

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

**MINUTES OF THE BOARD OF REGENTS  
October 4-5, 2011**

The 158<sup>th</sup> meeting of the Board of Regents was convened on October 4, 2011, 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 4:10 p.m., followed by a closed session for consideration of grant applications until 4:30 p.m. On October 5, the meeting was reopened to the public from 9:00 a.m. until adjournment at 10:30 a.m.

**MEMBERS PRESENT [Appendix A]:**

Ms. Virginia Tanji [Chair], University of Hawaii at Manoa  
Dr. Ronald Evens, Washington University School of Medicine  
Dr. David Fleming, University of Missouri School of Medicine  
Dr. Katherine Gottlieb, Southcentral Foundation  
Dr. Henry Lewis, Florida Memorial University  
Dr. Trudy MacKay, North Carolina State University  
Dr. Joyce Mitchell, University of Utah  
Dr. Ralph Roskies, University of Pittsburgh  
Ms. Mary Ryan, University of Arkansas for Medical Sciences Library  
Dr. Douglas Scutchfield, University of Kentucky College of Public Health

**EX OFFICIO AND ALTERNATE MEMBERS PRESENT:**

Ms. Eleanor Frierson, National Agricultural Library  
Ms. Gail Graham, Veterans Administration  
Dr. Boris Lushniak, Office of the Surgeon General, PHS  
Dr. Deanna Marcum, Library of Congress  
MGEN Kim Siniscalchi, United States Air Force  
Dr. Dale Smith, Uniformed Services University of the Health Sciences  
Dr. Howard Wactlar, National Science Foundation

**CONSULTANTS TO THE BOR PRESENT:**

Dr. Tenley Albright, Massachusetts Institute of Technology  
Dr. Marion Ball, John Hopkins School of Nursing

**SPEAKERS AND INVITED GUESTS PRESENT:**

Dr. Joan Ash, Oregon Health and Science University  
RADM Ann Knebel, Preparedness Planning, Office of the Secretary  
Dr. Isaac Kohane, Harvard Medical School  
Dr. Elaine Martin, University of Massachusetts  
Dr. Myat Htoo Razak, Fogarty International Center, NIH

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

Mrs. Mary Lindberg  
Mr. Thomas West, Krasnow Institute  
Dr. Stephen Weitzman, DataPharm

### **FEDERAL EMPLOYEES PRESENT:**

Dr. Donald A.B. Lindberg, Director, NLM  
Ms. Betsy Humphreys, Deputy Director, NLM  
Dr. Milton Corn, Deputy Director for Research and Education, NLM  
Dr. Sameer Antani, Lister Hill Center, NLM  
Ms. Stacey Arnesen, Division of Specialized Information Services, NLM  
Ms. Joyce Backus, Division of Library Operations, NLM  
Dr. Oliver Bodenreider, Lister Hill Center, NLM  
Ms. Florance Chang, Division of Specialized Information Services, NLM  
Ms. Kathy Cravedi, Office of Communications and Public Liaison, NLM  
Ms. Francesca Crawford, Division of Extramural Programs, NLM  
Mr. Todd Danielson, Executive Office, Office of the Director, NLM  
Mr. Ivor D'Souza, Office of Computing and Communications Systems, NLM  
Ms. Josseline de Saint Just, Division of Extramural Programs, NLM  
Dr. Kathel Dunn, Division of Library Operations, NLM  
Ms. Gale Dutcher, Division of Specialized Information Services, NLM  
Dr. Cathy Fomous, Office of Biotechnology Information, Office of the Director, NIH  
Ms. Allison Fisher, Office of Communications and Public Liaison, NLM  
Dr. Valerie Florance, Division of Extramural Programs, NLM  
Mr. Alan Graeff, National Center for Biotechnology Information, NLM  
Dr. Pertti Hakkinen, Division of Specialized Information Services, NLM  
Ms. Bethany Harris, Office of the Director, NLM  
Dr. Michael Huerta, Office of Health Information Programs Development, NLM  
Ms. Nicole Irby, Office of the Director  
Ms. Christine Ireland, Division of Extramural Programs, NLM  
Ms. Janice Kelly, Division of Specialized Information Services, NLM  
Dr. Mark Kirk, Department of Homeland Security  
Mr. John Koehner, Assistant Secretary for Preparedness and Response, DHHS  
Mr. Sheldon Kotzin, Division of Library Operations, NLM  
Ms. Lisa Lang, Lister Hill Center, NLM  
Dr. Daniel Le, Lister Hill Center, NLM  
Dr. David Lipman, National Center for Biotechnology Information, NLM  
Dr. Donna Maglott, National Center for Biotechnology Information, NLM  
Ms. Adriana Malheiro, National Center for Biotechnology Information, NLM  
Ms. Michele Mason-Coles, Office of the Director, NLM  
Dr. Clement McDonald, Lister Hill Center, NLM  
Ms. Melanie Modlin, Office of Communications & Public Liaison, NLM  
Mr. Dwight Mowery, Division of Extramural Programs, NLM  
Mr. David Nash, Office of the Director, NLM  
Dr. Aaron Navarro, Lister Hill Center, NLM  
Dr. James Ostell, National Center for Biotechnology Information, NLM

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Dr. Dina Paltoo, National Heart, Lung and Blood Institute, NIH  
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 Programs Development, NLM  
Dr. Soumi Ray, Lister Hill Center, NLM  
Ms. Suzy Roy, Office of the Director, NLM  
Dr. Angela Ruffin, Division of Library Operations, NLM  
Mr. Jerry Sheehan, Office of the Director, NLM  
Dr. David Siegel, National Institute of Child Health and Human Development, NIH  
Dr. Elliot Siegel, Consultant, NLM  
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM  
Dr. Alan Vanbiervliet, Division of Extramural Programs, NLM  
Ms. Jessica Van Der Volgen, Office of the Director, NLM  
Ms. Yani Yancey, Office of the Director, NLM  
Dr. Deborah Zarin, Lister Hill Center, NLM

