

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

**MINUTES OF THE BOARD OF REGENTS
May 13, 2014**

The 166th meeting of the Board of Regents was convened on May 13, 2014, 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 4:25 p.m., followed by a closed session for consideration of grant applications until 4:45 p.m.

MEMBERS PRESENT [Appendix A]:

Dr. Ronald Evens [Chair], Washington University School of Medicine
Dr. Katherine Gottlieb, Southcentral Foundation
Dr. Robert Greenes, Arizona State University
Dr. Trudy MacKay, North Carolina State University
Ms. Mary Ryan, University of Arkansas for Medical Sciences Library
Dr. F. Douglas Scutchfield, University of Kentucky College of Public Health
Ms. Gail Yokote, University of California, Davis

MEMBERS NOT PRESENT:

Dr. David Fleming, University of Missouri School of Medicine
Dr. Henry Lewis, American University of Health Sciences
Dr. Ralph Roskies, University of Pittsburgh

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Mr. Christopher Cole, National Agricultural Library
Dr. Joseph Francis, Veterans Health Administration
MGEN Dorothy Hogg, United States Air Force
Capt. Paul Jung, Office of the Surgeon General, PHS
Ms. Kathryn Mendenhall, Library of Congress
Col. Cathy Nace, United States 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
Dr. Holly Buchanan, University of New Mexico
Dr. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:

Dr. Philip Alberti, Association of American Medical Colleges
Dr. Philip Bourne, Associate Director for Data Science, NIH
Dr. Erin Holve, Academic Health
Dr. Steve Musser, Food and Drug Administration

May 13, 2014 – Board of Regents

Dr. William Pearson, University of Virginia

MEMBERS OF THE PUBLIC PRESENT:

Mr. Glen Campbell, Friends of the National Library of Medicine
Dr. Dennis Cryer, Friends of the National Library of Medicine
Dr. Lynne Holden, Friends of the National Library of Medicine
Mary Lindberg
Dr. Barbara Redman, Friends of the National Library of Medicine
Dr. Elliot Siegel, Consultant
Ms. Emily Tyrell, Southcentral Foundation
Mr. Thomas West, Krasnow Institute

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. Michael Ackerman, Lister Hill Center, NLM
Dr. Sameer Antani, Lister Hill Center, 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
Dr. Dennis Benson, National Center for Biotechnology Information, NLM
Dr. Dana Casciotti, Office of Health Information Programs Development, NLM
Ms. Kathleen Cravedi, Office of Communications and Public Liaison, NLM
Ms. Francesca Crawford, Division of Extramural Programs, NLM
Mr. Todd Danielson, Office of the Director, NLM
Mr. Mark de Jong, Division of Library Operation, NLM
Mr. Ivor D'Souza, Office of Computer and Communications Systems, NLM
Ms. Gale Dutcher, Division of Specialized Information Services, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Dr. Dan Gerendasy, Office of Health Information Programs Development, NLM
Dr. Zoe Huang, Division of Extramural Programs, NLM
Dr. Michael Huerta, Office of Health Information Programs Development, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Dr. David Lipman, National Center for Biotechnology Information, NLM
Dr. Robert Logan, Office of Communications and Public Liaison, NLM
Dr. Alexandros Karagyris, Lister Hill Center, NLM
Ms. Janice Kelly, Division of Specialized Information Services, NLM
Ms. Lisa Lang, Division of Library Operations, NLM
Dr. Clement McDonald, Lister Hill Center, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Mr. David Nash, Office of the Director, NLM
Mr. Benjamin Peterson, Division of Library Operations, NLM
Dr. Steven Phillips, Division of Specialized Information Services, NLM
Dr. Barbara Rapp, Office of Health Information Programs Development, NLM
Dr. Jeffrey Reznick, Division of Library Operations, NLM

May 13, 2014 – Board of Regents

Mr. Jerry Sheehan, Office of the Director, NLM
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
Dr. George Thoma, Lister Hill Center, NLM
Dr. Raymonde Uy, Lister Hill Center, NLM
Dr. Fred Wood, Office of Health Information Programs Development, NLM
Dr. Jane Ye, Division of Extramural Programs, NLM
Dr. Deborah Zarin, Lister Hill Center, NLM
Ms. Janet Zipser, Division of Library Operations, NLM

I. OPENING REMARKS

Dr. Ronald Evens, NLM Board of Regents Chair, welcomed the Regents, alternates and guests to the 166th meeting of the Board. He then introduced Captain Paul Jung, Chief of Staff, Office of the Surgeon General (OSG).

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

Capt. Paul Jung briefed the Board about two main activities in the OSG. First, he discussed the 50th Anniversary of the OSG's report on smoking. In 1964, then Surgeon General Luther Terry issued a groundbreaking report on smoking and convened a group to assemble the best scientific evidence on smoking and health. The report identified smoking as a causal factor in lung cancer in men and concluded that smoking was a health hazard. On January 11, 2014, the day of the anniversary of the Surgeon General's first report on smoking, the OSG went to Luther Terry's gravesite at Arlington National Cemetery to commemorate the historic day. Later that week, on January 17, the OSG released the 50th anniversary *Report on Smoking and Health* at the White House. The report covered three major topics: historical trend information on tobacco use over the past 50 years; new findings; and a call to action to end tobacco use in the US. He noted that since 1962, over 20 million lives have been lost to smoking and its ill effects. A campaign to end smoking, *Enough is Enough*, became the catch phrase for OSG's renewed efforts to end smoking.

