momentum

nationalMSsociety.org/momentum

WINTER 2019-20

Awesome aliases

Why did Ardra Shephard name her mobility device?

70

PHOTO BY ALKAN EMIN

National Multiple Sclerosis Society

Laura S., living with relapsing MS

Say **yes** to TECFIDERA—a pill that can **cut MS relapses in half**.

TECFIDERA is a twice-daily pill proven to **work against relapsing multiple sclerosis** (MS) in **3 important ways. TECFIDERA can:**

Cut RELAPSES IN HALF

Delay PROGRESSION OF PHYSICAL DISABILITY

Slow DEVELOPMENT OF BRAIN LESIONS

In a 2-year study, **TECFIDERA reduced risk of relapse by 49%** compared with placebo. People were also **38% less likely to experience physical disability progression**.

What is TECFIDERA?

Tecfidera® (dimethyl fumarate) is a prescription medicine used to treat people with relapsing forms of multiple sclerosis.

Important Safety Information

Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients.

Before taking and while you take TECFIDERA, tell your doctor about any low white blood cell counts or infections or any other medical conditions.

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

- **Allergic reactions**
- **PML, which is a rare brain infection that usually leads to death or severe disability.**
- **Decreases in your white blood cell count.** Your doctor should check your white blood cell count before you take TECFIDERA and from time to time during treatment
- **Liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed.

Tell your doctor right away if you get any symptoms of a liver problem during treatment, including:

- severe tiredness
- loss of appetite
- pain on the right side of your stomach
- dark or brown (tea color) urine
- yellowing of your skin or the white part of your eyes

The most common side effects of TECFIDERA include flushing and stomach problems. These can happen especially at the start of treatment and may decrease over time. Taking TECFIDERA with food may help reduce flushing. Call your doctor if these symptoms bother you or do not go away. Ask your doctor if taking aspirin before taking TECFIDERA may reduce flushing.

These are not all the possible side effects of TECFIDERA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. **For more information go to dailymed.nlm.nih.gov.**

Tell your doctor if you are pregnant or plan to become pregnant, or breastfeeding or plan to breastfeed. It is not known if TECFIDERA will harm your unborn baby or if it passes into your breast milk. Also tell your doctor if you are taking prescription or over-the-counter medicines, vitamins, or herbal supplements. If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

For additional Important Safety Information, please see Patient Information on the following page.

This is not intended to replace discussions with your doctor.

$0 CO PAY **yes** to finding support
You may be eligible for our **$0 Copay Program**.

*Based on number of prescriptions from IMS NPA™ Weekly Data (September 27, 2013 – February 23, 2018).

Are you ready to say **yes** to the possibility of fewer relapses?
Visit **yestoTEC.com** or call **1-844-TalkTec (1-844-825-5832)**.

Tecfidera® (dimethyl fumarate) delayed-release capsules 240 mg

Biogen

Patient Information
TECFIDERA® (tek″ fi de′ rah**)**
(dimethyl fumarate) delayed-release capsules

What is TECFIDERA?
- TECFIDERA is a prescription medicine used to treat people with relapsing forms of multiple sclerosis (MS)
- It is not known if TECFIDERA is safe and effective in children under 18 years of age

Who should not take TECFIDERA?
- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients. See below for a complete list of ingredients.

Before taking and while you take TECFIDERA, tell your doctor if you have or have had:
- low white blood cell counts or an infection
- any other medical conditions

Tell your doctor if you are:
- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby.
  - If you become pregnant while taking TECFIDERA, talk to your doctor about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting www.tecfiderapregnancyregistry.com. The purpose of this registry is to monitor the health of you and your baby.
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your doctor should decide if you will take TECFIDERA or breastfeed.
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

How should I take TECFIDERA?
- Take TECFIDERA exactly as your doctor tells you to take it
- The recommended starting dose is one 120 mg capsule taken by mouth 2 times a day for 7 days
- The recommended dose after 7 days is one 240 mg capsule taken by mouth 2 times a day
- TECFIDERA can be taken with or without food
- Swallow TECFIDERA whole. Do not crush, chew, or sprinkle capsule contents on food.
- Protect TECFIDERA from light. You can do this by storing the capsules in their original container.
- If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

What are the possible side effects of TECFIDERA?
TECFIDERA may cause serious side effects including:
- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)
- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your doctor should do a blood test before you start treatment with TECFIDERA and while on therapy.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your doctor right away if you get any of these symptoms of a liver problem during treatment.
  - severe tiredness
  - loss of appetite
  - pain on the right side of your stomach
  - have dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes

The most common side effects of TECFIDERA include:
- flushing, redness, itching, or rash
- nausea, vomiting, diarrhea, stomach pain, or indigestion
- Flushing and stomach problems are the most common reactions, especially at the start of therapy, and may decrease over time. Taking TECFIDERA with food may help reduce flushing. Call your doctor if you have any of these symptoms and they bother you or do not go away. Ask your doctor if taking aspirin before taking TECFIDERA may reduce flushing.

These are not all the possible side effects of TECFIDERA. Call your doctor for medical advice about side effects.
You may report side effects to FDA at 1-800-FDA-1088. **For more information go to dailymed.nlm.nih.gov.**

General Information about the safe and effective use of TECFIDERA
- Medicines are sometimes prescribed for purposes other than those listed in this Patient Information. Do not use TECFIDERA for a condition for which it was not prescribed. Do not give TECFIDERA to other people, even if they have the same symptoms that you have. It may harm them.
- If you would like more information, talk to your doctor or pharmacist. You can ask your doctor or pharmacist for information about TECFIDERA that is written for healthcare professionals.

What are the ingredients in TECFIDERA?
Active ingredient: dimethyl fumarate
Inactive ingredients: microcrystalline cellulose, silicified microcrystalline cellulose, croscarmellose sodium, talc, silica colloidal silicon dioxide, magnesium stearate, triethyl citrate, methacrylic acid copolymer - Type A, methacrylic acid copolymer dispersion, simethicone (30% emulsion), sodium lauryl sulphate, and polysorbate 80.
Capsule Shell: gelatin, titanium dioxide, FD&C blue 1; brilliant blue FCF, yellow iron oxide and black iron oxide.

Manufactured by: Biogen Inc., Cambridge, MA 02142, www.TECFIDERA.com or call 1-800-456-2255

This Patient Information has been approved by the U.S. Food and Drug Administration. Revised: 1/2017

momentum®

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Vol. 13, No. 1

WE'RE ELIMINATING 2 MILLION PLASTIC BAGS! Read CEO Cyndi Zagieboylo's Forward column to learn more.

The National MS Society is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

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Online exclusives!

Did you know that you can access **Momentum** articles online? In addition, you'll find web-exclusive content such as behind-the-scenes interviews, videos and photo galleries showing real-life stories of people living with MS that will help you live your best life with MS.

Visit **momentummagazineonline.com**.

2019 APEX® AWARDS FOR PUBLICATION EXCELLENCE

Momentum's Winter 2018–2019 Website and App won an Award of Excellence in the category "Campaigns, Programs & Plans (Health & Medical)"

CONTENT MARKETING AWARDS 2019 FINALIST

Momentum's Winter 2018–2019 issue received a 2019 Finalist Award in the category "Nonprofit Publication"

forward

A note from the President & CEO

Momentum readers aren't shy when it comes to expressing opinions about the magazine. We, **Momentum** Editor Jane Hoback and I, receive many comments—many positive and some negative. You tell us what you learned or enjoyed or were inspired to do and you share personal journeys. We also get complaints that the magazine is too positive, too pie in the sky, or that the articles don't reflect your struggles with multiple sclerosis. For some readers, the magazine speaks to them. For others, it doesn't.

Sometimes the same article can spur opposing viewpoints. For example, a story titled "Run the world" (Winter 2018–19) about a woman living with MS named Cheryl Hile who ran marathons on every continent over the course of a year drew both praise and protest.

Leslie Touchton of Pennsylvania wrote: "I've been getting more down over the past year over [my] foot drop, and I was running less because of it. The article and Cheryl Hile's determination made me feel so inspired! It was published at the most perfect time. It is making me get out there and just do it! I wanted to give her a huge thank you for her story."

Yet Dorothy R. Dickhaus of Indiana had a different reaction: "Please quit with the 'I can climb a mountain if I can pay someone to carry me,' 'I can run a marathon' baloney. While it might be reality for one person, this is BS for most people with MS. Shame on you for making us feel ashamed that we cannot all run marathons."

Of course, we don't want to shame anyone. I'm sorry that Dickhaus felt that way, even for a second!

Dorothy's letter (published in the Spring 2019 issue), titled "No more pie-in-the-sky stories" inspired a wave of comments from readers. From Robert Baznik of Pennsylvania: "Stories should be told about people like myself who are in a wheelchair and battle every day just to be able to get out of bed. That's my personal 'marathon' that more people, both with or without MS, should be made aware of."

PHOTO COURTESY OF THE NATIONAL MS SOCIETY

Robert Hickey of Louisiana hit us hard for a story about an active person with MS striving to overcome heat sensitivity to be able to play tennis again. "I rarely even read your publication because all the 'feel-good' BS makes me a little nauseous," Hickey wrote. "I have used a wheelchair exclusively since 2000 and my heat sensitivity is through the roof. I see some guy whining about not being able to play tennis. This is the kind of thing that makes me toss the unread magazine into the trash."

Rose Gentile of Virginia, on the other hand, found the story "super helpful. I just wanted to tell you how much I enjoyed reading every page of your Summer 2019 edition."

We aim for a balance of perspectives and stories in **Momentum**. We want to give everybody a voice. We don't want to shy away from the difficult issues you face. Our goal is to be a place where people connect, know they're being heard and find solutions. We don't always get it right. But we are trying, and we are listening.

How can we strike that balance? What are your ideas?

Let's keep in touch.

Cyndi Zagielboyko

P.S. Some of you have written to object to the plastic bags we used to send out **Momentum** and MSConnection. As you can see with this issue, we've eliminated the plastic bags. Your local MSConnection is attached inside the magazine. Thank you for your input! ■

Let me know your thoughts.
Email me at **cyndi@nmss.org**.

WINTER 2019-20

momentum®

26 Featured story

Christopher Rodney was diagnosed with MS in 2004 and maintains an herb garden to avoid cabin fever during the winter months.

PHOTO BY RIKU FOTO

departments

"Beautiful Decay" by Randy J. Huling, page 75

PHOTO COURTESY OF RANDY J. HULING

features

thrive

Conquering the cold
Despite winter weather, you can still make the most of the season. **26**

Look for these icons throughout **Momentum**.

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PHOTO COURTESY OF ARDRA SHEPHARD

Istock.com: sam thomas

more stories

IN THE NEXT ISSUE

Adoption is an option for people living with MS who want to start families. **PLUS**: Cognitive behavioral therapy can help improve MS symptoms, and advice on how to communicate your needs.

Contact Momentum

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Letters to the editor must include your name, your home state, and a way for our staff to contact you. Letters should be no more than 100 words and may be edited.

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Letters, thoughts and responses

Grateful for what I could do

Thank you for publishing the piece from Nicole Bradley-Bernard, "Four things I wish someone had told me after my MS diagnosis" (Fall 2019). This put me in a reflective mood. Diagnosed with MS in 2004 at age 50, I didn't suffer the loss of a disease-free youth as Nicole had. Truly, MS is a pig of a disease! We have heat sensitivity and mourning of lost capabilities in common. However, because I showed symptoms later in life, I was blessed to be able to play with our boys when they were little, dance with my wife at our son's wedding and pick up some of my first few grand-nieces and nephews. There are about 20 of them now and I can no longer pick up babies while standing. Nicole's words have caused me to reflect on what I was able to do that many others with MS have not. For that, I will always be grateful.

Phil Hoppert, Wisconsin

Four points hit home

Many thanks for this poignant article written by Nicole Bradley-Bernard ("Four things I wish someone had told me after my MS diagnosis," Fall 2019). All four points hit exactly true! I was diagnosed nearly 19 years ago and have never actually come to such finite terms with the disease as Nicole has stated. However, as I read this, it is helping me cope with the pain—or, as she puts it, the monster—taking over my body in a relapse. No one, not even another MS'er, really can feel your pain. It is a lonely, isolated disease that you come to terms with by yourself. That you FIGHT yourself. Continue the fight! My thanks for the article and the continued support.

Adriene Helt, Florida

Devices that can change lives

It was fascinating seeing all the new equipment that will be made available to disabled people that can change their lives ("Dream machines," Fall 2019). I think that manufacturers and local dealers think that disabled people have money. The line I always hear is,

PHOTO COURTESY OF PERMOBIL

"You're on disability. You must have money because you don't have to work." People don't realize that you are unable to work and usually your disability covers living and medical expenses. Lowering the price of things that insurance companies do not cover could generate sales from disabled individuals.

Cynthia Jacobs, North Carolina

Prevalence study is critical

While the statistic of 1 million people living with MS in the United States is eye-popping, the fact that prevalence data has not been studied since 1975 is equally surprising ("Strength in numbers," Fall 2019). MS can often present with nonspecific symptoms, and the lack of disease understanding and reliable diagnostic tools in 1975 makes those numbers unreliable. Two snapshots 40 years apart may suggest a "rise in the prevalence of MS," but, unfortunately, the comparison leaves us with more questions than answers. Thank you to the National MS Society for launching and supporting this critical study. My hope is that funding can be found to analyze MS prevalence on an ongoing basis so that the data can be more useful to researchers and clinicians.

Todd Tuttle, Ohio

Somebody gets it

Thank you for the excellent Summer 2019 edition of **Momentum**. I was diagnosed with relapsing-remitting MS about 30 years ago when I was young in my career and on the fast track with two little kids. Reading **Momentum** keeps me current with progress being made. The main reason for writing is to tell you how much the article and wonderful drawings by Jessie Ace affected me ("Understanding through images"). The old saying that a picture paints a thousand words is so true. I often struggle to explain how I feel at certain times on certain days, but when I saw her pictures, I got a chill because somebody truly gets it! Those pictures were amazing. Perhaps someone without MS still could not imagine what it actually feels like, but the pictures could help. To someone with MS, the pictures say it all, perfectly. Thank you so much.
The other article on volunteering and participating for medical research and trials caught my eye ("Testing ground"). I plan to do this as soon as I retire early in a few short months after a successful career in which MS helped expand my perspective tremendously. Thanks again. Keep up the good work.

Scott Jurek, Indiana

Informative and enjoyable issue

I just wanted to tell you how much I enjoyed reading every page of your Summer 2019 edition. The article on "Acing temperature control" was super helpful. "A big part of the MS puzzle" showcasing the work of Katerina Akassoglou, who was named a winner of the Barancik prize, was awesome. "Finding Neuro," which references words of wisdom from my physician assistant, Lisa Fox at Johns Hopkins, was very informative. In "Into the wind," it was inspiring and wonderful to learn about this annual regatta.
As a sailor since I was a child, I have reached out to volunteer at next year's event. And finally, thank you for introducing me to Jessie Ace, inspiring and so very talented ("Understanding through images"). What a great resource to help people express and connect as we deal with the many twists and turns that are, in my case, CIS and not actual MS.

Rose Gentile, Virginia

Let's hear it! Share your thoughts and comments about this issue's stories.

Email us at **editor@nmss.org**.

Like and comment on our page at **facebook.com/nationalMSsociety**.

Tag your thoughts **@mssociety** using **#Momentum**.

Join discussions at **MSconnection.org**.

Can you guess which superhero Ardra Shephard (pictured) named her mobility device after? Find out on page 70.

PHOTO COURTESY OF ARDRA SHEPHARD

Practical ideas for living well with MS

in the know

On the go

by Ardra Shephard

While you will almost always find a half-eaten candy cane and some gently used Kleenex floating around my winter bag, these are the essentials I'm always packing for the season.

10

Cambridge mask. This military-grade respirator may seem extreme, but if I have to fly during the winter or be anywhere that's likely to have a lot of airborne germs, I make sure this mask comes with me.

Kind bar. I manage my MS with a combination of medication and lifestyle modifications. A fruit bar is a quick pick-me-up when I'm on the go and don't want to reach for a bag of chips.

Red lipstick. A red lip can feel like a bit of armor. Ruby-Woo by MAC is one of my favorites.

Pill carrier. Cuter than any prescription pill bottle, I can keep a day's worth of pills in something that reminds me more of dessert and less of side effects.

Moisturizer. This lotion from L'Occitane is the perfect combo of healing and hydration. The lavender scent reminds me that springtime is coming.

The bag. I wear this belt bag by Free People as a cross-body bag, allowing me to have my hands free to hold on to my rollator or a warm cup of coffee.

Hand sani. It's cold and flu season, and both can wreak havoc on MS. A travel-sized hand sanitizer is a first line of defense against the pseudo-relapse these infections can cause.

Moving to Medicare

The switch from private insurance can be a shock for people who find they have to pay more for their MS medication.

by Brandie Jefferson

ILLUSTRATION BY BRIAN STAUFFER

Tod Gervich was looking forward to his 65th birthday. The self-employed financial adviser had been paying for health insurance for himself and his wife to the tune of about $1,000 per month each, and premiums were increasing annually. His private insurance covered his disease-modifying therapy, Copaxone, to treat his multiple sclerosis, leaving him responsible for a copay of about $50 a month. He thought it would be smooth sailing once Medicare kicked in.

"When I turned 65, I was actually looking forward to it," says Gervich, who lives in Cape Cod in Massachusetts. "'My expenses are going to be reduced substantially,' I told myself. I was rejoicing."

"Well, no" he adds. That didn't happen." Part A and Part B were reasonable for him, he says of the Medicare options that cover inpatient and outpatient costs. "But the way they handle drugs is entirely different."

For people with chronic conditions requiring expensive therapies—such as the disease-modifying therapies often prescribed for MS—switching to Medicare from private insurance can bring sticker shock, or worse. They may be forced to make difficult decisions: They may need to switch or even, in extreme cases, cease their medication due to cost.

How to become eligible for Medicare

Most people can enroll in the federal health insurance program once they turn 65, but others might also be eligible. "If you're an individual who has received Social Security disability benefits for 24 months, you are eligible for Medicare," says Sherry Perry, MS Navigator for the National Multiple Sclerosis Society. People receiving dialysis treatment and those diagnosed with ALS are automatically eligible for Medicare.

