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

## MINUTES OF THE BOARD OF REGENTS May 13-14, 2003

The 133rd meeting of the Board of Regents was convened on May 13, 2003, 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 14, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

## **MEMBERS PRESENT:**

Ms. Alison Bunting [Chair] Dr. Ernest Carter Dr. A. Wallace Conerly Dr. Richard Dean Dr. Thomas Detre Dr. Ralph Linsker Dr. Joseph Newhouse Ms. Eugenie Prime Dr. William Stead

## EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Ms. Eleanor Frierson, U.S. Department of Agriculture BGEN Joseph Kelley, U.S. Department of the Air Force Capt. Thomas McGue, U.S. Department of the Navy Rear Admiral Kenneth P. Moritsugu, U.S. Public Health Service Dr. Michael Pazzani, National Science Foundation Col. Kristen Raines, U.S. Department of the Army Dr. Robert Roswell, U.S. Department of Veterans Affairs Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs Mr. Beacher Wiggins, Library of Congress 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, Healthlink, Inc. Dr. H. Kenneth Walker, Emory University School of Medicine

## SPEAKERS AND INVITED GUESTS PRESENT:

Ms. Roberta Bishop, Western Governors' Association Capt. Richard Brooks, Baltimore County Fire Department Dr. Charles Delisi, Boston University

Ms. Claudia Jones, Wallowa County Library Dr. Raynard Kington, Deputy Director, NIH

#### **MEMBERS OF THE PUBLIC PRESENT:**

Mr. Marco de Palma, Next Century Corporation Mr. Bob Jones, Wallowa County, Oregon Mr. Alec Stone, Friends of the NLM Mr. Tom 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 Dr. Tanya Barrett, National Center for Biotechnology Information, NLM Dr. Carol Bean, Division of Extramural Programs, NLM Mr. Dmitriy Beloslyudtsev, National Center for Biotechnology Information, NLM Ms. Susan Buyer, Health Information Programs Development, NLM Ms. Marjorie Cahn, National Information Center on Health Services Research, NLM Ms. Patricia Carson. Office of the Director. NLM Dr. Keith Cogdill, Office of the Director, NLM Dr. Milton Corn, Division of Extramural Programs, NLM Ms. Kathy Cravedi, Office of Communication and Public Liaison, NLM Mr. Laurence Dash, Division of Extramural Programs, NLM Mr. Jason Donaldson, National Center for Biotechnology Information, NLM Dr. Elizabeth Fee, History of Medicine Division, NLM Dr. Valerie Florance, Division of Extramural Programs, NLM Ms. Jane Bortnick Griffith, Office of the Director, NLM Ms. Wendy Hadfield, Executive Office, NLM Ms. Janet Heekin, Lister Hill National Center for Biomedical Communications, NLM Ms. Betsy Humphreys, Division of Library Operations, NLM Ms. Christine Ireland, Division of Extramural Programs, NLM Dr. Mehmet Kayaalp, Lister Hill National Center for Biomedical Communications, NLM Dr. Donald W. King, Office of the Director, NLM Mr. Sheldon Kotzin, Bibliographic Services Division, NLM Ms. Janet Laylor, Office of the Director, NLM Mr. William Leonard, Audiovisual Program Development Branch, 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 Ms. Arnita Miles, Division of Extramural Programs, NLM Ms. Melanie Modlin, Office of Communication and Public Liaison, NLM Mr. Dwight Mowery, Division of Extramural Programs, NLM Mr. Jon Retzlaff, Executive Office, NLM Dr. P. Preston Reynolds, History of Medicine Division, NLM Ms. Karen Riggs, Office of Acquisitions Management, NLM Mr. J. Chris Robey, Division of Extramural Programs, NLM Dr. Merlyn Rodrigues, Division of Extramural Programs, NLM Ms. Julia Royall, Office of International Programs, NLM Dr. Angela Ruffin, Division of Library Operations, 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 Mr. Ronald Stewart, Executive Office, NLM Ms. Marti Szczur, Division of Specialized Information Services, NLM Mr. Denis Vakatov, National Center for Biotechnology Information, NLM Dr. Steve Wilhite, National Center for Biotechnology Information, NLM Dr. Terry Yoo, High Performance Computing and Communications Office, NLM

#### I. OPENING REMARKS

Ms. Alison Bunting welcomed the Regents, alternates, and guests to the 133<sup>rd</sup> meeting of the Board of Regents of the National Library of Medicine. She welcomed especially new Regent Dr. A. Wallace Conerly, Sr., Dean of the University of Mississippi School of Medicine. Three new ex officio members are attending: Dr. Robert Roswell, Under Secretary for Health of the Veterans Health Administration, Dr. Michael Pazzani, Director of the Information Intelligence Systems Division of the National Science Foundation, and Capt. Thomas McGue, USN. She also welcomed Mr. Alec Stone, Executive Director of the Friends of the NLM. Ms. Bunting announced that Dr. Kenneth Walker is the recipient of the 2003 Marion V. Creekmore Award for Internationalization, an honor he received at a reception hosted by Emory University.

