

# Quest

EMPOWERING FAMILIES WITH INFORMATION AND INSPIRATION

MDA.ORG/QUEST  
WINTER 2016

MDA<sup>®</sup>

For Strength,  
Independence & Life

## LEADING BY EXAMPLE

A business  
leader makes  
it cool to  
give back

## ACCESSIBLE FASHION

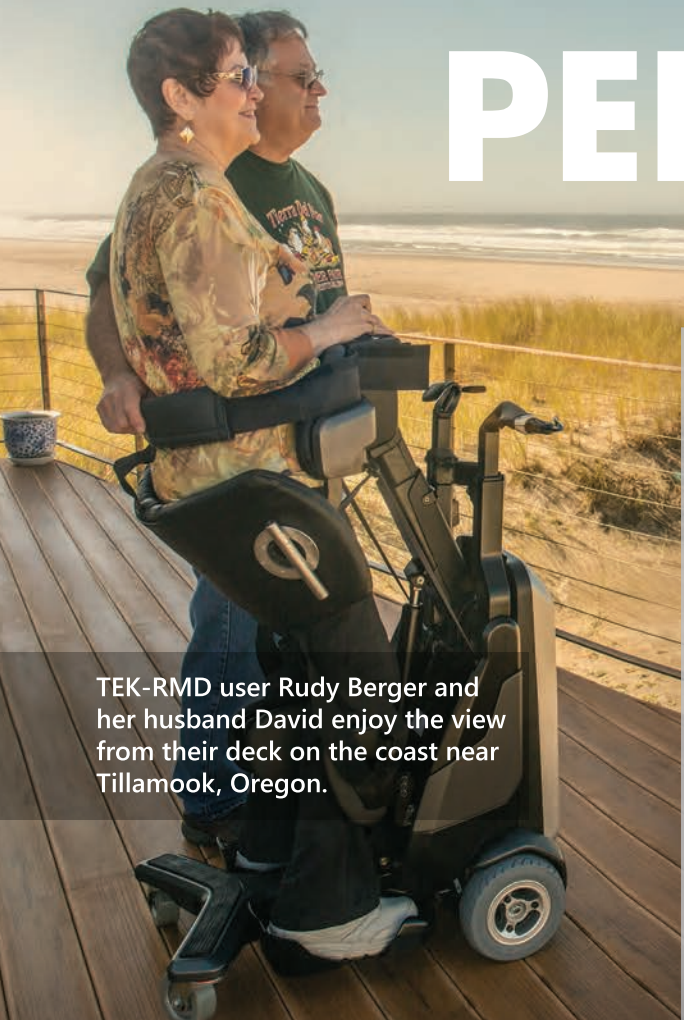
Style trends  
that don't  
compromise  
mobility

*Living*  
unlimited

MDA introduces  
new branding  
inspired by  
families



# PACIFIC PERSPECTIVE



TEK-RMD user Rudy Berger and her husband David enjoy the view from their deck on the coast near Tillamook, Oregon.

## THE NEW TEK-RMD VERTICAL MOBILITY DEVICE

Never before has a single device offered the enabling combination of better health, upright mobility, greater accessibility, and improved perspective now available with the TEK-RMD vertical mobility device from Innovations Health. With its tiny footprint, intuitive controls, and rear-entry feature, the TEK-RMD gives you back the freedom to use your home as it was meant to be used; upright and mobile.

Designed for individuals who present as paraplegics, the TEK requires hand and arm dexterity and strength in order to mount and unmount without assistance. Individuals who cannot use the TEK unassisted may still be able to realize the many benefits available of being vertically mobile. Learn more and experience for yourself the entire family of life-changing mobility and accessibility products only available from Innovations Health at [www.InnovationsHealth.com](http://www.InnovationsHealth.com).

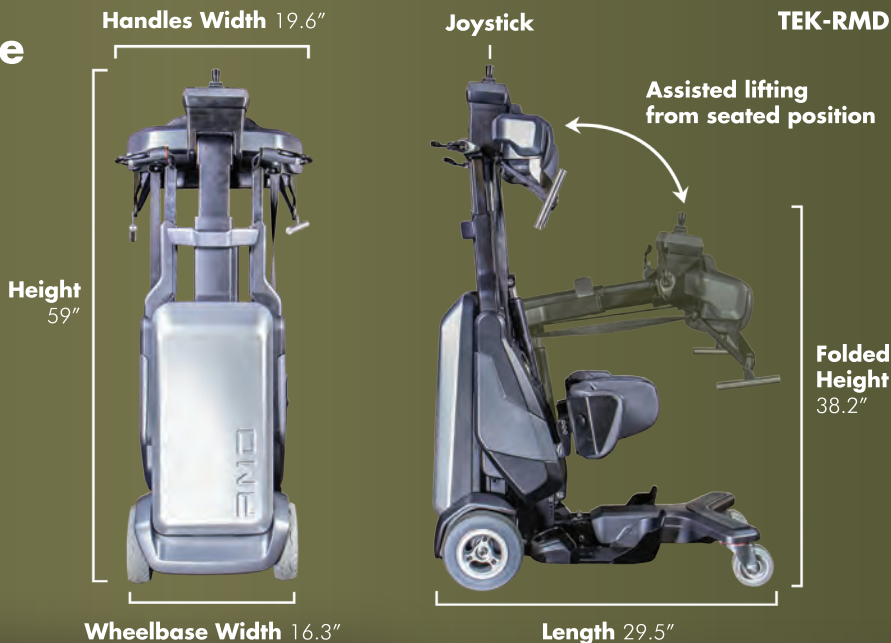
### Recommended User Profile

Indications for Use – Present as paraplegic. Hand & arm strength required for self-mounting; joystick control for self-driving. Other conditions as prescribed by physician.

**Height** – 4'8" to 6'3"  
**Weight** – 85 to 255 lbs

### Technical Data

**Max Speed** 3 MPH  
**Battery Capacity** DC 24V (2x12V) 22Ah  
**Turning Radius** 23.6"  
**Weight (empty)** 242.5 lbs  
**Charger** 24V 5A  
**Range** 3.7 Miles



(800) 659-4548  
[www.InnovationsHealth.com](http://www.InnovationsHealth.com)



MDA is leading the fight to free individuals – and the families who love them – from the harm of muscular dystrophy, ALS and related muscle-debilitating diseases that take away physical strength, independence and life. We use our collective strength to help kids and adults live longer and grow stronger by finding research breakthroughs across diseases; caring for individuals from day one; and empowering families with services and support in hometowns across America.

Learn how you can fund cures, find care and champion the cause at [mda.org](http://mda.org).

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## New Year, Renewed Priorities

**A**t MDA, we begin 2016 with families at the heart of our mission, literally with a heart representing them in our refreshed logo design. As we continue to fight with and for individuals with neuromuscular diseases — and the families who love them — we are excited






to introduce new offerings and enhancements to help the kids and adults we serve live longer and grow stronger. This year, you will see a number of new and

improved services to help provide better care and accelerate progress for our families:

- This spring, we will introduce our first national MDA Family Resource Center that individuals can call to obtain one-on-one information and support from MDA specialists. From providing disease-specific information to assistance with finding local resources, we will be here to guide families through every step of their journey.
- We will add to the more than \$1 billion we've invested to date in research aimed at accelerating therapy development.
- We will implement enhanced standards of care at all MDA Care Centers (formerly MDA Clinics) because early diagnosis, highly specialized care and access to promising clinical trials help ensure the best possible outcomes for families.
- We are evaluating our offerings for teens and young adults, and plan to improve and expand support for individuals transitioning into adulthood and living independently.
- After surveying thousands of families, supporters and Americans, we have launched a revitalized MDA brand reflective of the needs and desires you have told us you want and expect from MDA. In addition to a new look and feel, you'll notice *Quest* has a fresher, more modern design with updated colors and imagery.
- This summer, we will launch a campaign called Live Unlimited to unite consumers, companies and everyday Americans.

While focused on finding urgent solutions today, we also have a long-term plan to fuel future discovery and impact. With a new strategic plan in place, we intend to achieve the following goals for our families by 2020:

- 1. CURE:** Double our research spend on drug development and clinical trials to bring more treatments and cures to families. 
- 2. CARE:** Provide care and support for 50,000 more families — a 50 percent increase over the number of families registered with MDA today. 
- 3. CHAMPION:** Fund 20,000 kids at MDA Summer Camp at no cost to families as we expand our offerings for young adults. 

Our families inspire us every day as they break down barriers with a remarkable can-do spirit — whether it's crossing the street in a wheelchair, graduating from college or even skydiving. The courage our families show in defying limits is the inspiration behind MDA's revitalized brand.

I'm also proud to announce that Joe Akmakjian, a 24-year-old marketing specialist in Fort Collins, Colo., and MDA volunteer extraordinaire, will serve as MDA's National Goodwill Ambassador and family spokesman for 2016. This is the first time in our history a young adult is in this role, marking a new era in our work and signifying the progress we are making together. Be sure to read more about the new brand and take a moment to meet Joe in "The Heart of Our Mission" on page 20.

Thank you for your passion and partnership as we work together for strength, independence and life, as it says in our new tagline. We invite you to visit the new-and-improved MDA website and join our collective movement today at [mda.org](http://mda.org).

Steven M. Derks  
President and CEO  
Muscular Dystrophy Association

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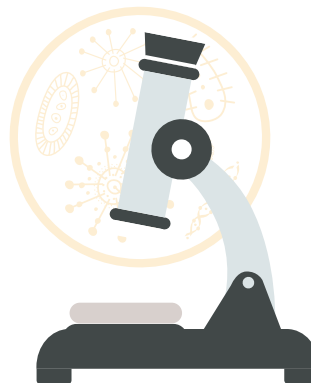
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Looking for a volunteer opportunity with MDA? Find out more here.

## MORE ONLINE

### MAKING LIFE WORK FOR YOU

Writer Dan Matelske, who lives with LGMD2i, shares the four lessons he follows to inspire himself to strive for greatness and not succumb to excuses.

Visit [mda.org/quest](http://mda.org/quest) for this and other stories.

### A STRONG BLOG

MDA has launched Strongly, a new blog that brings together the stories, voices and spirit of MDA and the families we serve.

Check it out today at [strongly.mda.org](http://strongly.mda.org).

COVER PHOTO BY TIM O'HARA



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## Focused on Families

Families are at the heart of MDA's mission to help kids and adults live longer and grow stronger. Here is a snapshot of how MDA supported our families in hometowns across America during 2015.

### CURE

**200** Number of current research projects funded by MDA

**103** Number of research grants awarded in 2015, with a total commitment of more than \$27.3 million

**\$300,000** Typical amount for an MDA research grant

**\$75,000** Amount MDA invests in research every business day

### CARE

**150+**  
Number of MDA Care Centers across the U.S. and Puerto Rico

**43**  
Number of MDA ALS Care Centers

Nearly **50,000** visits to MDA Care Centers in 2015

**100,000+** Individuals assisted by MDA annually

### CHAMPION

**3,800+** Kids who had the best week of the year at MDA Summer Camp in 2015

**140+** MDA support groups provided in hometowns across America

**9,500+** Number of local MDA events

**350,000** Number of volunteers for MDA events annually

### Let's go!

To learn more about all MDA is doing to support families nationwide – and how you can get involved – visit the new-and-improved MDA website at [mda.org](http://mda.org).

Every month, about **300,000** unique visitors come to [mda.org](http://mda.org) to find the information and resources they need – that's about **3.6 million** people a year.

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# progress now

Tracking research updates and breakthroughs that help accelerate treatments and cures across MDA diseases

## Amyotrophic lateral sclerosis (ALS)

### New Enrollment Halted in DPS

UK trials raise questions about potential harm to ALS patients who receive diaphragm pacing

In September, the Data Safety and Monitoring Board (DSMB) that oversees the Diaphragm Pacing System in Participants with Amyotrophic Lateral Sclerosis (DPS in ALS) study being conducted in the United States issued a recommendation that new enrollment be halted. At the same time, the DSMB recommended that **ALS** patients already randomized to the diaphragm pacing arm



continue to be actively stimulated and followed according to the protocol.

