National Cancer Institute

Appendix D

Survivorship Activities at Cancer Centers

Due to the amount of information available,
this appendix can be viewed at the following website:

www.cancer.gov/cancercenters/

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health

Appendix D

Survivorship Activities at Cancer Centers

Report from the NCI-Designated Cancer Center Directors

August 2006

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Abramson Cancer Center University of Pennsylvania
Model for Survivorship Care

In 2001, the Lance Armstrong Foundation (LAF) provided funding to support the development of an adult cancer survivorship program at the Abramson Cancer Center of the University of Pennsylvania. As a dedicated cancer survivorship program embedded within an NCI-designated Cancer Center, the LAF Living Well After Cancer (LWAC) Program is the first adult cancer survivorship program in a specialty care setting. The multidisciplinary composition of the LAF LWAC program team has expanded over time and the members of the team include the director of the program, a PhD-prepared oncology nurse practitioner, a behavioral scientist, a medical oncologist who specializes in urologic cancers, a breast oncologist, a pediatric oncologist and a general oncologist with an interest in survivors of childhood cancers, a cardiologist who focuses on the cardiovascular late effects of treatment, a cancer rehabilitation specialist, an exercise physiologist, a primary care provider with an interest in complementary and alternative medicine use for the late effects of cancer treatment, two psychosocial counselors, and a nutritionist.

The Penn survivorship program is a research, clinical, and education focused multidisciplinary effort that has evolved and expanded over the last 5 years. The LAF LWAC program team meets every other month to discuss program development, clinical issues, ongoing research projects, and ideas for new projects. At that meetings, team members also report on presentations, special projects, and publications.

Initially, the LAF LWAC team focused on program development and it was determined that the establishment of a strong research focus was critical to the success of the program for a number of reasons: 1) surveillance guidelines had not been established for adult cancer survivors; therefore, survivorship research protocols needed to be developed that focus on the clinical issues identified by survivors and their providers; and 2) research funding is necessary to support the program.

Subsequently, a research database was established, questionnaires developed, and tools were chosen to evaluate medical and psychosocial aspects of the survivorship experience. A few research proposals have been funded (e.g., DOD grant and an NIH-R21) and the team continuously works to develop, refine, and submit new proposals based on clinical evidence gathered in the clinical component of the program. Numerous abstracts resulting from studies conducted at Penn have been presented at national meetings as podium and poster presentations. Although a few of these studies have been funded by external sources, many pilot projects have been supported internally. Obtaining funding for survivorship research has been extremely difficult and this provides a serious barrier to expanding the program.

Clinical programs with testicular and breast cancer survivors were piloted and it was determined that more than one model of care was needed to meet the needs of patients as well as the Cancer Center. Consequently, the practice and consultative models were developed.

The practice model is designed with the intention of providing routine follow-up care, and monitoring for recurrence while at the same time developing an individual risk profile for late effects of treatment based on age, family history, comorbidities, and cancer treatment history. To date, this model is utilized with testicular cancer patients and adult survivors of childhood cancers referred to the LAF LWAC program for follow-up. This program has been very successful and efforts are in place to assure that clinical and research programs with these groups of survivors flourish in the years ahead.

The consultative model is structured as a research protocol outlining specific aims. Questionnaires and tools are used to collect primarily symptom and quality of life data. Baseline data is collected when patients present at diagnosis. In that way, data is collected through and post-treatment, providing a broader, clearer picture of the survivor's experience. The questionnaires used to collect data with the breast cancer survivors were designed and tested over the first year of the program in the clinical model and have been refined as the program evolved. Similar questionnaires are used with the other survivors seen in the clinical programs and will be used more broadly as the consultative program is expanded to include other cancer sites. Questionnaires are designed and revised to focus on population-specific issues.

The LAF LWAC team is currently developing innovative ways to address clinical issues reported by survivors on their questionnaires, such as summarizing these symptoms in a letter to the patient so that patients can discuss the management of these issues with the appropriate provider, e.g., their internist, oncologist, gynecologist, or cardiologist. The survivorship program team is also planning to expand their efforts to include more survivorship-focused talks at each of the Penn annual disease-specific conferences. In addition, informal consultation is available to the clinical practices regarding surveillance recommendations for late effects of treatment that may be related to surgery, chemotherapy, or radiation, as well as management strategies for symptoms resulting from the late effects of treatment. The nurse practitioners in the collaborative oncology practices at Penn have a major role in managing the care of and symptoms reported by cancer survivors.

The consultative program has been successful and provides an opportunity for the LAF LWAC team to heighten the awareness of late effects of treatment among the primary oncology practices and specialty care providers. The long-range plan is to extend this model to other disease-specific oncology practices at Penn with one of the nurse practitioners/MDs teams caring for a specific population taking the lead for managing the protocol with and identifying that group of eligible patients. This model will also be extended to the Penn Network Hospitals and plans are underway to include three Network Hospitals in the Penn Consultative Survivorship Program beginning in summer 2006. Support will be provided by the LAF LWAC Program for the mailing of research packets, following-up with patients, and data entry into the database at Penn.

Barbara Ann Karmanos Cancer Center
Survivorship Activities

Background

Karmanos Cancer Center (KCC) has numerous programs and services promoting and supporting survivors and their families. Currently, KCC offers 14 monthly, professionally facilitated peer support groups; 6 therapeutic 8-week classes held 6 times per year (3 are funded through a Komen Race-for-the-Cure grant); 9 complementary therapy offerings; a peer mentorship service; an annual Survivorship Day Celebration in June; and an annual Walk for Women's Cancer held in partnership with the National Arab American Medical Association. For the first time in 2006, several of our programs will be held in partnership with Gilda's Club of Metropolitan Detroit. Two community-based conferences are also held annually: one in the spring for gynecologic oncology patients and the other in the fall for breast cancer patients. The conferences are funded through pharmaceutical support.

Survivorship University

Based on the stages defined through the National Action Plan "living with, living through, and living beyond cancer", Survivorship University (SU) has been designed to help cancer survivors and their care givers (also been designated as "survivors") learn about this additional life role. The SU community-based programs are offered as semester-long adult education classes and began in June 2005. The goal is for survivors to enhance their quality of life, develop new strengths, learn "whys" and "hows", and define a personal new worldview of "normal." Resources and referrals are also provided. The inaugural program featured Doug Ulman, Director of Survivorship at the Lance Armstrong Foundation. This year's second community event was May 24, with Wendy Schlessel Harpham, MD, the author of *Happiness in a Storm.*

Three classes were scheduled three times each around the Metropolitan Detroit area to make transportation access easy. They included:

Ordering Social Security's Alphabet Soup, presented by SSA

> Description: A cancer experience can bring financial difficulties. Many people think that disability dollars (SSI, SSD) are the answer. At this presentation, the Disability Determination Service (which makes the decision) and Social Security Administratio (which issues the checks), along with an author of the disability reform legislation, will talk about how and when to file for Social Security disability.

Your Job & Cancer: Issues, Rights, Action, presented by a JVS

> Description: No one needs an employment issue to arise when being treated for cancer. This session will identify some common employment challenges and offer

resources and advice on how to address them. Information will be presented on the rights of employees as well as the rights of the employers when cancer enters the job picture.

Survivorship: A Motto, A Mantra, A Mission, presented by MSN, Nurse Practitioner with Psychiatric and Cancer Center experience

> *Description*: Cancer patients, along with their friends and families, experience many challenges, which can start from the time cancer is suspected, through treatment, and even after treatment is completed. It is natural during this time to think about who we are, look for ways to ease distress, and focus on what makes life meaningful. This talk will look at the power that reflection and re-evaluation has on the cancer experience, highlighting ways in which “a motto, a mantra, and a mission” can help patients keep going.

Research

The following study is currently underway:

National Institutes of Health/National Cancer Institute, #5R01CA100027-01 *Parental Role in Pediatric Cancer Pain and Survivorship*. Albrecht, T. (PI), Penner, L., Ruckdeschel, J., Pendleton, S., Bhambani, K., & Taub, J. (Co-Is). 9/19/03-8/31/06, $866,105.

Abstract: Many children with cancer experience extreme stress and trauma during certain treatment-related procedures (e.g., lumbar punctures, bone marrow aspirations, and even port starts). Negative behavioral/psychological reactions to treatments may make the child a more difficult patient and may place the child at greater risk for psychosocial disorders and possibly abuse/maltreatment (Bugental, 2000). Adverse reactions to cancer treatments may seriously affect the long-term quality of survivorship of the pediatric cancer patient. The goal of this study has been to determine the influence of the following variables on differences in children's reactions to painful treatments: prior medical history, personal attributes of the child, personal attributes of the child's primary adult caretaker, the nature of the child-caretaker relationship, and the adults' thoughts, feelings, and actions immediately prior to and during actual treatment sessions. The study aims of the first grant have been to: 1) identify patterns that covary with the child's affective and behavioral reactions to invasive/painful treatments; 2) examine the child’s' affective and behavioral reactions to treatment; and 3) conduct preliminary tests of portions of a multilevel model of the relationships between the hypothesized causes of children’s affective and behavioral reactions to treatments and the psychosocial, behavioral and medical consequences of those reactions.

Case Comprehensive Cancer Center

Survivorship Activities

I Pediatric Cancer Survivorship Activities at Rainbow Babies and Children's Hospital and Ireland Cancer Center

Survivorship Program Funding

Center for Survivors of Childhood Cancer opened in 2004 to preserve and enhance the well-being and quality of life of survivors of childhood cancer through clinical care, advocacy, education, and survivorship research. The Center is supported by a Survivorship Center grant from the Lance Armstrong Foundation.

Clinical Care

Long-Term Follow-Up Clinic is for patients who were diagnosed with cancer at age 18 or younger and have been off cancer therapy for at least 3 years. During this wellness-oriented visit each patient is evaluated by a pediatric oncologist and also by a psychologist specializing in the psychosocial and educational issues of childhood cancer survivors. Each patient receives a Cancer Survivor's Treatment Guide that includes a personalized summary of their cancer diagnosis and treatment as well as an explanation of their specific risks for medical and cognitive late effects. Appropriate ancillary testing and referrals to specialists are arranged as necessary. Ample time is also devoted to wellness education and strategies for healthy living and future health monitoring.

School Liaison Program provides evaluation and one-on-one advocacy for patients who are experiencing cognitive late effects of their cancer treatment. Services provided by the Center for Survivors of Childhood Cancer include consultation with patients and parents, neurocognitive and psychosocial assessment and testing, and consultations with school personnel to help provide information and appropriate support. This includes participation in the school IEP (individual educational plan) meetings.

Survivorship Education

Childhood Cancer Survivorship: A Workshop for Parents – Geared toward parents of children who were diagnosed with childhood cancer at least 3 years ago, the conference addresses long-term medical, emotional, and educational issues often faced by childhood cancer survivors and their families.

Survivorship: Life After Cancer – Pediatric Grand Rounds at Rainbow Babies and Children's Hospital, presented by Chad Jacobsen, MD, focuses on the physical and psychological impact of cancer and its treatment on survivors of childhood cancer, reviews of common late effects, and individual case presentation.

Survivors of Childhood Cancer **–** Presentation by Chad Jacobsen, MD, to the Case medical student pediatric and oncology interest groups.

Survivorship: What Needs to be Done **–** Lecture presented by Chad Jacobsen, MD, during the *Cancer Update for the Practicing Physician,* an educational program for community primary care physicians.

School Issues for Pediatric Cancer Patients – Presented during quarterly *School Nurse Updates*, an educational program for school nurses including a lecture on returning to school for pediatric cancer patients. Presented by Catherine Peterson, PhD, and Barbara Humrick, PNP.

Reintegration of Child and Adolescent Cancer Survivors into School – Presentation to Northeast Ohio Educators' Association Day. Presented by Catherine Peterson, PhD, and Barbara Humrick, PNP.

II Research Projects

The Effects of a Directed Nutritional and Physical Activity Intervention on the Psychosocial and Physical Well-Being of Children with Acute Lymphoblastic Leukemia
Chad Jacobsen, MD, Pediatric Hematology and Oncology
Two-year pilot project to study the effects of an exercise and nutrition intervention on quality of life of patients in treatment for acute lymphoblastic leukemia (ALL). Grant application pending with American Cancer Society.

Comprehensive Assessment of Psychological Well-being of Children and Adolescents with Pediatric Cancer
Dennis Drotar, PhD, and Catherine Peterson, PhD.
Behavioral Pediatrics Prospective longitudinal study to describe the psychological status of children and adolescents with pediatric cancer and to identify predictors of psychological and family outcomes of the survivors of pediatric cancer. An unfunded research protocol.

III Adult Survivorship Activities Within the Ireland Cancer Center

Clinical Care

Breast Cancer Survivorship Task Force has been formed and has met several times in early 2006. Plans are in development for a Breast Cancer Survivorship Clinic which will begin seeing patients in the fall 2006. This clinic will follow the guidelines set out in the Institute of Medicine's recent report *From Cancer Patient to Cancer Survivor*. Services will include provision of a comprehensive medical summary of the patient's cancer and treatment, assessment and management of cancer side effects, wellness education, and survivorship care plan as well as psychosocial support and education.

Survivorship Education

Phases of Survivorship: Information for the Post-Treatment Transition – A free community education program that focuses on recovery after cancer treatment and helps patients to identify strategies to promote physical and emotional wellness. Participants receive the Lance Armstrong Foundation's LIVESTRONG Survivorship Notebook.

Research Projects

Lifestyle Change and Quality of Life in Obese Endometrial Cancer Survivors
Vivian Von Gruenigan, MD, Obstetrics and Gynecology
Supported by a Young Investigator Research Award from the Lance Armstrong Foundation. Two-year pilot project to study the effect of exercise and dietary counseling on quality of life and weight loss in endometrial cancer survivors.

City of Hope National Medical Center & Beckman Research Institute

Research Activities Related to Cancer Survivorship

Decreasing Barriers to Pain and Fatigue Management in Cancer Patients (NCI-R01) (Ferrell, PI) This project evaluates current management of pain and fatigue in medical oncology and then tests a "Passport" intervention involving the education of patients and professionals and implementation of standardized care for treatment of these symptoms.

Discharge Rehabilitation Teaching Project for HCT Patients (NCI-R01) (Grant, PI) The overall goal of this project is to improve outcomes for patients undergoing HCT by testing a Program to improve the post-discharge care and follow-up period.

Quality of Life Intervention for Ovarian Cancer (Oncology Nursing Foundation) (Ferrell, PI) This project tests a psycho-educational intervention to improve QOL in ovarian cancer survivors.

Quality of Life and Symptoms in Lung Cancer (COH Seed Funds) (Ferrell, PI) The primary aims of this pilot study are to describe/measure symptom concerns in patients with lung cancer and to describe/measure quality of life concerns of patients with lung cancer.

Quality of Life in Colorectal Cancer Survivors (NCI-RO1, subcontract) (Grant, PI) This study involves a cross sectional survey of long-term colorectal cancer survivors with stomas in the Kaiser Permanente Health Systems for Northern California and the Northwest. Study includes mailed surveys to long term CRC survivors with and without ostomies, focus group interviews with those experiencing the highest and lowest quartile of outcomes to gather information about successes and challenges, and a dissemination plan targeted at providers, managers, and patients.

Quality of Life in Breast and Prostrate Cancer Patients undergoing Hormonal Therapy (AMGEN) (Juarez, PI) The goal of this project is to describe breast and prostate cancer patients' perspective of having multiple symptoms associated with advanced cancer and the impact of these symptoms on adjustment to illness, quality of life, mood, and functional status.

Symptom Clusters and Quality of Life Concerns in Chemo-induced Peripheral Neuropathy (Lance Armstrong Foundation) (Sun, PI) The goal of this project is to describe the symptom experience and symptom clusters in colorectal cancer (CRC) patients with chemotherapy-induced peripheral neuropathy (CIPN) associated with the platinum compound oxaliplatin and to describe the impact of the experience on patient's quality of life.

Quality of Symptom and Life Concerns in Hepatobiliary cancer patients (Oncology Nursing Foundation) (Sun, PI) The goal of this pilot study is describe the symptom concerns in patients with hepatobiliary cancers (hepatocellular, pancreatic) and to describe the impact of the symptom concerns on patient's quality of life.

Long-term Follow-up of Bone Marrow Transplant Survivors

Long-Term Follow-up Care for the BMT Program Project Grant at City of Hope Cancer Center (P01 – Core Director, Bhatia) The Long-term Follow-up (LTFU) core supports complete long-term follow-up of all patients receiving blood or marrow transplant (BMT) according to the various protocols of this program project.

Bone Marrow Transplant Survivor Study (R01-Bhatia, PI) Through collaboration between the City of Hope Cancer Center and the University of Minnesota, a large cohort of patients who have undergone BMT at these 2 centers and have survived at least 2 years has been constructed. This comprehensive study aims through an R01-funded mechanism to describe outcomes of BMT by merging extensive demographic, ethnic, and treatment data, and data on the prevalence of long-term complications and second cancers, with data on quality of life in survivors of BMT.

Role of Genetic Susceptibility in the Development of Secondary Myelodysplasia (Lymphoma SPORE, R01, Bhatia Co-PI) Secondary myelodysplasia occurs in some patients following therapy with alkylating agents and among patients undergoing autologous transplants for lymphoma. This study aims to evaluate prospectively, among patients with non-Hodgkin Lymphoma (NHL) and Hodgkin disease (HD) undergoing chemotherapy and autologous transplantation the sequence of acquisition of genetic and hematopoietic defects, from genotoxic insult to the development of overt therapy-related AML/MDS. The goal of this study is to determine the utility of genetic markers as biomarkers of risk of therapy-related MDS/AML after chemotherapy and autologous bone marrow transplantation for NHL/HD. Funding Source: Leukemia and Lymphoma Society Translational Research and the NCI.

Assessment of Health/Quality of Life in Survivors of Childhood Cancer (NCCF Funds – Bhatia, PI) A comprehensive self-report instrument designed to assess HRQOL among survivors of childhood cancer has been developed (MMQL), and is being utilized successfully in a variety of cancer survivor populations.

Outcome of Children with Acute Lymphoblastic Leukemia (R01 – Bhatia, PI) COH investigators have recently demonstrated that children with ALL have significant differences in survival by ethnicity. In order to understand the underlying causes for these differences, COH investigators have procured funding from the NCI through the R01 mechanism (PI, S Bhatia), and propose to explore whether there are ethnic/racial differences in the disease biology, pharmacogenetics, and compliance of therapy that could possibly account for the differences in survival.

Key Adverse Events After Childhood Cancer (LAF – Bhatia, PI) COH investigators have established a mechanism within the Children's Oncology Group to identify key adverse events developing in survivors of childhood cancer and obtain blood samples from these patients. The key adverse events of interest include congestive heart failure, myocardial infarction, ischemic stroke, avascular necrosis and subsequent malignant neoplasms. The investigators propose to test the hypothesis that patients who develop these key adverse events after treatment for childhood cancer may have a genetic susceptibility to do so. (Funding – Lance Armstrong Foundation)

Development of Guidelines for Follow-up of Childhood Cancer Survivors (NCCF – Bhatia, PI) As Chair of the COG Late Effects Committee, Dr. Bhatia has been responsible for facilitating the development of risk-based, exposure-related guidelines for long-term follow-up care of pediatric cancer survivors. These guidelines were developed with the goal of early identification of exposure-related late complications, potentially allowing for early intervention with resultant increased quality of life and decreased complication-related health care costs. Screening recommendations are organized by therapeutic exposure and accompanied by targeted health education materials; all are available free of charge at www.survivorshipguidelines.org. The guidelines were reviewed and scored by a 16-member multidisciplinary panel of experts in the late effects of pediatric cancer treatment and are supported by the Children's Oncology Group grant U10 CA098543 from the NCI.

Community Outreach

Ask The Experts-9x/Per Year for Various Cancers Such As Breast, Colorectal Cancer
Cancer Support Groups HCT, Long term Breast

Education

Survivorship Education for Quality Cancer Care (NCI-R25) (Grant, PI) The primary aim of this NCI-funded training proposal is to improve quality of care and quality of life for cancer survivors. The primary aim of this proposal will be achieved through 4 annual workshops for 2 representatives each from 50 cancer treatment centers. This proposal provides for 4 annual courses, which will prepare 400 individuals from 200 Cancer Centers across the United States to improve survivorship activities in these various institutions. The 2-½ day course features nationally-known speakers, goal development for each institution, and extensive follow up at 6, 12, and 18 months post course. The first course occurred in July 2006. Applications are already being processed.

Community Resource Information Web site Cancer Connections (telephone call-in line)

Follow-up calls from *Clinical Trials Online*

Hope Notes (Patient education newsletter)

Pink Links Education and Activity Group

Patient and Family Education Resource Center

Pediatric School Reintegration Program

Pet Therapy

The Center for Cancer Survivorship

Providing specialized long-term follow-up care for cancer survivors

At the Center for Cancer Survivorship, City of Hope provides unique, cutting-edge comprehensive, follow-up care for childhood cancer survivors in a clinical research setting. The Center supports the following activities:

Clinical Care: Comprehensive long-term follow-up services for childhood cancer survivors. Care is provided as a consultative service in collaboration with the patient's primary care provider and oncologist. Most patients are seen for yearly comprehensive assessments; however, one-time consultations are also available. All patients are offered the opportunity to participate in ongoing research through the Center.

Patient/Family/Community Education: Health education personalized for each survivor based on his/her diagnosis, treatment and current medical condition is provided during follow-up visits at the Center. In addition, the Center houses a patient education/resource library and plans to start hosting periodic educational seminars for survivors and their families, as well as educational outreach programs for the community.

Support: Extensive specialized support services for survivors are available through the Center, including individualized counseling, support groups, "Survivor Day" celebrations, school liaison/reintegration services, vocational counseling/assistance, physical and occupational therapy services, nutrition assessment and counseling, patient advocacy services related to work, school, and insurance issues.

Inspiration/opportunity: The Center offers survivors the opportunity to provide support to patients currently undergoing cancer treatment through its Patient Liaison Program. In addition, survivors are offered the opportunity to share inspirational stories of survival and hope with others. These stories will be featured on posters/murals in various locations throughout the Center, as well as on the Center's web site and via print media in the near future.

Research: The Center for Cancer Survivorship provides unique opportunities for collaborative clinical research across populations of survivors, involving researchers from multiple disciplines such as Medicine, Nursing, Psychology, Cancer Genetics, and Epidemiology/Etiology. Clinical research is the foundation from which we gain new knowledge regarding potential long-term complications of cancer treatment as well as the optimal follow-up care and education for cancer survivors. All survivors participating in the Center are offered opportunities to participate in clinical research.

Planned Activities

Other Populations: We plan to extend the paradigm successfully established in the childhood cancer population to Adult Cancer Programs (Prostate, Lung, Colorectal, and Breast) and to the survivors of adult hematological malignancies and hematopoietic cell transplantation.

Health care Professional Training: The Center, in collaboration with the Graduate School of Biological Sciences, will offer a post-graduate Fellowship Program in Cancer Survivorship for clinicians (physicians, nurse practitioners, physician assistants) and researchers (physicians, nurses, epidemiologists and others) planning careers in the cancer survivorship field. In addition, the Center will offer periodic seminars and workshops on cancer survivorship issues for healthcare professionals.

Ask the Experts - Topics for 2006 Season

Season = September 2005 to June 2006

September 22, 2005 – Ovarian Cancer "New Approaches in the Diagnosis and Treatment of Ovarian Cancer"– Dr. Morgan and Dr. Farias-Eisner

October 20, 2005– Breast Cancer "Advances in the Prevention and Treatment of Breast Cancer" - Dr. Wagman

November 9, 2005 – "Breathe for Hope: Lung Cancer". This event coordinated by Communications Group. Dr Grannis and Dr. Kernstine

January 26, 2006 – --"Diabesity-Obesity-related Diabetes in Children and Adults"
Dr. Ken Chiu, FACE, Dr. Michael Racine, Department of Diabetes, Endocrinology, and Metabolism

February 16, 2006 – "What You Need to Know about Prostate Cancer" Dr. Wilson and Dr. Crocitto

March 16, 2006 – "Colon Cancer: Prevention, Detection and Treatment" Dr. Shibata, Dr. David, Dr. Lai, Sally Pataky, RD. Co-sponsored by ACS.

March 20, 2006 – Community Forum (off-site) "Unequal Science, Equals Unequal Treatment, Equals Unequal Outcomes" Dr.Lovell Jones, M.D. Anderson Cancer Center, and Ted Krontiris. This lecture addresses the unequal representation of minority groups in clinical trials and the resulting affects. Partners: ACS, Wellness Community and Jackie Robinson Center of Pasadena

April 13, 2006 "What You Should Know about Anesthesia" Dr. Michael J. Sullivan, Anesthesiologist.

May 2006 Health Talk/Breast Cancer - Speakers/date TBD

June 2006 “Breaking Through the Age Barrier: Getting the Best Cancer Treatment” Tentative date- June 15, 2006. Liz Cooke, RN, NP and Dr. Mark Kirschbaum. Program for older adults with blood cancers. Co-sponsored by Leukemia-Lymphoma Society (LLS)

Comprehensive Cancer Center at Columbia University
Survivorship Activities at the Herbert Irving Center For Child, Adolescent Oncology and Young Adult Oncology, and Adult Oncology

Beginning in May 2006, survivors of pediatric cancers will be seen in the newly developed Warner Fund Center for Survivors' Wellness. The new Center will unite the clinical and research activities that are currently underway at the Herbert Irving Center into a holistic entity that addresses the medical, physical, nutritional, and psychosocial needs of pediatric cancer survivors and young adults with cancer. In addition, current and future research protocols related to survivorship issues will be coordinated through this center and will integrate the survivorship research activities of pediatric and adult patients. This will provide a unique clinical integration of a strong program in pediatric and adult survivorship.

1. Pediatric Survivorship Program

Clinical Care

At this time, patients receive medical follow-up care, including routine physical exams, surveillance studies, and referrals to appropriate subspecialists from their treating pediatric oncologist. Members of the Integrative Therapies Program for Children with Cancer provide nutritional counseling, exercise classes including yoga, and complementary and alternative medicine (including acupuncture, reiki, massage) services to survivors as needed.

All survivors who have received cranial radiation, intrathecal methotrexate before the age of 3 or who are currently experiencing academic problems receive a planned neuropsychological evaluation every 2 years to assist with educational planning.

Research

Preventing Late Effects Dr. Kara Kelly is the Principal Investigator for CCG study 59704, completed 10/03. The specific goal of this study was to reduce late effects of treatment for Hodgkin disease by modifying treatment to those patients who were early responders to induction therapy. This protocol paid specific attention to the risk of breast cancer in female survivors by excluding radiotherapy from treatment for those patients who were early responders.

Defining Late Effects The Herbert Irving Center is one of the 12 participating institutions in the "Long-Term Effects of Treatment in Patients Previously Treated for Childhood Hodgkin Lymphoma" study designed to further characterize risk for late complications and to compare self report of complications with those identified through involvement with clinical evaluation. This study is a joint collaboration between COG and the NCI.

Assessing Cognitive Functioning in Survivors Dr. Stephen Sands, the psychologist for the Herbert Irving Center for Child and Adolescent Oncology, is heavily involved in defining late cognitive effects of treatment, particularly for brain tumor patients. As the study psychologist, Dr. Sands conducts baseline neuropsychological evaluations prior to transplant and then every two years for patients enrolled on Head Start III. Dr. Sands is also the study psychologist for a new randomized Phase III COG germ cell tumor study that will open in the near future and will obtain baseline and bi-annual neuropsychological and quality of life evaluations. All adult brain tumor patients who are enrolled in an intra omaya chemotherapy study receive serial quality of life and neurocognitive evaluations after completing therapy.

Early Screening/Intervention The early screening/intervention protocols have been designed with the intent to develop new methods of identifying late effects of treatment at an earlier stage than in the current routine. At this time, we are evaluating newer laboratory and imaging markers of ovarian reserve in survivors of Hodgkin disease to assist in providing better information to them about their reproductive capacity. We are also evaluating survivors of Hodgkin disease for evidence of subclinical atherosclerosis, a marker for risk of cardiovascular disease using carotid artery ultrasound. The ultimate goal of this study is to develop an intervention study that will evaluate the use of statins and behavior modification in modifying the risk for cardiovascular disease.

2. Adult Survivorship Program

Clinical Care

At this time, patients receive medical follow-up care from their primary oncologists. However, investigators in Breast Oncology and GU oncology have specific interests in cancer survivorship. In combination with the pediatric program, we are initiating a program to develop a comprehensive survivorship program for adult and pediatric survivors of cancer. This program is in its infancy but has goals of providing a comprehensive evaluation including: routine physical exams, surveillance studies, and referrals to appropriate subspecialists (endocrinology, reproductive endocrinology, behavioral psychology). Members of the Integrative Therapies Program with Cancer provide nutritional counseling, exercise classes including yoga, and complementary and alternative medicine (including acupuncture, reiki, massage) services to survivors as needed.

Late Effects Dr Alfred Neugut, Dr. Dawn Hershman, and other investigators are using large administrative databases to understand the late effects of chemotherapy. They have recently published information on the risk and predictors of cardiac toxicity in women undergoing chemotherapy and radiation therapy for breast cancer. There are a number of similar projects currently underway.

Dr. Neuguts' Group have recently used SEER and other similar databases to evaluate the risk of secondary lung and esophageal cancers after radiation therapy for breast cancer. In addition they have evaluated the risk of lung cancer following breast cancer radiation in smokers as compared to nonsmokers.

Osteoporosis Prevention Dr Dawn Hershman is the Principal Investigator of a randomized clinical trial to evaluate Zometa for the prevention of osteoporosis in premenopausal women undergoing chemotherapy. This trial has accrued 115 of the 120 expected patients and will aim to determine risk factors for chemotherapy-induced bone loss.

In addition. Dr. Hershman is a study coordinator on the bone substudies of three intergroup studies with the aim of preventing bone-related complications of cancer. (S0307, S0308, and MA-27B)

Aromatase Inhibitor-Induced Joint Pain Dr. Crew and Dr. Hershman have developed a series of research protocols to evaluate the role of acupuncture in preventing joint pain and stiffness induced by aromatase inhibitors in breast cancer patients. A pilot cross-over study was just completed and they have funding from the Lance Armstrong Foundation to perform a randomized, placebo-controlled trial evaluating acupuncture in reducing joint pain/stiffness.

Dr. Greenlee and Dr. Hershman have a randomized clinical trial under review at the NCI from the Fox Chase Supportive Care CCOP to evaluate the benefit of glucosamine/chondroitin for the prevention of joint pain in a similar population of women with moderate to severe aromatase inhibitor induced joint pain/stiffness.

Assessing Cognitive Functioning in Survivors Dr. Felice Tager, Dr. Paula McKinley, and Dr. Hershman were funded by the ACS to study the relationship between adjuvant chemotherapy, cognitive change, sleep and hormonal changes in premenopausal women undergoing chemotherapy for breast cancer. This study follows a longitudinal study funded by the NCI of the cognitive effects of chemotherapy in post-menopausal women undergoing chemotherapy.

Secondary Breast Cancer Prevention Dr. Crew and Dr. Hershman have a Phase I study approved from the NCI to evaluate polyphenon E for breast cancer prevention in women with a history of hormone receptor negative breast cancer. Columbia is the lead site. Other sites include NY Hospital, Cornell, Memorial Sloan Kettering, and MD Anderson Cancer Center.

Hot Flash Prevention for Men with Prostate Cancer Julian Capodence (acupuncturist) and Dr. Aaron Kats are currently developing a protocol to evaluate the benefits of acupuncture in controlling vasomotor symptoms induced by androgen deprivation therapy. This study is currently under review for funding.

Lifestyle Modification Dr. Greenlee and Dr. Hershman have submitted an exercise intervention study aimed at minority breast cancer survivors that is currently under review.

Dana-Farber Cancer Institute
Survivorship Activities

Dana-Farber Cancer Institute has been committed to meeting the needs of cancer survivors for many years. Established in 2004, the Perini Family Survivors' Center serves as an umbrella organization for survivorship activities at Dana-Farber Cancer Institute. Building on more than a dozen years of success by the David B. Perini, Jr., Quality of Life Clinic for Childhood Cancer Survivors, the Perini Family Survivors' Center strives to provide comprehensive clinical care, research, and educational programming for cancer survivors across the life span. In addition to centralizing many survivorship activities, the Perini Family Survivors' Center works with a range of other departments within the Institute to support programs and conduct research in issues of cancer survivorship.

