July 15, 2025

The Honorable Morgan Griffith,
Chairman
House Committee on Energy and Commerce
Subcommittee on Health
2110 Rayburn House Office Building
Washington, DC 20515

The Honorable Diana DeGette,
Ranking Member
House Committee on Energy and Commerce
Subcommittee on Health
2111 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Griffith and Ranking Member DeGette:

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) thanks the Energy and Commerce Subcommittee on Health (the Subcommittee) for convening tomorrow's hearing titled "Legislative Proposals To Maintain And Improve The Public Health Workforce, Rural Health, And Over-The-Counter Medicines". In particular, we are incredibly grateful for the Subcommittee's consideration of the Newborn Screening Saves Lives Reauthorization Act of 2025, legislation that will strengthen and modernize our newborn screening ecosystem across the country. We ask that you support this legislation as part of your participation in tomorrow's hearing.

MDA is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For 75 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our community. MDA's mission is to empower the people we serve to live longer, more independent lives.

Newborn screening is one of the most successful public health programs in U.S. history. Put together, each state's program collectively screens nearly every newborn in the United States for over 35 conditions that, if diagnosed at birth, can be treated, thus avoiding some of, if not all, of the most challenging features of the disease. Newborn screening saves thousands of lives every year, is one of the most cost-effective public health programs in history, and will only grow in importance as additional targeted and genetic rare disease therapies are developed and made available.

Newborn screening is particularly important to the rare neuromuscular disease community that we serve. Two conditions, spinal muscular atrophy (SMA) and Pompe disease, are currently included on the Recommended Uniform Screening Panel (RUSP) with universal state adoption of SMA, and the vast majority of states screening for Pompe disease. We, along with Parent Project Muscular Dystrophy, have also submitted Duchenne muscular dystrophy for consideration to be added to the RUSP. While the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was disbanded this Spring, we remain hopeful that the Department of Health and Human Services and Secretary Kennedy will consider the evidence supporting our nomination and will add Duchenne to the RUSP.

The Newborn Screening Saves Lives Reauthorization Act is incredibly important to our community for a number of reasons. First, the legislation reauthorizes and updates programs at the Health Resources and Services Administration (HRSA) that support and guide states on which conditions for which to screen, how to construct follow up programs for those who are diagnosed, and more. Second, the legislation reauthorizes and updates programs at the Centers for Disease Control and Prevention (CDC) that are instrumental in assisting state public health laboratories on the process of collecting and assessing the dried blood spots that are tested in newborn screening as well as the confirmatory testing following positive screens. Finally, the legislation reauthorizes and updates the Hunter Kelly Newborn Screening Research Program at the National Institutes of Health (NIH) that researches new potential screens for diseases not currently on the RUSP among other newborn screening research endeavors.

This legislation gives the Subcommittee the opportunity to support a comprehensive update to our newborn screening ecosystem and infrastructure by ensuring the Federal programs dedicated to assisting states are robust, up-to-date, and well-funded. We urge Subcommittee members to support the legislation in this hearing.

We appreciate this opportunity to provide the Committee with the perspectives of the NMD community. For questions regarding MDA or the above comments, please contact Paul Melmeyer, Executive Vice President, Public Policy and Advocacy, at pmelmeyer@mdausa.org,

Sincerely,

Paul Melmeyer, MPP
Executive Vice President, Public Policy and Advocacy
Muscular Dystrophy Association