

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

**MINUTES OF THE BOARD OF REGENTS
May 10-11, 2005**

The 139th meeting of the Board of Regents was convened on May 10-11, 2005, at 9:00 a.m. in the NLM Board Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), and Bethesda, Maryland. The meeting was open to the public from 9:00 a.m. to 4:10 p.m., followed by a closed session for consideration of grant applications until 4:30 p.m. On May 11, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

MEMBERS PRESENT [Appendix A]:

Dr. Holly Buchanan, University of New Mexico
Dr. Ernest Carter, Howard University
Dr. A. Wallace Conerly, University of Mississippi Medical Center
Dr. Richard Dean, Wake Forest University
Dr. Thomas Detre, University of Pittsburgh
Dr. Vasiliki Karlis, New York University
Dr. William Stead [Chair], Vanderbilt University

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Ms. Eleanor Frierson, U.S. Department of Agriculture
Col. Gerard Caron, U.S. Department of the Air Force
RADM Ben Gaumer, U.S. Department of the Navy
Dr. Deanna Marcum, U.S. Library of Congress
Dr. Michael Pazzani, National Science Foundation
Col. John Powers, U.S. Department of the Army
Dr. Vernon Schinski, Uniformed Services University of the Health Sciences
Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs

CONSULTANTS TO THE BOR PRESENT:

Dr. Tenley Albright, Whitehead Institute for Biomedical Research
Dr. Marion Ball, Johns Hopkins School of Nursing
Dr. H. Kenneth Walker, Emory University School of Medicine

SPEAKERS AND INVITED GUESTS PRESENT:

Dr. Barbara Alving, Acting Director, of National Center for Research Resources
Dr. Richard Carmona, Surgeon General, Department of Health and Human Services
Ms. Cynthia Lindquist, Cankdeska Cikana Community College
Dr. Ted Mala, Southcentral Foundation
Dr. Lisa Schwartz, VA Outcomes Group
Ms. Gail Shearer, Consumers Union
Dr. Steven Woloshin, VA Outcomes Group

MEMBERS OF THE PUBLIC PRESENT:

Mr. Vince Haley, American Enterprise Institute
Ms. Jeannie Kenney, Consumer Reports
Ms. Lynn Ohmar, Consumer Reports
Mr. Tom West, Krasnow Institute
Ms. Amy Pearman, The Gingrich Group

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
Dr. Dennis Benson, National Center for Biotechnology Information, NLM
Ms. Diane Boehr, Division of Library Operations 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
Ms. Stephanie Dennis, Associates Program, NLM
Mr. Ivor D'Souza, Office of Computer and Communications Systems, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Dr. Charles Friedman, Division of Extramural Programs, NLM
Ms. Jane Bortnick Griffith, Office of the Director, NLM
Ms. Wendy Hadfield, Executive Office, NLM
Ms. Dana Haza, Office of the Director, NLM
Dr. Ying He, Lister Hill Center, NLM
Mr. Nick Ide, Lister Hill Center, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Dr. Mehmet Kayaalap, Lister Hill Center, NLM
Mr. Sheldon Kotzin, Division of Library Operations, NLM
Ms. Michelle Krever, Division of Extramural Programs, 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. Robert Logan, Lister Hill Center, NLM
Ms. Becky Lyon, Division of Library Operations, NLM
Mr. Robert Mehnert, Office of Communication and Public Liaison, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Dr. Aaron Navarro, Lister Hill Center, NLM
Ms. Wendy Nelson, National Cancer Institute, NIH
Dr. Jim Ostell, National Center for Biotechnology Information, NLM
Ms. Julia Royall, Office of Health Information Program Development, NLM

Ms. Anne Scanley, Office of Science Policy and Planning, NIH
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
Ms. Marti Szczur, Division of Specialized Information Services, NLM
Dr. Paul Theerman, Division of Library Operations, NLM
Dr. George Thoma, Lister Hill Center, NLM
Ms. Patti Tuohy, Division of Library Operations, NLM
Dr. Fred Wood, Office of Health Information Program Development, NLM
Dr. Deborah Zarin, Lister Hill Center, NLM

I. OPENING REMARKS

Dr. William Stead, Chair of the NLM Board of Regents, welcomed the Regents, alternates, consultants, and guests to the 139th meeting of the Board.

