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

MINUTES OF THE BOARD OF REGENTS

January 29-30, 1997

The meeting of the Board of Regents was convened on January 29, 1997, at 9 a.m., in the NLM Board Room, Building 38, National Institutes of Health (NIH), Bethesda, Maryland. The meeting was open to the public from 9 a.m. to 4:30 p.m., followed by the closed session for consideration of grant applications until 5:15 p.m. On January 30 the meeting was reconvened and open to the public from 9 a.m. until adjournment at 12:30 p.m. Dr. Steven Phillips presided as Chair.

MEMBERS PRESENT

Dr. Steven J. Phillips, Chair
Dr. Tenley E. Albright
Dr. Sherrilynne Fuller
Dr. Enriqueta Bond
Dr. Marion Ball
Dr. Michael DeBakey
Dr. James A. Zimble

EX OFFICIO MEMBERS PRESENT

Ms. Wendy Carter, representing Dr. Kenneth W. Kizer

Dr. Kathleen McCormick, representing Dr. Audrey Manley

Lt. Col. Kristen Raines, representing Lt. Gen. Ronald R. Blanck

Mr. Keith W. Russell, representing Ms. Pamela Andre

Capt. William Wurzel, representing Vice Adm. Harold Koenig

Dr. Klaus Schafer, representing Lt. Gen. Charles Roadman

Dr. Mary E. Clutter

CONSULTANTS TO THE BOR PRESENT

Dr. Kenneth Walker, Emory University School of Medicine

MEMBERS OF THE PUBLIC PRESENT

Dr. Bailus Walker, Jr., Howard University

Mr. Mark Tuttle, Lexical Technology, Inc.

Dr. Jay Sanders, Global Telemedicine Group

Dr. Douglas Perednia, Oregon Health Sciences University

Dr. Russell Maulitz, Allegheny University of the Health Sciences

FEDERAL EMPLOYEES PRESENT

Mr. Louis Brown, National Science Foundation

Dr. John Gallin, NIH Clinical Center

Dr. Donald A.B. Lindberg, Director, NLM

Mr. Kent A. Smith, Deputy Director, NLM

Dr. Harold Schoolman, Deputy Director for Research and Education, NLM

Dr. Elliot R. Siegel, Associate Director, Health Information Programs Development, NLM

Dr. Michael Ackerman, Assistant Director for HPCC, NLM

Dr. Milton Corn, Acting Associate Director for Extramural Programs, NLM

Mrs. Lois Ann Colaianni, Associate Director for Library Operations, NLM

Mr. Donald Poppke, Executive Officer, NLM

Dr. Melvin Spann, Deputy Associate Director, SIS/NLM

Mr. Fernando Burbano, Director, Information Systems, OCCS/NLM

Dr. Dennis A. Benson, Information Resources Branch, NCBI/NLM

Ms. Betsy Humphreys, Assistant Director for Health Services Research Information, NLM

Mr. Charles Kalina, Executive Secretary, HPCCIT/NLM

Dr. Lawrence Kingsland III, Assistant Director for Applied Informatics, NLM

Mrs. Ruth E. Bortz, Grants Management Office, OEP/NLM

Ms. Susan Buyer, Office for Health Information Programs Development, NLM

Ms. Patricia Carson, Office of the Director, NLM

Ms. Alberta Sandel, Office of the Director, NLM

Ms. Suzanne Aubuchon, Office of the Director, NLM

Mr. Peter Clepper, Office of Extramural Programs, NLM

Dr. Roger W. Dahlen, Biomedical Information Support Branch, OEP/NLM

Ms. Kathleen Gardner, Office of Inquiries and Publications Management, NLM

Mrs. Frances Howard, Office of the Associate Director, OEP/NLM

Dr. Alexa McCray, Chief, Educational Technology Branch, LHNCBC/NLM

Mr. Robert B. Mehnert, Chief, Office of Inquiries and Publications Managaement, NLM

Mr. Dwight Mowery, Grants Management Office, OEP/NLM

Dr. Steuart Nelson, Medical Subject Headings Section, LO/NLM

Ms. Karen Wallingford, Office of Health Information Programs Development, NLM

Ms. Kimberly Caraballo, Committee Management Assistant, NLM

Ms. Bonnie Kaps, Committee Management Specialist, NLM

Dr. Laura Lopes, NCBI Fellow, NLM

Dr. Michael Galperin, NCBI Fellow, NLM

Dr. Andrei Gabrielian, NCBI Fellow, NLM

I. OPENING REMARKS

Board Chairman Steven J. Phillips, M.D. welcomed Regents and guests to the 114th meeting of the Board of Regents of the National Library of Medicine. He noted especially the presence of new regent, Mr. John Gage of the Sun Microsystems Computer Corporation.

