

DEPARTMENT OF HEALTH AND HUMAN SERVICES

**NATIONAL INSTITUTES OF HEALTH
NATIONAL LIBRARY OF MEDICINE**

**MINUTES OF THE BOARD OF REGENTS
May 14-15, 2002**

The 130th meeting of the Board of Regents was convened on May 14, 2002, at 9:00 a.m. in the NLM Board Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), 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 May 15, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

MEMBERS PRESENT:

Ms. Alison Bunting
Dr. Henry Foster [Chair]
Dr. Richard Dean
Dr. Joshua Lederberg
Dr. Ralph Linsker
Dr. Joseph Newhouse
Ms. Eugenie Prime
Dr. William Stead

ABSENT MEMBERS:

Dr. Herbert Pardes
Gov. Lowell Weicker

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Dr. W. Richards Adrion, National Science Foundation
Ms. Eleanor Frierson, U.S. Department of Agriculture
Rear Admiral Kenneth P. Moritsugu, U.S. Public Health Service
Col. Robert A. Munson, U.S. Air Force
Capt. Tom Nunns, U.S. Navy
Col. Kristen Raines, U.S. Army
Dr. Vernon Schinski, Uniformed Services University of the Health Sciences
Mr. Winston Tabb, Library of Congress
Ms. Mary Ann Tatman, U.S. Department of Veterans Affairs
Dr. James Zimble, Uniformed Services University of the Health Sciences

CONSULTANTS TO THE BOR PRESENT:

Dr. Marion Ball, Johns Hopkins School of Nursing and Healthlink, Inc.
Dr. H. Kenneth Walker, Emory University School of Medicine

MEMBERS OF THE PUBLIC PRESENT:

Mr. Steven Foote, Perry Dean Rogers & Partners
Mrs. Jackie Gardner, Public
Dr. Reed Gardner, LDS Hospital, University of Utah
Mr. Chris Krahe, Aquilent, Inc.
Dr. Daniel Masys, University of California, San Diego
Ms. Nura Shehzav, The Blue Sheet
Dr. Ynez V. O'Neill, University of California, Los Angeles

FEDERAL EMPLOYEES PRESENT:

Dr. Donald A.B. Lindberg, Director, NLM
Mr. Kent A. Smith, Deputy Director, NLM
Dr. Michael Ackerman, High Performance Computing & Communications, NLM
Ms. Susan Anderson, National Center for Biotechnology Information, NLM
Mr. Jules Aronson, Lister Hill National Center for Biomedical Communications, NLM
Ms. Suzanne Aubuchon, Office of the Director, NLM
Ms. Joyce Backus, Public Services Division, NLM
Dr. Sergey Bazhin, National Center for Biotechnology Information, NLM
Dr. Carol Bean, Division of Extramural Programs, NLM
Dr. Dennis Benson, National Center for Biotechnology Information, NLM
Ms. Susan Buyer, Health Information Programs Development, NLM
Ms. Pat Carson, Office of the Director, NLM
Ms. Florence Chang, Division of Specialized Information Services, NLM
Mr. Charles Cook, National Center for Biotechnology Information, NLM
Dr. Milton Corn, Division of Extramural Programs, NLM
Mr. Jason Donaldson, Office of Administration, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Ms. Jane Bortnick Griffith, Office of the Director, NLM
Ms. Colleen Guay-Broder, National Center for Biotechnology Information, NLM
Ms. Laura Hileman, Associate Fellowship Program, NLM
Mr. Larry Holt, Office of Computer and Communications Systems, NLM
Ms. Vera Hudson, Division of Specialized Information Services, NLM
Ms. Betsy Humphreys, Lister Hill National Center for Biomedical Communications, NLM
Mr. Joseph Hutchins, Office of Computer and Communications Systems, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Ms. Sandra Jones, Division of Extramural Programs, NLM
Ms. Nancy Kamau, Associate Fellowship Program, NLM
Dr. Vipul Kashyap, Lister Hill National Center for Biomedical Communications, NLM
Dr. Ruth Kirschstein, Acting Director, NIH
Ms. Karen Kraly, Office of Computer and Communications Systems, NLM
Dr. Sergey Krasnov, National Center for Biotechnology Information, NLM
Dr. Dar-Ning Kung, Office of Computer and Communications Systems, NLM

May 14-15, 2002 - Board of Regents

Ms. Eve Marie Lacroix, Public Services Division, NLM
Ms. Teresa Lee, Associate Fellowship Program, NLM
Dr. Simon Liu, Office of Computer and Communications Systems, NLM
Ms. Becky Lyon, Division of Library Operations, NLM
Dr. Alexa McCray, Lister Hill National Center for Biomedical Communications, NLM
Mr. Robert Mehnert, Office of Communication and Public Liaison, NLM
Ms. Naomi Miller, Public Services Division, NLM
Dr. Joyce Mitchell, Lister Hill National Center for Biomedical Communications, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Dr. James Ostell, National Center for Biotechnology Information, NLM
Mr. Donald Poppke, Office of the Director, NIH
Dr. Barbara Rapp, National Center for Biotechnology Information, NLM
Dr. Merlyn Rodrigues, Division of Extramural Programs, NLM
Ms. Julia Royall, Health Information Programs Development, NLM
Dr. Elliot Siegel, Health Information Program Development, NLM
Dr. Lawrence Smith, Lister Hill National Center for Biomedical Communications, NLM
Dr. Jack Snyder, Division of Specialized Information Services, NLM
Dr. Sue Sparks, Division of Extramural Programs, NLM
Ms. Marti Szczur, Division of Specialized Information Services, NLM
Dr. Phillip Thomas, Division of Specialized Information Services, NLM
Ms. Claire Twose, Associate Fellowship Program, NLM
Ms. Cynthia Vaughn, Associate Fellowship Program, NLM
Ms. Jennifer Vyskocil, National Center for Biotechnology Information, NLM
Mr. Thomas West, Contractor, NLM
Dr. Fred Wood, Health Information Programs Development, NLM
Dr. Songmao Zhang, Lister Hill National Center for Biomedical Communications, NLM

