











NLM and brought together the Council of Scientific Editors Symposium on the occasion of the global health theme issue. There were over 1000 articles by over 5000 authors on global health published in many journals from around the world. Other areas in which FIC would like to collaborate with NLM are information technology, distance learning, and telemedicine.

In response to a question from Dr. Walker about whether Fogarty would continue to emphasize training people, Dr. Glass replied that it was easier to get money for individual diseases than for training people. NLM, he noted, is out in front in the training arena. Dr. Buchanan expressed an interest in the symposium that Fogarty is planning for 2008. She asked what technology would be important. Dr. Glass replied that Fogarty sponsors a small bioinformatics program with NLM and has a number of grantees conducting worthy projects overseas. There are a number of schools that put coursework on the Internet for free (or for a fee) for long-distance training. Fogarty sees a lot of possible partnerships in technology and is looking for the best ways to make an impact.

#### **IV. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING**

The Regents approved without change the minutes from the September 18-19, 2007 meeting.

#### **V. DATES FOR FUTURE BOARD OF REGENTS MEETINGS**

The Board of Regents will meet next on May 13-14, 2008. The fall Board meeting is September 16-17, 2008. The dates of February 10-11, 2009, were adopted for the following meeting.

#### **VI. REPORT FROM THE NLM DIRECTOR**

Dr. Donald Lindberg reported that NLM is looking at a flat budget. The 2007 budget was \$329 million, the current budget is \$320 million, and the 2009 President's budget is \$323 million. Almost 89% of NIH money is spent on extramural research. About 80% of the work NLM funds is intramural, so a flat budget is essentially a reduction for the Library itself.

Turning to personnel matters, Dr. Lindberg reported that Dr. Steven Phillips formerly a Deputy Director at the NLM, was appointed Associate Director for Specialized Information Services (SIS) in October 2007. He is also heading Trans-NLM Center on Disaster Information Management. He noted that Bob Mehnert retired after an extraordinary number of years of service at NLM. Kathy Cravedi was selected to replace him as Director of the Office of Communications and Public Liaison. Dr. Rob Logan has also relocated to OCPL from the Lister Hill Center and will continue his research there. Dr. Elliot Siegel introduced Dr. Barbara Rapp, who was appointed to the position of Chief of Planning and Analysis. She was formerly the head of the Associate Fellowship Program. Sheldon Kotzin introduced Margaret Haber, on detail to the National Information Center on Health Services Research and Health Care Technology (NICHSR) from the National Cancer Institute; Lisa Lang, the head of NICHSR, who was unable

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to attend the last meeting of the Board of Regents; and Dianne Babski the new Head of the MEDLARS Management Section. Dr. Simon Liu introduced Suresh Srinivasan, now Chief of the new Medical Language Branch in the Office of Computer and Communications Systems (OCCS). He previously worked on the UMLS project in the Lister Hill Center. Dr. Lindberg noted the retirements of Susan Buyer, former Chief of Planning and Analysis, and Marti Szczur, former Deputy and Acting Director of the Library's Specialized Information Services Division.

In the legislative arena, the failure of the genetic privacy act in the Congress is particularly problematic for NIH. Dr Lindberg noted that it is unfair to penalize someone for their genetic make-up for insurance purposes. Most everyone agrees. As NIH moves forward with its GWAS studies, the public may not trust the use of their information if legal protections are not in place.

The NIH *MedlinePlus* magazine is moving forward successfully. Dr. Lindberg asked the Regents to help increase distribution of the magazine, which is meant to help the public learn about matters affecting their health and research underway at the NIH. The magazine needs to get into the hands of the public. Dr. Lindberg also mentioned several projects related to research on interactive publications, in collaboration with the Optical Society of America and the Student National Medical Association.

The NIH Public Access Policy became mandatory with the passage of the appropriations act on December 26, 2007. NCBI has made it extremely simple for journal articles to be put in PubMed Central. Now we will see how NIH-funded authors and publishers respond to the new mandate. NLM will report on progress at the next meeting.