II. REMARKS FROM THE ACTING SURGEON GENERAL

Dr. Audrey F. Manley reported to the Board on recent changes in the Department of Health and Human Services: a new Deputy Secretary and Chief of Staff have been named; Dr. Philip Lee is retiring as of January 31 as Assistant Secretary for Health (an acting has been named). Secretary Shalala plans to merge the Assistant Secretary with the position of the Surgeon General and a nominee is being sought. Both the American Medical Association and the Commissioned Officers Association have passed resolutions encouraging President Clinton to name a new Surgeon General. A group within the PHS Commissioned Corps has completed and sent to the Secretary a "visioning document" that articulates a role for the Corps and makes a series of recommendations on the Corps' future. Two senior HHS officials have announced their retirement—the head of the Agency for Health Care Policy and Research and the FDA Commissioner. Dr. Manley reported that the Surgeon General's report on physical activity, released last July, continues to receive good coverage in the press. More than 250,000 copies of the Executive Summary have been distributed. Two Surgeon General reports that will be out within the next six months have to do with tobacco—one involves minority groups and the other cessation strategies. Oral health and mental health are the subject of two future Surgeon General's reports. Finally, Dr. Manley noted that many activities for the Public Health Service Bicentennial Celebration in 1998 are being planned.

Following Dr. Manley's presentation, Dr. Michael DeBakey suggested that the traditional role of the Commissioned Corps might be brought up to date with a new emphasis on disease prevention and other preventive measures. Dr. Manley agreed that the time is right for such a reevaluation and the PHS welcomes the advice and recommendations of such bodies as the Board of Regents on this and similar matters.

III. REPORTS FROM THE NATIONAL SCIENCE FOUNDATION

Mr. Louis Brown, a senior staff member in the Office of International Science Affairs, Α. National Science Foundation, reported on the December 1996 diplomatic conference in Geneva, sponsored by the World Intellectual Property Organization. The conference was called to address three draft treaties: (1) to extend copyright protections to the digital environment—the world of networking; (2) to extend copyright protections to sound recordings and audiovisual works; and (3) to give new rights to database makers to enable them to protect their works. The last draft treaty was much discussed in U.S. scientific, educational, medical, and library communities before the conference. Its primary champion was the European Union, which has called on its member countries to establish national legislation conferring property rights on database makers. Mr. Brown briefly described the issues that arose around each of the three proposed treaties. For example, in the first, there was much discussion about the impact of liability provisions on online service providers and on communications companies. Also, the fair use provisions were seen by some as restrictive and weak. In the second treaty, there were differences of views between the United States and European countries: the former was most interested in protecting sound recordings, the latter in protecting their movie industry. In the third treaty, the primary concern of the U.S. was that the case for the need for database protection has not been convincingly made and that there was not a balance between the needs of users and providers of databases. Mr. Brown described how the various points of contention in the three treaties were dealt with. For the first two, accommodations were reached and the treaties are ready for consideration in the various countries. For the third draft treaty, however, no such accommodations were reached and the conferees felt that issues required further study. The World Intellectual Property Organization has decided that it needs to pursue both the audiovisual (sound recording and movie) issue and the database treaty issue. WIPO will convene in March an international meeting to consider both issues. The National Science Foundation is working with interested U.S. agencies (including NLM) to develop a U.S. position and instructions for the American delegation.

Following Mr. Brown's presentation, Dr. Lindberg said that it was important that there be public meetings of American scientists and their societies so they can understand and discuss the issues related to database "protection."

B. Dr. Mary Clutter, NSF Assistant Director for Biological Sciences (and ex officio Regent) briefed the Regents about her recent visit to the NSF-supported U.S. research activities in the Antarctic.

IV. CONSIDERATION OF MINUTES OF PREVIOUS MEETING

The Regents approved without change the minutes of the September 24-25, 1996, meeting.

V. FUTURE MEETING DATES

The Board will meet next on May 13-14. Next fall's meeting will be September 23-24. The proposed dates of January 27-28, 1998, were accepted and confirmed for next winter's meeting.

VI. REPORT ON THE NIH DIRECTOR'S ADVISORY COMMITTEE MEETING

Dr. Steven Phillips reported that he was the Regents' representative at the December 1996 NIH Director's Advisory Committee. NIH Director Harold Varmus in his opening remarks praised NLM's outreach efforts. Dr. Phillips gave to the Regents packets of outreach information distributed by the NIH to be used by members of the various advisory councils. There were reports and discussions about plans to extensively refurbish and enlarge the NIH Clinical Center; NIH support for clinical research; the Fogarty International Center; the Small Business Innovative Research grant program; and HIV/AIDS research, including the effort to develop a vaccine.

VII. REPORT FROM THE NLM DIRECTOR

At the request of Dr. Lindberg, Mr. James Main of the Lister Hill Center showed the Regents the new connection capabilities (power, modem, Ethernet, and optic fiber connector) built into the table around which the Board sits. Dr. Lindberg reported briefly on the status of the NLM budget—the FY 1997 level of \$151.1 million is entirely adequate. The President's proposed FY 1998 budget has not yet been made public. In the area of personnel, NLM's ceiling was recently raised from 571 to 575, although this still represents a loss of some 75 positions over the last few years. Three new fellows at the National Center for Biotechnology Information were introduced to the Board: Drs. Laura Lopes, Michael Galperin, and Andrei Gabrielian. Ms. Bonnie Kaps, NLM's new Committee Management Officer, was also introduced to the Regents. In the area of legislation,

