JOHN JAGLER
STATE SENATOR • 13th SENATE DISTRICT

Phone: (608) 266-5660
Toll-free: (888) 291-3489
Sen.Jagler@legis.wi.gov

Room 415 South
P.O. Box 7882
Madison, WI 53707-7882

Testimony on Senate Bill 145

Thank you Chair Cabral-Guevara and members of the committee for hearing our testimony today.

The hardest news a new family can hear is that their child has a debilitating or even deadly condition. But early detection can help give those families the time they need to address or treat the illness. To help catch as many of these cases as possible, the state screens for 51 different blood disorders when every child is born. This is the heal prick they give your newborn hours after being born.

The program is administered by the Wisconsin Department of Health Services and the testing is done at the Wisconsin State Laboratory of Hygiene. Additionally, the Federal Government provides a list known as the Recommended Uniform Screening Panel, otherwise known as RUSP. States have the option of taking recommendations from the RUSP or adopting more of their own. Currently, the RUSP contains 38 tests, Wisconsin has adopted 34 of these.

Currently, there is no set timeline for when or how the state must review or adopt tests that are currently on or will be added to the RUSP in the future. Our bill simply sets a reasonable timeline in place for DHS to consider tests on the RUSP in a timely fashion. It does not require them to adopt every test but simply to consider them.

Finally, as some of you may have heard, the Federal Department of Health and Human Services has recently made a change to their procedure in adding tests to the RUSP. In April, DHHS disbanded the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), the committee that recommends additions to the RUSP.

JOHN JAGLER
STATE SENATOR • 13th SENATE DISTRICT

Phone: (608) 266-5660
Toll-free: (888) 291-3489
Sen.Jagler@legis.wi.gov

Room 415 South
P.O. Box 7882
Madison, WI 53707-7882

While we still don't know the future plans for the federal agency, we think it is still important to pass this bill. First, there are 4 conditions that are on the RUSP that have not been adopted by the state yet (MPS-1, MPS-2, GAMT and Krabbe). This bill would require the state DHS to consider these tests on the timeline in the bill and decide.

And for future cases, one of three possibilities could happen.

First, the federal DHHS adds no more tests to the RUSP making this bill moot, there will simply be no more tests for DHS to consider.

Second, they start up the advisory committee again and begin adding more tests to the RUSP, in this case the state is prepared, the timeline and structure are in place and DHS is ready to consider screenings again.

Finally, they change the name of the RUSP and use another mechanism for making recommendations. In this case, we may need to revisit this issue with a follow up bill to change the name of the RUSP to meet the new list. But it will still be good to have the structure of the bill in place, only needing a small change of language.

In any event, this is important legislation that can go a long way to help desperate families in need of answers to help their children. I encourage you to all vote yes on Senate Bill 145.

Thank you for considering this bill and we welcome any questions you may have.

BARBARA DITTRICH
STATE REPRESENTATIVE • 99th ASSEMBLY DISTRICT

Senate Committee on Health
Rep. Dittrich Testimony on Senate Bill 145
June 4, 2025

Chair Cabral-Guevara and members of the Senate Health Committee, thank you for considering Senate Bill (SB) 145 today. I also extend my gratitude to Senator Jagler for collaborating with me to reintroduce this vital legislation. Proactively screening for lifelong conditions empowers parents to secure timely, appropriate care for their newborns.

As discussed during our joint hearing on the administrative rule a few months ago, the Department of Health Services (DHS) administers the Newborn Screening Program, which tests newborns for a broad range of debilitating and life-threatening diseases. Wisconsin currently screens for 51 blood disorders, including 34 of the 38 conditions on the national Recommended Uniform Screening Panel (RUSP). However, despite these efforts, Wisconsin lags behind neighboring states in both the total number of conditions screened and those included from the RUSP. Our state ranks 41st in newborn screening, while Minnesota ranks 18th, and Illinois leads the nation.

SB 145 simply requires the screening panel at DHS to consider, not mandate, the addition of the 4 remaining conditions from the RUSP to the list of screened diseases at birth. Upon enactment, this bill authorizes DHS to efficiently establish rules to add new conditions to the screening list, aligning with standard practices in many of our health policies.

Again, thank you to the committee for your time. I am happy to answer any questions for the committee.

