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

# MINUTES OF THE BOARD OF REGENTS February 2-3, 2010

The 153rd meeting of the Board of Regents was convened on February 2-3, 2010, 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 4:30 p.m., followed by a closed session for consideration of grant applications until 5:00 p.m. On February 3, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

### **MEMBERS PRESENT** [Appendix A]:

- Dr. C. Martin Harris [Chair], The Cleveland Clinic Foundation
- Dr. Jordan Cohen, George Washington University
- Dr. John Connolly, University of California, Irvine
- Dr. Carol Friedman, Columbia University
- Dr. O. Wayne Isom, New York Presbyterian-Weill Cornell Medical School
- Mr. Bruce James, Nevada New-Tech, Inc.
- Dr. Joyce Mitchell, University of Utah
- Dr. Louis Rossiter, The College of William and Mary
- Ms. Eileen Stanley
- Ms. Virginia Tanji, University of Hawaii at Manoa

#### EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

- Dr. Michael Corriere, U.S. Department of the Navy
- Ms. Eleanor Frierson, U.S. Department of Agriculture
- Ms. Gail Graham, Veterans Health Administration
- BGEN Byron Hepburn, United States Air Force
- Dr. Haym Hirsh, National Science Foundation
- Dr. Deanna Marcum, Library of Congress
- Col. John Powers, U.S. Department of the Army
- Dr. Dale Smith, Uniformed Services University of the Health Sciences
- RADM Robert Williams, Office of the Surgeon General, PHS

### CONSULTANTS TO THE BOR PRESENT:

- Dr. Tenley Albright, Massachusetts Institute of Technology
- Dr. Marion Ball, Johns Hopkins School of Nursing/IBM Research
- Dr. Holly Buchanan, University of New Mexico
- Dr. Thomas Detre, University of Pittsburgh

## SPEAKERS AND INVITED GUESTS PRESENT:

- Mr. Selby Bateman, Vitality Communications
- Dr. Francis Collins, Director, NIH
- Dr. Amarendra Das, Stanford University
- Dr. Eric Green, National Human Genome Research Institute, NIH

## MEMBERS OF THE PUBLIC PRESENT:

Mary Lindberg, Public

### 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, High Performance Computing & Communications, NLM
- Mr. Terry Ahmed, Division of Library Operations, NLM
- Dr. Sameer Antani, Lister Hill Center, NLM
- Ms. Stacey Arnesen, Office of the Director, NLM
- Dr. Alan Aronson, Lister Hill Center, NLM
- Mr. Alexander Astashyn, National Center for Biotechnology Information, NLM
- Ms. Joyce Backus, Division of Library Operations, NLM
- Dr. Ryan Banez, Lister Hill Center, NLM
- Mr. Michael Barboza, Lister Hill Center, NLM
- Ms. Colleen Bollin, National Center for Biotechnology Information, NLM
- Mr. Tom Bowles, Division of Library Operations, NLM
- Dr. Leonid Boytsov, National Center for Biotechnology Information, NLM
- Dr. James Case, Division of Library Operations, NLM
- Dr. Deidre Clarkin, Division of Library Operations, NLM
- Mr. Robert Cohen, National Center for Biotechnology Information, NLM
- Ms. Kathy Cravedi, Office of Communications & Public Liaison, NLM
- Ms. Celeste Dade-Vinson, Office of the Director, NLM
- Mr. Todd Danielson, Executive Office, NLM
- Mr. Andrew Diggs, Division of Extramural Programs
- Ms. Darlene Dodson, Office of the Director, NLM
- Mr. Ivor D'Souza, Lister Hill Center, NLM
- Ms. Kathel Dunn, Division of Library Operations, NLM
- Ms. Gale Dutcher, Division of Specialized Information Services, NLM
- Ms. Martha Fishel, Division of Library Operations, NLM
- Dr. Valerie Florance, Division of Extramural Programs, NLM
- Ms. Loren Frant, Division of Library Operations, NLM
- Dr. Kin Wah Fung, Lister Hill Center, NLM
- Mr. Michael Gill, National Center for Biotechnology Information, NLM
- Dr. Vhan Grigoryan, National Center for Biotechnology Information, NLM
- Dr. Sally Howe, National Center for Biotechnology Information, NLM
- Dr. Zoe Huang, Division of Extramural Programs, NLM
- Ms. Christine Ireland, Division of Extramural Programs, NLM
- Dr. Johnson Jao, Lister Hill Center, NLM
- Ms. Lakeshia Jones, Department of Health and Human Services
- Ms. Brandi Kattman, National Center for Biotechnology Information, NLM
- Mr. Chris Klose, Office of Communications & Public Liaison, NLM
- Mr. Sergey Koshelkov, National Center for Biotechnology Information, NLM
- Mr. Sheldon Kotzin, Division of Library Operations, NLM
- Dr. David Landsman, National Center for Biotechnology Information, NLM

- Ms. Lisa Lang, Division of Library Operations, NLM
- Dr. Jennifer Lee, National Center for Biotechnology Information, NLM
- Dr. David Lipman, National Center for Biotechnology Information, NLM
- Dr. Simon Liu, Office of Computer and Communications Systems, NLM
- Dr. Robert Logan, Office of Communications & Public Liaison, NLM
- Ms. Becky Lyon, Division of Library Operations, NLM
- Ms. Rama Maiti, National Center for Biotechnology Information, NLM
- Dr. Clement McDonald, Lister Hill Center, NLM
- Dr. Dharitri Misra, Lister Hill Center, NLM
- Mr. Anatoly Mnev, National Center for Biotechnology Information, NLM
- Ms. Melanie Modlin, Office of Communications & Public Liaison, NLM
- Ms. Wendy Narez, Office of Communications & Public Liaison, NLM
- Mr. David Nash, Office of the Director, NLM
- Mr. Maxim Osipov, National Center for Biotechnology Information, NLM
- Dr. Glenn Pearson, National Center for Biotechnology Information, NLM
- Dr. Arthur Petrosian, Division of Extramural Programs, NLM
- Dr. Steven Phillips, Division of Specialized Information Services, NLM
- Dr. Barbara Rapp, Office of Health Information Program Development, NLM
- Dr. Jeffrey Reznick, Division of Library Operations, NLM
- Ms. Julia Royall, Office of International Programs, NLM
- Dr. Angela Ruffin, Office of the Director, NLM
- Dr. Nataliya Haropova, National Center for Biotechnology Information, NLM
- Mr. Jerry Sheehan, Office of the Director, NLM
- Dr. Yanna Shen, Lister Hill Center, NLM
- Dr. Elliot Siegel, Office of Health Information Program Development, NLM
- Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
- Mr. Vitaly Stakhovsky, National Center for Biotechnology Information, NLM
- Dr. Paul Theerman, Division of Library Operations, NLM
- Dr. George Thoma, Lister Hill Center, NLM
- Dr. Andrey Timonin, National Center for Biotechnology Information, NLM
- Mr. Craig Wallin, National Center for Biotechnology Information, NLM
- Dr. Fred Wood, Office of Health Information Program Development, NLM
- Dr. Xuan Zhang, National Center for Biotechnology Information, NLM
- Dr. Deborah Zarin, Lister Hill Center, NLM

