

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

NATIONAL LIBRARY OF MEDICINE

BOARD OF REGENTS

MINUTES OF THE 113TH MEETING

SEPTEMBER 24-25, 1996

BOARD ROOM

NATIONAL LIBRARY OF MEDICINE

BETHESDA, MARYLAND

PUBLIC HEALTH SERVICE

THE BOARD OF REGENTS OF THE NATIONAL LIBRARY OF MEDICINE

**Minutes of Meeting ^{1/2/}
September 24-25, 1996**

The Board of Regents of the National Library was convened for its one-hundred-and-thirteenth meeting at 9:00 a.m. on Tuesday, September 24, 1996, in the Board Room of the National Library of Medicine, Bethesda, Maryland. Dr. Steven J. Phillips, Senior Heart Surgeon, Iowa Heart Center, Mercy Hospital Medical Center, 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 to 11:30 a.m. and from 12 noon to 4:00 p.m. on September 24 and from 9:00 a.m. to adjournment on September 25. The meeting was closed on September 24 from 11:30 a.m. to 12 noon for the review and evaluation of intramural programs and from 4:00 to 4:30 p.m. for the review, discussion and evaluation of grant applications. A Board roster is enclosed under Attachment A.

Board members present were:

Dr. Steven J. Phillips, Chair	Dr. Michael DeBakey
Dr. Tenley E. Albright	Dr. Raymond J. Fonseca
Dr. Enriqueta Bond	Dr. Sherrilynne Fuller
Dr. Marion Ball	Dr. George H. Nolan
Dr. Edwin Cortez	Dr. James A. Zimble

Ex Officio Members present were:

Ms. Wendy Carter, representing Dr. Kenneth W. Kizer.
Lt. Col. Kristen Raines, 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 Vice Admiral Harold Koenig.
Col. Klaus O. Schafer, representing General Edgar R. Anderson.
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.

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, Assistant Director for HPCC
Dr. Dennis A. Benson, Chief, Information Resources Branch, NCBI
Dr. Mark Boguski, NCBI
Mrs. Ruth E. Bortz, Grants Management Specialist, Grants Management Office, EP
Dr. Donald Buckner, Special Assistant, LHNCBC
Mr. Fernando Burbano, Director, Information Systems, OCCS
Ms. Susan Buyer, OHIP
Dr. Marjorie Cahn, Special Expert, National Information Center on Health Services
Research and Health Care Technology, LO
Mr. Peter Clepper, Program Officer, Biomedical Information Support Branch, EP
Mrs. Lois Ann Colaianni, Associate Director for Library Operations
Dr. Roger W. Dahlen, Chief, Biomedical Information Support Branch, EP
Ms. Gale Dutcher, Special Assistant to the Associate Director, SIS
Ms. Kathleen Gardner, Special Expert, Office of Inquiries and Publications Management, OD
Ms. Maren Haaland, NLM Associate
Mr. Steven Haynie, NLM Associate
Mrs. Francis H. Howard, Special Assistant, Office of the Associate Director, EP
Ms. Betsy Humphreys, Assistant Director for Health Services Research Information
Mr. Charles Kalina, Executive Secretary, HPCCIT
Dr. Lawrence Kingsland III, Assistant Director for Applied Informatics
Dr. David J. Lipman, Director, NCBI
Dr. Alexa McCray, Chief, Educational Technology Branch, LHNCBC
Mr. Robert B. Mehnert, Chief, Office of Inquiries and Publications Management, OD
Mr. Dwight Mowery, Grants Management Specialist, Grants Management Office, EP
Ms. Holly Grossetta Nardini, NLM Associate
Mr. Donald Poppke, Executive Officer, OD
Ms. Nadgy Roey, Chief, Office of Personnel Management
Dr. Elliot R. Siegel, Associate Director, Health Information Programs Development
Dr. Melvin Spann, Deputy Associate Director, SIS
Dr. Greg Schuler, NCBI
Ms. Karen Wallingford, Office of Health Information Programs Development
Dr. Fred Wood, Office of Health Information Programs Development
Ms. Carol Wu, NLM Associate

Others present included:

Dr. Philip R. Lee, Assistant Secretary for Health, HHS
Dr. Audrey F. Manley, Acting Surgeon General, PHS
Ms. Anne Thomas, Associate Director for Communications, NIH
Dr. Lois E. DeBakey, Professor of Scientific Communications, Baylor College of Medicine,
Consultant to the Board of Regents

