For Strength, Independence & Life
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The Heart of Our Mission:
Accelerating Progress for Families

A message from

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

At MDA, families are at the heart of all we do. We are guided every day by our mission to free individuals — and the families who love them — from the daily challenges and life-threatening effects of muscular dystrophy, ALS and related diseases.

Each day across the country, everyday freedoms like walking, hugging, brushing one’s teeth, getting dressed and even breathing are taken away from kids and adults by neuromuscular diseases. MDA is fighting to give strength, independence and life to every child and adult affected so they can live longer and grow stronger.

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 2015:

• Research Progress Across Diseases: This section highlights 2015 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 2015 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 the impact MDA’s life-enhancing services and support programs had on families in communities across the country in 2015.

Muscle-debilitating diseases continue to impose enormous physical, emotional and financial challenges on individuals and their families. We’re committed to thinking bigger, working harder and accelerating the rapid progress currently underway.

We are extraordinarily grateful to every individual, company, team, organization and family who is making our shared progress possible. Together, we are moving forward in partnership with families, researchers and clinical partners to translate hope and progress into urgently needed answers and tangible results MDA families are counting on.

Steven M. Derks
MDA President & CEO
Cure: Research Breakthroughs Across Diseases

“A really important thing MDA does is not only push current therapies, but they spend a lot of money in trying to bring along the next generation of scientists. That’s critically important because research funding is drying up across the world, and a lot of young people today are discouraged from going into scientific and medical research.”

— Jeffrey Chamberlain, Ph.D., MDA Research Advisory Committee member
At MDA, we take a big-picture perspective across the full spectrum of neuromuscular diseases to uncover breakthroughs that accelerate treatments and cures. The power in our research approach is that we often can apply learnings from one disease to achieve progress in others — and bring urgently needed answers to families.

Since MDA’s inception more than 60 years ago, we’ve funded groundbreaking research and fostered communication and collaboration among scientists across the full spectrum of 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 2015 brought us a significant step closer to new answers and discoveries.
Research Breakthroughs Across Diseases

$16.4 million
Total 2015 research dollars invested

More than 150
Research projects funded in 11 countries

390
MDA-funded research projects active during 2015, with total funding commitment of $92.9 million

46
ALS research grants active during 2015, with total funding commitment of $12.1 million

103
New grants awarded in 2015, with a total funding commitment of $27.3 million

Nearly 200
Clinical trials underway for diseases in our program, testing dozens of promising therapies.
Research Breakthroughs Across Diseases

“Building a foundation of medical research requires early exciting studies, many of which are supported by MDA.”

— Jeff Rothstein, M.D., Ph.D., MDA Clinical Advisory Committee member

Research Progress in 2015

Noteworthy research advances supported by MDA funding:

- The exon skipping drug eteplirsen (brand name Exondys 51), under development to treat some forms of DMD, is under review by the FDA. [Note: Eteplirsen (Exondys 51) was granted accelerated approval by the FDA in September 2016.]

- Keveyis becomes the first FDA-approved drug for the treatment of hyperkalemic and hypokalemic periodic paralysis.

- MDA, Genzyme and Emory University team up to expand access to genetic testing for accurate diagnosis of limb-girdle muscular dystrophy.

- Transport between the nucleus and cytoplasm was shown to be disrupted in ALS, yielding novel drug targets and improving our understanding of the disease.

- Ionis Pharmaceuticals launches a phase 1 trial to test antisense therapy for ALS.

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

- American Academy of Neurology and American Association of Neuromuscular and Electrodiagnostic Medicine release a guideline for the diagnosis and care of people with facioscapulohumeral muscular dystrophy.

- Reveragen BioPharma launches phase 1, first-in-human clinical trial to test DMD drug vamorolone in healthy volunteers.


- In clinical trials sponsored by Biogen and Ionis Pharmaceuticals, infants with SMA who were treated with nusinersen show improved measures of muscle function.
Care: Caring for Kids and Adults from Day One

“Getting our daughter’s diagnosis when she was 2 years old was scary, shocking and isolating. Right off the bat, we knew MDA was on our team and would be there to support us. To have an organization there to provide a community and be a resource for us was and continues to be a huge asset for our entire family.”

