

The hidden symptom

Depression strikes 1 in 2 people with MS, and it can be difficult to recognize. But there are ways to cope.

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National
Multiple Sclerosis
Society

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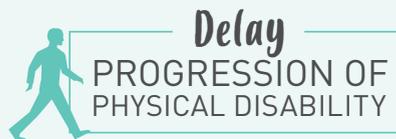
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Laura S., living with relapsing MS

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.

\$0 CO
PAY

yes to finding support

You may be eligible for our **\$0 Copay Program**.

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



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

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momentum

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More than 500,000 people living with multiple sclerosis have signed up with the National Multiple Sclerosis Society. People who have reached out for resources and information, to participate in programs and events and to make connections. That's more than the 1975 estimate of people with MS in the United States. Is it possible that everyone diagnosed with MS has joined the MS movement?

Several years ago, we commissioned an MS prevalence initiative and the results were recently published in the prestigious scientific journal *Neurology*. So, we have a much better estimate of the number of people with MS in the United States—it's twice as many as the '70's study estimated. That means there are almost twice as many people with MS who have not joined their National MS Society!

On one hand, that's understandable. Every day, people living with MS go about their lives. They take care of their families. They go to work. They navigate the challenges of their disease and find creative solutions to manage their symptoms. But when you have MS, things can go wrong. Managing the effects of the disease can be overwhelming. Yet some people don't reach out. Sometimes they want to forget about MS and just go about their lives. We get it! When people tell me they don't need anything from the Society, my response is "OK, I understand, but we need you. Together, we are stronger."

We know that when people connect with their National MS Society, they do better. They're more informed. They're more resilient and less isolated. They live better lives. So, we need to break through the barriers and connect with people as quickly as possible to establish a lifelong supportive partnership. To let them know that they don't have to figure it out by themselves. They have a National MS Society with comprehensive information and resources and people to help sort through what's most important right now. Like the right information about MS and treatments at the right time. Like MS Navigators, who can help make the overwhelming manageable. Like another person living with similar life circumstances who can share what worked for her.

How powerful would it be if everybody affected by MS were connected to our movement? That's twice as many people living with MS we need to join. We need twice as much awareness, twice as many resources, twice as many participants, twice as many donors, twice as many volunteers. Wouldn't it be great if Walk MS was twice as big?

What are your thoughts? What can you do to bring more people into the MS movement? ■



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

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



Events like Walk MS help people connect to each other as well as to the National Multiple Sclerosis Society.

Cyndi Zagieboylo



MS sat me down.

**I will
dance
at my daughters'
weddings.**

Jim

Dad. Podcaster.

Diagnosed in 1998.

Explore powerful stories of
people doing **whatever it takes** at
nationalMSSociety.org/jim



National
Multiple Sclerosis
Society

Less alone

I appreciated the article “A new phase” about secondary progressive multiple sclerosis in the Winter 2018–19 issue. Made me feel less alone and it gave me a boost, too!

Mary Zimmerman, Oregon



Victoria Reese has created a community for women living with MS.

PHOTO BY JOSEPH GRAY

Encouraged by fellow warriors

I was pleasantly surprised to see the article about a young black millennial with multiple sclerosis who created a community that she could relate to (“Still dope,” Winter 2018–19). The hip hop inspiration of WeAreILLmatic was sweet icing on the cake! I am not a millennial but am a woman of color with MS who feels encouraged by the strength and inspiration of fellow MS warriors! Another great surprise would be to see more articles about cannabis, holistic health and other alternate therapies.

Seneca Iscove, New York

Inspired by WeAreILLmatic

Thank you for the article “Still dope” (Winter 2018–19) profiling Victoria Reese and the WeAreILLmatic movement. Reese’s initiative to start a campaign designed to unite women of color diagnosed with multiple sclerosis is truly inspiring—that community is

too often forgotten in the conversation. I immediately made a donation to them and shared their campaign on Facebook. I would love to know if there is anything else I can do to support them as a white ally.

Chapin Cole, California

It is better to know

I would like to share my MS experience in hopes of offering some guidance to L.G., California (@momentum, “Is it better to know?” Winter 2018–19). I was diagnosed with multiple sclerosis 21 years ago. My symptoms were very mild and the only medications at that time were Avonex, Betaseron and Copaxone. I was crazy about putting these strange medications into my body, not knowing what they would do to me, and my doctor didn’t push the issue. Three years later, my MRI showed some new lesions, and I still didn’t go on medication because I felt fine. Six months later, I had a major relapse and decided to go on medication. That summer, I began to have issues with my left leg and knee and both of my feet. I felt like I was walking on rocks. I still do and have a difficult time finding comfortable shoes. I have been on this same medication now for almost 18 years and wouldn’t change a thing. I guess I’m one of the more fortunate ones in that my MS has not progressed since I’ve been on disease-modifying therapies. I have read everything I can about MS, the new medications, where MS can progress, and feel like I am better prepared now than I was before. I believe it’s better to know in advance than to react after the fact and not be able to change something that happens. Talk with your doctor. If you find the right medication and feel good about it, you can’t go wrong. Good luck!

Harriet Pinchouck, Florida

Keep trying

I read “Is it better to know?” by L.G., California (@momentum, Winter 2018–19) and felt compelled to respond. I also was diagnosed about 15 years ago, and my right leg and foot, stamina and energy levels

are also affected. Until I received this new infusion, I had a poor outcome with all the prescription drugs. I felt that reading the side effects and knowing all the possibilities set me up to be looking for them. With my current medication, I went into it not knowing what could happen, and so far I've had nothing but success. I think I finally received something that actually worked for me. I struggled with whether I did myself a disservice by avoiding knowledge and not taking action sooner. I did try numerous therapies and finally got the one that works, but as I have learned, things often will get worse before they get better. The important thing is we must always try. Success comes from failure.

Barbara Monroe, West Virginia

No more pie-in-the-sky stories

You have been my No. 1 go-to people for information about MS. Ten years into my multiple sclerosis I can barely walk around my apartment without my walker and will sooner rather than later be in a wheelchair. Kudos for helping me all these years with financial puzzles, medication decisions and other issues. But please quit with the “I can climb a mountain if I can pay someone to carry me,” “I can run a marathon” (“Run the world,” Winter 2018–19) baloney. While it might be reality for one person, this is BS for most people with MS. I figure skated for more than 20 years, earned a USFSA gold medal through eight years of training, and taught ice dancing to both children and adults. I obviously do not skate anymore as I cannot figure out what kind of footwear to put on the walker. No amount of wishful or positive thinking is going to change this. Shame on you for making us feel ashamed that we cannot all run marathons. MS is a physical disease; it is not a moral failing or absence of will

power. I face an obstacle course every time I get up from the TV and go to the fridge. Get in the same race as your constituents, or you will get run over (by people with canes, walkers and wheelchairs) and become obsolete! Your former biggest fan and now your biggest critic.

Dorothy R. Dickhaus, Indiana

Perfect timing

I was diagnosed with multiple sclerosis in 2001. I was always active and exercised. I started riding the City to Shore in New Jersey every year and the local MS Walk with my team. When I turned 40 in 2008, my doctor told me I should go on high cholesterol and high blood pressure medicine. I said, “No way, I can lower my numbers without medication.” I did just that through exercise and weight loss, mostly due to running. Ever since, I kept making personal goals to run farther and farther. I prefer the distance over running for speed. I ended up running two marathons, including the New York City Marathon in 2016. But during my training for the NYC marathon, I started to have problems, mostly foot drop, which caused me to stumble and fall many times. Yet I finished the marathon—before dark! I've been getting more down over the past year over the foot drop, and I was running less because of it. The article “Run the world” (Winter 2018–19) and Cheryl Hile's determination made me feel so inspired! It was published at the most perfect time. It is making me get out there and just do it! I wanted to give her a huge “thank you” for her story. I don't think I will ever run another marathon, but I definitely want to continue running 5Ks, 10Ks and some half marathons. ■

Leslie Touchton, Pennsylvania

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



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editor@nmss.org.



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on the cover

Brooke Pelczynski, diagnosed with MS in 2012, captures how MS impacts her life through her artwork. She created the cover illustration showing how depression strikes people with MS, specially for Momentum magazine.

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WEB EXCLUSIVE!

Watch a video and read about how Brooke Pelczynski lives with her MS at MomentumMagazineOnline.com/brooke.



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Uncertain diagnosis: What steps people take when their doctor can't provide a definitive diagnosis of MS. **PLUS:** Is a clinical trial right for you, adaptive clothing, forming a positive relationship with your neurologist, and more.



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

Wearable technology and accessibility

As you'll read in the following story, some cities are more accessible than others. But even cities with great accessibility can be improved. If you're out and see a problem such as broken sidewalks or storefronts without ramps, wearable technology devices can help you react in the moment.

Devices like Apple Watch and other smart watches provide a range of helpful features: You can call or text someone, send your location in a text, see where you are on a map and screenshot it, take photos, and talk to a virtual assistant (like Siri) if you need to look up a phone number for your local accessibility office. Other devices, such as Google Glass and fitness trackers, may also have features that can come in handy while you're navigating your city or town.

Practical ideas
for living well
with MS

in the know

 in the know

It's your community, too

People with disabilities encounter obstacles and opportunities in the cities where they live.

by Matt Alderton

Boston is the birthplace of American independence. Established nearly 400 years ago, it's where angry colonists revolted against British tea taxes, where the Revolutionary War commenced and where a judicial decree made Massachusetts the first U.S. state to abolish slavery.

For residents with disabilities, however, Boston hasn't always lived up to its promise of liberty. To them, Boston won't be a truly free city until it's a truly accessible one.



Boston is among the best-in-class communities that feature accessible transportation, sidewalks, housing, businesses and recreation.

in the know

“The city of Boston is an old city,” says Boston native Christos Koutrobis, whose father John Koutrobis has lived with multiple sclerosis for about 36 years—the last 18 of which he’s spent in a wheelchair. “Because of that, there are many different areas of the city that are considered historic. And for reasons I’ll never understand, that trumps people’s accessibility. For example, there’s Beacon Hill, where the Massachusetts State House is. All the sidewalks there are made of bricks that are sticking up. There’s no way that someone in a wheelchair could maneuver that part of the city by themselves.”

But there are bright spots, too. “My dad can’t drive anymore, so for the last two years of his work as a teacher with the Boston Public Schools, he took the RIDE, which is [an on-demand paratransit service] offered by the city’s train system, the ‘T,’” Koutrobis says. “They’ll pick you up and take you to whatever your destination is. It’s an unbelievable program.”

In that way, Boston is typical of many cities: There are both assets to love and deficits to lament. By becoming accessibility advocates, however, residents with disabilities and allies can help perpetuate what’s working in their communities and help fix what isn’t.

Accessibility: a civil right

According to the federal Americans with Disabilities Act (ADA), accessibility is a civil right.

Enacted in 1990, the ADA prohibits discrimination against individuals with disabilities and guarantees them equal opportunity in all areas of public life, including employment, education,

transportation, state and local government services, commerce and telecommunications.

“There are a lot of technical details in the ADA, but the overarching theme is that business and government have an obligation to make programs and services accessible,” explains Carol Fulkerson of Bend, Oregon, who was diagnosed with MS in 1993 and became an accessibility advocate when she witnessed the obstacles faced by members of her MS support group.

HOUSING

Many cities offer financial assistance to homeowners whose homes need adaptive modifications.

RECREATION

Many cities are putting a renewed focus on making it easy for people with disabilities to not only live, work and shop, but also to play. Look for accessible parks, playgrounds and recreation centers in your neighborhood.

SIDEWALKS

The ADA requires cities to install curb ramps when they build new roads or modify old ones.

“It was through helping my friends that it became very apparent to me: It is really hard to get around in one’s community using mobility equipment.”

Nobody knows that better than Scott Crawford, PhD, who returned to his native Jackson, Mississippi, after being diagnosed with primary progressive MS.

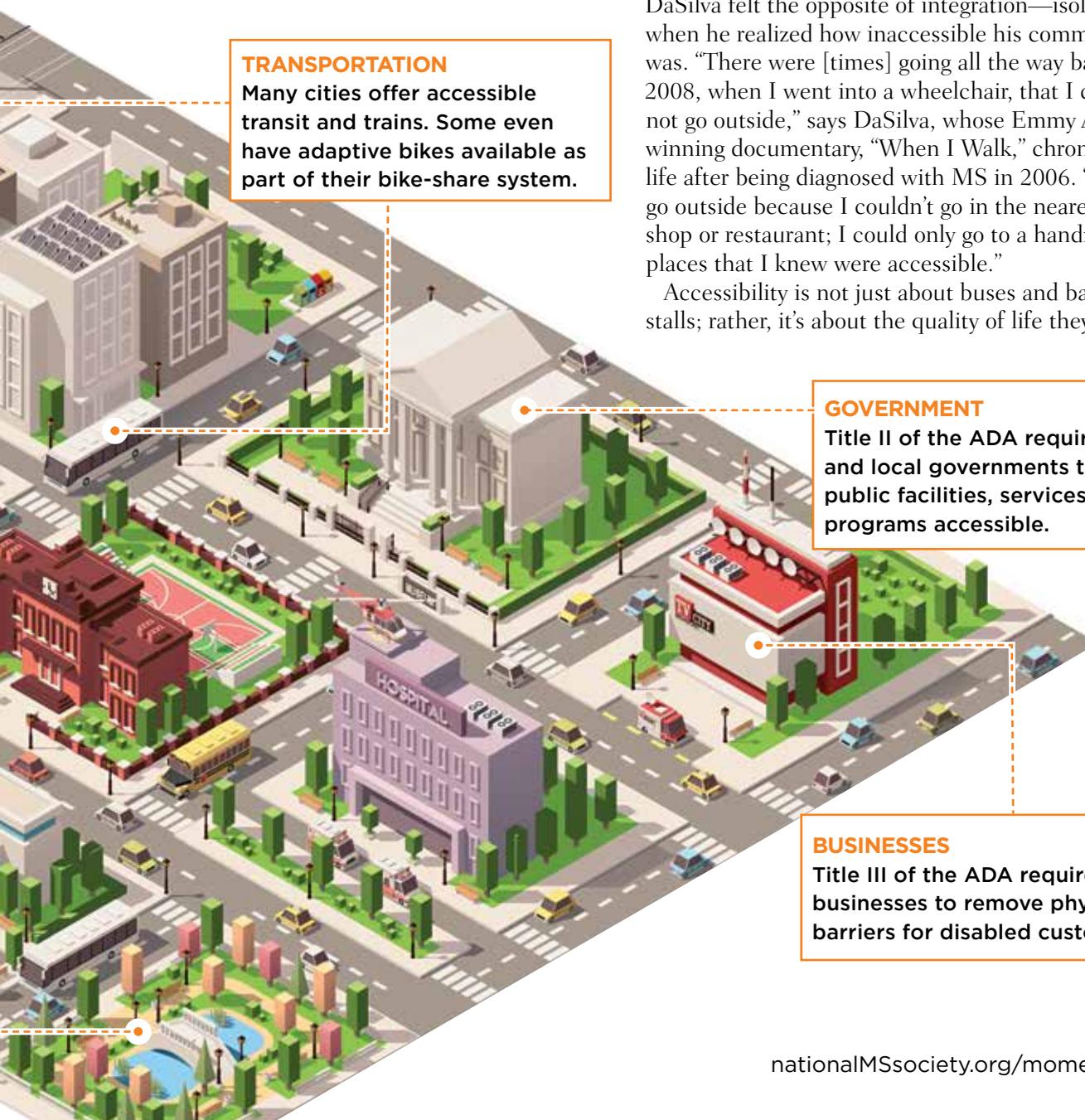
“When I returned to Jackson in late 2006, I tried getting around on my own utilizing the public transit system,” Crawford recalls. “Many of our buses were decades old with nonfunctioning wheelchair lifts, so I was frequently being left on the side of the road.