Post Office Box 8952 • Madison, WI 53708-8952 • (608) 237-9199 • Toll-Free: (888) 534-0099
Rep.Dittrich@legis.wisconsin.gov

State of Wisconsin
Department of Health Services
Tony Evers, Governor
Kirsten L. Johnson, Secretary

TO: Members of the Senate Committee on Health

FROM: Arielle Exner, Legislative Director

DATE: June 4, 2025

RE: Senate Bill 99 and Senate Bill 145

The Department of Health Services (DHS) appreciates the opportunity to submit written testimony in support of SB 99, which requires DHS to establish a program to award grants for spinal cord injury research, host symposia, and appoint a Spinal Cord Injury Council; and for information only regarding SB 145, which adds federally recommended conditions to the state's newborn screening panel, grants rulemaking authority, and exempts the process from emergency rule procedures.

SB 99

SB 99 appropriates $5 million every fiscal biennium for the grants and symposia. Governor Evers has consistently recognized the importance of advancing research in spinal cord injuries, and the Department expressed support for last session's version of this proposal, 2023 SB 27. This underscores the administration's commitment to enhancing the understanding and treatment of spinal cord injuries.

The information that would be generated by the research grants could help DHS identify future areas of need, action, and research for spinal cord injuries. Such information could be particularly beneficial for the Department's broader injury prevention and treatment efforts. Current law, Wis. Stat. § 255.20, requires DHS to: 1) maintain an injury prevention program that includes data collection, surveillance, education, and the promotion of intervention; 2) assist local health departments and community agencies by serving as a focal point for injury prevention expertise and guidance and by providing the leadership for effective local program development and evaluation; and 3) enter into memoranda of understanding with other state agencies to reduce intentional and unintentional injuries.

SB 99 does not change existing injury prevention laws but mandates DHS to establish a dedicated Spinal Cord Injury Council and allocate grant funding for related research. It is worth noting that DHS currently has an injury prevention program mandated in statute but does not have any additional funding or staff capacity for these important efforts. To effectively administer the initiatives outlined in SB 99, including grant oversight, symposia coordination, and Council management; DHS requires the creation of at least one full-time equivalent (FTE) position within the Department's Division of Public Health. The estimated annual cost for this position is approximately $91,300 in General Purpose Revenue (GPR). This staffing is essential to ensure the program's success and to fulfill the legislative intent of the proposed bill. The Department appreciates the Committee's consideration of this position and the associated funding.

SB 145

Wisconsin's Newborn Screening Program is an essential health program that identifies infants with conditions that can impact a child's long-term development, health, and/or survival. DHS operates this program in great partnership with the Wisconsin State Lab of Hygiene (WSLH) and screens babies for hearing loss, congenital heart disease, and currently 48 blood disorders. As the Committee is aware, two additional conditions, X-ALD and MPS1, are undergoing the rulemaking process to be added to the program.

Under current law, conditions are added to the screening panel based on the recommendation of the DHS Secretary's Advisory Committee on Newborn Screening (SACNBS). Individuals can nominate conditions to the committee for review. Each nomination is subject to subcommittee evaluation, committee evaluation, and ultimately, recommendation by the DHS Secretary. In addition to the current process for nominating conditions, SB 145 requires review of all conditions listed on the federal Recommended Uniform Newborn Screening panel (RUSP) for potential addition to the screening panel.

Since last session's version of this proposal 2023 SB 962 was considered, it has been reported that the U.S. Advisory Committee on Heritable Disorders in Newborns and Children, which had managed the RUSP, has dissolved.[1] The Advisory Committee has not met since November of last year and does not have future meetings scheduled to date.[2] In the Advisory Committee's absence, it is unknown if and how the RUSP will be updated to reflect the latest evidence regarding the benefits of screening for new conditions. The Department appreciates the Committee's careful consideration of the reliability of this resource moving forward as it reviews this proposal.

DHS thanks the Committee for the opportunity to provide testimony. The Department remains available as a resource to the Committee regarding these two proposals or any other matters.

[1] Henderson, Jennifer. "HHS Scraps Advisory Committee on Newborn Screening." Medical News, MedpageToday, 10 Apr. 2025, www.medpagetoday.com/special-reports/features/115070.

[2] "Meetings." HRSA, www.hrsa.gov/advisory-committees/heritable-disorders/meetings. Accessed 3 June 2025.