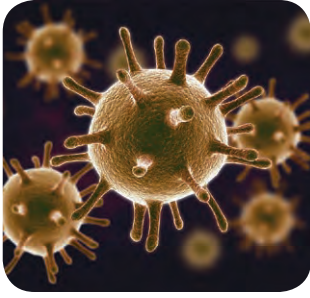
These recommendations were offered after consideration of published data from a randomized pacing trial in Great Britain, as well as press reports regarding a French study utilizing much different inclusion criteria than the U.S. study. Data from both of the studies conducted outside the U.S. suggested potential harm to patients who receive diaphragm pacing. The DSMB also reviewed data from a third open-label

study in the U.S. that found much longer survival in paced patients than was observed in the British study. In addition, data from the current U.S. study were analyzed. While results from this study are still preliminary, the investigators have not seen evidence of the risk to patients that was found in the other trials.



Read the full statement at [mda.org/media/press-releases](http://mda.org/media/press-releases).





## HERV-K in ALS

**An ancient virus may be reactivated in some people, causing ALS**

A new study suggests that reactivation of an ancient virus called human endogenous retrovirus K (HERV-K) may play a potential role in some cases of ALS. HERV-K has incorporated itself into the genome of all humans. Although the virus normally is dormant, previous studies have suggested that HERV-K may become activated in some people, where it may contribute to the development of sporadic ALS, the most common form of the disease and one for which the cause is unknown.

In the new study, investigators detected the virus in postmortem samples of brain tissue taken from ALS patients. Exposure to the virus caused the death of nerve cells in a dish and also induced a neurodegenerative disease in mice. The findings suggest antiviral drugs to inhibit activation of the virus may serve as a potential therapy for ALS.

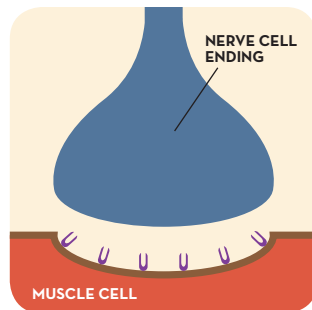


Read more about a potential connection between HERV-K and ALS at [mda.org](http://mda.org).

## Congenital myasthenic syndrome (CMS)

# Trial Seeks Participants

**Amifampridine phosphate may reduce muscle weakness in people with CMS**



*Amifampridine phosphate, a potassium channel inhibitor, prolongs nerve signals between nerve and muscle cells, allowing for greater stimulation of the muscle.*

Researchers are looking for children with **congenital myasthenic syndrome (CMS)**, ages 2-17, to participate in a phase 3 study being conducted by Catalyst Pharmaceuticals to test the experimental drug amifampridine phosphate (Firdapse), which is expected to help treat muscle weakness in CMS.

The goals of the study are to determine the safety and tolerability of amifampridine phosphate in children with CMS and to assess clinical efficacy. Study participants will receive treatment two to four times per day and be assessed for improvement while taking amifampridine phosphate. After study completion, participants will be eligible for an expanded access program in which they will be able to continue to receive the drug. Participants may be male or female, ages 2-17 and meet additional eligibility criteria. Those whose CMS has not been genetically confirmed will have genetic testing done at screening.

There are a limited number of study sites in the U.S., but travel costs may be provided for those who are eligible and willing to travel. MDA has supported previous studies to test amifampridine phosphate in children with CMS.



For additional information on this trial, search for “NCT02562066” at [ClinicalTrials.gov](http://ClinicalTrials.gov). Participants may be male or female and must meet additional eligibility criteria. If you or someone you know may be interested in participating in the study, please contact Steven Bramer, Ph.D., at [FirstStopCBPD@comcast.net](mailto:FirstStopCBPD@comcast.net) or (301) 473-3109.

Duchenne muscular dystrophy (DMD)

# Drisapersen Review

**FDA issues response to BioMarin’s exon-skipping treatment for DMD**

BioMarin reported Jan. 14 that it had received a Complete Response Letter from the U.S. Food and Drug Administration (FDA) indicating that the review cycle for the company’s New Drug Application for drisapersen (Kyndrisa) to treat **Duchenne muscular dystrophy (DMD)** is complete and that the application is not ready for approval in its present form as the standard of substantial evidence of effectiveness has not been met.

Drisapersen is an “exon-skipping” drug that targets a section of the dystrophin gene called exon 51, and may help up to 13 percent of DMD patients. Exon skipping is a treatment strategy in which sections of genetic code are “skipped,” allowing the creation of partially functional dystrophin, the muscle protein missing in DMD.

BioMarin is reviewing the Complete Response Letter and will work with the FDA to determine the appropriate next steps regarding this



application while the marketing authorization application remains under regulatory review in Europe. The company said that extension studies for drisapersen will continue, as will ongoing studies for other exon-skipping therapies targeting exons 44, 45 and 53, while it explores next steps for this application.

MDA has funded groundbreaking DMD research for over 60 years, including laboratory development of exon skipping since the 1990s.

**BREAKING NEWS ALERT**

Developments pertaining to the regulatory review status of drisapersen and eteplirsen are unfolding rapidly. Be sure to check back at [mda.org](http://mda.org) for the most up-to-date information.

 For more about BioMarin’s development of drisapersen to treat DMD, visit [BMRN.com](http://BMRN.com).

# New Data on Eteplirsen

**Sarepta reports favorable long-term clinical efficacy and safety for exon-skipping drug**

Sarepta Therapeutics in October reported additional long-term clinical efficacy and safety data from its pivotal phase 2b program of its exon-skipping drug eteplirsen to treat DMD.

The data demonstrated that over a three-year period of time, trial participants who were treated with eteplirsen experienced a slower rate of decline and were, on average, able to walk farther than what has been reported in similar patients who have not received treatment.



*In addition:*

- Pulmonary function remained relatively stable through approximately four years in eteplirsen-treated patients.
- Biopsy data confirmed the mechanism of action of eteplirsen, demonstrating exon skipping in all patients and dystrophin protein production in nearly all patients.
- Safety data remained consistent with prior results.

*Eteplirsen targets a section of the dystrophin gene called exon 51, and may help up to 13 percent of people with DMD.*

MDA supported the early development of eteplirsen via funding to Steve Wilton at the University of Western Australia in Perth and contributed funding toward a phase 2 clinical trial.

Results from Sarepta’s phase 2b program were included in a New Drug Application (NDA) for eteplirsen to treat DMD. Sarepta hopes to have an FDA decision on approval for eteplirsen in early 2016.

 For more about Sarepta’s development of eteplirsen to treat DMD, visit [sarepta.com](http://sarepta.com).

# Ataluren Trial Update

**Phase 3 trial results showed ataluren appeared to benefit some DMD patients**

PTC Therapeutics in October announced results from the phase 3 "ACT DMD" trial of ataluren, a protein restoration therapy for the treatment of DMD caused by a nonsense mutation.

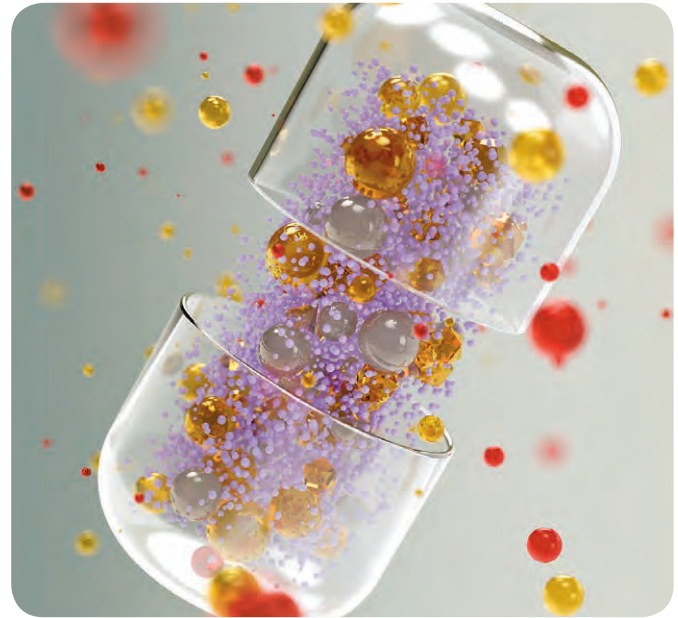
The trial results indicated the drug may slow functional decline in DMD patients, with some patients apparently responding more robustly to treatment than others.

Ataluren acts by changing the way muscle cells interpret genetic information, coaxing them to produce the muscle protein dystrophin despite the

presence of a mutation in the dystrophin gene. The drug, which is taken by mouth, targets a particular type of genetic mutation known as a "nonsense mutation" or "premature stop codon," which is present in about 13 percent of DMD patients. This type of mutation results in the making of a protein that is not complete and is therefore not functional.

MDA has contributed nearly \$3 million toward ataluren's development and phase 2 clinical testing.

Ataluren received "conditional approval" in the



European Union in August 2014 for use in people with DMD caused by a nonsense mutation who are at least 5 years old and able to walk.



**Read more about MDA grants, including those in support of ataluren, at [mda.org/gaag](http://mda.org/gaag).**

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**Duchenne muscular dystrophy (DMD)**

# Muscle Stem Cell Defects

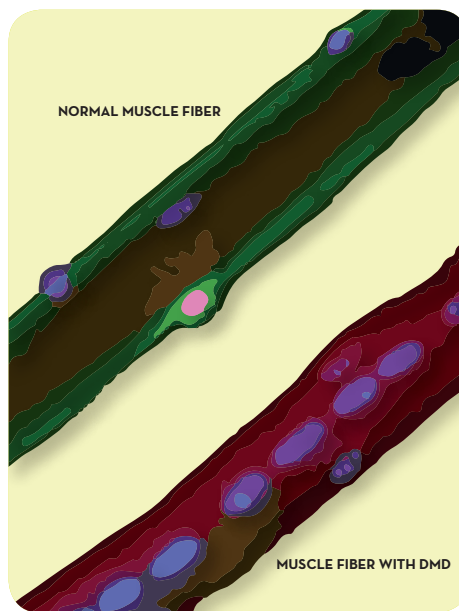
## Study shows links to weakness caused by DMD

Results from an MDA-supported study have demonstrated for the first time that DMD directly affects muscle stem cells.

“For nearly 20 years, we’ve thought that the muscle weakness observed in patients with Duchenne muscular dystrophy is primarily due to problems in their muscle fibers, but our research shows that it is also due to intrinsic defects in the function of their muscle stem cells,” says senior author of the study Michael Rudnicki, Ph.D., director of the Regenerative Medicine Program at The Ottawa Hospital and a professor at the University of Ottawa.

Rudnicki and colleagues showed that muscle stem cells express the dystrophin protein, and without this protein, they produce 10-fold fewer muscle precursor cells, which in turn generate fewer functional muscle fibers. They also discovered that dystrophin is a key member of the molecular machinery that enables muscle stem cells to sense their orientation in the surrounding tissue.

The new finding suggests that therapeutic strategies that aim to restore dystrophin in DMD will need to target muscle stem cells as well as muscle fibers.



A normal mouse muscle fiber (top left) is contrasted with a muscle fiber from a mouse model of DMD (bottom right). In normal mice, stem cells (● pink) express dystrophin (● green) and are able to easily generate new muscle fibers, but in the disease model, there is no dystrophin and the stem cells lose their sense of direction and have trouble generating new muscle fibers.

 Read more about Dr. Rudnicki’s MDA-supported research at [mda.org/research/gaag/dmdbmd-rudnicki](http://mda.org/research/gaag/dmdbmd-rudnicki).

**Friedreich’s ataxia (FA)**



# MDA Partners with FARA

## Partnership focused on improving FA research and collaboration

MDA and the Friedreich’s Ataxia Research Alliance (FARA) in September announced a partnership that will pave the way for advancements in **Friedreich’s ataxia (FA)** research, therapeutic development and clinical care, thus deepening understanding of the disease for patients and medical professionals.

