programs in nursing, so most of us got our doctorates in other disciplines, so we became experts in those disciplines. When we came back to nursing, our charge was to figure out how to take that knowledge and apply it to nursing and make it relevant for nursing.” Trained as a nurse and then a sociologist, Aaronson recalled that she had inherent advantages over her classmates who came out of undergraduate programs in sociology. “In studying medical sociology—health services, delivery systems, and such—it became very clear that, because I was a nurse and had different life experience and professional experience, I could relate to that content very differently than my colleagues in sociology.”¹⁴

Nevertheless, while Aaronson saw great potential in the interdisciplinary orientation of nursing science, she believed that the very youthfulness of nursing research was a two-edged sword. “In the research domain,” Aaronson said, “we are a young discipline. While we have done a tremendous job of preparing more nurse scientists in a short period if you compare us with our colleagues in other fields, we did not have a very large pool to select from initially.” As a result, there were fewer nurses to join multidisciplinary research teams, and “there is a tendency among nurses not to be particularly assertive in

interdisciplinary groups, and that's unfortunate. The knowledge we have gained from the research funded by the NINR has led to significant improvements in practice and the health of people. But it has been a quiet success. We need to raise nursing's visibility in the research community."¹⁵

Dr. Margaret Grey, the dean and Annie Goodrich Professor at the Yale School of Nursing, was more optimistic. Grey, whose research has focused on pediatric diabetes, including behavioral interventions that improve metabolic control of diabetes and the quality of life in young people and their parents, as well as preventing type 2 diabetes in high-risk youth, believed that the NINR had changed the face of nursing science. She recalled that "when I first started doing science, studies were relatively...simple, though that is too pejorative a term. Our science was at a point where we weren't doing studies that really tested complex models or involved many disciplinary teams." More recently, however, nursing science has tackled more complex studies, testing models rather than "the simple question of if you do this intervention, then you'll get this outcome." The degree of complexity in nursing research "is the primary thing that's changed over the past twenty years," Grey said. "We're seeing many more larger, multisite clinical trials that allow us to really test models. I feel very fortunate to have come up as a scientist at a time when nursing came into NIH. The NINR created an environment that allowed us, as junior scientists, to get funded and flourish as researchers."¹⁶

Grey noticed other changes as a result of the NINR. In 1970, when she graduated from the University of Pittsburgh, she recalled, "We didn't even have a *course* in research. It was not a component of the curriculum. Now research is included in every undergraduate program in nursing." When Grey finished her doctoral program in 1985, "good science was to conduct survey research. But the NINR made it clear that the goal was always to be able to do research that would change nursing practice. Ours is an applied discipline. We needed to move from what may be basic descriptive work to what we can do to fix this clinical problem."



Dr. Margaret Grey, right, with research scientist Dr. Sarah Jaser. Dr. Grey is dean and Annie Goodrich Professor at the Yale School of Nursing.

From 1991 through 1997, Grey was a member, then chair, of the Nursing Science Review Committee, the panel that reviews training applications. “It was an era where there was a real burgeoning of PhD programs in nursing,” she recalled. “We were getting a lot of applications, but many of them were very weak in terms of research design, methodology, and faculty mentoring. But over the course of six years, we began to see an increase in sophistication of the research proposals—not only from the students, but from the faculty as well. Our methods and statistics courses are much more challenging. We are now looking at far more complicated models. Things are just night and day from what they were when I was in school. It’s just a whole different world.”¹⁷

While the NINR catalyzed many of the major changes in nursing

science over the past twenty-five years, it has not always been able to achieve other goals that deans of nursing schools held dear. The NINR sought to bring parity for nurse scientists to NIH. One noticeable difference between nurse investigators and those in other fields at NIH was the age of nurses with PhDs. While other scientists were finishing their doctorates around the age of thirty, nurse scientists were encouraged to leave school and work clinically. Nurse scientists were in their mid-forties by the time they received their doctorates. To remedy this, the NINR pushed for young nurse scientists to go through graduate education earlier, straight from the baccalaureate to the PhD, and it set aside funding to make this possible. A recent analysis by the National Academy of Sciences indicated that there had been little change, despite the NINR's initiative. "Those data are not pretty for nursing," Grey declared. Even today, she observed, many faculty members advise their students to work in clinical settings for a few years after their bachelor's degree and again after the master's degree before pursuing the PhD. "I started graduate school three years out of my undergraduate program, and everybody told me not to do it. I was too young, I didn't know enough about nursing. And faculty are still giving the same message today. It's awful. We are educating twenty-first century students using eighteenth century pedagogy." Future change, she believes, cannot depend on the initiatives of the NINR. "What it's really going to take is the game-changing view of the world by the older nurse faculty."¹⁸

Other needed changes in educating nurse scientists can be made by the NINR, according to Larson of Columbia University. "The research workforce is aging," she emphasized. "We're losing a lot of researchers who are in their sixties and ready to retire. In addition, we have failed to attract enough new people with a passion for nursing research into the discipline." Larson recounted examples of nurse scientists seeing the hurdles of following an academic career and getting scared off. She faults the regulatory and funding systems that scientists face. "They're so daunting, many just give up," she said. "It's really hard for new scientists to independently write a grant that is of the level that



In an NINR-funded study, Dr. Elaine Larson (left) evaluated the effect of antibacterial home cleaning and handwashing products on infectious disease symptoms. She meets with project coordinator Delmy Miranda (right) in a storeroom containing a year's worth of supplies.

passes review. I think it's a good idea that the NIH gives priority to new investigators. I do not want to lose grants myself, but we have to make room for a new generation of scientists."¹⁹

To build this cadre of "new passionate investigators," Larson believes that there should be closer collaboration among the NINR, other funding groups, and the schools of nursing. "The schools need to be on top of what needs to happen," she argues, "which is more interdisciplinary training, more translational training, and more faculty willing and able to mentor new people." Like others, she stresses the urgency of nurse scientists pursuing their degrees at an earlier age. "You spend most of your career getting your own research funding; you are not in a position to provide the mentoring for new people coming along. So we have to mature faculty earlier in their careers so that they have the time, energy, and willingness to mentor new people."²⁰

Aiken sees the same trend at the University of Pennsylvania, which

is trying to attract students earlier to scientific research as undergraduates and “then promote these expedited BSN to PhD programs so that we have more nurses begin their research careers at a much earlier age, more comparable to the ages of people in other fields.” To accomplish this, Pennsylvania is developing a fast research track for freshmen and placing them in one of the university’s six research centers so they can “actually start working on and understanding NINR research.” But Aiken does not believe that the cadre of young nurse scientists is shrinking. “What gives us that perception that there are not enough nurse PhDs,” she explains, “is that because of the growth of demand for nurses with doctoral degrees, we have so much greater need.”²¹

The basic ingredient for successful nursing science has been, and remains, funding. The NINR and its funding levels gave nursing research both a symbolic and significant impact on nursing science. The Institute fostered the growth of the interdisciplinary nature of nursing research, according to Aiken. Interdisciplinary journals now publish the work of nurse investigators, “adding to the cumulative interdisciplinary knowledge base on a number of issues. The NINR made that possible.” But, she warned, “a lot of nursing research, especially funded by the NINR, is still small [scale].” Now, she said, skilled investigators are doing larger multisite trials, and these larger initiatives require greater funding. “So either the NINR must have a larger budget or nurses have to become more influential in other institutes” to get such trials funded.²²

Nevertheless, Aiken, whose role in the creation of the NINR goes back to the 1983 Institute of Medicine report, recalls that funding has long been a limiting factor. “The funding has never been as great as we imagined. For example, some of the agenda items that it has selected—like end-of-life care and management of chronic care, are different from curing diseases—there are no other institutes that really devote their attention to management of symptoms.” When her group made the recommendation about nursing research at NIH, she said, “We were anticipating that the NINR would be the institute that would establish

the science base of clinical care and fund any investigator of any discipline that had a good idea.” Unfortunately, the NINR has never had the resources to meet that ideal. One way to accomplish this goal, she believes, is for the NINR-funded scientists “to play a larger role in policy than they have played to date.” She believes that in addition to clinical research, when higher funding levels become available, the NINR should place a greater priority on studies examining the basis for science in health services, research, and policy.²³

But what of the future? There is widespread agreement that the NINR has been the impetus for enormous changes in the science of nursing research over the past twenty-five years. “It has transformed our science,” declared one nurse investigator. The NINR’s presence at NIH has given nursing science unmatched visibility and a reliable source of funding unknown to nurse investigators before the 1980s. Making progress on finding a cure for a disease has made NIH world famous. Meanwhile, the NINR has, in a sense, widened the NIH mission, giving credibility to maximizing the health and quality of life of patients and families even when afflicted with an acute or chronic disease. Over the past quarter-century, both the cure and the health promotion tracks have moved closer together as biomedical science and biobehavioral science have learned the value of—and come to respect—the other’s research approaches.²⁴

The idea that any one profession holds the key to solving the world’s health problems was and is “insanity” in the opinion of Dean Grey of Yale University. Just two decades ago, nurses would collaborate, often as part of a clinical team, but not as equal members of the research group, according to Grey. That is no longer the case, she claims. “We are recognized as part of a broader team trying to solve complicated problems.” Now, she says, “‘interdisciplinarity’ is the name of the game.” Society’s problems, Grey believes, are “way too complicated to even think about trying to solve using single disciplinary strategies. So I think we’re going to see nursing science become increasingly involved in transdisciplinary research training, and transdisciplinary research teams.”²⁵

Others agree with Grey's assessment. Moreover, they recognize not only the myriad of health care problems faced by society, but also the technological complexities arrayed against them, all of which nurse scientists must absorb if they are to be well prepared for the future. Larson of Columbia University sees a richer mixing of the biological and social sciences, where researchers from those disciplines have crossed over to develop more credible qualitative methodologies. Dracup, the dean of the University of California, San Francisco, School of Nursing, thinks the integration of technology will be a major trend in the future of nursing research and that the NINR will take the lead in this area. "It's so hard to imagine that we did not even have e-mail in the late eighties. Isn't that stunning?" She uses the example of her colleague, Dr. Yoshimi Fukuoka, who is developing an intervention to support exercise in older sedentary women using a cell phone. Such handheld devices, Dracup says, have the potential to reach patients and families and to support behaviors that keep people healthy and out of the hospital—and, not incidentally, at significant cost savings.²⁶

There are other technological advances that are rich with potential for nurse scientists. With the advent of inexpensive and fast DNA sequencing in the past five years, genetic studies have become a powerful way to uncover genes that make contributions—along with environmental influences and personal choice—in a person's overall risk for such chronic ailments as diabetes and coronary heart disease. In 2010, as technology has lowered the cost of decoding a genome to less than \$50,000 and the cost of sequencing is expected to drop to \$5,000 or less in two or three years, the understanding of diseases and patients' suffering will open a plethora of opportunities for nurse scientists.²⁷

Such work has momentous implications for nursing science, according to Dracup. She views the use of biomarkers of phenotypes for the surveillance and management of symptoms as an example of the evolving and complex strategies that are being incorporated by nurse scientists. The impediment to greater understanding of genomes will

not be technology, but the ability to understand and interpret what the technology reveals and how this is translated to patients and families. Nurse investigators will need to identify which biomarkers are important indicators of disease progression and which are diagnostic of either symptoms or disease, and then integrate them more fully into their research and practice. Disease management, she believes, especially for the nation's population that is aging and obese, will become the next big issue for the NINR. The challenges are many, she warns. "How do you get a sixty-five-year-old obese person to exercise more?" she asks. "People have been asking that question for decades. We have to figure out if technology will be the answer. Are there other things we should be measuring that we haven't been able to measure well that might be clues to how we could intervene in behavior?" In addition to technology, biomarkers, EOL care, and disease management, Dracup adds, the research will also have to demonstrate cost effectiveness. She sees this as a requisite for all of NIH, not solely the NINR. "Is there an institute that will look at a clinical trial that does not have a cost effectiveness analysis? It's just too hot a topic in health care right now."²⁸

