



Always
Forward
for Our
Families

MDA[®]
Fighting Muscle Disease

2014 Annual Report

Table of Contents



<u>A Time of Progress and Action</u>	<u>3</u>
<u>Research Breakthroughs Across Diseases</u>	<u>5</u>
<u>Caring for Kids and Adults from Day One</u>	<u>8</u>
<u>Supporting Families in Hometowns Across America</u>	<u>11</u>
<u>Community Spotlight: MDA Summer Camp</u>	<u>14</u>
<u>Community Spotlight: National Advocacy</u>	<u>16</u>
<u>People. Partners. Progress.</u>	<u>18</u>
<u>MDA Events: Strength in Numbers</u>	<u>22</u>
<u>Our Leaders</u>	<u>25</u>
<u>Financial Report</u>	<u>29</u>

A Time of Progress and Action



A message from



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



Steven M. Derks
MDA President & CEO

At MDA, we live and breathe a single purpose — to free our families from the daily challenges and life-threatening effects of muscular dystrophy, ALS and related diseases that limit muscle strength and mobility.

The freedom to run and walk. To hug. To play. To button a shirt or brush one's teeth. To talk. To breathe. These are just some of the everyday freedoms that can be taken away by neuromuscular diseases. MDA is fighting to ensure every child and adult affected — and the families who love them — can live longer and grow stronger.

MDA is a community of voluntary leaders, sponsors, researchers, clinicians, staff, donors, caring families and countless dedicated citizens unified by our desire to arrive at urgently needed discoveries while providing resources to help the families we serve not only survive, but thrive.

Great progress is underway, as is evidenced by the encouraging advances you'll see documented in this report on MDA's operations and activities during 2014:

- **Research Progress Across Diseases:** This section highlights 2014 research advances that were 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 during 2014 to serve our families from the moment of diagnosis throughout their entire journey to optimize health and well-being.
- **Supporting Families in Hometowns Across America:** This section highlights the impact MDA's life-enhancing resources and programs had on families in communities nationwide.

Neuromuscular diseases continue to impose enormous physical, emotional and financial challenges on kids, adults and their families. We're committed to innovating, working harder, thinking bigger and accelerating the rapid progress currently underway until it yields the life-changing results MDA families need.

We are extraordinarily grateful to every individual, company, team, organization and family who is making our shared progress possible. Together, we will continue to combine our shared strength to make today free from the harm of muscle-debilitating diseases — and tomorrow free from the diseases themselves.

