

# Year of the Volunteer



2023



Muscular  
Dystrophy  
Association

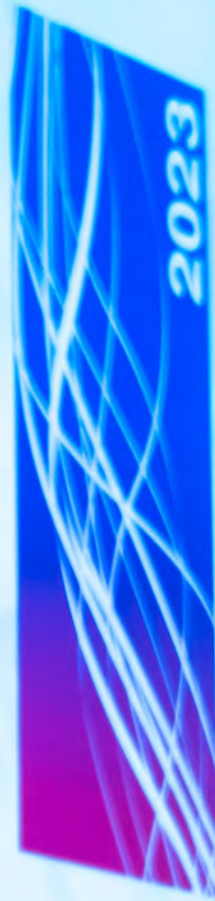
Annual Impact Report





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# A Letter From MDA's President & CEO

## Dear MDA Families, Partners, and Friends,

It's my privilege to share with you a comprehensive report on MDA's mission impact in 2023. Your participation in our work created opportunities for enduring impact across our community of children, adults and families living with neuromuscular disease. As you'll read further in our report, we achieved remarkable milestones in 2023.

We saw unprecedented output from our drug development pipeline of progress with FDA approval of eight new drugs and formulations. Notably, two new genetic therapies were approved, and we expect to see more coming forward in 2024.

With your support, we funded over 145 research grants totaling \$35 million, driving further progress in the way we understand and treat neuromuscular diseases.

MDA led important global conversations with leading researchers, clinicians and regulatory agencies on translational research and elevating the patient experience in the way we design research, treatment and care processes.

Our advocacy work on Capitol Hill and in White House policy discussions, positively influenced long-awaited changes that will redefine the way travelers with neuromuscular and other disabilities can fly without fear of injury or damage to mobility devices like power wheelchairs.

Also this year, you put broad and lasting smiles on the faces of 800 children and young adults participating in MDA's beloved Summer Camp tradition. Your partnership also enabled us to launch incredible initiatives that are being unveiled in 2024, including new ways to experience MDA's vast educational and informational resources, and our new College Scholarship program.

Your 2023 commitment to children, adults, and families living with neuromuscular disease has laid the foundation for continuous impact and momentum. As we continue to move forward in this new age of treatments, inclusion and unity, we are proud and grateful that you choose to stand with us. We could not do this work without you.

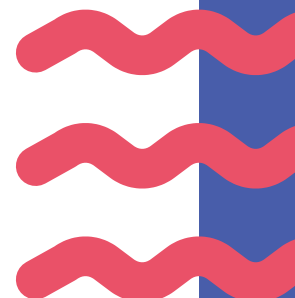
With deepest gratitude,



**Donald S. Wood, Ph.D.**

*President & CEO*

*Muscular Dystrophy Association*



# Advocacy & Public Policy: Championing Transformative Change

In 2023, MDA's Public Policy and Advocacy efforts achieved significant milestones, marking a transformative year for legislative progress and community empowerment. We showcased MDA's unwavering dedication to advocating for policies that empower and enhance the lives of people with neuromuscular diseases. Through strategic engagement, collaborative partnerships, and relentless advocacy, MDA continues to champion transformative change for the community it serves.

## MDA on the Hill

After a hiatus due to the pandemic, MDA's advocates returned to Capitol Hill in May 2023, advocating for accessible air travel. Thirty-one advocates from eleven states participated, engaging in 31 meetings with key lawmakers. Their strategic approach targeted decision-makers crucial to advancing air travel legislation, yielding impactful results.

MDA's relentless advocacy led to the passage of the House's version of the Federal Aviation Act (FAA) reauthorization. This bill heralds the most substantial air travel accessibility reforms since the 1980s, setting the stage for continued progress in 2024. Additionally, thanks to years of MDA advocacy efforts, the Department of Transportation (DOT) released regulations mandating accessible lavatories on single aisle airplanes with shorter implementation timelines.

In November, MDA announced a groundbreaking partnership with the Transportation Security Administration (TSA) to train officers on interacting with travelers with neuromuscular diseases, prioritizing safety, comfort, and dignity. This collaboration, including educational materials developed by MDA, promises to enhance the travel experience for individuals relying on mobility devices.





***MDA's relentless advocacy led to the passage of the House's version of the Federal Aviation Act (FAA) reauthorization.***



## **Access to Care and Equipment**

MDA's advocacy extended to healthcare access, with pivotal achievements such as advancing Duchenne muscular dystrophy (DMD) screening for newborns and securing Medicare coverage for wheelchair seat elevation systems. These victories exemplify MDA's commitment to ensuring equitable access to vital care and equipment for individuals with neuromuscular diseases.

## **Advocacy Collaboration Grants**

MDA awarded over \$100,000 in Advocacy Collaboration Grants to five organizations. These grants support innovative projects aimed at driving positive policy outcomes at federal, state, and local levels, fostering collaboration and amplifying advocacy efforts.

# Research

## Accelerating the Development of New Treatments in the Pipeline of Promise

**In 2023, the Muscular Dystrophy Association (MDA) continued its resolute commitment to advancing research and innovation in the field of neuromuscular disease.** With an investment exceeding \$1.1 billion since its inception, MDA remains a leading force in neuromuscular disease research. In 2023 alone, MDA supported 147 grants, totaling nearly \$35 million, through its research program. These efforts, guided by experts on the Research Advisory Committee, spanned the drug development spectrum, from early discovery to clinical trials infrastructure, ensuring a constant stream of promising projects aimed at improving treatments and outcomes for patients.

