

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

**MINUTES OF THE BOARD OF REGENTS
February 11-12, 2003**

The 132nd meeting of the Board of Regents was convened on February 11, 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 3:30 p.m., followed by a closed session for consideration of grant applications until 4:00 p.m. On February 12, 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. 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
Rear Admiral Kenneth P. Moritsugu, U.S. Public Health Service
Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs
Rear Admiral Nancy Lescavage, 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. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:

Dr. Steven Brown, Veterans Administration
Mr. Ned Collier, Perry Dean Rogers & Partners
Dr. Parvati Dev, Stanford University
Mr. Steven Foote, Perry Dean Rogers & Partners
Ms. Carol Jenkins, University of North Carolina at Chapel Hill
Dr. Stephen Katz, Director, NIAMS
Dr. Randy Levin, Food and Drug Administration
Dr. Steven Senger, University of Wisconsin, La Crosse
Ms. Christie Silbajoris, University of North Carolina at Chapel Hill

February 11-12, 2003 - Board of Regents

MEMBERS OF THE PUBLIC PRESENT:

Natalie Ochs, The Blue Sheet

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. Kristina Babones, National Center for Biotechnology Information, NLM

Ms. Joyce Backus, Public Services Division, NLM

Dr. Carol Bean, Division of Extramural Programs, NLM

Ms. Susan Buyer, Health Information Programs Development, NLM

Ms. Patricia Carson, Office of the Director, NLM

Dr. Milton Corn, Division of Extramural Programs, NLM

Mr. Jason Donaldson, Office of Administration, NLM

Ms. Gale Dutcher, Division of Specialized Information Services, 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. Betsy Humphreys, Division of Library Operations, NLM

Ms. Christine Ireland, Division of Extramural Programs, NLM

Dr. Donald W. King, Office of the Director, NLM

Dr. Lawrence Kingsland, Lister Hill National Center for Biomedical Communications, NLM

Dr. James Knobon, Office of the Director, NLM

Mr. Sheldon Kotzin, Bibliographic Services, Division of Library Operations, NLM

Ms. Y. Kathy Kwan, National Center for Biotechnology Information, NLM

Ms. Eve-Marie LaCroix, Public Services Division, NLM

Dr. David Lipman, National Center for Biotechnology Information, NLM

Dr. Simon Liu, Office of Computer and Communications Systems, NLM

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. Dwight Mowery, Division of Extramural Programs, NLM

Mr. David Nash, Office of Equal Employment Opportunity, NLM

Dr. Stewart Nelson, Medical Subject Headings Section, NLM

Ms. Maureen Prettyman, Computer Science Branch, NLM

Dr. Barbara Rapp, Associates Program, NLM

Mr. Jon Retzlaff, Executive Office, NLM

Mr. J. Chris Robey, Division of Extramural Programs, NLM

Dr. Merlyn Rodrigues, Division of Extramural Programs, NLM

Dr. Angela Ruffin, Division of Library Operations, NLM

Mr. Jonathan Schlaifer, Computer Science Branch, NLM

February 11-12, 2003 - Board of Regents

Ms. Sonya Shooshan, Computer Science Branch, 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
Dr. Fred Wood, Health Information Programs Development, NLM

I. OPENING REMARKS

Ms. Alison Bunting welcomed the Regents, alternates, and guests to the 132nd meeting of the Board of Regents of the National Library of Medicine. She noted the presence of two new Regents: Ernest L. Carter, M.D., Ph.D., of Howard University, and Thomas Detre, M.D., of the University of Pittsburgh. Two new Ex Officio members were in attendance: Air Force Brig. General Joseph E. Kelley, and Rear Admiral Nancy Lescavage. She introduced today's special guest speaker, Dr. Stephen Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

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 and said that a last minute schedule change prevented him from attending the meeting. Dr. Moritsugu announced that last Friday, the Assistant Secretary for Health, Dr. Eve Slater, resigned. Admiral Carmona, while in his present position, is also acting Assistant Secretary for Health. Dr. Moritsugu said that there are several evolving themes within the Office of the Surgeon General. The first is prevention, identified by the President as a major thrust for health in the U.S. "Healthier US" is a new initiative in this area and the HHS Secretary is making prevention one of five areas of Departmental emphasis. The others are Medicare reform, preparedness, "closing the gap," and information technology. The Surgeon General has three goals in the area of prevention: to reduce the need for medical interventional care, to improve health status, and to improve the public health infrastructure. The second evolving theme, as charged by the President, is preparedness. By improving the public health infrastructure we can also improve preparedness for all hazards, not merely for chem/bio and nuclear events. The third evolving theme for the Surgeon General is "closing the gap." On the surface this means, of course, closing the gap in disparities in health among racial and ethnic groups. However, we hope also to address the "gender gap," the "quality gap," and the gap between physical and mental health. Dr. Moritsugu said that the Office of the Surgeon General has several "works in progress" in the communications area: a Surgeon General's workshop and report on bone health and osteoporosis; a Surgeon General's report on the health consequences of tobacco use; and the development of a public/private national action plan for oral health. Under consideration are activities and reports in the following areas: correctional health, women and mental health, prevention, preparedness, and global health. Dr. Moritsugu said that the President's charge to create a Citizen Volunteer Medical Reserve Corps has been assigned to the Department and the Office of the Surgeon General for implementation. The goal of the program