Second, Capt. Jung discussed four calls to action initiated by the OSG. The first is a Call to Action to prevent skin cancer, the most commonly diagnosed cancer in the United States. The second one is a Call for Action to prevent prescription drug abuse among youth. In 2011, about 20% of adolescents between the years of 12 and 25 reported abusing a prescription. The third is a Call to Action to promote and support walking and walk-able communities. Less than half of the US adults meet 2008 physical activity guidelines. Finally, the fourth is a call to action for medication adherence. There are 133 million adults living with a chronic illness for which a prescription medication is required. Yet, studies show that about half of all medications prescribed are not taken as directed. All of these four calls to action are in the pipeline and should be out soon.

Dr. Evens noted that in the 1930s, the Washington University recruited a thoracic surgeon who collaborated on the first successful removal of a lung to treat cancer caused by cigarettes. He later conducted the first systematic research on the carcinogenic effects of cigarette smoking. The results were published in a 1950 *JAMA* paper.

May 13, 2014 – Board of Regents

Another Board member asked Capt. Jung if the OSG had considered extending the call to action to prevent prescription drug abuse to alcohol abuse as well. Capt. Jung said that the OSG's call to action was limited to drug medication abuse and did not extend to alcohol. But, a future call to action to prevent alcohol abuse is possible.

III. FEBRUARY 2014 MINUTES AND FUTURE MEETINGS

The Regents approved without change the minutes from the February 11-12, 2014 meeting. The 2015 spring meeting will take place on May 12-13, 2015.

IV. REPORT FROM THE NLM DIRECTOR

Dr. Lindberg began his report with the budget. He called on Deputy Director Betsy Humphreys to present a comparison of NLM's 1984 budget and FTE allocations with FY 2013 figures.

Ms. Humphreys reported that the biggest change, in terms of the percentage of the budget and FTEs, was the addition of the National Center for Biotechnology Information (NCBI) that did not exist in 1984 and was established late in calendar 1988. Interestingly, the relative percentages of the budget for the NLM programs that existed in 1984 have not changed significantly, although the overall NLM budget is of course much larger. Reimbursements from other NIH Institutes for NCBI activities are now between \$35-40 million; these should be part of NLM's base budget, but with continuing resolutions, this has not yet happened. Both the Office of Computer and Communications Systems and the Lister Hill Center show a decline in Federal FTEs, but NLM's use of contractors in both of those areas is considerably higher.

Ms. Humphreys said that the amount spent for overall Program Management did not increase as much as every other part of the budget. For example, the Office of the Director has only three more FTEs than it did back in 1984. In general, NLM increases went to its programs and not to central Administration activities.

Dr. Lindberg said that globally, the country is having trouble paying for all the things it wants to do. The 2014 budget did provide for a small increase, but effectively restored only about a third of what we lost due to the sequester.

Dr. Lindberg briefly mentioned that he was recipient of the 2014 Paul Even Peters Award by the Coalition for Networked Information (CNI), the Association of Research Libraries (ARL), and EDUCASE. Information about the significance of the award, which recognizes notable, lasting achievements in the creation and innovative use of network-based information resources and services that advance scholarship and intellectual productivity, was included in the Board briefing book. Previous winners include Tim Berners-Lee and Vint Cerf.

Dr. Lindberg congratulated Jerry Sheehan, NLM's Assistant Director for Policy Development, who was recently honored by CENDI, the federal Scientific and Technical Information Managers Group, with the 2013 CENDI Meritorious Service Award. The award recognizes Mr. Sheehan for his significant contributions to CENDI's information policy programs and discussions over several years.

May 13, 2014 – Board of Regents

Dr. Lindberg also congratulated Mehryar Ebrahimi, head of NLM's Office of Administrative and Analysis Management Services, who was the HHS recipient of the Federal Engineer of the Year Award for 2014. Mr. Ebrahimi will be leaving NLM after ten years of service to head the FDA's Design and Engineering Branch.

Joyce Backus, director of Library Operations (LO), announced additions to the LO staff— Mark de Jong, Ph.D. who became head of the Collection Access Section on February 29, 2014, and Benjamin Petersen, who began serving as head of the Preservation and Collection Management Section April 21, 2014.

Dr. Clem McDonald, Director of the Lister Hill Center (LHC), introduced new additions to the LHC staff. Alexandros Karargyris, PhD, was appointed a Research Fellow with the Communications Engineering Branch in February 2014. Also new to the LHC is Raymonde Uy, MD, MBA. He will be working with Dr. Paul Fontelo on telemedicine, mHealth, evidence-based medicine, and information access at the point of care for clinical decision support.

With respect to legislation, Dr. Lindberg mentioned that the federal commitment to public access to results of federally funded research is here to stay. On March 10, 2014, Rep. Larry Bucshon (R-IN) introduced the Frontiers in Innovation, Research, Science, and Technology Act of 2014 (FIRST) to require the National Science and Technology Council to develop a plan describing policies, procedures, and standards for federal science agencies (NASA, NSF, NIST, and the National Weather Service) to archive and increase public access to peer reviewed journal articles and data resulting from federally funded research.