### **I. OPENING REMARKS**

Ms. Virginia Tanji, Chairman of the NLM Board of Regents, welcomed the Regents, alternates, and guests to the 158<sup>th</sup> meeting of the NLM Board of Regents. Ms. Tanji also introduced new members of the Board of Regents and asked each to make brief remarks. They included: Dr. David Fleming, Chairman of Internal Medicine for the University of Missouri; Dr. Henry Lewis, President, Florida Memorial University; Dr. TrudyMacKay, Professor of Genetics and Genomics at North Carolina State University; and Dr. Ralph Roskies, Professor of Physics at the University of Pittsburgh and co-director of the Pittsburgh Supercomputing Center. Ms. Tanji noted that Dr. Regina Benjamin, Surgeon General of the United States, would not be able to present a report at the meeting today.

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

Boris Lushniak, M.D., MPH, RADM, USPHS, Deputy Surgeon General began his report for the Surgeon General by announcing the release of The National Prevention Strategy which stems from provisions of The Healthcare Reform Act related to prevention and established the National Prevention Council under the chairmanship of the Surgeon General. It is a group comprising 17 different federal department agencies with roles in prevention. It was their task to develop The National Prevention Strategy together with advice from an advisory group of nonfederal members. Now, he noted, it will be important to implement the recommendations set forth in the Strategy. This strategy delineates who is responsible for various facets. State, tribal, local and territorial governments, businesses and employers, health care systems, insurers and clinicians, families and individuals all are involved in the implementation of the prevention strategy. The Surgeon General's office will be actively involved in holding our federal partners accountable, encouraging partners to create and execute their own prevention strategy action plans, monitoring and tracking progress and shared successes. He concluded by noting that while this is not a new effort, the Surgeon General's office is excited about the opportunity to renew its commitment to ensuring the health and safety of our people.

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Dr. Lindberg asked how the Surgeon General intended to implement this strategy effectively and whether 30 minutes of walking a day actually produced a significant reduction in diabetes. Dr. Lushniak noted that an approach that works locally will be most effective, something simple that emphasizes school-based physical education programs and reaches our young people. He added that daily physical activity is crucial in our efforts to ward off diabetes and the current obesity trends in younger populations. Other Board members asked what role they can play in the National Prevention Strategy and what resources would be required. Dr. Lushniak said that the Strategy is a living document. He encouraged Board Members to review it and provide feedback. He observed that physicians and our health care systems need to be involved as well.

### **III. MEDICAL EDUCATION PARTNERSHIP INITIATIVE**

Dr. Myat Htoo Razak, Program Director of Fogarty International Center's Division of International Research and Training, discussed the Medical Education Partnership Initiative, or MEPI, which involves countries in Sub-Saharan Africa that receive PEPFAR (President's Emergency Plan for AIDS Relief) support to develop or expand and enhance models of medical education. Dr. Razak explained the goals of MEPI – to increase the number of new healthcare workers by 140,000, strengthen medical education systems in the countries in which they exist and build clinical and research capacity in Africa as part of a retention strategy for faculty of medical schools and clinical professors. He explained that Africa has less than 3% of the world's health workers who address 24% of the global burden of disease. He noted the recent release of the Sub-Saharan African Medical study that states that a quarter of medical graduates leave the country within 5 years. A third of faculty posts are vacant. Thirty percent of faculty must supplement their income. Fifty percent of medical schools are less than 20 years old and a third of new medical schools are private. The need to improve human resources in Africa is great. MEPI was launched in 2010 with support from PEPFAR, and is a fast moving project. PEPFAR and NIH provide funds. About \$130 million for 5 years comes from PEPFAR and \$25 million comes from the different ICs within the NIH. Thirteen African awardees in 12 African countries are developing transformative models of medical education in Sub-Saharan Africa by strengthening clinical and research capacity. The awards are made directly to African PIs. They do have US partners but the US partners are sub-awardees of the African PIs. We have a coordinating center that works with the 13 awardees, but the goal is to have the coordinating center roles transition to African institutions in 5 years. The countries are Botswana, Ethiopia, Ghana, Kenya, Malawi, Mozambique, Nigeria, South Africa, Tanzania, Uganda Zaire, and Zimbabwe. South Africa has two universities, University of KwaZulu-Natal and Stellenbosch University. That is why there are 13 awardees in 12 countries. 73% of the projects focus on TB, malaria and HIV/AIDS. We are working to make sure that all the awardee sites have access to good sources of health information from the NLM as well. NLM has been assisting institutions within MEPI to enhance the online learning and digital library and to explore mechanisms to establish partnerships between MEPI and African Medical Journal Editors.

Board members asked about the status of the MEPI institutions' relationships with the HINARI program for digital access to medical literature. Dr. Razak stated that they are working together. He also noted that MEPI is exploring partnership development with other nonprofits and private organizations as well.

**IV. MAY 2011 MINUTES AND FUTURE MEETINGS**

The Regents approved without change the minutes from the May 2011 meeting. Dates for the February 2012 and May 2012 meetings have already been agreed upon. The fall meeting was set for September 11-12, 2012.

**V. REPORT FROM THE NLM DIRECTOR**

NLM Director Donald A.B. Lindberg began his report by noting that the NLM is formulating its 2013 budget and currently operating on a continuing resolution.

Dr. Lindberg announced the death of Dr. Martin M. Cummings, NLM Director from 1964 to 1983. Under Dr. Cummings' leadership, NLM's mission and programs were greatly expanded to include the Lister Hill Center intramural research program, Specialized Information Services, the Extramural Grant Program, the National Network of Libraries of Medicine, and the international MEDLARS Centers, and the Library launched MEDLINE and many other online databases. A tribute to Dr. Cummings is located on NLM's website at [http://www.nlm.nih.gov/news/cummings\\_death\\_notice.html](http://www.nlm.nih.gov/news/cummings_death_notice.html). A new NLM Web exhibition, "Martin Cummings, MD, and the National Library of Medicine: Documents Online," is scheduled to open in early FY 2012. Dr. Lindberg also announced the death of Dr. William Gardner, the President of the Friends of the NLM and Executive Director of the American Registry of Pathology.

