

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

**MINUTES OF THE BOARD OF REGENTS  
February 10-11, 2004**

The 135th meeting of the Board of Regents was convened on February 10, 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 February 11, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

**MEMBERS PRESENT:**

Dr. Holly Buchanan  
Dr. Ernest Carter  
Dr. A. Wallace Conerly  
Dr. Richard Dean  
Dr. Thomas Detre  
Ms. Eleanor Frierson  
Dr. Vasiliki Karlis  
Dr. Ralph Linsker  
Ms. Eugenie Prime [Chair]  
Dr. William Stead

**EX OFFICIO AND ALTERNATE MEMBERS PRESENT:**

Dr. Richard Carmona, U.S. Public Health Service  
Ms. Eleanor Frierson, U.S. Department of Agriculture  
Gen. Gerry Harmon, U.S. Department of the Air Force  
Dr. Deanna Marcum, Library of Congress  
Dr. Michael Pazzani, National Science Foundation  
Col. Kristen Raines, U.S. Department of the Army  
Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs  
Capt. Dan Wonderlich, U.S. Department of the Navy  
Dr. James Zimble, Uniformed Services University of the Health Sciences

**CONSULTANTS TO THE BOR PRESENT:**

Dr. Tenley Albright, Whitehead Institute for Biomedical Research  
Dr. Marion Ball, Johns Hopkins School of Nursing  
Ms. Alison Bunting  
Dr. H. Kenneth Walker, Emory University School of Medicine

**SPEAKERS AND INVITED GUESTS PRESENT:**

Mr. Richard Mayer, CEO, MHA Nation  
Honorable Paul Rogers, Hogan and Hartson  
Mr. Buford Rolin, NCAI President's Task Force on Health Information

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Dr. Kelley Withy, University of Hawaii

**MEMBERS OF THE PUBLIC PRESENT:**

Ms. Jennifer Cabe, OPHS, DHHS  
Mr. Alec Stone, Friends of the NLM  
Ms. Tara Straw, March of Dimes  
Mr. Thomas West, The Krasnow Institute

**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. Stacey Arnesen, Division of Specialized Information Services, NLM  
Ms. Suzanne Aubuchon, Office of the Director, NLM  
Dr. Dennis Benson, National Center for Biotechnology Information, NLM  
Ms. Susan Buyer, Office of Planning and Analysis, NLM  
Ms. Pat Carson, Office of the Director, NLM  
Dr. Milton Corn, Division of Extramural Programs, NLM  
Ms. Kathleen Cravedi, Office of Communication and Public Liaison, NLM  
Ms. Gale Dutcher, Division of Specialized Information Services, NLM  
Dr. Elizabeth Fee, History of Medicine Division, NLM  
Dr. Valerie Florance, Division of Extramural Programs, NLM  
Mr. Gary Fox, Office of Computer and Communications Systems, NLM  
Dr. Charles Friedman, NLM Sabbatical/Division of Extramural Programs, NLM  
Ms. Cynthia Gaines, Office of Outreach and Special Populations, NLM  
Mr. Mike Gill, Lister Hill National Center for Biomedical Communications, NLM  
Ms. Jane Griffith, Office of the Director, NLM  
Ms. Wendy Hadfield, Executive Office, NLM  
Ms. Betsy Humphreys, Division of Library Operations, NLM  
Ms. Christine Ireland, Division of Extramural Programs, NLM  
Dr. Donald W. King, Office of the Director, NLM  
Ms. Michelle Krever, Division of Extramural Programs, NLM  
Ms. Eve-Marie Lacroix, Public Services Division, NLM  
Dr. David Lipman, National Center for Biotechnology Information, NLM  
Dr. Simon Liu, Office of Computer and Communications Systems, NLM  
Dr. Robert Logan, Lister Hill National Center for Biomedical Communications, 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  
Mr. David Nash, Office of Equal Employment Opportunity, NLM  
Dr. Stuart Nelson, Division of Library Operations, NLM  
Mr. Jon Retzlaff, Executive Office, NLM  
Ms. Julia Royall, Health Information Program Development, NLM

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Dr. Angela Ruffin, Division of Library Operations, NLM  
Mr. Wes Russell, Office of Computer and Communications Systems, NLM  
Mr. John Scott, Office of the Director, 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  
Ms. Marti Szczur, Division of Specialized Information Services, NLM  
Dr. Fred Wood, Health Information Program Development, NLM

### **I. OPENING REMARKS**

Ms. Eugenie Prime welcomed the Regents, alternates, consultants, and guests to the 135<sup>th</sup> meeting of the Board of Regents of the National Library of Medicine. She also welcomed to the meeting Alison Bunting, a former member of the Board.

