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

MINUTES OF THE BOARD OF REGENTS
September 20-21, 2005

The 140th meeting of the Board of Regents was convened on September 20, 2005, 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 September 21, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

MEMBERS PRESENT [Appendix A]**:**
Dr. Thomas Detre [Chair], University of Pittsburgh
Dr. Holly Buchanan, University of New Mexico
Dr. Ernest Carter, Howard University
Mr. Richard Chabran, California Community Technology Policy Group
Dr. Newt Gingrich, The Gingrich Group

MEMBERS NOT PRESENT:
Dr. A. Wallace Conerly, University of Mississippi Medical Center
Dr. Vasiliki Karlis, New York University, College of Dentistry

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:
Ms. Wendy Carter, U.S. Department of Veterans Affairs
Ms. Eleanor Frierson, U.S. Department of Agriculture
MGEN Bruce Green, U.S. Department of the Air Force
Dr. Deanna Marcum, U.S. Library of Congress
Capt. Thomas McGue, U.S. Department of the Navy
Dr. Michael Pazzani, National Science Foundation
Col. John Powers, U.S. Department of the Army
Dr. Charles Rice, Uniformed Services University of the Health Sciences

CONSULTANTS TO THE BOR PRESENT:
Dr. Marion Ball, Johns Hopkins School of Nursing
Dr. William Stead, Vanderbilt University
Dr. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:
Dr. Christopher Austin, National Human Genome Research Institute, NIH

Dr. Richard Carmona, Surgeon General, Department of Health and Human Services
Ms. Vicky Gregg, BlueCross BlueShield of Tennessee
Dr. Ronald Kikinis, Brigham and Women's Hospital
Dr. Kenneth Mandl, Harvard Medical School
Dr. Joyce Mitchell, University of Utah
Dr. Arthur Toga, University of California
Dr. Nora Volkow, Director, National Institute on Drug Abuse, NIH

MEMBERS OF THE PUBLIC PRESENT:
Mr. Vince Haley, American Enterprise Institute
Mr. David Kenton, Retired NLM
Mrs. Hedda Kenton, Public
Ms. Marion Crawford Kiley, Friends of the NLM
Mrs. Mary Lindberg, Public
Ms. Kathleen McCormick, SAIC
Mr. Thomas West, The Krasnow Institute

FEDERAL EMPLOYEES PRESENT:
Dr. Donald A.B. Lindberg, Director, NLM
Ms. Betsy Humphreys, Deputy Director, NLM
Dr. Donald King, Deputy Director for Research and Education, NLM
Dr. Michael Ackerman, High Performance Computing & Communication, NLM
Ms. Suzanne Aubuchon, Office of the Director, NLM
Ms. Joyce Backus, Division of Library Operations, NLM
Mr. Yiming Bao, National Center for Biotechnology Information, NLM
Dr. Dennis Benson, National Center for Biotechnology Information, NLM
Dr. Steve Bryant, National Center for Biotechnology Information, NLM
Ms. Susan Buyer, Office of Health Information Program Development, NLM
Dr. Milton Corn, Division of Extramural Programs, NLM
Mr. Todd Danielson, Executive Office, NLM
Mr. Timothy Doerr, National Center for Biotechnology Information, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Ms. Jessica Fong, National Center for Biotechnology Information
Dr. Charles Friedman, Division of Extramural Programs, NLM
Ms. Wendy Hadfield, Executive Office, NLM
Ms. Amy Harper, Associate Program, NLM
Ms. Cristina Horta, Associate Program, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Ms. Michelle Krever, Division of Extramural Programs, NLM
Ms. Mellanye Lackey, Associate Program, NLM
Dr. David Landsman, National Center for Biotechnology Information, NLM
Ms. Janet Laylor, Office of the Director, NLM

Dr. David Lipman, National Center for Biotechnology Information, NLM
Dr. Simon Liu, Office of Computer and Communications Systems, NLM
Dr. Robert Logan, Lister Hill Center, NLM
Dr. Matthew Mailman, National Center for Biotechnology Information, NLM
Ms. Lisa Massengale, Associate Program, NLM
Mr. Robert Mehnert, Office of Communication and Public Liaison, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Mr. David Nash, Office of the Director, NLM
Dr. Aaron Navarro, Lister Hill Center, NLM
Dr. James Ostell, National Center for Biotechnology Information, NLM
Dr. Arthur Petrosian, Division of Extramural Programs, NLM
Dr. Barbara Rapp, Division of Library Operations, NLM
Ms. Marianne Reynolds, Associate Program, NLM
Ms. Julia Royall, Office of Health Information Program Development, NLM
Dr. Steve Sherry, National Center for Biotechnology Information, NLM
Dr. Elliot Siegel, Office of Health Information Program Development, NLM
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
Dr. Jack Snyder, Division of Specialized Information Services, NLM
Mr. Tao Tao, National Center for Biotechnology Information, NLM
Mr. Oscencio Tom, Associate Program, NLM
Ms. Elizabeth Whipple, Associate Program, NLM
Dr. Fredrick Wood, Office of Health Information Program Development, NLM
Dr. Deborah Zarin, Lister Hill Center, NLM

I. OPENING REMARKS

Dr. Thomas Detre, Chair of the NLM Board of Regents, welcomed the Regents, alternates, consultants, and guests to the 140th meeting of the Board. He announced to the Regents that Dr. Donald Lindberg, NLM Director, had won the prestigious Frank Brown Berry Prize in Federal Healthcare. The Award is sponsored by *U.S. Medicine*.