### Leadership in the Era of Genetic Medicine

As genetic therapies enter clinical testing, MDA remains at the forefront, driving discussions on safety and clinical translation. In 2023, MDA participated in critical meetings at the National Institutes of Health (NIH) and hosted its second gene therapy summit, convening key stakeholders to address challenges in clinical translation. Notably, MDA's collaboration with CureDuchenne and Parent Project Muscular Dystrophy led to the funding of a clinical study, spearheaded by MDA's Chief Medical Advisor, Dr. Barry Byrne, to explore novel strategies for enhancing gene therapy inclusivity. In the words of Dr. Barry Byrne, "Our goal now is to figure out how to best maximize and achieve the biggest impact with the technology in our hands." With unwavering dedication and

collaborative efforts, MDA continues to drive progress and innovation, ushering in a new era of hope and possibilities for individuals and families affected by neuromuscular diseases.

### Nurturing Future Leaders in Research

MDA's commitment to cultivating the next generation of researchers is evident through initiatives like the Development Grant program, which has supported over 2500 early-stage scientists and clinicians with \$126 million in funding. In 2023, MDA awarded eight new trainees through its fellowship program and launched the Summer Undergraduate Research Experience (SURE) program, providing invaluable research opportunities for students from underrepresented backgrounds. These efforts will cultivate a diverse and skilled workforce dedicated to advancing neuromuscular disease research.







## A New Era of Treatments

2023 heralded a groundbreaking milestone with the FDA's approval of eight drugs and formulations for various neuromuscular diseases, marking the most significant year in drug approvals to date. Notably, the approval of the first genetic medicines for ALS and Duchenne muscular dystrophy represents a culmination of decades of MDA-funded research into disease-causing genes. These approvals underscore MDA's pivotal role in advancing genetic medicine and signal a transformative shift in disease management, offering hope for patients worldwide.



### Mentor Matthew Alexander

*"I enjoyed training an undergraduate student and seeing them get excited about a neuromuscular project. It is always very rewarding to get them interested at an early stage and see them visualize a career in the neuromuscular field."*



# MDA Care Center Network:

**\$6M+**

in grants awarded



**150+**

Care Center  
Network Sites

(including MDA Care Centers,  
MDA ALS Centers, and MDA  
Care Affiliates)

**70,000+**

unique patients visits

## Unparalleled Care

The MDA Care Center Network experienced substantial growth, awarding **\$6M+ in Care Center grants**. With 150+ Care Center Network sites, including MDA Care Centers, MDA ALS Centers, and Care Affiliates, the network provided vital care and support to over 70,000 unique patients at over 120,000 visits.

Strategic initiatives, including recertification efforts and enrollment, ensured the continued high standards for excellence and accessibility of Care Centers. Additionally, the launch of the Associated Provider Network program expanded community support and outreach, reaching expanded MDA awareness to other providers in effort to increase path to diagnosis for experts to know when to refer.





Dr. Han Phan, MD

# MDA Clinical & Scientific Conference

## Advancing Research and Collaboration

In 2023, MDA hosted its prestigious annual Clinical and Scientific Conference, a cornerstone event that brings together leading researchers, clinicians, and healthcare professionals dedicated to advancing the field of neuromuscular diseases. The conference featured groundbreaking presentations, collaborative workshops, and extensive networking opportunities, fostering an environment of innovation and shared knowledge.

A highlight of the conference was the presentation of the MDA Scientific Achievement Award to Dr. Peter Marks from the FDA. Dr. Marks was honored for his significant contributions to the field of neuromuscular disease research and regulation. His work has been instrumental in advancing new therapies and ensuring their safe and effective delivery to patients.

The MDA Clinical and Scientific Conference continues to be an essential platform for driving progress and inspiring collaboration within the neuromuscular disease community, reinforcing MDA's commitment to research excellence and improved patient outcomes.

***Dr. Marks was honored for his significant contributions to the field of neuromuscular disease research and regulation.***



**1,942**

in-person attendees from 18 countries

**567**

virtual live-stream attendees from 33 countries

**265**

posters

**55**

exhibitors

**236**

virtual posters



# Quest Media

## Connecting the Community with Stories and Insights

**The Quest Media Platform serves the neuromuscular disease and other disability communities** as a vital hub of well-researched information about adaptive lifestyles, current research and treatment options, adaptive products for work, play and home, challenges and opportunities facing families with disabilities affecting mobility, and policy news from Capitol Hill, National Institutes of Health and other legislative and regulatory agencies. Through its comprehensive suite of digital tools and resources, the platform empowers individuals to access valuable educational content, connect with peers and experts, and support to help people advocate for themselves, their children, partners and other loved ones.

### Expanding Reach and Impact

With its focus on inclusivity and accessibility, the platform attracted users from diverse backgrounds and communities, fostering a sense of belonging and support for all individuals affected by neuromuscular diseases. Throughout 2023, the Quest Media Platform witnessed unprecedented growth and engagement, reaching an ever-expanding audience of patients, caregivers, researchers, and advocates. Quest's digital traffic increased from approximately 5,000 visits per month in 2022 to approximately 20,000 visits per month in 2023 – and there is no slowing down in sight.

Building upon the success of the 2022 gift and giving guide, we partnered even more closely with the MDA ambassador team and launched the evergreen Quest Media product guide. The product guide is updated quarterly with new ambassadors recommending new products.