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

Rear Admiral Kenneth Moritsugu, Deputy Surgeon General, U.S. Public Health Service, presented greetings from Surgeon General Richard Carmona. He thanked the NLM and Dr. Lindberg for helping to host a meeting of the Flag Officers of the PHS. The Surgeon General continues to direct attention to the Administration's priorities, especially prevention, public health preparedness, and "closing the gap." The Secretary and Surgeon General hosted a large meeting on prevention in the last month—"Steps to a Healthier U.S." A major grant program will be targeted to large cities and states to put prevention into the communities. As to public health preparedness, Admiral Moritsugu brought the Board up to date on the Civilian Volunteer Medical Reserve Corps, which has been assigned to the Office of the Surgeon General for

implementation. Recipients of FY 2002 grants will be meeting in Chicago in June; their experience should help us to improve the program. In FY 2003 a new grant cycle will be implemented at about \$6 million (plus \$2 million in continuations). The proceedings of the Surgeon General's Workshop on Bone Health and Osteoporosis are now available on the Web. A coalition convened by the Surgeon General released a national oral health action plan in April. Upcoming are Surgeon General's issuances on the health consequences of smoking, women and mental health, mental health and terrorism, global health, correctional health, and prevention.

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

The Regents approved without change the minutes from the February 11-12, 2003 meeting.

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

The Board of Regents will meet next on September 9-10, 2003. The Board is meeting next winter on February 10-11, 2004. The dates of May 18-19, 2004, were adopted for the meeting next spring.

## **V. REPORT OF THE NLM DIRECTOR**

Dr. Donald Lindberg reported that the FY 2003 budget has been finalized for NLM at \$308,335,000, an increase of almost 12% over last year. This completes the doubling of the NIH (and NLM) budget over 5 years. The FY 2004 budget requested by the President would provide a 2.5% increase for NLM (to \$316,000,000). The Congressional appropriations hearings have been held and Dr. Lindberg's statement was provided to the Board. The NLM Director reported that Dr. David Lipman, Director of NLM's National Center for Biotechnology Information, was elected last week to the National Academy of Sciences. NLM continues to recruit successfully and Dr. Alexa McCray introduced two new senior staff of the Lister Hill National Center for Biomedical Communications, Dr. Robert Logan and Dr. Mehmet M. Kayaalp. Dr. Lindberg announced the retirement of Elizabeth Van Lenten, Assistant Head of the Index Section. On the subject of legislation of interest to the NLM, Dr. Lindberg directed the attention of the Regents to the distributed materials on HIPAA, privacy, and Homeland Security. NLM's Assistant Director for Policy Development, Jane Bortnick Griffith, briefed the Board about the new security rules that have just been issued as a companion to the privacy rules recently implemented. The new security rules move away from being restrictive and mandating specific technological approaches for implementing security and instead posit a model of security management that states what the security goals are, suggests approaches, but leaves the final decision on systems to be put in place to the implementing institutions. Dr. Lindberg reported on a meeting NLM held with the American Medical Publishers Association in March to discuss how best to ensure continuous access in the future to the medical literature. There was an opportunity both to discuss common aims and goals and to exchange technical information. Later in the meeting, he showed a video clip featuring brief segments of presentations at the conference, including several by NLM staff. Dr. Stead commented that we are at the stage where

we are shifting from archiving journals to archiving at the level of data; we need approaches that make it possible for authors and primary producers to archive their data.

At the Director's request, NLM Deputy Director for Research and Education, Dr. Donald King reported to the Board about an NIH Imaging Autopsy Conference, convened in March by the National Cancer Institute, attended by Dr. Lindberg and him. The purpose of the conference was to determine if imaging could replace the autopsy. After presenting a brief historical overview of the autopsy, Dr. King said that the percent of autopsies in academic centers has declined from 60%–80% in the fifties to about 8%–15% today. As a result, there are no valid statistics on cause of death. The conference considered whether modern imaging modalities (most notably MRI) could be employed in lieu of autopsies. Dr. King briefly discussed what such images could and could not distinguish. He was pessimistic about an increase in autopsy rates unless the Federal Government mandated them on all patients who die while in a clinical trial, and perhaps helped to fund them. Dr. Robert Roswell of the Veterans Health Administration said perhaps persons with ethnic or personal social reservations might decline to participate in clinical trials if autopsies were mandated. Dr. King said that the number of such autopsies would be quite small—happening primarily in high-risk trials, and he didn't believe that signing a pre-trial form would be much of a deterrent. Perhaps there could be a "conscientious objector" provision. Dr. Detre commented that the state of imaging technology available for autopsy purposes would undoubtedly be improving over time.