Legislation has also been introduced into the House and the Senate to clarify FDA's authority to regulate health IT.

In response to a question from Dr. Evens about the delayed implementation of ICD-10, Dr. Lindberg said that the delay does not have a direct impact on NLM. Betsy Humphreys noted that in another rulemaking from CMS it was indicated that ICD-10-CM and PCS would be implemented in 2015, but we will need to wait and see.

Dr. Lindberg provided an update on NLM's ClinicalTrials.gov. The database is the largest public registry of clinical research with nearly 164,000 studies as of March 26, 2014. In addition, 11,800 records with results entries from nearly 1,500 data providers are now publicly posted. ClinicalTrials.gov currently receives, on average, over 100 million page views per month and hosts over 950,000 unique visitors per month. NLM has worked with NIH, FDA and the Office of the General Counsel (OGC) to prepare a Notice of Proposed Rulemaking (NPRM) that would implement provisions of the FDA Act of 2007 (FDAAA) requiring responsible parties to register clinical trials and submit results to ClinicalTrials.gov. On March 11, 2014, the White House Office of Budget and Management accepted the Department's draft NPRM for regulatory review. OMB now has 90 days to complete its review. After any issues identified by OMB are addressed, the Department will be able to publish the NPRM in the Federal Register for public comment. Following the public comment period, NLM will work to review comments and make necessary revisions before it is published in the *Federal Register*.

May 13, 2014 – Board of Regents

Dr. Lindberg told the Board that the NLM and the Wellcome Trust recently signed a memorandum of understanding (MOU) to work together to make thousands of back issues of historically-significant biomedical journals freely available online. Terms of agreement include a donation of 750,000 £ to the NLM that will support coordination and scanning of materials. The Trust will take the lead in securing rights for digitization and electronic access from publishers.

An update on Internet access to NLM services was provided. Dr. Lindberg said that Americans now use smartphone and tablet apps more than they use PCs to access the Internet. At NLM, the percentage of users accessing NCBI's main databases on mobile devices has grown from 3 to 24 percent. Ken Walker asked if the volume of users had changed with the shift in access methods. Dr. Lindberg that volume is continuing to increase, but some of the mobile use represents a shift in access method by existing users.

Dr. Lindberg told the Board that NLM's efforts to create a joint training program in biomedical informatics with the Uniformed Services University for the Health Sciences (USUHS) had to be discontinued due to insufficient funding. Dr. Dale Smith, professor of military medicine and history at USUHS, said that it was due to the nature of Internet education and inability to control costs. The Department of Defense was concerned about uncontrolled costs. The partnership agreement that allowed the NLM to work with UHUHS to create the training program remains in place for future opportunities.

Dr. Lindberg explained that the current National Network of Libraries of Medicine (NN/LM) contract will expire and will need to be re-competed for award in May 2016. NLM is posting a Request for Information (RFI) the week of May 12, 2014 to invite interested individuals and organizations to respond to questions and recommend approaches to maximize effectiveness of the Network.

In an update on NLM's travelling exhibitions, Dr. Lindberg said that most of NLM's exhibitions travel with the help of the NN/LM. *Native Voices*, which can be seen in the Rotunda, should go to reservations as well and should be acceptable to the people featured in the exhibition. To determine what technical solutions will be required, the exhibition first travelled to Spirit Lake, North Dakota in October, where hundreds of visitors saw the exhibition over five months and where it was a great success. The mobile adaptation of *Native Voices* is now en route to The Queen's Medical Center, in Honolulu, Hawaii for an anticipated July 18, 2014 opening. A third copy of the exhibition is being fabricated for a scheduled opening at the Alaska Native Cultural Heritage Center in June 2014 and will travel to key Alaska sites over the next seven months. Another will be installed at the Chickasaw Nation's Artesian Gallery for three months, later in 2014.

Dr. Lindberg said that sites that show NLM's traveling exhibitions are encouraged to develop their own programs to best appeal to their unique visitors. In 2003, there were three copies of one traveling banner exhibition on the road. By 2013, 30 copies of 12 different exhibitions were traveling. In 2003, traveling exhibition went to 17 cities in ten states. A decade later, visitors saw traveling banner exhibitions in 391 cities in 48 states, three territories, and six countries. An estimated 250,000 people saw a traveling banner exhibition by 2003 and in the following ten

May 13, 2014 – Board of Regents

years, the cumulative number of visitors reached 3,066,750.

Dr. Lindberg told the Board that on April 25, 2014, a clone of the descendent of the Tree of Hippocrates originally presented to NLM by Greece in 1961 was planted next to the Herb Garden in front of the Library. A dedication ceremony was held to mark the occasion and the addition of gene sequence data from the 1961 gift tree to the Smithsonian's "Barcode of Life" project. Christos Panagopoulos, Ambassador of Greece to the USA, NIH Principal Deputy Director Dr. Lawrence Tabak, Dr. Lindberg, Dr. Constantine Stratakis, Scientific Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development and Dr. David Lipman, Director of NLM's National Center for Biotechnology Information were among those making brief remarks. A reception, sponsored by the Friends of the NLM, and a tour of historical books and manuscripts influenced by Greek scholarship followed the ceremony in NLM's lobby and History of Medicine reading room. NIH scientists of Greek extraction were special guests at the event.