II. REPORT FOR THE SURGEON GENERAL, PHS

Surgeon General Richard Carmona updated the Board on three of his highest priorities. The first, prevention, still has a long way to go if we are to reduce the burden of disease on our society. There is a tremendous economic debate: who is going to pay? The answer, he said, is that we *all* are going to pay. Whether the issue is caring for trauma (most of which is preventable) or chronic disease (much of which is preventable), we have difficulty in translating what we know from the bench to the bedside and to the community to effect behavioral change to reduce morbidity and mortality. This is largely a problem of “health literacy.” We have enough information to change the debate from one of economics to one of improved health. The problem is that it takes so long for that information to be applied and to result in improved health outcomes. The second major theme of the Surgeon General’s office is preparedness. This includes more than being prepared for terrorism. We now have the opportunity to rebuild and to focus on our disintegrating, antiquated public health system. Many local public health departments have closed in recent decades. Dr. Carmona said that we have an information gap in the biological and nuclear threats we face. The military is one repository of information on these threats and we are trying to disseminate it more broadly. We are also faced with natural threats—emerging infections and influenza, for example. The third area in the Surgeon General’s portfolio is health disparities. We are making some progress here, Dr. Carmona said, learning how to better penetrate communities at risk and translate science in a culturally competent manner in order to effect desirable behavioral change that will improve health and wellness. Nevertheless, people of color still bear a disproportionate amount of the disease burden in our country. Health literacy is the common currency that underlies all three of the Surgeon General’s main efforts: prevention, preparedness, and health disparities. He said that introducing a higher level of information technology into the health system would reduce the transactional costs of patient encounters, improve the quality of care, produce better data, and give portability to

patient records so that when people move their providers can have instant access to the information they need to treat patients. The President has put information technology on the “front burner,” and we are working with the Department of Defense where they have been dealing with these issues for some time. Finally, he said, the National Library of Medicine, under the leadership of Dr. Lindberg and the oversight of the Board of Regents, can play a pivotal role in all the areas he described. The key linkage is health literacy—providing information both to consumers and to our scientific peers—and that is what the NLM is all about.

III. REPORT FROM THE ACTING DIRECTOR, NATIONAL CENTER FOR RESEARCH RESOURCES

Dr. Barbara Alving said that NIH’s National Center for Research Resources (NCRR), with a one billion dollar budget, has four divisions dealing with biomedical technology, clinical research, comparative medicine, and research infrastructure. The NCRR has an important role in the part of the NIH Roadmap Initiative that deals with reengineering clinical research. She noted some of the challenges in clinical research: retaining and recruiting clinical researchers, a high regulatory burden, fragmented training, a perceived bias against clinical research in the NIH peer review process, cuts in research grant budgets, and disappearing infrastructure once a grant ends. She noted several shifts in priorities at academic health centers, including the explosion in clinical service demands, how young clinical faculty have trouble finding an institutional “home,” and that the complexity of knowledge needed to be an effective translational scientist is not easily acquired. What we have ended up with is a patchwork system—general clinical research centers, clinical trial networks, various training programs, specific disease centers, etc. What is needed is a “home” for the clinical and translational sciences, with degree-granting programs and career pathways. Components of such an integrated program would be to develop new research designs and services, better integration of education and career development, clinical research informatics, core technologies in laboratories, etc. She also described how such a program would provide opportunities for a variety of collaborations with other agencies and with industry. On May 23 there will be a meeting to develop this idea further. Dr. Alving also described another NCRR-supported program, the development of the biomedical informatics research network (BIRN). It was established in 2001 and currently includes 19 universities and 26 research groups. BIRN develops information technology infrastructure for managing distributed data and builds bridges across tools and data formats. She described some of the work going on at several BIRN centers. In the future the BIRN concept will be extended to more investigators and institutions, and we will extend the infrastructure model and software tools in a variety of research communities. The goal is to facilitate the integration of cutting edge computing and informatics advances into biomedical research. More information can be found at the NCRR Web site at <http://www.ncrr.nih.gov/>.