### **II. REPORT FROM THE SURGEON GENERAL, PHS**

Richard Carmona, M.D., Surgeon General of the U.S. Public Health Service, discussed with the Regents a subject he is deeply concerned about: health literacy. This is the ability of citizens to understand and use reliable health information and services to make appropriate health decisions. A high degree of health literacy is basic to success in the three priorities he has been assigned by the President: prevention, public health and emergency preparedness, and eliminating health disparities. Even well-educated Americans don't have sufficient background and training in the health sciences and are largely health-illiterate. Dr. Carmona is pleased that the NLM has extended its outreach from its original focus on health care professionals and scientists to include patients, families, and the general public. He cited the examples of MedlinePlus, Household Products Database, and NIHSeniorHealth.gov as products that provide reliable information and encourage health lifestyles and disease prevention. He said he is impressed by NLM's outreach initiatives that focus on minority and underserved communities, such as the projects in the lower Rio Grande valley of Texas. He also cited NLM's "Listening Circle" program with the Native American community as consistent with the Administration's commitment to community-based consultation and partnership. Talking again about health literacy, the Surgeon General said that we must close the gap between what health professionals know and the rest of America understands. Low health literacy adds as much as \$58 billion per year to health care costs. A study has shown that one third of patients in the hospital were unable to read basic health material, 26% could not read appointment slips, and 42% did not understand the labels on medications. This is especially a problem in the areas of pre-pregnancy and pregnancy; Dr. Carmona will appear on a major live television program next week on this subject. The lack of prenatal care, for example, is especially acute with African American and Native American women. He cited several more examples of severe problem areas involving pregnancy. There are several promising approaches to improving health literacy, ranging from high-tech interactive programs on the Internet to low-tech peer-to-peer education. He is directing that all communications from the Surgeon General's office be written in plain language. Although health

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communication alone cannot solve systemic problems such as poverty, environmental degradation, and lack of access to health care, we should ensure that the best practices of health literacy are incorporated into all our communications. The NLM is helping to meet these challenges. “Healthy People 2010,” the Department’s roadmap for the nation’s health, recommends activities to improve health literacy, including building a robust health information system that provides equitable access, developing audience-appropriate information and support services for all segments of the population, and training health professionals and scientists in the use of communications technology. “Health literacy is the currency for success for everything I am doing as Surgeon General,” he concluded.

Dr. Detre commented that the best way to address issues of health literacy is to create community groups with patients who have experienced a problem—hypertension, high cholesterol, arrhythmia, diabetes, etc. He has had experience working as a resource person for such a group and believes it is a much more effective way to impart information than what can be imparted during a brief in-office consultation with a physician. Dr. Lindberg added that ideally we should be doing more than imparting information; we should be improving *understanding* on the part of the patient. The crucial question is to how best to do this. He said that the health tutorials in MedlinePlus are one method. Dr. Zimble said that it is a “major indictment of our educational system” to have so many people who are health illiterate to the degree that Dr. Carmona indicated.

### **III. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING**

The Regents approved without change the minutes from the September 9-10, 2003 meeting.

### **IV. DATES OF FUTURE BOARD MEETINGS**

The Board of Regents will meet next on May 19-20, 2004. The Board is meeting next fall on September 21-22. The dates of February 15-16, 2005, were adopted for the meeting next winter.

### **V. NLM DIRECTOR’S REPORT**

Dr. Donald Lindberg said that NLM’s appropriation for FY 2004 is \$317,315,000; the FY 2005 President’s request is \$325,147,000, about a 2.5% increase. In the area of personnel, the Director announced the appointment of Dr. Valerie Florance as Deputy Director, Extramural Programs. Dr. Alexa McCray introduced to the Board Dr. Kin Wah Fung, a surgeon and medical informatician, who has joined the Lister Hill Center as a postdoctoral fellow. Dr. David Lipman introduced two new postdoctoral fellows of the National Center for Biotechnology Information: Dr. Barend Johannes Mans and Dr. Liran Carmel. Dr. Jack Snyder introduced Florence Chang, who has just been appointed Chief of the Biomedical Files Implementation Branch of the Division of Specialized Information Services. Dr. Lindberg noted several recent departures: Dr. Gabor Marth of the NCBI, Dr. Carol Bean and Dr. Merlyn Rodrigues of the Extramural Programs, PHS historian (and former Chief of NLM’s History of Medicine Division) Dr. John

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Parascandola, and Christa F. B. Hoffmann, Head of the Cataloging Section, Technical Services Division. Dr. Lindberg next turned to Jane Griffith, NLM Assistant Director for Policy Development to report on legislation of interest to the Library. She noted that database legislation (HR 3261) has been moving forward. The bill has support of the House leadership; NLM is working with other science agencies and organizations to make sure that issues involving providing protection for “facts” are addressed. NLM is concerned because the Library creates and provides free access to several “factual” (as opposed to bibliographic) databases and to factual information contained in the biomedical literature. Ms. Griffith also said that Senator Clinton introduced a bill (S.2003), the Health Information for Quality Improvement Act, which aims to improve the quality of care. The bill, which deals with providing support for IT applications and improving the interoperability of systems for exchanging clinical information by developing standards, reflects a growing interest in the Congress in these issues. NLM will participate in a briefing for the Senate Health Committee legislative staff to introduce them to what NLM, NIH, and HHS are doing in this area.

