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

## MINUTES OF THE BOARD OF REGENTS May 19-20, 2004

The 136th meeting of the Board of Regents was convened on May 19, 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 May 20, 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. Ralph Linsker

Ms. Eugenie Prime [Chair]

Dr. William Stead

## **MEMBERS NOT PRESENT:**

Dr. Thomas Detre

Dr. Vasiliki Karlis

## EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Ms. Eleanor Frierson, U.S. Department of Agriculture

MGEN Joseph E. Kelley, U.S. Department of the Air Force

Dr. Deanna Marcum, Library of Congress

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, Retired, University of California, Los Angeles

Dr. H. Kenneth Walker, Emory University School of Medicine

#### SPEAKERS AND INVITED GUESTS PRESENT:

Ms. Serena Arancibia, University of Chicago

Dr. G. Octo Barnett, Harvard University

Dr. Jeremy Berg, National Institute of General Medical Sciences, NIH

Dr. James Cimino, Columbia University

- Dr. Carolyn Clancy, Agency for Healthcare Research and Quality, DHHS
- Ms. Claire Hamasu, National Network of Libraries of Medicine, Midcontinental Region
- Ms. Lucy Hansen, South Texas High School for the Health Professions
- Ms. Jean Krause, American College of Physicians
- Dr. Vibha Thakral, Virginia Commonwealth University
- Ms. Debra Warner, University of Texas, San Antonio

#### MEMBERS OF THE PUBLIC PRESENT:

- Ms. Shannon Jones, Virginia Commonwealth University
- Dr. Carol Newton
- Dr. Atsutake Nozoe, Aichi Shukutoku University
- Ms. Dana Pavey, Office of the Honorable Newt Gingrich
- Ms. Jean Shipman, Virginia Commonwealth University
- 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. Suzanne Aubuchon, Office of the Director, NLM
- Ms. Theodora Bakker, Associates Program, NLM
- Dr. Milton Corn, Division of Extramural Programs, 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
- Dr. Charles Friedman, NLM Sabbatical/Division of Extramural Programs, NLM
- Ms. Jane Griffith, Office of the Director, NLM
- Ms. Wendy Hadfield, Executive Office, NLM
- Ms. Karen Hajarian, Bibliographic Services Division, 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
- Mr. Sheldon Kotzin, Bibliographic Services Division, NLM
- Ms. Michelle Krever, Division of Extramural Programs, NLM
- Dr. Daniel Le, Lister Hill National Center for Biomedical Communications, 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. Aaron Navarro, Lister Hill National Center for Biomedical Communications, NLM

Dr. Stuart Nelson, Division of Library Operations, NLM

Dr. Barbara Rapp, Division of Library Operations, NLM

Mr. Jon Retzlaff, Executive Office, NLM

Ms. Julia Royall, Health Information Program Development, NLM

Dr. Angela Ruffin, Division of Library Operations, NLM

Mr. Allan Savage, Division of Library Operations, NLM

Dr. Grace Shen, National Eye Institute, NIH

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. George Thoma, Lister Hill National Center for Biomedical Communications, NLM

Ms. Patricia Tuohy, History of Medicine Division, NLM

Dr. Fred Wood, Health Information Program Development, NLM

#### I. OPENING REMARKS

Ms. Eugenie Prime welcomed the Regents, alternates, consultants, and guests to the 136<sup>th</sup> meeting of the Board of Regents of the National Library of Medicine.

# II. REPORT FROM THE DIRECTOR, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY, DHHS

Dr. Carolyn Clancy, Director of the Agency for Healthcare Research and Quality (AHRQ), Department of Health and Human Services, reported to the Board of Regents about the mission and programs of that agency. The mission is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. The focus is patient-centered rather than diseasespecific, and on the intersection between the organization of the healthcare system and clinical care. The AHRQ mission involves both the production and use of evidence-based information. The 2004 budget for AHRQ is \$304 million; the agency has 300 staff. The agency was created in 1989 as the Agency for Healthcare Policy and Research and at that time focused on developing clinical practice guidelines. That shifted to focusing on facts, not guidelines. The agency systematically reviews evidence that can be used by professional groups, health clients, healthcare organizations, etc. to make guidelines that can serve as the substrate for quality measures. Medical organizations (including the NIH) nominate topics for consideration. There is also an AHRQ unit that concentrates on priority populations, defined as racial and ethnic minorities, rural populations, lower socioeconomic groups, etc. Dr. Clancy briefly described several current "portfolios" of research, including patient safety and informatics. There are a number of collaborative projects with other HHS agencies, including Medicare and HRSA. The Institute of Medicine study several years ago on preventable medical errors has given great impetus to AHRQ projects in patient safety. AHRQ also supports a national network of practicebased research—more than 50 networks of primary care physicians in practice who serve as a "living laboratory." There is a contract-supported Integrated Delivery System Research Network

that reaches more than 50 million patients (and the majority of U.S. physicians) that helps to understand the intersection between how health care is structured and the kind of care that is provided. She said it takes much too long for proven new practices to trickle down to patient care. She quoted Mark Chassin: "We need to make the right thing to do the easy thing to do." She said that information technology can enhance the precision and decrease the cost of measurement and can also enhance the translation of strategies to improve quality, for example, in decision support. AHRQ is investing \$50 million this year in the applications of health information technology to improve the quality and safety of care. Dr. Clancy concluded by saying that AHRQ and NLM could work together in several areas: in expanding and clarifying the continuum from standards to specific applications so that we can learn how to make clinical decision support real; closing the gap between the potential and actual applications of health information technology; and using information technology to customize evidence for different audiences.

