State of Wisconsin
Department of Health Services

Tony Evers, Governor
Kirsten L. Johnson, Secretary

TO: Members of the Senate Committee on Health and Assembly Committee on Health, Aging, and Long-Term Care

FROM: Arielle Exner, Legislative Director
Mark Thompson, Attorney

DATE: March 12, 2025

RE: Clearinghouse Rule 24-025, relating to: screening of newborns for congenital disorders

Chair Cabral-Guevara, Vice-Chair Testin, Chair Moses, Vice-Chair Brooks, members of the Senate Committee on Health and Assembly Committee on Health, Aging, and Long-Term Care, and staff, my name is Arielle Exner, and I am the Legislative Director for the Wisconsin Department of Health Services (DHS). Joining me today is Mark Thompson, an attorney within the Department's Office of Legal Counsel.

The Department proposes a series of changes to chapter 115 relating to the Newborn Screening (NBS) program. NBS 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). The Department appreciates the opportunity to provide more information about the importance of the NBS program as well as the proposed rule changes that ensure the sustainability of this program for Wisconsin babies and families for years to come.

Section 253.13(1) requires a screening of every baby born in a hospital prior to discharge, and within one week of birth for every baby born outside of a hospital. Blood screening is accomplished by placing a few drops of blood from the baby's heel on special test paper contained on the screening card. The card is then sent to WSLH, with whom the Department contracts to conduct testing and furnish materials for said testing, per Wis. Stat. § 253.13(2). Screening also for critical congenital heart disease and hearing loss occur at the hospital before discharge, or at home for home birthed babies.

Blood screening includes 48 disorders in Wisconsin. Over 55,000 babies in Wisconsin are screened annually, and approximately 130 babies born in Wisconsin each year will have one of the 48 disorders detected by the blood screen. Newborns with one of the disorders included in the blood screening receive follow-up diagnostic and counseling services, which may include special dietary treatment and ongoing clinical care. The Department contracts with ten agencies statewide, including specialty clinics and health departments, to provide these services. Patients with a confirmed diagnosis receive ongoing clinical care, are assessed for nonmedical needs, and receive services to promote transition to adult health care.

Special dietary treatment is the primary intervention recommended for 16 of the core conditions screened. In many cases, failure to initiate and continue this treatment results in significant disability or death. More patients with confirmed diagnoses are surviving into adulthood as a result of this treatment, which is provided for life. This treatment does account for the majority of the Department's program costs.

Wis. Stat. § 253.13(2) expressly requires that the Department impose a fee, by rule. As of July 7, 2023, statute states that fee cannot be less than $195 (via 2023 Wis. Act 19). All of the following related to the NBS program are statutorily required to be covered by said fee:

- The actual costs of testing (conducting testing and furnishing materials for testing),
- The provision of diagnostic and counseling services,
- Special dietary treatment,
- Periodic evaluation of infant screening,
- The cost of consulting with experts to periodically consult on, and evaluate the NBS program, per Wis. Stat. § 253.13(5),
- The cost of administering the hearing screening program under Wis. Stat. § 235.115, and
- The costs of administering the NBS program.

Since the fee was first set at $109, multiple factors caused the NBS program to operate at a deficit for at least the past six years. The overall cost for the NBS program continues to increase due to adding new conditions to the screening panel, increasing annual caseloads for those receiving special dietary treatment, and ongoing inflation of the costs of said treatment, counseling services, and administrative services year after year. The amount of special dietary treatment needed increases with patient weight and can cost up to $15,000 annually for an adult receiving service. Furthermore, the program's ongoing clinical care contracts don't cover the full costs of clinical care under the program, so many contract agencies use in-kind coverage for newborn screening related work.

