

**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**NATIONAL INSTITUTES OF HEALTH**

**NATIONAL LIBRARY OF MEDICINE**

**BOARD OF REGENTS**

**MINUTES OF THE 111TH MEETING**

**JANUARY 23-24, 1996**

**BOARD ROOM**

**NATIONAL LIBRARY OF MEDICINE**

**BETHESDA, MARYLAND**

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
PUBLIC HEALTH SERVICE**

**THE BOARD OF REGENTS OF THE NATIONAL LIBRARY OF MEDICINE**

**Minutes of Meeting <sup>1/2</sup>  
January 23-24, 1996**

The Board of Regents of the National Library was convened for its one-hundred-and-eleventh meeting at 9:00 a.m. on Tuesday, January 23, 1996, in the Board Room of the National Library of Medicine, Bethesda, Maryland. Dr. Carol M. Newton, Professor, Department of Biomathematics at the University of California School of Medicine, chaired the meeting. In accordance with P.L. 92-463 and the Determination of the Director, NIH, as announced in the Federal Register, the meeting was open to the public from 9:00 a.m. to 4:50 p.m. on January 23 and from 9:00 a.m. to 12:45 p.m. on January 24. The meeting was closed from 4:50 to 5:10 p.m. on January 23 for the review, discussion, and evaluation of grant applications. A Board roster is enclosed under Attachment A.

**Board members present were:**

Dr. Carol M. Newton, Chair	Dr. Michael DeBakey
Dr. Tenley E. Albright	Dr. Sherrilynne Fuller
Dr. Marion Ball	Dr. Robert J. Joynt
Ms. Naomi Booker	Dr. George H. Nolan
Dr. Mary E. Clutter	Dr. Steven J. Phillips
Dr. Edwin Cortez	Dr. James A. Zimble

**Alternates to ex officio members present were:**

Ms. Wendy Carter, representing Dr. Kenneth W. Kizer.  
Col. Eric B. Schoemaker, representing Lt. Gen. Alcide M. LaNoue.  
Dr. Kathleen A. McCormick, representing Dr. Audrey F. Manley.  
Dr. Richard Rowberg, representing Dr. James H. Billington.  
Capt. William Wurzel, representing Adm. Frederic Sanford.  
Col. Klaus O. Schafer, representing General Edgar R. Anderson.  
Ms. Sally Sinn, representing Ms. Pamela Q.J. Andre.

1/ For the record, it is noted that members absent themselves from the meeting when the Board is discussing applications (a) from their respective institutions or (b) in which a conflict of interest might occur. This procedure applies only to individual discussion of an application and not to "en bloc" actions.

2/ The Board of Regents, when considering the extramural programs of NLM, also constitutes and serves as the National Libraries Assistance Advisory Board.

**National Library of Medicine staff members attending this meeting included:**

Dr. Donald A. B. Lindberg, Director  
Mr. Kent A. Smith, Deputy Director  
Dr. Harold Schoolman, Deputy Director for Research and Education  
Dr. Michael Ackerman, Acting Associate Director, SIS  
Dr. Dennis A. Benson, Chief, Information Resources Branch, NCBI  
Mr. Fernando Burbano, Director, Information Systems  
Ms. Sally Burke, Acting Executive Officer, OD  
Dr. Marjorie Cahn, Special Expert, National Information Center on Health Services  
Research and Health Care Technology, LO  
Dr. Milton Corn, Acting Associate Director, EP  
Dr. Roger W. Dahlen, Chief, Biomedical Information Support Branch, EP  
Dr. Elizabeth Fee, Chief, History of Medicine Division, LO  
Mr. Earl Henderson, Deputy Director, LHCNCBC  
Ms. Betsy Humphreys, Assistant Director for Health Services Research Information  
Dr. Lawrence Kingsland III, Assistant Director for Applied Informatics  
Dr. Alexa McCray, Chief, Educational Technology Branch, LHCNCBC  
Mr. Robert B. Mehnert, Chief, Office of Inquiries and Publications Management, OD  
Dr. Elliot R. Siegel, Associate Director, Health Information Programs Development  
Dr. Melvin Spann, Deputy Associate Director, SIS  
Mr. Richard T. West, Chief, Office of Program Planning and Evaluation, EP  
Ms. Kathleen Cravedi, Special Expert, Office of Inquiries and Publications Management, OD  
Mr. Sheldon Kotzin, Chief, Bibliographic Services Division, LO  
Mr. Lou Knecht, Library Operations  
Dr. Steven Bryant, National Center for Biotechnology Information