Dr. Lindberg described work that has been ongoing for about five years, with the help of Dr. Phillips and Dr. King, to inspire high school students to pursue careers in science by putting them in contact with noted scientific experts. NLM has sponsored symposia for students in Washington, DC, Chicago, New York (in conjunction with New York University) and, most recently, in Houston, TX. This series is named after Dr. Michael DeBakey, the pioneering cardiac surgeon. Dr. Lindberg then showed a three-minute video with highlights from the December 2007 symposium in Houston. The panel of medical students and residents prompted enthusiastic questions and thoughtful answers from the high school students. One asked, "When did you use calculus?" And, she got an honest answer!

NLM will open a new exhibition in April 2008, *Against the Odds: Making a Difference in Global Health*, addressing factors that determine whether or not a global health program succeeds or fails. NLM will be experimenting with Acoustiguide technology, often used at art museums, which lets visitors hear commentary through a hand-held device.

Dr. Lindberg asked Dr. Jordan Cohen to comment on the report from the Josiah Macy, Jr. Foundation's Conference on *Continuing Education in the Health Professions: Improving Healthcare Through Lifelong Learning*, which both of them attended. Major recommendations

include the elimination of commercial funding for CME, given conflict of interest issues, and the transition from traditional CE, long shown to be ineffective in affecting practice, to providing relevant information and training at a “moment of decision”.

Dr. Lindberg ended by describing Julia Royall’s work in Uganda. A tutorial that she has developed with local Ugandans, based on MedlinePlus, has proven extremely helpful, explaining that malaria is spread not by mangos but by mosquitoes! Dr. Buchanan asked about the distribution of the NIH *MedlinePlus* magazine. If she put one in the hands of every patient, could NLM handle the volume? Unfortunately not in the current budget environment, but we still need to do a better job distributing the 300,000 copies we are currently printing. Other Board Members asked questions regarding Dr. DeBakey and the symposium, and the mandatory public access program and its implications for NLM.

## **VII. CLINICAL TRIALS UPDATE AND BOARD WORKING GROUP ON CLINICAL TRIALS REPORT**

Dr. Deborah Zarin began her report by noting the Clinical Trials Working Group, chaired by Dr. Morton, had met the day before. She then gave overview of the current state of ClinicalTrials.gov, the new legislation that will greatly expand it, and what NLM is doing to comply with the law, which reflects continuing and increasing concern about the transparency of clinical trial information.

ClinicalTrials.gov contains more than 50,000 trials, substantially more than any other public trial registry. Most are intervention trials: 32,000 involving drugs or biologics and about 2,600 device trials. The new law requires registration of device trials, which were not addressed in the under the previous law. About 50 percent of the trials are U.S. only; 32 percent are conducted outside the U.S.; and about 8 percent are mixed. Data come from a variety of providers: U.S. Federal agencies (including NIH) supply one-third; university or nonprofit from around the world is about 40 percent; and industry is just under 30 percent. NLM obtains trial data from about 5,000 different organizations.

Dr. Zarin reviewed the Food and Drug Administration Amendments Act, P.L. 110-85. Title VIII, and what the Library had to do within 90 days of its passage. Essentially, NLM had to expand the capacity of the registry to accept a broader range of trials and to require more information about each trial. Much of the newly required information was already being gathered on a voluntary basis. In addition, the law required NLM to put in certain links from trial records to related information on NLM and FDA websites. After 12 months, NLM must also have an operational “basic results database”. The law is ambiguous on many points, which makes it difficult to implement. For example, determining which trials are covered by the law and who is responsible for submitting data is not straightforward. NLM is working with NIH, FDA, and the Office of the Secretary to clarify how to interpret key provisions.

What has NLM done to date? ClinicalTrials.gov has changed the registration system to enable compliance with the expanded requirements. Even with the uncertainty, staff believes that if you fill out all of the data elements that NLM has put in the CT.gov database, then you will be in compliance. ClinicalTrials.gov has also established links to other sites as required in the law. The law has significant penalties for noncompliance and that is why a lot of people are paying a lot of attention to the implementation details. Both NIH and FDA are supposed to guarantee that their communities are complying with this new law. So, NIH — not specifically NLM — has to be concerned about what constitutes compliance by its grantees and intramural researchers.

NLM has always required the data elements needed to comply with FDA Modernization Act, which originally mandated the creation of ClinicalTrials.gov. Over time, a set of voluntary data elements developed and evolved to meet the needs of various users. The new law is now requiring data that was once voluntary, plus some new information. Examples of the new data elements were presented. Dr. Zarin also showed examples of different linkages — links to MEDLINE and to CHEMIDPlus. And, the law said to link to FDA device trials and drugs.