As the program costs continue to increase, card revenues are declining as annual birth rates in Wisconsin continue to decrease. For example, approximately 66,800 NBS cards were purchased in 2010, and approximately 59,000 NBS cards were purchased in 2022. The Department estimates approximately 55,300 cards will be purchased in fiscal year 2025. Despite declining revenues due to declining births, the costs and number of individuals served, especially for life, continue to increase. In 2021, there were a total of 1,291 individuals served by the congenital disorder treatment program, and in 2022, there were 1,444 individuals served by the program. The WSLH estimates that approximately 125 to 140 babies born in Wisconsin each year will have one of the 48 disorders detected by the blood screen, 90 will have hearing loss detected, and 100 will have identified critical congenital heart disease. Costs for dietary treatments, follow-up services, and administrative costs increased by 25.8% from 2010 to 2022, and are expected to continue increasing by about 2.1% per year. Thus, costs for providing services will *not* remain static despite decreasing revenues and increasing caseloads.

Although statute requires that the NBS card fee also fund the newborn hearing screening program, also known as Wisconsin Sound Beginnings, that program has primarily been funded by federal grants. The future of those grants is uncertain, and Wisconsin Sound Beginnings should be funded through the NBS card fee, per Wis. Stat. §. 253.13(2).

Last session, the Department supported a proposal to make up the NBS program's deficit and cover ongoing cost increases through GPR. This resulted in two separate proposals to supplement the Department and the WSLH through GPR:

(1) For DHS, approximately $3.5 million GPR in the first year of the biennium to help eliminate the program's deficit and fund ongoing costs, and approximately $1.7 million GPR in the second year of the biennium. *See* 2023 AB 43 § 257 (page 408); LFB Paper #436 § 1. (June 2023).
(2) For WSLH, approximately $2.2 million GPR to supplement the fee revenue used by DHS for treatment and follow-up services. *See* LFB Paper #816 § 12 (June 8, 2023).

The 2023-2025 biennial budget passed by both chambers of the legislature did not appropriate any GPR funding for the NBS program. Instead, a minimum card fee of $195 was set via 2023 Wis. Act 19. Despite the notable fee increase, the NBS program ended fiscal year 2023 with a negative balance of $681,000.

As such, the Department proposes increasing the fee to $223 to cover ongoing cost increases, eliminate the existing deficit, cover the cost of testing two new conditions, and permit ongoing biennial fee increases based on the average three-year Medicare Economic Index if deemed necessary. The proposed fee would be shared between the Department and WSLH and is based on both entities' projections for future testing costs and card volumes.

The two new conditions that would be included are X-ALD and MPS1 at an additional cost of $12 per card. The remaining amount ($211) would be split between DHS and WSLH based on the historically agreed upon distribution of the card fee (DHS at 46.33% and WSLH at 52.67%).

The Department's projections are based on an eleven-year timeline assuming two-percent annual inflation for core program costs and declining birth rates. At the request of the WSLH, the Department included the option to increase the fee in future years based on the Medicare Economic Index (MEI). As drafted, the rule allows the fee to be increased by the MEI only if costs exceed revenues over a two-year period. It is worth noting the MEI is a more conservative way to measure the increases in general practice costs within the medical industry. Other states allow their fees to increase based on the Consumer Price Index which is significantly higher.

The Department has engaged in discussions comparing Wisconsin's fee to other midwestern states' fees. While DHS acknowledges that comparison may seem reasonable on its face, Wisconsin has specific statutory requirements to cover certain services under the NBS program that other states do not. For example, Minnesota's fee is $235, higher than what DHS is proposing, and it does not comprehensively provide special dietary treatment or ongoing clinical care. Since LFB's June 2023 paper, Michigan and Iowa have both increased their fees. Michigan's fee increased from $144.50 to $176.61, is subject to an annual adjustment that reflects the Detroit Consumer Price Index, and does not explicitly cover comprehensive special dietary treatment or ongoing clinical care. Iowa's fee increased by $40 (from $122 to $162) and does not comprehensively provide special dietary treatment or ongoing clinical care. Again, special dietary treatment and ongoing clinical care account for the majority of the Department's NBS program costs.