Dr. Lindberg reported briefly on the interagency effort to develop health data standards. The HHS, VA, and DOD have agreed that there will be a uniform set of standards for the electronic interchange of clinical information. NLM's Unified Medical Language System<sup>®</sup> is a key part of the system. We hope to enhance the UMLS<sup>®</sup> with SNOMED<sup>®</sup>, which would be leased from the College of American Physicians. The resulting standards would be made available to all without cost. The Director described two recent events-in Georgia and Iowa-to launch Information Rx, a collaborative program of the NLM and the College of American Pathologists. This is a pilot project to encourage physicians in private practice to "prescribe" the Library's MEDLINEplus<sup>®</sup> as a Web site with up-to-date, reliable, consumer-friendly information about a particular health concern. NLM issued press releases directed to the news media in Georgia and Iowa and Dr. Lindberg showed a videotape of the press conferences in each state. NLM will report to the Board at a future meeting about what NLM has learned from the project. He also showed a brief video from the April 2003 Symposium at NIH in honor of the 50<sup>th</sup> Anniversary of the Human Genome. The NLM Director updated the Board on the NLM exhibition program. He gave the Regents an illustrated catalog of NLM's "Breath of Life" exhibition, which had just been received from the printer. He noted that NLM's "Frankenstein: Penetrating the Secrets of Nature" exhibition is now traveling to some 80 cities around the U.S. under a joint arrangement with the American Library Association. The last item reported by Dr. Lindberg is that the NLM is sponsoring a "health sciences libraries building" symposium this fall. The date has yet to be determined.

## VI. PRESENTATION OF AWARDS

Dr. Lindberg presented mementos to retiring Regent Dr. Joseph Newhouse. He also presented the NLM Director's Award to three staff members. Mr. William Leonard, AV producer/director, Lister Hill Center, was cited for his outstanding work in creating high quality audiovisual materials on behalf of the Library. Ms. Melanie Modlin, Public Information Specialist, Office of Communications and Public Liaison, received the Director's Award for her writing and editing skills and for coordinating the NLM Visitors Program. Ms. Karen Riggs, Contract Specialist in the Office of Acquisitions Management, was cited for the excellence of her work in ensuring the efficient awarding of a high volume of contracts and purchases.

#### VII. REPORT FROM THE DEPUTY DIRECTOR, NIH

Dr. Raynard Kington, Deputy Director of the National Institutes of Health (since February 9, 2003), described three major activities that are getting much attention in the NIH Office of the Director. The first activity is the NIH "roadmap" process, begun in August 2002 by Dr. Zerhouni as a way to identify the most compelling initiatives for NIH to pursue broadly in the next 3-5 years. Participants in the process (senior NIH staff and extramural scientists) were asked to identify what are the current scientific challenges, the roadblocks to progress, and what will be needed to overcome the roadblocks. Three broad areas were identified: pathways to discovery, research teams of the future, and re-engineering the clinical research enterprise. Dr. Kington briefly described the topics that fall within each area. The second major activity is improving the efficiency of NIH. Although we are no longer in a period of rapid budget growth, as a result of substantial increases in recent years we are faced with a period of opportunity to identify and pursue scientific areas that have great potential to improve the health of the public. We have an obligation to be prudent stewards of the resources entrusted to us. Dr. Kington heads an NIH committee, composed of Institute directors, leading managers, and senior scientists to systematically assess how NIH does it work and to identify ways to increase efficiency while maintaining the pursuit of high quality scientific research. The committee will have a draft report in the next several months. The third major activity, the NIH obesity research task force, is one that is representative of a number of similar activities under way. There is a compelling public health need in this area. Dr. Kington cited recent statistics that underlined its seriousness. A trans-NIH task force has been formed to develop a research agenda to look at opportunities for improving our understanding of genetic, behavioral, and environmental factors that influence the increase in obesity, developing new methods for prevention and treatment, promoting multidisciplinary teams to study it, and other steps to combat obesity. In response to a question from Dr. Stead, the NIH Deputy Director said that NIH recognizes NLM's unique role as a source of content and knowledge. Dr. Lindberg has been involved in a number of the roadmap efforts.