— Becky Bormann, whose daughter has congenital muscular dystrophy
Caring for Kids and Adults from Day One

Advancing Care for Families

Early diagnosis, highly specialized care and access to promising clinical trials help ensure the best possible outcomes for individuals and families.

MDA cares for kids and adults from day one at our network of MDA Care Centers across the United States and Puerto Rico. MDA Care Centers offer families best-in-class, comprehensive care. These state-of-the-art clinics, located at the top hospitals and medical facilities, bring health care specialists from a variety of disciplines together so families receive the care they need at one time and in one place.

These experienced clinicians have a depth of knowledge that allows them to recognize subtle differences between conditions that may resemble each other at onset, but which have very different underlying causes, rates and patterns of disease progression, and standards of care.

MDA Care Centers receive nearly 50,000 visits each year while also serving at the forefront of research by hosting clinical trials for the latest promising therapies.
Caring for Kids and Adults from Day One

- **100,000** Individuals served by MDA in 2015
- **50,000** Visits to MDA Care Centers in 2015
- More than **150** MDA Care Centers across the United States and Puerto Rico
- **43** MDA ALS Care Centers
- More than **400** Neuromuscular disease researchers and experts who shared knowledge at MDA’s 2015 Scientific Conference
Champion: Supporting Families in Hometowns Across America

“MDA means hope. It means strength. It means courage. MDA has been great helping [our child] overcome everyday limitations, and I can’t be more thankful.”

— Josh Lybrand, whose son has Duchenne muscular dystrophy
Supporting Families in Hometowns Across America

Progress in Supporting and Empowering Families in 2015

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.

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 and giving kids with muscular dystrophy and related diseases the best week of the year at MDA Summer Camp, MDA is here to help families maintain and improve their health and well-being while actively pursuing life goals to live unlimited.
Supporting Families in Hometowns Across America

- More than 3,800 Kids at MDA Summer Camp
- More than 3,000 Assistive devices provided to MDA families
- 73 MDA Summer Camps
- 4,000 Trained MDA Summer Camp volunteer counselors
- 400 MDA Summer Camp volunteer medical staff
- More than 100 support groups and educational gatherings in 2015
- 9,500 Visitors to mda.org every day
Supporting Families in Hometowns Across America

Making Families’ Voices Heard in Public Policy & Advocacy

MDA is dedicated to doing everything in our power to advocate for policies and programs that help save and improve the lives of kids and adults living with muscular dystrophy and related neuromuscular diseases. Together, we ensure that our community’s collective voice is heard.

Every year, MDA works closely with Congress, regulatory agencies and other leaders to ensure that issues impacting the neuromuscular disease community are a priority. MDA and our advocates fight for life-changing public policies, and we are proud to collaborate with other organizations and stakeholders in the disability community to ensure the passage and implementation of policies and programs supporting the families MDA serves.
Supporting Families in Hometowns Across America

In 2015, MDA and its community of advocates — including MDA families, leaders, scientists and clinical experts — supported the following legislation and had a pivotal role in the community-wide effort that led to these advances.

**Ensuring Access to Clinical Trials Act of 2015**

Signed into law Oct. 7, 2015, this legislation makes it possible for individuals to participate in rare disease clinical trials and receive up to $2,000 in compensation without the funds counting against income eligibility for Medicaid and Social Security Income (SSI). The collaborative effort, led by the Cystic Fibrosis Foundation in partnership with the National Organization for Rare Disorders and MDA, was supported by more than 75 organizations who worked to ensure the legislation passed.

**Increase Funding for the National Institutes of Health (NIH)**

MDA worked to increase funding for the National Institutes of Health (NIH), the largest funding source of biomedical research in the United States. In December 2015, Congress approved the largest funding increase — an additional $2 billion — in more than a decade. This funding increase translates into more federal funding for research that will help accelerate treatments and cures for the conditions in MDA's program.

