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

MINUTES OF THE BOARD OF REGENTS
September 10-11, 2002

The 131st meeting of the Board of Regents was convened on September 10, 2002, 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 11, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

MEMBERS PRESENT:
Ms. Alison Bunting [Chair]
Dr. Richard Dean
Dr. Ralph Linsker
Dr. Joseph Newhouse
Ms. Eugenie Prime
Dr. William Stead
Gov. Lowell Weicker

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:
Ms. Eleanor Frierson, U.S. Department of Agriculture
Rear Admiral Kenneth P. Moritsugu, U.S. Public Health Service
Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs
Capt. David Wade, U.S. Department of the Navy
Mr. Beacher Wiggins, Library of Congress
Mr. Peter Young, National Agricultural Library, USDA
Dr. James Zimble, Uniformed Services University of the Health Sciences

CONSULTANTS TO THE BOR PRESENT:
Dr. Marion Ball, Johns Hopkins School of Nursing and Healthlink, Inc.
Dr. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:
Dr. Mary Fissell, Johns Hopkins University
Dr. Ted Mala, American Association of Indian Physicians
Ms. Sylvia Ortiz, New Mexico State University Library
Dr. Elias Zerhouni, NIH Director

MEMBERS OF THE PUBLIC PRESENT:
Mr. Kemp Baker, Friends of the National Library of Medicine
Mr. David Fuller, Port Gamble Sklallam Tribe
Dr. Cynthia Lyndquist, University of North Dakota School of Medicine

FEDERAL EMPLOYEES PRESENT:
Dr. Donald A.B. Lindberg, Director, NLM
Mr. Kent A. Smith, Deputy Director, NLM
Dr. Michael Ackerman, High Performance Computing & Communications, NLM
Ms. Evangeline Alexander, Associate Fellow, NLM
Ms. Stacey Arnesen, Division of Specialized Information Services, NLM
Dr. Alan Aronson, Cognitive Science Branch, Lister Hill Center, NLM
Ms. Suzanne Aubuchon, Office of the Director, NLM
Ms. Joyce Backus, Public Services Division, NLM
Mr. Marcus Banks, Associate Fellow, NLM
Dr. Carol Bean, Division of Extramural Programs, NLM
Ms. Susan Buyer, Health Information Programs Development, NLM
Ms. Molynda Cahall, Associate Fellow, NLM
Ms. Patricia Carson, Office of the Director, NLM
Dr. Milton Corn, Division of Extramural Programs, NLM
Ms. Kathy Cravedi, Office of Communication & Public Liaison
Ms. Betsy Dean, Office of Science Policy and Planning, Office of the Director, NIH
Mr. Jason Donaldson, Office of Administration, NLM
Ms. Gale Dutcher, Division of Specialized Information Services, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Mr. George Franklin, Jr., Office of the Director, NLM
Mr. Clifford Gay, Cognitive Science Branch, Lister Hill Center, NLM
Ms. Jane Bortnick Griffith, Office of the Director, NLM
Ms. Betsy Humphreys, Lister Hill National Center for Biomedical Communications, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Ms. Shannon Jones, Associate Fellow, NLM
Ms. Natalie Kamper, Associate Fellow, NLM
Dr. Donald W. King, Office of the Director, NLM
Mr. Sheldon Kotzin, Bibliographic Services, Division of Library Operations, NLM
Ms. Eve Marie Lacroix, Public Services Division, NLM
Mr. Pierre Levermore, Office of the Director, NLM
Dr. David Lipman, National Center for Biotechnology Information, NLM
Dr. Simon Liu, Office of Computer and Communications Systems, NLM
Mr. Rodney Long, Communications Engineering Branch, Lister Hill Center, NLM
Ms. Becky Lyon, Division of Library Operations, NLM
Dr. Alexa McCray, Lister Hill National Center for Biomedical Communications, NLM
Mr. Robert Mehnert, Office of Communication and Public Liaison, NLM
Ms. Rachel Moore, National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH
Mr. James Mork, Cognitive Science Branch, Lister Hill Center, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Mr. David Nash, Office of Equal Employment Opportunity, NLM
Ms. Michelle Ochillo, Associate Fellow, NLM
Dr. Barbara Rapp, Associates Program, NLM

Mr. Jon Retzlaff, Executive Office, NLM
Dr. Merlyn Rodrigues, Division of Extramural Programs, NLM
Mr. Willie Rogers, Cognitive Science Branch, Lister Hill Center, NLM
Ms. Julia Royall, Health Information Programs Development, NLM
Ms. Sonya Shooshan, Computer Science Branch, Lister Hill Center, NLM
Ms. Marti Szczur, Division of Specialized Information Services, NLM
Dr. Elliot Siegel, Health Information Program Development, NLM
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
Dr. Jack Snyder, Division of Specialized Information Services, NLM
Dr. Sue Sparks, Division of Extramural Programs, NLM
Dr. George Thoma, Communications Engineering Branch, Lister Hill Center, NLM
Mr. Thomas West, Division of Specialized Information Services, NLM
Dr. Fred Wood, Health Information Programs Development, NLM

I. OPENING REMARKS

Ms. Alison Bunting welcomed the Regents, alternates, and guests to the 131st meeting of the Board of Regents of the National Library of Medicine. She also welcomed new Ex-Officio Members to the Board of Regents Peter Young, Director of the National Agricultural Library, and Beacher Wiggins of the Library of Congress, and special guests Sylvia Ortiz of the New Mexico State University Library and Dr. Ted Mala of the American Association of Indian Physicians.