II. REPORT FROM THE DEPUTY SURGEON GENERAL, HHS

Deputy Surgeon General Dr. Kenneth Moritsugu presented the Surgeon General's greetings and his regrets for missing the meeting. Dr. Carmona is meeting this morning with the HHS Secretary. One major theme Dr. Moritsugu reported on was Hurricane Katrina and the Public Health Service response. Of the 6,000 officers in the PHS Commissioned Corps, more than 1,000 have been deployed to the areas of devastation. It is the largest one-time deployment since the Korean War. Unpaid temporary Federal employees (volunteers) are also being used.
Dr. Moritsugu said that the Medical Reserve Corps (civilian volunteers), reported to the Board previously, has been greatly expanded over the last few years. Several units of this Corps have also been deployed to help health systems recover from the devastation. Moving from rescue to

recovery to rebuilding is turning into a long-term effort, he said. On other matters, the Deputy Surgeon General said that last month they released a first-ever "Call to Action" to improve the health and wellness of persons with disabilities. He summarized for the Board some of the main messages from that document. The Surgeon General's office also continues to place emphasis on the major themes of prevention, public health preparedness, and eliminating the gap in health disparities. Health literacy is another theme—we must communicate in such a way that the messages can be heard, understood, and put into action. We continue in 2005 the "Year of the Healthy Child," and many of the Surgeon General's messages and appearances focus on this theme.

III. REPORT FROM THE DIRECTOR, NATIONAL INSTITUTE ON DRUG ABUSE

Dr. Nora Volkow, Director of the National Institute on Drug Abuse (NIDA), NIH, characterized the drug abuse problem in the U.S. as "absolutely gigantic," with an estimated cost to the nation of 500 billion dollars. The Institute she leads has three priority areas: prevention research, treatment interventions, and HIV/AIDS research (drugs are a significant contributor to HIV/AIDS). Dr. Volkow briefly described the NIDA research effort in each of these priority areas. In the area of prevention, the emphasis is on genetics, brain development, environment (family, society), and co-morbidity (smoking or schizophrenia, for example). In treatment, the emphasis is on new targets and new strategies. She noted three roadblocks in developing effective treatments: the lack of interest on the part of the pharmaceutical industry, the erosion of the medical community's involvement in preventing and treating drug abuse and addiction, and the fact that those treatments that are available aren't being used by those who need them (only 15 percent have received treatment in the past year). Dr. Volkow described a network being supported by NIDA, the National Drug Abuse Treatment Clinical Trials Network with 17 nodes around the U.S. She also described the NIDA Criminal Justice Drug Abuse Treatment Studies network, which provides an extraordinary opportunity to bring treatment to and do research involving those who are incarcerated.

Dr. Kenneth Walker raised the problem of homeless people, who often have an addiction problem. Dr. Volkow acknowledged this and said that although science "can't solve all the social problems," NIDA can generate the knowledge that can lead to an improvement of those conditions. "The worst thing we can do is just ignore the problem," she said.

IV. REPORT OF THE NLM DIRECTOR

Dr. Lindberg reported briefly on the NLM budget prospect: basically it is a flat budget. However, there is language in the accompanying reports from Congress that affects NLM. These include injunctions to continue to support NIH's "public access" policy to enhance the accessibility of publications supported by NIH research dollars (this subject is on the agenda later in this meeting). Dr. Lindberg briefly described NIH's public access policy and how it evolved, and NLM's role in public access with PubMed Central. On another subject, the

Congress praised NLM's projects involving Native Hawaiians. These will be presented to the Board at a future meeting. PubChem, an NIH Roadmap initiative and another topic addressed by the Congress in the report accompanying the budget, will also be discussed later in this meeting. Dr. Lindberg noted that the need for a database of "small molecules" was the number one priority among the NIH Institute directors and that PubChem responds to this need. PubChem now includes some 500,000 chemicals screened by the National Cancer Institute and an additional 350,000 from NLM's toxicology and environmental health databases. This number should grow rapidly after data begin arriving from the institutions in the newly funded NIH Molecular Libraries Screening Center Network. The Congress wants NLM and NIH to continue with the PubChem operation while, at the same time, not competing unreasonably with the private sector.

