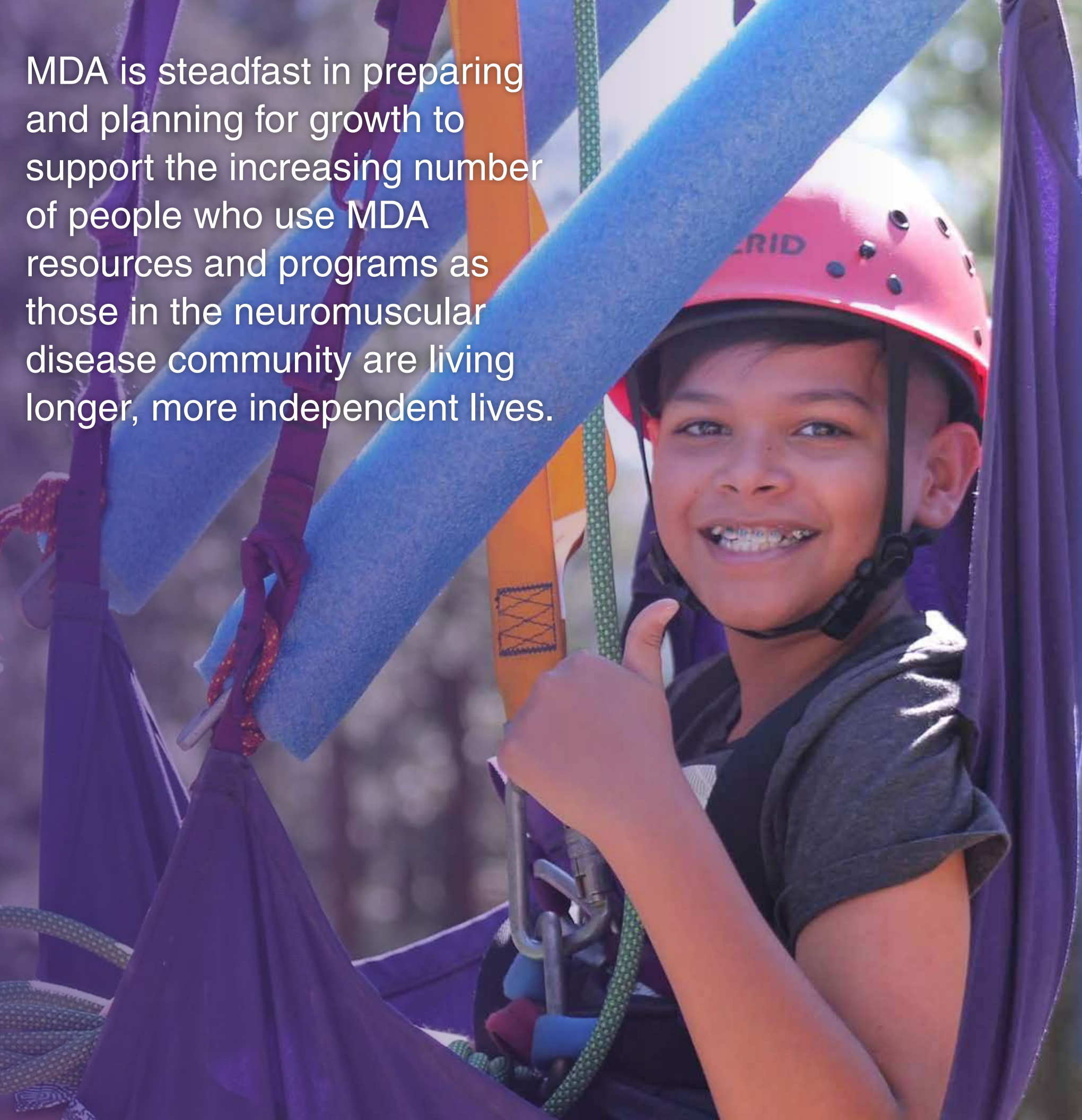




# YEAR OF INDEPENDENCE

2022 MDA Annual Impact Report



MDA is steadfast in preparing and planning for growth to support the increasing number of people who use MDA resources and programs as those in the neuromuscular disease community are living longer, more independent lives.

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To celebrate and recognize the power of our mission, we designated the year 2022 as the Year of Independence.



## A Letter from MDA's President and CEO

The mission of MDA since its inception 73 years ago has been to empower the people we serve to live longer, more independent lives. That mission has been a constant source of hope for more than a million people and their families during our seven decades. At MDA, families are at the heart of our mission, and the strength of the MDA community is resolute.

Steadily, relentlessly, and successfully, the MDA has delivered more and more on the hopes and dreams of those we serve. But one thing has never changed – and never will – that is our commitment to the promise of research and emerging therapies to treat – and one day, cure – neuromuscular disorders that are genetic in nature.

Although the deviations underlying a genetic disorder are present at birth, symptoms can be variable. For some, symptoms show up at birth. For others, symptoms may not become apparent until their teenage or adult years. In general, as symptoms occur in a neuromuscular disease, muscle weakness will progress causing an ever-increasing loss of function and mobility.

But through MDA's relentless focus on research to improve diagnosis and treatment, and its nationwide network of state-of-the-art multidisciplinary clinical facilities, more people with muscular dystrophy, spinal muscular atrophy, and other devastatingly progressive neuromuscular diseases are now feeling the extraordinary impact of MDA's mission: they are living longer and more independent lives.

To celebrate and recognize the power of our mission, we designated the year 2022 as the Year of Independence. The concept and spirit of independence have been reflected consistently throughout the year with inspiring stories from people living with neuromuscular diseases. We met a five-year-old girl who was being treated for a previously incurable and fatal form of infant spinal muscular atrophy just as she was starting elementary school. We met a young man under the latest treatment regimen for Duchenne muscular dystrophy (the most common and rapidly progressive form of childhood muscular dystrophy) as he was finishing college and launching a career. Stories like these are now abundant throughout the neuromuscular disease community including among people living with ALS and myasthenia gravis where newer FDA approved treatments are now available to slow disease progression.

MDA's operational focus on growth in 2022 was conceived strategically to address the wonderful outcome of more people with neuromuscular disease living longer, more independent lives. Programs, clinics, research, and advocacy in the service of those with neuromuscular disease grew in 2022 and will continue to grow in 2023. A significant share of our growth comes from the ever-increasing number of FDA-approved treatments becoming available each year. Clinics are needed more than ever to provide earlier and faster delivery of these treatments to people who can benefit from them. A substantial increase in advocates is also needed to lobby to advance access to these ground-breaking treatments. MDA helped to amplify patient voices in 2022 by advocating successfully for new diagnostic codes for people living with limb-girdle muscular dystrophy. Of course, expansion of our Research program continuously leads to new knowledge that drives progress in diagnosis and treatment.

We head into 2023 with great momentum. Our leadership in genetic medicine and neuromuscular disease treatment development will grow and that will bring new hope and possibilities to everyone living with muscular dystrophy, spinal muscular atrophy, ALS, and dozens of other neuromuscular diseases to live longer, more independent lives.

