Strength in Mission





- From the Interim President

A year of accomplishment and progress but also transition for MDA, 2011 was a time of uncompromising strength in our mission to make life better for those affected by neuromuscular diseases. Throughout this Annual Report, you'll read insights from individuals with unique perspectives on MDA's programs and activities during 2011.

MDA research pressed forward at an invigorating pace, including our translational research program which continued to forge innovative partnerships to accelerate the discovery process for new therapies.

Because strength derives from the sharing of ideas, we were excited by the participation of some 300 professionals in our MDA National Scientific Conference in Las Vegas. MDA also was proud to play a sponsorship role in the International Myotonic Dystrophy Consortium Meeting in Clearwater, Fla.

Leading neuromuscular specialists continued to provide diagnostic and follow-up care at our 200 MDA clinics nationwide, including 40 MDA/ALS centers. Once again, thousands of boys and girls with neuromuscular disorders experienced the joy of a week at MDA summer camp.

With the help of improvements in medical management, young people affected by these diseases are living longer while pursuing educational and career goals. As part of our Advocacy program, MDA's Transitions Summit in Washington, D.C., focused on the issues facing this growing population of young adults.

As we transitioned into 2012, I was proud and humbled when MDA's Board of Directors asked me to serve as Interim President, while still continuing as Medical Director, after MDA President & CEO Gerald C. Weinberg retired at the end of the year. With the unparalleled strength that comes from our sponsors, donors, volunteers, staff and other members of our extended MDA family, we're confident we can look forward to attaining new levels of excellence in the furtherance of MDA's crucially important mission.

Valerie A. Cwik, M.D. MDA Interim President and Medical Director



- From the Chairman of the Board

The year 2011 saw a continuation of MDA's commitment to translational research, which helps turn promising laboratory findings into potential treatments for neuromuscular diseases. At the same time, the Association continued full steam ahead with its basic research program, which is where promising laboratory findings originate.

In amyotrophic lateral sclerosis (ALS), a paralyzing and almost universally fatal disorder that strikes adults, MDA was thrilled to learn that the experimental drug it helped to develop for a familial form of the disease was well-tolerated in an early-stage clinical trial. The drug is designed to block synthesis of the SOD1 protein, which is toxic in this form of ALS.

In Duchenne muscular dystrophy (DMD), a devastating genetic disease that weakens muscles and shortens the lives of young men, MDA continued its support of a strategy called "exon skipping," which coaxes muscle cells to reinterpret flawed genetic instructions and produce a functional protein despite the flaw. Two exon-skipping drugs, both based on MDA-supported basic research, have entered clinical trials in boys who have specific genetic mutations.

This also was a banner year for research in facioscapulohumeral muscular dystrophy (FSHD). This genetic disease, which often strikes in adolescence, has a special predilection for weakening the muscles of the face, upper arm and shoulder area. Thanks to much MDA-supported research, it's now clear that a protein called DUX4 is inappropriately produced in muscle fibers in this disease. This finding represents a solid target at which potential therapies can now be aimed.

In two other diseases — Friedreich's ataxia (FA) and spinal muscular atrophy (SMA) — MDA's support of a biotechnology company has resulted in experimental medications targeting the underlying cause of each condition. The experimental drug RG2833 is designed to increase production of the frataxin protein, a deficiency of which causes FA. RG3039, developed by the same company with MDA's help, is meant to increase levels of the SMN protein, a lack of which is the basic cause of SMA. Both drugs are poised to enter clinical trials.

The U.S. economy began to recover in 2011, although many financial challenges remained for the Association. Through it all, without compromise, we have continued to fund the research projects that are the most likely to improve the lives of those we serve.

Pllodacy Howell

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



MDA-supported research made real progress in 2011, with significant findings announced for a number of neuromuscular diseases. The Association invested \$38.1 million in its research program, supporting nearly 300 research projects around the world — both basic laboratory research and translational research seeking to turn promising laboratory findings into pharmaceuticals to treat neuromuscular diseases.

The Association covers more than 40 neuromuscular diseases in its research program, all of them related to dysfunction of the muscles, the nerves that control them, or the signals that move between nerves and muscles. The majority of diseases in MDA's program are genetic, resulting from a variety of gene mutations; a few are autoimmune diseases, resulting from an attack by the immune system on muscle or nerve tissue.

Through its basic research program, applications from academic researchers were reviewed by the Association's prestigious Medical and Scientific Advisory Committees, comprised of the world's leading clinicians and scientists in the neuromuscular disease field. In addition, translational research grants were reviewed and awarded to biotechnology companies through the MDA Venture Philanthropy program.

Among the research grants were 12 career development awards, designed to increase the number of outstanding scientists working in the field. Recipients of development awards are young scientists working in the laboratory of a senior investigator.

In March, MDA launched its new annual national conference series, beginning with the MDA Scientific Conference. The conference brought together some 300 researchers, clinicians, representatives from biotech and pharmaceutical industries, and students specializing in neuromuscular disease to focus on the topic "Neuromuscular Therapeutic Strategies: Overcoming the Barriers from Microscope to Marketplace." Here are some other highlights of the 2011 research program:

Amyotrophic lateral sclerosis (ALS)

- A clinical trial of the experimental drug ISIS-SOD1-Rx, developed by Isis Pharmaceuticals of Carlsbad, Calif., with MDA support, showed the drug was safe and well-tolerated by individuals with ALS caused by a mutation in the SOD1 gene.
- A team of scientists that included an MDA grantee found that a mutation in a gene called C9ORF72 is the most common known genetic cause of familial ALS and also accounts for nonfamilial ALS in some people.
- MDA awarded \$3.2 million to the Cambridge, Mass.-based ALS Therapy Development Institute in 2011, bringing the total awarded to this institute to more than \$24.5 million since 2007. ALS TDI's goal is to identify biochemical targets in ALS and find drugs that hit them.