I. OPENING REMARKS

Dr. Henry Foster welcomed the Regents, alternates, and guests to the 130th meeting of the Board of Regents of the National Library of Medicine. He also welcomed presenters Dr. Reed Gardner, Dr. Daniel Masys, and Dr. Ynez V. O'Neill

II. REPORT FROM THE ACTING DIRECTOR, NIH

Dr. Ruth Kirschstein, Acting NIH Director, said that Dr. Elias A. Zerhouni will be sworn in Monday as the next NIH Director. She reported briefly on the Congressional hearings just past and said that several NIH officials (including Dr. Lindberg and Dr. McCray of NLM) have appeared at congressionally arranged public programs in Ohio and Wisconsin. The House appropriations hearing that Dr. Lindberg participated in, was focused on communication, and there was much discussion about how NIH communicates its science findings to the professions and the public. There is enormous support by the Administration and the Congress for the work of NIH, and the effort to double the NIH budget within 5 years will be accomplished with the FY

May 14-15, 2002 - Board of Regents

2003 budget. NIH has received considerable support for bioterrorism-related work. Dr. Kirschstein noted that the accepted terminology now for civilian-related activity is “biodefense”—“bioterrorism” is reserved for Department of Defense–related activities. She closed by thanking the Regents for their work on behalf of the NLM and the NIH, and she thanked Dr. Lindberg for his support during her 2 years and 5 months as Acting NIH Director.

III. CONSIDERATION OF MINUTES FROM PREVIOUS MEETING

The Regents approved without change the minutes from the February 12-13, 2002 meeting.

IV. DATES OF FUTURE BOARD MEETINGS

The Board of Regents will meet next on September 10–11, 2002. The Board is meeting next winter on February 11–12, 2003. The dates of May 13–14, 2003, were adopted for the meeting next spring.

V. REPORT OF THE NLM DIRECTOR

Dr. Lindberg said that the FY 2003 President’s budget for NIH is \$27.4 billion. NLM’s portion is \$315 million, a 16 percent increase over 2002. NLM is pleased that the budget allows us to use personal service contracts (we have almost 300 such contract workers now); we are also fortunate to be able to carry forward some funds without regard to fiscal year limitation. Both these advantages are a result of NLM having been designated a “reinvention laboratory.” In the area of personnel, Dr. Lindberg said that NLM’s Executive Officer, Donald Poppe, has accepted a promotion to the NIH Office of the Director. Jane Griffith has been appointed Acting NLM Executive Officer. Dr. Lindberg introduced to the Regents Dr. Jack Snyder as the newly named NLM Associate Director for Specialized Information Services. Dr. Snyder has degrees in medicine, law, public health, forensic science, and pharmacology. Dr. Lindberg said he was grateful to Marti Szczer for her interim leadership of the Division. Dr. Barbara Rapp has been appointed head of the NLM Associate Fellowship Program. Dr. Rapp then introduced the new Associates: Laura Hileman, Nancy Kamau, Teresa Lee, Claire Twose, and Cynthia Vaughn. Dr. Alexa McCray next introduced several new senior Lister Hill National Center for Biomedical Communications researchers: Dr. Vipul Kashyap, Dr. Lawrence Smith, and Dr. Songmao Zhang. Jane Griffith reported on several matters of legislation, including an update on the proposed modifications to the HIPAA rules on privacy now being considered by the Administration. Legislation to ban genetic discrimination remains on the legislative agenda for this session of Congress. Dr. Lindberg described an exhibition and event on March 7 at NLM celebrating the Pan American Health Organization centennial. A successful meeting at NLM of the Regional Medical Library directors was held on March 21–22; various aspects of outreach were principal subjects of discussion. Another meeting Dr. Lindberg brought to the attention of the Board was the “Informationist Conference” sponsored by the Medical Library Association and held at NLM on April 4–5. Betsy Humphreys said that “informationist” is an extension of the “clinical medical librarian,” a concept that was supported by NLM grant. The conference made clear the

May 14-15, 2002 - Board of Regents

need for a focus on high-end information support that is integrated as part of the clinical and research team. Attendees at the conference discussed the circumstances when informationist assistance is needed; how such a program can be funded, supported, and evaluated; and what NLM's role is in all this. Dr. Lindberg noted that he had discussed the "informationist" concept with Dr. John Gallin, Director of the NIH Clinical Center, who was enthusiastic about it and said that several such people had been brought on to NIH to work with research teams. This spring the NLM has sponsored a Wednesday night film series as an offshoot of the NLM exhibit, "The Once and Future Web." Each film is preceded by a short lecture by an authority and, Dr. Lindberg said the audience seems equally divided between those who are primarily interested in the history of medicine and movie buffs.

The NLM Director said that the Library for years has supported the PIR (Protein Information Resource). This work is being expanded with the creation of a central protein sequence database, a joint project of the National Human Genome Research Institute, the NLM, and several other NIH Institutes. As a result of a meeting of experts to describe what the profession needs, a Request for Applications has been issued by NIH, soliciting proposals to develop and maintain a database of curated protein sequences. In addition, NLM has begun doing gene indexing of MEDLINE articles; these are linked to LOCUSLINK. Dr. Lederberg commented that there has never been a time when we are so flooded with data: as much of a scientist's time and ingenuity is spent understanding what is already known as producing new information. The proposed work will greatly assist in this. Dr. Lindberg briefly described another Request for Proposals, this one seeking to fund projects that will result in a "Scalable Information Infrastructure" in health care, medical research, and disaster management. Quality of Service aspects, such as medical data privacy and reliability, are central to the projects. Examples of the capabilities that the projects are expected to involve are self-scaling applications, wireless applications, nomadic and/or GIS techniques, and biometrics or smartcards. Dr. Stead said that although the proposals are likely to be reviewed solely according to their technical innovation, attention should also be paid to "medical/sociologic challenges" that have to be resolved if in fact the engineering capabilities are to be useful. He believes that the way the current request is written may encourage proposals that take such challenges into account. NLM's Dr. Michael Ackerman, the project officer, said that the closing date for proposals is May 31 and that projects small in scope are also being encouraged. Dr. Lindberg agreed with a comment by Dr. Lederberg that Artificial Intelligence research in medicine has been "stalled" in recent years and that it would be worthwhile to find out why and to try to remedy it. Ending his presentation, Dr. Lindberg showed the Board a videotape of his recent testimony in the House of Representatives.