The goal of structuring the fee increase in this manner is to eliminate the accumulated program deficit, generate a reserve over the next few years to cover costs exceeding revenues through fiscal year 2035, and ultimately ensure the viability of this essential health program for all Wisconsin babies and families for the next decade.

DHS thanks both Committees for their review of Clearinghouse Rule 24-025 and appreciates the opportunity to provide testimony today. Mark and I are happy to answer any questions.

WISCONSIN HOSPITAL ASSOCIATION

ADVOCATE. ADVANCE. LEAD.

5510 Research Park Drive
P.O. Box 259038
Madison, WI 53725-9038
608.274.1820 | FAX 608.274.8554 | www.wha.org

TO: **Members, Senate Committee on Health**
Members, Assembly Committee on Health, Aging & Long-Term Care

FROM: **Ann Zenk, Senior Vice President Workforce & Clinical Practice**
Kyle O'Brien, Senior Vice President Government Relations

DATE: **March 12, 2025**

RE: **WHA Requests Modifications to CR 24-025 Related to Newborn Screening**

Wisconsin's newborn screening program is currently funded through fees assessed on Wisconsin hospitals and providers that are ***intended*** to be recouped through commercial insurance companies and the Medicaid program (managed care and fee for service), but hospitals and providers are often left to negotiate the recoupment of these government-imposed fee increases with health insurance companies.

Essentially, Wisconsin health care providers have become tax collectors for the state's newborn screening program, leaving hospitals at-risk for the total cost of newborn screening when they are unable to recoup costs from unwilling insurance companies. With the recent closure of several labor and delivery units, including those in some of your own legislative districts, we need to carefully examine any new regulatory or financial burden placed on those who are caring for new moms and babies in Wisconsin.

In 2011 the legislature adopted, and the Governor signed, a change in state law requiring newborn screening fee increases to be promulgated by rule rather than simply imposed by government agencies. This was done to ensure the legislature had oversight on fees being charged to the state's hospitals and health care providers for newborn screening.

In the last state budget, the legislature authorized the Wisconsin Department of Health Services (DHS) to increase the state's newborn screening fee from $109 to $159.25 to cover increased costs associated with newborn screening at the Wisconsin State Lab of Hygiene (WSLH). Additionally, the legislature's action in the last state budget attempted to ensure that DHS did not absorb this increase but, instead, specifically passed this increase onto the WSLH through their contract to provide newborn screening services.

Rather than accepting the legislature's proposed increase, the Governor struck the first "5", the period, and the "2" from $159.25 to require that DHS have a fee no less than $195. This veto instantly provided nearly $2 million in additional annual funding (and fees on hospitals) that the legislature did not authorize. Additionally, this veto removed the requirement that the legislature's increase be passed through to the WSLH.

Now, the Department is asking the legislature to approve a rule (CR 24-025) that increases the state's newborn screening fee to $223 per card, a $3.5 million annual increase from what the legislature authorized in the last budget bill, **along with** an automatic inflationary increase that avoids legislative oversight. This fee being imposed by DHS in CR 24-025 exceeds the fiscal needs stated to the legislature during the 2023-2025 budget process.

The Department's own analysis of their rule states that while their fee increase is $28 per card on top of the amount enacted through the Governor's veto, the costs associated with screening for two new conditions (also being added via CR 24-025) amount to only $12. If this rule is adopted as-is, fees paid by hospitals for newborn screening will have increased by 105% in the last two years alone and **will increase into perpetuity with no legislative oversight.**

Annual Fee Increase Approved by the Legislature	Annual Fee Increase Under Governor's Veto	Annual Fee Increase Following Governor's Veto & Agency Rule
$2.8 million	**$4.7 million**	**$6.3 million +**

Note: Amounts determined using DHS' projected estimate of screening cards sold in FY 2024, 2025 and 2026 at 55,000. Source: CR 24-025 Rule Summary

As WHA stated to the Department during the rulemaking process (attached), the need that appears to exist, based on the GPR request in the previous Governor's budget, is the equivalent of a $184 all-in fee. Yet, the fee currently being imposed (following the Governor's veto action) is already $195.