### Facilitating Knowledge Sharing and Collaboration

One of the highlights of the Quest Media Platform's success in 2023 was its role in facilitating knowledge sharing and collaboration within the neuromuscular disease community. Through interactive forums, webinars, and virtual events, users had the opportunity to exchange insights, share experiences, and collaborate on initiatives aimed at advancing research and improving patient care.

### Elevating Patient Voices

Central to the success of the Quest Media Platform is its commitment to amplifying the voices and experiences of patients and caregivers. Through user-generated content, personal stories, and testimonials, the platform provided a space for people to share their journeys, inspire others, and advocate for greater awareness and support for neuromuscular diseases.



# Launched

the Quest Media Product Guide



## Quest's Digital Traffic 2022-2023

approximately

# 5,000

visits per month in 2022



approximately

# 20,000

visits per month in 2023

# Programs and Support

## Offering Guidance and Resources for the Neuromuscular Community

In 2023, MDA accommodated significant growth and generated corresponding impact across its various programs and initiatives, reaffirming its commitment to serving children, adults, and families living with neuromuscular diseases.

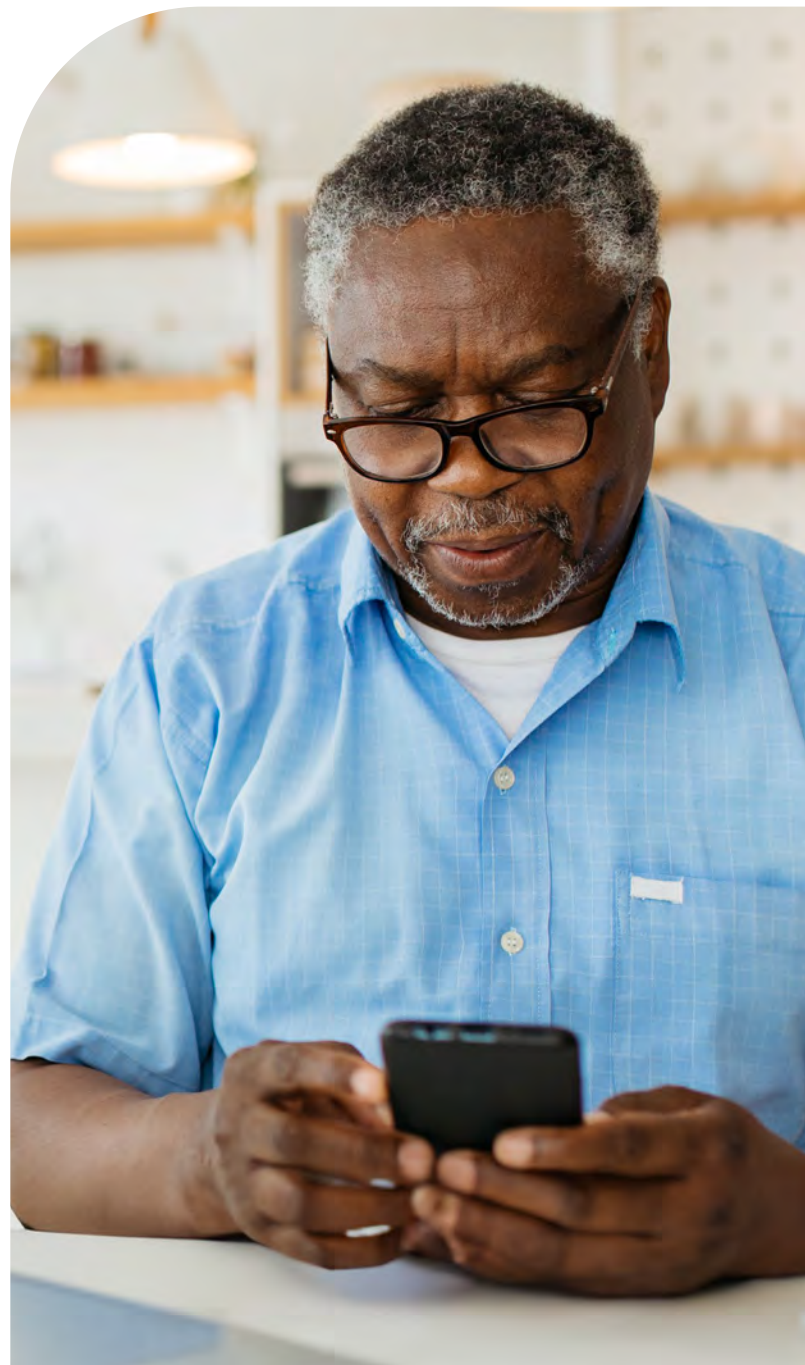
### Resource Center

The MDA Resource Center emerged as a pillar of support for the MDA community, handling 10K+ requests in 2023. With an average response time of less than a day, the Resource Center swiftly addresses inquiries, providing essential information and guidance on care, resources, and financial assistance. Inbound call statistics showcased the center's responsiveness, with an 83% connection rate for inbound calls and a 91% connection rate for outbound calls.

***MDA's Resource Center swiftly addresses inquiries, providing essential information and guidance on care, resources, and financial assistance.***



**17K+**  
cases in 2023







## Gene Therapy Support Network

In 2023, the Muscular Dystrophy Association launched the MDA Gene Therapy Support Network, including a dedicated “MDA Gene Team”. This expansion underscores our commitment to the NMD community and the MDA Care Center Network to facilitating access to advanced gene therapy treatments for people living with neuromuscular diseases.

