

Unusual Times Call for OUTSIDE-THE-BOX THINKING

► *Lynn O'Connor Vos, President and CEO of the Muscular Dystrophy Association, discusses the innovative approaches the organization is taking to remain connected with its population during the COVID-19 pandemic.*

PV: The Muscular Dystrophy Association (MDA) is the umbrella organization representing dozens of diseases; how is the COVID-19 pandemic impacting your operations — patients, caregivers, and researchers?

O'CONNOR VOS: MDA has never been more vital to the protection of the highly vulnerable community of neuromuscular patients, their caregivers, and clinicians. MDA is an essential charity; we are on the front-line delivering care to more than 50,000 patients and bringing critical education and resources to over 250,000 patients.

Because of their significant muscle deterioration, people with neuromuscular disease may have increased risk factors such as reduced respiratory and/or cardiac function. This is compounded as the challenges of caregiver burden and patient/family isolation escalate.

PV: How are you engaging with patients, caregivers, etc. during the crisis; virtually, online, etc.?

O'CONNOR VOS: MDA is on the frontline working with care centers sharing new treatment guidelines and best practices for telemedicine, as well as providing additional education and support to families. We have conducted digital sessions with all of our key stakeholders.

We held a virtual clinical research session with 1,200 researchers and clinicians attending nationwide in lieu of our annual Clinical & Scientific Conference. We also created the COVID-19 online resource center, which is updated regularly with new information, including COVID care guidelines for individuals with neuromuscular disease (NMD). We enacted virtual care center support and proactive outreach to patients and families and increased capacity in the MDA National Resource Center. We pivoted our Care Center Directors meeting to a virtual format, with more than 150 directors attending. We launched MDA Let's Play, a family game night with more than 1,400 families participating via Twitch and YouTube to help our families stay connected. We created MDA Frontline, an inter-

active Facebook Live program for patients to ask their questions about COVID-19. More than 500 patients were online for the first show featuring MDA Chief Clinical Advisor Dr. Barry Byrne.

In addition, MDA's advocacy team and network of constituents nationwide are making sure our collective voice is heard by advocating before Congress, governors, and federal agencies, including FDA and CMS, ensuring that policymakers understand the unique needs of people living with NMDs; advocating for policies that encourage social distancing in order to slow spread to vulnerable NMD population; enabling no-cost COVID testing for everyone; ensuring that state Medicaid programs have the funding they need to respond to the crisis and making sure that state and hospital triage policies do not discriminate against NMD.

PV: How is the COVID-19 pandemic impacting MDA's programs, such as its annual summer camp? What alternatives are you offering to these types of in-person events?

O'CONNOR VOS: MDA Summer Camps are places where, for a week, kids and teenagers with NMD can gain independence and have fun as they learn vital life skills, such as building confidence and learning self-advocacy as well as expanding their horizons and abilities with STEM activities. Since we are unable to offer in-person experiences this year, we are creating a virtual camp experience that will bring joy, innovative programming, and a way to stay connected to our campers and families. The best part is that not only have the campers given us their feedback on what they want to experience, but our valued volunteers have offered to step in and connect with their campers as well.

We begin with fun topics such as art, cooking, music, and gaming. Then when the summer officially hits, we will continue offering sessions like these and much more, including a virtual camp experience where campers can connect with others their age and engage in more interactive and age-specific experiences while they develop the interpersonal connections that are so cherished by our campers.



Lynn O'Connor Vos

PV: What about the MDA Care Center Network?

O'CONNOR VOS: The cornerstone of MDA's innovations in Care programming is MDA's National Care Center Network, a system of multidisciplinary medical clinics across the United States at more than 150 top medical institutions. MDA is on the frontline working with care centers sharing new treatment guidelines, best practices for telemedicine, and providing additional education and support to families. We have conducted digital sessions with all our key stakeholders. We enacted virtual care center support and proactive outreach to patients and families and increased capacity in the MDA National Resource Center. In addition, we created the COVID-19 online resource center and our MDA Frontline, our interactive Facebook Live program for patients to ask MDA medical advisors and care center directors their questions about COVID-19.

PV: How are you re-imagining your fundraising initiatives during the COVID-19 pandemic?

O'CONNOR VOS: At a time of year when we are normally seeing a surge in funding through our distinguished events, Muscle Walks and our Fill the Boot events with our passionate firefighters, our collective quarantine status has made the MDA vulnerable, putting the patients and families we serve at even greater risk. We are aggressively looking for new sources of revenue from government, foundations, and new sponsors. The teams are actively moving to virtual fundraising activities and finding novel ways to engage donors through gaming and social media. We are laser focused on significantly raising our profile and the urgency of our mission. **PV**

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