February 11-12, 2003 - Board of Regents

is to develop groups of civilian volunteers to help address health in communities around the U.S. and to augment existing emergency response efforts. Forty-two demonstration grants were awarded in the last year to do this; this year we hope to award even more. Using information technology is one way to provide technical assistance for training volunteers. Admiral Carmona is interested in reviewing the existing format for Surgeon General publications and reports, to make them more user-friendly and not merely focused on academics. The Surgeon General's web site is also being redesigned to make it more accessible to a broad range of the public.

III. REPORT FROM THE DIRECTOR OF THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

Dr. Stephen Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, discussed issues involving NIH clinical research. These are exciting times in medical research with the revealing of the human genome, the consequent development of new technologies, and the prospect of translating research findings to the bedside. There is current concern with the gap between what we know and what is actually done. This is a challenge, and one which the National Library of Medicine has taken on as an important part of its mission (for example, the ClinicalTrials.gov database). Many in medical research have been concerned over the years that clinical research is an "endangered species." Data show that the percent of medical school graduates choosing a career in research went from 16% (mid-eighties) to 10% (mid-nineties); it is probably even lower now, Dr. Katz said. The percentage of first-time applicants for NIH grants from MDs is declining compared to PhDs. It is clear that the biotech and pharmaceutical industries have provided much of the funding for the last 10–15 years for translational research. A study in the mid-nineties found that about 35% of NIH grant funds was spent on clinical research. Also, there is a consensus today that there is a shortage of clinical investigators. Dr. Katz described several NIH award mechanisms for training and career development of research medical professionals. Applicants for several types of grant have fallen off in recent years. Another identified need is to address the problem of the great debt of graduating medical school students, funneling them into more remunerative practice as opposed to research. NIH instituted several loan forgiveness programs (up to the equivalent of \$50,000 a year) with the support of the Congress for those who wished to engage in clinical research. NIH received about 1,000 applications the first year (2002), with a success rate of 80%. Eligibility criteria have been expanded for 2003. The challenge has been to get word about the program to students in a timely fashion.

Another issue discussed by Dr. Katz is that NIH has been criticized for not having enough clinical investigators on review panels. We hope to utilize at least 30% clinical researchers for study sections that routinely review clinical research proposals. He noted that NIH's new Mark Hatfield Clinical Center is nearing completion. It will have 241 beds and serve as a focal point for revitalizing clinical research on the campus as well as serving as a source for interacting with the entire national research community. Dr. Katz said that NIH Director Zerhouni's new "roadmap" initiative has three broad thematic areas: new pathways to discovery (fundamental infrastructure needs); multi-disciplinary research teams of the future (how to change the existing

February 11-12, 2003 - Board of Regents

culture); and re-engineering the clinical research enterprise (needs for translational research, training, and large databases). Finally, Dr. Katz focused on some of the things his Institute has done in the last several years in the area of clinical research support. One initiative has been to generate a large cohort of patients to look at osteoporosis in men. Another is to look for combination therapies for various forms of arthritis and osteoporosis; pharmaceutical and biotech companies are generally not interested in this. Another is surgical versus nonsurgical treatments for back pain. There is a large public/private partnership (NIH institutes and pharmaceutical companies) to create a research resource of “best practices” to be available freely on the Web. He also briefly described his Institute’s involvement in studying statistics for children and the genetics of complex diseases such as muscular dystrophy.

In response to a comment by Dr. Thomas Detre, Dr. Katz said he uses the term “clinical scientist” rather than “physician/scientist” because the former term includes many more health professionals than just physicians. In fact in many programs, the physician is less important than the person organizing the study, who may be a biostatistician, nurse, dentist, psychologist, etc. Dr. Kenneth Walker suggested that it would not be difficult to send e-mail to medical students about the loan forgiveness program as a way of encouraging applicants for NIH’s loan repayment programs. Dr. Richard Dean commented that students susceptible to becoming clinical scientists differentiate where they are going to go *after* they have decided what specialty they are going to enter. So it may be necessary to create information vehicles that tap into their residency and post-graduate environment to reach potential candidates. Dr. Katz agreed, saying that he thought both approaches were important. There was a general discussion about how, and when, to encourage medical students to consider careers in clinical research.

IV. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

The Regents approved without change the minutes from the September 10-11, 2002 meeting.

V. DATES OF FUTURE BOARD MEETINGS

The Board of Regents will meet next on May 13-14, 2003. The Board is meeting next fall on September 9-10, 2003. The dates of February 10-11, 2004, were adopted for the meeting next winter.