Mr. Timothy Lammers, Southwest Georgia Area Health Education Center
Dr. Henry Lowe, Department of Medicine, University of Pittsburgh
Ms. Pamela Reynolds, Southwest Georgia Area Health Education Center
Mr. William Walker, University of Pittsburgh

I. OPENING REMARKS

Dr. Steven J. Phillips, Chair, welcomed the Regents, consultants and guests to the 113th meeting of the Board of Regents of the National Library of Medicine. He noted especially the presence of two new Regents: Enriqueta Bond, M.D., and Raymond J. Fonseca, D.M.D. New Regent John Gage was unable to attend. Dr. Phillips noted that Regent Michael E. DeBakey was presently in Russia consulting with Boris Yeltsin's doctors about the Russian President's health.

II. REMARKS FROM THE ASSISTANT SECRETARY FOR HEALTH

Dr. Philip R. Lee noted the growing importance of what the NLM is doing in such areas as the World Wide Web, telemedicine, virtual reality, and imaging. He cited especially the Internet Grateful Med, introduced in April 1996, which is proving to be tremendously popular. Also, the Visible Human project has garnered much publicity and the planned workshop of applications developers on October 7-8 should be very exciting. NLM continues to play a lead role in telemedicine and a new series of major awards is about to be announced by the Library. The NLM-supported telemedicine study being conducted by the Institute of Medicine will soon be available and should provide much needed guidance. Dr. Lee said that NLM also plays an important role in the HHS Data Council that is charged with advising the Secretary on data policy issues concerning information systems. The Council provides a focal point for the HHS various agencies to resolve potential conflicts. As an example, Dr. Lee cited the Health Care Financing Administration, Agency for Health Care Policy and Research, and National Center for Health Statistics, all of which have responsibility for various health surveys. The Data Council will also help develop health data standards as required in the recently enacted Kennedy-Kassebaum legislation. Dr. Don Detmer (former NLM Regent) has been appointed to chair the National Committee on Vital and Health Statistics. On the budget front, Dr. Lee was optimistic that budget levels favorable to HHS's health agencies would be enacted in appropriations legislation in the next few days. He noted that 1998 will mark the 200th anniversary of the Public Health Service, and that NLM is helping in certain projects connected to the observance. The widely publicized new FDA regulations on smoking issued in late August are now facing challenge in a North Carolina court. We should have a resolution of the case next year. Following the Assistant Secretary's presentation, Dr. Albright asked about NLM's role in the Data Council. Dr. Lee said that NLM was one of the Department's "key intellectual centers" in such areas as biotechnology, telemedicine, and other "cutting-edge thinking." The Secretary is enthusiastic about NLM's critical role in these areas.

III. REMARKS FROM THE ACTING SURGEON GENERAL

Dr. Audrey F. Manley distributed to the Regents the latest Surgeon General's report on physical activity and health. Its release from the White House on July 11 resulted much national publicity. A task force led by the Assistant Secretary for Health is working with local and state health agencies, private industry, professional associations, and voluntary organizations to implement the report's recommendations.

IV. REMARKS FROM THE NIH ASSOCIATE DIRECTOR FOR COMMUNICATIONS

Ms. Anne Thomas said she was expanding on remarks made by NIH Director Varmus at the last Board meeting when he talked about the importance of improving public visibility of NIH and the role all NIH components have to play in this. She noted that her remarks would pertain only to talking to the general public, not to any of the specialized audiences NLM (and other institutes) have. Disseminating the results of research is in fact "part 2" of the NIH mission (number one of course is to support medical research). She cited as an example the high blood pressure education program of the National Heart, Lung, and Blood Institute that has existed since 1972 and has been a major factor in the decrease in deaths from stroke. This extremely successful program is based on scientific research and on social marketing research. One concern, however, from Ms. Thomas's point of view, is that each public service spot ends with the sponsor's name: the National High Blood Pressure Education Program Coordinating Committee (not the NIH or NHLBI). The coalition, of course, represents the many organizations brought together by NIH for the education effort. In more recent years, Ms. Thomas said, NIH has become much more attuned to linking its name to activities of this sort. The Congress has called for the NIH to do more to be sure that it gets credit for the research it conducts and supports. A 1993 survey showed that 66% of the public cited medical research as the most valuable kind of scientific research, far ahead of research on the environment, defense, etc. Surprisingly, the public highly values basic medical research, even if there is no immediate benefit. The mass media are critical to how the public learns about advances in medical research, and positive stories far overshadow the occasional negative item. She noted an important gap in the public's understanding: too often they don't know that the research they are reading about in the press is funded by the NIH--by their tax dollars. The NIH has been working with grantees and with the media to correct this by having reporters cite NIH as the source of funding. A single NIH letterhead for all press releases issued by the institutes has just been introduced and is now being used.

