
2018 Annual Report



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A Message from Rodney Howell, MD, chairman, MDA Board of Directors, and Lynn O'Connor Vos, president and CEO, Muscular Dystrophy Association

We are living through unprecedented times in neuromuscular disease. Our work, across all of MDA, is paving a new path forward in terms of understanding neuromuscular disease and enabling life-changing innovations in research, treatment, and care.



In 2018 many of our efforts came to fruition with critical impact. Spinal muscular atrophy (SMA) was added to the Recommended Uniform Screening Panel (RUSP) for newborns. In 2018 we also launched the neuromuscular Observational Research Data Hub in 25 MDA Care Centers with plans to expand to 50 in 2019. And in December, the U.S. Food and Drug Administration accepted an application for the first-ever gene therapy treatment for a neuromuscular disease under Priority Review status.

We began 2018 by dialoguing with key members of our community — neurologists and families — to gain deeper insight into their specific needs and respective experiences in working on and living with neuromuscular disease. Learning from this important research led to two landmark reports — “Understanding Neuromuscular Disease Care” and “ONEVoice.”

The Healthcare Partnerships Team was established in 2018 with the charter to build synergistic partnerships in the healthcare industry, starting with pharmaceutical and biotech companies and then expanding over time to other healthcare verticals including durable medical equipment (DME), retail and specialty pharmacy, diagnostics, and technology.

MDA has deepened its roots in the science of neuromuscular health and disease and

re-dedicated our commitment to the support of clinical research initiatives. Since its inception, MDA has invested more than \$1 billion in neuromuscular disease research to uncover new treatments and cures. We had 224 grants active during 2018 representing, a funding commitment of more than \$58M. We launched new educational seminars and programming for both healthcare professionals and our community.

We connected one-on-one with MDA individuals and families while responding to more than 20,000 inquiries received by our National Resource Center. And we made our annual Summer Camp program, “the best week of the year” for many of our kids and families, even better by offering families choices about where kids could attend.

In 2019, MDA has already seen some big accomplishments. In April we held our first ever combined Clinical & Scientific Conference, themed “Progress in Motion,” in Orlando Fla. Clinicians, scientists, policymakers, nonprofit, and industry leaders convened for a dynamic and informative five days. With more than 1,250 attendees, 23 sessions, 136 presentations, and 300 posters, this was MDA’s largest conference ever. Also in attendance were 30 exhibitors, five companies on Technology Row, and 13 nonprofit partners in our Patient Advocacy Pavilion. The major themes of the conference were genetic

medicine, clinical trials, regulatory science, emerging use of technology, and newborn screening. We were honored to have Dr. Janet Woodcock, director of the Center for Drug Evaluation and Research (CDER) at the Food and Drug Administration (FDA), provide the opening keynote address.

In May, the American Society for Gene and Cell Therapy (ASGCT) awarded MDA the Sonia Skarlatos Public Service Award for 2019. The award recognizes a person or group that has consistently fostered and enhanced the field of gene and cell therapy through governmental agencies, public policy groups, public education, or non-governmental charitable organizations.

We are so grateful and inspired by our Care Center teams, sponsors, volunteers, and donors for their unwavering support of our important mission.

Thank you!

Rodney Howell, MD
Chairman, Board of Directors
Muscular Dystrophy Association

Lynn O'Connor Vos
President and CEO
Muscular Dystrophy Association



**RODNEY
HOWELL, MD**



**LYNN O'CONNOR
VOS**

MDA is Changing with Changing Times

Fighting neuromuscular disease (NMD) today is about bringing together the best and brightest medical minds in search of a cure.

Not long ago, supportive care and mobility aids were all that could be offered to patients with NMDs. But the treatment and care landscapes have begun to change dramatically for many people living with NMDs. Recent breakthroughs in genetic medicine, along with other discoveries, are accelerating the development of new therapies, including some that not just address symptoms but also — for the first time — directly modify the underlying disorders.

Support enables MDA to fund leading research teams working toward breakthrough therapies that can have a life-changing impact on patients.

MDA supported 224 research projects in 2018.

MDA-funded breakthroughs include drugs for Duchenne muscular dystrophy (DMD), periodic paralysis, Pompe disease, and SMA.

And it's not just about new therapies. Thanks to research and advocacy efforts of MDA and its partners, new diagnostics and screening policies enable earlier detection and treatment. The goal: prolonging muscle function and lives.