With respect to recent retirements from the NLM, Dr. Lindberg noted that Julia Royall retired from federal service after 14 years at NLM. In 2001, she was made Chief of NLM's Office of International Programs. Focusing on Africa, she created programs which empowered medical librarians, medical journal editors, researchers, clinicians, medical students, healthcare workers and people at the village level for better health. Dr. Lindberg announced the appointment of Ivor D'Souza as Director, Information Systems and Director of NLM's Office of Computers and Communications Systems, Ms. Joyce Backus as the new Deputy Associate Director of Library Operations, Dr. Olivier Bodenreider as Chief of the Lister Hill Center's Cognitive Science Branch, and Ms. Beth Weston as the Deputy Chief of the Technical Services Division of Library Operations. Dr. Kathel Dunn introduced NLM's 2011-2012 Associate Fellows: Ms. Bethany Harris (MSI degree, University of Michigan); Ms. Michele Mason-Coles (MLS, St. John's University, Queens, New York); Ms. Suzy Roy (MLS, Indiana University, IN); and Ms. Jessi Van Der Volgen (MLIS, University of Wisconsin-Madison, WI).

Dr. Clement McDonald introduced three new Lister Hill Center Post-Graduate Fellows: Dr. Michael Cairelli who graduated from Philadelphia College of Osteopathic Medicine, Dr. Hamid Haidarian-Shahri who received his doctoral degree in Computer Science from the University of Maryland, College Park, MD, and Dr. Soumi Ray who received her doctoral degree from the Department of Computer Science and Electrical Engineering at University of Maryland, Baltimore County.

Dr. Lindberg updated the Board about legislative and regulatory issues. He noted that Senator Tom Harkin introduced a resolution congratulating NLM on its 175<sup>th</sup> anniversary. He mentioned that the House Energy and Commerce Committee approved the Pandemic and All-Hazards preparedness Reauthorization Act that establishes a number of programs related to public health preparedness and medical countermeasures. The primary focus of the bill is the Biomedical Advanced Research and Development Authority, which related to procurement of medical countermeasures for use in public

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health emergencies. He also discussed the Research Participant Protection Modernization Act that would provide all human subject research conducted by the HHS to be in accordance with HHS Human Subject Regulations. The agency is now seeking comment on issues raised by the bill's content.

NLM is in charge of the NIH Combined Federal Campaign this year, Dr. Lindberg observed. This annual fundraising drive for NIH is off to a great start with more than 1500 NIH volunteers. This year's motto is "Charity is in our Code!" NLM challenged the Institutes to a photography contest and is asking them to submit their "picture of giving" to the NIH CFC Web site. Winners will be selected during the campaign.

To highlight applications that use NLM information and to encourage more people to take advantage of the NLM's data, NLM held its first software development challenge, "Show Off Your Apps: Innovative Uses of NLM Information," Dr. Lindberg observed. Winners were announced and honored at an awards ceremony hosted by Aneesh Chopra, Chief US Technology Officer and Todd Park, HHS Chief Technology Officer on November 2, 2011. The winning applications are featured on the NLM Web site. Dr. Lindberg noted that NLM Video Search was named a finalist in HHS *Innovates* competition and that the papers of American surgeon Dr. Clarence Dennis (1909-2005) are now on NLM's Profiles in Science web site at <http://profiles.nlm.nih.gov>.

Because of NLM's longstanding interest in the application of artificial intelligence to biomedicine, Dr. Lindberg said he invited IBM's "Watson" team to NLM in September to discuss a future project to answer questions of patients, families, and the public about health care. He also invited researchers from Columbia University and the University of Maryland who are working on Watson-related health project to also present.

Dr. Lindberg stated that the NLM and the University System of Maryland at Shady Grove have entered into non-exclusive collaborative relationships that support mutual interests in medical and health education.

A conference cosponsored by the NLM and the Friends of the NLM was held this spring on clinical trials. This third in a series of conferences, featured remarks by NIH Director Francis Collins about the National Center for Advancing Translational Science and Dr. Deborah Zarin about NLM's role in making clinical trials more transparent. The full conference program and selected speaker presentations are available at [www.fnlm.org](http://www.fnlm.org). Dr. Lindberg mentioned that the annual NLM Informatics Training Conference was held at the NIH on June 28-30, 2011.

Dr. Lindberg concluded his remarks by presenting a news clipping of a blessing of NLM's healing totem in North Dakota during one of its stops on its way to open the new exhibition on "Native Voices: Native People's Concepts of Health and Illness."

## VI. NEW DIRECTIONS: NATIONAL NETWORK OF LIBRARIES OF MEDICINE (NN/LM) CONTRACTS

Dr. Angela Ruffin, head of NLM's Office of the National Network of Libraries of Medicine, reported on the accomplishments of the 2006-2011 contracts that ended on April 30, 2011, and discussed the new areas of emphasis in the NN/LM 2011-2016 contracts.

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2006-2011 accomplishments included the growth in membership by 228 new members. The NN/LM now has 2,600 hospital libraries, 1200 academic libraries, and 2,000 libraries of other types, including public libraries. The Regional Medical Libraries (RMLs), under contract to NLM, funded over 1,700 outreach projects during the last contract and continue to do a tremendous amount of training, conducting over 600 webinars and developing 158 classes.