Clinical Programs For Cancer Survivors

Established in 1993, the David B. Perini, Jr. Quality of Life Clinic for Childhood Cancer Survivors is Dana-Farber's original program for cancer survivors. The Perini Clinic sees approximately 400 patients annually for a comprehensive multidisciplinary, long-term follow-up visits. Patients in the Perini Clinic visit with a primary provider and have the opportunity to meet with a variety of subspecialty providers as needed. The staff of the Perini Clinic includes Nurse Practitioners with expertise in survivorship care as well as endocrinologists, reproductive endocrinologists, cardiologists and radiation oncologists. In addition to these medical subspecialties, every patient fills out a mental health screening and is offered a visit with a psychosocial provider. After their visit, Perini Clinic patients receive a summary of their treatment along with a document that outlines their potential risks and makes recommendations for follow-up. A copy of this information is also sent to the patient's primary care physician.

The Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic addresses the long-term needs that survivors of pediatric brain tumors may have, conducts research, and shares knowledge with other centers. The Clinic was established in collaboration with the Stop & Shop Family Pediatric Brain Tumor Clinic, a partnership between the Institute and Children's Hospital Boston that bears the name of the supermarket chain that has long supported it. Survivors of pediatric brain tumors are followed in a weekly, multidisciplinary, long-term follow-up clinic.

The newest addition to Dana-Farber's clinical programs for cancer survivors – the Lance Armstrong Foundation (LAF) Adult Survivorship Clinic – was established in 2005 and provides clinical services to survivors of adult-onset cancers. Building on the model established in the Perini Clinic, the LAF Clinic offers patients a multidisciplinary approach to their long-term follow-up care. The Nurse Practitioners in the LAF Clinic collaborate closely with patients' primary disease-specific oncologists to ensure continuity of care. Patients of the LAF Clinic receive a complete assessment designed to give the LAF clinicians a complete picture of each patient's cancer treatment history and current issues. This assessment, combined with the information gathered during a clinical visit, helps guide follow-up and long-term care recommendations. This information is sent to the patients after their visits so that they have a reference for their own information and for use as they meet with other health care professionals.

Educational and Support Programs for Cancer Survivors

The Perini Clinic and the Perini Center host a variety of educational and support opportunities for cancer survivors. Educational programs range from annual day-long programs that focus on survivorship issues of specific diseases (e.g. Hodgkin disease) to an annual event celebrating cancer survivorship to a 6-week education series for adult survivors. Support programs include a weekly support group series and an annual weekend retreat. Each program is designed to meet the needs of a specific group of survivor patients and is facilitated by a combination of Center staff and outside experts as appropriate. A copy of the annual program calendar is included in Attachment A.

Additionally, the Perini Clinic has developed a unique tool to help families as pediatric patients transition off treatment. The interactive notebook – entitled *Transition to Survivorship: What Every Parent Should Know* – is designed to educate families about the long-term health of their child as well to provide an overview of treatment history and a care plan. Staff within the Perini Center are in the process of adapting this tool for other patient groups.

The Gillette Center for Women's Cancer sponsors a number of survivorship activities including an annual conference for patients and, a collaboration with the Perini Center, the First Annual Breast Cancer Survivors' Symposium entitled *Knowledge, Strength, and Grace - Living Through Breast Cancer.*

The Department of Care Coordination runs three regular support groups for cancer survivors. One program, exclusively for adult patients who are post-bone marrow transplant (BMT), meets regularly and allows patients at various points post-BMT to share their experiences and support one another. Another recurrent program is designed specifically to be a psycho-educational program for breast cancer patients who are about to complete therapy for breast cancer. Facilitated by a social worker, this 6-week program is held twice a year. The third is an ongoing program for young women who are 6 months post treatment for breast or gynecologic cancer treatment.

Educational Programs for Health Care Professionals

The Perini Center is committed to providing ongoing educational opportunities for health care professionals. Last spring, the Center sponsored a workshop for researchers entitled *Funding Opportunities for Psychosocial Oncology Research*. This workshop – conducted by Diana Jeffrey, Program Manager at the NCI Office of Cancer Survivorship – was attended by psychosocial professionals from within Dana-Farber as well as other institutions around the city. This spring the Center will be cosponsoring an Advanced Practice Nurse Conference with the Department of Nursing Education. Nurse Practitioners from both the LAF Clinic and the Perini Clinic will be teaching various sessions on cancer survivorship.

For the last 2 years, the Perini Center has sponsored a Visiting Scholar program to provide an opportunity for clinicians and researchers here at Dana-Farber to share knowledge with survivorship experts from around the country. This year's visiting scholar agenda includes an opportunity for clinical fellows to visit with the scholar in small groups.

Survivorship Research

Individual investigators at Dana-Farber have conducted clinical research on issues facing cancer survivors for more than a decade. The Office of Research was established in 2005 to advance the research agenda of the Perini Center and to support the research efforts of disease-based survivorship efforts. The mission of the Perini Center Office of Research is to provide infrastructure for investigators to conduct clinical research in cancer survivorship. The Center is dedicated to improving quality of life after cancer through research on treatment of late effects and dissemination of information on the challenges facing today's growing population of cancer survivors. The Center's Office of Research initiates new research focusing on survivorship issues, supports cross-disease center survivorship research, and serves as a centralized resource for survivor research at Dana-Farber. By coordinating research with clinical activities, the Center strives to connect current research issues and outcomes with day-to-day challenges faced by survivors.

Investigators at Dana-Farber are involved in multiple research activities focused on survivors. These research studies include descriptive and analytic studies of morbidity in survivors, such as psychological distress, cognitive outcomes, growth, secondary cancer risk, and health services research (see Publications List in Attachment B). Dana-Farber is one of 26 sites in the multicenter, NCI-supported Childhood Cancer Survivor Study, a cohort study of almost 20,000 childhood cancer survivors. Research at the DFCI on psychological late effects after childhood cancer has led to the development of a computerized distress screening tool currently being evaluated in a multicenter study.

Several Center programs have focused on long-term survivors of Hodgkin disease. Collaborating with the High Risk Breast Cancer Program, investigators have studied tamoxifen for prevention of secondary breast cancer in women treated with chest radiation. Another study is developing an educational video intervention to improve knowledge of cancer risk and appropriate screening for these women. A recently funded study is studying the use of breast MRI screening in female Hodgkin survivors. Multiple investigators collaborate on a study of late effects in a cohort of Hodgkin patients, including two studies specifically on cardiac disease in these patients.

Specific research efforts, especially those within the Center for Community-Based Research (CCBR) focus entirely on survivorship issues in the community. The CCBR at Dana-Farber develops innovative ways to lower cancer risk by working with community groups and organizations. The CCBR uses the power of the community to study the factors that play a role in improving the prevention, early detection, and treatment of cancer. Current survivorship studies include a focus group study to better understand the health care and quality of life needs that are specific to low-income cancer survivors; a

Web-based smoking cessation intervention for cancer survivors; a study that looks at the gaps in primary care for cancer survivors; a focus group study will explore the information-seeking behaviors among short- and long-term cancer survivors; and a survey project assessing distress in breast cancer patients as they transition off treatment.

A list of actively recruiting and recently completed trials focused on survivors is included in Appendix B.

Community Outreach

A new initiative of the Perini Center strives to build on existing relationships with community partners and develop community-based survivorship programs. The Center proposes to establish a Survivor Outreach Consortium to address the needs of adult and childhood cancer survivors in New England.

The goals of this consortium are:

- To establish survivorship clinical services in the community
- To export survivorship expertise from a tertiary care setting to the community
- To provide patient education opportunities for survivors across the region
- To provide opportunities to a diverse population of survivors to participate in research studies

Initially, the consortium will target three different populations: 1) survivors in southern New Hampshire, primarily from rural areas; 2) childhood cancer survivors in New England who are not followed at a cancer treatment center with a designated cancer survivorship program ; and 3) survivors who receive their primary care in urban community health centers.

Funding

Survivorship activities at Dana-Farber are funded by a variety of sources. Clinical and educational programs are supported by a combination of private donor, foundation, and institutional support. Research efforts are supported by the NCI as well as the American Cancer Society, the Lance Armstrong Foundation, pharmaceutical companies, and private donors.

Appendix A

2006 Perini Family Survivors' Center
Survivorship Programs Calendar

The Perini Family Survivors' Center is the umbrella program for three survivorship clinics

- The Lance Armstrong Foundation Adult Survivorship Clinic
- The David B. Perini, Jr. Quality of Life Clinic
- The Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic

The Perini Family Survivors' Center, the David B. Perini, Jr. Quality of Life Clinic for Childhood Cancer Survivors and the Lance Armstrong Foundation (LAF) Adult Survivorship Clinic will be offering many exciting educational programs and events for survivors throughout the 2006 calendar year.

For information on programming offered by the Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic, please contact (617) 632-2680.

Survivorship programs are continually being developed. This brochure is printed once a year. For more information, including dates and times, please call (617) 632-3382.

Winter 2006

- *Nourishing Mind, Body and Soul for Cancer Survivors*: This seminar will explore how the mind/body connection relates to and impacts our eating behaviors. Participants will gain new skills to enhance their health and well being through eating with awareness.
- *Strength for Caring, Education and Support for Caregivers of Adult Cancer Survivors*: This program will focus on topics such as, family communication after treatment and common emotional and practical matters.

Spring 2006

- *Facing Forward*: A 6-week support group for adult survivors of childhood cancer which explores the challenges of survivorship in everyday life.
- *IMPACT*: This educational seminar is focused on the specific health and survivorship needs of Hodgkin survivors. The program will provide an opportunity for participants to learn more about late effects associated with Hodgkin disease as well as a chance to engage with providers in a number of specialties including psychology, cardiology, and endocrinology.
- *Healthy Lifestyles*: An event for survivors of ALL ages 6-14 and their families with activities focused on nutrition, exercise, and behavior.

Summer 2006

- *Living Proof: Survivorship Week:* A weeklong celebration of survivorship featuring guest speakers, informational tables, and concluding with a cocktail reception.
- *Perini Family Event*: This event will provide an opportunity for survivors and their families to meet one another and enjoy a day of fun and exciting activities. (Tentative)
- *Just for Me*: Just for Me is a recurring 1-day program dedicated to helping young cancer survivors, ages 15-18, integrate their cancer experience in to their lives in a fun, supportive, and engaging environment and to give them a place to talk about their experience and to teach them healthy lifestyle behaviors. (Tentative)

Fall 2006

- *Survivorship Education*: A 6-week educational workshop series for adult cancer survivors of childhood and adult onset cancers.
- *Facing Forward*: A 4-week support group for adult survivors of childhood cancer which explores the challenges of survivorship in everyday life.
- *Survivor Weekend Retreat*: A weekend of education, recreation, and support. Throughout the weekend, lectures and discussions are conducted on secondary cancers, heart issues, and fertility concerns. (Tentative)

Appendix B

Selected Current Protocols, Recent Publications, and Conference Presentations

CURRENT PROTOCOLS

PI	Collaborating Investigator(s)	Title
Bober, Sharon PhD		Hodgkin Disease Survivorship and Late Effects: A Focus Group Study
Bober, Sharon PhD	Ng, Andrea MD; Diller, Lisa MD	A Group Educational Intervention for Female Hodgkin Disease Survivors at Increased Risk for Breast Cancer
Chen, Ming Hui MD		Calculation of Cardiac Valve Irradiation In Lymphoma Patients Treated With Mantle Radiation
Cohen, Laurie MD	Mulder, Jean MD	Neuroendocrine Function in Survivors of Childhood Leukemia
Cohen, Laurie MD		Endocrine Late Effects After Treatment of Neuroblastoma
Diller, Lisa MD		Childhood Cancer Survivor Study
Diller, Lisa MD		Screening for Second Cancers in Retinoblastoma Patients
Diller, Lisa MD		An Analysis Of Perini Clinic Survivor Visits And The Impact On Care.
Earle, Craig MD		Survivor Care after Cancer Survey
Earle, Craig MD		Collection of Clinical Data and Specimens from Cancer Survivors
Earle, Craig MD		Adult Survivors' Consent for Future Contact
Emmons, Karen PhD	Earle, Craig	Exploring the Health Care Needs of Low Income and Minority Cancer Survivors
Emmons, Karen PhD	Diller, Lisa MD	Partnership for Health 2
Garber, Judy MD & Diller, Lisa, MD		Feasibility Sturdy of Tamoxifen Prevention of Breast Cancer in Hodgkin Disease Survivors
Grier, Holcombe MD		A Pilot Study of Cardiac Structure and Function in Long-Term Childhood Sarcoma Survivors
Kenney, Lisa MD		Detection of Microalbuminuria In Survivors Of Childhood Cancer: A Pilot Study.
Kenney, Lisa MD		Reproductive Endocrine Function In Adult Male Survivors Of Sarcomas
Kenney, Lisa MD		Late Effects in Very Long-Term Survivors of Childhood Cancer
Mauch, Peter MD	Chen, Ming Hui MD, Ng , Andrea MD, Fisher, David MD, Marcus, Karen MD	Cardiac Screening in Survivors of Hodgkin Disease Treated With Mediastinal Irradiation
Mauch, Peter MD	Ng, Andrea MD, Recklitis, Christopher PhD	Long-term Follow-Up Study of Individuals Treated for Hodgkin Disease

PI	Collaborating Investigator(s)	Title
Ng, Andrea MD	Diller, Lisa MD; Mauch, Peter, MD; Marcus, Karen MD; Boyajian, Richard, NP	Breast MRI Screening in Women Treated with Mediastinal Irradiation for Hodgkin Disease
Recklitis, Christopher PhD		Development of Computer-Assisted Survivor Screening for Adult Survivors of Childhood Cancer
Recklitis, Christopher PhD		Psychosocial Assessment of Childhood Cancer Survivors Using Empirical Measures
Recklitis, Christopher PhD		Response Bias in Childhood Cancer Survivors
Recklitis, Christopher PhD & Duffey-Lind, Eileen PNP		Quality of Life in Childhood Cancer Survivors Following a Survivor Program
Schneider, Katherine MPH	Recklitis, Christopher PhD	Assessing the Utility of Provding Genetic Counseling to Families of Patients with Childhood Cancer

Recent Publications (Dana-Farber investigators highlighted)

1. **Bober SL**, Hoke LA, Duda RB, Regan MM, Tung NM. 2004. Decision-making about Tamoxifen in women at high risk for breast cancer: Clinical and psychological factors. *Journal of Clinical Oncology, 22(24):* 4951-4957.

2. **Cohen LE.** 2005. Endocrine late effects of cancer treatment. *Endocrinology and Metabolism Clinics of North America, 34(3):* 769-789.

3. Sheen VL, Jansen AN, **Chen MH**, Parinni E, Morgan T, Ravenscroft R, et al. 2005. FLNA mutations cause a variant Ehlers-Danos syndrome associated with periventricular heterotopia. *Neurology, 64(2):* 254-262.

4. Gregory SA, Yepes CB, Byrne HG, D’Ambra MN, **Chen MH**. 2005. Atrial endocarditis – the importance of the regurgitant jet lesion. *Echocardiography, 22(5):* 426-430.

5. Carpentieri SC, **Diller LR**. 2005. Neuropsychological resiliency after treatment for advanced stage neuroblastoma. *Bone Marrow Transplantation, 35(11):* 1117-1122.

6. **Kenney LB**, Yasui Y, Inskip PD, Hammond S, Neglia JP, Mertens AC, Meadows AT, Friedman D, Robison LL, **Diller L**. 2005. Breast cancer after childhood cancer: A report from the Childhood Cancer Survivor Study. *Annals of Internal Medicine, 141(8):* 590-597.

7. Adams MJ, Lipsitz SR, Colan SD, Tarbell NJ, Treves ST, **Diller L**, Greenbaum N, **Mauch P**, Lipschultz SE. 2004. Cardiovascular status in long-term survivors of

Hodgkin's disease treated with chest radiotherapy. *Journal of Clinical Oncology, 22(15):* 3139-3148.

8. Pappo AS, Devidas M, Jenkins J, Rao B, Marcus R, Thomas P, Gebhardt M, Pratt C, **Grier HE**. 2005. Phase II trial of neoadjuvant vincristine, ifosfamide, and doxorubicin with granulocyte colony-stimulating factor support in children and adolescents with advanced-stage nonrhabdomyosarcomatous soft tissue sarcomas: A pediatric oncology group study. *Journal of Clinical Oncology, 23(18):* 4031-4038.

9. **Kenney LB**, Yasui Y, Inskip PD, Hammond S, Neglia JP, Mertens AC, Meadows AT, Friedman D, Robison LL, **Diller L**. 2005. Breast cancer after childhood cancer: A report from the Childhood Cancer Survivor Study. *Annals of Internal Medicine, 141(8):* 590-597.

10. **Mulder JE**, Bilezikian JP. 2004. Bone density in survivors of childhood cancer. *Journal of Clinical Densitometry, 7(4):* 432-442.

11. Das P, **Ng AK**, Stevenson MA, **Mauch PM**. 2005. Clinical course of thoracic cancers in Hodgkin's disease survivors. *Annals of Oncology, 16(5):* 793-797.

12. **Recklitis, C**, Parsons, S, Shih, MC, Mertens, A, Robison, L, & Zeltzer, L. 2005. Factor structure of the Brief Symptom Inventory (BSI-18) in adult survivors of childhood cancer: Results from the childhood cancer survivor study. *Psychological Assessment, In Press.*

Conference Presentations

1. **Duffey-Lind, E**. Transitioning to survivorship: A pilot study: Presented at the Association of Pediatric Oncology Nurses Conference, September 2005 and the Children's Oncology Group Nursing Conference, March 2005.

2. **Henderson T**, Robison L, Mertens A, Neglia J, Hammond S, Meadows A, Whitton J, Cook EF, Stovall M, **Diller L**. Sarcomas as a subsequent malignancy in survivors of pediatric malignancy: The Childhood Cancer Survivor Study. Presented at the American Society of Clinical Oncology Annual Meeting, May 13-17, 2005.

3. **Bober SL**, Park ER, Schmookler TJ, **Diller, L**. Awareness of breast cancer risk after Hodkgin's disease: A qualitative study. Presented at the 2nd Annual Symposium of the Dana-Farber/Harvard Cancer Center Program in Breast Cancer, March 2005.

4. **Bober SL**, Park ER , **Diller L**. Hodgkin's disease survivorship and breast cancer risk: A qualitative exploration of young women's perceptions. Presented at the Annual Psychosocial Oncology Conference, February 2005.

5. Lockwood R, **Diller L**, **Recklitis CJ**. Suicidal symptoms among childhood cancer survivors: Prevalence and risk factors. Presented at the Annual Psychosocial Oncology Conference, February 2005.

6. Rodriguez P, **Recklitis CJ**. Screening adult survivors of childhood cancer with the BSI-18: A comparison with the SCL-90-R. Presented at the Annual Psychosocial Oncology Conference, February 2005.

Duke Comprehensive Cancer Center
Survivorship Activities

The Duke philosophy is that individuals become cancer survivors at the time of their diagnoses and continue to be survivors the rest of their lives.

Research and Clinical Care Interventions

The Duke Comprehensive Cancer Center's Prevention, Detection and Control Program has a strong portfolio of research that provides, tests and evaluates interventions among cancer patients and survivors. The program includes approximately 30 funded investigators who currently hold more than $20 million in peer-reviewed grants and have published more than 160 papers since January 2005.

Drs. Wendy Demark-Wahnefried, Elizabeth Clipp, and Harvey Cohen are conducting several intervention studies. The first, funded jointly by NCI and NIA, tests whether a computer-generated correspondence course that promotes physical activity and a plant-based, low-fat diet is effective in changing behavior among breast and prostate cancer patients. Preliminary findings show significantly greater dietary and physical activity changes in the intervention group. Through a supplement awarded this year, Dr. Eric Eisenstein from the Duke Clinical Research Institute has joined the team to assess the intervention's costs and benefits. This program has been adapted for use in Australia and is currently being tested there under the title of the Logan Health Project.

Drs. Demark-Wahnefried, Clip, and Cohen are also collaborating on RENEW, a RCT aimed at improving physical functioning among long-term elderly survivors of breast, prostate, and colorectal cancer via a home-based diet and exercise program to promote weight loss. Finally, Dr. Demark-Wahnefried has developed both a clinic-based and a distance medicine-based program aimed at reducing sarcopenic obesity that results from chemotherapy (STRENGTH: Survivor TRaining for ENhancinG Total Health) and is currently leading a Phase II trial in collaboration with the Wake Forest University Community Cancer Outreach Program to test the home-based program.

Currently, Dr. Jones is PI on four externally funded studies spanning both basic and clinical research examining the effects of exercise on biopsychological outcomes in a broad range of cancer populations. Specifically, the first study is examining the feasibility of a preoperative exercise training program on exercise capacity and surgical complications in early-stage, non-small cell lung cancer patients. Preliminary findings reveal that exercise training is a safe and feasible intervention to significantly improve exercise capacity in these patients which may in turn lower perioperative and postoperative surgical complications. This is the first study to examine this question.

The second study is the examining the prognostic value of a cardiopulmonary exercise test in metastatic breast cancer patients and inoperable non-small cell lung cancer patients. The overall goal of this study is to determine if an objective measure of patients physical functioning such as an exercise test is a more sensitive predictor of clinical outcome in advanced cancer patients. Identification of more sensitive and accurate markers may allow more appropriate, individualized care. The goal of the third study, recently funded by the Lance Armstrong Foundation, is to examine the feasibility of endurance exercise training in early-stage, non-small cell lung cancer patients receiving adjuvant chemotherapy. The major purpose of this study is to determine if concurrent exercise training can lower chemotherapy-induced adverse side-effects and increase the number of patients completing a full course of chemotherapy.

The fourth study, funded by the U.S. Department of Defense Breast Cancer Research Program, is using a randomized controlled trial to determine the effects of an endurance exercise training program on chemotherapy effectiveness in early-stage breast cancer patients. This is the first study to examine if exercise training can improve the delivery and efficacy of conventional breast cancer treatment and may provide evidence for a new complementary nonpharmacologic approach for improving treatment outcome in this patient population. Finally, Dr. Jones also has several preclinical investigations underway examining the effects of exercise training on tumor growth and response to different anticancer agents using animal models.

Drs. Francis J. Keefe and Laura Porter continue to study pain prevention and treatment. The primary goal of the cancer control component of this research program is to develop and test new protocols for helping cancer patients and their partners/caregivers better cope with pain and other symptoms. With support from the NCI, Drs. Keefe and Porter are currently conducting four treatment outcome studies of partner- or caregiver-assisted interventions: 1) an R01-supported study testing the efficacy of a caregiver-assisted coping skills training for early stage lung cancer patients; 2) a study funded by an NCI supplement focusing on coping skills training for African American cancer patients; 3) an R01-supported study testing the efficacy of a partner-assisted emotional disclosure intervention for patients with advanced GI cancer; and 4) an R01-supported study testing the efficacy of a couple-based cognitive behavioral intervention for women with early stage breast cancer.

Dr. Amy Abernethy recently completed The Palliative Care Trial – the largest randomized controlled trial of health services interventions ever to be conducted with a palliative care population. Three interventions (case conferencing, educational visiting for GPs, and educational visiting for patients) were tested against a routine care control in a 2x2x2 cluster factorial design. Findings showed that service delivery models that include a case conference or educational visiting for patients lead to improved patient outcomes; patients with poor performance status derive the greatest benefit. The trial was funded by the Australian

Commonwealth Department of Health and Aging with supplements from the Doris Duke Charitable Foundation and the Ian Potter Foundation and Cancer Council of South Australia.

Dr. James Tulsky leads a team including Drs. Kathryn I Pollak, Celette Sugg Skinner, and Amy Abernethy in Studying Communication in Oncologist Patient Encounters (SCOPE) to observe and enhance discussions between oncologists and patients with advanced cancer. The goal is to identify key communication skills that may assist patients through difficult transitions and by creating an easily disseminable intervention to help oncologists implement these skills. More than 400 oncologist-patient discussions have been recorded during the last year; participating oncologists randomly assigned to the intervention group will receive tailored instructional CDs that will include state-of-the-art education as well as examples from their own recorded interactions (intervention development is currently underway).

Dr. Lori Bastian is leading a new program aimed at smoking relatives of lung cancer patients at Duke, the University of North Carolina at Chapel Hill, and the Durham V-A Medical Center. Bastian's team is asking lung cancer patients to provide names of relatives who are willing to attempt quitting smoking. Half the relatives receive brochures and a video that provides education on the deleterious effects of smoking and how to quit, along with a free supply of nicotine patches. The other half receive these same materials in addition to a series of telephone counseling sessions in which they are taught coping skills and stress management tools. The six counseling sessions teach strategies such as progressive muscle relaxation; the use of imagery to help smokers mentally gravitate to a relaxing and safe haven; positive self-talk and rewards that help smokers reframe their negative thoughts into positive ones; and practice sessions to incorporate these skills into daily living.

The Hereditary Cancer Clinic at the Duke Comprehensive Cancer Center, led by Dr. Kelly Marcom, offers cancer risk assessment and education to cancer patients and people with a family history of cancer or other cancer risk factors. Board-certified genetic counselors team with medical oncologists to provide patients with information about their risk of inherited cancers, ways to reduce the chance of developing cancer, and ways to increase the chance of early detection. Clinic staff work closely with other researchers from Duke and cancer centers nation-wide to better understand inherited cancers and to develop new tools for estimating cancer risk.

The Integrative Oncology Program focuses on cancer care activities which are designed to improve the experience of the Duke cancer patient. This program incorporates two important components: research and evaluation. The Integrative Oncology Program investigates and evaluates new and existing complementary, alternative, and mind/body/spirit medicine practices to determine their efficacy, effectiveness, and safety and to generate new knowledge which identifies best practices to care for the whole person, whether the origins are conventional or alternative. The Pathfinders program is one component of the Integrative Oncology program and is designed to address the mind, body and spiritual needs of each individual patient. Patients are matched with a Pathfinder, a trained professional with an advanced degree in social work, family counseling, or therapy. The Pathfinders serve as advocates for patients within the Duke University Medical System, providing unbiased guidance on complementary medicine, self-care, mind-body techniques, end-of-life planning, and spiritual connectivity. With the help of their Pathfinder, patients become knowledgeable about the available resources at Duke and in their home community which are important to their recovery. Pathfinders offer services including nutrition and exercise education, relaxation/stress reduction skills training, spiritual counseling, and life review and end-of-life planning. Certified practitioners at Duke or in the home community add additional therapies including acupuncture, massage therapy, yoga, pilates, reiki, and healing touch.

The Childhood Cancer Survivor Follow-up Program – established in 1992 within the Department of Pediatrics, Division of Hematology/Oncology – follows pediatric, adolescent, and young adult survivors of childhood cancers treated at Duke, as well as those referred nationally who are now part of the Duke community. The program provides a unique services in which the patients are followed from pediatric age to adulthood, thus eliminating the disconnect that is prevalent in many institutions.

Support and Educational Programs and Initiatives

Duke University Medical Center Oncology Services currently has the largest overall volume in the Southeastern United States with more than 150,000 outpatient visits and more than 7,600 inpatient discharges in 2005. The Tumor Registry has a database of more than 100,000 cancer patients and follows more than 26,000 active cancer patients worldwide who have been evaluated and treated at Duke since 1990. This database is used to identify specific audiences including high-risk populations in order to provide targeted outreach. At 25 affiliate sites in 6 states, another 15,000 new cancer patients are seen and have access to the services offered by the Duke Oncology Network, a collaborative effort by the Duke University Health System and the Duke Comprehensive Cancer Center to partner with hospitals and private practices throughout North Carolina and the Southeast. The Duke Oncology Network provides physicians in these communities with access to state-of-the-art research programs and provides education and training programs to physicians, nurses, and other health care professionals. The network provides new cancer education initiatives directed at patients in the communities and provides patients access to clinical trials for a variety of new cancer treatments. Because of these affiliations, hundreds of patients in these communities are enrolled each year in clinical trials.

The Duke Center for Cancer Survivorship was founded in 2005 to align and integrate support services for Duke oncology patients. The core objective of Center is to provide a patient-centric, interdisciplinary care approach to patients with cancer from the moment of diagnosis and through the balance of life. The Center offers pharmacologic and nonpharmacological services to address physical symptoms such as pain and fatigue; mental symptoms and psychosocial concerns, including support groups for patients, family caregivers, and children of patients; and therapy for lymphedema, as well as nutritional and pharmaceutical counseling. The disciplines represented include, but are not limited to: social workers, licensed marriage and family therapists, licensed professional counselors, advanced practice nurses, a recreational therapist, physical therapists, nutritionists, and a pharmacist. Most of these services are available at no charge to patients and family members receiving care at Duke.

The Center encompasses a number of programs directed at the care, support, and education of oncology patients:

- The Duke Cancer Patient Support Program was established in 1986 to address the psychological and social needs of patients and their families. It is one of the leading programs of its kind in the nation. The program has been awarded the American Medical Association Award for Excellence and was among the first to offer the "Look Good, Feel Better" program for patients. Program services include: individual and family counseling, support groups, volunteer assistance/companionship, self-image workshops and resources, and chemotherapy orientation. The Duke Cancer Patient Support Program distributes a semi-annual newsletter which provides information about program activities and current issues in psychosocial care in cancer treatment.

- The Cancer Patient Education Program is housed within Duke South Clinics and uses a multimedia approach to assist cancer patients and their families in understanding their treatment options, making decisions regarding treatment, and managing the effects of cancer and its treatment. The Patient Education Program also includes the Patient and Family Resource Center, the Cancer Education Closed Circuit TV Channel, the Patient Education Notebook, and a variety of other written and interactive educational offerings. The program distributes a monthly newsletter for patients and their families. The newsletter, entitled *In the Know,* is distributed by e-mail and provides information about cancer research, common medical treatments and their side effects, complementary and alternative therapies, financial issues, and end-of-life care, as well as personal accounts from cancer survivors.

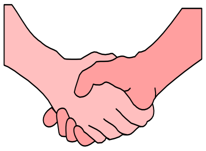
- Oncology Recreation Therapy has been a pioneer recreation therapy program in the U.S. since 1976. State and nationally certified therapists use treatment interventions and music, games, crafts, and humor to optimize functioning, coping and quality of life during treatment. The program matches the best medical care available with the use of treatment interventions to restore, remediate or rehabilitate in order to improve functioning and independence, as well as to reduce or eliminate the effects of illness or disability and long-term effects of treatment.

The Center for Survivorship's Patient Focus Group identifies issues relevant to the oncology patient experience that impact patient satisfaction, quality of life, and overall well-being from initial consult through the balance of long-term, follow-up care. Members currently include a broad spectrum from patients only recently diagnosed to those up to 2 years post-treatment. In addition, the Duke Center for Cancer Survivorship Advisory Council consists of physicians and other disciplines dedicated to the care of oncology patients and their family members. Council members contribute a wealth of knowledge and expertise and are dedicated to research for cancer prevention, detection, and control. This ensures the Center's goals and objectives are developed with the awareness of the diverse needs of patients receiving treatment for cancer; while improving the quality of life for all Duke patients with cancer.

The Duke Comprehensive Cancer Center hosts educational seminars on prevention, detection and treatment by Duke Oncologists each year in other communities throughout North Carolina, reaching more than 1,300 people. A Power of Knowledge seminar is also hosted each year by the Cancer Patient Support Program to educate women about cancer. Annual attendance is several hundred. For over 20 years, Duke has hosted a Melanoma Consortium for over 200 participants that include the public, patients, and health care providers. In celebration of National Cancer Survivors Day, the Duke Cancer Patient Support Program holds a special program each year and provides educational and support materials to patients and their families which focus on coping and survivorship issues.

The Duke Comprehensive Cancer Center has housed an office of the Cancer Information Service (CIS) since 1976. The CIS service area is North Carolina, South Carolina, and Georgia. The CIS, a program of the NCI, provides information ranging from cancer prevention and detection to current treatments, clinical trial information, and the latest research findings. The CIS can be accessed through a toll-free 1-800-4-CANCER call center. The 1-877-44U-QUIT number, and the 1-800-QuitNow lines provide individually tailored smoking cessation counseling. Call volume for the past 5 years totaled 71,498.

