

# Quest

EMPOWERING FAMILIES  
WITH INFORMATION AND  
INSPIRATION

MDA.ORG/QUEST  
SUMMER 2016

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For Strength,  
Independence & Life

## ACCESSIBLE ACCOMMODATIONS

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## EARNING POTENTIAL

How to work and  
keep your benefits

## CHALLENGING THE NATION TO

*live  
unlimited*

MDA families do remarkable things  
every day to live life to the fullest

pg 16



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Learn more about the TEK-RMD and the entire line of innovative mobility products on our website or by calling us at (800) 659-4548.

1 RESNA - RESNA Position on the Application of Wheelchair Standing Devices – 3/2007

2 Eng, et.al., Physical Therapy Journal of the American Physical Therapy Association, Use of Prolonged Standing for Individuals with Spinal Cord Injuries – 8/2001



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[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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PUBLICATION MANAGEMENT



## Living Unlimited Across America

**T**his summer, MDA launched a new campaign called Live Unlimited that was inspired by the stories of individuals and families we serve.

Together with our MDA community, we've challenged Americans to defy their limits — those we sometimes place on ourselves



and those defined by others — and live life to the fullest.

This campaign has sparked a national conversation about the importance of living

without limits and redefining what is possible. Many of you have shared your enthusiastic responses to what we're doing — we love hearing from our families.

As an extension of this campaign, I'm pleased to share an update on the bold five-year strategic plan we launched last year to effectively and consistently advance life-saving research, provide best-in-class care and enhance quality of life with important services and support.

Here's a glimpse at new and improved offerings you can expect from MDA:

### CURE

- Clinical trial finder tool on [mda.org](http://mda.org) to better connect families with trials for which they are eligible
- More clinical trials at MDA Care Centers
- Doubled research funding, including co-funding research with sister organizations to maximize impact

### CARE

- Enhanced experience and outcomes at MDA Care Centers through a quality improvement collaborative project at 20 Care Centers this year — results will be published and used at all Care Centers

- Piloting several new programs, including a project to reach families unable to travel to MDA Care Centers and another aimed at better transitioning individuals with pediatric-onset neuromuscular diseases to the adult care environment
- Expansion of MDA's Neuromuscular Disease Registry to learn more about neuromuscular disease and expedite clinical trial recruitment

### CHAMPION

- New MDA National Resource Center, which launched this month, to provide families one-on-one support from trained specialists
- More robust programming for young adults, including a new webinar series and interactive online tools
- Increasing public policy and advocacy efforts to help families with neuromuscular diseases

My hope is that the work we are doing together will help every individual living with a neuromuscular disease live longer, grow stronger and continue living unlimited.

In this issue, you will read about individuals and families in the MDA community who are living unlimited every day. I encourage you to visit [mda.org/LiveUnlimited](http://mda.org/LiveUnlimited) to read more stories and share your own Live Unlimited moments.

Thank you for your partnership as we work together for strength, independence and life.

Steven M. Derks  
President and CEO  
Muscular Dystrophy Association

## WHAT DO YOU THINK?

Visit [surveymonkey.com/r/mdaquest2016](http://surveymonkey.com/r/mdaquest2016) to let us know what you like about *Quest*, what we could do better and what you would like to see more (or less) of in these pages. Everyone who takes the survey will be entered into a drawing — first prize is an Apple Watch, sponsored by Disability Resource Link Inc., and second prize is a \$100 Visa gift card.



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Latondra Chappell shares her everyday Live Unlimited moments as part of this summer's campaign at [mda.org/LiveUnlimited](http://mda.org/LiveUnlimited).

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Ray Spooner

## MORE ONLINE

**IT GETS REAL**  
Becoming a mother taught Colleen Nichols some important lessons – like having a sense of humor. She shares this and more in a web-exclusive article. Visit [mda.org/quest](http://mda.org/quest) for this and other stories.

**MY FIRST MDA MUSCLE WALK**  
Darcy Leech, who lost two family members to myotonic dystrophy, discovers the life-changing experience of MDA Muscle Walk. Check it out at [mda.org/quest](http://mda.org/quest).

On the cover: Davion Bartlett



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## A Walk to Remember

MDA Muscle Walk is more than a fundraising walk. It's a powerful experience that forges lifelong connections, celebrates families and the barriers they overcome, and turns hope into answers. Every event includes a 1- to 3.1-mile lap designed for participants of all ages and abilities, including a wheelchair and equipment-friendly course. Leading up to the event, participants and teams fundraise to help MDA find research breakthroughs across diseases, care for kids and adults, and empower families with services and support to live longer and grow stronger.

**50,000+**

Total number of participants

**10,000**

Number of teams

**150**

Number of events each year in hometowns across America

**\$8.5 million**

Amount raised last year

**\$26 million+**

Amount raised since Muscle Walk began in 2011



**For more information** about Muscle Walk and to find an event near you, visit [mdamusclewalk.org](http://mdamusclewalk.org).



*"I am the captain of the Muscle Walk team Hope for Harrison. The team walks in honor of Harrison, my son, who was diagnosed with Duchenne muscular dystrophy in the summer of 2011. The biggest reason I support MDA is that MDA is about living a full life, including working to ensure those living with diseases like DMD live long, full lives."*

— Jessie Aldridge, parent

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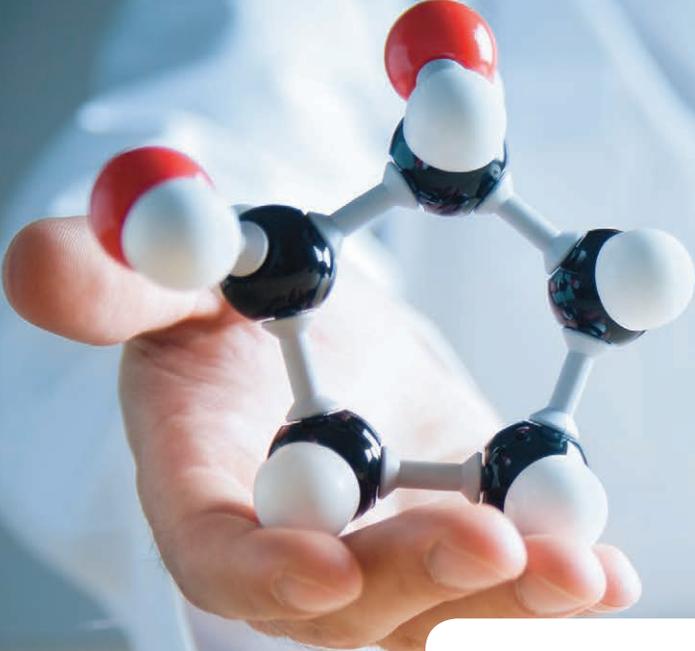
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# progress now

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

## Amyotrophic lateral sclerosis (ALS)

### Anti-Malarial Drug Takes Aim at ALS

Treatment may benefit people with a familial form of ALS



Results from an MDA-supported multicenter phase 1b clinical trial have shown that treatment with pyrimethamine was safe and well-tolerated and associated with reduced levels of SOD1 protein in people with ALS caused by a mutation in the gene for SOD1.

Pyrimethamine is a small molecule approved by the U.S. Food and Drug Administration for treatment in humans of the parasitic infections malaria and toxoplasmosis.

The results from the phase 1b trial, which enrolled 32 participants over a period of nine months, showed that SOD1 protein levels are significantly reduced in the cerebrospinal fluid after treatment with pyrimethamine.

A variety of mutations in the gene for the SOD1 protein account for approximately 20 percent of familial ALS

cases, or about 2 percent of all cases of ALS. SOD1 mutations are thought to cause ALS by creating a toxic form of the SOD1 protein. Reduction of levels of toxic SOD1 could have benefits for this population and is being pursued as a promising therapeutic strategy.



To learn more about current ALS research efforts, visit [mda.org/disease/amyotrophic-lateral-sclerosis/research](http://mda.org/disease/amyotrophic-lateral-sclerosis/research).

## Congenital muscular dystrophy (CMD)

# Omigapil on Fast Track

### Designation underlines unmet medical need for an effective therapy in CMD

The investigational drug omigapil, under development by Santhera Pharmaceuticals, has received U.S. Food and Drug Administration (FDA) fast track designation for the treatment of CMD.

Preclinical studies in disease models have shown the drug inhibits cell death and reduces body weight loss and skeletal deformation while increasing mobility and improving life span.

In collaboration with the National Institutes of Health (NIH), Santhera is conducting an ongoing phase 1 clinical study (CALLISTO) evaluating omigapil's pharmacokinetics (how the drug is absorbed, distributed and metabolized in the body), safety and tolerability in 20 ambulatory and nonambulatory patients ages 5-16, affected by either Ullrich or MDC1A subtypes of CMD.

Completion of the study is expected by early 2017.

The fast track designation is designed to facilitate the development and expedite the review of drugs to treat serious or life-threatening conditions, and that demonstrate the potential to address unmet medical needs.



To learn more about CALLISTO, including complete inclusion and exclusion criteria, visit [ClinicalTrials.gov](https://ClinicalTrials.gov) and enter NCT01805024 into the search box.



## Charcot-Marie-Tooth disease (CMT)

# Pivotal Trial Seeks People with CMT1A

### Three-drug combination will be evaluated for effectiveness



Researchers are looking for people with type 1A Charcot-Marie-Tooth disease (CMT1A) to participate in a new pivotal phase 3 clinical trial of the investigational drug PXT3003. The trial aims to determine whether PXT3003 is effective and well-tolerated in people with CMT1A.

PXT3003 is an oral low-dose combination of three different drugs designed to target the genetic cause of CMT1A by reducing levels of PMP22 protein. If shown to be effective, it could become the first approved treatment designed to stop or slow the progression of the disease.

The study, which expects to enroll 300 participants, is taking place at 28 trial sites in the United States (California, Connecticut, Florida, Massachusetts, Minnesota, Missouri, New York and Washington) and Europe

(France, Germany, United Kingdom, Spain, the Netherlands and Belgium). Trial participants will be treated with one of two doses of PXT3003 or placebo for 15 months.

Participants may be male or female, 16-65 years old, with a proven genetic diagnosis of CMT1A and must meet additional eligibility requirements.



To learn more about this trial, including site locations and complete inclusion and exclusion criteria, visit [ClinicalTrials.gov](https://ClinicalTrials.gov) and enter NCT02579759 into the search box.

Duchenne muscular dystrophy (DMD)



Eteplirsen is designed to change the way dystrophin gene instructions are processed so that functional dystrophin protein can be produced.

## Eteplirsen Update

At the time *Quest* went to press, the May 26 goal date for a decision had passed and Sarepta Therapeutics announced that the U.S. Food and Drug Administration (FDA) had requested additional data and was continuing review and internal discussions related to the company's New Drug Application for eteplirsen.

Eteplirsen is an exon-skipping drug designed to slow the progression of DMD in some kids and adults with the disease. MDA has been central to development of the exon-skipping approach from the beginning, having funded foundational work upon which the strategy was built.