#### **VIII. TOXICOLOGY & ENVIRONMENTAL HEALTH INFORMATION PROGRAM**

Dr. Jack Snyder, NLM Associate Director for Specialized Information Service (SIS), described the three parts of the SIS mission: to coordinate the development and operation of SIS

throughout the Library; to develop and operate a toxicology and environmental health information program (TEHIP); and to develop and administer a program that organizes, analyzes, and publishes information on the effects of drugs and chemicals on humans. An important question that SIS deals with is how do we improve the link between environmental information and health information? He said there are four "balancing acts"-between public domain information and private sources; between environmental and genetic information; between information for professionals and for the public; and between information on environmental health and human health. Dr. Snyder said that the important factors in human and environmental health are the effects of chemicals, biologicals, radiation, nuclear factors, explosives, other physical forces, and behavioral and social factors. The information needs assessment that they have done suggests that what is needed is (1) a better definition of the nature and scope of this information, (2) a better determination of what is objective, valid, reliable, and generally accepted information, (3) better organization of the information, (4) better integration and collaboration within government agencies and between the government and private sector, (5) better presentation of this information, and (6) better dissemination of the information.

Following Dr. Snyder's introduction, Marti Szczur, SIS Deputy Associate Director, discussed and demonstrated two SIS products: "WISER" and Tox Town. "WISER" (Wireless Information System for Emergency Responders) marries the capabilities of the Personal Digital Assistant (PDA) with the SIS's Hazardous Substances Data Bank (HSDB®) information resource with detailed, peer-reviewed information on more than 4,500 hazardous chemical substances. A needs assessment determined that emergency responders include first on-the-scene personnel, hazmat specialists, incident commander, and EMS personnel. They all have need for this information, but each group uses it in a different manner. A prototype WISER was developed that would be easy to navigate and have information tailored to the specific role of the emergency responder. Forty-four substances were selected for the prototype PDA application. Reaction from a "real user" was needed, so the SIS arranged to have two hazmat teams field test WISER: one in Fairfax County, Va., and the Baltimore County Fire Department. Captain Richard Brooks of the latter organization then told the Regents about their experience with WISER. He described how a hazmat situation might evolve, and how the many variations in individual circumstances result in different information requirements, for example, situations involving homeowners, transportation, or manufacturing. The first responder can be a fire company, paramedic, or police officer. Captain Brooks described to the Board a scenario involving leaking barrels in a warehouse. Using graphics, he demonstrated how the first responder could use WISER to identify the substance and learn what immediate actions to take. He said the firefighters have had a lot of fun with the system-they have seven WISER PDAs. Ms. Szczur said that changes are being made in WISER based on feedback from the users. The current WISER is stand-alone; in the next phase, she said, WISER will support wireless connectivity.

Ms. Szczur then described recent developments in Tox Town, the graphically striking Webbased information resource introduced for the general public last fall by SIS. She used a Web connection to display to the Board how the user would find information about toxic chemical and

environmental health concerns commonly encountered in different locations in a typical town. A true-life scenario involving a teen-age boy and mercury was described. She said that SIS would soon be releasing versions "Tox City." A "Tox Farm" is also in preparation. She gave the Regents a preview of some of the scenes that would be available in both. Ms. Szczur described the extensive questionnaire-based evaluation and online focus group that Tox Town has undergone. Information from both was very helpful in making improvements and suggesting topics for expansion. NLM's outreach efforts on behalf of Tox Town have resulted in many articles and it has been featured on other Web sites. She concluded by briefly summarizing a number of other SIS projects that will result in new products in the future, including a household products ingredients database that will soon be released.

Following these presentations, Dr. Kenneth Walker commented that he and Dr. James Zimble some years ago were asked to review the information products of the Specialized Information Services Division. The Division has come a long way since that time in creating easy to use services. The SIS is now also involved in creating information resources that are part of the national bioterrorism initiative. Dr. Zimble added that WISER is a "fantastic tool" and the military, which is issuing PDAs, should have access to this kind of information. He reminded NLM of its roots in the military and suggested that such new services as a "Tox Shipyard" would be most welcome. Dr. Jack Snyder said that he has actually worked in such an environment and will look into the possibility of creating such a "Tox" service. Eleanor Frierson suggested that the Agricultural Network Information Center program has more than 40 institutions and that they would be happy to review SIS's Tox Farm site. Also, a Western Rangelands Alliance would also be useful in this. Both organizations could feature SIS's sites. There was a discussion of whether there were any "private competitors" to WISER and whether, since there doesn't seem to be, the NLM could license its system to others. Dr. Lindberg said that NLM's products were in the public domain and that much work needs to be done on WISER before it is ready for more general dissemination.