VI. PRESENTATIONS: NLM DIRECTOR'S AWARD & FRANK B. ROGERS AWARD

Dr. Lindberg presented three NLM Director's Awards: **Donald Poppke**, until recently NLM's Associate Director for Administrative Management, in recognition of his "exemplary management and leadership of the National Library of Medicine's administrative programs and services that reflect the highest level of integrity and professionalism"; **Joseph Hutchins** of the Office of Computer and Communications Systems, for "exceptional vision, planning, and

May 14-15, 2002 - Board of Regents

implementation of the National Library of Medicine's systems reinvention initiative"; and **Naomi Miller** of the Public Services Division, for "outstanding management of the selection and organization of MEDLINEplus content, including the definition and maintenance of its high standards for quality, authority, and accuracy."

The Frank B. Rogers Award recognizes an employee who has made a significant contribution to the Library's fundamental programs and services. Dr. Henry Foster presented the 2002 Award to **Karen Kraly** of the Office of Computer and Communications Systems in recognition of "10 years of innovative contributions to NLM's DOCLINE system."

VII. THE NEW IAIMS

Dr. Daniel Masys, Director of Biomedical Informatics, University of California at San Diego Medical School, reported on a recent study of the Integrated Advanced Information Management Systems (IAIMS), funded by the NLM and conducted by the Association of American Medical Colleges. He gave a brief history of the IAIMS, and described its roots in an earlier AAMC study and how it has evolved over the past two decades. Over the last 18 years there have been a total of 66 IAIMS grants in the amount of \$55 million: 43 planning grants and the remainder prototype development and implementation grants. Currently there are 5 active planning grants, 3 Phase II (transition) grants, and 5 planning grant applications under review. Current NLM funding for the IAIMS program is about \$3 million per year. (Information about past and present recipients is available from the IAIMS Consortium at <http://www.cbmi.upmc.edu/iaims/consortium/index.htm>). The 1999 NLM long-range plan recommended that the IAIMS program should be revisited and the Library subsequently contracted for this with the AAMC. A review panel was assembled to conduct an assessment of the program and determine "lessons learned" over the entire program; provide an informed view of the information infrastructure as it currently exists; and determine "secular trends"—what implications current information technology has for academic health centers. The study included a review of the published literature, a new Delphi study, formal site visits to 13 institutions, and an external review of recommendations before publication of the report.

Dr. Masys described some of the uses to which the IAIMS funds had been applied over the years: hiring personnel devoted to organizational planning, support for planning, creating demonstration projects, and developing models for shared governance of the new infrastructure. The expected emergence of two or three common models never occurred: the common wisdom in the IAIMS community is that "if you've seen one, you've seen one." The IAIMS program was quite successful in establishing the NLM within the academic health community as a source of support and focus for institutional planning in a vitally needed area. IAIMS fostered a community of like-minded professionals who contributed articles to the literature and ran IAIMS workshops at major scientific meetings. It also provided leverage for other grants related to information technology. Among the problems encountered: keeping the IAIMS idea clear and energized over time; relocation of a key individual might result in a program "going into hibernation"; getting sustained institutional funding after the IAIMS grant ended; finding IAIMS

May 14-15, 2002 - Board of Regents

staff; finding affiliated community organizations with which to work; and keeping senior leaders of academic institutions engaged in the program. The legacy of the program over the years is that it has demonstrated a variety of viable approaches to integrating systems at an organizational level; it created sources of IAIMS expertise; it increased the total number of medical informatics R and D projects; it expanded the knowledge base in the health sciences and medical informatics; and it accelerated change in a positive manner for health sciences libraries by making them an equal partner in the IAIMS enterprise.

Is IAIMS still necessary? It is true that health sciences organizations are still *not* in the forefront of information technology management. Dr. Masys said that the reviewers firmly believe that there is a place for a new IAIMS that would be distinguished by focusing not *within* the traditional missions of the academic health center (patient care, education, research, libraries and knowledge management) but would provide linkages between several of those mission areas. IAIMS ideally should have an outward focus on information integration—regional, national, and global. An academic center, having integrated access to information it owns, should now develop robust linkages to information and resources it does not own. An IAIMS project should always incorporate a testable hypothesis that would result in “reusable knowledge” for the profession at large. In the area of **patient care**, the new scope envisions projects such as developing patient-centered rather than provider-centered systems; methods for coordination of health care services; integration of new forms of information such as functional genomics into clinical care; and methods for showing return on investment of key innovations in clinical information systems. In the area of **education**, new IAIMS projects would focus on testable hypotheses of performance-based (as opposed to curriculum-based) learning; a needs-driven curriculum so that the system knows what you already know and concentrates on what you don’t know or know imperfectly; learning at the point of service in clinical training environments; and performance tracking. In the area of **research**, IAIMS would encourage true collaboration tools (“collaboratories”); autonomous intelligent agents (such as “knowbots”); and regional and national information technology infrastructure for clinical and epidemiological research that would permit broad meta-analysis. In the last area, libraries and knowledge management, the new IAIMS would focus on an institution’s responsibility for stewardship of research records; the idea of “electronic laboratory notebooks” that are maintained for institutional investigators; the notion that the academic center can evolve to be a publisher and the home of “spectacularly large” databases; knowledge extraction from unstructured data; and quality measures and filters for Internet accessible high quality health science information. The original model of IAIMS was to provide access to information in the absence of networks. Today, access is not the issue. Overabundance of information requires us to filter it and bring it into effective action for health care providers, educators, scientists, and the public.