### I. OPENING REMARKS

Dr. C. Martin Harris, Chair, welcomed the Regents, alternates, and guests to the 153<sup>rd</sup> meeting of the Board. He called the meeting to order and introduced the first speaker, the representative from the Office of the Surgeon General (OSG).

### II. REPORT FROM THE OFFICE OF THE SURGEON GENERAL

Rear Admiral Robert Williams represented Surgeon General Dr. Regina Benjamin. He extended greetings from Dr. Benjamin and detailed OSG activities since the last Board meeting.

Dr. Benjamin was confirmed by the Senate in October 2009 and sworn into office in November. A ceremonial change of command event was held in January 2010.

RADM Williams stated that since taking office, Dr. Benjamin has been heavily involved in outreach activities, most notably addressing H1N1 and flu immunizations. She traveled to schools and other venues to advocate immunizing children and adults. She has also been involved in the U.S. response to the earthquake in Haiti and is in touch with policymakers every day.

Dr. Benjamin joined First Lady Michelle Obama and Health and Human Services Secretary Kathleen Sebelius to announce plans to combat overweight and obesity and to support healthy choices. At that event, the OSG released *The Surgeon General's Vision for a Healthy and Fit Nation*. RADM Williams said the document re-emphasizes the goals and objectives of the 2001 Surgeon General's call to action on overweight and obesity. But it also has Dr. Benjamin's personal touch—expressing her view that anyone can achieve health and wellness, and that the government should emphasize the positive aspects of what that means, rather than the negative consequences.

The OSG also is close to issuing a new Surgeon General report on tobacco, *How Tobacco Causes Disease:* the Biology and Behavioral Basis for Tobacco-Attributable Disease. It is expected to be released in the late summer or early fall.

### III. CONSIDERATION OF SEPTEMBER 2009 MINUTES AND FUTURE MEETINGS

The Regents approved without change the minutes from the September 15-16, 2009 meeting. The spring meeting is scheduled for May 11-12, 2010, the fall Board meeting is scheduled for September 14-15, 2010, and a winter Board meeting was approved for February 8-9, 2011.

### IV. REPORT FROM THE NLM DIRECTOR

The budget and personnel matters were the first topics addressed. The FY2010 budget included almost \$340 million, plus \$8.2 million for the National Information Center on Health Services Research (NICHSR). NLM also received about \$84 million in stimulus money. For FY2011, the NLM appropriation is roughly \$370 million, plus the \$8.2 million for NICHSR, which is about a 3.2% increase.

Personnel changes were noted. Todd Danielson was appointed NLM Associate Director for Administrative Management. Two retirements were announced—Lawrence Kingsland, PhD, retired as assistant director for applied informatics and chief of the Computer Science Branch and James Main is retiring as the chief of the Audiovisual Program Development Branch. Dr. Lindberg also announced that Simon Liu, PhD, is leaving his job as director of the Office of Computer and Communications Systems to become director of the National Agricultural Library. Ivor D'Souza will become acting director. New staff and staff changes also were announced for the Lister Hill National Center for Biomedical Communications and for the Division of Library Operations.

Dr. Lindberg updated the Board on legislative matters. Much attention has been focused on the Health Information Technology for Economic and Clinical Health (HITECH) Act. It gives money to the national coordinator for Health IT to support electronic health records. Rep. Patrick Kennedy introduced a bill

regarding personal health records but no action has taken place. And, no further action has been taken on two bills introduced to address public access policies.

Dr. Lindberg next spoke about numerous NLM projects and products. He noted the creation of a new user interface for PubMed. He told the Board that he has an interest in climate change and health, and that he took part in a December "Priorities for NIH Research on Climate Change and Health Workshop." Regarding exhibitions, NLM representatives met with representatives of the Smithsonian Institution, to explore a joint exhibit that would take place at both sites. The idea was well received; however, due to construction at the Smithsonian, a two-site exhibit could not take place before 2013. Dr. Lindberg also recapped a "Mentoring in Medicine" conference that took place in December at the Frederick Douglass Academy in Harlem. NLM supported part of the conference. The Mentoring in Medicine program pairs health professionals with students in disadvantaged communities. Dr. Lindberg also told the Board about the Medical Heritage Library Project, to create a freely accessible digital library of all published medical literature. It will involve NLM and other libraries.

Dr. Lindberg then yielded some of his time over to Dr. Steven Phillips, NLM Associate Director for Specialized Information Services, to tell the Board about NLM's response to the January 2010 earthquake in Haiti. NLM created a Web page containing information about Haiti and earthquakes. At the request of HHS, NLM created a Health Resources for Haiti widget that others could use. As part of a partnership between the National Network of Libraries of Medicine and journal publishers, free full-text articles from more than 200 journals were made available to medical teams responding to the earthquake. Multi-language resources were created with information in French, Haitian Creole, and Spanish. In addition, NLM's Lost Person Finder system was adapted for Haiti, thus enabling people to post pictures of quake victims who've been lost and found in an online system that can be searched. NLM also developed a "Found in Haiti" iPhone application.