Moreover, I discovered that Jackson had few sidewalks, and almost none of those were accessible to people with disabilities.”

More than 15 years after passage of the ADA, Crawford discovered that the local government hadn’t yet taken any steps to comply with it. “That’s when accessibility ... became a prime focus of my life,” Crawford says. “Without it, people with disabilities will never achieve the community integration called for by the ADA.”

Like Crawford, New York-based filmmaker Jason DaSilva felt the opposite of integration—isolation—when he realized how inaccessible his community was. “There were [times] going all the way back to 2008, when I went into a wheelchair, that I could just not go outside,” says DaSilva, whose Emmy Award-winning documentary, “When I Walk,” chronicles his life after being diagnosed with MS in 2006. “I couldn’t go outside because I couldn’t go in the nearest coffee shop or restaurant; I could only go to a handful of places that I knew were accessible.”

Accessibility is not just about buses and bathroom stalls; rather, it’s about the quality of life they afford.



TRANSPORTATION

Many cities offer accessible transit and trains. Some even have adaptive bikes available as part of their bike-share system.

GOVERNMENT

Title II of the ADA requires state and local governments to make public facilities, services and programs accessible.

BUSINESSES

Title III of the ADA requires private businesses to remove physical barriers for disabled customers.

What makes cities accessible?

Although no city is completely accessible, best-in-class communities include Chicago; Philadelphia; Portland, Oregon; and Washington, D.C. These and other highly accessible cities share a few common traits:

Transportation

Crawford's experiences illustrate the importance of accessible public transit: Without it, many people end up stuck, literally and figuratively.

Like Boston—whose public transit authority recently announced plans to develop a next-generation subway car that's 100 percent accessible—many cities boast accessible transit. In Washington, D.C., for instance, 100 percent of the city's Metro trains and train stations are accessible. In Philadelphia, meanwhile, all buses have wheelchair ramps, and the city is working with ridesharing companies like Uber and Lyft to create accessible transportation alternatives.

"We now have more than 70 wheelchair-accessible [rideshare] vehicles in Philadelphia," says Charles Horton Jr., executive director and accessibility compliance specialist for the Philadelphia Mayor's Commission on People with Disabilities.

Chicago requires ridesharing companies to offer accessible vehicles, and has more than 300 wheelchair-accessible taxis, plus 24/7 paratransit service.

Farther west, Portland, Oregon, is a leader. "Our public transportation system is consistently rated one of the best in the country," says Joanne Johnson, Portland's Disability Program coordinator. "All of the buses, all of the streetcars and all of the light rail have ramps, as they should. That's not true in every city."

The city even has adaptive bikes available as part of its BIKETOWN bike share system.

Sidewalks

Accessible transit is only effective if people with disabilities can get to and from a transit stop. That requires "complete streets" that are designed to be safe for everyone, regardless of ability.

"That inherently means well-maintained ADA-compliant sidewalks, crosswalks, accessible pedestrian signals, etc.," Crawford says.

The ADA requires cities to install curb ramps when they build new roads or modify old ones. But some



We now have more than 70 wheelchair-accessible [rideshare] vehicles in Philadelphia."

**—CHARLES HORTON JR.,
PHILADELPHIA MAYOR'S
COMMISSION ON PEOPLE
WITH DISABILITIES**

cities are moving at an accelerated pace. Chicago, for instance, has installed nearly 95,000 ADA-compliant curb ramps since 2007. Philadelphia, meanwhile, has an ADA Curb Ramp Partnership Program through which the city assesses curb ramp needs. And in Portland, the city recently pledged to create 1,500 curb cuts per year—more than double its current rate.

Government

Title II of the ADA requires state and local governments to make public facilities, services and programs accessible. Under the law, all governments must appoint an ADA coordinator to oversee Title II compliance. The most accessible cities, however, go above and beyond the role of ADA coordinator. Portland, for example, also has the Portland Commission on Disability, which advises the mayor on issues of import to disability communities.

"The Portland Commission on Disability is not a substitute for the ADA coordinator; it's a complement," Johnson explains. "Whereas the ADA coordinator is

one person making sure the city is compliant, the commission is about giving disability communities a voice in the way the government shows up for them.”

Similar bodies exist in Philadelphia, Chicago and Washington, D.C.

“There is a difference between just being an ADA coordinator and being an office in the mayor’s cabinet,” says Karen Tamley, commissioner of the Chicago Mayor’s Office for People with Disabilities. “The fact that we have the Mayor’s Office for People with Disabilities to keep watch on the day-to-day issues that come across not just our desk, but the city as a whole, is unique and something other cities often aspire to.”

Housing

Affordable and accessible housing is critical, according to Crawford. “Without affordable rental units with roll-in showers and fully accessible kitchens, sinks and toilets, people won’t be able to live in the communities of their choice,” he says. “The Fair Housing Act’s Accessibility Guidelines are insufficient for many wheelchair users. Also, some developers use loopholes to evade even these meager standards. Rent-controlled apartments are necessary for individuals like myself, whose income never rises.”

To help disabled residents with housing concerns, cities like Chicago, Philadelphia and Washington, D.C., offer financial assistance to homeowners whose homes need adaptive modifications.

“We provide home accessibility modification up to around \$10,000,” Tamley says of Chicago’s program, which also is available to apartment renters and condo owners. “It’s a really critical program, given that the stock of accessible housing in the Chicago area is very, very limited.”

In Philadelphia, the fire department recently purchased 4,000 adaptive smoke alarms for citizens who are deaf, hard of hearing, blind or have low vision. And in Portland, the city is considering a policy that would allow construction of new, compact residences—called infill housing—in between existing homes; if approved, the policy would likely require a portion of infill homes to be accessible, thereby increasing housing options for people with disabilities.

Businesses

Title III of the ADA requires private businesses to remove physical barriers for disabled customers when doing so is “readily achievable.”

“That leaves wide latitude to leave barriers in restaurants, stores and other privately-owned buildings,” Crawford says.

With that in mind, the most accessible cities educate and engage local businesses in ways that inspire and incentivize voluntary ADA compliance. In Philadelphia, for example, the Mayor’s Commission on People with Disabilities hosts an annual “Access Achievement Awards” ceremony during which it recognizes private businesses, public agencies, nonprofit organizations and individuals that have made outstanding efforts to improve and increase access for people with disabilities.

“We’ve given out well over 100 awards to businesses that have supported the disabilities community,” Horton says. “Those awards go to some of the largest companies in Philadelphia and to some of the smallest corner stores, restaurants and gas stations to thank them for their hard work and support.”

Recreation

People with disabilities need places to not only live, work and shop, but also to play. Cities like Washington, D.C., are therefore committed to accessible recreation.

“Going forward, we’re going to focus a lot on parks,” says Mathew McCollough, director of the Washington D.C. Office of Disability Rights. “In my mind, trying to access parks and recreation centers is the last frontier of accessibility; we need to make sure that grandparents and parents with disabilities are able to have fun with their children and grandchildren, and that children with disabilities are able to play with other kids. So over the next few years we’re going to assess each and every park, playground and recreation center in the District to address barriers to accessibility.”



Activating accessibility

If you live in an inaccessible community, there are many things you can do to affect positive change:

■ **Contact your ADA coordinator:** Step one is finding and contacting your city's ADA coordinator, according to Fulkerson, who says citizens should turn to that person first when they notice problems with sidewalks, curb ramps or traffic signals.

"Contact somebody in the local government and ask, 'Who is your ADA staff person?'" Fulkerson advises. "If they don't have somebody, your next question is, 'Why don't you have someone, and when are you going to hire them?'"

If the ADA coordinator is nonresponsive, escalate. "Contact the mayor or commissioner or city council member," says Fulkerson, who has successfully escalated issues all the way up to state legislators.

■ **Speak at public meetings:** When she began using a wheelchair seven years ago, Terri O'Hare wanted to participate in the same outdoor activities enjoyed by the rest of her neighbors in Albuquerque, New Mexico. Unfortunately, there were no accessible trails along the Rio Grande River, local hikers' and cyclists' most popular destination. So, she joined a citywide effort to create one. The advocacy effort was already underway, but her simple contribution—sharing her story in front of policymakers—helped it cross the finish line.

"This trail was on the verge of not getting built, so I went to the city council and spoke, which scared me a lot," says O'Hare, who was diagnosed with MS two years ago. "I said, 'I've lived here for eight years and I've never seen the river up close; I've only seen it in my car driving over it.'"

Ultimately, the city council decided in favor of the four-mile long ADA-accessible trail, which was completed in 2017.

■ **Organize:** If your community doesn't offer forums where you can speak, consider creating your own.

"It is incumbent upon us to make ourselves available, to get involved, reach out and offer our perspective," says Crawford, whose mantra is "nothing about us without us." "Often that means joining or forming an 'ADA Advisory Council' in your jurisdiction and inviting community leaders to visit."

Even informal efforts—letters to lawmakers, for instance—are more effective when they have multiple signatories. "More voices in the choir makes the song a little louder," Fulkerson says.

■ **Show, don't tell:** Showing your story can be even more effective than telling it, according to Crawford, who helps organize awareness-raising public transit "ride-alongs" on behalf of Working Together Jackson, a coalition of nonprofits and faith-based organizations working to rebuild metro Jackson. Even Jackson Mayor Chokwe Antar Lumumba has participated.

"He was there to see me left on the side of the road by an inaccessible bus," Crawford says. "He looked at me and said, 'I get it.'"

Fulkerson has likewise succeeded by organizing "Disability for a Day" events, wherein architects, engineers, construction managers and policymakers experience navigating their communities in wheelchairs. "It made a huge difference in our interactions with the commercial construction industry in central Oregon because we got the general managers and CEOs from five major construction companies to participate," she says. "The experience amazed them."

"Showing" also helped Judy Pollock Hallam of Meriden, New Hampshire, who was diagnosed with MS in 1995 and uses a power wheelchair. Frustrated at the frequency with which it happened, she began taking photographs of accessible parking spots where people had blocked the access aisle (the white or yellow striped area between accessible parking spaces) next to her vehicle.

"I decided to make up five small booklets with a cover letter explaining my dilemma and the photographs showing the problem," says Hallam, who sent the booklets to lawmakers and advocates, one of whom—the advocacy manager of the National Multiple Sclerosis Society's Greater New England area—arranged for her to testify before state legislators in hopes of passing a law. "As a number of people with disabilities testified, the legislators nodded their heads in agreement. I spoke last and handed out my booklet. Their faces lit up and they said in unison, 'Oh, that's what you're talking about!'"



A law was passed in 2004 making it punishable by a fine for anyone to park in the access aisle.” The law included a provision allowing photographs of the aisles to be sent to police with an affidavit as evidence. A campaign called “A Picture Is Worth A Thousand Words” was launched to raise awareness about the importance of the space.

■ **Engage businesses:** In private businesses, there is no ADA coordinator. There are, however, managers and owners, many of whom are receptive to accessibility concerns when they’re made aware of them. Often, all you have to do is ask. “I was finding myself not shopping in certain stores because of heavy doors and feeling angry. My father taught me that if you don’t speak up no one will know that there is a problem; I was being unfair to them by not giving them a chance to correct the situation,” says Hallam, who politely asked the managers of several stores and a bank if they would consider automatic door openers. “I told them something that became my mantra: If you can’t get in, you can’t spend money. Initially I was met with some resistance, but I continued to be polite, pointing out that door openers make [businesses] accessible for everyone. Advocacy became a little easier after my initial successes. It literally ‘opened doors’ for me.”

Tools like AXS Map—a mapping application that harnesses crowdsourcing to rate and review businesses across the country based on their accessibility—can help you further plead your case. “It’s helped our users, but the real target is business owners,” explains DaSilva, who created AXS Map. “We want to help them see that making places more accessible is going to increase not just quality of life for people with disabilities, but also business.”

Finally, tax incentives also can be persuasive. “There is a tax credit and a tax deduction available from the IRS for specific ADA improvements,” Fulkerson points out. “If you’re asking a business to spend money on improvements, it’s always good to say, ‘And did you know you may be eligible for a tax benefit, too?’”

At first blush, it may feel embarrassing or selfish to ask for accommodations. But consider this: Making a single sidewalk, bus or park accessible won’t just help you; it will help thousands of your neighbors, too.

“The bottom line is this: If you find a barrier you want to have fixed, go for it,” Fulkerson says. “It’s not self-serving. It helps everyone.” ■

Matt Alderton is a Chicago-based writer and editor.



Learn more about becoming an MS activist at ntlms.org/activist.



Find information about the Society’s Government Relations Advisory Committees at ntlms.org/GRAC.

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

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

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

AUBAGIO is available in 14 mg and 7 mg tablets.

INDICATION

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

IMPORTANT SAFETY INFORMATION

DO NOT TAKE AUBAGIO IF YOU:

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

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

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

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

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

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

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

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

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

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Medication Guide

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

Rx Only

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

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

AUBAGIO may cause serious side effects, including:

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

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

What is AUBAGIO?

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

Who should not take AUBAGIO?

Do not take AUBAGIO if you:

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

What should I tell my doctor before taking AUBAGIO?

Before you take AUBAGIO, tell your doctor if you:

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

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

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

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

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

How should I take AUBAGIO?

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

What are possible side effects of AUBAGIO?

AUBAGIO may cause serious side effects, including:

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

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

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

The most common side effects of AUBAGIO include:

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

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

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

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

How should I store AUBAGIO?

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

General information about the safe and effective use of AUBAGIO.

Medicines are sometimes prescribed for purposes other than those

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

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

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

What are the ingredients in AUBAGIO?

Active ingredient: teriflunomide

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

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

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

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November 2016

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

Please see Medication Guide for AUBAGIO and full Prescribing Information, including boxed WARNING, available on www.aubagio.com
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Depression facts vs. fiction

Depression is one of the most common symptoms of MS, affecting about 50 percent of the MS population. However, as with many mental illnesses, there is still confusion and stigma surrounding depression, which can prevent someone from seeking the help they need. Here, we debunk three myths regarding depression. You can read more about this mental health issue in the following Thrive story.

Myth #1: You can overcome depression if you're strong enough.

Like any physical condition, depression is an illness that can't be solved through pure will. It's important to talk to a healthcare professional about treatment and to seek help and support when you need it.

Myth #2: All depressed people have the same symptoms.

Depression varies by individual and can include a combination of symptoms, including sadness, loss of enjoyment of life, changes in sleep and appetite, low self-esteem, fatigue, poor concentration, suicidal thoughts, hopelessness and irritability.

Myth #3: Depression must be caused by one thing.

Depression in all people, and especially in those with MS, arises from many factors interacting together, including genetics, brain biology, and past and present life circumstances. Depression can also occur at any time. A diagnosis of MS does not guarantee you will eventually become depressed.



thrive

Forging a path
to your best life

Inside this section: The hidden symptom 24 // Coming to America 30

The hidden



symptom

Depression strikes 1 in 2 people with MS, and it can be difficult to recognize. But there are ways to cope.

by Aviva Patz

 Within six months of being diagnosed with multiple sclerosis in 2016, Dave Rosen lost his job, financial security, his health insurance, his company car—and, most devastating, an outlet for his passion, which was managing a chain of motorcycle stores and building custom bikes for celebrities. When his symptoms—including memory loss, difficulty speaking, balance and vision issues, headaches and overall body pain—became too limiting, Rosen’s wife, Staci, had to go back to work full time. “At that point, I understood what true depression really is,” says Rosen, who relocated from Connecticut to Florida for personal and financial reasons. “Because of MS, I felt like I was no longer the same person. Life is already difficult enough, but adding these continuing limitations wasn’t what I was prepared for.”