There are four parts to Medicare: Part A for inpatient services; Part B for outpatient services; Part C, known as Medicare Advantage (private plans that sometimes include drug coverage); and Part D, prescription drug coverage. Medicare Advantage plans bundle all of the same benefits covered by Medicare A, B and sometimes prescription drugs together in one plan, but also restrict enrollees' choice of doctors, therapists, hospitals and other providers.

Part A is paid for by the Medicare tax most people see in their paychecks. So typically, there are no additional premium costs to those receiving it, although annual deductibles and other cost-sharing amounts can kick in for inpatient services. Part B does require a monthly premium, but enrollment in it can be delayed if a person has other insurance coverage. If someone plans to opt out of Part B, Perry says, "make sure you opt out by following all the rules. If you don't, you could face penalties and risk not having any coverage."

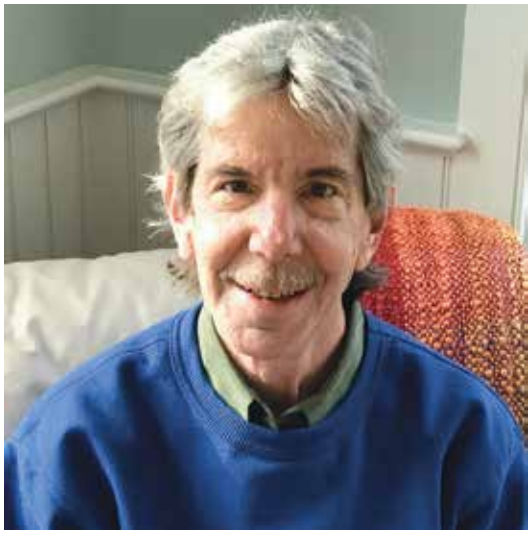


PHOTO COURTESY OF TOD GERVICH

Tod Gervich was shocked by his prescription cost increases when Medicare kicked in.

Then there's Part D, prescription drug benefits.

As an MS Navigator, Perry takes calls from people around the country who have questions about health insurance and concerns about how to pay for their medication. "Concern about cost and confusion about drug prices is one of the top five questions," she says. "'People ask 'How am I supposed to pay for this medication?'"

That's the question Gervich was asking.

When he paid for his own health insurance, his private insurance covered his Copaxone, leaving him with a $50 copay. Last year was different. "I had to spend $7,000 out of pocket," he says. "So all the savings I had got washed away on just that one drug."

In most 2019 Medicare drug plans, people were responsible for paying $3,820 toward the price of their drug before they hit a coverage gap, known as the "donut hole." Until recently, once they hit that coverage gap, people were responsible for the full price of their medications until they had paid up to $5,100.

Changes to coverage

However, changes made to Medicare under the Affordable Care Act resulted in a gradual elimination of the donut hole, scheduled to end for brand-name drugs in 2019 and for generic drugs in 2020. In the future, after the annual deductible has been met, people will be responsible for no more than 25% of the cost of brand-name drugs until they reach the catastrophic coverage phase. But 25% can still be a hefty sum for disease-modifying therapies, whose full cost is estimated at an average price of $80,000 a year.

For 2019, once you have paid $5,100 in prescription drug costs, you will be eligible for what is known as the

In most 2019 Medicare drug plans, people were responsible for paying $3,820 toward the price of their drug before they hit a coverage gap.

In the future, after the annual deductible has been met, people will be responsible for no more than 25% of the cost of brand-name drugs until they reach the catastrophic coverage phase.

ISTOCK.COM: RABBITTI, MIKE ROSIANA

catastrophic coverage phase and will be responsible for no more than 5% of the cost of brand-name drugs.

Perry cited an example of the costs of Copaxone for one Plan D offering from the **Medicare.gov** plan finder tool: A person would pay $2,225 the first month. The next month, $852. At that point, they would have reached the catastrophic coverage phase and would pay $400 a month for the rest of the year. (Perry cautions that these prices can vary from plan to plan.)

If you have reached age 65 and qualify for Medicare but also have coverage from another source (retiree coverage, for example), the rules are different regarding which is primary insurance coverage and secondary insurance coverage.

Choosing wisely can be confusing, to say the least. In some states, there are up to 25 drug plans from which to choose.

"I'm an expert and I still have to look up things," Perry says. "And I've been doing this for over 10 years."

Bridging the gap for medical coverage

Erin Bradshaw is the chief of mission delivery at the Patient Advocate Foundation. She has advice for anyone with a chronic condition who will be transitioning to Medicare.

"I strongly encourage purchasing supplemental insurance during Medicare enrollment," she says. "Having a medical condition will generate expenses. Supplemental insurance, known as Medigap, provides a safety net, adding coverage to pay medical expenses you incur."

Medigap insurance is sold by private companies that will cover some of the costs of Medicare deductibles, copays and coinsurance.

As supplemental insurance is a private insurance policy, companies can determine whether to accept new members. If you have a pre-existing condition, timing is of the essence when it comes to enrolling. "You've only got a small window of time to make those decisions," Bradshaw says.

Your state department of insurance can provide details about the Medigap plans available in your state.

All these options, fees, restrictions and offerings may seem overwhelming, but there are things you can do to make the process easier. One thing not to do, Bradshaw cautions, is compare your plans to others'.

"People will call and say, 'I don't understand. My friend has this plan,'" Bradshaw says. "The same plan may not work well in your situation."

What you can do is educate yourself:

- **Contact the Society's MS Navigators**, who can answer general questions, as well as complex questions about benefits and insurance. The MS Navigators also provide open enrollment services for Medicare beneficiaries. "We focus on educating people about their options so they can make the best choice available," Perry says. You can contact an MS Navigator by calling 800-344-4867, emailing **ContactUsNMSS@nmss.org** or online at **nationalMSsociety.org/navigator**.
- **Contact your local program.** "Every state has a free, one-on-one counseling program," Perry says. "They may not know the ins and outs of multiple sclerosis, but we can provide supplemental materials, and they can call and speak to an MS Navigator." Visit the State Health Insurance Assistance Program at **shiptacenter.org**.
- **Contact the Patient Advocate Foundation.** Find information about case managers, copay relief and financial aid at **patientadvocate.org**. Call 800-532-5274 for case management; 866-512-3861 for copay relief; or 855-824-7941 for information about financial aid.
- **Search for charitable copay organizations.** There are only a few, and they have limited funds. "I tell people to check these charities every

single day either by phone or their website," Perry says. They are open intermittently throughout the year, sometimes for just hours, until their limited funding runs out. Perry suggests trying PAN Fund Finder: **panfoundation.org/index.php/en/patients/fundfinder**.

- **Search for discounts and freebies.** Even though drug companies typically do not offer drug coupons to Medicare participants, some may have free drug programs. "Because of federal regulations, pharmaceutical companies cannot offer the same discounts as others with private insurance may receive," Bradshaw says. But some offer applications to free medication. "Not all of them, but it's worth the effort to try."
- **Involve your friends.** "Ask someone to help take notes and remember questions," Perry suggests, "especially if you're experiencing cognitive symptoms. Having a family member or friend help is always a good idea."
- **Talk to your doctor.** Unfortunately, the prices of these drugs can lead to some tough choices. "I hear it a lot," Perry says. "People making a choice between taking medication or getting food for the month. It's really rough out there."

Gervich knows how rough it is. "I feel punished financially for having a chronic disease," he says. "I've even considered stopping the drug."

This last resort—stopping medication—is one that advocates are fighting hard to eliminate. For now, people can best prepare themselves by seeking financial assistance when possible and, as Gervich has done, becoming familiar with the complex system that is Medicare.

Also, review your plan options every year because the plans make changes annually. MS Navigators can provide Medicare plan searches during fall open enrollment October 15 to December 7.

"Do your homework," Gervich says. "But because all the prices are about the same, there's not much maneuvering room there. So I'd say the biggest step is awareness. Just be sure you know what's coming." ■

Brandie Jefferson is a writer in St. Louis, Missouri. She was diagnosed with MS in 2005.

Learn more about the National Multiple Sclerosis Society's Access to MS Medication Initiative at **ntlms.org/AccessToMeds**.

Find detailed information about Medicare and how to enroll at **medicare.gov**.

Care to comment? Email us at editor@nmss.org.

WITH RELAPSING MS

YOUR GOAL IS TO KEEP

Whether you're new to treatment or ready for a change, talk

*Clinical Trial 1 (TEMSO) included 1,088 people over 2 years. AUBAGIO 14 mg and 7 mg achieved a significant relative risk reduction in relapse rate in TEMSO (31%, 31%) versus placebo. In TEMSO, AUBAGIO 14 mg, AUBAGIO 7 mg, and placebo, the percentage of people who remained free of disability progression were 80%, 78%, and 73% respectively. AUBAGIO 7 mg did not achieve a statistically significant reduction in risk of sustained disability progression. The most common side effects include: headache (18%, 16%, 15%), diarrhea (13%, 14%, 8%) nausea (8%, 11%, 7%), hair thinning or loss (10%, 13%, 5%), and abnormal liver test results (13%, 15%, 9%) for 14 mg, 7 mg, and placebo respectively.

SEE WHAT ONE PILL  ONCE A DAY CAN DO

INDICATION

AUBAGIO® (teriflunomide) is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS).

IMPORTANT SAFETY INFORMATION

DO NOT TAKE AUBAGIO IF YOU:

- **Have severe liver problems. AUBAGIO may cause serious liver problems, which can be life-threatening.** Your risk may be higher if you take other medicines that affect your liver. Your healthcare provider should do blood tests to check your liver within 6 months before you start AUBAGIO and monthly for 6 months after starting AUBAGIO. Tell your healthcare provider right away if you develop any of these symptoms of liver problems: nausea, vomiting, stomach pain, loss of appetite, tiredness, yellowing of your skin or whites of your eyes, or dark urine.
- **Are pregnant. AUBAGIO may harm an unborn baby.** You should have a pregnancy test before starting AUBAGIO. After stopping AUBAGIO, continue to use effective birth control until you have made sure your blood levels of AUBAGIO are lowered. If you become pregnant while taking AUBAGIO or within 2 years after stopping, tell your healthcare provider right away and enroll in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2.
- **Are of childbearing potential and not using effective birth control.**

  It is not known if AUBAGIO passes into breast milk. Your healthcare provider can help you decide if you should take AUBAGIO or breastfeed — you should not do both at the same time.

  If you are a man whose partner plans to become pregnant, you should stop taking AUBAGIO and talk with your healthcare provider about reducing the levels of AUBAGIO in your blood. If your partner does not plan to become pregnant, use effective birth control while taking AUBAGIO.

Do not take AUBAGIO if you have severe liver problems, are pregnant or of childbearing potential and not using effective birth control, have had an allergic reaction to AUBAGIO or leflunomide, or are taking a medicine called leflunomide for rheumatoid arthritis.

Your healthcare provider will run certain tests before you start treatment. Once on AUBAGIO, your healthcare provider will monitor your liver enzyme levels monthly for the first 6 months.

SANOFI GENZYME

Visit **myAUBAGIO.com**

- **Have had an allergic reaction to AUBAGIO or a medicine called leflunomide.**
- **Take a medicine called leflunomide for rheumatoid arthritis.**

AUBAGIO may stay in your blood for up to 2 years after you stop taking it. Your healthcare provider can prescribe a medicine that can remove AUBAGIO from your blood quickly.

Before taking AUBAGIO, talk with your healthcare provider if you have: liver or kidney problems; a fever or infection, or if you are unable to fight infections; numbness or tingling in your hands or feet that is different from your MS symptoms; diabetes; serious skin problems when taking other medicines; breathing problems; or high blood pressure. Your healthcare provider will check your blood cell count and TB test before you start AUBAGIO. Talk with your healthcare provider if you take or are planning to take other medicines (especially medicines for treating cancer or controlling your immune system), vitamins or herbal supplements.

AUBAGIO may cause serious side effects, including: reduced white blood cell count — this may cause you to have more infections; numbness or tingling in your hands or feet that is different from your MS symptoms; allergic reactions, including serious skin problems; breathing problems (new or worsening); and high blood pressure. Patients with low white blood cell count should not receive certain vaccinations during AUBAGIO treatment and 6 months after.

Tell your doctor if you have any side effect that bothers you or does not go away.

The most common side effects when taking AUBAGIO include: headache; diarrhea; nausea; hair thinning or loss; and abnormal liver test results. These are not all the side effects of AUBAGIO. Tell your healthcare provider about any side effect that bothers you.

Consult your healthcare provider if you have questions about your health or any medications you may be taking, including AUBAGIO.

You may report side effects to the FDA at 1-800-FDA-1088.

Please see Medication Guide for AUBAGIO on adjacent pages and full Prescribing Information, including boxed WARNING, available on www.aubagio.com.

PILL ACTUAL SIZE

Once-daily
AUBAGIO®
(teriflunomide) 14 mg tablets

AUBAGIO is available in 14 mg and 7 mg tablets.

Medication Guide **Rx Only**
AUBAGIO (*oh-BAH-gee-oh*)
(teriflunomide)
tablets

Read this Medication Guide before you start using AUBAGIO and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is the most important information I should know about AUBAGIO?

AUBAGIO may cause serious side effects, including:

- **Liver problems:** AUBAGIO may cause serious liver problems that may lead to death**.** Your risk of liver problems may be higher if you take other medicines that also affect your liver. Your doctor should do blood tests to check your liver:
  - within 6 months before you start taking AUBAGIO
  - 1 time a month for 6 months after you start taking AUBAGIO

  Call your doctor right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - loss of appetite
  - tiredness
  - your skin or the whites of your eyes turn yellow
  - dark urine
- **Harm to your unborn baby:** AUBAGIO may cause harm to your unborn baby. Do not take AUBAGIO if you are pregnant. Do not take AUBAGIO unless you are using effective birth control.
  - If you are a female, you should have a pregnancy test before you start taking AUBAGIO. Use effective birth control during your treatment with AUBAGIO.
  - After stopping AUBAGIO, continue using effective birth control until you have blood tests to make sure your blood levels of AUBAGIO are low enough. If you become pregnant while taking AUBAGIO or within 2 years after you stop taking it, tell your doctor right away.
  - **AUBAGIO Pregnancy Registry.** If you become pregnant while taking AUBAGIO or during the 2 years after you stop taking AUBAGIO, talk to your doctor about enrolling in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2. The purpose of this registry is to collect information about your health and your baby's health.
  - **For men taking AUBAGIO:**
    - If your female partner plans to become pregnant, you should stop taking AUBAGIO and ask your doctor how to quickly lower the levels of AUBAGIO in your blood.
    - If your female partner does not plan to become pregnant, you and your female partner should use effective birth control during your treatment with AUBAGIO. AUBAGIO remains in your blood after you stop taking it, so continue using effective birth control until AUBAGIO blood levels have been checked and they are low enough.

AUBAGIO may stay in your blood for up to 2 years after you stop taking it. Your doctor can prescribe a medicine to help lower your blood levels of AUBAGIO more quickly. Talk to your doctor if you want more information about this.

What is AUBAGIO?

AUBAGIO is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS). AUBAGIO can decrease the number of MS flare-ups (relapses). AUBAGIO does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if AUBAGIO is safe and effective in children.

Who should not take AUBAGIO?

Do not take AUBAGIO if you:

- have had an allergic reaction to AUBAGIO or a medicine called leflunomide
- have severe liver problems
- are pregnant or are of childbearing age and not using effective birth control
- take a medicine called leflunomide

What should I tell my doctor before taking AUBAGIO?

Before you take AUBAGIO, tell your doctor if you:

- have liver or kidney problems
- have a fever or infection, or you are unable to fight infections
- have numbness or tingling in your hands or feet that is different from your MS symptoms
- have diabetes
- have had serious skin problems when taking other medicines
- have breathing problems
- have high blood pressure
- are breastfeeding or plan to breastfeed. It is not known if AUBAGIO passes into your breast milk. You and your doctor should decide if you will take AUBAGIO or breastfeed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal supplements**.** Using AUBAGIO and other medicines may affect each other causing serious side effects. AUBAGIO may affect the way other medicines work, and other medicines may affect how AUBAGIO works.

Especially tell your doctor if you take medicines that could raise your chance of getting infections, including medicines used to treat cancer or to control your immune system.

Ask your doctor or pharmacist for a list of these medicines if you are not sure.

Know the medicines you take. Keep a list of them to show your doctor or pharmacist when you get a new medicine.

How should I take AUBAGIO?

- Take AUBAGIO exactly as your doctor tells you to take it.
- Take AUBAGIO 1 time each day.
- Take AUBAGIO with or without food.

What are possible side effects of AUBAGIO?

AUBAGIO may cause serious side effects, including:

- See *"***What is the most important information I should know about AUBAGIO?***"*
- **decreases in your white blood cell count.** Your white blood cell counts should be checked before you start taking AUBAGIO. When you have a low white blood cell count you:
  - **may have more frequent infections.** You should have a skin test for TB (tuberculosis) before you start taking AUBAGIO. Tell your doctor if you have any of these symptoms of an infection:
    - fever
    - tiredness
    - body aches
    - chills
    - nausea
    - vomiting
  - **should not receive certain vaccinations during your treatment** with AUBAGIO and for 6 months after your treatment with AUBAGIO ends.
- **numbness or tingling in your hands or feet that is different from your MS symptoms.** You have a greater chance of getting peripheral neuropathy if you:
  - are over 60 years of age
  - take certain medicines that affect your nervous system
  - have diabetes

  Tell your doctor if you have numbness or tingling in your hands or feet that is different from your MS.

- **Allergic reactions, including serious skin problems.** Tell your doctor if you have difficulty breathing, itching, swelling on any part of your body including in your lips, eyes, throat or tongue, or any skin problems such as rash or redness and peeling.
- **new or worsening breathing problems.** Tell your doctor if you have shortness of breath or coughing with or without fever.
- **high blood pressure.** Your doctor should check your blood pressure before you start taking AUBAGIO and while you are taking AUBAGIO.

The most common side effects of AUBAGIO include:

- headache
- diarrhea
- nausea
- hair thinning or loss (alopecia)
- increases in the results of blood tests to check your liver function

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AUBAGIO. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-332-1088.

How should I store AUBAGIO?

- Store AUBAGIO at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep AUBAGIO and all medicines out of reach of children.