**\$125M+**

invested in  
advancing gene  
therapy (GTx) for  
neuromuscular  
diseases



## Medical Education

In 2023, MDA’s Medical Education program made significant strides in professional education. The Allied Health Symposia, focus groups and workshops provided valuable learning opportunities. The program also featured four continuing education accredited Grand Rounds webinars, drawing substantial interest with 800+ registrations. Engagement was high, with 325+ live attendees and an impressive 2,300+ on-demand views, highlighting the program’s broad reach and impact to the medical community.

# Community Education

## Empowering People and Families with Knowledge and Understanding



MDA Community Education programs support people and families impacted by neuromuscular disease through the delivery of relevant, responsive, and actionable content from key opinion leaders. These programs focus on navigating critical life transitions, increasing disease understanding, and supporting access to independence.

### MDA Access Workshops

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

*“Thank you for putting together such an interesting and informative day. It gives me motivation to look into additional ways to help myself and make living with this disorder more tolerable.”*

– MDA Engage Attendee

## MDA Engage Seminars

MDA Engage Seminars provide live and on-demand virtual programs focus on providing in depth information about a specific disease or topic relevant to the neuromuscular disease community. 2023 saw the long-awaited return to in-person programming, at three MDA Engage symposiums that engaged 57 clinicians, representatives from 11 care centers, nearly 200 participants and over \$312,000 in funding secured.

## Print-ready Educational Materials

Including 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.

## MDA Mentorship Program

MDA's mentorship program is designed to increase the number of people living with neuromuscular disease in the workforce

by connecting youth to mentors who are established in a variety of fields, while providing hands-on learning in a supportive environment to discover their strengths and interests. In 2023, the program expanded to include a separate 5-week session for younger teens to explore a variety of careers.

A STEM focused session, now in its third year, serves young adults ages 16-21 who are specifically interested in STEM careers (science, technology, engineering, and math). Participants work with mentors from a specific field to complete an interactive project while also diving deeper into the ins and outs of STEM related fields.

***40 young people and 28 mentors participated in the MDA Mentorship Program in 2023.***



# Volunteers

## Driving Impact Through Dedication and Service

In a resounding declaration of respect and gratitude, MDA President & CEO Don Wood designated 2023 as **The Year of the Volunteer**, honoring the backbone of MDA—its **dedicated volunteers**. For over seven decades, MDA has been powered by selfless people from all walks of life who have helped shape MDA's legacy and its impact on adults, children, and families living with neuromuscular disease.

MDA's Year of the Volunteer led to revitalized communication and engagement with volunteers around the country. This initiative included work to refine data systems, ensuring more meaningful and effective interactions. It also provided a platform to celebrate volunteers with spotlight stories about their experiences and motivations for choosing to dedicate their time and their hearts to MDA and its community.

In 2023 alone, MDA attracted 850 volunteers from over 1600 applicants. Together, the 2023 cohort of volunteers contributed over 60,000 hours (about 7 years) to support mission programs. This includes volunteers who supported 800+ children with neuromuscular diseases at MDA's Summer Camp and advised fifty young mentorship and STEM participants. MDA volunteers also generated over 3,500

letters to elected officials advocating for consideration of policy reforms that would remove barriers to inclusion, safety and security for people with neuromuscular conditions. Ninety of our volunteers represent the MDA Ambassador program, who share their stories with the greater community to emphasize the need for MDA's continued innovations in neuromuscular medicine and research, advocacy and community-building.

# 60,000+

hours (the equivalent of 7 years!) to mission programs





**“It was honestly the best week of my life. The happiness brought to the kids was so contagious that I’ve never felt this happy before. I will definitely be coming back next year and would recommend everyone to be a part of this beautiful experience.”**

*- Volunteer from Florida Elks Camp, FL*

**“Camp is pure magic. If you’ve been once, it’s the easiest decision in the world to return year after year.”**

*- Volunteer from Timber Pointe Outdoor Center, IL*

**“I started volunteering at MDA Camp in 2018 as a medical provider. I know many of the campers from Care Center and camp provides a space I am able to bond with them in a different setting. I am able to witness the campers have opportunities they would not experience outside of the camp. Camp provides them adaptabilities to have a true summer camp experience! MDA Camp has become the best week of the year for me also and I look forward to it every summer!”**

*- Kathryn S. CPNP, Medical Team Volunteer & MDA Care Center Team Member*

# Recreation Programs

## Providing Meaningful Moments

Through our recreation programs, we provide MDA community members and their families with unique opportunities for inclusive leisure-time activity and connection that yield independence, empowerment, and lasting relationships.

### Summer Camp

In 2023, MDA welcomed 800+ campers and 570 volunteers to 22 in-person and two virtual camp experiences.

MDA Summer Camp is a beloved tradition for generations of children and the volunteers who support their camp experience. Camp is where barriers fade away and where kids with neuromuscular diseases can thrive in a fully adaptive environment designed to help them try new experiences and to build lifelong friendships as they acquire essential life skills, such as self-advocacy.