Katie Moureau
Cottage Grove, WI
kmoureau@wirare.org
608-217-5218
06-04-2025

Senate Committee on Health
Wisconsin State Legislature
Madison, WI

Dear Chairperson, Vice Chair, and Members of the Committee,

Thank you for allowing me to share my voice today in strong support of Senate Bill 145, a bill that means everything to families like mine—families navigating the unpredictable, often heartbreaking road of rare disease.

My name is Katie Moureau. I'm a mom to 5 boys, a fierce advocate, and a resident of Cottage Grove, Wisconsin. I'm here today not just with facts, but with lived experience. I know what a newborn screening can do—and I know what's lost when it doesn't happen in time.

My son Cade was diagnosed at birth with Prader-Willi Syndrome (PWS), a rare and incredibly complex genetic condition. We were one of the lucky families—but only because prenatal screening led us to test him immediately after birth. Wisconsin doesn't screen for PWS. If we hadn't known what to look for, Cade could have gone months—or years—without a diagnosis. And let me be clear: that delay could have changed the course of his entire life.

Because we caught it early, Cade started growth hormone therapy, nutrition support, and specialized care right away. These treatments aren't just improving his quality of life—they're changing the natural history of the disease.

But far too many families don't get that chance.

I've met parents who didn't receive a diagnosis until their child was already in crisis—when hyperphagia, the relentless and dangerous hunger caused by PWS, had already taken hold. At that point, you're not just dealing with a diagnosis. You're trying to undo damage that early intervention could have prevented. And that trauma stays with a family forever.

Here's the incredible part: PWS isn't on the federal Recommended Uniform Screening Panel (RUSP)… yet—but I know it will be. Cade helped complete a study to explore whether it could be added—and guess what? It can be. The science is there. The data is there. We're ready.

SB 145 ensures Wisconsin is ready too. This bill would require our Department of Health Services to annually review RUSP additions, start rulemaking when a condition qualifies, and

reevaluate when new treatments or breakthroughs occur. It also allows for emergency rulemaking, which is so important—because in rare disease, days and weeks matter.

But this isn't just about my child or PWS. It's about dozens of rare, life-threatening conditions—many of which can be treated or even prevented if caught at birth. Every year, medical science evolves. Every year, we can do more. But unless Wisconsin's process evolves too, we're holding families back from what could be life-saving answers.

SB 145 gives us a smarter, faster, and more compassionate system—one that meets families where they are, and puts our children's health first.

And if there's any reason someone is unsure about this bill, I hope you'll reach out to me. I know I don't have all the answers. I'm not a doctor, I'm not a policymaker—I'm a mom who learns and fights and advocates because I have to. And I am always willing to listen and understand more. But I ask that you do the same for our kids. Because they can't speak for themselves—and they can't wait.

Thank you for your time and for considering this critical legislation.

Sincerely,

Katie Moureau
Board Member, Wisconsin Rare
Board Member, Monona Grove Education Foundation
Governance Board Member, MG21 Charter School
Patient's Rising, Patient's Senate

June 4, 2025

Chairperson, Vice Chair, and Members of the Committee,

My name is Kari Lato. I lived in Wisconsin all of my life and am speaking on behalf of the Rare & Ready Coalition and the WI Rare Disease Alliance in support of **Senate Bill 145**, which brings our newborn screening programs in line with 21st-century science.

We have advanced treatments—some even curative—for rare conditions. But our newborn screening system has not kept pace.

This delay has real consequences. On average, it takes more than six years and 17 medical encounters to get a diagnosis after symptoms begin. A study shows the economic burden of a delayed diagnosis can exceed $500,000 per patient.

Half of those living with a rare disease are children and 30% of those children will not live to see their fifth birthday. These kids could have been saved through newborn screening.

If not diagnosed in time, the damage caused by the condition is irreversible. Additionally, some of the newest treatments like gene therapy must be administered in infancy, but many infants are not being diagnosed in time to receive the treatment. Imagine you are the parent that was told we could have saved your child if we caught this earlier.

By aligning our state screening panel with the federal RUSP, you give every newborn in this state the best possible chance to survive. All it takes is a single drop of blood. One drop of blood can test all these conditions. The decision to save these kids lies in your hands. I urge you to support SB 145.