Ms. Thomas outlined several strategies to be used in NIH outreach. One is to position the institution as a source of credible, science-based health information. NIH is unique in that it can offer an informed perspective on new research advances, so that members of the public have a context within which to consider new announcements and the relevance to their own lives. We hope to help the public tap into the wealth of health-related information we have, whether through the Internet and World Wide Web or by telephone, mail, and other traditional means. "Structures of access" must be in to place help the public tap into NIH information. Ms. Thomas described several recent

outreach/public affairs projects. One of these was to support two pilot shows for a "HealthWeek" series on Maryland Public Television (she showed a brief promotional video for the series). Outside funding will be required if the weekly show is to become a reality--it would cost about \$5 million for one year. Another project is to reach smaller market newspapers through "HealthWise"-- a compilation of NIH-sponsored health research-oriented news for consumers that will be mailed by Ms. Thomas's office as a test to two small or mid-size newspapers in each state. In another area, she said that more health information for the public is planned for the NIH Home Page on the World Wide Web, which is an extremely popular site on the Internet. A marketing effort will then be launched to let the public know that this resource for reliable health information is available to them. Also, there is a proposal for a public education campaign (print, television, radio) designed to establish in the public's mind the link between NIH and science-based health information. Finally, Ms. Thomas described preliminary findings from six NIH focus tests, some of which are surprising. For example: use the term medical (or health) research, not biomedical research, which has negative connotations; some terms we commonly use are to a large extent not understood by the public--basic research, clinical research, clinical trials are all very fuzzy concepts to the public; cutting edge and state-of-the-art are seen as negative terms--they have elitist connotations; the public wants to see health research as a *human* enterprise, not a technological one; when asked to cite breakthroughs they mention polio vaccine, laser eye surgery, organ transplantation, cancer detection and treatment, and antibiotics--they never cite, for example, advances in genetics or understanding DNA. It is encouraging to note that the public does not feel that progress in medical research is too slow; people seem to understand that the research process is very deliberate. Their highest priorities are cancer, AIDS, heart disease, Alzheimer's, and birth defects, although they are somewhat bothered when they see celebrities attracting attention for a particular disease or medical problem, or interest groups pushing their own agendas. NIH will place higher priority in the future in letting Congress and the public know how it sets research priorities. Another finding is that the public's positive attitude toward NIH takes a nose-dive when an explicit link is made to "The Federal Government." A final observation from the focus groups is that economic arguments sometimes made for the value of medical research (it pumps money into the economy, reduces workdays lost to sickness, etc.) are a disaster in trying to demonstrate to the public the value of health research.

V. CONSIDERATION OF MINUTES OF PREVIOUS MEETING

The Regents approved without change the minutes of the May 21-22, 1996, meeting.

VI. FUTURE MEETING DATES

The Board will meet next on January 29-30, 1997. Next spring's meeting will be May 13-14, 1997. The proposed dates of September 23-24, 1997, were accepted and confirmed for next fall's meeting.

