

Quest

EMPOWERING FAMILIES WITH INFORMATION AND INSPIRATION

MDA.ORG/QUEST
SUMMER 2017

MDA[®]

For Strength,
Independence & Life

new heights

The drive to live
beyond limits starts
at MDA Summer Camp

IN THE DRIVER'S SEAT
What you need
to know about
adaptive driving and
accessible vehicles

**SHARING AND
LEARNING**
How MDA conferences
support families



Non-profit Org
US postage
Paid
Bolingbrook, IL
permit 1446

Muscular Dystrophy Association
6400 East Grant Road, Suite 170
Tucson, AZ 85715

permobil

POWER WHEELCHAIRS



3.2MPH @ 14"
OF ELEVATION +
FULL SUSPENSION
AT ANY SPEED,
POSITION, OR
ELEVATION

TAKE THE HIGH ROAD.

M5 *Corpus*

PERMOBILUS.COM



Please refer to your owner's manual for warnings and instructions for the safe operation of your wheelchair in a variety of driving conditions.

MDA is leading the fight to free individuals – and the families who love them – from the harm of muscular dystrophy, ALS and related life-threatening 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.

For advertising opportunities:

Maureen Tuncer

Advertising Sales Manager
mtuncer@mdausa.org

For editorial queries:

Alyssa Quintero

Marketing Communications
aquintero@mdausa.org

To update personal information and your Quest subscription status, contact your local office at **(800) 572-1717**.

Published quarterly by

Muscular Dystrophy Association

222 S. Riverside Plaza, Suite 1500
Chicago, Illinois 60606 | (800) 572-1717

email: quest@mdausa.org

Available on the internet at mda.org/quest

ISSN 1087-1578

Postage paid at Bolingbrook, IL

Nonprofit postal permit number 840.

Postmaster: Treat as Standard A Mail Only

© 2017, Muscular Dystrophy Association. All rights reserved. MDA and QUEST are registered trademarks of the Muscular Dystrophy Association.

The acceptance of advertising in this magazine does not constitute or imply endorsement by MDA of any product or service. MDA accepts no responsibility for any claims made in any advertisement. Quest reserves the right to refuse to accept any advertisement. For advertising information, call (866) 775-8568.

Information contained in Quest may not be reproduced, published, transmitted or distributed in whole or in part without prior written consent of MDA.

Always consult your professional advisers as to how medical, legal or financial information in Quest pertains to you. MDA assumes no liability for any information in Quest.

FOLLOW MDA ON     



PUBLICATION MANAGEMENT

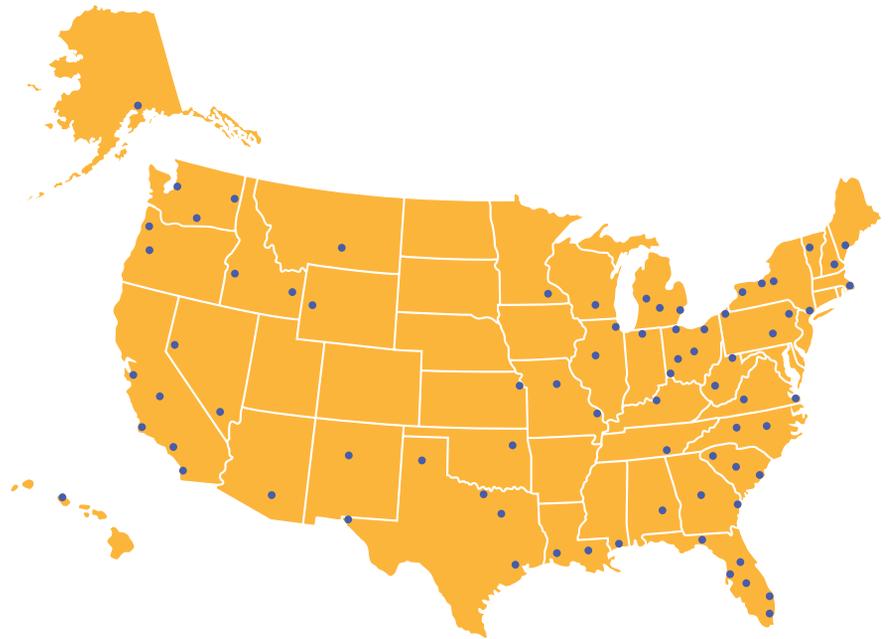


GLCDELIVERS.COM

Join us at one of the remaining MDA Muscle Walks of 2017!

Be part of this special event that unites families, friends, neighbors and local businesses to transform hope into answers.

Visit mdamusclewalk.org to find a walk near you and register today.



MDA®
Muscle Walk

mdamusclewalk.org
#MuscleWalk
Muscular Dystrophy Association

summer 2017

CONTENTS



DEPARTMENTS

04 SHARING OUR STRENGTH

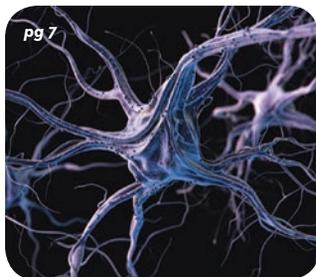
Individuals on MDA's Strongly blog are talking about how and why they advocate.

06 PROGRESS NOW

Read the latest news on medical research, scientific advances and clinical trials for MDA diseases.

16 THRIVE 365

How to make sure you, your family and caregivers are prepared for an emergency.



pg 7



pg 48

38 ACCESS MDA

Families share their love for MDA Muscle Walk, a swimmer pursues his passion and more stories from the MDA community.

50 FROM WHERE I SIT

A recent college graduate shares his experience.

52 LASTING IMPRESSION

MDA Team Momentum is making an impact mile by mile.

FEATURES

18 SPARKING THE LIVE UNLIMITED SPIRIT

The drive to live beyond limits starts at MDA Summer Camp.

FOCUS ON: MOBILITY

26 IN THE DRIVER'S SEAT

Learning to drive with adaptive equipment increases independence.

32 CHOOSE THE RIGHT WHEELS

What you need to know before purchasing an accessible vehicle.

34 SHARING, LEARNING + DISCOVERING

MDA conferences support families by advancing research, advocacy and clinical care objectives.



pg 40
Miguel crosses the finish line at MDA Muscle Walk

MORE ONLINE

READ STRONGLY

Find personal stories from individuals living with neuromuscular diseases, research updates, MDA news and more on Strongly, the MDA blog. Visit strongly.mda.org.

SHARE YOUR STORY

The Strongly blog is home to stories from all around the MDA community. If you'd like to share a story on Strongly, contact us at strongly@mdausa.org.



imagine
possibilities



making the world accessible

— SINCE 1987 —

Contact VMI to learn more about the industry's most spacious wheelchair accessible minivans.

Call or visit us online to find out about promotions to help offset the cost of a van!

vmivans.com | 855-VMI-VANS

Speaking Out and Taking Action

A delegation of nearly 90 advocates from 23 states visited Capitol Hill in April to speak to their representatives about the importance of programs and policies that help individuals and families living with neuromuscular diseases as part of MDA's inaugural Public Policy & Advocacy Conference in Washington, D.C. The excitement around this opportunity and the success of bringing our issues to the forefront got people on **MDA's Strongly blog** thinking about how and why we speak out.

"I became an advocate because I realized as a young adult that there were times in my life where I was going to have to confront discrimination, bullying and misconceptions about my disability and at the same time be able to assert my legal rights, ask for accommodations, teach people about my disability, etc."
 – Mario Damiani



"MDA is committed to ensuring access to meaningful health care coverage and is proud to be part of a coalition of 10 national organizations that have endorsed a set of principles necessary to ensure adequate coverage."
 – Kristin Stephenson, MDA's vice president of policy and advocacy

"I think people like me in the neuromuscular disease community make natural advocates because we are so used to talking to others about our needs and wants in our daily lives."
 – Joe Akmakjian



"If you believe strongly in someone or something, and feel the world at large pays too little attention, it may be up to you to change the equation." – Ed Tessaro

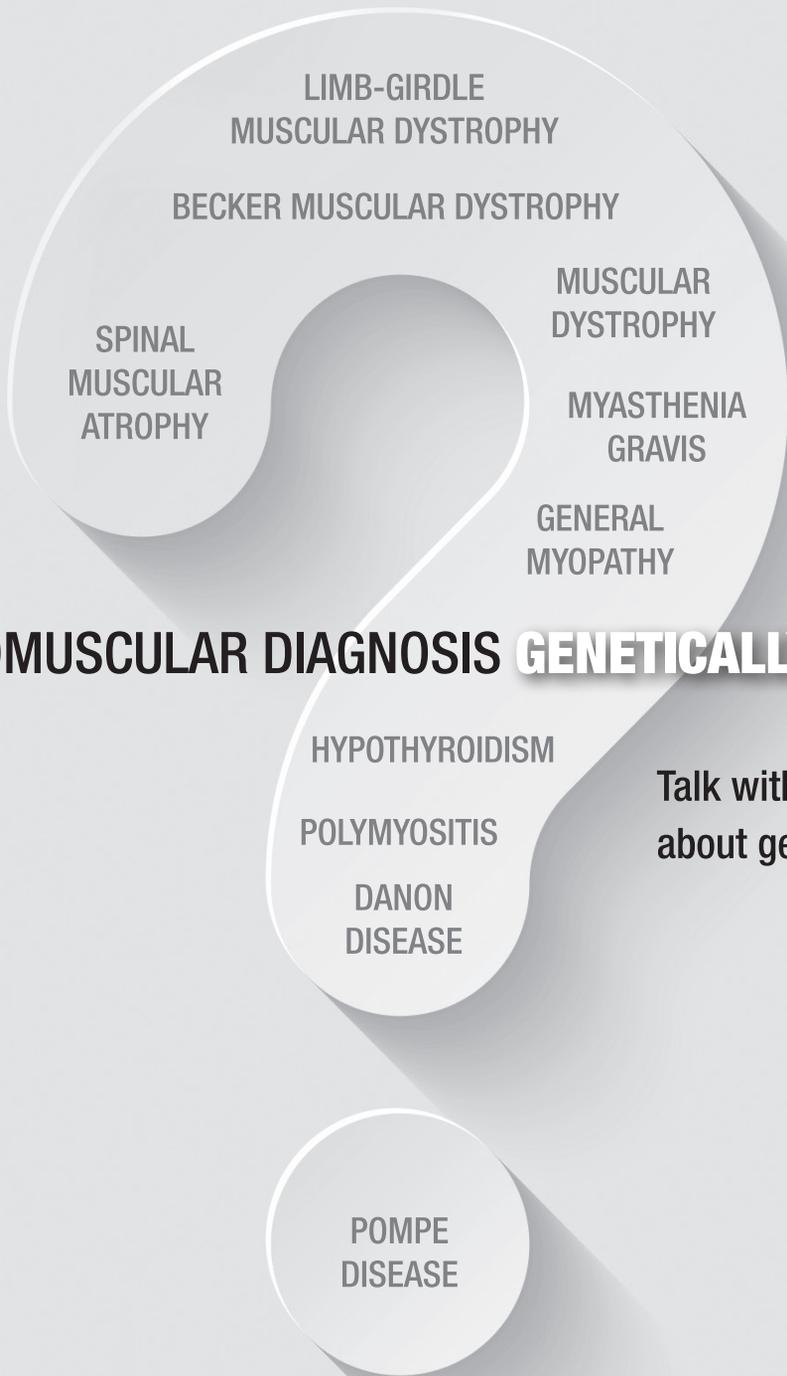


"Advocacy is necessary, because there is more love and strength in numbers."
 – Bridget Simpson



Make Your Voice Heard

It's never too late to get involved and make sure policymakers hear your voice on issues that are important to the neuromuscular disease community. Become an MDA Advocate and receive advocacy emails and action alerts. Sign up today at mda.org/advocate. Every voice matters, and together, we are stronger.



IS YOUR NEUROMUSCULAR DIAGNOSIS GENETICALLY CONFIRMED?

Talk with your MDA physician
about genetic testing.

progress now

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

ALS (amyotrophic lateral sclerosis)

FDA Approves Radicava to Treat ALS

Clinical trial data indicate Radicava may slow decline in function

The U.S. Food and Drug Administration (FDA) in May approved edaravone (brand name Radicava) to treat ALS. Under development by Mitsubishi Tanabe Pharma America, Radicava is the first drug to be granted FDA approval to treat ALS in the United States in more than 20 years.

Radicava is thought to work by relieving the effects of oxidative stress, which has been suspected to play a role in the death of nerve cells called motor neurons in people with ALS. (Oxidative stress is an imbalance between the production of free radicals and the ability of the body to counteract or detoxify their harmful effects with antioxidants.) Targeting this pathway could potentially preserve motor neuron health, which could in turn keep muscles functional for a longer period of time.

Efficacy of Radicava for the treatment of ALS was demonstrated in a pivotal phase 3 study that compared Radicava to placebo in 137 people with ALS. Over a period of 24 weeks, participants taking Radicava

saw a decline of approximately five points on the ALS Functional Rating Scale Revised (ALSFRS-R), whereas those who took the placebo saw a decline of 7.5 points. Trial participants also continued on to a 24-week open label extension period in which the efficacy of Radicava was demonstrated again in those who received the drug for the entire 48 weeks.

 **MT Pharma America has created Searchlight Support, a patient access program for people with ALS who are prescribed Radicava. The program offers personal case management, reimbursement support and 24/7 clinical support. To learn more, contact Searchlight Support at 844-772-4548. Sign up to receive Radicava updates at radicava.com/patient.**



Radicava is the first drug approved to treat ALS in the United States in more than 20 years.



The PGB study does not offer an experimental treatment or intervention, but genetic testing is performed and participants may choose to learn the results.

Phenotype, Genotype & Biomarkers in ALS and Related Disorders (PGB) Study Seeks Participants

Study results may help uncover biomarkers that could inform therapy development

Researchers are looking for people to participate in a clinical study designed to help scientists better understand the relationship between the phenotype (disease characteristics) and genotype (genetic makeup) of ALS and related diseases.

The CReATe Consortium's PGB study is a longitudinal observational study – a type of study in which investigators collect information at multiple time points from a group of participants according to a protocol or research plan. Unlike a clinical trial, the PGB study does not offer an experimental treatment or intervention, but genetic testing is performed and participants may choose to learn the results.

Data from the study could be used to develop and validate biomarkers that may help inform therapy development for these disorders.

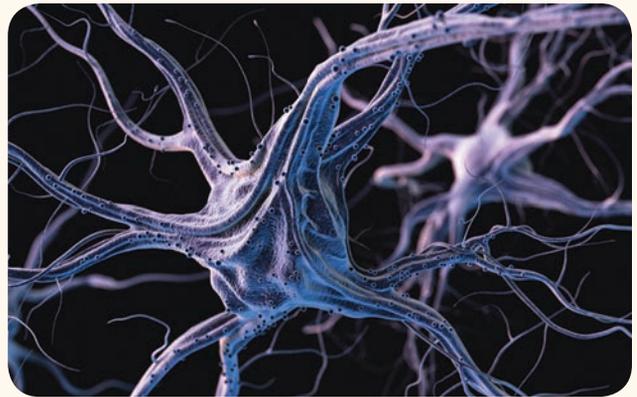
Each participant's involvement in the study is expected to last 18 to 24 months and requires participants to make a visit to one of the study sites every three to six months. In order to be eligible to participate, individuals must have a diagnosis of ALS or a related neurodegenerative disorder, be able and willing to comply with study procedures and meet other criteria.