A Time of Progress and Action



A day in the life of MDA

Cure

\$75,000

Research expense per day

Care

235

Patients at clinics per day

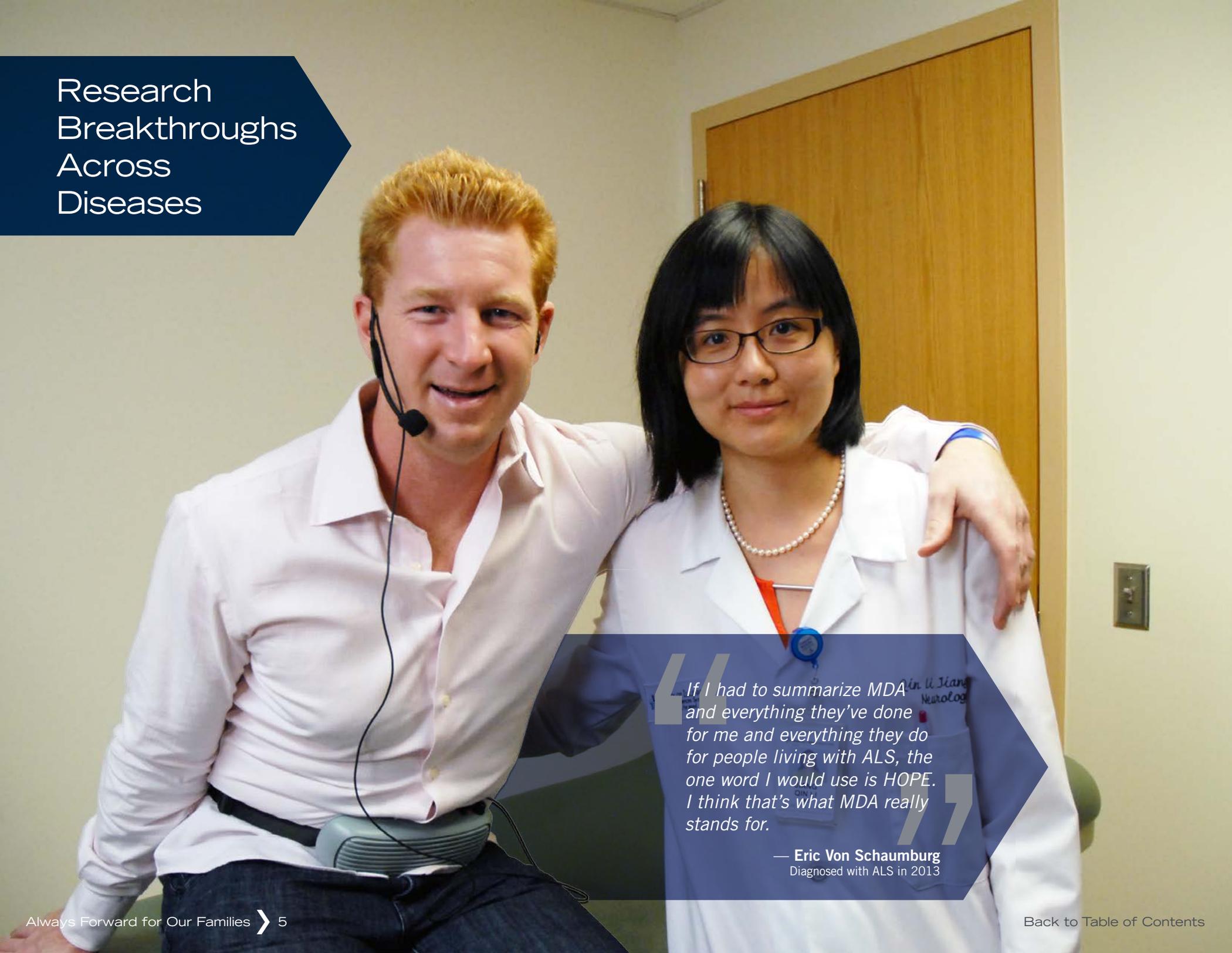
Champion

340

Campers per week



Research Breakthroughs Across Diseases



“If I had to summarize MDA and everything they’ve done for me and everything they do for people living with ALS, the one word I would use is HOPE. I think that’s what MDA really stands for.”

— **Eric Von Schaumburg**
Diagnosed with ALS in 2013

Research Breakthroughs Across Diseases



Since MDA's inception more than 60 years ago, we've funded groundbreaking research and fostered communication among scientists across the full spectrum of neuromuscular diseases.

This innovation and collaboration is leading to the development and imminent availability of new lifesaving therapies. 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 2014 brought us a significant step closer to new answers and discoveries.



64
Current ALS research grants



30

CLINICAL TRIALS

thanks in part to MDA's long-term investments

\$18.5 million
Total 2014 research funding



38

New grants
awarded by MDA

Research Breakthroughs Across Diseases



“MDA is the real deal. It is supporting patients, supporting physicians, supporting researchers and supporting legislation on Capitol Hill so the research can move forward and be useful for patients.”

— Alan Beggs, Ph.D.

Member, MDA Medical Advisory Committee

Progress in Research in 2014

Noteworthy research advances supported by MDA funding:

- Three promising drugs to treat **Duchenne muscular dystrophy (DMD)** moving closer to FDA approval
- Keveyis, first drug approved for the treatment of hyperkalemic and hypokalemic periodic paralysis
- Early-stage human clinical trial launched for type 1 myotonic dystrophy
- New mouse model to speed research in facioscapulohumeral muscular dystrophy
- Increased muscle strength observed in DMD boys during an ongoing phase 1b/2a clinical trial of HT-100, a powerful anti-inflammatory and anti-fibrotic drug
- Encouraging results in a Summit Therapeutics phase 1b trial of SMT C1100, targeting DMD and possibly Becker muscular dystrophy by raising utrophin protein levels
- DMD drug VBP15 moving into human clinical testing in healthy volunteers by ReveraGen BioPharma
- Updated American Academy of Neurology care guidelines for ALS, and a new guideline for all forms of limb-girdle muscular dystrophy and some forms of distal muscular dystrophy
- New thinking about **spinal muscular atrophy** therapy development focused on enhancing SMN production most intensely during infancy and childhood





Caring for Kids and Adults from Day One

“The MDA clinic is paramount to the health and well-being of JoeJoe and Dominik.”