The two organizations will work together to enhance the quality, quantity and scope of FA research; bolster the scientific review process; and increase collaboration among investigators. In launching the partnership, MDA and FARA plan to co-fund research and training grants, collaborate on infrastructure initiatives, coordinate regarding advocacy efforts and work together on active communications for FA families.

The partnership demonstrates a major step in MDA’s commitment to forming strategic alliances with both for-profit and nonprofit organizations.

 To view an up-to-date listing of ongoing clinical trials for FA, visit [curefa.org/patient-registry](http://curefa.org/patient-registry).

# Three FA Trials Enrolling Now

Researchers seek participants in studies to test three potential treatments

## A First in Human Study of RTO01 in Patients with FA

Retrotope Inc. seeks volunteers, ages 18-50, to participate in a phase 1-2 clinical trial to test the safety and tolerability of the investigational drug RTO01 in people with Friedreich's ataxia (FA).

In FA, free iron associated with the disease contributes to degradation of lipids in mitochondrial and cellular membranes. A chemically stabilized form of a natural membrane fatty acid that is resistant to lipid peroxidation, RTO01 is designed to shut

down and stabilize cellular membranes against attack.

Participants will be required to follow a diet low in polyunsaturated fatty acids during the study, and will need to keep track of everything they eat each day using an online or paper food diary.

Trial sites are located at the University of South Florida in Tampa and the Collaborative Neuroscience Network in Long Beach, Calif.

>> continues to next page



To learn more about this trial, search for "NCT02445794" at [ClinicalTrials.gov](https://clinicaltrials.gov).

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## Friedreich's ataxia (FA)

### 2 Safety, Tolerability and Efficacy of ACTIMMUNE Dose Escalation in FA (STEADFAST)


Researchers are recruiting children and young adults with FA, ages 10–25 years, for a phase 3 clinical trial called STEADFAST to study the safety, efficacy and pharmacokinetics (how the drug is absorbed, distributed and metabolized in the body)

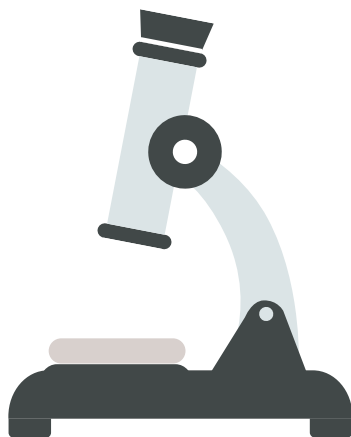
of interferon gamma-1b (brand name ACTIMMUNE) in FA.

Interferon gamma-1b is an engineered version of a protein that is similar to the interferon gamma protein naturally produced by the body, which plays multiple

roles in the immune response, including the availability of iron. It may provide benefit in FA by stimulating increased production of the frataxin protein.

The study, funded by Horizon Pharma Ireland Ltd., will include approximately 90 participants at four sites in the United States: Children's Hospital of Philadelphia (CHOP), University of Iowa Children's Hospital in Iowa City, University of Florida in Gainesville and UCLA (Calif.).

 **For more information about this trial, including inclusion and exclusion criteria, search "NCT02415127" at [ClinicalTrials.gov](http://ClinicalTrials.gov).**




### 3 RTA 408 Capsules in Patients with FA (MOXie)

Recruitment is open for a phase 2 clinical trial to test the experimental therapy RTA 408 in people, ages 16–40 years, with FA.

RTA 408, developed by Reata Pharmaceuticals, is designed to target the activation of the transcriptional factor Nrf2. Increasing Nrf2 could improve mitochondrial function by reducing oxidative stress.

The study is estimated to include 56 participants at six sites in the U.S.: UCLA (Calif.); University of Florida in Gainesville; USF Ataxia Research Center in Tampa, Fla.; Emory University Hospital in Atlanta; Ohio State University in Columbus; and Children's Hospital of Philadelphia.

Participation in the study may last five months, including 12 weeks of treatment.

 **For more information about this trial, including inclusion and exclusion criteria, search "NCT02255435" at [ClinicalTrials.gov](http://ClinicalTrials.gov).**



## FARA Patient Registry

**Database connects patients, keeps them up to date on trials and other opportunities**

As MDA and FARA work together to speed FA research, new therapies for FA are being tested in clinical trials, providing encouraging results and giving real hope for people living with the disease today. One way to stay up-to-date on the progress of these trials and be informed about opportunities to participate is to enroll in the FARA Patient Registry online.

Designed to serve the patient, physician and research communities, the FARA Patient Registry helps medical professionals and researchers reach people with FA and recruit those who would like to participate in clinical trials and studies. The only worldwide registry of FA patients, it currently contains demographic and clinical information for more than 2,400 people across the United States and internationally, which is estimated to comprise about 30 percent of U.S. patients and 15 percent of patients with FA worldwide.

### How does it help?

As with other patient registries, the FARA Patient Registry:

- enhances patient recruitment through targeted recruitment notices to patients who best match the key inclusion/exclusion criteria for clinical research studies and trials;
- informs pre-study planning with information on the size



of the FA patient population based on demographic features (e.g., age or geographic area) or clinical features (e.g., ambulation status); and

- provides the opportunity for clinicians and researchers to communicate with the patient community over time, while maintaining patient confidentiality.

**How does it work?**

When a clinical trial for FA opens, the registry may be used to identify individuals who might meet the enrollment criteria and email them directly, so that they are the first to be notified about the opportunity to participate.

Registration is simple and takes approximately 15 minutes to complete online. To complete the process, it's recommended that registrants have a copy of their genetic test results in order to be able to enter information about confirmation of diagnosis. Those who have registered in the past are encouraged to log in at least once a year to keep all information updated.

 **Enroll in the FARA Patient Registry at [curefa.org/patient-registry](http://curefa.org/patient-registry).**

# LIFT YOUR LIFE TOWARD INDEPENDENCE



Endorsed by Rob Roozeboom (above), member of MDA's National Task Force on Public Awareness

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## Myasthenia gravis (MG)

# Rituximab Trial Recruiting

### Drug may reduce the use of steroids to treat MG

Recruitment remains open for a phase 2 clinical trial to test the drug rituximab (Rituxan) in adults, ages 21-90 years old, with **myasthenia gravis (MG)** at 26 trial sites across the U.S.

Rituximab suppresses a specific part of the body's immune system and is approved by the U.S. Food and Drug Administration (FDA) to treat rheumatoid arthritis and other disorders.

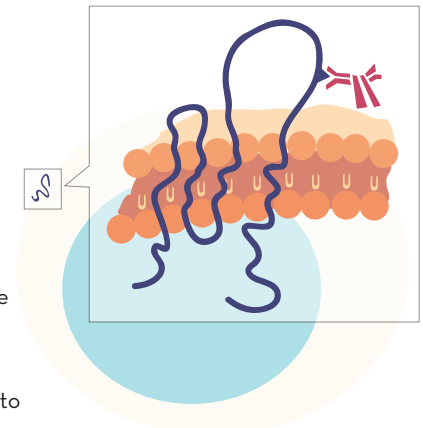
MG currently is treated with medications that prolong chemical signals from the nervous system and with drugs that suppress the immune system, particularly corticosteroid medications such as prednisone. However, corticosteroids often only partially control the disease and can have serious side effects when used for long periods of time.

The trial is planned to include approximately 50 adults with MG.

Participants must:

- have MG;
- be taking prednisone at a dosage of at least 15 milligrams per day or the equivalent on alternate days and have been on a stable dose for at least four weeks prior to screening; and
- meet other study criteria.

The goal of this study is to see whether rituximab can reduce the amount of the corticosteroid prednisone that MG patients require and whether it can do so safely.



Rituximab targets B cells (inset above) by binding specifically to CD20 on the cell surface. (Credit: NIAID)



To learn more about this trial, including inclusion and exclusion criteria, search for "NCT02110706" at [ClinicalTrials.gov](https://ClinicalTrials.gov).

# KNOWLEDGE CAN MAKE A DIFFERENCE



Get your copy of the new "About FSHD" patient brochure, with the latest information on genetics, symptoms, diagnosis, patient care and more, this is your essential guide to understanding facioscapulohumeral muscular dystrophy, whether you have just been diagnosed or have lived with FSHD for years. Learn more at [FSHSociety.org](https://FSHSociety.org).

[FSHSOCIETY.ORG](https://FSHSOCIETY.ORG)

YOUR RESOURCE FOR FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY



## Spinal muscular atrophy (SMA)

# Splicing Shift

## RG7800 shifts SMN2 splicing toward production of full-length SMN RNA

Results from the first group of participants in the phase 2 “MOONFISH” trial of RG7800 in adolescents and adults with **spinal muscular atrophy (SMA)** showed that the small-molecule splicing modifier increased levels of full-length, functional SMN RNA produced from instructions carried in the SMN2 gene. In addition, the drug also appeared to boost levels of the SMN protein in the blood of patients, and was safe and well-tolerated over a 12-week period.

Importantly, an increase in SMN protein levels has the potential to provide meaningful clinical benefit to SMA patients. In measurements taken from blood in MOONFISH trial participants, up to twofold increases in SMN protein were observed versus baseline.

MDA’s support of foundational research on the genetics of SMA and the production of SMN protein has contributed to this and other SMA drug trials.

*RG7800 is designed to change the way cells interpret genetic information from the SMN2 gene and cause more full-length SMN protein production.*



For more information on the MOONFISH study, search for “NCT02240355” at [ClinicalTrials.gov](https://ClinicalTrials.gov).

Did You Know that Heart Failure is Very Common and Often Fatal in Patients with **Duchenne Muscular Dystrophy?**

# HOPE

The **Hal**t cardi**O**myopathy Progr**E**ssion in Duchenne is a clinical trial that will evaluate whether an investigational cardiac cell therapy is safe and potentially effective in minimizing scar and improving heart function in DMD associated heart disease.

To find a site near you, please visit [ClinicalTrials.gov](https://ClinicalTrials.gov) (Study Identifier NCT02485938)

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## Spinal muscular atrophy (SMA)

### SHINE On

**New open-label extension study lets infants, children, continue taking ISIS-SMNRx**

ISIS Pharmaceuticals has initiated a new, open-label extension study, SHINE, which provides ISIS-SMNRx to infants and children with SMA who have completed participation in the company's phase 3 ENDEAR and CHERISH studies and are eligible to participate in SHINE.

All participants in the SHINE study will receive a 12-milligram




dose of ISIS-SMNRx every four months for infants who completed ENDEAR or every six months for children who completed CHERISH.

This announcement supports ISIS's continued commitment to the development of ISIS-SMNRx for infants and children

with SMA. The company has reported encouraging results from their phase 2 trials in which ISIS-SMNRx was tested in SMA patients.

MDA is not funding this trial, but has funded researchers in the past, such as Dr. Adrian Krainer at Cold Spring Harbor

Laboratory in New York whose discoveries formed the scientific base for the development of this therapy.

 **For more information on the SHINE study, search for "NCT02594124" at [ClinicalTrials.gov](https://clinicaltrials.gov).**

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Morgan Duffy 



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# At Your Service

Questions and tips to consider before bringing a service dog into your life and home

BY BARBARA AND JIM TWARDOWSKI, RN



Eric Cook relies on his service dog, Dusty, to help with everyday tasks and enable his independent lifestyle.

**E**ric Cook, who has limb-girdle muscular dystrophy (LGMD) and uses a power wheelchair, no longer struggles to pick up the TV remote or his glasses when he drops them on the floor. Instead, the 57-year-old retired engineer relies on his service dog, Dusty, to help him with these and other needs. In total, Dusty knows and responds to 40 different commands for everyday tasks

like turning on a light switch, pushing an elevator button or opening the refrigerator door. When Cook begins to slump in his wheelchair, he even has a command for Dusty to gently nudge him back into an upright position. In this way, with Dusty at his side, Cook is able to live independently in his own home.