Sincerely,

**Donald S. Wood, PhD**  
President and CEO  
Muscular Dystrophy Association



### A LOOK AHEAD: MDA at the Forefront of Genetic Medicine

“Programs, clinics, research, and advocacy in the service of those with neuromuscular disease grew in 2022 and must continue to grow in 2023. A big part of that growth comes from the ever-increasing number of FDA-approved treatments becoming available each year. More clinics are needed to provide earlier and faster delivery of these treatments to those seeking to slow or stop their progressive disorder.” - Dr. Wood

## Public Policy & Advocacy

MDA's Advocacy team and its grassroots network were relentless in ensuring key decision makers passed laws and policies that benefited people with neuromuscular diseases (NMDs). As a community, together, we achieved many victories that truly empower everyone MDA serves.

### Securing FDA and Clinical Trial Reforms

MDA worked tirelessly to ensure Congress passed a suite of incredibly important new FDA programs and initiatives, including programs to create innovative new rare disease clinical trial endpoints, expedite regulatory review, and invest in gene and cell therapies. In addition, new laws will ensure more diverse clinical trials, improvements in the accelerated approval pathway for future therapies, and renewals of critical rare disease programs.

### Ensuring Empowerment & Independence

MDA led efforts to achieve economic independence for the neuromuscular community, including the passage of the ABLE Age Adjustment Act. This legislation increases the age by which an individual must have established a qualifying disability to obtain an ABLE savings account from 26 to 46. Also, MDA continued to advocate for accessible air travel and celebrated the release of the Airline Passengers with Disabilities Bill of Rights by the Department of Transportation.

### Advocacy Collaboration Grants

MDA announced the opening of the 2022 Advocacy Collaboration Grants Program, which seeks to fund innovative and impactful advocacy projects across the country. These grants will promote and support key public

policy and advocacy initiatives and projects in coordination with fellow organizations.

### Increasing Access to Care

MDA advocated for \$450 million per year for the next three years for the Money Follows the Person program, which will make it easier for people to access Home and Community Based Services. MDA also celebrated a two-year extension of policies that increase access to telehealth.

Finally, MDA led the implementation of new limb-girdle muscular dystrophies (LGMD) diagnostic codes, which will potentially shorten the diagnosis timeline LGMD patients face, better deliver precise medical care, improve clinical trials, and increase future access to targeted treatments.

### Advocates Return to DC

After a three-year hiatus, advocates went back to Capitol Hill, but this time virtually during the MDA Virtual Summit & Hill Day. On September 28 and 29, families from across the country raised their voices and urged lawmakers to improve air travel, increase access to genetic counselors, and pass Food and Drug Administration (FDA) and clinical trial reforms. Together, MDA had 100 meetings with elected officials and now look to build on this momentum in 2023.



# 20K MDA Advocates



### A LOOK AHEAD: NEWBORN SCREENING

MDA successfully led a large coalition of organizations in a joint campaign to increase access to and expand newborn screening programs. Thanks to these efforts, Congress invested an additional \$3 million for lifesaving newborn screening programs at the Centers for Disease Control (CDC) and Prevention and \$2 million at the Health Resources and Services Administration. In addition, lawmakers funded \$1 million for a study to improve and modernize the national newborn screening program. Finally, MDA co-sponsored the nomination for Duchenne muscular dystrophy (DMD) to be added to the Recommended Uniform Screening Panel (RUSP) for newborn screening.

## Research

The neuromuscular disease field has entered an exciting decade of drug development and clinical translation, and MDA is proud to have provided steady support leading up to this achievement since the 1970s.

MDA has enabled the full spectrum of early scientific discoveries to uncover mechanisms of disease and identifying as well as testing therapeutic targets. We also fund vital infrastructure to expedite clinical trials and provide support for clinical network collaborations taking place all across the United States. Recognizing that promising research occurs worldwide, MDA funded a record number of international grants supporting research projects and early career fellowships, as we grow our reach beyond the United States.

### MDA Venture Philanthropy

In 2022, MDA Venture Philanthropy (MVP) invested in the future by awarding \$1.2 million to two promising start-up companies focused on developing novel therapies for neuromuscular disease. Myosana Therapeutics is developing non-viral gene therapy for muscle diseases, starting with Duchenne muscular dystrophy, while Pathmaker Neurosystems is developing a non-invasive neuromodulation device for amyotrophic lateral sclerosis.

### Invest

MDA invests in two biotechnology companies with projects in Duchenne muscular dystrophy, (DMD), gene therapy and amyotrophic lateral sclerosis (ALS) devices, respectively, and launches the MDA Kickstart Program, an in-house gene therapy program focused on ultra-rare genetic neuromuscular disease.

“MDA’s long investment in understanding the genetic causes of neuromuscular disease is paying off now in the development of very precisely targeted genetic medicines that have the potential to profoundly impact the course of a disease.”

- Sharon Hesterlee, PhD  
Executive Vice President, Chief Research Officer



“We are just beginning to realize the impact of the current revolution in the treatment of neuromuscular disorders. Newborn screening and access to newly-approved therapies are changing patients' lives when diagnosed with neuromuscular diseases; the MDA Care Center network is ready to provide these innovative treatments. Disease-modifying therapies are no longer a thing of the future. There is an urgent need to bring innovative care, cutting-edge clinical research, and new breakthrough treatments to the community.”

- Dr. Barry Byrne  
Chief Medical Advisor, MDA and Associate Chair of Pediatrics and Director of the Powell Gene Therapy Center at University of Florida

**\$19M+**

of committed funds to neuromuscular disease research

**80**

new research grants awarded by MDA



### A LOOK AHEAD: MDA KICKSTART PROGRAM

The MDA Kickstart Program is our very own ‘internal biotech incubator,’ supporting a selected gene therapy program towards key regulatory milestones in the process of clinical translation. Kickstart brings together a group of advisors and project specialists to guide the development of a gene therapy for a selected ultra-rare congenital disorder. Our program is anticipated to de-risk and provide incentives for future investment by pharmaceutical companies, serving as a framework to tackle drug development for other ultra-rare conditions in MDA’s portfolio.



## ***Realizing the Promise of Gene Therapy***

### **First MDA Summit on Challenges in Gene Transfer Therapy**

MDA has invested over \$125M in the development of gene therapy for neuromuscular diseases (NMDs) over the past 20 years. Recognizing that viral-based gene therapies have matured into a viable class of therapeutics for NMD, MDA hosted a highly anticipated summit with key stakeholders in the field to maximize the benefit and de-risk safety issues for patients receiving gene therapy. The outcome of these discussions highlighted key areas for further study and provided critical impetus for more sharing of information among investigators and companies developing gene therapies diseases targeted by MDA. A meeting report was accepted for publication in the Journal of Neuromuscular Diseases, and two research grants were awarded to address the safe translation of gene therapy in Duchenne muscular dystrophy.

# **\$125M**

invested by MDA for development of gene therapy for NMDs in the past 20 years

---



## MOVR Data Hub

The first data hub that aggregates clinical, genetic and patient-reported data for multiple NMDs to improve health outcomes and accelerate drug development.

