

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

**MINUTES OF THE BOARD OF REGENTS
MAY 12-13, 1998**

The 118th meeting of the Board of Regents was convened on May 12-13, 1998, at 9:05 a.m. in the NLM Board Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), Bethesda, Maryland. The meeting was open to the public from 9:05 a.m. to 2:15 p.m., followed by the closed session for consideration of grant applications until 2:45 p.m. On May 13 the meeting was reconvened and open to the public from 8:30 a.m. until adjournment at 12:30 p.m. Dr. Michael DeBakey presided as Chair.

MEMBERS PRESENT

Dr. Michael DeBakey, Chair
Dr. Tenley E. Albright
Dr. Marion Ball
Dr. Jordan Baruch
Dr. Enriqueta Bond

Dr. Sherrilynn Fuller
Mr. John Gage
Ms. Michele Klein
Dr. George Nolan

EX OFFICIO AND ALTERNATE MEMBERS PRESENT

Ms. Pamela Andre
Ms. Wendy Carter, representing Dr. Kenneth Kizer
Dr. Mary Clutter
Dr. Kathleen McCormick, representing Dr. David Satcher
Colonel Kristen Raines, representing Lt. Gen. Ronald Blanck
Brigadier General Klaus Schafer, representing Lt. Gen. Charles Roadman
Captain William Wurzel, representing Vice Adm. Harold Koenig
Dr. James A. Zimble



CONSULTANTS TO THE BOR PRESENT

Dr. Steven Phillips, Iowa Heart Center-Mercy Hospital Medical Center

MEMBERS OF THE PUBLIC PRESENT

Mrs. Mary Lindberg
Mr. Daniel Cunningham, Smart Card Industry Association
Mr. Keith Krueger, Friends of the NLM
Ms. Pam Moore, "Capital Publications"

FEDERAL EMPLOYEES PRESENT

Dr. Lawrence Shulman, NIH Ombudsman for Clinical Sciences
Dr. Daniel Maloney, Technology Innovations, DVA
COL Lynn Ray, Composite Health Care System II, DOD
Dr. Robert Kolodner, Business Enterprise Solutions & Technologies, DVA
Dr. Richard Ferrans, Medical Informatics & Telemedicine, LSR Medical Center
Dr. Donald A.B. Lindberg, Director, NLM
Mr. Kent A. Smith, Deputy Director, NLM
Dr. Michael Ackerman, Assist. Director for High Performance Computing & Communications, NLM
Ms. Suzanne Aubuchon, Office of the Director, NLM
Dr. Dennis Benson, Information Resources Branch, NCBI/NLM
Ms. Susan Buyer, Office for Health Information Programs, NLM
Ms. Kimberly Caraballo, Committee Management Office, NLM
Mr. Peter Clepper, Office of Extramural Programs, NLM
Mrs. Lois Ann Colaianni, Associate Director for Library Operations, NLM
Dr. Milton Corn, Acting Associate Director for Extramural Programs, NLM
Dr. Paul Fontelo, Office of High performance Computing & Communications, NLM
Ms. Kathleen Gardner, Office of Inquiries and Publications Management, NLM
Ms. Jeanne Goshorn, Biomedical Information Services Branch, SIS/NLM
Ms. Frances Johnson, Office of Extramural Programs, NLM
Mrs. Frances Howard, Office of Extramural Programs, NLM
Ms. Betsy Humphreys, Assistant Director for Health Services Research Information, NLM
Ms. Bonnie Kaps, Committee Management Office, NLM
Ms. Junga Kim, National Center for Biotechnology Information, NLM
Dr. Lawrence Kingsland III, Assistant Director for Health Services Research Information, NLM
Ms. Eve Marie Lacroix, Public Services Division, LO/NLM
Ms. Becky Lyon, National Network Office, LO/NLM
Dr. Thomas Madden, National Center for Biotechnology Information, NLM
Dr. Alexa McCray, Director, Lister Hill National Center for Biomedical Communications, NLM
Mr. Robert Mehnert, Office of Inquiries and Publications Management, NLM
Ms. Pamela Meredith, Reference Section, LO/NLM
Mr. Michael Moore, Biomedical Files Implementation Branch, SIS/NLM
Mr. Dwight Mowery, Office of Extramural Programs, NLM
Mr. David Nash, Office of Equal Opportunity, NLM
Dr. Sharee Pepper, Office of Extramural Programs, NLM
Mr. Donald Poppke, Executive Officer NLM
Ms. Julia Royall, Office for Health Information Programs, NLM
Ms. Alberta Sandel, Office of the Director, NLM
Ms. Kristine Scannell, Public Services Division, LO/NLM
Mr. John Seachrist, Office of Extramural Programs, NLM