“Well, after building it, did anything happen?” Yes. In response to the new legislation, ClinicalTrials.gov has shown a 45% increase in new registrations over this time last year. Between early December 2007 and January 20, 2008, about 3,000 new studies were registered, and double the normal rate of updates were received, since the law requires that additional data be added to records for many previously registered trials. Overall, Dr. Zarin’s staff has had a 100% increase in their workload. They used to clear a record within three days, and now their backlog is now about ten days. (The Law mandates fewer than 30 days.)

There is a special and somewhat problematic provision in the new law that affects trials of devices not yet approved or cleared by FDA. Records for those trials cannot be made available to the public (although they must be submitted to the database) until after the device is approved or cleared. This may be true even in cases where the responsible party wishes the registration to be public. HHS is studying this situation.

Dr. Zarin also discussed the new “Results” database, which is unlike anything that has been created before. It must be in place next September. NLM has been thinking about it for several years, and there has been a trans-NIH working group on this. Two basic models for results reporting include: structured narratives and tabular. The law requires the tabular version. If NLM can structure the data entry, then we control the data display. The law requires consultation with risk communication experts to figure out how best to display the data, but initially requires But tables that show demographics and baseline characteristics, explain participant flow, randomization, and retention, and any test of statistical significance.

NLM plans to develop a model for the initial results tables in consultation with trial experts, evaluate draft templates, and try the template on different types of trial designs. There will be opportunities for public comment. Dr. Zarin showed the Board what a *New England Journal of*

*Medicine* article's table of baseline characteristics looked like and what NLM's might very well look like. NLM will also have to think about how to facilitate rational use of the data and provide context. There is also a requirement to establish methods for reporting adverse events within 18 to 24 months of passage of the law. In sum, Dr. Zarin said that NLM is consulting broadly in the development of the database to create a system that will comply with the law. NLM is working with NIH, FDA, and HHS to more clearly define the law's requirements and to develop a system that facilitates compliance.

Dr. Morton thanked Dr. Zarin for her wonderful presentation and her obvious good work on this project and offered to share with the Members the agenda and list of members who were on the Clinical Trials Working Group. Dr. Cohen noted that the project is under fabulous leadership and, as an unfunded mandate, it is a poster child. Dr. Rossiter noted that we will have to be careful with rulemaking, and the Department will decide in the end. Piloting the default adverse events table will be tricky. NLM does not have specific data on who uses ClinicalTrials.gov and what they are looking for - since we do not require registration of individual users. It is an interesting topic and certainly worth determining. Lastly, who are the responsible parties that will be prosecuted for failing to comply with the Law? Dr. Zarin responded to questions from the Board regarding concerns about the tasks in front of NLM to develop a new results database.

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

Dr. Cynthia Morton presented Naomi Miller with the BOR's Award for scholarship and technical achievement: in recognition of her substantial contributions to the high standards and quality of NLM's consumer health products. Ms. Miller is the consumer health information manager in the Library Operations who has made substantial contributions to MedlinePlus and other NLM consumer health resources. Her dedication to excellence, knowledge of medical information and ability to coordinate efforts of a many organizations has contributed immeasurably to the quality and standards of the consumer health products from NLM.

#### **IX. UPDATE ON SIS INFORMATION SERVICES**

Dr. Steven Phillips, the recently named Associate Director of Specialized Information Services (SIS), provided an update on SIS efforts and reorganization. Dr. Phillips noted that the Office of Special Populations, headed by Gale Dutcher, is being converted to the Outreach & Special Populations Branch. He also announced the creation of the Disaster Information Management Research Center. He explained it is a trans-NLM effort, but programmatically a part of SIS because of the work SIS historically has done in the field.

Dr. Phillips discussed new SIS products. The dietary supplements labels database contains information on approximately 2,000 brands of dietary supplements, their ingredients, uses, and manufacturers. LactMed is a peer-reviewed database that lists nearly 600 drugs and other chemicals and provides information on mother's milk and the transmission of those chemicals

from mother to infant. He also noted the collaboration with NIH's Office of Research on Women's Health (ORWH), which is expected to eventually include links from the ORWH webpage to NLM databases on women's health. And, the ToxMystery interactive program for children is now available in Spanish. Dr. Phillips introduced George (Mike) Hazard, Ph.D., of the Biomedical Information Services Branch, who chronicled the creation of a drug information portal, designed to be easy to use and "Google-like." The portal, <http://druginfo.nlm.nih.gov>, consolidates resources at the NLM and other government agencies and provides information on thousands of drugs that can be used by both consumers and professionals.

