

momentum

nationalMSSociety.org/momentum

SPRING 2021

Facing MS

Communities of color experience disparities in diagnosis, treatment and perceptions.

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National
Multiple Sclerosis
Society

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MAVENCLAD is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include relapsing-remitting disease and active secondary progressive disease, in adults. Because of its safety profile, MAVENCLAD is generally used in people who have tried another MS medicine that they could not tolerate or that has not worked well enough.

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MAVENCLAD may cause serious side effects.

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Your healthcare provider will continue to monitor your health during the 2 yearly treatment courses, as well as between treatment courses and for at least another 2 years, during which you do not need to take MAVENCLAD. Your healthcare provider may delay or completely stop treatment with MAVENCLAD if you have severe side effects. It is not known if it is safe and effective for people to restart MAVENCLAD after the full 4-year period.

[†]Depending on your weight.

Please see Important Information, including **serious side effects**, on the following pages.

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MAVENCLAD can cause serious side effects, including:

- **Risk of cancer (malignancies).** Treatment with MAVENCLAD may increase your risk of developing cancer. Talk to your healthcare provider about your risk of developing cancer if you receive MAVENCLAD. You should follow your healthcare provider instructions about screening for cancer.
- **MAVENCLAD may cause birth defects if used during pregnancy. Females must not be pregnant when they start treatment with MAVENCLAD or become pregnant during MAVENCLAD dosing and within 6 months after the last dose of each yearly treatment course. Stop your treatment with MAVENCLAD and call your healthcare provider right away if you become pregnant during treatment with MAVENCLAD.**
 - For females who are able to become pregnant:
 - Your healthcare provider should order a pregnancy test for you before you begin your first and second yearly treatment course of MAVENCLAD to make sure that you are not pregnant. Your healthcare provider will decide when to do the test.
 - Use effective birth control (contraception) on the days on which you take MAVENCLAD and for at least 6 months after the last dose of each yearly treatment course.
 - Talk to your healthcare provider if you use oral contraceptives (the “pill”).
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 - For males with female partners who are able to become pregnant:
 - Use effective birth control (contraception) during the days on which you take MAVENCLAD and for at least 6 months after the last dose of each yearly treatment course.

What is MAVENCLAD?

MAVENCLAD is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include relapsing remitting disease and active secondary progressive disease, in adults. Because of its safety profile, MAVENCLAD is generally used in people who have tried another MS medicine that they could not tolerate or that has not worked well enough.

MAVENCLAD is not recommended for use in people with clinically isolated syndrome (CIS).

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

Do not take MAVENCLAD if you:

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- are pregnant, plan to become pregnant, or are a woman of childbearing age or a man able to father a child and you are not using birth control. See **“What is the most important information I should know about MAVENCLAD?”**
- are human immunodeficiency virus (HIV) positive.
- have active infections, including tuberculosis (TB), hepatitis B or C.
- are allergic to cladribine.
- are breastfeeding. See **“Before you take MAVENCLAD, tell your healthcare provider about all of your medical conditions, including if you:”**

Before you take MAVENCLAD, tell your healthcare provider about all of your medical conditions, including if you:

- think you have an infection.
- have heart failure.
- have liver or kidney problems.
- have taken, take, or plan to take medicines that affect your immune system or your blood cells, or other treatments for MS. Certain medicines can increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations. You should not receive live or live-attenuated vaccines within the 4 to 6 weeks preceding your treatment with MAVENCLAD. You should not receive these types of vaccines during your treatment with MAVENCLAD and until your healthcare provider tells you that your immune system is no longer weakened.
- have or have had cancer.
- are breastfeeding or plan to breastfeed. It is not known if MAVENCLAD passes into your breast milk. Do not breastfeed on the days on which you take MAVENCLAD, and for 10 days after the last dose. See **“Do not** take MAVENCLAD if you:”

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

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- Limit contact with your skin. Avoid touching your nose, eyes and other parts of the body. If you get MAVENCLAD on your skin or on any surface, wash it right away with water.
- Take MAVENCLAD at least 3 hours apart from other medicines taken by mouth during the 4- to 5-day MAVENCLAD treatment week.

- o If you miss a dose, take it as soon as you remember on the same day. If the whole day passes before you remember, take your missed dose the next day. **Do not take 2 doses at the same time.** Instead, you will extend the number of days in that treatment week.

Your healthcare provider will continue to monitor your health during the 2 yearly treatment courses, and for at least another 2 years during which you do not need to take MAVENCLAD. It is not known if MAVENCLAD is safe and effective in people who restart MAVENCLAD treatment more than 2 years after completing 2 yearly treatment courses.

What are the possible side effects of MAVENCLAD?

MAVENCLAD can cause serious side effects, including:

- o See **"What is the most important information I should know about MAVENCLAD?"**

- o **low blood cell counts.** Low blood cell counts have happened and can increase your risk of infections during your treatment with MAVENCLAD. Your healthcare provider will do blood tests before you start treatment with MAVENCLAD, during your treatment with MAVENCLAD, and afterward, as needed.

- o **serious infections such as:**

- **TB, hepatitis B or C, and shingles (herpes zoster).**

Fatal cases of TB and hepatitis have happened with cladribine during clinical studies. Tell your healthcare provider right away if you get any symptoms of the following infection related problems or if any of the symptoms get worse, including:

- fever
- aching painful muscles
- headache
- feeling of being generally unwell
- loss of appetite
- burning, tingling, numbness or itchiness of the skin in the affected area
- skin blotches, blistered rash and severe pain

- **progressive multifocal leukoencephalopathy (PML).**

PML is a rare brain infection that usually leads to death or severe disability. Although PML has not been seen in MS patients taking MAVENCLAD, it may happen in people with weakened immune systems. Symptoms of PML get worse over days to weeks. Call your healthcare provider right away if you have any new or worsening neurologic signs or 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

- o **liver problems.** MAVENCLAD may cause liver problems. Your healthcare provider should do blood tests to check your liver before you start taking MAVENCLAD. Call your healthcare provider right away if you have any of the following symptoms of liver problems:

- nausea
- vomiting
- stomach pain
- tiredness
- loss of appetite
- your skin or the whites of your eyes turn yellow
- dark urine

- o **allergic reactions (hypersensitivities).** MAVENCLAD can cause serious allergic reactions. Stop your treatment with MAVENCLAD and go to the closest emergency room for medical help right away if you have any signs or symptoms of allergic reactions. Symptoms of an allergic reaction may include: skin rash, swelling or itching of the face, lips, tongue or throat, or trouble breathing.

- o **heart failure.** MAVENCLAD may cause heart failure, which means your heart may not pump as well as it should. Call your healthcare provider or go to the closest emergency room for medical help right away if you have any signs or symptoms such as shortness of breath, a fast or irregular heart beat, or unusual swelling in your body. Your healthcare provider may delay or completely stop treatment with MAVENCLAD if you have severe side effects.

The most common side effects of MAVENCLAD include:

- o upper respiratory infection
- o headache
- o low white blood cell counts

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

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



Momentum's Spring 2019 issue won a Platinum Award in the category "Print Media | Design | 41. Publication Cover"



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



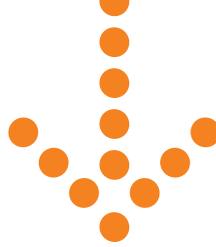
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The past two years — through 2020 and the beginning of 2021 — have been a test of resilience for all of us. We had to rise to face the pandemic, an economic recession, greater awareness of racial disparities and heightened social unrest. We had to adapt to meet challenges head on. We found that our MS movement is strong — support and encouragement can come from everywhere.

When the pandemic started in spring 2020, the National Multiple Sclerosis Society took a big hit. We experienced a sudden drop in revenue and had to cancel hundreds of events and programs.

The good news? We were prepared. We had disaster recovery and contingency plans that we activated immediately, so we could maintain a solid, stable organization while we addressed the immediate questions and concerns of people affected by MS.

We expanded connections and launched new research to learn about COVID-19 and MS. We rose to meet challenges, thanks to you and those in the MS movement. One way that has happened is through leadership volunteers, especially on our advisory committees. These committees work in concert with each other to tackle the Society's strategic plan and address current events.

For example, the use of telemedicine, for which we have been advocating over many years, became crucial during the pandemic. As people became more familiar with telemedicine, many became more comfortable with it. We saw an opportunity to expand access to healthcare immediately, as well as over the long run. Our National Medical Advisory Committee stepped up to develop guidelines for neurologists for



Cyndi Zagieboylo



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

successful virtual healthcare visits with people with MS. At the same time, our Activism Advisory Committee focused on insurers and Medicare to cover virtual visits as a routine part of MS care, continuing into post-pandemic times. (See “Health from home” on page 54.)

When COVID-19 vaccines became available, people with MS wanted to know, “Should I get vaccinated?” Our National Medical Advisory Committee brought together experts in the fields of vaccines, MS and viruses and developed guidance, gaining international consensus along the way. That guidance and information about COVID-19 and MS is regularly updated on nationalMSsociety.org/COVID19.

You can help build our MS movement. Ask your healthcare providers about their connections with the Society. Let them know that the Society is here to support them, too. Become an MS activist (ntlms.org/advocate) and amplify the voices of people affected by MS on the issues important to our community. Connect with others through a fun and interactive online version of Walk MS. Watch videos and find information about the event. Start a team and bring people together at walkMS.org.

There's a place for everyone in the MS movement. How are you participating in your National MS Society? I would love to hear from you. ■

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

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on the cover

Knowledge about MS in people of color can be lacking, but increased awareness and strides in research and treatment aim to close the gap.

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Look for these icons throughout **Momentum**.



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Treatment and strategies to manage relapses. **PLUS:** Tips to tolerate your MRI, how music might help improve how you walk and summer adventures close to home.