The 2011-2016 NN/LM contracts, which began May 1, feature several new emphases. There is a stronger focus on encouraging NN/LM Academic Health Sciences Libraries to propose outreach projects that promote the roles of libraries in institutions with NIH Clinical Translational Science Awards, e-science or computationally intensive science initiatives, evidence-based health information, and the electronic/Personal Health Record and MedlinePlus Connect. The RMLs will develop programs with the Regional Extension Centers, established by HHS to assist providers in adopting and using electronic health records (EHRs), and expand its outreach programs to reach health practitioners and students in community colleges and vocational schools, and institutions and organizations that focus on educating Native Hawaiians and Alaska Natives. The NN/LM will also participate in NLM's national cooperative medical journals print retention program to ensure the preservation and continued access to older literature.

Dr. Ruffin introduced Dr. Elaine Martin, Director of the New England Regional (NER) Medical Library at the University of Massachusetts, who discussed two projects that the NER has initiated. One provides access to full-text information to public health workers in state public health departments, under special rates negotiated with participating publishers. The second focuses on e-science and preparing librarians for roles related to the management of scientific data. An example is assisting researchers in developing the data management plans now required in NSF grant applications. Both the public health and e-science initiatives reach beyond the NER and have implications for all of the NN/LM.

Board member Mary Ryan expressed support for the projects and asked how much science does a librarian need to know in years to come? Dr. Martin noted that they are looking at people who are already in the field and moving them into these new roles. Dr. Kohane commented that another approach is to move scientists into the library context. Other Board members applauded the E-science initiative. Dr. Roskies commented that it had not occurred to him to consider the library as a source of assistance in preparing data management plans.

### **VII. PRESENTATION OF REGENTS' AWARD**

Ms. Tanji presented the Regents Award for Scholarship or Technical Achievement to Dr. Daniel Le, an electronics engineer in the Communications Engineering Branch of the LHCNB C. He led the design and development of a system that significantly reduces the level of human effort required to review and add data elements missing from the XML citations provided directly by publishers for articles indexed in MEDLINE and PubMed.

### **VIII. GENETIC TESTING REGISTRY AND CLINVAR**

Dr. James Ostell of the National Center for Biotechnology Information (NCBI) discussed the Genetic Testing Registry (GTR), project overseen by the NIH Office of the Director, which is being developed and implemented by NCBI. GTR is a result of an HHS advisory committee report that reviewed genetic

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testing and called for greater transparency. Some basic facts of assays of genetic disease were not well documented in commercial testing. Those basic facts were: analytical validity (can the test accurately measure the mutation in question); clinical validity (does this assay accurately predict a disease or condition); clinical utility (if it's determined a person has or is predisposed to a disease or condition, can anything be done to affect his/her health care).

Dr. Ostell explained GTR's basic design. The core unit is a particular test or protocol so that GTR is literally a registry of tests certified by a laboratory. The first version of the registry, which began running this summer, consists of three databases: GeneTests (an NCBI-hosted database of laboratories that test for diseases against genetic material usually); GTR; and ClinVar (a database about clinical variation). ClinVar is essentially a collection of assertions made by different sources about the relationship between a variation in the genome and a clinical consequence. It's also the source of standard disease names. There's an agreement to use SNOMED CT (Systematized Nomenclature of Medicine—Clinical Terms) for the names of genetic diseases so that users pick from a controlled vocabulary. By tying into SNOMED, and hopefully known variants and established references, GTR can tie into electronic medical records and begin to build out something.

Using a preview site, Dr. Ostell gave an overview of ClinVar and GTR and showed off a number of features. Users can search by laboratories, genes, tests, conditions and phenotypes. Disease pages contain links to a number of resources for scientists, physicians and consumers including PubMed, ClinicalTrials.gov, Genetics Home Reference, MedlinePlus.gov, and links to practice guidelines. Every test in GTR has an accession number, a version, and the last date it was updated. That creates a history so the tests can become identified items, like a PubMed record, so people can actually write about a particular version of the test, publish it, and have a trail back to the version of the test that was evaluated. The main page of the test record includes a number of items from which users can choose including: how to order the tests; indications for giving the test; methodology; and performance characteristics.

In the question period following the presentation, Dr. Joyce Mitchell and Dr. David Fleming applauded the work on the registry. Dr. Mitchell pointed out the challenge of dealing with millions of variants. Dr. Ostell said the technical challenge will be figuring out what the variants mean. Dr. Fleming noted that submissions are voluntary. Dr. Ostell said the report he referenced earlier did recommend it be mandatory, but NIH is not a regulatory agency. Dr. Fleming also asked about providing guidance to consumers on how to utilize genetic information. Dr. Ostell said the first version of GTR, while it is a public site, it is targeted at professionals. However they do link to consumer sites like Genetics Home Reference where there are references to patient advocacy and support groups for example.

## **IX. LHC BOARD OF SCIENTIFIC COUNSELORS REPORT**

Dr. Joan Ash, a professor at Oregon Health Sciences University and chair of the Lister Hill Center Board of Scientific Counselors (BoSC), described the Board's recent work. BoSC members have expertise that runs the gamut of informatics and information systems. They meet twice a year to make recommendations on Lister Hill projects.

In April 2010, the LHC BoSC evaluated two projects. One focused on quality assurance for terminologies and ontologies. Dr. Ash said there's good reason to do this research because errors in the terminologies do happen and can, for example, mean that the wrong drug is delivered to a patient. The

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LHC group is doing automated auditing to find out about discrepancies and what to do about them. The BoSC recommended the group continue its international leadership and strong collaboration and encouraged the group to expand its reach. The BoSC recommended the group share its tools for self quality assurance; serve the clinical decision support community; and do evaluation in a clinical context so the research team can see what's happening and how they can help. The second project the BoSC evaluated in 2010 studied online prescription data use in emergency care during a disaster situation. The study was done in collaboration with nearby Suburban Hospital. LHC scientists addressed the problem of medication reconciliation in emergency departments, which is extremely hard. The team compared manual lists of prescriptions that emergency department patients said they were taking to data from Surescripts. Surescripts bundles prescription data from many pharmacies and is supposed to be a good list of what a patient actually is taking. The team found the prescription history from Surescripts would indeed be valuable in disaster situations and also in regular emergency care. The BoSC recommended the team expand the study to find out why there are differences in the prescription drug information being reported and to look at presentation/visualization issues that could help clinicians. The BoSC also recommended expanding the research team.