WHA believes that this program should be funded through other sources, like general purpose revenue, rather than forcing hospitals, and ultimately patients and employers, to be the state's fee collector.

The Wisconsin Hospital Association respectfully asks that the Committee take a vote to request modifications to CR 24-025 that eliminates the automatic fee increase in this proposed rule and reduces the newborn screening fee to $195 per card.

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HOSPITAL
ASSOCIATION

ADVOCATE. ADVANCE. LEAD.

5510 Research Park Drive
Fitchburg, WI 53711
608.274.1820 | FAX 608.274.8554
www.wha.org

April 29, 2024

Tami Horzewski
Wisconsin Newborn Screening Program Coordinator
UW-Madison, State Laboratory of Hygiene
Wisconsin Department of Health Services
Division of Public Health
P.O. Box 2659
Madison, WI 53703

Sent via Public Comment Form at:
https://docs.legis.wisconsin.gov/feedback/agencyform?cite=cr/2024/25

Subject: Comments on CR 24-025
Proposed permanent rules
DHS 115 Screening of Newborns for Congenital Disorders

Dear Ms. Horzewski:

On behalf of our over 150 member hospitals and integrated health systems, the Wisconsin Hospital Association (WHA) appreciates the opportunity to comment on CR 24-025, the proposed permanent rules from the Wisconsin Department of Health Services (DHS) related to DHS 115, Screening Newborns for Congenital Disorders.

In Wisconsin, there are about 85 hospitals that deliver babies, several fewer than just five years ago. Since 2017, the state has lost at least 10 percent of its OB beds, in part due to reduced OB patient volumes, increased costs for hospitals, and below cost reimbursement from Medicaid, a significant payer of OB services. For services covered by commercial payers, hospitals are finding the insurers ever more disinclined to negotiate increased reimbursement rates based on increased hospital costs, like the increased cost of the Newborn Screening program (NBS) blood collection card. We believe it is important to note that the additional costs for hospitals DHS proposes in CR 24-025 and that we discuss below oftentimes would be borne by hospitals with low or negative margins working to provide crucial services in their communities. Note that for births occurring outside of hospitals, the fee schedule posted by the Medicaid program shows Medicaid continues to reimburse those providers $115 for the cost of the card, significantly below the current $195 card fee. **Contrary to representations made by some proponents of the program, providers generally do not recoup the increased costs of the NBS card fees from payers, even when the payer is in the same state agency as the NBS program.**

WHA welcomed and supported the Administration's proposal in the SFY 2024-2025 budget that would have provided General Purpose Revenue (GPR) for NBS instead of increasing NBS card fees for hospitals. While this funding was not approved by the state legislature, WHA continues to believe that GPR funding for NBS is appropriate – particularly as commercial insurance companies are making it more difficult for hospitals to recoup their costs through negotiated rates.

In CR 24-025, DHS proposes several changes to the current NBS rule, including the addition of conditions to the newborn screening panel, a higher fee charged to hospitals for the NBS blood collection cards, and a new automatic biennial fee increase equal to the average three-year Medicare Economic Index. WHA objects to DHS's proposal to increase the fee to $223, which would be a 105 percent increase since SFY 2023 and **would establish the fee as one of the highest NBS fees in the country**, and its proposal to create an ongoing automatic fee increase.

As DHS notes in its proposal, the statutes allow DHS to impose a fee sufficient to pay for services under its contract with the University of Wisconsin State Lab of Hygiene (WSLH) and for certain specified services provided by DHS. According to material provided by the WSLH during the recent state budget process, WSLH needed an additional $2.2 million annually for its increased costs related to testing the blood sample cards and other NBS services. The Administration indicated that DHS needed an additional $1.7 million annually to fund its ongoing costs under the program. The combined funding increase needed to fund the program, based on the information provided by DHS and WSLH, was about $3.9 million (requiring an NBS card fee of approximately $184 based on 52,000 births).