The Duke Comprehensive Cancer Center's communications program familiarizes survivors and their families with research achievements, new treatments, and other activities within the Duke Comprehensive Cancer Center through *Cancer Center Notes,* a newsletter that is distributed 3 times each year to 25,000 people. A web site is available to the public and offers a broad range of information including a listing of clinical trials at Duke, cancer risk factors, standard and new treatments, prevention programs, and survivor stories. The Cancer Center also hosts a number of community programs to inform and educate the community including cancer survivors. Each year in April, The Brain Tumor Center at Duke sponsors Brain Tumor Action Week to coincide with the national effort of the brain tumor community of patients, families, friends, health care providers, and others to educate elected officials about brain tumors. The Brain Tumor Center at Duke provides information about brain tumors at a booth that is staffed by professionals and set up inside Duke Hospital and Duke Clinics. In September, the Cancer Center's Gynecologic Oncology Program hosts a schedule of educational seminars for the public. Oncologists from Duke discuss the often ignored symptoms of ovarian cancer as well as the most current treatments and promising research.



Albert Einstein Cancer Center / Montefiore Medical Center
The Psychosocial Oncology Program / Quality-of-Life Cancer Research Program

Director
Alyson Moadel, PhD

Mission

This Psychosocial Oncology / Quality-of-Life Cancer Research Program is dedicated to improving the quality of life (QoL) of those affected by cancer. It strives towards this goal through both clinical and research efforts. In the realm of clinical service, this program provides supportive counseling and education to cancer patients, their family members, and health care providers. As an extension of the overall mission of cancer prevention and support, a smoking cessation program was developed to address the needs of all smokers interested in quitting. In the realm of research, there are a number of funded studies examining the effects of behavioral/mind-body interventions on the physical and emotional well-being of cancer patients. We also conduct regular program evaluations in an effort to monitor and improve the effectiveness and satisfaction of our services. All programs are offered free of charge or on a sliding-scale basis to accommodate the needs of this disadvantaged community.

The Psychosocial Oncology Program (PSOP)

This is the clinical arm of the program. Through individual counseling, education, and compassion, counselors support patients and their loved ones through cancer treatments, difficult decision-making, and the anxiety that accompanies the uncertainty of this illness. In addition to private counseling, the program offers general support groups as well as specialized psycho-education groups for ostomy patients. Below are three additional sub-services of the Psychosocial Oncology Program.

- *HOPE Program* (Helping Oncology Patients through Education) is an educational series that addresses the questions and concerns at the top of most patients' minds: Cancer Diagnosis and Treatment Options, Life after Cancer, Healthy Lifestyles, Cancer and Complementary Medicine, Legal Rights; Cancer Advocacy, and Coping with Cancer.
- *Psychosocial Oncology Fellow's Seminar* is a monthly seminar geared towards educating oncologists-in-training about psychosocial cancer issues including "Breaking Bad News," "Preventing Physician Burn-out," "Helping Depressed/Anxious Patients," "End-of-Life Care," and "Cultural Compassion in Medicine."

- *Psycho-Oncology Externship/Internship* is at the heart of this program as it provides the counselors who deliver the services. Psychology doctoral students are trained under Dr. Moadel's supervision to conduct psychotherapy and psycho-education around cancer and cancer prevention, whereby they receive the required training hours towards their degree.

Our Stop Smoking Program consists of a structured, multi-faceted, 6-week group series that arms Bronx residents with ample knowledge and a variety of tools to maximize their chances of quitting. The program includes aspects of behavioral therapy, group support, relaxation exercises, and self-hypnosis. The Ciggy Bank, homework assignments, and informational packets are learning incentives as well as quitting tools. The program also includes a variety of guest speakers including a physician, a health psychologist, a survivor of a smoking related illness, and an ex-smoker.

Quality-of-Life Cancer Research Program

We have two funded research programs examining complementary and behavioral medicine treatments and their effects on patients' physical and emotional functioning during cancer and its treatment.

- *Yoga Study*, begun in 2001, is a randomized-controlled trial that examines the effects of yoga versus standard care on quality of life in breast cancer patients. Early results are promising, as we are finding that patients receiving yoga are experiencing less emotional distress and greater social well-being than those in a control group. Starting in 2004, we began expanding this study to include patients with colorectal and lung cancers. Funding for this research comes from the NCI, the Langeloth Foundation, and the Balm Foundation.

- *Mind/Body Study* is a research initiative started at the end of 2004 that compares the effects of a spiritual-existential group to a psycho-educational group on quality of life and survival in advanced stage cancer patients. This study was conceived based on the high rate of patients who expressed a need for greater spiritual support in their cancer care. Funding for this study is from the American Cancer Society.

Infrastructure

The PSOP/QOL Program Team is comprised of the Director (a licensed health psychologist/researcher), Project Coordinator (Masters degree in psychology), bilingual research assistant and several student externs, interns, and volunteers all of whom meet regularly to implement strategies designed to achieve the goals of the programs. Members include:

Alyson Moadel, PhD – Director
Evelyn Kolidas, MA – Program Coordinator

Ruth Santizo, BA – Bilingual Research Assistant
Psychology interns/externs* (rotating)
Volunteers* (rotating)

The PSOP/QOL Volunteer Program is made up of a variety of undergraduate and graduate students, cancer survivors, and community members who donate hours of their time to almost every aspect of the program from peer counseling/support, data collection and entry, questionnaire administration, translation, and office support.

Cancer Survivorship Research (Ongoing)

"Evaluation of a Yoga-based Cancer Rehabilitation Program".
National Cancer Institute
4/1/01-3/31/03
Langeloth Foundation
Alyson Moadel (PI)
1/1/04-12/31/06 (one-year no-cost extension)

This randomized-controlled trial compares the effects of a 12-week yoga intervention on quality of life among English- and Spanish-speaking breast, lung, and colorectal cancer patients in comparison to a wait-list control group receiving standard care.

"Spiritual vs Educational Intervention on QOL in Low-Income Cancer Patients"
American Cancer Society Research Scholars Grant
(TURSG PBP-105665)
Alyson Moadel (PI)
7/1/03-6/31/06

This study compares the effects of a psycho-educational vs. psycho-spiritual intervention on quality of life and medical outcome of underserved, late-stage cancer patients.

Clinical Care

Individual Psychotherapy
One-on-one counseling is provided to cancer patients and their loved ones cope with the emotional challenges of living with cancer and its treatment. Bereavement counseling is also available for those who have lost loved ones. (Low cost/sliding scale)

The Albert Einstein *"Be Smart"* Quit Smoking Program
A 6-session smoking cessation program is offered several times per year in a warm, supportive environment. Features include pharmacotherapy discussion with hospital physicians, self-hypnosis and relaxation training, guest speakers, tips for breaking the habit, and tools for conquering urges and temptations. Accessible to all smokers interested in quitting. Run by a trained psychosocial oncology counselor.

Education

The HOPE Program

HOPE – *Helping Oncology Patients Through Education* – is a 6-week, educational program addressing many of the questions cancer patients and their families have about the illness with the help of expert speakers (e.g., doctors, nurses, nutritionists). Example topics include: coping with cancer, nutrition, complementary medicine, managing fatigue, and finding reliable information. Offered biannually in the fall and spring. (No cost)

Ostomy Support Group:

The Ostomy Support Group is a monthly educational support group with guest speakers for those with colostomies & urostomies, lead by an Ostomy Nurse and a trained Psychosocial oncology counselor.

The Psychosocial Oncology Fellows Seminar

This 10-session biweekly seminar is geared towards educating oncology fellows about psychosocial cancer issues including "Breaking Bad News," "Preventing Physician Burn-out," "Identifying Depressed/Anxious Patients," "End-of-Life Care," and "Cultural Competence". Through journal articles, videos, patient guest speakers, role-playing, and discussion, fellows are educated about the "art of medicine".

Fred Hutchinson Cancer Research Center

Cancer Survivorship Activities

Introduction

The Fred Hutchinson Cancer Research Center (FHCRC) holds a clear commitment to survivorship in the areas of research, clinical care, education, and advocacy, exemplified by our existing survivorship programs for survivors of hematopoietic stem cell transplantation (HSCT), pediatric oncology, prostate and breast cancer, and plans to extend services to cancer survivors across all age groups, treated by conventional therapy or transplantation. Within these programs, clinical services, patient and provider education, and clinical research are performed. We have over 50 active research studies examining a broad range of long-term, health-related outcomes.

Survivorship Programs

There are four well-defined and highly successful survivorship programs, which conduct standardized evaluations, adapted for cancer site, by a team of oncologists, mental health professionals, mid-level practitioners, subspecialists, and allied health professionals. Communication is maintained with referring community physicians and educational material is provided to patients and health care providers. The programs have nationally recognized leaders who conduct research to improve the health and quality of life for cancer survivors. These four programs include:

1) Long-term follow-up (LTFU) for hematopoietic stem cell transplant (HSCT) survivors

The transplant LTFU program was established in 1980. The LTFU program has active contact with most of its 3,900 survivors: 99% of those treated from 1-5 years ago, 85% of those treated from 5-15 years ago, and 76% of those treated more than 15 years ago. Approximately 400 survivors return each year for a comprehensive onsite evaluation.

The LTFU provides interactive consultative services in the management of patients who have participated in our clinical research studies. Following transplant, patients attend educational classes to assist in their transition to home. Referring physicians are provided care guidelines when they resume responsibility for patient management. Clinical services include: individual recommendations for continuing treatment at home and potential long-term complications; provision of written and web-based guidelines for patients and physicians; telephone consultations for patients and physicians to assist with management of complications; and evaluation and management of therapy-related complications at 1-year post transplant and, thereafter, as needed.

2) ACCESS program for childhood cancer survivors

The pediatric survivorship program was developed in 2001. The overall goal of this program is to improve long-term outcomes and quality of life for survivors of childhood cancer. The major research aim is to characterize and determine the incidence of adverse outcomes in childhood cancer survivors treated by conventional chemoradiotherapy in order to develop preventive and therapeutic strategies. Approximately 250 patients are seen annually and receive a comprehensive onsite evaluation. Telephone consultations are also available. Evaluations include: review of disease, treatment, acute and chronic complications and comorbidities; health history with attention to educational/vocational issues, health care utilization and health behaviors, family history, and intercurrent psychosocial or medical problems; risk-adapted physical examination, and appropriate laboratory, diagnostic, and imaging studies.

Schedule of visits and studies are based on host-, disease-, genetic-, and treatment-related variables. We utilize The Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers, developed by the Children's Oncology Group (COG) (www.survivorshipguidelines.org) to determine risk, appropriate clinical screening, and interventions.

After completion of the clinical evaluation, an individualized health education package is prepared for the survivor, which includes a treatment summary, health education and cancer prevention material and survivorship resources, all of which are reviewed with the patient and family by the nurse practitioner.

3) Prostate Cancer Clinical Research Program (PCCRP)

The PCCRP focuses on clinical trials and research. Survivorship research has focused on intermittent androgen suppression (IAS) as a treatment that will result in improved symptoms and quality of life. An aim of the IAS program is to document the effects of androgen deprivation therapy on men without metastatic disease and who are expected to live for 5 to over 15 years. The effects of IAS on both bone mineral density and cognition have been evaluated and additional projects are being designed to study the interaction of mood and cognition and fatigue/vitality and mood respectively.

As a result of interactions with patients and spouses, the program identified many unmet needs in the realm of sexuality, intimacy, marital difficulties, and mood. Prostate, testicular, and bladder cancer survivors are now offered the services of a psychologist, who provides consultation for patients individually, and with spouses. The program also provides access to a spousal support group, patient education and educational workshops, and support for interested health care providers and staff.

4) Women's Wellness Center (WWC)

The WWC was established in 2003 as an initiative from the Breast Cancer Research Institute at the SCCA, with the goal to promote transition from a model of illness to wellness for breast and ovarian cancer survivors.

There are currently over 250 women participating in the program. Patients receive medical follow-up with their primary oncologist, but the WWC provides education and advocacy training, referral to community resources, and onsite health promotion. Women have access to complementary and alternative medicine, weight and nutritional counseling, physical and occupational therapy, exercise training, and counseling as well as psychosocial services. The program is also dedicated to promoting research and alerts participants of relevant studies related to prevention, screening and survivorship.

LIVESTRONG Survivorship Outreach Center

This comprehensive cancer survivorship program was established in January 2006 and is a member of the LIVESTRONG Survivorship Centers of Excellence Network, funded by a grant by the Lance Armstrong Foundation. It will integrate and coordinate our current survivorship programs and includes plans for expansion to include all cancer survivors. The Survivorship Center will have three distinct, yet interrelated principal elements:

1. Comprehensive onsite evaluations
    - Review of diagnosis, treatment, acute and chronic complications, and comorbidities
    - Risk-adapted history and physical examination, laboratory, and diagnostic studies
    - Psychosocial and functional needs assessment
    - Fitness and exercise assessment
    - Referral to appropriate subspecialties and services
    - Preparation of treatment summary, guidelines and recommendations for follow-up
    - Patient education with our program nurse practitioner
2. Development of mixed-modality models of care to augment onsite evaluations
    - Reconfiguration of written, phone, and online survivorship resources to provide information about the risks relevant to specific cancers and their therapies, screening and monitoring recommendations, and information on research and resources inside and outside FHCRC
    - Availability of a dedicated toll-free helpline, with an onsite program coordinator who will provide navigation services to survivors and health care providers
3. Research designed to improve the well-being of diverse groups of pediatric and adult cancer survivors
    - Development of cross-program research initiatives and enhanced survivorship outreach

In addition, three community-based affiliate survivorship programs were established to provide survivorship activities to underserved populations:

Harborview Medical Center (HMC), Seattle, WA

This program will adapt the Case-Managers Cultural Mediators Program used at HMC to reach out to ethnically diverse cancer survivors residing in the inner city areas of Seattle and bring them back to the clinic for needed medical care and access to research studies.

Sacred Heart Children's Hospital (SHCH) and Providence Cancer Center (PCC), Spokane, WA

SHCH and PCC will develop a combined pediatric and adult survivorship program, where onsite comprehensive evaluations will take place. A risk-based approach to medical follow-up will be utilized, when appropriate, similar to that used at FHCRC. Treatment summaries and risk-based follow-up recommendations will be shared with the survivors and their primary care and oncology providers in the community. Data will be collected on barriers to implementing follow-up recommendations, so that appropriate interventions can be designed.

Providence Alaska Medical Center (PAMC), Anchorage AK

Approximately 15% of the pediatric oncology patients, 4% of the HSCT patients, and 2% of the general medical oncology patients seen annually in the SCCA are referred from Alaska for their acute oncology care. However, post-treatment, they return to Alaska and it becomes impractical for them to return to Seattle for survivorship care. A program will therefore be developed, also utilizing a risk-based approach to medical follow-up, similar to that used at FHCRC. Native Alaskan groups have committed their support for the program, with the hope that satellite survivorship programs may ultimately be developed in other community settings.

The programs at FHCRC and the community affiliates will work cooperatively with the NCI Cancer Information Services (CIS) to provide information to survivors in their programs. The Northwest Regional office for CIS is located at FHCRC, and regional offices are also located in Spokane and Anchorage, which will serve to foster these collaborations.

Contributions to Survivorship Research from Public Health Sciences (PHS)

A strong asset to survivorship research at the FHCRC is the Division of Public Health Sciences (PHS), which conducts epidemiologic research in the areas of early detection and cancer prevention. While these studies are not targeted solely for cancer survivors, the research has far reaching implications that may promote healthy behaviors and decrease risk of subsequent neoplasms in the high-risk survivor population. These studies can be summarized in the following categories:

- Etiologic studies designed to identify environmental, nutritional, and genetic risk factors for cancer

- Biomarker development focused on the identification of novel screening markers
- Genetic registry studies that recruit cancer patients and their family members in order to investigate inherited causes of cancer and interactions between genes and environmental exposures
- Community-based interventions and surveillance studies that improve access to screening and other prevention services and test primary prevention strategies
- Clinical trials that are particularly focused on promising chemoprevention agents and strategies, dietary and physical activity interventions, and on counseling strategies in high-risk groups
- Quality of life and cost-effectiveness studies to assess the viability of screening, intervention, and treatment modalities

PHS also demonstrates a commitment to pediatric cancer survivorship research, supporting the statistical centers for two large pediatric late effects research studies, the National Wilms Tumor Study (NWTS) and the Childhood Cancer Survivor Study (CCSS). PHS also supports the NCI CIS and the statistical centers for the national Women's Health Initiative and the Southwest Oncology Group, all of which can promote research collaboration across the cancer continuum.

Appendix A

Selected survivorship-related research publications by FHCRC faculty

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Appendix B

Selected long-term outcomes research in survivorship at FHCRC/SCCA

Table 1: Hematopoietic stem cell transplant studies

Study	Principal Investigator
Longitudinal neuropsychological assessment of the effects of CNS treatment and/or TBI in children with hematologic malignancies	Sanders
The impact of pediatric marrow transplantation on late pulmonary function	Sanders
The quality of life of adult survivors who received a marrow transplant as a child	Sanders
The quality of life of adult survivors of childhood leukemia	Sanders
Master protocol for collection of clinical data and storage of leftover specimens from patients treatment accruing to FHCRC protocols	Martin
A multi-center Phase III double-blind clinical trial to evaluate the efficacy of mycophenolate mofetil added to prednisone plus cyclosporine or tracrolimus for treatment of newly diagnosed CGVHD	Martin
A randomized single-blind study of extracorporeal photoimmune therapy with UVADEX in conjunction with standard therapy alone for the treatment of patients with corticosteroid refractory, dependent or intolerant CGVHD	Flowers
A Phase II clinical trial to evaluate the safety and efficacy of sirolimus for secondary treatment of CGVHD	Carpenter
Genetic predisposition to second malignancy after childhood cancer treated with HSCT	Friedman
Radiation sensitivity, DNA repair and second cancers	Friedman
Radiation sensitivity in lymphocytes and skin fibroblasts	Deeg
Monitoring of lung function decline after hematopoietic stem cell transplant	Chien
Genetic variability in the innate immune response of patients and donors and its relationship with post transplant complications	Chien
Chemotherapy toxicity: Biopsychological and biosocial determinants, manifestations and consequences of stress in bone marrow transplant patients	Syrjala
Workshops in preparation for returning home after bone marrow transplantation	Syrjala
Multisite randomized clinical trial comparing standard recovery preparation to extended recovery preparation to enhance long term function after marrow or stem cell transplant	Syrjala
Trajectories of health and adaptation after pediatric stem cell transplantation	Syrjala

Internet and phone intervention to enhance function in long term survivors of HSCT	Syrjala
Emotional needs of caregivers and patient/spouse couples during and after HSCT	Langer
Computer-mediated support for transplant recipients and their caregivers at the Pete Gross House	Abrams
Quality of life of adult medium-term survivors of bone marrow transplantation	Bush
Dynamic quality of life after hematopoietic cell transplantation	Donaldson

Table 2: Pediatric oncology studies

Study	Principal Investigator
Investigator-initiated studies	
Genetic predisposition to second malignancy after childhood cancer treated with conventional chemoradiotherapy	Friedman
Radiation sensitivity, DNA repair and second cancers	Friedman
Health-related outcomes for Hodgkin disease survivors (also a cooperative group study)	Friedman
Nutrition and exercise for teens	Friedman
Social activity and exercise for teens	Friedman
Impact of illness	Whitsett
Renal effects of ifosfamide	McCune
Coping after cancer	Katz
National Wilms tumor late effects study	Breslow
Neurobehavioral outcomes in childhood acute lymphoblastic leukemia	Kadan
Key Adverse Events after Childhood Cancer	Bhatia
Childhood cancer survivor study (CCSS)	Robison
Project VISION for Hodgkin disease survivors in the CCSS	Oeffinger

Table 3: Prostate cancer studies

Study	Principal Investigator
Strength training and step intervention for prostate cancer patients	McTiernan
Effects of androgen deprivation therapy (ADT) on cognitive function in asymptomatic men with risk PSA treated with intermittent androgen suppression (IAS)	Higano
Assessment of cognitive and brain metabolic changes in response to IAS	Higano
Cognitive, emotional and quality of life changes in men treated who have a rising PSA without evidence of bone metastases treated with ADT	Cherrier
Transdermal estrogen versus GnRH analog for treatment of prostate cancer: comparison of effects on bone mineral density, lipids, cognition, FMRI, BMI, visceral fat, coagulation factors, quality of life and treatment-related symptoms	Beer
Effect of IAS on bone mineral density in men with rising PSA and no evidence of bone metastases	Higano

Table 4: Breast cancer studies

Study	***Principal Investigator***
Weight loss lifestyle intervention in post-menopausal women with breast cancer	McTiernan
Combined exercise and diet intervention in breast cancer patients and survivors	McTiernan
Observational data of physical activity, weight and prognosis in breast cancer	McTiernan
Modifiable risk factors for arm lymphedema in breast cancer survivors	Rossing

Appendix C

Funding sources for survivorship studies at FHCRC/SCCA

Research components of the survivorship programs are funded by a combination of NCI, Foundation, Philanthropy and Center funding. Some selected examples follow:

P50 CA 97186-04 (P.I.: Lange, P.) 9/19/2002 - 6/30/2006

NCI

Pacific Northwest Prostate Cancer SPORE

The Pacific Northwest Prostate Cancer Spore is a coordinated effort of four institutions with strong programs in prostate cancer research and career development: the Fred Hutchinson Cancer Research Center; the University of Washington and its affiliated institutions; the Institute for Systems Biology, and the University of British Columbia and the Prostate Center and Institute of Vancouver General Hospital. These three Seattle-based and the British Columbia based institutions have a large number of investigators and laboratories dedicated to prostate cancer research. The purpose of this SPORE is not only to perform the research projects proposed, but in a larger sense to form the "central supporting piece" to a large developing "mosaic" of coordinated translational CaP research in the Pacific Northwest. Dr. Higano leads the clinical core.

FND 7040-04 (P.I.: Bernstein, I.D.) 10/1/2002 - 9/30/2007

LEUK & LYMPH

Immunotherapy of Hematological Malignancies

The goal of this SCOR program is to develop effective, non-toxic strategies for treating patients with advanced hematologic malignancies using adoptive cellular and humoral immunotherapy. Dr. Martin leads the long-term follow up core.

R01 CA 098906-03 (P.I.: Martin, P.) 8/1/2003 - 5/31/2008

NIH

Myconfenolate Mofetil for Treatment of Chronic GVHD

The major goals of this project are to evaluate the efficacy of mycophenolate mofetil (MMF) for treatment of newly diagnosed chronic GVHD and to evaluate the health-related quality of life for patients with chronic GVHD treated with standard therapy plus MMF as compared to those treated with standard therapy alone.

P01 CA 18029-31 (P.I.: Appelbaum, F.) 12/1/2001 - 11/30/2006

NIH/NCI

Adult Leukemia Research Center

The overall goal of this Program Project is to improve the outcome of allogeneic hematopoietic stem cell transplantation in the treatment of hematologic malignancies. Dr Martin leads the long-term follow-up core. Dr. Friedman is a co-investigator.

P01 HL 36444-25 (P.I.: Storb, R.) 8/1/2001 - 7/31/2006

NIH/NHLBI

Stem Cell Transplantation: Basic/Clinical Research

This represents an integrated program of basic and clinical research to improve allogeneic hematopoietic stem cell transplantation for the treatment of patients with nonmalignant hematologic diseases, myelodysplastic syndromes and myeloproliferative diseases. Dr. Martin leads the long-term follow-up care. Dr. Friedman is a co-investigator.

P20 CA 103728-03 (P.I.: Rabinovitch, P.) 9/30/2003 - 8/31/2008

NCI/NIA

Seattle Cancer and Aging Program

The purpose of this research planning and development grant application is to support activities of the Fred Hutchinson Cancer Research Center / University of Washington Cancer Center Consortium that will expand our capacity to engage in research that concentrates on aging and age-related aspects of human cancer. Dr. Syrjala has a project examining the behavioral and biologic mechanisms for musculoskeletal problems in long-term cancer survivors.

R01 CA 112631-01A1 (P.I.: Syrjala, K.) 6/15/2005 - 5/31/2010
NIH/NCI
Interdisciplinary Studies to Enhance Long-Term Survival

This proposal targets survivors with two of the most prevalent complications in adult long-term survivors of hematopoietic stem cell transplantation (HSCT): fatigue and depression/distress. The primary hypothesis is that survivors with one or more targeted complication who are randomized to treatment, compared with survivors randomized to active nutrition control intervention, will report fewer aggregate number of problems with fatigue, physical function, distress related to illness, uncertainty and depression at 3 and 12 month outcome assessments. Our second hypothesis is that survivors in the subset with a targeted complication who are randomized to the intervention, compared with survivors randomized to active nutrition control, will have improved outcome for that complication at 3 and 12 months. This interdisciplinary research proposal integrates medical and biobehavioral treatments in addressing the interrelated needs of long-term survivors.

SUB RSGBP-02-186-01 (P.I.: Syrjala, K.) 4/1/2005 - 6/30/2006
TUFTS
Trajectories of Health and Adaptation after Pediatric Stem Cell Transplantation

The specific aim of this proposal is to quantify changes in children's health-related quality-of-life in the first year following pediatric hematopoietic stem cell transplantation. The secondary aim of this proposal is to examine the contribution of dispositional and psychological factors such as premorbid psychopathology, mood, and coping in predicting health-related quality-of-life over time and the impact of the acute transplant experience on subsequent functioning.

R01 CA 102542-01A1 (P.I.: Friedman, D.) 9/15/2004 - 8/31/2009
NIH/NCI
Radiation Sensitivity, DNA Repair, and Second Cancers

This project will examine the effect of inherent radiation sensitivity and inherited differences in DNA repair on the risk of second malignancies following hematopoietic stem cell transplant.

R21 CA 104123-01A2 (P.I.: Friedman, D.) 9/6/2005 - 8/31/2007
NCI
Social and Physical Activity of Childhood Cancer Survivors

This is a pilot project to develop a physical and social reintegration program for survivors of childhood cancer, and examine its effect of psychosocial well-being.

R01 CA 106750-02 (P.I.: Friedman, D.) 9/21/2004 - 8/31/2008

NIH/NCI

Health Outcomes for Hodgkin Disease Survivors

Using a cohort of HD survivors treated in Children's Oncology Group, the proposed research will: 1) determine the cumulative incidence and characterize the spectrum of selected adverse physiologic and psychosocial outcomes; 2) compare the cumulative incidence and spectrum of self-reported adverse outcomes with a cohort of patients treated from 1976 to 1986, with data collected at a comparable time period since diagnosis; and 3) compare and validate self-reported health-related outcomes with those detected by clinical evaluation or medical review.

R21 CA 106960-01 (P.I.: Friedman, D.) 9/20/2004 - 8/31/2006

NIH/NCI

Exercise and Fitness in Childhood Cancer Survivors

This proposed research will outline pilot research to evaluate a physical exercise intervention to improve young childhood cancer survivors' physical fitness and involvement in physical activity. The goal of this research will be to provide vital information regarding the long-term physical sequelae of childhood cancer, and will direct interventions to mitigate these outcomes and enhance quality of life.

R01 CA 54498-10 (P.I.: Breslow, N.) 12/1/2001 - 11/30/2006

NIH/NCI

Late Effects in Wilms Tumor Survivors and Offspring (subcontract)

This is a cooperative group study (NWTSG) investigating long-term outcomes in survivors of Wilms tumor and their offspring.

U24 CA 55727-12 (P.I.: Robison, L.) 12/1/2005 - 11/30/2010

NIH/NCI

Childhood Cancer Survivor Study - Expanded Cohort (Subcontract on U Minn Application)

The major goal of this study is the investigation of late effects among childhood cancer survivors, such as mortality, secondary malignancy, cardiac and pulmonary complications, and the effect on offspring.

U10 CA 98543-03 (P.I.: Reaman, G.) 7/7/2003 - 2/28/2008

NCI/NCCF

Children's Oncology Group

The Children's Oncology Group is a national consortium of pediatricians participating in research projects addressing childhood cancers. Dr. Friedman has leadership roles in Hodgkin disease, late effect, survivorship transition, and retinoblastoma.

FND TE 4198 (P.I.: Friedman, D.) 1/1/2006 - 12/31/2010

LANCE ARMSTRONG

Survivorship Center Grant

This proposal presents the unique opportunity to create a comprehensive survivorship program, with outreach to cancer patients throughout the lifespan, treated with conventional therapy or transplantation. With the community-based centers as part of the network created by the Lance Armstrong Foundation (LAF), we will develop stronger community resources, targeting currently underserved populations. Lastly, we will be able to establish and evaluate unique models of care, which are designated to overcome some of the current barriers to optimal health services and access to research for survivors.

Cancer Research Center of Hawaii
Cancer Survivorship Activities

The Cancer Research Center of Hawaii (CRCH) has conducted numerous activities related to cancer survivorship: research conducted by Center researchers; clinical trials research and continuing education conducted by the Clinical Trials Unit (CTU); activities of the Cancer Information Service (CIS); special populations networks; and specific Center-directed initiatives. CRCH faculty have received recognition for this work.

Research Activities

The CRCH has maintained an active portfolio of extramurally-funded cancer survivorship research over the past decade, with selected grants and publications listed on the attached pages. Most of this research was conducted by researchers in the Prevention and Control Program, including Carolyn Gotay, PhD, Gertraud Maskarinec, MD, PhD, and Miles Muraoka, PhD. The Epidemiology Program also includes research projects that have been used for survivorship research. These projects include: the Hawaii Tumor Registry (a SEER registry, Marc Goodman, PI); a P01 that supports a cohort study with over 200,000 participants (Laurence Kolonel, MD, PhD, PI); and a familial colorectal cancer registry (Loic LeMarchand, MD, PhD).

CTU Activities

The CTU facilitates the conduct of cancer clinical trials in the state of Hawaii, primarily through the Hawaii Minority-Based Community Clinical Oncology Program (MB-CCOP) (Brian Issell, PI). About 150 protocols are open at any one time, most of them Phase III studies from national clinical cooperative groups. Some of these protocols deal directly with survivorship issues. CRCH researcher Carolyn Gotay chaired S9832, a study conducted through the Southwest Oncology Group (SWOG) to test an intervention to reduce distress in breast cancer survivors newly diagnosed with recurrence. The MB-CCOP includes the Children's Oncology Group (COG) as one of its research bases, and there are many protocols specific to pediatric cancer survivorship. The major medical center conducting the COG research (Kapiolani Medical Center for Women and Children) maintains a follow-up clinic specific to pediatric cancer survivors. The CTU also maintains a monthly clinical trials update meeting which provides CME credit for attendees who come from CRCH and the community at large.

CIS Activities

NCI's Cancer Information Service (CIS) Pacific Region (Brian Issell, PI) forms partnerships with community organizations and researchers in Hawaii and the Pacific to facilitate the conduct of research and dissemination of information. Among activities specific to survivorship, the CIS has developed recruitment plans for several cancer survivorship studies and cancer clinical trials. The CIS serves as a key partner in the Hawaii Prostate Cancer Coalition, a newly created statewide association of prostate cancer survivors, oncologists, and advocates with aims to increase awareness about prostate cancer across the state and to promote quality of life in men diagnosed with prostate cancer and their families. The CIS is also instrumental in disseminating NCI publications including those that focus on survivorship issues.

Special Populations Networks

CRCH faculty and staff are key personnel for two NCI-funded community cancer control networks: `Imi Hale, for Native Hawaiians, and AANCART, for Asian Americans. These networks have both undertaken specific activities (research and outreach) directed at cancer survivorship in their particular ethnic populations.

Cancer Research Center of Hawaii Activities

The CRCH sponsors a number of activities that reach cancer survivors. These include a newly-established annual "cancer research day," which provides a full day of cancer research presentations directed at the general public and participation in health fairs, local professional meetings and conferences, and other community programs.

Recognitions Dr. Gotay is recognized as a leader in cancer survivorship research. She has published widely in this area and in 2001 was named as "Professor of Survivorship" by the Susan G. Komen Foundation. She served as co-chair of the NCI Cancer Outcomes Measurement Working Group, which assessed the scientific evidence regarded outcomes measurement across the cancer diagnosis, care, and survivorship trajectory. She is currently serving as co-chair on the Health-Related Quality of Life Working Group of the Adolescent and Young Adult Oncology Progress Review Group, sponsored by NCI and the Lance Armstrong Foundation.

Selected Survivorship Research Projects

Susan G Komen Breast Cancer Foundation – Gotay (PI) 05/01/05 – 04/30/07
Quality of Life in Long-Term Multiethnic Breast Cancer Survivors

This study describes Quality of Life (QOL) in Asian and Pacific Islander and Anglo breast cancer survivors to provide an understanding of QOL challenges, survivor needs and ethnic differences in breast cancer survivorship.