Charcot-Marie-Tooth disease (CMT)

• A multinational study supported by MDA and the National Institutes of Health began studying correlations between genetic mutations and symptoms in four types of CMT.

Congenital myasthenic syndromes (CMS)

• Seventeen of 18 people with either of two forms of CMS who received albuterol in an MDA-supported study reported that their quality of life had improved.

Duchenne muscular dystrophy (DMD)

- Since the 1990s, MDA's basic science research program has been supporting development of a strategy for DMD known as exon skipping. The strategy coaxes cells to skip over erroneous genetic instructions and produce a functional dystrophin protein. In 2011, AVI BioPharma (which became Sarepta Therapeutics in 2012) began testing its exon-skipping drug eteplirsen in a clinical trial at Nationwide Children's Hospital in Columbus, Ohio, under the direction of neurologist Jerry Mendell. A longtime MDA clinic co-director and research grantee, Mendell received MDA support to help conduct this trial.
- Another experimental strategy for DMD involves increasing levels of a protein called utrophin at the muscle-fiber membrane. Utrophin appears capable of partially compensating for a lack of dystrophin in this location.
 MDA began supporting Summit Corporation PLC in Oxford, United Kingdom, to develop its experimental compound SMT C1100 to raise utrophin levels. The Association also began supporting Tivorsan Pharmaceuticals in Providence, R.I., to develop its experimental drug TVN-102, which is designed to attract utrophin to the membrane.
- An MDA-supported study comparing two dosing schedules of the drug prednisone, which slows the course of DMD, found that daily dosing or compressed, weekend-only dosing had similar benefits and side effects.

Facioscapulohumeral muscular dystrophy (FSHD)

• A protein called DUX4, made at the wrong time and the wrong place in people with FSHD, gained increasing attention from MDA as a possible target for therapeutic development in this disease. Several MDA research grants in 2011 reflect this.

Friedreich's ataxia (FA)

• MDA's extensive investment in development of the experimental compound RG2833 for FA bore fruit, as plans for a clinical trial of this drug solidified. RG2833 is being developed with MDA support by Repligen Corp. of Waltham, Mass.

Myasthenia gravis (MG)

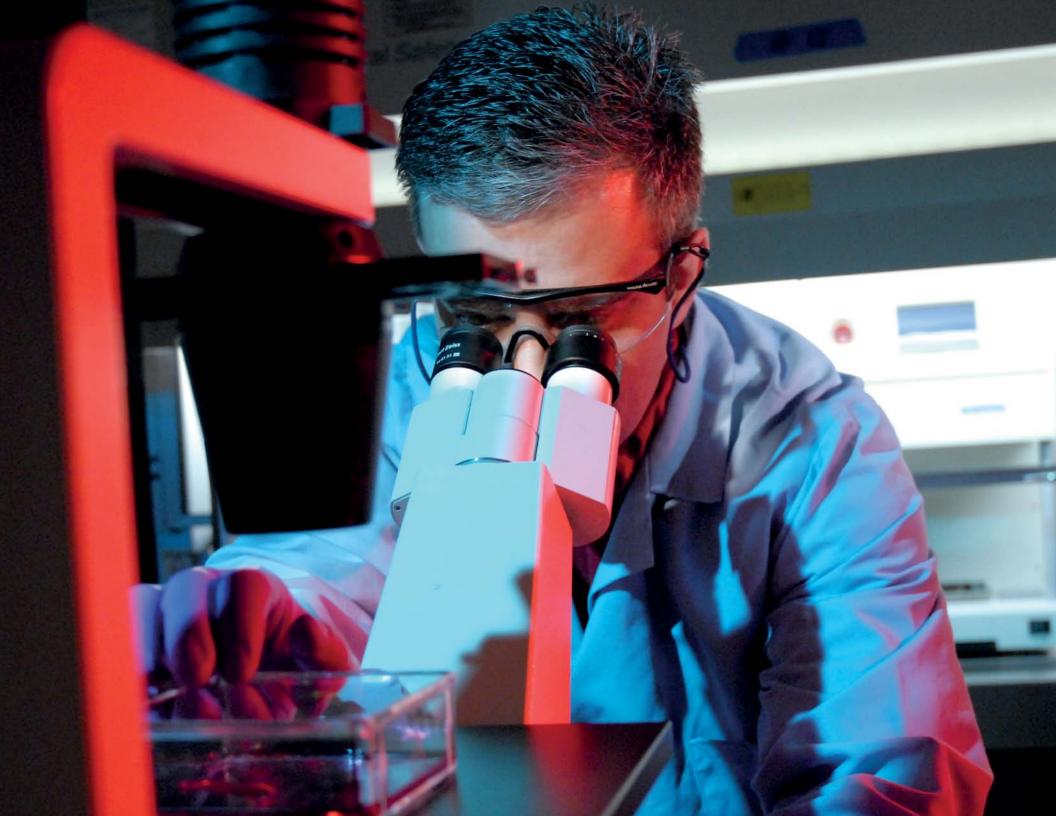
• MDA awarded a \$530,480 grant to a University of Illinois at Chicago researcher to test the effects of an experimental immune system modulator called GM-CSF as a potential treatment for MG.

Myotubular myopathy (MTM)

• MDA awarded \$369,365 to a researcher at Wake Forest University to develop gene therapy for MTM using the myotubularin gene.

Spinal muscular atrophy (SMA)

- The U.S. Food and Drug Administration gave a green light to a clinical trial of the experimental drug RG3039, developed to treat SMA by Repligen Corp. with a \$1.4 million grant from MDA.
- MDA-supported scientists found that, in mice with an SMA-like disease, the experimental drug ASO-10-27, an antisense oligonucleotide, prolonged survival and improved function better when injected systemically than when injected into the central nervous system alone.