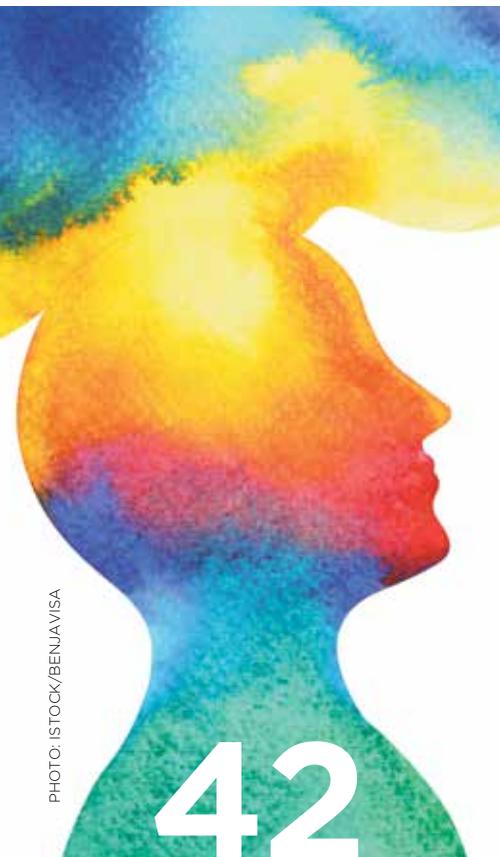


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Not the only one

I really enjoyed the Winter 2020–21 issue of **Momentum**. Although I was diagnosed nearly 10 years ago, I often look back on those early days of hearing the doc's conclusion. I so yearned to feel like, "I'm not the only one." Hearing the occasional story of someone thriving with the disease is what often reassured me. I didn't know anyone with it. I felt "too busy" for it. I certainly wasn't going to tell anyone I needed help. Today I'm an avid fly fisher (which is such a healing, tranquil and interesting sport) and feeling amazing! Most days I forget I even have MS.

Sarah Zoric, Vermont

Research for progressive MS

I wanted to thank you for this article on the medical research that is specific to progressive MS ("Halting nerve damage," Winter 2020–21). I have progressive MS, and I find there is so much research for relapsing-remitting MS. This article about the research being done for medication that might stop the neurological progression of progressive MS is really the first hope that people that have this form of MS have had.

Carole Thuesen, Montana

Steep learning curve

The article "Roll with it" (Winter 2020–21) struck me as very personal, as do most of your articles. I have had MS since 1983. I served almost nine years as a pilot in the Air Force, then 20 years as an airline pilot. I have taken most of the medication out there and now use a walker at home and a wheelchair out of the house. It has been a steep learning curve for me, as I have gone from college baseball player to pilot to cane walker to wheelchair rider on my own (with help from my wife,

an OT). I still travel throughout the country, as well as Canada and Mexico. Getting the chair and baggage through the airport by myself is a challenge most times. The article really hit home. I hope others with MS know that even though it is frustrating, it is doable to travel by yourself. Your magazine inspires me to keep up the fight.

Mike Pompoco, Ohio

Finding my outlet

Amy Black's article "MS as a cure for mediocrity" (Summer 2020) felt like a page from my life. Like her, when I was diagnosed in December 1997, I took it in stride. I thought, "OK, now what?" My folks and my future ex-husband were shocked enough for all of us. I didn't see it as a death sentence. However, I was flooded with information, pamphlets and the works, courtesy of my family. Like Amy, my personality fit MS. I was a loner. I stayed home a lot. The only activity I did was go to work, which felt like a monumental undertaking most days. I needed to do more than that — make use of this body before it went sideways. Then I found my outlet, the Walk MS events. They were my purpose and my joy for 18 years. We formed a team, named Kelly's Heroes. It was a way for my family and friends to be involved and to stay connected, until the walks were canceled. I've since found other outlets. Now I've adopted the "outing reconnaissance" Amy spoke of. How big is the store? How far away is parking? Where are the bathrooms? Where I used to dread doing anything, I crave it now. But I wanted to thank you, Amy. Your article made me feel I wasn't so alone or different from other people who have this "fictional character's disease." ■

Kelly Westerdahl, New York

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



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Not so green thumb?

You can enjoy the beauty of a garden with low-maintenance plants that are easy to grow and don't require much effort.

- **Marigolds:** Bring shades of yellow, red and gold to your garden with marigolds, which thrive in full sun and can withstand hot summers.
- **Rosemary:** A tasty seasoning and fragrant plant, rosemary thrives in well-drained soil and full sun. You can also plant rosemary in containers to bring inside during colder months.
- **Snapdragons:** These unique flowers can stand up to cooler weather in spring and fall. Bonus: They may attract butterflies to your garden.
- **Cosmos:** These daisy-like blooms do well even in poor soils and tolerate drought once they're up and growing.

For tips for gardening with MS, turn to **page 18**.

Practical ideas
for living well
with MS

in the know

5 tips for managing foot drop

Strategies to cope with this common MS symptom.

by Vicky Uhland

Ellie Tillotson has long been an avid runner, but in 2014, she found she couldn't complete a 5K race without repeatedly tripping over her feet. Alarmed, she visited her doctor and was diagnosed with multiple sclerosis.

One of Tillotson's symptoms is mild foot drop in her left foot. This common MS symptom occurs when the front part of one or both feet point downward instead of upward when you're taking a step. As Tillotson discovered, foot drop can lead to tripping, stumbling or even falls.

Foot drop has several causes. Spasticity or weak muscles in your calves and ankles can be a significant contributor. MS-related damage to the nerves that control the muscles used to flex your foot can also cause foot drop. Fatigue and heat sensitivity also make it harder for your muscles and nerves to fire correctly and lift your toes.

MS-related foot drop is not easily cured, but it can be successfully managed. Below are the top five strategies that physical therapists and people with MS say are the most effective.

1 Stretch and strengthen. It sounds a bit counterintuitive, but the ankle is just as important as the foot when managing foot drop. Muscles that cross our ankle joints help control how we use our feet, says Sara Migliarese, a physical therapist and associate professor at Winston-Salem State University in North Carolina. "It's essential to maintain both strength and standard range of motion in each ankle," she says.

A physical therapist can help you determine ankle exercises that work best for your form of foot drop. There are also some simple stretching and strengthening





ANTERIOR VIEW WITH DROP FOOT



Foot drop is a condition of weakness in the muscles of the foot and ankle, caused by poor nerve conduction, which interferes with a person's ability to flex the ankle and walk with a normal heel-toe pattern. The toes touch the ground before the heel, causing the person to trip or lose balance.

LATERAL VIEW WITH DROP FOOT



PHOTO: ALAMY.COM

Ellie Tillotson, an avid runner, was diagnosed with MS after experiencing foot drop as a symptom during her races.

techniques you can do at home every day. Migliarese recommends the following stretching exercises: Stand facing a wall. Place one foot about 18 inches in front of the other, then lean into the front foot while keeping the back foot on the ground. She also suggests walking on your heels for 10 steps, using a wall or railing to help you balance. Then turn around and walk 10 steps back.

Meredith Drake, a physical therapist at The Johns Hopkins Hospital in Baltimore, says exercises that stretch the calf muscle can give you the flexibility to pick up your toes. She recommends runners' stretches

in which you lunge forward with your front knee straight or bent. Another good stretching exercise is to let your heel hang down off the edge of a step, while gripping something stable to maintain your balance.

Drake also recommends strengthening the front muscles in the calf. Research shows that for neurological conditions, it's best to do these types of exercises while completing a task, like walking or biking.

For people who need something less challenging to their balance, Migliarese suggests strengthening and stretching exercises that can be done while seated. From your chair, place a towel or resistance

in the know

band under your foot with your knee straight, then pull your foot toward your body using the ends of the towel or bands. Or you can sit and tap your toes to the rhythm of a song.

Balance exercises are also important. Drake says activities like standing on foam or walking heel to toe challenge the foot, strengthen the ankle and improve proprioception — your awareness of where your body is in space.

2 Slow the pace. Like Tillotson, Heather Goodrich is an avid runner. In the middle of preparing for a race in 2012, she lost the use of her left leg. After she was diagnosed with MS, Goodrich regained functionality in her leg, but her foot drop didn't improve. Later she developed foot drop on her right side. She also has fatigue and heat-sensitivity issues.

"I've learned that when I'm too tired or too hot, the most vulnerable part of my body is foot drop — that's what goes first," she says.

Foot drop hasn't stopped Goodrich from running, but she's learned to pace herself. She now runs marathons in 5-kilometer increments, stopping every 30 to 35 minutes to cool down, get a drink and rest.

Even if you don't run marathons, taking steps to prevent exhaustion and overheating while exercising can help lessen foot drop.

Physical therapists say the quality of movements is more important than the quantity when performing stretching and strengthening exercises. Three to five reps of runners' stretches a few times a day is less strenuous than 20 to 30 repetitions once a day. So is both low- and moderate-intensity interval training while walking or biking.

Migliarese says on a fatigue scale of one to 10, you should stop and rest as soon as you feel like you've hit a level that is two to three points above your level when starting exercise. Stop when you first notice signs of fatigue affecting movement, either while performing exercises or going about your

daily activities. Cooling neck towels, scarves or vests are a good option when you're exercising or even just sitting outside on a hot day. Or you can try Goodrich's unorthodox but effective solution — tucking ice packs in her bra. She also recommends walking or running in a swimming pool to stay naturally cool while still getting a workout.

3 Adjust your gait. Foot drop extends the foot, making the affected leg feel longer than the other. To compensate, people may walk less efficiently, says Travis Gawler, a physical therapist with Prisma Health



Heather Goodrich still runs marathons with her foot drop by pacing herself in 5k increments.

in Columbia, South Carolina. Someone with foot drop can develop a “steppage gait,” raising their knee higher or relying more on their hip flexors to help pick up their feet. A steppage gait uses more energy overall, creating a vicious cycle in which the walking pattern used to overcome foot drop generates the fatigue that can worsen foot drop and affect the overall safety and quality of mobility-related activities of daily living.

“It’s like you’re moving from being a nice, efficient Prius to a gas-guzzling Expedition,” Gawler says.

To counter this, he suggests slowing down when you walk. The faster you walk, the more you work and tire your muscles, resulting in more foot drop.

Diane Meyer, a physical therapist in Cary, North Carolina, says another option is to add no larger than a three-eighths-inch shoe lift to the stronger side. “This allows more space for clearance of the dropped foot when advancing the more affected or weaker leg forward,” she says.

Gawler recommends snug-fitting shoes — slip-ons may slide off the feet while walking. He cautions against heavier shoes with rubber soles, which can fatigue muscles faster. He says any heel higher than a normal tennis shoe can make walking less stable and require more force from lower leg muscles. And consider shoes with higher tops to help stabilize the ankle.

4 Brace yourself. Goodrich wears a special kind of brace called an ankle-foot orthosis, or AFO, on both legs most of the time. AFOs reach down into the shoe and are designed to keep the ankle in place and help control its movement. Depending on how high the brace goes up your leg, it can also help stabilize the calf or knee. And AFOs can reduce high-stepping walking patterns.

Dozens of AFOs are available, with varying degrees of quality and construction. Some are made of molded plastic, which offers more stability but can get hot and bulky. Others are constructed from carbon fiber, which is lighter and has fewer contact points on your leg — a plus if you’re sensitive to touch.

There are rigid braces designed to keep the ankle from rolling for people with spasticity in their ankles. “You need to explore, especially if you’ve

had bad experiences with bracing before,” Gawler says. “No one size fits all.”

