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DEDICATED TO THE HEALTH OF ALL CHILDREN™

Minnesota Chapter

Governor Dayton Signs Bill to Restore Minnesota's Newborn Screening Program

Backed by many Minnesota pediatricians and other medical experts, a bill that would remove exceedingly short time frames for storing newborn screening data was signed into law by Governor Dayton on May 6.

5/6/14 (St. Paul, MN) – A bill aimed at strengthening Minnesota's newborn screening program, which affects nearly all babies born in the state, was signed into law by Governor Mark Dayton on Tuesday, May 6 with the full support of the Minnesota Chapter of the American Academy of Pediatrics (MNAAP) and other medical organizations. The bill passed the House 69-58 and the Senate 36-20.

MNAAP has been leading the effort to preserve newborn screening data to ensure it remains available to parents and physicians for future health-related testing. The group advocated that long-term storage is also critical to new test development.

The new law removes arbitrary time frames that limit how long newborn screening blood spots and test results can be kept. Under the old law, a child's newborn screening data automatically had to be destroyed by age 2, rendering it unavailable for future analysis or testing. Additionally, most newborn screening blood spots had to be destroyed before a child was 71 days old, though it can take up to six months to confirm a diagnosis in some cases.

Minnesota had become one of a handful of states to destroy newborn screening data soon after birth. Many pediatric experts believed the old law put babies and families at risk.

"Newborn screening is a critical component of pediatric care -- one that saves many lives each year," said Robert M. Jacobson, MD, FAAP, president of MNAAP. "The data from these tests is also critical and should be preserved by default so that it's available to parents and providers in cases of missed, delayed or false diagnoses. The new law positions Minnesota to save as many lives as possible while upholding parents' rights to refuse testing, request destruction of test results, or both. Restoring the program protects the health of children born now and in the future."

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.

The bill garnered broad support from many parent and medical groups, including Children's Hospitals and Clinics of Minnesota, the University of Minnesota Amplatz Children's Hospital, Hennepin County Medical Center, Gillette Specialty Health Care, Mayo Clinic Children's Center and Shriners Hospitals for Children - Twin Cities. Additional supporters include the Minnesota Hospital Association, the Minnesota Medical Association, the Minnesota Chapters of the March of Dimes and American Heart Association as well as the Save Babies through Screening Foundation.

"Saving newborn screening data saves lives," Jacobson said. "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. We applaud Senator John Marty and Representative Kim Norton, chief authors of the bill, for restoring the program and allowing Minnesota to continue to serve as a model for the rest of the country. "

Co-authors included Rep. Erin Murphy (St. Paul); Rep. Carlos Mariani (St. Paul); Rep. Diane Loeffler (Minneapolis); Rep. Jim Davnie (Minneapolis); Rep. Melissa Hortman (Brooklyn Park); Rep. Tom Huntley (Duluth); Rep. Tina Liebling (Rochester); Sen. Tony Lourey (Kerrick); Sen. Melissa Wiklund (Bloomington), and Sen. Jeff Hayden (Minneapolis).

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

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