II. REPORT FROM THE OFFICE OF THE SURGEON GENERAL, PHS

Rear Admiral Kenneth Moritsugu, Deputy Surgeon General, U.S. Public Health Service, presented Surgeon General Richard Carmona's apologies for missing the meeting. He fully expected to attend the meeting and dinner, but was called away by the White House at the last minute to go to New York City to participate in September 11 observances. Dr. Moritsugu briefly recounted the new Surgeon General's background. The Surgeon General has been charged by the President with three priorities: to lead the Commissioned Corps' response to bioterrorism; to encourage healthy behavior and the prevention of disease and disability; and to send a recurring message about the dangers of substance abuse and alcohol abuse. Rear Admiral Moritsugu updated the Regents on the subject of Surgeon General reports being undertaken: bone health and osteoporosis (due early in 2004), and a follow-up report on tobacco use. The Surgeon General is open to suggestions for additional topics that would be of interest to the American people. In this year's State of the Union message, the President talked about volunteerism. The USA Freedom Corps has been established by the White House, one subset of which is a civilian Medical Reserve Corps that the Office of the Surgeon General is responsible for. Rear Admiral Moritsugu emphasized that the Medical Reserve Corps will be composed of local civilian volunteers. Their purpose would be to assist community existing health entities and other public health efforts, such as health education and immunization campaigns. Surgeon General Carmona expects to be able to attend the next Regents' meeting, Rear Admiral

Moritsugu concluded.

III. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

The Regents approved without change the minutes from the May 14-15, 2002 meeting.

IV. DATES OF FUTURE BOARD MEETINGS

The Board of Regents will meet next on February 11–12, 2003. The Board is meeting next spring on May 13–14, 2003. The dates of September 9–10, 2003, were adopted for the meeting next fall.

V. REPORT OF THE NLM DIRECTOR

Dr. Lindberg reported that Presidential rescissions would reduce the FY 2002 budget by an amount that is currently unknown. The Senate Appropriations Committee bill allows NIH $27 billion for FY 2003 (a 16% increase) of which the NLM would receive $310 million (an increase of 12%). The Senate bill comments favorably on the need for expanded facilities for the NLM and requires a report from NIH to the Congress by April 1, 2003, that delineates the features of the new facilities and lays out a fast-track schedule. The House of Representatives has not yet acted on the FY 2003 budget. In the area of new personnel, Dr. Lindberg introduced NLM's Executive Officer, Jon G. Retzlaff, Dr. Donald W. King, the NLM Deputy Director for Research and Education, and Dr. Jack Snyder, Associate Director for Specialized Information Services. Dr. Barbara Rapp, who manages NLM's Library Associate Fellowship Program, introduced the new Associates for 2002–2003: Evangeline K. Alexander, Marcus A. Banks, Molynda A. Cahall, Shannon D. Jones, Natalie J. Kamper, and Michelle H. Ochillo. Dr. Lindberg said that NLM is very proud of the Library Associate Fellowship Program and he cited how a recent Associate, who returned to her native Africa, was able to use skills learned at NLM to enable the *African Journal of the Health Sciences* to be submitted to NLM in electronic form, thus allowing it to be included in PubMed/MEDLINE. This impressed the World Health Organization who invited her to a conference on how to improve African medical journals. The NLM Director noted several retirements, including Dr. Dennis Black, Contracts Officer, and Joseph Hutchins, Supervisory Computer Specialist.

Dr. Lindberg reported briefly on a symposium last week at the National Academy of Sciences on the role of scientific and technical data/information in the public domain. One question raised was where is the funding for research in genomics? He was surprised to learn that some $3.5 billion is being invested in this area, most of it ($1.9 billion) from the commercial sector, the remainder from the government and foundations. The NIH investment in this area "is not at all excessive, indeed is being dwarfed by the others," he said. Another point made at this meeting was the large amount of patenting being done by the academic community, which results in income of $1.9 billion a year for the universities. Jane Griffith, also at that meeting, said there was discussion of the various legal, technological, and economic pressures on the public domain

in science and technology information. One of the areas NLM and NIH have been following is the progress of database protection laws in this country and Europe. The U.S. academic and library communities have been working to ensure that we don't follow the European path of excessive protection that would harm scientific progress. Dr. Lindberg reported briefly on a direct mail project to promote MEDLINEplus and ClinicalTrials.gov to 16,000 public libraries and the 4,500 member libraries of the National Network of Libraries of Medicine. There were encouraging return rates of 21% for medical libraries and 17% for public libraries of institutions requesting additional promotional materials. He drew the Regents' attention to the extensive entry in their agenda book on the subject of NLM bioterrorism and disaster management activities. There are descriptions there of the basic research supported by NLM (e.g., genomics databases), informatics R&D related to bioterrorism, information provided to the public (via MEDLINEplus and other services), training for health professionals in using NLM's informatics tools and resources, working with other agencies to augment the public health network, crisis management (e.g., SIS information for first responders), and cybersecurity for NLM's own systems. The Director's remarks about the state of preparedness for managing disasters led to a discussion about the inadequate state of the public health infrastructure and its balkanization, and to what extent scientific and other databases should carry information that could conceivably aid bioterrorists.