Dr. Lindberg noted that in April the NLM hosted the fourth conference for users of its Journal Archiving and Interchange Tag Suite (JATS), developed under NCBI's direction and adopted in 2012 as an American National Standard. JATS provides a set of XML elements and attributes for describing textual and graphical content of journal articles and other materials. Originally developed as a data structure for journals participating in NLM's PubMed Central (PMC) archive, the Suite has achieved strong acceptance among publishers and authors and has been adopted by the Portico and Highwire Press archives, the British Library, and the Library of Congress for electronic journal articles. The proceedings and links to videos of previous Conference presentations are available online at <http://www.ncbi.nlm.nih.gov/books/NBK65129/>.

Dr. Lindberg observed that the NLM is participating in the inaugural year of the National Digital Stewardship Residency (NDSR), a new program created by the Library of Congress (LC) in partnership with the Institute of Museum and Library Services (IMLS). The program offers recent master's program graduates in specialized fields the opportunity to gain professional experience in digital preservation. NLM is a host institution for NDSR Resident Maureen Harlow, a graduate of the University of North Carolina at Chapel Hill. She is embedded in NLM's History of Medicine Division under the mentorship of Christie Moffatt, Manager, Digital Manuscripts Program, through May 30, 2014. She is developing a thematic Web archive collection "Disorders of the Developing and Aging Mind: Autism and Alzheimer's on the Web." Dr. Lindberg concluded his remarks by announcing that on the following day, May 14, 2014, the NLM Board of Regents is cosponsoring a symposium, *The National Library of Medicine, 1984-2014: Voyaging to the Future*, with the Friends of the National Library of Medicine and the Medical Library Association. The purpose of the meeting is to review the influence of NLM's long range planning, as it interacted with outside developments, over the past 30 years; to reflect on key factors that contributed to successes and setbacks; and to consider opportunities for the future— all as background for the development of the next NLM long range planning effort, to commence in 2015.

V. SEQUENCING FOODBORNE PATHOGENS

Dr. Steve Musser of the Food and Drug Administration (FDA) discussed what he deemed one of the most exciting things he has worked on in his career, setting up a national network to look at

foodborne disease.

While most people believe that eating in the US is safe, and that's largely the case, approximately 9.4 million episodes of foodborne illnesses are reported each year, resulting in over 55,000 hospitalizations and about 1,300 deaths. The FDA looks at these as being preventable, with earlier interventions.

One foodborne pathogen with unfortunate health outcomes is *Listeria monocytogenes*. The average cost of medical care currently exceeds a million dollars per person infected. Dr. Musser then showed a typical epidemiological curve: a contaminated food product enters the market and, a few days later, people start to get sick. After several victims have been identified, the Centers for Disease Control and Prevention (CDC) perform surveillance of how widespread the problem seems to be. Figuring that the source is an FDA-regulated product, they hand the investigation off to us. Unfortunately, the outbreak is well underway before either agency can determine what's going on.

Complicating matters is that fact that the US has an enormous and varied number of food facilities and receives edible items from around the world. The FDA has been working for several years with whole genome sequencing and its use with food pathogens. They wondered whether there was new technology that could have a major impact on the public health. It would need to be inexpensive, easy to use, and taking the same amount of time or less as our current process. That led them to NCBI.

The current technology used by the CDC to identify the DNA fingerprint of foodborne disease-causing bacteria is pulsed-field gel electrophoresis (PFGE). What we can do now with whole genome sequencing (WGS) is, in a little less time, basically sequence the whole organism and upload it to NCBI, and have a level of specificity that significantly improves our ability to accurately and rapidly determine whether two isolates of bacteria are from the same outbreak.

As an experiment, the newly-formed team of FDA and NCBI sequenced over 40 strains of *Salmonella* Bareilly, which were associated with an outbreak of foodborne illness in 2012. The bacteria, found in a tuna served in sushi bars, sickened several hundred people across the US. This was a retrospective study of several well-known isolates from around the world. When they sequenced one strain of *Salmonella* Bareilly, they found that the outbreak strain was most similar. It was about 15 SNPs (single-nucleotide polymorphisms) away from its nearest neighbor. The processing plant that caused the contamination in 2012 and the plant where they obtained a similar sample, from five years ago, were six miles apart in India. That pinpoint accuracy convinced the group that they could probably be successful.

The goal was to get this technology into a distributed network of laboratories that could help us do the sequencing. Of course, some organization must store and provide access to the data, which is a large cost of the project. At the time we had been working with David Lipman. He indicated that NCBI could help with that task and that led to a much closer partnership. We figured out our methods and we developed this initiative called "Genome Tracker."

There were two key things. One is the distributed model, putting as many bench top sequencers

May 13, 2014 – Board of Regents

across the United States to work on it as we possibly could, given our budget. It was about \$200,000 per lab, which included someone to do the work, a sequencer and reagents for a year. This distributed network idea is new and had never been done before, but it is clearly the best way to go. It's kind of like crowd sourcing.

The other thing that we did, in line with the President's directive on Open Government, which says we have to make data produced with public funds available to the public, was to open access to the sequence data as soon as the NCBI group could load it into the SRA (Sequence Read Archive).