David Hale of the Biomedical Files Implementation Branch then discussed efforts to create a pill identification database, to help identify unknown solid dosage oral medications. It is a trans-agency effort that includes SIS, other areas of NLM, the NIH Clinical Center, the Department of Veterans Affairs, and the Food and Drug Administration. Lister Hill Center developed a photography station to obtain high-resolution images of pills in the VA's solid dosage formulary for the prototype of the project. Hale explained how the database will bring together details about the color, composition, shape, and size of pills; the FDA's prescription product labeling information; the Department of Veterans Affairs trade names and identification numbers; and the NLM's DailyMed ingredient information. Targeted users are poison control center staff, first responders, health professionals, concerned citizens, pharmaceutical manufacturers, and researchers. Longer term objectives are to include an image with all product information for drug labeling and to develop a mobile, stand-alone resource for a PDA or mobile phone. The team also hopes to include over-the-counter products and supplements. Lister Hill Center's research goal is automated identification of unknown pills based on their physical appearance. After the presentation, Hale fielded questions about the technology, and the drugs that are being included, noting that it will include both brand and generic drugs.

Nicole Dancy, MPH, with SIS's Office of Outreach and Special Populations, addressed the Equal Access Initiative and Computer Grants program, which began in 1990. The National Minority AIDS Council (NMAC), which represents more than 3,000 organizations that deliver HIV/AIDS care to communities of color nationwide, facilitates the program. The NIH Office of AIDS Research provides funding. The program has provided computer workstations for 100 community-based organizations. In 2007, NLM joined the effort. In addition to the computers, the organizations got a scholarship package to attend the United States Conference on AIDS and training from NLM on HIV/AIDS information resources. . SIS surveyed participants and found a majority were not aware of NLM's online resources. Familiarity with AIDSInfo was 66%, but 78% were not aware of PubMed, 66% were not aware of ClinicalTrials.gov, and 60% were not aware of MedlinePlus. SIS held training sessions at the 2007 Conference on AIDS to teach participants how to find and use these and other reputable resources. Dancy said the training was successful, and that tests done before and after showed an average 42% change in participants' ability to access HIV/AIDS information. Dancy said the there is a "continuing need for funding and training for community organizations in order for them to effectively meet the needs of clients and those in the HIV/AIDS community." She said the program will continue in 2008 and

training will be provided at the 2008 Conference on AIDS. Dr. Walker praised SIS saying, “It has evolved in a remarkable fashion and it is something we can be proud of.” Dr. Ball noted it was both interesting and frightening to hear how many people were not aware of MedlinePlus and other “invaluable” resources. This led to a discussion of raising awareness in nursing and medical schools.

## **X. LIBRARIANS’ ROLE IN DISASTER RESPONSE**

Robin Featherstone, a second-year NLM Associate Fellow, discussed her oral history project, “Library Roles in Disaster,” which she conducted at the request of Becky Lyon, Deputy Director of Library Operations and Angela Ruffin, Head of the National Network Office. Over two months last summer, Featherstone recorded stories from librarians across North America about the roles they played in disaster planning, response and recovery. The project included stories of collection recovery, but also focused on community response efforts, which were not considered traditional library work. Featherstone said they covered all kinds of disasters, hurricanes, fires, floods, and other man-made disasters. Featherstone invited 37 participants and recorded 23 full-length stories. Each story is about 10 pages long. Librarians from public, special, and academic libraries are represented, but the majority are from academic health sciences libraries and hospital libraries. Featherstone said medical libraries were deliberately selected because they are NLM’s network and because their contribution was absent from literature.

