

2016 Annual Report

# For Strength, Independence & Life



Muscular Dystrophy Association

[mda.org](http://mda.org)

# Table of Contents

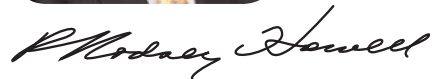


<b>Executive Summary:</b> <b>Helping Kids and Adults Live Longer and Grow Stronger</b> .....	<b>3</b>
<b>Cure: Research Breakthroughs Across Diseases</b> .....	<b>4</b>
<b>Care: Caring for Kids and Adults from Day One</b> .....	<b>7</b>
<b>Champion: Supporting Families in Hometowns Across America</b> .....	<b>10</b>
<b>Partners in Progress</b> .....	<b>13</b>
<b>Strength in Numbers</b> .....	<b>16</b>
<b>Volunteer Leaders</b> .....	<b>20</b>
<b>Financial Report</b> .....	<b>25</b>

# 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.





## Cure: Research Breakthroughs Across Diseases

*“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



# Research Breakthroughs Across Diseases

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





# Caring for Kids and Adults from Day One

## 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.

# Partners in Progress



# 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 2016 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

We are grateful to the following partners whose efforts and generosity each helped generate more than \$3 million in 2016 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 \$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





# 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.



# 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](http://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](http://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](http://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](http://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](http://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](http://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](http://mda.org/get-involved/fundraise-your-way).

Go to MDA's website and check out the **Get Involved** section to join us.



# Volunteer Leaders



# 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.

# Volunteer Leaders 2016–2017 National Vice Presidents (one-year term beginning June 23, 2016)

## Arizona

Todd Bresnahan  
Derrick Hall

## California

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

## Colorado

Jake Jabs

## Connecticut

Richard Graziano

Lynn Malerba

## District of Columbia

Fredric Rolando  
Harold Schaitberger

## Florida

Jay Feely

## Georgia

Bruce Lucia  
Jack Markwalter Jr.  
Tom Robinson

## Illinois

Chris Clawson

## Iowa

Reynolds Cramer

Robert Myers

## Kansas

Richard Seithel

## Maryland

Barry Sheaffer

Jennifer Smith  
Stepanek

## Minnesota

Marc Moeller

## Missouri

Don Breckenridge Jr.  
Gary Drawing

## Nevada

Jim Prather

## New Jersey

Anthony Cammarata Jr.  
John Crowley  
Chris Snee

## New York

Candace Beinecke

Vincent DeLazzero

Charles Fazzino

Steve Furnary

Lel and Tom Gimbel

Neil Golub

James Halpin

Michio Hirano, M.D.

Scott Masterson

John McGinley

Hiroshi Mitsumoto, M.D.

Natalie Morales

Ted Moudis, AIA

Mike Neary

Lewis Rowland, M.D.

Ray Tierney

Lisa Utasi

## North Carolina

John Clark

Clifton Rutledge

Kevin Urban

## Ohio

Maureen McGovern

John Quinlan, M.D.

## Oklahoma

Susannah Adelson

Jim Brown

Nadia Comaneci

## Oregon

Mike Bellotti

## Pennsylvania

Ty Ballou

DeLight Breidegam

Dave Carroll

Peter Dectis

Mike Dunleavy

Kara Fox-LaRose

Joe Gentile Jr.

Dan Hilferty

Jack Krol

## Puerto Rico

Juan Larrea

Aniceto Solares

## South Carolina

Randy Kibler

## Texas

Eric Affeldt

Bill Breetz

Stuart Crum

Rusty Hardin

Bill Klesse

Pierce Marshall

Mike Withers

## Wisconsin

Gordie Boucher Sr.

# Volunteer Leaders

## Clinical Advisory Committee

(members as of January 1, 2016)

Yaacov Anziska, M.D.  
Susan Apkon, M.D.  
Jan Bonner  
Joline Dalton, CGC  
Richard Finkel, M.D.  
Daragh Heitzman, M.D.  
Neil Holland, M.D.  
Tomas Holmlund, M.D.  
Irwin Jacobs, M.D.  
Wendy King, PT  
John Kissel, M.D.  
Katherine Mathews, M.D.  
Dennis Matthews, M.D.  
Tahseen Mozaffar, M.D.  
Jeffrey Rothstein, M.D., Ph.D.  
Barry Russman, M.D.  
Ericka Simpson, M.D.  
Jonathan Strober, M.D.

## Research Advisory Committee

(members as of January 1, 2016)

### Chairmen

Stanley Appel, M.D.  
Louis Kunkel, Ph.D.

### Members

Robert Baloh, M.D., Ph.D.  
Elisabeth Barton, Ph.D.  
Aaron Beedle, Ph.D.  
Alan Beggs, Ph.D.  
Sanjay Bidichandani, MBBS, Ph.D.  
Mark Bromberg, M.D., Ph.D.  
Dean Burkin, Ph.D.  
Jeffrey Chamberlain, Ph.D.  
M. Casey Childers, D.O., Ph.D.  
Thomas Cooper, M.D.  
Thomas Crawford, M.D.  
Merit Cudkowicz, M.D., M.Sc.

John Day, M.D., Ph.D.  
James Dowling, M.D., Ph.D.  
Heather Durham, Ph.D.  
Fen-Biao Gao, Ph.D.  
Emanuela Gussoni, Ph.D.  
Matthew Harms, M.D.  
Lawrence Hayward, M.D., Ph.D.  
Michio Hirano, M.D.  
Joe Kornegay, D.V.M., Ph.D.  
Jun Li, M.D., Ph.D.  
Catherine Lomen-Hoerth, M.D., Ph.D.  
Christian Lorson, Ph.D.  
Giovanni Manfredi, M.D., Ph.D.  
Nicholas Maragakis, M.D.  
Katherine Mathews, M.D.  
Elizabeth McNally, M.D., Ph.D.  
Lynn Megeney, Ph.D.  
Matthew Meriggioli, M.D.