Dr. Musser then showed a chart illustrating the network and its components. NCBI is in the center; they collect all of the data from our network of sequencers. In October of 2013, the CDC joined with us by proposing a project that we could do—a real-time monitoring of Listeria cases. Dr. Musser showed charts chronicling the gathering and analysis of sequence data. Since the FDA has been working with NCBI, they've clearly defined 15 outbreaks of Salmonella and Listeria. They've sequenced more than 3,000 Salmonella and about 1,000 Listeria strains. Basically, with NCBI's help, they have grown the amount of bacteria information available to us and other scientists by more than tenfold. We will probably do a hundredfold in the two or three years.

Dr. Musser closed with slide illustrating the real success of this project. The WGS pilot project on Listeria was instrumental in a recent FDA action related to a multi-state outbreak of listeriosis linked to cheese products made by Roos Foods of Delaware. WGS analysis showed that the Listeria strains isolated from the company's cheese products were highly related to the strains isolated from patients in the outbreak. The company issued a recall of the products in February and in March the FDA suspended the firm's food facility registration.

Board member Dr. Douglas Scutchfield asked why pulsed-field gel electrophoresis, which is a state-of-the-art technique, would not have picked this up as opposed to the WGS. The problem is the resolution, replied Dr. Musser. Samples that are actually different can all look identical with PFGE method.

Dr. Musser described next steps. FDA and NCBI both have a small army of people that work on this because it really is becoming the next big public health thing. Future applications might be in hospital environments for determining the source of hospital infections. The other thing we are discovering is how to clearly convey the WGS data in a way that it can be understood by epidemiologists, physicians, lab managers and others. There will undoubtedly be some innovative software solutions coming in the future to address data display.

NCBI Director Dr. David Lipman agreed about how productive this partnership has been. NCBI has established in effect a computational pipeline, but they are trying to improve every part of it because they think this going to really scale up a lot.

The key to dealing with a foodborne illness is to detect the source as soon as possible so you can start your investigation, find the problem, stop the spread, and also learn from what happened, to reduce that as a cause in the future. He described in more detail the pulsed-field gel approach and

its limitations. The CDC project was a great one to start with. But, for the future, we want to be able to get these things turned around really quickly, so you want the sequencers where the labs are and as close to the isolates as possible. Then you send the raw sequence data, for example, to NCBI, we can do the analysis and the reports and can send it back out to all of the parties.

Dr. Lipman described how this partnership is working with state health departments directly, too, to gather and share information. But the better our infrastructure gets and the easier we can make it for some of these people at hospitals or at the state labs to get data to NCBI, we'll get valuable input without a targeted project, just because some of the states and hospitals are getting sequencers anyway.

Dr. Ronald Evens said that some hospitals might not want to be known as the site of some epidemic. Dr. Lipman agreed, but pointed out that there are over a dozen major hospitals where the hospital epidemiologist has already indicated that if there were any possibility for a network to start that they're really interested. Undoubtedly, there are issues as to what's the granularity of the information that is made public. Our goal right now in terms of testing is to handle a thousand isolates a day, doing the full assembly, all these comparisons, and whatever else. It's a lot of computation but I predict that within a very short period of time the volume coming to us would actually be higher when you start including the hospitals and other sources of isolates.

Board member Dr. Trudy MacKay asked whether there is ever an outbreak that can't be explained. How soon is it going to be necessary to move to full-blown environmental metagenomics that cannot be cultured? Dr. Lipman replied that this is an example of addressing the simple problem first, since in foodborne outbreaks we can detect what caused a lot of the problems.

VI. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Subcommittee Chair Mary Ryan reported that the Subcommittee on Outreach and Public Information received an update on internet access to NLM's services and resources by Dr. Eric Sayers, Stephanie Dennis, Jennifer Jentsch, and Joyce Backus. Increasing numbers of users are reaching the NLM through social media outlets, Twitter and Facebook, both in English and in Spanish. MedlinePlus Connect enables information links to electronic health records. In 2010, NLM introduced mobile MedlinePlus, but it hasn't been heavily used and the full MedlinePlus site is actually more heavily accessed via mobile devices (tablets, smartphones) than the mobile MedlinePlus. The Subcommittee heard about efforts underway to produce websites in responsive design. This is a flexible grid based-layout which responds to user's needs and delivers content in the manner that is best suited for the user's device or a browser.

NCBI's Dr. Sayers reported that PubMed users are accessing PubMed on mobile devices much more than they did in the past. About 15 percent of PubMed access is now from mobile devices and that number is growing. PubMed Reader makes it easier for users to read articles from PubMed Central on mobile devices and about 25 percent of those viewing PubMed Central articles are viewing them on mobile devices. He said that the NCBI homepage will be redesigned in responsive design.

The Subcommittee also heard from SIS's Dr. Bert Hakkinen, who reported on NLM's response to the January chemical spill into the Elk River in West Virginia. Spills often involve chemicals that we know very little about. There are about 80,000 chemicals and there are only about 6,000 records in the Hazardous Substances Data Bank (HSDB). When the chemical spill in West Virginia happened on January 9th, there was nothing in TOXNET or the HSDB about this chemical. Originally developed by Eastman Kodak to process photographs and manufactured and used under circumstances that posed less environmental risk, it is now being used to wash coal. That was the use that was being made of it when the West Virginia spill occurred. NIEHS, CDC, and others at HHS relied upon NLM to obtain toxicological studies originally done by Kodak, summarize the information, and get the HSDB scientific panel to review and finalize a new HSDB record for the chemical. Work was essentially complete, based on 10 studies provided by Kodak, when another 5 studies surfaced and the record has to be revised and reviewed again to accommodate the additional information. A week after the spill a fully vetted HSDB record was made public and pointed to by the various government agencies involved in responding to the event. NLM's current process for process for developing information for HSDB worked well and rapidly in this instance.

