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SPRING 2018

Sense of self

MS may challenge you to redefine who you are and what you want out of life.

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National
Multiple Sclerosis
Society

MANAGING THE
MS HUG **page 10**

BONE HEALTH
AND MS **page 40**

GETTING
SUPPORT **page 56**

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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

Have fewer maybes with OCREVUS.

In **relapsing MS**, OCREVUS was consistently proven superior to REBIF®,*† a commonly used treatment.

OCREVUS demonstrated:

- **Reduction** of relapses
- **Slowing** of disability progression
- **Significant impact** on brain lesions

In **primary progressive MS**, OCREVUS is the first and only treatment proven effective.

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.

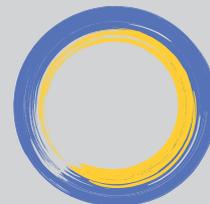
Most common side effects include infusion-related reactions and infections.

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.

OCREVUS™
ocrelizumab 300MG/10ML
INJECTION FOR IV



Visit OCREVUS.com or call 1-844-627-3887 to learn more.

*In two 2-year clinical studies vs REBIF.

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‡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

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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.
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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.

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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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Cyndi Zagieboylo

Research into the causes and treatments of multiple sclerosis goes on around the world. At the National MS Society, we seek to ensure that the research answers the questions that people with MS have, and that means we must ask and listen. People with MS need to be included in the process of making decisions about everything we do, including funding

research. This basic premise is key to designing research that is most relevant to people with MS and provides information that ensures people can live their best lives.

The premise of including people with the disease is core to how decisions about funding are made at the Patient-Centered Outcomes Research Institute (PCORI), whose work is featured in this issue of **Momentum** on page 47. This nonprofit organization was authorized by Congress in 2010 specifically to fund research to answer practical questions focused on the quality of life of people living with various diseases.

PCORI leadership determined that they could have an impact in MS research, and the Society is pleased to work in collaboration with them to provide perspective on the questions people with MS have about managing symptoms and making treatment choices. We've worked with PCORI since it was first established. That includes sharing access to our research team, which focuses on keeping up-to-date on the state of MS research. We provided data collected from our strategic planning process where we asked people what they need to move their lives forward. We also share the topics people discuss with our MS Navigators. We recommended research reviewers—people with MS—to help with the selection of projects to fund. And we are thrilled that PCORI is funding topics that are relevant and important to people with MS. When combined with the research that the Society funds, it feels like a wonderful extension of our portfolio of research.

It's also gratifying to see that four of five of PCORI's recent grants were awarded to researchers whose careers were supported by the Society's fellowship program—these are scientists who are in the field of MS research at least partly due to the support they've received from the Society. Their research includes things like comparing the effectiveness of different strategies for treating symptoms of MS-related fatigue and answering questions about how long people can benefit from disease-modifying therapies. The Society's fellowship programs seek to attract and train promising young investigators and doctors in the field of MS, and many prominent researchers credit their ongoing focus on MS to the fellowships they received early in their careers.

Including the perspective of people living with MS is part of the Society's advisory process. People with MS are members of our own research program's advisory committee as well as the International Progressive MS Alliance's scientific steering committee, where they provide pivotal information and perspectives on the design of studies and weigh in on the most important research to fund.

If you'd like to learn more about the National MS Society research funding process, PCORI or the International Progressive MS Alliance, visit **nationalMSSociety.org/research**, **PCORI.org** and **progressivemsalliance.org**.

These combined efforts and others always have one thing in mind: to find answers so that people with MS can live their best lives and to, ultimately, achieve a world free of MS.

What are your thoughts about MS research? What would you like to know and how would you like to contribute? As always, I'd love to hear from you. ■



733 Third Ave., Third Floor, New York, NY 10017



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



Voices of others

Thank you so much for publishing the “On the rise” story on diagnoses of MS increasing in Latinos and Hispanics in the Winter 2017–18 issue. As a Latino with MS, having representation of my identity presented with care and precision has pleased and comforted me greatly. Since being diagnosed, I have wondered—but admittedly hadn’t sought out—if any study of MS in the Latino community had been made. Please continue to seek out other demographics of people affected by MS, not only in the United States, but internationally. We need to learn from and relate to voices of others that share our diagnosis. Keep up the good work.

Antonio Manriquez, California

MS can’t take our creativity

Great creative outlet, John Roy (“American montage,” Winter 2017–18). MS can deprive us of many things, but not our creativity. Sometimes that is all I have. Since my diagnosis (2005) and leaving my job in 2007, I needed something to do to continue to make a difference in people’s lives and a place to direct my creativity. Since then, I have been watercolor painting (no formal training) and turning the paintings into cards to sell to raise money for MS research and programs. We generally make \$13,000 per year that we are able to donate. Very satisfying. Go, John! Your work is inspirational.

Pat Heller, Wisconsin

Bruce is amazing

Thank you for the article about Mr. Tuttle (“My friend Bruce,” Winter 2017–18). Bruce is an amazing man.

Guy Swentek, California

Pesky companion

I just wanted to express my surprise and gratitude at reading the article about Tarita Davenock (“Globe trotting,” Fall 2017). As a plus-sized gal myself, I was so happy to see someone like me represented on the cover of **Momentum**. Let’s be honest, when it comes to traveling, no one really wants that pesky companion, MS, along for the ride. But, it was so refreshing to read about all the things Tarita has accomplished when it comes to traveling with MS. Thank you!

Kelly Westerdahl, New York

Not alone

Thank you for addressing how some individuals handle the problem of embarrassing symptoms (“No shame,” Fall 2017). I was diagnosed with MS in my 50s. My main concerns are bladder issues and balance, but I walk without assistance. I was encouraged to realize that I am not alone. Thank you for the honesty in this article.

Brenda Fritschen, Texas

Long road to SSDI approval

Your Winter 2017–18 “In the know” section reminded me of when I applied for Social Security Disability Insurance over 20 years ago. The examiner wanted to know if I’d seen a psychiatrist! She had no clue as to what a neurological disease was and had never heard of MS. I don’t know how I did it, but eventually I convinced her that MS was a neurological disease and got approved. ■

Paul Tarr, Washington

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



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on the cover

Elizabeth Jameson has found a renewed sense of self as her MS progresses. She transforms her brain scans into colorful images.

COVER ART BY ELIZABETH JAMESON

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Sense of self

MS may challenge you to redefine who you are and what you want out of life. Here's how six different people with MS answer the question: "Who am I now?" **22**



PHOTO COURTESY OF LOIS KIPNIS

Lois Kipnis reflects on 30 years of living with MS.

Look for these icons throughout **Momentum**.



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IN THE NEXT ISSUE

When disaster strikes: Summer brings hurricanes, tornadoes and wildfires. People with MS face unique challenges dealing with these emergencies, but a variety of resources are available.

Plus: Stories about U.S. military veterans living with MS and a look at high-risk research projects.

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Telephone: 1-844-675-4787



Momentum Editor
National MS Society
900 S. Broadway, Suite 200
Denver, CO 80209



editor@nmss.org
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**Chair of the
Board of Directors**
Peter Galligan

President and CEO
Cyndi Zagieboylo

Editor
Jane Hoback

Advertising
Amy Lawrence
303-698-6100 x15204
amy.lawrence@nmss.org

**Design and
Production**



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Correction:

The story "A fresh perspective" published Spring 2017, contained an incorrect percentage. The sentence should read: "A 2015 article written by six noted MS researchers and published in Neurology Clinical Practice, reported that out of the nearly 60,000 published articles about MS, only 113, or about 0.2 percent, focus on African Americans." We regret the error.

Awards for Momentum



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Gold Award for Print, Website and Tablet App —
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Association Media & Publishing 2016
Excel Bronze Award for Magazine Website
Excel Bronze Award for Feature Article Design,
"Yes, you can regain bladder control" (Spring 2015)

✉ National MS Society
733 Third Avenue, Third Floor
New York, NY 10017

☎ Telephone
1-800-344-4867

@ editor@nmss.org

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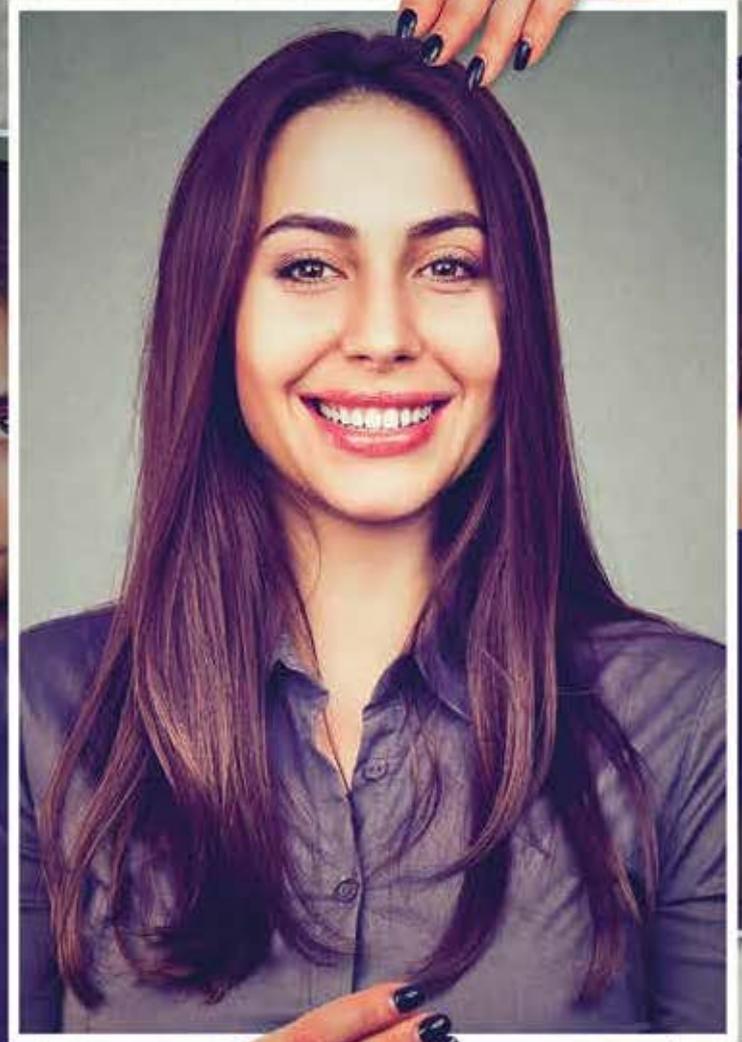
MS can have a physical and emotional impact on how you feel and function in everyday life. Because MS affects parts of the brain that control mood, mood changes are considered a symptom of MS as well as a reaction to it. But mood changes are not a sign of weakness. In fact, dealing with them is a sign of strength.

In this section, you'll find resources to help you deal with the many changes that MS can bring: How to manage what's known as the "MS hug" (see next page), plus apps that can help monitor your MS symptoms and moods.

Visit nationalMSSociety.org/moodandMS to learn more.

Practical ideas
for living well
with MS

in the know



Strange sensation

The MS hug can cause painful constrictions, but there are ways to ease the symptoms.

by Aviva Patz

Erika Richardson, 47, of Green Cove Springs, Florida, twice experienced pain and pressure in her chest so extreme that emergency room doctors suspected she was having a heart attack. “They started administering baby aspirin, ordering nitroglycerin and running an electrocardiogram,” says Richardson, who has had progressive multiple sclerosis since childhood. Her mother, who was acting as her care advocate, explained the possibility that the intense chest pressure and stabbing sensations between Richardson’s ribs were actually from an “MS hug”—and proceeded to educate the bewildered hospital staff on what that is.

The MS hug, a type of pain associated with MS that goes by the medical term dysesthesia, feels different for each person. “Some people describe a boa constrictor-type squeezing that is almost constant. Other people describe a band of burning pain that comes and goes,” explains Mary Alissa Willis, MD, associate program director of the Mellen Center for MS at the Cleveland Clinic. “The pressure can be so intense at times that taking a deep breath is difficult.” And yet no actual tightening is taking place. Rather, the sensation is caused by lesions—or scarring from MS disease activity—affecting the sensory pathways in the spinal cord. The brain may respond to the signals with a mix of sensations that include tightening, tingling, burning, stabbing pain or an electric-shock-like feeling. It ranges from “annoying” to “very painful,” and can last a few seconds or persist. Some people feel the sensations in their hands, their legs and feet, or around their head.

MS Hug

The MS hug, a type of pain associated with MS that goes by the medical term dysesthesia, feels different for each person. Some people describe a boa constrictor-type squeezing that is almost constant. Other people describe a band of burning pain that comes and goes.

Not everyone with MS experiences the MS hug, but some 15 to 20 percent of people with MS report painful spasms, and 25 percent or more report dysesthesias, abnormal or unpleasant sensations, according to Dr. Willis. MS hugs may develop as a symptom of an MS relapse or flare-up and may be worsened by fatigue, heat, infection, stress or overexertion. There’s no specific treatment, and people who experience it deal with it in a variety of ways.

How medication can help

No medications address the MS hug specifically, but because it’s linked to hypersensitivity of damaged nerves, doctors may prescribe drugs that stabilize the irritated nerve membranes. Those include anti-convulsants like Neurontin, Trileptal and Lyrica. A muscle relaxer, such as baclofen, also may be helpful, Dr. Willis says. An antidepressant such as Elavil, can help as well, as it modifies how the central nervous



Andrezza Haddaway, diagnosed with MS in 1997, captures the pain of an MS hug through her photography. Her friend, Shelby Cross (pictured), wears a corset to show how Haddaway felt when she experienced her first MS hug. “I felt like I was suffocating. Like it was taking my breath away and crushing my ribs.”

PHOTO BY ANDREZZA HADDAWAY

system reacts to pain. Some patients find relief with topical lidocaine. Traditional pain-relieving medications such as Ibuprofen, Tylenol and topical diclofenac, another non-steroidal anti-inflammatory drug (NSAID), don't work because they don't affect the nerves, Dr. Willis says.

Richardson, who has experienced MS hugs for 28 years, takes an anticonvulsant, muscle relaxer and Percocet, a prescription painkiller.

Caroline Kyriakou, 37, of Boston, received IV steroids to treat an MS hug that lasted two weeks—

during the flare-up that led to her diagnosis in 2006, as well as during a relapse. “The steroids luckily helped decrease my symptoms,” she says.

Different ways to cope

Medications work best when paired with other coping mechanisms, according to Heidi Maloni, PhD, national nursing clinical director of the Veterans Affairs, MS Centers of Excellence, at the VA Medical Center in Washington, D.C. “You might not be able to eradicate MS hugs altogether—you might need to live with a

little bit of tightness,” she says. “Non-pharmacological treatments help with management and empower patients.”

Non-drug coping mechanisms.

■ **Avoid triggers.** Ashley Ringstaff, 29, of Austin, Texas, tries to minimize stress and heat, and she avoids wearing anything constricting, which can trigger her MS hugs. “It feels like I’m being squeezed in a bear hug from the inside out,” she says. But she can’t control weather change, which also sets off her MS hugs.

