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sensitivity

22



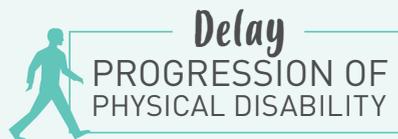
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Laura S., living with relapsing MS

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

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



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

What is TECFIDERA?

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

Important Safety Information

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

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

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

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

opens up possibilities

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

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

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

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

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

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.

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



Tecfidera
(dimethyl fumarate) delayed-release capsules 240mg



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

What is TECFIDERA?

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

Who should not take TECFIDERA?

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

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

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

Tell your doctor if you are:

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

How should I take TECFIDERA?

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

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

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

The most common side effects of TECFIDERA include:

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

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

General Information about the safe and effective use of TECFIDERA

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

What are the ingredients in TECFIDERA?

Active ingredient: dimethyl fumarate

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

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

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

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

momentum

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on the cover

Samir Chandiwala can play tennis again in the summer after moving to a cooler climate to relieve his heat sensitivity.



PHOTO BY MATTHEW ALLEN

departments

- **forward 6**
What a cure for MS means
- **@momentum 7**
Readers sound off
- **pulse on MS 9**
Nearly 1 million people live with MS in the U.S.
- **move 56**
Bike MS: Miles to go
- **connect 63**
Finding a neurologist
- **impact 68**
Sailors with MS
- **fired up 72**
Tell me something interesting
- **this is me 76**
Understanding through images

features

thrive

Acing temperature control
How to cope with heat sensitivity **22**

State of limbo
A definitive MS diagnosis can take time—and patience. **30**

"I got 99 problems, and 87 of them are side effects."



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10

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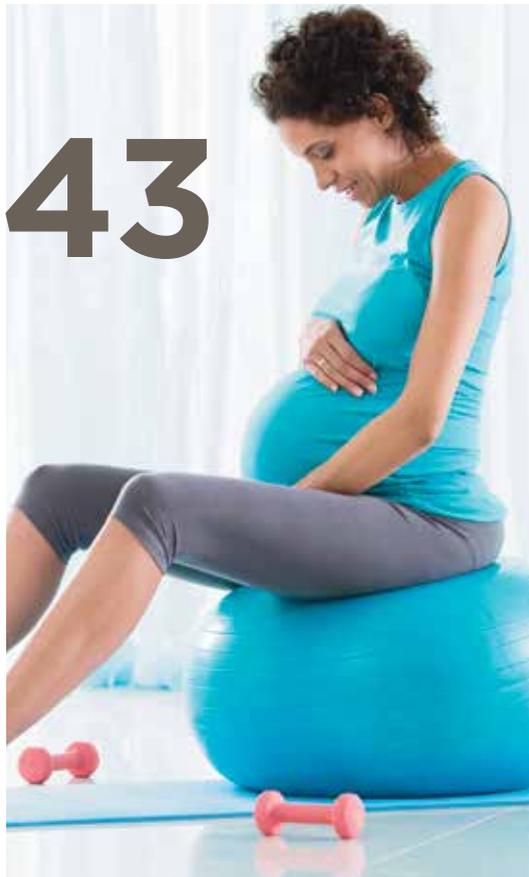
Function and fashion 11

Testing ground 15

solve

A big part of the MS puzzle 44

Pregnancy and MS 49



43

IN THE NEXT ISSUE

Teens with MS face the challenges of growing up with their disease.

PLUS: Caring for carepartners and reactions to data showing 1 million people in the U.S. live with MS.

Contact Momentum

 nationalMSSociety.org/momentum



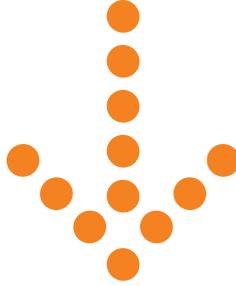
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When I wrote about finding a cure for multiple sclerosis in this column last year (Forward, Summer 2018), I asked, “What does a cure mean to you?” I received many replies that were powerful and moving. A cure can be described in several ways that can be categorized as follows:

- **Stop MS in its tracks:** No additional damage, no progression of the disease.
- **Restore what has been lost:** Get back the abilities I had before I had MS, a reversal of symptoms.
- **End MS:** No one else gets diagnosed with MS.

For some, a cure means one of these definitions specifically. For others, it means all of them. A sampling of what I heard:

“My idea of a cure is first things, first—whether it is relapsing, progressive or whatever—just stop it from getting worse.” —Rand Garrett

“To me, a cure means I can walk, run, skip, jump again. I can think of what to say. I will feel alive, play with my granddaughter. It means to live a normal life, to be able to walk next to my husband, have friends and go out for lunch and shopping again, just like I used to.” —Jayne Almonrode

“A cure means complete eradication of this terrible disease, not just slowing its progress or relieving symptoms. Eradication means no one will ever get it again. A cure also means people like myself who already have MS will be able to have the damaged myelin and nerves repaired and restored to normal function. Yes, I want it all before I will call it a cure.” —Marge Carter



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

733 Third Ave.,
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At the National MS Society, we are relentlessly pursuing the fastest path to a cure for MS (see our FY2019 to 2021 Strategic Plan at nationalMSSociety.org/About-the-Society/Vision/Strategic-Plan).

Our approach is to seek input from experts—scientists and clinicians with various expertise—as well as people affected by MS because no one knows their MS better than a person living with the disease. We invest more than \$40 million a year in innovative research and expanding the MS research workforce while we promote collaboration and shared learning to speed discoveries. We launched a global conversation: “What are the specific pathways to the cures that people with MS want and need?” We strive to gain international consensus to focus worldwide investments in MS research to get us down those pathways quickly, investing in the research that has the most promise.

To achieve a Stop Cure, we need to understand what causes MS disease activity to flare up. A Restore Cure requires therapies that will promote repair, getting the central nervous system to heal and get back to a pre-MS state. The End MS Cure pathway starts with knowing the cause of MS and who is at risk for the disease.

We have brilliant, passionate, committed people working on these pathways. I hope you have the opportunity to meet some of them, and when you do, to share your perspective and your encouragement.

I love hearing what’s on your mind. What are you thinking about these days? What do we, at your MS Society, need to know about you? ■

Cyndi Zagieboylo



Getting help for depression

I just read and appreciated the article about the hidden symptom of depression (“The hidden symptom,” Spring 2019). I’ve dealt with MS symptoms for 37 years. Hearing that depression is an MS symptom freed me to get help for depression as [when I was] 23 with no visible MS symptoms. In the past 27 years, I have been slowly disabling. I am now in a wheelchair and totally dependent on a caregiver (my husband) for meeting my daily needs. I am now dealing with depression specifically connected with grieving, for almost three decades, the continual loss of functioning. I am seeking specialized counseling to deal with the disabling grief I feel for now and for the past. Fortunately, I live two miles from the Mayo Clinic and this help is available. Thank you for addressing this issue.

Therese Anderson, Minnesota



PHOTO BY RIKU FOTO

The feeling is familiar

Thank you and Brooke Pelczynski for her article, “New ways of creating” and her cover illustration (Spring 2019). I really connected with her illustration of depression: having one’s head in the sand, preventing you from seeing the beauty all around you. I know that feeling. Acceptance of my situation while finding a way to appreciate the good is a daily challenge. My first grandchild is a major motivator for me.

Sid Burwell, California

The ability to create

Thank you so much for your article by Brooke Pelczynski, “New ways of creating” (Spring 2019). I was diagnosed with MS in 1997. At the time it never occurred to me that I would leave a job I loved and start disability benefits, that I’d end up needing a walker or that my physical activities would become so limited it changed the way we lived. What saved me was my ability to create. My love of making jewelry brought me joy while keeping me sane when other parts of my body refused to respond. As the progression and loss from MS has continued over the last 21 years, so have I. I’ve adjusted my creativity to my abilities. Working with leather took the place of beads. Working with paper in all forms lets me create cards and gifts. My newest passion is felting. I start small. I try to set myself up for success. Being able to still create in any form somehow makes me feel like I’m winning the battle.

Debbie Salazar, Washington

A powerful diagnostic tool

While perusing my Winter 2018–19 issue of **Momentum**, I happened upon the article, “A better look,” about Dr. Frederik Barkhof regarding MRIs. I was 24 in 1980 when the neurologist I initially met with did a “spinal tap” and CT scan and gave me a cursory diagnosis of MS, saying I could look forward to being in a wheelchair and living a handicapped life in two to three years! I was beginning a new career as an accountant, newly wed, with a 6-year-old daughter. That evening, my new husband consoled me and said we would fight through this together. At the time I was living in Northern Colorado, 50 miles from Denver and the University of Colorado Medical Center. There were no support groups or websites or any new research known by “lay” people. I located a neurologist at the medical center who was working in immunology and the new diagnosis of MS. At the time, MRI was a new entity. This physician believed in the MRI and had me take one. He said it would be a much better test for the diagnosis and so it was. It showed obvious scarring in the right brain. He also said to keep working and living my normal life. Don’t change anything! In 1996, things

in my life changed, with great periods of stress. My MS reared its ugly head and showed its true colors. I walk now with a walker and travel with a wheelchair. MRI is definitely a great diagnostic tool.

Colleen Richardson



Doing the right thing

The article on cognitive function in the Spring 2019 **Momentum** magazine (“A closer look at cognition”) reassured me that I am doing the right thing. I was diagnosed with relapsing-remitting MS in 2003. I recently took an MS cognitive evaluation at Lehigh Valley Hospital in Allentown, Pennsylvania. The test was administered by a neuropsychiatrist and was covered by Medicare. I am waiting for the results. One thing notable about this test was that it only took two and a half hours. Before the test, I was concerned about fatigue. I know if I am fatigued, my cognitive function goes down. It is one of my biggest sources of disability and can be very scary. This shortened version of testing took that into consideration. On a side note, I had to chuckle about the line in the article about rewashing clothes. I compensate for that problem by using liquid detergent and throwing the measuring cup in the washer with the laundry. Recently, I did laundry before bed and went to bed wondering if I had remembered the detergent. In the morning, I saw the cup in the washer and knew I had remembered. I felt good that I came up with this solution myself.

Nancy Wilson, New Jersey

Rooms not always accessible

Thank you for publishing the article, “It’s your community, too” (Spring 2019). My husband’s MS does

not allow him to transfer, and when we travel I have a portable Hoyer lift. The problem is many hotel chains do not accommodate for under the bed clearance. The beds are usually on a platform base. It is frustrating because I call the individual hotel and ask to speak to a manager who is usually unavailable and the front desk does not know. On occasion you check in and the bed is on a platform and he ends up sleeping on a pull-out sofa bed, which is uncomfortable and not acceptable. Once we encountered that our reservation was booked over and our room was given to someone that did not even need an accessible room. It is a simple task and I don’t understand why all the major chains cannot accommodate with at least a couple of rooms.

Colleen and John Petersen, Michigan

My personal marathon

I want to thank Dorothy R. Dickhaus for her comments about all the “success stories” written by this magazine (@Momentum, “No more pie-in-the-sky-stories,” Spring 2019). Stories should be told about people like myself who are in a wheelchair and battle every day just to be able to get out of bed. That’s my personal “marathon” that more people, both with or without MS, should be made aware of. ■

Ronald Baznik, Pennsylvania

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


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Study: Nearly 1 million people live with MS in U.S.

More than twice the previous estimate.

by Marcella Durand



Learn more about the prevalence study at ntlms.org/prevalence.



In the first national study of the prevalence of multiple sclerosis in the U.S. since 1975, researchers have determined that nearly 1 million people currently live with MS, more than twice the original estimate.

“For the first time in 40 years, [the study] provides an accurate estimate of the number of people living with MS in the United States,” says Nicholas G. LaRocca, PhD, former vice president of healthcare delivery and policy research for the National Multiple Sclerosis Society and now an independent contractor. The study was published February 2019 in the journal *Neurology*.

“Having an accurate MS prevalence estimate along with incidence on a recurring basis helps to more optimally plan for clinical care needs and can provide helpful clues for researchers to better understand risk factors for onset and progression,” says Mitchell T. Wallin, MD, associate professor of neurology at George Washington University and University of Maryland School of Medicine, and the director of the VA MS Center of Excellence-East.

The updated estimate has already yielded fresh insights and understanding into the disease.

“The study demonstrated that there has been a steady rise in the prevalence of MS over the past five decades in the U.S., that the prevalence of MS remains higher for women than for men, and that a north-south geographic gradient still persists,” says Dr. Wallin. “Future research will be needed to assess how prevalence is different within racial groups, how aging impacts the course of MS, and how MS incidence and mortality are changing in the U.S.”

Dr. Wallin and LaRocca worked together with a team of epidemiologists, neurologists and statisticians to develop the algorithm that allowed them to accurately identify people with MS based on health claims data. The team has noted that this algorithm has the potential to be used for other chronic neurological conditions, as well.

“This study tells us many things, but one thing in particular: Twice as many people need a cure,” says Cyndi Zagieboylo, president and CEO of the Society, which launched and supported the study. ■

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

“Enclothed cognition”

What clothes we wear certainly make an impression on those around us. Now, studies show that the clothing we wear can affect our own personal physical and mental states, including how we feel about ourselves. Scientists have coined this phenomenon “enclothed cognition.”

In one study, participants wearing a coat associated with a doctor showed heightened and sustained attention compared to participants who wore a coat associated with a painter or who only looked at a doctor’s coat.

Wearing clothes you like can also give you confidence or make you feel more comfortable. Adaptive clothing—apparel designed to help solve challenges and improve the quality of life for people facing mobility, sensory or cognitive challenges—is gaining popularity, and with more attention comes more fashionable choices. Read more about adaptive clothing in “Function and fashion” on the next page.

Source: Journal of Experimental Social Psychology

Practical ideas
for living well
with MS

in the know

in the know

Function and fashion



PHOTO COURTESY OF VAN AND LUANNE VAN DIBERNARDO

Adaptive clothing can look good, too.

by Shara Rutberg

“I looked like a fisherman. An industrial fisherman.” That’s how Van DiBernardo described a cooling vest he wore years ago to help regulate his body temperature. “It was not a good look for me,” he says, laughing. And the 54-year-old knows a good look when he sees it. He spent years as a globetrotting shoe designer for DKNY. After he was diagnosed with MS at 26, he tried different cooling vests designed for industrial



Above: Rally UHC Cycling team members wear cooling vests to regulate body temperature.

Left: Coolture’s simple design makes cooling vests easy to use.

settings to help reduce symptoms. He appreciated the cooling, but hated how they felt and looked. When he complained to his sister Luanne DiBernardo that he looked way too Field and Stream, she told him, “You’re a designer. Why don’t you design a better one?” After much research and innovation, they created Coolture and its Signature Cooling Vest. With a contoured cut, clean lines and high-tech fabrics, it proved way more GQ than Deadliest Catch.

Historically, adaptive clothing—apparel designed to help solve challenges and improve the quality of life for people facing mobility, sensory or cognitive challenges—has been “quite horrific,” said Deborah Weinswig, founder and CEO of retail research firm Coresight Research, during a presentation at the 2018 “One Size Does Not Fit All:

Inclusive Design & the Modern Consumer” conference. The focus has been on functional, not fashionable, she said. That’s changing.