The health care debate of 2010 swirled around no single topic with more passion and bluster than EOL care. Whatever the outcome of that debate, nurse scientists will be central to those decisions, as EOL care has long been a specialty for nurses and nursing research. For years, nurse clinicians have understood the importance of establishing advance directives in EOL care. Yet studies done by nurse scientists have demonstrated low rates of completing those directives among the critically ill. Even when in place, living wills and other advance directives are often seen as vague and difficult to interpret. Moreover, in the absence of any advance directives, neither family members nor clinicians have been able to predict accurately the health decisions of critically ill patients. Using new technology, a group of NINR researchers developed an innovative multimedia decision aid, "Making Your Wishes Known: Planning Your Medical Future," to translate preferences into a specific plan that can be implemented by

a health care team. Not only were the results of the program overwhelmingly embraced by the patients involved, the peace of mind for patients and families as well as the long-term cost savings to be gained from the widespread implementation of such programs seemed readily apparent.²⁹

In the spring of 2009, Hinds, the head of nursing research at The Children's National Medical Center, served as the facilitator for a focus group of investigators and nursing leaders from across the country to suggest to the NINR where EOL science, including palliative care, stood and where it needed to go. "The NINR is leading the charge for palliative and EOL research on the NIH campus. I am thrilled that the NINR has gone after that area of science and how to benefit it," she said. Hinds complimented the NINR on the amount of thought that went into assembling the group, which included advocates, nurses and non-nurses, and individuals who had never been funded before "but represented very important voices in terms of palliative and EOL research," as well as funded investigators. "There was a tremendous cross-cutting of interests so that it just wasn't your senior funded investigator. The feedback sessions were a kind of informed grassroots interaction with NINR leadership."³⁰

For Hinds, the diverse panel represented the future of the NINR in setting priorities for nursing science. Echoing others who praised the trend for interdisciplinary research, she stressed the importance of such an array of fields being brought together in EOL care. "The inclusiveness of the panels has gone way beyond our own discipline. I think that's quite an evolution of the process, and a maturation sign as well. I have been impressed with how skillfully the NINR and attendees learn where the science needs to go and subsequently develop content areas for formalizing, galvanizing, and then funding efforts in those areas. We are going to learn the most where the NINR puts its resources."³¹

Nonetheless, as the NINR approaches its twenty-fifth anniversary, some issues remain. For many nurse scientists, the size of the Institute's budget has not matched the level of its achievements. Continuation

of this trend, they believe, will hinder future research. For example, Hinds observes that nurse scientists have “demonstrated very exciting research at the practical bedside, the science needed to provide excellent care to a patient; but that has yet to be translated into an equally impressive increase in budget. My concern for the future is being able to grow the program in a way that is reflected by the budget.” She sees the future of nursing research in developing more low-cost interventions, including developing more international research programs with selected partners for “low-resource countries.” According to Hinds, these partners “have tackled some of the same issues we are tackling, and because of limited resources, they may well have identified low-cost interventions that will assist us in reassessing how we are giving care in the same area.” She points to several countries in South America that have developed low-cost care interventions related to how premature babies maintain body temperature. “The more we can learn from our international partners about what the mechanism of these actions can do, the better our perspective will be. They will provide new eyes to look at possibilities we might not otherwise have considered.”³²

Dracup also sees budgetary issues as a hindrance to the NINR’s future. Like many nurse investigators, she looks at the gains of the NINR through the larger lens of NIH. “We’ve been really lucky with the directors we have had in both Ada Sue Hinshaw and Patricia Grady. They both had tremendous credibility on the NIH campus for different reasons. Ada Sue was an outsider who quickly gained credibility. Patricia brought even more credibility because of her familiarity with NIH and other institutes and her own research portfolio, the kind of portfolio familiar to NIH.” But, she added, “at the end of the day, budgets talk, and compared to other institutes, I would say we are still struggling for our place.” While both Hinshaw and Grady advocated collaboration with other institutes to increase funding possibilities for nurse scientists, Grady also emphasized working with other institutes in co-funding research that would meet the strategic priorities of the



Dr. Ada Sue Hinshaw, NIH Director Elias Zerhouni, and Dr. Patricia A. Grady marked NINR's 20th anniversary.

NINR. While this strategy has expanded nursing science, Dracup maintains that one of the main difficulties lies in the nature of nursing research itself. “The NINR has provided a place for scientists who are interested in the priority issues stemming from coping and stress, disease prevention, and EOL care. It is research that affects the quality of every day of patients’ lives. It’s what makes people feel better or worse in their day if they have cancer or some other debilitating disease. But fortunately or unfortunately for society, quality of life is not what is publicized as hot *New York Times* science advances, like a new vaccine or the discovery of the AIDS virus. I think that’s a stumbling block for the NINR. That’s always the challenge for the NINR director, because when she goes to Congress [for appropriations], they are looking for dramatic findings.”³³

Aiken registers the same concern. “The funding has never been as great as we imagined it could be, and so the overall funding is a constraining factor in terms of the ability of the NINR to really make

significant progress.” The NINR agenda, she notes, has selected EOL care and chronic care coordination to establish a science base for patient care as other institutes did for cure. “As a result, progress in terms of nursing research on policy-relevant issues has not grown as rapidly as it could grow with greater resources. So for nursing to really come into its own, it’s got to utilize more fully its knowledgeable and highly skilled investigators and scale up with larger multisite trials. To do this, the NINR must have a budget comparable to the other Institutes or nurse scientists have to continue to be more creative in raising the money elsewhere.” She recommends placing a greater emphasis on the significance of research itself, especially as it applies to policy makers and legislators.³⁴

And what will be the future of nursing science in the next twenty-five years? With the spectacular advances in technology accompanied by lower costs, no one can know for certain, but a reasonable guess would be that technology and science will continue to evolve, creating an ever more complex mix of interdisciplinary concepts, while at the same time driving down the costs of technology and making its application more widespread. Arguably, these new combinations will, by the very nature of their complexities, become part of a broad systems approach to health care management. For nursing science, this will particularly include information science and its application into large-scale clinical trials, as well as mining and combining previous, smaller trials to reconfigure data with new approaches or perspectives. In addition, e-mail and electronic journals have expanded the flow and increased the speed of exchanging ideas and information in nursing science. This is especially important for drawing on the results of nurse investigators throughout the world. Already, electronic submissions of manuscripts from nurse investigators around the globe have changed the content of and internationalized nursing science, according to the editor of one national journal. As this trend continues, then, nursing science will increasingly enhance its international perspective, or, as one nurse scientist says, “expand its scope of voices.”³⁵

In reviewing the NINR's 2006 Strategic Plan, Director Patricia A. Grady wrote that "the time is right for the NINR to become a leader in addressing some of the most important health care issues facing our society. For the NINR, and for all of nursing science, the possibilities are endless." Grady, who became head of the Institute in 1995, brought a decade of historical perspective to her observation. Her words still ring true, but in the interim the NINR has assumed that leadership role in several of the areas anticipated in that strategic plan. The Institute's commitment to eliminating health disparities and its focus on health promotion and disease prevention have positioned it as a leader in strategic planning on health outcomes for underserved populations. In addition, the NINR has played a critical role within NIH in developing a research infrastructure in minority-serving institutions and making research findings and methods more widely accessible in those communities.³⁶

The NINR leadership has emerged most noticeably in the area of EOL and palliative care science. Many are surprised to learn that even though civilization has coped with death throughout history, research into EOL care is still in its infancy in terms of rigorous testing and evaluation of models of care, of patient and family outcomes, and of resource utilization. NINR initiatives have expanded EOL research through research training, interdisciplinary programs, supplemental awards, and targeted grants. As part of this research effort, the Institute has funded the Center for End-of-Life Transition Research at the University of Illinois at Chicago. The focus of the center and other NINR-supported research is to identify factors that influence and develop strategies to improve decision making and treatment at the end of life. For example, a recent study examined the decision to remove patients in an intensive care unit (ICU) from life support. The investigators found that the life support withdrawal process from feeding tubes, intravenous fluids, ventilators, or medications, though relatively common, was often sequential as clinicians sought to balance the complex needs of the patient and the patient's family. Of particular

interest was the finding that families of patients who had experienced a longer ICU stay tended to prefer the more extended, sequential withdrawal process. Another study indicated that improved communication between ICU staff and families to provide them with accurate information on which to base decisions and prepare them emotionally for the eventual loss of a loved one greatly reduced feelings of stress and depression in family members.³⁷

The NINR has evolved with the country's changing demographics and increasing diversity as the nation's population ages. By 2020, more than 20 percent of the population will be age sixty-five or older. Longer life expectancy of individuals with chronic and acute conditions will challenge the health care system's ability to provide efficient and effective continuing care. Increases in the diversity of the population will continue to affect access to care, morbidity, and mortality among underserved population groups. Nurse training and nursing science must keep up with these changes, adapting emerging digital technologies and genomic advances to clinical diagnosis and treatment. Nurses of the future will need to be as knowledgeable about health promotion as disease prevention and to demonstrate management skills in epidemiology, biostatistics, and behavioral science. They will need to collaborate with ever-shifting teams of nurses, physicians, social workers, pharmacists, and other health care providers to explore fully the wide range of knowledge and skill necessary to manage and resolve patient needs. Over the past quarter-century, nursing science has become an integral part of improving the nation's health as nursing research continues to build an independent body of knowledge. Nevertheless, the challenges incumbent with shifting demographics, expanding technology, and the globalization of health care will continue to demand the latest and most original approaches from nursing science.³⁸

As the NINR celebrates its twenty-fifth anniversary and looks to the future, the lessons of the past are particularly pertinent to nurse investigators: to sift the evidence and study problems from all sides

and angles, to challenge old methodologies, to reveal new patterns of inquiry, and to apply fresh strategies to nursing science. As the country's health care system expands, the demand for nurses will be even higher. Schools of nursing will need to find the nurse scientists to become the faculty to teach this anticipated influx of new students. Never have the opportunities for nurse scientists been so promising in terms of training, research, and outcomes. Never have resources been more available. Fortunately, for a quarter of a century, nurse scientists funded by the NINR have been preparing for such challenges and opportunities. Working in tandem with, and in support of, nurse educators and scientists, the NINR has developed the conceptual frameworks to guide a full range of systematic research for its programs, integrating emerging technologies, collaborating with diverse disciplines, and tackling both widely recognized and understudied societal needs to strengthen nursing science and the nation's health care system. As the Institute's research portfolio evolves, so too must nurse scientists continue to question old assumptions, initiate new research approaches, and embrace unexpected opportunities. For twenty-five years the NINR, with planning, resources, and leadership, has held the door open for nurse investigators, let the future in, and changed the face of nursing science. With that foundation, the next quarter-century for the NINR and nursing research promises to be even more stimulating, significant, and accomplished.³⁹

Epilogue Endnotes

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- 6 NINR: An Overview, August 2006, <http://www.ninr.nih.gov/NewsAndInformation/NINRPublications/>.
- 7 *NINR Strategic Plan, 2006-2011*, “Prologue from the NINR Director,” October 2006, n.p.
- 8 Dr. Pamela Hinds, telephone interview by Philip L. Cantelon, August 23, 2009, 5, 9 (hereafter Hinds Oral History).
- 9 Dr. Kathleen A. Dracup, telephone interview by Philip L. Cantelon, September 2, 2009, 4-6 (hereafter Dracup Oral History).
- 10 Dr. Elaine L. Larson, telephone interview by Philip L. Cantelon, August 19, 2009, 18-19 (hereafter Larson Oral History).
- 11 NIH Roadmap for Medical Research, <http://nihroadmap.nih.gov/interdisciplinary/>; “NIH Roadmap in Gear for 3rd Year,” *NIH Record* 58, no. 12 (June 16, 2006); Larson Oral History, 4.
- 12 Linda H. Aiken, telephone interview by Philip L. Cantelon, August 17, 2009, 11-12 (hereafter Aiken Oral History).
- 13 Lauren S. Aaronson, telephone interview by Philip L. Cantelon, September 4, 2009, 5 (hereafter Aaronson Oral History).
- 14 *Ibid.*, 5-6.
- 15 *Ibid.*, 11-13.
- 16 Margaret Grey, telephone interview by Philip L. Cantelon, August 14, 2009, 2 (hereafter Grey Oral History).
- 17 *Ibid.*, 4-5, 7-8.
- 18 *Ibid.*, 8-9, 11.
- 19 Larson Oral History, 20.
- 20 *Ibid.*, 21.
- 21 Aiken Oral History, 7-8.

