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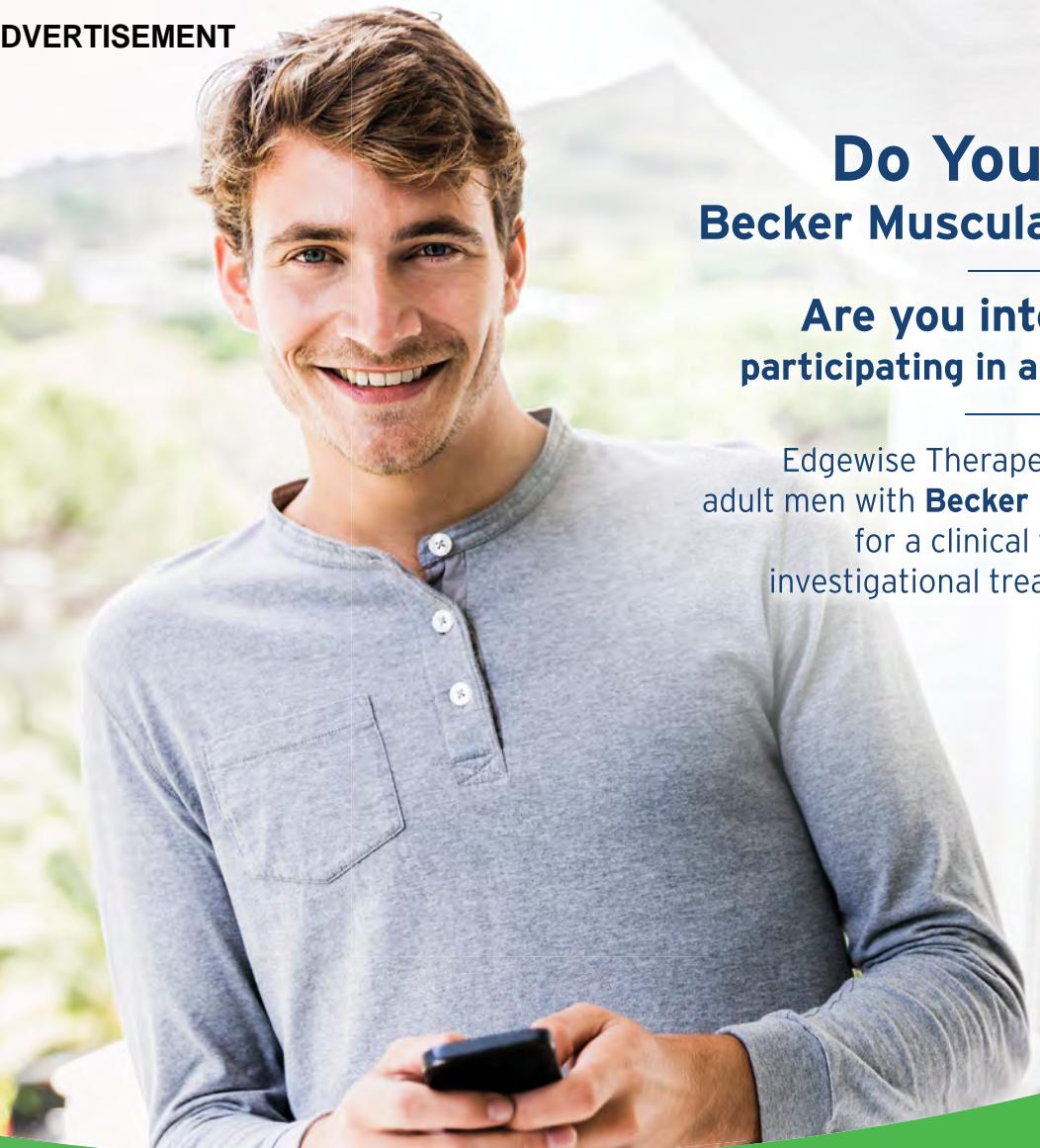
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MDA is committed to transforming the lives of people affected by muscular dystrophy, ALS, and related neuromuscular diseases through innovations in science and innovations in care.

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Planning for What's Ahead

We made it. 2020 asked much of us — voluntary isolation, patience, adjustment, perseverance — in new ways, even for those of us in the neuromuscular disease (NMD) community who've had to face similar demands in our disease journeys. We leaned on our knowledge, on each other, on hope. Today, as I'm writing this, there is, indeed, incredibly, more hope. The US Food and Drug Administration (FDA) has authorized the use of two vaccines for the novel coronavirus that's changed our world. By the time you read this, you may already have received a dose.

For many of us, the new question is: What now? Where do we go from here?

It's difficult to predict how the pandemic will continue to impact our long-term future. We can't yet know what our economy, industries, and social gatherings will look like by the end of this new year. But even as we can embrace uncertainty (certainly, living with NMD, we're called to do so), we can take the steps possible to plan for what's ahead, whatever it may be.

In this issue, we're taking a close look at what is, for many of us, our security baseline: finances. (See "Plan for a Bright Future" on page 12.) Savings accounts, benefits programs, and long-view planning help ensure we're prepared for both expected and unexpected events — and there are options specifically designed for the unique experience of living with disability. Financing home and vehicle modifications can be particularly stressful; we're also highlighting how to make simple investments to increase accessibility — and make some critical contacts in the process. (See "Affordable Accessibility" on page 18.)

As we begin to transition into what will be the post-pandemic world, our resilience relies on our ability to stay connected, share resources, and keep planning for the future we want. *Quest* is here to support you in that, this year, and into our future.

Sincerely,

Lindsey Baker

Quest Editor-in-Chief and General Manager
Muscular Dystrophy Association



Lindsey Baker

THANK YOU, READERS

Quest readers gave us great feedback in our 2020 Reader Survey. Thank you to everybody who completed the survey; your responses help shape the content we provide in *Quest*.

We'd like to offer special congratulations to Elizabeth Field from Lewes, Del., who won the survey drawing for a \$100 Visa gift card. Readers like Elizabeth help us make *Quest* a valuable resource for the MDA community.

98% of readers consider *Quest* a valuable benefit of being part of MDA.

92% of readers live with a neuromuscular disease or have a family member living with one.

79% of readers share what they learn in *Quest* with family members, caregivers, and others.



Mindy Henderson, pictured with her husband, Michael, redefines the word "disability."



22

CONTENTS

ISSUE 1 2021

FEATURES

12

Plan for a Bright Future

Financial tools and savings plans help individuals and families achieve their financial goals.

18

Affordable Accessibility at Home or On the Go

Take these steps to manage home or vehicle modifications.



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DEPARTMENTS

4

CONNECT & LEARN

Explore MDA's educational offerings.

6

PROGRESS NOW

Read about recent medical research, scientific advances, and clinical trials.



10

SPOTLIGHT

Mark Rich, MD, PhD, answers questions about myotonia congenita.

21

ACCESS MDA

MDA brings community members together, and more.



22

FROM WHERE I SIT

Mindy Henderson turns challenges into advantages.

24

LASTING IMPRESSION

Last summer, MDA brought the magic of Summer Camp to kids at home.

ONLINE



GOT QUESTIONS?

WE'D LIKE TO ANSWER THEM

MDA's Resource Center wants to know what's on your mind. Their trained specialists can provide support for every part of your journey. Send your questions for the Resource Center to quest@mdausa.org and we might select your question to be answered by a Resource Center specialist in an issue of Quest.

