

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

**MINUTES OF THE BOARD OF REGENTS  
September 24-25, 1998**

The 119th meeting of the Board of Regents was convened on September 24-25, 1998, at 9:00 a.m. in the NLM Board Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), Bethesda, Maryland. The meeting was open to the public from 9:00 a.m. to 4:00 p.m., followed by the closed session for consideration of grant applications until 4:55 p.m. On September 24, the meeting was reconvened and open to the public from 9:00 a.m. until adjournment at 12:13 p.m. Dr. Tenley Albright presided as Chair.

**MEMBERS PRESENT**

Dr. Tenley Albright, Chair  
Dr. Jordan Baruch  
Dr. Enriqueta Bond  
Dr. Raymond Fonseca  
Dr. Sherrilynne Fuller  
Mr. John Gage  
Ms. Michele Klein  
Dr. Joshua Lederberg  
Dr. Herbert Pardes

**EX OFFICIO AND ALTERNATE MEMBERS PRESENT**

Dr. Mary Clutter  
Dr. James A. Zimble  
Ms. Wendy Carter, representing Dr. Kenneth Kizer  
Colonel Kristen Raines, representing Lt. Gen. Ronald Blanck  
Dr. Richard Rowberg, representing Dr. James Billington  
Mr. Keith Russell, representing Ms. Pamela Andre  
Captain William Wurzel, representing Vice Admiral Richard Nelson

**CONSULTANTS TO THE BOR PRESENT**

Dr. Marion Ball, First Consulting Group  
Dr. Steven Phillips, Iowa Heart Center-Mercy Hospital Medical Center  
Dr. Kenneth Walker, Emory University School of Medicine

**MEMBERS OF THE PUBLIC PRESENT**

Dr. Henry Lowe, University of Pittsburgh  
Ms. Dorothy Piravano, Public Communications, Inc.

**FEDERAL EMPLOYEES PRESENT**

Mr. Brian Kahin, Office of Science & Technology Policy  
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  
Ms. Nancy Bladen, NLM Associates Program  
Dr. Steven Bryant, National Center for Biotechnology Information, NLM  
Ms. Susan Buyer, Office for Health Information Programs, NLM  
Ms. Kimberly Caraballo, Committee Management Office, NLM  
Ms. Patricia Carson, Office of the Director, NLM  
Ms. Karen Casey, Office of Computer and Communications Systems, NLM  
Ms. Liza (Ming Wai) Chan, NLM Associates Program  
Mrs. Lois Ann Colaianni, Associate Director for Library Operations, NLM  
Ms. Joanne Correllus, NLM Associates Program  
Dr. Milton Corn, Acting Associate Director for Extramural Programs, NLM  
Ms. Rebecca Marni Dittma, NLM Associates Program  
Dr. Elizabeth Fee, Chief History of Medicine Division, NLM  
Ms. Kathleen Gardner, Office of Public Communications and Public Liaison, NLM  
Ms. Karen Hajarian, Acting Coordinator, NLM Associates Program  
Ms. Betsy Humphreys, Assistant Director for Health Services Research Information, NLM  
Ms. Bonnie Kaps, Committee Management Office, NLM  
Dr. Kenneth Katz, National Center for Biotechnology Information, NLM  
Dr. Lawrence Kingsland III, Assistant Director for Health Services Research Information, NLM  
Ms. Paula Kitendaugh, NLM Associates Program  
Ms. Eve-Marie Lacroix, Public Services Division, LO/NLM  
Ms. Sue Levine, Office of Financial Management, NLM  
Dr. Alex Lash, National Center for Biotechnology Information, NLM  
Dr. David Lipman, Director, National Center for Biotechnology Information, NLM  
Ms. Becky Lyon, National Network Office, LO/NLM  
Ms. Wei Ma, Office of Computer and Communications Systems, NLM  
Dr. Alexa McCray, Director, Lister Hill National Center for Biomedical Communications, NLM  
Mr. Robert Mehnert, Office of Public Communications and Public Liaison, NLM  
Mr. Michael Moore, Biomedical Files Implementation Branch, SIS/NLM  
Dr. Sharee Pepper, Office of Extramural Programs, NLM  
Mr. Donald Poppke, Executive Officer NLM  
Ms. Susan Rondon, NLM Associates Program

Ms. Julia Royall, Office for Health Information Programs, NLM  
Ms. Alberta Sandel, Office of the Director, NLM  
Mr. Ed Sequeria, Office of Computer & Communications Systems, NLM  
Ms. Mary Beth Schell, NLM Associates Program  
Ms. Peggy Schnoor, Office of the Director, Office of Science Policy, NIH  
Dr. Elliot Siegel, Associate Director for Health Information Program Development, NLM  
Ms. Elizabeth Smigielski, NLM Associates Program  
Dr. Melvin Spann, Associate Director for Specialized Information Services, NLM  
Mr. Roy Standing, Acting Director, Office of Computer & Communications Systems, NLM  
Dr. George Thoma, Chief Computer Services Branch, LHCBC/NLM  
Dr. Fred Wood, Office for Health Information Programs, NLM