## IX. PARTNERS IN INFORMATION ACCESS FOR THE PUBLIC HEALTH WORKFORCE

Ms. Marjorie Cahn, head of NLM's National Information Center on Health Services Research and Health Care Technology (NICHSR), a part of the Division of Library Operations, briefed the Board on the "Partners in Information Access for the Public Health Workforce" program. Using the newly redesigned Partners Web site (<<u>http://phpartners.org</u>>), Ms. Cahn briefly described the founding of the Partners in 1999, how it has grown since, and its current status. She walked the Regents through the major branches of the site, showing its various links and how redundancy was built into the site. She highlighted a major part of the site, the "Healthy People 2010 Information Access Project" (HP2010 IAP), and how NLM designed a one-stop mode of access for the public health workforce to selected objectives in Healthy People 2010. She said the Partners were working on expanding the HP2010 IAP site and hope eventually to include all 28 HP2010 focus areas. There are also many links to non-partner Web sites. There are plans for a comprehensive evaluation of the site when it is more fully populated. Ms. Cahn said the current

site gets heavy use. She next showed the Health Services and Sciences Research Resources (HSRR) database, also available on the Partners Web site and the NICHSR homepage. This is a new NLM resource that provides links to information on health services research, behavioral and social sciences, and public health. Ms. Cahn discussed the continuing emphasis on outreach by the Partnership and the National Network of Libraries of Medicine (NNLM). A series of 21 outreach projects devoted to the public health workforce was funded through the NNLM. She described several of local, state, and regional projects, and a public health "grand rounds" satellite broadcast, "Wired Communities—Putting the E in Public Health." Finally, Ms. Cahn described their plans, working with the Regional Medical Library in New England and the Medical Library Association, to look into the possibility of having an Academy for Health Information Professionals track specifically for public health.

Dr. Joseph Newhouse commented that the program is "stunning in its breadth." He asked about who is actually using the site—public health practitioners? Researchers? Domestic vs. international use? He wondered about the involvement of such organizations as AHRQ and the Institute of Medicine. Ms. Cahn said that they are not gathering specific information about the nature of users. That will be part of the evaluation that they hope to undertake. As to AHRQ and IOM, she said that NLM looked to CDC to identify the critical partners in the venture. As the project grew, we have not actively gone out to recruit partners but waited for them to come to us. However, there are many links to IOM studies and AHRQ materials on the site. She agreed that maybe it is time to more actively seek out additional partners. In response to a question about how well the public health community is wired to the Internet, Ms. Cahn said that it has much improved since the project began. From 70 percent of state and local health departments being connected (in a minimal way, frequently) in 1999, the figure has risen to 95 percent today.

# X. AFRICAN AMERICANS IN MEDICINE: RESOURCES IN THE NLM'S COLLECTIONS

Dr. Elizabeth Fee, Chief of the History of Medicine Division, said that several years ago the Division began a modest Visiting Scholar Program. Visiting scholars spent a month or so at NLM to assess the collection in their specialty and make recommendations on how to enhance the collections and improve access. She introduced P. Preston Reynolds, M.D., Ph.D., current NLM Scholar in Residence, who looked at the Library's holdings on "African Americans in Medicine." Dr. Reynolds gave the Regents copies of a 54-page guide on the subject and then, using projected images, described some of her major findings. She did not limit her inventory to the historical holdings, but included the entire NLM collection. Her survey included books, manuscripts and oral histories, photographs and online images, and videos and films. She said it was very difficult to find materials on African Americans in Medicine under the cataloging scheme. She described her method of locating materials: reading "finder's guides" and oral histories, searching images on wwwihm.nlm.nih.gov, walking the NLM's stacks, watching videos and films, and searching the Locatorplus catalog. The resulting guide, for the first time, identifies the primary and secondary materials that exist at NLM on this subject. Since this subject is emerging as a field within the history of medicine, the guide should greatly facilitate

use of the collection by historians and scholars in the medical humanities. Among Dr. Reynolds's recommendations: be proud that you are further along than you knew; add images, both historical and portrait; concentrate on acquiring manuscript collections of African American scientists at NIH and other Federal health institutions; and conduct oral histories with individuals who deposit their papers at the NLM. As to specific next steps, she recommended that NLM: develop curriculum materials that group primary and secondary resources together by topic; disseminate curriculum materials to Departments of Medical History and Medical Humanities; publish the "Guide" on NLM's website; publish articles in the medical literature about the collection; and update "Guide" every other year.

Following Dr. Reynolds's presentation, Dr. Ernest Carter commented that he is gratified to find that there is so much information on this subject at NLM. He asked about the existence of information linked to traditional African medicine and whether there is much pre-Civil War information in the collection. Dr. Reynolds said that the NLM collection was much more recent; there are a few 19<sup>th</sup> century hospital images but the bulk of the collection is 20<sup>th</sup> century. She said there is material on African medicine, but that she focused on materials dealing with African Americans. Mr. Beacher Wiggins said he too was impressed by the amount of information in the NLM collections on this subject. The images, especially, will help to entice students and others to do research in the field. He suggested digitizing some of the images and putting them online; he agreed that the "Guide" itself should be put online. He also wondered about the possibility of NLM collaborating with Howard University in Washington, D.C. to enrich the field. Dr. Fee said that HMD would be putting the "Guide" on the Web. Dr. Stead commented that not only has Dr. Reynolds put together a great resource, she has given us a case study on how to examine the NLM collection. It could serve as an example for similar projects in the future. Dr. Dean asked how the NLM collection compares to what might be available at Howard, Meharry, or Morehouse Universities. Dr. Reynolds replied that there may be duplication in secondary sources-historical books-but that NLM's primary resources (manuscript collections, for example) are unique. No one has "cornered the market." Ms. Bunting suggested that librarians in the history of medicine be apprised of the "Guide" so that other scholars might be encouraged to work in this area. Dr. Fee said that one of the NLM Associate Fellows was collecting information about African Americans in medicine that exists in institutions around the U.S. and plans to publish a guide so that scholars would know what materials area available.