R21 AT02218-01A1 Gotay (PI) 04/01/05 – 03/31/07
NIH/NCCAM
Complementary and Alternative Medicine Use in Asians and Pacific Islanders

Examines the use of complementary and alternative medicine (CAM) in cancer patients from a primarily Asian and Pacific Islander population. The overall aim is to understand predictors of CAM use and effects of CAM use in Asian and Pacific Islander minority cancer survivors.

U10 CA63844 Issell (PI) 08/01/94 – 05/31/10

NIH/NCI
Hawaii Community Clinical Oncology Program

The aim of this project is to enable Hawaii residents to participate in national cancer prevention and treatment clinical trials.

R21 CA97372-01A1 Gotay (PI) 05/01/03 – 04/30/06
NIH/NCI
A Pilot Writing Program for Multiethnic Breast Cancer Patients

This study examines the feasibility of an intervention to improve well-being in newly diagnosed cancer survivors through expressing their feelings in writing.

R01CA 61711 Gotay (PI) 09/30/93 – 09/29/97
NIH/NCI
Quality of Life Assessment in Cancer Patients in Hawaii

This study examined the psychometric properties of a commonly used quality of life questionnaire in Asians and Pacific Islander cancer patients and survivors.

N01 CN 77001 (Supplement) Goodman/Gotay) (PIs) 10/01/96 – 09/29/99
NIH/NCI
Quality of Life in Multiethnic Cancer Survivors

The aim of this project was to investigate ethnic differences in quality of life in cancer survivors.

N01-CN-67001 (Supplement) Goodman/Gotay (PIs) 09/30/97 – 06/30/01
NIH/NCI
Beating the Odds: A Study of Patients Who Exceed Expected Survival Times

The aim of this project was to investigate the impact on quality of life of having survived a fatal cancer.

N01-CN-67001 (Supplement) Goodman/ Maskarinec (PIs) 09/30/97 – 09/29/00
NIH/NCI
Ethnic Differences in Attitudes and Experiences Related to Alternative Cancer Treatment

The purpose of this study was to estimate the prevalence of and reasons for CAM use among Hawaii cancer patients.

N01 CN 77001 (Supplement) Goodman/Gotay (PIs) 07/01/99 – 06/30/03
NIH/NCI
Quality of Life in Patients Who Experience Multiple Primaries

The aim of this project was to investigate the impact on quality of life of having experienced more than one primary cancer.

R21 CA87259 Gotay (PI) 08/01/00 – 07/31/03
NIH/NCI
Exploratory Study of Treatment Decision-Making in Multiethnic Breast Cancer Patients

The aim of this study was to identify factors involved in treatment decision-making among breast cancer survivors in Hawaii.

N01 CN 77001 (Supplement) Goodman/Gotay (PIs) 09/29/00 – 07/31/03
NIH/NCI
Quality of Life in Long-Term Survivors of Cervical Cancer

The aim of this project was to investigate the long-term impact on quality of life of having survived cervical cancer.

RP 951598 Coltman/Gotay (PIs) 10/01/96 – 05/30/05
US Army Medical Research
Enhancing Well-Being During Breast Cancer Recurrence

The goal of this project was to evaluate the efficacy of an intervention to improve well-being among patients experiencing a first recurrence of breast cancer.

R01 AG 16601 Gotay (PI) 08/01/98 – 05/30/05
NIH/NIA
Well-Being in Long-Term Multiethnic Prostate Cancer Survivors

This study evaluated well-being in survivors of localized prostate cancer and their spouses 5, 8, and 11 years post-diagnosis.

R03 CA 017980 Muraoka (PI) 09/27/06 – 08/31/06
NIH/NCI
Quality of Life in Multiethnic Testicular Cancer Survivors

This study evaluates well-being in survivors of testicular cancer.

Selected Survivorship Publications

1. Gotay, CC, Muraoka, M. (1998). Quality of life in long-term survivors of cancer. *Journal of the National Cancer Institute 90*, 656-67.

2. Gotay, CC, Hara, W, Issell, BF, Maskarinec, G. (1999). Use of complementary and alternative medicine in Hawaii cancer patients. *Hawaii Medical Journal 58*,49-55.

3. Gotay, CC & Dumitriu, D. (2000). Health food store recommendations for breast cancer patients. *Archives of Family Medicine 9,* 696-8.

4. Maskarinec G, Shumay D, Kakai H, Gotay C. (2000). Ethnic differences in alternative medicine use among cancer patients. *Journal of Alternative and Complementary Medicine* 6, 531-8.

5. Maskarinec, G, Gotay, CC. Tatsumura, Y, Shumay, D, Kakai, H. (2001). Cancer causes and use of complementary and alternative medicine. *Cancer Practice 9,*183-90.

6. Gotay, CC. (2001). Quality of life research in Hawaii's cancer survivors. *Hawaii Medical Journal.60,*189-190.

7. Shumay DM, Maskarinec G, Kakai H, Gotay CC. (2001). Why some cancer patients choose complementary and alternative medicine instead of conventional treatment. *The Journal of Family Practice, 50,* 1067-1074.

8. Maskarinec G, Murphy S, Shumay DM, Kakai H. (2001). Dietary changes among cancer survivors. *European Journal of Cancer Care* (Engl).10:12-20.

9. Tasaki K, Maskarinec G, Shumay DM, Tatsumura Y, Kakai H. (2002). Communication between physicians and cancer patients about complementary and alternative medicine: exploring patients' perspectives. *Psychooncology 11*:212-20.

10. Gotay, CC, Holup, JL, Muraoka, MY. (2002). The challenges of prostate cancer: A major men's health issue. *International Journal of Men's Studies, 1,* 59-72.

11. Gotay, CC, Holup, JL, Pagano, I. (2002). Ethnic differences in quality of life among early breast and prostate cancer survivors. *Psycho-Oncology* 11:103-113.

12. Braun, K, Mokuau, N, Hunt GH, Ka`anoi, M, & Gotay, C. (2002). Native Hawaiian cancer survivors: Supports and barriers to survival. *Cancer Practice* 10:192-200.

13. Gotay, CC, Blaine, D, Haynes, SN, Holup, I, Pagano, I. (2002). Assessment of quality of life in a multicultural cancer patient population. *Psychological Assessment 14:* 439-450.

14. Shumay DM, Maskarinec G, Gotay CC, Heiby E,, Kakai H. (2002). Determinants of the degree of complementary and alternative medicine use among patients with cancer. *Journal of Alternative and Complementary Medicine* 8: 661-672.

15. Gotay, CC, Lau, AK (2002). Preferences for psychosocial interventions in newly-diagnosed cancer patients from a multiethnic population. *Journal of Psychosocial Oncology 20:* 23-38.

16. Tatsumura Y, Maskarinec G, Shumay DM, Kakai H. (2003) Religious and spiritual resources, CAM, and conventional treatment in the lives of cancer patients. *Alternative Therapies Health Medicine 9*:64-71.

17. Kakai H, Maskarinec G, Shumay DM, Tatsumura Y, Tasaki K. (2003). Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. *Social Science & Medicine 56*:851-62.

18. Efficace, F, Bottomley, A, Osoba, D, Gotay, C, Flechtner, H, D'haese, S, Zurlo, A. (2003). Beyond the development of health-related quality of life (HRQOL) measures. Does evaluation in prostate cancer research provide informed clinical decision-making? *Journal of Clinical Oncology 21:*3502-3511.

19. Gotay, CC, Isaacs, P, Pagano, I (2004). Quality of life in patients who survive a dire prognosis compared to control cancer survivors. *Psycho-Oncology 13:* 882-892.

20. Gotay, CC. (2004). Assessing quality of life in cancer across a spectrum of applications. *Journal of the National Cancer Institute Monographs No. 33:*126-133.

21. Matsunaga, DS, Gotay, CC. (2004). Characteristics contributing to an enduring prostate cancer support group in an Asian and Pacific Islander community. *Journal of Psychosocial Oncology 22:*1-30.

22. Gotay, CC, Holup, J. (2004). Ethnic identities and lifestyles in a multiethnic cancer patient population. *Pacific Health Dialog 11*:191-198.

23. Ka`opua, L, Gotay, CC, Hannum, M, Bunghanoy, G. (2005). Adaptation to long-term prostate cancer survival: The perspective of elderly API wives. *Health & Social Work 30*: 145-154.

24. Bottomley, A, Therasse, P, Pickart, M, Efficace, F, Coens, C, Gotay, C, et al., (2005). Health-related quality of life in survivors of locally advanced breast cancer: An international randomized controlled Phase III trial. *Lancet Oncology 6*: 287-94.

25. Braun,K, Fong, M, Gotay, C, Chong, C. (2005, in press). Ethnicity and breast cancer in Hawaii: Increased survival, but continued disparity. *Ethnicity & Disease.*

26. Kobayashi, K, Green, J, Shimonagayoshi, M, Kanemoto, N, Kasai. R, Yoichi, I, Fujiki, Y, Ohashi, Y, Gotay, C,, Kudoh, S. (2005). Validation of the care notebook form measuring physical, mental and life well-being of patients with cancer. *Quality of Life Research 14*: 1035-1043.

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Holden Comprehensive Cancer Center University of Iowa
Survivorship Activities

Clinical Survivorship Components

Routine follow-up care is provided to cancer survivors by each of Holden's multidisciplinary oncology groups. In addition, a number of supportive care components are aimed specifically at improving outcomes in survivors.

Adult Survivors

Unless otherwise noted, all activities are funded by University of Iowa Hospitals and Clinics (UIHC).

ACS Emergency Patient Housing Fund Provides hotel rooms for cancer patients who need to remain in the area for diagnosis/treatment and cannot pay. Funded by donations to American Cancer Society.

Center for Pain Management and Regional Anesthesia Care for cancer patients with pain using pharmacological and invasive treatment methods.

Complementary and Alternative Medicine Clinic Designed specifically for cancer patients, guides the patient in selecting safe and potentially helpful therapies based on specific cancer and treatment plan.

Fertility Options The Center for Advanced Reproductive Care offers sperm banking for men and assisted reproductive technologies for women. The Gynecology department offers a menopause clinic.

Financial Counseling Counseling by Patient Financial Services is available each day, Monday-Friday.

Helen K. Rossi Volunteer Guest House An affordable and safe place for adult patients and their families to stay while patient is receiving medical treatment at Holden Comprehensive Cancer Center. Funded by UIHC Volunteer Program.

Lymphedema Therapy Complete decongestive therapy provided by Department of Rehabilitation Therapies.

Mindfulness-Based Stress Reduction Program helps people learn to use their own internal resources to change their relationship to stress or chronic conditions such as pain or illness.

Nutritional Therapy Dieticians ensure patients receive appropriate nutrition to support healing.

Occupational Therapy Promotes independent functioning and quality of life.

Palliative Care/Spiritual Support Pain/symptom management, support in dealing with emotional stress, and spiritual support.

Patient Emergency Support Fund Assistance fund designed to meet the emergency financial needs of patients.

Psychology and Psychiatry Social workers, psychologist, and psychiatrist provide behavioral and pharmacologic interventions.

Sexual Dysfunction in Men and Women Clinics offered by Urology and Gynecology.

Speech and Swallowing Therapy Comprehensive rehabilitation.

Support Groups Face-to-face support groups and computer online support group.

College of Dentistry Provide consultations on xerostomia. Funded by University of Iowa College of Dentistry.

Coming Soon**:** *American Cancer Society Hope Lodge* Funded by contributions to American Cancer Society.

Children and Parents

<u>Provided by Child Life and funded by UIHC</u>

- All inpatient rooms have sleeping accommodations for parent
- Children's Hospital Family Suite accommodations for parents with child in intensive care
- Daily child development activities
- Procedural support (blood draws, IV lines, spinal taps, bone marrow aspirations)
- Diversion activities during procedures and lengthy infusions
- Emotional support and help with adjustment to hospital setting/illness for parents and patients
- Support group for siblings
- Music therapy in small groups or one-on-one
- New Do Program: head covers for children
- Hospital Teacher: works with all children and their home school

<u>Funded by Dance Marathon of Iowa</u>

- Weekly massage for parents
- Friday morning breakfasts for parents
- Vouchers for gas, food, phone cards, and hotel rooms for parents
- Annual gift of $500.00 per family to assist with insurance co-pays

- Teenage males: cost of sperm banking covered

Funded by Project Sunshine

- Spa for parents

Funded by Nationwide Contributions:

- Ronald McDonald House for families

Research Efforts

Holden survivorship research is conducted primarily by the Cancer Epidemiology Program. The overall goal of the Cancer Epidemiology Program is to perform epidemiologic research that provides additional knowledge for educational and service-oriented activities aimed at decreasing cancer incidence and mortality, increasing survival, and improving quality of life.

A major strength of the Cancer Epidemiology Program is its extension beyond the walls of the medical center, as its primary research population is residents across the state of Iowa. This is based on the role played by the University of Iowa College of Public Health in public health across Iowa, including cancer epidemiology. Dr. Charles Lynch, program leader of the Cancer Epidemiology Program is Director of the Iowa Cancer Registry, which is part of NCI's Surveillance, Epidemiology, and End Results (SEER) Program. This resource allows researchers in the Cancer Epidemiology Program to perform outstanding population-based cancer research. Information gained from these studies can then be applied to other states and other populations.

Holden's key quality of life researcher is Susan Lutgendorf, PhD, associate professor of psychology. She has done numerous studies on biobehavioral mechanisms in cancer, the effects of behavioral medicine interventions (such as cognitive behavioral stress management, medical hypnosis, and relaxation) on immunity, adjustment to chronic illness, and complementary medicine. Among her studies:

- "Quality of life and mental health in cervical and endometrial survivors" funded by University of Iowa Department of Psychology
- "Biobehavioral-cytokine Interactions in Ovarian Cancer" R01-CA1045-25
- "Healing Touch in Advanced Cervical Cancer Patients: Immune Effects and Mechanisms" funded by National Center for Complementary and Alternative Medicine
- "Healing Touch, Immunity and Fatigue in Breast Cancer" funded by NCI, "Cancer Attributions, Distress, and Health Practices among Gynecologic Cancer Survivors" R21 CA88293 and R01CA1045-25.

The Cancer and Aging program is funded by the NCI and the National Institute on Aging**.** The purpose of the grant is to promote interdisciplinary research that brings together the interests and skills of experts in aging studies and geriatrics and applies them to the health problems of older cancer patients. The Cancer and Aging Program research program, led by Robert Wallace, MD, focuses on three thematic areas: free radical biology and aging, chemotherapy pharmacology in older patients, and effects of comorbidities on treatment outcomes. Two core facilities are being planned: a database for providing health care analytical data for original studies of comorbidity and other epidemiological investigations of older cancer patients; and an analytical laboratory for pharmacodynamic and pharmacokinetic studies.

Current Survivorship/Quality of Life Studies at Holden Comprehensive Cancer Center

Quality of Life, Employment, and Information Care Cost Analysis in Women Receiving Adjuvant Chemotherapy for Node-Negative Breast Cancer: funded by CALGB.

Healing Touch and Breast Cancer Study: A randomized trial of Healing Touch vs standard care among early stage breast cancer patients who are also receiving chemotherapy and radiation: funded by National Cancer Institute.

Influence or Coping Style and Treatment on Quality of Life for Women Being Treated for Gynecologic Cancer: funded by UIHC.

Neurobehavioral Outcomes in Childhood Acute Lymphoblastic Leukemia: funded by Children's Oncology Group.

Key Adverse Events After Childhood Cancer: funded by Children's Oncology Group.

Education and Outreach Efforts

Dr. George J. Weiner, director of the Holden Comprehensive Cancer Center, is also chair of the Iowa Consortium for Comprehensive Cancer Control (ICCCC). The ICCCC is an organization of over 100 individuals representing 50 plus organizations in Iowa. The mission of the ICCCC is to reduce cancer incidence and mortality in Iowa through collaborative efforts that provide services and programs directed toward comprehensive cancer prevention and control. The ICCCC is currently funded by a Centers for Disease Control and Prevention grant. In addition to Dr. Weiner, a number of Holden Cancer Center members and staff are active members of the ICCCC.

The University of Iowa Cancer Information Service (CIS) http://www.uihealthcare.com/depts/cancercenter/patients/cis.html is an educational outreach program of the Holden Comprehensive Cancer Center for patients, family members, friends, and health care professionals. Established in 1987, the CIS provides services to survivors from diagnosis until the end of life. Literature is provided from a variety of state and national organizations. Recommended web sites on survivorship issues are developed and maintained by the staff. The staff makes numerous community presentations and exhibits at approximately 50-60 conferences and fairs each year. The CIS coordinates the bereavement educational mailing program which includes a series of four mailings sent over a one-year period to family members of cancer patients who have died.

The CIS is an active participant in the Iowa Consortium for Comprehensive Cancer. In addition to the CIS web pages listed above, the staff developed the statewide cancer web portal (www.canceriowa.org), a project of the ICCCC. CIS staff also participates in the Patient and Family Resources implementation group, which has ongoing educational projects dealing with pain management and end of life care. The current project of this group is working to develop a template for survivors, based on the Institute of Medicine recommendations. The Holden CIS is funded by University of Iowa Hospitals and Clinics and an educational grant from Genentech, Inc.

Partnership Position A new position, Partnership Program Coordinator (PPC), has been funded by the Iowa Comprehensive Cancer Program (a CDC grantee) and NCI's Cancer Information Service. This staff member is located at Holden Cancer Center and is working with the Comprehensive Cancer Consortium and other partner organizations to address cancer health disparities on a state level, including issues dealing with survivorship. Current projects include developing a statewide network of cancer treatment facilities to address follow-up care needs and assessing current capacity to fulfill those needs. The PPC is also revising sections of the comprehensive cancer control state plan to reflect a broader understanding of survivorship, based on the new NCI definition, which will guide the Consortium's future implementation efforts. The PPC will continue to apply to outside funding sources such as the Lance Armstrong Foundation to support these projects.

Health for Your Lifetime programs Each year, a series of community educational programs are offered, with one or two of these focusing on cancer issues. Previous topics have included the latest treatments available for colon and prostate cancer. Funded by UIHC.

Cancer Survivor's Day Annual event for both inpatients and outpatients. Funded by UIHC.

Transplant Reunion Celebration Annual event for patients and families who have undergone bone marrow transplant at Holden Comprehensive Cancer Center. Funded by UIHC.

Weekly Palliative Care Conference An educational conference designed for medical students, residents, fellows, staff physicians, nurses, social workers, and other health care workers interested in palliative care. Funded by UIHC.

Annual Psychosocial Oncology Conference Offered annually, this conference is designed for social workers, nurses, PAs, and other health care workers to address psychosocial program components that facilitate patient and family coping with cancer. Funded by conference registrations and some pharmaceutical donations.

Scofield Advanced Oncology Nursing Conference Meeting is designed for nurses and other health care practitioners who address the issues and concerns of patients and families living with cancer. Funded by various pharmaceutical companies.

Networks

Cancer Care of Iowa City (CCIC) is a partnership between Mercy Hospital and University of Iowa Health Care to deliver high quality oncology services to residents of Iowa City and the surrounding communities. CCIC benefits from the expertise of both university-based and private practice physicians supported by a caring staff of oncology professionals.

Patients receive primary oncology care, including chemotherapy, in a private office setting, yet patients have access to the full range of treatment resources of both Mercy Hospital and the nationally recognized oncology programs of the Holden Comprehensive Cancer Center at the University of Iowa.

In addition to the complete services afforded at its Iowa City locations, Holden Comprehensive Cancer Center reaches out to patients and their families in the surrounding area. Holden medical oncologists hold regular clinics in the Iowa communities of Fairfield, Ft. Madison, Keosauqua, Mt. Pleasant, and Muscatine. Radiation oncologists provide regular clinics in Clinton, Iowa.

In addition to clinics, support groups for cancer patients are offered in Ft. Madison, Keokuk, Washington, and Mt. Pleasant.

Huntsman Cancer Institute

Survivorship Activities

Huntsman Cancer Institute (HCI) has a number of ongoing clinical, research, educational, and outreach programs that address the issues of survivorship.

HCI has recently created a Wellness/Survivorship Program and designated a nurse practitioner to direct program operations, identify areas in survivorship on which to focus, serve as liaison to the community, patients, and staff about survivorship issues and identify areas of future research proposals in this field. In addition to the nurse practitioner, a full-time registered dietician will be available to assist patients and their families with guidance with nutritional issues they face, not only during, but also following active cancer treatment.

To help patients improve strength and endurance, ameliorate fatigue, and improve quality of life, HCI's Fitness Program was initiated this year. Located in the Cancer Center and staffed by a physiatrist who is an associate professor in the Department of Physical Medicine and Rehabilitation, as well as a cancer exercise specialist, the program offers the following to patients during and/or after active treatment: 1) cardiopulmonary, strength, flexibility, and balance assessments; 2) individualized exercise programs focusing on the results of that assessment and the patient's personal goals; 3) monitoring of exercise programs two to three times per week; 4) nutrition counseling; 5) group weight training sessions for cancer survivors at a local community center focusing on transitioning patients to independence in managing their own wellness programs; and 6) preparation for involvement into a variety of community-based activities.

The first of these, the Huntsman Rowing Program**,** started last fall by inviting cancer survivors to learn the skill of rowing and then participate in a survivorship team, which aimed not only at improving physical and psychological well being, but also became "floating support groups." The team participated in the Great Salt Lake Regatta in October 2005. Plans are in development for an Art Therapy Program (music and graphic arts), the development of a nurse practitioner-run Survivorship Clinic, and partnering with providers of complementary therapies. A yoga program at HCI also started this year.

As the concept of survivorship includes not only the person with cancer, but his or her extended family as well, Huntsman Cancer Institute includes several Familial Cancer Registries that deal with survivorship issues.

On the research side, there are four high-risk clinics that focus on specific organs; breast (ovarian), colon, melanoma, and pancreas. Each of those clinics enrolled individuals with cancer as well as extended family members and provides education about the inherited component of cancer. For many individuals, learning about their mutation status (especially if they have a mutation) alerts them to other cancers for which they might be at risk. Research participants also provide questionnaire data and biospecimens for local, national, and international research efforts, since the High Risk Breast Cancer Clinic is part of the Cancer Family Breast Registry, and the Familial Colon Cancer

Registry is an active participant in the Collaborative Group of the Americas for Colorectal Genetic Studies. Some of the research participants at HCI have been providing periodic updates about family history and personal health status for over ten years. All Registry participants receive periodic newsletters with information relevant to the specific organ of interest. In addition, the Familial Colon Cancer Registry has produced two one-day workshops on inherited colon cancer syndromes, inviting all Registry participants, as well as the general public, which included some survivors and family members.

The Family Cancer Assessment Clinic is another survivorship resource for patients who present to HCI. It is an outpatient, fee-for-service clinic that provides genetic consultation to individuals with cancer as well as their family members. Referrals to the Family Cancer Assessment Clinic come from community physicians, appropriate patients who are reviewed in weekly tumor board meetings, and others who are self referred or referred by family members or friends who have come to the clinic.

When fully staffed, five full-time and one part-time genetic counselors are available to provide research and clinical services, as well as serve as faculty in the genetic counselor training program and participate in community outreach programs. The genetic counselors actively participate in the Utah Cancer Action Network, which has a survivorship component. Specifically, there is an Ovarian Working Group and a Breast Cancer Task Force which are involved in a variety of educational and supportive survivorship programs. Also, one of the genetic counselors is currently president of the local affiliate of the Susan G. Komen Breast Cancer Foundation, which grants funds to agencies dealing with survivorship issues as well as celebrates breast cancer survivors several times during the year at various fund-raising activities.

The Pain Medicine and Palliative Care Program at HCI is a holistic program offering a variety of pain treatments including medications, anesthetic and surgical procedures, physical therapies, psychological, cognitive, and behavioral interventions. Additionally, the palliative care aspect of the program focuses on psychological and spiritual support for patients and their families, rehabilitation, and referrals to complementary medicine practitioners in the areas of guided imagery, relaxation, acupuncture, and massage therapy. Under the direction of medical doctor, a nurse practitioner and nurse are also active care providers in the program. The program hosted the first World Hospice and Palliative Care Day activities in Salt Lake City in 2005, which was open to the public, and plans to continue these activities on an annual basis.

At Huntsman Cancer Institute and Hospital there are an array of supportive social services provided to people diagnosed with cancer and their loved ones that address the psychological, emotional, mental, and spiritual aspects to this disease as a part of the healing process. These services are provided by licensed clinical social workers who partner with the medical team to care for patients and families during and after cancer treatment. These services are provided throughout the continuum of the disease process to include life beyond cancer and after treatment. The social work staff has found that survivorship brings with it a host of issues that are often unexpected and for which they need professional guidance and support. People attempt to live life the way it was before they were diagnosed, and this rarely happens. They may have permanent body image issues due to the physical impact of the disease. They may not be able to do things that were once easy due to fatigue, pain, memory impairment, as well as a change in values and belief systems. People express fear and worry of cancer recurring, often just as the period of their treatment is completed and they have less and less contact with the medical team.

Issues of job discrimination and obtaining medical and life insurance are other social problems that may arise. These are just a few of the psychosocial concerns that our counselors help patients cope with after cancer treatment. To support people living life after cancer treatment, HCI provides individual, couples, and family therapy as well as group therapy for people who are facing life after cancer care. There are two groups which have been active for 6 years at Huntsman Cancer Hospital and Clinics which address common concerns, fears, and other issues associated with the end of cancer treatment. One group is for those who have been diagnosed with the disease and the other is a group for the loved ones of people who have cancer, survive the disease, or for loved ones grieving the loss of the person they loved.

The Department of Patient and Public Education at HCI has three programs that address the needs of cancer survivors with respect to education and outreach:

- *Huntsman Cancer Learning Center* (HCLC) is a multimedia resource center containing over 3,300 items available for checkout. Many of these items address the concerns of cancer survivors. HCLC has had over 49,000 visitors since it opened in 1999 and has 2,353 registered patrons. Staff members participated in a NCI pilot study evaluating how the *Facing Forward* series for cancer survivors was being used. Survivorship displays are also set up in the Learning Center on a rotating basis.
- *Huntsman Cancer Information Service* (HCIS) is a toll-free telephone service taking cancer-related inquiries from Utah and the rest of the nation. HCIS has had over 50,000 callers since 1997. Survivorship issues are addressed by staff members with callers.
- *Community Outreach and Prevention Education* is a community outreach program. Staff members participate on committees within the Utah Cancer Action Network that deal with survivorship issues. Staff members also create displays and activities for National Cancer Survivors Day in June.

Indiana University Cancer Center

The CompleteLife Program

The Indiana University Cancer Center's services that attend to the emotional, social, spiritual, and physical needs of adult patients are referred to as the CompleteLife program. The goal of CompleteLife is to improve the well-being of individuals with cancer, their families, and their community. Our team of experts provides comprehensive and compassionate care for the whole person that is therapeutic as well as complementary to conventional care. The services provided include activities of artistic expression, massage therapy, musical experience, oncology pharmacy consult, nutritional consult, psychological counseling, psychiatric care, social work services, and spiritual care. Table-top cancer information displays are presented monthly by the CompleteLife program about timely topics.

Riley Cancer Survivorship Program

The goal of the Riley Cancer Survivorship Program is to help young cancer patients reintegrate into normal life at home, school, and work – identifying and addressing any barriers that may interfere with this process along the way. Nutritional and complementary medicine approaches such as exercise are used to help young cancer survivors adapt to and achieve a certain level of well-being after cancer treatment.

Riley Hospital is the pediatric hospital of the Indiana University School of Medicine.

IU Cancer Center Patient Resource Center

The IU Cancer Center Patient Resource Center is a library of free cancer information resources covering the full cancer care continuum from prevention and diagnosis through recurrence and end-of-life care. Resources available to patients and families include free brochures, authoritative and reliable cancer information web sites, easy-to-understand bilingual information via a touch screen computer, and a Natural Medicines Database with information regarding common dietary supplements and possible reactions with conventional cancer therapies.

IU Cancer Resource Center at Wishard

The IU Cancer Resource Center at Wishard is a place for Wishard Health Services' patients and their families to turn for information and assistance. The center provides up-to-date cancer information in a relaxing atmosphere, featuring pamphlets with helpful facts about cancer, computers with access to the latest information, televisions with educational DVDs and videos, phone access to the American Cancer Society's hotline and National Cancer Institute's Cancer Information Services, and displays about cancer and cancer-related issues. There are also a number of resources available allowing a cancer patient to get feedback from others, including a conference room to discuss information with health care professionals, cancer support groups, educational programs and spiritual counseling through Wishard Chaplaincy. Wishard Health Services is a community health system with a special emphasis on vulnerable populations in Marion County of Indianapolis. The IU Cancer Center provides cancer care at this hospital affiliated with the IU School of Medicine.

Clarian Tobacco Control Center

The IU Cancer Center is a clinical partner of the Clarian Tobacco Control Center, a state-of-the-art program using proven approaches to help participants achieve and maintain a tobacco-free lifestyle. Of noteworthy accomplishment is the 1-year quit rate achieved by 33% of persons participating in the IU tobacco cessation program.

Look Good, Feel Better

The IU Cancer Center hosts this American Cancer Society-sponsored program four times a year. Look Good, Feel Better is a free program that teaches women in active treatment beauty tips for skin care or disguising hair loss in a fashionable way.

Community Screenings

The IU Cancer Center partners with the American Cancer Society and other community hospitals to provide free colorectal and prostate cancer screenings during the respective national awareness months.

NCI Cancer Information Service

IU Cancer Center is a NCI Cancer Information Service (CIS) site, benefiting the public by providing the latest news and developments in the prevention and understanding of cancer risk and treatment. The CIS information specialists serve physicians, health care professionals, organizations, and the public by providing both telephone and online assistance through LiveHelp.

Indiana Cancer Consortium

The Indiana Cancer Consortium (ICC) is a statewide network of public and private organizations dedicated to collaboratively reducing the cancer burden through the implementation of a state cancer control plan completed by the consortium in 2004. The organization of ICC was a major initial goal of the IU Cancer Center and now has about 65 member organizations. The plan calls for prevention, early detection, treatment, and quality of life actions for breast, cervical, colorectal, prostate, and tobacco-related cancers. Priorities are based on existing cancer data, scientific research findings, and recognition of the significance of quality data and cancer-related advocacy.

The ICC has received planning funds from the CDC and now is funded by the CDC for implementation of its state cancer control plan. IU Cancer Center members and leaders provide much of the leadership of the Consortium, including its chair and chair of the ICC steering committee.

Health Fairs

The importance of clinical trials as well as the prevention and early detection of cancer are emphasized by the IU Cancer Center as an exhibitor in numerous community health fairs held in a variety of settings, including hospitals, workplaces, churches and schools. Health fairs are staffed by oncology nurses, social workers, physicians, and patient educators. The IU Cancer Center was a sponsor and exhibitor at both the 2004 and 2005 Black Expo Summer Celebration’s Black and Minority Health Fair, which is the largest health fair in the nation and provides over 100,000 health screenings each year.

National Cancer Survivor’s Day

Celebrating Life and the Spirit of Survivorship is the IU Cancer Center’s annual celebration of National Cancer Survivor’s Day which includes a health fair about current survivorship topics of interest. The IU Cancer Center is also a participating organization in the Indianapolis community’s *Cancer Survivors Celebration.*

Hoosier Oncology Group (HOG)

The HOG is a network of community oncologists in Indiana and surrounding states that has joined IU Cancer Center physicians and nurses for the conduct of clinical trials. It was founded in 1984 and annually enrolls a few hundred patients in therapeutic clinical trials, including a few supported by extramural, peer-reviewed funding. IUCC investigators provide the majority of scientific leadership, but most patients are enrolled on trials by community physicians. To date, the HOG has not been used extensively for QOL or survivorship studies, but could do so in the future, providing a unique patient population. Further, the HOG provides an excellent network for implementation of potential survivorship programs of various types.