Keisha Kuma, 45, who lives in Atlanta, isn’t sure of her exact triggers but has noticed some patterns. “If I’m tired and keep pushing myself, especially in the heat, all my symptoms are more prevalent.” Her MS hugs last 5 to 20 minutes. “It feels as if the Incredible Hulk is getting a mammoth from prehistoric times and placing it on my chest,” she says.

■ **Relaxation techniques.** Kuma, who experiences MS hugs about every other month, lies down in a cool, quiet place to wait for the feeling to pass. “It calms the body and focuses the mind away



PHOTO COURTESY OF CAROLINE KYRIAKOU

Caroline Kyriakou found relief through steroid treatment for an MS hug that lasted two weeks.

from the pain,” Maloni explains. Richardson uses deep breathing techniques to relax. Kyriakou also tries to relax and not panic. “The MS hug is a very uncomfortable feeling, but stressing out will only make it worse,” she says.

■ **Managing clothing.** While tight clothing can be a trigger for some people, others find it actually helps ease MS hugs. One of Maloni’s patients wears an abdominal brace. “It’s the gate theory of pain,” Maloni explains. “You close the gate on one type of pain and open the gate on a lesser sensation,” in this case, pressure.

■ **Warm compresses.** Temperature sensations travel along the same nerve pathways as pain, so heat can tamp down pain. “When you have pain, there are chemicals that are released in the muscles—histamine (a compound involved in the body’s immune response) and prostaglandins (compounds that act like hormones),” Maloni explains. “Heat decreases the expression of both.” Richardson finds it helpful to wrap a heating pad around the affected area. Topical capsaicin, made from hot peppers, can also bring heat to the skin.

■ **Exercise.** Walking, stretching, yoga, gentle swimming and other movement can help manage MS hugs. “When we have pain, signals coming



PHOTO COURTESY OF ERIKA RICHARDSON

Erika Richardson’s experience with the MS hug twice put her in the emergency room. Her mother told the hospital staff about the possibility that the intense chest pressure was from an MS hug.

into the body from the central nervous system, the pain is sensed, and our body modulates it with the neurotransmitters serotonin, adrenaline and endorphins,” Maloni says. “Exercise is pain modulation” in that it stimulates those same neurotransmitters. It’s also a distraction, she adds.

■ **Nutrition.** Certain minerals are known to reduce muscle spasms and may help with MS hugs. In a blog on Multiple Sclerosis News Today, Judy Lynn writes that after testing her mineral levels, a naturopath suggested potassium, calcium and magnesium supplements to ease her MS hugs.

■ **Meditation.** You can train your brain to interpret something bad as something good, or at least neutral, so you might try to see the sensation of pressure as warmth, for example. “You control your perception of the sensation by bringing your consciousness to it,” Maloni says. “You’re able to manage the pain instead of just trying to ignore it or distract yourself from it.”



PHOTO COURTESY OF ASHLEY RINGSTAFF

Minimize your exposure to stress and heat, advises Ashley Ringstaff (left), who also avoids wearing constricting clothes, which can trigger her MS hugs.



PHOTO COURTESY OF KEISHA KUMA

Keisha Kuma manages her MS hugs by staying calm and cool, lying in a quiet place and waiting for the sensations to pass.

- **Acupuncture.** The Chinese medicine practice has been shown in clinical trials to reduce pain in general, and may be a way to help manage MS hugs.
- **Hypnosis.** Studies at the University of Washington show that it helps ease neuropathic pain. “Hypnosis is self-management at its best because you own it, and you can use it anytime you feel out of control,” Maloni says.
- **Cognitive behavioral therapy.** Seek out a therapist who specializes in pain psychology. “If you’re thinking, ‘I’ll never get rid of this or none of these medicines work...’ then they won’t,” Maloni says. “Changing your thinking can help change your reaction to the pain.” ■

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



To learn more, see nationalMSSociety.org/pain or MomentumMagazineOnline.com/pain-pain-go-away/.

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

Tracking your health

by Vicky Uhland

Apps can help monitor symptoms, physical activity and medical records, but choose carefully.

Want to eat right, get more exercise or reduce your stress? How about track your MS symptoms, manage your care or join a virtual support group?

There are 250,000 apps for that.

“But systemic reviews show that few of these health apps are evidence-based, use behavioral-change therapy or are tailored to the person using them,” says Amy Sullivan, PsyD, director of behavioral medicine, research and training at the Cleveland Clinic’s Mellen Center for Multiple Sclerosis Treatment and Research. Add to that the fact that the Food and Drug Administration currently doesn’t oversee or test health apps, and you’re basically on your own when it comes to deciding how effective or safe an app’s medical advice may be. Privacy can also be an issue, especially if an app asks for sensitive medical information. And, of course, just sifting through the thousands of offerings in your device’s app store can be exhausting and confusing.

So does that mean you should just give up on health apps? Not at all, say Sullivan and Matthew Plow, PhD, assistant professor at Case Western Reserve University’s Frances Payne Bolton School of Nursing. Apps that track your symptoms can be very helpful for both you and your doctors, Sullivan says. And Plow says apps that monitor your behavior can make you aware of what you’re currently doing regarding your health—and how to change it.

But how do you choose the right health apps? Sullivan and Plow offer the following tips.

Take your pick! There are about 250,000 apps that can help track your health. Before you download, just be sure they’re up-to-date, effective and can protect your privacy.



Is the app effective?

There are several key questions to ask when evaluating whether a health app will actually deliver the results you're looking for:

- **How reputable is the app developer?** Check the app homepage in the app store for a link to the developer's website. Does the site look professional? Does it cite peer-reviewed, scientific information supporting the app?
- **How popular is the app?** Rankings and reviews can reveal an app's effectiveness.
- **How is the app paid for?** If the user buys the

app, that's self-explanatory. But if it's free, you need to do some sleuthing. If the app has advertising, Sullivan cautions that it could be collecting your personal information. Plow points out that some apps are free to download but then offer in-app purchases, like a fee to remove ads. He also says some free apps are developed by pharmaceutical companies, so be aware of bias toward a certain drug.

- **When was the app last updated?** If it's been more than a year, Sullivan says that's a clue that the developers may not put much effort into the app.



■ **Does the app do what you want?** Define your goals and see which apps meet them. Plow suggests starting with the free apps and then uninstalling them if they don't work for you.

■ **Does the app accommodate disabilities?** Although they're rare, some apps allow you to use voice commands if you have trouble reading the screen or pushing buttons. Check user reviews to see if an app is difficult to operate.

Is the app safe?

Just as you would with any health advice, be wary when evaluating apps. In particular, ask yourself the following questions:

■ **Will the app protect my privacy?** There should be a privacy policy on the app homepage in the app store. Check to see if the developer will share your information with third parties, and if the app is compliant with the Health Insurance Portability and Accountability Act (HIPAA). "Basically, find out what information they're asking for, why they need that information, and then decide if you're comfortable sharing that," Plow says.

■ **What does my medical provider think?** Check with your doctors to see which apps they recommend. Sullivan's and Plow's favorites include:

■ **MS Care Connect.** This free app offers research-supported surveys and tests that help you and your doctors monitor your symptoms and measure your physical and mental functioning.

■ **My MS Manager.** This free app tracks disease activity and allows you to generate charts on things like your daily moods or pain level. The charts can be securely shared with your doctors.

■ **MS Buddy.** This free app helps you connect with others with MS, either virtually or in person. "It's like being in a support group, but you can do it on your own time," Sullivan says.

■ **Breathe2Relax.** This free app shows you how to use breathing exercises to fight stress, anxiety and insomnia.



MS Care Connect

MS Buddy



My MS Manager



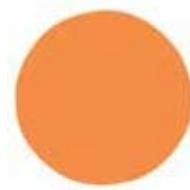
Breathe2Relax



Lose It!



iPro Habit Tracker



Headspace

■ **Headspace.** This app is "probably the most widely used mental health app," Sullivan says. It's designed to teach meditation and mindfulness, and is free for the first 10 sessions.

■ **Lose It!** Plow included this free app in one of his studies. It helps you track your nutrition and physical activity, and allows you to share your goals with friends.

■ **iPro Habit Tracker.** This app (99 cents in the Apple Store, free or \$1 versions in Google Play) helps you pay attention to helpful and harmful habits. "It can help you set self-management goals for reducing stress, fatigue and pain," Plow says.

"While an app is not a substitute for a doctor, the more feedback you can get from an app that you're feeling better or doing better, the more likely you're going to keep doing what's working for you," Sullivan says. ■

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



To learn more about assistive technology, visit nationalMSSociety.org/technology.

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

FOR RELAPSING FORMS OF MULTIPLE SCLEROSIS (MS)

HEY MS,
**WE'D RATHER
 CALL THE SHOTS,**
 NOT TAKE THEM.



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.

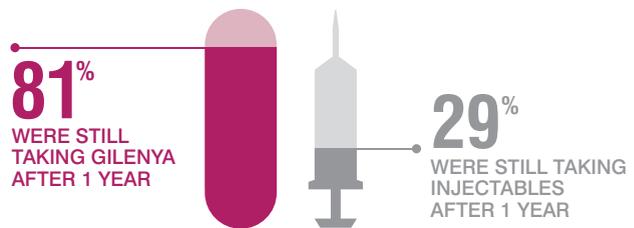


Thinking about a different treatment option?

Think about this: GILENYA® is the only once-a-day* pill proven to cut relapses by more than half. In a 1-year study, it reduced the number of relapses by **52%** vs a leading injectable and, in a 2-year study, by **54%** vs placebo.

Here's another reason to consider GILENYA:

More people who started on GILENYA stayed on GILENYA compared to people taking injectables†



In a separate study, 352 people out of 433 (81%) who started GILENYA were still taking it 1 year later, but only 125 people out of 428 (29%) who started on an injectable were still sticking with it. At the start of the study, everyone was taking either GILENYA or an injectable MS therapy.

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.

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.

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,

*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.

†Interferon beta or glatiramer acetate.

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

Connect with the community and tell your MS to **"Take This!"**

Learn more at gilenya.com



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 page.



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 healthcare professional when you take your next dose. Call your doctor if you miss a dose of GILENYA. See “How should I take GILENYA?”

2. Infections. GILENYA can increase your risk of serious infections 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.** AA 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.



Share a snapshot

Living with MS is tough, and it's understandable that you might not always feel like smiling. But don't let that stop you from capturing photos of your MS journey. Researchers at the University of California, Irvine, found that using a smartphone camera to take and share photos could have a positive impact on mood and emotional well-being, important factors in managing MS.

People felt reflective and mindful when they took pictures of things that made them happy, according to the study. Those who took smiling selfies felt more confident and comfortable, but only when they weren't forcing or faking a smile.

Taking photos is just one way to foster a sense of self throughout your MS journey. Turn the page for stories of how others with MS find a sense of self in their daily lives.

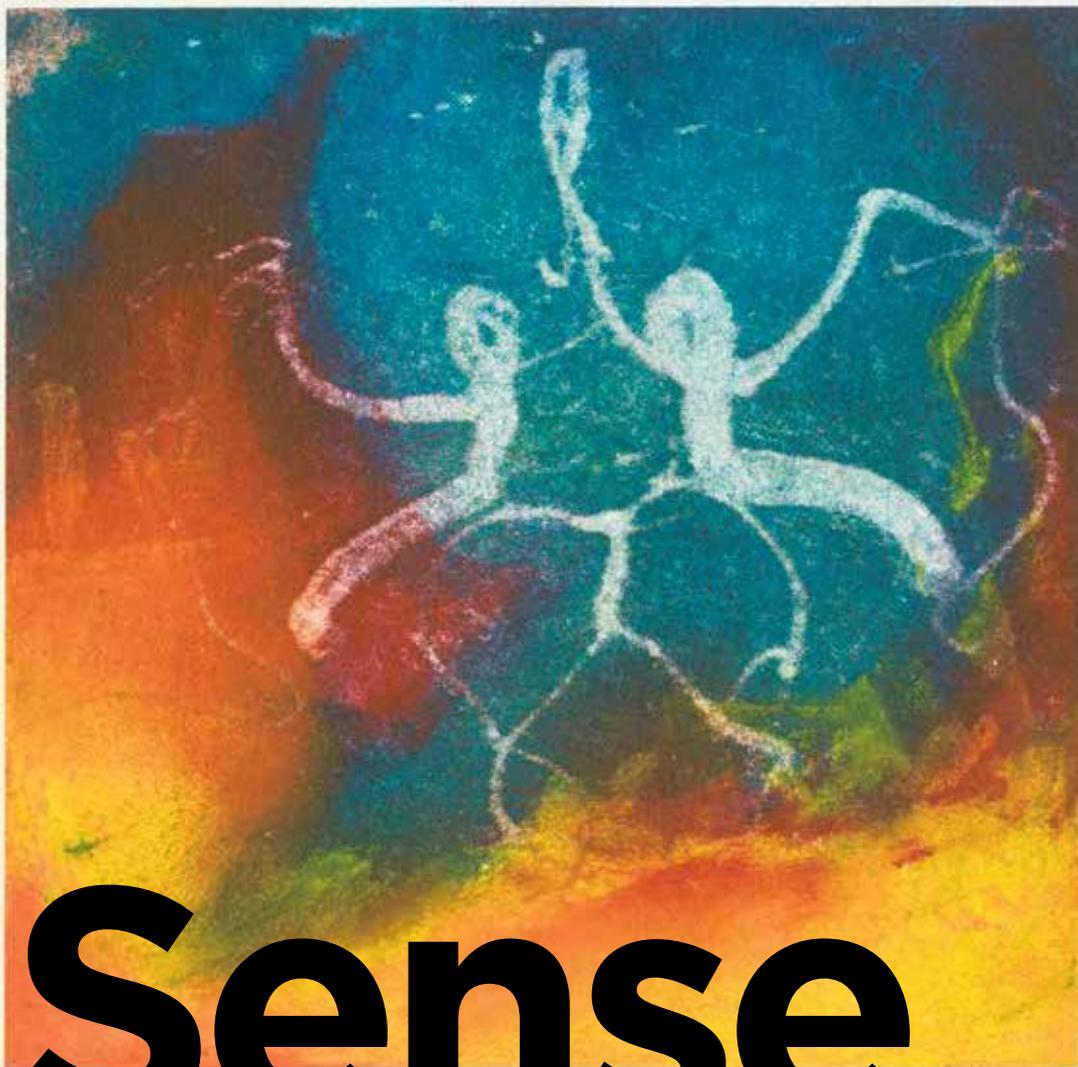


Tag and share your selfie or snapshot reflecting your MS journey with **#ThisIsMS** on our social media channels.

thrive

Forging a path
to your best life

Inside this section: Sense of self 22



ARTWORK BY ELIZABETH JAMESON

Sense of self

MS may challenge you to redefine who you are and what you want out of life.

by Vicky Uhland



Multiple sclerosis is not like other diseases. The lack of a cure, the numerous and varying symptoms, and the uncertainty of exacerbations can affect you on every level—physically, emotionally, mentally and spiritually.