At an explosive pace, advances in care, communication, and collaboration are now upending long-held assumptions about people with NMDs; never have so many possibilities existed for a community that once faced progressive disability and premature death. While most NMDs still remain extremely challenging to live with and treat, today more people than ever before can look forward to lives with potential unimaginable just a few years ago.

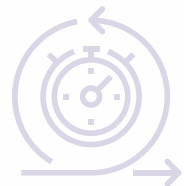
Yet a tremendous amount of work remains to be done.

Our Mission: Transformation Through Innovation

As the largest and longest-established organization for people with NMDs, MDA works tirelessly on the NMD community's behalf. We've done so for nearly seven decades. Now, with growing scientific knowledge and the expansion of improved treatment options come new ways for us to transform the lives of people with muscular dystrophy, ALS, and related neuromuscular disease through innovations in science and innovations in care.



More than \$1 billion invested to date in accelerating the development of therapies and cures.





Innovations in Science

Support for MDA's research enables us to fund teams working toward breakthrough therapies, which may have a life-changing impact on patients.

Research

MDA is the largest source of funding for neuromuscular disease (NMD) research outside the federal government.

Therapies

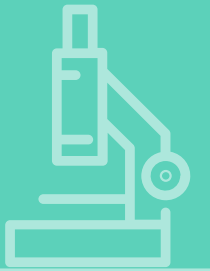
Research supported by MDA is directly linked to life-changing therapies across multiple neuromuscular diseases. Importantly, MDA's network model works across the full spectrum of NMDs to cross-pollinate ideas and cross-link disease-specific developments to potential applications that help the entire NMD community.

As knowledge about NMDs has vastly expanded, so has the complexity of diagnosis and treatment. Science has uncovered scores of specific genetic dysfunctions underlying NMD subtypes.

We are therefore bringing new resources and skills to rapidly transfer this exponentially growing body of knowledge from laboratory to clinic, where it can change lives as never before.

Parts of MDA's new role include:

- Working with investigators on new, improved clinical trial designs and real-world evidence
- Helping scientific partners view, track, and interpret unbiased and up-to-date data to make fully informed decisions about future innovations
- Convening clinical stakeholders to change standards of care as new approaches become available



RESEARCH GRANTS IN 2018

224

GENERAL RESEARCH

64

ALS

42

DMD/BMD

10

SMA

14

LGMD

2

POMPE

11

FSHD

15

DM

12

CMD

13

CMT

ALS = amyotrophic lateral sclerosis; DMD/BMD = Duchenne muscular dystrophy/Becker muscular dystrophy; SMA = spinal muscular atrophy; LGMD = limb-girdle muscular dystrophies; FSHD = facioscapulohumeral muscular dystrophy; DM = myotonic dystrophy; CMD = congenital muscular dystrophy; CMT = Charcot-Marie-Tooth disease.



Innovations in Science

Big data is a key part of MDA's evolution.

MDA launched the MOVR (neuroMuscular ObserVational Research) Data Hub as a transformative platform, combining MDA's Care Center Network with a state-of-the-art information-management system.



As the largest centralized data hub for multiple neuromuscular diseases, MOVR aggregates clinical, genetic, and patient-reported data across broad communities of healthcare providers, researchers, and industry partners that will lead to rapid developments in patient care, treatments, and cures.

MOVR will be an unparalleled one-stop resource, an asset to researchers probing for answers that could unlock new NMD science, and a powerful force for improved coordination of care for individuals.

Healthcare Partnerships Team

In 2018, the Healthcare Partnerships Team was created to develop relationships with leading pharmaceutical and biotech companies in the NMD space. In addition, the team established and now manages an agency-caliber healthcare communication and educational platform. This includes offering accredited continuing medical education (CME) programs as well as community educational initiatives.

The team also manages MDA's annual conference, which in 2018 brought together more than 500 medical and scientific neuromuscular experts. The conference focused on providing opportunities for physicians and allied health professionals to learn about new approaches and techniques for clinical management, hear about the latest information regarding clinical trial results, and engage in dialogue and networking among peers.

The team is responsible for publishing Quest, MDA's quarterly publication, which has nearly 800,000 touch points annually.