VII. REPORT FROM THE NLM DIRECTOR

Dr. Donald A. B. Lindberg said that the "NIH Revitalization Act of 1996" hearings on June 21, chaired by Senator Kassebaum and co-chaired by Senator Kennedy, went very well. Although not every NIH component had the opportunity to appear before the committee, NLM was chosen to present testimony. As outlined by Dr. Lee earlier, the budget situation for FY 1997 is not yet settled. The President's request for NLM had additional earmarked funds for High Performance Computing and Communications and AIDS information services. The Senate bill contains special reinvention authorities for the Library, including the ability to continue to carry money forward into a new fiscal year in certain circumstances. It also urges NLM to use its increased funding to expand support for outreach activities to health professionals in underserved areas and to make NLM services more readily available at the least possible cost to the user. This would be significant, Dr. Lindberg said: in the past, some in the Congress have suggested that NLM services be priced at a higher level. In the area of staff, the Director introduced to the Board of Regents: Dr. Stuart J. Nelson, head of the Medical Subject Headings Section; Dr. Zoe Stavri, head of the Library Associate Program; and three new members of the National Center for Biotechnology Information--Dr. Mark Alan HersHKovitz, Dr. Aaron Marchler-Bauer, and Mr. Shih-Hsin Yang. Dr. Lindberg next updated the Board on the resolution of NLM's problem with the contract to input MEDLINE citations (this was reported at the last Board meeting). The Library made an award on August 9 to Atllis Systems, Inc., and the company is now gearing up to resume full scale input activity. In the meantime, NLM took a number of actions that will reduce the possibility of a similar problem in the future: multiple contract awards have been made to different companies; some SGML-tagged citations and abstracts are being received directly from the publishers; and scanning, or optical character recognition, is being investigated with the help of Carnegie Mellon University. On the issue of whether NLM's computer center should be consolidated with other Departmental facilities, Dr. Lindberg said that the welcome decision by the Department was that NLM should be exempted from the requirement. He thanked the Regents for their resolution to the Secretary earlier in the year that supported the NLM position. He briefly updated the Board on the set of 12 research contracts the NLM has let to apply the benefits of the National Information Infrastructure to health. Two areas of special emphases: evaluation (both the quality of health care delivery and economics) and medical data privacy. They are the subject of studies now being conducted by the Institute of Medicine, sponsored by the NLM. Related to the 12 earlier awards, the Library will announce within a week 19 telemedicine awards totaling some \$42 million. Plans are progressing well for the upcoming long range planning sessions on NLM's international programs. The NLM Long Range Plan was prepared and is updated under the sponsorship of the Regents; Dr. Marion Ball will be the Board's representative at the three meetings. Dr. Lindberg drew the attention of the Regents to the display in the back of the room that highlighted recent newspaper items and articles about the NLM. As his last item, Dr. Lindberg reiterated his belief that if we are to make progress in implementing telemedicine systems, Federal legislation is needed to ensure confidentiality for patient records.

VIII. 1996 REGENTS' AWARD

Dr. Steven Phillips presented the 1996 Regents Award for Scholarship or Technical Achievement to Wen-Min Kao of the Technical Services Division (Library Operations) for her intellectual and editorial contributions to the fifth edition of the National Library of Medicine Classification.

IX. INFORMATION DELIVERY THROUGH ELECTRONIC ACCESS (IDEA)

Ms. Pamela Reynolds, director of the Southwest Georgia Area Health Education Center (SOWEGA AHEC), said that her agency serves a primarily rural and medically underserved area. It attempts to move academic health-related training and education from an urban area (in this case Atlanta) into a rural setting. After an initial six years of Federal funding, Area Health Education Centers are expected to get local, state, and private funding to continue their work. The SOWEGA AHEC has finished with its Federal funding and is now being supported (with other Georgia AHECs) by the state.

Ms. Reynolds said that Southwest Georgia is a 150-mile by 200-mile corner of the state that contains some of Georgia's poorest and most rural counties. The population is about 700,000. There are four medical schools in the state (none in Southwest Georgia) that send medical students for clinical training to the SOWEGA AHEC. She briefly described several SOWEGA AHEC programs for training physician's assistants and nurses and a residency program for medical students. As an example, in the case of the PAs, she said, there were 28 in Southwest Georgia in 1991 when the program began; there are now 88. The ratio went from 1 per 23,000 in the population to 1 per 7,000.

Following Ms. Reynolds's presentation, Mr. Timothy Lammers, the SOWEGA AHEC's outreach librarian, described the NLM-funded IDEA (Information Delivery through Electronic Access) project. The purpose of IDEA is to improve the quality of patient care and health care professional training in the rural environment of Southwest Georgia by enhancing access to health information among students and professionals throughout the region. Among the ways this was done was to provide them with access to GaIN (Georgia Interactive Network for Medical Information), "PeachNet," and the Internet. Mr. Lammers described how the project was organized, the equipment that was purchased, and the 34 sites that were established throughout SOWEGA. The present system, which is used by both institutions and individuals, is bulletin-board based, but will soon be shifted to a new Web site. More than 400 health professionals have received instruction in using the system and have logged more than 2,000 hours online since it became active in March 1993. Although e-mail is the most frequently accessed function, the most connect time was spent using MEDLINE via GaIN. One unexpected benefit was that three hospitals said the new system helped them greatly in meeting the information standards for JCAHO hospital accreditation. Even at the high school level, health students, teachers, and counselors are using the system. Continuing medical education courses will become popular with users once the network goes on the Web. Fees for certain network services were introduced in 1994 and more than \$5,000 has been collected to date. Mr. Lammers said that an important lesson learned about providing medical information in a rural setting is that the energy and imagination of the site contact person is critical to the success of the project.