Through words and pictures, Featherstone shared some of the stories that stood out for her: a librarian at the Toronto Public Health Agency who, after the second SARS epidemic, was asked to organize all the information that was being sent to their emergency call center; a librarian from the University of Southern Mississippi who described watching her emergency manual float away in the flood waters after Hurricane Katrina; a hospital librarian at the New Jersey Hospital Association who created a patient-victim database after 9/11; the library director at Tulane in New Orleans who lost his home and a staff member who drowned while trying to save his elderly mother; a public librarian in Houston who set up a stand-alone library in the evacuation center and repeatedly helped Katrina victims see what happened to their homes by coordinating satellite imagery with Google earth. Featherstone says librarians not only performed the traditional roles to keep their libraries running, they performed non-traditional roles acting in the community or as government partners, acting as educators and trainers to teach emergency responders, collaborating with sister libraries to establish buddy networks and keep access available.

Featherstone developed a prototype for the NNO Web site for librarians to share their stories. She hopes to submit an article on this project to the *Journal of the Medical Library Association*, and she’s presenting at two conferences in the spring. After the presentation, Ms. Stanley said Featherstone’s project is a wonderful way to honor and recognize librarians for their efforts. Stanley also applauded Dr. Phillips’ efforts to create ways for librarians to be part of disaster planning and recovery. Mr. James noted that the Department of Homeland Security is looking to librarians as a source for information dissemination in a disaster. He suggested collaboration

with NLM and other agencies. Ms. Humphreys responded that NLM is very interested in that.

## **XI. NLM GRANTEE — PREDICTING STRUCTURE FROM SEQUENCE**

Dr. Morton introduced NLM grantee Krzysztof Fidelis, Ph.D., a senior scientist and director of the Protein Structure Prediction Center of the University of California, Davis. Much of his current work is carried out with grant support from the NLM for the center for Critical Assessment of Structure Prediction (CASP). The CASP experiment was devised to see what could be expected of methods for protein structure prediction. Dr. Fidelis gave examples of how modeling can be useful, including how it can help in drug design. Dr. Fidelis then explained how CASP differs from what was done previously. He said previously a scientist would develop a method and then select a number of test cases. Predictions were made and the assessment was done by the person who authored the predictions. With CASP, there is the opportunity to compare a large number of methods on target sequences that are selected by organizers. Independent assessors are used to bring as much objectivity to the process as possible. Fidelis said CASP works because of community participation. Seven CASP experiments have been done so far. CASP7 (as this group is called) involved more than 500 researchers from 25 countries. Fidelis noted that some problems remain, including refinement of high accuracy models. Following his talk, Fidelis fielded questions about the history of CASP, next steps, and what remains to be learned.

## **XII. EXTRAMURAL PROGRAMS REPORT**

Dr. Milton Corn, Associate Director of the Division of Extramural Programs, started his report with a procedural matter. The Board reaffirmed operating procedures, giving NLM the right to adjust the dollar value of grants up or down if it is in the interest of research, NLM and NIH. Corn then addressed the cut in the grants program's budget, which is down about 7%. He said most of the pain will be felt by new applicants.. Given that the average grant is for four years, three-quarters of the budget is not touchable. NIH determined that very little cut will be made in the out-year grants of people who have existing grants. This means that a 7% cut in our budget is really a 28% cut in the amount of money available for first time people this year. Corn said the most important thing done in the division of extramural programs is training scientists in informatics and computational biology. He introduced Dr. Valerie Florance to discuss NLM's Informatics Training Program. She said that, in the 1980s, training was primarily in clinical informatics, but it has evolved to include bioinformatics, imaging, public health, early engineering and early clinical research informatics. NLM has trainees at 20 locations across the country. Demographics in 2006: of 232 trainees, 69% White, 21% Asian, 10% African American, 13% unreported; 37% female; cost of a pre-doc trainee \$56,000 per year for four years and the cost of a post-doc trainee \$76,500 per year for three years; 17 PhDs awarded to NLM informatics trainees. Florance said the division is looking at ways to evaluate the outcome of training programs and supplied some statistics. Between 1996 and 2005, 507 NLM trainees completed their training, 67% of them worked on research with funded researchers, and 38% of

them published at least once with their mentor before they left the program. The trainees who left the program went into a variety of employment sectors including academic, business and industry, and health care. With regard to the training programs: on average, each program received 54 applications and made offers to 24% of applicants; 90% retention rate; 81% of core faculty had active research grants; 38% co-authored papers with trainees. Between 1996 and 2006, 50.7% of NLM trainees were lead or co-author on one or more articles, conference papers, abstracts or books; 1,452 peer-reviewed publications were produced. New initiatives launched this year include a short-term trainee position for minority or disadvantaged for a three-month period, and a caregiver leave program that offers extended leave for birth or adoption or care of a sick family member. The presentation led to a discussion on the work force and the need for people trained in informatics. Florance said they have been looking at “stealth training.” Every research grant NLM funds is an informatics research project and they often have trainees (post-docs and graduate students) working on them. So, the Extramural Programs Division is analyzing its research grants and cataloguing the different roles people have to see how much additional training is going on. The group also discussed the fact that informatics is a field where people go back and forth between academia and industry.