General information about the safe and effective use of AUBAGIO.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AUBAGIO for a condition for which it was not prescribed. Do not give AUBAGIO to other people, even if they have the same symptoms you have. It may harm them.

This Medication Guide summarizes the most important information about AUBAGIO. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about AUBAGIO that is written for healthcare professionals.

For more information, go to www.aubagio.com or call Genzyme Medical Information Services at 1-800-745-4447, option 2.

What are the ingredients in AUBAGIO?

Active ingredient: teriflunomide

Inactive ingredients in 7 mg and 14 mg tablets: lactose monohydrate, corn starch, hydroxypropyl cellulose, microcrystalline cellulose, sodium starch glycolate, magnesium stearate, hypromellose, titanium dioxide, talc, polyethylene glycol and indigo carmine aluminum lake.

In addition, the 7 mg tablets also contain iron oxide yellow.

This Medication Guide has been approved by the U.S. Food and Drug Administration.

Genzyme Corporation
Cambridge, MA 02142
A SANOFI COMPANY

March 2019

TER-MG-SA-MAR19

Connected to care

Remote rehab and exercise programs serve people with MS regardless of location, schedule or mobility.

by Matt Alderton

Convenience, comfort and quality are benefits provided to people with MS using telefitness.

Although she isn't a physicist, Susie Keith lives her life according to Newton's first law of motion: An object at rest stays at rest, while an object in motion stays in motion.

"I've always known how important exercise is," says Keith, 62, of Omaha, Nebraska, who fills her free time with activities like weightlifting, swimming and yoga. "The Lord blessed me with this body. If I just lay around not taking care of it, it's not going to stay healthy."

Staying healthy is especially important—and difficult—for Keith because she has Type 1 diabetes and was diagnosed with multiple sclerosis when she was 19. During 13 subsequent years spent in and out of exacerbations, her most pronounced MS symptom was her stiff, lumbering walk.

"I got better, but my left foot and ankle were never quite right," says Keith, whose gait eventually improved with the help of a physical therapist. That is, until she broke her foot in 2015, at which point she had to rely on a rollator (a walker with wheels) and lost confidence in her ability to walk.

Literally and figuratively, she found her footing again nine months later at Omaha's MSforward, a nonprofit gym for people with MS, where a combination of coaching and community had her walking independently within six months—until she experienced a seizure.

"For three months I couldn't drive and had


ALEKSANDR_PETRUNOVSKYI, AJ_WATT

to stay home," recalls Keith, who was determined to stay active. Her saving grace: MSforward provides a telefitness program where participants can join remote group exercise classes led by founder and owner Daryl Kucera, who also has MS. Five times a week, he livestreams personalized, MS-specific physical training to participants via their computer, tablet or smartphone.

"I survived those three months at home because of [telefitness]," says Keith, who continues to work out remotely once a week. "I can't say enough how much it's benefited me."

Telehealth advocates say remote exercise and rehabilitation can benefit a lot of people like Keith. Unfortunately, insurance in most cases doesn't cover it, which means programs for now are few and far between. But that's changing thanks to a growing body of research that's gradually making the case that "virtual" is valuable.

Remote rewards

Although exercise and rehabilitation are not identical—exercise is supposed to be ongoing and routine in pursuit of overall physical health, while rehabilitation is finite and targeted to help overcome specific symptoms or challenges—they offer similar benefits when provided remotely to people with MS. These benefits include convenience, comfort and quality.

Convenience is especially important for people who live in rural areas. "We are in a rural state, and it's not uncommon for patients to drive two or three hours each way to see us," says Dr. Gabriel Pardo, director of the Multiple Sclerosis Center of Excellence at the Oklahoma Medical Research Foundation (OMRF)

PHOTOS COURTESY OF SUSIE KEITH

(Left and above) Susie Keith, who was diagnosed with MS when she was 19, knows the benefits of staying active. When she broke her foot and couldn't drive to the gym, she relied on a telefitness program for remote group exercise classes.

in Oklahoma City, where he conducted a successful telerehab trial in 2016. "That may be OK for visiting your neurologist, whom you see once every four to six months. But for physical therapy, you may have two or three visits a week for six to eight weeks."

Commutes also can be challenging for urbanites, particularly those with physical disabilities, visual impairments, extreme fatigue or other limitations. "Even if you live in a large urban center … if you have to use a rolling walker and negotiate transportation, that is a significant hassle," Pardo says. Even if distance and mobility aren't issues, time can be. "There are some people—moms like me, for example—who are busy and can't or won't take time for themselves to do [onsite physical therapy or exercise]," says occupational therapist Tracy Tracy, clinical research coordinator at the Tanner Foundation in Birmingham, Alabama. The foundation is studying the benefits of telerehab for people with MS.

Another consideration is quality of care. "Just finding physical therapists who have the right expertise and experience can be a barrier," Pardo says.

There may be psychosocial benefits to remote rehab and exercise services, too—particularly in the case of remote group exercise programs like those offered by MSforward and Horizon Rehabilitation Centers, another Omaha-based organization that offers telefitness for people with MS. "Not only are we able to create an environment where participants can exercise safely with a professional who understands MS, but we are able to offer a sense of community and understanding between participants," says Lindie Schreiner, a physical therapist assistant at Horizon. "The connections that are made in the class help participants with accountability and mutual support."

Healthy data

Sure, they're convenient. But do remote programs actually work as well as in-person programs? Research suggests some might.

Take Pardo's 2016 trial. Completed over eight weeks, the study of 30 participants with MS compared one group that completed supervised remote physical therapy via videoconferencing twice weekly to another that completed in-person physical therapy, also twice weekly.

"The patients who underwent telerehab performed pretty much the same as the ones who received in-person physical therapy," says Pardo, who evaluated patients' gait, balance and self-reported health. "Our conclusion: Telerehab for most parameters is as beneficial as in-person rehab."

A 2016 study by German researchers found similar benefits for remote exercise: Among 59 people with MS who received physical training via the internet for six months, it observed positive gains in muscle strength, lung function and physical activity.

During a 2017 pilot project, University of Alabama at Birmingham physical therapy professor Robert Motl found that even virtual education can be helpful. He divided 47 people with MS into two groups: a control group and an intervention group. For six months, the latter received behavioral coaching by video chat and education via an e-learning website, the goal of which was learning strategies for increasing physical activity. Compared to the control group, they not only exercised more, but also experienced less fatigue, depression, anxiety and pain, as well as improved quality of life, walking, cognition and body composition.

Motl is part of an effort to gather "the strongest evidence to date" on the effectiveness of telerehab for people with MS. The multiyear "Tele-Exercise and

"We are in a rural state, and it's not uncommon for patients to drive two or three hours each way to see us."

—DR. GABRIEL PARDO

PHOTO COURTESY OF TRACY TRACY

Tracy Tracy, clinical research coordinator at the Tanner Foundation

PHOTO COURTESY OF DR. GABRIEL PARDO

Dr. Gabriel Pardo, director of the Multiple Sclerosis Center of Excellence at the Oklahoma Medical Research Foundation

Multiple Sclerosis," or TEAMS, study will include 820 participants who will receive a tablet preloaded with video exercise routines to follow unsupervised at home, which makes the program more inclusive of rural populations that lack high-speed internet connections.

"We don't have any results yet, but so far we've recruited 516 people out of 820—which tells me that people are actually very interested in this type of program," says Tracy, who is working on the study with Motl.

A systematic review conducted in 2018 by the U.S. Department of Veterans Affairs (VA) Multiple Sclerosis Center of Excellence shows that results span more than just a few studies. Researchers reviewed the results of 28 different studies conducted between 2001 and 2018 and concluded that—despite "a range of outcomes with variable quality"—telehealth overall is "beneficial, cost-effective and satisfactory for patients and providers."

Tele traction

Although the TEAMS study is exploring the potential benefits of unsupervised programs—self-guided, home-based exercise or rehab using recorded videos—the secret ingredient in many remote programs is live video chat with a therapist or trainer who can coach, observe and direct participants in real time.

"With MS, everybody's illness is so different, so a recorded video is not going to address your unique needs," says MSforward's Kucera. "When you're live, you can make the program specific to the individual, not the illness."

But even the most tailored remote programs can have drawbacks. People at home typically have limited equipment, for example, and lack the benefit of a therapist's physical touch.

"[In order to] reinforce quality movement patterns and correct exercise form, tactile or physical cues are most helpful," says Mandy Rohrig, a physical therapist with Schreiner at Horizon Rehabilitation Centers.

Then there's cost. Currently, Medicare does not cover telerehabilitation, although private insurers and Medicaid in some states do. In its most recent analysis, published in 2017, the American Telemedicine Association indicated that while Medicaid plans have some type of coverage, only 26 states reimburse for telerehabilitative services, each with varying degrees of coverage. Because reimbursement is so limited and inconsistent, telerehab programs for people with MS so far consist principally of pilots and trials.

Although participants must pay for them out of pocket, options are greater in the telefitness area, according to Rohrig. In addition to her program at Horizon, which costs $30 per month, and MSforward, which costs $14.95 per month, she cites MS Workouts and My MS Gym as options. Both cost about $30 per month, or $288 per year.

Whether you're interested in rehab or exercise, Schreiner says your neurologist or physical therapist can help you find a remote program that suits you. And if they can't, Rohrig adds, "there are other online exercise programs for yoga, Pilates or seated exercises—just to name a few—that are not specific to people with MS but are still quite valuable."

One thing is certain: More options are just around the corner. "Legislators are taking notice, and policy is catching up," says Shane Chanpimol, a physical therapist at the VA Multiple Sclerosis Center of Excellence, where he is administering a telerehab pilot program for veterans with MS. "I think this trend will accelerate as the benefits become clearer, clinicians become more comfortable using the technology and processes for reimbursement are standardized." ■

Matt Alderton is a Chicago-based writer and editor.

Find more virtual exercise resources at **ntlms.org/Exercise**.

Read more about rehabilitation at **nationalmssociety.org/Treating-MS/Rehabilitation**.

Learn about a clinical trial in telerehab at **ntlms.org/telerehabresearch**.

Find information about MS Centers of Excellence at **ntlms.org/finddoctorsandresources**.

Care to comment? Email us at editor@nmss.org.

The watch (and listen) **list**

Podcasts, videos and blogs about MS are springing up left and right. Here are a few to check out for those days when it's so cold or wet you just don't want to go outside:

■ FOR A RAINY DAY:

yvonnedesousa.com (blog)

myelinandmelanin.com (podcast)

truthbetold.ca/podcasts (podcast)

■ NEW PARENTS:

livinglikeyou.com (blog)

youtube.com/channel/UCX5ytLCAT_lhy5Y5bOzDJFg (YouTube)

trippingthroughtreacle.com/category/spoonie-parenting (blog)

■ COOKING WITH MS:

mssavedmylife.com (blog)

elanaspantry.com (YouTube)

wellandstrongwithms.com (blog)

thrive

Forging a path to your best life

Inside this section: Conquering the cold 26

Conquer the Cold

Despite winter weather, you can still make the most of the season.

by Vicky Uhland

After a searing summer, winter weather can feel like a relief to many people living with multiple sclerosis. The high temperatures that play havoc with demyelinated nerves and lead to a temporary—but often agonizing—worsening of symptoms are no longer a worry.

But before you breathe that cool sigh of relief, beware that winter comes with its own set of woes for people with MS.

"As with everything in MS, symptoms that are impacted by the cold are unique to each person. However, generally speaking, sensory symptoms such as numbness and tingling or pain, spasticity and fatigue are exacerbated by the cold," says Mandy Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska.

Snow and ice can cause problems for people with MS. Snow can disguise uneven surfaces, creating treacherous walking conditions for people with balance issues. It can also make walkers, wheelchairs and scooters difficult to maneuver. And, of course, slipping on ice is a potential peril for everyone.

Humidity also is a concern in winter just as it is in summer. "Rain or snow can have the same effect on MS symptoms as heat, even when it's nice and cool outside," says Herb Karpatkin, a physical therapist and associate professor at Hunter College in New York City.

When you combine all of these elements, it's no wonder that people with MS may choose to stay inside as the temperatures plummet. But winter shut-ins risk cutting themselves off from the activity and socialization that

Christopher Rodney was diagnosed with primary progressive MS in 2004. He maintains an herb garden to help avoid cabin fever during winter when he can't get outdoors as often.

ing

PHOTO BY RIKU FOTO

are vital for staying physically, mentally and emotionally healthy.

This winter, don't get a case of cabin fever. Here's how to get out, get moving and make the most of the season.

Feeling the cold

It's a no-brainer that you need to dress warmly when you go outside in freezing temperatures. But for people with MS, that sounds easier than it might actually be.

For example, people who have sensory issues might not get the physical cues that they're not dressed warmly enough for the weather and are in danger of frostbite.

"I work with one woman who just loves the cold weather because it allows her to walk more," Karpatkin says. "One day when it was 25 or 30 degrees, I saw her walking outside in sandals with no socks. Because she had no sensation in her feet, she couldn't feel that they were ice cold."

Christopher Rodney, who was diagnosed with primary progressive MS in 2004 when he was 35, spent 20 years in Maine as a young man, so he's used to cold weather. But now that he uses a power chair to get around, he's had to make some adjustments when he ventures outside his Freehold, New Jersey, apartment.

"I believe in getting 15 minutes of sunshine every day, so I try to get outside every day the sun is out in the winter," he says. But like Karpatkin's sandal-wearing patient, Rodney says he doesn't feel the cold as much after his diagnosis. "I'll be out thinking it's a beautiful day and not realize I'm cold until I come inside and get warm. So I have to be careful how long I spend outside."

Rodney says because sitting in a chair doesn't generate as much body heat as

People with MS who experience sensory issues might not get the physical cues that they're not dressed warmly enough for the cold weather and may risk getting frostbite.

ISTOCK.COM: JEKA33, SUNNYFROG

Christopher Rodney's power chair can provide stability in snow but can slide on ice. He carries a bag of sand and sprinkles it in front of his chair as he moves.

walking, he makes sure to wear boots with a good tread whenever he goes outside in the winter. "The tread part might sound silly when you're in a chair, but you have to transfer," he says. "And you need the warmth that boots provide."

Karpatkin said sensation issues may also cause people to wear too many clothes and overheat, which, ironically, leads to the symptom exacerbation common with summer weather.

The key is to dress in layers, so you can adjust with the temperature. Those layers should be lightweight, Karpatkin says, because bulky clothing can restrict movement. It also adds weight—and the heavier you are, the more energy you use, making it more difficult to be active in winter weather.

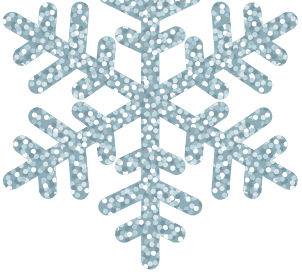
Your inner layer should be thermal socks and underwear, Rohrig says. Then you can add warm outerwear like flannel-lined jeans and a cardigan, or a wool or lightweight down vest or coat. She also suggests wearing scarves, hats or gloves both indoors and outdoors if you're particularly sensitive to cold.

Navigating snow and ice

Rodney says his heavy power chair can provide stability in snow less than 6 inches deep, but it can slide on ice. "If it's icy and you're on ground that's at a slight angle, your chair will go in that direction, and you can't control it. You have to always be aware of the angle of the surface you're traveling on."

Rodney recommends only going outside in winter with a buddy, who can call for assistance if there's a problem. His girlfriend also uses a power chair, but they're careful to travel a safe distance apart. "It can be dangerous to have anyone in front of you when you're in a power chair in case you slide into them," he says.

You can protect yourself from slipping on ice or getting stuck in snow by adding



chains to the wheels of a chair or scooter, but they can be a pain to take on and off. An easier option is to swap out your wheels with all-terrain versions for the winter, just as you replace the regular tires on your car with snow tires.

> **People with MS have worse outcomes from being sedentary than from falling."**
>
> —HERB KARPATKIN

Rodney says one simple solution is to carry a small bag of sand and sprinkle it in front of your wheelchair as you move along. You can also spray windshield deicer (available at auto supply stores or websites) on the path in front of you.

If you go outside on a scooter, it should have a wide wheel radius to provide extra stability, Karpatkin says. He recommends checking with the manufacturer to find out about a scooter's snow or ice capability.

Even if you don't normally use a mobility device, trekking poles, a cane or a walker can be good options when you're walking outside in the winter. You can find traction tools for canes by doing an internet search for "claw crampon for cane," "crampon tips" or "cane ice tip attachments." Because crampons can tear up carpets or floors, Karpatkin recommends having separate indoor and outdoor canes so you don't have to waste time and effort removing the crampons when you go inside.

Karpatkin doesn't recommend crampons or traction devices for shoes because they're easy to trip over—especially for people who have trouble lifting up their feet as they walk. Instead, he suggests buying shoes with a sturdy tread.

Finally, being inactive due to fear of falling on snow or ice may actually be worse for you than the fall itself, Karpatkin says. "People with MS have worse outcomes from being sedentary than from falling."

Of course, that doesn't make the fear any less real. One way to overcome it is to practice gentle falling techniques with a physical therapist, such as rolling to the side, or falling uphill or in a sitting position—along with strategies for getting up after a fall. (The National Multiple Sclerosis Society's "Free From Falls" DVD and brochure also teaches these skills. Visit **ntlms.org/FreeFromFalls**.)

Outdoor activities adapted for MS

Simply going for a winter walk can have significant mental and physical benefits. So can zipping through the scenery in a snowmobile. But if you want to up the ante even more, there are a variety of winter activities that have been adapted for people with MS.

Sit-skis and -snowboards allow people with mobility issues to glide down the slopes or cross-country ski while seated, steering themselves with poles that have miniature skis on the end. These "outrigger" poles require less balance and upper-body strength than standard poles because they slide rather than having to be planted. For extra safety, sit-skiers or -snowboarders can be tethered to an instructor who skis behind them and helps control their speed and turns.

If you like to ice skate, there are walker-type devices available that have plastic nubs on the legs so they can glide along the ice in front of you. There are also adaptive poles for snowshoeing. And there's even sled hockey, in which participants sit upright on a metal sled that has a pair of specialized hockey skates attached to the bottom. The players use adapted hockey

Free ways to stay active indoors

THROW A DANCE PARTY.
Research shows dancing—either standing or seated—can be beneficial for people with MS. One fun option is freeze dancing: Designate someone as a DJ. When he or she stops the music, everyone freezes until the music starts again.

