



MDA ADVOCACY

DURING THE

PANDEMIC

It has been a year since the novel coronavirus was discovered. In that year the virus that causes COVID-19 spread around the world, affecting daily life, businesses, and how we receive healthcare. While the past year has been difficult for everybody, the neuromuscular disease (NMD) community has faced particular challenges.

“For our community, it’s been complicated by the fact that many individuals with NMDs are at increased risk of the effects of COVID-19, or they have to get regular care from a provider in an in-person setting,” says Brittany Johnson Hernandez, senior director of policy and advocacy at MDA. “While many folks feel confident leaving their homes with their masks on and staying socially distanced, it remains true that this pandemic is more dangerous for much of the NMD community, so those individuals have been even more isolated than others.”

Advocating for the Community

Vaccination is a key tool in the effort to end the pandemic. MDA’s Advocacy team has been working to ensure access to COVID-19 vaccines for NMD patients and caregivers by engaging with policymakers from the Centers for Disease Control and Prevention (CDC), the US Food and Drug Administration (FDA), and leaders of state and local jurisdictions.

“We are advocating for the people we serve to have Phase 1 access to COVID-19 vaccines,” Brittany says. “We’re also working with the FDA to ensure that ongoing clinical trials for NMD therapies aren’t unduly disrupted by the pandemic, and we’ve seen a number of positive changes in trial design to ensure that trials can continue in order to speed more therapies to the people who need them.”

In addition, MDA recognizes that telehealth has opened doors to better healthcare access for many individuals in our community. “We are pleased to partner with a number of other patient advocacy organizations and provider groups to try to ensure that many of the telehealth access changes made during the COVID-19 pandemic can remain in place once the public health emergency (PHE) ends,” says Brittany. “Of course, we want to ensure that if a patient wants to see their provider in person, they won’t be discouraged from doing so, nor will they feel pressured to continue with telehealth visits after the PHE is over.”

Critical Initiatives

MDA Advocacy started 2020 with a plan to execute on our priorities of ensuring access to care and therapies from day one, accelerating therapeutic development, and fostering empowerment and independence for the NMD community. “While the pandemic certainly added more to our plate, we still have been successful in the work we set out to do last January,” says Brittany.

MDA’s accomplishments in 2020 include:

- » Protecting the national newborn screening program
- » Forging critical and lasting working relationships with the FDA through MDA’s first Patient-Focused Drug Development Meeting
- » Helping to ensure access to air travel for people with disabilities

Looking Forward

“We are successful because we prioritize working from a collaborative position — we’re more likely to get things done when we bring more stakeholders to the table,” Brittany says. “That’s why MDA tries to engage our fellow patient advocacy organizations as often as possible in our work.”

While 2021 promises to be another challenging year, we feel confident that MDA Advocacy will continue to make a positive impact on the policies and issues that affect our community.

You Can Be an Advocate

Anybody can become an MDA Advocate, including researchers, healthcare providers, and other members of the neuromuscular disease community. Learn more about MDA’s advocacy and how to get involved at mda.org/get-involved/advocacy.