To learn more about the PGB study, including complete inclusion and exclusion criteria, visit ClinicalTrials.gov and enter NCT02327845 in the search box, or contact Sumaira Hussain, CReATe Project Manager, at 844-837-1031 or projectcreate@med.miami.edu.

Encouraging Trial Data Reported for Masitinib

ALS drug aims to slow disease progression



Masitinib targets a cell type called microglia, potentially reducing these cells' ability to initiate an inflammatory response and helping motor neurons survive longer.

AB Science has reported encouraging topline trial results from its completed phase 2/3 study in Europe of the experimental drug masitinib in ALS.

Masitinib inhibits the activity of an enzyme called a tyrosine kinase – a type of protein that acts as an “on” or “off” switch for many cellular functions. It's designed to work by targeting cells called microglia, potentially reducing these cells' ability to initiate an inflammatory response during the course of ALS. Targeting these cells may help motor neurons survive longer, which could in turn keep muscles functional for a longer period of time and slow the progression of the disease.

In the trial, 394 patients were randomly assigned to groups and treated with low-dose masitinib in combination with riluzole, high-dose masitinib in combination with riluzole or placebo in combination with riluzole. After 48 weeks, there was a significant difference in patient function between participants in the trial who were treated with the highest dose of masitinib versus those on placebo.

AB Science has said it expects to begin a confirmatory study for masitinib later in 2017. In addition, the company is working with the FDA to determine next steps for development and potential commercialization of the drug in the United States.



To read about MDA's current ALS-related research efforts, visit mda.org/gaag.

ALS (amyotrophic lateral sclerosis)

Participants Sought for Microbiome ALS Study

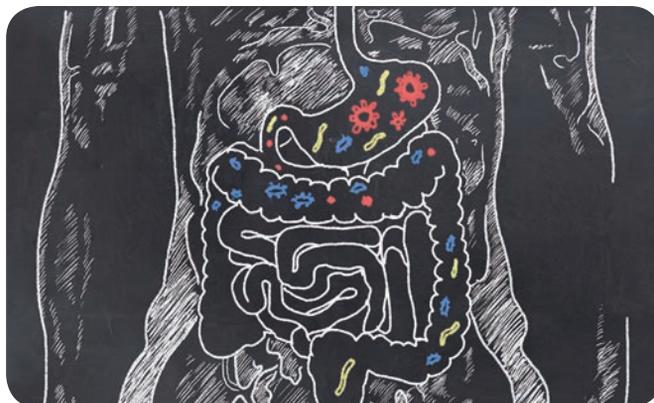
Improved understanding of the bacteria living in the gut could lead to development of ALS treatments

Researchers are looking for people with ALS and healthy volunteers to participate in the Microbiome Assessment in People with ALS (MAP ALS) study, sponsored by the Neurological Clinical Research Institute at Massachusetts General Hospital (MGH).

No studies have previously examined whether the overall composition of bacteria in the gut, or specific types of bacteria, are associated with ALS. The goal of MAP ALS is to develop preliminary data on the interplay between bacteria in the gut and its potential influence on the onset and course of neurodegenerative diseases. In addition, the researchers hope to find unique biological markers that could be used to develop new therapies.

Participants will provide clinical information and participate in a one-time stool collection. Those with ALS will have the option to participate in up to two additional brief visits (three months and six months after the first visit) at which only clinical information will be collected.

In order to be eligible to participate, individuals must be at least 18 years old and meet other eligibility criteria.



No studies have previously examined whether the overall composition of bacteria in the gut, or specific types of bacteria, are associated with ALS.

The trial site is located at MGH in Boston, but stool sample collection will be done at home. Participants do not need to visit MGH to enroll in this study.

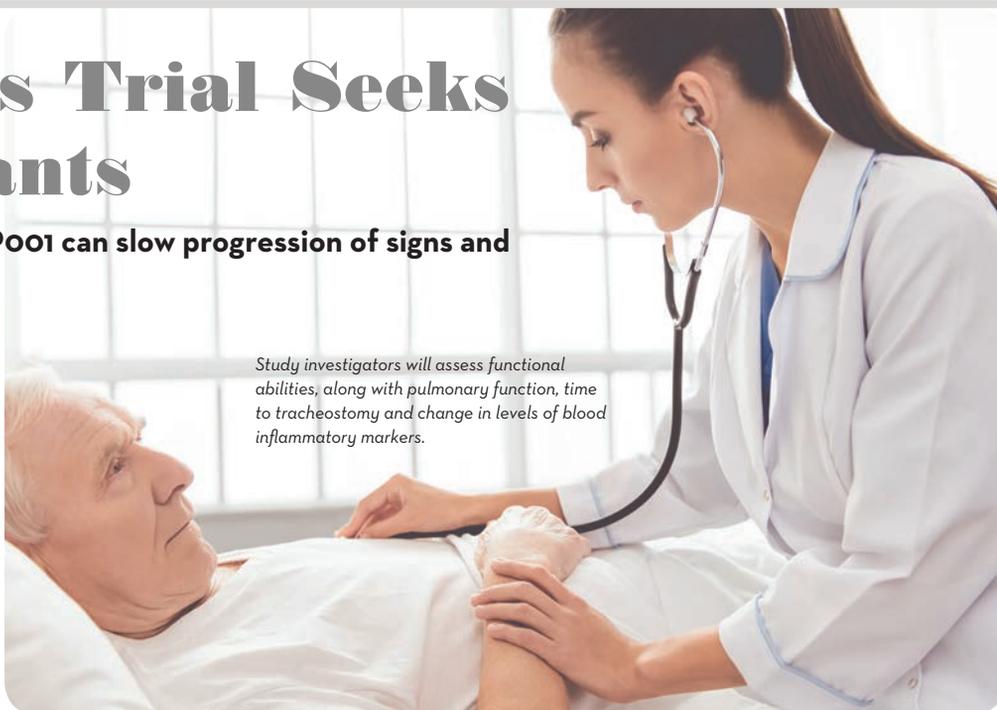
 **To learn more about this trial, contact study coordinator Maryangel Jeon at 617-724-9196 or mjeon2@partners.org.**

Neuraltus Trial Seeks Participants

Trial will test whether NPO01 can slow progression of signs and symptoms in ALS

Researchers are looking for people to participate in a phase 2 clinical trial, sponsored by Neuraltus Pharmaceuticals, that is designed to test whether the investigational drug NPO01 slows progression of signs and symptoms in ALS.

NPO01 is designed to exert its effect by converting activated inflammatory white blood



Study investigators will assess functional abilities, along with pulmonary function, time to tracheostomy and change in levels of blood inflammatory markers.



cells known as macrophages back to their normal state.

In the study, which is expected to last approximately seven months, participants will receive treatment with either NPOO1 or placebo and will be required to visit the study site approximately 23 times. Study investigators will measure the change from baseline in score on the ALS Functional Rating Scale-Revised, a scale that enables physicians to evaluate an ALS patient's degree of functional impairment. They also will assess change in pulmonary function, time to tracheostomy and change in levels of blood inflammatory biomarkers.

Participants must have a diagnosis of ALS with onset of ALS-related weakness less than three years prior to the first dose of study drug and meet additional criteria. Trial sites are located across the United States. Travel support may be available.

 To learn more about this trial, including site locations and complete inclusion and exclusion criteria, visit ClinicalTrials.gov and enter NCT02794857 in the search box, or go to the Neuraltus trial site at neuraltus.com/clinicaltrials. You also may contact study coordinator Frances Faurot at 415-912-1981 or ffaurot@neuraltus.com.

LIFT YOUR LIFE TOWARD INDEPENDENCE



POWER TOILET AID™

Battery-powered toilet seat lift

- Perfect for those with muscle weakness
- Standard or mobile models available
- Lifts straight up; no forward push



STAND AID™

Manual or battery-powered lift

- Rehab facility model with power height adjustment available
- No transfer required! Stand while directly lifted from wheelchair

Standing program provides many physical and psychological benefits



NEW

FREEDOM Chair™

Battery-powered chair lift

- From sitting to standing in home, office or other environment
- Comfort and style for use anywhere

Ask about our 30-Day return guarantee

800-831-8580 for information and a FREE demo video

www.stand-aid.com

sales@stand-aid.com

YouTube product videos on our website

Becker muscular dystrophy (BMD)

Participants Sought to Test Beetroot Juice

Investigators will assess effects of beetroot juice on muscle

Beetroot juice is rich in molecules called nitrates, which are converted to nitric oxide in the body. Study researchers will evaluate whether increased levels of nitric oxide produced in the body after consuming beetroot juice extract cause an increase in blood flow to muscle.

Researchers are looking for people to participate in a clinical trial, sponsored by Cedars-Sinai Medical Center, to test the safety and efficacy of beetroot juice extract in people with BMD.

Beetroot juice is rich in molecules called nitrates, which are converted to nitric oxide in the body. Study researchers will assess whether increased levels of nitric oxide produced in the body after consuming beetroot juice extract cause an increase in blood flow to muscle.

In the phase 1 open label study, all participants will receive treatment with beetroot juice orally or via intravenous injection. Study investigators will assess whether treatment has positive effects on blood flow and handgrip strength.

Participants will be asked to make up to three clinic visits. Medical tests performed during each visit may include contrast-enhanced ultrasound, EKG and handgrip testing.

To be eligible to participate, individuals must be ages 18 to 60, have a diagnosis of BMD and meet additional criteria.

This study is recruiting at Cedars-Sinai Medical Center in Los Angeles. Travel and hotel accommodations may be provided for those who must travel to the test site for clinic visits.

For additional information on travel and accommodations or to inquire about participation, contact Dr. Matthew Hakimi at 310-248-8080. To find more information about the study, visit ClinicalTrials.gov and enter NCT02653833 in the search box.

OPEN Your Door to Independence

Now you can open your own door to independence with the new, residential door opener from Power Access. Empower all the doors in your home or apartment, from front to interior, with this easy-to-install, lower-cost unit. Use our convenient remote control, or use ECU, sip, puff & other controls to effortlessly access your space.

POWER ACCESS
AMERICA'S DURABLE DOOR OPENER™

800-344-0088
handicap-access.net

Inspired by drive

A New Company Inspired by You

PLAY, ENGAGE, PARTICIPATE

Visit our website and join our community today!

> 800.454.6612
> www.inspiredbydrive.com
> @inspiredbydrive

Live Inspired!

Duchenne muscular dystrophy (DMD)

HT-100 Back on Track

FDA gives Akashi Therapeutics green light to resume clinical development

Akashi Therapeutics has announced that the U.S. Food and Drug Administration (FDA) has cleared the way for the company to resume clinical development of HT-100 in boys with DMD.

The news comes a year after Akashi suspended dosing and enrollment in the phase 1b/2a HALO clinical trial to test HT-100 in DMD after a trial participant experienced a medical emergency and later passed away.

The company has said it plans to launch a new study, called HALO-DMD-04, as quickly as possible and noted that it is in discussions with potential investors and development partners regarding clinical development and commercialization of HT-100.

HT-100 is a delayed-release, orally delivered, small molecule drug candidate designed to reduce fibrosis and inflammation and promote healthy muscle regeneration in DMD patients, regardless of genetic mutation. It potentially could be used on its own or in conjunction with other treatments.

MDA has contributed more than \$1 million toward the development and testing of HT-100 as a therapy for DMD.



HT-100 is designed to reduce fibrosis and inflammation and promote healthy muscle regeneration.



To learn more about Akashi Therapeutics' development of HT-100 to treat DMD, visit akashirx.com.

LOOK FOR US ON:
YouTube, Blogger, Facebook

THE SCOUT POOL LIFT
easy and safe
POOL & SPA ACCESS

THE LEADERS IN AQUATIC ACCESS

THE AQUA WALKER
innovative
AQUATIC THERAPY

Aqua Creek Products
THE LEADERS IN RECREATION, FITNESS AND ABILITY!

888.687.3552
www.aquacreek.com

amramp
MAKING LIFE ACCESSIBLE

For all your accessibility needs!

Wheelchair Ramps, Stair Lifts, Platform Lifts, Grab Bars and More

Stairlifts

Vertical Platform Lifts

888-715-7599 • www.amramp.com/quest

Duchenne muscular dystrophy (DMD)

FDA Will Review Translarna for DMD

Translarna potentially could help approximately 13 percent of boys with DMD



An FDA decision on Translarna is expected on or before Oct. 24, 2017.

PTC Therapeutics has reported that the FDA will review its investigational drug ataluren (brand name Translarna) for the treatment of some forms of DMD. An FDA decision on the drug is expected Oct. 24, 2017.

Translarna is under development by PTC to treat DMD caused by a type of genetic mutation known as a “nonsense mutation” or “premature stop codon.” This type of mutation results in production of a protein that is not complete and therefore not functional.

A “read-through” drug, Translarna is designed to act by changing the way muscle cells interpret genetic information, coaxing them to produce dystrophin protein despite the presence of a

nonsense mutation in the DMD gene. The drug, which is taken by mouth, may help approximately 13 percent of people with DMD.

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

 To learn more about PTC Therapeutics’ development of Translarna to treat DMD, visit ptcbio.com.

Lift & Care® Systems *as versatile as a pair of hands*

SUREHANDS® transferring solutions are designed to enable users and caregivers to maximize abilities and function.



SUREHANDS® launches new and innovative versions of their Ceiling Motor, Body Support and Handi-Slings
See how these advanced solutions can assist you...

- activities for daily living
- bathing • hygiene care
- repositioning • transferring
- accessing pools & spas
- exercising, ambulating and standing
- a back-saver for caregivers

SUREHANDS LIFT & CARE SYSTEMS

1-800-724-5305

website: www.surehands.com

Call today for your free catalog or to request a free home demo.



**iLEVEL
CHANGED
MY LIFE!**

Q
QUANTUM®

▶ 🐦 f 📌



Over **8,000** lives changed and counting.
Learn how iLevel® can change **your** life.

quantumrehab.com



Duchenne muscular dystrophy (DMD)

FDA fast track designation can speed the review of an investigational drug, potentially leading to more rapid regulatory approval.

Vamorolone Gets Fast-Track

‘Dissociative steroid’ may convey the same benefits as traditional steroids without unwanted side effects

The investigational drug vamorolone (formerly VBP15), under development by ReveraGen BioPharma, has received FDA fast track designation for the treatment of DMD. This designation could speed the review of efficacy and safety data for vamorolone in boys with DMD, potentially leading to more rapid regulatory approval.

Vamorolone, a “dissociative steroid,” is an anti-inflammatory compound that researchers hope will convey the same benefits of traditional glucocorticoids, such as prednisone and deflazacort (brand name Emflaza), 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.

MDA grants totaling nearly \$3 million supported preclinical development and validation of the drug, as well as phase 1 clinical trial testing to evaluate safety and tolerability in healthy adult volunteers.



To learn more about ReveraGen’s development of vamorolone to treat DMD, visit reveragen.com.

