



Out-stressing stress

How to identify and
manage the tension
MS might cause

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National
Multiple Sclerosis
Society

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Laura S., living with relapsing MS

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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.

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- **Liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed.

opens up possibilities

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.**

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

This is not intended to replace discussions with your doctor.

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

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



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
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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
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- 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

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Capsule Shell: gelatin, titanium dioxide, FD&C blue 1; brilliant blue FCF, yellow iron oxide and black iron oxide.

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

We want a cure for multiple sclerosis. What does that mean to you?

Cure is a powerful word that means different things to different people. Some see it as eradicating disease such as when vaccines were developed for polio and smallpox. For others, it might mean an immediate halt to disease progression or restoring lost function. Leadership volunteer and passionate activist Bill MacNally describes a cure this way: “That’s when I’ll be saying, I USED to have MS.” And I’ve heard others share their view by saying, “Don’t worry about me. Just make sure that my children and my grandchildren don’t have to worry about getting MS. For me, that would be a cure.”



Cyndi Zagieboylo

Regardless of the definition, we at the National Multiple Sclerosis Society are relentless in our pursuit of finding a cure. But as you can see, we need a cure for everyone. And just as there are different definitions of what a cure is, there must

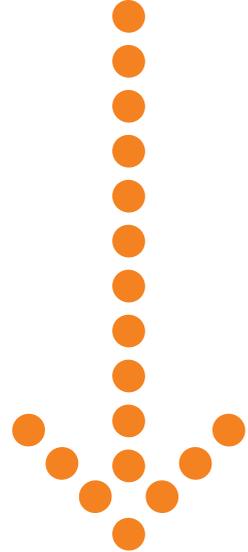
be different approaches—different pathways—to working toward that cure, or cures.

We tackle this big, important issue by bringing people together to focus on solutions. People who have various perspectives, expertise and experience share information about the most promising and fastest ways forward. Scientists with expertise in immunology, genetics, neurology and epidemiology. Health care providers, including physical therapists, nutritionists and psychologists. And most important, people with MS and family members. We must be clear about what we must achieve so we can make decisions about the best research investments. People affected by MS are essential thought leaders.

In the Society’s upcoming strategic plan for 2019 through 2021, one of the four impact statements is “Deliver Breakthroughs to a Cure.” We want people to know what they can do right now to take control of their MS and live better while we relentlessly pursue a cure. One way we will measure our success is to reach an international consensus on pathways to a cure so that we can all be clear about what we are going for—cures for each person.

What do you think? What does a “cure” mean to you? I’m interested in your perspective. Let’s keep in touch. ■

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Approaching MS in our own ways

I am a woman with MS, and when I started reading your “Sense of self” article in the Spring 2018 issue, I thought, “Here we go again. Another doctor/lawyer/actor talking about how they turned their diagnosis and life into a positive experience for themselves and the community.” How happy I was to read the variety of stories from different INDIVIDUALS who approach their own kind of MS in their own ways. I’m not saying that famous people do not have problems, but the problems are a bit different. We all deal with what we have of ourselves after and during our MS diagnosis. We all do the best we can with what we have. Life gives you what it gives you and those are the tools we have. I just call it reality. Thank you again for such a real article.

Lisa M., Pennsylvania

Keep going

I’ve enjoyed the past two issues very much. I’ve been struggling with my “sense of self” since I had to quit my job as a science writer in 1997. If I’m not a writer anymore, who am I? I think my coping style is much like Stacey Dorton’s: Prepare for the worst but hope



ARTWORK BY ELIZABETH JAMESON

for the best, and above all, keep going while you still can. I had been riding horses since I was 9 years old and my lifelong dream was to have horses, so I bought a pregnant mare. People (including my parents and neurologist at the time) said, “You can’t do that, you have MS.” But the horses gave me a reason to get up every morning—rain or snow, heat or cold. They gave me joy and physical exercise for 12 years before I had to give them up. Now, I have a huge photo album of mom and baby, and incredible memories of our many trail rides into the wilderness areas of the Rocky Mountains. What an empty life I would have had if I had listened to those naysayers who said, “You can’t do that, you have MS.”

Linda Brown, Colorado

Leading a productive life

I want to express my appreciation for Lois Kipnis’ letter to her adversary MS in “Dear adversary” (Spring 2018). I was diagnosed in 1970 at the age of 37 with relapsing-remitting MS. I am now 85 and have lived with MS for 48 years. Though I have had my struggles along the way, I am still leading a productive life. Like her, “I’ve fought to force you (MS) back.”

My youngest son was 6 at the time of my diagnosis and feared I was going to die. In the early years, I wasn’t too sure of that myself or what the outcome would be. Thankfully, I have seen my grandchildren graduate from high school and college, as well as work in their chosen fields. I have had the privilege of seeing my two granddaughters marry and now am the great-grandmother of two. At the onset of MS, I had no idea of what the future held for me, but fight I did. Again, thank you for the encouraging words of Lois Kipnis.

Mary Lou Sharp, Ohio



PHOTO COURTESY OF LOIS KIPNIS

Lois Kipnis



Color-coordinated canes

After reading the article “No shame” (Fall 2017), I would like to share my situation. When I was diagnosed with MS, I bought canes to match my clothes. Many people are so fascinated with my colorful canes they hardly notice I’m handicapped.

A friend gave me a Santa cane many years ago, and even little kids stop me and want to look at the cane. This year, I needed a brace for my left foot and leg and I went to the orthotics person kicking and screaming, but he taught me a trick. If you get a white or even pink brace, others will look at it like a handicap, but if you get a print or bright color, people will know you are not ashamed of wearing it and even stop you and tell you how good it looks.

Fran Jenkins, Oregon

Be more realistic

I was dismayed to see what appears to be a stock photo glamorizing disability in the article “Vocal control” (Winter 2017-18). The lead photo is of an unidentified couple: a beautiful, heavily made-up young woman embracing a handsome man with just the right amount of stubble in a manual push wheelchair, clearly not a chair for anyone with much disability at all. The subject of the article was Michael Ogg, who described using his wheelchair with a joystick controlled by his chin. He is pictured secondarily in a large automated wheelchair. And he lives alone. There is no shortage of Hollywood films depicting beautiful young women falling for quadriplegics. However, I would expect the National MS Society to have a more nuanced view. My husband, Matt, became a quadriplegic due to MS three years ago at age 45. It has had a decidedly non-glamorous impact on our family of four despite his and our best efforts. A photo of Mr. Ogg alone would have been a more realistic editorial decision.

Sarah Poggi, Maryland

Strength in faith

I am one of the many who has dealt with exacerbations of MS for decades, made worse later by a broadside car accident. I could go on and on, but the bottom line is we must still have strength in faith and do as much as it takes, no matter how long or the pain involved. I have learned to never give up, to do the needed things that will help my condition. I have gotten a PhD in nutrition from La Salle University and, since then, have helped others and myself to never give up, do what it takes to be stronger, and do more despite the pain of the disease or any other health conditions. ■

Christine M. Pantilione, PhD, New Jersey

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



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Join discussions at [MSconnection.org](https://www.msconnection.org).

SUMMER 2018

momentum®



on the cover

Clarisa Walcott says she feels stronger mentally, physically and emotionally when she practices yoga.

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COVER PHOTO BY KEITH CARLSEN

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PHOTO COURTESY OF JESSICA SPIKER

A chain saw inspires an undiscovered talent.

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Out-stressing stress

How to identify and manage the tension MS might cause. **24**

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Fatigue affects 75 percent of people living with MS, but a variety of strategies are available to help manage it. **PLUS:** Stories on self-help groups, healthy diets and fitness plans.

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"My MS soundtrack" by Ashley Ringstaff

1. **The Fighter** by Gym Class Heroes
2. **I Stand Alone** by Godsmack
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4. **Demons** by Imagine Dragons
5. **Numb** by Linkin Park (MS Remake)
6. **Crawling** by Linkin Park
7. **One Step Closer** by Linkin Park
8. **Bring Me to Life** by Evanescence
9. **Time of Your Life** by Green Day
10. **Fighter** by Christina Aguilera
11. **Stronger** by Kelly Clarkson
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16. **Brave** by Sara Bareilles
17. **Fight Song** by Rachel Platten
18. **Wasted** by Carrie Underwood

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PHOTO BY RIKU FOTO

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Turn it up

Listening to or making music can be an outlet for expressing your emotions. It's a fact that multiple sclerosis can have an impact on a person's emotions, not only because MS is challenging to live with, but because it affects parts of the brain that control mood. "Whenever I'm in a certain mood or just want to hear something I can relate to when it comes to my MS, I turn to my MS playlist on my phone," says Ashley Ringstaff, who was diagnosed with MS in 2010.

Learn more about how music can help improve your physical, mental and emotional health and well-being on the **next page**.

Practical ideas
for living well
with MS

in the know



"My MS soundtrack" by Ashley Ringstaff

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Music therapy might help ease MS symptoms.

Thriving in harmony



PHOTO COURTESY OF CHUCK KNIGHT

Chuck Knight listens to music as he works out on a recumbent elliptical.

by Elizabeth Michaelson
Monaghan

When Chuck Knight of Erie, Pennsylvania, participated in a research study for people with multiple sclerosis, he found himself listening to pre-recorded music while walking a half-mile every day for two weeks.

“The music was upbeat, almost like a marching band,” recalls Knight, chair of the National MS Society’s board of trustees in the Pennsylvania Keystone area. “I tried to match the beat with my walking [gait]. It helped me to keep going at a consistent pace.”

The experience prompted him to incorporate tunes into his workout: “Now, I use my own music—older rock and pop—when I go to the gym and use the elliptical machine or bike,” explains Knight, who was diagnosed with MS in 2000. “The music helps with my energy because it diverts my attention from working out when it gets hard, especially toward the end.”

> **Music therapy is searched more than 33,000 times a month on Google.**



Music therapy techniques

Music therapy—the use of music to improve people’s physical, mental and emotional health and well-being—has a long history, but its modern growth as a practice and an established health care profession dates to the 1940s.

In the last few decades, the development of neurological music therapy techniques has spurred the use of music therapy to “enhance neurological functions (e.g., walking, speech) in patients with conditions that affect the nervous system,” including MS, explains Francois Bethoux, MD. Dr. Bethoux is the medical director at Ohio’s Cleveland Clinic Arts and Medicine Institute; director of rehabilitation services at the Cleveland Clinic Mellen Center for Multiple Sclerosis Treatment and Research; and professor of medicine at the Cleveland Clinic Lerner College of Medicine of Case Western Reserve University.

There are several neurological music therapy techniques that people with MS may find helpful, according to Concetta M. Tomaino, the executive director and co-founder of the Institute for Music and Neurologic Function in Mount Vernon, New York. These include:

- Music composition and composition exercises to help improve attention and short-term memory.

- Familiar song lyrics to help with speech articulation and word finding.
- Therapeutic singing for clearer speech, breath control and posture.
- Playing instruments to boost range of motion, endurance and strength.

What the studies say

Dr. Bethoux and his colleague Lisa Gallagher recently reviewed several studies on the effects of various art therapies on people with MS. Despite a “need for more research,” Dr. Bethoux says that potential benefits of music therapy include improved “emotions and quality of life, coping, self-efficacy, energy, memory and movement.”

For instance, the Cleveland Clinic study Knight was enrolled in found that listening to specially designed music set to a tempo 10 percent faster than their comfortable cadence (number of steps per minute) helped some participants increase their walking speeds. Dr. Bethoux adds that with this technique, known as Rhythmic Auditory Stimulation, “we have also found that walking to music 20 minutes per day results in improved gait [walking] in some individuals.”

Music and music therapy could also help reduce pain and stress in people with MS, who may “report worsening of various symptoms [for example,

tingling, pain, spasticity and fatigue] with stress,” Dr. Bethoux points out.

And as Knight discovered, music could help some people stick to their exercise plans. “[It] would be harder to stay motivated without it,” he notes.

What to expect at a session

“Although music therapy sessions are individualized, the therapist typically begins by assessing the patient for pain, anxiety, mood and current issues,” explains Gallagher, a board-certified music therapist and research program manager at the Cleveland Clinic Arts & Medicine Institute.

Next, the therapist and participant identify goals such as addressing emotional, physical or speech concerns, and “the therapist offers choices of interventions,” Gallagher says. These might include “singing, moving to music, songwriting, music-assisted relaxation, instrument playing, song choices and music listening. The session continues with the interventions.”

In general, the person’s preferences should inform the choice of music, Dr. Bethoux says. However, “depending on the goal to be achieved, certain characteristics may be sought in the music, such as a strong and steady beat for Rhythmic Auditory Stimulation.”

The session concludes with “the therapist once again assesses[ing] the current status of the patient. They may discuss plans for future sessions,” Dr. Bethoux says.

Why music therapy is helpful

“Music is enjoyed by most people, triggers emotions, can be linked to memories, promotes motivation and engagement, and activates many brain circuits in ways that we are just beginning to understand,” Dr. Bethoux says. It’s also “widely available—a person can continue to enjoy it outside of music therapy sessions.” He notes that anyone who is interested could benefit from music therapy, and that music can be adapted to the person’s situation, abilities and preferences.

Dr. Bethoux believes these benefits will increase with time:

“I am convinced that further research will lead to the discovery of other benefits [of music therapy for people with MS] and to a better understanding of the mechanisms underlying the changes seen.”

Even without professional music therapy, listening to music might help lift a person’s mood or help them exercise longer.

What music therapy costs

After an initial assessment, music therapists typically charge from \$75 to \$125 per hour-long session, says Judy Simpson, a managed-health care professional and director of government relations at the American Music Therapy Association (AMTA) in Silver Spring, Maryland.

While it’s not covered by traditional Medicaid, “some states cover music therapy

under Medicaid Waiver programs for certain patient populations, such as individuals with autism,” Simpson notes. Separately, “Medicare recognizes music therapy as a covered service but only when provided as part of a treatment team within health care facilities. At this time, music therapists cannot bill Medicare directly.”

If you have private insurance, a letter of medical necessity or a prescription from your doctor may help. Many music therapists will work with insurance companies to facilitate coverage and reimbursement. Patients can contact **info@musictherapy.org** with questions about insurance coverage, Simpson adds.

How to find a music therapist

The AMTA (**musictherapy.org**) and the Certification Board for Music Therapists (**cbmt.org**) can help you find a music therapist near you, while the Academy of Neurologic Music Therapy (**nmtacademy.co**) maintains a list of music therapists with neurological music therapy training. Go to **nmtacademy.co/home-2**, then click on the link “registry-by-residence.” ■

Elizabeth Michaelson Monaghan is a freelance writer and editor in New York.



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

Weathering the storm

When disaster strikes, people with MS face unique challenges. Here's how to find help.

by Vicky Uhland



PHOTO COURTESY OF LISA HEITKEMPER

Lisa Heitkemper, who uses a power wheelchair, took precautions and evacuated with her family as soon as they learned that a fire was close to home.

In the early morning of Oct. 8, 2017, Lisa Heitkemper's husband woke her up with a message anyone would dread: "Our hill is on fire!"

Although the fire was large and dramatic, it was still a couple of miles west of their house in Napa County. Normally, the Heitkemper family would wait to see if the fire moved closer before leaving their home. But because Heitkemper, who was diagnosed with multiple sclerosis in 2012, uses a power wheelchair, they decided to evacuate immediately.

"Had I not had MS, if I had been able to run and jump in the car at a moment's notice, we probably would have stayed and watched the fire from home," she says.

Heitkemper only had enough time to wake her 20-year-old son and grab the family's 13-year-old labradoodle. "I didn't have my medication or our important papers," she says. "I didn't even get a chance to get some clothes on. As I was slowly trying to get changed, my husband said, 'Are you kidding me? We need to go now!' So I just brought some clothes and shoes with me, and got in the car in my nightgown." She remembers looking at their wedding album up high on a shelf where she couldn't reach it and realized she had to let it go.

The Heitkemper family drove to a vantage point where they could overlook the hills surrounding their house. "It was basically a fire horseshoe—we could see three different wildfires to the east, west and north," Heitkemper says. She didn't know it at the time, but they were in the midst of the 2017 Northern California firestorm—the most destructive wildfire in the history of the state.



The view near Lisa Heitkemper's Napa County home during the 2017 Northern California wildfires.

PHOTO COURTESY OF LISA HEITKEMPER

After a couple of hours watching the fire and wind progress, the Heitkemper's decided they would be safe if they returned home. Although they lost power and cellphone service for more than three days and at one point were under an evacuation advisory, they and their property made it through the wildfires unscathed.

