

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL LIBRARY OF MEDICINE**

**MINUTES OF THE BOARD OF REGENTS
September 21-22, 2004**

The 137th meeting of the Board of Regents was convened on September 21-22, 2004, at 9:00 a.m. in the NLM Board Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), Bethesda, Maryland. The meeting was open to the public from 9:00 a.m. to 4:30 p.m., followed by a closed session for consideration of grant applications until 5:00 p.m. On September 22, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

MEMBERS PRESENT:

Dr. Holly Buchanan, University of New Mexico
Dr. Ernest Carter, Howard University
Mr. Richard Chabran, California Community Technology Policy Group
Dr. A. Wallace Conerly, University of Mississippi Medical Center
Dr. Richard Dean, Wake Forest University
Dr. Thomas Detre, University of Pittsburgh
The Honorable Newt Gingrich, The Gingrich Group
Dr. Vasiliki Karlis, New York University, College of Dentistry
Dr. William Stead [Chair], Vanderbilt University

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Ms. Eleanor Frierson, U.S. Department of Agriculture
MGEN Joseph E. Kelley, U.S. Department of the Air Force
Dr. Deanna Marcum, U.S. Library of Congress
Dr. Michael Pazzani, National Science Foundation
BGEN Melissa Rank, U.S. Department of the Air Force
Dr. Vernon Schinski, Uniformed Services University of the Health Sciences
Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs
Capt. Carol Turner, U.S. Department of the Navy
Mr. Beacher Wiggins, U.S. Library of Congress

CONSULTANTS TO THE BOR PRESENT:

Dr. Tenley Albright, Whitehead Institute for Biomedical Research
Dr. Marion Ball, Johns Hopkins School of Nursing and Healthlink, Inc.
Ms. Alison Bunting, Retired, University of California, Los Angeles
Dr. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:

Dr. David Brailer, Office of the Secretary, Department of Health and Human Services
Dr. Richard Carmona, Surgeon General, Department of Health and Human Services
Ms. Kari Hastings, Spaulding Rehabilitation Hospital
Dr. Karl Heinz Hoehne, University of Hamburg

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Dr. Sharon Hrynkow, Fogarty International Center, NIH
Dr. Sharon Inouye, Yale University
Dr. Daphne Preuss, University of Chicago
Dr. George Stetten, University of Pittsburgh

MEMBERS OF THE PUBLIC PRESENT:

Ms. Janet Coleman, Blue Sheet/Washington Fax
Dr. Thomas Bryant, Friends of the NLM
Mrs. Mary Lindberg
Ms. Dana Pavey-Haza, American Enterprise Institute
Mr. Thomas West, The Krasnow Institute

FEDERAL EMPLOYEES PRESENT:

Dr. Donald A.B. Lindberg, Director, NLM
Ms. Jane Bortnick Griffith, Acting Deputy Director, NLM
Dr. Michael Ackerman, High Performance Computing & Communications, NLM
Ms. Suzanne Aubuchon, Office of the Director, NLM
Ms. Joyce Backus, Division of Library Operations, NLM
Dr. Stephen Bryant, National Center for Biotechnology Information, NLM
Ms. Margaret Basket, Associates Program, NLM
Dr. Dennis Benson, National Center for Biotechnology Information, NLM
Ms. Susan Buyer, Office of Health Information Program Development, NLM
Dr. Milton Corn, Division of Extramural Programs, NLM
Ms. Kathleen Cravedi, Office of Communication and Public Liaison, NLM
Ms. Stephanie Dennis, Associates Program, NLM
Ms. Judith Eannarino, Division of Library Operations, NLM
Dr. Elizabeth Fee, History of Medicine Division, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Ms. Loren Frant, Associates Program, NLM
Dr. Charles Friedman, NLM Sabbatical/Division of Extramural Programs, NLM
Ms. Tricia Gibbons, Office of Acquisitions Management, NLM
Ms. Rachel Gyore, Associates Program, NLM
Ms. Wendy Hadfield, Executive Office, NLM
Ms. Karen Hajarian, Bibliographic Services Division, NLM
Ms. Betsy Humphreys, Division of Library Operations, NLM
Ms. Lidia Hutcherson, Associates Program, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Ms. Christine Kanyengo, Associates Program, NLM
Dr. Donald King, Office of the Director, NLM
Mr. Sheldon Kotzin, Bibliographic Services Division, NLM
Ms. Michelle Krever, Division of Extramural Programs, NLM
Ms. Janet Laylor, Office of the Director, NLM
Dr. David Lipman, National Center for Biotechnology Information, NLM

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Dr. Simon Liu, Office of Computer and Communications Systems, NLM
Dr. Robert Logan, Lister Hill Center Cognitive Sciences Branch, NLM
Ms. Becky Lyon, Division of Library Operations, NLM
Ms. Kate Majewski, Technical Services Division, NLM
Dr. Alexa McCray, Lister Hill National Center for Biomedical Communications, NLM
Mr. Robert Mehnert, Office of Communication and Public Liaison, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Dr. Stuart Nelson, Medical Subject Headings Section, NLM
Dr. Barbara Rapp, Division of Library Operations, Associate Program, NLM
Mr. Jon Retzlaff, Executive Office, NLM
Ms. Julia Royall, Office of Health Information Program Development, NLM
Dr. Angela Ruffin, Division of Library Operations, NLM
Dr. Elliot Siegel, Office of Health Information Program Development, NLM
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
Dr. Jack Snyder, Division of Specialized Information Services, NLM
Ms. Marti Szczur, Division of Specialized Information Services, NLM
Dr. George Thoma, Lister Hill Center Communications Engineering Branch, NLM
Ms. Michelle Trout, OD Office of Federal Advisory Committee Policy, NIH
Ms. Yanli Wang, National Center for Biotechnology Information, NLM