Facioscapulohumeral muscular dystrophy (FSHD) and limb-girdle muscular dystrophy (LGMD)

Encouraging Trial Data Reported on Resolaris in FSHD and LGMD

Data confirmed a favorable safety profile and increased muscle function

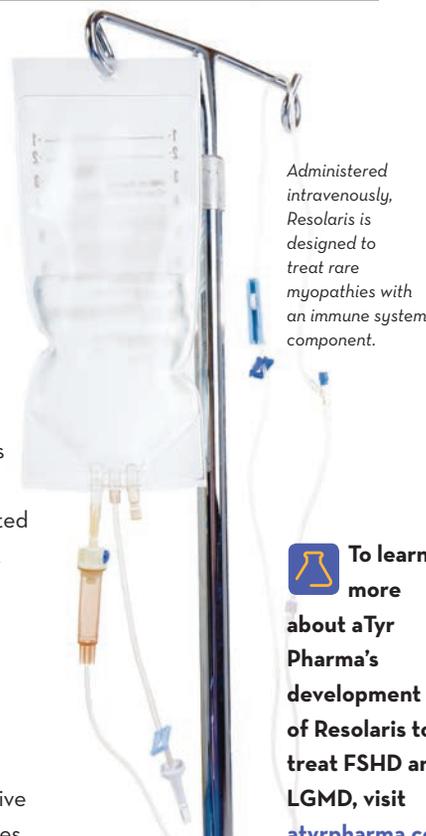
Results reported by aTyr Pharma on the company’s phase 1b/2 clinical trial to test Resolaris in people with early-onset FSHD and LGMD type 2B suggest the drug is safe and shows potential signals of clinical benefit.

Resolaris is derived from a naturally occurring protein released by human skeletal muscle cells. It may provide therapeutic benefit to people affected by rare myopathies with excessive immune cell involvement.

Analysis from the recent trial showed that Resolaris was generally well-tolerated across all doses tested. After 14 weeks of treatment with Resolaris, 78 percent of trial participants with LGMD2B and 50 percent of those with FSHD demonstrated increased muscle function as measured by manual muscle test (MMT) scores. Due to small trial size, additional studies will be required to confirm efficacy.

In January, the U.S. Food and Drug Administration (FDA) granted fast track designation for Resolaris in LGMD2B, and in February it was also given orphan drug status. The drug was granted fast track designation to treat FSHD in October 2016.

The company indicated it believes the new data are supportive of further development of Resolaris for rare muscular dystrophies.

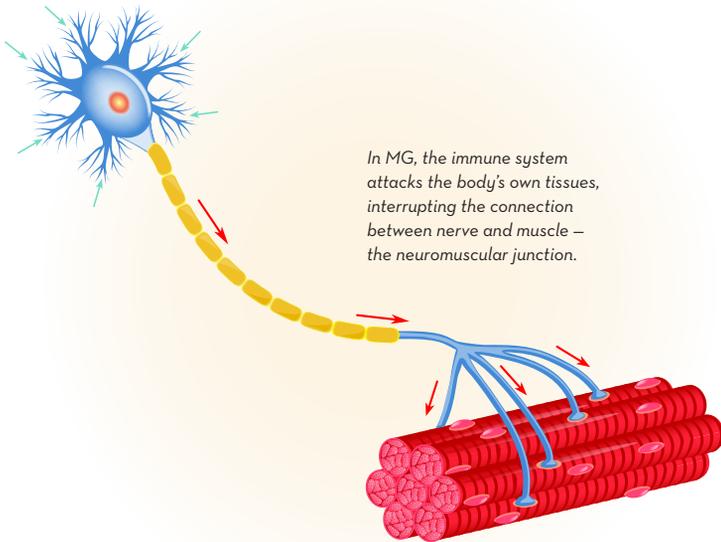


Administered intravenously, Resolaris is designed to treat rare myopathies with an immune system component.



To learn more about aTyr Pharma’s development of Resolaris to treat FSHD and LGMD, visit atyrpharma.com.

Myasthenia gravis (MG)



FDA Will Review Soliris for MG

Study results have demonstrated clinically meaningful improvements in patients treated with Soliris

Alexion Pharmaceuticals has announced that the U.S. Food and Drug Administration (FDA) will review its investigational drug eculizumab (brand name Soliris) for the treatment of refractory generalized MG. An FDA decision on the drug is expected on or before Oct. 23, 2017.

Soliris is a terminal complement inhibitor that targets a part of the immune system called the complement system, which is responsible for helping antibodies clear damaged cells and potentially toxic microbes that could cause infections. In MG, antibodies whose job it is to target these toxic pathogens, instead inappropriately recruit the complement system and target the space across which nerve fibers transmit signals to muscle fibers, called the neuromuscular junction (NMJ). Soliris is thought to work in MG by inhibiting the complement pathway to prevent NMJ destruction.

If approved, Soliris could address a significant unmet need for patients with refractory generalized MG who have largely exhausted conventional therapy.



To learn more about Alexion Pharmaceuticals' development of Soliris to treat MG, visit alexion.com.

Spinal muscular atrophy (SMA)

Promising Results in Phase 1 SMA Gene Therapy Trial

Treatment was associated with an increase in survival rate

AveXis has announced encouraging results from its completed phase 1 trial to test the investigational therapy AVXS-101 in infants with type 1 SMA. Treatment with the therapy was associated with an increased survival rate compared to the normal course of the disease and the achievement and maintenance of motor milestones infants with type 1 SMA normally would not be expected to achieve – such as head control, the ability to roll and the ability to sit with assistance.

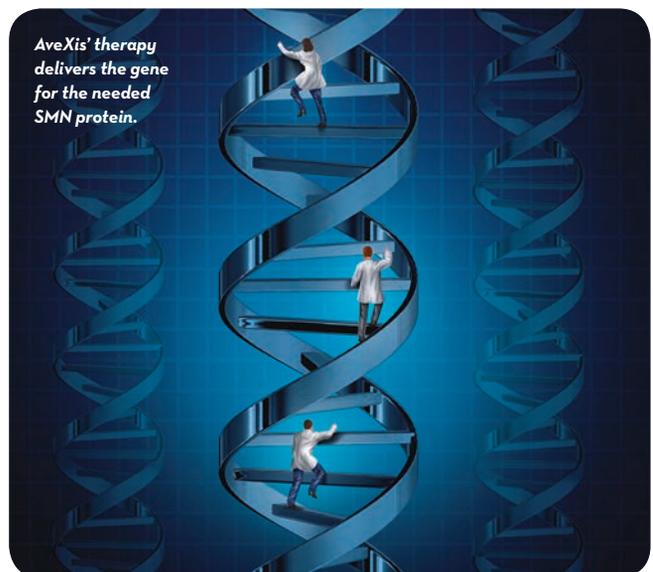
SMA is caused by a loss of the SMN1 gene, which results in a deficiency of SMN protein.

AVXS-101 contains the SMN1 gene, which produces the SMN protein, encased in the shell of a type 9 adeno-associated virus (AAV9 “vector”) that serves as a “gene transfer” or “gene therapy” delivery vehicle.

AveXis plans to initiate two new trials in the United States during the second half of 2017. One will test AVXS-101 in infants with type 1 SMA, and the second will test the therapy in children with type 2 SMA.



To learn more about AveXis' development of AVXS-101 to treat SMA, visit avexis.com.



In Case of Emergency

How to make sure you, your family and caregivers are prepared for the unexpected

BY DONNA ALBRECHT



Emergency situations present real challenges for individuals affected by neuromuscular diseases. For example, in February, when the Oroville Dam threatened to fail in California, downstream residents were given just one hour to leave their homes. Local news reported that a resident with a disability was left behind for hours due to lack of accessible transportation.

By preparing an emergency plan, you'll be in the best position to protect yourself, your family and personal care assistants when the unexpected happens. Vance Taylor, chief of the Office of Access and Functional Needs in the California Governor's Office of Emergency Services, recommends starting your plan by making sure you have what you need whether you have to evacuate or stay put.

EVACUATING

You need:

- A prepared go-bag for each person that includes medication, medical information, toiletries and contact information for family, friends and neighbors. The information can be kept on a thumb drive. Check it for accuracy every

six months when you change your smoke alarm batteries. If you have room, pack playing cards, coloring books, etc., to help pass the time while you're waiting in a safe place.

- A list with your go-bag of last-minute items you need.
- A plan to get out of your home and get to a safe place. If you need help, keep a list of at least four different people you can call on, since not

all are likely to be available when you need them.

- A list of accessible emergency transportation and shelter options. Call your local emergency services department and ask them about evacuation plans for individuals with disabilities and amenities at local shelters. For example, where can you go if you need an accessible bathroom or power supply for a wheelchair or respirator?

SHELTERING IN PLACE

You need:

- Bottled water (three days' worth for each person)
- Medications
- Non-perishable food
- Flashlights and extra batteries
- Radio or computer for news and official updates
- Ability to charge phones and power necessary medical equipment. You may need a generator or be able to connect your computer battery to small device chargers with a USB cable.

MDA volunteer Frances Kiperman has been active in emergency response since she was 19 years old. She currently serves as a Community Emergency Response Team (CERT) volunteer in her local community. Even though myasthenia gravis (MG) has slowed her down, she is still active in teaching CERT

MDA IS READY TO HELP FAMILIES

Following local weather emergencies, MDA actively tries to reach all individuals it serves in the affected areas to assess their well-being and offer assistance. If you have evacuated to a different area and need MDA services (including help with durable medical equipment or visiting an MDA Care Center), find the nearest MDA office by going to mda.org and entering the ZIP code of your current location. Also, be sure to contact the MDA Resource Center at **800-572-1717** or resourcecenter@mdausa.org. MDA's trained resource specialists are available Monday through Friday, 8 a.m. to 5:30 p.m. Central time. They typically are able to answer questions within 24 hours of a request (or on the next business day). Find more emergency resources at mda.org/services/emergency-resources.

MAKE YOUR FAMILY EMERGENCY PLAN

In the event of a fire, gas leak or other emergency, you, your family members and caregivers may need to leave your house immediately. Create a Family Emergency Plan that determines which people are responsible for dependent family members and pets. Don't forget these two essentials:

Get together. Designate a nearby (like across the street) meet-up spot to be sure everyone got out of the house safely. But disasters don't always wait for your family to be together. In the case that some of you are at work, school or elsewhere, designate a meeting place like a local church or school. Also, have a designated check-in person – perhaps an out-of-the-area family member – who can be called if some family members are not able to get to the meeting spot right away.

Practice. Sometimes the best laid plans don't work as expected. Vance Taylor, chief of the Office of Access and Functional Needs in the California Governor's Office of Emergency Services, and his family designed what seemed like a fail-proof plan to evacuate their home. When Taylor called an emergency practice, the kids, pets and his wife gathered across the street – but the plan hadn't ensured someone was responsible for getting Taylor and his wheelchair out. Giving your plan a run-through is the best way to work out the kinks.

Watch and Learn

MDA's Emergency Preparedness Webinar for Individuals with Disabilities explores how important it is for individuals with disabilities or with access and functional needs to create an emergency plan for themselves and their families so they are prepared and empowered to handle any kind of emergency or disaster. Vance Taylor, chief of the Office of Access and Functional Needs in the California Governor's Office of Emergency Services, led the presentation. Taylor has a form of muscular dystrophy and uses a power wheelchair. Watch the presentation at youtu.be/DEfs2NXiKrc.

skills. "As for me, I have two go-bags," Kiperman says. "One has all the necessary essentials if I had to stay in a shelter, and I keep this one in my hallway closet and update my kit right before hurricane season. I also keep a small go-bag in my vehicle."

DON'T PROCRASTINATE

There's a very human desire to hope that the situation

won't get as bad as "they" say. If you are told to evacuate, "sooner is better," says Taylor, who was diagnosed with muscular dystrophy as a child and uses a power wheelchair. From a comfort standpoint, you're likely to get better lodgings if you're one of the first to arrive. From a safety standpoint, having complex physical needs often means getting out takes longer than it does for others. And, as

Taylor warns, when you're dealing with the unexpected, "you have to accept that things are going to go wrong."

Once an emergency or disaster strikes, it's too late to plan. Take time now to ensure you and your loved ones have the very best chance of staying safe and sound. [Q](#)

Donna Albrecht is a writer and speaker in Northern California.



Vance Taylor (left); Frances Kiperman (right)

SPARKING
THE LIVE
UNLIMITED

800.876.8768





*MDA families
experience live
unlimited moments
every day. Many of
them start at MDA
Summer Camp.*



At MDA, we believe our limits do not define us. Limits are meant to be overcome. Turning perceived limits into unlimited opportunities means different things to all of us. For some, living unlimited means taking on an extraordinary challenge, like summiting a mountain or skydiving. For others, it means making a new friend, going to college or pursuing a career goal. What these moments have in common is a sense of confidence and a willingness to live beyond what some may see as physical or societal limits created by living with a neuromuscular disease.

For many MDA families, the drive to defy limits begins at MDA Summer Camp. Campers often credit the experiences they have at Summer Camp with helping them gain the self-confidence and independence they need to take on everyday challenges as they grow older.

Right now, thousands of kids with muscular dystrophy and related diseases are at MDA Summer Camps across the nation, enjoying adventures like horseback riding, swimming and fishing. MDA's weeklong camps affect not just the children who attend, but the family members and counselors who watch them grow and thrive in an environment without barriers.

Leila, a four-time camper, enjoys all the activities at camp.



“Leila has a very independent and determined soul, and it shines brightest when she has found a way to get around whatever obstacle she is facing.”

— JoAnna Noble,
mom of Leila

Here, current campers and their families, camp alumni and counselors share in their own words how MDA Summer Camp has encouraged them to live unlimited every day.

LEILA, AGE 13, CURRENT CAMPER

Leila, who is living with central core disease, is attending MDA Summer Camp for the fourth year. Leila has had 20 surgeries, and her mom, JoAnna Noble, discusses how camp has impacted her daughter's life.

“Leila has a very independent and determined soul, and it shines the brightest when she has found a way to get around whatever obstacle she is facing. We have a saying in our house, ‘when there is a Leila, there is a way,’ because when she puts her mind to it, she will figure out how to do it no matter what. Like when she told me in the fourth grade, ‘Mom, I’m going to do my hair by myself because I need to figure it out for myself and if it’s not perfect that is fine. I’m learning, and if someone has a problem with it, they can just go away.’ Yes, she went to school with her

hair in a messy ponytail and said it looked fabulous.

“I think a big part of why Leila loves MDA Summer Camp is because it gives her a sense of independence that she doesn’t get the rest of the year. It’s hard for kids who have limitations because they are often very physically dependent on their family members, even when they don’t want to be. MDA Summer Camp proved to Leila that she wasn’t alone in the world when it came to having a disability.”

EMILY GARCIA, 10-YEAR CAMP COUNSELOR

As a young girl, Emily heard the stories her sisters, Cynthia and Ashley, who live with a type of congenital myopathy, brought home from MDA Summer Camp, and she always wished she could go with them. When she was asked to volunteer, Emily jumped at the chance.