VI. REPORT OF THE NLM DIRECTOR

Dr. Donald Lindberg reported that the NIH budget may complete its doubling in 5 years in FY 2003; at this time, however, there is no appropriation. We are still operating under a Continuing Resolution, which means that we cannot initiate any new programs. The President is proposing a 2% increase for NIH in FY 2004. As to NLM staff, the Director reported on two retirements, Chuck Herbert of the Lister Hill Center and Dr. Susan Sparks of Extramural Programs. Dr. Alexa McCray introduced to the Board several new professional staff members of the Lister Hill Center: Dr. C. Carl Jaffe, Dr. Bisharah Libbus, and Dr. Alexandra Lord. Betsy Humphreys

February 11-12, 2003 - Board of Regents

introduced Beth Weston as the new head of the Serial Records Section, Library Operations. In the area of legislation, Dr. Lindberg reported that NLM is working to support both the new Electronic Government Act and the Homeland Security Act. He said it was interesting that the latter includes the creation of senior positions in the area of information analysis and infrastructure, science and technology, and a security advanced research projects agency. Jane Griffith next reported on a Government ethics provision that requires Federal employees (including advisors like the Regents) to identify their foreign activities and specifies that employees cannot receive emolument from foreign governments. This has led to some confusion as to just what advisors can and cannot do that may involve foreign governments or research institutions. She offered to work with any Regents who may be in this situation to find a satisfactory solution. Ms. Griffith then updated the Board as to the Privacy Rule mandated by the Health Insurance Portability and Accountability Act. The Department is working to get out advisory information and explanatory materials about the new Rule and its ramifications. It goes into effect in April. NIH is working on HIPAA privacy materials that will affect the research community; the National Network of Libraries of Medicine will be an important avenue for getting this information out. Ms. Griffith noted that the NLM was mentioned in the report language accompanying the E-government act as being a participant in the interagency committee that will advise OMB about long-term access to electronic government resources. She also mentioned that the European Union continues to press for a treaty at the World Intellectual Property Organization (WIPO) dealing with database protection, a prospect we view with some reservations. We will continue to monitor the situation to ensure that the scientific community is well represented to protect its interests.

Dr. Lindberg introduced the subject of “A-76”—the government’s effort to promote “competitive sourcing,” that is, President Bush’s initiative to have contractors compete to perform functions that do not necessarily have to be done by the Federal government. Jon Retzlaff, NLM’s Executive Officer, reported to the Board how NIH is complying with A-76. Each year NIH has to submit two lists to the Office of Management and Budget: a list of all functions that are inherently governmental and a list of staff who occupy positions that might be done by contract. It is estimated that about half of NIH’s 20,000 employees are in this second category. NLM has 396 employees in functions that have been identified as inherently governmental and 295 in functions that are commercially viable. NIH has been directed to review 50% of all commercially viable positions. NLM looked at 18 positions in 2002; it was determined that all could be done by employees more cheaply than by contractors. Functions will be studied by generating a “performance work statement” which is the “deliverables” of the function, allowing outside contractors and the government to bid to perform that function, and then choosing the low cost option. Secretary Thompson has guaranteed that everyone will have a job at the completion of this exercise. Dr. Lindberg announced that NLM was co-sponsoring with the American Medical Publishers’ Association an Archiving Forum on March 4 in Philadelphia. NLM meets regularly with the Association to exchange views and the Forum will explore preserving digital data—an issue of concern to both parties. As a national library, NLM has a special interest in this area and works closely with the Library of Congress, the National Archives and Records Administration, and others. The NLM Director noted that the Library

February 11-12, 2003 - Board of Regents

could now make the entire MEDLINE file available by ftp over the Internet—some 5.3 gigabytes (compressed). More than 50 (of 127) licensees have elected to receive the MEDLINE file this way, some in as little as one hour. The two temporary subcommittees, approved by the Board at its last meeting, are being established. One is the Bioethics Subcommittee (to be chaired by Dr. Thomas Detre with Dr. Richard Dean also a member), the other the Biomedical Imaging and Bioengineering Review Subcommittee (to be chaired by Dr. Morris Collen, with Dr. Ralph Linsker and Dr. Ernest Carter as members). A report will be made of their deliberations at a future Board meeting. The “Turning the Pages” project, which the Board has seen in the past, will soon add two new volumes: Ambroise Paré’s *Oeuvres*, and Conrad Gesner’s *Historiae Animalium*. These will be in addition to Elizabeth Blackwell’s *A Curious Herbal*, and Vesalius’s *De Humani Corporis Fabrica*. Another of NLM’s innovative information resources, the Web-based *Profiles in Science*, has been enriched with the papers of Linus Pauling. This will be the subject of the celebration tonight (February 11) on Capitol Hill. Dr. Lindberg’s last report was on the excellent notices NLM’s exhibit, “Dream Anatomy,” was receiving in the press. A 3-page article, with color pictures, (distributed to the Board) was in the November 27, 2002, *JAMA*. Also distributed to the Regents was a catalog on NLM’s Frankenstein exhibit (“Penetrating the Secrets of Nature”); that exhibit is now traveling around the U.S. in 80 different cities under the auspices of NLM and the American Library Association. Finally, a 1-page description of the current exhibition of photographs in honor of African-American History Month was distributed. By photojournalist Chester Higgins, Jr., the exhibition, titled “Invoking the Spirit,” is being loaned to NLM by the Schomburg Center for Research in Black Culture.