In September 2010, the BoSC reviewed the "Openi" project to improve information retrieval. The team is exploring how to improve information retrieval in PubMed Central by targeting visual content in addition to text. Researchers are relating patient information to the image in the literature. The BoSC recommended engaging users, both clinicians and patients; scaling up; keep publishing; making tools available; and collaborating with other interested researchers.

In April 2011, the BoSC offered recommendations on a portfolio of projects related to moving, managing and mining clinical data for care and research.

LOINC (Logical Observation Identifiers Names and Codes), which started out mainly as a vocabulary for lab tests, now has more than 60,000 terms and has become an international standard. The board is encouraging more evaluation of LOINC. The board wants to broaden the scope and share the tools in a data mining project involving a large database of de-identified patient data. The BoSC is pushing for collaboration on the NLM Scrubber, which is used to de-identify text. The BoSC is urging continuation of an image analysis project in Kenya that involves portable X-rays because it is important for global health initiatives. The BoSC says it's time to start engaging users in the personal health record project.

Following the presentation, Dr. Trudy MacKay, asked whether the BoSC just reacts to what's being studied or tries to jump start new directions for research. Dr. Ash said the BoSC does brainstorm and raise ideas for the future. Dr. Ralph Roskies asked how the BoSC distinguishes between the projects that the Lister Hill Center undertakes and the projects you'd expect to fund in the extramural program. Dr. Ash said BoSC members have been extramural researchers and believe the Lister Hill investigators can probably take more risk than extramural researchers because outside researchers are always looking for the next grant. Dr. Joyce Mitchell noted that there seems to be an opportunity for the LHC to work with NCBI on projects. Dr. Ash agreed and said the BoSC keeps pushing collaborations within the library.

## **X. INFORMATICS FOR INTEGRATING BIOLOGY AND THE BEDSIDE**

Dr. Isaac S. Kohane, of Harvard University, discussed his funded project, Informatics for Integrating Biology and the Bedside (I2B2). Dr. Kohane said his 2003 I2B2 grant was unusual at the time because

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many people were looking into systems biology, while he was looking at our health care system as a whole. He and his partner, who was then the CIO at a health care system, asked the following question: “Can we use our very expensive health care system, which is investing more and more in information technology, can we use that expensive investment in health care and the documentation of health care to run the discovery research using the informational byproducts of healthcare and the biological projects of health care?” He said there was skepticism and that it was something of a bet that observational data out of health care systems would be valuable. Then he described I2B2 results demonstrating the value. He showed a slide with 1997-2006 data from two hospitals indicating an 18% increase in heart attacks. He said no one knew about that until his study. His slide noted the increase happened in between the time the drug Vioxx was introduced and withdrawn. He also said FDA hearings into the drug Avandia cited the I2B2 study among others. As another example, Dr. Kohane presented a slide showing the numerous stops one patient made in the health care system—for respiratory, eye and dental problems—before finally receiving a diagnosis of domestic abuse. He said with his tools, he was able to identify domestic abuse two years before anybody else in the health care system. He emphasized that there is important data in our health care system and it is under-exploited because we haven’t had the tools to introspect.

Dr. Kohane said I2B2 has had success beyond those results because his team has made it possible for hospital administrators, scientists, geneticists and clinical researchers to introspect into these large data sets. The challenge, he said, is to efficiently reach large numbers for population studies. He said the costs for studies of one million people would come from: high throughput genotyping; high throughput phenotyping; and high throughput sample acquisition. Dr. Kohane said his team has developed a free and open source tool kit (software) for I2B2. More than 60 academic health centers, and 12 international users, have adopted I2B2 to introspect their own systems. “A bunch” of small companies are making millions of dollars installing the software to pull the data out of electronic medical record systems.

Dr. Kohane argued his team has enabled a new mode of population research, Electronic Health Record Driven Genomic Research (EDGR). He said EDGR has several advantages: timeliness (you can immediately take data out of the health system); clinical relevance; underserved populations (they are under-represented in many cohorts yet over-represented in tertiary health care systems); controls; comorbidity recognition. By looking down at electronic health records in a phenome-wide association study, you can actually see all the phenotypic features of a variant, so the electronic health record is enabling a completely different kind of research.

I2B2 also looked at whether genetics and clinical factors could be used to predict things like healthcare utilization. Using “smoking history in asthmatics” as an example, Dr. Kohane said with natural language processing they were able to get better than 95% predictive values to stratify patients by medications, by family history, pulmonary function and by a variety of exposures like smoking. Dr. Kohane said I2B2 is faster and cheaper—it’s what’s been called disruptive technology—his team has actually disrupted population studies and that’s why so many people are picking this up. Dr. Kohane gave a timeline for the use of electronic health records in human disease genomics. He said, among other things, he’s hoping for standardized consent for this kind of research by 2016 and he predicted by 2018 genomic data will be entered into electronic health records for clinical reasons, not research purposes. He then discussed the challenges: consent; cost of EHRs; quality of EHR data; lack of family history codification; lack of EHR standardization; cultural gulf between clinical informatics and bioinformatics. Dr. Kohane also discussed the Shared Health Research Informatics Network (SHRIN), which allows searching routine clinical records from five major hospitals for: demographics, diagnosis, medications, and lab results. Data are

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exported from hospitals, imported into I2B2, hospital i2b2 systems are connected with a secure network and enforce agreed-upon usage rules. He said they have a national network about to form based on the bottom up investment NLM has made.

In questions and answers that followed, Dr. Henry Lewis inquired about the possibility of analyzing more minority patients. Dr. Kohane said this is a way to study under-served populations cost-effectively where they actually are getting their care.

