# The NLM and Grateful Med: Promise, Public Health, and Policy

# Donald A.B. Lindberg, MD

With the good news that medical knowledge was expanding rapidly after World War II came some bad news: by the early 1960s, a vast amount of new biomedical information was not reaching those who needed it most—researchers, educators, and practicing health care professionals.

In 1965, the President's Commission on Heart Disease, Cancer, and Stroke, chaired by pioneer heart surgeon Dr. Michael DeBakey, set as a goal "to achieve fingertip control of the literature, of all that is known about the causes, treatment, and prevention of heart disease, cancer, and stroke, and to make this knowledge available to researchers, educators, and practitioners." One outcome of this Commission was the Medical Library Assistance Act of 1965, which, among other things, called for the creation of a nationwide cooperative arrangement among health science libraries. The eight-region National Network of Libraries of Medicine is the result (see box).

The need was to develop new information technologies to automate library services and make them widely available. Since then, numerous developments in access to medical information have had a profound impact on medical practice, consumer knowledge, and public health and raise important policy questions.

An important first step in making the medical literature more available

was the development of MEDLINE, which, today, is the most comprehensive, up-to-date source of computerized medical information in the world. Launched by the National Library of Medicine in 1971, MEDLINE has long allowed physicians all over the world to keep current on medical research and to track down treatments for rare diseases.

Early on, professionals relied on medical librarians for help in retrieving this electronic information. In 1986, MEDLINE became more generally accessible when NLM unveiled software known as Grateful Med (a title which may bring to mind but does not reference either the musical group the Grateful Dead or the bibli-

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cal quotation from which it took its name). The new software could be used on personal computers to search MEDLINE and other NLM online databases.

Health professionals throughout the United States (and in many other countries) now had immediate access through modems to current databases containing some 20 million references to the world's biomedical literature, all housed at the NLM. While MED-LINE is the most frequently used NLM database, Grateful Med software also provides access to databases for specialized areas of public health such as cancer, AIDS, and environmental health. Last year, some 7.3 million searches were conducted on the NLM online databases, more than half of them for treating patients, and the rest by scientists and for education and training purposes.

Today, the NLM is making MED-LINE and other services accessible on the Internet. We have a program to provide funds to help medical institutions—including small hospitals and freestanding clinics as well as large medical centers—connect to the Internet.

In April 1996, at a medical conference sponsored by the Friends of the National Library of Medicine at Georgetown University, Dr. Michael DeBakey and Senator and heart surgeon Bill Frist (R-TN) demonstrated the NLM's most recent technological innovation, Internet Grateful Med, a software program that allows anyone with Internet access to search MED-LINE and other databases with a rapidity and degree of flexibility never before possible. By logging on to the NLM Grateful Med Internet site, researchers gain access to MEDLINE data and records that are compiled at the NLM. Researchers no longer need to purchase or upgrade individual copies of Grateful Med software.

As expected, Grateful Med's first applications have been clinical and have had a large impact on patient care. For example, doctors outside of major medical centers can now easily access crucial information to treat unusual symptoms. One physician in a remote Alaska town had a patient who could not taste or smell. Through a MEDLINE search using Grateful Med, he found 20 useful citations, determined that allergies could be the cause, and used drug therapy to alleviate the symptoms.

A doctor in Watertown, New York, baffled when an otherwise healthy patient became beet red on one side of his body and chalky white on the other whenever he exercised, discovered through Grateful Med articles describing an extremely rare condition called harlequin syndrome,



Jean Hoffman Anuta used the National Library of Medicine's collection of medical research to find medical treatments that eventually helped her and her husband, Michael Anuta, have a baby, I I-month-old Sam, at left. Big brother Michael, age 7, watches as his mom uses a laptop computer that can now reach the library's collection on the Internet.

which he was then able to treat. And a general internist at Nanticoke Memorial Hospital in Seaford, Delaware, who specializes in the care of patients with AIDS is frequently challenged with unfamiliar AIDS-related problems. When the usual treatment failed to relieve a patient's abdominal pain, he ran an AIDSLINE search and was able to retrieve needed treatment information.

Grateful Med users are not limited to physicians; many individuals have used its databases to obtain clinical information on their own. A Maryland woman, heartbroken after experiencing six first-trimester miscarriages, consulted Grateful Med and discovered a way to prevent these recurrent losses. She and her husband now have a healthy 14-month-old son. And a Chevy Chase, Maryland couple, Augusto and Michaela Odone, researched MEDLINE for nearly six months to uncover a cure for their son's rare inherited illness—a search that became immortalized in the movie *Lorenzo's Oil*.