Sincerely,

Kari Lato
W1402 Valley View Court
Ixonia, WI 53036

Thank you for the opportunity to share my family's story. My name is Amy Medina. I am the mother of three beautiful children who have Spinal Muscular Atrophy.

I became a mother on July 10, 2011. Mateo made me proud the minute I saw him. He forever changed me that day, after 20 plus hours of labor. When he was born, he barely cried, and I thought I was lucky to have a chill baby. The doctors talked about Mateo being low tone, which after being drugged up and tired, I thought it meant his skin tone, due to him being half Hispanic. I did not think much of this until the following morning when several pediatricians were looking him over. After several hours of this we were told that Mateo needed to be transferred to the Children's Hospital an hour away. Mateo was transferred by ambulance and my husband and I had to follow behind our 2-day old child. When we arrived at the hospital, we saw our precious baby hooked up to many things and we were unable to hold him. After four days in the PACU and many tests later we were able to take Mateo home and told he was going to "outgrow whatever he had".

After Mateo came home, we noticed issues with his breathing and brought him to the local ER. We were told we were overreacting, first time parents and that nothing was "wrong" with him. My husband and I dreamed of having a large family, wanting six children. However, on August 10, 2011, our world was forever changed when we were told Mateo had SMA and would not see his 2nd birthday.

Mateo was born at a time when there was no treatment. His prognosis was less than 2 years old however we were blessed to celebrate his 11th birthday this year! Despite not being able to breathe on his own or move, he lives a very happy life. Mateo was able to get the first FDA approved treatment at 6 years old. At first, we saw an improvement in his leg movement but after a couple years of every-four-month spinal injections we no longer saw improvements. We felt that being put under anesthesia and having exposure to the OR every four months was no longer in his best interest. Mateo began a different FDA approved treatment that he receives daily via g-tube. With this different treatment we saw an increase in his baseline oxygen saturation, however less leg movement. He is now able to move the corner of his mouth more and is more "vocal".

SMA had a horrible prognosis, but we felt our family was not complete. We rolled the dice again, hoping for the 75% chance our second child would not be affected. After over 4 weeks of waiting for the results of an amniocentesis we learned our second child was also affected. That diagnosis was not any easier than the first despite knowing he could be eligible for a clinical drug trial.
Javier was enrolled in a trial at 12 days old, after several days of testing. He received his first dose at 12 days old and continues to get a spinal injection every four months. Javier also has 2 copies like his older brother but due to getting early treatment he can walk and talk, something Mateo has never been able to do. Javier has been able to do more than a "Type 1" SMA child (the most severe form) could ever do before any treatment, but we still need to see more improvement. We literally almost lost Javier on two separate occasions when he choked. While attempting to enjoy a

French fry, the fry was stuck in Javier's throat, due to his weakened swallow, and caused him to choke. Both occasions required an attempt of the Heimlich remover and CPR. No parent should ever have to attempt to save their child's life in his manner. Seconds feel like hours. Thankfully both incidents had parents who were able to jump into action and save their child's life. Both incidents were also very traumatic to all the household members despite everyone jumping into action. Javier was able to get dual treatment for SMA for two months.
During this time, we saw an increase of his swallow and his speech. After I resigned from my job, we lost the insurance that approved for this second treatment. Since Javier has been off this second drug his smile is nonexistent, and his swallow has weakened to the point he has choked. Spinraza (the first and only treatment at this time) has not targeted his mouth and throat area and therefore we need a drug that can do both. Javier is now 6 years old and is very aware that he has SMA. The one thing he wishes is to be able to eat with his peers and not worry about choking. Something as simple as sitting at a lunchroom, laughing, and talking with his peers while he eats safely.

Two years after having Javier our family was blessed with our Princess, Amelia. She was also diagnosed with SMA via amniocentesis. Amelia received Zolgensma via clinical drug trial at 11 days old. Amelia does not require any breathing or feeding intervention currently. Although this drug is the closest thing we have to a cure, it is not and there is still a need to continue research for a cure or at the minimum dual treatment.

Early diagnosis and access to treatment has made a huge difference in my second and third child's lives. And it is only because of newborn screening that children across the United States are now able to gain access to treatment before SMA can start to break down their muscles and take away their ability to live lives as fully as they deserve to. Every day is a blessing with my children, and all families deserve the same - to have access to diagnoses and treatment as soon as possible.