It's hard to put a label on Jerry R. Mendell, M.D. Mendell is a longtime MDA research grantee specializing in muscular dystrophies, and, as a neurologist, he's a longtime co-director of the MDA Clinic at Nationwi de Children's Hospital in Columbus, Ohio.

At Nationwide, he's also the director of the Center for Gene Therapy, head of the MDA Duchenne Muscular Dystrophy Clinical Research Center, director of the Neurosciences program and the Neuromuscular Disorders program, and co-director of the Neuromuscular Genetic Therapeutics Fellowship program.

In the 1990s, MDA research funding allowed Mendell to be among the first to test an experimental cell transplantation therapy in children with Duchenne muscular dystrophy.

More recently, he's received MDA support to test "gene therapy" — the insertion of a therapeutic gene — in people with Duchenne and limb-girdle muscular dystrophies, and to test a new strategy known as "exon skipping" in Duchenne MD.

Exon skipping doesn't insert a new gene but instead coaxes muscle cells to "make the most" of existing genetic material, despite its flaws. In Duchenne MD in particular, exon skipping may prove superior to gene insertion therapy because of the immune system's apparent tolerance of the treatment.

"I started working in the neuromuscular field in 1969 at NIH and every year since then I've been funded by MDA," said Mendell. "They funded the first major trial for steroids in muscular dystrophy, gene therapy research and are now supporting exon skipping. Without MDA, we wouldn't have a chance at conquering Duchenne."



Jerry R. Mendell, M.D.

"Today, we're encouraged to see so many innovative concepts being advanced to clinical trials, and to see progress that could only be dreamed about in earlier decades. There's great optimism among our MDA-funded researchers that new therapeutic answers are on the horizon."

- Valerie A. Cwik, M.D., MDA Interim President and Medical Director





Strength in Health Care Services

Thanks to MDA, families living with neuromuscular disease are not alone. MDA stands with them, ready to listen, providing resources and guidance, offering support and facilitating personal connections with others affected by these disorders.

Throughout 2011, individuals and families were assisted by caring local MDA staff around the county who helped coordinate medical and support services. In addition, a national community of clinicians, researchers, sponsors, volunteers and donors helped the Association provide "strength for the journey."

There were a number of Health Care Services highlights in 2011:

- Individuals with neuromuscular diseases received expert diagnostic medical care at 200 MDA clinics, including 40 MDA/ALS centers, around the country. Many of the Association's clinics also served as sites for clinical trials of emerging therapies.
- The Association's support group program provided a vital way for MDA families to connect with others living with neuromuscular disease. Some groups were disease-specific, some focused on caregivers or the unique experiences of young adults, but all shared the common theme of helping people connect with others to gain strength through shared experiences.
- Because a simple case of the flu can be life-threatening for those with neuromuscular disease, the annual MDA flu shot program provided thousands of free influenza vaccines to individuals served by the Association. MDA's online Flu Season Resource Center on mda.org helped individuals and families stay informed and take steps to protect themselves and their loved ones from complications of influenza.
- To help individuals maintain mobility and independence, assistance with a wide range of repairs was provided through the Association's national medical equipment program. Additionally, donations of gently used medical equipment enabled MDA to provide thousands of devices to individuals at no cost to them or their families, when prescribed by an MDA clinic physician.

- The Association's "myMuscleTeam" online tool offered a valuable resource to MDA families. By creating private, secure Web pages, those affected by neuromuscular disease could post updates for family and friends, and were able to easily and effectively seek assistance when needed, such as with transportation to medical appointments, meal preparation, household chores and more.
- Two national awareness campaigns ALS Awareness Month and National Family Caregivers Month highlighted personal stories of strength from those living with neuromuscular diseases while educating the American public about the impact these disorders have on families across the country.
- Meetings of MDA's Clinical Advisory Committee and the opportunity for families to complete the Association's "Tell Us About Your MDA Clinic" online survey were part of a continued effort to ensure that families with neuromuscular diseases receive state-of-the-art medical services.
- Community and empowerment were the themes at the third annual Becker Muscular Dystrophy Conference held in Los Angeles in August 2011. The MDA-sponsored event, attended by both professionals and individuals and families affected by BMD, featured a number of experts speaking on the latest research advancements, medical management and clinical trials.
- The eighth International Myotonic Dystrophy Consortium Meeting (IDMC-8), sponsored in part by MDA, was held in Clearwater, Fla., in December 2011. Researchers, physicians and students gathered to explore new developments in types 1 and 2 myotonic muscular dystrophy. A joint session with professionals and families affected by myotonic dystrophy featured research updates and a valuable question-and-answer session. Importantly, others around the world who could not attend in person were able to participate free through MDA's live Internet stream of the interactive session.



MDA Summer Camp

MDA summer camp is a magical place. In addition to providing a wide range of activities designed for the needs and abilities of youngsters with neuromuscular disease, MDA camp gives campers an unmatched opportunity to share interests, develop long-lasting friendships and build self-confidence. At MDA camp, children with neuromuscular disease find a place where they are "just like everyone else."

The wildly popular program served nearly 3,400 youngsters ages 6 to 17 at 75 weeklong camps throughout the country. More than 4,300 volunteers (counselors, physicians, nurses, allied health professionals and activity leaders) gave their time and expertise to help make the fun and memories happen.