Following Dr. Masys’ presentation, Dr. Valerie Florance of the Extramural Programs Division spoke of the shift of focus in the IAIMS program in light of the review panel’s recommendations. She said there would be more points of entry into the program and a broader range of participants will be sought. The fundamental areas of activity to be focused on will be context-appropriate information (getting the right information to the right person in a useful

May 14-15, 2002 - Board of Regents

form), standards-based information management (using common vocabularies and national standards), and continuing the evolution of “digital libraries.” The next generation IAIMS consists of a family of five grants categories: two resource grants (planning and operations), two investigational grants (pilot study and testing/evaluation), and a training fellowship program. Dr. Florance described some of the features of each category. Both investigational grant categories are new. They are in response to the need expressed to find seed money for information-technology related investigations especially in the clinical environment, and the need to provide case studies in a structured environment so what is learned can be shared and the literature advanced. The review panel thought it was particularly important for IAIMS grantees to reach out to organizations outside the grantee institution, for example, a public health department, a Historically Black College or University, a tribal college or a community-based organization. There is also a desire to focus on consumers and on rural and urban underserved communities. IAIMS grants are now available to for-profit organizations.

Following the presentations, Dr. Stead (an IAIMS grantee) congratulated all involved with the new look at the IAIMS program. The “take-home” messages, he said, are that the program continues to focus on organizational development rather than computer science, there is an emphasis on managing information instead of the technology, and the new family of grants provides a flexibility lacking in the old program structure. He believes the Board of Regents should support the new program. Dr. Stead stated, “IAIMS is the program that makes the rest of what the NLM does matter.” IAIMS is about how an organization manages its information assets so they are current and accessible and how those assets are linked to like assets globally. IAIMS, he said, is about how to enable people to work in a way that the information is available at the time and place they have to make a decision. If this new family of grants is as successful as we hope, it will result in an increased demand for funding.

In the following discussion, Dr. Lindberg said that the only disappointment he had with the original IAIMS program was that most successful applicants were prestigious and highly ranked schools. He hopes the newly constituted IAIMS program will remedy this, making the program available to other organizations. Dr. Dean commented that he hoped the IAIMS would help underserved communities, reaching people who otherwise wouldn't have access to high quality information. Expanding on this, Dr. Stead said that we have to figure out how to get public health departments and community organizations to apply for an IAIMS grant—the new structure permits this. Dr. Walker said that one of the problems has been at the executive level of academic medical centers—many don't know what IAIMS is about. Is there some way we can “advertise” IAIMS at that level? Dr. Foster suggested that the Association of Academic Health Centers would be one avenue. Dr. Stead suggested that shortening the grant review cycle would be helpful. Dr. Milton Corn said that Extramural Programs staff would look into alternatives that allow this without compromising the review process. A motion to approve the newly constituted IAIMS grant program was made, seconded, and approved unanimously by the Board.

VIII. SUMMARY OF NCBI ACTIVITIES

Dr. James Ostell, Chief of the Information Engineering Branch, National Center for Biotechnology Information, introduced new NCBI staff members Sergey V. Bazhin and Dr. Sergey Krasnov. Dr. Dennis Benson, Chief of the NCBI Information Resources Branch, reported on the exponential growth of NCBI data usage and the nature of that usage. Ten years ago, the GenBank sequence data was doubling every 18 months; the current doubling rate is 10 months. There are now about 75 complete genomes available on the NCBI website; 400 additional genomes are in progress. The NCBI website, which ranks in the top 5 government sites in usage, has become a magnet for researchers worldwide, Dr. Benson said. We want to know more about how people are using the site, whether we are doing a good job, and what the future directions are. Sources of this information are web log data that provide country of origin, date/time, amount downloaded, etc., external response time monitoring, which gives performance data, and user surveys that yield data about user satisfaction and user demographic information. An example was shown of PubMed web log data showing the increase in usage since introduction of PubMed in 1997. We are now doing as many searches in a day (1 million) as we did in an entire month in 1997. Usage is divided about evenly between searches originating inside and outside the U.S. Japan is the heaviest non-U.S. user. Usage peaks about noon each weekday, but because PubMed is being accessed worldwide across various time zones, there is substantial activity throughout a 24-hour period. Response time for PubMed searches averages just under 2 seconds from most U.S. sites; internationally, 3 seconds is typical. Measured availability to end-users is 99.6%. At the end of March 2002, the NCBI conducted a random survey of 4000 PubMed users over a 2-week period. One in 3000 users got a choice to fill out the survey, or not. The data have not yet been reviewed in depth, but Dr. Benson gave a few preliminary highlights: most respondents were repeat users; 51% were researchers and 20% were health professionals; there was heavy usage for basic research and bibliographic checking; keeping up to date on research, looking up information on a specific disease or condition, and obtaining full text of articles were frequently cited as the purpose of searching; attributes noted were accuracy of information, fast response times, and ease of navigation. Overall satisfaction with the web site was high, Dr. Benson said, with 78% “extremely” or “very” satisfied, and 19% “satisfied.” NCBI is striving to broaden the reach of its web pages to the general public so that the site may serve as a primary source of basic biological information. A project called “About NCBI” was launched in January to create explanatory text about the NCBI site and some of the basic science behind it. Dr. Benson showed several of the “About NCBI” web pages. NCBI is now working on a set of tutorials to guide web users through the various resources.