Aside from such direct assistance, service dogs like Dusty, as well as other types of helper animals, provide companionship and social support. But they are still pets that require their own care, so it's important to carefully evaluate whether an assistance dog would be a good fit for you and your family before starting the application process.

## BEFORE YOU LOOK

As a starting point, consider each of the following:

**Accommodations:** Is your home large enough for a dog? Do you have a fenced yard? Do you have other pets already? Most organizations that train and place service dogs recommend that the assistance dog be the only animal in the home.

**Lifestyle and time:** While service dogs help with everyday tasks, keep in mind that many types of dogs shed and require at least some degree of additional housekeeping. Caring for a dog also involves

feeding, grooming and medical checkups.

**Budget:** Beyond those basic needs, a dog requires leashes, a crate and additional toys and supplies. In total, you should be prepared to pay between \$1,500 and \$2,000 annually to keep your dog happy and healthy. On average, an assistance dog serves a family or individual for eight years.

## FINDING YOUR MATCH

If you determine that your home and lifestyle are ready to accommodate a service dog, the next step is to find an accredited organization and begin the matching process. A good place to start is Assistance Dogs International (ADI), a coalition of nonprofit assistance dog organizations around the world. ADI has a comprehensive accreditation system, and its members are routinely assessed. The ADI website ([assistancedogsinternational.org](http://assistancedogsinternational.org)) offers a searchable database to help you find an accredited assistance dog organization in your area.

### Boy's Best Friend

To read about how a service dog made a difference for a child with Duchenne muscular dystrophy, find this Web-exclusive article on [mda.org/quest](http://mda.org/quest).

These organizations strive to match each applicant with the animal that best fits his or her needs — and vice versa. For instance, Cook received Dusty from Canine Companions for Independence, which has placed roughly 4,800 dogs since its founding in 1975. This nonprofit provides the dogs free of charge to people with qualifying disabilities. The process starts with a multi-step application consisting of:

- an online form;
- phone interview;
- medical paperwork; and
- in-person interview.

Accepted applicants are

approximately 14 months old, a professional trains it for six to nine months. Then, once matched, the dog is introduced to its new partner during an intensive two-week Team Training. Cook and his wife attended the Team Training in California where they were introduced to Dusty and learned how to give commands and care for him.

#### A DOG'S LIFE

Once you are matched with a dog and have mastered the commands, you can begin to establish some routines and begin bonding. According to Cook, who quickly bonded

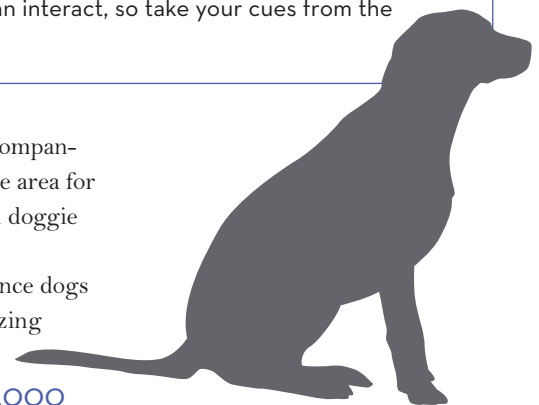
### APPROACHING ASSISTANCE DOGS

The Americans with Disabilities Act (ADA) makes it possible for people with disabilities to be accompanied by a service animal in public areas. When you encounter a service dog:

- Always approach the dog calmly and address the person first.
- Never touch or talk to the dog without permission. Remember, unlike most pets, the dog is working and your presence can be distracting and might be an interruption.
- Most dogs need to be “released” from work mode before they can interact, so take your cues from the dog’s owner.

the other Canine Companion graduates in the area for potluck parties and doggie play dates.

In short, assistance dogs like Dusty are amazing



*In total, you should be prepared to pay between \$1,500 and \$2,000 annually to keep your dog happy and healthy. On average, an assistance dog serves a family or individual for eight years.*

then placed on a waiting list until they are invited to a training class and matched with a service dog. For Cook, this arduous process took two-and-a-half years.

The dogs from Canine Companions have been bred by the organization and are either Golden Retrievers, Labrador Retrievers or a mix of the two breeds. Volunteer puppy-raisers socialize and teach the dogs basic commands, like how to walk on a leash. When a pup reaches

with Dusty, service dogs like his offer both direct companionship and a means to connect with others.

“He is an attention magnet,” Cook says of Dusty. Whether Cook is out in a restaurant or at church, people are drawn to his lovable 80-pound canine companion, he says. Cook and Dusty also visit area schools to educate children about the role of service dogs and how they help people with disabilities. And once a month, Cook and his wife meet with

animals that enhance the lives of people with disabilities. And since service dogs work for praise, owners fulfill their dogs’ needs, too, stresses Cook — who has nothing but praise for his pal Dusty. **Q**

*Barbara Twardowski has Charcot-Marie-Tooth (CMT) disease and uses a power wheelchair. Jim, her husband, is a registered nurse. The couple lives in Louisiana and writes about accessible travel, assistive technology and related issues.*

*MDA's revitalized brand strategy puts families first as we strive to increase urgency and action to save and improve lives*



the heart OF OUR  
MISSION

*My* “My doctors told me I wouldn’t live past 12 years old. They told my parents I wouldn’t go to high school or graduate from college. I’m grateful I’ve proven them wrong.”



*Joe Akmakjian will serve as MDA's new National Goodwill Ambassador, serving as a family spokesman, for 2016.*

Joseph (Joe) Akmakjian, who was diagnosed with **type 2 spinal muscular atrophy (SMA)** when he was 15 months old, will turn 25 this year. In 2015, to celebrate his 24th birthday and doubling his life expectancy, he didn't have the standard cake and ice cream with friends and family. Instead, he and 11 friends went skydiving to mark the occasion. Akmakjian was securely strapped to his skydiving instructor, wore a neck brace, and his arms were restrained across his chest. As he got ready to feel the wind on his face at 120 miles per hour, he shouted, "YOLO!" short for "You only live once."

"My dream is to inspire all types of people to live beyond their perceived limitations and achieve the success inside them," Akmakjian says.

But it isn't defying limits, like jumping out of a plane, that Akmakjian is most proud of each day.

"People often see my wheelchair and my physical limitations and think about the things I can't do," Akmakjian explains. "The No. 1 question people ask me is what I would do if I could walk. The truth is, I'm redefining what's possible and doing remarkable things every day.

"For me, defying limits has many meanings. While skydiving was an amazing experience I'll never forget, I need to also recognize the simpler accomplishments I've made — like learning how to cross the street on my own, being active in nightlife with friends, graduating college

*Live Unlimited is the newest MDA fundraising platform that will engage corporate partners and consumers, starting this summer, to support MDA's lifesaving work.*

and beginning my career by entering the workforce independently. That's what living unlimited means to me."

### LISTENING TO MDA FAMILIES

The challenges and limits courageous individuals with neuromuscular diseases like Akmakjian and their families are overcoming every day are the inspiration behind MDA's revitalized brand and new campaign, which launched in

January in New York City — the very place where MDA first started.

In June 1950, founder Paul Cohen gathered a group of individuals with a personal connection to muscular dystrophy to advance research to end this disease. Today, MDA's refreshed brand and inspiring consumer campaign represent its relentless commitment to fulfilling Cohen's lifelong dream of freeing individuals — and the families

## WHAT MDA'S NEW BRAND MEANS FOR FAMILIES

As part of MDA's new brand, you can expect to see:

- A newly designed **mda.org** with better information that is easier to find, including a special area for the newly diagnosed.
- A new MDA blog that will share engaging, weekly content from neuromuscular disease experts and families on everything from breaking research updates to first-person family stories and daily living tips.
- Revitalized services for families, including new care standards to enhance our MDA Care Centers (formerly called MDA Clinics).
- A new resource center opening in 2016 that will connect families with trained experts to find information, resources and emotional support.
- More promotion and story sharing across digital channels like social media and in stores with new partners this summer.
- Revamped logos for all of MDA's community programs that are consistent with the new visual identity and that better connect each initiative back to the organization and its families.



who love them — from the devastating effects of muscle-debilitating diseases so they can live longer and grow stronger.

After hearing from thousands of MDA families, donors and potential supporters, MDA launched a refreshed logo, updated messaging and a new look and feel to more accurately represent the needs and desires of the people it serves — with families at the center of its mission.

“MDA was started by families, for families. Families are at the heart of our mission, and we wanted to make sure our brand truly reflects that,” says MDA Chief Marketing & Communications Officer Steve Ford.

The heart in the center of the new logo represents all the kids and adults MDA serves, and the bright marigold color symbolizes optimism for the future as MDA works to find research breakthroughs across diseases, care for kids and adults from day one and empower families with enhanced services and support in hometowns across America.

“While our new visual identity tested extraordinarily well when we surveyed families and donors, MDA’s brand revitalization is not about a new logo or tagline. It’s about delivering on our mission with excellence,” Ford explains.

### LIVING BEYOND LIMITS

In addition to looking and sounding more modern, passionate and personal — all things families and donors said they wanted to see more



## MEET MDA NATIONAL GOODWILL AMBASSADOR JOE AKMAKJIAN

**Age:** 24

**Location:** Fort Collins, Colo.

**College:** Colorado State University (2013)

**Degree:** Bachelor’s degree in Journalism and Public Relations, with a double major in Speech and Communication Studies

**Current job:** Marketing director for a local pain management clinic

**Family:** Dad is a surgeon, mom is a registered nurse, and has two sisters

**Favorite food:** Happy Hour Tapas

**MDA experience:** Has spoken on behalf of MDA for 18 years and is a former State Goodwill Ambassador for Colorado (2007 and 2008)

**Best MDA moments:** Too many to choose just one –

developing greater independence at MDA Summer Camp, interacting with our heroes, the fire fighters, and being asked to serve as MDA National Goodwill Ambassador

**Interests:** Enjoys swimming, craft beer and red wine, live music, dancing, festivals, traveling and doing anything fun with friends

visibly from MDA — the organization has launched a new campaign called Live Unlimited.

“For individuals like me, the world often imposes man-made limits on us,” Akmakjian explains. “People see that I can’t walk or that I need help from others for the majority of my daily activities. It may be easy to see what we’re limited by, but it’s more important to

know that with MDA’s support we can defy limits and live life to the fullest.”

Live Unlimited is the newest MDA fundraising platform that will engage corporate partners and consumers, starting this summer, to support MDA’s lifesaving work. It’s inspired by MDA families and amplified by everyday Americans to celebrate what we *can* do and be relentless in



## MDA FAMILIES LIVING UNLIMITED

**ETHAN LYBRAND** is a bit of a daredevil. He enjoys playing with Transformers, going down the slide at the playground and spending time with his family. Ethan dreams of being a train engineer or a pilot when he grows up.

Six-year-old Ethan received a diagnosis of **Duchenne muscular dystrophy (DMD)** two days before his second birthday. As his mom, Jordan Lybrand, explains, Ethan is living life to the fullest.

“We don’t tell Ethan he cannot do this or cannot do that because of DMD,” Jordan says. “We let him live life every day without a care in the world. We encourage him to do that by simply living each day to the fullest and making each day better than the one before.”

Ethan gets tired quickly, falls and has trouble climbing and jumping, but in spite of these daily challenges, the Lybrand family “just keeps moving on, taking one day at a time, one moment at a time and making it the best possible.”

In this way, the Lybrands, like thousands of other MDA families, exemplify the spirit of MDA’s Live Unlimited campaign. As such, the family’s wish for Ethan is to grow up fighting back against limitations and to never give in to statistics or challenges that may come along with this diagnosis.

“Our dream is for Ethan to live a full long life, full of happiness and adventure,” Jordan explains. “Our dream for Ethan is to not be upset with his diagnosis but to use it to share a story of overcoming and living like there is no tomorrow, no matter what he faces in life. In reality, shouldn’t we all be doing this regardless?”