During the biennial budget process, the Legislature provided a fee increase intended to support NBS testing at WSLH (increasing the fee from $109 to $159.25 per card). DHS, however, received an annual increase of over $4.6 million in the budget due to a line-item veto by the Governor that changed the Legislature's proposed increase by striking the first five, a decimal point and the two in $159.25, resulting in an even higher fee of $195.

DHS now proposes a fee through CR 24-025 that would increase revenue by over $6 million ($223 per card), reflecting the sizable increase in the budget and providing more than $2 million in extra funding beyond what DHS and the WSLH said is needed. The statute does not authorize and WHA strongly objects to fees that generate revenue in excess of specified program costs.

DHS states that part of the proposed increase, $12 per card or about $660,000, is related to the addition of X-ALD and MPS I to the NBS test panel. According to the NBS website, however, the program started testing for X-ALD about a month after the program received the more than $4.6 million annual increase in the state budget and presumably determined it had sufficient funding for the test.

WHA believes the card fee should be aligned with the actual cost of the NBS program which, according to DHS and WSLH, would be about $184 per card instead of the current $195 fee, the amount DHS and WSLH have implemented as a statutory mandate. Because DHS is receiving annually about $700,000 more than the Administration said DHS needed for NBS (*see 2023-*

2025 Biennial Budget Legislative Fiscal Bureau Paper #436), WHA requests that the fee increase in CR 24-025 be removed.

WHA also objects to the DHS proposal to create an automatic fee increase equal to the average three-year Medicare Economic Index, an index that even the Medicare program does not use to automatically increase physician reimbursement fees and which the American Medical Association describes as covering, among other things, redistributive costs from other programs and investments in medical practices. These are not costs related to the NBS program and are not the program costs the statute authorizes DHS to include as part of the fee. According to LFB, special dietary treatment accounts for most of DHS' costs, which are not similar to the costs included in the MEI. DHS writes that the automatic increase would cover the added costs of new conditions, but DHS does not know how many or whether any new conditions might be approved for the panel.

WHA believes any proposed increase, but especially an automatic increase, in the NBS card fee that does not reflect specified program costs and that avoids ongoing scrutiny by both the Administration and the Legislature through the administrative rule process is not only bad public policy but also conflicts with current state law and the legislative intent of the rulemaking requirements.

DHS explains that the automatic fee increase will avoid future deficits in the administration of the program. But DHS also can avoid future deficits by controlling program costs or, when needed, proposing a fee increase through the rule process, better ensuring the Administration and the Legislature are aware of and can exercise the required oversight over program decisions and costs, as provided for in the statute.

Thank you for the opportunity to comment on CR 24-025.

Sincerely,

Laura Leitch
Policy Counsel

WI Senate Committee on Health, Public Hearing, Madison, WI, 3/12/2025
Testimony in Support of CR24-025

My name is Matthew Rasberry. I live in Madison, WI. I am currently a metabolic dietitian working in the Biochemical Genetics Clinic at the Waisman Center. I am speaking today to support CR24-025 which will help adequately fund the WI Newborn Screening Program now and into the future. I am here today as a private citizen.

I have had the opportunity to be a metabolic dietitian for the past 13 years. I've worked at two different centers; Children's National in Washington DC and currently at the Waisman Center in Madison, WI. I provide nutritional management to individuals with metabolic disorders; most of which are picked up by the WI Newborn Screening Program. With early detection, comprehensive ongoing nutritional and medical management, and close monitoring; we can profoundly change the lives of these individuals. Newborn screening is truly a marvel of modern medicine.