- 22 Ibid., 10-12.
- 23 Ibid., 10-11.
- 24 Grey Oral History, 18.
- 25 Ibid., 13-14.
- 26 Larson Oral History, 4-5; Dracup Oral History, 9.
- 27 *The Washington Post*, September 7, 2009; *The New York Times*, August 11, 2009. The pursuit to sequence a genome for \$1,000, "as cheap as the price of a Broadway ticket," according to *The New York Times*, is the goal of a global race toward an era of personalized medicine that would offer significant improvements in diagnosis and treatment. See *The New York Times*, October 6, 2009.
- 28 Dracup Oral History, 10-11.
- 29 "Interactive Computer Program Demonstrates Improvements in the Advance Care Planning Process at the End of Life," *Monthly Summaries of Nursing Research: April 2009*, <http://www.medscape.com/viewarticle/702792>.
- 30 Hinds Oral History, 6-8.
- 31 Ibid., 9, 10-11.
- 32 Ibid., 10, 14-15.
- 33 Dracup Oral History, 7-8.
- 34 Aiken Oral History, 10-12, 15.
- 35 Larson Oral History, 26-27, 25; Hinds Oral History, 16. Larson also calls on nurse scientists in the United States to collaborate more with nurse researchers in Europe and Asia.
- 36 *NINR Strategic Plan, 2006-2011*, "Prologue from the NINR Director," October 2006, n.p.; *ibid.*, "Eliminating Health Disparities," n.p.
- 37 "Prolonging the Withdrawal of Life Support in the ICU Affects Family Satisfaction with Care," *NIH News*, October 15, 2008; "Improving Communication in the ICU about End-of-Life Care in the ICU Reduces Symptoms of Stress, Anxiety, and Depression in Family Members," *NIH News*, February 1, 2007.
- 38 See Barbara R. Heller, et al., "The Future of Nursing Education: Ten Trends to Watch," *Nursing and Health Care Perspectives* 21, no. 1 (January-February 2000): 9-13.
- 39 *The Washington Post*, November 6, 2009.

Appendix A

National Institute of Nursing Research Oral History Interviews

Conducted by Dr. Philip L. Cantelon

Aaronson, Dr. Lauren, September 4, 2009

Aiken, Dr. Linda, June 10, 2008, and August 17, 2009

Bednash, Dr. Geraldine “Polly,” June 3, 2008

Bulger, Dr. Roger, March 10, 2008

Dracup, Dr. Kathleen, September 2, 2009

Elliott, Jo Eleanor, May 1, 2008

Felton, Dr. Geraldene, June 30, 2008

Grady, Dr. Patricia A., January 26 and February 4, 2009

Grey, Dr. Margaret, August 14, 2009

Heinrich, Dr. Janet, March 6, March 21, and April 11, 2008

Hinds, Dr. Pamela S., August 23, 2009

Hinshaw, Dr. Ada Sue, August 20 and 28, 2008, and April 22, 2009

Kirschstein, Dr. Ruth L., January 17, 2008

Larson, Dr. Elaine, August 19, 2009

Merritt, Dr. Doris, April 28, 2008

Moritz, Dr. Patricia, March 13, 2008

Raub, Dr. William F., May 21, 2008

Rudy, Dr. Ellen, June 16, 2008

Woods, Dr. Nancy Fugate, March 24, 2008

Appendix B

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xii, 2, 4, 8, 15, 25, 30, 38, 49, 54, 58, 64, 82, 88, 93, 100, 103, 112, 115, 116, 119, 130, 137, 143, 162, 167, 171, 190, 192, 208, 229

Wikimedia Commons

13, 52

NIH Record

43, 71, 98, 102, 123, 141, 147, 217

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105

Dr. Loretta Sweet Jemmott

148

Dr. Kate Lorig

150

Dr. Linda Aiken

152

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Dr. Mary Naylor

153

Dr. Nilda Peragallo

177

Dr. Judith Matthews

179

Dr. Kathleen Buckwalter

181

Dr. David Dinges

182

Yale University School of Nursing

210

Dr. Pamela Hinds

214

Dr. Margaret Grey (Michael Marsland photographer)

220

Dr. Elaine Larson

222

Appendix C

National Advisory Council for Nursing Research Member List

Name	Date of Service	Institution/Organization (State)
Abdellah, Faye G.*	02/1987-08/1989	U.S. Public Health Service (MD)
Affonso, Dyanne D.	02/1987-09/1988	University of California, San Francisco (CA)
Alt-White, Anna*	01/2004-present	Department of Veteran Affairs (DC)
Archbold, Patricia G.	06/1990-01/1994	Oregon Health Sciences University (OR)
Austin, Joan K.	02-2004-01/2008	Indiana University (IN)
Baun, Mara M.	06/1990-02/1992	University of Nebraska (NE)
Beck, Cornelia M.	02/1994-01/1998	University of Arkansas for Medical Sciences (AR)
Behrman, Richard E.	02/1998-01/2001	Center for the Future for Children, The David and Lucile Packard Foundation (CA)
Berman, Richard A.	06/1991-01/1995	Howe-Lewis International (NY)
Berning, Randall K.	02/1994-01/1998	Health Care Attorney & Consultant (CA)
Blumenreich, Gene A.,	02/1998-01/2002	Nutter, McClennen & Fish, LLP (MA)
Broome, Marion	02/2008-01/2012	Indiana University (IN)
Brooten, Dorothy	02/1997-01/2001	Case Western Reserve University (OH)
Bryant L. Edward, Jr.	06/1990-01/1994	Gardner, Carton and Douglas (IL)
Buckwalter, Kathleen C.	06/1997-01/2002	The University of Iowa (IA)
Buehler, Meta E.	06/1993-01/1997	Medical College of Virginia (VA)
Buerhaus, Peter	02/2002-01/2006	Vanderbilt University (TN)
Burgess, Ann W.	02/1987-09/1998	University of Pennsylvania (PA)

*Ex-officio members

Name	Date of Service	Institution/Organization (State)
Burgio, Louis	02/2002-01/2006	University of Alabama (AL)
Cammermeyer, Margarethe	02/2001-01/2003	Lecturer/Consultant (WA)
Conway, Elaine W.	02/1987-09/1998	Community Leader (NY)
Conway-Welch, Colleen	06/1989-02/1993	Vanderbilt University (TN)
Cordes, Donald W.	02/1987-09/1990	Cordes & Associates, Inc. (IA)
Counte, Michael A.	03/2005-04/2009	St. Louis University (MO)
Cournoyer, Paulette R.*	02/1987-05/2003	VA Boston Healthcare System (MA)
Cowan, Marie J.	06/1993-01/1997	University of Washington (WA)
Crisp, Rosemary B.	03/2003-02/2007	Consultant (IL)
Cronenwett, Linda R.	06/1992-01/1996	Dartmouth Hitchcock Medical Center (NH)
Cupples, Sandra A.*	02/1987-02/1990	Washington Hospital Center (DC)
Curtis, J. Randall	06/2006-01/2010	University of Washington (WA)
Damus, Karla H.	02/1987-02/1990	Albert Einstein College of Medicine (NY)
Dinges, David F.	08/2005-02/2009	University of Pennsylvania (PA)
Dowling, Glenna A.	02/2010-01/2014	University of California–San Francisco (CA)
Dracup, Kathleen A.	02/2004-01/2008	University of California, San Francisco (CA)
Dunbar-Jacob, Jacqueline M.	02/2001-01/2005	University of Pittsburgh (PA)
Elliott, Jo Eleanor*	02/1987-05/1989	Department of Health and Human Services (MD)
Felton, Geraldene	06/1991-01/1998	University of Iowa (IA)
Ferguson, Stephanie	02/2002-01/2005	George Mason University (VA)
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Kennedy-Scott, Patricia	09/1994-02/1995	Michigan Health Center (MI)
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Kirchoff, Karin T.	02/1987-02/1992	University of Utah (UT)
Kjervik, Diane K.	02/1987-02/1992	University of Texas (TX)
Lake, Diana E.	02/2008-01/2012	Memorial Sloan Kettering Cancer Center (NY)
Lancaster, Joan	02/2008-01/2010	Community and Government Relations (TN)
LaRosa, Judith H.	06/1997-01/2001	Tulane University School of Public Health and Tropical Medicine (LA)
Larson, Elaine	02/2010-01/2014	Columbia University (NY)
Lindsey, Ada M.	06/1997-01/2001	University of Nebraska
Linn, James W.	09/2005-01/2009	Lewis, Longman & Walker (FL)
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MacDonald, Elizabeth A.*	02/1989-09/1989	Office of the Assistant Secretary of Defense for Health Affairs (DC)
Marshall, Jean R.	06/1997-01/2000	Meridian Health System (NJ)
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McSweeney, Jean C.	02/2007-01/2011	University of Arkansas for Medical Sciences (AR)
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Miller, Karen L.	06/1997-01/2000	School of Allied Health (KS)
Millon-Underwood, Sandra M.	02/2004-04/2008	University of Wisconsin Milwaukee (WI)
Morrow, Gary	02/2004-06/2008	University of Rochester Medical Center (NY)
Munet-Vilaro, Frances	02/2003-02/2007	University of Washington (WA)
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Patton, Curtis L.	03/1998-01/2002	Yale University (CT)
Pender, Nola J.	02/1987-02/1990	Northern Illinois University (MI)
Potempa, Kathleen	02/2009-01/2013	University of Michigan (MI)
Portillo, Carmen J.	01/1999-09/2003	University of California (CA)
Powell, Dorothy L.	02/2000-01/2004	Howard University (DC)
Reardon, Judy E.	06/1995-01/1996	New Hampshire Public Affairs Director (NH)
Reinhard, Susan C.	02/2010-01/2014	AARP (DC)
Richard, Maggie L.*	01/2009-Present	Department of the Navy (MD)
Rudy, Ellen B.	06/1997-01/2000	University of Pittsburgh (PA)
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Salmon, Marla E.	02/2008-Present	University of Washington (WA)
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Sanford, Sarah J.	03/1998-01/2002	American Association of Critical Care Nurses (CA)
Schempp, Catherine M.	02/1987-05/2005	Tripler Army Medical Center (HI)
Shaver, Joan	02/2001-01/2005	University of Illinois at Chicago (IL)
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Smith-Williams, Betty	01/1999-01/2003	California State University Long Beach (CA)
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Trofino, Joan	02/1987-09/1990	Riverview Medical Center (NJ)
Udall, King S.	02/2007-01/2011	Family Practice (UT)
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Williams, Betty Smith	09/2000-01/2003	California State University Long Beach (CA)
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Woerner, Louise	06/1990-01/1994	Home Care of Rochester (NY)
Woods, Nancy A. F.	06/1989-02/1993	University of Washington (WA)
Zeller, Janice M.	06/1992-01/1996	Rush University (IL)

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Index

Note: Boldface page numbers indicate illustrations.