Grateful Med is also becoming increasingly important in the public health arena, where the databases are being used to assess or prevent toxic emergencies, to improve care in medically underserved or remote areas, and to prevent and treat disease in disenfranchised populations.

Several years ago, a large tractortrailer carrying a variety of chemicals was involved in an accident on Interstate 95 in Howard County, Maryland. A county Fire Department searcher trained in using the NLM's online TOXNET system was able, with the information he found there, to help the site emergency team safely remove the chemicals. The information was credited with averting a major explosion and fire that might have occurred with the release of hydrogen fluoride, chlorine, and other toxic fumes. Following this incident, the Fire Department Commander had all his firefighters trained to contact TOXNET.

In another instance, a chemical warehouse in a densely populated area in New York City was found to contain more than 100 different explosive chemicals, poisons, and air- and water-reactive chemicals in old boxes and other containers. Hazardous waste disposal teams were afraid to move any of these chemicals because of the potential for fire and the overall condition of the warehouse. To learn how to best remove the various chemicals,

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health personnel searched NLM's Hazardous Substances Data Bank and forwarded information describing each chemical to New York authorities. The chemicals were safely removed.

Grateful Med has also been instrumental in the assessment and alleviation of illness affecting large populations. In 1992, in La Plata, Argentina, it was discovered that all those afflicted with an unknown but deadly illness had been taking propoleum, a nonprescription natural product derived from bees. Widely used in Argentina as a heal-all, propoleum is found in a variety of forms, from candies to syrups. Chemical analysis

The following is a list of the Regional Medical Libraries and the areas served by each:

## 1. MIDDLE ATLANTIC REGION

New York Academy of Medicine 1216 Fifth Avenue New York NY 10029 Tel. 212-876-8763 Fax 212-534-7042 E-mail <rml1@nyam.org> URL http://www.nnlm.nlm.nih.gov/mar States served: DE, NJ, NY, PA NATIONAL ONLINE CENTER FOR ALL REGIONS

2. SOUTHEASTERN/ATLANTIC REGION University of Maryland at Baltimore Health Sciences Library 111 South Greene Street Baltimore MD 21201-1583 Tel. 410-706-2855 Fax 410-706-0099 URL http://www.nnlm.nlm.nih.gov/sar States served: AL, FL, GA, MD, MS, NC, SC, TN, VA, WV, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands

#### 3. GREATER MIDWEST REGION

University of Illinois at Chicago Library of the Health Sciences (M/C 763) 1750 W. Polk Street Chicago IL 60612-7223 **Tel.** 312-996-2464 **Fax** 312-996-2226 **URL** http://www.nnlm.nlm.nih.gov/gmr States served: IA, IL, IN, KY, MI, MN, ND, OH, SD, WI

#### 4. MIDCONTINENTAL REGION

University of Nebraska Medical Center Leon S. McGoogan Library of Medicine 600 South 42nd Street Omaha NE 68198-6706 Tel. 402-559-4326 Fax 402-559-5482 URL http://www.nnlm.nlm.nih.gov/mr States served: CO, KS, MO, NE, UT, WY

#### 5. SOUTH CENTRAL REGION

Houston Academy of Medicine-Texas Medical Center Library 1133 M.D. Anderson Boulevard Houston TX 77030-2809 Tel. 713-790-7053 Fax 713-790-7030 E-mail <nnlm@library.tmc.edu> URL http://www.nnlm.nlm.nih.gov/scr States served: AR, LA, NM, OK, TX

## 6. PACIFIC NORTHWEST REGION

Health Sciences Libraries and Information Center Box 357155 University of Washington Seattle WA 98195-7155 Tel. 206-543-8262 Fax 206-543-2469 E-mail <nnlm@u.washington.edu> URL http://www.nnlm.nlm.nih.gov/pnr States served: AK, ID, MT, OR, WA

### 7. PACIFIC SOUTHWEST REGION

University of California, Los Angeles Louise M. Darling Biomedical Library 12-077 Center for the Health Sciences Box 951798 Los Angeles CA 90095-1798 Tel. 310-825-1200 Fax 310-825-5389 URL http://www.nnlm.nlm.nih.gov/psr States served: AZ, CA, HI, NV, and U.S. Territories in the Pacific Basin

