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25 Years of Commitment

For more than 60 years, MDA's lifesaving mission has provided hope and paved the way for treatments and cures. Recent advancements and breakthroughs, including three FDA-approved treatments, have provided tangible results with more therapies on the way.

We are especially grateful to the following partners whose efforts, generosity and commitment to our mission over the past 25 years or more have helped MDA fund the years of work that has made the recent progress possible and helped provide a renewed sense of hope for MDA families. Together, we forge ahead with even greater urgency to accelerate progress in research, care and support.



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fall 2017

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Joe Akmakjian with Mitch, one of his personal care attendants.

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Artist
Karen
Condron

MORE ONLINE

MAKE A GOOD CAREGIVER MATCH

As a young adult living independently with spinal muscular atrophy (SMA), MDA National Ambassador Joe Akmakjian has a lot of experience hiring personal care attendants (PCAs). He's learned a good PCA match has as much to do with personality as skill. In a Quest online exclusive article, Akmakjian shares his favorite interview questions. (Some are surprising.) **Read "The Unconventional Interview" at mda.org/quest.**

On the cover: Rocco Arizzi, National Ambassador 1979-1980, with Jerry Lewis

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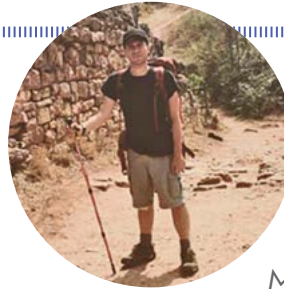
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Living Unlimited

MDA's Strongly blog (strongly.mda.org) is a treasure trove of stories by and about individuals who live life to the fullest with neuromuscular diseases. Here are excerpts from some of those stories that capture the live unlimited spirit. Although each story is unique, they all contain a common message: Never give up.



"I could lose the ability to use my hand in the future, but I'll find another way to adapt. I don't let it bother me. I've adapted and dreamt big my whole life, and I'm going to continue to do that."
 – AJ Brockman, an artist who lives with spinal muscular atrophy (SMA)



"Knowing that this condition will most likely put me in a wheelchair one day makes me want to stay active and do all I can do while I am still able. My decision to walk the Camino came from my desire to push myself to the edge of my abilities, to explore new cultures, experience nature and become more spiritually enlightened."
 – Bryan Steward, who hiked the 500-mile Camino de Santiago in Spain and lives with Becker muscular dystrophy (BMD)



"He has shattered the capabilities of what a child with SMA type 1 could accomplish. Looking at him you don't know he has SMA."
 – Amy Medina, whose younger son, Javier, is receiving Spinraza. Her older son, Mateo, also has SMA, and she continues to advocate for him to receive the same treatment.



"I never had to come out as a person with a disability. When you first meet me, you will see that I use a wheelchair. ... However, I did have to come out as a gay man with a disability. This was a different matter altogether."
 – Hugo Trevino, who lives with spinal muscular atrophy (SMA)

"After two years I graduated with my bachelor's degree in psychology. ... Achieving that goal was such an accomplishment for me because there had been many roadblocks that seemed like dead ends. But I rerouted and allowed myself time to find another way. I refused to let my daughter see me give up."
 – Pearl Burgin, who lives with limb-girdle muscular dystrophy (LGMD)



Live Unlimited Moments

Read more live unlimited stories from the MDA community at strongly.mda.org. Be sure to visit liveunlimited.mda.org to learn more about MDA's Live Unlimited movement.

LIMB-GIRDLE
MUSCULAR DYSTROPHY

BECKER MUSCULAR DYSTROPHY

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ALS (amyotrophic lateral sclerosis)

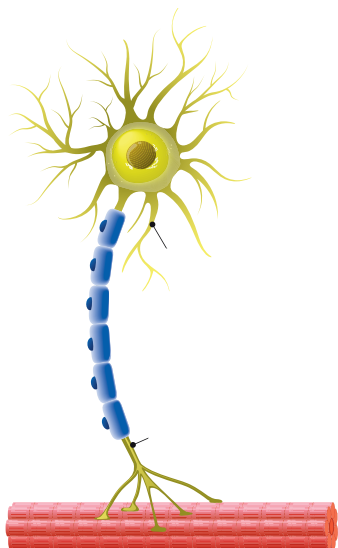
Answer ALS: Participants Sought

The biological data collected for the trial will be combined with clinical measures of ALS symptoms and progression.

Initiative aims to leverage big data and machine learning technologies to uncover new clues about ALS

Researchers are looking for people with ALS, as well as others with motor neuron disease, and healthy volunteers to participate in the Answer ALS: Individualized Initiative for ALS Discovery study, sponsored by Johns Hopkins University School of Medicine.

Goals of the study include creation of a large repository of induced pluripotent stem cells (iPSCs), motor neuron cell




lines and bio-fluid samples for comprehensive genetics and data analyses. The biological data collected for the trial will be combined with clinical measures of ALS symptoms and progression.

The research team has aligned with Google, Microsoft and others to leverage big data and machine learning technologies to integrate all the data points with the goal to uncover new clues into the causes of ALS, identify subgroups of people with different ALS types, find new therapeutic targets and identify biomarkers.

Trial length is approximately one year, during which participants will make five visits to the study site where they will undergo strength testing, tests to assess respiratory function, cognitive testing and will have blood samples taken.

Trial sites are located in California, Georgia, Maryland, Massachusetts, Missouri and Ohio.

 **To learn more about this trial, visit ClinicalTrials.gov and enter NCT02574390 in the search box, or visit answers.org.**



New Biomarker for C9 ALS

Could help speed clinical trials, assess drug effectiveness

A multinational research team has identified abnormal proteins – called dipeptide repeat proteins – as a promising biomarker that could be used in developing and testing therapeutics to treat ALS caused by a mutation in the C9ORF72 gene. (A biomarker is a biological indicator that can be used to measure phenomena such as the onset or progression of a disease, how a disease is reacting to a treatment or how a drug is behaving in the body. Biomarkers are particularly important for clinical trials, where experimental treatments are being tested and their effects carefully measured.)


In the study, scientists found elevated levels of dipeptide repeat proteins in the cerebrospinal fluid of C9 ALS patients but not in controls, and that protein levels remained constant over time. (Such consistency is needed for these proteins to serve as a valid biomarker. If the levels were variable, the investigators would not be able to tell the difference between a normal fluctuation in the protein levels and a drug-induced decrease.)

The researchers also found that treating C9 patient cells in culture or treating a mouse model of C9 ALS with an “anti-sense oligonucleotide” (ASO) therapy resulted in decreased levels of the abnormal proteins, suggesting the new biomarker potentially could be used as a readout to test whether an ASO drug has an effect in reducing toxic protein levels. (Antisense oligonucleotide is a class of experimental therapeutic molecules designed to target genetic instructions at the RNA stage. The RNA stage is an intermediate step between the original genetic instructions – DNA – and protein synthesis inside cells.)

Development of biomarkers such as this one are important for clinical trials, as they could help researchers gain insight into whether or not a drug is effective and also potentially reduce the length of the clinical trial, allowing promising drugs to progress to the next step more quickly.



MDA supported Tania Gendron at the Mayo Clinic in Jacksonville, Fla., for her work on this project.

 **To learn more, visit mda.org/gaag and search for MDA grantee Tania Gendron, who received a grant in August 2016.**

Dermatomyositis



Orphan drug designation provides incentives for Octapharma to develop Octagam for dermatomyositis.

Octagam Receives Orphan Drug Designation


Experimental dermatomyositis drug may modify immune system activity

The investigational drug intravenous immunoglobulin, or IVIG (brand name Octagam), under development by Octapharma USA to treat dermatomyositis, has received U.S. Food and Drug Administration (FDA) orphan drug designation.

IVIG therapy involves the injection of a pool of nonspecific antibodies (immunoglobulin) that may work by dialing down the immune system's production of its own antibodies, much as warm air tells a thermostat to stop pumping out heat. It is used in the treatment of a wide variety of autoimmune and inflammatory conditions.

Orphan drug designation may help facilitate development of Octagam for the treatment of dermatomyositis, as it provides incentives meant to encourage Octapharma to develop and market it.

Octapharma currently is conducting a phase 3 clinical trial to test the safety and efficacy of Octagam in dermatomyositis. Trial sites are located in Arizona, Kansas, Michigan, New York, Ohio and Pennsylvania.

 For more information about the phase 3 clinical trial to test Octagam, visit ClinicalTrials.gov and enter NCT02728752 in the search box.

Duchenne muscular dystrophy (DMD)

Online DMD Study Seeks Parents to Participate

Study will evaluate the use of online screening tools to help identify early effects of DMD

Parents of young boys with DMD, as well as parents of age-matched non-affected boys, are being sought to participate in an online observational study, being conducted at the University of California-Davis Neuromuscular Research Center in Sacramento. The study will explore the use of online screening tools to identify possible developmental delays and behavioral challenges in young boys with DMD.

Participation in the study requires approximately 60 to 90 minutes for parents to complete online questionnaires about their child's development and behavior.

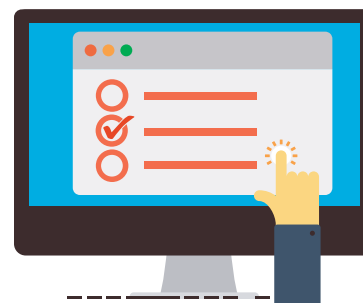
Parents for a total of 125 boys with DMD and 125 non-affected boys are needed. Inclusion criteria for parents of sons with DMD are:

- Parents must have a son under 7 years old with a diagnosis of DMD from a medical professional.
- Parents must be able to read and write English.
- Parents must have access to the internet.


Parents of boys with DMD will be encouraged to invite a parent of a non-affected male peer to participate in the study, too.

The parent-completed questionnaires will be housed in a local data center at UC Davis Health System and all web-based information transmission is encrypted.

No doctor visits are required. Online surveys can be completed from home.



Online questionnaires will help assess whether online screening tools can help identify developmental and behavioral challenges in young boys with DMD.

 To learn more, or if you are interested in participating, visit ucdmc.ucdavis.edu/pmr/research/DMD-study.html, or contact Principal Investigator Amy Wagner at alwagner@ucdavis.edu or 530-564-8310.

Myotonic dystrophy (DM)

AMO-02 on the Fast Track

Drug may counteract increased activity of an enzyme called GSK3 β in myotonic dystrophy

The U.S. Food and Drug Administration (FDA) has granted fast track designation for the investigational drug AMO-02 (tideglusib), which is under development by AMO Pharma for treatment of congenital type 1 myotonic dystrophy. This designation can potentially lead to more rapid regulatory approval if the drug proves to be an effective therapy.

Drugs that receive fast track designation are eligible for more frequent meetings and written communications with the FDA, accelerated review and priority approval, and rolling New Drug Application review.

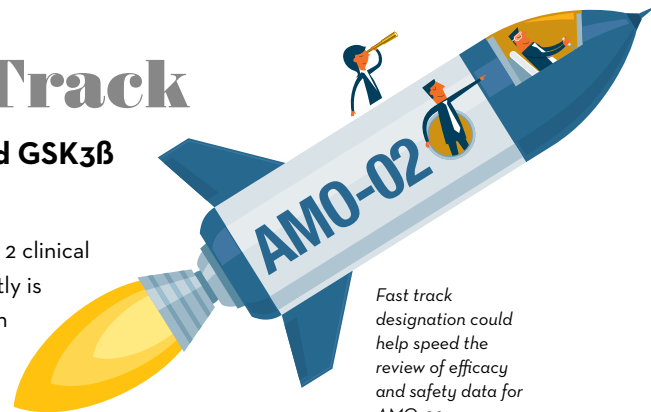
In a May 30, 2017, press release, AMO Pharma noted that AMO-02 is designed to work by inhibiting activity of a protein called glycogen synthase kinase 3 beta (GSK3 β) and has demonstrated preclinical efficacy in transgenic models and tissue samples derived from patients with congenital DM1.

A phase 2 clinical trial currently is underway in the United Kingdom to evaluate

the safety and efficacy of AMO-02 in people with congenital and juvenile-onset DM who are between the ages of 16 and 45 years old.



For more information about the phase 2 clinical trial, visit ClinicalTrials.gov and enter NCT02858908 in the search box.