IV. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

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

V. DATES FOR FUTURE BOARD MEETINGS

The Board of Regents will meet next on September 20–21, 2005. The Board meeting next winter is on February 7–8, 2006. The dates of May 9–10, 2006, were adopted for the following meeting.

VI. REPORT OF THE NLM DIRECTOR

Dr. Lindberg said that the Administration's request for the NLM Fiscal Year 2006 (\$326,291,000) is 0.9% above 2005. A budget at this level would mean lean times for the Library. The Congress has yet to act on the budget. As to new NLM staff, the Director noted that Mr. David Nash, NLM's EEO Officer, has been appointed NLM's Education and Outreach Liaison in the Office of the Director. Ms. Diane Boehr has been appointed Head of the Cataloging Section in the Technical Services Division. Ms. Jane Griffith, NLM Assistant Director for Policy Development, retired after 32 years of Federal government service. Dr. Lindberg thanked her for her outstanding service to the Library, including serving as Acting Deputy Director after the departure of Kent Smith. Dr. Donald King introduced two new members of the Lister Hill Center staff: Dr. Deborah Zarin, Assistant Director for Clinical Research Projects, and Dr. Ying (Joanna) He, an electrical and computer engineer. In the area of proposed legislation, Dr. Lindberg said there is a FACT (Fair Access to Clinical Trials) Act of 2005, introduced in the Senate, that would require NIH to operate a data bank of information on clinical trials. It would expand NLM's current ClinicalTrials.gov database to include device trials and it would create an additional "results" database for all trials. Also, a Genetic Anti-Discrimination bill passed by the Senate would prohibit discrimination based on predictive genetic information. The Director briefly noted that there are several bills dealing with electronic health information: an American Health Security Act of 2005 (which specifies that NLM will operate an information program dealing with primary care and prevention research); the Freedom to Read Protection Act of 2005, which would limit the Government's access to library and bookseller records; and a bill that would allow libraries to make copies of digital materials under "fair use."

Dr. Lindberg noted that on April 11–12 a "Strategic Visions Working Group" met in Washington, D.C. to take a broad look at NLM's mission, current situation, and potential future contributions. A brief summary of what took place will be distributed to the Regents shortly, as will two other pieces—"strategies for decision-making"—contributed by members of the Working Group. The NLM Planning Subcommittee will meet tomorrow morning and will report to the Board later in the meeting. The NLM Director gave a brief report on the development of PubChem, the new database containing data on small molecules that was created by NLM's NCBI. It is part of the NIH Roadmap Initiative. NIGMS, NIMH, NHGRI, and NLM are all closely involved in its development. There are roughly 850,000 small molecules in PubChem at the present time. The American Chemical Society has objected to the Federal government creating PubChem, claiming that it is in unfair competition with the ACS's fee-based Chemical Abstracts Service. Dr. Lindberg showed a brief video from a recent event in Florida where the

NLM, the AMA Foundation, and the Fisher Center for Alzheimer's Research Foundation launched the Information Rx program in five Florida counties. The Information Rx program encourages physicians to "prescribe" MedlinePlus for the patients. The Director presented a progress report on the Commission on Systemic Interoperability, housed at the NLM. Board Chairman Dr. Stead is a member, as are past Regents Dr. Don Detmer and Dr. Herb Pardes. The CSI Web site is at http://www.nlm.nih.gov/csi/csi_home.html. Dr. Lindberg noted that NLM is in the process of recompeting the five-year contracts for the eight Regional Medical Libraries within the National Network of Libraries of Medicine. Proposals are due to NLM July 15. Also, he announced that a new CD about MedlinePlus has been produced by staff, and there are two new states in the MedlinePlus "Go Local" service—Indiana and Massachusetts. NIHSeniorHealth.gov has been expanded with the addition of new topics from the National Eye Institute—there will be 19 senior-related topics in all by the end of June.