Following Dr. Benson’s presentation, Dr. Ostell described the NCBI program to create a genome-oriented resource—the Reference Sequence Project—begun 5 years ago. GenBank has reports of sequences by individual submitters akin to the primary biomedical literature—submitted by an author, rarely updated, frequently redundant. RefSeq, on the other hand, is more like a review article about that literature—selective, synthesized, and updated. NCBI tries to

May 14-15, 2002 - Board of Regents

create a sequence for each macromolecule. It is nonredundant and comprehensive: NCBI tries to enumerate and measure naturally occurring molecules. RefSeq is a curated resource—authoritative by genome. Where an authoritative genome doesn't exist, NCBI will do it. The data is publicly distributed on the NCBI web site. The first reference sequence done, Dr. Ostell said, was for HIV. He showed computer-produced images of that and other examples, including bacterial genomes. A human example of broad public health interest is Fanconi Syndrome, for which he showed how data might be searched and retrieved. The current status of RefSeq is that there are a large number of organizations for which NCBI is collecting and assembling the genomes, curated mRNAs, and other data. It is very widely used. The RefSeq human mRNAs are now the standard resource used by genome centers. The human genome assembly done at NCBI is the standard worldwide resource for analyzing the human genome. It is reassembled and reannotated at NCBI every 2 months and we hope eventually to get it down to every 2 weeks. The number of proteins represented in RefSeq is 281,000, making it one of the largest such database in the world. In collaboration with other divisions at NLM, NCBI is working to connect MeSH indexing of articles to reference sequence data contained in the article. Extrapolating from a pilot project, this would mean approximately 27,000–53,000 articles a year containing links between protein data and the published literature. Two other publishing projects briefly described by Dr. Ostell are an effort to put books online (about a dozen are up already and many more are in the pipeline) and PubMedCentral (for the text of articles), which has been previously reported to the Board. In conclusion, he said that the “library of the future” is not just books, but the information and data underlying biomedical articles. Computationally we can make connections between different pieces of the information and authors can have their published articles connected automatically to the framework.

Following these demonstrations, Dr. Lederberg commented that he used to worry that the exponential growth of science meant that we humans would be unable to cope with it and be left far behind. Today, as we have just seen, we have tools that will begin to be up to the task of handling this data. He said that he finds he can get useful information directly off the web from such services as Google. Has NLM thought of connecting PubMed with the web so that, in addition to getting “related articles,” you can get “related sites”? This would require some filtering. Dr. Ostell said that although NCBI has not tried that, they have introduced the “LinkOut” mechanism that allows people to register their web sites to any of the objects in the Entrez system. They have thought about the inverse problem—going to Google and entering a term like “diabetes,” which almost never leads you to NCBI. The reason is that Google is indexing static web pages and not covering results generated from a database.

IX. UPDATE ON NEW NLM FACILITY

Mr. Kent Smith, NLM Deputy Director, presenting several views of the new facility, stated that its design neatly creates and integrates an entrance to three NLM facilities—the NLM Building (#38), Lister Hill Center (#38A), and a new building to house the programs of the National Center for Biotechnology Information and the NLM Office of the Director. Total NLM staff is well in excess of 1000 squeezed into space designed for 650. Shelf space for the NLM

May 14-15, 2002 - Board of Regents

collection will run out about 2004. The new facility with its 350,000 gross square feet (building and underground storage) would solve these problems. Mr. Smith pointed out several features of the new facility, including the Visitors Center, Collaboratory, and briefing/press conference room. He quoted Dr. Stead's comments at the last Board meeting about the need for a "Next Generation Library" and how it would serve as a hub that would use the most modern communications technology to bring together people and information resources. Dr. Stead had suggested that the Board put together a brief report to convey the urgency of the expanded facility. The Board's Facility Planning Subcommittee has drafted such a report and is now presenting it to the full Board. Mr. Smith briefly described the sections of the report. He concluded his remarks by outlining the design schedule: the "15 percent" drawings are completed; the "35 percent" design stage will be completed by August; "70 percent" by March 2003; and final construction documents should be completed and approved by July 2003.

Following Mr. Smith's presentation, Mr. Steven Foote of the architectural firm Perry Dean Rogers & Partners, showing a series of different views, "walked" the Regents through the new facility and provided details of its various features. He answered several questions about NIH plans on the periphery of the NLM facility and the parking garage. Dr. Foster said that the real challenge now was to get support for actually constructing the facility. Dr. Stead suggested that we need to focus people on the expanding role of the NLM, and that we are at a point where if this is not done *now*, the process will stop. He read to the Board his rewritten introduction to the report. Dr. Foster, as Regents' Chair, has written a cover letter that would accompany the report.

After discussion, the Board of Regents unanimously approved the report, "Medicine's Library of the 21st Century," with the introduction as rewritten by Dr. Stead and the covering letter by Dr. Foster on behalf of the Board.

X. GRANTEE REPORT: CLINICAL SOFTWARE QUALITY REVIEW

Dr. Reed M. Gardner, Professor of Medical Informatics at the University of Utah, and with the LDS Hospital in Salt Lake City, Utah, reported on a joint research project of the LDS Hospital, University of Utah, Vanderbilt University (Nashville), and Brigham and Women's Hospital (Boston). The project, funded by an NLM Informatics Research Grant, was to test the feasibility of creating a local Clinical Software Process Quality Committee (CSP-QC). He said that all the systems he will report on are used in day-to-day operation. The Integrated Clinical Data Base, as it is called, is available through a computer terminal at every bedside at LDS Hospital. Nurses do all the charting for medications and observations; physicians use the computer for data review and some data entry. Data from more than a dozen sources (pharmacy, laboratories, etc.) are integrated into the database. Dr. Gardner described briefly the involvement of FDA with medical devices. Dr. Frank Young, FDA Commissioner in the late 80s, determined that this should not extend to hospital information systems. However, blood bank software was regulated by the FDA beginning in 1995. There was a joint FDA-NLM meeting in 1996 as to whether this responsibility should extend to the regulation of medical software. Dr. Gardner's grant application to test the idea of Software Oversight Committees in individual hospitals was funded