Fast track designation could help speed the review of efficacy and safety data for AMO-02.

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Myotonic dystrophy (DM)

MDA, AAN and ABF Award Fellowship

Award to Johanna Hamel will support her work in myotonic dystrophy




"I feel grateful and honored to receive this award," Hamel says. "I am excited to help advance our knowledge of genetic disorders and am looking forward to working with patients and families with myotonic dystrophy."

MDA has partnered with the American Academy of Neurology (AAN) and the American Brain Foundation (ABF) to award a clinical research training fellowship in muscular dystrophy to Johanna Hamel, M.D., a neurologist at the University of Rochester in New York, for her work in comparative studies of RNA toxicity in DM.

The two-year fellowship, which began July 1, will provide a total of \$130,000 to support Hamel's work to shed light on the molecular processes that drive DM.

Hamel is working to determine the extent to which toxic RNA and dysfunction of proteins within the muscle cell nucleus relate to the severity of symptoms of DM. For example, it is generally thought that the longer the repeat (the abnormally expanded section of DNA that causes DM), the more toxic the RNA and the bigger the problems. However, in type

2 myotonic dystrophy (DM2) the repeat lengths are usually much longer than in the type 1 form of the disease (DM1) and there seems to be greater accumulation of toxic RNA, but DM2 is typically a milder disease. Understanding this discrepancy may shed light on other mechanisms involved in causing the disease.

 **Read "Five Questions with Researcher Johanna Hamel" to learn more at strongly.mda.org.**



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Disclosing Disability

How to talk with an employer about your neuromuscular disease

BY KAREN HENRY



Chase Miller, who lives with BMD, works as a fundraising coordinator for MDA.

Talking with employers about neuromuscular disease can be challenging. Given the broad spectrum of neuromuscular diseases and their often unpredictable nature, some may find it difficult to navigate exactly when and how much to disclose.

“The very first thing a person needs to consider is why you want to disclose,”

says Sharon Rennert, senior attorney advisor at the U.S. Equal Employment Opportunity Commission (EEOC). Doing so for the right reason at the right time keeps the focus on your performance as an employee, rather than on your disability.

FOCUS ON THE JOB

If you are applying for jobs and choose to disclose, Rennert encourages individuals to limit the discussion. “Under the Americans with Disabilities Act (ADA), and many state laws, it is illegal for employers to ask about the presence of disability prior to making a job offer,” she says. “Keep the job interview focused on performing the job, and make any disclosure about disability incidental.”

That’s exactly what Kushal Parikh did when he entered the workforce. Parikh, who has Becker muscular dystrophy (BMD) and uses a wheelchair for mobility, chose not to disclose his disability until the job interviews. At the end of each interview, he asked if the employer had any questions about his disability. “I feel like it’s necessary to talk about it,” says Parikh, who currently is a social worker at ComPsych in Chicago. “If you can’t talk about disability with your employer, it’s not going to be a good work experience.”

Even when you disclose information about your condition, the employer is still limited in what they can ask about it, Rennert notes. “With disclosure, what would be lawful is if the employer wants to ask specifically about any reasonable accommodations you need to perform the job.”

SPEAK UP

While your employer is permitted to ask if an accommodation is needed once you disclose your disability, the employer may not readily offer accommodations. It is up to the employee to state what accommodations are needed. “Even if someone has disclosed having a disability, it doesn’t relieve them of the legal obligation to ask for something from the employer when they need it,” Rennert says. “The requirement is on the individual to speak up.”

For some, that is easier said than done. “It can be difficult to have that conversation with yourself, let alone other people,” says Chase Miller, who works as a fundraising coordinator for the Muscular Dystrophy Association. “You have to know your limits, and you have to be honest with yourself about them.”

Miller has BMD and is ambulatory. Over the years, based on his requests, MDA has accommodated him with

THE ADA AND REASONABLE ACCOMMODATIONS

Title I of the Americans with Disabilities Act (ADA) of 1990 prohibits private employers, state and local governments, employment agencies and labor unions from discriminating against qualified employees with disabilities. They also must make reasonable accommodations employees with disabilities need to perform their jobs.

According to the U.S. Equal Employment Opportunity Commission (EEOC), a reasonable accommodation is any change in the workplace or the way things are customarily done that provides an equal employment opportunity to an individual with a disability. “The types of accommodations an employer could provide are quite broad,” says Sharon Rennert, senior attorney advisor at the EEOC. “It is often easier to talk about what employers are not required to do.”

1. Employers do not have to remove essential job functions. A person with

a disability must be able to perform all essential duties of the job with or without reasonable accommodations.

2. Employers do not have to change their performance standards. However, reasonable accommodations can be made to help an employee meet those standards.
3. Employers are not required to supply personal use items. These are generally items that a person needs on and off the job, such as a wheelchair, walker or cane.
4. Employers are not required to make accommodations that would pose an undue hardship on the operation of the business. Undue hardship is defined as an “action requiring significant difficulty or expense,” according to the ADA National Network, and is determined on a case-by-case basis.

ADA requirements apply to employers with 15 or more employees. For people who work for smaller businesses, protections may still exist under state or local law.

More About the ADA

Learn about the Americans with Disabilities Act (ADA) and what it means to the MDA community in a Q&A with Kristin Stephenson, MDA vice president of policy and advocacy. To find it, search for “ADA 25th Anniversary” at mda.org/quest.

a sit/stand desk to relieve pressure on his hips; a gaming chair to reduce stress on his knees, back and hips; and a flexible work schedule



Kushal Parikh, who lives with BMD, is a social worker in Chicago.

so he can come in later on days when he’s experiencing increased pain or fatigue.

WHEN TO DISCLOSE

Ultimately, disclosing information about your disability to your employer is a personal choice. Choosing not to disclose your disability might be the most appropriate choice if you are able to perform all your essential job functions without extra assistance. However, if your disability begins to impact your job performance, you could be held accountable for performance issues if you have not disclosed your disability and

asked for reasonable accommodations.

“Even if you’re not quite sure what accommodations might help you, it is better to get the ball rolling,” Rennert says. “The last thing anybody wants is for there to be disciplinary action based on poor performance.”

Miller agrees. “It’s OK to let people around you know what you’re going through. It’s OK to take accommodations that are necessary for your disability.” **Q**

Karen Henry is a freelance writer and editor in the Denver area. She is living with limb-girdle muscular dystrophy (LGMD).



CA

REER

BY CHERYL ALKON

starters

An internship provides on-the-job training and a path to employment

For Victoria Haire, landing a summer internship in the Dallas MDA office this year wasn't simply a way to see what it was like to work in the business world; it was life-changing.



“The experience was invaluable because it confirmed where I want to be and what I want to do.”

— Victoria Haire

Haire, who hails from Louisville, Ky., was diagnosed with limb-girdle muscular dystrophy (LGMD) at age 5. As part of her five-week internship with MDA, she got to work in an MDA Care Center alongside MDA’s family care specialists. “I knew right in that moment that this is what I need to do,” says Haire, 21, a University of Southern Illinois student studying communications with a minor in social work. “I texted my parents on the first day and said, ‘This is my calling.’”

Internships help both students and career-changers learn how different companies or industries work and gain on-the-job training.

FINDING AN INTERNSHIP

Although some programs hire interns throughout the year, summer is high season for internships. Many organizations begin accepting applications the fall prior and continue through the spring. Start your search with these programs and resources.

► **Emerging Leaders Internship Program for College Students with Disabilities**, run by the National Business & Disability Council (NBDC) at the Viscardi Center, places undergraduate and graduate college students with disabilities into paid internships with Fortune 1000 companies across the country. Applications are accepted year-round, but most companies recruit in the fall. viscardicenter.org/nbdc/emerging-leaders

► **Entry Point**, a program of the American Association for the Advancement of Science, recruits students with disabilities to fill internship opportunities in the STEM fields. Applications are accepted in the fall. aaas.org/program/entrypoint

► **Lime Connect Fellowship Program** matches students who have disabilities with summer internships at Lime Connect’s corporate partners. Applications are accepted year-round. limeconnect.com

► **MDA**, an equal opportunity/affirmative action employer, is committed to recruiting, hiring and promoting people with disabilities and veterans. Career opportunities, including internships, are listed at mda.jobs.net.

► **Project SEARCH** includes internships as part of a comprehensive program to help high school students with significant disabilities transition to meaningful employment and adult life. Applications are accepted in winter and spring. projectsearch.us

► **Rising Leadership Mentoring Program**, offered by the US Business Leadership Network (USBLN), pairs individuals with disabilities with business professionals for six-month mentorships. USBLN also offers the Rising Leadership Academy, a free two-day networking and career readiness program. Applications for both programs are accepted in the fall. usbln.org

Identifying, applying for and succeeding at internships help build a foundation for seeking employment and launching a career.

GETTING STARTED

Haire landed her internship by contacting the Dallas MDA office during the school year and asking what opportunities were available over the summer.

“The experience was invaluable because it confirmed where I want to be and what I want to do,” she says. “It made a mold for my career. I have one more year of school, then I want to get back down there to try to get into my dream job, which would be a family care specialist working with individuals and families one-on-one.”

For people like Haire who have a good idea of the industry or organization they want to join, reaching out directly to ask about opportunities is a great way to land an internship. But for those who want to explore their options, there are a variety of national and local programs that match employers with people looking to gain job experience — some specifically for individuals with disabilities.

These include the Emerging Leaders Internship Program for College Students with Disabilities, run by the National Business & Disability Council (NBDC) at the Viscardi Center. This year, NBDC placed interns with 28 Fortune 1000 companies, including Merck, General Motors and SpaceX. Michael J. McGowan, a corporate services specialist

with NBDC, says the program “provides [interns] with meaningful leadership development and networking opportunities that enable them to get their foot in the door for employment.” Meanwhile, corporate partners have told McGowan that they are impressed by the caliber of students they meet through the program.

Although it is not a traditional internship, the US Business Leadership Network’s (USBLN) Rising Leadership Mentoring Program offers another way for individuals with disabilities to get started. This program pairs individuals with disabilities with professionals from corporations ranging

from Aetna to Southwest Airlines for six-month-long mentorships. Mentees get career guidance from their mentors and access to unique professional development and networking opportunities. “Mentorship has a direct relationship with employment opportunities,” says Elaine Kubik, director of marketing and communications at USBLN. “In 2016, over half of our mentees had received employment by the end of the year.”

FINDING OPPORTUNITIES

In some cases, employers come to college campuses to recruit applicants for their internship programs.

MDA’s Young Adult Employment Resources

MDA is committed to supporting young adults through resources, community-building and programming as they pursue education, employment and independent living. Check out the Employment Resources page, including internship resources, at mda.org/young-adults/employment. And be sure to join the MDA young adult community at mda.org/young-adults.



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Experience of a Lifetime

Read more about Chris Anselmo's internship experience and the valuable lessons he learned inside and out of the office in "Changing Directions" on mda.org/quest.

MAKE THE MOST OF YOUR INTERNSHIP

Landing and shining at an internship requires smarts, savvy and hard work. Follow these five tips from interns and those who hire them to make a good impression:

1 Know what you want from the experience, and do your research. "Map out the points you want to learn in an internship, and figure out how you can connect to staffers or employers on these topics," says Elaine Kubik of the US Business Leadership Network. "It helps to have a plan and an idea on how you can learn these things during your internship, and never be afraid to ask questions."

2 Present yourself professionally. Start by polishing your resume and proofreading your cover letter or application. When meeting face-to-face, "be prepared, ask questions, and come to an interview in a business suit," says Michael McGowan of the National Business & Disability Council.



"Doing my internship gave me a ton of confidence – it was one of the most challenging things I ever did."
– Chris Anselmo

Chris Anselmo, 31, earned his MBA from Boston College in 2016. Shortly after starting the program, Anselmo learned about a finance-based summer internship program with Pfizer, one of the largest pharmaceutical companies in the United States. After an interview with a campus recruiter, he was invited to interview at Pfizer's headquarters in midtown Manhattan.

In both interviews, Anselmo, who has a form of distal myopathy called Miyoshi myopathy, cited his experience with a disability. "I talked about why I was interested in health care through my own experience navigating the industry," he says. "I was able to leverage that experience and use it to my advantage."