**MEETING CLOSED FOR REVIEW OF GRANT APPLICATIONS - 4:30-5:00 P.M.**

### **XIII. DIGITAL PRESERVATION OF HISTORICAL BROADCASTS**

Dr. Morton introduced Ms. Nan Rubin, project director for “Preserving Digital Public Television” (PDPT), an initiative spearheaded by Channel 13/WNET-New York, to design an archive and retrieval system for the long-term preservation of public television. The pioneering educational television station is collaborating with WGBH-Boston, PBS and New York University (NYU), to select past programs for preservation, determine ways to preserve current programs, explore a variety of technical issues, and establish roles and responsibilities for long-term preservation within the public television community.

The Library of Congress, through its National Digital Information and Infrastructure Preservation Program, is sponsoring this groundbreaking effort. Long-term preservation of digital TV content has been underway for a decade, but the growing number of formats and media presents unique challenges. PDPT strives to bring the notion of preservation into the mix. Also, the public expects online access to past programming, so that has to be taken into consideration as well. Ms. Rubin praised NYU’s invaluable involvement; the university library there is a leader in digital preservation efforts and has also helped with the “access” part of the project, by teaching the public television group about metadata and other concepts that allow searchers to find the particular item they seek. Now in the third year of its four-year grant, the PDPT project is a leader in repository design and technical operations for preserving video. Why does any of this matter? Ms. Rubin presented a quotation from *Television and Video Preservation 1997: A Study of the Current State of American Television and Video Preservation, A Report by the Librarian of Congress*: “Public television has been responsible for the

production, broadcast and dissemination of programs which form the richest audiovisual source of cultural history in the US.” To illustrate that point, Ms. Rubin played a montage of television film clips, featuring such notables as Eleanor Roosevelt, Edward R. Murrow, Big Bird and Julia Child.

Dr. Buchanan mentioned that the University of New Mexico had lost some audiovisual materials to fire and flood. She thought NLM, the American Association of Medical Colleges (AAMC) and others should consider aiding medical schools, hospitals, health centers and other such groups in the preservation of curricula, digital laboratory notebooks, distance learning materials and other education media. Dr. Lindberg said that the Library of Congress had just commissioned a report along those lines, about cataloging for the next century, and that he would address it if it could be presented to the Board at a future date. Dr. Hirsh commented that the National Science Foundation is involved in international collaborations regarding digital preservation. He would be happy to confer with Ms. Rubin and her group. Ms. Rubin noted that NYU, and in particular Dr. Howard Besser, had put her in touch with several stellar international digital preservation efforts. Mr. James expressed hope that Ms. Rubin and her group would urge the U.S. government to take a seat at the table regarding the establishment of international standards for digital preservation. In the past, on such matters as passports, the U.S. has gone its own way, with unfortunate consequences. He also recommended that Ms. Rubin consider enlisting the National Endowment for the Humanities as a collaborator and possible sponsor.

#### **XIV. PERSONAL HEALTH RECORD (PHR) INFRASTRUCTURE – THE PHR AS A CENTROSOME FOR NLM’S VOCABULARY AND KNOWLEDGE RESOURCES**

Dr. Clement McDonald, Director of NLM’s Lister Hill National Center for Biomedical Communications (LHNCBC), put forth his analogy of the PHR infrastructure, with NLM’s knowledge resources and vocabulary standards, as the “centrosome,” because that part of the cell pulls the chromosomes in the cell into new cells when the cell divides. He showed a record of various vital signs for patient “John Smith,” in NLM’s pilot PHR format, and talked about personal health records as solutions to many of the problems posed by patient medical records, which can be in many formats and in many locations. This pilot version of the NLM PHR will be targeted at adults caring for elderly parents and/or young children. They are in greatest need of recordkeeping and, in Dr. McDonald’s experience; they work hardest at keeping records of current medication use, immunizations, test results and so forth. The initial goal is an electronic notebook, for entering and managing patient data, and reminder notices about screenings, immunizations, etc. The early version takes data directly from users, but LHC aims to accept data from institutions, too. How will this work? The pilot PHR will be a pure Web product, with no plug-ins. Dr. McDonald called the form-building tool developed at Lister Hill Center “A Form For All Reasons,” because it is very flexible and the user can add or remove fields with ease. The form does the data entered, based predominantly on NLM-supported vocabulary standards. The form generator also provides auto-completion, strong edit checks, the use of incomplete dates (if the patient can remember the year of an appointment but not the month; for

