

States expand newborn screening for life-threatening disorders

February 18 2009

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

All 50 states and the District of Columbia now require that every baby be screened for 21 or more of the 29 serious genetic or functional disorders on the uniform panel recommended by the American College of Medical Genetics (ACMG) and endorsed by the March of Dimes. If diagnosed early, these disorders can be successfully managed or treated to prevent death, disability, or other severe consequences such as mental retardation.

Although all states now have laws or rules that require the screening, as of December 31, 2008, Pennsylvania and West Virginia still must implement their expanded programs, according to the March of Dimes report card.

"Today we announce that expanded screening is required by the states for nearly 100 percent of the more than 4 million babies born each year in the U.S. The clear beneficiaries are babies and their families," said Jennifer L. Howse, PhD, president of the March of Dimes. "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. This is a success story."

"This is a sweeping advance for public health," said R. Rodney Howell, MD, chairman of the federal Health & Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, (ACHDNC). "The March of Dimes and its chapters nationwide can be proud of their leadership role to essentially eliminate the geographic gaps in the state newborn screening safety net. Now, whether babies are screened and can get the immediate treatment they need to lead a healthy life no longer depends on the state in which they are born."

March of Dimes will maintain its watchdog role on newborn screening, said Dr. Howse, and will continue to promote consistent guidelines nationwide, and to advocate for funding for the Newborn Screening Saves Lives Act (P.L. 110-204). The intent of this legislation is to help improve state newborn screening programs by providing education for families and provide additional funding for follow-up and treatment for infants who test positive for disorders identified through screening.

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, 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. Twenty-four states and the District of Columbia require screening for all 29 disorders, with more

states expected to join them this year. In fact, 46 states and the District of Columbia screen for 26 or more of these conditions.

"Newborn screening saved Giana's life," said David Swift, of California, whose daughter was diagnosed with 3MCC (3-methylcrotonyl-CoA carboxylase deficiency) because of newborn screening. "It was only thanks to March of Dimes advocacy efforts that the hospital Giana was born in was part of a pilot program to expand newborn screening in California."

3MCC is a serious disorder that leaves newborns unable to metabolize leucine — an essential amino acid found in many forms of protein. But because Giana, now age six, was diagnosed early, she was put on a special diet and is living a relatively normal life.

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, and given treatment as soon as possible.

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

The March of Dimes Newborn Screening Report Card details state-by-state newborn screening requirements. The March of Dimes contracts with the National Newborn Screening and Genetics Resource Center to collect the data.

The ACMG recommendation to screen for 29 conditions has been endorsed by clinicians and researchers alike, including the American Academy of Pediatrics (AAP) and the ACHDNC. Both the March of Dimes and the AAP have called for national newborn screening

guidelines as well as federal funding to help states improve their programs and help affected families receive needed services.

A list of which screening tests are provided by each state can be found on the March of Dimes Web site at marchofdimes.com/peristats , which is updated regularly, or at the National Newborn Screening and Genetics Resource Center Web site at genes-r-us.uthscsa.edu .

Source: March of Dimes Foundation

Citation: States expand newborn screening for life-threatening disorders (2009, February 18)
retrieved 10 April 2024 from

<https://medicalxpress.com/news/2009-02-states-newborn-screening-life-threatening-disorders.html>

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