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**ON BEHALF OF THE
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**REGARDING FISCAL YEAR 2011 APPROPRIATIONS FOR THE
NATIONAL INSTITUTES OF HEALTH'S
NATIONAL LIBRARY OF MEDICINE**

**SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATION'S SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED
AGENCIES**

FRIDAY, APRIL 16, 2010

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2011:

- 1) CONTINUE THE COMMITMENT TO THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL LIBRARY OF MEDICINE (NLM) BY INCREASING FUNDING LEVELS 12% TO \$35 BILLION FOR NIH AND \$402 MILLION FOR NLM**
- 2) CONTINUE TO SUPPORT THE NIH PUBLIC ACCESS POLICY, WHICH REQUIRES THAT ALL FINAL, PEER-REVIEWED MANUSCRIPTS ARE MADE AVAILABLE THROUGH NLM'S PUBMED CENTRAL DATABASE WITHIN 12 MONTHS OF PUBLICATION, AND SUPPORT THE ESTABLISHMENT OF SIMILAR POLICIES IN OTHER FEDERAL AGENCIES**
- 3) CONTINUE TO SUPPORT THE MEDICAL LIBRARY COMMUNITY'S IMPORTANT ROLE IN NLM'S OUTREACH, TELEMEDICINE, DISASTER PREPAREDNESS AND HEALTH INFORMATION TECHNOLOGY (HEALTH IT) INITIATIVES AND THE IMPLEMENTATION OF HEALTH CARE REFORM**

On behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL), thank you for the opportunity to present testimony regarding FY 2011 appropriations for the National Library of Medicine (NLM).

MLA is a nonprofit, educational organization with approximately 4,000 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

AAHSL is composed of the directors of 116 libraries of accredited U.S. and Canadian medical schools, as well as 28 associate members. AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health practitioners is trained in information seeking skills that enhance the quality of information delivery.

Together, MLA and AAHSL address health information issues and legislative matters of importance through a joint legislative task force and a Government Relations Committee.

1. THE IMPORTANCE OF ANNUAL FUNDING INCREASES FOR NLM.

We are pleased that the FY 2010 Appropriations package contained funding increases for NIH and NLM and bolstered their baseline budgets. We encourage the Subcommittee to continue to provide meaningful annual increases for NIH and NLM in the coming years, and recommend a 12% increase for FY 2011.

Recovery funding and the FY 2010 budget increases stimulated the economy and biomedical research. In the case of NLM, Recovery Act funding allowed timely and much needed increases in support for leading edge research and training in biomedical informatics—the kinds of programs that will influence future developments in health information technology. In FY 2011 and beyond, it will be critical to augment NLM's baseline budget to accommodate expansion of its information resources, services, and programs, which must collect, organize, and make accessible rapidly expanding volumes of biomedical knowledge, including the influx of data from high-throughput genome sequencing systems and genome-wide association studies. Increased funding will also position NLM to strengthen its contributions to successful implementation of recent Congressional priorities related to health care reform, health information technology, drug safety through its efforts to: enhance access to the results of comparative effectiveness research, maintain and disseminate health information technology standards, and to expand its clinical trial registry and results database in response to legislative requirements.

GROWING DEMAND FOR NLM'S BASIC SERVICES

As the world's foremost digital library and knowledge repository in the health sciences, NLM provides the critical infrastructure in the form of data repositories and online integrated services, such as GenBank and PubMed that are helping to revolutionize medicine and advance science to the next important era which includes individualized medicine based on an individual's unique genetic differences. PubMed, with more than 20 million citations to the biomedical literature, is the world's most heavily used source of information about published results of biomedical

research, and GenBank, with its international partners, has become the definitive source of gene sequence information. Their content continues to grow, as does their usage by medical librarians, biomedical researchers, clinicians, students, and the public. New resources, such as the Sequence Read Archive and database of Genotypes and Phenotypes enable NLM to collect, organize, and make available for research the incredible volumes of data flowing from high-throughput genome sequencing machines and from genome wide association studies that aim to link genetic variations to specific diseases and conditions.

As the world's largest and most comprehensive medical library, services based on NLM's traditional and electronic collections continue to steadily increase each year. These collections stand at more than 11.4 million items-books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare. Without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients have come to expect.

2. SUPPORT AND EXTEND PUBLIC ACCESS

The Appropriations Committee has shown unprecedented foresight and leadership by using the annual spending bills as the vehicle to establish a mandatory public access policy at the NIH. This highly beneficial policy, which requires all NIH-funded researchers to deposit their final, peer-reviewed manuscripts in NLM's PubMed Central database within 12 months of publication, is improving access to timely and relevant scientific information, stimulating discovery, informing clinical care, and improving public health literacy. We ask the Committee to remain a strong voice in support of the NIH policy, and to support the extension of public access policies to other federal science and education agencies. MLA and AAHSL strongly support the expansion of public access policies to other agencies, because it would bring the benefits of public access to other fields of research and because research in other fields is increasingly relevant to biomedicine.

3. SUPPORT AND ENCOURAGE NLM PARTNERSHIPS WITH THE MEDICAL LIBRARY COMMUNITY.

Outreach and Education

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general public about NLM's services and to train them in the most effective use of these services. NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. One example of NLM's leadership is the "Partners in Information Access" program, which is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well

positioned to ensure that every public health worker has electronic health information services that can protect the public's health.