Thank you for the opportunity to share my 11 years as an advocating mother who loves her children unconditionally.

Constituent:
Amy Medina
34 N Kayser St
Fond du Lac, WI 54935

Hello, my name is Christina Hayes. My husband, Rob, and I have two sons, Logan (10) and Dylan (7), and we would like to share with you our experience after welcoming our second son to our family.

We had a rough birth experience with our oldest son, so when Dylan was born we were thrilled when everything went smoothly. A few short days later we were sent home to be a happy family of four. Just five weeks into Dylan's life we noticed that things seemed a little different. He was not moving his arms and legs as much as you would expect, and he seemed really tired. When we picked him up to cradle him, his arms and legs would just flop down beside him. We were out of town so we kept an eye on it for a couple of days, but the parental instincts kicked in that something just wasn't right. We made an appointment with his pediatrician and drove home to get him checked out. His pediatrician knew something was not right, but thought we could run better tests and get faster results if we went to the ER. After many tests, they initially suspected Dylan had Guillain Barre Syndrome. We spent almost a week in the hospital receiving treatment for this. On the day we were to be discharged, we had a different neurologist that happened to be on rounds. She evaluated Dylan for about two minutes before asking if anyone had mentioned the possibility of this being Spinal Muscular Atrophy (SMA). This was the first time we had heard anything about it....after we had been in the hospital for almost a week. We had a blood test done, and a week later it was confirmed that Dylan did in fact have SMA. Two days later, Dylan started receiving Spinraza which, at the time, was the only treatment approved by the FDA for SMA.

SMA is a neuromuscular disease where your body does not produce as much protein as your muscles need in order to function. Your muscles aren't getting that protein, so they start to atrophy, or waste away. The progression and symptoms of SMA are very similar to ALS. SMA Type I, which is what Dylan has, is the most severe form. Kids born with this type are diagnosed in the first six months of their life. They are never able to walk, crawl, or even sit up on their own. They will eventually lose the ability to move their muscles. That includes all muscles, even the ones that you don't necessarily think about – for example, they will no longer be able to smile. They will need a feeding tube

because they will lose their ability to swallow. Most will lose their fight with SMA or need to be placed on a permanent ventilator before their second birthday. SMA is the number one genetic cause of death for infants.

With the treatment that Dylan is receiving, all of this is changing. There are now three different FDA approved treatments that stop the progression of SMA. As you can imagine, if it stops the progression of the disease, the sooner a child receives it, the better they will likely do in the future. The disease has less time to take over. Their bodies have less time to lose muscle strength. Dylan is doing remarkably well because he received treatment so fast. The progression of Dylan's SMA has stopped and he has even gained a lot of strength back. Through weekly physical therapy visits and daily exercises we're hoping he continues to gain even more. He does not yet have a feeding tube, he can sit up unassisted, scoot around our house, even stand with assistance for short periods of time, and best of all - he has the most amazing smile!

However, there are still many things Dylan cannot do. He cannot stand or walk on his own. There are many activities of daily living he cannot do on his own (use the restroom, shower, get dressed, etc.). If he's sitting and reaches too far, he cannot stop himself from falling over. We still watch him closely as he eats to make sure he doesn't choke. We are monitoring the curvature of his back because his core muscles were not strong enough to support his body, and he has developed significant kyphosis (a hunchback). He is only seven years old, but it is very likely that there will be a major back surgery in his future.

Dylan lost all of these abilities in the first seven weeks of his life, before he started receiving treatment. Just seven weeks. Less than two months. Imagine what he could be doing if he would have started receiving treatment as soon as he was born.

In the SMA community Madison was known for having one of the best SMA hospitals in the country. This was the place to be if you had SMA. We were here. And yet we were still misdiagnosed. We saw multiple pediatric neurologists who came up with a different

diagnosis for Dylan. It still took being in the right place, at the right time, and seeing the right doctor to know what was going on with our son. I hate to think of what would have happened if we would have been discharged that day without seeing her, how long it would have taken before we would have eventually received a diagnosis, and how much more strength my son would have lost. Because time is so important with this disease, as well as many other diseases. We are talking about time as short as weeks, days, even hours making a huge impact on our children's quality of life.