For other families traveling along a similar journey, Jordan adds, “Slow down. The statistics are in the back of your head constantly, but you cannot let them hold you back. Fight back, keep living, take it one day at a time and enjoy every minute. Live unlimited.”

*The Lybrand family’s dream for their son Ethan, who has Duchenne muscular dystrophy, is to live life to the fullest.*

our pursuit to make more can-do moments possible.

“Live Unlimited is a steadfast belief that every child and adult should be free from the harm and physical limits of muscular dystrophy, ALS and related life-threatening diseases,” says MDA CEO Steven M. Derks. “We can all relate to facing limits in life, and we can all feel proud when we turn perceived ‘can’ts’ into ‘cans.’”

MDA’s Live Unlimited movement is designed to rally supporters around taking

urgent action to help make more moments, opportunities and dreams possible for MDA families — because everyone deserves to live unlimited. MDA families can expect to see more about the campaign, including how they can get involved in the coming days and weeks. (To meet a few of the MDA profile families for Live Unlimited, read the sidebar above and on page 25.)

### A NEW FACE

To help rally the nation around this important cause,

Joe Akmakjian will be MDA’s new National Goodwill Ambassador for 2016, serving as a family spokesman and driving force for change for the organization. He has been involved with MDA since he was 6 years old, having served as a State Goodwill Ambassador and camper in his younger years, and today as brand champion in his home state of Colorado. He’s most excited about helping forge better connections between families, engaging with current and prospective



**More information about MDA’s new Live Unlimited campaign will be available over the coming days and weeks. For ongoing updates about the campaign, including how you and your family can get involved, visit [mda.org](http://mda.org).**

## WHAT LIVE UNLIMITED MEANS TO ME

**SARAH COGLIANESE**, 37, received a diagnosis of **ALS (amyotrophic lateral sclerosis)** in 2012. She is a wife and mother, and along with her sister, Liz, was featured in a 2015 Quest article on the role of sibling caregivers. Sarah and her family are now also an MDA profile family for the new Live Unlimited campaign. Here, Sarah shares a little about herself and her approach to living unlimited.

*On how she is trying to make more can-do moments possible and how she's trying to live unlimited in spite of the daily challenges of living with ALS:*

"I face many challenges as a result of living with ALS, but by focusing on the good things in my life and the things that I can do, I take back some of the power in the situation. It's my goal to be an example of strength for my daughter, and that guides my actions and behavior every day. It allows me to live beyond my physical limitations because there's so much more involved in day-to-day life.

Sarah Coglianesse, who has ALS, lives unlimited by finding happiness in the little things in life.



There are a lot of different ways to be strong, and despite my illness, I'm able to find happiness and purpose every day."

*On finding happiness and strength in the little moments that we sometimes take for granted:*

"I think I've always been able to find happiness in the little things. A nice long walk, a cup of tea, reading a book with my daughter, learning something new. So even if I'm now in a wheelchair for that long walk, I'm still deeply appreciative of my ability to be a part of it. Something I particularly love is holding my daughter, Scarlett, on my lap and either reading to her, or telling her a story, or watching a movie. Just being with her makes me so happy."

*On facing limitations she never anticipated:*

"It's important to me to feel like I'm still making a contribution in the world despite facing limitations that I never anticipated. Being with my family, writing and taking a really active role in my life are all ways that I defy the limitations placed on me by ALS. My life is so much more than just this disease."



To read more about Sarah's story, find "My Brother's (or Sister's) Keeper" in the Quest archives at [mda.org/quest](https://mda.org/quest).

sponsors, deepening MDA's reach among millennials and helping champion improved services for young adults transitioning from childhood to adulthood.

"Joe is an incredible example of how the work MDA is doing thanks to our supporters is helping kids live into adulthood and thrive," Derks notes. "But there are still too many individuals and loved ones who we are losing too soon to these devastating diseases. We believe our refreshed brand and Live Unlimited campaign will help re-engage Americans in a conversation and inspire urgently needed action and donations to find more treatments and cures." [Q](#)

A man with glasses and a red sweater is smiling and looking down, surrounded by a blurred crowd of people. The background is filled with people, some wearing red, suggesting a group event or rally.

# LEADING

*by example*

*Mike Rowlett, who lives with a form of muscular dystrophy, is a strong believer in paying it forward, and as the CEO of his own company, he's created a company culture built on giving to worthwhile causes like MDA's lifesaving mission.*



## *Mike Rowlett makes it cool to give, inspiring a wave of like-minded champions*

BY DONNA SHRYER

American author, speaker and salesman Hilary Hinton “Zig” Ziglar once quipped, “You can have everything in life you want if you will just help enough other people get what they want.”

For Mike Rowlett, these words are more than a nice sentiment; they are a personal philosophy that he lives by every day. And he credits that ethos with helping him achieve what he calls “a blessed life” with his wife, Beverly, and their blended family.

Rowlett’s blessings also extend to his professional life, where over the course of his career, the now-62-year-old suburban Dallas-Ft. Worth

resident has worked his way up the corporate ladder at Womack Machine Supply Company, from salesperson to becoming the company’s owner and CEO in 2006.

Womack’s market niche is that of an industrial distributor of hydraulic, pneumatic and automation equipment. But in drawing inspiration from Mr. Ziglar’s words, Rowlett also has created a company culture built on

“We started small, only about 12 of us. It felt like a good way to give back, so over the years Team Womack grew.”  
— Mike Rowlett

giving — to his customers, his vendors, his employees and scores of philanthropic endeavors, including MDA.

“Zig’s words are at the core of my existence,” Rowlett stresses. “If you selflessly serve others, you’ll always get everything you need.”

What does *not* define Rowlett’s existence is his diagnosis. In 2000, at the age of 47, he was diagnosed with **facioscapulohumeral muscular dystrophy (FSHD)**, which primarily affects the muscles of the face, shoulder blades, upper arms and lower legs.

“My disease hasn’t slowed me down — maybe a little over the last couple of years — but for the most part I power through,” Rowlett says. “I have

a variety of walking sticks for stability, but I’m not in a wheelchair. Beverly is always here for me, but I don’t need hands-on care.”

Choosing to focus on life’s positives, Rowlett sees his diagnosis as yet another opportunity to help fulfill his innate drive to help other people get what they want out of life.

### A PASSION FOR COMPASSION

When Rowlett took hold of Womack’s reigns in 2006, his personal desire to give back rose to top-priority status companywide. The plan was to nurture a corporate culture rooted in philanthropic efforts. It’s right there in

Womack’s vision statement: “We will be known for our superior customer service, products and solutions; philanthropy; entrepreneurial spirit; consistent profits; employee-oriented, enjoyable atmosphere; career and growth opportunities; and use of the Golden Rule.”

Fact is, Rowlett kick-started the company’s giving spirit even before moving into the “corner office.” In 2004, he created Team Womack to raise funds through organizational events in support of an annual MDA event in Dallas-Ft. Worth that today is known as MDA Muscle Walk. “We started small, only about 12 of us. It felt like a good way to give back, so over the years Team Womack grew,” he recalls.

Carolyn Minnerly, MDA national director of summer camp and volunteer program, recalls Team Womack’s evolution, although she tells the story with a different emphasis: “That first year, Team Womack raised about \$25,000 — and every year since they’ve raised at least \$100,000.

“What amazes me,” Minnerly continues, “is how Team Womack raises thousands and thousands of dollars for MDA and also uses their fundraising efforts as a team-building activity. The team raises money for our kids, and the money raised brings the employees together. I think that’s why the team includes about 300 people today. It’s grown into a big deal.”

Reinforcing Team Womack’s unity, Mike and Beverly Rowlett host a celebration

## GET INVOLVED

Every day, dedicated volunteers all across the country lend their time and talents to help support kids and adults living with neuromuscular diseases.

MDA-sponsored summer camps, led by MDA volunteers, medical personnel and skilled staff, are created especially for 6-to-17-year-olds with neuromuscular diseases. The weeklong sessions give campers an opportunity to discover activities they might have once imagined impossible — from zip-lining and horseback riding to arts and crafts and talent shows.

Volunteer counselors, who must be at least 16 years old, receive extensive training so they can help campers enjoy the MDA camp experience to the max.

Additional MDA events — such as MDA Muscle Walk, MDA Team Momentum and MDA Lock-Up — offer fun, family-friendly ways to raise vital funds that support research across MDA diseases to accelerate treatments and cures; care for kids and adults from day one; and the empowerment of families via services and support in hometowns across America.



To volunteer or learn more about events in your local area, please sign up with MDA at [mda.org/ways-to-help/volunteer](http://mda.org/ways-to-help/volunteer).

brunch after the close of each MDA Muscle Walk. A feast awaits family, friends and anyone who went the distance for MDA's families, especially its "kiddos," as Rowlett calls the young recipients of Team Womack's efforts.

**IN GOOD COMPANY**

As Team Womack increased its impact, Rowlett called upon Rodney Bryan to assume the position of Womack's Vice President of Company Culture and keep the giving mojo going. "Our company was growing, but we didn't want to lose any of our great people. So early on, we went through a crash course in how to build employee morale, loyalty and unity. Creating a company culture based on



Each year, Rowlett encourages his employees to volunteer as counselors at MDA Summer Camp, giving them paid time off for their week of helping kids have the "best week of the year."

philanthropy did the trick," Bryan says.

Womack gave "company culture" a broad definition, in that the common ground is giving back, but how employees follow their philanthropic

passion is an individual choice, with no charity off limits or favored over another. "If an employee supports a charitable effort, whether with money or sweat equity, we match the effort with a



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Through MDA Muscle Walk, Rowlett and his Team Womack employees dedicate their time to raise funds that benefit MDA services and support.

donation,” Rowlett stresses. “In a typical year, Womack will give money to nearly 100 different events.”

Often, Womack employees choose to rally around a certain cause as a group or by work location. As an example, Bryan explains how Womack’s Dallas, Houston and Tulsa locations support MDA, specifically by raising funds each year through Muscle Walk to help support MDA Summer Camp and other support programs. Womack’s Salt Lake City office is dedicated to Make-A-Wish. Other company employees donate time and

money to a local children’s hospital. “Our core value is philanthropy. We live by that and expect our managers to seek out opportunities to get their group involved. And to give our employees the confidence to get involved, we do whatever we can to inspire the spirit and help them succeed,” Bryan explains.

One way Womack taps into this spirit in its Dallas, Houston and Tulsa locations is by allowing employees to volunteer for up to a week at MDA Summer Camp. The opportunity is paid time off that doesn’t count against an

## SEEING IS BELIEVING

Donating time, funds and energy to help support families served by MDA feels good. But to make fundraising a far more personal experience, MDA allows you to earmark funds. In this way, raised funds directly support your passion. Here are a few ways to raise funds to help kids and adults with neuromuscular diseases:

1. Consider the price attached to MDA research, care and support, and let your dollars follow your heart.
  - \$100 provides care coordination for one MDA Care Center visit.
  - \$150 provides a physical therapy consultation at an MDA Care Center.
  - \$500 provides a week of medical supplies at an MDA Summer Camp.
2. MDA Your Way enables supporters to turn their everyday activities and interests into their very own personal fundraiser. Visit [mda.donordrive.com](http://mda.donordrive.com) to get started today.
3. Personally watch your dollars in action.

Womack Machine Supply Company, headquartered in Dallas has raised many thousands of dollars for MDA’s lifesaving mission since 2004. To deepen Team

Womack’s connection to their fundraising efforts, the company’s CEO and owner, Mike Rowlett, makes it easy, and fun, for his employees to watch their money in action.

“Team Womack works so hard to raise these extraordinary funds particularly to benefit MDA Summer Camp, and then Mike encourages his team to volunteer as summer camp counselors. And volunteers don’t forfeit vacation time; it’s a powerful way to strengthen Womack’s company culture,” explains Caitlin Carter, MDA associate executive director based in Dallas. “Womack employees get to literally see what their fundraising accomplishes – like maybe helping a child with Duchenne muscular dystrophy (DMD) climb out of his wheelchair and go swimming or horseback riding for the first time. That can be very rewarding, and it reinforces Team Womack’s commitment to MDA.”