The Healthcare Partnerships Team exists today to support the tremendous growth being seen in drug development and the critical educational needs of our community in response to new therapies and treatments being brought forward through R&D.



Innovations in Science

MDA has long appreciated that gene therapy, by targeting the very root cause of the disease, has tremendous therapeutic promise in a wide array of neuromuscular diseases.

Genetic medicine

MDA has contributed greatly to the field of muscle disease and toward landmark research advances, including the identification of the first human disease-causing gene, as well as the first human trial of gene transfer for a muscle disease.

For several decades, MDA-supported researchers have discovered the gene-causing mutations for many other neuromuscular disorders, developed and refined gene delivery tools and methods, and established protocols for safe and effective gene therapy clinical trials. This was achieved by robust and rigorously-reviewed MDA grant programs aimed at driving the field of gene therapy forward, as well as MDA taking a leadership role in continually raising awareness and convening key experts to address challenges.

Indeed, that several experimental gene therapies are in advanced clinical trials in our diseases is the result of decades of effort from a large community of partners—including families, donors, researchers, clinicians, and members of industry. ■

Industry recognition

In 2019, MDA was granted the Sonia Skarlatos Public Service Award from the American Society for Gene & Cell Therapy (ASGCT).*

* This award recognizes a person or group that has consistently fostered and enhanced the field of gene and cell therapy through governmental agencies, public policy groups, public education, or non-governmental charitable organizations.





Innovations in Care

MDA programs and services enrich the lives of people with neuromuscular disease.

The cornerstone of MDA's Innovations in Care programming is MDA's National Care Center Network, a system of multidisciplinary medical clinics across the US at more than 150 top medical institutions. These centers conduct 70K+ medical visits annually for individuals living with muscular dystrophy, ALS, and related neuromuscular diseases. Each of our MDA Care Centers offers individuals and families best-in-class, comprehensive care from an integrated multidisciplinary team of

healthcare specialists conveniently sited at one location. In a single day, patients can see multiple healthcare providers who work together to ensure coordinated individual care for every patient to best fit their specific needs. Highly trained MDA Care Specialists serve as an important part of the care team, helping families navigate the health system, answering questions, distributing MDA educational materials, coordinating MDA services, and assisting with community resource referrals.



NATIONAL CARE CENTER NETWORK



70,000+
ANNUAL
PATIENT VISITS

200+
CONVENIENT
LOCATIONS



50,000+
INDIVIDUALS
HELPED



2,000
CLINICAL
PROVIDERS



12,000
PEOPLE ENGAGED IN
NMD RESEARCH

MDA Care Centers also serve as regional and local hubs of NMD research activity for clinical trials and natural history studies. As major gateways to the MOVR Data Hub — both as expert accumulators of NMD knowledge and as sites where this knowledge can be tapped firsthand — the centers perform a vital function in advancing care.



Innovations in Care

MDA has taken a leadership position in promoting newborn screening.

Now that we understand better the crucial role genetics plays in NMDs, access to early screening, diagnosis, and treatment is vitally needed. For example, we know that SMA is the leading genetic cause of death in infants in the US, and that early identification and intervention are key to treating the disorder.

Tactics to support newborn screening include peer-reviewed journal articles, convening coalition partners to promote federal engagement around congressional and regulatory actions, engagement with state policymakers to encourage implementation, the establishment of an advocacy grant program, and partnering with researchers to help them complete studies of new testing technology.

The International Association of Fire Fighters and MDA are also collaborating on a campaign to encourage states to expand their

newborn screening programs by adding tests for specific neuromuscular disorders so that all newborns with these conditions can have the best possible chance at receiving the care and support services they need as early as possible.

Once babies with these conditions are identified via state newborn screening programs, MDA Care Centers can play a key role in confirmatory diagnosis, treatment, and long-term follow up and care.

In many cases, the follow-up care may be lifelong and, in some situations, the clinical symptoms may not manifest until later in life.

We are committed to understanding the natural history of neuromuscular disease. When babies are diagnosed early in life, it allows the opportunity to learn more about how the disorders manifest and to obtain insights into how early intervention affects disease course.





Innovations in Care

MDA is changing with a clear mission, an expanded vision, and a renewed focus to meet the needs of a community undergoing a remarkable transition.