### V. REPORT FROM THE NATIONAL HUMAN GENOME RESEARCH INSTITUTE

Dr. Eric Green, the new director of the National Human Genome Research Institute (NHGRI) at NIH, gave the Board an overview of the Institute's activities and its thinking on the critical opportunities in genomics. NHGRI is working on a new strategic plan, with a draft expected in the summer. Dr. Green noted the strategic planning process has included a number of topic-specific workshops. Two that are planned for the spring are relevant to NLM: exploring cloud computing and data analysis.

Dr. Green said these are exciting times in the field of genomics. He outlined the opportunities and bottlenecks NHGRI envisions in the future. He anticipates continued partnerships between NHGRI and NLM, notably the National Center for Biotechnology Information (NCBI), on genomic issues. He also said NLM will be a key partner in capturing the history of the Human Genome Project and NHGRI.

The future, as many see it, will be genomic medicine—tailoring how patients are cared for based on some form of genomic information. Dr. Green said a central component of NHGRI's future mission will be to foster the maturation and practice of genomic medicine. The Institute already has been taking small steps that way. The first thing has been to understand how the human genome sequence works, and to understand how people have various variants that can impact health. He noted that one key area of work is implicating genetic variants with human disease. There's been an explosion of genome wide association

studies in which researchers look at large groups of people with common diseases and identify small regions of the genome that contain variants that increase the risk of getting those diseases.

Dr. Green said the developments in DNA sequencing technology are mindboggling. There's been a technological surge over the last three to four years. NHGRI wants to reduce the cost of sequencing an individual's genome to \$1,000, so that lots of genomes can be sequenced and that process can eventually become part of routine clinical care. This sets up the opportunity to sequence thousands of genomes to gain a better understanding of human variation across the globe. But, the reality is these new DNA sequencing technologies put out huge amounts of data that needs to be shared. That puts tremendous pressure on places like NLM, to take on the data and get it out to users.

In addition to opportunities, Dr. Green noted there will be bottlenecks. One will be a computational bottleneck. The future research will require hardware and infrastructure, new software and tools, and people trained to do the work. He said he thinks the infrastructure requirements have changed; now, what are needed are a small sequence production group and a large bioinformatics group to deal with the data. He said there also could be an informational bottleneck in trying to understand all the information coming out of the data.

Following the presentation, Board member Dr. Joyce Mitchell asked about quality control in coordinating all of this international knowledge to determine what it means and what should be done. Dr. Green said that will be a huge challenge. A fundamental cultural feature of the discovery process should be to make sure that the information is available, accessible, and understandable. Board Chair Dr. Harris asked how all of this medical knowledge will be delivered. Dr. Green said that delivery of this information is likely not to be at the physician level but with other health professionals. There is a branch in the institute that is looking at how to better do genetic competencies and education for groups like physician assistants, nurses, and genetic counselors.

# VI. BETHESDA HOSPITALS EMERGENCY PREPAREDNESS PARTNERSHIP RESEARCH REPORTS

Dr. Steven Phillips updated the Board on the Bethesda Hospitals Emergency Preparedness Partnership (BHEPP) research program. In 2004, Congress funded the partnership to create a partnership between three hospitals that could respond to a disaster in the area, and to create a model that could be used around the country. The three hospitals are the NIH Clinical Center, the National Naval Medical Center, and Suburban Hospital. NLM joined the partnership in 2007, to carry out research related to disaster issues. Eleven different research projects are taking place throughout NLM. The research falls into several categories: communications between the hospitals, patient information management, information access, family reunification, and hospital staff training. Dr. Phillips then played a video about the partnership. The video included interviews with Dr. Lindberg and the leaders of the other partner institutions.

OCCS Director Dr. Simon Liu demonstrated one of the BHEPP research projects, a digital pen that can be used to help triage patients during a disaster. If emergency medical personnel create on-the-spot medical reports on paper, they run the risk of losing those papers, or of seeing the information compromised or altered in challenging conditions. The digital pen is being studied as a possible solution. The pen captures data via a small camera inside. It's used on a paper form that has a unique pattern of dots telling the pen

where it is on the page. The camera inside the pen can take up to 50 pictures per second and store up to 1000 forms. The information can then be transferred to a laptop, BlackBerry or other mobile device and shared with staff at the three hospitals within seconds. The information is sent through laser devices installed on the hospital rooftops, ensuring clear transmission in the event that other communication methods crash. OCCS is also working with Julia Royall, chief of NLM's Office of International Programs, to test the digital pen in Uganda. Medical professionals there sampled the pen and two possible research areas are being considered. One would use the digital pen to survey the impact of mosquito nets in reducing incidence of malaria. The other would integrate the digital pen into a health management system. There is also the possibility of NLM participating in a project with Israel, Dr. Liu noted.

Dr. Kin Wah Fung, biomedical technologies specialist in the Lister Hill Center, discussed access to electronic prescription data for disaster victims. Accurate information about a patient's medication history is an important part of patient care, diagnosis, and treatment, but it may be hard to get a medication history during a disaster. Dr. Fung and other NLM researchers are exploring the use of Surescripts prescription history information during a disaster. Surescripts is the largest electronic prescribing network in the U.S. Its database covers about 65% of all patients in the country. The research project looked at the feasibility of accessing Surescripts prescription history information in the emergency department of Suburban Hospital—and the potential value of this additional source of information for patient care.

To study the potential value of Surescripts data, the researchers collected data on patients coming to the Suburban Hospital emergency department. It came from two sources—what the triage nurse gathered, and the Surescripts data on file. The research team received information on about 10,000 patients (deidentified, for confidentiality, before being sent to NLM). The research team found that using the Surescripts information is both feasible and valuable. The Surescripts data was the only source of medication information for 7% of patients, a figure which would probably be higher in a disaster situation.

In discussion after the presentation, Board member Dr. Wayne Isom raised the possibility of using a digital pen when seeing patients outside of a trauma situation. Col. John Powers said that he was glad to see the digital pen also has ink, so you can still have a hard copy and, thus, redundancy during a disaster. He also noted that the pen provides multiple, simultaneous input to your headquarters—another helpful feature.