In the area of personnel, Dr. Jack Snyder (Associate NLM Director, Specialized Information Services) introduced Mr. Brent Bolin, a health law information specialist. Dr. Milton Corn (Associate Director, Extramural Programs) introduced Dr. Arthur Petrosian, newly appointed Scientific Review Administrator. Dr. Barbara Rapp introduced the new NLM Associate Fellows: Amy Harper, Mellanye Lackey, Lisa Massengale, Elizabeth Whipple, Oscensio Tom, and Christina Horta. Dr. David Lipman, Director of the National Center for Biotechnology Information, introduced five new NCBI scientists: Dr. Timing Bao, Dr. Timothy Doerr, Dr. Jessica Fong, Dr. Matthew Mailman, and Dr. Tao Tao. In the area of legislation, Dr. Lindberg briefly described the Patient Safety and Quality Improvement Act that became law this past summer. It is one response to the Institute of Medicine report, "To Err is Human." The Act encourages voluntary reporting of patient safety data. He also noted that several bills have been introduced relating to clinical trials that would broaden the requirement that they be registered in a database like NLM's ClinicalTrials.gov. There is also legislation relating to clinical trials on the State level—Maine being one example. The recent requirement by prominent medical journal editors that papers submitted for publication must have any associated clinical trials registered in a database has resulted in a surge of studies registered in ClinicalTrials.gov.

The Department of Health and Human Services is actively promoting health data standards activities. As previously reported to the Regents, NLM plays a key role in the area of standardization by supporting key standard clinical vocabularies, and distributing them within the Unified Medical Language System. Since the May Board meeting, HHS has enabled health care providers to apply for a National Provider Identifier. There is also a White House backed HHS initiative to develop an Electronic Patient Record for all citizens. (The lack of such a record was felt during the recent hurricane disasters.) A new advisory organization, the American Health Information Community (AHIC), consisting of members from the private and public sectors, has been created that will assist in reaching the goal of adopting standards that lead to an Electronic Health Record. AHIC will be chaired by the HHS Secretary. Dr. Lindberg also noted that there is in the works a final rule that would specify e-prescribing standards under the Medicare Prescription Drug, Improvement, and Modernization Act.

The NLM Director distributed to the Board a 4-page addendum to the Board book that describes NLM's disaster management activities. The report was prompted by Hurricane Katrina. Dr. Lindberg described a number of these activities, including how we have helped identify victims by DNA, funded biosurveillance techniques through grants, created and distributed information products such as Wireless Information System for Emergency Responders (WISER), and how we have just created a new Enviro-Health Links page on Hurricane Katrina.

The NLM Director noted that the Board Planning Subcommittee, co-chaired by Dr. Stead and Dr. Newt Gingrich will be meeting tomorrow morning. Four planning panels are being created that will meet over the next few months to prepare a Long Range Plan for the period of 2006–2016. A list of the panels, with members, will be distributed to the Board tomorrow. Dr. Lindberg said that as to ClinicalTrials.gov, "the venture is thriving." Dr. Deborah Zarin and her staff are doing an outstanding job in successfully dealing with a huge number of contributors, both at the NIH and elsewhere, especially in the last few weeks. This shows the influence of the major medical journals, whose editors now require registration of a clinical trial before an article about it is published. On another issue, Dr. Lindberg reported on the highly successful annual Informatics Training Conference, held at NLM in July. There were 350 attendees: directors, faculty, staff, and trainees from the 18 current major NLM training programs.

V. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

The Regents approved without change the minutes from the May 2005 meeting.

VI. DATES FOR FUTURE BOARD MEETINGS

The Board of Regents will meet next on February 7–8, 2006. The Board meeting next spring is on May 9–10, 2006. The dates of September 19–20, 2006, were adopted for the following meeting.

VII. MEDLINEPLUS AND CONSUMER HEALTH HIGHLIGHTS

Ms. Joyce Backus, Head of Reference and Web Services, Public Services Division, NLM, updated the Board on the status of MedlinePlus and other NLM consumer health resources. MedlinePlus now has some 700 health topics (more than 650 are also in Spanish). The weekly e-mail lists offered to MedlinePlus users are very popular—some 58,000 subscribers have signed up for them. Usage continues to grow: some 6.5 million unique users each month look at more than 60 million pages on MedlinePlus. Ms. Backus displayed a typical MedlinePlus health topic page and gave a brief tour of the information that is available from it. She conducted brief demos, for example, of the interactive tutorials, ClinicalTrials.gov, NIHSeniorHealth.gov, and new surgical videos. All are easily accessible through MedlinePlus. She also described MedlinePlus' "Go Local" facility, which links users to health services in their region. Go Local is expanding across the country as more states and regions add their information. Ms. Backus

demonstrated the Household Products Database, maintained by NLM's Specialized Information Services Division. That database contains information about chemicals in and properties of 6,000 household products. NIHSeniorHealth.gov, another Web site for consumers, is maintained by the NLM in collaboration with the National Institute on Aging. Ms. Backus showed some of the special features that make NIHSeniorHealth.gov accessible to older users. At present there are 22 topics of interest to seniors, prepared in cooperation with 9 NIH Institutes. Ms. Backus showed some of newspaper articles about NIHSeniorHealth.gov that have appeared. The last topic she addressed was the American Customer Satisfaction Index, which measures many Web services in the private and public sectors. NLM's MedlinePlus is still the highest rated Federal Web site; second highest is MedlinePlus en español.