HAVE A SCAVENGER HUNT.
Hide "treasures" around your house or apartment and get a group together to search for them. You'll get exercise walking from room to room, not to mention fun and socialization.

HOST AN INDOOR OLYMPICS.
Invite friends or family to compete in indoor sports like broom hockey, beanball tossing, balloon volleyball, hallway races or whatever else you can dream up.

HULA HOOP.
If you don't have balance issues, try a few rounds with a hula hoop. You can do it in a small space, and it's a great way to strengthen your core.

CLEAN YOUR HOUSE. ▸
You'd be surprised how many calories you expend cleaning your residence or even a single room. And you'll get pleasure from your spick-and-span surroundings. To lessen the drudgery, listen to music or a podcast while cleaning.

REARRANGE THE FURNITURE.
Moving the couch might be a bit taxing, but shifting some chairs or end tables will keep you active and change your perspective.

LEARN A CRAFT.
Sewing, quilting, painting, cooking, playing a musical instrument, building a birdhouse and other creative endeavors keep you physically, mentally and emotionally active.

WALK AND SHOP.
If you live in an area with a mall, there's likely a mall-walking group you can join. Or start your own with your neighbors.

PHONE IN YOUR WORKOUT.
Move around while you're chatting on the phone. Depending on your level of mobility, you can walk, do arm exercises or try a few stretches.

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sticks to propel themselves around the ice and shoot pucks.

To find these and other adaptive winter sports programs in your area at no or minimal cost, visit **disabledsportsusa.org** or **usaparalympics.org**.

Indoor winter physical fun

Jerry Noble, a New Jersey resident who was diagnosed with MS in 2008 at age 40, finds that the combo of MS; arthritis in his knees, feet and hands and cold weather can make his joints and muscles hurt more than usual. "My ability to move is not as good in the winter," he says.

Noble relies on an electric scooter to get around when he's outside and an electric wheelchair inside his apartment. But when ice and snow make him feel unsafe using his scooter, he uses a New Jersey Transit program for people with disabilities called Access Link. Many city transit systems have similar options; call an MS Navigator at 1-800-344-4867 to see what's offered in your area.

Noble uses Access Link to attend church and MS support group meetings, and to visit his local rec center. "I like to sit in the sauna at the rec center. Even just 20 minutes warms me up and alleviates the pain in my joints," he says.

He also does exercises at home, including lifting 1- or 2-pound hand weights and working out on a Cubii Under Desk Elliptical, which is a type of seated treadmill. "I'm also looking to buy a foot massager to stimulate blood flow in my calves," Noble said.

Rodney has a vigorous home workout program as well, including grip exercises and using an exercise ball with handles to strengthen his core.

Rohrig says other home exercise options include online exercise groups like MSforward (**msforward.org**), MS Workouts (**msworkouts.com**) or the MS Gym (**themsgym.com**). "These groups can provide structured exercise, guidance and interaction with others who have MS," she says. You can also find online videos for MS-friendly exercises like yoga, Pilates and seated workouts. As always, check with a physical therapist or other healthcare professional to find out if an exercise video or program is right for you.

"Another often forgotten resource is the community library," Rohrig says. "Often, libraries have exercise videos or DVDs that can be checked out for free."

PHOTO BY RIKU FOTO

Christopher Rodney's home workout program includes grip exercises and an exercise ball to strengthen his core.

Avoiding cabin fever

"January and February are long months. The majority of my time is spent in my

PHOTO BY RIKU FOTO

small apartment," Rodney says. "But I don't look at it as being stuck inside. I look at it as an opportunity to pursue things normal people don't have the time for."

For instance, Rodney, who was a chef for 20 years, spends time freezing, fermenting and pickling the produce he grew in his community garden during the summer. He researches new recipes and bones up on the latest health and nutrition information. He also maintains an indoor herb garden.

"Green in my house is very, very important," Rodney says. "I have an amazing garden 3 feet in front of me."

Noble makes an extra effort to be social during the winter, which helps him feel less shut in. He invites members of his church men's group and choir to his apartment, and chats with his housekeeper when she comes by once a week.

"I also take the opportunity to make phone calls and catch up with people," Noble says. "When you have a disease like MS, you run the risk of getting disconnected from the community."

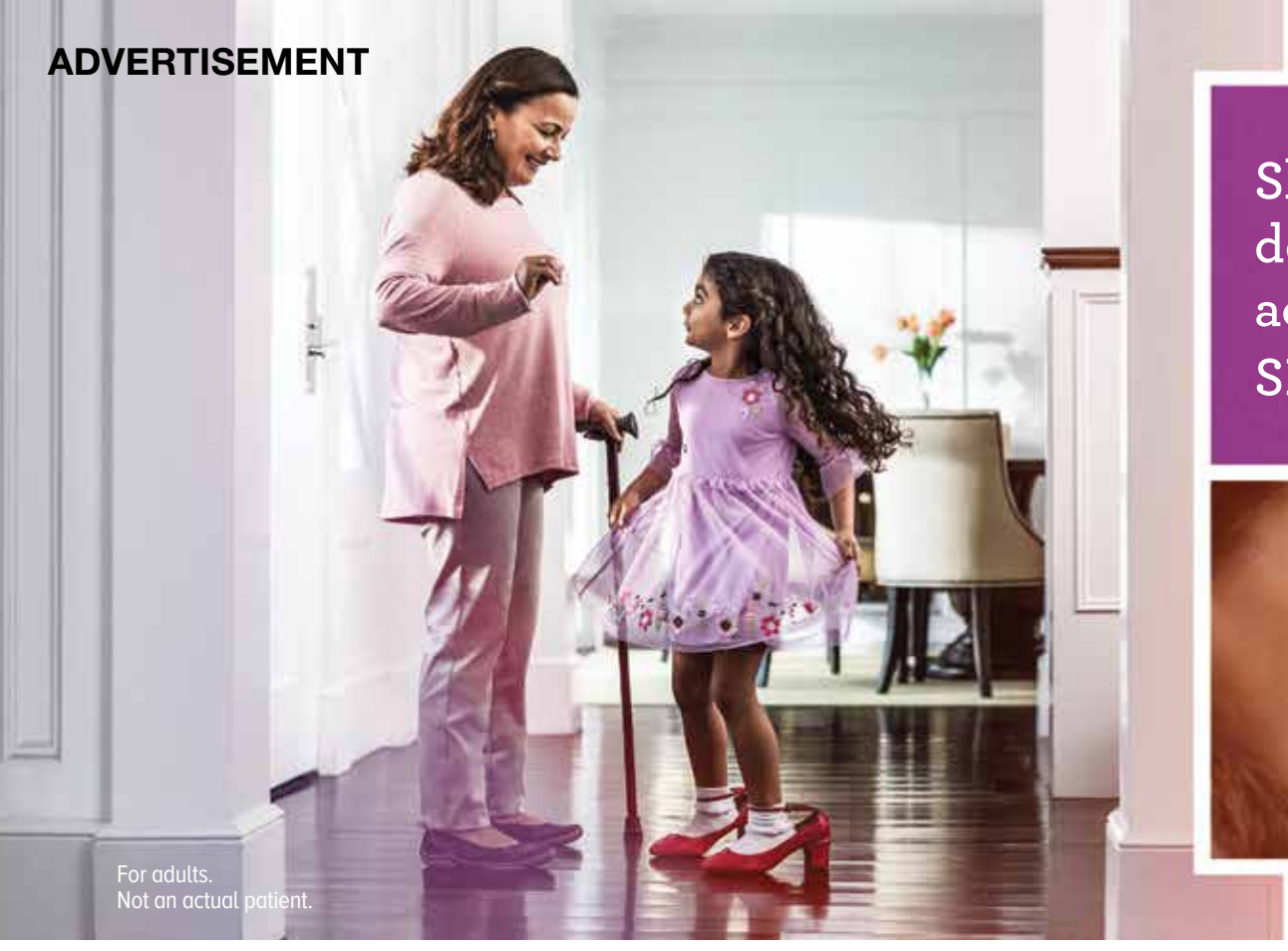
Above all, Rodney says, find ways to avoid the winter doldrums.

"I mitigate the emotional roller coaster of MS through writing poetry or short stories," he says. "Just because my body is stuck in this apartment doesn't mean my mind is. I travel around the world in my head every day." ■

Vicky Uhland is a writer and editor in Lafayette, Colorado.

Learn more about temperature sensitivity at **ntlms.org/TemperatureSensitivity**.

Care to comment? Email us at editor@nmss.org.



What is MAYZENT® (siponimod) tablets?

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults. It is not known if MAYZENT is safe and effective in children.

IMPORTANT SAFETY INFORMATION

Do not take MAYZENT if you:

- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your health care provider. Ask your health care provider if you are not sure.
- have had a heart attack, chest pain called unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

MAYZENT may cause serious side effects, including:

1. **Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT.** MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of MAYZENT.

   During the initial updosing period (4 days for the 1-mg daily dose or 5 days for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the updosing. Call your health care provider if you miss a dose of MAYZENT.

2. **Infections.** MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your health care provider should review a recent blood test of your white blood cells before you start taking MAYZENT.

   Call your health care provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:

   - fever
   - tiredness
   - body aches
   - chills
   - nausea
   - vomiting
   - headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 1 to 4 months after you start taking MAYZENT. Your health care provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

   Call your health care provider right away if you have any of the following: blurriness or shadows in the center of your vision, a blind spot in the center of your vision, sensitivity to light, or unusually colored (tinted) vision.

Before taking MAYZENT, tell your health care provider about all of your medical conditions, including if you:

- have an irregular or abnormal heartbeat
- have a history of stroke or other diseases related to blood vessels in the brain
- have breathing problems, including during your sleep
- have a fever or infection, or you are unable to fight infections due to a disease or are taking medicines that lower your immune system. Tell your health care provider if you have had chickenpox or have received the vaccine for chickenpox. Your health care provider may do a blood test for chickenpox virus. You may need to get the full course of vaccine for chickenpox and then wait 1 month before you start taking MAYZENT.
- have slow heart rate
- have liver problems

means holding on to more moments like this

The first and only pill studied and proven in active SPMS

In the overall study, nearly **3 out of 4 people taking MAYZENT®** showed no 3-month confirmed disability progression.*

Talk to your doctor about holding on to more moments with MAYZENT. Visit **mayzent.com** to learn more.

MAYZENT®
(siponimod) tablets
0.25 mg • 2 mg

SPMS=secondary progressive multiple sclerosis.
The effect of MAYZENT was significant in patients with active SPMS and not considered significant in patients with nonactive SPMS.
*74% of people taking MAYZENT, compared to 68% of people taking placebo.

- have diabetes
- have eye problems, especially an inflammation of the eye called uveitis
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your health care provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
  - If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your health care provider about the best way to feed your baby if you take MAYZENT.

Tell your health care provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements. Especially tell your health care provider if you take medicines to control your heart rhythm (anti-arrhythmics), or blood pressure (antihypertensives), or heart beat (such as calcium channel blockers or beta-blockers); take medicines that affect your immune system, such as beta-interferon or glatiramer acetate, or any of these medicines that you took in the past.

Tell your health care provider if you have recently received a live vaccine. You should avoid receiving **live** vaccines during treatment with MAYZENT. MAYZENT should be stopped 1 week before and for 4 weeks after receiving a live vaccine. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with MAYZENT.

MAYZENT may cause possible side effects, including:

- **increased blood pressure**. Your health care provider should check your blood pressure during treatment with MAYZENT.
- **liver problems.** MAYZENT may cause liver problems. Your health care provider should do blood tests to check your liver before you start taking MAYZENT. Call your health care provider right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - tiredness
  - loss of appetite
  - your skin or the whites of your eyes turn yellow
  - dark urine
- **breathing problems.** Some people who take MAYZENT have shortness of breath. Call your health care provider right away if you have new or worsening breathing problems.
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your health care provider right away if you have any of the following symptoms: sudden severe headache, sudden confusion, sudden loss of vision or other changes in vision, or seizure.
- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your health care provider if you have worsening symptoms of MS after stopping MAYZENT.

The most common side effects of MAYZENT include: headache, high blood pressure (hypertension), and abnormal liver tests.

These are not all of the possible side effects of MAYZENT. Call your doctor for medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see Consumer Brief Summary on following pages.

NOVARTIS

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080

CONSUMER BRIEF SUMMARY

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about MAYZENT® (siponimod) tablets, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.mayzent.com.

What is the most important information I should know about MAYZENT?

1. **MAYZENT may cause serious side effects, including: Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT.** MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of MAYZENT.

   During the initial updosing period (4 days for the 1 mg daily dose or 5 days for the 2 mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the updosing. Call your healthcare provider if you miss a dose of MAYZENT. See **"How should I take MAYZENT?"**

2. **Infections.** MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your healthcare provider should review a recent blood test of your white blood cells before you start taking MAYZENT.

   Call your healthcare provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:

   - fever
   - tiredness
   - body aches
   - chills
   - nausea
   - vomiting
   - headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 1 to 4 months after your start taking MAYZENT. Your healthcare provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

   Call your healthcare provider right away if you have any of the following:

   - blurriness or shadows in the center of your vision
   - a blind spot in the center of your vision
   - sensitivity to light
   - unusually colored (tinted) vision

See "What are possible side effects of MAYZENT?" for more information about side effects.

What is MAYZENT?

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.

It is not known if MAYZENT is safe and effective in children.

Who should not take MAYZENT?

Do not take MAYZENT if you:

- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your healthcare provider. Ask your healthcare provider if you are not sure.
- have had a heart attack, chest pain called unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

What should I tell my healthcare provider before taking MAYZENT?

Before taking MAYZENT, tell your healthcare provider about all of your medical conditions, including if you:

- have an irregular or abnormal heartbeat
- a history of stroke or other diseases related to blood vessels in the brain
- breathing problems, including during your sleep
- a fever or infection, or you are unable to fight infections due to a disease or taking medicines that lower your immune system. Tell your healthcare provider if you have had chicken pox or have received the vaccine for chicken pox. Your healthcare provider may do a blood test for chicken pox virus. You may need to get the full course of vaccine for chicken pox and then wait 1 month before you start taking MAYZENT.
- have slow heart rate
- have liver problems
- have diabetes
- have eye problems, especially an inflammation of the eye called uveitis
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your healthcare provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
  - If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take MAYZENT.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements. Especially tell your healthcare provider if you:

- take medicines to control your heart rhythm (antiarrhythmics), or blood pressure (antihypertensives), or heart beat (such as calcium channel blockers or beta-blockers)
- take medicines that affect your immune system, such as beta-interferon or glatiramer acetate, or any of these medicines that you took in the past
- have recently received a live vaccine. You should avoid receiving live vaccines during treatment with MAYZENT. MAYZENT should be stopped 1 week before and for 4 weeks after receiving a live vaccine. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with MAYZENT.

Know the medicines you take. Keep a list of your medicines with you to show your healthcare provider and pharmacist when you get a new medicine.

Using MAYZENT and other medicines together may affect each other causing serious side effects.

How should I take MAYZENT® (siponimod) tablets?
The daily maintenance dose of MAYZENT is either 1 mg or 2 mg, depending on your CYP2C9 genotype. Ask your healthcare provider if you are not sure about your daily maintenance dose.

Start your treatment with MAYZENT using the following titration schedule:

For the 1 mg daily maintenance dose:	Tablets a day
Day 1	1 x 0.25 mg tablet
Day 2	1 x 0.25 mg tablet
Day 3	2 x 0.25 mg tablet
Day 4	3 x 0.25 mg tablet
Day 5 and every day after	4 x 0.25 mg tablet

For the 2 mg daily maintenance dose, use the starter pack:	Tablets a day
Day 1	1 x 0.25 mg tablet
Day 2	1 x 0.25 mg tablet
Day 3	2 x 0.25 mg tablet
Day 4	3 x 0.25 mg tablet
Day 5	5 x 0.25 mg tablet
Day 6 and every day after	1 x 2 mg tablet

- Take MAYZENT exactly as your healthcare provider tells you. Do not change your dose or stop taking MAYZENT unless your healthcare provider tells you to.
- Take MAYZENT 1 time each day.
- Take MAYZENT with or without food.
- If you miss 1 or more doses of MAYZENT **during** the initial dose titration, you need to restart the medication.
- If you miss a dose of MAYZENT **after** the initial dose-titration, take it as soon as you remember.
- If MAYZENT treatment is stopped for 4 days in a row, treatment has to be restarted with the titration.
- **Do not stop taking MAYZENT without talking with your healthcare provider first.**

What are the possible side effects of MAYZENT?
MAYZENT may cause serious side effects, including:

- **See "What is the most important information I should know about MAYZENT?"**
- **increased blood pressure.** Your healthcare provider should check your blood pressure during treatment with MAYZENT.
- **liver problems.** MAYZENT may cause liver problems. Your healthcare provider should do blood tests to check your liver before you start taking MAYZENT. Call your healthcare provider right away if you have any of the following symptoms of liver problems:
  - o nausea
  - o vomiting
  - o stomach pain
  - o tiredness
  - o loss of appetite
  - o your skin or the whites of your eyes turn yellow
  - o dark urine
- **breathing problems.** Some people who take MAYZENT have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems.
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your healthcare provider right away if you have any of the following symptoms:
  - o sudden severe headache
  - o sudden confusion
  - o sudden loss of vision or other changes in your vision
  - o seizure
- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping MAYZENT.

The most common side effects of MAYZENT include:

- headache
- high blood pressure (hypertension)
- abnormal liver tests

Tell your healthcare provider if you have any side effects that bother you or that do not go away.

These are not all of the possible side effects of MAYZENT. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store MAYZENT?
Before opening:

- MAYZENT 0.25 mg and 2 mg tablets should be stored in a refrigerator between 36°F to 46°F (2°C to 8°C).

After opening:

- MAYZENT 0.25 mg tablets **in the Starter Pack** may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 week after opening.
- MAYZENT 0.25 mg and 2 mg tablets **in bottles** may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 month after opening.

Keep MAYZENT and all medicines out of the reach of children.

General information about the safe and effective use of MAYZENT

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use MAYZENT for a condition for which it was not prescribed. Do not give MAYZENT to other people, even if they have the same symptoms you have. It may harm them. You can ask your pharmacist or healthcare provider for more information about MAYZENT that is written for health professionals.

