

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

**MINUTES OF THE BOARD OF REGENTS
May 13-14, 2008**

The 148th meeting of the Board of Regents was convened on May 13-14, 2008, at 9:00 a.m. in the Board Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), in Bethesda, Maryland. The meeting was open to the public from 9:00 a.m. to 3:45 p.m., followed by a closed session for consideration of grant applications until 4:15 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 [Appendix A]:

Dr. Cynthia Morton [Chair], Brigham and Women's Hospital
Mr. Richard Chabran, California Community Technology Policy Group
Dr. Jordan Cohen, George Washington University
Dr. John Connolly, University of California, Irvine
Dr. Carol Friedman, Columbia University
Dr. C. Martin Harris, The Cleveland Clinic Foundation
Mr. Bruce James, Nevada New-Tech, Inc.
Dr. Louis Rossiter, The College of William and Mary
Ms. Eileen Stanley, Ecolab, Inc.

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Ms. Eleanor Frierson, U.S. Department of Agriculture
Dr. Steven Galson, Office of the Surgeon General, Public Health Service
Ms. Gail Graham, U.S. Department of Veterans Affairs
Dr. Haym Hirsh, National Science Foundation
Col. David Louder, U.S. Department of the Air Force
Dr. Deanna Marcum, Library of Congress
Ms. Kathryn Mendenhall, Library of Congress
Col. John Powers, U.S. Department of the Army
Dr. Dale Smith, Uniformed Services University of the Health Sciences

CONSULTANTS TO THE BOR PRESENT:

Dr. Tenley Albright, Massachusetts Institute of Technology
Dr. Marion Ball, Johns Hopkins School of Nursing/IBM Research
Dr. Holly Buchanan, University of New Mexico
Dr. Thomas Detre, University of Pittsburgh
Ms. Virginia Tanji, University of Hawaii, Manoa
Dr. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:

Dr. James Cimino, Clinical Center, NIH
Dr. Daniel Reininger, Semandex Networks, Inc.

MEMBERS OF THE PUBLIC PRESENT:

Mr. Tom West, The Krasnow Institute
Mrs. Mary Lindberg

FEDERAL EMPLOYEES PRESENT:

Dr. Donald A.B. Lindberg, Director, NLM
Ms. Betsy Humphreys, Deputy Director, NLM
Dr. Donald King, Deputy Director for Research and Education, NLM
Dr. Michael Ackerman, High Performance Computing & Communications, NLM
Ms. Stacey Arnesen, Division of Specialized Information Services, NLM
Ms. Dianne Babski, Division of Library Operations, NLM
Ms. Joyce Backus, Division of Library Operations, NLM
Ms. Elizabeth Bland, Division of Library Operations, NLM
Ms. Diane Boehr, Division of Library Operations, NLM
Ms. Renee Bougard, Division of Library Operations, NLM
Mr. James Charuhas, Lister Hill Center, NLM
Mr. Victor Cid, Division of Specialized Information Services, NLM
Ms. Kathy Cravedi, Office of Communications & Public Liaison, NLM
Dr. Milton Corn, Division of Extramural Programs, NLM
Ms. Celeste Dade-Vinson, Office of the Director, NLM
Ms. Nicole Dancy, Division of Specialized Information Services, NLM
Mr. Todd Danielson, Executive Office, NLM
Ms. Donnetta Demyers, Office of the Director, NLM
Mr. Andrew Diggs, Division of Extramural Programs, NLM
Ms. Gale Dutcher, Division of Specialized Information Services, NLM
Dr. Elizabeth Fee, Division of Library Operations, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Mr. David Gillikin, Lister Hill Center, NLM
Mr. Alan Graeff, National Center for Biotechnology Information, NLM
Dr. Zoe Huang, Division of Extramural Programs, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Ms. Alla Keselman, Division of Specialized Information Services, NLM
Dr. Lawrence Kingsland, Lister Hill Center, NLM
Ms. Lou Knecht, Lister Hill Center, NLM
Mr. Sheldon Kotzin, Division of Library Operations, NLM
Ms. Lisa Lang, Division of Library Operations, 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 Center, NLM
Ms. Jennifer Marill, Division of Library Operations, NLM
Ms. Dianne McCutcheon, Division of Library Operations, NLM
Dr. Clement McDonald, Lister Hill Center, NLM

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Ms. Melanie Modlin, Office of Communications & Public Liaison, NLM
Ms. Elizabeth Mullen, Division of Library Operations, NLM
Mr. David Nash, Office of the Director, NLM
Dr. Aaron Navarro, Lister Hill Center, NLM
Dr. Judy Ozarin, Division of Library Operations, NLM
Ms. Jennifer Pakian, Division of Specialized Information Services, NLM
Ms. Manon Parry, Division of Library Operations, NLM
Dr. Arthur Petrosian, Division of Extramural Programs, NLM
Dr. Steven Phillips, Division of Specialized Information Services, NLM
Ms. Shana Potash, Office of Communications & Public Liaison, NLM
Dr. Barbara Rapp, Office of Health Information Program Development, NLM
Mr. Thomas Rindfleisch, Lister Hill Center, NLM
Ms. Jane Rosov, Division of Library Operations, NLM
Dr. Angela Ruffin, Office of the Director, NLM
Mr. Jerry Sheehan, Office of the Director, NLM
Mr. Mark Siegal, Division of Extramural Programs, NLM
Dr. Elliot Siegel, Office of Health Information Program Development, NLM
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
Mr. Kent Smith, National Center for Biotechnology Information, NLM
Ms. Claire Torella, Department of Veterans Affairs
Ms. Patricia Tuohy, Division of Library Operations, NLM
Ms. Susan Von Braunsberg, Division of Library Operations, NLM
Rear Admiral Robert Williams, Acting Deputy Surgeon General, PHS
Dr. Frederick Wood, Office of Health Information Program Development, NLM
Dr. Jane Ye, Division of Extramural Programs, NLM
Dr. Deborah Zarin, Lister Hill Center, NLM

