

MDA ACCESS WORKSHOPS HELP

FAMILIES FACE BARRIERS WITH

KNOWLEDGE AND RESOURCES

It comes as no surprise that people in the neuromuscular disease (NMD) community face access barriers every day, ranging from challenges in schools to difficulty getting mobility equipment. MDA's new Access Workshops are designed to address common access barriers that the community faces.

MDA's Access Workshops are on-demand, online community learning programs. "This is an expansion of our educational programs," says Elise Qvale, MDA's director of professional and community education and chief privacy officer. "Access Workshops are focused on how our families live with disabilities, what barriers they may face, and how we can help them tackle those barriers and be their own advocates."

Self-paced programs

The first Access Workshop, released in May, is titled "Access to Coverage: Equipment & Assistive Devices." Other workshops coming this year will cover K-12 and higher education, access to insurance, and access to therapies.

Each workshop is composed of a series of modules with important information, educational videos and interactive elements, like quizzes, that build participant's knowledge and understanding of the topic.

"It's meant to be a self-paced program," Elise says. "If someone's interested in a whole topic, they may want to go through the complete workshop from start to finish to learn a lot about that topic and take away all of that material. Other people may want to go to the specific module that speaks to where they are in the process. For example, if someone just got denied a piece of equipment, they've already passed a few of the stages in our modules so they might just go to the module on denials and pull the information they need from there."

For healthcare professionals

While MDA's Access Workshops are designed with families in mind, they are also a great resource for healthcare professionals who want to learn more about access issues that confront their patients. They also include useful resources, tools, and takeaway materials that would be helpful to share with patients, such as downloadable sample letters addressing getting prior authorization for care, appealing an insurance denial, and requesting an evaluation or meeting at school.

"We hope that the medical community will use these as resources while also sharing them with their patients," Elise says.

Each Access Workshop ends with a collection of all the resources mentioned in the workshop, as well as additional resources and takeaway materials, making them easy to find and share.

Good response

So far, more than 250 people have taken the first Access Workshop, and many have been willing to share their thoughts on it. Participants called the workshop "easy to understand" and said it was "presented in an orderly/accessible way."

Other participants were especially excited about the resources provided in the workshop, including the takeaway materials. "It gave me ideas for how to work with the insurance company to get mobility items covered," one person said.

More feedback from the NMD community will be coming in late summer, when MDA releases the results of the Access Survey MDA rolled out earlier this year. This data will help those who work with the NMD community gain an even deeper understanding of the barriers they face and will be used to shape future Access Workshops.

To find MDA's current Access Workshops and learn about upcoming ones, visit mda.org/accessworkshops. For questions and to collaborate on or suggest Access Workshop topics, email access@mdausa.org