Dr. Elliot Siegel, Associate Director for Health Information Program Development, NLM
Dr. Melvin Spann, Associate Director for Specialized Information Services, NLM
Dr. Sue Sparks, Office of Extramural Programs, NLM
Mr. Roy Standing, Acting Director, Office of Computer & Communications Systems, NLM
Dr. Fred Wood, Office for Health Information Programs, NLM

I. OPENING REMARKS

Board Chairman Dr. Michael DeBakey welcomed the Regents and guests to the 118th meeting of the Board of Regents of the National Library of Medicine. He noted that this is his last meeting and he said that his association with the Library and the Regents has been satisfying and enjoyable.

II. REMARKS BY THE NIH OMBUDSMAN FOR CLINICAL RESEARCH

Dr. Lawrence Shulman was appointed by the NIH Director as NIH Ombudsman (or "emissary") for Clinical Research in 1994. He is Director Emeritus of the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Dr. Shulman has made extended visits to more than 21 academic health centers in his efforts to learn their views and gather their suggestions about how to improve the state of clinical research, that is, patient-oriented research where the scientist and the subject are in the same room at the same time, both "being warm and alive." He noted some of the perceived obstacles cited to doing first-class clinical research: it is inherently "weak" and not meritorious; there is no good career path; mentors are in short supply; funds and time limits are minimal; and communication with basic scientists is limited. He noted some of the schools he visited and described briefly the interesting and important clinical research and the training programs being conducted in those institutions. Dr. Shulman discussed career development issues for clinical scientists, and described several NIH career development programs and awards intended to support training of MDs and PhDs for clinical research. Statistics related to these programs were presented. The objective of his review is to develop recommendations that will lead to a whole new cadre of superb clinical scientists and to provide them with the "methodological, quantitative, and intellectual skills that will allow them to perform first-class research." Dr. Shulman outlined several recommendations for NIH clinical research career awards and said that on April 6, 1998, three new programs were launched by NIH: K23 K24 (individual awards), and K30 (institutional). He briefly described each. Projected funding for the next years is for a 10% increase in new awards, with an increase of about 9% in funds for new grantees. Also, there are two new award programs in the private sector, by the Burroughs Wellcome Fund and the Robert Wood Johnson Foundation. At Dr. Shulman's invitation, Regent Dr. Enriqueta Bond briefly described the Burroughs program.

Following Dr. Shulman's presentation, Dr. Steven Phillips asked about the possibility of a "political arrangement" whereby the Health Care Financing Administration would selectively reimburse clinical research. Dr. Shulman said that the National Cancer Institute and the National Heart, Lung,

and Blood Institute are looking into this possibility. Dr. DeBakey said that there is a perception in the scientific community that the funding rate at NIH is so low that scientists are discouraged from applying for clinical research support. He asked if there is any possibility of NIH segregating funds specifically for this purpose, so that clinical researchers can compete among themselves and not with basic scientists. Dr. Shulman replied that NIH is sensitive to this dilemma and that the NIH Center for Scientific Review is working to solve the problem.

III. CONSIDERATION OF MINUTES OF PREVIOUS MEETING

The Regents approved without change the minutes of the January 27-28, 1998, meeting.

IV. FUTURE BOARD MEETINGS

The Board of Regents will meet next on September 24-25, 1998. Next winter's meeting will be January 26-27, 1999. The proposed date of May 25-26, 1999, was accepted for the meeting next spring.

V. REMARKS BY THE DIRECTOR, NLM

Dr. Lindberg reported that the President's FY 1999 budget for NLM is \$174,725,000, an increase of 8.4% over the current appropriation. The 1999 budget contains increases for High Performance Computing and Communications/Next Generation Internet (\$5.0 million), genetics in medicine (\$3.0 million), AIDS information services (\$1.0 million), and \$5.4 million for basic library services. The NLM Director introduced several new staff members: Dr. Paul A. Fontelo (Special Expert, LHC/HPCC Office); Neil Rambo (Intergovernmental Personnel Act, Library Operations); Dr. Thomas Madden, National Center for Biotechnology Information; and Junga Kim (NCBI). Jeanne C. Goshorn and Michael D. Moore have been selected for two Branch Chief positions in the Specialized Information Services Division. There is an important loss to report: Fernando Burbano, who headed NLM's Office of Computer and Communications Systems, has moved on to the State Department where he is the Chief Information Officer. Also, Gerard T. Guthrie (Specialized Information Services) has retired. Dr. Lindberg briefly described a bill on the Next Generation Internet that in effect extends existing HPCC legislation to authorize NGI work. NLM and NIH are specifically mentioned in the Senate version of the legislation. There is still no legislative closure on the important subject of confidentiality and privacy of electronic medical data, previously reported to the Board of Regents. Dr. Lindberg reported briefly on the Friends of the National Library of Medicine annual conference on the Emerging Health Information Infrastructure (HII98). He showed a videotape containing clips from House Speaker Newt Gingrich's presentation to the conference, a few remarks of his own, and a 30-second Public Service Announcement made by Dr. Michael DeBakey on behalf of the NLM. Another recent conference, co-sponsored by NLM and held at the New York Academy of Medicine, was on "Accessing Useful Information -- Challenges in Health Policy and Public Health." Dr. Lindberg brought the Regents up to date on the