I. OPENING REMARKS

Dr. Cynthia Morton, Chair of the NLM Board of Regents, welcomed the Regents, alternates, consultants, and guests to the 148th meeting of the Board. She introduced Ms. Virginia Tanji, Director of the Health Services Library, John A. Burns School of Medicine, University of Hawaii, Manoa. Ms. Tanji will officially join the Board following this meeting. Dr. Morton also welcomed Rear Admiral Steven Galson, MD, the Acting Surgeon General, Public Health Service, Rear Admiral Robert Williams, the Acting Deputy Surgeon General, Public Health Service, and Colonel Dave Louder, who is the Alternate Ex-Officio Member for the Surgeon General's Office for the U.S. Air Force. Lastly, she welcomed Dr. Daniel Reininger from Semandex Networks, Inc., who will speak to the Board later today.

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

Dr. Steven Galson, who has served as Acting Surgeon General since November 2007, stated that his last position in the government was as Director of the Center for Drug Evaluation Research at the Food and Drug Administration. In that capacity, he worked with NLM to put drug label information on the Internet, via DailyMed and ClinicalTrials.gov. Dr. Galson noted his office's priorities: (1) preventive medicine, because the US spends the vast majority of its resources treating chronic conditions that are preventable; (2) health disparities, which impact life expectancy, maternal mortality, and the prevalence of a large number of health conditions; (3) public health preparedness for disasters; and (4) health literacy. NLM has a special role in the latter, communicating important health messages to the public despite language barriers and literacy problems. Other key issues for the Surgeon General's office are the prevention of pediatric obesity and underage drinking. To address these and other topics, Dr. Galson has started a new column, "The Surgeon General's Perspective," in the monthly *Public Health Reports*.

III. LIBRARIAN INFOBUTTON TAILORING ENVIRONMENT PROJECT AND THE BIOMEDICAL TRANSLATIONAL RESEARCH INFORMATION SYSTEM AT THE NIH CLINICAL CENTER

Dr. James Cimino, Chief of the NIH Clinical Center's Laboratory for Information Development and a Senior Scientist at NLM's Lister Hill Center, described two initiatives: (1) the Librarian Infobutton Tailoring Environment Project (LITEB), the current phase of the longstanding Infobutton research initiative funded by NLM and begun when Dr. Cimino was at Columbia University, and (2) the Biomedical Translational Research Information System (BTRIS), which is the system that he was brought to NIH to create.

The goal of Infobuttons is to anticipate clinicians' information needs while they are interacting with electronic medical records and to link them to other information sources that meet those specific needs. The Infobutton grants clinicians access to information from the electronic medical record, determines what additional medical information resources are available to address that information need, and formulates queries to these resources in the terminology that is understood by those resources. When you set up Infobuttons at different institutions, you have to gauge the information needs of each, the context in which the needs arise, and the range of resources available in that particular setting. To Dr. Cimino and his team, the institutional librarian is the best person to make those determinations. As a result, the current phase of the research is focused on developing a Librarian Infobutton Tailoring Environment (LITEB), a tool that will help librarians figure out how to produce the set of links appropriate for their specific institutional environments. Librarians at a variety of institutions will be involved in testing and providing feedback on the tool.

The Biomedical Translational Research Information System (BTRIS), which Dr. Cimino is developing for the NIH Clinical Center, will be a central NIH patient care and clinical research database collected from a wide variety of sources, including the Clinical Center's patient record

system, the many clinical and research laboratories used by NIH institutes, etc. With BTRIS, Dr. Cimino is looking at how to bring the wide-ranging data together into a single repository and provide multiple modalities of information access. NIH clinicians and researchers could then do data mining and cross-patient queries, and see how protocols are progressing. BTRIS will be involved in a number of processes in the acquisition of data including the de-identification of data, getting permissions for the use of data, incorporating analysis tools, etc. The first version will roll out of NLM in July 2008. More information can be found on the Web site: www.BTRIS.nih.gov.

In response to questions, Dr. Cimino noted that the purpose of BTRIS is not to provide up-to-the-minute information on patient care, but a more long-term, “big picture” aim, for researchers to have access to clinical data, and to establish queries for them to use. Asked for a snapshot of the Clinical Center, Dr. Cimino said that it’s a hospital where all the patients are on protocols; currently, there are 1,600 of them. While a lot of the data is collected because of research, it is also collected from regular patient care.

IV. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

The Regents approved without change the minutes from the February 12-13, 2008 meeting.

V. DATES FOR FUTURE BOARD OF REGENTS MEETINGS

The Board of Regents will meet next on September 16-17, 2008. The winter Board meeting is February 10-11, 2009. The dates of May 5-6, 2009, were adopted for the following meeting.

VI. REPORT FROM THE NLM DIRECTOR

Dr. Donald Lindberg discussed the NLM FY09 budget, noting that there had been no congressional action as yet. Technically, there is \$2 million more in the NLM budget but, with inflation, it’s essentially flat. Salaries can’t be reduced, so, unfortunately, most cuts must come out of the extramural grants program. On the personnel front, Associate Director for Library Operations Sheldon Kotzin introduced Renée Bougard, who joined the NN/LM National Network Office as Outreach Librarian. She was previously Associate Director of the Regional Medical Library at the Houston Academy of Medicine/Texas Medical Center.