What are the ingredients in MAYZENT?
Active ingredient: siponimod
Inactive ingredients: colloidal silicon dioxide, crospovidone, glyceryl behenate, lactose monohydrate, microcrystalline cellulose, with a film coating containing iron oxides (black and red iron oxides for the 0.25 mg strength and red and yellow iron oxides for the 2 mg strength), lecithin (soy), polyvinyl alcohol, talc, titanium dioxide, and xanthan gum.

Distributed by: Novartis Pharmaceuticals Corporation, East Hanover, New Jersey 07936
For more information, go to www.pharma.us.novartis.com or call 1-888-669-6682.

solve

Research to stop disease progression, restore lost function and end MS forever

Inside this section

SOCIAL MEDIA ANXIETY

More people are using social media to document their lives with MS, creating a community to share and connect over struggles, hopes, symptoms and advice. While this can be a positive experience, social media also can cause increased anxiety. In fact, this anxiety now has a name: social media anxiety disorder.

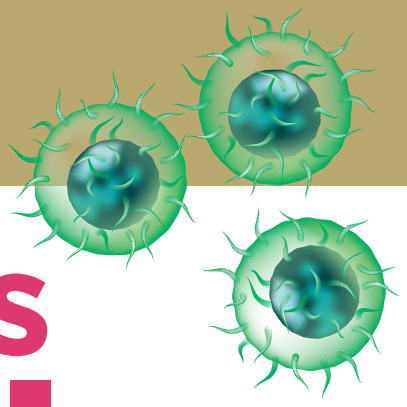
FEAR OF MISSING OUT, OR FOMO

Jealousy or sadness can pop up when you're viewing photos or updates about social events that you weren't invited to or couldn't attend. Curb FOMO with gratitude—focusing on the things you are able to do or currently have that you love—making plans with friends or directly messaging someone to start a meaningful conversation.

Recognizing these feelings and taking steps to balance social media with your offline life can help lessen anxiety and let you connect with others in a positive way.

Find more information about ways to connect online by reading "Unofficial channels" in Connect on page 51.

ISTOCK.COM; SAM THOMAS



Breakthroughs in B cells

Dr. Anne H. Cross receives Dystel Prize for advancing MS research.

by Mary E. King

Dr. Anne H. Cross received the 2019 John Dystel Prize for MS Research for her far-reaching work in several areas of multiple sclerosis: from clarifying the role that B cells play in the disease, to advancing new imaging techniques, to understanding how diet affects MS. Cross is professor of neurology and the Manny and Rosalyn Rosenthal – Dr. John Trotter Multiple Sclerosis Chair in Neuroimmunology at the Washington University School of Medicine in St. Louis.

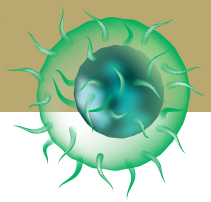
The prize is awarded jointly by the National Multiple Sclerosis Society and the American Academy of Neurology in memory of John Jay Dystel.

"The selection committee of her peers enthusiastically chose Cross on this 25th anniversary of the Dystel Prize," says Bruce Bebo, PhD, the Society's executive vice president of research. "She epitomizes the goal of this prize: to recognize someone who has changed the way we think about

Dr. Anne H. Cross is described by her peers as a giant in the field of MS research.

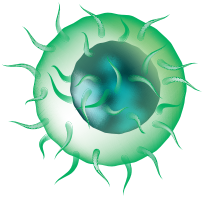
PHOTOS BY WHITNEY CURTIS

ISTOCK.COM: TTMZ



The John Dystel Prize

Each year, the National Multiple Sclerosis Society and the American Academy of Neurology jointly award the John Dystel Prize for MS Research to recognize outstanding contributions to the understanding, treatment or prevention of MS. The late Society Board Member Oscar Dystel and his wife, Marion, established the prize to honor their son, John Jay Dystel, an attorney who died of complications from MS in 2003. 2019 marked the 25th anniversary of the prize.



MS. She has certainly done that, namely for her pioneering work on the role of immune B cells in driving MS immune attacks and her use of new imaging techniques to detect disease activity."

"I think it's notable that the Society recognized Cross' potential early in her career, first with a postdoctoral fellowship and then with a prestigious Harry Weaver Neuroscience Scholar Award [in 1990], given to junior faculty judged to have promising futures," Bebo adds.

Dr. Emmanuelle Waubant, director of the Pediatric MS Center at the University of California San Francisco, who nominated Cross, describes her as a giant in the field of MS research. "Cross' research has always been at the forefront of the field. She very boldly investigated the role of B cells at a time when most other research focused on T cells. She made the key observation that B cells are in fact critical for MS progression."

A passion for her work

"Receiving the John Jay Dystel Prize is an incredible honor. It is probably the biggest honor of my career," Cross says. "To be named as one of a small group of scientists and clinician-researchers for whom I have much respect and admiration is extremely validating and has renewed my motivation to keep working to figure out the puzzle of MS."

Cross' passion for her work is twofold. "I was very interested in immunology and neurology. I tried to combine the two in MS," she says. "My other reason to go into MS is that it is so common and prevalent. I was distressed when, as a resident, I was often called upon to make the diagnosis of MS. But in those days, the 1980s, there were no treatments to alter the long-term course for the better."

And she has a personal stake as well. "I pursued neurology as a career because of several family members, including my only sibling, a younger brother, with neurological diseases," Cross says. "I also had two friends who were diagnosed with MS before I decided to do MS research myself. One was a fellow medical student at the University of Alabama in Birmingham and the other was a co-resident with me at George Washington University in D.C."

B cell focus led to new drug

Asked why she pursued the study of B cells in MS when most researchers were so focused on T cells, Cross replies: "I had a talented postdoctoral fellow named Jeri-Anne Lyons who worked with me in the 1990s. She and I both thought it might be interesting to look more at the role of B cells, precisely because they were, at the time, not being studied much." They discovered that B cells

“I was distressed when, as a resident, I was often called upon to make the diagnosis of MS. But in those days, the 1980s, there were no treatments to alter the long-term course for the better.”

—DR. ANNE H. CROSS

Dr. Anne Cross turned her focus to B cells and made a crucial discovery.

were, in fact, very critical in an animal model of MS, a first step toward defining a role for these immune cells in human MS.

“At approximately the same time, rituximab was being studied as a treatment for B cell malignancies,” Cross says. (Rituximab is a specialized antibody that binds to the surface of B cells and leads to their removal.) “I realized it might be used for treating people with MS to determine whether B cells had a role in MS,“ Cross says. “I began to try to figure out a way to put together a study using it in MS.”

Cross then led the first clinical trial of rituximab in people with MS who did not benefit from other available treatments. Its use in MS at the time was an exciting and innovative approach to MS treatment.

Dr. Peter Calabresi, director of the Johns Hopkins MS Center, supported Cross’ nomination. “Dr. Cross’ phase 2 trial, published in 2010, showed that adding rituximab [to beta interferons or glatiramer acetate] reduced gadolinium-enhancing brain lesions [detected by MRI] in people with MS, foreshadowing the positive phase 3 trial results.” Gadolinium, a contrast agent, helps clinicians identify areas of new inflammation in the brain.

Bebo says this important work also helped lead the way to the development and eventual FDA approval of ocrelizumab (Ocrevus) for primary progressive MS in 2017, and later for relapsing forms of MS.

Additional groundbreaking research

Cross has also pioneered other investigations in MS. She is trying to solve the problem of how to better identify early nerve damage in progressive

MS. "Cross has contributed to the development of new MRI techniques in collaboration with her Washington University colleague and professor of radiology Sheng-Kwei ['Victor'] Song," Waubant says. The Society helped fund this research to detect MS progression before damage can be detected in a clinical exam.

Waubant notes that Cross has also been a pioneer in understanding the effect of diet on MS progression: "She identified how diet can modify the immune response and the progression of EAE, an animal model of MS." Dr. Dennis Bourdette, chair and Roy and Eulalia Swank Family research professor and executive director, Multiple Sclerosis Center Department of Neurology at the Oregon Health & Science University also notes Cross' research in this area. "There is growing interest now in the role that diet may play in treating MS. Dr. Cross was one of the first serious investigators in this field. Her research formed the basis for clinical trials of caloric restriction in MS being conducted at Washington University and elsewhere."

Calabresi calls Cross "a creative, productive and humanistic leader" who has excelled as a clinician educator.

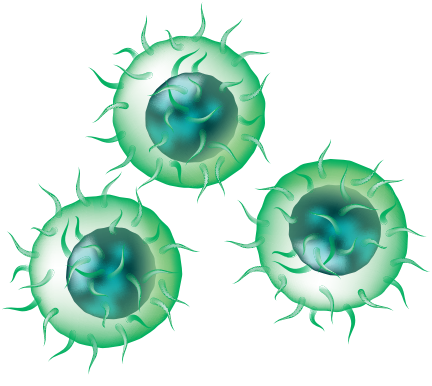
> **"Her outstanding creativity and mentoring skills have allowed her to build a world-class MS center that is now making major contributions..."**
>
> **— DR. PETER CALABRESI**

"In addition to being an outstanding researcher who has made many contributions to the field of MS, her expansive knowledge of MS combined with her outstanding creativity and mentoring skills have allowed her to build a world-class MS center that is now making major contributions to several other unique domains of research," he says.

Future directions

Cross plans to continue her work in neuroimaging in the hopes of finding ways to assess neuropathology in MS without a brain biopsy. "I think this is important because we don't yet have very good treatments for progressive MS," she says. "Part of that is because we don't have good biomarkers to assess progressive MS." Cross also plans to pursue research in the immunology of MS that involves some clever genetic testing. "Together with several colleagues, we are sequencing the genes expressed by invading CNS inflammatory cells, obtained by spinal taps, in people with MS and comparing those to the genes expressed in inflammatory cells in healthy controls and people with other neurological diseases." She will also continue to look at the mechanisms of actions of B cell depleting therapies "in the hope that this will help us better understand the disease process." ■

Mary E. King is a medical writer in Boulder, Colorado.



Learn more about MS research at **nationalmssociety.org/Research**.

Care to comment? Email us at editor@nmss.org.

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Repair and restore

Researchers study ways to reduce neurological symptoms of MS.

by Lori De Milto

Researchers are studying different ways to restore or repair myelin in hopes of developing new treatments for multiple sclerosis.

Myelin is the protective coating around the nerve fibers in the central nervous system, which comprises the brain, spinal cord and the optic (eye) nerve. Cells called oligodendrocytes make myelin. When myelin is damaged, the electrical signals that send messages between your brain and your body slow down or stop, causing neurological symptoms like problems with seeing, thinking, remembering and moving. Doctors and researchers also think that myelin loss makes the underlying nerve fiber (axon) more vulnerable to injury.

Four research teams are trying to stimulate natural myelin repair capabilities and are studying drugs to treat MS and models for myelin repair. "In the initial stages of MS, the body can repair itself. As the disease progresses, that ability fails," says Meredith Hartley, PhD, a National MS Society postdoctoral fellow at Oregon Health & Science University in Portland, Oregon, who is a member of one of the teams.

Dr. Bruce Cree, a neurologist who also has a doctorate in biochemistry and a master's in advanced studies in clinical research, is conducting clinical trials to test therapies in people living with MS and neuromyelitis optica. Cree is the George A. Zimmermann Endowed Professor in Multiple Sclerosis and a professor of clinical neurology at the University of California, San Francisco (UCSF). He is also the clinical research director of the UCSF Weill Institute for Neurosciences.

With support from the National Multiple Sclerosis Society, three other scientists are delving into how myelin is repaired and ways to stimulate that

process. Hartley has a PhD in biological chemistry. Ethan G. Hughes, an assistant professor of cell and developmental biology and the Boettcher Investigator at the University of Colorado School of Medicine in Aurora, Colorado, has a doctorate in neuroscience. Babette Fuss is a professor of anatomy and neurobiology at Virginia Commonwealth University in Richmond, Virginia. Her doctorate is in neurobiology.

Drugs to repair or restore myelin

Cree has been participating in several completed or ongoing research studies of experimental therapies that could help repair or restore myelin. The ReBUILD study, conducted from January 2014 to April 2015, used clemastine, an existing oral antihistamine. This study showed that clemastine promotes oligodendrocyte development and wrapping of myelin. The other studies are testing an experimental drug called elezanumab, given intravenously. UCSF and the Rachleff family supported the study of clemastine, while the pharmaceutical company AbbVie, Inc. is supporting the studies of elezanumab. These are all phase 2 studies in which researchers study a drug's effectiveness and safety.

The ReBUILD study, conducted at UCSF studied 50 people with relapsing-remitting MS who have chronic damage to the optic nerve. Half of the participants received clemastine first and then a placebo. The other half received a placebo first and then clemastine.

Researchers found that clemastine modestly improved the speed of electrical signals in the optic nerve. "The study findings suggest that myelin can be repaired, even following prolonged damage," Cree says. The results were published in Lancet in 2017.

The use of clemastine was based on the work of Jonah Chan, a professor of neurology at UCSF. Chan tested thousands of compounds (ingredients that could be made into drugs) and FDA-approved drugs looking for any that might stimulate myelin repair and restoration. He identified clemastine as a possible treatment. The Society awarded him the first Barancik Prize for Innovation in MS Research in 2013.

Another phase 2 two study of clemastine is underway at UCSF, led by Dr. Ari Green. This study is testing clemastine in people with acute optic neuritis, an inflammation that can lead to vision loss. Vision problems are often the first symptom of MS.

An experimental therapy under study by Cree is elezanumab (ABT-555), a monoclonal antibody that is engineered to target a specific molecule. Studies of elezanumab in lab models showed that it enables axons to regrow and begin to transmit nerve messages again. Elezanumab also reduced inflammation and showed some ability to grow myelin.

A phase 1 safety study of elezanumab conducted by Cree showed that elezanumab did not cause serious side effects or discomfort, or lead to consistent symptom worsening. Twenty people living with MS participated: 18 had relapsing-remitting MS and two had secondary progressive MS. Cree presented results at an American Academy of Neurology meeting in 2018.

Based on the phase 1 safety study, Cree is now conducting two phase 2 studies of elezanumab, one in people with relapsing-remitting MS and the other in people with progressive forms of MS. Both studies compare two different doses of elezanumab to placebo, an inactive, nondrug compound that's designed to look just like elezanumab. In both trials, elezanumab is used as an add-on therapy to existing anti-neuroinflammatory medications that participants already may be taking. "This is very good news for patients because the product has the potential to be useful in both relapsing and progressive forms of MS," Cree says. UCSF is one of dozens of locations in the United States and Canada that are part of these studies.

For more information, visit **ClinicalTrials.gov**:

- Study in relapsing MS
- Study in progressive MS

A new compound and a new model

Under a postdoctoral fellowship from the Society, Hartley is part of a research team at the lab of Thomas Scanlan, PhD, at Oregon Health & Science University. The team has discovered a compound that stimulates myelin repair. Hartley was the lead author on an article with study results published in JCI Insight ("Myelin repair stimulated by CNS-selective thyroid hormone action," April 2019).

PHOTO BY SCOTT SARACENO

PHOTOS COURTESY OF DR. BRUCE CREE, ETHAN G. HUGHES, MEREDITH HARTLEY AND BABETTE FUSS

(Clockwise from top) Dr. Bruce Cree; Ethan G. Hughes, PhD; Meredith Hartley, PhD; Babette Fuss, PhD; and Jonah Chan, PhD, are all researching new approaches to treating MS.

This research tested an orally active thyroid hormone-like drug called sobetirome, discovered in the Scanlan Lab. Thyroid hormone naturally stimulates myelin production in infants and improves myelin repair in models of MS. But high levels of thyroid hormone aren't safe in people.

"We demonstrated that sobetirome can stimulate myelin repair and saw improvements in motor abilities and the amount of myelin," Hartley says. Sobetirome repaired myelin without the potentially severe side effects of high-dose thyroid hormone therapies.

To translate sobetirome from mice to people, Oregon Health & Science University has licensed the technology to Llama Therapeutics Inc., which is currently working on preclinical development. If results are promising, clinical trials will be the next step.

The team has also developed a new lab model for studying myelin repair. The model involves mice genetically engineered to mimic MS. "This model provides opportunities for better studying the effects of myelin repair therapeutics," Hartley says.

Along with Hartley's postdoctoral fellowship, this research was also supported by the National Institutes of Health, the Race to Erase MS and the Oregon Health & Science University Laura Fund for Innovation in Multiple Sclerosis. In 2020, Hartley plans to start a research lab focused on myelination and re-myelination at the University of Kansas, where she'll be an assistant professor of chemistry.

A new way to see myelin repair and test treatments

Hughes and his team are focusing on the brain's cortex, where thinking begins. MS causes cells in the cortex, the outermost layer of the brain, to shrink. This is partly due to destruction of myelin. While oligodendrocytes can repair or make some new myelin, this natural repair process is slow and incomplete.

Under a research grant from the Society, Hughes is using two-photon microscopy to see and study

oligodendrocytes in the brains of mice before and after damage to myelin. Two-photon microscopy uses lasers that produce long wavelength light to see deeper into the brain than other types of microscopy. This produces clear images of individual cells in living animals ("in vivo"). Hughes and his team at the University of Colorado School of Medicine are looking at the myelin repair process as it happens naturally and after the mice receive a behavioral intervention such as learning a new motor skill.

"Our in vivo imaging approach allows us to test interventions in a different manner than has been done before. Now, we can watch how individual cells repair myelin in living animals," Hughes says.

The results of the research grant, which continues through September 2020, may provide new information on the role of oligodendrocytes in myelin repair that other researchers can study. Eventually, this line of research could lead to new therapies to repair or restore myelin. "I'm excited by the possibility that myelin repair could be a therapeutic approach for patients," Hughes says.

The role of cells in myelin repair and restoration

Fuss and her team at Virginia Commonwealth University are focusing on how oligodendrocytes differentiate and form new myelin. Their research is funded by a grant from the Society. They are exploring the potential of a signaling pathway called autotaxin-LPA to promote oligodendrocytes differentiation and restore myelin in MS. In general, a signaling pathway describes a group of molecules within a cell that work together to control one or more cell functions, in this case oligodendrocyte differentiation. Identification and characterization of individual components of such signaling pathways is important, since it has the potential to lead to the development of therapeutic drugs.