MOVR efficiently captures clinical data from visits already happening with a unique level of stability and scalability. These attributes are accomplished by combining the MDA Care Center infrastructure with strong existing relationships with principal investigators and staff, while expanding the number of active MOVR sites and the number of indications provided.

### Benefits for the Whole Community

MOVR is designed to serve the entire neuromuscular disease community:

- Researchers can better understand the relationship between health outcomes and genes, and between health outcomes and medical interventions (such as drugs, surgeries, and medical devices).
- Clinicians can quickly match their patients to clinical trials, approved therapies, and personalized care.
- Individuals at all ages and stages of neuromuscular disease gain a platform to be “seen and counted” by the medical and scientific communities.

### Growth

On average, 140 new participants are enrolled in MOVR each quarter, leading to a 30% increase in MOVR participants each quarter.

# 54

active MOVR sites

## MDA Care Center Network

MDA leads the way in caring for people living with muscular dystrophy, ALS, and related neuromuscular diseases through the largest nationwide network of multidisciplinary MDA Care Centers.

Starting in 1953 at a single clinic in New York, the Care Center Network has grown to clinics at more than 150 top medical institutions across the country, including 48 designated MDA/ALS Care Centers.

At MDA, we are committed to ensuring that the MDA Care Center network operates with a multidisciplinary approach which brings together the expertise of professionals from a wide range of disciplines in one location to provide coordinated, patient-centered care.

Each Care Center offers a team of physicians, nurses, and other healthcare professionals with unique expertise in meeting the ever-changing needs our community. This is considered the gold standard model of care for individuals with complex medical needs.

What is equally important is that MDA's nationwide clinic network of NMD specialists are connected to the latest clinical trials and FDA approved treatments and also provide

critical access to genetic therapies and diagnostic testing while serving more than 70,000 people living with neuromuscular diseases annually.

“Advances in genetic medicine have provided opportunities for advances in care through the MDA Care Center Network, empowering the NMD community to live longer, more independent lives.”

-- Nora Capocci  
Vice President, Healthcare Services



# 70,000+

individuals living with NMD receiving care each year

# 3,200+

clinicians and other healthcare professionals providing specialized care

# 150+

MDA Care Centers with 48 designated MDA/ALS Care Centers



MDA Care Centers operate with a multidisciplinary approach that includes the expertise of physicians, nurses, genetic counselors, and other healthcare professionals. MDA invested over \$6 million into the MDA Care Center Network in 2022.



### A LOOK AHEAD: JOIN MDA

Whether you are newly diagnosed, a family member, a dedicated physician, caregiver, friend, advocate, or lifelong member of the MDA community, together we are making the impossible possible. MDA is here for you today and every moment along the way. [Become an MDA member today!](#)



## Clinical & Scientific Conference

In March we gathered in Nashville, Tennessee for the 2022 MDA Clinical and Scientific Conference. The four-day event was our first hybrid conference offering attendees the opportunity to convene in-person or virtually. Once again, the conference offered unparalleled access to key leaders in the field of neuromuscular disease research and care and explored all aspects of pre-clinical, translational, and clinical research and care across NMD to support the development of better care and treatments for our community.

### MDA Legacy Award for Clinical Research

MDA presented the inaugural MDA Legacy Award for Excellence in Clinical Research to Dr. Carsten Bönnemann, Senior Investigator and Chief of the Neuromuscular and Neurogenetic Disorders of Childhood Section at the National Institute of Neurological Disorders and Stroke (NINDS), for outstanding achievement in neuromuscular disease research and care.

Dr. Bönnemann was bestowed the Legacy Award because of his considerable contributions to the field of neuromuscular disease research, including:

- Identifying genetic causes of limb girdle muscular dystrophies (LGMDs)
- Elucidating molecular pathways and developing preclinical models for congenital muscular dystrophies such as Bethlem myopathy
- Using genomic technologies to discover new disease-causing genes in children with complex neuromuscular conditions
- Establishing natural history and outcome measures for use in clinical trials for congenital myopathies
- Conducting the first gene therapy trial for giant axonal neuropathy in humans

Upon acceptance of the Legacy Award, Dr. Bönnemann provided the conference's keynote address where he thanked the MDA for establishing and continuing to develop the field of genetic medicine and emphasized the use and importance of genetic discoveries to guide precision medicine, specifically development of targeted therapeutics, gene therapies, and robotic interventions that can help manage NMDs. Dr. Bönnemann went on to say that gene discovery and translation into precision medicine is a global team effort that benefits from information sharing in a centralized database.

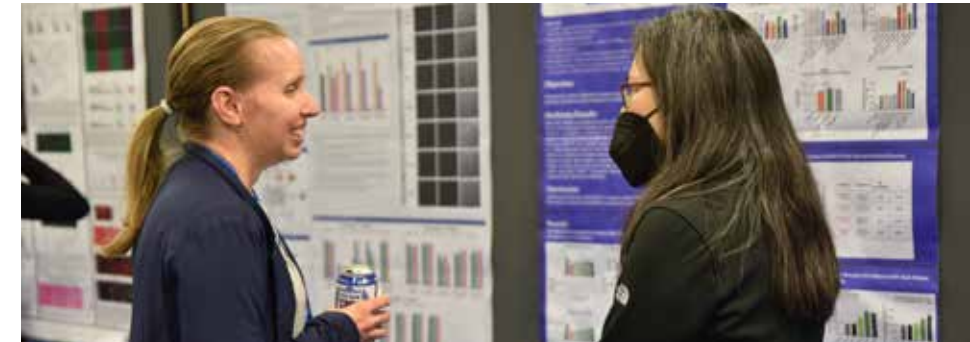


“

MDA has amongst the longest histories in the development of gene therapies for neuromuscular disorders and has always been instigating new developments to advance the field with funding opportunities for projects and investigators. This conference shows that MDA continues to strive to anticipate challenges, seeking to understand where to best put resources and issue requests for applications to help steer the field into the right direction.

”

- Dr. Carsten Bönnemann  
National Institutes of Health



1,700+

in-person and virtual attendees

32

sessions with 120+ speakers

19

countries represented



### A LOOK AHEAD: 2023 CLINICAL & SCIENTIFIC CONFERENCE

*Turning Gene Therapy into Reality*

Peter Marks, M.D., PhD to deliver Keynote Address at 2023 Clinical & Scientific Conference. Dr. Marks is the Director of the Center for Biologics Evaluation and Research (CBER) at the US Food and Drug Administration (FDA).