I. OPENING REMARKS

Dr. William Stead, Chair of the NLM Board of Regents, welcomed the Regents, alternates, consultants, and guests to the 137th meeting of the Board. He noted especially two new appointed Board members: Mr. Richard Chabran, Chair of the California Community Technology Policy Group, and the Honorable Newt Gingrich, former Congressman and Chief Executive Officer of The Gingrich Group.

II. REPORT FROM THE SURGEON GENERAL, PHS

Surgeon General Richard Carmona said that the National Library of Medicine is a strong partner with his office in the effort to advance and protect the well-being of American public, and he thanked Dr. Lindberg for his leadership of the NLM. The Surgeon General has three priorities: prevention, public health preparedness, and eliminating health disparities. Successful prevention activities have the potential of reducing both the disease burden and the economic burden associated with diseases and conditions that are preventable. Public health preparedness, in the post- 9/11 sense, is also high on the Surgeon General's agenda. People of color in the United States typically have less access to health care and are disproportionately affected by diseases; thus, working to eliminate health disparities is also a priority. Improving the health literacy of the population is a cornerstone in dealing with these problems. Dr. Carmona said that next month he will release the first-ever Surgeon General's report on bone health and osteoporosis. The report will be a starting point for more concentrated national action to prevent, diagnose, and treat bone disease. In this regard, he said that NLM's MedlinePlus and NIHSeniorHealth.gov help citizens find the type of

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exercise they need to prevent bone loss and the latest information on osteoporosis, calcium, and bone diseases. He cited a number of other actions being taken by other HHS health agencies on this subject. The PHS is also preparing a magazine-style plain language guide based on the Surgeon General's report. Bone health is a key element of the "Healthy People 2010" roadmap plan for improving the nation's health, and the PHS has set a goal of reducing by 20 percent the proportion of adults with osteoporosis and adults who are hospitalized for fractures associated with osteoporosis by 2010. Other areas being targeted by the PHS are childhood maltreatment, community and correctional health, and disabilities and health. Two new Surgeon General's reports are also being prepared: on global health, and women and mental health. Finally, Dr. Carmona said that his office is partnering with the National Human Genome Research Institute to ensure that the benefits of genomic research get out to the public by introducing this fall a "family history" project.

III. REPORT FROM THE FOGARTY INTERNATIONAL CENTER, NIH

Dr. Sharon Hrynkow, Acting Director of NIH's Fogarty International Center, said that the Center and NLM collaborate on several important projects, including the Multilateral Initiative on Malaria, an informatics and global health program, and a pilot project to bring together editors from the north and south hemispheres as a way of exchanging information and expertise. She described the Fogarty International Center's "diplomatic role" on behalf of NIH to engage foreign governments, the U.S. State Department, and the Office of the HHS Secretary on the international agenda. The other major role of the Center is to design programs that build science capacity in low and middle income countries. The "Fogarty Model" is to pair a U.S. institution with a low and middle income country in an ongoing research project. The Center then supports the training on top of the research: the investigators on both sides decide what kind of training they need in order to advance the research. Research topics are primarily in areas that the Center considers being of global health import. Examples are AIDS, emerging infectious diseases, maternal and child health, and trauma and injury. The longest standing programs are those devoted to AIDS-related training. They have built significant scientific capacity in more than 100 nations. Dr. Hrynkow addressed the issue of "brain drain." The Fogarty International Center by helping to train foreign scientists in the U.S. hopes to build the research capacity in those countries. She described several incentives that the Center provides to encourage these scientists to return to their countries and to become partners with NIH. Another new Center initiative is to entice young idealistic medical and public health students from the U.S. into the arena of international health. She distributed to the Regents a press release about the program. A new program now being developed recognizes that there are other organizations interested in global health issues besides schools of medicine and public health—for example, schools of business, journalism, and engineering. The Fogarty International Center hopes to develop teams of scientists that draw on these disciplines who can work on global health issues.

IV. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

The Regents approved without change the minutes from the May 19–20, 2004 meeting.

V. DATES FOR FUTURE BOARD MEETINGS

The Board of Regents will meet next on February 15–16, 2005. The Board meeting next spring is on May 10–11, 2005. The dates of September 20-21 were adopted for the meeting next fall.

VI. REPORT OF THE NLM DIRECTOR

Dr. Donald Lindberg reported that as a result of action in the Congress it is being proposed that the NIH (and NLM) budget be increased by 2.7% in fiscal year 2005. This would mean an increase of about \$8 million for the Library. In the area of staffing, the Director noted several new key staff members: Patricia Gibbons as head of the acquisitions section and Joyce Backus as head of the reference section. He noted that Ms. Backus recently presented to the Regents about NIHSeniorHealth.gov, which just received an award from the International Council on Aging.