example), help text and personal decision support. The new forms can be captured as spread sheets or as XML (or other format) downloads. Data on the forms will include medications, diagnoses (including International Classification of Diseases codes) and problems, diet, surgeries, immunizations, allergies, preventive test results and questions for doctors. They are HIPAA compliant and completely confidential. In phase 2, Dr. McDonald said that many sources of patient data will be allowed. The system will be able to send e-mail reminders about procedures and to communicate in other ways. The NIH Clinical Center and Suburban Hospital in Bethesda are under consideration as test sites for this product.

Dr. Friedman asked Dr. McDonald who the competition was, for devising PHRs. Dr. McDonald said that there are stand-alone versions, as is the case for certain hospitals and WebMD, and there are much larger networked versions, using the Google/Microsoft approach. Dr. Lindberg commented that the key issue in any patient health record is trust, implying that factor might make NLM's initiative attractive. Dr. Lindberg mentioned the VISTA (Veterans Health Information Systems and Technology Architecture) program, used by the Department of Veterans Affairs, is a good portal system, but doesn't allow patients or their families to download data onto a thumb drive. Ms. Graham said that veterans are able to download information to their own thumb drives now, and VISTA does send them reminders and have some of the functions Dr. McDonald mentioned. Their next step will be to add a delegation feature, so that a patient can delegate a relative in another state to have access to his or her records. If that could be done electronically, instead of the relative having to come directly to the VA facility for access, of course, that'd be much simpler and would increase overall usage. Also, people do prefer ordering their medications online and making their appointments online. Dr. Harris remarked that the Cleveland Clinic has some 120,000 patients and they, too, are working on the patient health record challenge. He noted that there are challenges with granting family members access to medical records. He also asked whether NLM saw their new PHR as an attempt to provide patients themselves with their health records, or whether to widen the audience to include hospitals and doctors. Dr. Lindberg replied that this effort was meant to put the focus of health care delivery back on the patient, and not on the doctor, the AMA, lawyers, etc. Dr. Harris commented that this matter presented NLM with an enormous opportunity, and he urged Dr. McDonald and his staff to start out with a streamlined product, not awash in data but having all the essentials. This would get us further down the road, faster, toward the goal of a confidential patient health record, and also tells patients that this is truly their responsibility. Dr. Friedman mentioned that physicians haven't always been good about entering patient data electronically. Do we think patients themselves will be diligent about that? Ms. Stanley thought it would need to be effortless. Dr. Rossiter suggested that family history would be another good thing to include.

## **XV. MYMEDICATIONLIST**

Dr. Stuart J. Nelson, head of the Medical Subjects Heading (MeSH) Section, Library Operations, discussed *MyMedicationList*, a prototype application to allow users to manage their medication

profiles. It uses *RxNorm*, a standard drug vocabulary, and stresses medical profiles in a standard format derived from HL7's Clinical Document Architecture. A principal aim is to give patients control over their own information; they can store, update, add and delete medications from their personal medication lists, either on their computer or via a thumb drive. This is actually a specialized type of Patient Health Record, written in Java. The patient, reading off their bottle of pills, can fill in the name of the medication, the dosage and special instructions. The Board had questions about whether this system would point out drug interactions and, if so, whether that data would be reliable and up-to-date. Dr. Nelson agreed that drug interactions was an important function that is not available in *MyMedicationList*. Dr. Ball said that she had her own list of medications on a thumb drive but that her provider wouldn't look at it, over fear of viruses. Ms. Stanley said that it can be hard to figure out dosage from some labels, or even which particular medication one is taking. Dr. Nelson said that the pictograms should help with the latter, showing not only the image of the pill but instructions on how to take it. Health literacy is definitely a concern with this project.