## In Your Community

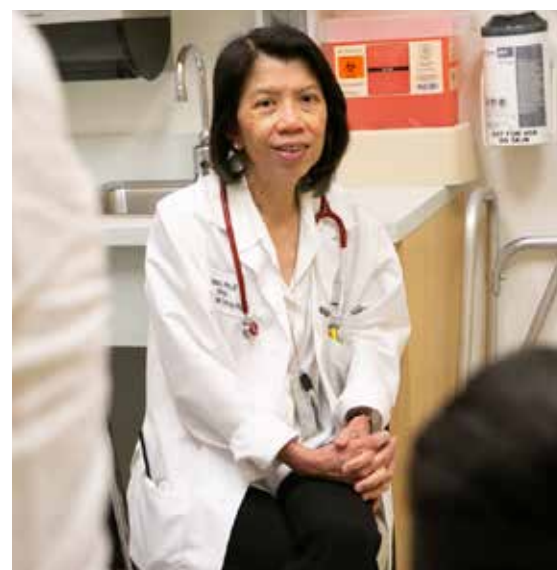
### MDA Launched the Tribute Tour

Throughout MDA's history, local volunteers and communities have been at the heart of MDA's mission-focused efforts. In 2022 we celebrated these individuals and MDA partners with the inaugural Tribute Tour. Each tour stop — Nashville, Houston, St. Louis, and Boston — hosted a series of celebrations including the presentation of the MDA Tribute Awards that honors the legacy and life's work of those who have been tireless in their efforts to support the patients and families we serve. Read what one of our Award Recipients had to say during her speech below.



“It is indeed a privilege to be in the company of all of you who care so much about the MDA, it's mission and our families. The MDA has supported our families and work for many years. The support of this wonderful organization give us all hope which makes a huge difference for patients and their families. Thank you again to the MDA, your support is truly making the impossible possible.”

– Dr. Brenda Wong,  
MDA Care Center Director at University of Massachusetts Memorial Medical Center, Director of the Duchenne Muscular Dystrophy Center at University of Massachusetts Medical School, Professor of Pediatrics & Neurology at University of Massachusetts Medical School



### Working and Advocating for the Neuromuscular Disease Community

#### Highlighting LGMD at Chan Zuckerberg Initiative

Paul Melmeyer, MDA's Vice President of Public Policy and Advocacy, joined the Chan Zuckerberg Initiative's Rare As One project annual convening this summer to present MDA's efforts to improve diagnostics for different types of limb-girdle muscular dystrophy (LGMD) by obtaining vital diagnostic codes. Healthcare providers in the United States use a coding system to record all diagnoses, symptoms, and procedures. Obtaining disease-specific codes is critical for financial coverage and increases healthcare providers' awareness of the types of LGMD.

“The LGMDs are under-researched diseases with limited efforts to capture their true prevalence and incidence. Adopting codes for the most prevalent LGMDs should substantially accelerate the understanding of LGMD, thus advancing efforts to better treat these diseases.”

– Paul Melmeyer

### MDA National Ambassadors

MDA's Ambassadors are pivotal to our mission and serve it by telling their personal stories to inspire millions to help MDA through donations or volunteer action. Each year MDA has two National Ambassadors – one child and one adult – to represent the range of people living with neuromuscular diseases. Meet our 2022 MDA National Ambassadors below.



#### Meet Amy Shinneman

Amy lives with a type of muscular dystrophy called Bethlem myopathy. She lived without a diagnosis until the age of 44, even though she has had symptoms of the disease since birth. Finally, in 2018, through genetic testing, she received a diagnosis after years of searching.

“After receiving my diagnosis and connecting with MDA, [i]t was like the final piece of the puzzle was snapped into place and I finally felt complete. Connecting with others and sharing my story with others who share similar struggles and truly understand has been life changing for me.”

– Amy Shinneman  
2022 MDA National Ambassador



#### Meet Ethan

Ethan is 13-years-old and lives with Duchenne muscular dystrophy. He was diagnosed in June 2011, two days before his second birthday. The next month, Ethan's parents, Jordan and Josh, found MDA. Ethan loves his family and enjoys spending time with his parents and sister. In school, his favorite subject is history — he loves learning about the past. Ethan is hoping MDA will make history for future generations of kids like him, too, with new treatments and cures for all types of muscular dystrophy.

“I hope to make other kids happy. I always appreciate sharing my story with people, talking about having this disease and living life to the fullest every day.”

– Ethan  
2022 MDA National Ambassador

## Quest Media

Quest is a newly expanded and innovative adaptive lifestyle platform — including a magazine, a blog, a podcast, and an e-newsletter — owned and operated by MDA. With the power of this platform, we use our collective voices to raise awareness by having important conversations with experts, thought leaders and our community about topics that matter to them, in the interest of empowering and creating more progress for the community of individuals with disabilities.

### BRAND-NEW and ALL-INCLUSIVE

MDA rebranded the four Quest properties into a single adaptive lifestyle platform called Quest Media, bringing together the podcast, the magazine, the blog, and the e-newsletter. The platform moved beyond being a medical resource to being a more fully adaptive lifestyle platform, which includes all the same medical, science and research information, but also provides tools, resources, and information about living independently.

### 2022 Blog Series: Quest For Success

Success looks different to everyone and this monthly blog detailed the different paths that individuals with neuromuscular disease have taken to get where they are today. Each month shined a spotlight on one individual from our community and shared his or her journey to independence and accomplishment.



“

Just by being visible and telling my story, I think helps other people with disabilities, and helps people who aren't disabled see what's going on.

”

– Hon. Robert Pipia



2022 Quest Media Highlights

40%+ user growth

27K monthly page views



### Quest Survey Results Highlights

99%

consider Quest Media a valuable resource

75%

read/listen to Quest content at least once a month



## Innovations with Quest Media

### First-ever Holiday Gift & Giving Guide!

The Quest Media website hosted our first-ever inclusive gift and giving guide, comprised of 90 products curated by MDA ambassadors. Products ranged from beauty and fashion, to electronics, to home and kitchen, and more. All products were identified as well-designed and easy to use for individuals with neuromuscular disease and other related disabilities.

### Bronze Award for MDA Quest Media Website!

MDA's Quest Media won a bronze award for its newly created website in the 'microsites' category from the 3rd Annual Healthcare Digital Marketing award program. It recognizes the best healthcare websites, digital content, electronic communications, mobile media and social media. Judged by a national panel of healthcare marketers, creative directors, marketing and advertising professionals, work was evaluated for creativity, marketing execution, message impact, technology application and innovation content. Entries were received from nearly one-thousand healthcare and medical organizations across the country.

“

**As a newly established digital platform, we're proud Muscular Dystrophy Association's Quest Media has been recognized by industry experts as being one of the best in the country for our expansion for more inclusive coverage for the disability community we serve.**

”

– Mindy Henderson  
MDA Editor-In-Chief, Quest Media

## Support & Programs

At MDA, we know that life with a neuromuscular disease can be a challenging journey requiring a multitude of resources and support relating to education, careers, accessibility, caregiving, transportation, connecting with community, general disease education and more.

As the first line of interaction between our community and MDA, the MDA Resource Center and supporting teams supply resources and support to the community at every point in their journey. We are committed to providing quality, compassionate care so no one must navigate the neuromuscular disease journey alone – whether you are a patient, parent or caregiver – we are here to help.

### Navigating the World of DME

If you have questions about where and how to get durable medical equipment (DME), the MDA Resource Center can help. The MDA Resource Center is a collective of individuals with personal and professional experience who strive to empower our diverse neuromuscular community with resources supporting a world of independence and possibility.

