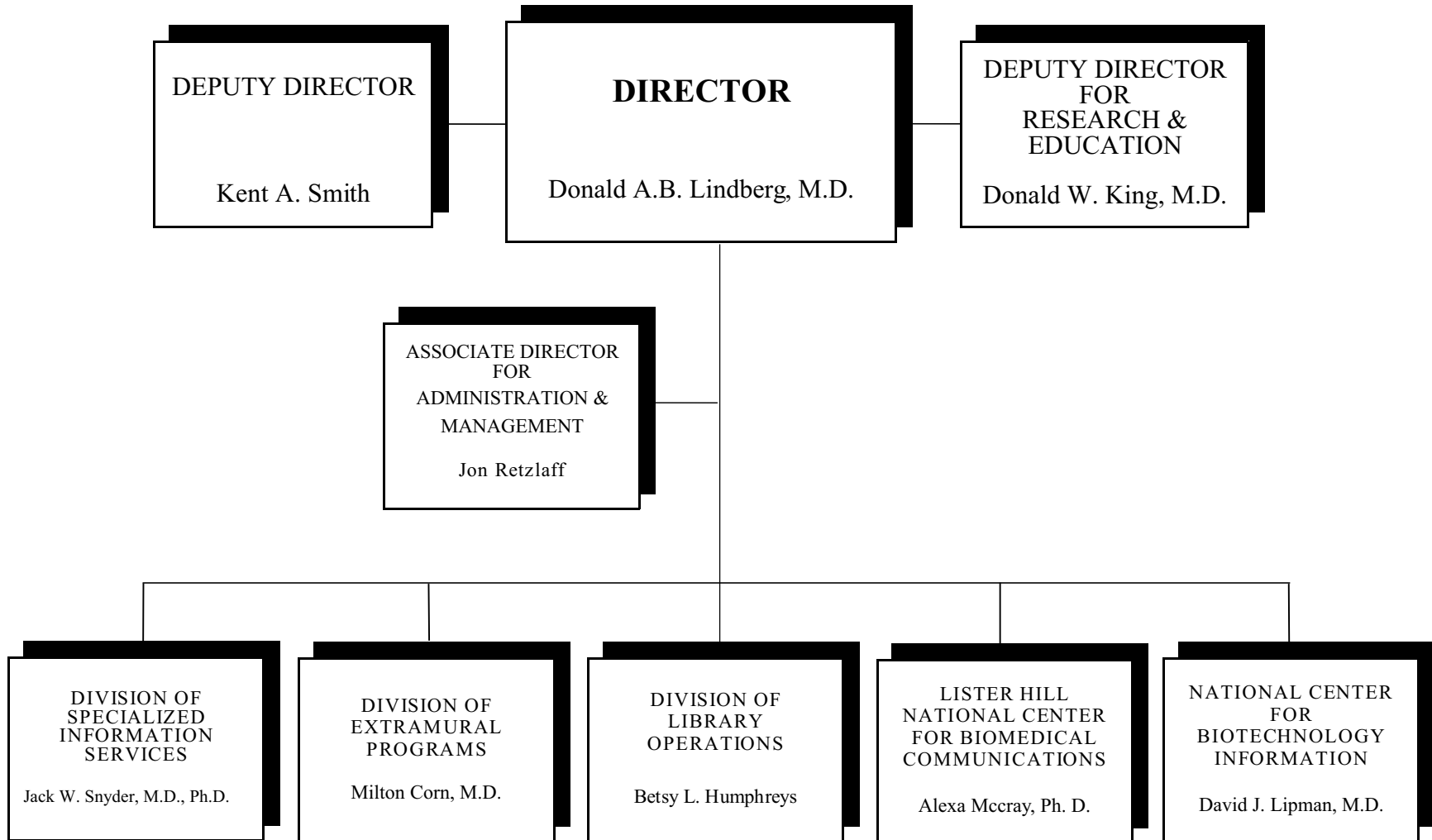DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

National Library of Medicine

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NATIONAL INSTITUTES OF HEALTH
NATIONAL LIBRARY OF MEDICINE
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NATIONAL INSTITUTES OF HEALTH

National Library of Medicine

For carrying out section 301 and title IV of the Public Health Service Act with respect to health information communications, [$311,635,000] *$325,147,000,* of which $4,000,000 shall be available until expended for improvement of information systems: <u>Provided</u>, That in fiscal year 2005 the Library may enter into personal services contracts for the provision of services in facilities owned, operated or constructed under the jurisdiction of the National Institutes of Health.

[Departments of Labor, Health and Human Services and Related Agencies Appropriations Act, as enacted by the Omnibus Consolidated Appropriations Act for Fiscal Year 2004]

National Institutes of Health
National Library of Medicine

Amounts Available for Obligation 1/

Source of Funding	FY 2003 Actual	FY 2004 Final Conference	FY 2005 Estimate
Appropriation	$302,099,000	$311,635,000	$325,147,000
Enacted Rescissions	(1,964,000)	(2,520,000)	---
Subtotal, Adjusted Appropriation	300,135,000	309,115,000	325,147,000
Comparative transfer from: Fogarty International Center for International Services Branch	13,000	0	0
Comparative transfer to NIBIB for Radiology Program	(0)	(0)	(0)
Comparative transfer to Buildings and Facilities	(591,000)	(569,000)	(0)
Comparative transfer to Office of the Director for Public Health Reports	(70,000)	(70,000)	(0)
Comparative transfer to Office of the Director for program changes	(1,642,000)	(0)	(0)
Subtotal, adjusted budget authority	297,845,000	308,546,000	325,147,000
Unobligated Balance, start of year	301,000	563,000	0
Unobligated Balance, end of year	(563,000)	0	0
Subtotal, adjusted budget authority	297,583,000	309,109,000	325,147,000
Unobligated balance lapsing	(102,000)	---	---
Total obligations	297,481,000	309,109,000	325,147,000

1/ Excludes the following amounts for reimbursable activities carried out by this account:
   FY 2003 - $17,134,000;FY 2004 - $8,934,000;FY 2005 - $8,934,000
   Excludes $2,558 in FY 2003 and $14,790 in FY 2004 for royalties.

Justification

National Library of Medicine

Authorizing Legislation: Section 301 and Title IV of the Pubic Health Service Act, as amended. Reauthorizing legislation will be submitted.

Budget Authority: (dollars in thousands)

FY 2003 Actual		FY 2004 Final Conference		FY 2005 Estimate		Increase or Decrease	
FTEs	BA	FTEs	BA	FTEs	BA	FTEs	BA
690	$297,845	663	$308,476	665	$325,147	2	$16,671

INTRODUCTION

For more than 150 years one institution has been the nation's primary source of published medical information—the National Library of Medicine (NLM). Innovation in disseminating medical information has been a hallmark of the Library since the 19th century, including the first successful application of computers (40 years ago) to a large-scale bibliographic system. Today the NLM not only maintains the world's largest collection of biomedical books and journals, but it has become, via the Web, a source of authoritative information for scientists, health professionals, and consumers around the world.

A distinguishing feature of the NLM of the 21st century is that it is the major repository of human genome information. The NLM, through the Web operations of its National Center for Biotechnology Information (NCBI), receives more than a quarter million visitors a day seeking molecular biology information ranging from DNA sequences and protein structures to the related research literature.

Another feature of the contemporary NLM is that it is now placing great emphasis on creating online information resources for the general public. This was prompted by the realization that when MEDLINE/PubMed became available freely on the Web, fully one third of the usage was not by scientists and health professionals, but by consumers. The NLM Board of Regents encouraged the Library to create information resources directed to the public and, as a result, a number of useful Web sites, described below, have become available.

STORIES OF DISCOVERY

For Scientists and Health Professionals

In its role as the world's largest medical library, the National Library of Medicine continues to provide access to the enormous literature of the health sciences, including even priceless historical treasures dating to the 11th century. Most medical researchers and health professionals have, directly or indirectly, availed themselves of the Library's services some time in their career; there are those who access MEDLINE/PubMed (to take one popular example) almost daily. Another heavily used information resource is GenBank (with DNA sequence data).

On March 7, 2003, a major milestone was reached when the 12 millionth journal article was added to the National Library of Medicine's MEDLINE database. MEDLINE is a database of references and abstracts to the world's medical literature published since the 1950s. It has links between references and publisher websites so users can in many cases retrieve the full text of articles. Today, some 4,000 of the 4,600 publications indexed for MEDLINE have such links. PubMed is the Web-based retrieval system that makes this wealth of information freely and easily searchable by health professionals and others. PubMed now handles more than 45 million searches per month, making it the world's most heavily used database of peer-reviewed scientific medical information. Adding to this figure the traffic on other NLM databases (MedlinePlus, ClinicalTrials.gov, and others), the total approaches three quarters of a billion searches per year. Millions of additional searches are performed through some 170 nongovernmental organizations that freely lease the database.