*“This summer was my second time going to MDA Summer Camp. Whenever I go to camp, I feel so welcomed and loved. MDA Camp is a place where you create lifelong friendships – this summer I got to see some of my old friends and make new ones. It is always so nice to have people who understand me, and I can relate to. MDA Camp is truly a place of acceptance and rejuvenation. I would like to thank all of the nurses and volunteers for making MDA Camp possible. Thank you for giving me and so many others so much joy.”*

- Leah, MDA NJ Camper and  
MDA National Ambassador

*“MDA camp has been the highlight of my summers since I was eight. It has taught me how to come out of my shell and make new friends. Those friendships have now become permanent and ones that I look forward to reestablishing every summer. Camp is where I feel most comfortable and where I want to be.”*

- Abby, MN Camper



**97%** of parents value the summer camp program and the effect it has had.

**96%** of parents shared that summer camp has helped their child become more independent.

**96%** of parents say that camp has helped their child increase their confidence levels.





**3,000**

lights used at the Neon Dance



**7.7k oz**

of shaving cream used at the Messtival



**93**

bananas used in the Banana Olympics



## Camp Fun

### Favorite Activities:

- Neon Dance
- Messtival
- Banana Olympics
- Talent Show
- Ziplining
- Swimming

*"I am absolutely amazed at my son's confidence and self-reliance after just one week at camp! Thank you, MDA, volunteers, and sponsors!"*

- Camper Parent

*"My son LOVES camp!! It is the only place in the world, besides our home, that I think he doesn't feel like an outsider, a burden, a spectacle, or just too different. It brings him so much joy to go every year, & he is always sad to leave & have to wait another year for the experience."*

- Camper Parent





46 Families

4 Sites

153 Attendees

### Puerto Rico Family Getaway Participant

*“I loved this, I needed this, I feel like I finally found my planet. Everybody here is like me, I don’t even have this at my ‘home’ because here we all have the same pain, they walk, run and jump around like I do.”*



### Getaways for MDA Families

MDA’s Family Getaway Program was introduced in 2023 to offer meaningful experiences for families living with neuromuscular disease. Family Getaway weekends provide opportunities for families to bond and connect with the broader MDA community while enjoying a variety of accessible activities in fully accessible resort locations. With four sites hosting forty-six families and 150+ attendees and 17 volunteers, the impact of these getaways extends far beyond the weekend itself.



# Community Programs

## Cultivating Connection & Belonging

**Community Programs at MDA empower members of the neuromuscular disease community to make social connections, bond over shared hope, raise awareness, and feel a sense of belonging.**

### Let's Play

MDA Let's Play brings the fun and joy of a community center to individuals' homes. Using the online platform Discord, MDA provides community members with a safe and welcoming environment online. We provide all 2,500+ community members with entertainment through gaming, art, content creation, and other activities while socializing with others who can truly understand the unique situations in everyone's lives. It is our goal to enable members to both be themselves and share themselves while instilling a sense of belonging for all.

### MDA Ambassadors

MDA Ambassadors are young people and adults living with neuromuscular disease who share their stories and authentic perspectives to connect within the community to raise awareness, inspire support, and advance the MDA mission. Ambassadors share their story and experiences in print, on video, at MDA events, and more, engaging with MDA's partners and the greater community to spread awareness and garner support. In 2023, MDA was represented by 102 Ambassadors, including two National Ambassadors, one child and one adult. MDA Ambassadors share their stories to raise awareness and hope, while reflecting the breadth and diversity of the neuromuscular community.



## Amy Shinneman

2023 MDA National Ambassador

*“When I set out on this journey as National Ambassador, making connections with others through sharing my story was one of my main objectives. I have met many great people living with neuromuscular disease, as well as some of their families. These connections have been life changing for me and motivate me to continue to share my story even after my role as an MDA National Ambassador is over. Meeting fellow National Ambassador Leah and her family has been a highlight as well. Our families will be friends for a long time to come!”*



## Leah Zelaya

2023 MDA National Ambassador

*“I am so grateful for the opportunities that I have had in my life to represent people with disabilities. I am blessed that I have been able to do this through the arts and ambassadorship. Being this year’s National Ambassador for MDA has been a dream come true. It has been so rewarding to be able to share my story with others in order to raise awareness and encourage others living with neuromuscular disease. I am DEFINITELY living my BEST life! (Thank you, MDA!)”*

# Fundraising Events

## Empowering Communities to Make a Difference

### Team Momentum

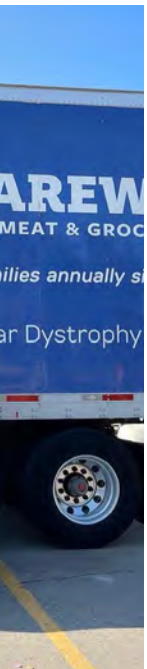
- 4 marathons and 1 half marathon
- \$540k+ raised
- 168 participants



### Muscle Walk

- 7 live events and 1 virtual
- Over \$869k raised
- 2,200+ participants
- 140 volunteers
- 239 Muscle Walk teams





# 33

## Golf & Gala Events

# 5,000+

Participants

# \$6.5M+

Raised



*“Sharing our son’s diagnosis was not an easy decision, but my good friends reminded me that now was the time to lean on my village, and that they were part of our family’s village. Hearing that instantly brought me comfort. From that moment, I knew that we were not alone in this journey, and it is a reminder that we all need a village to lean on during difficult times and that having a strong support system can make all the difference.”*

– Team Milo, 2023 First Year Muscle Walk Participant

### Top Committees

- Atlanta Night of Hope
- Boston Muscle Team
- Dallas Uncork A Cure
- Arizona Passport To A Cure
- Mike Bellotti’s Toast to Strength Gala & Golf Tournament
- Berks Black -N- Blue

# Partners

## Building Strong Alliances for Greater Impact

MDA's corporate partners play a pivotal role in advancing our mission to transform the lives of people living with neuromuscular diseases. Through strategic alliances, these partners provided essential support, funding, and resources that fueled groundbreaking research, enhanced care, and raised awareness.