Big brands join in

In recent years, not only have small, innovative companies like Coolture launched stylish adaptive clothing, big brands and retailers have stepped up, too, which is bringing down prices and increasing the availability of the clothing. The category is big business. The U.S. adaptive fashion market will reach \$44.5 million in 2019 and \$51.1 million by 2022, according to Coresight, which forecasts the global adaptive fashion market to hit \$278.2 billion this year and \$325.8 billion by 2022.

One in five Americans lives with a disability, according to the U.S. Census Bureau, providing a huge opportunity in the market. And as more manufacturers work to fill the void, people living with disabilities, like those caused by MS, will have more options for clothes that are easy to wear and that they feel good about wearing.

In 2015, Nike introduced FlyEase technology, engineering sneakers with zips in the back for easy entry and wider widths to accommodate orthotics. In 2016, Tommy Hilfiger partnered with Runway of Dreams, a nonprofit founded by Mindy Scheier, a

mother of a child with muscular dystrophy, to create Tommy Adaptive, a clothing line more inclusive to children with disabilities. The next year, Tommy Adaptive expanded to include “modified mainstream” clothing for adults, too. “Inclusivity and the democratization of fashion have always been at the core of my brand’s DNA,” Hilfiger said in a statement. “These collections continue to build on that vision, empowering differently abled adults to express themselves through fashion.”

Target launched Cat & Jack in 2016 and expanded the line to include sensory friendly and adaptive apparel in 2017. In 2018, Target added Universal Thread, a women’s lifestyle line that includes select sensory friendly and adaptive apparel items, to its

own brand portfolio. The same year, Zappos debuted its adaptive clothing line, Independence Day. The retailer now has a department called Zappos Adaptive featuring its own brands and others that are designed to make life easier—and more fashionable—for people with disabilities.

These new lines include features like ultra-soft materials and heat transfer labels (instead of hanging tags) to avoid irritating skin, necklines with wider openings and more forgiving waistbands and wider legs for easier on-off, magnetic closures, denim with flattened seams to reduce pressure points, zip closures, and hidden openings for abdominal access and outerwear with zip-off sleeves.

Features that make things easier

Features that make clothes easier to put on and take off are particularly helpful to people living with MS, says Kathleen Zackowski, PhD, senior director of patient management, care and rehabilitation research for the National Multiple Sclerosis Society. “It may sound like a small thing, but for some people with MS, getting dressed can use all of the energy someone has for the rest of the day,” she says. “More sophisticated [with external zipper but elastic waistband] easy on-off pants are ideal for people with MS who have issues with



When you wear clothing that makes you feel good, you have more confidence.”

— KATHLEEN ZACKOWSKI, PhD



incontinence, who have a hard time getting to the bathroom on time.”

Adaptive clothes with features like magnetic closures have been “liberating,” says Tim Hilton, 51, whose MS makes it difficult to manipulate buttons and zippers. “It’s like when a person with MS gets a scooter or a car they can drive with their hands. With these clothes, you can get dressed by yourself and be independent again.”

Pants with wider legs or zippers up the ankles that allow them to be worn over leg braces can also be key items for people with MS. That way, the pants don’t draw attention to the equipment, Zackowski says. “Unfortunately, there’s a big problem in our society with assumptions made about the cognitive abilities

Van and Luanne DiBernardo created a cooling vest that is stylish and functional. Van, diagnosed with MS at 26, tapped into his design and fashion background to create adaptive clothing.



PHOTOS COURTESY OF VAN DIBERNARDO

in the know

of anyone who needs any kind of extra equipment to walk. These assumptions lead to misunderstandings, especially for people with MS who are not impacted cognitively,” she says.

One category designers need to address is bras, Zackowski says. “It’s a big issue for women. It’s really a personal necessity, with few adaptive options. Putting on a bra requires some strength and fine motor coordination. And adaptive bras are often expensive.”

Innovative technology, like the materials in the Coolture cooling vests and headbands, can help people with MS regulate body temperatures. “It’s an absolute lifesaver,” says Kristine Moor, 30, who has relapsing-remitting MS, of the cooling vest she wears over her clothes nearly every day in the summer to prevent overheating.

Designers are using other technology to create clothing directed at symptoms of other conditions, too, like pneumatic “hugging” compression vests for people with autism and clothing with QR codes that “speak” a description of each item for blind people. For nearly four years, designers, engineers, occupational therapists and people with various disabilities have gathered at Open Style Lab, a nonprofit sponsored by Parsons School of Design, to create technology-based wearable solutions for people of all abilities without compromising on style. Each summer the team produces bespoke outfits for four or five people who have disabilities ranging from nerve sensitivity to paralysis.

The self-confidence factor

The power of stylish adaptive clothing goes beyond making clothes more comfortable and easier to take on and off. Wearing clothes you love that don’t look “disabled” can make a big impact psychologically. “Clothing may sound trivial, but I really don’t think it is,” Zackowski says. “Clothes can represent the person you’re seen as in public. When you wear clothing that makes you feel good, you have more confidence. There’s a different mental outlook that you get from wearing clothes you like.”

“It’s a total confidence builder to be able to go to a function where people are going to be dressier, and



PHOTO COURTESY OF TARGET

Target’s Cat & Jack clothing line was expanded to include sensory friendly and adaptive apparel in 2017.

be able to step up and present yourself like you used to,” says Hilton, who notes what a relief it is to no longer worry about having to open and close pants or ask for help if he has to use the restroom during an event. Being able to wear stylish clothes again is also empowering, he says. “With MS, life becomes very functional, as opposed to fashionable,” he says. “It’s great to be able to add a touch of flair. It helps you feel ‘normal’ again.”

Not having the proper work clothes poses a real barrier for people with disabilities in the workforce, according to a recent University of Missouri study published in the journal *Society*. The study found that workplace participation can be hindered by lack of appropriate clothing, which can increase the stigma of people living with a disability. When people wear appropriate clothing, their effectiveness is enhanced tremendously, according to the study. Researchers have recently coined the term “encloded cognition” to describe the impact that clothes have on mood and health.

“The clothes you wear describe you,” Van DiBernardo says. “And it’s great to feel like you’re describing yourself, not a disease.” ■

Shara Rutberg is a writer in Evergreen, Colorado.



Find more resources and support at
[nationalmssociety.org/
Resources-Support](https://nationalmssociety.org/Resources-Support).

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

in the know

Testing ground

Pros and cons of participating in clinical trials for MS research.

by Aviva Patz

Karen Jackson, diagnosed with MS in 1996, has benefited from medications from clinical trials.



PHOTO COURTESY OF KAREN JACKSON

Karen Jackson has been happily filling out surveys, giving extra vials of blood and undergoing MRIs and lumbar punctures for clinical trials since 2006. The 58-year-old from Alexandria, Virginia, was diagnosed with relapsing-remitting multiple sclerosis in 1996, then with primary progressive MS in 2003. “For me, it’s a no-brainer,” she says. “There aren’t a lot of treatment options for primary progressive MS. This is a way for me to continue to be part of the solution, part of the answer.”

Clinical trials are at the heart of finding new and better treatments for MS. They help scientists understand how MS develops and whether treatments—from disease-modifying therapies (DMTs) to rehabilitation strategies—are safe and



effective. Participating has pros and cons, but one thing is certain: There can be no progress without it. “Everyone owes a debt of thanks to people who have participated in clinical trials, who have helped pushed the field forward, because all trials, even unsuccessful ones, teach us valuable lessons,” says Ari Green, MD, director of the MS Center at the University of California at San Francisco. “Everyone with MS has benefited because of the risk or the inconvenience of the people who came before them.” Read on to learn more about participating in clinical trials for MS and whether they’re right for you.

How to find clinical trials

There are two main sources of MS clinical trial listings: One is the National Multiple Sclerosis Society website ([ntlms.org/Trials](https://www.nationalmssociety.org/Trials)), which allows you to search for trials by state, type of MS or keyword. You can also check the website of the National Institutes of Health (clinicaltrials.gov), where you can search more than 290,000 research studies in all 50 states and in 207 countries. Search by condition to find MS-related trials.

Details of trials

Studies can last from weeks to months to years or even the rest of your life, in the case of long-term research. Timing depends on the phase of the research, what it’s testing and other variables. How you participate will also vary widely—you might be trying an app, modifying your diet, taking vitamins or pills (including disease-modifying therapies), giving extra vials of blood or having extra MRIs, getting your skin biopsied, getting injections or infusions, or testing out different ways of walking, exercising or doing physical therapy.

How to enroll

You can ask your physician to refer you, or you can apply directly by emailing or calling the contact listed in the trial description. The researchers will then determine if you meet the eligibility requirements—for example, you may need to be over 18, live within 150 miles of the research facility and fall within certain levels of disability and duration of disease. Check with your neurologist to ensure it makes sense for you, and put your doctor in touch with the

An interventional clinical trial is one that tests new therapies as well as complementary therapies, such as a special diet.

researchers running the study to ensure that it's a fit. It isn't always. For example, you might like the idea of testing a DMT, but therapies are sometimes compared to inactive placebos. If you end up getting a placebo instead of the medication and that could put you at risk, it's not safe for you to participate.

Types of studies

There are two basic types of studies in which people with MS might participate, according to Joan Ohayon, senior nurse consultant with the Neuroimmunology Clinic at the National Institutes of Health.

The first type simply gathers information to understand more about the disease and doesn't involve interventions. For example, the School of Communication Sciences and Disorders at the University of Memphis is studying how different neurological conditions impact speech. Researchers at the University of Illinois in Urbana-Champaign and Carle Hospital are exploring the relationship between nutrition and eye health among people with MS. Then there's a USC Multiple Sclerosis Center study looking to validate a smartphone app called "myMS," which helps track MS at home.

For longer-term information gathering, you can get involved in a registry designed to capture the real-life experience of people living with MS. One example is iConquerMS, which involves completing surveys about daily experiences and symptoms, sharing medical records, and suggesting research topics and questions (iconquerms.org).

The second type of study is an interventional clinical trial that tests new therapies and rehab strategies, whether it's a new treatment or an add-on treatment, or a complementary therapy such as a special diet, yoga or meditation. For example,

Dr. Green is studying ways to take advantage of the body's existing capacity for repair. "In MS, primary early damage occurs to the myelinating cells of the central nervous system," he explains. "There are cells that are meant to repair that damage, but for some reason in MS they don't do what they're supposed to do—we're looking to help those cells overcome the barriers keeping them from doing their job." Results of his first trial with a medication, which were promising, were published in *The Lancet* in 2017, and he's now doing a second trial to evaluate the best timing for that medication.

Key factors to consider

Obviously, you want to consider logistics like the time commitment, scheduling, and whether you can handle what's involved (like hour-long MRIs every six months) and any risks the study might pose. "It may depend how risk-averse you are," Ohayon says. Then you're going to want to start asking questions. You can find a complete list of questions on the website of the Center for Information and Study on Clinical Research Participation, (ciscrp.org/education-center/questions-to-ask), but these are among the most important:

■ What are we trying to learn?

You might think the answers are in the trial description, but it can be complicated, according to Dr. Green, so ask for a breakdown in simple language.

■ What is the background data to support this approach?

Ask the investigators to provide evidence of why they believe this therapy will work. Beware of a hard sell, warns Dr. Green. "If you feel like the researchers are making false promises or painting an overly rosy picture of the possible results, that's a reason to be skeptical," he says.



Participating in a clinical trial could include commitments and tests, such as getting MRIs.

■ **Has the treatment been tested before?**

If so, on how many people? What are the possible side effects?

■ **What kinds of tests and treatments are involved?**

If you're not comfortable with any of the elements, that's a deal-breaker.

"There's no reason to feel coerced to participate—it's your body, it's your condition," Dr. Green says.

■ **What are the possible risks and benefits in the study** compared with my current treatment?

■ **Who will pay for the experimental treatment,** or any of the tests, and will I be reimbursed for other expenses such as mileage, parking or meals?

■ **If the treatment works, can I continue receiving it?**



PHOTO COURTESY OF ANITA WILLIAMS

Benefits of enrolling

What's in it for you? The short answer: You'll receive regular and careful medical attention from a team of doctors and other health professionals; you'll possibly have access to new treatments before they're widely available; and you'll help others by contributing to understanding of new treatments or procedures. "Sometimes negative studies are just as informative or more informative than positive ones, so it's good to go into the study thinking, yes, this may benefit me, but more important, I'm benefiting the greater good," Ohayon says.

Anita Williams, 49, of Aurora, Colorado, has volunteered in clinical trials since 2015 for that very reason. "I said 'yes' because I wanted to contribute to MS research, especially as a black woman who would like to see more African Americans represented," she says. "It's the MS patients who came before me and

participated in clinical trials that gave us the information we have today. The DMTs are all possible because of them, and I want to do the same for others."

Jackson did benefit from one experimental medication. But more gratifying for Jackson has been having access to top-notch teams of dedicated and passionate clinicians. When she developed a pressure sore on her right hip, it was successfully treated the same day by the study team's wound department. "Had it not been for my connection to the National Institutes of Health, I wouldn't have gotten that early intervention and would have suffered so much longer," she says.

Anita Williams volunteers for clinical trials as a way to contribute to MS research.

Potential downsides of enrolling

What are the risks? Besides logistical inconveniences—the time, interventions and even costs involved—the experimental

treatment you're getting may not be effective. Or you could be in the control group and not get active medicine. Worse, you could take the active medicine and have unpleasant and even serious side effects. "It could be that you take a medication and suddenly your disease gets worse—it's definitely a risk," Ohayon says. "But there are many steps along the way to minimize the risk category." It's important to note that participants are monitored closely for side effects and other issues.

Phases of clinical trials

Every therapy undergoes several phases of testing:

- **Phase I** is a small study that determines the safe dose range and flags any safety concerns and side effects.
- **Phase II** starts looking at the effectiveness of the therapy and further evaluates its safety.
- **Phase III** is a bigger study, sometimes with thousands of people and spanning years, that compares this therapy with standard or similar treatments or no treatment (placebo). To earn FDA approval, the drug must prove to be as good as or better than what already exists.
- **Phase IV** follows FDA approval and is designed to monitor how the treatment is working. "It's not just boom, it's approved, we're done," Ohayon says. "We still monitor safety and effectiveness for a long time."

Ultimately, volunteering for MS research could benefit your disease, but in Dr. Green's experience, it will definitely benefit your state of mind. "In my years of doing this, I've seen that the people who participate in clinical trials are happier because they're part of the work that's helping overcome something they're living with," he says. "There's an injustice to MS—



it harms people at a crucial time of their lives and robs them of certain opportunities and experiences, so it really helps people psychologically to be fighting back." ■

Karen Jackson (center) at the National Multiple Sclerosis Society's Public Policy Conference in Washington, D.C.

Aviva Patz is a writer in Montclair, New Jersey.



Learn more about enrolling in clinical trials at [ntlms.org/Trials](https://www.ntlms.org/Trials).