Jonsson Comprehensive Cancer Center at UCLA

Survivorship Activities

For the past decade, the Jonsson Comprehensive Cancer Center (JCCC) has had a CCSG funded Patients and Survivors (PS) program, led by Dr. Patricia Ganz and Dr. Lonnie Zeltzer. The PS program area has as its major goal the reduction in avoidable morbidity and mortality among patients with cancer, long-term survivors of cancer, and family members/care givers of patients with cancer. In targeting these populations for prevention and control research, the two main scientific thrusts of the program are:

1. *Quality-of-life outcomes* along the developmental phases of the life span continuum (e.g., infants, children, young adult survivors, adult cancer patients and survivors, elderly cancer patients and survivors), including late medical and psychosocial effects. Key program area investigators – Drs. Thomas Belin, Julienne Bower, Jacqueline Casillas Patricia Ganz, Gail Greendale, Michael Irwin, Clifford Ko, Mark Litwin, Sally Maliski, Rose Maly, Arash Naeim, Christopher Saigal, Linda Sarna, Annette Stanton, Margaret Stuber, May Tao, Lonnie Zeltzer.

2. *Quality of cancer care,* its measurement and evaluation. Key program area investigators – Drs. Ganz, Katherine Kahn, Ko, Litwin, Jennifer Malin, Maly, Naeim, Saigal, Tao.

Investigators at the JCCC have been doing extramurally-funded research on cancer survivorship for the past two decades. Their research has involved survivors recruited from the UCLA Tumor Registry, community hospital cancer registries, and office practices in the Los Angeles region, as well as the California Cancer Registry. Program members Dr. Mark Litwin and Dr. Rose Maly have focused on the particular needs of prostate and breast cancer survivors served by the California state programs serving indigent individuals with these diagnoses. Drs. Zeltzer and Casillas are investigators on the Childhood Cancer Survivors Study (CCSS) cohort, and they have recruited young adult survivors of childhood cancer into that cohort from several Los Angeles hospitals. Thus, a variety of local, regional, and state resources have been used to identify and recruit survivors for JCCC research studies.

This research is enriched by the fact that UCLA is located in the most populous and diverse county in the United States (9, 519,338 residents; 72% 18 years and older; 9.7% 65 years and older; 48.7% White, 9.8% Black or African American, 11.8% Asian, 0.8% American Indian or Alaska Native, 0.3% Native Hawaiian/Other Pacific Islander, 23.5% some other race, 4.9% two or more races; 44.6 % self-identified as Hispanic or Latino. Source U.S. 2000 Census).

Clinical Programs for Cancer Survivors at UCLA Medical Center

Revlon/UCLA Breast Center Follow-up Program was established by Ms. Sherry Goldman, RN, NP, in the mid-1990s as a means of providing multidisciplinary follow-up care for breast cancer survivors. Nutrition, management of post-menopausal symptoms, prevention of lymphedema, and other issues related to quality of life are emphasized. Ms. Goldman, who herself is a breast cancer survivor, clinically evaluates all women and they are also seen by a social worker from the Ted Mann Family Resource Center (see below). The weekly, half-day session provides care for 6-8 survivors.

Childhood Cancer Survivor Follow-up Program was established by Dr. Jacqueline Casillas in 2003 within the clinical program of the Department of Pediatrics, Division of Hematology/Oncology. This program follows pediatric, adolescent and young adult survivors of childhood cancer who were treated at UCLA, as well as survivors referred from community primary care providers. The program provides a comprehensive health evaluation, a psychosocial assessment, and targeted subspecialty referrals. Survivors are seen by a pediatric oncologist with expertise in late effects, a family nurse practitioner, a social worker, and a school reintegration specialist. Referrals and screening for patients experiencing late effects is based on a thorough review and summary of all previous therapies. Health education is provided based on the medical risks for late effects, including counseling on health promoting/cancer prevention behaviors, and opportunities for participation in survivorship research studies. Survivors at higher risk for possible psychological effects of childhood cancer are screened and monitored in a more targeted way. Lastly, the clinic serves as a local community resource to conduct informational and educational activities for both health care professionals and the general public regarding childhood cancer survivorship issues.

UCLA Pediatric Pain Program (http:/www.healthcare.ucla.edu/pedspain)**,** directed by Dr. Lonnie Zeltzer**,** offers state-of-the-art medical and complementary therapies to treat children suffering from acute, chronic, and debilitating pain. Many children served by the program are cancer survivors or have other complex problems that have not been helped adequately by standard medical care. The program is led by a medical doctor and a medical psychologist, reflecting the importance of the integration of mind and body. In addition, the team also integrates a variety of other healing disciplines including: acupuncture, biofeedback, hypnotherapy, yoga, art therapy, massage therapy, movement therapy, and physical therapy. The medical team develops an individualized approach for each child that involves orientation of the child and family to the mind-body therapeutic process.

Ted Mann Family Resource Center (http://cancerresources.mednet.ucla.edu/), directed by Dr. Anne Coscarelli, is part of the JCCC at UCLA and is a Center designed to help patients and their families face the challenges brought about by cancer and its treatments. The staff is experienced in the areas of oncology and mental health, with background in clinical and health psychology, clinical social work, art therapy, holistic healing, QiGong, individual, couples and family therapy, bereavement, and the psychology of women. The Center provides comprehensive psychosocial care including a variety of educational and support groups, a library of information, and a monthly lecture series called "Insights Into Cancer," which is open to the community. These services are available at no charge to patients and survivors receiving care at UCLA. Center staff also offers individual, family support, and advocacy as needed.

UCLA Center for East-West Medicine (CEWM) (http://www.cewm.med.ucla.edu/) was established in 1993 to provide health care that is safe, effective, affordable, and accessible through the integration of the best of Chinese medicine with Western medicine. Under the direction of Dr. Ka-Kit Hui, the Center has initiated professional educational programs and is developing a research program that focuses on cancer patients and survivors. To optimize patient care, clinicians at the Center individualize the course of treatment for each patient that may include trigger point injections, acupuncture, massage, herbal dietary advice as well as medication adjustment. Clinicians also discuss lifestyle changes that are essential in improving the patient's condition and overall health. Instructions in Tai-Chi and Qi-Gong exercises, stretching exercises, and acupressure may be prescribed to complement the clinical treatment.

CCC Research Activities with a Clinical Focus that Provide Services to Survivors

UCLA Family Cancer Registry (http://www.jccf.mednet.ucla.edu/registry/reg_web2/index.html), was established by Dr. Ganz in 1997 as a means of combining state-of-the-art cancer genetic counseling and testing, with cutting edge research. The Registry has two full-time genetic counselors who provide free counseling to individuals with a family history of cancer. The Registry has become a regional resource for individuals who wish genetic counseling and testing in a research setting. All participants are invited to participate in the research, which permits the collection of questionnaire data and biological specimens (blood, tissue), including annual follow-up to update family history and health status. Currently, about 700 individuals from 550 families are enrolled in the Registry. Half of the Registry participants are cancer survivors who are interested in their personal risk for second cancers, as well as gaining information for their family members. This NCI-funded shared resource provides a unique setting for the genetic counselors to maintain long-term follow-up of the Registry participants. Data and specimens collected from participants can be used in future research projects, and participants are informed about new research studies that become available.

Norman Cousins Center for Psychoneuroimmunology (http://www.npi.ucla.edu/center/cousins/) investigators have become increasingly involved in research with cancer survivors in the past 3 years since Dr. Michael Irwin became director of the Center. Since relocating to UCLA, Dr. Irwin joined the JCCC's Patients and Survivors program and has been doing collaborative work on some of the late effects of cancer in breast cancer survivors, such as sleep, cognitive dysfunction, and fatigue. He has developed a psychoneuroimmunology working group within the JCCC, which is focusing on understanding the biobehavioral mechanisms of these late effects. Important laboratory resources are available through the Cousins Centers to study immunological aspects of behavior and symptoms in cancer survivors.

JCCC Patients and Survivors Program researchers have many active studies underway that provide some clinical services to survivors as part of the research, including a study of yoga as an intervention for fatigue in breast cancer survivors, cancer prevention studies in cancer survivors, studies that do physical examinations, and neurocognitive testing for survivors. Participants in these studies are recruited through UCLA’s clinics and Tumor Registry, as well as the community at large.

Professional Education

The David Geffen School of Medicine at UCLA is currently funded to develop medical education materials on cancer survivorship for medical students via an NCI R-25 grant mechanism. Dr. Margaret Stuber, from the Patients and Survivors Program is a Co-Principal Investigator of this activity.

Kimmel Cancer Center

Survivorship Activities

The Kimmel Cancer Center at Thomas Jefferson University in Philadelphia is committed to meeting the physical, emotional, and psychosocial needs of people with cancer. We offer a number of programs to help support patients and their families through the cancer experience and beyond.

Patient Advocacy and Survivorship Committee is comprised of 19 cancer survivors who serve to advise the Kimmel Cancer Center on patient-related issues, programs, and activities. The committee meets with cancer center administrators on a quarterly basis for this purpose. Patient advocates also served on a number of subcommittees within the Cancer Center including the Clinical Cancer Research Review Committee, the Web Site Editorial Board, the Special Events Planning Committee, and the Internal Cancer Center Advisory Committee. New members are continually recruited. This committee has helped to design a number of our patient programs.

Buddy Program, established in 1999, allows newly diagnosed cancer patients to receive short-term support over the telephone from cancer survivors. Since January 2000, 150 cancer survivors were trained in communication and helping skills in preparation to be volunteers for the program. The buddies are available to be matched by diagnosis and demographic characteristics with newly diagnosed patients. From 2000 until now, 700 newly diagnosed patients (with a wide variety of cancer diagnoses) were matched with buddies through this program.

Navigating the New Normal For a young person diagnosed with cancer, the term “new normal” reflects the need for a whole new way of looking at the future. The Kimmel Cancer Center – thanks to a grant from the Lance Armstrong Foundation – started a comprehensive psychosocial support and education program to help young adult cancer survivors navigate the “new normal” that a cancer diagnosis can bring. The program is for cancer patients between the ages of 18 and 40, an age group of individuals that has different or more intense informational, emotional, and concrete needs. The program offers an experienced oncology social worker for case management and counseling with young adult survivors, a lecture series presented by experts in the field, an expanded Web site to include information targeted to young cancer survivors, and a buddy program.

Support and Educational Groups

Kimmel Cancer Center conducts a number of monthly information and support groups, among them are Facing Breast Cancer with Information and Support, Facing Cancer Before, During and After Treatment, Man to Man, Brain Tumor Support Group, and A Place for Me for children whose parent or grandparent has cancer.

Jefferson Cancer Network

Jefferson has a network of 21 member institutions, which can enroll patients to clinical trials. There have been 30 clinical trials activated in this network.

UNC Lineberger Comprehensive Cancer Center

Survivorship Programs

Research

The UNC Lineberger Comprehensive Cancer Center (LCCC) has a strong track record in survivorship research ranging from behavioral interventions to promote healthy survivorship to epidemiologic studies of factors affecting survival. Research addresses newly diagnosed survivors, long-term survivors, and survivors facing the end of life.

Behavioral Interventions

- The North Carolina Strategies to Improve Diet, Exercise, and Screening Study (NC STRIDES), directed by Marci Campbell, is an NCI-funded study to promote healthy behavior among colon cancer survivors and the general public. The study evaluates the effectiveness and cost-effectiveness of computer-tailored printed newsletters versus tailored telephone-based motivational interviewing in encouraging healthy diets, increased physical activity, and colon cancer screening. Dr. Campbell and colleagues have enhanced understanding of diet/dietary change, supplement use, and other related behaviors, as well as how behavior changes over time. Dr. Campbell has considerable experience in developing and evaluating interventions to promote dietary and other behavior change, particularly in underserved populations. She is a leader in the emerging field of dissemination research and is involved in studies examining the use of new technology. She has conducted formative research comparing face-to-face and online focus groups to determine salient issues and messages relevant to lifestyle change (diet, physical activity, screening, and advocacy) among colon cancer survivors. Online focus groups yielded valuable information in a more comfortable setting than face-to-face groups.

- Merle Mishel has evaluated telephone-based interventions for men with localized prostate cancer. Men receiving the intervention improved on measures of urinary continence and satisfaction with sexual function. Men in the treatment group also improved their cancer knowledge scores and their ability to solve problems related to their situations, and viewed their circumstances as more manageable. Dr. Mishel's research includes an RO1 funded by NINR/NCI focusing on decision-making in men newly diagnosed with localized prostate cancer. In an NCI-funded study of breast cancer survivors 5 to 9 years post-diagnosis, Dr. Mishel evaluated an intervention to help women manage uncertainty about recurrence and manage long-term treatment side effects and other symptoms. Women who received the intervention reported a more positive view of the survivorship experience, improved cancer knowledge, better communication with health care providers, and improved coping skills. Based in part on data from a pilot study, a competitive renewal has been submitted to NIH to adapt the intervention for use with younger women.

- Barbara Rimer leads Health eCommunities, a Health eTechnologies Initiative funded by the Robert Wood Johnson Foundation. In this study of online cancer survivor communities in collaboration with the Association of Cancer Online Resources

(ACOR), Dr. Rimer and colleagues are using a multimethod evaluation to assess the impact of participation on patients, survivors, and others (including caregivers) in 15 cancer-related mailing lists managed by ACOR. They are conducting a content analysis of a subset of threaded discussions from archived mailing list pages to identify a comprehensive set of themes and key outcomes. Using surveys, they are evaluating the impact on subscribers to ACOR mailing lists by following a cohort of new subscribers for four months.

- Don Baucom leads “Can Thrive,” an ongoing NCI-funded RO1 controlled trial to evaluate a couples-based cognitive counseling intervention to improve coping and quality of life for women with early-stage breast cancer. In collaboration with colleagues at Duke, he leads UNC’s participation in an NCI funded RO1 controlled trial evaluating the effect on quality of life of partner-assisted emotional disclosure for patients with advanced gastrointestinal cancer.

- Laura Linnan leads the ACS-funded NC BEAUTY and Health project working with African American beauty salons as settings for cancer prevention and control and health promotion interventions.

Epidemiologic Studies

- Marilie Gammon leads the Long Island Breast Cancer Study (LIBCSP) Follow-up Study. Funded by the NCI, the Lance Armstrong Foundation, and the Department of Defense, this study is following postmenopausal women diagnosed with primary breast cancer in 1996-1997 in New York state. In addition to investigating the influence of environmental factors on breast cancer mortality, the study will obtain information on medical treatment, including complementary and alternative medicines. Dr. Gammon, in collaboration with Dr. Ralph Coates, is also leading a follow-up of primarily pre-menopausal women diagnosed with primary breast cancer in 1990-1992 in New Jersey and in Atlanta, GA. Analyses of data from these studies have helped identify factors related to survival, including body size, physical activity, and smoking. Substantial proportions of survivor participants (GA: 25%; NJ: 12%) are African Americans. Dr. Gammon has also examined survivorship among men and women diagnosed with esophageal and gastric cancers. Predictors of survival included higher income, overweight, and female sex.

- Andrew Olshan is developing a follow-up survivorship study that will be the largest among African Americans ever conducted. The study will examine survival determinants including: comorbid conditions, socioeconomic status, access to health care, genetic and molecular markers, tobacco and alcohol use, and clinical factors. Patterns and determinants of quality of life will also be assessed. Dr. Olshan is also planning a separate longitudinal quality of life study that will identify 540 newly-diagnosed African American head and neck cancer survivors and follow them for 18 months. This proposal, which is under consideration by the Lance Armstrong Foundation, will provide needed insight on the experiences of African American head and neck cancer survivors. In addition, in non-population-based studies, Dr. Olshan collaborates with clinical colleagues on investigation of factors related to head and neck cancer survival.

- Robert Sandler is PI of the NC Colon Cancer Study (NCCCS) and the NC Colorectal Cancer Outcomes Study (CanCORS) studying outcomes of care for colon cancer survivors; as part of CanCORS Marci Campbell is studying the impact of health literacy on colon cancer treatment and survivorship.

- Jessie Satia-Abouta**,** supported by an NCI career development award, is examining changes in dietary and lifestyle factors among cancer survivors and the general public, with a special focus on minority populations. Using data from NCCCS and NC STRIDES, she found that older and female survivors were more likely to use dietary supplements. Survivors reported making significant improvements in multiple health-related behaviors. Dr Satia's focus on survivorship takes advantage of her experience in colon cancer epidemiology and disparities.

Services

Located in the North Carolina Clinical Cancer Center, the UNC Lineberger Patient/Family Resource Center provides support, resources, and programs for cancer patients, survivors, and their families. Resources include computers for online searches, as well as the more traditional books, pamphlets, and videos. Programs include massage therapists, wigs and turbans, support groups, and special events. The Center works closely with Cornucopia House, a local non-profit Center for cancer patients and survivors that offers a wide range of programs including complementary and alternative approaches.

Lombardi Comprehensive Cancer Center

Survivorship Activities

Survivorship Research

1. Using data from an NCI/AHRQ funded study of older women (RO1 HS08395), members of the Cancer Control have studied the impact of breast cancer treatment experiences on the quality of life among older breast cancer survivors.

2. Dr. Mandelblatt is presently conducting a longitudinal study of decision-making surrounding chemotherapy use and the effects of decisions on quality of life among breast cancer patients and survivors age 65 and older ("older" women). This study is unique in its use of the platform of a cooperative group (Cancer and Leukemia Group B (CALGB) to conduct health services and survivorship research (U10CA084131).

3. The CALGB study served as a platform for the successful award to Dr. Vanessa Sheppard of a minority supplement (U10CA084131-03S1) and new awards from the Komen Foundation and American Cancer Society to Dr. Sheppard to examine older African American women's experiences in obtaining breast cancer treatment. Dr. Sheppard will then follow the cohort to describe the survivorship experience of the cohort.

4. Dr. Mandelblatt is collaborating on a DOD Center of Excellence grant (PI: Neuget at Columbia; sub-contract PI: Mandelblatt) (BC043120) to examine racial differences in adherence to and outcomes from chemotherapy.

5. Dr. Davis has applied for NCI and ACS funding to examine whether symptom monitoring can improve the quality of life and medical care of prostate cancer survivors. In her preliminary work, she is examining the feasibility of using a symptom and quality of life monitoring system in routine clinical practice among prostate cancer survivors 12 - 18 months post treatment.

Dr. Davis is a cadre member of the quality of life and symptom control committees of CALGB.

6. Drs. Taylor and Davis are planning a PLCO ancillary study of quality of life among prostate cancer survivors who are 5 or more years post-diagnosis and they have been invited by the ACS to submit the study for funding. The primary goal of this study is to quantify the long-term complications (i.e., urinary, sexual, bowel, and general quality of life) of prostate cancer treatment by comparing these participants to an age-matched group of PLCO participants who have not been diagnosed and treated for prostate cancer.

7. Our program is extending work on survivorship to previously under-studied populations, including Latinos. In one small grant (UO1CA086114), Dr. Figueiredo, a

post-doctoral fellow, is working with a community advocacy group, Nueva Vida to describe the post-treatment quality of life of Latina breast cancer survivors.

8. Dr. Mandelblatt, as chair of the DC Cancer Coalition, has collaborated on the Cancer Control Plan for the District. The plan includes priorities for cancer education and outreach to survivors.

9. Lombardi, in partnership with MedStar Health operates a community-based breast center (Capital Breast Cancer Center) that navigates survivors to needed services.

10. Dr. Marshall, Associate Director for Clinical Research, directs a clinical network that conducts outreach and education for cancer survivors.

11. Lombardi provides patient education and support groups for survivors through its clinical services.

Mayo Clinic Cancer Center

Survivorship Initiatives

Mayo Clinic Cancer Center has a vibrant presence in all three of the Mayo Clinic campuses, located in Rochester, Minnesota; Jacksonville, Florida; and Scottsdale, Arizona. The Cancer Center has had a long history of commitment to education, outreach, and research to enhance the quality of life and to meet the needs of cancer patients and survivors. The following table summarizes activities and categories, and detailed descriptions follow.

Cancer Center Survivorship Activity	Research	Clinical Care	Education	Community Outreach
Patients and Survivors, CCSG Programs: GI cancer, hematologic malignancies, neuro-oncology, prostate cancer, women's cancers	X	X		
Mayo Clinic Cancer Education Program			X	
American Cancer Society partnership and Navigator programs active in Rochester, MN; Jacksonville, FL; and Scottsdale, AZ			X	X
CIS Partnership			X	X
Cancer Patient Education Network			X	X
Cancer Plan Minnesota				X
Together patient newsletter			X	X
Mayo Clinic Cancer Center classes and support groups			X	X
Advocacy and patient support networks through NCCTG and SPOREs in prostate cancer, brain tumors, pancreatic cancer, lymphoma, and breast cancer			X	X
Native American Programs: People Living with Cancer	X			
Native CIRCLE			X	X
Spirit of EAGLES			X	X
Native WEB	X		X	X
Indian Health Service collaborations	X	X	X	X
American Indian/Alaska Native Community Networks Program	X		X	X
Phoenix Indian Medical Center		X		X
Collaboration of staff from Mayo Cancer Center campuses in Rochester and in Arizona with Diné College (Navajo tribal college in Arizona and New Mexico)			X	X
Symptom Control Research	X			
Quality of Life Research	X			

Cancer Center Survivorship Activity	Research	Clinical Care	Education	Community Outreach
Cancer Prevention Studies (research that focuses on prevention of recurrence or second cancers)	X			
CAM Studies	X			
Immunogenic determinants of survival (lymphoma)	X			
Iowa Women's Health Study cohort	X			
Spiritual well being and interventions	X			
Determinants of lung cancer survival	X			
Determinants of glioma survival	X			
Education, decision making and communication	X			

Education and Outreach

The mission of the Mayo Clinic Cancer Education Program is to educate all audiences on cancer-related issues including prevention, risks, treatment, end-of-life care, and survivorship (http://www.mayoclinic.org/cancer-education-rst/programs.html). The Cancer Education Program offers educational programs, classes, and support to people diagnosed with cancer, their family members and friends, staff, and the public. Cancer Education and support activities are active at all three campuses of Mayo Clinic.

The Cancer Education Center (http://www.mayoclinic.org/cancer-education-rst/education-center.html) on the Rochester campus is one of the largest cancer resource centers in the country. It provides reliable up-to-date information on prevention, diagnosis, treatment, nutrition, clinical trials, support, caregiving, alternative and complementary therapies, and end-of-life care. The Center's collection includes books, interactive computer programs, medical journals, and the latest cancer information. Multiple satellite cancer education rooms and kiosks are located in Rochester, Jacksonville, and Scottsdale campuses where patients, survivors, and family members can browse or obtain copies of cancer-related materials.

Partnerships and affiliations with others in the cancer community work together effectively on mutual cancer-related goals. These include:

- American Cancer Society (ACS) and Mayo Clinic work together on a variety of programs in Rochester, Jacksonville, and Scottsdale. In addition to Mayo Clinic Cancer Center employees, ACS Navigators also work in the Cancer Education Center. The Navigators assist cancer patients and families with their educational resource and referral needs, regardless of where they are getting treatment. ACS Navigators help cancer patients find their way through the system and provide general assistance with Internet resources, books and periodicals, services, support groups, supplies, materials, and medical equipment.
- NCI Cancer Information Service Partnership Program (NCI-CIS Partnership Program). Coordinators collaborate with national, state, and regional organizations to

bring cancer information to minority and medically underserved audiences. Through the Partnership Program, the staff provides assistance to organizations developing programs that focus on breast and cervical cancer, clinical trials, tobacco control, and cancer awareness for special populations.

- Cancer Education Patient Education Network (CPEN) is a network of cancer patient education leaders from NCI-designated comprehensive and clinical cancer centers from across the United States and Canada. Education and program planning resources are actively shared among colleagues.
- Minnesota Comprehensive Cancer Control Plan includes members and staff from the Mayo Clinic Cancer Center working with representatives from around the state in the Cancer Plan Minnesota (http://www.cancerplanmn.org/) initiatives, which include survivorship among its goals.
- The Cancer Education Program publishes the patient newsletter "Together" (http://www.mayoclinic.org/cancer-education-rst/newsletters.html) for Mayo Clinic patients and support persons affected by a cancer diagnosis. The purpose of the newsletter is to: provide information about cancer, research, treatment, physical and psychosocial concerns, and survivorship issues; help family members learn about the needs of a person diagnosed with cancer and how to provide family support; and help patients and family members navigate Mayo Clinic and make use of resources available through the clinic for people facing cancer.
- Examples of classes and support groups offered through Mayo Clinic for cancer survivors include topics and sessions on: Nutrition During and After Cancer Treatment, Providing Spiritual Support, Look Good ... Feel Better Program, Creative Renewal, and Releasing Stress and Renewing Energy.
- The training of hematology and oncology fellows includes multiple topics each academic year that focus on physician-patient communication, physician well-being and psycho-oncology. These sessions are designed to enhance the coping and communication skills of the physician and the physician's care of the patient.
- A number of advocacy and support networks for cancer survivors and loved ones have been developed through the North Central Cancer Treatment Group, and SPOREs in prostate cancer, brain tumors, pancreatic cancer, lymphoma, and breast cancer.

Native American Initiatives

Dr. Judith Kaur directs the activities of the Native American Programs in the Cancer Center. She supervises Native American Cancer Research supported by the NCI and the Lance Armstrong Foundation, and research through People Living with Cancer. She is principal investigator of two major educational and outreach focused NCI-funded grants, Native CIRCLE and Spirit of Eagles. Native WEB (Women Enjoying the Benefit) brings Mayo trainers into the tribal and Indian Health Service clinics to train community health aides in cancer prevention and support education, and to train nurses to help women with cancer. Mayo Clinic also partners with the Indian Health Service and the American Indian/Alaska Native Community Networks Program to conduct cancer-related outreach activities.

At Mayo Clinic Arizona, Dr. Tom Fitch helps facilitate outreach and support to cancer patients at the Phoenix Indian Medical Center. Cynthia Claus is the Cancer Center's outreach coordinator in Arizona, and focuses on interfacing with the Native American community as well as the Hispanic community in Arizona.

In addition, Dr. Christi Patten shares direction with Dr. Ed Garrison of collaborative grants between Mayo Clinic Cancer Center and the Navajo tribal college (Diné College). Among planned activities of the two institutions are public colloquia on cancer, and development of a Navajo cancer dictionary (P20 CA118774).

Research

The Cancer Center has tremendous depth and experience in studying ways to improve symptoms, pain, and quality of life following treatment in cancer patients. The following table summarizes a variety of projects that have translated successfully to improve survivorship, or are currently in progress.

Investigator	Title	Description
Dr. Charles Loprinzi	Symptom Control Studies (Cancer Control Program)	• Methods of preventing or alleviating mucositis. • Treatment of cancer anorexia/cachexia. • Therapy of hormone deprivation symptoms/problems in patients where hormonal treatment is contraindicated. • Methods of improving ability to care for patients suffering from pain. • Studies aimed at finding ideal therapy with erythropoietic agents for patients with anemia. • Osteoporosis prevention in cancer survivors • Prevention/treatment of skin toxicity from cancer therapy (e.g. radiation dermatitis, capecitabine induced hand foot syndrome, and EGFR inhibitor induce rashes • Sexuality issues in cancer survivors • Fatigue • Cognition/mood troubles (e.g., cognitive dysfunction associated with chemotherapy) • Prevention/treatment of chemotherapy-induced neuropathy
	Screening Studies (Cancer Control Program)	• HemoQuant screening trial (NCCTG 84-46-51). • Mammographic patterns in Native American Women (NCCTG 96-92-52).

Investigator	Title	Description
	Cancer Prevention Studies (Cancer Control Program)	• Intergroup trial (NCCTG 89-51-51): evaluate relatively low doses of difluormethylornithine (DFMO); a promising cancer chemoprevention agent in experimental models. • Intergroup protocols: evaluate: 1) 13 cis-retinoic acid as an agent that might be able to prevent new lung cancers in patients with a history of resected stage I non-small cell lung cancer (NCCTG 91-24-52); 2) 13 cis-retinoic acid as a chemoprevention agent in patients with resected head and neck cancers (NCCTG 88-74-51); and 3) aspirin as an agent to prevent colon polyps (NCCTG 94-92-51).
	Complementary and Alternative Medicine (CAM) Studies (Cancer Control Program)	• NCCTG CAM trials: the NCCTG Cancer Control Program conducted two studies looking at hydrazine sulfate in patients with advanced cancer (NCCTG 892451 and NCCTG 894951). • Three NCCTG CAM studies involved means of trying to alleviate chemotherapy-induced mucositis: two of these trials regarded the use of oral cryotherapy (ice chips) for prevention of 5-FU induced mucositis (NCCTG 889253 and NCCTG 899258); another trial evaluated chamomile tea for prevention of mucositis (NCCTG 909256). • CAM protocol: Capsaicin (the active substance of chili peppers) cream for study of neuropathic pain (NCCTG 909254). • Three NCCTG hot flash studies have involved CAM agents: evaluate: 1) vitamin E (NCCTG 959253); 2) soy phytoestrogen product (NCCTG 969258); and 3) black cohosh in a placebo-controlled manner, as a therapy for hot flashes (N01CC). • Coumarin was evaluated in patients with post-mastectomy lymphedema (NCCTG 949255). • An aloe vera gel preparation was studied as a potential means of trying to prevent radiation-induced dermatitis (NCCTG 909255). • The NCCTG was awarded special funds to complete a trial to evaluate shark cartilage in patients with advanced cancer (NCCTG 971151).
Dr. Charles Loprinzi		Open NCI-Approved CAM Protocols: evaluate: 1) zinc sulfate as an agent to prevent radiation therapy induced dysgeusia (N01C4) with accrual expected to be met in September 2005; 2) gingko biloba as an agent to try to prevent cognitive dysfunction in patients receiving

Investigator	Title	Description
		adjuvant chemotherapy for breast cancer (N00C9); 3) valerian as an agent to help alleviate insomnia (N01C5); 4) creatine, an agent which has been favored by muscle builders, to alleviate cancer anorexia/cachexia (N02C4) and a protocol designed to look at ginseng as an agent to try to alleviate cancer-related fatigue.
Dr. Paul Limburg	Chemoprevention Trials (the Cancer Prevention Network)	Multi-center, interdisciplinary consortium funded through an NCI contract (N01-CN-25000-39) to conduct phase I and phase II clinical trials of candidate cancer preventive agents. The Cancer Prevention Network includes investigators from over 30 institutions across the United States and Canada and has capacity to conduct early phase cancer prevention trials for at least 7 target organs (including breast, colorectum, esophagus, genitourinary tract, hematologic system, hepatobiliary tract, and lung). Studies include prevention of second cancers in cancer survivors.
Dr. Jim Cerhan	Immunogenic Determinants of Non-Hodgkin Lymphoma Survival	Prognostic cohort study to identify host immunogenetic factors that predict survival after diagnosis of non-Hodgkin lymphoma. (NCI R01 CA96704)
Dr. Jim Cerhan	Immune and Pharmacogenetic Determinants of NHL Survival	SPORE project to evaluate whether genes with functional, common variant polymorphisms involved in determining host immune status, metabolism and function of specific therapeutic agents, and DNA repair are associated with overall survival from NHL. (Lymphoma SPORE Project 5: NCI P50 CA97274)
	Epidemiology of Cancer in a Cohort of Older Women	Subcontract from University of Minnesota for conduct of the Iowa Women's Health Study, a prospective cohort study of the determinants and outcomes of cancer in 41,837 Iowa women originally enrolled in 1986. (NCI R01 CA39742)
Drs. Jim Cerhan & Tom Habermann	Long-term Survivorship After Lymphoma Diagnosis	Pilot study to collect data on Mayo lymphoma patients who survived greater than 5 years after diagnosis, focusing on impacts on psychosocial function, health behaviors, and quality of life.
Mary E. Johnson	Spiritual well being and overall quality of life of women with ovarian cancer and their partners	This study has accrued 60 women with advanced ovarian cancer, their partners and 60 women in a comparison group. They are followed for 36 months. We hope to identify changes in their spiritual well being and quality of life and to compare these endpoints among groups. This will assist us in better understanding of these dynamics so that spiritual interventions can be better-timed and enhanced.