- It's described by campers as the "best week of the year."
- Surrounded by supportive camp counselors and volunteers, the children have opportunities for personal growth while experiencing the independence of being away from home.
- Youngsters leave camp each year with new friendships, heightened self-esteem and increased confidence in their abilities.
- Examples of activities at camp include: swimming, karaoke, adaptive sports, horseback riding, arts & crafts, and much more.
- Volunteers must be at least 16 years old. Volunteers work one-on-one with campers, providing around-the-clock care, friendship and fun.
- The cost of sending one child to MDA camp for one week is \$800, but there is no cost to families for their child to attend MDA summer camp. Camp is funded entirely by public contributions made to MDA year-round.

"I always love going to MDA summer camp because I get to hang out with my friends and meet new ones. And I get to do things I don't always do, like the zip line and play soccer."

— Tony, MDA camper, Colorado



Strength in Independence

Angela Wrigglesworth knows all about being empowered and becoming self-sufficient. For the 35-year-old teacher from Houston, independence has been a childhood dream that she achieved years ago and continues to maintain well into adulthood.

She thrives on being active and independent, showing her strength in commitment and resourcefulness. And, she says, MDA has helped her get there.

"MDA helped to shape me into a successful, independent woman," says Wrigglesworth, who was diagnosed as having spinal muscular atrophy at 16 months. "Without the life lessons gained during my years as a camper at MDA summer camp, I quite possibly would not have mastered the art of asking for help. Without that skill, it is impossible to live independently and maintain a longtime career."

MDA summer camp isn't just about playing with ropes, but learning them, too. It's about forwardthinking and, eventually, paying it forward. For more than 10 years, Wrigglesworth has accomplished each by being one of Texas' top teachers.

"The knowledge and help that I provide my students has value," she said. "Knowing that I've helped someone learn and grow, and achieve some independence is great ... It's huge."

Wrigglesworth says she is inspired by "the privilege of watching my students and co-workers help me to accomplish common tasks — from picking up pencils to opening doors. I get to watch others, young and old, in their most helpful capacity. That is a joy not everyone sees in mankind on a regular basis."



Angela Wrigglesworth and MDA camper

"I learned I could grow up and be successful ... I learned. I learned. I learned. I am forever changed by it because every day I've been able to incorporate camp into my journey through life."

- Angela Wrigglesworth, fourth-grade teacher, Houston, Texas





MDA's advocacy program, based in Washington, D.C., works to ensure that the voice of the neuromuscular disease community is heard and considered by policymakers and federal officials.

In 2011, MDA's advocacy program formally launched a bold new initiative, the MDA Transitions program, which addresses the needs of a "new generation" — young adults living with what were once considered "pediatric" diseases, thanks to improved medical interventions and comprehensive care that have extended life span. However, significant societal and resource barriers continue to exist for young people with disabilities seeking higher education, employment and independent living.

MDA's Transitions program works with youth and families to identify the multifaceted needs of our young adult community, and then identify the supports and services needed to navigate the existing systemic barriers.

MDA also is working to create a social and political environment that supports independent living, and encourages young people to pursue their hopes and dreams for the future.

Some highlights from MDA's advocacy program include:

- MDA launched a dynamic online Transitions Center (transitions.mda.org), providing a "peer-to-peer" outlet for resources, information and advice from young adults with muscle diseases.
- MDA conducted a national Transitions Survey through its online Transitions Center and presented data at several conferences showing that more comprehensive supports and resources are needed both for family caregivers and adults with muscle diseases seeking independent living options.

- In September, MDA hosted the National Neuromuscular Transitions Summit in Washington, D.C. The Summit focused on the areas of employment, education and independent living, and provided an opportunity for federal policymakers to hear from successful young adults within the MDA community as to the key factors that contributed to their successes, the difficult resource barriers they encountered, and the opportunities for policy improvements that exist.
- MDA launched a Transitional Services Task Force, a multidisciplinary group of clinical professionals and MDA community members who serve as advisers to MDA's Transitions program. The Task Force developed the "Road Map to Independence" to aid in the transition from pediatric to adult clinical care settings (mda.org/publications/road-map-independence-young-adults).
- The third annual "MDA Fly Out," MDA's annual grassroots outreach campaign, was conducted in August during the congressional recess when elected officials were in their home disticts. The 2011 MDA Fly Out focused on transitions policy efforts and the Achieving a Better Life Experience Act (ABLE Act).

"MDA's shift in focus on transitions services has been critical to providing a path to independence for young adults living with neuromuscular diseases. By taking the lead in providing access to tools for independent living, hiring and paying for a personal care attendant, and navigating college and post-college obstacles, MDA has shown that it is invested in the post-adolescent future of its constituency."

— Aaron Bates, attorney, Orlando, Fla.

Strength in Advocacy





It's a new dawn and a new day, and the outlook is bright.

And it involves a rising generation and fresh voices — "the population that was hoped for ... and now we're here," as Vance Taylor so eloquently put it at the MDA National Neuromuscular Transitions Summit in Washington, D.C., in September 2011.

Taylor, a 34-year-old husband and father of two daughters, epitomizes what the national summit was all about and what MDA's Transitions Center personifies: strength in community, strength in independence, strength in education and strength in a strong vibrant future.

MDA has paved the way, helping the new generation of adults living with so-called "pediatric" neuromuscular diseases, to live longer and stronger and more independently than ever before.

"It's a platform for people with neuromuscular diseases to say: you can achieve, you can go to college, you can have kids, you can be a professional, and you can have success in every facet of your life," says Taylor, who was diagnosed with limb-girdle muscular dystrophy at age 9. "Having a disability no longer means you are precluded from doing those things and achieving your dreams. You CAN do it."

MDA's advocacy program is important, Taylor says, because, "in order for us to reach our potential we need to have them change the system that is in place right now. The system that was originally designed was good for a time, but that has changed. Our needs have evolved. We want to be out, we want to be working, and we want to be productive members of society. We've got the technological and mental capacity to do that."