Dr. Lindberg reported on several recent unsuccessful bills on privacy and confidentiality for patient health data. The recently enacted Health Insurance Portability and Accountability Act states that Congress has a responsibility to address this need within 3 years; failing that the HHS Secretary is empowered to act in this area. NIH authorization hearings will be held again this year. Dr. Lindberg reported briefly on the makeup of House and Senate health appropriation and authorization subcommittees. He noted that NLM last week was visited by the staff of Alaska Senator Ted Stevens; they were much interested in several NLM programs that affect that state. The NLM Director said that he had been appointed by HHS Secretary Shalala as the U.S. representative in the area of health to the G-7 group of seven industrialized nations. He reported briefly on a meeting hosted by NLM on January 27-28 of the G-7 national coordinators for health. One of the items covered at the meeting was the use of a health data card or "smartcard"; the Regents discussed the NLM's possible role as a contributor of "linguistic" expertise arising from its work with the Unified Medical Language System. Dr. Lindberg reported on a successful meeting at NLM of applications developers using the Visible Human datasets. There was much welcome coverage in the print and electronic media—including a major cover story in the current issue of LIFE. Also receiving much press coverage was NLM's announcement of 19 telemedicine awards in October, which was followed by a meeting of telemedicine contractors at NLM in December. The NLM Director drew the attention of the Regents to a new exhibit, "Emotions and Disease," in the NLM lobby and catalog area. Finally, he reported on a press conference in October to announce the availability on the World Wide Web of the new "Human Gene Map" created by NLM scientists and others. announcement was timed to coincide with the publication of an article about the Gene Map in Science; a copy of the colorful map was distributed to Board members. That event also was widely reported in the scientific and lay media.

VIII. ADMINISTRATIVE ACCOMPLISHMENTS, FY 1996

Mr. Donald Poppke, NLM Executive Officer, reviewed for the Board a number of recent "behind the scenes" actions and accomplishments in the area of administration. There are some 60 NLM employees engaged in various administrative functions—personnel management; financial management; acquisitions (small purchasing and contracting); and administrative services (such as mail, printing, shipping/receiving, safety, inventory management, and liaison with NIH's Division of Engineering Services—which is in charge of facilities management). Administrative costs at NLM run about 4.8 percent of the budget. Mr. Poppke concentrated on three areas: the establishment of NLM's Diversity Council; safety, security, and access improvements; and streamlined administrative systems. A recent NIH Diversity Congress recommended that NIH component organizations consider forming "Diversity Councils," which would bring all voices to the table in a single advisory body to discuss issues of common concern. Under the leadership of Dr. Lindberg, NLM became the first (and so far the only) NIH component to establish a Diversity Council. The 11-member body, which has a formal charter, represents a broad spectrum of staff. Mr. Poppke next presented a series of facilities management actions, including those taken to enhance employee security (such as installing 35 security cameras in the parking garages and stairwells), to improve emergency systems (such as improved emergency lighting in power outages), and to improve access for the disabled (especially to building 38 elevators and rest rooms). There is in place a wellconceived disaster plan to protect the collection in case of fire, flood, or other emergency.

Mr. Poppke reported on a number of administrative improvements: in personnel (for example, new

pass/fail appraisals, and simplified award and training systems); in contracting (NLM is now a designated NIH "Service Center" that can provide contract support to other NIH components); and in decentralizing such administrative functions as computer procurement and conference room reservation. NLM is beginning to make use of an Intranet service to provide staff access to a variety of administrative and other employee-related information. Continuing improvements are being made to NLM's telephone system. Finally, Mr. Poppke briefly described several moves that are now under way that will have the effect of providing more space for the National Center for Biotechnology Information.

Following Mr. Poppke's presentation, Dr. DeBakey asked when additional space would be needed to house NLM's expanding collection. Mr. Poppke said that according to an internal December 1995 report NLM will run out of space about 2014. Increasing rates of journal publication, new technologies, expanding NLM services, and off-site storage are all ingredients that may affect the long-range outlook for space requirements. Dr. Fonseca commented that universities are faced with very similar security problems. He complimented NLM on creating its Diversity Council and asked about what specific problems it was currently addressing and how it would implement solutions. Mr. Poppke said the Council, which is now taking a "snapshot" of the NLM workforce as a first step in its deliberations, is advisory to the NLM Director. Mr. Russell of the National Agricultural Library said that they will be watching NLM's experience with the new appraisal system, the Diversity Council, and staff security and safety. He complimented NLM on being so progressive in these areas.

