March 17, 2009

Representative Paul Thissen, Chair
Health Care and Human Services Policy and Oversight Committee
351 State Office Building
St. Paul, MN 55155-1206

RE: H.F. 1341 Newborn Screening Program

Dear Representative Thissen:

Mayo Clinic supports the passage of H.F. 1341 to preserve the valuable public health protection afforded the children born in Minnesota and their parents through mandatory screening a child at birth for inherited and congenital disorders. The bill is essential to assure the effective operation of the newborn screening program and clearly articulates state policy that the 2006 passage of M.S. 13.386 was not a stealth measure to undermine this valuable program.

Under the current program the Department has stored the blood samples indefinitely, providing a most valuable resource for obtaining new information that may be needed if future health issues arise for the child or a sibling. The storage of samples has also allowed the improvement in current tests and the development of new tests. The bill will allow those activities to continue even though it reduces the time the blood spots are stored to 24 months. While this deprives the parents, health care providers and children the availability of this material after that, the time period reflects the retention period used in a majority of other states.

The bill continues to balance the duty of the state to protect is most vulnerable citizens, our children, with the rights of parents. The bill adds additional information, including new emphasis on the parents’ right to deny their child the screening while clearly articulating the purpose and benefits of the program. The additional obligations on hospitals and those attending the birth of newborns will assure that parents are fully informed about the need for newborn screening and their wishes regarding the handling of their child’s blood spot is documented and carried out.

We urge you to pass this bill and resist efforts by opponents using fear tactics about the DNA that could be identified from the blood spot. The protection of our children is of paramount importance and outweighs any speculative harm that might occur if the program is made voluntary as that diminishes the need for this program.

Sincerely,

Franklin W. Iossi
Director, State Government Relations
Mayo Clinic and Mayo Health System