Dr. Lindberg also announced that Kent Smith, NLM Deputy Director for many years, had retired, and that Jane Griffith is now acting in that position. Among other actions: Bob Cross has retired as Education Specialist and Jon Retzlaff is resigning as NLM Executive Officer to take a position with the Federation of American Societies for Experimental Biology. The Library was saddened by the unexpected death of Bill Leonard, NLM Audiovisual Information Officer, who was responsible for many fine audiovisual productions over the years at NLM. Dr. Barbara Rapp next introduced to the Board the 2004–2005 NLM Associate Fellows: Margaret A. Basket, Stephanie N. Dennis, Loren R. Frant, Rachel A. Gyore, Lidia Y. Hutcherson, and Sandy D. Tao. Dr. Alexa McCray introduced two new staff of the Lister Hill National Center for Biomedical Communications: Dr. Incheol Kim and Dr. Haixia Du.

Dr. Lindberg next discussed several items related to legislation. He cited language by both the House and the Senate that backed the need for an expanded NLM facility to accommodate both the increase in biotechnology-related information and the expanding physical collection. These are essential endorsements, he said. Jane Griffith reported briefly on several bills related to the establishment of a National Health Information Infrastructure. Although they are unlikely to pass during this session, they will help in drafting legislation in the new Congress next year. Similarly, the “Genetic Information Nondiscrimination Act” is not likely to be passed this year (although approved by the Senate), but is likely to be considered again next year. Proposed legislation affecting digital media and copyright is in the same category. She said that the Office of Civil Rights and other HHS divisions continue to issue guidance materials to make it easier to understand and comply with HIPAA privacy rules. On another issue, Dr. Lindberg reported on NIH involvement with “public access” to published NIH-funded research results. NIH recently had three meetings with publishers, scientists, and public interest groups—to discuss how (and when) to make published research results available to the public via NLM’s PubMedCentral. NIH has put forward a proposal that would require taxpayer-supported articles be made available free through PubMedCentral six months after initial publication. The proposal is on the NIH Web site and comments are invited. Jane Griffith noted that the House of Representatives has been strongly behind the movement to provide public access to publicly funded research. Dr. Lindberg said that the Wellcome Trust has recently joined with NLM to expand the content of PubMedCentral by digitizing some 1.7 million pages of

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back journal issues. On another matter, HHS Secretary Thompson held a Health Information Technology summit this past summer, where Dr. David Brailer, the newly appointed National Health Information Technology Coordinator, laid out his strategy for health IT. The Board will hear from Dr. Brailer later in this meeting. Related to this, Dr. Lindberg reported that NLM will serve as the base of operations for the Commission on Systemic Interoperability, chartered by Congress under PL 108-173 (the Medicare Prescription Drug, Improvement and Modernization Act of 2003). This is now being formed to develop a comprehensive strategy for the adoption and implementation of health care information technology standards.

The NLM Director said that it is time to extend the NLM Long Range Plan. The current plan carries through 2005. This is an opportune time to create a plan for the next 10 years, recognizing that technology has made great advances and there is increased awareness of the importance of information systems by both the scientific community and the public. The subject of the need for a comprehensive listing of clinical trials has been much in the news lately. NLM's ClinicalTrials.gov is frequently cited as the logical base for such an expanded data set that would include more trials from pharmaceutical companies and also trials being conducted in other countries. An editorial on the subject of the need for a clinical trials repository, written by a committee of medical journal editors, appeared simultaneously in a number of distinguished biomedical journals. They stated that ClinicalTrials.gov was the only existing site that meets their criteria. There is no technical problem with this, Dr. Lindberg said, rather there is a question of authentication—how to ensure that a trial has been properly and accurately described. This is especially an issue in the case of clinical trials in other nations. There was a discussion by the Regents of the need to also include negative results in a database so that research is not unnecessarily repeated. In a related matter, Dr. Lindberg said that NLM was pleased that the ClinicalTrials.gov database received the prestigious Innovations in American Government Award from Harvard University, which carries an award of \$100,000 to be used to enhance and replicate the database. The NLM Director briefed the Board about the visit he led of several NLM senior staff to Alaska to participate in a “Listening Circle” with Alaska Natives and to conduct site visits with various Alaska Native health organizations. On another topic, he announced that NLM was beginning the process of recompeting the eight Regional Medical Library contracts that form the backbone of the National Network of Libraries of Medicine. Awards will be announced in April 2006. Dr. Stead noted that this presents an opportunity to join the interests of the Network and the NLM Long Range Planning process that is just beginning. Finally, Dr. Lindberg showed two brief videos: a clip from the upcoming PBS/NOVA show dealing with Typhoid Mary that was supported in part by a grant from the NLM; and a news clip about NLM's Information Rx Project from a local television station in Denver.

VII. HIGHLIGHTS FROM THE NATIONAL CENTER FOR BIOTECHNOLOGY INFORMATION

NCBI director Dr. David Lipman, assisted by Dr. Jim Ostell, demonstrated to the Board how he made a discovery of a potential disease gene during a visit from HHS Secretary Thompson. He said that one goal of the NCBI is to “connect,” for example, from the x-y-z coordinates of protein atoms to the bases of the DNA, to all of the supporting information in terms of other kinds of functional

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genomics (expression data, etc.), to the literature. Tying all this together improves the speed of biologic discovery by making it easier to find the next piece of vital information and by combining computational tools to this process we can gain new insights and make completely new discoveries. Dr. Lipman and Dr. Ostell demonstrated online (using Fanconi's syndrome and other subjects) how this might be done. Another NCBI service they demonstrated is the "Bookshelf," where the NCBI gets biomedical textbooks and chapters of textbooks from publishers and makes the full text freely available on the Web and tightly integrates access to the text with other NCBI information services (including PubMed). They demonstrated *The Genetic Landscape of Diabetes*, a new addition to the Bookshelf written by Dr. Laura Dean and Dr. Jo McEntyre of NCBI. The entire NCBI Web site is being accessed by approximately one million users daily, he said.