Dr. Lindberg brought to the Board's attention that, as a result of partnership between the Library and the NIH Recreation and Welfare organization, there is now a Web site (www.nlmgiftshop.org) where NLM logo products and gifts may be purchased. There was a meeting at the University of Utah in June of the NLM Training Program directors, faculty, and students, 250 in all. Dr. Lindberg briefly described some of the topics discussed. The NLM Director and several senior staff have been meeting representatives of the American Medical Publishers Association over the past several years. Among the topics discussed at their meetings are concerns about submitting data electronically for indexing and cataloging, preservation and archiving issues, electronic cataloging in publication data, and acid content of journals. At the last joint meeting we agreed to hold a one-day seminar on archiving digital information in conjunction with the Association's annual meeting in March 2003. Another meeting Dr. Lindberg reported on was a workshop on July 22 of 60 representatives of Historically Black Colleges and Universities to discuss an NLM project with the United Negro College Fund Special Programs Corporation to help increase awareness and use of NLM's online resources. Former Surgeon General Joycelyn Elders gave the keynote address and several existing health information programs were presented as models. NLM hopes to fund a minimum of three projects that might involve activities associated with curriculum development, training, faculty research, or community outreach. The Director showed several pictures of his recent visit to the University for Informatics and Technology in Tyrol, Austria. He delivered the opening address and participated in ceremonies dedicating that facility. On another matter, Dr. Lindberg asked the Board to consider appointing two subcommittees: one to review whether NLM is properly covering the literature pertaining to bioengineering and imaging, the other to consider NLM's coverage of the literature of bioethics and the continuing relationship between the Kennedy Institute of Ethics at Georgetown University and NLM. The last item reported by the Director

was the establishment at NLM of the Network Operations and Security Center. He showed pictures of the Center, which is visible from the hallway between NLM's two buildings. The Center features a public information display system of four 32-inch wide plasma screens with live statistics and usage trends for the major NLM services. Dr. Lindberg showed sample page displays of how the Network Operations and Security Center monitors usage, including potential break-ins and other cyberthreats.

VI. WEB METRICS—INTERNET AUDIENCE MEASUREMENT

Dr. Elliot Siegel, NLM Associate Director for Health Information Programs Development, said that NLM began offering MEDLINE on the Internet via Grateful Med in the mid 1990s. After introducing the database free via PubMed in 1997, the Library saw a dramatic increase in usage by an expanded user base. No longer was MEDLINE usage almost exclusively the domain of scientists, health professionals, and librarians, but the general public was making great use of it also. From 7 million searches (1997) the figure has risen to 400 million per year. MEDLINEplus, intended specifically for consumers, was introduced in 1998; more than 1 million unique visitors come to MEDLINEplus each month. Dr. Siegel said that these increased usage figures prompt us to look more closely at just who is using the databases, and for what purposes. Are we *really* doing a good job? Are our information services helping to address the health disparities that exist in our society? Knowing our audiences better will enable us to serve them better in the future. The challenges posed in answering these questions are considerable, and include technical, legal, ethical, and bureaucratic issues. For example, our users access our services anonymously and protecting their privacy is important. We realize that measuring Web usage is still an evolving art. OMB clearances required for Federal surveys complicate things further. Dr. Siegel said that the measurement activities to be reported this morning are the result of close collaboration of staff from many parts of the NLM. There are five broad categories of evaluation activity: end-to-end Internet performance testing; broadband infrastructure capacity assessment; usability testing; audience measurement; and information-seeking behavior and user satisfaction. The next presentation will concentrate on the last two of these categories.

Dr. Fred Wood of the NLM Office of Health Information Programs Development described the Library's efforts to measure Internet usage of its services. The Library works with several companies—comScore Networks Inc. with a panel of 1.5 million people who have agreed to have their Web usage monitored, and Nielson Net Ratings Inc. with a panel of 70,000. The companies mainly monitor the top-level domain (nih.gov); drilling down for NLM-related information required special arrangements with the companies. Dr. Wood revealed drill-down data for May 2002 that showed unique visitors, total visits, and pages viewed. NLM totals for those categories: 5.21 million unique visitors, 9.44 million total visits, and 58.6 million pages viewed. This last figure represented 79% of all NIH pages viewed. He presented a graph with usage trends since February 2000 that showed nih.gov usage steadily increasing in contrast to other services such as Mayo, Intelihealth, Medscape, and Dr.Koop.com, which remained stable or declined over time. WebMD recently partnered with aol.health (and also bought Medscape) and its total usage is substantial. Dr. Wood compared unique visitors for a number of

government agency Web sites, showing that NIH usage was among the four highest. He also compared usage of six Federal health agencies Web sites (NIH, CDC, FDA, HHS, VA, and HCFA), showing that NIH usage, whether counting visitors or pages, was the highest. The NIH international component (as much as 40% of use) is especially high. On the subject of user satisfaction, Dr. Wood showed some results of a recent survey of users of the NLM home page. This survey was consistent with previous NLM surveys of other services (e.g., PubMed/MEDLINE)—it was a randomized pop-up survey that resulted in more than 4,000 completed responses (slightly less than a 5% response rate). He summarized some of the results: usage is distributed among researchers, librarians, health care professionals, students, and the public. Repeat users were more likely to be scientists and librarians; first-time users were more likely to be students and the public. The reason for this is that most users were coming to the NLM home page as a way to get to NLM databases and to "health information." Thus, an important function of the home page is to serve as a portal to other NLM sites. As to how users found out about the NLM Web site, the three main routes are search engines, links from other sites, and libraries, although newspapers, other organizations, health providers, and schools all have a role. First-time users were significantly skewed to search engines and other Web site links as a means of reaching NLM. The primary impacts of usage (as the users reported) were to learn where to find health information, learn how to access materials, and learn about NLM services. He compared the most recent data with previous surveys of other NLM services as to country of origin, reported frequency of usage, satisfaction ratings, and status of user (scientist, librarian, health professional, consumer, etc.). Dr. Wood drew several conclusions from the most recent survey: satisfaction is very high, with most users saying they will return; there is a core of loyal users; the predominant user groups are matched to the intended purpose of the sites surveyed; taken together, the sites seem to be meeting the needs of a broad spectrum of users; high quality content and effective site design are keys to satisfaction; first time users seem to have slightly lower levels of satisfaction and are less likely to fill out the survey; users find out about the sites in many ways; online user surveys provide useful information about our users and a diversified Web evaluation strategy is warranted. MEDLINEplus, in both English and Spanish, will be surveyed in 2003, Dr. Wood concluded.