Rosen’s story is all too common in MS. While depression strikes 20 percent of the general population, it affects about 50 percent of people living with MS, according to Rosalind Kalb, PhD, a clinical psychologist and consultant for the National Multiple Sclerosis Society. “And if you consider the people who feel down and depressed but don’t meet the criteria for clinical depression, that number is a lot higher,” she says.

There are numerous causes of depression beyond the life challenges that are inevitable with MS. In fact, brain changes brought on by the disease play a huge role. “The key message is that depression is one of the most common symptoms of MS, and it’s very treatable,” Kalb says. Here’s what you need to know.



PHOTO COURTESY OF DAVE ROSEN

Dave Rosen (right) finds that spending time with family helps with his depression.



PHOTO COURTESY OF JANE WELZANT

Jane Welzant is open about her symptoms, such as loss of interest and anxiety.



Depression is one of the most common symptoms of MS, and it's very treatable."

—ROSALIND KALB, PhD

What depression looks like

The cardinal criteria for depression is feeling sad, tearful, hopeless and irritable most of the day every day for at least two weeks, or experiencing loss of interest in favorite activities, Kalb explains. And certainly, some people with MS fit that classic picture.

Jane Welzant, who was diagnosed with MS in 1995 at age 38, says she has “difficulty starting the day, loss of interest, loss of appetite, anxiety and fear of going anywhere.”

But according to Kalb, irritability may be more pronounced in people with MS. “People may seem very touchy or quick on the trigger,” she says. Feeling hyper-reactive is a main symptom for Sabrina A. Davis, of Houston, Texas, who has lived with MS for 22 years. “Without my antidepressant medication, I’m angry and emotional all the time,” she says.

How depression is diagnosed

It’s tricky to spot depression in MS because the symptoms of depression may overlap with symptoms of the disease itself. “If you look at the diagnostic criteria for depression, they start with fatigue—and that’s the most common symptom of MS,” says Boston-based psychiatrist and MS expert Sarah Minden, MD. “People think, ‘my thinking is slowed down, and I have trouble concentrating, but it’s from my MS.’ Same with trouble sleeping or sleeping too much—people often discount or deny the possibility of depression. It’s easy to say, ‘It’s the MS.’”

One way mental health professionals tell the difference is by considering timing and severity. Take fatigue, for example. “While everyone is different, for many people [MS-related] fatigue is worse in the afternoon when your battery wears down,” Dr. Minden says. “But the fatigue that comes with depression tends to be worse upon waking, so it is hard to get out of bed.”

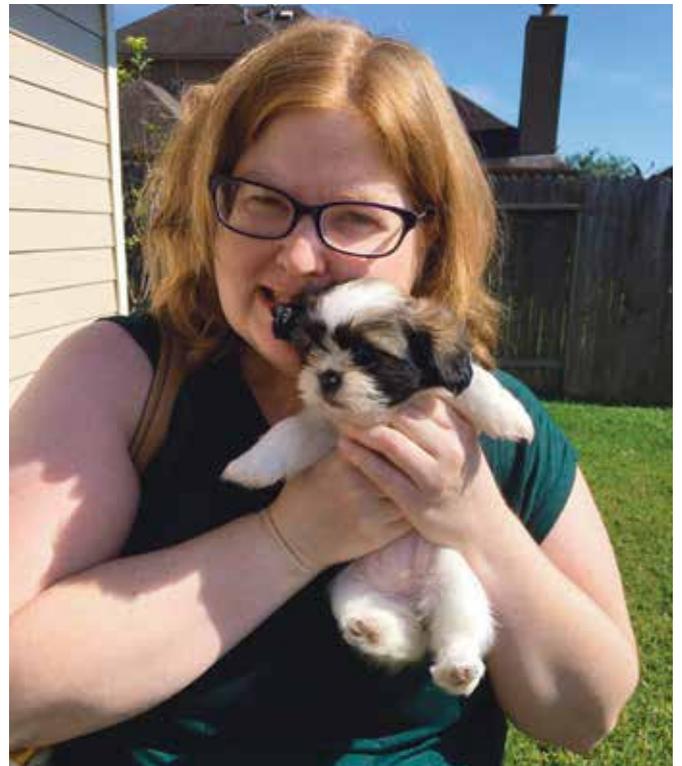


PHOTO COURTESY OF SABRINA A. DAVIS

Feeling hyper-reactive is a main symptom for Sabrina A. Davis, of Houston, Texas, who has lived with MS for 22 years.

She adds that fatigue with MS will often improve if you rest, take a nap, or “recharge your batteries,” but that the weariness of depression is more persistent.

Causes of depression

Depression in MS can be a reaction to challenges, as Rosen’s experience shows. “The adversity and disability itself can make people feel depressed,” says Anthony Feinstein, MBB, PhD, a professor of psychiatry at the University of Toronto and Sunnybrook Health Sciences Centre who studies causes of depression in MS. “There’s also the uncertainty—you can’t predict what your symptoms will be tomorrow, let alone in 20 years. The unknown can itself be a cause of depression,” Dr. Feinstein adds.

Imaging (such as MRI) studies show that depression can also come from biological brain changes that occur

in MS. According to Dr. Feinstein, lesions in frontal and temporal parts of the brain are associated with clinically significant depression, as is brain atrophy (shrinkage) in these regions. “There’s good data to show that if there are these specific brain changes, the chances of developing depression increase significantly,” he says.

A second biological trigger for depression may be inflammation, which comes with MS. Similarly high rates of depression occur with other neuroinflammatory diseases, such as rheumatoid arthritis and inflammatory bowel disease. “There’s something about the inflammatory nature of the illness that may contribute to higher risk of depression,” Kalb says. There’s not much research on inflammation and depression in MS specifically, but according to Dr. Feinstein, it likely plays a role in depression.

A third possible cause of depression in MS is related to the stress hormone cortisol. A research team funded by the Society found, in a 2010 study reported in *Biological Psychiatry*, that depression is linked to loss of brain volume—specifically in the hippocampus, an area of the brain important for memory, and that this pattern of shrinkage is related to abnormal levels of cortisol. “Levels of cortisol obey a circadian rhythm—they’re higher in the morning when you wake up and dip as the day progresses,” Dr. Feinstein explains. “One of the theories behind major depression is that the

cortisol levels can remain persistently high or that the fall-off over the course of 24 hours somehow is less.”

According to the Society, depression can be a side effect of some medications, including corticosteroids such as methylprednisolone, prescribed to treat relapses, and interferon medications, disease-modifying therapies used to slow disease progression. Several DMTs, such as Avonex, Betaseron, Extavia and Pelgridy, come with a warning that people with a history of depression should be closely monitored while taking the medication.

When screening is most important

There are three situations most likely to trigger depression in MS: around the time of diagnosis—when people may be grieving and fear the worst about the future; after an exacerbation, when there’s renewed pain, discomfort and disability; and during a crisis point, when grief and losses are magnified. It’s also true that people with a personal or family history of major depression are more at risk, especially at these moments of heightened vulnerability. For those reasons, friends and family should watch for signs of depression.

Stigma against mental illness

Few people want to admit to having depression, and people with MS are no exception. Three main factors get in the way of a diagnosis. The first is the persistent stigma against mental illness, as if it’s a personal weakness or moral failure. When friends advised Ann Borsellino, diagnosed with MS at age 38, to seek help for depression, she responded, “Who me? A psychiatrist? I am NOT crazy.”

The second is the mistaken belief, Kalb says, that, “I have MS—why wouldn’t I be depressed?” But depression should never be accepted as “normal.” Many people with MS are not depressed, she adds, and dealing with MS is challenging enough without the added pain of depression. Third, she says, people say “my body is betraying me, so I don’t want to think there’s also something going on with my mind. I’ve got enough problems with the physical stuff.” But depression is a known symptom of MS, and it must be addressed. “This isn’t about pulling yourself up by your



Grant Gordon, shown with his sister Devin Tomiak, lived with depression and MS.

PHOTO COURTESY OF DEVIN TOMIAK

bootstraps or being a tough cookie,” Kalb says. “It’s about getting treatment for a condition that won’t get better on its own.” Welzant is open about her struggles with depression because she feels it’s just like any other illness that needs to be treated. “There is help out there,” she says. “Professionals are not judging you. Actually who cares if they are? You can feel better, so why hide?”

Risk of suicidal thoughts

Grant Gordon, 28, was a sociable guy with a “gazillion friends” and a “supportive, connected family,” according to his sister, Devin Tomiak. He was a successful chef (a James Beard nominee), who had decided to open his own restaurant and had already secured investors. On the morning he took his life, four months after his diagnosis with MS, he’d opened a bank account for the business and had been on the phone with architects.

“I don’t know why Grant committed suicide,” Tomiak says. When he got his diagnosis, he told his family, but he didn’t tell any of his friends. “That’s a lot to hold inside.”

With greater depression comes greater risk of suicide. “The rates of completed suicide appear to be double what they are in the general population,” Dr. Feinstein confirms. Most at risk, he adds, are young males within the first five years of diagnosis—which highlights the fact that the primary risk factor for suicide may not be disability, as might be expected. Gordon, for example, just had a little numbness in his feet. “The major risk for suicide,” Kalb says, “is untreated depression.”

Signs of depression in MS

Depression varies by individual, but generally, it includes some combination of sadness, loss of enjoyment of life, changes in sleep and appetite, low self-esteem, fatigue, poor concentration, suicidal thoughts and feelings of hopelessness, according to Dr. Feinstein, plus a tendency to be irritable. Depression can also exacerbate MS symptoms, so you might also notice “every single MS issue feels worse—pain, sleep, or problems with thinking, concentration and memory,” Kalb says.

If you’re experiencing depression

Ask your healthcare provider for a referral to a mental health professional for a full evaluation or call an MS Navigator (1-800-344-4867) for help identifying mental health resources in your community. You can also do a free, private self-screening on the website of Mental Health America (mentalhealthamerica.net), a partner of the Society. Kalb recommends printing out your results and bringing them to your healthcare provider, saying “this is how I tested, what do you think we should do?”

Strategies for coping

Don’t keep it to yourself, Kalb urges. “This is not something you should try to manage on your own because it doesn’t work that way.” Treatment may involve adjusting your DMTs, if necessary, and some combination of cognitive behavioral therapy (a type of talk therapy that examines and reprograms negative thought patterns) and antidepressant medication, because they may also help with MS symptoms such as sleep issues, pain and bladder control. If your depression stems mainly from the challenges of living with MS, consider joining a local MS support group—you can search by ZIP code on nationalMSsociety.org.

By talking about her brother, Tomiak hopes she might be able to help people living with MS who experience depression. Tomiak says that people with MS expect to have side effects and that “depression could be one of them. And that’s OK. It can just be part of the disease. There’s nothing shameful about it. The important thing is to get it treated. Don’t be afraid to take measures to ensure your safety.”

Although Ann Borsellino’s friends had to bribe her with beer to get her to see a psychologist, it eventually turned her life around. “If only someone had told me early on that depression was a symptom of MS, just like all the other ‘strange’ things that were happening, I would have sought treatment for it like I did for the numbness and tingling 19 years ago,” Borsellino wrote in a blog on MSconnection.org. “The ‘happy pill’ has helped me cope, not feel sad, and be part of what’s going on at work, with my family and special events.”



As for Dave Rosen, he's appreciating that time at home taking care of his kids. He also practices yoga, meditates and prays. He consciously focuses not on limitations but on possibilities. "My drive to help with depression is to find what moves me and follow that," he says. "I find whatever thing helps get me through that minute and that day—a work project, an accomplishment for the day and, most important, staying engaged and connected with supportive people who help me stay positive and inspired." ■



If you're experiencing depression: Ask your healthcare provider for a referral to a mental health professional for a full evaluation or call an MS Navigator (1-800-344-4867) for help identifying mental health resources in your community.

Aviva Patz is a writer in Montclair, New Jersey.



For more information about depression, visit: ntlms.org/depression.

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

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#ProgressiveMSDay | March 28th



"To have a day dedicated to Progressive MS reassures me we aren't forgotten, but that we are an important part of the MS community. It empowers those of us living with this disease and means so much."

Jennifer Digmann wants people to know – just because she has a progressive form of multiple sclerosis doesn't mean she cannot speak for herself, and it doesn't mean she can't have fun.

Jennifer was first diagnosed with MS a few days after her 23rd birthday. Like others who are affected, Jennifer's symptoms have continued to worsen over time. Today she lives with a progressive form of the disease and uses a wheelchair to get around. But that doesn't keep Jennifer and her husband, Dan, from doing the things they love, like going out with friends and grilling outside on their patio.

"I want to live my life in spite of this disease," said Jennifer. "MS is just a small part of me. There's so much more to all of us that are living with the disease. We are still out there, and we're still active and vital members of the community."

On March 28, 2019, Jennifer, Dan and many others in the MS community will come together to observe the second annual Progressive MS Day. This day of awareness recognizes people living with progressive forms of MS, sharing stories, showing support and, most importantly, calling for further research to advance care and reduce disability.

Jennifer and Dan, who lives with relapsing MS himself, count themselves among the most enthusiastic supporters of Progressive MS Day. As a couple, the Digmans have dedicated their lives to inspiring and helping others living with MS by sharing their own experiences and perspectives through their blog and radio show.

Get Involved

- Share stories of challenges, perseverance and hope by uploading photos, videos, artwork and more on social media using the official hashtag, #ProgressiveMSDay.
- Use #ProgressiveMSDay to share resources and services for people living with Progressive MS or just follow along with the conversation.
- Update your Facebook profile image with a Progressive MS Day Facebook frame by selecting "Update Profile Picture," selecting "Add Frame" and searching for "Progressive MS Day."

Progressive MS Day is a collaboration between Genentech and the MS patient advocacy community.

Coming to America



People with MS who immigrate to the United States encounter new experiences surrounding their disease.

by Vicky Uhland

Sara Qureshi had finished medical school in Pakistan in 2007 when her sister, Kiran Ali, woke up from a nap one day with double vision. Ali visited an ophthalmologist, who referred her to a neurologist. When the neurologist performed an MRI and concluded that Ali likely had multiple sclerosis, the sisters were dumbfounded. MS is so rare in Pakistan that neither of them knew anyone with the disease. “I was attending the biggest medical school in Pakistan and even I hadn’t seen any cases of MS,” Dr. Qureshi says.

The sisters began questioning the neurologist—who also didn’t know much about MS—about Ali’s prognosis. “The first thing my sister asked was: ‘Can I continue hiking?’ and the neurologist said no,” Dr. Qureshi remembers. “Given the lack of experience with MS in the country, we were not able to get the right kind of counseling that should come with a diagnosis of MS. Access to medications was a major issue too.”

It wasn’t until the sisters traveled to the United Kingdom to consult MS specialists that they learned more about the disease. “And it wasn’t until much later, when I was training in the United States as an MS specialist, that I learned the importance of emphasizing that having MS doesn’t prevent you from following your dreams in life,” Dr. Qureshi says.

MS worldwide

In 2013, the MS International Federation (MSIF) estimated that 2.3 million people worldwide live with MS. The data from MSIF's Atlas of MS showed that most of them lived in North America or Europe and that the highest incidences of MS are in these two world regions. The Atlas showed that East Asia and Sub-Saharan Africa had the lowest incidence and prevalence of MS. However, this data is changing, says Nick Rijke, MSIF Interim Deputy CEO. Newer epidemiological studies are showing much higher rates of MS than has previously been the case. This is due to a range of reasons, including better patient record keeping, improved diagnosis and people with and without MS living longer. However, whether or not there is an underlying increase in MS remains less clear. Interestingly, Rijke says, evidence from a number of studies shows that when people migrate from low to high prevalence areas, over time the risk that they and their offspring will develop MS becomes much closer to the risk level of their adopted home country. MSIF will publish the third edition of the Atlas of MS in 2020. It will be very interesting to see how rates of MS in North America and Europe compare to other parts of the world, Rijke says. With funding from the National Multiple Sclerosis Society, a study published in February 2019 in the journal *Neurology* reported that nearly 1 million people are living with MS in the United States.

