

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

Fiscal year 2004 Budget Request

Donald A. B. Lindberg, M.D.
Director, National Library of Medicine

April 3, 2003

Kerry N. Weems, Acting Assistant Secretary for Budget, Technology and Finance, HHS

William R. Beldon, Acting Deputy Assistant Secretary for Budget, HHS

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Statement by

Donald A. B. Lindberg, M.D.
Director, National Library of Medicine
on
Fiscal Year 2004 President's Budget Request
for the National Library of Medicine

Mr. Chairman and Members of the Committee:

I am pleased to present the President's budget request for the National Library of Medicine (NLM) for Fiscal Year 2004, a sum of \$316,040,000, which reflects an increase of \$9,334,000 over the Fiscal Year 2003 enacted level of \$306,706,000 comparable for transfers proposed in the President's request.

For more than 150 years one institution has been the nation's primary source of published medical information—your National Library of Medicine (NLM). Originally part of the Army, the Library became a civilian organization in the 1950s and a part of the NIH in the 1960s. 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 NLM not only maintains the world's largest collection of biomedical books and journals, but it has become, via the Web, a ubiquitous source of authoritative information for scientists, health professionals, and consumers around the world. Some half a *billion* searches of the various NLM databases are done each year.

The NLM in the 21st century is distinguished especially by two features unknown to it just two decades ago: the institution has become the leading source of human genome information and at the same time an important source of nontechnical health information for the public. The proximate source of the information that makes both these features possible is the National Institutes of Health. The NLM, through the Web operations of its National Center for Biotechnology Information, 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. On the other hand, the extensive health information issued by the various NIH

institutes and centers forms the backbone of the MEDLINEplus information service offered to the general public.

An unusual aspect of the NLM's contemporary role that there is a direct connection between the Library's research and information programs and the defense against bioterrorism and medical and public health preparedness for disaster management and terrorist attack. 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 R & D 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. As to post-9/11 information services, NLM quickly placed pages on its Web site about post-traumatic stress disorder, biological and chemical warfare agents, anthrax, and other information related to bioterrorism.

TOOLS 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).

MEDLINE is a database of 12 million references and abstracts to the world's medical literature published since the 1960s; PubMed is the Web-based retrieval system that makes this wealth of information freely and easily searchable to health professionals and others. MEDLINE/PubMed is an evolving system. The database expands at the rate of about half a million records a year. Several years ago NLM introduced links between MEDLINE references and publisher websites so users could retrieve the full text of articles. Today, more than 3,000 of the 4,600 publications indexed for MEDLINE have such links. Another element in the evolution of MEDLINE is converting information from the 1950s, MEDLINE form, so that valuable research data, on smallpox and tuberculosis to take just two pertinent examples, will be available to today's scientists. A recent improvement is a text version of PubMed for users who require

special adaptive equipment to access the web. This has had the additional benefit of making the system much more friendly for those using hand-held devices.

GenBank, on the other hand, is 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 here at home, is available for further research and for further analysis and for gene discovery. GenBank is maintained by NLM's National Center for Biotechnology Information (NCBI) and now contains more than 15 million sequences and 29 billion base pairs from over 130,000 species. These are limited to chromosome maps, gene protein products, and other relevant genetic information for human and many smaller species.

An increasingly popular NCBI service for the scientist and health professional is PubMedCentral. This is a digital archive of life sciences journal literature under which publishers electronically submit peer-reviewed research articles, essays, and editorials to be included. NLM undertakes to guarantee free access to the material; copyright remains with the publisher or the author. Creating “digital archives” is an important NLM responsibility in this electronic age.

Electronic health data standards are also part of the information infrastructure of the 21st century. Such standards are needed for safe and effective health care, efficient clinical and health services research, and timely public health and bioterrorism surveillance. NLM plays an important role in HHS initiatives to promote standardization of electronic patient data by supporting the maintenance, distribution, and linking of key clinical terminologies within the Unified Medical Language System (UMLS) Metathesaurus. As a result, these clinical terminologies are available for use throughout the U.S. in clinical research databases, patient care, and public health surveillance. NLM is providing funding for the development, enhancement, and distribution of several clinically specific vocabularies. The UMLS Metathesaurus provides a common distribution vehicle for such vocabularies and a mechanism for linking them to HIPAA-mandated administrative code sets, basic research vocabularies, and thesauri designed to index the scientific literature. In addition, pilot projects for testing the use of the vocabulary in different settings will be critical for maximizing the benefit of electronic health data standards for improving patient safety, reducing costs, and enhancing effective information exchange to combat bioterrorism.

INFORMATION SERVICES FOR THE PUBLIC

Since 1998, NLM has expanded its mission beyond serving health professionals and researchers to encompass providing high quality electronic health information services for the public. To serve this audience, the Library developed a new information resource, MEDLINEplus, a Web-based service that provides integrated access to the high quality consumer health information produced by NIH and HHS components and other reputable organizations. About 1.8 million unique visitors obtained health information from MEDLINEplus in January 2003.