### **I. OPENING REMARKS**

Board Chair Dr. Tenley Albright welcomed the Regents and guests to the 118<sup>th</sup> meeting of the Board of Regents of the National Library of Medicine. She noted that Secretary Shalala has appointed three new members: Henry Foster, M.D., Joshua Lederberg, Ph.D., and Herbert Pardes, M.D. Dr. Albright welcomed Dr. Lederberg and Dr. Pardes and noted that Dr. Foster will attend his first Board meeting in January 1999. She welcomed Board consultants Dr. Marion Ball, Dr. Steven Phillips, and Dr. Kenneth Walker, and also Ms. Dorothy Piravano of Public Communications, Inc.

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

The Regents approved without change the minutes of the May 12-13, 1998, meeting.

### **III. FUTURE BOARD MEETINGS**

The Board of Regents will meet next on January 26-27, 1999. Next spring's meeting will be May 4-5, 1999. The proposed date of September 28-29, 1999, was accepted for the meeting next fall.

### **IV. REMARKS BY THE DIRECTOR, NLM**

Dr. Donald A.B. Lindberg noted that, approaching the end of the fiscal year, the budget situation is uncertain. If an appropriation bill is passed, the outlook for NIH and NLM is good: the President's request for NLM is \$174,200,000; the House level is \$176,492,000; the Senate's is \$181,309,000. (NLM's FY 1998 operating budget was \$160,885,000.) Dr. Lindberg announced a major change in NLM's senior staff: the retirement of Lois Ann Colaianni, Associate Director for Library Operations since 1984. Ms. Colaianni is returning to California later this month to take on a special assignment, and will retire officially at the end of 1998. Among other major personnel actions: Fernando Burbano, Director of Information Services, has left NLM to become Chief Information Officer of the State Department; Karen B. Casey has been appointed Chief of the Information Collection Section in the Office of Computer and Communications Systems (OCCS); and Wei Ma has been appointed Chief of the Software Development Section in OCCS. Dr. David Lipman, Director of NLM's National Center for Biotechnology Information, introduced a new senior staff member of that

Division, Dr. Alex Lash, a pathologist with a special interest in imaging informatics. Dr. Lindberg briefly described the recently expanded NLM Library Associate Program for training recent library school graduates, and Ms. Karen Ginter, coordinator of the program, introduced to the Regents the eight new Library Associates for 1988-89. In the area of legislation, Dr. Lindberg mentioned briefly a bill recently introduced into the Congress that would affect how Federal agencies print their publications by recentralizing all publishing functions. The "Government Publications Reform Act" is opposed by the Administration and is unlikely to be acted on during this session, he said. As to legislation on the confidentiality of patient records, discussed by the Regents several times in the past, Dr. Lindberg said that there is nothing new to report. One aspect that has been much debated at NIH is if, when, and how to divulge personal information to patients that results from their participation in research and clinical trials. NLM's position is in favor of releasing information to patients who desire it. There was a discussion among the Regents of the pros and cons of this. The NLM Director next announced that the Library was about to make 13 awards to help public health officials get access to electronic health information via the Internet. The NLM is working with the CDC, other Federal agencies, the National Network of Libraries of Medicine (NN/LM), and associations of public health officials in a program called "Partners in Information Access." There is at least one award in each of the eight regions of the NN/LM. Dr. Lindberg noted that Dr. Michael E. DeBakey, immediate past Chairman of the Board, would be receiving the John P. McGovern Award for Science at the Cosmos Club in Washington, D.C. NLM will also be the site of an exhibit honoring Dr. DeBakey's 50 years of service at the Baylor College of Medicine. The NLM Director reported briefly on a meeting he attended to update the HHS Secretary's staff about telemedicine. He went over with the Regents some of the examples he used of successful telemedicine projects being supported by the NLM. On the subject of Next Generation Internet, Dr. Lindberg said the NLM is now an integral part of that multiagency program.

Following Dr. Lindberg's report, Dr. Sherrilyne Fuller said that the White House Committee on High Performance Computing and Communications (new name: President's Information Technology Advisory Committee), on which she serves, has just released an interim report on the future of HPCC. The Committee recommends that the Federal Government invest in basic research; health care is one of the areas addressed. Comments on the interim report are welcome (a final report will be issued next spring).