Dr. Lindberg announced that NLM, reluctantly, has made the decision to cease publication of the monthly *Index Medicus* with the December 2004 issue. The expense of its production was no longer justified by use—subscriptions have declined drastically in recent years. At the same time, usage of its online version—MEDLINE/PubMed—has increased dramatically; each year a half billion searches of this database are done by scientists, health professionals, and the public worldwide. The NLM Director next noted that progress is being made on the “Information Rx” project. This is the joint project with the American College of Physicians to encourage practicing physicians to “prescribe” MedlinePlus as a source of information for their patients. The Board has heard in the past about the first two states to participate, Georgia and Iowa. After introducing the project in Virginia and then Florida later this spring there will be a national rollout of the Information Rx program at the ACP annual meeting. This program will be the subject of a future presentation to the Regents. On a different subject, Dr. Lindberg said that the National Committee on Vital and Health Statistics, an important committee (chaired in the past by Dr. Don Detmer, a former chair of the Board of Regents) has done valuable work and reflects the importance being placed on standards for health care and for collecting, analyzing, exchanging, and using health data. HHS Secretary Thompson agreed with the Committee’s recommendations regarding terminology standards and he has supported (and formally announced) NLM’s arrangement for the SNOMED CT vocabulary to serve as a core vocabulary for clinical care standards. There is still much work to be done—NLM is incorporating SNOMED CT into the Library’s Unified Medical Language System Metathesaurus. NLM’s Betsy Humphreys, who led the interagency effort to arrange SNOMED CT contract, said that NLM has received \$3.25 million from HHS to help the Library respond to the most recent set of NCVHS recommendations, which proposed that NLM serve as the coordinating body for the alignment and distribution within the UMLS Metathesaurus of standard clinical terminologies. Dr. Lindberg spoke briefly about the NIH Roadmap initiative. Before NIH Director Zerhouni arrived, he said, there was essentially no mechanism by which NIH and all its Institutes and Centers could make a decision on a matter of common interest. An early outcome of Roadmap activity was the almost universal agreement that at the top of the priority list of needs was a

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chemical database. NCBI will be involved in building this, and it will be the subject of a future presentation to the Board. Dr. Lipman, Dr. Corn, Dr. McCray, Ms. Humphreys, and Dr. Lindberg are all involved in various aspects of the Roadmap work.

Dr. Lindberg said that the new database, NIHSeniorHealth.gov, was successfully launched at a ceremony in the Congress on October 23, 2003. Senator Tom Harkin of Iowa did the honors and conducted the “first search.” NIHSeniorHealth.gov, a joint project of the NLM and the National Institute on Aging, was demonstrated to the Regents at their last meeting. The new database was widely covered by newspapers and as a result the level of usage is encouraging. Other Institutes are now also contributing topics to the database. Dr. Lindberg showed a video clip from the launch, including an example of the television coverage. Dr. Lindberg said he was pleased with the work of the two ad hoc Regents subgroups that were created to look into (1) bioethics information, chaired by Dr. Thomas Detre and (2) biomedical imaging and bioengineering, chaired by Dr. Morris Collen. The report of each subgroup was given to the Board. Dr. Lindberg briefly summarized their findings. He said that staff would periodically update the Board as to progress made in implementing the recommendations. The NLM Director said that we very much regret that for health reasons, Dr. C. Everett Koop would be unable to join the Regents tonight as originally planned. Finally, he showed some pictures from an outreach trip by Dr. Elliot Siegel, Gale Dutcher, and him to a remote village in Hawaii. Although the village did not have running water or regular electricity it did, in fact, have a small library and a computer powered by a gasoline generator.

Following Dr. Lindberg’s report, Alison Bunting suggested that NLM might consider producing the *Index Medicus* on CD-ROM. If the decision is to go ahead and cease publication, it will be important for the NLM to describe to the Library community the extensive backup and contingency plans for safeguarding the MEDLINE database to ensure that it cannot be lost in a catastrophe.

During the coffee break, the Regents were escorted through the new NLM exhibit, “Changing the Face of Medicine.”

## **VI. NEW ENTREZ DATABASES AND FEATURES**

Dr. David Lipman, Director of the National Center for Biotechnology Information, said that one of their goals was to move all of their Web-based databases into one integrated retrieval system—so that one search query would run against all. A visiting Microsoft expert urged the NCBI to deal with the technical issues involved and to make this single-search capability a reality. With Ms. Kathi Canese assisting him, Dr. Lipman demonstrated to the Regents that this has now been accomplished and he showed a number of features of the system. In the first two weeks after it went up, PubMedCentral and the Book Site usage both rose by a third; we are now receiving about 25,000 queries a day on the new system alone. In response to a comment from Dr. Detre about the different searching needs and priorities of different users, Dr. Lipman said we have to recognize that our users occupy various niches and we therefore need to tailor

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different “defaults” for different groups. We should be identifying these groups and, since we now have the technology, we should begin creating such a capability for them. One aspect of this is the need to allow users to authorize “persistent cookies” that would allow our systems to tailor defaults and screens for a particular user. We have received Departmental approval for the cookies and are now working on this, Dr. Lipman stated. He and Ms. Canese then described two other NCBI resources: Entrez Gene (curated information for a wide range of organisms) and GENSAT (the Gene Expression Nervous System Atlas), a collaborative project with the NINDS.