**Preserve Access to Complex Rehabilitation Technologies**

As part of an organized coalition, MDA supported legislation preventing cuts to the Medicare program that would limit access to life-enhancing complex rehabilitation technology (wheelchair accessories) that individuals with disabilities rely on every day to maintain independence, mobility and optimal health. Congress passed a bill in December 2015 delaying the cuts for 12 months. MDA continues to advance this critical issue.

**Led Collaborative Effort to Inform FDA About Biomarkers to Promote Therapy Development**

MDA led a collaborative effort to provide the U.S. Food and Drug Administration (FDA) with biomarker information about disorders in MDA's program. MDA provided current scientific data about biomarkers and how those measures could be used in the drug and therapy development process for multiple neuromuscular diseases. These markers, or signals, can provide crucial information for researchers conducting clinical trials, helping them determine early on whether a treatment is effective.
Partners in Progress
In 2015, MDA continued to find ways to innovate our fundraising programs to fuel our lifesaving mission. The 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.

Together with our generous partners and supporters, we continue to work to help families find much-needed hope, answers and support, whenever and wherever they need us. Since MDA's founding in 1950, our strength and our hope lie in the hearts of the people and partners who embrace our mission.
The International Association of Fire Fighters (IAFF) committed by proclamation in 1954 to support MDA until a cure is found. During its 60-year partnership with MDA, the IAFF has raised a staggering $583.5 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 2015, the IAFF contributed more than $25 million through more than 2,000 Fill the Boot events and other special fire fighter events to benefit MDA.

As MDA’s largest corporate partner, CITGO Petroleum Corporation and its nearly 5,500 locally owned retail locations have raised more than $180 million for MDA through a wide variety of fundraising events, including golf tournaments, fundraising at checkout and socials. In 2015, 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 2015 at more than 1,700 Lowe’s locations to achieve more than $7.5 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 million for MDA in 2015 through events such as Black-N-Blue Galas and special MDA rides, including the EHDDA MDA Ride for Life in Pennsylvania. During its 35-year partnership with MDA, the Harley-Davidson family of dealers, customers, employees, suppliers and H.O.G. chapters has raised more than $96 million to help save and improve the lives of MDA families.
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.

In 2015, that incredible spirit of generosity and involvement was as vibrant as ever and visible in a variety of special events that generated funds and raised awareness for MDA’s life-changing mission.

MDA’s cause is strengthened by our army of more than 350,000 volunteers in hometowns across America. Their tireless efforts and passionate support translate into an unparalleled commitment to helping MDA accelerate progress in research, care and support for our families.
**MDA Events: Strength in Numbers**

**MDA Muscle Walk**
MDA Muscle Walk is a life-changing event that inspires and strengthens families and communities. Muscle Walk is more than a fundraising walk. For MDA families, friends, volunteers, donors and sponsors, it’s a powerful experience that forges lifelong connections, celebrates families and the barriers they overcome and turns hope into answers. In 2015, about 40,000 people participated in 150 MDA Muscle Walks, raising $8 million to support the families we serve. Since 2011, MDA Muscle Walk has raised more than $34 million to help bring strength to life for MDA families in hometowns across America.

**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. More than 100,000 fire fighters across the country participate in this spirited tradition each year. In its first year in 1953, fire fighters in Boston raised $5,000 for MDA. In 2015, more than $25 million was raised by fire fighters at more than 2,000 Fill the Boot events and other local events. To aid in their efforts, MDA launched Fill the Boot Online in August 2015 to assist fire fighters in collecting online donations, which raised more than $11,000 in four short months.

**MDA Shamrocks**
From early February through the end of March, 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. Retailers sold paper Shamrocks (scannable cards) at checkout, and customers purchased the paper Shamrocks for $1, $5 and larger contributions for the retailer to display in support of MDA. Among our dedicated supporters were Lowe’s Home Improvement, Burger King, CITGO Petroleum Corp., Kroger and 7-Eleven. Shamrocks raised nearly $18 million in 2015. The paper Shamrocks continue to stand as a symbol of strength, independence and life.
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 break free from the harm of muscle-debilitating diseases. Business leaders joined forces with MDA in neighborhoods across America, taking part in MDA Lock-Up events. Jailbirds agreed to be “locked up” while they raised money for their “bail.” In 2015, MDA Lock-Up events raised nearly $14 million nationwide.

