MDA® Muscular Dystrophy Association

MDA Advocacy Is Working for the Research and Patient Communities

Advocacy is an essential part of MDA's mission. Currently, MDA's Advocacy team is actively working to protect funding for neuromuscular research and preserve affordable healthcare for people with neuromuscular diseases.

Here are some of the issues MDA Advocacy is involved in.

HHS staffing reductions

In April, the US Department of Health and Human Services (HHS) announced substantial staffing reductions and office restructuring. The US Food and Drug Administration (FDA), National Institutes of Health (NIH), Administration on Community Living (ACL), and many other crucial agencies fall under the HHS and are affected by these changes.

MDA is gravely concerned about these actions. "The adjustments in the sweeping reforms affect offices, programs, and services that play a critical role in research, drug, and therapy development, and access to care and services. These are vital programs that serve children and adults across the MDA community," said Paul Melmeyer, MDA's Executive Vice President, Public Policy and Advocacy in a statement released following the cuts. "MDA will work with our community and the legislature to evaluate unintended consequences of these recent actions on the programs and services our community needs. We are eager to engage with policymakers in the Congress to safeguard critical programs and services for our community."

NIH funding cuts on indirect costs

The NIH was already affected by a policy change earlier this year. The NIH is a critical funding source for academic researchers in the neuromuscular field. NIH-funded research led to the discovery of the underlying mechanisms of genetic neuromuscular diseases, breakthroughs in gene therapy, and effective treatments for spinal muscular atrophy (SMA), Pompe disease, Duchenne muscular dystrophy (DMD), and more.

A critical portion of this funding covers the unavoidable indirect costs of conducting research, such as utility bills, lab cleaning, and administrative expenses.

In February, the NIH announced that all indirect costs will be capped at 15% in all grants (down from roughly 50% to 70%). “That would be a massive loss for the research community,” says Joel Cartner, Director of Access Policy at MDA.

The MDA Advocacy team immediately released a statement condemning the NIH’s new policy guidance and spread the word on social media (@MDA_Advocacy).

Although the policy has been paused as courts review it, they have already impacted the research community.

“We were hearing a lot from our research community about how devastating these cuts are and what the cap on indirect costs could mean in their lab,” says Mark Fisher, Director of Advocacy Engagement at MDA. He encourages people to contact the Advocacy team to tell them how these and other policies and actions affect them by emailing advocacy@mdausa.org.

Federal Register notice freeze partially lifted

In February, the Trump administration blocked the NIH from posting any new notices in the Federal Register, which is required before many federal meetings can be held. This prevented the agency from reviewing thousands of grant applications and awarding grants. “It's stopping the disbursement of these grants that have already been appropriated by Congress,” Joel says.

Later in the month, the freeze was partially lifted, allowing NIH to schedule some meetings, but the effects are long-reaching.

Even when a policy is reversed, we're seeing that sometimes the change doesn't hit the ground,” Mark says. “We're monitoring the situation, and we're encouraging the administration to reverse course on these policies that hurt research, but it's challenging for us to know exactly what's happening on the ground. That’s why we need to hear from the folks who are really affected by this.”

Mark notes that in addition to emailing advocacy@mdausa.org, people can visit MDA’s Advocacy Action Center (votervoice.net/MDA/home) to find and contact their members of Congress. “Congress still has the power of funding, and NIH funding hits every state in this country,” he says.

Protecting Medicaid

In late February, the US House of Representatives passed a budget resolution that instructs the House Committee on Energy and Commerce, which has jurisdiction over Medicaid, to cut $880 billion in spending.

The Congressional Budget Office (CBO) — a nonpartisan agency that analyzes legislation for its effects on the budget — reported that to reach the House's goals, cuts will have to come from Medicaid and the Children's Health Insurance Program (CHIP) or from Medicare.

"The majority of neuromuscular disease community members use Medicaid in some form. By cutting Medicaid, the U.S. House's plan threatens access to crucial services our community needs," Joel says.

MDA's Advocacy team set up a website that provides information about the issue and makes it easy to contact lawmakers at mda.org/medicaid.

We're also mobilizing grassroots advocates to share their stories," Mark says. "We'd love to get the clinician's perspective on how valuable the program is."

Resources

The information in this article was accurate as of publication time, but policies and funding are continuously changing. These resources can help you stay up-to-date and take action:

- Read MDA's statement on HHS restructuring.
- Read MDA's statement on NIH funding cuts for grants.
- Review MDA's latest statements and communications to policymakers.
- Visit the MDA Advocacy Action Center at votervoice.net/MDA/home to learn about issues, find your lawmakers, and contact them.
- Visit mda.org/medicaid to learn about this issue and contact your lawmakers.
- How are you and your patients affected by funding cuts and policy changes? Email MDA's Advocacy team at advocacy@mdausa.org.