NORTH Dakota | Health & Human Services
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PUBLIC HEALTH DIVISION
Healthy and Safe Communities Section
Newborn Screening & Follow-Up Program
600 E Boulevard Ave - Dept 325
Bismarck, ND 58505-0200
hhs.nd.gov
1-800-755-2714

MEMO

To: North Dakota Newborn Screening Specimen Submitters

From: Joyal Meyer, Manager, ND Newborn Screening & Follow-up Program (NDSFP)
Kenneth Coursey, Program Manager, State Hygienic Laboratory (SHL) at the University of Iowa

RE: Newborn Blood Spot Screening Fee Increase and Addition of Conditions to the Newborn Screening Panel: X-linked Adrenoleukodystrophy (X-ALD), Mucopolysaccharidosis Type II (MPS II) and Krabbe Disease

Date: December 16, 2025

The North Dakota Department of Health and Human Services (HHS) is committed to promoting the health of infants born in North Dakota (ND). Early detection of treatable hereditary and congenital conditions allows for the prevention or reduction of symptoms and, ultimately, saves babies' lives.

Sherry Adams, State Health Officer, has authorized the NDSFP to begin screening for X-linked Adrenoleukodystrophy (X-ALD), Mucopolysaccharidosis Type II (MPS II), Krabbe Disease and Guanidinoacetate Methyltransferase Deficiency (GAMT). Screening for X-ALD, MPS II and Krabbe Disease will begin with specimens received on February 3, 2026. Screening for GAMT Deficiency will begin at a later date in 2026 and a separate notification will be sent when a date is confirmed. The addition of the three conditions requires no change in the current collection or transportation of specimens (courier services are available through Meadowlark Logistics for all birthing facilities, various clinics and midwives in ND). Testing will continue with the ND designated contract laboratory, the SHL at the University of Iowa.

For specimens received on February 3, 2026, the newborn blood spot screening fee will increase from **$122 to $129**. Please ensure your billing department is aware that newborn blood spot screening specimens are send out labs and your facility is not processing the specimens so that each individual condition on the panel is not billed separately. Please note that **individual** CPT codes should not be used for the newborn screening panel. The newborn screening panel Healthcare Common Procedure Coding System (HCPCS) Code is S3620. It is appropriate to bill a collection fee for the supplies and staff time. Please note, the SHL does not charge submitters/facilities for repeat specimens, so please verify with your billing department that patients are not being billed for specimens that may have been poor quality due to an error in collection.

The result specifications for the North Dakota Newborn Screening Panel are located here. Please have your Information Technology staff build the new components (highlighted in yellow) into your Electronic Medical Record.

X-ALD is a rare genetic disorder that affects the white matter of the nervous system and the adrenal cortex. Affected individuals may experience serious neurological problems during childhood and/or during adulthood. Some affected individuals also have adrenal insufficiency, which means that reduced amounts of certain hormones such as adrenaline and cortisol are produced, leading to abnormalities in blood pressure, heart rate, sexual development and reproduction. ALD is an X-linked recessive disorder that is caused by disease-causing variants in the *ABCD1* gene. Because it is an X-linked disorder, males can develop more serious complications than females, while some females will have no symptoms. In males, X-ALD can manifest with adrenal insufficiency, cerebral ALD, and adrenomyeloneuropathy in adulthood; very rarely it can be asymptomatic. In women, X-ALD can manifest with adrenomyeloneuropathy in adulthood.

The SHL will test for elevated levels of the very long-chain fatty acid C26:0 Lysophosphatidylcholine (LPC) using tandem mass spectrometry. This methodology can detect males and females with X-ALD.

MPS II is a lysosomal storage condition that results in the inability of a body to produce an enzyme called lysosomal iduronate-2-sulfatase. Lack of this enzyme leads to build up of long chain sugar molecules called glycosaminoglycans. MPS II can be classified as a severe or attenuated case based on the age of onset, and severity of symptoms varies. Severe cases are characterized by deposits of glycosaminoglycans leading to skeletal abnormalities, cognitive impairment, heart disease, respiratory problems, enlarged liver (hepatomegaly) and spleen, characteristic facies, and reduced life expectancy. Attenuated forms of MPS II show a variability in onset and progression of disease and degree of cognitive impairment. MPS II is an X-linked condition and will most often affect boys.

The SHL will test for the level of enzymatic activity for the enzyme Iduronate 2-sulfatase using liquid chromatography with tandem mass spectrometry. Second tier testing will be performed for all specimens found to be presumptive positive on the first-tier screen.

Krabbe Disease (also called globoid cell leukodystrophy) is a severe neurological condition. It is part of a group of disorders known as leukodystrophies, which result from the loss of myelin (demyelination) in the nervous system. The most common form of Krabbe disease, called the infantile form, usually begins before the age of one. Initial signs and symptoms typically include irritability, muscle weakness, feeding difficulties, episodes of fever without any sign of infection, stiff posture, and delayed mental and physical development. As the disease progresses, muscles continue to weaken, affecting the infant's ability to move, chew, swallow, and breathe. Affected infants also experience vision loss and seizures. Without treatment, the average age of death is 24 months. Currently available treatment consists of hematopoietic stem cell (bone marrow or umbilical cord blood) transplant but must be performed before the onset of symptoms, typically within the first month of life.

The lab will test for the level of enzymatic activity for the enzyme Galactosylceramidase using liquid chromatography with tandem mass spectrometry. Second tier testing will be performed for all specimens found to be presumptive positive on the first-tier screen.

Newborn screening follow-up program staff will follow up on all out-of-range results with the patient’s primary care provider or hospital the newborn is currently receiving care, with results, recommendations, and education. Medical consultants will be available to assist with all abnormal assay results.

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As a reminder, newborn screening is not considered a diagnostic test; confirmatory testing is always needed. A false negative or a false positive result must always be considered when screening. Clinical findings and status should be considered whenever interpreting laboratory results.

Questions may be directed to any of the following individuals:

Administrative Questions:	Joyal Meyer Manager, Newborn Screening & Follow-up Program North Dakota Department of Health & Human Services 701-328-4534 jbmeyer@nd.gov
Laboratory Questions:	Kenneth Coursey Newborn Screening Program Manager State Hygienic Laboratory, University of Iowa 319-467-1022 kenneth-coursey@uiowa.edu
Short-term Follow-up Questions:	Tiffany Williams North Dakota Short-term Follow-up Nurse Iowa Newborn Screening Program 319-356-1429 tiffany-williams@uiowa.edu
Information Technology Questions:	Mike Hayek IT Support Consultant State Hygienic Laboratory, University of Iowa 319-335-4254 michael-hayek@uiowa.edu