VII. PUBMED CENTRAL UPDATE

Dr. David Lipman, Director of the National Center for Biotechnology Information, introduced several new and reassigned NCBI staff members, describing briefly their areas of expertise: Dr. Anjanette Johnston, Dr. Lori Black, Dr. DeAnne Cravaritis, Dr. Steve Wilhite, Mr. Aleksey Y. Ogurtsov, Mr. Aaron Ucko, Mr. Viatcheslav Khotomlianski, Dr. Leonardo Mariño-Ramírez, Dr. Mohammad Al-Ubaydli, Dr. Laura C. Dean, Ms. Hsiu-Chuan Chen, Dr. Ming Xu, Dr. Teresa Przytycka, and Mr. Jason Donaldson. Dr. Lipman then brought the Regents up to date on the subject of PubMedCentral (PMC), NLM’s digital archive of the life sciences journal literature. There are now more than 100 journals in PMC, totaling more than 80,000 items (articles, letters, etc.). There are some 100,000 unique users monthly. Most content still comes to NLM in SGML format. NLM attempts to map all incoming data, whatever the format, into a single form that will allow us to transfer more easily to new technologies in the future. Center staff have developed the “NLM XML Archival Suite,” a highly modular XML format, that has resulted in a Journal Archive DTD into which all incoming journal data is beginning to be mapped. NCBI has almost finished a Journal Article DTD, which we hope to be able to provide to publishers so they may submit their data to NLM in this format. We believe that the Journal Archival Suite and the Journal Article DTD are good candidates to push for in the “open software standards” arena. Plans to scan back journal issues (a cooperative program with Library Operations) are progressing under a contract; we plan to scan more than 500,000 pages. Going online, Dr.

February 11-12, 2003 - Board of Regents

Lipman then demonstrated to the Board some of PubMedCentral's new features for retrieval made possible by integrating PMC into the Entrez retrieval system.

Eugenie Prime commented that by providing new tools and features for access, as Dr. Lipman demonstrated, this will "push" publishers to cooperate further. Dr. Lipman said that was a "hopeful" scenario; the other possibility is that when publishers see all the useful and flexible PMC tools for getting at their content, they will fear that users might prefer going to PMC rather than the publishers' own sites. Dr. Kenneth Walker said that the presentation recapitulates nicely the important things that the NLM does well—developing new ways of presenting (visualizing) data and creating links or associations within the data. In response to a question about scanning back issues, Dr. Lipman said that we are finding that people *do* go back to look at older material online that they would not have otherwise bothered to retrieve. So it is important for us to make such material easy to look at. Dr. Joseph Newhouse asked about the built-in lag time between when a journal is published and when it is made available in PMC—is this time stable or likely to change? Dr. Lipman said that because most journals are facing decreased subscriptions, this is difficult to predict; there is no uniform response by the journals. Some are comfortable with immediate access on PMC, others require a delay period of different lengths.

VIII. APPOINTMENT OF NOMINATING COMMITTEE FOR BOR CHAIR

Ms. Bunting appointed a committee to nominate the Board Chair for 2003–2004: Dr. James Zimble, Chair, and Dr. H. Kenneth Walker and Ms. Mary Ann Tatman, members. The committee will report to the Board in May.

IX. ARCHITECTS' REPORT

Mr. Steven Foote of the architectural firm Perry Dean Rogers & Partners said that since the last update to the Board plans have progressed to 70% of the design stage. The balance of the work should be completed early this summer. If funding is available, construction could begin early in 2004. Construction of the new facility would take 3 years. Mr. Foote showed a series of diagrams and views of the building; updating the Board on the latest new features. Dr. William Stead asked about the timing of the construction and how NLM will operate between now and 2007. Dr. Lindberg said that the present plans are on a "fast track." Mr. Kent Smith said it may be necessary to move parts of the collection to off-site leased space, although we will try to avoid this approach as studies have shown it to be inefficient for a national library. Mr. Foote briefly described the necessary phases of sequential construction; there really isn't much opportunity to speed up the process. He noted that although there will be construction noise, there won't be much disruption of the actual work environment of staff in Buildings 38 and 38A. There was a discussion about the funding of the construction: Mr. Smith said that the total (estimated at \$165 million) would need to be authorized up front, although it could be incrementally funded over 3 years. Mr. Ned Collier of Perry Dean Rogers & Partners then showed the Regents several pieces of the materials proposed to be used in the construction—samples of marble, slate, etc.

