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National Organization
for Rare Disorders

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April 4, 2025

NORD CEO Statement on the Termination of The Advisory Committee on Heritable Disorders in Newborns and Children

The National Organization for Rare Disorders (NORD®) is a nonprofit, nonpartisan organization representing the more than 30 million Americans living with rare diseases.

The sudden termination of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) raises serious concerns for the rare disease community and families nationwide. The ACHDNC is a critical part of the U.S. newborn screening system, providing guidance to the Secretary of the Department of Health and Human Services (HHS) on the most appropriate application of universal newborn screening tests, technologies, policies, guidelines, and standards. This committee played a critical role in reviewing evidence and making recommendations to the Secretary on which conditions are added to the Recommended Uniform Screening Panel (RUSP), a list that helps states determine which serious, treatable rare diseases should be added to the state newborn screening program. Without this expert oversight, we risk delays in diagnosis and treatment that could save children's lives and improve health outcomes for children and families.

Each year, newborn screening helps identify approximately 14,000 babies with serious conditions. Elimination of the ACHDNC risks the preventable death and suffering of children with treatable rare disorders. It is particularly crushing for the individuals and families impacted by conditions currently going through the RUSP nomination process who are left in limbo by this decision.

NORD remains steadfast in our commitment to advocating for robust and well-supported newborn screening programs. We are actively monitoring developments at HHS as it unfolds, and we will be working with policymakers on both sides of the aisle and partners across the newborn screening system to expeditiously work toward a solution and ensure all newborns born in the United States can benefit from early diagnosis and treatment of serious rare medical conditions.

Sincerely,

Pamela Gavin
Chief Executive Officer
National Organization for Rare Disorders (NORD)