In terms of recent legislative developments, the most important was the passage of the Genetic Information Nondiscrimination Act (GINA), prohibiting discrimination in health insurance and employment on the basis of predictive genetic information. Genome-Wide Association Studies (GWAS) will also benefit from our having this legislation in place, Dr. Lindberg remarked. Dr. Morton mentioned that if you believe in the personalized, predictive, and preventive model of medicine, this legislation is the beginning of the predictive part; it will help the public live out the promise of the human genome project.

Dr. Lindberg next discussed NIH's Congressionally-mandated public access policy. NIH is prepared to provide funds to help NLM deal with the expected increase in manuscript deposits. Former Lister Hill Center Director Dr. Daniel Masys has suggested that NLM consider whether an information service concerning the policies of the publishing houses would be useful to universities as they try to comply with this new law. Librarians are frequently asked questions about publishing policies by individuals who are considering publishing a paper. Perhaps the general university library community could take this on, with guidance from NLM. Ms. Eleanor Frierson noted that the National Agricultural Library was closely monitoring the progress of the NIH Public Access Policy for its USDA government authors.

Dr. Lindberg mentioned the Medical Library Association (MLA)/NLM electronic personal health record (PHR) project, which is reviewing available PHR products and hopes to interest product developers in linking to MedlinePlus resources and referring their users to librarians as additional sources of health information. NLM's own PHR effort, led by the Lister Hill Center, is designed to enable patients to take their personal records on a thumb drive and go wherever they wish. LHC Director Dr. Clement McDonald mentioned that his staff has evaluated many PHR products for strengths, weaknesses and costs. LHC is partnering with the NIH Clinical Center, the Jewish Community Center, a multi-level nursing home, and Suburban Hospital, to test their PHR prototypes.

Regarding the expansion of ClinicalTrials.gov (CT.gov) mandated by legislation in September 2007, NLM staff are heavily engaged not only in expanding the CT.gov system, but also in drafting guidance and regulations for implementing the law's provisions. CT.gov Director Dr. Deborah Zarin confirmed that the revised system for submitting summary results of trials has to be in place by September 22. Mockups of the Web site will be able for the public to comment next week. Dr. Lindberg noted that NLM's desire is to allow investigators to describe their trials as they wish: "one size fits all" doesn't work here. Ms. Humphreys noted that a *Federal Register* notice will come out soon, containing a formal announcement that there will be rulemaking to implement the law. It will also invite public comment.

Dr. Lindberg referred to the Government-wide Internet Connection Consolidation effort, which he termed "a nightmare." The Office of Management and Budget believes the number of federal Internet connections should be reduced from thousands to 50. They believe this will improve security, but the NLM Director believes exactly the reverse.

Dr. Lindberg provided an update on NLM's initiatives related to interactive publications. NLM wants to collaborate with commercial publishers to find out what it costs to publish in such a way that the reader is able to interact with publications, e.g., to point and click to see more underlying data and animations, ask questions, etc., and whether interactive publications make a difference in learning speed, retention, etc.. NLM Associate Director Dr. Elliot Siegel has worked with medical students, to obtain their views on what interactive features may be

important. They did well, but so far publishers don't seem too interested. NLM is also in a pilot project with the Optical Society of America (OSA) to determine whether people learn better and faster reading OSA journals in an interactive format. Dr. Michael Ackerman is the NLM point person for this project.

In April, NLM sponsored a symposium celebrating GenBank's 25th anniversary. That rich NCBI resource was actually born at the Department of Energy in Los Alamos, New Mexico, but later transferred to NIH. Dr. Lindberg commended NCBI Director Dr. David Lipman and his staff for their fine work.

Dr. Lindberg concluded by mentioning the creation of a women's health Web site (http://orwh.od.nih.gov/nat_lib_med.html), a collaborative effort by the Division of Specialized Information Services (SIS) and the NIH Office of Research on Women's Health (ORWH).

Throughout his presentation, Dr. Lindberg referred to additional supporting information on all of these topics in the Board book.

VII. CLEVELAND CLINIC-GOOGLE PILOT PERSONAL HEALTH RECORD PROJECT: BRIEF STATUS REPORT

Dr. C. Martin Harris presented an overview of the Cleveland Clinic-Google Pilot Personal Health Record Project in the context of the Clinic's broader efforts to provide patients with access to their medical records. He noted that this project is an attempt to help consumers manage their health care information across a diverse health care system.

When the Internet took off, Cleveland Clinic knew that patient care services were someday going to be managed via that new technology. So, they drove their strategy toward the concept of eCleveland Clinic (<http://my.clevelandclinic.org/eclevelandclinic/default.aspx>), an online resource designed to provide services to patients, educators and researchers. The group's first move toward consumerism was a physical one, building several integrated family health centers. Dr. Harris noted that they had to "e-enable" the medical community, setting up technology so that as a patient who travels from one facility to another, their charts move, too, and are always available to the practitioner. Over time the Clinic acquired 10 other hospitals, each with its own information system. The only way to make a system out of this patchwork was to e-enable the whole enterprise again.

Dr. Harris next described how patients themselves determine the members of their health care team. The Clinic created a tool called "MyPractice Community." It is essentially the same tool that the Cleveland Clinic doctors use but is delivered to non-Cleveland Clinic doctors for a fee. Physicians pay for their computers and their Internet service, and buy any other system-related services from the Clinic. With this set-up, if a patient leaves that private practitioner and goes to one of the Clinic's doctors, or vice versa, their information will be transferred between the doctors. This fastest-growing service started about 10 months ago.