Dr. Lipman introduced the subject of the new PubChem system, a part of the NIH Roadmap initiative in molecular libraries and imaging. The NIH specific objective of the molecular libraries initiative is to fund centers that would screen chemical compounds to find small molecules and to make the data openly available. Although there are many legacy databases on the NIH campus for specific aspects of small molecules, they have not been integrated. The new PubChem system will start to coordinate much of this work and serve as a small molecule repository. NCBI's Dr. Steve Bryant, who has led the PubChem project, demonstrated the new system to the Regents using the drug gleevec as one example.

Following these presentations, Dr. Daphne Preuss of the University of Chicago, who chairs the NCBI Board of Scientific Counselors (BOSC), thanked the Regents for their support of the NCBI and she assured the Board that its work is well worth the investment NLM has made. The NCBI, as can be seen by the vignettes presented by Dr. Lipman and Dr. Bryant, is an incredibly important resource. It facilitates research efforts of basic scientists, clinical scientists, the commercial world, pharmaceutical industry, and the biotechnology industry, not only in the U.S. but around the world. She said that biology could not go forward in its present form if the NCBI "were to disappear." It saves time—the most important commodity for scientists. With PubChem, the Center is going beyond biology into chemistry. This is very exciting, she concluded.

Dr. Stead asked about how well scientists pick up the complete spectrum of resources created by NCBI and available to them. Do we need to be teaching them in addition to creating the resources? Dr. Lipman said that typically scientists who use these resources only stay on the surface and that we need to do a better job on informing them about what more is available. The BOSC has emphasized this. Over the next year one of our most important initiatives is to come up with ways to make it easier for scientists to use the full power of the system. Dr. Preuss said that so many entry points have been added to the data that "we get there." She added that her graduate students in their twenties "do a lot better than I do," and that the next generation of scientists won't find this a difficult problem. There was a discussion of the NCBI "coffee break" part of the Web site that facilitates learning about the services. Dr. Gingrich asked about the capacity of the service to serve simultaneous users. Dr. Lipman said that peak usage now is about 1300 Web hits a second (1.3 terabytes per day are being transferred) and that we could easily accommodate ten times the current usage in hits—the hardware costs to this is would be minimal. Dr. Gingrich said that one could

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imagine the familiar world of textbooks and libraries disappearing and that you would have eighth-graders who are amateur scientists going “head to head with you and doing better than most of your advanced researchers because they would intuit the system....this could change the whole underlying pattern of how we do science in this country.”

VIII. PRESENTATION OF REGENTS AWARD

Dr. William Stead presented the 2004 Regents Award for Scholarship or Technical Achievement to Dr. Stuart Nelson, chief of NLM’s Medical Subject Headings Section. Dr. Nelson was cited for “initiating, designing, and directing the development of RxNorm, a clinical drug nomenclature designated as a U.S. government-wide interoperability standard. In developing RxNorm, Dr. Nelson made a major contribution to the U.S. health data standardization and brought great credit to the National Library of Medicine.”

IX. APPOINTMENT OF PLANNING SUBCOMMITTEE

The Board unanimously approved the creation of a Planning Subcommittee to guide the Library in preparing the Long Range Plan Dr. Lindberg discussed in his presentation. The Subcommittee will be co-chaired by Dr. Stead and Dr. Gingrich. Members are Dr. Buchanan, Dr. Dean, Dr. Detre, and Dr. Walker.

X. EXTRAMURAL PROGRAMS REPORT

Dr. Milton Corn, NLM Associate Director for Extramural Programs, reviewed the history and purpose of the NIH Roadmap’s “National Centers for Biomedical Computing initiative.” Forty-one applications were received. Although available Roadmap funds of \$12 million were sufficient for only three Centers, supplemental contributions by several Institutes, including NLM, increased the pool, and four applications have been selected for funding. The four selected were described. Dr. Corn announced that one of them, led by Zack Kohane at Harvard’s Peter Bent Brigham, was assigned to NLM for purposes of program management.

The annual NLM Informatics Training Conference was held on June 9–10, 2004, at the Regenstrief Institute, in Indianapolis, Indiana. The 250 attendees included directors, faculty, staff, and trainees at all 18 current NLM training programs, as well as NLM staff and guests. Research projects were presented in plenary and semi-plenary sessions by 34 informatics trainees. An additional 37 trainees presented research-related posters at the meeting. A picnic and museum tour was held on the evening of June 9. A meeting on training in public health informatics was held in the afternoon on June 10, to receive input from the training directors to help shape a potential collaborative training initiative of the Robert Wood Johnson Foundation and the NLM.