Following these presentations, Dr. Ralph Linsker asked whether what we have learned has resulted in NLM making changes or doing things differently. Dr. Wood said that we have learned the importance of partnerships with other organizations to carry out a diverse communications strategy. Linking to our services from other Web sites is crucial. Dr. Siegel noted that in our review of MEDLINEplus, we discovered how popular the health tutorials were and we therefore placed special emphasis on having them translated into Spanish prior to the release of MEDLINEplus en Español. Dr. Linsker asked whether the NLM sites allow users to make comments to us and record their satisfaction or dissatisfaction. Betsy Humphreys responded that all NLM sites have a "comment" capability and we in fact do receive a great many comments. Dr. Linsker also commented on the issue of "response bias," suggesting that NLM find out which groups were completing the survey at a lower rate (since only 2/3 of those who started filling out the survey actually completed it). Dr. Wood agreed. Dr. Siegel noted that the companies conducting the surveys were "comfortable" with the response rates the NLM was

receiving and that they are in line with those conducted for commercial clients whose users' identities they know. Alison Bunting suggested that it would be interesting to get statistics from the commercial companies that lease MEDLINE from NLM. Dr. William Stead said that he is struck by the richness of the potential resource if we could mine the patterns of how people actually use NLM's information. Of course we would have to deal with privacy concerns. We should encourage basic research on decoupling "identity" from the kind of information we need to explore these patterns.

VII. PRESENTATION OF THE REGENTS' AWARD

Ms. Alison Bunting, Board Chair, presented the 2002 Board of Regents Award for Scholarly or Technical Achievement to Rodney Long, Electronics Engineer, of the Lister Hill National Center for Biomedical Communications for the "design and development of the Web-based medical information retrieval system, WebMIRS, an original technical accomplishment that furthers the state of the art in biomedical multimedia database design. The system enables biomedical researchers access to a multimedia database of digital x-rays and textual data as well as serves as a tool for the analysis of data."

VIII. LISTER HILL CENTER ACTIVITIES

Dr. Alexa McCray, Director of the Lister Hill National Center for Biomedical Communications, introduced four new staff members and visiting scientists of the Center: Sherri Calvo, Dr. Zhan Zhang, Dr. Marcelo Fiszman, and Dr. Patricia Brennan. Dr. McCray characterized the LHC's programs as falling into four main areas: language and knowledge processing (e.g., the Unified Medical Language System); information systems; image processing (e.g., the Visible Human Project); and training programs. LHC staff have backgrounds in a variety of professions and disciplines—in the health professions, computer sciences, and many aspects of technical communications. Dr. McCray reviewed for the Regents progress in developing the Unified Medical Language System: there are today almost 900,000 concepts in the Metathesaurus, representing 2.1 million strings. About 60 "families" of vocabularies are represented. There are 160,000 lexical entries in the Specialist Lexicon that give the user information about the linguistic properties of words. These, and the suite of lexical tools that have been developed, are heavily used in natural language processing applications. The UMLS Semantic Network is a high-level view of the terms and concepts in the biomedical domain; it contains 134 "semantic types" and 54 potential relationships between them. LHC staff are looking into the need to add more semantic types in the area of molecular biology and genetic information. The UMLS Knowledge Sources are now released four times a year, Dr. McCray said. Using fibromyalgia as an example, she showed to the Board the new Knowledge Source Server Web interface. There are 2,002 UMLS licensees, including 1,884 registered users of the Knowledge Source Server. She next turned to the Lister Hill Center's work in the area of digital libraries. "Profiles in Science" is a prominent example of this work. There are currently eight scientists in Profiles, with Dr. Donald Fredrickson and Dr. C. Everett Koop soon to be added. Dr. McCray discussed plans for the next major NLM exhibit (in mid-2003) on the History of American Women

Physicians. There is an ad hoc advisory committee and a collaborative Web site has been built to allow the committee members and others to post comments and share information.

On another subject, LHC staff are looking at some of the technical aspects of digital preservation. An "Image Migration Framework" has been developed, a prototype for experiments in image conversion and preservation. Dr. McCray briefly described some of their experiments to see what loss occurs in converting images from one format to another. She also noted some of the metadata elements that were being developed for the images. A major Lister Hill Center project is ClinicalTrials.gov, a consumer site that NLM developed as a result of a mandate to the FDA, and which the Library launched in February 2000. At that time there were 4,400 trials; today there are 6,600 trials in 70,000 locations around the U.S. and in 70 other countries. A heavily used registration and data entry system has been developed for entering new trials. Dr. McCray said that the Center has a number of outreach activities, aimed at urban and rural audiences, primarily with the National Network of Libraries of Medicine. A new LHC project is to develop the "Genetic Disease Home Reference" that would make genetic disease information readily available to the public by linking MEDLINEplus topics to NCBI and other genetic information resources. She showed a prototype system that included a dozen diseases. Dr. McCray ended her presentation by reporting on the LHC Fellows Program, describing the types of assignments and appointments and the number of participants (33 in the last year, including 9 full-time). She gave some details about the new Rotation Program for informatics trainees who are already in a medical informatics program sponsored by NLM. They come to NLM full-time during two summer months, then have two months tacked on to the end of their formal training program.