A

- Aaronson, Lauren, 237
nursing research of, 218–219
- Abdellah, Faye G., **4**, 241
development of federal nurse
specialist training program by, 3
- Abraham, Ivo, **58**
- Academic Investigator Award, launch
of, 55
- Academic Research Enhancement
Awards (AREA), 139
- acute illness. *See also* National Center
for Nursing Research (NCNR) Acute
and Chronic Illness Branch
National Center for Nursing
Research (NCNR) on, 52, 55, 81
symptoms associated with, 78, 170
- Advanced Cognitive Training for
Independent and Vital Elderly
(ACTIVE), 183
- Advisory Panel on Alzheimer's Disease,
179
- Affonso, Dyanne D., **130**, 241
as member of National Advisory
Council, 56
- Agency for Healthcare Research and
Quality (AHRQ), 91
Clinical Practice Guidelines of, 151
- Agency for International Development
(AID), 174
- Aging Asian Study, National Institute
of Nursing Research (NINR)
participation in, 143
- aging population, 179. *See also*
demographics; elder care
- AIDS. *See* HIV/AIDS
- Aiken, Linda H., 237
nursing research of, 104–105, 151,
152, 217, 222–224, 229–230
- Alcohol, Drug Abuse, and Mental
Health Administration (ADMHA), 12
- alcohol use, National Center for
Nursing Research (NCNR) research
on, 84
- Alexander, Duane, support for Grady
as candidate for director of National
Institute of Nursing Research
(NINR), 124
- Alt-White, Anna, 241
- Alzheimer's disease. *See also* Cognitive
diseases
National Institute of Nursing
Research (NINR) research on,
180–182, 185
National Institutes of Health (NIH)
research on, 17
- Alzheimer's disease or related
dementias (ADRD), 180
- American Academy of Nursing (AAN)
Hinshaw as fellow of and member
of the governing council of, 66
support for Grady as candidate for
director of National Institute of
Nursing Research (NINR), 124
- American Association of Colleges of
Nursing (AACN), 11
assistance from, in structuring
National Center for Nursing
Research (NCNR) into branches,
51
on creation of nursing research
institute, 21, 22
on end-of-life (EOL) research, 193
Grady as speaker at, 139–140
promotion of nursing education
programs, 16
- American Journal of Nursing*, honoring
of Goodrich, Annie Warburton, as

- “Tomorrow’s Nurse,” 209, **210**, 211
- American Medical Association (AMA), opposition to nursing institute, 12–13
- American Nurses Association (ANA)
- assistance from, in structuring National Center for Nursing Research (NCNR) into branches, 51
 - on creation of nursing research institute, 17, 21, 27–28
 - on defining nursing research, 14–15
 - endorsement of, by Mondale and Ferraro, 26
 - Goodrich, Annie Warburton, as president of, 209
 - nurse researchers at, vi
 - support for Grady as candidate for director of National Institute of Nursing Research (NINR), 124
- American Nurses Association (ANA) Cabinet on Nursing Research
- campaign for nursing research and, 7–8
 - Hinshaw as member of, 66
- American Nurses Association (ANA) Commission (later Cabinet), on nursing research, 6
- American Nurses Association (ANA) Council of Nurse Researchers, lobbying activities for nursing research, 6
- American Nurses Foundation (ANF), nursing research funding by, 5
- Amos, Linda, nursing research of, 18
- antiretroviral therapy, 109
- Approaching Death: Improving Care at the End of Life* (report), 189
- Archbold, Patricia G., 241
- arthritis. *See also* National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
- exercise and, 172
 - health disparities and, 149, 150
 - in Hispanics, 149
 - proposed new institute for, 13, 27, 44
- Association of Academic Health Centers (AAHC), end-of-life (EOL) research and, 193
- Association of American Medical Colleges (AAMC), opposition to nursing institute, 12–13
- Association of Collegiate Schools of Nursing, Goodrich, Annie Warburton, as president of, 209
- Atwood, Jan, research of, 68
- Austin, Joan K., 241
- Avalon Foundation, nursing research funding by, 5
- AWIS Magazine* (journal), 125
- Aydelotte, Myrtle, 4
- ## B
- Baby Boomers, 140–141
- basic research on pain, 170
- basic science
- at National Institute of Nursing Research (NINR), 118, 163, 177
 - at National Institutes of Health (NIH), 83, 113, 119
 - promoting, 27
 - transcending into clinical care, 130
- Baun, Mara M., 241
- Beck, Cornelia M., 241
- Bednash, Geraldine “Polly,” 237
- behavioral research
- defined, 154
 - National Institute of Nursing Research (NINR) interest in, 89, 154, 176, 216
 - National Institutes of Health (NIH) support for careers in, 168–169
- Behavioral Science and Nursing Theory* (Wooldridge and Leonard), 67
- Behrman, Richard E., 241

- “bench to bedside,” 148
- Bergstrom, Nancy, 151
- Berman, Richard A., 241
- Berning, Randall K., 241
- Better Patient Care Through Nursing Research* (Abdellah), 3
- Beyer, Judith E. *See also* Pain
development of OUCHER scale
and, 106
- biomedical research
National Institutes of Health (NIH)
support for careers in, 168–169,
188
patient-oriented perspective to, 132
- Bishop, J. Michael, as recipient of Nobel
Prize in Medicine, 118
- Bixby, M. Brian, 153
- Blank, Deidre M.
at Health Promotion and Disease
Prevention Branch at National
Center for Nursing Research
(NCNR), 54–55
at National Center for Nursing
Research (NCNR), 47–48
- Bloch, Doris, 54
Division of Nursing and, 75, 76
Madigan amendment and, 75
at National Center for Nursing
Research (NCNR), 47–48, 53
on nursing research, 21–22
- Blumenreich, Gene A., 147, 241
- Bowen, Otis R., 50
as Secretary of Health and Human
Services, 66
- Braden scale, 151
- Brandt, Edward, 29
- Broome, Marion, 241
- Brooten, Dorothy, 130, 241
nursing research of, 87, 146–147
- Brown, Esther Lucille, 2
- Broyhill, James T., blocking of bill
calling for National Institutes of
Health (NIH) to initiate research,
16–17
- Bryant, L. Edward, Jr., 241
- Buckwalter, Kathleen C., 130, 147, 181,
241
research of, 181
- Buehler, Meta E., 241
- Buerhaus, Peter, 241
- Bulger, Roger, 237
- Bureau of Health Resources
Development (BHRD), nursing
research and, 6–7
- Bureau of Medical Services, Division of
Nursing Resources in, 2
merger of, with Division of Public
Health Nursing, 3
in nursing research funding, 20
- Burgess, Ann W., 241
as member of National Advisory
Council, 56
- Burgio, Louis, 242
Alzheimer’s research by, 185
- Bush, George H. W., veto of National
Health Revitalization Act (1991), 95
- ## C
- Cabinet on Nursing Research, support
for nursing research, 9, 17
- cachexia, National Institute of Nursing
Research (NINR) on, 144, 186
- caffeine consumption, National Center
for Nursing Research (NCNR)
research on, 84
- California, graduate programs in
nursing in, 3
- Cammermeyer, Margarethe, 242
- cancer. *See also* National Cancer
Institute (NCI)
end-of-life (EOL) care and, 192, 193
National Center for Nursing
Research (NCNR) on, 84

- National Institute of Nursing
 Research (NINR) on, 144, 156
 nursing research on, 59, 95–96, 127
 symptom clusters in, 194
 teaching at-risk populations about
 hereditary, 186
- cardiovascular disease. *See also* heart
 disease
 research on risk factors of, 105, 156,
 186
- Carroll, Harriet D. “Bunny,” 75
 as head of Nursing Systems and
 Special Programs Branch, 55
 position of, at National Center
 for Nursing Research (NCNR),
 47–48
- Center for End-of-Life Transition
 Research, National Institute of
 Nursing Research (NINR) funding
 for, 231
- Center for Research in Chronic
 Disorders at University of Pittsburgh
 School of Nursing, 154
- Centers for Disease Control and
 Prevention (CDC), 18
 distribution of “Be Proud! Be
 Responsible!” by, 149
 report on AIDS cases, 84
- Chang, Betty L., 58
- children
 diabetes in, 219
 pain assessment in, 170
 reducing prevalence of risk factors
 for cardiovascular disease in
 rural, 105
- chronic illness
 family adaptation to, 78
 in Hispanics, 149
 as leading cause of disabilities, 141
 long-term impact of, 213
 National Center for Nursing
 Research (NCNR) on, 52, 55, 81
 patient care and, 151–154
 as public health problem, 140
 research on, 225
 successful adaptation to, 73
 symptoms associated with, 78, 141,
 170
 treating, 164
- chronic obstructive pulmonary diseases
 (COPD), research on, 114, 144, 191
- chronic wounds, nursing research on,
 132
- cigarette smoking
 longitudinal study on, 91
 National Center for Nursing
 Research (NCNR) on, 84
- Cleland, Virginia, nursing research
 and, 6
- clinical bioethics, National Institute
 of Nursing Research (NINR) as lead
 institute in investigating, 142
- clinical ethics, 128–129
- Clinical Investigator Award, launch of,
 55
- clinical research, 99–100
 Bureau of Health Resources
 Development (BHRD) and, 6–7
 into cancer, 59
 dissemination of, in academic and
 other research centers, 10–11
 into drug therapies, 145
 into genetics, 136
 investigator-initiated, 138
 at the National Institute of Nursing
 Research, 139–140, 149, 151,
 163–164
 nurse involvement in, 19, 41, 59,
 72–73, 90, 104, 113–114, 131,
 148, 155, 174, 214, 224
 into pain, 170
 public health aspects of, 137
 success of, 146
- Clinical Therapeutics Laboratory, 97
 foundation of, 89
- clinical trials, 146
 into Alzheimer’s disease or related
 dementia (ADRD), 180

- clinical ethics and, 128–129
 - large-scale, 230
 - managed care and, 146
 - at the National Institute of Nursing Research (NINR), 151
 - testing models in, 219
 - Clinton, William (Bill)
 - administration of, 98–99
 - in election of 1992, 98
 - in election of 1996, 129
 - health care and, 96, 114
 - cognitive diseases. *See also* Alzheimer's disease
 - National Institute of Nursing Research (NINR) on research on, 179–185, 196
 - Collins, Francis S., as director of National Human Genome Research Institute, 188
 - Commissioned Corps of U.S. Public Health Service, Scott as two-star admiral in, 4
 - Commission (later Council) on Nursing Research, shaping of health care agendas and policy at, 72–73
 - community-based health care, nursing research and advances in, vii
 - compliance, research on patient, 59
 - Conference on Nursing Research Priorities, 99–100, **100**
 - development of national nursing research agenda of, 76–78
 - National Center for Nursing Research (NCNR) convening of second, 99–100, **100**
 - Congestive heart failure. *See* Heart failure
 - Contract with America, 114
 - Conway, Elaine W., 242
 - as member of National Advisory Council, 56
 - Conway-Welch, Colleen, 146–147, 242
 - Cordes, Donald W., 242
 - Coronary heart disease. *See* cardiovascular disease; heart disease
 - CORP I, 117
 - CORP II, 117
 - Council of Baccalaureate and Higher Degree Programs of National League for Nursing, support for nursing research, 3
 - Council of Nurse Researchers, 69
 - lobbying efforts of, 94–95
 - Merritt attendance of meeting at, 45–46
 - on National Center for Nursing Research (NCNR), 94
 - Counte, Michael A., 242
 - Cournoyer, Paulette R., 242
 - Cowan, Marie J., **58**, 242
 - nursing research of, 178
 - Crisp, Rosemary B., 242
 - Cronenwett, Linda R., **58**, 242
 - Cunningham Foundation, funding for nursing research and, 5
 - Cupples, Sandra A., 242
 - Curtis, J. Randall, 242
 - end-of-life (EOL) research of, 195
- D**
- Daly, Barbara, research on chronically critically ill, 151–154
 - Damus, Karla H., 242
 - degenerative diseases
 - National Institute of Nursing Research (NINR) research on, 184
 - nursing research on symptom management for, 183
 - treating, 164
 - dementia
 - coexistence of Alzheimer's disease with vascular disease and, 182
 - financial burden of, 179
 - in Honolulu-Asia Aging Study, 97