But the fire taught Heitkemper a lesson. "You talk about what to do in an emergency, but once it's happening, you're like a deer in the headlights," she says. She realized that because she lives with MS and uses a wheelchair to get around, natural emergencies pose added challenges. Whether it's a fire, earthquake, tornado, flood, hurricane or blizzard, extreme weather events require extra preparedness for people with MS.

Here's what the Heitkemper's and others with MS who lived through last summer's wildfires and hurricanes learned, along with tips from experts about how to deal with natural emergencies before, during and after they happen.

Be prepared

Ready.gov is a good resource for disaster preparedness plans. But if you have MS, you'll need to add other items to the emergency checklist this website recommends.

Register with local authorities. Experts recommend signing up for alerts from your local office of emergency management. Most counties have one—Google your county name and "emergency management," or find a statewide organization at fema.gov/emergency-management-agencies.

They advise contacting your local police and fire departments and ambulance service and telling them ahead of time you have a disability. You may also want to inquire about a registry in your locality for people who may need extra help evacuating in an emergency. The registry will provide vital information for local emergency planners and responders about any special needs you may have.

"It gives you peace of mind," Debbie Fagan says. "You can give them your phone number, address, contact information for relatives and where you would be in your home if they need to come in. All of that is added to the database that comes up if you call 911."

The Fagans also recommend that you check with your local electricity provider to see if it maintains a registry of people with health conditions that require electricity-related aids like air conditioning or refrigeration for medications. People on this registry can get status updates and priority for power restoration during an emergency.

Michael Fagan, who was diagnosed with MS in 1993 and uses a wheelchair, and his wife, Debbie, have weathered three major hurricanes since they moved to the Houston/Galveston, Texas, area—Rita, Ike and last summer's Harvey. The Fagans invite guest speakers from emergency-management organizations to their area MS support group to provide programs on emergency and hurricane preparedness.

Shelter. Since 2010, the Red Cross and Federal Emergency Management Agency (FEMA) have committed to providing general-population evacuation shelters that also have accommodations for people with disabilities. The reason, says Mary Casey-Lockyer, Red Cross senior associate for disaster health services, is to keep people with disabilities and their families or caregivers together. You can find the closest shelters at DisasterAssistance.gov. You can also find a list of hotels that participate in FEMA's Transitional Sheltering Assistance program at femaevachotels.com. FEMA may pick up the tab for your stay at these hotels, but availability is limited. Call in advance, especially if you need an accessible room, since hotels usually only have a few of these rooms.

Inside your go-bag



Batteries

Important documents like birth and marriage certificates, insurance inventories, deeds, IDs, stocks and bonds, and bank information

Portable radio

First aid kit

A list of all your prescription drugs, including the dosage, prescription number and pharmacy name, address and phone number

A medical alert tag or bracelet

Flashlight

But some states, including Florida, have statutes mandating that people who want to use special-needs shelters must register with their local facility first.

Susan Struder, who was diagnosed with MS in 1992 and uses a scooter, registered at her Hudson, Florida, shelter even though she didn't intend to evacuate her sturdy condo building when Hurricane Irma hit her hometown last September. But her friend, who also has MS and was alone during the storm, wanted company. The shelter, which was full at that point, directed Struder and her friend to a backup shelter at an elementary school, which was able to not only accommodate Struder's scooter, but also her friend's two cats. The lesson? Don't panic if you can't get

into a shelter specifically geared toward people with disabilities.

Support system. The Red Cross suggests you identify a minimum of three people who can assist you during an emergency, or who can simply check to make sure you're OK. You should also include someone outside of your immediate area who you can stay with or who can relay information to your family and friends.

And don't forget your pets. The Fagans say many shelters during Hurricane Harvey were pet friendly. But it's wise to make a plan for your pets' care just in case. The Humane Society of the United States (go to humanesociety.org and type "disaster" in the

search box) and the Centers for Disease Control and Prevention ([cdc.gov/features/Petsanddisasters](https://www.cdc.gov/features/Petsanddisasters)) offer tips for caring for animals during an emergency, along with a list of pet-friendly hotel websites.

If an emergency happens while you're at work, the bad news is that your employer is not required to have an evacuation plan. However, the Job Accommodation Network (JAN) notes that employers covered under the Americans with Disabilities Act that do have evacuation plans must include people with disabilities in those plans. If your employer hasn't established evacuation procedures, you can consult materials like JAN's emergency evacuation checklist (askjan.org/media/emergency.html).

Documents. Any basic emergency preparedness plan calls for taking important documents like birth and marriage certificates, insurance inventories, deeds, IDs, stocks and bonds, and bank information with you.

It's also important to include your medical records, health insurance cards, contact information for your healthcare providers, names and model numbers of your medical devices, and a list of all your prescription drugs—including the dosage, prescription number and pharmacy name, address and phone number. Heitkemper recommends making an extra copy of this list and giving it to a member of your support network. And make sure to wear a medical alert tag or bracelet.

Equipment and medications. If you use a motorized wheelchair or scooter, consider having a lightweight foldable manual chair as backup.

Ready.gov suggests having an extra battery for your wheelchair. You should also include a patch kit or a flat-tire sealant, along with an extra inner tube, in your emergency bag. And make sure to teach your support network how to operate your wheelchair or other equipment.

If you're in an area that's frequently in danger of power outages, consider buying a gas- or battery-powered generator. And it's a good idea to store a second set of mobility devices like canes or walkers at your workplace or a friend's house in case you need to evacuate without them.

Most experts also recommend packing at least a week's worth of medications in your bag.

Visit nationalMSsociety.org/emergencyprep for an extensive disaster preparedness plan and emergency resource list. Although the Society is not a crisis agency, MS Navigators are available before, during and after emergencies to help you connect with disaster-related resources and services. Angela Taylor, one of the managers of the Society's MS Navigator Services Delivery, says MS Navigators can help you, your family or your caregivers find solutions for a wide variety of needs.



Call 1-800-344-4867 or visit nationalMSsociety.org/navigator.

Get out safely, and stay safe

Along with checking weather reports and information from local emergency preparedness offices, also keep the following in mind during an emergency.

Transportation. The Red Cross doesn't offer emergency transportation, but local law enforcement and emergency management services do. These services will usually transfer you to shelters or a hospital, if needed. If you want to go elsewhere, you'll need to make private transportation plans.

Basic needs. Casey-Lockyer says Red Cross and FEMA shelters provide food, toiletries and emergency needs like incontinence supplies. They also have medical equipment like wheelchairs, walkers and canes, and can work with pharmacies and public health facilities to replace medications you were unable to bring with you. "There could be a gap of two to three days, though, depending on the state of the infrastructure," Casey-Lockyer says. Some pharmaceutical companies will replace MS medications that have been lost or destroyed in a disaster.

There will usually be a power source for recharging a wheelchair battery, but "we can't guarantee air conditioning," Casey-Lockyer says. If heat is an issue, pack a cooling vest in your go-bag. Struder

recommends bringing a pillow and inflatable air mattress, as you may be sleeping on the floor. Red Cross shelters also offer physical and mental health services, and can transport you to a hospital if you need advanced medical care.

After the disaster

Even if you aren't hurt or your home isn't damaged during a natural emergency, there can still be a psychological and financial toll. Fortunately, there are a variety of resources available at no charge.

General assistance. Dialing 211, or visiting **211search.org**, connects you with your local United Way, churches and community organizations that offer financial assistance, counseling and other forms of help.

The Disaster Assistance Improvement Program (DAIP) is designed to make applying for federal funds easier. DAIP administers **DisasterAssistance.gov**, where you can find more than 70 forms of assistance from 17 federal agencies, including emergency housing and food.

The federal government's multilingual Disaster Distress Helpline provides counseling and emotional support 24 hours a day. Call 1-800-985-5990 or text TalkWithUs to 66746.

Casey-Lockyer says the Salvation Army, Red Cross or other federal agencies and partners operate multiagency resource centers. "They're like a one-stop shop" for financial, medical and mental health assistance, she says. For instance, after hurricanes Harvey and Irma, Medicare and Medicaid waived the usual three- to five-year waiting period for people who needed new wheelchairs. You can find resource centers in your area at **redcross.org/about-us/our-work/disaster-relief**.

Salvation Army Disaster Relief Services provides meals, hygiene kits, social services, and emotional and spiritual care to disaster survivors. Check **disaster.salvationarmyusa.org** to see what's offered in your area.

There's no getting around the fact that natural emergencies are traumatic—especially if you have

MS. But preplanning can help lessen the impact. "I have terrible spasticity, and the stress during last summer's fires caused my legs to go straight out and stiff as boards," Heitkemper says. "But I learned that if you're organized, prepared and have an emergency plan, that really helps minimize the stress." ■

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



For help with disaster preparedness and emergency resources, visit **nationalMSsociety.org/emergencyprep**.

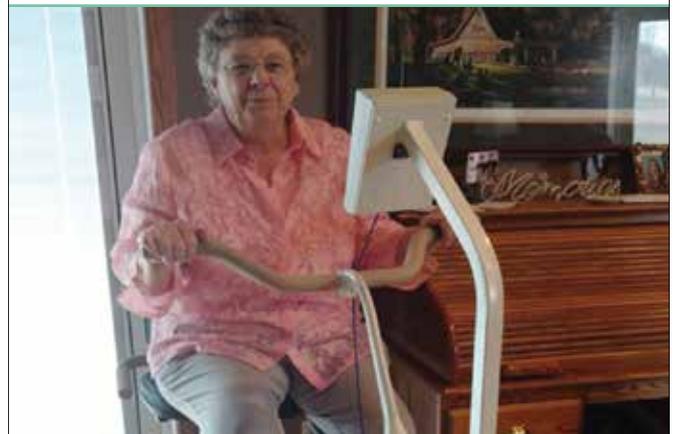
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What is OCREVUS?

OCREVUS is a prescription medicine used to treat adults with relapsing or primary progressive forms of multiple sclerosis.

It is not known if OCREVUS is safe or effective in children.

Who should not receive OCREVUS?

Do not receive OCREVUS if you have an active hepatitis B virus (HBV) infection.

Do not receive OCREVUS if you have had a life threatening allergic reaction to OCREVUS. Tell your healthcare provider if you have had an allergic reaction to OCREVUS or any of its ingredients in the past.

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

OCREVUS can cause serious side effects, including:

- **Infusion-related reactions:** OCREVUS can cause infusion-related reactions that can be serious and require you to be hospitalized. You will be monitored during your infusion and for at least 1 hour after each infusion of OCREVUS for signs and symptoms of an infusion-related reaction. Tell your healthcare provider or nurse if you have any symptoms (see accompanying Patient Information).

These infusion-related reactions can happen for up to 24 hours after your infusion. It is important that you call your healthcare provider right away if you have any of the signs or symptoms listed in the accompanying Patient Information.

If you get infusion-related reactions, your healthcare provider may need to stop or slow down the rate of your infusion.

• **Infection:**

- OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any signs of infection (see accompanying Patient Information). These signs can happen during treatment or after you have received your last dose of OCREVUS. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.
- **Progressive Multifocal Leukoencephalopathy (PML):** Although no cases have been seen with OCREVUS treatment in clinical trials, PML may happen with OCREVUS. PML is a rare brain infection that usually leads to death or severe disability. Tell your healthcare

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For people with relapsing or primary progressive forms of multiple sclerosis (MS)

MS

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OCREVUS is given every 6 months.‡

Ask your healthcare provider about OCREVUS.

provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness on 1 side of your body, strength, or using your arms or legs (see accompanying Patient Information).

- o **Hepatitis B virus (HBV) reactivation:** Before starting treatment with OCREVUS, your healthcare provider will do blood tests to check for hepatitis B viral infection. If you have ever had hepatitis B virus infection, the hepatitis B virus may become active again during or after treatment with OCREVUS. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. Your healthcare provider will monitor you if you are at risk for hepatitis B virus reactivation during treatment and after you stop receiving OCREVUS.
- o **Weakened immune system:** OCREVUS taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

What are the possible side effects of OCREVUS?

OCREVUS may cause serious side effects, including:

- **Risk of cancers (malignancies) including breast cancer.** Follow your healthcare provider's instructions about standard screening guidelines for breast cancer.

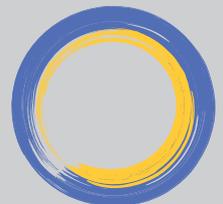
Most common side effects include infusion-related reactions and infections.

These are not all the possible side effects of OCREVUS.

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

For additional Important Safety Information, please see accompanying Patient Information.

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* In two 2-year clinical studies vs REBIF.

† REBIF® is a registered trademark of EMD Serono, Inc.

‡ First dose of OCREVUS is split—given as 2 separate infusions 2 weeks apart.

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PATIENT INFORMATION

OCREVUS™ (oak-rev-us)

(ocrelizumab)

injection, for intravenous use

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

OCREVUS can cause serious side effects, including:

- **Infusion reactions:** OCREVUS can cause infusion reactions that can be serious and require you to be hospitalized. You will be monitored during your infusion and for at least 1 hour after each infusion of OCREVUS for signs and symptoms of an infusion reaction. Tell your healthcare provider or nurse if you get any of these symptoms:
 - itchy skin
 - rash
 - hives
 - tiredness
 - coughing or wheezing
 - trouble breathing
 - throat irritation or pain
 - feeling faint
 - fever
 - redness on your face (flushing)
 - nausea
 - headache
 - swelling of the throat
 - dizziness
 - shortness of breath
 - fatigue
 - fast heartbeat

These infusion reactions can happen for up to 24 hours after your infusion. It is important that you call your healthcare provider right away if you get any of the signs or symptoms listed above after each infusion. If you get infusion reactions, your healthcare provider may need to stop or slow down the rate of your infusion.

• Infection:

- OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any of the following signs of infection including fever, chills, a cough that does not go away, or signs of herpes (such as cold sores, shingles, or genital sores). These signs can happen during treatment or after you have received your last dose of OCREVUS. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.
- **Progressive Multifocal Leukoencephalopathy (PML):** Although no cases have been seen with OCREVUS treatment in clinical trials, PML may happen with OCREVUS. PML is a rare brain infection that usually leads to death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness on 1 side of your body, strength, or using your arms or legs.
- **Hepatitis B virus (HBV) reactivation:** Before starting treatment with OCREVUS, your healthcare provider will do blood tests to check for hepatitis B viral infection. If you have ever had hepatitis B virus infection, the hepatitis B virus may become active again during or after treatment with OCREVUS. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. Your healthcare provider will monitor you if you are at risk for hepatitis B virus reactivation during treatment and after you stop receiving OCREVUS.
- **Weakened immune system:** OCREVUS taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

What is OCREVUS?

OCREVUS is a prescription medicine used to treat adults with relapsing or primary progressive forms of multiple sclerosis.

It is not known if OCREVUS is safe or effective in children.

Who should not receive OCREVUS?

- **Do not** receive OCREVUS if you have an active hepatitis B virus (HBV) infection.
- **Do not** receive OCREVUS if you have had a life threatening allergic reaction to OCREVUS. Tell your healthcare provider if you have had an allergic reaction to OCREVUS or any of its ingredients in the past. See "**What are the ingredients in OCREVUS?**" for a complete list of ingredients in OCREVUS.

Before receiving OCREVUS, tell your healthcare provider about all of your medical conditions, including if you:

- have or think you have an infection. See "**What is the most important information I should know about OCREVUS?**"
- have ever taken, take, or plan to take medicines that affect your immune system, or other treatments for MS. These medicines could increase your risk of getting an infection.
- have ever had hepatitis B or are a carrier of the hepatitis B virus.
- have had a recent vaccination or are scheduled to receive any vaccinations. **You should receive any required vaccines at least 6 weeks before you start treatment with OCREVUS.** You should **not receive** certain vaccines (called 'live' or 'live attenuated' vaccines) while you are being treated with OCREVUS and until your healthcare provider tells you that your immune system is no longer weakened.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if OCREVUS will harm your unborn baby. You should use birth control (contraception) during treatment with OCREVUS and for 6 months after your last infusion of OCREVUS.
- are breastfeeding or plan to breastfeed. It is not known if OCREVUS passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take OCREVUS.

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

How will I receive OCREVUS?

- OCREVUS is given through a needle placed in your vein (intravenous infusion) in your arm.
- Before treatment with OCREVUS, your healthcare provider will give you a corticosteroid medicine and an antihistamine to help reduce infusion reactions (make them less frequent and less severe). You may also receive other medicines to help reduce infusion reactions. See "**What is the most important information I should know about OCREVUS?**"
- Your first full dose of OCREVUS will be given as 2 separate infusions, 2 weeks apart. Each infusion will last about 2 hours and 30 minutes.
- Your next doses of OCREVUS will be given as one infusion every 6 months. These infusions will last about 3 hours and 30 minutes.

