2025 ANNUAL REPORT

LEGACY. IMPACT. MOMENTUM.

75TH

75 Years of Progress for the Neuromuscular Community

MDA®
Muscular Dystrophy Association

This is a story about **legacy, impact, and momentum**, and the community that delivered it.

Across the neuromuscular community, families are experiencing new possibilities that would have seemed impossible a generation ago. New therapies are reaching more people, and expert care teams are administering treatments that were not available even just ten years ago.

Today, scientists continue to explore new ideas in labs worldwide, and advocates work alongside lawmakers to advance federal policies that improve access, independence, and quality of life. At the same time, families are connecting in new ways, finding reliable information, and building constructive communities locally, across diagnoses, and across life stages.

This progress is the result of 75 years of dedication and united effort. And it only gets better from here.

LETTER FROM THE PRESIDENT & CEO

When the Muscular Dystrophy Association (MDA) was founded in 1950, the field of neuromuscular medicine was defined more by hope than progress.

Families and clinicians each sought basic answers about the cause and progression of neuromuscular diseases. Treatments were still decades away: there was no drug pipeline, no gene therapies, no disease-modifying treatments, and few places to turn for support.

What did exist were determination, grit, and generosity. These attributes are foundational to the neuromuscular disease community, and they continue to power MDA's work today.

Because of MDA's singular focus on, and investment in, exploring muscle biology and the role of genetics in neuromuscular diseases, the field has experienced a sea change over the decades since our founding. Together, we have helped advance more than 25 approved disease-modifying therapies for neuromuscular diseases. MDA-supported research helped lay the scientific foundation for treatments such as SPIRANZA for spinal muscular atrophy and QALSODY for amyotrophic lateral sclerosis (ALS).

Through MDA Venture Philanthropy, we also supported the development of AGAMREE, a steroid alternative for Duchenne muscular dystrophy, while **MDA-funded research led by Dr. Michio Hirano contributed to breakthroughs that recently resulted in the first approved therapy for a rare mitochondrial disease**.

These and many other advances have helped people live longer, live more independently, and make their voices heard across the scientific,

From Research to Real World

When Arturito Estopinan was diagnosed with thymidine kinase 2 deficiency (TK2d) at just 17 months old, his condition was progressing rapidly. He had lost nearly all movement, could no longer swallow, and required breathing support. At the time, there were no approved treatments for this rare and often fatal mitochondrial disease.

Desperate for options, Arturito's parents connected with Dr. Michio Hirano, a neurologist and researcher at Columbia University, who was developing a TK2d therapy with MDA support. Because Arturito was not eligible for the clinical trial, Dr. Hirano secured access to the investigational treatment through the FDA's expanded access pathway. Arturito began therapy at 20 months old.

Today, Arturito is 14 years old. He attends school, breathes independently during the day, and has regained much of the movement he once lost.

In 2025, the same therapy became KYGEVVI®, the first FDA-approved treatment for TK2d. Arturito's story reflects what is possible when research, clinical care, advocacy, and family determination come together. It is also a powerful example of how MDA's long-term investment in science can help transform a laboratory discovery into a treatment that changes lives.

clinical, legislative, and regulatory systems that shape their lives. This progress would not be possible without decades of collaboration and a shared belief in a better future.

If 75 years have taught us one thing, it is that progress is possible only when we join forces.

Our longtime partners, like the International Association of Fire Fighters (IAFF) and CITGO, stood with our families long before today's breakthroughs. They raised funds and drove awareness, helping ensure research and care could move forward.

As IAFF, CITGO, and tens of thousands of MDA supporters know, progress matters only when it reaches people. That is why our commitment exceeds the basics. We focus on strengthening the entire ecosystem that supports people with neuromuscular diseases, their families, and their caregivers.

In 2025, we launched our Community Advisory Task Force, giving families and people living with neuromuscular diseases a stronger voice in defining our path. This philosophy of convening, listening, and engaging community guides our work, from the launch of the MOVR 2.0 data hub to Quest Media, MDA Engage symposia, and MDA's signature Clinical & Scientific Conference.

The work ahead is significant, and the opportunity is greater than ever. MDA will keep uniting people, expertise, and resources to ensure progress reaches every family that needs it.

That has always been the story of MDA: progress powered by a determined and powerful community.

> "If 75 years have taught us one thing, it's that progress is possible only when we join forces." — *Sharon Hesterlee, PhD*

Sharon Hesterlee, PhD
Sharon Hesterlee, PhD
President & CEO

LEGACY

Seventy-five years ago, many of the diseases we treat today were still unnamed and their origins not yet fully understood. In those earliest attempts to understand disease origins, genetics, and progression, there were no gene therapies, no disease-modifying treatments, and no coordinated systems of care.