The Clinic next designed a system for practitioners who were not quite ready for the electronic medical record (EMR); it's called "DrConnect." If you refer a patient to the Cleveland Clinic and are an Internet user, you have signed up for the service. When their patient comes to the Cleveland Clinic there is a pop-up on their file asking them if they want their personal doctor e-mailed; if so, he or she can go into DrConnect and become a virtual partner in that patient's care. To date, about 2,000 physicians joined this system, which can be accessed internationally, too.

To help patients keep track of their own records, "MyChart" was born. Patients see the same lab results, medication lists and appointment schedules that their physicians see, and receive personalized health reminders linked to consumer-friendly information about their diseases and disorders. Patients can request a renewal of their medication; the physician sees it, signs it, and ships it to their pharmacy of choice. Cleveland Clinic has over 135,000 patients who use this tool every day.

Another tool, "MyConsult," allows patients anywhere in the world to get a medical second opinion. Especially helpful for those who don't live in dense medical markets, MyConsult connects them to the specialty physician expertise they need when faced with a serious diagnosis. Staff reviews their medical records and diagnostic tests, then renders a second opinion that includes treatment options or alternatives. The patient asks questions and Clinic staff answer them.

As Dr. Harris noted, as systems such as this expand regionally and even nationally, new challenges will arise. State laws may have to be made regarding information sharing, and new networks may need to be found to handle multi-state data.

Cleveland Clinic's approach was to find a "plumbing company" that makes connections one at a time to the other institutions in the health care system. The agreement with Google is necessary for this connection to take place. For example, because physicians send their patients to a local pharmacy, hospital and a commercial lab, all three need the patient's information in electronic form. If the Clinic is able to make those connections, they then have the ability to move an electronic form. Secondly, the patient needs to be put right in the middle. No information in this model moves unless the patient authorizes it. This model levels the playing field. When such an interoperable personal health record is available, that information can be accessible to clinicians when and where they need it, as the transition is made to an online model. Cleveland Clinic has 1,600 patients who have signed up for this Personal Health Record project. In the course of its development, the Clinic learned a lot about the design of the user interface and privacy issues, including the use HIPAA guidelines.

Dr. Harris concluded by noting that this system will empower the patients to be active participants in their own health care decision-making. Board members commented that responsibility for the data rests with the owner of the information and, therefore, that a

redefinition of HIPAA would be appropriate. Asked what it would cost for a community doctor to participate in the system, Dr. Harris said about \$600 a month, irrespective of the number of patients in a practice.

VIII. INTRODUCTION TO “AGAINST THE ODDS: MAKING A DIFFERENCE IN GLOBAL HEALTH”

Dr. Elizabeth Fee, Chief of the History of Medicine Division at the NLM, discussed themes in the new NLM exhibition, which opened in April. The exhibition emphasizes that “global health” is as much about the US as it is about the rest of the world. Among the many achievers featured, “Against the Odds” showcases Dr. Jack Geiger, who brought the community health care movement back from South Africa to Mississippi. It tells the story of Bangladeshi community health workers bringing oral rehydration therapy to Afghanistan. As one of the people in the exhibition said, “Ordinary people can do extraordinary things.” “That is our message, especially to young people,” Dr. Fee explained. Dr. Lindberg then introduced the exhibition video, which was followed by a tour of the exhibition led by Patti Tuohy, Exhibition Program manager, Manon Perry, exhibition curator, and other members of the History of Medicine Division staff.

IX. DISASTER INFORMATION MANAGEMENT PLAN

Steven J. Phillips, MD, NLM Associate Director, Specialized Information Services, discussed the objective of making NLM the federal government’s main portal to provide tools, literature and research methods to assist with disaster preparedness, response and recovery. He began by describing some of the Library’s previous involvement in disaster preparedness and response. NLM has worked to provide information useful to disaster sites at least since the 1984 Bhopal disaster. NLM has also responded robustly when other disasters struck, including the September 11th attacks, Hurricane Katrina, and the recent California wildfires. NLM started to take a leading role in disaster management efforts in 1998, when Mitch, one of the most devastating hurricanes in history, struck the Atlantic basin. The NLM teamed with the Pan American Health Organization (PAHO) and other Central American institutions, and eventually the Central American Network for Disaster and Health Information (CANDHI) was created. CANDHI helps health professionals in Latin America and the Caribbean get information before disasters strike. Today, there are 10 CANDHI centers in this region. NLM has helped these active centers by providing training, work stations and Internet connectivity.

The *NLM Long Range Plan 2006-2016* recommended the creation of a Disaster Information Management Research Center (DIMRC) and an expansion of NLM activities in this arena to provide a platform for demonstrating how libraries and librarians can be part of the solution to the pressing need for preparedness for man-made and natural disasters. NLM is developing the DIMRC within the context of overall U.S. government disaster preparedness policy, including the Pandemic and All Hazards Preparedness Act (2006) and Homeland Security Presidential Directive 21 (2007).

Although located programmatically at the Specialized Information Services (SIS) Division, the DIMRC is a trans-NLM effort, which draws from the talents of all areas of the Library, to ensure the security of NLM's own resources in the event of emergencies and to assist with disaster preparedness and response around the nation. The National Network of Libraries of Medicine (NN/LM) is playing an important role, with all Regional Medical Libraries (RMLs) developing disaster plans and the network libraries encouraged to develop their own disaster plans to ensure uninterrupted access to critical health information services. To assist in that process, the Network has developed an Emergency Preparedness & Response Toolkit, at <http://nmlm.gov/ep>.) In addition, the "Go Local" feature of MedlinePlus is being enhanced with listings of state and local emergency and disaster resources.