“I get to meet so many amazing campers each year. While there are so many stories of kids finding their true selves at Summer Camp, one very important moment stands out to me. I was lucky

enough to be the counselor for two amazing young women, Holly and Abigail. It was Holly’s last year of camp, so Abigail and I kept encouraging Holly to participate in the talent show. Holly has such a beautiful soul and an amazing voice. She debated all week whether or not to participate. Come talent show night, Holly and Abigail got on that stage together and performed their hearts out. I know how amazing both these young women are, and that night the rest of the camp knew, too.

“MDA Summer Camp is a place where you can just be yourself, where there are no limitations, and it’s an experience you will never forget.”

REESE, AGE 8, CURRENT CAMPER

Reese, who is living with a form of congenital muscular dystrophy, was a first-time camper in 2016 and received the Female Rookie Camper of the Year Award. Her mom, Kim Strayer, shares how camp has changed their lives for the better.

“Children with muscular dystrophy have limited mobility, but it doesn’t limit their ability to live life to the



Counselor Emily Garcia (left) enjoys building friendships with campers.



Reese (right) made a lasting bond with a counselor during her first year at camp.

in the background until I walked into my first MDA Summer Camp. Boy, did that change my life! I felt special. I felt empowered. At camp, I could be myself and people understood. They showed me all

the wonderful qualities that I possess and how I could tailor those to make life work for me. They challenged me. They laughed and cried with me. They shared life with me. They gave me life.

AMANDA ZUREK, AGE 19, CAMP ALUM

Amanda, who is living with spinal muscular atrophy (SMA), is an honors student studying cell biology and neuroscience at Montana State University.

“When I first came to camp, I thought I was alone. I didn’t think there were many people who had muscular dystrophy. As much as I love them, not even my parents could genuinely understand the challenges I faced. Because of this, they couldn’t really help me find ways to adapt and move forward. I didn’t have great confidence, so I always was

the wonderful qualities that I possess and how I could tailor those to make life work for me. They challenged me. They laughed and cried with me. They shared life with me. They gave me life.

“I graduated from camp in 2015, but everything they’ve taught and given has stayed with me and helped me become my own person and live life to the fullest. Before MDA entered the picture, I wasn’t really involved in my life; I just let it happen around me. Now, I am making my life my own in the way I know how – by helping others. Next year, I will be working in a lab that studies familial dysautonomia, a neurodegenerative disease similar to SMA. I will actually be conducting my own experiments in the lab. Everything MDA has taught me has set me up for an amazing future, and I can’t wait to see what lies ahead.”



Amanda Zurek (second from left) says camp helped her learn to live life to the fullest.

CHRISTOPHER, AGE 11, CURRENT CAMPER

Christopher, who is living with Duchenne muscular dystrophy (DMD), is attending MDA Summer Camp for the sixth time in 2017. His mom, Sima Perez, shares what camp means to their family.

“Christopher’s live unlimited moment was when he zip-lined and thought for a moment that he could fly. He felt empowered and free. He doesn’t feel different because he is in a wheelchair. MDA Summer Camp has given Christopher the ability to interact with other kids as special as he is.

“Christopher is a fighter. He continues to live a full, happy life. What we



Christopher (right), a six-time camper, has made lifelong friends at camp.

How safe are your hand controls?

- Can you steer with both hands?
- Can you tilt your steering wheel?
- Is your knee airbag functional?
- Is your knee space free of rods?

With DARIOS, all answers are YES!

DARIOS digital accelerator ring and main hand brake

- Lifetime warranty - Free at home pick-up + delivery
- DARIOS is VA accepted.

kempf-usa.com
1-888-453-6738

MAKING ANYTHING POSSIBLE



The lasting impact of MDA Summer Camp

MDA Summer Camp offers a world of possibilities to kids with neuromuscular diseases. Campers have the freedom to discover new interests in a safe, healthy and enriching environment while gaining self-confidence and making lifelong friendships.

This data from an online survey sent to parents of 2016 campers helps show how MDA Summer Camp impacts the lives of kids and helps them learn valuable life skills that prepare them to advocate for their needs, become independent and live beyond limits.

99%

of parents appreciate the activities their child is able to experience at MDA Summer Camp.



90%

of parents agree that MDA Summer Camp has motivated their child to try new things outside of camp.



97%

of parents agree that MDA Summer Camp has increased their child's confidence.

93%

of parents believe MDA Summer Camp has helped their child become more independent.



Luda Gogolushko carries lessons from camp into her professional life.

sometimes take for granted, he enjoys to the fullest. He loves to give us hugs, crack jokes and be silly. He defies limits because he doesn't like to be restricted."

LUDA GOGOLUSHKO, AGE 29, CAMP ALUM

Luda, who is living with SMA, runs a diversity press called INCLUDAS Publishing. It represents authors and illustrators with various abilities, as well as fictional works about characters with disabilities.

"MDA Summer Camp helped prepare me for the next chapter in my life by helping me to not be afraid to be myself. I had always struggled with how people saw me. Camp helped me embrace myself, and it taught me that whether I am in a wheelchair or not, I can still live life in my own way. When I started camp, I was a pretty shy kid, but I did everything because I knew it was only a week, and I wanted camp to last a lifetime. Putting myself out there and participating in everything was the best decision I could have made, because I got to Jet Ski and do funny skits and eat s'mores and laugh like I'd never laughed before. Sometimes life is hard, but camp takes me to a place where none of that matters because the focus is on enjoying life, whether it's dressing up as a dragon or creating the best team flag.

"Camp is always a reminder for me that I can live unlimited, because it was the first place that I realized I wasn't the only kid in a wheelchair. Being in a wheelchair isn't my entire life; it's just part of my life. I am still the same person who has dreams, feelings, aspirations, fears and pain like everyone else."

MASON, AGE 8, CURRENT CAMPER

Mason, who is living with a type of congenital myopathy, is attending MDA Summer Camp for the second time in 2017. He and his mom, Alicia Miro, are members of MDA Team Momentum.

"Going away from home [to MDA Summer Camp] was new for him, and it was the best experience to help boost his confidence, freedom and independence. He came home more outgoing, able to talk to people he would normally be silent around.

"Mason is a marathoner, a trooper and an inspiration to me. He does not let his disability slow him down and he will not let his disability define who he is. Mason decided that he wanted to run a half marathon with MDA Team Momentum while looking through a *Quest* magazine. He asked if we could, and I couldn't tell him no. We participated in the Boston Half Marathon in September 2014 and didn't stop there. Since then, Mason's Movers has raised more than \$25,000 for MDA while participating in three half marathons and the Marine Corps Marathon in October 2016. MDA Team Momentum has let Mason participate in events that normally he would not be able to accomplish on his own. It's inspiring watching him get out of his push chair, hold my hand and cross that finish line with me, because he is what gets me through those miles."



Mason (right) gains confidence at camp.

Tandin Dorji is fearlessly pursuing his professional goals.



TANDIN DORJI, AGE 25, CAMP ALUM

Tandin, who is living with SMA, graduated this summer from the University of Vermont with a Master of Science degree in biostatistics. He's accepted a fellowship with the Centers for Disease Control and Prevention (CDC) as a research statistician.

"MDA [Summer Camp] has given me the opportunity to go out in the world and not be afraid of my disability. I have always been interested in improving public health through studying infectious diseases. During my third semester of my graduate program, I was able to work with a faculty member in the biology department to research antibiotic resistance. This experience made me realize the many different areas of public health and how my skills in statistics can contribute to the overall goal of reducing infectious diseases. My ultimate goal is to work for the CDC as a public health statistician. This fellowship will allow me to improve and grow my skills to be a more proficient research statistician.

Eventually, I would like to contribute to my home country of Bhutan to help improve public health and expand the knowledge on controlling infectious diseases. Moving to Atlanta will definitely be a huge challenge to overcome since I am getting weaker, but that will not stop me."

PAYTON RULE, AGE 18, CAMP ALUM

Payton, who is living with Charcot-Marie-Tooth disease (CMT), graduated from high school this summer and will be taking a gap year to train and bond with her new service dog. She will attend Washington University in St. Louis in fall 2018.

"MDA Summer Camp has given me confidence and perspective I will carry with me into college, the work force and beyond. When I first started camp, I was 7 years old, and I



ENVISION THE POSSIBILITIES

In 1988, I had a car accident that left me quadriplegic and using a wheelchair. Dependent on others to compensate for my physical limitations, the JACO robotic arm gave me back some of the autonomy I had lost. Thank you JACO. – Isabelle Ducharme

Talk to your healthcare professional to see if JACO is right for you.

KINOVA
ROBOTICS

kinovarobotics.com

1-855-6-KINOVA

f t in

JOIN US! AOTA - Philadelphia, March 30 - April 2, 2017
PVA - National Harbor, MD, August 29-31, 2017



Payton Rule, soon to be a college freshman, feels confident she can do anything she sets her mind to.

“Camp taught me to have gratitude for my abilities and not to be afraid to step out of my comfort zone.”

– Payton Rule, camp alum

viewed my disability as a bad, limiting thing and focused on what I couldn't do. Throughout my time at camp, I have met so many incredible people and had experiences that have changed my perspective and taught me to focus on my abilities and truly strive to live unlimited. This change in mindset has allowed me the freedom to try new things and accomplish obstacles that

before I never would have thought possible.

“Camp taught me to have gratitude for my abilities and not to be afraid to step out of my comfort zone and do the things I want to do. That contributed to my decision and determination to do a half marathon. I didn't believe I would ever be able to complete a half marathon; it wasn't possible with my weak muscles. After my experiences at camp and hearing about my fellow campers overcoming obstacles, I realized I no longer had any excuse not to participate in any activity as other people with neuromuscular disease were overcoming difficult obstacles every day. I started focusing on my ability to walk. I spent the next seven months training. My

first day, I walked two miles and couldn't imagine walking another 11. However, the determination and mindset I gained at MDA camp helped me push through, and I gradually started increasing my distance. A little over a year ago, I finally competed in my first half marathon in Carlsbad, Calif., with my family. It was such a freeing experience to overcome obstacles I never imagined possible.

“Camp also laid the groundwork for my passion for medicine. I hope to one day become a neurologist specializing in neuromuscular disease or an occupational therapist. I want to enter this field so I can help people do the things they want to do, just like Summer Camp taught me.” [Q](#)

Introducing

DuchenneAndYou.com

a comprehensive Website for information about Duchenne muscular dystrophy and support for you and your family



Get the latest on:

Understanding Duchenne

Understanding genetics

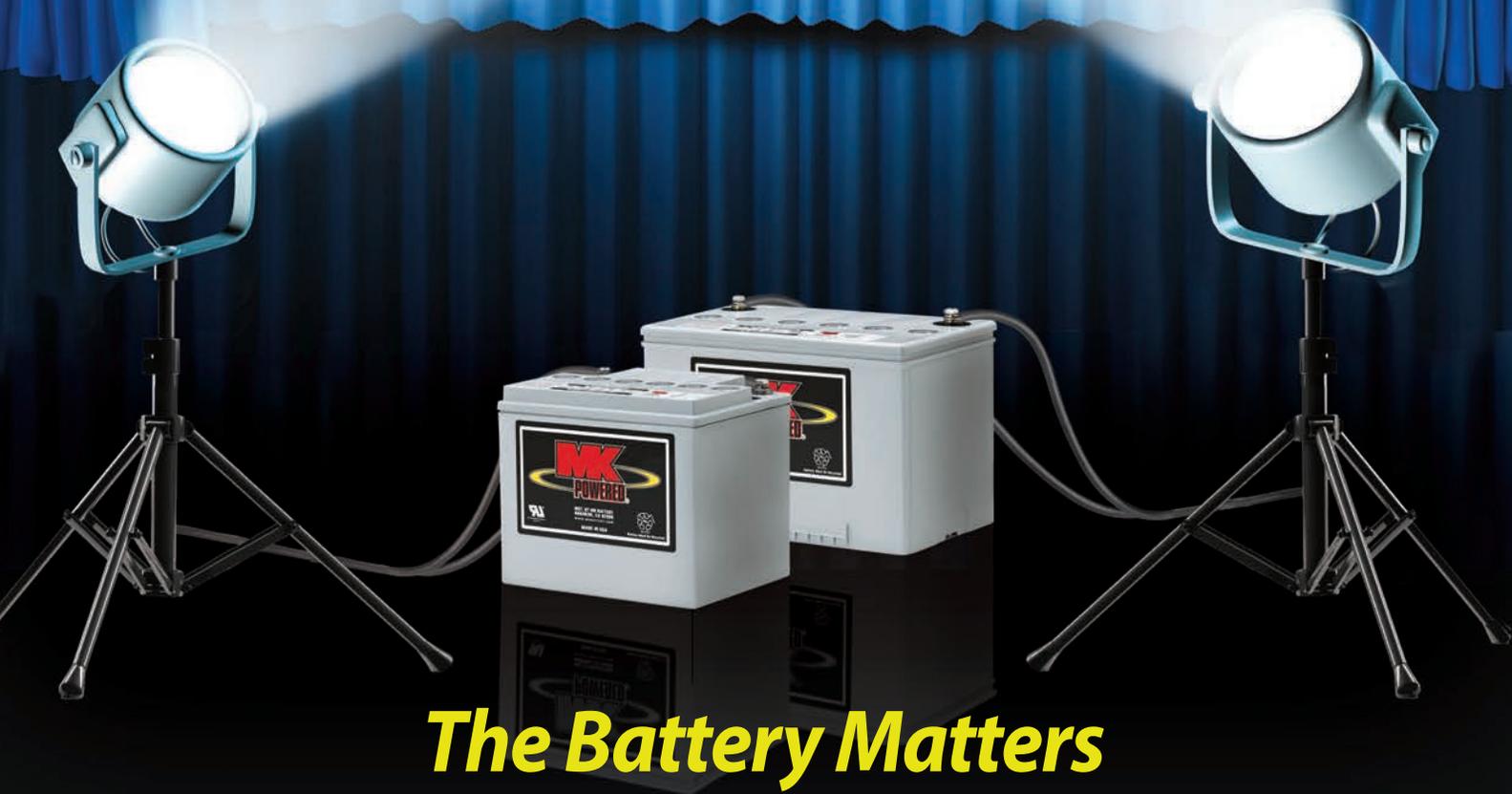
Living with Duchenne

Support resources

Visit DuchenneAndYou.com Today!

Register to receive information, news, and updates

MK Battery Salutes The World Cup Athletes



The Battery Matters



Demanding mobility applications like the World Cup of Power Soccer call for a robust breed of battery. MK Gel Batteries handle the rigors of Power Soccer just as they meet the demanding performance needs of everyday use.

For over 30 years, MK Battery has set the standard for batteries used in complex rehab power chairs. It is no wonder that leading wheelchair manufacturers and providers trust MK as the energy source for their equipment. For long life, high performance, superior reliability and less frequent battery replacements, **DEMAND MK GEL BATTERIES.**



MK is a proud sponsor and the official battery of the United States Power Soccer Assoc. and TEAM USA National Power Soccer Team.

(800) 372-9253 mkbattery.com © MK Battery 2017



Why MK Gel?



IN THE driver's SEAT

*Learning to drive
with adaptive
equipment
increases
independence*

BY CHERYL ALKON

Like many teenagers, Casey Stark wanted to learn to drive when she turned 16. But living with spinal muscular atrophy (SMA) and using a power wheelchair meant that preparing for and completing a driving test required extra planning.