Vance Taylor

"I see eyes of greatness in the youth and individuals served by MDA. Now, it's what we do with it that counts. The Transitions Center and other advocacy efforts help empower a dynamic set of individuals who are longing to contribute and make a meaningful impact on society."

- Vance Taylor, homeland security consultant, Washington, D.C.

Strength in Information

The individuals and families MDA serves have never been more informed. From instantaneous "tweets" to in-depth guidebooks to in-person presentations, the Association provided a wealth of information in 2011 on research, health care, advocacy and daily living with neuromuscular disease.

MDA.org — MDA's award-winning website provided instant information about the Association's multiple programs and services. In 2011, the site had 8.5 million page views from more than 200 countries and territories.

MDA Online News — Visitors to mda.org found a steady stream of the latest information about research, health care and legislation, presented and explained in easy-to-understand language.

MDA Social Media — Instant news updates and rich opportunities for community connection and support were provided through Facebook (facebook.com/MDANational), Twitter (@MDAnews) and YouTube (youtube. com/user/MySpaceMDA).

Quest Magazine — The Association's award-winning quarterly publication provided information about research, caregiving, education, adaptive products and independent living, as well as lively opinion pieces and profiles of inspiring individuals.

MDA/ALS Newsmagazine — Published bimonthly, this award-winning newsmagazine presented news and analysis of amyotrophic lateral sclerosis research, as well as helpful information for daily living.

MDA Guidebooks and Booklets — Available in print and/or online in an easy-to-print format, these practical and informative publications about the more than 40 neuromuscular diseases in MDA's program were accessed by people in 180 countries, including the United States.

MDA Webinar Series — Throughout 2011, MDA's free online webinars enabled individuals and families to hear from — and ask questions of — expert hosts speaking on topics such as medical management, research, education, transitioning to adulthood and independent living.



MDA Ambassadors — MDA was proudly represented by two energetic and articulate ambassadors in 2011 — Abbey Umali (Redlands, Calif.) and Luke Christie (Due West, S.C.). Umali, a 13-year-old who has a form of Charcot-Marie-Tooth disease, served an unprecedented fourth term as National Goodwill Ambassador. Christie, 19, served a third term as National Youth Chairman. Christie is affected by spinal muscular atrophy. Their duties included traveling the country to share information about MDA's mission of help and hope.

ALS Division Co-Chairs — Augie and Lynne Nieto (Corona del Mar, Calif.) served a sixth year as co-chairs of MDA's ALS Division. The pair made appearances in 2011 on behalf of Augie's Quest, MDA's ALS research initiative, on national television and at Augie's Quest events.

MDA Art Collection — The celebrated Collection added 10 new pieces in 2011 and now has more than 385 works, showcasing artists with neuromuscular diseases from every state and Puerto Rico from ages 2 to 84. Pieces are displayed at MDA's national headquarters and in museums and galleries across the country.

MDA Research Leaders Report — This informative publication, sent biannually to high-level MDA donors, provided clear explanations of current MDA-funded research into the diseases under its umbrella.

For decades, outstanding companies and organizations have aligned with MDA in community events and cause-marketing campaigns. MDA promotions are custom-tailored to meet marketing, business and organizational needs, thereby benefiting both our partners and our mission of help and hope for the families we serve.

Partnerships

- ACOSTA Sales & Marketing
- Augie's Quest
- Burger King Corporation
- CITGO Petroleum Corporation
- ClubCorp
- DECA
- Dr Pepper Snapple Group/7UP
- ERA Real Estate
- Harley-Davidson Motor Company
- International Association of Fire Fighters
- Jiffy Lube International
- Kappa Alpha Order
- Lowe's Home Improvement
- National Association of Letter Carriers
- The National Beta Club
- 7-Eleven/National Coalition of Associations of 7-Eleven Franchisees
- Safeway Foundation
- Tall Cedars of Lebanon of North America

Community Events

- Aisles of Smiles
- Clubs for the Quest
- Fill the Boot
- Hop-a-Thon
- Lock-Up
- Make a Muscle, Make a Difference
 mobile campaign
- MDA Labor Day Telethon
- Motorcycle Rides
- Muscle Walk
- Shamrocks Against Dystrophy

Signature Events

- Black and Blue Ball
- Muscle Team
- Golf Classic



Strength in Partnership & Community

MDA Officers

(Board members serve one-year terms beginning July 13, 2012)

Chairman of the

Olin F. Morris

Memphis, Tenn.

Executive Committee

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

Board of Directors

(Board members serve one-year terms beginning July 13, 2012)

Stanley H. Appel, M.D. Houston, Texas

*Robert M. Bennett

Los Angeles, Calif.

Bart Conner Norman, Okla. Upper Marlboro, Md. **Steve Farella**

New York, N.Y.

Harold C. Crump

St. Paul, Minn.

Lois R. West Hilton Head Island, S.C.

Daniel G. Fries

New York, N.Y.

Edmond, Okla.

Vice Chairman of the

Executive Committee

Secretary **Timmi Masters** Beverly Hills, Calif. Treasurer Charles Schoor, Esg. Los Angeles, Calif.

Assistant Secretaries Gail Schmertz Kerner, Esq. New York, N.Y.

Assistant Treasurers Stephen Evans, CPA Jodi Walters Tucson, Ariz.

Judith Laurel Tucson, Ariz.

> *Lois R. West Hilton Head Island, S.C.

Joseph S. DiMartino New York, N.Y.

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

*The Honorable Brad Henry

Beverly Hills, Calif.

Memphis, Tenn. Christopher J. Rosa, Ph.D. New York, N.Y.

*Olin F. Morris

*Charles D. Schoor, Esg. Los Angeles, Calif.