Investigator	Title	Description
Mary E. Johnson & Teri B. Pipe	The use of a spiritual intervention to enhance mood states, spiritual well being and quality of life in women with recurrent ovarian cancer	This study accrued 10 women with recurrent ovarian cancer who were receiving chemotherapy. They were taught a form of meditation called "centering prayer" and practiced it during and in between treatments. Their mood, spiritual well being and quality of life were measured before, during and after the experience. We hope to discover the usefulness of a self-administered spiritual intervention. (Funded by the Minnesota Ovarian Cancer Alliance.)
Mary E. Johnson & Teri B. Pipe	The assistive nature of religious and spiritual activities as coping resources for women with advanced ovarian cancer or early stage endometrial cancer	This study just opened and is accruing 20 participants at Mayo Clinic Rochester and Mayo Clinic Arizona. Women with advanced ovarian cancer or early stage endometrial cancer will be interviewed regarding the contribution of their faith-related activities to effective coping. We hope to begin our discovery of the value-added of faith for coping and maintenance of spiritual well being. (Funded by The Fraternal Order of Eagles.)
Julie Ponto, MS, RN	The experiences of the partners of women with ovarian cancer: A pilot study	This study accrued 30 partners who were interviewed to gather data regarding their lived experience of their loved one's ovarian cancer.
Dr. Ping Yang	Genetic Determinants of Lung Cancer Survival	This study will confirm or refute whether genotypes indicative of deficient or absent enzyme activities in the GSH system predict better short-term survival, suggesting new directions to enhance lung cancer chemotherapy by suppressing or depleting the relevant enzymes. (NCI RO1 CA84354)
	Association of Chromosome 19 Q-arm Polymorphisms with Glioma Development, Survival and Response to Therapy	This project proposes to employ two fundamental study designs to achieve three aims: a case-control study design to identify single nucleotide polymorphisms (SNPs) associated with glioma risk, and a patient cohort study design to identify SNPs associated with survival and response to therapy. (NCI Brain Tumor SPORE -Project 4)
	Health and Quality of Life of Long Term Lung Cancer Survivors	This proposed study will be focused on both descriptive epidemiology of clinical outcomes and general health and analytic epidemiology of predictors of a longer and better life of lung cancer survivors. (NCI RO1 CA 115857)
Dr. Steve Ames	Quality of Life Intervention for Biochemical Recurrence of Prostate Cancer	The primary aim of this pilot investigation is to evaluate the needs of men with biochemical recurrence of prostate cancer, develop, and pilot test the feasibility of a novel behavioral stress management intervention designed to reduce the psychological stress associated with biochemical recurrence and serial PSA monitoring. Since distress lowers an individual's QOL, such an intervention

Investigator	Title	Description
	Quality of Life of Patients with Renal Cell Carcinoma	is likely to improve multiple aspects of QOL for these individuals. (Lance Armstrong Foundation) The primary aim of this investigation is to evaluate the psychosocial needs and quality of life of individuals with localized renal cell carcinoma. A secondary aim is to explore the smoking cessation treatment needs of cigarette smokers with renal cell carcinoma. (James & Esther King Biomedical Research Program)
Dr. Lara Petersen	Psychosocial and Personality Correlates of Quality of Life in Breast Cancer Patients	The objective of this study is to examine the relationship between optimism and quality of life in women with breast cancer.
Dr. Marlene Frost	Surgical Decision-Making Intervention for Women with Hereditary Breast Cancer Changes in Ovarian Stromal Function and Associated Symptoms in Premenopausal Women Undergoing Chemotherapy for Breast Cancer	The objective of this study is to identify the issues, concerns, and difficulties experienced by women as they are making decisions about the treatment of their breast cancer and risk reduction/screening approaches for their contralateral breast. This information is critical in developing interventions aimed at facilitating the decision-making process, a proposed second step to this research. (Funded by Eagles Auxillary.) The objective of this study is to look for evidence of whether androgen levels are adversely affected as a result of adjuvant chemotherapy for breast cancer and whether low androgen levels are linked to any unwanted symptoms. (DAMD 17-03-1-0593.)
Dr. Marlene Frost & Teri B. Pipe	What Newly Diagnosed Breast Cancer Patients Say They Know and Don't Know Following Initial Consultation with the Oncology Team	The purpose of this study is to identify and describe remediable deficits in women's knowledge or understanding of their disease and treatment.
Dr. Teresa Rummans	A structured multidisciplinary intervention to improve quality of life in patients with advanced stage cancer (MC997C)	The primary aim is to examine the efficacy of a structured multidisciplinary intervention compared to standard medical care on improving the subject's QOL as measured by a Linear Analogue Self. The secondary aims of this project are to examine the effect of a structured multidisciplinary intervention on improving the subject's mood, increasing physical performance and activity level, increasing social well-being, increasing spiritual well being and improving QOL of the care giver.

Investigator	Title	Description
Dr. Matthew Clark	A Structured Multidisciplinary Intervention to Improve Quality of Life of Patients Receiving Active Oncological Treatment and their caregivers: A Randomized Trial (MC0491)	The primary aim of the study was to examine the efficacy of a structured multidisciplinary intervention compared to standard medical care on improving patient's quality of life as measured by a Linear Analogue Self-Assessment Scale. The secondary aims were to examine the effect of a structured multidisciplinary intervention on improving mood, improving physical performance and activity, social well-being, spiritual well-being, and quality of life of the caregiver.
Dr. Jeff Sloan	A Pilot Study of Assessing Social Support Among Cancer Patients Enrolled Onto Mayo Clinic Comprehensive Cancer Center Clinical Trials: A Comparison of Younger Versus Older Adults (MC9991)	This study was hypothesis generating for future studies in the level of social support in younger and older cancer patients.
Dr. Jeff Sloan	Quality of Life Assessment of Patients Participating in Phase I Clinical Trials (MC0115) Incidence of Sleep Problems in NCCTG and Mayo Oncology Patients (N0493) A Meta Analysis of QOL Differences by Race in Patients on NCCTG and Mayo Trials	This study addressed the impact of phase I trial participation on cancer patients and was a pilot study for the phase II/III N0392 ("was it worth it" protocol) which is currently in development. This currently accruing study is developed to evaluate the incidence and severity of sleep problems for NCCTG and Mayo oncology patients. This study will investigate the impact of age, race, sex, and treatment on sleep disturbance. The primary aim of this study is to determine the extent of baseline QOL differences between minority and non-minority patients on NCCTG and Mayo oncology clinical trials. Secondary aims are to investigate minority QOL differences within subsets of tumor sites, demographic differences between minorities and non-minorities on oncology clinical trials, and survival differences between minorities and non-minorities within tumor sites.
Dr. Henry Pitot	Randomized Phase III Trial of Combinations of Oxaliplatin, 5-Fluorouracil, and Irinotecan as Initial Treatment of Patients With Advanced Adenocarcinoma of the Colon and Rectum (N9741)	This phase III study provided data for the line of research linking quality of life and genetics within a sub-study.

Investigator	Title	Description
Dr. Aminah Jatoi	Parallel Phase II Trials of ZD1839 Alone or Weekly Carboplatin and Paclitaxel Followed by ZD1839 for Metastatic Non-Small Cell Lung Cancer in Patients ≥65 Years of Age (N0222)	This phase II study provided an opportunity for investigating the level of social support for elderly cancer patients. The level of social support was compared between females and males, between responders and nonresponders, and between those experiencing severe toxicity and those who do not experience severe toxicity.
Dr. Aminah Jatoi	A Phase II Study of Carboplatin and Paclitaxel in Elderly Patients with Metastatic or Recurrent Unresectable Non-Small Cell Lung Cancer (N9921)	This provided pilot data for investigating social support in elderly cancer patients which was further investigated in N0222.
	Cetuximab (C225) and Radiation in Elderly and/or Poor Performance Status Patients with Locally Advanced Non-Small Cell Lung Cancer: A Phase II Study to Evaluate Survival and Toxicity (N0422)	The psychosocial component of this study investigates whether fear of death is less severe in the oldest of old patients and whether it appears to predict survival.
Dr. Sumithra Mandrekar	A Pilot Study Assessing the Quality of Life (QOL) and the Psychosocial Needs of Newly Diagnosed Advanced Stage (IIIB or IV) or Metastatic Melanoma Patients and their Caregivers	The aims for this study are: 1) to describe the global QOL issues in advanced stage melanoma patients as well as explore the relationship between QOL data and clinical characteristics, specifically the relationship between toxicity and QOL endpoints, in both cohorts. 2) to examine and characterize the psychosocial behavioral patterns in advanced stage melanoma patients in terms of anxiety, depression and other psychosocial adaptations in both cohorts and to identify the sub populations in need of psychosocial interventions. 3) to describe the QOL and level of burden in caregivers of advanced stage melanoma patients in both cohorts.
Dr. Michelle Taylor & Dr. Matt Clark	Pre-transplant psychosocial distress as a predictor of medical outcome in patients receiving bone marrow transplantation (MC0191)	The primary aims were: 1) to examine the relationship between distress as measured by the Symptom Checklist-90-Revised (SCL-90-R) and survival at a 24 month follow-up and 2) to examine the relationship between distress as measured by the SCL-90-R and morbidity as indicated by days hospitalized over a 24 month period. Secondary aims include examining the relationship between psychological factors (including DSM-IV diagnosis, psychotropic medication use, and past psychiatric, trauma and substance abuse history) with both survival and morbidity at a 24 month follow-up.

Investigator	Title	Description
Dr. Tom Fitch		NCCTG clinical trials to be initiated at Mayo Clinic Arizona. Treatment trials initially, leading to affiliate/network research of prevention/survivorship.
Dr. Donald Northfelt; Beth Moore	Structure of a Physician Assistant (PA)-Managed Survivorship Practice within a Multidisciplinary Breast Clinic	The Survivors' Clinic is housed within the Breast Clinic at Mayo Clinic Arizona. Activities include: assessing issues pertinent to patient survivor status, including cancer screening, bone density, lipid levels, familial predisposition to breast/ovarian cancer, weight/diet issues, long-term complications of prior anti-cancer therapies, etc. This study profiles the development of a PA-managed breast cancer survivor subspecialty practice within a multidisciplinary breast center.
Dr. Wes Petersen	Disease and Treatment Knowledge Differences Between Single, Never Married Women and Married Women with a Recent Breast Cancer Diagnosis	The objective of this study is to explore differences between identify themes and thematic categories that may distinguish between single, never married, women and married women in two areas: (1) their ability to receive or acquire, remember, understand, and retrieve information during the stressful period between diagnosis and determination of their treatment course and (2) their perceptions of what they know, don't know regarding their diagnosis and treatment. (Funded by Anthony Marchionne Foundation)

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M. D. Anderson Cancer University of Texas

Survivorship Programs

M. D. Anderson at the University of Texas is an NCI-designated Comprehensive Cancer Center committed to providing research-driven cancer patient care in the broadest sense, from the time of diagnosis and throughout the lifespan of our patients. Our emphasis on assessing the needs of cancer survivors and enhancing the quality and duration of their survivorship is evidenced by the broad range of related programs, services, and funded research in this area.

To guide our efforts over the next decade, we have established a Cancer Survivorship Task Force, which is charged with the development of a comprehensive strategic plan for both the optimal delivery of related services and the implementation of research programs that will most significantly impact the lives of cancer survivors in the 21st century. Ongoing activities, new opportunities, and existing challenges are being critically evaluated to facilitate new and novel models of evidence-based health care delivery and innovations driven by our research findings.

Implicit in the development of a Task Force to analyze and plan for the future is the sense that we are on the threshold of a new era in cancer treatment, one where cancer will be managed over extended periods of time. This trend when combined with the growing success in the management of certain cancers has highlighted the inadequacy current approaches to long-term management of cancer survivorship.

Our experience in this area to date, however, has highlighted certain recurring themes. The first is the clustering of health-related issues into 3 broad areas: sequalae of their malignancy or its treatment; psychosocial issues; and concern about cancer recurrence or development of a second malignancy. It is in this context that the compilation of survivorship programs outlined below provide a useful beginning for the construction of a more comprehensive program.

The following is a brief overview of many (although far from all) of the ongoing survivorship-related programs, services, and activities in our institution.

Long-term Multidisciplinary and Disease-Oriented Adult Clinics

Several clinics provide evaluation, surveillance, and management of both disease status and treatment-related sequelae. Examples include the Life after Cancer Care (LACC) clinic, which provides evaluation of medical sequelae for survivors of any malignancy. Other long-term follow-up clinics include those for breast cancer and prostate cancer survivors; the Cancer Screening and Prevention Clinic, which provides surveillance for the early detection of cancer, including second malignancies; a Fatigue Clinic, for evaluation and treatment of cancer- or cancer treatment-related fatigue; and the General Internal Medicine (GIM) clinic, which provides comprehensive evaluation and treatment of our survivors' medical comorbidities. In particular, one program which has been developed in the GIM clinic is focused on the study of "fatigue", a common and disabling problem for cancer survivors. A novel program, in the Behavior Interventions Clinic is designed to address and remediate cognitive dysfunction in cancer survivors, and provides compensatory strategy training for common areas of difficulty (i.e., memory, attention, problem-solving, visual neglect), as well as patient and family education.

Other Clinical Services

M. D. Anderson also provides a broad array of services to our survivors, including pain management and palliative care, physical and occupational rehabilitation, and pulmonary rehabilitation to restore/enhance pulmonary function diminished by radiation, surgical resection, or damaging chemotherapies. In addition, the *Place...of Wellness* program offers complementary therapies for use with standard care to manage symptoms such as pain or nausea and to relieve stress and enhance quality of life. This clinic is open to current and former cancer patients, their family members and caregivers, regardless of where their treatment is or has been received.

Adult Research Activities

A number of research programs are well established or underway.

Life After Cancer Care (LACC) program: self-reported health information has been gathered from 11,000 cancer survivors most of whom were treated at M. D. Anderson. Descriptive analyses of the information are ongoing.

The Department of Symptom Research in the Division of Internal Medicine has a well-established program focused on understanding the pathophysiology of cancer-related symptoms and is seeking to identify pathophysiologic correlates for symptoms. Their current focus is on the role of cytokines in the genesis of fatigue and other treatment-related symptomatology

.

Other examples include studies of the association between smoking and quality of life and smoking patterns in cancer patients following diagnosis and treatment, interventions in melanoma patients and their families, studies regarding cancer survivors' quality of life, and physician – patient communication, to name a few.

Additional studies are evaluating the long-term effects of radiation, risk factors and genetic susceptibility for the development of secondary cancers in survivors, late toxicities of graft versus host disease, and job performance status of cancer survivors.

Investigators in the Division of Cancer Medicine have ongoing protocols on the psychosocial status of male breast cancer survivors, neurocognitive function of patients with hematological malignancies and testicular cancer, quality of life and health behaviors of testicular cancer, prostate cancer and anal cancer survivors.

The Section of Alternative Medicine (Divisions of Cancer Medicine and Prevention) has a robust research program focused on the examination of a broad spectrum of alternative pharmacologic agents and treatment techniques on cancer-related symptoms.

Pediatrics Services and Research

At M. D. Anderson, the Division of Pediatrics and the Children's Cancer Hospital take the approach that preparation for survival starts at the time of diagnosis and initial treatment for cancer. This has been the philosophy since the 1960s when it became clear that some children were surviving cancer. It is based on the premise that children have age specific goals and milestones in their lives that need to be achieved and not ignored just because the child has cancer. Developmental and educational achievement, social skills, and independence and dependence variables all are a part of growing up whether or not a child has cancer.

To help a pediatric cancer patient reach his or her goals and milestones, the Children's Cancer Hospital has created services that allow a child to be a child while under our care. These include child life specialists, an in-hospital school system, programs in art education and art therapy, music, exercise, vocational and educational assessment and counseling, field trips and camps that facilitate patient-to-patient support networks, outreach programs to facilitate re-entry of children and adolescents into their local schools, and group and individual therapy provided by psychologists and psychiatrists. Finally, scholarships are available to many of our patients for post high school education or vocational training.

The Division of Pediatrics' Long-Term Follow-up (LTFU) Program for Survivors is more than 40 years old. Patients who have survived childhood cancers for more than three to five years after diagnosis are routinely followed in the Long-Term Follow-up clinic on an annual basis for as long as possible. Their evaluations include:

- Disease surveillance studies for known complications of the original cancer or the treatments used and general assessment of overall well being.
- Sharing information about how other patients with similar conditions are adjusting.

LTFU patients are invited to participate in research studies investigating various aspects of survivorship. The LTFU Clinic is one of 33 clinics in the nation that support the Childhood Cancer Survivors Study (CCSS), which follows more than 14,000 survivors of childhood cancer. It continues to discover important problems and issues facing survivors and documents the incidence of complications, subsequent medical status and well being of these patients. This information is then used to modify treatment where possible to minimize these problems.

Local collaborative studies are underway with the institution's Department of Epidemiology, Baylor College of Medicine and Texas Children's Hospital to determine whether certain adverse events seen during or after treatment are related to patients with specific genotypes and therefore are predictable and potentially preventable. Another study is evaluating a unique approach to treating cardiac problems seen in cancer

Education and Outreach

M.D. Anderson faculty is integrally involved with state-wide programs through the Texas Medical Association and the Texas Cancer Council to address the health needs of cancer survivors by organizing and conducting regular educational workshops and seminars directed at family physicians and health care professionals. The M.D. Anderson Network and volunteer services also provide information and support to patients with cancer and cancer survivors. An annual conference, "Living Fully with Cancer," is targeted to cancer survivors and caregivers and has been an extremely successful program for almost 10 years.

The Tobacco Outreach and Education Program (TOEP) focuses on the education of healthcare professionals, and post-doctoral education in nicotine and tobacco dependence.

The Anderson Network is a unique cancer support group of more than 1,300 current and former patients who offer the patient-to-patient advice and encouragement. Patients are matched with a member who has had the same diagnosis and treatment, and access to a patient and caregiver telephone support line (1-800-345-6324) and weekly educational forums featuring M. D. Anderson and community experts.

It is the goal of the MDACC Survivorship Task Force to begin the process of consolidating the many faces of survivorship into a cohesive program centered around patient care. What has become clear from this brief overview is that this group of patients is unique, has a number of well-defined health issues that have been poorly addressed outside major cancer centers and suboptimally addressed within. The goal of the Task Force will be to address not only those issues identified by cancer survivors, but to also more broadly define and study health care problems that may appear decades after primary therapy and not be identified by patients as related to their cancer therapy. Most importantly, it is the consolidation of these programs into a more cohesive patient-oriented research and care pathways will better define success in this area.

Memorial Sloan-Kettering Cancer Center

Survivorship Activities

Clinical Care Programs

Sexual Health Program This program offers specialized services and individual consultations with professionals to address concerns about Sexual Health including fertility and reproductive health counseling. The "*Sexual Health Program*" offers gynecologic and psychological consultations with Social Workers or Psychiatrists in order to address sexual, hormonal, and reproductive issues; urologists specializing in male sexual dysfunction are also available for consultation. Furthermore, Patient Education Resources related to Sexuality, Fertility, and Intimacy are available. The program was established in 2003 by Drs. Michael Krychman and John Mulhall.

Clinical Genetics Service The Clinical Genetics Service offers hereditary cancer risk assessment, genetic counseling, and genetic testing by specially trained genetic counselors and physicians to people who are concerned about their personal and/or family history of cancer. This information may be helpful to family members in making medical decisions about how to manage risk for cancer. The genetic counseling session focuses on questions and concerns about a patient's risk for cancer; it aims to provide clear and clinically relevant information about genetic risk factors in an atmosphere of support and education.

Long Term Follow-up Program To meet the health care needs of childhood cancer survivors, Memorial Sloan-Kettering developed a unique, multifaceted Long-Term Follow-Up Program in 1991. Charles Sklar, a pediatrician specializing in endocrinology and the care of childhood cancer survivors, acts as director of the program. Memorial Sloan-Kettering's Long-Term Follow-Up Program is available to children and young adults who have been off treatment for approximately two years. The program offers the following services:

- Initial Consultation and Treatment Summary
- Screening and Treatment for Late Effects
- Referrals and Coordination of Health Care
- Health Education

Living Beyond Cancer Program for Adults Treated as Children This is a new program at MSKCC, directed by Dr. Kevin Oeffinger, and is targeted to individuals who had a pediatric cancer and are now age 25 or older. The Adult Survivor program was designed to meet the individualized health care needs of childhood cancer survivors.

Living Beyond Cancer Program for Adults In recognition of the needs of our growing survivor population, Memorial Sloan-Kettering has established the Cancer Survivorship Initiative, a comprehensive program of services for adults who have completed treatment for cancer and their families. In addition to the routine follow-up care for patients who have completed treatment for cancer, this program offers expanded services with an emphasis on wellness and cancer prevention including:

- Follow-up care by a nurse practitioner with expertise in survivorship issues who was a member of the patient's original treatment team
- Continuity of care from active treatment to follow-up care and continued access to the extensive expertise of the Center's oncologists
- Expanded medical and psychosocial programs for the specific care of cancer survivors

Psychosocial screening is performed at each visit including:

- Assessment of needs, recognizing the interaction between physical and emotional well-being
- Referral to appropriate health professionals for patients and family members as needed

Pilot clinics have been initiated for survivors of prostate cancer, lymphoma, lung cancer, and breast cancer.

BMT Program People who have undergone bone marrow transplants (BMT) continue to be assessed regularly by their medical team. The treatment team closely monitors transplant patients for signs of immune system recovery, late complications arising from the agents used in the regimen, and any recurrence of cancer. Particular attention is given to the emotional and social challenges associated with this patient population including isolation, financial difficulties, and infertility which can all lead to depression and anger.

Queens Cancer Center Program In 2002, the Health and Hospitals Corporation established QCC as a new "Cancer Center of Excellence" at Queens Hospital Center (QHC), the first such center in the expansive New York City municipal hospital system. Soon after, the director of QCC, Dr. Margaret Kemeny and the MSK Physician-in-Chief, Dr. Robert Wittes, established a partnership that has developed on several tracks.

The two centers have collaborated in the creation of a primary care clinic within the QCC. This model of care is designed to address patients' health problems and late effects of treatment, to ensure that there is continuity of care with patients' community providers during and after cancer treatment, and to better understand the special issues involved in the long-term management of diverse, low income cancer survivors. The clinic opened in August of 2005 and is grown to over 110 patients; procedures have been established to track patient needs and outcomes, in the hopes of further growth and expansion of this unique program.

Several joint programs in cancer prevention and screening have been established. In August 2004, the New York State Department of Health provided support for the implementation of "Queens Quits," a project to set up a network for tobacco cessation in primary care that will reach over 1,000 primary care providers affiliated with Queens Hospital over five years. In 2006, a major new project will be initiated with NCI support, to promote cancer screening and access to primary care through the Queens Public

Library System. QCC and MSK have also been working to develop projects in colorectal cancer screening and patient navigation.

Over the past several years, the collaboration between QCC and MSKCC has grown to multiple investigators, and to attract support from federal, state, and private sources. Partnerships including municipal safety net hospitals and academic centers have great potential to address health disparities faced by the most vulnerable segments of the community.

Support Programs

Post-Treatment Resource Program This provides a full range of educational support services to survivors and their families, to help them adjust when their medical treatment ends. The Post-Treatment Resource Program welcomes all former cancer patients and their families, including those treated outside of Memorial Sloan-Kettering Cancer Center. Established in the 1988, the program has since worked with thousands of cancer survivors and family members over the years. Services address a range of social, practical, and personal concerns including individual and family counseling; periodic lectures or workshops to provide medical updates; professionally led support groups; and practical guidance on employment and insurance issues. The program is directed by Penny Damaskos in the Department of Social Work.

Integrative Medicine Service The Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center was established in 1999 by Dr. Barrie Cassileth to complement mainstream medical care and address the emotional, social, and spiritual needs of patients and families. It is designed to enhance quality of life through healing regimens that address the body, mind, and spirit. Beneficial complementary therapies include various types of massage, acupuncture, hypnotherapy, meditation, visualization and other mind-body therapies, music therapy, and nutritional counseling, as well as classes such as yoga, t'ai chi, and chair aerobics. In addition, the Service provides unique access to otherwise unavailable information about over-the-counter products and unproven cancer treatments and their impact in the context of cancer care. The Integrative Medicine Service has become an internationally known model program, with over 1,000 patient visits each month and a roster of funded laboratory research and clinical trials.

Memorial Sloan-Kettering Counseling Center Under the auspices of the Department of Psychiatry, the Counseling Center offers individual and family counseling sessions to help cancer survivors and their families address the problems that they may encounter in adjusting to life after treatment. Among the many services available through the Counseling Center are:

- <u>Individual, Family & Group Counseling</u>

  Counseling sessions are most often structured as individual or family sessions, but the Counseling Center also sponsors some group sessions for patients or family members who might benefit from working with others in similar circumstances. Counseling

Center staff may also refer patients to other mental health specialists for longer-term counseling.

- Quitting Smoking & Improving Health Habits

The Counseling Center offers help to patients and their families who want to adopt healthy new behaviors during and after cancer treatment, such as exercising, eating healthy foods, and quitting smoking. The Smoking Cessation Program specializes in addressing the specific needs of cancer patients, cancer survivors, and their families who want to improve their health by quitting smoking. A range of individually tailored methods to help each person find alternative, healthy ways to resist the craving to smoke, and to quit smoking permanently are employed.

Physical Rehabilitation The occupational and physical therapists who staff Memorial Sloan Kettering's physical rehabilitation department have special expertise in the care of cancer patients and survivors. These therapists work closely with physiatrists and other medical staff at Memorial Sloan-Kettering to provide physical and occupational therapy, and to improve patients' sense of well-being after cancer treatment. MSK's therapists employ therapeutic exercise, neuromuscular training, patient and family education, and pulmonary rehabilitation to allow patients regain their optimal functional capacity.

Memorial Sloan-Kettering's physical and occupational therapists work closely with patients, their families, and the medical team to enhance quality of life throughout treatment, recuperation, and life after cancer. Members of Memorial Sloan Kettering's physical rehabilitation department work both with patients treated at Memorial Sloan-Kettering and those treated at other hospitals in the region. Among the Physical Rehabilitation services offered are:

- Physical Therapy

The physical therapy division is dedicated to enabling patients achieve their highest level of functional independence. Physical therapists help patients improve their quality of life by planning and administering individualized therapeutic exercise programs to restore function, diminish pain, increase endurance and strength, increase safety awareness, and incorporate patients' personal goals.

- Occupational Therapy

Members of the occupational therapy division are dedicated to helping patients regain and improve the skills essential for independent functioning. Through skilled assessment techniques and a holistic approach to care, occupational therapists help patients regain independence in their daily activities, and work with patients to improve the psychological, social, and environmental factors that may contribute to patients' quality of life.

- Rehabilitation Medicine

Rehabilitation medicine, or physiatry, is the medical discipline concerned with restoring and improving patients' function and quality of life. Physiatrists treat neuromuscular, musculoskeletal, and cardiopulmonary disorders in patients, and they assist in the treatment of a variety of other medical conditions related to cancer such as muscle or tendon injuries, spinal stenosis, neuropathies, stroke, brain injury, amputations, and chronic pain syndromes. MSK's physiatrists also provide patients with customized orthotics and prosthetics to improve their function and independence with daily activities.

Patient Education

In addition to the programs and services offered at MSKCC, many information and education resources are available for survivors. The hospital patient library has more than 12,000 books, current magazines, audiotapes and Internet access. The collection includes a special section on health and medicine, as well as a section covering Integrative Medicine topics. The MSKCC medical library has the unique policy of encouraging patient/survivor open access to the services and information. The center web site is undergoing revision and will soon have a Survivorship section that will serve as a comprehensive resource for survivors, their families and caregivers.

Research

1. Quality of Life

TITLE	PI
LONGITUDINAL ASSESSMENT OF HEALTH RELATED QUALITY OF LIFE IN MEN WITH LOCALIZED PROSTATE CANCER	PETER T SCARDINO
PILOT STUDY OF QUALITY OF LIFE ASSESSMENT OF GASTRIC CANCER PATIENTS BEFORE AND AFTER SURGICAL RESECTION	DENNIS GRAHAM
QUALITY OF LIFE OUTCOMES FOLLOWING TREATMENT FOR ESOPHAGEAL CANCER	MANJIT S BAINS
A PROSPECTIVE STUDY ASSESSING THE EMOTIONAL, SEXUAL AND QUALITY OF LIFE CONCERNS OF WOMEN UNDERGIONG RADICAL VAGINAL TRACHELECTOMY VERSUS RADICAL HYSTERECTOMY FOR TERATMENT OF EARLY STAGE CERVICAL CANCER	JEANNIE CARTER
PROSPECTIVE ASSESSMENT OF CLINICAL AND QUALITY OF LIFE OUTCOMES AFTER OPEN OR LAPAROSCOPIC RADICAL PROSTATECTOMY	JAMES ANDREW EASTHAM

QUALITY OF LIFE AMONG LONG-TERM SURVIVORS OF RESECTED GASTRIC CANCER	DANIEL G COIT
QUALITY OF LIFE IN WOMEN SURVIVING OVARIAN CANCER	MARTEE L HENSLEY
PROSPECTIVE EVALUATION OF QUALITY OF LIFE AND DEVELOPMENT OF MEASURES IN PATIENTS WITH CANCER OF THE ORAL CAVITY	DAVID W KISSANE
A PROSPECTIVE STUDY OF QUALITY OF LIFE IN PATIENTS UNDERGIONG TOTAL PELVIC EXENTERATION	DENNIS S CHI
QUALITY OF LIFE AND PAIN OUTCOMES FOLLOWING VIDEO-ASSISTED THORACIC SURGERY (VATS) LOBECTOMY VERSUS THORACOTOMY AND LOBECTOMY	BERNARD J PARK
A GLOBAL ASSESSMENT OF MEDICAL MORBIDITIES AND QUALITY OF LIFE AMONG SURVIVORS OF HODGKIN LYMPHOMA	DAVID J STRAUS
REORGANIZATION OF LANGUAGE FUNCTION IN PATIENTS WITH BRAIN TUMORS	ANDREI I HOLODNY
A STUDY OF SURVIVORSHIP SERVICE CAPACITIES AMONG HEALTH CARE AGENCIES IN NEW YORK CITY	DAVID LOUNSBURY
QUALITY OF LIFE IN LUNG CANCER SURVIVORS	JAMIE S OSTROFF
EVALUATING STUDY PARTICIPANTS PERCEPTIONS OF THE PROCESS AND IMPACT OF RECEIVING RESULTS OF N9831	DIANA E LAKE

2. Psychosocial

TITLE	PI
MEANING-CENTERED GROUP INTERVENTION FOR CANCER PATIENTS	WILLIAM S BREITBART

A SURVEY OF THE PSYCHOSOCIAL CONCERNS OF WOMEN WITH CANCER-RELATED INFERTILITY	JEANNIE CARTER
ADULT SURVIVORS OF CHILDHOOD CANCER: KNOWLEDGE AND ADJUSTMENT	CHARLES A SKLAR
DEFIBROTIDE FOR HEMATOPOIETIC STEM CELL TRANSPLANT (SCT) PATIENT WITH SEVERE HEPATIC VENO-OCCLUSIVE DISEASE (VOD): A RANDOMIZED PHASE II STUDY TO DETERMINE THE EFFECTIVE DOSE	NANCY A KERNAN
A PHASE II STUDY OF CHEMOTHERAPY AND PAMIDRONATE FOR THE TREATMENT OF NEWLY DIAGNOSED OSTEOSARCOMA	PAUL A MEYERS
HEALTH BEHAVIORS IN ADOLESCENT SURVIVORS OF CANCER OR SIMILAR ILLNESSES	JENNIFER S FORD
ASSESSING INFORMATION NEEDS FOR PATIENTS AND THEIR FAMILIES BEING SEEN AT THE RALPH LAUREN CANCER CENTER	PATRICIA AGRE
THERAPEUTIC MASSAGE VERSUS MEANING-CENTERED PSYCHOTHERAPY IN CANCER PATIENTS: A STUDY COMPARING TOUCH VERSUS NON-TOUCH INTERVENTIONS TO ENHANCE SPIRITUAL WELL-BEING	WILLIAM S BREITBART
DEVELOPMENT OF A COMPUTER ASSISTED SURVIVOR SCREENING FOR ADULT SURVIVORS OF CHILDHOOD CANCER	JENNIFER S FORD
COGNITIVE BEHAVIORAL INTERVENTION FOR BMT/SCT SURVIVORS: LOOKING FORWARD	JACK BURKHALTER
A STUDY OF SURVIVORSHIP SERVICE CAPACITIES AMONG HEALTH CARE AGENCIES IN NEW YORK CITY	DAVID LOUNSBURY
MEASURING PATIENT SATISFACTION WITH BREAST SURGERY: DEVELOPMENT AND VALIDATION OF A PATIENT-REPORTED OUTCOMES INSTRUMENT	PETER G CORDEIRO
PARTNERSHIP FOR HEALTH: A WEB-BASED SMOKING INTERVENTION FOR CANCER SURVIVORS	JENNIFER S FORD
PHYSICAL ACTIVITY AND INACTIVITY IN LUNG CANCER SURVIVORS	JAMIE S OSTROFF

