



Muscular  
Dystrophy  
Association

# 2017 Annual Report



# MDA Executive Summary:

## Helping Kids and Adults Live Longer and Grow Stronger

### A message from



*R. Rodney Howell*

### R. Rodney Howell, M.D.

Chairman of the Board, Muscular Dystrophy Association

Professor of Pediatrics, Chairman Emeritus

Member, Hussman Institute for Human Genomics

Miller School of Medicine

University of Miami, Miami, Florida

President, International Society for Neonatal Screening

2017 was a truly remarkable year for Muscular Dystrophy Association (MDA).

After nearly 70 years and more than \$1 billion in MDA research investments, groundbreaking treatments have become available for conditions that were not treatable when I was a resident.

Today, we can offer life-changing and lifesaving treatments to children with spinal muscular atrophy (SMA) and Duchenne muscular dystrophy (DMD) that didn't exist just a year or two ago. These new treatments are helping children maintain muscle strength and slow muscle decline. It is truly unprecedented.

As a physician and geneticist, the drug-development pipeline and clinical trials underway represent tremendous promise for more medical and scientific breakthroughs to transform and save lives.

2018 is sure to be another remarkable year as we work together to advance research and care.

- **In research**, we're expanding our national neuromuscular disease registry that captures data to help scientists search for treatments and cures and connect more individuals with promising clinical trials. We also have more than 180 research projects underway around the world that I believe will hold answers for the next breakthroughs for our community.
- **To improve care**, we're working with neuromuscular disease leaders to advance genetic testing for newborns to ensure that babies with spinal muscular atrophy and Pompe disease are treated as quickly as possible after birth, when treatments are likely to provide the greatest benefit.

We are on the brink of changing the course of neuromuscular diseases forever. That's why we must put the full force of our support behind these efforts now.

We are extremely 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 neuromuscular disease. We look forward to fulfilling our promise of progress in 2018 and continuing on this unprecedented journey.

# A Message from the President & CEO:

## Lynn O'Connor Vos

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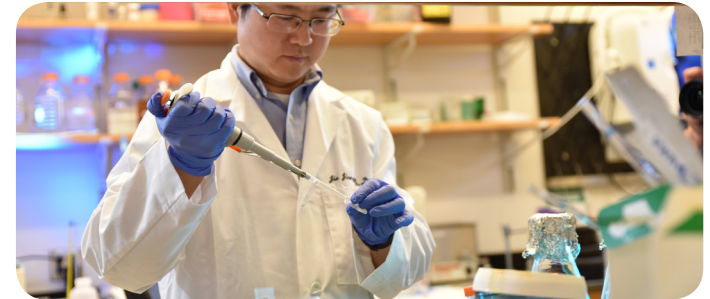
Since joining MDA as president and CEO in October, I've had the sincere pleasure of spending time with and learning from our families, leading clinical experts, renowned researchers, dedicated sponsors, and passionate MDA staff and volunteers. The progress we're making together is unprecedented, and I know it is only the tip of the iceberg. Working together, I see incredible opportunities to push the limits of neuromuscular disease research and provide an even better health care experience for individuals and their families.

When I learned about the opportunity to lead MDA, it felt like my entire career was coming full circle. I have decades of experience in the commercial and nonprofit sectors transforming health care organizations and driving lasting change, but I started my career as a pediatric nurse. Focusing on patient and family care at MDA feels like returning to my roots.

With tremendous progress underway as an unprecedented number of new therapies and drugs to treat neuromuscular diseases are becoming available, I believe my deep understanding of the drug approval process and the way to work with industry partners, clinicians, researchers and providers will help break new ground in neuromuscular disease research and care. I came to MDA to help improve the lives of more families and transform their health care experience. I'm looking forward to partnering with our community to make that happen.



*Lynn O'Connor Vos*



# 2017 Year in Review

## Progress is Our Promise

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A year ago, Faith couldn't lift her arms above her head. Today, she can.

*Progress is our promise.*

In 2017, MDA helped thousands of families live better and longer lives. In the past 24 months, four drugs — including Exondys 51, Spinraza, Keveysis and Emflaza — have become available thanks to support from MDA.

To keep the momentum going, we awarded \$18.2 million in new research grants in 2017.

Among the research grants awarded by MDA in 2017, highlights include:

- Identifying new drugs for ALS (amyotrophic lateral sclerosis)
- Facilitating new gene discovery in neuromuscular diseases (NMDs)
- Testing a potential therapy for Duchenne muscular dystrophy (DMD)
- Searching for drug targets in facioscapulohumeral muscular dystrophy (FSHD)
- Optimizing dosing for a drug to treat mitochondrial disease
- Testing a potential therapy for spinal-bulbar muscular atrophy (SBMA)

MDA was here for families when and where they needed us in 2017.