#### **V. UPDATE ON DIGITAL MANUSCRIPT PROJECT**

Dr. Alexa McCray, Director of NLM's Lister Hill National Center for Biomedical Communications and leader of the Digital Manuscripts Project, unveiled a new NLM Web site called "Profiles in Science" (<http://profiles.nlm.nih.gov>). An announcement has just been mailed to the press. The Digital Manuscripts project has been reported to the Board on previous occasions. The site has now been made public, with the papers of Oswald T. Avery (1877-1955) as the first collection. Dr. McCray showed the Regents a variety of the materials now accessible: the full text of several books about Avery, his seminal journal (1944) that proved that DNA from the nucleus of the cell is the genetic material, lab notebook pages, diary entries, photographs, etc. Dr. McCray then turned to

(new Regent) Dr. Joshua Lederberg, who donated much of the material to NLM. Dr. Lederberg described for the Board the tremendous significance of the work of Avery (along with collaborators Colin MacLeod and Maclyn McCarty). "By 1958, nobody doubted it; in 1944 nobody believed it. It represented a total revision of biological thinking." Dr. Lederberg noted that there are many more materials about Avery's career for which we are still trying to get copyright permission to include on the web. The '4 documents now in the web collection might expand to about 350. He ended his remarks by expressing his gratitude to the Library and to the staff who worked to create the new web site. Dr. McCray then gave a brief synopsis of Avery's life and demonstrated the web site for the Board.

Following the presentations and demonstration, Dr. Enriqueta Bond complimented the NLM on the fruitful collaboration that produced the "Profiles in Science" web site. She said a method was needed to develop a "list" of possible subjects for the site. There are many wonderful potential collections of scientific papers that should be assembled and put out on the web. Making this scholarly information available will help interest the public in science and how it is done. She noted that the technical hurdles are easier to overcome than the copyright issues. Are there ways we can get to scientists early enough to avoid some of these problems? Dr. Lederberg commented that if the copyright is held by a publisher, getting to them is easy, getting their permission is not so easy. If an individual holds rights to the material, getting to them is very difficult, but getting their permission is almost guaranteed. Dr. Lindberg commented that we are in contact with the Nobel Foundation to link future "Profiles in Science" subjects to the information they are assembling. Dr. McCray noted that we are also working with the Lasker Foundation to be able to link to information about scientists who are honored by them.

## **VI. AUTOMATING DATA ENTRY INTO MEDLINE**

Dr. George Thoma, Chief of the Lister Hill Center's Communications Engineering Branch, described the development of a production system that is now used routinely at NLM to prepare and enter bibliographic records for MEDLINE. An automated system for entering data into MEDLINE is highly desirable both because of the high labor costs associated with manual processing and because the amount of information continues to increase. Since MEDLINE adds about 40,000 citations each month there are great potential economies to be realized by automation. NLM looked at several existing systems that used some combination of manual keying, scanning, and optical character recognition (OCR), but we found that their experience was not directly transferable to the Library's situation. NLM adopted a gradualist approach: to combine OCR technology to enter the abstract (the largest part of a MEDLINE citation) with manual entry for all the other fields. The first phase system, named MARS (Medical Article Record System), was installed. In the first year after the installation of MARS, the daily production rate went from 67 a day to 600. Dr. Thoma described the three types of workstations and three servers that make up the initial production system, and using a visual schematic he outlined for the Regents the steps in document processing. One advantage of the system is that there is no fixed sequence of events in the workflow; operations can be done concurrently. Dr. Thoma showed slides of the scanning and keyboarding workstations being

used by operators. With the success of the first phase of MARS, attention is being turned to designing a database-driven system that would provide more comprehensive automation and a lower per-unit cost. This will be done by incorporating subsystems for autozoning, page segmentation, automatic field identification, automatic syntax reformatting, and developing a system for handling Greek letters and other symbols that OCR does not recognize. Dr. Thoma described how these changes will be approached through improvements in the present scanning, editing, and reconciling operations.

Following his presentation, Dr. Thoma answered several questions from the Regents about the system, including the kind of scanners used and how the fields on a page are identified automatically. Dr. Lindberg commented that NLM's goal is to have one third of MEDLINE citations prepared by Dr. Thoma's OCR system (already achieved, to receive one-third electronically from the publishers, and to do only one-third manually). Dr. Fuller said that NLM is making a contribution to the broader community with its efforts in this area; there will be many spin-off applications from this work, even beyond medicine and health care.

#### **VII. NLM REGENTS' AWARD**

Dr. Albright presented the 1998 Regents' Award for Scholarship or Technical Achievement to two NLM staff. Dr. George R. Thoma was cited for his "outstanding leadership in designing and implementing an automated data entry system for producing MEDLINE citation records." Dr. Steven H. Bryant of the National Center for Biotechnology Information was also presented the award for his "outstanding work in designing a molecular modeling database and for developing innovative approaches to protein structural comparisons."

