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**American Academy  
of Pediatrics**



DEDICATED TO THE HEALTH OF ALL CHILDREN™

Minnesota Chapter

## **Minnesota Chapter of the American Academy of Pediatrics Urging Legislators to Pass Newborn Screening Bill**

*The chapter, which represents nearly 1,000 pediatricians in the state, says the bill is critical to health-related testing that saves children's lives.*

2/27/14 (St. Paul, MN) – Legislation aimed at strengthening Minnesota's newborn screening program, which affects nearly all babies born in the state, was introduced today by Rep. Kim Norton (Rochester) and Sen. John Marty (Roseville) with the full support of the Minnesota Chapter of the American Academy of Pediatrics and other organizations.

The bill is intended to reverse legislative changes made to the program in 2012 that limit how long the Minnesota Department of Health (MDH) is allowed to store newborn screening data. Co-authors include Rep. Erin Murphy (St. Paul), Rep. Tom Huntley (Duluth), Rep. Tina Liebling (Rochester), Sen. Tony Lourey (Kerrick) and Sen. Jeff Hayden (Minneapolis).

Under the current law, a child's newborn screening data is automatically destroyed at age 2, rendering it unavailable for future analysis or testing. Additionally, most newborn screening blood spots are destroyed before a child is 71 days old, though it can take up to six months to confirm a diagnosis in some cases.

Minnesota has become one of just a handful of states that destroys newborn screening data soon after birth. Many pediatric experts believe the current law is putting babies and families at risk.

"Saving newborn screening data and test results are critical to saving lives," said Robert M. Jacobson, MD, FAAP, president of MNAAP. "Long-term storage of this data assures proper diagnosis and timely follow-up for critically ill children. It also provides the basis for quality control and the development of new tests that can save even more lives."

In 2013, 99 percent of Minnesota newborns were screened for more than 50 rare, yet treatable disorders. Newborn screening has saved more than 5,000 children from death, chronic illness and physical disabilities since 1965.

"We cannot allow one more child to suffer or die due to a needlessly burdensome system that makes it more difficult to identify rare, hidden disorders," Jacobson said. "This bill impacts nearly every baby born in the state as well as their families who may not be aware that their child's data has been destroyed until it is too late. Now is the time to restore Minnesota's newborn screening program, position it as a national leader again, and save as many lives as possible."

The newborn screening legislation is supported by the pediatric leaders at Children's Hospitals and Clinics of Minnesota, the University of Minnesota Amplatz Children's Hospital, Hennepin County Medical Center, Gillette Specialty Health Care and Mayo Clinic Children's Center. Additional partners in the effort to restore Minnesota's newborn screening program include the Minnesota Chapters of the March of Dimes and American Heart Association.

Representing nearly 1,000 pediatricians and pediatric providers, MNAAP is committed to improving the health of all infants, children and teens in Minnesota. For more information, visit [www.mnaap.org/newbornscreening.htm](http://www.mnaap.org/newbornscreening.htm)

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