While you can buy braces off the shelf, most physical therapists recommend having a prescription brace custom made or custom fitted by an orthotist. These types of AFOs can cost around \$500 or more, Migliarese says. Tillotson says her private insurance company paid for 90% of her custom-designed, carbon-fiber brace, which she recently got to replace an off-the-shelf AFO.

“I’ve run five marathons in my AFO,” she says. “It helps with tripping, but it’s not 100% effective.”

5 Get stimulated. In essence, braces do the work for you, which doesn’t help strengthen your leg or ankle muscles, Migliarese says. But functional electrical stimulators (FES) cycle on and off with each step, creating muscle activation, reducing spasticity and promoting a more normal gait.

FES devices, marketed under brand names like Bioness and WalkAide, deliver an electric current from a cuff below your knee to a sensor on the nerve that directs your muscle to lift your foot. Because an FES doesn’t fit inside your shoe like a brace, you can use it when barefoot or wearing sandals. It’s also less bulky and more discreet than a brace.

FES sensors need to be fitted to your nerve endings by a physical therapist. Because they deliver an electrical zap every time you take a step, they can take some getting used to. “You need to build up a tolerance,” Drake says.

FES devices are not cheap, ranging from \$5,000 to \$8,000 per leg. And because they’re considered experimental, they’re usually not covered by insurance. But Goodrich swears by her bilateral Bioness FES devices and is even running marathons in them.

“I have no doubt in my mind that exercise has kept my MS from progressing,” she says. “My left foot is completely dropped, and I don’t trust my right foot. But I’ve found that foot drop is not a reason not to be active.” ■

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

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

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TO FIND A WAY TO KEEP

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

*Clinical Trial 1 (TEMPO) included 1,088 people and Clinical Trial 2 (TOWER) included 1,165 people over 2 years. AUBAGIO 14 mg and 7 mg achieved a significant relative reduction in relapse rate in TEMPO (31%, 31%) and TOWER (36%, 22%) versus placebo. In TEMPO, AUBAGIO 14 mg, AUBAGIO 7 mg, and placebo, the percentage of people who remained free of disability progression were 80%, 78%, and 73% respectively. AUBAGIO 7 mg did not achieve a statistically significant reduction in risk of sustained disability progression. The most common side effects include: headache (16%, 18%, 15%), diarrhea (14%, 13%, 8%), nausea (11%, 8%, 7%), hair thinning or loss (13%, 10%, 5%), and abnormal liver test results (15%, 13%, 9%) for 14 mg, 7 mg, and placebo, respectively.

SEE WHAT ONE PILL  ONCE A DAY CAN DO

INDICATION

AUBAGIO® (teriflunomide) is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.

IMPORTANT SAFETY INFORMATION

DO NOT TAKE AUBAGIO IF YOU:

- **Have severe liver problems. AUBAGIO may cause serious liver problems,** including liver failure that can be life-threatening and may require a liver transplant. Your risk may be higher if you already have liver problems or 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.

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.

MOVING FORWARD*

talk to your doctor about once-daily AUBAGIO



Patient Portrayal



Visit myAUBAGIO.com or scan here to learn more

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), over-the-counter medicines, vitamins or herbal supplements.

AUBAGIO may cause serious side effects. Tell your doctor if you have any of the following:

- o **decreases in white blood cell count** — this may cause you to have more infections. Symptoms include fever, tiredness, body aches, chills, nausea, or vomiting. Patients with low white blood cell count should not receive certain vaccinations during AUBAGIO treatment and 6 months after
- o **allergic reactions** such as difficulty breathing, itching, or swelling on any part of your body including lips, eyes, throat, or tongue
- o **serious skin reactions** that may lead to death. Stop taking AUBAGIO if you have rash or redness and peeling, mouth sores or blisters
- o **other allergic reactions that may affect different parts of the body** with or without a rash; other

symptoms you may have include fever, severe muscle pain, swollen lymph glands, swelling of your face, unusual bruising or bleeding, weakness or tiredness, yellowing of your skin or the white of your eyes

- o **numbness or tingling in your hands or feet that is different from your MS symptoms**
- o **high blood pressure**
- o **breathing problems (new or worsening)** — these may be serious and lead to death

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

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

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

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



PILL ACTUAL SIZE

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

Medication Guide
AUBAGIO® (oh-BAH-gee-oh)
(teriflunomide)
tablets, for oral use

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, including liver failure that can be life-threatening and may require a liver transplant. Your risk of developing serious liver problems may be higher if you already have liver problems or 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), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.
- It is not known if AUBAGIO is safe and effective in children.

Who should not take AUBAGIO?

Do not take AUBAGIO if you:

- have severe liver problems.
- are pregnant or are of childbearing age and not using effective birth control.
- have had an allergic reaction to leflunomide, teriflunomide, or any other ingredients in AUBAGIO. Please see the end of this Medication Guide for a list of ingredients in AUBAGIO.
- take a medicine called leflunomide.

What should I tell my doctor before taking AUBAGIO?

Before you take AUBAGIO, tell your doctor about all of your medical conditions, including 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 over-the-counter 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.
- **allergic reactions.** Call your doctor right away or get emergency medical help if you have difficulty breathing, itching, swelling on any part of your body including in your lips, eyes, throat, or tongue.
- **serious skin reactions.** AUBAGIO may cause serious skin reactions that may lead to death. Stop taking AUBAGIO and call your doctor right away or get emergency medical help if you have any of the following symptoms: rash or redness and peeling, mouth sores or blisters.
- **other types of allergic reactions or serious problems that may affect different parts of the body such as your liver, kidneys, heart, or blood cells.** You may or may not have a rash with these types of reactions. Other symptoms you may have are:
 - fever
 - severe muscle pain
 - swollen lymph glands
 - swelling of your face
 - unusual bruising or bleeding
 - weakness or tiredness
 - yellowing of your skin or the white part of your eyes
- **numbness or tingling in your hands or feet that is different from your MS symptoms.** You have a higher chance of getting these symptoms if you:
 - are over 60 years of age
 - take certain medicines that affect your nervous system
 - have diabetesTell your doctor if you have numbness or tingling in your hands or feet that is different from your MS.
- **high blood pressure.** Your doctor should check your blood pressure before you start taking AUBAGIO and while you are taking AUBAGIO.
- **new or worsening breathing problems.** These may be serious and lead to death. Call your doctor right away or get emergency medical help if you have shortness of breath or coughing with or without fever.

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

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-FDA-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 the 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.

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

What are the ingredients in AUBAGIO?

Active ingredient: teriflunomide

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

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

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

Manufactured for:

Genzyme Corporation
Cambridge, MA 02142
A SANOFI COMPANY

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Rx Only

How does your garden

Digging in the dirt can yield a bushel of benefits for people with MS.

by Vicky Uhland



Thirteen years ago, Iona Creedon's life was upended. She had just given birth to her daughter when she was diagnosed with multiple sclerosis. To destress and unwind, Creedon turned to gardening.

Even though she lives in the aptly named Letchworth Garden City in Hertfordshire,

England, Creedon hadn't been a dedicated gardener before her diagnosis. But she felt she needed the mental, emotional and physical solace that only digging in the dirt can give.

"There's such a sense of achievement in making something attractive, in creating a space that makes your heart sing when you're outside," she says. "I use gardening as a form of therapy. It's incredible for my mental health."

Gardening can be intimidating even if you don't have MS. It can be physically punishing and emotionally brutal — ask someone who has watched a sudden hailstorm shred the rare rosebush they've nurtured since its infancy. But gardening can also create a Shangri-La for mind, body and spirit.

"Gardening is one of those perfect activities for many people with MS. It's calming, relaxing, meditative, physically challenging and requires some planning and cognitive work," says Simon Gale, an occupational therapist and adventure guide at Swedish Neuroscience Institute's Multiple Sclerosis Center in Seattle.

Stephanie Scharf, an occupational therapist at Prisma Health in Columbia, South Carolina, who's studying to become a master gardener, has found that gardening can have other pluses as well. "It can actually boost my energy levels because it's fun to do," she says.

Since her diagnosis, Creedon has learned how to do everything from building a patio to hauling compost while experiencing MS symptoms. She's prone to fatigue and heat sensitivity, along with dizziness and cognitive issues when she's tired. But she makes accommodations that allow both her and her garden to thrive.

Creedon shares her gardening advice in her blog, *Gardening within LiMitS* (gardeningwithinlimits.com). Here's what she, Gale, Scharf and other gardening experts recommend for specific MS symptoms that can make gardening challenging.



Iona Creedon took up gardening to help manage stress after her MS diagnosis.



PHOTO: ISTOCK/AZMANJAKA

grow?

Fatigue and heat sensitivity

While Creedon was experiencing MS symptoms, she dug a pond. But gardening tasks don't have to be that Herculean.

Relying on family members or hiring someone to mow, weed, rake leaves or do other strenuous tasks you don't like can free up your energy for planting or other gardening activities that bring you joy.

You can also minimize the effort needed in your garden by choosing plants and shrubs that don't require a lot of cutting back or constant tending. Herbs are excellent options, and perennial flowers don't have to be replanted every year as annuals do.

Low-water plants can also reduce the need to lug a heavy hose around. Another option is an irrigation system or soaker hoses that don't have to be moved. And put plants that require more watering closer to the edge of a garden bed to make them easier to care for.

"Find plants that suit your condition as well as the garden's condition," Creedon says. To make sure she doesn't become so fatigued that she can't garden the next day, Creedon limits physically demanding tasks to an hour, then sits and writes a blog entry. Others might need shorter gardening time

frames and longer rest periods. Because gardening can be deceptively labor-intensive, pace yourself as you would if you were exercising.

"Have a plan for what your gardening session will look like, along with a threshold for when you're done," Gale says. "If you hit a wall, know where you can go to rest, like a lawn chair nearby."

Another option is to incorporate gardening tasks into your daily activities. Take a short walk or ride around the garden, pulling a couple of weeds from each bed. Or deadhead the flowers in your container garden while drinking your morning coffee on the terrace.

Creedon also reduces fatigue by using a wheeled utility cart to haul her tools and heavy items like bags of compost. And she opts for ergonomically designed gardening implements that reduce unnecessary movement and are easier to grip if she's feeling weak in her hands.

Ergonomic or other high-quality tools can reduce fatigue in other ways, Gale says.

"Attention is a limited resource. For instance, if you have a hand tremor and a small tool doesn't work well, it can be a distraction that tips you over the edge into neurological fatigue. And that can reduce

“
Find plants that suit your condition as well as the garden's condition.”