How to submit questions

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MDA-072



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Learning at Your Fingertips

The 2020 MDA Engage Myasthenia Gravis (MG) Symposium brought the MG community together online to get the latest updates in MG care and research from experts including Gil Wolfe, MD, FAAN, University of Buffalo/SUNY; Emmanuelle Tiongson, MD, Children's Hospital Los Angeles; and Charlene Hafer-Macko, MD, University of Maryland School of Medicine. Attendees left with fresh knowledge on pediatric and adult care, physical therapy, and clinical research for MG.

This event is an example of how MDA's Engage community education program provides access to important, up-to-date, and relevant educational content. We invite you to explore our offerings.

■ **MDA Engage Disease Symposia** Each virtual symposium focuses on a diagnosis. Experts in the disease

Upcoming MDA Engage Events

Event	Date
Engage Seminar — Transitioning from Pediatric to Adult Care	April 10
Engage Myotonic Dystrophy Symposia	April 28 & 29
Engage ALS Symposia	May 12 & 13
Engage Seminar — Adult Care	May 22
Engage LGMD Symposium	June 5

community present information on medical management for the diagnosis and provide updates on clinical trials and the treatment pipeline. Learn more at mda.org/engage.

■ **MDA Engage Webinars**

These online presentations cover a variety of disease-specific and daily living topics. Find upcoming and past webinars at mda.org/engage.

■ **Educational Materials** MDA's printable educational materials include disease fact sheets, teachers' guides, and clinical trial basics. Explore these materials and more at mda.org/education.

■ **On-Demand Videos** All MDA Engage events are recorded for on-demand viewing, allowing you to replay a session you attended, view an event you missed, or share a video with family and friends. Find on-demand programming at mda.org/videos.

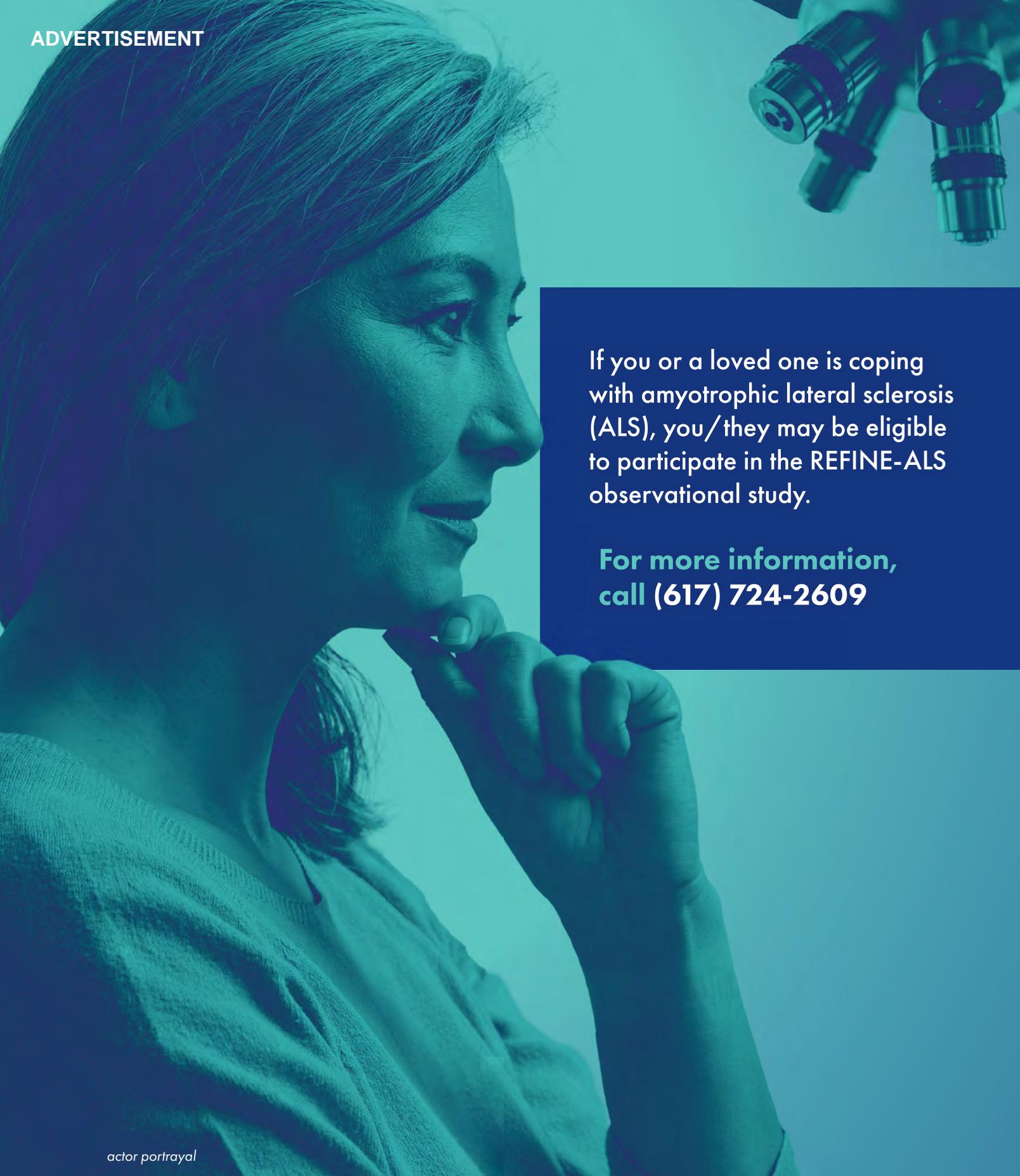
SUPPORT MDA AND QUEST NOW

For more than 25 years, *Quest Magazine* has been telling the stories of MDA's community. With your donation to MDA, we can continue to educate and engage families and the physicians and researchers who help them with the latest news on neuromuscular disease research, health and wellness, mobility, travel, advocacy, and everyday thriving through *Quest* and our complementary educational channels.

To make a tax-deductible donation to MDA, visit www.mda.org/questsupport

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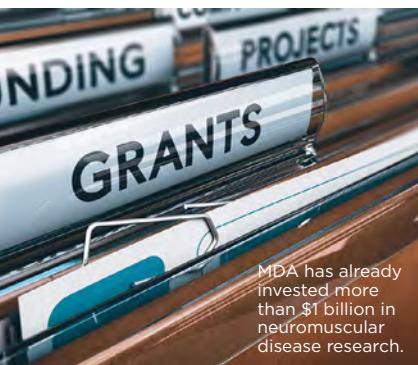


PROGRESS NOW

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

MDA research in action

MDA Awards 15 Research Grants



In September, MDA announced 15 new grants totaling more than \$4 million for research focused on a variety of neuromuscular diseases, including Duchenne muscular dystrophy (DMD), Charcot-Marie-Tooth disease (CMT), Becker muscular dystrophy (BMD), spinal muscular atrophy (SMA), amyotrophic lateral sclerosis (ALS), myotonic dystrophy type 1 (DM1), and facioscapulohumeral muscular dystrophy (FSHD).

The newly funded projects aim to advance research discoveries and new therapy development in multiple areas. The awarded grants are funding studies to further advance understanding of genetic causes of, and risk factors for, neuromuscular diseases and investigate new approaches to developing gene therapies and other innovative potential treatments, including stopping disease progression and improving genetic testing technologies.

This round of grant funding builds on the more than \$1 billion MDA has already invested in research to uncover new treatments and cures for neuromuscular diseases since its inception.