**IAFF** | International Association of Fire Fighters

raised \$700M since 1954

**CITGO**

raised \$272M in 38 years

**Acosta Group**

raised \$100M in 38 years

**Price Chopper**

raised \$30M in 39 years

**Dutch Bros**

raised \$2.5M in 2023



## Transformer (\$5M+)

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## Visionary (\$1M - \$5M)

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## Leader (\$500K - \$1M)

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## Innovator (\$250K - \$499K)

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# Board of Directors

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For close to 75 years, the Muscular Dystrophy Association has pioneered advancements in research, care, and advocacy for individuals and families living with neuromuscular diseases. As we approach this significant milestone, we reflect on our past achievements and look forward to a future filled with hope and continued progress.

MDA's Board of Directors continues to steer the organization with a forward-thinking mission and a clear vision for the future. Our board is a diverse group of leaders, including top researchers, clinicians, entrepreneurs, business executives, disability advocates, and philanthropists. This distinguished panel of advisors brings exceptional wisdom, experience, and dedication. Their expertise and commitment ensure that MDA remains the leading voluntary health organization for the neuromuscular disease community in the US, empowering families and strengthening the communities in which they live.

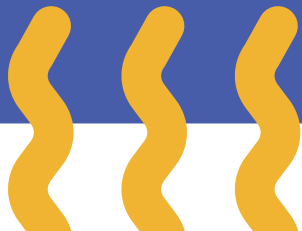
In addition to their professional expertise, the members of our board bring a deep personal commitment and connection to MDA's mission. This personal investment adds a layer of empathy and understanding that is reflected in all aspects of MDA's work.

With the strong leadership and vision of our Board of Directors, we will continue to ensure that every person with neuromuscular disease can live longer, more independent lives.

“

Inspired by the volunteers who made such a difference in my life, I chose to give back and advocate for others facing similar challenges. This path of service led me through my academic and professional career, eventually to my role as a judge in New York State. It's a journey that illustrates the transformative power of volunteering—not just for those we help, but for us as volunteers. ”

- Honorable Robert E. Pipia  
*New York District Court*





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Chairman  
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Chair of the Stanley H. Appel  
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Distinguished Chair in ALS at  
Houston Methodist Hospital, and  
Professor of Neurology at Weill  
Cornell Medical College

**Bart Connor**  
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Gymnast, SEC/ESPN/ABC  
Commentator and Inspirational  
Speaker

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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

# 2023 COMMITTEE MEMBERS

## Audit Committee Members

**Mark Smith**  
Chairperson  
Chief Financial Officer and Corporate Secretary, Guidon Energy

**Lilian Wu**  
Former Executive, IBM Global

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

**Gov. Brad Henry**  
26th Governor of Oklahoma

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**Honorable Robert Pipia**  
Chairperson  
Nassau County District Court

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

**Gov. Brad Henry**  
26th Governor of Oklahoma

## Executive Committee Members

**Mark Smith**  
Chairperson  
Chief Financial Officer and Corporate Secretary, Guidon Energy

**Honorable Robert Pipia**  
Nassau County District Court

**Charles D. Schoor, Esq.**  
Former Law Firm Partner (Ret.)

**John Costantino**  
Managing General Partner, NGN Capital, LLC (Ret.)

## Finance and Investment Committee Members

**John Costantino**  
Chairperson  
Managing General Partner, NGN Capital, LLC (Ret.)

**Dan Fries**  
Senior Vice President, Managing Director, Segal

**Steve Furnary**  
Founding Equity Partner of Clarion Partners

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

**Charles D. Schoor, Esq.**  
Former Law Firm Partner (Ret.)

**Nancy Kindelan**  
Former Non-Profit CEO (Ret.)

## Governance Committee

**Charles D. Schoor, Esq.**  
Chairperson  
Former Law Firm Partner (Ret.)

**Beth McNally**  
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**Nancy Kindelan**  
Former Non-Profit CEO (Ret.)