Dr. David Fleming asked about consent and how the patients who do participate get access to the data. Dr. Kohane said we created a system called informed cohort where we give all the data to the patient and the anonymized database.

### XI. EXTRAMURAL PROGRAMS REPORT

Dr. Valerie Florance, Director of Extramural Programs, discussed a recent NIH study published in *Science* magazine that looked at the relationship between self-identified race and ethnicity and the probability of getting an NIH R01 research grant. The study examined NIH R01 research grants awarded from 2000 to 2006, the principal investigators of which were PhDs. The hypothesis was that scientists of different races and ethnicities with similar research records and affiliations would have a similar likelihood of getting a research grant. The study found that proposals with good scores were equally likely to be funded, but Asians were 4% and black or African American applicants were 13% less likely to receive grants than whites. When controlling for background and employer, the researchers still found a 10% disadvantage for black applicants. Other findings: Blacks and Asian Americans resubmitted their applications more times before getting an award, but they were also less likely to resubmit; NIH fellowships or training improved chances getting scored, but didn't mitigate the difference in award probability; and traditional measures of scientific achievement for the PI didn't translate to the same level of success across these groups. Dr. Florance said NIH believes in part that subtle reviewer bias could be at work. More studies are going forward and there will be pilots of review where there's an attempt to de-identify the applications to control for bias.

Because NLM reviews about 80 percent of its research grants, the Library got its own data to look at separately. NLM had 878 applications during the study period, compared to 83,188 for NIH. NLM had: more applications from Asian Americans, Blacks and African Americans; fewer for Hispanic Americans; none from Native Americans; fewer from Whites; and more people who chose not to declare their race or ethnicity. Dr. Florance said for the NLM applicants during the 2000 to 2006 period, the experience was different than NIH. The success rates for white and black applicants were comparable, but the success rate for Asian Americans was worse for NLM. It will take more analysis to find out why.

In discussion after the presentation, Dr. Lindberg said the grants are funded in the order of their priority. If there's something going wrong, it's happening at the study section level and not at the level of NIH, the Institutes or his office. Dr. Lewis commented that NLM was to be commended for looking into the issue.

Dr. Florance also told the Board that EP is developing a framework to evaluate the career outcomes for NLM- funded trainees and post-doctoral fellows. EP has done focus groups with trainees and training faculty to get advice.

## **XII. CHEMM: A COMPREHENSIVE NEW NLM/ASPR TOOL TO MANAGE CHEMICAL EMERGENCIES**

NLM Associate Director for Specialized Information Services (SIS) Steven J. Phillips, MD, next addressed the Board. Making the point that access to information and communication of that information is critical during emergencies, he discussed NLM's long history of work in disaster preparedness and response, and the many efforts by NLM and its National Network of Libraries of Medicine to create and share resources. The Emergency Access Initiative, for example, offers emergency responders free access to pertinent books and journals when local sources of information are disrupted. ToxMap, a geographic information system, uses maps to show the amount and location of toxic chemicals released into the environment. (In the aftermath of the east coast earthquake in August, SIS is adding the location of nuclear power plants to ToxMap.)

He then described NLM's "disaster-response triad." WISER (Wireless Information System for Emergency Responders) is a popular tool for emergency responders. Based on the emergency response guidebook that all HazMat and emergency responders use, it contains, to date, 438 chemicals and related radiologic and biologic information. WISER has an occupation pull-down menu, so that EMTs, HazMat professionals and others can quickly access the information they need. REMM (Radiation Emergency Medical Management) and CHEMM (Chemical Hazards Emergency Medical Management) have more recently been added to the suite of NLM disaster resources. Dr. Phillips next introduced Rear Admiral Ann Knebel, Deputy Director for Plans and Preparedness in the Office of the Assistant Secretary for Preparedness and Response (ASPR), U.S. Department of Health and Human Services. She is the principal advisor to the Assistant Secretary and Deputy Secretary and is responsible for developing plans and programs to enhance preparedness across local, state, regional and tribal lines. During response operations, RADM Knebel serves as the plans section chief on the HHS Emergency Management group.

RADM Knebel said that her presentation would highlight the collaboration that has been ongoing between ASPR and NLM in recent years, and the unique skills and abilities that NLM brings to disaster preparedness and response. The Assistant Secretary and head of ASPR is Dr. Nicole Lurie, and the office's mission is to prevent, prepare for, respond to and assist the nation to recover from the adverse health effects of emergencies and disasters. The Pandemic and All Hazards Preparedness Act (PAHPA) required the creation of the National Health Security Strategy and ASPR drafted that document. This was the first time that the government made the connection between health and security. PAHPA makes the important point that health security revolves around building community resilience and strengthening and sustaining the health and emergency response systems of the nation. The goals of national health security are supported by ten strategic objectives. Several of these relate to the unique skills and abilities that NLM can bring to bear: informed and empowered individuals and communities; science evaluation and quality improvement; and timely and effective communications.

NLM's Disaster Information Management Research Center (DIMRC) works to ensure access to information during disasters and conducts research to develop strategies for doing so. DIMRC has information tools and research support that come together to support resilient communities that can recover faster from disasters. She next discussed REMM, crediting staff from ASPR, NLM and the National Cancer Institute who have made this tool available. Launched in 2007, REMM is the toolkit for medical response to radiation emergencies. Several years ago, the nation's preparedness for radiation emergency was minimal, but REMM constitutes a major step forward. REMM provides guidance for

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health care providers. It is targeted primarily to physicians and deals with the clinical diagnosis and treatment of radiation injuries.

The information in REMM is downloadable in advance, so that if the Internet isn't available responders can still access it. Of course, the information is constantly being updated. REMM currently contains 350 pages, 100+ of which are multi-media assets. Like WISER, REMM can be downloaded to a mobile device, so that the information is readily available almost everywhere. REMM takes complicated information and distills it down to the basics, also making best use of animations, illustrations and photos.