— Iona Creedon

in the know

your ability to plan and control the various movements required for gardening.”

Creedon likes to garden in the early morning or early evening when the temperatures are lower. Even then, it can be useful to wear cooling cloths, scarves or vests. Wide-brimmed hats can shade your face, and a veil hanging from the back of the hat will keep the sun off your neck.

Mobility and balance issues

Scharf is a big fan of raised gardening beds, which eliminate the need to bend down and accommodate people in wheelchairs or scooters. The ideal bed is 24 to 30 inches tall, she says. It also should be narrow enough so you can reach the middle while seated. Raised beds should be placed at least four feet apart to accommodate a mobility device.

It's also crucial to consider tripping or falling hazards when designing paths between your raised beds or other parts of your garden. “Other than bathroom falls, gardening falls are amongst the top falls we hear about,” Gale says.

“Gardening for Life,” an adaptive gardening guide produced by Washington State University Master Gardeners in Spokane County (pnwmg.org/pdf/mggardenforlife.pdf), points out that gravel, rock, grass or bark paths are poor choices for people who use mobility devices or have balance issues. The guide suggests concrete, stone slab, crushed stone or brick paths instead.

If you need to tend garden beds at ground level, Scharf suggests using a garden kneeling bench with an adjustable height and a metal bar to help you get up. Make sure the bench is sturdy enough so you can sit or kneel on it. She avoids garden carts with lids you can sit on unless there's a way to lock the wheels or keep the cart from moving and tipping you off the seat.

“Gardening for Life” recommends placing garden beds near your house or driveway for quick accessibility. Container gardens on patios or balconies can bring your landscaping even closer.

And make sure to provide plenty of seating throughout your garden for rest breaks.

Vision and cognitive challenges

Creedon recommends drawing a plan of your garden that identifies the plants in every bed. Planting in clumps, like amaryllis in one area and ginger in another, can also help you remember and visualize what's in each bed.

For people with vision issues, “Gardening for Life” suggests choosing plants with high contrast like coleus, lamium, coral bells, variegated red-twig dogwood, emerald and gold euonymus, and tri-color beech. It also recommends plants with bright red, orange or pink flowers, which are easier to see than blue or purple blooms. And avoid cacti, roses or other plants with painful thorns or spikes.

To keep track of your plants and where they're planted, try metal markers that identify plants. Scharf also suggests writing the name of the plant on a ribbon and tying it to the plant. “Make sure the ribbon is not so tight it will affect the growth of the plant,” she says.

“If you use a ribbon or some type of color marker without the plant name, write down the plant name on a piece of paper or graph paper so you can keep track of what is planted in that location,” Scharf adds.

Creedon likes to focus on all of the senses while gardening. So, if you can't see a plant well, you can still touch, hear, smell or taste it.

“There are amazing plants to feel, like lamb's ear. You can hear the rustle of certain grasses when the wind is blowing,” she says. “And the sound of a water feature is a gentle way to appreciate your garden.” ■



A planter box can make a garden more accessible.

PHOTO: ISTOCK/T623

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

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

Facing MS

People of color are raising awareness about the ways they experience MS. And they're taking the lead in advocating for more research and improvements in diagnosis and treatment. They hope that a new focus will lead to a better understanding of their symptoms and disease progression and begin to erase some long-standing disparities and misperceptions.



PHOTO: ISTOCK/WILDPIXEL

thrive

Forging a path
to your best life

Inside this section: Confronting inequities in research, diagnosis and treatment 22 // Experiences unique and shared 30 // Obstacles to access 35

Confronting inequities

in research, diagnosis and treatment

Uncovering the gaps in knowledge and awareness.

by Brandie Jefferson

Diagnosing multiple sclerosis can be a lengthy, circuitous, sometimes frustrating process no matter what the person's background is. Although some research suggests Black and brown people get diagnosed sooner — perhaps because they have more severe symptoms earlier — some of the stories Dr. Mitzi Williams, MD, has heard in her clinic paint a very different picture.

“In my clinical experience, a fair amount of my Black patients have had delays in diagnoses,” says Williams, a neurologist and MS specialist at the Joi Life Wellness Group in the Atlanta metro area. “They said, ‘The doctor told me Black people don’t get MS.’”

There is no blood test or single genetic marker to tell a doctor that someone does or does not have the disease. Instead, a diagnosis is pieced together by ruling out other things (such as Lyme disease) and using MRI scans to look for lesions in the brain, spinal cord or optic nerve. Doctors also question patients about their history, teasing out stories that might

indicate a prior flare-up or perhaps suggest a different diagnosis altogether.

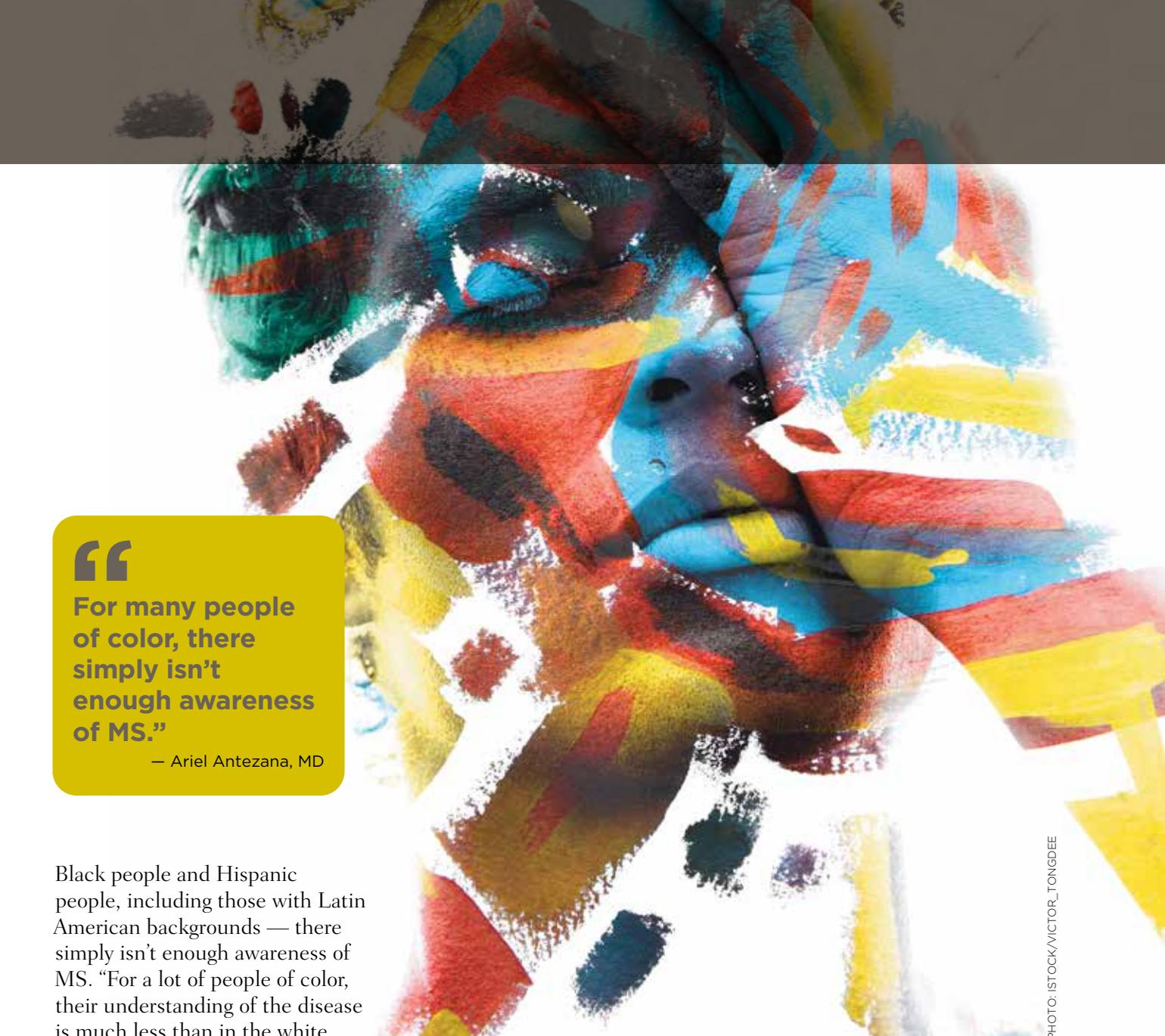
In short, MS doesn't always present itself. You have to go looking for it.

“MS symptoms can be common to other conditions, so if a patient is not a classic phenotype, a doctor may not go looking for it,” Williams says.

Awareness often lacking

In particular, the expected phenotype of MS is a person of European descent. Recent research, however, indicates a higher incidence of MS in Black people than previously thought — consistent with the rate in white people.

Many times, people with MS can be their own best advocates, but only if they know what they're advocating for. Knowledge about MS is spreading, but in his experience, Dr. Ariel Antezana, MD, director of the NeuroMedical Clinic of Central Louisiana MS Center, says for many people of color — particularly



“For many people of color, there simply isn’t enough awareness of MS.”

— Ariel Antezana, MD

Black people and Hispanic people, including those with Latin American backgrounds — there simply isn’t enough awareness of MS. “For a lot of people of color, their understanding of the disease is much less than in the white population,” he says.

That was true of 30-year-old Jovany Hernandez, who lives in Florida. In 2016, he went to the emergency room with pain radiating from his testes into his legs. He was told he might need surgery if he wanted to have children in the future. In his late 20s and recently married, Hernandez was planning a family, so he decided to have the surgery. The pain went away, and so did his concerns, until he experienced severe vertigo, which morphed into double vision.

He went back to the ER. “They did an MRI, and they found lesions, the whole shebang,” Hernandez says. “They called them ‘abnormalities.’” This was the first

time he heard “multiple sclerosis,” but that wasn’t his diagnosis. Doctors told Hernandez that he probably did not have MS, but an MS mimic, specifically, acute disseminated encephalomyelitis.

Then, as is common with relapsing-remitting MS, Hernandez’s symptoms simply went away. “I forgot about MS, to be honest,” he says.

Just before Christmas of 2017, his face went numb. Hernandez waited it out through the holidays and returned to the hospital on December 26 for another MRI. “Within two hours, they diagnosed me with MS.” No one told Hernandez, “Latinos don’t get MS,”

PHOTO: ISTOCK/VICTOR_TONGDEE

and he says bias or any preconceived ideas on the part of the medical system wasn't something he even considered. "I just wanted to get better."