subject of the G7 Global Health Care Applications Project. NLM is involved with Sub-Project 3, on the subject of cardiovascular disease, seeking to incorporate the informatics-related work of the NHLBI's National Heart Attack Alert Program. A 2-day meeting of the NHLBI program was held at NLM in the past month. Other sub-projects in which the NLM has a vested interest are on telemedicine, Internet connectivity, health data cards, multilingual databases, and medical images. The NLM Director reported that the NLM has announced a funding initiative for Next Generation Internet work. Also, the Library is sponsoring a study by the National Research Council to define the technical capabilities that NGI must provide in order to meet the requirements of health care applications. Dr. Lindberg noted two recent honors: the James Madison Award, from an American Library Association group, was presented to the NLM for furthering the "public's right to know" and Dr. Michael DeBakey was the recipient of Research!America's Lifetime Achievement Award. The NLM will once again sponsor a medical informatics course at the Woods Hole Marine Biological Laboratory. This highly competitive 1-week for 30 students is now in its sixth year. The next major history of medicine exhibit at the NLM, Dr. Lindberg announced, will be "Asthma: the Breath of Life." The exhibit will be installed by the end of 1999. The last item reported by Dr. Lindberg was the meeting at NLM on April 16 of 15 health sciences librarians to discuss with Library staff some problems encountered by librarians when searching MEDLINE using PubMed and Internet Grateful Med. Test questions were put to the system in advance by the librarians, and the searchers' experiences collated and discussed at the meeting. Michelle Klein, who attended the meeting, described the meeting from a user's point of view. She said that there was a productive exchange of views between the librarian users of MEDLINE and NLM system developers. The NLM developers displayed a great receptivity to incorporating as many of the suggested search features and improvements as possible.

Following the NLM Director's presentation, Dr. Jordan Baruch suggested that there be an effort to try to break electronic patient records into two sections: one would be private and accessible to the physician and patient; the other would be a public resource of non-identifiable data that could be used for research and other purposes for the public good. Dr. Lindberg agreed with a comment by Dr. Bond that as important as the budget increases for the NLM will be increases in staffing limits and improvement of facilities.

VI. NN/LM SURVEY OF INTERNET ACCESS

Becky Lyon, Head of the National Network of Libraries of Medicine Network Coordinating Office, reported on a survey of the NN/LM members' Internet access conducted by the Network office between April and July 1997. One purpose of the 1997 survey was to update a 1993 survey of Internet connectivity in the NN/LM. Another aim was to see whether, in our rush to put information on the Web, smaller institutions, particularly some hospital libraries, might end up with access to less information than they now have. Network members were surveyed to find out: who is connected and what kind of access they have; and who is not connected, what are the perceived

barriers to access, and when do they anticipate being connected. Ms. Lyon briefly described the methodology, including the telephone-based "interactive voice response" technique they used. A pre-test was conducted that helped to refine the survey. Finally, letters of invitation (which reproduced the survey questions) were sent out to the Network members. There were follow-ups to non-respondents, first by postcard, and later by telephone. Of the 4,500 surveys sent, usable responses were received from 3,491 libraries (78%). Ms. Lyon presented the results in a series of graphs. Among the data: 96% of the reporting academic libraries are connected; 73% of the hospitals; and 89% of "other libraries." (The corresponding 1993 figures were 72%, 24%, and 21%, respectively.) Concerning their type of connectivity, 91% had e-mail capacity and 96% had access to the World Wide Web. Among the hospital libraries, 19% were operating at speeds of less than 14.4 Kbs, 28.8% at speeds equal to or greater than 28.8 Kbs, and 34% were connected to a Local Area Network. Of those hospital libraries that were not connected, 42% planned to be connected within a year. Among the perceived barriers to connectivity cited by the respondents: computer cost, lack of in-house expertise, and lack of management support. Ms. Lyon said that as a result of the findings, the NN/LM will focus on (1) helping to connect the 665 unconnected libraries and (2) helping the libraries who are "under-connected" with outdated equipment or low modems speeds. She concluded by noting that a 1997 survey of public library connectivity showed that 72.3% of public library systems were connected to the Internet (remarkably close the figure reported for hospital libraries). Of these, 60% provide access to library patrons.