# III. REPORT FROM THE DIRECTOR, NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES (NIGMS), NIH

Dr. Jeremy Berg, director of NIH's National Institute of General Medical Sciences (NIGMS), described the mission and organization of the NIGMS. The Institute, which is over 40 years old, was founded with the mission of tracking and supporting research training with respect to general or basic medical sciences and related behavioral sciences. It is focused on basic research—fundamental biological research related to health care. There are also several clinical areas that fit into the Institute's scope. NIGMS has four divisions and a center each of which has a substantial research and training component. The Institute is responsible for about 50% of all the training supported by NIH. Investigator-initiated extramural research project grants are a major focus of the Institute; there is practically no intramural research program. There were 3,700 NIGMS RO-1 grants in FY 2003. These accounted for about \$1.1 billion of the Institute's \$1.8 billion total budget. This approach has been very successful, Dr. Berg said. One measure is that NIGMS has supported research that has led to 55 Nobel prizes in physiology/medicine and chemistry. The recent doubling of the NIH budget has allowed the Institute to initiate several large-scale programs, for example the protein structure initiative that is based on the genome sequencing effort. Dr. Berg briefly described this and several other NIGMS research initiatives, including the Pharmacogenetics Research Network. In closing, he said that one of the lessons from the large-scale initiatives is that the informatics components, that is, publicly available databases, are in many cases the main products of the centers. Another lesson is that everyone always underestimates how much these informatics components are going to cost. As a result, we are now paying much more attention to informatics at the beginning of projects.

## IV. FEBRUARY 2004 MINUTES AND FUTURE MEETINGS

The Regents approved without change the minutes from the February 10-11, 2004 meeting.

The Board of Regents will meet next on September 21-22, 2004. The Board is meeting next winter on February 15-16, 2005. The dates of May 10-11, 2005, were adopted for the meeting next spring.

#### V. NLM DIRECTOR'S REPORT

Dr. Donald Lindberg said that NLM's FY 2004 budget is \$309.1 million, an increase of \$9 million over FY 2003. The FY 2005 President's request has an increase of \$16.7 million (5.4%) for NLM. Although the dollars are expected to rise, Dr. Lindberg said, the staff ceiling is projected to be reduced, from 690 (FY 2003) to 665 (FY 2005). He noted that, counting contractor assistance, NLM has about 1,100 staff equivalents. There have been several retirements of senior staff since the last meeting: Duane Arenales as Chief of the Technical Services Division and Mr. Ted Youwer, Chief, Office of Administrative Management and Analysis Services. Dr. Lindberg reported on several pieces of legislation that the Board has heard about before: genetic non-discrimination (no new action), and intellectual property rights and database protection. Two competing database protection bills have been reported by the House Judiciary and Energy and Commerce Committees resulting in a stalemate in Congress on the issue. Jane Griffith reported on the proposed legislation on information technology and healthcare that is being sponsored by Senator Clinton. NLM's Betsy Humphreys has gone to Capitol Hill several times to brief staff on this subject and provide technical assistance. Senator Kennedy has also recently introduced a bill that would provide grant funding and loan guarantees for the implementation of IT systems and support adoption of health data standards. On another subject, Dr. Lindberg said that the NLM has, in effect, purchased a nationwide license for the use of the clinical vocabulary known as SNOMED CT®, and that it is now being made available free for medical purposes in the United States as a part of NLM's Unified Medical Language System<sup>®</sup>. He also announced that the *Index-Catalogue of the Library of the* Surgeon General's Office, published by the Library from 1880 to 1961, is now available in an Internet version known as IndexCat. He briefly described the contents of the Catalogue and said that this is an historic accomplishment.

The NLM Director reported that PubMedCentral continues to expand. There are now 292,000 articles from 148 journals. The number of archived articles has increased by 230% in the last 12 months. An important step forward is a partnership with the Wellcome Trust in the United Kingdom. NLM is endeavoring to go back to Vol. 1, No. 1 of the journals in PubMedCentral and to digitize and make available all back issues. Dr. David Lipman, NCBI Director (the NLM component responsible for PubMedCentral) commented that the Wellcome Trust has succeeded in persuading additional publishers to participate. He predicted that more societies and publishers will join PubMedCentral as they see that the system will make their journals' contents freely available in perpetuity. He believes it will take an international consortium to organize the effort and to find the money to scan and make available what will be a tremendous amount of content. Dr. Lindberg next brought the Board up to date on the MedlinePlus "Go Local" project. This project seeks to allow MedlinePlus users to have access to sources of local health information in their areas. The first "Go Local" state (previously reported to the Board) was

North Carolina. A second state, Missouri, is about to be announced. The NLM Director said that we hope the lessons learned in creating these two "Go Local" services can be applied in other areas of the country. Dr. Lindberg also reported to the Board that several NLM Web sites continue to score extremely high on the American Customer Satisfaction Index. This is a university/private sector-developed online customer survey system. MedlinePlus, one of the sites evaluated, leads all Federal Web sites. He stated that this has resulted in much good publicity for the Library.