GenBank, on the other hand, is a rapidly expanding resource accessed primarily by scientists—some 50,000 of them each day. It is a collection of all publicly available DNA sequences and is thus a key element in ensuring that the flood of data resulting from research around the world, including the Human Genome Project at NIH, is available for further research, analysis, and gene discovery. GenBank, maintained by the National Center for Biotechnology Information, now contains more than 27 million sequence entries totaling 33 billion base pairs from over 130,000 species. These resources include chromosome maps, gene protein products, and other relevant genetic information for human and many smaller species.

Scientists use not only the sequence data stored in GenBank, but avail themselves of the sophisticated computational tools developed by the growing cadre of NCBI intramural investigators, such as the BLAST suite of programs for conducting comparative sequence analysis. BLAST can execute sequence searches against the entire DNA database in less than 15 seconds. Entrez is NCBI's integrated database search and retrieval system. It allows users to search enormous amounts of sequence and literature information with techniques that are fast and easy to use. Using this system, one can access NCBI's nucleotide, protein, mapping, taxonomy, genome, and structure databases, as well as PubMed, the retrieval system for biomedical literature. All of NCBI's databases and software tools are available free online.

A major focus of NCBI's efforts in data integration is to develop systems that will offer researchers the capability of readily analyzing large sets of molecular data to shorten the path from experimentation to application in human health and disease. For example, the NCBI Collection of Reference Sequences (RefSeq) provides a unified view of our genetic knowledge of organisms. RefSeq makes it possible to undertake large-scale comparative analyses among different organisms to investigate basic molecular biological processes and medical problems, such as different disease susceptibilities for individuals or targeted individual drug treatment approaches. Similarly, the NCBI initiative of classifying protein domains by computational sequence analysis is a powerful means to deduce the function of newly discovered proteins. In the context of proteins associated with human disease, this analysis can generate hypotheses concerning the metabolic pathways in which the proteins act and greatly accelerate research into the molecular basis of disease. The development of these and other new systems and services will be significantly facilitated by the new Collaboratory space to be created.

An increasingly popular NCBI service for the scientist and health professional is PubMedCentral (PMC). This is a digital archive of life sciences journal literature to which publishers electronically submit peer-reviewed research articles, essays, and editorials. NLM undertakes to guarantee free access to the material; copyright remains with the publisher or the author. NLM considers interaction and input from the medical library community important for the development and continued success of PubMed Central. Advice is provided by a PubMed Central National Advisory Committee of outside experts charged with ensuring that PMC remains responsive to the needs of researchers, librarians, publishers, and the general public. In 2002, the librarians on the PMC committee joined other members in strongly recommending that

NLM digitize the back issues of the journals in PMC in order to make complete sets available online. NLM has acted on that recommendation and, in November 2003, released an online version of the first such journal, the *Bulletin of the Medical Library Association*, dating back to 1911.

Another area of NLM concentration is "AIDSinfo," a unified information service for HIV/AIDS information. Research information about HIV/AIDS is being published at a high rate, with new discoveries often being made more quickly than many clinicians and patients can stay abreast of. AIDSinfo serves as a centralized dissemination point for information about current treatment regimens for HIV infection and AIDS-related illnesses, including prevention of HIV transmission from occupational exposure and mother-to-child transmission during pregnancy. This service also provides information on HIV/AIDS-related clinical trials—both public and privately funded—for all stages of HIV infection. AIDSinfo works closely with the federal agencies and their committees that create and update the treatment guidelines and also maintains them as "living documents on the Web site. By providing a single source of this type of information, AIDSinfo helps support the goal of providing the very best treatment to all HIV positive patients.

For the Public

The past year has seen the launching of a variety of major Web-based information services aimed at the general public. They join the consumer-oriented MedlinePlus and ClinicalTrials.gov in being made freely available to all.

MedlinePlus

MedlinePlus, introduced in 1998, continues to grow in both the breadth and depth of its content and the use made of it by the public. This free information service provides integrated access to the high quality consumer health information produced by NIH and HHS components and other reputable organizations. It has more than 630 "health topics," from Abdominal Pain to Yeast Infections, consumer-friendly information about thousands of prescription and over-the-counter drugs, and an illustrated medical encyclopedia. There are also medical dictionaries, directories of hospitals and health professionals, a daily health news feed from the major print media, 160 interactive and simply presented tutorials (with audio and video) about diseases and medical procedures. Users of MedlinePlus are also linked to current clinical trials related to any topic of interest. A completely Spanish-language version of MedlinePlus has been introduced and is receiving heavy use.

Early in 2003 a prototype MedlinePlus "Go Local" system was introduced in North Carolina, a joint effort of the University of North Carolina and the NLM. This system allows MedlinePlus users access to "NC Health Info," which contains links to local, county, and state health services in North Carolina. Conversely, users of NC Health Info can link into the detailed, authoritative health information about particular diseases and conditions in MedlinePlus. The experience gained and documentation created by NC Health Info will benefit future "Go Local" initiatives in creating successful Web sites to bring local health services information to MedlinePlus users in other states.

There are now about one million "page views" on MedlinePlus every day, three million unique visitors every month, and the numbers continue to grow. To help publicize the database, NLM works closely with the Public Library Association and other organizations not associated with NLM's traditional mandate, as well as with the 4,700 member institutions of the National Network of Libraries of Medicine. Network librarians not only assist in identifying and evaluating information to be included in MedlinePlus, but are of tremendous help in demonstrating MedlinePlus locally and publicizing it.

A unique "Information Rx" pilot project was begun in 2003 when the NLM teamed with the American College of Physicians (ACP) to encourage physicians to "prescribe" information in MedlinePlus for their patients. In Georgia and Iowa participating ACP members were introduced to MedlinePlus and given information prescription pads tailored to their practices and other promotional items. The results are positive so far, and NLM and the ACP are considering taking the program to a national level.

ClinicalTrials.gov

Clinical trials are medical research studies used to evaluate promising new treatments in people. Experimental drugs, medical procedures, and devices must be shown to be safe and effective in human participants before becoming available for widespread clinical use. The database ClinicalTrials.gov integrates previously fragmented information on human studies for different conditions into a single, coherent system, providing the public with an easy-to-use and convenient "one-stop" site for comprehensive information on clinical trials. Created by NLM's Lister Hill National Center for Biomedical Communications and launched in 2000, the site currently includes information on approximately 8,800 trials for hundreds of diseases and conditions conducted in about 90 countries. The site also contains numerous resources for promoting public awareness on the role of clinical trials, including potential risks and benefits to participants.

ClinicalTrials.gov has been designed with an emphasis on ease of use and providing relevant medical information for non-health professionals, including patients, family members, and other health consumers. Visitors may access comprehensive, accurate, and timely information on clinical trials with a few mouse clicks, either by searching or browsing by condition or sponsor. ClinicalTrials.gov supports end-user searching in many ways, including spelling suggestions, as medical terms are often difficult to spell. All study data are presented in a standard format with four sections: Purpose, Eligibility, Locations and Contact Information, and More Information. From within a record, users may access related health topics in MedlinePlus and citations in PubMed/MEDLINE. ClinicalTrials.gov receives approximately 16,000 visitors daily and over 3 million page views monthly.

Profiles in Science

Profiles in Science is a growing resource for students, educators, researchers, and the public. The site makes the 20th century successes of science readily accessible to anyone who is interested in the scientific process and the people who have dedicated their lives to scientific discovery. It does this by collecting and linking to the digitized papers, unpublished items, books, manuscripts, correspondence, photographs, audiotapes, and video clips of notable scientists. Created by the Lister Hill Center in cooperation with the History of Medicine Division, Profiles in Science currently features eleven scientists in three categories: biomedical research, health and medicine, and fostering science and health. In the past year, the papers of Donald Fredrickson (scientist and former NIH director), Florence Sabin (first woman elected to the National Academy of Sciences), and Fred Soper (public health scientist and administrator) were added to the collection. The collections are particularly strong in the areas of cellular biology, genetics, and biochemistry, but also reflect issues in such areas as health and medical research policy, the application of computers in medicine, and the search for extraterrestrial life. Allied to the Profiles site is the digitized collection of all the Reports of the Surgeon General, created by NLM staff and available on the NLM Web site.

