

To: All providers of newborn screening (NBS) specimens
From: Dr. Kara Levinson, Laboratory Director
Date: June 25, 2025
Subject: Removal of NBS Screening for Nonketotic Hyperglycinemia (NKH)

Effective August 1st, 2025, the Tennessee Department of Health (TDH) Division of Laboratory Services (DLS) will discontinue screening and reporting results for the condition Nonketotic Hyperglycinemia (NKH) in dried blood spots (DBS). This change is based on the vote and recommendation of the Tennessee Genetics Advisory Committee to remove NKH from its newborn screening panel.

Reasons for this recommendation and removal include:

- NKH is not currently a diagnosis on the Recommended Uniform Screening Panel (RUSP), which is the standardized list of disorders recommended by the Secretary of the Department of Health and Human Services (HHS).
- NKH was originally added to the Tennessee Newborn Screening Panel in 2006. Since that time, there have been six infants identified with the condition through newborn screening and over 1,000 false positives. Positive specimens require repeat testing that delays reporting results and can lead to stress and anxiety for parents.

Due to the challenges with screening for NKH and limited availability of treatment options, the Genetics Advisory Committee believes removing NKH from the newborn screening panel is the appropriate step.

Alternative test options can be sought through commercial or reference laboratories if this type of testing is needed. Infants with NKH can be diagnosed clinically and should be suspected in any infant with signs and symptoms (such as hypotonia, lethargy, coma, apnea, seizures, poor feeding, and developmental delays), laboratory findings (elevated glycine in plasma and CSF), and neuroimaging findings of NKH.

Questions regarding these changes can be directed to Newborn Screening Assistant Director, Dr. Jennifer McKenzie at (615) 262-6352 or jennifer.mckenzie@tn.gov.

Thank you for your continued partnership,



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