Society MS Navigator Ileana Martinez—one of two Spanish-speaking MS Navigators—says that in the last two years, she's seen an uptick in calls from refugees who have emigrated from Venezuela, Honduras, El Salvador and Haiti. "There are also people who are coming in on tourist visas and in other ways, seeking medication and treatment," Martinez says. "One caller shared that people are willing to sell everything to seek treatment in the U.S."

María De Los Angeles Chiquito immigrated to the U.S. in search of better support for her disease. Chiquito, who was diagnosed with MS in 2004 in her native Venezuela, came to the U.S. as a political refugee in 2017. "The [MS] treatment is better in the United States. There are more resources, more possibilities," says Chiquito in an email translated from

Spanish. "It was the determining factor for my decision to move from my country."

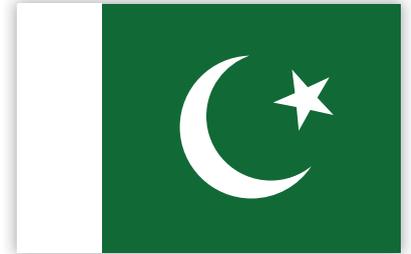
But while the U.S. may seem like the promised land to people from countries with limited MS treatment options, new immigrants can face some unique challenges. The confusion and despair of an MS diagnosis cuts across many boundaries, but for immigrants, those feelings can be multiplied. Language and cultural barriers, lack of adequate healthcare or health insurance, financial and transportation issues and isolation can amplify the physical, mental and emotional aspects of MS diagnosis, treatment and support.

Here's how four immigrants from countries around the world have dealt with those issues.

Sara Qureshi, MD, Pakistan

After her sister's diagnosis, Dr. Qureshi decided to devote the rest of her medical career to neurology and the study of MS. She went to New York for neurology training, followed by a two-year MS Society fellowship in neuroimmunology at the University of Texas Southwestern in Dallas. She then moved to Billings, Montana, and in 2017, achieved her dream of opening an MS Center for Comprehensive Care at the Billings Clinic.

Her experiences in Pakistan convinced her of the need for



Sara Qureshi, MD, (left) helped her sister Kiran Ali (right) find treatment for MS in the United Kingdom. MS is rare in Pakistan, their home country.

PHOTO COURTESY OF SARA QURESHI



MS centers that cover all facets of patient care. For instance, she says there are only two MS medications available in Pakistan—Betaseron and Aubagio. If people want a different option, they have to find a source and pay for the medication out-of-pocket, as most people in Pakistan don't have insurance. This can make treatment unattainable for many Pakistanis with MS.

Kiran Ali's experiences after her diagnosis also showed Dr. Qureshi how important counseling and other emotional support is for people with MS.

"The diagnosis of MS in the wrong hands, without counseling, is traumatizing," she says. "I make sure to tell my patients that MS is a spectrum, mild to severe. And I tell them that in the last 10 years, MS has changed tremendously because of disease-modifying

therapies. Life is not over. It's possible to control the disease."

Dr. Qureshi says another difference between MS care in the U.S. versus Pakistan is that disability is more of a stigma in Southeast Asia. Her sister Ali, who stabilized in 2011 after developing weakness in her left leg, balance issues, fatigue, heat sensitivity and some pain, felt discriminated against in her job because of her disabilities.

In the U.S., Dr. Qureshi says she rarely sees Asian immigrants with MS, even when she worked in areas of the country with large immigrant populations. But she believes Asian-Americans who do have the disease might not have many issues with accessing care and support. "Many Asians in the U.S. are highly educated and

skilled—those are the people who get the visas,” Dr. Qureshi says.

Khadra Abdi, Somalia

Like many rural Somalis, Khadra Abdi isn't sure when she was born. She was never issued a birth certificate, so she didn't know what to put on government forms after she immigrated to the U.S. Her father told her she was born in the winter of 1958, but he didn't know the exact date, so she decided her birthday would be Jan. 1, 1958.

In 1991, Abdi and one of her daughters fled war-torn Somalia and spent the next decade with family in Yemen. In 2002, Abdi was able to join her son and another daughter in Fairfax, Virginia. But Abdi's joy at the reunion was short-lived. In 2004, she began having frequent headaches, tingling in her left hand and leg, double vision and sleeplessness. After an MRI, CT scan and spinal tap, she was diagnosed with MS.

Abdi, who speaks English with a heavy accent, says she hasn't had an issue communicating with her doctors or understanding her disease. Paying for treatment also hasn't been much of a problem. Abdi became a citizen in 2007, and now has Medicaid,

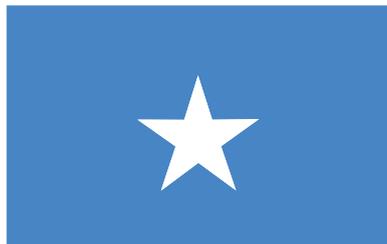


PHOTO COURTESY OF KHADRA ABDI

Khadra Abdi was diagnosed after immigrating to Yemen, then to the U.S. from Somalia.

Had she been diagnosed with MS in Somalia, “I would have had no treatment.”

—KHADRA ABDI

Social Security Disability Income, food stamps and subsidized housing. She also received a pharmaceutical company grant for assistance with her MS medication for one year when she didn't have insurance.

But paying for other necessities is a problem. Abdi says she was assigned a case worker who helped her find jobs, but as her MS progressed, she became unable to work. Consequently, she can't afford a car, which is an issue when she has to walk more than a half-mile to get to the bus line, especially while carrying heavy items such as groceries.

Abdi lives with her son, but he works nights at a local hotel. She feels isolated, relying on a few friends or taxis to get around—including to meetings for an MS support group in a nearby city. But at \$20 in taxi fare per round trip, she wonders how long she can afford to attend the support group. Her lack of transportation also keeps her from going to physical therapy, and she worries her left-leg heaviness will progress.

Until recently, Abdi didn't know any other Somalis with MS. But a young Somali man moved into her apartment building and has MS-like symptoms. “He's from the same tribe as me, and I told him he has MS and should go to the doctor,” she says. But because MS is virtually unknown in Somalia and disability carries a stigma there, she thinks he doesn't believe her.

Still, Abdi feels fortunate. Had she been diagnosed with MS in Somalia, “I would have had no treatment,” she says.

Ana Guerrero, Mexico

Ana Guerrero was working as a veterinarian in Mexico City when she decided she needed a change. So in 2016, at age 29, she got a visa to work in rural Holyoke, Colorado, as a caretaker on a pig farm. “I thought it would be an adventure,” she says.

But it turned out to be more adventurous than she had imagined.

In 2017, Guerrero began experiencing tingling in her arms, hands and legs. She visited a doctor, who found a spinal lesion but told her it wasn't a big deal. But Guerrero's brother, who lives in Mexico City, was diagnosed with MS when he was 18, so she knew the symptoms. She made the four-hour drive to Denver for an MRI, which showed she had MS.

Navigating the foreign world of healthcare

Finding and paying for healthcare can be difficult enough for U.S. citizens. But imagine if you're an immigrant trying to navigate America's complex health insurance system.

"The main questions we answer are how to get health insurance and how to obtain medications and medical services without health insurance," says Spanish-speaking MS Navigator Jocelyn Cuevas Tellez.

According to [Healthcare.gov](https://www.healthcare.gov), "lawfully present immigrants" can buy private insurance through the Affordable Care Act marketplace and qualify for rebates just as a U.S. citizen can. This applies to green card holders, refugees and asylees (including people from Cuba and Haiti), victims of trafficking or other humanitarian issues, and a few other categories.

But in many cases, these immigrants have to wait five years to qualify for Medicaid. The Refugee Center says people who enter the U.S. as refugees may be eligible for Medicaid and CHIP (Child Health Insurance Program) sooner, but it varies from state to state. Also, 29 states plus the District of Columbia provide health coverage to pregnant women and child immigrants without any waiting period.

All of this applies only to documented immigrants, however. Consequently, undocumented immigrants tend to avoid visiting doctors, going to a hospital emergency room only if they have severe MS symptoms. "But when they're released with a diagnosis, they're not able to see a specialist to start treatment because they have no health insurance," says MS Navigator Ileana Martinez.

In areas like Texas and California that have large populations of undocumented immigrants, Martinez says community clinics can help connect these immigrants with neurologists and other MS specialists. Similar clinics are available in other states, but people may have to travel some distance to reach them. Tellez says California also has Medicare emergency programs for undocumented people looking for neurologists.

Some pharmaceutical companies offer patient-assistance programs that provide free or discounted medications to people in need; however, this may only apply to documented immigrants due to different eligibility criteria, Martinez says.

Tellez says another problem for both documented and undocumented immigrants is a lack of vital information and support about their disease. "Sometimes I feel like clients don't have a full understanding about what the neurologist is telling them or is expecting from them," she says. "Things get lost in translation, especially when someone is shy to communicate or look for resources because they don't speak English or aren't fluent."

Tellez says in-person support groups for first-generation immigrants living with MS are rare, unless someone lives in a big city that's a hub for immigrants from their native country. And unfamiliarity with technology, or lack of access to the internet, can make online resources difficult to access.

National Multiple Sclerosis Society MS Navigators can help immigrants (both documented and undocumented) and others with the financial intricacies of MS treatment, and provide information and resources about the disease. To speak with an MS Navigator, call 1-800-344-4867.

“I went home, called my mom in Mexico and cried,” Guerrero says. “I feel so lonely in this small town in Colorado where I don’t have any friends.” Guerrero does have a boyfriend, but he lives 30 minutes away. “Sometimes I come home from work and feel so anxious that I cry like a little baby,” she says. “I tried an MS support group on Facebook, but there was lots of depression and it made me feel bad.”

Guerrero is grateful she can talk to her brother about their disease and their treatments. She’s learned there are pluses and minuses to living with MS in the U.S. versus Mexico. “Here, the diagnosis is so fast,” she says. “In Mexico, you first have to go to family doctor, then a specialty doctor. And then the doctor does tests and sends them to the USA [for a neurologist’s opinion].”

But the intricacies of health insurance and medical payments are much more difficult in the U.S., Guerrero says. She has health insurance from her job, but was shocked that it doesn’t cover all of her treatment. “I had to pay \$4,000 for my diagnosis,” she says. “It’s very scary when you receive the mail and it says: ‘You need to pay, you need to pay.’”

Guerrero says her biggest problem has been MS medications. Her doctor prescribed Ocrevus, but her insurance balked at payment. Between December 2017 and October 2018, she only had one dose of the drug, which is supposed to be given every six months as an infusion. “I don’t understand the steps I need to take or



Ana Guerrero has experienced the pros and cons of living with MS in Mexico vs. the U.S.

PHOTO COURTESY OF ANA GUERRERO

where I can go to get help,” she says.

Her brother has fewer financial issues, but also fewer medication options, she says. “And sometimes they run out of the medications.” Because of this, Guerrero worries that she may not be able to leave the U.S. “I would have to start over [with treatment] if I move back to Mexico,” she says.

On the plus side, there’s much less stigma associated with MS in the U.S. compared to her home country. “Here, people are more kind about having a disease,” Guerrero says. “In Mexico, they treat you like you are stupid. They say: ‘You can walk if you try.’”

Yarina Ricardo, Cuba

When Yarina Ricardo was diagnosed with MS in her native Cuba in 2013, she had never heard of the disease. “The impact was terrible for my family—and for me, a change of life completely,” she says in an interview translated from Spanish.

Two and a half years later, she and her family immigrated to the U.S. as part of a family reunification program. They initially lived in Miami but moved to Texas when her husband found a job. Ricardo says her husband makes just enough money to cover the family’s living expenses. And that frightens her because in June 2016, the temporary Medicaid the family was originally granted as refugees expired.

Even though they have green cards (which grant



I cannot find medical insurance that can cover my needs regarding my illness. I have gone to several places to ask for help and guidance, but it is very difficult...”

—YARINA RICARDO

permanent resident status), Ricardo and her family won't qualify for Medicaid again until they've been in the country for five years—which isn't until October 2020.

"I have been told that in the U.S. people are not discriminated against because of illness or disability," she says. "But I cannot find medical insurance that can cover my needs regarding my illness. I have gone to several places to ask for help and guidance, but it is very difficult to make people understand. I have received very bad treatment."

Ricardo said in Florida, doctors gave her discounted rates. But Texas doctors haven't done the same. She's reaching out to local organizations and agencies for assistance in covering her rent or utilities, which would free up money to pay for her MS treatment.

Ricardo's only symptom currently is optic neuritis, but "I'm terrified of getting worse and not having health insurance," she says.

Despite these worries, Ricardo does see some benefits to living with MS in the U.S. A pharmaceutical company is providing her MS medication free for one year. And she notes that there are many more resources for her disease in her newly adopted country. ■

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



MS Navigators can offer help to a variety of non-English speakers. Call an MS Navigator at 1-800-344-4867.



Café con Leche is a telephone-based support group for native Spanish speakers. Visit ntlms.org/CaféconLeche.



For resources in Spanish, go to nationalMSsociety.org/Espanol.

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

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



MS
shouldn't
make you
question
your plans

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



In **relapsing MS**, OCREVUS demonstrated[†]:

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

In **primary progressive MS**, OCREVUS is the first and only FDA-approved treatment.

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TALK TO YOUR DOCTOR TODAY

on 1 side of your body, strength, or using your arms or legs (see accompanying Patient Information).

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

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.

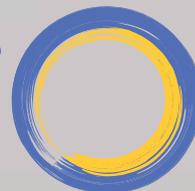
For additional Important Safety Information, please see the accompanying Patient Information.

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

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

[‡]REBIF® is a registered trademark of EMD Serono, Inc.

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ocrelizumab 300MG/10ML
INJECTION FOR IV



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PATIENT INFORMATION

OCREVUS® (oak-rev-us)

(ocrelizumab)

injection, for intravenous use

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- 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

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

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

- have or think you have an infection. See "**What is the most important information I should know about OCREVUS?**"
- have ever taken, take, or plan to take medicines that affect your immune system, or other treatments for MS. These medicines could increase your risk of getting an infection.
- have ever had hepatitis B or are a carrier of the hepatitis B virus.
- have had a recent vaccination or are scheduled to receive any vaccinations.
 - **You should receive any required '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.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
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For more information, go to www.OCREVUS.com or call 1-844-627-3887.

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

Issued: 11/2018

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43



solve

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

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Creative activities such as making art can help boost your brain.

ACTIVITIES TO IMPROVE COGNITIVE FUNCTION

More than half of all people with MS will develop problems with cognition, but many can benefit from strategies and tools to help function effectively. Along with cognitive function screenings or evaluations from your healthcare provider as well as cognitive rehabilitation, certain activities can help boost your brain.

- Aerobic exercise and strength training
- Getting a good night's sleep
- Writing and doodling
- Video games, particularly those that include mind- or body-strengthening features like Lumosity or the Nintendo Wii
- Learning something new, such as a language, musical instrument or dance.