Sarepta said the FDA had notified the company that it would continue to work past the original decision date to complete its work as quickly as possible. No new decision date was released.

Be sure to check back at [mda.org](http://mda.org) for the most up-to-date information.

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

## Drisapersen Discontinued

### Clinical and regulatory development halted

BioMarin Pharmaceutical announced May 31 that it has withdrawn its Marketing Authorization Application (MAA) from the European Medicines Agency (EMA) following discussions at the May 2016 Committee for Medicinal Products for Human Use (CHMP) meeting that indicated the CHMP intended to issue a negative opinion.

Based on discussions at the CHMP meeting and the decision in January by the U.S. Food and Drug Administration (FDA) that drisapersen was not ready for approval in the U.S. at that time, BioMarin noted that it has discontinued clinical and regulatory development of the drug. In addition, it has discontinued development of three other exon-skipping drugs, BMN 044, BMN 045 and BMN 053, which have similar chemistry to drisapersen and had been in phase 2 studies for different forms of Duchenne muscular dystrophy.



*BioMarin is working with physicians, patient groups and regulatory authorities to develop a transition plan for individuals who were being treated with drisapersen, BMN 044, BMN 045 and BMN 053. The company says it will continue to explore the development of next generation oligonucleotides for the treatment of Duchenne muscular dystrophy.*

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

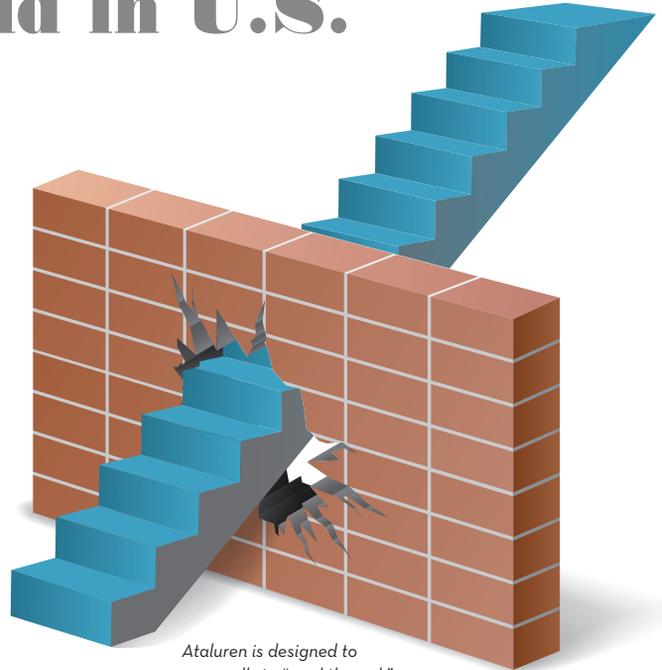
# Translarna on Hold in U.S.

## PTC Therapeutics continues to pursue regulatory approval

In a May 5 corporate update, PTC Therapeutics reported that it is continuing efforts to make Translarna available in the United States to people with DMD who could benefit from it.

Translarna, under development by PTC to treat DMD caused by a “premature stop codon” or “nonsense” mutation, is a “stop codon read-through drug.” It is designed to coax cells to “read through” (ignore) the premature stop codon in the gene for the muscle protein dystrophin, allowing for the production of functional protein. Nonsense mutations are responsible for dystrophin deficiency in 5 to 15 percent of people with DMD.

The company noted it remains engaged in ongoing conversations with the U.S. Food and Drug Administration about concerns raised in a Refuse to File letter it received from the agency earlier this year. PTC has said discussions are aimed at determining a potential path forward that would allow the company to provide Translarna to patients in the United States.



*Ataluren is designed to coax cells to “read through” erroneous stop signals in the dystrophin gene and make full-length dystrophin protein.*



For more about PTC Therapeutics’ development of Translarna to treat DMD, visit [ptcbio.com](http://ptcbio.com).



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**Duchenne muscular dystrophy (DMD)**

**MoveDMD**

**Phase 1-2 study seeks participants**



Researchers are looking for boys with DMD to participate in a phase 1-2, multisite clinical trial of the investigational drug CAT-1004. The trial aims to evaluate the safety, efficacy, pharmacokinetics (how the drug is absorbed, distributed and metabolized in the body) and pharmacodynamics (effects the drug has on the body) of CAT-1004 in pediatric patients with a genetically confirmed diagnosis of DMD.

CAT-1004 is an orally administered small molecule designed to inhibit NF-kappa-B, a molecule that is activated from infancy in DMD and which is thought to be central to causing muscle damage and preventing muscle regeneration. In animal models of DMD, CAT-1004 inhibited NF-kappa-B, reduced muscle degeneration and increased muscle regeneration.

The study, which expects to enroll approximately 30 participants, is taking place at four trial sites in the United States (California, Florida, Oregon and Pennsylvania). In addition to having funded preclinical work in the early-stage development of CAT-1004, MDA currently is supporting costs associated with travel for this trial.

Participants must be male, 4-7 years old, with a confirmed genetic diagnosis of DMD, and must meet additional eligibility requirements. Data on magnetic resonance imaging of the lower and upper leg muscles, physical function (including timed function tests) and muscle strength will be studied.



**To learn more about this trial, including site locations and complete inclusion and exclusion criteria, visit [ClinicalTrials.gov](https://ClinicalTrials.gov) and enter NCT02439216 into the search box.**

**FOR-DMD**

**Ongoing phase 3 clinical trial seeks participants**

Researchers are looking for boys with DMD to participate in the ongoing phase 3 clinical trial titled Finding the Optimum Regimen for Duchenne Muscular Dystrophy (FOR-DMD). The trial will compare three different corticosteroid regimens in boys with DMD, ages 3-7.

Corticosteroids, such as prednisone and deflazacort, work as anti-inflammatories or immunosuppressants, and have been shown in clinical trials to stabilize or improve muscle function and strength in boys with DMD. Benefits often include prolonged ability to walk, increased respiratory function, decreased incidence of spinal surgery and stabilized cardiac function. Among the frequent side effects of steroid treatment are weight gain, osteoporosis, fat redistribution, growth slowing, cataracts, and behavioral and mood changes.

The FOR-DMD trial aims to determine which of three corticosteroid treatment regimens increases muscle function the most, and which causes the fewest side effects.

Study results are expected to provide patients and families with clearer information about the best way to take these drugs.

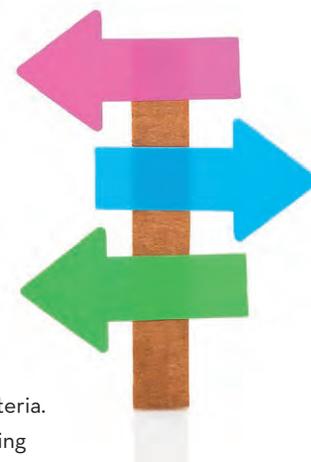
The study, which expects to enroll 225 participants, is currently enrolling at more than 35 trial sites in the United States, Canada, Germany, Italy and the United Kingdom.

Participants must have a genetically confirmed diagnosis of DMD, be able to rise independently from the floor and meet other eligibility criteria.

MDA has a long history of supporting research and clinical study into the effects of corticosteroids in DMD and related diseases, with studies to determine mechanism of action, drug effects, side effects and best dosing regimen. An MDA human clinical trial grant currently is providing funding support to cover travel expenses for participants in the FOR-DMD trial.



**To learn more about this trial, including site locations and complete inclusion and exclusion criteria, visit [ClinicalTrials.gov](https://ClinicalTrials.gov) and enter NCT01603407 into the search box, or contact Kimberly Hart at 585-275-3767 or [Kim\\_Hart@urmc.rochester.edu](mailto:Kim_Hart@urmc.rochester.edu).**



# Vamorolone Moves to Phase 2 Testing

**'Dissociative steroid' may provide benefits of glucocorticoids, without unwanted side effects**



ReveraGen BioPharma has announced that it has received a \$3 million grant from the National Institute of Neurological Disorders and Stroke

(NINDS) of the National Institutes of Health to conduct phase 2 clinical trials of vamorolone (previously VBP15) in boys with DMD.

Vamorolone, a “dissociative steroid,” is an anti-inflammatory compound. Researchers hope it will provide the same benefits of traditional glucocorticoids, such as prednisone and deflazacort, without the unwanted side effects – including stunted growth, insulin resistance and weight gain – of those drugs. In clinical trials, glucocorticoid steroids have been shown to benefit DMD patients, but many find the side effects to be burdensome or intolerable.

The news follows encouraging results from a phase 1 trial conducted in healthy adult

volunteers, and is an example of the success of MDA's Venture Philanthropy program (MVP), which provided \$2.9 million in support for early-stage and pre-clinical development of the drug, along with phase 1 clinical testing.

The phase 2a multiple ascending dose studies to test safety, tolerability and pharmacokinetics (the drug levels in the body) will be conducted in boys with DMD, ages 4-7. A six-month extension study will follow, with the goal to test clinical efficacy, safety and pharmacodynamics (effects the drug has on the body).

 To learn more about the phase 2 trials for vamorolone, visit [ClinicalTrials.gov](https://ClinicalTrials.gov) and enter **NCT02760264** and **NCT02760277** into the search box.

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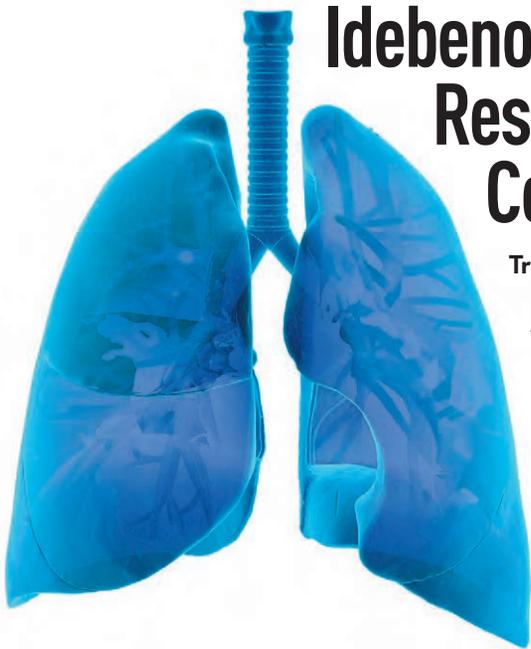
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## Duchenne muscular dystrophy (DMD)



# Idebenone May Reduce Respiratory Complications

### Treatment could prevent hospitalizations

Analysis of results from a completed phase 3 clinical study to test idebenone in people with DMD showed that trial participants who were treated with the drug for one year had fewer bronchopulmonary problems, such as upper respiratory tract infections and bronchitis, than participants who received a placebo.

Idebenone, which scientists believe works by improving the way muscles utilize fuel to power movement, is a synthetic version of coenzyme Q10.

