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My name is Susan Berry, and I am a professor of pediatrics at the University of Minnesota where I am the director of our Rare Disease Center of Excellence. More relevant to today's discussion, I am a doctor that specializes in Medical Genetics and one of my major responsibilities is to care for children with genetic conditions, particularly babies identified by our state of Minnesota newborn screening program.

I am writing today on behalf of HF 1502 (SF 1175), Presumptive disability determination process for medical assistance eligibility establishment particularly those elements that will facilitate medical coverage for an infant with a positive newborn screen for either congenital heart disease, or a heritable or congenital disorder included on the Commissioner of Health's newborn screening list that urgently requires diagnostic testing or treatment.

Newborn screening is designed to detect serious, often life-threatening conditions that are found in children that are not physically evident in the first days of life. The priority is to identify conditions that need early treatment, sometimes urgently, to prevent disability or death. This is so important that screening is done on all Minnesota babies in hopes of accomplishing a prompt diagnosis and effective treatment. If a screen indicates the presence of one of the target disorders, we need to act quickly to confirm a diagnosis and begin treatment. In some cases, this means a change in diet with special foods, in others the therapy is more difficult, requiring expensive medications or procedures.

For example, our state is one that screens for a very rare but dangerous condition called Krabbe disease. This is a devastating genetic disorder where the baby looks normal at birth but in the first months of life, without intervention, begins a rapid deterioration in their nervous system leading to death. The only treatment that has been found to have an impact on this is a bone marrow transplant, but the transplant must be done before 30 days of life to have a chance for success. The timeline for doing all that is necessary to accomplish this is rigorous and must be begun as soon as possible to meet that goal. Families may not even accomplish assured health care coverage for their infant in that time frame, much less endure the trauma of the diagnosis and the need to make informed decisions about a treatment that is in itself difficult.

Unfortunately, even though eventually the overwhelming majority of these children would eventually qualify for Medicaid, the lack of certainty around insurance coverage can cause devastating delays, potentially even leading to the child missing the chance for a life-altering treatment.

It is simply wrong to screen for a treatable disorder as a public health measure but then have a family be unable to begin the only possible lifesaving intervention because they do not have the financial means for treatment. This revision would ensure that we can promptly diagnose and treat the children identified by our newborn screening without a family risking delaying diagnosis and treatment for financial reasons. The revision would relieve families of that impossible dilemma and allow them to focus on working with their doctors to make the best plans for their child's care. I urge your support for this important revision in this legislation. Thank you!

SBerry

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Minnesota Chapter

INCORPORATED IN MINNESOTA

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

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April 1, 2025

Human Services Finance and Policy Committee
Minnesota State Capitol
75 Rev Dr Martin Luther King Jr Boulevard.
St Paul, MN 55155

Dear Members of the Human Services Finance and Policy Committee,

On behalf of the over 1,000 members of the Minnesota Chapter of the American Academy of Pediatrics (MNAAP), I am writing in support of HF 1502. This legislation would establish a presumptive disability determination process for medical assistance (MA) eligibility, particularly for infants with a positive newborn screening or a compassionate care allowance determination. The bill would be an essential step toward ensuring timely access to necessary medical care for some of our most vulnerable children.

Delays in disability determinations may leave infants and children with severe or life-threatening conditions and without access to critical medical services. By aligning presumptive eligibility with a positive newborn screening result or a compassionate care allowance determination, HF 1502 ensures that infants with urgent medical needs receive immediate access to care, reducing barriers and preventing adverse health outcomes.

This policy will have profound impacts by:

- Providing immediate access to care: infants who test positive for congenital or heritable disorders often require urgent medical intervention. Presumptive eligibility ensures they receive care without unnecessary delays.
- Improving health outcomes: early intervention is critical for infants diagnosed with severe conditions. By facilitating prompt access to medical assistance, we can improve survival rates and long-term health outcomes.
- Enhancing healthcare efficiency: streamlining the eligibility process reduces administrative burdens on hospitals and healthcare providers, allowing them to focus on patient care rather than bureaucratic hurdles.

MNAAP urges your support for HF 1502 to ensure that all eligible infants receive the timely and necessary medical assistance they deserve.

Sincerely,

Katie Smentek, MD, FAAP
President, Minnesota Chapter American Academy of Pediatrics

Newborn screening and early treatment saved my son Edan's life from his genetic disease, Spinal Muscular Atrophy (SMA). SMA is a degenerative motor neuron disease that before the availability of treatments used to be like ALS but in children. It used to mean a slow, heartbreaking death; in fact, SMA used to be the leading genetic cause of death in children. In SMA, like in many diseases, early intervention is crucial and can mean the difference between life and severe disability or even death. In the most severe form of the disease, which is the most common, even days of delay can cause permanent and irreversible motor neuron loss, impacting a child's ability to walk, move, swallow, and even breathe.

Thanks to swift medical care, my son Edan is our miracle child, developing normally today. Every child deserves the same chance at life that Edan has. I encourage the Minnesota legislature to pass HF 1502/SF 1175, a common-sense and lifesaving policy that would ensure health care coverage for newborn babies. Not only is my son Edan developing completely normally today, he has very few expensive doctor visits and other follow-up care that he would have otherwise had if his treatment were delayed even by a few days. With many conditions affecting newborn babies, early diagnosis and treatment saves lives and money.

gillette
CHILDREN'S

April 1, 2025

Dear Chair Schomacker, Chair Noor, and members of the House Human Services Finance and Policy Committee:

- **We write in support of HF 1502 (Reyer, Murphy, Elkins, Hemmingsen-Jaeger, Bierman, Franson):** Presumptive disability determination process for medical assistance eligibility establishment.