What are the possible side effects of OCREVUS?

OCREVUS may cause serious side effects, including:

- See **“What is the most important information I should know about OCREVUS?”**
- **Risk of cancers (malignancies) including breast cancer.** Follow your healthcare provider’s instructions about standard screening guidelines for breast cancer.

Most common side effects include infusion reactions and infections. See **“What is the most important information I should know about OCREVUS?”**

These are not all the possible side effects of OCREVUS.

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

General information about the safe and effective use of OCREVUS.

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

What are the ingredients in OCREVUS?

Active ingredient: ocrelizumab

Inactive ingredients: glacial acetic acid, polysorbate 20, sodium acetate trihydrate, trehalose dihydrate.

Manufactured by: Genentech, Inc.,
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For more information, go to www.OCREVUS.com or call 1-844-627-3887.

This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 3/2017

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PRIMAL



Anquette was diagnosed with MS in 2013.



Just breathe

Living with MS can be stressful. In this section, discover ways people with MS can manage stress. The deep breathing exercise below is a simple tool from the U.S. Department of Veterans Affairs that anyone can try for an instant pick-me-up.

1. **Sit** comfortably or lie down.
2. **Place** one hand on your stomach and one hand on your chest.
3. **Breathe** in slowly through your nose.
4. **Feel** your stomach expand as you inhale. If you are breathing from the stomach, the hand on your chest shouldn't move.
5. **Focus** on filling up your lower lungs with air.
6. **Slowly** exhale, releasing all the air out through your mouth.
7. **Use** your hand to feel your stomach fall as you exhale.
8. **Practice** breathing four to six breaths per minute (about one full inhale and exhale per 10-15 seconds).
9. **Repeat** this up to 10 times.

If you begin to get lightheaded, return to your normal breathing.

thrive

Forging a path
to your best life

Inside this section: Out-stressing stress 24

Out-stress stress



by Aviva Patz

Clarisa Walcott, 40, of Portland, Oregon, gets stressed every six months, when she's scheduled to get her infusions of Rituxan, an intravenous drug used for the joint pain and swelling that she experience with her multiple sclerosis.

"Most of the time my MS is in the background, but when it's close to infusion time, my anxiety goes up," says Walcott, a mother of three. "All of my symptoms start flaring—the chronic pain in my feet, vibrations in my legs and general weakness. Anxiety is a real trigger for me."

Life with MS is almost like having two diseases: the MS itself and the stress of getting care for the disease.

"One of the things stress does is create anxiety, which can lead to depression, and that makes people with MS feel like they're having a relapse, whether they are or not," says Emily Riser, MD, medical director of the Tanner Center for MS in Birmingham,

sing

How to identify and manage the tension MS might cause



PHOTO COURTESY OF LAURIE LEE

Laurie Lee uses breathing and meditation exercises to help manage her stress.

Alabama. “We don’t have all the evidence, but we do know that as with any other chronic disease, like heart disease and diabetes, stress leads to more symptoms and more visits to the doctor.”

Here are some of the top stressors for people with MS, how to recognize their impact on symptoms and strategies to help cope with stress.

Defining stress

Stress originally meant the chemical fight or flight reaction that prepares the body to face danger, but today it can be the result of anything that causes psychological tension—whether it’s a new symptom, a new medication or navigating the complex world of insurance.

Causes of stress

MS is unpredictable. That’s the top stressor, according to Rosalind Kalb, PhD, a clinical psychologist who has counseled people with MS for 35 years. “If we could tell people what is going to happen next week with their disease, they could manage it. It’s the not knowing that causes the most stress and anxiety.”

Clarisa Walcott says she feels stressed right before getting infusions. Yoga helps to calm her.

Jessica Oler, 31, of San Francisco, says that when she was diagnosed in 2012, “there was fear, there was depression, there was suicide stuff.” Walcott wakes up every day “wondering if something else is going to happen today with my MS,” and some days she cries about it.

Many symptoms are invisible to the world—and to your health care team. “Unless you tell your doctor, he or she can’t tell if you’re in a lot of pain, if you’re not sleeping at night, if you’re struggling at work because of cognitive issues,” Kalb says. “Then you leave the appointment with a renewal for your disease-modifying therapy (DMT), but you don’t know how to deal with your day-to-day symptoms.” Not treating those less-visible symptoms can lead to more stress.

Before attorney Laurie Lee, 71, retired from her law firm in Portland, Oregon, she occasionally had trouble talking and finding words. Her ability to prepare written analyses to clients was impaired, and she developed facial tics because of overwhelming stress. Now when she’s stressed, she still has trouble tracking and talking and then becomes irritable because

she can't communicate the way she wants to. She discovered she sometimes has aphasia (temporary inability to verbalize an important point or describe an event) only because her symptoms once occurred in front of her neurologist during an appointment.

With MS, choice—ordinarily a good thing—can also be a stressor. Today, thanks to an expanded toolbox of options, there are a variety of treatment decisions to be made. “Back in the 1980s, people were told to go home and rest, but today we have more than a dozen approved treatments with several different mechanisms of action,” Kalb says. “So if one doesn't work for you, your doctor will recommend another.” But the menu of options can leave people feeling confused and overwhelmed: “What's the best choice for me?” and “What if I don't choose the right one?” are common concerns.

It's normal to not know what to do first. Care for MS can involve any number of tasks: keeping up with doctor appointments and physical therapy; obtaining and remembering medications; keeping track of symptoms; filing for insurance claims; and figuring out how to pay for everything. “Many times, the abundance of these disease-specific tasks can feel overwhelming,” says Meghan Beier, PhD, assistant professor in the division of Rehabilitation Psychology and Neuropsychology at Johns Hopkins University School of Medicine.

Effect of stress on symptoms

Stress manifests differently for everyone. “For some people, it's hearts pounding, sweaty palms, stomachaches and headaches,” Kalb says. “For others, it's a chronic feeling of upset and worry and just feeling overwhelmed.” Stress might



For some people, it's hearts pounding, sweaty palms, stomachaches and headaches.”

—Rosalind Kalb, PhD

involve symptoms such as irritability or nervousness; expecting the worst and having difficulty making everyday decisions; constipation or diarrhea; headaches; shallow breathing and fatigue.

Any challenge people with MS face may seem worse when they're stressed, because it further taxes their already limited reserve of energy. Ultimately, Beier says, stress may play a role in secondary conditions such as insomnia, chronic pain, cardiovascular diseases such as high blood pressure, or even obesity.

Strategies that might help

Treatment decisions and doctors' appointments aren't going to go away, but the way a person handles them can help lower the stress they may bring. A variety of stress management techniques might help people become more resilient in general. Among them:

Yoga

Coping strategy: Walcott started practicing yoga when she was first diagnosed and had pain in her feet and the sensation of banding around her knees. “I would do yoga, and for 20 minutes afterward, I felt fairly close to normal. I don't know if it's the circulation or the breathing or the calming at the end, or some combination,” she says. “Now when I do yoga,” Walcott says, “I feel mentally, physically and emotionally stronger.”

Research shows: A 2016 study in the *Journal of Diagnostic Resources* shows that yoga is likely to “increase self-efficacy of MS patients through enhancing physical activity, increasing the strength of lower limbs and balance, decreasing fatigue and pain, and finally to promote social functioning and to relieve stress and anxiety.”



Practicing yoga can help decrease fatigue and pain.

Mindfulness meditation

Coping strategy: Lee tries to breathe and meditate for about 20 minutes a day using mobile apps like Insight Timer and Calm. She attended two retreats sponsored by complementary-medicine advocate and author Deepak Chopra, MD, where she learned health principles of Ayurveda and was given her own personal mantra. Over those intensive several days and in the weeks that followed, Lee says she was able to gradually cut back on her antidepressants and get off her anti-anxiety medication entirely (under the advice of her physician).

Research shows: In a 2016 study in the journal *Caring Sciences*, people with MS who received eight two-hour sessions of mindfulness-based stress reduction training (MBSR) saw improvements in physical health, emotional well-being, health distress, health perception, satisfaction with sexual function, fatigue severity and overall quality of life. A 2017 study in the journal *Mindfulness* adds that MBSR can also help with cognitive function in addition to stress reduction.

Positive affirmations

Coping strategy: Like the famous “I think I can” chant in “The Little Engine That Could,” affirmations can help you stay positive and feel in control. “I’ve found that it really helps me not catastrophize,” says Oler, who watches motivational videos on YouTube. “It reminds me that I’m strong and capable and I can handle all of this.” She says affirmations when she wakes up in the morning and throughout the day as needed, especially when she has an infusion coming up. “I have to stay strong on all levels,” she says.

Research shows: In a 2013 study in *PLOS ONE*, researchers found that people

Jessica Oler says she experienced depression around the time of her MS diagnosis.



can boost their ability to solve problems under pressure by using self-affirmation. In fact, study participants who were chronically stressed and completed a self-affirmation activity before a problem-solving task performed at the same level as participants with lower stress levels.

Manage the unpredictability

Coping strategy: If the fear factor is overwhelming, counseling can be a good place to start. In her work as an occupational therapist, Walcott teaches practices based on cognitive behavior therapy (CBT), which involves changing thoughts to change behavior, and incorporates them into her own daily life to manage her anxieties. For example, she was training for a 10K race when she started developing foot drop. “My brain kept ruminating on this one thing—how it’s going to affect me, my run, my children, my work, everything, so I stopped running,” she says. But then she realized she could ask her doctor to prescribe physical therapy, which allowed her to continue training. “Once I realized that I have a team of people who are there to guide me when I feel like this disease is taking over, I was able to change everything I thought,” Walcott says, “and changing my thoughts helped me change my behavior.”

Experts say: “When people get diagnosed, they immediately picture themselves sitting in a wheelchair and it’s terrifying. How can we get over that?” Dr. Riser asks. Her approach involves assembling a team that might include a medical care provider whom the person with MS can trust, family members and perhaps a dietitian, an exercise physiologist and a psychologist. She also encourages access to research and resources. Having this team in place and access to



Read more at
[nationalMSSociety.org/stress](https://www.nationalMSSociety.org/stress).



Call 1-800-344-4867 for a list of support groups near you or visit [nationalMSSociety.org/supportgroup](https://www.nationalMSSociety.org/supportgroup).

information helps people feel more in control with the support they need.

Other strategies

Advocate for your priorities:

Bring a list of your concerns to your appointments. “If your fatigue or sexual problems or mood or pain are at the top of the list, that’s what you need to present to your provider,” Kalb says. Schedule a follow-up appointment if necessary to get all your concerns addressed.

Seek out resources: Visit [nationalMSSociety.org/wellness](https://www.nationalMSSociety.org/wellness) to learn about wellness strategies, consult the MS Society brochure on Taming Stress and hear how other people are getting their MS needs addressed by joining an MS support group. Call 1-800-344-4867 for a list of groups near you or visit [nationalMSSociety.org/supportgroup](https://www.nationalMSSociety.org/supportgroup). You can also join the MS online community ([MSconnection.org](https://www.MSconnection.org)) to trade tips.

Make decisions for today and course-correct as needed: Work with a health care team you trust to sort out the best treatment option for you today, knowing that if it’s not effective, you can switch. “It’s not a personal failure,” Kalb says. Keep an open line of communication with your providers to assess your treatments as you go along. One way to track your symptoms is by downloading an app such as one from the MS Association of America ([mysaa.org/msaa-community/mobile](https://www.mysaa.org/msaa-community/mobile)).

Break down your to-dos into bite-sized chunks: Beier recommends taking one step each day. For example, if you start to experience a new symptom or sensation, there are steps you can take to name and address it:

Steps

1

Don't panic. Document your experience. How often does it occur, what time of day, in reaction to something specific? Writing things down can help bring clarity. You can also track the frequency or severity with a symptom tracker, which is a beneficial resource for your doctor when deciding on a treatment plan.

2

Try to understand whether what you're experiencing is from MS, a side effect of a medication or something completely unrelated. You may need your nurse's or doctor's help with this—don't spend too much time attempting to self-diagnose on the internet. Make an appointment to see your doctor.

3

Gather (and continue) your documentation, and prepare a list of questions for your upcoming appointment. Talk to a trusted friend or family about it, if it feels good to talk.

4

If you're feeling overwhelmed or stressed, consider talking with a counselor. An MS Navigator at the Society can refer you to a professional in your area. Call 1-800-344-4867.

5

Once you and your doctor have agreed on a plan of action or treatment, it may be helpful to continue documenting your experience. Check in with your health care providers as scheduled, and move on with life.

"The tasks and steps will be different for each person, but breaking them down always reduces the stress of getting them done," Beier says.

“

When people get diagnosed, they picture themselves sitting in a wheelchair and it's terrifying. How can we get over that?"

—Emily Riser, MD

What doesn't work

Some types of online research are counterproductive. "People get on the internet and start freaking out," says Dr. Riser. "Don't get into chat rooms [with someone making negative remarks] because it's just going to make you more depressed and more anxious." Instead, look for trusted sources of information online, and limit your time on social media if you find you feel more depressed afterward instead of connected and affirmed.

Untreated depression and anxiety may also lead to alcohol and drug use and smoking, which can make MS symptoms worse. "Smoking impacts the disease, and alcohol increases neuropathy and affects the liver, cognition and balance," Dr. Riser says.

When Oler would try to "drown her sorrows" with alcohol, it just made her feel more lonely and depressed, she says. It also threw off her balance and heightened her pain and other symptoms.

Today Oler says she has learned the importance of self-care and being an advocate for herself. She goes to talk therapy, and she meditates and repeats affirmations every morning to stay positive. "Now instead of dreading the day," she says, "I'm excited to see what it holds." ■

Aviva Patz is a freelance writer in Montclair, New Jersey.

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



We all face the obstacles of relapsing MS the same way: with determination.

WHAT IS LEMTRADA?

LEMTRADA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS). Because of its risks, LEMTRADA is generally used in people who have tried 2 or more MS medicines that have not worked well enough. It is not known if LEMTRADA is safe and effective for use in children under 17 years of age.

IMPORTANT SAFETY INFORMATION

LEMTRADA can cause serious side effects including:

Serious autoimmune problems: Some people receiving LEMTRADA develop a condition where the immune cells in your body attack other cells or organs in the body (autoimmunity), which can be serious and may cause death. Serious autoimmune problems may include:

- Immune thrombocytopenia, which is when reduced platelet counts in your blood cause severe bleeding that, if not treated, may cause life-threatening problems. Call your healthcare provider right away if you have any of the following symptoms: easy bruising; bleeding from a cut that is hard to stop; heavier menstrual periods than normal; bleeding from your gums or nose that is new or takes longer than usual to stop; small, scattered spots on your skin that are red, pink, or purple
- Kidney problems called anti-glomerular basement membrane disease, which can, if untreated, lead to severe kidney damage, kidney failure that needs dialysis, a kidney transplant, or death. Call your healthcare provider right away if you have any of the following symptoms: blood in the urine (red or tea-colored urine); swelling of legs or feet; coughing up blood

It is important for you to have blood and urine tests before you receive, while you are receiving and every month, for 4 years or longer, after you receive your last LEMTRADA infusion.

Serious infusion reactions: LEMTRADA can cause serious infusion reactions that may cause death. Serious infusion reactions may happen while you receive, or up to 24 hours or longer after you receive LEMTRADA.



Join the many others who asked their healthcare providers about LEMTRADA. Learn more at Lemtrada.com

- You will receive your infusion at a healthcare facility with equipment and staff trained to manage infusion reactions, including serious allergic reactions, and urgent heart or breathing problems. You will be watched while you receive, and for 2 hours or longer after you receive, LEMTRADA. If a serious infusion reaction happens while you are receiving LEMTRADA, your infusion may be stopped.

Tell your healthcare provider right away if you have any of the following symptoms of a serious infusion reaction during the infusion, and after you have left the healthcare facility:

- swelling in your mouth or throat
- weakness
- chest pain
- trouble breathing
- fast, slow, or irregular heartbeat
- rash

To lower your chances of getting a serious infusion reaction, your healthcare provider will give you a medicine called corticosteroids before your first 3 infusions of a treatment course. You may also be given other medicines before or after the infusion to try to reduce your chances of having these reactions or to treat them after they happen.

Certain cancers: Receiving LEMTRADA may increase your chance of getting some kinds of cancers, including thyroid cancer, skin cancer (melanoma), and blood cancers called lymphoproliferative disorders and lymphoma. Call your healthcare provider if you have the following symptoms that may be a sign of thyroid cancer:

- new lump
- pain in front of neck
- trouble swallowing or breathing
- swelling in your neck
- hoarseness or other voice changes that do not go away
- cough that is not caused by a cold

Please see continued Important Safety Information and Medication Guide, including serious side effects, on adjacent pages and full Prescribing Information on Lemtrada.com.

