

## State health officials announce improvements to screening program

The Minnesota Department of Health recently announced a series of measures to improve and strengthen the state's newborn screening program. The measures are designed to address concerns about the long-term storage and use of infants' dried blood spots for non-screening purposes and to improve the information that new parents receive about all aspects of the program.

In collaboration with birthing hospitals and other health-care providers, the department screens for 53 disorders and hearing loss in 73,000 babies born in Minnesota each year. All of the screened disorders are treatable. Each year, approximately 140 infants are found to have a confirmed metabolic or congenital disorder. For many of these children, early diagnosis and medical intervention can prevent death or severe disability. Another 150 babies receive early hearing loss detection and intervention services that greatly increase their chances for improvement in cognitive and language development.

These key measures were announced:

- MDH will propose legislation this session for the department to keep the dried blood for two years in order to manage the newborn screening program and develop and perfect screening tests. After two years, the department would destroy the blood spots unless parents give consent for longer storage.
- The department has launched a revamped newborn screening program Website that provides parents, parents-to-be and health-care professionals with improved information on newborn screening for infants born in Minnesota. The new Web site ([www.health.state.mn.us/newbornscreening](http://www.health.state.mn.us/newbornscreening)) provides important information for families and professionals, including how parents may request destruction of their baby's specimens or test results or opt out of the screening. All required forms are available to download from the new site.
- Minnesota Health Commissioner Dr. Sanne Magnan is sending a letter to all hospitals in the state to strengthen efforts to educate parents about the importance and benefits of screening and the right of parents to opt out of the program or request destruction of the samples or test results.

- MDH officials will engage in detailed discussions in February with representatives from the largest birthing hospitals in the state on how to improve parent education and awareness about newborn screening.
- MDH will report to the governor and Legislature about the current efforts for enhancing parental education about the newborn screening program and parents' options under the program. "We believe these measures improve the newborn screening program by protecting the health of children and the rights of parents," Magnan said.

The proposed bill would address concerns raised by Gov. Tim Pawlenty in a 2008 veto letter regarding the long-term storage and use of dried blood spots. If passed, the bill would require babies' spots be destroyed after 24 months and within 25 months of the date of birth, unless a parent or legal guardian gives written, informed consent for longer retention. The bill would maintain the newborn screening program as an "opt-out" program, according to current law.

An additional feature on the redesigned Web site gives families the chance to share the benefits of newborn screening. Parents are invited to send pictures and stories about how screening made a difference for their family.

Initial postings include the story of a boy who was found by newborn screening to have MCAD (Medium-chain acyl-CoA dehydrogenase deficiency). He is now in kindergarten, but as his mother explains in the Screening Spotlight, without early identification of the disorder by screening, he might not have survived.

Fact sheets on MCAD and the other disorders on Minnesota's newborn screening panel are available on the Web site. Separate information on these rare and life-threatening conditions is provided for families and health-care professionals at the time of detection and follow-up diagnosis.

More information about Minnesota's Newborn Screening Program can be found at [www.health.state.mn.us/newbornscreening/](http://www.health.state.mn.us/newbornscreening/).