IX. REMARKS BY THE DIRECTOR, NIH CLINICAL CENTER

Dr. John Gallin described the role of the Clinical Center (Building 10) in conducting research at the NIH. The 325-bed Clinical Center, built in 1953, contains 40 percent of all the laboratories on campus. It has a staff of 1850 and an annual budget of \$220 million. The number of research protocols being conducted at any one time is about 900. Last year there were 7,000 in-patients and 70,000 out-patient visits. Patients come from all over the world to participate in NIH-sponsored protocols. A few of the notable accomplishments there: the pathogenesis of the first AZT therapy for AIDS, first successful artificial heart valve, immunosuppressive therapy for diseases such as lupus, use of lithium for bipolar disorders, first gene therapy, and many of the blood tests for hepatitis and AIDS. Because changing research patterns have resulted in reduced in-patient activity in recent years and because the infrastructure of the Clinical Center is aging, the HHS Secretary commissioned a thorough review of the facility. The resulting report had four primary recommendations in the area of governance, funding, strategic planning, and applying reinvention principles to the operation of the Clinical Center. Dr. Gallin reported briefly on several initiatives now under way that were prompted by the report's recommendations. One important change will allow the Clinical Center to collect third-party payments for patients treated there. Another change, already implemented, is to put up on the World Wide Web a database containing Clinical Center intramural protocols—a brief synopsis of the study, exclusion and inclusion criteria, and an e-mail contact for more information. He also described a new training program for NIH clinical investigators. Finally, Dr. Gallin showed an architect's views of the new "Mark O. Hatfield Clinical Research Center," which will have 250 beds and 100 "day hospital chairs," and 850,000 square feet of space (to be added to the existing Clinical Center's 3.5 million square feet). There will be little

net change in area because some of the existing space will lose its functionality. The cost of renovation and new construction is projected at \$330 million; completion is scheduled for the fall of 2001.

Following Dr. Gallin's presentation, there was a general discussion by the Regents about the desirability of seeking third-party reimbursement for patients in research protocols in the Clinical Center. This would be a radical departure from previous practice.

X. LONG RANGE PLANNING PANEL ON INTERNATIONAL PROGRAMS

Dr. Elliot R. Siegel, NLM Associate Director for Health Information Programs Development, briefly described NLM's plans (previously presented to the Board) to review the Library's international programs. A Planning Panel, chaired by Dr. Donald Fredrickson, met last fall and will meet twice more before presenting a draft report to the Board of Regents in September 1997. Several basic questions were put to the panel, involving what NLM should do overseas, where it should do it, and whether certain types of biomedical information and communications methods or strategies should receive special attention. The Panel, at its first meeting, was unequivocal in its support for NLM to engage in international activities. Dr. Siegel said there was support for focusing on a regional orientation for NLM's activities—a sort of "International Network of Libraries of Medicine," although there was no clear direction as yet on just what NLM's role would be in forming or coordinating such a network. As to the content of NLM's services, molecular biology information, clinical practice guidelines, and patient care information were classes of information suggested. In the area of new technologies electronic publishing was much discussed, although there are many uncertainties not the least of which is intellectual property rights. Online full-text retrieval of journal articles, as will be possible in such systems as NLM's PubMed, is another aspect of this that has exciting potential for areas of the world where there are no medical libraries. The panelists recommended that NLM stay alert to new and perhaps unanticipated telecommunications developments (beyond the Internet and World Wide Web) with application to international communications. The next panel meeting will have added expert consultants in electronic publishing and telecommunications. Dr. Siegel noted that next month NLM will welcome a new MEDLARS International Center in Russia, bringing the total of such Centers to 21.

Following Dr. Siegel's presentation, Dr. Fredrickson said that the Planning Panel realizes the profound changes in information and communication that are coming rapidly as we move toward the Millennium. Elaborating on several of the points made by Dr. Siegel, he said that there is great uncertainty as to just how many institutions around the world might qualify for membership in an "International Network of Libraries of Medicine." Gradually we will find ways to coalesce functions with institutions around the globe to provide better services to all. As international research (such as that on malaria recently discussed at the G7 meeting) becomes an ever greater reality, there will be great opportunities for the Library to become involved in organizing and linking the database and information aspects of such research. Disseminating data across large fields of activity long before they become journal articles will be a possible role for NLM in the research process. NLM's PubMed and GenBank will also undoubtedly become part of the Library's contribution to international research. Dr. Marion Ball, who is representing the Regents at the Planning Panel's meetings, commented that the amount and quality of information pulled together by Dr. Siegel's office has been of inestimable help to the Panel.

Dr. Kenneth Walker, former chairman of the Board of Regents and a member of the Planning Panel, made some comments about the nature of international communication. He spoke of his experiences in the Republic of Georgia, where he has been involved with improving the neglected medical library resources. Dr. Walker said that NLM has an historic opportunity with its international program, and that the direction to take is not at all obvious. In the final analysis, the leadership for change must come from the Board of Regents.

XI. NLM'S HBCU TOXICOLOGY INFORMATION OUTREACH PROGRAM UPDATE

Dr. Melvin Spann, NLM Associate Director for Specialized Information Services, briefly reviewed the outreach project, which has been presented to the Board in the past. He showed a segment from a television news program about a toxic waste site in Texarkana; it exemplifies a widespread problem in the South where there are a number of toxic dumpsites located in minority communities. The pilot project, begun in 1991, has provided to health professional programs at Historically Black Colleges and Universities (HBCUs) the equipment, software, and training needed to access the NLM's toxicology and environmental health information databases. It has since been expanded from HBCUs to other minority institutions, for example in Puerto Rico. Today, almost 70 institutions are participating. After Dr. Spann described the genesis and evolution of the program since that time, Dr. Bailus Walker, Jr., Associate Director of the Cancer Center at Howard University, who has chaired the committee of institutional representatives that oversees the project, complimented Dr. Lindberg and the Library on its foresight in establishing the program. The seed planted by the NLM is bearing fruit: not only have many faculty, students, and community leaders been trained in using the databases, but NLM's lead has resulted in new curricula and departments being formed in the universities and additional support coming in from private foundations, state agencies, and other Federal agencies. An invited article and commentary will be published in an upcoming issue of the Chronicle of Higher Education on the development and growth of the outreach program.