Dr. Detre asked about the amount of foreign use of MedlinePlus. Ms. Backus replied that in the case of MedlinePlus en español, the usage is quite high—about 90 percent. For MedlinePlus overall, non-U.S. use is about 30 percent. Mr. Chabran said that it is wonderful how MedlinePlus continues to develop and incorporate new features. It is surely one of NLM's most important information tools. At a recent trans-border library conference in Mexico, he showed diabetes information in Spanish from the site. Part of our challenge to see that this kind of information is available in more and more homes, including those without broadband access. Dr. Buchanan asked whether the upsurge in MedlinePlus usage since January is the result of the new surgical procedure videos available. She also observed that it might not be clear that some of NLM's information products actually come from the Library—a question of the need for "branding." Ms. Backus said that the Library is sensitive to having the NIH "umbrella" imprimatur on our sites; also, NIH Institutes contributing the information have to be recognized. She agreed it was an important, and sensitive, issue. As to the spurt in usage, it is difficult to attribute any changes in usage to specific incidents or outreach efforts. Dr. Stead asked about funding models for the Go Local aspect of MedlinePlus. Ms. Backus said that the Library provides one-time funding of $25,000. The cost of the individual Go Local efforts varies widely with the size of the geographic area and the population involved. Betsy Humphreys added that as we accumulate experience with more regions, we may be able to assemble some cost metrics.

VIII. PRESENTATION OF REGENTS AWARD

Board Chair, Dr. Thomas Detre, presented the 2005 Regents Award for Scholarship or Technical Achievement to Dr. Fred Wood of the NLM Office of Health Information Programs Development. Dr. Wood was cited for "trans-NLM leadership in the development and implementation of the multidimensional Web evaluation research strategy that has contributed to more effective operation of major NLM Web sites."

IX. BOARD RESOLUTION HONORING DAVID KENTON'S RETIREMENT

David Kenton, who for many years was the chief programmer for NLM's bibliographic retrieval system, is retiring on September 30, 2005. His accomplishments were lauded by Dr. Lindberg, Ms. Humphreys, and Dr. Lipman. Dr. Detre presented Mr. Kenton with a framed resolution of

the Board of Regents honoring his contributions to the NLM and to the world of biomedical communications. The text of the resolution is in Appendix B.

X. NATIONAL CENTERS FOR BIOMEDICAL COMPUTING

Dr. Ronald Kikinis of Harvard University and Dr. Arthur Toga of the University of California, Los Angeles (UCLA), presented to the Board of Regents what their institutions are doing as recipients of NIH grants in support of the National Centers for Biomedical Computing (NCBC). Dr. Kikinis, who has been a grantee of the NLM for many years, described his one-year-old program at Harvard University. His earlier supported work enabled him to compete effectively for the center grant in neuroscience imaging. He said they face many challenges in computational biology from a brain mapping perspective. He showed a series of images of brain structure and function and the importance of the relationship between the two to understanding health and disease. The goal of computational biology in his center is to integrate the different observations in a way that allows us to establish relationships between them and to examine trends that may occur in individuals, across modalities, over time, etc. This modeling will enable us to understand the relationships between these disparate observations. His program is developing new strategies to extract more information and knowledge from the data. Dr. Kikinis showed images of the brains of Alzheimer's patients to illustrate his point. The NCBC program structure identifies several core strategies, including developing computational strategies and a set of tools that can be used in different settings. He showed some examples of data analysis tools being developed at his center. These tools are being put on the Web—it is an open system so that the results can be leveraged and co-developed with other partners. They have put considerable emphasis on developing ways in which the mathematical and quantitative data can be visualized. He showed examples of what they have achieved—*U.S. News & World Report* and *National Geographic* have both featured some of the work from the Harvard Center for Biomedical Computing.

Dr. Arthur Toga of UCLA said they were looking at the problem of diagnostic imaging in radiology, where scanners produce a tremendous amount of data. Taking the data and turning it into useful information is their goal. One simple way is to take just a sample slice of data rather than displaying the entire volume. He showed an example. What is needed is an algorithm that will "connect the dots" of the various slices. This is fairly complex mathematically and demanding of computational requirements. He showed how this could be used in a clinical situation. The disease process that his center is concentrating on at the present time is schizophrenia. They are doing training and have created PowerPoint presentations for dissemination. Dr. Toga talked about the National Alliance for Medical Image Computing (NAMIC) and the different medical emphases at the different member centers. There is much interaction and e-mailing among the members. Dr. Toga said that Insight Segmentation and Registration Toolkit, an NLM-supported open-source software project, is a very important package being used in medical imaging. He said that "open source" was a key to the products and systems the NAMIC members develop: "open source leads to open science."

Dr. Stead complimented the presenters on their approachable presentations for what is complex work. He said what they are doing is really difficult because it represents a sea change in how people in the field work. Everything the biologists have been taught is now backwards: we are going from a few data points about many people to many data points about a few samples. This same challenge is faced by biologists, computer scientists, and tool builders. Putting this triangle together in an iterative cycle is at the core of these projects. NIH is doing the right thing by having a cross-institute approach to supporting the field. Dr. Stead asked what will it take to scale this up? One answer to this is to link the NCBCs closely into a network, eliminating some overlap between the programs.