The Center's dedicated budget for FY2008 is \$600,000. Initial NLM-wide efforts have included taking stock of NLM's current disaster-related resources, e.g., materials in the NLM collection, journals indexed in MEDLINE/PubMed, vocabulary in the Medical Subject Headings, and identifying any needed improvements. PubMed has reasonable coverage of published articles on disaster-related topics, but there are many valuable resources which aren't peer reviewed and don't appear in journals.

One way to determine which of these resources are most important to on-the-ground disaster preparation and response teams is to put librarians "in context" within these teams to study and respond to real information needs as they arise. For the last nine months, under the leadership of staffer Cindy Love, DIMRC has been conducting a Disaster Information Specialist Pilot Project involving librarians from a range of institutions. It is hoped that "disaster information specialist" may evolve into a subspecialty in the library profession.

Dr. Phillips demonstrated NLM's new DIMRC Web site (<http://disasterinfo.nlm.nih.gov>) and several resources to which it links, such as Enviro-Health Links. He noted that DIMRC is dedicated to improving access to disaster-related tools. Sections of the REMM (Radiation Event Medical Management) site are being formatted for portable handheld devices, and users can currently download WISER (the Wireless Information System for Emergency Responders) to their smartphones and, soon, to their BlackBerrys. DIMRC is working on programs for geographic information systems (GIS), too. Other areas receiving serious consideration are triage management for first responders, post-traumatic stress disorder and traumatic brain injury.

DIMRC has worked for about a year with the NIH Clinical Center, the National Naval Medical Center and Suburban Hospital in the Bethesda Hospitals Emergency Preparedness Partnership (BHEPP). The partners share information, devise emergency plans and regularly conduct drills, thus creating a state of readiness, should a disaster strike the Washington, DC area. NLM expects to receive about \$2 million from the Navy to undertake research and development projects related to the Partnership.

With its increased disaster R&D funding, DIMRC continues experimenting with 2nd Life, creating virtual disasters and then sending in virtual emergency personnel to address them. This technology allows the BHEPP to conduct its drills in cyberspace, before undertaking the real thing. Since actual drills cost \$4-5 million dollars, the simulated 2nd Life version lets responders work out any kinks before the “real” drill gets underway, in the real world.

NLM is also an active participant in the Bethesda Medical Libraries Emergency Preparedness Partnership, with the NIH Staff Library, National Naval Medical Center Library, USUHS Library and the Suburban Hospital Library. This group shares information that can be used by each institution’s emergency preparedness force. NLM also participates in the Trans-NIH Biodefense Research Coordinating Committee, the Institute of Medicine Forum on Public Health Preparedness for Catastrophic Events, and the Chemical Warfare Group, a collaboration of the U.S. government, Canada, Mexico and Argentina.

Several members expressed appreciation for DIMRC’s progress to date. Mr. James asked whether any other country had undertaken such a coordinated national disaster response plan. Dr. Phillips replied that he knew of none, although a librarian at the CANDHI center in Honduras plays a vital role in that country’s disaster response team. Dr. Cohen asked whether NLM envisioned the development of a formal certificate that could be awarded for library science students specializing in disaster information. Dr. Phillips noted that DIMRC and its partners are developing a curriculum for that specialty and will solicit guidance from the MLA, too. Mr. James asked how NLM would get out the word on the work of DIMRC in general, and on the concept of a Disaster Information Specialist in particular. Dr. Phillips replied that the National Network does a wonderful job of transmitting information about DIMRC to the library community, and beyond. Mr. James thought the U.S. National Commission on Libraries and Information Science might also be helpful in spreading the word about a new library subspecialty, disaster information. Dr. Connolly commented that the library at the University of California, Irvine School of Medicine, where he works, has formed a disaster division and regularly send out e-mails to all university faculty about wildfires and other threats. Dr. Phillips said that he’d like for DIMRC to collaborate with staff there. Dr. Detre mentioned a software system created at Carnegie Mellon University to help communities ensure that physicians can be mobilized to disaster sites. Dr. Phillips said he would follow up regarding that system. Dr. Rossiter asked what the relationship was like between NLM and the Department of Homeland Security and Dr. Phillips replied that DHS is, frankly, a bit territorial. That agency sees NLM in a supportive role, not as “boots on the ground.” In addition, Dr. Phillips expressed concern about the lack of up-to-date technology at FEMA, and at the frequent number of personnel changes at federal partner agencies. Should we stop at medical information, Board members asked? If we could link on Go Local to gas stations, sources of water and food, bridges, emergency generators, etc., we would definitely aid the public health in a time of disaster. Dr. Phillips said that DIMRC is developing a toolkit along those lines for all Go Local partners. Mr. Chabrán noted that there are special architectural maps available in some communities, to guide residents out of disaster areas and guide emergency responders in. How does NLM plan to connect to such

existing resources? Dr. Phillips replied that, if those are available open source, NLM can link directly to them, and ask the RMLs to publicize their existence. Dr. Lindberg returned to the question, what information is within the Library's purview? After Katrina, medical libraries worked with personal medical information and other resources to reunite missing children with their parents. Libraries should try and perform such public services whenever possible, he said. Ms. Stanley remarked that, besides helping plan for disasters, librarians have the power to release helpful information immediately following a disaster. A seasoned librarian in Minneapolis provided a much-used link on his library's Web site to the architect's plans for the bridge that collapsed August 1, 2007. Post-Katrina, public service-minded librarians provided similar links to the plans for the levees that failed and other background information.