**Benjamin Cumbo III**  
Former Government Executive (Ret.)

**Mike Rowlett**  
Former CEO of Womack Machine Supply Company

**Matt Plummer**  
Designer, Matt Plummer Designs

**Honorable Robert Pipia**  
Former Government Executive (Ret.)

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

## Development Committee Members

**Nancy Kindelan**  
Former Non-Profit CEO (Ret.)

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

**Mike Rowlett**  
Former CEO of Womack Machine Supply Company

**Adam Gerber**  
Head of Ads Commercialization, Netflix

## Research Advisory Committee 1 Members

**Louis Kunkel, PhD**  
Chairperson  
Boston Children's Hospital, MA

**Elisabeth Barton, PhD**  
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

## **2023 COMMITTEE MEMBERS**

### **Research Advisory Committee 1 Members Cont'd**

**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**  
Weill Cornell Medical College, NY

**Katherine Mathews, M.D.**  
University of Iowa, IA

**Lynn Megeney, PhD**  
Ottawa Health Research Institute, CAN

**Carlos Moraes, PhD**  
University of Miami, FL

**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

**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

### **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

## 2023 COMMITTEE MEMBERS

### 2023 MDA Venture Philanthropy (MVP) Program Advisory Committee

**Suma Babu, MBBS, MPH**  
Massachusetts General Hospital / Harvard Medical School

**Alan Beggs, Ph.D.**  
Boston Children's Hospital / Harvard Medical School

**Robert Bloch, Ph.D.**  
University of Maryland

**Jeffrey Chamberlain, Ph.D.**  
University of Washington School of Medicine

**Stephen Chang, Ph.D.**  
Independent NMD Consultant

**Merit Cudkowicz, M.D., MSC**  
Massachusetts General Hospital / Harvard Medical School

**Tania Gendron, Ph.D.**  
Mayo Clinic

**Dione Kobayashi, Ph.D.**  
Mass General Brigham

**Louis Kunkel, Ph.D.**  
Boston Children's Hospital / Harvard Medical School

**Clothilde Lagier-Tourenne, M.D., Ph.D.**  
Massachusetts General Hospital / Harvard Medical School

**Melanie Leitner, Ph.D.**  
Brown University / Accelerating NeuroVentures, LLC

**Elizabeth McNally, M.D., Ph.D.**  
Northwestern University

**John Porter, Ph.D.**  
Independent NMD Consultant

**April Pyle, Ph.D.**  
David Geffen School of Medicine at UCLA

**Robert Rugani**  
Independent Business Consultant

**Rita Sattler, Ph.D.**  
Barrow Neurological Institute

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

**Noah Weisleder, Ph.D.**  
Ohio State University

**Bruce Wentworth, Ph.D.**  
Independent NMD Consultant

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

### 2023 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

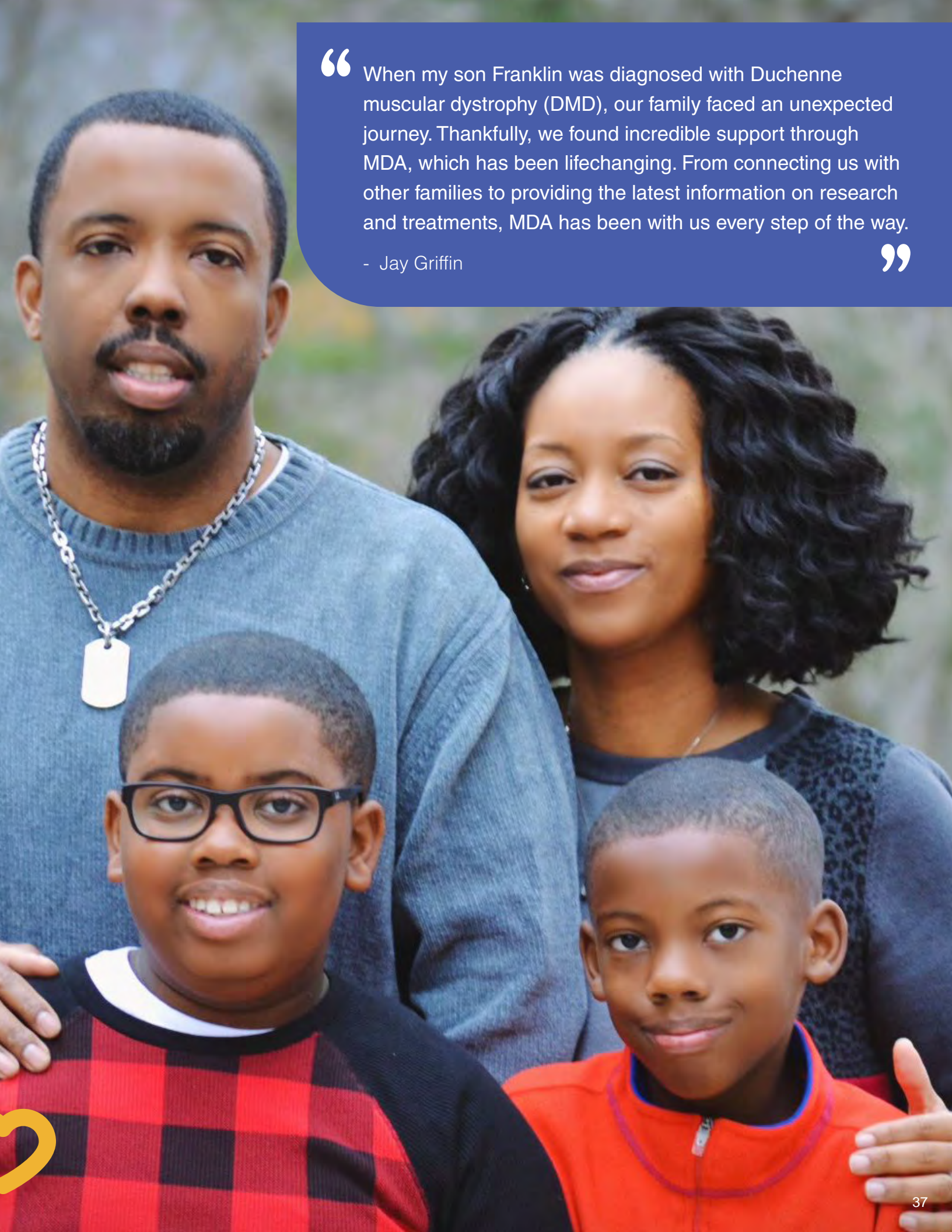
**R. Rodney Howell, MD**  
University of Miami  
Professor and Chairman of Pediatrics Emeritus  
Miller School of Medicine

**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



“ When my son Franklin was diagnosed with Duchenne muscular dystrophy (DMD), our family faced an unexpected journey. Thankfully, we found incredible support through MDA, which has been lifechanging. From connecting us with other families to providing the latest information on research and treatments, MDA has been with us every step of the way.