NLM Communications Director Kathy Cravedi mentioned that this was a good example of the importance of coordinating communication. Many government agencies were involved in responding to the spill: the DHHS, the NIEHS, the NLM, and the CDC. Only one agency is designated to respond with a single message to the press. In this instance, it was the CDC. It is critical to have a consistent message for the public during such disasters. Of course, the work of the NLM was critical in this particular disaster and its role was duly noted in press that resulted.

Board consultant Dr. Tenley Albright noted that the members always learn about NLM's fascinating work during Subcommittee meetings. But, it is largely unknown by the public. She said that many physicians are probably unaware of NLM's research.

Mary Ryan agreed and added that health science librarians probably don't understand a lot of the work that NLM funds either. It is important to get the word out about the work of the NLM.

Another Board member observed that we do a very poor job about promoting but did not have a solution to suggest.

Betsy Humphreys said that the statistical profile on the number of times that NLM is mentioned in electronic media is really very substantial and it's growing and has been throughout time.

Dr. Ronald Evens said that promotion activities should be considered in future strategic planning sessions. Board consultant Dr. Holly Buchanan said that they received a small grant from the NN/LM to produce ten public service announcements for the state. They will see how effective the radio campaign is in getting the word out about NLM.

Ex officio member Dr. Dale Smith asked if there is any evidence that people who might benefit from the information that NLM makes available are not getting it. ClinicalTrials.gov seems to be growing on an annual basis. What indications do we have that people that need us don't know about us? Let's target outreach efforts to those who can most benefit.

VII. BOR CHAIR NOMINATING COMMITTEE REPORT

Nominating Committee Chair Kathryn Mendenhall announced that the Committee recommended that Dr. Trudy MacKay serve as the next chair of the NLM Board of Regents. Dr. MacKay holds the post of Distinguished University Professor of Genetics at North Carolina State University. She is one of the world's leading authorities in quantitative genetics and has served on numerous editorial boards and advisory committees including the NCBI Board of Scientific Counselors. The Board unanimously approved the nomination of Dr. Trudy McKay to serve as the Chair of the NLM Board of Regents.

VIII. PRESENTATION OF OUTGOING BOR CERTIFICATES, NLM DIRECTORS' AND FRANK B. ROGERS AWARDS

Dr. Lindberg presented Dr. Ronald Evens with a certificate and a gavel in recognition of his service as the Chairman of NLM's Board. He also presented outgoing Board members Dr. Douglas Scutchfield, Katherine Gottlieb and Mary Ryan with certificates for their service.

Dr. Lindberg presented the Frank B. Rogers award to Janet Zipser. This award recognizes employees who have made a significant contribution to the library's fundamental operational programs and services. Ms. Zipser was given then award "for outstanding leadership in reinventing training in the use of NLM databases, incorporating new technologies, adult educational practices, and user feedback."

The NLM Director's Honor Award, which was established in 1969 to recognize and acknowledge the work of NLM employees who have made exceptional contributions to the achievements of the library, was presented to Barbara Rapp for "exceptional contributions as NLM's Planning and Evaluation Officer, synthesizing information and formally reporting NLM's progress in meeting key goals of its mission and its comments on draft NIH and HHS documents."

IX. NIH PLANS FOR DATA SCIENCE

Dr. Philip Bourne addressed NIH's plans for data science. Dr. Bourne, a chemist and former member of the PubMed Central advisory committee, was recently named NIH's first permanent Associate Director for Data Science. He will lead NIH's initiative to take better advantage of the exponential growth of biomedical research datasets.

Dr. Bourne shared initial observations and a vision for data science. His initial observations included good and bad news. The bad news includes the fact that NIH doesn't have a data sustainability plan. The good news, he said, is that NIH has a willingness to address the problems, including the resources and the data scientists needed to solve them.

He and others have identified five programmatic themes to be addressed. They are: sustainability; education (training in data sciences); innovation (Big Data to Knowledge BD2K); process (grant review); collaboration (more cooperation among federal agencies and international partners). Dr. Bourne highlighted one theme, sustainability. He said NIH has been

talking with NCBI director Dr. David Lipman and Dr. Jim Ostell about a data “Commons,” a concept that enables community data sharing, with the goal of promoting scientific innovation. He said he views the Commons as an “extramural NLM/NCBI.” Participants could include NIH awardees; the rest of academia; government; and the private sector. The idea that two researchers could discover each other through data in the Commons is a hypothetical dream that he’d like to try and test. He said some ideas for the Commons have been bubbling up and he hopes to explore them throughout the spring, summer and fall of this year.

Board Chair Dr. Ronald Evens asked how much authority Dr. Bourne has. Dr. Bourne says the reason he came to NIH is because he’s worked with communities from the bottom up. While that’s rewarding, you also need to do something from the top down.

