

STATE NEWBORN SCREENING PROGRAMS ADVANCE, BUT MOST INFANTS STILL NOT FULLY COVERED

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Expanded newborn screening is now required by law in dozens of states, but most infants still are not covered by the full panel of 29 tests recommended by experts, according to the March of Dimes 2005 state-by-state report card on newborn screening.

The March of Dimes recommends that every baby born in the United States receive screening for a uniform panel of 29 disorders that includes metabolic conditions and hearing deficiency. All of these disorders can be successfully managed or treated to prevent severe consequences, if diagnosed early.

"Parents need to know that the extent of newborn screening for serious and treatable disorders depends entirely on the state in which their baby is born," says Dr. Jennifer L. Howse, president of the March of Dimes. "For infants affected with these conditions, the tests can mean the difference between life and death, or health and lifelong disability."

As of June 1, 2005, 23 states (see attached list and map) have expanded their newborn screening programs to include more than 20 of the 29 disorders recommended in the 2005 report by the American College of Medical Genetics -- accounting for about 38 percent of the approximately four million babies born each year in the U.S. Twelve states -- which account for about 20 percent of babies -- require screening for between 10 and 20 disorders. Another 15 states, plus the District of Columbia -- involving about 43 percent of babies -- currently screen for fewer than 10 conditions.

"This is a snapshot of the progress that's been made by states in newborn screening over the past year or so," says Dr. Howse. "There is a growing understanding that newborn screening is a simple, safe, and efficient way to prevent a potentially devastating problem. We applaud those governors, legislators, parents, and volunteers who have come together to make the health of newborns a high priority. However, much more work remains to be done. For example, only Mississippi --which is home to just 1 percent of babies born in the U.S. each year -- currently provides screening for all 29 recommended conditions. Only eight states are screening for cystic fibrosis, despite the fact that CF is one of the most common genetic diseases in America."

"We urge continued expansion of newborn screening programs so that all babies across America will receive the benefits of testing for all of these 29 core conditions," Dr. Howse says.

Newborn screening is done by testing a few drops of blood, usually from a newborn's heel, before hospital discharge. If a result is positive, the infant is re-tested and given treatment as soon as possible, before becoming seriously ill from the disease. In states where testing is limited, parents can arrange for additional tests, but these often come at additional expense.

A new brochure entitled "Newborn Screening," containing a list of the 29 disorders and other important information, can be ordered from the home page of the March of Dimes Web site at <http://www.marchofdimes.com>.

The list of tests currently provided by each state also is available at <http://www.marchofdimes.com/nbs>. Parents should check with their state Health Department for any updates since June 1 or check online at <http://genes-r-us.uthscsa.edu/resources/consumer/statemap.htm>.

The March of Dimes is a national voluntary health agency whose mission is to improve the health of babies by preventing birth defects, premature birth and infant mortality. Founded in 1938, the March of Dimes funds programs of research, community services, education, and advocacy to save babies and in 2003 launched a campaign to reduce the rate of premature birth. For more information, visit the March of Dimes Web site at <http://www.marchofdimes.com> or its Spanish Web language site at <http://www.nacersano.org>.

Courtesy of Saving Babies Through Screening Foundation