The main features of MEDLINEplus: 600 “health topics,” from Abdominal Pain to Yeast Infections, consumer-friendly information about thousands of prescription and over-the counter drugs, an illustrated medical encyclopedia and medical dictionaries, directories of hospitals and health professionals, a daily health news feed from the major print media, 150 interactive and simply presented tutorials (with audio and video) about diseases and medical procedures, and connections from the health topics to current clinical trials.

Like MEDLINE, MEDLINEplus is a constantly evolving system. Links are checked daily and new health topics added weekly. A completely Spanish-language version of MEDLINEplus was introduced in 2002 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 and, conversely, users of NC Health Info can link into the detailed, authoritative health information about particular diseases and conditions in MEDLINEplus.

The NLM casts a wide net in creating and promoting MEDLINEplus, working closely with the Public Library Association and other organizations not associated with NLM’s mission, 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.

Another major consumer information resource, ClinicalTrials.gov, was developed by the NLM on behalf of the entire NIH in response to a mandate from Congress. The database provides patients and families access to information about clinical trials and opportunities to participate in the evaluation of new treatments. The site was launched in February 2000 and currently contains approximately 7,200 clinical studies sponsored by NIH, other Federal agencies, and the pharmaceutical industry.

NLM RESEARCH AND DEVELOPMENT PROGRAMS

The Library is at the cutting edge of research and development in medical informatics—the intersection of computer technology and the health sciences. NLM has a program of grants and contracts to university-based researchers and also a cadre of in-house scientists in the Lister Hill National Center for Biomedical Communications and the National Center for Biotechnology Information. The Lister Hill Center sponsors many exciting communications research projects, such as those in telemedicine and the Visible Human Project. The NLM-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. The expectation is that this system will both raise the quality of health care and lower costs. Another Lister Hill Center program is the initiative to fund projects that demonstrate the medical community’s technical needs in using high-speed communications networks for critical healthcare applications, including computing in support of disaster management.

The Visible Human Project comprises two enormous data sets, male and female, of anatomical MRI, CT, and photographic cryosection images. These data sets, licensed to more than 1,700 individuals and institutions in 43 countries, are being used in a wide range of educational, diagnostic, treatment planning, virtual reality, artistic, mathematical, and industrial applications. Projects run the gamut from teaching anatomy to practicing endoscopic procedures to rehearsing surgery. NLM’s AnatLine is a web-based image delivery system that provides retrieval access (even from a home computer) to large anatomical image files of various parts of the Visible Human male thoracic region, such as the heart and stomach, including 3D images.

The other major NLM component involved in R & D is the National Center for Biotechnology Information, noted above as the source of the GenBank database of DNA sequence information. NCBI is more than just assembler of genomic data, however. NCBI

investigators have developed sophisticated computational tools such as the BLAST suite of programs that makes it dramatically easier for researchers to scan huge sequence databases for similarities, and to evaluate the resulting matches. Another NCBI product, Entrez, is an integrated database that allows users to easily and quickly search enormous amounts of sequence and literature information. The newest tool is the “Reference Sequence Collection” that is serving as a foundation for genomic research by providing a centralized, integrated, non-redundant set of sequences, including genomic DNA, transcript (RNA), and proteome (protein product) sequences, integrated with other vital information for all major research organisms. As genomic sequence data continues to accumulate and be made available in ingenious ways through the web, we can expect discoveries that promise future medical breakthroughs.

NLM extramural programs have an important role in supporting R & D in biocommunications. One timely example is the early warning public health surveillance system developed at the University of Pittsburgh and recently demonstrated to the President. NLM’s grant program also is a key supporter of NIH’s “Biomedical Information Science and Technology Initiative.” The Library has expanded its support from 12 to 18 training programs at universities across the nation to train experts to carry out research in general informatics and in bioinformatics. The NLM has recently augmented each of the training programs with a “BISTI supplement” and has also funded two planning grants that will eventually lead to the development of what are called National Programs of Excellence in Biomedical Computing.

SERVING SPECIAL COMMUNITIES

The NLM has been working with the National Institute on Aging to create NIHSeniorHealth.gov. Accessible from MEDLINEplus, the new site contains information in a format that is especially usable by senior citizens. At present NIHSeniorHealth.gov contains information on topics like Alzheimer’s and exercise for older adults, but it will soon be expanded to include more topics of special interest to seniors as other NIH institutes contribute to it. NLM is working on adapting special software that would allow the visually impaired to exercise control and hear Web pages read to them. This would also be a boon to some senior citizens.

The National Network of Libraries of Medicine, noted above in connection with MEDLINEplus, places a special emphasis on outreach to underserved populations in an effort to reduce health disparities. 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 NLM outreach 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 training. Through these schools, NLM is working to promote high-quality Internet connectivity and using technology for research and education.

