Executive Summary: Helping Kids and Adults Live Longer and Grow Stronger
Cure: Research Breakthroughs Across Diseases
Care: Caring for Kids and Adults from Day One
Champion: Supporting Families in Hometowns Across America
Partners in Progress
Strength in Numbers
Volunteer Leaders
Financial Report
MDA Executive Summary:
Helping Kids and Adults Live Longer and Grow Stronger

A message from

R. Rodney Howell, M.D.
Chairman
MDA Board of Directors

Families living with muscular dystrophy, ALS and related life-threatening diseases face daily physical challenges and life-threatening realities. These diseases take away everyday freedoms like walking, running, hugging, getting dressed, brushing one’s teeth and even breathing. That’s why MDA is fighting to give strength, independence and life to every child and adult affected so they can live longer and grow stronger.

At MDA, families are at the heart of all we do. We are driven every day to change the future for families by finding research breakthroughs across diseases, caring for kids and adults from day one and providing support to help them thrive and live unlimited.

In 2016, for the first time in our history, a young adult — Joe Akmakjian of Fort Collins, Colo. — shared his time and talents to help lead us as MDA’s National Ambassador, marking a new era in our work and signifying the progress we’re making together.

The FDA’s approval of Exondys 51 for Duchenne muscular dystrophy and Spinraza for spinal muscular atrophy — both developed and tested with MDA’s support — transformed the neuromuscular research landscape in 2016.

Significant and exciting progress is underway, as is evidenced by the encouraging advances you’ll see documented in this report on MDA’s operations and activities during 2016:

• **Research Breakthroughs Across Diseases:** This section highlights 2016 research advances made possible in part by MDA’s long-term investment in neuromuscular disease research.

• **Caring for Kids and Adults from Day One:** Here you will see MDA’s efforts to care for families from the moment of diagnosis throughout their entire journey by optimizing health, quality of life and independence.

• **Supporting Families in Hometowns Across America:** This section highlights our efforts to empower families with resources and support to live unlimited.

We are extraordinarily grateful to every individual, company, team, organization and family who is committed to helping us save and improve the lives of kids and adults with muscle-debilitating diseases. Together, in partnership with families, researchers and clinical partners, we are translating hope and progress into urgently needed answers MDA families are counting on.
"MDA supports research innovation needed to create breakthroughs for therapeutic development, as well as brings together scientists, fellows and families to work collaboratively and synergistically, which are essential to solving the complexities of muscle disease and development of therapies."

— MDA research grantee Charles Emerson, Ph.D., professor of neurology and director of the Wellstone Muscular Dystrophy Program at University of Massachusetts Medical School in Worcester
Strength. Independence. Life. This is what MDA’s research program is all about.

MDA takes a big-picture approach in how we fund research to accelerate treatments and cures across the full spectrum of neuromuscular diseases. What we learn on the frontlines in one area can be applied to positively impact other diseases. Years of research are leading to progress for families with dozens of clinical trials underway and more new drugs available today than we’ve seen in decades.

With a commitment to innovative solutions and collaboration with the world’s top researchers, young investigators and industry experts, we’re helping translate discoveries in the lab into treatments for numerous diseases.

A Pipeline of Promise

Largest non-federal source of neuromuscular disease research funding with $1 billion+ invested since 1950

Treatments available for Duchenne muscular dystrophy, spinal muscular atrophy, ALS, myasthenia gravis, Pompe disease and periodic paralysis

MDA’s online clinical trial finder connects families with dozens of trials to test new treatment approaches
Research Breakthroughs Across Diseases

Research Progress in 2016

By partnering with the world’s top researchers, biotech and pharmaceutical organizations, and families who play an essential role in clinical trials, MDA’s research efforts in 2016 brought us a significant step closer to new answers and discoveries.

Noteworthy research advances supported by MDA funding:

• The exon skipping drug eteplirsen (brand name Exondys 51) was granted accelerated approval to treat some forms of Duchenne muscular dystrophy (DMD) by the U.S. Food and Drug Administration.

• The antisense drug nusinersen (brand name Spinraza) was approved by the U.S. Food and Drug Administration to treat spinal muscular atrophy (SMA).

• The U.S. Food and Drug Administration began review of the corticosteroid deflazacort (brand name Emflaza) for treatment of Duchenne muscular dystrophy (DMD).