- National Institute of Nursing
 Research (NINR) research on,
 178, 184
 nursing research on, 164
- demographics, challenges provided by
 changes in, 145, 232
- Denyes, Mary J., 106
- Dewey, Thomas E., 209
- diabetes
 health disparities and, 149, 150
 pediatric, 219
 research on, 219, 225
 risk for, 225
 as treatable, 212
- Dinges, David F., **182**, 242
 research of, 182-183
- disability
 chronic illness as leading cause of,
 141
 fears of, 84
 National Institute of Nursing
 Research (NINR) mission on, 164
- disease management, research on, 215,
 226
- disease-oriented perspective, 141
- disease prevention
 National Center for Research
 (NCNR) focus on, 81
 National Institute of Nursing
 Research (NINR) focus on, 214,
 229, 231, 232
 shift to, 213
- Division of Nursing. *See under*
 Health Resources and Services
 Administration (HRSA)
- Division of Research Resources, 92
- Dock, Lavinia, 2
- Donaldson, Sue, 130, **130**
- Dowling, Glenna A., 242
 research of, 182
- Dracup, Kathleen A., 237, 242
 on budgetary issues as hindrance
 to National Institute of Nursing
 Research (NINR) future, 228-229
 on disease management, 226
 nursing research and, 184-185,
 215-216, 225-226
- Dreher, Melanie C., **58**
- drugs
 clinical research on, 145
 National Center for Nursing
 Research (NCNR) on, 84
- Dumas, Rhetaugh
 concerns on nursing research, 23,
 28, 67-68
 as dean of University of Michigan
 School of Nursing, 11, 92, 102
 at National Institute of Mental
 Health, 11-12
 opposition to proposed National
 Institute for Nursing Research, 90
 at Virginia-Carolinas Doctoral
 Consortium in Nursing, 17-18
- Dunbar-Jacob, Jacqueline M., 154, 242
- E**
- elder care. *See also* aging population
 National Center for Nursing
 Research (NCNR) research on, 84
 National Institute of Nursing
 Research (NINR) research on,
 133
 as public health problem, 140
- Elders, Joycelyn, 96
- Elliott, Jo Eleanor, 237, 242
 on nursing research, 11, 18, 40
 on nursing research institute, 19, 21
 as successor to Scott, Jessie, 23
- emerging diseases, challenges presented
 by, 130
- Endicott, Kenneth M., nursing research
 and, 7
- end-of-life (EOL) care
 Association of Academic Health
 Centers research on, 193
 Curtis, J. Randall, on, 195

- in health care debate of 2010, 226–227
 - Kaufman, Sharon, on, 195
 - National Advisory Council for Nursing Research on, 142
 - National Institute of Nursing Research (NINR) leadership role on research on, 139–140, 142, 144–145, 175, 191–197
 - as public health concern, 178
 - research on, 164, 231
 - Tennstedt, Sharon L., on, 191–192
 - Environmental Health Sciences Working Group, 137, 138
 - environmental sciences
 - incorporation of nursing research into, 136–137
 - nature of research on, 137–138
 - epidemiology
 - basic research into, 145
 - need for management skills in, 232
 - ethics
 - clinical, 128–129
 - end-of-life, 191–192
 - ethnic groups, health disparity among, 176
 - An Evening of Wit and Wisdom: The Science of Care and Compassion at the End of Life*, National Institute of Nursing Research (NINR) co-sponsorship of, 192, 192–193
- F**
- Faculty Research Development Grants, 4
 - Fauci, Anthony, 73
 - support for Grady as candidate for director of National Institute of Nursing Research (NINR), 124
 - Felton, Geraldene, 58, 237, 242
 - on nursing research, 11, 23
 - opposition to proposed National Institute for Nursing Research (NINR), 90
 - Ferguson, Stephanie, 242
 - Ferraro, Geraldine, American Nurses Association (ANA) endorsement by, 26
 - Ferrell, Betty R., 242
 - Fife, Rose S., 242
 - Finkelstein, Stanley, 242
 - Finkler, Steven A., 243
 - Fogarty International Center, 31
 - Food and Drug Administration (FDA), 18
 - food consumption
 - longitudinal study on, 84
 - National Center for Nursing Research (NCNR) research on excess, 84
 - Fralic, Maryann F., 243
 - Frederickson, Donald, 44
 - Freeman, Everette J., 243
 - Frick, Kevin, 243
 - Fukuoka, Yoshimi, nursing research of, 225
 - Funk, Sandra G., 58
- G**
- gender
 - bias in establishing nursing research institute, 39
 - as factor in pain, 144, 171, 196
 - gene therapy, research on, 134, 186
 - genetic counseling, National Institute of Nursing Research (NINR) contributions to, 129–130
 - genetic research, 225
 - as emerging field, 166, 196–197
 - ethical issues associated with, 135
 - Meininger, Janet, on, 186
 - National Institute of Nursing Research (NINR) support for, 134–136, 186–189

- need for basic, 134
 Genetics Research Workgroup, 134–135
 genetic therapy, research on, 131–132
 Geolot, Denise, 243
 George Mason University, conference at, 22
 Giger, Joyce N., 243
 Gingrich, Newt, 114
 Gioiella, Evelyn, 243
 Goldstein, Murray, 73
 retirement of, 120
 Goodrich, Annie Warburton, **2**
 as director of Henry Street Visiting Nurse Service, 209
 in founding of U.S. Army School of Nursing, 209
 in founding of Yale School of Nursing, 209
 honoring of, as “Tomorrow’s Nurse,” 209, **210**, 211
 as president of American Nurses Association (ANA), 209
 as president of Association of Collegiate Schools of Nursing, 209
 as president of National League of Nursing Education (NLN), 209
 Graduate Partnerships Program (GPP) in Biobehavioral Research, 188
 Grady, Patricia A., **130**, **141**, **181**, 237
 academic studies of, 122
 accomplishments of, as director of National Institute of Nursing Research (NINR), **112**, 125–156, 178, 187, 228–229
 as acting director of the National Institute of Neurological Disorders and Stroke (NINDS), 120, 122, **123**
 advice to young nurse scholars, 131–132
 application for directorship, 123–124
 as chair of National Institute of Nursing Research (NINR) Director Search Committee, 120
 as combination of advocate, teacher, counselor, and cheerleader for nursing science, 132–133
 confidence in, by Varmus, Harold E., 126–127
 development of National Institute of Neurological Disorders and Stroke (NINDS) policies, priorities, and program activities, 122–123
 early career and credentials of, 121–123, 126
 goal of, in advancing nursing science, 164–165
 leadership skills of, 171–172
 long-term strategic goal of, 126–127
 at National Institute of Nursing Research (NINR) 20th anniversary, **229**
 on National Institute of Nursing Research (NINR) clinical ethics program, 128–129
 on National Institute of Nursing Research (NINR) logical lead for end-of-life (EOL) research, 191–197
 on National Institute of Nursing Research (NINR) research, 132, 179, 181–182, 231
 philosophy of, 213
 recognition of value of history, 131
 research work of, 122–123, 133
 scientific and management expertise of, 124–125
 as speaker at American Association of Colleges of Nursing (AACN), 139–140
 stress of, on value of student research, 133
 training of, 155
 Varmus encouragement to compete for director, 120–121
 vision for National Institute of Nursing Research (NINR), 189,

191
 writings of, 125
 Graham, Robert, on nursing research, 29
 Gramm-Rudman-Hollings Balanced Budget Act, 40
 Great Society, 3
 Grey, Dean, nursing research and, 224–225
 Grey, Margaret J., 237, 243
 nursing research of, **220**, 219–220
 Guthrie, Barbara, 243
 Gypsy Moths, 81

H

Hagey, Antoinette, 243
 Hall, Geri, 181
 Hanley, Daniel F., 243
 Harkin, Tom, support for National Center for Nursing Research (NCNR) as institute, 100
 Harrigan, Rosanne C., 243
 Hatch, Orrin G.
 on nursing research, 24–25, 31–32
 role of, in creation of National Institute of Nursing Research (NINR), vi, 20, **25**, 26
 Hawkins, Paula, support for nursing research institute, 25
 head injury, research on, 122
 Health and Health Services, U.S.
 Department of, National Institute of Nursing Research (NINR) spearheading of End-of-Life Scientific Interest Group, 193
 health care reform
 under Clinton, 114–115
 current debate over, vii
 end-of-life care in, 226–227
 health care system, dramatic changes in, 212–213

health disparities
 among ethnic groups, 176
 efforts to eliminate, 214, 231
 end-of-life research (EOL) and, 195
 Minority Health Research Development for Nurse Investigators Conference on, 169
 as public health issue, 174, 176
 as research focus at the National Institute of Nursing Research (NINR), 141, 148–149, 166, 169, 172, 174
 health promotion
 National Center for Nursing Research (NCNR) focus on, 81
 National Institute of Nursing Research (NINR) focus on, 214, 231–232
 Health Research Extension Act (1983), 19
 Health Research Extension Act (1985), 30–31
 Reagan veto of, 31
 override of, 32
 Health Resources and Services Administration (HRSA), 3, 81
 Division of Nursing in, 3
 Advanced Nursing Resources Branch of, 48
 Center for Nursing Research at
 establishment of, 1, 23–24, 29, 40
 mission of, 31
 grant-making culture at, 46
 as location for research grants, 7
 Madigan amendment and, 21–23
 nurse investigators under, 165
 peer review system for research proposals developed at, 57
 Scott as director of, 4
 Healy, Bernadine

- as director of National Institutes of Health (NIH), 100-101
- Hinshaw and, 101
- heart disease. *See also* cardiovascular disease
- in Hispanics, 149
 - risk for, 225
 - as treatable, 212
- heart failure
- congestive, 191
 - health care expenditures on, 151
 - National Institute of Nursing Research (NINR) research on, 151
 - research on, in rural areas, 184, 185
- Heckler, Margaret, establishment of center for nursing research within Division of Nursing, 29
- Heinrich, Janet, 45, 237
- on nursing research, 14-15, 178
- Heller, Leonard E., 16, 243
- as member of National Advisory Council, 56
- Henderson, Virginia, 4
- Henry Street Visiting Nurse Service, Goodrich, Annie Warburton, as director of, 209
- Heredia, Jimmy, 177
- Hernandez, Gloria, 243
- Highly Active Anti-Viral Therapy (HAART), 109*n*39
- high-risk behaviors, as public health issue, 174
- Hill, Martha, research of, using multidisciplinary health teams, 149
- Hinds, Pamela S., 237
- as director of nursing research at The Children's National Medical Center in Washington, 187-188, 214, 215, 227-228
- Hinshaw, Ada Sue, 64, 102, 237
- accomplishments of, as director of National Center for Nursing Research (NCNR), 66-106, 113, 174, 228-229
 - application of, for director, 69-70
 - avocation of nursing institute, 95-96
 - campaign for nursing research and, 8
 - as chair of American Nurses Association (ANA) Cabinet on Nursing Research, 46
 - credentials of, 66-67
 - as dean of School of Nursing at University of Michigan, 102-103
 - departure from National Center for Nursing Research (NCNR), 102-103, 103, 113, 119
 - education and early career of, 67-69
 - as Fellow of American Academy of Nursing, 66
 - goals of, for National Center for Nursing Research (NCNR), 73-75
 - grant applications at National Center for Nursing Research (NCNR) offices and, 82
 - as Health Leader of the Year, 102
 - Healy, Bernadine, and, 101
 - interview with Merritt, Doris, 70
 - interview with Wyngaarden, 70
 - as member of American Nurses Association (ANA) Cabinet on Nursing Research, 66
 - as member of governing council of American Academy of Nursing, 66
 - as member of National Institute of Mental Health Task Force on Nursing Research, 66
 - on National Center for Nursing Research (NCNR) centers program, 104-105
 - at National Institute of Nursing Research (NINR) 20th anniversary, 229
 - on nursing research, 71-72, 94
 - on nursing science as family and

