

Advocating for the MDA Community

MDA's Advocacy team is standing up for those with neuromuscular disease in numerous ways.

"We have three overarching areas of focus," says Paul Melmeyer, MDA's vice president of Public Policy and Advocacy. They are:

1. Increasing access to care, including access to medical devices, therapies, specialists, telehealth, and any healthcare the community might need in managing their condition.
2. Accelerating therapy development to get more and better therapies to the community. In doing so, we work with the US Food and Drug Administration (FDA) and Congress to try and increase safe and effective therapies for neuromuscular diseases.
3. Breaking down societal barriers in areas such as transportation, employment, educational opportunities, and receiving governmental benefits.

Right now, the Advocacy team is working on several campaigns and initiatives in those three areas.

Access to healthcare

MDA recently launched a campaign to increase access to genetic testing, counselors, and specialists through legislation that would expand Medicare and Medicaid coverage for these services. "It's important to those with genetic disease to understand their condition and be able to seek treatment for their condition," he says.

MDA also is advocating for legislation to increase home healthcare access and support the home and community-based service workforce, along with helping to reorient benefit structures.

Therapy development

MDA's Advocacy team is advocating for several reforms in FDA policy that would lead to developing more patient-centric treatments, better clinical trial structure, and faster regulatory review. MDA also is urging Congress to increase funding for biomedical research.

Social barriers

To make air travel more accessible, MDA's ongoing campaign involves working with Congress and the US Department of Transportation to make airplane lavatories accessible, make the experience of traveling on airplanes more dignified for wheelchair users, and ensure mobility equipment is not damaged during baggage handling.

"There is also an independence campaign with several bills on Capital Hill to help the community more easily find employment, take advantage of benefit programs, and continue their independence," Paul says. "We must continue to address the misunderstandings and stigma our community still faces when looking for jobs."

Take Action

Paul says healthcare professionals can be integral to the success of MDA's Advocacy campaigns, as they see the importance of these issues in their patients' lives every day. By lending their voice, they can help move the needle.

"MDA invites everyone to join in advocating for legislation at mda.org/advocacy and to email congresspersons and senators to share their support for these important campaigns," Paul says. "We can make a difference together."