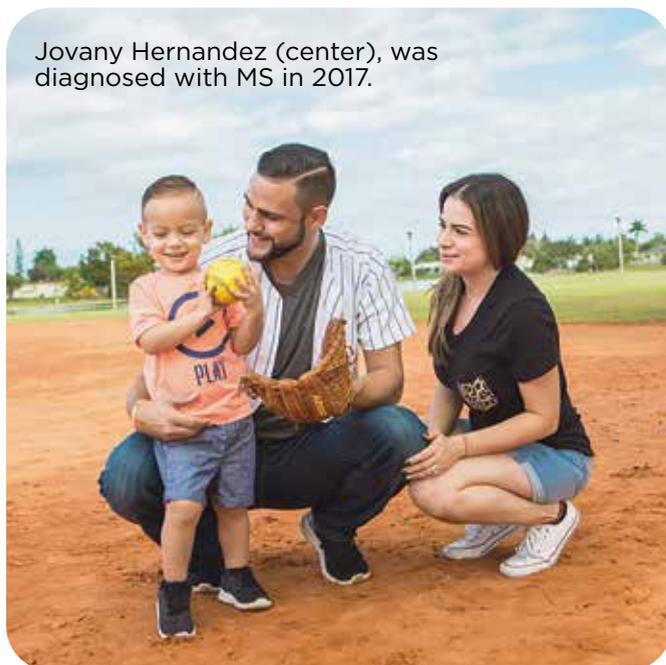
But Hernandez, the son of two Cubans, had a symptom that is relatively common among some in the broad demographic under the umbrella of "Latin American" — vision issues. After his bout with vertigo and double vision, he could have pressed the MS issue, but he didn't know enough about the disease to do so.

By the time it came to talk about treatment options, Hernandez was prepared and had immersed himself in MS research. He was able to be his own advocate.

Gaps in knowledge, lack of trust

For others, crossing the bridge from diagnosis to treatment can be difficult.

When that time comes, a person might meet with a clinical pharmacist like Jenelle Montgomery, who works for the Duke University Hospital. She helps people understand their medication options and works with them to navigate questions about insurance and other logistics. Montgomery answers a lot of questions. Many factors affect how much people understand therapies, their efficacy and their importance.



Jovany Hernandez (center), was diagnosed with MS in 2017.

PHOTO: SONYA REVELL

"Knowledge gaps in education for Black and brown people do exist as an extension of the socioeconomic and health disparities we see in the U.S. as a whole," Montgomery says.

"I think these disparities can have greater consequences with Black and brown patients," Montgomery adds. Because even with a similar knowledge gap, Black and brown people face a higher disadvantage than their white counterparts. "Research shows Black people with MS might have more aggressive disease and greater disability," she says. "And in Hispanic and Latin American populations, people are diagnosed at a younger age."

Therefore, it's crucial that newly diagnosed people and their doctors move as quickly as possible to knock down any potential barriers to care and put together a treatment plan, Montgomery notes.

On its own, though, being better educated about therapies won't persuade everyone to consider taking a disease-modifying therapy (DMT) or unfamiliar medication. "Particularly with African Americans, you sometimes see a mistrust of the healthcare industry, that it's going to exploit them or treat them unfairly," says Dr. Nuhad Abou-Zied, MD, an MS specialist at Wake Forest Baptist Health in North Carolina.

The mistrust is warranted. From the "Father of Modern Gynecology" James Marion Sims, who experimented on enslaved women, to the Tuskegee Study, which for 40 years observed Black men with syphilis, not treating them even after the discovery of penicillin, history is rife with mistreatment of Black and brown men, women and children.

This history is not ancient — the last living participant in the Tuskegee Study died in 2004 — and many communities have not forgotten.

Trust must be earned. Having more Black and brown neurologists, more doctors who implicitly understand this history, would help, Montgomery says. "I do think that giving knowledge and education to patients can be more effectively delivered, and more effectively received if they build trust," she says. "That could be done by seeing people who look like you."

In 2019, the American Academy of Neurology counted 2.7% of its members as Black and 8.5% as Hispanic or Latinx. Even without a shared cultural

“Hey, how are you?
I have MS. OK, cool.”

Jovany Hernandez isn't shy about sharing his MS diagnosis.

PROFILE

In 2016, when Jovany Hernandez started to have a radiating pain in his testes that shot down his leg, he took his symptoms seriously. But as many people do, he let the experiences fade once the pain had passed. “I didn't go back [to the doctor] as much as I should have,” he says.

It took several trips to the ER for Hernandez to be diagnosed with multiple sclerosis. MS is notoriously difficult to diagnose. He thinks his attitude toward his symptoms may have delayed his treatment.

“If I would've gone to the hospital sooner, I'm sure they would have diagnosed me sooner,” he says.

At 30, Hernandez isn't a stereotypical I-don't-go-to-the-doctor kind of guy. “I go more than anyone else in my family,” he says. “I see my primary care physician once a month.” A history of cancer runs in his family, so he has always been mindful of his health.

So, what happened?

When his MS symptoms started, “I thought maybe this is normal. It just feels like pins and needles when I take a shower, but it'll go away.” And it did, so he could relax for a while.

Now, however, “relax” doesn't seem to be in his vocabulary. He was laid off from his job while taking the time to spend with his new baby in 2018. “I just thought, maybe now I need to do everything I can to start doing what I love.”

He's joined multiple softball leagues. “I play softball five days a week — Sunday through Thursday, every night, sometimes two or three games a day,” he says. He bought his dream turntable setup and started his own DJ business. He belongs to an MS support group.

Hernandez says he stays engaged with the MS community so that he can be an effective messenger to a public that doesn't always understand the disease.

“I feel like we need to spread awareness, and that's why I work with the National MS Society,” he says. “I feel like I'm doing my due diligence.” And as a young Latin American man, he checks off several boxes that contradict the narrative of who gets MS.

So, he's not shy about sharing his illness.

“I tell everyone,” he says. “I just met you? ‘Hey, how are you? I have MS. OK, cool.’”



PHOTO: SONYA REVELL

perspective, Abou-Zied says, respecting another person's beliefs and culture can go a long way toward earning trust. When people do not want to start on MS therapies, there are a few things she might do: If they are stable, she might agree to observe for a while. If a patient wants to lean on their religion, or a safe, non-medical treatment, she agrees. "Most of the time, once I follow up, I say, 'Why not do both? Yes, pray or use CBD lotion, but also start on a DMT.'"

"Doctors will sometimes dismiss people if they don't want to be on medication," she says, "But most people are quite reasonable. I'll just explain the options."

However, there are cases where it's clear patients do not understand the potential repercussions of not starting a DMT.

"I never use scare tactics," Abou-Zied says. "I try to be mindful and have a positive outlook, but I do sometimes tell people, 'Look, we have to stop this.'"

A mindful approach is particularly crucial in Black and brown populations because of the course the disease takes. "Most of the damage happens in the first few years," Abou-Zied says. "And by the time there is disability, there is little I can do."

Even if someone decides to use a DMT, they still face decisions. They may hear conflicting information when it comes time to choose one of the now 19 available options. It's not infrequent to hear, for instance, that some drugs work better in Black patients than others. There is some data to support this, but not much. When it comes to any question about the biological relationships between race and MS, there just isn't enough evidence to say, one way or another.

Race and disease

To better understand how race may affect the way people experience MS, one first has to understand what "race" means in the context of medicine and if the categories we use — which are predominantly based on how people look — suggest any underlying biological similarity.

In a paper published earlier this year in the *Multiple Sclerosis Journal*, authors J.L. McCauley of University of Miami's Miller School of Medicine and Lilyana Amezcua of the University of Southern California's Keck School of Medicine looked at this question

in service of MS research. The National Multiple Sclerosis Society funded the study.

From a genetic standpoint, most Black Americans have genes with a mixture of European origins and African origins. People who fall under the category of Hispanic have in their genes differing amounts of DNA originating in America, shared with Native American people, in addition to Europe and Africa. And of course, any individual can have genetic material with origins from anywhere in the world — whether or not they know it.

The categories used in everyday language are insufficient when it comes to studying the disease. For example, the authors write:

"The use of a single Hispanic ethnic category is insufficient to distinguish genetic variability between Mexican and Puerto Rican populations, which could be important when examining why a certain disease that has a genetic basis is more common among individuals with Puerto Rican ancestry versus those individuals of Mexican ancestry."

Or, as Abou-Zied says: "It's more about genetics and not about appearance or color of skin."

Race is not a substitution for genetic markers, but race can function as a starting point.

"MS is far behind in genetic research," compared to certain cancers, for instance, Williams says. "We see worse outcomes in Black and Hispanic populations, and we're working our way backward to see if there is some underlying biology to it, or is it socially determined, or some combination of both. We just don't have the data." There aren't a lot of biomarkers to help determine disease severity, she says.

Symptoms and disease progression

"We have to be very careful about generalizing, but the trends we see are that Black people with multiple sclerosis tend to have more disability earlier in the disease," Williams says.

Black people with MS also tend to have more lesions on the optic nerve and spinal cord, correlating with disability, according to Amezcua and McCauley's research. "Black people have to use a cane up to six years earlier than their white counterparts. They are

“How do I survive with this? Because I’m going to.”

Billie Walker was determined to remain strong after her diagnosis.

PROFILE



Just as any individual labeled as a particular race can have genetic material from any part of the world, an individual’s experience of MS is just that — individual.

Billie Walker, diagnosed with relapsing-remitting MS in 2008, didn’t want to tell her family about her diagnosis.

One August day, Walker had parked her car and was on her way to the grocery store when the left side of her body just feel asleep. “Like when your foot falls asleep,” she recalls. She knew something was wrong but was confused by people’s reactions — or lack thereof.

“I looked around like, ‘Why isn’t anyone coming to help me?’” assuming she was visibly debilitated. But she could get back in her car and go home, where she noticed she looked perfectly fine.

She was confused — and alone.

She started visiting doctors to figure out what was wrong. There were tests and steroids — but she didn’t get better.

Finally, she had a lumbar puncture. “Mind you,” she says, “I was going through this all by myself.” And she absorbed the results by herself as well. “I said, ‘I have ... what?’ I didn’t know what that

meant,” she says of when she first received her MS diagnosis. When she looked it up online, “They give you the scariest scenarios.”

So Walker was determined not to share the news. “I knew when I told my family, they were going to think I was dying,” she says. She

waited three months before she finally told her sister.

“I didn’t want to burden anybody.” That doesn’t mean she sat back and ignored the problem. “Whatever this is,” Walker recalls thinking, “it isn’t getting me.”

At 36, she graduated with a bachelor’s degree in human resources while working full time and raising her infant daughter. “I had to research how people lived with MS. I had to ask, ‘How do I survive with this? Because I’m going to.’” Then, she says, “I took it on with a vengeance.”

admitted to nursing homes earlier. They have more MRI lesions, as well as faster atrophy or shrinkage of the brain.