#### XI. NCBI BOARD OF SCIENTIFIC COUNSELORS REPORT

Dr. David Lipman, Director of the National Center for Biotechnology Information, introduced several new NCBI staff members: Dr. Tanya Barrett, Dmitriy Beloslyudtsev, and Denis Vakatov. He then introduced Dr. Charles DeLisi, Chair of the NCBI Board of Scientific Counselors, who reported to the Regents about recent activities of that body. Dr. DeLisi said that NCBI is by far the world's leading center of bioinformatics. NCBI conducts research into computational methods to address important questions in cell biology, develops tools for storage, retrieval and analysis of genome data that are used daily by tens of thousands of users, and conducts training in the use of NCBI tools. The Board of Scientific Counselors regularly reviews NCBI programs

and the work of the Center's staff and makes recommendations affecting them. As an example of the sort of issue the BOSC addresses, Dr. DeLisi discussed the question of whether investigators around the world would be able to analyze mouse genome data and publish it, even before, possibly, the centers that produced the data. He described how the policy of unrestricted international access to genomic sequence data evolved and how the Board took a strong position on it. The transition of GenBank<sup>®</sup> from Los Alamos to the NLM/NCBI was another issue on which the Board had a strong influence. As to the future, Dr. DeLisi said that although the quantity of genomic data coming out of laboratories is staggering, we are really seeing just the tip of the iceberg. Within the next 10 to 20 years, he said, biomedical science will become the most computationally intensive of all the sciences. How we will respond to this challenge still has to be resolved. There are budget and space restraints, and the BOSC will help to both order the Center's priorities and develop a strategy for the longer term.

Following Dr. DeLisi's presentation, Dr. Lipman commented on the problem of keeping the NCBI's momentum in the face of budget and space constraints. Dr. Stead said that the NCBI focus on creating a "shared resource" is the real importance to the country, even beyond its importance in bioinformatics. It is "the model for large-scale science." It is important for NIH to understand that the Center's relevance is more cross-cutting than simply bioinformatics; the Regents might wish to help foster this understanding. Dr. Stead wondered whether the Board of Scientific Counselors could be helpful in making the case for the new building. Dr. Lipman replied that the BOSC was enthusiastic about the plans for the facility and its potential to serve as a "collaboratory" for visiting groups and scientists.

## XII. EXTRAMURAL PROGRAMS REPORT

## Dr. Milton Corn, NLM Associate Director for Extramural Programs, reported on three items:

## Workshop Supported by NLM

Biomedical computing in support of biology increasingly must deal with varied and enormous quantities of data. On February 2–3 NLM, Department of Energy and NSF (lead organization), sponsored a Workshop on Data Management Technology for Molecular and Cell Biology held in NLM's Lister Hill Auditorium. The aim of the workshop was to define a research agenda for data management technology in support of bioinformatics applications. Workshop recommendations were presented.

## NIH Symposium Relevant to BISTI

The National Institutes of Health is convening an inaugural symposium—Digital Biology: the Emerging Paradigm. The purposes of this meeting to be held at the NIH Natcher Conference Center, November 6–7, 2003 are two-fold:

- 1. To demonstrate how computational approaches to biomedical research have yielded breakthroughs that advance the prevention, diagnosis, and treatment of disease, and
- 2. To set national direction for research and development in the computational and

quantitative sciences critical to the future of biomedical discovery. This meeting is expected to produce recommendations to NIH about future research needed in biomedical computing. The agenda is based on recommendations of senior scientific advisors developed at a planning workshop convened by BISTIC, January 15–16, 2003. (A full report on that workshop may be viewed at <http://www.bisti.nih.gov/2003meeting/report.cfm>.

#### **Review of NLM's SBIR/STTR Program**

An overview of the Federal Small Business Innovation Research (SBIR) / Small Business Technology Transfer Research Program (STTR) program was presented, followed by review of the NLM experience, and current NLM interests in this area. Examples of grants supported by NLM were given.