— a mom to two boys affected by spinal muscular atrophy

Caring for Kids and Adults from Day One



Progress in Care

From the moment a family member is diagnosed with a neuromuscular disease and onward, MDA is here to provide meaningful, multidimensional support — not just for the individual but for the entire family.

Our nationwide network of specialized clinics offers families life-changing care from neuromuscular specialists from a variety of disciplines all at one location. These experienced clinicians have a depth of knowledge that allows them to recognize subtle differences between diseases that may resemble each other at onset, but which have very different underlying causes and standards of care.

Additionally, MDA clinics are at the forefront of research and treatment methods with many serving as sites for clinical trials of potential therapies.

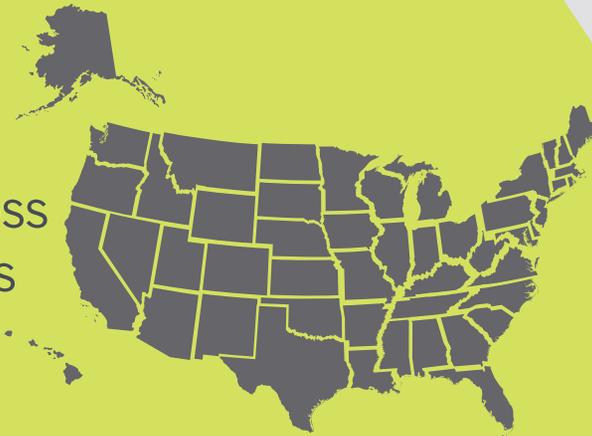


Caring for Kids and Adults from Day One



200

MDA clinics across the United States and Puerto Rico



500

neuromuscular disease clinicians and experts who shared knowledge at MDA's 2014 Clinical Conference

100,000

Individuals served by MDA during 2014



43

ALS research and clinical centers

57,000

visits to all MDA clinics



MDA has invested

\$344 million

in ALS research and services since its inception



Supporting Families in Hometowns Across America



I was connected with MDA at our very first clinic visit when Kasey was first diagnosed. A representative from MDA came and told us that there's a lot of things that they can help us with as we go through this journey.

— a mom whose son has Duchenne muscular dystrophy

Supporting Families in Hometowns Across America



Progress in Supporting Families in 2014

In communities nationwide, MDA stands alongside our families, implementing vital initiatives to assist and empower the kids and adults we serve.

From offering support groups and educational seminars that help caregivers, parents and individuals through their journey — to connecting families with information when and where they need it — to giving kids with neuromuscular diseases the best week of their year at MDA summer camp, MDA is here to help families maintain and improve their health while actively pursuing life goals.

Whether we're sharing information and resources through webinars, blogs, educational conferences or specialized websites like our transitions center for young people transitioning into adulthood, we're dedicated to empowering families as they pursue education, passions, careers, dating, marriage and other goals associated with living as an independent adult.



Supporting Families in Hometowns Across America



145

MDA support groups nationwide in 2014



407

camp volunteer medical staff



10,000

people visit us online every day

Nearly

80

MDA summer camps

More than

3,700

campers at MDA summer camp



4,026

MDA summer camp volunteer counselors

More than

1,200

support group sessions in 2014



Community Spotlight: MDA Summer Camp



Community Spotlight: MDA Summer Camp



Creating Awesome Adventures for Kids

“He loves MDA camp. He loves the swimming. He loves the horseback riding. He looks forward to it every year. That’s his happy place.”

— a mom whose son has spinal muscular atrophy

At MDA summer camp, kids with muscular dystrophy and related diseases discover a world created specifically for them, in which acceptance, inclusion, encouragement, achievement and fun are the benevolent guiding principles. All activities — often including horseback riding, swimming, adaptive sports, arts and crafts and camp dances — are designed with safety and the special abilities of these kids in mind.

Almost all campers agree that it’s “the best week of the year.”

After graduating from camp and becoming young adults, many look back and say that while camp clearly provides awesome doses of fun and friendship, it also can be a transformative experience.

Being away from home and learning to depend on help from volunteers can increase self-esteem and boost a camper’s sense of confidence and independence, a first major step toward becoming an independent adult.

Parents also receive a well-deserved break from their roles as caregivers and can rest easy knowing their child’s medical and physical needs will be met by a team of dedicated health professionals and trained camp volunteers.