May 14-15, 2002 - Board of Regents

by NLM in 1998. FDA's recent guidelines about the regulation of software said nothing about hospital information systems or clinical decision support systems. Dr. Gardner described briefly the systems in place at each of the four collaborating institutions. At the LDS Hospital, the HELP Clinical Computing System was developed which has decision-making capability (e.g., wean patients from ventilators, interpret blood gases, recommend antibiotics). At the University of Utah, the OASIS clinical hospital information system replaced the locally developed eChart. At the Brigham and Women's Hospital they developed the Brigham's Integrated Computing System (BICS) with computerized physician order entry and clinical results review. At Vanderbilt University, an IAIMS implementation site, they moved from a commercial system to a locally developed WizOrder physician order entry system. Dr. Gardner cited several recent articles from the *Journal of the American Medical Informatics Association* and the *Annals of Internal Medicine* that discussed Software Oversight Committees. The role of the SOC is to make sure there is ongoing monitoring to detect adverse events, address them, and to ensure that the system performs as designed. Such oversight must be a process, not a single event: review at one point in time does not guarantee safety or efficacy later. Using LDS Hospital data as an example, Dr. Gardner briefly described the preliminary results of their analyses of almost 3000 responses to questionnaires of users of the systems (nurses, pharmacists, physicians). The data from all four institutions are still being analyzed and there will be a report issued later. He contrasted the SOC at LDS Hospital which had representatives from medical staff, nursing staff, risk management, quality assurance, administration, corporate legal person, patient relations, and medical informatics, with the Vanderbilt Hospital SOC which had a 40-member voluntary committee with a 7-member Executive Committee that meets at least twice a month and reports to the hospital CEO. He described some of the problems reported by the four member institutions, ranging from "bad data" to system down time, "brown outs," and legal issues. The conclusions Dr. Gardner draws from their experience so far is that the Software Oversight Committees do work in these four institutions that have sophisticated computing systems; that many of the problems they experienced they had in common; that the SOC detects and solves problems that other hospital mechanisms don't; and that the electronic interfaces between multiple clinical systems are problematic. He said that the investigators will be publishing their results and they are planning to conduct a tutorial session at the next American Medical Informatics Association annual conference. They are working with the FDA to optimize, not regulate clinical computing. Finally, they are working with the JCAHO to explore alternative methods to foster the concepts that they have developed.

Following Dr. Gardner's presentation, Dr. Newhouse commented on the complaints about "bad data," asking "compared to what?" As to the percentage of mistakes, airline pilots, for example, would not tolerate the same percentage of software mistakes in life-threatening situations. In the case of down time or slow response times, Dr. Newhouse said that clearly is not an FDA issue, but may be a JCAHO issue. Ms. Prime agreed with the statement that software review must be treated as an oversight process and not a single event is a crucial observation. Also, she was encouraged by the expressed need for educating the participants in the software review process. The participants in this project, she noted, are large and sophisticated institutions: what guidance is there in all this for smaller, underserved institutions? On this last point, Dr. Lindberg

commented that this is a real problem; this is one of the reasons the HIPAA regulations are so problematical. Dr. Stead said one of the lessons they learned in the Vanderbilt IAIMS is that you need to manage your information separately from the tools that automate a facility. Dr. Zimble commented that the Department of Defense has been remiss in not sharing what it has been doing in this area over the last two decades. It has a fully integrated system throughout all the DOD hospitals, interlinking order entry, inpatient and outpatient systems, pharmacies, and laboratories, etc., and linking them with the logistical and inventory systems so that as materials are being used they being replaced.

XI. DIVISION OF SPECIALIZED INFORMATION SERVICES ACTIVITIES

Ms. Marti Szczur, Acting Associate Director for Specialized Information Services, using a live connection to the Internet, gave the Board a snapshot of some of the new initiatives of the SIS. She briefly described a recent online survey done on the TOXNET system: 84% of repeat users were extremely or very satisfied with TOXNET, as were 65% of the first-time users; 86% of repeat users “always” find the information they are looking for; and 97% of repeat users and 79% of first-time users said they would be very likely to come back to TOXNET. Most of the users were accessing the system from work and 68% had graduate or professional degrees. Ms. Szczur showed a number of the features of the new, friendlier web interface to TOXNET, including multi-database (factual as well as bibliographic) searching. She also showed a number of “special topics” oriented toward health professionals (biological warfare, for example). “HAZMAP” is another brand new service put up on the web by SIS. It is a relational database that maps hazardous chemicals and occupational diseases. Ms. Szczur used as an example a carpenter whose symptoms, when put into HAZMAP, suggested arsenic as a possible cause. She showed the variety of information on this subject that HAZMAP would lead one to. A household products ingredients database is in the early stages of development. She showed how a weekend handyman could retrieve information about a hazardous chemical used in car repairs. The database should go up in about 6 months. Next she demonstrated the prototype “TOX TOWN,” a graphically rich consumer information resource with links to chemical and environmental health information scenarios that might be found in a typical town: schools, parks, factories, rivers, homes, etc. Ms. Szczur also showed a prototype TOXMAP, a system that integrates GIS data into TOXNET. She demonstrated how searching on a hazardous substance name could produce a map of where it had been released into the environment. The facility data is based on the EPA’s Toxic Release Inventory (TRI), and TOXMAP provides scaleable maps and links to relevant information in the TOXNET databases. She briefly demonstrated a TOXNET chemical spellchecker, which is another project SIS has been working on. The last project she described was called a TOX PORTAL, a metasearching tool that remembers a user’s favorite site (e.g., for toxicology and environmental health information), searches them all simultaneously or in various combinations, allows modifying websites to search on the fly, and finds related terms and concepts. She showed an early version of such a system. Ms. Szczur said that the various projects she showed are being evaluated in prototype form and decisions about which to implement would be dependent on the results of the evaluations.

May 14-15, 2002 - Board of Regents

Following the presentation, Dr. Walker commented that at least 8 years ago he and Dr. Zimble were asked to evaluate the NLM toxicology databases. The progress made in improving the interfaces and ease of use has been amazing. Dr. Zimble said that people in CDC, DOD and the Homeland Security Office should become aware of these powerful tools.

XII. REPORT OF THE ASSOCIATE DIRECTOR FOR EXTRAMURAL PROGRAMS

Dr. Milton Corn, Associate Director for Extramural Programs, said that the World Trade Towers incident has focused national attention on management of disasters affecting large population groups. Because almost all aspects of prevention and response to such disasters require rapid coordination of people, data, and resources, efficient use of information technology can have a major impact. However, we face a host of technical, political and cultural problems for which informatics research is necessary. NLM is considering an extension of its existing informatics research program to solicit from the research community grant applications that address informatics issues of disaster management. A recent informal sampling of the disaster-related work now being done at our Informatics Research Training Programs yielded a surprisingly rich array of projects. We believe that a call for applications would be popular and fruitful.