One of the things to be expected in a catastrophic event like nuclear detonation would be a shortage of life-saving materials. The creators of REMM have had subject matter experts willing to work with them to develop guidance for dealing with this challenge. Following the Fukushima radiation event in Japan, the REMM Web site saw a spike in hits, as well as downloads with iPhone applications. So these resources are clearly being put to use in real world events. In fact, certain pages of the REMM site were translated into Japanese, so that people could get quick access to the information.

RADM Knebel next mentioned CHEMM, acknowledging contributors from ASPR and NLM, as well as the National Institute of Child Health & Human Development (NICHD) and the Department of Homeland Security (DHS). Work on CHEMM began in 2008 and it was released to the public in July of this year. Other collaborators include the Centers for Disease Control and Prevention (CDC), and the National Oceanic and Atmospheric Administration (NOAA).

CHEMM fills a unique niche, providing information on the medical management of patients who have been exposed to the broad range of chemicals. Like REMM, CHEMM is available live on the Web. CHEMM provides just-in-time, evidence-based information that is very usable in terms of telling people what to do in situations where there is often a dearth of information. It can be downloaded to any PC or Mac, and SmartPhone applications are being developed. There has been extensive outreach about CHEMM to emergency responders, HazMat experts, clinical toxicologist, industrial hygienists and others. As with WISER, information is targeted to the profession of the person accessing the information.

RADM Knebel next introduced the CHEMM Intelligent Syndromes Tool (CHEMMIST). Unlike similar tools, CHEMMIST starts with symptoms and works backwards from there to the chemical group that the person may have been exposed to. The Acute Patient Care Guidelines provide detailed, step-by-step medical management guidelines, not only for first responders on the scene but also for providers at the hospital.

Dr. Mark Kirk, a practicing emergency physician and medical toxicologist with the DHS Office of Health Affairs, then demonstrated CHEMMIST. In a typical chemical attack, many people suddenly fall ill and there is no immediate confirmation of the substance released. In Tokyo, during the 1995 attack on the subways, there was a 2.5-hour gap from the time the release of sarin, a nerve agent which caused almost immediate symptoms and killed several people, and local hospitals' confirmation of the cause. CHEMMIST is designed to fill that gap. It helps first responders and emergency department personnel feel confident about the decisions they make early on.

The first part of the process presents a question with several choices. It's intended for someone who is at the bedside or kneeling over a patient. The second part is a syndrome prediction, and there are over

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70,000 chemicals in the system that might match those syndromes. Importantly, antidotes are also provided. The third part of this is the progress bar. Dr. Kirk showed a typical example, capturing the symptoms of a 43-year-old woman involved in a subway station. He went through the CHEMMIST process, answering questions, and in short order had sufficient information to allow a medical professional to take action. In addition to its serving as a practical guide to coping with disasters, CHEMMIST is also an excellent teaching tool, which includes a number of disaster scenarios.

Dr. David Siegel, a pediatric emergency care physician and pediatric hospitalist from NICHHD, then demonstrated the Acute Care Patient Guidelines component of the CHEMM Web site. A major focus of the Web site is special populations, including children, pregnant women, and the elderly. You first select your profession, like “first responder.” The next part is “acute management overview”—the site offers a comprehensive step-by-step guide that takes users through the entire process, from the time they meet the patient in the hot zone, identify the chemical, provide rescue, decontamination, protection and health care. In another part of the site, “ABC Reminders,” users find links to information about basic and advanced life support. The advanced treatment section for the hospital provides step-by-step management guidelines for taking care of children, adults and seniors. There are very few resources out there that provide this knowledge base. Dr. Siegel invited the Board to look at the site.

RADM Knebel added that, for next steps, the creators of REMM and CHEMM want to continue to sustain and develop the resources, continue to engage with experts to keep the content up to date and ensure that the information is available on mobile devices. They want to create similar tools for scenarios such as terrorists’ use of explosives, as well as biological agents and are exploring options for offering continuing education. She then asked the Board, given the government’s current fiscal constraints—what other collaborations and novel sources of funding might we look at to sustain the work that’s been done?

Dr. Scutchfield asked whether the team had actually worked with Japanese officials, following the 2011 radiation emergency. Yes, Dr. Norm Coleman who was instrumental in developing REMM, was in Japan providing advice during the Fukushima accident. The validation of REMM has been gratifying and the site’s information was quite useful to the Japanese during their response.

Also, he said he wondered whether they have thought about a comparable tool for biological warfare and biological exposure. RADM Knebel said that they had not moved in to the biological realm yet. That will certainly be one of their priorities for the future, though, along with terrorists’ use of explosives.

Finally, regarding RADM Knebel’s question about possible partnerships, Dr. Scutchfield continued, you might be able to take advantage of businesses concerned with chemical exposures and partner with them. When chemical explosions hit plants or other facilities, there can be serious financial consequence to nearby businesses. Have they had any discussions on, for example, looking to the US Chamber of Commerce or others on possible partnerships?

RADM Knebel said she appreciated the suggestion about engaging with private industry for support and enhancement of CHEMM, because their major concern is to make sure that the information available is the most up-to-date and available across all mobile platforms.

Dr. Scutchfield observed that the US has a tendency to neglect things until a serious problem arises, and then suddenly pour considerable money into it. The problem with PAHPA is that it was well funded after

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9/11, but the situation of US public health preparedness has deteriorated substantially since. RADM Ann Knebel agreed. We as a country have a short memory and people move on to other things and budgets get tight. Sadly, preparedness is one of the first things that get cut.

Dr. Lindberg asked how close science is to coming up with something that would actually help the people in Fukushima who volunteered to go in and shut stuff down in the nuclear plants there? RADM Ann Knebel replied that a major risk of going into the hot zone is cancer long term. There was lots of discussion during the Fukushima accident about whether or not potassium iodide would protect the thyroid from cancer in this situation.