I also hate to think of all the hospitals throughout the state that have doctors similar to our first ones, that are not familiar with SMA. Or clinics with pediatricians that don't know anything about SMA. That say you just have a lazy baby, give them time. How long is it going to take for those children to receive a diagnosis and get started on treatment? I've heard the stories of families continually taking their children back to their pediatrician knowing that something wasn't right, only to finally get a diagnosis six, seven, eight months later or even longer. That was typically what happened, not like our story. Dylan would not have made it that long. If we were at one of those hospitals, Dylan would not be with us today. Weeks or a few short months is the difference between life and death with some of these children.

Dylan is doing remarkably well, but he could be doing so much more. If we just would have known sooner. This is true for so many other disorders as well, not just SMA. The sooner a family is aware of an issue, the sooner these children can get the help they need. I urge you to include all of the disorders that are listed on the federally recommended panel to the Wisconsin newborn screen. Please let these future families know right away that there is an issue with their children. Let them get started on treatment before their babies lose any more strength. Let these kids (and their families) have the ability to smile for many years to come.

Constituent:
Christina Hayes
2939 Scotland Parkway
Sun Prairie, WI 53590

My name is Dany Sun, and I am a mom to two children with Spinal Muscular Atrophy, or SMA, a degenerative neuromuscular disorder. My husband, Terence, and I live in Greendale, WI, and our children are Ruby (14 years old) and Landon (11 years old). Both Ruby and Landon were diagnosed with SMA in 2013.

At the time of their diagnoses, there were no treatments available for SMA. Ruby was diagnosed when she was just shy of her 2nd birthday. Since she was 15 months old, I'd expressed concerns to her pediatrician that she wasn't "taking off running" like she should be doing. We were referred to a physical therapist, who recognized right away that there was something more serious going on with Ruby than just low muscle tone or a simple developmental delay. We were there referred to a pediatric neurologist, who tested her for SMA. On February 5, 2013, we received the devastating news that Ruby did indeed have SMA. We learned that there were no treatments available, told that we should "take her home and love her", and referred to a neuromuscular clinic for ongoing care.

Six months later, after educating ourselves on the variety of ways we could grow our family and after much soul-searching and prayer, we decided to "roll the dice" and try for a second baby. Because SMA is a genetic disorder that is autosomal recessive, there was a 1 in 4 chance that any baby that my husband and I (who are both SMA carriers) would result in an SMA diagnosis. We quickly became pregnant and when I was just 11 weeks pregnant, we had the baby tested for SMA. In a chorionic villus sampling test (CVS test), an 18 gauge, 18-inch-long need was inserted into my abdomen and into my uterus to gather the DNA sample to be sent out for testing. Within three weeks, we had learned two things – we were expecting a baby boy, and he would have SMA like his sister. We were again gutted upon receiving this news. But this time, we had something we didn't have before – we had knowledge and time to prepare. When Landon started to show symptoms, just over a year later, at 9 months old, we knew what was happening and were able to take steps immediately to get him the support he needed.

Neither of our children were diagnosed with SMA via newborn screening (SMA was not added to the NBS panel until 2019), but I can tell you that there was a vast difference in our experience of their diagnosis because of *when* we received their diagnoses. We felt prepared, at least as prepared as we could be, with our son. We were able to connect with other parents who were having the same experiences that we were, ask them questions, and get advice on steps even before Landon started to show symptoms. Whereas at the point when Ruby was diagnosed, we had spent months staying up late searching the internet for answers and for others' experiences that could explain why our daughter was losing the ability to climb, walk, and stand up on her own. It was terrifying, and cost us time, severely impacted our mental health, and put a financial strain on us as we tried to find answers. Alternatively, we didn't have to wait in the purgatory with for our son's diagnosis. We could get his answers right away and take action to get him the support and care he needs.

So today, I am writing you to share our family's story and to ask you to support SB145, a bill that would ensure that more families in Wisconsin can receive diagnoses for a wide range of recommended disorders to be screened at birth, so that they can take immediate action and work to give their children the full, happy lives that they all deserve.

Constituents:

Dany & Terrance Sun
5106 Russell Dr
Greendale, WI 53129

Verbal Testimony:
Kimberly Haugstad
3974 Windemere Dr
Colgate, WI 53017

Hello. My name is Kimberly Haugstad, and I am here today representing the **WI Rare Disease Alliance**. I am also a rare disease parent.