#### XIII. WESTERN GOVERNORS' ASSOCIATION HEALTH PASSPORT PROJECT

Dr. Alexa McCray, Director of the Lister Hill National Center for Biomedical Communications, said that NLM has been cosponsoring the Health Passport Project of the Western Governors' Association for the last several years. She introduced Roberta Bishop, who has been site manager for the project since 1997. Ms. Bishop said that the Health Passport Project was the first multi-state, multi-agency smartcard project ever completed in the U.S. It uses smartcard technology to help integrate the delivery of an array of state and Federal public health services. The project had five goals: improve quality of family care; streamline access and delivery of public/private health care services; promote personal responsibility; improve customer satisfaction; and reduce costs. There were three levels of partnering: federal (including NLM) for financial support, state agencies for supporting project staff (ND, WY, and NV), and the local level "worker bees" in those three states. Ms. Bishop listed the partner agencies at the three levels and described some of the differences in how they operated. The pilot project was kept small, to see if the smartcard and kiosk-based technology would work. The working partners included the WIC Program, Head Start, immunization services, private physicians, Medicaid, and others. After evaluations and feasibility studies, the Health Passport Project was launched over a year from 1999 to 2000. She described how the smartcards were developed and the kind of information that was put on them.

The Urban Institute completed a Project evaluation in December 2001. Information from the evaluation will be used when they launch Phase II of the Project. The most important success was the building of relations among the agencies. Other positive results were the introduction of new technology, improved client services, reduction in client intake duplications, immunization records available after hours, appointment reminders, and less phoning for lab results. Ms. Bishop briefly described each improvement. Among the lessons learned: they learned that they have to make a better business case for the private physicians to participate; they also found that changing office routines is not easy. She discussed administrative challenges and how they were met. One difficult area was the sharing of money among different government agencies. She said that the kiosks worked although maintenance was expensive. The clients accepted and liked the kiosks and smartcards and Ms. Bishop and her colleagues were surprised by the heavy usage

they got. After discussing a number of the lessons they learned from the pilot project, she described briefly plans for the future. North Dakota and Wyoming, because of budget problems, have decided not to move forward with the Health Passport Project. Nevada is going to continue the program; it has allowed them to reduce their staff by about one third at the WIC site. Health Passport Phase II will include a demonstration program in San Diego, with (possibly) four partners. With expanded Internet access and better online security available there will be more online transactions, and also an expanded kiosk program (featuring MEDLINEplus).

Following Ms. Bishop's presentation, Dr. Thomas Detre said he was not surprised to hear that there was reluctance to give up "old ways" for new methods. He asked whether this project has been presented to third-party payers, such as Kaiser Permanente. Ms. Bishop said that they did not, but that this is an excellent idea. Third party payers would be able to make the business case to the private sector. Dr. Lindberg gave the Board a brief history of how NLM became involved with this Western Governors' Association project. He said that the smart card could go a long way in solving the privacy issues surrounding health data medical records. There was a discussion about the use of the smart cards in the U.S. military.

#### XIV. HEALTH INFORMATION ACCESS TO RURAL AREAS IN THE NORTHWEST

Becky Lyon, Deputy Associate Director for Library Operations, introduced Claudia Jones, Director of the Wallowa County (Oregon) Libraries. Wallowa County is extremely rural, a fact that brings with it special challenges in providing library services. The project Ms. Jones will describe received the Public Library Association's 2002 award for small or rural public library service. Ms. Jones then described how Dr. Lindberg, on a vacation visit to Wallowa County, discovered that the County's public library system was in need of assistance for online access to information, and he encouraged them to apply for funding from the NN/LM. She showed the Regents a number of striking photographs of the spectacular mountain country of Wallowa County, and how road transportation among towns was long and arduous. There are two people per square mile. Ms. Jones is the only full-time librarian in the county. Two communities have a part-time librarian (at slightly above minimum wage) in a small autonomous library. Ms. Jones's budget this year for materials (for both the branch sites and main site) is \$2,500. There was only one hand-me-down computer, in the main office, and it was used for word processing and (incredibly slow) dial-up Internet access. Ms. Jones showed pictures of the main library and two branches. The funds (\$10,000) provided by NLM through the Regional Medical Library were used for computer equipment, Internet access, training, and other resources for all three libraries. Since the new technology was installed, many more people are using the facilities. One of the most exciting aspects of the new capabilities is that they can now offer interactive training for nine people who want to become EMTs. She expressed her appreciation to the NLM and to the staff of the Regional Medical Library who worked closely with them in developing and implementing the project.