Camps

Throughout our evolution, many of MDA's most admired efforts and activities have stayed constant. Our MDA Summer Camps remain places where, for a week, kids and teenagers with NMD can gain independence and have fun as they learn vital life skills, like building confidence and learning self-advocacy. Each camp is staffed with dedicated health professionals and trained camp volunteers who meet the medical and physical needs of each camper — all at no cost to families.



Collaboration

Key events such as MDA Muscle Walk, MDA Team Momentum, and the MDA Shamrocks Program continue to unite our community and bring awareness to our mission. As we expand our collaborative efforts with new partners, we continue to cherish and nourish our long-standing links to groups and individuals who have helped make us who we are today, including:

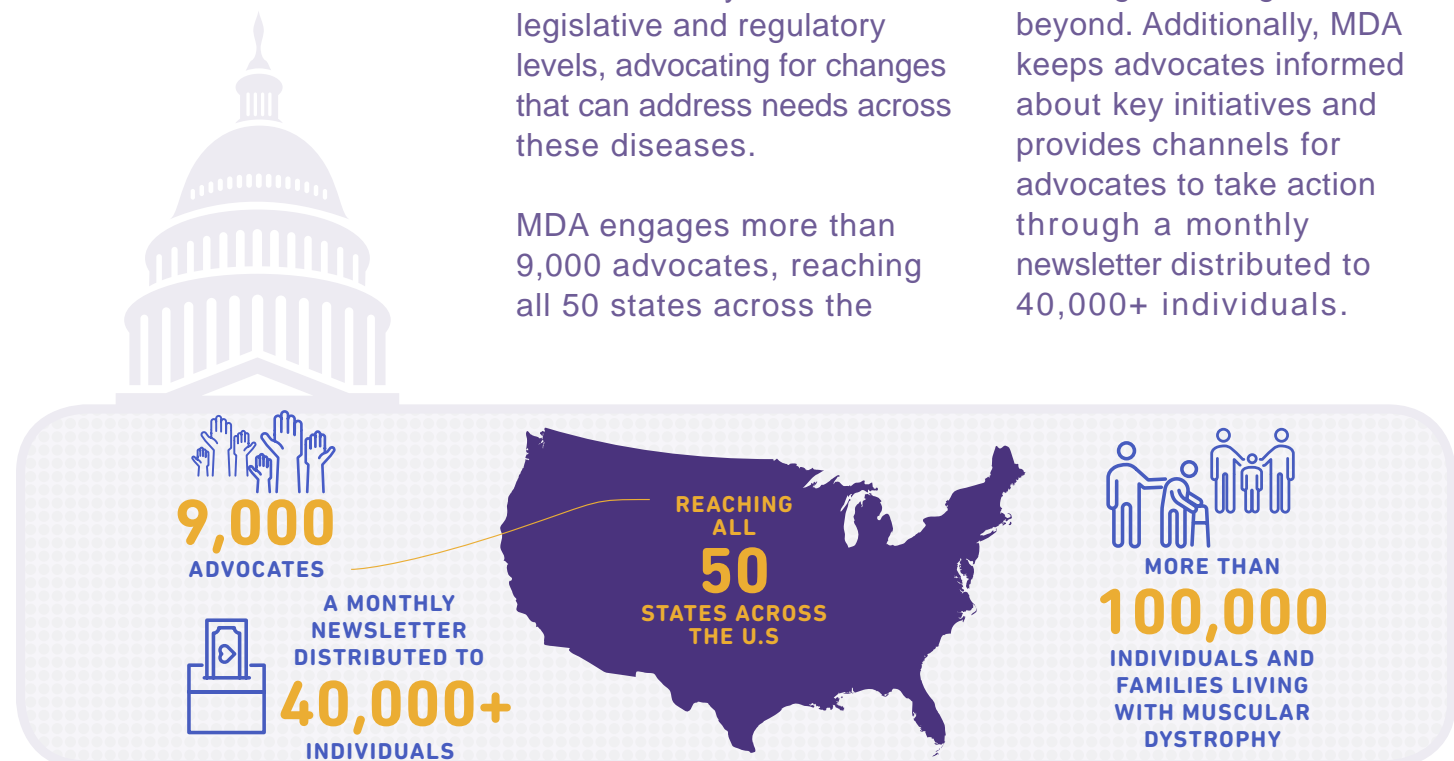


Advocacy amplified via collective impact

As the group whose constituency spans a broad range of NMDs, MDA helps focus and unify efforts at the legislative and regulatory levels, advocating for changes that can address needs across these diseases.