• MDA, Sanofi Genzyme and EGL Genetics expanded access to genetic testing for accurate diagnosis of limb-girdle muscular dystrophy (LGMD).

• An MDA-supported worldwide study validated surgery to remove an organ called the thymus as a treatment for myasthenia gravis (MG).

• Results from a natural history study for familial ALS (amyotrophic lateral sclerosis) caused by a mutation in the SOD1 gene confirmed that a variation of the mutation called SOD1 A4V is associated with a more aggressive disease course when compared to non A4V SOD1 ALS — the SOD1-specific data from the study is expected to help design and implement future ALS clinical trials.

• MDA and the CMT Association launched a partnership to advance treatments and care for Charcot-Marie-Tooth disease (CMT).

• MDA and Target ALS announced a partnership aimed at advancing ALS research and therapy development.

• MDA and the RYR-1 Foundation announced a partnership aimed at advancing research and clinical care, raising awareness and improving education of affected individuals, medical professionals and the public about RYR-1 myopathies.

• Dystrophin gene editing, using a strategy known as CRISPR-Cas9, continued to show promise to treat DMD in cultured cells and mice.

• Encouraging results from an MDA-supported study revealed a potential new antisense strategy to treat SMA — the approach involves using a strand of modified DNA to bind to and block a long non-coding RNA present in nerve cells to increase SMN protein production.

• Following encouraging results from a phase 1 trial in healthy volunteers, Reveragen BioPharma launched phase 2 clinical trials to test safety, tolerability and pharmacokinetics (how the drug is absorbed, distributed and metabolized in the body) of the experimental drug vamorolone in boys with DMD ages 4 to 7 years.

• The award of a nearly $1 million MDA clinical research network grant provided continued support for the Myotonic Dystrophy Clinical Research Network, which aims to spur advances in myotonic dystrophy (DM) research.

• MDA supported and participated in the ALS Clinical Trials Guidelines 2016 Workshop, where international leaders gathered to critically reassess how drugs are developed and tested for ALS and update clinical trial guidelines for the disease.


Care: Caring for Kids and Adults from Day One

“I can’t express how helpful the team of physicians, therapists and nurses have been throughout my life since I started attending the MDA Care Center at Children’s Hospital of Colorado. They work tirelessly to maintain every aspect of my care and health so that I can live longer and grow stronger.”

— Joe, who is living with spinal muscular atrophy
Caring for Kids and Adults from Day One

MDA supports care for kids and adults from day one through the nation’s largest network of neuromuscular disease clinics. But not just any care — multidisciplinary care.

At MDA Care Centers, individuals and families can access the expertise of many different health care specialists at one time to prevent the need for multiple appointments and added time away from school or work. This coordinated, multidisciplinary care enhances quality of life, prolongs life and creates a better health care experience.

Located in many of the nation’s top medical and academic institutions, MDA Care Centers are home to the most advanced research and treatment methods, often with many serving as clinical trial sites for the latest experimental therapies.

A Big-Picture Approach to Care

100,000+
Kids and adults registered with MDA

150+
MDA Care Centers nationwide

MDA Neuromuscular Disease Registry identifies best practices to standardize and optimize care and prolong and improve quality of life
Advancing Care for Families

Highly specialized multidisciplinary care, access to clinical trials, and early diagnosis and intervention help ensure the best possible outcomes for individuals and families. As we continue to strive to revolutionize care and support, here are some of the key ways we helped kids and adults in 2016:

- MDA helped more than 100,000 kids and adults and their families registered with MDA to receive care, services, support and information through MDA Care Centers and other MDA local and national programs.

- MDA provided comprehensive multidisciplinary care at more than 150 MDA Care Centers nationwide through nearly 50,000 visits, providing treatment and care for nearly 35,000 kids and adults at MDA Care Centers.

- MDA Care Centers are designed to give families access to many health care specialists from different areas of expertise all in one place. This ensures the best possible health outcomes while reducing the need for families to schedule and attend multiple appointments or experience added time away from school, work or life.

- MDA awarded nearly $7 million in grant funding to help support MDA Care Centers at top hospitals and health facilities across the United States and Puerto Rico.

- More than 2,200 multidisciplinary health care experts cared for individuals and families at MDA Care Centers, including neurologists, nurses, social workers, genetic counselors and more.