To give some examples:

- For Phenylketonuria (PKU), if treated at birth, we can prevent profound intellectual disability. The patients that I follow born before newborn screening, are profoundly intellectually impaired and require 24/7 care in long-term care facilities. Meanwhile, the patients I treat picked up by newborn screen, have the potential to live normal lives and thrive. We currently follow many patients with PKU who are nurses, teachers, pharmacists, lawyers, social workers, truck drivers, fathers, mothers, etc.
- In the case of Glutaric Acidemia Type 1 (GA-1), with rigorous dietary management when sick and when well, we can prevent a basal ganglia stroke. A basal ganglia stroke that can leave a child in a body that is devastated, and that the child can no longer properly control.
- For the case of fatty acid oxidations disorders, we can give specific feeding regimens that can prevent a child from dying overnight due to severe hypoglycemia and energy deficiency. Without newborn screening, they would just attribute it to sudden infant death syndrome (or SIDS).
- Some of the conditions we treat can make you profoundly sick, very quickly, if not properly treated. Examples of these include Organic Acidemias, Urea Cycle Disorders and Maple Syrup Urine Disease. Many of these patients get critically sick within a few days of life, right when the newborn screening result comes in. With that screen, we now have the treatment plan to prevent brain damage, neurological devastation and/or death. They then face this risk their entire lives, so they must be extremely diligent with their treatment all the time.

These examples highlight what we all want to do in healthcare. Prevent the damage before it occurs. Because once the damage happens, there isn't any going back. The human, societal and financial costs of not providing this care greatly outweighs the cost of administering it based on the examples mentioned above. Because I've worked both in WI and DC, I have some familiarity to other states such as Maryland, Virginia, Minnesota, Iowa, Michigan and Illinois. My personal experience and opinion is that the Wisconsin Newborn Screening Program shines bright and is example of excellence. It embraces the motto of "Forward", setting a national example.

Once the diagnosis is made thanks to the diagnostic services provided by the Newborn Screening Program, there is a life-long and ongoing effort to prevent the devasting consequences that these patients can face. With the newborn screening program, we can make sure that patients and families have the support and resources they need from a few days of life and as they grow.

Funding from the NBS card in Wisconsin also helps provide special dietary treatments that are specific to these conditions. These metabolic formulas are necessary to prevent the brain damage, the devastation and/or death as mentioned previously. Unfortunately, these metabolic formulas are often not very accessible to families. In many other states, there isn't a program like ours. In those states, one must go through insurance. But unfortunately, many insurances do not cover these formulas or families can have very large out of pocket costs. Families may have to chose between financial devastation or neurological damage to their child. A teen or adult with PKU may just go off diet and live with a life of impaired executive function, neurological decline, significant mood disorders and poor quality of life. In addition, it can be extremely difficult to find a vendor that will provide these products as Medicaid and even private insurance reimbursement rates can be too low (thus they'd lose money). So, without this aspect, patients would be given the diagnosis without proper access to the treatment.

The NBS card also helps fund ongoing clinical care. These patient's care is complex and requires significant coordination and counseling. We see them outpatient, we see them inpatient, we are on call at nights and during the weekends, and we are constant contact with patients in between visits. We are with them every step of the way as they overcome these difficult conditions. They get to know us very well; we become a lifeline for them. These funds help support a dedicated team of physicians, metabolic dietitians, genetic counselors, nursing and other essential staff. There are only 3 centers in Wisconsin – Milwaukee, Madison and Marshfield. Other clinics may have never even heard of some of these conditions, let alone be able to treat them.

In conclusion, I am strongly urging support for CR24-025, so that the program can continue to effectively screen every child in the State of Wisconsin for these conditions now and into the future. And, to support access to effective treatments and ongoing clinical care once the program diagnoses them.

Thank you,

Matthew Rasberry, RD, LD
Madison, WI
262-408-0347
mdrasberry@gmail.com

Senate Committee on Health Public Hearing, Madison, 3/12/2025
In support of: *Clearinghouse Rule 24-025*

My name is Emily Singh and I am a resident of Greendale. I am a certified genetic counselor at Medical College of Wisconsin and Children's Wisconsin with a decade of experience working with rare metabolic genetic diseases and the Wisconsin newborn screening program. I serve as the genetic counselor representative on both the Secretary's Advisory Committee on Newborn Screening and the Newborn Screening Metabolic Subcommittee. However, I am here today to provide testimony as a private citizen. I implore the committee members before me to support Rule 24-025 and the proposed increase in the NBS card fee to $223.