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

Ms. Ellen Stanley, Subcommittee chair, reported on the group's February 12, 2008 meeting. The Subcommittee is exploring new distribution methods for NIH *MedlinePlus* magazine. Circulation has risen dramatically, to 300,000, but they'd like to explore ways of expanding that number and broadening the readership. Ideas under exploration include distribution to hospitals, health education facilities and other health-related sites, to ensure that the publication gets into the hands of patients. Also, should the magazine target youth? If so, it may have to go electronic, since that age group relies less and less on paper for information. The Subcommittee saw a demonstration of the new [ClinicalTrials.gov](http://ClinicalTrials.gov) link within [NIHSeniorHealth](http://NIHSeniorHealth). Now, users can view information on trials directly from the entry point on [NIHSeniorHealth](http://NIHSeniorHealth), which also has great features such as enlargeable type, to improve accessibility. At the Subcommittee meeting, the group saw a demonstration of *ToxTown en español*, as well as *ToxMystery en español*, by SIS staff member Cindy Love. Both of these rich resources should be promoted to science teachers and via other educational channels. As previously mentioned, NLM has sponsored four Michael DeBakey Seminars in Science. So far, these sessions have offered glimpses of high-level medical careers, like surgery. The group asked whether that programming could be altered at future events, also emphasizing allied health careers that will become increasingly important with the graying of America. Dr. Ball suggested that the seminars be held for students of *junior high* age, or even younger, because, by high school, many students have already picked a career. Mr. James agreed. Ms. Humphreys suggested that NLM do more outreach using science materials on its Web site, like *ToxTown*, *Profiles in Science*, and the educational modules that the History of Medicine Division develops for its exhibitions. Traveling versions of the exhibitions can be used for educational purposes, too.

## **XVII. NLM'S USE OF VIVISMO**

Dr. Simon Liu and Ms. Joyce Backus presented NLM's new search engine, Velocity (a product of the Vivisimo company), launched in October 2007 on three major Web sites: NLM's home page, MedlinePlus and MedlinePlus en español. Why a new search engine? As Liu put it, it helps users search less and find more quickly. Vivisimo was selected in an open competition. NLM staff worked closely with the company to meet its high expectations. The Library acquired a perpetual license and enterprise-wide coverage, meaning that the search engine can be used across many sites, if desired. It negotiated for knowledge transfer training and technical support, as well. Currently, NLM is installing all features and functionalities for the search engine, and adding additional Web sites. We are presently halfway through that list, Liu reported.

Ms. Backus indicated that the home page is not the most popular portal to NLM. About half of the traffic to the NLM site comes in via Google or some other interface. Right now, in Vivisimo, NLM is crawling NCBI and SIS (not their actual databases, but user guides, tutorials, description of programs and services, etc.), Lister Hill Center, MedlinePlus (over half of all terms typed on the home page search screen are medical terms, not the names of NLM programs) and the top level of Profiles in Science. Backus then showed the difference with "before" and "after" Vivisimo searches for various health and wellness topics, as well as prescription drugs. Using customer input from NLM to tailor the computer-generated results is what the new search engine does best, producing much improved and better focused results. Vivisimo's flexibility and extensibility will let NLM make continued improvements in the future. Mr. James asked whether NLM staff were at all concerned at the small size of the Vivisimo company. Liu said NLM had considered this, but that so far the smaller size has meant more attention and a desire on the company's part to customize Velocity engine to fit the Library's needs perfectly. Ms. Stanley expressed her positive reaction to the new search engine, and commented that NLM is unique, being both research-oriented and customer service-oriented. Dr. Hirsh said that Vivisimo had an excellent product, and he was glad that NLM was working with them. Mr. James said he liked to see that NLM is willing to fund ideas that might not get private support. To that, the newest Board member added, "I like it here."

## **XVIII. ADJOURNMENT**

The Board of Regents meeting was adjourned at 12:00 p.m. on February 13, 2008.

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

- Approval of the September 18-19, 2007 Regents Minutes
- Approval of February 10-11, 2009 Meeting Dates
- Discussion of the first Working Group on Clinical Trials Meeting
- Reaffirmation of the Grant Operating Procedures

Appendix A - Roster - Board of Regents

**February 12-13, 2008 - Board of Regents**

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

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

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