



Strengthen Newborn Screening Program

Fiscal Impact (\$000s)	FY 2014	FY 2015	FY 2016	FY 2017
State Gov Special Revenue Fund				
Expenditures	2,148	2,154	2,160	2,166
Revenues	2,300	2,450	2,460	2,504
Net Fiscal Impact	(152)	(296)	(300)	(338)

Summary

This proposal improves health outcomes for newborns and reduces medical costs by strengthening Minnesota’s Newborn Screening Program. The changes include adding tests for severe immune system disorders and serious heart defects, expanding public education efforts, and adjusting fees to match costs.

Background

Newborn Screening is a legally mandated initiative that screens babies at birth for serious, but treatable health conditions. Approximately 68,000 infants are born in Minnesota each year, nearly all of whom receive newborn screening.

The screening detects harmful or potentially fatal conditions in newborns to protect them from the serious problems that develop without early treatment. The conditions for which screening is performed may affect the infant’s metabolism, endocrine or immune systems, blood, breathing, or hearing and cannot be detected only through examination of the baby.

By working closely with physicians, hospitals, specialists, and parents, Minnesota’s Newborn Screening Program ensures all babies have access to

screening and that babies who have one of the conditions are linked quickly with care and treatment before symptoms develop.

The Minnesota Department of Health (MDH) has screened Minnesota newborns since 1965.

Approximately 180 children per year are found to have one of the 54 conditions on the screening panel. An additional 250 children each year are identified with hearing loss.

The Newborn Screening Program is fee based and is funded through the sale of cards used to collect the screening specimens. Hospitals and midwives purchase the cards, and the cost is included in the amount billed for the infant’s delivery and hospital stay and/or is reimbursed by insurance. The fee was last increased for screening purposes in 2007, from \$61 to \$101, primarily to support mandated hearing tests. In 2010 the fee was raised by five dollars to provide outreach to parents of children with hearing loss.

Proposal

This proposal raises the newborn screening fee from \$106 to \$140 per specimen screened. The \$34 increase per specimen funds the following four activities:

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Severe Combined Immune Deficiency (SCID) and other T-Cell Lymphopenias Screening

SCID, sometimes called “Bubble Boy” disease, refers to a group of conditions that result in a severe inability of the immune system to fight infection. If unrecognized and untreated, SCID often leads to serious chronic health problems or death. Survival beyond one to two years is rare without treatment.

Through newborn screening, babies with SCID can be diagnosed and treated before three months of age. Long-term survival for children treated before three months is greater than 95 percent. Without newborn screening, diagnosis is almost always delayed, increasing the risk of death and higher health care costs for treatment. Cost studies show that treatment for an infant with a late SCID diagnosis costs an average of \$2.2 million. Medical care for a child with an early SCID diagnosis is \$250,000. This proposal funds lab equipment, testing supplies, and staff to administer SCID screening.

Critical Congenital Heart Defects (CCHD) Screening

Congenital heart defects are the most common and lethal of birth defects, accounting for nearly 30 percent of all infant deaths due to birth defects.

Critical Congenital Heart Defects (CCHDs) are heart defects that require surgery or intervention within the first year of life. Babies with a CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth. While some heart defects are found prenatally or at birth, not all are found before babies leave the hospital. By measuring blood oxygen levels, the screening detects critical heart conditions before visible

symptoms emerge. This proposal funds technology costs for CCHD reporting and follow-up.

Health Education

The effectiveness of newborn screening depends on a strong partnership between the Newborn Screening Program and doctors and midwives who administer screening and on quick follow-up by parents whose children test positive for a condition. This proposal funds educational efforts to ensure parents and providers are aware of program changes and updated processes. It also supports enhanced education about newborn screening in the prenatal period and a broader health education initiative to increase parental, provider, and public awareness of newborn screening.

Fee Program Deficit

A portion of the fee increase fixes a structural deficit in the Newborn Screening Program. By law, MDH must monitor fee accounts and recommend fee level changes to ensure that revenues approximate the costs to operate its programs. The current deficit emerged as program costs increased for equipment, technology, contracts, and supplies while revenues fell due to a steady decline in birth rates since 2007. Also, significant expenses to the program resulted from a number of recent lawsuits and a recent Minnesota Supreme Court ruling.

Rationale

This proposal implements a recent U.S. Department of Health and Human Services recommendation that state newborn screening programs expand screening panels and improve educational and testing practices. Investing in new tests and enhanced education allows the program to further improve health outcomes for babies and reduce costs.

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