Anatomic Images for the Public

The Visible Human Project consists of two enormous (50 gigabytes) data sets, one based on a male cadaver and one on a female, of anatomical MRI, CT, and photographic cryosection images. These data sets are available through a free license agreement to more than 1,700

individuals and institutions in 45 countries where they are being used in a wide range of educational, diagnostic, treatment planning, virtual reality, artistic, and industrial applications. In keeping with the NLM's current emphasis on providing valuable medical information for the public, the Library has launched "*Anatomic Images for the Public Web.*" This site provides widespread access via the Internet to anatomic images from the Visible Human database to the public. The site offers users thumbnails of the cross-section, sagittal and coronal images of the Visible Male and Female, from which full resolution views are accessed. Low bandwidth connections are accommodated by a combination of adjustable viewing areas and image compression techniques. Users may zoom in and out as they navigate through the images.

The demand for the Visible Human anatomic images has been steadily growing by medical researchers and educators throughout the world. Anatomic Images for the Public has increased their value and utility by allowing a wide variety of lay users to access these images easily, by combining rapid retrieval of high-resolution images with effective visual navigation. Anatomic Images for the Public has the potential to generate improvements in the state-of-the-art that would benefit access to any image database, in the exploration of suitable models for linking term queries and images, and in the development of system architectures for image processing and handling. Since its release, access to the site has grown steadily and currently surpasses 83,000 hits per month. In addition to the Web version of Anatomic Images for the Public, a kiosk version was also developed for NLM visitors and patrons. Users may access onsite exhibits through a touch screen monitor and display various anatomic images.

New Information Resources for Consumers

In the last year, five new Web-based information services for the general public have been introduced by the National Library of Medicine. Three different divisions of the NLM have been involved in their development and, in one case, other NIH institutes have made major contributions. They are described in the order in which they were introduced.

The Library's Division of Specialized Information Services, which operates a Toxicology and Environmental Health Information Program, launched **Tox Town** late in 2002. Tox Town looks at an ordinary town and points out many environmental hazards that might exist there. Users can click on a town location, like the school, and see a colorful dollhouse-style cutaway view of that building. Toxic chemicals that might be found in the school are listed, along with links to selected Internet resources about school environments. There are similar cutaways for offices, factories, parks, and other locations. NLM has plans to add new scenes, such as an urban community and a farming region.

Another site for consumers created by the Toxicology and Environmental Health Information Program in 2003 is the *Asian American Health* database. This information resource is a portal to a variety of information resources specifically related to the health of one of the nation's largest minorities—the 11 million Americans of Asian ancestry. This population is exceedingly diverse, coming from nearly 50 countries and ethnic groups, each with distinct cultures, traditions, and histories, and they speak over 100 languages and dialects. Although Asian Americans in the United States suffer from the same health problems as the population at large, certain illnesses predominate. The Asian American Health database contains links to an assortment of useful documents, Web sites, databases, and other resources with important information related to health issues affecting this population.

NLM's Lister Hill National Center for Biomedical Communications introduced yet another consumer health information resource in 2003: the *Genetics Home Reference.* The Human Genome Project has generated a great deal of interest in the promise of genomic medicine. However, the public has been left struggling to understand how genetics applies to human health. Genetics is a complex subject, and much of the primary data and literature are difficult to

understand without formal training. Although the sequence data from the Human Genome Project are readily available on the Internet, little of this information or its implications for human health are accessible to the general public. To address this problem NLM has developed an online resource called the Genetics Home Reference (GHR). The GHR website augments MedlinePlus, NIH's consumer health resource, with summaries of genetics information and an overview of the fundamentals of genetic science. GHR's integrated Web-based approach provides brief, consumer-friendly summaries of genetic conditions and related genes. You can browse by a specific disease/condition or by gene. It also has a geographic list of genetic counselors and information for care-givers. Additional links to consumer information from MedlinePlus, applicable clinical trials, and relevant patient support groups are provided. GHR currently offers more than 100 condition summaries and 80 gene summaries. New content for genes and disorders are being added to GHR and updated continuously.

A new consumer service launched by the Toxicology and Environmental Health Information Program in 2003 is the *Household Products Database.* This is a guide that provides easy-to-understand information on the potential health effects of more than 2,000 ingredients contained in more than 4,000 common household products. The new database provides information on many of these substances and their potential health effects, in consumer-friendly language. For more technical information, users can launch a search for a product or ingredient from the product's page into NLM's TOXNET, a cluster of databases on toxicology, hazardous chemicals, and related areas.

The most recent Web service for consumers, *NIHSeniorHealth.gov*, was launched on October 23, 2003. The new site contains information in a format that is especially usable by senior citizens. To create this unique site, the National Institute on Aging (NIA) and the NLM brought together researchers who study cognition, web site designers, and communications experts at the two institutes to fashion a site that is easy for older adults to read, understand, remember, and navigate. For example, the site features large print and short, easy-to-read segments of information repeated in a variety of formats—such as open-captioned videos and short quizzes—to increase the likelihood it will be remembered. Consistent page layout and prompts help older adults move from one place to another on the site without feeling lost or overwhelmed. Each topic provides general background information, quizzes, frequently asked questions (FAQs), open-captioned video clips, transcripts for the videos, and photos and illustrations with captions. NIHSeniorHealth.gov has a "talking" function, which allows users the option of reading the text or listening to it as it is read to them. Finally, in addition to being senior-friendly, the new site also complies with Section 508 of the Rehabilitation Act of 1973, making it accessible for persons with disabilities.

The risk of many diseases increases with age, so the site sponsors are focusing on health topics or specific diseases that are of particular interest to older people, including Alzheimer's disease, arthritis, balance problems, breast cancer, colorectal cancer, exercise for older adults, hearing loss, lung cancer, and prostate cancer. In coming months, topics will include complementary and alternative medicine, diabetes, falls, shingles, vision changes, and others. Along with the NIA and the NLM, other NIH components contributing topics to the web site so far include the National Cancer Institute, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and the National Institute of Deafness and other Communication Disorders. More Institutes and Centers will be working with the NIA and the NLM to bring on the additional topics.

SCIENCE ADVANCES

Bioinformatics

Molecular biology is arguably the primary driver of medical advances in the 21st century. The staggering volume of molecular data and its cryptic and subtle patterns have led to an absolute

requirement for computerized databases and analysis tools. The challenge is in finding new approaches to deal with the volume and complexity of data and in providing researchers with better access to analysis and computing tools to advance understanding of our genetic legacy and its role in health and disease. The National Center for Biotechnology Information, noted above in connection with GenBank and other information resources for professionals, has expanded rapidly in terms of staff and equipment since its founding in 1987.

The Center is now also conducting research using the human genome sequence to begin exploring the history of human populations. The researchers, working with other collaborators, first assembled a set of 500,000 high-confidence variations and then compared the distribution of these variations on the genome to that predicted by several models of population history. They found that the data best fit a model in which the human population shrank dramatically about 40,000 years ago, a time when modern humans first appeared in Europe. The model also suggests that the population subsequently grew about 30,000 years ago, consistent with archaeological evidence of a population expansion during that period. The model also predicts rates of genetic recombination, a major cause of genetic variation in populations. Although this is an initial study, the results indicate that databases of genetic variation constructed alongside the human genome project can provide a unique insight into the history of human populations. The study supports data from archeological studies, and as future studies are performed with the increasing amount of variation and genomic data available, the picture of our genetic past will be brought more into focus. These efforts are expected to reveal not only the genetic basis of human populations, but also how these populations may respond differently to selective pressures such as infective disease.

Another important study carried out by the NCBI concerns the mutations in the human genome that are responsible for genetic variations in human populations that can lead to either an increased or decreased susceptibility to disease. Common genetic mutations fall into one of three classes: changes in a single letter, or nucleotide, of the 3 billion letters representing the sequence of the genome, deletions of segments of the genomic sequence, or insertions of segments. In this study, an estimate was made of the rates of spontaneous mutations of several kinds for 20 disease-linked genes including those involved in retinoblastoma, neurofibromatosis, Duchenne muscular dystrophy, hemophilia, and nephrogenic diabetes insipidus. The study contributes to our understanding of the mechanisms of genetic disorders. More comprehensive studies encompassing additional genes will be required to broaden the picture of human mutational processes, but the statistical methods and results presented here provide a foundation for future research.

Lister Hill National Center for Biomedical Communications

NLM's Lister Hill National Center for Biomedical Communications sponsors high-technology communications research projects. Several of these have already been described—ClinicalTrials.gov, Profiles in Science, the Visible Human Project and Anatomic Images for the Public, and the Genetics Home Reference database. Over the years the Center has also funded many test bed projects that demonstrate the need for state-of-the-art networking for the delivery of healthcare and health information, including advanced telemedicine. The newest phase, Scalable Information Infrastructure, demonstrates how health-related applications can be designed to guarantee the quality of the telemedicine signal delivered by the network and can scale dynamically to make full use of whatever changing network capability may be available. The Center-supported "A Clinic in Every Home" is an especially promising telemedicine project for medically underserved rural Iowa residents to provide them with access to high quality health care. This demonstration project as a model system is one with the potential to raise the quality of health care and lower costs.