Following Ms. Lyon's presentation, Dr. Sherrilyne Fuller said that great progress has been made since the earlier survey and that she was encouraged by the most recent findings. She commented that some of the hospitals reporting no library Internet connectivity probably did not have a medical librarian on the staff. Ms. Lyon agreed and said that the follow-up telephone calls confirmed this observation. Dr. Fuller also said that some have the erroneous impression that connecting to the Internet or World Wide Web somehow compromises security or data confidentiality. Michele Klein commented that the response rate to the survey was excellent. She noted that the cited barrier of lack of in-house expertise would be a difficult problem to address. Dr. Jordan Baruch suggested that local high school students would be an excellent source of technical computer support for hospital libraries.

VII. AWARD PRESENTATIONS

Dr. DeBakey presented the Frank B. Rogers Award to Karen Sinkule of the Public Services Division (Library Operations) for "her foresight in the planning and implementation of the Conservation and Book Repair Laboratory in the National Library of Medicine, thus enabling scholars to use more items in the collection today and for many years to come."

Dr. Lindberg presented the 1998 NLM Director's Award to two NLM employees: Patricia Williams, Administrative Officer, Division of Library Operations, "for outstanding and innovative

administrative support for NLM's basic library services." Also receiving the award was Dr. James Ostell of the National Center for Biotechnology Information for "creative design and development of essential biomedical information resources."

VIII. MONITORING, EVALUATING, AND MANAGING NLM'S INTERNET PERFORMANCE

A. Dr. Fred Wood of NLM's Office of Health Information Programs Development reported to the Regents on his recent study of Internet connectivity to three NLM Web sites: the NLM Home Page, Internet Grateful Med, and PubMed. With the help of Mr. Victor Cid of NLM's Office of Computer and Communications Systems and medical librarians from around the country, Dr. Wood tested the quality and speed of domestic and international connectivity to these three pages. We hope that the study will indicate ways in which we can improve Internet connections to Web-based NLM information resources. Also, Internet measurement is a new field, and the NLM study is a contribution to its methodology and metrics. There was a 3-level testing strategy: testing by "real users" at terminals who measured response times for downloading pages and conducting searches; technical testing between NLM and the actual terminal on a user's desktop; and testing between NLM and the user's Web site (where one exists). Dr. Wood presented several graphs that depicted the study's findings. The transmission capacity of various Internet paths varies widely depending on local equipment (servers, LANs, routers) and the backbone connections. Users varied greatly in the speed of their local connections, from 14.4 Kbs modems to T-3 lines. He also showed graphs that showed the speed of international Internet traffic to the G-7 countries over a 24-hour day. Dr. Wood said the data are being prepared for publication in journal articles.

B. In introducing the topic of monitoring PubMed performance, Dr. Dennis Benson of the National Center for Biotechnology Information described the increase in MEDLINE and PubMed over the past 18 months since the PubMed system became operational (January 1997). When PubMed was planned, the ELHILL retrieval system was handling 500,000 queries per month; as a result systems designers planned for a load factor approaching 2 million. That figure was actually reached in May 1997, before the public announcement of the system. Currently PubMed is handling in a single day nearly the same number of queries ELHILL used to handle in an entire month. Usage continues to rise dramatically, at a doubling rate every 8 months. Dr. Benson said there are three components of the search response time as it appears to the user: the end user's local connectivity; the Internet communication paths; and the search processing capability at NLM. He described the NLM servers that provide "front-end" and "back-end" processing service for PubMed users. Several graphs showed the ebb and flow of queries from different countries over a 24-hour day. Currently, 80% of incoming PubMed queries are responded to in less than 4 seconds; 99.5% in less than 10. Dr. Benson also described the results from a Web monitoring service which measures the response time of the PubMed web site every 15 minutes from 30 different locations worldwide.