Following the presentations, Dr. Sherrilynne Fuller reported that an Institute of Medicine report on environmental health and toxicology information resources for health professionals will soon be released. It recognizes NLM's leadership role in this area and will recommend that even more be done, especially in the area of coordinating disparate efforts. NLM consultant Dr. Lois DeBakey, who could not attend the meeting, sent comments about the program that were read by Dr. Phillips. She reaffirmed the critical need for the program and praised the progress to date. In response to a question she raised, Dr. Lindberg said that the IOM study referred to by Dr. Fuller will evaluate NLM's Toxicology and Environmental Health Information Program. Dr. Fuller added that the NLM-sponsored program could serve as a model for colleges and universities nationally and that we should be able to clone the program at other sites.

XII. UNIFIED MEDICAL LANGUAGE SYSTEMS PROGRESS REPORT

Update on UMLS Progress

Ms. Betsy Humphreys, NLM Assistant Director for Health Services Research, noted that last fall marked the tenth anniversary of the beginning of NLM's Unified Medical Language System project. This is a long-term research and development effort involving NLM staff, medical informatics research groups working with NLM under grant and contract, and more than 700 UMLS users worldwide. The goal of the UMLS project is to make it easier to retrieve and integrate relevant information from disparate machine-readable sources, including such things as patient records. bibliographic databases, full-text sources, practice guidelines, factual databases, and expert systems. The UMLS effort has produced knowledge sources and programs designed to help system developers overcome two major barriers to biomedical information retrieval: the variety of ways the same concept can be expressed in different sources and the sheer number and wide distribution of machine-readable information sources that might contain information relevant to a query. The UMLS project has developed four knowledge sources: the Metathesaurus, the Semantic Network, the Specialist Lexicon, and the Information Sources Map. Ms. Humphreys briefly described each. New editions of these products are issued annually on CD-ROMs and are also accessible via an Internet-based UMLS Knowledge Source Server. They are available free to those who sign an agreement governing their use. The 1997 edition of UMLS Knowledge Sources will be released in the next few weeks. Major changes include a significant increase in the size of the Metathesaurus (which now contains 332,000 concepts and 713,000 terms) and the beginning of a redesign of the Information Sources Map. The Regents have in the past seen demonstrations of UMLS applications; the Internet Grateful Med is a prime example. Later in this meeting Mr. Mark Tuttle will be demonstrating another application -- the "Problem List Tool Kit." In addition to being used in operational information systems, UMLS products have figured prominently in many research studies such as the NLM/Agency for Health Care Policy and Research large-scale vocabulary test. The purpose of the test is to see how well a set of controlled vocabularies covers the concepts needed in patient records and other types of electronic health data. Use of the Internet and World Wide Web made it possible for researchers at many sites in the United States and Canada to contribute terms to the test. Participants were drawn from the VA, CDC, academic medical centers, hospitals, managed care companies, libraries, commercial software developers, and specialty societies.

NLM/AHCPR Large Scale Vocabulary Test

Dr. Alexa McCray, of NLM's Lister Hill Center, described the Large Scale Vocabulary Test conducted by the NLM and the Agency for Health Care Policy and Research between July 1996 and January 1997. More than 60 participants submitted some 40,000 terms. Testers used their own preferred terms to enter over the World Wide Web into the Metathesaurus; the system responded with controlled vocabulary terms to match the input. Dr. McCray demonstrated the system, signing on as a user and entering various terms (from actual test participants) to see how the system responded. A rank ordered list of what the system believes to most closely match the entered term is returned to the user. Testers found exact matches for 59 percent, partial matching for 30 percent, and no match for 11 percent. These results are now undergoing a second level review by subject experts who are finding additional matches. A complete report of the final results of the test will be available to the Regents at a future meeting.

Following the demonstration, Dr. Kathleen McCormick commented that AHCPR was pleased to participate in the test. The UMLS holds great promise, she said, in sidestepping the major problem of diverse vocabularies that AHCPR faces in outcomes research. It also will be critical in the success of work being done on the electronic patient record. She commented about the need for plans to introduce the UMLS into the educational process. At present only medical informatics specialists seem to grasp fully the importance of the vocabulary issue. She said NLM needed to plan a continuous process for adding and deleting terms. Wendy Carter commented that the VA was pleased to participate in the test and they were impressed with closeness of the matches found. Ms. Humphreys commented that in the last year there has been a substantial increase in interest in the UMLS from commercial software developers, in part prompted by the needs and requirements of the VA and Defense agencies who contract with them for services.