**Others present included:**

Dr. Audrey F. Manley, Acting Surgeon General, PHS  
Dr. Philip R. Lee, Assistant Secretary for Health, DHHS  
Dr. Ruth Kirschstein, Deputy Director, NIH  
Mr. Thomas Bryant, President, Friends of the National Library of Medicine  
Ms. Sarah B. Carr, Office of Science Policy and Technology Transfer, OD, NIH  
Dr. Lois E. DeBakey, Professor of Scientific Communications, Baylor College of Medicine,  
Consultant to the Board of Regents  
Dr. Don E. Detmer, Senior Vice President, University of Virginia  
Ms. Jianping Fu, WHO Fellow  
Mrs. Ernesta Greenidge, WHO Fellow  
Mr. Keith Kruger, Executive Director, Friends of the National Library of Medicine  
Dr. Seong Ki Mun, Director, Division of Imaging Physics, Department of Radiology,  
Georgetown University and Chair, Board of Scientific Counselors, LHCNCBC  
Ms. Susan K. Newbold, University of Maryland at Baltimore  
Capt. Vernon Schinski, Assoc. Dean, USUHS  
Ms. Akira Shimauka, WHO Fellow  
Dr. Alvy Ray Smith, Graphics Fellow, Microsoft Computer Corp.  
Dr. Mr. Laresh Jarasanker, Reporter, "The Blue Sheet"  
Mr. Peter Ballard, Reporter, "The Blue Sheet"

## **I. OPENING REMARKS**

Dr. Carol Newton, Chair, welcomed the Regents, consultants, and guests to the 111th meeting of the Board of Regents of the National Library of Medicine.

## **II. REPORT FROM THE ASSISTANT SECRETARY FOR HEALTH**

Dr. Philip R. Lee thanked the Library for its "providing a home" for the 117-year-old PHS journal, *Public Health Reports*, and for the Public Health Service Historical Office. The recent reorganization of the Office of the Assistant Secretary for Health made such moves necessary. Dr. Lee described the "reinvention" of the Public Health Service, including the merger of the Office of the Assistant Secretary for Health with the HHS Secretary's Office. He has a joint role as the senior advisor to the Secretary on health and science issues and as coordinator the programs of the Public Health Service. Several advisory councils have been established to coordinate and advise the Secretary on cross-cutting health issues such as AIDS, immunization, and smoking. One beneficial result of the new arrangement is that the Secretary herself has been very active in public health issues since the merger. The health-related agencies now make up 90 percent of the Department's total staff and, in the long term, we hope to create a Department of Health. Three of the major PHS agencies have their appropriation for 1996--the Food and Drug Administration, Centers for Disease Control and Prevention, and National Institutes of Health. The NIH actually has an increase in its budget. The other PHS programs were faring less well in obtaining funding. Dr. Lee said that, as part of the reinvention, a number of important delegations, particularly in the personnel area, have been made from the OS level to the operating agency heads. The most important issue we are facing for the 1997 budget is that concerning how to finance major improvements to the NIH Clinical Center.

Following Dr. Lee's presentation, Dr. Michael DeBakey asked about quality issues, including "denial of care," in connection with managed care. Dr. Lee responded that the Department and the Health Care Financing Administration are now actively involved in developing quality standards for HMO's--linking both Medicaid standards and health plan standards for non-Medicaid patients. HCFA is also working with the Indian Health Service on quality issues affecting the health of native Americans. In a major advance, the National Cancer Institute and the Defense Department health system (CHAMPUS) have agreed that CHAMPUS will pay for the medical care of any of its 9 million beneficiaries involved in an NCI-approved clinical trial. This is a model for other insurers. Dr. Phillips said that one disturbing aspect of this is the rapidly growing and uncontrolled alternative medicine in this country. Dr. Lee said that we spend more money in the U.S. on alternative medicine than we do on primary care.

## **III. REMARKS BY THE ACTING SURGEON GENERAL**

Dr. Audrey F. Manley, Acting PHS Surgeon General, reported on the recent organizational changes in the Public Health Service. The proposal to eliminate the Office of the Surgeon General has been

successfully resisted, at least for the time being. The furlough had a major impact on all PHS offices-- because many operations could not be shut down, scheduled annual leave for Commissioned Corps officers had to be canceled in many cases. Another current concern is the draft report by the Government Accounting Office, requested by several members of Congress, that suggested that funds could be saved by converting Commissioned Corps personnel to the Civil Service. Dr. Philip Lee and the Department have formally taken strong exception to the findings of the report. Following Dr. Manley's report, Dr. Lindberg thanked Dr. Lee for his strong support of the National Library of Medicine, the Public Health Service, and the nation's welfare.

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

The Regents approved the minutes of the September 26-27, 1995 meeting.

#### **V. FUTURE MEETING DATES**

The Board will meet next on May 21-22. Next fall's meeting will be September 24-25. The proposed dates of January 28-29, 1997, were accepted and confirmed for next winter's meeting.