NLM is also at the forefront of efforts to provide consumers with trusted, reliable health information. With help from Congress, NLM, NIH and the Friends of NLM, launched NIH *MedlinePlus Magazine* in September 2006. This quarterly publication is distributed in doctors' waiting rooms, and provides the public with access to high quality, easily understood health information. Its readership is now estimated at 5 million people nationwide and is poised to grow thanks to the launch of a Spanish/English version, *NIH MedlinePlus Salud* in January 2009. NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus "information prescriptions" to their patients, directing them to relevant information on NLM's consumer-oriented MedlinePlus information system. This initiative also encourages genetics counselors to prescribe the use of NLM's Genetic Home Reference website. A growing number of clinical care organizations are implementing specific links to MedlinePlus from electronic health record systems as an effective way to provide patient-specific educational materials and to achieve an emerging criterion for achieving meaningful use of health IT.

NLM also provides access to information about clinical research. Launched in February of 2000, ClinicalTrials.gov lists more than 88,000 U.S. and international trials for a wide range of diseases. The clinical trials database is a free and invaluable resource to patients and families who are interested in participating in cutting-edge treatments for serious illnesses. In recent years, it has become an even more valuable resource for patients, clinicians, researchers, and others. In response to the Food and Drug Administration Amendments Act of 2007, NLM quickly expanded ClinicalTrials.gov to accept summary results of clinical trials, including adverse events. Such information is not available systematically from other publicly accessible resources, and all too often is not published in the scientific literature. As of April 2010, more than 1600 results records had been posted in the database, with more than 100 additional records being submitted each week.

MLA and AAHSL applaud the success of NLM's outreach initiatives, particularly those initiatives that reach out to medical libraries and health consumers. We ask the Committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in FY 2011.

EMERGENCY PREPAREDNESS AND RESPONSE

MLA and AAHSL are pleased that NLM has established a Disaster Information Management Research Center to expand NLM's capacity to support disaster response and management initiatives, as recommended in the *NLM Board of Regents Long Range Plan for 2006-2016*. Presently, libraries are a significant, but underutilized resource for community disaster planning and management efforts, which NLM can help to deploy.

Following Hurricane Katrina, NLM worked with health sciences libraries across the country to provide health professionals and the public with access to needed health and environmental information by: 1) quickly compiling web pages on toxic chemicals and environmental concerns; 2) rapidly providing funds, computers and communication services to assist librarians in the field who were restoring health information services to displaced clinicians and patients; and 3)

rerouting interlibrary loan requests from the afflicted regions through the NLM. More recently, in response to the earthquake in Haiti, NLM developed and posted a Health Resources for Haiti web page, within a week of the earthquake, with information in English and Haitian Creole. It also activated the emergency access initiative it had developed with libraries and American publishers to make available free full-text articles from hundreds of biomedical journals and reference books for medical teams responding to the disaster. NLM also deployed a system it had developed for use in the National Capitol Region to assist in reunifying family members who were separated during the earthquake, sharing information with other lost - person finder systems, such as those set up by Google, CNN, and the International Red Cross.

Such initiatives demonstrate the role that NLM can play in emergency preparedness and response. We ask the Subcommittee to show its support for this initiative, which has a major objective of ensuring continuous access to health information and effective use of libraries and librarians when disasters occur.

HEALTH IT AND BIOINFORMATICS

NLM has played a pivotal role in creating and nurturing the field of medical informatics, which is the intersection of information science, computer science and healthcare. Health informatics tools include computers, clinical guidelines, formal medical terminologies, and information and communication systems. For nearly 35 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country. Many of the country's exemplary electronic and personal health record systems benefited from NLM grant support.

The importance of NLM's work in health IT continues to grow as the nation moves toward more interoperable health IT systems. A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free US-wide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records. It has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems.

MLA and AAHSL encourage the Subcommittee to continue their strong support of NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also supporting health information technology initiatives in ONCHIT and the Agency for Healthcare Research and Quality that build upon initiatives housed at NLM.

BUILDING AND FACILITY NEEDS

The tremendous growth in NLM's basic functions related to the acquisition, organization and preservation of an ever-expanding collection of biomedical literature, combined with its growing contributions to health care reform, health information technology, drug safety, and exploitation of genomic information is straining the Library's physical resources. NLM now houses 1,100 staff in a facility built to accommodate only 650. This increase in the volume of biomedical information and in the number of personnel has led to a serious space shortage. Digital

archiving—once thought to be a solution to the problem of housing physical collections—has only added to the challenge, as materials must often be stored in multiple formats and as new digital resources consume increasing amounts of data center storage space. As a result, the space needed for computing facilities has also grown, further squeezing out staff. In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. Further, Senate Report 108-345 that accompanied the FY 2005 appropriations bill acknowledged that the design for the new research facility at NLM had been completed, and the Committee urged NIH to assign a high priority to this construction project so that the information-handling capabilities and biomedical research are not jeopardized.

MLA and AAHSL encourage the Subcommittee to continue its strong support of NLM's goals in order to strengthen the Library's ability to provide support for implementation of health care reform. At a time when medical and health science libraries across the nation face growing financial and space constraints, ensuring that NLM continues to serve as the archive of last resort for biomedical collections is critical to the medical library community and the public we serve.

Thank you for the opportunity to present the views of the medical library community.