Director Emeritus:

*Executive Committee Members

Translational Research Advisory Committee

(Members as of July 2012)

Stanley H. Appel, M.D. Methodist Neurological Institute Houston, Texas

Cristina Csimma, PharmD, M.H.P. Independent Consultant Lincoln, Mass.

Kenneth H. Fischbeck, M.D. National Institutes of Neurological Disorders and Stroke Bethesda, Md.

John E. Howell Prometheus Partners Holdings LLC Fairfax Station, Va.

John Kissel, M.D. The Ohio State University Columbus, Ohio

Louis M. Kunkel, Ph.D. Harvard University/Children's Hospital Boston, Mass.

Elizabeth McNally, M.D., Ph.D. University of Chicago Chicago, III.

John D. Porter, Ph.D. National Institutes of Neurological Disorders and Stroke Bethesda, Md.

Jefferv D. Rothstein, M.D., Ph.D. Johns Hopkins University Baltimore, Md.

University of Rochester Rochester, N.Y. Lee Wrubel, M.D.

Charles Thornton, M.D.

Foundation Medical Partners Norwalk, Conn.

Clinical Advisory Committee

(Members as of July 2012)

Jan Bonner Parent Fairfax, Va.

Tom Crawford, M.D. Johns Hopkins University Baltimore, Md.

Joline Dalton, CGC Gillette Children's Hospital University of Minnesota Minneapolis, Minn.

Kevin Felice, D.O. Hospital for Special Care New Britain, Conn.

Rich Finkel, M.D. Nemours Children's Hospital Orlando, Fla.

Ed Goldstein, M.D. Children's Healthcare of Atlanta Atlanta, Ga.

Daragh Heitzman, M.D Texas Neurology Dallas, Texas

Neil Holland, M.D. Monmouth Medical Center Long Branch, N.J.

Tomas Holmlund, M.D. Dent Neurological Institute Amherst, N.J.

Irwin Jacobs, M.D. MetroHealth Medical Center Cleveland, Ohio

Wendy King, PT The Ohio State University Columbus, Ohio

John Kissel, M.D. The Ohio State University Columbus, Ohio

Dennis Matthews, M.D. Children's Hospital of Denver Denver, Colo.

Julie Rowin, M.D. University of Illinois Chicago Chicago, III.

Barry Russman, M.D. Shriners Hospital, OHSU Portland, Ore.

Ericka Simpson, M.D. Methodist Neurological Institute Houston, Texas

Jonathan Strober, M.D. University of California, San Francisco San Francisco, Calif.

Dave Hutton Valencia, Calif.

Louis M. Kunkel, Ph.D. Boston, Mass

Timmi Masters

Benjamin F. Cumbo III

Medical Advisory Committee

(Members as of July 2012)

*Stanley H. Appel, M.D. Methodist Neurological Institute Houston, Texas

Robert Baloh, M.D., Ph.D. Cedars-Sinai Medical Center Los Angeles, Calif.

Elisabeth Barton, Ph.D. University of Pennsylvania Philadelphia, Pa.

**Alan Beggs, Ph.D. Children's Hospital Boston Boston, Mass.

Mark Bromberg, M.D., Ph.D. University of Utah Salt Lake City, Utah **Thomas Crawford, M.D.** Johns Hopkins University Baltimore, Md.

Merit Cudkowicz, M.D., M.Sc. Massachusetts General Hospital Boston, Mass.

Heather Durham, Ph.D. Montreal Neurological Institute Montreal, Quebec, Canada

Richard Finkel, M.D. Nemours Children's Hospital Orlando, Fla.

Michio Hirano, M.D. Columbia University Medical Center New York, N.Y. James F. Howard, M.D. University of North Carolina Chapel Hill, N.C.

Joe Kornegay, D.V.M., Ph.D. Texas A&M University College Station, Texas

Se-Jin Lee, M.D., Ph.D. Johns Hopkins University Baltimore, Md.

Jun Li, M.D., Ph.D. Vanderbilt University Nashville, Tenn.

Katherine Mathews, M.D. University of Iowa Iowa City, Iowa Kanneboyina Nagaraju, D.V.M., Ph.D. Children's National Medical Center Washington, D.C.

Sally Nelson, Ph.D. University of Colorado Denver, Colo.

M. Kerry O'Banion, M.D., Ph.D. University of Rochester Rochester, N.Y.

Michael Shy, M.D. University of Iowa Iowa City, Iowa

Charles Thornton, M.D. University of Rochester Rochester, N.Y. Ex officio member R. Rodney Howell, M.D. University of Miami Miami, Fla.

> *Chairman **New member effective January 1, 2013

Ex officio member R. Rodney Howell, M.D. University of Miami Miami, Fla.

> *Chairman **New member effective January 1, 2013

Scientific Advisory Committee

(Members as of July 2012)

*Louis M. Kunkel, Ph.D. Children's Hospital Boston Boston, Mass.

John Adelman, Ph.D. Oregon Health Sciences University Portland, Ore.

Kurt G. Beam, Ph.D University of Colorado Denver, Colo.

Carmen Bertoni, Ph.D. University of California, Los Angeles Los Angeles, Calif.

Jeffrey S. Chamberlain, Ph.D. University of Washington Seattle, Wash.

Dongsheng Duan, Ph.D. University of Missouri Columbia, Mo. **Emanuela Gussoni, Ph.D.** Children's Hospital Boston Boston, Mass.

Kenneth Hensley, Ph.D. University of Toledo Toledo, Ohio

Bernard Jasmin, Ph.D. University of Ottawa Ottawa, Ontario, Canada

Michael King, Ph.D. Thomas Jefferson University Philadelphia, Pa.

Rashmi Kothary, Ph.D. Ottawa Health Research Institute Ottawa, Ontario, Canada

Christian Lorson, Ph.D. University of Missouri Columbia, Mo. **Giovanni Manfredi, M.D., Ph.D.** Weill Cornell Medical College New York, N.Y.