Gillette Children's operates an independent, nonprofit, specialty care, 60-bed pediatric hospital in St. Paul along with pediatric specialty clinics across Minnesota, including clinics in Burnsville, Maple Grove, St. Paul, Baxter, Bemidji, Duluth, Willmar and Mankato.

We serve children with complex disabilities, rare conditions, and traumatic injuries with a focus on brain, bone and movement conditions needing specialized expertise. Each year, we treat patients from all 87 Minnesota counties.

Gillette Children’s participates in the state’s current hospital presumptive eligibility program which allows participating hospitals to determine temporary eligibility for Medical Assistance. This legislation expands the presumptive eligibility option to allow hospitals to make a presumptive determination of disability based on condition. Disability would be presumed for conditions included on Minnesota’s Newborn Screening Panel. Disability would also be presumed for conditions included on the Social Security Administration's list of compassionate allowances, which is comprised of diseases and other medical conditions that, by definition, meet the Social Security Administration’s standards for disability benefits.

Presumptive eligibility provides access to Medical Assistance coverage without having to wait for an application to be fully processed. This can prevent delays in care, which is important for conditions that have a narrow window of time for treatment, such as Spinal Muscular Atrophy (SMA), where timely administration of therapies can prevent the rapid and irreversible loss of motor function caused by the disease.

We ask that you support this legislation. Please reach out to Marnie Falk, Gillette’s Director of Public Policy, with any questions at marniesfalk@gillettechildrens.com.

Sincerely,

Barbara Joers
President and CEO

MINNESOTA
RARE DISEASE ADVISORY COUNCIL

ISSUE

Expanding Presumptive Eligibility for Infants with Positive Newborn Screening Results (HF 1502/ SF 1175)

Minnesota Rare Disease Advisory Council Position

Infants who receive a positive newborn screening result for a serious medical condition require immediate access to life-saving care. HF 1502/ SF 1175 expands Minnesota's existing Hospital Presumptive Eligibility (HPE) program to allow a presumptive eligibility determination for Medical Assistance (MA) for these infants, as well as for those with a Social Security Administration (SSA) Compassionate Care Allowance determination. This bill also includes presumptive eligibility for adults requiring a disability determination before discharge to a long-term care facility.

Background – Presumptive Eligibility & Newborn Screening

Presumptive eligibility (PE) allows immediate, temporary Medicaid or CHIP coverage while a full application is processed, ensuring patients receive necessary care without delays. Minnesota's Hospital Presumptive Eligibility (HPE) program currently allows participating hospitals to enroll eligible patients in MA using basic demographic and financial information. HF 1502/ SF 1175 extends this process to infants with urgent medical needs identified through newborn screening. Minnesota is a national leader in newborn screening, testing for over 60 conditions that, if left untreated, can cause illness, disability, developmental delays, or death. Early diagnosis and intervention save lives and reduce long-term healthcare costs.

Background – Hospital Capacity & Long-Term Services and Supports (LTSS)

Hospitals face significant capacity challenges, with delays in MA eligibility prolonging hospital stays for patients needing long-term services and supports (LTSS) or home and community-based services (HCBS). Many patients cannot transition to appropriate care settings until MA benefits are active, contributing to unnecessary hospital stays and increased healthcare costs. HF 1502/ SF 1175 facilitates hospital decompression by streamlining the eligibility process.

Facts

- **Immediate Access to Care:** HF 1502/ SF 1175 ensures infants with serious medical conditions receive timely treatment without delays due to insurance status.
- **Early intervention saves lives and reduces costs.** Early diagnosis of rare diseases can **save up to $500,000 per patient** in medical expenses and productivity losses[1]. By identifying these disorders early, interventions, medications, or changes in diet can help prevent most health problems caused by the disorders on the newborn screening panel.[2]
- **Administrative Efficiency:** The bill reduces burdens on hospitals and healthcare providers by streamlining MA eligibility determinations.
- **Support for Hospital Decompression:** By ensuring MA eligibility for patients needing LTSS, HF 1502/ SF 1175 helps free up critical hospital space and improves patient flow.
- **Safeguards Against Over-Identification:** The rigorous review process for newborn screening ensures accuracy and minimizes false positives. Data from Minnesota's newborn hearing screening program demonstrates a high specificity rate, with only a small percentage of false positives.[2]
- **No Shift from Commercial Insurance:** MA remains the payer of last resort. Some children will be dual eligible for commercial insurance and Medicaid, ensuring comprehensive coverage without shifting costs unnecessarily.

HF 1502/ SF 1175 is a common-sense, life-saving policy that streamlines care for some of Minnesota's most vulnerable children. By ensuring infants with urgent medical needs can access treatment immediately, we can prevent devastating health outcomes and reduce long-term healthcare costs.

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[1] EveryLife Foundation for Rare Diseases. (2023, September). *Cost of delayed diagnosis in rare disease*. https://everylifefoundation.org/wp-content/uploads/2023/09/EveryLife-Cost-of-Delayed-Diagnosis-in-Rare-Disease_Final-Full-Study-Report_0914223.pdf

[2] Minnesota Department of Health. *Hearing Screenings Programs*. https://www.health.state.mn.us/people/childrenyouth/ctc/hearingscreen/programs.html.