- MDA brought together nearly 450 neuromuscular disease clinicians, allied health professionals and scientific experts for the 2016 MDA Clinical Conference in Arlington, VA. MDA's Clinical Conference provided the opportunity for clinicians and providers to learn about new approaches and techniques for clinical management, to hear about the latest information regarding clinical trial results, and to engage in dialogue and networking among peers.
Champion: Supporting Families in Hometowns Across America

“I’m so glad we found MDA, since they have always been there to support me and my family. Today, I probably wouldn’t be attending college and pursuing my education goals if not for the confidence I gained from MDA programs and events.”

— Anuar, who is living with Duchenne muscular dystrophy
Supporting Families in Hometowns Across America

At MDA, we believe our limits don’t define us. That’s why we provide services and support in hometowns across America to help individuals with muscular dystrophy, ALS and related diseases transform limits into unlimited possibilities.

From summer camps and educational tools for young adults that build confidence and independence to a National Resource Center that connects families with information and services, we are here to support individuals as they pursue their dreams, overcome physical and societal limits and live life to the fullest.

Services and Support to Live Unlimited

- 3,800 kids experience best week of the year at MDA Summer Camp at no cost to their families annually
- 10,000 emails and calls answered by MDA’s National Resource Center in 2016
- 10,000 MDA advocates support public policies to help individuals with muscle-debilitating diseases
Supporting Families in Hometowns Across America

Empowering Families in 2016

MDA is here for families in hometowns across America, ready to assist and empower the kids and adults we serve to help them thrive and maintain independence. Here are some of the key ways MDA helped families actively pursue life goals to live unlimited in 2016:

- In July 2016, MDA launched the National Resource Center, which connects individuals impacted by neuromuscular disease with trained specialists who provide one-on-one support and resources. During the first six months it was open, MDA provided 10,000 individuals with the answers and assistance they needed.

- About 3,800 children attended 71 weeklong, accessible MDA Summer Camps — at no cost to their families. MDA Summer Camp provides opportunities for children to learn life skills, gain self-confidence, grow in independence and make lifelong friendships.

- Every month, nearly 300,000 visitors came to mda.org and related MDA websites to find key information and resources — that’s about 3.4 million people a year.

- MDA provided more than 340 educational activities for families, including support groups, educational events and family gatherings, to learn, connect and address daily needs and challenges.

- Through MDA’s equipment assistance program, MDA provided more than 3,000 gently used assistive devices to kids and adults to help them maintain mobility and independence.

- MDA supported young adults through new online tools and services, helping them navigate education, employment and independent living through resources, programming and community connections.

- MDA’s award-winning Quest Magazine delivered critical information on research, care and independent living to families, reaching nearly 800,000 people in print and online.

- Through MDA’s public policy and advocacy program, MDA worked together with families, clinical experts, scientists and other key stakeholders to ensure policymakers understand the needs of the neuromuscular disease community. MDA advocates continued fighting for life-changing public policies, and MDA collaborated with other organizations and stakeholders in the disability community to ensure the passage and implementation of policies and programs supporting the families MDA serves.

- The MDA community’s collective voice was heard and helped impact public policy, thanks to the thousands of letters and emails to members of Congress, in-person meetings with lawmakers in Washington D.C., and in district offices, and by spreading the word about issues that are important to the disability community.
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.

Our strength and our hope lie in the hearts of the people and partners who embrace our cause. We are grateful to the following partners who each helped generate $250,000 and above in 2016 to help kids and adults live unlimited in hometowns across America.

Go to MDA’s Meet Our Partners page to learn more.
The International Association of Fire Fighters (IAFF) committed by proclamation in 1954 to support MDA until a cure is found. During its more than 60-year partnership with MDA, the IAFF has raised more than $607 million for MDA families. The organization’s commitment has remained rock-solid, as more than 100,000 dedicated fire fighters across our nation dedicate time every year to raise money on street corners and visit kids at MDA Summer Camp. In 2016, the IAFF contributed more than $24 million through more than 1,500 Fill the Boot events and other special fire fighter events to benefit MDA.