Stark, who was a high-performing high school student, knew she could pass a written test, but she wondered how she was going to get behind the wheel. The cost of adapting a vehicle with hand controls and other driving aids was prohibitive, and she didn't need to drive to manage her day-to-day student activities, so Stark put that dream on hold.

Three years later, when she needed to complete an internship for her studies in biology and cellular biology at the University of Wisconsin-Whitewater, Stark approached her local Division of Rehabilitation Services to ask about vehicle funding possibilities. Because her program was in another city, the office agreed she needed to drive to pursue her career goals. She qualified for funding, was evaluated for her adaptive equipment needs and spent a summer taking 120 hours of driving lessons. When she passed her driving test, she bought a Toyota Sienna minivan and waited several months for it to be outfitted with a ramp; a joystick hand control for acceleration, deceleration, braking and steering; and a dashboard computer monitor that handles parking, driving in reverse, windshield wiping and other common signal functions.

Stark, who now works as a research program coordinator at Medical College of Wisconsin, has been driving for five years. “It has been a huge asset for my independence,” she says. “I don’t have to rely on anyone or miss out on things. It helps me out professionally to be able to go to and from work by myself, and I can travel whenever I want to.”

GETTING STARTED

The process of learning to drive with adaptive equipment might seem intimidating, with multiple steps for evaluation and licensing, as well as funding challenges. This is

Casey Stark drives using a joystick hand control and dashboard computer monitor.



true whether you are a new driver or one who is transitioning to driving with adaptive equipment. Fortunately, each state has resources to help drivers navigate the process. And the added mobility of independently traveling beyond where a power wheelchair or public transit can take you often makes it worth the time and effort.

To find out if you can use adaptive equipment to drive, look for a certified driver rehabilitation specialist (CDRS) in your area. The Association for Driver Rehabilitation Specialists (ADED) maintains a list of specialists who can evaluate your driving ability based on your range of motion, strength, coordination, vision and cognition to determine what you need to drive safely.

“The range of adaptive driving equipment is huge. Some people will require hand controls, which are a mechanical adaptation to the vehicle, and others can use an electronic computer-based joystick or an electronic steering wheel,” says Jenny Nordine, a registered and licensed occupational therapist and CDRS with Driving to Independence in Tempe, Ariz. When looking for an adaptive driving program, Nordine recommends calling and asking what kinds of adaptive equipment they work with to make sure they have what you need, whether that’s a car with hand controls or a wheelchair-accessible van. > continues on page 29

“It has been a huge asset for my independence. I don’t have to rely on anyone or miss out on things. It helps me out professionally to be able to go to and from work by myself, and I can travel whenever I want to.”

– Casey Stark

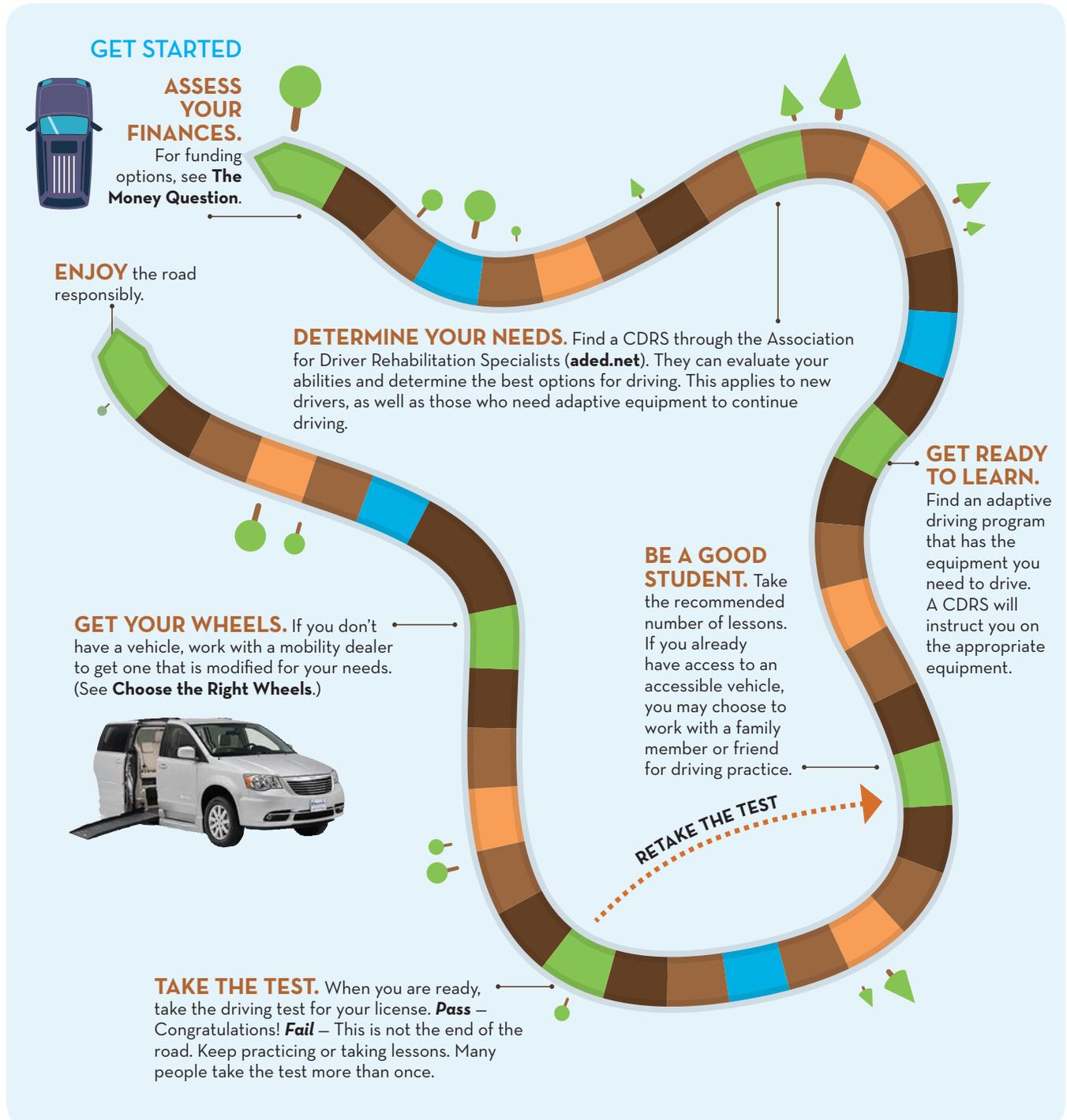
THE ROAD TO INDEPENDENT DRIVING

Each road to adaptive driving is different – some are bumpy, some are smooth and some have lots of twists and turns. Advocating for yourself often is the key to navigating that road, according to occupational therapist Jenny Nordine, who is a certified driver rehabilitation specialist (CDRS).

While each person, diagnosis and situation is unique, many drivers follow a similar path to taking control of the wheel.



Jenny Nordine



Carolyn Barrett drives an accessible minivan.



DRIVING LESSONS

Once your CDRS understands what tools you need and your driving experience, it's time for lessons. "The number of lessons differs based on the person," says Nordine. "I think about driving as three main concepts: knowing the rules of the road, vehicle operation and defensive driving. With a brand new driver, I need to teach them all those things. With an experienced driver, I just need to teach them how to operate the vehicle in a new way."

That was the case for Cal Cooper, 69, who began driving with hand controls in 2016 after decades of driving conventionally. Cooper, who lives with a condition with symptoms consistent with Charcot-Marie-Tooth disease (CMT), felt increasing weakness and neuropathy in his feet. After being assessed for driving with hand controls, he took driving lessons and had hand controls installed on his vehicle.

"There was a learning curve, and the challenge was to retrain my brain not to react with my foot every time I wanted to brake," he says. "I was a little anxious when I first drove in icy conditions or in heavy traffic, but now, six months later, I have no problem. My instructor helped me with the competence to do what I needed to do, and then I just needed to do it often enough to gain the confidence."

ADAPTATION OPTIONS

There is a wide range of adaptive driving equipment that can help people of varying abilities to drive safely, and as technology has improved and become more widely available, the number of people driving accessible vehicles has increased.

"The first time I took myself somewhere was the coolest moment I ever had."

— Carolyn Barrett

For drivers with no leg mobility, hand controls allow for braking and accelerating. Limited upper body mobility can be addressed with modifications such as a joystick that works a bit like a power wheelchair joystick. Drivers can use a control panel installed near the driver's seat to operate the vehicle's lights, horn, gears, heating and air conditioning.

Turning chairs are driver's seats that rotate to allow a person to transfer into a vehicle from a wheelchair. There are also ramps and lowered-floor vehicles that will allow a power wheelchair user to drive the chair directly into the space where

Developing Therapies for Duchenne Muscular Dystrophy



 **Capricor**
Therapeutics™

Proud Sponsor of the **HOPE** Clinical Trial

 @Capricor_News
    Capricor Therapeutics

www.capricor.com

Resources for Driving

Learning to drive and purchasing an accessible vehicle is often a team effort. MDA can help by connecting you to community resources. Get in touch with trained resource specialists by contacting the MDA Resource Center at resourcecenter@mdausa.org or 800-572-1717.

THE MONEY QUESTION

Paying for a driving evaluation, lessons and an accessible vehicle with the appropriate modifications can be costly. But there are options for financing the expense or at least offsetting some of the cost. The key is to be persistent and patient when researching all the possibilities.



HEALTH INSURANCE Check with your insurance provider to find out if your plan covers any part of the evaluation and training process or pays for adaptive equipment.



GOVERNMENT FUNDING Resources vary by state. Contact your state's vocational rehabilitation department and city and county social services to learn about state and local programs that may help provide financial assistance for all or part of the vehicle modification cost. Also, look for an Assistive Technology Act Program in your state by visiting ataporg.org/programs.



GRANTS Some local nonprofits that advocate for individuals with disabilities have programs that help pay for adaptive equipment. Your state vocational rehabilitation department may be able to point you to resources in your community.



REBATES Many vehicle manufacturers offer rebates when you purchase a new vehicle and need modifications for accessibility. Your mobility dealer should be familiar with the available rebates.



TAX BREAKS Some states waive sales tax on the purchase of adaptive equipment if you have a doctor's prescription. Also, look into whether the cost of your adaptive equipment is tax deductible.



LOANS Some banks have auto loans specifically for individuals with disabilities, and some mobility dealers and conversion companies offer financing.

they will operate the vehicle. Tie-downs or locks secure the wheelchair so that it stays put while the vehicle is moving.

"Almost anything needed is available to make driving possible," says Martine Kempf, the founder and CEO of KEMPF Inc., a California-based company that designs, manufactures, and installs adaptive driving equipment. While many people with limited mobility worry about their ability to drive safely, studies have found that traffic accident risk for drivers of accessible vehicles does not differ significantly from the risk for drivers in general. Kempf believes that drivers in this population are even more careful. "Those with disabilities know that if they don't have a car,

[they often] have no other method of transportation."

"Driving has been such an enormous addition to my independence," says Carolyn Barrett, 23, who lives with spinal muscular atrophy (SMA), operates a power wheelchair and drives with hand controls. "The first time I took myself somewhere was the coolest moment I ever had. It was a whole new level of independence I'd never had before." 

"Almost any [modification] needed is available to make driving possible."

— Martine Kempf

Cheryl Alkon is a freelance writer based in Massachusetts.

Thank you for helping families

#LiveUnlimited®



Thank you to these generous partners for helping kids like Davion who lost his ability to walk by age 8. That hasn't stopped him from finishing a mini marathon with his teacher's help and a running wheelchair.

When you give to MDA at mda.org/LiveUnlimited, you help kids and adults with muscular dystrophy defy limits.



Muscular Dystrophy Association • MDA.org

CHOOSE THE RIGHT

wheels



What you need to know before purchasing an accessible vehicle

BY BARBARA AND JIM TWARDOWSKI, RN

Purchasing a vehicle can be a daunting experience for many people. Choosing one that accommodates an individual who uses a wheelchair often presents an additional layer of decision-making. When you are ready to buy an accessible vehicle, be prepared to ask and answer a lot of questions.

TEAM APPROACH

The process typically begins with an evaluation by a certified driver rehabilitation specialist (CDRS). A CDRS conducts an assessment of your abilities and limitations, provides driving instruction and can collaborate with a mobility dealer to determine which vehicle and equipment is the best fit.

Find a mobility dealer in your area that is a member of the National Mobility Equipment Dealers Association (NMEDA). The association requires members to follow safety standards set by the National Highway Traffic Safety Administration, as well as their own guidelines that ensure quality and service.

So much more than an automotive dealer, the mobility dealer's job is to understand your physical capabilities, budgetary concerns and lifestyle. Armed with this knowledge, the dealer customizes a vehicle and any necessary adaptive equipment, such as hand controls, to create the best fit for you.

Individuals with neuromuscular diseases should be especially discerning and anticipate

future needs as their mobility changes. An accessible vehicle is a significant financial expense, and ideally, it will serve you well for many years.

VEHICLE CHOICES

Minivans are the most popular choice for accessible vehicles due to their adaptability. Minivans come with side-entry or rear-entry ramps. If you plan to drive or want to ride in the front row, scratch rear-entry ramps off the list of choices.

Two types of ramps are available: foldout and in-floor ramps. The foldout is mounted in the passenger side doorway, folding and unfolding in an accordion-style motion. The in-floor ramp is housed under the floorboard, sliding in and out in a horizontal movement.



The MV-1 is built for accessibility.



Individuals with disabilities who want to drive or ride in the front row need a side-entry ramp.

There are pros and cons to each ramp, which you'll want to discuss with your mobility dealer. For example, both BraunAbility and Vantage Mobility International (VMI) offer a converted Chrysler Pacifica, but the door hinge opens differently on each of their ramps. Buyers should compare all options carefully to determine what is best for their needs and lifestyle.

In side-entry minivans, the entire floor of the vehicle is lowered, making maneuverability easier. Both the driver and front passenger seats are removable. An individual can remain in his or her own chair or transfer to the seat. For safety, wheelchairs must be properly tied down.

Your wheelchair dimensions dictate which vehicle is the best match. For example, those who sit high in their wheelchair may need an Extra Tall (XT) model, which provides more head room.

WHAT'S NEW

The wheelchair-accessible Chrysler Pacifica made its debut this year, replacing the Town & Country. A new version of the Honda Odyssey will be rolled out in 2018.

An alternative to vans, the Ford Explorer MXV is an SUV by BraunAbility. Introduced to consumers less

than two years ago, the sporty vehicle can accommodate some power wheelchairs. The category-defying MV-1, introduced in 2011, is an innovative vehicle designed from the ground up for accessibility.

NEW OR USED?

When you're ready to buy an accessible vehicle, you have three choices:

- **New:** The vehicle and the conversion are brand new. Both come with manufacturers' warranties.
- **Pre-owned:** The conversion is brand new and comes with a warranty. The vehicle is 1 to 3 years old and usually has less than 30,000 miles on it. You'll need to determine if the vehicle includes a warranty.
- **Used:** The conversion and vehicle are used. You may find them through mobility dealers or individuals. You'll need to determine if any warranty is still valid.

TEST DRIVE

Individuals who use wheelchairs usually can't test drive vehicles, because each adapted vehicle is custom-made. However, many

mobility dealers offer the chance to take a ride in an accessible vehicle before buying. Some dealers will even bring a vehicle to your home or pick you up and drive you to the showroom.