Following Dr. Lindberg's presentation, Dr. Stead asked about alternative mechanisms to fund NLM projects. For example, how is the SNOMED license funded? In the case of SNOMED, Dr. Lindberg said that the one-time initial payment was co-funded with other Federal agencies; continuing maintenance fees for the next 5 years will be paid out of NLM's budget. On other occasions, the Director said, we have been able to pool money from industry; the latest co-funded project is on public health training with the Robert Wood Johnson Foundation. So other mechanisms do exist and can be used.

VII. PRESENTATION OF AWARDS

Dr. Lindberg presented the Frank B. Rogers Award to two NLM staff: Lillian Kozuma of the History of Medicine Division "in recognition of exceptional contributions to the transformation of many of NLM's historical printed bibliographical tools into electronic form thereby significantly increasing their value," and Frances Spina of the Bibliographic Services Division "for outstanding management of the data creation, maintenance, and quality assurance of citations for MEDLINE which included phasing out the keyboarding of citations, improving the currency of the data, and increasing the cost effectiveness of the operation."

Dr. Lindberg presented the 2005 NLM Director's Honor Award to three NLM staff:

- Ronald Stewart, Deputy Executive Officer in the Office of the Director, "for valuable insight, knowledge, expertise, and leadership spanning seventeen years of dedicated service to the National Library of Medicine";
- Christine Ireland, Committee Management Officer in the Extramural Programs, "for technical expertise and outstanding management of all the National Library of Medicine's committee management activities"; and
- Jane Bortnick Griffith for "outstanding policy development and management of the National Library of Medicine."

Dr. Lindberg presented certificates of appreciation for their service on the Board of Regents to

Dr. Richard H. Dean and Dr. William W. Stead whose terms expire in 2005.

VIII. UNVEILING OF PORTRAIT, TOUR OF EXHIBITION

The Regents adjourned to the History of Medicine Division where there was a brief ceremony and unveiling of an oil portrait of Kent Smith, former NLM Deputy Director, who retired in 2004. The portrait will hang in the NLM Main Reading Room. Following the ceremony, the Regents viewed an exhibit “Shell Shock”, the psychological disorder first noted in World War I, curated by Carol Clausen of the HMD staff: “Strange Hells with the Minds War Made.” The exhibition will be up through the end of this month.

IX. UPDATE ON CLINICALTRIALS.GOV

Dr. Deborah Zarin, newly appointed Assistant Director for Clinical Research Projects, Lister Hill Center, gave an overview of the current issues surrounding the registration of clinical trials—a subject much in the news lately. She briefly recounted the history of the development of ClinicalTrials.gov, created by the NLM and launched in 2000. It currently has more than 13,000 records that represent both public and privately funded clinical trials. ClinicalTrials.gov gets about 17,000 visitors each day. The law that established the database is clear about the mandatory elements it should contain; we hope to have the trial sponsors submit data for the optional elements so that more information is available to the scientific community and to the public. NLM has recently broadened the range of potential submitters of registration data to include any trial, U.S. or non-U.S., that has IRB approval and that conforms with regulations of the health authority under which it is being done. Dr. Zarin briefly described the Web-based data input system and how the entries are reviewed. She provided ClinicalTrials.gov data (as of April 14, 2005) that showed the breakdown of interventional versus observational studies, how many are recruiting and how many completed, and the source of the studies (NIH, university, pharmaceutical company, etc.). NIH accounts for about half of the 13,000 studies in ClinicalTrials.gov.

There is a problem in knowing just how many trials fit the criteria for ClinicalTrials.gov. The original legislation calls for trials of “serious and life-threatening” diseases to be included, but there is no established definition of that phrase. Dr. Zarin discussed some of the policy issues surrounding the registration of clinical trials and the interest of the Congress and the World Health Organization in the subject. Medical journal editors (the International Committee of Medical Journal Editors—ICMJE) also continue to show interest in the subject—an editorial in leading journals last September (and reiterated in an editorial in May 2005) announced that beginning this July any manuscript about a clinical trial would not be considered for publication unless the trial had been registered at its onset. She noted the variety of people interested in the data in ClinicalTrials.gov, and described some of the many uses to which the information could be put. Another policy issue is what to do about unpublished—or incompletely published—results of a clinical trial. Enforcement is a serious issue: the original legislation mandating the