X. PORTFOLIO ANALYSIS: HEALTH DISPARITIES-FOCUSED HEALTH SERVICES RESEARCH

Lisa Lang, NLM’s Assistant Director for Health Services Research Information and Head of NLM’s National Information Center on Health Services Research and Health Care Technology (NICHSR), introduced a project conducted by AcademyHealth and the Association of American Medical Colleges (AAMC) that made use of NICHSR resources.

NICHSR, which recently marked its 20th anniversary, has had a longstanding relationship with AcademyHealth, which represents the diverse communities engaged in health services research (HSR). HSR studies issues such as health care access, cost, quality, utilization and improvement of outcomes. Established in the early 1990s, the NICHSR database HSRProj is a searchable database of funded HSR projects. It is managed by AcademyHealth with help from the Cecil Sheps Center at the University of North Carolina. People involved in health services research can use HSRProj to identify potential colleagues and funders. The database also can be used as a tool for assessing the national HSR portfolio. Academy Health and the AAMC recently used the HSRProj to examine recent trends in investments in health disparities research.

Dr. Erin Holve of AcademyHealth and Dr. Philip Alberti of AAMC were the principal investigators for the project. Dr. Holve provided background and context about HSRProj, indicating that there are more than 26,000 research projects in the database, of which about 10,000 represent projects in progress or recently completed. Nearly 150 funding organizations are represented including federal and state agencies, foundations, private organizations, both foreign and domestic. Previous special analyses using the database have addressed such diverse topics as investments in comparative effectiveness research, research that could inform health reform, and public health systems and services research.

Dr. Alberti outlined the project objectives: to develop a reliable query in HSRProj to analyze health disparities-focused HSR funded during 2007-2011, with regard to trends in funders and grantees, populations of interest and approaches to disparities research. The nearly 1,300 studies discovered through the HSRProj query showed that adolescents and children, blacks/African Americans and low SES groups were the most common population groups studied. Dr. Alberti noted that, while so-called “third-generation” health equity research, addressing causes and amelioration strategies for health disparities, nearly doubled over this five-year period, certain

populations, such as Native American groups, remained relatively understudied. The study also found that over 40 percent of disparities-focused HSR during the period was conducted at AAMC-member institutions. In summarizing the study, Dr. Alberti noted that HSRProj is valuable in identifying ongoing research trends in the field. He felt that the results of the project could serve as a guide for resource allocation, to address health outcomes and population groups currently underrepresented in disparities-focused HSR. The AAMC can also benefit greatly from such portfolio analyses, as the Association builds member capacity to conduct health equity research.

The brief discussion following the presentation focused on the identity terms used in the query, and collaborations with public health departments.

XI. PILL IMAGE IDENTIFICATION CHALLENGE

Dr. Michael Ackerman, Chief of NLM's Office of High Performance Computing and Communications, told the Board about the upcoming pill identification challenge. He gave two examples of why a system for identifying pills is needed—to identify unknown medications during a disaster or emergency; to verify a consumer has the right medication.

Dr. Ackerman said OHPCC's 3D informatics group took on the task as a way to explore image/pattern recognition. The team has a proposed mechanism for identifying pills: use a smartphone equipped with an NLM pill app to photograph an unidentified pill; the app would then send a picture to NLM and get pill identification and supporting information; the app would display the pill identification, including the NLM database pill image and essential supporting information.

Because there are no open source pill images, the team is creating a database of prescription solid-dose pharmaceuticals (pills) and the associated metadata. The team believes 5,000 unique images will allow for the identification of at least 85% of the prescribed pill medications. About 2,500 images have been captured so far.

To make this a more “social” effort, NLM is preparing to launch a pill identification challenge. The challenge will be to develop the algorithms NLM will use to match the unknown product picture to the pictures in the NLM database. The challenge is expected to start in fall 2014 with a test of the testing system, and end in fall 2015 with the winner announced. Dr. Ackerman said the timing was done, in part, so that the challenge could be included in college courses.

The team doesn't expect anyone to score 100%. It's anticipated that some participants will be better at discriminating shape, while others will do better with color and others with characters. NLM can then learn what participants are doing and create an app that takes the best of each to get close to 100%. To demonstrate the difficulties associated with the challenge task, Dr. Ackerman showed a series of slides highlighting, for example, what happens to a pill's color and shape depending on the lighting and the background used in the photo. The pill project, he said, seemed simple at the start, but is getting more exciting all the time.

XII. FROM SEQUENCES TO SCIENCE—LESSONS AND CHALLENGES FROM 30 YEARS OF PROTEIN SEQUENCE COMPARISON

Dr. William Pearson is a Professor and Vice-Chair of the Department of Biochemistry at the University of Virginia. He has received NLM research grant funding since 1988. His presentation covered a foundational period in bioinformatics. He began by asking, in 30 years of similarity searching what have we learned, and what did we miss?

He first noted that Darwin was right, all species are related and homologous sequences of the proteins of thousands of species prove it. In collaboration with David Lipman and others, Dr. Pearson developed computational tools to search and detect similarities.

He then explained the basis for protein sequence comparison and protein structure comparison and the use of statistics to compute similarity, deriving a similarity score.