### VII. PRESENTATION OF REGENTS AWARD

Chairman Harris presented the Regents Award to Dr. Alan R. Aronson of the Lister Hill Center, for his work on MetaMap, a widely-used concept search program for biomedical text. His award read: "For the development of two natural language processing tools, MetaMap and the NLM Medical Text Indexer which provides in-house assistance to NLM indexers." Dr. Aronson accepted the award with thanks, sharing credit with his talented LHC colleagues.

## VIII. HEALTH DATA STANDARDS UPDATE

NLM Deputy Director Betsy Humphreys began by restating the priorities in the report from the Board Working Group on Standards, submitted May 2009. She mentioned that the report's subtitle, *Enhancing NLM's Contribution to the Nation's Health IT Agenda*, was key. (Board Chairman Martin Harris is on the national planning panel.) Ms. Humphreys noted that a proposed rule on "meaningful use" of electronic

health records (EHRs) was issued December 30, with comments due by March 15. An interim final rule for EHR certification criteria is currently in place. Another rule is in preparation, governing certification of EHR products. "Meaningful use" requires that some electronic health information be captured in coded format by 2011, with more added over time. The initial certification criteria mention three standards developed by NLM and now available free of charge nationwide: SNOMED CT, RxNorm, and LOINC.

The Health IT Standards Committee also has a Vocabulary Task Force, with NLM representatives Betsy Humphreys (co-chair), LHC Director Dr. Clement McDonald, and head of Medical Subject Headings (MeSH) Dr. Stuart Nelson.

People are more likely to use standards if the subsets are available of key vocabularies. LHC's Dr. Kin Wah Fung has presented to the Board on this before, and Dr. Clem McDonald, working with the Regenstrief Institute in Indiana, has created LOINC, a value set of university laboratory order codes for 200-300 lab tests which account for 95% of all tests. There are also 1,000-2,000 test results that those folks are working on, and if medical organizations would all adopt LOINC, this would constitute a major step toward standardization.

Ms. Humphreys described the CORE Problem List Subset of SNOMED CT and RxTerms, under UMLS. On January 29, NLM and the US Department of Veterans Affairs (VA) signed an agreement for integrated distribution of RxNorm and VA Drug Classes. NLM is also working with the US Food and Drug Administration (FDA), for earlier creation of RxNorm names and codes so that those are in place when FDA approves new drugs. In addition, FDA is reviewing their names and codes for over-the-counter drugs, so NLM can add them to Daily Med and RxNorm. Another development is a way of mapping from clinical vocabulary to billing codes. Enhanced user support is key, to encourage widest possible usage of electronic health records. Strategies include redesigned Web sites for documentation (such as one for UMLS, in the Entrez "Bookshelf" collection), and additional training opportunities (such as webinars) and materials.

Much has been done, but there is much to do. "Meaningful use" and EHR certification should yield what's needed most of all: feedback from EHR developers and user who are motivated (in spite of themselves) to use standard vocabulary. She credited LHC, LO, OCCS, NCBI, and SIS for their involvement in this landmark effort.

Chairman Harris added that, in the next 24 months, the federal Health IT initiative would be taking every acute care facility in the US into the world of IT, and about 800,000 doctors, as well. Effective use of a standard vocabulary will help drive their adoption of the new system. Many of the tools and technologies that will be used have been developed by NLM and its grantees. Dr. Tenley Albright said that these standards will have an impact throughout the nation, and perhaps all over the world. She hoped that NLM's role in this work could be communicated more widely. Perhaps members of the Friends of the NLM (FNLM) could attend future Board meetings. Ms. Humphreys replied that they are welcome anytime. She asked what was still missing in the development of medical standards. Ms. Humphreys answered that MeSH staff is looking into missing issues and problems with SNOMED CT. She would like an expansion of drug therapies, beyond drugs currently on the US market. In addition, medical devices need to be included in the standards. Chairman Harris agreed, commenting that many devices are used outside the hospital—sometimes implanted in patients themselves, or used in their homes.

### IX. REPORT FROM THE NIH DIRECTOR

NIH Director Dr. Francis Collins listed five areas ripe for major advances that could reap substantial benefits in the future: (1) applying high-throughput and computational techniques to understand fundamental biology and uncover the causes of diseases; (2) translating basic science discoveries into new and better treatments; (3) putting science to work for the benefit of health care reform; (4) a greater focus on global health; and (5) reinvigorating and empowering the biomedical research community.

For FY 2010, 84% percent of NIH spending (\$26.0 billion) was spent extramurally and 16% (\$5.0 billion) intramurally. Research project grants account for roughly 53% of that funding. President Obama's FY 2011 budget proposes \$32.2 billion for NIH, an increase of \$1 billion or 3.2%. However, American Recovery and Reinvestment Act (ARRA) funds will go away after FY 2010, Dr. Collins explained, and that will stress NIH.

NIH advances knowledge through basic research, as the steward of medical and behavioral research for the nation. Investigator-initiated research is the foundation of biomedical advances, and he mentioned the NIH scientist who cracked the genetic code, Nobel Laureate Dr. Marshall Nirenberg, as an excellent example.

Next, Dr. Collins discussed NIH's other mission: applying knowledge to extend healthy life. A graph showed the steady decline in US age-adjusted death rates over the past decade. In fact, the US sees one year added to the average life span every 5.5 years (obesity may threaten that), and disability rates among the elderly continue trending downward.

Does medical research benefit the economy? A 2007 National Academy of Sciences study stated that economists estimate that about half of US economic growth since World War II has been the result of technological innovation. According to Families USA, each dollar in the NIH budget generates \$2.21 in state economic growth annually, and each NIH grant creates seven jobs.

ARRA appropriated \$10 billion to NIH; of that, \$8.2 billion went to scientific research. New were created, like Challenge Grants, Grand Opportunities (GO) Grants, and summer laboratory jobs for students and teachers. By now, almost all ARRA money has been allocated, with 13,000 grant awards to 1,885 new investigators. Estimated job creation and retention is about 50,000 over two years. President Obama and HHS Secretary Kathleen Sebelius visited NIH September 30, 2009 (the last day of the fiscal year), to reiterate their strong support for science and to highlight NIH's ARRA awards.