- community orientation, 90–91
- push for more resources for nurse scientists, 69
- as recipient of Nurse Scientist of the Year Award, 66–67
- selection of, by Wyngaarden, James B., 70–71
- starting of intramural research program within National Center for Nursing Research (NCNR), 97–98
- swearing in of, as National Center for Nursing Research (NCNR) director, 71, 73–75
- testimony before Congress, 79–80
- training of, 155
- as vice chair of Commission on Nursing Research, 73
- HIV/AIDS
 - health disparities and, 176
 - National Center for Nursing Research (NCNR) on research in, 84–85, 88–89, 127, 173–178, 196
 - National Institute of Nursing Research (NINR) research on, 133
 - as public health concern, 84, 174
 - research on, 133
- Hodes, Richard J., 124
- Hodge, Felicia Schanche, 243
- Honolulu Heart Program, National Institute of Nursing Research (NINR) participation in, 143
- Howard, Monique, **148**
- Howell, Doris A., 243
- human genome, mapping of, 141
- Human Genome Project (HGP), 141
 - completion of, 188–189
- Hurd, Suzanne S.
 - as acting director of National Institute of Nursing Research (NINR), **112**, 114–119, 178
 - administrative strengths of, 114
 - budget appropriations hearings and, 115–116
 - credentials of, 115
 - interest in more innovative research proposals, 117
 - on linkage of biological findings from medical research with biological research, 178
 - praise for conferences on research priorities, 117
 - on strengths and weaknesses of the Institute, 118
- I**
 - Image: Journal of Nursing Scholarship* (publication), 131
 - immune disorders, symptom clusters in, 194
 - immunology, nursing research on, 133
 - Indiana University-Purdue University-Indianapolis (IUPUI), 44
 - information science, nursing science and, 230
 - Inouye, Daniel K., support for nursing research, 25, 100
 - insomnia, National Center for Nursing Research (NCNR) research on, 80, 84
 - Institute of Medicine (IOM) report (1983), 16, 19, 45, 223
 - on nursing research, 9–11, 17
 - in Reagan's veto message, 26–27
 - Interdisciplinary journals, publication of work of nurse investigators in, 223
 - interdisciplinary research, National Institute of Nursing Research (NINR) support for, 217
 - interdisciplinary training, 222
 - “it's not the therapy, it's the nurses” (Daly quote), 154
- J**
 - Jacobson, Sharol F., **58**
 - Jacox, Ada

as advocate of nursing research, 6, 7–8, 9, 40–41, 57
 position of, on nursing research institute, 21
 as president of the American Nurses Association (ANA), 9

Jaser, Sarah, **220**

Jemmott, Loretta Sweet, **130, 148, 243**
 research of, on behavioral interventions, 149

Jenkins, Jean, as senior clinical advisor, 189

Jennings, Bonnie L., 243

Johnson, Jane, 67

Jones, Susan L., **58**

K

Kaufman, Sharon, end-of-life (EOL) research of, 195

Kellogg, W. K., Foundation, funding for nursing research and, 5

Kennedy, Edward M., on nursing research, 20, 31–32

Kennedy-Scott, Patricia, 243

kidney failure, research on diet therapy for, 17

Kim, Hesook Suzie, 243

Kim, Mi Ja, **58, 244**

Kinney, Marguerite R., 244

Kirchoff, Karin T., 244

Kirschstein, Ruth L., 237
 as director of National Institute of General Medical Sciences, 48, 73, 75–76

Kjervik, Diane K., 244

Konick-McMahan, JoAnne, **153**

Kramer, Marlene, nursing research of, 68

L

Laboratory for the Study of Human Responses to Health and Illness, 97

Lake, Diana E., 244

Lancaster, Joan, 244

LaRosa, Judith H., 244

Larson, Elaine L., **222, 237**
 on educating nurse scientists, 221, 225
 on nursing research, 216, 217, 221–222, 244

Lenfant, Claude, support for Grady as candidate for director of National Institute of Nursing Research (NINR), 124

Leonard, Robert C., 67

Levine, Jon D., research on pain relief, 144, 170–171

“Lewin Report” on nursing research, 29, **30**

Light, Judith, **192**

Lindberg, Donald, location of National Center for Nursing Research (NCNR) and, 48, **49**

Lindsey, Ada M., 244

Linn, James W., 244

Lister Hill Center, location of National Center for Nursing Research (NCNR) offices in, 48, 56

Local 41 of American Federation of Government Employees (AFGE), 50

Lorig, Kate, **150**
 research of, 149–150

low birthweight infants
 National Center for Nursing Research (NCNR) research on, 78, 79, 87–88, **88**
 National Institute of Nursing Research (NINR) research on, 127–128, 133
 nurse-directed transitional care and, 146

- prevention of, 156
 - as public health problem, 140
 - transitional care with, 104
 - Lucas, Mary, research of, 178
 - Lum, Jean L. J., 244
 - lung disease, health disparities and, 149–150
 - Lunney, June, 175
- M**
- MacDonald, Elizabeth A., 244
 - Madhany, Zehra, 177
 - Madigan, Edward R.
 - amendment, 66
 - in emerging nursing community, 21
 - Tri-Council for Nursing backing of, 23
 - role of, in creation of National Institute of Nursing Research (NINR), vi, 15, 16, 18, 19–20, 23, 25–26, 31
 - managed care, National Institute of Nursing Research (NINR) research on, 145–146
 - managed care organizations (MCOs), nursing research and, 146–147
 - Marshall, Jean R., 147, 244
 - Mason, James, 101
 - Matsunaga, Spark M., 25
 - Matteson, Mary Ann, research of, 180
 - Matthaei, Frederick C., Jr., 244
 - as member of National Advisory Council, 56
 - McCormick, Patricia
 - as head of Acute and Chronic Illness Branch at National Center for Nursing Research (NCNR), 55
 - position of, at National Center for Nursing Research (NCNR), 47–48
 - McFarland, Gertrude K. “Trudy,” 55, 58
 - McKenna, Catherine, 153
 - McSweeney, Jean C., 244
 - medical community, opposition to institute status for nursing at National Institutes of Health (NIH), 101–102
 - Meininger, Janet, genetic research of, 186
 - Merritt, Donald, 42, 44
 - diagnosis of terminal cancer, 51
 - Merritt, Doris H., 64, 237, 244
 - as acting director of National Center for Nursing Research (NCNR), 1, 41–42, 43, 44–47, 50, 56, 60, 65, 163–164
 - appointment of, by Wyngaarden, James B, 44–45, 60
 - attendance at Council of Nurse Researchers meetings, 45–46
 - early career of, 42–44
 - education of, 42
 - efforts to integrate National Center for Nursing Research (NCNR) into National Institute of Health (NIH), 57–59, 75–76
 - on HIV/AIDS research, 56–57, 173
 - on integration of National Advisory Council into National Institutes of Health (NIH), 57–59
 - on multidisciplinary nature of nursing, 163–164
 - recognition of, for start-up work, 75
 - on staffing of institute, 47–48
 - Meyer, Charles A., 95
 - Miaskowski, Christine, research of, 170–171
 - on pain relief, 144
 - Miller, Karen L., 244
 - Millon-Underwood, Sandra M., 244
 - minorities
 - health of, as public health issue, 174
 - pain in, 106
 - Minority Health Research Development for Nurse Investigators Conference, 142, 169–170

Mondale, Walter, American Nurses Association (ANA) endorsement by, 26

Montgomery, Kathy, 124

Moritz, Patricia M., 75, 237
 as branch chief of Nursing Systems Branch, 55–56
 position at National Center for Nursing Research (NCNR), 48

Morrow, Gary, **130**, 244

Mukamel, Dana, 191

multiple sclerosis, 40

Munet-Vilaro, Frances, 244

Murdaugh, Carolyn, 97
 intramural program under, **98**

Murray, John S., 244

N

Natcher, William H., 79

National Advisory Council for Nursing Research (NACNR), 59, **147**
 on end-of-life (EOL) research, 142
 integration of, into culture of National Institutes of Health (NIH), 57–58
 priorities for nursing research and, 78, 166
 recommendations of, on centers for nursing research, 89–90

National advisory group, establishment of, for National Center for Nursing Research (NCNR), 51

National Association of Hispanic Nurses (NAHN), 169

National Black Nurses Association (NBNA), 169

National Cancer Institute (NCI), 27
 collaboration between National Institute of Nursing Research (NINR) and, 170, 189
 Division of Cancer Epidemiology and Genetics at, 169

National Center for Nursing Research (NCNR)
 accomplishments of, 59–60, 94–95
 Acute and Chronic Illness Branch at, 52, 55
 acute illness research at, 52, 55, 81
 alcohol use research at, 84
 alignment of operations with National Institutes of Health (NIH) institutes, 96–97
 attainment of institute status, **102**, 102–103, **103**
 Biological Sciences Task Force at, 176–177
 biological theory research and, 177–178
 budget of, 59, 60, 79, 85–87, 92, 94, 96
 bureaucratic problems in creation of, 39–40
 cancer research at, 84
 chartering of, v
 cigarette smoking research by, 84
 collaboration with other groups, 57–58, 85
 commitment to funding good science, 82–83
 convening of second Conference on Nursing Research Priorities, 99–100, **100**
 creation of “Directions for Nursing Research Toward the Twenty-First Century,” **8**
 creation of Division of Intramural Research, 97–98
 on disease prevention, 81
 Division of Extramural Programs at, 53
 drug use research at, 84
 elder care research at, 84
 establishment of centers for nursing research, 89–90
 establishment of national advisory group for, 51
 focus of, on disease prevention, 81
 food consumption research at, 84

- funding for nursing research at, 50, 90–92, 96, 113
 - funding of behavioral research, 89
 - goal of, 53
 - grant making by, 52, 52–53
 - health and behavior research at, 90–91
 - on health promotion, 81
 - Health Promotion and Disease Prevention Branch of, 54–55, 81
 - Hinshaw as director of, 66–106, 71, 113, 174, 228–229
 - HIV/AIDS research at, 84–85, 88–89, 173–177
 - identification of research priorities for nursing science, 79–81
 - inability to lobby, 95
 - on insomnia, 80, 84
 - integration of, into National Institutes of Health (NIH) network, 73–75, 113
 - intention of setting national nursing research agenda, 76–77
 - intervention-based research under, 175
 - intramural program of, 83, 97–98, 113
 - on investigator-initiated research, 174
 - launch of national research agenda by, 166
 - location of, in Lister Hill Center, 48, 49, 50
 - long range plans and goals of, 56–57
 - under Merritt as acting director, 1, 41–42, 43, 44–47, 50–51, 56, 60, 65, 163–164
 - National Advisory Council for Nursing Research (NACNR) at, 56, 57–58, 59, 74
 - navigating National Institutes of Health (NIH) grants process, 52
 - Nursing Research Study Section at, 59
 - Nursing Systems and Special Projects Branch at, 52, 56
 - physical space for, 56
 - professional staff for, 53–56
 - on public health, 90, 197, 214
 - on quality of life, 78
 - Reagan opposition to, v
 - Research Development and Review Branch of, 55
 - research on cancer, 84
 - research on chronic illness, 52, 81
 - as rite of passage, 40
 - search for permanent director, 59, 65–66
 - on setting nursing research priorities, 165–166
 - on sexual activity, 84
 - on sleep disorders, 80
 - structuring of, into branches, 51
 - symptom management research at, 78, 85, 88
 - technology transfer conferences between National Institute of Allergy and Infectious Diseases and, 173
 - in training of investigators, 90
 - very low birthweight infants research at, 87–88, 88
 - on women's health, 89
- National Coalition of Ethnic and Minority Nursing Associations (NCEMNA), 142, 169
- National Forum on Doctoral Education, 71
- National Health Revitalization Act (1991), 95
 - Bush's veto of, 95
- National Heart Lung and Blood Institute (NHLBI)
 - collaboration between National Institute of Nursing Research (NINR) and, 184–185
 - collaboration of National Center for Nursing Research (NCNR) with, 57
- National Human Genome Research