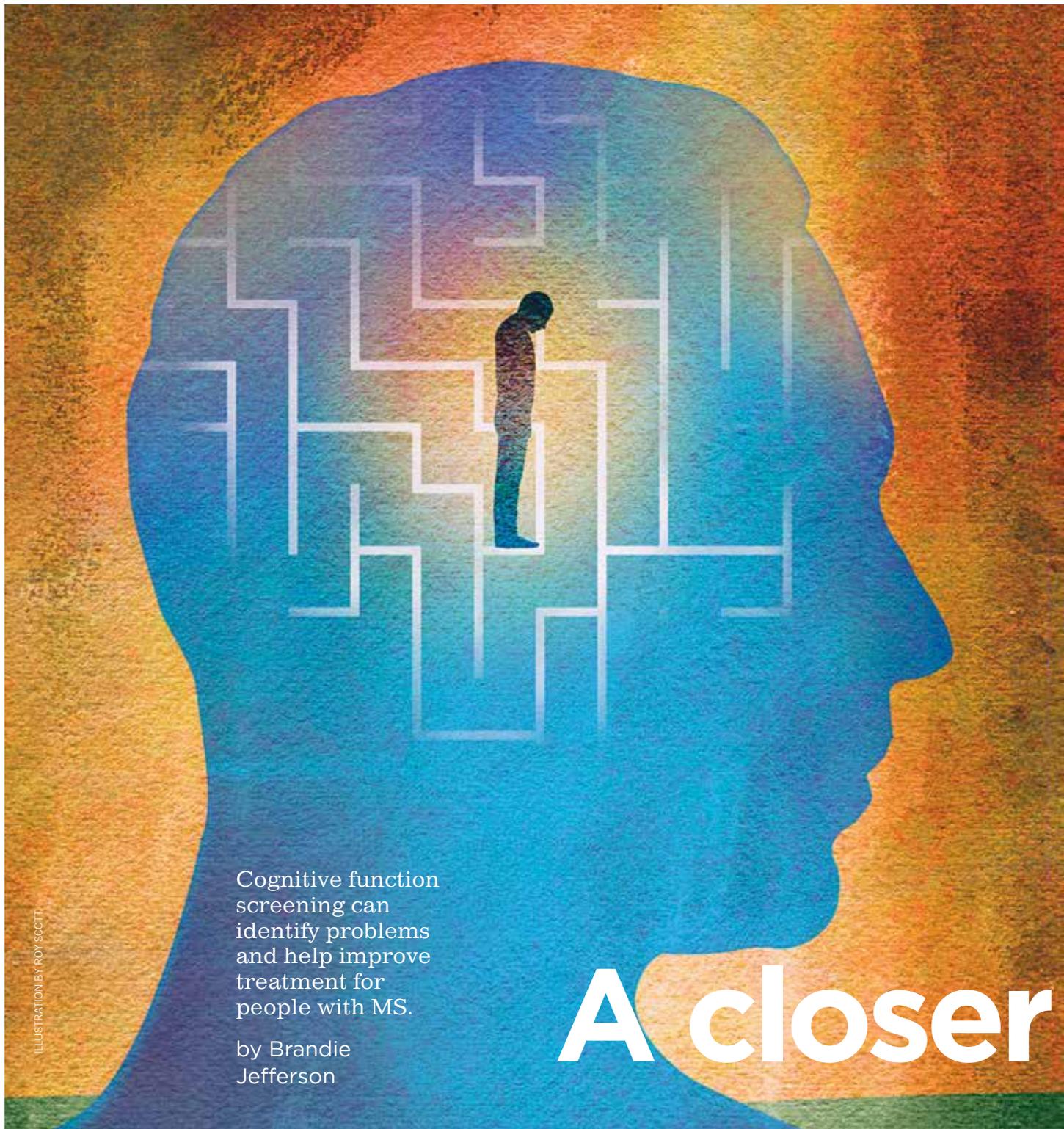


ILLUSTRATION BY ROY SCOTT

Cognitive function screening can identify problems and help improve treatment for people with MS.

by Brandie Jefferson

A closer

In hindsight, there were plenty of clues that multiple sclerosis had affected Diane Kramer's cognitive function.

She was diagnosed in 2010, but it would be four years before a doctor verified cognitive impairment. In the interim, she remembers all sorts of little things that suggested something wasn't right.

"Little things," she says, "that feel so much bigger."

Re-washing clothes because she couldn't remember if she had put detergent in the machine. Getting lost while walking her dog. She even stopped cooking because it was becoming increasingly difficult to follow steps in a recipe.

Researchers estimate about 60 to 70 percent of people diagnosed with MS will face some level of cognitive impairment. Although it has only been since the mid- to late 1980s that the medical profession has understood this connection, there is now a suite of treatment options available to help people mitigate the effects and regain control over their lives.

"Until the 1960s and '70s, maybe even later, medical students were taught that cognitive problems were not a feature of the disease itself," says John DeLuca, PhD, senior vice president of research and training at Kessler Foundation. "In the '70s it was thought that only about 3 percent of people with MS had cognitive problems. We know today it's up to two-thirds of people."

The research may be clear, but it's still not easy for many people to get the support they need.

When Kramer was diagnosed, her doctors discussed long-term therapies, medications to deal with symptoms—and wheelchairs. "My second doctor said I'd be in a wheelchair within a year," she says. No one suggested she might also have to deal with difficulty remembering things, getting lost or losing her temper.

Cognitive screening is rare

That's not surprising. A 2012 Consortium of Multiple Sclerosis Centers member survey found that 52 percent of healthcare professionals who worked with people with MS said that they did nothing at all to screen for cognitive function, and 19 percent asked patients about cognitive issues, but did no formal testing. "You can see where patients can get frustrated," DeLuca says. "It's time for patients to get the help they need."

For Kramer, that started with "self-referring" herself to a new hospital in a different state. The Pennsylvania resident made an appointment at the Johns Hopkins Hospital in Baltimore. At the time she was working full time as a nurse in a small cosmetic surgery office. The doctors were accommodating, letting Kramer nap midday and take time off as needed.

But in the spring of 2014, things happened at work that a nap or a day off couldn't fix. Kramer walked into a room to set up machinery that she'd used plenty of times before. "All of a sudden, I had no idea what I was doing," she says. Then she recalls co-workers commenting, "Let's see how many times she says, 'Now I know I put that right here.'"

Just as she was going to talk to her boss about her problems, Kramer was called in for a meeting. Her boss told her that in responses to a survey, "People are noticing you're getting distracted, abrasive, and you're getting frustrated and blowing up at other people."

Noticing changes in behavior

Who hasn't walked into a room and forgotten what they were looking for or spent too much time looking for keys? While there is no definitive way to know if any individual lapse in memory is related to clinical impairment, Kramer

look at cognition

experienced a telltale sign that it was time to seek help.

“Most people, all people really, are pretty bad at judging their own cognition,” says Meghan Beier, PhD, assistant professor of physical medicine and rehabilitation at Johns Hopkins Medicine. What is more accurate is if friends, or family or coworkers are starting to notice changes, Beier says.

When that happens, Beier suggests a person do what Kramer did and tell their neurologist. “If people are wondering about symptoms, don’t brush them off.”

Kramer’s doctor referred her to Abbey Hughes, PhD, who specializes in neuropsychological assessment, cognitive rehabilitation and MS rehabilitation. Kramer underwent a comprehensive cognitive assessment, which included tasks that evaluated not only memory but also her ability to learn and store information. The evaluation included tests on information processing speed and the status of her executive functioning abilities, which include paying attention, organizing and regulating emotions.

A formal assessment is important because, according to DeLuca, studies have shown a typical neurological exam, done in the course of, say, a six-month checkup, is no better than chance at identifying a specific cognitive problem in people with MS.

Comprehensive assessment

“The No. 1 complaint is memory,” he says, but often for people with MS, the problem may not be memory itself, but other aspects of cognition such as processing speed or executive functions. “Say you are listening to a lecture. If your processing speed is slowed down, you’re not going to learn as well. When you try to remember what you heard, you say, ‘I don’t

remember.’ But that’s because you didn’t learn it to begin with.” A comprehensive assessment can pinpoint exactly what kind of impairment a person is dealing with, allowing healthcare providers to prescribe a more focused treatment.

Kramer found out that she did, in fact, have cognitive impairment. “What a relief it was,” she says. “Now there was a very clear way I could start working on it.”

That would not have been the case just a few decades ago. “At first, there were no recommendations at all for treatment,” says Jeffrey Wilken, PhD, professor of neurology at Georgetown University Medical Center and director of the Washington Neuropsychology Research Group. “Now people realize that there can be interventions.”

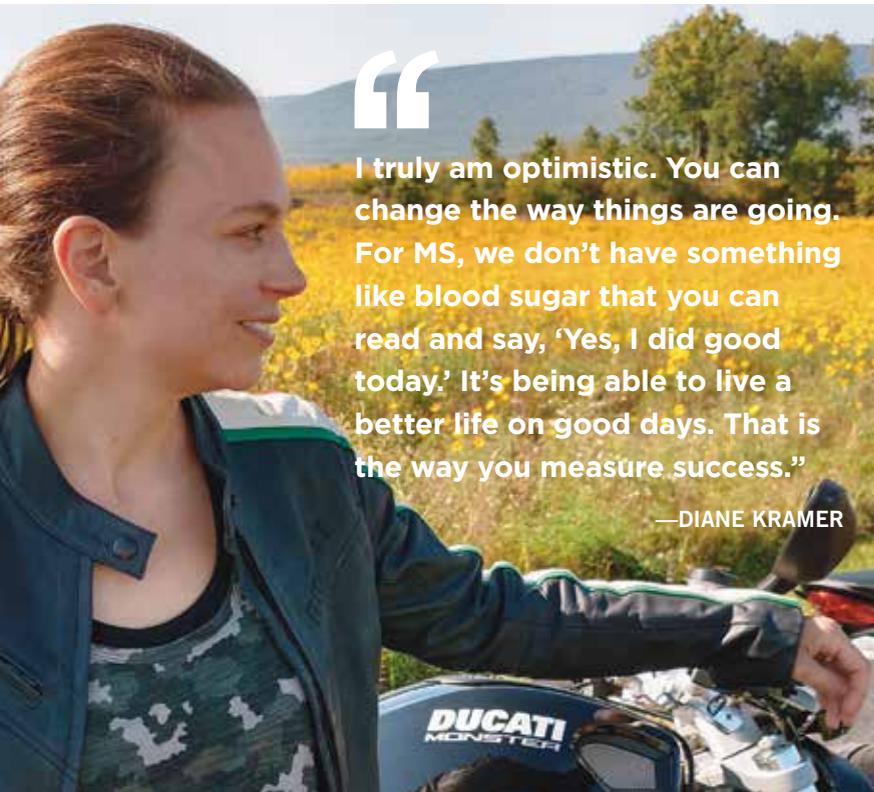
Interventions range from medications to help focus, to looking at whether specific disease-modifying drugs have a positive impact on cognition, Wilken says. Recently, Wilken says more providers are turning to cognitive rehabilitation programs.

These programs are aimed at understanding what impairments a person is dealing with and then working to either strengthen those areas or compensate for them. For example, if a person is having difficulty remembering something she has read, she can strengthen her ability to retain information by “space training”: reading a passage three times, spaced 10 to 15 minutes apart. “Simply by adding that space,” DeLuca says, “people learn better and, consequently, remember information better.”

Much of Kramer’s therapy has focused on behavior modification to compensate for loss of function. “I need routine, if I get off that routine, things become difficult,” she says. For instance, to make sure she takes her medications correctly, she makes a note each time she takes



A cognitive assessment helped Diane Kramer pinpoint a treatment plan to improve her memory and better focus on the activities she enjoys.



“

I truly am optimistic. You can change the way things are going. For MS, we don't have something like blood sugar that you can read and say, 'Yes, I did good today.' It's being able to live a better life on good days. That is the way you measure success.”

—DIANE KRAMER

PHOTO COURTESY OF DIANE KRAMER

a pill, and her husband fills her pillbox.

To help her in the kitchen, she says, “I print out recipes and put them inside a plastic protector and cross off things as I go. It's just small little deviations. You feel so smart when you come up with them.”

Some changes come from her rehab specialist, with whom she checks in every three months.

In fact, Kramer, DeLuca, Wilken and Beier say anyone with MS could benefit from a cognitive assessment as a baseline against which they can compare their ability down the road. At Hopkins, for example, Beier says processing speed tests are now performed at every visit.

In a paper published in the Multiple Sclerosis Journal, DeLuca and co-authors outline guidelines for cognitive treatment that have been recommended by the National Multiple Sclerosis Society. They include a baseline cognitive screening assessment and an annual re-evaluation screening.



Researchers estimate about

60% to 70%

of people diagnosed with MS will face some level of cognitive impairment.

Access to screening

For many people, however, getting these tests won't be easy.

DeLuca says that patients who visit large clinics or university hospitals may be more likely to have access to comprehensive cognitive screening. Right now, he says, “I am not sure that most people will see this at their local neurologist.”

“This should be something that a patient expects,” DeLuca says, “but there are two big challenges: Are there enough people trained in cognitive rehab and familiar with MS? The answer is no. Will insurance pay for this? The answer right now is, generally no. Some will, but in general, treatment for MS is poorly insured.”

In addition to insurance coverage,

various factors affect the price of an exam. “Whether it is being done at a hospital or a clinic or a private practice, whether it is being done by the psychologist or a testing technician,” Beier says. “Also, region of the country matters. For example, an assessment in Maryland would likely be less than in New York City.” Add in the varying lengths of assessments and Beier says, on average, the price could range from \$1,200 to \$5,000.

For the near term, the good news is that recent research shows simple tests can give neurologists an overview of their patients’ cognitive abilities. “We’re finally seeing some very simple screens looking promising,” Wilken said. “The Symbol Digit Modalities Test is a short, 90-second screen that can help neurologists determine whether someone might have a problem.”

In the longer term, DeLuca says, cognitive screening will have to be an advocacy issue for patients, clinicians and



PHOTO COURTESY OF MEGHAN BEIER, PHD

Meghan Beier, PhD, advises telling your neurologist about any cognitive changes.



PHOTO COURTESY OF JOHN DELUCA, PHD

John DeLuca, PhD, says that a formal assessment is the best way to identify a specific cognitive issue.

societies “to get insurance companies to pay for these tests, and to make sure they are available to everyone who needs them.”

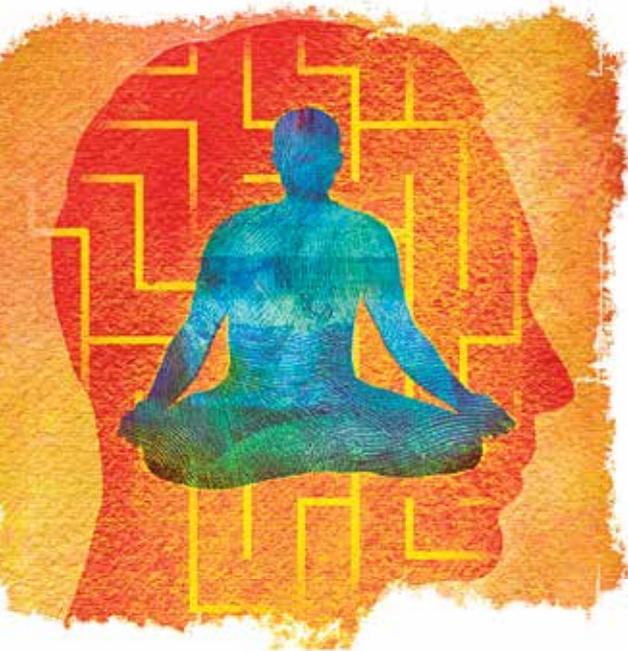
Kramer has been stable for several years now. Despite her previous doctor’s projection that she’d be using a wheelchair, she ran the Hershey Half Marathon in 2012, and completed three 150-mile Keystone Country rides. Shortly after she was called in by her boss, however, she stopped working in the office. She applied for Social Security Disability Insurance and receives full disability benefits.

Kramer may not go into the office, but she is constantly working. “I work very, very hard at maintaining the life that I do,” she says. In addition to volunteering at her daughter’s school, she easily puts in five hours a day of various cognitive therapies.

“I truly am optimistic. You can change the way things are going. For MS, we don’t have something like blood sugar that you can read and say, ‘Yes, I did good today,’” Kramer says.