Fuss and her team are studying the ability of autotaxin-LPA signaling to promote oligodendrocyte differentiation in a variety of model systems: cultures of oligodendrocytes, the developing zebrafish, and mice in which myelin damage and repair can be investigated in both the absence and presence of autotaxin-LPA signaling. So far, the group was able to demonstrate that myelin repair is attenuated in the absence of autotaxin-LPA signaling, and they were able to identify a set of receptors that are important in activating the autotaxin-LPA signaling pathway in oligodendrocytes.

In its basic definition, a receptor describes a cell surface molecule that interacts with a specific ligand, in this case LPA, to activate cellular responses, which may be different in different cell types. In the case of LPA binding receptors, some receptors have been shown to participate in tumor formation. Thus, Fuss and her team are focusing their research on those receptors that specifically promote oligodendrocyte differentiation without causing adverse effects.

"We hope to be able to stimulate an individual receptor toward a signaling cascade that causes oligodendrocytes to repair myelin without causing negative side effects," says Fuss.

The ultimate goal of this research is to develop a synthesizable ligand that can be used to promote oligodendrocyte differentiation and myelin repair in MS patients. Since responses to individual therapeutic drugs may vary from person to person, Fuss and her team are also studying other ways to stimulate myelin repair and growth. "We need to identify more than one good strategy, since different therapeutic approaches may be needed for different populations of patients," she says. ■

Lori De Milto is a Sicklerville, New Jersey-based freelance writer.

Learn more about repairing what's been lost at **ntlms.org/RestoreResearch**.

Care to comment? Email us at editor@nmss.org.

(CONTINUED FROM PREVIOUS PAGE)

IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

- Slow heart rate, especially after first dose. Adults and children will be monitored by a health care professional for at least 6 hours after the first dose or after a child takes the first dose of 0.5mg of GILENYA when switching from 0.25mg daily dose. Your pulse and blood pressure will be checked hourly. You'll get an ECG before and 6 hours after your first dose. If any heart problems arise or your heart rate is still low, you'll continue to be monitored. If you have any serious side effects, especially those that require treatment with other medicines, or if you have certain types of heart problems, or if you're taking medicines that can affect your heart, you'll be watched overnight. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor, or seek immediate medical attention if you have any symptoms of slow heart rate, such as dizziness, tiredness, feeling like your heart is beating slowly or skipping beats, or chest pain. Symptoms can happen up to 24 hours after the first dose. Call your doctor if you miss 1 or more doses of GILENYA—you may need to repeat the 6-hour monitoring.
- Increased risk of serious infections, some of which could be life threatening and cause death. You should not receive live vaccines during treatment with GILENYA and for 2 months after you stop taking GILENYA. Vaccines may not work as well when given during treatment with GILENYA. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test to check your white blood cells before you start GILENYA. Call your doctor right away if, while taking GILENYA or for 2 months after your last dose, you have fever, tiredness, body aches, chills, nausea, vomiting, or headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion. These may be symptoms of meningitis.
- Progressive multifocal leukoencephalopathy (PML). PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems. Call your doctor right away if you have any new or worsening symptoms of PML that have lasted several days, including changes in your thinking or memory, changes in your vision, decreased strength, problems with balance, weakness on 1 side of your body, loss of coordination in your arms and legs, confusion, or changes in your personality.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. If it happens, macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA, 3 to 4 months after you start GILENYA, and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Swelling and narrowing of the blood vessels in your brain. A condition called PRES (posterior reversible encephalopathy syndrome) has happened rarely in adults taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you experience any symptoms, such as sudden severe headache, sudden confusion, seizures, or sudden loss of vision.
- Liver damage. Your doctor should do blood tests to check your liver before you start GILENYA and periodically during treatment. Call your doctor right away if you have nausea, vomiting, stomach pain, tiredness, loss of appetite, dark urine, or if your skin or the whites of your eyes turn yellow.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Severe worsening of MS after stopping GILENYA. Many people who have worsening of MS symptoms after stopping GILENYA do not return to the level of function that they had before or during treatment with GILENYA. This can also occur in women stopping due to pregnancy or planning a pregnancy. This worsening happens most often within 12 weeks after stopping GILENYA, but can happen later. Do not stop taking GILENYA without talking with your doctor. Tell your doctor if you have worsening symptoms of MS after stopping GILENYA.
- Increases in blood pressure (BP). BP should be monitored during treatment.
- Cancers including basal and Merkel cell carcinoma and melanoma. Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, new darkened area in your skin, a sore that does not heal, or growths on your skin such as a bump that may be shiny, pearly white, skin colored, or pink. While taking GILENYA, limit the amount of time you spend in sunlight and ultraviolet (UV) light as well as use sunscreen with a high sun protection factor and wear protective clothing. Lymphoma has also occurred in patients receiving GILENYA.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. It is not known if GILENYA passes into breast milk. Talk to your doctor about the best way to feed your baby if you take GILENYA. A pregnancy registry is available for women who become pregnant during GILENYA treatment. For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by e-mailing gpr@quintiles.com, or by going to www.gilenyapregnancyregistry.com.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; stroke or mini-stroke; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections due to a disease or are taking medicines that lower your immune system, including corticosteroids, or have taken them in the past; eye problems; diabetes; breathing or liver problems; or uncontrolled high blood pressure. Also tell your doctor if you have had chicken pox or have received the chicken pox vaccine. Your doctor may test for the chicken pox virus, and you may need to get the full course of the chicken pox vaccine and wait 1 month before starting GILENYA. Children 10 years and older should complete their vaccination schedule before starting GILENYA.

If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

The most common side effects with GILENYA were headache, abnormal liver tests, diarrhea, cough, flu, sinusitis, back pain, abdominal pain, and pain in arms or legs.

In the pediatric study:

- The safety in children 10 years and older receiving GILENYA was similar to that seen in adults.
- The rate of seizures was higher in GILENYA-treated patients compared to that of a leading injectable.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088

Please see additional Important Safety Information on previous page.

GILENYA™ (fingolimod) capsules 0.5 mg

Please see Brief Summary of Important Product Information on next pages.

BRIEF SUMMARY

Important Facts About GILENYA® (fingolimod) capsules

The risk information provided here is not comprehensive. If you are the parent of a child who is being treated with GILENYA, the following information applies to your child. This information does not take the place of talking to your doctor about your medical condition or your treatment.

To learn more about GILENYA, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-800-GILENYA or visit www.GILENYA.com.

What is the most important information I should know about GILENYA?

GILENYA may cause serious side effects, including:

1. **Slow heart rate (bradycardia or bradyarrhythmia) when you start taking GILENYA.** GILENYA can cause your heart rate to slow down, especially after you take your first dose. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of GILENYA.

   All adults and children will be observed by a healthcare professional for at least 6 hours after taking their first dose of GILENYA. Children should also be observed by a healthcare professional for at least 6 hours after taking their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose.

   After you take your first dose of GILENYA and after a child takes their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose:

   - Your pulse and blood pressure should be checked every hour.
   - You should be observed by a healthcare professional to see if you have any serious side effects. If your heart rate slows down too much, you may have symptoms such as:
     - dizziness
     - tiredness
     - feeling like your heart is beating slowly or skipping beats
     - chest pain
   - If you have any of the symptoms of slow heart rate, they will usually happen during the first 6 hours after your first dose of GILENYA. Symptoms can happen up to 24 hours after you take your first GILENYA dose.
   - 6 hours after you take your first dose of GILENYA you will have another ECG. If your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be observed.
   - If you have any serious side effects after your first dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. You will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA the next day.
   - If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight after you take your first dose of GILENYA.

   Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA. Call your doctor or go to the nearest hospital emergency room right away if you have any symptoms of a slow heart rate.

   If you miss 1 or more doses of GILENYA, you may need to be observed by a healthcare professional when you take your next dose. Call your doctor if you miss a dose of GILENYA. See **"How should I take GILENYA?"**

2. **Infections.** GILENYA can increase your risk of serious infections that can be life-threatening and cause death. You should not receive live vaccines during treatment with GILENYA and for 2 months after you stop taking GILENYA. Talk to your doctor before you receive a vaccine during treatment and for 2 months after treatment with GILENYA. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with GILENYA.

   GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test to check your white blood cells before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection during treatment with GILENYA and for 2 months after your last dose of GILENYA:

   - fever
   - tiredness
   - body aches
   - chills
   - nausea
   - vomiting
   - headache with fever, neck stiffness, sensitivity to light, nausea, or confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

3. **Progressive multifocal leukoencephalopathy (PML).** PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems. Symptoms of PML get worse over days to weeks. Call your doctor right away if you have any new or worsening symptoms of PML, that have lasted several days, including:
   - weakness on 1 side of your body
   - loss of coordination in your arms and legs
   - decreased strength
   - problems with balance
   - changes in your vision
   - changes in your thinking or memory
   - confusion
   - changes in your personality

4. **A problem with your vision called macular edema.** Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 3 to 4 months after you start taking GILENYA. Your doctor should test your vision before you start taking GILENYA and 3 to 4 months after you start taking GILENYA, or any time you notice vision changes during treatment with GILENYA. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

   Call your doctor right away if you have any of the following:

   - blurriness or shadows in the center of your vision
   - a blind spot in the center of your vision
   - sensitivity to light
   - unusually colored (tinted) vision

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults and children 10 years of age and older.

It is not known if GILENYA is safe and effective in children under 10 years of age.

Who should not take GILENYA?

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or mini-stroke (transient ischemic attack or TIA) or certain types of heart failure in the last 6 months.
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA.
- have a heart rhythm problem that needs treatment with certain medicines.
- are allergic to fingolimod or any of the ingredients in GILENYA. See the end of this leaflet for a complete list of ingredients in GILENYA. Symptoms of an allergic reaction may include: rash, itchy hives, or swelling of the lips, tongue or face.

Talk to your doctor before taking GILENYA if you have any of these conditions or do not know if you have any of these conditions.

What should I tell my doctor before taking GILENYA?

Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:

- an irregular or abnormal heartbeat (arrhythmia).
- a history of stroke or mini-stroke.
- heart problems, including heart attack or angina.
- a history of repeated fainting (syncope).
- a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.
- recently received a vaccine or are scheduled to receive a vaccine.
- chickenpox or have received the vaccine for chickenpox. Your doctor may do a blood test for chickenpox virus. You may need to get the full course of the vaccine for chickenpox and then wait 1 month before you start taking GILENYA.
- your child has completed their vaccination schedule. Your child needs to have completed their vaccination schedule before starting treatment with GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes.
- breathing problems, including during your sleep.
- liver problems.
- high blood pressure.
- types of cancer called basal and Merkel cell carcinoma, melanoma and lymphoma.
- are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
  - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
  - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

Pregnancy Registry: There is a registry for women who become pregnant during treatment with GILENYA. If you become pregnant while taking GILENYA, talk to your doctor about registering with the GILENYA Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health.

For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by sending an email to gpr@quintiles.com, or go to www.gilenyapregnancyregistry.com.

- are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. Talk to your doctor about the best way to feed your baby if you take GILENYA.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Especially tell your doctor if you take medicines that affect your immune system, including corticosteroids, or have taken them in the past.

Know the medicines you take. Keep a list of your medicines with you to show your doctor and pharmacist when you get a new medicine.

Using GILENYA and other medicines together may affect each other causing serious side effects.

How should I take GILENYA?

- Adults and children will be observed by a healthcare professional for at least 6 hours after taking their first dose of GILENYA. **Children should also be observed by a healthcare professional for at least 6 hours after taking their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose.** See **"What is the most important information I should know about GILENYA?"**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- Call your doctor right away if you miss a dose of GILENYA. You may need to be observed by a healthcare professional for at least 6 hours when you take your next dose. If you need to be observed by a healthcare professional when you take your next dose of GILENYA you will have:
  - an ECG before you take your dose
  - hourly pulse and blood pressure measurements after you take the dose
  - an ECG 6 hours after your dose
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight by a healthcare professional in a medical facility after you take your dose of GILENYA.
- If you have serious side effects after taking a dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. If you were observed overnight, you will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA. See **"What is the most important information I should know about GILENYA?"**

What are possible side effects of GILENYA?

GILENYA can cause serious side effects, including:

- See **"What is the most important information I should know about GILENYA?"**
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened rarely in adults taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you have any of the following symptoms:
  - sudden severe headache
  - sudden confusion
  - sudden loss of vision or other changes in your vision
  - seizure
- **liver damage.** GILENYA may cause liver damage. Your doctor should do blood tests to check your liver before you start taking GILENYA and periodically during treatment. Call your doctor right away if you have any of the following symptoms of liver damage:
  - nausea
  - vomiting
  - stomach pain
  - tiredness
  - loss of appetite
  - your skin or the whites of your eyes turn yellow
  - dark urine
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have new or worsening breathing problems.
- **severe worsening of multiple sclerosis after stopping GILENYA.** When GILENYA is stopped, symptoms of MS can return and become worse compared to before or during treatment. Many people who have worsening of MS symptoms after stopping GILENYA do not return to the level of function that they had before stopping GILENYA. This worsening happens most often within 12 weeks after stopping GILENYA, but can happen later. Always talk to your doctor before you stop taking GILENYA for any reason. Tell your doctor if you have worsening symptoms of MS after stopping GILENYA.
- **increased blood pressure.** Your doctor should check your blood pressure during treatment with GILENYA.
- **types of cancer including basal and Merkel cell carcinoma and melanoma.** Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, a new darkened area on your skin, a sore that does not heal, or growths on your skin such as a bump that may be shiny, pearly white, skin-colored, or pink. Your doctor should check your skin for any changes during treatment with GILENYA. Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear protective clothing and use a sunscreen with a high sun protection factor. Lymphoma has also occurred in patients receiving GILENYA.
- **allergic reactions.** Call your doctor if you have symptoms of an allergic reaction, including a rash, itchy hives, or swelling of the lips, tongue or face.

The most common side effects of GILENYA include:

- headache
- abnormal liver tests
- diarrhea
- cough
- flu
- inflammation of the sinuses (sinusitis)
- back pain
- stomach-area (abdominal) pain
- pain in arms or legs

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all of the possible side effects of GILENYA. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Keep GILENYA and all medicines out of the reach of children.

General information about the safe and effective use of GILENYA.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms that you have. It may harm them. This document summarizes the most important information about GILENYA. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about GILENYA that is written for health professionals.

What are the ingredients in GILENYA?

0.25 mg capsules

Active ingredient: fingolimod

Inactive ingredients: mannitol, hydroxypropylcellulose, hydroxypropylbetadex, magnesium stearate, gelatin, titanium dioxide, yellow iron oxide.

0.5 mg capsules

Active ingredient: fingolimod hydrochloride

Inactive ingredients: mannitol, magnesium stearate, gelatin, titanium dioxide, yellow iron oxide.

Manufactured by: Novartis Pharma Stein AG, Stein, Switzerland

Distributed by: Novartis Pharmaceuticals Corporation, East Hanover, New Jersey 07936

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PHOTO COURTESY OF JON STRUM

Jon Strum, host of the RealTalk MS podcast

Unofficial channels

People with MS are discovering worlds of ways to connect with each other, from podcasts to blogs.

by Shara Rutberg

In 2014, Jim Fairchild was in a "really deep, dark spot."

Slammed by major exacerbations of his multiple sclerosis, the 49-year-old Vancouver, Washington, resident stopped working and driving at the same time.

"I'd lost my purpose. I'd lost my connection with people," recalls Fairchild, who was diagnosed in 1998.

Then he found something that "saved his life."

It wasn't pills. It wasn't a diet.

It was podcasts.

When a friend of Fairchild's wanted to talk to him about podcasts, he assumed he was going to be interviewed. Instead, Fairchild's friend suggested that he start a podcast of his own that focuses on MS. Though Fairchild didn't really even know what a podcast was at that time, he agreed.

He asked himself, "How am I going to do this? How open and vulnerable will I be?"

"When I interviewed my first guest, I ended up admitting I wear [adult diapers]," Fairchild says. "I saw the guest's jaw drop. Listeners say they heard his jaw drop. It has been my most talked-about interview."

Conversation can be powerful, especially when

PHOTO COURTESY OF JIM FAIRCHILD

PHOTO COURTESY OF KATHY REAGAN YOUNG

Above: Jim Fairchild, pictured with his daughters, hosts the "How You REALLY Doin'?" podcast, which features conversations with people living with MS.

you're both vulnerable and willing to speak, Fairchild says. He realized he needed to get his emotions out and talk to people who understood. Podcasts allowed him to do that. Twenty-two episodes later, his "How You REALLY Doin'?" podcast (**howyoureallydoin.com**) features conversations with a range of people living with MS. It's connected him with an entire community of listeners.

Podcasts are just one way people with MS can connect beyond the "official channels" of organizations like the National Multiple Sclerosis Society or MS centers. Instagram, Facebook, blogs, Twitter and online chats also can offer worlds of connection online.

Take it with you

"As a person with MS, we get a lot of information thrown at us, and it doesn't always come in a way we can digest immediately or at a good time," Fairchild says. Listeners can take their time and listen to podcasts when they want to, at a time when they don't feel stressed, he says.

"I often hear from people who listen on their ride to work or when they're getting medicine infused," says Kathy Reagan Young, host of the "FUMS: Giving MS the Finger" podcast (**fumsnow.com/podcast**), which provides information and inspiration with a wicked dose of humor.

"It's such a user-friendly medium," says Jon Strum, host of the RealTalk MS podcast (**realtalkms.com**), which delivers the latest on research, advocacy and caregiving. It's far easier to listen to something than to navigate a website, he says. "A computer can be challenging for people with MS—seeing the screen, manipulating the mouse. Podcasts are the easiest, most accessible way of sharing information. You can literally take it with you, and you can listen to it while you're doing something else."

Podcasts can offer a more intimate experience. "When I listen to podcasts, it really feels like it's a friend talking to me," says Reagan Young. "It's such a different way of communicating."

Left: Kathy Reagan Young is the host of the "FUMS: Giving MS the Finger" podcast, which combines information and inspiration with a wicked dose of humor.

Right: Dan and Jennifer Digmann, who both have MS, started their own blog to create a positive online community in which to connect with other people with MS.