Visit [mda.org/ways-to-help](http://mda.org/ways-to-help) to learn more. For details on national sponsorship opportunities and how to become an MDA Partner in Progress, visit [mda.org/partners-in-progress](http://mda.org/partners-in-progress).



employee's personal or vacation time. Since supporting MDA Summer Camp is a primary motivator for Team Womack, Rowlett feels it's imperative that employees experience firsthand how their fundraising efforts help children with muscular dystrophy and related neuromuscular diseases.

But the highlight of Womack's summer camp involvement each year, at least as far as the kids and other counselors are concerned, is the barbecue meal Rowlett and his employees provide. "Team Womack brings a complete meal fit for a king," Minnerly says. "Campers and volunteer counselors feel so special and pampered. And all Mike wants in return is a smile from his kiddos. That's all! Giving others something to smile about brings Mike so much happiness. That's who he is."

### THE RIPPLE EFFECT

So what about the other half of Mr. Ziglar's promise, the part that says giving begets getting? According to Bryan, Womack does indeed profit, albeit indirectly, from its philanthropic efforts. "Our employees feel good about themselves, the company and their co-workers," he says. "So our company culture creates an environment where employees feel encouraged to speak up with solutions and work toward career growth. They want to be here." And that positive environment, he adds, triggers a ripple effect that checks off each of Womack's seven vision statement goals.

Leading Team Womack to participate in MDA Summer

Camp also gave Rowlett's family a new layer of love. As the treasured story goes, his son, Tracy, became an MDA camp volunteer counselor after turning 18. It was during his second year at camp that Tracy met Whitney, another dedicated MDA Summer Camp volunteer — who is now his wife. It's another one of those "ripple effects" that Rowlett never tires of sharing.

What's more, Rowlett's drive to help others brings gentle waves of unconditional admiration — a fact that often escapes him because of his inherent modesty.

"Personally, Mike changed my life," says Caitlin Carter, MDA associate executive

*“Our core value is philanthropy. We live by that and expect our managers to seek out opportunities to get their group involved. And to give our employees the confidence to get involved, we do whatever we can to inspire the spirit and help them succeed.”*

— Rodney Bryan



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Laura Bairett, 18

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For Mike Rowlett, actions speak louder than words. Through his involvement with MDA Muscle Walk, for example, he's helped inspire Womack's employees through his philanthropic values and passion to make a positive difference for others.



*“There are no cures and few treatments for many of our diseases, but seeing Mike’s positive attitude changed me. Everything he does is to make a difference. He’s taught me to focus on solutions – for today and the future.”*

– Caitlin Carter

director based in Dallas. “There are no cures and few treatments for many of our diseases, but seeing Mike’s positive attitude changed me. Everything he does is to make a difference. He’s taught me to focus on solutions — for today and the future.”

The way Rowlett lives life serves as an inspiration for his kiddos, too, Carter adds: “Mike gives our MDA campers hope. He’s living proof that being affected physically doesn’t mean you can’t become the very best version of yourself. It’s the example he sets

for our kids, especially the older ones.”

If, however, you ask Rowlett about the well-deserved and heartfelt praise for his compassion, he’s prone to politely blow it off. “Mike’s wired to give; it’s a natural response and never done for recognition,” Bryan says. “One day he said to me, ‘I’ve never seen anybody not smile with an ice cream cone in their hand.’ So we put a soft-serve ice cream machine in our break room. If Mike can help make you smile, he’s had a good day.” [Q](#)

*Donna Shryer is a freelance writer in Chicago.*



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# Fashion Forward

Products and tips that bring style into a wardrobe without sacrificing mobility

BY ELIZABETH MILLARD



Nike Zoom Soldier 8 FlyEase

**C**hildren and adults living with neuromuscular diseases often have to make a choice between fashion and function. Skinny jeans and tall lace-up boots may be all the rage, but items like those present plenty of challenges in terms of getting them on and then staying mobile afterward. Even regular jeans and sneakers can be a hassle, leaving many to simply don sweatpants and slip-on shoes, but self-esteem can take a hit as a result.

“Sometimes people just want to look stylish, or they may need clothes that are more professional,” says Sharon Greenberg, an occupational therapist at the MDA Care Center at Seattle Children’s Hospital. “Let’s face it, when you look good, you tend to feel good. And when you wear sweatpants every day, it can be difficult to achieve that.”

Fortunately, there are an increasing number of options that give people some style and flair — without adding extra time to routines or limiting mobility. One of the most high-profile launches has been the Zoom Soldier 8 FlyEase shoe (\$130) from Nike ([news.nike.com/news/the-flyease-journey](https://news.nike.com/news/the-flyease-journey)). A wrap-around zipper extending

from the shoe’s front to the base of the heel makes it easier to get it on and off. This is especially helpful since adult shoes with Velcro seem to be getting harder to find, says Cathy Scott, an occupational therapist for the MDA Care Center at Michigan State University.

“I see many people having trouble with shoes because they need the extra support for knees and ankles, but slip-on shoes don’t provide that,” she says, adding that shoes that do offer support usually have laces that require a caregiver’s help. A zippered shoe like the Flyease earns her praise for offering support and ease of use.

Another issue Scott often sees comes with pants, and jeans in particular can be an issue. Most brands have small

## RESOURCE CORNER MORE ACCESSIBLE FASHION OPTIONS



### Long sleeve Velcro front dress shirt

Classic dress shirts are standard in professional settings, but the buttons

can be challenging for those with limited strength or dexterity. Buck & Buck, which specializes in adaptive clothing, offers an option that looks like a button-down shirt but is fastened by Velcro instead. Another choice for a similar look is a magnet-fastened shirt (\$70) from adaptive clothing maker Silvert’s, which is available for men and women.

**How much:** \$36  
**Where:** buckandbuck.com

### Plaid blazer

For women who want a more stylish look by adding a blazer to an outfit, but find that standard blazers bunch up in the back, or around the waist and hips, this plaid number is a nice choice. It’s offered by IZ Adaptive, which also has a leather biker jacket with easy-zip back for women. Outerwear options for men include an easy-zip back pea coat, as well as parkas for

both men and women.  
**How much:** \$215  
**Where:** izcollection.com



Adaptations by Adrian's Pre-Made  
Sitter/Wheelchair Shorts

fasteners and buttons, and she often advises that people add a key ring to the zippers to make them easier to pull up — a tip that works on any clothing item. But jeans are still appealing to younger people in particular, she notes, since they are a fashion mainstay among their peers.

Greenberg appreciates the style shown by ABL Denim ([abldenim.com](http://abldenim.com)), which creates jeans for people with limited mobility. For example, the WCH Jean for men has an extra-long center front zipper, with rubber string lasso pull for easier opening. The back is higher than the front — especially important for those who use wheelchairs — and there are leg pockets for storing a

phone or wallet, as well as a catheter zip opening.

The company's line for women even has a skinny jean-type item with its Adaptive Legging (\$42). Also using a high-back waist for wheelchair users, the leggings have a reversible waistband that can be helpful for those with limited mobility, and the lightweight denim is soft and stretchy for comfort.

In addition to denim, Adaptations by Adrian ([adaptationsbyadrian.com](http://adaptationsbyadrian.com)) specializes in shorts and



pants for wheelchair users. Their sitter line of pants and shorts are cut higher in the back and lower in the front so they don't hit the ribs in front, or ride down in back, making them much more comfortable for people who spend much of their day in a wheelchair.

Coats and jackets also can be problematic, leading some women to switch to a shawl or poncho, says Scott. But in colder climates, that's not always an appropriate weather choice, and men don't tend to like ponchos. "Unfortunately,

*“Let's face it, when you look good, you tend to feel good. And when you wear sweatpants every day, it can be difficult to achieve that.”*

*— Sharon Greenberg*

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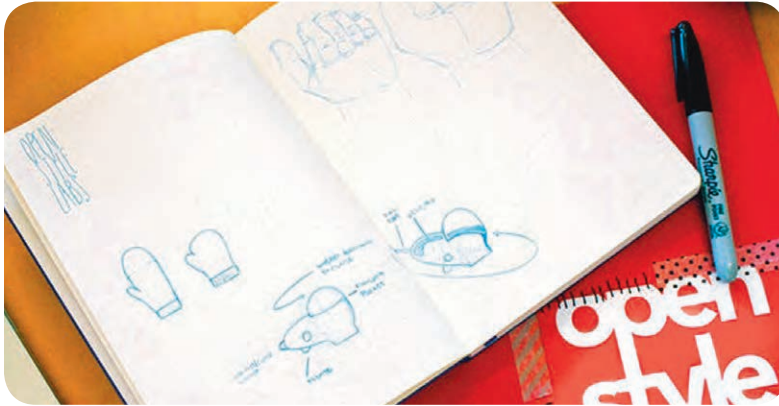
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A glove sketch by an MIT Open Style Lab fellow; the program focuses on accessible clothing for individuals with disabilities.

this leaves many people staying indoors more, rather than having to deal with outerwear that's too difficult to get on, or that gets bunched up in the back for those in wheelchairs," Scott notes.

One choice that may become available commercially is the Rayn Jacket

protects the wearer's upper legs and wheelchair seat from rain.

Not only do these clothing, outerwear and shoe options offer features that are geared toward more mobility and independence, but they also can improve quality of life, Scott believes. She says, "People with mobility issues and

([openstylelab.com](http://openstylelab.com)), developed at MIT for a competitive biker who is living with a spinal cord injury. The waterproof jacket has a rear zipper that allows a caregiver to put the garment on more quickly, and a "lap flap" pro-

*“People with mobility issues and physical disabilities want to feel the confidence that comes with looking good.”*  
 – Cathy Scott

physical disabilities want to feel the confidence that comes with looking good. The fact that there are more clothing options to help them do that is great.” Q

*Elizabeth Millard is a freelance writer in Minnesota.*



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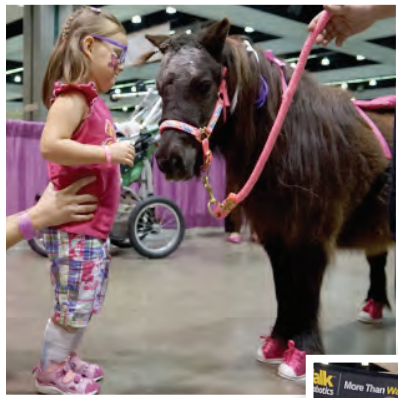
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# access MDA

Your guide to the MDA community, from news briefs to inspiring profiles

## Be an MDA Champion

Sign up to be an MDA volunteer today and make a difference for families where you live

*“At camp, the resiliency of the human spirit is evident all around you. It is a place where ‘I can’t’ becomes ‘I can,’ the ‘impossible’ becomes ‘possible’ and ‘limited’ becomes ‘limitless.’”*

— Kaitlyn, volunteer counselor

Families are at the heart of all MDA is doing to deliver its lifesaving mission. Every day, MDA relies on the support of its dedicated volunteers all across the country who volunteer in local offices, who lend their time and talents to MDA special events like MDA Muscle Walk and MDA Galas, and who commit one week every summer to help kids experience life beyond limits at MDA Summer Camp.

Volunteering with MDA will enrich your life and inspire you in ways you never dreamed possible. It’s a great way to

develop important leadership skills while simultaneously giving back to your community. And, studies show that people who volunteer are happier with their overall work-life balance. It’s a win-win for everyone!



Volunteers help give kids a week where anything is possible at MDA Summer Camp.



**Are you ready to lend your time and talents to support and empower kids and adults fighting muscular dystrophy, ALS and related muscle-debilitating diseases and the families who love them? Join the cause today at [mda.org/ways-to-help/volunteer](http://mda.org/ways-to-help/volunteer).**



# A Hero's Journey

**A mom combines running and MDA fundraising to support her son**

When Gloria Smith first heard from her family doctor that her son, Harry, now 3, had **Emery-Dreifuss muscular dystrophy (EDMD)**, which is characterized by wasting and weakness of muscles in the shoulders, upper arms and calves, she struggled with how to cope with the news.