Mr. John Gage commented that these two reports were very well done. He said that you could see the importance of the "last little bit of connectivity between you and your Internet Service Provider." The numbers reported were remarkable: only 8 of 1,600 PubMed searches took more than 10 seconds. Mr. Gage "put them to the test" by downloading the NLM Home Page live on his own laptop computer (the time required was, in his words, "reasonable"). He described briefly how the capacity of the computer network grew over the years, e.g., a 1,000-fold increase from 1993 to 1997. Users are becoming "spoiled" and will not tolerate delays at their terminal. New processors are doubling the speed of systems every 9 months. Mr. Gage showed the Board the wireless connection that allowed him to download the NLM Home Page and he went on to demonstrate a variety of cutting edge devices, smartcards, and connections that he brought with him.

IX. REPORT OF THE ACTING ASSOCIATE DIRECTOR FOR EXTRAMURAL PROGRAMS

National Heart Attack Alert Program (NHAAP)

Dr. Milton Corn presented a brief overview of the National Heart Attack Alert Program. Approximately 250,000 heart attack victims die each year within an hour of heart attack. There is general acceptance that thrombolytic therapy, if given within the first hour, would provide a 30 percent savings of life. The cause for delay of treatment can be divided into three phases: recognition of symptoms by the patient or bystander; transportation of the victim to the hospital; and action taken by emergency department personnel. NLM, on behalf of NHLBI, has initiated a three-phase program to study application of medical informatics to this complex problem, which will include planning, modeling, and wide deployment. In FY 1988 eight planning awards will be made with a total budget of \$800,000. Proposals may address any aspect of the thrombolysis delivery problem.

Digital Libraries Initiative - Phase 2 (DLI-2)

The Digital Libraries Initiative involves broad multi-agency sponsored support for research related to the development and use of digital libraries. The total budget for this initiative will be approximately \$50 million over a 5-year period. The first phase of the initiative involved sponsorship by NSF, ARPA and NASA with six large multi-year awards made in 1994. A more extensive second phase began earlier this year as reported by Dr. Alexa McCray at the January Regents' meeting. NLM's involvement in the second phase intends to expand the pool of researchers involved in digital library research in the health care community. The UMLS and Visible Human Project datasets are available for use by the health-related applicants. Dr. Corn and Dr. McCray are the NLM members of the Project Management Group, composed of representatives of the sponsoring agencies.

International Training In Medical Informatics

As a result of NLM's Long Range Plan and consideration of NLM's role internationally, the Library is co-sponsoring with NIH's Fogarty International Center a new program in international

training in medical informatics in Africa. NLM's representative for this project is Dr. Elliot Siegel. Selection of three new awards by FIC will be made in FY 1998 with a total budget of \$400,000, with another \$350,000 expected from the Center for two or three additional awards in FY 1999. A wide range of proposals will be accepted from applicants involving U.S. or African-based training.

CLOSED PORTION OF MEETING - May 12, 1998, 2:15-2:45 p.m.

This portion of the meeting was closed to the public in accordance with the determination that it was concerned with matters except 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 Board reviewed 66 applications requesting \$25,420,371 and recommended 36 applications with a total cost of \$17,736,524.

X. SMART CARD TECHNOLOGY: OVERVIEW

Mr. Daniel A. Cunningham, President and CEO of the Smart Card Industry Association, used a Power Point presentation to give the Regents an overall picture of the state of development of smart cards. There are several types of smart cards: serial memory (no security); protected memory (limited security; most frequently used for storing value); and microprocessor-based (most secure). There are also various kinds of packaging: those requiring physical contact with a reader; contactless (from 1cm to 1m distance); hybrid (magnetic stripe and contact); and dual interface (contact and contactless on single chip). Chip technology is advancing, Mr. Cunningham said, and a new generation will have much more processing power and memory. New smart card readers are also on the market; he showed several, including one called a "Smarty" that looks like a 3.5-inch floppy disk and can be used in a PC. Smart cards have several advantages over competing technologies. They are portable, potentially very secure, they have increasing capacity, speed, and reliability, and they are flexible in that application can be added after the card is issued. Prices will continue to decline. Mr. Cunningham described several applications in use around the world: the serial memory card being used in the German health care system (80 million cards issued); the protected memory telephone application of US West; the US-Canada microprocessor card application for the Global System for Mobile Communications (GSM); and the contactless system for the Seoul bus system. He said that there are several reasons that other countries are more advanced than the United States

in their smart card applications: there is no Government telephone monopoly in the United States; there is no concentration of business firms in this country in such areas as banking; U.S. telecommunications networks are reliable and inexpensive, a disincentive for smart cards that eliminate online authorizations; in our political environment, the U.S. Government is unlikely to mandate a health care for all. Among the areas where smart cards are gaining a foothold in the United States: the GSM (mentioned above), digital satellite TV, Government programs (military, state social programs), colleges and universities, sports and entertainment, and mass transit (San Francisco is beginning this year). One significant recent development is New Jersey's plan to issue state driver's licenses that will have a chip, magnetic stripe, and barcode.