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

Dr. Donald A. B. Lindberg reported that the FY 1996 budget for NIH reflects an increase of 5.8 percent, to \$11.9 billion. NLM has also fared well, with an increase of \$8 million for High Performance Computing and Communications and \$0.2 million for AIDS information services. The total NLM FY 1996 appropriation is \$141.4 million. The HPCC increase will be used primarily to supplement existing grant and contract supported research projects on such subjects as telemedicine, testbed networks, imaging, and electronic patient records. In addition, NLM could put out new solicitations late in FY 1996 and early FY 1997 in targeted HPCC areas. Dr. Lindberg said that because telemedicine is the most highly leveraged of these areas, the NLM is funding a study by the Institute of Medicine to determine how best to evaluate telemedicine projects. A second IOM study, co-sponsored by NLM, is on the subject of protecting medical data privacy. Dr. Lindberg asked the Board's guidance on NLM's plans to utilize the HPCC funds and whether this is a sound approach. Dr. Michael DeBakey said that HCFA has been reluctant to fund telemedicine projects and that NLM was to be commended for its plans to supplement existing HPCC and telemedicine projects in FY 1996. He urged that the plan be approved by the Board.

Dr. Lindberg reported that on March 26-27, the policy and technical representatives from the 20 international MEDLARS centers will meet at NLM to exchange information and discuss other matters of mutual interest. Any interested member of the Board may attend. The NLM is now forming a Planning Panel on International Programs, authorized by the Board of Regents, to advise the Library on its international information policies and programs. The NLM Director said that although the biennial report of the Board of Regents to the Congress is not being required this year, NLM staff will consult with the Regents and prepare a draft Report summarizing the Board's activities. On another matter, the Library is concerned that an OMB requirement that Federal data centers be consolidated

may be applied to the NLM. Dr. Lindberg said that it would be a disaster for the Library to lose control over its computer-based activities and to have its computer operation consolidated with other Federal activities. It would be counter to the spirit of the reinvention activities the Library is now engaged in. He asked for the guidance of the Regents in this matter. Dr. Michael DeBakey moved that the Regents draft a resolution that would be considered later in the meeting. The motion was unanimously approved. [Dr. McCormick abstained from this and all subsequent votes by the Board.] This resolution, and one on telemedicine will be considered tomorrow by the Board.

Dr. Lindberg raised the topic of how proposals for molecular databases are reviewed and funded by NLM and how they are interdigitated with databases supported by other components of the NIH. This was the subject of a presentation at the Board meeting in May 1995 by Dr. Richard Roberts, Research Director of New England Biolabs. Dr. Roberts, who has been a member of several NLM advisory committees, has agreed to head an ad hoc committee to look into this, should the Board of Regents agree that it should be done. The proposal presented to the Regents in their agenda book was unanimously approved by the Board. (The action is in Tab A.) Dr. Lindberg noted that Dr. Donald Detmer, former Regent, will be asked to join the ad hoc committee. In the area of personnel, the NLM Director said that staffing ceilings were being reduced but that the Library was being treated fairly in the allocation of the cuts. As a result of the recent reorganization of Dr. Lee's office, which he described, NLM has agreed to take on the office of the journal *Public Health Reports* and the office of the PHS historian. Dr. Lindberg introduced both Dr. Anthony Robbins, the editor, and Dr. John Parascandola, the PHS historian. Several other new senior positions at the NLM: Mr. Donald Popke, Executive Officer; Ms. Kathleen Cravedi, a special expert on outreach programs; and Mr. Fred Wood, a special expert in the area of information policy. Two staff members who are retiring are Mr. Charles Goldstein, Chief of the Lister Hill Center Information Technology Branch, and Ms. Karin Colton, Committee Management Officer in Extramural Programs. Finally, Dr. Lindberg noted that the Library was able to assign a small around-the-clock staff to maintain MEDLINE services during the recent furlough and blizzard; if it had lasted much longer, however, there was a real danger that the flow of new references into MEDLINE would be choked off.

Following Dr. Lindberg's presentation, Dr. Carol Newton presented a special Board of Regents Achievement Award to Karin Colton, who was cited for "her outstanding service and dedication to the National Library of Medicine Board of Regents."

## VII. REPORT FROM THE NIH DIRECTOR'S OFFICE

Dr. Ruth L. Kirschstein, NIH Deputy Director, reported briefly on a subject touched on by Dr. Lindberg in his report—the reorganization (consolidation) of Federal computer facilities. She said that a decision is imminent as to which groups will be designated as "data centers." She said that NIH is gratified with the outcome of its 1996 budget and that it is a measure of the deep regard that the Administration, the Congress, and the American people have for biomedical research. However, NIH is deeply concerned about the budget prospects of other agencies within the Department and such non-HHS agencies as the National Science Foundation that have not yet received 1996 funding. When the second furlough began, Dr. Kirschstein said, NIH was 2,000 grant awards behind in processing;

we are now about 4,000 grants behind. NIH hopes to be caught up within six to nine months. She said that information about grant deadlines, study section schedules, and other grant-related information is being kept up to date on NIH's Home Page (<http://www.nih.gov>).