MDA engages more than 9,000 advocates, reaching all 50 states across the

US. The MDA Advocacy Conference brings together individuals and families living with muscular dystrophy, ALS, and related neuromuscular diseases to carry a unified message to Congress, and beyond. Additionally, MDA keeps advocates informed about key initiatives and provides channels for advocates to take action through a monthly newsletter distributed to 40,000+ individuals.



MDA is a leading voice in the patient advocacy community in our work with policymakers to ensure that all individuals living with neuromuscular disease have access to the healthcare they need through comprehensive health coverage.

We advocate for policies that maximize opportunities for independence. We also maintain an Accessible Air Travel Resource Center because the ability to travel by air impacts many aspects of life, including options for employment, education, and whether you can get back and forth from a clinical trial or a specialist's office that is far from home.



Innovations in Care

MDA has taken on a vastly expanded role in meeting the evolving educational needs of healthcare providers, patients, and families.

Medical and community education

We offer a broad and expanding array of resources and events expertly developed to respond to the rapidly changing treatment landscape.

Our resources for providing relevant medical education to professionals are unparalleled, and our services and initiatives reflect our leadership in this area. We provide both accredited continuing medical education (CME) and non-CME programs.

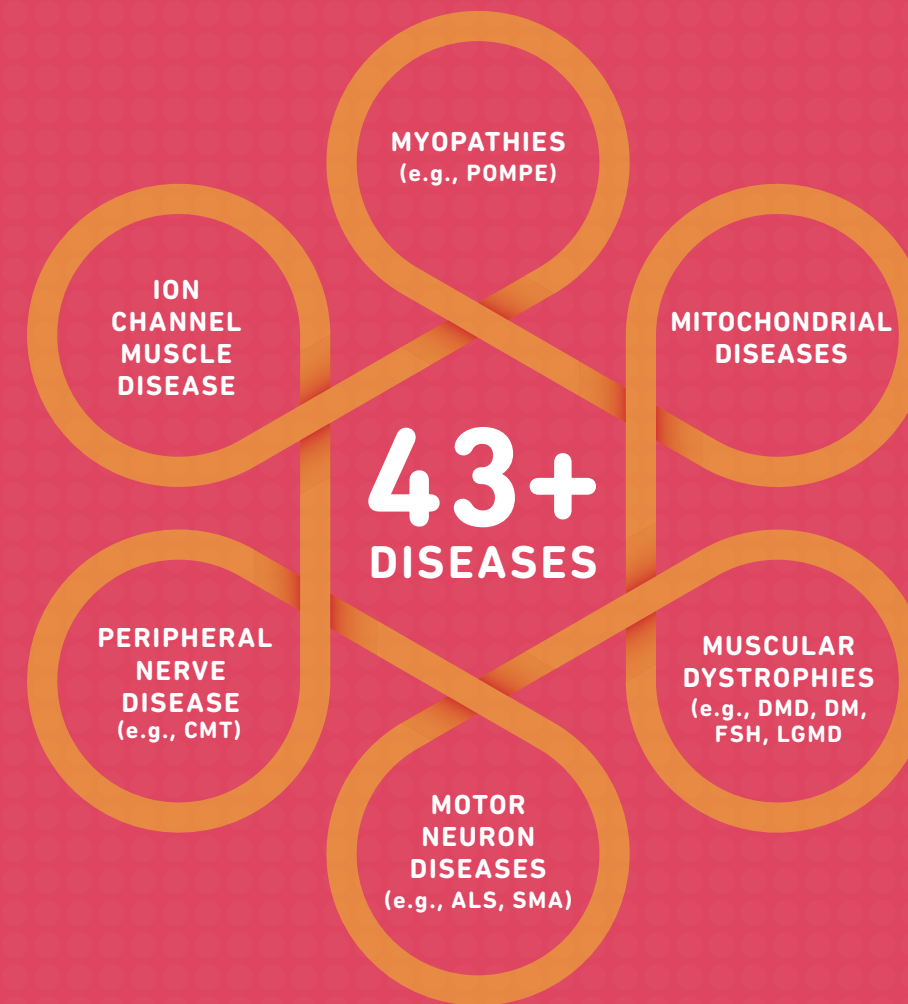
As the most comprehensive neuromuscular disease meeting, in the US, our annual MDA Clinical & Scientific Conference provides a unique

opportunity to learn from, be inspired by, and share ideas with experts from academia, medicine, government, and industry.