“In essence, your sense of self can be challenged by MS,” says Kevin Alschuler, PhD, a psychologist with the University of Washington Medicine Multiple Sclerosis Center.

MS can refocus who you are in relation to your family and friends, your vocations and avocations, and the world around you. At its deepest level, this disease can make you rethink your life’s values.

“Most of us don’t slow down enough to really take a hard look in the mirror,” Alschuler says. “I have patients who say while they would rather not have MS, it has created an opportunity to recognize who they are and what they want to focus on in life.”

Alschuler says both nature and nurture can affect how people with MS build and keep a sense of self. The age you’re diagnosed, the course of your disease, how tolerant you are of uncertainty, whether you tend to fix or flee distressing challenges in your life—all of these

factors and more help shape how you live with MS.

Just as no two MS disease trajectories are the same, no two approaches to defining your sense of self are the same. Here’s how six different people with MS answer the question: “Who am I now?”

Elizabeth Jameson, 65, California

In 1991, Jameson was in a park pushing her two young sons on a swing set when she suddenly lost the ability to speak. Doctors suspected a stroke or a brain tumor—until they gave her an MRI and found lesions in her brain.

Jameson was 39, and she had just been diagnosed with MS.

“I felt like my life was over,” she recalls. “I had to totally redefine who I was as a wife and mother, and in the work I loved. I learned that MS is the good, the bad and the ugly. It’s everything.”

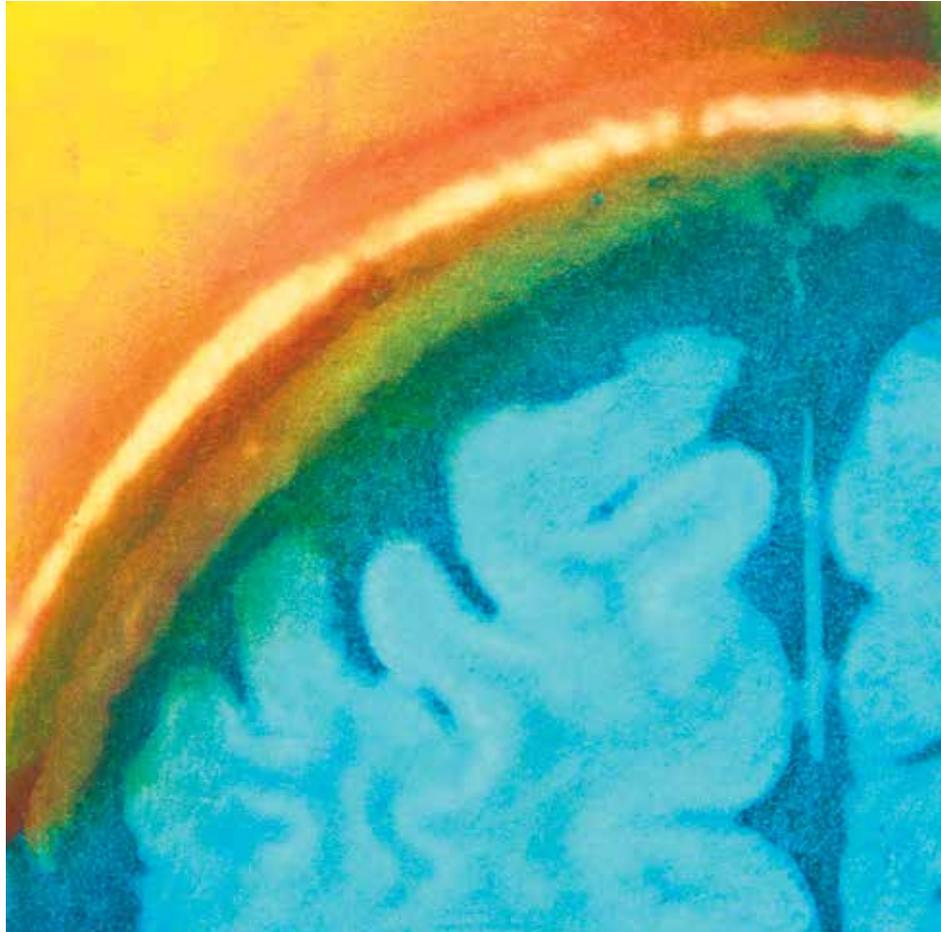
Jameson’s new life with MS was complicated by frequent exacerbations. “Each one made me feel smaller and smaller psychically, like I was a lesser person,” she says. Eventually, she was diagnosed with

Elizabeth Jameson uses colored pencils to bring out the detail and color in her prints.

PHOTO COURTESY OF ELIZABETH JAMESON



Elizabeth Jameson, formerly a social justice lawyer, continues her impact through her newfound artistic talent. Her colorful MRI projects (left) are exhibited by nonprofits, researchers and physicians.



Elizabeth Jameson transforms her brain scans into colorful works of art using Solarplate etching. Her goal is to spark conversation about what it means to live with MS.

primary progressive MS, and is now quadriplegic.

“In a way, it’s much easier because I don’t have the ups and downs in my disease anymore,” she says. “For me, the hardest thing about relapsing-remitting MS was you’re constantly redefining your identity after each exacerbation.”

That also includes the identity of her 34-year marriage. “My husband and I were absolute equals when we married, but now I don’t always feel equal to him because I’m so disabled,” she says. “And I no longer make money, so I feel less powerful sometimes in the relationship.”

Before her diagnosis, Jameson was a social justice lawyer, advocating for children’s rights in federal court. But the exacerbation in the park left her unable to talk for a month. When her speech returned, her voice was altered and she had problems remembering words.

“My job was based on my oral skills, and it was too traumatic and embarrassing for me to talk in court anymore,” she says. So she made the difficult decision to quit the vocation that she felt defined her.

But she still wanted to make an impact through her work. The solution presented itself in an unlikely way: Her neighbor persuaded her to take an art class.



PHOTOS COURTESY OF ELIZABETH JAMESON

Jameson had never drawn or held a paintbrush before. But the first day of class was a revelation. She adored the texture and patterns of painting. She loved the opportunity to play with colors. “One neurologist thinks my MS lesions woke up a part of my brain I had never used before,” she says.

Jameson’s MS informs her art in other ways as well. One day, when she came across a stack of her MRIs, she realized she had never really looked at them because the black-and-white images seemed so frightening.

“Going into an MRI machine is profound, life-defining, traumatic. You’re never quite the same

emotionally afterward,” she says. “I realized my calling is to transform brain scans—one of the symbols of MS—into images that would invoke conversations with ourselves and our medical providers. I decided I wanted to be a public-interest artist to do as an artist what I did as a lawyer.”

Jameson uses Solarplate etching to create her colorful MRI art. Her work is exhibited by nonprofits, universities, researchers, physicians and other people with MS. She’s also working on art projects designed for health care waiting rooms to encourage people with MS and their caregivers to communicate with each other.

“I want to break the silence of the waiting room—the one area where you can be with your tribe,” Jameson says. “It’s hard to feel powerful when you can’t speak to one another in a safe space.”

Angel Muniz Jr., 38, Connecticut

Muniz was living his dream life when he was diagnosed with MS in 2002, at age 21. He traveled across the United States, competing in martial arts competitions with his father. His day job as a loan originator financed a carefree lifestyle without any fears or concerns.

For the first few years after he was diagnosed, Muniz says, he was in denial about his disease—helped by the fact that he was virtually symptom-free. He continued working and playing hard, got married, and accumulated property and investments. But in 2008, his marriage ended. Within a year, Muniz’s father died from pancreatic cancer.

And Muniz began experiencing MS exacerbations. “Things started changing dramatically with my disease,” he says. “I didn’t know at that time that stress plays a huge role in MS. I was having trouble walking, and I was getting more fatigued.”

No longer able to work, Muniz applied for Social Security Disability Insurance and moved in with his mother. “I went from being 100 percent self-sufficient to living in my mom’s basement,” he says.

And then, in 2013, Muniz says his body “shut down.”

“I couldn’t walk. I couldn’t feel my legs for a whole week,” Muniz says. After the exacerbation ended, he began using crutches. “It took me a year just to feel confident enough to go out with my crutches in public,” he says. “I used to be able to go out anywhere and feel at ease meeting new people all the time, but I didn’t have the confidence to do that with my crutches. Being Puerto Rican, we have a lot of family and social events. I didn’t feel comfortable going for a while because of how hard it had gotten for me to walk.”



PHOTO COURTESY OF ANGEL MUNIZ

Angel Muniz Jr. focused on building a stronger mind and body after he began experiencing MS exacerbations. As an athlete, he continues to exercise regularly and does CrossFit.

But as an athlete, Muniz has always lived by the credo that “anything the mind can see, the body can achieve.” About a year ago, he saw a video of a person in a wheelchair doing pullups. “That was my aha moment,” he says. “I realized I can only depend on [myself] to make me stronger in body and mind.”

So he started a CrossFit program and began working with a personal trainer.

“Working out, going to the gym has boosted my confidence physically,” Muniz says. “But I also didn’t realize it would give me the confidence to not let my crutches affect me emotionally and mentally. That’s not to say I don’t want to cry, don’t want to scream every day. But the world’s not going to feel pity for me. I have to get up, have to move.”

That acceptance of his disease has finally allowed Muniz to think about who he wants to be for the rest of his life.

“Before MS, I was so materialistic. I allowed objects to define who I was. I had everything, but I was never happy,” he says. “MS has made me so much more humble. It’s made me be the man I should be.”

Stacey Dorton, 44, California

For Dorton, who was first diagnosed with MS in 1994 at age 21, the adage “I have MS but MS doesn’t have me” sometimes makes her want to scream.

“Phrases like that really chap my hide because I feel my life has continually fluctuated because of my MS,” she says. “There are patches in my life where I do great for a few years, but then I lose my job because I can’t get time off after an exacerbation, and I have to start over. And that means I have to think about things like how will I pay rent or buy groceries? Should I sign up for long-term or short-term disability? Do I have people I can count on to look for me if I’m not around for a few days?”

It’s “100 percent true” that MS defines many aspects of her life, Dorton says. “I don’t see that as a negative or a positive—it just is what it is.”

Dorton walks with a cane, and she also has fatigue, heat sensitivity, vision issues, and bladder and bowel problems. She believes her realistic approach to her disease helps prepare her for a future of uncertainty.

“I know something bad is going to happen, so I need to be ready for it. That way I don’t get bothered by flare-ups,” she says. “This doesn’t make me unhappy. It actually prompts me to move forward in life because I need to do all I can to make sure I can deal with this disease.”

For instance, Dorton, who works in administrative jobs, doesn’t hesitate to ask for raises. Not only does she believe she deserves the extra pay, but she’s motivated by the need to save money in case she can no longer work because of her MS.

Dorton’s practicality also extends to her goals in life. “I don’t have lofty dreams and ideas,” she says.



PHOTO BY ELIZABETH JAMESON

Stacey Dorton takes a practical approach to life with MS. She sets attainable goals that help her live her life and leads a Facebook group called “Fight Club,” where members discuss tough topics about MS.

“I have very realistic, attainable goals that help me live my life.” This includes helping other people with MS figure out the day-to-day aspects of dealing with their disease. Dorton administers a closed Facebook group called Fight Club, where, twice a month, members discuss a specific topic related to their MS. And she gives talks on living with disabilities to public health classes at the University of California, Berkeley.

She doesn’t shy away from the tough topics in these chats. “I talk about how MS messes with relationships, and how I think a lot of the MS-related depression comes from pushing people to be positive. We don’t let people grieve for the life they thought they’d be living before they were diagnosed.”

The bottom line, Dorton believes, is to acknowledge that sometimes MS does have you. “Don’t pretend it doesn’t, but get back up. It can have you, but don’t let it keep you.”



PHOTOS COURTESY OF GRACE RAGLAND

Grace Ragland, 56, Alabama

Ragland believes she had her first MS symptom at age 10. During her teenage years, she experienced numbness, fatigue, balance issues, headaches and heat sensitivity. And then when she was 18 and a freshman in college, she lost the vision in her right eye.

That was in 1979, before MRIs and other means of reliably diagnosing MS were common. But Ragland's doctor suspected she had MS. He told her mother, who then had to deliver the bad news to her daughter.

"The way my mother told me about my disease really set the precedent for the rest of my life with MS," Ragland remembers. "She handed me some MS brochures, told me to read them and then throw them away, because MS is not going to define me. She told me, 'You're going to live your life, live your dream.'"

Ragland says she only had two questions for her mother: Is MS hereditary, and could she have children?

Reassured on both counts, Ragland went back to college and basically forgot about her diagnosis. She was used to her symptoms, after all, having lived most of her life with them.

In 1988, Ragland gave birth to a son. Four months later, she experienced major fatigue and weakness in her limbs, and was left with permanent numbness in her hands. "That's when I started to think this disease is for real," she says.

Realizing she had to take control of her own care, Ragland started an exercise, diet and sleep regimen she still practices today. And she adjusted her vocation to accommodate her MS. Although her dream was to be a home economics teacher, her neurologist said a school environment wouldn't be a good fit because of her compromised immune system (from the disease-modifying medication that keep relapses and progression at bay). And her cognitive problems

wouldn't allow her to have a "typical, punch-the-clock job." So today, Ragland works as a seamstress and a mountain bike instructor—despite finger numbness that means she can't differentiate between velvet and corduroy, and a right leg that wobbles so much she calls it her "Elvis leg."

She also became an MS advocate for a pharmaceutical company. "I used to cover up my disease because I didn't want anybody to feel sorry for me," she says. "But now, I realize I'm a living example of MS, and I feel like I have a responsibility in life to inspire as many people as I can."

Despite having major disease exacerbations in her 40s, Ragland says she doesn't worry that more are on their way. "I can't predict them, so I refuse to live in fear.

I figure I'll deal with it if it happens." But she did panic when she had a mountain bike accident in 2017 that necessitated knee surgery. "I was so scared because exercise clears and stimulates my brain and fights depression. I was afraid that without it, my MS would consume me and take over."

But her knee healed, Ragland got back on her bike and outraced her MS. "When you're riding a bicycle, you have to have momentum to keep your balance, and I transfer that over to life," she says. "You just have to keep moving."

When MS made it difficult to work as a school teacher, Grace Ragland switched gears. Today she sets her own schedule as a seamstress and mountain bike instructor.



Mike, 30, Texas

In early 2013, Mike, who asked that his real name not be used to protect his privacy, was lying on an exam table with a needle in his back. The doctor who was performing the spinal tap to confirm Mike's MS diagnosis asked him if he had health insurance.

Mike had just turned 25 and could no longer be covered by his parents' insurance. And he had recently started his own bankruptcy law business, so didn't have insurance through an employer. The doctor's response: Go home and get health insurance. Pronto.