Due to respiratory muscle weakness, DMD patients often have impaired cough and a reduced ability to clear their airways. This leads to greater incidence of respiratory infections and hospitalization.

If proven safe and effective, idebenone could someday be used to help reduce the risk of respiratory infections in people living with DMD.

 To learn more about current DMD research efforts, visit [mda.org/disease/duchenne-muscular-dystrophy/research](http://mda.org/disease/duchenne-muscular-dystrophy/research).

## Paramyotonia congenita

# Ranolazine Trial Recruiting

### Drug may treat symptoms of paramyotonia congenita

Researchers at The Ohio State University are looking for adults, ages 18 years or older, with paramyotonia congenita to participate in a phase 2 open-label study being sponsored by Gilead Sciences to test the experimental drug ranolazine.

Ranolazine currently is approved by the U.S. Food and Drug Administration to treat chest pain in people with heart disease. The goal of the study is to determine whether or not the drug is a safe and effective treatment for the symptoms of paramyotonia congenita.

Study participants will receive treatment with ranolazine and will visit The Ohio State University in Columbus four times in a period of one and a half months to complete questionnaires, physical tasks and evaluations to assess efficacy. Funding is available to cover travel costs, and a \$100 stipend will be provided for each in-person visit.

Participants must have a diagnosis of paramyotonia congenita and must meet additional requirements.



 For additional information on this trial, including trial inclusion and exclusion criteria, visit [ClinicalTrials.gov](http://ClinicalTrials.gov) and enter NCT02251457 into the search box. If you or someone you know may be interested in participating in the study, please contact Amy Bartlett at 614-366-9050 or [amy.bartlett@osumc.edu](mailto:amy.bartlett@osumc.edu).

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Let's  
Go  
Places

# The Competitive Edge

*Playing adaptive sports scores health benefits and possibly higher achievement in employment*

BY DONNA SHRYER



Scott Hatley

**S**cott Hatley, 37, began playing adaptive sports soon after he was diagnosed with Duchenne muscular dystrophy (DMD) at age 4. He began with wheelchair basketball, playing with friends in his garage. From there, he went on to

adaptive skiing, wheelchair rugby and a few other activities before finding his current passion, electric hockey. E-hockey relies on battery-powered carts that can zoom up to 10 mph and turn on a dime.

Swapping out his team jersey for a dress shirt and tie, Hatley is co-founder and development and community relations director of Incight, a Portland, Oregon-based nonprofit created to

unlock the potential of people with disabilities through education, employment and independence. Since its debut in 2004, Incight has awarded nearly 800 college scholarships to students with disabilities and sponsored an annual stream of employment and networking events.

### DYNAMIC DUO

While Hatley sees his athletic prowess and business acumen as

two distinct sides of himself, a 2015 study from the University of Houston Department of Health and Human Performance suggests otherwise. The study, which surveyed 131 wheelchair rugby and wheelchair basketball athletes, concludes that

participating in adaptive sports positively impacts athletes with disabilities and their potential for employment and economic independence.

According to Michael Cottingham, Ph.D., associate professor and the study's principal investigator, adaptive sports provide a strong social support system, as well as increased self-confidence and a peer-education system. "These factors are probably directly and indirectly impacting employment," Cottingham says. "To what extent we don't yet know, but what seems clear is that disability sport is a catalyst."

### GET IN THE GAME

Adaptive sports embrace an ever-increasing array of options. In addition to e-hockey and its close cousin power hockey, Disabled Sports USA's list of available adaptive sports proves that almost any enjoyable activity can be made accessible, from baseball to biathlon and soccer to scuba diving.

The accommodating nature of adaptive sports explains in part the growing participation. For example, Shelby Vanvliet, a 16-year-old high school student with congenital muscular dystrophy (CMD), sees how her sport — power hockey — is



Shelby Vanvliet



Sarah Heinsch contemplates her next move on the power hockey rink.

## BE A SPORT

To find a sport, start with your local MDA office, or do an internet search for “adaptive sports” in your city. You also can talk to your MDA Care Center physical therapist or physician. “Many colleges and universities have excellent adaptive sports programs,” advises Scott Hatley. “If you live near a campus, check out what they offer.”

In addition, many national and local organizations provide sports and recreation opportunities for people with disabilities. Here is a list to get you started:

- Incight, Scott Hatley’s organization in Portland, Ore., hosts a robust schedule of adaptive recreation and social events. [incight.org](http://incight.org); 971-244-0305.
- Disabled Sports USA provides opportunities for people with disabilities to develop independence, confidence and fitness through sports. [disabledsportsusa.org](http://disabledsportsusa.org); 301-217-0960.
- The National Ability Center provides sports and recreation programs for individuals of all abilities. [discovernac.org](http://discovernac.org); 435-649-3991.
- The National Center on Health, Physical Activity and Disability (NCHPAD) is dedicated to helping people with disabilities and chronic health conditions participate in physical and social activities. [nchpad.org](http://nchpad.org); 800-900-8086.
- The National Sports Center for the Disabled (NSCD) is one of the largest outdoor therapeutic recreation and

adaptive sports agencies in the world. [nscd.org](http://nscd.org); 303-316-1518.

- Wasatch Adaptive Sports, in Snowbird, Utah, provides instruction in winter and summer recreational pursuits for people with adaptive needs and their families. [wasatchadaptivesports.org](http://wasatchadaptivesports.org); 801-933-2188.
- Endeavor Games, sponsored by the University of Central Oklahoma, provides athletes with physical disabilities an opportunity to display their talents in a competitive setting. [uco.edu/wellness/sr/endeavor/index.asp](http://uco.edu/wellness/sr/endeavor/index.asp); 405-974-3140.
- U.S. Paralympics, a division of the nonprofit United States Olympic Committee, promotes excellence in the lives of people with Paralympic-eligible impairments, including physical disabilities and visual impairments. [teamusa.org/US-Paralympics](http://teamusa.org/US-Paralympics); 888-222-2313; 719-632-5551.
- Special Olympics International is a global organization with athletic programs in more than 220 countries. [specialolympics.org](http://specialolympics.org); 800-700-8585.



*“Whether you’re playing or watching, there’s camaraderie. You’re compelled to get involved, and that’s so healthy. If you don’t use your social skills you lose them.”*

– Floyd Miller

tweaked for anyone who wants to play. “If you’re too weak to participate fully, we attach the hockey stick to your wheelchair — so there’s less physical effort, but you still get the whole team experience.”

When you find a sport that interests you, Floyd Miller, a 31-year-old diagnosed with myosin storage myopathy, a form of congenital myopathy, suggests attending a few games as a spectator. “Talk to the team members and if it looks good, just do it! Get out there. Give it a shot. You’ll probably fall in love with it.”

Miller’s love is e-hockey, and he’s quick to add that anyone who feels uncomfortable joining the team is welcome to join the audience. “Whether you’re playing or watching, there’s camaraderie. You’re compelled to get involved, and that’s so healthy. If you don’t use your social skills you lose them,” he stresses.

### TEAM SPIRIT

Sarah Heinsch, 35, is an avid power hockey player with impressive stats, including being a member of the three-time defending PowerHockey Cup Champion Minnesota Saints and the 2014 PowerHockey Cup Championship Game MVP.

Heinsch, diagnosed with spinal muscular atrophy (SMA), loves talking about power hockey, although she quickly segues into the social support system her team represents. “My teammates are some of my best friends, and we love hanging out together. In fact, two players on my team fell in love and got married. The whole team went to their wedding!” Heinsch says with happiness in her voice.

A national survey conducted by Harris Poll on behalf of Career-Builder discovered that this team spirit is yet another link between playing adaptive sports and professional success. Of the top 10 skills companies look for when hiring, 60 percent of those surveyed seek team-oriented candidates. According to Vanvliet, that is a huge benefit of adaptive sports. “Everyone talks to everyone, and it’s impossible to sit by yourself. Someone will sit next to you and start a conversation. Now you’re part of the team — whether playing or watching — and everyone deserves to feel that!” 

*Donna Shryer is a freelance writer in Chicago.*

# CHALLENGING THE NATION TO

*live  
unlimited*

*MDA families are doing remarkable things every day to live life to the fullest — and we're calling on all Americans to live beyond limits and support MDA families*

**W** MDA families face daily challenges that often make walking, playing, running, getting dressed, hugging and talking difficult — sometimes seemingly impossible. But these courageous families are defying their limits every day and inspiring a nation to do the same.

For example, Davion Bartlett was diagnosed with Duchenne muscular dystrophy when he was 4 years old. He quickly learned as a young child that his disease would never define him or hold him back.

“Strength doesn’t come from your muscles,” Bartlett says. “It comes from your ability to keep going when things get tough.”



“Strength doesn’t come from your muscles. It comes from your ability to keep going when things get tough.”

— Davion Bartlett, who has Duchenne muscular dystrophy

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DAVION BARTLETT

## HALEY FRIELER



Bartlett, who will be a freshman in high school this fall, recently completed the One America Mini Marathon in Indianapolis, a half marathon covering 13.1 miles and finishing on the Indianapolis Motor Speedway track. His teachers convinced him to complete the race as they pushed him in a special chair to raise money for MDA.

“People always used to tell me I couldn’t do things,” Bartlett shares. “Today, I continue to prove them wrong. Just watch me.”

Bartlett’s mom, Marilyn, believes crossing that finish line was a life-changing experience for him. “Davion is strong. He embodies what it means to live unlimited.”

Bartlett’s persistence to live beyond his limits and to refuse to believe in the word “can’t” is the inspiration behind MDA’s new six-week campaign

called Live Unlimited, which launched on June 20, 2016 — the first day of summer.

It was born from the stories of individuals and families in the MDA community who are doing things every day to break through perceived barriers and live life to the fullest. From everyday moments that help maintain independence to life-defining milestones, Live Unlimited is about both the small and big ways individuals overcome life’s barriers.

### CREATING A WAVE OF MOMENTUM

The Live Unlimited campaign kicked off with a digital takeover sponsored by National Seating and Mobility that included celebrity performances streaming on Facebook Live from sunrise to sunset. Celebrities, including X Ambassadors, Billy Ray Cyrus, JoJo, American Authors, Steve Aoki, Lauren Alaina, Mario Lopez and

*“I credit a lot of my independence and well-being to my parents treating me exactly the same as my siblings. ... I think my biggest triumph is being as independent as I am. I’m going on five years of living completely on my own, independently running my own care workers and really living life the way I want to.”*

— Haley Frieler, who has spinal muscular atrophy



## JOIN THE LIVE UNLIMITED MOVEMENT

MDA is challenging Americans nationwide to defy their limits and support MDA families. Here’s how you can get involved:

1. Share how you #LiveUnlimited at [mda.org/LiveUnlimited](http://mda.org/LiveUnlimited). You can create a unique Live Unlimited graphic that can be customized and uploaded to social media channels to show the world that limits don’t define you. For every moment shared through July 31, a generous sponsor will donate \$1 to MDA, up to \$30,000.
2. Download MDA’s new app MDA Amplify to receive and share the latest updates and news on social media. See “Become an Amplifier” for details on how to use this new tool.
3. Purchase a special-edition Live Unlimited bracelet at [endorphinwarrior.com/live-unlimited](http://endorphinwarrior.com/live-unlimited) — \$6 from every bracelet sold will go directly to MDA.
4. Encourage your networks to make a donation at [mda.org](http://mda.org) to help more kids and adults with muscular dystrophy live unlimited.

