

# LYNN O'CONNOR VOS

## For Creating a Greater Impact in the Nonprofit Industry

After more than 30 years on the agency side of the healthcare industry, Lynn O'Connor Vos has flipped the table and left her role as global CEO of greyhealth group (ghg), part of WPP, to become president and CEO of the iconic nonprofit, Muscular Dystrophy Association (MDA), in October 2017.

Throughout her multifaceted career, Lynn has been a trailblazer, building powerful relationships and partnerships with institutions, providers, patients, and nonprofits to positively impact healthcare. That, combined with her deep background in nursing, clinical research, pharmaceutical marketing, and health communications, make Lynn uniquely qualified to take the reins of this legacy nonprofit.

Under Lynn's leadership, MDA's mission is to transform the lives of individuals with neuromuscular diseases such as ALS, muscular dystrophy, through innovations in both science and care. Lynn has also brought to MDA her personal style of leadership, seeking out individuals with a desire to be innovative, creative, and who have a passion for helping patients and families.

MDA raises millions of dollars and is the largest nongovernmental funder of research on muscular dystrophy, ALS, and other neuromuscular diseases. Lynn aims to elevate MDA's visibility and build on its historic and recent scientific developments to propel cures, help more patients engage in clinical trials, and match patients with the most beneficial treatments through the use of innovative technologies.

One of Lynn's first major announcements at MDA has been a collaboration with IQVIA, a global provider of information and technology solutions, to expand the organization's current disease registry into the new MOVR (NeuroMuscular Observational Research) data hub. MOVR is designed to aggregate healthcare, genetic, and patient-reported data, transforming health outcomes and drug development in neuromuscular diseases. As a core component of MDA, MOVR is the largest centralized repository of data to cross neuromuscular disease disciplines, storing the most useful, impactful, and influential information for broad communities of healthcare providers, researchers, nonprofits, and the pharma/biotech communities.

At ghg, Lynn oversaw the firm's global expansion and diversifications strategy, helping grow the company from a small, domestic professional agency into an award-winning global enterprise with fully integrated, multichannel offerings. She also infused her belief that companies should give back to the communities and patients that they represent at ghg, and she placed a premium on the personal and career development of her team and peers, adhering to ethical standards, and maintaining balance. Lynn was a founding board member of The Jed Foundation, a leading mental health nonprofit, as well as the Multiple Myeloma Research Foundation (MMRF). She has also served on numerous public and private boards. As CEO of MDA, she knows there is a big job to do, but with Lynn at the helm, the organization is up to the challenge.

As CEO of MDA, she knows there is a big job to undertake, but with Lynn at the helm, the organization is up to the challenge and committed to making a positive impact for people affected by neuromuscular disease.

**PV: What is your leadership style and how does this fit with MDA's objectives?**

**O'Connor Vos:** I have found that people are excited about learning and stretching themselves. The idea is to think and dream big and execute seamlessly. I also select team members who are great communicators. Individuals with neuromuscular disease tend to be incredibly resilient and

optimistic, and their stories are amazing. It is our privilege to share them.

**PV: Can you describe some of the initiatives you have helped to put in place at MDA?**

**O'Connor Vos:** One of the biggest accomplishments is the agreement we've established with IQVIA to create the MOVR data hub. MOVR, will be launched at 25 MDA Care Centers this September and will enable more patients to participate in

PASSIONATE. DETERMINED.



Lynn O'Connor Vos is bringing her creative energy to the Muscular Dystrophy Association, setting audacious goals and redirecting how the iconic organization operates.

clinical trials, provide better ways to track clinical and genetic data, help monitor the safety and effectiveness of new treatments, and spur advances in gene therapy. We will be able to perform genome sequencing of every patient who comes to the data hub. As a result, we will be able to access significant amounts of genetic data as well as practice data. This will enable the different care centers to compare notes to improve the standard of care. It's a big initiative, and I'm really excited to say the senior team dove in and we got it done. We're now looking to bring in a significant science and medical expert to lead work on the data hub and the research we're doing.

There's also the information side. People are hungry to learn more about neuromuscular disease; some 300,000 people come to our Website each month looking for answers. When I first joined MDA, we fielded an original study to learn more from our patients and families about their pain points. It is learnings such as these that will enable us to have a much more responsive portal for anyone seeking insights. Another great source of information for our community is our dedicated resource center, which is mostly staffed by individuals with one of our diseases. We provide one-on-one support via phone or email for individuals and families looking for information about the diseases in our program, services, activities, and more.

**PV: How do you think you are impacting the way MDA operates?**

TRANSFORMATION IS:

## INNOVATIONS IN SCIENCE AND CURES

**O'Connor Vos:** MDA is an umbrella organization representing 43 neuromuscular diseases. As the largest organization focused on neuromuscular diseases, we have a responsibility to invite other entities to participate with us. This is one of the core values that we're going to be pushing forward as we build the data hub and other programs. The new MDA is an open, collaborative organization and we fundamentally believe that if we can get collective impact among many players we will deliver better care and more cures to patients.