X. CLINICAL VOCABULARY DEVELOPMENT

Betsy Humphreys, NLM Associate Director for Library Operations, said that NLM's interest in clinical vocabulary development is based on the assumption that electronic health data standards are part of the information infrastructure needed to support health care, clinical and health services research, and public health and bioterrorism surveillance. NLM's involvement in this subject is reflected in numerous government and other reports and in action items in the Library's Long Range Plan. NLM's first intramural exploration of the state of clinical vocabularies occurred when Dr. Lindberg began the Unified Medical Language System (UMLS) in 1986. Ms. Humphreys briefly described the characteristics of three that were de facto standards in the mid-1980s. None of them was clinical, two were for billing (ICD and CPT) by HCFA regulation, and third was NLM's own Medical Subject Headings (MeSH). The MeSH is a de fact standard not due to regulation but based on the success of MEDLINE and constant feedback and improvement from users. The attributes of Medical Subject Headings (general availability, lack of restriction, high quality electronic format) are, in fact, what we are seeking in clinical vocabulary standards. The first version of the UMLS Metathesaurus, released in 1990, included MeSH and several clinical vocabularies. The latest 2003 edition has 100 vocabulary sources contributing 875,000 concepts and 2.14 million concept names. The Metathesaurus has been very influential in the field of medical informatics and it provides an excellent vehicle for uniform distribution of and mapping between any administrative or clinical vocabularies that are selected as national standards. However, it does not fill gaps in existing vocabularies, it doesn't confer standard status on the vocabularies it contains, and it doesn't circumvent the intellectual property restrictions that affect some of its contents. NLM is frequently urged to remedy these lacks.

In the late 1990s, two existing clinical vocabularies merged to create an obvious frontrunner. As the value of a controlled clinical vocabulary became apparent to more people in the 1990s, the barriers to terminology standards became clearer. NLM has been among those devoting considerable energy to address the initial barriers that must be removed before we can start on the really difficult problems. These initial barriers include: uncertainty about which clinical vocabularies will be adopted by Federal agencies, lack of stable funding for ongoing maintenance of clinical vocabularies, and intellectual property restrictions on some excellent vocabularies. NLM developed a strategy to encourage upfront Federal support for ongoing maintenance and free distribution of clinical vocabularies. LOINC (Logical Observations, Identifiers, Names, Codes), developed at the Regenstrief Institute, was the first case. LOINC was developed with support from foundations, the Agency for Health Care Research and Quality, and, to a lesser extent, from NLM. This vocabulary is designed for use in electronic messages about laboratory tests. The Federal agencies formed a coalition to set up a contract (1999) to support its continuing maintenance and free distribution. A follow-on contract for 5 years has just been issued. In 2000, NLM launched an effort by the agencies to negotiate a U.S.-wide arrangement for the use of SNOMED-CT. In 2001 NLM began to work to develop a clinical drug vocabulary in conjunction with the VA and FDA to fill an important gap in existing clinical

February 11-12, 2003 - Board of Regents

vocabularies. Meanwhile, in July 2000, the National Committee on Vital and Health Statistics issued a report on actions the Federal government should take to further standards for “patient medical record information,” in response to a requirement in the Health Insurance Portability and Accounting Act of 1996. The NCVHS urged Federal agencies to be early adopters of clinical data standards and urged also that there be Federal support for maintenance and low-cost (or free) distribution of clinical vocabularies. In 2001, the Office of Management and Budget launched the E-gov Initiative. The e-health component became the Consolidated Health Informatics (CHI) Project, which focused on establishing common, government-wide clinical data standards. CHI, at the end of last year, recommended LOINC be considered as the first standard clinical vocabulary. Ms. Humphreys said that we look forward to a public announcement that HHS, VA, DOD, and others have agreed on the first target national clinical data standards that will include LOINC and messaging standards previously recommended by NCVHS. This year both CHI and NCVHS will probably review and recommend additional clinical vocabulary standards. We now await the FY 2003 budget that will allow us to move forward.

Dr. Stuart Nelson, Head of NLM’s Medical Subject Headings Section, described RxNorm, a standard way of representing “clinical drugs” that was developed by the HL7 Standards Development Organization, and NLM. RxNorm was issued in the January 2002 UMLS Metathesaurus. RxNorm, a standard way of naming clinical drugs, is needed for order entry, decision support, medical records, and for linking to various kinds of knowledge. The decision was to develop a standardized format within the UMLS for representing clinical drugs. This representation would have an ingredient, strength, and dosage form, but not a route of administration or standard dose. The HL-7 Standards Development Organization established a value set—a short list of orderable dose forms. A standardized way of representing strength (in milligrams) was also established. Dr. Nelson showed to the Board several examples of drug representations. The plan is to identify everything in the UMLS with the semantic type of clinical drug and relate it to something in an RxNorm graph. The graph would show a user relationships between ingredients, tradenames, and generic equivalent drugs. He showed examples of how this could be done. In doing this, the problem of “islands of information” is being addressed, as well as providing the foundation for decision support systems, pharmacy control systems, and FDA labels on medications. It might be possible for RxNorm to provide the basis for the core names for computerized physician order entry. It is believed that this would greatly reduce prescription errors.