What does the future of NIH look like? The NIH Common Fund (formerly the NIH Roadmap) now supports: the NIH Director's Pioneer Award, given to exceptionally creative individual scientists; the New Innovator Award, funding promising new investigators; and the Transformative R01 grant, for exceptionally innovative, high-risk, original research projects.

A chart on grant success showed the rates averaging 25-35% but, with flat budgets since 2003, the rate has fallen to 20%. FY 2011 is not yet clear. Challenge Grant applications numbered 20,000, of which 800 could be funded. The other 96% percent are likely to come back in the next fiscal year and success rates will plummet. Dr. Collins said that success rate data does not resonate much on Capitol Hill; lawmakers want to hear about the science itself.

Finally, the NIH Director noted the importance of making the case for NIH. He has an e-mailbox, <u>NIH-LISTENS@nih.gov</u>, which solicits ideas for outreach and innovation at NIH. A new booklet, *NIH...Turning Discovery into Health*, helps tell the NIH story. A Web site, <a href="http://recovery.nih.gov">http://recovery.nih.gov</a>, has a wealth of information on ARRA-funded projects.

Board Member Dr. Jordan Cohen asked how NIH could deal with the falling success rate for grants. Dr. Collins replied that, although ARRA was meant as a short-term infusion of funds, there are ways NIH can soften the landing. It's a challenging situation, but NIH will do all it can, making sure that early-stage investigators get sufficient funding. Board member Dr. John Connolly asked about other nations which are seeing greater longevity, due in part to NIH research. Dr. Collins said people in other countries have learned the lessons of NIH research better than Americans, sadly. NIH must focus more on the science of health care delivery and behavior change. Dr. Connolly asked what other nations are spending on biomedical research, and Dr. Collins replied that China is rapidly accelerating its percentage of GDP, as is India. If other nations do the research and the US just takes advantage of it, which will not aid the US economy. Dr. Detre told Dr. Collins that NLM is NIH's most important laboratory and needs larger quarters and more resources. Dr. Collins agreed but said that the forecast for the next two years is bleak. Congress is facing a \$9 billion federal deficit. Chairman Harris asked how the US could contain health care costs. Prevention is key, said Dr. Collins. There should be incentives for individuals and institutions, to foster healthy behavior. Adverse drug reactions are the fifth leading cause of death in the US; better record keeping would help, along with expanded studies in pharmacogenomics. NIH may team with a group of HMOs in rapid response collaboration, exploring payment incentives based not on services but on patient outcomes.

### X. INTELLIGENT QUESTION ANSWERING IN THE HIV DOMAIN

Dr. Amar Das, Assistant Professor of Medicine and Psychiatry/Behavioral Sciences at Stanford University School of Medicine, discussed: "The QuADRI (Question Answering about Drug Resistance Information) Project: Intelligent Question Answering in the HIV Domain." It is the subject of a two-year NIH ARRA challenge grant which addresses one of NLM's priority topic areas: the development of an intelligence search tool for clinical questions.

Drug-resistant mutations are a major obstacle to HIV treatment success. Genotype testing is recommended before selecting a regimen, but clinical interpretation of results can be difficult. Clinicians generally gather as much data as possible, to see patterns and determine the best regimen. How can clinicians follow courses of treatment for similar patients and see outcomes?

QuADRI lets doctors to ask questions in English, and then maps them to a logical form. The information in the answers would come from the published literature (PubMed, for example) and clinical data. Often, clinicians ask questions in a dense way, using a lot of clinical terminology. For these queries, the question maps to some form of structured knowledge, such as a guideline. Questions in QuADRI are resolved by deductive and temporal reasoning. The results are retrieved from fragmented data and knowledge sources, including databases, software, and formal ontologies.

Dr. Das next showed the Board a sample query and put QuADRI to the test, with a question about a patient taking one drug. The sources of data and knowledge for the answer are the Stanford HIV Drug Resistance

Database and RxNorm, the NLM Unified Medical Language System product. Answer fragments provided by the resources are composed into answers to the original English question. He described the BRIDGE System, built on a platform of existing resources and algorithms, and the SNARK Reasoner, a fully automatic, first-order theorem prover with special facilities for temporal reasoning—performing date and time computations for various regimens and their outcomes.

Dr. Das and colleagues have built a prototype system. Once it's fully functioning, they will have clinicians test it for flexibility, accuracy and thoroughness.

Dr. Thomas Detre praised the presentation and pronounced this tool as the beginning of a promising future. He thought the tools and techniques used in QuADRI could easily be applied to the treatment of diabetes and other ailments, and in personalized medicine.

NLM Acting Director of Extramural Programs Dr. Valerie Florance asked whether Dr. Das and colleagues knew what the answers to queries will look like, although the clinician won't see that entire process. He said that they have been awarded an NLM grant for that purpose.

Board member Dr. Carol Friedman asked how many mappings would be needed, to answer a wide range of questions. Dr. Das said his team has a dozen key concepts that clinicians always use. Most of the work has to be done on the ontology side. There are probably about 100 rules.

Board member Dr. Louis Rossiter asked whether the medical record showed information on adherence. No, replied Dr. Das, and the de-identified data does not include dosages either. Chairman Harris asked about prospects for portability of this system. Dr. Das said that standard terminology helps a lot, but the challenge is the knowledge base, which can vary from institution to institution. Dr. Lindberg noted that the group has wrestled with the temporal aspect of treatment. Have they looked into cause and effect, too? Dr. Das said that that was their ultimate goal, but they haven't yet done so, because of lack of adherence data. Dr. Lindberg also noted that there can be idiosyncratic drug reactions among adults.