The Affordable Care Act hadn't kicked in yet, and now Mike had a preexisting condition. Every insurance provider he contacted either turned him down or quoted unaffordable premiums. Panicked, he decided he needed to give up his dream of being an entrepreneur and get a job that provided health insurance. MS-related fatigue meant he couldn't withstand the long hours he'd need to work at a law firm. So he took a job as a high school teacher, even though constant pain in his legs and back make standing in the classroom difficult.

"I'm working this job because I have to," he says. "I feel like my life is literally in my employer's hands."

Five years after his diagnosis, Mike says, "80 percent of my mind still goes to thinking about health care. I rarely think about what I could do to make this disease better through exercise, diet, things like that." The other part of his mind obsesses about his future. Mike, who admits he uses "humor, coffee and wine" as a way to make himself and others feel better about his MS, is uncharacteristically serious when he says, "When I'm alone with my thoughts, I worry about how I'm going to die young, broke and in a wheelchair. If I didn't have my wife to talk to about this, I don't know what I'd do."



PHOTO COURTESY OF MONA SEN

Mona Sen describes in her memoir growing up in many places, including India, and moving to the United States, which held more challenges for her identity as she attempted to chart out a career while managing her MS.



If I tell my story and one person feels better for 10 minutes, I feel like my MS is worth it.” —Mike, 30, Texas

Mike also worries about how his MS affects his wife and young daughter. “I think I’m ruining everything for them, because my MS takes so much energy, time and money that could be spent on other things,” he says. “If I didn’t have MS, we could go on more vacations, have a nicer house, newer cars—you know, the American dream.”

He feels like every decision he makes now is influenced by his disease. “It’s almost like I died and was reborn the day I was diagnosed with MS,” he says.

But he does see some positives. “If I fight my MS hard and do it with a smile, that can be an example for my daughter,” he says. And knowing what it’s like to be in pain and struggling makes him want to help others in the same situation. “If I tell my story and one person feels better for 10 minutes, I feel like my MS is worth it.”

Mona Sen, 52, New York

As the daughter of an academic from India, Sen lived on three continents during her childhood. She grew up without a sense of home or identity. And then, in 1987, at the age of 20, she was diagnosed with MS—which further complicated her search for self.

Sen felt like things that traditionally define people in their 20s were out of her reach. “While my friends were having children and starting their careers, I was dealing with my medication’s side effects and college deferment because of optic neuritis,” she says. “I spent a lot of time comparing myself to others and feeling like a failure.”

After her diagnosis, Sen moved in with her parents and worked a series of unfulfilling jobs. By age 35, she felt like the only thing defining her life was MS. In an effort to change that narrative, she went to graduate school to study occupational therapy. But her cognitive issues made school difficult. Although she eventually graduated, her MS symptoms made it impossible for her to complete the occupational therapy licensing exam.

“I felt like my life had truly ended,” she says. “I felt fragile, weak and like I had no direction.”

In her early 40s, Sen began seeing a therapist. After two years, she felt stronger. “I realized I needed to start focusing on something besides my need to be something,” she says. “I started looking at the world and saw so many people in worse predicaments than me.”

Around this time, she moved in with her partner David, who gave her stability, and she began receiving disability insurance. She was also diagnosed with secondary progressive MS. “Now I’m just in a slow decline,” she says. “It made me realize I need to make every day work as well as it can.”

Sen became very active in her local National MS Society support group, and she began writing. In 2016, she published a memoir, “The Shifting Creek.” Shortly afterwards, she began blogging for a health website. Today, she feels like she’s defined by her writing rather than by her MS.

“Life is very different now. Not like a miraculous transformation, because it took a number of years to get here, but it feels like a cloud has been lifted,” Sen says.

“Once in a while I sit back and realize I’ve lived more than half my life with MS. But now, finally, it’s not staring me in the mirror anymore. I truly believe each of us has a spirit within us—whatever it may be—that gives us the strength to make living with this disease work for us.” ■

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



To learn more about emotional well-being, visit nationalMSSociety.org/emotionalhealth.

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**

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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.

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alemtuzumab 12mg iv

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39



solve

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

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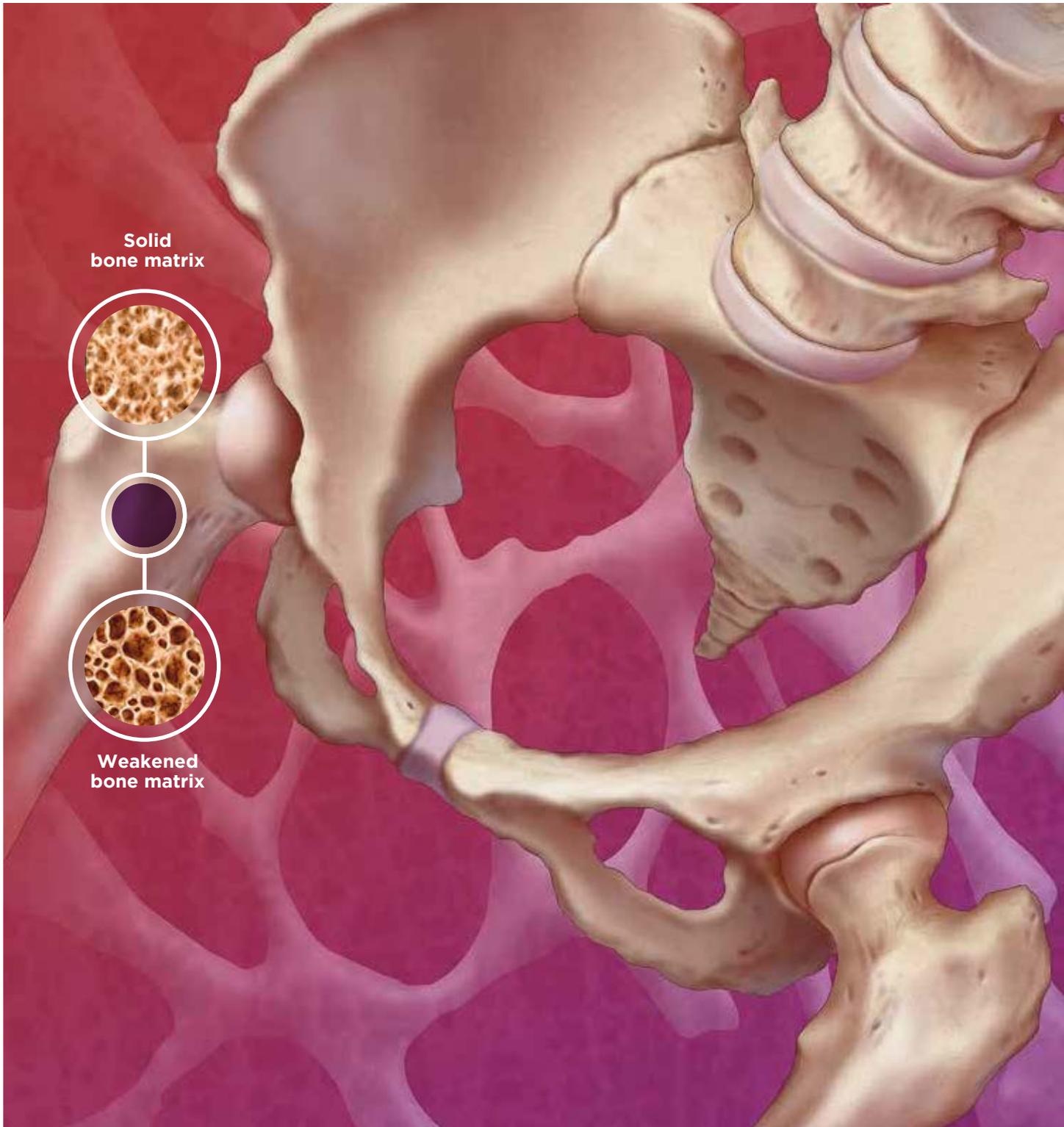
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EAT BETTER, AND YOU'LL LIKELY FEEL BETTER, TOO.

Healthier diets and lifestyles are associated with lower levels of disability, according to a survey involving more than 6,900 people enrolled in the North American Research Committee on MS (NARCOMS) registry. People with the highest diet quality score—indicating a diet higher in fruits, vegetables, legumes and whole grains, and lower in added sugars and red meat—were 20% less likely to have severe disability than those with the lowest quality diet scores. Second helping of salad, anyone? **On the next page:** Read more about factors that could affect your bone health and MS.



Bone health

Osteoporosis is more common in people with MS.

by Lori De Milto

Osteoporosis, a disease that makes bones fragile and more likely to break, is about three times as common in people with multiple sclerosis than in other people, according to results of a study funded by the National Multiple Sclerosis Society. “Of people with MS, 17.3 percent had osteoporosis, compared with 6.5 percent of people without MS. This is a big problem, particularly since the rate of falls is much higher in people with MS than in people without MS,” says Marcia Finlayson, PhD, principal investigator of the study and a professor and director of the School of Rehabilitation Therapy at Queen’s University in Canada. A broken bone in the hip, spine or wrist—usually due to a fall—is often the first sign of osteoporosis. “The findings emphasize the need to pay more attention to bone health in people with MS,” Finlayson says.

Finlayson and colleagues at Queen’s University and the University of Manitoba in Canada used health records for people living in Manitoba to compare 5,729 people with MS with 3,915 people without MS who were similar in age and gender in their study, “Bone Mineral Density Screening and Fracture Risks in People with MS.”

What’s the link between bone health and MS?

Researchers are exploring how common low bone mineral density (BMD) and osteoporosis are in people with MS. Low BMD, called osteopenia, means the bones have less than the normal amount of minerals and strength, but not yet osteoporosis. Studies where people with MS provided information suggest that up to 73 percent have osteopenia and up to 29 percent have osteoporosis.

Primary care doctor Janet Piehl, MD, believes that just having MS doesn’t increase the risk of osteoporosis and broken bones. “Many people with MS do not have risk factors for low bone mineral density. The risk is not specific to MS per se, but due to high-dose, long-term steroid use as well as inactivity,” says Dr. Piehl, who is also the associate medical director for clinical quality at the UW Neighborhood Clinics and an associate clinical professor of family medicine at the University of Washington. Spending most of the day seated or lying down increases risk because lack of weight-bearing activity weakens the bones.

Finlayson also studied anticonvulsants (used to fight seizures) and antidepressants (used to treat depression), which increase the risk of osteoporosis and broken bones, as well. Of the people with MS in Finlayson’s study:

- Fewer than 4 percent were long-term steroid users (more than 90 days in one year);
- 12 percent used antidepressants; and
- 3.7 percent used anticonvulsants long-term (more than 180 days in one year).

So far, there’s no evidence about whether MS disease-modifying therapies affect the bones.

Both MS and osteoporosis are more common in women than in men. However, even people with MS who have little disability may have general risk factors. Along with being female, other general risk factors for osteoporosis include being Caucasian or of Asian descent, a history of broken bones, smoking cigarettes, heavy alcohol consumption, having small bones, being thin, family history of osteoporosis, early menopause and older age.

Who gets screened for osteoporosis?

Dual-energy X-ray absorptiometry (DXA) is a common test for low BMD and osteoporosis. Researchers found

(From left) Nicole, diagnosed in 1995, Melanie, diagnosed in 1997, and Autumn, diagnosed in 2013, of Memphis, Tennessee, enjoy Zumba together regularly for the social connection as well as the physical exercise. Zumba can help build muscle and endurance and support bone mass. Zumba, without adaptations, can be risky for osteoporotic spines because of the quick moves and twists and some spinal flexions.



that doctors sent people with MS for these screens more often if they were older, female, living in an urban area, or had a recent fracture, prolonged steroid use or breast cancer. While many people who have MS as well as risk factors for osteoporosis are being screened, some are slipping through the cracks, says Finlayson, who argues that screening guidelines are needed.

How can you strengthen your bones?

“There are many things under your control,” Dr. Piehl says. “Taking charge of those things is very important.”

Regular, weight-bearing exercise and strength training help strengthen bones, and balance exercises help prevent falls. “Keep moving. Exercise most days, doing whatever weight-bearing exercise you are able to do,” Dr. Piehl says. Some people with MS may be able to walk or run, while others may need to use a recumbent bicycle that simulates weight bearing, or do chair

exercises. Even if you use a wheelchair, you can do strength and resistance training. A physical therapist can help you design an appropriate exercise program.

Take steps to reduce the risk of falls, adds Finlayson, like removing clutter and throw rugs, and adding grab bars or handrails on stairs and in bathrooms. Programs like the Society’s “Free From Falls” are helpful.

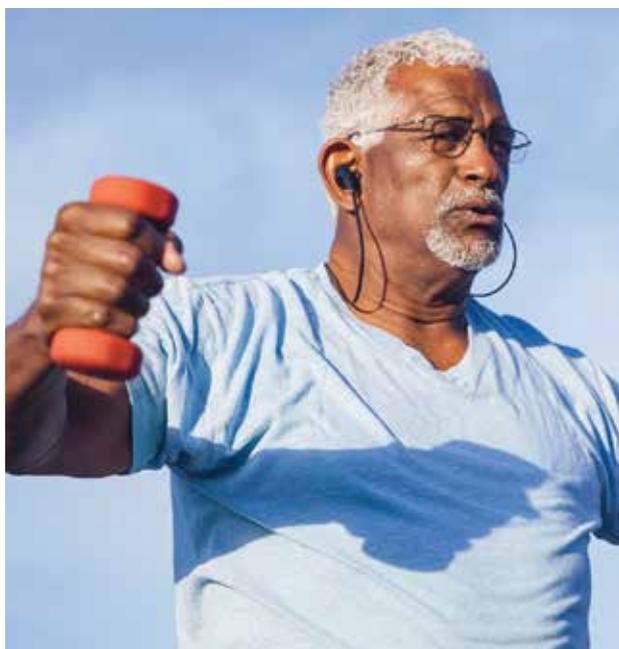
Other ways to help prevent osteoporosis include:

- Not smoking
- Having no more than two alcoholic drinks per day
- Maintaining good nutrition, especially enough calcium or vitamin D (through diet and/or supplements)
- Talking to your primary care doctor or neurologist about how to strengthen your bones and whether you should be screened for osteoporosis.

How well can broken bones be predicted?

The researchers also studied how well a fracture-risk assessment tool called FRAX worked in predicting broken bones in people with MS. FRAX calculates the probability of a broken bone within 10 years based on risk factors like age, gender, use of steroids, secondary osteoporosis (caused by certain medical conditions or treatments) and BMD score at a part of the hip called the femoral neck. People with MS were 3 to 4 percent more likely to break bones than FRAX predicted, and the tool worked best when BMD was included or when MS was considered a secondary cause of osteoporosis. The researchers believe that adding MS as a risk factor would increase FRAX's accuracy and that these results also highlight the need for screening guidelines for people with MS.