Dr. William Stead complimented the Lister Hill Center on the way it was dealing with basic research, services, and the tools to help people "build systems to access systems." He commented that the Unified Medical Language System is the answer to the oft-made suggestion, especially by those in the clinical information systems community that "someone" should work on creating standards. There should be some way for the NLM to use the UMLS to begin to change the policy debate on this. Betsy Humphreys agreed with this comment and Dr. McCray said that the medical informatics community is well aware of the UMLS and its potential benefits.

IX. REMARKS BY THE NIH DIRECTOR

Dr. Elias Zerhouni, newly appointed Director of the National Institutes of Health, said that he appreciates the work of advisory councils like the Board of Regents. NIH has an enormous challenge in effectively communicating what the institution is doing. He has repeatedly encountered the question that, now that the NIH budget has been doubled, what are we doing that is worthwhile to justify the increase? Addressing this will be a challenge. For NLM this may be less of a problem, because the Library as an institution has been recognized nationally over the years. Another challenge is for NIH to adapt to the changes that are occurring in science. There is a concern by some that NIH may not be organized optimally to respond to the

environment of today's science. One of Dr. Zerhouni's first tasks was to organize a set of meetings trying to identify the common themes that permeate the entire NIH, that is, the areas of research that are converging. The emergence of computational biology, supercomputing capabilities, the difficulty in managing the quantity of data coming out of the laboratories—these are all challenges that must be addressed. A series of "road map" meetings of NIH directors (and others) was held at NIH over the summer, each group composed of a different combination of institutes. The level of convergence in the issues facing the field was remarkable. Everyone understands that without better information technology, better information infrastructure, and better algorithmic development in understanding the complexity of biological data, progress will be slow. At a recent retreat of NIH IC directors, this was the recommendation that came at the top of everybody's list. Clearly the NLM has taken a lead role—a visionary role—in this area. We are going to have to rely on your input and your advice on how to best bring this about. Dr. Zerhouni noted the role in this sphere of NLM's National Center for Biotechnology Information. He referred to a slide he showed at the retreat related to his own research in trying to establish a relational image database of the evolution of the normal human brain through aging. We could, using current technology, look at the normal structure of the brain: if you use a CAT scan, you are talking about 16 to 80 megabytes of data; but if you want to go to the level of the white matter tract using diffusion energy, you are talking about 84 gigabytes. If you wanted to understand the brain at the cellular level, it would require 84 terabytes of data. At the retreat there was also a sense that NIH needs a renewed commitment to basic science; that what we have done in the past needs to be transformed into an understanding of complex networks of molecules and micromolecular systems. This also will require tremendous information technology support, not just computer memory, but at the intelligent level— where mathematical modeling and predictive models will have to emerge if we truly want to grasp the complexity of the systems. There was a clear direction from the Institute directors that we need to invest more in understanding the systems and subsystems in biology.

Dr. Stead asked about the themes of the "road map" meetings. Dr. Zerhouni said they were nonspecific and transdisciplinary in nature. For example, one addressed the challenge of bringing into biology scientists from other disciplines. NIH, in fact, spends as much on the physical sciences as the National Science Foundation does. Dr. Jack Snyder asked about curing the gaps in the current educational and career "pipelines" for scientists. Dr. Zerhouni said that one issue discussed was whether our "translation pipeline" is well designed, not only for scientists but also for K–12. We need more emphasis on "quantitation" and more objective data input if we are to have effective biomedical research. Alison Bunting asked about what other kinds of accountability would come into play now that the NIH budget has doubled. Dr. Zerhouni said that another way to look at it is "how efficiently is the NIH dollar invested?" We need to understand the leveraging effect of NIH investment. The trend over time of the proportion of U.S. biomedical research supported by NIH (not including pharmaceutical research) has ranged from 75–80% in the seventies to today's approximately 50%. When you consider the growth of NIH support over those years, it is obvious that NIH's investment has greatly increased the nation's capacity for research. In that same period we have more than doubled the number of basic scientists available for research. Another way of looking at the

change, and one that is relevant to NLM, is how many more people today have rapid access to needed biomedical information. One criticism heard of NIH is that it doesn't translate enough of its basic research findings into "reality," or into medical practice.

X. AMERICAN INDIAN AND ALASKA NATIVE HEALTH INFORMATION OUTREACH

Dr. Fred Wood of the NLM Office of Health Information Programs Development presented a brief overview of NLM's outreach programs for American Indians and Alaska Natives. Many of the people NLM has been working with are in remote areas. He showed several views of tribal health facilities. NLM's priorities in working with Native Americans are to: encourage access to and use of health information; help reduce health disparities and the digital divide; work with and empower local health professionals and communities; help tribal members make effective use of the information; and measure the difference our programs might make. NLM's programs in this area are multifaceted: MEDLINEplus as a source of information; a new Arctic Health Web site; tribal connections Web site; training in using Web-based health information resources; partnership in tribal conferences; tribal internships; and a Powwow initiative in the Mid-Atlantic region. Dr. Wood showed several photographs from the Powwows and described the Library's work there. Dr. Wood introduced to the Board the next two speakers: Dr. Ted Mala, immediate past president of the American Association of Indian Physicians (AAIP), and Dr. Sherrilynne Fuller, former Regent, Director of the Pacific Northwest Regional Medical Library, and Principal Investigator for the Tribal Connections Project.