- Institute (NHGRI), 188-189
- National Institute of Aging,
collaboration of National Center for
Nursing Research (NCNR) with, 57
- National Institute of Allergy and
Infectious Diseases (NIAID), 174
collaboration with, 85
- National Institute of Nursing
Research (NINR) collaboration
with, 191
- technology transfer conferences
between National Center for
Nursing Research (NCNR) and,
173
- National Institute of Arthritis, Diabetes,
and Digestive and Kidney Diseases,
44
- National Institute of Arthritis and
Musculoskeletal and Skin Diseases
(NIAMS)
creation of, 44
- National Institute of Nursing
Research (NINR) collaboration
with, 172, 191
- National Institute of Child Health and
Human Development (NICHD), 174
collaboration of National Center
for Nursing Research (NCNR)
with, 57
- National Institute of Deafness and
Communicative Disorders (NIDCD),
92
- National Institute of Dental Research
(NIDR), National Institute of Nursing
Research (NINR) collaboration with,
170
- National Institute of Environmental
Health Sciences (NIEHS), 138
- National Institute of Health (NIH)
spinal cord regeneration research
at, 17
- sudden infant death syndrome
(SIDS) research at, 17
- National Institute of Mental Health
(NIMH)
collaboration of National Center
for Nursing Research (NCNR)
with, 57
- Hinshaw as member of Task Force
on Nursing Research at, 66
- National Institute of Neurological
Disorders and Stroke (NINDS), 120,
122, 125
- National Institute of Nursing Research
(NINR), 19
- ability to save health care dollars,
127-128
- Academic Investigator Awards, 168
- accomplishments of, vii-viii, 131,
148-149
- advancement of nursing science
and, vi, 164-165
- Ageing Asian Study participation
of, 143
- basic science at, 176-177
- behavioral research at, 154, 176-
178, 216
- breadth of research of, 191
- budget for, 41, 115-116, 127, 138,
155-156, 227-228
- on cachexia, 144, 186
- on cancer, 144, 156
- cancer research at, 144, 156
- Career Transition Award, 169
- catalyzation of changes in nursing
science and, 220-221
- celebrating fifteen years of nursing
research at National Institutes of
Health (NIH), 115
- celebration of tenth anniversary
of nursing research at National
Institutes of Health (NIH), 129-
131, 130
- Clinical Investigator Awards, 168
- clinical research and, 139
- Clinical Therapeutic Laboratory
(CTL) at, 143
- on cognitive impairment research,
179-185, 196

- collaborative research efforts with other institutes, 18–185, 170, 172, 189, 191
- co-sponsorship of *An Evening of Wit and Wisdom: The Science of Care and Compassion at the End of Life*, **192**, 192–193
- creation of, 102, **102**, **103**
- degenerative disease research at, 183–184
- on dementia, 178, 184
- development of “Making Your Wishes Known,” 226–227
- on disability, 164
- Division of Intramural Research (DIR) at, 143
- efforts to eliminate health disparities, **141**
- efforts to improve scientific reputation, 120
- end-of-life (EOL) care research at, 139–140, 142, 189–197
- Environmental Health Sciences Working Group, 137, 138
- evolution of, with country’s changing demographics, 232
- extramural funding and, 117–118
- focus on attracting nurses from underrepresented groups, 169
- focus on disease prevention, 214, 229, 231, 232
- focus on research priorities on health promotion and disease prevention, 214
- focus on symptom management research, 142–144
- on functional ability in, 183–184
- funding for, 129, 139, 196
- genetics research at, 134–136, 186–189
- Genetics Workgroup at, 134–135
- goals of, 126, 178–179
- under Grady, 125–156, 189, 191
- on health disparities, 166
- health disparities as research focus at, 149–150
- on health promotion, 214, 231, 232
- HIV/AIDS research at, 195–196
- Honolulu Heart Program
 - participation of, 143
 - under Hurd as acting director of, **112**, 114–119, 178
- improvement of sophistication of research, 215
- initiative in self-management strategies for diabetics, 142
- initiative of, on self-management, 142, 149
- interdisciplinary and multidisciplinary collaboration and, 138, 168–169, 217
- Intramural Research Training Awards at, 169
- issuance of Program Announcements and Requests for Application (RFAs), 194–195
- as leader in nursing science, 215
- leadership in, 231–232
- as lead institute in clinical bioethics, 142
- as lead institute of National Institutes of Health (NIH), **190**
- low birthweight delivery research at, 127–128
- Madigan’s role in establishment of, 81
- managed care research at, 145–146
- Mentored Research Scientist Development Award-Nursing, 168
- National Institute of Dental Research (NIDR) collaboration with, 170
- National Nursing Research Agendas of, 170, 185–186
- new clinical ethics program of, 128–129
- on nurse scientists training, **167**, 166–169
- Nurse Scientist Training Program, 168
- offering of post doctoral fellowships

- that linked training in nursing research and genetics, 141
- organization of Minority Health Research Development for Nurse Investigators Conference, 169–170
- origins of, 1–32
- on pain research, 170–173, 196
- partnerships with other National Institutes of Health (NIH) groups in training nurse scientists, 168–169
- planning process at, 129
- on preventive health, 166
- priority in funding research project grants, 138–139
- promotion of incorporation of nursing research into environmental sciences, 136–137
- recognition of importance of ethnic and cultural changes, 141–142
- reflection of, on past achievements, 215
- research agenda of, 129, 132, 224
- in setting priorities for nursing science, 227
- spearheading of DHHS-wide End-of-Life (EOL) Scientific Interest Group, 193
- sponsorship of “Minority Health Research Development” conference, 142
- sponsorship of Terminal Illness Workshop, 144–145
- strategic planning by, 154–155, 168, 214, 231
- strengths and weaknesses of, 118
- strengths of, for parity in National Institutes of Health (NIH), 126
- success rate of, 116–117
- Summer Genetics Institute (SGI) at, 136, 137, 187–188
- support for basic and clinical science, 163, 170–171
- support for Program for All-inclusive Care for the Elderly (PACE), 194
- support for Resources for Enhancing Alzheimer’s Caregiver Health (REACH), 185
- support for translational research, 217
- support of cost effectiveness research, 162
- on symptom management, 78, 85, 133, 141, 142–143, 166, 170, 175, 180, 183, 191, 196, 214
- terminal illness research at, 144–145
- twenty-fifth anniversary of, v–viii, 211–212, 232–233
- on women’s health, 133
- National Institute of Nursing Research (NINR), on value of nursing care, 166
- National Institute on Aging (NIA), 27, 124, 174
 - collaboration with National Institute of Nursing Research (NINR) and, 185, 189
 - creation of, 44
- National Institutes of Health (NIH), **facing page 1**
 - AIDS Executive Committee, 174
 - basic research at, 83, 113, 119
 - Center for Scientific Review, 55
 - Center on Minority Health and Health Disparities, 169–170
 - early opposition to nursing institute, 12, 14
 - launching nursing science at, 39–63
 - mission of, 31
 - National Center for Nursing Research (NCNR) alignment of operations with, 73–74, 96–97
 - National Institute of Nursing Research (NINR) role in forming End-of-Life Special Interest Group, 192
 - nursing research at, v–vii, 28, 216–217
 - Office of Behavioral and Social

- Sciences Research (OBSSR) at, 138
- Office of Medical Applications of Research on end-of-life (EOL) care, 193–194
- pecking order at, 126
- Reagan veto of reauthorization bill, 26
- reputation for pioneering
 - intramural research programs, 83
- research budgets of, 138
- Roadmap of, 216–217, **217**
- support for careers in biomedical research, 168, 188
- Task Force on Nursing Research, report on need for nursing research, 27
- National Institutes of Mental Health (NIMH), 12, 57
 - AIDS Policy Subcommittee, 174
 - Task Force on Nursing Research at, 66
- National League for Nursing (NLN)
 - assistance from, in structuring National Center for Nursing Research (NCNR) into branches, 51
 - on creation of nursing research institute, 21
 - as voice for nursing education, 16
- National League of Nursing Education, Goodrich as president of, 209
- National Library of Medicine (NLM), collaboration of National Center for Nursing Research (NCNR) with, 57
- National Nursing Research Agendas
 - development of, 74, 76–79, 185–186
 - identification of priority areas for nursing research, 78–79
 - impact and effectiveness of, 86
 - low birthweight infants and mothers identified as priority of, **88**
 - research priorities phases into, 99
 - setting guidelines for nursing science, 86
- National Research Service Award (NRSA), 168
- Naylor, Mary, **153**, 245
 - research of, 151
- neurology, 73, 155
- Nolan, Marie T., 191
- Nurse-Family Partnership, 149
- nurse scientists, research careers for, 80, 155, 166, 167, 168, 221–223
- Nurse Scientist Training Grants, 4
- nurse training, 121
 - National Institute on Nursing Research (NINR) on, 169, 186, 232
 - research grants on, 7
- Nurse Training Act (1964), 5, 17, 18
- Nursing and Nursing Education: Public Policies and Private Actions* (report), 9–11
- Nursing for the Future* (Brown), 2
- Nursing home residents, 183
- Nursing Outlook*, 6, 132, 137
 - concerns on nursing research, 23
- nursing profession, pressure on, to help balance federal budget, 127
- nursing research
 - American Journal of Nursing* and, 13
 - attitude on use versus generation of information, 13–14
 - on cancer, 84, 95–96, 127
 - on cognitive diseases, 179–185, 196
 - defined, 14
 - on degenerative diseases, 183–184
 - division of nursing community on, 7–8
 - on end-of-life (EOL) care, 139–140, 142, 191
 - establishing priorities in, using handheld voting machines, **100**
 - funding for, 96
 - genetics in, 134–136, 166, 185–188
 - on HIV/AIDS, 84–85, 88–89, 173–

177, 195-196
 incorporation of, into
 environmental sciences, 136-137
 on insomnia, 80
 on managed care, 145-147
 National Institutes of Health (NIH)
 researchers' position on, 44
 on pain, 170-173, 196
 on patient care, vi
 pioneers of, 4
 on pressure sores, 80
 Reagan's opposition to, 31
 on sleep disorders, 80
 on symptom management, 85, 142-
 143, 170, 183, 191
 on urinary incontinence, 80-81
 on very low birthweight infants
 (VLBWI), 87-88, **88**
 World War II changing of approach
 to, 2
Nursing Research (journal), 96
 Nursing Research and Education
 Advisory Committee, 57
 Nursing Research Grants and
 Fellowship Program, establishment
 of, 2
 nursing schools, early changes in
 curricula at, 2
 nursing science
 future of, 164, 213-214, 230-231
 launching of, at National Institutes
 of Health (NIH), 39-63
 as new member of scientific
 community, 1-2
 transformation of, 209-233
 Nursing Science Review Committee,
 Grey as member and chair, 220
 Nursing Systems and Special Programs
 Branch, Carroll, Bunny, as head of, 55
 Nutting, Mary Adelaide, 2, 209

O

Oakley, Debora J., 245

Oberst, Marilyn T., **58**
 obesity, basic research on, 134, 156
 O'Connell, Kathleen A., **58**
 Office of Management and Budget
 (OMB), funding for National Center
 for Nursing Research (NCNR) and,
 50, 52
 Office of Research on Minority Health,
 139
 Office of Research on Women's Health,
 139
 Olds, David, 149
 OUCHER scale, **105**, 106, **171**. *See also*
 Pain
 ovarian cancer, 192

P

Page, Gayle, **130**
 research on pain, 172-173
 pain
 assessment of, in children, 170
 basic and clinical research on, 170
 biological and behavioral aspects
 of, 132
 gender as factor in, 144, 171, 196
 immunological implications of, 130
 Levine, Jon D., on relief from, 144,
 170-171
 medication for, 144
 in minorities, 106
 National Institute of Nursing
 Research (NINR) leadership on
 research on, 130, 142, 144, 164,
 170-173, 196
 OUCHER scale on, **105**, 106, **171**
 as public health problem, 140
 symptom management and, 78, 85
 palliative care science. *See* End-of-life
 (EOL) care
 Parkinson's disease, sleep disorders in,
 182
 pathophysiology, nursing research on,
 133-134, 145