Following Dr. Corn's presentation, the Regents unanimously approved the concept of extending the program to include informatics research for disaster management.

XIII. REPORT FROM THE OFFICE OF THE PHS SURGEON GENERAL

Rear Admiral Kenneth Moritsugu, Acting Surgeon General, U.S. Public Health Service, said that the Surgeon General-designate, Dr. Richard Carmona, should be confirmed and sworn in soon. Dr. Moritsugu described Dr. Carmona's background and said that the President has listed three expectations for the Surgeon General: to lead the PHS Commissioned Corps in its response to bioterrorism; to lead a national program that encourages healthy behaviors on the part of citizens; and to be a spokesperson for the national campaign against substance abuse. Dr. Moritsugu gave an update on the subject of Surgeon General reports: the recent report, "Closing the Gap," on mental retardation, has proven to be popular; a report on osteoporosis is in preparation; on the "radar screen" is an updated Surgeon General's report on the health consequences of tobacco use; and there is a follow-up planned to the "call to action" to reduce and prevent overweight and obesity. Subsequent to 9/11, the President has called for an increased level of volunteerism. This is being translated into programs. There is a new U.S. Freedom Corps, one component of which, a medical volunteer program, has been assigned to the HHS and the Office of the Surgeon General.

XIV. PERSPECTIVES ON NLM IT SECURITY

Dr. Simon Liu, Director of the NLM Office of Computer and Communications Systems, gave the Board a comprehensive overview of NLM's IT (information technology) security operation. He described the several categories of persons (hackers, cyberthieves, industrial spies, saboteurs,

May 14-15, 2002 - Board of Regents

etc.) who attempt to harm IT operations. Tools for hacking web sites have become increasingly sophisticated, easy to use, and available, he said. He showed a chart that demonstrated the increasing number of attempts to breach the NLM system. These challenges come, for example, by way of e-mail and attached viruses, attempts to gather system information that can be used in an attack, and “denial of service” attacks that attempt to overload our systems. Dr. Liu introduced to the Regents the key staff involved. He said that the security program consists not only of specialized hardware, software, and technical staff, but a heightened awareness on the part of employees that security is everybody’s business. Using diagrams and graphic images, he gave a high level perspective of NLM’s security program from three angles: conceptual, functional, and architectural. He said that NLM hires outside experts to test the strength of its security measures. Password security is an area of special attention as is scanning at various levels (server, desktop) for virus detection in e-mails. Dr. Liu said that NLM was experimenting with several biometric devices to allow entry into restricted areas. These devices include those based on fingerprint, hand geometry, and iris. He showed a brief video depicting two of these devices in action. Experience with security concerns has provided a number of lessons: security is an investment; it is “a journey, not a destination”; good security now is better than perfect security never; and there are different levels of threats—imagined, probable, real, known, unknown. It is best to concentrate on known, real threats, he concluded.

Following the presentation, Dr. Linsker asked about the magnitude of attempted system break-ins. Dr. Liu defined what he meant when he said there were 13,000 denial-of-service attempts last month. In response to another question from Dr. Linsker, Dr. Liu said that NLM provided no special arrangements for people outside the firewall to run scripts or executable programs. NLM and NIH don’t have problems of the same magnitudes as agencies like the Department of Defense. However, because our systems have to be open to “the whole world,” we need to make sure that the availability of our service is not inhibited. Dr. Liu said that in the 2 years he has been at NLM there have been no shutdowns of NLM’s external services. NLM transactions with the outside world average 65-70 megabits per second, with a peak of 120 megabits during unusual activity; NLM’s capacity is 155 megabits. The Library also has a connection to Internet 2 with a connection of 622 megabits. NCBI has a mirror site at the University of California at San Diego. Ms. Frierson suggested that the Regents would like to learn more about NLM’s mirroring, archiving, and backup capabilities. Dr. Liu briefly described NLM’s present outside backup capabilities and how the Library could recover from a system crash. Dr. Newhouse asked whether NLM benchmarked its performance with other government agencies or with private sector services. Dr. Liu said this is difficult, because other agencies are reluctant to disclose their figures. NLM might, however, be able to get general overall figures for various industry groups.

XV. NIHSeniorHealth.GOV WEBSITE

Ms. Susan Anderson of the Public Services Division said that NLM has just released a beta site of NIHSeniorHealth.gov. The design of the site is based on research conducted by the National Institute on Aging (NIA) about how seniors use computers. User evaluations were conducted

May 14-15, 2002 - Board of Regents

that resulted in modifying the site's design. The primary audience is the 60+ segment of the population that accesses the web from home. The site is the result of a partnership between NLM and NIA. The content is full-text information on topics that seniors would be interested in: the first three topics are Alzheimer's disease, caring for someone with Alzheimer's, and exercise for older adults. NIHSeniorHealth.gov also has photographs, videos, animation, and interactive quizzes. There are many links to relevant information in MEDLINEplus. Ms. Anderson demonstrated the new site and described the various design challenges that had to be overcome. For example, buttons and links are large to ease navigation for those who have difficulty using a mouse. Scrolling has been minimized. Special attention has been paid to type fonts, white space, and color. Information is simply written, linearly presented, and provided in small chunks. She briefly described how NLM conducted user evaluations and online focus groups on NIHSeniorHealth.gov, and how the site was modified in response to what they learned. Because the NLM site was being developed at the same time the Federal Government was implementing the 1998 Rehabilitation Act that calls for web sites to be accessible to the disabled, NIHSeniorHealth.gov is completely compliant with the Act. Ms. Anderson described how NLM put much effort into ensuring that seniors could easily view the videos (the site accommodates both QuickTime and Windows Media Player, and the proper player and speed is launched automatically).