**We are also submitting several parent stories in written form today. These are families who were personally impacted by newborn screening. These are meaningful testimonies to review separately.*

I am here to stress how vital newborn screening is for WI babies.

Today, babies in WI are screened at birth for several dozen different diseases. The newborn screening process is quick and simple: a heel stick and obtain a few drops of blood. This happens within 1-2 days of birth. Nearly 99% of all newborns are tested.

This screening is critical for early diagnosis. Missing this narrow window of just days or weeks after birth can be catastrophic, even fatal for the baby. And for these diseases, treatments exist, and that early diagnosis can be life-saving. In some cases, a simple diet change or therapy can prevent irreversible damage —or even cure the disease. **I know we all want this for our babies.**

Financially, this bill also has long-term common sense.

Realistically without a diagnosis at birth, hundreds of thousands of dollars per child will be incurred in the diagnosis odyssey. These costs are preventable expenses if detected in newborn screening.

This includes extensive hospitalizations, ER visits, unnecessary tests, specialist care, and complex medical care that could have been avoidable if newborn screening at birth.

Example: *there are more than 130 babies born with one of these diseases each year.*

For easy math, just consider if 100 of these babies were not screened? It averages to be about $390,000 to diagnosis but let's use a highly conservative number of $200,000. That math: 100 x $200,000 = $20M. <u>All could be avoided.</u>

This Bill aligns WI with national RUSP recommendations, so RUSP-designated diseases are automatically triggered for review within a defined period.

This is good process, reducing wasted time and money spent on lengthy submissions of diseases already being reviewed across the country.

Adding a small cost at birth, just a few dollars per test, pales in comparison to the staggering long-term health utilization costs on the table.

Importantly, this bill does – not - stop WI from considering and adding non-RUSP diseases to our newborn screening process. Autonomy for WI! **WI NBS Lab is one of the best in the country and we have multiple RD Centers of excellence in WI.**

So we can make a minimal investment at birth to add and detect these babies early, or we can bear the extraordinary and avoidable costs and unnecessary burden to our healthcare system later on.

For our newest baby Wisconsinites, the choice is clear.

I urge you to support Senate Bill 145. Thank you for your time and consideration. I welcome any questions.

Imagine a silent killer deep inside you. Something so destructive, so damaging and the longer it goes unnoticed the more damage it does until there is nothing left for it to destroy. Now imagine this silent killer was in your own newborn baby girls' body and there is nothing you can do because you don't know it's there. Sadly, this is real reality for every 1 in 11,000 kids that were born, or it was until 2018 when Spinal Muscular Apathy (SMA) was added to the newborn screening list.

Let me start by telling you a bit about myself and my family. We are from Wisconsin. Me and my wife have been married for 13 years and have 3 beautiful/pain in the butt children. Our last Alizabeth was born in 2022. Before then I never even heard of SMA. Turns out me and my wife were both carriers of this silent killer and we hit the lottery to only pass the disease on to one of our 3 children. Let me first tell you what SMA is. SMA is a neurological disease that affects your muscles. In simple terms your muscles are not able to grow so they begin to die, this happens at a rapid pace. Your arms, legs, and neck become limp. Your chest and lungs begin to weaken and shut down. Most children with SMA type 1 (the type Alizabeth has) do not live to the age of 2. Back to winning the lottery. When Alizabeth was born there were 3 FDA treatments for SMA that were approved, they are not cures but treatments. These treatments work best when they are administered right away. Think of it like this, wildfires spread like crazy with the right environment and conditions. Well, SMA is the wildfire in your body and the treatment is the fire crew stopping it from spreading. Alizabeth is now 3 years old, she is amazing. She is walking, jumping, running, laughing and everything else a normal 3-year-old would or could do. This is all because of getting the treatment at just 28 days old. She was able to do that because of Newborn screening.

Now SMA is on all newborn screening tests in all 50 states. This is a huge step in the fight to cure this horrible disease. Imagine all the other silent killers that are not being detected by Newborn screening. All the other children who are born or grow sick because of some unknow illness that can be tested for at birth. All the other families are told that there is nothing they can do for their kids, all the other hearts that are broken. As a father, my worse fear is not being able to help my kids. Not being able to keep them safe and protect them. Please help me and all other parents across the globe protect their children by supporting SB145.

Constituent:

Joe Burnette
2803 Concord Dr
Racine, WI 53403