Undeterred, a groundswell of determined and hopeful community formed and, together, built the foundation and the field that have propagated for today's progress. Despite naysayers from the medical establishment of the day, researchers pursued causal factors such as genetics and the environment. As clinicians worked to improve comprehensive care models, families became advocates for research and inclusion in their hometowns and on Capitol Hill. Volunteers built communities to keep families, researchers, and doctors connected and informed while generations of donors generously funded MDA to ensure breakthroughs were not just theoretical, but real and accessible to the people who need them.

Together, they built the foundation for today's expansive progress and, in doing so, forged MDA's standing reputation as a convener, a prolific builder of partnerships and collaborations, and a resource not only for people living with neuromuscular diseases but also for physicians, allied health professionals, researchers, family members, caregivers, and policy advocates.

That role has become increasingly important as the field has grown more complex. Advances in research demand coordinated care. New therapies require education and support. Policy changes require collaboration among advocates, clinicians, researchers, and families. Progress depends on connection.

Legacy is never simply a story about the past. It is the reason today's progress is possible.

IMPACT

Progress matters when it tangibly changes people's lives, and it was a prolific year for research.

Six new FDA approvals arrived in 2025. These new treatments, label expansions, and formulations are rewriting the trajectory of spinal muscular atrophy (SMA), myasthenia gravis (MG), thymidine kinase 2 deficiency (TK2d), and other neuromuscular diseases. More families than ever before are making decisions about treatment options rather than wondering whether treatment will ever exist.

In 2025, MDA maintained a robust research portfolio of approximately 135 active grants, representing nearly $33 million in funding commitments. Building on that foundation, MDA awarded nearly 40 new grants during the year, committing more than $6 million to accelerate the next generation of discovery. These investments are guided by MDA's Research team and its Research Advisory Committee.

Research Grants in Action

Thanks in part to funding provided by MDA, KYGEVVI is now available as the first therapy for TK2d, one of the rarest mitochondrial disorders. In 2025, ITVISMA became the first gene therapy available to older children, teens, and adults living with SMA. Additionally, IMAAVY was approved as an advanced treatment for people living with MG.

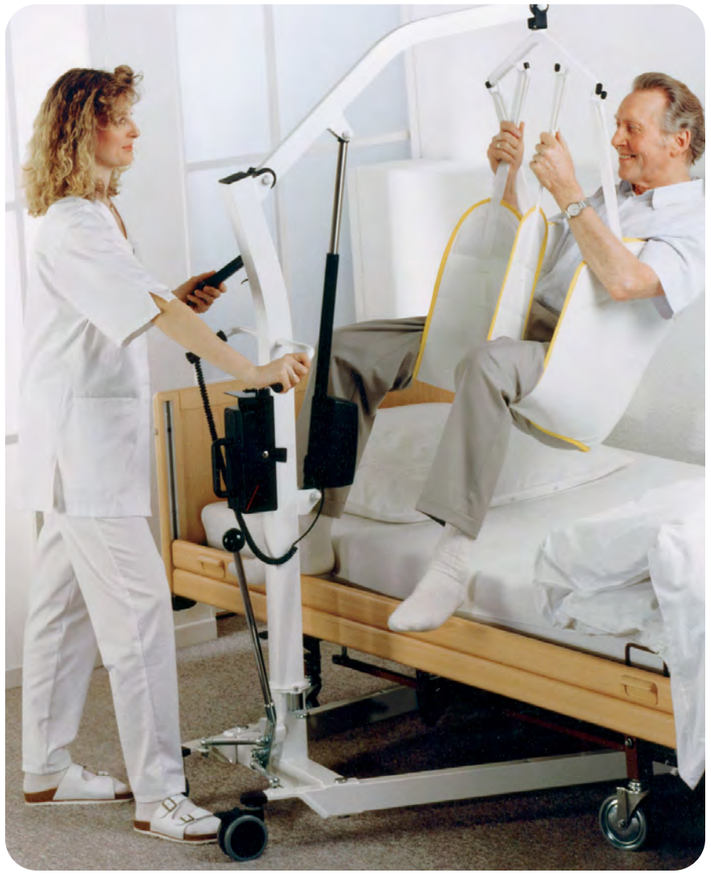
Other important advances included FDA approval of UPLIZNA as a new treatment option for generalized MG, expanded access to SOLIRIS for children living with the disease, and a new tablet formulation of EVRYSDI that offers greater convenience for people with SMA. Together, these milestones reflect a remarkable shift in the neuromuscular landscape, where more people are gaining access to therapies that can change the course of their disease, improve quality of life, and create possibilities that did not exist just a few years ago.