## 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 year-round.

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.

### How to Join:

1. Download MDA Amplify for free from the App Store via your Android or iOS phone.
2. Choose and join a group based on the updates you'd like to receive and share.
3. Connect your personal social networks to the app. Be sure to accept all permissions. The app will never post anything without your permission.
4. Permit the app to send push notifications to let you know when new information is available.
5. Approve MDA-supplied posts or edit them to make them your own.
6. That's it – you're an MDA Amplifier!



**Keep sharing your stories of how you – or someone you know – live beyond limits every day, and continue sharing news and updates via MDA Amplify.**

## 12 to Watch

From learning how to drive, graduating high school or getting a wheelchair for the first time to stay independent, to being pushed in a half marathon or even skydiving to celebrate doubling life expectancy, 12 MDA families are sharing their everyday Live Unlimited moments big and small as part of this summer's campaign. To learn more about the Live Unlimited campaign and to read and watch their stories, visit [mda.org/LiveUnlimited](http://mda.org/LiveUnlimited).

more, sang and shared their Live Unlimited moments to support MDA. They joined social influencers and MDA's network of families and friends who created a wave of momentum by sharing how they live unlimited in their

own words on Facebook, Twitter and Instagram.

On [mda.org/LiveUnlimited](http://mda.org/LiveUnlimited), people have been sharing how they live unlimited by creating a custom graphic that can be uploaded to social media to spread the

word and encourage others to support MDA families.

Additionally, the first-ever MDA smartphone app called MDA Amplify is available to make receiving and sharing content about neuromuscular disease news, stories and

“When Ray was first diagnosed and he wanted to go across country on his bicycle, people thought he was a little bit crazy. But I knew we were going to do it. I knew Ray was going to be able to do it, and I went along with him to make sure he did.”

– Rae Spooner, wife of Ray who has ALS



RAY SPOONER

“Ethan’s live unlimited moment was him being able to play sports. We were told that he could never play sports and that we should get him involved in music or art, so him being able to play t-ball last year was huge.”

– Jordan Lybrand, mom of Ethan who has Duchenne muscular dystrophy

ETHAN LYBRAND



other relevant updates easier than ever before. (See “Become an MDA Amplifier” on page 19.)

“Live Unlimited speaks to a fundamental human truth in society: No matter who you are, where you live or what you care about, we all have the power to overcome our personal limits and those defined by others to live life to the fullest,” says MDA President and CEO Steven M. Derks.

“We believe this universal understanding will spark a national conversation that shifts the focus away from our limitations to the power of possibilities, and in turn shines the light once again on the urgency and action needed to help more kids and adults with muscle-debilitating diseases live unlimited.”

#### FINDING A WAY AROUND YOUR LIMITATIONS

“Living unlimited means breaking through barriers and not letting people

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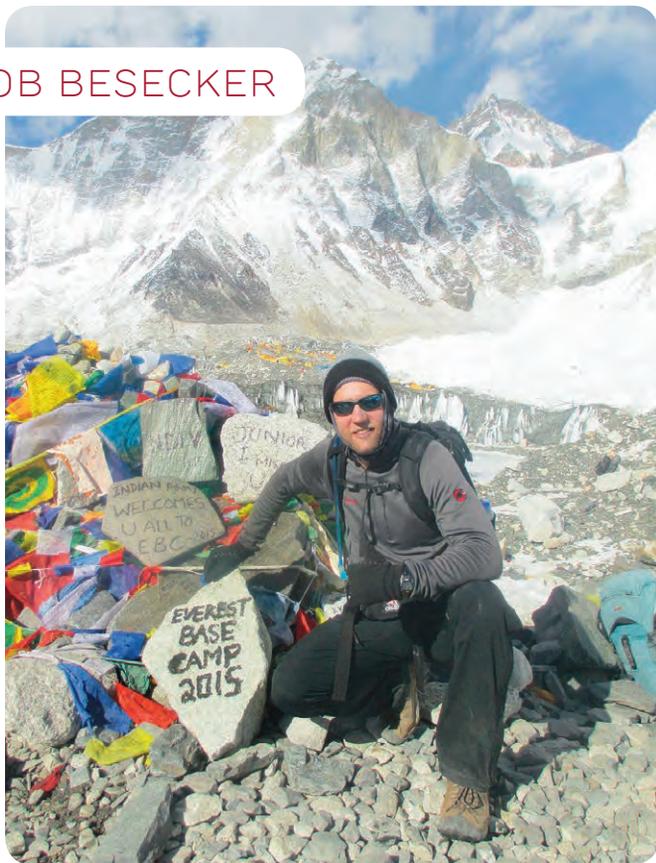


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Why MK Gel?



ROB BESECKER



“Everybody has obstacles on a day-to-day basis. It’s a matter of getting through those obstacles and continuing to pursue your goals, your dreams and your ambitions.”

– Rob Besecker, who has myotonic dystrophy

tell you what you can and cannot do,” says Rob Besecker, 41, who was diagnosed with myotonic muscular dystrophy in 2006. “Live for your goals; live for your dreams; and pursue every one of them. Living unlimited means finding a way around your limitations.”

An athlete in college, Besecker’s diagnosis of myotonic muscular dystrophy in 2006 came as a shock. He experienced months of cardiac issues, muscle problems, muscle fatigue and muscle pain before finally learning what was causing it.

“When you get hit with a heavy diagnosis, you have two choices: give up and quit or move forward,” Besecker says. “Quitting is just not an option for me.”

Besecker has traveled to all seven continents, visited every Major League baseball stadium in the United States, and last

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year he accomplished his biggest adventure yet — hiking to the base camp of Mt. Everest.

“If somebody tells me I can’t do something, my first response is always, ‘Why?’ My next response is typically: ‘Oh yes, I can.’ The Everest hike was one many told me I should never attempt,” Besecker recalls. “But this trip was not just a milestone for me; it represented an exclamation point in my journey. It was a grueling experience and encompassed significant challenges to my physical and emotional well-being.

“I’m not doing anything that anybody else couldn’t do. I’m not special. I’m just living my life the way I want to live, and I’m not letting little things or big things get in the way.” 

## HOW AMERICANS PERCEIVE LIMITS

MDA has released the findings of a recent survey\* that asked Americans about their own experience facing limitations and uncovered the following:

A majority of those who face limitations say they have overcome them (**69%** of those facing limitations). This sentiment is stronger among millennials (**78%**) and those with a connection to a muscle-debilitating disease (**77%**).

Two-thirds of respondents (**65%**) say they have done something they once thought was impossible.

A majority of survey respondents (**57%**) say they have faced a limitation that has made it very difficult or impossible to do something they wanted to do.

The most common limitation cited was financial (**58%**) among those who said they have faced limitations, followed by lack of self-confidence (**38%**), physical limitations (**37%**) and fear (**32%**). Fewer said they have faced limitations because of their educational background (**24%**), professional status (**17%**) or mental abilities (**15%**).

When it comes to defying the impossible and overcoming limitations, the vast majority (**82%**) of those surveyed believe in the power of support and encouragement from friends and family more than they do in new research and technology (**70%**). Even more (**87%**) feel that if you have enough drive and willpower, you can overcome almost any limitation.

\* The survey was designed by Edge Research in partnership with MDA and fielded by OMNIWEB using the KnowledgePanel™, a national online omnibus service of GfK Custom Research North America. Respondents included 1,000 male and female adults 18 years of age and older, and were weighted to ensure accurate and reliable representation of the total population. Field dates: April 29–May 1, 2016

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# where to stay when away



*Tracking down accessible accommodations doesn't have to be complicated – if you know where to look and how to book*

BY BARBARA AND JIM  
TWARDOWSKI, RN

The Horans have 14 cousins. Every year, they make the trek from Denver to Chicago to attend a high school graduation or other special occasion with their relatives. Finding accessible accommodations can be a challenge for this family of five and their bulky medical equipment. The Horans' three adult sons have Duchenne muscular dystrophy (DMD), and each uses a power wheelchair.

In their years of travel, the Horans have learned a thing or two about booking hotels. First, they look for newer hotels. "Accessibility in older properties means it has grab bars [in the bathroom]," says Brian Horan. The family has booked what they thought would be accessible lodging only to discover that their room was on the second floor and there was no elevator. "Never make assumptions," says Horan. He books using a hotel's toll-free reservation line, and then follows up with a phone call to the property a week later to reiterate his requests.

## HOTEL BOOKING TIPS

Great rates abound online, but discount hotel search engines typically do not address accessibility. Even when these sites list accessible features, the information may be inaccurate or incomplete. For example, a quick review of Dallas hotels on Room77.com returned only two “ADA Accessible” options from a list of 500 rooms. If you find a room you like through a third-party website, contact the hotel directly to confirm you’ll get exactly what you need.

WheelchairTravel.org is an informative website describing the accessibility of destinations around the world. The founder is John

Morris, a triple amputee and power wheelchair user, who often has arrived at his hotel only to be told the accessible room he reserved was given away or does not exist. On a trip to Beijing, China, he was assured his room would have a roll-in shower, yet the entire property had none. This scenario left him with two options: change hotels, which almost always costs more, or find a way to adapt the room. His Beijing bathroom had a drain in the middle of the floor. The hotel secured a manual wheelchair for Morris, who showered using the long retractable showerhead installed in the bathtub.



The Horan sons in front of Wrigley Field during their trip to Chicago.

When traveling abroad, the standards regarding access vary from one country to another, which is why Morris prefers U.S.-based hotel chains. He recommends travelers book a minimum of a month prior to their travel dates and choose refundable rates.

## INSIDER TIPS FOR HOTEL STAYS

The nonprofit Open Door Organization’s mission is teaching businesses how to succeed in the disability market. Their 2015 study of travelers with disabilities found nearly half of those surveyed encounter obstacles at hotels. The most common areas of dissatisfaction are inconvenient rooms, difficulty opening doors and lack of proper shower facilities.

*Here are some tips for overcoming these and other challenges at a hotel:*



**Speak up.** When booking a hotel room, be specific about what you need. If you can’t walk long distances, ask to be close to the elevators. Want to spend time in the swimming pool or spa? Confirm the hotel has a lift. Be patient when speaking to hotel staff. They may not be familiar with accessible terminology. Always ask for the name of the person with whom you speak in case there is a problem.

**Shower comfortably.** Many hotels with roll-in showers lack a built-in shower bench. Ask the front desk or housekeeping department if the hotel can supply a portable bench. Consider traveling with your own portable bath seat. Roll-in showers are messy; always ask for extra towels.