Dr. Lindberg also reported on the status of "outsourcing" at NIH and NLM. This is a systematic effort to "compete" selected NIH activities against the private sector. Four staff members of NLM's Extramural Programs Division are being affected by the review of grant activities that was recently conducted. Future surveys are slated for Visual and Medical Arts, Information Technology, and Network Service Support. Dr. Lindberg reported that the new Collection Development Manual of the NLM is almost ready for release. This important resource is updated every 8–10 years. Alison Bunting, former Board chair, has been helping NLM with the new edition. The Board was also informed about the National Science Advisory Board for Biosecurity, an initiative that seeks to enhance biosecurity activities, including implementing the Public Health Security and Bioterrorism Preparedness and Response Act. Finally, Dr. Lindberg showed to the Board a brief videotape depicting "Local Legends," the part of the new "Changing the Face of Medicine" exhibition that recognizes outstanding women physicians in various parts of the U.S. nominated by members of Congress and others. He encouraged the Regents to recommend candidates for the exhibition. The last issue raised by Dr. Lindberg, not on the agenda, is a proposal for NLM to create a public domain searchable database of laws, rules, and regulations relevant to public health activities. Dr. Jack Snyder of the Specialized Information Services Division (SIS) will discuss the database during his presentation later in the meeting.

#### VI. PRESENTATION OF AWARDS

Dr. Lindberg presented the NLM Director's Honor Award to Patricia Tuohy of the History of Medicine Division for her work with the NLM Exhibition Program, Kathy Kwan of the National Center for Biotechnology Information who developed the Link-Out program for PubMed, and Julia Royall of the Office of Health Information Programs Development for her work in developing the Malaria Research Communications Network in Africa. He also presented the Frank B. Rogers Award to Gale Dutcher of the Specialized Information Services Division for her work in developing NLM outreach programs, including outreach to minorities, consumer health, and HIV/AIDS communities.

#### VII. PRESENTATION OF CERTIFICATES TO OUTGOING BOR MEMBERS

Dr. Lindberg presented mementoes of their service on the Board to Ralph Linsker, M.D., Col. Kristen Raines, and Eugenie Prime.

#### VIII. INFORMATION RX PROJECT UPDATE

Dr. Elliot Siegel, Associate NLM Director for Health Information Programs Development, introduced NLM's Information Rx project, noting that this is the latest of several updates on the project. He said that NLM's MedlinePlus, now almost 6 years old, is a "shot across the bow" of health literacy, a problem that Surgeon General Carmona has addressed several times in his presentations to the Board. It is also the subject of a recent report from the Institute of Medicine. Seeking health information on the Internet is the third most common activity of Web users, behind looking for a product or service and using e-mail. Since patients trust their physicians to recommend good health information, the Information Rx project seeks to encourage physicians to make information referrals to MedlinePlus. We want MedlinePlus to be the "Web site your doctor prescribes." Dr. Siegel said that our collaboration with the American College of Physicians Foundation (ACPF) began in the fall of 2002. The Foundation sees it as an opportunity to help their physicians provide health information for their patients. We have worked with the ACP governors in several states to pilot the project—specifically in Georgia, Iowa, and Virginia. More than 1,000 physicians have participated. Dr. Siegel briefly described the extensive evaluation that is taking place—focus groups, pre- and post-intervention mail surveys, patient survey forms on the ACPF Web site, telephone interviews with physicians, and monitoring hits on the MedlinePlus Web site. Dr. Siegel said that participating physicians were enthusiastic—67 percent ranked MedlinePlus as their first or second choice for referring patients. He said that the project has been modified to take into account the personal preferences and different practices of the physicians so as to make it easy for them to use it. Ninety-seven percent of the participants made referrals to MedlinePlus, 92 percent of them did so daily. Dr. Siegel described the variety of materials that were developed for the project—posters and information prescription pads, for example. Perhaps the weakest link is in getting patient feedback, he said. Those who do respond to the online surveys on the ACPF site are positive in their evaluation. NLM is now exploring with the U.S. military's TRICARE system the possibility of expanding the project by providing MedlinePlus to service members and their families. Another pilot project will take place in South Florida centered on the Fisher Center for Alzheimer's Research. Except for these organizations, we will not be making any additional formal arrangements in the near future. However, so as not to turn away any individual physicians who wish to join the project, we will allow any M.D. to register for Information Rx. We will report to the Board in the future about how these projects progress. Dr. Siegel showed a videotape of the national launch of the Information Rx project at the ACP annual meeting in New Orleans last month. He then introduced Jean Krause, Executive Vice President of the ACP Foundation.

Ms. Krause said that MedlinePlus is one answer to the "time crunch" faced by busy physicians. The feedback she has received from ACP physicians has been overwhelmingly positive. She described the relationship between the ACP Foundation and the American College of Physicians, the nation's largest specialty medical organization with 115,000 members. The Foundation was created to reach beyond the physician to focus totally on the patient. Six thousand ACP members attended the launching last month and she showed the Regents several articles resulting from the

announcement to the media. Before the annual session, the Foundation placed an ad for the Information Rx project in the "ObserverWeekly" with a subscription base of 80,000. The Foundation is using many different venues to keep the Project before the membership. There will be programs about MedlinePlus at state ACP conferences. The feedback from physicians indicates that once MedlinePlus is integrated into a physician's practice, it is a time saver and significantly improves communication between physician and patient. She said that the project will be a great help in the ACPF's program to improve health literacy. She said one of the goals of the Foundation is to bring patient information materials down to a second grade reading level. Ms. Krause concluded by saying that the collaborative project over the past two years has been very rewarding for both partners and the Foundation looks forward to continuing it.