“In just about every domain,” Williams says, “they do worse.” But she points out that the research is limited and that more studies are necessary to understand why. She adds many Black people with MS do well.

Among the populations that make up Hispanic and Latin Americans, MS tends to present itself earlier, according to a study published this year by Amezcua in the *Journal Practical Neurology*. Although the rate of disease is lower than in white Americans, outcomes are poorer, Williams says. “We see optical disease, long spinal lesions and poorer outcomes in terms of disability.” To narrow the gap, researchers and healthcare professionals need reliable data. In its absence, however, there are steps that clinicians and

people with MS can take to help ensure the best possible outcomes.

Abou-Zied trained for 14 years to specialize in MS. In general, she says doctors training in neurology do not have a lot of exposure to many of the varied illnesses under that umbrella, including MS.

“In my four years, I only saw a few MS patients,” Abou-Zied says of her residency. “MS was kind of tucked away, aside from a few inpatients,” who would not necessarily present in the same way a new patient with suspected MS would. Many non-specialist neurologists do take a particular interest in MS, keeping up to date with the latest developments and research, she says. Still, she says, the field could benefit from more exposure to different MS populations during residency.

"I walk people through the process of starting a medication."

Jenelle Montgomery draws solutions from experience.

PROFILE



Jenelle Montgomery, a clinical pharmacist at Duke University Health, works with people at some of their most critical intersection points with healthcare.

She works in the neurology clinic, helping people with MS and their medical teams devise effective treatment plans and then follow through.

"I walk people through the process of starting a medication," she says. She answers questions about efficacy, expectations, potential side effects and cost. Then she follows up with people receiving care and with providers to answer questions about side effects.

Because she sees people so soon after their diagnoses and gets so many questions, Montgomery can spot some of the areas where the system could better address disparities that tend to put Black people and other people of color with MS at a disadvantage.

As a result of her experience, she has suggestions for solutions:

- Increase awareness about MS, MS symptoms and disease progression in people of color with MS.
- Make sure educational materials are available in languages other than English.
- Improve efforts to understand cultural perceptions so that instructions are easily understood.
- Encourage self-advocacy and stress the importance of networking and building communities with other people with MS.
- Establish a minimum percentage of minority enrollment in clinical trials.

For more information, visit ntlms.org/minoritiesinresearch.

Williams, also an MS specialist, agrees. "I would love to broaden access to MS-specific care," she says. Although, she says, merely having access to a general neurologist would be an improvement in many communities.

Presenting a clearer picture of what's at stake is also something the doctors all agreed could go a long way to improve outcomes. "I've seen a number of people who were diagnosed but did not take a DMT because they weren't informed of the consequences of the disease," Williams says. "They've said, 'Oh, I didn't realize what was at stake.'"

Antezana has seen the same at his clinic in Louisiana. "Lots of patients know the disease, but they don't know how bad it can be," he says. "It can be debilitating if not treated, but it can also be a chronic, manageable condition if it's diagnosed in time and, critically, if it's treated appropriately."

Cultural considerations

The culture of medicine isn't the only external factor affecting outcomes; in some Black and brown communities, traditions, perceptions and expectations can be an influence for better or worse.

Antezana says it's not unusual in immigrant communities, where people shun the hospital for fear of being looked on with suspicion or, if they don't have documentation, fear of being deported. He tries to reach people where they are, hosting community events and speaking at seminars and webinars.

Being an immigrant from Bolivia, Antezana also can speak to a wide range of people in their first language. He recently spoke in Spanish at a National Multiple Sclerosis Society webinar, discussing the relationship between COVID-19 and DMTs.

"I enjoy it," he says. "When I see patients in a busy clinic, there's not a lot of time to discuss everything. You have to focus on the patient him/herself." Webinars give him a chance to discuss a broader range of topics.

Williams notes that people may not recognize that in marginalized communities, they can seek other opinions, even if their needs are not being addressed. "If you don't get what you need, it's OK to get a second opinion," she says. She is quick to add, "That doesn't

mean you get up and leave a doctor that doesn't say what you want to hear."

Some communities may perceive chronic illness as a sign of weakness, Montgomery says, or fear it means losing independence. Those perceptions can lead to delaying treatment or even impact a decision to go see a neurologist in the first place — all of which can lead to poorer outcomes, according to Montgomery.

It's unclear whether societal factors are the only ones at play. It's not clear what biological mechanisms might underlie poorer outcomes for Black and brown people with MS. There isn't much data either way.

A lack of data

"One of the biggest limitations we have is that most of the data we have is not clinical trial data," Williams says of data specific to Black and brown people with MS. "Clinical trial data is key." It eliminates the gaps that may be caused by socioeconomic factors. Medication is most likely free. Access to a doctor is guaranteed. If a trial participant has any changes in condition — such as a relapse — a doctor will see them quickly.

"With everybody getting essentially the same care, we will be better able to see trends and actual outcomes," Williams says. What is clear from the limited clinical trial data that is available is both promising and disheartening: "People do very similarly."

But she cautions that research with larger numbers of people is needed.

"If you look at most of our trials, probably the largest number of Black people enrolled in any clinical trial program is about 60 out of several thousand people," Williams says. Most trials average 10–20 Black participants. "You cannot make a generalization about a whole population based on 15 people."

There is even less data for Hispanic, Latin American and Native American people with MS. There are a few possible reasons for the lack of Black and brown people involved in clinical trials: a history of being experimented on as opposed to being willing participants in experiments, difficulty traveling to and from a medical institution, the potential to need to miss work. All of these factors are potential

barriers to anyone, but they hit Black and brown communities harder.

Still, information coming directly from Black and brown people with MS suggests they face additional roadblocks when studying participation. A survey of 2,600 people, including about 400 Black and brown people, conducted by the MS Minority Partner Engagement Network, asked for people's attitudes toward research. "Most of the responses about research were very positive," Williams says. When asked, a majority of participants of all backgrounds said they would participate in research. Looking at the reasons Black respondents said they didn't participate, "Many said they weren't asked and didn't know where to find info about being involved in clinical research."

And on the clinical side, enrollment criteria can often rule out people with certain conditions that are more likely to be found in Black and brown communities, Williams says, such as diabetes or high BMI (body mass index).

Diversity in research

Williams is hopeful, however, that change is coming. "COVID has brought attention to the disparities of healthcare in our country," she says. "I hope that this will have a ripple effect in terms of increased funding about the differences we see."

"I'm hopeful we'll get some answers," Williams says, "because now tools are more readily available and there is more of a focus on this work." ■

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



Watch a video about the importance of minority engagement in clinical trials. Visit nflms.org/clinicaltrials.

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

Experiences unique and shared

Three Black women offer their personal insights about healthcare.

by Kimberly Kishpaugh

Disparities in healthcare — diagnosis, treatment and access — are among the top issues that affect people of color. Three Black women living with multiple sclerosis share their experiences and stories with **Momentum**.

What did your healthcare professional initially believe was causing your symptoms?

“MS never came up,” says Antoinette Pick-Jones, an attorney who was diagnosed with MS in 2019. Although she provided doctors with spreadsheets of symptoms and test results, which included the presence of multiple lesions, one neurologist even told her, “This is kind of concerning, but there is probably nothing wrong with you.” Another neurologist said bluntly: “You just don’t have MS.” Instead, she was asked repeatedly about HIV, lupus and sickle cell anemia. “The majority of people who are diagnosed with those illnesses are Black,” Pick-Jones says. “And that was really problematic.”

Robin Carr McClure first experienced vision problems in 2011. After the symptoms didn’t go away, she made an appointment with an ophthalmologist. When the ophthalmologist couldn’t find anything wrong with McClure’s eyes, she looked for answers elsewhere. “She decided I needed to get lab tests,

as what I was describing was a symptom that was common in syphilis or AIDS,” McClure recalls. “That was an unexpected thing to hear when you just wake up, and you have a vision problem. Everyone I know who has MS is Black. It seems like the first test everyone gets is for STDs. I’m not sure if that’s across the board, but everyone I’ve talked to who’s Black has had that experience.”

Did you feel that your feelings and symptoms were taken seriously?

“Many MS symptoms can be invisible,” says Lawaunda Stephens, who was diagnosed with MS in 2000. “I had to fight to have medical professionals take my symptoms seriously. The MRI sometimes doesn’t match what’s really going on.”

“There is just a ‘Black woman thing’ where people don’t take us seriously,” Pick-Jones says. “When I told my current neurologist, who’s great, about my symptoms [the first time], he said, ‘It’s just shocking that someone didn’t flag this years ago.’”

What do you think are the barriers to staying on a disease-modifying therapy (DMT)?

“I ended up spending \$15,000 out of pocket to get this diagnosis. And thankfully, I had the resources to do that,” Pick-Jones says. “But if I didn’t ... Some people