**Rest easy.** The height of hotel beds varies and can be several inches higher or lower than a wheelchair. Pack a transfer board to avoid struggling in and out of bed.



**Count the beds.** Accessible hotel rooms, especially those with roll-in showers, routinely have one king size bed. If you are traveling with a companion and need two beds, ask if a roll-away bed or sofa sleeper is available. Another option is to choose an all-suite or extended stay hotel.

Homes with accessible features are available through house-sharing services.



### HOTEL ALTERNATIVES

Not all accessible accommodations are in a hotel. More unique lodging is available, but finding a cozy cabin in the mountains with no stairs or a Paris apartment with a roll-in shower will take some research.

### HOUSE SHARING

#### [accomable.com](http://accomable.com)

This London-based startup compares itself to Airbnb, the most popular accommodation-sharing website in the world — except Accomable focuses on accessible accommodations. Company CEO

Srin Madipalli, who has spinal muscular atrophy (SMA) and uses a power wheelchair, anticipates the website will have several thousand accessible properties around the world listed by the end of this year and hopes to add equipment and adaptive vehicle rental.

#### [matchinghouses.com](http://matchinghouses.com)

Matching Houses is an international house swapping service created by people with disabilities for people with disabilities. Membership is free after completing a detailed survey regarding

your home's accessibility. Some homeowners even allow guests to use their personal vehicle or ask you to care for their pets.

### INNS AND B&Bs

#### [emerginghorizons.com](http://emerginghorizons.com)

If you are looking for an intimate getaway, consider an inn or B&B. Accessible travel expert Candy Harrington has covered the topic for 20 years. Her book, *There Is Room at the Inn: Inns and B&Bs for Wheelers and Slow Walkers*, includes 117 properties in 40 states. Each year, Harrington travels thousands of miles as the editor of *Emerging Horizons*, an online accessible travel publication, which features accommodations.

### VACATION HOMES

#### [homeaway.com](http://homeaway.com)

HomeAway has more than 1 million vacation home rentals in 190 countries. If a property has wide hallways and doors, ramps (if needed), zero-step entry and a large main floor bathroom, it is listed as “wheelchair accessible.” (Owners self-report this

## The World at Your Wheels

Accommodations are just the tip of the iceberg when it comes to accessible travel topics. Check out [curbfreewithcorylee.com](http://curbfreewithcorylee.com), a blog about destinations, air travel advice and more by Cory Lee, a travel enthusiast who has spinal muscular atrophy (SMA). Be sure to read about how Lee finds a place to stay when he travels in a web-exclusive article at [mda.org/quest](http://mda.org/quest).



The Horans enjoy the sun during a visit to Aruba.



## FLY WITHOUT LIMITS

Access to air travel is an important element of living life without limits. To learn how MDA works to improve the experience for air travelers with disabilities and how you can be a part of it, turn to page 42. You can also learn about these efforts in our Strongly blog. Go to [strongly.mda.org](http://strongly.mda.org) and search for "accessible air travel."

information.) Renters looking for additional accessible features, such as a roll-in shower, will need to peruse the listings and speak with the owners.

### HAVE YOUR SAY

Wherever you decide to rest while traveling, let the company or owner know you appreciate their accessible accommodations by writing favorable reviews, joining loyalty programs or simply dropping them a note. Travelers with disabilities represent a growing segment of the market, and the travel industry needs to know accessible accommodations are needed and generate income. [Q](#)

*Barbara Twardowski has Charcot-Marie-Tooth (CMT) disease and uses a power wheelchair. Jim, her husband, is a registered nurse. Both have degrees in journalism. They live in Louisiana and write about accessible travel, health and lifestyle, and related issues.*

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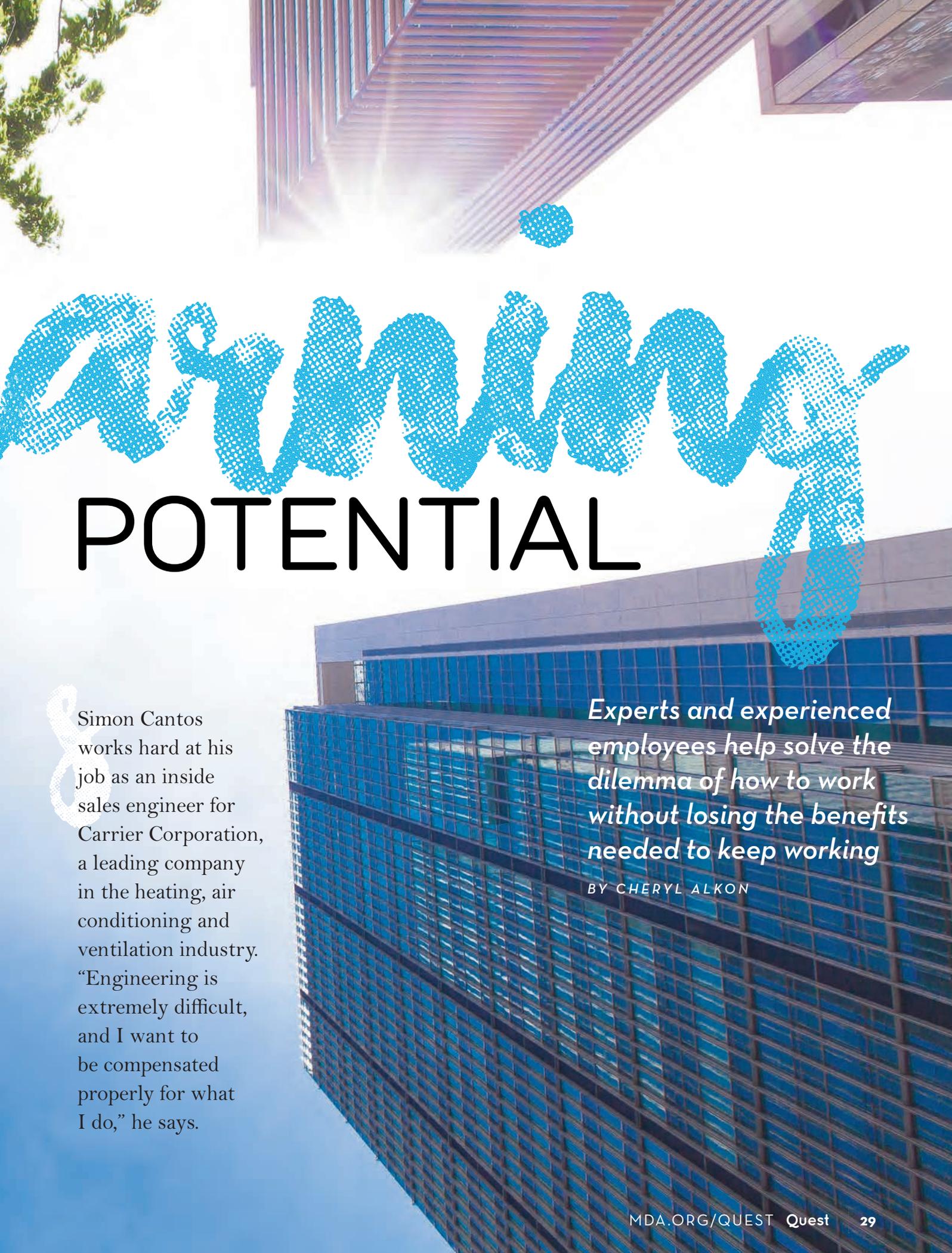
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# dreaming

## POTENTIAL

Simon Cantos works hard at his job as an inside sales engineer for Carrier Corporation, a leading company in the heating, air conditioning and ventilation industry. “Engineering is extremely difficult, and I want to be compensated properly for what I do,” he says.

*Experts and experienced employees help solve the dilemma of how to work without losing the benefits needed to keep working*

BY CHERYL ALKON



“It puts us in a weird spot. If we work, we stay healthy, but then we’re too healthy to keep the benefits for the attendant care.”

— Simon Cantos

Cantos, 33, who lives with Ullrich congenital muscular dystrophy (CMD), receives funding for dependent care from a state-sponsored program called Medical Assistance for Workers with Disabilities. He pays an out-of-pocket rate to stay in the program that provides funding for his personal care attendant to help with daily needs. The rate is based on a percentage of his salary and

isn’t available once income thresholds are reached. Cantos says he is close to, but hasn’t yet exceeded, that ceiling.

“Without that reduced rate, I’d be working just to keep my assistance,” he says. “If I wanted to maintain the comfort of a salary of \$55,000 a year — the program’s income threshold — I’d need to be earning about \$300,000 a year to offset the expenses of the attendant care and assistance that I need. That’s roughly the salary of the boss of my boss — I can’t earn that much money.”

It’s a dilemma that Cantos and others in similar situations say is common: how to work without losing the benefits one needs to keep working.

“It puts us in a weird spot,” says Cantos. “If we work, we stay healthy, but then we’re too healthy to keep the benefits for the attendant care. If we don’t work, we keep our benefits, but we end up being sicker. It’s a Catch-22.”

## FINDING SOLUTIONS

Experts who understand the intricacies for individuals with disabilities who work say it is possible to keep government-sponsored benefits while employed. Doing so requires knowing the rules intimately and being prepared before accepting a job.

“You need to develop a framework and have a goal in mind: Do you want to work full time or part time?” says Alexandra McArthur, MDA senior program manager for transitions. “Then figure out the benefits planning and support that will help you meet that goal. Start big and work backward from there to determine the details that are necessary to help you meet each goal.”

The array of programs for people with disabilities can be dizzying. There are federal programs such as Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), Medicare and Medicaid, along with local

## HELPFUL RESOURCES

Want to maximize your benefits while you work? These resources can help you figure it out.

**Medicaid:** A joint federal and state program that provides health insurance for some people with limited income and resources. [medicaid.gov](http://medicaid.gov)

**Ticket To Work:** A free program through the Social Security Administration that encourages people with disabilities ages 18-64 to work and build financial independence.

[chooseworkttw.net](http://chooseworkttw.net)

**U.S. State/Territory Vocational Rehabilitation Agencies:** Each state has an

agency charged with helping people with disabilities to pursue meaningful careers. Find a list of agencies at [soar.askjan.org/IssueConcern/214](http://soar.askjan.org/IssueConcern/214).

### Work Incentives and Planning

**Assistance (WIPA):** A free program through the Social Security Administration that helps people with disabilities understand the programs they are eligible for so that they can maximize their income without sacrificing their government-issued benefits. WIPA agencies employ community work incentives coordinators (CWIC). [ssa.gov/work/WIPA.html](http://ssa.gov/work/WIPA.html)



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“The day I got hired, I had a real sense of pride in myself.”