- patient care
 - chronically critically ill and, 151–153
 - nursing research and, vi
- patient-oriented perspective
 - in biomedical research, 132
 - in nursing, 141
- Patton, Curtis L., 147, 245
- Pender, Nola J., 245
 - campaign for nursing research and, 7–8, 21
 - as member of National Advisory Council, 56
- Peragallo, Nilda, HIV research of, 176, 177
- periodontal disease, 40
- personalized medicine, 235–27
- pesticide exposure, impact on reproductive functions, 138
- Physician Scientist and Dental Scientist award programs, 90
- Poodry, Clifton, 141
- Porter, John Edward
 - as chair of appropriations subcommittee, 115–116, 116
 - as supporter of medical research, 116
 - as supporter of National Institutes of Health (NIH), 128
- Portillo, Carmen J., 245
- postdoctoral students, research careers for, 169
- Potempa, Kathleen, 245
- Powell, Dorothy L., 245
- pressure sores, nursing research on, 80, 151, 170
- prevention. *See* disease prevention
- preventive health, National Institute of Nursing Research (NINR) on, 166
- Program Announcements and Requests for Application (RFAs), National Institute of Nursing Research (NINR)
 - issuance of, 194–195
- Program for All-inclusive Care for the Elderly (PACE), National Institute of Nursing Research (NINR) support for, 194
- Progressively Lower Stress Threshold (PLST) model, 181
- Psychiatric Nursing Education Branch of the Division of Manpower and Training Programs, 12
- public health, 77
 - American Nurses Association strategy on, 28
 - contemporary concerns on, 164
 - development of strategies in, 163–164
 - emerging risks in, 213
 - end-of-life (EOL) issues and, 179
 - environmental research and, 137
 - health disparities and, 177
 - HIV/AIDS as major concern in, 84, 174
 - medical understanding of questions in, 171
 - National Center for Nursing Research (NCNR) on, 90, 197, 214
 - research agenda on, 166, 173
 - traditional paths of inquiry in nursing science and, 140
 - very low birthweight infants (VLBWI) as problem in, 87
- Public Health Nursing, Division of, Division of Nursing Resources merger and, 3
- Public Health Service, U.S.
 - funding for nursing research and, 50
 - initiatives at, in stimulating nursing research, 4
- Public Health Service Act (1944), 2
- Public Health Service Executive Task Force on AIDS, 174
- Pursell, Carl D., 66, 81–82, 83

on creation of National Institute of Nursing Research (NINR) in National Institutes of Health (NIH) reauthorization bill, 101
 grant applications at National Center for Nursing Research (NCNR) offices and, **82**
 legislation introduced by, 95
 as nursing constant champion, 92
 pushing of nursing research program by, 89
 support for National Center for Nursing Research (NCNR) as institute, 94–95, 100

Q

quality of life, 191–196
 HIV/AIDS and, 89
 National Center for Nursing Research (NCNR) on, 78
 symptom management and, 214

R

radiation therapy, 84
 Raub, William F., 237
 as acting director of National Institutes of Health (NIH), 94
 Reagan, Ronald, **13**
 budget cuts under, for social programs, 81
 opposition to fetal research, 25
 opposition to National Center for Nursing Research (NCNR), v, 12, 14
 vetos of, 26–27, 31, 41
 Reardon, Judy E., 245
 Reinhard, Susan C., 245
 research careers
 biomedical and behavioral, 169
 for nurse scientists, 80, 155, 166, 167, 168, 223
 for postdoctoral students, 168–169
 Resources for Enhancing Alzheimer's

Caregiver Health (REACH), National Institute of Nursing Research (NINR) support for, 185
 Richard, Maggie L., 245
 Richards, Kathy, research of, 182
 Roberts, Joyce, **58**
 Robert Wood Johnson Foundation, funding for nursing research and, 5
 Rockefeller Foundation, funding for nursing research and, 5
 Rodriguez, Teresa M., **177**
 Ropka, Mary, 143
 Rosenthal, Gerald, nursing research and, 7
 Roy, Sister Callista, **58**
 Rubert, Mark, 191
 Rudy, Ellen B., 237, 245
 Ruffin, John, **141**
 Russell Sage Foundation, funding for nursing research and, 5
 Rutledge, Everard O., 245

S

Salmon, Marla E., 245
 Sands, Delores, 245
 Sanford, Sarah J., **147**, 245
 Schempp, Catherine M., 245
 Schoenrich, Edyth H., on nursing research, 28
Science on nursing institute amendment, 20
 Scott, Jessie M., **4**, 59
 on creation of Division of Nursing as location for research grants, 7
 education of, 4–5
 on nursing research, 4–6, 18, 21, 22
 successor of, 23
 warning to Nursing Research and Education Advisory Committee, 57
 self-management, 149–150

- in chronic disorders, 154
- in end-of-life (EOL) research, 195
- in maximizing and improving overall health, 213
- sexual activity
 - longitudinal study on, 91
 - National Center for Nursing Research (NCNR) on, 84
- sexual behavior
 - among low-income Latina women, 176
 - research on adolescent, 175
- Shalala, Donna E.
 - creation of National Institute of Nursing Research (NINR), 102, **102**
 - executive redesignation order and, 102
 - making of Grady's appointment official, 124
 - as Secretary of Health and Human Services, 96, 100, 102, **102**, 120
- Shannon Awards, 139
- Shaver, Joan, **181**, 245
- Siantz, Mary De Leon, 245
- sickle cell disease, art therapy protocols in dealing with pain in, 172
- Sigma Theta Tau International (STTI), 131
 - assistance from, in structuring National Center for Nursing Research (NCNR) into branches, 51
 - funding for nursing research and, 5
- Simmon, Hillary, research of, 178
- sleep disorders
 - National Center for Nursing Research (NCNR) on, 80
 - nursing research on, 80
 - in patients with Parkinson's disease, 182
- Smith-Williams, Betty, 245
- Social Interaction and Patient Care* (Leonard), 67
- spinal cord regeneration, National Institutes of Health (NIH) research on, 17
- staffing levels, impact of, on patient care, 151
- Stafford, Robert T., support for nursing research institute, 25
- Stevenson, Joanne S., campaign of, for nursing research and, 7–8, 9, 28
- Stewart, Isabel, **2**
- Stokes, Louis, **181**
- Strickland, Ora L., 245
 - campaign for nursing research and, 8
- strokes
 - depressive signs and symptoms in patients, 89
 - research on, 122–123, 178
- Stuart, Gail, 245
- sudden infant death syndrome (SIDS), National Institutes of Health (NIH) research on, 17
- Sullivan, Louis, 101
 - Shalala, Donna E., as replacement for, 102
- Summer Genetics Institute (SGI), 136, **137**
 - National Institute of Nursing Research (NINR) launch of, 187–188
- Surgeon General's Consultant Group on Nursing on need for funding for nursing research, 3
- symptom clusters, research on, in cancer and immune disorders, 194
- symptom management
 - for degenerative diseases, 183
 - extramural research on, 144
 - National Center for Nursing Research (NCNR) on, 78, 85, 88
 - National Institute of Nursing Research (NINR) on, 78, 85, 133, 141–143, 166, 170, 175, 180, 183,

191, 196, 214
 “Symptom Management: Chronic Disease and End of Life” (NIH Institute and Center Directors’ meeting), 195
 symptom monitoring. *See* symptom management

T

Teacher’s College at Columbia University, doctoral program in nursing at, 2
 telehealth, applications of, 155
 Tennstedt, Sharon L., 245
 research on end-of-life (EOL) care ethics, 191–192
 terminal illness. *See also* end-of-life (EOL) care
 research into critical areas of, 144
 Terminal Illness Workshop, National Institute of Nursing Research (NINR) sponsorship of, 144–145
 Terry, Luther, 5
 therapy. *See specific*
 Therrien, Barbara, **130**
 Tilden, Virginia, 144
 Tinkle, Mindy, as National Institute of Nursing Research (NINR) intramural training director, 187
 translational research, National Institute of Nursing Research (NINR) support for, 217
 translational training, 222
 Trevino, Fernando, 246
 Tri-Council for Nursing
 backing of Madigan amendment, 23
 on budget for National Institute of Nursing Research (NINR), 127–128
 lack of support for Hatch alternative, 24–25
 support for creation of National

Institute of Nursing (NIN) at National Institutes of Health (NIH), 15–19, 46

Trofino, Joan, 246
 Truman, Harry S., 209

U

Udall, King S., 246
 U.S. Army School of Nursing, founding of, by Goodrich, Annie Warburton, 209
 urinary incontinence, nursing research on, 80–81

V

Varmus, Harold E.
 appointment of Hurd as acting director of National Institute of Nursing Research (NINR), 114, 119
 confidence in Grady, 120–121, 124, 126–127
 as National Institutes of Health (NIH) director, 118–120, **119**, 129, 191
 as recipient of Nobel Prize in Medicine, 118
 vascular disease, coexistence of Alzheimer’s disease and, 182
 very low birthweight infants (VLBWI). *See also* low birthweight infants
 National Center for Nursing Research (NCNR) research on, 87–88, **88**

Villarruel, Antonia M., **143**
 Virginia-Carolinas Doctoral Consortium in Nursing, 17–18

W

Wald, Lillian, 2
 Walker, Carolyn J., **58**

- Ward, David, 246
- Waxman, Henry A.
 sponsorship of Democratic reauthorization bill, 16–17
 support for creation of nursing research institute, 20, 25–26
- Weicker, Lowell P., Jr., on nursing research, 31
- Weinert, Clarann, 246
- Wells, Thelma J., **58**
- Werley, Harriet, **4**
- Western Society of Nursing Research (WSNR), 69
- Williams, Betty Smith, **141**, 246
- Williams, Carolyn, 75–76
 campaign for nursing research and, 8
- Williams, Janet K., 246
- Williams, T. Franklin, 73, 75
 as chair of task force on nursing research, 27
 as director of National Institute on Aging (NIA), 65
 as head of committee for search for permanent director, 65–66
- Wilson, Ruby
 on nursing research, 11, 28
 at Virginia-Carolinas' Doctoral Consortium in Nursing, 17–18
- Woerner, Louise, 246
- women's health
 National Center for Nursing Research (NCNR) on, 89, 106
 National Institute of Nursing Research (NINR) research on, 133
 research on, 106
- Wood, Darlene, **58**
- Woods, Adele, 75
 as head of Research Development and Review Branch at National Center for Nursing Research (NCNR), 55
 position of, at National Center for Nursing Research (NCNR), 47–48
- Woods, Nancy Fugate, 130, 237, 246
 campaign for nursing research and, 8, 9
 on nurse scientists, **130**
- Wooldridge, Powhatan J., 67
- Workgroup on Opportunities in Genetics Research, 185
- working conditions, impact of, on patient care, 151
- World Health Organization (WHO), on emerging public health risks, 213
- Wykle, May, **181**
- Wyngaarden, James B. (director of NIH), 1, **13**, 81–82, 119
 appointment of Merritt by, 44–45, 60
 congressional testimony of, 79
 creation of Advisory Council by, 47
 creation of National Institute of Nursing Research (NINR) and, 1, 12, 40, 41
 on nursing research, 1, 27, 45
 on search for permanent director, 65
 selection of Hinshaw by, 66, 70–71, **71**
 set up of National Center for Nursing Research (NCNR) and, 48, 88
 on support for intramural programs, 83
 testimony before Congress, 79–80
- ## Y
- Yale School of Nursing
 Goodrich, Annie Warburton, founding of, 209
 nursing research at, 67

Z

Zeller, Janice M., 246

Zerhouni, Elias, 217
at National Institute of Nursing
Research (NINR) twentieth
anniversary, 229