The MDA Resource Center can also help you locate an organization in your community that loans out DME or accepts equipment donations.

With nearly 20 years of experience in resource navigation, the MDA Resource Center team is committed to providing quality, compassionate care.

“

As a dad of a 10-year-old boy with DMD, I called about financial assistance options for a more portable power wheelchair. The Resource Center Specialist was able to share with me options that I wasn't aware of. It was such a positive conversation and I was grateful to learn about new options.

–Resource Center inquiry

”

### Medical Education

MDA partners with leading medical experts to support ongoing education for clinicians who manage and treat individuals living with neuromuscular disease. Hosted as live and on-demand webinars and resources, programs include CME-accredited Grand Rounds, What's New in NMD updates, clinical focus groups, and more.



“

Thank you for being the trailblazer in the area, providing the links, knowledge, and empathy for individuals and their families. It feels as if parents are heard, and their children's health and well-being is at the forefront of research.

– MDA Engage attendee

”

20+

Medical Education programs



### A LOOK AHEAD: INTRODUCING MDA CONNECT – A LIVE ONE-ON-ONE VIDEO PLATFORM

We are proud to launch this new program that will bring MDA closer to our community. [MDA Connect](#) will provide convenient access for MDA members, families, caregivers, and other individuals in the neuromuscular disease community to connect through 30-minute video calls with an MDA Specialist who can aid in locating resources, navigating care within MDA's Care Center Network, sharing tools, education resources, and information on MDA programs and opportunities for engagement.



## Community Education

These programs support every individual and family living with a neuromuscular disease through the delivery of relevant, responsive, and actionable content. These programs focus on navigating critical life transitions, increasing disease understanding, and supporting access to independence. MDA partners with medical thought leaders at MDA Care Centers, social workers, allied health professionals, community resource leaders, and other experts to develop programming that provides accurate and up-to-date information.

### 2022 Community Education Programs:

#### MDA Engage Seminars and Symposia

Live and on-demand virtual programs focus on providing in-depth information about a specific disease or topic relevant to the neuromuscular disease community.

#### Community Education Materials

Print-ready materials include disease fact sheets, at-home physical therapy guides, emergency room alert cards, and more. Many of these materials are also available in Spanish.

#### ONEvoice Community Insights

Structured opportunities for MDA to hear and learn from the neuromuscular disease community through surveys and family roundtables.

#### Access Workshops

On-demand learning focused on increasing health literacy, empowerment, and self-advocacy to overcome barriers to education, employment, insurance, equipment and more.

**35+**

Community  
Education Programs

**9K+**

on demand  
views

# Volunteers

At MDA, volunteers expand our mission in significant ways, from participating in Muscle Walks to raise awareness and funds, to creating change by planning MDA Hill Day, to staffing MDA Summer Camps. Every volunteer's effort makes an impact on the greater good, and on MDA and our ability to provide funding and opportunities to our community. Every volunteer makes a difference.

“

The ability to work with the MDA Volunteer Advisory Committee has been tremendously rewarding. Collaborating together with other members of the committee has provided both a learning experience and the application of distinct backgrounds and perspectives to developing a national MDA volunteer program. Through our work, we know that there are thousands of individuals across the country willing and able to volunteer for the association and all the families we serve. There is a tremendous opportunity ahead to positively impact our communities.

”

Alan Cohen  
Chairman of the MDA Volunteer Advisory Committee



# 6K

## ways to volunteer for MDA



### A LOOK AHEAD: YEAR OF THE VOLUNTEER

We couldn't fulfill our mission without the volunteers who work tirelessly to support the neuromuscular disease community in so many ways. That is why we have proclaimed 2023 the Year of the Volunteer. Volunteering takes many forms including donating time and talents to things like MDA Summer Camp and gala events, but also philanthropy — giving strategic gifts to help over the long-term. The generosity of our volunteers allows us, year after year, to continue to provide the research, access to care, and programs that are empowering individuals with neuromuscular diseases to live longer, more independent lives. Our volunteers and donors say they also experience enormous rewards from taking the time to give back. Volunteering leads to new friendships and lasting relationships. It creates the opportunity for individuals to connect with one another and develop new skills and a sense of purpose. And whether you are an MDA volunteer or donor, you benefit by knowing that you are strengthening our mission and expanding our reach. [Volunteer Now!](#)

“

Volunteering for MDA is one of the best experiences I've had. Whether a small group or massive event, MDA ensures everyone is having a good time. Go volunteer! It's an unforgettable experience!

”

- Dario  
MDA Muscle Walk Volunteer



**The Best Week of the Year!**



## **MDA Summer Camp**

### **In-person Summer Camp**

MDA Summer Camp is a magical place where anything is possible — from swimming to zip-lining, to sports and games, to dancing under a disco ball, all while gaining valuable life skills.

MDA strives for every camp session to provide a true camp experience, which includes connecting with the outdoors, developing life skills, building lifelong friendships, and providing opportunities to try new things. When kids attend MDA Summer Camp they gain independence as they spend time away from home, learn to accept personal care from someone other than their parents, develop greater self-esteem and confidence, and spend time with other kids who understand what it's like to live with a neuromuscular disease.

### **Virtual Camp**

MDA also provides a virtual option for Summer Camp – an online program that brings the magic of camp to campers virtually. The program features daily Cabin Chat video calls, supply boxes sent to all participants, daily theme inspired camp activities with arts and crafts, STEM activities and more. Virtual Camp provides a meaningful and accessible experience to campers wherever they are.

**19**

**in-person camp sessions**

---

**3**

**virtual camp sessions**

---



# MDA Summer Camp



“ I never thought my child would be able to attend camp and am so glad she did. She did more than I could have ever imagined. ”

- Camper Parent



“ The experience was arguably the most fulfilling I've ever had. Starting from the enviroment created by the staff and volunteers on day one... it was always one of positivity and excitement, there was always something to look forward to. Overall the week was incredibly impactful for me both as a person and as the Program Manager of MDA Let's Play. ”

- MDA Summer Camp Volunteer

700+

total campers registered

600+

camp volunteers



We surveyed campers and parents after camp and this is a small preview of what they had to say about their experience!

**98%** of campers said MDA Summer Camp provides chances to make new friends or get closer with an old friend

**88%** of respondents said MDA Summer Camp helps to develop a positive self-identity



“ My camper had an awesome second year at MDA Virtual Summer Camp! ”

- Virtual Camper Parent

# Community Programs

## MDA Ambassadors

MDA Ambassadors share their stories and authentic perspective to connect within the community to raise awareness, inspire support, and advance the MDA mission. Today, the MDA Ambassador Program features over 70 young children, teens, young adults, and adults as spokespeople for MDA, representing the breadth of the MDA Community.



## STEM Connections

Now in its second year, MDA STEM Connections provides intentional STEM learning opportunities for children and youth living with neuromuscular disease. In 2022, over 700 campers put their engineering, math, and science skills to use as they designed bridges, built a catapult, and combined ingredients to make a calming jar. In the fall of 2022, 35 young adults ages 16-21 registered for the second aspect of MDA STEM Connections: a mentoring program for youth interested in pursuing STEM careers.