— Joshua Moser

### Finance and You

Quest covers a series of financial topics in previous issues and online. You can find “Investing in the Future” from our Spring 2016 issue as well as an online exclusive Q&A about taxes, asset development and federal benefits at [mda.org/quest](http://mda.org/quest).

programs that vary from state to state. To fully understand what you are eligible for, look for a benefits coordinator in your state, known as a community work incentives coordinator (CWIC). These counselors meet with individuals and their families to determine what benefits they already have or may qualify for, and learn about how job income may affect those benefits.

Michele Boardman, 30, who lives with limb-girdle muscular dystrophy (LGMD), works as a CWIC for AHEDD, a nonprofit organization in Pennsylvania that offers employment services to people with disabilities. She knows both sides of the issue.

When talking with someone who wants to work but is concerned about losing their benefits, she addresses

the individual’s occupational goals, expected income, health care benefits provided by an employer or through Medicare or Medicaid, and what other programs, called waivers, are available for personal care attendant services or home/vehicle modifications. “We go over all the details to help you make an informed choice,” she says. “We encourage anyone capable of work to do so, but financially, it also has to make sense.”

Boardman has seen the importance of being persistent when applying for SSI or SSDI. “Two-thirds of people applying get turned down the first time. We encourage people to appeal.”

### LEARN FROM OTHERS WHO HAVE BEEN THERE

Erica Madge, 28, works as a drug and alcohol therapist and intake coordinator at NHS, an education and human services provider serving Northeast and Mid-Atlantic states. Living with type 2 spinal muscular atrophy (SMA), Madge relied on SSI before she began her job, but she no longer qualifies due to her salary. She receives Medicaid for health insurance and gets a waiver for her personal care attendant. While on SSI, Madge submitted paperwork monthly and now submits it every six months to prove her income is within threshold limits for her benefits. Her advice is to stay on top of everything and file paperwork in person.

“I don’t want to say it’s difficult, but it can be time-consuming,” she says.

“Be aware and read up on your state’s laws. Knowing what your needs are and being able to verbalize them is important. I’ve had cases where the people [at a government office] didn’t recognize the importance of having a personal care attendant, but if you stay organized and keep all your paperwork together, you’ll be more successful. Doing it over the phone — for me, 95 percent of the time, it’s been a failure.”

Self-advocacy is necessary, adds Joshua Moser, 31, who works as a quality assurance associate for a financial firm and lives with Duchenne muscular dystrophy (DMD). Moser became financially independent from his parents at age 18 so he could qualify for SSI. He’s been working for eight years and pays a percentage of his attendant care based on his income, but says it’s worth it. “The day I got hired, I had a real sense of pride in myself.”

It’s impossible to make a blanket statement about what will work best for every person with a disability who wants to work, but setting goals and working with benefits counselors or other financial or legal experts can help you determine how to work while maximizing your benefits.

“I always think knowledge is power,” says Boardman. “I want people to make informed choices about how working will impact their financial situation.” **Q**

*Cheryl Alkon is a freelance writer based in Massachusetts.*

Some said independence might be impossible.

I said  
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"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 to have proven them wrong."  
– Joe Akmakjian, 25, living with spinal muscular atrophy

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# Choice Seating

*However you roll, wheelchair accessories can enhance your mobility and independence*

BY SHAILA WUNDERLICH

**M**anufacturer, brand and model are merely the first choices in the methodical process of wheelchair seating assessment. These days, it's wheelchair accessories that present the widest selection and biggest potential for enhancing independence and mobility. There are accessories for comfort, attachments for smoother rides and additions designed to maximize independence for people living with neuromuscular diseases.

This brief roundup of proven and promising products can help you make sense

of the vast accessories market. Be sure to consult with your MDA Care Center team for help selecting the best mobility equipment to meet your needs.



Spinergy's FlexRims

## MANUAL CHAIR ACCESSORIES

Some of the most ingenious accessories to become available within the past several years are those meant to maximize comfort and mobility for people using manual wheelchairs.

"With muscular dystrophy, we talk about conserving

energy and optimizing function and efficiency," says Laura Case, an assistant professor and occupational therapist who works with MDA families at the MDA Care Center at Duke University.

Casters for tighter turns, brake tips for easier grip and levers for distance all maintain

### KNOWLEDGE SOURCE 5 TIPS FOR BUILDING A BETTER CHAIR

The category of wheelchair accessories is not just huge; it's growing exponentially. Combine this with spotty insurance coverage and the progressive nature of muscular dystrophy and related muscle-debilitating diseases, and you're left with one overwhelmingly complicated purchasing process.

"It's an exciting time to be in this field – on the other hand, Medicare and Medicaid are not keeping up," says Andrea Van Hook, communications manager for RESNA, the society for assistive technology professionals (ATPs). "Access is becoming more restricted at a time when innovation and technology are exploding."

How do you keep up with the constantly changing marketplace? The answer is simple – but not easy. "You have to be your own advocate," says Van Hook. Here are her top tips:

- 1. Keep up on what's new.** Subscribe to mobility-related magazines, websites and blogs. Keep files of tear sheets and notes. Attend expos, if possible.
- 2. Establish an ongoing relationship** with certified occupational therapists (OT) affiliated with an MDA Care Center and assistive technology professionals (ATP). Wheelchair assessments always involve OTs and ATPs. Call them, and send them notes and links as you hear of

relevant accessories. Visit [resna.org](http://resna.org) to find an ATP in your area, or consult with your MDA Care Center team for assistance.

- 3. Choose your accessories when choosing your wheelchair.** "That way the accessories can be customized according to your chair and measurements," says Laura Case, assistant professor and physical therapist at Duke University. It also saves money, as insurance requires accessories be deemed medically necessary by a professional assessment.
- 4. "Test drive" the equipment as much as possible.** Most manufacturers don't permit their equipment to be tested outside the clinical setting, but you may be able to request additional testing time above the average two-to-three-hour assessment appointment. Another smart move: Ask your OT or ATP for references of other patients using the accessory in question. Last but not least, remember most manufacturers limit product returns to 30 days. Do all your test-driving and question-asking within that time period.
- 5. Seek alternative funding.** When a desired accessory isn't covered, contact the manufacturer directly to ask about alternative funding, such as grants or financing.

manual chairs' advantages without overtiring users. Spinergy's FlexRims (\$1,270; [spinergy.com](http://spinergy.com)) have become a favorite custom touch among wheelchair users, occupational therapists and assistive technology professionals. The rubber-like rims make for a tight grip that is easy on hands and shoulders. *Bonus:* The supple rims allow an approximately 1-inch give when pushing through tight entries and hall spaces.

Power-assist attachments have been equipping manual wheelchairs with as-needed motors for several years. In August 2015, Max Mobility rolled out the second version of its popular Smart Drive attachment. SmartDrive MX2 (\$6,655; [max-mobility.com](http://max-mobility.com))

packages driving, turning and stopping power into an impressively small, lightweight attachment.

A Bluetooth-connected wristband detects the most nuanced of hand motions and communicates them to the motor, so that a soft push of the wheels gets a chair rolling for up to 12 miles. A light tap stops it on a dime — even on hills.

## POWER WHEELCHAIR ACCESSORIES

In the power wheelchair world, occupational therapist Katie Rybczynski sees lighting-fast advances not only in attachable devices but also in the manner that individuals access them. "Access methods

are one of the first things I look at in a seating assessment," she says.

"Right now we're playing around with a lot of exciting products." Rybczynski, who is part of the MDA Care Center team at Washington University School of Medicine, works with people with neuromuscular diseases in a weekly augmentative speech clinic at The Rehabilitation Institute of St. Louis. They have been using stylus, head-array, joystick and eyegaze technologies to control their augmentative speech systems for a while; what's new is the ability to control those systems — as well as many other functions — wirelessly.

Curtiss-Wright's various Bluetooth Modules (\$200; [cw-industrialgroup.com](http://cw-industrialgroup.com)) pair with any computer, tablet or device, including augmentative speech devices. Health care professionals like Rybczynski can then select a controller that best matches the user's "most consistent movement," such as a Curtiss-Wright's new CJSM2 Joystick (\$350) or the hands-free Blue2 Bluetooth Switch by Ablenet (\$179; [talktometechnologies.com](http://talktometechnologies.com)).

This summer, Stealth Products launched its new Bluetooth i-Drive system, (\$2,300 to \$3,600; [stealthproducts.com](http://stealthproducts.com)), which allows wheelchair users to wirelessly control systems

using head and facial movements — perfect for individuals who have trouble manipulating switches and joysticks by hand.

## SEATING ACCESSORIES

Although cushions are associated with comfort, they are often considered essential, and all or part of their cost may be covered by insurance. "One focus of wheelchair assessment is to determine the chair's base — frame, type of power, power positioning components, power standing, etc.," Case says. "The other critical focus is seating." Comfort Company's new Vicair Vector X cushion (\$300-\$400; [comfortcompany.com](http://comfortcompany.com)) contains air chambers that can be added or removed to account for imbalances in body posture and to relieve pressure sores. Aquila Corporation's recently developed SofTech (\$4,300; [aquilacorp.com](http://aquilacorp.com)) is a cushion system that automatically changes pressure distribution to prevent pressure sores. What's new is the battery, pump and controller are built right into the cushion. **Q**

*Shaila Wunderlich is a St. Louis-based freelance journalist who has worked for a variety of magazines, journals and newspapers for nearly 20 years.*



CJSM2 Joystick



Vicair Vector X cushion



SmartDrive MX2

*"With muscular dystrophy, we talk about conserving energy and optimizing function and efficiency."*

— Laura Case



# access **MDA**

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

## A Strong Team

Friends and family rally for Tampa Bay family, help lead largest local MDA Muscle Walk team



Gabe Aviles and his parents at the MDA Muscle Walk of Tampa Bay.

When Jessica Aviles' son Gabe was diagnosed with Duchenne muscular dystrophy (DMD) in November 2015, it was a complete shock.

"I literally knew nothing [about the disease,]" Aviles says. "I had to look it up in the parking lot."

Over the next six months, Aviles went from knowing nothing about DMD to heading the largest Muscle Walk team at the MDA Muscle Walk of Tampa Bay. Early on in her research, Aviles came across MDA and Muscle Walk and decided to get involved so she

and her family could join and support MDA's cause.

"It's frustrating that you can't really do anything," she says. "It feels like a hopeless situation for a parent, and short of praying, we can do zero. But, we can raise money for people who might be able to help Gabe."

So Aviles created Team Gabe and started selling T-shirts with 'Team Gabe' on the front and '68' (referring to the exon number missing in Gabe's diagnosis) on the back. Once Aviles shared her Muscle Walk plan with her family, friends and local church, she

found an incredible amount of support.

"We had family fly in from Puerto Rico," she says, "and we had a cousin drive nine hours. My mother-in-law who lives in Puerto Rico couldn't be there, but they organized a walk in San Juan on the same day. We have cousins in North Carolina and Alaska who all wore their Team Gabe shirts at the same time."

While Team Gabe raised more than \$3,000 at the MDA Muscle Walk of Tampa Bay, for Aviles the sense of community she experienced was the highlight.