Following Dr. Lipman’s presentation, Alison Bunting commented that one of the recent NCBI accomplishments—putting all back issues of the *Bulletin of the Medical Library Association* on the Web—is a real boon to the profession. She said it is interesting to note that the early members of the Association were primarily physicians. In response to a question from Dr. Deanna Marcum, Dr. Lipman said that the Entrez software that forms the backbone of the NCBI services, although it is complex and was created specifically for the Center, does have a component—the DTD (specified format) for PubMedCentral—that we are interested in having other groups use.

## VII. REPORT FROM THE OFFICE OF THE DIRECTOR

Dr. Raynard Kington, NIH Deputy Director, said that NIH was on schedule for implementing the Roadmap plan. Senior NIH officials are being invited by universities around the country to visit and explain the Roadmap initiative. There will be a February 27 Web-based videoconference on the subject of the Roadmap that will be open to all. On the subject of NIH organization and administrative restructuring, Dr. Kington said that he co-chaired an advisory committee that prepared a report to improve efficiencies across a wide range of domains that is now being implemented. Associated with this is the “A-76” related restructuring in such areas as grants management that is now taking place. The National Academy of Public Administration has been enlisted to serve as a consultant in these matters, and eight NIH working groups have been formed at NIH to implement the changes. Dr. Kington addressed how NIH is dealing with conflict-of-interest issues. Questions have been raised in the Congress about awards to NIH employees, and the press has raised questions about outside consulting activities on the part of scientists. Some of those press accounts had serious inaccuracies, he said. No patient has been harmed as a result of any of these issues and there is no evidence that any of the relationships resulted in changes in decision-making at NIH. Nor is there any evidence of substantial illegal activity, he added. Nevertheless, because perceptions are important, Dr. Zerhouni has taken several strong steps to address the issues: the role of lead ethics counselor has been delegated to Dr. Kington; a new NIH Ethics Advisory Committee has been formed (co-chaired by Dr. Kington); NIH is reviewing every outside activity of every NIH employee since 1999; much more information is being requested from an employee before granting approval for outside activity; NIH is requesting changes in the regulations governing these matters from the Office of Government Ethics; and a blue-ribbon commission, to be chaired by the President of the National Academy of Sciences, is being formed as an advisory committee to the NIH Director. Finally, Dr. Kington stated that a number of senior NIH positions are being recruited for: the

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directors for the Center for Scientific Review; National Heart, Lung, and Blood Institute; National Institute of Environmental Health Sciences; Fogarty International Center; and the NIH Deputy Director for Management. He noted that several senior NIH positions have recently been filled. Following Dr. Kington's presentation, there was a discussion of how NIH uses "Title 42" authority to pay senior NIH scientists above the regular Federal pay scale.

### **VIII. "LIBRARY AS PLACE" SYMPOSIUM**

Becky Lyon, NLM Deputy Associate Director for Library Operations, described to the Board the November 5-6, 2003, "Library as Place" Symposium held at the NLM. A similar symposium, co-sponsored by NLM and the University of Maryland Health Sciences Library, was held in 1994. The 2003 symposium was jointly sponsored by the Library and the Association of Academic Health Sciences Libraries. Mr. Rick Forsman, Director of the University of Colorado Health Sciences Library chaired the event, the purpose of which was to focus on library building and renovation projects in the 21<sup>st</sup> century. The symposium explored what is the role of librarians and libraries in our institutions and society in the 21<sup>st</sup> century. Should we even consider building or renovating libraries when there is so much well-organized information available on the Web? The symposium also gave NLM the opportunity to share in some detail with the library community its plans for expanding its own facilities. Ms. Lyon said the symposium was attended by 170 librarians, architects, scientists, administrators, and other stakeholders. It was also shown on a live Webcast (and is still available for viewing). She described briefly the agenda and the keynoters and said that there were also 19 poster presentations. There was a symposium Web site and there are plans to produce a DVD with all presentations, interviews, and poster presenters. She then showed the Regents a video that contained highlights from the symposium.

The Board Chair then introduced to the Regents the Chairman of the Friends of the National Library of Medicine, the Honorable Paul Rogers. Mr. Rogers served in the House of Representatives for 24 years, retiring in 1979. Ms. Prime recounted highlights of Mr. Rogers's illustrious career, saying that he was known as Mr. Health in the Congress because he was a prime mover in enacting much of the important health legislation of the 1960s and 70s. He was an early proponent of the idea that the Federal government has a responsibility to disseminate health information directly to the public, a mission that the NLM is today engaged in.

Mr. Rogers told the Board that he goes back many years with the NLM and the NIH. Each year he was impressed with the testimony of then-director Martin Cummings, M.D. The uniqueness of this institution has become even more apparent under the leadership of Don Lindberg and his able staff. He said that he closely followed the computerization of the Library's services from the early days of MEDLARS to today's MEDLINE/PubMed with its annual usage of an astounding half billion searches a year. He recalled some of the highlights of the last 20 years of Dr. Lindberg's leadership, including the establishment of the National Center for Biotechnology Information in 1988, in which the Friends of the NLM played a role. The NCBI today is the public repository of the DNA sequence data resulting from the Human Genome project. Another major change in the Library is its assuming responsibility for providing consumers with access to



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reliable health information. It is doing this through such well-received resources as MedlinePlus, ClinicalTrials.gov, NIHSeniorHealth.gov, and other Web-based databases. Mr. Rogers emphasized the importance of having useful information, including guidelines, which will help the public in dealing with their health professionals. “There will be some that won’t like that,” he said, but providing such information “is perhaps as significant a service that this Board and the Library can give to the American public.”