## **XV. SUBCOMMITTEE AND WORKING GROUP REPORTS**

#### Subcommittee on Outreach and Public Information

Eugenie Prime, Chair of the Subcommittee, reported on yesterday morning's meeting. The NLM/American College of Physicians "Information Rx" partnership (discussed by Dr. Lindberg yesterday in his report) was a primary agenda item. Some 700 physicians have registered for the program in Iowa and Georgia. She passed around to the Board a sample of the materials provided to the physicians, including individually customized prescription pads. She also read from a positive article about the project in the *Atlanta Constitution* written by a participating physician. The Subcommittee also heard about a planned new NLM outreach initiative aimed at the Native American community. Built on the successful Tribal Connections Project of recent years, the new project has as one goal the improvement of information and computer technology that can also support the creation of new jobs for Native Americans in Alaska, Hawaii, and North Dakota. The Subcommittee also heard about and saw a demonstration of a new NLM information service, the recently launched Genetics Home Reference. It is written for the general public and will be expanded in the coming months. There was also an update on ClinicalTrials.gov, which now has more than 7,600 studies. The Subcommittee also received an update on publicity the NLM has been receiving in various media.

### **Bioethics Working Group**

Dr. Thomas Detre, who chairs the Working Group, said the charge to the group is to examine the quality of the bioethics literature that NLM has collected and supported and the indexing and cataloging coverage of bioethics literature. These collections have not been reviewed in recent years. Dr. Detre listed the members of the Working Group; NLM's Sheldon Kotzin is the Executive Secretary and Dr. Jack Snyder is providing additional staff support. NLM's collection is supplemented by indexing and cataloging records produced under contract by the Kennedy Institute of Ethics at Georgetown University. There is a separate contract with the National Reference Center for Bioethics Literature at Georgetown University. NLM's PubMed/MEDLINE and Locatorplus are used extensively by health professionals doing research in bioethics. A unified database, BIOETHICSLINE existed from 1973 to 2000. It was discontinued and its data incorporated into other NLM databases. There was some unhappiness with its discontinuance by those who have difficulty using PubMed/MEDLINE or Locatorplus. As one of its first acts, the Working Group has sent out a questionnaire to a number of bioethics centers in the U.S. and Canada and to find out their experience with using the NLM services. Eight have so far been returned. Although the data are still being analyzed, it is clear that most of them use the NLM collections for research purposes and that they have little problem accessing PubMed/MEDLINE, although Locatorplus was not used. The Working Group will meet again this afternoon (May 14).

## **Biomedical Imaging and Bioengineering Working Group**

Dr. Ralph Linsker reported on the group's May 12 meeting. The establishment of the Working Group was motivated by NIH's creation of the NIBIB—the National Institute of Biomedical Imaging and Bioengineering. Among the issues considered by the members were: What is the

important literature in this field and is NLM indexing it? Are the Medical Subject Headings vocabulary headings adequate to describe the literature? Dr. Lindberg also asked the members to consider "visions of the future." Dr. Linsker discussed briefly the backgrounds of the group's members; Ms. Becky Lyon and Dr. Michael Ackerman are NLM staff members assisting the Working Group. At the meeting on May 12, there were presentations on current coverage in the collection, indexing journals in the field, MeSH vocabulary, and the experience of an outside science and engineering library. The subsequent discussion was wide-ranging. There are many different types of critical literature in these fields-especially bioengineering-that are not commonly used literature sources in conventional areas of medicine: these can include conference proceedings, patents, technical reports, and electronic archives of primary data (as in genomics). Dr. Linsker discussed some of the characteristics of the various sources of bioengineering and biomedical imaging literature. At the meeting, Dr. Ackerman presented the results of an informal survey that asked workers to list the top 10 journals in two specified fields of biomedical imaging. Of the top 5, two were currently being indexed by NLM; three were not. In the field of bioengineering, there was less consensus in journal choice. There was general agreement within the group that the informal survey should be expanded with a uniform set of questions being sent to colleagues. The results should uncover gaps in NLM's coverage and suggest areas that should be looked at for collecting and indexing. At the next meeting, the group will make recommendations as a result of the survey.

After the presentations from the two Working Groups, Dr. Lindberg commented that both chairs had done an extraordinarily good job of summarizing complicated issues.

## XVI. REPORT FROM THE NOMINATING COMMITTEE

Dr. James Zimble said that the Nominating Committee, appointed at the February meeting, was unanimous in recommending Ms. Eugenie Prime as Chair of the Board of Regents. Ms. Prime was elected without dissent.

## XVII. MEMENTO FOR OUTGOING BOARD CHAIR

Dr. Lindberg presented to Ms. Alison Bunting a ceremonial gavel, symbolic of her having served as Chair of the Board of Regents.

## XVIII. ADJOURNMENT

The meeting was adjourned at noon on May 14, 2003.

## ACTIONS TAKEN BY THE BOARD OF REGENTS:

- > Approval of the February 11-12, 2003 Board of Regents Minutes
- > Approval of May 18-19, 2004 Meeting Dates
- > Selection of New Board of Regents Chair Ms. Eugenie Prime
- > 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

Alison Bunting, M.L.S. Chair, NLM Board of Regents