Changes to bone mass can start soon after being diagnosed with MS. Finlayson and her colleagues recommend using FRAX along with DXA scans to screen people with MS who have risk factors such



Weight-bearing exercise and strength training can help strengthen bones.

as being female, a recent fracture, prolonged steroid use and breast cancer. If results show osteoporosis, discuss taking an osteoporosis medication with your doctor to help maintain bone density and decrease the risk of broken bones. ■

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



To learn how to help prevent falls, visit nationalMSSociety.org/freefromfalls.

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Use

COPAXONE® (glatiramer acetate injection) is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS).

Important Safety Information

Do not take COPAXONE® if you are allergic to glatiramer acetate or mannitol.

Some patients report a short-term reaction right after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, 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 COPAXONE® 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 COPAXONE®. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking COPAXONE®.

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 brief summary of full Prescribing Information on the adjacent page.



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COP-44997 January 2018

COPAXONE®
(glatiramer acetate injection)



Patient Information
COPAXONE (co-PAX-own)
(glatiramer acetate injection)
for subcutaneous use

Read this Patient Information before you start using COPAXONE 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 COPAXONE?

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

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

Who should not use COPAXONE?

- Do not use COPAXONE if you are allergic to glatiramer acetate, mannitol or any of the ingredients in COPAXONE. See the end of this leaflet for a complete list of the ingredients in COPAXONE.

What should I tell my doctor before using COPAXONE?

Before you use COPAXONE, tell your doctor if you:

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

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

COPAXONE may affect the way other medicines work, and other medicines may affect how COPAXONE 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 COPAXONE?

- For detailed instructions, see the **full Prescribing Information** for complete information on how to use COPAXONE.
- Your doctor will tell you how much COPAXONE to use and when to use it.
- COPAXONE is given by injection under your skin (subcutaneously).
- Use COPAXONE 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 COPAXONE 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 COPAXONE injections.

What are the possible side effects of COPAXONE?

COPAXONE may cause serious side effects, including:

- **Post-Injection Reactions.** Serious side effects may happen right after you inject COPAXONE 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 COPAXONE. Call your doctor right away if you have chest pain while using COPAXONE.

COPAXONE® (glatiramer acetate injection)

- **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 COPAXONE. 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 COPAXONE
 - choosing a different injection area each time you use COPAXONE. **See Step 4 in the Instructions for Use, "Choose your injection area"**.

The most common side effects of COPAXONE 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 COPAXONE. 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 COPAXONE?

- Store COPAXONE in the refrigerator between 36°F to 46°F (2°C to 8°C).
- When you are not able to refrigerate COPAXONE, you may store it for up to 1 month at room temperature between 59°F to 86°F (15°C to 30°C).
- Protect COPAXONE from light or high temperature.
- Do not freeze COPAXONE syringes. If a syringe freezes, throw it away in a sharps disposal container. **See Step 13 in the Instructions for Use, "Dispose of your needles and syringes"**.

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

General information about the safe and effective use of COPAXONE.

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

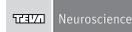
This Patient Information Leaflet summarizes the most important information about COPAXONE. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about COPAXONE that is written for health professionals.

For more information, go to www.copaxone.com or call 1-800-887-8100.

What are the ingredients in COPAXONE?

Active ingredient: glatiramer acetate

Inactive ingredients: mannitol



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This brief summary is based on COPAXONE FDA-approved patient labeling, revised: August 2016.

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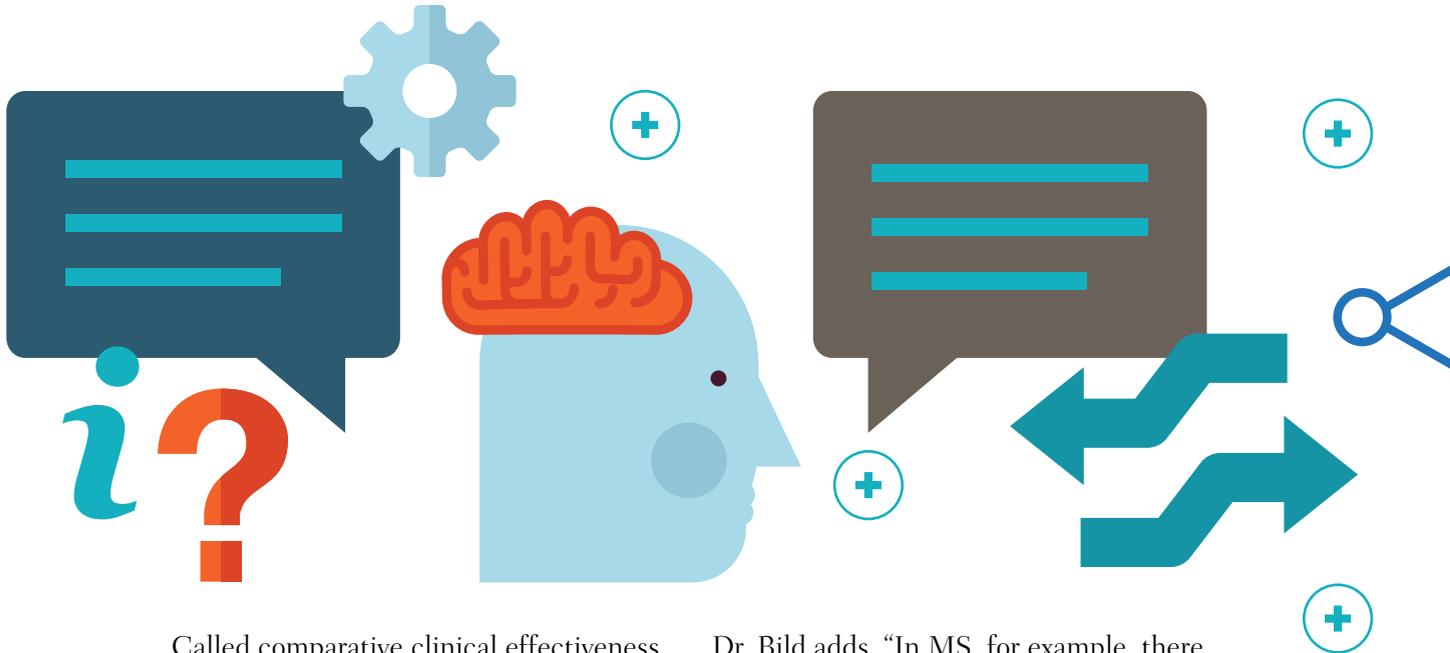
People who face the daily realities of multiple sclerosis and their doctors have practical questions about day-to-day issues, such as the best treatment approach, dealing with fatigue or the side effects of medications. But each person's concerns may not be addressed by traditional research. Fortunately, people with real-life experience now can help guide the thinking behind the design, implementation and funding of certain MS studies.

The Patient-Centered Outcomes Research Institute (PCORI) is an independent nonprofit organization authorized by Congress in 2010 to fund research to answer practical, patient-focused questions.

Pressing questions

People with MS can help guide research addressing the disease.

by Mary E. King, PhD



Called comparative clinical effectiveness research (CER), the studies PCORI sponsors compare current health care options to help patients and doctors choose the right ones. PCORI funds studies in a number of conditions, including cardiovascular and kidney diseases, cancer, dementia, and pain care, and the organization is already making a real difference for MS research working in collaboration with the National Multiple Sclerosis Society.

“We focus on patient-centered outcomes—it’s even in our name,” emphasizes Diane E. Bild, MD, associate director in the Clinical Effectiveness and Decision Science Program at PCORI. “For example, how do different treatments for a condition such as MS affect quality of life? While other research funding organizations may emphasize basic science questions, such as identifying a new biochemical marker for a disease, we look at the impact on patients.

“Our focus is not on identifying new therapies, since others are doing that, but rather on gathering the information that will enable clinicians and individuals with a disease to choose the optimal approach from among the many options available,”

Dr. Bild adds. “In MS, for example, there are many different disease-modifying therapies [DMTs], but it is not always clear which ones will have the best ratio of benefits to harms for a specific individual.”

Dr. Bild also stressed that PCORI involves a variety of stakeholders in MS research—individuals with the disease, family members, caregivers and organizations like the Society that represent them—to identify the most pressing MS questions to fund. PCORI also seeks input from those with professional experience with MS and influence on decisions that affect patients, such as clinicians, researchers, the pharmaceutical industry, hospitals and insurers.

Three questions specific to MS are among the subjects of PCORI-funded research that exemplify its mission to increase timely, useful, trustworthy information to support health decisions: Can an older person with MS stop taking the DMT without experiencing disease activity? What is the best way to treat pain and pain-related depression? How can more minorities participate in MS research?



Can I ever discontinue my treatment?

“We are looking at a big picture question. While we may know an individual will likely benefit from a given therapy, we really don’t yet know how long the treatment must continue. Could some individuals stop a DMT for MS at some point?” asks John Corboy, MD, professor of neurology and co-director of the Rocky Mountain MS Center at the University of Colorado Hospital Anschutz Medical Campus in Aurora, Colorado.

“To begin to answer this, we are looking at individuals with MS who are 55 and older, but only at those who have had no relapses or brain magnetic resonance imaging [MRI] changes for at least five years while continuously taking DMTs,” Dr. Corboy explains. “We will randomly assign half of the participants to continue their current treatment and the other half to discontinue it. We will monitor all of the participants closely, including identifying any relapses, new MRI lesions, disability progression and quality-of-life issues.” He also emphasized that it will always be up to the patient and his or her physician to

decide whether to maintain or change treatment during the study.

“We want to learn whether the older individual with MS is really still deriving benefit from DMT [if they are not having] relapses or changes to brain MRI scans,” says Dr. Corboy. “While published studies show that DMTs are clearly beneficial for younger patients with MS, we don’t know if that is true for older patients, who tend to have less frequent and less severe relapses as they age or even stop having relapses. It may be safe to discontinue these medicines. We may learn they will do no worse than their peers [in the study] who continue on medication, or we could learn that the disease still recurs and continued DMT is needed.”

The trial, funded in part by the Society, is underway but still enrolling additional participants at 15 clinical sites. The enrollment goal is 300 individuals with MS who meet all enrollment criteria. Dr. Corboy hopes to have results available as early as 2020.



Better care for pain and depression?

2

“People with MS don’t always have access to pain and depression care,” explains Dawn M. Ehde, PhD, clinical psychologist and professor of rehabilitation medicine at the University of Washington Harborview Medical Center in Seattle. “It is a complex disease, so the primary focus is on disease modification, as it should be. But these individuals often have difficulty getting additional care for pain and/or depression.

And added to that, they may have problems physically getting to a site that offers this support.”

PCORI funding allowed Ehde and colleagues to create and study the impact of a novel approach to care delivery. Their program featured a special care manager, a nurse supervised by physicians, psychiatrists and psychologists who helped coordinate and provide high-quality, evidence-based treatments for depression and pain. To help those who had difficulty visiting the medical center, the study added the option to provide care by phone or in person, based on the participant’s preferences.

“Our study has wrapped up, and we are now analyzing the data and writing up the results for publication,” Ehde says. “This approach significantly improved pain and depressive symptoms. Our preliminary numbers indicate that 57 percent of those in our program had good pain and depression control, compared with less than a third of those in usual care. Participants also described less pain severity, disability and fatigue, and greater satisfaction with pain and depression care.” They also found a very high rate of adherence to this program, she added.

Ehde also stresses that people with MS truly partnered with the research team, including helping them figure out the optimal study design.

New research projects

PCORI announced five new MS research awards totaling \$38 million in September 2017. These projects address issues that people with MS, clinicians, researchers and other health care stakeholders have identified as priorities. Topics include managing fatigue, comparing outcomes of more aggressive versus less aggressive treatment in newly diagnosed relapsing-remitting MS, and using exercise to improve mobility.

Of the new grantees, three were National Multiple Sclerosis Society Sylvia Lawry

Physician Fellows who received training in how to conduct clinical research in MS: Ellen M. Mowry, MD, Johns Hopkins University; Tiffany Braley, MD, University of Michigan; and Daniel Ontaneda, MD, Cleveland Clinic Foundation. One was trained through the Society’s Mentor-Based Postdoctoral Rehabilitation Fellowship program: Matthew Plow, PhD, Case Western Reserve University. The fifth grantee is Deborah Backus, PhD, Shepherd Center. With these awards, PCORI has now invested \$64 million to fund 12 comparative clinical effectiveness studies in MS.

3

How can more minorities participate in MS research?



“The number of minority participants in MS clinical trials is quite low,” says Hollie Schmidt, vice president of scientific operations for the Accelerated Cure Project for Multiple Sclerosis (ACP), a national nonprofit organization in Waltham, Massachusetts. Founded by a person with MS, the organization focuses on meeting the research needs and interests of people with MS. “We know this is true for other diseases as well, and that barriers include mistrust of the scientific establishment as well as logistical and practical considerations,” Schmidt says. The first step in the PCORI-funded project, which has now completed its first year, was to gather more information. “We needed MS-specific data about what motivates people of different racial and ethnic groups to participate in research as well as factors that discourage participation,” Schmidt explains. Researchers also wanted to know where these individuals would go for trusted information about research if they do want to participate in a study.

ACP, working collaboratively with individuals with MS and other stakeholders, created and disseminated an online survey via email and social media for people with MS to explore these issues. Schmidt says the response was excellent, with more than 2,600 replies that included many different racial and ethnic groups. Most of the responses came from the United States, but investigators received some international feedback,

too. The research is being analyzed and will soon be summarized in two ways, both as a scientific report and as a lay language report that will be posted on the ACP website, Schmidt says.

The next step will be to take what the researchers have learned from the survey and apply it to outreach efforts to minority communities. Schmidt explains that they will use the survey suggestions about where to post information, for example, social media, magazines and online, to link individuals with MS to clinical trials. “We will also reach out to researchers who wish to increase minority participation, to clinicians and to interested organizations to provide them with toolkits to help them improve outreach efforts to minorities,” she says.

Schmidt summarizes the importance of the work in this way: “If your ethnic or racial group is not included in a clinical trial, say for a new drug, as often happens for minorities, then anyone who looks at the data from that research won’t be able to tell if your group will or will not benefit as much. We are moving toward personalized medicine, including for MS, but we are still far from this goal. This research will help us move toward this important objective.” ■

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



Learn how you can be a part of MS research at nationalMSSociety.org/researchparticipation.

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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.

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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.

What can we do?

Finding ways for family and friends to provide help and support

by Mike Knight

Krystal Windley sat in her neurologist's office in disbelief. It was July 2017, and Windley, a 35-year-old single mother living in Malden, Massachusetts, could barely open her right hand. Searing pain hit her when she did.

Windley was diagnosed with multiple sclerosis in 2010. She'd had flare-ups and other symptoms before. But this one was different. This one was disabling.

This one scared her.

"Just to touch it was excruciating, like pins and needles times one thousand," Windley says. "I couldn't put on a shirt by myself, I couldn't close my car door." But, save for steroid injections that might reduce inflammation in her hand, there was little to be done except wait for the flare-up to pass.