Following Ms. Anderson's presentation, Ms. Bunting commended the research into seniors' cognitive and motor skills that went in to making the new site. She said the dubbing underneath the videos was especially welcome. She suggested that when a drug name is mentioned, perhaps there could be a link directly to information about it. Dr. Dean said that NLM has identified exactly the issues that will be important as more and more an aging population goes to the web for health information. Dr. Stead asked whether the sorts of tools being developed for NIHSeniorHealth.gov (and for the SIS information resources previously described) are being assembled into an "NLM Architectural Toolkit." Ms. Anderson said there is extensive internal collaboration within NLM in building the site and that much of the technology used has been replicated throughout other NLM sites. We plan to give this technology to other NIH components. Ms. Frierson commented that many of these techniques should be applied to general public sites and not reserved exclusively for seniors. Mr. Tabb suggested that NLM should be aware of analogous work going on at the Library of Congress's National Library Service for the Blind and Visually Handicapped. Dr. Linsker suggested that the site could be clearer about how the user can enlarge the font size. Ms. Anderson said that these suggestions were all welcome and would be looked into.

XVI. SPECIAL PRESENTATION

Dr. Kenneth Walker gave a brief PowerPoint presentation about his recent experience in starting a western-style nursing school in the Republic of Georgia. He teamed up with a "lobbyist" to arrange an earmark appropriation in the House and the Senate that "strongly recommends that the Agency for International Development extend and expand this program." They asked for \$4 million and will receive \$600,000 this year. Dr. Walker showed photos of his recent visit to

May 14-15, 2002 - Board of Regents

Georgia, including various medical and university settings and a typical hospital. The proposal envisions setting up a nursing school, a public health school, a health care management school, and a distance learning facility. The university has a mini-NIH campus that has several institutes and a 200-bed hospital. The distance learning facility will serve the campus and hospital as an information resource and as a center for telemedicine. These institutions in Georgia form an excellent testbed, since that region is at the confluence of several cultures—Islamic, Asian, and Indian.

XVII. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Dr. Henry Foster, Subcommittee Chair, reported on yesterday's meeting of the Subcommittee. The Regents heard reports from staff about how NLM receives user feedback about its websites. Methods employed include random online user surveys, focus groups, usability laboratories, users given the opportunity to email comments directly from the website, feedback from NLM exhibits that feature the web services, feedback components of special outreach projects (such as reaching out to Hispanic audiences in the lower Rio Grande valley), nationwide syndicated surveys of health information users (NLM subscribes to several such surveys), and information received indirectly by analyzing web log data. The Subcommittee reviewed a newly produced 4-minute videotape about MEDLINEplus that will be incorporated into a CD and used for promoting the service throughout the National Network of Libraries of Medicine. Dr. Foster showed the video to the Regents.

XVIII. GRANTEE REPORT: VESALIUS, PARÉ, AND THE DEATH OF HENRY II

Dr. Ynez V. O'Neill, Research Professor of Medical History at the University of California, Los Angeles, has an NLM publication grant to create an index of medieval images. She was the first woman and the first American to be president of the International Society for the History of Medicine. Dr. O'Neill spoke of the decades-long attempt to bring the reputation of Andreas Vesalius, the Belgian anatomist born in Brussels in 1515, to a wider audience. She described the work of her and her colleagues to create a dramatic video about Vesalius and the 1540 dissections in Bologna that eventuated in his monumental *De Fabrica*. For the video, she drew on another project of her and her colleagues being funded by NLM called IMMI, or the Index of Medieval Medical Images, which has over 2500 images created before 1500 now in North American Collections. The resulting 36-minute video, *The Young Vesalius*, took 5 years to complete. The success of this film provided the impetus for three others: the first showed the thrust of Vesalius' career leading to the production of the *Fabrica* in 1543, the second focused on Vesalius' clinical work as a royal physician, first to Charles V Holy Roman Emperor, and then to his son, Philip II of Spain. In 1559, when Henri II of France was injured in an accident during a joust celebrating the marriage of his daughter Elizabeth and Philip II, Vesalius was called to attend the French king. Intriguingly, the famous French surgeon, Ambroise Paré stood beside Vesalius at the king's bedside and both wrote accounts of the case, which comprise most of the medical facts we know about the king's condition and his progressive deterioration. Despite

May 14-15, 2002 - Board of Regents

being attended by the most eminent medical practitioners of the time, the French king died. Dr. O'Neill showed a series of images and clips from the work she did. She would like to produce a third and final film in Vesalius. This would examine perhaps the most extensively documented medical case of the sixteenth century, the life-threatening cerebral injury sustained by Don Carlos, eldest son of Philip and heir to the Spanish throne. King Philip brought Vesalius to attend the prince, who eventually recovered. The main focus of this video, however, will be on the genetic background that produced Philip (the product of a marriage between first cousins, as was his father) and others of his family. Two of Philip's four marriages were with cousins, one with a niece. Dr. O'Neill believes by studying the genetic background of Don Carlos and his family, they can contribute an historical component to this exciting field. The video will explore the family background of the unfortunate prince, and then a modern geneticist will comment on the findings. Another product of her work will be an interactive CD that contains images from Vesalius' work. Ultimately, she said, they hope to produce the "Digital IMMI" and to upload over 2500 images of manuscript drawings now in North American collections. They hope to open up the story of pre-modern medicine to 21st century students.

XIX. CERTIFICATES FOR OUTGOING BOARD MEMBERS

Dr. Lindberg presented certificates of appreciation to outgoing Board of Regents members Henry Foster, Joshua Lederberg, and Herbert Pardes.

XX. REPORT OF THE NOMINATING COMMITTEE

Mr. Tabb said that the Nominating Committee, consisting of Dr. Zimble, Col. Raines, and himself, places the name of Ms. Alison Bunting in nomination for Board of Regents Chair. Ms. Bunting was elected unanimously.

XXI. ADJOURNMENT

The meeting was adjourned at noon on May 15, 2002.

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

Henry Foster, M.D.
Chair, NLM Board of Regents