database has no specific enforcement mechanism. Dr. Zarin briefly described the data elements and other information—those required and those encouraged (such as Web links)—for ClinicalTrials.gov. She showed how future clinical trial records might link to published and unpublished full-text results. Key issues facing us are how to find out what trials exist and expand the reporting of results, how to verify the data reported (there is no easy answer to this), how to implement the ICMJE criteria, and how to work with the World Health Organization to establish, for example, one numbering system for all clinical trials. A trans-NIH working group looking at results will soon issue its report. Dr. Zarin said that the report will encourage listing published study results and recommend studying the ways unpublished results can be included.

X. METHODS OF REPORTING CLINICAL RESEARCH RESULTS

Dr. Steven Woloshin, Associate Professor of Medicine and Community and Family Medicine, Dartmouth Medical School, said that the scientific community can do a better job in communicating the results of medical research. He and his colleague, Dr. Lisa Schwartz (also at the Dartmouth Medical School and Director of the VA Outcomes Group), presented four examples of problems that illustrate the miscommunication of scientific information. The first example involved a claim for a drug by an ad agency of “68% reduction in clinical vertebral fractures.” The problem here is that it is unclear what exactly the 68% refers to. With some digging, it turns out that the absolute risk reduction was only 0.5%. This is called “framing”—where the same information feels very different when you see the actual event rates. He showed several other misrepresentations of this type, not only from the news media but from medical journals. A second example presented by Dr. Woloshin is from ABC’s Nightline show. The program (citing a medical journal article) told how blacks and women with chest pain are 40% less likely than whites or men to be referred by physicians for cardiac catheterization. He showed how, because confusion between “probabilities” and “odds,” the 40% figure is misleading. He explained how the probability of referral was 91% for whites and men, and 85% for blacks and women. He described other problems with the way the study was reported. To its credit, the journal later published a critique by Dr. Woloshin and colleagues with an editorial note acknowledging the problem. Many newspapers with stories based on this article also published corrections. The “take home” message from these two examples: provide event rates and translate odds ratios to relative risks.

Following Dr. Woloshin’s presentation, Dr. Lisa Schwartz described two more “communication problems.” The first involved two drugs for Alzheimer’s. Memantine was touted in the media as showing that patients taking it had a better outcome than those receiving a placebo. She demonstrated that the figures given were not enough to be able to make sense of the claim. To make sense of scores, we have to know what is being measured, what is possible, “which end is up,” and what actually matters. After going through the reported scores, she showed that although patients taking memantine had somewhat slower decline in their cognitive functioning, it is not clear how important these differences are. She also showed a consumer ad for the drug Aricept that claimed it was “clinically proven to treat the symptoms of mild to moderate

Alzheimer's." Although there were differences in the score of the drug versus a placebo, there were no differences in clinical outcomes, such as institutionalization or disease progression. It is important, Dr. Schwartz said, to help readers to understand what magnitude of change in scores translates into clinically meaningful events. The way to do this is clarify what is being measured, present the magnitude of the difference, and provide clinical correlation for the difference. Her second communication example involved "5-year survival statistics." The claim in the study was that low-dose CT can greatly improve the likelihood of detection of small non-calcified nodules, and thus of lung cancer at an earlier and potentially more curable stage. The claim: "A painless, 20-second test could save more than 100,000 lives annually.... The current five-year survival rate for lung cancer is only 14%. But that could soar to 80% if all smokers and ex-smokers received annual CT exams." Dr. Schwartz demonstrated how improved 5-year survival doesn't tell you about how many people are dying. This study demonstrates that CT screening finds more early stage cancer than chest X-ray screening. It does not demonstrate that CT screening saves lives or does more good than harm. Five-year survival is meaningful, she said, as a measure in a randomized trial of treatment—like the testing of a new drug where everyone starts off at the same stage of disease.

Following these presentations, Dr. Woloshin said that they are developing a primer for journalists to teach them about how to interpret statistics. They also are working directly with journals to improve the quality and accuracy of the press releases they issue to make a story newsworthy. Dr. Lindberg said that the *New England Journal of Medicine* and the *Journal of the American Medical Association* are aware of these problems in how data are presented and interpreted, and are taking positive steps to lessen them.