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



*IF YOUR MS SYMPTOMS
SEEM DIFFERENT*

***CHANGE THE
CONVERSATION
TO SPMS***

Everyone's multiple sclerosis (MS) is different. But if you're having fewer relapses, yet more difficulty walking and staying balanced, it could be time to talk with your doctor about secondary progressive MS (SPMS). The important thing is to recognize changes, ask questions, and start a new conversation with your neurologist today.

- Finding it more difficult to walk and stay balanced?
- Having muscle spasms or general pain more often?
- Feeling like it's harder to remember things or stay focused?

Noticing any of these or other changing symptoms?

If so, talk to your doctor and visit TalkSPMS.com



Cool places to spend time and beat the heat

Not everyone has the time or resources to jet off to a cooler climate to escape the summer heat, which can be particularly challenging for people with multiple sclerosis. Fortunately, there are usually places located in your own community that might be able to provide some relief. They include:

- **Gyms.** People are active and working up a sweat, so many gyms are kept cool. Consider joining a daily or weekly wellness program, which can give you a chance to exercise and socialize. Or, find a gym with a pool kept cool enough that you feel comfortable doing laps or other forms of water exercise.
- **Senior or community centers.** Another way to socialize could be visiting air-conditioned senior or community centers. Some cities even advertise their community centers as heat relief or cooling centers during the summer months.
- **Museums and galleries.** Whether you're into art, natural history or space travel, museums are perfect places to stay cool and learn something new, because temperature and humidity are controlled in order to protect the exhibits.
- **Movie theaters or entertainment theatres.** Large crowds watching movies, plays or comedy shows together tend to produce a lot of body heat, so theaters are usually kept cool for the comfort of their patrons.
- **Libraries.** Many air-conditioned libraries offer free Wi-Fi and computer access, as well as a variety of classes and workshops if you don't want to spend all of your time there reading.

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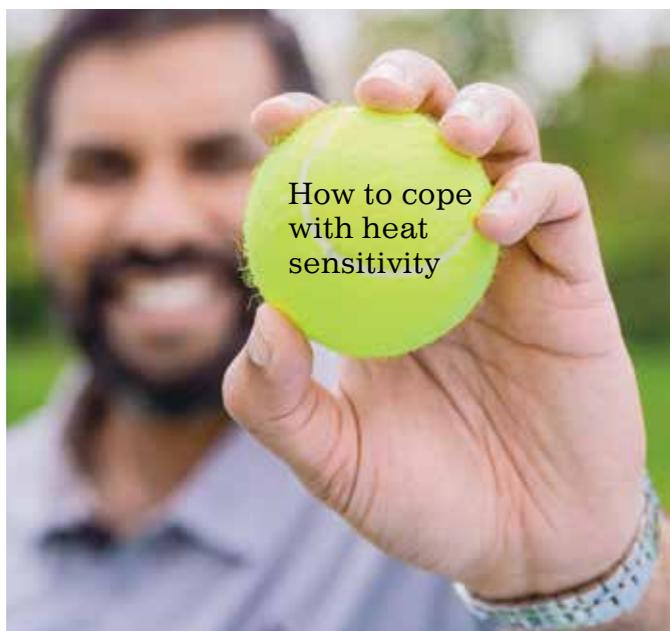
Inside this section: Acing temperature control 22 // State of limbo 30



Samir Chandiwala is able to play tennis again in the summer after moving to a cooler climate.

Acing temperature control

by Vicky Uhland



How to cope
with heat
sensitivity

PHOTOS BY MATTHEW ALLEN

Samir Chandiwala loves to play tennis. But after he was diagnosed with multiple sclerosis in 2005, he gave up the sport. The heat and humidity in Augusta, Georgia, where he lived, affected him so much that he was barely able to go to his office in the summer—let alone the tennis courts.

“I have spasticity in my back, legs and chest that became worse each summer in Augusta. I’d have full body spasms just crossing the parking lot into work. Sometimes I couldn’t even walk,” Chandiwala says. “I got so anxious about whether the heat would exacerbate my MS symptoms that I think that made my symptoms worse. And then that would give me even more reason not to go outside in the summer.”

Chandiwala is one of the 60 to 80% of people with MS whom researchers estimate have a temporary worsening of their symptoms when they become overheated. In fact, heat sensitivity is such a common symptom of MS that in the 19th and early 20th centuries, one of the main ways of diagnosing the disease was to immerse people in water around 105 to 110 degrees and observe if neurologic symptoms appeared or worsened.

Like most people with MS-related heat sensitivity, Chandiwala tried the common coping strategies. He cranked up the air conditioning in his home and car.



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they become overheated.

He drank cold beverages. He wore cooling vests but found that even the ones filled with ice packs weren't effective in the Georgia humidity. And the vests caused other problems as well. Chandiwala and his wife, Sarah Taufique, who wears a hijab, are Muslim. When they visited a butterfly show in a greenhouse, a woman pointed them out to police because she mistook Chandiwala's bulky cooling vest for an explosive device.

Chandiwala decided he would need to take more drastic measures to beat the heat. He works as an engineer at a large manufacturing company with multiple U.S. locations, so he asked for a transfer to a cooler climate. There was an opening in Cincinnati, so Chandiwala and his family packed up and moved in 2007.

Cincinnati summers are hot, but Chandiwala has found there are breaks in the heat that allow his symptom exacerbations to subside. He also switched his medications, which he believes has had an impact on his heat sensitivity. And he started swimming and lost 15 pounds. He says weighing less helps him feel cooler on hot days.

Thanks to all these changes, it's been three years since Chandiwala has used a cooling vest when he's outside in the summer. He was recently able to take a beach vacation in Hawaii. And last year, he started playing tennis again.

"I don't know anyone else who has as much heat sensitivity as me, but now I feel like I can cope. The heat is no longer something I have to work my whole life around," he says. Here's what Chandiwala and medical experts recommend to beat the heat when simple strategies aren't cutting it.

Remember it's temporary

The most important thing to know about summer heat is that it won't make your MS worse. But it can make your symptoms feel worse. That's because, according to research, raising your body temperature by even as little as half a degree can affect how your nerve impulses operate.

"Demyelinated nerves are already not doing a normal job of conducting electricity, and heat impedes

electrical transmission even more," says Barbara Giesser, MD, a professor of neurology at UCLA.

This can create what's known as pseudoexacerbation—a temporary, reversible worsening of physical and cognitive MS symptoms that is caused by a known precipitant, such as heat or an infection. "You feel crummy, but it's important to know that you're not going to have any more nerve damage," Dr. Giesser says. So when your body temperature returns to normal, your symptoms should revert to the level they were before you became overheated.

"I have patients ask me: 'Do I need to move because living here is going to make my MS worse?'" says Jonathan Carter, MD, a neurologist with the Mayo Clinic in Phoenix. "I tell them they're not going to develop new lesions in their brain or spinal cord

because they live in Phoenix. They're not harming themselves or making their MS worse by living in a hot climate."

But because MS is unpredictable, heat sensitivity can vary from person to person, he says.

Evidence suggests that heat sensitivity becomes more common as the disease progresses, but not in

everyone. If you have fairly mild symptoms, you may be able to tolerate the heat better than someone with more severe symptoms, Dr. Carter says. And he points out that people who already have difficulty walking may find that their mobility worsens dramatically after as little as a few minutes in high temperatures.

"People with more mobility issues tend to have more nerve damage, so it's like you've got less to work with when you get overheated," Dr. Giesser says.

In some cases, it's also possible to temporarily develop symptoms you haven't had before. "If you have an area of damage that's functioning normally under normal conditions, it could get worse with heat. But those symptoms should disappear when your body temperature is cooled," Dr. Giesser says. So, for instance, you could have lesions in a "silent area," like the part of your brain that affects cognition, which could produce symptoms only when you get overheated.

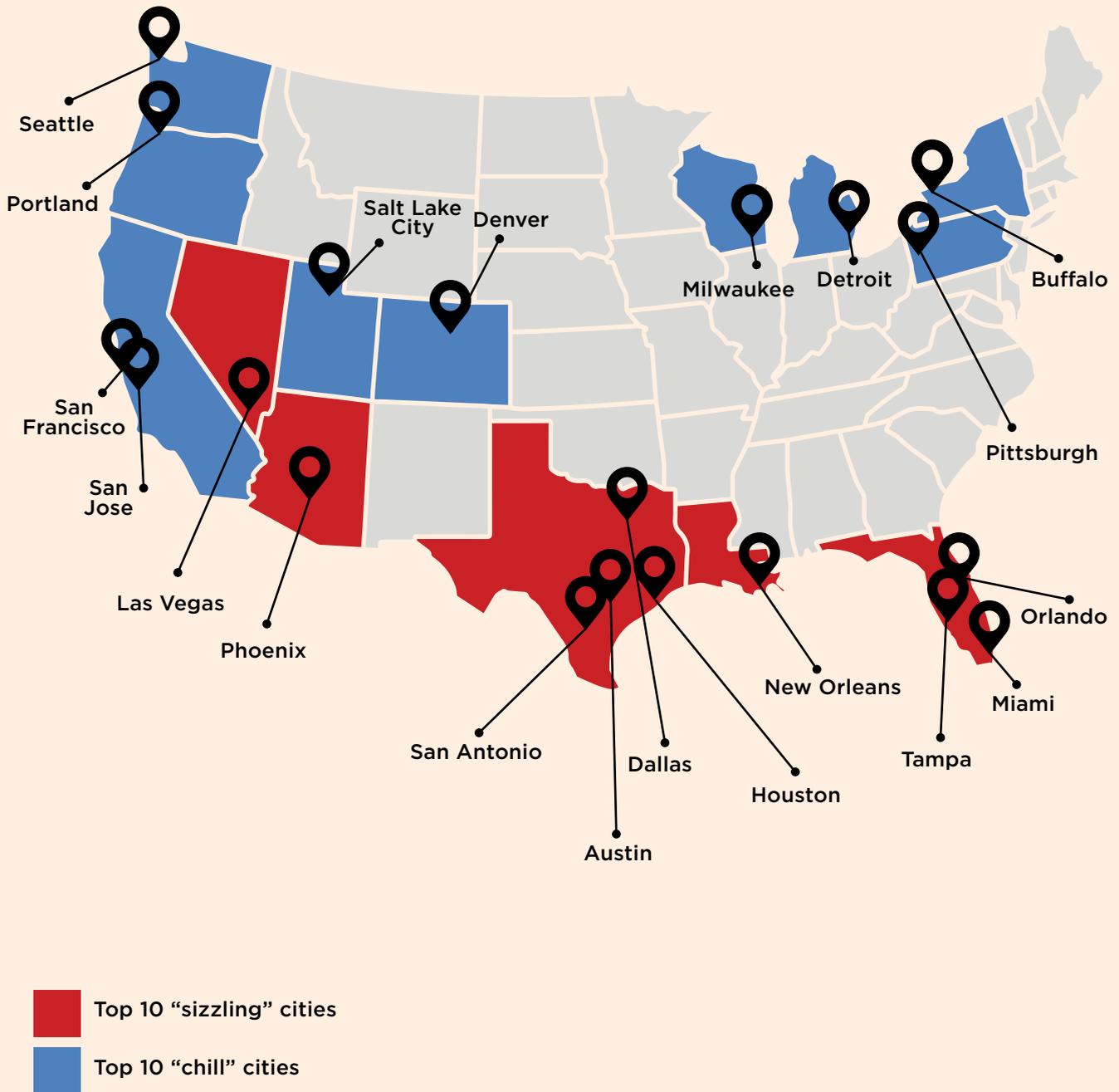


Evidence suggests that heat sensitivity becomes more common as the disease progresses, but not in everyone."

— JONATHAN CARTER, MD

The hottest and coolest places to live

Considering a move? Bert Sperling, who operates the website bestplaces.net, has created the Sperling Heat Index to analyze the hottest and coolest U.S. cities. Sperling's index is based on a city's average summer high and low temperatures, along with its dew point (a measure of humidity).



Track the heat index

The old adage “it’s not the heat; it’s the humidity,” can be particularly true for people with MS.

“When it’s humid, it’s harder for your body to cool down,” Dr. Giesser says. “This affects everybody, but if you have MS, you tend to feel the humidity more.”

One theory is that sweat—the body’s natural cooling system—doesn’t evaporate well in humidity, so it can make MS symptoms like fatigue, leg heaviness and lack of energy feel worse. The key is the word “feel,” though. Researchers don’t know how much of this is attributable to the disease of MS itself, says Kathy Zackowski, PhD, an occupational therapist and senior director of patient management, care and rehabilitation research for the National Multiple Sclerosis Society.

Dr. Carter says what you really need to pay attention to is the heat index—the weather report that tells you how hot it feels outside. For instance, when it’s

110 degrees in Phoenix, the heat index is the same as when it’s 97 degrees in Nashville, Tennessee, because Nashville’s average summer humidity is double that of Phoenix.

The higher the heat index, the more risk of pseudoexacerbation of previous symptoms—in most cases. “I’ve found that humidity has as great an impact on mobility symptoms as temperature alone,” Dr. Carter says.

Summer shut-ins

Dr. Carter works with retirees and other patients who are able to leave Phoenix for cooler climes in the summer. But that’s not financially or logistically possible for many others with MS. These people can become summer shut-ins, afraid that even a few minutes out in the hot sun can worsen their MS symptoms—particularly the ones that have the potential for social embarrassment.

“For instance, many people with MS time their bathroom visits when they go out. But if you’re walking slower because of the heat, it may take you too long to get to the bathroom. Or if the heat increases hand numbness, you may worry about how you’ll wipe yourself after a trip to the bathroom. And people with



Samir Chandiwala and his family moved from Augusta, Georgia, to Cincinnati. He swims and plays tennis when there are breaks in the heat.



PHOTOS BY MATTHEW ALLEN

Simple strategies to beat the heat

Here's what Samir Chandiwala; Kathy Zackowski, PhD; and Jonathan Carter, MD, recommend to lower your body temperature and reduce symptom exacerbation when the heat and humidity skyrocket.

■ **Start with pre-cooling.** If you know you're going outside on a hot day, Zackowski suggests drinking some ice water beforehand. And then take regular sips from a thermos of ice water when you're out in the heat.

Of course, this can create other problems if you have bladder issues. Chandiwala is a big fan of sports drinks like Powerade. "I feel like I don't have to pee right after drinking," he says. Experiment to see what works for you, but it's best to avoid alcohol or caffeinated beverages. Both are diuretics that can reduce your sweat levels and hamper your body's ability to regulate its internal temperature.

■ **Keep your environment temperate.** Air conditioning is the most powerful—and expensive—way to make summer heat bearable. If you can't afford it, check with your utility company or your state's public utilities commission. Some offer rate discounts for people with disabilities.

Air conditioning units or systems may be covered under your health insurance or could be deductible on your taxes, so check with your insurer and accounting service. You can also contact an MS Navigator (ContactUsNMSS@nmss.org or call 1-800-344-4867) to discuss other cooling options and resources.

■ **Do some device shopping.** Cooling vests are effective "to some degree," Dr. Carter says.

But he says his patients rarely ask about them—perhaps because so many are cumbersome and unattractive.