As MDA’s largest corporate partner, CITGO Petroleum Corporation and its family of marketers, retailers, customers, refineries, terminals and employees have raised more than $210 million for MDA through a wide variety of fundraising events, including golf tournaments, sporting events, in-store programs and social events. In 2016, CITGO contributed nearly $15 million to support MDA’s lifesaving mission.

Lowe’s Home Improvement, which has contributed more than $57 million since partnering with MDA in 2001, teamed up with customers in 2016 at more than 1,700 Lowe’s locations to achieve more than $7 million through sales of MDA Shamrocks. Dedicated Lowe’s employees also volunteer at MDA Summer Camps across the country, helping kids develop lifelong friendships, build self-confidence and enjoy a week of barrier-free fun.

Harley-Davidson Motor Company, which has put its commitment to freedom and independence into action by supporting MDA since 1980, raised more than $3.1 million for MDA in 2016 through events, such as Black-N-Blue Ball galas and special MDA rides, including the EHDDA MDA Ride for Life in Pennsylvania. During its more than 37-year partnership with MDA, the Harley-Davidson family of dealers, customers, employees, suppliers and H.O.G. chapters has raised more than $100 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 more than 60 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.

MDA Constituent Snapshot:
- **55%** Male
- **45%** Female
- Most common diseases affecting MDA families: CMT, ALS, MG, DM, DMD, SMA
- **15%** Millennials

Nearby 100 field offices

31,000 retail locations participating in MDA events

9,500+ local fundraising events

Nearly 500 golf events and galas with 35,000 participants

Nearly 300,000 unique monthly visitors to mda.org — that’s about 3.4 million people a year

350,000 volunteers supporting the cause in hometowns across America

1.5 million+ powerful social media community

Nearly 1 million combined readers of Quest Magazine & MDA’s Strongly blog

Nearly 35,000 retail locations participating in MDA events

Nearly 1 million combined readers of Quest Magazine & MDA’s Strongly blog

For Strength, Independence & Life

17

Go Back to Table of Contents
Strength in Numbers: MDA Fundraising Events

MDA special events are a fun way for generous donors, event participants and dedicated volunteers to join their community in raising vital funds and awareness to support families living with muscle-debilitating diseases. Here’s a look at the contributions they helped raise to support MDA families and programs in 2016.

MDA Muscle Walk
MDA Muscle Walk is more than a fundraising walk — it’s a life-changing event that strengthens families and communities. In 2016, about 40,000 people participated in 145 MDA Muscle Walks, raising $7.2 million. Since 2011, MDA Muscle Walk has raised more than $34 million to help bring strength to life for the families we serve.

To learn more, go to mdamusclewalk.org.

Fill the Boot
For more than 60 years, our nation’s heroes have been collecting donations — one dollar at a time in their boots — from generous motorists, shoppers and neighbors through Fill the Boot events in hometowns across America. In 2016, more than $24 million was raised by more than 100,000 fire fighters at more than 1,500 Fill the Boot events and other local fire fighter events. To assist fire fighters in collecting online donations, MDA’s Fill the Boot Online raised more than $21,000.

To learn more, go to mda.org/get-involved/fill-the-boot.

MDA Shamrocks
MDA’s iconic St. Patrick’s Day fundraiser is supported by more than 25,000 retail locations across the country — including supermarkets, convenience stores, restaurants and other community-minded businesses. In 2016, MDA Shamrocks raised nearly $17 million, and for more than 30 years, partners, employees and donors have helped raise more than $300 million.

To learn more, go to mda.org/shamrocks.
Strength in Numbers: MDA Fundraising Events

MDA Lock-Up
MDA Lock-Up is a fun and inspiring community event that unites business leaders to raise funds and awareness to help kids and adults with muscular dystrophy. In 2016, MDA Lock-Up events raised $10.4 million nationwide.

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

MDA Distinguished Events
Galas, golf tournaments and other MDA signature events — more than 320 in total with 35,000 participants — raised awareness and $19.1 million to help MDA families in 2016.

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

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 2016, MDA Team Momentum — and its more than 950 participants — raised more than $1.1 million to help families. Since 2014, MDA Team Momentum has had 1,925 participants and raised a combined $2.65 million.

To learn more, go to mdateam.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 2016, thanks to the public’s creative ideas, Your Way for MDA raised $87,350. Since the program began in 2015, MDA supporters have raised more than $205,000.

