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## Senate Committee on Health SB 962 Testimony

Good morning committee members and chairwoman Cabral-Guevara. Thank you for being here today and hearing SB 962.

Screening newborns for ailments can oftentimes save lives or prevent the child from suffering from life-long debilitating conditions. This is why state statute directs the Dept. of Health Services(DHS) to require screening newborns for certain congenital and metabolic disorders. DHS relies on the Newborn Screening Advisory Group (made up of public health professionals, health care providers, and parents) to make recommendations of adding any new condition to the state's newborn screening panel. This panel in turn uses many of the sicknesses contained in the federal government's Recommended Uniform Screening Panel (RUSP) list.

While Wisconsin currently screens for 48 blood disorders, including 33 of the 37 conditions RUSP has recognized, the state currently ranks #31 in screening newborns for health conditions. We are far below Illinois(#5) and Minnesota(#6). As you can see, there is room for improvement. Under our bill, the State newborn screening panel would be required to consider (not mandated to approve) the addition of the remaining diseases on the federal RUSP (MPS-1, MPS-II, ALD, and GAMT). In addition, the bill would require the state's newborn screening panel to consider any future conditions added to the RUSP. Should they agree to add a condition, the bill establishes a reasonable timeline of 6 months for DHS to add that condition via administrative rule making, which is the same process that is used today.

Thank you again for hearing SB 962. I'll be happy to answer any questions you may have.



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# BARBARA DITTRICH

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STATE REPRESENTATIVE • 38<sup>th</sup> ASSEMBLY DISTRICT

February 6, 2024

## Senate Committee on Health

**Rep. Dittrich Testimony on SB 962** - the procedure for adding federal newborn screening recommendations to the state-required newborn screenings, granting rule-making authority, and providing an exemption from emergency rule procedures.

Thank you Chair Cabral-Guevara and members of the Senate Committee on Health for hearing Senate Bill 962 today on what has proved to be a long day with many bills to consider. I want to thank Senator Jagler for his leadership on this bill and for allowing me the opportunity to join him today before this committee. Given the full slate before this committee today, I'll keep this brief. However, I'd like to think we've saved the best for last.

SB 962 is an important piece of legislation for the committee to consider before we wrap up session. As you may already know, the Newborn Screening Program, administered by the Department of Health Services, screens newborn babies for a wide array of debilitating and deadly diseases. WI currently screens for 48 blood disorders, including 33 of the 37 conditions on the national Recommended Uniform Screening Panel (RUSP). Despite the efforts being put forth in screening for these conditions, WI still falls behind neighboring states in the number of conditions screened overall as well as the number listed in RUSP. WI currently ranks #31 in newborn screening whereas MN ranks #6, and IL ranks #5.

This bill would simply require the screening panel at DHS to CONSIDER, not mandate, adding the other 4 condition from RUSP to the list of diseases screened at birth. The bill, if it becomes law, also allows DHS to promulgate rules to adopt the new procedures so they can incorporate them within a reasonable timeline. This practice is already in place with many of our other health policies.

Again, thank you to the committee for your time. Senator Jagler and I are happy to answer questions.



State of Wisconsin  
Department of Health Services

Tony Evers, Governor  
Kirsten L. Johnson, Secretary

**TO:** Members of the Senate Committee on Health

**FROM:** HJ Waukau, Legislative Director

**DATE:** February 6, 2024

**RE:** SB 962 relating to: the procedure for adding federal newborn screening recommendations to the state-required newborn screenings, granting rule-making authority, and providing an exemption from emergency rule procedures

The Wisconsin Department of Health Services (DHS) would like to submit written testimony in support of Senate Bill 962 (SB 962) regarding adding conditions to the state's newborn screening (NBS) program from the federal Recommended Uniform Screening Panel (RUSP). Under SB 962 DHS would be required to evaluate each disorder included in the RUSP as of January 1, 2024, for inclusion in the NBS program. Conditions added to the RUSP after January 1, 2024, would also have to be evaluated by DHS for inclusion in the NBS program. However, DHS would not have to evaluate RUSP conditions currently part of the NBS program. Additionally, for any new disorder added to the RUSP, DHS would have to evaluate whether to include the condition in the NBS program and if added, submit a scope statement to the legislature within 18 months. If a new RUSP condition is not added to the NBS program DHS must evaluate the condition annually based on criteria specified in SB 962. SB 962 also provides DHS with rulemaking, including emergency rulemaking, for any new conditions added to the NBS program.

