

The Honorable Members of the New York State Legislature

RE: Urgent Need for Funding and Implementation of Duchenne Newborn Screening in the New York State Budget

Dear Members of the New York State Legislature,

On behalf of Parent Project Muscular Dystrophy (PPMD) and the thousands of families affected by Duchenne muscular dystrophy, I write to strongly urge the legislature to ensure funding for Duchenne newborn screening is included in the state budget. Furthermore, I encourage the legislature to expedite the implementation of this critical public health initiative.

As you are aware, the New York State Legislature overwhelmingly recognized the importance of Duchenne newborn screening when it unanimously passed A 5042/S 6814. This legislation was a landmark step forward in addressing a devastating, progressive disease that affects approximately 1 in every 5,000 newborn boys. Furthermore, New York has already demonstrated leadership by conducting a successful Duchenne newborn screening pilot, affirming both the feasibility and necessity of this program. Despite these significant milestones, the Governor's proposed budget did not include funding for its implementation, and Duchenne screening remains absent from New York's standard newborn screening panel.

This delay is unacceptable. Duchenne is a fatal genetic disorder that causes progressive muscle degeneration. There are currently eight FDA-approved treatments for Duchenne, and early diagnosis through newborn screening is critical—it allows for earlier access to these and other emerging treatments, better clinical care, and the opportunity to improve health outcomes and extend life expectancy. Without newborn screening, children with Duchenne are often not diagnosed until significant and irreversible muscle damage has already occurred.

The exclusion of funding for Duchenne newborn screening contradicts the will of the Legislature and neglects the urgent needs of affected families. Assemblyman Hevesi's leadership in bringing attention to this issue is commendable, and we fully support his call for immediate action from the administration. New York can lead the nation in ensuring that no family has to endure the devastating consequences of a delayed Duchenne diagnosis.

We implore the Legislature to take decisive action and include dedicated funding for Duchenne newborn screening in the final state budget. Moreover, we urge the administration to swiftly implement screening, fulfilling the commitment made when A 5042/S 6814 was passed and reinforcing New York's position as a leader in public health.

We appreciate your time and commitment to this critical issue and stand ready to support efforts to make Duchenne newborn screening a reality in New York.

Sincerely,

Pat Furlong
President & CEO
Parent Project Muscular Dystrophy