#### **VIII. PUBLIC LIBRARIES AND CONSUMER HEALTH INFORMATION**

Becky Lyon, Head of NLM's National Network Office, gave a brief description of the pilot project NLM intends to launch on October 22. This is a joint effort with 40 public libraries to improve the public's access to health information. NLM's partners in the project are the National Network of Libraries of Medicine (NN/LM), the Friends of the NLM, the Kellogg Foundation, the Medical Library Association, and the Public Library Association (a part of the American Library Association). As the Board heard at their last meeting, the project was first announced at the April 1998 HII Conference in Washington, D.C. One prime determinant of NLM's embarking on this ambitious undertaking was the introduction last year of free MEDLINE searching via the Web and the enthusiastic response of users, including the public. As the Regents have heard, some 120 million searches a year are being done--one third by the public. Our main goal is to help public libraries meet the health information needs of consumers. Although 40 percent of the public have access to the Internet, some 60 percent still do not have access. We hope that we can reach them by working through the public libraries (a 1997 survey showed that 72 percent of the libraries had access to the Internet). Another goal of the project is to strengthen linkages between the public libraries and the members of the NN/LM. If the pilot project is successful, we hope to learn what resources might be required to begin a national program. Ms. Lyon described where the sites are

located (in three NN/LM regions) and the criteria used to select them to ensure that a variety of institutions were represented. One requirement was that the public library already be connected to the Internet. She noted that some of the 40 were actually local library systems, with numerous branch libraries. The total is well over 200. Each public library is matched with an NN/LM network library that will provide such services as training and advice, assistance with publicity, and document delivery. Representatives of most of the 40 libraries and systems met for two days at NLM in July. The visiting librarians learned about NLM and the project we were embarking on; NLM heard from each of the libraries briefly about their local situation. Dr. Tenley Albright attended the meeting and gave an enthusiastic presentation to the librarians on behalf of the Board of Regents. The visiting librarians also saw a demonstration of NLM's new consumer health information website, which was received with great excitement. NLM plans for evaluation were discussed. There were also two half-day training sessions: for *Internet Grateful Med* and *PubMed*.

Following Ms. Lyon's presentation, Eve-Marie Lacroix, Chief of the Public Services Division, demonstrated a prototype consumer health information service that is being proposed as an important addition to the NLM web site. It has been built using Oracle database and a web development tool called "Cold Fusion." It will be announced later in October at the same time the pilot public library project is inaugurated. Ms. Lacroix showed the various features of the new web site, including access to NIH consumer health information, medical dictionaries, clearinghouses, health-related organizations, and MEDLINE, for example. At present, it lists about 20 diseases and conditions ("Health Topics") to make it easy for the public to access. We expect this number to grow into the hundreds. One special feature is of the health topics is a "canned" (preformulated) search that goes out to search MEDLINE and returns current references and abstracts that would be useful to consumers.

Following the demonstration, Kathleen Cravedi of the NLM Office of Communications and Public Liaison described the public outreach and media aspects of the project. The name of the new project (announced last spring) is "Medical Questions? MEDLINE Has Answers." NLM is sending brochures and posters to the cooperating public libraries. A press release announcing the pilot project went out in July to the community press serving the local libraries. A number of the libraries have already indicated that they plan media events to announce the kickoff of the project on October 22. Ms. Cravedi said that a 28-second video news release featuring Dr. Michael DeBakey will be made available to the television stations in the local communities. A national press release will be issued on October 22 by the Library to announce the project. NLM will also provide help as needed to the local libraries for future community and media events. Ms. Cravedi introduced Dorothy Piravano, Senior Vice President of Public Communications, Inc., which is helping NLM with the media aspects of the project. Ms. Piravano said that this project is made to order for a "how-to kit" that will help the local librarians create outreach opportunities in their communities by organizing special events and dealing with the media. The advantage of a pilot project is that it allows you to test out your program and the how-to kit. NLM will be able to collect all their good ideas at the end

of the project and incorporate them into a future national campaign. She described how the manual will be organized and what it will contain.

Dr. Fred Wood, of the NLM Office of Health Information Programs Development, said that the evaluation component of a pilot project like this is extremely important. The basic objective of the evaluation is to inform NLM's future decision-making on whether and how to move ahead beyond the pilot project in the consumer health information and public libraries initiative. We also hope to learn about the effectiveness of the various health information resources demonstrated by Ms. Lacroix. Ultimately we will learn about the potential effect of such a program on the basic operation of the NLM and on the National Network of Libraries of Medicine. Dr. Wood described the various evaluation methods to be employed: focus groups, monitoring MEDLINE usage by some of the sites, and, possibly, a written survey. We have found that some of the libraries have an inadequate number of terminals or lack a high-quality Internet connection. Librarian training has also been identified as an important need. The focus groups we conducted in July with the public library participants were very successful; we must now concentrate on determining how to get further librarian feedback and some direct consumer feedback in the months ahead.

