DIVISION OF PUBLIC HEALTH

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Date: July 10, 2025

- To: Hospital Administrators, Newborn Nursery Managers, Neonatal Intensive Care Units (NICU), Special Care Nurseries, Primary Care Providers, Wisconsin Academy of Family Physicians, Wisconsin Chapter of the American Academy of Pediatrics, Wisconsin Guild of Midwives, Wisconsin Section of the American College of Obstetricians and Gynecologists, Wisconsin Association of Perinatal Care, Wisconsin Hospital Association, and Wisconsin Medical Society
- From: Paula Tran, MPH State Health Officer and Administrator Division of Public Health

James J. Schauer, PhD, PE, MBA Director Wisconsin State Laboratory of Hygiene School of Medicine and Public Health University of Wisconsin-Madison

Re: Rule Issued to Add X-ALD and MPS I Conditions to Newborn Screening Panel

The Wisconsin Department of Health Services (DHS) has added, by rule, screening for X-ALD (X-Linked Adrenoleukodystrophy) and MPS 1 (Mucopolysaccharidosis type I) conditions to the Wisconsin Newborn Screening Program's panel of conditions. This rule will go into effect once it is published in the Wisconsin State Journal, which is expected to occur on August 1, 2025.

In Wisconsin, newborn screening is required by law (<u>Wis. Stat. § 253.13</u>). Infants have newborn screening within 24/–48 hours after birth.

With the issuance of this rule, the newborn screening blood card fee will be \$223. The fee adjustment supports the program's ability to carry out all required newborn screening activities, including the implementation of these new screenings.

Why is it important to screen for X-ALD and MPS I condition?

X-ALD and MPS I are very serious disorders that can be fatal or cause significant disability when diagnosis and/or treatment is delayed. When X-ALD and MPS I are detected early, and proper treatment is started many babies remain relatively healthy or have minimal disability.

How is screening for X-ALD and MPS I condition done?

As with all other newborn screening conditions detected in the blood spot, X-ALD and MPS I are screened by laboratory tests. This condition will be added to the current newborn screen panel; no additional blood spot card is required.

What happens if a newborn has a positive screen for either condition?

If a newborn has a positive screen, they will need a definitive test for the condition. When the positive screen is obtained, the Wisconsin State Laboratory of Hygiene where the screening tests are performed, will contact the newborn's primary care provider to let them know of the need for further testing. An appropriate specialist will also be informed so the baby's primary care provider will have necessary professional support. This will be true for babies born out of hospital as well.

How can I find out more information about X-ALD and MPS I conditions?

Additional information on X-ALD can be found at <u>MedlinePlus</u> and the <u>National Library of</u> <u>Medicine</u>. Additional information on MPS I can be found at <u>MedlinePlus</u> and the <u>National</u> <u>Library of Medicine</u>.

For questions for the Wisconsin Department of Health Services, you can reach Robert Steiner, MD, medical director for the Newborn Screening Program in the Bureau of Community Health Promotion by email at <u>Robert.Steiner@dhs.wisconsin.gov</u>, or by phone at 608-267-7148.

For questions for the Newborn Screening Laboratory at the Wisconsin State Laboratory of Hygiene, you can reach Mei Baker, MD, director for the Newborn Screening Laboratory by email at <u>Mei.Baker@wisc.edu</u>, or by phone at 608-890-1796.