For a complete list of awards in this grant cycle, visit mda.org/science/grants-at-a-glance.

Amyotrophic lateral sclerosis (ALS)

MDA Grants Boost Research



MDA awarded five new grants totaling more than \$1.6 million to fund ALS research:

- > A three-year \$500,000 grant was awarded to Sabrina Paganoni, MD, PhD, to support development of the first platform trial for ALS, enabling researchers to conduct clinical trials testing more than one experimental therapy at a time.
- > A \$917,261 grant was awarded to Michael Benatar, MD, PhD. The three-year funding will support the launch of the ALS Toolkit — a software module incorporated on the Epic electronic health record (EHR) that will help collect data for research and quality-of-care improvements.
- > A one-year research grant totaling \$137,228 has been given to Jonathan Glass, MD, PhD, for his team's work to determine if failures in clinical trials of ALS may be due to unknown disease subtypes that do not respond to the therapy being tested.
- > A one-year grant of \$54,785 was given to Jeffrey Rothstein, MD, PhD. The funds will be used to develop a new gene therapy delivery system based on an adeno-associated virus (AAV) to treat individuals with ALS and frontotemporal degeneration (FTD).
- > A one-year MDA research grant of \$54,784 was given to Hiroshi Mitsumoto, MD, to support work aiming to discover new risk factors for ALS, as well as a potential cause for the disease.

Read more about MDA-funded neuromuscular disease research at mda.org/science/grants-at-a-glance.

Study Shows Benefits From AMX0035

In an update from its phase 2/3 CENTAUR trial evaluating the effects of the investigational drug AMX0035 on overall survival in people with ALS, pharmaceutical company Amylyx noted that trial participants receiving AMX0035 over a period of up to three years were shown to have a 44% lower risk of death compared to participants who received a placebo.

AMX0035, a combination of the small molecules sodium phenylbutyrate and taurursodiol, is designed to promote the function of the mitochondria (the “powerhouse” of the cell) and the endoplasmic reticulum (a continuous membrane system responsible for functions including protein folding), potentially reducing the damage and death of motor neurons.

Previously, Amylyx announced results indicating slower functional decline in individuals receiving AMX0035.



Data indicate that AMX0035 is associated with both functional and survival benefits in people with ALS.

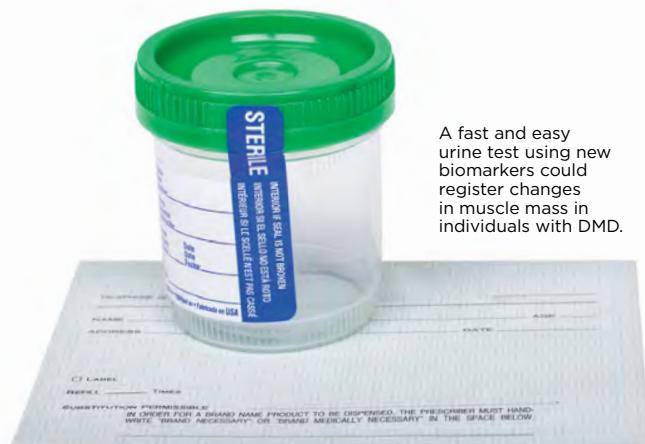
Amylyx is continuing the CENTAUR study in an open-label, compassionate extended-use study. The researchers hope to track individuals over a longer period of time to further explore how the treatment affects neurological decline.

For information about the CENTAUR trial, visit clinicaltrials.gov and enter NCT03127514 in the “Other terms” search box.

Duchenne muscular dystrophy (DMD)

MDA Collaboration Helps Fund DMD Biomarker Study

MDA, Duchenne UK, and Parent Project Muscular Dystrophy (PPMD) announced a jointly funded grant of \$686,500 to William Evans, PhD, at the University of California,



A fast and easy urine test using new biomarkers could register changes in muscle mass in individuals with DMD.

Berkeley, to use a new method to measure changes in total muscle mass in individuals with DMD through biomarkers in urine samples.

Biomarkers are naturally occurring molecules, genes, or measurable signals found in blood and urine that reflect changes in the body. For people with DMD, biomarkers can help establish or confirm a diagnosis, show the disease's progress, and show how drugs and other therapies are working.

In 2018, Duchenne UK (with Solid Biosciences) made a grant of \$162,600 to Duke University and UC Berkeley for an initial study of new biomarkers for DMD. The study successfully demonstrated that an accurate measurement of functional muscle mass could be made using biomarkers.

Now, MDA, Duchenne UK, and PPMD are supporting the next phase of research in hopes of reproducing the results in a larger study consisting of approximately 150 boys with DMD.

This work could demonstrate a better way to assess new treatments for DMD while reducing invasive muscle biopsies or expensive MRI scans that are not available at all clinical trial sites.

Read more about MDA-funded neuromuscular disease research at mda.org/science/grants-at-a-glance.

Duchenne muscular dystrophy (DMD)

FDA Lifts Hold on IGNITE Trial

The US Food and Drug Administration (FDA) lifted the clinical hold placed on Solid Biosciences' IGNITE DMD phase 1/2 clinical trial. As announced in July 2020, the FDA requested further manufacturing information and updated safety and efficacy data for all individuals dosed with the study drug, SGT-001. The FDA also provided direction on total viral load to be administered per individual. Based on the company's response to these requests, the FDA acknowledged that all clinical hold questions had been addressed to its satisfaction.

SGT-001 delivers to the body a synthetic dystrophin gene called micro-dystrophin. This micro-dystrophin acts as a surrogate, standing in for missing dystrophin protein.



At the request of the FDA, Solid Biosciences modified IGNITE DMD trial protocols and improved manufacturing processes to support safety.

As requested by the FDA, Solid Biosciences implemented and shared manufacturing process changes intended to support safe dosing of SGT-001 for the duration of the IGNITE DMD trial. The company also submitted data from a new, quantitative *in vitro* micro-dystrophin expression examination that showed the similarity between SGT-001 manufactured by each of the two processes. In addition, the company provided the FDA with updated safety and functional efficacy data (including six-minute walk test and North Star Ambulatory Assessment data) for all individuals dosed to date in the IGNITE DMD trial.

No additional drug-related adverse events were reported up to 30 months post-dosing.

Read more about SGT-001 at solidbio.com.

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Spinal muscular atrophy (SMA)

Promising Interim Results in TOPAZ Trial

Biopharmaceutical company Scholar Rock announced positive results from an interim analysis of its phase 2 TOPAZ clinical trial evaluating SRK-015, a therapy for treating SMA. After six months of treatment with SRK-015, individuals with SMA types 2 and 3 demonstrated significant motor function improvements, as measured by the

Hammersmith scale, with higher-dose treatments associated with greater improvements.

SRK-015, a human monoclonal antibody, works by binding to myostatin, a protein that inhibits muscle growth. This interaction blocks myostatin function and is expected to improve muscle strength and motor function in individuals with SMA.

The TOPAZ phase 2 trial enrolled 58 individuals with SMA types 2 and 3 across 16 study sites in the US and Europe.

No severe adverse events were reported, and no safety concerns were identified during the interim analysis. All individuals receiving SRK-015 demonstrated functional improvements on the Hammersmith scale.

The TOPAZ trial is ongoing and is evaluating the safety and efficacy of intravenous injection of SRK-015 given every four weeks over a 12-month period.