XI. ONLINE SHOPPERS GUIDE FOR PRESCRIPTION DRUGS

Ms. Gail Shearer, director of health policy for the Washington office of the nonprofit Consumers Union, presented the project "Consumer Reports Best Buy Drugs," which was funded in part by a grant from the NLM. The goal of the project is to develop an online shoppers' guide for prescription drugs that will enable consumers nationwide to save money on their prescription drugs without sacrificing quality or safety. The project, which does this by providing unbiased information to consumers and their doctors, was launched last December. The primary audience is people who lack any drug coverage or insurance—one important segment of this audience is seniors. They were surprised, however, to find that the new site is also popular with people under 65 and with those who do have coverage. Ms. Shearer said that a key ingredient in the "Best Buy" program is the Drug Effectiveness Review Project which is operated by a group of institutions in 14 states (based at the Oregon Health and Science University). This Project creates 400–800 page systematic reviews of the comparative effectiveness of drugs in various therapeutic categories. These extensive and detailed reviews are then translated by Consumers Union for a consumer audience. Consumers Union went to great lengths to encourage consumers to open a conversation with their doctors about prescription drugs. Ms. Shearer described briefly how the information is assembled and carefully reviewed before being put on the Web. So far

they have six categories of drugs available. They plan to release a new category a month. A vigorous outreach campaign to seniors is also an important part of the “Best Buy” project. She distributed to the Regents some of their print materials (in English and Spanish), and then she went online and did a live demonstration of the site.

Following Ms. Shearer’s presentation, Dr. Tenley Albright commented that this is a good example of the NLM becoming involved in an “empowering” program that will have a positive impact on the general public. There is no more important subject today than evidence-based medicine and the need to get such information to citizens—not just to seniors and those on Medicare but to the public at large. She is pleased that Dr. Schwartz and Dr. Woloshin, the previous presenters, are both on the Best Buy Advisory Board for Consumers Union. Ms. Shearer said that Consumers Union was hoping to partner with professional medical organizations to get this information to the point of prescribing so physicians would be mindful of both the efficacy and the cost of the drugs they prescribe.

XII. EXTRAMURAL PROGRAMS REPORT

Dr. Milton Corn, NLM Associate Director for Extramural Programs, discussed the NIH Director’s Pioneer Award. He presented information about the winners of the 2004 awards, with some analysis of their location, degrees, academic rank, and field of science. Basic features of the 2005 competition, now under way, were presented.

To promote healthy replenishment of the professoriate, NLM and other NIH Institutes that support training programs, are upgrading efforts to nurture graduates of the training programs in the early phases of their professional research careers. Obtaining NIH grants is often a critical factor in establishing a career, but new investigators often have some difficulty in obtaining their first NIH research grant. Dr. Corn presented a summary of NLM programs designed to support trainees, new faculty members, and others who are inexperienced in applying for NIH grants:

- Training in grantsmanship during the training period;
- Coaching and advice from NLM staff by email, telephone, face-to-face meetings, and presentations at meetings;
- Loan replacement awards for potential clinical researchers as a means of lessening the debt burden of education;
- Early faculty development awards that provide three years of support at the beginning of a career as an independent investigator; and
- Some judicious leniency during review and funding decisions for applications from novices.

The effects of such efforts on success rate of applications from new investigators will be tracked.