There are other NLM 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 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.

FUTURE PROSPECTS

NLM is responsible for acquiring, indexing, cataloging, and preserving the world's biomedical literature—in all languages and media—and for providing reference and research assistance and document delivery from this comprehensive collection. NLM also collects, processes and distributes genome sequence data through NCBI. Both of these core areas are experiencing unprecedented growth. The cost of purchasing the biomedical literature typically increases about 10% per year, irrespective of general inflation, and the move to electronic publishing has not diminished this rate of increase. NLM uses advanced technology to improve the efficiency of its basic operations, and contractors currently perform the majority of activities required to provide NLM's basic services.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health
Biographical Sketch

NAME : Donald A. B. Lindberg, M.D.
POSITION : Director, National Library of Medicine, NIH
BIRTHPLACE : Brooklyn, NY
DATE : September 21, 1933
EDUCATION : A.B., magna cum laude, Amherst College, 1954;
M.D., College of Physicians and Surgeons,
Columbia University, 1958;
Diplomate: Anatomic and Clinical Pathology, 1963

EXPERIENCE

1984-Present : Director, National Library of Medicine, NIH

1992-1995 : Director, National Coordination Office for High Performance Computing and Communications, Office of Science and Technology Policy, Executive Office of the President

1996-2000 : U.S. National Coordinator for the G8 Global Healthcare Applications Project, Global Information Infrastructure Initiative

1969-1984 : Professor of Pathology and Director, Information Science Group, University of Missouri-Columbia

HONORS AND AWARDS

: Phi Beta Kappa

: Simpson Fellow of Amherst College

: Markle Scholar in Academic Medicine

: Surgeon General's Medallion, 1989

: First AMA Nathan Davis Award for Outstanding Member of the Executive Branch in Career Public Service, 1989

: Walter C. Alvarez Memorial Award of the American Medical Writers Association, 1989

: Presidential Senior Executive Rank Award, 1990

- : Founding Fellow of the American Institute of Medical and Biological Engineering, 1992
- : Outstanding Service Award of the Uniformed Services University of the Health Sciences, 1992
- : Federal Computer Week's Federal 100 Award, 1993
- : Computers in Healthcare Pioneer Award, 1993
- : Association of Minority Health Professions Schools Commendation, 1995
- : RCI High Performance Computing Industry Recognition Award, 1995
- : U.S. National Commission on Libraries and Information Science Silver Award, 1996
- : Council of Biology Editors Meritorious Award, 1996
- : Presidential Rank Award of Meritorious Executive in the Senior Executive Service, 1996
- : Fellow of the American Association for the Advancement of Science, 1996
- : Medical Library Association President's Award, 1997
- : American College of Medical Informatics Morris F. Collen, M.D. Award of Excellence, 1997
- : Johns Hopkins University School of Medicine, Ranice W. Crosby Distinguished Achievement Award, 1998
- : New York Academy of Medicine Information Frontier Award, 1999
- : Cosmos Club Award, 2001
- : Surgeon General's Medallion, 2002
- : Honorary Doctorates: Amherst College, State University of New York, Syracuse; and University of Missouri-Columbia

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF MANAGEMENT AND BUDGET
BIOGRAPHICAL SKETCH

NAME: Kerry N. Weems

POSITION: Deputy Assistant Secretary for Budget
BIRTHPLACE: Portales, New Mexico

EDUCATION: B.A., Philosophy, New Mexico State University, 1978
BBA, Management, New Mexico State University, 1978
MBA, University of New Mexico, 1981

EXPERIENCE:

January 24-Present Acting Assistant Secretary for Budget, Technology and
Finance

June 2002- Present Deputy Assistant Secretary for Budget, HHS

2001 - 2002 Acting Deputy Assistant Secretary for Budget, HHS

1996 - 2002 Director, Division of Budget Policy, Execution and
Management, HHS

1991 - 1996 Chief, Budget Planning Branch, HHS

1988 - 1991 Program Analyst, Office of Budget, HHS

1983 - 1988 Program and Budget Analyst, HHS
(Social Security Administration)

1981 - 1983 Staff Member, United States Senate

HONORS AND AWARDS:

2001 Presidential Rank Award

1995 Secretary's Distinguished Service Award

1993 HHS Senior Management Citation

Department of Health and Human Services
Office of Budget

William R. Beldon

Mr. Beldon is currently serving as Acting Deputy Assistant Secretary for Budget, HHS. He has been a Division Director in the Budget Office for 16 years, most recently as Director of the Division of Discretionary Programs. Mr. Beldon started in federal service as an auditor in the Health, Education and Welfare Financial Management Intern program. Over the course of 30 years in the Budget Office, Mr. Beldon has held Program Analyst, Branch Chief and Division Director positions. Mr. Beldon received a Bachelor's Degree in History and Political Science from Marshall University and attended the University of Pittsburgh where he studied Public Administration. He resides in Fort Washington, Maryland.