Daniel Miller, M.D., Ph.D.  
Carlos Moraes, Ph.D.  
Kanneboyina Nagaraju, D.V.M., Ph.D.  
M. Kerry O'Banion, M.D., Ph.D.  
Bradley Olwin, Ph.D.  
Robin Parks, Ph.D.  
John Ravits, M.D.  
Rita Sattler, Ph.D.  
Michael Shy, M.D.  
Shanthini Sockanathan, Ph.D.  
Melissa Spencer, Ph.D.  
Charlotte Sumner, M.D.  
Eric Wang, Ph.D.  
C. Chris Weihl, M.D., Ph.D.

### Ex officio member

R. Rodney Howell, M.D.



# Volunteer Leaders

## Registry Advisory Board

(members as of January 1, 2016)

Alan Beggs, Ph.D.

Joshua Benditt, M.D.

James Berry, M.D.

Thomas Crawford, M.D.

Kevin Flanigan, M.D.

Eric Hoffman, Ph.D.

Emily Munson, Esq.

Rachel Richesson, Ph.D., MPH

Jeffrey Rosenfeld, M.D., Ph.D.

Carly Siskind, M.S., CGC

## MDA Venture Philanthropy Advisory Committee

(members as of January 1, 2016)

Stanley H. Appel, M.D.

Andrew Billin, Ph.D.

Barry J. Byrne, M.D., Ph.D.

Thomas Cheever, Ph.D.

Cristina Csimma,  
PharmD, MHP

Kenneth H. Fischbeck, M.D.

Amelie Gubitz, Ph.D.

John E. Howell

Louis M. Kunkel, Ph.D.

Melanie Leitner, M.D.

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
<b>Total assets</b>	<b>91,933</b>

## 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
<b>Total liabilities</b>	<b>84,003</b>

## Net Assets

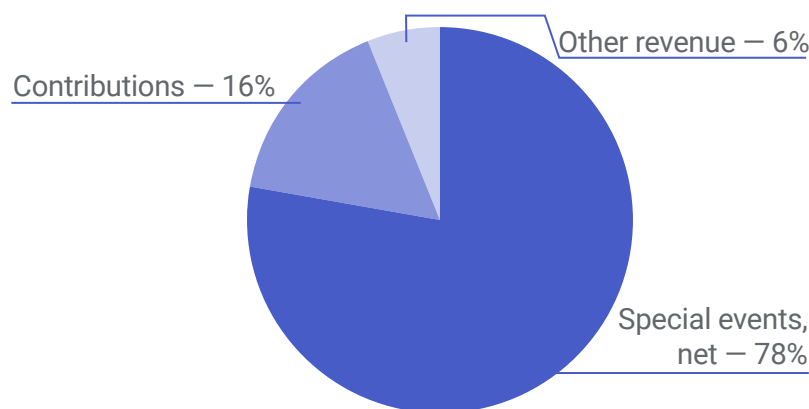
Unrestricted	3,424
Temporarily restricted	3,902
Permanently restricted	604
<b>Total net assets</b>	<b>7,930</b>

**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.**

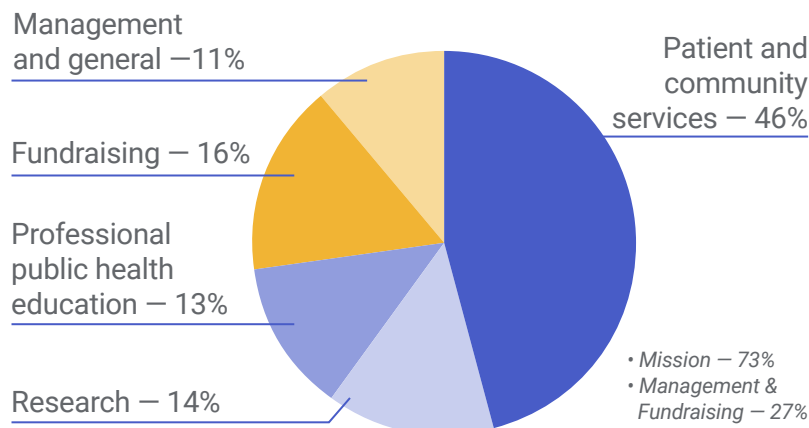
## Revenue

Special events, net	\$96,336
Contributions	19,910
Other revenue	6,744
<b>Total revenue</b>	<b>\$122,990</b>



## Expenses

Patient and community services	\$54,809
Research	15,993
Professional public health education	15,275
Fundraising	18,760
Management and general	13,244
<b>Total expenses</b>	<b>\$118,081</b>



# An Organization You Can Trust



**Top Rated Charity**  
by the American Institute of Philanthropy

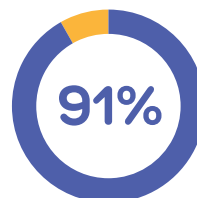
MDA is the first nonprofit to receive an



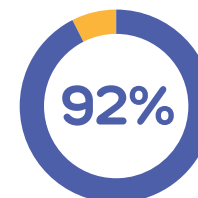
**Lifetime Achievement Award**  
for "significant and lasting contributions to the health and welfare of humanity."



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



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.



For Strength, Independence & Life

Muscular Dystrophy Association

 [mda.org](http://mda.org)

 800-572-1717

 [mda@mdausa.org](mailto:mda@mdausa.org)

 [facebook.com/MDAnational](https://facebook.com/MDAnational)

 [@MDAnews](https://twitter.com/MDAnews)

 [@mda\\_usa](https://www.instagram.com/mda_usa)

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](http://mda.org).