I speak from experience to tell you that Wisconsin's newborn screen program is a well-oiled machine. The proposed addition of the conditions X-Linked Adrenoleukodystrophy and Mucopolysaccharidosis type I reflects careful consideration and consultation with experts. This ensures that any additions made to our program are supported by the science and that there are adequate resources in the state of Wisconsin to care for individuals with these conditions.

The program's thoughtful approach to lab operations and long-term services has allowed us to identify and care for babies born over the last 60 years with nearly 50 conditions and counting. The DHS NBS report found that the total patient population served by the NBS program nearly doubled from fiscal year 2009 to 2022. This increase reflects not just new babies born and quickly diagnosed and treated due to newborn screening, but also the fact that our children are living into adulthood. Listen to that again. Children born with rare, severe metabolic conditions are growing up, going to school, entering the workforce, and thriving. This future can be taken away in a matter of hours or days if their condition is not identified through newborn screening or if treatment is delayed or interrupted due to barriers to care.

I'd like to highlight the program's long-term services and their measure of success in the form of healthy lives for Wisconsin children. These services go beyond DHS and the NBS lab to the ongoing clinical care provided by the geneticists, dietitians, genetic counselors, and nurses who are supported in part by NBS funding . WE o provide the lifetime of appointments and many, many hours of the behind-the-scenes, unbillable care our patients require. This includes doctors' appointments to tailor the healthcare plan, dietitian assessment (sometimes weekly in the first year of life!) to make sure the child's special dietary treatment plan is growing with them, and consultation with a genetic counselor to learn about this rare disease they've never heard of and identify other family members who need testing and treatment before it's too late (maybe that's an older sibling born just months before screening started for that particular condition). The specialty centers like Children's Wisconsin and UW Health already absorb a portion of the cost for unbillable services, but funding through the NBS program helps to offset the financial impact of this highly specialized care.

I also want to highlight that the medical formulas and foods, called special dietary treatment, provided by the NBS program are a critical part of our patients' and program's success. You cannot achieve the benefits of newborn screening without the use of special dietary treatment. These specialized formulas can cost thousands of dollars out of pocket annually and are very often not covered by insurance, but our patients need to take them for life. In Wisconsin, Medicaid reimbursement is so low that many specialty pharmacies refuse to stock the formulas, meaning our families very simply could not access them without the current system in place. Imagine being told that your baby can only live or develop normally if he eats a very special low-protein formula and then not being able to access or

Re: Joint Public Hearing between Senate Committee on Health and Assembly Committee on Health, Aging and Long-Term Care re: Clearinghouse Rule 24-025

In support of funding increases for Newborn Screening through a fee increase to newborn screening sample collection card.

My name is Jessica Kopesky. I am employed as a Senior Clinical Dietitian at Children's Wisconsin and I serve as a dietitian representative on the Newborn Screening Metabolic Subcommittee. I am writing today as a private citizen and resident of Brookfield, WI to request your support for the proposed rule **CR24-025** relating to screening of newborns for congenital disorders, currently in review by the Senate Committee on Health and the Assembly Committee on Health, Aging and Long-Term Care.

The Newborn Screening Program (NBSP) is one of the most successful public health programs, saving countless lives through early detection of congenital and inherited disorders that may not present symptoms at birth, but can cause permanent disability or death if not detected and treated within the first few days of life. In my job, I get to work with patients of all ages who have been diagnosed with a variety of conditions collectively known as inherited metabolic disease (IMD), almost all of which are identified through NBS. All the conditions we treat have the potential to be completely devastating, both cognitively and/or physically, and can often lead to early death if treatment is not started urgently and continued for life. But they ***are*** treatable, and those tragic outcomes ***are*** preventable.