Mr. Rogers said he has been privileged to Chair the Friends of the National Library of Medicine. The Friends is made up of scientists, physicians, medical librarians, academic institutions, nonprofit groups, corporations, and the general public. The Friends actively supports and promotes the initiatives of the NLM, including those involving the National Network of Libraries of Medicine. It has helped to arrange supporting action in the Congress. The Friends back wholeheartedly the themes of the “Library as Place.” Mr. Rogers said that it is obvious that the NLM, like a hermit crab, has outgrown its shell—you have more than 1,000 people in facilities designed for 600—clearly more room is needed and the Friends will join with the staff and the Board to do all we can to help with an expanded facility. He concluded: “With broadened service to the public, which you have already started... our citizens will demand proper support of the Library of Medicine—from the Administration and from the Congress.”

Following the presentation, Eugenie Prime, on behalf of the Board of Regents, presented to Mr. Rogers the Distinguished Service Award for his long and illustrious service to the National Library of Medicine. “We present this to you knowing that this institution, in which we take great pride in serving, owes so much to your hard work in the halls of Congress and your wise judgment as Chair of the Friends of the National Library of Medicine.”

Dr. Thomas Detre and Dr. William Stead next presented to the Regents a draft statement on the need for expanded NLM facilities. They were asked to prepare a succinct and persuasive document at the last meeting of the Board. The statement could be used individually by the Regents to assist the Library in making the case for the need for an expanded facility. Dr. Stead and Dr. Detre briefly summarized the main points of the statement. Dr. A. Wallace Conerly said that he fully supported the statement and would do whatever is within his power to help with the new facility. Dr. Holly Buchanan said that this is a “wonderful articulation” of the need for a new building—it is important to remember that NLM has not only a national role, but is vital to local institutions. Dr. Deanna Marcum said that the Library of Congress would support the NLM in any way it could as the NLM goes forward with its space planning. Two suggestions were offered by Dr. Detre that the statement should note that many students and visitors use the NLM directly, and by Eleanor Frierson that the dependence of hospital libraries on the NLM should be explicitly noted—were agreed to, and the statement was unanimously approved and adopted by the Board. The statement is in Attachment B.

## **IX. NLM USER STUDIES**

Dr. Fred Wood of NLM’s Office of Health Information Programs Development presented to the

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Board an update on evaluation and user studies of its Web sites conducted by the Library. Over the years the NLM has sponsored both external and internal studies. The reasons we conduct such studies are to better understand our position in the health information arena, get feedback on user satisfaction, learn more about our users, and gain insights into how we can improve and monitor trends and changes. NLM has developed a multidimensional approach that is described in a paper published in 2003 in *IT PRO* by Dr. Wood et al. He described briefly the Internet audience measurement panels (an external review) and NLM's online user surveys (internal). The external panels consist of large numbers of people who have their Web usage monitored 24/7. Dr. Wood described some of their findings and how they accord with NLM's own Web log monitoring. The external panels are the only way we can obtain reasonably reliable information about usage of other Web sites besides NLM's. They show that NLM constitutes a very large segment (more than half) of the traffic on the overall NIH.GOV top level domain. Dr. Wood presented statistics on how NLM's Web traffic compared with a variety of others. He next described how NLM has been doing onsite user surveys for several years. This allows us to get more "drill-down" information about visitors to our Web sites. We are now in our "third generation" of user surveys that allow continuous sampling of a smaller number of users who respond to a randomized pop-up series of questions. We are now piloting the American Customer Satisfaction Index (ACSI), a system increasingly being used by federal agencies. Five NLM Web sites are included in this pilot study. Preliminary results show that two NLM Web sites—MedlinePlus and MedlinePlus en español—scored very high. We are now comparing the data from the ACSI with data from our earlier surveys. We believe that Web evaluation techniques are important tools for continuing to improve NLM information services.

Following Dr. Wood's presentation, Eve-Marie Lacroix, Chief of the Public Services Division, said that NLM has in the last year done in-depth user testing for MedlinePlus and MedlinePlus en español, both with pop-up online surveys (12,000 respondents) and online focus groups. User feedback has always been important to NLM, she said. There is a comments link on every page of MedlinePlus. The last usability study revealed several problem areas that resulted in confusion for users; Ms. Lacroix showed how these were being fixed. She said that much Spanish information, including a daily news feed, has been added to MedlinePlus en español recently. A Spanish language drug index will be completed this August. Some health topics (for example, "diabetes") have become so large that we are working on ways to reorganize and make them more navigable and accessible. Usage of the English version of MedlinePlus is about 79% U.S.; surprisingly, MedlinePlus en español usage is about 94% non-U.S. We need to do more outreach to U.S. Spanish-speakers. We have also responded to suggestions by combining all the easy-to-read items into one part of the site. The ACSI survey revealed that the NLM home page did not score as high as other NLM sites. We are now redesigning the page for launch this spring. The new design has been tested and we look forward to seeing how it fares (compared to the old) on the ACSI. Ms. Lacroix showed the new design and described some of its features.