A few weeks later, Pfizer offered him an internship at their headquarters for the following summer.

"Then it became real, and I had to think it through," Anselmo says. At the time, he used crutches and leg braces to compensate for his

3 Be proactive about asking for accommodations at the appropriate time. If you don't need an accommodation to participate in an initial phone interview, don't mention it. "You don't want to raise a red flag before you get to sell yourself," McGowan says. But if you need an in-person interview, let the interviewer know when they reach out to you to schedule it. If you will need accommodations once the position is yours, bring it up when you are offered the job. (Learn more in "Disclosing Disability" on page 12.)

4 Don't sell yourself short, either when talking about your qualifications for the internship or when advocating for accommodations you need. If you are given a stipend for housing, for example, ask if there's any flexibility if you'll need elevator access. "It is up to the student to request an accommodation in order for the employer to provide one; employers are not allowed to ask if the student needs one," says McGowan.

5 Be a team player. "Go into the internship with an open mind and be willing to work," says Victoria Haire, a summer intern in the Dallas MDA office. "I was eager to learn and eager to know what's next. When you are done with a project, don't be afraid to ask for another opportunity to work. Even if it's filing paperwork, it's always important to the organization."


diminished muscle strength. Living and working in Manhattan would be a challenge. But Anselmo had always wanted to live in New York City, and taking the internship allowed him to do so without making a long-term commitment.

He talked to the hiring manager about accommodations once he was offered the job. "I made it known that I couldn't do a lot of walking, and that I wanted to have a place where I could get off the elevator and plop into a chair," he says. Pfizer also provided a specialized chair so he could sit comfortably.

During the two-month internship, Anselmo learned a lot and found that his duties took him all over the multistory Pfizer building. "I'd come home and be fulfilled but exhausted," he says. "It wore me down a bit, but it was still a unique and exciting experience."

Today, Anselmo is working as an independent consultant and believes that the knowledge he gained in that internship will continue to help him personally and professionally.

"Doing my internship gave me a ton of confidence — it was one of the most challenging things I ever did," he says. "Now, when I have future challenges, I can

refer back and say, 'If I could do that, then I can do this.'" 

Cheryl Alkon is a freelance writer based in Massachusetts.



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CHOOSING WITH

BY SHAILA WUNDERLICH

Amid the wave of anxiety and emotion that can accompany living with a neuromuscular disease, Bill and Sharon Sumner saw a few things clearly the day they learned of Sharon's ALS diagnosis. "I knew we would keep her at home, and I knew I would be the one to take care of her," Bill says.

The Sumners were in a prime position to make such choices. Having sold his successful manufacturing business, Bill had the time to devote to his wife and the money to hire personal care attendants (PCAs) as her condition progressed. But for many families, when a diagnosis is made or a disease progresses to the point where daily care is needed, the decision isn't as clear-cut. Financial means, work schedules, family dynamics and the extent of a support system are among the many factors that go into planning in-home care.

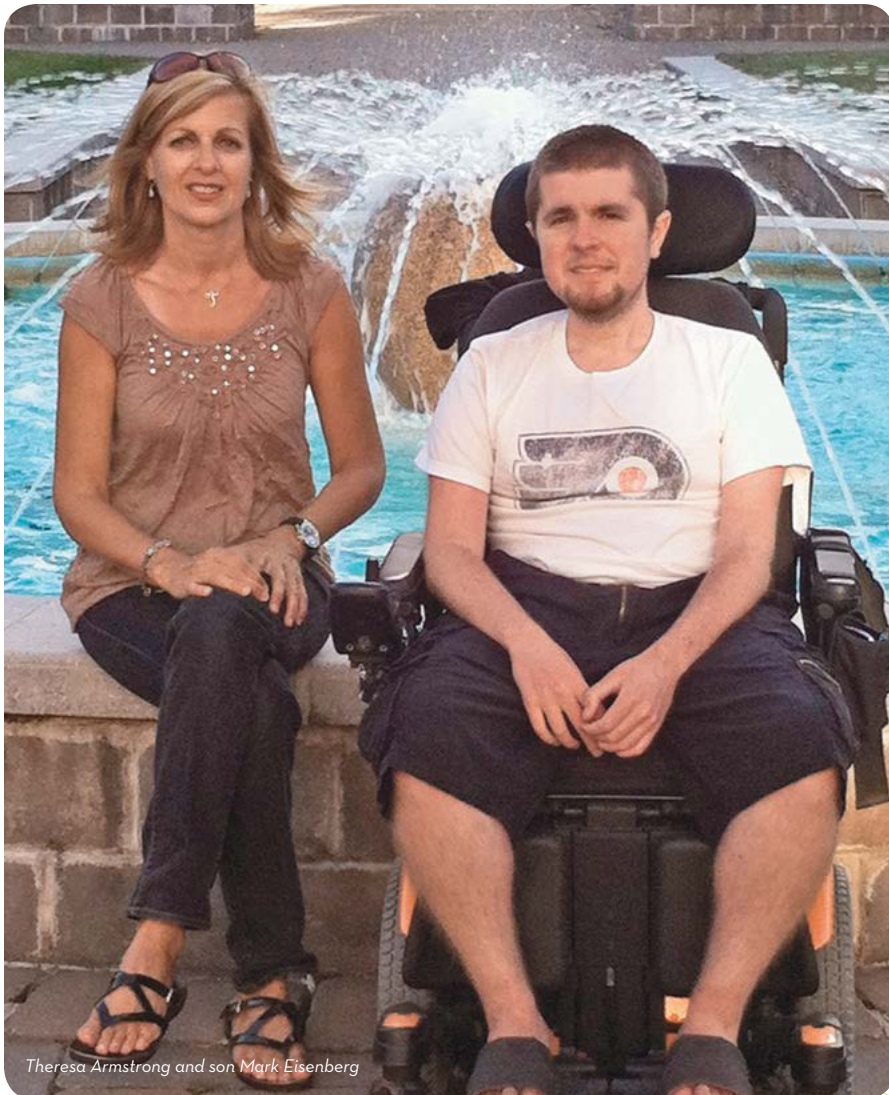


Joe Akmakjian with caregiver Mitch



Nancy and Gary Sullivan

Deciding whether family members or professionals serve as primary caregivers comes down to a nuanced calculation of means, availability and personal preference



Theresa Armstrong and son Mark Eisenberg



Bill and Sharon Sumner

SUPPORT FOR FAMILY CAREGIVERS

Family caregivers need support – whether it’s in the form of a sympathetic ear, practical advice or getting a break. Here are some ways to find the support you need.

Extend your support network. A care community is a group of people involved in one individual’s care. Lotsahelpinghands.com is a free online service that allows you to set up and manage a community of family members, friends and neighbors. You can keep everyone in the loop on your loved one’s needs and post requests for support. Members of your community sign up for tasks knowing they’re providing exactly the help you need.

Get educated. Learning about your loved one’s disorder and how to care for them can make you a more confident caregiver and help alleviate stress. Work with your local MDA family care specialist and the local MDA Care Center team to learn more about your loved one’s medical condition. Many hospitals offer CPR and first-aid training courses. Medical equipment manufacturers and suppliers often are willing to help you learn to use their products. Bill Sumner, whose wife has ALS, has arranged one-on-one ventilator, suction machine and trachea tube training through his wife’s equipment provider. “They’ve been tremendous,” Sumner says. “They’ll spend hours with us until we get it right.”

Find an MDA support group. Support groups allow families to share their experiences with and receive guidance from others who face similar challenges. Nancy Corrigan Briggs runs a monthly ALS Caregiver Support Group in Collegeville, Pa., attended by MDA families. “We let the group guide us,” she says. “Some days we discuss how to handle the mountains of paperwork, some days we discuss how to afford equipment rental and some days we just allow people to vent their emotions.” Contact your local MDA office to find support groups in your community. Learn more at mda.org/services/support-groups.

EXPLORING YOUR OPTIONS

When a family learns of their care needs, the first thing they should do is assess their financial situation. “Once we get through that difficult moment after diagnosis, financials are the first things

we discuss,” says Rebecca Axline, a supervisory licensed clinical social worker who works with families at the MDA ALS Care Center at Houston Methodist Neurological Institute. “Income and assets definitely narrow the focus.”

Families whose income falls below a certain level qualify for complete coverage of in-home care professionals through Medicaid. Families whose income is well above that level typically can afford caregivers out-of-pocket. It’s the households in between that may find themselves in a quagmire.

“Say you have a family where both parents work, and they discover that their child is going to need around-the-clock care,” says Michileen Oberst, an advanced licensed clinical social worker at the MDA Care Center at Stanford University in Palo Alto, Calif. “Each year, those parents have to evaluate how much it would cost to hire a full-time caregiver, versus how much income they would forfeit if one of them leaves the workplace to care for the child, versus the chance that a one-paycheck income would give them access to federal or state benefits.”

Options are further impacted by where the family lives. Some states, such as Tennessee and California, subsidize the cost of any in-home caregiver (related or otherwise) who meets certain criteria. “Essentially I get to choose, hire and manage my own caregivers,” says Gary Sullivan, a retired attorney with limb-girdle muscular dystrophy (LGMD) in Franklin, Tenn. His wife, Nancy,

started out as his primary caregiver, but as his disease progressed, he transitioned to a team of professional caregivers, with Nancy taking over three nights a week. “It puts the power in the hands of the person with a disability, which in my opinion raises the quality of care tremendously,” he says.

For help in navigating all the financial intricacies, MDA Care Centers have multidisciplinary care teams that include social workers who can help families navigate specific issues and find the right type of support, which may include Medicaid/insurance options. Social workers often can connect families with other helpful professionals and organizations if necessary. “The conversation is anchored in, ‘If you do have to pay dollars privately, let’s maximize them as much as possible,’” Axline says.

CHOOSING A CAREGIVER

Once financial parameters are established, the focus shifts to selecting the caregiver. In those early, anxious days after diagnosis, it’s a natural reaction to want a family member. “I find parents in particular really want to be the ones to care for their child,” Axline says. “A lot of spouses want to care for each other, too.”

Family members can make outstanding caregivers, often joining support groups and attending courses to learn all the skills required to accommodate their loved ones’ physical, medication and equipment needs. Bill Sumner regularly attends his hospital’s CPR and first-aid

courses, in addition to getting one-on-one tutorials from Sharon's equipment provider. "They come to the house and show us how to work the ventilator, suction machine, trachea tubes, all of it," he says.

"We've had people who, by the time all is said and done, we swear they could work as professional nurses," Axline says.

Aside from the caregiver subsidies available in certain states, family caregivers generally aren't paid. On the surface, that can translate to big savings. Of course, if the relative is giving up a paid job with benefits, that must be weighed in the financial equation.

The family member should enter their role with the understanding that caregiving is not a typical 40-hour-per-week job. It comes with around-the-clock responsibilities, and while family caregivers often feel that caring for their loved one is rewarding, it is also taxing.

"If you're a caregiver working for me, you're not coming over to have coffee with grandpa," says Sullivan. "You're working."

Baths, transfers, meals and midnight repositioning are among the duties that may be required. And as the individual's disease progresses, so does the work. "When you switch from basic caregiving to a ventilator, you triple the level of care needed," says Nancy Corrigan Briggs, who facilitates an MDA ALS caregiver support group in Philadelphia and has cared for several family members with ALS. Even the most devoted parent, spouse or



Joe Akmakjian cooks dinner with a caregiver.

sibling may become ill or need an occasional break from daily responsibilities.

HIRING PROFESSIONAL CAREGIVERS

In her role as a social worker, Oberst, helps families understand that, at some point, they will likely need to look outside the home for caregiver assistance. "The approach has to evolve," she says. "Family members, of course, make extremely devoted caregivers, and it makes sense for a parent to be the primary caregiver when a child is young. As that child enters young adulthood, though, you may encounter the polarized circumstance of their physically needing more care while intellectually being mature and independent enough to manage their own care."

Joe Akmakjian, 26, who lives with spinal muscular atrophy (SMA), turned to outside caregivers in his middle school years, when he saw the relationship with his mother, who was his caregiver, becoming strained. "It got to a point where every day we were fighting about the smallest things," he says. "Now, my mom is just my

mom, and the people who provide my care are here because they're getting paid. I prefer it that way."