XI. DNA IDENTIFICATION OF DISASTER VICTIMS

Dr. Stephen Sherry of NLM's National Center for Biotechnology Information (NCBI) described the work he and his colleagues in the NCBI have been doing in collaboration with other government agencies, state crime labs, and researchers, to look at the process of DNA identification as a model system that might have application for emerging computational issues and information management challenges. Are there lessons or "best practices" that we can learn from other fields that are using genetic information as we begin to move toward individualized medicine and its potential? Dr. Sherry was personally involved in disaster identification issues and the Federal and state response to 9/11. [Dr. Robert Shaler of Pennsylvania State University, who was scheduled to speak at this meeting following Dr. Sherry, and was the director of the New York City Office of the Chief Medical Examiner, was unable to be at the meeting.]
Dr. Sherry outlined some of the informatics challenges in DNA identification: collecting samples, analyzing and interpreting the data, assuring the quality of the procedures, creating a matching or identification statement, and reporting and sharing the data. He showed a schematic diagram of the entire workflow process and briefly described each of the steps. What was missing was a rapid way to reinterpret the data that is collected by instruments. In response to this general community need, NCBI has developed the Open Source Independent Review and Interpretation System (OSIRIS) as a public domain software tool. After 9/11 the National Institute of Justice (a research branch of the Department of Justice) established an interagency relationship with the NLM to formalize the commitment for NCBI's service to develop computational tools for forensic identification. OSIRIS, developed in response to requests from state labs, is designed to quickly find problems and important features of peak morphology with de novo interpretation and to export data and interpretation in a structured manner to support laboratory-based management, third party access, and future re-use of the data. OSIRIS is now in beta testing with five labs. Dr. Sherry showed graphs of how OSIRIS is performing in test cases. OSIRIS can handle about 10,000 profiles in about 2½ minutes; it typically takes a human about 20 minutes to do one sample. NCBI is now partnering with commercial companies to develop a broader framework for secure exchange of forensic DNA information.

Following Dr. Sherry's presentation, Colonel John Powers (U.S. Army) asked how they dealt

with the issue of interoperability and he also raised the question of how they dealt with requests to use the data for purposes for which it wasn't intended. Dr. Sherry replied that capturing metadata was a major emphasis of the program early on—evaluating what software was suitable for every component. This meant a lot of ad hoc programming, writing custom scripts that would accommodate the software to the different organizations. These activities could be simplified if public data format standards were coupled with robust authentication and encryption technologies. As to the reuse of the data, Dr. Sherry said that, although there is no national standard on the use and reuse of this data, there are in general conservative and restrictive policies of access to forensic material in the various states. In response to comments from Dr. Carter, Dr. Sherry said that one of the shortcomings of the present system is the difficulty in having mistakes in the data corrected. This problem is being worked on by NCBI in conjunction with the Federal Bureau of Investigation and other community stakeholders. Also, he elaborated on the "chain of custody" concept that permits the data to be used by authorized people only; users have to sign off that they have it and that no one else will have access. Dr. Sherry concluded with the observation that effective quality assurance is required for success in any high-throughput activity. Applications of genetic information in medicine, forensics, or biometrics share the common step of data interpretation with attendant risks to success if insufficient attention is paid to QA issues. Likewise, while best practices for interpretation address general problems through specific solutions, these may inform the design of analogous tools in other fields.

XII. AUTOMATED BIOSURVEILLANCE

Dr. Kenneth Mandl, an NLM grantee, heads a biosurveillance group at the Children's Hospital Informatics Program at the Harvard-MIT Division of Health Sciences and Technology. In 2004, the NLM nominated Dr. Mandl for a Presidential Early Career Award for Scientists and Engineers; his nomination was accepted and Dr. Mandl received his award from President Bush in 2005. Dr. Mandl said his work began in the late nineties when they started to apply public health informatics techniques to look at data across regions and populations and to understand signature patterns of disease. These systems were put into widespread use in 2001. The original idea was to answer a question like: "If there was an anthrax attack that nobody knew about, how would you find out about it?" The initial emphasis focused on early detection. Dr. Mandl described syndromic surveillance, which refers to methods relying on detection of individual and population health indicators that are discernable before confirmed diagnoses are made. This has been the focus of much research in the last 5 years. He said he used easily available data about the chief complaints presented to Emergency Departments to plot out a precise temporal progression of complaints about respiratory infections over an 11-year period. Dr. Mandl described how they used the data to plot patterns and cycles—for example, seasonal trends. The AEGIS System (Automated Epidemiologic Geotemporal Integrated Surveillance) now has eight member hospitals in Massachusetts; a pediatric hospital network is also being developed. Future work on the system will include more functionality, more data sources, and integrating AEGIS with the personally controlled health record. In the area of disaster management, Dr. Mandl said

that the Katrina experience highlighted both our strengths and our shortcomings. We didn't know who or where the victims were or what their health needs were. We need data: just as clinicians need accurate facts before a diagnosis, syndromic surveillance needs to cultivate new and better data sources—electronic health records, sensor data, environmental data—all in standardized data formats. We need to integrate surveillance data collection into disaster workflows.