LEMTRADA[®]
alemtuzumab iv^{12mg}

ADVERTISEMENT

IMPORTANT SAFETY INFORMATION (continued)

Have your skin checked before you start receiving LEMTRADA and each year while you are receiving treatment to monitor for symptoms of skin cancer.

Because of risks of autoimmunity, infusion reactions, and some kinds of cancers, LEMTRADA is only available through a restricted program called the LEMTRADA Risk Evaluation and Mitigation Strategy (REMS) Program.

Do not receive LEMTRADA if you are infected with human immunodeficiency virus (HIV).

Thyroid problems: Some patients taking LEMTRADA may get an overactive thyroid (hyperthyroidism) or an underactive thyroid (hypothyroidism). Call your healthcare provider if you have any of these symptoms:

- excessive sweating
- unexplained weight loss
- eye swelling
- nervousness
- fast heartbeat
- unexplained weight gain
- feeling cold
- worsening tiredness
- constipation

Low blood counts (cytopenias): LEMTRADA may cause a decrease in some types of blood cells. Some people with these low blood counts have increased infections. Call your doctor right away if you have symptoms of cytopenias such as:

- weakness
- chest pain
- yellowing of the skin or whites of the eyes (jaundice)
- dark urine
- fast heartbeat

Serious infections: LEMTRADA may cause you to have a serious infection while you receive and after receiving a course of treatment. Serious infections may include:

- **Herpes viral infections.** Some people taking LEMTRADA have an increased chance of getting herpes viral infections. Take any medicines as prescribed by your healthcare provider to reduce your chances of getting these infections.
- **Tuberculosis.** Your healthcare provider should check you for tuberculosis before you receive LEMTRADA.
- **Hepatitis.** People who are at high risk of, or are carriers of, hepatitis B (HBV) or hepatitis C (HCV) may be at risk of irreversible liver damage.
- **Listeria.** People who receive LEMTRADA have an increased chance of getting a bacterial infection called listeria, which can lead to significant complications or death. Avoid foods that may be a source of listeria or make sure foods that may contain listeria are heated well.

These are not all the possible infections that could happen while on LEMTRADA. Call your healthcare provider right away if you have symptoms of a serious infection such as fever or swollen glands. Talk to your healthcare provider before you get vaccinations after receiving LEMTRADA. Certain vaccinations may increase your chances of getting infections.

Inflammation of the gallbladder without gallstones (acalculous cholecystitis): LEMTRADA may increase your chance of getting inflammation of the gallbladder without gallstones, a serious medical condition that can be life-threatening. Call your healthcare provider right away if you have any of the following symptoms:

- stomach pain or discomfort
- fever
- nausea or vomiting

Swelling of lung tissue (pneumonitis): Some people have had swelling of the lung tissue while receiving LEMTRADA. Call your healthcare provider right away if you have the following symptoms:

- shortness of breath
- wheezing
- coughing up blood
- cough
- chest pain or tightness

Before receiving LEMTRADA, tell your healthcare provider if you:

- are taking a medicine called Campath® (alemtuzumab)
- have bleeding, thyroid, or kidney problems
- have HIV
- have a recent history of infection
- have received a live vaccine in the past 6 weeks before receiving LEMTRADA or plan to receive any live vaccines. Ask your healthcare provider if you are not sure if your vaccine is a live vaccine
- are pregnant or plan to become pregnant. LEMTRADA may harm your unborn baby. You should use birth control while receiving LEMTRADA and for 4 months after your course of treatment
- are breastfeeding or plan to breastfeed. You and your healthcare provider should decide if you should receive LEMTRADA or breastfeed. You should not do both.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. LEMTRADA and other medicines may affect each other, causing side effects. Especially tell your healthcare provider if you take medicines that increase your chance of getting infections, including medicines used to treat cancer or to control your immune system.

The most common side effects of LEMTRADA include:

- rash
- nausea
- herpes viral infection
- pain in your arms or legs
- dizziness
- headache
- urinary tract infection
- hives
- back pain
- stomach pain
- thyroid problems
- feeling tired
- itching
- diarrhea
- sudden redness in face, neck, or chest
- fever
- trouble sleeping
- fungal infection
- sinus infection
- vomiting
- swelling of your nose and throat
- upper respiratory infection
- joint pain
- mouth pain or sore throat
- tingling sensation

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of LEMTRADA.

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

Please see Medication Guide, including serious side effects, on adjacent pages and full Prescribing Information on Lemtrada.com.



Register for more information at Lemtrada.com, or speak to an *MS One to One*® Nurse at 1-855-676-6326

SANOFI GENZYME 

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GZUS.LEMT.15.07.1872(1)b(1) January 2018

LEMTRADA[®]
alemtuzumab ^{12mg} iv

MEDICATION GUIDE
LEMTRADA® (lem-TRA-da)
(alemtuzumab)
Injection for intravenous infusion

Rx Only

Read this Medication Guide before you start receiving LEMTRADA and before you begin each treatment course. There may be new information. This information does not take the place of talking to your healthcare provider about your medical condition or treatment.

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

LEMTRADA can cause serious side effects, including:

1. Serious autoimmune problems. Some people receiving LEMTRADA develop a condition where the immune cells in your body attack other cells or organs in the body (autoimmunity) which can be serious and may cause death. Serious autoimmune problems may include:

- **immune thrombocytopenic purpura (ITP).** LEMTRADA may cause the number of platelets in your blood to be reduced (ITP). ITP can cause severe bleeding that, if not treated, may cause life-threatening problems. Call your healthcare provider right away if you have any of the following symptoms:

- easy bruising
- bleeding from a cut that is hard to stop
- heavier menstrual periods than normal
- bleeding from your gums or nose that is new or takes longer than usual to stop
- small, scattered spots on your skin that are red, pink, or purple

- **kidney problems.** LEMTRADA may cause a serious kidney problem, called anti-glomerular basement membrane disease. If this happens and you do not get treated, anti-glomerular basement membrane disease can lead to severe kidney damage, kidney failure that needs dialysis, a kidney transplant, or death. Call your healthcare provider right away if you have any of the following symptoms:

- blood in the urine (red or tea-colored urine)
- swelling in your legs or feet
- coughing up blood

Side effects may happen while you receive LEMTRADA and for 4 years after you stop receiving LEMTRADA. Your healthcare provider will order blood and urine tests before you receive, while you are receiving, and every month for 4 years after you receive your last LEMTRADA infusion. You may need to continue these blood and urine tests after 4 years if you have any autoimmune signs or symptoms. The blood and urine tests will help your healthcare provider watch for signs and symptoms of serious autoimmune problems.

It is important to have your blood and urine tested, even if you are feeling well and do not have any symptoms from LEMTRADA and your multiple sclerosis. This may help your healthcare provider find any problems early and will increase your chances of getting better.

2. Serious infusion reactions. LEMTRADA can cause serious infusion reactions that may cause death. Serious infusion reactions may happen while you receive, or up to 24 hours or longer after you receive LEMTRADA.

You will receive your infusion at a healthcare facility with equipment and staff trained to manage infusion reactions. You will be watched while you receive and for 2 hours after you receive LEMTRADA. **It is important** that you stay at the infusion center for **2 hours** after your infusion is finished or longer if your healthcare provider decides you need to stay longer. If a serious infusion reaction happens while you are receiving LEMTRADA, your infusion may be stopped.

Tell your healthcare provider right away if you have any of the following symptoms of a serious infusion reaction during the infusion, and after you have left the healthcare facility:

- swelling in your mouth or throat
- trouble breathing
- weakness
- fast, slow, or irregular heart beat
- chest pain
- rash

To lower your chances of getting a serious infusion reaction, your healthcare provider will give you a medicine called corticosteroids before your first 3 infusions of a treatment course. You may also be given other medicines before or after the infusion to try reduce your chances of these reactions or to treat them after they happen.

3. Certain cancers. Receiving LEMTRADA may increase your chance of getting some kinds of cancers, including thyroid cancer, skin cancer (melanoma), and blood cancers called lymphoproliferative disorders and lymphoma. Call your healthcare provider if you have the following symptoms that may be a sign of thyroid cancer:

- new lump
- swelling in your neck
- pain in the front of your neck
- hoarseness or other voice changes that do not go away
- trouble swallowing or breathing
- cough that is not caused by a cold

You should have your skin checked before you start receiving LEMTRADA and each year while you are receiving treatment to monitor symptoms of skin cancer.

Because of your risk of autoimmunity, infusion reactions and the risk of some kinds of cancers, LEMTRADA is only available through a restricted program called the LEMTRADA Risk Evaluation and Mitigation Strategy (REMS) Program. Call 1-855-676-6326 to enroll in the LEMTRADA REMS Program.

- You and your healthcare provider must be enrolled in the LEMTRADA REMS Program.
- LEMTRADA can only be given at a certified healthcare facility that participates in the LEMTRADA REMS Program. Your healthcare provider can give you information on how to find a certified healthcare facility.
- Read the LEMTRADA REMS “What You Need to Know About LEMTRADA Treatment: A Patient Guide” and “What you Need to Know About LEMTRADA Treatment and Infusion Reactions: A Patient Guide” after you are enrolled in the program.
- Carry your LEMTRADA REMS Patient Safety Information Card with you in case of an emergency.

What is LEMTRADA?

LEMTRADA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS). Because of its risks, LEMTRADA is generally used in people who have tried 2 or more MS medicines that have not worked well enough. It is not known if LEMTRADA is safe and effective for use in children under 17 years of age.

Who should not receive LEMTRADA?

Do not receive LEMTRADA if you are infected with human immunodeficiency virus (HIV).

What should I tell my healthcare provider before receiving LEMTRADA?

Before receiving LEMTRADA, tell your healthcare provider if you:

- are taking a medicine called Campath®. Alemtuzumab, the active ingredient in LEMTRADA, is the same drug as Campath.
- have bleeding problems
- have thyroid problems
- have kidney problems
- have a recent history of infection

- have HIV
- have received a live vaccine in the past 6 weeks before receiving LEMTRADA or plan to receive any live vaccines. Ask your healthcare provider if you are not sure if your vaccine is a live vaccine.
- are pregnant or plan to become pregnant. LEMTRADA may harm your unborn baby. You should use birth control while receiving LEMTRADA and for 4 months after your course of treatment.
- are breastfeeding or plan to breastfeed. It is not known if LEMTRADA passes into your breast milk. You and your healthcare provider should decide if you should receive LEMTRADA or breastfeed. You should not do both.

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

LEMTRADA and other medicines may affect each other causing side effects. Especially tell your healthcare provider if you take medicines that increase your chance of getting infections, including medicines used to treat cancer or to control your immune system. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How will I receive LEMTRADA?

- LEMTRADA is given through a needle placed in your vein (IV infusion).
- It takes about 4 hours to receive a full dose of LEMTRADA each day.
- You will receive LEMTRADA over 2 treatment courses.
- You will receive LEMTRADA for 5 days in a row (consecutive) for the first treatment course and then for 3 days in a row (consecutive) about 1 year later for your second treatment course.

What are the possible side effects of LEMTRADA?

LEMTRADA may cause serious side effects including:

- See **"What is the most important information I should know about LEMTRADA?"**
- **thyroid problems.** Some people who receive LEMTRADA may get thyroid problems including an overactive thyroid (hyperthyroidism) or an underactive thyroid (hypothyroidism). Your healthcare provider will do blood tests to check how your thyroid is working. Call your healthcare provider if you have any of the symptoms of thyroid problems.
Symptoms of **hyperthyroidism** may include:

- excessive sweating
- nervousness
- unexplained weight loss
- fast heartbeat
- eye swelling

Symptoms of **hypothyroidism** may include:

- unexplained weight gain
- worsening tiredness
- feeling cold
- constipation

- **low blood counts (cytopenias).** LEMTRADA may cause a decrease in some types of blood cells. Some people with these low blood counts have increased infections. Symptoms of cytopenias may include:

- weakness
- dark urine
- chest pain
- fast heartbeat
- yellowing of the skin or whites of eyes (jaundice)

Your healthcare provider will do blood tests to check for cytopenias. Call your healthcare provider right away if you have symptoms listed above.

- **serious infections.** LEMTRADA may cause you to have serious infections while you receive and after receiving a treatment course. Serious infections may include:

- **herpes viral infections.** Some people taking LEMTRADA have an increased chance of getting herpes viral infections. Your healthcare provider will prescribe medicines to reduce your chances of getting these infections. Take these medicines exactly as your healthcare provider tells you to.
- **human papilloma virus (HPV).** Females have an increased chance of getting a cervical HPV infection. If you are a female, you should have an HPV screening each year.
- **tuberculosis.** Your healthcare provider should check you for tuberculosis before you receive LEMTRADA.
- **fungal infections.**
- **listeria.** People who receive LEMTRADA have an increased chance of getting an infection caused by the bacteria listeria, which can lead to significant complications or death. Avoid foods that may be a source for listeria (for example, deli meat, unpasteurized milk and cheese products, soft cheeses, or undercooked meat, seafood or poultry) or make sure that the food you eat which may contain listeria is heated well if you receive treatment with LEMTRADA.

Call your healthcare provider right away if you have symptoms of a serious infection, such as fever or swollen glands. You may need to go to the hospital for treatment if you get a serious infection. It is important to tell the healthcare providers that you have received LEMTRADA.

Talk to your healthcare provider before you get vaccinations after receiving LEMTRADA. Certain vaccinations may increase your chances of getting infections.

- **Inflammation of the gallbladder without gallstones (acalculous cholecystitis).** LEMTRADA may increase your chance of getting inflammation of the gallbladder without gallstones, a serious medical condition that can be life-threatening. Call your healthcare provider right away if you have any of the following symptoms of acalculous cholecystitis, which may include:
- stomach pain or discomfort
- fever
- nausea or vomiting
- **swelling of lung tissue (pneumonitis).** Some people have had swelling of the lung tissue while receiving LEMTRADA. Call your healthcare provider right away if you have the following symptoms:

- shortness of breath
- chest pain or tightness
- cough
- coughing up blood
- wheezing

The most common side effects of LEMTRADA include:

- rash
- headache
- thyroid problems
- fever
- swelling of your nose and throat (nasopharyngitis)
- nausea
- urinary tract infection
- feeling tired
- trouble sleeping
- upper respiratory tract infection
- herpes viral infection
- hives
- itching
- fungal infection
- joint pain
- pain in your arms or legs
- back pain
- diarrhea
- sinus infection
- mouth pain or sore throat
- tingling sensation
- dizziness
- stomach pain
- sudden redness in face, neck, or chest
- vomiting

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

These are not all the possible side effects of LEMTRADA. For more information, ask your healthcare provider or pharmacist.

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

General information about the safe and effective use of LEMTRADA.

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

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

For more information, go to www.LemtradaREMS.com or call Genzyme at 1-855-676-6326.

What are the ingredients in LEMTRADA?

Active ingredient: alemtuzumab

Inactive ingredients: sodium chloride, dibasic sodium phosphate, potassium chloride, potassium dihydrogen phosphate, polysorbate 80, disodium edetate dihydrate, and water for injection.