Elizabeth McNally, M.D., Ph.D. University of Chicago Chicago, III.

Lynn Megeney, Ph.D. Ottawa Health Research Institute Ottawa, Ontario, Canada

Jeffrey Milbrandt, M.D, Ph.D. Washington University St. Louis, Mo.

Carlos Moraes, Ph.D. University of Miami Miami, Fla.

Bradley Olwin, Ph.D. University of Colorado Boulder, Colo. Robin Parks, Ph.D. Ottawa Health Research Institute Ottawa, Ontario, Canada

Grace Pavlath, Ph.D. Emory University Atlanta, Ga.

John Ravits, M.D. University of California, San Diego San Diego, Calif.

****Shanthini Sockanathan, Ph.D.** Johns Hopkins University Baltimore. Md.

Melissa Spencer, Ph.D. University of California, Los Angeles Los Angeles, Calif.

Maurice Swanson, Ph.D. University of Florida Gainesville, Fla.

National Vice Presidents

(VPs serve one-year terms beginning July 13, 2012)

Arizona

Todd Bresnahan Phoenix, Ariz.

Julie Brinks Tucson, Ariz.

Ginny Clements Tucson, Ariz.

Jay Feely Queen Creek, Ariz.

Derrick M. Hall Phoenix, Ariz.

Dana Moeller Phoenix, Ariz.

California

Max Adler Beverly Hills, Calif.

Brandon Barash Los Angeles, Calif.

Alexander Cappello Santa Monica, Calif.

Jann Carl Pasadena, Calif.

Norm Crosby Los Angeles, Calif.

Frank DiBella, C.P.A Whittier, Calif.

Robert J. Donato Los Angeles, Calif.

W. King Engel, M.D. Los Angeles, Calif.

Lou Ferrigno Santa Monica, Calif.

Marc L. Foster Newport Beach, Calif.

Evan Lamberg Santa Monica, Calif.

Jeffrey S. Moorad San Diego, Calif.

S. Paul Musco Santa Ana, Calif.

Augie Nieto Corona del Mar, Calif.

Nancy O'Dell Pasadena, Calif.

Charo Rasten Beverly Hills, Calif.

Larree Renda Pleasanton, Calif.

Petra Robinson San Marcos, Calif.

Bert Selva Walnut, Calif. **Alison Sweeney** Los Angeles, Calif.

Tom Thomas Rancho Dominguez, Calif.

Ace Young Sherman Oaks, Calif.

Colorado

Jake Jabs Englewood, Colo.

Connecticut

Kara Fox-LaRose Uncasville, Conn.

Richard Graziano Hartford, Conn.

Lynn Malerba Uncasville, Conn.

District of Columbia

Thomas R. Donahue Washington, D.C.

Fredric V. Rolando Washington, D.C.

Harold A. Schaitberger Washington, D.C. Florida

Gary R. Chartrand Jacksonville, Fla.

Mario Kreutzberger Miami, Fla.

Ted Morse Delray Beach, Fla.

Georgia

Bruce Lucia Atlanta, Ga.

Illinois

Chris Clawson Schiller Park, III.

Christopher Ondrula Downers Grove, III.

Mike Sheehan Chicago, III.

Indiana

James F. Ackerman Indianapolis, Ind.

lowa

Fred Greiner Boone, Iowa Robert J. Myers Ankeny, Iowa

Kansas

Richard L. Seithel Overland Park, Kan.

Louisiana

Michael A. Barras Lafayette, La.

Tom Odisho Charenton, La.

Maryland

Lon Rosenberg Landover, Md.

Massachusetts

Robert A. Sigel Mashpee, Mass.

Jennifer Smith Stepanek, Ph.D. Rockville, Md.

Michigan

John A. Krol Troy, Mich. Minnesota

Mark Moeller St. Paul, Minn.

Missouri

Lynn Beall St. Louis, Mo.

Don Breckenridge Jr. St. Louis, Mo.

Gary Drewing Columbia, MO

Tom Henry St. Louis, Mo.

Nevada

James P. Prather Las Vegas, Nev.

New Jersey

anek, Ph.D. John F. Crowley Cranbury, N.J.

> **Patricia Laus** Manasquan, N.J.

Antrel Rolle North Bergen, N.J.

Chris Snee Franklin Lakes, N.J. **Carol Stillwell** Edison, N.J.

Phil Villapiano Rumson, N.J.

Steve Weatherford East Rutherford, N.J.

New Mexico

William S. Anderson Albuquerque, N.M.

New York

Robin Arnold White Plains, N.Y.

Candace K. Beinecke New York, N.Y.

Anthony Cammarata Jr. New York, N.Y.

Vincent DeLazzero Bronx, N.Y.

Charles Fazzino New Rochelle, N.Y.

Stephen J. Furnary New York, N.Y.

Tom & Lel Gimbel Glen Cove, N.Y.

Neil Golub Schenectady, N.Y. Jack Haire New York, N.Y.

James Halpin New York, N.Y.

Kenneth W. Heath New York, N.Y.

Scott Masterson New York, N.Y.

Raymond Mays New York, N.Y.

John McGinley New York, N.Y.

Hiroshi Mitsumoto, M.D. New York, N.Y.

Natalie Morales New York, N.Y.

Ted Moudis, AIA New York, N.Y.

Michael Neary New York, N.Y.

Lewis P. Rowland, M.D. New York, N.Y.

Raymond M. Tierney III New York, N.Y.

Lisa Marie Utasi New York, N.Y. North Carolina

John Clark Clinton, N.C.

Randy Kibler Charlotte, N.C.

