

For Immediate Release
September 15, 2009

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New Web Site Promotes Interoperable Newborn Screening Data *Standardization Will Support Quality Health Care for Children*

The National Library of Medicine (NLM) today launched the Newborn Screening Coding and Terminology Guide (<http://newbornscreeningcodes.nlm.nih.gov>), an important step toward efficient electronic exchange of standard newborn screening data. The new Web site was created in collaboration with the Office of the National Coordinator for Health Information Technology, the Health Resources and Services Administration, and the Centers for Disease Control and Prevention, all components of the U.S. Department of Health and Human Services, as well as a number of professional organizations, to enable more effective use of newborn screening test results in assessing child health and improving lifelong health care.

Newborn screening is an important part of public health, but use of test results is complicated by wide variations among states in the ways tests are conducted and results recorded — and by inefficient, paper-based communications. The current situation can delay rapid attention to a child's health problems, and it creates frustration and extra work for parents, health care providers, and public health authorities. The new Web site is a “translator,” to help deal with current complexity and to promote more efficient electronic exchange of newborn screening information in the future.

The Web site is designed to help states move toward the use of common terminology and coding standards, a key step in enabling electronic exchange of laboratory test information as well as readying newborn screening information for inclusion in electronic health records (EHRs). The site covers more than 100 conditions and lists the terminologies and codes used for each. It also identifies the tests that may be used in screening for each condition. For all the conditions and tests included, the preferred standard terminology and codes are indicated. Users of the Web site can view the information interactively or download electronic datasets of standard names and identifiers for use in their systems.

“The Web site can also help researchers untangle the confusion of terms and tests that exist today,” said Dr. Clem McDonald, director of NLM's Lister Hill National Center for Biomedical Communications. “But beyond research, the most important goal for the new Web site is to help bring about efficient electronic exchange of newborn screening information. The big gain for patients and providers will come when we can include this information in a child's permanent EHR.”

The goal of the Newborn Screening Codes and Terminology Guide is to provide a standard framework for reporting the results of newborn screening tests whose contents can be accurately

interpreted by recipient electronic systems for use in care, follow-up and analysis. This standard framework will also enable the use and comparison of data from different laboratories.

“For decades, the NLM has been a trailblazer in conducting and supporting research in clinical informatics and electronic medical records,” said NLM Director Dr. Donald A.B. Lindberg. “Harmonizing standard coding, terminology and electronic messaging methods in newborn screening will support quality health care for children. Moreover, public health agencies will be better equipped to observe and compare nationwide trends from newborn screening test results, which will also support efforts of the biomedical research community at NIH and elsewhere to improve newborn screening methods and evaluation.”

The National Library of Medicine is the world’s largest library of the health sciences. It is located on the NIH campus in Bethesda, Maryland. For more information, visit the Web site at <http://www.nlm.nih.gov>.

The National Institutes of Health (NIH) — *The Nation’s Medical Research Agency* — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.