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

Manufactured and distributed by:

Genzyme Corporation

500 Kendall Street

Cambridge, MA 02142

US License Number: 1596

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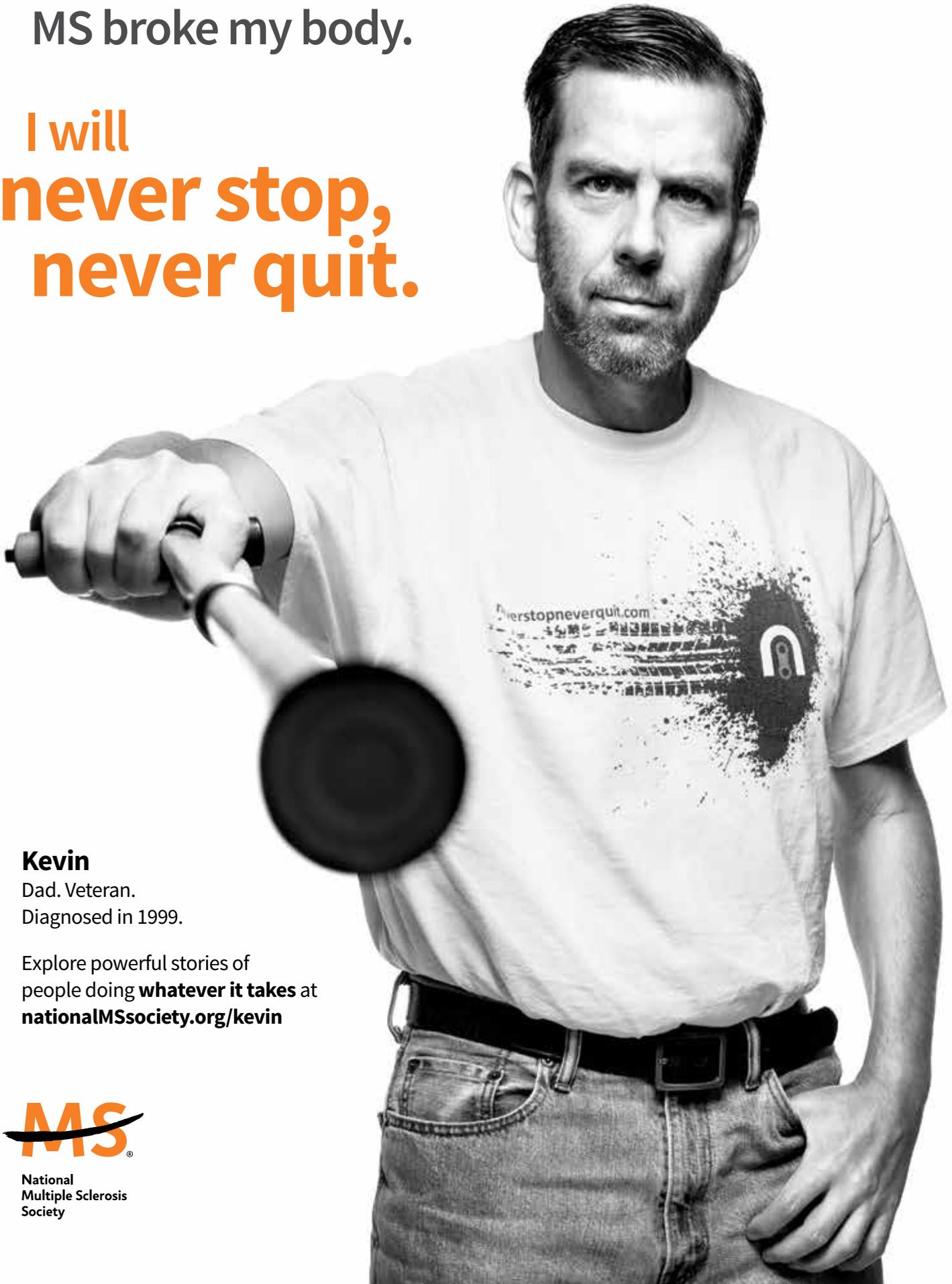
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MS broke my body.

I will
**never stop,
never quit.**



Kevin

Dad. Veteran.

Diagnosed in 1999.

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people doing **whatever it takes** at
nationalMSSociety.org/kevin



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Glatopa®: a generic glatiramer acetate with an identity all its own.



COPAXONE
(glatiramer acetate injection)

Glatopa
(glatiramer acetate injection)

If your doctor has prescribed glatiramer acetate for your relapsing-form of multiple sclerosis—go Glatopa. Glatopa is the first FDA-approved generic for Copaxone® (glatiramer acetate), and it's made in the USA. With Glatopa, you're backed by GlatopaCare®, which provides free, ongoing individualized support—no matter if you're new to glatiramer acetate or making a switch. And it's all provided by Sandoz, a Novartis Division, known for high-quality generics. **Rethink Generic. Go Glatopa**

Go Glatopa—the medicine you expect and the support you deserve

Find out more about Glatopa and GlatopaCare by calling **1.855.GLATOPA** (1.855.452.8672) or visiting glatopa.com/enroll

Indication

Glatopa® (glatiramer acetate injection) is indicated for the treatment of patients with relapsing-forms of multiple sclerosis.

Important Safety Information

Do not take Glatopa® if you are allergic to glatiramer acetate, mannitol, or any of the ingredients in Glatopa.

Some patients report a short-term reaction within minutes after injecting glatiramer acetate. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, fast heartbeat, anxiety, and trouble breathing. These symptoms generally appear within minutes of an injection, last about 15 minutes, and do not require specific treatment. During the postmarketing period, there have been reports of patients with similar symptoms who received emergency medical care. **If symptoms become severe, call the emergency phone number in your area.** Call your doctor right away if you develop hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the injection site. If any of the above occurs, do not give yourself any more injections until your doctor tells you to begin again.

Chest pain may occur either as part of the immediate postinjection reaction or on its own. This pain should only last a few minutes. You may experience more than one such episode, usually beginning at least one month after starting treatment. Tell your doctor if you experience chest pain that lasts for a long time or feels very intense.

A permanent indentation under the skin (lipoatrophy) or, rarely, necrosis at the injection site may occur, due to local destruction of fat tissue. Be sure to follow proper injection technique and inform your doctor of any skin changes.

The most common side effects in studies of glatiramer acetate injection are redness, pain, swelling, itching, or a lump at the site of injection, flushing, rash, shortness of breath, and chest pain. These are not all of the possible side effects of glatiramer acetate. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking Glatopa.

To report SUSPECTED ADVERSE REACTIONS, contact Sandoz Inc. at 1-800-525-8747 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Please see Brief Summary of full Prescribing Information on the following page.

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Glatopa
(glatiramer acetate injection)
20mg/mL • 40mg/mL

Patient Information

Glatopa® (glatiramer acetate injection) for Subcutaneous Use

Read this Patient Information before you start using Glatopa 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 Glatopa?

Glatopa is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS).

It is not known if Glatopa is safe and effective in children under 18 years of age.

Glatopa is supplied as a 1 mL single dose glass syringe with attached 1/2 inch length and 29 gauge needle.

Who should not use Glatopa?

- Do not use Glatopa if you are allergic to glatiramer acetate, mannitol, or any of the ingredients in Glatopa.

What should I tell my doctor before using Glatopa? Before you use Glatopa, tell your doctor if you:

- are pregnant or plan to become pregnant. It is not known if glatiramer acetate will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if glatiramer acetate passes into your breast milk. Talk to your doctor about the best way to feed your baby while using Glatopa.

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

Glatopa may affect the way other medicines work, and other medicines may affect how glatiramer acetate works.

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.

How should I use Glatopa?

- For detailed instructions, visit www.glatopa.com for complete information on how to use Glatopa.
- Your doctor will tell you how much Glatopa to use and when to use it.
- Glatopa is given by injection under your skin (subcutaneously).
- Use Glatopa exactly as your doctor tells you to use it.
- Since every body type is different, talk with your doctor about the injection areas that are best for you.
- You should receive your first dose of Glatopa with a doctor or nurse present. This might be at your doctor's office or with a visiting home health nurse who will teach you how to give your Glatopa injections.

What are the possible side effects of Glatopa?

Glatopa may cause serious side effects, including:

- Post-Injection Reactions.** Serious side effects may happen within minutes after you inject Glatopa at any time during your course of treatment. Call your doctor right away if you have any of these post-injection reaction symptoms including:

- redness to your cheeks or other parts of the body (flushing)
- chest pain
- fast heart beat
- anxiety
- breathing problems or tightness in your throat
- swelling, rash, hives, or itching

If you have symptoms of a post-injection reaction, do not give yourself more injections until a doctor tells you to.

- Chest Pain.** You can have chest pain as part of a post-injection reaction or by itself. This type of chest pain usually lasts a few minutes and can begin around

1 month after you start using Glatopa. Call your doctor right away if you have chest pain while using Glatopa.

- Damage to your skin.** Damage to the fatty tissue just under your skin's surface (lipoatrophy) and, rarely, death of your skin tissue (necrosis) can happen when you use Glatopa. Damage to the fatty tissue under your skin can cause a "dent" at the injection site that may not go away. You can reduce your chance of developing these problems by:
 - following your doctor's instructions for how to use Glatopa.
 - choosing a different injection area each time you use Glatopa.

The most common side effects of Glatopa include:

- skin problems at your injection site including:
 - redness
 - pain
 - swelling
 - itching
 - lumps
- rash
- shortness of breath
- flushing (vasodilation)

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 Glatopa. 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.

How should I store Glatopa?

- Store Glatopa in a refrigerator between 36°F to 46°F (2°C to 8°C).
- When you are not able to refrigerate Glatopa, you may store it for up to 1 month at room temperature between 59°F to 86°F (15°C to 30°C).
- Protect Glatopa from light or high temperature.
- Do not freeze Glatopa syringes. If a syringe freezes, throw it away in a sharps disposable container.

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

General information about the safe and effective use of Glatopa.

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

This Patient Information summarizes the most important information about Glatopa.

If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about Glatopa that is written for health professionals.

For more information, go to www.glatopa.com or call Sandoz GlatopaCare® at 1-855-452-8672.

What are the ingredients in Glatopa?

Active ingredient: glatiramer acetate

Inactive ingredient: mannitol

Marketed By: Sandoz Inc., Princeton, NJ 08540

Distributed By: Sandoz Inc., Princeton, NJ 08540

Product of the USA

This brief summary is based on Glatopa FDA-approved patient labeling, revised: 02/2018



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41



solve

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

Inside this section

Beautiful melody | 42

Novel ideas | 50

Habits that improve cognitive function

- Physical activity
- Openness to experience
- Curiosity and creativity
- Social connections
- Mindfulness meditation
- Brain-training games
- Getting enough sleep

Cognitive function and working memory are often a concern for people with MS. While there are many ways to improve brain function in general, such as increasing physical activity and getting enough sleep, a new pilot research project by Janet Shucard, PhD, is determining whether computer-based training can help improve the cognitive function in people with MS.

Learn more about the initial results of Shucard's study on page 53.

Source: Christopher Bergland, Psychology Today



Dawnia, diagnosed in 2006

Beautiful melody

Robin Franklin, PhD, is pioneering research in myelin repair to reverse damage associated with progressive MS.

by Susan Worley

Robin Franklin, PhD, has been named the fifth recipient of the National Multiple Sclerosis Society's Barancik Prize for Innovation in MS Research for his pioneering research focusing on regenerating myelin to halt or reverse damage associated with progressive MS.

Franklin is a professor of stem cell medicine at the Wellcome Trust-MRC Cambridge Stem Cell Institute and director of the MS Society Cambridge Centre for Myelin Repair in Cambridge, England.

"Professor Franklin continues to make significant advances in myelin repair, offering real hope that solutions will be found that restore function to people living with MS," notes Bruce Bebo, PhD, Society executive vice president of research.

The Barancik Prize, funded by the Charles and Margery Barancik Foundation, is the world's largest award created exclusively for the recognition of MS research. Major supporters of MS research for more than 20 years, the Baranciks established the \$100,000 international prize to reward exceptionally innovative scientific research geared toward treating or curing MS.

Early career

The many intriguing facets of Franklin's research career began with an intense scientific curiosity about cells in the brain, including those that play a significant role

in the repair of damage caused by multiple sclerosis.

"Two things have interested me most during my career as laboratory scientist," Franklin says. "One is the brain, which is by far the most interesting and most complex of all the organs in the body. And the other is tissue regeneration, a property of biology that is unique to living organisms. These two primary interests led naturally to a focus on regenerative processes in the brain."

The focus of Franklin's earliest research on the brain was oligodendrocytes, the cells that produce myelin—the protective sheath that surrounds neurons in the brain and enables them to successfully transmit signals. It is damage to myelin and the underlying nerve fibers that is responsible for a variety of MS symptoms, which range from visual problems to difficulties with movement and balance.

"Before the 1980s, scientists were taught that cells in the brain couldn't regenerate," Franklin says. "But from the early 1980s onward, it became apparent that while this was generally true, it was not true of oligodendrocytes. My PhD supervisor at the University of Cambridge, Bill Blakemore, was a real pioneer in describing the process by which myelin was regenerated in the brain, and in demonstrating that myelin was actually a component of the brain that can regenerate very well."

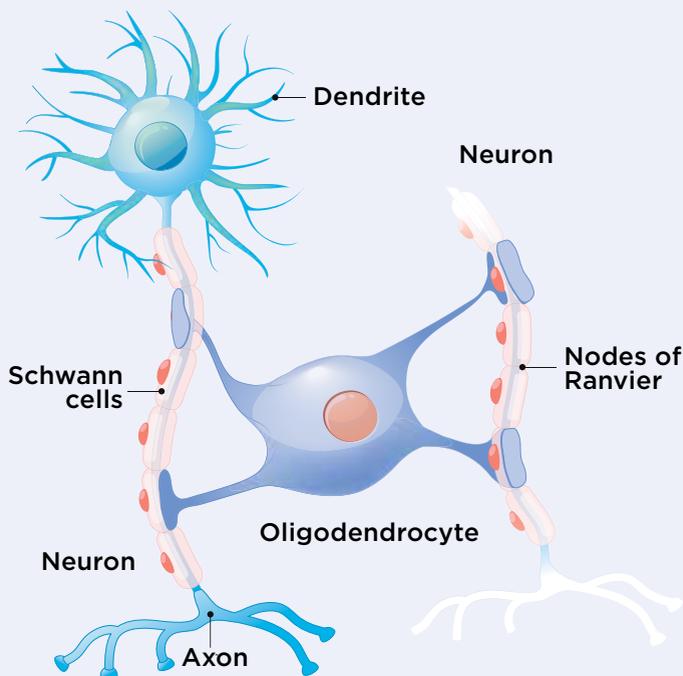
Robin Franklin, professor of stem cell medicine at the Wellcome Trust-MRC Cambridge Stem Cell Institute and director of the MS Society Cambridge Centre for Myelin Repair, has received the 2017 Barancik Prize for Innovation in Multiple Sclerosis Research.



PHOTO COURTESY OF ROBIN FRANKLIN

For the past 20 years, Franklin has continued the work of his first mentor—deepening his examination of oligodendrocytes and taking a closer look at the stem cells (known to scientists as oligodendrocyte progenitor cells) that produce them. These stem cells are especially important because when oligodendrocytes are lost or damaged during MS relapses, or episodes involving myelin damage, they must be replaced.

Stimulating myelin repair



The Society is supporting research looking at key molecules that are important to the cells that make myelin (oligodendrocytes) and that may serve as targets for promoting myelin repair.

Jonah Chan, PhD, the first recipient of the Society's Barancik Prize who also focuses on myelin repair, commented on the originality that characterizes Franklin's exploration of the remyelination process.

“It would be nearly impossible for me to highlight a single achievement from professor Franklin's tremendous body of work. I can only say that his work, which has recently resulted in an ongoing clinical trial, is transformative. I feel truly fortunate to have Robin as a colleague, an example and a friend.”

—JONAH CHAN,
RACHLEFF PROFESSOR IN THE DEPARTMENT OF
NEUROLOGY AT UCSF SCHOOL OF MEDICINE

“The general belief used to be that it was necessary to transplant stem cells in order to regenerate tissue in any part of the body,” Franklin explains. “But my work has helped advocate the idea that in fact you don't have to transplant stem cells, because there are plenty of them already in the brain. If you understand what controls those stem cells and what they do, you can design drugs to control the behavior of stem cells in a way that is helpful to the regenerative process.”

The effect of aging on myelin repair

Franklin was the first scientist to describe the impact of aging on the formation of new oligodendrocytes and to clearly establish the connection between aging and secondary progressive MS.

“Remyelination is a beautiful and exquisitely orchestrated process that occurs spontaneously and works efficiently after injury in the early stages of MS,” Franklin notes. He explains that after stem cells are activated in the area of injury, they migrate and undergo cell division so that they become abundant in the vicinity of injury. Finally, they undergo a change that allows them to become myelin-forming cells.

“When this process is working correctly, it is like a great symphony orchestra, with all the instruments playing in tune and producing a beautiful melody,” he explains, “But as you get older, this very complex and highly regulated process gets a bit tired, and after a while the instruments don’t necessarily all play at the right time. Or they may begin to play the wrong notes, or play certain notes too softly or too loudly, so that the music they play becomes unrecognizable.”

In individuals with MS, the process of remyelination becomes less well-regulated and less well-orchestrated with age. Eventually it results in an inability to produce myelin, which coincides with the onset of secondary progressive disease.

“Nearly all people with MS eventually reach this phase where the regenerative process is so inefficient that it can’t prevent the loss of nerve fibers,” Franklin says. “It is necessary to find a way to put myelin back on the nerve fibers to stop them from degenerating, because once nerve fibers degenerate, they are lost forever.”

Developing a therapy to promote remyelination

For Franklin and his colleagues, the road to developing a therapy that encourages remyelination began with defining the key stages of the regenerative process and understanding the molecules involved.

“One of the things that we have tried to do is identify who the key players are in each movement of the symphony—that is, who the key players and the conductor are during the regenerative process,” Franklin says. “And a few years ago my colleague Charles French-Constant and I discovered that there is a receptor, called RXR, which is critically important in the final step of making a stem cell into a new oligodendrocyte.”