Becky Lyon, NLM Deputy Associate Director for Library Operations, showed the Regents the original suite of materials developed for the project—posters (2 sizes), book marks in a Lucite holder, a health record card, and the Information Rx prescription pad itself, personalized with the physician's name and customized with a list of a dozen conditions frequently encountered in the physician's practice (and URLs linking them to the appropriate MedlinePlus health topic). She described some of the alterations to these materials based on feedback from the physicians and office staff. Ms. Lyon then showed the Board the changed materials that were used first in Virginia. There was an increased effort there to get feedback from patients; in addition, librarians were involved more in the project. Now that the project has become nationwide, the ACP Foundation is promoting it widely to the membership. NLM is setting up a link on its Web site that will allow physicians to sign up and, eventually, to be able to order the materials. In the Virginia project, three academic medical center libraries and two hospital libraries participated over a four-month period. Ms. Lyon described how the project was promoted in Virginia and how libraries were signed up (150 public librarians and library staff were trained) and how physicians were recruited (almost 500 were signed up). She showed the "Information Rx Toolkit" that was developed for librarians by Theodora Bakker, an NLM Associate Fellow.

Dr. Vibha Thakral, a participating physician from the Virginia Commonwealth University Medical Center at Stony Point, a satellite clinic of the Medical College of Virginia, described to the Regents how she and her five physician (and one nurse practitioner) colleagues used the Information Rx project at the Women's Health Center there. The original contact with them was made by the director of the Virginia Commonwealth University medical library. Dr. Thakral said that essentially they gave an information prescription to every patient, and they directed those who could not use the Internet to the librarian. The posters advertising the MedlinePlus Web site were installed in every examination room. They plan to have someone staff a computer in the clinic so that as patients walk out they can get their "prescription" filled. The biggest challenge, she said, is the "time crunch" that sometimes leads to their neglecting to issue a prescription. They need to make it a habit in every patient encounter. The other challenge was to devise a consistent, easy method of marking the chart when a patient has received a prescription. She said that her patients (who are generally Internet savvy) have had a positive reaction to the information prescription. Although the fact that MedlinePlus is free and has no advertising is appreciated, Dr. Thakral said that patients are most impressed with the fact that their physician is

recommending the site. The bottom line, she said, is that MedlinePlus is a "logical way to provide up-to-date reliable medical information." She hopes in the final analysis that the system will save time—that less time will need to be spent in the patient room discussing basic concepts.

Following the presentations, Dr. Zimble said that this a "terrific" project and that he prefers the blank prescription pad, as opposed to having the pads list MedlinePlus URLs for various conditions. Ultimately, he said, as the number of conditions in MedlinePlus grows, we will need a sort of "PDR" for them. He suggested that NLM look into using pharmacies to help promote the project and to direct patients to MedlinePlus. We should also be pushing MedlinePlus in the medical schools (he does this at the Uniformed Services University of the Health Sciences). Dr. Dean commented that the program has "infinite potential to change the way health care is provided." He suggested that the program be promoted to the office staff of clinicians—and that a notation about MedlinePlus be added to patient charts. He said that NLM needs a strategic "downstream plan" so that there are specific end goals in sight. Dr. Linsker asked if it might be possible to have consumers who use MedlinePlus set up a screen name with no identifying data. NLM might then be able to track "user x" to see how the system is actually being used. Dr. Lindberg said that NLM has thought of a system like this. It is a worthwhile idea and he would like to pursue it in partnership with other organizations. Dr. Stead suggested a "link-in" capability that would allow clinical institutions to link automatically deep into MedlinePlus information to point patients in the right direction.

#### IX. JUST IN TIME INFORMATION FOR CLINICIANS

Dr. James Cimino, Professor of Medicine and Biomedical Informatics at Columbia University, discussed "Just-in-Time Education: Linking Clinical and Educational Systems," a project funded by the NLM. He visually presented a timeline and described some of the work done on this idea since 1984. The bottom line in all these studies is that information needs occur often in the course of patient care, that they often go unresolved, and that, although computer-based resources are available, they are under-utilized. The reasons for under-utilization are several: clinicians might not know they exist; they might not have access to the resources; they might lack the navigational skill to use them; and they may not think they have the time to use them. The clinical information system (CIS) must know who you (the user) are, who the patient is, and what the user (at a computer terminal) is doing. Dr. Cimino presented a hypothetical situation where the physician is faced with a question and he described how the CIS could be used to find the answer. Going back to the timeline, he noted that the UMLS was begun by NLM in the 1980s, a "MEDLINE button" was developed in the early 1990s to assist with a mainframe-based CIS (a technical success but a practical failure), and Web-based systems (including PubMed and its integration with DXplain) were introduced in the mid 1990s.

Returning to the CIS, Dr. Cimino said that it would provide education at the moment that people needed it—"just-in-time education." First, however, he said we have to understand what the user's information needs are. Then we have to pull the information out of the electronic medical

record and figure out what resource could be used to answer the question. We have to know what terminology that resource uses and figure out how to translate the clinical data into something the information resource will recognize. The results then have to be presented back to the user. Dr. Cimino described how they studied the different facets of the process using a portable usability lab. An "Infobutton Manager" takes the context of the question and matches it against specific questions. The investigators are now looking at how to use natural language processing to identify important terms in text reports. Next steps include repeating the observational study, inspecting the system logs to determine usage, placing Infobuttons on the order entry, collaborating with other institutions, and making the Infobutton Manager an ANSI standard. Among the conclusions: information needs arise while using CIS and Infobuttons are easy to build. Questions remain: Are they the right buttons? Can retrievals be standardized? Will information needs be satisfied? Will care improve?