Following Mr. Cunningham's presentation, Mr. Daniel Maloney, Director of Technology Innovation at the Department of Veterans Affairs, said that in the health area, the smart card works with the network - -it is not independent. There are roles for both provider and patient cards: the former is involved with access and security; the latter is also, but in addition it can carry personal health information. Standardization of data content and technical interoperability are crucial elements in successful health care smart card applications. He said that the international G-7 Health Care Data Card Project is focusing on emergency data set and technical interoperability aspects. "Cardlink" is an international project that foresees personal health care data on a card that is translated into different languages as the person travels across borders - -the project has 10 pilots in 9 countries. Strong authentication over the network is another aspect. Health care providers and patients will be identified by individual private keys: when both enter their PIN, the system will operate. The role of the smart card in payment schemes has also yet to be worked out.

There was a general discussion of authentication, "fail-safe," and other security issues by the Regents. The possibility of abuse of patient data systems by those with criminal intent was discussed. It was said that there are no "ultimate" security measures. It is desirable to build in a number of safeguards or deterrents to prevent criminal action.

XI. GOVERNMENT COMPUTER-BASED PATIENT RECORD

Betsy Humphreys, NLM Assistant Director for Health Services Research, said that NLM has a strong interest in the development of health data standards that can be used in computer-based patient record systems to facilitate care, to support links to knowledge-based information from digital libraries, and to generate data that is useful for research and public health. The NLM's Unified Medical Language System is contributing to progress toward vocabulary standardization. Recently the DOD, VA, Indian Health Service, and Louisiana State University began a joint effort to establish a Government Computer-based Patient Record (GCPR). This project has great potential to advance clinical data standardization. NLM is collaborating on some of the data content and vocabulary aspects. Ms. Humphreys introduced Army Colonel Lynn Ray (DOD), Dr. Robert Kolodner (VA), and Dr. Richard Ferrens (LSU), who discussed their various roles in the project

using PowerPoint presentations.

Col. Ray said that the partnership made sense since there were duplicative efforts going on at various places. Based on the Persian Gulf illness, there was a Presidential directive that DOD and VA would cooperate in developing a comprehensive model medical record for their populations. A military medical tracking system has also been mandated by law. There are also economic pressures that encourage collaboration - it would be very burdensome for one agency to accomplish on its own. The first joint meeting of the partners was in January 1998. The stated goal is to share clinical information appropriately via a standard GCPR. Standards are necessary and, where they do not exist, the partnership will seek to establish them. Col. Ray said that other agencies that have the same goal may join the partnership. As a result of their meeting, the partners realized there was a joint need to address: common data models, common data representations, event triggers to read or write information, communications protocols, and security/privacy.

Dr. Ferrens spoke about the business characteristics of the GCPR. He emphasized the importance of providing flexible access by authorized caregivers to patient record data across the entire continuum of health care. The partners in the GCPR came to realize that there was no "one size fits all" solution. They hope to devise solutions that are "unobtrusive" to the patient/provider relationship. At the LSU Medical Center they have had some experience with systems that the patients did not like; others were more acceptable to patients but introduced delays in providing care. Simple and complex decision support at the point of care is another goal. The data generated from systems across large populations should allow comparative studies. Also, Dr. Ferrens said, it is important that the GCPR effort adhere to a vendor-independent, open systems architecture. This is perhaps the key technical underpinning of the entire project.

Dr. Robert Kolodner said that the partners first focused on the need to be able to exchange information among themselves and to provide access worldwide while protecting security. They are essentially commissioning a "new utility company" that will provide medical information. Like the long-distance phone company, it may use wires it doesn't own, but standards and security will be imposed as you connect in. Common data representation and common data elements among the partners are needed, including a knowledge representation scheme. The partners will be working with NLM and its Unified Medical Language System in the area of knowledge representation. Each of the partners will have information in the GCPR that will not be transmitted to, or accessible by, the others. We have to identify the "trigger events" that will allow exchanging information among the partners. It will be necessary also to identify the communications standards and protocols to be used. The GCPR project hopes to select a contractor in the coming months to help develop the new system. A statement of objectives has been issued, vendor proposals are due this summer, and we hope to issue a contract by October.