X. MEDICAL EMERGENCY DISASTER RESPONSE NETWORK

Dr. Morton introduced Dr. Daniel Reininger, President and Co-Founder of Semandex Networks in Princeton, New Jersey. He spoke about a Phase II NLM Grant to develop an operational prototype of a Medical Emergency Disaster Response Network that provides public health, first responders and crisis managers the information they need in order to best allocate resources, to recover from and mitigate the effects of disasters.

Dr. Reininger said that his firm has been working on this project for two years. During that time, the Web has undergone a revolution, with content now being generated instantaneously, through vehicles like Wikipedia and YouTube. Now, the general public, not just Webmasters, can launch content that can be downloaded by the entire world. This "grassroots" Web is called Web 2.0, but what Dr. Reininger's group is exploring is Web 3.0, or the "semantic" Web. The semantic Web links top-down information (from libraries, emergency procedures manuals, etc.) to grassroots information being generated by health care workers, police and others who are present at the disaster site. It involves an easy-to-use (important for people in stressful situations, who need to find answers in a hurry) semantic application that gathers, organizes and updates information, alerts disaster response personnel to new developments (like the fact that a hospital's front entrance is flooded) and empowers collaboration. The importance of such a network is that it provides the actionable information needed to help communities recover from and mitigate the adverse health effects of disasters.

Interestingly, Dr. Reininger had participated in a simulation drill with the U.S. Navy, regarding a catastrophic event in Myanmar. The bleak prospect for relief efforts in such a scenario unfortunately came to pass a week later, when Cyclone Nargis made landfall in Myanmar on May 2nd. How can we avoid a repeat of such a catastrophically flawed disaster response? A technology called Tango serves as an interface between people and technology, and gives them the power to turn data into action. The Tango Semantic Server offers users the ability to collect data from a wide variety of sources, organize it and actually visualize it. Information captured in this semantic Wiki of shared resources might include a list of hospitals with the number of beds available and a list of facilities where medical supplies are close to running out.

Tango is driven by a powerful semantic engine. It collects information in many formats (e-mails, Word and Excel documents, RSS feeds, etc.), organizes it and delivers an easily navigable final product that is as fluid as the conditions surrounding the disaster itself.

The challenge to any disaster information management system is to maintain all-hazard and all-situational readiness. There is a constant cycle of preparation, monitoring and response, and each of those phases requires (and generates) considerable information. To track, organize and share it all is a tall order, because disaster-related information ages quickly and limited IT budgets preclude the use of expensive system integration solutions to solve the problem.

For its Medical Emergency Disaster Response Network (MEDRN) project, Semandex, in Phase I, assessed the information needs of disaster management professionals and presented its proof-of-concept prototype to key opinion leaders, for refinement. In Phase II, they are evaluating Tango's effectiveness for MEDRN uses, developing an Emergency Management semantic data model and conducting a pilot trial with the Maryland Joint Operations Center (MJOC), a branch of the Maryland Emergency Management Agency. Dr. Reininger then demonstrated a typical MEDRN Wiki page, capturing information on a New Jersey hospital. It shows that the facility's operating status is normal, that there are beds available, that they have supplies, etc. If the facility were compromised by a disaster, those indicators could be changed very quickly, to alert emergency responders. Information from all nearby hospitals can be exported to a geospatial map, which would show whether operations were normal (green on the map), in need of some attention (yellow) or completely unavailable (red). With such data, physicians and emergency professionals can find at a glance which hospitals are open for patient care. Community Emergency Response Teams (CERTs) have their own Wiki page, with information on available facilities, how many CERT workers are available nearby and what training they have, etc.

Dr. Reininger described the pilot project with the MJOC, which monitors possible threats to all of Maryland and the DC area, 24/7/365. The Center has only five work stations from which to monitor many threats: explosives, severe weather, human and animal disease outbreaks, Internet and 911 outages, etc. MEDRN organizes these many threats into a "Smart List," providing links to pertinent resources for each. In addition, interested parties can subscribe to e-mail alerts relating to these threats, which cull information from some 150 news feeds. (The Center processes over, 1,000 articles and generates 15-40 alerts daily.) With this information, responders can stay on top of all kinds of events. Semandex is involved in a pilot study with NLM's DIMRC. The aim of the MEDRN-DIMRC collaboration is to empower librarians to become a source of information dissemination in a disaster. MEDRN is a vital tool that can link Disaster Information Specialists (DIS's) with Emergency Information Centers (EIC's). Also, MEDRN would use existing NLM resources, like the Unified Medical Language System (UMLS) schema, to help with the organization of data. Proper organization of information naturally makes it much more easily accessible.

Dr. Harris asked how a MEDRN system worked in two different scenarios — like the external environment, such as something the MJOC would oversee, like a natural disaster on a large scale, and an internal environment, like conditions in a hospital or school. In the former, there are trained professionals who are probably used to inputting data. In the latter, there are likely civilians, maybe even non-medical staff, inputting the information and accessing it. How easy is this system for them to use? Dr. Reininger replied that ease of use is a high priority in the Tango system. Often, it's as easy as uploading a file from Excel or another commonly used format, as hospital workers and others regularly update statistics regarding their beds, blood supply, etc. MEDRN, from there, will map the information to the semantic structure. The workers themselves would go to a Web site and change a number there to update data. In other cases, some manipulation of the data may be required.