Franklin and his colleagues also discovered that a drug called bexarotene, which has the ability to activate that receptor, already exists and is used in the clinical treatment of a type of lymphoma. One advantage of studying a drug currently in clinical use is that it already has undergone significant testing. Thanks to Franklin’s discoveries, a clinical trial examining the use of bexarotene to regenerate myelin is underway.

“What is most exciting now is that we are gaining a deeper understanding of how age affects the defects in stem cells that occur as you get older,” Franklin says. “And, as a result of that deeper understanding, we are beginning to identify ways to rejuvenate stem cells and make them work as efficiently in the older person as they do in young people. Our future goals are to refine that understanding and enable the development and implementation of highly effective drugs to treat secondary progressive MS.” ■

Susan Worley is a freelance medical writer in Bryn Mawr, Pennsylvania.



To learn more about the Barancik Prize, visit nationalMSsociety.org/Barancik.

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

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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.

Once-daily
AUBAGIO[®]
(teriflunomide)^{14 mg}
Tablets

AUBAGIO is available in 14 mg and 7 mg tablets.

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.
- **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 are encouraged to report side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 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.

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Medication Guide

AUBAGIO (*oh-BAH-gee-oh*) (teriflunomide) tablets

Rx Only

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 AUBAGIOCall 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, hydroxypropylcellulose, 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.

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November 2016

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relapsing MS in the background

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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.

Please see Medication Guide for AUBAGIO and full Prescribing Information, including boxed WARNING, available on www.aubagio.com
SAUS.AUBA.17.05.3505

Once-daily
AUBAGIO[®]
(teriflunomide) 14 mg tablets

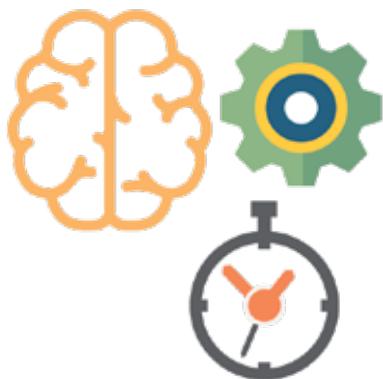
AUBAGIO is available in 14 mg and 7 mg tablets.

Novel ideas



The Society wants to fund a variety of research, whether it be training or large or small research grants, to maximize every dollar, and to have part of its research portfolio available to take high-risk ‘moon shots.’”

—CLAUDE SCHOFIELD, PHD



Pilot projects focus on cutting-edge, innovative MS research.

by Mary E. King, PhD

Finding funding for a truly novel idea can be difficult. Granting agencies want to know two important things before seriously considering whether to fund a proposal for multiple sclerosis research. First, does the investigator already have a good track record in MS research? And second, is the proposed study likely to succeed, which means the investigator must provide data or a published study to support the proposal? Agencies want to make sure that their investments have a high likelihood of producing useful results.

But how does an investigator get that very first grant to test a new idea and get the first bit of data? The National Multiple Sclerosis Society funds high-risk pilot grants to quickly test novel ideas and allow researchers to gather preliminary data so they can apply for longer-term funding.

Maximizing every dollar

“The Society wants to fund a variety of research, whether it be training or large or small research grants, to maximize every dollar, and to have part of its research portfolio available to take high-risk ‘moon shots,’” says Claude Schofield, PhD, director of discovery research for the Society. “Our one-year, \$40,000 pilot grants allow us to fund this type of research and see if an idea has potential.”

“The high-risk pilot grant is a very popular funding mechanism with our researchers,” Schofield says. “This gives them seed money to test out novel ideas and see if they will develop into a larger project. It attracts researchers who are already in the MS field as well as new investigators at the beginning of their careers, for whom this may be the very first grant. It also attracts experienced investigators from other related research fields who have an idea that may translate into MS research.”

Here are three pilot projects with promising results that led to larger Society grants.



ILLUSTRATION BY ROY SCOTT



Ovarian aging and MS progression



PHOTO COURTESY OF JENNIFER GRAVES

Jennifer Graves, PhD, is researching how aging and hormonal changes affect the course of a woman's MS.

Researcher:

Jennifer Graves, MD, PhD, assistant professor, Department of Neurology, UCSF School of Medicine, University of California, San Francisco

The details:

Dr. Graves looked at whether “ovarian aging” might help explain the course of MS in women. Dr. Graves explains: “We know the mean age of transition from an inflammatory to a progressive phase of MS in women is around 45, conspicuously during perimenopausal changes. This is different from men, who, unfortunately, tend to progress faster and earlier in terms of disability.”

Dr. Graves received a pilot grant to measure the concentrations of anti-Müllerian hormone (AMH), a hormone whose levels in the blood decline as the ovaries age, in women with MS and in women without MS. These individuals were participating in a research study in which they were followed for 10 years, with annual examinations and MRI scans. AMH was selected for study in part because its concentration doesn't vary significantly during the menstrual cycle.

Results:

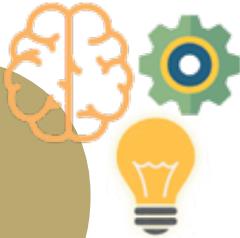
The results support Dr. Graves' hypothesis. “We found associations between AMH levels and MS severity metrics, including decreasing brain volume and worsening clinical outcomes,” she says.

The success of this study led her to propose a much larger study, recently funded by the Society, to continue to study AMH in women, looking at whether it correlates with additional MRI findings and other aging markers. The new larger study also will include men using markers specific for their biologic aging, such as testosterone.

Dr. Graves emphasizes the importance of the Society's pilot grants: “It's very challenging, if not impossible, if you have a brand-new hypothesis, to go straight to larger grants. Those all require a substantial amount of pilot data and proof of concept. This pilot was absolutely critical for my ability to show evidence to support my hypothesis and to obtain larger research funding. We were also able to write a high-profile story that brought this hypothesis to the forefront both at MS research meetings and as a published paper.”



2



Improving cognitive function



PHOTO COURTESY OF JANET SHUCARD

Can a computer-based program help improve memory in people with MS? Janet Shucard, PhD, led a study that shows cognitive improvement is possible.

Researcher:

Janet Shucard, PhD, associate professor of neurology, associate director of the Division of Cognitive Neuroscience, Jacobs School of Medicine and Biomedical Sciences, the State University of New York at Buffalo, along with her colleagues David Shucard, PhD, and Thomas Covey, PhD

The details:

The team used a pilot grant from the Society to study whether a computer-based program designed to train working memory improved cognitive performance in people with MS compared to people without MS. Shucard points out that people with MS are often concerned about changes in cognitive function, including working memory. Working memory is the part of memory that provides temporary storage and processing of the information necessary for such complex cognitive tasks as language comprehension, learning and reasoning.

Results:

“The pilot study showed that people with MS did, in fact, improve, and that they improved at a similar rate as healthy control participants,” Shucard says. This improvement with training had been shown in healthy controls in the past, she emphasizes. “Our study was the first to use dense electrophysiological scalp-recorded measures of brain function that allowed us to detect changes in the brain after training in both healthy controls and in individuals with MS.”

The baseline pre-training results from the study group with MS were only slightly lower than the healthy participants, so they were representative of individuals who might benefit from early intervention to stave off later problems with cognition, Shucard explains.

Shucard had previously done similar work to examine neurocognitive deficits in working memory in individuals with lupus, but the pilot grant allowed her to apply this approach to a new area of research: MS. “A very nice thing about the Society is that it provides a means for researchers to obtain a small amount of funding to collect data and test out a hypothesis like this. The results [from the pilot study] showed promise and led us to apply for and receive a larger grant to do a full-scale study in MS,” Shucard says.



3 Internet intervention to increase physical activity



Learn more about the Society's approach to research at nationalMSSociety.org/research.

PHOTO COURTESY OF ROBERT MOTL



Get moving! Initial results of Robert Motl's study show that online coaching to increase physical activity can help improve quality of life in people with MS.

Researcher:

Robert Motl, PhD, associate director of research, UAB/Lakeshore Research Collaborative; and professor, department of physical therapy, University of Alabama at Birmingham

The details:

This pilot project examined the feasibility and efficacy of combining an internet-based intervention with short video-chat sessions with coaches, to increase physical activity and improve symptoms, cognition, mobility and quality of life in people with MS. Motl obtained a Society pilot grant for conducting this six-month clinical trial.

Motl and his colleagues used a website to provide participants with a great deal of information about changing behavior and increasing physical activity. "And then the second part of [the intervention] was provided by behavioral coaches who interacted with these individuals over video conferencing," Motl says. "The coaches really helped individuals understand what they were learning and how to apply and individualize it," in 15 10-minute video chats. Activity was tracked with step counters, and other effects were measured with questionnaires and other assessment tools.

A control group consisted of individuals with MS who waited for six months to receive the same intervention. They completed all the same measures at the same time as the study group but before beginning the program.

Results:

The intervention not only increased physical activity but also reduced fatigue, depression, anxiety and pain, and improved quality of life, walking, cognition and body composition in the group. "This shows the potential for an intervention that increases physical activity to broadly improve many outcomes in people with MS," Motl says.

Motl is continuing his research with a larger grant from the Society to explore the effects of the program in a much larger sample size. He hopes to learn how effective it is in a broader population of individuals with MS, and to understand how and why it works for some and not for others.

"These awards give researchers the confidence and the courage to boldly step forward to detect new approaches that can really have demonstrable effects in the lives of people with MS," Motl says. ■

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

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

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As of January 2018, people here have taken GILENYA and have been compensated for their time. The patients featured may no longer be taking GILENYA today.

More than **225,000** people have been treated with GILENYA worldwide. This includes people in clinical trials and those prescribed GILENYA—join them and say, **“HEY MS, Take This!”**

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

IMPORTANT SAFETY INFORMATION You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, or certain types of heart failure. Do not take GILENYA if you have an irregular

or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT as seen on an ECG, or if you take medicines that change your heart rhythm. Do not take GILENYA if you are allergic to fingolimod or any of the other ingredients.

*GILENYA can result in a slow heart rate when first taken. You will be observed by a health care professional for at least 6 hours after you take your first dose. You may need to repeat this monitoring if you miss a dose.

Please see additional Important Safety Information on the next page and Brief Summary of Important Product Information on the following pages.



Talk to your health care professional to see if GILENYA is right for you.



Visit gilenya.com to learn more.

IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

- Slow heart rate, especially after first dose. You will be monitored by a health care professional for at least 6 hours after your first 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 feeling dizzy or tired or feeling like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after the first dose. Do not stop taking GILENYA without consulting with your doctor. 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. 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 before you start GILENYA. GILENYA may decrease the way vaccines work in your body, especially the chicken pox vaccine. Call your doctor right away if 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. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with thinking, eyesight, strength, balance, weakness on 1 side of your body, or using your arms and legs.
- 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 may be 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 occurred rarely in patients 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 headache, confusion, seizures, loss of vision, or weakness.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.

- Liver problems. Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.
- Increases in blood pressure (BP). BP should be monitored during treatment.
- Skin cancers including basal cell carcinoma (BCC) and melanoma. Talk to your doctor if you notice any skin nodules (shiny, pearly nodules), patches or open sores that do not heal within weeks, or unusual moles which may appear to change in color, shape, or size over time. These may be signs of skin cancer.

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. Women who take GILENYA should not breastfeed, as it is not known if GILENYA passes into breast milk. 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; 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.

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. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while taking GILENYA and for at least 2 months after stopping GILENYA treatment.

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.

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.



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

BRIEF SUMMARY

IMPORTANT FACTS ABOUT GILENYA

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 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 (ECG) before you take your first dose of GILENYA.

You will be observed by a health care professional for at least 6 hours after you take your first dose of GILENYA.

After you take your first dose of GILENYA:

- Your pulse and blood pressure should be checked every hour.
- You should be observed by a health care 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
- 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 health care 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 and decrease the way vaccines work in your body to prevent certain diseases, especially the chicken pox vaccine. 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 before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:

- fever
- tiredness
- body aches
- chills
- nausea
- vomiting
- headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion (these may be symptoms of meningitis)

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. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with:

- thinking
- eyesight
- strength
- balance
- weakness on 1 side of your body
- using your arms and legs

4. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as an 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 may be 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) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if GILENYA is safe and effective in children under 18 years of age.

Who should not take GILENYA?

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or warning stroke, 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
- are taking certain medicines that change your heart rhythm
- are allergic (hypersensitive) to fingolimod or any of the other ingredients of GILENYA listed at the end of this medication guide. Allergic reactions, which could include symptoms of rash or itchy hives, swelling of lips, tongue or face, are more likely to occur on the day you start GILENYA treatment but may occur later. If you think you may be allergic, ask your doctor for advice.

If any of the above situations apply to you, tell your doctor.

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 warning 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 taking medicines that lower your immune system. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the full course of the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure

- skin cancers such as basal cell carcinoma (BCC) and melanoma.
- 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.gilenya-pregnancyregistry.com.

- Are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

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.

Especially tell your doctor if you take vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.

How should I take GILENYA?

- You will be observed by a health care professional for at least 6 hours after your first dose of GILENYA. 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 health care professional for at least 6 hours when you take your next dose. If you need to be observed by a health care 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 health care 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.

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

Serious side effects include:

- **Swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients 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 headache
 - confusion
 - seizures
 - loss of vision
 - weakness
- **Breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **Liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. 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
- **Skin cancers including basal cell carcinoma (BCC) and melanoma.** Talk to your doctor if you notice any skin nodules (e.g., shiny pearly nodules), patches or open sores that do not heal within weeks, or unusual moles which may appear to change in color, shape, or size over time. These may be signs of skin cancer.

The most common side effects of GILENYA include:

- headache
- abnormal liver tests
- diarrhea
- cough
- flu
- sinusitis
- back pain
- 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 the FDA at 1-800-FDA-1088.

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

General information about GILENYA

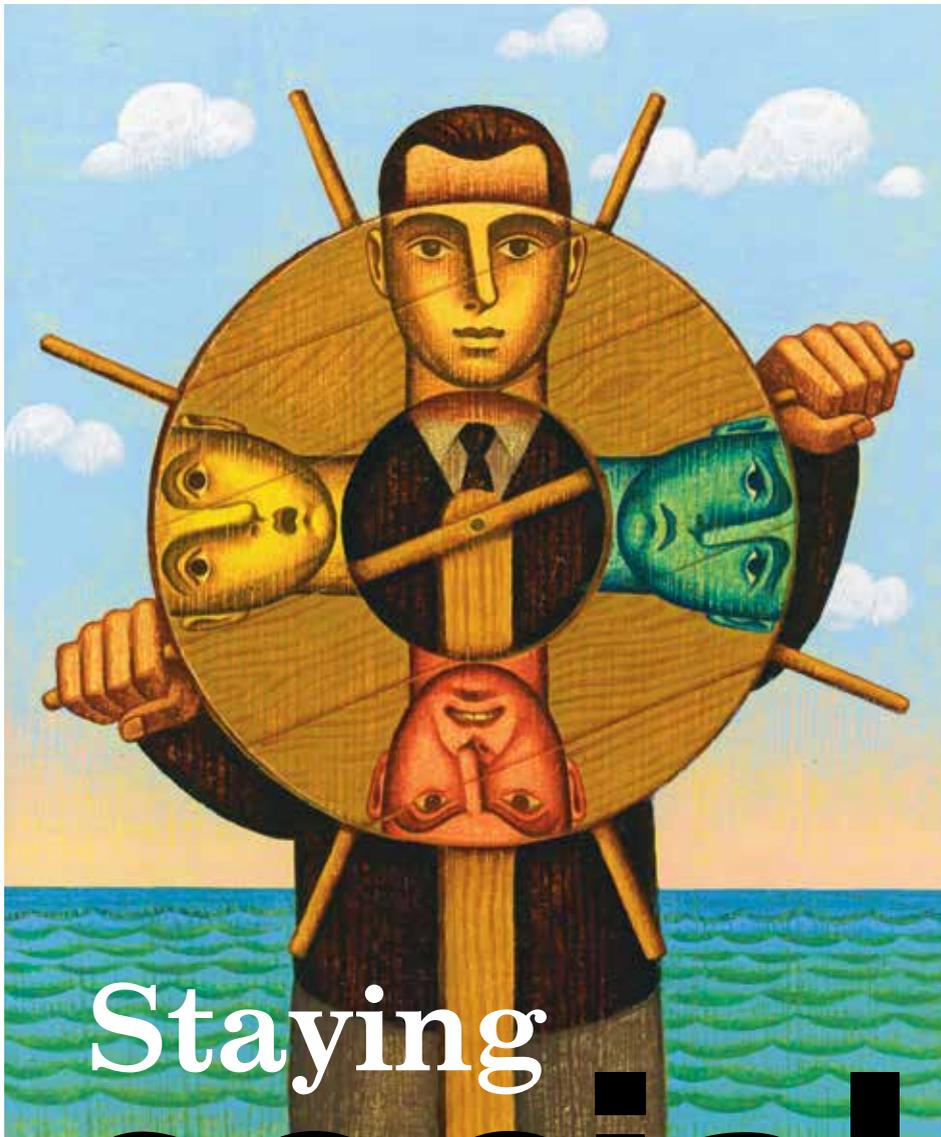
Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms you have. It may harm them.