In 30 years of protein sequence comparison, what researchers have learned is that sequence searching can miss homologs, some of which are very easy to find but others are difficult to identify. Structure comparison is more sensitive than sequence comparison, but produces many errors. Inferring function from structure is also difficult. He showed that there is an evolutionary basis for structural/functional similarity, but function does not follow universal rules.

Dr. Pearson commented that, with early NIH funding and the award of several grants for comparison of protein sequences and structures, including work by Dr. Pearson and now-NCBI Director Dr. David Lipman, researchers had method and database, and people got very enthusiastic about finding things. It's all very promising, he noted, but what if we could be doing better? The world has changed enormously since the 1980s because we have lots more sequences than we used to.

He then moved to discuss the challenges that lie ahead. The first challenge is finding everything that is homologous. Once you've found the structure of something, you want to know what it does. He noted that people often say that, once you have the genome, you have the parts list. But what researchers care about, is figuring out what proteins do, how changes affect them, and how the effects of those changes on human health can be predicted. Prediction of protein function is still difficult. What might be needed is a way to incorporate other kinds of information – active sites, domains, variation, etc – as part of protein function prediction. For this to happen, more integration is needed across research disciplines, so elements and functions are annotated in a way that supports new approaches. In closing, Dr. Pearson thanked NLM for its grants and other forms of support through the years.

Board member Dr. Robert Greenes asked whether there was a measure of closeness for amino acids. Yes, replied Dr. Pearson. When we look for homologs, we use a measure of closeness and that is how we find that these things are all similar to each other. When he talks about the fact that proteins are random, what he means is that you have that family of serine proteases and those are not random; they are what they are.

XIII. EXTRAMURAL PROGRAMS REPORT: A REVIEW OF NLM RESEARCH FUNDING, 1984-2014

Extramural Programs Director Dr. Valerie Florance discussed the R01 grants program, the bread-and-butter research grant of NIH, reaching back to capture the historical roots of research grants at NLM. She also touched on past long range plans to show the evolution of our research grant program.

In 1965, NLM had an appropriation of \$20,000 for support of research and training in the history of medicine. Those grant functions were transferred from the National Institute of General Medical Sciences to us. In 1970, with the extension of the Medical Library Assistance Act, R01-type research really started to flourish, with the funding of information science research and early informatics grants. Dr. Florance next presented a chart showing NLM's appropriated grant funding through the years, excluding ARRA.

In 1978, there was a task force which recommended that NLM support more computer science research, which helped lay the groundwork for informatics research. By 1980, NLM had informatics grant programs in place and important work was being done. Highlights include Donald Walker's natural language access to medical text and Harry Pople's Internist, two of the first informatics grants that NLM awarded. Dr. Florance provided a profile of Dr. Ira Kalet, an early NLM grantee who sent comments saying that his NLM grant set in motion many good things in his career, including the development of a bioinformatics training program at the University of Washington, authorship of often-cited articles and a book. By 1985, 50% of the research grants NLM awarded had medical decision support as a focus.

Dr. Florance then noted how each of NLM's long range plans expanded the scope of the grant program. In the first NLM Long Range Plan, biotechnology information was a big, important area, and there was also a comment in the section on medical informatics that we should emphasize research on fundamental issues and methods. By 1998, 44 percent of grants were for biotechnology research, where there had been none on that topic before, except book grants.

With a new long range plan in 2000, the extramural research focus was expanded to include consumer health information, patient-specific data, and access to knowledge-based information. In that new decade, the size of grants rose dramatically. Profiles were presented of James Cimino, a NLM trainee and grantee in informatics who is now at the NIH Clinical Center and NLM, and Atul Butte, an NLM trainee and grantee currently at Stanford. These and other NLM grantees are among the most heavily cited researchers in the informatics field.

She showed that the average cost of an R01 grant awarded by NLM has gradually increased and now matches other NIH research grants. Through the years, depending on funding available and number of applications, success rates have gone up and down. In most years, NLM's success rates for R01 grants are similar to those of other NIH Institutes. In the recent period of fiscal constraint, NLM took cost-cutting steps to award the greatest number of meritorious research grants, protecting the success rate at the expense of resource grant programs.

Moving ahead to the present, Dr. Florance noted that NLM awarded 12 new R01 grants last year

May 13, 2014 – Board of Regents

down from the average has been 15-17 per year, showing effects of the 7% sequestration cut to the grant program budget. Reviewing other highlights of NLM's extramural research, Dr. Florance also noted the history of collaboration between NLM's intramural and extramural researchers, and provided several examples. And since 1997, five NLM grantees have received the prestigious Presidential Early Career Award for Scientists and Engineers (PECASE).

She closed by asserting that NLM has been on the leading edge in biomedical informatics research for decades, and was once seen as the only supporter of informatics at NIH. Today, the context has changed at NIH and beyond, with more funds available for biomedical informatics research via PCORI, BD2K and other private and public organizations. The timing is right for the next NLM long range to consider new directions for NLM's extramural grant program.

XIV. ADJOURNMENT

Dr. Evens thanked Dr. Florance and adjourned the public portion of the Board of Regents meeting at 4:25 p.m.

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the February 11-12, 2014 Board Minutes
- Approval of the May 12-13, 2015 Future Meeting Dates
- Appointment of the new Board Chair, Dr. Trudy MacKay

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

Ronald G. Evens, M.D.
Chair, NLM Board of Regents