Dr. Friedman said that, with a semantic ontology, it often takes a lot of knowledge, in order to organize the information properly. Dr. Reininger was asked, "What if a user decided that another type of data should be included in the MEDRN record, but it wasn't in the ontology?" Dr. Reininger replied that the program allows certain users to download the ontology directly from the Web and add to it new concepts that Semandex originally didn't think about. In this way, users can add new semantic structures to the ontology, which is constantly evolving, meant to be tailored to the users' needs. Dr. Friedman asked whether there were many rules on how to use MEDRN, and Dr. Reininger answered that the users create those rules themselves. Here, an example was the fact that, for the "hospital" model, emergency response personnel established one criterion for a "yellow" rating of a hospital as "fewer than five available beds." They could have chosen any number.

Dr. Lindberg asked about the commercial applications of Tango, like looking out for corporate assets or keeping bankers and others safe from kidnapping. Dr. Reininger did say that his company has worked with military Special Forces on such activities, and that the company works to ensure the human and other assets of Fortune 500 companies that operate globally.

XI. INTRODUCTION OF NEW STAFF MEMBERS, LISTER HILL CENTER

Lister Hill Center Director Dr. Clement McDonald introduced his office's two new fellows: Dr. Nisar Hundewale, who will be conducting research on personal health record infrastructure, and Dr. Xiaoli Zhang, who is working on machine learning techniques for the automated extraction of bibliographic data from electronic journals.

XII. EXTRAMURAL PROGRAMS REPORT

Director of Extramural Programs Dr. Milton Corn spoke to the group about the proposed delegation of application approval to the Board's Extramural Programs (EP) Subcommittee. Since the introduction of "Electronic Council Books," most NIH Councils have instituted a grant approval system that permits a Council subcommittee to act for the Council, in order to permit "expedited review." For NLM, such a group would be the EP Subcommittee. Such delegation

can save time at full Board meetings but, more importantly, can be used to shorten the current protracted period between application and award for those who apply to NIH for grant support.

At present the Board does a “second review” of grant applications to ensure that the first review of merit has been carried out fairly and completely. If the traditional responsibility for second review is delegated to a Subcommittee which could be convened without waiting for a full Board meeting, up to three months could be cut from the normal processing time. Delegation would be complete in that the Subcommittee vote would be final. Subcommittee actions would be reported to the full Board for information, not for action. All Board members would continue to have access to all applications and could request discussion of any specific application by the full Board member before it was acted on by the Subcommittee.

Dr. Corn requested a vote by the Board on the proposal that its authority to conduct a second review of grants is delegated to the BOR’s Extramural Programs Subcommittee for a one-year trial period beginning June 1, 2008. Discussion of the motion included questions about need for statutory authority for such delegation, meeting schedule for the Subcommittee, probable time savings in grant processing, and need for the BOR to be diligent as individuals in monitoring the list of applications up for approval. Discussion also noted that with application voting delegated to the Subcommittee, the full Board could focus more on strategies and priorities of NLM’s grant program.

The motion passed unanimously.

Dr. Corn next began his regular presentation, “Grants: What Are We Getting for Our Money?” Evaluating the success of a funded research project is difficult but several tools are available and others can be developed. Conventional NIH criteria of “success” include reputation, annual progress reports, final progress reports, and publication number. Additional analyses of publications can provide more refined data, and several possible approaches were demonstrated on a sample of research grants funded by NLM five years ago. Presented were data on publications per grant, cost per publication, citations per publication, cost per citation, and several measures of the quality of the journal in which funded research was published. PubMed, Web of Science, and Google were all used as data sources. Discussion of such measures and other potential tests, including both value and hazards, ensued. EP will continue to develop output measures and intends to report to the Board on this topic from time to time.

XIII. PRESENTATION OF AWARDS

Dr. Lindberg presented the NLM Director’s Award to Dr. Lucy Ozarin, a volunteer in the History of Medicine Division. She was recognized for outstanding volunteer efforts that improved access to NLM’s resources in the history of medicine and uncovered hidden gems in the historical collection. Ozarin found two inscribed copies of a 1768 dissertation of physician Benjamin Rush, a signer of the Declaration of Independence. Susan Von Braunsberg, a librarian

in the MEDLARS Management Section, received the Frank B. Rogers Award for her dedication, technical proficiency, and outstanding organizational skills related to the creation of electronic versions of citations published before 1966, furthering the NLM mission to provide access to biomedical literature.

Dr. Lindberg presented a certificate to outgoing board member Richard Chabrán.

XIV. THE FUTURE OF BIBLIOGRAPHIC CONTROL

Dr. Deanna Marcum, associate librarian for library services at the Library of Congress (LC), and Diane Boehr, head of cataloging at the National Library of Medicine, discussed a recently published report on the future of bibliographic control in a digital environment.

Dr. Marcum said a project looking at the future of bibliographic control began in 2006. An external working group was created by LC that included representatives from library associations and organizations, the program of cooperative cataloging, plus Google, and Microsoft and two at-large members of the Board. Ms. Boehr was the representative for the MLA. The group began looking at this question: In an era when we can put digital content onto the Web, and people are searching it directly, what is the role of a surrogate, a cataloging record in an online catalog that describes that work?

Marcum said the working group had three major tasks: (1) to present findings on how bibliographic control and other descriptive practices can effectively support management of and access to library materials in the evolving information and technology environment; (2) to recommend ways in which the library community can collectively address some of these problems; and (3) to advise the Library of Congress on its role and priorities. Ms. Boehr summarized the group's findings thus: "The future of bibliographic control will be collaborative, decentralized, international in scope, and Web-based." It will definitely include many stakeholders in addition to libraries.

Ms. Boehr summarized the group's recommendations first on a broad level, and then provided some specifics in more detail. On a broad level, the working group recommends: improving the efficiency of bibliographic record production and maintenance; enhancing access to rare, unique and other special hidden materials; positioning technology for the future; positioning the community for the future; and strengthening the library and information science profession.