For more information about the TOPAZ trial, visit [clinicaltrials.gov](#) and enter NCT03921528 in the "Other terms" search box.



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New Research Channels for Myotonia Congenita

A Q&A with Mark Rich, MD, PhD

Myotonia congenita is an inherited myopathy that prevents affected individuals from relaxing certain muscles after contracting them. The disorder causes muscle stiffness but not atrophy or shrinkage. On the contrary, it often leads to larger, stronger muscles.

There are two types of myotonia congenita: Becker disease and Thomsen disease. The Becker type is inherited as an autosomal recessive trait, meaning it is produced when both parents contribute a defective gene. Becker is the more common and more severe form of the disease. It generally shows up between ages 4 and 12, though in rare cases it may occur as late as age 18. Symptoms tend to worsen over time.

The milder Thomsen disease is inherited as an autosomal dominant trait, meaning it is produced when one parent contributes a defective gene. It usually becomes apparent between infancy and ages 2 to 3. Muscles of the hands, legs, and eyelids are generally most affected.

Neurologist Mark Rich, MD, PhD, is considered one of the world's top experts on developing treatments for myotonia congenita, having published more than 80 peer-reviewed articles for scientific journals on a variety of neuromuscular diseases.

Since 2005, Dr. Rich has been at Wright State University in Dayton, Ohio, where his research focuses on mechanisms

underlying muscle dysfunction in myotonia congenita. In 2019, MDA awarded him a \$300,000 grant to pursue research on blockage of TRPV4 channels as a novel approach to treat myotonia congenita.

RARE DISEASE SPOTLIGHT

Read more Q&As about rare diseases at mda.org/quest/spotlight.



People with the disease may have debilitating muscle stiffness and difficulty moving certain muscles, especially after a period of inactivity, such as getting up from a chair, starting to walk or run, and climbing stairs.

Here, Dr. Rich answers questions about the disease and his research.

What causes myotonia congenita?

Myotonia congenita is one of a family of diseases called the channelopathies. These are caused by mutations in muscle proteins. But unlike dystrophin — the missing protein in Duchenne muscular dystrophy that is essential for building muscle — the mutated proteins in myotonia congenita are involved in electrical signaling.

Every time you want to contract your muscle, there's an electrical signal that has to travel across that muscle. If someone with myotonia congenita squeezes your fingers, and you say, "now let go," they can't let go for a while. The muscle keeps contracting even though the brain says "stop."

What is it like to live with myotonia congenita?

It occurs in fewer than 1 out of 100,000 people, and they often struggle to get diagnosed and treated because

physicians haven't seen it much. People often look very muscular, as if they're always working out. But they may be slow and clumsy; everything stiffens on them. If they keep moving, the muscles eventually do relax, but it takes a minute or two.

Myotonia congenita is not fatal, and it does not affect life expectancy. But it can be quite unpleasant. People with the disease may have debilitating muscle stiffness and difficulty moving certain muscles, especially after a period of inactivity, such as getting up from a chair, starting to walk or run, and climbing stairs.

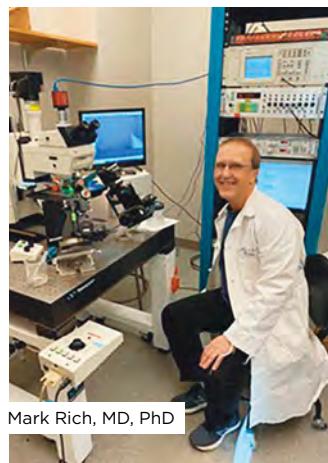
What treatments are currently available?

The most common is mexiletine [sold under the brand names Mexitol and NaMuscla]. It blocks sodium channels and works reasonably well. The problem is that it can affect the heart because it blocks all the electrical signaling, and very rarely it causes sudden death. More common side effects are abdominal pain, headache, nausea, and skin reactions. So it would be nice to have other drugs. My job is to come up with whole new ways to treat this disease without blocking the sodium channels.

How are you looking for new treatments?

I'm pursuing a mouse model of the disease, which has the same mutation as in the human disease. I'm studying the

muscle electrical signaling in detail to figure out all of the steps that happen to cause the stiffness and whether other ion channels besides the sodium channel are involved. I'm hoping to find ion channels that aren't quite as important as the sodium channel, because then we can block the channel and we won't get as many side effects.



Mark Rich, MD, PhD

Is there anything promising on the horizon?

In my MDA-funded research, I found that the ion channel TRPV4 contributes to muscle stiffness. When we block this protein, the stiffness gets much better. Drugs that block this TRPV4 channel are being tried right now in clinical trials for chronic obstructive pulmonary disease [a lung disease]. I'm hopeful from the lung disease studies that this drug will be approved. And if it is, I want to try it in people with myotonia congenita, as well. ☺

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PLAN for a Bright Future



Financial tools and savings options help individuals and families living with neuromuscular disease achieve their goals

BY KAREN DOSS BOWMAN

Josie Badger, DHCE, CRC, has used everything that life has handed her, including her disability, to pursue her dreams. Diagnosed with congenital myasthenic syndrome (CMS) at age 11, Josie now relies on a ventilator, power wheelchair, and 24-hour care. While many would see such challenges as a roadblock to pursuing an occupation,

she has used them to fuel a career she is passionate about: advocating for disability rights.

Along with the ability to achieve personal goals, maintain employment, and live independently comes the challenge of managing finances, budgeting, and saving for the future. Long-term financial planning ensures provision for medical



expenses, equipment needs, nursing or attendant care, and the pleasures of ordinary life.

"For me, financial planning was just as important as obtaining employment in the pursuit of my dreams and calling," says Josie, founder and president of J Badger Consulting, which provides youth development and disability consulting services to organizations. "As a person with a disability, I am reliant on governmental benefits [Medicaid] for my survival. I have to be aware of and utilize all the current financial-planning tools and savings options available to people with disabilities to be able to live the life that I have worked for."

Plan for life

Today, more Americans with disabilities, like Josie, are working, starting families, and leading full lives.

"Because planning for someone with special needs is complex, it is critical to work with specialists in the field," says Cynthia Haddad, CFP, co-founder and partner of Special Needs Financial Planning, a specialty practice of Affinia Financial Group. "Working with knowledgeable professionals helps you prevent mistakes as well as take the emotions out of what are often very emotional decisions. Each planning strategy, financial tool, or legal document you use will have an impact on government benefits and potential government benefits, as well as on you, your family, and your network of support, today and in the future."

Addressing financial concerns can be daunting, but there are many financial tools and programs available to individuals and families impacted by disabilities.

ABLE accounts

The Achieving a Better Life Experience (ABLE) Act, passed into law by Congress in 2014, allows people with disabilities to save money in ABLE accounts. These tax-exempt savings plans cover qualified expenses in areas such as education, housing, and transportation. Money in an ABLE account does not affect qualification for public assistance like Medicaid, though savings greater than \$100,000 may impact an individual's benefit amount.

When Josie and her husband set out to buy their first house, they leveraged her ABLE account — comprising contributions from Josie and her parents — to save \$18,000 for a down payment.

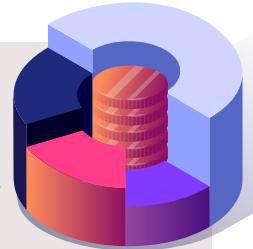
"With an ABLE account, the person with the disability can control their own money," says Susan Tachau, co-founder and chief executive officer of the Pennsylvania Assistive Technology Foundation. "They can use it for utilities, rent, and food, but also for things that improve their quality of life, such as assistive technology."