Concept review was requested for NLM’s Informatics Research Program for which a new announcement in the NIH Guide is planned. NLM, a pioneer in using and studying computer applications to biomedicine, has supported informatics research for two decades. Initially focused on

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clinical applications, the grant program has included a growing number of research projects in biomedical informatics of basic science—“bioinformatics”—during the last 14 years. The breadth of NLM’s informatics research program is suggested by noting some of the areas for which grants are made: information and knowledge processing, tools for analyzing and/or storing very large datasets, knowledge representation, linkage of clinical and genomic information to benefit health care, innovative uses of information technology in health care delivery, efficient management and utilization of information and data, human-machine interaction, high-performance computing and communications relating to biomedical applications, and innovative uses of technology to enhance learning, retention and understanding of health-related information. Dr. Corn said that because a number of Institutes have initiated certain types of informatics research activities in recent years, NLM at this time wishes to reiterate its intention to continue supporting research in informatics. A new Program Announcement describing the NLM Informatics Research Grant program is being planned. Approval from the Board of Regents for such an announcement was requested and received by unanimous vote.

Dr. Corn discussed the impact to date of the movement to provide public access to full-text medical literature. A U.S. House of Representatives committee has recommended that the NIH provide free access to all research it funds and asked the NIH to submit a plan by December 1, 2004 for implementing the new policy in fiscal year 2005. The committee’s report stipulates that NIH deposit the final manuscript and any supplemental materials from NIH-funded research to PubMed Central 6 months after publication, and if any publishing costs are covered by NIH funds, the research would be available immediately upon publication. The recommendation must be approved by the Senate before going into effect. The effect of such legislation, if passed, on NIH grants and grant processing was discussed.

XI. HHS STRATEGIC FRAMEWORK FOR HEALTH INFORMATION TECHNOLOGY

Dr. David Brailer, appointed on May 6 by HHS Secretary Tommy G. Thompson as National Health Information Technology Coordinator, thanked NLM for its leadership in this field, singling out especially Dr. Lindberg and Betsy Humphreys. In April, the President issued the Executive Order that created his office as a way to address errors and inefficiencies through the use of information technology. Dr. Brailer said he is specifically charged with four things: directing HHS programs on health information technology; coordinating government-wide activities in health information technology (including budget, communications, goals and strategies); coordinating programs between the public and private sectors; and developing a strategic plan within 90 days. One important aim is to not say in a different way, things that have already been agreed on—“evergreen truths.” He discussed in some detail four main goals of his office: (1) bringing information tools, including the electronic health record, to the point of care (and how to encourage and provide incentives to accomplish this); (2) interconnecting clinicians—allowing clinicians to have access to relevant information about their patients when they are making point-of-care decisions; (3) personalization of care—highly customized information about you as a consumer—information to help you choose physicians and hospitals; and (4) improving population health, including learning

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how to collect information to monitor, manage, and improve the system. Dr. Brailer concluded by saying that we have a long way to go. Our goal today is to develop better market forces so that the demand side of the market works as well as the supply side. For many years NLM has labored on the supply side, making sure that the know-how, standards, technologies, reference models, and trained people are there. We see the next step as taking these positives and pairing them with demand-side stimulation—making a more favorable milieu for investment on the part of doctors and hospitals.

Following Dr. Bailer's presentation, Dr. Walker commented that we need to tie reimbursement to electronic medical records and that we should be building up a gigantic database that can be mined. Dr. Bailer said that the creation of an anonymized database underlies our vision of public health improvement. We must differentiate between a database that is stored centrally versus the ability to collect data under certain conditions when there is permission to do so. We do not want to see centralized databases of personally identifiable information. As to the economic question of reimbursement, we must keep in mind that the federal government has considerable leverage here—it is a reimbursor for care, the largest purchaser for health benefits, a major contractor for health services (e.g., TRICARE, VA), and, of course, a tax collector. Should we be using these levers to achieve a social goal? Dr. Bailer believes we should, but said that this is an area of debate. Dr. Ball asked about interoperability and the issue of patient identifiers. Dr. Brailer responded that we cannot achieve interoperability without attaining the goal of common patient identifier. The public has expressed its significant concerns about creating a “master national identifier” for people. He noted that an influential study group representing various factions has agreed on the rules of the road for a “federated identity infrastructure.” The federated identity infrastructure means that there is not one real-world identifier for an individual but a variety of arbitrary identifiers in different settings. Such a system to protect privacy is currently being installed in banking, he said. Dr. Gingrich commented that the federal government is by far the largest purchaser of health care in the world and that we should be paying for “health” rather than “health care”: we have more than enough technology already to make a real difference.

XII. NLM GRANT-SUPPORTED PROJECTS

A. Hospital Elder Life Program (HELP)

Dr. Sharon K. Inouye, a geriatrician and Professor of Medicine at Yale University, is the Principal Investigator of an NLM Information Systems Grant, “National Hospital Elder Life Program (HELP) Internet Project.” Thirty-five percent of the over-65 U.S. population is hospitalized in any one year, accounting for over fifty percent of all in-patient days of hospital care. Loss of function and independence are the unfortunate frequent outcomes of this hospitalization. Every day in the hospitalization of an elderly patient there are more than 200 decision nodes where adverse events might occur. Many of these are preventable, and the HELP program concentrates on them. Delirium, or acute decline in attention and cognition, is considered to be the leading complication of hospitalization among older patients, with rates ranging from 25 to 60 percent. The hospital cost to Medicare is more than \$8 billion a year. At least forty percent of this is preventable, she said. In addition there are many post-hospital costs. Preventing delirium and functional decline in hospitalized older patients is the area Dr. Inouye has chosen to focus on. She outlined the goals of