A man with dark hair, a mustache, and sunglasses is smiling. He is wearing a blue and white checkered shirt and a blue and white striped tie. He is seated in a wheelchair, which is partially visible behind him. The background is the United States Capitol building in Washington, D.C., with its iconic dome and classical architecture. The sky is clear and blue.

Community Spotlight: National Advocacy

By partnering with MDA and sharing stories of hope and struggle with corporate sponsors, legislators and the general public, families are uniting to advance the cause of research like never before.

— **Vance Taylor**

MDA voluntary leader who is affected by limb-girdle muscular dystrophy

Community Spotlight: National Advocacy



Every year, MDA works closely with legislators and engages regulatory agencies to ensure that issues impacting the neuromuscular disease community are a priority, and to fight for passage of life-changing legislation and policies.

We are proud to collaborate with and amplify the voices of leaders in the disability community who seek to ensure the rights and well-being of everyone living with muscular dystrophy, [ALS](#) and related disorders. In 2014, MDA helped advance this effort by supporting the following legislation:

Updates to the Muscular Dystrophy Community Assistance, Research and Education Amendments (MD-CARE) Act

Impact: Originally enacted in 2001, the MD-CARE Act established centers of excellence for muscular dystrophy research and created the Muscular Dystrophy Coordinating Committee (MDCC). Important updates were enacted in 2014 and included adding agencies and Institutes to the MDCC to ensure that patient and research needs were being addressed. MDA played an instrumental role in the community-wide effort that led to these updates.

The Achieving a Better Life Experience (ABLE) Act

Impact: The ABLE Act provides a means for individuals with qualifying disabilities and their families to engage in financial planning by allowing savings to accumulate in special tax advantaged accounts to be used for qualified expenses related to maintaining health, independence and quality of life, without counting against eligibility limits for critical supports.

Newborn Screening Saves Lives Reauthorization Act (NBSSLA)

Impact: This law ensures that the system of federal, state, and local public health agency coordination remains in place for the newborn screening program to continue to facilitate earlier diagnosis and intervention for certain diseases, thereby improving treatment outcomes that can have lifesaving impact.

People.
Partners.
Progress.



People.
Partners.
Progress.



MDA took decisive steps in 2014 to reinvigorate its fundraising programs and bring our mission forward into a new age of digital marketing. At the same time, highest standards of careful stewardship and fiscal transparency were applied across the management of MDA's financial operations to ensure stability and vitality for our lifesaving work.

As has been the case since MDA's founding in 1950, our strength and our hope lie in the hearts of the people and partners who embrace our mission — people like you.



People.
Partners.
Progress.



Partnerships Achieving Results

For decades, 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.

Throughout 2014, we celebrated our historic 60-year partnership with the [International Association of Fire Fighters \(IAFF\)](#). This invaluable relationship began in 1954 when the IAFF committed by proclamation to support MDA until a cure is found. The organization's commitment has remained rock-solid, as dedicated fire fighters across our nation dedicate time every year to raise money on street corners and visit kids at MDA summer camp.

During the past 60 years, the IAFF has raised an incredible \$558 million for MDA — a staggering accomplishment and a testament to the fact that fire fighters are not only heroes who risk their lives to save others, but deeply compassionate men and women who are helping save the lives of kids and adults with muscular dystrophy and related diseases.

For almost three decades, [CITGO Petroleum Corporation](#) and its nearly 6,000 locally owned retail locations have raised \$180 million for MDA through a wide variety of fundraising events, including golf tournaments, fundraising at checkout and socials. During 2014, CITGO contributed \$13.6 million to support MDA's lifesaving mission.

[Lowe's Home Improvement](#), which has contributed more than \$45 million since partnering with MDA in 2001, teamed up with customers in 2014 at more than 1,700 Lowe's locations to achieve \$7.1 million through sales of MDA shamrocks.

[7-Eleven](#) joined MDA as a national sponsor in 1976. Initially supporting MDA through in-store canister collections, 7-Eleven has also helped through golf tournaments, dinner auctions, shamrocks sales and other initiatives. In 2014, through caring efforts of franchisees, employees and customers, 7-Eleven raised over \$1 million to support MDA, bringing their cumulative total since 1976 to a remarkable figure of more than \$95 million.

[Harley-Davidson Motor Company](#), which has put its commitment to freedom and independence into action by supporting MDA since 1980, raised an extraordinary \$3 million for MDA during 2014 through electrifying events such as Black-N-Blue Galas and Ride for Life. In 2014 alone, riders and the dealer network made 70 MDA summer camp visits and hosted 261 rides and events.