More than 70,000 people received MDA's gold-standard care through our Care Center Network. In total, more than 130,000 visits were made to 150-plus MDA clinics. The Care Center model reflects one of MDA's defining strengths: bringing together multidisciplinary expertise so people receive coordinated care rather than fragmented care.

MDA's newly launched Durable Medical Equipment (DME) Grant Program showed another dimension of impact. Over 75 DME grants were awarded when this program launched in Q4 2025, supporting the purchase of lift systems, adaptive beds, shower chairs, and communication devices that helped people in the community remain active, independent, and engaged. These items may not generate headlines, but they often have an immediate effect on quality of life. **91% of DME grant recipients reported that the award partly or fully eliminated the financial barrier to the equipment they needed.**

Community Members Speak About DME Grants

- **"The generosity from MDA gave me my life back."**
- **"This is such an amazing program to help eliminate barriers for families like mine. As a hardworking mom with all the responsibility to make my disabled son's independence and positive sense of self a reality, programs like this are just as important as physician sustenance."**
- **"Our family would like to thank MDA not just for the shower chair, but for the dignity and independence it restored. Having LGMD means almost always having to ask for help; the shower chair fixes that problem."**



MDA is a place to come for answers. **More than 15,500 people turned to MDA's Resource Center and family support teams for help and guidance.** Staffed by knowledgeable and caring specialists, the Resource Center and family support teams serve as a port in the storm for people and families who need information, resources, guidance, and sometimes just to know that they are seen and heard.

Guidance with Heart

"Mariam" is one of many parents who reached out to MDA this year. After her child's diagnosis, her pediatrician handed her a stack of brochures. By the time she got to the car, she realized she did not understand what any of it meant or what to do next. She called MDA's Resource Center and, in one call, connected to a specialist who could answer her questions in plain language. She was guided to a multidisciplinary MDA Care Center and went from overwhelmed to having a plan.

What Do Scientists Think of the MDA Clinical & Scientific Conference?

"I have been to a lot of meetings in my career. This was one of the best I have ever been to. The format was fantastic, the speakers were great, and the mix of stakeholders (academics, foundations, industry, patients, etc.) was amazing. The mix of single sessions and tracked sessions was also perfect. This is just the type of meeting that has the potential to significantly move therapeutics ahead. The last day was particularly thrilling, with results coming in for so many diseases using so many therapeutic platforms. It was fun to see our outcomes used in so many of these trials."

The annual MDA Clinical & Scientific Conference continued its role as one of the premier gatherings in the neuromuscular field. Over 2,500 research scientists, clinicians, industry leaders, and community members came together across eight tracks and over three dozen sessions to share discoveries, discuss emerging therapies, and accelerate collaboration across disciplines. Progress moves faster when people learn from one another.

Reliable, Accessible, Real

We receive hundreds of comments from virtual and in-person educational program attendees, most of whom appreciate MDA and its sponsors for "seeing" them and providing information that is accessible, relevant, and, in many cases, eye-opening.

- "Great connectivity [at Engage]! This session changed the way I've been thinking about my disease for nearly two decades."
- "So many resources and networking options we've not known existed in the 30 years we've been living with CMT. So very happy we came [to Engage]."
- "I really appreciated [the Home Solutions for Greater Independence] webinar. I'm reaching a point in my disability that I am going to need more assistance, and this information was spot-on!"

Over 14,000 people took time in 2025 to tune into MDA's expert-led educational programs, connecting the community with trusted information on research, advocacy, care, and daily living with neuromuscular diseases.

Overall, MDA delivered more than 45 educational programs, a 35% increase over 2024. Among them were MDA Engage symposia in Dallas and San Francisco, where families, caregivers, and people living with neuromuscular diseases connected directly with experts and with one another. They learned about emerging therapies and engaged in significant conversations with others in the community who are confronting similar experiences. Engage affirms the significance of no-cost, community-centered programs that meet people where they are and support real-world care and life decisions. Given the symposia's popularity and impact, MDA is offering four Engage sessions in 2026.

In addition to providing education, mentorship is a key part of our support portfolio. The MDA Mentorship Program helps teens and young adults living with neuromuscular diseases explore education and career opportunities while building confidence, skills, and professional networks. Offered virtually and at no cost to participants, the program connects young people ages 14–22 with professionals from a variety of career fields who provide guidance, encouragement, and real-world insights on higher education, work, and life with a neuromuscular disease.