However, with a little searching, you can find lightweight, unobtrusive cooling vests. A good resource is activemssers.org, which is operated by Dave Bexfield, who was diagnosed with MS in 2006. Bexfield has tested a variety of cooling vests in various situations and offers unbiased reviews.

Chandiwala keeps an ice-filled cooling vest in a small cooler in his car. He puts it on as soon as he gets in the car, and it keeps him comfortable until the air conditioning kicks in. And if he knows he's going to be outside in the heat for a while, he dips an undershirt made of a wicking material, like Under Armour, in water and wears it as a base layer.

Handheld misters or fans can be surprisingly effective, says Zackowski, as can cold, wet towels applied to your wrists, neck or other parts of your body.

■ **Ask your doctor about your medications.**

Chandiwala found that his ability to tolerate heat and humidity improved when he switched from Rebif to Copaxone. Rebif is a beta-interferon, which research shows may temporarily increase body temperature about six hours after injection.

It's also worth discussing with your MS care provider any secondary medications you may be taking. There is some evidence that anticholinergic medications, which are sometimes used for bladder overactivity in MS, may reduce sweating and the body's ability to cool itself.

cognition symptoms may feel like they're slower with their thinking, or they're not as quick to respond to others," Zackowski says. "So it's no surprise that many people think the safest solution is to just not leave the house in the summer."

But Dr. Carter says holing up in your home for months on end can create its own issues. The isolation can make you feel depressed and lower your quality of life. And you may exercise less, which could impact energy levels, fitness and mobility.

If you have an MS clinic nearby, one solution is to participate in a daily or weekly wellness program.

"We keep the gym so cold here that the therapists wear sweatshirts and sweaters," says Ian Flannery, therapy manager at the Shepherd Center's MS Rehabilitation and Wellness Program in Atlanta. "Some people come here in the morning and say it's the only time they leave the house during the summer. Not only do they get a chance to exercise, but they get the social component, too."

Another option is to walk or swim in a cool, shallow lake or a swimming pool. Chandiwala's wife called local gyms and recreation centers and asked the temperatures of their lap pools. After she found one lower than 80 degrees, Chandiwala started to visit regularly.

"At first, I was very afraid to exercise because I felt like I would overheat," he says. "So I started out basically just walking around and worked my way up to swimming. I work from home a lot in the summer, and I've found that the pool exercise is good for me both mentally and physically."

Zackowski also recommends visiting air-conditioned senior centers or other community centers where you can interact with others. If that's not possible, she suggests using a computer at home to become part of a virtual community or play games. "You can do that safely, and it helps keep you from being isolated," she says.

Finally, Flannery recommends venturing out in the heat with a friend or family member until you understand how your body reacts to various temperatures and humidity levels.

"You may find you can't go out if it's warmer than 75 degrees. Or you only have 45 minutes outside until your cooling techniques fail," he says. "But that still means you've got 45 minutes. If you do some planning, you can accomplish a lot during that time." ■

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

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State of

For 12 years, Kathy Volk, PhD, has not just been in limbo, but “way in limbo,” she says. That’s because for more than a decade, she has been unwell. For more than a decade, she and her doctors have struggled, unsuccessfully, to understand how her symptoms—numb feet, a squeezing feeling in her core and extreme fatigue—came together in a single diagnosis.

At one point, after MRIs, a lumbar puncture, bladder surgery, medications and a neurologist who said he just didn’t know how to help, she asked him to refer her to another doctor.

He said he would, but added, “I just don’t know who to refer you to.”

Eventually, the Maryland resident, wondering if she had multiple sclerosis, took it upon herself to see an MS specialist. She was under his care for a decade while also seeing other doctors for different conditions. Ten years later, one of her doctors diagnosed her with common variable immune deficiency. Her MS specialist suggested that the treatment for that condition might solve her mysterious health problems. It turned out that he thought she might not have MS, after all.

Searching for answers

In September 2017, around her 51st birthday, Kathryn Knapp came down with a bad cold. A week later, she had trouble feeling her feet. Knapp, who lives in Pennsylvania, had a family history of health problems, so she was health-conscious and active. She thought the problems might be related to a running injury.

An orthopedic specialist prescribed steroids. On a Sunday, Knapp felt better. The following Thursday, she lost feeling below her waist. Knapp spent the next three weeks in the hospital. She couldn’t walk. Doctors suspected transverse myelitis, inflammation of the spinal cord. After the results of a lumbar puncture came in, she finally had a diagnosis.

“I was told I have MS and I should treat it aggressively,” she says. Knapp saw a second neurologist. “I was told I don’t have MS.” She saw a third neurologist. “He said, ‘We’re not sure.’”

A waiting period

Although there is no solid data regarding how many patients are in this state of diagnostic limbo, neurologists say it’s not unusual. In fact, a period of waiting is often integral to making an accurate diagnosis of MS. This waiting can be scary and frustrating. For some patients, however, a diagnosis seems like it will never come, and it can elicit a more fundamental question: Why is it taking so long to figure out what’s wrong?

An MS diagnosis is far from straightforward, in large part because there is no biomarker for the disease. No single test can rule out or verify its presence. In principle, the diagnostic process is simple, laid out by the McDonald Criteria: a syndrome typical for MS, two or more lesions in the brain, spinal cord and/or optic nerve that occurred at two different points in time.

A definitive MS diagnosis
can take time—and patience.

by Brandie Jefferson

limbo



There are many other rare syndromes that are tricky to diagnose and can mimic MS.”

—ANDREW SOLOMON, MD

Critically, also, any other causes that might be responsible for symptoms or lesions must be ruled out.

In practice, however, a diagnosis can be much more complicated. It often takes time and persistence to make an accurate diagnosis of MS.

“Overall, MS is not always hard to diagnose, and we have diagnostic criteria that work well,” said Andrew Solomon, MD, associate professor of neurological sciences and division chief, Multiple Sclerosis at the Larner College of Medicine at The University of Vermont. “Yet people still get misdiagnosed because in the majority of patients, the diagnostic criteria were not being applied correctly. There are a lot of clinical judgments involved in making a correct diagnosis that can be prone to error. Right now, without a biomarker, the neurologist is the screening tool.”

Pinpointing MS

In 2007, Volk had just turned 54. She was hiking with her husband when all of a sudden, “I just wet myself. I didn’t feel it.

It just happened,” she says. It kept happening. A gynecologist recommended bladder suspension surgery, a common procedure to cure incontinence.

After the surgery, both of Volk’s feet went numb. Her primary physician suspected Guillain-Barré syndrome, a disorder in which the immune system attacks the peripheral nervous system. Volk’s doctor told her to see a neurologist

if it didn’t clear up soon.

She didn’t go right away. “I didn’t want to see a neurologist,” she says. It wasn’t that Volk was afraid of a diagnosis. At the time, she didn’t even know what a neurologist might be looking for. “I wasn’t scared. I just thought, ‘Oh come on, this is crazy.’”

When she did see a neurologist, he suspected Volk had a virus. When the tests came back negative, he told her

ILLUSTRATION BY DAVE CUTLER





to follow up in a few months, but she returned sooner. Volk had woken up one night with a horrendous squeezing in her ribcage. The neurologist ordered a spinal MRI.

“I had no idea what he was looking for,” Volk says. “I thought maybe I had a pinched nerve.” She was confused and starting to worry. “None of this was going away. It was scary.” Her job involved driving around the state of

Maryland, but she didn’t feel that she could keep it up. “I couldn’t do it. It was way too much. My feet were a mess. My legs were a mess. I was scared.”

In the fall of 2007, she took medical leave from her job. Volk had worked in education as a teacher and administrator for three decades and was about to apply for a professor position at a local private college. “I didn’t know what

was going to happen,” she says.

There were more tests, no answers. A spinal tap that was, in Volk’s words, “very difficult.” No answers. Another MRI, this one of her brain. There were lesions in her brain, but still no answers. What made it worse, Volk says, is that her neurologist never said what he was looking for, leaving her with a fear of the unknown. It was her primary care physician who ultimately suggested that all of the scans, the lumbar puncture and physical exams were looking for MS.

But Volk’s symptoms never fully met the diagnostic criteria. “My doctors were very confused,” she says, “and I was getting more scared.”

A second and third opinion

Knapp’s first neurologist treated her with Ocrevus, at the time a newly approved therapy for MS. “I was so happy to hear that we were going to treat it aggressively. That’s what a patient wants to hear,” Knapp says.

At the same time, Knapp said she didn’t feel that her doctor was communicating with her as well as he should be. He didn’t run any additional MRIs or tests but instead relied on the information from her stay in the hospital.

“I thought, ‘This is not right.’

PHOTO COURTESY OF ANDREW SOLOMON



Andrew Solomon, MD, has studied common diseases and conditions that can be mistaken for MS.

PHOTO COURTESY OF BARDIA NOURBAKHSH



Bardia Nourbakhsh, MD, notes that it's important to get treatment while gathering clues for a diagnosis.

And you have to go with your gut feeling," she says. She sought a second opinion.

Her second neurologist, after reviewing her MRIs, wasn't sure that Ocrevus was the right thing to do.

"He said, 'I'm not sure you have MS from your MRIs. I never would have gone with Ocrevus without definitely confirming the diagnosis,'" Knapp recalls. Part of that confirmation entailed ordering new MRIs, but it also meant sitting down and listening to Knapp give a detailed history of her symptoms, past and present.

There are many common diseases and conditions that can be mistaken for MS. In a small 2016 study, a team of researchers led by Dr. Solomon identified 110 patients who had been misdiagnosed with MS. The most common correct diagnosis was migraine, but patients also had conditions such as fibromyalgia, psychiatric disease and small vessel disease.

"There are many other rare syndromes that are tricky to diagnose and can mimic MS," Dr. Solomon says. "Only with time is it often possible to tell that it is something else."

So Knapp and her doctors began the integral step of ruling out other possible causes of her symptoms. Her initial MRI revealed an issue with a disc, so she had neck surgery. After multiple MRIs, a lumbar

puncture, steroids, starting and stopping Ocrevus, and then surgery, Knapp was ready for a third opinion. She traveled from Pennsylvania to Baltimore to see Bardia Nourbakhsh, MD, at Johns Hopkins University.

"Sometimes, I'm the third or fourth neurologist a patient has seen," Dr. Nourbakhsh says. "One important element is listening to patient history. Many times we can get clues from what happened to them years ago that can help with the process."

There is no guarantee, however, that the process will move along quickly. "This is a difficult disease to diagnose," Dr. Nourbakhsh says. "Based on the situation, we may be able to tell patients there's a good likelihood of MS, but sometimes we need time."

It's not the best situation for a patient to find themselves in, Dr. Nourbakhsh says. "I could imagine it's difficult for the patient," he says. "The first step would be embracing this uncertainty, being transparent with the patient and letting them know that despite all the testing, talking and examining, I'm still not sure." During that time, those weeks, months or even years, a person can feel hopeless, but there are ways you can continue to move forward, including getting relief for symptoms.

"Uncertainty should not prevent us from treating

“Uncertainty should not prevent us from treating patients to the extent possible.”

—BARDIA NOURBAKHS, MD



patients to the extent possible,” Dr. Nourbakhsh says. “For example, whatever this disease is that’s causing nerve pain, there are medications for that pain regardless of the etiology, the cause.”

Dr. Nourbakhsh will even send his patients to other specialists. “Many patients will come to me with prolonged dizziness. They’ve been sent to me because they also have lesions on an MRI. I may not think they have MS, and

I don’t know the cause of their dizziness, but I have colleagues who specialize in treating patients with chronic dizziness. I tend to refer patients to them.”

“We shouldn’t forget to provide that treatment while patients are waiting to get more clues about the diagnosis,” Dr. Nourbakhsh says. “Knowing a diagnosis may help prevent future damage, but it won’t help the current symptoms. Treating them should still be a priority.”

Moving forward

Volk, too, decided to start over with a new neurologist. Her neurologist did more tests and eventually diagnosed her with secondary progressive MS. Then he left the hospital, and she had to find a new doctor.

For the next 10 years, Volk was under the care of a neurologist at an MS clinic. But she was never put on a disease-modifying therapy.

“Always, in the back of my mind, I wondered if I really had MS,” Volk says. She thinks her doctor had the same hesitation because, even when Ocrevus was approved for secondary progressive MS, he didn’t

prescribe it.

Volk was able to treat some of her symptoms, however. She found several medications and therapies that have been effective, particularly regular massages.

Then, what started as a simple cold led her down another path, one with more specialists, more tests and more uncertainties.

Complex considerations

Complicating an MS diagnosis even further can be this obvious yet sometimes overlooked reality: “You can have more than one medical condition. You can have MS and something else, like migraines,” says Beverly Layton. She started as a nurse in 1979, and by 1987 she was working with John Whitaker, MD, professor and chair of neurology at the University of Alabama at Birmingham, assisting with research looking for a biomarker for MS disease activity. Now retired, Layton works as an MS nurse consultant.

The possibility of multiple conditions makes it important for people who are being evaluated for a diagnosis to keep track of and make available all their past medical records. “If they’ve seen two or three neurologists already, bring that imaging CD [and] bring those

reports,” Layton says. “If there’s spinal fluid testing, any other neurological testing or laboratory testing, get those results to us so we can sort it out and determine if we need to repeat certain testing.”

“Let’s say a patient has fatigue. Are they having depression?” Layton asks. “Are they having trouble getting up? Let’s say they’re fatigued first thing in the morning. Could they have a sleep disorder? There can be many differential conditions that can cause fatigue, such as anemia or thyroid disorders. Lab testing may be needed to help complete the workup.”

Underlying conditions

Volk had bronchiectasis, a condition in which injury or an infection causes scabs and loss of elasticity in the airways that carry air in and out of the lungs. Her pulmonologist suggested it was the result of another underlying condition, common variable immune deficiency, which impaired her immune system, leading to respiratory infections. She is now being treated for that with immunoglobulin replacement therapy (IRT), supplementing her blood with antibodies from donors.

When she next saw her neurologist, he said he’d been following her progress with her other doctors and was hopeful about the new treatment. Volk, however, was nonplussed.

For years, she’d been asking him if he was sure she had

MS. “He would say, ‘It has to be MS.’ He’s the only one who supported me this whole time,” Volk says, “and now he says, ‘I don’t think it’s MS after all.’” He told her that she didn’t need a follow up, but since he’d seen her for so long, she could return in a year.

“That really upset me. I felt like I lost the one person who had listened to me. You were the doctor that listened,” she says. “And now you’re not going to listen?”

More follow-ups

Once Knapp made the move to Johns Hopkins, Dr. Nourbakhsh asked her if she had been sick before her sensory problems began. She told him about the cold.

“He said I definitely had transverse myelitis,” she says, which can be caused by a number of conditions, including viral infection or a few conditions that also affect the spinal cord. It can sometimes be the first manifestation of MS.

“Dr. Nourbakhsh said it might have developed into MS, but we’re not sure,” Knapp says. “He felt more comfortable with not treating me for MS than moving ahead.

“Dr. Nourbakhsh made me comfortable,” Knapp says. “The way he presented the information was very clear, the way he said, ‘This is what I can say definitively, and this is what I cannot say because we don’t know.’”