Another option is to attend a disability trade show. At Abilities Expos (**abilities.com**), companies display vehicles and adaptive equipment and will answer questions.

Take your time choosing an accessible vehicle. Once you've made a choice, call insurance companies and compare policies. You'll want to have the best coverage possible before you get behind the wheel. **Q**

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

Vehicle Q&A

Go to mda.org/quest and search for "Accessible Vehicles Q&A" to read answers to common questions about how to get the most value for your dollar when purchasing an accessible vehicle.

BUYER BEWARE

Imagine this: It's a holiday weekend and you find an incredible deal on a new Honda Odyssey that looks exactly like your neighbor's wheelchair-accessible van. Should you buy it on the spot and take it to a mobility dealer to be converted? "Not necessarily," says Dawn McCool, field marketing director for Superior Vans and Mobility, which has mobility dealerships in four states. "Not all chassis (standard vehicles) can be converted."

According to McCool, different versions of the same model may be configured differently, or sometimes the two-wheel drive can be converted, but the four-wheel drive cannot be converted. Before making a purchase on your own, give your mobility dealer the VIN number so they can determine if the vehicle's configuration supports modifications.



SHARING, LEARNING + dialogue

While it's easy to understand how funding research and providing care for kids and adults from day one help individuals with neuromuscular diseases live longer and grow stronger, hosting conferences and facilitating dialogue also have tremendous benefits for saving and improving lives.

MDA-supported conferences bring together the world's best researchers, top clinicians, industry leaders, other stakeholders and

families to share knowledge, ideas and best practices; to foster collaboration; to strategize around advocacy initiatives and to connect with like-minded individuals. These experts and influencers in the muscular dystrophy community come together with one goal in mind: to accelerate progress for our families.

scientific breakthroughs to save and improve lives for MDA families.

At the 2017 conference in March, more than 500 scientists, clinicians, industry partners, and pharmaceutical and biotech representatives had ample opportunities to engage in dialogue and an exchange of ideas and updates, gain insight into others' research methods and results, and find ways to collaborate and build off successes as they work to unlock the secrets of neuromuscular diseases and develop therapies to treat them.

As one presenter remarked, MDA's Scientific

Elisabeth and Keegan Kilroy, siblings from Maine, meet with Senator Susan Collins (center).



MDA conferences support families by advancing research, advocacy and clinical care objectives

Conference and other such gatherings are valuable in a number of ways — including the fact that they can be the catalyst for a therapy developed for one neuromuscular disease to lead to a treatment for other diseases that have similar underlying mechanisms or outward effects. We may envision scientists locked away in their labs, hunched over microscopes and studying complicated-looking tables and graphs. But the truth is that attending meetings like MDA's Scientific Conference plays a vital role in advancing science and making breakthroughs.

For MDA, the Scientific Conference represents not only our commitment to advancing science but also to fulfilling a promise to our families to work tirelessly to create real results.

MDA PUBLIC POLICY & ADVOCACY CONFERENCE

Elisabeth Kilroy, a second-year doctoral student at the University of Maine, is working to identify the genetic cause of her brother Keegan's muscular dystrophy. She relies on federal funding for her research, so when she and Keegan had the chance to speak to veteran Senator Susan Collins as part of MDA's inaugural Public Policy & Advocacy Conference in Washington, D.C., they wasted no time with their ask: fully fund the National Institutes of Health.

"I've read about you two!" Senator Collins replied with a smile. "Tell me more about your work."

In April, Elisabeth and Keegan were among a group of nearly 90 advocates from 23 states who visited more than 100 congressional offices on Capitol Hill during the Public Policy & Advocacy Conference. The advocates spoke to their representatives about the importance of programs and policies that help accelerate the development of treatments and cures for individuals and families living with neuromuscular diseases.

Before they headed to the Hill on the final day, MDA families attending the conference heard from a variety of experts in research, health care reform and accessible air travel. MDA's scientific program officers addressed the unique nature of research across diseases and shared information about current therapy development pipelines and clinical trials. Their presentations helped demonstrate

the importance of the requests the advocates made on the Hill by shedding light on the mechanisms of research funding, the role of regulatory science and the drug development process.

The conference also featured guest speakers from the National Organization for Rare Disorders, Cystic Fibrosis Foundation, U.S. Department of Transportation and other national organizations. They addressed concerns about health care reform and issues around accessible air travel.

Once attendees were prepared with background information to support their advocacy efforts, they fanned out within the House and Senate buildings to put a human face on the issues that matter to the MDA community. Many families found that congressional members were genuinely interested in the issues they discussed during the Capitol Hill meetings.

"To know that [Senator Collins] is on my team and ready to support research is a boost of motivation and dedication for me as I endure the long days and nights in the lab," Elisabeth explains. "Even though Senator Collins was already an advocate for research funding, I believe our story showed her the impact that research

Learn More

Learn more about getting involved with MDA at mda.org. For the latest updates on news, research, advocacy and more, follow our Strongly blog at strongly.mda.org.

UPCOMING CONFERENCES

MDA's BMD Conference

Aug. 26, 2017

Houston, Texas

This conference — available free of charge to anyone affected by Becker muscular dystrophy (BMD), as well as the individual's family and friends — is designed to bring together members of the BMD community for informative presentations and discussions.

2018 MDA Clinical Conference

March 11-14, 2018

Arlington, Va.

MDA's Clinical Conference connects neuromuscular disease clinicians, allied health professionals and scientific experts who are committed to driving the best medical outcomes and optimizing care for individuals living with neuromuscular diseases.

Before they headed to the Hill on the final day, MDA families attending the conference heard from a variety of experts in research, health care reform and accessible air travel.



MDA advocates from Missouri in front of the U.S. Capitol.

has, not just for me who is dependent upon the money to support [my research], but for my brother, for my father and for the thousands of other individuals living with muscular dystrophy.”

Elisabeth was one of many participants who left the conference with renewed optimism. “I have shared my experience at this conference with every person I know. I am not ready to stop. I am

going to ride this wave of momentum until there is a cure for all types of muscular dystrophy. I will forever be an MDA Advocate,” she says.

MDA CLINICAL CONFERENCE

MDA Care Centers make it possible for MDA to help care for kids and adults from day one so they get the very best treatment. MDA’s commitment to providing multidisciplinary care at our more than 150 Care Centers across the United States ensures that families can receive comprehensive clinical care and support from a wide variety of health care specialists at one location on the same day.

Every two years, MDA holds a Clinical Conference, bringing together neuromuscular disease clinicians, allied health professionals and scientific experts from across the country to share information and learn about new approaches and techniques for clinical management of neuromuscular disorders, hear about the latest information regarding clinical trial results, and engage in dialogue and networking among peers.

MDA is excited to partner with families and medical and scientific experts as we drive consistent, high-quality clinical care and work to ensure MDA Care Centers are prepared to serve as clinical trial sites. The MDA Clinical Conference is an ideal setting to share ideas about strengthening MDA’s multidisciplinary approach and our overall emphasis on family-centered care. [Q](#)

MULTICHAIR Tub/Slider Systems

ALL NEW! MULTICHAIR 6000Tilt



NUPRODX CAN SAVE YOU \$1,000s

With a MULTICHAIR 6000Tilt you can use your existing tub and save \$1,000s in remodeling costs. Its Center-of-Mass design keeps the user’s weight centered through the entire tilt range, for a small footprint. Log on to www.nuprodx.com to see the entire range of shower and commode systems that will improve the quality of life for users and caregivers alike. It’s the one system that can last a lifetime!

Features Include:

- Center of Mass Tilt-in-Space controlled by a side-mounted hand crank for easy care-giver or user adjustment of tilt angle
- Eliminate bathroom transfers with an effective alternative when installing a roll-in shower isn’t possible or affordable
- Fold-back padded locking arm rests / adjustable swing-away footrests
- 5" casters with Total-Lock brakes
- Seat height adjusts to the highest toilets required by the ADA
- Removable locking bridge section
- Won’t rust or corrode: Aluminum, brass, stainless steel and plastic construction—it’s going to last!

nuprodx inc

www.nuprodx.com
(855) 220-5171

Connect With What Matters



Being there makes a difference

It could be a simple trip to the mall, a ride to the movies or just a visit to a friend's home. The little things in life can make a big difference. It's why MobilityWorks has been helping people connect with who and what matters most since 1997. Our clients have unique needs so we treat each of them as individuals. First of all, we listen. Then, we work together to find the best solution.

MobilityWorks has more than 65 locations across the country with the largest selection of accessible vehicles and adaptive solutions:

- Converted minivans, full-size vans and SUV's — Chrysler, Dodge, Ford, Honda and Toyota
- Pre-owned accessible vehicles
- The latest in adaptive technology including transfer and turning seats, scooter lifts and hand controls
- Complete maintenance and service on adaptive driving equipment, lifts and conversions
- Daily, weekly and long term rental vans
- Financing options to fit your personal needs
- 24-hour roadside assistance with wheelchair transportation

MobilityWorks is committed to serving you. Contact us today so we can evaluate your needs and find a solution that best fits your lifestyle.

PLEASE JOIN US IN

Celebrating 20 Years

Customer Appreciation Days

June 1 – August 31

- Green Tag Savings Event
Save Up To \$5,000^a On Select Inventory
- Limited Time Offer! Chrysler Pacifica starting at \$44,995 with Braun Ability Rear-Entry Conversion^{*}
- \$75 Mobility Maintenance Inspection[#]



^a Subject to vehicle availability. While supplies last. Discount varies by vehicle. No other rebates or incentives are applicable. See store for complete details. Cannot be combined with other offers.

^{*} Includes rubberized flooring. While supplies last.

[#] Pre-scheduled appointment required. Cannot be combined with other offers. Valid through 8/31/17.

USA's largest accessible van dealer!

For more information, call toll free 1-888-608-1659
or visit www.mobilityworks.com





access MDA

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

Walking with Warhorse

The Robinson family raises awareness and money for MDA Muscle Walk

When Valerie Robinson came home from her first visit to her MDA Care Center in Texas after her son, Ryan, had been diagnosed with limb-girdle muscular dystrophy (LGMD) at age 14, the first thing she did was go to the MDA website and set up her MDA Muscle Walk team.

"The clinic was an amazing experience, despite what we were there for," she says. "At the end of the appointment, the MDA coordinator mentioned the upcoming Muscle Walk and asked if we would be interested in forming a team, and we just said, 'Yes.'"

The Robinsons shared their team link with friends and family, and it gained attention quickly. They called the team Warhorse Nation because Valerie and her husband were in the 1st Cavalry Division of the U.S. Army. Being a military family, they have a competitive streak, so even though they didn't reach the top spot in the 2012 MDA Muscle Walk of Austin – which was the first year they participated – that only meant they came back with more enthusiasm the next year.

"Our first year, we were in third, and the next two years we were in second," she says.

"The first year that we took first place, I wrote about it on Facebook and said 'We held a little plastic WWE Championship belt over our heads like we accomplished the cure.' That's the kind of feeling we had in that moment."

Over the years, Warhorse Nation has raised a staggering amount for MDA – more than \$115,000 total. The Robinsons have put a lot of effort into fundraising, including recruiting volunteers from Ryan's high school ROTC to go door to door to raise funds for their MDA Muscle Walk team.



Ryan (center) with parents Rich and Valerie Robinson.

Ryan, now 20, will soon start working for the Department of Veterans Affairs in Texas.

 **Help bring strength to life at your local MDA Muscle Walk by getting involved today. Visit mdamusclewalk.org to find your local walk, register and begin recruiting your family and friends.**

Five Reasons to Join MDA Muscle Walk in 2017

MDA families weigh in on why they support these events

MDA Muscle Walk is a life-changing event that strengthens families and communities, helps fund research breakthroughs, provides care for kids and adults, and empowers families with services and support to live longer and grow stronger. For these reasons alone, it's obvious why we love Muscle Walk. But don't just take our word for it. Learn why five MDA families are equally dedicated to Muscle Walk and why you should also support this incredible cause.

1. HELP OTHERS.

Former MDA Georgia State Ambassador Alexas, 9, who lives with spinal muscular atrophy (SMA), participates in Muscle Walk to help other MDA families.

"Alexas has the biggest heart," shares her mother Tammy. "She knows and loves the fact that when she participates in MDA Muscle Walk, she is doing something to help others."

She also loves the opportunity to meet and talk with other kids who have shared similar experiences.

2. CREATE MOMENTUM FOR TREATMENTS AND CURES FOR NEUROMUSCULAR DISEASES.

Stuart Horton, who has Charcot-Marie-Tooth disease (CMT), participates in Muscle Walk in the hope of finding a cure for the next generation, including his daughter Samantha, who also has CMT.

"I am hopeful that they find something for the youth and the younger generation – a promise that they will have a better life, a better future and fewer complications," shares Horton.

Although getting out of the house can prove challenging for Horton at times, he knows that his efforts are going to help find treatments and cures for others impacted by neuromuscular diseases. ➤



**WSPE
BEST IN STATE
Engineering
Excellence
Award 2015**

Call or visit our website for more information and to see a video of our cushion being pressure mapped.

The most important component of a wheelchair is the cushion. It is your only protection against a pressure injury.

Choose the **SofTech** automatic cushion. Engineered to treat and prevent injuries by alternating up to 60 times per hour. Custom built for each client.



Medicare Code E2609

AQUILA CORPORATION
Seat Cushion Systems

AquilaCorp.com



866-782-9658

3. DO SOMETHING PROACTIVE.

After a decade of being misdiagnosed with everything under the sun and undergoing an unnecessary foot surgery, Melanie Carson finally discovered the truth: she lives with Miyoshi myopathy. Armed with this information, Carson knew she had to take a proactive approach in the fight against neuromuscular disease.

“Instead of sitting there and wallowing and feeling bad about myself,” she says, “why not go out there?”

And that’s exactly what she did. Carson started her own MDA Muscle Walk team in 2013, and since then, “Melanie’s Indomitable Will” has raised more than \$30,000 for MDA.

4. BUILD A COMMUNITY.

Tammy Gregory and her two sons, Kyle and Travis, who both live with Becker muscular dystrophy (BMD), find strength and comfort at their local MDA Muscle Walk in Columbus, Ohio, when meeting other families who have had similar experiences and are facing the same diagnosis.

“It’s nice because you realize you’re not alone and you’re not the only one. There are other people like you,” Gregory says of the walk.

“You can talk to them and they know what you’re going through, because they’ve been through it, or they’re going through it. I think it helps the boys out – to see that they’re not alone,” Gregory adds.

5. MAKE MEMORIES AS A FAMILY.

For Stacy Santiago and her husband, MDA Muscle Walk is about making special memories with their son, Miguel, who lives with Duchenne muscular dystrophy (DMD).

“I took him out of his wheelchair at the end of the course so he could walk over that finish line to prove that we will get him through anything,” shares Santiago. “To hear everyone cheering and clapping his great accomplishment was wonderful for him. We are making memories for Miguel!”



Stacy Santiago and her son, Miguel, walk over the finish line at MDA Muscle Walk.



There are so many reasons to walk. Find yours and get started at mdamusclewalk.org.