Looking for a way to channel her emotions, Smith “found a local gym and started kickboxing, just to get myself active,” she recalls. And with that, between doing everything she could to support her child in his journey, Smith says she started her own “fitness journey.”

Little did Smith know, her new stress-releasing hobby would soon turn into a charity called Harry's Heroes that would raise more than \$14,000 for MDA in 2015 through its Team Momentum endurance running program.

“The first event was a small race with my sister where we made 10 cups that said something about being a hero for Harry,” she says. “After that, we thought maybe we could do another race and get more people involved, and the idea just snowballed from there.”

By March, Smith and Harry's Heroes began to hit their fundraising stride for the Philadelphia Love Run Half Marathon. “It wasn't an official MDA Team Momentum event, but we worked with Team Momentum to raise money through the endurance series,” Smith says. “We ended up with 13 people running for Team Momentum, but 30 people ended up running for Harry's Heroes altogether. All these people I had never met before were running for Harry. I burst into tears when I hit the finish line. It was the first time we had everyone come together for the cause; it was overwhelming.”

Since then Smith says that Harry's Heroes has been “exploding,”



*Smith shares the joy of crossing the finish line with her son, Harry.*




*Gloria Smith (left) with MDA Team Momentum at the 2015 Marine Corps Marathon.*

and they had their largest run yet at the Marine Corp Marathon in Fredericksburg, Va., in October. She credits social media, friends and family for the incredible success. And while Smith is blown away by the success, she also loves seeing how Harry's Heroes has inspired others.

“My favorite moments are when people message me or call me and say ‘I ran today, and I thought of Harry,’” Smith says. These personal connections inspire and push Smith every day – as do the parallels she sees between endurance running and her son's struggles.

“I kept thinking about how my son wakes up every day with a challenge ahead of him,” she says, “and I thought: Why can't I take on a challenge that seems impossible, too?”

 **For more on Harry's Heroes, visit [harrysheroes.us](http://harrysheroes.us). To learn how you can get involved in MDA Team Momentum, visit [mdateam.org](http://mdateam.org).**

## UPCOMING RACES

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**Boston Marathon**  
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**Marine Corps Historic Half-Marathon (Fredericksburg, Va.)**  
May 15, 2016

**Colfax Marathon and Half Marathon (Denver)**  
May 15, 2016

**Michelob Ultra Chicago Spring 13.1**  
May 22, 2016

**Boston's Run to Remember**  
May 29, 2016

**Rock 'n' Roll San Diego Marathon & Half-Marathon**  
June 5, 2016

# Thrill Seeker

An adventure enthusiast tests the limits of his abilities – and the limitations imposed by his disability



Rob Besecker exploring Antarctica (above) and cheering on MDA Team Momentum participants during the 2014 Chicago Bank of America Marathon (below).



Rob Besecker, a health care marketing professional, self-professed adventurer and now author, from Illinois, was diagnosed with **myotonic muscular dystrophy (MMD)** in 2006, just a few years after being diagnosed with heart problems. While Besecker has experienced a lot of hardship in the ensuing years between managing his diseases and dealing with the passing of his mother, father and brother, he hasn't let that stop him from seeking out life's adventures.

"For me, being an adventurer is about finding enjoyment in life and just doing a variety of things," Besecker says. "I think it's important to set realistic and achievable goals about the different things you want to see and do, and not to let your disability get in the way."

*“Whatever the case may be, everyone has different things in life they want to do and accomplish, and I challenge them to go do them. That’s what my book is about and why I support MDA.”*

– Rob Besecker

Over the years, that spirit of adventure has taken Besecker to every Major League Baseball stadium, to 45 of the 50 U.S. states, and to all seven continents – including exploring Antarctica and surviving an earthquake in Nepal while climbing Mt. Everest.

Besecker also has enjoyed a few adventures as a long-time MDA supporter. He has participated in MDA Muscle Walk events since 2007 and was an early supporter of MDA Team Momentum, which gives participants the opportunity to run or walk marathon and half-marathon endurance events. Besecker also shares his personal story and volunteers for Chicago-area events that are part of MDA Team Momentum.


"In 2014, we did a lot of training runs on Saturdays, and I would take my bike out

and bike alongside [the Team Momentum runners] as they were training,” Besecker says. “And on race day, I went to the marathon, wore my Team Momentum shirt and tried to support everyone that was doing it.”

What advice does this serial adventurer have for other members of the MDA community?

“The sky is the limit,” Besecker says. “Your goal doesn’t have to be something athletic. It could be something as simple as seeing a movie. Whatever the case may be, everyone has different things in life they want to do and accomplish, and I challenge them to go do them. That’s what my book is about and why I support MDA.”



 **Rob Besecker’s new book, *For Ever Strong*, catalogues his amazing story of perseverance and his many adventures. For details, visit [robbesecker.com](http://robbesecker.com).**

*Besecker’s spirit of adventure informs everything that he does, from supporting MDA, to traveling the world, to competing in race competitions like the Warrior Dash.*



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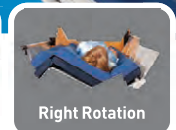
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# Playmaker

A high school student with DMD makes an impact through football and MDA Muscle Walk



Teagan House and his high school football teammates raise funds for MDA Muscle Walk in 2015.



Teagan House, a sophomore at Spaulding High School in Rochester, N.H., who has **Duchenne muscular dystrophy (DMD)**, served this past season as captain of his school's football team, the Red Raiders. While he enjoyed all the time he spent with friends at games and practices and supporting his teammates from the sidelines, House's most memorable moment took place on the field.

For one game this past season, House's coach and teammates coordinated with the opposing team to bring him into the game for a play.

"It was a surprise to me," House says. "I found out about it that night. It was really fun and exciting. I was nervous."

In the end, House had nothing to worry about: The play worked just as the team drew it up, and House scored his first touchdown.

According to House, that kind of support from his teammates is the norm. In addition to

## DID YOU KNOW?

This year, approximately 150 Muscle Walk events will take place across the country, featuring more than 10,000 teams and 50,000 registered participants coming together to walk and raise money for MDA. To get involved, visit [mdamusclewalk.org](http://mdamusclewalk.org).

helping him around school with things like carrying his lunch tray, they also support House's MDA Muscle Walk team – Teagan's Red Raiders – at the MDA Muscle Walk of Greater Manchester. In 2015, House and his team raised more than \$1,500 for MDA New Hampshire.

"I was really happy that they came out to support me and help me fight for MDA," Teagan says.

## MDA SHAMROCKS FOR STRENGTH, INDEPENDENCE AND LIFE

We are excited to have more than 25,000 retail locations join us for our 2016 MDA Shamrocks season! We encourage you to visit participating locations, and thank them for partnering with MDA and supporting our lifesaving mission. And, be sure to share your story and why MDA is important to you and your family with employees.



# Caring for Families from Day One

MDA's clinical conference to be held March 20-23, 2016, in Arlington, Va.

MDA fights to give individuals – and the families who love them – strength, independence and life to help them live longer and grow stronger. One of the ways we do this is to care for kids and adults from day one.

To help achieve this mission priority, MDA hosts an annual conference series, with clinical and scientific conferences held in alternate years. The 2016 MDA Clinical Conference will leverage the expertise of



clinicians, clinical researchers and allied health professionals across neuromuscular diseases, and will include representation from the clinical and corporate drug development arenas.

The meeting will focus on diagnostic strategies in

neuromuscular disease, disease management, specialized care, and therapeutics and clinical trials.



To learn more, visit [mda.org/2016](http://mda.org/2016)

[ClinicalConference/overview](http://mda.org/2016/ClinicalConference/overview).

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# A Passion for Politics

## Derek Reeve finds his calling as mayor of San Juan Capistrano

For as long as Derek Reeve can remember, he's lived with **spinal muscular atrophy (SMA)** – he was diagnosed at age 1. And for nearly as long, he's known he had a future in politics. “Even in sixth grade, I was student body president,” he says.

Today, Reeve is mayor of San Juan Capistrano, Calif., where he lives with his wife, Jocelyn, and two stepsons.

Reeve's passion for serving the residents of his hometown is evident, but his path to getting there wasn't without hurdles. He worked for a law firm in Los Angeles right out of law school before moving back to San Juan Capistrano and opening up his own law practice. Around that same time, he decided to get involved in local politics and ran for city council in 2000 and 2002. He lost both times, by only 212 votes the second time. After this tough loss, he put his goal for public office on the back burner for about eight years, teaching history at a local college and practicing law instead.


But in 2010, Reeve once again decided to jump back into the fray – and this time, he won. He's been on the city council of San Juan Capistrano ever since, and in December 2014 he was elected among the council members to serve as mayor.

Today, Reeve keeps busy campaigning, working with constituents and pursuing policies for the city – all while balancing his family life and the care needs that come with his diagnosis.

“We're a small city by California standards,” he says. “We have about 35,000 people. A lot of what I've tried to achieve are small steps: keeping the traffic going, filling potholes, really basic things like that. I've also been working on other specific problems like the droughts and how to supply water to our residents.”

Reeve takes pride in his accomplishments as mayor but says he has even more work to do in this and future roles.

“[Our town has] such a dynamic character; just the fact that I've been elected to be the town's representative means a lot,” he says. “However, I'm not planning on this being my last step. We're going to continue going on a new journey after my time as council member is up.”

 To read other inspiring stories from the MDA community, and find education and career resources, visit the MDA Transition Center page at [transitions.mda.org](http://transitions.mda.org).



Derek Reeve's journey led him to being elected mayor of San Juan Capistrano, Calif., but Reeve knows there's more to his journey ahead.



# The National ALS Registry: Get The Facts

The National Amyotrophic Lateral Sclerosis (ALS) Registry enables persons with ALS to fight back and help defeat ALS (Lou Gehrig's Disease). By signing up, being counted, and answering brief questions about your disease, you can help researchers find answers to critical questions.

Learn more at [www.cdc.gov/als](http://www.cdc.gov/als) or (800) 232-4636



## Who can sign-up?

Anyone with ALS

**No computer?** Don't worry! A family member, caregiver or friend with a computer can help you. You can also contact your local ALSA chapter or use the computer at your public library



## What do I need?

- A computer with an internet connection
- An email address



## What if I need help?

Caregivers and others can help you in person or even over the phone



## What kind of information is collected?

- Basic demographics (e.g., age, sex, height, weight)
- Military history
- Physical activity
- Family history



## Do I need to update my information?

YES! Every six months – you'll get an email reminder



## Will my information be private?

- YES! Only approved registry scientists can see it, NOT employers or insurers
- You CANNOT be looked up in the registry by name



**YOU JOINING**



More information for research

A better understanding of ALS

The chance to help create a better future for persons with ALS

# Become an MDA Amplifier

**A new mobile app for MDA supporters**



Every day, kids and adults living with muscle-debilitating diseases like muscular dystrophy and ALS are finding ways to live beyond limits. MDA needs your help to raise awareness and amplify their stories on social media.

MDA Amplify is a new mobile app that revolutionizes the way MDA supporters and families can share MDA news on their own social media channels. MDA Amplifiers receive notifications on their phone when there are posts to approve. Amplifiers review the

posts and can choose to post them to their profiles automatically or with personalized changes.

**Joining is easy:**

1. Download MDA Amplify for free from the app store via your Android or iOS phone.
2. Connect your personal social networks to the app.
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4. Approve MDA-supplied posts or edit them to make them your own.
5. That's it.

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# Pushing Up MDA

**A teenager with neuromuscular disease raises funds for MDA with his black belt project**

Noah Rodenfels, a 16-year-old from Ohio who has a form of **congenital muscular dystrophy**, has been learning taekwondo since he was 8 years old and is now training to receive his black belt. As part of his training, Rodenfels is raising money to help support MDA Summer Camp through his black belt community service project.