Dr. James Zimble said that it was extremely gratifying to hear the progress being made. Since 99% of VA patients come from the DOD, it never made sense to have noncommunicating programs. The

Uniformed Services University of the Health Sciences is hosting a program later this month on standards and the GCPR. General Klaus Shafer (USAF) said that the move is long overdue; dealing with problems such as the Persian Gulf illness and Agent Orange would have been much facilitated if records could have been shared. He said that agreeing on a unique patient identifier and selecting a master patient index would be most welcome. Ms. Wendy Baldwin said that since there are fewer barriers between cooperation of agencies like the VA and DOD she is optimistic about the prospects of the project. Local variations in language and standards make it extremely difficult to aggregate data and to make healthcare decisions and monitor outcomes. Agreeing to standards will help resolve this problem. Dr. Fuller suggested that the GCPR needs "an early win" to show the world that it is going to succeed; perhaps a decision support tool that would be complementary to patient-based information and would provide access to a shared knowledge resource (a single point of access to PubMed, or an integrated drug database, for example). Mr. Gage suggested that several terms should be key concepts in the GCPR project: "heterogeneity," "extensibility," and "multilingual." Even something as seemingly simple as agreeing on how to format and sort patients' names has to be carefully attended to. "Archival" is also a concept that must be a part of a GCPR system: every acquisition of data today must be readable by future devices. Ms. Michele Klein asked about the extent of NLM's involvement with the project. Dr. Kolodner said that the group has had discussions with Dr. Lindberg and Ms. Humphreys, and that there would be close collaboration involving not only the UMLS but other Library programs as appropriate.

XII. REPORT OF THE NOMINATING COMMITTEE

Dr. James Zimble, who headed a committee to nominate a Board Chair to replace retiring Dr. Michael DeBakey, placed in nomination the name of Dr. Tenley E. Albright, who was unanimously elected.

XIII. REPORT: OUTREACH AND PUBLIC INFORMATION SUBCOMMITTEE

[Before Subcommittee Chair Dr. Tenley Albright made her report, Dr. Michael DeBakey showed the Regents a short video about Dr. Albright produced by NBC in preparation for the recent Winter Olympics. The video mentioned that she was a supporter of the National Library of Medicine.]

Dr. Albright reported on yesterday morning's Subcommittee meeting. Among the subjects covered: the continuing publicity resulting from the "free MEDLINE" announcement, plans for updating the Lister Hill Center's auditorium, the planned announcement in December of completing the genome of the nematode *C. elegans*, the Board's letter to Secretary Shalala asking that she reverse her Office's disapproval of NLM's planned catalog for the Frankenstein exhibit, the new MEDLINE brochure (to be used in a pilot project in 30 public libraries) produced in cooperation with the Friends of the NLM, a report on the Friends' recent HII '98 conference, a planned hearing on the use of the Internet by seniors, the meeting of Visible Human applications designers in October, the

Internet connectivity study, and NLM outreach to Native Americans. Dr. DeBakey suggested to the Subcommittee that NLM might create a branch that would devote itself to consumer health information. The Subcommittee members strongly support the NLM's plans for a consumer health section on its Web site and offered the Board's assistance in speeding up its development.

Following Dr. Albright's report, Dr. George Nolan commented that he was pleased to see that House Speaker Gingrich went on record supporting the need to improve medical information services for inner city areas as much as for rural areas. Dr. Nolan applauded the NLM's role in arranging this. Dr. Steven Phillips said that the Outreach Subcommittee is like a "mini Board meeting," touching on many crucial issues facing the NLM. Dr. DeBakey thanked NLM staff Kathy Gardner and Bob Mehnert for their work in supporting the Subcommittee. Dr. Albright suggested that Regents who attend professional meetings might suggest, when asked to fill out an evaluation form, that future meetings include a presentation from the NLM and reports on new information technology.

XIV. UPDATE FROM THE NATIONAL CENTER FOR BIOTECHNOLOGY INFORMATION

Dr. Johanna McEntyre of the National Center for Biotechnology Information gave the Regents an update on the Human Gene Map. This information resource was first put up on the World Wide Web in October 1996. It is now being reorganized into two parts: the Gene Map (aimed at researchers) and Genes and Disease (aimed at students and the public). Dr. McEntyre described the information that appears on both sites. The recently completed second edition of the Gene Map contains markers and "unigene clusters" for over 30,000 distinct genes. Using a web connection, she demonstrated how a scientist might use the Gene Map to find information. The Genes and Disease site contains information about 60 diseases, both general and more specific information intended for nonexperts. She demonstrated the site to the Regents, showing how a variety of textual and graphic information could be found. It also offers links to other NCBI information resources, including PubMed, and to many outside sources of information on a particular disease.