We were also pleased to award 16 college scholarships to outstanding scholars from within our community. Beyond providing financial support, the scholarship program spotlights the accomplishments and aspirations of young people living with neuromuscular diseases and reinforces MDA's commitment to supporting individuals as they transition to adulthood.

Parents Speak About MDA Summer Camp

- "It was, perhaps, the single most meaningful experience of my child's life. We've taken a lot of trips to a lot of fun places ... But nothing compared to spending a week having a ton of fun with kids just like her. She felt a sense of belonging there that she'd never experienced before."
- "My child was nervous going into camp, and I was a little worried at first. Within moments of arriving, I could tell she started to feel more comfortable. And fast-forward to pick-up: She didn't want to leave! There were many tearful goodbyes, and already anticipation for next year. This gave her the opportunity to meet others with similar neuromuscular diseases. She had never met anyone like her before. It made her feel less alone."
- "It truly is the best week of the year for a young person with a muscle disease. [My son] has made meaningful relationships with campers and counselors, unlike other relationships. Even though he doesn't say it, I know, as his mom, that he feels seen, heard, and cared about like no other environment."

- "My kid has a new light in his eyes and an optimism we haven't seen in a long time. It's hard to put into words just how much of a change we see in him."
- "We schedule our summer around MDA camp every year. It is my son's only real opportunity to have complete freedom away from his parents/grandparents. It provides a perfect situation for him to rely on new caregivers and requires him to advocate for himself in a setting away from family. It is great practice for when he transitions out of high school and into real life. On top of all of that, he always has a blast!"

Combined with programs such as MDA Mentorship, the College Scholarship program helps equip the next generation of leaders, professionals, advocates, and innovators with the resources and support they need to pursue their ambitions and build independent futures.

At MDA Summer Camp, nearly 850 campers and more than 800 volunteers created a community defined by possibility, friendship, confidence, and belonging.

> 98% of parents reported that MDA Summer Camp provides campers with opportunities to develop a **positive self-identity**.

> 94% of parents shared that MDA Summer Camp promotes **independence and agency** in their child.

> 93% of parents shared that MDA Summer Camp provides their child with opportunities to **make friends who share their challenges** — and their victories!

“Every time I volunteer, I get more than I give. There is no better way to spend a week than with the kids at MDA camp.”

Think it’s just kids leaving camp with a restored sense of possibilities? It is not. **For our specially trained and qualified volunteers, MDA summer camp is also fulfilling and magical.**

Developing confidence and a sense of agency as a young person is one of the first steps to becoming an effective advocate — for yourself and for your community. MDA remains highly focused on elevating advocacy as a means of securing rights, access, research funding, and recognition from federal legislators and regulatory agencies.

In 2025, MDA convened more than 13,000 grassroots advocates (ages 7 to 70) and 40 single-disease organizations around a shared policy agenda for the neuromuscular community. Together, they generated nearly 20,000 advocacy actions supporting accessibility, healthcare access, research funding, accessible air travel, and other priorities.

Important multi-year efforts culminated in 2025, including the addition of Duchenne muscular dystrophy (DMD) to the Recommended Uniform Screening Panel. This means more families will have answers sooner from the very beginning of their child’s journey. In these cases, answers equal direction, confidence, and possibility.

In 2025, advocates secured an ICD-10 code for limb-girdle muscular dystrophy type 2I (LGMD2I). These codes are critical to ensure that people living with a specific disease can receive proper diagnosis, coverage, and treatment. It’s one more way MDA and its advocates contribute to improving access to care and support.

Volunteers Get the Gift of Giving

“MDA camp was one of the best things I’ve ever been a part of. Watching the relationships campers formed with each other and watching them thrive in a space that was meant for them and that they feel included in was the most heartwarming thing. It truly impacted my perspective on the [MDA] community and inspired me to work with MDA in the future to make more of an impact on these kids and their families.”

“I’ve told so many people that I wish everyone would be able to experience MDA Summer Camp at least once in their life. Not only do we get to help create unforgettable memories for the kiddos, but I truly think this event is life-changing for so many of the counselors as well.”

“I honestly thought this was an amazing experience. I initially started off volunteering with MDA because I am pre-med, and I wanted to get a hands-on experience working with kids with disabilities. But now not only have I created such a lasting impact on these kids’ lives, but they have also made such a lasting impact on my life.”

MOMENTUM

If Impact tells us what changed in 2025, Momentum helps explain why the future looks different than the past. One of the clearest lessons emerging across healthcare, research, and patient advocacy is that expertise takes many forms.

Scientific expertise matters.

Clinical expertise matters.

Lived experience matters.

