

March 22, 2012

The Honorable David Hann
Minnesota Senate
328 Capitol Building
St. Paul, MN 55155

Dear Senator Hann:

I am writing today on behalf of the Mayo Clinic in support of Minnesota's newborn screening program. Newborn screening, simply put, avoids death or permanent disability through early detection of treatable conditions.

I'd like to highlight three key points that SF2463 addresses.

First and foremost, SF2463 maintains the newborn screening program as an "opt-out" test. Newborns are required to be screened by the Department of Health unless the parents request that the child not be tested.

The newborn screening test detects conditions that if treated can prevent serious illness, physical disability, mental retardation, or death. 1 child in every 500 on average has a treatable condition detected. If only 5% of parents choose not to have their newborn tested, approximately 5-10 children per year will go undetected with serious health implications for the child and heartbreak for the family. If parents are required to "opt-in" for the test, participation will diminish and more children and families will be impacted by what would have been treatable conditions.

Second, SF 2463 helps maintain program operations. Minnesota's newborn screening program has one of the lowest false positive rates in the world, a metric that translates into less angst for the family as well as reduced health care costs by preventing unnecessary referrals and costly additional testing. The bill defines permitted quality assurance activities to ensure that we can maintain a low rate of false positives.

Third, SF2463 creates a process for storage and retention of the newborn blood spots if authorized by the parents or legal guardians of the newborn. The current test panel only covers a fraction of those who could benefit from early identification and medical intervention, BEFORE the onset of irreversible damage. To date, there are more than 20 additional conditions under active investigation because new effective treatments are made available. In most cases, the missing piece is a reliable screening test, and this obstacle can be resolved only by a strong research and development effort. This research and development effort can only take place if the newborn's blood spots are available after their testing is completed.

The newborn screening program exists to avoid death or serious disability – it is that simple and that important. Thank you for your consideration for SF2463.

Sincerely,



Patricia Simmons, M.D.
Pediatrician
Mayo Clinic