### XI. EXTRAMURAL PROGRAMS REPORT

NLM Deputy Director for Research and Education, Dr. Milton Corn mentioned the declining success rates for grant. This may not be of great concern to Congress, but is a major worry for NLM and other NIH ICs. Dr. Lindberg said that Congress actually is concerned about the data, as he's heard from Dr. Collins in a previous conversation, but the US Office of Management and Budget (OMB) is not. Dr. Corn noted that NLM can't sustain its unique segment of science—the application of computation and computer science, and behavioral science, to biology and medicine, if there's not a reasonable success rate for proposals. The talented scientists will move on to other pursuits. A 35% success rate is reasonable. Drs. Corn and Florance will present updates on what they're doing to increase success rates at future Board meetings.

Dr. Corn asked the Board's formal approval of the NLM grants program's operating procedures. When the Board approves a set of recommended grants, they are also approving each grant's budget. Over time, that budget may be revised downward or upward. Under the proposed guidelines, identical to those approved since 2002, NLM staff will have the discretion to approve those adjustments. However, if either kind of adjustment is \$40,000 or more, NLM EP would be required to report that fact at the next Board

meeting—not for approval, but just as a notification of that fact. The notion was made and seconded, and the carried unanimously.

Dr. Corn sought the Board's review of two new concepts. The first is a grant program to encourage collaboration between extramural scientists and intramural researchers at NLM. The rigid divide should be relaxed, Dr. Corn said, so that NLM scientists (mostly in LHC and NCBI) can work as a functioning collaborative unit with outside scientists, to address key research questions with a combined expertise distinctly more powerful than if the same individuals worked towards similar goals in isolation. NLM intends to commit \$1.0 million for the first year of this funding opportunity and expects to make three to five awards of about three years' duration. Extramural researchers would put in the application and undergo peer review. The grant announcement would include a list of topics and pertinent NLM investigators with whom the applicant could collaborate. Dr. Mitchell hailed the idea but asked whether intramural investigators would be compensated, too. The work would have to be something that the NLM division was already interested in and working on, Dr. Corn replied. Mr. James asked whether intra- and extramural investigators are compensated the same and Dr. Corn said that they roughly are. Chairman Harris asked about the origins of the wall and Dr. Lindberg said it was based on the fallacious idea that intramural scientists, with access to grant applications, would steal all the good research ideas from the extramural group. Ms. Humphreys noted that NLM scientists do collaborate frequently with outside scientists, but up to now it has not been formally encouraged. Mr. James asked whether possible conflicts of interest would be carefully monitored. Yes, Dr. Florance replied, during the peer review process. Would the study section review criteria remain the same, Dr. Rossiter asked. Absolutely, replied Dr. Corn. The motion to approve carried unanimously.

The second new concept is a remote virtual dialogue software research project. Dr. Michael Ackerman, NLM Associate Director for High Performance Computing and Communications, said that it would take the "Dialogues in Science" interface, currently on view in the NLM Visitor Center, and make the technology available online. NLM never wants to charge its users for any service, so it needs to locate open-source free software, or else invent its own. The project would cost roughly \$1.5 million and take two years. Ms. Stanley asked whether it was doable and Dr. Ackerman replied, yes, although it would be a leap of faith, like the Visible Human Project. It's potentially an important educational tool. The motion was made and seconded, and passed unanimously.

Dr. Florance noted that the details of her presentation were in the Board book. Dr. Collins already covered NIH/ARRA reports (viewable at <a href="http://report.nih.gov/recovery">http://report.nih.gov/recovery</a>). Enhancing electronic health records (EHRs) is one of NLM's Recovery Act signature programs. In FY 2009, nearly \$20 million in ARRA funds were invested in NLM's program on EHRs. These grants fall into three categories: Assistance for Health Care Decisions; Support for Clinical Research; and Real-time Health Research. She next discussed efforts at enhancing peer review at NIH. In March 2008, two steering committees were formed to address the issue, internally and externally. Implementation of recommendations began in June 2008. One goal is a continuous quality review of NIH peer review. NIH has a Web site (<a href="http://enhancing-peer-review.nih.gov">http://enhancing-peer-review.nih.gov</a>), detailing the recommendations. These include new incentives to long-time reviewers, streamlined application forms, enhanced review criteria, and a new scoring system. The continuous evaluation of peer review will include surveys of multiple audiences and the establishment of metrics for key elements of the process. Dr. Lindberg said that finding reviewers for NLM applications has never been a problem. He added that, in the past, NLM and other ICs made lots of site visits to prospective

grantees. This is hardly done at all anymore but was a valuable exercise. You could gauge institutional support, which can't be measured in an application. Mr. James asked whether applications could undergo blind reviews, without investigators' or institutions' names. No, other members replied. Reviewers need to see those names, to know the pedigree, plus other clues in the proposal would probably give away the applicant's identity.

# XII. MEDLINEPLUS TO GO: MOBILE MEDLINEPLUS AND MEDLINEPLUS MAGAZINE DISTRIBUTION

Loren Frant, head of the Health Information Products Unit, Public Services Division, discussed a new program launched in January, 2010 at the NLM—a mobile version of MedlinePlus, in English and in Spanish. Mobile MedlinePlus was created to reach the rapidly growing mobile Internet audience. According to a 2009 Manhattan Research study, about 196 million adults in the United States own a cell phone or a smart phone. The overall growth of mobile in the US is driven by three factors: the proliferation of higher end phones that can do more for you, the unlimited availability of data packages, and faster and better network speeds. A 2009 report by Morgan Stanley predicted that more people will be accessing the Internet from mobile devices than from the desktop or laptop. Most importantly for NLM is that mobile users are seeking health information. Manhattan Research data shows a doubling in searching for health information on the mobile Web, from February 2008 to February 2009.

NLM's goal was to take the content of the English and Spanish versions of MedlinePlus and optimize it for a mobile environment. That is not as simple as it sounds. An important decision had to be made at the outset: whether to make a mobile Web site or a mobile "app" (application). Mobile apps are device-specific, so a different app must be built for each device you want to support. For this reason, NLM developed a mobile Web site instead. A mobile Web version of MedlinePlus will reach a broad audience and be usable on a variety of devices.

One of the greatest challenges in mobile Web site development is the wide range of devices that can access a mobile Web site. It is called device diversity. The technology behind Mobile MedlinePlus uses an open source standard called WURFL (Wireless Universal Resource File), to recognize the device used to access the site and display images, font size, and other layout elements—optimized for that device.