Axline sees this scenario play out in many families. "There is a real potential for deterioration of the natural familial dynamic," she says. "The roles change. Time and time again I get family

Caregiver Resources

MDA is here to provide help, support and hope to families whenever, wherever they need us. To find caregiver resources, visit mda.org/services/caregiver-resources.

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WHAT IS A PERSONAL CARE ATTENDANT?

For individuals with neuromuscular conditions, finding, managing and paying for personal care attendants (PCAs) can be one of the greatest challenges to living on your own. A PCA can be anyone from a registered nurse to a neighbor who helps with daily care tasks.

Who you hire as a PCA and their level of training will depend on your personal and medical needs. For example, a young adult living independently might hire a student to help with bathing and dressing, as well as household tasks like cooking and cleaning. Others might need a PCA with a nursing degree who can administer medication or perform more complex procedures, such as changing G-tubes. PCA schedules can range from a few hours a week to 24-hour live-in care.

For tips and tools to help you find and manage PCAs and additional resources, visit mda.org/young-adults/independent-living.

members coming back saying, 'I just want to be a mom (or a husband or a wife or a sister) again.'"

Axline encourages engaging caregivers from outside the family as early as possible. "The longer they wait, the harder it is going to be to bring in someone new," she says.

Sullivan waited nearly 10 years to hire his first PCA. By that point, he and his wife had a well-established routine, and it was difficult to adjust. "I think part of it was Nancy not wanting to hand it over," he says. "She had a hard time letting go."

Mark Eisenberg, 24, hired his first PCA in college. His mom, Theresa Armstrong, had been his primary caregiver since he was diagnosed with Duchenne muscular

dystrophy (DMD) at age 4. Through the years, mother and son established an almost non-verbal rhythm.

"For so long, you let your doctors or family direct your care, and when the time comes to tell a stranger what you need, you find yourself asking, 'Wait — what do I need?'"

In his dorm room 30 miles from home, Eisenberg struggled through several unsuccessful hires before finding a reliable, capable PCA. "His second year he texted me at 1 a.m. saying his aide never showed up," Armstrong says. "I had to drive up at 2 a.m."

Eisenberg, who now lives at home with Armstrong and works as a blogger, pulls on all his experience — good and bad — to design a

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custom-fit schedule of sharing care between his mom and paid PCAs.

“The whole experience actually makes you more attune to your own care needs,” Eisenberg says.

THE BEST OF BOTH WORLDS


“I am constantly trying to balance the well-being of the family unit with the age, stage and physical needs of the individual,” Oberst says. All things considered, she believes a combination of family and paid caregivers works well for most families. “But in the end, only a family can determine what’s best for them.”

Speaking as he packed his bag for a brief trip, Bill Sumner’s reflections were much the same. “My heroes are the families who take on



Nancy and Gary Sullivan with caregiver Rebecca

the whole of care themselves, but I wish it didn’t have to be that way,” he says. “Here I am about to take a much-needed respite, which wouldn’t be possible without the group

of reliable caregivers I have supporting us.” 

Shaila Wunderlich is a freelance writer in St. Louis who has been a journalist for nearly 20 years.

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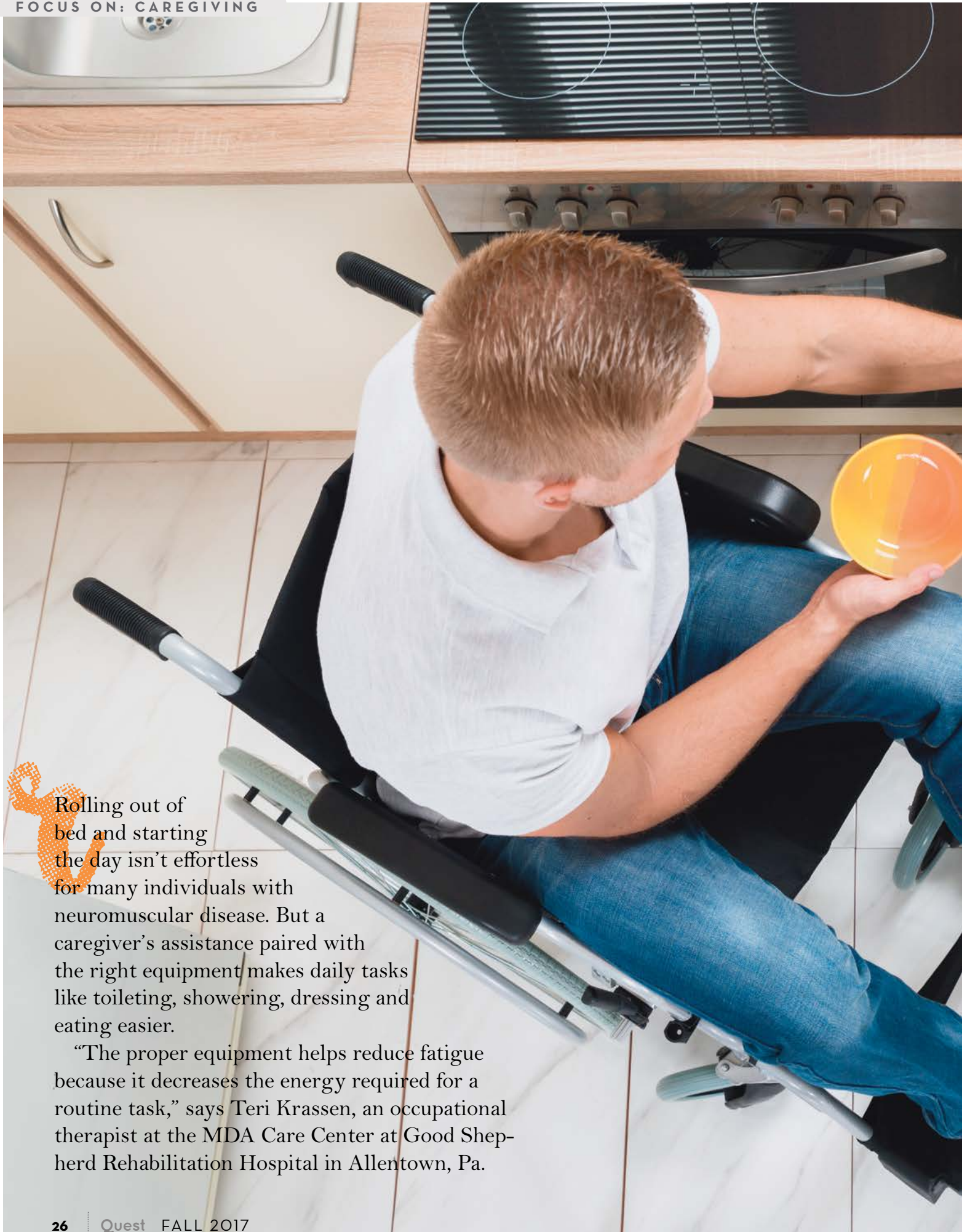


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Rolling out of bed and starting the day isn't effortless for many individuals with neuromuscular disease. But a caregiver's assistance paired with the right equipment makes daily tasks like toileting, showering, dressing and eating easier.

"The proper equipment helps reduce fatigue because it decreases the energy required for a routine task," says Teri Krassen, an occupational therapist at the MDA Care Center at Good Shepherd Rehabilitation Hospital in Allentown, Pa.



Caregiving
products for
daily living

TASK masters

BY BARBARA AND JIM TWARDOWSKI, RN



Folding Commode

Health care professionals at MDA Care Centers can provide guidance in selecting products, train clients and their caregivers to use them, and give advice on individual issues or answer questions. According to Krassen, the best products help an individual and their caregiver find a balance between how much they can do independently

and the amount of support needed from the caregiver. Some products allow individuals to be more self-sufficient, which can boost self-confidence and promote better relationships with caregivers. Other products help caregivers provide crucial assistance more quickly or with less physical strain.

Krassen recommends periodically re-evaluating how you approach routine tasks, as the balance may shift as one's disease progresses, as the individual ages and when there is a change to the individual's environment.

BATHROOM STRATEGIES

For adults, "using the toilet is a huge concern," says Krassen. "The toilet height that is standard for the Americans with Disabilities Act (ADA) is not really high enough to help most people [living with a neuromuscular disease]." She frequently recommends the addition of a three-in-one commode, which adjusts to a comfortable height the same way a walker does. (For example, see the Folding Commode at easyc comforts.com.)

Some of Krassen's clients like using the Power Toilet Aid by Stand Aid of Iowa (stand-aid.com). The device mechanically lowers and raises a toilet seat over the existing toilet, saving an individual or their caregiver additional effort in getting the individual on and off the toilet.

Individuals who use wheelchairs and need to bridge the gap from their

chair to a bed, toilet or shower seat may find a transfer board (also called a sliding board) helpful. Transfer boards come in all shapes and sizes and can be used independently or with assistance from a caregiver.

Mounting a long-reach handheld shower head allows an individual to shower from a seated position. A sturdy shower chair is paramount. The Nuprodx Multichair (nuprodx.com) comes in a range of styles for adults and children. The versatile chair is designed for placement in a shower or tub and over a toilet, and it can be disassembled and packed compactly for traveling.

BEST DRESSED

When you look good, you feel good. But dressing independently can be difficult for individuals with low dexterity and those who dress while seated in a wheelchair. The Button Aid and Zipper Pull (caregiverproducts.com) is an easy-to-hold tool that helps individuals fasten and unfasten their own clothing. Another option is to invest in adaptive clothing that replaces standard closures with Velcro or is specifically designed for people who use

Some products allow individuals to be more self-sufficient, which can boost self-confidence and promote better relationships with caregivers.



Obi

wheelchairs. (For options, search for “Fashion Forward” at mda.org/quest.) This type of clothing can be useful for independent dressers, as well as caregivers.

In the rush of morning activities, it is often easier for parents to dress their children. Emilie Lam, an occupational therapist at the MDA Care Center at Children’s Medical Center of Dallas, advises parents to practice dressing skills with youngsters after an evening bath or on weekends, when the pace is slower.

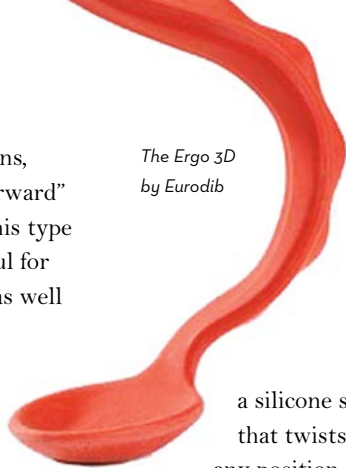
EATING WITH EASE

Occupational therapists generally know a few no- or low-cost tricks to promote independent eating. One favorite is sliding foam tubing on utensils for a better grip. (This can be used on pencils, toothbrushes and other items, too.) Medical supply distributors sell tubing made for this purpose, but Lam recommends purchasing inexpensive foam pipe insulation from your local hardware store and cutting it to size.

Another trick for those who have shoulder weakness or difficulty lifting their arms, is propping the arms on stacks of books. This allows the individual to use the muscles from the elbows down to lift food to their mouth.

Specially designed utensils and dishes can make dining more pleasant. The Ergo 3D by Eurodib (eurodib.com) is

The Ergo 3D
by Eurodib



a silicone spoon that twists into any position to aid self-feeding or feeding by a caregiver. Some may choose to invest in Obi (meetobi.com), a portable robotic-armed device that allows individuals without use of their arms to feed themselves.

WHERE TO SHOP

Caregiving products are sold through medical distributors, as well as conventional retailers. “Amazon has almost everything,” says Lam. In addition, online retailer Zappos recently added a special section for adaptive clothing (zappos.com/adaptive).

Sometimes, people aren’t aware of a product that can make their life easier until they do a little online research or consult with the health care professionals on their MDA Care Center team. And with more retail options, Lam believes that comparison shopping is easier than ever. **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, health and lifestyle, and related issues.



The Button Aid and Zipper Pull

APPS FOR CAREGIVERS



Your smartphone isn’t just good for texting and taking pictures. It also can help you manage caregiving tasks on the go.