Extramural Programs

NLM's Extramural Programs Division not only has an important role in supporting research and development in biomedical informatics, but the program also funds hundreds of innovative local projects to improve the public's access to electronic health information. NLM recognizes that many health-related organizations, especially smaller ones and those in rural or inner-city settings, lack resources to take full advantage of the Internet's ability to help the public make informed decision on health matters. NLM grants are targeted to help such organizations by improving access and tailoring information resources to meet the needs of special populations. NLM's grant program also is a key supporter of NIH's "Biomedical Information Science and Technology Initiative." The Library supports 18 training programs at U.S. universities to train experts to carry out research in general informatics and in bioinformatics. The NLM has also funded four planning grants for what are called National Programs of Excellence in Biomedical Computing.

Standard Terminology for Patient Data

The need for national standards for patient data has been apparent for more than a decade. Such standards would enable the development of robust clinical systems and support the efficient use of clinical data to improve patient care and to facilitate research. Until recently there were no regularly maintained vocabularies that could be recommended for even selected elements of the automated patient record. Fortunately, a number of organizations, including the College of American Pathologists, the National Health Service of the United Kingdom, and the Regenstrief Institute, have been actively engaged in efforts to expand and improve existing vocabularies to meet a broader range of clinical needs or to develop very specialized nomenclatures to address specific problems, such as automated exchange of laboratory test results. These efforts resulted in improved clinical vocabularies. The essential next steps were to establish mechanisms for selecting the target clinical vocabularies for use in the U.S., for making these generally available at low or no cost via the NLM Unified Medical Language System (UMLS) Metathesaurus, and for encouraging broad testing.

In 1996, the Health Insurance Portability and Accountability Act expanded the role of the National Committee on Vital and Health Statistics (NCVHS) and charged it to produce a report by August 2000 on actions that the federal government should take to promote standards for "patient medical record information." As this report was being developed, NLM led a coalition of government agencies, including the Department of Defense, the Department of Veterans Affairs, and the Centers for Medicare and Medicaid Services (then the Health Care Financing Administration), in establishing a contract arrangement for the ongoing maintenance and free distribution of LOINC (Logical Observations: Identifiers, Names, Codes), which was emerging as a de facto international standard for identifying laboratory tests and test results. The 2000 NCVHS report initiated a process for selecting appropriate clinical data standards, including vocabularies, for use in the U.S.; identified a major gap in available terminologies for drugs; validated that need for federal support for ongoing maintenance and low/no cost dissemination of clinical vocabularies; and recommended that federal agencies serve as early adopters of clinical data standards.

In this environment, NLM enhanced the UMLS and its distribution mechanisms, began an interagency effort to create RxNorm, a clinical drug terminology to fill the gap identified by the NCVHS, and also began negotiations for a U.S.-wide license for use of SNOMED CT, which was then being formed by the merger of two excellent clinical terminologies developed by the College of American Pathologists and the U.K. National Health Service. In 2001, the Administration set up the Consolidated Health Informatics e-Gov initiative which became the vehicle for early federal adoption of clinical data standards, including those that the NCVHS began to recommend in 2002. More than a decade of work to make standard terminology for patient data generally available within the U.S. reached fruition in 2003. LOINC (Logical

Observations: Identifiers, Names, Codes) was designated as the first U.S. government-wide clinical terminology standard in March. NLM and the College of American Pathologists signed a contract and license for U.S.-wide use of SNOMED CT as distributed within the UMLS on June 30. In November, the NCVHS recommended that SNOMED CT and RxNorm also be designated as core terminology standards for patient information and that NLM be assigned responsibility as the coordinating center for the maintenance and distribution of clinical terminologies. Now that the standard terminologies have been selected and made available for use throughout the U.S., they can receive the level of testing and use necessary to identify their strengths and shortcomings. Broad use and feedback will lead to the improvements needed to make standard vocabularies a powerful tool for improving health care quality, speeding public health surveillance, and facilitating clinical research.

BIODEFENSE INFORMATION

NLM also has a role in providing information and research resources in biodefense research efforts. To cite a few examples: genomics research databases for targeted development of drugs, vaccines, and other forms of treatment for such diseases as smallpox, anthrax, plague, Ebola, and cholera; informatics research and development related to terrorism and disaster management; training for health professionals in the use of pertinent information resources; developing experimental information resources targeted at first responders; and improving the information infrastructure so that vital data can be shared during a crisis. The Library's extensive and rapidly expanding collection of biomedical materials has allowed it to react rapidly in the case of public health disaster (such as the September 11 attacks) by putting on the Web vital information for use by health professionals and the public.

NIH ROADMAP

The National Library of Medicine has an important role in the NIH Roadmap. The Roadmap recognizes that one of the most powerful and unifying concepts of 21st century biology is that of bioinformatics—the concept that by understanding and manipulating molecular data, correlated with known morphological structures and physiological functions, we can understand and, ultimately, deal with disease. One of the highest priority projects emerging from the Roadmap initiatives is "Molecular Libraries." This is an ambitious project that seeks to take advantage of genome project data, developments in combinatorial chemistry, availability of small-molecule compounds, and robotic technology in order to obtain a set of chemical probes that interact at certain levels of specificity with a substantial fraction of human proteins. Not only will this initiative permit the study of cellular pathways in greater depth than ever before, but it will also open the way to discovering new drugs by systematically screening thousands of small molecules.

NLM/NCBI will develop a repository, PubChem, for chemical structure and assay data on compounds developed for this initiative as well as a wide range of small molecules of interest to the various NIH Institutes. In particular, the repository will contain legacy data from existing chemical structure databases at NIH, including those from the National Cancer Institute, the National Institute of Mental Health, and the NLM. By providing chemical structure validation and structure-structure matching, PubChem will play an invaluable role in making this information useful to medicinal chemists and other biomedical researchers by enabling cross-referencing assay results and providing cross-links to descriptions of the compound's biological activity in scientific journal articles.

A second tie between the NIH Roadmap and the NLM is in the need to re-engineer the national clinical research enterprise. One aspect of this is NLM's leadership role in working with biomedical vocabularies and with the recently announced arrangement with the SNOMED clinical vocabulary (described above). Another is the high priority NLM has placed on

expanding the NIH clinical trials database. Both of these will be important in improving clinical research as called for in the Roadmap.

NLM INITIATIVES

Outreach

A continuing initiative of the National Library of Medicine is to engage in a variety of outreach activities so that health professionals and the public will be aware of, and take advantage of, the NLM's many information services. The National Network of Libraries of Medicine, noted above in connection with MedlinePlus, is an important partner of NLM in this endeavor. Network libraries more and more rely on the NLM to have on its shelves materials that smaller libraries either cannot afford or do not have space to accommodate.

Many of the Network's outreach programs are directed at minority populations. For example, there are programs to assist in remedying the disparity in health opportunities experienced by such segments of the American population as African Americans, Latinos, Native Americans, senior citizens, and rural populations. One of the most successful of such efforts involves a telemedicine "connections" program for Native Americans in the Pacific Northwest conducted through the Regional Medical Library at the University of Washington.

Another highly successful NLM outreach program has been strengthening Historically Black Colleges and Universities so that they can train people to use information resources in dealing with environmental and chemical hazards. Under this program, faculty and students in more than 80 minority institutions have received such technical training. Through these schools, NLM is working to promote high-quality Internet connectivity and using technology for research and education. The latest aspect of this outreach effort is NLM's collaboration with the United Negro College Fund Special Programs Corporation to work with the HBCUs in the area of consumer health to encourage the use of reliable electronic health information (such as that provided by the NLM) by the public.

There are other NLM outreach programs targeting groups of citizens with special health information needs. In the past several years, the Library has made more than 50 awards to continue its HIV/AIDS-related outreach efforts to community-based organizations, patient advocacy groups, faith-based organizations, departments of health, and libraries. This program supports local programs to improve information access for AIDS patients, the affected community, and caregivers. Emphasis is on providing information in a way that is meaningful to the target community, and may include training in information retrieval, sending interlibrary loans, and providing Internet access.

NLM's efforts to reach special populations in need are not limited to the United States. An international partnership in which the NLM is a key player is the Multilateral Initiative on Malaria. NLM's mandate as leader of the Communications Working Group has been to leverage partnerships (at 13 installations) to create a malaria research network in Africa, enabling scientists there to have full access to the Internet and the Web as well as access to medical literature. The aim is to allow researchers, any time of the day or night, to have instantaneous Internet access that will enable them to send and receive e-mails, search for literature, interrogate databases, share files and images with colleagues, and generally move to a new and more efficient way of doing collaborative research.