**MEETING CLOSED FOR THE REVIEW OF GRANT APPLICATIONS
May 10, 2005, 4:10 P.M.**

XIII. REPORT FROM THE PLANNING SUBCOMMITTEE

Dr. William Stead, who co-chairs the Board Planning Subcommittee, described briefly some of the ideas that emerged in discussions of a Strategic Visions Working Group on long range planning for NLM at the Cosmos Club in Washington, D.C. on April 11–12. The 21st century NLM centers on one basic idea—that publication and reading, while necessary, are not going to be sufficient to accommodate the vast amounts of new information and the global interconnections that are evolving. We have begun to develop a vision that involves the concept of “collaboratory” (people working with people and information), society’s “brain” (information working with information), and the informatics research and training that are needed to support the techniques of interaction among people and information. We need the infrastructure—facilities—to make all of this happen. As all this relates to the NLM, he said, we are at a “point of crisis” because the current budget situation coincides with the NLM running out of room for its collections. At the same time we craft a future vision for the Library, we have to come grips with how to deal with the long-term infrastructure to support that vision and the short-term infrastructure to deal with the growth of the collection. With this as a framework, the planners considered the roles that the NLM would have to play. The NLM should serve as a model of this 21st Century Health Science Library and also be the hub for a national and global health sciences information network. The Cosmos Club planners identified three mission-specific focuses for the NLM: (1) provide information and tools to support systems of Individualized Evidence-Based Health; (2) support the informatics infrastructure for biomedical research; and (3) serve as the hub of a “Global Health Village.” Dr. Stead briefly described NLM’s role in each. This vision will structure how we approach creating long range planning panels. With the Regents’ tacit agreement that this is a reasonable approach, he said, we will lay out a timeline that calls for a final planning report to be presented to the Board of Regents next May. A report from the Cosmos Club Strategic Visions Working Group will be distributed to the members of the planning panels before they begin their deliberations.

Dr. Stead said that since this is his last meeting, he wanted to express his gratification for serving such an admirable institution as the National Library of Medicine. He urged his colleagues on the Board to communicate their role as Regents in such a way as to encourage increasing the national investment in informatics, an action that will “bring down the cost of doing everything else.” He hopes this will be uppermost in the minds of Regents in the next four years.

XIV. NATIVE AMERICAN LISTENING CIRCLES

Dr. Elliot R. Siegel, NLM Associate Director for Health Information Programs Development, said that we are concluding one phase of the Listening Circles program and about to begin another. He said that he met with Dr. Ted Mala two years ago to discuss how NLM could

improve its outreach to Native Americans. Dr. Mala advised that NLM should be getting “out there” to listen to what Native Americans had to say on the subject of how to improve their health and lives. Dr. Siegel said that on several occasions a number of senior NLM staff (including Dr. Lindberg) went out to attend “Listening Circles” to do just that. The next phase of the program is to engage in several projects, for example, to improve tribal college libraries, to improve NLM’s own collections and databases in the area of Native American traditions and healing, and to arrange for Native Americans to accomplish certain tasks that NLM needs done. Dr. Siegel then introduced Ted Mala, M.D., Director of Traditional Healing at the Southcentral Foundation (Alaska) and former NIH Council of Public Representatives (COPR) member, and Ms. Cynthia Lindquist, President of the Cankdeska Cikana Community College of the Spirit Lake Nation (North Dakota) and a newly appointed COPR member.

Dr. Mala showed a number of pictures from the three Listening Circles in which Dr. Lindberg and other NLM staff participated: North Dakota, Alaska, and Hawaii. NLM is a pioneer in many areas, for example, telemedicine, which is so important in life of Alaska villages. Health aides in these villages are critical in the delivery of health care. Dr. Mala described how the essence of the Listening Circles was that NLM representatives would come, not to engage in dialogue so much as to listen and to learn. He said that earlier this year he arranged for a number of outreach representatives from several NIH components to visit Alaska; Mr. David Nash represented NLM in this group. Dr. Mala discussed the real differences among the Native American communities in different geographic areas of the country. Ms. Lindquist organized the visit of Dr. Lindberg and NLM staff and the Listening Circle in North Dakota. They went to different communities there so as to give the NLM a taste of the distinctions among them. She noted that she attended her first COPR meeting recently and that Listening Circles are being touted by Dr. Zerhouni as a model and as an important means of outreach to native communities. She has recently testified about the overwhelming problems facing Native Americans and the need to address these problems not piecemeal but in an integrated fashion. She complimented NLM on its willingness to participate in Listening Circles and to help in solving some of the problems. The NLM, through the National Network of Libraries of Medicine, has also been helpful in training tribal college librarians and setting up Internet connections.