PHOTO COURTESY OF DAN DIGMANN

The blogosphere beckons

When Dan Digmann was first diagnosed in 2000, he says, "the first website I found about MS was playing a Muzak version of Celine Dion's 'My Heart Will Go On.' It had me bawling my head off." Digmann and his wife, Jennifer, who also has MS, decided to create their own blog to put something more positive online, **danandjenniferdigmann.com**.

"We both have MS, we're dealing with so many things, and we don't sugarcoat it," says Jennifer. "But at the same time, we want there to be positive voices out there. To be honest, I'm in a wheelchair, and when people are diagnosed, that's one of their biggest fears. I hope I show that life is still worth living and you can have an amazing quality of life if you're in a wheelchair."

MS can be very isolating, says Dan. "You're not able to get out as often as you like. With social media, you're still able to connect with people."

Blogs and all forms of social media are a two-way street, the Digmanns say. "It's the back and forth it creates that's special," Dan says. "We get to hear other people's stories."

Much of that back and forth is with other MS bloggers. "We've never met face to face, but I count them as our friends," Jennifer says. "It's a very tight-knit community. We comment on others' posts. We keep tabs on each other."

"I know what this disease is like, and I don't want anyone to feel alone living with MS," says Jennifer, who says having a community makes it easier to deal with the disease—and an online community can be just as powerful as an in-person community.

Simonne Simpson started her blog "Staying Healthy With MS" (**stayinghealthywithms.com**) when she found it hard to find anything online that she could relate to when she was diagnosed at age 31 in 2015. After delving into research on diet and lifestyle, she wanted to share what she'd found.

Blogging empowers Simpson to turn her MS challenges into something positive: help for others. "I share the experience in a blog post, and through that, I've connected with many who say they've been through the same thing or that my blog is helping

PHOTO COURTESY OF SIMONNE SIMPSON

Simonne Simpson uses Instagram to share images of healthy meals she prepares as well as images of her daily life.

PHOTO COURTESY OF NAOMI RIDGE

Naomi Ridge is one of six administrators of the Women with MS Facebook Group, which has 16,000 members.

them," she says. "I've had some beautiful emails from people saying my blog has really helped them, which literally makes my day." Like many blogs, her posts have links to audio translations for those who have vision issues.

Insta community

Simpson uses Instagram (**instagram.com/stayinghealthywithms**) to share gorgeous images from her life on the northern beaches of Sydney, Australia, along with luscious, healthy meals she prepares. She also shares photos of her arm during infusions.

"I'd feel lost without my Insta community," she says. "We chat about medications, symptoms and misconceptions. But mainly we all encourage and support each other. There's a lot of love. Everyone I've followed and connected with has taught me so much about MS; people I would never have met otherwise."

The image posts on Instagram let people connect with your message almost immediately, says Alex Safford, a 26-year-old self-described "gym addict" whose Instagram account (**instagram.com/the_ms_press**) shares not only muscle and meal photos but also heartfelt insight about living with the disease that readers say bring them to tears.

"When I was first diagnosed, I had a very difficult time talking about it with anyone," Safford says. "Face-to-face [talk] felt too personal, so starting with social media felt like the best way to connect with others going through the same thing. It gave me the opportunity to connect with new people as 'The MS Press' and not as Alex. I felt I could be more open and honest about my experiences."

Facebook groups

When Naomi Ridge, 44, of Watertown, Massachusetts, joined the Women with MS Facebook Group in 2015, it had about 2,500 members. Today, 16,000 members share on the site, where Ridge is one of six administrators. Why such growth? It's really filling a need—a place where women can talk openly about MS topics related specifically to them, she says. "Since the group is closed, people can be very open and talk about some of the more taboo topics," she says. "It's an amazing community of women," and one that spans a

PHOTO COURTESY OF DAN DIGMANN

Dan and Jennifer Digmann use live chat to connect with others from across the country. They have hosted conversations on several different platforms about how MS affects them.

range of ages. According to Facebook statistics, Ridge says 20% of members are 25–34, about 30% are 35–54 and 18% are 55–65.

Twitter

Dan Digmann likes the 280-character limit required by Twitter. "It really makes you more efficient and effective with the words you use," he says. RealTalkMS' Strum also finds the platform an effective way to communicate. He compares it to television. "There's a lot of junk, but there's also a lot of really great things," Strum says. "It's your job as a critical viewer to separate the wheat from the chaff."

Chats and forums

Online chat rooms like **MSWorld.org** have been bringing people with MS together for decades. Founded in 1996 with six members, it now serves more than 220,000 members living with MS. Members can participate in several forums and join a continuous live chat. The MS Buddy Chat app for iOS and Android devices also connects people. Reagan Young (FUMS podcast) facilitates hour-long live chats five nights a week on the app, covering topics such as "MS and career." "It's a very inspiring and supportive community," she says.

Jennifer and Dan Digmann are also fans of live chats, having hosted conversations on several different platforms about how MS impacts them. "There's an added level of anonymity on the computer, where with face-to-face conversations, it can get a little more embarrassing," Jennifer says. They also value the opportunity to talk live with people across the country. "The internet makes the country and the world seem so much smaller," she says.

Users worried about typos and embarrassing auto-corrects shouldn't, Jennifer says. "The MS community understands dexterity issues."

Buyer beware

Keep in mind that not everything you encounter on social media is true. Some platforms and moderators do rein in inaccurate information. "If we spot things, we'll try to chime in and warn users of pseudoscience," Ridge says of the moderators of the Women With MS Facebook group. She says the site users themselves do a good job of calling out suspect posts.

Getting started

There are so many options for connecting online that it can seem overwhelming. Do a Google search and sample one or two accounts to get a feel for the format, topic and personality of the users that resonate with you. Then branch out to see what other users on that account are following. Hashtags make finding your niche on Instagram easy. "You can go to any of the multiple sclerosis hashtags and connect with people from all over the world and follow their journey, all within minutes," Simpson says. Instagram and Facebook groups both suggest other similar accounts to try as you go.

"Social media is really easy," she says. "I love meeting and seeing people all over the world going through the same thing as me. It helps me feel like I'm not alone. I can literally pick my phone up, open Instagram and I'm surrounded by a supportive community straight away, wherever I am. My main support network for MS is online." ■

Shara Rutberg is a writer in Evergreen, Colorado.

Check out the Society's online community at **MSConnection.org**. Find virtual support, read the blog or start a discussion.

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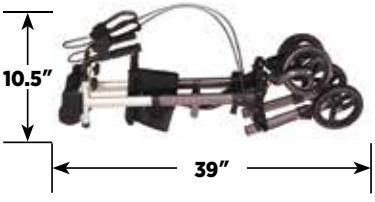

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Walking tall

Fraternity brothers spend spring break fundraising for MS.

by Robert Lerose

Every year since 2012, about 20 Alpha Tau Omega (ATO) fraternity members trudge 160 miles over eight days from Traverse City, Michigan, to Grand Valley State University's Allendale campus to raise awareness and money for MS.

PHOTO COURTESY OF CONNOR CAVALLARO

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On the first day of the walk, Connor Cavallaro sprained his ankle—and still had 150 miles to go. Popping blisters became a nightly ritual for Matthew Bertoia. Chad Jarvie carried a fallen walker on his back.

Hordes of college students head south for fun and sun during spring break. But the members of the Alpha Tau Omega (ATO) fraternity at Grand Valley State University (GVSU) in Michigan use their vacation time for ATO Walks Hard, a grueling trek by foot to raise awareness and money for multiple sclerosis.

ATO Walks Hard is one of the National Multiple Sclerosis Society's DIY events, a program in which people create their own activities to benefit the Society. "The possibilities are endless when it comes to what people can think of in this area of do-it-yourself fundraising," says Tammy Willis, Society executive director, Michigan.

Every year since the first walk was held in 2012, about 20 ATO members trudge 160 miles over eight days from Traverse City, Michigan, to their Allendale campus, sleeping in churches at night. The trail snakes through heavy woods, along busy urban roadways and over an historical railroad route. ATO walkers have raised over $250,000 in total, while the event has become part of GVSU lore.

PHOTO COURTESY OF CONNOR CAVALLARO

Connor Cavallaro took part in the 2019 ATO Walks Hard.

All kinds of support

For the 2019 walk, 21-year-old Cavallaro led the support team—making meals, helping the walkers stretch and prepping their gear at night. But it was only after he signed up for the walk as a freshman in 2017 that he learned he had a family member with MS. "When I came into college, I had no clue what MS was, and now it's such a personal part of my life," he says.

Cavallaro remembers the unpredictable weather on the walk: warm enough to walk shirtless some days, but fierce winds on other days that ripped trees loose and hit a walker. As Cavallaro was looking at the scenery, he accidentally stepped into a pothole and rolled his ankle after just 10 miles. He spent the evenings icing it and the mornings feeling the stiffness. Then he slapped on an ankle brace and, through pain, limped across the trail for the next seven days. "After this event, it made me closer to a lot of

> **Knowing that I can change people's lives with what I'm doing—that's what motivated me to do [ATO Hard Walks in 2019].**"
>
> —CHAD JARVIE

these people with MS and helped me understand the difficulties they go through that you really don't see on the outside," he says.

Being best friends

As the organizer of the 2019 walk and a participant for the third time, 21-year-old Bertoia had his hands full. But in a way, doing the walk was a nice change of pace.

"Honestly, it's pretty fun. We have nothing else to do but hang out. There's 30 of your best friends messing around in a church, walking on trails and having nothing to do but talk and be with them," he says.

After covering an arduous 27-mile section in one day during his first walk in 2017, Bertoia couldn't bend his knee. Eventually, he managed to move again by swinging his other leg around—and getting good-natured "roasting" from his fellow brothers.

Bertoia compared their nighttime breaks in churches to a big sleepover in elementary school. In between popping blisters and stretching, they would huddle in sleeping bags, play cards, watch movies—and even soak each other when they found a squirt gun. "You get 30 20-year-old guys in a room together for a week, especially if they're already best friends, and some crazy stuff happens," he says.

Carrying on

Bonding with his fraternity brothers appealed to 19-year-old Jarvie when he participated for the first time in 2018. "But this year, I realize it's so much bigger than that. Knowing that I can change people's lives with what I'm doing—that's what motivated me to do it [in 2019]," he says.

Jarvie didn't have to wait long to change a life. After a winter storm dumped a foot of snow on the trail in 2018, one of the walkers rolled both his ankles on the ice. Jarvie picked him up and carried him piggyback for a half-mile until the walker could get back on his feet and walk on his own again.

Listening to "old-school" Eminem helped Jarvie stay upbeat, including powering through a 13-minute mile. "I tried walking slow, but walking fast was so much less painful. I was trucking."

Committed to helping others

As a volunteer at a muscular dystrophy summer camp and a sophomore majoring in biomedical science, 19-year-old Nate Stuart is no stranger to working on behalf of others. Hearing people around campus speak passionately about ATO Walks Hard resonated strongly with him. He signed up for his first walk in March 2019.

Stuart did a 7½-mile practice walk and stretched every night, but he knew that nothing could adequately prepare him for the magnitude of the event or the pain that came with it. It would have been understandable to bow out, but Stuart's resolve toughened after listening to past walkers and to people living with MS.

"The first thing they'll say is that it's the hardest thing you'll ever do, but it's the greatest thing you're ever going to do. People with MS come and talk at the kickoff event, and you see how grateful they are that we're giving up our spring break to help them out. It's really a ripple effect. If I can possibly make life better for someone [who lives with] MS, that's really my goal. I've always had a passion for helping other people, and that's a large part why I chose to do ATO Walks Hard," he says. ■

Robert Lerose is a Long Island, New York-based writer.

Visit **ntlms.org/DIY** to start your own DIY Fundraiser.

To learn more about ATO Walks Hard, visit **atowalkshard.com**.

Care to comment? Email us at editor@nmss.org.

Wagons ho!

Horse-drawn rigs pony up funds for MS.

by Robert Lerose

Kimi Deyarmond's parents saw an opportunity to turn the family's passion for horses into a DIY fundraising event called Wagon Train.

Four months after giving birth to her second child, Kimi Deyarmond woke up with cloudy vision in her right eye. By noon, she couldn't see out of it at all. Following an MRI ordered by a neuro-ophthalmologist, she was diagnosed with multiple sclerosis in October 2016.

Deyarmond, a preschool teacher, comes from a close-knit family in Durand, Michigan. But when her parents invited her and her husband out for dinner in September 2018 because they had something to propose, she was puzzled. "With my mother, I never know what that's going to entail," Deyarmond, 28, says.

Donna and Kevin Doneth, Deyarmond's parents, own Percherons—a breed of towering, 2,000-pound draft horses. They love doing things with the horses: transporting guests to outdoor wedding sites in a wagon or carrying the grand marshal in local parades. After attending a session at the World Percheron Congress Show on how other owners had used their horses for charitable purposes, Donna came up with the idea of a Wagon Train as a National Multiple Sclerosis Society DIY event.

DIY events encourage people to mount their own fundraising and awareness activities for MS research. "What makes DIY great is that the sky is truly the limit. The more creative you can get, the better. Sometimes it's taking what you know and running with it, like what Donna put together," says Stephanie Ford, the Society's development specialist for DIY events in Michigan.

Donna reached out to people

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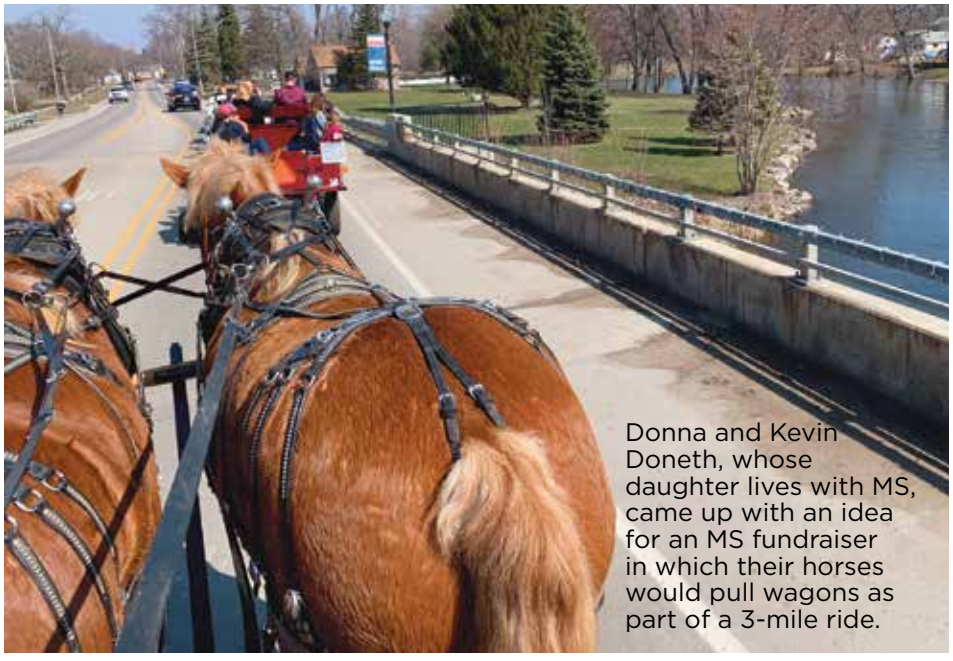

PHOTO COURTESY OF KIM DEYARMOND

Donna and Kevin Doneth, whose daughter lives with MS, came up with an idea for an MS fundraiser in which their horses would pull wagons as part of a 3-mile ride.

who drive horses at a county fair for their support and was thrilled with the response. "In the end, we had nine teams of two horses that carried 20 people each in wagons called surreys and five single-draft horses that pulled small wagons of two to four people. About 15 people rode on regular saddle horses," she says.

A family undertaking

In April 2019, the Wagon Train took off for a three-mile ride from the Shiawassee County Fairgrounds to a pavilion in McCurdy Park in downtown Corunna, Michigan. A stately line of Clydesdales, Percherons and Belgian breeds clopped through town. Deyarmond's brother drove horses and her sister supervised the pavilion. Donna and Kevin supplied a barbecue lunch, followed by a silent and live auction before the return trip.

Lori Bedell, a first-grade teacher, and her husband, Ed, hitched up their draft horses, Randy and Roger, and pulled about a dozen people to the fairground in their surrey. "It was a slow-paced ride with lots of people. We had a police escort [at the front and back of the line]. They stopped traffic at all the intersections so we could get through," she says.

Deyarmond and her two kids rode on the wagon driven by her father, while her husband, Brad, followed in his tool truck in case of any breakdowns. Even though her kids were used to being around horses, it was still an exciting time, especially for her 4-year-old daughter, Delaney.

"On the way back, one of the girls that babysits for me was riding her horse saddleback, so she let my daughter ride saddleback with her for the hour-and-a-half trip back, which was quite a feat in itself to have to hold her on the saddle," Deyarmond says.

Brenda Turner, an occupational therapist who works with Deyarmond's 2-year-old son, Oliver, and has become a family friend, brought along her husband and their friends, the Tyler family, including their 3- and 4-year-old kids, on the ride.

"The kids loved it. They were so excited to see the horses—going up to them and patting them," Turner says. "The people leading them were really good about helping them touch the horses. They totally loved the ride and waving at everybody like they were little princesses. They were trying to take in everything. It was really a good activity for young kids to participate in."

Surprise gifts

Kevin Doneth ran the auction, with some unexpected outcomes.

Turner had her eye on one item in particular: an afghan that Donna had crocheted by hand and embroidered with the Society's MS ribbon logo. "When it went up for the raffle, I bid on it—not knowing that

Kimi's husband was bidding on it also. It was cool because I actually got it and gave it back to Kimi because it was something that really meant a lot to her," she says.

Deyarmond's doctor's office staff donated a large wagon for carrying garden supplies, like stepping stones, seeds and mulch. A bidding war broke out between two men, and the wagon eventually went for $500. "I went to [the winner] afterwards and said that I was curious about his connection to MS. He said [he had] none, that his wife wanted to go for a horse ride that day, and he needed a present for her," Donna says.

When everything was tallied, the Wagon Train drew around 200 people, raised $7,565 and revealed some surprising connections to MS.

"I never realized how many people are affected by MS. We've known some people for 20 years and didn't realize they had MS, like the mom of a neighbor girl that went to school with our daughter," Donna says. "Until [a disease] affects you personally, you always think it's going to happen to somebody else. As parents, we can't make the disease go away for our daughter. All we can try and do is help the doctors come up with anything and everything to make her life better—hers and everybody in the same boat." ■

Robert Lerose is a Long Island, New York-based writer.