Web Evaluation

Because the NLM relies heavily on the Internet to provide information services, it is important that the Library monitor and evaluate the performance of its systems. To do this, NLM has embarked on an ambitious evaluation program that seeks to evaluate End-To-End Internet

Performance, Broadband Infrastructure Capacity, Usability Testing, Audience Measurement, and Information Seeking Behavior and User Satisfaction. This multidimensional strategy has been successful in pinpointing areas where improvements can be made to speed up or make more useful NLM's Web-based services. Moreover, the evaluation program complements and leverages NIH's investment by providing a metric for gauging the impact of NIH programs by answering the broad question of how many people today have rapid access to needed biomedical and health care information.

Permanent Access and Research Resources

Despite the NLM's extensive involvement with advanced computer and communications technology, the staff is ever mindful of its responsibility to maintain the integrity of the world's largest collection of medical books and journals. Increasingly, this information is in digital form, and the NLM, as a national library responsible for preserving the scholarly record of biomedicine, is working with the Library of Congress and others to develop a strategy for selecting, organizing, and ensuring permanent access to digital information. Regardless of the format in which the materials are received, ensuring their availability for future generations remains the Library's highest priority.

NLM BUDGET POLICY

The Fiscal Year 2005 budget request for the NLM is $325,147,000, an increase of $16,671,000 and 5.4 percent over the FY 2004 Final Conference Level. Also included in the FY 2005 request, is NLM's support for the trans-NIH Roadmap initiatives, estimated at 0.63% of the FY 2005 budget request. This Roadmap funding is distributed through the mechanisms of support, consistent with the anticipated funding for the Roadmap initiatives. A full description of this trans-NIH program may be found in the NIH Overview.

A five year history of FTEs and Funding Levels for NLM are shown in the graphs below. Note that the Fiscal Year 2001 FTE figure is not comparable to the figures in the succeeding years due to NIH's consolidation of its Human Resources function in FY 2003.
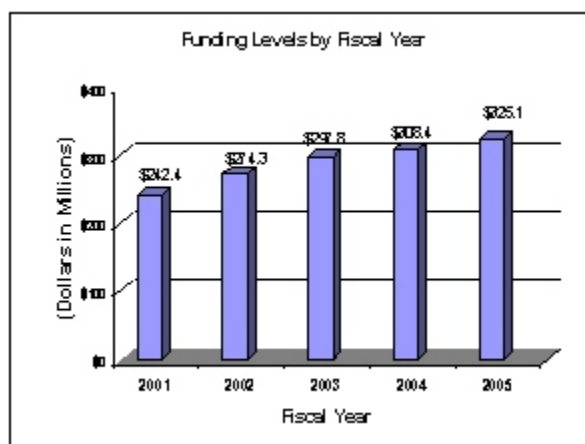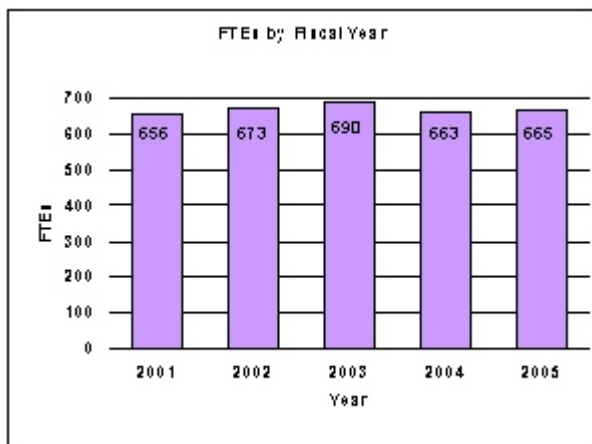
The request continues to support health care applications; improve consumer health information; utilize advanced computer and communications technologies; emphasize support for library operations including literature acquisition, management, dissemination, and preservation; funds grants in Integrated Advanced Information Management Systems, training, medical informatics, biotechnology and other research and development activities.

The increase requested is targeted towards special activities which include Consumer/Minority Health and Genetics of Medicine. It also provides for funding Health Services Research activities with appropriated funds rather than PHS Evaluation authority.

The FY 2005 budget request for NLM by budget activity is illustrated below:

FY 2005
Budget Mechanism
(Dollars in thousands)

Lister Hill Center $61,876 19%

Biotechnology Center $73,145 22%

Specialized Information $14,469 4%

RM&S $11,708 4%

Extramural Programs $70,810 22%

Library Operations $93,139 29%
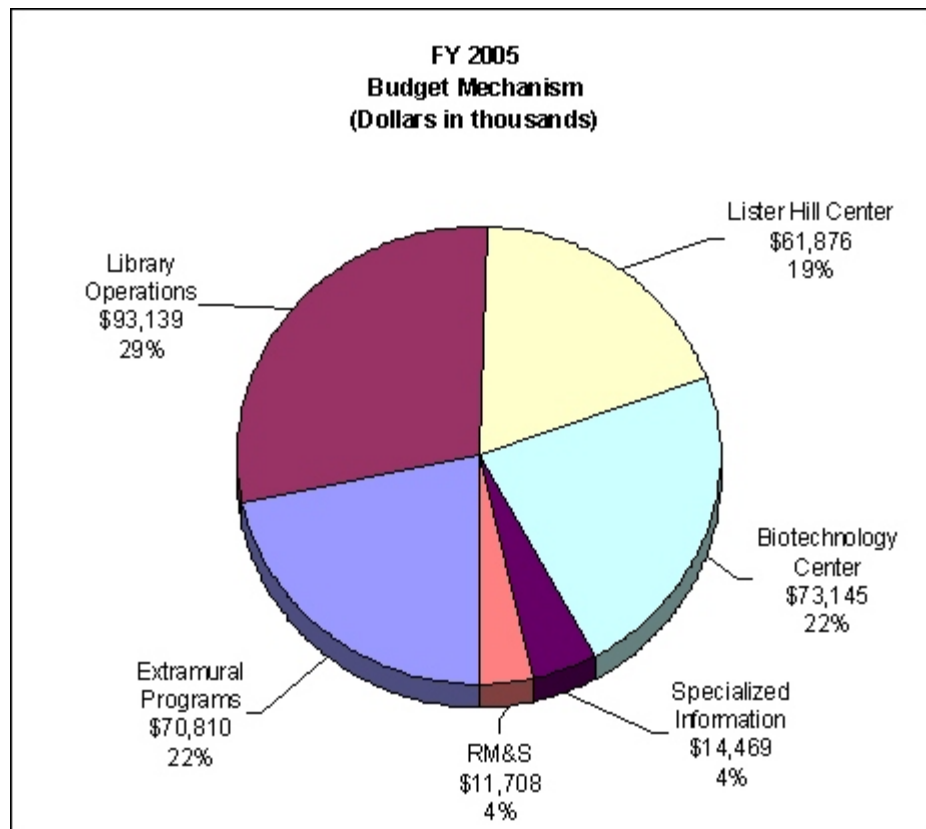
NATIONAL INSTITUTES OF HEALTH

National Library of Medicine

Budget Mechanism - Total

MECHANISM	FY 2003 Actual		FY 2004 Final Conference		FY 2005 Estimate	
	No.	Amount	No.	Amount	No.	Amount
Grants:						
Noncompeting	120	$37,539,000	125	$40,561,000	127	$44,972,000
Competing	76	14,335,000	73	13,378,000	58	11,001,000
SBIR/STTR	2	663,000	2	930,000	10	1,000,000
Subtotal, Grants	198	52,537,000	200	54,869,000	195	56,973,000
Contracts:						
Noncompeting	10	13,842,000	8	12,928,000	9	13,337,000
Competing	12	291,000	7	1,800,000	7	500,000
Subtotal, Contracts	22	14,133,000	15	14,728,000	16	13,837,000
Total, Extramural	220	66,670,000	215	69,597,000	211	70,810,000
	FTEs		FTEs		FTEs	
Intramural Programs:						
Library Operations	350	79,963,000	334	81,695,000	333	93,139,000
Lister Hill Center	78	59,452,000	75	60,674,000	74	61,876,000
Biotechnology Center	137	66,730,000	138	71,073,000	142	73,145,000
Specialized Information	34	13,996,000	31	14,156,000	31	14,469,000
Total, Intramural	599	220,141,000	578	227,598,000	580	242,629,000
Research management and support	91	11,034,000	85	11,281,000	85	11,708,000
Total, NLM	690	297,845,000	663	308,476,000	665	325,147,000
(RoadMap Support)				(1,060,000)		(2,051,000)

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NATIONAL INSTITUTES OF HEALTH

National Library of Medicine
Budget Authority by Activity
(dollars in thousands)