Dr. Ted Mala introduced Cynthia Lindquist, President of the Native Indian Women's Health Resource Center. Dr. Mala thanked Dr. Wood and Dr. Siegel for their coming to AAIP meetings and demonstrating NLM information resources. He said that the AAIP, which was founded in 1971, encourages Native Americans to learn more about their health and to become more involved in the healing process, through both allopathic and traditional healing methods. Dr. Mala briefed the Board about the composition of the 4 million members of the American Indian/Alaskan Native population. The health disparities affecting this population are staggering, and include alcoholism, diabetes, and tuberculosis, among many other ills. Health sites, such as NLM's, must be clear and provide information that can be readily put into practice. Dr. Mala said he is working with NIH's National Center for Complementary and Alternative Medicine to look into providing information in the "gray" areas. Native American health care expenditures per capita are 42% less than the rest of the U.S. population. Native Americans are underrepresented in the medical schools (less than 1%). The 280 members of the AAIP, from 110 tribes, try to be a bridge between traditional healing and allopathic medicine. The AAIP works with NIH and with tribal leaders in communities around the country, and also is active in recruiting students to go into the health professions. The AAIP receives Federal funding from NIH and CDC, and private funding from such institutions as the Ford Foundation.

Dr. Sherrilynne Fuller said she was privileged to participate in the recent AAIP Powwow in Anchorage, Alaska, at Dr. Mala's invitation. She briefed the Board on a number of outreach

projects to Native American communities that she has been involved with in the Pacific Northwest and which have since been expanded to other parts of the country. One of the earliest was the Tribal Connections Program, which the Regents have heard about in the past that was intended to connect Native Americans to the Internet for access to health information. That Project has undergone three phases that: connected 16 sites in the Pacific Northwest (1997–2001), connected 4 sites in the Pacific Southwest (1999–2002), and conducted an intensive community-based outreach to and evaluation of 3 sites from Phase 1 in 2001–2003. Dr. Fuller showed maps with the locations of the tribal connections participants in Alaska and in the Pacific Northwest (Washington, Oregon, Montana, and Idaho). She described how the Project made alliances with the tribal community leaders, oftentimes through scientists of the forestry and fisheries agencies. This proved to be an extremely effective approach. A "train the trainer" model was used. Working with tribal librarians was also very successful. The National Network of Libraries of Medicine provides a wonderful framework within which to continue and expand the tribal outreach activities. Dr. Fuller addressed the question of how do we measure the impact of what we have done: Are there changes in the way people access information? How is health information viewed in the community? How do we get health professionals and community leaders to make this a priority? Most fundamentally, do our activities have a positive effect in improving health in the community? We are still working on approaches to answer these questions. Dr. Fuller showed the design of their new Web site that would soon be going public.

Following these presentations, Dr. Richard Dean commented that in dealing with different cultures we have to be sure we are providing information in a format that is effectively received and is in fact the information that is needed. Are we providing the right information in a way that is clear and simple? We need a feedback loop that tells us if we are on the right track. Dr. Fuller agreed that this is the crux of the situation. She described what they have learned in contributing to MEDLINEplus, that there is a great interest in visual information—people want to see graphic information. Another observation is that we have to be very concerned with providing material that is aimed at the right reading level. Dr. Mala agreed that, although visual elements are important, we have to realize that many users (especially those in rural Alaska) can't receive streaming video on their terminals. Dr. Kenneth Walker commented that this is a superior example of providing information access to recipients who can use it in the context of their culture. It demonstrates another aspect of the value of Regional Medical Libraries. This project is a template that needs to be expanded and extended.

XI. EXTRAMURAL ACTIVITIES REPORT

Dr. Corn, NLM Associate Director for Extramural Programs, introduced to the Board Hua-Chuan Sim, M.D., who joined the staff of the Scientific Review Office, Division of Extramural Programs as a Health Scientist Administrator/Medical Officer (Research) in June. Dr. Corn described the K22 award, which is used by many Institutes to facilitate the transition of investigators from the mentored phase to the independent stage of their careers in research, by providing "protected time" for newly independent investigators to develop and receive support for their initial research programs. To apply, a candidate must have completed two years or

more of postdoctoral, mentored research or have been in an independent position for less than two years at the time the application is submitted. The unique feature of this award is that individuals may apply without a sponsoring institution while they are still in a "mentored" position. The customary stipends and conditions were presented. After discussion the Board of Regents gave unanimous approval to the program in concept.

Also presented was the recent revision of NLM's Research Training Fellowship program. This program serves the useful purpose of providing training in informatics research for those candidates who seek such training in sites other than those supported by NLM institutional training grants. In 1992, the research track was augmented by an option for training in application of informatics to a medically relevant domain; to encourage career development, the applied fellowship offered higher than usual stipends as a replacement for lost income during the training period. To respond to the changed milieu, NLM revised the individual fellowships in FY 2002 with some changes in eligibility, a greater emphasis on bioinformatics training, and a revised pay scale to facilitate recruitment of computer scientists, engineers, librarians and nurses. The applied fellowship will be converted to a senior fellowship available to those with 10 or more years of post-training professional experience. NLM was joined in the new Program Announcement by the National Human Genome Research Institute, which is interested in providing training at the genome centers it funds.

Dr. Corn then explained the recent termination of NLM's long-standing Access Grants and Connection Grant programs. In recent years, many applicants as well as members of the Biomedical Library and Informatics Review Committee have come to believe that these two Outreach programs, each of which supported Internet access to health information, had developed a sometimes confusing overlap. Accordingly, a new program "Internet Access to Digital Libraries" (IADL) was created, incorporating key features of both Access and Connection grants and adding some additional options based on our experience in recent years. To launch IADL an RFA was announced in FY 2002 to which there was an unusually heavy response. The more than 100 applications received varied markedly in scope, cost, and sophistication. Communities covered were dispersed widely among the states and included a number of inner city facilities as well as rural areas; faith-based organizations were significantly represented. A special review panel considered almost half to be worthy of funding with an aggregate budget request of over $3.5 million. Applications in the "pipeline" for the old programs were accepted during a transition phase, but only IADL grants will be processed in FY 2003.