"I kind of broke down crying," says Windley, whose family lives four hours away. "They were telling me I would be back to normal in six months," she says. "I thought to myself, 'I've got my daughter. There has to be something you can do, just do something to open my hand. At least let me use it.' And there was nothing."

But Windley was right: She did have her 10-year-old daughter, Jaiden. "She was in the doctor's office with me," Windley says. "She knew that [news] was huge. She came and sat right next to me and held my hand and said, 'It's going to be OK. I'll help you.'"

And for a moment at least, that was all Windley really needed.

Even when it's no more than calming reassurance, help and support are musts for those living with MS. But building a support network for the incurable, lifelong disease isn't always easy. The complexity of

MS can make it frustratingly hard to explain, making it difficult for family, friends and others to understand, which makes it harder for them to know how they can help. Determining what kind of support you'll find valuable may not be any easier, and even asking others for help may feel awkward or uncomfortable. And some may be reluctant to help no matter what you do.

So how do you create a support network if you have MS? What can you do to encourage your family, friends and others to hop on your MS bandwagon? And where do you—or they—start when it comes to looking for more education and information along the way?



Winning the head game

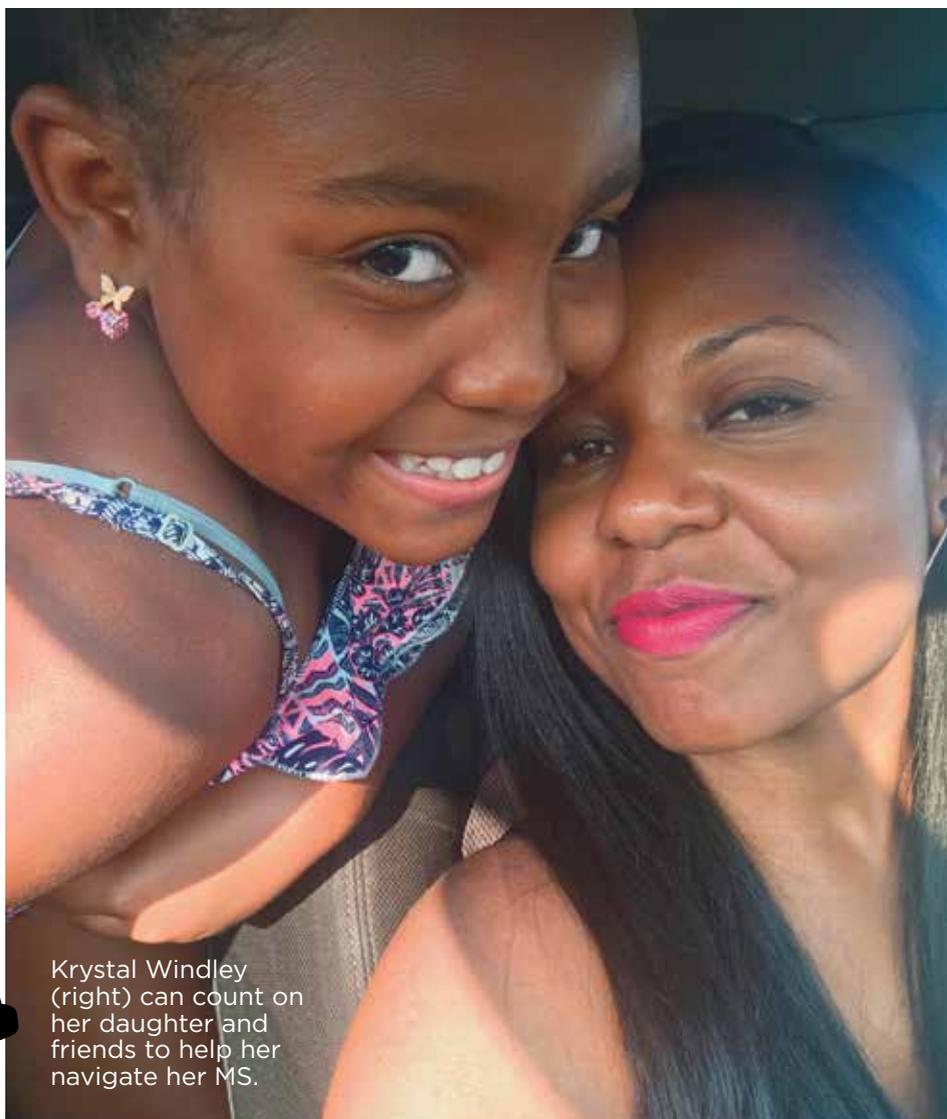
The first step, says Lisa Kempainen, 53, a Colorado-based psychotherapist, is learning to ignore the voices in your head. “Truthfully, most people know how to ask for help. They know the words,” Kempainen says. “What they don’t know is if their request will actually be heard. And that keeps many people from asking in the first place.

“Lots of us have experienced as kids saying, ‘This is what I need,’ and having a parent say, ‘No it’s not’ or somehow shutting us down,” she says. “And we carry that as adults.” Further compounding the problem is a “pull yourself up by your own bootstraps” mentality that may cause people to go it alone.

Diagnosed with MS herself in 1998, Kempainen says people create horror stories that they use as shields against the scarier fears of the unknown and the vulnerability that fear creates. “What you

find is that human beings resist, resist, resist because they have all these stories in their heads,” Kempainen says. “No one is going to show up for me,’ ‘I shouldn’t have to ask for help,’ and ‘If I ask for help, I’m weak.’” And that can become just as disabling as the disease itself.

“The risk is isolation because you just can’t physically do what it takes to put yourself out in the world,” Kempainen says. That isolation feeds on itself by straining your ability to connect emotionally with



Krystal Windley (right) can count on her daughter and friends to help her navigate her MS.

PHOTO COURTESY OF KRISTAL WINDLEY



others—which leads to more isolation. Yet when people do ask, they almost always discover that the fear was unfounded. “If you take the risk, 9.9 times out of 10 it will be beneficial,” Kempainen says.

Once you’ve quieted those voices, Kempainen recommends creating an inventory of what your needs really are. “Is it a person to listen to you for 10 minutes? Is it someone to sit with you while you cry? Is it someone to go to the grocery store for you or walk your dog?”

Mastering the approach can pay long-term dividends to both parties. “When [people] do this, they start to figure out that when you ask for what you need, you give other people permission to do the same thing,” she says. “It doesn’t have to go one way just because you’re the one with MS. Because healthy friends still have needs, right?”

Help your helpers help you

Now retired, 66-year-old Janet Werner spent her career teaching high school science in Long Island, New York. She was diagnosed with MS in 1986. Perhaps not surprisingly, Werner believes others might need to be educated about the disease and its effects before they’re comfortable enough to help.

Werner points to a lesson she shared with a biology class before she disclosed having the disease. “We did a whole program on MS symptoms without telling them that I had it,” she says. Some students were asked to stand on one leg with their eyes closed to mimic imbalance. Others held a 2-liter bottle of water in front of them while standing on one foot to compound the effect. Some held dark paper over their eyes to replicate impaired vision. “They were all laughing, and we had a good time with it,” Werner says. “And I said, ‘You all felt what a symptom of MS is like.’”

Once she disclosed her MS, her students were tireless supporters, as were teachers and staff. After explaining to the school principal that her classroom was very hot and how that affected her symptoms, she asked for an air conditioner. “I had it in the next day.”

That type of experiential education, Werner says, can also help those who are skeptical about the disease and its effects come around. “When people see what

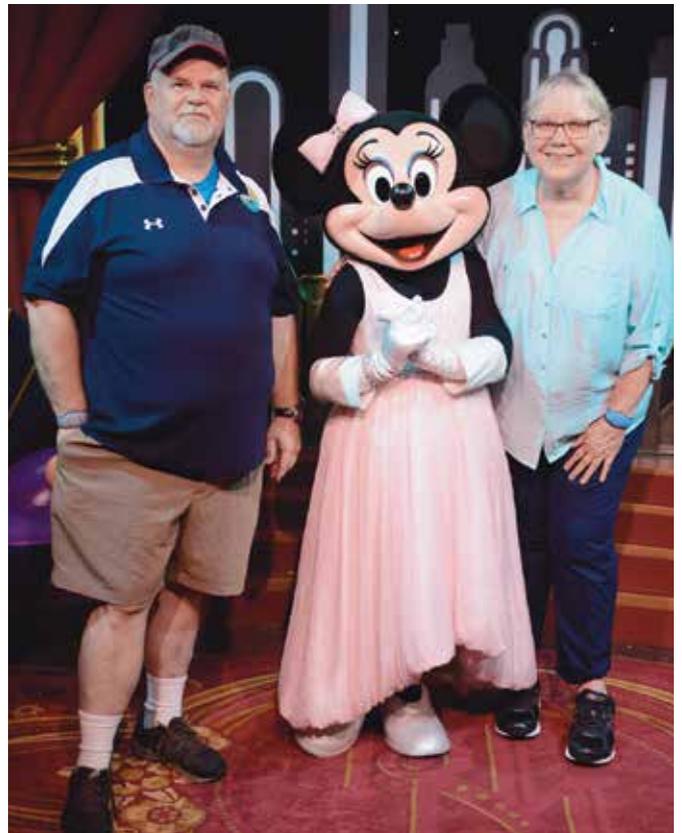


PHOTO COURTESY OF JANET WERNER

Janet Werner (right), with her husband, Ernest, believes that it’s important to educate people about MS before they’re comfortable enough to help.

kind of lifestyle you do have, what your needs are and how you handle it,” she says, “They go, ‘OK, now I understand.’ So instead of just telling somebody, they have to see it.”

Windley says she’s even taught her friends about MS while she educated herself. “Because of my flare-up I had to change medications,” she says. “I was given an encyclopedia of a pamphlet to read through about the medications and it was kind of overwhelming.”

Windley shared her dilemma with a friend, who then brought her boyfriend over to Windley’s to decipher the dense language. “We read through all of the materials, and we each made a little speech about which one was best or about the pros and cons about each of them,” Windley says. “I’m down to two options right now just because they took the time to do that.”

Plenty of help to go around

A school librarian from Memphis, Tennessee, 39-year-old Autumn Scott was diagnosed with MS in late 2013. Married and the mother of two sons, Scott is also a self-help group leader for the Society in her area. Scott says there are “ample” resources for the diverse community of those with MS and those who want to help. Online and in-person programs, services and information that explain the disease, its symptoms and how they affect people with MS are available from the Society (nationalMSsociety.org) and Can Do MS (mscando.org), a Colorado-based national not-for-profit organization.

Both sites feature “Resources” sections. The Society’s website also offers “A Guide for Caregivers,” a downloadable brochure featuring caregiving activities. It also includes suggestions for soliciting—and receiving—support. “Someone You Know Has MS”

is a brochure meant to help children understand MS and simple ways they can help. Can Do’s website features in-person events and monthly live and pre-recorded webinars, including “Together in MS: Supporting Family and Friends of People with MS,” to help those with MS and their supporters “identify the skills, strategies and tools needed to live fully with MS together.”

People also can contact a Society MS Navigator at 1-800-344-4867 or ContactUsNMSS@nmss.org.

No goes, no shows and moving on

Not everyone you ask for help will react as you expected or hoped. For Windley, that included her daughter’s father. “He wasn’t super supportive,” Windley says. “One of the first things he said was, ‘How do you know I want to be around to deal with this [MS]?’”



Autumn Scott (center), a mother of two living with MS, helps empower others with MS by leading a self-help group and sharing MS resources.

PHOTO COURTESY OF AUTUMN SCOTT

Lisa Kemppainen, with her son Issac, encourages people to be direct about asking for help and to always prepare for a Plan B or alternate supporters.



Kemppainen says that's not uncommon. "Some people are uncomfortable around people who are sick, and they're uncomfortable around somebody who's sick for no rhyme or reason," Kemppainen says. And people often don't know how to talk about things that make them uncomfortable, so "they just avoid."

Kemppainen says it's important to be prepared for that possibility by including it in your "story"—or expectations—and by "front-loading" your request for help by noting that it's OK to say no for any reason. That can give others the space they need to talk about it honestly with you, which can be valuable in and of itself. Then be sure to have a Plan B of alternative tasks or supporters.

That approach worked for Windley. "I'm an independent person and I don't like asking people for help," she says. "But this year taught me that I can't be like that anymore." During her recent flare-up, Windley made a trip to the hospital emergency room and asked her daughter's godfather for help.

"I didn't know it would be a long stay," she says. "He picked [Jaiden] up from me [at the hospital] and took her to his work where he needed to work a bit and back to my home." The two waited there until Windley was discharged and joined them.

"So he stepped into that, he came and got her [from the hospital] and he checked in on me and he took her home for me," Windley says. "I would say, 'Don't worry if you can't, I understand,' and of course he dismissed whatever I was saying and said, 'That's what I'm here for.'" ■

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



To contact an MS Navigator, email ContactUsNMSS@nmss.org.

To learn more, visit nationalMSSociety.org/relationships.

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

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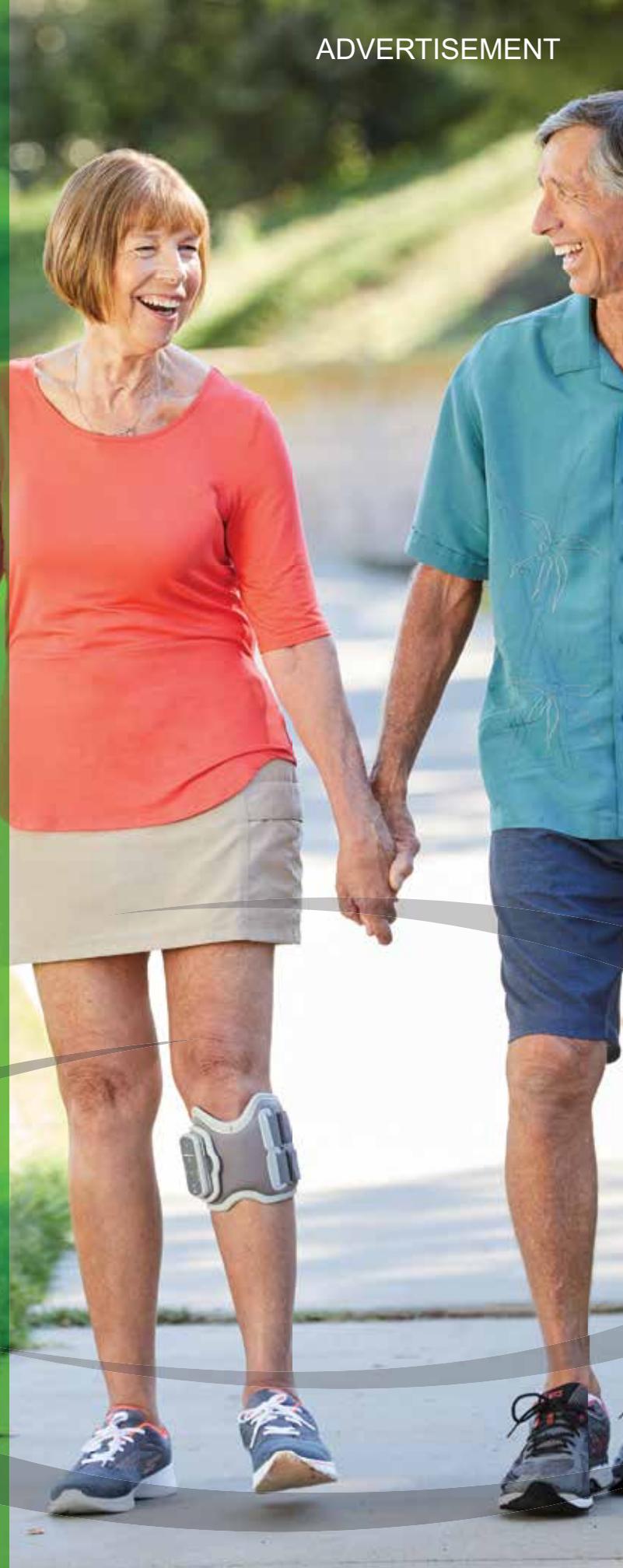


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Spokespeople

Couple completes Bike MS rides in all 50 states

by Shara Rutberg



David Fox and Koreen Burrow have completed Bike MS rides in all 50 states. And they've raised \$175,000 as they've pedaled across the country.