Following the staff presentations, Dr. Albright commented that she was impressed with the caliber of the public librarians assembled at NLM in July. Dr. Fuller, who has experience as a public librarian in providing health information for consumers, said that NLM's program to provide help for the public is a step in the right direction. Ms. Klein said that as a result of this pilot project, NLM should learn the types of information that consumers need, for example, information about wellness, fitness, patient education, illnesses, medical decision-making, self-help, etc. This will help NLM determine the kind of information resources it should be providing access to. Also, NLM's information will have to span the spectrum of reading levels. Dr. Zimble commented that physicians should be involved in this whole process. Whether the NLM likes it or not, it may wind up being perceived as a sort of "FDA for medical information." There needs to be explicit caveats about what is and what is not scientifically reviewed information. There are some caveats in place, but they do not go quite far enough. Also, he said, physicians need to know what their patients are looking at and the physicians need to be able to direct patients to the specific information they want them to have. Dr. Richard Rowberg of the Library of Congress commented that this is one of the most exciting projects ever to come out of the NLM. Although there is risk involved, there is much potential for having a positive impact on the Nation's health. He asked that since there are so many things involved when considering health impacts, how would NLM be able to disentangle them in its evaluation? Dr. Wood agreed that this is difficult, and that NLM would be considering the impacts on a site by site basis. Mr. Keith Russell (National Agricultural Library) said that he thought NLM's plans look extremely well thought out. The NAL is doing much the same thing for agricultural information, working with 22 land grant universities. He will get in touch with Ms. Lacroix to compare information and approaches. Ms. Wendy Carter (Department of Veterans Affairs) complimented NLM's approach in providing direct access to the information (as opposed



to referring to secondary sources). Dr. Steven Phillips suggested that many physicians themselves may access the site seeking information outside of their specialty.

#### **IX. REPORT FROM EXTRAMURAL PROGRAMS**

Dr. Milton Corn, NLM Associate Director for Extramural Programs reported on the Digital Libraries Initiative, Phase 2 (DL2), which concerns innovative digital libraries research and applications. The program extends the previously sponsored Research on Digital Libraries Initiative. The DEI-2 is administered by the National Science Foundation and is jointly sponsored by the National Science Foundation, the Defense Advanced Research Projects Agency, the NLM, the Library of Congress, the National Aeronautics and Space Administration, the National Endowment of the Humanities, and others. Of the 207 applications received, approximately 15 percent involved some aspect of health. The final review process will take place on September 30 at the National Science Foundation.

Dr. Corn also reported on NLM's involvement with the National Heart Attack Alert Project. He noted that thrombolytic therapy significantly improves survival rates for patients with acute myocardial infarction and improves the quality of life for the patients. However, despite much effort at education of the public and professionals, only a minority of heart attack victims receive this form of therapy. Following a symposium sponsored jointly by the National Heart, Lung, and Blood Institute, the Agency for Health Care Policy and Research, and the NLM, the Library published a Broad Agency Announcement intended to obtain contract research and development services related to the use of medical informatics as an approach to reducing or eliminating some or all of the various obstacles which are hindering the ability of the NHAAP to reach its goals. NHLBI transferred \$800,000 to NLM for the project. The project will be carried out in three stages: planning, modeling, and implementation. The current BAA called for planning proposals. Twenty responses were received and eight were selected for contract funding of the Phase I planning. Of particular interest to NLM was that some of the programs were looking at language issues and that two Hispanic communities are going to be involved, as well as elderly groups and lower socioeconomic groups. Diagnosis in women was another area of concern since classic symptoms are much less prevalent in women with acute heart attack. A discussion followed about treatment by emergency medical technicians and treatment received in an emergency department. Dr. Lindberg noted that failure by patients to recognize symptoms is a primary cause of delay in treatment. Dr. Corn pointed out that if the current rate of salvage of life could be raised from 20 percent to 30 percent there would be a significant increase in lives saved, and a valuable decrease in morbidity.

Another project he reported on is the Fogarty International Center's Program for Informatics Training. Following an international workshop at NIH on February 24, 1998, held by the NLM and the Fogarty International Center, the FIC announced a grant program calling for training projects designed to increase informatics expertise in sub-Saharan Africa. Short and long-term training programs both in Africa and the United States were eligible for consideration. For Fiscal Year 1998, U.S. applicants were required to have an African institution as partner; FIC offered to promote

liaisons for interested American organizations that lacked African connections. FIC made \$400,000 available with the goal of funding about four programs. NIAID will contribute an additional \$150,000. Eleven applications were received.

Dr. Corn also reported on an NLM-AHCPR Symposium on Training for Health Services Research. The Agency for Health Care Policy and Research recently announced awards for a number of grants in support of training for health services research. These programs are germane to the medical informatics training programs supported by NLM. Accordingly, NLM initiated a series of meetings with representatives of AHCPR resulting in plans for a symposium to explore opportunities for productive educational and research collaboration among training programs in medical informatics, health services research, and public health. Dr. Robert Beck, of Baylor, will chair the planning committee. NLM will be represented by Dr. Corn and Ms. Betsy Humphreys.

*Following Dr. Corn's presentation, Dr. Fuller applauded NLM and the efforts taken to partner with so many different agencies, resulting in an increased interest in informatics by those agencies and funding to support these efforts.*

#### **X. COPYRIGHT AND DATABASE PROTECTION LEGISLATION**

Dr. Brian Kahin, Senior Policy Analyst in the White House of the Office of Science and Technology Policy, said that the database protection issue is part of a larger copyright bill that is working its way through the Congress. He gave some background information about the historical basis of copyright protection for databases. Since a 1991 Supreme Court ruling there has been essentially no protection for collections of information that did not meet certain tests of originality and creativity. In 1996 a European database directive became effective and there has been a movement in Europe to pass a treaty under the auspices of WIPO (World Intellectual Property Organization). In the past year, a bill has been making its way through the Congress, the "Collections of Information Antipiracy Act." It was passed by the House in May 1998 and in August a bill was introduced into the Senate. The bill is opposed by the library, research, and information industry communities. The Administration articulated its position in a letter (August 4) to Senator Orrin Hatch (Chairman of the Committee on the Judiciary) from the General Counsel's Office in the Department of Commerce. There have been no Senate hearings yet. Dr. Kahin said that the bill is directed at preventing "market harm" against those who make a "substantial investment" into gathering, organizing, or maintaining data. There is no threshold for determining what is "market harm." The prospects for the bill are uncertain at this time.