## **VIII. RESOLUTION ON TELEMEDICINE**

At the Board's last meeting, there was a general discussion among the Regents about the importance of medical informatics and telemedicine. It was decided that a strong statement from the Board on this subject would be appropriate, and Captain Vernon Schinski volunteered to draft a resolution. Captain Schinski distributed such a draft which was then discussed and several suggestions were made for its improvement. Mr. Mehnert will incorporate the suggestions in a redraft and the Board will consider the resolution later in the meeting.

## **IX. REPORT FROM THE LISTER HILL CENTER BOARD OF SCIENTIFIC COUNSELORS**

Dr. Seong Ki Mun, Chairman of the Lister Hill Center Board of Scientific Counselors, reported to the Regents that the BOSC reviewed four NLM intramural research projects in 1995. The goal of the first, DXPNET, is to develop an image archive of 17,000 digitized x-rays. Dr. George Thoma and his colleagues have developed the image archive, two specialized workstations, and Internet access to the archive. The BOSC believes that DXPNET is a significant engineering achievement with a potentially wide application. The second project reviewed was related to the Visible Human Project--a structural labeling contract for anatomical image identification. Mr. Earl Henderson presented the project to the BOSC and obtained the Board's approval. The third project reviewed, presented by Dr. Alexa McCray and Dr. Lawrence Kingsland, was related to the Lister Hill Center's educational programs. The Center sponsors several fellowship, clerkship, and student programs, including high school, undergraduate, graduate, and post-doctoral students, as well as continuing education. The BOSC felt that although these were very useful programs, the fact that they are not separately funded (but are "add-ons") limits their effectiveness. A more structured approach is needed. The fourth project reviewed was the Information Sources Map of the Unified Medical Language System Program, presented by Dr. Richard Rodgers. The BOSC found the technical approach to be sound and that it will, when fully implemented, greatly improve access to the Library's information resources. The reviewers did note that there is no established evaluation plan based on a hypothesis to be tested; it was recommended that one should be implemented. Dr. Mun made several general observations: the vacancy for the Lister Hill Center Director should be quickly filled; the BOSC is very pleased with the quality of LHC's researchers--however scientists working in developmental areas should be given the same status as those doing more "hypothesis-driven" work; in the area of educational programs, there were serious mismatches between the resources available and the goals of the programs; and LHC investigators should follow NIH practices when presenting programs for review. Following Dr. Mun's presentation, Dr. Harold Schoolman, NLM Deputy Director for Research and Education, commented that the Library wants to increase the number of students and fellows and is creating a more systematic approach to conducting its educational programs.

## **X. REPORT ON NIH DIRECTOR'S ADVISORY COMMITTEE MEETING**

Dr. Carol Newton distributed to the Board members a 4-page outline of the December 7 NIH Director's Advisory Committee meeting that she attended. She said that there were a number of topics discussed: budgetary matters, "trans-NIH" issues, Howard Hughes Medical Institute training programs, public information issues at NIH, the NIH "Mini-Medical School," the NIH panel on gene therapy, the NIH Recombinant DNA Advisory Committee, and the benefits to the national economy derived from biomedical research, and the future of Federally supported clinical research in the face of the for-profit managed care industry. Dr. Newton said that the NIH Director's Advisory Committee would welcome suggested topics to be raised at future meetings and also invites nominations for subcommittee members. She said that experts in biomedical information systems are not well represented on the Committee, and she suggested that interested Board members might wish to become involved. Dr. Michael DeBakey said that the reason for forming a panel on the future of clinical research was the perception that NIH concentrated too much on basic research and was not effectively supporting clinical research. Dr. Lindberg commented that NIH funds only about 25 percent of the nation's clinical trials; 75 percent is funded by private companies and others.