XII. GENE INDEXING

Dr. David Lipman, Director of the National Center for Biotechnology Information, introduced two new senior staff member of the Center: Dr. Yi-Kuo Yu and Dr. Medha Bhagwat. He said that NCBI has always wanted to enhance the links between sequence data and the literature. The Center has worked closely with the Indexing staff of Library Operations to enable them to make connections between the genes and the literature. There are now thousands of records

that have been linked up and already it is a tremendously valuable resource. Following his remarks, James Marcetich, Head of NLM's Indexing Section, demonstrated how "LocusLink" works. Using as an example an article from the August 15, 2002, issue of *Blood*, he showed how an indexer would call it up on a terminal and see the descriptive data and abstract that go into a standard MEDLINE record. The indexer would then call up the full text and review the Medical Subject Headings. To perform gene indexing, the indexer would need to recognize that the article is about one of the six organisms for which gene indexing is available (human, mouse, rat, fruitfly, zebrafish, and HIV-1) and that there is a gene or protein that is the main point of the article. Mr. Marcetich showed how the indexer would create a link from this article to the gene or protein record in LocusLink and then attach a brief explanatory phrase or statement. The record is then ready to be made public. The goal was to index 500,000 citations for MEDLINE this year; about 13,000 links have been added so far.

Following Mr. Marcetich's presentation, Dr. James Zimble remarked that LocusLink is user-friendly and an extremely impressive accomplishment. It will make the NLM also the "National Library of Genomics." Dr. Lindberg said that the staff have done a "phenomenally good job" and that this will turn out to be a milestone development.

XIII. AUTOMATED AND SEMI-AUTOMATED INDEXING

Dr. Alexa McCray said that the Lister Hill Center's indexing project began several years ago. It is especially important because the quality of NLM indexing will be reflected in the retrieval from the databases. At NLM, indexing has traditionally been a manual intellectual process. Dr. McCray said the goal of the LHC indexing initiative was to investigate automated and semi-automated methods that would result in acceptable retrieval performance. A number of algorithms have been developed that are "concept-based" and make use of the Unified Medical Language System resources. A prototype system has been developed to test the various algorithms that were developed. A "Medical Text Indexer" and other tools are now used in NLM indexing environments and have been integrated into the Document Control and Management System (DCMS). Following this introduction, Dr. Alan R. Aronson described the Medical Text Indexer (MTI) system, including the various components that go into the algorithm, e.g., title, abstract, UMLS terms, and Medical Subject Headings (MeSH) headings, and the processes that operate on these components to yield indexing results. There are three basic indexing methodologies: MetaMap Indexing, Trigram Phrase Matching, and the PubMed Related Citations algorithm. He described how the results are restricted to MeSH headings and how postprocessing is done on that list to end up with a coherent, relatively short list of recommended terms. Using examples, Dr. Aronson described how each of the three indexing methodologies would be employed. He said that the fully automatic MTI system was used to generate indexing data for some 60,000 records that would not be undergoing manual indexing. These records were made available through the NLM Gateway. Evaluation would be done by doing retrieval experiments on the records. In deploying the semi-automated system, MTI presented suggestions to NLM indexers (10 volunteers) within the DCMS. Evaluation was based on their feedback. An analysis showed the system presented 8 useful MeSH terms (3 main

headings) for each record. The indexers made a number of helpful suggestions and, overall, the results were encouraging. The semi-automated system was provided to all indexers on August 29, 2002.

Following the presentation, Alison Bunting said it was wonderful how the tools that Lister Hill Center staff have been working on are now coming to fruition and being applied in exciting areas. She agrees with the decision to use the automated indexing on certain types of literature. The plans for evaluation are sound. Mary Ann Tatman asked whether using semi-automated indexing actually saved time for the indexers. Dr. Aronson said that this is an open question, but at least one indexer has told him that it does. Dr. McCray said that their initial thesis was that experienced indexers would not be interested in using the system; this may not turn out to be true—senior indexers may well find it useful. Dr. Linsker said that the system demonstrated was a very nice example of building advanced automatic search methods on top of a base of human conceptual knowledge. Dr. Stead agreed, saying that the computer's ability to identify the set of things the human needs to consider is very good, whereas the human's ability to decide which elements of that set are appropriate to be used is better than the computer's. Dr. Newhouse commented that it is important to compare consistency and reliability among indexers, as well as between indexers and the computer. Ms. Humphreys said that the last time this was studied with any rigor was during the 70s, when NLM inadvertently indexed (and entered into MEDLINE) the same set of articles twice. NLM plans to study interindexer reliability, this time intentionally.

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During Dr. Aronson's presentation, at 10:00 a.m., there was a break for a live video presentation by President Bush in observance of the anniversary of the September 11, 2001 attack. Following his presentation, at 10:30 a.m., the Board observed a moment of silence.