“ I liked that I was able to explore a field in STEM that peaked my interests. During the groups I was able to gain insight which allowed me to see whether or not I want to pursue the field as a career later in life. ”

— STEM Connections participant

**93%** shared the program increased their interest in pursuing a STEM-related field

## A LOOK AHEAD: NEXT STEP SEMINARS

Seminars will offer information and resources on key topics related to life transitions including receiving a new diagnosis, transitioning to adulthood, and end-of-life care. Delivered virtually over multiple days, the seminars will connect attendees with experts in the field and other members of the neuromuscular disease community to share experiences and provide support.

## A LOOK AHEAD: TRANSITION GUIDE



MDA is collaborating with clinicians to provide a comprehensive guide to help youth and their caregiver(s) plan for, and navigate, the transition to adult care. Successful transition in medical care requires intentional planning as well as the acquisition of new skills such as self-advocacy. To support this process, the guide will be designed as a workbook with actionable steps for the learner and will be created with a young audience in mind.

## MDA Let's Play

Gaming is bringing good into people's lives



Let's Play is a community united by the love of gaming and an opportunity for MDA to connect people in an inclusive environment.

## Meet Charlie!

MDA Ambassador. Content Creator. Disability influencer. Singer. MDA Let's Play host.

“ No matter what you are going through in life just keep being you and do what you love! ”

- Charlie, MDA Ambassador and Let's Play host



“ Dear MDA Community, I love what you guys do for us, MD patients. You guys help us embrace who we are and why we keep thriving! I joined in 2019, the week of Christmas. After I joined, it was a memory I'll never forget! You're helping other people have a more accessible and confident life... Thank you MDA for everything you have given me and the community. ”

-Willow, Let's Play Gamer



## **A Look Ahead on Young Adult Transitions**

### **Expanding the Mentorship Program**

MDA will expand the Career Mentorship Program in 2023 to include a general career exploration program for high school-age students living with neuromuscular disease. Youth entering high school are often just beginning to think about what they want to do after graduation and it can be difficult for any teenager to know what path to pursue, but youth living with a disability may especially feel their options are limited. MDA aims to dispel this myth and show what is possible by connecting youth to mentors living with neuromuscular disease who are established in a variety of fields including fashion, marketing, business, STEM and more.

### **MDA Scholarship Program**

The MDA Scholarship Program aims to provide financial and supplemental support to young adults living with neuromuscular disease interested in pursuing higher education. Youth with neuromuscular disease are living longer and reaching important life milestones such as going to college. MDA is eager to support this community by launching a scholarship program that will encourage youth to pursue their academic and career goals by recognizing their current achievements, providing leadership resources, creating a supportive network and lessening the financial burden of higher education. By supporting pursuits in higher education, young adults with neuromuscular disease will be better prepared to enter the workforce and contribute significantly to the innovation and progress of tomorrow.

# Fundraising Events

MDA events are a fun way for generous donors, event participants, and dedicated volunteers to join their communities in raising funds and awareness to empower families living with neuromuscular diseases. Here's a look at the contributions they helped raise in 2022.

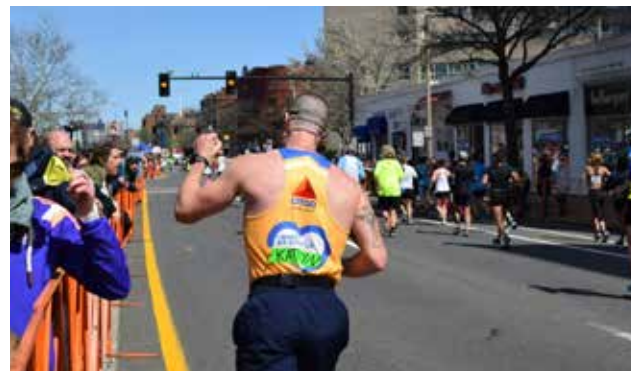
### 2022 Muscle Walk

8 Muscle Walk live & virtual events  
1.7K+ participants  
\$780K+ raised



### 2022 MDA Team Momentum

4 Team Momentum partner events in Boston, Chicago, and New York  
230 participants  
\$450K+ raised



### 2022 Healthcare Partnerships

57 partners  
\$4.2M raised



“

Our business partners and communities have always shown the immense depth of their generosity for MDA at these events. This year's record fundraising results combined with our longstanding partnership demonstrate our continued commitment to MDA's critical mission.

”

- Carlos Jordá  
CITGO President and Chief Executive Officer

14

gala events

29

golf events

7K

participants

\$8.6M

raised through  
Golf & Gala



## Top Committees

Atlanta Night of Hope

Mike Bellotti Toast to Strength Gala & Golf Tournament

Berks Black-N-Blue

Boston Muscle Team

Dallas Uncork a Cure

Passport to a Cure

Ride for Life

## MDA Partners

Together, with our generous partners, we are raising funds and awareness for families with muscular dystrophy and related diseases. Since 1950, MDA has been proud to team up with caring corporations, organizations, and brands that generate tens of millions of dollars each year through creative campaigns, cause marketing, and year-round special events.

# \$11.9M

raised by IAFF Locals at Fill the Boot campaigns

# \$6M

raised by CITGO



# \$95M

raised by Acosta since 1985

# \$2.3M

raised by Dutch Bros in 2022

“ I think it’s important to have continued education, and build advocacy and awareness. That’s why I think the work that MDA does is so critical. The more you can introduce people to the talents and gifts of people with disabilities, the better it is for companies, associates, and the person with disabilities. Everyone benefits when we are more inclusive. - Brian Wynne, Acosta Chief Executive Officer ”

Transformer  
\$5M+



Visionary  
\$1M+



Leader  
\$500K - \$1M



Innovator  
\$250K - \$499K



## Disability Inclusion

MDA has been there all along, promoting diversity, equity, and inclusion, elevating the conversation of *disability is diversity*. We work to ensure everyone has the same access to personal freedoms and independence to fully participate in all aspects of community life. Our advocacy efforts through the years have provided better access to health care, higher education, disability employment and more accessible travel.

### Disability Inclusion

MDA led many legislative efforts to ensure the neuromuscular community faces less discrimination and fewer barriers in living their everyday lives, including working with the Department of Transportation and Congress to improve accessibility on airplanes. MDA worked with partner organizations, and together they took on legislative policies that will increase the number people living with NMD in the workforce.

MDA also joined forces with other disability experts and advocates to bridge the gap between people living with disabilities and organizational ability to connect with the largest untapped pipeline of talent. As employers embrace a remote work environment, they realize that the workplace is now infinitely more accessible to people with disabilities.

Our goals are to: elevate awareness and create an accessible world where every individual can participate in all aspects of community life; promote and deliver opportunities for dialogue that enhances understanding and emphasizes the lived experience of our community; provide education, programming, and resources aimed at overcoming barriers to accessing life's milestones; and collaborate with other thought-leaders to ensure access and inclusion for all.