Following Dr. Cimino's presentation, Dr. G. Octo Barnett, Professor of Medicine at Harvard University, described the NLM-funded "Just-in-Time Clinical Information" project. The project provides evidence-based medicine written by Massachusetts General Hospital (MGH) physicians. The information is germane to the MGH environment and it provides focused information relevant to specific problems. He said that the information has to be rapidly accessible (3 seconds max), easy to use (no training required), authenticated with references, and updated regularly. The information resources provided include evidence-based guidelines, patient instructions, drug and insurance information, medical calculators, clinical alerts, integrated knowledge access with workflow support (for example, referral information and forms), and a portal to other network resources (for example, PubMed). Using osteoporosis as an example, Dr. Barnett gave a quick overview of the system, showing a variety of Web pages and how they would be used by clinicians to retrieve relevant information. He noted that getting the information written in "plain English" was one of the problems they encountered. Some of the information is also available in Spanish. Drug information is one of the most valuable categories of information made available on the system. Dr. Barnett said they have support from the hospital's leadership and described how they organized the tremendous amount of writing and review necessary to obtain the information. There is also heavy promotion of the system within the institution—all users get an e-mail at least once a week telling them about new material and new features. The site is growing steadily both in content and in usage—there are more than 3,500 sessions per week by MGH staff. A paper-based survey reveals strongly growing support for the system by the users—70 percent of the providers say that the system allows them to give better patient care and 63 percent say that it saves them more than 10 minutes a day. Dr. Barnett says they are now faced with the challenge of getting the system used in underserved areas; since it is so MGH-specific, much modification is needed for other institutions. Another challenge is to evaluate the impact of the system: Does it improve patient care? Save time? Reduce errors? Improve institutional efficiency? Reduce cost? More surveys and user feedback are needed. There are also unanswered questions about the scalability of the system when it is transferred to other sites and what happens when the grant terminates. He is not very optimistic about commercial adaptation for the system.

Following these presentations, Dr. Conerly asked whether they thought it was "worth the effort" to continue to pursue these methods for updating information for physicians and providers. Dr. Barnett replied that the idea that physicians have instant recall of all the information that's available is obviously not true. Systems to make information readily available, like these, are needed. Dr. Conerly asked how can we get providers involved in such systems? How can we get the systems into the medical curriculum? Dr. Barnett said he didn't know about teaching them in medical school (but we should definitely try), but that physicians are "enormously effective" in judging their time and that if we could demonstrate that the systems save time and provide better care, they would use them. There was a discussion of the pharmacy/insurance provider information part of the system and how labor-intensive it is to keep it up to date.

#### X. REPORT FROM THE MIDCONTINENTAL REGIONAL MEDICAL LIBRARY

Dr. Angela Ruffin, Head of the NLM National Network Office, said that on May 1, 2001, NLM awarded a 5-year contract to the Spencer Eccles Health Sciences Library at the University of Utah to serve as the Regional Medical Library for the six states that make up the Midcontinental Region. She introduced two staff from the Midcontinental Region: Wayne Peay, Director, and Ms. Claire Hamasu, Associate Director. They have introduced a different approach in the Midcontinental Region—a totally decentralized mode of operation. They use this approach not only for outreach (which all the Regions do) but also for delivering basic network services.

Wayne Peay said that the national network is a terrific accomplishment, delivering services for more than 30 years. He showed the geographic outline of the Midcontinental Region, the last region to be established. To bring Regional Medical Library (RML) services to the diverse constituencies in the Region, their model relies heavily on collaboration and exploring new technologies. They redefined their mandate for outreach to include all citizens. The model is based on decentralizing RML resources and building partnerships with the Resource Libraries. The RML Liaisons in these libraries have "vertical authority and horizontal responsibility." This activity has revitalized the Resource Libraries.

Ms. Claire Hamasu described the core programs as including library support in each of the states through a state liaison, DOCLINE coordination, services to unaffiliated health professionals, and evaluation and assessment activities that are integrated into the entire program. There are also seven special project areas: consumer health information, public health, education, community outreach, network membership, assessment and evaluation, and technology. Using several examples from around the Region, she described how activities in these areas were planned, coordinated, and carried out. She also discussed collaborative projects with other RMLs, such as the Tribal Four Corners Project in Arizona, Colorado, New Mexico, and Utah that is being carried out with the Pacific Northwest, Pacific Southwest, and South Central RMLs. Among the elements of this project are an inventory of assets, work on a "Go Local" MedlinePlus, a needs assessment of the Indian Health Service and Tribal Health Departments, a database of effective practices, and a database of contacts. She summarized the differences she sees in the centralized and decentralized RML model: decentralized network members like having their "own" liaison;

it is a challenge to ensure that the state liaisons also have a broader, regional vision; and there is less impact on Regional programs when one state liaison moves on—others can temporarily fill the gap.

Mr. Peay concluded their presentation by discussing the future of their RML model. Although each RML is in a different situation, the decentralized model serves well the philosophy of getting services as close as possible to constituents. The Midcontinental Region does not devote many resources to document delivery: "this is a great service, but its days are numbered." Local and resource libraries have to change as a result of moving from paper-based to electronic based services. We have to look beyond information management and move to knowledge management. Bioinformatics is a great challenge, and we look to NLM for guidance in this. Finally, the Midcontinental RML believes there are no boundaries to library services, and at the University of Utah they serve many international users. The infrastructure that the NLM has built makes this possible.