XIV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Ms. Eugenie Prime, Subcommittee Chair, reported on yesterday's meeting of the Subcommittee. The focus of the meeting was on the partnership between NLM and the American College of Physicians to promote MEDLINEplus. The partnership, as described at the meeting by Dr. Elliot Siegel, will begin as a pilot project in two states: Iowa (600 physicians) and Georgia (2100 physicians). The project will conclude next June. Ms. Prime showed the Board a promotional kit that is being prepared to distribute to the physicians. It includes an "information prescription pad" for the physician to use, mouse pad, poster, bookmarks, and a Lucite holder for the materials. NLM will be able to roughly track use of MEDLINEplus by patients. There will be focus groups at the beginning and end of the project. Subcommittee members discussed benchmarks—how will we determine what constitutes success? There was also discussion about the legal liability of NLM providing medical information to patients. The Subcommittee heard about the publicity plans to launch the new MEDLINEplus en Español, the subject of the next presentation. Following Ms. Prime's presentation, there was a brief discussion about the extent

to which NLM could engage in "marketing" its products. Dr. Lindberg said that although the Library cannot buy advertising time, we encourage public information and outreach activities to get the word out. In answer to a question from Dr. Zimble, Ms. Becky Lyon said that the focus groups of physicians and office staff were being selected with the help of the ACP. Dr. Zimble suggested that NLM consider working with the Department of Defense's TRICARE system, which is now preparing a Web site portal for patient outreach, to have MEDLINEplus featured as a patient information link. Dr. Lindberg agreed that this would be well worth looking into.

XV. MEDLINEPLUS EN ESPAÑOL

Ms. Joyce Backus of the Public Services Division said that two days ago NLM put up for the public MEDLINEplus en Español. She demonstrated the system for the Board. The intended audiences are Spanish-speaking patients, their friends and family, public and medical librarians, and English-speaking health care providers who serve Spanish-speaking patients. The Spanish version of MEDLINEplus has nearly 500 health topics, 4,000 encyclopedia articles that are illustrated, and 150 tutorials, all in Spanish. MEDLINEplus en Español uses the same stringent evaluation criteria as the English version. NLM is dependent on the availability of good health information in Spanish from NIH, other government agencies, and voluntary organizations. Some health topics have much information in Spanish and others do not. In all cases it is possible to toggle back and forth from English to Spanish (where the information exists in Spanish). There is as yet no counterpart in Spanish to the daily health news from the media or the drug information. These are planned for the next year. Ms. Backus described the extensive feedback NLM sought and received as it built the site, from the University of Texas, focus groups, and others. She shared with the Board several positive comments received from online users already.

Following Ms. Backus's presentation, Dr. Marion Ball congratulated the MEDLINEplus team on their work. The challenge now is to get it into the hands of those who can benefit from it. She said that NLM should look to public libraries, churches, and hospitals to help promote its use. Dr. Richard Dean commented that services like this offer a good opportunity to study the links between providing health information to the public and improving actual health outcomes. Dr. Joseph Newhouse said that an important adjunct to providing information would be to connect users to the health care system; this is especially crucial for those who don't have insurance. Ms. Backus said that NLM recognizes this need and that we have a pilot project in North Carolina to link MEDLINEplus users to local health care resources.

XVI. GRANTEE PRESENTATION: "BORDER HEALTH INFORMATION AND EDUCATION NETWORK"

Ms. Sylvia Ortiz, head of the Reference Department of the New Mexico State University Library (Las Cruces), described the work of her and her colleagues in the Border Health Information and Education Network (BIEN). BIEN is a group of 17 partner institutions (libraries, hospitals, schools, and public health agencies) that was organized in 1999 to promote and provide quality

health information to those who live in the New Mexico border area. This is an area of extreme poverty, inadequate infrastructure, significant immigrant populations, and low levels of educational attainment—and it is one of the fastest growing areas in the U.S. In 2000, NLM funded an information access grant to support BIEN's goals: to provide quality health information to consumers in online and other formats, to provide research information to health professionals and students, to develop a network for the participating institutions, and to provide health information literacy training (in both English and Spanish). Ms. Ortiz, principal investigator for the grant, described how decisions were made, including selecting an Internet Service Provider and providing equipment for and connecting to the Internet those sites that weren't already connected. After installing infrastructure, BIEN identified a number of high-quality online sources for health information, including PubMed and MEDLINEplus. Selected commercial database subscriptions were obtained, and individualized core collections of print and digital health information made available to each member institution. The librarians of member organizations fielded reference questions by email, telephone, and in person; provided efficient interlibrary loan service; and provided training to consumers, health professionals and others. The partners kept in touch constantly through email and periodic meetings. BIEN participated in a number of community health fairs and larger conferences, and BIEN was selected as one of 50 awardees in the Best Practices conference sponsored by the National Institute for Science and Technology (NIST). Among the lessons learned, according to Ms. Ortiz: the project was far too ambitious to be accomplished in one year and they underestimated the need for a multi-faceted marketing campaign. She concluded that the project was entirely successful in meeting its goals of providing improved access to reliable health information in English and Spanish for a wide audience. They have located support to temporarily continue the Web site, training, and services.

XVII. ADJOURNMENT

The meeting was adjourned at noon on September 11, 2002.

ACTIONS TAKEN BY THE BOARD OF REGENTS:
- ➢ Approval of the May 14-15, 2002 Board of Regents Minutes
- ➢ Approval of September 9-10, 2003 Meeting Dates
- ➢ Establishment of two subcommittees to the Board of Regents: (1) Subcommittee on Bioethics and (2) Subcommittee on Biomedical Imaging and Bioengineering
- ➢ Presentation of 2002 Regents' Award to Mr. Rodney Long, Lister Hill National Center for Biomedical Communications for the "design and development of the WebMIRS information retrieval system"
- ➢ Concept approval of K-22 grants award program
- ➢ Concurred with recommendations of the Extramural Programs Subcommittee

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

Donald A.B. Lindberg, M.D.   Alison Bunting, M.L.S.
Director, National Library of Medicine   Chair, NLM Board of Regents