Barrier Free Lifts

to meet the individual's needs

We serve individuals with disabilities, caregivers, and health care institutions with an extensive line of patient lifts and slings.



1620 SW 17th St. Ocala, FL 34471
Phone: 1-800-582-8732
Fax: 1-866-378-3318
Email: us-ffice@barrierfreelifts.com
www.barrierfreelifts.com

OPEN SESAME

REMOTE CONTROL DOOR SYSTEM

Automatically opens and closes a door from any mobility device

- Release a locked door
- Simple to Install
- Adaptable/Portable for most doors



OPEN SESAME

CALL FOR OUR BROCHURE
1-888-973-7263
www.opensesamedoor.com



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 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

Pursuing Your Passion

Andrew Baker is a dedicated student and competitive swimmer at Brandeis University



Andrew (left) with his sister, father and former NFL player Steve DeOssie.

When he was younger, Andrew Baker, a 21-year-old junior at Brandeis University in Waltham, Mass., who has Charcot-Marie-Tooth disease (CMT), knew he wanted to compete. He tried baseball and soccer, but found that with his CMT he was

unable to be a competitive player. Serendipitously, he was recommended swimming as a form of physical therapy, and with some encouragement from his younger sister who also has CMT, he decided to try swimming competitively.

“Water is a great equalizer,” he says. “In the water, you can fly. I fell in love with the sport because of its accessibility and because I could be a part of something as a team.”

Baker’s first tryout in seventh grade didn’t land him a spot on the swim team, but he came back the next year and earned his place on the team with his improved skills and a passion for the sport. Baker carried his passion through high school to his college career, and he now competes as a swimmer for the Brandeis Judges, where he has formed a strong bond with his team.

“The camaraderie is a huge part of why I love swimming,” Baker says. “My team at Brandeis is really supportive and understanding.”

Beyond his swimming and schoolwork – he is currently studying international relations and Russian with a minor in health policy – Baker also has been an MDA Ambassador, an MDA Summer Camp counselor and an MDA Muscle Team volunteer. After

Innovative Head Control Solutions

The Savant Headrest

- Rotational and lateral control
- Headband for anterior support
- Shape by hand for custom fit
 - Cool and lightweight
 - Three sizes



Makers of the Headmaster Collar



1-800-537-1724
www.symmetric-designs.com

Granny Jo Products

For Dignity and Independence

wrap yourself...



...in comfort

Visit us online at
www.GrannyJoProducts.com
or call 863-698-9130

discussing his experiences as an ambassador and at MDA Muscle Team with his coaches and swim team captains, they wanted to help him give back.

In 2015, the Brandeis Judges volunteered at the MDA Boston Muscle Team Gala, assisting with the silent auction and acting as runners for the live auction. They came back in 2016 to help again but were unable to participate in the 2017 Gala because it occurred on the same weekend as their championship. They are planning to come back next year.

"The entirety of Brandeis is a huge family, and we all support each other in our personal and academic endeavors, and this is my team's way of supporting me," Baker says. "It's an amazing time. Not only getting to give back to MDA, but I'll admit it is fun seeing the sports stars. You get a little starstruck."

Baker knows firsthand how important giving back is, having seen both sides of MDA Summer Camp as a camper and a counselor.

"Being able to go to Summer Camp and do activities I wouldn't normally do, like riding in a motorcycle, was a fun experience," he says. "But it was also the experience of seeing how many other kids there were, both with similar conditions to mine and with far more severe conditions. It made me appreciate my own condition, and it was actually for that reason that I came back to be a counselor."

While Baker has been a counselor for two summers, he was

unable to participate last year. Instead, he worked as an intern in the Office of Civil Rights in Washington, D.C.

"I was able to learn how to process and complete cases of discrimination, and I was trained on equal employment opportunity processes," Baker says. "I actually got my first professional article published through the U.S. Department of State."

Baker plans to build on his experiences in D.C., as well as his internship this summer where he will be working on the Boston Children's Hospital's Healthmap program. He will be translating and cataloguing information on disability cases occurring in Russia and former Soviet Union countries, as he pursues an eventual career in disability law.

"I started Brandeis wanting to be a biomedical engineer," he says, "but I also really had a passion for Russian, and I wanted to find a career that combined my passion for Russian with helping people with disabilities. I took a disability awareness class my freshman year that helped fuel my passion and showed me there is a career that combines disability policy and Russian."



MDA's Young Adult Program is committed to supporting individuals with neuromuscular diseases navigating education, employment and independent living through resources, programming and community connections. Learn more about the Young Adult Program at mda.org/young-adults.

Three models with hundreds of combinations available!

Why get a hospital bed? Yuk!



Mobile Twin

*Twin Size
Raised Panel / Mahogany
Shown without mattress*



Signature Series

*Queen Size
Raised Panel / Mahogany
Shown without mattress*



Platform Series

*Full Size
Mission Style / Espresso
Shown without mattress*

An Assured Comfort® adjustable bed offers you many hospital bed features without looking like one! Perfect for the ones you care for, allowing more comfort while reading, watching TV or relaxing.

DOWNLOAD MODEL INFORMATION
AT ASSUREDCOMFORTBED.COM



- Side safety and assist rails are available
- Quiet remotely-controlled articulation
- Twin, full, queen, split-king or custom sizes
- Hi-Lo option for adjusting mattress heights
- Exclusive headboards and footboards
- Typically can retrofit existing bed surrounds
- Several mattress options or maybe use your own

Bassett, VA · Call **866-852-2337** or email: ckenan@AssuredComfortBed.com

Insurance coverage will vary. Your DME may be able assist you with availability.



From Apples to Advocacy

Teacher Dayniah Manderson embraces her role as Ms. Wheelchair NY 2017

For Dayniah Manderson, a teacher, writer and mother with spinal muscular atrophy (SMA) from New York City, being in a pageant at age 37 wasn't really on her radar. But when she received a nomination for Ms. Wheelchair NY 2017, she was taken aback – at first.

“Initially, I was disinterested because I didn't know what the world of pageantry is about,” she says. “But after someone contacted me and explained it to me, it became more appealing. They had to do a little convincing, but ultimately I appreciate them pushing me to do it.”

Ms. Wheelchair America is an advocacy platform for women with disabilities. The program operates in 27 states, including New York. (Visit mswheelchairamerica.org to learn more.)

“When I was completing the [Ms. Wheelchair] application, I didn't consider myself an advocate, but once I did think about it, [I saw] that my teaching and way of living life in general make me an advocate,” Manderson says. “Once I had fully wrapped my head around what this would mean, I realized that I was only helping myself and others on a larger scale, and I was thinking about that perspective and utilizing the time I have to enact that change I'm hoping to see.”

This year, Manderson is fundraising to represent New York in the 2018 national Ms. Wheelchair pageant and enjoying her Ms. Wheelchair NY duties, including doing media interviews and attending panel discussions that have covered topics, including sexuality and inclusive environments for individuals with disabilities. Manderson says that she loves doing the “grunt work” of getting out there and starting conversations with people.



Dayniah Manderson is Ms. Wheelchair NY 2017.

“We're trying to build compassion in society by exposing people to the accomplishments of people [with disabilities] and to our day-to-day lives,” she says. “There are shared experiences between ambulatory and non-ambulatory people, between disabled and able-bodied people. We do integral things in the community just like anyone else.”

And like so many others, Manderson gets up every day to go to work, takes care of her 11-year-old daughter and finds time to nurture her hobbies, like writing. While she acknowledges juggling all of her commitments is tough, she wouldn't have it any other way.

“It's a fulfilling journey, but it's a lot of work,” she says. “Anyone who teaches public school can tell you it's no walk in the park, and I'm a single parent of a middle-schooler, and I'm responsible for supervising my home attendants, and all of those things existed before I got the [Ms. Wheelchair NY] title. But I love committing. It's good to push my boundaries and stretch my limits.”

Thanks to her love of pushing her own limits, Manderson has been able to spread her disability awareness message wider than ever before.

“I just want people to become more sensitive to the deficit in society,” she says. “We all grow old, anyone can have a child with a physical or developmental disability, and unless people make a strategic decision to make society in general more equitable – for things to be in place when they need it – that person with a disability will be a burden. It's about the future, and it has to be collaborative.”

 Find more stories of individuals living beyond limits at strongly.mda.org.

DO YOU WANT RELIEF FROM...

- Painful Bedsores?
- Pneumonia and Other Respiratory Problems?
- Being Awakened for Turning?

AUTOMATED BODY ROTATION

PROGRAMMABLE TIMES AND ANGLES

SMOOTH AND SILENT OPERATION

The Freedom Bed provides many proven medical benefits PLUS the guarantee of a good nights uninterrupted sleep, every night.

The Freedom Bed is funded by private insurance plans and state programs.





Left Rotation



Right Rotation



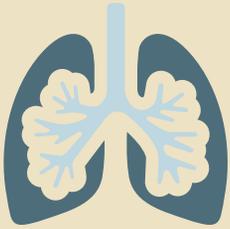
PRO BED
Medical Technologies Inc.

“ I am writing to help promote the awareness of the FREEDOM BED within the Muscular Dystrophy Community. If our son's story can help families get the bed that will change their lives it will be worth it. The FREEDOM BED is heaven sent! It has dramatically improved our lives and allows the whole family to live normally. It is appropriately named the FREEDOM BED. ”

The Azar Family

FOR MORE INFORMATION CALL
TOLL FREE: 800.816.8243 | WWW.PRO-BED.COM

**IR CONTROL
OPTION AVAILABLE!**



A chance to **advance DMD therapy**

Join a study of respiratory function in Duchenne muscular dystrophy (DMD).

The *SIDEROS* study

is a clinical trial that will study whether a therapy called idebenone is safe and effective at delaying the loss of breathing function in boys and men with DMD.

The study will compare the efficacy of idebenone to placebo in those currently on steroids (either prednisone or deflazacort).



The therapy

Idebenone is an oral tablet developed by Santhera Pharmaceuticals, a specialty company focused on developing novel treatments for DMD.

Who can participate?

- Males with DMD, any mutation
- Age 10 or older
- Ambulatory or non-ambulatory
- On corticosteroids for at least 12 months
- Forced Vital Capacity between 30% and 80%

*Find out more about the study or who can participate at **SiderosDMD.com** or by emailing us at **sideros@santhera.com**.*



CITGO Gives Back

MDA honors CITGO with a special research award for their impressive fundraising efforts in support of MDA families

At the 2017 MDA Scientific Conference in Arlington, Va., on March 20, MDA presented CITGO Petroleum Corporation Assistant Vice President of Supply and Marketing Alan Flagg with a special research award to honor CITGO's unprecedented contribution to MDA's research program over the years. In the past 30 years, CITGO has donated more than \$200 million to MDA to support the search for new treatments and cures for neuromuscular diseases.

"We started raising funds in 1986," Flagg says. "We started very modestly, but it's been a great run for us."

CITGO achieved this staggering number through supporting many different MDA fundraising events, from golf tournaments to the MDA Shamrocks program. During the award ceremony, Flagg was presented with a white coat by MDA Chairman of the Board R. Rodney Howell, M.D. The coat serves as a symbol of CITGO's commitment to funding treatments and cures for neuromuscular diseases.

"The CITGO employees, the CITGO retail operators, our marketers, our suppliers and our customers all participate and all contribute," Flagg says. "We're just excited that we're here to help raise some of those funds. Where the research is going, where the science is going, is truly exciting."

A Strong Tradition

A millennial fire fighter works to keep the IAFF-MDA connection strong

Like many kids, Vince Van Binsbergen, 26, wanted to be a fire fighter when he grew up.

"I used to run around with a fake EMT bag," says the California native, laughing.

Van Binsbergen never outgrew that dream, and at age 15, he enrolled in a fire explorer program, where he learned what being a fire fighter is all about. After high school, he moved to Colorado and served as a volunteer fire fighter for the Elk Creek fire department while working as an EMT. After about three years, a paid position opened up, and he's been working for the Elk Creek Fire Department Local 4710 ever since.

Even before becoming a fire fighter, Van Binsbergen experienced the strong connection between fire fighters and MDA. ➤

GUARANTEED FOOT DROP SOLUTIONS

DORSI-LITE™ FOOT SPLINT

USE WITH
OR WITHOUT
SHOES



- Outstanding comfort.
- Easy On & Off
- Ultra-low profile, 30Z
- Near-Normal Gait
- Will not slip off
- Also use in bath or swimming pool
- \$60/EA. + \$7 Shipping/Order
- Optional EXPRESS shipping: \$25
- Low cost replacement parts available

DORSI-STRAP™ FOR FOOT DROP

FOR USE
WITH
SHOES



Also available,
Dorsi-Strap PRO Heavy-Duty, \$46

- No Special Shoes Needed
- Nothing put into the shoe
- Outstanding comfort
- Ultra-low profile, 30Z
- Near-Normal Gait
- Easy On & Off
- In White, Black, or Brown
- \$43/EA. + \$7 Shipping/Order
- Optional EXPRESS shipping: \$25
- Low cost replacement parts available

30 DAY MONEY-BACK WARRANTY

X-STRAP SYSTEMS
9 Stonegate Drive
Hyde Park, NY 12538

www.x-strap.com
(845) 233-4713

01/17

SPECIAL \$3 OFF/ORDER: CODE MDAX

Give Your Family The Freedom They Deserve!

LIFTKAR PT is a battery powered, attendant operated, stair climber for all ages! Use inside and outdoors. Works on angled, curved and straight stairs...and yes, even carpet! Use with or without a wheelchair. Lightweight and easy to disassemble, fits compactly into the car. No modifications to home, school, church, business, airplanes and RV's.

MobilityLifter For more information call **615.530.1374**
Or view our website www.mobilitylifter.com

Experience Abilities Expo!



Achieve greater independence through:

- Latest products and services
- Expert-led workshops
- One-on-one engagement
- Revitalizing sports
- Kid-friendly fun
- Adaptive dance
- Service animals
- Daily living aids for seniors

**FREE
ADMISSION**

www.AbilitiesExpo.com
Register online today. It's free!



Chicago
June 23-25, 2017

Houston
August 4-6, 2017

Boston
September 8-10, 2017

San Mateo
October 27-29, 2017

DC Metro
December 1-3, 2017

Toronto
January 19-21, 2018

Los Angeles
February 23-25, 2018

New York Metro
May 4-6, 2018

"It goes back to when I was an explorer in California," he says. "They helped out with Fill the Boot, and that was my first time being involved with MDA. When I got out here as a volunteer, I did Fill the Boot, and once I became full time, they handed me the reins of MDA coordinator."

As MDA coordinator, Van Binsbergen saw the effect his fundraising has on the MDA community firsthand.

"What really got me into it was going to a boot camp and meeting all the families and the kids," he says. "Hearing the stories of how MDA has helped them, that made me want to continue being the coordinator to raise more money."

And Van Binsbergen has taken that role to heart, helping his department raise more than \$58,800 for MDA since he started as coordinator.

"We're a small department with nine full-time fire fighters, and the only stoplight we have is on the highway, so we fill the boot in front of stores," he says.

Beyond his impressive fundraising, Van Binsbergen is also a member of the MDA/IAFF National Millennial Committee, which aims to deepen the relationship between millennial fire fighters and MDA. Having seen what MDA can do for its families, Van Binsbergen is excited about engaging his colleagues in the cause.