- Jay Griffin

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# **MDA Executive Leadership**

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**President and Chief Executive Officer**

Donald S. Wood, Ph.D.

**Chief Research Officer**

Sharon Hesterlee, Ph.D.

**Chief Operating Officer & Chief Financial Officer**

Michael J. Kennedy, MBA, CPA

**Chief Marketing Officer**

Morgan Roth

**Chief Legal Officer, General Counsel**

Henry Lanman

**Chief Development Officer**

Ruth Ann Dailey

**Executive Vice President, Healthcare Services**

Nora Capocci, MPH

**Executive Vice President, Community Engagement**

Alicia Dobosz

**Executive Vice President, Human Resources & Volunteers**

Peri Gondim

**Executive Vice President, Public Policy & Advocacy**

Paul Melmeyer

# Financial Report

(\$ in Thousands)

2023

2022

|               |    |        |    |        |
|---------------|----|--------|----|--------|
| Total Revenue | \$ | 63,971 | \$ | 51,067 |
|---------------|----|--------|----|--------|

## Functional Expenses

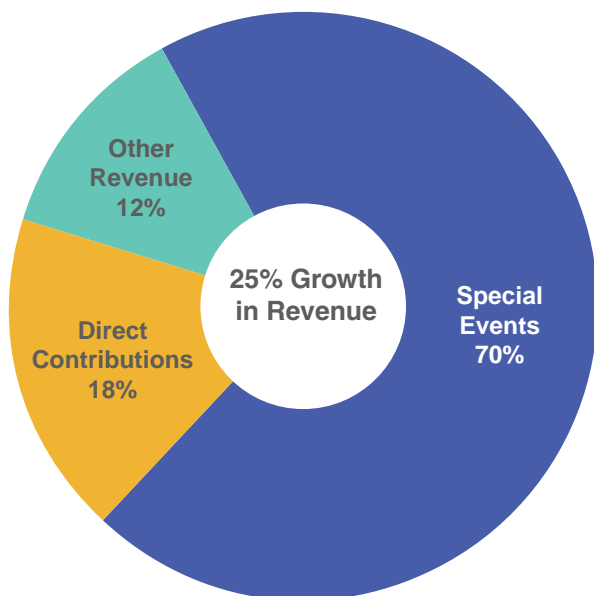
|                                      |  |        |  |        |
|--------------------------------------|--|--------|--|--------|
| Patient and community services       |  | 20,277 |  | 19,839 |
| Research                             |  | 9,446  |  | 6,423  |
| Professional public health education |  | 13,150 |  | 12,224 |
| Total program services               |  | 42,873 |  | 38,486 |
| Fundraising                          |  | 14,732 |  | 16,008 |
| Management and general               |  | 3,833  |  | 3,502  |
| Total expenses                       |  | 61,438 |  | 57,996 |

## Other Non-Operating

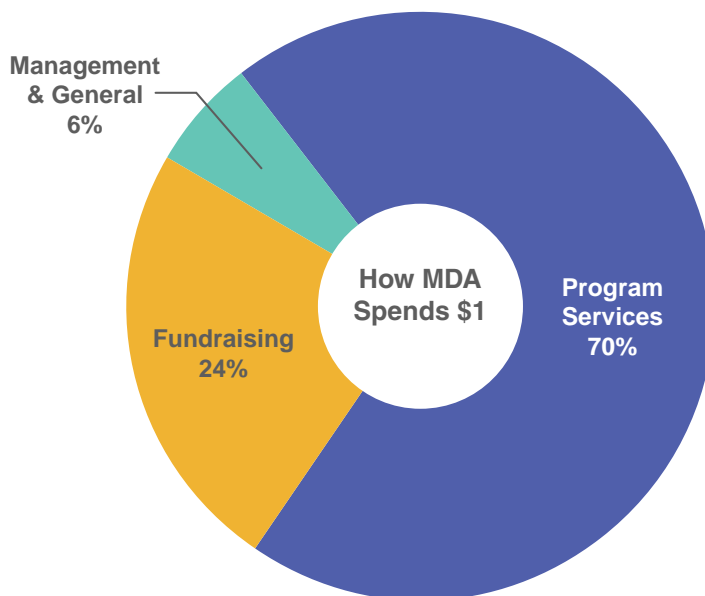
|  |  |       |  |       |
|--|--|-------|--|-------|
| Changes in unrecognized benefit plan costs |  | (948) |  | 9,016 |
|--|--|-------|--|-------|

|                      |    |       |    |       |
|----------------------|----|-------|----|-------|
| Change in net assets | \$ | 1,585 | \$ | 2,087 |
|----------------------|----|-------|----|-------|

## Revenue



## Expenses



Note: In 2023, \$0.70 of every dollar MDA spends goes directly to our mission programs

## Join the Community

 Instagram: @mdaorg

 Facebook: MDAorg

 X: @MDAorg

 LinkedIn: Muscular Dystrophy Association

 YouTube: YouTube.com/MDA

 Advocacy X: @MDA\_Advocacy

 TikTok: @mdaorg

 Twitch: MDA\_LetsPlay

 Discord: MDA Let's Play