CareZone allows the user to record physicians’ instructions, track medications and organize health care records. You also can invite family and friends to view information and participate in caregiving tasks. *Free for iPhone and Android.*

First Aid by the American Red Cross has step-by-step instructions and videos on handling common emergencies, such as choking, broken bones and burns. It also includes disaster preparedness information and can connect you to 911. *Free for iPhone and Android.*

Medisafe provides medication tracking, reminders and educational information. It is even possible to connect with physicians through the app. *Free for iPhone and Android.*

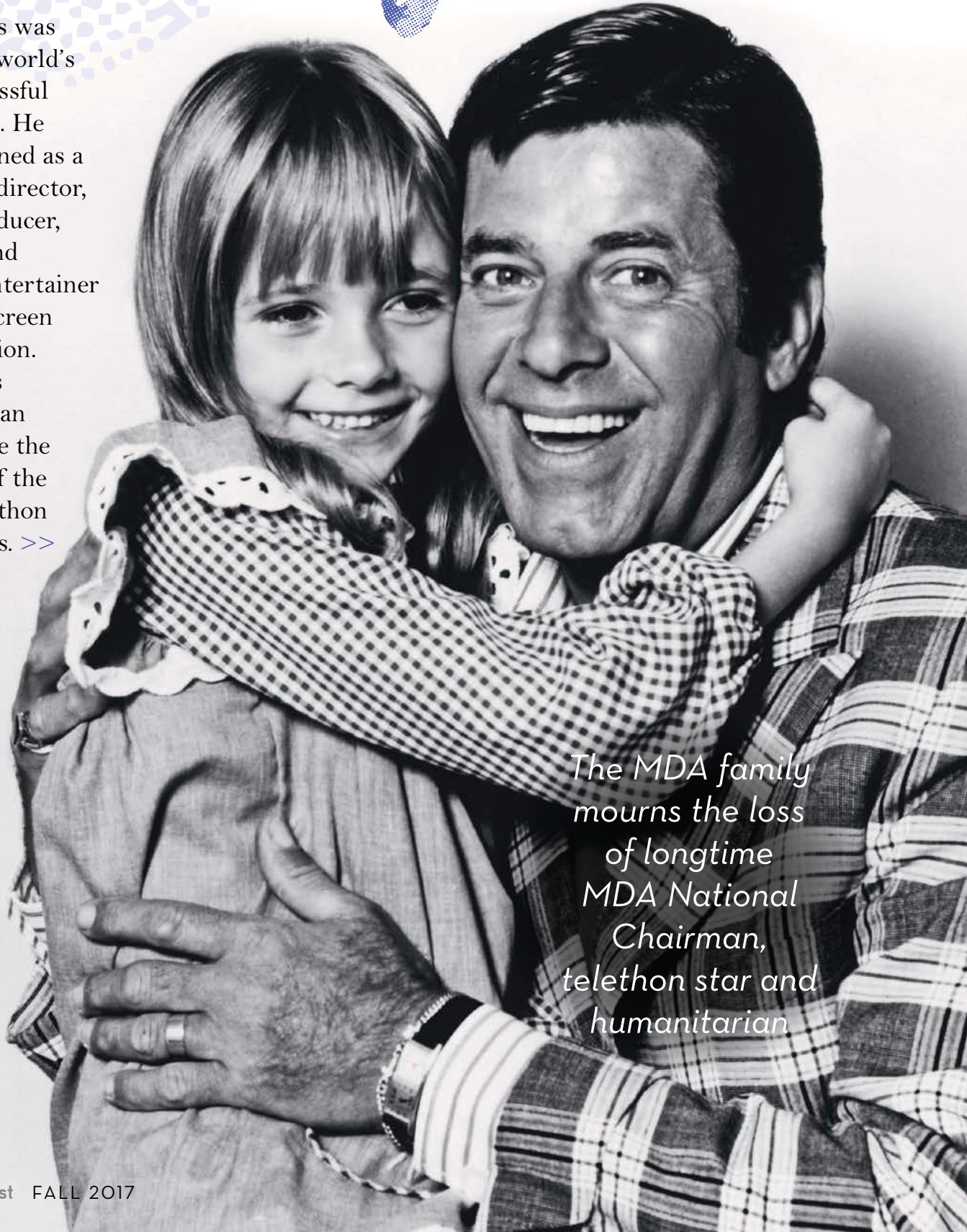
Symple is designed for tracking symptoms over time, such as pain, anxiety, fatigue or sleeplessness. You can create reports to share with health care professionals at your local MDA Care Center. *Free for iPhone.*

IN LOVING
MEMORY OF

(1926-2017)

Jerry Lewis

Jerry Lewis was one of the world's most successful performers. He was renowned as a comedian, director, writer, producer, inventor and headline entertainer on stage, screen and television. His tireless humanitarian efforts were the hallmark of the MDA Telethon for 45 years. >>



*The MDA family
mourns the loss
of longtime
MDA National
Chairman,
telethon star and
humanitarian*

*Jerry Lewis and
Lisa Cagle, National
Ambassador 1975-1976*

MDA's telethons raised more than \$2 billion with Lewis' support, along with support from the devoted American public and MDA's generous partners. Because of Lewis' leadership and the telethon, MDA is at a pivotal point in research today with new drugs having been approved in the last year for Duchenne muscular dystrophy (DMD), spinal muscular atrophy (SMA) and ALS (amyotrophic lateral sclerosis), and there are more drugs in clinical trials in the last five years than in the previous 50.

MDA ACHIEVEMENTS

Lewis served as MDA's honorary national chairman during the decades when the organization was developing the most comprehensive program of research and medical and community services of any nonprofit health agency in the country. He committed himself to a cause and mission that impacts families across the country to this day. Through telethons and other fundraising activities carrying his name, Lewis brought worldwide attention to the fight against neuromuscular diseases. Without a doubt, there would be no MDA as we know it without Lewis making that commitment so many decades ago.

During Lewis' lifetime, MDA-funded scientists discovered the causes of most of the diseases in MDA's program, developing treatments, therapies and standards of care that have allowed many living with these diseases to live longer and grow stronger.

One of the most notable turning points in understanding neuromuscular disease came in October 1986, when Louis Kunkel, Ph.D., discovered the genetic defect that causes DMD. Kunkel, a member of MDA's Board of Directors, is a longtime MDA research grantee whose achievement, said Lewis, "was staggering."

"To see this breakthrough tells me that indeed in my lifetime, I'm going to see 'my kids' better than they are today," Lewis said at a press conference during the announcement of the discovery.

In September 2016, Jerry, at 90 years of age, once again witnessed remarkable progress when the FDA approved the first-ever drug for the treatment of DMD. MDA has funded more than \$1 billion in neuromuscular disease research since 1950, with an unprecedented three drugs approved for DMD and SMA in the last year, illustrating the vibrancy of its research program and the impact Lewis has had on neuromuscular research.

YEARS OF SERVICE

Lewis became associated with MDA in 1952, shortly after the organization was formed by a few adults with muscular dystrophy, parents of children with the disease and the late Dr. Ade T. Milhorat, then virtually the only American physician specializing in muscle diseases.

During the next 60 years, Lewis appeared at openings of MDA care and research centers; addressed meetings

of civic organizations, volunteers and the MDA Board of Directors; courted sponsors for MDA; successfully lobbied Congress for federal neuromuscular disease research funds; and made countless phone calls and visits to families served by MDA.

The children with neuromuscular diseases who Lewis met during numerous personal appearances for MDA called themselves "Jerry's kids" in gratitude for his compassion. "Jerry's kids" eventually became a familiar phrase to millions.

In January 2016, MDA unveiled a revitalized brand reflecting a renewed commitment to accelerate treatments and cures for the kids, adults and families it serves. To mark the occasion, Lewis taped a special message to the MDA community, urging continued support for MDA and the families he has championed for decades.

"I think it's great that MDA has a new look and tagline — we've got to keep giving strength, independence

"The highlight of my time as MDA National Ambassador was interacting with Jerry. Not a moment could pass without an opportunity to laugh myself silly. Jerry Lewis will always be synonymous with pure dedication to a cause."

*— Rocco Arizzi,
National
Ambassador
1979–1980, pictured
on the cover with
Jerry Lewis*

*Jerry Lewis and
Abbey Umali in 2009*





From left: Dean Martin, Frank Sinatra and Jerry Lewis in 1976

Lewis asked the top stars of music, theater, film, television and sports to appear on the telethon – without pay – to help spread the MDA message.

and life to all the kids and adults who are fighting muscular dystrophy and other life-threatening diseases,” Lewis said. “Today, there are signs of real progress — and progress can’t come fast enough for my kids and our MDA families. Our work is not done.”

THE TELETHON

In the early 1950s, Lewis and his show-business partner, Dean Martin, held an occasional telethon for MDA. In 1966, the first official Jerry Lewis MDA Labor Day Telethon was broadcast on a single television station in New York, WNEW (now WYNY), as Labor Day became America’s day for MDA. By 2010, Lewis’ last telethon with MDA, the show was broadcast on more

than 150 stations known as the MDA “Love Network.” The show became part of our culture, an American tradition with viewership comparable to the Super Bowl and the Academy Awards. MDA held its last telethon in 2014.

Anyone who was anyone, including the top stars of comedy, music, theater, film, television and sports, appeared on the telethon — without pay — to help spread the MDA message because Lewis asked them. Viewers saw hundreds of the biggest celebrities, including John Lennon, Jerry Seinfeld, The Rolling Stones, Johnny Cash, Cher, The Jackson 5 and Celine Dion, appear on the telethon over the years.

In addition to all the celebrities, the MDA families were an indispensable part

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of the telethon. They spoke from their hearts, sharing their hopes and dreams, and emphasized the importance of the fight against muscular dystrophy and related diseases. As Jerry said many times, "they are the true stars of the show."

WORLDWIDE HONORS

Lewis was honored around the world for his efforts on behalf of MDA.

In 1977, then-Congressman Les Aspin nominated him for the Nobel Peace Prize, the first time an entertainer was so honored. In his nomination, Aspin said, "Jerry Lewis is a man for all seasons, all people and all times. His name has, in the hearts of millions, become synonymous with peace, love and brotherhood."

Lewis was often asked why he chose muscular dystrophy and MDA for his humanitarian work, and he answered with this quote: "I shall pass through this world once. Any good therefore that I can do or any kindness that I can show to any human being, let me do it now. Let me not defer or neglect it, for I shall not pass this way again."

Lewis also received the Jefferson Award from the American Institute for Public Service; U.S. Department of Defense Medal for Distinguished Public Service; honorary doctor of humane letters degrees from Mercy College in Westchester, N.Y., Emerson College in Boston and Chapman University in Orange, Calif.; and numerous other humanitarian awards. In 1996, Lewis and MDA were recognized by the American Medical Association with

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Jerry Lewis and Luke Christie in 2007

Lifetime Achievement Awards “for significant and lasting contributions to the health and welfare of humanity.”

Regarded as the most effective fundraiser in television history, Lewis was inducted into the National

Association of Broadcasters Hall of Fame in 1991 and the International Humor Hall of Fame in 1992.

In the past three decades, Lewis received a number of lifetime achievement awards, including a cable television ACE Award for Comic Lifetime Achievement, the International Press Academy’s TESLA Award in recognition of visionary achievements as an innovator in the field of visual technology for the cinema arts, and the Academy of Television Arts & Sciences Governors Award for his accomplishments with the telethon. During the 2009 Academy Awards ceremony, Lewis was presented with the Jean Hersholt Humanitarian Award. This award, one of the Academy of Motion Picture

Arts and Sciences’ greatest honors, is bestowed by the Academy on an individual in the motion picture industry whose humanitarian efforts have brought credit to the industry.

Lewis is survived by his wife, Sam; his daughter, Danielle; five sons, Gary, Ronald, Scott, Christopher and Anthony; several grandchildren and great-grandchildren; and was preceded in death by his son Joseph. A celebration of Lewis’ life was held, appropriately, on Labor Day at the South Point Hotel and Casino in Las Vegas, where he helmed his final MDA telethons and his last Vegas performance in October 2016. Jerry Lewis made a beautiful difference for so many, and his contributions continue to resonate. Q



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- An email address



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What kind of information is collected?

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- Family history



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Do not use if you are allergic to deflazacort or any of the inactive ingredients in EMFLAZA.

Please see the Important Safety Information on the next page.