Dr. Steve Brown, Department of Veterans Affairs, said that the VA’s computerized patient records system (including a provider entry system) is running at VA medical centers. September 2002 statistics show that providers directly entered 91% of all medication orders. Another interesting aspect of the system is extensive bar coding, for example, nurses’ nametags, patients’ wristbands, and unique dose medications. The VA National Drug File (NDF), a centrally maintained and distributed terminology resource, drives much of the system. The NDF is also used for decision support, that is, class-based alerting at the point of order entry. VA is also interested in looking at the formal reference terminologies as a way of providing tools for

February 11-12, 2003 - Board of Regents

improving the enormous maintenance required for such a large far-flung system. Another critical issue is improving interoperability with the VA's partners—DOD and HHS particularly. Finally, Dr. Brown said, the VA is looking at a clinical perspective (as opposed to pharmacy management perspective). NLM has played a key role not only for RxNorm, but also in the VA's efforts to extend that. MeSH is used in a variety of areas and our underlying hypothesis is that the same approach can be used for clinical use as is valuable for the literature. The biggest problem the VA anticipates is not *how* to do it but to keep it going: there are several thousand changes a month needed.

Dr. Randy Levin, Food and Drug Administration, said that the FDA is working to improve drug labeling as part of the initiative Betsy Humphreys and Stuart Nelson described. Computer labeling should be made more "people-friendly, computer-friendly, and information system friendly." The label format is being changed and the label content is being made electronic. These changes will make the labels compatible with RxNorm. To make the labeling more information system friendly, FDA is working with NLM so that the Library can distribute the data and also provide links to the published literature. The FDA plan is to include *all* marketed products in their plan; the system will be updated daily. Manufacturers will provide proposed changes for label information electronically to the FDA.

Following these presentations, Dr. Lindberg asked if there was any possibility of getting information about foreign products into these information services. Dr. Levin said that they were working on a project (with NLM) that would identify ingredients that would not be limited to the U.S., where they would create a database with the structure of the ingredient and give it a unique identifier. There was a general discussion about the problems and opportunities involved in dealing with international pharmaceutical companies and products. Dr. Joseph Newhouse commented that he believes the standards arrived at should be in the public domain. He also noted that it is important to get the system established soon, to avoid confusion, competition, and expense in dealing with another system. He suggested that the VA should track and measure error-reduction resulting from the new system. In response to a question from Dr. James Zimble, Dr. Levin said the FDA would include the ingredients of food supplements in their codes.

XI. EXTRAMURAL PROGRAMS REPORT

The Board unanimously approved 2003 Operating Procedures (unchanged from previous year.) Dr. Corn reviewed NLM's Publication Grant program. NLM awards small grants, for up to three years, to provide short-term assistance for the preparation of book-length manuscripts about information of value to U.S. health professionals. The program is authorized by the Medical Library Assistance Act and its extensions, and is administered by NLM's Extramural Programs using the G13 mechanism. Grants are awarded for major critical reviews, historical studies, and current developments in informatics, technology, librarianship, and secondary reference materials in the biomedical field. Publication in media other than traditional hardcopy (e.g., electronic, film, etc.) are encouraged, as are new and innovative ways of organizing and presenting information. Publication grants do not support journals or other serials and are not

February 11-12, 2003 - Board of Regents

suitable for operation of established databases. Work judged to have significant commercial viability is not supported by these grants. Support is usually limited to \$50,000 direct annual costs and a maximum duration of three years of support. The average grant award is for two years, and publication is usually through an academic press, professional scientific society website, etc.

Also presented was an overview of the NIH Loan Repayment Program in which NLM is participating this year for the first time. The Program, discussed briefly by Dr. Stephen Katz earlier in this meeting, was created as a means of encouraging careers in clinical research by reducing the debt burden for those, like many physicians, who must choose between practice and research. It provides for the repayment of educational loan debt of qualified health professionals who agree to conduct clinical research for two years. Awards can repay up to \$35,000 of the principal and interest of the loans. The program also covers the Federal taxes on the loan repayments. As of February 1, six of the applicants responding to the NIH announcement had been assigned to NLM. All six were physicians connected in one way or another with NLM's Informatics Research Training program, although such a relationship is not a prerequisite. The results of the peer review and funding decision will be presented at the May 2003 meeting of the Regents.

XII. IMPROVEMENT IN INFORMATION ACCESS

A.) MEDLINEplus GOES LOCAL

Joyce Backus of NLM's Public Services Division briefed the Regents about MEDLINEplus, NLM's consumer health information Web site. She described its main features, including 600 health topics, a medical encyclopedia, extensive information about prescription and nonprescription drugs, a daily feed from the public news media, health tutorials, a medical dictionary, etc. Last September MEDLINEplus en español was introduced. What MEDLINEplus is lacking, Ms. Backus said, is the ability to tell consumers how to get in touch with local, county, or state health services. "NC Health Info," a new "Go Local" service introduced in North Carolina last month, and supported by the NLM is a first step in remedying this gap.