Antoinette Pick-Jones

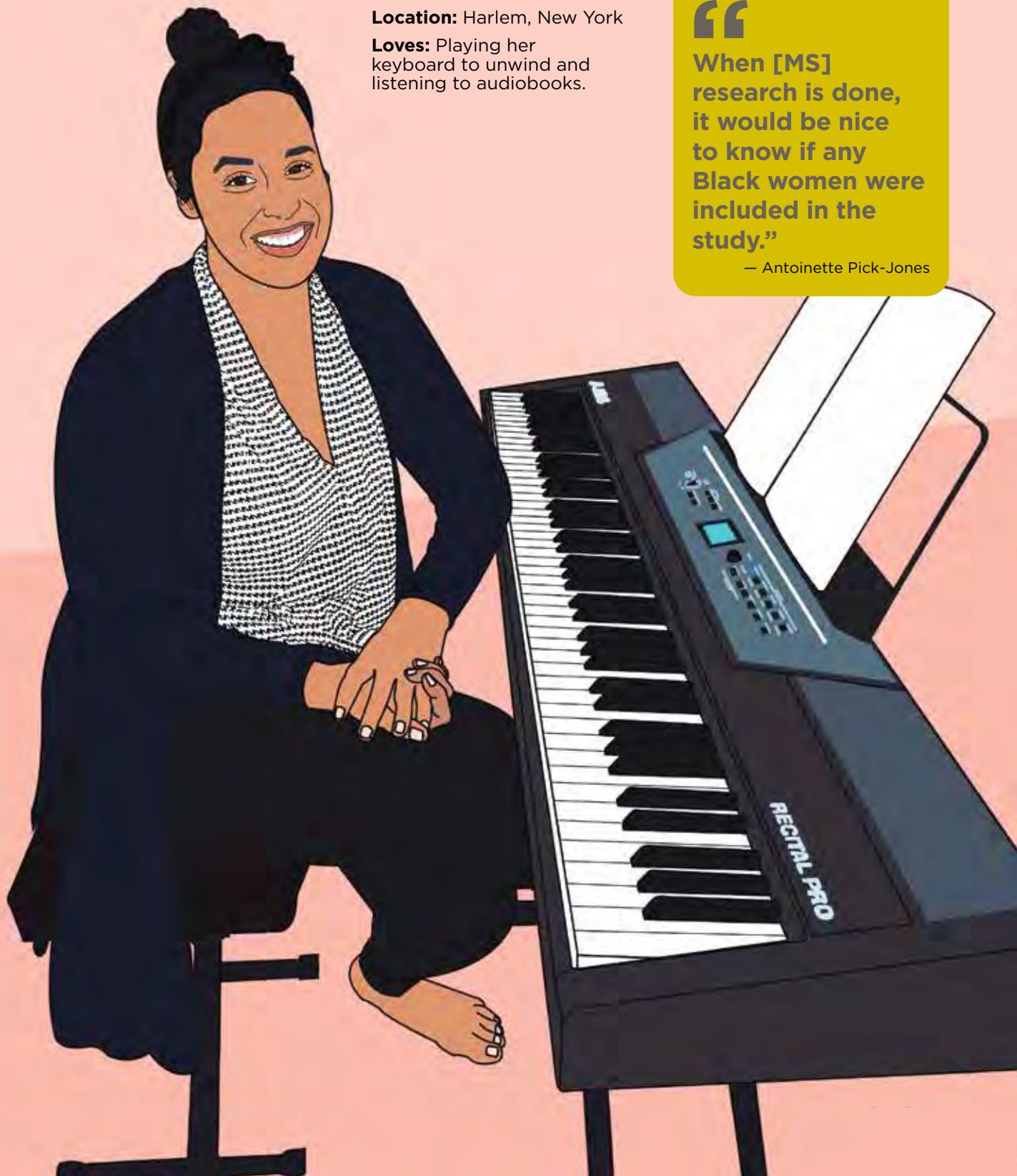
Location: Harlem, New York

Loves: Playing her keyboard to unwind and listening to audiobooks.

“

When [MS] research is done, it would be nice to know if any Black women were included in the study.”

— Antoinette Pick-Jones





Robin Carr McClure

Location: Washington D.C.

Loves: Collecting art, learning from others and spending time with loved ones.

“

My experience being diagnosed is different than what I've seen from white women.”

— Robin Carr McClure

don't even have the resources to pay for a co-pay."

"If you really want a patient to stay on a DMT, listen to what they say," Stephens says. "If they say they're having trouble with a DMT, don't blow them off. Because once you blow them off, they're going to stop taking it, and that could lead to more progression."

What is your greatest hope for research?

"[I hope for] research into diagnosis, or lack of diagnosis of women — Black women — with MS. I think that would be really interesting," Pick-Jones says. "The most pressing populations are poor and working-class Black people."

"When research is done, it would be nice to know if any Black women were included in the study. That way, maybe when a Black woman comes to the doctor, the first thing they're thinking is not HIV. Maybe they're thinking MS a little sooner."

Do you believe MS is uncommon in Black people?

"It's interesting to me in that a lot of what you see online or anything related says this is uncommon in Black people," McClure says. "And I think now people are more aware of history some of us have been aware of our whole lives. Me being Black doesn't mean there wasn't somebody white in the bloodline as well. And in my case, it's true. There were some, not by choice, white ancestors in the line [who had raped my ancestors, who were slaves], which led to me. And so, I do have a Scottish ancestor. And nobody by marriage and nobody by choice, but it's part of my genetic makeup. So, if [physical characteristics are being used to determine race], it's a very narrow view about what race is."

McClure says her neurologist told her, "People in your community don't have this disease." But genetically speaking, I did an ancestry DNA test a while ago, and I'm 53% white," Pick-Jones says. "So technically, if we're talking about race as being a risk factor, it's more likely with someone who's like me. I said there's no

real research about mixed-race people and how the statistics pan out for people who are mixed race."

Do you think your race affected your diagnosis or treatment?

"Diagnosis, definitely. I don't think anyone was looking for MS, so it took a long time," McClure says. "And wondering if you have HIV or syphilis or anything that could have been prevented. That was pretty agonizing. When I talk to some people about their diagnosis — and again, I only know Black women who have MS — we've all thought being diagnosed was a relief instead of a sad moment. 'Ok, I'm not crazy. And these doctors who've said there's nothing wrong with me, I'm not crazy. There really is a medical issue.'

I think it takes longer to get to that point for a lot of Black women."

"A lot of medical professionals don't take Black women's concerns or pain as seriously as they would other people's. There are a lot of medical professionals who literally do not believe that Black people feel pain in the same way," McClure says. "I went to Brown University for grad school. My dad also attended Columbia for law school and he always wore a Columbia T-shirt when he went to the doctor. I never paid any attention because most of his T-shirts have schools on them. But when I started to talk to him about my treatment by professionals, he would say, 'Make sure you have your law school shirt on' or 'Do you have your Brown shirt on?' And I did. And I noticed that the times that I wore regular clothes it was OK. But if I wear a shirt that says Brown University on it, there is a discussion around that. They talk to me at a much higher level."

Do you think you experienced any injustices or discrimination in the healthcare system?

"I think the hard thing is, you only know by comparison sometimes. You only know what you're



“

I had to fight to have medical professionals take my symptoms seriously.”

— Lawaunda Stephens

not getting when you see what someone else is getting,” McClure says. “I never had any outright discrimination. I know that my experience being diagnosed is different than what I’ve seen from white women, not all, obviously.”

“Oh, I could write a book on it,” Stephens says. “I could hear [the doctors] in the other room with the other patient and hear how [they] address the other patient. But then when [the doctors] look at me ... because when you have especially ethnic, African features, you’re going to get judged off the top.” ■

Kimberly Kishpaugh is a senior specialist for content development with the National Multiple Sclerosis Society.

Lawaunda Stephens

Location: Purvis, Mississippi

Loves: Gardening for physical, mental and emotional therapy.



Learn more about how MS affects African Americans at [nationalmssociety.org/What-is-MS/Who-Gets-MS/African-American-Resources](https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS/African-American-Resources).

Obstacles to access

Despite barriers, people of color are speaking up for themselves and their communities.

by Elaine Shelly

People of color living with multiple sclerosis face challenges beyond differences in symptoms, diagnosis and treatment. They also confront issues with lack of access to healthcare and participation in research projects, as well as language and cultural differences. But many people of color are advocating for themselves and their communities to improve their care.

Mayté Ramos advocates for people with MS who don't speak English. Clarissa Hernandez-Hidalgo offers a unique perspective on the privileges that come with perceptions — and misperceptions — about a person's skin color. Veronica Daniels-Lewis focuses on healthcare professionals who make mistaken assumptions about their patients of color.

And Dr. Jacqueline Rosenthal, MD, a neurologist at the Shepherd Center in Atlanta, argues that most current research lacks focus on the possible causes of health disparities, such as which parts are due to societal inequities and which factors are due to biological differences.

"It's important to acknowledge that it's not just access to care and may be some disease factors," Rosenthal says.

"We can't compare groups of people without acknowledging that."

Different experiences

Rosenthal sees these disparities reflected in her patients. She says her Black patients with MS generally have more disability over time and have worse MRI findings, with more brain atrophy than her white patients. Hispanic patients also have more disability and transverse myelitis, or inflammation of the spinal cord — which can correlate with more disability — than her white patients.

"The most distressing suggestion is differences in how one responds to treatment," Rosenthal says of a possible

Clarissa Hernandez-Hidalgo, diagnosed with MS in 2010, advocates for people of color with MS.



reason for MS racial disparities. “How much is this a complicating factor?”

Rosenthal points to research that indicates African Americans don’t do as well on interferons, the earliest MS disease-modifying therapies (DMT), as do other people in clinical trials for the medications. She acknowledges other issues, such as insurance complications or delayed diagnoses, that might play a role in poorer outcomes for people of color with MS. “By the time they get in to see me, there’s likely to have been a delay,” she says. “That could result in severe MS symptoms by the time individuals are diagnosed.”

A delayed diagnosis

Daniels-Lewis’ story illustrates the delays in diagnosis that people of color can experience. Daniels-Lewis, who is Black, experienced her first symptoms in 1988. She repeatedly sought medical help, but her symptoms were dismissed and minimized. She wasn’t diagnosed until 1996. She currently sees an MS specialist who also is Black, and she emphasizes that makes a difference in her treatment.

Daniels-Lewis recalls a time when she was experiencing symptoms she feared pointed to an MS exacerbation. Her regular neurologist was unavailable, so she had to see another neurologist.

“I had tingling in my feet, and my balance was off,” Daniels-Lewis recalls. “I didn’t feel he was taking my concerns seriously. He was mostly dismissive. It was so uncomfortable.”

Veronica Daniels-Lewis experienced a delay in her diagnosis.



Mental health issues

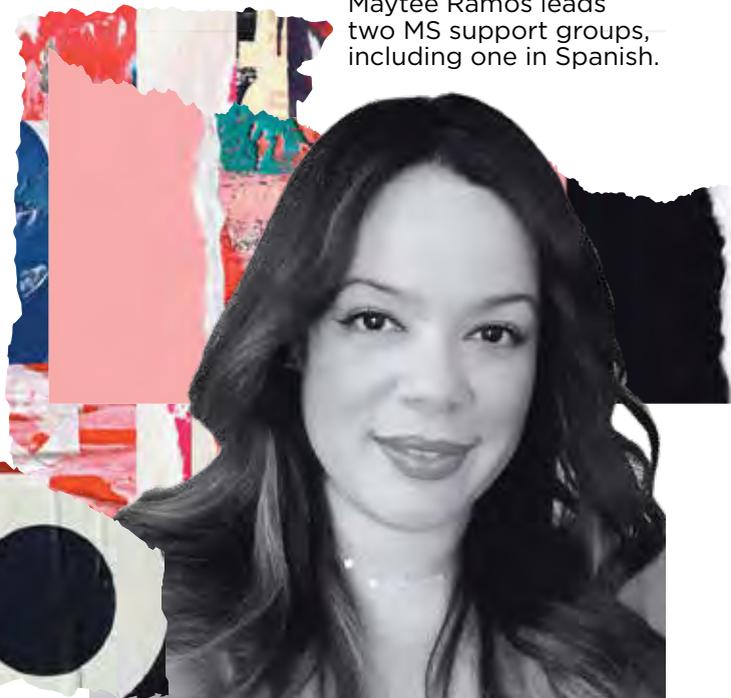
Delays in diagnosis and treatment as well as misperceptions about symptoms and their causes can affect a person’s mental health as well. Katrina Marsh, a counselor with offices in San Francisco and Oakland, California, has seen this among her patients with chronic illnesses, many of whom are people of color and LGBTQIA+. She’s seen her patients struggle with finding adequate healthcare and come to her feeling dismissed, judged and worthless. Marsh works with them to make plans to get the healthcare resources they need and advocate for themselves.