3. Medical

TITLE	PI
IMPROVING THERAPEUTIC OUTCOMES IN THE TONGUE CARCINOMA PATIENT: ASSESSMENT OF ADAPTATION USING FUNCTIONAL MAGNETIC RESONANCE IMAGING AND DIFFUSION TENSOR IMAGING	DENNIS H KRAUS
ACUPUNCTURE FOR THE TREATMENT OF HOT FLASHES IN BREAST CANCER PATIENTS: A RANDOMIZED CONTROLLED TRIAL	BARRIE R CASSILETH
TOTAL ANORECTAL RECONSTRUCTION WITH THE AMERICAN MEDICAL SYSTEMS, INC. ACTICON NEOSPHINCTER PROSTHESIS AFTER ABDOMINOPERINEAL RESECTION	W DOUGLAS WONG
A PILOT STUDY OF ORAL LINEZOLID FOR TREATMENT OF BREAST AND ARM SKIN AND SKIN STRUCTURE INFECTION REQUIRING HOSPITALIZATION IN PATIENTS WITH BREAST CANCER	GIANNA ZUCCOTTI
MASSAGE FOR THE TREATMENT OF PAIN IN CANCER: A RANDOMIZED PHASE II STUDY	BARRIE R CASSILETH
A PHASE II STUDY OF CHEMOTHERAPY AND PAMIDRONATE FOR THE TREATMENT OF NEWLY DIAGNOSED OSTEOSARCOMA	PAUL A MEYERS
ADJUNCTIVE DONEPEZIL THERAPY AND GENETIC RISK FACTORS OF COGNITIVE DYSFUNCTION IN BRAIN TUMOR SURVIVORS	DENISE CORREA
DISORDERS OF GLUCOSE HOMEOSTASIS IN YOUNG ADULTS TREATED WITH TOTAL BODY IRRADIATION DURING CHILDHOOD: A PILOT STUDY	CHARLES A SKLAR
SEXUAL FUNCTIONING AFTER PRIMARY TREATMENT OF OVARIAN CANCER	MARTEE L HENSLEY
A MULTI-CENTER LONG-TERM FOLLOW-UP STUDY OF PATIENTS WITH LOW-GRADE NON-HODGKIN'S LYMPHOMA PREVIOUSLY TREATED WITH TOSITUMOMAB AND/OR IODINE I 131 TOSITUMOMAB IN STUDIES RIT-I-000, RIT-II-001, RIT-II-002, RIT-II-004, OR CP-97-012 (CC-51)	ANDREW D ZELENETZ

RADDOMIZED PROSPECTIVE STUDY COMPARING PROPHYLACTIC SILDENAFIL CITRATE USAGE ADMINISTERED DURING AND AFTER RADIOTHEARAPY FOR THE PRESERVATION OF ERECTILE FUNCTION VERSUS RADIOTHERAPY ALONE FOR PATIENTS WITH CLINICALLY LOCALIZED PROSTATE CANCER	MICHAEL J ZELEFSKY
A RANDOMIZED, DOUBLE-BLIND, PLACEBO-CONTROLLED STUDY TO ASSESS THE SAFETY AND EFFICACY OF PROGRAF (TACROLIMUS, FK 506) FOR THE PREVENTION OF ERECTILE DYSFUNCTION FOLLOWING BILATERAL NERVE-SPARING RADICAL PROSTATECTOMY	JOHN P MULHALL
A PILOT STUDY OF BONE MINERAL DENSITY (BMD) IN POSTMENOPAUSAL WOMEN AFTER TREATMENT FOR BREAST CANCER	CATHERINE VAN POZNAK
IMPROVING FUNCTIONAL OUTCOMES IN PATIENTS WITH UNILATERAL VOCAL CORD PARALYSIS: ASSESSMENT OF ADAPTATION USING FUNCTIONAL MAGNETIC RESONANCE IMAGING	DENNIS H KRAUS
REORGANIZATION OF LANGUAGE FUNCTION IN PATIENTS WITH BRAIN TUMORS	ANDREI I HOLODNY
FUNCTIONAL VOICE AND SPEECH OUTCOMES FOLLOWING SURGICAL VOICE RESTORATIONS: A COMPARISON OF PHARYNGEAL RECONSTRUCTION APPROACHES	DENNIS H KRAUS
ASSESSING LYMPHEDEMA AFTER AXILLARY SURGERY FOR BREAST CANCER	KIMBERLY VAN ZEE

4. Epidemiology

TITLE	PI
KEY ADVERSE EVENTS AFTER CHILDHOOD CANCER ALTE03N1 (COG)	CHARLES A SKLAR
PATTERNS OF COLORECTAL CANCER TREATMENT: A NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) COLLABORATIVE STUDY	MARTIN R WEISER

Moffitt Cancer Center

Current Survivorship Activities

Moffitt's existing activities that are aimed specifically at cancer survivors include clinical, research, educational, and outreach efforts. Research efforts are conducted primarily by members of the Center's Health Outcomes and Behavior Research Program, which is part of the Division of Cancer Prevention and Control. The Program Leader of this research program is Paul Jacobsen, Ph.D., a senior investigator who has published extensively on quality of life issues in cancer survivors. Past research accomplishments of Center investigators include studies that have led to a greater understanding of the common mental and physical problems experienced by survivors. Center members have also developed interventions that are effective in reducing morbidity and improving the quality of life in survivors. A list of recent publications on cancer survivorship by Center members documenting these and other accomplishments appears below.

Examples of current research efforts in cancer survivorship at Moffitt include funded peer-reviewed studies of: the course and determinants of fatigue in breast cancer survivors (NCI 2R01CA82822; P. Jacobsen, PI); the course and characteristics of cognitive problems in blood and marrow transplant survivors (ACS RSG-01-070-PBP; M. Booth-Jones, PI); the benefits of Mindfulness Based Stress Reduction for breast cancer survivors (NCI R21CA109168; C. Lengacher, PI); the prevalence and characteristics of cognitive problems in prostate cancer survivors treated with LHRH agonists (NCI P20CA103676; P. Jacobsen, PI); the benefits of resistance exercise training for prostate cancer survivors (NCI P20CA103676; R. Wilson, PI); the characteristics and determinants of problems in sexual functioning among cervical cancer survivors (ACS IRG9303210; K. Donovan, PI); and oncologist's perceptions of barriers to fertility preservation in cancer patients (G. Quinn, PI; ACS IRG9303210).

In addition to the routine follow-up care provided to cancer survivors by each of Moffitt's multidisciplinary disease-oriented clinical programs, there are several clinical efforts aimed specifically at improving health outcomes in survivors. These efforts are conducted primarily by members of the Center's Psychosocial and Palliative Care Clinical Program, also directed by Dr. Jacobsen. The mission of this multidisciplinary program, which has been in existence since Moffitt opened, is to improve the quality of life of both patients and their family members. The disciplines represented in the program include neurology, palliative care, clinical psychology, psychiatry, social work, rehabilitation medicine, and integrative medicine.

Clinical services provided at Moffitt to survivors are comprehensive and include: pharmacological, invasive, and behavioral services to address physical symptoms (e.g., pain and fatigue); pharmacological and behavioral services to address problems in functioning (including cognitive and sexual functioning); pharmacologic and nonpharmacological services to address mental symptoms and psychosocial concerns (including support groups for patients, family caregivers, and children of patients); therapy for speech and swallowing problems; therapy for lymphedema; and therapy for occupational and mobility problems. In addition, Moffitt provides survivors with access to nutritional counseling aimed at evaluating and modifying dietary intake, pharmaceutical counseling aimed at evaluating use of nutraceuticals and dietary supplements, and yoga classes and therapeutic massage aimed at improving overall well-being.

Educational and outreach efforts are the third component of programs geared to cancer survivors. Moffitt maintains a Patient Education and Resource Center that provides cancer survivors with materials prepared locally and by national organizations that address survivorship issues as well as advice on and direction to websites providing high quality information for cancer survivors. Moffitt also operates an Outreach Program that focuses specifically on outreach to medically underserved populations. Recent accomplishments relevant to cancer survivorship include a weekend retreat for Hispanic/Latina breast cancer survivors that attracted women from throughout Central Florida, and the establishment of a support group for young Hispanic/Latina breast cancer survivors that is open to all community members. These outreach efforts will be further enhanced by the recent award to Moffitt of a grant from NCI to establish the Tampa Bay Community Cancer Network (U01 CA11462701; C. Meade, PI). This award provides funding for a model program aimed at reducing cancer-related health disparities.

Moffitt Affiliate Network

The 19 institutional members of the Moffitt Affiliate Network are all community-based providers of cancer treatment services. Collectively, they and the Center are estimated to provide care to upwards of 25% of all Floridians diagnosed with cancer. Thus, the Center's relationship with its affiliates provides an important opportunity for Moffitt to meets its mission of reducing the burden of cancer for all Floridians. Activities currently being conducted through the affiliate network include clinical trials and observational research, continuing education activities (in person and via teleconferencing), joint tumor boards, and professional consultation on individual cases. There is considerable interest at the Center in expanding its relationship with the affiliates to include efforts geared specifically toward improving the lives of cancer survivors.

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Norris Cotton Cancer Center

Survivorship Activities

Community Outreach and Education

Cancer Help Line (1-800-649-6918) is a toll-free service to provide information to callers about a broad range of issues related to cancer treatment, prevention, second opinions, screening, detection, and new treatment information. In addition, the operator can assist family caregivers and survivors with information on appropriate support groups, cancer education, patient resources, and supportive local and regional community events.

Cancer Support and Information Groups Led by experienced facilitators, these groups exist to support survivors of breast cancer, ovarian cancer, head and neck cancer, brain tumor, prostate cancer, women's cancers, pancreatic, and biliary cancer.

Patient and Family Libraries are located in the Medical Hematology/Oncology Out-patient, Radiation Oncology, and In-Patient areas of the Cancer Center. These libraries provide reliable and understandable information about cancer. Reading and audiovisual materials can be borrowed to use at home. Computers are linked to the Internet, and information can be printed immediately and taken home.

The Women's Health Resource Center supports women in making informed, efficient decisions about health care. It offers books, videos and audio tapes, and interactive programs on decisions about breast cancer, and publishes a quarterly newsletter. The WHRC coordinates public health programs and events for women with cancer.

Community Information and Education

- Cancer Survivors Day Celebration annually includes lectures related to patient support, research directions, and quality of life.
- Community-Based Conferences: Women's Cancer, Prostate Cancer, Melanoma, Patient-Centered Care
- Community Lectures – e.g., Fertility and Cancer; The Impact of Cancer on Family Relationships; Screening, Diagnosis and Treatment; Transforming Cancer Care: Patients at the Center of Science and Service

Charting Your Course This web site < http://www.growthhouse.org/dartmouth/> presents a self-paced, online version of Charting Your Course, a holistic approach to living with cancer. The Charting Your Course program is a series of four seminars, meant to help patients learn how to navigate the cancer treatment process. Charting Your Course is intended for people recently diagnosed with cancer, their family members, and friends. The seminars address such topics as:

- Symptom Management
- Sense of Personal Control

- Identification of Support Networks
- Financial Issues
- Spiritual Issues
- Decision Making & Planning
- Communication with Health Care Providers
- Stages of Grief
- Listening Skills
- Impact of Illness on Family & Friends

Programmatic Development at the State Level Dr. Lynn Butterly co-chairs the New Hampshire Comprehensive Cancer Collaboration to develop the New Hampshire State Cancer Plan, which includes detailed priorities for Survivorship and Palliation and Patient-Centered Care. Yvonne Corbeil of the Section of Palliative Medicine serves as Co-Chair of the New Hampshire Comprehensive Cancer Collaboration's Palliation Workgroup. Dr. Ira Byock and Paula Caron, ARNP, serve on the Steering Committee of the New Hampshire Pain Initiative, a committee of the New Hampshire Hospice and Palliative Care Organization.

American Cancer Society Norris Cotton Cancer Center hosts several ACS programs of support to people living with cancer: the "Man to Man Prostate Support Group"; "I Can Cope" programs to help survivors and their families increase their knowledge of cancer, positive attitudes, and skills in a supportive environment; "Look Good. . .Feel Better" programs to help patients enhance appearance and self-image during treatment; and "Reach to Recovery" to provide peer support to breast cancer survivors. ACS also offers drivers and help with travel to Norris Cotton Cancer Center treatment facilities through "Road to Recovery." Information about cancer developed by ACS is available to survivors through the Cancer Center's libraries and social services consultations.

Survivorship Research

The NCCC conducts research in cancer prevention and risk reduction, screening and early detection, quality of life and quality of care.

Cancer Prevention and Risk Reduction

Chemoprevention Research Dr. John Baron and colleagues have demonstrated that supplemental calcium and cyclooxygenase inhibition with aspirin can suppress colonic polyp formation and thereby lead to the reduction of colon cancer. They are currently investigating the role of vitamin D signaling in this chemoprevention model. Dr. Michael Sporn and colleagues have continued to advance their seminal work on the synthesis and pre-clinical and animal model testing of novel chemopreventive agents (such as the triterpenoids and their derivatives). These studies have shown anti-neoplastic activity of these agents in leukemic as well as in non-hematopoietic models. Collaborative work with Dr. Ethan Dmitrovsky shows promise for applications in lung and breast cancer.

SunSafe is the name of several National Cancer Institute sponsored projects based at Dartmouth, led by Dr. Ardis Olson and others. The projects develop and evaluate the impact of school, recreation area, and primary care educational materials that promote sun protection.

Tobacco Control Dr. James Sargent and colleagues have established a link between youth smoking and exposure to smoking in movies, and have determined that smoking behavior in movies is associated with adolescent smoking behavior, which is further influenced by the effects of favorite star status. They further determined that restrictions enforced by parents on R-rated movie viewing is associated with reduction in tobacco and alcohol use.

Cervical Cancer Prevention Dr. Diane Harper and colleagues have shown extremely promising results for a vaccine against the most common causes of cervical cancer. The vaccine is targeted to immunize against two types of high risk Human Papillomavirus (HPV-16 and HPV-18) that cause an estimated 70 percent of cervical cancer cases. The vaccine has the potential to greatly reduce deaths from cervical cancer, one of the leading causes of cancer mortality among women worldwide.

The Familial Cancer Program offers comprehensive cancer genetics services, including family history analysis, risk assessment, screening and prevention recommendations, genetic counseling, and genetic testing. The program helps patients understand their risks of cancer, and recommend appropriate screening measures. For some people, genetic tests are recommended to help determine inherited tendencies to develop cancer.

Screening and Early Detection

Breast Imaging Dr. Keith Paulsen and colleagues are working to develop alternative imaging techniques to improve beast cancer early detection and diagnosis. Four innovative breast imaging modalities are being developed and tested: infrared lasers, microwave technologies, electrical impedance technologies, and magnetic resonance imaging.

The New Hampshire Mammography Network, led by Dr. Patricia Carney, efficiently obtains demographic, risk factor, and radiologic data on approximately 90% of women having mammography in New Hampshire, and then links mammographic encounter information to breast pathology outcomes. The objectives are to assess the accuracy of mammography by comparing interpretive results with pathology and tumor-registry reports and to improve mammographic performance by reporting findings to facilities, radiologists, and pathologists statewide.

The National Lung Screening Trial (NLST) Norris Cotton Cancer Center is the primary screening site for Northern New England for the National Lung Screening Trial (NLST). The trial is designed to determine if screening people with either spiral computerized tomography or chest X-ray, prior to evidence of symptoms, can improve early detection and reduce deaths from lung cancer. Dartmouth's William Black, M.D., is one of five co-chairs in the national study and was involved in developing the protocols for the massive trial, expected to accrue 50,000 current and former smokers.

Interdisciplinary Prostate Cancer Risk Clinic Men with elevated PSA levels or prostate nodules can be referred to this clinic for consultation and additional testing, including an ultrasound-guided biopsy if necessary.

Primary Care Colon Cancer Screening Consortium A long-term effort to enhance knowledge and quality of colon cancer screening in primary care with an emphasis on addressing health care disparities in colon cancer screening.

Quality of Life/Quality of Care

Psycho-Oncology Psycho-Oncology research at Dartmouth focuses on Management of pain and symptoms secondary to cancer and cancer treatment; development and evaluation of interactive, multimedia programs designed to educate providers of patient care; improving end-of-life care; the impact of cancer and cancer treatments on quality of life; and the cognitive impact of systematic chemotherapy. Research findings:

- Dr. Tim Ahles has determined that Standard Dose Chemotherapy is associated with subtle deficits in memory, concentration, and the ability to remain focused or organized, which affect quality of life in general and especially influence career and educational goals of patients. His research continues to refine our understanding of these effects.
- Dr. Andrew Saykin is evaluating breast cancer patients with neuropsychological testing and structural and functional MRI at pretreatment, and 1 and 12 months post-treatment (NCI RO1 CA101318). Both studies seek to determine the role of APOE as a genetic marker of increased risk of cognitive side effects of chemotherapy.
- Dr. Robert Ferguson conducts research to assess a cognitive rehabilitation intervention for breast cancer survivors who continue to have cognitive problems following chemotherapy
- Dr. Raine Riggs is examining the relationship between sleep architecture, as measured by polysomnography, and cognitive functioning in breast cancer survivors.
- Dr. Ahles conducts palliative care research (NCI RO1 CA101704) designed to improve end-of-life care in patients with late-stage lung, GI, GU, and breast cancers.
- Marie Bakitas, ARNP, is completing a study of neuropathic pain in patients receiving chemotherapy.
- Dr. Ira Byock and colleagues are engaged in an NIH-supported project to build a user-friendly system to acquire, analyze and feed-forward patient-generated health status information to oncology clinicians at the time of clinic visits. They also Dr. are conducting a survey study of regional hospice program practices with regard to “comfort packs” for urgent management at home of symptoms such as pain, seizures, and agitation.
- Dr. Dale Collins is investigating new ways to incorporate decision support into routine care of women with breast cancer.

Clinical Care/Supportive Services for Cancer Survivors

Clinical care is provided to cancer patients through 11 multispecialty clinical oncology groups, which address the needs of the whole patient through an individualized approach to care across the journey that begins with diagnosis. In addition to the surgical, radiation, and medical oncology modalities of care, clinical care services can include nutrition consultation, lymphedema management, psycho-social support, surgical reconstruction, and a variety of supportive services:

Multidisciplinary Second Opinions Norris Cotton Cancer Center is committed to providing second opinions as requested and working closely with referring physicians to ensure that each patient receives the best possible medical advice. Second opinions are provided by individual specialists, or by multidisciplinary clinical oncology groups expert in diagnosing and treating specific kinds of cancer. Second opinions on pathology reports are also available.

The Palliative Care Program addresses the needs of patients and their families as they "live with, through, and beyond" cancer. Palliative care brings a specialized team approach to the goals of comfort and quality of life for people living with cancer along with support for their families. In addition to pain and symptom management, palliative care clinicians can help clarify goals of care and assist patients and families adapt to changes in function, outlook, and priorities that advancing illness can bring. Palliative care addresses not only physical needs, but also the spiritual, emotional, and social aspects of life for patients and their families. The team contributes to development of post-hospital and home care plans and works closely with regional home health agencies, hospice programs, and skilled nursing and rehabilitation facilities to provide for smooth transitions of care.

The Haelan Program of Complementary Therapies seeks to improve the well-being and comfort level of individuals going through cancer treatment. The core services offered by the Haelan Program are massage, reiki, relaxation stress management classes, and gentle Yoga classes. By caring for the whole patient, Haelan practitioners strive to support each patient through a life-altering experience and speed the healing process. Art and music therapy offerings are offered to both inpatients and outpatients.

Peer Mentorship The BeFriend Program offers breast cancer patients insight and advice from other breast cancer survivors. Volunteers are trained to know when a question needs to be addressed by a physician rather than a peer, and they offer the experience and perspective of someone who has dealt with a particular decision or situation.

Programs for Pediatric Cancer Survivors Recognizing that cancer treatment has potential to cause significant physical and cognitive effects in children, Pediatric Oncology provides several programs to address their needs: school integration for the chronically ill child; the STAR Program (Steps Toward Adolescent Responsibility) for teenagers with chronic physical health conditions; and the Late Effects Clinic.

The Center for Shared Decision Making at Dartmouth-Hitchcock Medical Center offers a broad range of decision aids to help cancer patients understand the likely outcomes of the options they face, by presenting a balanced picture of the available evidence. It also helps patients think about their values as they related to the risks and benefits of each option.

Chaplaincy Services Chaplains at Dartmouth-Hitchcock Medical Center provide an interfaith ministry with the goal of helping each individual make the best possible use of their own spiritual beliefs. A chaplaincy program specific to cancer patients is under development.

Rehabilitation Patient-care rehabilitative services following cancer treatment include physical therapy after mastectomy; management of lymphedema with complex decongestion therapy; rehabilitative programs for survivors of head and neck cancer to help with swallowing and speech; pulmonary rehabilitation for lung cancer survivors; and other programs to meet the needs of cancer survivors.

Case Management and Financial Planning Consultation In the Office of Care Management, social workers who specialize in cancer care can provide assistance and information about financial and legal assistance, advance directives, support groups, transportation, and other resources. Short-term counseling for patients and families is offered.

University of Pittsburgh Cancer Center and UPMC Cancer Centers

Selected Examples of Survivorship Activities
Ronald B. Herberman, MD, Director

Us TOO® Prostate Cancer Education and Support Network

For the past decade, UPMC Cancer Centers has sponsored a chapter of Us TOO for men diagnosed with prostate cancer and their families. Monthly meetings feature a guest speaker, who is an expert in some area of prostate cancer, for the first hour. After a short break, there is an hour long support/discussion group session led by an oncology social worker. In addition, UPMC Cancer Centers developed an Us TOO Peer Counseling Program. Us TOO volunteers (currently 10 survivors and 2 spouses) are specially trained to talk one-on-one with newly diagnosed men and/or their family members about the peer counselor's experience with a particular treatment modality, and provide resource information as well as social support. These services are offered at no charge to the patient/family.

A Reason to Hope

UPMC Cancer Centers offers a monthly, evening lecture series, *A Reason to Hope*, for survivors and the community. Topics are selected based on national cancer awareness months and also feature the importance of participating in clinical trials. This service is available at no charge to participants.

African American Cancer Program (AACP)

African American Self-Help Cancer Group (AASHCG) Another activity of the AACP is the establishment of self-help groups that serve the needs of cancer patients and survivors. The present self-help group was established in 1994. The first official meeting of this group was held January, l995. There are 136 group members on file. The African American Cancer Self-Help Group continues to meet the third Saturday of each month from 11:00AM – 1:00PM at the Hillman Cancer Center in Shadyside. The purpose of the group is to provide support and information to African American cancer survivors and their friends and families. The group initially focused on women's survivor issues, but now includes both men and women.

The Celebration of Life Dinner The University of Pittsburgh Cancer Institute/UPMC Cancer Centers has implemented a yearly "Celebration of Life Dinner" for African Americans who are surviving cancer. Its purpose is to increase awareness and encourage early detection within the community. The 14th Annual Celebration of Life dinner was held on Sunday, April 23, 2006.

Komen Race for the Cure Sponsored by the Susan G. Komen Breast Cancer Foundation:

UPCI / UPMC Cancer Centers Volunteer & Community Services coordinated RACE registration for employees in Oakland and at the Hillman Cancer Center in Shadyside who were interested in joining the UPMC Health System team. The registration process, which began in March, included distributing registration forms to various locations, collecting the registration forms and payments, and ordering UPMC t-shirts for team members. On the event day, a representative from the Volunteer & Community Services program attended the event and handed out giveaways and cancer-related information to participants. All activities were coordinated with UPMC Shadyside and Magee-Womens Hospital, who were also part of the sponsorship. More than 120 employees registered through UPCI / UPMC Cancer Centers Volunteer & Community Services for the 2005 event which took place on Mother's Day, Sunday, May 8.

American Cancer Society's Quality of Life Committee

UPMC Cancer Centers/ UPCI is represented on the American Cancer Society's Quality of Life Committee. This committee is comprised of survivors and representatives from all of the health systems and hospitals in western Pennsylvania, and nearby neighboring areas of West Virginia and Ohio. The committee is dedicated to having equal representation and support to provide quality patient services to the tri-state area. They meet once a month throughout the year, and each representative is responsible for encouraging the growth and success of the ACS' 'Look Good Feel Better' classes, 'Reach to Recovery', 'Man to Man', 'Road to Recovery', and 'Relay for Life.' In addition, this committee plans, develops, and coordinates the annual 'Cancer Survivor's Conference.'

2005 ACS Survivor's Conference The 2005 Survivor's Conference took place on the afternoon of August 7th in the Great Hall at Heinz Field. There were 363 people in total attendance, of which 291 were survivors. The two main cancers that were featured were prostate and breast. Mr. Bill Cardille was the emcee. Dr. Joel Nelson, chairman of the Department of Urology at the University of Pittsburgh's School of Medicine was the first speaker, followed by Dr. Karlovitz from the West Penn Allegheny Cancer Institute who spoke on the role of a cancer caregiver. The last speaker was Dr. Adam Brufsky, the Co-Director of the Women's Cancer Center at Magee Women's Hospital. Dr. Nelson and Dr. Brufsky, both of UPMC, were the highlights of the day. Both talks were followed by questions from the audience. In addition to the speakers, there were Community Resource tables: A clinical trial table, one from Pfizer who contributed gifts, the Latino Health Advocacy Leadership Program, the United Ostomy Assoc., the Komen Foundation, the Burger King Cancer Caring Center, Us Too, the National Ovarian Cancer Coalition, and Gilda's Club.

Look Good Feel Better Classes A total of 37 patients attended the LGFB classes held at the Hillman Cancer Center in 2005. Classes are scheduled bimonthly on a Monday from 10:00 am - 12:00 pm. Marina Posvar coordinates the classes.

Hillman Cancer Center Gumberg Library

The Library is a resource center for information as well as an informal support area for patients and families. It is staffed by an oncology nurse and oncology social worker. Multiple "Drop In and Learn" classes are held weekly. All the major pamphlets and books from the American cancer Society, Leukemia/Lymphoma Society, National Cancer Institute, as well as other organizations are available. There is also a collection of books on various cancer sites, treatments, and psychosocial concerns.

Additional Survivorship Information

Faculty in the Cancer Genetics Program lecture in the community.

The following support groups and educational opportunities are offered to help individuals diagnosed with cancer cope with the diagnosis, as well as to live their life as a cancer survivor.

- Lung Cancer Support Group
- Leukemia /Lymphoma Support Group
- Adult Oncology Support Group
- African American Self Help Group
- Breast Cancer Support Group and Peer Support Program (Magee)
- Breast Cancer Survivor Group (Magee)
- Ovarian Cancer support and Peer Support Program (Magee)
- Family Support and Caregiver Information and Support Program
- Drop in Classes :
    - Ask the Nurse
    - Ask the Social Worker
    - Ask the Dietician
    - Ask the Radiation Oncology Nurse
    - Ask the Pharmacist
    - Chemotherapy classes

Listings of Support Groups in multiple counties in the area and listings of important and dependable web sites for cancer information:

Last Name	First Name	Grant Num	Funding Source	Title	Program Code	% PRG	Begin Date	End Date
Arnold	Robert	R25 CA92055	NIH/NCI	End of Life Communication Skills for Oncology Fellows	6	100	09/01/2001	08/31/2006
Barnard	David	R25 CA90595	NIH/NCI	Undergraduate Medical Education for End of Life Care	XYZ	100	06/01/2001	05/31/2006
Baum/Baum	Andrew	DAMD17 01 1 0373	DOD	Center for Biobehavioral Research and Breast Cancer-trainee	6	100	09/01/2001	08/31/2005
Bigbee	William L.	R25 CA89507	NIH/NCI	UPCI Cancer Education and Career Development Programs	5	100	02/01/2001	03/31/2005
Carlos	Timothy	Aventis	Aventis	Educational Scientific Activities Grant	10	100	12/07/2001	12/06/2006
Cohen	Sheldon	T32 MH19953	NIH	Pre- and Post-doctoral Training Grant in Health Psychology	6	100	07/01/01 -	06/30/2006
Greenspan	Susan	K24 DK062895	NIH	Osteoporosis in Older Men and Women	7	100	01/01/2003	11/30/2007
Manuck	Stephen	T32 MH019953 08	NIH/Carnegie Mellon University	Pre and Post Doctoral Training in Health Psychology	6	100	09/15/1995	06/30/2006
Modugno	Francesmary	KO7 CA80668	NIH/NCI	Ovarian Cancer Risk and Survival in BRC A Carriers	7	100	07/01/2000	06/30/2005
Studenski	Stephanie	K07 AG023641-01	NIH	Training in Aging Research for MD Investigators	7	100	05/15/2004	04/30/2009

Robert H. Lurie Comprehensive Cancer Center of Northwestern University

Survivorship Activities

Community Outreach and Education

Cancer Survivors' Celebration and Walk is a community awareness event held in downtown Chicago on Cancer Survivors' Day each June that draws more than 3500 participants of which over 600 are survivors. It is supported by registration fees and commercial sponsors.

Survivors' Day with the Chicago White Sox is a collaborative awareness event held at U.S Cellular Field for approximately 1000 survivors and family members each year. This ballgame event is underwritten primarily by the Cancer Center's affiliated hospitals.

Community Education Program series are held throughout the year generally focusing on a specific type of cancer. The Cancer Center partners with community advocacy and support organizations on the planning and promotion of these events. Attendance typically ranges from 75-150 people.

Lynn Sage Breast Cancer Town Hall Meeting This event is hosted annually immediately following the Cancer Center's annual professional breast cancer symposium and is open to the public. This is an open discussion on the latest breast cancer screening, early detection and treatment options. Advocacy and support groups are invited to exhibit as are many pharmaceutical companies with their patient educational materials. This event draws about 400 participants including survivors.

Patient Advisory Board is supported to bring together cancer survivors, family members, physicians, nurses and educators to advance the Cancer Center's understanding and commitment to quality cancer care in a patient and family oriented manner. Some members help educate medical students about cancer survivorship and others review informed consent documents to be sure they are consumer friendly.

Health Learning Center Satellite will open in 2006 on the outpatient oncology clinic floor. This will be an extension of the main hospital Health Learning Center and will be fully staffed by a health educator.. The area will be equipped with computers with web access as well as print materials. New patients will be able to immediately access user friendly information while waiting for or following their doctor visits.

Patient Support Groups meet weekly, monthly, and quarterly for various types and stages of cancer are hosted by the Cancer Center (e.g., new patient, Multiple Myeloma, Prostate, Young Women with Breast Cancer, Stem Cell Transplant, etc.)

Office of Special Population Initiatives has recently been established and is charged with identifying populations who may have special needs related to cancer and developing outreach programs to address those needs. Defined broadly, special populations not only addresses racial, ethnic and cultural disparities, it includes subsets of cancer patients who may have special concerns (e.g. cancer patients of reproductive age, elderly cancer survivors, gay/lesbian patients, etc.). The Office will also look at clinical trial recruitment among minorities.

Survivorship Services

Psychosocial Oncology Program focuses on evaluating and treating the social, psychological, emotional, physical, functional and practical aspects of cancer from prevention to cancer survivorship to the end of life. The program creates free workshops, seminars and support groups designed for patients and caregivers. Individual and family counseling is available. Education and research are part of this program to improve decision making, understanding finances, sexuality, etc.

Geriatric Oncology Consultation Service was established to meet the needs of seniors with cancer. This service is available to do geriatric evaluations consisting of assessing social support, cognitive and functional ability, gait assessment, medications, nutrition and financial concerns to help improve patient outcomes. Home visit evaluations are available as part of this service as well.

Patient Navigator Program supports a full-time, trained social worker on-site to help cancer patients find resources for support groups and counseling services as well as financial assistance, transportation, lodging and other concrete services. This program is funded by the American Cancer Society.

STAR Program (Survivors Taking Action and Responsibility) is a comprehensive follow-up program for long-term adult survivors of pediatric cancer.

Fertility Preservation Program is a navigation process that insures that information on fertility preservation is available to cancer patients who are concerned about infertility due to cancer therapy. Resources have been identified to assist patients who wish to explore their fertility preservation options in a timely manner. Workshops and seminars are periodically held for Cancer Center staff and members to ensure that they are informed about the latest technologies and how to best navigate their patients to the appropriate specialists. The Cancer Center also offers a research protocol for ovarian tissue banking.

Hospice/Palliative Medicine Program offers clinical care and symptom control while attending to patients' and families' psychological and spiritual needs.