There was a general discussion among the Regents about the effect such legislation would have on NLM's database activities. Dr. Lindberg commented that he had never seen such unanimity among Federal agencies in opposing the intent of legislation. The Board of Regents later considered and unanimously passed the text for a letter to the Secretary of Health and Human Services to go on record urging that hearings be held on the issue.

[Note: the antipiracy legislation was later passed and signed into law by President Clinton, after a House-Senate conference committee dropped the provision that would have given copyright protection to databases.]

**CLOSED PORTION OF MEETING - September 24, 1998 4:00-4:55 p.m.**

This portion of the meeting was closed to the public in accordance with the determination that it was concerned with matters exempt 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<sup>1</sup>**

The Board reviewed 57 applications requesting \$8,103,046.

**XII. SPECIAL RECOGNITION FOR LOIS ANN COLAIANNI**

Dr. Albright read a special certificate of appreciation from the Board of Regents for Mrs. Colaianni in honor of her service to the NLM as Associate Director for Library Operations. Dr. Lindberg then presented Mrs. Colaianni with the NLM Director's Award for "exceptional leadership and innovative contributions to the Library's programs." He briefly described some of the many advances and improvements in the programs of the Library Operations since her arrival at NLM. Mrs. Colaianni said that her 18-year experience at the NLM has been wonderful, and she thanked her "marvelous staff." She also thanked the NLM's leadership and the Board of Regents for their support.

**XIII. "IF YOU BUILD IT, WILL THEY COME?"**

Dr. Henry Lowe, Associate Professor of Medicine and Director of the Clinical Multimedia Laboratory, Section of Medical Informatics, at the University of Pittsburgh, reported on the Image Engine Multimedia Medical Record System project. He last reported to the Regents on this project two years ago. Multimedia electronic medical records integrate textual, numeric, imaging, and audio data in support of effective clinical decision making. It is, in effect, the "patient record of the future." There are several reasons to take this approach: medical data itself is inherently multimedia; the patient record is increasingly fragmented; and it presents an opportunity to implement a

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<sup>1</sup>Minutes prior to September 1998 included the number of both scored and non-scored applications. Since the BOR does not review non-scored applications, they will no longer be included in the minutes.

"clinician's workstation," something that has long been talked about. Existing electronic medical record systems are built on the technology of largely text-based business applications. Dr. Lowe said that we are now on the threshold of a clinical, real-time, physiological imaging revolution. That is, to be able to visualize what is going on inside an individual, combining anatomic and physiological information in a graphic way. This kind of data will be absolutely crucial for patient care in the 21<sup>st</sup> century. Also, our medical information systems should mirror the way we function cognitively - - most of us are very visual-oriented. Today's medical record is extremely fragmented: little but important bits of data are stored in many different places. Integration is thus a key component of the system he and his colleagues have built. The clinical workstation has to be ubiquitous, graphical, computer platform independent, inexpensive, probably Internet-based, and it must ensure comprehensive protection of patient data, he said. The overall goal of the clinical information system that can seamlessly integrate a wide range of important medical images with the textual parts of the medical record, and produce in real time the kind of data you need to support patient care. The project began in 1992, got its first award from NLM in 1994, and is now in the process of being adopted by the University of Pittsburgh Medical Center. The first implementation is in an image-intensive environment at the University's Cancer Center. Dr. Lowe then got online and demonstrated the system to the Regents. Among the research questions that we are answering: Can we build a reliable system that effectively integrates textual and imaging data? Can users retrieve the information they need? Does image compression affect clinical utility? Will clinicians use imaging data if it is readily available? What is the added value of images over reports? As to the technical evaluation, Dr. Lowe said that the robust Image Engine has met their technical goals. They found that image compression techniques, carefully applied, have no negative impact on diagnostic utility. He noted that physicians were not the primary users of the system; nurses and other nonphysicians retrieve the data and print it out for the physicians. The developers have to figure out how to get the physician "right up close" to the computer. This is especially important if the system is to be used for decision support, which depends on two-way interaction between the computer and the physician/operator. Dr. Lowe said they found that oncology data is very image-intensive and that large numbers of imaging studies are ordered by the physicians. Radiology images (especially CT scans) are the most frequently retrieved; pathology images, on the other hand, are not retrieved often. He discussed how oncologists use the stored images for assessing response to therapy, for measuring tumor mass, and for patient education, and teaching residents and fellows. One thing that needs yet to be determined is just which images need to be stored and for how long. As digital images become more accessible, physicians will acquire new skills and learn how to use them. One major "sociological" challenge is that data integration will be perceived as a loss of "data sovereignty" on the part of the specialist. Dr. Lowe said that there are still several issues that must be addressed: adding *all* patients to the Image Engine; providing *immediate* access to radiology images; providing secure, cross-platform, multi-site access (including home); and creating clinical information summaries. The developers are creating a "library database" of images that contains no patient identifiable data. It is being indexed using NLM's Unified Medical Language System (UMLS). To answer the question in the title of this presentation, Dr. Lowe said: "absolutely!" While there are