### MDA's DEI Coalition

MDA is committed to leveraging its voice and platforms to promote diversity, equity, and inclusion. At MDA, we believe unity is strength. Together, let's lead the way to create a more inclusive and accessible world.



### Discussing STEM Accessibility at the Smithsonian

MDA participated in a session during the Smithsonian Science Education Center's (SSEC) Zero Barriers in STEM Education Summit held in Washington, DC where we shared insights from our MDA STEM program and the value of providing opportunities like this for youth with disabilities. Additionally, educators from the SSEC's Zero Barriers in STEM Education program attended a panel discussion with our youth in MDA's STEM program. Our youth discussed their experiences in school and shared advice.

“ It was great to share how the STEM programs are impacting the lives of young people living with neuromuscular diseases. Individuals with disabilities are underrepresented in STEM fields, and we want to change that. ”

- Marissa Lozano, M.Ed  
Community Education Director, MDA



### Disability Rights

In 2022, MDA joined the Consortium for Constituents with Disabilities (CCD), the largest coalition of national organizations working together to advocate for federal public policy.

“ MDA's Advocacy staff represent MDA on many CCD task forces, including those on Education, Employment, Financial Security, Healthcare, Rights, and Transportation. CCD is committed to 'advocacy for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society, free the Americans with Disabilities Act, and all civil rights law.' ”

- Michael Lewis,  
Director, Disability Policy, MDA

“ People have rights, but we don't necessarily know how to use them... [g]etting people to that first step of being able to say, 'No, I don't accept second class citizenship. No, I don't accept people looking at me as being inferior.' And being able to bring yourself forward, that's advocacy, it's the beginning of respect for yourself and articulating it. ”

- Judith Heumann 1947 - 2023  
Author & Disability Rights Activist,  
Mother of the Disability Rights Movement

“ We will deeply feel her loss, but also remember and cherish her triumphs that changed the world for all of us. ”

- Dr. Chris Rosa  
President & CEO, The Viscardi Center



# Board of Directors

For over 70 years, the Muscular Dystrophy Association has been the leading organization for research, care, and advocacy for individuals and their families, living with muscular dystrophy, ALS, and related neuromuscular diseases and [MDA's Board of Directors](#) helps lead the organization's compelling mission and clear vision.

The board is comprised of renowned researchers, clinicians, entrepreneurs, business leaders, disability advocates, and philanthropists and together they constitute a panel of advisors that provides unparalleled wisdom, experience, expertise, and commitment. They are an incomparable body of experts who work to make MDA the #1 voluntary health organization for the neuromuscular disease community in the US and empower families and the communities in which they live.

“It's surreal to be on the (MDA) Board of Directors as an individual with a neuromuscular disease and someone who's had a lifelong experience with the Muscular Dystrophy Association. From the beginning, all I wanted to do was be a voice for people like me and for everyone who needs to be heard. So being given the opportunity to be that voice and be among others on the board living with neuromuscular disease is an incredible honor.”

- Matt Plummer  
Designer, Matt Plummer Designs



## MEMBERS OF THE BOARD

**Governor Brad Henry**  
Chairman  
26th Governor of Oklahoma  
Member of the Executive Committee of the Board

**Christopher Rosa, PhD**  
President & CEO of The Viscardi Center

**Donald S. Wood, PhD**  
President & CEO of the Muscular Dystrophy Association  
Member of the Executive Committee of the Board

**Anjan Aralihalli**  
Venture Partner, CTI Life Sciences

**John R. Costantino, Esq.**  
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Member of the Executive Committee of the Board

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President & Co-Founder, ComSovereign Holding

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**Matt Plummer**  
Designer, Matt Plummer Designs

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## IN MEMORIA

**Victor Wright**  
Former Partner of Goldman Sachs & Co (Ret.)

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**Dr. Stanley Appel**  
Co-Director of Houston Methodist Neurological Institute, Chair of the Stanley H. Appel Department of Neurology, Peggy and Gary Edwards Distinguished Chair in ALS at Houston Methodist Hospital, and Professor of Neurology at Weill Cornell Medical College

**Bart Connor**  
1984 Olympic Gold Medal Gymnast, SEC/ESPN/ABC Commentator and Inspirational Speaker

**Dr. R. Rodney Howell**  
Professor and Chairman of Pediatrics Emeritus at Miller School of Medicine, University of Miami

**Olin Morris**  
Former President and General Manager of New York Times Broadcast Group

## **2022 COMMITTEE MEMBERS**

### **Research Advisory Committee 1 Members**

**Louis Kunkel, PhD**  
Chairperson  
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University of Florida, FL

**Aaron Beedle, PhD**  
SUNY Binghamton, NY

**Andrew Berglund, PhD**  
University at Albany, NY

**Sanjay Bidichandani, MBBS, PhD**  
University of Oklahoma, OK

**Dean Burkin, PhD**  
University of Nevada, NV

**James Dowling, M.D., PhD**  
Hospital for Sick Children, CAN

**Vandana Gupta, PhD**  
Brigham and Women's Hospital, MA

**Lawrence Hayward, M.D., PhD**  
University of Massachusetts, MA

**Michio Hirano, M.D.**  
Columbia University, NY

**Jyoti Jaiswal, PhD**  
Children's National Research and Innovation Campus  
Washington, DC

**Peter Kang, M.D.**  
University of Minnesota Medical School, MN

**Dwi Kemaladewi, PhD**  
University of Pittsburgh School of Medicine, PA

**Linda Kusner, PhD**  
George Washington University, DC

**Giovanni Manfredi, M.D., PhD**  
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**Katherine Mathews, M.D.**  
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**Lynn Megeney, PhD**  
Ottawa Health Research Institute, CAN

**Carlos Moraes, PhD**  
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**Udai Pandey, PhD**  
University of Pittsburgh, PA