Dr. Roskies mentioned that, during this discussion, he Googled chemical emergency and CHEMM comes up as the 7<sup>th</sup> site listed. Above it were CDC and FEMA Web sites. Is there coordination between CHEMM and these Web sites? Yes, RADM Ann Knebel replied, they have worked very closely with CDC and FEMA as partners in the development of CHEMM. CHEMM, however, is focused on the medical management piece and providing a different way of looking at just-in-time information to manage patients. So, while the collaborations with other agencies have been helpful and important, CHEMM occupies a unique niche.

In closing, Dr. Lindberg asked what would be of most help to move the important work of ASPR, and specifically CHEMM, forward. RADM Ann Knebel replied that a stable source of funding would be the most important thing. The collaboration of ASPR and NLM have been invaluable, and brought about excellent results, but her biggest concern is that they won't be able to sustain what they have built, or to expand beyond what we have already done.

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

Subcommittee Chair Virginia Tanji reported on the group's meeting yesterday morning. As one way of introducing the public to NLM resources, the group has proposed working with health benefit managers at employee benefit programs, giving them free, reliable and important information. Gale Dutcher of SIS reported on a pilot effort along similar lines (2006-2007), in which they cold called corporations in the area, offering NLM resources. It was very labor intensive. They did 50 calls and finally met with 17 companies. However, Ms. Dutcher reported, this type of engagement does have great potential, and companies were interested and enthusiastic, once they understood what was available. Board consultant Dr. Marion Ball recommended working through organizations that have medical directors, such as IBM, as a way of getting a foot in the door and then establishing a relationship with the human resources department. NLM consultant Dr Elliot Siegel suggested another approach, talking to benefit managers about the prospect of subscriptions to MedlinePlus magazine for their employees.

NNO Director Dr. Angela Ruffin updated the group on the work done by the National Network of Libraries of Medicine out in the field, to also expand NLM's reach. This has already started in the Washington state area with the Puget Sound Alliance. This project shows how there is potential for small grants being available to NN/LM members to reach out to benefit managers in local areas.

The subcommittee heard an update on the "Show Off Your Apps" contest from Dianne Babski, head of the Medlars Management Section, who led this project. The contest was posted in the challenge.gov Web

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site, because this is where many app developers look for opportunities. News of the apps contest also went out via social media. The response was gratifying. There were 42 submissions, using 20 different NLM data sources. Ms. Babski reported that NLM is considering ideas for future challenges. Next, Dr. Robert Logan from OCPL talked about the Association of Health Care Journalists (AHCJ) Fellows who are at NLM this week. This is third year of that program and this year's group represents such organizations as *PBS News Hour*, CNN and *The Boston Globe*. They get extensive training in use of the NLM databases and hear from a wide variety of speakers from NLM and NIH.

Next, the group saw a wonderful compilation of the news coverage of the healing totem voyage. Someone then asked about the type of K-12 information that is available on the NLM Web site and, as it turns out, there is plenty. The environmental talks, ToxMystery and there is a page on resources for teachers. Developing resources that will inspire future scientists, librarians, health professionals is an ongoing activity, but great progress has been made. It was a very nice meeting.

Dr. Lindberg commended the Outreach Subcommittee for seeing something that needs to be done and setting about doing it. An idea is one thing but getting something accomplished is another matter.

Ms. Tanji replied that she thought the CHEMM database would be perfect for a "Hawaii Five-O" segment. She hoped to find the right connections in her home state, so that the popular TV series could be pitched the idea. Continuing with the idea of focusing on employee benefit managers, she asked whether any Board members with ties to large companies could let her know, as this is vastly more successful an entry point than making cold calls.

Dr. Scutchfield pointed out that the American College of Occupational and Environmental Medicine is basically the medical directors of all of the major companies. They're doctors. Most of them have quit taking care of people on the plant floor and are now advising the HR people on what benefit structures to create. He encouraged the Outreach Subcommittee to talk to people from that group.

Dr. Ball added that NLM has got a great list through its connection with some of the users of Epic's EHR. Epic founder Judy Faulkner has been to NLM and is a great advocate of the Library. Another good contact would be Paul Grundy, the medical director of IBM Corporation. NLM could probably find the employee benefit managers of the IT companies through HIMSS (Healthcare Information and Management Systems Society). Ms. Tanji noted that these were very good ideas and the Subcommittee would follow through.

In its discussion, the group agreed on the importance of personal contacts, in spreading word of NLM products and services to employee benefit managers and others. Ms. Tanji said, though, that some of that work is already underway. For example, Dr. Martin Harris, former NLM Board chair and chief information officer of the Cleveland Clinic, has been involved in connecting Epic with a lot of the NLM databases. Ms. Ryan said that she had a thought about the use of CHEMM and how to promote it: to look at the companies that are the most responsible for chemical hazards. In Arkansas, for example, it's the railroads. Those trains are always derailing and that's one of biggest chemical problems in Arkansas, along with the pesticides dropped by planes which are "cropdusting" the fields and end up dusting our cars with chemicals as well. If NLM were to look at the companies that are the most responsible for chemical accident exposures in the US, that might be a natural focus for promoting the use of CHEMM.

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Perhaps some would come up with money to limit their liability in those chemical accidents. So the Library might want to work through them to get to the medical directors of those companies. The better those people who are exposed get treated, the more the liability will be limited for those companies. They might really see an effect on the bottom line.

### **XIV. ADJOURNMENT**

The Board of Regents meeting was adjourned at 10:30 a.m. on October 5, 2011.

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

- Approval of the May 3-4, 2011 Board Minutes
- Approval of the September 11-12, 2012 Future Meeting Dates

Appendix A - Roster - Board of Regents

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

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

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Virginia Tanji, M.S.L.S., MED  
Chair, NLM Board of Regents