Following the SOWEGA AHEC presentations, Dr. Edwin Cortez characterized the project as one of “understated elegance”—not because of the technology used but because of the level of commitment, energy, and enthusiasm of those involved. He said it is an example of a project that is both “content-smart” and “technology-smart” (for example, moving to the World Wide Web is a good idea). One of its notable strengths is the emphasis on training and evaluation components. Wendy Carter commented that it is remarkable that the project has been able to retain 100 percent of its membership and she asked how they plan to add new individuals and institutions to the project. Mr. Lammers replied that there are still some areas of Southwest Georgia that are not served, and the AHEC is concentrating on these. Another population still not adequately served are prisoners in the state correctional institution. Dr. Sherrilynne Fuller said that in the Pacific Northwest they are using family medicine clerkship students to train their preceptors in the use of computers and information technology. In response to a question from Dr. Lindberg, Ms. Reynolds said that they hope to become a line item in the Georgia state budget in future years. She said that although there are more than 30 AHEC programs around the nation, the Southwest Georgia electronic information delivery program is unique.

X. REPORT OF THE BOARD OUTREACH SUBCOMMITTEE

Dr. Tenley Albright, who chaired the subcommittee’s meeting in the absence of Dr. Michael DeBakey, reported briefly on their deliberations. The Friends of the National Library of Medicine was represented at the meeting by Keith Krueger. The subcommittee reviewed the favorable publicity results to date of the Internet Grateful Med media coverage, including the letter from Dr. Michael DeBakey about IGM published by Ann Landers in her daily column. Dr. Albright drew the attention of the Board to packets of information summarizing the news coverage. Another recent outreach effort is the mailing of news columns about Internet Grateful Med to 10,000 daily and weekly newspapers across the country. An event coming up in a couple of weeks—a workshop of applications developers who are using the Visible Human datasets—should result in additional publicity for the NLM. The annual conference sponsored by the Friends of the NLM will for the first time be co-sponsored next April by the Public Health Service: the theme will be health information for consumers. Mr. Krueger said that he still hopes to update the 1991 print public service announcements done on behalf of the NLM, but he is having difficulty in getting financial support for the project. Dr. Albright distributed to the Board a report of NLM’s outreach activities over the last 5 years, written by the NLM Office of Health Information Programs Development and printed by the Medical Library Association as a supplement to its Bulletin. She read from a letter from Dr. Lois DeBakey about recent outreach efforts by her and her brother, including writing to medical reporters of the television networks to inform them about the Internet Grateful Med. Later in the meeting, the Board was shown a highly successful 30-second television commercial about the NLM and MEDLINE that was done 10 years ago by ITT. Dr. Marion Ball suggested that NLM work with the Joint Commission on the Accreditation of Health Care Organizations to facilitate electronic information access for hospitals.

XI. REPORT FROM THE EXTRAMURAL PROGRAMS

Budget

Dr. Milton Corn, Acting Associate Director for Extramural Programs, reported on the status of EP. Using slides, Dr. Corn reviewed the budget. The Medical Library Assistance Act (MLAA) of 1965 was designed to permit the NLM to build up the national library infrastructure in the United States. Under the MLAA programs, IAIMS has a total of \$3.3 million, which is not available this year because it is partially committed to existing grants. Available for new grants in FY 97 are sufficient funds to fund about four planning grants, 18 training grants, and seven publication grants. The PHS 301 grant program, which includes informatics research, biotechnology, bioethics and SBIR/STTR has a total of \$16.2 million, and will support approximately 25 new research grants. Dr. Corn noted that, on average, one in five EP research grants are funded. Overall, the total budget for EP will be \$33.7 million.