Carol Jenkins, Director of the University of North Carolina Health Sciences Library, said that the basic concept behind Go Local is that MEDLINEplus would provide its extensive health information while NC Health Info would allow users to augment that information with specific information about health services available in their local community. The Go Local service is accessible from any MEDLINEplus page; alternatively Go Local users can easily access MEDLINEplus health information. Ms. Jenkins said that the UNC brought to the project their knowledge of local and community health needs and the ability to identify, evaluate, and connect to local health resources. Their partnership with the UNC School of Library and Information Science has been a critical part of the success of the project. The pilot NC Health Info site was developed over one year and there are plans to work with community groups over the next year to expand it. An advisory board is being set up. North Carolina Senator John Edwards, Representative David Price, the State Health Director, the N.C. Secretary of Health and Human

February 11-12, 2003 - Board of Regents

Services have all been key supporters of the project. Ms. Jenkins said the project began with some NLM funding in 2001 to do a feasibility study. In 2002, with additional NLM support, the prototype database was built. Documentation of the whole process was important, so the project might be replicated in other parts of the country. Go Local was launched at a ceremony at the Pittsboro Memorial Library on January 14, 2003. Ms. Jenkins briefly described the ceremony and demonstration and showed some photographs. One key goal for the coming year is to add more resources to the database.

Christie Silbajoris of the University of North Carolina Health Sciences Library, and the NC Health Info Project Director, said that there currently are over 900 approved organizations in the database with over 1,500 displayed sites. Health care professionals are suggesting many new sites. We learned that local health information really translates into “local health services.” Ms. Silbajoris said that much work has gone into analyzing the terms used in describing the local programs and services; as a result, a growing listing of 132 terms has been created, each linked to corresponding MEDLINEplus topics. The ability to efficiently make changes, additions, corrections, and deletions is crucial. Automatic reviews of local resources are conducted every 6 months. Ms. Silbajoris logged on to NC Health Info and demonstrated to the Board its various features using Alzheimer’s disease as an example. The plan is to work with the Regional Medical Libraries to help the “Go Local” idea expand.

Dr. Richard Dean said that UNC had done a “phenomenal job” and he hopes the model that has been set can be replicated in other states. There will be a challenge in implementing it in a state that does not have as many connected resources as North Carolina. He suggested that the state’s Area Health Education Centers be involved with the project. He also suggested that it might be possible to partner with such national organizations as the Robert Wood Johnson Foundation to propagate the project elsewhere. Dr. James Zimble said that the network that has been put together might be useful in disaster response. He said that the Department of Defense was launching its TRICARE online portal for 8.5 million beneficiaries and that they might investigate using MEDLINEplus and its links to local services. Dr. Thomas Detre asked about how to deal with the sensitive political issue of selecting the right authoritative sources for information. Dr. Lindberg said that this really was a health services research project to see if we could in fact build a system that works; much has been accomplished, but there is work yet to be done. Ms. Silbajoris said that the NC Health Info builders were very sensitive to this issue and tried to be inclusive in scope while keeping harmful sites out. Dr. Dean said we should not worry about the “upper 20%” issues at the expense of getting anything to a huge population of people that do not know where to go for good health information—we can tolerate a certain margin of error and still be “way out on the curve” of benefit vs. risk.

B.) LINK OUT FOR LIBRARIES

Kathy Kwan of the National Center for Biotechnology Information demonstrated to the Board LinkOut for libraries, the Entrez feature that provides links to Web resources at organizations around the world and is used 9 million times per month. Entrez is NCBI’s primary information resource that provides access, for example, to PubMed. LinkOut allows users to move

February 11-12, 2003 - Board of Regents

seamlessly from an Entrez record to pertinent other resources that clarify or extend the information in Entrez. She showed a typical LinkOut page with all the links to a PubMed record. LinkOut takes users to resources that are specific to an Entrez record. Participation in LinkOut is free and voluntary. There are today more than 800 providers around the world supplying NCBI with links to their resources for LinkOut. More than 25 million records in various Entrez databases have links managed by LinkOut; PubMed has the most links among the Entrez databases—most of them for online full-text (3600 journals) and library holdings. There are three ways a user can see LinkOut resources from a PubMed record: through an icon on the PubMed abstract, choosing LinkOut from the links menu, and going to the LinkOut display to see all available resources for a record. A key feature is the ability of the user to know whether the local library has a subscription to the journal being retrieved. LinkOut has been extremely well received by the library community, Ms. Kwan said. She showed how libraries could sign up for the system. More than 550 libraries are participating and that number is growing. There are plans to expand links to non-SERHOLD libraries and to link to more freely available full text, and to link to authors' Web sites. Finally, Ms. Kwan discussed plans for LinkOut working in concert with "open URL" services.