#### 8. NEW ENGLAND REGION

University of Connecticut Health Center Lyman Maynard Stowe Library 263 Farmington Avenue Farmington CT 06030-5370 Tel. 860-679-4500 Fax 860-679-1305 URL http://www.nnlm.nlm.nih.gov/ner States served: CT, MA, ME, NH, RI, VT determined that diethylene glycol had somehow been substituted for propylene glycol, the typical solvent used in the syrup. A toxicology institute in Buenos Aires contacted NLM's TOXNET to determine the toxicity of diethylene glycol and approaches to medical treatment. By this time, there had been 23 deaths, hundreds experiencing symptoms, and thousands of inquiries from citizens. TOXNET information not only confirmed the toxicology institute's findings but provided needed information for treatment and follow-up.

Another important use of the new medical information technology has been in improving the care of underserved populations. In 1990, the NLM established a partnership with Sister Anne Brookes, a Mississippi nun and physician who, with a small staff, offers medical, educational, and social services in an area declared by Congress to be the poorest in the nation. Initially, NLM provided Dr. Brooks with a modem and free use of Grateful Med and the online databases. When it became apparent that, like other rural health care providers, Dr. Brooks traveled through a wide territory, NLM provided a laptop computer that she could use to search for information from wherever she was located.

In the area of infectious diseases such as AIDS, such databases as AIDSLINE, AIDSDRUGS, and AIDSTRIALS, all accessible via Grateful Med, provide computerized up-to-date information for patients, their families, and health care providers about the prevention and treatment of AIDS, clinical trials, and drug therapies. A particularly urgent need is for the dissemination of such information to the disadvantaged groups in this country-gays, lesbians, Hispanics, and African Americanson which the disease takes a disproportionate toll. The NLM is funding projects nationwide to provide or improve access to electronic AIDSand other health-related information for patients and their affected communities. For example, building on an existing collaboration with historically

black colleges and universities, the NLM is funding training of health professionals working closely with communities of color heavily affected by AIDS. Emphasis has also been placed on community-based organizations or patient advocacy groups and public libraries. Last year, the Library made 19 awards to enable local groups to design their own programs for improving access to AIDS informa-

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tion by patients, caregivers, and the general public.

In conclusion, the increasing access to high speed computers and communications by consumers, health care providers, public health professionals, and scientists is having a fundamental impact on health and human services throughout the nation. The NLM is investing in medical application that make use of these technologies. The applications, which all involve the latest information and communications technology, are in such areas as telemedicine, model networks for health care, computer-based patient data, integrating access to health-related information, medical linguistics, and health services research. These projects are being carried out at universities and nonprofit research institutions with funds provided by the NLM.

Increased use of these technologies, however, also creates public policy issues concerning access and privacy. These issues are not insurmountable, but they need to be addressed.

Regarding access, there are far too many health professionals in this country who are not aware that such programs as Grateful Med can be of immense benefit in their work. We must work together, at all levels of government, to provide professionals with access to up-to-date medical information-without regard to where they are located or to the time of day. To that end, the NLM is publicizing its services through exhibits, brochures, videos, and television public service announcements. Such publicity efforts must be greatly increased in number and scope if the health professional community is to realize the extensive benefits of accessing the latest biomedical information. An important step in increasing awareness will be identifying technical, behavioral, or financial impediments to the use of computerized biomedical databases.

In addition, sending medical information such as individual patient records over the Internet, we are quite aware, will warrant Federal legislation to assure medical data privacy, or at least confidentiality. To this end the NLM is supporting several studies by the National Academy of Sciences that should be released publicly later this year. We hope they will provide important background concerning practical measures to protect data privacy as well as suggestions for methods to evaluate the medical and social worth of using the Internet.

Dr. Lindberg is the Director of the National Library of Medicine.

Internet Grateful Med can be accessed by going to the World Wide Web address <http://igm.nlm.nih.gov> and opening an account with the National Library of Medicine. Signing up is free, but users are charged an online fee that averages \$2.00 per search.

Address correspondence to Dr. Lindberg, National Library of Medicine, 8600 Rockville Pike, Bethesda MD 20894; tel. 301–496–6221; fax 301–496–4450; e-mail <lindberg@nlm.nih.gov>.