**Rita Perlingeiro, PhD**  
University of Minnesota, MN

**Rita Sattler, PhD**  
Barrow Neurological Institute, AZ

**Christine Vande Velde, PhD**  
University of Montreal, CAN

**Stephan Züchner, M.D., PhD, FAAN**  
University of Miami Miller School of Medicine, FL

### **Research Advisory Committee 2 Members**

**Elizabeth McNally, M.D., PhD**  
Chairperson  
Northwestern University, IL

**Matthew Alexander, PhD**  
Children's of Alabama/University of Alabama at AL  
Birmingham, AL

**Alan Beggs, PhD**  
Boston Children's Hospital/Harvard Medical School, MA

**Robert Bloch, PhD**  
School of Medicine, University of Maryland,  
Baltimore, MD

**Joel Chamberlain, PhD**  
University of Washington School of Medicine, WA

**Yi-Wen Chen, DVM, PhD**  
Children's National Research Institute, Washington, DC

**Thomas Cooper, M.D.**  
Baylor College of Medicine, TX

**Charles Emerson, PhD**  
University of Massachusetts Medical School, MA

**Fen-Biao Gao, PhD**  
University of Massachusetts Medical School, MA

**Matthew Harms, M.D.**  
Columbia University, NY

**Nicholas Johnson, M.D.**  
Virginia Commonwealth University, VA

**Joe Kornegay, D.V.M., PhD**  
Texas A & M University, TX

**Clothilde Lagier-Tourenne, M.D., PhD**  
Massachusetts General Hospital, MA

**Christian Lorson, PhD**  
University of Missouri, MO

**Nicholas Maragakis, M.D.**  
Johns Hopkins University, MD

**Joseph Metzger, PhD**  
University of Minnesota MN

**Kathrin Meyer, PhD**  
Nationwide Children's Hospital, OH

**Daniel Michele, PhD**  
University of Michigan Medical School, MI

**Douglas Millay, Ph.D.**  
Cincinnati Children's Hospital Medical Center, OH

**Brett Morrison, M.D., PhD**  
Johns Hopkins University, MD

## **2022 COMMITTEE MEMBERS**

### **Research Advisory Committee 2 Members**

**Michael Shy, M.D.**  
University of Iowa, IA

**Melissa Spencer, PhD**  
University of California, Los Angeles, CA

**DeWayne Townsend, D.V.M., PhD**  
University of Minnesota, MN

**Eric Wang, PhD**  
University of Florida, FL

**C. Chris Wehl, M.D., PhD**  
Washington University, MO

**Nicolas Wein, PhD**  
Nationwide Children's Hospital, OH

**Noah Weisleder, PhD**  
Ohio State University, OH

### **2022 MDA Venture Philanthropy (MVP) Program Advisory Committee**

**Alan Beggs**  
Boston Children's Hospital / Harvard Medical School

**James Berry**  
Massachusetts General Hospital / Harvard Medical School

**Andrew Billin**  
Independent NMD Consultant

**Bob Block**  
University of Maryland

**Dean Burkin**  
University of Nevada

**Merit Cudkowicz**  
Massachusetts General Hospital / Harvard Medical School

**James Dowling**  
Hospital for Sick Children

**Justin Fallon**  
Brown University

**Keith Gary**  
The ALS Association

**John Howell**  
President & Co-Founder, ComSovereign Holding

**Dione Kobayashi**  
Mass General Brigham

**Lou Kunkel**  
Boston Children's Hospital / Harvard Medical School (MDA Board Member)

**Melanie Leitner**  
Brown University / Accelerating NeuroVentures, LLC

**John Porter**  
Independent NMD Consultant

**Jeff Rothstein**  
Johns Hopkins University

**Seward Rutkove**  
Seward Rutkove Laboratory / Harvard Medical School

**Rita Sattler**  
Barrow Neurological Institute

**Paul Strijbos**  
Roche

**Chris Ward**  
University of Maryland

**Noah Weisleder**  
Ohio State University

**Bruce Wentworth**  
Independent NMD Consultant

**Stephan Züchner**  
University of Miami

### **2022 MDA Neuromuscular Observational Research (MOVR) Research Advisory Committee (RAC)**

**James Berry, MD, MPH**  
Harvard University Massachusetts General Hospital  
Director, MGH Neurological Clinical Research Institute  
(NCRI) Chief, Division of ALS and Motor Neuron Diseases

**Barry Byrne, MD, PhD**  
University of Florida  
Associate Chair of Pediatrics

**John Day, MD, PhD**  
Stanford University Medical Center  
Professor of Neurology, of Pediatrics (Genetics) and, By  
Courtesy, of Pathology

**Rod Howell, MD**  
University of Miami  
Professor and Chairman of Pediatrics Emeritus  
Miller School of Medicine

**Monkol Lek, PhD**  
Yale University  
Assistant Professor

**Nicholas Maragakis, MD**  
Johns Hopkins Medicine  
Director, ALS Center for Cell Therapy and Regeneration  
Research Professor of Neurology

**Sabrina Paganoni, MD, PhD**  
Harvard University Massachusetts General Hospital  
Co-Director, MGH Neurological Clinical Research Institute  
(NCRI)  
Assistant Professor

**Eric Schultz**  
Ocean Genomics, Inc.  
Co-Founder, Strategic Advisor



# MDA Executive Leadership

## President and Chief Executive Officer

Donald S. Wood, Ph.D.

## Chief Research Officer

Sharon Hesterlee, Ph.D.

## Chief Financial Officer

Michael J. Kennedy, MBA, CPA

## Chief Development Officer

Jeremy Kraut-Ordover, CFRE

## Vice President, Healthcare Services

Nora Capocci, MPH

## Vice President, Community Engagement

Alicia Dobosz

## Vice President, Human Resources & Volunteers

Peri Gondim

## Vice President, General Counsel

Henry Lanman

## Vice President, Public Policy & Advocacy

Paul Melmeyer

## Vice President, Marketing & Communications

Morgan Roth

# Financial Report

For the year ended December 31, 2022 (\$ in Thousands)

## Assets

Cash, cash equivalents, and investments	\$55,235
Contributions receivables and other assets	6,335
Fixed assets, net	2,834
<b>Total assets</b>	<b>\$64,404</b>

## Liabilities and Net Assets

Accounts payable and accrued expenses	\$10,407
Research and training grants payable	2,898
Credit facilities outstanding	7,969
Pension and post retirement plan obligations	36,321
<b>Total liabilities</b>	<b>57,595</b>
Net assets	6,809
<b>Total liabilities and net assets</b>	<b>\$64,404</b>

## Revenue

Special events, net	\$42,041
Contributions	14,547
Other revenue	986
<b>Total revenue</b>	<b>57,574</b>

## Functional Expenses

Patient and community services	19,839
Research	6,423
Professional public health education	12,224
<b>Total program services</b>	<b>38,486</b>
Fundraising	16,008
Management and general	3,502
<b>Total expenses</b>	<b>57,996</b>

## Other Non-Operating

Net investment return	(8,507)
Forgiveness of SBA PPP loan	2,000
Changes in unrecognized benefit plan costs	9,016
<b>Total other gains (losses)</b>	<b>2,509</b>
<b>Change in net assets</b>	<b>\$2,087</b>

In 2022, the Muscular Dystrophy Association (MDA) has remained strong, with 12% growth in fundraising revenue and 42% growth in program services compared to prior year. Change in Net Assets was \$2.1 million.

While total revenue has increased 12%, the underlying special events revenue grew by 19% from the prior year.

Program services, which includes research grants, totaled \$38.5M; this represented 66% of total expenses versus 52% in the prior year.

Overall for 2022, fundraising revenue growth allowed MDA to increase its investment in program services. MDA maintained its financial strength, with a strong cash balance on hand, reduced debt obligations, and a reduction in pension and post retirement plan liability.

## Join the Community

 Instagram: @mdaorg

 Facebook: MDAorg

 Twitter: @MDAorg

 LinkedIn: Muscular Dystrophy Association

 YouTube: YouTube.com/MDA

 Advocacy Twitter: @MDA\_Advocacy

 TikTok: @mdaorg

 Twitch: MDA\_LetsPlay

 Discord: MDA Let's Play