Following these presentations, Dr. Vasiliki Karlis congratulated NLM and MedlinePlus for the high score it achieved on the ACSI. She noted that health literacy, which Dr. Carmona spoke about this morning, and Dr. Lindberg's question about how do we really know if patients

*understand* the health information, both have relevance to the surveys and user studies Dr. Wood and Ms. Lacroix have described. There was a general discussion of the usage of MedlinePlus by the U.S. Spanish-speaking community and how this usage could be increased. Alison Bunting commented that this usage initially is probably from the more educated individuals in Spanish-speaking countries; U.S. Spanish speakers, many of who are immigrants, and may be less likely to access this information on the Web.

## **X. HAWAII ACCESS TO COMPUTERIZED HEALTH INFORMATION**

Dr. Kelley Withy, Associate Professor of Family Practice at the University of Hawaii School of Medicine, and Director of the Statewide Area Health Education Center, was awarded an NLM information system grant for a project known as Hawaii Access to Computerized Health (HATCH). The aims of the HATCH program are to improve access to health information for community members and professionals, improve health information availability in under-served areas, provide video connectivity between community learning centers, to promote sharing, and to monitor health statistics. Dr. Withy described how health education is provided in the communities beginning in kindergarten. There are unique challenges in Hawaii. For example, Native Hawaiians have higher rates of many diseases than other ethnic groups in the State, and mortality rates two to eight times that of Caucasians. Rates of unemployment, accidents, teen pregnancy, and incarceration, are all high. There are a large percentage of immigrants from underserved areas. There is also often a lack of trust on the part of the people being served. The idea of the project was to educate peers to be able to counsel peers, with a health professional being available. Dr. Withy showed a map and described briefly the situation on the various Hawaiian islands; she also showed a map of the widely scattered island groups in the Pacific Basin area and described their situation. She said that MedlinePlus and other Web-based consumer health information resources are encouraged; for health providers, she gets the word out about Medline/PubMed and other databases, including several from NIH, are provided. The faculty at the University of Hawaii have access to PubMed's LinkOut to access full text. To improve the situation in underserved areas, Dr. Withy listed the attributes of the information resources they encourage: accessible, affordable, applicable, trustworthy, non-threatening, culturally sensitive, and user-friendly. She used as an example the Diabetes Education & Counseling Center in Hilo. She discussed how video teleconferencing is done among the scattered health education centers and other sites using the State of Hawaii Telehealth Access Network. This videoconferencing is expensive and, for a variety of reasons, difficult. A better solution is Internet connectivity, the "HATCH" project. There are almost 30 sites, almost all of which have high-speed access. The network is easy to use, inexpensive, accessible in rural areas, encourages learning, and provides for additional job skills. Dr. Withy showed images of a number of the sites on different islands. They even have an Internet-based "ask-the-doc" service. Although there is more local acceptance of computers, there is still the challenge of identifying what the people need and getting them to learn to use the service. She described how they are conducting surveys and gathering data to evaluate the network and learn how to improve it.

Following Dr. Withy's presentation, Dr. Ernest Carter said that the grantee has done an excellent

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job and that this was an example of very good use of NLM money. He believes that this community-centric approach is the wave of the future in how to improve health care in communities that are underserved. There is a parallel between what is happening in Hawaii and what is happening right here in Anacostia in Washington, D.C, in the lower Mississippi Delta, and on Native American reservations in North Dakota. He said that through a project like this we learn how to use technology to solve some of the problems and to improve health outcomes.

### **XI. EXTRAMURAL PROGRAMS REPORT**

Dr. Milton Corn, NLM Associate Director for Extramural Programs, presented a summary of FY 2003 grant expenditures for each of NLM's grant programs in the Medical Library Assistance Act and in the PHS 301 categories. The history and current status of NLM's Publication Grant program was reviewed with presentation of funding parameters, eligible grants, and recent history. A large sample of books published after NLM support to the author was made available in the Board Room for perusal by interested members. Also presented was a history of the goals and structure of NIH's Loan Repayment program. NIH experience and NLM experience for FY 2003 and for FY 2004 were presented. Dr. Corn also presented an overview of NIH's Roadmap Initiative, including its rationale, themes, announced programs to date, and issues relevant to funding and management. Several Board members provided questions from the floor and there was some general discussion.