At the community level, we established MDA Engage, a flagship educational event series that brings local high-impact educational programs to the NMD community. Each of the Engage programs incorporates multiple modules of interest, from therapy development roundtables to disease management to genetic testing, designed specifically for community audiences. Each event also includes a social element for families and participants with the aim of strengthening the community and helping attendees make personal connections.



Neuromuscular Diseases Addressed by MDA



Since 1950, MDA has served as the only national patient advocacy group supporting more than 43 neuromuscular diseases and the communities affected by these conditions.

Moving forward

Recent changes in care paradigms for neuromuscular diseases have greatly intensified the clinical, informational, and advocacy needs of the communities we serve. MDA is changing with a clear mission, an expanded vision, and a renewed focus to meet the needs of

a community undergoing a remarkable transition — and whose prospects for transformation have never been better. Join us in our revitalized efforts to create a new, better world for people with NMDs.

For more information, visit www.mda.org

Meet our Partners

We believe great impact cannot be made alone. Together, with our generous partners, we're raising life-changing 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, sales promotions, and year-round special events.



Go to <https://www.mda.org/get-involved/meet-our-partners> to learn more



Partners in Progress

We are grateful to the following partners whose efforts and generosity each helped generate more than \$3 million in 2018.



Continuing a 65-year tradition of giving strength to the MDA community, 100,000 dedicated firefighters hit the streets or storefronts in 2018 with boots in hand asking pedestrians, motorists, customers, and other passersby to donate to MDA raising more than \$22 million. The partnership between the IAFF and MDA

began in 1954 when the organization committed by proclamation to support MDA until a cure is found, and the organization's unwavering commitment to MDA has remained strong to this day. As MDA's largest national partner, they have raised more than \$650 million for MDA to date.



As MDA's largest corporate partner, **CITGO Petroleum Corporation** has raised more than \$240 million for MDA through a wide variety of fundraising events, including golf tournaments, sporting events, in-store retail programs, and social events. CITGO also organizes special events in Houston; Lemont, Ill.; Corpus Christie, Texas; and Lake Charles, La., where the company has major operations. CITGO marketers and retailers throughout the country participate annually in the MDA Shamrock Program and other events.



Harley-Davidson Motor Company has put its commitment to freedom and independence into action by supporting MDA since 1980. During its more than 38-year partnership with MDA, the Harley-Davidson family of dealers, customers, employees, suppliers, and H.O.G. chapters raised more than \$103 million to help save and improve the lives of MDA families.

Strength in Numbers

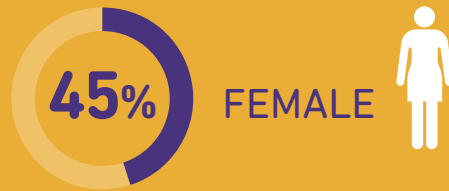
It takes a village to achieve a mission as important as ours. When lives are at stake, every voice, every dollar, and every individual matters.

MDA is proud to be a grassroots organization with a national reach. Although we've been leading the fight against muscular dystrophy and related diseases for almost 70 years, we haven't done it alone.

In decades past, people held backyard carnivals, participated in bike-a-thons, and donated to the telethon. Today, that incredible spirit of creativity, generosity, and unparalleled passion is as vibrant as ever in a new era of giving and innovation.



CONSTITUENT SNAPSHOT:



MOST COMMON DISEASES AFFECTING MDA FAMILIES:
CMT, ALS, MG, DM, DMD, SMA



31,000 retail locations participating in **MDA** events

9,500+ local fundraising events

Nearly **500** golf events and galas with **35,000** participants

Nearly **600,000** unique monthly visitors to **mda.org** — that's about **7.2 million** people a year

350,000 hometowns across America

1.5 million+ people with a connection to muscular dystrophy reached through email

POWERFUL SOCIAL MEDIA COMMUNITY



Nearly **65** field offices

Nearly **1 million** touchpoints for readers of **Quest** Magazine & MDA's Strongly blog

MDA Fundraising Events

MDA special events are a fun way for generous donors, event participants, and dedicated volunteers to join their communities in raising vital funds and awareness to support individuals and families living with muscle-debilitating diseases. Here's a look at the contributions they helped raise to support individuals and families and programs in 2018.