Taking care of people with rare IMD conditions does not stop with early identification via NBS. On the contrary, people with IMD require lifelong access to highly specialized ongoing clinical care, including frequent contact with highly specialized physicians, dietitians, genetic counselors and/or nurse clinicians. The many hours spent in coordination and ongoing care are often not considered billable services. While the consulting agencies do absorb a portion of those operating costs, funding through the NBS program is critical to maintaining those services.

Additionally, many of the conditions require lifelong access to Special Dietary Treatment (SDT), including medical food and medically modified low protein foods. Unfortunately, these medically necessary products are often **not** covered by insurance. When insurance does "cover" these products, reimbursement is so low that many home care companies refuse to stock these products, making it exceedingly difficult for people living with IMD to access their life-saving treatments. We frequently hear from our dietitian colleagues in other states that have lost state funding for SDT about people who are no longer able to access and afford their medical food or families who can only afford a small portion of their child's necessary treatment, and the spiraling negative effects that has on their ability to function in and contribute to society.

The Wisconsin NBSP is funded by a user-generated fee; no state tax dollars are provided to support it. Prior to 2023, the user fee had not increased since 2010 despite increases in: conditions screened, number of babies screened (due to population and birth rate changes), an increasing caseload that nearly doubled between 2009 and 2022, inflation, and operational costs. As such, the program operated at a loss for several years and accumulated a deficit.

WISCONSIN DEPARTMENT
of HEALTH SERVICES

Division of Public Health

Newborn Screening Program Overview

Newborn screening (NBS) is a vital public health program implemented 60 years ago that identifies infants with conditions impacting long-term development, health, or survival. Every year, approximately 60,000 babies in Wisconsin are screened for congenital disorders. Most disorders detected by NBS program are life-threatening or have permanent detrimental effects on health if appropriate treatments are not provided shortly after birth.

By Wisconsin state statute (Wis. Stat. ch. 253), the newborn screening program:

- Screens newborns for congenital disorders (blood).
- Provides special dietary and other treatment to individuals with congenital disorders identified by NBS.
- Provides follow-up diagnostic and counseling services.
- Administers the newborn hearing and heart screening programs.

Details

NBS is a three-part system. Blood screening run by Wisconsin Department of Health Services (DHS) and contracted agencies including the Wisconsin State Lab of Hygiene (WSLH). WSLH carries out laboratory testing for nearly 50 conditions.

NBS was initially developed to screen for Phenylketonuria (PKU) but currently screens for that condition plus many others including Cystic Fibrosis and Sickle Cell Disease. The conditions chosen to be screened are informed by the Recommended Uniform Screening Panel (RUSP) at the federal level and guided by the DHS Secretary's Advisory Committee on Newborn Screening (SACNBS) at the state level. Heart and hearing screenings are run by DHS staff and contracted agencies to detect serious heart conditions and hearing impairment.

Costs

The newborn screening program's costs are funded primarily through a fee paid by hospitals and birthing centers.

- The fee was increased to $195 per card through the biennial budget process in 2023.
- The fee had been $109 per card since 2010 with no increase in 13 years.
- Hospitals bill the fee to the family's health insurance where possible.
- The Medicaid program reflects the blood card fee cost in its reimbursement rate for births for families enrolled in Medicaid.
- Revenue that supports the program is split between WSLH 53.7% (~$105 per card) and DHS 46.3% (~$90 per card).

The proposed increased fee to $223 per card would:

- Support WSLH to carry out blood screening (~$125 per card).
- Allow DHS to administer the program (~$98 per card), avoiding deficit spending.

Overall, NBS program costs increase when new conditions are added to the screening panel. This happens through a formal nomination and review process administered by DHS. Also, ongoing Special Dietary Treatment (SDT) costs are subject to rise, as the treatment is provided for life, affected by inflation, and involves critical functions such as rapid courier transport of blood cards to the lab.