Dr. Buchanan commended the NLM for its support over the decades of the Regional Medical Library Network, which has been a great boon to the nation. She asked about the extensive collaborative programs fostered by the Midcontinental RML—both intra- and interregional—how do they recognize and reward such cooperation? Mr. Peay said the key aspect of collaboration is creating and maintaining the "larger vision." In the face of day-to-day pressure to deliver services, this is the primary challenge both to the Region and to the national network. Dr. Albright, who participated in a site visit to the Midcontinental RML, congratulated the presenters on their accomplishments and said that their vision and daring has demonstrated that all Regional Medical Libraries do not need to be the same. Dr. Walker concluded the discussion by saying that Dr. Angela Ruffin, Head of the NLM National Network Office, does a remarkable job in coordinating the entire network.

### XI. REPORT FROM THE DIVISION OF SPECIALIZED INFORMATION SERVICES

Dr. Jack Snyder, Associate NLM Director for Specialized Information Services (SIS), introduced the topic of the International Toxicity Estimates for Risk (ITER) database, the latest addition to the TOXNET information service sponsored by the SIS. Mr. Philip Wexler, of the Division of SIS, discussed the subject of how to estimate risk in the area of environmental health, primarily human health risks from chemicals. Most of the data are quantitative. The primary purpose of having such data is to protect the public health through preventive measures, or to assist in remediation in the case of a spill or other exposure. Some of the elements involved: hazard identification (what does this chemical do?); dose-response assessment (at what dose does this chemical cause its effect?); exposure assessment (how are populations exposed?); and risk characterization (at this exposure who might be harmed?). Mr. Wexler briefly discussed the IRIS (Integrated Risk Information System) database that is also available on NLM's TOXNET. IRIS is one of the databases within ITER. There are limitations and uncertainties in risk assessment values, for example, because of different assumptions and methods of analysis.

Following Mr. Wexler's presentation, Dr. Mike Dourson of TERA (Toxicology Excellence for Risk Assessment), described that non-profit organization's mission to protect the public health and educate people on risk issues. He said that 80% of TERA's activities involve the government, 20% involve industry. TERA sponsors expert peer consultation and peer review of risk values, methods, and research, and compiles and distributes the resulting ITER database. ITER is available free on the Internet and contains human health risk values for 620+ chemicals. ITER is still accessible via the TERA Web site, but its reach has been greatly extended since it joined NLM's TOXNET system, through which it can offer more powerful search capabilities in a multi-database environment. The database allows users to identify and quickly compare toxicity values, conduct analyses of differences, and, very importantly, identify the efforts of others so as to help reduce duplication of effort. The data vary greatly and come from many governmental and nongovernmental organizations in the U.S. and other countries. Adding data from World Health Organization members and other countries is a high priority, as is enhancing ITER's search functions. Following Dr. Dourson's presentation, Mr. Wexler presented to the Regents a number of screen shots, showing how ITER could be reached via TOXNET and then entering a chemical (arsenic) to retrieve a variety of pertinent ITER records.

Following the presentation on ITER, Marti Szczur, Deputy Director of SIS, updated the Regents on the Wireless Information System for Emergency Responders (WISER) project that was first presented to them last year. The system is designed to be used by HAZMAT specialist teams, emergency medical teams, law enforcement and military personnel, and others involved in responding to hazardous situations involving dangerous chemicals. SIS objectives in developing WISER are to make it easy to navigate, tailor the information to the specific role of the emergency responder, focus on identifying unknown substances, and create a cross-platform system that has both stand-alone capabilities and can be connected to other sources of information. Ms. Szczur described how chemicals were selected, information formatted, and the PDA interface developed. She played an audio clip from last year's presentation to the Board by Captain Brooks of the Baltimore Fire Department who tested the prototype WISER. Among the wish list of those who have used the system are: more chemicals, the ability to find chemicals by name (and aliases, registration numbers, etc.), additional physical properties, and the ability to sort a candidate chemical list. These suggestions have been incorporated into the operational version (Version 1) that will soon be released. The number of hazardous chemical substances contained in WISER has been increased from 44 to 398. As of early May there are 135 registered users of the system. Ms. Szczur described the various steps they took to improve and expand WISER preparatory to launching it as an operational system publicly in the summer 2004. She then did a demonstration of how the system works using a real road spill scenario from Hopkins County in Texas. She showed how WISER could be used to identify the unknown substance and provide information about how the chemical should be dealt with. Now that they have an operational system, SIS is looking into possible enhancements, such as having WISER work on other devices in addition to Palm, adding biological and radiological data, and providing for wireless interaction and dynamically transferring datasets. Ms. Szczur also noted several areas of potential R&D, for example, using artificial intelligence for "unknowns" that would result in relevancy rankings. After focus groups and feedback sessions are held this summer, a Version 2

that incorporates enhancements will be released in the fall of 2004. WISER is available for downloading at http://wiser.nlm.nih.gov.

Following the presentations, Dr. Walker commented that WISER would have great potential in the military. Ms. Szczur said that SIS staff was in fact in touch with Dr. Zimble about that possibility. Eleanor Frierson commented that government; trade unions, manufacturers, shippers, and employers are all very interested in the subject and may be helpful in popularizing WISER. She will provide to SIS a number of contacts for them to pursue. She also offered to help popularize the system to the agricultural community through the National Agricultural Library.

Dr. Jack Snyder presented to the Board of Regents the concept of a searchable database of laws, rules, and regulations relevant to public health activities. He presented a one-page concept proposal that was discussed and approved by the Regents [See Appendix B]. The SIS Division will report back to the Board in one year.

#### XII. EXTRAMURAL PROGRAMS REPORT

Dr. Corn reviewed NLM's Small Project Grant Program with description of purpose and award characteristics. Examples of recent such awards were presented.

