

2026 Policy Changes: Wins and Challenges

In February 2026, MDA applauded the bipartisan passage of the annual federal funding bill that sustains critical investments in biomedical research, rare disease infrastructure, and access to high-quality healthcare.

“Within the consolidated appropriations, there were a number of policies that will directly impact the neuromuscular disease community and the neuromuscular disease care ecosystem, including our Care Centers,” says Paul Melmeyer, Vice President, Public Policy and Advocacy at MDA.

Addressing Medicaid barriers

One of the most impactful provisions in the bill is the [Accelerating Kids’ Access to Care Act](#), which will make it easier to provide Medicaid-covered care for children across state lines.

This addresses longstanding barriers that can delay timely specialty care for children with rare and complex conditions, an issue MDA advocates have elevated for years.

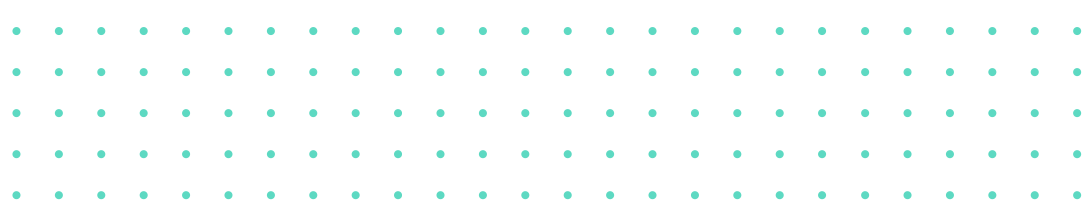
Paul provided an example of the legislation’s impact: “Previously, clinicians at Cincinnati Children’s Hospital may have had difficulty seeking coverage and reimbursement from Kentucky or Indiana Medicaid. This bill will streamline that process, so they won’t have to jump through hoops on a yearly basis, delaying coverage and reimbursement, and delaying access to care, which we’ve heard has happened for those in our community because of this process.”

MDA Care Centers serving patients covered by Medicaid and the Children’s Health Insurance Program (CHIP) in other states will see improvements over the next couple of years as the legislation is fully implemented.

Funding important research

The bill also included important appropriations for research:

- \$48.7 billion for the National Institutes of Health (NIH), which helps sustain biomedical research critical to rare disease progress
- \$90 million to continue to implement ACT for ALS, which accelerates access to investigational therapies for people living with amyotrophic lateral sclerosis (ALS)
- \$40 million for the Amyotrophic Lateral Sclerosis Research Program and \$12.5 million for the Duchenne Muscular Dystrophy Research Program under the Department of Defense (DoD) Congressionally Directed Medical Research Programs Funding



The NIH funding includes policy language that prohibits arbitrary indirect cost caps and protects essential funding for long-term research stability.

“The many MDA Care Centers that participate in research may have an even greater opportunity to have research funded within their clinic because of this law that passed in early February,” Paul says. “And, for the first time, facioscapulohumeral muscular dystrophy (FSHD) is now eligible to participate in the DoD’s peer-reviewed medical research program, opening up a new source of dollars for research into FSHD.”

In addition, the bill reauthorized the [Rare Pediatric Disease Priority Review Voucher Program](#) through September 2029. This program incentivizes the development of therapies for rare pediatric neuromuscular diseases. “This is by far the most important incentive for developing treatments for those very rare pediatric conditions that don’t necessarily have strong commercial market potential upon FDA approval,” Paul says. “For our clinicians, knowing that the drug development ecosystem for these rare pediatric diseases is still going to be incentivized and will remain strong will be very important.”

Looking forward

One of the MDA Advocacy team’s priorities is to push for [reauthorization of the ACT for ALS](#), which is set to expire in September 2026.

“This is very important to our clinicians for a number of reasons,” Paul says. “Within the legislation is the expanded access program, in which NIH offers grants to clinics to administer investigational ALS therapies through expanded access. And then other aspects of the bill involve funding some research into other rare neurodegenerative diseases. We know that a number of our clinics have gotten grants through the ACT for ALS to conduct research on conditions such as myotonic dystrophy and Friedreich’s ataxia.”



The Advocacy team is also concerned that states are accelerating their efforts to cut Medicaid programs this year due to 2025’s H.R.1 (also known as the “One Big Beautiful Bill Act”), which [reduced federal Medicaid spending](#).

Paul notes that there are already reports of states reducing coverage for home- and community-based services for people with disabilities.

“Many states are already taking action, and every state is going to have to face this situation,” he says. “There are also intersections with reimbursements for clinics under Medicaid. The clinics may be faced with challenges because state policymakers are deciding to make cuts to their Medicaid programs.”

To meet these challenges, MDA’s dedicated Advocacy team and grassroots advocacy network will continue working with lawmakers, federal agencies, researchers, and industry partners to promote policies that drive innovation forward and ensure access to high-quality healthcare for people and families living with neuromuscular diseases.

Resources

- Read MDA’s [press release](#) for more details about the February 2026 annual federal funding bill.
- Learn about the MDA Advocacy team’s [current initiatives](#) and how to [take action](#).