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22.75 mg/mL oral suspension

INDICATION & IMPORTANT SAFETY INFORMATION FOR EMFLAZA™ (deflazacort)

INDICATION

EMFLAZA™ is indicated for the treatment of Duchenne muscular dystrophy in patients 5 years of age and older.

IMPORTANT SAFETY INFORMATION

Contraindication: Do not use if you are allergic to deflazacort or any of the inactive ingredients in EMFLAZA.

Do not stop taking EMFLAZA, or change the amount you are taking, without first checking with your healthcare provider, as there may be a need for gradual dose reduction to decrease the risk of adrenal insufficiency and steroid “withdrawal syndrome”. Acute adrenal insufficiency can occur if corticosteroids are withdrawn abruptly, and can be fatal. A steroid “withdrawal syndrome,” seemingly unrelated to adrenocortical insufficiency, may also occur following abrupt discontinuance of corticosteroids. For patients already taking corticosteroids during times of stress, the dosage may need to be increased.

- **Hyperglycemia:** Corticosteroids can increase blood glucose, worsen pre-existing diabetes, predispose those on long-term treatment to diabetes mellitus, and may reduce the effect of anti-diabetic drugs. Monitor blood glucose at regular intervals. For patients with hyperglycemia, anti-diabetic treatment should be initiated or adjusted accordingly.
- **Increased Risk of Infection:** Tell your healthcare provider if you have had recent or ongoing infections or if you have recently received a vaccine or are scheduled for a vaccination. Seek medical advice at once should you develop fever or other signs of infection, as some infections can potentially be severe and fatal. Avoid exposure to chickenpox or measles, but if you are exposed, medical advice should be sought without delay.
- **Alterations in Cardiovascular/Kidney Function:** EMFLAZA can cause an increase in blood pressure, salt and water retention, or a decrease in your potassium and calcium levels. If this occurs, dietary salt restriction and potassium supplementation may be needed.
- **Behavioral and Mood Disturbances:** There is a potential for severe behavioral and mood changes with EMFLAZA and you should seek medical attention if psychiatric symptoms develop.
- **Effects on Bones:** There is a risk of osteoporosis or decrease in bone mineral density with prolonged use of EMFLAZA, which can potentially lead to vertebral and long bone fractures.
- **Effects on Growth and Development:** Long-term use of corticosteroids, including EMFLAZA may slow growth and development in children.
- **Ophthalmic Effects:** EMFLAZA may cause cataracts or glaucoma and you should be monitored if corticosteroid therapy is continued for more than 6 weeks.
- **Vaccination:** The administration of live or live attenuated vaccines is not recommended. Killed or inactivated vaccines may be administered, but the responses cannot be predicted.
- **Serious Skin Rashes:** Seek medical attention at the first sign of a rash.
- **Drug Interactions:** Certain medications can cause an interaction with EMFLAZA. Tell your healthcare provider of all the medicines you are taking, including over-the-counter medicines (such as insulin, aspirin or other NSAIDS), dietary supplements, and herbal products. Alternate treatment, dosage adjustment, and/or special test(s) may be needed during the treatment.

Common side effects that could occur with EMFLAZA include: Facial puffiness or Cushingoid appearance, weight increased, increased appetite, upper respiratory tract infection, cough, frequent daytime urination, unwanted hair growth, central obesity, and colds.

Please see the consumer brief summary of the full FDA-approved product information on the next page.

For medical information, product complaints, or to report an adverse event, please call **1-866-562-4620** or email at **usmedinfo@ptcbio.com**.

You may also report adverse events directly to FDA at **1-800-FDA-1088** or **www.fda.gov/medwatch**.

EMFLAZA™ (deflazacort) Consumer Brief Summary of the FDA-Approved Product Information Initial US Approval: 2017

What is EMFLAZA?

EMFLAZA™ is a corticosteroid indicated for the treatment of Duchenne muscular dystrophy (DMD) in patients 5 years of age and older.

When should I not use EMFLAZA?

- Do not use if you are allergic to deflazacort or any of the inactive ingredients in EMFLAZA

What should I tell my healthcare provider before taking EMFLAZA?

It is important to tell your healthcare provider if you have had recent or ongoing infections, develop a fever, have recently received a vaccine or are scheduled for a vaccination, or experience any other side effects.

What warnings should I know about EMFLAZA?

Do not stop taking EMFLAZA, or change the amount you are taking, without first checking with your healthcare provider, as there may be a need for gradual dose reduction to decrease the risk of adrenal insufficiency and steroid “withdrawal syndrome”. Acute adrenal insufficiency can occur if corticosteroids are withdrawn abruptly, and can be fatal. A steroid “withdrawal syndrome”, seemingly unrelated to adrenocortical insufficiency, may also occur following abrupt discontinuance of corticosteroids.

For patients already taking corticosteroids during times of medical stress, the dosage may need to be increased.

Cushing’s Syndrome: Cushing’s syndrome occurs with prolonged exposure to exogenous corticosteroids, including EMFLAZA. Symptoms include high blood pressure, truncal obesity and thinning of the limbs, purple striae, facial rounding, facial plethora, muscle weakness, easy and frequent bruising with thin fragile skin, posterior neck fat deposition, osteopenia, acne, amenorrhea, hirsutism, and psychiatric abnormalities.

Hyperglycemia: Corticosteroids can increase blood glucose, worsen pre-existing diabetes, predispose those on long-term treatment to diabetes mellitus, and may reduce the effect of anti-diabetic drugs. Monitor blood glucose at regular intervals. For patients with hyperglycemia, anti-diabetic treatment should be initiated or adjusted accordingly.

Increased Risk of Infection: Medical advice should be sought immediately if you develop a fever or other signs of infection as some infections can potentially be severe and fatal. Avoid exposure to chickenpox or measles, but if you are exposed, medical advice should be sought without delay.

Alteration in Cardiovascular/Kidney Function:

EMFLAZA can cause an increase in blood pressure and water retention or a decrease in your potassium or calcium levels. If this occurs, dietary salt restriction and potassium supplementation may be needed.

Behavioral and Mood Disturbances: There is a potential for severe behavioral and mood changes with EMFLAZA and you should seek medical attention if psychiatric symptoms develop.

Effects on Bones: There is a risk of osteoporosis or decrease in bone mineral density with prolonged use of EMFLAZA, which can potentially lead to vertebral and long bone fractures.

Effects on Growth and Development: Long-term use of corticosteroids, including EMFLAZA may slow growth and development in children.

Ophthalmic Effects: EMFLAZA may cause cataracts or glaucoma and you should be monitored if corticosteroid therapy is continued for more than 6 weeks.

Vaccination: The administration of live or live attenuated vaccines is not recommended. Killed or inactivated vaccines may be administered, but the responses cannot be predicted.

Serious Skin Rashes: Seek medical attention at the first sign of a rash.

What are the side effects that could occur with EMFLAZA?

- facial puffiness or Cushingoid appearance
- weight increased
- increased appetite
- upper respiratory tract infection
- cough
- frequent daytime urination
- unwanted hair growth
- central obesity
- colds

What other medications might interact with EMFLAZA?

Certain medications can cause an interaction with EMFLAZA. Tell your healthcare provider of all the medication you are taking, including over-the-counter medicines (such as insulin, aspirin, or other NSAIDs), dietary supplements, and herbal products. Alternate treatment, dosage adjustment, and/or special test(s) may be needed during treatment. Do not take EMFLAZA suspension with grapefruit juice.

The information presented is not comprehensive. Talk to your healthcare provider for more information or see www.EMFLAZA.com for the full FDA-approved product information.

For medical information, product complaints, or to report an adverse event, please call **1-866-562-4620** or email at **usmedinfo@ptcbio.com**.

You may also report adverse events directly to FDA at **1-800-FDA-1088** or **www.fda.gov/medwatch**.



access MDA

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

Walking the Walk

Team Matthew brings in more than \$24,000 for MDA Muscle Walk

Tammy Silver and John Nash created Team Matthew, an MDA Muscle Walk team named in honor of their 9-year-old son who has Duchenne muscular dystrophy (DMD), on a whim last year. Even though they claim they didn't do much planning, they raised more than \$7,000.

"That encouraged us to start early this year," Nash says. "And we ended up being No. 4 in the nation."

Team Matthew raised more than \$24,000 this year through many different avenues: social media, the family's friends and

relatives, and Nash's work in the wine industry. Beyond feeling great about raising money for a cure, the experience of being at the MDA Muscle Walk of St. Louis provided the family with fond memories.

"This year, we had a bunch of relatives, and it was almost like a family reunion," Silver says. "And just seeing all the other families that were there was awesome. ... There's so much camaraderie — everyone is out there doing what they can."

Silver also appreciates that the money helps to send children like Matthew to MDA Summer Camp, where kids grow in independence and learn important life skills. Matthew himself has attended MDA Summer Camp for the past three years and he loves the accessible activities, especially swimming.

Matthew also participated in the phase 3 clinical trial of eteplirsen (brand name Exondys 51), and he has seen great results.

"It's made a huge difference," Silver says. "Luckily, they were having the trial [at a location that was] a 20-minute commute from where we live. We're blessed to be so close."



John Nash (left) with Matthew (right) and Team Matthew supporters.

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



Partners in Progress

Casey's General Stores celebrates 10 years of partnership with MDA

Since 2006, Casey's General Stores have supported MDA through MDA Muscle Team and the MDA Summer Camp Pinup Campaign, which lets shoppers purchase a \$1 or \$5 pinup (which includes a 7UP coupon) to display in the store. Over the past 10 years, Casey's stores have raised more than \$8 million with this campaign, including \$1.5 million in 2016 alone.

Casey's and its employees have a special commitment to the MDA mission. In 2016, more than 100 Casey's employees visited MDA Summer Camps and participated in activities with campers. Casey's mascot, Pepperoni Pete, even made a special visit to the Iowa MDA Summer Camp. Casey's also sponsors the MDA Iowa Muscle Team Gala, bringing together MDA families, Casey's employees and other guests for a night of fun and fundraising. Since Casey's began sponsoring the event, it has raised more than \$1.2 million for MDA.

 For more information about MDA's partnership with Casey's General Stores, visit mda.org/get-involved/meet-our-partners, and select the Casey's logo.



Nine-year-old James enjoys playing with the ACTIVE-seated technology.

Game On

Technology adapted from video games helps individuals with muscular dystrophy participate in clinical trials

Participating in a clinical trial often means meeting some stringent requirements. One common requirement is the six-minute walk test, which measures the distance walked in six minutes and which may be used to help determine whether a drug is having an effect. This requirement can be a challenge for some individuals with neuromuscular diseases.

"If you walk too well, you aren't eligible, and if you don't walk well enough, you aren't eligible, and sometimes young kids will have trouble paying attention [for six minutes]," says Linda Lowes, a researcher in the Center for Gene Therapy at the Research Institute of Nationwide Children's Hospital.

Because of this, the researchers at Nationwide Children's began to test a new technology that could measure progression for participants with ambulatory issues through a video game. Using Microsoft's Xbox Kinect camera tracking system, the researchers created the ACTIVE-seated system, which

tracks arm movements.

"It measures participants' abilities based on their function," Lowes says. "We think it can be used for just about anything where the participants have trunk or arm limitations."

To play the game, participants sit in a chair where they can see a computer monitor and the Xbox Kinect camera facing them. Unlike most video games, there is no controller involved; the players simply move their hands around the space in front of them.


"My favorite thing is that you get to smash spiders and knock out gems," says James, a 9-year-old with Duchenne muscular dystrophy (DMD), who has played the game about 10 times over the past two years through his participation in clinical trials.

James is a fan of video games and plays his Xbox at home. His favorite game is Madden NFL, but he says he actually likes playing with the ACTIVE-seated technology better.

"It's really fun, and it's

easier using my hands than the controller," he says. "I hope that other MDA clinics get it for their kids."

Lowes says the ACTIVE-seated technology is starting to "catch on." They have completed validity trials for its use with limb-girdle muscular dystrophy (LGMD), spinal muscular atrophy (SMA) and facioscapulothoracic muscular dystrophy (FSHD) trials. It's also being used in several clinical trials: natural history studies in SMA and myotubular myopathy, two gene therapy trials and a large, multisite DMD trial.