Dr. Nourbakhsh made me comfortable. The way he presented the information was very clear, the way he said, ‘This is what I can say definitively, and this is what I cannot say because we don’t know.’”

—KATHRYN KNAPP

For now, Knapp says, Dr. Nourbakhsh continues to monitor her, keeping an eye out for new lesions and helping her treat her symptoms.

“For me personally, I’d rather hear, ‘I don’t know,’” Knapp says. “I would love to know ‘yes you have MS’ or ‘no you don’t have MS.’ But if they can’t tell me, they can’t tell me.”

For now, they can’t tell her. “I left my house on a Friday in September at 8 a.m. for a doctor’s appointment. That day, I had a work call at 9 a.m. I thought I’d be home for the call, then all of a sudden I’m in the hospital for three weeks,” Knapp says. “It’s just hard to get your head around that.”

Staying strong

Volk isn’t so concerned with a diagnosis. She just wants to feel better. “I don’t care if it’s MS or not. I really don’t,” she says. “I don’t care if there’s a name to it. I just want to be able to sleep at night.” The uncertainty touches her life beyond the sleepless nights, the pain and the medical tests. “I’m a really strong person,” Volk says, “so I don’t think anybody else gets

it.” At first, people understood she was sick, but once she discovered what was wrong, Volk figured she’d be able to fix it, or at least explain to friends and family why she couldn’t do something.

“In the beginning, it was different, but it’s been so long,” Volk says of her 12-year medical limbo. “I think I’ve lost friends over it. They expect me to do things, and when time after time I couldn’t, they stopped talking to me. I wish they understood.”

Volk is still seeking answers. “Before I had this, I worked full time, taught at least two classes and was getting a PhD,” she says. “I’m not somebody

who’s just going to sit around and feel sorry for myself.”

Volk now teaches as an adjunct professor at Towson University and sits through whole classes if necessary. “I need it for me,” she says. “For my brain. I love to teach.” Continuing to do something for herself, not just for her illness, helps her remain grounded.

Volk remains diligent with her doctors, seeking treatment for her symptoms as best she can. For years, she had counseling, as well, but the cost grew to be prohibitive. Still, she carries on.

“If somebody watched how I get through the day, they would

not believe it,” Volk says. “I lie down a lot, but then I gather my energy, and then I get up and do what I have to do.” ■

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



Learn more about how MS is diagnosed at ntlms.org/diagnosis.

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

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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 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 symptoms (see accompanying Patient Information).

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 in the accompanying Patient Information.

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 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 provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness



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- 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.

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

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 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.

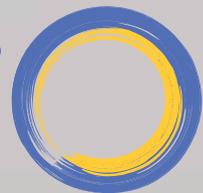
For additional Important Safety Information, please see the accompanying Patient Information.

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

†In two 2-year clinical studies vs REBIF.[‡]

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

OCREVUS can cause serious side effects, including:

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

- itchy skin
- rash
- hives
- tiredness
- coughing or wheezing
- trouble breathing
- throat irritation or pain
- feeling faint
- fever
- redness on your face (flushing)
- nausea
- headache
- swelling of the throat
- dizziness
- shortness of breath
- fatigue
- fast heart beat

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.
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- **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 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with OCREVUS.** You should not receive '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.
 - **When possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with OCREVUS.** If you would like to receive any non-live (inactivated) vaccines, including the seasonal flu vaccine, while you are being treated with OCREVUS, talk to your healthcare provider.
 - If you are pregnant or planning to become pregnant talk to your doctor about vaccinations for your baby, as some precautions may be needed.
 - 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

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Inside this section

A big part of the MS puzzle | 44

Pregnancy and MS | 49

OH, BABY! Women with multiple sclerosis are getting pregnant at a higher rate than women without MS. This could be because, as more studies and research become available, women with MS and their healthcare providers are more comfortable with pregnancy than they have been in the past. However, pregnancy while living with MS is still a different experience.

■ **Discussions with your healthcare provider.** Talk about your symptoms and whether it's safe for you to start or continue with disease-modifying therapies (DMTs). Common symptoms such as fatigue, bladder, bowel and gait issues may be worse during pregnancy.

■ **Postpartum challenges.** After giving birth, the risk of an MS relapse spikes, and you may need extra support. Since depression and anxiety are twice as common among people living with MS, postpartum depression might also be more common.

■ **Breastfeeding.** Many doctors advise against using DMTs while breastfeeding. However, breastfeeding seems to provide a modest protective benefit against postpartum MS relapses during the first six months. Discuss the possibility of breastfeeding with your healthcare provider.

Read more about new research in “Pregnancy and MS” in this section.





“

We identified a new pathway not addressed by any existing MS medications.”

—KATERINA AKASSOGLU, PhD

PHOTO COURTESY OF KATERINA AKASSOGLU, PhD

A big part of the MS puzzle

Barancik Prize winner Katerina Akassoglou, PhD, studies links between the brain, immune system and blood-brain barrier.

by Vicky Uhland

Back in 1994, shortly after she began work on her doctorate at the University of Athens and Greece's Pasteur Institute, Katerina Akassoglou, PhD, made an important discovery. She and her fellow researchers found that mice that had certain types of immune system-regulating molecules in their brain developed mobility symptoms similar to those experienced by people with multiple sclerosis.

Scientists at that time didn't know much about how immune cells acted inside the brain, especially in people with MS. Most of the studies prior to Akassoglou's work focused on the role of the immune system in the body. The brain's immune system was a whole new frontier, with the potential for more treatment options and targets for MS therapies than previously thought.

"We were very surprised," says Akassoglou, the winner of the 2018 Barancik Prize for Innovation in Research. "We realized that we might be missing a big part of the pathology of MS."

The discovery was so groundbreaking that it set the course for Akassoglou's career. She realized that to understand MS and other neurologic diseases well enough to develop a cure, she needed to research how the brain, the blood-brain barrier and the immune system interact throughout the disease course.

At the time, Akassoglou didn't know anyone with MS, and she viewed the disease mainly from a laboratory standpoint. But after she began her postdoctoral work at Rockefeller University in New York City, MS became personal to her.



Barancik Prize

The Barancik Prize for Innovation in Research was created in 2013 by the Charles & Margery Barancik Foundation and is administered by the National Multiple Sclerosis Society. The Baranciks have been major supporters of MS research projects for more than 20 years. They developed the Barancik Prize to recognize exceptional scientists who have demonstrated outstanding innovation and originality in MS research. Barancik Prize winners receive \$100,000 that can be used at their discretion.

"I had the opportunity to interact with MS patients at events organized by the National Multiple Sclerosis Society, and it was truly transformational to meet them and see the belief and hope they had in our research," she says. "I developed a sense of urgency when I met with patients. I had the revelation that our work could really make a difference, and we had to hurry."

Stopping MS in its tracks

For the last two decades, Akassoglou has put that sense of urgency to good use, conducting a series of studies that are creating a new understanding of the origins

of MS and pushing the boundaries of biomedical technology. She's developing an antibody that has the potential to not only halt damage to brain cells in people with relapsing-remitting or progressive MS, but also may repair MS-related nervous system damage.

This experimental therapy has the potential to "stop MS in its tracks," says Bruce Bebo, PhD, executive vice president of research for the Society. "Her relentless pursuit of a fundamental question in MS and the tenacity to translate this knowledge into potential therapies is why she is being recognized with the 2018 Barancik Prize."

"Katerina richly deserves the Barancik Prize because her work is pathbreaking and important. It's also a great example of the risk-taking science that the Baranciks and the MS Society are hoping to foster with this award," says Daniel Reich, MD, PhD, winner of the 2016 Barancik Prize.

Reich, who nominated Akassoglou for the 2018 prize, believes she could be "the most creative scientist currently working in the MS field. I rarely leave a conversation with Katerina without wondering whether I should change my own research focus based on her novel findings."

Is it in your blood?

After Akassoglou's research revelation in 1994, she set out to study what turns on the brain's own immune system in MS. She focused her studies on finding the link between the brain, the immune system and the blood-brain barrier. But she soon discovered that the technology she needed didn't exist. So she developed several cutting-edge imaging techniques that allowed her to see in real time how MS disease develops in the brain.

This helped her discover that a blood protein called fibrinogen is present in the brain very early in the disease. Fibrinogen, which helps blood clot, isn't normally found in the brain. But Akassoglou's research shows it can enter when there's a leaky blood-brain barrier, making clots called fibrin that start early, but can also last for long periods of time and promote damage in the brain.

"We've known for decades that the blood-brain barrier is leaky in MS, but we didn't understand what

An international researcher

Katerina Akassoglou, PhD, was born and raised in Greece, the only child of a mechanic and a seamstress. She was the first in her family to go to high school, where a biology teacher piqued her interest in science. She went on to study at the University of Athens, earning with first-class honors a bachelor's degree in biology and a doctorate in biological sciences, specializing in neuroimmunology.

A truly international researcher, Akassoglou has worked at the University of Vienna, Rockefeller University in New York City, New York University and the University of California, San Diego. She's currently a senior investigator at the Gladstone Institutes, a professor of neurology at the University of California, San Francisco, and founder and director of the Center for In Vivo Imaging Research at the UCSF Gladstone Institute.

Akassoglou has written more than 85 peer-reviewed papers and has been awarded seven U.S. patents, with another nine pending. The Barancik Prize is the latest of numerous awards she's won over the last two decades. Akassoglou is one of two women to receive the Barancik Prize. (Laura Balcer won as part of a trio of scientists in 2015.)

"I have always promoted diversity in my lab, including women and underrepresented minorities in science," Akassoglou says. "I hope that winning the Barancik Prize underscores that the originality and impact of scientific discovery is not defined by gender, ethnicity or socioeconomic status. Scientific innovation can come from all genders and all ethnic groups as long as inclusive environments are in place in academia for innovation to flourish."



PHOTO COURTESY OF KATERINA AKASSOGLOU, PHD

Barancik Prize winner Katerina Akassoglou, PhD, is researching the role that fibrin in the brain plays in promoting MS.

effect that had,” Akassoglou says. In essence, it was a chicken-and-egg question: Was there more fibrin in the brain because of MS, or did fibrin play a role in promoting MS?

Through research partially supported by Society grants, Akassoglou has found answers to that question. She’s discovered that fibrin can control communication between the brain, immune system and blood vessels. It can bind to receptors of the brain’s immune cells, which can kill neurons and cause the inflammation that contributes to MS. And it hinders repair of myelin, the protective nerve coating that MS attacks.

“While others dismissed the idea that blood factors could be involved in the nervous-system damage that

causes MS, Akassoglou saw this as an important clue,” Bebo says. “Over the past several years, she doggedly pursued the hypothesis that the blood-clotting factor fibrin plays a critical role in MS.”

Expanding the MS toolbox

Akassoglou was thrilled when she made the fibrin discovery. “We were very excited that we identified a new pathway not addressed by any existing MS medications,” she says. “Strategies blocking the toxic effects of blood proteins could be very important tools in the toolbox of MS therapies.”

Akassoglou and her research team have developed a unique antibody that can keep fibrin from finding the brain’s immune cells and binding to them—without interfering with fibrin’s vital role in blood clotting. Tests show this antibody has a huge effect on the course of MS in mice, including significantly decreasing the severity of their MS symptoms and reducing damage to neurons, myelin and inflammation.

The next step is to see if the antibody has the same effect in humans. Akassoglou co-founded a biotech company called MedaRed to research this and develop a medication using the antibody. If she’s successful, there would then need to be years of safety and clinical trials before an actual drug could be available to people living with MS.

“If it pans out, the therapy could protect the nervous system from damage in both early and late phases of the disease, which could have profound impacts for stopping MS progression,” Bebo says. ■

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



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Pregnancy and MS

New research sheds light on effects of the disease.

by Lori DeMillo

New research focusing on women with multiple sclerosis who are pregnant is shedding light on how the disease can affect them both during and after pregnancy. Key findings of two studies conducted by Maria Houtchens, MD, and her research team at Harvard Medical School and Brigham and Women's Hospital show that more women with MS are getting pregnant, although most do not use disease-modifying therapies for a year before and a year after pregnancy. Women with MS also tend to have more complications around the time of pregnancy compared to women without MS.

“Two-thirds of people with MS are women, and most are young when they get the MS diagnosis. The question of childbearing is at the forefront of most of our patients' lives. It is crucial to understand what happens when they get

Research shows that more women with MS are getting pregnant.

pregnant and during pregnancy,” Dr. Houtchens says. She is an assistant professor in the department of neurology at Harvard Medical School and an associate neurologist and director of the Women’s Health Program at the Partners MS Center at Brigham and Women’s Hospital.

Researchers used data from nine years of medical insurance claims (2006–2015) to study pregnancy rates and outcomes, as well as relapses and treatments with disease-modifying therapies (DMTs). They published their results in *Neurology* in 2018.

These are the first studies on pregnancy in MS to use medical insurance claims databases. “Database studies allows researchers to look at a large number of patients over time,” says Wendy Gilmore, PhD, associate professor of research emerita and research adjunct associate professor at the Keck School of Medicine of University of Southern California.

Higher rates

Pregnancy rates in women with MS increased from 7.9% to 9.47% between 2006 and 2014. At the same time, the pregnancy rates for women without MS decreased from 8.83% to 7.75%. “That was very surprising. I would have expected similar trends or slightly lagging pregnancy rates

for women with MS,” says Dr. Houtchens. Pregnant women with MS were also older (average age: 32.5 years) than pregnant women without MS (average age: 29.3 years).

“Women with MS appear less afraid of pregnancy than in the past,” adds Gilmore. While these studies were not designed to show the “why” behind the results, Dr. Houtchens believes that women with MS and their doctors are more comfortable with pregnancy now.

Low use of DMTs

Not taking a DMT is generally known to increase the risk of relapse, which could delay childbearing and cause long-term disability. Yet, researchers found that less than 25% of

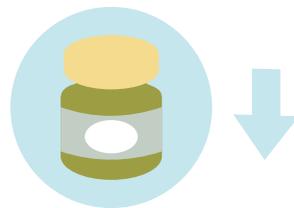


Talk to your doctor about how your medication interacts with pregnancy.

women with MS took a DMT during the year before getting pregnant and the year after giving birth. Of 2,158 women with MS:

- About 20% took a DMT at any time before getting pregnant
- 12% took a DMT during the first trimester; this decreased to 3% during the third trimester
- 25.5% were taking a DMT 9 to 12 months after giving birth.

“This is a big concern,” Dr. Houtchens says. “We need a lot more education for patients and providers about the safety of some of these medications.” While some DMTs are not compatible with pregnancy, many can be taken



Not taking a DMT is generally known to increase the risk of relapse.

Researchers used data from nine years of medical insurance claims (2006–2015) to study pregnancy rates and outcomes, as well as relapses and treatments with disease-modifying therapies (DMTs).

Average age of pregnant women with MS

32.5 years

Average age of pregnant women without MS

29.3 years



until the time of pregnancy. Injectable DMTs tend to be safer than oral DMTs. “Talk to your doctor about how each medication interacts with pregnancy,” Dr. Houtchens says.

