Parent Project Muscular Dystrophy
MDA® | Muscular Dystrophy Association

December 22, 2025

Office of the General Counsel
Ohio Department of Health
246 N. High St.
Columbus, Ohio 43215

Re: Newborn Screening Test Kit Fee Increase and Duchenne muscular dystrophy

To whomever it may concern,

The Muscular Dystrophy Association (MDA) and Parent Project Muscular Dystrophy (PPMD), leading organizations who collectively serve the Duchenne muscular dystrophy (DMD) community, urge you to consider any proposals that ensure DMD newborn screening continues unimpeded in Ohio, including by raising the fee of the newborn screening test kit to cover the costs of procuring the kits and maintaining the program.

Duchenne muscular dystrophy (DMD) is a genetic disorder characterized by progressive muscle degeneration and weakness. Parents often notice symptoms when their baby is 2 or 3, but without newborn screening it often takes years for a family to receive a diagnosis. These are lost years in which parents are often paying for unnecessary or damaging procedures while their child's muscle goes unprotected without treatment. As DMD progresses, children lose the ability to walk and start to face weakness to their heart and respiratory muscles, leading to heart or respiratory failure.

Newborn screening for DMD holds the promise of vastly accelerating the time to diagnosis and subsequent access to disease-modifying care, thus resulting in better health and life experiences for children with DMD. Delayed identification has lifelong consequences from missed treatment windows, irreversible medical complications, and a heavier emotional and financial burden on families. We routinely hear from families who spent years searching for answers while their children's precious time and muscle were lost. Newborn screening prevents that harm. This is why we strongly supported Ohio becoming the first state in the nation to screen for DMD, and are incredibly grateful to Ohio for leading the nation in prioritizing the health and wellbeing of children born with DMD and their families.

The fee adjustment proposed by the Department of Health is essential to sustaining this mission. We understand that the revenue collected by the current newborn screening test kit fee is not keeping up with the expenses of the Department, and Federal funding that helped offset these costs will not be available. The proposed change would ensure that families continue to receive timely results and appropriate follow-up. Failure to approve this adjustment would jeopardize not only screening for conditions recently added to the panel like DMD, but also the infrastructure that underpins the entire program and forms the foundation to add new conditions in the future to support more families.

Ohio has been a national leader in newborn screening. To maintain that leadership and preserve the health and futures of newborns across the state, the Department of Health must be equipped with the resources necessary to run a modern, robust newborn screening system. Thank you again for the opportunity to provide our viewpoints on the importance of newborn screening for Duchenne muscular dystrophy in Ohio. For questions on DMD or newborn screening, please contact Paul Melmeyer at MDA at pmelmeyer@mdausa.org or Lauren Stanford at PPMD at lauren@parentprojectmd.org.

Sincerely,

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

Lauren Stanf

Lauren Stanford
Senior Director, Advocacy
Parent Project Muscular Dystrophy