MDA Care Centers provided expert care for tens of thousands of individuals this year. MDA Care Centers are some of the only places families can meet with many of their health care specialists at one time, in one place.

Trained MDA specialists answered your emails and phone calls with resources and a shoulder to lean on... *20,000 times.*

MDA made it easier for families to participate in clinical trials, which play a key role in the discovery and development of new treatments. MDA's clinical trial finder tool at [mda.org/clinical-trials](http://mda.org/clinical-trials) is designed to make it easier for families to find clinical trials for which they may be eligible

We announced the release of the Highlights of the MDA U.S. Neuromuscular Disease Registry (2013-2016) report, which describes data collected during the pilot phase of the MDA U.S. Neuromuscular Disease Registry.

On April 23-25, individuals and families came together in Washington, D.C., at MDA's first public policy and advocacy conference, which focused on advocating for policies and programs important to the neuromuscular disease community.

Thousands of kids gained independence, self-confidence, and important life skills at MDA Summer Camp. They told us it's the best week of the year.

All of this and much more was possible thanks to you.

Thank you for helping MDA make 2017 a remarkable year for the families we serve.

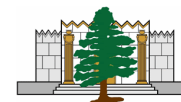


# Partners in Progress

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 2017 to help kids and adults live unlimited in hometowns across America.

Go to MDA's [Meet Our Partners](#) page to learn more.



# Partners in Progress

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We are grateful to the following partners whose efforts and generosity each helped generate more than \$3 million in 2017 to help kids and adults — and the families who love them — in hometowns across America.



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 \$630 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 2017, the IAFF contributed approximately \$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 \$222 million for MDA through a wide variety of fundraising events, including golf tournaments, sporting events, in-store programs and social events. In 2017, CITGO contributed nearly \$12 million to support MDA's lifesaving mission.



**Harley-Davidson Motor Company**, which has put its commitment to freedom and independence into action by supporting MDA since 1980, raised more than \$3 million for MDA in 2017 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.

# Financial Report

For the year ended December 31, 2017 (in thousands)

## Assets

Cash, cash equivalents and investments	\$88,869
Receivables and other assets	4,814
Fixed assets, net	556
<b>Total assets</b>	<b>94,239</b>

## Liabilities

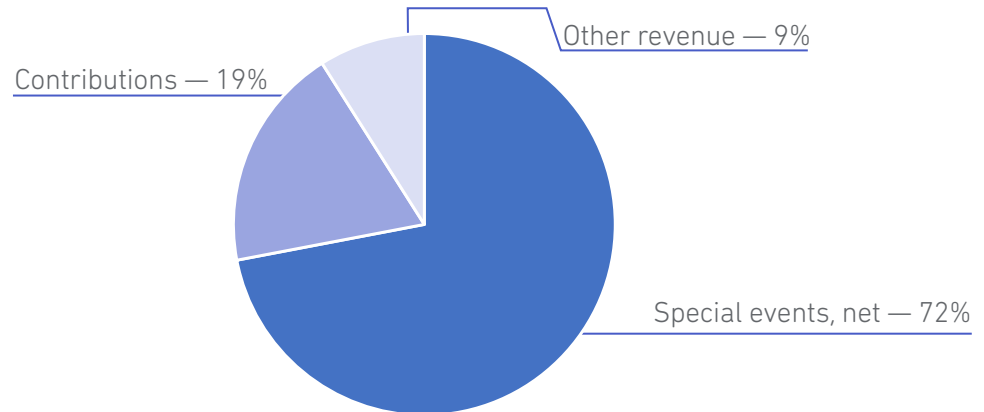
Accounts payable and accrued expenses	5,713
Research and training grants payable	9,675
Line of credit	10,000
Pension and postretirement plan obligations	52,682
<b>Total liabilities</b>	<b>78,070</b>

## Net Assets

Unrestricted	10,090
Temporarily restricted	5,160
Permanently restricted	917
<b>Total net assets</b>	<b>16,168</b>
<b>Total liabilities and net assets</b>	<b>\$94,239</b>

## Revenue

Special events, net	\$89,448
Contributions	23,180
Other revenue	11,234
<b>Total revenue</b>	<b>\$123,862</b>



## Expenses

Patient and community services	\$48,616
Research	18,276
Professional public health education	14,307
Fundraising	16,591
General and administrative	14,294
<b>Total expenses</b>	<b>\$112,083</b>