Dr. Detre asked about a graph Dr. Mandl presented that showed how the volume of emergency room visits declined during World Series Red Sox games. Dr. Mandl replied that it is obvious that some portions of those visits were unnecessary and that some were no doubt postponed. Wendy Carter (Department of Veterans Affairs) described a mix-up they had with the Centers for Disease Control about how certain data was coded. This prompted her to ask who uses the data and what rules are there pertaining to its use by local institutions and public health departments. Dr. Mandl said this was still being worked on. As much of the raw data as possible is made available. Privacy concerns are addressed through rule-based access. If there's an alarm, it is sent up to the health department.

XIII. EXTRAMURAL PROGRAMS REPORT

Dr. Milton Corn, NLM Associate Director for Extramural Programs (EP), presented an overview of success rates for applications assigned to NLM in recent years. Success rates have been decreasing because applications received are growing at a faster rate than EP's grant budget, particularly in the research area supported by PHS 301 funds. In the period 2002–2005 the success rate for MLAA resource grant applications fell from 32% to 15%, and for PHS 301 research applications from 32% to 9%. The pressure was unusually severe in FY 2005 because of large commitments to previously awarded grants in a fiscal year which provided a flat grant budget. EP expects success rates to be somewhat improved in FY 2006 as a number of existing grants expire, releasing funds for new awards. However, success rates will probably be in the mid-teens for some years to come.

Dr. Corn also presented an overview of NLM's Informatics Training Programs, one of its most important and well-recognized programs, and the single most costly EP Division program as well. In preparation for the upcoming recompetition for these Training Awards, EP staff visited all 18 of the existing programs during the past 18 months. A brief overview of the site visit findings, and key issues for the new Request for Applications were presented.

As an update on Roadmap's National Centers for Biomedical Computing (NCBC), Dr. Corn announced that the second and final round of NCBC competition was recently concluded and an additional three national centers were funded to complement the four funded in 2004. Characteristics of the new centers at Columbia, University of Michigan, and Stanford were presented, as well as an overview of NLM involvement with the centers.

Dr. Valerie Florance presented an overview of the Library's Integrated Advanced Information Management Systems (IAIMS) grant program. IAIMS grants assist organizations that want to build a comprehensive information environment that brings usable, useful information to the places where decisions and learning occur. The IAIMS grant program has three grants: Planning, Testing and Evaluation, and Operations. The NLM has awarded $60,000,000 in IAIMS grants to scores of organizations since the program began in 1984. As of FY 2005, there are four active planning grants, four active operations grants, and two testing and evaluation grants. Examples were provided of current IAIMS activities at Ohio University (Planning) and the University of Cincinnati (Operations).

The Board Members received a short briefing on several Electronic Research Administration (eRA) initiatives at NIH. The NIH is moving to electronic submission of grant applications beginning in 2006. By the end of 2007, all NIH grant applications will be submitted through grants.gov, which requires organizations to register before a grant can be submitted. Grants.gov is intended to be a one-stop shopping center for all federal grants. To simplify the application process, all Federal agencies will use the same grant application form. In addition, applicants and their home organizations must register with the NIH Commons to receive notification of priority scores and summary statements. The NIH Commons provides an investigator with instantaneous access to scores and grant status information. In addition to these changes in the application submission process, technology is now a fundamental component of the review of grant applications. NIH study sections use internet-assisted review, which requires reviewers to upload their written comments from home in advance of a study section meeting. One benefit is that reviewers can read written comments of other reviewers on the same grant before coming to the review meeting.

MEETING CLOSED FOR THE REVIEW OF GRANT APPLICATIONS
September 20, 2005, 4:30 P.M.

XIV. NIH PUBLIC ACCESS UPDATE

Dr. David Lipman, NCBI Director, presented a follow-up report on the subject of the NIH public access initiative. At its last meeting, the Board heard about the policy becoming effective on May 2, 2005. After that date, NIH-supported authors are encouraged to submit their peer-reviewed manuscripts to NLM's PubMed Central data archive. He views PubMed Central, which began 5 years ago, as a success—it has 1.5 million unique users monthly, it contains hundreds of thousands of articles, and an infrastructure for digital archiving has been developed by NCBI that is truly unique and is increasingly being adopted throughout the industry. The NIH public access initiative seeks to ensure that the investment of the American public in medical research is paralleled by access to the product of that investment—the publications of NIH-funded researchers. The initial arguments against this system, that it would be too expensive and would be too onerous for the scientists, have been proved wrong. The system has been developed within the budget, and it is relatively easy and painless for grantees to submit their documents to

it (50% of authors complete the submission process in less than 8.5 minutes). Dr. Lipman said that NCBI has developed an automated system for uploading the documents into PubMed Central. Conversion of the authors' files to a common PubMed Central archival format can now be done efficiently under contract. Voluntary participation by NIH grantees has not been high (less than 5%), although we are getting enough to be able to test the system. Many scientists don't see access as a problem—they already have free access to many articles through their institutions. Nevertheless, Dr. Lipman said, we have demonstrated that the technical issues and practical challenges to creating such a system have been successfully met and overcome.