We're also expanding MDA's partnerships to include pharma and biotech companies. This will enable us to transform from a community-based organization to one that is driving scientific, medical, and care innovations. We want to retain our outstanding services, such as sending thousands of kids to camp every year at no cost, while infusing a new energy, which is to transform our patients' lives through innovations in both science and care.

**PV: As CEO of MDA how are you making this change in direction possible?**

**O'Connor Vos:** Coming from the world of advertising, communications, and digital I bring a different perspective and I am encouraging the organization to be more bold, innovative, and creative in the way we approach both science and care communications. My experience has taught me that communication is the cure, and it is communication that will enable us to achieve our ambitious

objectives. We are also providing the training and support to ensure that our staff members are fully skilled to take on new roles and grow as the organization grows.

**PV: With so many diseases represented under the MDA umbrella, how do you harness a collective knowledge and spirit?**

**O'Connor Vos:** It starts with defining our purpose, which is that we are here to transform the lives of those affected by neuromuscular disease. This is a lofty goal and it requires many people to help and participate. As the new CEO, I've been able to go out with a very different discussion than perhaps prior leadership might have done. I also had the incredible opportunity last year to be on the Robert Kraft Precision Medicine Accelerator with Kathy Giusti, founder of the Multiple Myeloma Research Foundation (Kathy is also a PharmaVOICE Red Jacket). Part of what we did, and what they continue to do, was to work with several smaller oncology organizations to see how to generate a more collective impact in that space. They demonstrated that through collaboration, we can change a one-on-one meeting opportunity to become a one-plus-one-equals-five dynamic.

Another piece is about the industry that we serve. MDA runs an annual conference, which next year will be more like a convention, to enable researchers, healthcare providers, industry, nonprofits, and suppliers to congregate, share information, and improve best practices.

**PV: MDA has a profile familiar to older generations. What are you doing to get millennials engaged?**

**O'Connor Vos:** We have something called Team Momentum, which sponsors marathons and all types of extreme sports. Another millennial-based initiative involves a company out in Medford, Ore., called Dutch Bros. Two brothers started a drive-through coffee chain that's hip and fun; one of the

brothers died from ALS. For the past decade, Dutch Bros has dedicated one day a year where they give MDA 100% of their profits. They call it Drink One for Dane and the organization is growing. We are also working with our partner organizations to help them demonstrate to their millennial employees that they are socially responsible. This is a win-win for them and for us.

**PV: Do you see the approach you are driving as a way to blaze a path for other organizations to follow?**

**O'Connor Vos:** The influence that larger nonprofits can have is certainly important. We have access to patients and scientists; we are engaged in government. It's a pivotal moment for nonprofits, particularly those that have partnerships with industry and government, to make a significant difference for individuals with conditions such as neuromuscular disease or diabetes. We hope the MOVR data hub sets an example for the industry.

**PV: What do you believe the future of the life sciences will be? Will it be a large collaborative environment, or will we still operate in a siloed fashion?**

**O'Connor Vos:** Things are changing. For example, I was at a meeting recently where the CEOs of Novartis and Sanofi were on the same stage with the heads of Blue Cross and Blue Shield discussing AI. There are moves to improve claims management following the Amazon model. We're going to be able to deliver the right treatment to people when they need it and help them navigate their disease. This is going to require private-public partnerships and we're seeing those happen. Every company we've spoken with wants to talk about how we can partner better and they're incredibly open to all of the programs that we're putting together. IQVIA plus the pharmaceutical companies plus MDA and other organizations coming together to attack these diseases is going to be extremely powerful.

Earlier I mentioned the study we did with families to identify their pain points in managing diseases on their own. We will be inviting companies from many industries to a roundtable to talk about what we can do to help people manage their conditions. Our role will be as convener to engage other companies.

**PV: What advice do you give to future leaders?**

**O'Connor Vos:** Go with your strengths. Don't be shy. Everyone has something great inside them; dedicate yourself to unleashing it. Find a cause you believe in and support it. Giving back, or even doing as I did and joining a nonprofit, can turn out to be one of the most satisfying things you do in life. **PV**



*Be audacious.*

## Lynn O'Connor Vos

**TITLE:** President and CEO

**COMPANY:** Muscular Dystrophy Association

**EDUCATION:** BS and BSRN, Alfred University

**AWARDS/HONORS:** HBA Woman of the Year

**ASSOCIATIONS:** Healthcare Businesswomen's Association

**SOCIAL MEDIA:**



**TWEET:** @lynnvos

**PERSONAL BRAND:** You can't park up front unless you drive there.