## **XI. DEMONSTRATION OF GENOME AND 3-D STRUCTURE DATA WITHIN GENBANK**

Dr. David Lipman, Director of NLM's National Center for Biotechnology Information, said that a primary justification for the Human Genome Project is that the NIH can sponsor various pieces of the difficult, time-consuming, expensive biology involved, and then connect the resulting sequence information using sequence similarity techniques. He showed how this has been done using *e-coli* and yeast, for example, and how this research has application to the human genome. Using a World Wide Web connection, Dr. Lipman called up *Science* magazine's table of contents and pulled up an abstract of article on a new candidate tumor suppressor gene. The authors have isolated a gene that is associated with a high percentage of pancreatic tumors. Dr. Lipman showed that information in one of the NCBI databanks can be connected to several snippets of the newly discovered gene and that this reveals the tumor suppressor gene is actually a variant of existing sequence information from another species. He also showed how the NCBI is trying to provide a chromosome- or genome-level view of the information. Following Dr. Lipman's presentation, Dr. Steve Bryant of the NCBI presented to the Board "a tale of two molecules," the first of which is based on the "obese gene" discovered in mice a year ago. At that time it was not possible to discover homologues to the gene by sequence comparison. A new technique by NCBI scientists, comparing the obese gene product sequence against a 3-dimensional structure database, revealed that the obese gene product is very much like that of interleukin-2. The second molecule in the "tale," which we just learned about a few weeks ago, is the receptor in the obese gene product. It confirms that using the 3-dimensional structure did lead the NCBI scientists to the correct inference about the obese gene and how it works. The scientists also learned that it would have been possible a year ago to identify the receptor using those techniques. Dr. Bryant, using a terminal connected to the World Wide Web, demonstrated how that could be done using NCBI tools and databases.



## **XII. NLM'S VISIBLE HUMAN PROJECT**

Dr. Michael Ackerman, NLM Assistant Director for High Performance Computing and Communications, reported on the announcement about the Visible Female he and Dr. Lindberg made in Chicago at the Radiological Society of North America on November 24. One year earlier, they had announced the Visible Male at the same meeting. Dr. Whitlock and Dr. Spitzer of the University of Colorado, the contractor for the Visible Human Project, were also on hand for the announcement. Dr. Ackerman passed out a new NLM fact sheet that included information about the Visible Female, and also copies of an article from the current issue of *JAMA* on the subject. He showed to the Regents several slides of both the male and female. The female was sectioned at one-third millimeter increments (5,189 slices); this is a considerably higher resolution than was done for the male (1 millimeter resulting in 1878 slices). This difference in resolution could be seen from the slides. There are many sample images from the Visible Human project on the World Wide Web, including on NLM's own Home Page. Dr. Ackerman described briefly just a few of the applications of the Visible Human datafiles now being developed (there are at present more than 400 licensees of the data). Finally, he said that at a meeting on virtual reality last week in San Diego there were a half dozen papers based on the Visible Human. Because the project had such a great impact on the papers presented, the prize for the "best paper," the Satava Award, was given not to a paper but to the Visible Human project for "reinventing the way medical education will be taught." *Science* magazine declared the project one of the 10 notable events in science in 1995. Finally, Dr. Ackerman showed the Board several of the videotapes based on the Visible Human that have recently been done by others. He said that the project is now in its second phase, to develop a database (as opposed to a dataset) of labeled and segmented structures in the chest. An NLM contract to do this was awarded to Engineering Animation, Inc. A short videotape produced by that company about human anatomy was shown to the Board. Following Dr. Ackerman's presentation, Dr. Alvy Ray Smith, former Regent and a "godfather" of the Visible Human Project, strongly encouraged the Board of Regents to continue its support for the program and to keep in mind the distinction between geometrical and nongeometrical computer picturing. What the Board just saw was a mixture of both. He also that the NLM continue to increase the quality of the dataset and to take the Visible Human Project to "new dimensions." For example, age, race, and pathology could all be introduced to the data. Dr. Michael DeBakey commented that the Visible Human Project is a "tremendous contribution to the study of anatomy." It is another example of the value of the National Library of Medicine to the medical community and to the public. Dr. Marion Ball noted that much of the credit for the Visible Human Project goes to the Long Range Plan in which it was first described, where the strategic vision of the NLM's many planners was codified and laid out as a plan of action.

## **XIII. OUTREACH AND PUBLIC INFORMATION**

Dr. Michael DeBakey, who chairs the Board's Subcommittee on Outreach and Public Information, reported that the subcommittee has held two meetings, most recently this morning. The members discussed a number of items, including the plans of the Friends of the NLM to create and distribute print public service announcements, how to get NLM's services mentioned on such a television show such as *ER* or *Chicago Hope*, and how to get articles into such widely ready magazines as "Family Circle" and "Parade." Dr. Lois DeBakey urged the Regents to engage in outreach and public information activities on behalf of NLM in their institutions. She said that it disturbs her to read in