ACTIVITY	FY 2003 Actual		FY 2004 Estimate		FY 2005 Estimate		Change	
	FTEs	Amount	FTEs	Amount	FTEs	Amount	FTEs	Amount
Extramural Programs:								
Medical Library Assistance		$37,862		$39,206		$39,841		$635
PHS 301		27,761		29,461		29,969		508
SBIR/STTR		1,047		930		1,000		70
Subtotal, Extramural		66,670		69,597		70,810		1,213
Intramural Programs:								
Library Operations	350	79,963	334	81,695	333	93,139	(1)	11,444
Lister Hill Center	78	59,452	75	60,674	74	61,876	(1)	1,202
Biotechnology Center	137	66,730	138	71,073	142	73,145	4	2,072
Specialized Information	34	13,996	31	14,156	31	14,469	0	313
Subtotal, Intramural	599	220,141	578	227,598	580	242,629	2	15,031
Research management and support	91	11,034	85	11,281	85	11,708	0	427
Total	690	297,845	663	308,476	665	325,147	2	16,671

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Summary of Changes

FY 2004 Final Conference				$308,476,000
FY 2005 Estimated Budget Authority				325,147,000
Net change				16,671,000

	FY 2004 Budget Base		Change from Base	
CHANGES	FTEs	Budget Authority	FTEs	Budget Authority
A. Built-in:				
1. Intramural research:				
a. Within grade increase		$52,968,000		$954,000
b. Annualization of January				
2004 pay increase		52,968,000		542,000
c. January 2005 pay increase		52,968,000		595,000
d. One less day of pay		52,968,000		(203,000)
e. Payment for centrally furnished services		7,844,000		235,000
f. Increased cost of laboratory supplies, materials, and other expenses		166,786,000		2,829,000
Subtotal				4,952,000
2. Research Management and Support				
a. Within grade increase		7,854,000		141,000
b. Annualization of January				
2004 pay increase		7,854,000		80,000
c. January 2005 pay increase		7,854,000		89,000
d. One less day of pay		7,854,000		(30,000)
e. Payment for centrally furnished services		0		0
f. Increased cost of laboratory supplies, materials, and other expenses		3,427,000		112,000
Subtotal				392,000
Subtotal, Built-in				5,344,000

CHANGES	FY 2004 Budget Base		Change from Base	
	No.	Amount	No.	Amount
B. Program:				
1. Research project grants:				
a. Noncompeting	125	$40,561,000	3	$4,411,000
b. Competing	80	15,178,000	(15)	(2,377,000)
c. SBIR/STTR	2	930,000	8	70,000
Total	207	56,669,000	(4)	2,104,000
2. Research and development contracts	8	12,928,000	0	(891,000)
Subtotal, extramural				1,213,000
	FTEs		FTEs	
3. Intramural research	578	227,598,000	2	10,079,000
4. Research management and support	85	11,281,000	0	35,000
Subtotal, program	663	308,476,000	2	11,327,000
Total changes	663		2	16,671,000

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Budget Authority by Object

	FY 2004 Final Conference	FY 2005 Estimate	Increase or Decrease
Total compensable workyears:			
Full-time employment	663	665	2
Full-time equivalent of overtime & holiday hours	3	0	(3)
Average ES salary	$149,158	$154,677	$5,519
Average GM/GS grade	10.6	10.6	0.0
Average GM/GS salary	$67,842	$70,352	$2,510
Average salary, grade established by act of			
July 1, 1944 (42 U.S.C. 207)	$90,676	$94,031	$3,355
Average salary of ungraded positions	100,921	104,655	3,734

OBJECT CLASSES	FY 2004 Final Conference	FY 2005 Estimate	Increase or Decrease
Personnel Compensation:			
11.1 Full-Time Permanent	$33,566,000	$34,823,000	$1,257,000
11.3 Other than Full-Time Permanent	13,405,000	13,907,000	502,000
11.5 Other Personnel Compensation	1,138,000	1,138,000	0
11.7 Military Personnel	458,000	458,000	0
11.8 Special Personnel Services Payments	662,000	1,000,000	338,000
Total, Personnel Compensation	49,229,000	51,326,000	2,097,000
12.1 Civilian Personnel Benefits	11,573,000	11,965,000	392,000
12.2 Military Personnel Benefits	20,000	21,000	1,000
13.0 Benefits for Former Personnel	0	0	0
Subtotal, Pay Costs	**60,822,000**	**63,312,000**	**2,490,000**
21.0 Travel & Transportation of Persons	1,329,000	1,350,000	21,000
22.0 Transportation of Things	150,000	152,000	2,000
23.1 Rental Payments to GSA	3,000	3,000	0
23.2 Rental Payments to Others	50,000	51,000	1,000
23.3 Communications, Utilities &			
Miscellaneous Charges	2,522,000	2,555,000	33,000
24.0 Printing & Reproduction	583,000	591,000	8,000
25.1 Consulting Services	45,860,000	46,456,000	596,000
25.2 Other Services	40,728,000	50,146,000	9,418,000
25.3 Purchase of Goods & Services from			
Government Accounts	41,897,000	43,154,000	1,257,000
25.4 Operation & Maintenance of Facilities	2,133,000	2,161,000	28,000
25.5 Research & Development Contracts	27,768,000	28,129,000	361,000
25.6 Medical Care	0	0	0
25.7 Operation & Maintenance of Equipment	9,097,000	9,215,000	118,000
25.8 Subsistence & Support of Persons	0	0	0
25.0 Subtotal, Other Contractual Services	**167,483,000**	**179,261,000**	**11,778,000**
26.0 Supplies & Materials	1,562,000	1,582,000	20,000
31.0 Equipment	20,528,000	21,372,000	844,000
32.0 Land and Structures	0	0	0
33.0 Investments & Loans	0	0	0
41.0 Grants, Subsidies & Contributions	53,431,000	54,905,000	1,474,000
42.0 Insurance Claims & Indemnities	0	0	0
43.0 Interest & Dividends	13,000	13,000	0
44.0 Refunds	0	0	0
Subtotal, Non-Pay Costs	**247,654,000**	**261,835,000**	**14,181,000**
Total Budget Authority by Object	**308,476,000**	**325,147,000**	**16,671,000**

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Salaries and Expenses

OBJECT CLASSES	FY 2004 Final Conference	FY 2005 Estimate	Increase or Decrease
Personnel Compensation:			
Full-Time Permanent (11.1)	$33,566,000	$34,823,000	$1,257,000
Other Than Full-Time Permanent (11.3)	13,405,000	13,907,000	502,000
Other Personnel Compensation (11.5)	1,138,000	1,138,000	0
Military Personnel (11.7)	458,000	458,000	0
Special Personnel Services Payments (11.8)	662,000	1,000,000	338,000
Total Personnel Compensation (11.9)	**49,229,000**	**51,326,000**	**2,097,000**
Civilian Personnel Benefits (12.1)	11,573,000	11,965,000	392,000
Military Personnel Benefits (12.2)	20,000	21,000	1,000
Benefits to Former Personnel (13.0)	0	0	0
Subtotal, Pay Costs	**60,822,000**	**63,312,000**	**2,490,000**
Travel (21.0)	1,329,000	1,350,000	21,000
Transportation of Things (22.0)	150,000	152,000	2,000
Rental Payments to Others (23.2)	50,000	51,000	1,000
Communications, Utilities and Miscellaneous Charges (23.3)	2,522,000	2,555,000	33,000
Printing and Reproduction (24.0)	583,000	591,000	8,000
Other Contractual Services:			
Advisory and Assistance Services (25.1)	45,860,000	46,456,000	596,000
Other Services (25.2)	40,728,000	50,146,000	9,418,000
Purchases from Govt. Accounts (25.3)	27,628,000	28,525,000	897,000
Operation & Maintenance of Facilities (25.4)	2,133,000	2,161,000	28,000
Operation & Maintenance of Equipment (25.7)	9,097,000	9,215,000	118,000
Subsistence & Support of Persons (25.8)	0	0	0
Subtotal Other Contractual Services	**125,446,000**	**136,503,000**	**11,057,000**
Supplies and Materials (26.0)	1,562,000	1,582,000	20,000
Subtotal, Non-Pay Costs	131,642,000	142,784,000	11,142,000
Total, Administrative Costs	**192,464,000**	**206,096,000**	**13,632,000**

NATIONAL INSTITUTES OF HEALTH

National Library of Medicine

SIGNIFICANT ITEMS IN HOUSE AND SENATE APPROPRIATIONS COMMITTEE
REPORTS

FY 2004 House Appropriations Committee Report Language (H. Rpt. 108-188)

Item
Outreach - The Committee encourages NLM to continue its outreach activities aimed at educating health care professionals and the general public about the Library's products and services, in coordination with medical librarians and other health information specialists (p. 89)

Action taken or to be taken
NLM carries out a diverse set of activities directed at building awareness and use of its products and services by health professionals in general and by particular communities of interest. Considerable emphasis has been placed on reducing health disparities by targeting health professionals who serve rural and inner city areas. Additionally, starting in 1998, NLM has undertaken new initiatives specifically devoted to addressing the health information needs of the public. These projects build on long experience with addressing the needs of health professionals and on targeted efforts aimed at making consumers aware of medical resources, particularly in the HIV/AIDS area.