Dr. Detre distributed to the Board the minutes of the July 11 meeting of the NIH Public Access Working Group (which he chairs). Dr. Deanna Marcum, who is also on the Working Group, said that one important result of the meeting was the realization that publishers have a real concern with "version control." This will have to be addressed at future meetings. Dr. Newt Gingrich said that as it becomes more and more obvious that it is desirable to accelerate the flow of information from the laboratory to practice, there may come a time when participating in public access is a condition of getting an NIH grant. Betsy Humphreys noted that this was in fact one of the suggestions made at the Working Group meeting. Dr. Gingrich suggested also that NIH lead an effort to get all the major grant-making foundations in the country to agree that the purpose of their grants is the creation of public knowledge, and that this knowledge should be available in a central archive. If "ten bullet points" were prepared on this subject, he offered to turn it into an op-ed piece and a letter to the Congress.

XV. PUBCHEM DATABASE

Dr. David Lipman briefly described PubChem, begun about a year ago, as an "unbelievable success." It is an integral part of NIH's Molecular Libraries Initiative, which itself is an important component of the NIH Roadmap Initiative. Although NIH has traditionally not funded heavily in the area of chemistry, with the advent of the genome project high-throughput biology can now generate huge amounts of data. The National Center for Biotechnology Information manages this information—2¼ terabytes of data is being downloaded daily. A critical part of the picture is missing however—small molecules, which are crucial in drug development and in the study of toxins. The NIH Molecular Libraries Initiative uses robotics and other high throughput techniques to find small molecules by having a library of more than 200,000 compounds that can serve as targets of interest for scientists and drug developers. Dr. Lipman said that NCBI has built a database of small molecules, not by going through the literature but by requesting scientists to send their data to our repository. He then introduced Dr. Christopher Austin of the National Human Genome Research Institute.

Dr. Austin briefly characterized the NIH Roadmap Initiative and said that the goal of the Molecular Libraries Initiative, a key part of the Roadmap, is to empower the research community to use small molecule compounds in their research, whether as tools to perturb genes and pathways, as imaging probes in basic or clinical applications, or as starting points to the

development of new therapeutics for human disease. He briefly described how compounds are being screened at centers around the U.S. so that their data may be added to PubChem. He said that NIH's investment in the Molecular Libraries Initiative and the development of tools for screening compounds will be of great help to the pharmaceutical industry and shorten the time of drug development. Dr. Steve Bryant of NCBI then demonstrated PubChem to the Regents, using a named chemical, retrieving basic structure information and showing how one can easily link to a wide variety of useful associated information, including the scientific literature. He also demonstrated how PubChem can be approached from the point of view of a particular disease, in the example he used, Gaucher's Disease.

XVI. COMMISSION ON SYSTEMIC INTEROPERABILITY UPDATE

Vicky Gregg, R.N., President and CEO of BlueCross BlueShield of Tennessee, and member of the Commission on Systemic Interoperability (Commission), updated the Regents on progress made by the Commission since the last Board meeting. The staff of the Commission, which will finish its work by the end of October 2005, is housed at the NLM; the final report is scheduled to be delivered to the Congress on October 25. She described the workings of the Commission and how, although many points of view were represented by the diverse membership, they agreed that their recommendations should be unanimous. That is what happened, she said. Ms. Gregg briefly described the major themes of what the report would cover. The report is intended to address both consumers and policy makers. Among the advantages of interoperability for consumers cited in the report are convenience, 24/7 access, safety, security, and peace of mind. There are a number of "stories" of real patients and health care providers and how the power of interoperability and the Electronic Health Record affect them. For policy makers, health IT is encouraged as a solution to many of the safety and quality issues facing healthcare. She characterized the final report (called "Ending the Document Game") as a "friendly document" and she showed images of what it will look like. The URL is http://endingthedocumentgame.gov/. The report is also available in CD-ROM format. She noted that two members of the Commission were asked to look at the interoperable drug record and, as an example of how it could be done, to lay out a timeline for achieving it. Finally, Ms. Gregg described how the report is to be brought to the attention of the members of the House and Senate, the Congressional committees, and their staffs. She thanked Dr. Lindberg and Betsy Humphreys for their support of the Committee's work.

Following Ms. Gregg's report, Dr. William Stead reinforced what Ms. Gregg presented and he said that it is, in fact, doable. The Commission's 14 recommendations are not prescriptive but provide in one document the set of things that need to happen. They will be a helpful guide to the Congress and to the Administration. If we can standardize information content, for example for drugs or lab results, at the time it is produced and in a way that allows the information to be passed through the supply chain, as has been done in retail, the tasks described by Ms. Gregg become quite doable.

