

news release

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COUNTRY EXPANDS NEWBORN SCREENING FOR LIFE-THREATENING DISORDERS

Pennsylvania Shows Improvement in 2009 March of Dimes Report Card

King of Prussia, PA, FEB. 18, 2009 - Regardless of where they are born in the United States, nearly all newborns now receive required screening for many life-threatening, but treatable, disorders, a remarkable public health advance of the last four years, according to a new report issued today by the March of Dimes.

That will be the case in Pennsylvania on July 1, 2009, when the state is scheduled to begin screening for all 29 of the treatable metabolic and functional disorders as recommended by the American College of Medical Genetics (ACMG) and endorsed by the March of Dimes and the American Academy of Pediatrics. Legislation requiring the expansion was signed by Governor Rendell on July 4, 2008.

In the materials released by the March of Dimes today, Pennsylvania is reported as screening for nine conditions, although state law has been updated to require screening for all 29 treatable conditions. However, the lower number is used in the report because the program expansion is not yet implemented.

“The March of Dimes applauds Governor Rendell, Senator Jane Clare Orie, and members of the legislature for putting the law on the books that will move

Pennsylvania to the forefront of newborn screening,” said Public Affairs Chair, Catherine Houska. “We commend our State Department of Health for their dedication to implementing the expanded program by the July first deadline. A critical safety net for our newborns will be assured. Failure to diagnosed and treat newborn metabolic and functional disorders shortly after birth can lead to disability, other severe consequences such as mental retardation, or even death.”

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Newborn screening is done by testing a few drops of blood, usually from a newborn’s heel, before hospital discharge. A positive result does not always mean the infant has a disorder. If a screening result is positive, the infant is referred for additional testing, and if the diagnosis is confirmed, treatment is begun as soon as possible.

“With the help of volunteers, parents and our partners, we have nearly erased the cruel injustice that sentenced babies to an undetected but treatable metabolic or functional condition based on their birth state,” said Jennifer L. Howse, PhD, president of the March of Dimes. “When every state is screening—not just with the law on the books but actually screening—for the 29 ‘core’ treatable conditions, we will celebrate a tremendous success story. The true beneficiaries will unquestionably be babies and their families.”

The recent advent of tandem mass spectrometry provided the means to identify many conditions from one blood spot. In 2000, the March of Dimes recommended criteria for adding screens in an editorial published in *Pediatrics* and launched its advocacy efforts

to require comprehensive newborn screening in every state at a time when most states screened for only four conditions. In 2005, the ACMG issued a report recommending that 29 screens be mandated for every newborn.

In 2005, the first year that the March of Dimes report card measured state-by-state requirements on expanded newborn screening, Pennsylvania screened for nine conditions; in fact, only 38 percent of infants were born in states that required screening for 21 or more of 29 core conditions. Today, as a result of years of intensive bi-partisan volunteer advocacy efforts led by March of Dimes chapters, nearly all babies born in the U.S. live in states that require screening for 21 or more of these treatable disorders. Moreover, 24 states as well as the District of Columbia require screening for all 29 disorders; Pennsylvania will join this number once the expanded program is implemented on July 1, 2009.

The March of Dimes will maintain its longstanding support for newborn screening, said Dr. Howse, and will continue to work toward the development of federally approved national guidelines and full funding for the Newborn Screening Saves Lives Act (P.L. 110-204) to help support state programs.

Parents can find a brochure about the recommended newborn screening tests at the March of Dimes Web site: marchofdimes.com/nbs.

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A list of disorders for which infants are screened in each state can be found on the March of Dimes Web site at marchofdimes.com/peristats, and at the National Newborn Screening and Genetics Resource Center Web site at genes-r-us.uthscsa.edu.

The March of Dimes is the leading nonprofit organization for pregnancy and baby health. With chapters nationwide and its premier event, March for BabiesSM, the March of Dimes works to improve the health of babies by preventing birth defects, premature birth and infant mortality. For the latest resources and information, visit marchofdimes.com or nacersano.org.