XIII. REPORT FROM THE EXTRAMURAL PROGRAMS

Dr. Milton Corn presented for review, as required annually, the Board operating procedures "Guidelines for Adjustments by Staff in Time or Amount of Grant Award." Procedures were reaffirmed unanimously.

As an overview of NLM's extramural funding activities, a summary of grants and contracts awarded in the last three fiscal years was presented. In part because of the expense of maintaining the collection, NLM disburses less than 40 percent of its budget for extramural projects, rather than the 80-90 percent allocated for this purpose by the other Institutes. Grant projects are authorized either by the Medical Library Assistance Act, which is unique to NLM, or by PHS 301, which covers most of grants issued by NIH. Contracts are usually used for specific projects with defined endpoints, such as UMLS, Visible Human, and the current telemedicine work. MLAA grants are for resources, training, and publications; PHS 301 grants are for research and research resources, and educational technology. Most of these are on-going programs, but occasionally a time-limited request for applications is published for a topic of current interest. Graphs presenting relative allocations of funds to grants, contracts and the sub-categories were presented. About 25 percent of the research funds are reserved for new investigators.

Dr. Corn then introduced Mr. Mark Tuttle of Lexical Technology, Inc., who presented to the Board an overview of a "problem list manager." This is an illustration of a project funded as an NLM grant under the Cooperative Agreement for Electronic Medical Record Systems. The problem list manager is intended to extend UMLS into the clinical vocabularies used by physicians and appears to have a greater potential for physician acceptance as a working tool than previous attempts to adopt technology useful for computerized patient records.

A Problem List Toolkit: A UMLS Clinical Application

Lexical Technology, Inc. (LTI), in collaboration with the Mayo Clinic and the Harvard/Beth Israel Deaconess Medical Center is developing a Problem List Toolkit (Pl/Tk) for release with the 1998 UMLS Knowledge Sources. Pl/Tk development is being supported by the NLM/AHCPR Electronic Medical Record (EMR) collaborative program. The central component of Pl/Tk is a problem-picker module called MetaphraseTM, a UMLS-based component with a Web-based interface intended for

use by both caregivers and medical records personnel. Metaphrase helps convert the informal language used by a caregiver to describe patient problems and indications into terms or expressions from formal vocabularies in its database. The current version of Metaphrase makes use of the 1997 UMLS Metathesaurus as well as over 10,000 problems from vocabularies prepared by Mayo and Beth Israel. Metaphrase can perform word completion on any word fragment given to it that ends in an asterisk, and it will correct simple spelling errors. It can also "compose" expressions consisting of one or more of a repertoire of qualifiers applied to terms. Usability testing of the current Metaphrase prototype at the Mayo Clinic began this month, and deployments there as part of Mayo's emerging EMR will begin later in 1997. Deployment at Beth Israel is scheduled for early summer 1997. Access to LTI's Web-based interface to Metaphrase must currently be restricted because of copyright issues.

XIV. TELEMEDICINE

Dr. Michael Ackerman, NLM Assistant Director for High Performance Computing and Communications, said that telemedicine is the bringing together of information at a distance for medical decision-making. The proper information, applied at the right time in a medical situation-either to the practitioner or the patient will have a positive influence on the health outcome. But the question, how can this be proven still remains. Current schemes tend to rely on qualitative anecdotes and are not rigorously quantitative. To help rectify this, NLM sponsored a study by the Institute of Medicine, "Telemedicine: A Guide to Assessing Telecommunications in Health Care." Copies have been given to the Regents. Dr. Ackerman noted the presence of Dr. Marilyn Field, who was Executive Secretary of the IOM Committee that produced the report. He next introduced Dr. Jay Sanders, President of the American Telemedicine Association and President of the Global Telemedicine Group, who described for the Regents current issues in telemedicine and how they were handled in the recently published report.

Telemedicine: A Guide to Assessing Telecommunications in Health Care

Dr. Sanders referred to Dr. Michael DeBakey's pioneering live satellite-mediated two-way transmissions of heart surgery between Houston and Geneva, Switzerland, some 30 years ago. There has long been a great need for a scientific evaluation of the efficacy of telemedicine; unfortunately most of our efforts did not sustain themselves long enough to collect the type of data required for systematic evaluation. Dr. Sanders praised the Library, the study chairman Dr. John Ball, and Dr. Marilyn Field for their excellent work in preparing the current report. The fact that it took 30 years to get to this point demonstrates that medicine is prone to embrace technology more for its intuitive logic than from a scientific standpoint. Telemedicine is one of the few technologies in health care for which we now have an appropriate evaluative platform to use in testing. CAT scan, MRI, ultrasound—all widely used and reimbursed by third party payers—have never been subjected to a rigorous evaluation. The new report stands as a foundation for evaluating new medical technologies in general. Dr. Sanders said it was his opinion that telemedicine would disappear in the next 5 years, "for all the right reasons." Just as no one today thinks twice about the telephone, or the fax, as telecommunications media, so will e-mail and multimedia transmission be accepted routinely in the near future. Perhaps we should get rid of the extravagant term "telemedicine"; we are merely expanding the multimedia component of transporting information. The great virtue of the present report is that it takes common evaluative principles and applies them to the evaluation of telemedicine. The study members were predominantly people who had never done telemedicine but who were familiar with the principles of research and evaluation. We now can integrate evaluative efforts done around the world, in large institutions and small, into "one large research and evaluation platform." Dr. Sanders identified some of the barriers to telemedicine: state licensure restrictions; reimbursement by HCFA; transmission costs for e-mail and multimedia, especially for rural and remote providers; and, of course, data privacy and confidentiality issues.