People.
Partners.
Progress.



At MDA, we're deeply proud to stand alongside these national and regional partners who are bringing help and hope to MDA families. Click on the logos to find out more about our partners' extraordinary efforts on behalf of MDA.



MDA Events: Strength in Numbers



MDA Events: Strength in Numbers



MDA is proud to be a grassroots organization with a national reach. In decades past, people helped MDA in many unique and innovative ways, from holding backyard carnivals to riding in bike-a-thons and collecting pennies to bring to local telethons.

That incredible spirit of generosity and involvement is as vibrant as ever, finding enthusiastic expression in a variety of modern events to generate funds and awareness.

Having access to the passionate support of some 350,000 volunteers in hometowns across America means that tremendous human energy is being harnessed to move progress forward for our families.



MDA Muscle Walks have become a central rallying opportunity in communities nationwide for MDA families, friends, volunteers, donors and sponsors to celebrate unity in fighting neuromuscular diseases. In 2014, about 50,000 people participated in MDA Muscle Walks, raising \$8.5 million to support the families we serve.



Through the International Association of Fire Fighters' spirited Fill the Boot community event proudly supported by more than 100,000 fire fighters and through income generated from charity baseball games and other local events, IAFF contributed an extraordinary \$26.8 million to MDA in 2014.



From early February through the end of March, thousands of supermarkets, convenience stores, restaurants and other community-minded businesses sold paper shamrocks, scannable cards at checkout that customers purchase to make a donation. Among our dedicated supporters were Lowe's Home Improvement, Burger King, CITGO Petroleum Corp., Corner Stores, Kroger and 7-Eleven. Shamrocks raised \$21.5 million in 2014.



Business leaders in communities across the country took part in MDA Lock-Up events, for which they secured donations in order to raise "bail" and break free for MDA families. The fun jail-themed events focused on breaking out to fund breakthroughs for MDA families built awareness in local communities, raising nearly \$15 million nationwide.



Galas, golf tournaments and other signature events in 2014 raised \$18 million to help MDA families.



MDA Team Momentum offers beginners and endurance pros alike the opportunity to participate in a marathon or half marathon while raising funds to accelerate progress for MDA families. In its inaugural year, MDA Team Momentum raised more than \$600,000 to help MDA families.

MDA Events: Strength in Numbers



Progress in Events
in 2014



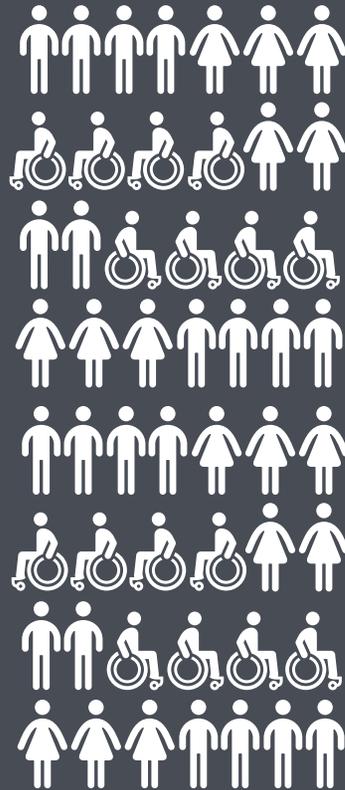
31,000

retailers
selling Shamrocks

50,000

participants

MDA
MUSCLEwalk[®]



350,000

volunteers



210,000

IAFF members
Filling the Boot

8,510

local events
through our
100
offices



Total MDA
fundraising
events in
2014

Our Leaders

MDA
ighting Muscle Disease



Our Leaders



2014-2015 Officers

(one-year term beginning June 26, 2014)

Chairman of the Board

R. Rodney Howell, M.D.
Miami, Fla.

Chair, Executive Committee

Olin Morris
Memphis, Tenn.

Vice Chair, Executive Committee

Christopher Rosa, Ph.D.
New York, N.Y.

Treasurer

Charles Schoor, Esq.
La Cañada, Calif.

Secretary

Timmi Masters
Beverly Hills, Calif.

2014-2015 Directors

(one-year term beginning June 26, 2014)

Stanley Appel, M.D.
Houston, Texas

Bart Conner
Norman, Okla.

Harold Crump
St. Paul, Minn.

Benjamin Cumbo III
Upper Marlboro, Md.