the newspapers and see on television pieces about projects that the NLM has sponsored and for which the Library does not get credit. Popular television would be an excellent venue for messages about NLM programs; Dr. DeBakey recently wrote to the medical consultants of the programs ER and Chicago Hope to see if this might be possible. She has received an encouraging response from ER and NLM staff are following through. Following Dr. DeBakey's remarks, Dr. Marion Ball commented that another subject discussed at this morning's subcommittee meeting was how to create an "NLM-approved" curriculum element that would define a minimal competency for today's entering health science students and instill the notion that learning is a life-long process that today involves the use of computer-based information resources. Dr. Tenley Albright, also on the subcommittee, said she was optimistic that with the addition of special expert Kathleen Gardner Cravedi to the NLM staff the subcommittee would make good progress. The Regents then saw a 60-second commercial made by the ITT company that featured how MEDLINE could be used from France in a patient care situation. It was seen by many millions of Americans when it was aired in prime time in the mid-eighties. Dr. Michael DeBakey invited all the members of the Board to submit their ideas on outreach to the subcommittee. Dr. Kathleen McCormick suggested that using the Internet might be one way of implementing the kind of educational component suggested by Dr. Ball. Ms. Naomi Booker commented that the NLM should pay particular attention to outreach efforts aimed at professional groups that have a special mission to help minority populations, such as the National Medical Association and the National Association of Community Health Centers. Dr. Lindberg agreed, and noted that NLM was encouraged by the success it had in working with the Coolidge High School in Washington, D.C. and with the special toxicology outreach project to minority health science schools that Dr. Melvin Spann has implemented.

#### **XIV. REPORT FROM EXTRAMURAL PROGRAMS**

Dr. Milton Corn, Acting Associate Director for Extramural Programs, reported on EP's budget. The processing of approximately 4,000 grants at NIH has been delayed due to the government furlough as have over one billion dollars in payments. Grantees who were paid during this FY received pay cuts because the formula used to calculate payments was based on a lower budget outlook. Because NIH subsequently received funding which included a budget increase of over five percent, Extramural programs is currently notifying grantees that restitutions will be made to restore funds which were cut in recent payments. In managing the backlog of grants, EP's foremost consideration is competing renewals which are ongoing projects that have salary payments due. Because processing grant awards takes some time, pre-award commitments will be issued that permit grantees to spend in anticipation of an award. Because the summary statements needed to revise applications for resubmission were also delayed, the resubmission deadline for revised applications scheduled for March 1, is likely to be extended by two or more weeks.

Dr. Corn discussed the budget situation for other agencies. The current budget authority expires January 26 for many. Included among underfunded agencies are NSF, which has joint ventures with NLM, and AHCPR.

## **Small Business Innovation Research Program**

Dr. Corn discussed the Small Business Innovation Research Program (SBIR). In recent years, Congress decided to facilitate the transfer of research and technological advances by private enterprise. The SBIR is funded by set-asides based on the total amount expended for research project grants by each institute. The set-aside amount for 1996 is 2.5 percent. NLM's total Extramural budget is approximately 30 million, with nine million in the category of research projects, resulting in a set-aside amount in FY 1995 of \$182,000. The SBIR program offers small businesses some research and development support for commercially viable uses of technology. There must be a potential for eventual profit. Applications are submitted to NIH and are peer-reviewed in a process similar to that used for other applications, and are assigned to an institute depending on the area of interest. NLM awards are through grants and consist of three phases. Phase I support provides up to \$100,000 for six months and covers early research and development and feasibility studies. Phase II provides up to \$750,000 over two years for testing and establishing a commercially viable program. Phase III is for operation of the business, and receives no government support. Currently, NLM supports only Phase I grants. Dr. Corn discussed some examples of SBIR grant applications EP has funded.

As required annually, Dr. Corn presented for review the Board Operating Procedures, "Guidelines for Adjustments by Staff in Time or Amount of Grant Award." The procedures were amended by raising the budget adjustments that must be reported to the Board by staff from \$3,000 to \$10,000. The Guidelines were amended and reaffirmed unanimously.

## **XV. ISSUES SURROUNDING PRIVACY LEGISLATION**

Dr. Don E. Detmer, Vice-President, University of Virginia at Charlottesville, said there are four concepts surrounding the security of personal health data: privacy, confidentiality, accuracy, and integrity. To expect total privacy in a society with legitimate concerns with billing, public health issues, and law enforcement, for example, is unrealistic. On the other hand, confidentiality is important and achievable--using information you have control over for rightful purposes only. It is his opinion that Federal legislation is desirable to protect the confidentiality of personal health data, Dr. Detmer said. Accuracy, the third concept, is obviously an important requirement. A unique personal identifier is desirable to help ensure the accuracy of health records. The fourth, integrity, is a requirement that goes without challenge. In the United States today, about half the states do not allow citizens access to their personal medical records. Dr. Detmer said that the computer-based patient record, long seen as a desirable goal, is still only about half way to achievement. The evolving NLM Unified Medical Language System is an important component of the computerized patient. Today we have a patchwork of state law that would be superseded by the "Medical Records Confidentiality Act," introduced by Utah Senator Bennett in October 1995. Dr. Detmer has been on research leave at NLM over the past year and investigating medical confidentiality issues was one of his priorities. He met with a number of officials in the Congress and Senator Bennett agreed to sponsor the legislation that he and others drafted. Senator Kassebaum was a strong supporter and held hearings on the legislation. The bill has strong bipartisan support and Dr. Detmer said that although the final outcome is uncertain, he is hopeful that it, and a companion bill in the House, will move forward to passage. Following Dr. Detmer's presentation there was a lively discussion that

elicited opinions on a variety of aspects concerning the privacy and confidentiality of patient medical records.