“It’s being able to live a better life on good days. That is the way you measure success.” ■

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



Find resources and more information about cognitive changes at ntlms.org/cognitivechanges.

Find more information about recommendations for cognitive screening at ntlms.org/ManageCognitiveImpairment.

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

Research investigations on immune cells have the potential to lead to new MS treatment strategies.



New takes on immune activity in MS

Studies could advance treatment options.

by Mary E. King, PhD

Researchers are conducting novel studies involving the immune system that could lead to new clues about the cause and cure of multiple sclerosis as well as additional treatments for all types of the disease.

“We encourage early, fundamental research investigations that have the potential to lead to whole new treatment strategies for MS,” says Bruce Bebo, PhD, executive vice president of research for the National Multiple Sclerosis Society,

which provided funding for the projects.

One study involves research on a type of immune cells called B cells. MS research had long focused on another type of immune cell, the T cell, a major player in autoimmune attacks on the brain and spinal cord. B cells were better known for producing antibodies that bind to and attack bacteria and other microorganisms to help keep us healthy. In MS, however, B cells appear to play additional roles that contribute

to damaging disease activity. The potential roles of B cells in MS and, in particular, the design of MS therapeutics to target B cells, were being overlooked by granting agencies in favor of what seemed to be much more promising T-cell-oriented studies.

“The National MS Society funded early work on B cells and on anti-B cell agents when no one else was taking the risk to fund this new line of research,” Bebo says. B cell research led to further investigations and eventually to a new treatment for primary progressive MS, ocrelizumab, a B-cell-depleting therapy, he explains.

Effects of calorie restriction

Why—and exactly how—does restricting calorie intake affect the immune system? Nancie MacIver, MD, PhD, associate professor of Pediatric Endocrinology at Duke University School of Medicine in North Carolina, and her team observed that fasting or calorie-restricted mice are relatively (but not perfectly) protected against inflammation caused by T cells. Dr. MacIver investigated this in mice that are induced to develop an animal model of MS called experimental autoimmune encephalomyelitis (EAE). These mice, Dr. MacIver learned, are relatively

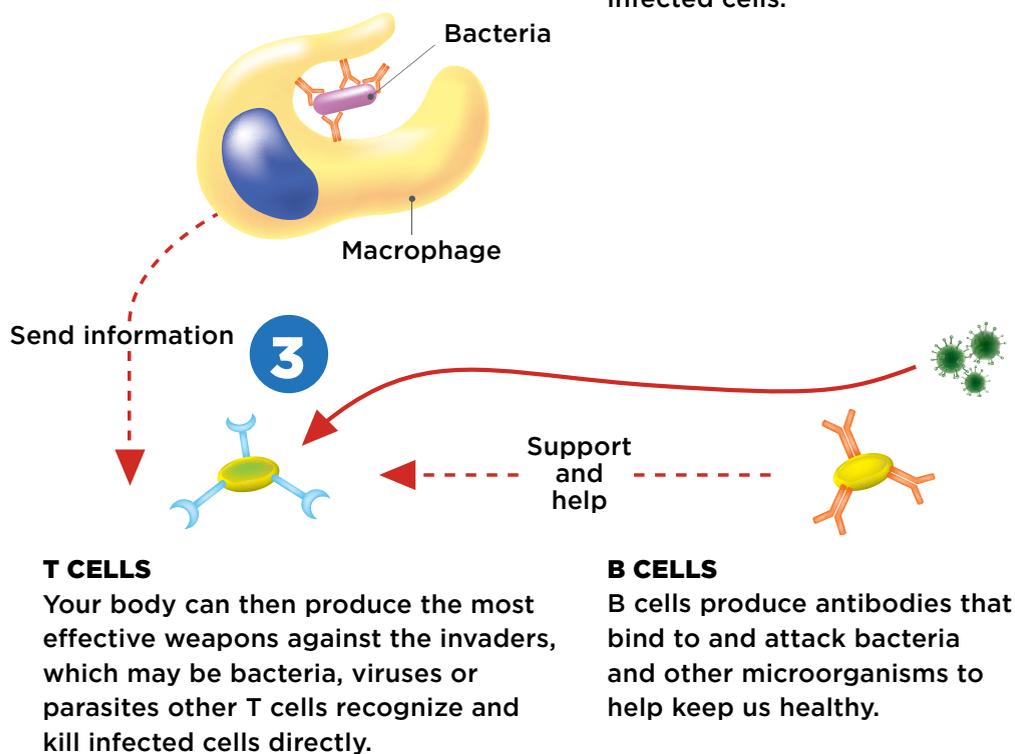
The immune system's internal defense

1

PHAGOCYTES are living cells that ingest or engulf other cells or particles.

2

NATURAL KILLER CELLS are a type of a white blood cell and a component of the immune system. Natural killer cells play a major role in the host-rejection of virally infected cells.



protected from EAE if calories are restricted.

“We then turned our attention to leptin, a hormone secreted from fat cells that is known to communicate nutritional status to immune cells, particularly T cells,” Dr. MacIver says. “The amount of leptin produced by fat cells is proportional to the amount of body fat. Calorie-restricted animals have less leptin in their blood circulation than those of a greater weight.”

“We gave leptin to [calorie-restricted] EAE mice and discovered they lost their protection against EAE. So leptin provides a critical signal to inflammatory T cells that fuels inflammatory function,” Dr. MacIver says.

Dr. MacIver extends this to MS: “Many people with MS make dietary changes [like calorie restriction] in the hope that their disease will improve, because there is some anecdotal evidence that it may help. We want to understand how that might occur. Does calorie restriction really improve disease? If true, does it happen because leptin levels get lowered?” She adds, “If so, we may be able to develop strategies that mimic lowered leptin levels without necessarily restricting food intake.”

“There is some evidence that obesity during adolescence increases risk of developing MS as an adult, particularly in girls,” Dr. MacIver says. “I believe



There are still many questions to be answered in terms of understanding the connection between nutrition and immunity.”

—NANCIE MACIVER, MD, PhD

that this may be mediated, in part, through hormones such as leptin. However, there are still many questions to be answered in terms of understanding the connection between nutrition and immunity,” she stresses.

A new type of B cell

Bonnie Dittel, PhD, senior investigator at the Blood Research Institute at BloodCenter of Wisconsin in Milwaukee, now part of Versiti, is studying B cells and has discovered that their story is much more complex than initially thought. “Mice whose B cells are completely missing, through either genetic engineering or the use of an ocrelizumab-like agent, cannot recover from EAE,” she explains. This perplexing result triggered Dittel’s curiosity: Why would removing all B cells affect EAE recovery in mice?

The puzzle led Dittel to identify a new B cell population in mice that have protective activity. Removing all B cells removes these protective B cells, too. The net result in mice prevents EAE recovery.

Dittel learned that these protective B cells have regulatory activity. (Cells with regulatory activity are cells that help “regulate” the immune system; that is, they keep the immune system from going too far out of balance in the direction of inflammation.) Dittel has already figured out special techniques to pull out only the protective B cells from the larger B cell population in mice.

Adding just the protective B cells, but not the other B cells, back to B-cell-deficient mice with EAE restores their ability to recover. Dittel is now working to identify, isolate and study human protective B cells, including in people with MS. She explains that learning more about protective B cells may lead to a more specific agent for treating MS—or perhaps to an agent that will work alongside ocrelizumab to protect protective B cells from being removed.

A blood component that inhibits myelin repair

In another project, Bebo explains that in MS, the barrier that prevents components

PHOTO COURTESY OF NANCIE MACIVER, MD, PHD



Nancie MacIver, PhD, is studying whether calorie intake impacts the immune system in MS.

PHOTO COURTESY OF ANDREW MENDIOLA, PHD



Andrew Mendiola, PhD, is studying the activity of molecules that may cause inflammation.

PHOTO COURTESY OF BONNIE DITTEL, PHD



Bonnie Dittel, PhD, is studying B cells in mice to develop new MS treatments.

of blood from entering the brain, the “blood-brain barrier,” becomes leaky. One of the molecules in our bloodstream is fibrinogen, which normally helps blood to clot. When it leaks into the brain, however, fibrinogen has a different effect—it promotes inflammation, Bebo says.

Andrew Mendiola, PhD, a postdoctoral fellow in the research laboratory of Katerina Akassoglou, PhD, at the Gladstone Institute of Neurological Diseases and the University of California at San Francisco, is studying this harmful activity of fibrinogen.

Mendiola is focusing his research in mice with EAE as a first step. He is using mice in which individual types of immune cells are labeled with fluorescent dyes. “Our lab is able to visualize and record the movement and function of different types of immune cells in the brain and spinal cord of living animals, which lets us study in detail the effects of fibrinogen on these immune cells,” Mendiola explains. He continues, “I am excited to share that we have recently used state-of-the-art technology to identify the actual targets of fibrinogen action in the mouse brain. We think these targets, which we know are part of the mouse’s genetic material, may



It is our laboratory’s hope that this research may ultimately provide novel targets for therapeutic intervention in MS.”

—ANDREW MENDIOLA, PhD

in turn activate disease-causing immune cells.”

Mendiola adds, “We hope to test the relevance of these findings in human MS in future studies. I want to use this information to identify new ways to selectively turn off the immune cells affected by fibrinogen that promote and exacerbate MS. It is our laboratory’s hope that this research may ultimately provide novel targets for therapeutic intervention in MS.” ■

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



Learn more about MS research at nationalMSSociety.org/Research.

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- 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) 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.
- Skin 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.

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.

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

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

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

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

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

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

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

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) 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.
- are taking certain medicines that change your heart rhythm.
- 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 skin cancer called basal or Merkel cell carcinoma or melanoma.
- are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
 - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
 - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and

for at least 2 months after you stop taking GILENYA.

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

For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by sending an email to gpr@quintiles.com, or go to www.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 skin cancer called basal or Merkel cell carcinoma or 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.

• **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.

Manufactured by: Novartis Pharma Stein AG, Stein, Switzerland

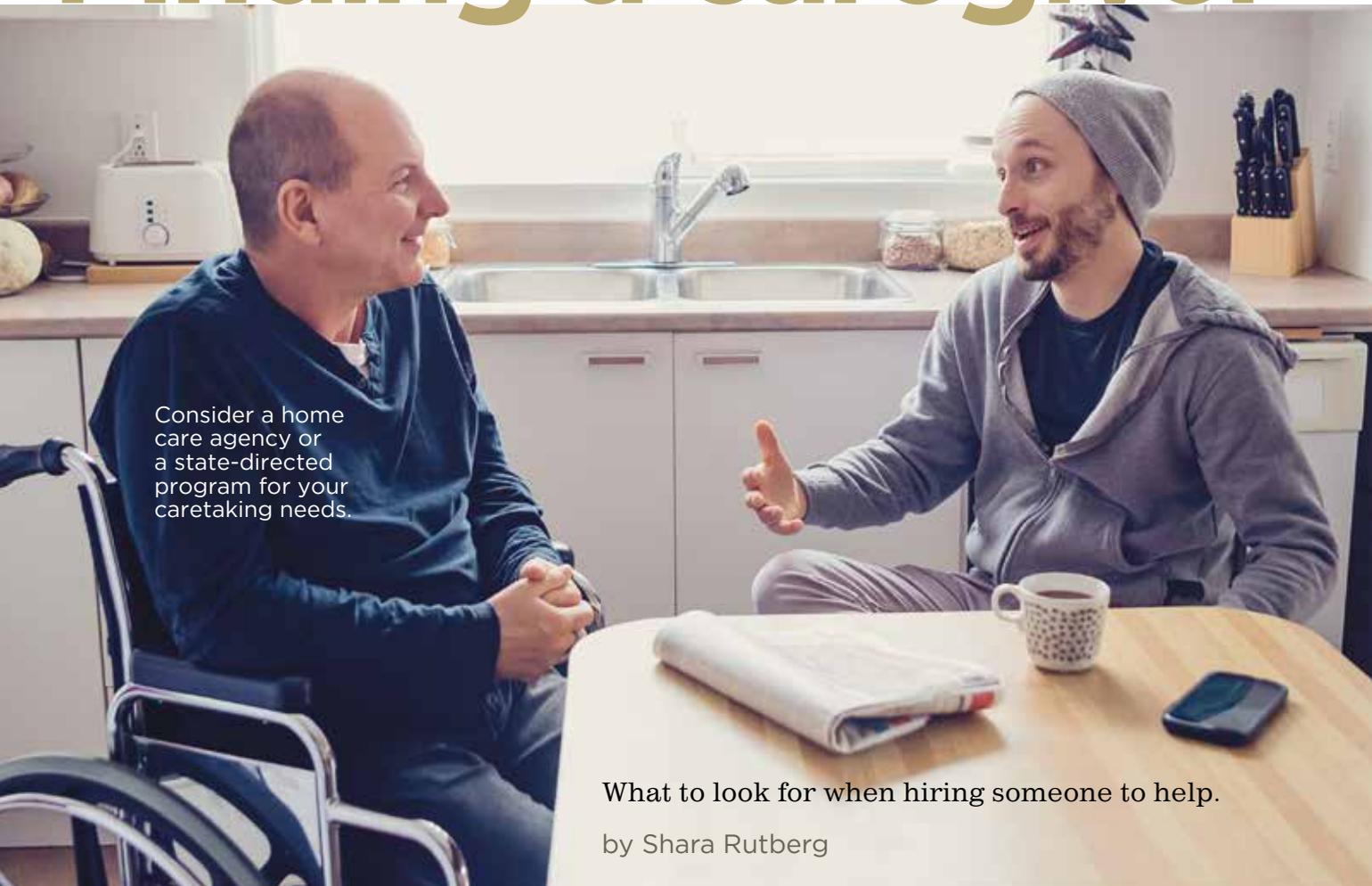
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Finding a caregiver



Consider a home care agency or a state-directed program for your caretaking needs.

What to look for when hiring someone to help.

by Shara Rutberg

Juliet Cuorato's hired caregiver, Hafida Kaoukaji, helps Cuorato in her Philadelphia apartment 45 hours a week. Cuorato appreciates how Kaoukaji cleans the kitchen and bath exactly the way she likes it, how she understands the different symptoms of Cuorato's secondary progressive multiple sclerosis and how she can best help when the symptoms flare up. Cuorato appreciates how Kaoukaji even drove her home from the hospital after her surgery and helped her stick to her daily schedule of physical therapy exercises. But what brightens the 61-year-old's voice the most

when Cuorato talks about her caregiver of 10 years is not how Kaoukaji cleans her kitchen, but what she makes in it. Kaoukaji has introduced Cuorato to fabulous dishes from her native Morocco. "She's a very, very good cook," Cuorato says. "Not just good—professional level. Her food is amazing! It's like I have a pastry chef!"

Kaoukaji works for Cuorato through a home care agency, one option for people with MS who do not have a spouse or partner who is able or willing to help with the sorts of tasks that people with MS often need or want.

Jason DaSilva, who lives in New York, works through that state's consumer-directed personal assistance program and hires his own crew of four to six independent caregivers. Jackie Garrison, of Pineville, Louisiana, relies on her 16-year-old daughter, Emily, as her main caregiver.

These are three resources—a home care agency, a state-directed program, and family—that people living with MS have found work for their individual situations.

Cuorato's rheumatologist referred her to JEVS Human Services, the nonprofit agency she uses to employ Kaoukaji. "It was a good thing he did, because I wouldn't have known where to start," Cuorato says. There are more than 700 home care agencies across Pennsylvania.

"It can be very overwhelming," says Juliet Marsala, vice president of Community Health and Long Term Supports at JEVS, which serves more than 30,000 people in the mid-Atlantic region. "What programs are out there? Which one is right for you? How can you pay for it? It can be daunting," she says.

