Parent Project Muscular Dystrophy
MDA Muscular Dystrophy Association
LITTLE HERCULES FOUNDATION

May 19, 2026

The Honorable Elgie R. Sims, Jr.
Chair, Senate Appropriations Committee
Via email:

Re: Urgent timeline for funding to implement Duchenne newborn screening in Illinois

Dear Senator Sims,

As leaders within the Duchenne community, we write to express **our strong support for Senate Bill 2767,** which would add funding to ensure Illinois follows through on its promise from 2024 to implement Duchenne newborn screening.

In May 2024, Governor Pritzker signed Senate Bill 2658 which added Duchenne to the state's newborn screening panel into law after the bill *unanimously* passed the Senate and the Assembly. Since then, action has languished and families in Illinois who may have children born with Duchenne continue to face a long and expensive diagnostic journey, resulting in irreversible muscle damage.

Almost two years later, despite the legislative intent and the readiness of Illinois' leading children's hospitals, newborn screening for Duchenne has yet to begin. The sole reason is lack of funding.

As you may remember, Duchenne is a fatal, progressive disease that affects approximately 1 in every 5,000 boys. Duchenne is a race against time. Children often go undiagnosed until age 4 or 5, by which point irreversible muscle damage has occurred. Newborn screening changes that paradigm. It enables families to access care and intervention from day one, potentially preserving mobility, cardiac and respiratory function, and quality of life. Today, eight FDA-approved therapies exist to treat Duchenne, and the pipeline for additional treatments continues to grow. Yet the benefits of these interventions are maximized only when initiated early.

Families impacted by Duchenne do not have the luxury of time. Every month of delay robs children of precious muscle function and families of the chance to intervene early. The promise made with the passage of SB 2658 must be fulfilled. I urge you to act now and include funding for Duchenne newborn screening in the budget.

We are ready to support implementation efforts and answer any questions you may have about how to ensure immediate readiness. The time to act is now. Thank you for your leadership and dedication to the health and future of Illinois' children.

Sincerely,

Lauren Stanford

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