XVII. REPORT FROM THE PLANNING SUBCOMMITTEE

Subcommittee co-chair, Dr. William Stead reported on the meeting this morning of the Planning Subcommittee. At that meeting, Dr. Elliot Siegel described progress in creating the "vision statement" that emerged from the planning conference at the Cosmos Club on April 11–12, 2005. Dr. Stead said that the Subcommittee's discussions centered on three questions: How to deal with the science of biomedical informatics as a focused topic? How can we "salt" the planning panels with leading generalists and clinical thinkers? How do we ensure that the NLM provides the architecture—the toolkit—that supports a continuum of health knowledge that ranges from what the consumer needs, to what practitioners need, to what scientists need?

Co-chair Dr. Newt Gingrich said he believes three factors will come together to provide a "tipping point" to change how the future of biomedical communications unfolds. These factors are (1) outside (non-healthcare) technology developments; (2) consumer "pull" for health knowledge ("what's in it for me?") rather than professional "push" or outreach; and (3) inventing a consumer-centric "Web of knowledge"—NLM could take the lead in this. Dr. Gingrich also noted that Hurricane Katrina provided an impetus for moving to the Electronic Health Record and electronic prescription data.

There was a discussion by the Regents about whether "outreach" or "push" was still a perceived need in ensuring that the public has access to good health information. Dr. Lindberg noted that NLM has outreach programs aimed at special populations that frequently don't have access to the Web—Native Americans, for example. Dr. Gingrich said that another target for such outreach should be to view churches as centers of information—most have at least one computer with Web access. Also, he said that an audio component (for example, cell phone access to information) would help reach audiences that would otherwise be missed, the illiterate for example.

XVIII. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Mr. Richard Chabran briefly reviewed yesterday's meeting of the Subcommittee on Outreach and Public Information. The Subcommittee heard reports from staff on current outreach and publicity efforts, and reviewed examples of media coverage. The Local Legends Web site that contains profiles of leading American women physicians was also presented to the Subcommittee. Local Legends is a part of the "Changing the Face of Medicine" exhibition currently at the NLM. NLM's Dr. Jack Snyder told the Subcommittee about how the Wireless Information System for Emergency Responders (WISER) is being used in Louisiana to help cope with the aftermath of Hurricane Katrina. He noted that cell phone access in that area was problematic and that, in fact, many of those displaced did not know how to use the cell phones. The Subcommittee discussed NLM's long range planning effort and noted that it should address the fact that many Americans still do not have access to the Internet.

Following Mr. Chabran's report, the Dr. Gingrich said that there is a new generation of cell phones that do not require dialing—the user simply speaks the name of the intended recipient. If we are determined that every American have an opportunity to be in a web, we can find ways to facilitate technologically a tool that would bring them in, and it would be cheaper actually to give them the tools than to engage in traditional outreach. Dr. Gingrich said that perhaps 80% of what we mean by "underserved" in health terms is a cultural problem that we have not come to grips with. Obesity, for example, is not a medical problem but a profound cultural problem. As NLM works toward an information Web, we have to acknowledge that what we mean by "good health" has many significant cultural implications.

XIX. GENETICS HOME REFERENCE

Dr. Joyce Mitchell, Chair, Department of Medical Informatics at the University of Utah School of Medicine, and a consultant to NLM, reported to the Board on NLM's Genetics Home Reference (GHR). The GHR is a Web-based information system intended for the public that focuses on the health implications of research arising from the Human Genome Project. Dr. Mitchell is senior advisor to the project. Since this is the first time the GHR has been discussed with the Board of Regents, she presented some background leading up to its creation and launch. GHR bridges consumer health information (for example, MedlinePlus) and bioinformatics data (for example Entrez Gene), and it links to many existing resources, both at NLM and at other reliable sites. From the research world to the consumer health world is a large chasm, she said. At its launch in February 2003, GHR covered a handful of diseases that had a prominent genetic component. As of a month ago, GHR covered about 450 topics (150 health conditions). All topics receive close review by experts before they are put in the database. An online handbook to help consumers understand genetics has been created and made available in the process. The reaction to GHR has been positive, with links to it installed by CNN, Nature, and Forbes, for example. Educators, physicians, and parents have praised it in e-mails to the NLM. The GHR is developed in close cooperation with other Federal health agencies, among them the Health Resources and Services Administration, National Cancer Institute, the National Human Genome Research Institute, and the Office of Rare Diseases. Dr. Mitchell demonstrated with screen shots the kind of information available in and through GHR using Parkinson's disease as an example. She said that among the challenges they face as GHR evolves is the rapidly growing and changing body of genetic information that has to be incorporated. The URL for the GHR is http://ghr.nlm/.nih.gov.

Dr. Ernest Carter said the GHR is an excellent source of understandable information on a complicated subject. He is concerned whether the NLM will have the facilities to store and process the tremendous amount of information being accumulated by the GHR and other NLM data resources, such as the NCBI's. He said this should figure prominently in NLM's planning.

XX. ADJOURNMENT

The meeting was adjourned at 12:00 p.m.

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the May 9-10, 2005 Board of Regents Minutes
- Approval of September 19-20, 2006 Meeting Dates
- Board Resolution Honoring David Kenton's Retirement

Appendix A - Roster - Board of Regents
Appendix B – Board Resolution Honoring David Kenton's Retirement

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

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

Thomas Detre, M.D.
Chair, NLM Board of Regents