Internet Connections Awards in FY 1996

A total of \$880,000 was awarded for 26 Internet Connection Awards for a success rate of 20 percent. Dr. Corn discussed the different types of sites which received awards, including academic centers, city clinical centers, rural area clinical nets, and specialty care. In response to a question at a previous Board meeting, Dr. Corn said that some of the awards were made to larger institutions to fund connections to affiliated hospitals.

Streamlining NIH Grant Policies

Using overhead slides, Dr. Corn briefly discussed various efforts at NIH to streamline grant application and administration. Areas under evaluation are: just-in-time information requirements; the grant review process; post award grant administration; structural/organizational changes in OER and restructuring of DRG; redefining grant-related functions of councils/boards; database changes; and improving access to NIH policy documents.

XII. HPCC CONTRACTOR PROGRESS REPORT

Dr. Henry J. Lowe of the Section on Medical Informatics, University of Pittsburgh, is the principal investigator of the NLM/HPCC-supported "Image Engine Project." This is an effort to develop a prototype system that will provide an integrated view of the Electronic Medical Record, including both images and text. The conventional text-based Electronic Medical Record represents a fragmented view of the patient's record. Also, existing systems for Electronic Medical Records frequently consist of multiple sources of data, making it confusing and difficult to retrieve information in an integrated way. The goal is not a monolithic system that stores everything, but to integrate information from heterogeneous databases both within and outside the parent institution. "One-stop shopping" is the

ideal model to strive for. Among the questions to be tested: will the multimedia record: Improve clinical decision-making? Reduce the cost of delivering care? Facilitate life-long learning? Enhance patient understanding? Dr. Lowe said that some of the domains in which they have made progress: gastroenterology (endoscopy images), pathology images, radiology, and clinical oncology. The Electronic Medical Record that has been developed has been likened to a "string of pearls," where each pearl consists of a time-ordered patient/clinical encounter. The images of each encounter are stored in an object-oriented database. The storage and retrieval system is based on a series of servers, each of which has a 30-gigabyte capacity for compressed images. Although the servers could theoretically be anywhere on the Internet, for security purposes they are now only at the University of Pittsburgh. Dr. Lowe then did a live demonstration of the system for the Board of Regents, accessing the University of Pittsburgh via the Internet. He said that he is convinced that the future of the Electronic Medical Record is on the Internet: for example, access is cross-platform (it does not matter what kind of machine you use to access it); it is available anywhere in the world; encryption will be available.

Following Dr. Lowe's presentation and demonstration, Dr. James Zimble commented that what is being developed is a true "living patient record" and that it will certainly change how medicine is practiced in the future. Dr. Cortez said that the use of the Unified Medical Language System in the Electronic Medical Record is an excellent use of that resource. In reply to a question from Dr. Phillips, Dr. Lowe said that the aggregated information from Electronic Medical Records can be used in particular cases, for example, a physician can look at a patient's angiogram and with the click of a button say "find me other images (and cases) like this." Using the Unified Medical Language System to represent the data will permit such use of the medical records.

XIII. AIDS COMMUNITY OUTREACH

Ms. Gale Dutcher of NLM's Specialized Information Services reported on the NLM program of information outreach to the HIV/AIDS community—patients, family, friends, care-givers, etc. The program had its origin in recommendations made at a conference on that subject held at NLM in June 1993. One point made repeatedly at the conference was that community AIDS programs often do not have access to personal computers or have the skill necessary to use them for online information retrieval. In response, the Library instituted a program of small contracts (under \$25,000) to local groups—community-based AIDS organizations, advocacy groups, and public and health sciences libraries that serve those groups—to support over an 18-month period locally designed and implemented information programs for the HIV/AIDS community. There are several categories of emphasis from which the projects can choose: providing basic information retrieval (access to electronic health-related information, including equipment purchase); training in using the resources; using Internet and World Wide Web resources; developing culture- or language-specific informational collections and materials; and developing connections to local health-science libraries for access to documents. NLM made 19 awards in 1994, 16 in 1995, and 22 in 1996. A change in 1996 allowed for awards up to \$35,000 for projects involving consortia of local groups. Also, earlier awardees were

permitted to propose extensions to their awards in 1996 based on what they had learned. In 1996, 7 of the 22 1996 awards were such extensions; 7 were new awards for consortia; and 8 were new single institution awards. Ms. Dutcher briefly described several successful programs: a Staten Island, N.Y. project based on the public library there; a consortium headed by the public health library of the University of Texas Medical Center in Houston (a local television news clip about the project was shown to the Board); and the Southern Tier AIDS program based in Johnson City, N.Y. with a large program (staff of 28) and both state and Federal funding, serving a predominantly rural area. Ms. Dutcher said that based on the number of proposals received each year, there is a definite need for NLM's program. Two positive outcomes are that the program supports local information infrastructure (in many cases by providing their first access to electronic information, including the Internet), and that it fosters networking among institutions that might not otherwise interact. Among the lessons we have learned: awards for 18 months may not be long enough; that since personnel levels of public libraries are often so tight, the project may become fragmented over many staff; and that a competent manager is necessary for the success of a project.