Steve Farella
New York, N.Y.

Daniel Fries
New York, N.Y.

Brad Henry
Norman, Okla.

Dave Hutton
Valencia, Calif.

Louis Kunkel, Ph.D.
Boston, Mass.

Patricia Nazemetz
Sleepy Hollow, N.Y.

John Tognino
Ardsley, N.Y.

Victor Wright
New York, N.Y.

Our Leaders



2014-2015 National Vice Presidents

(one-year term beginning June 26, 2014)

Arizona

Todd Bresnahan
Derrick Hall
Dana Moeller

California

Brandon Barash
Todd Beck
Alexander Cappello
Jann Carl
Frank DiBella
Robert Donato
W. King Engel
Lou Ferrigno
Marc Foster
Evan Lamberg
S. Paul Musco
Augie Nieto
Nancy O'Dell
Larree Renda
Petra Robinson
Bert Selva
Mark Smith
Alison Sweeney
Tom Thomas
Ace Young

Colorado

Jake Jabz

Connecticut

Richard Graziano
Lynn Malerba

District of Columbia

Fredric Rolando
Harold Schaitberger

Florida

Jay Feely
Mario Kreutzberger
Ted Morse

Georgia

Bruce Lucia
Tom Robinson

Illinois

Chris Clawson
William Emmons
Chris Ondrula

Iowa

Fred Greiner
Robert Myers

Kansas

Richard Seithel

Maryland

Tom Henry
Lon Rosenberg
John Seabers
Barry Sheaffer
Jennifer Smith Stepanek

Massachusetts

Robert Sigel

Minnesota

Marc Moeller

Missouri

Don Breckenridge Jr.
Gary Drawing

Nevada

Jim Prather

New Jersey

Kevin Boothe
Anthony Cammarata Jr.
John Crowley
Patricia Laus
Chris Snee
Steve Weatherford

New Mexico

William Anderson

New York

Robin Arnold
Candace Beinecke
Vincent DeLazzero
Charles Fazzino
Steve Furnary

Lel and Tom Gimbel
Neil Golub
James Halpin
Michio Hirano, M.D.
Scott Masterson
Raymond Mays
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
Randy Kibler
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

Alan Cohen
Juan Larrea
Aniceto Solares

Tennessee

Pete Fisher
Bill Mayne

Texas

Eric Affeldt
Bill Breetz
Stuart Crum
Rusty Hardin
Bill Klesse
Pierce Marshall
Mike Rowlett
Mike Withers

Wisconsin

Gordie Boucher Sr.

Our Leaders



Medical Advisory Committee

(members as of June 26, 2014)

Chairman

Stanley Appel, M.D.

Robert Baloh, M.D., Ph.D.
Elisabeth Barton, Ph.D.
Alan Beggs, Ph.D.
Mark Bromberg, M.D., Ph.D.
Thomas Crawford, M.D.
Merit Cudkowicz, M.D., M.Sc.
Heather Durham, Ph.D.
Richard Finkel, M.D.
Michio Hirano, M.D.
James Howard, M.D.
Joe Kornegay, D.V.M., Ph.D.
Se-Jin Lee, M.D., Ph.D.
Jun Li, M.D., Ph.D.
Katherine Mathews, M.D.
Kanneboyina Nagaraju, D.V.M., Ph.D.
Sally Nelson, Ph.D.
M. Kerry O'Banion, M.D., Ph.D.
Michael Shy, M.D.
Charles Thornton, M.D.

Ex officio member

R. Rodney Howell, M.D.

Clinical Advisory Committee

(members as of June 26, 2014)

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.

Registry Advisory Board

(members as of June 26, 2014)

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

Consultants

Julie Bolen, Ph.D., MPH
Amelie Gubitz, Ph.D.
John Porter, Ph.D.

Scientific Advisory Committee

(members as of June 26, 2014)

Chairman

Louis Kunkel, Ph.D.

Kurt Beam, Ph.D.
Carmen Bertoni, Ph.D.
Jeffrey Chamberlain, Ph.D.
Dongsheng Duan, Ph.D.
Emanuela Gussoni, Ph.D.
Kenneth Hensley, Ph.D.
Bernard Jasmin, Ph.D.
Rashmi Kothary, Ph.D.
Christian Lorson, Ph.D.
Giovanni Manfredi, M.D., Ph.D.
Elizabeth McNally, M.D., Ph.D.
Lynn Megeney, Ph.D.
Carlos Moraes, Ph.D.
Bradley Olwin, Ph.D.
Robin Parks, Ph.D.
Grace Pavlath, Ph.D.
John Ravits, M.D.
Shanthini Sockanathan, Ph.D.
Melissa Spencer, Ph.D.
Maurice Swanson, Ph.D.