Breastfeeding may be one reason for the low use of DMTs after childbirth, but the data did not include breastfeeding. “While it’s probably OK to use an injectable and breastfeed, there are no guidelines about this, so most doctors would tell patients not to take anything while breastfeeding,” says Dr. Houtchens. Some studies indicate that exclusive breastfeeding may provide a modest protective benefit against postpartum relapses during the first six months in women with MS. Women who wish to breastfeed should discuss the possibility with their healthcare providers.

More complications in pregnancy

Researchers found that women with MS had more complications than women without MS, including premature labor, infections during pregnancy and birth defects or damage. However, Dr. Houtchens advises, “Take these findings with a grain of salt.” More research is necessary, and many factors may have contributed to the data. For example, doctors may provide extra care and order more tests for pregnant women

with MS, where complications could be discovered.

“Although complications were not much higher in women with MS than women without MS, there is still a need for more information to help with pregnancy decisions and care,” Gilmore adds.

Known relapse rates

Relapse risk decreased during pregnancy, increased within six months after childbirth, and decreased at six to 12 months after childbirth. “It’s not a surprise that women (with MS) do better in pregnancy,” says Dr. Houtchens. “Pregnancy is a state of reduced immune reactivity and many autoimmune conditions get better during pregnancy.”

Safer pregnancies

At the Women’s Health Clinic at the Partners MS Center, Dr. Houtchens is raising awareness of the need to better manage DMTs for women who plan to become pregnant. She recommends that women who are thinking about having a baby discuss this at every doctor’s visit.

Cautions about the studies

Some important information isn’t available in medical insurance claims and couldn’t

be studied. For example, the results don’t cover MS types or severity. “Nevertheless, these studies do provide information that can lead to more definitive studies in the future,” Gilmore says.

Future research

More research is needed to help women with MS make decisions about pregnancy and to help doctors provide the best care during pregnancy. Dr. Houtchens also leads PREG-MS: New England MS Pregnancy Registry, designed to learn more about the effects of MS on pregnancy and childhood development up to three years. Women with MS who live in New England and are pregnant or trying to get pregnant can join the registry.

Gilmore would like to see more research on changes to the immune system in each trimester of pregnancy, along with before and after pregnancy. “Understanding what changes in the immune responses can tell us a lot about what happens with the disease,” she says. ■

Lori De Milto is a Sicklerville, N.J.-based freelance writer.



Learn more about pregnancy and MS at [natlims.org/pregnancy](https://www.natlims.org/pregnancy).

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

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

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

AUBAGIO is available in 14 mg and 7 mg tablets.

INDICATION

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

IMPORTANT SAFETY INFORMATION

DO NOT TAKE AUBAGIO IF YOU:

- **Have severe liver problems. AUBAGIO may cause serious liver problems, which can be life-threatening.** Your risk may be higher if you take other medicines that affect your liver. Your healthcare provider should do blood tests to check your liver within 6 months before you start AUBAGIO and monthly for 6 months after starting AUBAGIO. Tell your healthcare provider right away if you develop any of these symptoms of liver problems: nausea, vomiting, stomach pain, loss of appetite, tiredness, yellowing of your skin or whites of your eyes, or dark urine.
- **Are pregnant. AUBAGIO may harm an unborn baby.** You should have a pregnancy test before starting AUBAGIO. After stopping AUBAGIO, continue to use effective birth control until you have made sure your blood levels of AUBAGIO are lowered. If you become pregnant while taking AUBAGIO or within 2 years after stopping, tell your healthcare provider right away and enroll in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2.
- **Are of childbearing potential and not using effective birth control.**
It is not known if AUBAGIO passes into breast milk. Your healthcare provider can help you decide if you should take AUBAGIO or breastfeed — you should not do both at the same time.
If you are a man whose partner plans to become pregnant, you should stop taking AUBAGIO and talk with your healthcare provider about reducing the levels of AUBAGIO in your blood. If your partner does not plan to become pregnant, use effective birth control while taking AUBAGIO.
- **Have had an allergic reaction to AUBAGIO or a medicine called leflunomide.**
- **Take a medicine called leflunomide for rheumatoid arthritis.**

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

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

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

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

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

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

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

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

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Medication Guide

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

Rx Only

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

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

AUBAGIO may cause serious side effects, including:

- **Liver problems:** AUBAGIO may cause serious liver problems that may lead to death. Your risk of liver problems may be higher if you take other medicines that also affect your liver. Your doctor should do blood tests to check your liver:
 - within 6 months before you start taking AUBAGIO
 - 1 time a month for 6 months after you start taking AUBAGIOCall your doctor right away if you have any of the following symptoms of liver problems:
 - nausea
 - vomiting
 - stomach pain
 - loss of appetite
 - tiredness
 - your skin or the whites of your eyes turn yellow
 - dark urine
- **Harm to your unborn baby:** AUBAGIO may cause harm to your unborn baby. Do not take AUBAGIO if you are pregnant. Do not take AUBAGIO unless you are using effective birth control.
 - If you are a female, you should have a pregnancy test before you start taking AUBAGIO. Use effective birth control during your treatment with AUBAGIO.
 - After stopping AUBAGIO, continue using effective birth control until you have blood tests to make sure your blood levels of AUBAGIO are low enough. If you become pregnant while taking AUBAGIO or within 2 years after you stop taking it, tell your doctor right away.
 - **AUBAGIO Pregnancy Registry.** If you become pregnant while taking AUBAGIO or during the 2 years after you stop taking AUBAGIO, talk to your doctor about enrolling in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2. The purpose of this registry is to collect information about your health and your baby's health.
 - **For men taking AUBAGIO:**
 - If your female partner plans to become pregnant, you should stop taking AUBAGIO and ask your doctor how to quickly lower the levels of AUBAGIO in your blood.
 - If your female partner does not plan to become pregnant, you and your female partner should use effective birth control during your treatment with AUBAGIO. AUBAGIO remains in your blood after you stop taking it, so continue using effective birth control until AUBAGIO blood levels have been checked and they are low enough.

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

What is AUBAGIO?

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

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

Who should not take AUBAGIO?

Do not take AUBAGIO if you:

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

What should I tell my doctor before taking AUBAGIO?

Before you take AUBAGIO, tell your doctor if you:

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

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

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

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

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

How should I take AUBAGIO?

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

What are possible side effects of AUBAGIO?

AUBAGIO may cause serious side effects, including:

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

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

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

The most common side effects of AUBAGIO include:

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

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

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

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

How should I store AUBAGIO?

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

General information about the safe and effective use of AUBAGIO.

Medicines are sometimes prescribed for purposes other than those

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

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

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

What are the ingredients in AUBAGIO?

Active ingredient: teriflunomide

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

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

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

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Please see Medication Guide for AUBAGIO and full Prescribing Information, including boxed WARNING, available on www.aubagio.com
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AUBAGIO[®]
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Tablets

AUBAGIO is available in 14 mg and 7 mg tablets.



Cyclists discover hidden strengths in Bike MS rides.

by Robert Lerosé

Brandi Denton Gatewood got lost but found resilience. Brooke Simon met llamas. C.B. Dushane climbed higher. As cyclists who participate in I Ride with MS know, it's not the destination. It's the journey.

Since 2014, the National Multiple Sclerosis Society's I Ride with MS program has celebrated and recognized riders who live with MS. Anyone who participates in Bike MS may sign up. In 2017, nearly 70,000 cyclists hit the road in 72 rides, raising \$68 million for MS research and services and spreading awareness of the disease from coast to coast.

Cyclists can choose routes between 15 to 150 miles and ride individually or as part of a team. A well-coordinated volunteer staff, including support and gear vehicles, and well-stocked rest stops every 10 to 12 miles keep riders safe on the open road courses.

"This is not a race; it's a ride. People aren't racing to the finish line," says Kris Rauh, associate vice president of Bike MS experience. "Each ride has its own flavor."

Advocating for herself

As a partner in a Mississippi law firm, Gatewood fights for the underdog, but she never imagined that her biggest fight would be for herself. That changed when she was diagnosed with MS in June 2017 at age 35. “I was angry about it and thought that it’s not doing me any good to sulk, so I turned to the National MS Society to find ways to get involved,” Gatewood says.

In April 2018, she signed up for Bike MS: Tour De Beach, held annually each September. Inspired by Supreme Court Justice Ruth Bader Ginsburg and using her own initials, Gatewood cycled under Team Notorious BDG and wore a multi-colored jersey, with each stripe signifying a different health issue.

On the first day, she logged 14 miles along the beautiful Gulf Coast and Mobile Bay without a problem. Expecting to do an easy 11 miles on the second day, Gatewood took a wrong turn and got lost, adding another five miles to her ride, but raising around \$7,000.

Discerning litigant that she is, she uncovered an important truth. “The ride was a lesson in self-endurance and pushing myself. It showed me I could do more than I thought after hearing I have MS.”

No hill too high

After her second child was born, 33-year-old Simon of Denham Springs, Louisiana, began feeling numb on her left side and had trouble holding her newborn. She thought it had something to do with her C-section, but in May 2017 a neurologist confirmed that she had MS.

Simon temporarily lost the ability to walk and used a wheelchair for almost a month. To stay active, she started riding with a local group that was training for Bike MS: Dat’s How We Roll and readily accepted



PHOTO COURTESY OF BRANDI DENTON GATEWOOD

Participating in Bike MS helped Brandi Denton Gatewood (left) come to terms with her diagnosis.



PHOTO COURTESY OF BROOKE SIMON

Brooke Simon stayed active as a new mom by training for Bike MS.

the challenge to join. “I had 150 miles as a goal to prove to myself that I can keep going and to do it for my sons. I can’t let them see their mommy just sit,” she says.

Starting at Hammond, Louisiana, and heading to McComb, Mississippi, in October 2018, Simon promised herself that she would ride every hill without getting off the bike and walking. Even though she had to stop and ice down her legs when they went numb, she refused to get in a vehicle and ride to the end. Simon crossed the finish line last, but under her own steam, raising over \$3,000—and unexpectedly stumbling across a llama farm during her ride.

“I went toward what I needed to do to make the change for me to be happy. Now, I’m cycling my foot off and loving it,” she says.

Pushing himself further and farther

Fifty-one-year-old Dushane had worked out often, racing bikes and lifting weights, so he ignored the tingling in his legs. Walking down to his kitchen one morning, he lost sensation in his feet and tumbled down the stairs. At his wife’s urging, he saw his doctor. He was surprised to learn in December 2017 that he had MS.

After his diagnosis, he got in touch with a friend who worked for Primal Wear, the clothing sponsor for Bike MS, and said he’d like to ride with the team. Dushane used his skills as a salesman for a cybersecurity company to tell his story and seek donations, raising more than \$17,000.

In June 2018, he joined cyclists in Westminster, Colorado, for a two-day ride that would go through Fort Collins before returning the following day. As he got close to his one-day goal of 82 miles, Dushane felt energized and continued along the 102-mile path.

“The three hardest climbs were in that section—not super long, but very steep.



PHOTO COURTESY OF C.B. DUSHANE

You’re grinding up these hills and then you head back out towards the plains after you come out of the mountains and foothills of Colorado. I felt I owed it to the people who gave on my behalf and showed them that I’m willing and able to push myself hard,” he says.

No sooner had he gotten off the bike, he was tapped to do a Facebook Live interview for the Society, laughing when he remembers that he didn’t even have time to get cleaned up first. That Sunday, Dushane bumped into a fellow rider he had met earlier and cheerfully finished the last leg with him, completing 176 miles over the weekend.

“Whether you have MS or not, it’s a fantastic way to push yourself physically, but it’s also for such a great cause. I’d love to know we’ve found a cure for MS,” he says. ■

C.B. Dushane raised \$17,000 and has completed several rides for MS.

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



Learn more about I Ride with MS at ntlms.org/IRWMS.



Register to ride or volunteer for Bike MS at bikems.org.

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INDICATION GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults and children 10 years of age and older.

IMPORTANT SAFETY INFORMATION You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure. Do not take GILENYA if you have an irregular or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT

as seen on an ECG, or if you take medicines that change your heart rhythm. Do not take GILENYA if you are allergic to fingolimod or any of the other ingredients.

*GILENYA can result in a slow heart rate when first taken. You will be observed by a health care professional for at least 6 hours after you take your first dose. You may need to repeat this monitoring if you miss a dose or are a child who is moving to 0.5 mg from the 0.25 mg dose.

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



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



Visit gilenya.com to learn more.

IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

- Slow heart rate, especially after first dose. Adults and children will be monitored by a health care professional for at least 6 hours after the first dose or after a child takes the first dose of 0.5mg of GILENYA when switching from 0.25mg daily dose. Your pulse and blood pressure will be checked hourly. You'll get an ECG before and 6 hours after your first dose. If any heart problems arise or your heart rate is still low, you'll continue to be monitored. If you have any serious side effects, especially those that require treatment with other medicines, or if you have certain types of heart problems, or if you're taking medicines that can affect your heart, you'll be watched overnight. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor, or seek immediate medical attention if you have any symptoms of slow heart rate, such as dizziness, tiredness, feeling like your heart is beating slowly or skipping beats, or chest pain. Symptoms can happen up to 24 hours after the first dose. Call your doctor if you miss 1 or more doses of GILENYA—you may need to repeat the 6-hour monitoring.
- Increased risk of serious infections, some of which could be life threatening and cause death. You should not receive live vaccines during treatment with GILENYA and for 2 months after you stop taking GILENYA. Vaccines may not work as well when given during treatment with GILENYA. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test to check your white blood cells before you start GILENYA. Call your doctor right away if, while taking GILENYA or for 2 months after your last dose, you have fever, tiredness, body aches, chills, nausea, vomiting, or headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion. These may be symptoms of meningitis.
- Progressive multifocal leukoencephalopathy (PML). PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems. Call your doctor right away if you have any new or worsening symptoms of PML that have lasted several days, including changes in your thinking or memory, changes in your vision, decreased strength, problems with balance, weakness on 1 side of your body, loss of coordination in your arms and legs, confusion, or changes in your personality.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. If it happens, macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA, 3 to 4 months after you start GILENYA, and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Swelling and narrowing of the blood vessels in your brain. A condition called PRES (posterior reversible encephalopathy syndrome) has happened rarely in adults taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you experience any symptoms, such as sudden severe headache, sudden confusion, seizures, or sudden loss of vision.
- 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.
- Severe worsening of MS after stopping GILENYA. Many people who have worsening of MS symptoms after stopping GILENYA do

not return to the level of function that they had before or during treatment with GILENYA. This can also occur in women stopping due to pregnancy or planning a pregnancy. This worsening happens most often within 12 weeks after stopping GILENYA, but can happen later. Do not stop taking GILENYA without talking with your doctor. Tell your doctor if you have worsening symptoms of MS after stopping GILENYA.

- Increases in blood pressure (BP). BP should be monitored during treatment.
- Cancers including basal and Merkel cell carcinoma and melanoma. Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, new darkened area in your skin, a sore that does not heal, or growths on your skin such as a bump that may be shiny, pearly white, skin colored, or pink. While taking GILENYA, limit the amount of time you spend in sunlight and ultraviolet (UV) light as well as use sunscreen with a high sun protection factor and wear protective clothing. Lymphoma has also occurred in patients receiving GILENYA.