Alison Bunting said that one of the exciting features of LinkOut is that users at institutions learn that their institution through license agreements with the publishers is actually providing the "free access" to electronic full text on the Web. The program is an excellent example of NLM having the "brilliant idea" of how to provide LinkOut, but then working collaboratively with libraries throughout the country to develop the actual mechanism. Dr. Ralph Linsker asked about NLM's responsibility in pointing to authors' Web sites that may, in fact, have copyrighted material on them. Ms. Kwan said that merely providing the link would not necessarily make NLM responsible; Ms. Bunting noted that many authors are naïve about the fact that they may have signed away their copyright.

C.) NLM GATEWAY

Dr. Lawrence Kingsland of the Lister Hill Center brought the Regents up to date on the status of the NLM Gateway, the "first-stop" service that allows unified access to more than a dozen NLM electronic information resources. Examples are PubMed, MEDLINEplus, Locatorplus, ClinicalTrials.gov, and OLDMEDLINE. The NLM Gateway searches in multiple NLM retrieval systems from one interface. The individual systems retain their own interfaces for those who wish to do focused searches on one system. Gateway's retrieval shows counts from all the retrieval sets of the places it has looked; the user can choose which results to display. The results are reported by information category: journal articles; books, monographs and audiovisuals; consumer health; meeting abstracts, etc. Dr. Kingsland described recent additions and enhancements to the NLM Gateway, for example the DIRLINE database of organizations that provide health information to the public. Because NLM database systems are constantly evolving (a "moving target") it is a substantial challenge for the Gateway to add its own new functionality while keeping pace with their changes. He showed how Gateway would parse several queries: "heart attacks and traffic accidents," an author search for AIDS abstracts, and canker sores. Recent functionality added to the system includes the ability to search

February 11-12, 2003 - Board of Regents

ClinicalTrials.gov and the ability to use data from NLM's automated indexing service. Access to information resources of the Specialized Information Services (for example, the Hazardous Substances Data Bank) will be added in the future, as may access to Images from the History of Medicine and Profiles in Science. Dr. Kingsland then demonstrated the Gateway to the Board using a variety of queries that elicited a variety of different kinds of information.

Dr. Ralph Linsker asked whether the truly "naïve user" might be overwhelmed. Dr. Kingsland said that many such users are in fact looking for consumer health information and that the system searches multiple consumer health resources including three in MEDLINEplus. Dr. Linsker asked whether features that are being introduced for the first time in the Gateway would be readily transferable to the target NLM databases. Dr. Kingsland said that Gateway developers work closely with the developers of many of the NLM databases and information systems to ensure interoperability. He added that the Gateway is designed to add user search functionality for those target systems that have a simple front-end. On the other hand, Gateway defers to target systems that have more sophisticated search functionality. Dr. Linsker suggested the Gateway developers might want to add the ability to do a Boolean search on two retrieved subsets. Eleanor Frierson of the National Agricultural Library said that the NLM system was "awesome" and suggested that the Regents might want to look at SCIENCE.GOV, a low-cost, much simpler way to give users access to science information across many Federal agencies.

XIII. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Eugenie Prime, Chair of the Subcommittee, said that a major item of discussion yesterday was the collaborative "Go Local" program with the University of North Carolina. The members were especially interested in the possibility of extending this model to other areas of the country. The need for a manual that would help others develop similar systems was discussed. Another project discussed was the upcoming NLM/American College of Physicians collaborative program whereby ACP physicians in two states (Georgia and Iowa) will be encouraged to write "information prescriptions" for the patients based on MEDLINEplus. The Georgia rollout will be in March, Iowa in April. There will be ceremonies involving NLM officials, the press, and local health officials. The Committee appreciates that this project is more complex than it might first seem and, in fact, there is no guarantee of success. NLM's Dr. Jack Snyder suggested another possible venue for similar outreach: the American College of Occupational and Environmental Medicine. Dr. Tenley Albright said that the NLM/ACP project has the potential for being a great time-saver for busy physicians who can give pertinent information to their patients with the knowledge that it comes from an authoritative source.

XIV. ADVANCED NETWORKING FOR IMPROVEMENT OF DELIVERY OF HEALTHCARE

A demonstration of "Visuo-Haptic Applications for Anatomy and Surgery Education Over the Next Generation Internet" was held in the Lister Hill Center Auditorium for the Board of

February 11-12, 2003 - Board of Regents

Regents. This is a project funded by the National Library of Medicine. The presenters were Dr. Parvati Dev of Stanford University and Dr. Steven Senger of the University of Wisconsin at La Crosse.

XV. ADJOURNMENT

The meeting was adjourned at noon on February 12, 2003.

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the September 10-11, 2002 Board of Regents Minutes
- Approval of February 10-11, 2004 Meeting Dates
- Appointment of Nominating Committee for Board of Regents Chair
- Affirmation of Operating Procedures
- 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