Ms. Frant showed the NLM MedlinePlus home page on three different devices. She explained that a subset of content from the full Web site, called "snackable bits of information," can be accessed and digested quickly. She noted that there is some content that is not supported by a wide variety of phones, like Flash. Knowing the best practices and technical constraints helped to determine which types of content to use on the mobile device. Mobile MedlinePlus includes summaries of over 800 diseases, conditions and wellness topics, as well as the latest health news, an illustrated medical encyclopedia, and information on of prescription and over-the-counter medications.

Ms. Frant also described her office's use of DeviceAnywhere, a mobile testing platform. For the test phase, a variety of cell and smart phones were hooked up to servers to test, virtually, the MedlinePlus Web site on this device. Ms. Frant provided Board Members with sample phones, so that they could try out Mobile MedlinePlus for themselves. Early research shows that people still like viewing the content, even in the smaller format. The search engine on Mobile MedlinePlus is Vivisimo, also used for the full

MedlinePlus and other NLM Web sites. Vivisimo provides a robust search experience and leads users to many desirable items from the full MedlinePlus Web site.

The launch of the mobile Web site and has received favorable coverage in *The Los Angeles Times* and other prominent news outlets. So far, over 73 percent of usage is from the United States. The MedlinePlus team monitors feedback closely and encourages users to write them with comments and suggestions.

NLM Director of Communications Kathleen Cravedi discussed another example of MedlinePlus on the go: *NIHMedline*Plus magazine. She showed a video clip produced by the local CBS station featuring Loren Frant, discussing the MedlinePlus Web site and *NIHMedline*Plus magazine. Ms. Cravedi noted that the magazine was initiated in large part because of a FY 2006 report by the US House Labor/HHS/Education Appropriations Committee, which called upon NIH and NLM to sensitize the public about NIH-sponsored research. The report endorsed the efforts of NLM to produce the magazine, and to distribute it in physicians' offices, for their patients. She pointed out that the magazine reaches people who do not have Internet access and that it is a public/private partnership between the NIH, the NLM, and the non-profit Friends of the NLM. It is a free, 32-page quarterly for consumers, and contains no advertising. It is designed to translate NIH research results into "news you can use" for the public and to link readers to medlinelineplus.gov.

NIHMedlinePlus magazine was launched in a Capitol Hill event in 2006. In attendance were Sen. Tom Harkin (D-IA), the Chair of the Senate Labor/HHS Appropriations Subcommittee, Cong. Ralph Regula (R-OH), then-NIH Director Dr. Elias A. Zerhouni, NLM Director Dr. Donald Lindberg, the late FNLM President Congressman Paul Rogers, and the issue's cover personality, Mary Tyler Moore. Ms. Cravedi mentioned that NLM was successful in launching the Spanish-English version of the magazine, NIH MedlinePlus Salud, in February, 2009. It, too, is free. Salud is distributed to clinics and other medical care sites nationwide. It is a partnership of the FNLM, NLM, NIH, and the National Alliance for Hispanic Health (NAHH).

Both versions of the magazine became available online in February, 2009. They are Section 508 compliant and have enjoyed more than 700,000 page views to date. All articles are indexed by the MedlinePlus search engine, Vivisimo, and are sent to about 200,000 doctor's offices nationally, plus all health science libraries, congressional offices, and federally-supported community health centers. Copies are sent to the press, the NIH community, individual and bulk subscribers coast to coast, a select number of hospitals, and to professional conferences where NLM has a presence.

NLM launched the magazine with a circulation of around 30,000. Today, that figure is around 500,000. How does that translate into readership? There is a pass-along formula that is used to determine how many eyes will see each copy. The readership in 2006 was 300,000; today, it is around 5 million. There are about 40,000 individual and bulk subscriptions, averaging out to an increase of 10,000 each year.

Selby Bateman is managing editor of *NIH Medline*Plus magazine and the editor of Vitality Communications, the largest publisher of health materials in the US. Mr. Bateman discussed the distribution of the magazine. He noted that, in 2008, the magazine partnered with the Peripheral Arterial Disease (PAD) coalition to produce 200,000 additional copies. NLM also received additional HIV/AIDs funding, to produce 100,000 copies and, in 2009, the American Diabetes Association funded an additional

150,000 copies. Salud is supported by NLM's partner, the National Alliance for Hispanic Health.

He noted that most funding for the magazine has come from NLM. NIH Institutes all contribute their time and over half have also contributed financial support, totaling over \$200,000. Private partners have provided nearly \$600,000, and NLM has furnished the remainder—\$3 million since 2006. By partnering with other government agencies, voluntary health societies, drug companies and other businesses, and foundations, increased distribution may be possible and a broader audience reached. Educational grants are another possibility for increased funding. Issues of the magazine can be customized, too, for partner organizations. Lastly, Mr. Bateman detailed the magazine's strategy for growth, its communications plan, and its proposal for evaluation.

Members of the Board admitted that it would take awhile to adjust to the new mobile environment for health information, but they are eager to do so. Board member Eileen Stanley said that the Outreach Subcommittee, which she chairs, discussed distribution of the magazine. She said that, just as Highlights is the magazine for children, and Consumer Reports is the magazine for consumers, NIH MedlinePlus magazine should be the magazine for trusted health information. Creating an index of all previous magazine articles was suggested. Board member Bruce James and others discussed the need to focus on preventive health care. Dr. Lindberg mentioned there is a *Prevention* magazine but that NLM should help readers focus on understanding as well as preventing illness. The fact that the magazine does not have advertising may or may not be helpful, noted Mr. James. Even so, there are ways to customize it so it will be of interest to partners. Chairman Harris asked whether the magazine reaches out to the NIH extramural research community for content. Mr. Bateman said that this was an important focus of the magazine and important to potential funders. Dr. Lindberg said that NLM has to start more than a year ahead, to get funding for specific issues. NLM Deputy Director for Research and Education Dr. Milton Corn said that research should be prominent in the magazine. Asked whether the magazine had a mission statement, Mr. Bateman mentioned it was embedded in the originating papers of the magazine but could be made more prominent. It was suggested that NLM might consider partnering with AARP, as the Library of Congress does. Chairman Harris suggested that further discussion take place at a future meeting.