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

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

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

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

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

In the pediatric study:

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

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

Please see additional Important Safety Information on previous page.



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

GILENYA is a registered trademark of Novartis AG.

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BRIEF SUMMARY

Important Facts About GILENYA® (fingolimod) capsules

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

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

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

GILENYA may cause serious side effects, including:

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

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

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

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

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

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

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

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

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

3. Progressive multifocal leukoencephalopathy (PML). PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems.

Symptoms of PML get worse over days to weeks. Call your doctor right away if you have any new or worsening symptoms of PML, that have lasted several days, including:

- weakness on 1 side of your body
- problems with balance
- loss of coordination in your arms and legs
- changes in your vision
- decreased strength
- changes in your thinking or memory
- confusion
- changes in your personality

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

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

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

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults and children 10 years of age and older.

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

Who should not take GILENYA?

Do not take GILENYA if you:

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

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

What should I tell my doctor before taking GILENYA?

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

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

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

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

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

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

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

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

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

How should I take GILENYA?

- Adults and children will be observed by a health care professional for at least 6 hours after taking their first dose of GILENYA. **Children should also be observed by a health care professional for at least 6 hours after taking their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose.** See **"What is the most important information I should know about GILENYA?"**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- Call your doctor right away if you miss a dose of GILENYA. You may need to be observed by a 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, including:

- See **"What is the most important information I should know about GILENYA?"**
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened rarely in adults taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you have any of the following symptoms:
 - sudden severe headache
 - sudden confusion
 - sudden loss of vision or other changes in your vision
 - seizure
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have new or worsening breathing problems.

• **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
- tiredness
- loss of appetite
- your skin or the whites of your eyes turn yellow
- dark urine

• **severe worsening of multiple sclerosis after stopping GILENYA.**

When GILENYA is stopped, symptoms of MS can return and become worse compared to before or during treatment. Many people who have worsening of MS symptoms after stopping GILENYA do not return to the level of function that they had before stopping GILENYA. This worsening happens most often within 12 weeks after stopping GILENYA, but can happen later. Always talk to your doctor before you stop taking GILENYA for any reason. Tell your doctor if you have worsening symptoms of MS after stopping GILENYA.

• **increased blood pressure.** Your doctor should check your blood pressure during treatment with GILENYA.

• **types of cancer including basal and Merkel cell carcinoma and melanoma.** Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, a new darkened area on your skin, a sore that does not heal, or growths on your skin such as a bump that may be shiny, pearly white, skin-colored, or pink. Your doctor should check your skin for any changes during treatment with GILENYA. Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear protective clothing and use a sunscreen with a high sun protection factor. Lymphoma has also occurred in patients receiving GILENYA.

• **allergic reactions.** Call your doctor if you have symptoms of an allergic reaction, including a rash, itchy hives, or swelling of the lips, tongue or face.

The most common side effects of GILENYA include:

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

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

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

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

General information about the safe and effective use of GILENYA.

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

What are the ingredients in GILENYA?

0.25 mg capsules

Active ingredient: fingolimod

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

0.5 mg capsules

Active ingredient: fingolimod hydrochloride

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

GILENYA is a registered trademark of Novartis AG.

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Finding neuro

How to develop a positive relationship with your neurologist.

by Mike Knight

It was 2016 and Julia Fritze-Singh knew something was wrong. Diagnosed with relapsing-remitting multiple sclerosis in 2008, she understood her MS symptoms might worsen if she transitioned into the disease's secondary progressive state. But it wasn't just the disease Fritze-Singh was worried about—it was also the care she was receiving from her neurologist.

ILLUSTRATION BY DAVE CUTLER



“I was getting progressively worse, but every time I went into [my neurologist’s] office, she was telling me how I was fine, [that] things looked good,” Fritze-Singh says. “I knew I wasn’t fine, and things weren’t good. I just felt like I wasn’t getting the attention or the care I needed.”

Fritze-Singh’s neurologist agreed. “She was like, ‘You know, I’m getting ready to retire. You seem to be wanting to get more advanced medication, and I’m just not keeping up on those anymore. Maybe it’s time you see someone else.’”

Finding someone else wasn’t easy, but Fritze-Singh, a vice president of a Denver-based software startup, saw her search as more than finding another neurologist. It was also a chance to develop a better relationship with a new neurologist, one with the background and focus she wanted and one who would make sure her perspective, questions, ideas and concerns factored into her MS care.

Fritze-Singh’s search ultimately led her to the Mayo Clinic’s Center for Multiple Sclerosis and Autoimmune Neurology in Rochester, Minnesota. She made her first visit to the clinic’s campus in December 2017 and now goes twice a year. While she’s there, she meets with a team of experts, including physical and occupational therapists, a urologist and others, then returns home armed with treatment directions she can carry out with local healthcare professionals. A patient portal on the clinic’s secure website and videoconferencing let her communicate with her neurologist and others remotely.

Besides feeling better, Fritze-Singh is happy with the neurologist who oversees her care. “I wanted to be with somebody who’s staying at the forefront and knows what’s going on in the research area,” she says. “It’s been a really good fit with him.”



PHOTO COURTESY OF JULIA FRITZE-SINGH

Julia Fritze-Singh found the right fit for her MS treatment only after seeing several neurologists.

Though Fritze-Singh found what she needed at the Mayo Clinic, other people living with MS find what they need at a clinic or practice closer to home. No matter the location, finding a qualified neurologist you trust and connect with is important to your MS treatment plan, long-term health and quality of life.

Finding the right fit

Different types of neurologists treat people living with MS. General neurologists often care for people with MS, as well as others with stroke, Parkinson's disease, epilepsy and neurologic disorders. Some neurologists focus on MS, and some—MS specialists—complete additional education focused on the disease. MS specialists might work in private practice or in regional MS centers. General neurologists practice in offices and clinics located in cities and communities across the country.

Lisa Fox, a certified physician assistant at the Johns Hopkins Precision Medicine Center of Excellence for Multiple Sclerosis in Baltimore, worked in general neurology before beginning her focus on MS. Fox compares finding the right neurologic expert to interviewing candidates for a job. As a first step, "Reference check your physician before you see [him or her] in order to know that this may or may not be the right fit," Fox says. She recommends asking trusted healthcare providers, including general practitioners, OB/GYNs, physical therapists, physiatrists or family and friends for referrals. "Everybody knows someone with MS," she says.

You may want to also explore the possibility of being a "shared patient" of both your local neurologist and an MS specialist at a regional center, says Jacqueline Nicholas, MD, an MS specialist at OhioHealth Neuroscience Center in Columbus, Ohio. Shared patients, she says, typically travel to a regional center once a year for MRIs and for updates about new treatments and research opportunities while they visit their local neurologist throughout the year. "That's a nice collaboration where somebody is very comfortable with their local neurologist, but the patient can still check in with an MS specialist."



I wanted to be with somebody who's staying at the forefront and knows what's going on in the research area."

—JULIA FRITZE-SINGH

The National Multiple Sclerosis Society has developed partnerships with many healthcare providers. These include Partners in MS Care who have demonstrated a keen interest, knowledge and experience in MS care. The Society's "Find Doctors and Resources" (nationalMSSociety.org/Resources-Support/Find-Doctors-Resources) allows users to locate providers throughout the country who are Partners in MS Care.

The Society's MS Navigator service lets you chat online or by phone confidentially with navigators who can help you identify healthcare providers, Partners in MS Care and Centers for Comprehensive MS Care across the United States. For more information, call 1-800-344-4867.

How to prepare for your first visit

Once you've identified a neurologist you'd like to see, you'll schedule a "new patient" visit. You will need to sign a waiver giving your current neurologist permission to send your records to the new neurologist you're considering. If you're worried that may result in an awkward conversation, don't be.

"You can say, 'I would like for my records to be sent to this provider; I'm seeing them for evaluation,'" Fox says. "If you're considerate and do it in an honest and respectful way, nobody will ever fault you for that."

Fox recommends asking about what insurance the provider accepts before you go. If you don't have the right coverage—or if you don't have coverage, period—financial assistance may be available. Some centers for comprehensive care, including Johns Hopkins, have social workers who work with those who don't have insurance, and many MS drug manufacturers offer co-pay assistance programs to help cover the costs. Local providers may be willing to create a payment plan to make it easier for you, too. The Society also might be able to point you to information or resources that can help.

It's the connection that counts

Like all good relationships, the one you have with your neurologist begins by establishing a personal connection and commitment to shared decision-making. It might take time and effort to create. Keeping lines of communication open and being honest with your provider are essential.

Donald Negroski, MD, a general neurologist practicing in Sarasota, Florida, also recommends developing good relationships with “physician extenders” that might include a physician assistant or advanced registered nurse practitioner, who participate in your care along with the neurologist.

“Patients are the center of this multi-dimensional team,” Dr. Negroski says. “And if they don't have the proper relationship with one of the lead members of the team, the neurologist, or the physician extenders, it doesn't work as well.”

Debbie Bright was diagnosed with relapsing-remitting MS in 1988 and has since transitioned to secondary progressive MS. She's seen two neurologists in that time frame. Her first neurologist, she says

Building a positive relationship

Here are things you can do to build a positive and collaborative relationship with your neurologist:

Make sure you keep your appointment, and show up on time (or even better, get there early). Besides being respectful of your doctor and others, this will help make sure you get the most from your time with your healthcare providers.

Create and keep a list of new symptoms and issues you want to talk about, preferably by priority, and share that list at the beginning of your appointment.

Know that you may only have 20 to 30 minutes with your neurologist or physician assistant. It's a good idea to raise the issues and questions that are most important to you first. Bring an up-to-date list of your current medications, allergies, other physicians and any other medical issues so that your MS provider can be aware of them

Be honest about your symptoms and adherence (or lack of) to your medication. Talk about what you want out of life, even with MS, and about your mood and feelings. MS is a multifaceted disease with many complications. Your provider can't help with them if she or he isn't aware of them.

Be patient. MS is a complicated disease, and your doctor may need some time to understand your symptoms and help you better understand the state of your disease. It may take a few visits to get in sync and assess the relationship and fit.

Work in collaboration with your neurologist to develop a treatment plan together that includes recommendations and prescriptions, then follow that plan. That will help your provider assess your treatment's efficacy and address medication concerns or any side effects. It will also help your doctor prescribe additional healthcare services such as physical therapy, psychological help or mobility aids that will help you manage your MS. And if you don't think that parts of your MS care are working for you, don't hesitate to raise questions or concerns with your doctor.

“If you have MS, you need to find a provider that you have a good connection with.”

—LISA FOX



PHOTO COURTESY OF DEBBIE BRIGHT

Debbie Bright prepares for her doctor's visits by doing research and bringing a list of questions.

with a laugh, was “a one-man operation” and definitely “old school.”

“He literally had a doctor's bag that included a stethoscope, blood pressure cuff and reflex hammer that he would get out when I came,” she says. “One thing I loved about him was he would dictate notes in front of you from the visit. You heard everything.” When that doctor retired, Bright, who lives in Baltimore, began seeing a neurologist at Johns Hopkins. Though

her treatment has changed over time, her approach as a patient hasn't.

“I try very hard to go in with a positive attitude,” she says. “When you meet with the doctor, certainly it's not their fault that you have MS. I also think it's very important to go in with a list of questions. I mean, that's kind of basic, but especially when you have cognitive issues, it's very helpful to have your questions outlined on a piece of paper and to take with you so you don't forget something.”

Like many people living with MS, Bright has access to a patient portal that allows her to send and receive secure messages with her neurologist and other team members. Bright tries to do her homework before asking for help. “I'm a fan of doing your own research, too, so you're educated before you are asking for their input or opinion,” she says.

Regardless of what type of neurologist or MS care provider you choose, Fox says to trust your instincts. “If you have MS, you need to find a provider that you have a good connection with,” she says. “You need to listen to your gut, because you're never going to trust anybody when your gut says ‘Hey, something's off.’” ■

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



Find an MS care provider at nationalMSSociety.org/Resources-Support/Find-Doctors-Resources.

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Into the wind

Sailors with MS challenge themselves and others.

by James Townsend





J.R. Hardenburgh (left) and Nick Bryan-Brown sail into the wind during the U.S. Parasailing Championship on Narragansett Bay in Newport, Rhode Island. Newport Bridge is in the background.

J.R. Hardenburgh and Nick Bryan-Brown take the motto “embrace the challenge” to heart. The two met at a multiple sclerosis support group in 2014 in Boston and became friends when they discovered they shared a life-long love for sailing. So, they decided to challenge each other in races.

They were invited to race in the fall regattas in 2015, 2016 and 2017 at the Y-Knot Sailing Center in Lake George, New York. In June 2018, they raced in the national parasailing championship held during the Clagett Regatta in Newport, Rhode Island.

After two days of preparation and three days of racing, Hardenburgh and Bryan-Brown won the bronze medal at the C. Thomas Clagett, Jr. Memorial Clinic and Regatta, known by its shortened name, the Clagett. The late C. Thomas Clagett, Jr., was a lifelong sailing devotee with a love of honest rivalry and quality competition. His namesake event is North

America’s premier race-training event for sailors with disabilities, most of whom are amputees or those with spinal cord injuries. “Out of 46 competitors, we were the only MS patients in the race,” Hardenburgh says.

Motivating others

Hardenburgh and Bryan-Brown hope to change that and help motivate other people with MS to do things they didn’t think they could do. Hardenburgh and Bryan-Brown work with the director of Y-Knot and its adaptive racing director to tell people with MS about the adaptive sailing program. “J.R. has been the driving force behind

MS Sailing days at Y-Knot for the past two years,” Bryan-Brown says of his friend.

“We plan to get people with MS interested in sailing by hosting MS Sailing Days at the Y-Knot Sailing Center on Lake George and Community Boating on the Charles River in Boston,” Hardenburgh says. He and Bryan-Brown will skipper the boats, taking people for a leisurely sail so they get a feel for the experience. The two partner with the MS Cure Fund in Boston to get the word out. In addition, one of the Y-Knot volunteers whose wife has MS attends MS support group meetings in upstate New York and encourages group members to participate in the sailing days.

“In the disabled sailing community,” Hardenburgh says, “competition is as fierce as any other sport, but parasailing is really an open, honest and collegial environment where we’re all cheering for one another, rooting for other sailors to do better.” It’s what adaptive sailing programs around the nation are all about, he says.

A look back

Hardenburgh, 63, grew up in Connecticut and learned to sail on the Long Island Sound at age 12. Diagnosed with relapsing-remitting MS in 1995, he gave up sailing and experienced a long period of decline. “Although I was managing my MS and its symptoms, I was missing a decent quality of life,” he says. His pivotal moment came in 2013 while attending a Can Do Multiple Sclerosis event in Denver. “It was my annus horribilus, Latin for worst year ever,” he says. “My MS was progressing, and my career and marriage were dissolving, but two of my best friends encouraged me to try adaptive sailing. Prior to being diagnosed, sailing and skiing were my passions, so I pursued adaptive versions of both with vigor, and the outcome was

PHOTO COURTESY OF CLAGETT REGATTARO FERNANDEZ



PHOTO COURTESY OF CLAGETT REGATTARO FERNANDEZ

Coming into an inflatable buoy marker that must be rounded, Nick Bryan-Brown skippers a 18-foot sailboat as J.R. Hardenburgh assists.

very rewarding, greatly improving my quality of life each year.”