Start with the money

Begin by finding out whether your health insurance or your long-term care insurance covers home health care. If you have Medicare, you may qualify for home health care if you meet certain criteria ([medicare.gov/coverage/home-health-services](https://www.medicare.gov/coverage/home-health-services)). In some states, Medicaid can pay a family member to work as a caregiver. If insurance does not cover home care, determine if you can afford to pay for it out-of-pocket, or if community funding might be an option.

Public funding for programs like Medicaid varies widely by state. DaSilva's situation is a frustrating—and heartbreaking—example. Living in New York, DaSilva, 40, an Emmy Award-winning documentary filmmaker and activist, is able to finance caregivers in his apartment through a state-based program that allows him to choose his own aides. "My caregivers not only help me with everyday care," says DaSilva, who uses a wheelchair and has blurry vision and limited use of his hands. "They also help me maintain my independent life and business, doing things like helping with email."



Good communication is critical in maintaining a healthy caregiver-client relationship.

Choosing a caregiver

When interviewing a potential caregiver, take the time to write down your specific needs in a job description you can share with the candidate. Find a job description worksheet on the Society's website at ntlms.org/hiringhelp.

Don't be tempted to not mention chores that may embarrass you, like changing a catheter bag or helping you bathe. Talking about these things openly is essential to employing someone who will be able to meet your needs. Have a family member or friend with you and if possible, do the interview outside your home to protect your privacy.

Ask about the applicant's work history. "Some people prefer a highly skilled caregiver with a lot of experience," says JEVS at Home's Maryann Ludwig. "I don't believe that experience is the most important factor to consider. It's more important to find a caregiver who is reliable, respectful, trustworthy and compassionate. These are attributes that generally cannot be taught."

Make sure you can communicate clearly in your preferred language. Check that candidates have reliable transportation. Ask situational questions, like "How would you go about doing laundry?" and listen for an answer that indicates they would start by learning your preferences about how you would like to have things done, suggests Juliet Marsala, vice president of Community Health and Long Term Supports at JEVS at Home. Putting your preferences first is critical, she says.

Then ask yourself a key question: Would you feel comfortable with that person as a caregiver? "You're going to have a very close relationship," says Marsala. "That caregiver will become a significant part of your life, so take the time to really interview to your needs."

Watch out for an applicant who is late to the interview and for applicants with no references. Also, beware of applicants that direct their questions to a family member instead of you, or anyone who asks you if you're willing to sign a blank time sheet. When you do choose a caregiver, have them sign a written agreement outlining their responsibilities.

However, DaSilva wants to move to Texas to be closer to his young son, who lives there with his mother. But while New York is ranked in the top 15 states in terms of disability care, "Texas is dead last," DaSilva explains in a short film that appeared with his op-ed in the New York Times (nytimes.com/2018/07/24/opinion/disability-trap-state-medicaid.html) about what he calls "the disability trap." To receive the same type of care in Texas that he does in New York, DaSilva would have to live in a nursing home and give up his independence.

Support organizations

The National Multiple Sclerosis Society's MS Navigators can provide a variety of resources and point you in the right direction for your situation. Local public support agencies can help you wade through your financial and program options, Marsala says. "They're a great place to start." Every state has local centers for independent living and area agencies on aging. The United Way's 2-1-1 and the individual states' departments of human services are other helpful resources, along with the Eldercare Locator from the U.S. Administration on Aging, which connects older adults, families and caregivers to community resources.

The agency route

While Cuorato feels “very, very, very fortunate,” for her current caregiver, the first two experiences with the caregivers she found through an agency did not work out. She found Kaoukaji on her own through a recommendation of the caregiver of an acquaintance in her neighborhood and was eventually able to sign her up for employment through JEVS. The agency handles recording hours, payment and billing. (The cost of care is covered through a combination of state and federal programs).

Working through an agency also means there’s often a supervisor to oversee the situation and to provide back-up attendants in case the main caregiver cannot make it to work, says Marsala. Some agencies also provide continuing training programs to caregivers. “When selecting an agency, ask pointed questions, like ‘how do they handle snow emergencies?’ For example, some provide Uber and Lyft vouchers to caregivers,” she says. Be sure to select an agency that runs background checks on caregivers.

Once you do select an agency, be very open about what you want in a caregiver, says Marsala. “The more information you give, the better an agency can do at matching. And don’t be afraid to change agencies if something’s not going right.” Working with a paid caregiver is very different from having a family member or friend help you. “They should be working hard at the direction of the person, respect professional boundaries and confidentiality, trained in universal precautions and have basic awareness of medication distribution needs,” says Marsala. Another big difference is that a hired caregiver (through an agency) has a supervisor to support the relationship.

Whether you’re working with a paid or volunteer caregiver, such as a family member or friend, it’s important to review the services that will be provided and discuss each person’s expectations, says Maryann Ludwig, chief strategy officer of JEVS at Home, the home care affiliate of JEVS. “Volunteers are generally less skilled than trained caregivers, so they may not be able to assist with all activities. If that’s the case, it’s important to know that from the start,” she says.

Resources for finding care

U.S. Department of Health and Human Services

[longtermcare.acl.gov/the-basics](https://www.longtermcare.acl.gov/the-basics)

National Association for Home Care and Hospice

<https://www.nahc.org/consumers-information/home-care-hospice-basics/standard-billing-and-payment-practices>

Family Caregiver Alliance

[caregiver.org/frequently-asked-questions#faq](https://www.caregiver.org/frequently-asked-questions#faq)

Center for Independent Living

[ilru.org/projects/cil-net/cil-center-and-association-directory](https://www.ilru.org/projects/cil-net/cil-center-and-association-directory)

National Association of Area Agencies on Aging

[n4a.org](https://www.n4a.org)

United Way 2-1-1 Referral Service

[unitedway.org/our-impact/featured-programs/2-1-1#](https://www.unitedway.org/our-impact/featured-programs/2-1-1#)

Eldercare Locator

eldercare.acl.gov/Public/Index.aspx

Family member caregivers

Emily Garrison, 16, has been her mother Jackie’s main caregiver since her MS diagnosis when Emily was 12. Emily’s sister Riley is 15. Jackie’s husband is undergoing treatment for prostate cancer and is less able to help. Jackie says that with Emily, “There’s a level of comfort that I can’t describe.”

While Emily cooks dinners and assists with Jackie's artisan soap business, some of the most important help Emily provides is mental and emotional. When side effects of Jackie's medication wracked Jackie with pain through the night, "I held her hand, and told her it was going to be OK," says Emily. She often helps her mother sift through "word salads," what they call the jumble of words in your mind's bowl that can be a symptom of MS. Often, her mother picks out the wrong word. Emily usually knows what one she's reaching for. "Almost like a translator," she says.

Emily says she enjoys caring for her mother, though it can be difficult to "always be helping, without a lot of break time."

The most critical piece of support Emily provides Jackie, is acceptance. "She seems to recognize that I feel like I'm not the mom she signed up for. She can see that I'm doing the best I can with the hand I'm dealt," says Jackie.

Knowing how much to ask of her daughter as caregiver is a "difficult balance," says Jackie. "At the end of the day, she's still the child and I don't want her to not do something because she feels obligated to stay with me." Plus, she says, like herself, her daughter is unlikely to ever complain about helping. The key, she says, is also what Marsala, Ludwig and Cuorato say is critical for maintaining healthy caregiver-client relationships: good communication. "No one can read your mind," says Cuorato—even people who bake heavenly pastries. ■

Shara Rutberg is a writer in Evergreen, Colorado.



For information on hiring a caregiver, visit [ntlms.org/hiringhelp](https://www.ntlms.org/hiringhelp).



Important attributes to look for in a caregiver include reliability, respect, trustworthiness and compassion.

The National Multiple Sclerosis Society can provide information on resources about caregivers and support for family members who are care partners. To learn more, contact an MS Navigator at 1-800-344-4867 or visit [nationalMSSociety.org/Helpful-Links/Contact-Us](https://www.nationalMSSociety.org/Helpful-Links/Contact-Us).

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



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Nichole Taylor fights MS her way

A 500-mile walk to give back to the community

by Mike Knight

It was 2013, and Nichole Taylor, MD, sat in her car outside a Target store while it rained. Rachel, the youngest of Taylor's two daughters, sat next to her. It was supposed to be just a routine trip to the retailer before the two returned home. It was anything but.

Dr. Taylor, an anesthesiologist living and practicing in Winston-Salem, North Carolina, had been diagnosed with relapsing-remitting multiple sclerosis in 2010 after experiencing loss of function in her left arm and left

leg, along with nystagmus, an optical condition that causes vision impairment. Active throughout her life, Dr. Taylor had quickly gone from hiking and chasing after Rachel and her older sister, Laura, to needing first a cane, then a walker and then a scooter just to get around.

After finding the right disease modifying therapy (DMT), Dr. Taylor had spent much of the three years since her diagnosis working to regain her mobility and

strength so she could return to being the mother she once was. Those efforts were beginning to pay off. Dr. Taylor slowly began regaining her mobility.

Four months after she began walking without her cane, Dr. Taylor decided to try the 30- to 50-mile long Challenge Walk MS fundraiser. To her surprise, she finished the entire walk. “I was shocked,” Dr. Taylor says.

Now, the pair watched it rain from inside Dr. Taylor’s car, sizing up the distance to the store. Then they decided to make a break for it. “We got out of the car, and I started running through the rain with her,” Dr. Taylor says. “And I thought I would never do that again. Because for so long, I had slid so far.”

A six-year quest

For Dr. Taylor, the quick dash became a rediscovery of a part of herself she feared had been lost forever. “I felt like I was back,” says Dr. Taylor. Though she did not know it at the time, it was also the beginning of a six-year-long quest to give back to the MS community.

In May 2019, Dr. Taylor will begin a 500-mile pilgrimage on El Camino de Santiago de Compostela (The Way of St. James) that will take her through the Pyrenees mountains in France to Santiago de Compostela in Spain. Dr. Taylor hopes to raise \$50,000 through the National Multiple Sclerosis Society’s Finish MS, a fundraising program for cause-driven athletes to be used for research that may one day find a cure for the disease. Besides the first day’s

15.6-mile, 4,500-foot climb, Dr. Taylor knows she’ll face drastic swings in elevation, weather and terrain along with fatigue, tendinitis and other physical

challenges. Though many make the trek in 30 days, Dr. Taylor plans to allow an extra five rest days.

Dr. Taylor’s Finish MS campaign won’t be the first time she’s raised money to end MS. “I donated to MS events a year prior to being diagnosed to support a co-worker participating in the Bike MS: Tour to Tanglewood,” Dr. Taylor says. After learning she had the disease, Dr. Taylor began taking part in Bike MS, Walk MS and Challenge Walk MS, as well as MuckFest MS. She’s advocated for MS issues in Washington, D.C., on behalf of the Society and she’s been a camp doctor for the MS Adventure summer camp for children whose parents have MS.



PHOTO COURTESY OF NICHOLE TAYLOR

Nichole Taylor, MD, (left) and her daughter Laura started a Finish MS campaign that involves painting inspirational messages on rocks and hiding them for others to find.

Inspired by a movie

Dr. Taylor says the idea to hike the Camino de Santiago came to her when she could barely even walk. “I watched a movie from behind my scooter with

popcorn one day, and I was just so moved by it,” she says. “The Way,” a story of a father who travels overseas to collect the remains of his estranged son who died on the trail and then decides to make the pilgrimage himself. Released in 2010, “The Way” starred father and son Martin Sheen and Emilio Estevez.

“I watched the movie and was intrigued by it,” Dr. Taylor says, “but I never really thought, ‘I’m

going to walk that someday' because my function was so limited."

The Camino de Santiago is actually a network of nine main routes leading to Santiago de Compostela and the Catedral de Santiago de Compostela, the home of what is believed to be the tomb of the apostle St. James. Dr. Taylor will be traveling what is known as the French Way. One of the most heavily traveled routes, the French Way winds through the monasteries, mountains and scenic countryside and also passes by the Cruz de Ferro (Iron Cross). Believed to have been erected in the 11th century (the Camino dates back to the 9th century), the Iron Cross is located between Foncebadón and Manjarín, Spain. Though there are several theories regarding the origin of the cross, pilgrims often place stones representing a burden or sin at the base of the cross; some of the stones contain words or messages to a loved one.

Kindness rocks

In 2015, life coach, freelance writer and activist Megan Murphy created the Kindness Rocks Project, which "encourages people to leave rocks painted with inspiring messages along the path of life." After Dr. Taylor and her daughters saw examples of the painted rocks, they began painting their own, which Dr. Taylor left on her training walks.

Dr. Taylor's older daughter, Laura, 14, thought it would "be cool if we could know where they went," Dr. Taylor says. "And the only place I could think of to do that was Facebook." Besides painting inspirational messages on the rocks, they wrote "Facebook/Finish MS/Find/Post/Hide Again" on the backs so those who found the rocks could visit the page and identify where they discovered the rock before deciding to keep it or hide it again.

Dr. Taylor's Facebook page also leads donors to her Finish MS page. A Do It Yourself (DIY) fundraising program of the Society, Finish MS was created for cause-driven athletes like Dr. Taylor to push their own personal and physical limits while working to end MS.

According to the Society's Christina Carro, senior director, DIY Events and Challenge Walk MS, DIY events raise nearly \$4 million annually. And the



Rocks are labeled "Facebook/Finish MS/Find/Post/Hide Again" so those who find the rocks can visit the page and identify where they discovered the rock before deciding to keep it or hide it again.

program is growing. Carro says more than 1,500 people participated in more than 100 DIY events in 2018, raising \$5.3 million to fund the mission of the Society. Carro says the DIY program is especially suited for driven supporters such as Dr. Taylor. "It appeals to somebody who just is mission-connected and really wants to try to do something that will make a difference," Carro says.

Dr. Taylor plans to wear a necklace made from stones representing each donor, which she will place at the Cruz de Ferro. "I'm also going to spend time with each of those stones for each donor," she says, "because not everybody can walk it, and I want them to know I'm walking it not just for me, I'm walking for everyone with MS. And I am bringing them with me." ■

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



Visit ntlms.org/DIYfundraising to start your own DIY fundraiser.

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The **meat** of the

What started as a backyard kegger has grown into a major MS fundraiser and bicycle program.

by Kelsey Blackwell

Imagine this: Before you, slice upon slice of melt-in-your-mouth beef brisket beckons. Ridiculously tender pork ribs that basically shimmy off the bone. What's more, plump smoked sausages compete for your attention. Where to begin? After eating your fill, you wash it all down with a cold beer and maybe a shot of whiskey or two. No, this isn't a dream. It's a Meat Fight, and it's the kind of fight many dream of being in the middle of.

As its name implies, Meat Fight is about meat, but that's not the only draw for the more than 700 attendees who descend on Dallas, Texas, from across the country every November. Each tender meaty morsel is made all the sweeter by the true intention of the event: to raise funds to support people living with multiple sclerosis.

Toward that end, Meat Fight raised over \$225,000 in 2018. "That's really an extraordinary amount," says Leah Weatherl, associate vice president for the National Multiple Sclerosis Society's Bike MS. Since its inception in 2011 though, Meat Fight hasn't had to put up much of a fight to attract attention.

"It started as a kegger in my backyard," says Alice Laussade, Meat Fight's CEO, aka "The Mother of Meat Fight."

A modest start

After her brother Jim Casey was diagnosed with MS in 2010, Laussade and her husband, Mike Laussade, threw the backyard party to raise the fundraising minimum necessary to join Casey at the Bike MS: Round Up Ride in Dallas.

"Our goal was \$600," Alice Laussade says. "That day, we brought in more than \$2,000. We were pretty proud and excited about that, but then one of my friends said, 'This 2K is cute, but you could raise so much more if you made this a public event.' I was like, 'I'm not an event planner. This is my backyard. This is not a public thing.'"

