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Newborn Screening Update

by

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NEWBORN SCREENING UPDATE

As of May 17, 2004

The March of Dimes has been a long-time advocate of newborn screening. In fact, it was March of Dimes grantees who developed the first screening tests for PKU, biotinidase, congenital-adrenal hyperplasia, and MOD grantees also participated in the development of the screen used to test for hypothyroidism.

The Foundation is working to ensure that every baby born in the United States and its territories is tested for a minimum of nine metabolic disorders plus hearing deficiencies. As the technology improves, the number of conditions for which testing is possible grows and guidance from experts especially that of the newly constituted Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases—is needed to help develop national recommendations for improving state screening programs. See attached March of Dimes Newborn Screening Field Advisories used to guide Chapters in working with Governors and State Legislators.

Since the 1970s, the Foundation has worked at the Federal and State levels to create and strengthen newborn screening programs. Most notably in 2000, the March of Dimes spearheaded the advocacy effort that resulted in enactment of Title 26 of the Children's Health Act. This program is designed to strengthen States' newborn-screening programs by providing screening, counseling, testing, and special services for newborns and children at risk for heritable disorders. The legislation also is explicit in its call for improving states' ability to develop, evaluate, and acquire innovative testing technologies.

Last year, the March of Dimes worked with Senators DeWine (OH) and Dodd (CT) and others to secure funding for Title 26. Although we did not obtain the \$10 million requested, we were successful in securing an earmark of \$2 million through the SPRANS section of Title 5 for newborn-screening activities authorized in Title 26. Two recent funding recessions have shaved that dollar amount to \$1.97 million, but the good news is that funding for Title 26 activities has begun.

On the state side, in 2004, 29 March of Dimes Chapters are leading newborn- screening advocacy initiatives. As of May 2004, 14 states (HI, IL, IN, ME, MA, MS, NY, NV, OR, RI, TN, VA, VT, and WI) have expanded their programs to include all 10 “core” tests recommended by the March of Dimes.

In addition, 11 states (AL, CT, DE, FL, GA, IA, MI, MN, MO, SC, and WA) have authorized or appropriated funds to expand newborn-screening programs to include all 10 “core” tests—these expansions have just been approved; therefore, the program changes called for by the legislative or regulatory changes have not yet been implemented.

For example, in Florida, the State recently authorized billing third-party payors to cover the cost of screening. When fully implemented, \$2.4 million in State matching funds will enable Florida to qualify for \$4 million in Federal Medicaid dollars which will be used to expand the newborn screening program to test for 30+ disorders (Florida currently tests for six). In Alabama, the Department of Public Health reports that it will soon expand its newborn screening program to include all 10 tests recommended by the March of Dimes. In Michigan and Minnesota, the Department of Community Health and the Department of Health respectively indicate that implementation of the 10th test recommended by the March of Dimes will be completed shortly.

So, despite tight budget times, we’re moving the needle on newborn screening in States across the country—but there is much left to be done.