Presented for Concept Review was NLM participation in the upcoming announcement of a collaborative effort, Interagency Opportunities in Multi-Scale Modeling in Biomedical, Biological and Behavioral Systems. Partners and purpose of the initiative were described. NLM participation was approved unanimously by the Board of Regents.

Also presented for Concept Review was possible NLM participation in a broad variety of initiatives announced as NIH RoadMap activities. Although NLM is not now planning to originate an initiative, it is a partner in a number already announced. Specifically described were:

- Re-Engineering the Clinical Research Enterprise: Feasibility of Integrating and Expanding Clinical Research Networks
- Training for a New Interdisciplinary Research Workforce
- Interdisciplinary Health Research Training: Behavior, Environment and Biology
- Short Programs for Interdisciplinary Research Training Exploratory Centers (P20) for Interdisciplinary Research
- National Centers for Biomedical Computing

Because more RoadMap initiatives will be announced in the future, the Board was also asked to approve NLM participation in such RoadMap activities considered to be germane to NLM mission by the Director, NLM. Concept Review for RoadMap participation was approved by unanimous vote of the Board.

# MEETING CLOSED FOR THE REVIEW OF GRANT APPLICATIONS MAY 19, 2004, 4:30 P.M.

In closed session, the BOR heard the report of the Subcommittee for Extramural Programs that had considered a selected set of applications. Subcommittee recommendations for approval were unanimously approved. BOR then unanimously approved *en bloc* the remainder of the applications assigned to the May 2004 Council Round.

#### XIII. FACILITATING FOREIGN LANGUAGE VERSIONS OF MeSH

Dr. Stuart J. Nelson, Chief of the Medical Subject Headings Section, Library Operations, said that MeSH, a controlled vocabulary used for indexing and cataloging the biomedical literature, is over 40 years old. There are many translations of MeSH into other languages; seven of them (French, German, Italian, Dutch, Finnish, Portuguese, Russian, and Spanish) are also in the Unified Medical Language System. Translations are used to identify correct terms in another language, to help authors identify keywords for articles, to help indexers, and to provide links to other databases, such as NLM's PubMed. Dr. Nelson used as an example the Japan Medical Abstracts Society, which has a Web interface to 5 million citations from 2000 serials, 1983 to the present. The Japanese propose to use their MeSH translation both to facilitate the searching of their Web site as well as linking to PubMed. There are certain difficulties in preparing translations of MeSH. MeSH is oriented toward terms that are sometime difficult to track because of nonsynonymous entry vocabulary. As an example, up until 2000 the entry term "federal aid" pointed to "financial support"; the next year it was decided that it should point to "government financing." In some cases there is no English equivalent for a term in another language. The effort in the late 1990s to move the MeSH off the mainframe resulted in a new data structure for the vocabulary that had three principal objects: descriptor classes that are composed of concepts, concepts that are composed of terms, and terms themselves. Using cardiomegaly as an example, Dr. Nelson demonstrated how there are attributes at each level: descriptors are arranged in a hierarchical tree structure; concepts are assigned definitions; and terms have sources assigned. The new MeSH Translation Maintenance System (MTMS) built by the MeSH and OCCS staff allows the correct linking of terms to the correct concept, easy insertion of terms into the NLM's Unified Medical Language System (UMLS), support for non-English concepts, and, since it is Web-based at NLM, it is easier to maintain currency. Allan Savage of the Medical Subject Headings Section logged into the system and, using a variety of terms and concepts as examples, demonstrated it to the Regents. Dr. Nelson said that the MTMS went into production this year and is currently being used by the Germans, French, Italians, and Vietnamese. Eleven other languages will be starting soon to work with the MTMS.

Following the presentations, Dr. Stead asked whether others, outside of medicine, were engaged in similar projects involving terminology and translation. Dr. Nelson said he was not aware of any such projects. Dr. Stead commented that the new tool could be useful in other venues in

handling distributed terminology translation. Dr. Ball thanked Dr. Nelson and his staff for an "exquisite contribution" to the world; the fact that NLM is developing an international standard (while keeping control at NLM) is crucial in an age when we are desperately trying to develop standards in the field of health informatics. In response to a question from Dr. Walker, Betsy Humphreys commented that there are already many translations in the UMLS and that the new tool will make it easier to incorporate more translations.

# XIV. FROM KEYBOARDING TO MARS TO WEBMARS – DATA EXTRACTION FROM ONLINE JOURNALS

Dr. George Thoma, Chief of the Communications Engineering Branch, Lister Hill National Center for Biomedical Communications, described the program to create bibliographic data for citation records MEDLINE. Up until 1996, this was done exclusively by manually keying the data (first with a typewriter, later at a computer terminal) to create the records. Beginning that year the NLM began to apply new technologies to assist in this: networked optical character recognition (OCR) stations (MARS-1), submission of XML-formatted citations by publishers, image analysis and lexical analysis of scanned images (MARS-2), and R&D to accommodate online journals (WebMARS). A WebMARS prototype has been tested and it is proposed to place it in production later this year. Dr. Thoma described the evolution of MARS, which stands for Medical Article Records System. In 2004 it is estimated that there will be 575,000 indexed citations added to the database. Of the approximately 22,000 journal titles received at the NLM, 4,697 are indexed for MEDLINE. The bibliographic data for 59% of the articles is received as XML data directly from the publishers; data derived from manual input and from MARS/WebMARS accounts for 31%. Dr. Thoma outlined the R&D in document imaging that was done over the years to deal with the many challenges of developing a system that could recognize and extract text and graphics from digitized documents. He also took a typical journal issue through the entire MARS process, from check-in of the journal to the appearance of bibliographic citations in the database. He did the same for an electronic journal issue, using the prototype WebMARS system. The testing for WebMARS is being done on 64 online journal titles (1,149 articles). The total error rate was a low 2.09%. The level of effort in the WebMARS system was very low (79 seconds per article) compared to manual processing, MARS, or even publishers' XML data. NLM plans to implement WebMARS and to eliminate keyboarding completely.