still issues to be solved, many clinicians are very enthusiastic users and evangelists of the Image Engine.

Following Dr. Lowe's presentation, Mr. Gage commented that the chips coming on the market will allow 10 to 100 times the current speed in image manipulation. Three-dimensional imagery will dramatically improve the ability to display and manipulate medical images in the next few years. The cost of terminal devices is dropping; as we move from "single board" to "single chip" the price will go down by a factor of 10. The hard part is what Dr. Lowe and his colleagues are doing--figuring out how to retrieve from these Balkanized, completely separate entities, each with different security regimes, the equivalent of a comprehensive patient record. Mr. Gage said it's the human part, not the technical part, that is most difficult. Dr. Lowe agreed that the socio-political and organizational issues were most challenging. Dr. Steven Phillips commented that the transplant specialists at the University of Pittsburgh might be very interested in having image data available in their clinic when they are seeing patients. Now that such a system has been developed, he said, the challenge is to get people to use it. Perhaps NLM should solicit suggestions for ways to do this. Dr. Lowe said that the most important barrier in making such systems ubiquitous is the issue of data security and patient information confidentiality. *We must* be able to guarantee to the patient that data will be protected. Dr. Kenneth Walker commented that administrators, who frequently make decisions about the adoption of such systems as Dr. Lowe's, need to be won over. If, as many say, each physician is "good at only one thing," he questioned the need for an extensive workstation that provides them with other information. The face to face interaction of (for example) the clinician with the radiologist is important to the ultimate benefit of the patient. Making this interface extremely easy from different locations should be one of the goals of the project, Dr. Walker said. Dr. Zimble discussed the desirability of patients being able to carry their own medical records; this is especially useful in the military where there are many sites of patient care.

### **XIII. REPORT OF SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION**

Dr. Albright reported briefly on yesterday morning's meeting of the Board of Regents Subcommittee on Outreach and Public Information. Mr. Mehnert, Ms. Cravedi, and Dr. Siegel reported to the Subcommittee on recent outreach activities, including several press announcements, publicity for next week's workshop on the Visible Human Project, a change in name of the NLM Office of Public Information (to Office of Communications and Public Liaison), activities surrounding the honoring of Dr. Michael DeBakey, NLM's asthma-related exhibit ("The Breath of Life") which opens next year, and the media activity concerning the upcoming public library initiative. Dr. Albright distributed to the Regents a collection of representative press clippings about the NLM. There were a number of suggestions from the Subcommittee members for improving outreach, including the possibility of putting a series of NLM-related graphics on the web so that Regents could pull them down and use them in presentations about the Library. Another suggestion was that the NLM hold a seminar or workshop for medical and science writers to let them know about the Library's programs and services. Former Regents Dr. Marian Ball and Dr. Steven Phillips, now serving as consultants, have offered to help NLM's outreach program between Board meetings. Dr. Phillips

suggested that the Committee needs more time to meet. Board members might wish to take an active part in some of the many events and activities that the NLM sponsors, he added.

#### **XIV. TOXNET WEB INTERFACE**

Mr. Michael Moore, Chief of the Biomedical Files Implementation Branch in the Division of Specialized Information Services, gave the Regents a brief description of the Toxicology Data Network (TOXNET) and how the new World Wide Web interface for it was developed. [Note: The Board received an Institute of Medicine report in September 1997 recommending improvements in NLMs toxicology information services, including a web interface.] TOXNET consists of 10 databases containing toxicological and environmental health information, primarily factual and peer-reviewed scientific data. Fee-based access to TOXNET has been in place since 1985; free access via the web has just been introduced. Mr. Moore described the contents of several of the key TOXNET databases. They are useful to a variety of audiences, including scientists, health professionals (including pharmacists), patients and the public, occupational and environmental health specialists, emergency medical treatment professionals, and health sciences librarians. After moving TOXNET to a new Unix platform and relocating it to NLM from a contractor's machine, the free web interface was made operational in August 1998. Mr. Moore then demonstrated the TOXNET system to the Board, using as examples searches on the Hazardous Substances Data Bank and the Toxic Chemical Release Inventory. They are accessible from the NLM home page ([www.nlm.nih.gov](http://www.nlm.nih.gov)) under the entry for Toxicology and Environmental Health Information Program. Although the web interface was released only in August, it is already being searched at double the rate of the traditional command-language searching. Many positive comments are being received from users, Mr. Moore said. Future enhancements to TOXNET include a more robust search engine that will allow cross-file searching, access to TOXLINE and ChemID (now on another system), natural language queries, relevancy ranking, results formatting, and direct links to other environmental information resources.