A few examples of NLM outreach activities aimed at educating health care professionals and the general public about the Library's products and services include:
Creating the "Health Information Prescription" program. This program provides customized

prescription pads that doctors can use to point patients to first-rate online health information in NLM's MEDLINEplus database.
Working with numerous Texas entities to promote NLM's MEDLINEplus En Espanol.

Traveling to speak with native American groups in the Dakotas, Alaska, and Hawaii to

identify opportunities for collaboration on tribal outreach projects.
Initiating a pilot project intended to establish a mechanism to strengthen the capacity of

Historically Black Colleges and Universities (HBCUs) to train medical and other health professionals in the use of NLM's toxicology, environmental, and occupational health and hazardous waste information resources.
Establishing an agreement with the United Negro College Fund Special Programs

Corporation (UNCFSP) to provide awareness about health information to a selected group of HBCUs and support small information outreach projects initiated by faculty on several campuses.

Item
PubMed Central - The Committee commends NLM for its leadership in developing PubMed Central, an electronic online repository for life science articles. Because of the high level of expertise health information specialists have in the organization, collection, and dissemination of medical information, the Committee believes that health sciences librarians have a key role to play in the further development of PubMed Central. The Committee encourages NLM to work with the medical library community regarding issues related to copyright, fair use, peer-review and classification of information on PubMed Central (p. 89)

Action taken or to be taken
NLM considers interaction and input from the medical library community essential for the development and continued success of PubMed Central(PMC). The PubMed -Central National Advisory Committee advises the Directors of NIH, NLM, and the National Center for Biotechnology Information on the content and operation of the PMC repository. A primary charge of the committee is to ensure that PMC remains responsive to the needs of researchers, librarians, publishers, and the general public. Medical librarians have played an active role in the committee since its inception. The current membership includes four librarians. In 2002, the librarians on the PMC committee joined other members in strongly recommending that NLM digitize the back issues of the journals in PMC in order to make complete sets available online. NLM has acted on that recommendation and in November 2003 released an online version of the first such journal, the Bulletin of the Medical Library Association, dating back to 1911. Members of the medical library community have been especially pleased with this development.

Item
Minority Health - The Committee encourages NLM to enhance its support of annual conferences sponsored by the minority health professions community designed to foster increased interest among minority students in the fields of biomedical science and bioinformatics (p. 89)

Action taken or to be taken
In FY 2003, NLM exhibited at a number of annual conferences, including the following: American Indian Science and Engineering Society, Black Psychiatrists of America, National Black Nurses Association, National Medical Association, Student National Medical Association, National Alaska Native American Indian Nurses Association, Hispanic Association of Colleges and Universities, National Hispanic Medical Association, and the Minority Health Professions Foundation. We plan to continue and expand this activity.

In FY 2003, NLM participated in the NIH American Indian Pow-Wow Initiative. This included exhibiting at 8 pow-wows in the Mid-Atlantic area. An estimated 8,000 persons visited the NLM booth over the course of these pow-wows. These activities proved to be another viable way to bring NLM's health information to the attention to segments of the Native American community and the general public. We will continue to expand this activity in FY 2004.

Item
Bioethics literature - As Congress and other Federal and state decision makers contemplate important policy decisions in the field of bioethics, the Committee commends NLM for its support of the National Reference Center for Bioethics Literature (NRCBL) and the Bioethics Information Retrieval (BIR) Project. The NRCBL and BIR Project have created comprehensive interdisciplinary information resources which serve as models for bioethics research centers worldwide. The Committee is aware that the NLM is undertaking a review of how it manages bioethics research materials. As that process moves forward, the Committee would like to be kept fully informed about that review (p. 90)

Action taken or to be taken
In the spring of 2003, the NLM Board of Regents established a Working Group to assess the combined: (1) breadth and quality of the collections of bioethics literature and (2) indexing and cataloging coverage of the bioethics literature produced directly by NLM or by the Kennedy Institute of Bioethics with NLM funding. The Working Group on Bioethics is comprised of outside experts and is chaired by NLM Board member Dr. Thomas Detre of the University of Pittsburgh Medical Center. It has met twice, in May and September of 2003, and corresponded often by email. The Working Group has concluded that NLM and the Kennedy Institute of Ethics (KIE) have very complete and high quality resources, but need to do better at promoting awareness of these resources and providing better retrieval mechanisms. The Working Group expects to submit a report with recommendations to the NLM Director in early calendar 2004.

FY 2004 Senate Appropriations Committee Report Language (S. Rpt. 108-81)

Item
Bioethics Research - The Committee urges the NLM to maintain strong support for the National Reference Center for Bioethics Literature [NRCBL] and the Bioethics Information Retrieval [BIR] Project. The BIR Project provides critically important enhancement to NLM's indexing of journal articles, thus facilitating searches on the Bioethics Subset of the NLM's MEDLINE database (p. 164)

Action taken or to be taken
Please refer to the above House item for NLM's response to this significant item regarding Bioethics on page 24.

Item
Digital Human - Advances in medical research depend increasingly on using simulations to integrate the flood of biomedical research information in ways that can greatly enhance research aimed at understanding human health and curing disease, improve the practice of medicine, contribute to health and science education and training. The Committee acknowledges the pioneering work NIH has done in this area including at the: NIGMS, NINDS, NHLBI, NCRR, and NLM. Stronger NIH-wide management and coordination of this work could, however, achieve efficiencies and speed progress, and minimize duplication and costs in this critical and rapidly expanding research field and coordination with all NIH institutes and centers. The Committee encourages the NLM to develop consensus standards, ensure that simulation components developed by different groups work together efficiently, manage a review and error correction process, and provide a publicly available repository of models, simulations, and associated data. The Committee encourages NIH to develop a plan describing how coordination can best be achieved. The Committee further requests NIH to consider convening a conference of experts in biomedical simulations related fields to gather advice about where strengthened coordination of research and information is most needed and options for undertaking an NIH-wide effort to implement these recommendations (p. 164)

Action taken or to be taken
NIH has recently completed plans for a five-year initiative for the National Institutes of Health entitled, "The Roadmap." NIH has consulted over 300 experts in the fields of biology and technology in order to ascertain the present state of knowledge in several fields and the potential for development in the near future. From these discussions we have concluded that while entirely worthwhile, there is at the present time insufficient knowledge in both the biological database and the expertise in computer modeling techniques to initiate a full Digital Human Project. NIH recognizes the past successes of the Manhattan, Space, and Genome Projects, which also apparently faced insuperable obstacles in their early stages.

NIH is taking steps toward the eventual initiation of a full Digital Human Project. The NIH Roadmap includes the development of National Centers for Biomedical Computing. NIH has dedicated $14 million in the first year for three or four National Centers to be funded in October 2004. The seven cores of each center will provide a foundation in technology, research projects, training and education similar to that outlined in proposals for the Digital Human Project. In addition, NIH will continue to fund thousands of projects in the biological and medical sciences that will contribute the necessary knowledge for the advancement of this program.

In addition, NLM is planning to survey all the mathematical computer modeling programs in the 26 NIH Institutes and Centers to ascertain the nature of the intramural projects now being undertaken in these areas. A similar survey is being developed for extramural grants funded by the various institutes.

Item
Expanding Library Facility - The Committee was pleased to receive the reports it requested on expanding the facility for the National Library of Medicine, and to learn that the design work will be completed by August 2003. If NLM's cutting-edge biotechnology and other communications programs are to make their maximum contribution to advancing the Nation's biomedical research agenda, it is clear that the Library must have adequate facilities. In this regard, the Committee believes that construction should begin now on an expedited schedule. The need is mission-critical and a delay could significantly increase the cost (p. 164)

Action taken or to be taken
The design work for a new National Library of Medicine building is complete.

Item
Home Medical Consultations - The Committee expects the NLM to support an expansion of a demonstration called for in last year's report to test the use of state-of-the-art telemedicine technology for home medical consultations. This innovative approach holds great promise for improving the care and lowering health care costs for home-bound individuals who require frequent monitoring (p. 165)

Action taken or to be taken
The National Library of Medicine has been funding a model project at the University of Iowa in cooperation with the Iowa Department of Public Health to develop tele-home health care as a vehicle for enhancing the delivery of medical care. The Iowa prototype is a state-wide tele-home health care model that can then be deployed in similar rural or underserved areas. Initially the impact of tele-home health care on preventive care, monitoring of "at-risk" patients, acute care, and chronic illness management is being assessed.