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the program as maintaining physical and cognitive function throughout hospitalization, maximizing independence at discharge, assisting with the transition from hospital to home, and preventing unplanned readmission. Their aim is that by preventing delirium they will prevent a cascade of other adverse outcomes (e.g., falls, pressure sores, incontinence). They have identified six risk factors related to delirium: cognitive impairment, vision/hearing impairment, immobilization, psychoactive medication use, dehydration, and sleep deprivation. Dr. Inouye then described the various targeted interventions carried out by an interdisciplinary team and trained volunteers. All patients 70 and over are screened. The effectiveness of the HELP program has been demonstrated by four studies published in the *New England Journal of Medicine* and other peer-reviewed publications. The program has been disseminated and is now in operation at 40 sites in 11 states and 3 countries. She described the HELP program materials used by the sites—manuals, business tools, videotapes, software, etc. Last December Dr. Inouye received a 3-year Information Systems Grant from NLM to help develop a Web site (with both public and private sections) to assist the dissemination sites. Chat rooms for the dissemination sites are being created to facilitate communication among them. A centralized program evaluation that uses aggregate data (no patient-specific identifiers) is the next step in HELP's evolution. A Web site evaluation is also being planned. The URL for the project is www.hospitalelderlifeprogram.org.

B. CINID—Model Disability Information Network

Ms. Kari Hastings, an instructor of clinical investigations at the Massachusetts General Hospital Institute of Health Professions and Director of Research and Training at the Spaulding Rehabilitation Hospital, is the recipient of an NLM Information Systems Grant for the project known as CINID, Community Information Network for Individuals with Disabilities. CINID is a model for information delivery, technical training, and access to assistive/adapted hardware and software for individuals with disabilities throughout the Boston area. The Spaulding Rehabilitation Hospital, a member of Harvard's health care system, is a 296-bed facility with seven outpatient centers. Ms. Hastings said that there are 54 million Americans with disabilities; more than one million in Massachusetts over the age of 4. Most of those disabled have never used a computer, and more than 95 percent of Web sites are inaccessible to those who are visually-, hearing-, or mobility-impaired. Key elements of the CINID program are providing computer/Internet technology and assistive technology, training, a Web site (www.DisabilityExchange.org), and a "Disability Issues" newsletter. She described the various roles of CINID's network partners, information partners, and technology access partners. The CINID computer access sites offer free access to computers, the Internet, and assistive/adaptive devices that address various limitations and impairments. She described several of the assistive/adaptive devices and software used for input and output. Their Web site at www.DisabilityExchange.org is a state-of-the-art, one-stop online resource center for individuals with disabilities that will address their needs for information, community collaboration, and products and services. She read from several letters of users to attest to the impact of the system. Ms. Hastings concluded by describing CINID's future, including widening the geographic area of its dissemination, broadening its base of support (for example, from The Boston Foundation), finding additional collaborating organizations, activating an online shopping feature, and activating an online job board for both employers and job seekers.

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Dr. Thomas Detre commented that geriatricians, on the outpatient level, have the opportunity to coordinate the care of their patients so as to involve the input of various specialties. Certain problems such as drug-drug and drug-disease interactions are better controlled. What Dr. Inouye has done in the hospital setting is outstanding, he said. He believes that the ultimate solution—and not just for the elderly—is to introduce systematically the “hospitalist” concept. Having a single person who assumes overall responsibility and coordinating function will ultimately be critical to solving the problem. Dr. Detre said he has little confidence in quality assurance programs as they are conducted today. A weekly review of adverse events in a hospital would be better than collecting such data every several months. He also discussed the problems inherent in finding sources for continued funding of such projects. Dr. Lindberg commented that in the case of the HELP project it would be very useful to have a list of errors identified.

MEETING CLOSED FOR THE REVIEW OF GRANT APPLICATIONS September 21, 2004, 4:30 P.M.

XIII. CONSUMER HEALTH HIGHLIGHTS

Ms. Joyce Backus, Head of Reference and Customer Services, Public Services Division, gave the Regents an overview of NLM’s interlinking consumer health information services. MedlinePlus is the Library’s main Web site for consumer health information. She used her mother as an example of how these services can provide needed information, in this case, about type II diabetes, high blood pressure, a current case of achilles tendonitis, and macular degeneration—a disease of her retina that has limited her mother’s vision to the extent that she’s given up driving. Ms. Backus said that information could be retrieved easily from MedlinePlus for each of those problems. She noted that more than 50 percent of those responding to a survey of MedlinePlus users are categorized as consumers. Health care providers, educators, students, scientists, and librarians make up the remainder. Web search engines are by far the primary reason people come to NLM’s site and Ms. Backus typed in “macular degeneration” into Yahoo, showing that MedlinePlus was, in fact, the second site listed in the extensive Yahoo retrieval. She linked to MedlinePlus.gov and reviewed for the Regents the variety of the information on macular degeneration that could be found there—current news, information from NIH, an interactive slideshow tutorial, clinical trials, and a real-time preformulated search of the medical literature on PubMed/Medline. She also showed the parallel MedlinePlus en español site. She demonstrated several new services on MedlinePlus: “find a hospital” (with data from the American Hospital Association), “go local” that lets users find health-related services in their area (so far available in North Carolina and Missouri), and NIHSeniorHealth.gov (in partnership with the National Institute on Aging). A special MedlinePlus outreach initiative that the Board has heard about in the past is the Information Rx Project—NLM working with the American College of Physicians to encourage members to “prescribe” MedlinePlus for their patients who need information. Ms. Backus said that usage of MedlinePlus continues to climb steadily: today it stands at more than 5 million unique users and 50 million page hits per month. NLM gets considerable feedback from customers—information that helps us improve the site. Also, we conduct usability studies and focus groups. NLM also carefully analyzes the search