Teledermatology on a Budget

Following Dr. Sanders's presentation, Dr. Ackerman introduced Dr. Douglas Perednia of the Oregon Health Sciences University (OHSU). Dr. Perednia presented to the Board a report on the "Comprehensive Teledermatology Program" funded by a 3-year NLM contract at OHSU. He prefaced his report with brief comments about telemedicine in general and previous work in the area of transmitting images of skin diseases. The goal of the Oregon teledermatology system was to devise the least expensive, most efficient system to deliver dermatology services in rural areas and then to see if it "made a difference." Did it improve health care delivery? Did it save money? Did it change referral patterns of rural health care providers? There were three phases to the project. The first was to collect data on current practice. Phase two was to specify, test, and install an image system for transmitting dermatology information. Dr. Perednia described the three rural family practice clinics in Oregon. Health providers at these sites use a still camera (with flash) to record skin problems which are then transmitted via computer link to the specialists at OHSU. Phase three involves the actual operation of the system, referring patients for telemedicine consultation, and collecting data. There have been 120 consultations so far. Using slides, Dr. Perednia showed the Board photographs of examples of the problems presented by patients and how they were resolved. About 50 percent of the time the dermatologist believes he knows exactly what the problem is; in the remainder a differential diagnosis is generated. The most important question to be answered by all this is: does it change the way health care services are provided? The answer is yes: about 65 percent of the time the treatment plans prepared by the primary care physician and the dermatologist were completely different. The likelihood of a patient seeing a specialist, either in person or by telemedicine consultation, went up by a factor of ten.

Following the presentations on telemedicine, Dr. Sherrilynne Fuller commented that projects such as that described by Dr. Perednia take an inordinate amount of time to set up, conduct, and evaluate. She suggested that the amount of time allowed for the NLM-funded telemedicine projects may be inadequate and that extensions may be required. The true test of their success will be whether they survive after external funding ends. She made the point that the benefits of telemedicine aren't only applicable to rural and long-distance situations; they may also be of great benefit in big-city situations where the barrier is time rather than distance. Lt. Col. Raines presented some of the comments that Col. Schoomaker (who was unable to be at the meeting) wished to make. The Army is struggling with the same question of how to evaluate the effectiveness of telemedicine. The services are fortunate in that many of the barriers of the sort presented by Dr. Sanders (licensure across state lines, for example) don't pertain to the military. Dr. Raymond Fonseca asked about the reaction of the specialists to telemedicine—what is the long-term outlook for their relationship with primary care providers? Dr. Perednia commented that there has been some unfavorable reaction

from specialists who perceive a threat to their practice. On the other hand, the practicing dermatologists in Oregon will end up receiving referrals from the primary care MDs once the project is over; hopefully those dermatologists will join subspecialty teleconsultation networks.

XV. COMPUTER-BASED OLDER MATERIALS

Lois Ann Colaianni, NLM Associate Director for Library Operations, said that with the myriad databases and other computerized medical data sources it is often overlooked that the pre-1966 journal literature is not available in machine-readable form. Printed catalogs and indexes must be consulted for older materials. There is much that is valuable in the older literature, including information about tuberculosis treatment prior to the introduction of effective drugs, and radiation experiments, for example. Older material indexed by NLM begins with the 1880 Index-Catalogue of the Library of the Surgeon General's Office covering books and journal articles, and Index Medicus in 1879, covering journal articles on a more current basis. Mrs. Colaianni showed a chart listing all the NLM-produced indexes and catalogs down to 1964, when MEDLARS began. Although there had been talk over the years about computerizing earlier materials, it wasn't until the last few years that NLM actually began doing something about it.

OLDMEDLINE

Mrs. Colaianni described "OLDMEDLINE," which contains 307,000 citations from 1964-1965. These references have the MEDLINE citation format and the original Medical Subject Headings index terms. There are no abstracts, however. NLM is planning this year to go back and pick up the 1962 and 1963 citations from the Cumulated Index Medicus. She introduced Ms. Lou Knecht, Deputy Chief of the Bibliographic Services Division, who demonstrated OLDMEDLINE using a test version of the Internet Grateful Med. She searched on the subject of transplantation using Michael DeBakey, M.D. as an author's name and retrieved nine references from OLDMEDLINE. She did a second search on Donald A. B. Lindberg, M.D., finding eight citations, and a third on the subject of MEDLARS, which retrieved 11 records. The Loansome Doc feature, available with the current MEDLINE databases to permit ordering copies of the articles, will be implemented soon.