Government benefits

The federal government offers a number of support programs, including Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and the Children's Health Insurance Program (CHIP). Each state has specific options and rules about how much an individual can earn or save while receiving these benefits.

3 TIPS TO GET STARTED

Financial planning can give caregivers and individuals with disabilities a sense of security for the future. Here's how to get started:



1. Parents first. Parents should focus on their own retirement planning first. Ensuring their own financial security will benefit the whole family.

2. Set goals. Parents of young children with neuromuscular disease can prepare a "letter of intent," a non-legally binding document that lays the groundwork for the child's future well-being. It covers everything from benefits received and financial goals to medical history and daily schedule.

3. Build a team. Your team should include a financial advisor, accountant, and lawyer. You may also consult with close relatives or trusted friends, and it's helpful to talk to families in similar situations. "There's no magic solution to these challenges," says Jonathan Greeson, CFP, a financial advisor living with SMA. "The key is to realize we aren't alone — it's a team effort."

"Part of financial planning is making sure we protect an individual's eligibility for government benefits," Cynthia says. "If you don't plan, you may unintentionally disqualify the person for these benefits, which are a lifeline for medical services, personal attendant care, personal care services, equipment needs, and more."

Programs such as the Individual Development Account (IDA), offered by the Social Security Administration, help people with lower incomes grow their assets and achieve financial stability. IDAs can be used to pay for education, start a business, or purchase assistive technology. In many states, every dollar an individual puts into their IDA is matched by the state's Temporary Assistance for Needy Families (TANF) program or other special funds. In exchange for the matching dollars, the IDA account holder must follow certain rules, such as making regular contributions to the account or taking free classes on money management.

Employer benefit programs

Benefits offered by employers may be useful tools for budgeting income and care needs and retirement planning. These options include long-term disability insurance, long-term care insurance, and life insurance. A company retirement plan may offer early retirement for rollovers, loans, or

CHOOSING A SAVINGS PROGRAM

ABLE Account	Individual Development Account (IDA)	Roth IRA
WHAT IS IT?		
A savings plan that covers qualified disability-related expenses, such as education, housing, and transportation.	A savings program to help adults under a certain income level save money, purchase assets, and build financial skills.	An individual retirement account, funded with post-tax contributions, that allows certain types of withdrawals on a tax-free basis.
EXPERTS SAY		
 <p>"It's a wonderful way to save money because it allows people to manage their own resources." —Susan Tachau, Pennsylvania Assistive Technology Foundation</p>	<p>"IDAs provide an opportunity to save money with a match, so your money will go further." —Susan Tachau</p> 	<p>"Roth IRAs allow flexibility to distribute the funds over a lifetime or all at one time without a large tax bill when the funds are needed." —Alexandria Nadworny, CFP, CTFA, Special Needs Financial Planning, Affinia Financial Group</p>
DOLLARS AND CENTS		
The allowable annual contribution is \$15,000. Total ABLE savings is capped between \$235,000 and \$529,000, depending on your state.	Individual funds contributed are matched, often dollar-for-dollar, depending on the state and program rules.	Individuals making less than \$140,000 and married couples earning less than \$208,000 can contribute to Roth IRAs. The annual contribution limit for 2021 is \$6,000. People 50 and older may deposit up to \$7,000.
FRIENDLY REMINDER		
 <p>To qualify, disability onset must have occurred before age 26.</p>	<p>Account holders must follow certain rules, such as making regular contributions to the account or taking free classes on money management.</p>	<p>Money can be drawn from a Roth IRA once the account has been owned for five years, or if the account holder is 59 or older.</p>
HOT TIP		
Family and friends can contribute directly to an individual's ABLE account, avoiding tax obligations for the recipient. Most ABLE programs allow out-of-state residents to open accounts, as well.	Individual and state contributions do not count as income or resources, so the IDA will not cause a reduction in Supplemental Security Income (SSI).	There are no restrictions on how Roth IRA money can be used.
Learn more: ablenrc.org	Learn more: prosperitynow.org/map/idas	Learn more: irs.gov/retirement-plans/roth-iras



Cynthia Haddad co-founded a special needs financial planning practice.

distributions. Some plans waive the 10% penalty when early withdrawal is made because of disability.

Money can be set aside for medical expenses and other qualifying needs through flexible spending accounts (FSAs) or health savings accounts (HSAs), which accompany high-deductible health plans. Money

saved into these accounts is taken out of the payroll check before taxes.

Cynthia also points out that some life insurance policies offer riders for early access, or a “disability waiver rider” option, allowing the holder to stop making premium payments without losing death benefit coverage. Review your policy’s options with your insurance provider or a financial advisor.

Individual retirement accounts

Adults who are earning an income might consider setting up a Roth IRA, an individual retirement account that allows certain types of withdrawals on a tax-free basis. Unlike the traditional IRA, which is funded with pretax contributions, the Roth IRA is established with money that has already been taxed. It offers flexibility, allowing contributions with earned income at any age and setting no minimum distribution requirements.

With documentation of a disability, it might be possible to take funds out of a Roth IRA before the age of 59½. The Roth IRA also may be a good option for funding a special needs trust.

Estate planning

Parents can make financial provisions for children of all ages

through a special needs trust, ensuring that assets will be available in the future. A third-party special needs trust is set up and funded by someone on behalf of the disabled person. Jonathan Greeson, CFP, a financial advisor living with spinal



Jonathan Greeson is a financial advisor living with SMA.

muscular atrophy (SMA), says the special needs trust his parents established on his behalf provides an inheritance for him while protecting benefits he currently receives.

“It also protects my parents by allowing them to decrease their assets for Medicaid planning purposes in the event that they need to go to an assisted living facility,” Jonathan says.

A first-party special needs trust is established by the disabled individual using their own funds. Upon their death, the government can get paid back (claw back) for any public services the beneficiary received. Another type, the pooled special needs trust, is funded through a charitable entity.

Monique Castillo, a financial advisor

at Higher Ground

Financial Services, says a special needs trust can work well in combination with tools such as an ABLE account.

“The ABLE account has more immediate access, while the special needs trust requires planning and timing to access,” she says. “The ABLE account can be used more actively to round out a person’s life, while the special needs trust can be a great receptacle for a larger inheritance they might receive. ABLE accounts and special needs trusts are very different but complementary tools that can really help in planning for the future.”

Don’t wait

Time is everyone’s greatest investment tool. Whatever your situation, it’s important to start financial planning as soon as possible.

“When we wait to start planning, we lose that much time,” says financial advisor Jonathan. “Especially with the medical advances we have today, those of us with disabilities can start planning for a longer life. My parents were told I would die at 2 years old, but now I’m 38. It’s hard to imagine where we would be if they hadn’t planned with the hope that we would make it this far.” 

REAL STORIES

Learn how some members of our community are coping with financial impacts of the COVID-19 pandemic in “Creativity and Adaptability” at mda.org/quest.

Karen Doss Bowman is a freelance writer and editor living with progressive muscular atrophy, a subset of ALS, in Bridgewater, Va.



Monique Castillo is a financial advisor who works with special needs clients.

THIS MOMENT

L COMES
FROM WITHIN

ASHLEY // AGE 7

LATER-ONSET SMA, TREATED WITH SPINRAZA



NICOLE // AGE 45

LATER-ONSET SMA, TREATED WITH SPINRAZA

Individual results may vary based on several factors, including severity of disease, initiation of treatment, and duration of therapy.