Ex officio member

R. Rodney Howell, M.D.

MDA Venture Philanthropy Advisory Committee

(members as of June 26, 2014)

Stanley Appel, M.D.
Cristina Csimma, PharmD, M.H.P.
Kenneth Fischbeck, M.D.
John Howell
John Kissel, M.D.
Louis Kunkel, Ph.D.
Elizabeth McNally, M.D., Ph.D.
John Porter, Ph.D.
Jeffrey Rothstein, M.D., Ph.D.
Charles Thornton, M.D.
Lee Wrubel, M.D.

Financial Report

December 31, 2014
(in thousands)

Assets

Cash, cash equivalents and investments	\$89,792
Receivables and other assets	6,769
Fixed assets, net	1,227
Total assets	97,788

Liabilities

Accounts payable and accrued expenses	7,472
Research awards and grants payable	12,161
Line of credit	15,500
Pension and post retirement plan obligations	56,494
Total liabilities	91,627

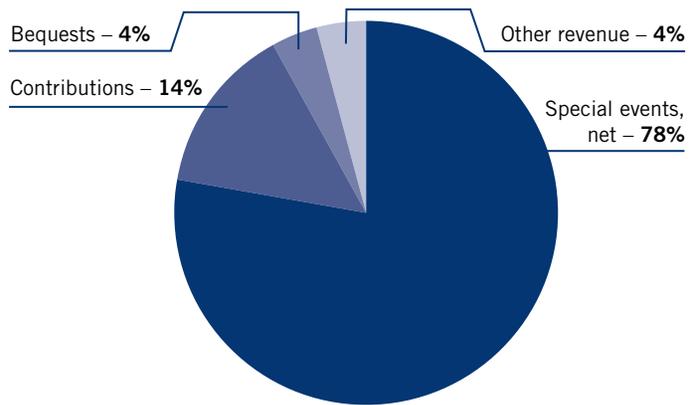
Net Assets

Unrestricted	56
Temporarily restricted	5,616
Permanently restricted	489
Total net assets	6,161

Total liabilities and net assets \$97,788

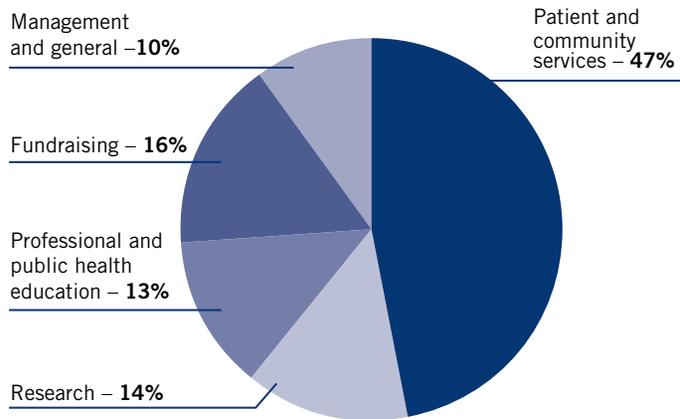
Revenue

Special events, net	\$108,534
Contributions	20,358
Bequests	5,459
Other revenue	5,400
Total revenue	\$139,751



Expenses

Patient and community services	\$61,378
Research	18,499
Professional and public health education	17,460
Fundraising	21,355
Management and general	12,824
Total expenses	\$131,516





Making Progress Toward Lifesaving Results

The Muscular Dystrophy Association is the leading organization dedicated to freeing kids and adults — and the families who love them — from the harmful effects of [muscular dystrophy](#), ALS and related muscle-debilitating diseases so they can live longer and grow stronger. By taking a big-picture perspective, we use our collective strength to find research breakthroughs across diseases, care for kids and adults from day one throughout their journey and empower families in hometowns across America with critical resources and support.

Designated a “Top-Rated Charity” by the American Institute of Philanthropy, MDA is the first nonprofit to receive a Lifetime Achievement Award from the American Medical Association for “significant and lasting contributions to the health and welfare of humanity.”



mda@mdausa.org



facebook.com/MDAnational



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



bbb.org/charity