Tom Robinson Salisbury, N.C

Kevin Urban Jonesville, N.C.

Ohio

Tony Cammerata Berea, Ohio

Ron Hemelgarn Toledo, Ohio

John Quinlan, M.D. Cincinnati, Ohio

Oklahoma

Susannah Adelson Tulsa, Okla.

James M. Brown Oklahoma City, Okla.

Nadia Comaneci Norman, Okla.

Oregon

Mike Bellotti Eugene, Ore. Pennsylvania

Ty Ballou Pittsburgh, Pa.

DeLight Breidegam Jr. Lyon Station, Pa.

Dave Carroll Temple, Pa.

Peter N. Dectis Allentown, Pa.

Michael Dunleavy Pittsburgh, Pa.

Joseph J. Gentile Jr. Dunmore, Pa.

Daniel F. Hilferty Broomall, Pa.

Harvey Willard Jr. Harrisburg, Pa.

Ed Williams Fairless Hills, Pa.

Puerto Rico

Alan Cohen San Juan, Puerto Rico

Juan Antonio Larrea San Juan, Puerto Rico

Aniceto Solares San Juan, Puerto Rico

Tennessee

Linda Davis Hermitage, Tenn.

Pete Fisher Nashville, Tenn.

Wynonna Judd Nashville, Tenn.

Bill Mayne Nashville, Tenn.

Texas

Eric L. Affeldt Dallas, Texas

Bill Breetz Shenandoah, Texas

Stuart Crum Houston, Texas

Wayne Denningham Fort Worth, Texas

Thomas Ehlmann Fort Worth, Texas

William H. Emmons Fort Worth, Texas

Rusty Hardin Houston, Texas

Timothy A. Hawk Conroe, Texas **Daryl Johnston** Dallas, Texas

Bill Klesse San Antonio, Texas

Eric Lassberg Austin, Texas

Jerry Reynolds Carrolton, Texas

Mike J. Rowlett Farmers Branch, Texas

John Seabers San Antonio, Texas

Mark D. Smith Houston, Texas

Virginia

Edward Davis, Ed.D. Reston, Va.

Wisconsin

Gordie Boucher Greenfield, Wisc.

Statement of Financial Position

December 31, 2011

Assets

Cash and cash equivalents	\$ 12,168,782
Contributions receivable, net of allowance for	3,255,370
doubtful accounts of \$50,000	
Prepaid expenses and other assets	2,243,603
Investments	64,537,346
Fixed assets, net	16,102,772
Total assets	\$ 98,307,873

Liabilities and net assets

Liabilities:

Accounts payable and accrued expenses	\$ 10,067,863
Research awards, grants and fellowships payable	24,878,925
Pension and post-retirement plan obligations	50,003,889
Total liabilities	84,950,677

Net assets:

Unrestricted:	
Available for program and support services	(8,450,081)
Net investment in fixed assets	16,102,772
Temporary restricted	5,374,272
Permanently restricted	330,233
Total net assets	13,357,196
Total liabilities and net assets	\$ 98,307,873

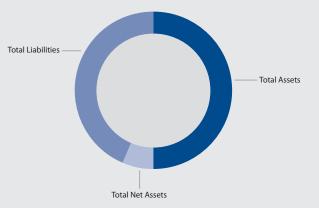
Statement of Activities

Revenue	
Year Ended December 31, 2011	
Public support:	
Received directly:	
Special events, including Telethon	\$ 153,111,017
Less fundraising direct benefit costs	(25,448,211)
Special events, net	127,662,806
Contributions	21,579,068
Bequests and legacies	6,209,417
Total received directly	155,451,291
Received indirectly: Combined Federal	
Campaign and Combined Health Appeals	778,888
Total revenue from the public	156,230,179
Total investment (loss) income and other revenue	(551,605)
Total unrestricted revenue	155,678,574
Net assets released from restrictions	3,322,818
Total unrestricted revenues and support	\$ 159,001,392

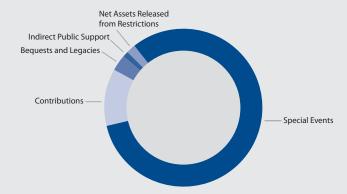


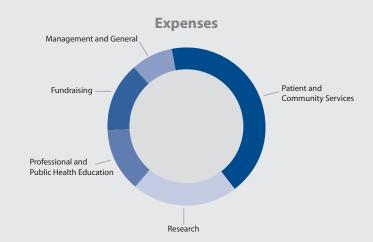
MDA spent more than 77 cents of every dollar on patient and community services, research, and professional and public health education in 2011.

Financial Position









Expenses

Year Ended December 31, 2011

Program services:

Patient and community services, net of third-party	
reimbursements of \$270,617	\$ 74,563,817
Research	38,126,006
Professional and public health education	22,909,284
Total program services	135,599,107
Supporting services:	
Fundraising	24,632,642
Management and general	15,362,456
Total supporting services	39,995,098
Total expenses	175,594,205
Decrease in unrestricted net assets from operations	(16,592,813)
Changes in unrecognized benefit plan costs	(35,428,896)
Decrease in unrestricted net assets	(52,021,709)
Changes in Temporarily Restricted Net Assests	
Contributions	1,379,628
Net assests released from restrictions	(3,322,818)
Decrease in temporarily restricted net assets	(1,943,190)
Changes in Permanently Restricted Net Assests	
Contributions	50,000
Investment income	452
Increase in permanently restricted net assets	50,452
Decrease in net assets	(53,914,447)
Net assets, beginning of year	67,271,643
Net assets, end of year	\$ 13,357,196

MDA is the nonprofit health agency dedicated to finding treatments and cures for muscular dystrophy, ALS and related diseases by funding worldwide research. The Association also provides comprehensive health care and support services, advocacy and education.