### XIII. APPOINTMENT OF BOR CHAIR NOMINATING COMMITTEE

The Members of the BOR Chair Nominating Committee were announced by Dr. Harris. They are Dr. Deanna Marcum, Dr. Charles Rice, and Ms. Gail Graham.

# XIV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Chairperson Stanley noted that the Board spent time discussing Outreach Subcommittee topics relating to the NIH MedlinePlus magazine, the Lost People Finder, and Resources for Haiti. Due to a busy agenda, some items on the Subcommittee agenda were postponed until the May meeting. They include: NLM's online newsletter, *NLM in Focus*; Careers in the Health Sciences; and MedlinePlus African Tutorials. Ms. Stanley introduced Dr. George Thoma, chief of the Lister Hill Center's Communications Engineering Branch, and his team, to demonstrate the Lost Person Finder (LPF).

The LPF will be used to reunite families in Haiti. The program was created to allow the public to

systematically search online photos and learn the status of lost loved ones. When a hospital admits a patient, his or her photo and other identifying information goes into this database. A prototype of this project was shown during an emergency drill held in October 2009 by the BHEPP, mentioned yesterday. From that exercise, NLM learned how information could and could not be entered into the Lost Person Finder program by triage personnel during emergencies. Following the drill, the system was modified to reflect lessons learned. When the earthquake struck in Haiti, it was felt that LPF would be of help. For that to happen, though, the LPF had to be transformed from a hospital triage system to a general, community-wide system. Technical changes were made and the system was deployed yesterday. There are three ways to enter the information into the Haiti Earthquake People Locator, as it is now known: by iPhone app; by e-mail from a cell phone; or by computer. The data comes to the NLM site and can be searched in Google as well. Other research opportunities remain to be pursued. Lister Hill Center electronics engineer Mike Gill and staff scientist Dr. Sameer Antani demonstrated the site for the Board. Afterwards, members whether both missing and found people can be displayed on the same screen. Others asked about the availability of cell phones in Haiti and whether they were equipped with the cameras to take photos. Members suggested it would be smart to create photo archives in advance of an emergency, in the US and abroad.

### XV. IMAGES IN THE HISTORY OF MEDICINE

Dr. Paul Theerman, head of Images and Archives in the History of Medicine Division, noted that NLM suffered a great loss with the passing of Dr. Marshall Nirenberg on January 15. Dr. Nirenberg was awarded the Nobel Prize in 1968 for his work on the genetic code and had a long and distinguished career as a researcher, virtually all of it spent at NIH. He had a significant relationship with NLM and with the History of Medicine Division in particular. The past and present directors of NHGRI, Drs. Francis Collins and Eric Green, have presented work that was dependent upon the work of Dr. Nirenberg at this meeting of the Board. Dr. Theerman gave a biographical sketch of Dr. Nirenberg. In 1959, he began his investigations into the relationship between deoxyribonucleic acid (DNA), ribonucleic acid (RNA) and the production of proteins. With J. Heinrich Matthaei, a researcher from Bonn, Germany, he initiated a series of experiments using synthetic RNA. The two scientists were able to show how RNA transmits the "messages" that are encoded in DNA and direct how amino acids combine to make proteins. By 1966, Nirenberg had deciphered all the RNA "codons"—the term used to describe the "code words" of messenger RNA—for all 20 major amino acids. Two years later, in 1968, Nirenberg's received the Nobel Prize in Physiology or Medicine for "interpretation of the genetic code and its function in protein synthesis." Images from Dr. Nirenberg research, including his code chart, were shown to the Board. From the late 1960s until his death, he worked in neurobiology. NLM's connection with Dr. Nirenberg came about when he entrusted his collection to NLM, as an actual archive and as part of its online *Profiles* in Science collection. For many staff members, it was a joy to know and work with him.

Dr. Theerman then discussed the April 2009 launch of a new image platform for its premier database, *Images from the History of Medicine (IHM)*. The database, one of the earliest online systems to make images available to the public, provides access to nearly 70,000 images in the HMD collections and assists users in finding and viewing visual materials for private study, scholarship, and research. The system is catalogued by Voyager and exported into a new system that uses software developed by Luna Imaging, Inc. The new system also provides unwatermarked images for the public. Eighty percent of the images are publically accessible because of age or because they were produced by a federal entity. The new *IHM* 

offers enhanced searching and viewing capabilities to patrons, who can view search results in multi-image display, download higher resolution copies of images, zoom in on image details, move images into a user-defined workspace, and create media groups for presenting images. These functions provide great flexibility in assembling, studying, and presenting images from throughout the collection, as well as from outside the Library. Images include portraits, photographs, caricatures, genre scenes, posters, and graphic art illustrating the social and historical aspects of medicine dated from the 15<sup>th</sup> to the 21<sup>st</sup> century. Originals are found chiefly in the Prints and Photographs collections of the History of Medicine Division, but include photographs and other images from HMD's Archives and Modern Manuscripts collections. Dr. Theerman then demonstrated the database.

Dr. Deanna Marcum asked whether NLM was looking into the possibility of making images available on Flickr. Dr. Theerman replied that that was under exploration, because Flickr would expand the public's access to HMD images. Other Board members observed that, if you Google an image, you can also retrieve a Flickr image. It makes sense to post NLM's outstanding print and photograph holdings in a place where people can easily see them.

### XVI. ADJOURNMENT

The Board of Regents meeting was adjourned at 12:00 p.m. on February 3, 2010.

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

- ➤ Approval of the September 15-16, 2009 Board Minutes
- ➤ Approval of Grant Operating Procedures for 2010
- Concept Review and Approval of a New Grant Program to Encourage Collaboration Between Extramural Scientists and Intramural Researchers at NLM
- ➤ Concept Review and Approval of Remote Virtual Dialogue Software Research

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

C. Martin Harris, M.D. Chair, NLM Board of Regents