PHOTOS COURTESY OF DAVID FOX AND KOREEN BURROW

David Fox watched his wife, Koreen Burrow, pedal through freezing Alaskan rain that blew sideways during her first Bike MS ride in 2007. He recalls thinking at the time, “Well, this will be the last time she ever does this.”

He couldn’t have been more wrong. Burrow, 53, who was diagnosed with multiple sclerosis in 1991, has completed 67 Bike MS rides. And although Fox, 55, who, when presented with a road bike couldn’t believe he could fit his rear end on a seat so tiny and often mentions his preference for the couch, has pedaled with her on every ride since that first one.

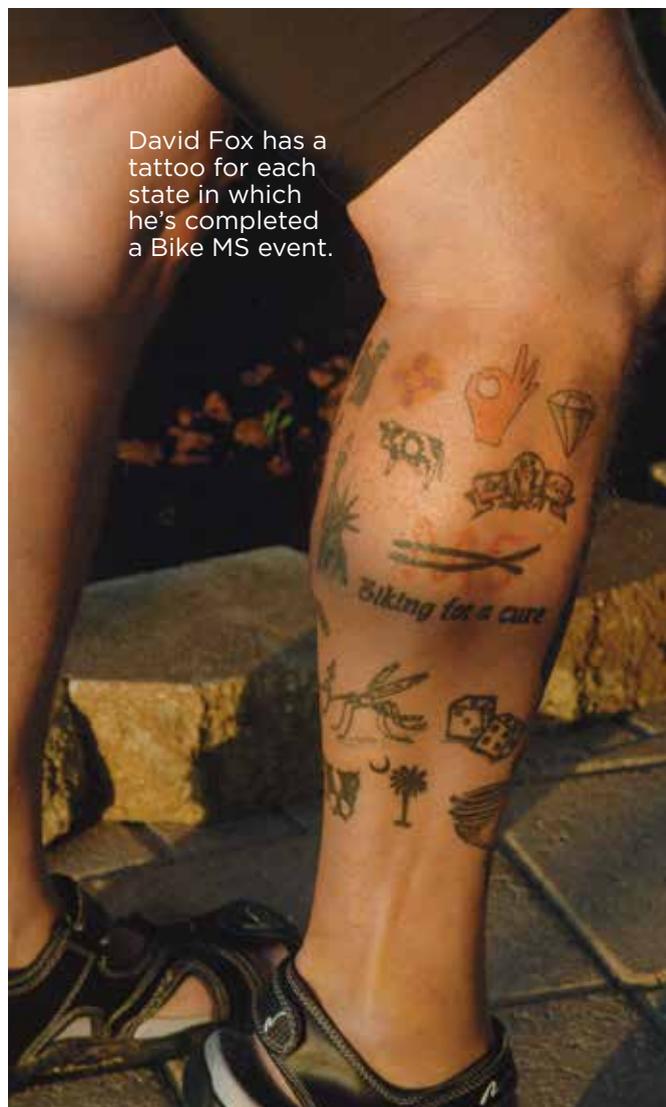
With more than 80 events across the country, Bike MS is the largest fundraising bike series in the world. In October 2017, the couple completed their goal of riding in Bike MS events in all 50 states when they pedaled across the finish line at Bike MS: Breakaway to the Beach in North Carolina. The accomplishment is even more impressive when you learn that in spring 2017, Burrow was diagnosed with breast cancer, underwent surgery and radiation, and was back on her bike with Fox by her side within weeks. So far, she’s cancer-free. “It will take more than MS and cancer to turn that smile upside down,” says Fox of his wife’s infectious grin. “Burrow is the toughest person I know.”

Every year, more than 80,000 participants and 7,000 teams take part, according to Stacy Mulder, vice president of Bike MS at the National Multiple Sclerosis Society.

Shortly after Fox proposed to Burrow, she received her MS diagnosis. Burrow says she “gave him an out” before the wedding but “he insisted on going through with it, and we’ve never looked back.”

Upping their game

Before that first Alaska ride, Burrow hadn’t even owned a bicycle until college. But a friend loaned her a bike and helped her train. Fox drove behind the whole way in case she needed help. After that, the couple was hooked. They did a few rides out of state through the national Bike MS Passport program, which allows cyclists who have raised at least \$5,000 through Bike MS to ride in any other Bike MS event within the year without additional fundraising. “When my disease flared up, it became clear that we needed to up our



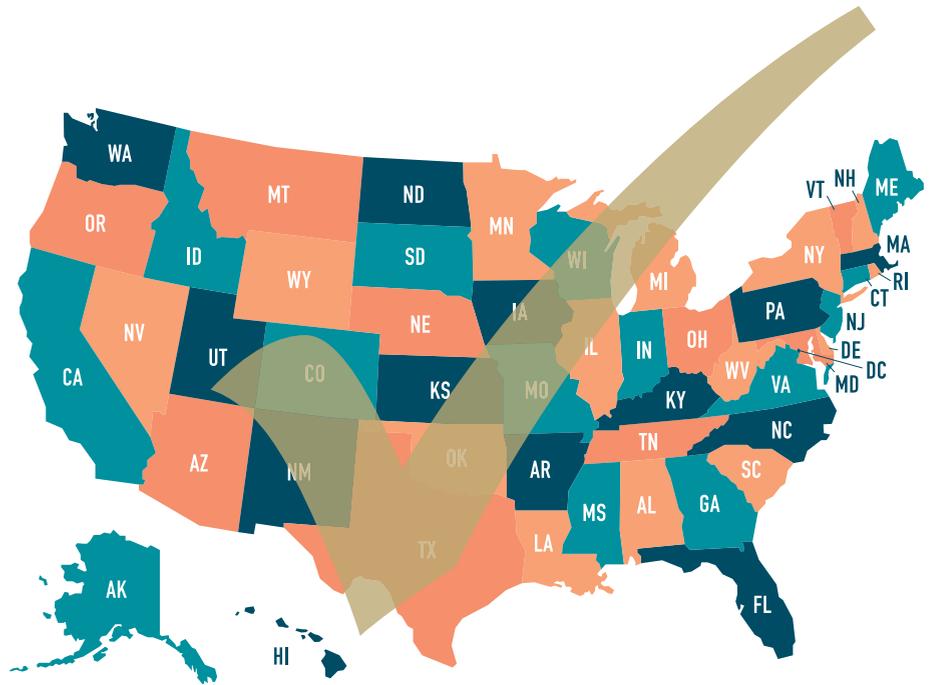
David Fox has a tattoo for each state in which he’s completed a Bike MS event.

game to raise awareness for a cure,” Burrow says. “That’s when we decided to commit to a Bike MS ride in every state.”

Fox pledged that commitment in ink: For each state they’ve ridden, he’s added a tattoo to his leg with a symbol for that state. The Alaska ride got a mosquito, the state’s unofficial mascot. New York got Lady Liberty, Nevada a pair of dice. “That way, we know which ones we’ve done, and she can’t make me repeat any,” Fox jokes.

“The Alaska ride is gorgeous and will always have a special place in our hearts because it was our first.”

— Koreen Burrow, who completed Bike MS in all 50 states with her husband, David Fox



The biggest challenge has been the logistics, the couple says. Many rides occur on the same weekend and traveling across the country with bikes in tow can be difficult. At first the retired couple tried flying to events and renting bikes, but that was a hassle. So they bought a 20-foot-long travel trailer, which they live in for five to six months each year, traveling throughout the country with their rescue cat, Francis. When they're not on the road, they live in Las Vegas.

The couple has raised more than \$175,000 for the Society. However, their nomadic lifestyle makes fundraising challenging, they say. For example, they're not in one place long enough to plan fundraising events they can promote for very long. They believe their bigger impact has been attracting new riders to the cause. "It's so critical that rides include new riders every year for the sustainability of the program," Burrow says.

Mulder says their efforts have "created incredible awareness about the Bike MS series as a whole. They are also developing great relationships in [areas] where they participate and serving as an inspiration for many."

Favorite experiences

Of all the miles they've pedaled, what were their favorite rides? "It's pretty hard to beat Hawaii," Burrow says. "It's just beautiful. And the Alaska ride is gorgeous and will always have a special place in our hearts because it was our first."

Burrow's favorites are based on the level of challenge and the scenery. Fox's are based on food. "Maine has a lobster dinner at the end," he says. "And Alabama's got a big seafood buffet."

Different rides have also offered unique, incredible experiences. In Las Vegas, the couple got to ride their bikes around the Las Vegas Speedway. In California, they pedaled across the Golden Gate Bridge. "Every state has something special," Burrow says.

The best part, they agree, has been the people they meet along the way. They've even repeated rides in some states they already completed just to ride with friends—and no, Fox says, laughing, he didn't add additional tattoos. He's running out of leg. ■

Shara Rutberg is a freelance writer in Evergreen, Colorado.



To learn more about Bike MS, visit bikems.org.

See the couple's Facebook page by searching for "David & Koreen Bike the US 4 MS."

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

opens up possibilities

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.

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

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

- **Allergic reactions**
- **PML, which is a rare brain infection that usually leads to death or severe disability.**
- **Decreases in your white blood cell count.** Your doctor should check your white blood cell count before you take TECFIDERA and from time to time during treatment
- **Liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your doctor right away if you get any symptoms of a liver problem during treatment, including:
 - severe tiredness
 - loss of appetite
 - pain on the right side of your stomach
 - dark or brown (tea color) urine
 - yellowing of your skin or the white part of your eyes

Important Safety Information (continued)

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

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

For more information go to dailymed.nlm.nih.gov.

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

For additional Important Safety Information, please see Patient Information on the following page. This is not intended to replace discussions with your doctor.

*Based on number of prescriptions from IMS NPA™ Weekly Data (September 27, 2013 – December 8, 2017).



Patient Information
TECFIDERA® (tek" fi de' rah)
(dimethyl fumarate) delayed-release capsules

What is TECFIDERA?

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

Who should not take TECFIDERA?

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

Before taking and while you take TECFIDERA, tell your doctor if you have or have had:

- low white blood cell counts or an infection
- any other medical conditions

Tell your doctor if you are:

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

How should I take TECFIDERA?

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

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

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

The most common side effects of TECFIDERA include:

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

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

General Information about the safe and effective use of TECFIDERA

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

What are the ingredients in TECFIDERA?

Active ingredient: dimethyl fumarate

Inactive ingredients: microcrystalline cellulose, silicified microcrystalline cellulose, croscarmellose sodium, talc, silica colloidal silicon dioxide, magnesium stearate, triethyl citrate, methacrylic acid copolymer - Type A, methacrylic acid copolymer dispersion, simethicone (30% emulsion), sodium lauryl sulphate, and polysorbate 80.

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

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

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

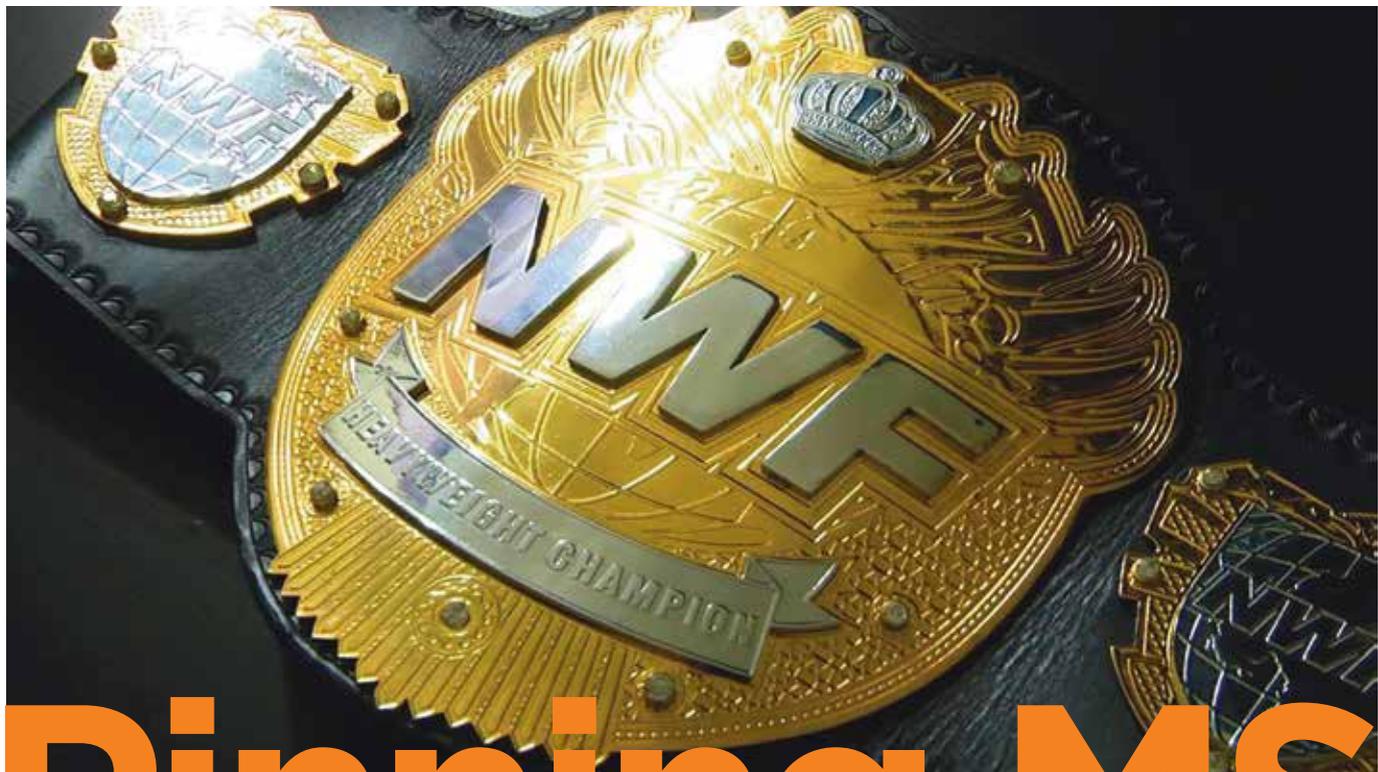


PHOTO COURTESY OF ROGER BACHMAN

Pinning MS

Fundraiser helps wrestling promoter feel more powerful.

by Kelsey Blackwell

Picking up a guy in the air and slamming him to the mat may not be the first image that comes to mind when considering ways to support multiple sclerosis research, but for Roger Bachman, creator of the Bachman Body Slam, it was a no-brainer. When Bachman's daughter Kellie was diagnosed with relapsing-remitting MS at the age of 26, she and her family were devastated.