Following Mr. Moore's presentation, Dr. Kenneth Walker said that TOXNET databases contain data of immense value and that the present search system is an elegant solution to the problems of the former search system. He also commented that the agenda for this Regents' meeting has a recurrent theme of outreach: the digital manuscript project, the public libraries and consumer health program, the image engine project at the University of Pittsburgh, and the TOXNET/web item. Toxicology is perhaps the most important global problem today and it is clear that these information resources will grow tremendously in the next few years and that they will be very valuable tools for Government planners, healthcare workers, etc. He ended by saying that this work, in a sense, memorializes Dr. Charles Walker, who strongly advocated NLM outreach to the Mississippi delta area to help them address the many environmental threats they face there.

#### **XV. COBWEBS AND COMMUNICATION IN AFRICA**

Julia Royall, a Special Expert in the Office of Health Information Programs Development, subtitled her report "Snapshots of Change in Africa." It is an account of her visit to malaria research sites in

Africa in the spring 1998. The visit was in connection with NLM's work with the Communications Working Group of the Multilateral Initiative on Malaria (MIM). Dr. Elliot Siegel has reported to the Board in the past about this program. Ms. Royall briefly recounted the toll malaria takes on the people of Africa. Forty percent of the rural population is at risk of infection. There are 1.5 to 2.7 million deaths each year from malaria, 90 percent of them in Africa. Mass insecticide programs are ineffective; there is increased resistance to drugs on the part of the malaria parasite; and there are ecological and environmental changes. MIM has as its objective to combat morbidity and mortality of malaria through research and also to build capacity among African scientists. Dr. Siegel chairs the MIM Communications Working Group. Using photographs she took, Ms. Royall reported to the Board on her work to conduct site assessments of the communications technology in place and the research being done at field sites in Kenya and Tanzania. One special success story is in Mali, where a microwave link allows a connection from the Malaria Research and Training Center to the ISP, and thus there is full communication for researchers there, with each other and with colleagues around the world, as well as literature and database searching. At rural locations, Internet connections can be nonexistent or slow, ranging from 300 to 9600 bps. From the ISP to the world, the connections are 28.8 kbs. She described the facilities and capabilities of the various sites she visited. Early in 1999, some of the staff from Mali will come to NLM for training. NLM's work in improving their telecommunications and information infrastructure has the potential to lessen the toll in Africa from this dread disease.

#### **VXI. ADJOURNMENT**

The meeting was adjourned at 12:13 p.m.

#### **ACTIONS TAKEN BY THE BOARD OF REGENTS:**

- The Board of Regents concurred with the recommendations of the Extramural Programs Subcommittee.
- Dr. Albright presented the NLM Regents' Award for Scholarship or Technical Achievement to Dr. George Thoma for his "outstanding leadership in designing and implementing an automated data entry system for producing MEDLINE citation records" and to Dr. Steven H. Bryant for his "outstanding work in designing a molecular modeling database and for developing innovative approaches to protein structural comparisons."
- A Resolution of Appreciation for Lois Ann Colaianni was adopted by the Board of Regents acknowledging on behalf of the U.S. medical and health communities a debt of gratitude to Ms. Colaianni for seventeen years of outstanding service to the National Library of Medicine and to the Nation.

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- Dr. Donald Lindberg presented Mrs. Colaianni with the NLM Director's Award for "exceptional leadership and innovative contributions to the Library's programs."
- The Board of Regents unanimously passed the text for a letter to the Secretary of Health and Human Services to go on record urging that hearings be held on the "Collections of Information Antipiracy Act."

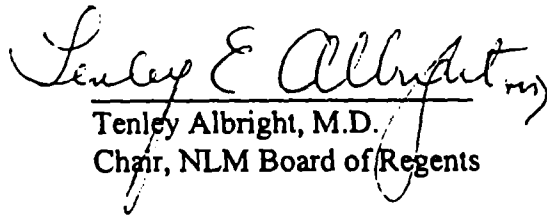
**ATTACHMENTS:**

- Roster - NLM Board of Regents
- September 23, 1998 - Extramural Programs Subcommittee Meeting
- September 24, 1998 - Subcommittee on Outreach and Public Information Meeting
- August 4, 1998, letter to Senator Orrin Hatch from the General Counsel's Office, Dept. Of Commerce, regarding "Collections of Information Antipiracy Act."
- September 25, 1998, letter to Secretary Donna Shalala, HHS, from Dr. Tenley Albright, Chair, NLM Board of Regents, regarding the Board's position on the "Collections of Information Antipiracy Act."
- Resolution of Appreciation for Lois Ann Colaianni

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



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



Tenley Albright, M.D.  
Chair, NLM Board of Regents