### **XII. SACRED ROOT: NATIVE AMERICAN INFORMATION INTERNSHIP PILOT PROJECT**

Ms. Gale Dutcher, Head, Office of Outreach and Special Populations, Specialized Information Services, presented some background about the Sacred Root Native American intern pilot project that is beginning its third year. The purpose of the internship is ultimately to improve the capacity of American Indian tribes, Alaska Natives, and Native Hawaiian communities to use health information and health information technology to improve the health of their communities. The year-long program is designed for mid-career professionals working for their tribe or on a reservation, village, or community. There have been two participants from each group—one person with a health background and one who is familiar with information technology. A stipend is paid, as are travel, additional training, and conference participation. A laptop computer with Internet connection is provided to each intern. They start the year spending about two weeks at NLM and receive online training and an orientation to NLM programs and services. A year-long schedule is laid out to meet their specific interests and needs. A trip to their Regional Medical Library is arranged. The year ends with the development of a project for implementation for the tribe: the interns write a proposal (with help from NLM staff) for an information access project, to be completed over a year and a half, which NLM will then fund (for up to \$50,000). Ms. Dutcher described how the program had its beginning in FY 2001, when the National Center for Minority Health and Health Disparities requested submissions from components of NIH that would help overcome disparities in health. NLM is now working with the National Congress of American Indians President's Task Force on Health Information to

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implement this pilot project in all eight tribes or communities represented on the Task Force. In 2002 there were two interns from MHA Nation, Richard Mayer and Deborah Thompson, who successfully completed the program. There were two interns from the Nez Perce tribe in 2003; their internship is concluding this month. The most recent set of interns are native Hawaiian and start April 2004. NLM plans to continue to work with the Task Force and is now starting to develop an evaluation plan for the project.

Following Ms. Dutcher's presentation, Mr. Richard Mayer, one of the interns from the 2001 class thanked Dr. Lindberg and Gale Dutcher for their part in making the program a reality. He also said that the program could not exist without the support of Tex G. Hall, President of the National Congress of American Indians, and Chairman of the Executive Council of the MHA Nation (also known as the Three Affiliated Tribes) in North Dakota. Mr. Mayer gave a brief overview of the history of the reservation and the treaties entered into with the U.S. government. He showed pictures of the forced relocation of Indians on the Ft. Berthold Reservation as a result of building the Garrison Dam and the flooding of reservation lands in the 1940s. He also showed photographs of schools, hospitals, bridges, and agricultural land that were subsequently submerged under the lake created. A series of 19<sup>th</sup> century paintings by artist George Catlin showed scenes in Mandan Indian villages. Mr. Mayer then showed pictures of the "MHA Nation Health Information Mobile Computer Lab," with laptop computers and projectors, that was the subject of his project. His partner in the project was Deborah Thompson, RN, who has a master's degree in management. Under the NLM award, tribal member Bruce Hall was hired to be Tribal Health Coordinator. He works with community workers to train them how to access web-based health information so that they were able to provide this information to community members. He also meets with various elders throughout the Reservation to provide health information, one on one. In a future project, Mr. Hall suggested training radio station personnel so that for one hour each day they could answer people's health questions using NLM information resources. Mr. Mayer presented some statistics about the number of students trained.

Mr. Buford Rolin, Vice-Chair and Health Administrator of the Poarch Band of Creek Indians, Atmore, Alabama, and Chair, NCAI President's Task Force on Health Information, said that after Tex Hall was elected President of the National Congress of American Indians (NCAI), one of his first actions was to form a national Task Force on Health Information comprised of elected leaders representing American Indians, Alaska Natives, and Native Hawaiians. The goal of the NCAI Task Force is to improve the availability of and access to quality health information and clinical services in Native communities. What distinguishes this Task Force is the level of commitment by elected tribal and Native community leaders to focus attention on outstanding health needs and to take steps to resolve these needs on behalf not only of the communities represented by Task Force members but also the 579 federally recognized Native American and Alaskan Native tribes and Native Hawaiian communities throughout the U.S. Mr. Rolin cited statistics showing the severe effect of various diseases and social problems on Native Americans. The aim of the Task Force is to turn these trends around, and improving the dissemination of health information is an important part of the effort. Since its beginning, the Task Force has enjoyed a good working relationship with NLM and has, for example, recommended members

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for NLM's Environmental Health Information Outreach Program. Dr. Lindberg and NLM staff recently took part in a Listening Circle in Hawaii hosted by Task Force member Hardy Spoehr, Executive Director of Papa Ola Lokahi. In addition, NLM was invited as a keynote participant in the Idaho Tribal Leaders Health Information Summit convened by the Task Force and Senator Mike Crapo last month in Boise, Idaho. Since the commitment made by Dr. Lindberg at the first Task Force meeting in November 2002 in Bethesda, the Sacred Root Internship Program has been one of the most prized initiatives of the Task Force. The name Sacred Root was given to the training program at the most recent Task Force meeting in recognition of the common positive symbolism of roots within native communities: Strong roots make strong trees. Mr. Rolin concluded by saying that the Task Force has support in the Congress. For example, through recent Congressional appropriations, facilitated by the Task Force, an Internet-based diabetes management program is being introduced in eight tribes and two Native Hawaiian communities. Also, the U.S. Senate Committee on Indian Affairs will host the next Task Force meeting which will be convened on Capitol Hill at the end of March. In order to recognize the valuable support of NLM, the Task Force has invited Dr. Lindberg to introduce the *Sacred Root Internship Program* at this meeting.