Visit **ntlms.org/DIY** to start your own DIY Fundraiser.

The 2019 Wagon Train event included nine teams of two horses that carried 20 people each in wagons and five single-draft horses that pulled small wagons of two to four people. Plus, about 15 people rode on saddle horses.

PHOTOS COURTESY OF KMI DEYARMOND

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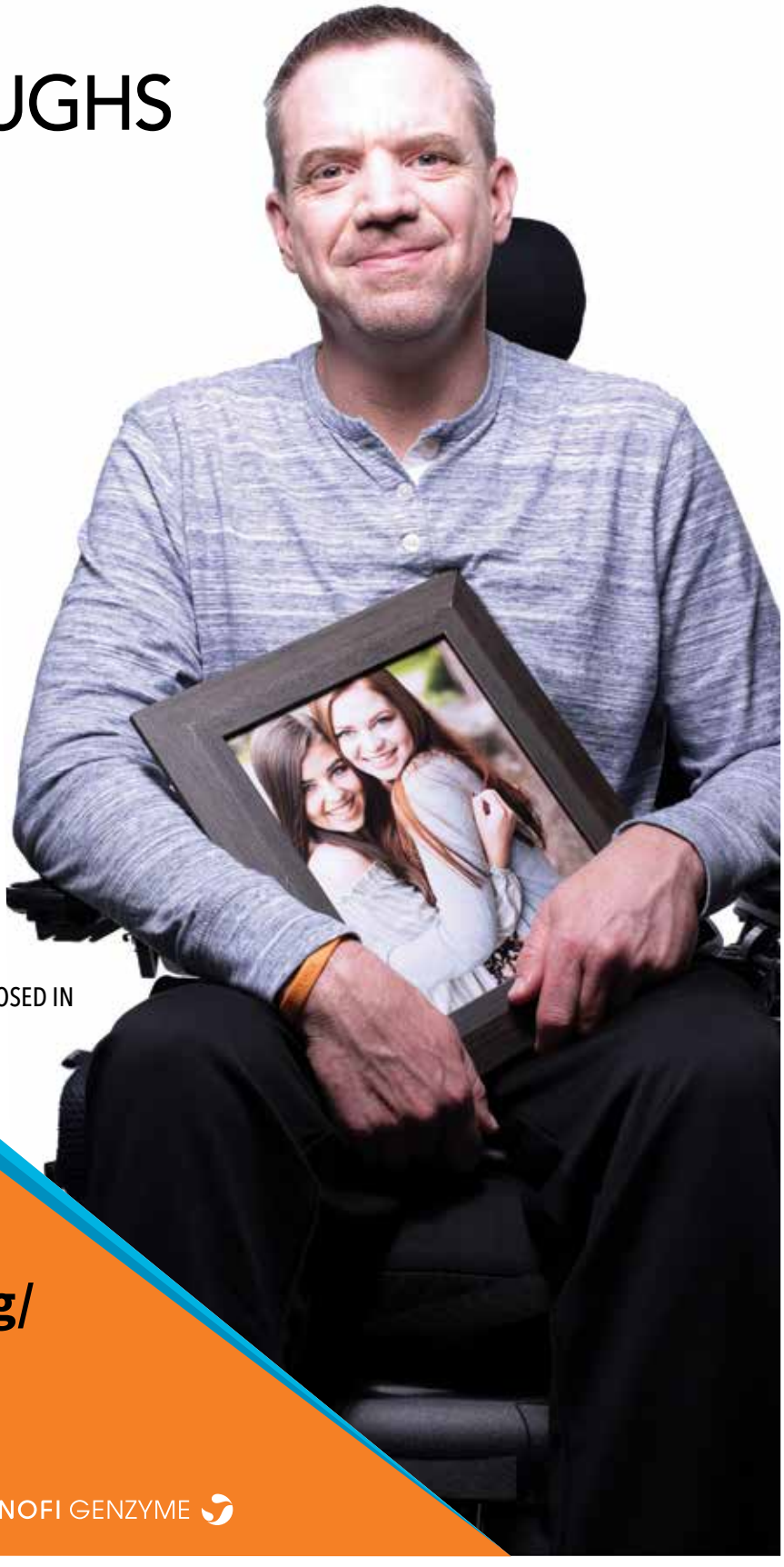

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The man behind the meme

Bike MS cyclist raises more than $30,000 after asking the internet for donations.

by Laura Pemberton

PHOTOS COURTESY OF DREW SCANLON

Drew Scanlon (left, above) recently revealed himself to be the man behind the popular "White Guy Blinking" meme on the internet.

You might know him as 'The Blinking White Guy', but Drew Scanlon—as he's known in real life—is using his hilarious meme to raise serious funds and awareness to benefit people affected by multiple sclerosis.

After taking to Twitter to reveal himself as the man behind the meme and ask the internet for donations, Scanlon raised more than $30,000 in 10 days. His story went as viral as his meme and was shared on major

news outlets including the Washington Post, NPR and Time.

We sat down with the San Francisco-based online celebrity (actually, we called him on our office landline phone. Very '90s of us.) to learn why creating a world free of MS matters to him and how he feels about the viral reaction he's gotten.

PHOTO BY WAYNE FAN

Q. First, how did the meme get started?

Scanlan: This is kind of the second wave of this. It first got popular in 2017. It wasn't an experience I was totally unused to. I worked for a video game company called Giant Bomb. We would do a lot of videos as part of site content, and our audience would quite often make GIFs of us.

One of those GIFs jumped species out of our own little video game community to the internet at large. I attribute it to internet chaos theory. It just kind of snowballed.

Q. What made you want to reveal yourself as 'The Blinking White Guy?'

Scanlan: I hadn't tried to hide the fact it's me, but I typically don't use it myself. It feels uncool—like if a rock band was wearing their own T-shirt. But I thought I could make an exception if I could leverage it for a good cause. The MS cause is one that's very close to me.

Q. Why is the mission of the National MS Society important to you?

Scanlan: Two friends of mine have MS – Chelsea and Katie. Katie's mom, Ellie, also lives with MS. Her family's been doing Bike MS for more than 30 years, and Katie brought her team out here to the West Coast, and we've been riding as friends for four years.

Q. What do you like about Bike MS?

Scanlan: It's just a fun event. I think that comes from a lot of things. The fact that I'm there with my friends really helps. It's also just well designed. There are plenty of rest stops with food and bathrooms. [Riding] 86 miles is a challenge, but it's a fun challenge because you've got support.

The general attitude is also great. Everyone's really positive. I like the vibe that everyone has. These rides are really fun, and I think people should get out there and try them even if they seem intimidating. I can't recommend this one specifically (Bike MS: Waves to Wine) enough. I look forward to it every year!

Q. What kind of reaction have you gotten?

Scanlan: I think MS is something that people have heard of, but they don't hear about very often. I'm so glad that the tweet and meme have taken off and are associated with MS now.

Left: Drew Scanlon (left) in support of his friend Katie Bernstein (right), who has has been riding to fight MS.

Right: Katie Bernstein and the rest of her family form Team "Big EL" (named after her mom Ellie). Since 2016, Bernstein has joined her West Coast friends to ride from San Francisco to Sonoma to raise money to fight MS. as part of "The Big EL West" (pictured right).

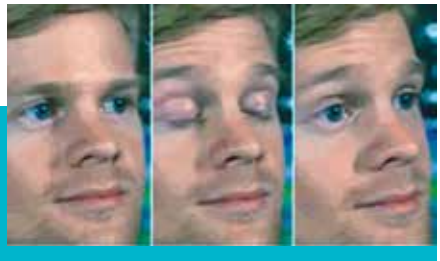
PHOTO COURTESY OF BRIAN TANAKA

I think someone in Scandinavia donated. And I've had several people say, 'thank you for what you're doing,' or, 'I know someone living with MS.' If I had gotten even one of those messages or one donation, this would have been a success.

Q. How do you feel about your story going viral and the impact you've made?

Scanlan: It makes me feel really proud to be able to do this. It's given me a little more confidence in the goodness of people. This money has come in large part from random people on the internet. They didn't have to give money, but they're choosing to do that. That's really heartening. ■

Laura Pemberton is director of content for the National MS Society. She lives in Birmingham, Alabama.



What is a meme?

A humorous image, video, piece of text that is copied (often with slight variations) and spread rapidly by Internet users.

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To find a Bike MS event near you, visit **bikeMS.org**.

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Awesome aliases

Why I name my mobility devices

by Ardra Shephard

According to some not-so-scientific stats I got off the interwebs, more than 25% of people name their cars. We trust our rides with our lives, so it feels reasonable to humanize the machines we'd like to believe have a vested interest in our well-being. It's a comforting concept, if not exactly a correct one. A rose by any other name would smell as sweet, but would we trust Siri if she wasn't a she at all, but simply—and more accurately—plain, old artificial intelligence?

It's not just because the robots are taking over and we feel the need to get on their

PHOTO BY ALKAN EMIN

“Tagging my transport chair gives it a personality beyond the medical, and the impact of seeing mobility aids in this empowered context can give those struggling to adjust the courage to accept mobility aids.”

good side that we find ourselves slapping “Hello, My Name Is” stickers on cars. From boats to plants to pets to semi-inflated volleyballs, we humans have a long history of naming the things we value most.

After all, our possessions are part of our personal brands.

When I was diagnosed with multiple sclerosis and optic neuritis in my early 20s, I was told that because of my significant vision loss, I was no longer a legal driver.

I’d never have a car of my own to name, but that didn’t mean I’d be immune to a lifetime of anthropomorphizing my stuff. I’d already been calling my period Brenda since circa Beverly Hills 90210. My dependence on my heating blanket has long led me to refer to it as Linus, and more recently, the one wiry chin hair that, despite my best efforts, promises to be the

Ardra Shephard says it can be beneficial to figure out a more personal way to identify mobility devices rather than default to their generic titles, which can come with negative connotations.

Ardra Shephard didn't name her first borrowed cane, but she quickly came around to the idea.

PHOTO BY ALKAN EMIN

most consistent relationship of my life has earned the nickname "Harry." Naturally, it makes sense that my arsenal of assistive devices all have awesome aliases, but it wasn't always so.

Seeing aids as the enemy

My first cane wasn't one I'd even commit to owning, let alone labeling. I'd borrowed it from a friend, telling myself it was temporary. I was determined to remain ill-at-ease with something that made my illness so easy to ID. I had zero affection for that first cane, and if I'd been inclined to give it a name at all, it would have been a mean one, like Stick-Face. I was afraid of what MS could do to me, of course, but compounding that fear was how I'd been conditioned to believe mobility aids themselves to be the enemy.

Ironically, the first such aid I found worthy of a proper moniker was the most extreme one I've acquired to date: a convertible rollator/transport chair I'd been anxious to own back when I couldn't see it as anything more than a symbol of my decline. Despite my skepticism, I soon found myself gushing about how it moved from rollator to push-chair, like a real-life Transformer. My machine had the characteristics of a superhero, and I started comparing it to Optimus Prime. I realized that despite the very real grief I was going through, I was proud of my possession. The nickname stuck, and before I knew it, I had named my mobility aid.

As original as I thought I was, I soon learned that fake-statistically speaking, people are naming their medical devices at even higher rates than they are naming their cars. Instagram is littered with examples of people who've embraced the name game, providing powerful proof that it's healthy to make friends with the tools that do the work our bodies should be

capable of but aren't. Tagging my transport chair gives it a personality that goes beyond the medical, and the impact of seeing mobility aids in this empowered context can give those struggling to adjust the courage to accept mobility aids, and the confidence to reject the stigma with which they are too often associated.

Putting help in a positive light

When it comes to disability, it can be especially beneficial to figure out a more personal way to identify our devices than by defaulting to the generic titles that come loaded with negative connotations. It's hard for me to even say the word "wheelchair" without it getting caught in my throat. For better or worse, language has the power to redirect our thinking, to shape our perception. Where the accepted language around disability, and particularly wheelchairs, consists of phrases like "being confined to" or "ending up in," it may sound radical to suggest that mobility aids are not, in and of themselves, the thing that is scary. Mobility aids only exist to help, not hinder; to liberate rather than restrict.

Baptizing my devices not only helps me frame my need for them in a positive light, it tells the world what my attitude toward them is: that I think of my mobility aids favorably, and by extension, that is how I see myself. The world may stigmatize disability and the tools we need to thrive, but elevating our devices to high-status heroes is a tiny act of rebellion that rejects this toxic thinking, that refuses to buy into the fear and insists we are not tragedies. We are simply people who move differently in the world.

So, have you named your mobility aid? ■

Ardra Shephard is a Toronto-based writer whose blog "Tripping On Air" provides an irreverent insider scoop about MS.

PHOTO COURTESY OF ARDRA SHEPHARD

Ardra Shephard says Instagram is full of examples of people who have embraced the name game.

See more at **trippingonair.com**.

You can follow Shephard on Facebook at **facebook.com/trippingonair** and on Instagram at **instagram.com/ms_trippingonair**.

Care to comment? Email us at editor@nmss.org.

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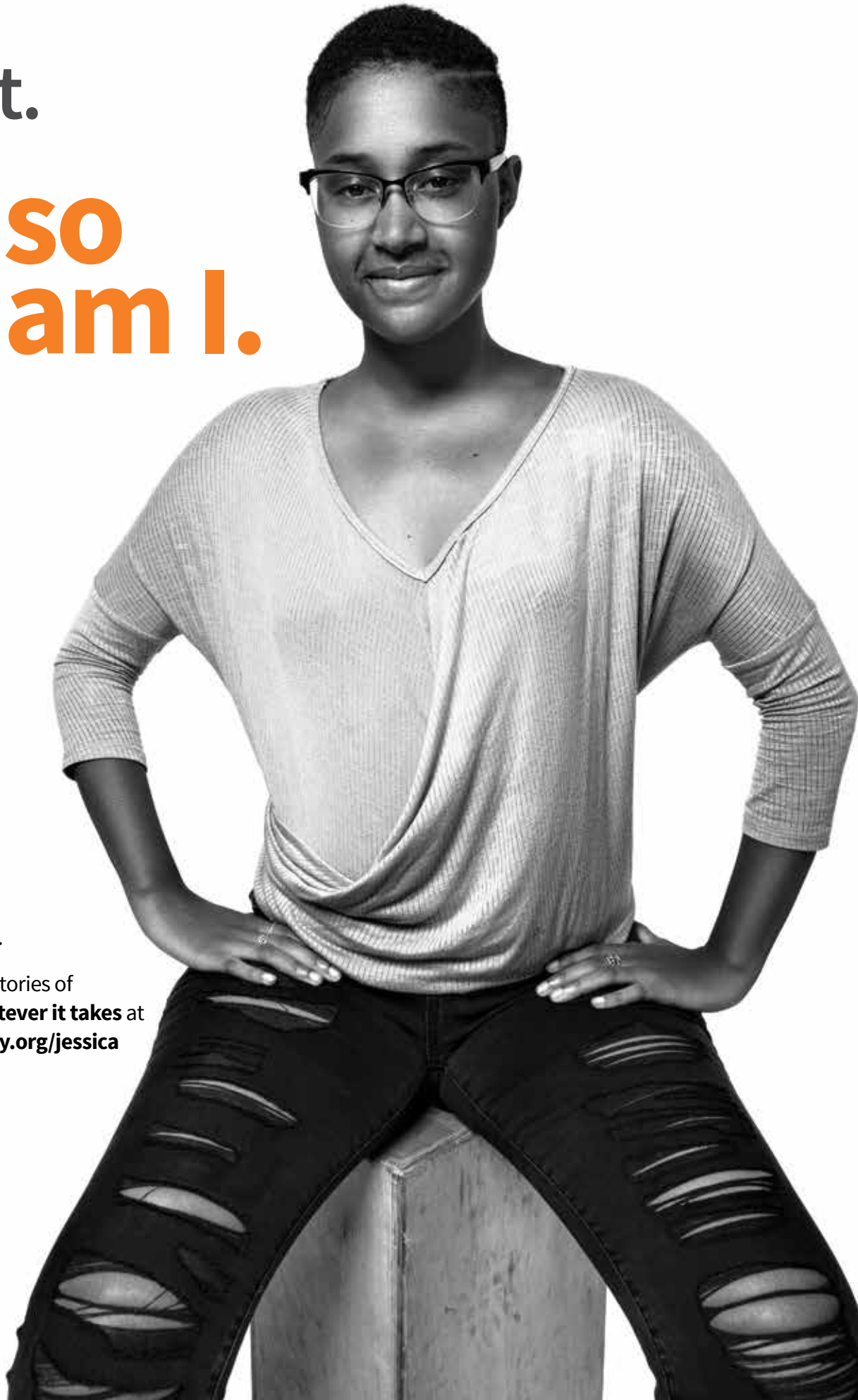

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Fragments from my brain

My MS gives me even more reason to draw.

by Randy J. Huling

My name is Randy J. Huling, aka Random Ran. I'm an illustrator/artist/music maker based in Northern California. On Sept. 1, 2016, I was diagnosed with multiple sclerosis. I had an MRI done to see why I was losing vision in my right eye. They found lesions all over my brain and then a week later, in my spine.

Randy J. Huling helps cope with the challenges of living with MS by drawing. His work pictured above is called "Beautiful Decay."

PHOTO COURTESY OF RANDY J. HULING

“To help me cope, I draw. I’ve always drawn, but getting diagnosed with MS gave me even more reason to draw.”

—RANDY J. HULING

I have a severe case of demyelination of the nerves. To help me cope, I draw. I’ve always drawn, but getting diagnosed with MS gave me even more reason to draw. A lot of my illustrations feature frayed nerves exploding through broken skulls with slivers. Or octopus and nautilus fragmenting, exposing the “nerves,” or a severed hand, due to the lack of feeling in my hands and arms. I choose this subject matter because at times this is how my body and head feel.

Painting or drawing helps take my mind off my mind. When I can’t draw, I try to make music.

I produced a song about my diagnosis with the help of my friend Overturned Big Rig to help me cope. ■

Randy J. Huling was diagnosed with MS in 2016.

Many of Huling’s illustrations feature frayed nerves exploding from broken skulls because at times that’s how his body and head feel.

randomran.bandcamp.com/track/i-got-that

See more illustrations at **randomran.com**.

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