"We want to get more people involved and continue the tradition between IAFF and MDA," he says. "That's really what the committee is doing – trying to keep that tradition alive."



Vince Van Binsbergen (left) enjoys coordinating Fill the Boot for his fire department.



Get involved and support MDA Fill the Boot events near you by becoming an MDA volunteer.

Visit mda.org/volunteer and sign up today.



PREVENT SURGERIES & FALLS



Specializing CMT Bracing
Improve Balance, Comfort
Walking & Running!

**CHECK OUR YOUTUBE
CHANNEL TO LEARN HOW
WE CAN HELP YOU!**



Email: CMTBracing@aol.com
www.DynamicBracingSolutions.net

Check for a Licensed DBS Clinician Closest To You!

(866) 999-WALK (9255)

*Also Provide Solutions For: Foot Drop, Foot & Ankle Pain, Multiple Sclerosis, and Various Neuromuscular Disorders

LIFT YOUR LIFE TOWARD INDEPENDENCE

Battery-Powered Chair Lift



From sitting to standing in home, office or other environment

Comfort and style for use anywhere

Ask about our 30-Day return guarantee

800-831-8580

for information and a FREE demo video

www.stand-aid.com

sales@stand-aid.com

YouTube product videos on our website

Saint Romain

ADAPTED EATING UTENSILS



made in FRANCE



DISTRIBUTED BY



1 888 956 6866

m&bility
Roadside Assistance™

Provides peace of mind through full-service towing assistance including paratransit pick-up for you, your family & equipment.

mobilityroadsideassistance.com



Honor a family member by making a tribute gift to MDA in your will or trust.

To learn more, visit mdalegacy.org.



Muscular Dystrophy Association



Wheelchair Van Loans

New & Used Vans for Consumers, Dealers & Fleets

- Loans for more than the chassis blue book value
- Competitive Rates
- Loans For Most Credit Scores



Apply online quickly to finance your van:

www.brandlmobility.com

(866) 829-1900

Loans based on the full value of handicapped-equipped van, more than just the chassis blue book



Surviving and Thriving in College

A recent graduate with spinal muscular atrophy describes his approach to campus life

BY KEVIN SCHAEFER



Kevin Schaefer on campus at North Carolina State University.

College is a blast, but it can come with a pile of challenges the size of a mountain. Just look at the hundreds of articles there are advising students on how to conquer stress, manage time and deal with that one professor who may as well have been stripped from an '80s movie. College can be the best — and the most draining — time in a person's life.

If college is difficult for able-bodied students, imagine the challenges it presents to someone like me, who has spinal muscular atrophy (SMA). If you think trying to balance 15 credit hours of classes with a job at Starbucks is hard, try

crossing campus in a power wheelchair during the winter while your driving hand is frozen.

I'm not going to lie: Surviving college was no easy feat. But despite the obstacles I faced, my four-and-a-half years at North Carolina State University were some of the best years of my life. The advice and tips I got helped me, so, in case it's helpful for those who are skeptical about college due to their own disability, here is how I survived college with SMA.

1 *My first stop was the Disability Services Office.* Since high school, I knew that I wanted to go to NC State.

Once I was accepted, my mom and I visited the Disability Services Office, and thank God we did. They directed me to Vocational Rehabilitation (VR), a state-supported division of services that assists individuals with disabilities who are pursuing meaningful careers. VR ended up covering my tuition.

The Disability Services Office also helped me with academic accommodations, like note-takers in my classes. Growing up, I always had an adult aid with me at school, but these were students who were paid to sit in on my classes to take notes and record lectures. They were all very easy to work with, and it was a tremendous help to have accommodations in the classroom.

2 *I got involved with groups on campus.* I lived at home throughout college, but that didn't stop me from being active in student organizations. I wasn't interested in Greek life, so I joined the student newspaper, the Technician, and a campus ministry called Intervarsity Christian Fellowship.

The newspaper is where I had my first published work and where I received my first paychecks (even though the

Supporting Students

MDA's Young Adults Program is dedicated to supporting individuals with neuromuscular diseases as they pursue education, employment and independent living. Find resources and community at mda.org/young-adults.

amount on those paychecks was laughable). Eventually, I became the co-features editor and ran the section with my friend Taylor.

I have a long list of great memories with my friends from the Technician and Intersarsity: late-night meals at Cook Out and Wendy's, midnight premieres of Marvel movies, getting free passes at the local bowling alley when the elevator broke, going to a Halloween party that got shut down by the cops for a capacity fire hazard, and my 21st birthday party at my friend Sam's house. I had fun.

But being involved had other benefits. I made lifelong friends who understood my physical limitations and were willing to help when I needed it. For example, through the state's Independent Living Rehabilitation Program, I was able to hire two friends to drive me to classes and activities. This provided a break for my parents and more independence for me.

3 *I built relationships with my professors.* Nine out of 10 times, professors are cool people who want you to succeed. I only ever had two who could outdo the principal from "Ferris Bueller's Day Off" in terms of their utter lack of personality.

Communicating with my professors on a regular basis helped them better understand my needs. Anytime I asked for extended time on a test or an alternative assignment, my professors were perfectly willing to make those accommodations.

4 *I planned each day as much as I could.* I'll be the first to tell you that I'm not the most organized person. I hate entering stuff in my calendar, my inbox tends to overflow with junk mail and unread messages, and I procrastinate regularly. Yet, I found it was vital to plan each day as best as I could.

Like many individuals with SMA, my upper-body strength has deteriorated as I've gotten older. When doing homework between classes, I'd have to make sure my hand stayed close enough to the joystick on my chair so I didn't get stuck in the hallway. Eventually, I couldn't eat, drink or work without assistance.

In 2015, I began using a JACO robotic arm, but before that, I was entirely dependent on other people. As such, if I knew I'd be on campus for lunch or dinner, I made sure to plan in advance to eat with someone. Eventually, it kind of turned into a weekly schedule: dinner in the school newspaper office on Mondays, lunch with Jed on Tuesdays, eat at home on Wednesdays, lunch with Lucas on Thursdays, hang out with a friend on Fridays.

Planning my day didn't just help with eating. I made sure that I could get where I needed to be and get there on time. It required some additional effort to plan each day out carefully, but it's better than getting stuck in the hallway.

5 *I asked strangers for help.* At least 99.9 percent of the time, I found people were more than willing to help if I just articulated

what I needed. At a large university where I constantly needed help with things like opening doors and picking up stuff, this skill became an essential part of my survival. Particularly in situations where a friend had to cancel at the last minute for lunch, I had no choice but to ask someone I didn't know for help. Is it easy admitting to the guy behind the counter at Jimmy John's that you need help lifting your arms to eat? It's difficult and pretty embarrassing at first, but I'll take it over starving.

Heck, it even allowed me to flirt with girls: "Hey, I know you were planning on going home, but I kinda need help with my lunch. Wanna go to Bruegger's Bagels?" I also have a service dog, which is code for chick magnet. In my experience, no girl will ever say no to helping you feed your dog.

Having SMA or another physical disability while trying to pursue a degree can seem impossible at times. The truth is, it's hard, but it's certainly possible. And I'm not even one of those straight-A students who goes on to get a Ph.D. that you see at SMA conferences. I graduated with a decent GPA, but I spent a lot of time goofing off and playing on my iPad. I'm just a dude, and this is how I made it through college. [Q](#)

Kevin Schaefer, 23, graduated from NC State in 2016 and is now a columnist for SMA News Today. He lives with his parents in North Carolina.

"The advice and tips I got helped me, so, in case it's helpful for those who are skeptical about college due to their own disability, here is how I survived college with SMA." – Kevin Schaefer

Running the Country

The faces and places of MDA Team Momentum

MDA Team Momentum participates in a dozen (and counting) marathon and half-marathon events every year. These events feature hundreds of runners and walkers who raise money for MDA, and they take place all across the United States, from San Diego to Chicago to Boston. Here are some of the groups of runners who have made an impact fundraising for and raising awareness of MDA.



Above: Sterling Procter, who has inclusion-body myositis, supports his wife, Carol Anne, as she trains for the Chicago Marathon. **Right:** Patrick Sawhill, (in gray shirt) of Traverse City, Mich., has run five marathons with Team Momentum for his son, Finley (in blue shirt), who has nemaline myopathy. **Below:** Tonya Jones (center) recruited friends and family to run the SoCal Ragnar Relay in honor of her grandfather, who had ALS.



Above: Mason, age 8, lives with a type of congenital myopathy. Along with his mom, Alicia Miro (center), and other members of the Mason's Movers team, he has participated in three half marathons and the Marine Corps Marathon. **Left:** Jon and Stephanie Betts started the team Henry's Heroes in honor of their son, who was diagnosed with congenital muscular dystrophy. Each year, along with friends and family, they run in the Chicago Marathon and other races. They also serve as an MDA ambassador family for teams across the country.



MDA Team Momentum

Join MDA Team Momentum to cross the most meaningful finish line of your life. Upcoming events include the Superheroes Half Marathon Weekend (Nov. 9-12, Anaheim, Calif.) and Dallas Marathon (Dec. 10). Our spring 2018 events will be unveiled in October. Learn how you can get involved with MDA Team Momentum at mdateam.org.

We're looking for people with LEMS or CMS.

Do you have Lambert-Eaton Myasthenic Syndrome (LEMS)? Congenital Myasthenic Syndrome (CMS)? Or, do you know someone who does?

You can help make a difference.

Catalyst Pharmaceuticals is conducting important clinical studies in both LEMS and CMS to study the safety and efficacy of the oral investigational medicine FIRDAPSE® (amifampridine phosphate). Your participation can help support getting an FDA-approved treatment and advance the cause of other patients struggling with these rare diseases.

"BREATHING PROBLEMS" "EASILY FATIGUED"
"WEAKNESS" "DROOPY EYELIDS"
"DIFFICULTY MOVING"
"DIFFICULTY CLIMBING STAIRS" "FATIGUE"
"TROUBLE WALKING" "FALLING"
"SLURRED SPEECH" "CAN'T MOVE"



LEMS Patients

Adults with a confirmed diagnosis of LEMS may become eligible to participate in this brief study (usually 7-9 days in duration) to be conducted in Los Angeles and Miami. Travel, hotel, and meal costs will be covered for both you and a companion.

CMS Patients

People age 2 and older who have a body weight greater than or equal to 10 kg (22 lb) and have been diagnosed with CMS, including certain genetically confirmed defects, are candidates for this brief trial to be conducted in Atlanta, Baltimore, Boston, Columbus, OH, and Los Angeles. All travel related costs will be covered for both you and a companion.

Learn More

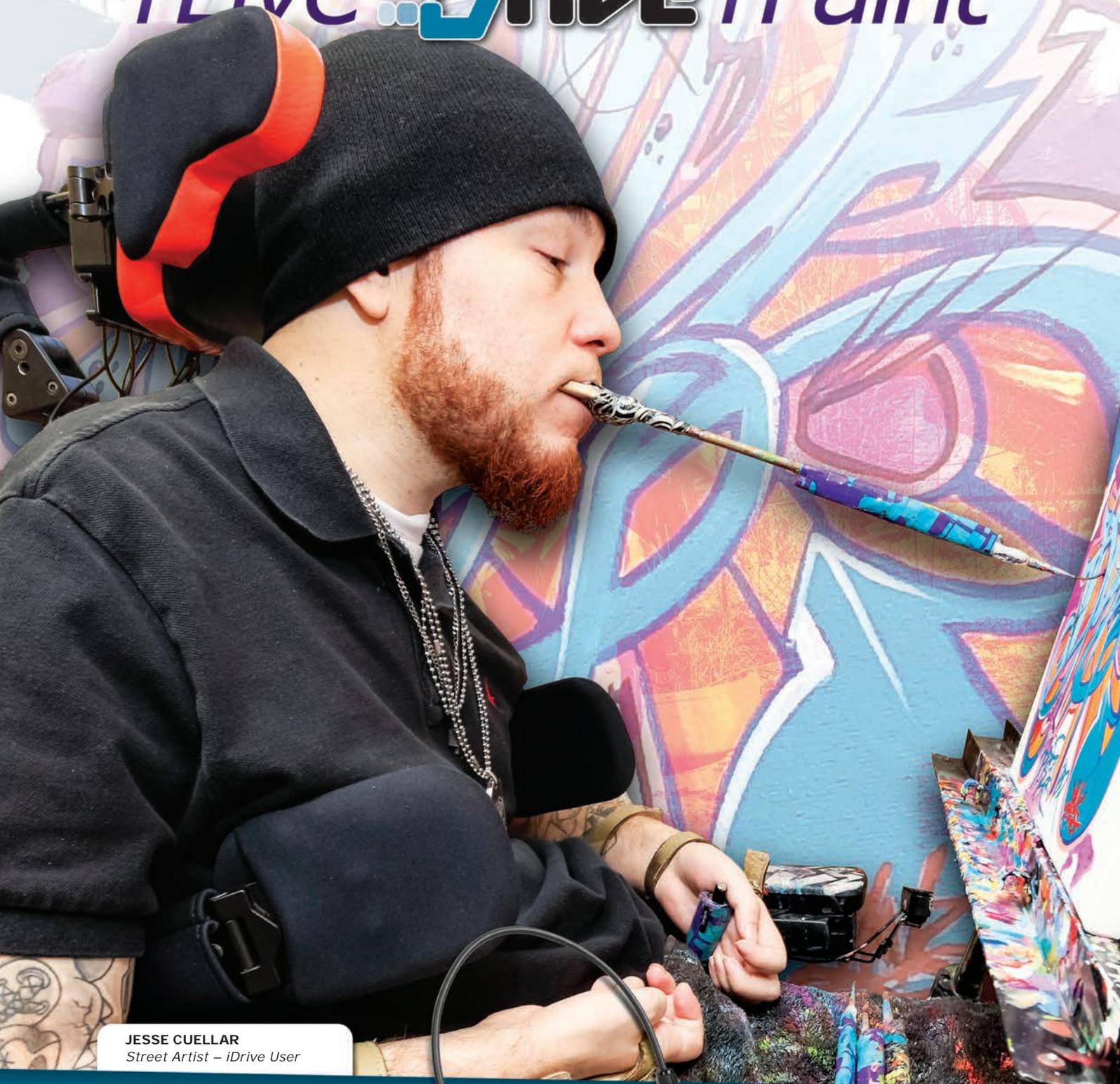
For more information about Catalyst's Expanded Access Program (EAP) and/or our clinical studies, contact Catalyst at EAP@catalystpharma.com or call 1-844-347-3277. More information about both trials is also available on the Catalyst website at www.catalystpharma.com

Catalyst Cares

Catalyst Pharmaceuticals is a pharmaceutical company focused on developing prescription drugs to treat rare neuromuscular and neurological diseases, including LEMS and CMS. Catalyst has been dedicated to providing education to LEMS/CMS patients and physicians. For more information on our work, please visit us on the web at www.catalystpharma.com



iLive **iDrive**® *iPaint*



JESSE CUELLAR
Street Artist – iDrive User

CREATIVITY COMES FROM WITHIN,
and iDrive 4.0 gives me the outward
control to bring my artwork to life.



Learn more at StealthProducts.com