Index-Catalogue Project

Mrs. Colaianni introduced Dr. Russell Maulitz, who described a project in association with the American Association of the History of Medicine (AAHM) to convert the first series of the Index-Catalogue. Dr. Maulitz is the Associate Director for the Institute of Academic Informatics at Allegheny University of the Health Sciences and chair of the Committee on Electronic Media of the AAHM. The goal of the project is to convert the 1880-1895 Index-Catalogue (16 volumes) into SCML tagged data. Initially this would be accessible on a compact disk but these are plans for a Web-accessible database. NLM would also have this data searchable in its system. The I-C, a monument to the industry and genius of John Shaw Billings, is the "Rosetta Stone" for medical bibliographers -- the chief source of late 19th and early 20th century journal and monographic literature in the health sciences. Because the 1-C is not indexed with Medical Subject Headings, it will be a challenge for the developers to make the content searchable and user friendly. The time is propitious, he said, with keyboarding, scanning, and markup technologies all available. The

AAHM would like to see the I-C available to every medical student and graduate student in the history of medicine. The team assembled to carry out the project includes the AAHM Committee on Electronic Media (medical historians, clinicians, and library/information specialist); the team will be expanded to include vendors and potential funders. NLM specialists are providing their expertise to help in the project. A pilot phase will be launched next year.

Following Dr. Maulitz's presentation, Dr. Michael DeBakey commented that these presentations were especially enjoyable for him -- he looks forward with great eagerness to being able to search the pre-1966 literature. Citing Santayana's dictum that those who ignore history are condemned to repeat it, Dr. DeBakey said that at scientific meetings in the vascular field he sees presentations that repeat data that had been reported in the fifties. In the bypass field, a great deal of important experimental and conceptual work was published even as far back as 1910. Bringing this literature into line with current storage and retrieval methods is very important to the profession.

Dr. Enriqueta Bond said that the Burroughs Wellcome Fund is interested in the I-C project. The Fund has awarded a million dollars in the history of medicine to support young investigators who are studying the history of American science and medicine. As a part of this process a proposal came to the Fund to help support the project described by Dr. Maulitz; they have decided to provide pilot support. Dr. Lindberg said he is enthusiastic about both OLDMEDLINE and the I-C projects - they are starting at opposite ends of the chronological spectrum with the intention of someday meeting. He is especially enthusiastic about the prospect of putting this material up on the Web.

XVI. OUTREACH

Dr. Michael DeBakey gave a brief report on yesterday morning's meeting of the Board Subcommittee on Outreach and Public Information. Bob Mehnert gave some of the details about the several public events held by NLM since the last Board meeting: two press conferences, on the Visible Human Project and the Human Gene Map; the press releases sent out by HHS and NLM announcing the telemedicine awards; and the new exhibit in the NLM's lobby and catalog area. There was a discussion among Subcommittee members about the outreach value of traveling NLM exhibits. The Subcommittee also saw new designs for a "family look" for NLM publications. Mr. Kotzin spoke to the Subcommittee about his efforts to have commercial vendors of NLM data give proper acknowledgement to the Library as the source. Plans for approaching Paul Harvey, Larry King Live, and Readers Digest as possible outlets for information about NLM were also discussed. Kathleen Gardner showed the Board a videotape of television news clips resulting from the Visible Human, Gene Map, and other outreach activities.

Following the presentation and video clips, Subcommittee member Dr. Marion Ball commented that the amount and quality of publicity the NLM has received over the past year is amazing. She complimented the NLM staff and also Dr. Lois DeBakey who works tirelessly on the Library's behalf. Dr. Phillips and Dr. Albright, both members of the Subcommittee, agreed.

Dr. Phillips said that people need to know about the Library if it is to be of maximum value; the recent publicity is one way of doing this. Dr. DeBakey noted that it is important for the general public to know about the Library and to understand its importance to the national health effort. He said that an NLM exhibit that circulated among American museums of science would be another way of accomplishing this.

CLOSED PORTION OF THE MEETING - January 29, 1997 4:30 p.m. - 5:15 p.m.

This portion of the meeting was closed to the public in accordance with the determination that it was concerned with matters execpt from mandatory disclosure under Sections 552b(c)(4) and 552(c)(6), Title 5, U.S. Code and Section 10(d) of the Federal Advisory Committee Act, as amended (5 U.S. C. Appendix 2).

There was a discussion of procedures and policies regarding voting and confidentiality of application materials, committee discussions and recommendations. Members absented themselves from the meeting during discussion of and voting on applications from their own institutions, or other applications in which there was a potential conflict of interest, real or apparent. Members were asked to sign a statement to this effect.

Grant Review

The Council reviewed 42 applications requesting \$16,216,162 and recommended 30 applications with a total cost of \$10,793,345.

XVII. ADJOURNMENT

The meeting was adjourned at 12.30 p.m.

CERTIFICATION

I hereby certify that the foregoing minutes are accurate and complete

Steven J. Phillips, M.D.

Chair

Board of Regents, NLM

Donald A.B. Lindher M.D.

Director

National Library of Medicine

ATTACHMENTS

Meeting of the Extramural Programs Subcommittee was held from 2 p.m. to 3:30 p.m. on January 28, 1997. (Attachment B)

Meeting of the Subcommittee on Outreach and public Information was held from 8 a.m. to 9 a.m. on January 29, 1997. (Attachment C)