Following these presentations Dr. Holly Buchanan, asked how the Task Force plans to share the "lessons learned" with the broader community, including tribes who may not be members. Mr. Mayer responded that through regional consortia of tribes what has learned can be taken back to the tribes who can then assign individuals to look into available resources. Also, by working through the existing network of libraries in 33 tribal community colleges around the U.S. it will be possible to spread the benefits of the program. NLM can play an important role in this. Mr. Rolin said that by using the political system and through newsletters we can get this information out to the tribes. Dr. Kenneth Walker observed that this is a striking example of progress under NLM's 2000-2005 published strategic plan to reduce racial and ethnic health disparities. It has been said that the U.S. is the most diverse nation in the world, and NLM has been "prescient and precocious" in recognizing this. He said that this program is truly an example of a bilateral relationship, and that NLM can learn much from the process that will stand it in good stead in the future.

### **XIII. NIH CONSOLIDATED COLLOCATON SITE**

Dr. Simon Liu, Director of the Office of Computer and Communications Systems, said that with leadership from the NLM, a trans-NIH committee has established under contract a backup capability for NIH's extensive computer-based operations. The facility, known as the NIH Consolidated Collocation Site (NCCS), is located in northern Virginia some 25 miles from the NIH. It provides for load-balancing and also a level of security for continuing operations in the event of a power- or disaster-related occurrence, or other threat to the infrastructure. Using photographs, Dr. Liu took the Regents on a tour of the new facility, describing its environmental situation (temperature, etc.), power capabilities, security arrangements, Internet connections, and other features. He then did a live demonstration, actually interrupting the NLM system and shifting the load to the backup system at the NCCS.

Dr. Ralph Linsker complimented the team that put together the NCCS. He asked about preparations to repel software intrusions and viruses. Dr. Liu said there is layered security—on the perimeter and network level, on the system level, and on the desktop level. There are separate security measures at the NCCS. Dr. Walker asked whether there should be more than one backup site, one that is more remote from Bethesda. Dr. Liu said that in fact three copies of the databases are maintained on tape; one of them is in a secure remote locations. Dr. Buchanan asked about the wisdom of keeping the NCCS backup so close to the NLM. Dr. Liu described how the organizing committee addressed this question and how it evaluated the many factors that went into the decision on where to locate the NCCS. If the purpose was only for disaster recovery, he agreed that the site could be a thousand miles away. However, for load-balancing purposes, we need a dedicated connection and that limits the distance. Dr. Stead asked whether a user’s online interaction with the system would be interrupted in the case of a switchover from NLM to the NCCS. Dr. Liu stated that in most NLM operations, this will not pose a problem.

#### **XIV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION**

Ms. Eugenie Prime, who chairs the Subcommittee on Outreach and Public Information, reported on the meeting yesterday morning. The Subcommittee members heard an update on the Information Rx program, the collaborative outreach program of the NLM and the American College of Physicians. She passed around the “MedlinePlus prescription pad” and other materials associated with the project. Initial feedback from the first two pilot states—Georgia and Iowa—has been extremely positive. Virginia will become a third test state and a national launch is scheduled by NLM and the ACP for April 2004. Public libraries will provide technical support for participating physicians and also serve as a route of access for those who are not connected to the Internet. There was discussion in the Subcommittee about how to expand the program to other professions and associations. The members suggested that NLM prepare a report outlining the short- and long-term goals of the project—a sort of roadmap that would stimulate discussion. There was also a brief update of the Native American Listening Circles and the recent visit by staff to Hawaii, reported on earlier to the full Board. Following Ms. Prime’s report there was a discussion of how to take full advantage of what is being learned in the NLM/ACP project. Dr. Lindberg said that one next logical step would be to expand the program to internists and the military.

#### **XV. APPOINTMENT OF NOMINATING COMMITTEE FOR BOR CHAIR**

Ms. Prime appointed a Nominating Committee to suggest candidates for the next Board of Regents Chair. The Nominating Committee is chaired by Col. Kristin Raines. She is joined by Dr. Deanna Marcum and Ms. Mary Ann Tatman.

**XVI. POSTCARDS FROM AFRICA: SNAPSHOTS OF CHANGE**

Ms. Julia Royall, Chief of International Programs, presented an illustrated program that summarized some of the recent progress in the Multilateral Initiative on Malaria. There have been two previous briefings to the Board about the program. NLM's role in this (beginning in 1997) is to establish and maintain the first malaria research communications network, MIMCOM. There are now 17 research sites in 9 countries participating, with full access to the Internet and the resources of the World Wide Web. More than 20 U.S. government agencies, international organizations, and African institutions are involved. NLM sponsors training and workshops for the scientists and librarians, a document delivery service, and Web sites supporting research agendas. Ms. Royall presented photos of the participants, with a background of music (a synthesis of traditional music from Gabon and J.S. Bach). There was also a series of brief interviews with African scientists who attested to the value of the communications network.

**XVII. ADJOURNMENT**

The meeting was adjourned at 12:00 p.m., February 11, 2004.

**ACTIONS TAKEN BY THE BOARD OF REGENTS:**

- Approval of the September 9-10, 2003 Board of Regents Minutes
- Approval of February 15-16, 2005 Meeting Dates
- Approval of the Board Operating Procedures for 2004
- Draft Board Statement on "Library of the 21<sup>st</sup> Century"
- Appointment of Nominating Committee for BOR Chair
- Concurred with recommendations of the Extramural Programs Subcommittee

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

Eugenie Prime, M.A., M.S., M.B.A.  
Chair, NLM Board of Regents