Bryan-Brown, 65, grew up in New Zealand and began sailing at the age of 5. “Sailing has been my passion since I was young and continues almost 30 years after my diagnosis in 1989,” he says. Bryan-Brown, who has primary progressive MS and uses a wheelchair, maintains his real estate business and remains active in sailboat racing. He teamed up with Robie Pierce, another sailor with MS who was organizing events for sailors with disabilities. Together, they won several national championships, then took a gold medal in the 1993 World Disabled

Sailing Championships in Marblehead, Massachusetts. Pierce is famously quoted as saying, “I’m not going to let this MS stand in the way of me racing. If I have to crawl to the boat, I’ll go.”

“When I first was diagnosed with MS,” Bryan-Brown says, “my future was uncertain, not knowing if I could continue my prior activities that bring satisfaction to my life. Parasailing brings a quality to my life that I didn’t think possible.”

Adaptation

Sailing presents unique challenges to those with MS, summer temperatures along with mental and physical fatigue among the

biggest. “Summer heat is our kryptonite and sometimes temperatures on the water are in the 80s,” Hardenburgh says. “We have to wear cooling vests and constantly stay hydrated. Maintaining balance is a frequent problem for people with MS on land, but on the water, we leave our disabilities behind on the dock.” Adaptive sailboats are equipped with stationary seats that keep sailors in a fixed, centralized position regardless of the boat’s movement. There is a joystick to control the rudder (for steering) and lines to control the sails, all within reach of the skipper’s or crew’s fixed seat. For those in wheelchairs, like Bryan-Brown, there is dockside equipment to lift him into the boat. “Sailors with disabilities in boats properly equipped like this frequently beat able-bodied sailors in competitive events,” Hardenburgh says.

But it’s not all about competition, Hardenburgh adds. Many parasailing centers welcome people with physical challenges and no prior sailing experience as passengers.

Hardenburgh says one of the best aspects of the Clagett is the extraordinary coaching he and Bryan-Brown received from Betsy Alison, five-time Rolex Yachtswoman of the Year, inducted in the 2011 inaugural class of the National Sailing Hall of Fame. Before the races, and every day during the race, participants meet with top racers like Alison for personal instruction. “When you get a member of the sailing hall of fame telling you what to do to win, you listen,” Hardenburgh says.

“Sailing is one of the very few sports that offers a level playing field for both disabled and able-bodied competitors,” says Sam Crichton, PR consultant to the Clagett and other sailing competitions. She loves the intense passion and joy in those involved with the program. “The Clagett is a deeply

Sail away



A variety of opportunities exist for sailors with disabilities to get involved beyond the Clagett Regatta. Among them: the U.S. Sailing Association’s adaptive sailing program (ussailing.org), the Judd Goldman Adaptive Sailing Foundation in Chicago (juddgoldmansailing.org) and the Disabled Sports USA produces parasailing events nationwide (disabledsportsusa.org).



PHOTO COURTESY OF CLAGETT REGATTA/RO FERNANDEZ

inspiring event,” she says. “When these sailors come out of their boats at the end of a race, you couldn’t get bigger smiles if you paid them for it.” ■

Nick Bryan-Brown being Hoyer-lifted into a sailboat before the race.

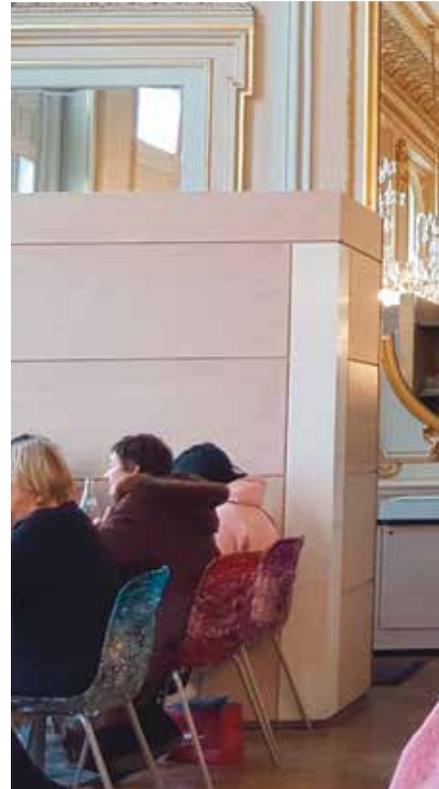
James Townsend is a writer in Boulder, Colorado.

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

Tell me something interesting

My wife, Carol, was a courageous world traveler.

by Paul Huebner



“Tell me something interesting!” That was how Carol Huebner liked to begin her English lessons, encouraging her Chinese students, young and old alike, to use the language creatively. Despite living with multiple sclerosis for 35 years and weathering two bouts of cancer, Carol happily donated her time over the last 10 years to help students practice their English. Her life in China spanned an exceptional period of vast change and she was a part of it, encouraging her students to see their own country in a positive light. Cancer finally took her life, but not before she had contributed so much to our community as well as writing frequently about her experiences living abroad. She was a true friend of China!

An English teacher turned high school administrator, Carol raised two prize-winning professional musicians, one joining the New York Philharmonic and another building a performance career in country western

music. Carol also wrote and self-published three books. After the gradual decline in her physical abilities required her to retire early, she became restless. She convinced me, her husband, to retire by promising to accompany me to China so I could pursue my interest in Chinese language and music. We moved to Shenyang, where I had studied at Liaoning University. Shenyang was not exactly a wheelchair-friendly city, but Carol soon discovered that where convenience failed, warm offers of help instantly appeared. Carol called this “people power” and found that using a wheelchair in China was never a barrier to wonderful friendships. With the help of my tutor, Carol soon had a nightly English practice group and college student book club.

After our first year in Shenyang, my tutor, who lived in Dalian, suggested we try life in her hometown. It soon became clear that this charming coastal city was



Carol Huebner was not only a dedicated English tutor to Chinese students but also a great friend to them.

PHOTOS COURTESY OF PAUL HUEBNER

a place retired people could call home. We found a wonderful apartment with a view of the ocean and within walking distance from Dongbei University, where I would continue to study. It wasn't long before Carol invited students in our building to participate in a reading club. She also formed a lasting friendship with a local artist and teacher, Sarah, and began to teach English to her and her son as well as one or two of Sarah's art students. Sarah's gifted son painted us a brilliant image of old Dalian on a large canvas that still hangs in our dining room.

Crisscrossing the globe

Carol was a courageous world traveler, crossing the globe between China, America and Europe as well as traveling extensively in China. She faced many obstacles that would have made so many others in her situation call it quits! On the first leg of our journey

from America, she had to be pulled to the front of the airplane on a blanket because there was no aisle wheelchair available. Boarding and leaving the aircraft were always a challenge, but on several occasions, flight attendants offered their help. Once, a wonderful Korean ground supervisor hoisted Carol on his back and carried her to her seat. Another time, a kind young Chinese flight attendant offered to help her to her seat, and as she lunged forward into his arms, the surprised look on his face was priceless.

When traveling in China, airport ground service was not particularly convenient for wheelchair travelers. There were forms to fill out to be able to use the airport wheelchairs and complicated procedures to check your own wheelchair. But then came that wonderful day when the front page of the Dalian newspaper pictured an army of attendants standing behind empty wheelchairs, all prepared to take on travelers with

■ fired up

disabilities. I have to feel that Carol's willingness to put up with the inconvenience of travel might have made a slight impact. We traveled often enough in China that service staff in airports would sometimes recognize us and agree to communicate problems to their managers.

Hotels in many countries seem to have no real standard for what constitutes an accessible room. We got in the habit of calling hotels directly and requesting pictures of the bathroom!

Always time for students

Without the heroic assistance of Carol's energetic caregiver Susie, we would have had a very difficult time. Susie, who is Chinese, helped smooth the way. Her knowledge of food often led us to wonderful local dishes.

She was always patient and aware of the limited time Carol could be out and about. Together, Susie and I helped Carol shower and use the bathroom as well as get in and out of bed and dress.

At home, what Carol's students didn't see was the trial of preparation that she had to go through: dressing, using the bathroom, eating, putting on makeup and dealing with fatigue. Even one student a day could sometimes be very tiring for her and sometimes two or three were too much. Yet she continued to donate time to her students.

When her cancer returned and it became obvious that Carol just wasn't going to make it this third time, she accepted the diagnosis bravely and refused further treatment. "Tell Susie to sell the clothes!" she said. Her children were able to make one last visit. Her wonderful students and their parents poured out their love visiting her, preparing food and expressing concern.

There is a Chinese proverb that says, "If you are a teacher for one day, you are a parent for life." The day before Carol died, her oldest student called from his workplace in Chongqing. He was crying as he told her that she was like a grandmother to him. The next day, as I held her, Carol left this world quietly and at peace. It was her way of finally defeating all the physical ills that had plagued her.



PHOTO COURTESY OF PAUL HUEBNER

Paul and Carol Huebner traveled extensively throughout China, where they had lived for 10 years.

Later, one of her student's parents wrote in Chinese: "Thank you for letting me know about the many fine elements of human nature: kindheartedness, beauty, strength and bravery. Your eyes have always been so clear, your smile always so lovely. I miss you. I am sorry, with my English so poor, I am unable to write even a few words, but you in heaven certainly can read Chinese!" ■

Paul Huebner received a master's degree in music at UCLA and spent 30 years as a piano teacher in the Los Angeles area. He and his wife, Carol, were married for 50 years, the last 10 of which were spent in China. Paul continues to live in Dalian, studying at Dalian University of Finance and Economics, as well as continuing his musical studies at Zhong Yin School, playing guqin and guzheng.

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Understanding through images

Illustrating life with MS.
by Jessie Ace

The last day of university was a blur for 22-year-old me. I'd been spending every minute finishing my degree and setting up a business as an illustrator. Unfortunately, the final day of university didn't exactly go as planned.

I spent that day trying to convince myself that I'd slept funny and that's why I'd lost feeling in the left half of my body. After a week, it was still there so I decided to see a doctor, who thought I'd had a stroke and immediately sent me to the emergency department. After three days of constant tests in 2013, I found out that I had multiple sclerosis. I freaked out, associating it with wheelchairs and worried I wouldn't be able to walk down the aisle at my wedding. I was forced to leave my job as a graphic designer in fashion due to the long hours and commute. I couldn't stay awake through the work day and the "cog fog" made it impossible to fulfill tasks.

I started working on designing wedding invitations and set up a group on Facebook of more than 3,700 brides to provide them with wedding advice and doing confidence coaching through Facebook Live videos. I also sold bridesmaids dresses that helped take the stress away from the bride. I spoke to a lot of brides with disabilities who were worried about how to disguise their oxygen tank on their big day or decorate their wheelchair, providing confidence from all angles.

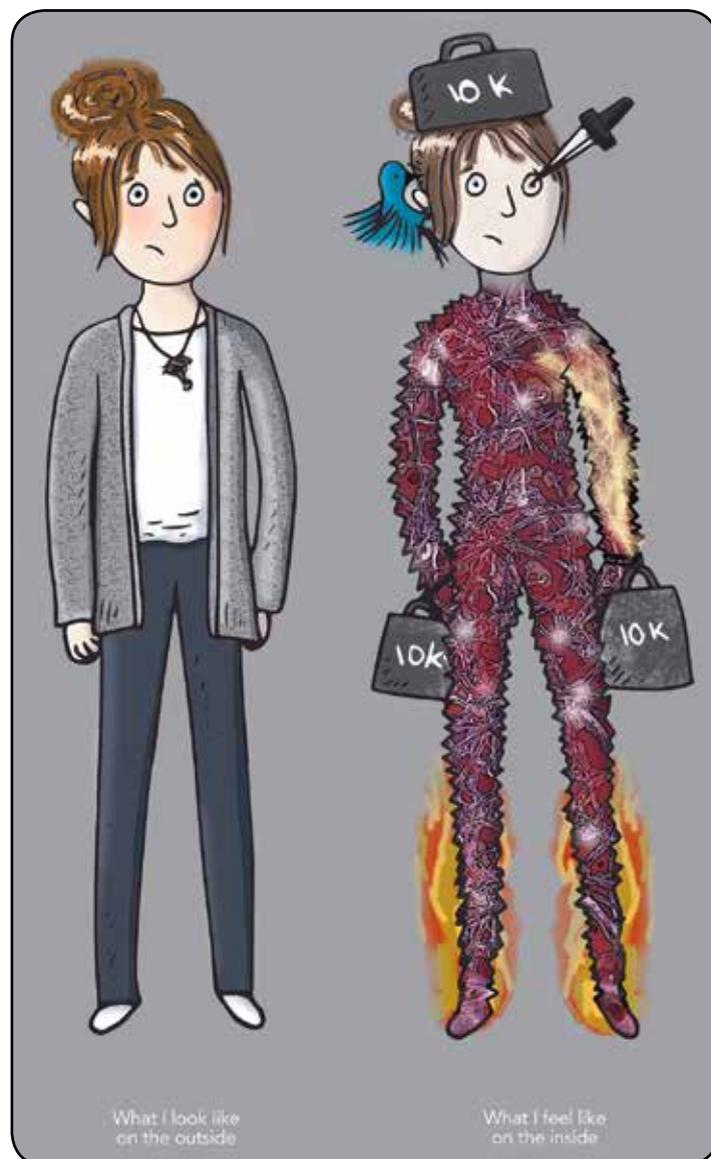




PHOTO COURTESY OF JESSIE ACE

Above: Jessie Ace, diagnosed with MS in 2013, is an artist and blogger.

Left and bottom: Ace draws illustrations to convey what it's like to live with MS. Some of them, like the one at the bottom, have been published on **MSConnection.org**.



PUBLISHED ON MSCONNECTION.ORG

Around the start of 2018, I had accepted my diagnosis more because I'd gotten so used to discussing it on Facebook Live with the brides—especially the brides-to-be with disabilities. We chatted and compared our symptoms and it made me feel so much more at ease. I decided I wanted to help other young people who had been diagnosed. I became a blogger for the National Multiple Sclerosis Society in May 2018, and I was encouraged to include an illustration with each blog. It was the first time I had illustrated since I lost most of the use of my hand to MS six years before, and I was understandably anxious. It was like my hand had turned into a claw, not quite a fist, but close. I couldn't straighten my fingers because I had no strength in my hand whatsoever. It was frightening.

The support of the blog readers and the staff at the Society were so encouraging. And now that the use of my hand is back, I want to pursue illustration full time and help to convey MS in images so that more people can understand the illness. It still frightens me a little that it could go again at any time, but while it's here, I'm going to appreciate it and enjoy it! I'm 28 now and I believe that what you're given or have experienced doesn't define you. It's how you react to your situation and what you do with it that defines you as a person. I want to turn MS into something good that can help other people feel accepted and understood. ■

Jessie Ace lives in Swadlincote, Derbyshire, in the middle of England, with her husband and fur baby shadow, Lucy.



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