Cancer Therapy Cutaneous Adverse Reaction Clinic focuses on the early diagnosis and treatment of dermatologic and ophthalmologic reactions to cancer therapy in order to ensure patient compliance and optimize treatment.

Survivorship Education for Health Professionals

Many of the professional seminars, workshops and conferences supported by the Cancer Center include education on quality of life and survivorship issues. A representative sample of these offerings is listed below:

Annual Pain and Palliative Care Conference is an opportunity for caregivers to discuss the effects of unrelieved pain on patients and their family and to analyze the assessment and management of pain and other symptoms.

Annual Lynn Sage Breast Cancer Symposium draws over 800 clinicians and includes sessions on supportive care for patients.

Weekly Lunchtime Lecture Series in Cancer Prevention and Control often features researchers conducting survivorship and quality of life studies.

EndLink (www.endoflife.northwestern.edu) is an education resource for people involved in end-of-life care. It is a web based resource written primarily for health care professionals who work with dying patients and their families. The material presented on the site encompasses the complex, multidimensional considerations involved in caring for individuals at the end of life. It was created by a multidisciplinary group of clinicians, educators, and scientists. The Cancer Center provides a home to this site.

EPEC-O Project (Education in Palliative and End-of-life Care – Oncology) is an initiative to provide training to health care professionals on end-of-life and palliative care issues. It expands the EPEC curriculum specifically for cancer care. The project also conducts train-the-trainer conferences in collaboration with the American Society of Clinical Oncology. See www.epec.net

Survivorship/Psychosocial Research

Faculty in the Division of Cancer Prevention and Control study detailed survivorship and quality-of-life information to improve outcomes, costs, health services, supportive care, palliative care and rehabilitation.

Roswell Park Cancer Institute

Current Survivorship Activities

Roswell Park Cancer Institute's current survivorship activities include clinical, research, educational, and outreach components. The clinical program in survivorship includes a Long-Term Follow-Up Clinic started in 1986 for survivors of cancer diagnosed during childhood or adolescence, the Multidisciplinary Breast Center which offers continued support for survivors of breast cancer and the multidisciplinary Head and Neck Oncology Center.

All cancer survivors have access to several additional programs, including the Clinical Genetics service to assess patients and family members who may have an inherited susceptibility to cancer or who have related genetic concerns, the Physical Therapy program for patients following surgery (e.g. assess post-operative range of motion following breast/axillary node procedures; assess strength and range of motion following limb conserving surgery for extremity sarcoma), post-laryngectomy speech therapy and rehabilitation, and the Lymphedema Therapy program (physical assessments/measurement, manual lymphatic drainage, and education for patients on wrapping techniques, compression sleeves, and prevention of complications).

Research efforts are conducted by members of the Departments of Pediatrics, Psychology, Medical Oncology, and Cancer Prevention and Population Science. Daniel M. Green, M.D. is the head of the Long-Term Follow-Up Clinic. He is also a member of the Steering Committee of the Childhood Cancer Survivor Study, a multi-institutional cohort study of five-year survivors of childhood cancer diagnosed between 1970 and 1986 (CA 55727) as well as the principal investigator for the Roswell Park Cancer Institute component of this grant. He is a co-investigator on the grant Late Effects of Wilms' Tumor Survivors and Offspring (CA 54498). He has published analyses of pregnancy outcome, fecundity and fertility, and congestive heart failure based on these cohort studies as well as analyses of late mortality and incidence of second malignant neoplasms in the Roswell Park Cancer Institute cohort.

Roswell Park Cancer Institute is a member of the Children's Oncology Group Late Effects/Cancer Control Consortium, a fifteen institution consortium formed to rapidly complete Children's Oncology Group studies in these areas. Martin L. Brecher, M.D. and Patricia Duffner, M.D. have collaborated on studies of the late effects of therapy for childhood brain tumors and acute lymphoblastic leukemia. Michael A. Zevon, PH.D., Chair, Department of Psychosocial Oncology is a member of the Psychology and Neurosciences Working Group of the childhood Cancer Survivor Study. In addition his research has focused on the psychological, developmental, interpersonal, and social impact of the cancer experience on long term adjustment of pediatric cancer patients, including a recent effort focusing on the ideographic investigation of quality of life among pediatric survivors of differing developmental stages.

Tracey L. O'Connor, M.D., a member of the Breast Cancer Disease Site Research Group, is a co-investigator on the grant Determinants of Weight Gain in Women with Early Stage Breast Cancer (DOD BC 050410-Chi-Chen Hong, Department of Cancer Prevention and Population Science, Principal Investigator). The Department of Psychosocial Oncology has focused in addition on survivors of breast cancer and bone marrow transplantation where the "surviving family" has been identified as a meaningful target for research and clinical efforts even in the case where the identified patient has died. A goal of this research is a tailored bereavement intervention based on the unique constellation of psychosocial effects left by the diagnosis and treatment of cancer in a bereaved family.

The Legal Services Project is a collaboration with Neighborhood Legal Services to provide services to Roswell Park Cancer Institute patients. The program is staffed by two attorneys who provide free legal services to patients with metastatic or recurrent cancer and whose household income does not exceed 200% of the Federal poverty level. The long term objective of this project is to identify the legal needs of patients and their families with cancer and provide the services and resources necessary to address these legal problems, ultimately improving the quality of life for these individuals and their families.

Carolyn D. Farrell, M.S., C.N.P., C.G.C., through a Robert Wood Johnson Foundation award, Development of a Family History-Cancer Risk Assessment Strategy: Model Building Based on Cancer Screening Data, has developed a screening model for application to, among other groups, cancer survivors and their extended families.

K. Michael Cummings, Ph.D. is the principal investigator on several studies of smoking cessation, an issue pertinent to reduction of second cancer risk in patients treated with lung or mediastinal irradiation, and those with oropharyngeal or lung cancer. These include: The Impact of Product Information on Smoking Behavior (CA101946), New York State Smoker's Quitline (CO20137), Community Partnerships for Tobacco Control: Erie-Niagara Tobacco Free Coalition (CO20037), and Tobacco Cessation Center of Western New York – North (CO20110).

Roswell Park Cancer Institute sponsors a semi-annual meeting – the International Conference on Late Effects of Treatment of Children and Adolescents for Cancer (CA95124) – which is attended by approximately 250 international professionals involved in research and clinical management of adult survivors of childhood cancer.

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Washington University Alvin J. Siteman Cancer Center

Current Survivorship Activities

The Alvin J. Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine has many ongoing activities focused on or incorporating cancer survivorship in cancer research and care.

Psychosocial Clinical Service

The Psychosocial Clinical Service includes clinical activities supporting cancer patients, including counseling, medical, and psychiatric services; patient support groups; nutritional counseling; and quality of life assessment. The clinical program is led by Teresa Deshields, PhD.

Help Us Give Support (HUGS)

HUGS is an ongoing Susan G. Komen Foundation(local) funded-program led by Teresa Deshields, PhD that provides support services and fellowship for children or grandchildren of breast cancer victims. This program includes group/support activities and educational/support materials.

Young Women's Breast Cancer Program

The Young Women's Breast Cancer Program, led by Jennifer Ivanovich, MS, Paul Goodfellow, PhD, and Alison Whelan, MD provides education and genetic counseling for women and their families who are at high risk for breast cancer. This program has Susan G. Komen Foundation (local) funding.

St. Louis Witness Program

With funding from the Susan G. Komen Foundation, the St. Louis Witness Project, led by Katherine Mathews, MD, MPH, promotes breast and cervical cancer education and screening programs for African Americans based on the model developed by the Arkansas Cancer Research Center. These programs have reached **over** 8,000 African American women in St. Louis and have directly linked nearly 400 women to breast cancer screening services. These programs are based on lay women sharing their experiences in community and church settings.

Cancer Center Support Grant Shared Resources

The *SCC Hereditary Cancer Core*, led by Paul Goodfellow, PhD and Allison Whelan, MD, provides 1) project management, 2) consultation on local and national issues, 3) serves as a liaison with the Human Studies Committee, and 4) assists with collection of samples from high-risk families as well as cases and controls for studies dealing with genetic risk factors for cancer. The core provides direct support to investigators to design, implement and complete genetic studies in existing research programs.

The SCC Health Behavior and Outreach Core (HBOC), directed by Donna Jeffe, PhD, is one of 14 SCC shared resources. The HBOC provides tools and services in the areas of: (1) Epidemiology, Survey Research and Data Management, (2) Psychological Aspects of Cancer and Quality of Life, (3) Health Education, in connection with the Health Communication Research Laboratory at Saint Louis University, and (4) Outreach and Recruitment.

Community Education and Screening Activities

The SCC has established a number of community-based programs designed to enhance understanding of cancer and improvement in quality of life for patients and families in the region. Programs and events are promoted through mailings, the SCC web site (www.siteman.wustl.edu), and paid or free media coverage on TV, radio, and in newspapers. In addition Siteman participates in and sponsors a variety of health and wellness events (e.g., the annual Cancer Wellness Fair), specific cancer events (e.g., Susan G. Komen Race for the Cure) and cancer screening events throughout the community. Approximately 30,000 people participate annually.

Clinical Support Services

A number of clinical support services are provided at the Siteman Cancer Center location at Barnes-Jewish—St. Peters Hospital in St. Peters, MO. These programs include the AWARE program (guided imagery and relaxation techniques); Conquer (a general support group); KIDScope (support group for children 4-13 whose parent or caregiver has cancer/adults meet at the same time to discuss parenting); massage therapy (offered weekly to patients and caregivers); DHHS/CDC skin cancer prevention/education/screening programs; and American Cancer Society (ACS) programs (Look Good, Feel Better; Daffodil Days; ACS Days).

A number of support programs are also offered at the Siteman Cancer Center location at Barnes-Jewish—West (St. Louis) County location.

The Siteman Cancer Center/Washington University School of Medicine Divisions of Stem Cell Biology and Bone Marrow Transplant support services for survivors, including an annual patient celebration event that recognizes patients who have had stem cell and bone marrow transplants at Siteman Cancer Center. Services also include a patient support group that meets every Thursday (except for the third Thursday of every month), with a focus on patients and their caregivers.

Palliative Care Service

Barnes-Jewish Hospital and Washington University School of Medicine have developed a palliative care service, led by Jane Loitman, MD (clinical service director), Ira Kodner, MD (research director), and Michael Naughton, MD (medical oncology director). This service has been established to provide appropriate management for patients and their families, and to improve quality of life and patient satisfaction. The palliative care program is currently establishing research project based on physician-patient/family communication, outcome, and survival.

Barnard Health and Cancer Information Center (BHCIC)

The Barnard Health and Cancer Information Center (BHCIC), located in approximately 4,600 square feet in the SCC lobby, provides a broad spectrum of information to providers, patients, and the community, including a lending library, many informational brochures, access to the world wide web and other computer educational tools, and educational programs. Free on-site educational sessions cover such topics as enhancing quality of life.

Program for the Elimination of Cancer Disparities (PECaD)

Formally initiated in 2003, the PECaD, co-directed by Dione Farria, MD, MPH and Katherine Mathews, MD, MPH, encompasses SCC efforts to address pervasive issues of disparities of cancer diagnosis, treatment, prevention and control, and education. A strategy was developed that targets systemic problems of access and trust, for which outstanding community and institutional participants were recruited to serve on advisory and steering committees. Advisory and steering committees oversee all SCC efforts in this area and work to identify barriers and key associated issues, as well as to match appropriate resources to overcome them. This program was recognized by the NCI in 2005 with funding through the Community Networks Program (PI: D. Farria). During 2005-6, disease-focused, community-based action teams were developed to improve coordination of cancer efforts and build community-based participatory research

Prevention and Control Research Program

This research program, led by Ross Brownson, PhD, and Mario Schootman, PhD, has as its overall goal to advance fundamental knowledge, develop, advance, and evaluate improved interventions in smoking prevention and cessation, early detection, cancer communication and interventions, psychosocial aspects of care, and chemoprevention. This program scientifically integrates faculty at both Washington University and the St. Louis University School of Public Health. Survivorship is a growing theme of this program, which features a number of key research projects.

- Donna Jeffe, PhD, leads work supported by NCI and the Barnes-Jewish Hospital Foundation to explore psychosocial factors associated with delay in diagnosis among women with locally advanced breast cancer, and factors associated with quality of life among women with DCIS, many of whom are minority patients.
- Mario Schootman, PhD, conducts NCI-sponsored research examining geographic, socioeconomic, and psychological factors related to geographic and other variability in cancer screening and care.

- Jay Piccirillo, MD, is conducting NCI-funded research on how comorbidity in older cancer patients impacts survival and use of preferred cancer therapies.
- Matthew Kreuter, PhD, leads a Center for Excellence in Cancer Communication Research (CECCR) provides a number of cancer education initiatives, evaluating communication strategies, content analyses, and new tools to evaluate and improve dissemination of cancer communication, with a particular focus on African American populations.
- Kreuter also holds a Minority Pre-doctoral Education to Reduce Disparities grant in the St. Louis University School of Public Health's Health Communication Research Laboratory.
- Supported by NCI, Mark Walker, Ph.D. is examining clinical, psychological, and social factors (including socioeconomic indicators, social support) related to maintenance of nonsmoking among patients with lung cancer.
- Walker also is conducting a study of mental health history and survival among breast cancer patients, supported by the Longer Life Foundation.

Translational and Clinical Research Program

The Translational and Clinical Research Program focuses on translating basic science research into new clinical studies, diagnostics, and therapeutics. However, a substantial part of the program is closely aligned with the Prevention and Control Research Program. A few examples are given below:

- Supported by funding from Avon/NCI, Matthew Ellis, MB, BChir, PhD, is conducting a phase II trial of estradiol therapy for advanced breast cancer that includes a substantial quality of life component.
- Rebecca Aft, MD is conducting a breast cancer clinical trial examining the effect of bisphosphonates on micrometastatic and distant disease development in women with locally advanced breast cancer, in collaboration with Katherine Weilbaecher, Michael Naughton, and Donna Jeffe, who is assessing quality of life.
- Through an NCI-funded program led by Paula Fracasso, MD, PhD; Mark Walker, PhD; and Nancy Bartlett, MD, newly diagnosed minority breast, prostate, lung, and colorectal cancer patients are randomized to be followed by a peer, health "coach" or to usual care.
- Yan Yan, PhD received funding from the Longer Life Foundation to estimate the probability of death from prostate cancer or other competing risk factors based on demographic, clinical and treatment variables in SEER-Medicare datasets.

Siteman Clinical Research Affiliates

The Siteman Cancer Center has a number of ongoing clinical research affiliations. Chief among them are the Siteman Cancer Center locations at Barnes-Jewish – St. Peters and Barnes-Jewish – West (St. Louis) County locations, at which patients are enrolled on an extensive clinical trials menu. In addition, the Siteman Cancer Center, has affiliations with a number of location institutions for cooperative group and investigator-initiated clinical studies. Siteman is developing an affiliation with Boone Hospital and Missouri

Cancer Associates in Columbia, MO (central Missouri) for prevention and control studies and services. In addition, the Siteman Cancer Center is a participating institution in the Mayo Phase II Consortium and the Northwestern Phase II Chemoprevention Consortium.

St. Jude Children's Research Hospital

Introduction

As the only NCI-funded cancer center dedicated solely to childhood cancer, St. Jude Children's Research Hospital has unique strengths that foster the development of survivorship research in childhood cancer patients. The SJCRH faculty is involved in research-based activities that encompass a wide spectrum of survivorship issues and are multi-disciplinary in nature. Research is conducted within the SJCRH patient population, as well as through multi-institutional efforts coordinated through the St. Jude Cancer Center. Patients establish a strong relationship with the institution as a result of the extraordinary comprehensive medical services provided to all patients, regardless of the family's ability to pay.

The tremendous institutional commitment to patient services, which includes all aspects of clinical care as well as financial support for meals, domiciliary care and transportation, facilitates comprehensive ascertainment of treatment sequelae and research initiatives evaluating late treatment toxicities in pediatric cancer survivors. The combined population of active and alumni St. Jude long-term survivors currently exceeds 5000 and represents one of the largest single institution cohorts available for research investigations.

After Completion of Therapy Program

Survivors who remain in remission at least 2 years following completion of antineoplastic therapy and 5 years from diagnosis of childhood cancer are transferred to the St. Jude's After Completion of Therapy Clinic (ACT) for late effects monitoring. The ACT Clinic was established in 1984 to specifically address the medical and psychosocial needs of childhood cancer survivors treated at St. Jude. Patients who are in remission 5 years after diagnosis and at least 2 years after completion of therapy are eligible for transfer to this clinic. Survivors are evaluated annually by the clinic staff until they are 18 years of age or 10 years post-diagnosis. After "alumni" survivors are discharged to the care of community physicians, the St. Jude Cancer Registry continues to perform annual follow-up for the lifetime of the patient. The St. Jude Cancer Center also supports the evaluation of cohorts of "alumni" survivors who are invited to return for specific cancer control protocol investigations.

The annual evaluations of survivors have evolved from a cursory screening examination in the early years of the clinic to a series of focused educational interventions designed to enhance awareness about health risks following cancer treatment and preventive measures to reduce these risks. Late effects risk counseling and communication with local care providers are facilitated by a personal ACT Clinical Summary, which is developed for each survivor and updated during the annual evaluation. Personal health records are organized for survivors graduating from ACT follow-up and to alumnus requesting information after experiencing medical events, e.g., second malignancies, to assist their local physicians with treatment planning.

The routine services provided by the ACT Clinic support the long-term follow-up program's mission to improve the quality of life of long-term survivors treated at St. Jude. Specifically, this mission is accomplished through clinical initiatives aiming to 1) identify cancer-related physical and emotional sequelae; 2) provide interventions to reduce cancer-related morbidity; 3) educate about cancer-related health risks and risk-reduction measures; 4) enhance communication with community health care providers; and 5) improve compliance with long-term monitoring by the St. Jude Tumor Registry. The ACT interventions described above not only represent important aspects of clinical care, but also facilitate the numerous research initiatives targeting long-term survivors. One of the priority goals of the clinical and technical ACT staff is the development of a codified research database including demographic, diagnostic, and targeted health outcomes information.

The large population of childhood cancer patients and long-term survivors available for St. Jude studies, plus the institution's established commitment of resources to long-term follow-up and evaluation of treatment sequelae, provide a remarkable opportunity to pursue cancer control investigations aimed at reducing cancer-related morbidity and mortality in pediatric oncology patients. The Cancer Center is also committed to assembling the multidisciplinary research faculty essential to the development of productive translational cancer control investigations. In this atmosphere, programs of research evaluating the effects of growth, development, aging, health behaviors, and genetics on the incidence of cancer treatment sequelae are eminently feasible. Information gained from these studies about the biological, clinical, and psychosocial factors contributing to cancer-related morbidity and mortality would expedite the development and implementation of ameliorative interventions.

Other Cancer Center Survivorship Research Initiatives

The SJCRH faculty are engaged in the conduct numerous investigations relating to pediatric and adolescent survivor populations. Examples of active protocols include:

- Health-related behaviors in childhood cancer survivors
- Health promotion in childhood cancer survivors
- The epidemiology of chronic hepatitis C infection in childhood cancer survivors
- Avascular necrosis in patients with hematologic malignancies
- Health-related outcomes for Hodgkin’s Disease survivors
- Learning impairments among survivors of childhood cancer
- Bone density in survivors of childhood ALL
- Randomized trial for prevention of diminished bone mineral density in survivors of ALL
- Neurologic morbidity and disability in childhood ALL survivors
- CNS effects of conformal radiation therapy in children
- Quantification of radiation-related endocrine effects
- fMRI for detecting neural sequelae of pediatric brain tumor
- Neural systems for reading in medulloblastoma survivors

- Measures of adaptive style in childhood cancer
- Psychosocial impact of pediatric bone marrow transplant

University of California San Diego
Survivorship Activities

Please find attached the Survivorship Activities from UCSD. Below are responses from Walter Eckhart (Salk) and Kristiina Vuori (Burnham).

Survivorship Activity Title	Funding source(s):	Targeted Population:	Name or title of network, if exists:	Primary Investigator
Components of Depression and Predictors of Dietary Adherence in Breast Cancer Survivors Major goals: 3-year study to determine characteristics of subgroups of depressed breast cancer survivors and predictors of adherence to the WHEL breast cancer Study plant-based diet.	Lance Armstrong Foundation	Breast cancer survivors who have completed initial treatment up to 4 years prior to enrollment.		Wayne A. Bardwell, Ph.D.
Functioning, Fatigue, and Distress in Breast Cancer: A 4-year Follow-up Study Major goals: 3-year study to understand the trajectory and predictors of fatigue, general psychological distress, and	Susan G. Komen Foundation	Breast cancer survivors who have completed initial treatment up to 4 years prior to enrollment.		Wayne A. Bardwell, Ph.D.

overall functioning in breast cancer survivors.				
Post-treatment fatigue among women with breast cancer	NCI	Breast cancer survivors		Georgia Sadler, PhD, MBA, RN
Post-treatment fatigue among African American Cancer Survivors	UCSD Cancer Center Pilot Funding	African American cancer survivors		Georgia Sadler, PhD, MBA, RN
Research Scholar Grant in Psychosocial, Behavioral, and Cancer Control Research	American Cancer Society	Overweight or obese breast cancer survivors	Weight Reduction Intervention for Breast Cancer Survivors	Cheryl Rock, PhD, R.D
The **N**utrition **E**xercise **a**nd **T**houghts (NEAT) Trial	Jenny Craig, Inc.	Overweight women		Cheryl Rock, PhD, RD
The **W**omen's **H**ealthy **E**ating and **L**iving (WHEL) Study	NCI	Early stage breast cancer survivors		John Pierce, PhD
The **M**en's **E**ating and **L**iving (MEAL) Study	CALGB (NCI)	Prostate cancer survivors with localized, low-risk disease		John Pierce, PhD
San Diego County Cancer Navigator	County of San Diego, Kaiser	Patients, families, caregivers,	Cancer Navigator is part of survivorship/support	Joe Raffa, Ed.D, Georgia Sadler, PhD,

	Permanente, Cal Endowment, Alliance Healthcare Foundation, American Cancer Society	Underserved populations, Latino population with language, cultural, income barriers	network: American Cancer Society, PODER program, Partners for Community Access, Caring Community - Living with Cancer, and Cancer Survivorship: San Diego! UCSD Cancer Center participates with Network partners in Annual Survivorship Education Event, Advisory Council and research. Cancer navigator also helps to staff the cancer center Patient Education and Resource center	MBA, RN, Ira Goodman, MPA, MS, Matthew Loscalzo, MSW
Partners in Survival	CDC	Underserved and minority caregivers of women with cancer	Men Against Breast Cancer, Washington, DC and other groups focusing on the underserved, such as, National Black Leadership Initiative on Cancer II: Network Project; Mayo Clinic Comprehensive Cancer Center's Spirit of Eagles; Program; Nueva Vida (New Life).	Matthew Loscalzo, MSW
Biopsychosocial Problem-Based Screening	UCSD	Prospective Universal screening of cancer patients at all stages at cancer center		Matthew Loscalzo, MSW, Georgia Sadler, PhD, MBA, RN, Karen Clark, MS

Cancer Survivors' Celebration	UCSD	Cancer survivors and family members	San Diego Consortium of organizations	Nancy Stringer, Joanne Mortimer, MD, Barbara Parker, MD, Cheryl Rock, PhD, RD, Georgia Sadler, PhD, MBA, RN

Wake Forest University Comprehensive Cancer Center

Current Survivorship Activities

The survivorship activities at the Comprehensive Cancer Center at Wake Forest University (CCCWFU) that are aimed specifically at cancer survivors include clinical, research, educational, and outreach efforts. Research efforts are conducted primarily by members of the Cancer Control Program, but are also conducted by members of the Clinical Research Program. The Director of the Cancer Control Program, Nancy Avis, Ph.D., and the Director of the Clinical Research Program, Edward G. Shaw, M.D., are senior investigators who have published on quality of life issues in cancer survivors.

Past research accomplishments of Center investigators include studies that have led to a greater understanding of the common mental and physical problems experienced by younger women who are breast cancer survivors and long-term cancer survivors, as well as energy, mood, and cognitive function problems experienced by brain tumor survivors. Center members are currently developing interventions to reduce morbidity, alleviate symptoms, and improve the quality of life in survivors. A list of recent publications on cancer survivorship by Center members documenting these and other accomplishments appears below. Examples of current research efforts in cancer survivorship at CCCWFU include the following peer-reviewed funded studies:

- DOD behavioral Center of Excellence in Breast Cancer "Functional Status and Quality of Life Across the Lifespan" (DAMD 17-01-1-0447; PI: M. Naughton). This Center grant includes 3 projects:
    - Menstrual Cycle Maintenance and Quality of Life Following Treatment for Breast Cancer: A Prospective Study (PI: Michelle Naughton). This is a continuation and expansion of a previous DOD grant (DAMD17-96-1-6292) begun in 1996 to study menstrual cycle patterns following treatment for breast cancer.
    - Investigating Mechanisms to Explain Age Associated Differences in Quality of Life Among Breast Cancer Patients (PI: Nancy Avis). The purpose of this project is to examine and explain psychosocial and medical factors related to age differences in adjustment to breast cancer. Newly diagnosed women with breast cancer are recruited into the study and followed for 18 months to examine predictors of quality of life.
    - Research on Optimal Recovery Practices in Breast Cancer (PI: Roger Anderson) is testing two exercise interventions in recently diagnosed women with breast cancer.
- A Treatment Stage Specific Approach to Improving Quality of Life for women with Ovarian Cancer (DAMD 17-01-1-0734; PI: Nancy Avis). This is a prospective study of women who are newly diagnosed with ovarian cancer to examine the problems

women face and their quality of life issues at different treatment stages of having ovarian cancer: newly diagnosed, in-treatment, post-treatment, and at recurrence.

- Acupuncture Treatment for Menopausal Hot Flashes (NCI; R21 CA104427; PI: Nancy Avis. This project is designed to test the feasibility of conducting a randomized trial on the effectiveness of acupuncture treatment for menopausal hot flashes.
- Randomized Study of Soy Protein and Effexor on Vasomotor Symptoms of Men with Prostate Cancer (U10 CA081851-06S2; PI: Mara Vitolins). This study is randomly assigning 166 men receiving hormonal manipulation treatment for prostate cancer to receive: 1) soy protein powder, 2) Effexor, 3) a combination of soy and Effexor, or 4) a placebo.

- A Phase II Study of St. John's Wort for the treatment of Hot Flashes in Women with a History of Breast Cancer (CCCWFU CCOP Research base Protocol 98301; PI: Michelle Naughton). The purpose of this study is to determine the efficacy of St. John's Wort in reducing hot flushes in breast cancer survivors at least 2 years post-treatment and determine the effect of St. John's Wort on tamoxifen levels, in those women taking the medication.

- Breast and Prostate Cancer Data Quality and Patterns of Care (CDC DP300026401; PI: Roger Anderson). This project is testing the efficiency and effectiveness of a targeted audit protocol for registry data to improve the overall quality of registry data in describing the receipt of standard of care for breast and prostate cancer.

- Outcomes of Omission of Radiation with Lumpectomy (BCS) Among Low-Income Women (NCI R01CA121317; PI: Roger Anderson) seeks to ascertain the extent to which omission of radiation is causally linked to poorer survival.

- Is Stroke a Late Effect of Chemotherapy? (NCI R01 CA121303; PI: Ann Geiger) aims to use automated data to estimate the association of stroke with chemotherapy among a group of over 110,000 ethnically diverse patients diagnosed with diverse cancers.

In addition to the routine follow-up care provided to cancer survivors, there are several clinical efforts aimed specifically at improving health outcomes in survivors. The Cancer Patient Support Program (CPSP) and Psychosocial Oncology Program (POP) were developed to enhance the quality of life of patients and family members during diagnosis, treatment and survivorship. These services were cited by the National Cancer Policy Board as a model for Comprehensive Cancer Centers.

The CPSP and POP provide professional counseling and clinical research activities. Research has focused on quality of life following treatment, orienting new patients to treatment, group support for young women breast cancer patients and restorative (gentle) yoga. The CPSP staff provides individual counseling, support groups, hospital visitation, professional education for medical center employees, patient and community education, financial assistance, and appearance consultation including wigs, turbans and caps. All CPSP services are provided without charge.

Educational and outreach efforts are the third component of programs geared to cancer survivors. Our CCC maintains a Patient Education and Resource Center that provides cancer survivors with materials prepared locally and by national organizations that address survivorship issues as well as advice on and direction to websites providing high quality information for cancer survivors

Recent Publications On Cancer Survivorship

1. Avis NE, Assmann SF, Kravitz HM, Ganz PA, Ory, M. Quality of life in diverse groups of midlife women: Assessing the influence of menopause, health status and psychosocial and demographic factors. Quality of Life Research 2004;13:933-946.

2. Avis NE, Smith KW, McGraw S et al. Assessing quality of life in adult cancer survivors. Quality of Life Research 2005;14:1007-1023.

3. Avis NE, Crawford, SL, Manuel J. Quality of life among younger women with breast cancer. J. Clin Oncol 2005;23: 3322-30.

4. Avis, NE, Crawford SL, and Manuel J. Psychosocial problems among younger women with breast cancer. Psycho-Oncology 2004;13:295-308.

5. Avis, NE, Smith KW, Link CL, Hortobagyi GN, Rivera E. Factors associated with participating in breast cancer treatment clinical trials. Journal of Clinical Oncology 2006, 24.

6. Brown PD, Buckner JC, Uhm JH, Shaw EG. The Neurocognitive Effects of Radiation in Adult Low-Grade Glioma Patients. Neuro-Oncology 2003; 5(3):161-167.

7. Brown PD, Bucker JC, O'Fallon JR, Iturria NL, Brown CA, O'Neill BP, Scheithauer BW, Dinapoli RP, Cascino TL, Arusell RM, Curran WJ, Abrams R, Shaw EG. Effects of Radiotherapy on Cognitive Function in Patients with Low-Grade Glioma Measured by the Folstein Mini-Mental State Examination. J Clin Oncol 2003; 21:2519-2524.

8. Burwell SR, Case, LD, Kaelin C, Avis NE. Sexual problems in younger women following breast cancer surgery. Journal of Clinical Oncology, in press.

9. Burke GL , Legault C, Anthony M, Bland DR, Morgan TM, Naughton MJ, Leggett K, Washburn SA, Vitolins MZ. Soy protein and isoflavone effects on vasomotor

symptoms in peri- and postmenopausal women: the Soy Estrogen Alternative Study, Menopause 2003;10(2):147-153.

10. Foley KL, Farmer DF, Petronis VM, Smith RG, McGraw S, Smith K, Carver CS, Avis NE. 2005. A qualitative exploration of the cancer experience among long-term survivors: Comparison by cancer type, gender and age. Psycho-Oncology, 2005 (ePub ahead of print, DOI:10.1002/pon.942).

11. Geiger AM, West CN, Nekhlyudov L, Herrinton LJ, et al. Contentment with quality of life among breast cancer survivors with and without contralateral prophylactic mastectomy. J Clin Oncol (in press).

12. Gold EB, Colvin A, Avis NE et al. Longitudinal analysis of vasomotor symptoms and race/ethnicity across the menopausal transition: Study of Women's Health Across the Nation (SWAN). American Journal of Public Health, in press.

13. Naughton MJ., Herndon JE, Shumaker SA, Miller AA, Kornblith AB, Chao D, Holland J. The health-related quality of life and survival of small-cell lung cancer patients: Results of a companion study to CALGB 9033. Quality of Life Research 2002;11:235-248.

14. Petrek JA, Naughton MJ, Case LD, Paskett ED, Naftalis EZ, et al. Incidence, Time Course, and Determinants of Menstrual Bleeding After Breast Cancer Treatment: A Prospective Study. J Clin Oncol (in press).

15. Shaw EG and Robbins ME. The management of radiation-induced brain injury. Cancer Treat Res 2006;128:7-22.

16. Shaw EG, Rosdhal R, D'Agostino Jr RB, Lovato J, Naughton MJ, Robbins ME, and Rapp SR. A Phase II Study of Donepezil in Irradiated Brain Tumor Patients: Effect on Cognitive Function, Mood, and Quality of Life. J Clin Oncol (In Press, 2006).

17. Walsh SR, Manuel JC, Avis NE. The impact of breast cancer on younger women's relationships with their partner and children. Family Systems & Health.2005;23:80-93.

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