Following Ms. Dutcher's presentation, Lt. Col. Kristen Raines commented that the NLM program is obviously much needed and very successful; it also shows how difficult it is to deal with such diverse agencies and populations--to be all things to all people. Dr. McCormick asked if NLM has yet shared any of its findings with the leadership in the AIDS clinic network—to see if there is the possibility of collaborating with the education components of the Centers for Disease Control and Prevention and Health Resources and Services Administration. Ms. Dutcher says she talks regularly with those who manage the AIDS Education and Training Centers (for health professionals), although there is no formal collaboration.

XIV. HUMAN GENE MAP

Dr. David Lipman, Director of NLM's National Center for Biotechnology Information, said that scientists are now discussing "post-genome" biology, that is, the opportunities to use the information from the genome project in research. The entire sequence of the human genome, as well as model organisms, should be known in 5 to 8 years. The project being described today is a collaborative effort of NCBI scientists (Mark Boguski and Greg Schuler) with scientists in major genome centers around the world to develop a "human gene map" with available data representing about 16,000 genes (roughly 20 percent of the entire human genome). A scientific paper on the map (including a poster) will be published next month in Science, and NLM will hold a press conference to announce it. The map will not only be a tremendous research tool, Dr. Lipman said, but it changes the way in which scientists can collaborate to pool their data. Another exciting aspect of it is that the map's developers have fashioned a "tourist's map" that allows the public, including students, to look at some of the highlights and see where genes associated with diseases are. There will be brief textual descriptions of molecular diseases in lay terms and pointers to the pertinent research itself (including GenBank records, information from the Online Mendelian Inheritance in Man, etc.). This educational aspect of the project is made possible by the gene map being made available on the World Wide Web (URL:

<http://www.ncbi.nlm.nih.gov/science96>). Following Dr. Lipman's presentation, Greg Schuler described how the map was put together and he demonstrated how it will look when it is made available to the public later in October.

Following the presentations and demonstrations, Dr. Marion Ball commented that getting the major gene research centers to collaborate and to provide information in a common format is a major achievement.

XV. REGENTS AWARD FOR SCIENTIFIC OR TECHNICAL ACHIEVEMENT

Board Chairman Dr. Steven Phillips presented the Board of Regents Award for Scientific or Technical Achievement to Dr. Mark Boguski and Dr. Greg Schuler of the National Center for Biotechnology Information for their work in developing the Human Gene Map.

XVI. ADJOURNMENT

The meeting was adjourned at 12:00 noon, Wednesday, September 25.

Subcommittee Meeting on Monday, September 23:

Extramural Programs Subcommittee--2:00-3:30p.m.
(Attachment B)

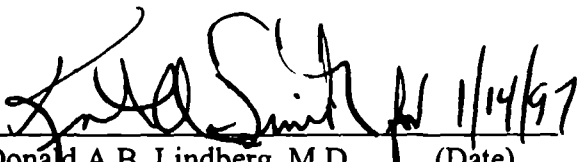
Subcommittee Meeting on Tuesday, September 24:

Subcommittee on Outreach and Public Information--8:00-9:00 a.m.
(Attachment C)

ACTIONS TAKEN BY THE BOARD OF REGENTS

1. Dr. Steven Phillips presented the 1996 Regents Award for Scholarship or Technical Achievement to Wen-Min Kao of the Technical Services Division for her intellectual and editorial contributions to the fifth edition of the National Library of Medicine Classification.
2. Dr. Steven Phillips presented the Regents Award for Scientific or Technical Achievement to Dr. Mark Boguski and Dr. Greg Schuler of the National Center for Biotechnology Information for their work in developing the Human Gene Map.

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


Donald A.B. Lindberg, M.D. (Date) 1/14/97

Steven J. Phillips, M.D. (Date)