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

Go to MDA’s website and check out the Get Involved section to join us.
Volunteer Leaders

2016–2017 Officers
(one-year term beginning June 23, 2016)

Chairman, Board of Directors
R. Rodney Howell, M.D.
Miami, Fla.

Vice Chair, Board of Directors
Christopher J. Rosa, Ph.D.
New York, N.Y.

Secretary
Charles D. Schoor, Esq.
Valley Village, Calif.

Treasurer
Victor Wright
New York, N.Y.

2016–2017 Directors
(one-year term beginning June 23, 2016)

Stanley Appel, M.D.
Houston, Texas

Harold Crump
Nashville, Tenn.

Benjamin Cumbo III
Upper Marlboro, Md.

Steve Farella
New York, N.Y.

Daniel Fries
New York, N.Y.

Honorable Brad Henry
Norman, Okla.

Dave Hutton
Valencia, Calif.

Louis Kunkel, Ph.D.
Boston, Mass.

Patricia Nazemetz
Sleepy Hollow, N.Y.

Mike Rowlett
Farmers Branch, Texas

Mark Smith
Houston, Texas

John Tognino
Ardsley, N.Y.

Kristine Welker
Hartsdale, N.Y.

Lilian Wu, Ph.D.
Armonk, N.Y.
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<th>State</th>
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<td>Arizona</td>
<td>Todd Bresnahan, Derrick Hall</td>
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<td>California</td>
<td>Brandon Barash, Todd Beck, Alexander Cappello, Jann Carl, Frank DiBella, Evan Lamberg, S. Paul Musco, Nancy O’Dell, Larree Renda, Bert Selva, Alison Sweeney, Tom Thomas, Ace Young</td>
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<td>Colorado</td>
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<td>Gordie Boucher Sr.</td>
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Wendy King, PT
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M. Kerry O’Banion, M.D., Ph.D.
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Charlotte Sumner, M.D.
Eric Wang, Ph.D.
C. Chris Weihl, M.D., Ph.D.

Ex officio member
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Volunteer Leaders

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Elizabeth McNally, M.D., Ph.D.
Thomas A. Rando, M.D., Ph.D.
Jeffrey D. Rothstein, M.D., Ph.D.
Lee Wrubel, M.D.
Financial Report
For the year ended December 31, 2016
(in thousands)

**Assets**
Cash, cash equivalents and investments $86,645
Receivables and other assets 4,649
Fixed assets, net 639
Total assets 91,933

**Liabilities**
Accounts payable and accrued expenses 6,162
Research and training grants payable 9,061
Line of credit 13,500
Pension and postretirement plan obligations 55,280
Total liabilities 84,003

**Net Assets**
Unrestricted 3,424
Temporarily restricted 3,902
Permanently restricted 604
Total net assets 7,930

Total liabilities and net assets $91,933

The highest standards of careful stewardship and fiscal transparency were applied across the management of MDA’s operations to ensure stability and vitality for our lifesaving work.

**Revenue**
Special events, net $96,336
Contributions 19,910
Other revenue 6,744
Total revenue $122,990

**Expenses**
Patient and community services $54,809
Research 15,993
Professional public health education 15,275
Fundraising 18,760
Management and general 13,244
Total expenses $118,081

**Net Assets**
Unrestricted 3,424
Temporarily restricted 3,902
Permanently restricted 604
Total net assets 7,930

Total liabilities and net assets $91,933
An Organization You Can Trust

Top Rated Charity by the American Institute of Philanthropy

Lifetime Achievement Award for “significant and lasting contributions to the health and welfare of humanity.”

91% of families who have received MDA services are likely to recommend MDA to others.

92% of MDA constituents say they have chosen to support a company because of its involvement with MDA.

MDA is the first nonprofit to receive an Lifetime Achievement Award.

MDA enjoys high awareness and favorability among donors, families and potential supporters.

MDA is the first nonprofit to receive an Lifetime Achievement Award.

MDA is leading the fight to free individuals — and the families who love them — from the harm of muscular dystrophy, ALS and related diseases that take away physical strength, independence and life. We use our collective strength to help kids and adults live longer and grow stronger by finding research breakthroughs across diseases; caring for individuals from day one; and empowering families with services and support in hometowns across America.

Learn how you can fund cures, find care or champion the cause at mda.org.