You can ask your doctor or pharmacist for information about GILENYA that is written for health care professionals.

What are the ingredients in GILENYA?

Active ingredient: fingolimod

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



Staying social

Some people with MS may have difficulty interpreting what others are feeling.

by Lori De Milto

After Meg Balter was diagnosed with multiple sclerosis at age 21, she began experiencing cognitive changes that made it harder for her to think, focus and remember things. What she didn't realize was that she also had changes in her social cognition: how people process and apply information about other people and social situations.

Also called reading social cues, social cognition includes interpreting facial expressions, understanding how other people are feeling and being able to show empathy. People who have problems reading social cues may not recognize, for example, that someone with downturned lips is sad, or that a furrowed brow means confusion or annoyance. Without being able to read social cues, people can't react appropriately.

"Only in the past few years have we become aware of these problems with social cognition in MS," says Helen Genova, PhD, assistant director of neuropsychology and neuroscience at the Kessler Foundation in West Orange, New Jersey. "If you're not aware of it, it's very hard to treat it."

"I wasn't aware that I wasn't 'getting it' until I participated in a study at the Kessler Foundation," says Balter, who lives in Roseland, New Jersey.

The study took place more than 30 years after Balter had been diagnosed with MS.

Genova and Jean Lengenfelder, PhD, conducted the pilot study, in which Balter and other participants looked at photographs of faces while having a functional MRI—a type of brain scan that can measure areas of brain activity by monitoring blood flow. They had to decide what emotions the faces were showing, such as happy, sad or angry. The participants also received training in how to recognize emotions. The researchers used the brain scans to see how participants were processing different emotions to compare them to people without MS.

Subtle changes in the brain

In one recent study, researchers in Portugal found that people with MS had more problems with social cognition than people who did not have MS, and these problems were linked to subtle changes in the brain. The researchers, led by Sonia Batista, MD, of the University of Coimbra, published study findings in the journal *Neurology* in May 2017.

Researchers found that people with MS had much lower scores on “Theory of Mind” tests than those without MS. The tests measured how well participants read other people’s beliefs, desires and intentions after looking at photos and videos. The results suggested that people with MS had lower than average scores interpreting photos and videos than people who did not have MS, though no participants had perfect scores.

The results:

- **Photo test average score:**
 - 59 percent for people with MS
 - 82 percent for healthy participants
- **Video test average score:**
 - 75 percent for people with MS
 - 88 percent for healthy participants.

This confirmed findings in earlier studies. The scores for people with MS were not related to their level of physical disability or how long they had been living with MS. But lower scores were related to the loss of myelin in the brain’s “social network,” the areas of the brain experts think are associated with social cognition.

Problems reading social cues may be linked to other cognitive problems such as processing speed, says

Social cognition study

Participants

- 120 participants
 - 60 people with MS
 - 60 people of the same age and education level who didn’t have MS
- Type of MS
 - Relapsing-remitting MS: 50 people
 - Secondary progressive MS: 10 people
- Average time since diagnosis: 11 years

Tests

- Measuring how well participants could read other people’s beliefs, desires and intentions (Theory of Mind tests) after looking at photos and videos
- MRI brain scans

Genova, who also conducts research on cognitive function in MS. “A lot of times people with MS understand other people’s emotions, but it takes them much longer to understand and process the social cues and come to the correct response,” she says.

Why social cues are important

Social cues guide our interactions and relationships with family, friends, colleagues and strangers. “The ability to interpret other people’s feelings and intentions is very important for people with MS, since having good support is one of the main factors in whether people have a good quality of life,” Dr. Batista said.

People with MS who have problems reading social cues sometimes limit or even stop their social activities. For example, Deanna Lagrand Yeakle enjoys going to her local art center to do ceramics, but she tends to avoid parties and crowds, where she’s afraid she might say the wrong thing. “There is always someone to talk to at the art center. It’s light chatter, so I don’t feel lost in a sea of words, nor do I feel the challenge to prove myself intellectually,” says the 55-year-old Salem,



PHOTO COURTESY OF DEANNA LAGRAND YEAKLE

Deanna Lagrand Yeakle finds that her ceramics class provides the perfect balance of social and individual activity. Her family has been supportive of her hobby. She's wearing an apron her sister made for her and using tools her son gave her.

Oregon, resident, who was diagnosed with MS at age 35.

Balter also worries about what she might say and finds being in a crowd difficult. "Over the years, I stopped initiating conversations. I would listen and maybe comment," she says.

Are you missing cues?

Like Balter, other people with MS might not know that they have problems reading social cues.

If you're having problems in relationships with friends or family members, such as fighting more often or hearing from them less often, you might be missing their social cues. You can also explain the problem to family members and friends and ask them to tell you if you're not recognizing their feelings.

Strengthen skills with practice

While not being able to read social cues is frustrating and embarrassing, avoiding other people isn't the answer. "This problem is likely to get worse if you stop interacting with people. It's a use it or lose it type of thing," Genova says. Practicing your social skills helps you strengthen them.

A few good friends, a supportive family and humor help Lagrand Yeakle cope with her cognitive problems. "You don't need 100 friends. You need a couple of good friends and some acquaintances," she says. "Be willing to laugh at yourself. Your good friends will laugh with you."

Balter is a member of the Public Discipleship and Social Justice Committee at St. Thomas Moore Church. She enjoys researching projects and interacting with other committee members and uses what she learned in the Kessler Foundation study to help her read people's emotions and respond appropriately. "The study taught me how to listen and to look," she says.

Ways to make socializing easier

1. Bring a friend or family member to support you.
2. Spend time with people one-on-one or in small groups.
3. Take exercise classes for people with MS.
4. Join an MS support group.

Deanna Lagrand Yeakle enjoys walking with her dog and chatting with neighbors along the way.

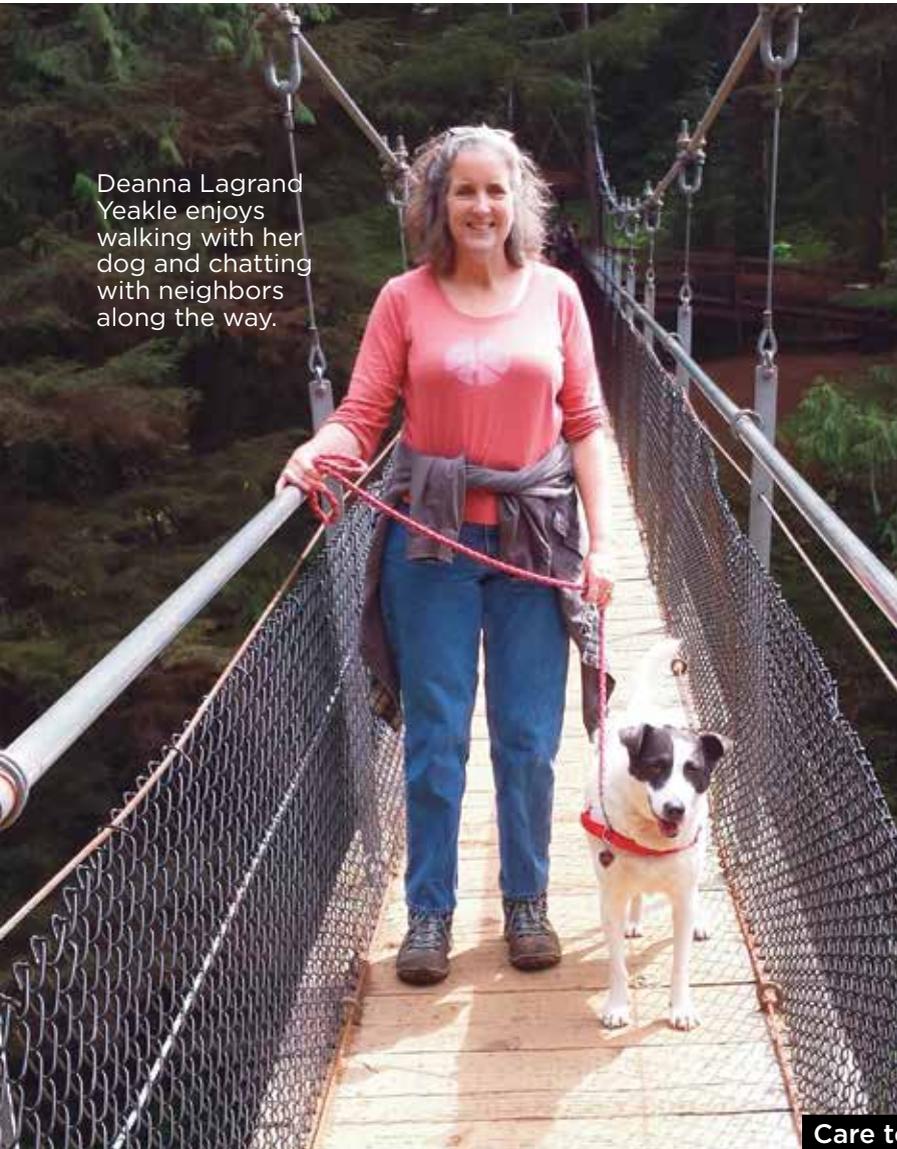


PHOTO COURTESY OF DEANNA LAGRAND YEAKLE

Be social, even if it's difficult for you. "It's never a good idea to just stay home," Genova says. "That leads to increased social isolation and the feeling that you can't handle this." Lagrand Yeakle agrees. "Even if the only thing I do is walk my dog and chat with neighbors along the way, I have to get out," she says. Genova suggests asking family and friends to tell you how they are feeling, instead of expecting you to recognize their emotions, and interacting with other people with MS.

More research on social cues

Dr. Batista and Genova both say that more research on social cognition in MS is needed. "We don't know how many people have these deficits, and we don't know why people have them," Genova says. With funding from the National Multiple Sclerosis Society, Genova is working on a pilot study using functional MRI to examine changes in the brains of people with MS after they have completed a program to help them process emotions. The study will be completed in 2019. ■

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



Learn how others embrace their MS. Start or join a conversation on **MSconnection.org**.



Contact an MS Navigator with your questions at 1-800-344-4867.

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

NEW!



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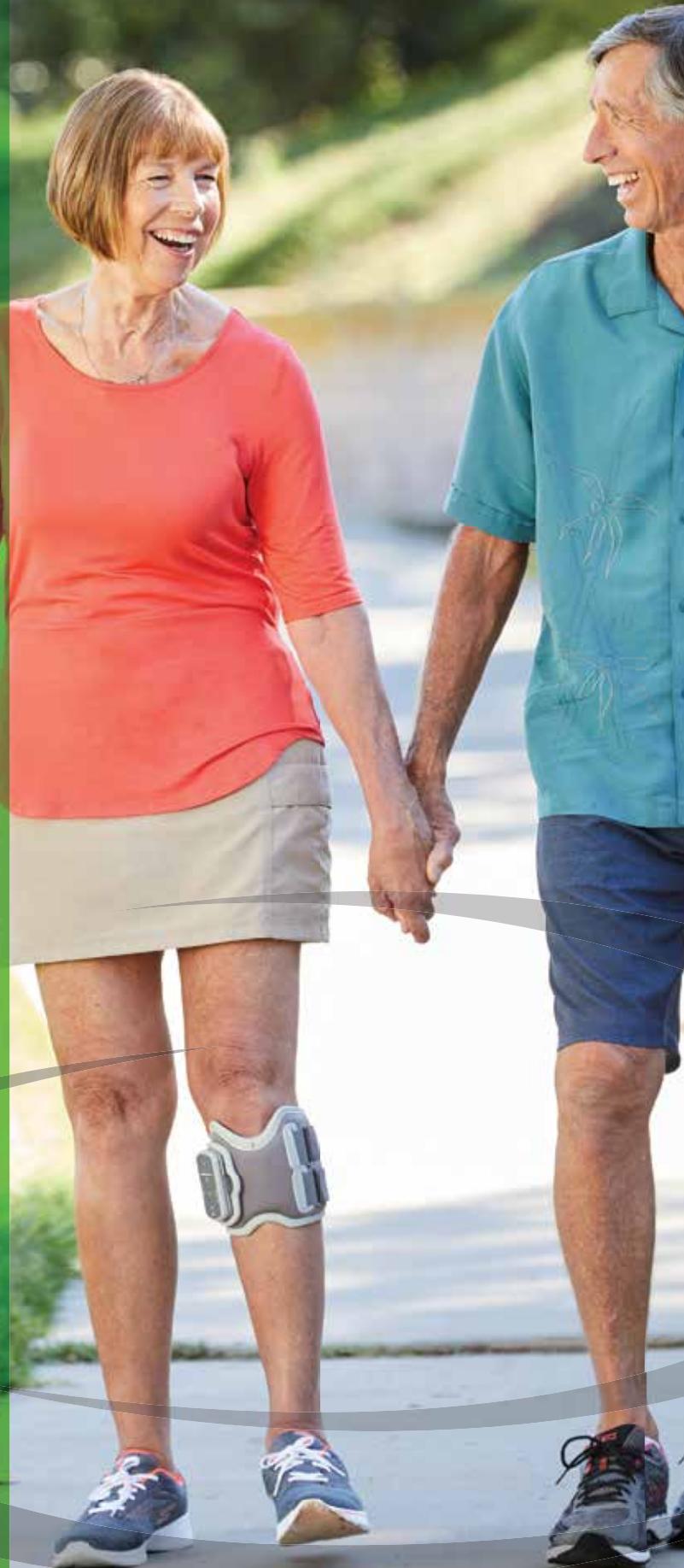
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Sheila Timmons participated in her first MuckFest MS in 2015, recruiting friends and family to join her on the muddy obstacle course.

PHOTO COURTESY OF SHEILA TIMMONS

Muddied but unbowed

MuckFest MS offers laughs and obstacles to raise funds.

by James Townsend

After nearly a year and a half of trying to discover why she was feeling weak and tired all the time, Sheila Timmons finally found a doctor in 2013 who diagnosed her with multiple sclerosis. The diagnosis came as quite a shock, but being a go-getter, she quickly began researching MS online.

She discovered a Facebook page for Texas' MuckFest MS 2015, the first year for the fun-filled, muddy 5K obstacle course to raise funds for the National MS Society. Timmons jumped right in. "I'm an outdoorsy kind of girl," she says, "and I decided right away I wanted to do it."

MuckFest MS has proven to be quite popular, according to Annamarie Dober, Society senior manager for development. "It has been a great way to introduce people to the MS movement," she says. The event has raised \$29 million since its inception. MuckFest MS is being held in Boston, Philadelphia, Denver, Detroit, Chicago, Dallas, and New Jersey in 2018.

The runs provide lots of laughs and some physical challenges. Typically there are about 18 obstacles to overcome—or bypass if they prove too challenging—including Big Balls (nine or more swinging balls that runners must navigate), Slippery Sloppy (a slip and slide), Swing Set (runners catapult themselves into water from three



MuckFest MS participants enjoy laughs and physical challenges.



MuckFest MS has become a family tradition for Sheila Timmons' family, with 14 to 17 runners participating each year.



Sheila Timmons' team, Dirty Dudes and Divas, raised \$19,000 over the last three years.

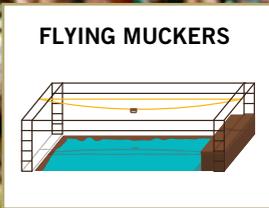
steel-constructed swinging platforms that the runners stand on and rock to gain momentum), Walk on Water (runners run single-file and jump over round pontoons on a thin walkway that floats on top of the water), and the Spinner (a carousel-like structure with ropes that runners hold onto while spinning over a muddy moat below).

For Timmons, entering MuckFest MS was life-changing. But it took some preparation. In order to deal with her symptoms—the loss of peripheral nerves in her legs, urinary incontinence, sexual dysfunction, bowel slowing, brain fog and loss of appetite—she was taking nearly 25 medications a day. “Then I needed more meds to help with all the side effects. They were making me crazy! I had to cut back, figure out what was working and what wasn’t.” Today she takes only two meds: her MS disease-modifying therapy and melatonin.