Victories are personal for the **11,000+**
who have been treated with SPINRAZA worldwide.*

For US individuals taking SPINRAZA:

40%

>40% of patients taking SPINRAZA are adults[§]

3-80
DAYS YEARS

Has treated SMA in patients 3 days[†] to 80 years old^{‡§}

85%

>85% of patients who started SPINRAZA remain on treatment[§]

*Based on commercial patients, early access patients, and clinical trial participants through December 2020.

[†]Includes clinical trial patients.

[‡]Clinical studies of SPINRAZA did not include sufficient numbers of subjects aged 65 and over to determine whether they respond differently from younger patients.

Clinical studies of SPINRAZA included patients from 3 days to 16 years of age at first dose.

[§]Based on commercial patients in the US (including Puerto Rico) through December 2020.

INDICATION

SPINRAZA® (nusinersen) is a prescription medicine used to treat spinal muscular atrophy (SMA) in pediatric and adult patients.

IMPORTANT SAFETY INFORMATION

Increased risk of bleeding complications has been observed after administration of similar medicines. Your healthcare provider should perform blood tests before you start treatment with SPINRAZA and before each dose to monitor for signs of these risks. Seek medical attention if unexpected bleeding occurs.

Increased risk of kidney damage, including potentially fatal acute inflammation of the kidney, has been observed after administration of similar medicines. Your healthcare provider should perform urine testing before you start treatment with SPINRAZA and before each dose to monitor for signs of this risk.

The most common side effects of SPINRAZA include lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome.

These are not all of the possible side effects of SPINRAZA. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Before taking SPINRAZA, tell your healthcare provider if you are pregnant or plan to become pregnant.

Please see full Prescribing Information on SPINRAZA.com.

This information is not intended to replace discussions with your healthcare provider.

**BYRON // AGE 15**

LATER-ONSET SMA, TREATED WITH SPINRAZA



Individual results may vary based on several factors, including severity of disease, initiation of treatment, and duration of therapy.

Learn more at SPINRAZA.com

IMPORTANT FACTS ABOUT SPINRAZA® (nusinersen)

USES

SPINRAZA is a prescription medicine used to treat spinal muscular atrophy (SMA) in pediatric and adult patients.

WARNINGS

Increased risk of bleeding complications has been observed after administration of similar medicines. Your healthcare provider should perform blood tests before you start treatment with SPINRAZA and before each dose to monitor for signs of these risks. Seek medical attention if unexpected bleeding occurs.

Increased risk of kidney damage, including potentially fatal acute inflammation of the kidney, has been observed after administration of similar medicines. Your healthcare provider should perform urine testing before you start treatment with SPINRAZA and before each dose to monitor for signs of this risk.

COMMON SIDE EFFECTS

- **The most common side effects of SPINRAZA include** lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome (headache related to the intrathecal procedure).
- Serious side effects of complete or partial collapse of a lung or lobe of a lung have been reported.

Talk to your healthcare provider about any side effect that bothers you or that does not go away.

OTHER INFORMATION

SPINRAZA is a medication that should be administered as an injection into the lower back (a procedure called intrathecal injection) by, or under the direction of, an experienced healthcare professional.

Before taking SPINRAZA, tell your healthcare provider if you are pregnant or plan to become pregnant.

QUESTIONS?

The risk information provided here is not comprehensive. To learn more, talk about SPINRAZA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at www.SPINRAZA.com or 1-844-4SPINRAZA (1-844-477-4672).

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Biogen, Cambridge, MA 02142



Affordable Accessibility

at Home or On the Go

*Wondering how you can manage home or vehicle modifications?
Start with these steps*

BY ELIZABETH MILLARD



Whether converting a van for wheelchair access, modifying a shower, or widening doorways, maximizing accessibility is at the top of the to-do list for many individuals and families living with neuromuscular disease. However, the cost and the difficulty of planning these changes keep many people from checking those items off their list.

"When you're making home or vehicle changes, it can add up quickly and be a financial strain in many cases," says occupational therapist Brittany Ferri, OTR/L, founder of Simplicity of Health in Rochester, NY. "Fortunately, many families find that there's help out there and resources that can make their investment go further than they might think."

Not sure where to look or how to get started? Brittany and other experts suggest these steps.

Assess your needs

When determining what you need to spend, consider whether the items on your list are truly necessary — some of them may be nice to have but not worth the expenditure. Talk with your healthcare team before making decisions on modifications.

"When making modifications less costly, it helps to be a bit creative," says Rafael Salazar, OTR/L, owner of Rehab U Practice Solutions in Augusta, Ga. ADA guidelines can give you benchmarks for doorway and ramp dimensions. From there, an occupational or physical therapist can point you toward adaptive equipment that may meet standards and be individualized for you without requiring a total home overhaul.

"Focusing on equipment that can take the place of potential modifications could save you a lot of money when hiring contractors," Rafael says. "For example, you may not need to tear down walls or redo the entire bathroom; maybe you just need to change a doorway or be more strategic with grab bars."

Get expert help

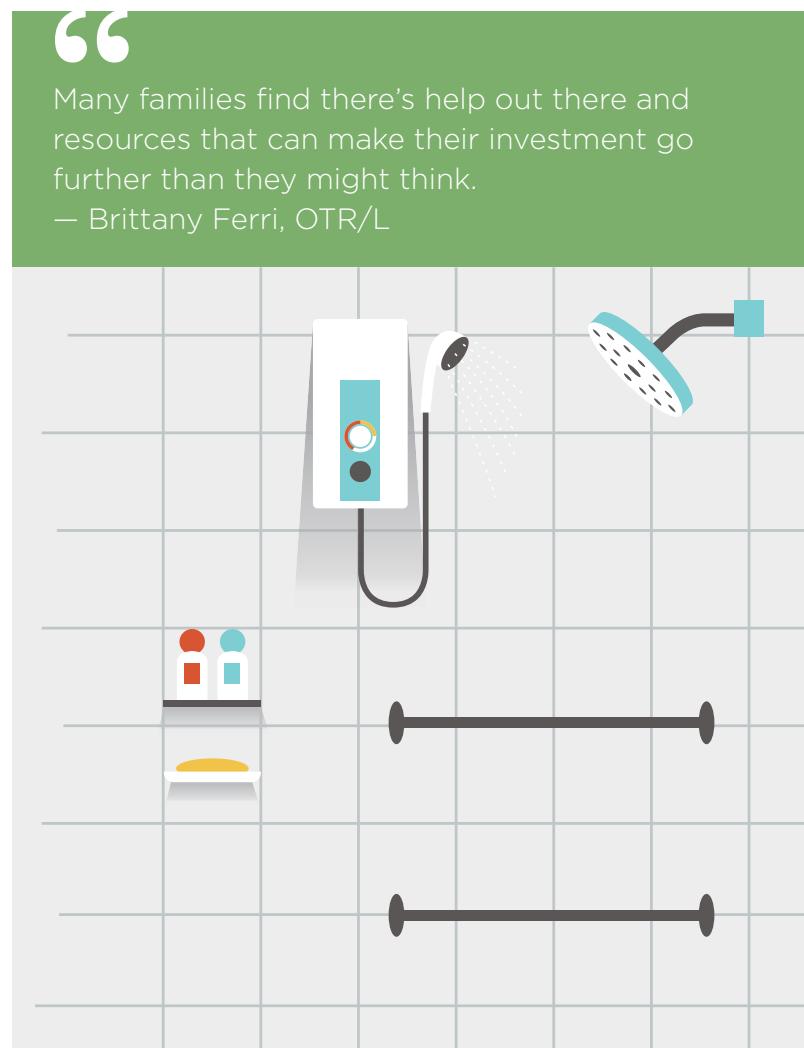
In addition to occupational therapists, other professionals can offer advice on affordable modifications. Having conversations with several contractors could be useful — not just about what they can provide, but also whether they know of any local programs that can assist with financial help.

