

MLS Laboratory Update: Krabbe Disease Screening

FEBRUARY 26, 2024

Purpose of this Message:

To inform MLS Laboratories that screening for Krabbe disease will begin shortly.

Action Item:

Read the notification and share with other laboratorians and clinical partners at your site.

Laboratory Specific Information:

- Effective Monday, February 26, 2024, samples received by our laboratory will be tested for Krabbe disease.
- No change in specimen requirements or cost.
- No changes have been made to the newborn screening report, results will be included in the “Lysosomal Disease Profile” field already present in the newborn screening report.

Background:

The Minnesota Newborn Screening Program is pleased to announce that we are screening for Krabbe disease. The addition of Krabbe disease will not add to the cost of newborn screening specimen cards at this time. Krabbe disease will be included in the “Lysosomal Disease Profile” field, so there will be no changes to the report template. However, you may see new results within that row related to Krabbe.

Krabbe disease is a rare, genetic condition in which the newborn cannot fully break down certain fats. These fats build up in the body and can lead to damage to the nerves affecting a person’s ability to eat, walk, and speak. In the most severe form, infantile Krabbe disease, symptoms can progress to death within the first 2 years of life. There is no cure for Krabbe disease, but treatment can help manage symptoms and improve quality of life. Currently, the only treatment is a stem cell transplant, which is ideally performed before a baby identified with infantile Krabbe disease is 30 days old. Due to the importance of early treatment, the process from screening, diagnostic exams, and treatment appointments must move quickly.

Identifying infantile Krabbe disease in newborns allows families to receive early diagnosis and monitoring, education, and appropriate medical care.

Additional Information:

As a reminder, S3620 is a valid healthcare common procedure coding system (HCPCS) code for newborn metabolic screening panel, it includes test kit, postage, and the laboratory tests specified by the state for inclusion in this panel. For repeat screens, report S3620 with the

appropriate modifier for repeat services (-76, -77). This HCPCS code is provided as a resource to healthcare professionals. The final billing-related decisions must be made by the healthcare provider.

Please share this letter and its enclosure with the appropriate personnel within your hospital system. We hope you find this information helpful in your preparation, and we thank you for your continued support of newborn screening.

Questions: Please contact: Carrie Wolf, our interim Newborn Screening Program manager at carrie.wolf@state.mn.us or 651-201-5458.

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PLEASE FORWARD THIS TO ALL APPROPRIATE PERSONNEL WITHIN YOUR INSTITUTION AND HEALTH SYSTEM

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To obtain this information in a different format, call: 651-201-5200.