Following Dr. Thoma's presentation, Dr. Linsker said this is an impressive example of research applied within an extensive production context. He asked about tagging as "low confidence" the numeric data that arrive online in WebMARS; how could an error in such data be detected and corrected? Dr. Thoma said that no decision has been made yet about this point. It may not turn out to be a problem. Dr. Linsker asked whether there were similar systems being created outside of NLM and whether what NLM was creating was generalizable to other situations. Dr. Thoma said he was aware of two other systems that had been providing OCR information to operators but had gone back to manual entry. He does not know of any other current work into automating citation creation and entry. Dr. Marcum asked about the relationship with publishers; how

receptive and cooperative have they been? Dr. Thoma said that the growth in the system is one measure of acceptance by publishers. Betsy Humphreys commented that publishers, as they gradually increase their electronic and technical capabilities, are increasingly willing to collaborate with NLM to get citations to their articles into MEDLINE rapidly and accurately. Kent Smith commented that the development of MARS and WebMARS was a fine example of NLM R&D and production systems working well together to improve the Library's operations. Ms. Frierson asked, which do we take as accurate? Do we use the print version to verify the publisher-supplied electronic data? The publisher's electronic data to verify the Web data? Sheldon Kotzin, Chief of the Bibliographic Services Division, responded by saying that NLM determines which has been designated by the publisher as the "journal of record," print or electronic. That governs which is considered authoritative.

# XV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Ms. Prime reported on yesterday's meeting of the Board Subcommittee on Outreach and Public Information. Much of the material covered—the Information Rx Project—the Board heard about in the update provided to the full Board yesterday by Dr. Siegel, Ms. Lyon, Ms. Jean Krause, and Dr. Vibha Thakral. Ms. Prime said that Dr. Siegel will provide to the Regents next February a "roadmap" about where the program is, where it proposes to go, the resources that will be required, etc.

### XVI. REPORT FROM NOMINATING COMMITTEE FOR BOR CHAIR

Col. Kristen Raines, chair of the Nominating Committee, placed in nomination the name of Dr. William Stead to be chair of the Board of Regents in 2004–2005. Dr. Stead was elected unanimously.

#### XVII. HIGH SCHOOL STUDENTS CONNECT WITH MEDLINEPLUS

Dr. Fred Wood of the Office of Health Information Programs Development introduced an outreach project supported by the NLM that trained a small group of (predominately Hispanic) high school students on how to use MedlinePlus so that they could in turn spread its use throughout their community. The health professions magnet high school where the project was centered, in Mercedes, Texas, is known as Med High. The project, with the University of Texas Health Science Center (San Antonio) and the Regional Academic Health Center in the lower Rio Grande Valley, began three years ago. Dr. Wood introduced three key people from the project: Ms. Debi Warner, director of the library at the University of Texas Regional Academic Health Center, Ms. Lucy Hansen, the librarian at Med High, and Ms. Serena Arancibia, now a student at the University of Chicago, who was one of the first members of the peer tutoring group at Med High. Dr. Wood said that the project received the Texas Library Association of the Year Award; a paper about the project has been accepted for publication in the *Journal of the Medical Library Association*. The three presenters took turns in presenting to the Board

various aspects about the project, including an introduction to the geography and the social and economic milieu of the lower Rio Grande Valley. They also showed a series of images and videos that described the project and showed the students and teachers being tutored and spreading the word about MedlinePlus as a source of high quality information in English and in Spanish. The program of student peer tutors was highly successful and should be replicated in other parts of the country, they concluded.

Following the presentations, Dr. Carter commented that this is a great model for how health information should be spread within a community. He believes it could well serve as a model for such programs nationally. Dr. Walker said that the project has the potential for being a profound agent for change. He asked about the concept of a "Med High." Ms. Hansen said that it is not unique. There is a Medical Magnet High School, established by Dr. Michael DeBakey in Houston, which served as the germinating idea for the Med High in the lower Rio Grande Valley. Dr. Linsker said that the success of this effort appeared to depend strongly upon the very active involvement and enthusiasm of the students and staff involved in this particular project, and that the NLM should be selective in seeking to expand such a program to other geographic areas, using the degree of demonstrated or anticipated local commitment as a strong selection criterion.

#### XVIII. ADJOURNMENT

Before the meeting was adjourned, Dr. Lindberg gave special thanks to Dr. James Zimble, who is retiring as President of the Uniformed Services University of the Health Sciences. Dr. Zimble has attended Board meetings for 17 years as an ex-officio member. Eugenie Prime also noted that this was her last meeting. She said serving on the Board of Regents was an extremely satisfying experience. The meeting was adjourned at 11:40 a.m., May 20, 2004.

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

- Approval of the February 10-11, 2004 Board of Regents Minutes
- > Approval of May 10-11, 2005 Meeting Dates
- ➤ Approval of Concept for Roadmap Initiatives
- > Approval of Multi-Agency Modeling Project
- > Approval of Concept for SIS Public Health Law Information Project
- Concurrence with Recommendations of the Extramural Programs Subcommittee, and Conducted En Bloc Approval of Grants
- ➤ Selection of New Chair of BOR for 2004-2005 Term

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