Columbia University used telemedicine technology to provide disease prevention and chronic illness management information to patients at home. Patients entered blood pressures, glucose levels and pulmonary function test results into an electronic medical record using applications which ran on home based personal computers connected to the Internet. Patients received alerts and reminders when their individual goals for immunization, diabetes management and asthma control were not achieved. The project demonstrated techniques to safeguard the confidentiality of electronic personal health care records and evaluated the impact of home telemedicine provided via the Internet.

In a cooperative effort with the Science Applications International Corporation (SAIC), University of California, San Diego launched PCASSO, a project designed to enable at home patients, health care providers and medical researchers to access clinical information over the Internet without any breaches of confidentiality. PCASSO uses everyday World Wide Web technology to support information search and retrieval, and state of the art security technology to ensure patient privacy and the integrity of patient information. The project represents a new thrust within the health care industry: to provide at home patients more control over and access to their own medical records while preserving the confidentiality of that information.

NLM used many of the lessons learned from these projects as a basis for including home telehealth under its new Scalable Information Infrastructure Program. This program seeks to explore technologies that would be useful in a home telehealth setting including home telehealth applications which are dependent on wireless technology, those which involve the use of advanced authentication methodologies, e.g. biometrics or smartcards, and nomadic technology applications which would benefit from the use of geographic information systems (GIS).

Item
Minority Health - The Committee encourages NLM to expand its support of annual conferences sponsored by the minority health professions community designed to foster increased interest among minority students in the fields of biomedical science and bioinformatics (p. 165)

Action taken or to be taken
Please refer to the above House item for NLM's response to this significant item regarding Minority Health on page 24.

Item
Outreach - The Committee encourages NLM to continue its outreach activities aimed at educating health care professionals and the general public about the Library's products and services, in coordination with medical librarians and other health information specialists (p. 165)

Action taken or to be taken
Please refer to the above House item for NLM's response to this significant item regarding Outreach on page 23.

Item
PubMed Central - The Committee commends NLM for its leadership in developing PubMed Central, an electronic online repository for life science articles. Because of the high level of expertise health information specialists have in the organization, collection, and dissemination of medical information, the Committee believes that health sciences librarians have a key role to play in the further development of PubMed Central. The Committee encourages NLM to work with the medical library community regarding issues related to copyright, fair use, peer-review and classification of information on PubMed Central (p. 165)

Action taken or to be taken
Please refer to the above House item for NLM's response to this significant item regarding PubMed Central on page 23.

Item
Senior Citizen Outreach - The Committee again notes that senior citizens would benefit greatly from expanded access to NLM's databases, and it supports NLM's efforts to pursue this goal. The Committee encourages innovative means to reach older Americans, including Internet access at senior centers and congregate meal sites (p. 165/166)

Action taken or to be taken
The NLM remains committed to making health information on the Internet easily available to all citizens -- especially older Americans. NLM's interest in reaching older Americans is two-fold: 1) more and more older people are using the Internet as a source of health information, and 2) Americans over the age of 65 are twice as likely to be hospitalized than their younger-aged counterparts. Clearly, seniors can benefit tremendously from increased access to good, reliable, up-to-date health information from the National Institutes of Health. To better meet the growing information needs of seniors, the National Library of Medicine and the National Institute on Aging (NIA) have developed NIHSeniorHealth.gov -- a new website that is compatible with the cognitive, visual and perceptual changes that occur with age. This new site was beta-tested in late 2002 and early 2003. In October, 2003, the NLM and the NIA launched NIHSeniorHealth.gov at a congressional event on Capitol Hill. Efforts are now underway to work with other NIH Institutes to assist them in the transfer vital health information into this new senior-friendly format.

In addition to developing a senior-friendly website, the NLM also remains dedicated to increasing the access seniors have to good health information. Therefore, NLM is partnering with the American College of Physicians and the American Society of Internal Medicine

(ACP/ASIM) to sensitize patients about the availability of MEDLINEplus -- NLM's free, comprehensive, authoritative health information website. Beginning in the spring of 2003, ACP/ASIM members in Georgia, Iowa, and Virginia, will begin writing "Information Prescriptions" directing their patients to MEDLINEplus as a source of health information on the Internet. Research shows that the public is eager to obtain good sources of health information on the web and are more likely to trust a website that has been recommended by their physician. After incorporating findings from these early pilots, the NLM plans to join the ACP Foundation in launching this project nationally.

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Authorizing Legislation

	PHS Act/ Other Citation	U.S. Code Citation	2004 Amount Authorized	2004 Final Conference	2005 Amount Authorized	2005 Budget Estimate
Research and Investigation	Section 301	42§241	Indefinite		Indefinite	
National Library of Medicine	Section 465	42§286	Indefinite	$308,476,000	Indefinite	$325,147,000
National Research Service Awards	Section 487(d)	42§288	a/	0	b/	0
Total, Budget Authority				308,476,000		325,147,000

a/ Amounts authorized by Section 301 and Title IV of the Public Health Act.
b/ Reauthorizing legislation will be submitted.

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Appropriations History

Fiscal Year	Budget Estimate to Congress		House Allowance	Senate Allowance		Appropriation 1/	
1996 2/	$136,311,000		$138,277,000	$136,781,000		$141,439,000	
Rescission						(257,000)	
1997	143,268,000	2/	146,738,000	145,164,000	2/	151,103,000	3/
1998	152,689,000	2/	161,171,000	159,411,000	2/	161,185,000	
1999	170,738,000		176,492,000	181,309,000		180,742,000	
Rescission						(120,000)	
2000	185,654,000	2/	202,027,000	210,183,000		215,214,000	
Rescission						(1,146,000)	
2001	230,135,000	2/	256,281,000	256,953,000		246,801,000	
Rescission						(399,000)	
2002	275,725,000		273,610,000	281,584,000		277,658,000	
Rescission						(1,567,000)	
2003	313,534,000		313,534,000	331,443,000		302,099,000	
Rescission						(1,964,000)	
2004	315,401,000		315,401,000	319,396,000		311,635,000	
Rescission						(2,520,000)	
2005	325,147,000						

1/ Reflects enacted supplementals, rescissions, and reappropriations.
2/ Excludes funds for HIV/AIDS research activities consolidated in the NIH Office of AIDS Research.
3/ Excludes enacted administrative reductions of $275,000.

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Detail of Full-Time Equivalent Employment (FTEs)

OFFICE/DIVISION	FY 2003 Actual	FY 2004 Final Conference	FY 2005 Estimate
Division of Library Operations	350	334	333
Lister Hill Nat'l Ctr. For Biomedical Co	78	75	74
National Center for Biotechnology Info.	137	138	142
Div. Of Specialized Information Service	34	31	31
Office of the Director	27	27	27
Office of Administration and Management	46	42	42
Division of Extramural Programs	18	16	16
Total	690	663	665
FTEs supported by funds from Cooperative Research and Development Agreements	(0)	(0)	(0)

FISCAL YEAR	Average GM/GS Grade
2001	10.2
2002	10.2
2003	10.5
2004	10.6
2005	10.6

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

Detail of Positions

GRADE	FY 2003 Actual	FY 2004 Final Conference	FY 2005 Estimate
ES-6	0	0	0
ES-5	1	1	1
ES-4	2	2	2
ES-3	1	1	1
ES-2	2	2	2
ES-1	0	0	0
Subtotal	6	6	6
Total - ES Salary	$845,086	$928,062	$962,400
GM/GS-15	30	30	30
GM/GS-14	47	47	47
GM/GS-13	106	106	106
GS-12	139	139	139
GS-11	35	35	35
GS-10	3	3	3
GS-9	23	23	23
GS-8	80	80	80
GS-7	31	31	31
GS-6	12	12	12
GS-5	9	9	9
GS-4	36	23	21
GS-3	12	12	12
GS-2	5	5	5
GS-1	0	0	0
Subtotal	568	555	553
Grades established by Act of July 1, 1944 (42 U.S.C. 207):			
Assistant Surgeon General Director Grade	2	1	1
Senior Grade	1	1	1
Full Grade			
Senior Assistant Grade			
Assistant Grade			
Subtotal	3	2	2
Ungraded	143	133	137
Total permanent positions	522	522	522
Total positions, end of year	720	696	698
Total full-time equivalent (FTE) employment,end of year	690	663	665
Average ES level	ES-3	ES-3	ES-3
Average ES salary	$140,848	$149,158	$154,677
Average GM/GS grade	10.5	10.6	10.6
Average GM/GS salary	$64,062	$67,842	$70,352

NATIONAL INSTITUTES OF HEALTH
National Library of Medicine

New Positions Requested

	FY 2005		
	Grade	Number	Annual Salary
Senior Staff Scientists	Ungraded	4	$100,921
Total Requested		4	