Following Dr. McEntyre's presentation, Dr. Enriqueta Bond applauded NCBI's step in broadening the audience for its site on the human gene map. She said it was possible that NLM would need more resources to cope with the private sector's recently announced plan to speed up the sequencing the human genome and the resulting increase in data that would be generated. Dr. Mary Clutter said that NLM's challenge, in the face of the recent announcement, would be to continue to offer a high-quality value added database, such as GenBank. She added that the National Science Foundation is supporting a plant genome research program that would produce much information valuable to agriculture. They and the Department of Agriculture will be consulting NCBI scientists.

XV. TELEMEDICINE IN ALASKA

Dr. Michael Ackerman, NLM Assistant Director for High Performance Computing and Communications, is Assistant Project Officer for an NLM-sponsored telemedicine project in remote Alaska. He and the Project Officer, Dr. Sue Sparks, recently made a site visit. People tend to think of telemedicine as discussion across a TV link. NLM uses a broader definition, he said, namely that telemedicine is the use of communications to bring information together at a distance for the purpose of clinical decision-making. The NLM project in Alaska is north of the Arctic Circle; tremendous distances, tremendous cold (permafrost), and very small villages are involved. Modern technology and the discovery of oil are having a tremendous effect on native society. Two years ago cable TV (with programs picked up from satellite) came to those who were close enough to have a wire run to their house. One result of all this was a change from a nomadic existence to life in settled villages. All electronic communication is by satellite--whether from a village to Anchorage or from one village to another. Internet communication in Alaska is limited to a 56k link. In the early seventies, the NLM had several telemedicine projects with Alaska. Dr. Ackerman showed a video clip about one of those projects. Medicine in the villages is delivered by native health aides, by themselves or with the consultation of remote professionals, must be flown out by bush pilot. Dr. Ackerman described NLM's current telemedicine project. A PC with attached otoscope will be used to capture images of a patient's ear drum. The images will be sent via modem at 2400 baud (the highest speed possible over the communication links available) to the hospital at Kotzebue in order to diagnose ear infection more accurately. Dr. Ackerman showed the Board a series of slides from his visit and also "home movies" he took with a video camera.

XVI. RETIRING REGENTS

Dr. Lindberg presented copies of *The Selected Papers of John Shaw Billings* to the three retiring Regents: Dr. Marion Ball, Dr. George Nolan, and Dr. Michael E. DeBakey. He also presented a gavel to the retiring chair (Dr. DeBakey). Dr. DeBakey said that he has been pleased to serve the National Library of Medicine over the years on various boards and committees. The advances made by the NLM over the years, and the dedication of the people associated with the Library, have been remarkable. Dr. Steven Phillips noted, to the applause of the Regents, that this is Dr. DeBakey's 50th year in medicine.

XVII. ADJOURNMENT

The meeting was adjourned at 12:30 p.m.

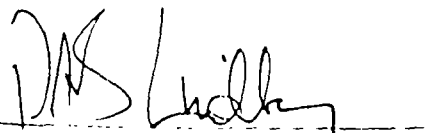
ACTIONS TAKEN BY THE BOARD OF REGENTS:

- The Board of Regents concurred with the recommendations of the Extramural Programs Subcommittee.
- The Board of Regents unanimously elected Dr. Tenley Albright as Chair for the coming year.
- Dr. DeBakey presented the Frank B. Rogers Award to Karen Sinkule of the Public Services Division (Library Operations) for "her foresight in the planning and implementation of the Conservation and Book Repair Laboratory in the National Library of Medicine, thus enabling scholars to use more items in the collection today and for many years to come."
- Dr. Lindberg presented the 1998 NLM Director's Award to two NLM employees: Patricia Williams, Administrative Officer, Division of Library Operations, "for outstanding and innovative administrative support for NLM's basic library services." Also receiving the award was Dr. James Ostell of the National Center for Biotechnology Information for "creative design and development of essential biomedical information resources."

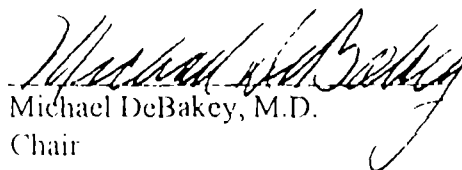
ATTACHMENTS:

- Roster - NLM Board of Regents
- May 11, 1998 - Extramural Programs Subcommittee Meeting
- May 12, 1998 - Subcommittee on Outreach and Public Information Meeting

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



Donald A. B. Lindberg, M.D.
Director
National Library of Medicine



Michael DeBakey, M.D.
Chair
Board of Regents, NLM