"You can prepare yourself all you want for a situation like that, but when you finally hear those words, well, it was earthshaking," Bachman says. "She was really upset and kind of leaning on us [her parents] to give

her a positive outlook. We tried to do that as best as we could, but being an emotional person myself, it was difficult to reassure her that everything was going to be all right. It was a rocky road."

Bachman set out to find something that he and his family could do to feel more powerful.

Bachman is the owner of the Cincinnati-based Northern Wrestling Federation (NWF) and has been a promoter of wrestling shows throughout Ohio, Indiana and Kentucky for 22 years. So finding a way for his passion to support his daughter seemed obvious. "Throughout the years, we'd done fundraisers

After his daughter's diagnosis, Roger Bachman, a wrestling promoter, stages a tournament to raise money for research and put on a show at the same time.

PHOTOS COURTESY OF ROGER BACHMAN



Kellie Bachman (left), with her son and her father, Roger Bachman (right).

for everything from local Little League teams to fire departments—why not MS?” he asks.

The Bachman Body Slam was born in 2015. “We chose that name because it’s about body slamming MS,” Bachman says. “Plus, Bachman is Kellie’s last name so it goes together. She’s been around the wrestling shows since she was a very, very, little girl. She’s grown up, basically, in the Northern Wrestling Federation.”

Throughout the year, the Bachmans sell T-shirts, donating 100 percent of the proceeds to the National Multiple Sclerosis Society.

In November, fundraising efforts intensify with a raffle and bake sale. The Bachman Body Slam culminates in a “main event” wrestling match, which draws attendees from across Ohio and Kentucky. The reason they come is clear: Besides helping raise funds for MS research, they’re treated to a first-class show. After noshing on homemade baked goods and perhaps entering to win a big-screen TV, participants watch several wrestling matches complete with a baritone-voiced announcer and classic melodramatic storylines key to any wrestling show. Wrestlers from the NWF’s roster

intimidate each other and initiate wrestling moves like the brain buster, choke slam, cutter, face buster, neck breaker, and yes, the body slam.

More than 200 fans turned out for the 2017 Bachman Body Slam, cheering on 25 wrestlers who competed in eight matches. The event raised \$1,595, according to Bachman.

“We were very happy with the turnout,” he says. “We are looking forward to participating and helping the Society in any way possible.”

Says Kellie: “I’m so proud of my dad for putting together this event. It’s so incredible to see and feel support, and it gives



The Bachman Body Slam started in 2015, when Kellie Bachman was diagnosed with MS.

me such hope that one day this disease will be curable. Until then we will fight, raise money and be hopeful.”

While raising money is the body slam’s primary goal, it’s not the only motivation for the event. “In a selfish way, it just feels good,” Bachman says. “It makes us feel a little bit better about the situation, along with helping to be able to donate money and help with the research.”

Feel-good fundraising

That “feel good” is a natural reason to be drawn to the Society’s Do It Yourself Fundraising MS, says Rachael

Nuwash, associate vice president of special events for the Society.

“We find that there are a lot of people who are very connected to the cause, either because they live with MS or someone near and dear to them is living with MS, and they want to do something more than just participate in [Society] fundraising events we put on every year. It’s really inspiring to see how people engage.”

Nuwash has seen successful DIY campaigns that range from bake sales and bowling tournaments, to a girls’ brunch with pedicures and mimosas. The most successful, she says, often put the host’s own passions and creativity front and center.

For those inspired to create an event, the Society provides a variety of information, including a link to a DIY participant fundraising page, which includes templates for building your fundraiser page,

sample emails for your donation requests and resources for promoting your fundraiser via social media. Society staff members also can help.

“I love to hear about the successes of people like the Bachmans,” Nuwash adds. “It’s that kind of creativity that makes for a lively and exciting event. These gatherings become more than fundraisers, they’re part of people’s lives.” ■

Kelsey Blackwell is a freelance writer in Berkeley, California.



To learn more about DIY Fundraising MS, see diyMS.org.

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

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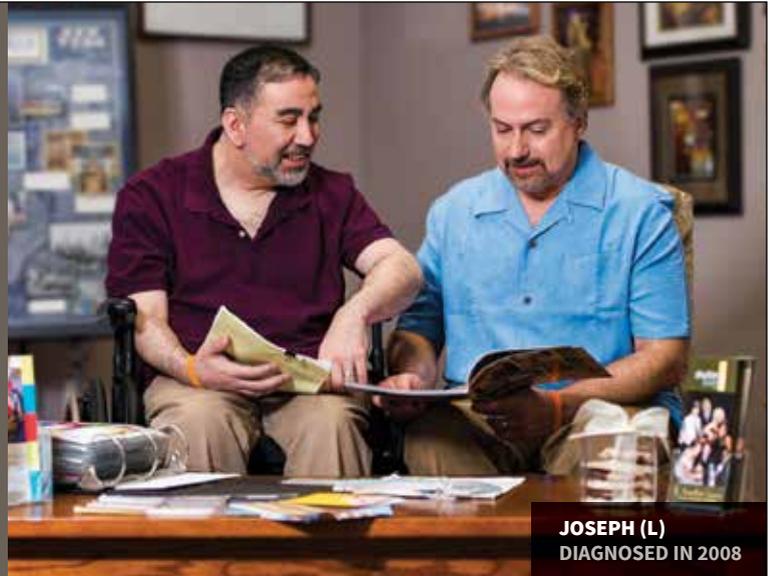
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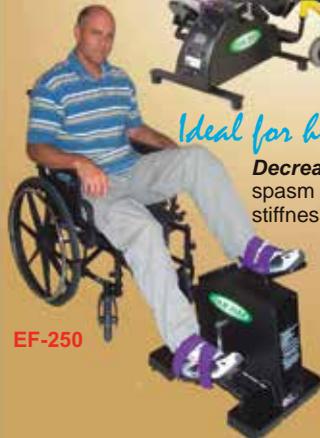
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PHOTO COURTESY OF CAT STAPPAS

**“MS is part of my life.
But I won’t allow it
to control me
or who I am.”**

One of the things I enjoy most about blogging is the interaction with my readers—the exchange of information, experiences and encouragement, along with the reassurance that I am not alone.

It’s a two-way street. When I write, no matter the subject, I am always sure to work in a positive spin, not just because I’m writing for an audience, but because I’m often also writing for myself, to myself.

I’m often told by friends and strangers alike, “Cat, you’re so strong.” They call me courageous. Brave. But no one has explained to me what it is specifically that makes me appear strong.

People tell me they admire my resilience and my ability to stay optimistic. Are they referring to the self-deprecating jokes I crack about the state of my physical body? Because those do not come from a place of confidence and strength. Quite the opposite, actually.

I make the jokes first, to beat you to them.

Like the fluid ways and timelines in which our symptoms manifest, the way I view myself changes from day to day. Lately—especially after being diagnosed with osteoporosis at 33 and learning that my multiple sclerosis is still not responding well to treatment—when I look at my reflection in the mirror, it almost feels like I’m having an out-of-body experience, looking at someone else. Someone who is not me.

I see someone who is broken. Old. Frail. Fragile. Weak. Ugly. Afraid. Lonely.

Now, it is absolutely normal, natural and OK to go through dark periods. It’s my right as a human being. But there’s a lesson in everything, especially in these times of heightened distress.

These past few years have been an evolution.

In the beginning, I was convinced I could reverse the disease with positive thinking, and when that wasn’t happening, I shut down for a while and I allowed myself to actually become MS: toxic and self-attacking.

Claiming

Knowing what you are not

by Cat Stappas

Cat Stappas performs American tribal belly dancing, which helps her gain confidence and improve her balance.

victory

PHOTO COURTESY OF JUSTIN HERNANDEZ

■ fired up

“ I realized that admitting I have MS is not the same as admitting defeat.”

A wonderful integrative doctor pointed this out to me, the way my behavior was mimicking the actual disease. And then something changed. I realized that admitting I have MS is not the same as admitting defeat.

I realized that I had the power to make this a victory.

No one awarded me that power and no one can take that power away. I had it all along. All I had to do to harness the power was to decide to let go of what I can't control. Instead of hiding from my fears, I immersed myself in them. I learned as much about the disease as I could. I started a blog in hopes that other people like me might stumble across it on their darkest day and maybe receive a message they needed to hear in that moment.

Now a couple years later, a simple Google search shows that my name is forever synonymous with MS. I never expected to become as involved in the MS community as I have, and it has been proven persistently to be a very real risk to do so—to my relationships and, most of all, to my livelihood.

People are quick to judge and many times assume I'm a liability or useless. I don't see myself that way or as “disabled,” in the literal sense of the word. I do, however, recognize the hurdles in front of me, so maybe “disadvantaged” is a better term. But my hope is if people see how open and vulnerable I make myself, how much I accept this part of my life, others will be more accepting as well. I want people, whether they are disabled or not, to know that Cat Stappas is not MS, but that MS is part of my life. And that's OK. I can handle it. I do not allow it to control me.

And isn't that what a warrior does? Doesn't a warrior know what he or she is up against and charge into battle anyway, without knowing the outcome, all in the name of helping other people?

So I guess the reality is that I am strong, despite waking up every day not knowing what will come next, but being very much aware of what could come next.

I show up.

I am strong. I am a dancer. I am a writer. An advocate. Fierce friend. Lover of animals. Wife, daughter, sister, stepmother. An activist.

But I am not MS. ■



Check out Cat Stappas' video on the **Momentum** app.

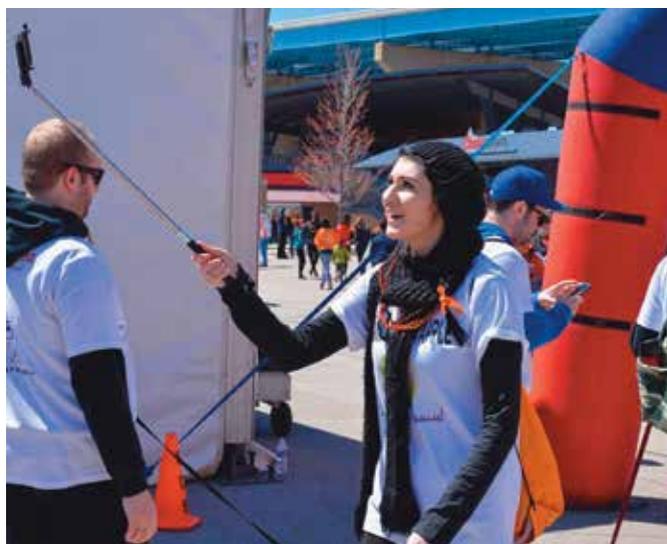


PHOTO COURTESY OF CAT STAPPAS

Cat Stappas shoots video for her blog at last year's Walk MS event in Milwaukee.

Cat Stappas, who was diagnosed with MS in 2013, lives in Milwaukee, Wisconsin. She writes about her experiences in her blog, “It's Only a Bruise,” as well as at the Society's [MSconnection.org/blog](https://www.msconnection.org/blog) and other online MS resources. She's active on the It's Only a Bruise Facebook page, Twitter, Instagram and YouTube. She hopes to make the dark corners of the internet a little less scary for both the newly and the longtime diagnosed with some honesty, positivity and a bit of tongue-in-cheek humor.



See more at Cat Stappas' blog
itsonlyabruise.com.

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



See more at
loiskipnis.com.

Dear adversary

30 years of living with MS

by Lois Kipnis

Veteran's Day, 2016

Dear MS, on our 30th anniversary:

Do you recall our first encounter?
The beach. Intense heat. Knocked me off my feet.
I stumbled in the sand. You grabbed my hand,
Touched my spine. Electric shocks. Tingling.
Weakening my myelin sheath covering.

You lingered a while, then disappeared.
Woody me, pursued me for over a year.
I loathed not knowing when you'd reappear,
Or the tease when you stuck around longer.
My resistance weaker; feelings stronger.

But thirty years ago, on Veteran's Day,
I learned your true name when you came to stay.
Pitched your tent. In my face. Under my skin.
Jabs which made my body a pincushion
Affecting speech, balance and cognition.

It's then, dear adversary, we went to war,
For I understood what MS stood for.
Self-pity at first was my reaction,
Passive until I opted for action.
And so I declared you my enemy.

Battle cry? "Possibility, not negativity!
Rehabilitation, not debilitation!"
You exacerbated; I retaliated.
You captured, held me in submission,
I regrouped; went into remission.

My ammunition? Determination,
A stockpile of books, information.
Outsmarted you with an education.
Camouflaged my fatigue. Never succumbed.
Made humor my captain. Stuck to my guns.

Thought you'd wear me down and rank me squeamish,
But I mustered courage for each skirmish.
When you immobilized, I mobilized.
Showed you muscle, changed diets, exercised.
Prioritized. Fortified. Strategized.

So, MS, master of surprise attacks,
For thirty years, I've fought to force you back.
I'm a Veteran now. Scars. Earned my lesions.
Proven a warrior for all seasons.
Course of progression? No rhyme. No reason.

But I'll fight battles to the bitter end.

Determinedly,

Lois Kipnis
Your War of Nerves Friend

Lois Kipnis, who was diagnosed with MS in 1986, is a creative arts consultant with 40 years of experience as a drama teacher and arts administrator. She's the author of "Without a Script: A Caregiver's Journey" and "Things Can Always Be Worse!" and the co-author of three educational books, including "Together We Can Improvise." Kipnis lives in Massapequa, New York, and enjoys spending time with her family, attending writing workshops and reading her stories and poems at bookstores, libraries and other venues. Writing has always been a catharsis for her, whether she writes about living with MS, the past eight years as caregiver for her mom, or humorous and serious short stories. "Writing engages my mind, provides me with a creative outlet when physical activities are a challenge, and is a vehicle for me to educate and share my philosophies about life," Kipnis says.

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

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