MDA Muscle Walk

MDA Muscle Walk is more than a fundraising walk — it's a life-changing event that strengthens families and communities. In 2018, about 29,000 people participated in 140 MDA Muscle Walks, raising \$6.1 million. Since 2011, MDA Muscle Walk has raised more than \$43 million to help bring strength to life for the families we serve.

To learn more, and to sign up and participate, go to mdamusclewalk.org.



Your Way for MDA

Your Way for MDA is an online platform that gives MDA supporters the opportunity to decide how they'll raise money for kids and adults in their community. In 2018, thanks to the public's creative ideas, Your Way for MDA raised \$110,919. Since the program began in 2015, MDA supporters have raised more than \$500,000.

To learn more, and contribute to Your Way, go to mda.org/get-involved/fundraise-your-way



MDA Team Momentum

Team Momentum is MDA's endurance training program that empowers individuals of all athletic abilities to train for a half or full marathon while supporting families with muscular dystrophy. In 2018, MDA Team Momentum — and its more than 725 participants — raised more than \$1.2 million to help families. Since 2014, MDA Team Momentum has had 3,591 participants and raised a combined \$5.29 million.

To learn more, and join a race event, go to mdateam.org



MDA Distinguished Events

More than 36,000 people participated in 330 galas, golf tournaments and Topgolf tournaments across the country in 2018. More than \$22 million was raised through these signature events to help advance MDA's mission.

To learn more, go to mda.org/get-involved/participate-in-an-event



MDA Shamrocks and other pinups

Each year MDA's iconic St. Patrick's Day fundraiser is supported by more than 20,000 retail locations across the country — including supermarkets, convenience stores, restaurants, and other community-minded businesses. The public also joined in our first Green Day for MDA, which was held in conjunction with the Shamrocks campaign. In 2018, MDA Shamrocks, including all pinups, raised more than \$14 million, and for more than 35 years, partners, employees, and donors have helped raise more than \$310 million.

To learn more, go to mda.org/shamrocks.



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Victor Wright
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Don Wood
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Lilian Wu, PhD
Armonk, NY

Research Advisory Committees

2018 RESEARCH ADVISORY COMMITTEE MEMBERS

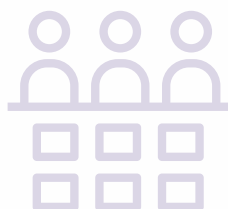
Stanley Appel, MD - Chair	Methodist Hospital, TX
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Elisabeth Barton, PhD	University of Florida, FL
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Melissa Spencer, PhD	University of California, Los Angeles, CA
Charlotte Sumner, MD	Johns Hopkins University, MD

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*R. Rodney Howell, MD	University of Miami, FL
*Ex Officio Member	062017
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R. Rodney Howell, MD	University of Miami



Financial Report

FOR THE YEAR ENDED DECEMBER 31, 2018 (IN THOUSANDS)

Assets

Cash, cash equivalents, and investments	\$72,285
Receivables and other assets	\$10,735
Fixed assets, net	\$645
Total assets	\$83,665

Liabilities

Accounts payable and accrued expenses	\$5,758
Research and training grants payable	\$10,469
Line of credit	\$7,500
Pension and postretirement plan obligations	\$49,991
Total liabilities	\$73,718