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terms input by users and the Web log data. As the Board has heard in the past, the American Customer Satisfaction Index rates MedlinePlus and MedlinePlus en español very highly among all the Web sites it surveys.

Following Ms. Backus's presentation, Dr. Buchanan suggested that, in keeping with the discussions of the Board Planning Committee, NLM should develop MedlinePlus metrics that, several years down the line, can tell us how we are doing. For example, we should be trying to increase the number of referrals to MedlinePlus on the part of health care professionals and librarians. NLM should also strive to be recognized as a source of help for other NIH components and Federal agencies to revise their Web sites and make them more consumer-friendly from a health information standpoint. Dr. Gingrich said that the MedlinePlus demonstration was very impressive and that the right metrics for MedlinePlus are "most authoritative and most useful." He suggested going to every member of the House and Senate (and every staff member) and soliciting their suggestions for improving MedlinePlus. NLM could then offer to help them prepare information for mass mailings to Congressional districts and provide a MedlinePlus representative to demonstrate at town hall meetings. These steps would guarantee that you have permeated the Congressional system. He suggested working with AARP to bring information about NIHSeniorHealth.gov to its members and with CMS to include information about MedlinePlus in its mailings to Medicare users. NLM might also contact state governors to form collaborations so that the states use, and publicize, MedlinePlus. Finally, Dr. Gingrich said that NLM might monitor the health problems of news personalities and then ask them to evaluate MedlinePlus. This would gain much media exposure. Dr. Stead said that NLM should encourage other sites to connect into a pertinent place in MedlinePlus; we should be trying to get "inside" of partner sites. Two interesting questions to get the answer to, he continued, are "Did you get the information you needed to get the right help?" and "Did you get the information you needed to know whether your health provider was doing the right thing?" Dr. Lindberg commented that WebMD was interested in connecting to MedlinePlus, particularly the tutorials. There was also a suggestion by Dr. Gingrich that NLM approach the medical schools to integrate MedlinePlus into the learning process.

XIV. COLLECTION DEVELOPMENT MANUAL

Ms. Betsy Humphreys, Associate NLM Director for Library Operations, said that "collection development," although a behind-the-scenes activity, is very important to NLM's services. These are the guidelines that are followed by staff who select and acquire material for the Library's collection, the largest in the world. Decisions about what to collect are made on the basis of the "Collection Development Manual" (CDM). The CDM is prepared under the overall guidance of a Board of Regents policy. The manual is updated continually, but every 5–10 years it is completely and systematically reviewed and a new version is issued. Ms. Humphreys then introduced Ms. Judith Eannarino of the Technical Services Division. Ms. Eannarino said that the NLM has a global acquisition process that is very complex; no other library collects biomedical works in all the countries and all the languages that the NLM does. The CDM contains Board of Regents policy, a history and overview of NLM collections, an articulation of the Library's collecting philosophy and role as a national library, a description of subjects and formats of collecting interest at NLM, and

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links to related resources. It is used internally by NLM staff and managers and externally by book dealers, publishers, exchange partners, and vendors who enter into acquisition arrangements with the Library. Ms. Eannarino described the process for updating the CDM—the appointment of an external oversight committee of experts (chaired by Ms. Alison Bunting, former Regent), an internal committee of NLM staff charged with making the revisions, and numerous working groups. A draft of the new CDM was presented to the oversight committee in June 2004. Revisions were made over the summer and the completed draft is now being presented to the Board of Regents for approval. Ms. Eannarino briefly described highlights of actions taken to update the CDM: all subject and format categories were reviewed and rewritten; the new edition reflects the changing research environment, emerging public health threats, and electronic publishing trends; there is a new emphasis on complex, interdisciplinary and emerging disciplines; it is being published on the Web, in html and PDF versions, with search engine; and it is in an easy-to-use format. Some of the specific changes involve an increased focus on fundamental life sciences research; a greater emphasis on chemistry, physics, and engineering; more attention to public health issues; a new statement on complementary and alternative medicine; and an expanded statement on the Library's approach to electronic collection development. She noted that having the CDM on the Web will allow NLM to keep it current by making minor updates. A major revision would be done in 5–8 years. Following Ms. Eannarino's presentation, Ms. Katherine Majewski demonstrated the Collection Development Manual Web site and showed the breadth of the content and the way various subjects were listed and described.

Ms. Alison Bunting, who chaired the oversight committee, said that now that the CDM is on the Web, this will allow other libraries to coordinate efficiently with NLM in how various collections are developed. She said that the revised CDM requires approval by the Board of Regents. A motion to approve the Collection Development Manual was made, seconded, and unanimously approved by the Board.