"Contractors are usually very connected to their communities; they tend to have large networks," says Amber Ward, OTR/L,

occupational therapy coordinator at Atrium Health in North Carolina. "Maybe there's a community resource you didn't think about, such as clubs or programs, and getting the word out can help you get connected to those."

For example, local organizations like the Elks, Rotary, and even the Boy Scouts could result in additional funding or labor. Amber notes that in one case, a client had a ramp installed as part of an Eagle Scout project. If you're doing straightforward home modifications, consider calling vocational schools with carpentry programs — you could be part of an apprenticeship project or learning opportunity.

Another major expert to consult: Your local mobility equipment dealer or a car dealer that has experience with wheelchair-accessible vehicles. States offer various grants and assistance programs for vehicle modifications, and dealers typically know what's available in your area. Plus, you could get a more affordable option through the dealership itself, adds Trevor Jennings, director of partner relations at the National Mobility Equipment Dealers Association.



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Many families find there's help out there and resources that can make their investment go further than they might think.

— Brittany Ferri, OTR/L

STRETCH YOUR BUDGET

Cash grants, rebates, used equipment, and donated labor are all options to make your home or vehicle modification budget cover more. These resources can help.

Disabled Dealer: Online marketplace for used accessible vehicles and other equipment. disableddealer.com



National Mobility Equipment Dealers Association: Offers information on funding and financing, a guide to mobility equipment options, and a dealer locator. nmeda.org

The Mobility Resource: Lists state grants and other resources for financing accessible vehicles. themobilityresource.com/financing-handicap-accessible-vehicles

Rebuilding Together: Helps people build new homes or modify existing ones to make them more accessible. rebuildingtogether.org

Rural Housing Repair Loans and Grants: Funded by the US Department of Agriculture. Recipients must be 62 years or older and from low-income households, and funds may be used to modify existing residences. benefits.gov/benefit/402

The Benevolent and Protective Order of Elks: Offers support at individual and community levels. elks.org



National Resource Center on Supportive Housing and Home Modification: Offers a state directory for finding local resources for home modification financial aid. homemods.org/national-directory

State Grants: Find the Housing and Urban Development (HUD) office in your state to look for grants related to modifications. hud.gov/states

"Nobody knows more about how to finance a vehicle than the people who sell them," he says. "They want to help you get funding, and if you find a dealer who has experience with modifications, that's even better."

For instance, nearly every car manufacturer has a mobility rebate program that can pay for between \$1,000 and \$3,000 in modifications for their vehicles. That amount won't cover a full van conversion, according to Trevor, but if you need hand controls installed or other modest tweaks, the rebate could go a long way toward covering the cost.

Look at larger organizations

In addition to community groups and statewide organizations, Amber suggests thinking big — as in national — when assessing your options. For example, some nonprofits, like

Rebuilding Together or Rural Housing Repair, fund home modifications that enable independent living for families all over the nation. Also, if you're a veteran, talk to the Veteran's Administration about possible options.

Even some national retailers can be useful. If you buy a product at Best Buy, especially smart home products

that need to be set up, talk to the Geek Squad about coming to your home for installation.

"In many cases, simply explaining your situation may be enough to have them waive an installation fee," says occupational therapist Brittany. "Large companies sometimes have programs and policies in place that they don't advertise but will offer if you ask."

The most prevalent advice: Keep asking. As Amber noted about contractors, you simply never know what resources are available until you put the word out. In addition to finding funding sources, keeping this communication going also can be useful for hearing about new mobility products, strategies other people have tried in their own homes and vehicles, gently used equipment or vans that might be coming up for sale, or community programs.

"Making a home and vehicle more accessible is tough enough without adding the stress involved with affording it," Brittany says. "Although you can see these modifications as investments, it's very possible you don't need to do as much as you think to see benefits, and you may not have to cover the whole cost on your own."

FIND RESOURCES

The MDA Resource Center can help guide you to national and local resources for improving accessibility. Contact us at [833-ASK-MDA1](tel:833-ASK-MDA1).

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It's very possible you don't need to do as much as you think to see benefits.

— Brittany Ferri,
OTR/L

Elizabeth Millard is a freelance writer in northern Minnesota.



A Win for Travelers With Wheelchairs

Thanks to collaboration between MDA and other disability advocates, flying with a power wheelchair just got a bit easier.

After learning in November about an American Airlines restriction that prohibited wheelchairs weighing more than 300 pounds on smaller regional flights, MDA and collaborating organizations sent a letter to the airline asking for a reversal. They explained that, while some wheelchairs can be disassembled to meet weight limits, taking them apart can be tedious for travelers and airline personnel, and parts can be lost or damaged — a liability to both the traveler and airline.

Within a few weeks, American Airlines amended the restriction. Now wheelchairs can weigh up to 75 pounds per square foot, which is a limit approved by the Federal Aviation Administration (FAA).

“Everyone — advocate organizations and individual advocates — took action to do this,” says Brittany Hernandez, MDA’s senior director of Policy and Advocacy. “We laid out the issues and said why it was restrictive, and American Airlines reversed course quickly. It’s a win for everyone.”

MDA Brings Together Community Members

The past year has proven the importance of connection, and with the new National Connections Program, MDA is helping members of the neuromuscular disease community build bonds with one another.

Anyone in the community is welcome to join the program operated by MDA’s National Resource Center. Participants specify that they’re open to being connected to others in MDA’s community. They can choose to be matched based on criteria including diagnosis, age, or interests, and they can note their preferred form of communication. MDA Care Center Specialists will help people connect to other individuals living with a neuromuscular disease, caregivers, parents, spouses, or siblings.

Craig Wood and Curt Sweely, who both live with Becker muscular dystrophy (BMD) in Pennsylvania, found meaningful connection through the program. “Having a neuromuscular disease or being the spouse or caregiver of someone with a disease can be challenging,” says Curt’s wife, Mary. “Dealing with a pandemic can make it much worse, leading to isolation or even depression. We are very thankful that Craig accepted [the offer to connect], because he has been a blessing to us. We live in a rural area, so for us, this program works much better than support group meetings.”

Kirk Kemp of Colorado has enjoyed bonding with others who share his diagnosis of facioscapulohumeral muscular dystrophy (FSHD). “Just connecting with others has done a great deal to lift my spirits,” he says.

To sign up for or ask questions about the National Connections Program, reach out to MDA’s Resource Center at [\(833\) ASK-MDA1](tel:(833)ASK-MDA1) or resourcenter@mdausa.org.

A Lucky Donation

What

This annual fundraiser has, over the last 38 years, raised more than \$330 million toward finding a cure for neuromuscular diseases.

Where

More than 20,000 retail locations nationwide are selling paper shamrocks that benefit MDA.

How

Buy a shamrock or make a donation online. Learn more at mda.org/shamrocks.

Disability ... or Superpower?

