January 14, 2026

The Honorable Kathy Hochul
Governor of New York State

Dr. James McDonald
Commissioner
New York State Department of Health

Re: Funding and Implementation of Duchenne Newborn Screening in New York State

Dear Governor Hochul and Commissioner McDonald:

As two leading patient advocacy organizations representing individuals and families affected by Duchenne muscular dystrophy (Duchenne), we write to urge the immediate funding and implementation of newborn screening for Duchenne in New York State, as mandated by A5042/S6814, which became law in 2023.

More than two years have passed since this legislation was enacted. During that time, the national landscape has moved decisively forward: Duchenne muscular dystrophy was added to the federal Recommended Uniform Screening Panel (RUSP) last month, formally recognizing DMD newborn screening as a national public health priority. New York's continued delay in implementing a program authorized by statute now places the state not only behind its own law, but behind federal recommendations and peer states, at the direct expense of newborns and families.

This delay is not due to lack of readiness. New York State's public health laboratory has already demonstrated feasibility through a successful pilot and subsequent assay validation. Clinical follow-up systems are established, with neuromuscular centers across the state prepared to receive referrals, confirm diagnoses, and provide timely, evidence-based care. The infrastructure exists. What is missing is funding and execution.

Duchenne is the most common childhood-onset muscular dystrophy, affecting approximately 1 in 5,000 boys. Muscle damage begins at birth, well before symptoms are clinically apparent. Early identification through newborn screening enables timely use of disease-modifying therapies, enrollment in early-intervention services, and informed family planning. Just as importantly, screening prevents the prolonged diagnostic odyssey that too many families still endure, often marked by misdiagnosis, unnecessary or invasive testing, and irreversible disease progression.

The intent of the Legislature was clear when A5042/S6814 was passed. The recent addition of Duchenne to the RUSP reinforces the Legislature's clear intent and aligns New York's statutory mandate with national public health standards. Continued inaction now falls short of both.

We respectfully and urgently request that New York State include dedicated funding for Duchenne newborn screening in the enacted budget and establish a clear timeline for program launch. New York has long been a leader in newborn screening. Allowing this delay to persist risks undermining that legacy and, more importantly, deprives families of the benefits that early diagnosis makes possible.

We stand ready to work with the Department of Health and the Governor's Office to support implementation and ensure that New York families receive the standard of care they deserve.

Sincerely,

Lauren

Lauren Stanford

Senior Director, Advocacy

Parent Project Muscular Dystrophy

Paul Melmeyer, MPP

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