In 2025, the Community Advisory Task Force brought together a cohort of MDA Ambassadors representing people living with neuromuscular diseases, caregivers, and parents. Their purpose was to inform and guide decisions to align MDA's mission deliverables more closely with the needs and priorities of the people we serve. Their message was clear and consistent: People in the neuromuscular community want more than services — they want a voice in creating what comes next for the community they know best.

The same philosophy is reflected in MOVR. In 2025, MDA launched a pilot of the next generation of MOVR — a modernized platform designed to make participation easier and more accessible for people living with neuromuscular diseases, regardless of where they receive care. Instead of relying solely on clinic visits, the new platform is being designed to allow individuals to securely enroll from home and, with their permission, contribute electronic medical records that help tell the story of their healthcare journey over time.

Once fully implemented, this next-generation approach will create new opportunities to accelerate research, improve our understanding of disease progression and treatment outcomes, and support the development of future clinical trials and therapies. Most importantly, it will give more people across the neuromuscular community the opportunity to contribute directly to research, ensuring that future discoveries are informed by the real-world experiences of those living with these diseases.

MOVR is evolving to make research participation more accessible — giving people more opportunities to securely contribute to their health journeys and help shape the future of neuromuscular research.

Every day, we are moved by the generosity of so many people within our extended community, who share ideas, data, money, and time to advance MDA's mission. Volunteers invested over 114,000 hours — or about 13 years' worth — of time and expertise. Thousands of people supported MDA fundraising events, from golf events and galas, to Muscle Walk and Team Momentum adventures. We are grateful for everyone who gets involved and shows care.

Quest Media continues to connect audiences within and adjacent to the neuromuscular disease community with trusted information and perspectives from across the field. More than 230,000 readers rely on its quarterly magazine, blog, newsletter, and podcast to help them navigate research, care, advocacy, and daily life.

Across the Task Force, MOVR, Quest, MDA Engage, Clinical & Scientific Conference, Advocacy, Summer Camp, and Care Center Network, a common theme emerges: Progress accelerates when people learn from one another. Momentum is being generated by a community that is increasingly connected, collaborative, and involved in crafting its own future.

THE THROUGHLINE

Progress has never belonged to a single organization. It has always belonged to a community built of complementary parts:

+ Families determined to create a better future
+ Researchers willing to pursue tough questions
+ Clinicians committed to delivering expert care
+ Advocates working to ensure that progress is accessible
+ Volunteers and Ambassadors giving their time and energy in service
+ Partners standing alongside the neuromuscular community year after year
+ Donors generously helping transform possibility into reality

Each contributes something different. Together, they make progress possible.

The breakthroughs, milestones, and stories reflected in these pages are the result of people choosing to participate in something larger than themselves.

Legacy formed the foundation.

Impact shows what is possible.

Momentum points toward what comes next.

The throughline is the community itself. And we are moving forward. Together.

MDA FINANCIAL HIGHLIGHTS

FOR YEAR ENDED DECEMBER 31, 2025 ($ IN THOUSANDS)

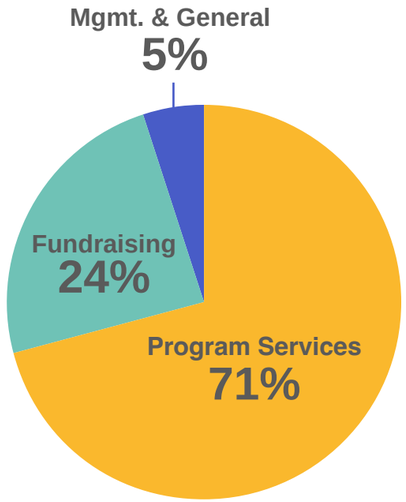
Balance Sheet

Assets	
Cash, cash equivalents, and investments	$44,577
Contributions receivables and other assets	5,906
Fixed assets, net	392
Total assets	**$50,874**
Liabilities and Net Assets	
Accounts payable, accrued expenses, and deferred revenue	$8,175
Research grants	179
Credit facilities outstanding	10,180
Pension and post retirement plan obligations	22,644
Total liabilities	**41,177**
Net assets	9,697
Total liabilities and net assets	**$50,874**

Statement of Activities

Total revenue	**$60,844**
Functional Expenses	
Patient and community services	21,283
Research	7,773
Professional public health education	14,532
Total program services	**43,587**
Fundraising	15,106
Management and general	3,051
Total operating expenses	**61,745**
Other non-operating income / (expense)	7,163
Change in net assets	**$6,262**

HOW MDA SPENDS $1



In 2025, $0.71 of every dollar MDA spent went directly to our mission programs.

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