Net Assets

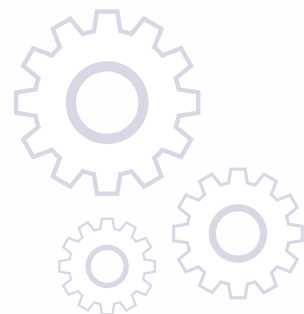
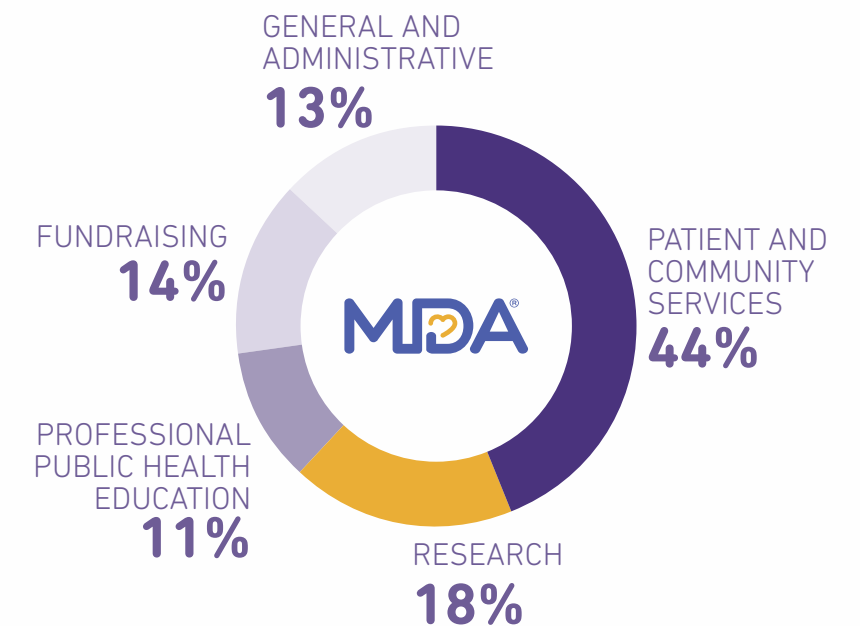
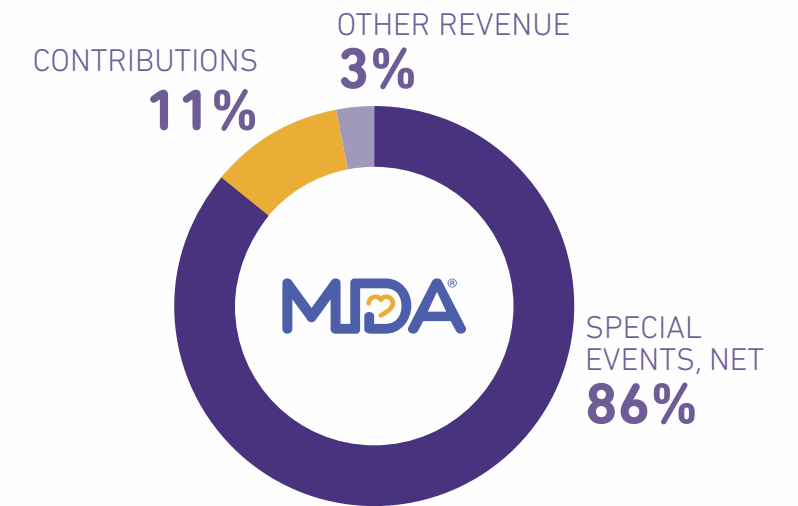
Without donor restrictions	\$5,364
With donor restrictions	\$4,583
Total net assets	\$9,947
Total liabilities and net assets	\$83,665

Revenue

Special events, net	\$90,926
Contributions	\$12,043
Other Revenue	\$3,499
Total revenue	\$106,468

Expenses

Patient and community services	\$46,664
Research	\$18,763
Professional public health education	\$12,220
Fundraising	\$15,348
General and administrative	\$13,714
Total expenses	\$106,709



Recognition and Accreditations



BBB
ACCREDITED
CHARITY



TOP RATED
CHARITY

by the American
Institute of
Philanthropy

MDA
IS THE FIRST
NONPROFIT
TO RECEIVE AN



LIFETIME
ACHIEVEMENT
AWARD

for "significant and
lasting contributions to
the health and welfare
of humanity."



MDA IS A GOLD-LEVEL
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ITS COMMITMENT TO
TRANSPARENCY

MDA
Muscular
Dystrophy
Association

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ABOUT THE MUSCULAR DYSTROPHY ASSOCIATION

MDA is committed to transforming the lives of people affected by muscular dystrophy, ALS, and related neuromuscular diseases. We do this through innovations in science and innovations in care. As the largest source of funding for neuromuscular disease research outside of the federal government, MDA has committed more than \$1 billion since our inception to accelerate the discovery of therapies and cures. Research we have supported is directly linked to approved, life-changing therapies across multiple neuromuscular diseases. We support the largest network of multidisciplinary clinics providing world-class care at more than 150 of the nation's top medical institutions, and each year thousands of children and young adults learn vital life skills and gain independence at MDA Summer Camp and through recreational programs.

For more information, visit mda.org.