Despite her reservations, Laussade decided to give it a go. As a James Beard Award-winning food writer for the Dallas



matter



PHOTO COURTESY OF ALICE LAUSSADE

“

To say that my bike has changed my life is an understatement. I got on my Meat Bike and trained each week. I would set small goals, like I want to go 15 miles today and then 17 miles next time.”

—WENDY ROBERTS

Observer, she leveraged her industry connections to see if she could get things smokin’. “We decided that if we could get four chefs and one brewery, we would go public,” she says. “The brewery came on first, and we ended up with 12 chefs.” Since that first public event in 2012, Meat Fight has continued to sizzle. From hosting Parks and Rec star and self-proclaimed bacon aficionado Nick Offerman as a guest judge in 2013 to the more than 700 attendees and 50 chefs who participated in the event in 2018, the nonprofit organization is clearly clued in to a not-so-secret ingredient for success.



PHOTO COURTESY OF ALICE LAUSSADE

Left: Wendy Roberts, with her husband, Ryan Roberts, was presented with the “Most Inspirational Rider” award.

Above: Smoked sausages were cooked to feed more than 700 people at the 2018 Meat Fight.

It's called 'fun-lanthropy'

"Fun is at the center of everything," Weatherl says. "They're doing extraordinary things, but they're making sure that people are having a good time while they're doing them." Attendees agree. "It was 100 times more spectacular than anything I could have imagined," says Jeana Nozykowski, who was diagnosed with MS in 2003, of her first time at Meat Fight, which she attended with her husband. "We had the most fun stuffing ourselves with barbecue. It was a party—a party in my stomach and a party all around."

"Fun-lanthropy" isn't just about fun though, it's also about getting a younger group of people interested, involved and excited about philanthropy. So Meat Fight Inc. launched two more events: Chicken Thang, which takes place in February and raised \$23,000 in 2018; and Meat Fight 1K, which takes place in August and raised \$45,000 in 2018. During the 1k event, if attendees eat at 12 of 40 food and beverage stations, they get a finisher medal. "So if they're posting pictures online it looks like you did some sort of athletic event, but all you did was drink beer and eat barbecue all day," Laussade says.

Did you say "Meat Bike?"

If the food events are the "meat" of Meat Fight, call the nonprofit group's Meat Bike program the dry rub, which is to say, completely essential.

Meat Fight Inc. launched Meat Bikes in 2014 as a way to break down the barriers preventing people with MS from participating in Bike MS events. Meat Bike provides a bicycle, gear and training to support anyone with MS willing to cross the start line of a Bike MS event, Laussade says.

While grit and determination are essential qualities for anyone gearing up for a Bike MS ride, for many people the first step is just believing that getting on a bike is possible.

"I was lying in bed, and I just decided, why not? I'm going to fill out the application [to get a Meat Bike]," says Quincy Wallace, who was diagnosed with MS in 2010 and lives in Fort Worth. "I was fat, and I knew I needed to exercise. I knew I wasn't feeling good. I had been told that exercise was key, and I wasn't exercising



It's not just about the Meat Fight events or putting people on bikes and asking them to exercise...They're getting healthy, they're raising money to cure MS and they're having a good time."

—LEAH WEATHERL

at all. I was approved [for Meat Bike] within a couple of weeks."

Laussade notes that the organization looks for people who are reliable and committed to doing the training to prepare for their Bike MS ride. To receive a bike, applicants commit to crossing the starting line of a race by the end of the following year. So far, more than 166 bikes have been donated.

"Since I got my bike in 2016, I've lost 40 pounds," Wallace says. He now has a goal of riding his bike 150 miles a week and has completed several long-distance bike events in addition to Bike MS. "My wife says she got her husband back. It's truly been a life-changing experience. Sometimes I don't even think I'm sick because I've done so much more than I did before I was sick."

166 bikes, 166 stories

For the 166 bikes Meat Fight has now given away, there are likely 166 stories similar to Wallace's.

"To say that my bike has changed my life is an understatement," says Wendy Roberts who was diagnosed with MS in 2016 and lives in Longmont, Colorado. "I got on my Meat Bike and trained each week. I would set small goals, like I want to go 15 miles today and then 17 miles next time. On days my legs hurt really bad, I would just get on and go as far as I felt comfortable. Biking was something my husband and I could do together. In riding with each other, we both lost weight, we enjoyed more time together, and we are both happier as a result of this little Meat



PHOTOS COURTESY OF ALICE LAUSSADE



Top left: Wendy Roberts, Alice Laussade and Ryan Beck from Performance Bicycle. Beck coached Wendy for her first ride.

Top right: Alice Laussade, Meat Fight's CEO, is also known as "The Mother of Meat Fight."

Bottom: Meat Fight raised more than \$225,000 in 2018.

Bike of mine. I now think of myself as a Meat Fight ambassador. I have recruited several Meat Bike riders and have formed an amazing pack of Meat Fight friends across the U.S.”

The success is in the numbers. Meat Fight Bike Team has grown from seven riders in 2011 to more than 300 riders spanning 17 states.

“It’s become a \$1 million fundraising team for Bike MS,” Weatherl says. “There have only been about 100 teams in the roughly 40-year history of Bike MS to do that. And to do it in just seven years? Phenomenal!”

Go baby go

And why just stop at bikes? At Meat Fight, more is more.

Meat Fight launched Project 13 in 2016, which offers funding and coaching to a select group of athletes living with MS interested in participating in endurance challenges. So far, the program has funded 65 individuals willing and eager to take on a marathon, half marathon and/or Ironman event. Like the Meat Bike program, the first step to getting involved is believing in yourself.

“I wasn’t an unfit person, but I definitely didn’t have that thing that I did on a regular basis. I’ve never been a runner,” says Nozykowski who’s training for her first half Ironman in April 2019. “I had a bike to go around town to get a coffee or go to the bookshop, but I wasn’t a road cyclist. Heat was always an excuse, too.”

From simply falling in love with Meat Fight to donating money to fund Meat Bikes to receiving one herself and now gearing up for her first endurance challenge, you could say that Nozykowski is pickin’ the Meat Fight bone clean.

“When I completed just the bike portion of the Half Ironman relay last year, I kind of drank the Kool-Aid,” she says. “Now I want to do the whole thing. I can’t imagine doing these things even before I had MS. It’s so strange how in so many ways a weakness has become a strength. I have MS. I have this disease that sometimes can present weaknesses in your physical abilities. If I hadn’t ever been diagnosed who knows if I would have seen all these opportunities to do all these things. I feel so much stronger and so much more confident in my abilities than I ever would have been.”



PHOTO COURTESY OF ALICE LAUSSADE

From left to right, Kazumi Kojima, Michael Laussade and Emily Strittmatter at Meat Fight 2017.

And that is what Meat Fight relishes: Helping people with MS feel better now, while going further than they ever thought they could go.

“It’s a culture that they’re creating,” says Weatherl. “It’s not just about the Meat Fight events or putting people on bikes and asking them to exercise. They’re creating rolling support groups. That becomes very inspirational and motivational for people. They’re getting healthy, they’re raising money to cure MS and they’re having a good time. That’s ultimately a win on everybody’s part.” ■

Kelsey Blackwell is a writer in Berkeley, California.



Are you a person living with MS who’s ready to take on the Meat Bike Challenge? Want to apply to take on an Ironman with Project 13? Go to meatfight.com for more details.

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For a type-A athlete, a new normal

After my MS diagnosis,
I'm learning to
slow down.

by Katie Klingsporn



Katie Klingsporn
on her mountain
bike in Colorado.

When I moved to the ski town of Telluride, Colorado, at the age of 24, it was under the guise of finding work at the local newspaper. But really, I moved to Telluride for the rugged San Juan Mountains that knifed the sky, the sprawling canyonlands of the Colorado Plateau nearby and the endless adventures that lay waiting in these wrinkled landscapes.

And for nearly a decade, I plied these adventures by bike, foot and snowboard, happily falling in with the hard-charging ranks of Telluride. Like most mountain towns, Telluride's outdoor culture reflects its landscape—exacting and extreme. Here, the expectations for work and play are outsized, every other person is an elite athlete and badges of honor are earned through punishing physical feats in the mountains. It's common for people to ski laps in the backcountry before going to work, spend weekends bagging 14,000-foot peaks and routinely complete epic suffer-fest bike rides.

As a lifelong athlete, I dove in to this work-hard-play-harder-sleep-when-you-die lifestyle with relish. I worked long, deadline-driven days at the paper, and then stuffed the rest of my time with early morning bike rides, laps on the ski slope, difficult yoga classes, steep hikes through the aspen groves and weekend excursions to the desert. I was always on the move, and considered restful activities like naps and massages terrible wastes of time. I felt the harder I pushed myself, the better I would be. I lived by rigorous to-do lists, considered seven hours of sleep sufficient and rarely took a day off from working out.

Knocked flat by diagnosis

I burned and burned, my identity becoming inextricable with pushing my body to extremes. I won some races and built a

reputation as an athlete who could keep up with the guys, a hardy mountain denizen.

That all came crashing down in March 2015. That's when, a couple days after taking a tumble at the ski resort, my torso went numb. Soon after, I was visited by a host of terrifying symptoms: tingly hands that could no longer perform nimble tasks, random bouts of itching, a current of electricity dancing under my skin, a constriction around my middle. After an ER visit, two MRIs and a spinal tap, I was diagnosed with multiple sclerosis.

The diagnosis knocked me flat. And instead of jumping back to my feet like I always had before, this time the best I could do was crawl.

So I started small, with an activity I had previously discounted as yawn-inducing: walking. One mile here, then two. Mellow yoga with words like “restorative” in the class title was next. I began meditating. I even adopted a new mantra that would have appalled the previous me: Do less. It was all I could do, but it was enough.

And as counterintuitive as it was, once I put this mantra into place, I realized I had been crashing through life at a reckless pace. I had been too busy piling on activities to enjoy engaging conversations, to notice the songs of birds in the forests, or to bask in the pleasure of lying under a tree with nowhere to be. And by refusing to practice self-care, I had beat up my body when I thought I was caring for it.

Staying slow

Over time and with plenty of rest, the symptoms calmed down to a low hum. And I did get back on my bike and snowboard. But when I pushed myself—be it on an exhausting ride, overcommitted social schedule or hectic workweek—I paid for it with fatigue, headaches and vision problems.



PHOTOS COURTESY OF KATIE KLINGSPOHN

Katie Klingsporn enjoys hikes and day trips with her husband and dog.

So I've learned to stay slow. These days, I spend more time wandering along the backyard trail than going on bike rides in the alpine. I sleep in on weekends, nap when I'm tired and draft much less ambitious to-do lists.

I can no longer define myself as the badass mountain biker and snowboarder I was at 28. My Instagram posts no longer depict epic days in the mountains, my weekends are no longer stuffed with high-flying adventures. Instead, accomplishments are measured by hikes with the dog, day trips to the desert with my husband and road rides along rolling country lanes.

This is my new normal. Achieving it has required patience, self-acceptance and a pointed effort to stop comparing the new me with the old. But I've emerged more mindful, deliberate and grateful for the small wonders. The ones I was rushing through life too fast to notice before. ■

Katie Klingsporn lives in southwestern Colorado with her husband, daughter, dog and three chickens.



Learn how others have embraced their MS. Start or join a conversation on [MSconnection.org](https://www.msconnection.org).

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New ways of creating

The beauty in deterioration.
And the joy in laughter.

by Brooke Pelczynski



Brooke Pelczynski works in her art studio in her home in Brooklyn.

The day I was diagnosed with multiple sclerosis in 2012, the thought of not being able to use my hands was all I could focus on. I was 22, finishing my last year as an illustration major at the School of Visual Arts in New York, and it was like being slapped in the face over and over again. I am in love with the process of simply creating: all the hands-on grunt work of making art, the all-nighters with a large canvas and a brush, the movement of my body to convey the feeling and emotion in a piece. My fine art work focuses primarily on the beauty in deterioration. I capture the feeling of things falling apart but remaining beautiful, which is what I feel my MS is doing to my body and my work. Repetition of shapes are a device to invite viewers to travel through the whole image and prevent them from getting lost in one section. It asks the viewer to step back and absorb the whole image. MS is a part of my life, but it is not my whole life. I create with the feeling of urgency, never knowing if one day I won't be able to hold a brush.

The comics that I create about MS take a moment to laugh about my situation. Yeah, it's pretty horrible sometimes, but it could always be worse. My main objective is to produce as much work as possible, to learn how to adapt, and to be open to new ways of creating. ■

Brooke Pelczynski created the comic seen to the left and the cover of this issue specially for **Momentum** magazine.



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Watch a video and read about how Brooke Pelczynski lives with her MS at **MomentumMagazineOnline.com/brooke.**



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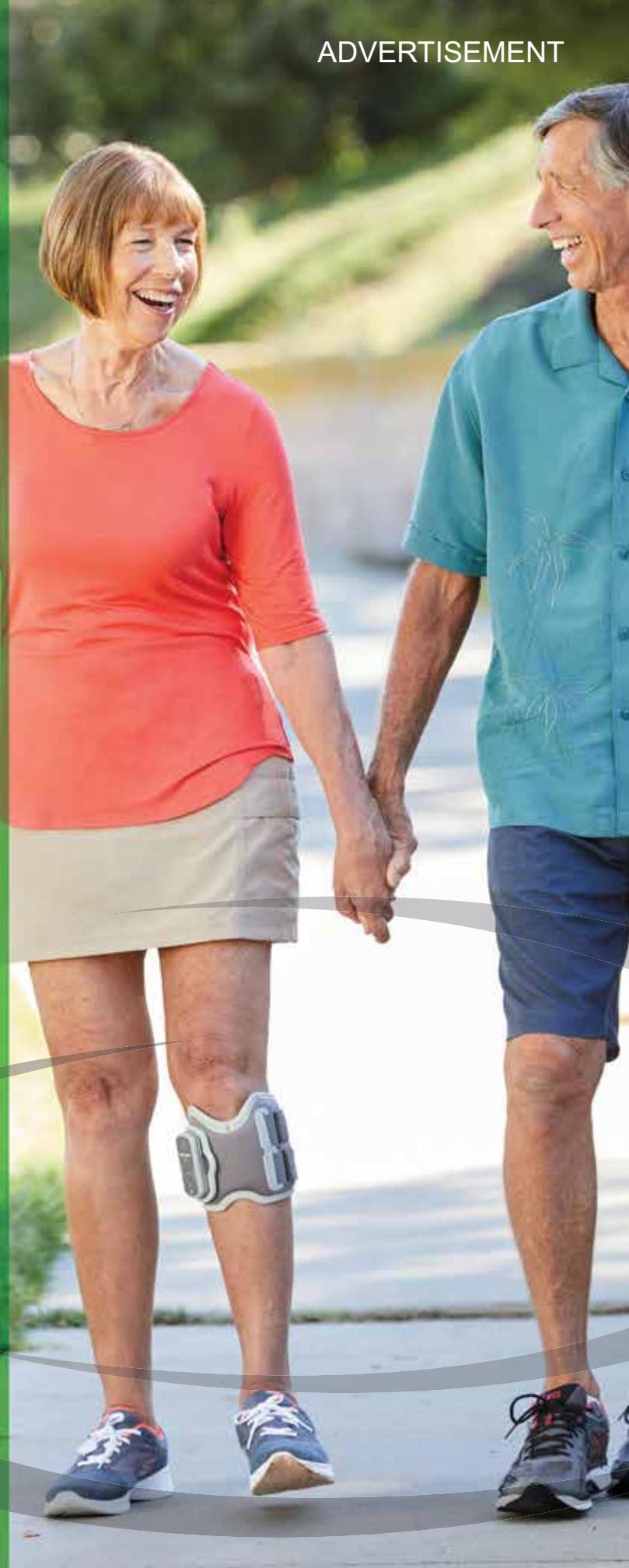
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