## **XVI. TRENDS IN MEDLARS USAGE**

Mr. Sheldon Kotzin, Chief of the Bibliographic Services Division, reported to the Board on recent trends in usage statistics pertaining to NLM's online databases. He gave a brief history of the appearance of MEDLINE in 1971 and its evolution over the 25 years since. There are at present some 40 databases, the largest of which is MEDLINE (and its backfiles). By the end of 1995, there were 115,000 user codes in the U.S. and abroad. In addition, about 100 organizations lease the MEDLINE databases to provide service (both directly online and on CD-ROM) to hundreds of thousands of additional users. The introduction of Grateful Med in 1986 greatly expanded the potential user base; the Board has seen demonstrations of the new Internet Grateful Med that is scheduled for release in April 1996. Mr. Kotzin described several methods of measuring database usage: connect hours (no longer the most reliable method because faster modems and more efficient computers deliver more information per unit of time); number of searches; number of user codes assigned; and number of characters of data transmitted from NLM to the user. MEDLINE (and its backfiles) contain the most references (more than 8 million) and are accessed most often by the public (about 72 percent of all MEDLINE use on NLM's network). Mr. Kotzin showed how the other databases are grouped in categories--AIDS, toxicology and environmental health, cancer, technical services, health care research, and specialty databases. Mr. Kotzin showed trends in connect time (steady since 1991, between 300,000 and 350,000 per year), characters transmitted annually (up during the same period by a factor of two and a half, to over 100 billion), and number of searches (steady steep growth since the introduction of Grateful Med in 1986 (from about than 3.5 million a year to more than 7 million). This steady growth of database use on NLM's computers during a time when many new commercial MEDLINE products were introduced in the private sector is impressive. He showed how the trends in usage varied by database. NLM has 20 international MEDLARS Centers that provide services in various areas of the world. Some provide service on their own computers, some provide codes for their users to come online to NLM. International access has been flat over the last 5 years. New centers that come online will be required to use the Internet as their mode of access. This requirement, and the advent of the Internet Grateful Med likely will result in a substantial increase in international usage in the coming years. Mr. Kotzin noted that when commercial CD-ROM usage is taken into account, 152 countries around the globe have access to MEDLINE and certain other NLM databases (namely, HEALTH, TOXLINE, POPLINE and BIOETHICSLINE). He said that CD-ROM sales seem to be leveling off as vendors shift to Internet access. Some system usage figures over the last 5 years: user codes increased from 48,000 to 115,000; searches increased from 5.8 to 7.3 million; and Grateful Med subscriptions increased from 38,000 to 90,000. Grateful Med users now account for 76 percent of all search sessions. Two other recent developments are the flat-rate agreements with a half-dozen professional organizations and the fixed-fee arrangements with some 30 sites around the country. Flat-rate agreements allow medical society members (about 7000 members in all) to do all the searching they wish for one annual fee. A fixed-fee arrangement is essentially a site license that permits an institution to pay one annual fee for a certain number of codes that may be used without further cost by its faculty, staff, and students. There are about 21,000 codes (100,000 potential users) distributed under fixed-fee arrangements. These two methods, only about 3 years old, are extremely popular and growing rapidly in use. In

summary, Mr. Kotzin said that NLM's outreach programs, which received their impetus from the 1989 Long Range Planning Committee chaired by Dr. Michael DeBakey, have been very successful in reaching new users and are responsible for much of the system's growth in recent years.