Following these presentations, NLM’s Dr. Fred Wood briefly described one of the projects that have come out of the Listening Circle effort—an outreach project with the MHA Nation of North Dakota to improve economic conditions there by building the capacity of a tribal start-up IT company (MHA Systems Inc.) and thus create jobs. NLM is providing hardware, software, and technical and management training. Scanning work is now being done by MHA Systems to support NLM’s History of Medicine Division.

Dr. Buchanan asked whether what NLM is learning from the Learning Circles experience might be transferable to other planners in other settings. She also questioned whether, with the prospect of very small future budget increases for NLM, the project is viable for the long term. Ms. Lindquist agreed that there are aspects of the Listening Circles that are applicable to other

groups. Urban Indians are a target group for an outreach campaign, she suggested, as are the tribal colleges. As to funding, Ms. Lindquist said that she and Dr. Mala have good political connections, and they plan to discuss the great value of their NIH and NLM connections with their Congressmen and Senators. Eleanor Frierson said that the National Agricultural Library is involved in the annual Tribal College Library Institute and the NAL has worked with tribal college libraries to get several of them to join the agricultural library network. She suggested that the NAL and NLM work together in this matter.

XV. IMPLEMENTING THE NIH PUBLIC ACCESS POLICY

Dr. David Lipman, Director of NLM's National Center for Biotechnology Information (NCBI), said that the Wellcome Trust has just announced that it is setting up a site for PubMed Central in the UK, initially to be a mirror site but eventually to gain functionality of its own. The Wellcome Trust is planning a future requirement that their grantees submit accepted papers within six months to the U.K. PubMed Central. The NIH policy on public access was announced in February 2005 and the NCBI had the challenging task of moving quickly to devise a submission system so NIH-supported scientists could submit their accepted manuscripts into PubMed Central beginning May 2.

Dr. Stead passed out to the Regents a draft charge for the new: "NIH Public Access Working Group of the NLM Board of Regents" (Appendix B). Dr. Lindberg said he thought the statement was a good one. Dr. Detre, who will Chair the Working Group on Public Access moved its acceptance. It was approved unanimously.

XVI. REPORT OF THE NOMINATING COMMITTEE

Mary Ann Tatman, chair of the Nominating Committee, said the Committee nominates Dr. Thomas Detre to be Chairman of the Board of Regents for 2005–2006. Dr. Detre was unanimously elected.

XVII. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Dr. Richard Dean briefly reported on yesterday's meeting of the Subcommittee. Some of the subjects they discussed have already been covered in the Board's meeting. The expansion of health topics in NIHSeniorHealth.gov was discussed. As was the Information Rx program and a planned public event in West Palm Beach, Florida. The Subcommittee heard about a mass mailing to Hispanic households about NLM's MedlinePlus en español. They also discussed the encouraging response to the recent press release announcing NLM's Wireless Information System for Emergency Responders (WISER). Finally, the Subcommittee heard about the latest two additions to the MedlinePlus "Go Local" utility—Indiana and Massachusetts. More states will be signing on in the coming months.

XVIII. THE RETURN OF THE BUFFALO NICKEL

Mr. Joseph Fitzgerald, Chief of Graphics in NLM's Lister Hill Center, will be retiring the end of this month. He has been at NLM almost 25 years. Mr. Fitzgerald has the distinction of being the designer of the obverse (featuring Thomas Jefferson) of the new "buffalo" nickel just released by the Bureau of the Mint, Treasury Department. He also designed both sides of a nickel to be released this summer, with Jefferson on one side and a scene of Lewis and Clark reaching the Pacific Ocean on the other. Mr. Fitzgerald gave an entertaining account of his odyssey in designing the nickel and submitting it in the highly competitive process by which the Bureau of the Mint selects new coin designs.

XIX. ADJOURNMENT

The meeting was adjourned at 11:45 p.m.

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the February 15-16, 2005 Board of Regents Minutes
- Approval of May 9-10, 2006 Meeting Dates
- Acceptance of Draft Charge: NIH Public Access Working Group of the NLM Board of Regents
- Election of New Board of Regents Chair

Appendix A - Roster - Board of Regents

Appendix B – Draft Public Access Working Group Statement

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

William W. Stead, M.D.
Chair, NLM Board of Regents