"It was so much fun, and so great to be around other people walking the same walk as you," she says. "It's a rare disease, and sometimes it's kind of isolating. It was great to be around other people who had been doing it so much longer than us and to get emotional support from them. The whole atmosphere at the park, it wasn't a pity party – it was a celebration."



**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. Visit [mdamusclewalk.org](http://mdamusclewalk.org) to find a walk near you and register today.**

## Making Bail ... and More

### Longtime MDA jailbird Tom Seboldt leaves his mark with MDA Lock-Up

For Tom Seboldt, vice president of merchandise at an auto parts company in Missouri, the MDA Lock-Up has become an annual tradition. Since 2004 Seboldt has been an MDA jailbird to support his goddaughter, who has Charcot-Marie-Tooth (CMT) disease, as well as other friends he knows with families affected by neuromuscular disease. In the past 12 years, he has personally raised a staggering amount for MDA: upwards of \$140,000.

Seboldt credits his network of co-workers, friends and families for supporting him and helping his donation totals

reach such incredible heights.

"I'm able to reach out every year and thankfully every year [my supporters] give similar amounts, and they're very supportive," Seboldt says. "Some of them have family members or friends affected by muscular dystrophy, so they support me and the cause."

Heading to the Lock-Up in Springfield, Mo., and turning in his bail money has become a yearly ritual for Seboldt.

"I just always enjoy seeing all the MDA staff and the people I know every year," he says. "We get to catch up, and it's one of the only times we see each other. They have a little lunch, everybody gets

their picture taken. It's a neat social deal."

And, of course, beyond the activities of the day, Seboldt enjoys knowing his efforts have gone to a good cause and to helping kids and adults live unlimited.

"More than anything, I hope [my fundraising] can help anybody that has a problem that MDA can help with," he says. "The money we help raise really helps the people who need support and services, and that's important."



**If you – or someone you know – want to go behind bars for MDA, please visit [mda.org/lockup](http://mda.org/lockup).**

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*Kevan Chandler takes in the view from a rooftop with a friend in downtown Greensboro, N.C.*



# Seeking Adventure

**A young man with SMA gives ‘backpacking through Europe’ a whole new meaning**

A few years ago, Kevan Chandler, a 30-year-old postproduction editor with spinal muscular atrophy (SMA) from Fort Wayne, Ind., was hanging out with his friends when one of them brought up urban spelunking. This activity is exactly what it sounds like: underground exploration in an urban environment, such as tunnels or sewers. Chandler hadn't heard of urban spelunking at the time, but his friends encouraged him to try it. Because Chandler uses a wheelchair, they had to find a way to carry him.

“I think the biggest challenge was making the backpack [to carry me],” Chandler says. “It was very makeshift.”

The backpack may have been makeshift, but it worked, and soon Chandler and his friends were exploring the underground and sewers of North Carolina, where he was living at the time.

“It was really cool,” he says. “It’s not like we had any creepy experiences – we can’t say we found an alligator or something like that – but it was just the fact that it was something I never thought I would see or experience. If you’ve ever watched the old *Teenage Mutant Ninja Turtles*, it was kind of like that – cold, wet and dark. We’re guys; we like that stuff.”

Chandler has always been a traveler. Growing up, he lived in Florida and North Carolina, and he visited Toronto, Vancouver and California with his ➤

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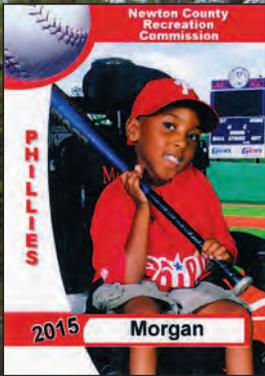
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 **M. Green** Love it! It has given back my independence!

 **S. Mahoney** Mine has been approved by insurance and just about to be ordered.



*Chandler's friends encouraged him to join them on an urban spelunking adventure in North Carolina, providing the inspiration for a European trip.*

family. But the urban spelunking got him thinking about exploring other places he never thought he could visit.

"The fact that we did that really opened up my mind to

not really dismissing any ideas," he says. "Before that it would have been me and my friends talking about how cool it would be to try this, but we never would have actually done it.

So when I thought it would be great to go to Europe and [using this backpack] is the way we could do it, I didn't just shrug it off."

Chandler had always wanted to go to Europe and this gave him the perfect opportunity. In order to get his dream off the ground, Chandler and his friends created We Carry Kevan, a GoFundMe project and website to raise money for a three-week journey over the summer. Their itinerary included France, where they would attend the Django Reinhardt Music Festival; England, where they would hike the countryside; and Ireland, where they would climb the mountain Skellig Michael.

While he was certainly looking forward to those

experiences, before he left, Chandler told Quest that he was most excited about the challenge of being thrust into new, unknown environments.

"I think SMA, and MD as a whole, is a really difficult disease," he says. "It's a challenge to live with, but it's definitely possible. And I think sometimes we find a comfortable spot, we find a routine that works so we stick with that. Something I'm really excited about is [this trip] is going to shake that routine. It's terrifying, but I'm going for it."

 **Be sure to follow the MDA Strongly blog at [strongly.mda.org](https://strongly.mda.org) for inspiring stories of individuals living beyond limits. Follow Kevan's journey on his blog at [wecarrykevan.com](https://wecarrykevan.com).**



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**References:** **1.** Kishnani PS, Steiner RD, Bali D, et al. Pompe disease diagnosis and management guideline. *Genet Med.* 2006;8(5):267-288. **2.** American Association of Neuromuscular & Electrodiagnostic Medicine. Diagnostic criteria for late-onset (childhood and adult) Pompe disease. *Muscle Nerve.* 2009;40(1):149-160. **3.** van der Beek NA, de Vries JM, Hagemans MLC, et al. Clinical features and predictors for disease natural progression in adults with Pompe disease: a nationwide prospective observational study. *Orphanet J Rare Dis.* 2012;7:88.

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# Taking Action on Airplane Accessibility



The ability to access air travel impacts many aspects of life – from the kind of job you can have and where you can live, to whether you can access a provider or participate in a clinical trial that is far from home.

While the Air Carrier Access Act (ACAA), now 30 years old, requires equal access to travelers with disabilities, there is still much work to do to make air travel truly accessible.

To that end, MDA is working with policymakers, travel advocates with disabilities, families and airlines to support measures that will make airplanes even more accessible.

MDA also is participating in the Transportation Security Administration's (TSA) Disability Coalition and in the Department of Transportation's (DOT) negotiated rulemaking process.

MDA is supporting legislation that aims to improve the air travel experience for people

with disabilities by studying in-cabin wheelchair restraint systems, identifying best practices in airport accessibility, examining training policies, and creating an advisory committee to investigate and report on the needs of passengers with disabilities for Congress.

**We need your help!**  
**Become an MDA Advocate and support efforts to make air travel more accessible. Sign up today at [cqrcengage.com/mda/advocate](http://cqrcengage.com/mda/advocate). For more information on MDA's accessible air travel resources, visit [cqrcengage.com/mda/accessibleairtravel](http://cqrcengage.com/mda/accessibleairtravel).**

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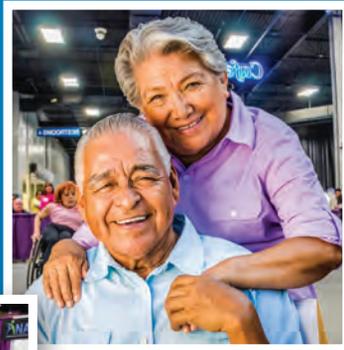
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# Passing on the Knowledge

**Dr. Raymond Huml and his daughter, Meredith, collaborate on a new guidebook covering muscular dystrophy**

When Dr. Raymond Huml, scientist and drug researcher, first found out his daughter Meredith had facioscapulohumeral muscular dystrophy (FSHD) in 2003, he started looking for information on the disease. He was surprised to find that most of the information out there was highly technical in nature and generally not very useful to the average family trying to learn about muscular dystrophy.

As years went by, Dr. Huml would get questions from fellow families dealing with a muscular dystrophy diagnosis, and he recognized that there

was a need for a book about muscular dystrophy, written in plain English. Dr. Huml was familiar with the publishing process, so he decided to spearhead the project himself.

“I had written several other books, so I thought I should take these skills and do it for people with muscular dystrophy,” he says. “But I thought I really couldn’t write this by myself, because I’m not a physician and I don’t have experience on all the topics.”

So Dr. Huml sent out a mass email to caregivers and experts he knew, asking if anyone was interested in contributing to



Leslie and Ray Huml attend the Royal Ascot horse race in England with their children Jonathan and Meredith, both of whom have FSHD.

the project. Most of them were and contributed chapters on their areas of expertise.

Among the contributors to the book, *Muscular Dystrophy:*

*A Concise Guide*, is Dr. Huml’s daughter Meredith, now a 23-year-old student and writer.

“[My dad] told me about the book and asked if I was

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interested, and I was,” Meredith says. “We both agreed patient advocacy would be the best topic for me to cover.”

Patient advocacy is an important topic to Meredith, because she realizes that for many people with muscular dystrophy – including herself – their knowledge of the disease comes mainly from personal experience.

“From a patient’s perspective, educating yourself on your muscular dystrophy is important,” she says. “A lot of people I meet haven’t heard of muscular dystrophy, and a lot of [other people with MD] I’ve met don’t know a lot of people with MD. For me, it was important to be open about it, ask for help and realize the importance of reaching out to others for them and for yourself.”

Meredith’s chapter, titled “U.S. Patient Advocacy Groups,” covers these issues and details resources available for people with each type of muscular dystrophy. These resources include local and national organizations, such as MDA and its network of Care Centers, and community groups that provide support. Meredith concludes her chapter with her personal story and tips for patients about connecting with advocacy groups and living life with muscular dystrophy.

Now that the book is available, Meredith is planning to do more writing, but that isn’t the only way she wants to get more involved in the community.

“I was a dancer from when I was 3 years old up until my

senior year of high school when I had to give it up,” she says. “I’d really like to do something with that. I was thinking about how cool it would be to start a dance studio for kids with mental and physical disabilities. When I was dancing, I was the only one dealing with that in class. It would be really cool for kids with disabilities to have a place to go.”



**To learn more about Dr. Huml and Meredith Huml’s book, *Muscular Dystrophy: A Concise Guide*, visit [springer.com](http://springer.com). You can also read a blog post about the book by Laura Hagerty, an MDA scientific program officer, by going to [strongly.mda.org](http://strongly.mda.org) and searching for the book title.**

## Sharing Our Strength

Read stories from around the MDA community – and share your own – on Strongly, the MDA blog ([strongly.mda.org](http://strongly.mda.org)). Here you’ll find everything from personal posts by people living with neuromuscular diseases to the latest research news and fun videos. If you’re interested in blogging or sharing your story on Strongly, contact us at [strongly@mdausa.org](mailto:strongly@mdausa.org).