Dr. Deanna Marcum of the Library of Congress applauded the work done by the NLM collection development committee. She said that the national libraries had traditionally been the “library of last resort.” Now with the Web, we are becoming the “first stop” for users. She said that printed materials are not decreasing, Web-based materials are exploding, but budgets are not expanding. She posed several questions: How much of our budget will we spend on print versus Web material? University-based Web sites, important as they are, are not always being kept on the Web. Are we collecting them in our national libraries? Are we acquiring a decreasing portion of the published literature? It is very important that the collection policy be kept up to date. She asked whether NLM was seeing a decrease in published biomedical literature. Dr. Lindberg noted that NLM collects much more than it indexes for its databases. He said that we are not falling behind in collecting published material, but we are struggling to estimate how well we are doing with the electronic literature. Eleanor Frierson of the National Agricultural Library discussed the subject of licensing very expensive resources—they license for staff of the Department of Agriculture certain materials that they are not able to provide outside the Department. There was a general discussion by the Regents of collecting print and electronic materials in the new communications environment. Dr. Marcum said that all these things change the way we think about what a library is—it's not just a

storage place for vetted information, it's an information conduit with authentication being conducted somehow.

XV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Dr. Richard Dean, Subcommittee Chair, said that the meeting yesterday morning was devoted largely to an update on initiatives that have already been reported to the Board, including the Information Rx and Listening Circles projects. The members discussed how these projects are progressing, the need for step-by-step plans as they mature, and how NLM's outreach program must be truly interactive with the audiences it intends to reach.

XVI. VISIBLE HUMAN PROJECT

Dr. Michael Ackerman, head of the Office of High Performance Computing and Communications, Lister Hill Center, said that this November 28th is the tenth anniversary of the release of the data for the Visible Human male. He discussed the inception of the program, back in the 1980s, when the Long Range Plan was issued and presciently said that NLM should be the library of record in the medical field for pictures as well as text. A special committee set up by the Board of Regents recommended in a report that the Library create anatomical images from a normal adult male and female cadaver—based on cryosection, CAT scan, and MRI. Dr. Ackerman described how the project to create the Visible Humans was competitively bid out; the University of Colorado submitted the winning proposal. The Board was shown some of the old videotape that appeared in the media when the availability of data (over 1800 slices, 15 gigabytes) based on the Visible Human Project was first announced in 1994. The Visible Human female data (over 5100 slices, 40 gigabytes) was released a year later. NLM licenses the data without charge. One of the important improvements to the dataset made by the user community since it was released was to add labels so that users would know what they were looking at—“changing data into knowledge.” Dr. Ackerman described how this was done in several steps; one result was a functional atlas of the head and neck. He also discussed how a consortium of three companies and three universities created an open source toolkit (Insight—“ITK”) for segmenting and registering Visible Human images; he showed several examples. Dr. Ackerman then introduced two visitors who have used the Visible Human data extensively: Dr. Karl Heinz Höehne of the University of Hamburg in Germany, who has created a series of CD-ROMs called “Voxel-Man” based on Visible Human data,” and Dr. George Stetten of the University of Pittsburgh, who has created an imaging tool called the “sonic flashlight” based on ITK software.

Dr. Höehne said that his laboratory has long been engaged in attempting to make realistic 3D images of human anatomy. The Visible Human Project has been a wonderful help in this pursuit. He showed the Board a number of pictures of reconstructions of anatomical entities, including inner organs, based on his use of the Visible Human data. One recent major project is to make a very detailed model of the human hand. Dr. Höehne showed various images from of the “Voxel-Man” programs, which are available for purchase from Springer-Verlag. More information is at www.uke.uni-

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hamburg.de/zentren/experimentelle_medizin/informatik/gallery/. He pointed out that it is important to attach descriptive information—ontologies—to the morphological data if the images are to be maximally useful.

Dr. Stetten said that his Visualization and Image Analysis Laboratory, associated with the University of Pittsburgh Bioengineering Department and the Carnegie-Mellon Robotics Institute, has been part of the ITK Consortium since its founding. Part of their Visible Human ITK endeavor has been to develop a device that “fuses” human vision with all the incredible imaging that comes from inside the patient. They call it the “sonic flashlight.” With pictures he showed how, using the device, a real-time ultrasound image from inside the patient could be displayed with a view of the outside of the body, like Superman’s x-ray vision. You can actually “stick a needle into the ultrasound image of an artery or tumor and hit the actual artery or tumor...or all sorts of things that we haven’t even begun to think of.” As the probe moves around “inside” the body, the image slice that is normally displayed statically on a screen is now moving through 3D. “Your mind can put together a 3D picture of what’s going on. It really is a new way of displaying images,” Dr. Stetten said. He showed examples using Visible Human data and even discussed the possibility of future holographic images.

XVII. ADJOURNMENT

The meeting was adjourned at 12:08 p.m. on September 22, 2004.

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the May 19-20, 2004 Board of Regents Minutes
- Approval of September 20-21, 2005 Meeting Dates
- Approval of Concept for NLM Support for Informatics Research
- Approval of Revised Collection Development Manual
- Concurrence with Recommendations of the Extramural Programs Subcommittee, and Conducted En Bloc Approval of Grants

I certify that, to the best of my knowledge, the foregoing minutes and attachments are accurate and complete.

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

William W. Stead, M.D.
Chair, NLM Board of Regents