Wisconsin's NBS program is administered through a partnership between DHS and Wisconsin State Laboratory of Hygiene (WSLH), and screens babies for 48 blood disorders, hearing loss, and congenital heart disease. Although rare, many of the conditions detected by newborn screening allow babies to get early treatment if needed, inform families so they can plan for their baby's needs, and allow providers and families time to find the right specialists.<sup>1</sup> As specified under Wis. Stat. 253.13 the NBS program requires all babies born in Wisconsin hospitals to have a newborn screening before they leave the hospital. Babies born at home must be tested within a week of birth and ideally within the first days of life. Parents may also opt out of screening for their babies. The NBS program is funded through program revenue generated by a fee assessed to hospitals, or medical professionals attending a birth outside of a hospital, by purchasing blood collection cards from WSLH.<sup>2</sup> The NBS program also has several committees (Secretary Advisory Committee, Umbrella Committee, Education Subcommittee, and disorder-specific subcommittees), which evaluate and advise on which conditions to add to the NBS program. Committee members include physicians, clinical specialists, parents, patient groups, nurses, and local health departments among others.

<sup>1</sup> "Newborn Screening Program," Wisconsin Department of Health Services, last revised July 7, 2023, <https://www.dhs.wisconsin.gov/newbornscreening/index.htm>.

<sup>2</sup> "Newborn Screening Program, Paper #436," Wisconsin State Legislature, June, 2023, [https://docs.legis.wisconsin.gov/misc/lfb/budget/2023\\_25\\_biennial\\_budget/302\\_budget\\_papers/436\\_health\\_services\\_public\\_health\\_newborn\\_screening\\_program.pdf](https://docs.legis.wisconsin.gov/misc/lfb/budget/2023_25_biennial_budget/302_budget_papers/436_health_services_public_health_newborn_screening_program.pdf).

The RUSP is a list of disorders that the Secretary of the U.S. Department of Health and Human Services (HHS) recommends for states to screen as part of their universal NBS programs.<sup>3</sup> Disorders are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.<sup>4</sup>

At present, Wisconsin's NBS program tests for 33 of the 37 core RUSP conditions. Two additional conditions, X-Linked Adrenoleukodystrophy (X-ALD) and Mucopolysaccharidosis type 1 (MPS-1), are currently undergoing rulemaking to be added to the program.<sup>5</sup> While HHS recommends states test for all conditions listed in the RUSP, no state currently tests for all conditions. A list of all conditions currently tested for under the NBS program can be found in DHS Administrative Code Ch. 115.

DHS worked with the bill authors and advocates to craft a bill that would be responsive to the dynamics of the current NBS program while expanding the purview of conditions to be considered for addition to the program. SB 962 as drafted reflects those conversations and DHS thanks the bill authors and advocates for their collaboration and partnership. Under SB 962 Wisconsin would maintain local control of its NBS program in line with its current capacity and resources. It would also allow the NBS program to continue operating within its current programmatic structure rather than automatically adding conditions which the program may not be able to appropriately fund, nor the NBS program committees find are appropriate for Wisconsin. This is especially important as the NBS program needs to obtain legislative approval for funding, which may need to be increased if and when new conditions are added. SB 962 would also assure the NBS program is continuously monitoring and evaluating new conditions to be added to the program.

DHS again thanks the bill authors for their collaboration and partnership in crafting SB 962, and thanks the Committee for the opportunity to submit written testimony in support of SB 962.

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<sup>3</sup> "Recommended Uniform Screening Panel," Health Resources Services Administration, last reviewed August 2023, <https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp>.

<sup>4</sup> Ibid.

<sup>5</sup> "Scope Statement SS 056-23," Wisconsin State Legislature, last viewed February 5, 2024, [https://docs.legis.wisconsin.gov/code/scope\\_statements/all/056\\_23](https://docs.legis.wisconsin.gov/code/scope_statements/all/056_23).