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# In It for the Long Run

Carol Anne Taylor raises money and runs in honor of her husband with inclusion-body myositis



Carol Anne Taylor represents MDA Team Momentum with her husband, Sterling Procter.

For Carol Anne Taylor, crossing the finish line at the Boston Marathon in April as part of Team Momentum was an overwhelming emotional experience.

“It was breathtaking,” she says. “It’s hard to describe and put into words. I saw myself – and I told my husband, Sterling – I’ve never seen myself smile like that.”

Taylor’s husband of three years, Sterling Procter, was diagnosed with inclusion-body myositis (IBM) in 2009. Taylor and Procter had known each other for years through the Dallas music scene but only began dating in 2012.

“She is absolutely wonderful and the best medicine possible,” says Procter.

Taylor is a longtime runner and had run in marathons for other charities in the past, so she was excited to learn about MDA Team

*“It was breathtaking. It’s hard to describe and put into words. I saw myself – and I told my husband, Sterling – I’ve never seen myself smile like that.”*

Momentum and combine her passion for running with her support for her husband.

“I thought, ‘Oh my goodness, I can run a marathon in honor of Sterling,’” she says.

And not only did she finish the Boston Marathon in Procter’s honor, but she also raised more than \$13,000 for MDA in the process. However, it wasn’t the fundraising that made Taylor so emotional after she finished; it was the incredible support she felt for herself and her husband while she ran.

“I cut a little portion of the bib they give you and wrote on it: ‘This one’s for Sterling,’” she says. “Throughout the race, people were saying ‘Go Sterling,’ and every time his name was yelled out I thought ‘I’m Sterling today, I’m running for him.’”

Procter wasn’t able to attend the marathon with Taylor, but he did watch remotely via the event’s livestream on the Web.

“I’m watching the lead runners and the packs and I thought about how Carol Anne will be running along here ▶

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# 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



## TEAM MOMENTUM UPCOMING EVENTS

Get out and walk or run with MDA Team Momentum at any of these upcoming premier races. Some of the races sell out and MDA Team Momentum has limited entries. Register today at [mdateam.org](http://mdateam.org).

**Bank of America Chicago Marathon**  
Sunday, October 9, 2016

**Rock N Roll Denver Half-Marathon**  
Sunday, October 16, 2016

**Marine Corps Marathon & 10K**  
Washington, D.C., Sunday,  
October 30, 2016

**TCS New York City Marathon**  
Sunday, November 6, 2016

**Dallas Marathon & Half-Marathon**  
Sunday, December 11, 2016

**Miami Marathon & Half-Marathon**  
Sunday, January 29, 2017

soon, and I could see what she would be seeing and what she would be doing," says Procter. "This whole process has meant a great deal; she's so wonderful. I don't need to hear thousands of people to cheer her on, but I love it all the same."

After her amazing experience in Boston, Taylor plans to continue running for MDA Team Momentum in future marathons. She is already preparing for the Bank of America Chicago Marathon this October and already has entry into the New York City Marathon in November.

"I just checked my page, and the funds are already rolling in for Chicago," says Taylor. "It's just amazing for me, and I feel like we're inspiring and making a difference in people's lives."



Procter joins Taylor during a run.

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## EDUCATING AND SUPPORTING FAMILIES WITH BECKER MUSCULAR DYSTROPHY

On Sept. 24, 2016, MDA will present the National Becker Muscular Dystrophy Conference at Children's National Medical Center in Washington, D.C. The 2016 conference will include presentations on clinical care, research updates, information on clinical trials and panel sessions. There is no charge to attend the conference, but registration is required. The conference is open to all individuals with Becker MD, their families and friends. A social gathering will take place on the evening of Friday, Sept. 23.

 To learn more and to register, visit [mda.org/conference/BMD/2016](http://mda.org/conference/BMD/2016).

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# Love, Marriage, Science and a Baby Carriage

*Technology brings hope for having a healthy baby*

BY COLLEEN NICHOLS



*Colleen Nichols thought she would never have a biological child, but technology changed that.*

**I'm not going to lie to you:** Writing this article is making me sweat. I'm going to talk to you about a topic that changed my life in the most profound, positive way, but I still feel scared to share it.

I was diagnosed with myotonic muscular dystrophy (MMD, or DM) when I was 20 years old. I had been dating my now-husband, Cory, for about a year, and I knew that he was the one. While

I was head-over-heels and floating on cloud nine, I also struggled with a deep sense of dread and responsibility.

My dad has MMD, and I had no idea if I did; but I knew that if I was going to spend the rest of my life with Cory, he deserved to know early on what his future might look like, because we all know this disease can affect the spouse in a tremendous way.

I told Cory before the DNA test that he needed to

think about what he would do if it came back positive. I essentially tried to talk him out of being with me, because I didn't want to possibly burden him decades down the road.

Cory also wanted children, but if I had the disease, I knew I wouldn't have them. After seeing how this disease affected my dad (and mom), there was no way I was taking the chance of passing it on to someone else.

## More Online

Read about the important lessons Colleen Nichols has learned as a first-time mom in a web-exclusive article at [mda.org/quest](http://mda.org/quest).

You've never met Cory, but I can assure you that at this point in the story, he'd interject that not being with me was never up for consideration. (Well, maybe when he found out that I didn't actually like football, like I said I did when we first met, or maybe when he realized that I leave a pair of shoes in every room of the house, or maybe when he learned that I'm anxious and prone to worry; but muscular dystrophy? Not a chance.)

We were engaged in May 2010, and spent that summer backpacking through Europe and planning a wedding. When we got married the following August, the thought of children seemed so far away that I had almost forgotten to worry about it.

It was around the time of our engagement that I heard of a procedure called pre-implantation genetic diagnosis (PGD). It sounded space-agey and impossible to understand, but I knew that it might give us our one shot at giving MMD the big middle finger and taking control of our family's future.

By 2014, the late-night parties had been attended, the travel had happened, and I was surprised to find myself actually wanting a baby. It was a reality that I had distanced myself from, so as not to become too attached and disappointed, but PGD gave me hope.

By that time, we had looked further into PGD and had found an in vitro fertilization (IVF) doctor in our area who was familiar with the process.

I'm not a doctor, nor do I play one on TV, so bear with

me when I explain PGD as an option for people with chromosomal diseases to have healthy biological children.

The process started with a simple blood draw from me, and mouth swabs from my parents. All of that DNA was sent to a lab in Chicago, where they spent several weeks essentially developing a DNA map.

I then went through the egg retrieval that any IVF patient would experience (appropriately, on Easter weekend). I admit, I felt like a bit of a back-alley junkie with all the needles and pills that overtook my bathroom during the weeks leading up to my retrieval, but that's par for the course.

The initial baby-making part happens in a lab. Never in a million years would I have guessed that my child would be created under fluorescent lab lights while I sat in a separate room recovering from anesthesia, but I'm essentially a Jetson.

News came quickly that 18 eggs were retrieved and introduced to sperm, and not long after, we learned that nine survived until the day five biopsy.

Then we waited.

My biggest fear was that I would have no healthy embryos, but about a month later, we received news that five of the embryos were healthy! We were in business, folks, and we were overjoyed.

At that point, I went through a typical IVF cycle and frozen embryo transfer. I got pregnant after our first transfer, and our healthy son was born in March 2015.

## HOW DOES IT WORK?

Preimplantation genetic diagnosis (PGD) is a procedure used by prospective parents who are trying to prevent a disease-causing genetic mutation from being passed on to their offspring.

Couples first go through in vitro fertilization (IVF), in which their sperm and egg cells are brought together in a laboratory dish. PGD then requires removing a cell from an IVF-produced embryo and testing it for the specific genetic mutation. An embryo that doesn't show the mutation can be implanted in a woman's uterus.



**Families interested in fertility options should always consult with their MDA Care Center physician and health care team. The MDA Care Center team can also assist with finding a genetic counselor in their area if there isn't one who is a member of the MDA Care Center team. Locate your nearest MDA Care Center at [mda.org](http://mda.org).**

I'm living a life that, eight years ago, I didn't think could ever be a possibility. This story isn't meant to be a parade of my good fortune, but to serve as a real message that my family is not an exception to the rule. While PGD is a complicated process and outrageously expensive, it's a real, viable option for the average person.

Do we have an outstanding loan for the procedure? You bet. But we'll have no qualms telling our future teenage son, "You're helping us pay for your college; we covered the conception bill." **Q**

---

*Colleen Nichols, 28, is a freelance writer and life coach ([colleennichols.com](http://colleennichols.com)) in Richmond, Va., living with type 1 myotonic muscular dystrophy.*

### Editor's note

MDA wants everyone in the community to have a space to share their personal stories. We also work to ensure our families receive information that helps keep them up-to-date on all available options. If you'd like to share your experience, send an email to [QUEST@mdausa.org](mailto:QUEST@mdausa.org).

# All in the Family

Sisters Michelle Murphy and Christine Southard join MDA Team Momentum



Michelle Murphy shows her Team Momentum pride.



The Murphy family on vacation



Michelle skydiving

**M**ichelle Murphy, a marketing coordinator from Albany, N.Y., with myotonic muscular dystrophy (MMD, or DM), has been running for as long as she can remember. So when she was diagnosed with MMD in the summer of 2014, she began looking for ways she could use her passion for running to raise money to fight the disease.

“I was disheartened for a while, because I was looking for something that would benefit [MMD],” she says. “One day I searched for MDA, and I saw Team Momentum on their website and it made me so happy. That was the first time I cried from happiness in a long time.”

Murphy’s desire to support MDA Team Momentum came not only from her own diagnosis, but also that of her father, Anthony Murphy, and sister, Christine Southard, who had also been recently diagnosed with MMD. Each of them experienced the characteristic “Christmas tree” cataracts, common in people with MMD.

“Christine didn’t even realize [she had a problem] until an eye doctor referred her to a neurologist,” Murphy says. “And I didn’t have any symptoms besides the cataracts. My dad found

out after me and my sister because we knew it was inherited from one of our parents, and he was the only one with cataracts.”

Excited to learn about MDA Team Momentum and the fundraising opportunity it provides, Murphy

convinced her sister, her sister’s husband and her best friend to join her in running the Bank of America Chicago Marathon in October 2016 as members of MDA Team Momentum.

“I haven’t been a runner before, but when Michelle was looking into running for a charity that benefits people that have what we have, I told her if she could find a way, then I would do it too,” Southard says. “I didn’t really expect it to happen.”

But now the whole team is on board and looking forward to the race in October. Murphy and Southard even paid a visit to the Boston Marathon in April to get a feel for the marathon experience and support MDA Team Momentum.

“Being there was a little nerve-wracking, because it’s starting to seem more real,” says

Southard. “But it was also really inspiring. We saw people that were blind running with a guide, and people that have had legs amputated running with prosthetics. It was just really inspiring.” **Q**

Ready to cross the most meaningful finish line of your life? Learn how you can get involved in MDA Team Momentum at [mdateam.org](http://mdateam.org).

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\*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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