More detailed recommendations include: increasing efficiency by sharing responsibility for creating and maintaining bibliographic records; increasing access to hidden collections by digitizing materials when copyright allows; and recognizing the Web as infrastructure, which would require developing a more flexible and extensive metadata carrier compatible with today's Web technology. Ms. Boehr said the report provides a vision and broad directions for the future

rather than a specific implementation plan. The report can be found at <http://www.loc.gov/bibliographic-future/>.

With regard to the report's impact on NLM, Ms. Boehr said implementation of the report's recommendations has the potential to streamline the cataloging process, which would give NLM catalogers more time for tasks such as subject assignment and classification and providing access to NLM's hidden collections. NLM can also pursue research and development projects that would support the goals outlined in the report, e.g., developing automated means of disambiguating authors, crosswalks between the vocabularies of NLM and LC, and experiments with user tagging of bibliographic citations.

Dr. Marcum said she will respond to every recommendation and will report to the American Library Association in June.

In the discussion that followed, Ms. Frierson stressed the importance of recognizing that people now expect simple searching — they expect to go to a search box and find what they want without very much work. Dr. Hirsh noted another challenge is the notion of permanency. He said people are exploring how to come up with permanent metadata so users will know something was an online source and that it will persist as an online source.

XV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Board member Eileen Stanley reported on the Subcommittee on Outreach and Public Information. She said subcommittee did not hold its typical meeting. Instead, members discussed a communication plan for the expanded registration of trials into the clinical trials database, which will include adding results into the database. Stanley said the group had a lively discussion about a communications plan for compliance as well as for conveying the benefits. Some of the suggestions raised by subcommittee members included working with IRBs, the American Association of Medical Colleges, the National Network of Libraries of Medicine, nurses, and public health writers to educate them about the new registration requirements and enhancements to the clinical trials database which will benefit all.

XVI. NIH COUNCIL OF COUNCILS REPORT

Board member Richard Chabrán gave an overview of the NIH Council of Councils. Chabrán serves on this relatively new committee, which is made up of 27 members selected from the NIH Institute and Center advisory groups.

Mr. Chabrán explained the history of the Council of Councils. It was created by the NIH Reform Act of 2006, which also established the use of a common fund to support trans-NIH research. He said the Council guides trans-NIH priorities and is one advisory body in the process and is not

the final decision maker on grants that are funded. The funds are meant to promote new areas of research.

The Council held its inaugural meeting in the spring of 2008. Mr. Chabrán said the agenda is ambitious. He said the databases generated by successful trans-NIH projects may need to be supported beyond the initial funding period and that may have implications for NLM.

XVII. NCBI UPDATE

NCBI Director Dr. David Lipman updated the board on NCBI programs. He started with PubMed Central and the NIH Public Access Policy passed by Congress last year. Dr. Lipman said that the number of journal articles submitted to the PubMed Central digital archive has risen dramatically, now that submission is mandatory for investigators who get NIH funding and publish a peer-reviewed article. Dr. Lipman said he is optimistic that the number of submissions will continue to improve. He was asked if he could expect 100% compliance in 18 months. The NCBI Director said he thinks they could be approaching 100% compliance in two years, with most journals telling authors they will take care of the submission for them. He also said PubMed Central usage grows as more content is entered. There were 16 million page views in April 2008 and 13 million retrievals.

Dr. Lipman then turned to “dbGaP,” which is the database of Genotype and Phenotype. He explained that because of the genome project, there is now the infrastructure to do high-density, high-throughput genotyping of thousands of individuals for a reasonable cost so that investigators can study common diseases that have a hereditary basis. Investigators can begin looking at people affected by the disease, people who are controls, compare and find the blocks of DNA that tend to be associated with the disease.

Dr. Lipman described some of the scientific opportunities this provides. Because NIH has funded a number of studies for a number of years on illnesses such as heart disease, lung disease, mental illness, investigators (with appropriate participant consent) can genotype the participants and look for genetic associations where there is rich phenotypic data. Another benefit is that, in the past, only principal investigators and their collaborators have had access to the data. By creating this consolidated database and making it available to authorized people, more researchers will have access to the information. Thirdly, because genes can be involved in more than one disease, researchers will be able to learn more by accessing all of the information together in one place. Dr. Lipman said they will be getting into a steady state of about 25-30 studies a year in the database. He said that, as this ramps up, there could be hundreds of groups around the world working on this whereas, in the past, there would be one group per study that could lead to new discoveries. He segued into sequencing and showed examples of how next generation sequencing technology generates more information.

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Dr. Lipman then detailed the NLM “Discovery” initiative, to improve the quantity, quality, and relevance of information users get from its databases. The initiative would build quantitative models of how people use our Web sites, modify our pages with explicit goals, and then test the pages and see if the model works. As an example, NCBI looked at how many hits people get to a PubMed query, and why, and where there could be improvement.

Dr. Friedman called the presentation exciting. She asked about computers being used as users, to do number crunching. Will NCBI be doing research in that area? Lipman said they have a two-pronged approach — end users who look and view material, and those who download material to compute.

XVIII. ADJOURNMENT

The Board of Regents meeting was adjourned at 12:00 p.m. on May 14, 2008.

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the February 12-13, 2008 Regents’ Minutes
- Approval of May 12-13, 2009 Meeting Dates
- Delegation of Grant Application Approval to the Board of Regents’ Extramural Programs Subcommittee

Appendix A - Roster - Board of Regents

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

Donald A.B. Lindberg, M.D.
Director, National Library of Medicine

Cynthia C. Morton, Ph.D.
Chair, NLM Board of Regents