 For more information about the ACTIVE-seated technology project, you can contact Linda Lowes at Linda.Lowes@nationwidechildrens.org. The researchers at Nationwide Children's Hospital are also interested in speaking with programmers in the MDA community who might be able to volunteer time to help improve the game's graphics.

Support System

Medical coder with LGMD lives an independent life thanks to a little help from family and friends

When Cindi Reamer, a 58-year-old auditor and coder with limb-girdle muscular dystrophy (LGMD) was a child in Fort Wayne, Ind., she told her orthopedist that she wanted to work for him one day. At age 20, she did just that. Steven Glock, M.D., hired her as a telephone switchboard operator, and she has been working in his practice ever since, moving from the switchboard into coding.

Holding down a job for more than 30 years as her LGMD progressed has been challenging at times.

"There's something every year that I could do last year but I can't do this year," she says. "I had a huge challenge five years ago when driving foot-to-brake became uncomfortable for me, and I took myself off the road. It was a two-year process to go through vocational rehab, and now I'm finally driving on my own with two joysticks. I should have done it a long time ago, but sometimes pride gets in the way."

Reamer says she's able to take on challenges such as driving independently and living beyond limits with the help of her support system.

"My family keeps me moving," she says. "And the girls at work. I love coming into work because of those girls."

Reamer explains that on an average day, her husband helps her in the morning, her sister does her hair, and co-workers help her transfer between her wheelchair and her desk chair.

"It takes a village," she says. "If it wasn't for my sister and my husband and the lovely ladies I work with, I wouldn't be working. I also had great parents. My mom and dad were huge supporters."

All of this support has helped Reamer not only with her work, but also to become a coding teacher at her local community college and participate in MDA events such as the MDA Lock-Up. This year, she raised almost \$4,000 for the Fort Wayne MDA office. And while she stays busy with work and teaching, that doesn't mean she doesn't make time for some fun.

"I like to go to concerts, I like to travel – I've been on many cruises – and I love going to the movies," she says. "I'm also a knitter and crocheter, and I love to paint pottery."



Cindi Reamer








You're not alone in your journey.

MDA is here every step of the way, ready to provide resources and guidance, support groups and ways to connect with others in hometowns across America. To find support, visit mda.org/services/finding-support. And, to learn more and get involved with MDA Lock-Up in your community, visit mda.org/lockup.

Fundraise Your Way for MDA

Your ideas are the best ideas. From hosting a bake sale to running a 5K, you can fundraise your way to help kids and adults living with muscular dystrophy. We'll give you the tools to make the fundraiser a success and cheer you on every step of the way!

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-  **Bowling Parties** – Book a date at your favorite bowling alley and bowl for donations.
-  **Special Occasions** – Turn your special day into one that gives back.
-  **Athletic & Sporting Events** – Turn your exercise or fitness challenge into donations.
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Helping Hands



Lowe's employees help improve an MDA Summer Camp in Nebraska.

An MDA partner since 2001, Lowe's takes great pride in improving the communities it serves. To date, Lowe's and its loyal customers have raised more than \$63 million to support MDA's mission. Lowe's also supports MDA by encouraging their employees to volunteer throughout the year and to join together in select improvement projects. This year's projects included helping to construct new decks and ramps for the

MDA Summer Camp at Camp Calvin Crest in Nebraska. Five Lowe's locations participated, and 22 Lowe's employees helped to build the ramps and decks over two days with all materials donated by Lowe's.

"Building the ramps and decks, then returning to see the campers enjoying their camping experience was truly rewarding for us," says Mary Mulvey from Lowe's store 2611 in Papillion, Neb. "I feel fortunate to work for a company that allows us to get out in the community and give back. MDA has been a great partner over the years!"

Carry On

A veteran letter carrier shares his connection with MDA

For Ed Walsh, who has been a U.S. Postal Service letter carrier for 23 years, getting involved with MDA came naturally. Walsh is a member of the National Association of Letter Carriers (NALC) Branch 358 in New York. NALC was one of MDA's first national sponsors, originally partnering with MDA in 1952. Beyond that official partnership, Walsh and his fellow branch members have found personal connections to MDA.

For Walsh, the cause hit home 12 years ago when he met his colleague's nephew, Derek, who has Duchenne muscular dystrophy (DMD).

"I met Derek, and I saw that he wasn't giving up," says Walsh. "When you see a 4-year-old running in braces playing with his bigger brothers, trying to do what they're doing, you're inspired. We had to work for everything growing up in a

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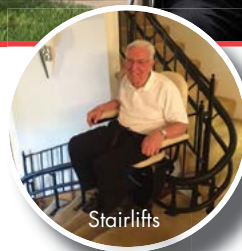
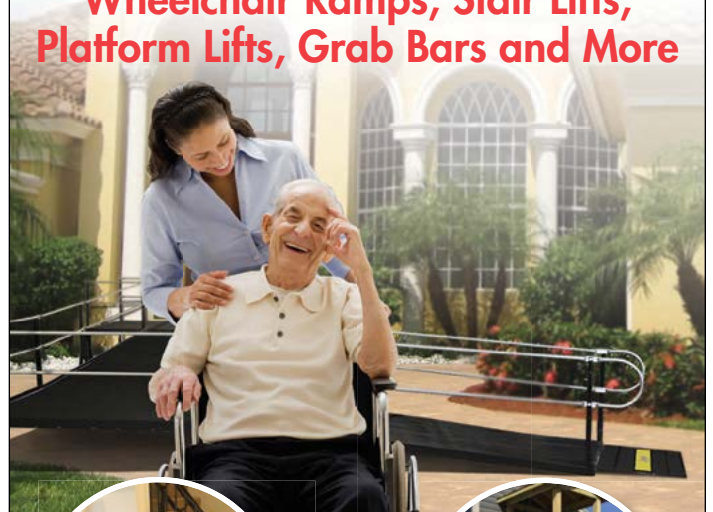
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low-income area, and seeing Derek trying his hardest, it felt like a great fit.”

Walsh is now the lead MDA representative for Branch 358, and he helps to organize fundraising events throughout the year – from satchel drives to golf tournaments to bowl-a-thons. Walsh estimates that, over the 14 years they’ve been doing these events, Branch 358 has raised more than \$270,000. In its 65-year history with MDA, NALC has raised more than \$100 million.

For Walsh, who lives in Wynantskill, N.Y., with his wife and two children, every event is his favorite, because it means he gets to raise money for a great cause while spending time with his co-workers, family and friends.

“Community service in 358 has always been a branch effort,” he says. “We’re out there doing events, and the reason is Derek – and all the people affected [by neuromuscular diseases]. When you have such a strong bond, that gives you the go and the energy. I try to make it infectious, because that’s what I believe.”

 **Find your passion, and get involved in the MDA community in a way that’s meaningful for you. Learn more at mda.org/get-involved. Learn more about our dedicated partners like NALC that work year-round to help MDA families at mda.org/get-involved/meet-our-partners.**



Students learn aerial arts at SaltAer circus school.

Flying High

An entrepreneur brings her passion for acrobatics to her community

When Christine “Kippy” Hoene, a 57-year-old acrobat and entrepreneur with facioscapulohumeral muscular dystrophy (FSHD), first opened her SaltAer circus school in Jacksonville, Fla., earlier this year, it represented a culmination of her passions. At age 35, Hoene decided she wanted to learn a new skill every year, and after seeing Cirque du Soleil perform in Las Vegas, she set out to learn acrobatics.

“I was always trying new things, and I tried this and just loved it,” she says. “I really enjoyed the challenges it brings, and how you >>

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Hoene learned acrobatics while living in St. Louis. However, after buying back a company located in Jacksonville that she had started in her 30s, she found herself splitting her time between the two cities. Her inspiration for starting SaltAer was simple.

“It really is my passion, and I was a little selfish,” she says. “I wanted a place [to do acrobatics] in Jacksonville, and there wasn’t anything. I also thought it would be great for the community.”

SaltAer – a play on words that refers to the school’s location on the beach and aerial silks that are used in acrobatics – opened its doors in June 2016 and has been hosting classes, open gyms and free educational sessions for community members. Hoene attributes her ability to stay active after being diagnosed with FSHD five years ago to her passion for acrobatics.

“I just feel like it’s really kept my body strong, and that makes me happy,” she says.

In addition to attending MDA Muscle Walks with her circus stilts, Hoene finds time to volunteer for other charities and projects, including creating an app called DanceEmoji that helps support the Center for World Health in St. Louis.

 Find more personal stories about individuals with neuromuscular disease living unlimited at strongly.mda.org.

Team USA at the FIPFA World Cup



PHOTOS BY SCOT GOODMAN


Going for the Gold

U.S. power soccer team competes in the FIPFA World Cup

This July, four athletes with neuromuscular diseases competed in the Federation Internationale De Powerchair Football Association (FIPFA) World Cup for Team USA, which came in

second place overall. Jordan Dickey, Natalie Russo, Ben Carpenter and Nathan Mayer all competed in the tournament, which pits teams of four individuals operating wheelchairs with wheel guards against each other in a game commonly called power soccer. The goal is to maneuver your team’s ball into the other team’s goal through dribbling, passing and shooting.

Fans and players from all over the world came to Kissimmee, Fla., for the event. And while Team USA went undefeated in its opening rounds, they were bested in the end by Team France in an intense championship match. The FIPFA World Cup takes place every four years, and it will be held again in 2021.

 For more information on power soccer, visit the **U.S. Power Soccer Association** at powersoccerusa.net.

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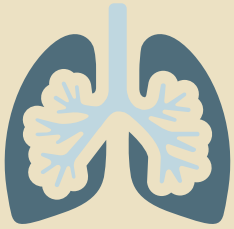
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The study will compare the efficacy of idebenone to placebo in those currently on steroids (either prednisone or deflazacort).



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.



Pushing Their Limits

Lifelong friends partner with MDA to bring their journey to the big screen




Patrick Gray (top) and Justin Skeesuck

In 2014, two lifelong friends set off on a journey that, in addition to deepening their friendship and teaching them life lessons, would eventually inspire a book, speaking engagements and a documentary called "I'll Push You," which is premiering November 2.

Justin Skeesuck and Patrick Gray have been friends since birth. When Skeesuck was 16 years old, he began to feel the effects of a rare form of neuromuscular disease.

In 2012, he learned about the Camino de Santiago, a 500-mile trail in Spain, and he asked his friend Gray what he thought about taking it on. They decided to go for it, and that grueling but awe-inspiring journey is documented in "I'll Push You."

"We set out to accomplish this impossible journey, and we made it," says Skeesuck. "To have it documented on film is a dream come true. But to finally be able to share it with the world, I'm not sure I have words to adequately describe the joy I feel."

 **To learn more about "I'll Push You" and to purchase tickets, check out ilpushyou.com.**

Skeesuck and Gray have partnered with MDA and its Live Unlimited Campaign to bring the documentary to select theaters this November, so even more people can enjoy their adventure.

"Every life has challenges; some are harder than others," Skeesuck says. "But regardless of the challenges we face, our ability to overcome them rests in our relationships. That's what this film is about – our ability to live well rests in the community we surround ourselves with."

MDA Offers LGMD Genetic Testing Program

Talk with your MDA physician about testing options

MDA families are at the heart of all we do. To help provide the MDA families we serve with the best possible care and support from day one, we are pleased to announce the continuation of the limb-girdle muscular dystrophy (LGMD) genetic testing program, thanks to additional support from Sanofi Genzyme.

MDA Care Centers and MDA Care Affiliates are offering genetic testing for individuals experiencing limb-girdle muscle weakness who do not already have a genetic diagnosis. This advancement in >>



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 August 3-5, 2018

Boston
 September 21-23, 2018

diagnosis will help more individuals living with LGMD and their clinicians find the most accurate treatment path available.

Why is a genetic diagnosis important? Genetic testing is important because definitive results allow clinicians to diagnose and treat individuals with more accuracy as some subtypes of LGMD require different therapeutic strategies. In addition, participation in most clinical trials requires a confirmed genetic diagnosis.

The simple test requires only a small saliva or blood sample, which can be collected at any of MDA's Care Centers or Care Affiliates across the country. From there, it is sent to EGL Genetics, and within three to four weeks results are returned to the MDA physician, who shares the findings with individuals and their families.

To learn more about how LGMD genetic testing is improving lives, read "Genetic Testing Provides Answers and Hope" at strongly.mda.org.