Following Mr. Kotzin's presentation, Dr. Sherrilyne Fuller commented that the data presented, although impressive, are really only the tip of the iceberg. Many more people have access to MEDLINE than those that show up in NLM's online statistics. At her institution, the University of Washington (Seattle), they are averaging 60 simultaneous user on MEDLINE. She noted also that NLM's databases are higher in quality than those offered by any other organization she knows of. She commented that, unfortunately, many users--such as those at the University of Washington--don't realize that the database they are searching (frequently MEDLINE) is produced by the NLM. It would be good if every citation in the Library's databases noted its source as the National Library of Medicine. Dr. George H. Nolan said that it is amazing to consider how many databases NLM has developed since 1971; even more important is the extensive utilization of the databases. Dr. Edwin M. Cortez commented that although it is true that usage has grown sharply, we must always keep in mind the qualitative aspects of what these services mean to the user. Has the shift from intermediary searching to end user searching had a price? Is the user retrieving all the pertinent information the database contains? In response to a question from Dr. Mary Clutter, Mr. Kotzin said that NLM has eliminated two databases--one on biotechnology that got folded into MEDLINE and one cataloging database (Name Authority File). NLM constantly reviews database usage and overlap to see where consolidation or elimination can be effected. Dr. Michael DeBakey inquired about plans to extend MEDLINE back in time before 1966. Mr. Kotzin said that NLM has looked into this and, if funds are available, we hope to be able to mount earlier citations. Dr. Lindberg added that this would be the subject of a future presentation to the Board of Regents.

## **XVII. REPORT ON NLM FRIENDS ACTIVITIES**

Dr. Thomas Bryant, President of the Friends of the National Library of Medicine, briefly outlined the history of the organization. It began in 1986 and its first major task was to assist in the NLM Sesquicentennial Celebration that same year. The success of NLM's Friends organization has led to the formation of other such groups, for example, for the National Agricultural Library. Dr. Bryant then introduced Keith Krueger, Executive Director of the Friends, who described the activities of the organization over the past year. The top priority was to educate and inform the new Congress and the Administration about the NLM role in health care. The Friends also has had a key role over the last several years in promoting the High Performance Computing and Communications initiative. Last year the Friends co-sponsored with the Public Health Service the First Conference on Networked Consumer Health Information. A second is being planned. Also last year the FNLM co-sponsored (with the Congressional Caucus on Telemedicine and the Western Governors Association) a conference on telemedicine activities in the states. Senators Hatfield and Harkin were honored at last year's Patron Dinner. Planned for this year is the HII'96: Emerging Health Information Infrastructure Conference, scheduled for April 14-16 at Georgetown University. Mr. Krueger said that they have received widespread support and endorsements for the Conference. The Friends' annual meeting will be held the first day of the conference. The 1996 Patron Dinner will be held next fall, probably in September. Vice President Gore will be invited to be the honoree. The Friends has sponsored, with the Regional Medical Libraries, a series of very successful regional technology awareness conferences

in recent years. That program will be continued in 1996. Mr. Krueger noted that the Friends have not been successful in finding support for a new series of print public service announcements for the NLM.

#### **XVIII. NOMINATING COMMITTEE**

Dr. Newton appointed a committee to put forward names for the Regents chair to be elected at the next meeting: Dr. Zimble, Col. Schoomaker, and Ms. Carter. Dr. Zimble will chair the nominating committee.

#### **XIX. RESOLUTIONS ADOPTED BY THE BOARD**

The Board discussed two resolutions requiring action: one on supporting NLM's telemedicine activities, the other to go on record against the proposed consolidation of NLM's data center with other PHS data center activities. Minor changes in the wording of both resulted from the discussions. The motions were independently seconded and adopted unanimously (Note: Dr. Kathleen McCormick of the Public Health Service abstained from all votes taken at the meeting.) The resolutions are in Tab A.

#### **XX. NEW NLM FILM**

Mr. Robert Mehnert, NLM Public Information Officer, showed to the Board a first version of a new 11-minute video about the NLM. It would replace the present "Pathways" film that is shown to visitors and also widely used in the National Network of Libraries of Medicine. After viewing the video, the Regents made a number of suggestions for improvement.

#### **XXI. ADJOURNMENT**

The meeting was adjourned at 12:30 p.m., Wednesday, January 24, 1996.

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Subcommittee Meeting on Monday, January 22:

Extramural Programs Subcommittee--2:00-2:30 p.m.  
(Attachment B)

Subcommittee Meeting on Tuesday, January 23:

Subcommittee on Outreach and Public Information--8:00-8:50 a.m.  
(Attachment C)

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**ACTIONS TAKEN BY THE BOARD OF REGENTS**

1. **The Board approved a resolution to retain the integrity of the NLM Computer Center and the potentially catastrophic consequences of disrupting MEDLARS.**
2. **The Board approved the request to appoint an ad hoc committee to review NIH funding of molecular databases.**
3. **The Board approved a resolution recommending that NLM receive active support to maintain its leading role in advancing telemedicine and the National Information Infrastructure.**
4. **The Board amended and reaffirmed the Board Operating Procedures.**
5. **Dr. Newton appointed the Nominating Committee to select a chair for the coming year.**

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

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Donald A.B. Lindberg, M.D. (Date)

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Carol M. Newton, M.D., Ph.D. (Date)