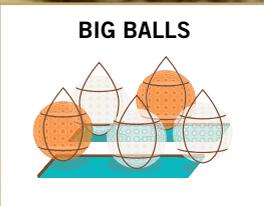
A family affair

Timmons persuaded her family to join her and became team captain of the Dirty Dudes and Divas. “My brothers all signed up, and my mother and sister-in-law,” Timmons says. Since that first year she participated, MuckFest MS has become a tradition for her family and friends with the team ranging from 14 to 17 runners. “My daughters and girlfriends all run with me now, too. Well, actually, we walk fast,” she says. “It’s so much fun that I wait all year for it. We laugh and joke the whole distance, mostly with my mom, Sheryl Hayes, about keeping up with the team. She is 60 and a little slower, but she’s also our top fundraiser, and we all try to compete with her and each other. Mom’s the team treasurer/guru, and she’ll go right up to anyone in the grocery store or a restaurant and ask them to donate for the cause.”





Soar over muddy waters on a zip liner.



Navigate nine swinging spheres through mud.

Timmons laughs when recalling how her brother Ricky tripped at the top of the waterslide and plummeted head first into the mud below. “Then there was the Spinner, where my mom had to hold onto Ricky for dear life. That was really funny,” she says.

Dirty Dudes and Divas are fundraising champs, bringing in nearly \$19,000 over the last three years.

Timmons, 40, lives in Alvin, Texas. “It’s a little town of about 25,000, some seven miles south of Houston,” she says. “I love the small-town atmosphere. Lots of people know each other here and have been very supportive, my husband, Chad, in particular. It shook his world when he first realized things were harder for me, because I have always been the mom who keeps things rolling. The hard part of having MS is knowing my limitations and asking for help. He’s truly been my rock and salvation in all this transition. We celebrated 22 years together in January this year.”

MuckFest MS also has given Timmons a new sense of meaning. For the first race, she says, she and her family were mostly focused on the fundraising competition. “But then it really began to hit home why we do it: The money we raise [for research] is ... going to help find a cure for the disease someday.” ■

James Townsend is a Boulder, Colorado-based freelance writer.



Learn more about MuckFest MS at muckfestms.com.

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



Bite club

An apple orchard is the star of a successful MS fundraiser.

by Mike Knight

It was 2004 and Dave Flannery was stumped. For years he'd tried to figure out how to raise money to help people living with multiple sclerosis. Flannery had three very important reasons for wanting to find a cure.

Flannery, now 71 years old, is one of eight siblings—three boys and five girls. In the early 1980s, Flannery's sister Peggy was diagnosed with MS. Then two other sisters, Sheila and Jan, were diagnosed with the disease. Flannery wanted to help.

"I always felt that I owed it to them to try and do what I could to help, to contribute in some small way to solving the MS puzzle and doing what we could to support people living with the disease," Flannery says.

Flannery wanted to try fundraising, but he struggled to see the forest for the trees. And then it dawned on him: The trees were the answer.

Autumn and apples

In 1987, Flannery and his wife, Vicki, bought a dairy farm off Interstate 94 between Milwaukee and Chicago. Besides the standard livestock on the property—cows, pigs and horses—there was an orchard with aging apple trees. Over the ensuing three decades

the couple transformed the property into a 78-acre "agri-tainment center" named Apple Holler Family Farm and Restaurant.

The "center" includes a family-style restaurant known for its slow-roasted prime rib, daily fish fry and big breakfasts featuring apple buttermilk pancakes covered with warm baked apples. The center also features a bakery and country store, pedal cart racing and a petting zoo. But the chance to pick apples, peaches and pears from the 30,000 trees in the orchard was, and is, the farm's main attraction.

So Flannery—along with Sheri Gavin, the business's marketing manager—decided to hold the first "Apple Holler MS Orchard Walk" to raise money for the cause that was so near and dear to him. It would be held in late August 2004 to take advantage of two key Wisconsin assets: the first breath of fall and the first apples ready to be picked and eaten—in this case, a crisp, tangy McIntosh derivative named "Paula Red." Entrants would receive a colorful commemorative T-shirt and 1/2 peck bag for picking apples, and then walk



PHOTO COURTESY OF APPLE HOLLER FAMILY FARM AND RESTAURANT



PHOTO COURTESY OF APPLE HOLLER FAMILY FARM AND RESTAURANT



Above: Participants complete a mile-long course through the orchard at Apple Holler Family Farm in Sturtevant, Wisconsin. Each entrant receives a ½ peck bag for picking apples.

Left: After the walk, participants enjoy entertainment and a raffle in the barn.

a mile-long course through the orchard picking their own apples. Proceeds from the entry fees would go to the National MS Society.

Flannery had no idea if it would work.

“I had for several years prior wanted to put something together,” Flannery says. “I didn’t know if an orchard walk would really fly as far as a fundraiser is concerned, but finally we just went ahead and did it.”

A walk and much more

But fly it did. To date, the Apple Holler MS Orchard Walk has raised more than \$110,000. Some 300 people are expected to participate in the 14th annual walk on August 25. And like past events, they’ll find a fun, family-friendly event that’s far more than a walk through the orchard.

After registering, paying a \$25 entry fee and receiving their T-shirts, Gavin says participants gather for an all-you-can-eat pancake breakfast, then, following the national anthem, begin the orchard walk.

“The best part is if you are not able to do the walk, you can board a tractor-drawn wagon that will take you to the orchard to drop you off and pick you up where you can pick your apples,” Gavin says. “So you can still enjoy the scenery and the orchard by taking a tractor-drawn wagon. Or you can just pick apples out of a bin, as well.”

After the walk, participants gather in a recently completed barn for entertainment and children’s activities. Participants can also win flat irons and haircuts, as well as other goods and services from local sponsors and businesses, such as gift certificates to memorabilia from the Green Bay Packers.

A growing community of support

Sydney Clark, a development specialist in the Society’s Wisconsin office, says the apple-picking event is special for a number of reasons.

“What makes this do-it-yourself event special is that [Flannery] and his family are not just running this event, they are using their business to do it,” Clark says. “So not only is it a good ‘friends and family event,’ but they are a really great corporate partner of the Society.”



PHOTO COURTESY OF APPLE HOLLER FAMILY FARM AND RESTAURANT

Colleen Kalt (center), president of the Society’s Wisconsin area, with Sherri Gavin (left) and Vicki Flannery, who helped organize the 2017 Apple Holler MS Orchard Walk event, which raised more than \$110,000 to date.

And Clark sees an even wider appeal. “It’s really an introduction to fall, which I think is a really nice thing for a lot of people,” she says. “Fall is my favorite season. Being able to go out there and see families come. Going out to the farm and picking apples and pumpkins is something I did as a child. And on top of that, it’s raising money for a great cause.”

Flannery says what makes the event special to him is the ever-growing community of people who participate to raise the money needed to end MS. It’s part of the reason he bought the farm in the first place. “I’ve always enjoyed growing things,” he says. “Growing plants and trees as well as animals, having animals as pets and that sort of thing. Growing things is something that I enjoy.” ■

Mike Knight is a freelance writer in Indianapolis, Indiana. He was diagnosed with MS in 2013.



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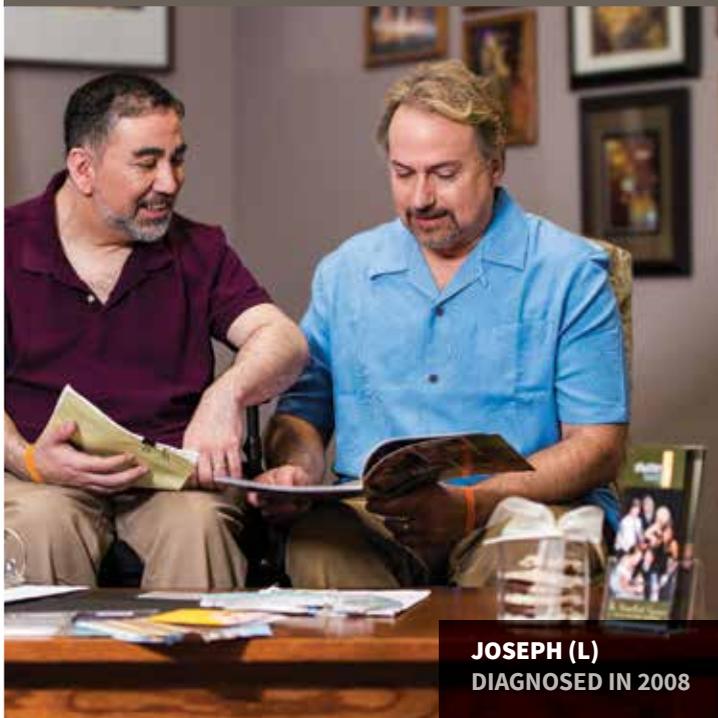
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The public face of multiple sclerosis is very different than the private one.

by Scott Rice



Outward appearances

Thirteen years ago, the love of my life was diagnosed with multiple sclerosis. Knowing very little about the disease at the time, we were thrown into a whirlwind of confusion and uncertainty. Real friends showered her with love and support while others showed their true colors and abandoned her as if she were contagious. Luckily for me, I married an incredibly smart, determined and downright stubborn woman.

My wife, Donna, does everything in her power, both emotionally and physically, to avoid showing that she is a victim of this progressive, debilitating disease. She has never been the “woe is me” type, and ever since she was diagnosed, she has kept her composure publicly, vowing to stand tall and confident, just as she always has—emphasis on the term, “publicly.” It’s mainly her close friends and immediate family who know she lives with MS. But there are still those few who, when they discover her situation, utter a phrase she has come to loathe: “Well, you don’t look like you have MS.”

That phrase, however, raises a good question: What DOES MS look like? What do people expect to see when they hear that someone lives with MS? Do they need to see a cane, a walker, a wheelchair? Some people with MS do need such assistance, but Donna is not there yet and might not ever be. But just because she does not show outward appearances of having MS, does that mean she doesn’t suffer on the inside?

The unseen struggle

It’s difficult for people to understand that Donna wakes up each morning and lies in bed for an hour, crying and praying because it feels like she has 30-pound sacks of sand on each limb. Friends and family wonder why we don’t take vacations with them any longer. It’s because she feels as though she wastes half their day waiting for her body to function and she doesn’t want to feel guilty for it. Just waking up at 5:30 a.m. to get ready so she could watch her daughter graduate from college and her son graduate from boot camp took every ounce of energy that she could muster, leaving her no strength for the remainder of their special days.

fired up

No one can see what a struggle it is for her to sit and eat a meal for a half hour, hoping she doesn't drop her fork or glass and then worry if her legs will function when she stands up after sitting for so long. They laugh when she face-plants in the middle of the parking lot because her brain forgot to tell her leg to take the next step. They have no idea that she's scared to death to hold her future grandchildren for fear of dropping them, and she cries inside knowing that she won't be able to pick them up to feed them, change their diapers and be the fun grandma she wants them to see and love. No one notices her immediately scope out the location of the nearest restroom every time she goes into a new restaurant. They don't know that she has to practically perform a surgery-like sterilization just to self-catheter in a public restroom because the connection between her brain and her bladder has short-circuited.

Three years ago, her body rejected her latest MS medicine, virtually wiping out her white blood cells and lymphocytes. Her doctor told her to stop the medicine, saying it should only take one or two months for the counts to get back to normal. Three years later, they have barely risen, and now she's in constant fear of catching a "bug" because of her weak immune system.

By no means am I vying for sympathy or pity for my wife. That is the last thing in the world she would ever want. Donna is still the strong, beautiful woman I married 32 years ago, and I believe that her stubbornness has been her best medicine in dealing with this disease. But maybe by reading this, those who know nothing about MS will gain a better understanding that the effects are not only visible on the outside, they can sometimes be even more devastating on the inside. ■

Scott and Donna Rice live in Issaquah, Washington. Donna was diagnosed with MS in 2005.

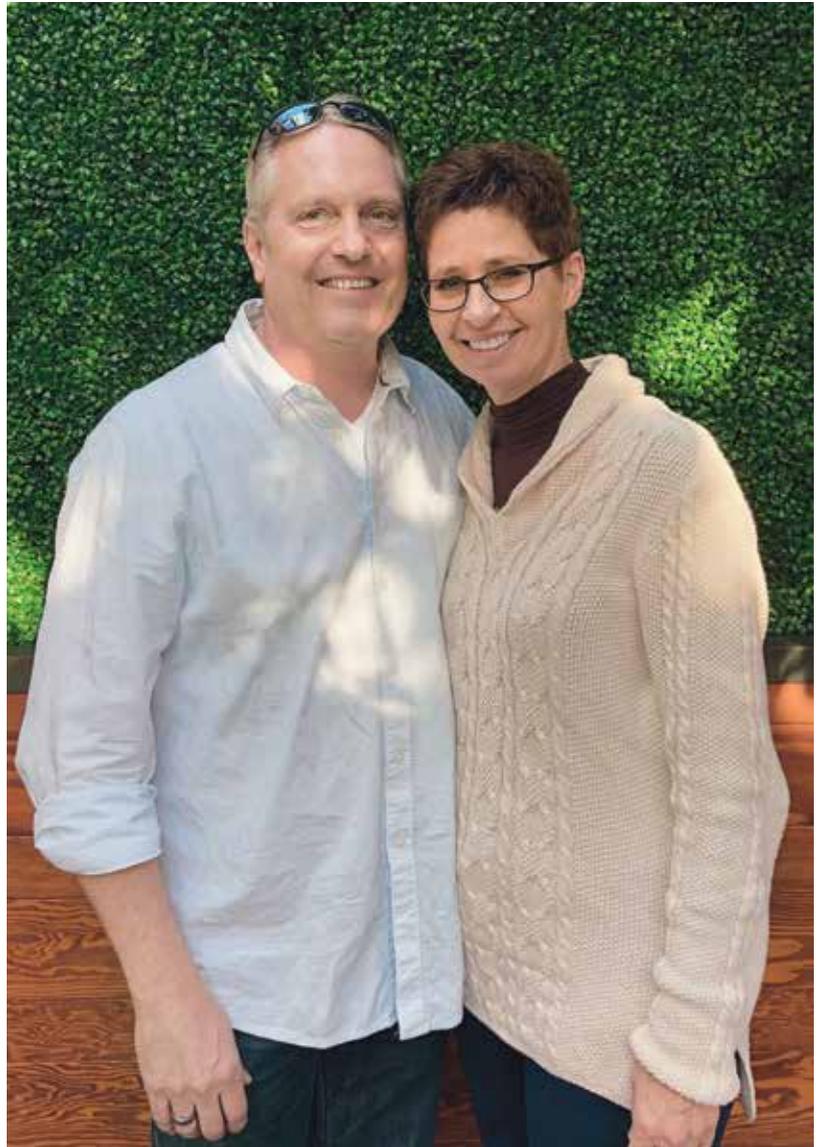


PHOTO COURTESY OF SCOTT AND DONNA RICE

Scott and Donna Rice have remained strong throughout the course of Donna's MS.



Read more about approaches to many MS symptoms—including invisible ones—at nationalMSSociety.org/symptoms.



Learn strategies for addressing the challenges that MS can bring by contacting an MS Navigator at 1-800-344-4867 or nationalMSSociety.org/navigator.

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Carving out a new goal

A chain saw inspires an undiscovered talent.



PHOTO COURTESY OF JESSICA SPIKER

Jessica Spiker has carved dozens of pieces from her home workshop in Meyersdale, Pennsylvania.

If asked to picture a chain saw carver, most people probably imagine a burly bearded guy who resembles Paul Bunyan. At 5 feet 2 inches tall, Jessica Spiker defies the stereotype. Diagnosed with multiple sclerosis in 2010 at the age of 23, she worried that “I could no longer pursue my goals.” Spiker, who lives in Meyersdale, Pennsylvania, had no way of knowing that soon her goals would be more daring than she ever expected.

Through her work volunteering for the Special Olympics, Spiker was asked to help athletes purchase a carved wooden eagle as a thank-you gift for the veteran’s organization that had hosted a recent event for them. She was shocked to see the price of the hand-carved eagle. But she had a picture and an idea of what the athletes had in mind. She went home and fired up an old chain saw belonging to her dad and uncle. The fact that she had never operated a chainsaw before didn’t seem like a problem at the time. Two days later, she had created an eagle wall hanging that was very similar to the professional carving pictured in the photo.

In the last three years, Spiker has created and sold dozens of pieces at her home workshop and at local festivals. Without formal training, she continues to learn and push her abilities. Her health has continued to improve since she’s begun carving. “It feels like divine intervention that I decided to pick up the chain saw that day,” she says.

Her carvings reflect her belief that she can do anything she sets her heart and mind to and that nothing is beyond her abilities. ■

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