MDA Distinguished Events

Galas, golf tournaments and other signature events — 362 total — in 2015 raised $17.8 million to help MDA families.

MDA Team Momentum

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 second year, MDA Team Momentum — and its more than 600 participants — raised more than $850,000 to help MDA families. In its first two years, MDA Team Momentum had a total of 954 participants and raised a combined $1.55 million.

Your Way for MDA

Launched in June 2015, 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 and hometowns across America. Your Way gives the American public the choice and tools to raise money in the most creative ways — from hosting a bake sale to running a 5K to an activity that speaks to your unique story. Thanks to the public’s creative ideas, Your Way for MDA raised $117,707 through the end of 2015.
Volunteer Leaders

“MDA families are — and always have been — at the heart of MDA’s lifesaving mission. We were started by families, for families, and we are 100 percent dedicated to freeing families from the harmful effects of muscle-debilitating diseases.”

— MDA President and CEO Steven M. Derks with Torrance, 10, who is living with spinal muscular atrophy
Volunteer Leaders

2015–2016 Officers  
(one-year term beginning July 15, 2015)

**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.

2015–2016 Directors  
(one-year term beginning July 15, 2015)

Stanley Appel, M.D.  
Houston, Texas

C. Thomas Caskey, M.D.  
Houston, Texas

Harold Crump  
St. Paul, Minn.

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 2015–2016 National Vice Presidents (one-year term beginning July 15, 2015)

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For Strength, Independence & Life 25
Volunteer Leaders

Clinical Advisory Committee
(members as of June 26, 2015)
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, 2015)

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

Members
Robert Baloh, M.D., Ph.D.
Elisabeth Barton, Ph.D.
Kurt Beam, 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.
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Dongsheng Duan, Ph.D.
Heather Durham, Ph.D.
Richard Finkel, M.D.
Emanuela Gussoni, Ph.D.
Kenneth Hensley, Ph.D.
Michio Hirano, M.D.
Bernard Jasmin, Ph.D.
Joe Kornegay, D.V.M., Ph.D.
Rashmi Kothary, 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.
Sally Nelson, Ph.D.
M. Kerry O’Banion, M.D., Ph.D.
Bradley Olwin, Ph.D.
Robin Parks, Ph.D.
John Ravits, M.D.
Michael Shy, M.D.
Shanthini Sockanathan, Ph.D.
Melissa Spencer, Ph.D.
Maurice Swanson, Ph.D.
C. Chris Weihl, M.D., Ph.D.

Ex officio member
R. Rodney Howell, M.D.
Volunteer Leaders

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(members as of June 26, 2015)

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Joshua Benditt, M.D.
James Berry, M.D.
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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.

MDA Venture Philanthropy Advisory Committee

(members as of January 1, 2015)

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Cristina Csimma, PharmD, MHP
Kenneth H. Fischbeck, M.D.
Amelie Gubitz, Ph.D.
John E. Howell
Louis M. Kunkel, Ph.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, 2015
(in thousands)

**Revenue**
- Special events, net $99,375
- Contributions 22,336
- Other revenue 474
- Total revenue $122,185

**Expenses**
- Patient and community services $56,468
- Research 17,150
- Professional and public health education 14,963
- Fundraising 19,741
- Management and general 12,489
- Total expenses $120,811

**Assets**
- Cash, cash equivalents and investments $87,787
- Receivables and other assets 5,590
- Fixed assets, net 869
- Total assets 94,246

**Liabilities**
- Accounts payable and accrued expenses 5,303
- Research awards and grants payable 11,487
- Line of credit 14,500
- Pension and post-retirement plan obligations 54,536
- Total liabilities 85,826

**Net Assets**
- Unrestricted 3,908
- Temporarily restricted 4,028
- Permanently restricted 484
- Total net assets 8,420

**Total liabilities and net assets** $94,246
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.”