"I chose MDA because it's close to my heart," he says, "and I chose summer camp because I had a lot of fun [when I attended]."

"I was so impressed that Noah took the initiative to speak with his taekwondo teacher about fundraising for MDA Summer Camp," says Ryan Wright, MDA fundraising coordinator in Cincinnati. "At camp last year, Noah came up to me and asked for a business card. I didn't think anything of it until a few days later when I found out Noah is shy, and that it was a big deal for him to step out of his comfort zone."




He went from that shy kid to someone who has led his taekwondo class to raise funds. This is a real tribute not just to the impact MDA Summer Camp has on our campers but also to Noah's strength and will to fight back."

Rodenfels' project is a collaboration with his instructors at the Asian Arts Center Taekowndo School in Dayton, Ohio. For every \$0.25 donated to the project, one of his instructors will do 10 push-ups.

By mid-December, Rodenfels' project had already raised more than \$800 – prompting 32,000-plus push-ups!

Rodenfels, who participates in the same classes as his friends and even does some instructing of his own for the younger participants, says he is drawn to taekwondo because of its focus on perseverance and strength.

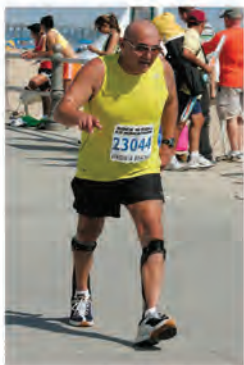
"For me, it is kind of challenging, but fun," Rodenfels says.

 **Have an idea for a personal fundraiser? Be sure to visit MDA Your Way to start your own fundraising activity to help benefit kids and adults living with neuromuscular diseases. Visit [mda.donordrive.com](http://mda.donordrive.com) today to get started!**

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# Make 'Em Laugh

**Shannon DeVido brings a unique perspective to the comedy world**

Shannon DeVido is an actress, singer and comedian whose star is on the rise. You may know her from her recent appearances on the Hulu original series "Difficult People" or Comedy Central's "The Nightly Show" with Larry Wilmore. But DeVido, who lives with **spinal muscular atrophy (SMA)** and uses a power wheelchair, is perhaps best known from her popular Web series, "Stare at Shannon," in which she uses comedy to challenge conventional beliefs about individuals with disabilities.

In one video from her "Stare at Shannon" series, DeVido goes to a grocery store to see what kind of absurd behavior she can get away with, playing off the customers' and the staff's pre-conceived notions about people in wheelchairs. At one point, a fellow customer helps a deadpanning DeVido open a gallon of milk and pour it into a cup of cereal she's holding, so she can eat it right in the middle of the dairy aisle.

DeVido's unique brand of comedy blends wit and intelligence without taking her topics, or herself, too seriously. But she does

Shannon DeVido is a comedian, singer and the star of her own Web series.



aim to challenge others as well as herself with her work.

"I think that when you start doing something, if you do it long enough, you get into a comfort zone and stop pushing yourself,"

DeVido says. "I struggle a lot with self-confidence, like any woman, not just as a woman with a disability. It's something I would like to try to inspire people to work on, as well, and know that they are worth it."

DeVido says her role in "Difficult People" was particularly satisfying in this respect because she auditioned and received the part even though it was not written for a person with a disability.

"I think I'm very lucky to have the opportunities I've had so far," she adds. "I'm moving forward, but I don't think I'm there yet. I'd love to star in my own sitcom. I'd love to tackle the issues of being a woman — and not necessarily the issues of a woman in a wheelchair — but being able to show that I'm a quirky, weird, funny woman that deals with issues that everyone deals with. I feel like that could break open doors for people coming after me."

 **For more information about DeVido's Web series and other performances, check out [shannondevido.com](http://shannondevido.com).**

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# An Attitude of Gratitude

*Choosing to see life's unexpected detours as opportunities to appreciate the scenic route*

BY PATTY BLAKE



**L**ife is certainly full of surprises, isn't it? Just when you think you've figured things out, you round a curve and — surprise — you hit a detour!

Being diagnosed with **ALS (amyotrophic lateral sclerosis)**, also known as Lou Gehrig's disease, in 2012 at age 55 was a most unwelcome detour, to put it mildly. We

were not completely taken by surprise since it had been clear something was wrong with me for quite some time. When tests and clinical observations eventually ruled out everything else, we were faced with the awful truth: I had a disease that would take away my mobility, my independence and, eventually, my life. Scientists are working

hard to find answers. But as I write this, there is no effective treatment or cure for ALS.

So how does one cope with having a physical disability as an active adult? What class can you take? Where do you turn?

For me, my Christian faith has been my unending source of strength, comfort and joy. When I am always striving to count my blessings, there is no room for pity parties — though they do sneak in from time to time. Nobody's perfect.

It might sound strange to talk about gratitude and a terminal, disabling disease in the same breath. But my faith teaches me to “give thanks in all circumstances” (1 Thessalonians 5:18). But how does someone find anything to be thankful for with a diagnosis like mine? Let me explain.

It begins with a little perspective. We are all “terminal,” really. How many people do you know who cannot die? You may know some who “cheated death” a time or two by surviving an accident, illness or disaster against improbable odds. This happens. But nobody lives forever. There are no guarantees in life, so we need to

*It might sound strange to talk about gratitude and a terminal, disabling disease in the same breath. But my faith teaches me to “give thanks in all circumstances.”*

savor every precious moment. Carpe diem!

Since we know each day is a gift, unique and finite, pause for a moment to consider what makes it so. What senses are you using right now? Be thankful for them.

Once you open up to the idea that there just might still be some good in the world, and in your life, you begin to see it. It may seem small and insignificant, at least at first. But if it's good, notice it. Acknowledge it. Give thanks for it.

A cooling breeze. Your dog's happy greeting. That

awareness of ALS brought about by the 2014 Ice Bucket Challenge led to millions of dollars in donations, helping to fund more research that, one day, will lead to a cure. The public awareness alone is a big help to people with ALS. This is something for which I am very grateful.

Because this disease invaded our lives, we chose to join an MDA ALS support group. There, in addition to practical and emotional support, we have met some of the world's nicest people who soon became dear friends. Each one I count as a blessing. Yes, ALS

### **Don't Go It Alone**

MDA offers a number of support groups, including many that are disease- or group-specific (for caregivers, parents, etc.). To find MDA resources in your area, visit [mda.org](http://mda.org).

to communicate at all. The sense of isolation must have been so frightening.

In addition to communication aids, there are other tools that make the journey with a disability safer for me and those who care for me. These include a hospital bed, power

*Once you open up to the idea that there just might still be some good in the world, and in your life, you begin to see it. It may seem small and insignificant, at least at first. But if it's good, notice it. Acknowledge it. Give thanks for it.*

lady who held the elevator door for you. A memory that makes you smile. All are reasons for gratitude

For me, since I have been dealing with the challenges ALS presents, I am amazed by the number of things I now notice because I am more "tuned in." When you are forced into stillness, you have two choices: You can fight it and be angry and bitter all the time; or you can embrace it and allow your senses to make you aware of all you can still appreciate.

There are the little everyday things as I've already mentioned. But, oh, there is so much more! For example, the increased public

is the reason we meet, but it is also what helps us connect in a very unique way. These people get it. And that is truly something for which to be thankful.

I also am particularly grateful that, if I had to get ALS, it happened at a time and place where technology has completely changed the way we interact with the world around us — from smartphone apps to the eye-tracking device I used to type these words. (Yes, I am able to write using only my eyes!)

Years ago, people with ALS who lost the use of their hands and their voices were cut off from the world, unable

wheelchair, a van with a ramp, a special shower chair and a Hoyer lift. What a blessing such products are to so many.

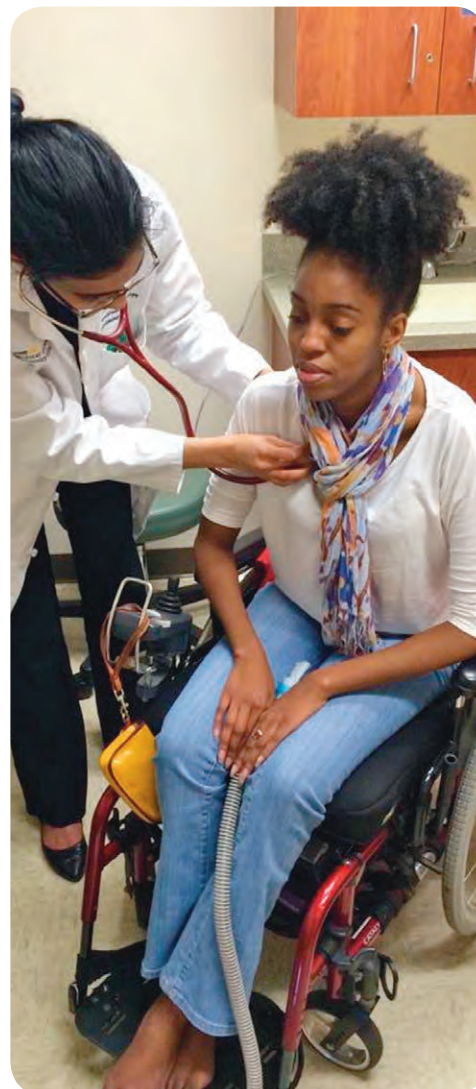
From practical help to loving friends; from music, art and books to movies, sports and technology, there is so much life that surrounds me. For these and for so much more, I am grateful.

Sometimes detours offer some of the most amazing views. You just need to keep your eyes open. [Q](#)

*Patty Blake, 59, was diagnosed with ALS in 2012 and began writing about this journey on her blog, [pattysoksofar.com](http://pattysoksofar.com). She lives with her husband, Alan, in Southern California.*

# A Passion for Helping Others

*Recent college graduate lives life the best way she can*



**T**he reward of giving back isn't something 23-year-old Brandi Hawkins focuses on as she embarks on a career in social work. She just wants to help people. "There are so many people out there who are in need of special resources that aren't aware of how much the system can assist them," she explains. "Social workers tend to be a voice for those in need."

This mindset stems in part from the fact that Brandi lives with the ups and downs of **nemaline myopathy**, which causes weakness and poor tone in the muscles of the face, neck and upper limbs, and often affects the respiratory muscles. Brandi's hope is to take her experiences and life lessons and turn them into a positive for others. Today, the recent George Mason University graduate interns at a nonprofit that provides assistance and counseling to low-income families in need of local services.

"I've overcome a lot, so I can relate to people and what they're dealing with. I've always had someone to talk to, but there are some people out there who need professional help to find assistance and better ways to deal with challenges," Brandi explains.

In addition to her internship, Brandi is active in the MDA Muscle Walk and Young Adults support group for the Greater Washington, D.C., area. Brandi enjoys reconnecting with her old friends from MDA Summer Camp and discussing topics such as dating, daily struggles, how to adjust in the adult world and the high school to college transition.

Brandi, who uses a wheelchair for long distances or prolonged walking, doesn't focus on the fact that her muscles are weaker, and that she can't lift heavy things or that it takes her longer to walk up steps. She focuses on what she can do every day.

"I'm fighting — and I'm going to continue to fight — to live life the best way I can. If you have goals, try to reach your goals. You can do anything you set your mind to. At the end of the day, only you can stop you, so don't let your disability live your life." **Q**

## Get Involved

Visit [mda.org](http://mda.org) to learn more about connecting with other members of the MDA community through events like MDA Muscle Walk and local MDA support groups.

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- ◆ Once ordered by an **ACCESS DMD™** participating physician, deflazacort\* will be sent directly to enrolled patients or their caregivers. Talk to your physician who treats your DMD about the possibility and risks of taking part in **ACCESS DMD™**.

\*Deflazacort is an investigational medication that has not been approved by the Food and Drug Administration (FDA) and is therefore not proven to be safe and effective.

To learn more about **ACCESS DMD™**, please visit [www.accessdmd.com](http://www.accessdmd.com)

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