To learn more about MDA's LGMD genetic testing program, schedule an appointment with your MDA Care Center or Care Affiliate physician. Visit mda.org and type your state or ZIP code in the box and select "Find MDA in Your Community." If you have questions, contact your local MDA office or the MDA Resource Center at 800-572-1717 or ResourceCenter@mdausa.org.

Running Strong

Every year, hundreds of endurance runners combine their passion for the sport with their passion for MDA, raising thousands of dollars for MDA. Matt Kendall, father of 5-year-old Archer who has Duchenne muscular dystrophy (DMD), raised more than \$50,000 when he ran the United Airlines NYC Half-Marathon with MDA Team Momentum in March.

"We want to fund more promising trials," Kendall says. "There is a lot of research out there that needs capital to get to the next level toward disease-modifying therapy. The opportunity is now."

Join runners like Kendall who are supporting MDA at one of the many races where MDA Team Momentum will participate in spring 2018, including:

- **NYRR United Airlines NYC Half**, New York, NY – March 18, 2018
- **Reebok Ragnar So Cal**, Southern, CA – April 6-7, 2018
- **Boston Marathon Presented by John Hancock**, Boston, MA – April 16, 2018
- **Chicago Spring Half Marathon & 10K**, Chicago, IL – May 20, 2018
- **Boston's Run to Remember Half Marathon & 5 Mile**, Boston, MA – May 27, 2018



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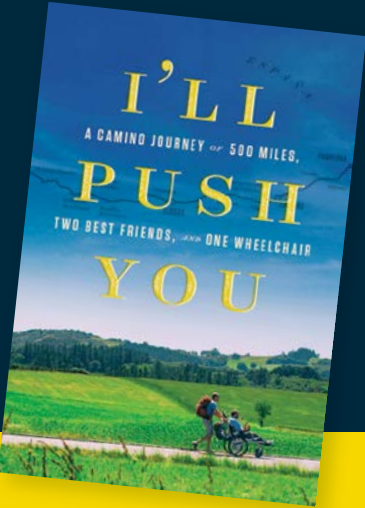
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In Sickness and in Health

A newlywed with SMA learns that the joys and challenges of marriage are similar with or without a disability

BY KATRINA GOSSETT KELLY

Katrina Gossett Kelly looks radiant on her wedding day.



wild ride so far — joyous and frustrating, challenging and wonderful.

Our relationship hasn't been without its bumps and turns, but as we grow, I am learning that these are the same bumps and turns everyone faces. They may just look a little different from a wheelchair.

I had always been cautious about imagining myself in a relationship. I feared I would have less to offer my partner than my able-bodied friends and would need more from a partner. Our marriage has been a learning experience for me — learning that I'm not so different, that we're not so different.

TO GIVE

When I was younger, I feared that I would not be able to contribute enough to a relationship. I knew that I couldn't cook or clean or do many of the things that spouses are expected to do. Trust me, I am no June Cleaver — but really, who is?

Over the years, I've had to abandon my images of the "ideal wife" and accept my reality. I may not be perfect, but I'm perfectly his. Through this process, I am also discovering that, despite my previous conceptions,

Have you seen the ridiculous meme going around the internet that asks people if they would stay with their spouse if their spouse ended up in a wheelchair? Every time I see it, it makes my blood boil, especially when people hesitate with their answer. It is upsetting that this is even a question to be asked. Marriage is a commitment, and a disability should

not change that. But not everyone sees it that way. Fortunately, my husband Russel and I both do.

Russel and I were married in April 2016. We met online, started dating long-distance and soon became not-so-long-distance when Russel moved to my city so that we could be closer. We dated for a year and a half before we were engaged, and then got married 10 months later. It's been a

Follow Katrina

Katrina Gossett Kelly has been a past contributor to *Quest*. Find articles where she discusses employment, weight loss and women's wellness by searching for "Gossett" at mda.org/quest.

my husband and I are not so different from the average American couple with their 2.5 kids.

Everyone has strengths and weaknesses. Some of my weaknesses are a little more obvious: I will not be setting out the place settings and punch bowl when we host a party, nor will I help with cleaning out the garage.

On the other hand, some of my strengths are also quite clear. I have a silly sense of humor and can lighten the mood when things are getting dull. I can draft a legal document in 30 minutes flat. And I am a fierce advocate for myself and for the people I care about. I will never let anyone trample on my toes or my husband's toes — that's my wheelchair's job.

My husband has other strengths and weaknesses. He is kind, compassionate, far more organized than I am and has two good arms for changing the batteries in the smoke detector. Somehow, we just have to fit our strengths and weaknesses together — just like every other couple that we have met.

AND TO RECEIVE

When I was younger, I also worried that my needs would be too great for any partner to choose me. So I tried to downplay my disability on dating profiles, only to get rejected once I started communicating with someone. Gradually, I learned that I needed to be straightforward about who I am, and the right person would come along. He did.

I have spinal muscular atrophy (SMA), and I need



More Online

Read stories from around the MDA community — and share your own — on Strongly, the MDA blog. Visit strongly.mda.org to find personal stories from individuals living with neuromuscular diseases, research news and more. If you're interested in sharing your story on Strongly, contact us at strongly@mdausa.org.

Katrina and her husband, Russel, enjoy sightseeing in Chicago.

assistance with basically everything. From the bathroom to the kitchen to hair and makeup to feeding the dogs, I rely on someone else's hands. Many times those hands belong to one of my personal care attendants, but often they are my husband's hands.

From the start, I knew that I would not want to rely on my husband for all physical assistance. That's never really been my style. I wanted my own independence, and I wanted our marriage to be a marriage, not just a job. For that reason, I still rely on attendant care for many of my needs.

But the fact is that marriage is work. With or without a disability, a spouse is constantly working to meet the needs of his or her partner. My husband wants to be a part of my care because

it is an important part of my life. He is ready to step in any time that I need him. When an attendant is sick, he can get me showered and ready in an hour and a half. He feeds me dinner several days a week, which really just means that we get to sit down and have dinner together without someone else interrupting. And he is there day in and day out helping with the important "little" things, like making coffee or taking off my shoes.

I hope to always be there for him, as well. I want him to feel he can always turn to me for a kiss. [Q](#)

Katrina Gossett Kelly, 32, is a business litigation attorney at Faegre Baker Daniels in Indianapolis. She lives downtown with her husband, Russel, and their three dogs. She also performs improv at ComedySportz Indianapolis.

Picture Perfect

Artist with ALS takes inspiration from her surroundings



Artist Karen Condron doesn't allow ALS to stifle her creativity and self-expression.

Artful Expression

Read about another inspired artist, AJ Brockman, who is living with spinal muscular atrophy (SMA) and paints the world using cutting-edge technology and his left index finger at strongly.mda.org.

Karen Condron's passion for painting dates back to her first art lessons in 1968, but she only began showing her work at festivals in 2013, the same year she was diagnosed with bulbar-onset ALS. When ALS begins in the bulbar motor neurons, the muscles used for swallowing and speaking often are affected first.

As her ALS progressed, Karen lost her ability to speak. But, she is still able to express herself through her paintings (karencondron.com), many of which are inspired by her favorite places. Peaceful, forested scenes and windswept coast-



lines populated by birds soaring over crashing waves are common subjects. She paints from her memory and imagination, recalling

the surroundings around her Connecticut home and summers at the beach.

Jim, her husband, says Karen was active before her diagnosis, enjoying running and swimming. Although she can no longer run, Karen is still able to paint and exercise, and she stays involved in their community. Throughout her journey as an artist and adjustments to living with ALS, Karen credits Jim with being her rock.

"He helps me all day with all my needs, and he is the most important thing to me," she communicates via email. [Q](#)

Looking for people with LEMS, CMS, or MuSK-MG

Do you have Lambert-Eaton Myasthenic Syndrome (LEMS)? Congenital Myasthenic Syndrome (CMS)? Myasthenia Gravis with antibodies to Muscle-Specific Kinase (MuSK-MG)? Or do you know someone who does?



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LEMS Patients

Adults with a confirmed diagnosis of LEMS may be eligible to enroll in the Expanded Access Program (EAP).

Learn More

For more information about our clinical studies in CMS or LEMS, contact Catalyst at EAP@catalystpharma.com or call **1-844-347-3277**. For more information about MuSK-MG contact Catalyst at MuSKMG@catalystpharma.com or call **1-844-347-3277**. More information about our trials is also available at catalystpharma.com.

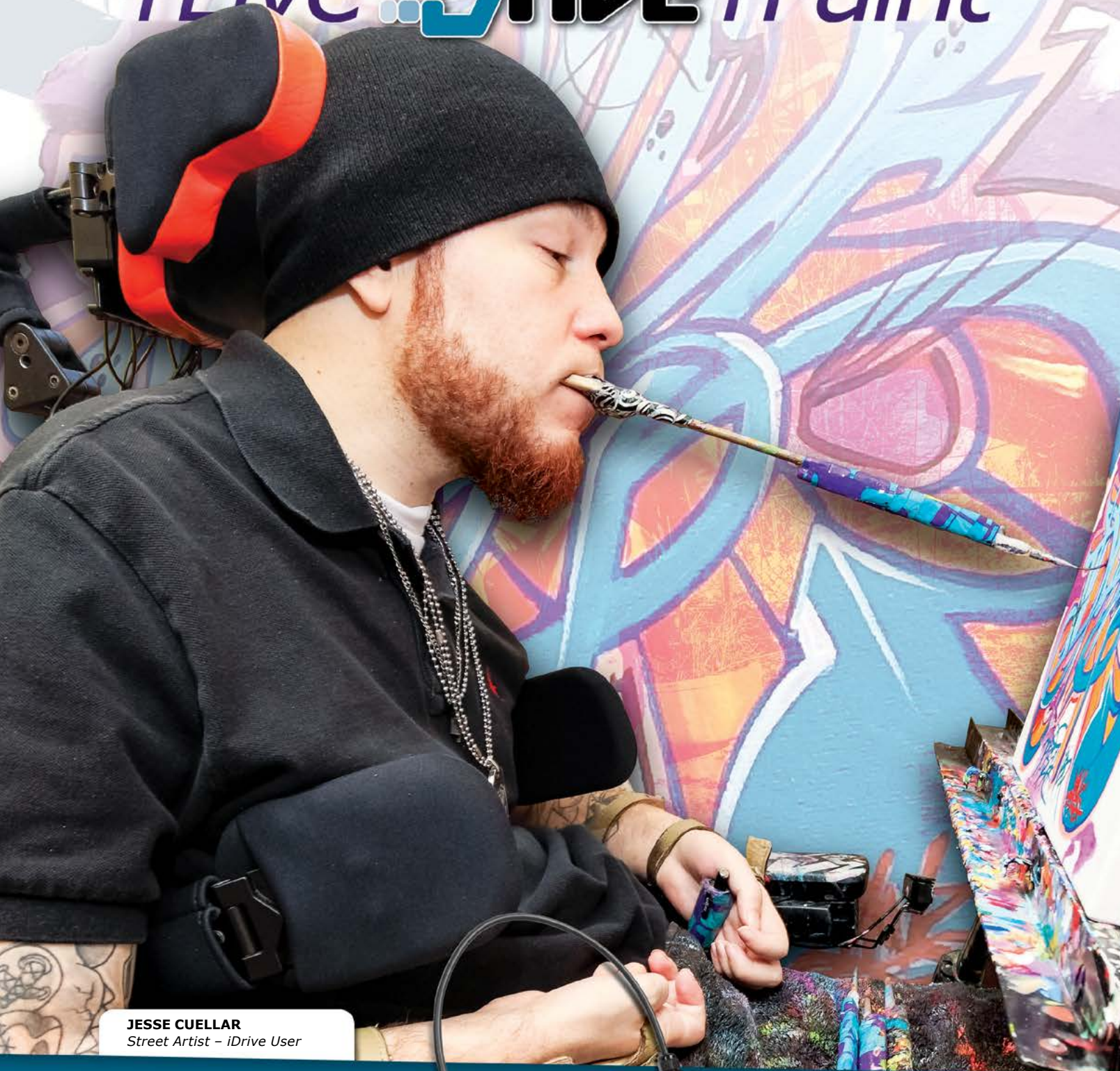
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