Our biggest challenges can be our greatest advantages

BY MINDY HENDERSON



Mindy Henderson

When I Google the definition of the word “disability,” this is what is returned: a physical or mental condition that limits a person’s movements, senses, or activities. Period. End of story. That’s all they have to say about that.

But I have my own definition of disability. I define it as an opportunity to learn or heighten skills like positivity, determination, problem-solving, and about a billion others. It is a differentiator. (Who wants to be like everyone else, anyway?) It is an opportunity to do hard things and show the world the ease with which you can pull them off. It is an opportunity to laugh at the surprising and ridiculous things that

occur daily. And it is a tool you can employ — just by existing and being who you are — to impact people around you with lessons on compassion, kindness, and open-mindedness.

I like my definition better.

Early lessons

I was diagnosed with spinal muscular atrophy (SMA) type II when I was 15 months old. In 1975, when that diagnosis was handed to my parents, it was a death sentence. They were told I would not live to be 3 years old. They were told there was no treatment, no cure, and nothing they could do to make it better. But my parents didn’t give up. They continued talking to medical professionals and chased the diagnosis all the way to the Mayo Clinic, where a doctor finally agreed that physical therapy could be helpful. And guess what? It was. Forty-five years later, I’m still here.

Obviously, I was too young to understand what was happening at the time, but I grew up hearing this story. My parents became my first examples of having hope in the face of what seemed like a hopeless situation. The way they approached those early days set the tone for my life. Always, always have hope, and always try, no matter what.

Fast-forward a lot of years. (I was going to say a few years, but who would I be kidding?) I went to college, earned a master’s degree, sang on national television, recorded music, learned to drive a car that looks like NASA built it, got married, and adopted a daughter from a country that initially said my disability made me unfit. Along the way, my progressive disease threw

“

I define [disability] as an opportunity to learn or heighten skills like positivity, determination, problem-solving, and about a billion others. It is a differentiator.



In 2019, Mindy hosted and spoke at a workshop called The Bright Side of Adversity.

me curveballs and tried to make me believe that I could not, in fact, achieve the goal du jour.

But here is what I find interesting: The very thing that made my life and achieving my goals difficult also gave me exactly what I needed to accomplish my goals. Determination. Patience. Humor. Project management and problem-solving skills. An aversion to the word “no.”

Life lessons

Two years ago, I was laid off after a 20-year career in high-tech. I started this career fresh out of college, working in a junior role and ending in a managerial position where I led an international team to develop a new function for my company, then I built the team and managed the department.

Because of my deep experience, I wasn’t worried about getting another job at first. But 10 months later, I was worried. I’d applied for almost 400 jobs and had gotten deep into the interview process for a lot of them.

I can remember the moment — the actual moment — when everything changed.

That day I got news from another company about another job for which I’d thought I was a shoo-in informing me that they had selected a different candidate. I sat in my bathroom looking in the mirror and listening to my thoughts. They weren’t pretty. They were not the positive, optimistic thoughts I was used to, and it scared me.

Then it hit me: I had a choice. In that moment, I could become the very worst version of myself — angry, bitter,

and frustrated, blaming everything and everyone I could think of. Or I could use my skills to write a book about overcoming adversity — while sitting in a big, fat pile of adversity.

I chose the latter. Now, I have a literary agent and a nonfiction book proposal that we are shopping to publishers. Over the years, I did a lot of public speaking on behalf of MDA, and I loved it. Now, I work as a motivational speaker, health/accountability coach, podcaster, and guest contributor to the “Morning Motivations” segment on a local lifestyle TV show. My goal in all my endeavors is to teach others to navigate

their own adversity well, to stop making excuses, and to see possibilities instead of limitations.

Finding a superpower

What happens to you in life need not have the final say unless you let it. We are capable of doing and enduring so

much more than we let ourselves believe. Maybe it’s because we are afraid to acknowledge how much we could actually do if we put our minds to it. But, you see, I believe that a negative mindset can actually be far more disabling than what any wheelchair represents.

In my opinion, it’s not what happens to you in life that matters, but how you respond to it. Don’t like the way the world tries to define you? Write your own definition.

I believe that, if we look through the right lens, our biggest challenges can become our greatest advantages. They may call it a disability. I call it my superpower. 

+TELL YOUR STORY

Sharing your journey can be daunting, but it can make a world of difference to someone going through similar struggles. If you’d like to share your story with Quest, email us at quest@mdausa.org.

Mindy Henderson, 47, is a former MDA State Ambassador for Texas and Florida. She has a daughter in college and lives with her husband, Michael, in Austin, Texas. Connect with her [@mindyhenderspeaks](https://www.instagram.com/mindyhenderspeaks) on Instagram, visit mindyhenderspeaks.com, or listen to her podcast, “The Truth About Things That Suck.”

Happy (Virtual) Camper

Last summer, MDA brought the magic of Summer Camp to kids in the comfort of their homes

For Lily Ruta, 12, the 2020 virtual MDA Summer Camp offered one of her favorite activities — arts and crafts — plus an added bonus: connecting with kids like her all over the country.

"After the first day of camp, Lily was so excited to talk to me about another child she met with CMT [Charcot-Marie-Tooth disease] type 1A who has a mom with CMT, too — same as us — and who wears braces, too. She also found a friend who loves the same book series," says Lily's mom, Melissa, who also lives with CMT.

Lily, who attended in-person Summer Camp in Wisconsin four years in a row, signed up for one of the six weeks of last summer's camp, which was revamped and prepared as an entirely virtual experience using the Microsoft Teams platform. "During the pandemic, we knew we wanted camp to bring the community together, to continue to provide fun and creativity at a time of social isolation," says Alicia Dobosz, MDA's director of Recreation & Camp Programs. "There is no replacement for being together in person, but there was no question that we would work to build something new that could still provide some of the most important elements of camp."

Campers participated in a variety of daily activities, which included things like trying out a virtual escape room, playing round-robin games like hangman, participating in STEM projects, engaging in rounds of trivia, and following recipes to make their own camp snacks. Kids were able to interact in

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I love Summer Camp. I want to be able to help and interact with campers with muscle disease. —Lily



Lily Ruta with the nebula jar craft she made during Summer Camp.

chat rooms and by posting pictures of themselves and their creations in the chat, all moderated by Summer Camp volunteers.

"The counselors really created great opportunities for the kids to do arts and crafts, and Lily was able to spend all day doing it," Melissa says, adding that the virtual version reinforced all the best aspects of Summer Camp.

"Summer Camp has given Lily confidence, the ability to be accepting of others, accepting of herself, have empathy, and self-advocate," Melissa says. "She's definitely come home from camp feeling empowered. She even did a presentation to educate her classmates about CMT."

Thanks to the invaluable lessons she's learned there, Lily plans to be a Summer Camp counselor when she's old enough.

"I love Summer Camp," Lily says. "I want to be able to help and interact with campers with muscle disease." 

+2021 SUMMER CAMP

It's right around the corner. Sign up or learn more at mda.org/virtual-camp.



**TALK TO YOUR DOCTOR
IF YOU HAVE EXPERIENCED
ANY OF THE FOLLOWING:**

- Morning headaches
- Difficulty climbing stairs
- Trouble getting up from a chair
- Unexplained weight loss
- Difficulty breathing—especially while lying down
- Sleep disorders (sleep apnea)
- Excessive daytime fatigue

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*Not an actual patient

Know the Pompe Spectrum
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