“There’s sadness, physical and emotional pain, and sometimes heartbreak and despair,” Marsh says, but she tells them, “You are worthy of receiving great care. Accept nothing less.”

Language barriers

Ramos, who worked as a medical interpreter before her MS diagnosis, also sees how delays in diagnosis and treatment can occur for people who aren’t fluent in English. Some Spanish speakers spend precious time

Mayteé Ramos leads two MS support groups, including one in Spanish.



looking unsuccessfully for a nearby Spanish-speaking healthcare provider or MS specialist.

“They go through a lot,” Ramos says. “At a big hospital, someone with a low income can apply for a low-income charity program and see a doctor, but they might have to wait three months or more for an appointment.”

Ramos’ professional experience allowed her to see firsthand the difficulties Spanish-speaking people encounter when trying to obtain medical care in primarily English-speaking settings.

“If the doctor’s office doesn’t offer interpreter service, you cannot ask questions,” Ramos says. “If you don’t understand the instructions, things can go wrong.”

Ramos’ path to diagnosis was quick. In December 2015, she suddenly had trouble writing, and she developed lower back pain and difficulty controlling her right leg. She was diagnosed with MS within a week. Because of her symptoms, she had to quit her job. Ramos leads two MS support groups, one in English and one in Spanish.

Advocating for family and friends

Hernandez-Hidalgo of Merced, California, also was diagnosed quickly. A multi-racial yoga instructor and the mother of two girls, she remembers the exact date she first heard a neurologist tell her that she had MS: Dec. 24, 2010. At the time, she was a 19-year-old psychology major at the University of California at Merced. After experiencing vision problems, she had an MRI and was diagnosed with MS the same day.

“It was a fast diagnosis,” she says. “I know people who go months and years, so I’m grateful.”

Hernandez-Hidalgo has blonde hair and white-appearing skin. She says her appearance affords her privilege that she can use to advocate for her relatives and for other people with MS who don’t have the same privilege. She points to her grandmother, who lives in an assisted living center. Hernandez-Hidalgo says she has gone to the center to help her grandmother with basic care, things she argues the staff members should do as a matter of course.

Rosenthal points out that many of her patients of color carry their experiences of medical bias with them,

making any visit to a healthcare professional stressful. “They are wondering, ‘Am I being judged?’” she says. “Sometimes, you have to address that and look for ways to make your patients feel comfortable.”

Rosenthal believes that things may also begin to improve for people of color with MS when healthcare providers question the personal attitudes and assumptions that lead them to treat some patients differently. “A lot of doctors are oblivious to their own bias,” Rosenthal says. “You have to acknowledge first that it may be there.”

Diverse research participants

Abbey Hughes, PhD, a rehabilitation psychologist at Johns Hopkins University School of Medicine, Department of Physical Medicine and Rehabilitation, is learning how to make research projects more inclusive and accessible and eliminate barriers to participation for people of color with MS. She points to her psychology colleague, Jagriti “Jackie” Bhattarai, PhD, whose research focuses on reducing racial disparities in MS care. One of their projects saw a higher level of minority participation by Black, Indigenous and other people of color when the pandemic forced the project to go online instead of requiring participants to drive to Johns Hopkins for weekly appointments.

Hughes and her colleagues direct a postdoctoral fellowship that will engage fellows in projects focused on addressing psychosocial wellness in people with MS, especially communities of color. There is a need for more researchers to include people of color and for more projects, like Bhattarai’s, that seek to decrease disparities in disease outcomes, Hughes says. ■

Elaine Shelly is a freelance writer in Oakland, California. She was diagnosed with MS in 1991.



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ASK YOUR HEALTHCARE PROVIDER or get more details at **KnowVUMERITY.com**

 **VUMERITY**[®]
(diroximel fumarate) delayed-release capsules 231 mg

Patient Information
VUMERITY (vue mer' i tee)
(diroximel fumarate) delayed-release capsules

What is VUMERITY?

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

Do not take VUMERITY if you:

- have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to diroximel fumarate, dimethyl fumarate, or any of the ingredients in VUMERITY. See **"What are the ingredients in VUMERITY?"** below for a complete list of ingredients.
- are taking dimethyl fumarate.

Before taking and while you take VUMERITY, tell your doctor about all of your medical conditions, including if you:

- have liver problems.
- have kidney problems.
- have or have had low white blood cell counts or an infection.
- are pregnant or plan to become pregnant. It is not known if VUMERITY will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if VUMERITY passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while using VUMERITY.

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

How should I take VUMERITY?

- Take VUMERITY exactly as your doctor tells you to take it.
- The recommended starting dose on days 1 to 7 is one capsule by mouth 2 times a day. After 7 days, the recommended dose is 2 capsules by mouth 2 times a day.
- If taken with food, avoid taking VUMERITY with a high-fat, high-calorie meal or snack.
 - Your meal or snack should contain no more than 700 calories and no more than 30 g of fat.
- Swallow VUMERITY whole. Do not crush, chew, or sprinkle capsule contents on food.
- If you take too much VUMERITY, call your doctor or go to the nearest hospital emergency room right away.

What should I avoid while taking VUMERITY?

- Do not drink alcohol at the time you take a VUMERITY dose.

What are the possible side effects of VUMERITY?

VUMERITY may cause serious side effects including:

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing). Stop taking VUMERITY and get emergency medical help right away if you get any of these symptoms.
- **PML (progressive multifocal leukoencephalopathy)** a rare brain infection that usually leads to death or severe disability over a period of weeks or months. Tell your doctor right away if you get any of these symptoms of PML:
 - weakness on one side of the body that gets worse
 - vision problems
 - confusion
 - clumsiness in your arms or legs
 - changes in thinking and memory
 - personality changes
- **herpes zoster infections (shingles)**, including central nervous system infections.
- **other serious infections**
- **decreases in your white blood cell count.** Your doctor should do a blood test to check your white blood cell count before you start treatment with VUMERITY and while you are on therapy. You should have blood tests after 6 months of treatment and every 6 to 12 months after that.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking VUMERITY 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 VUMERITY 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 VUMERITY with food (avoid high-fat, high-calorie meal or snack) 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 VUMERITY may reduce flushing.

These are not all the possible side effects of VUMERITY. 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

How should I store VUMERITY?

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

General Information about the safe and effective use of VUMERITY

Medicines are sometimes prescribed for purposes other than those listed in this Patient Information. Do not use VUMERITY for a condition for which it was not prescribed. Do not give VUMERITY 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 pharmacist or doctor for information about VUMERITY that is written for healthcare professionals.

What are the ingredients in VUMERITY?

Active ingredient: diroximel fumarate

Inactive ingredients: crospovidone, colloidal silicon dioxide, magnesium stearate (non-bovine), methacrylic acid and ethyl acrylate copolymer, microcrystalline cellulose, talc, and triethyl citrate. **Capsule Shell:** carrageenan, hypromellose, potassium chloride, and titanium dioxide. **Capsule Shell Ink:** iron oxide, potassium hydroxide, propylene glycol, and shellac.

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

solve

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

Try exercising for at least 30 minutes, 3 times a week

A little bit of exercise goes a long way toward making a difference in the part of your brain known as the hippocampus, which is linked to learning and memory.

Try these easy functional activities you can incorporate into your weekly routine for brain-boosting benefits.

- **Walk the dog at a brisk pace** — just fast enough to get your heart pumping.
- **No pets? Try a farmer's walk.** Just pick up some light weights or objects that you can grip easily while you walk around, keeping your shoulders back, abs tight and glutes squeezed.
- **If you use a wheelchair,** try hand-eye coordination exercises, such as holding your

arms out to the sides, then bringing them in front of you, pretending to pass a small ball back and forth between your hands (use a real ball for an extra challenge).

These exercises move the arms and hands in ways that work neuromotor function (i.e., balance, coordination) and improve range of motion, flexibility and dexterity.

Break up any of the activities into smaller increments throughout the day if you're unable to complete the full 15 minutes in one round. Learn more about a new brain and exercise study on the next page.

Brain gain

Study shows exercise may improve learning and memory.

by Aviva Patz

“

For many years we've known that on a symptom level, exercise helps with reducing fatigue, easing mobility and improving cognition.”

— ALON KALRON, PhD

Studies show that exercise is good for the brain, not to mention the body and even the soul. But if you have multiple sclerosis, there's an extra incentive to get moving: It also could help build your brain.

“For many years we've known that on a symptom level, exercise helps with reducing fatigue, easing mobility and improving cognition,” explains Alon Kalron, PhD, senior lecturer at the Sackler Faculty of Medicine at Tel-Aviv University. Kalron, the lead author of a new study, is also a researcher at the Sheba MS Center, Tel-Hashomer. “Today, we see that from a disease perspective, exercise preserves an important part of the neural system.”

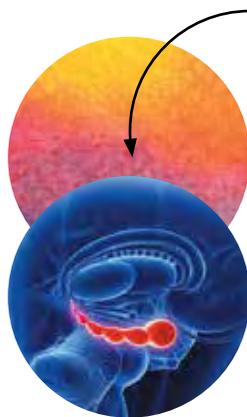
“In fact,” Kalron adds, “there is more and more evidence pointing that it can slow the progression of the disease.”

Your brain on exercise

To determine exactly how regular exercise boosts the brain, Kalron and his colleagues asked 153 people with MS to rate their level of leisure-time physical activity over the prior week, from “strenuous” (running or jogging) to “moderate” (fast walking), or “mild” (strolling). He then divided them into one of two groups according to their exercise level — “active” or “insufficiently active.” The researchers then looked at brain MRI scans of these same people and examined eight regions of the brain, searching for differences. They not only compared the scans of the active participants with those of the inactive participants, but they also measured both groups' brain scans against standard measures of those parts of the brain.

Active vs. inactive brains

The scans showed significant differences in both the right and left sides of one critical brain region — the hippocampus —



between the active and inactive people with MS, even after taking disability and cognition challenges into account. The volumes of the right side of the hippocampus alone accounted for 20% of the differences between the groups. “Those who do regular physical activity have a larger hippocampus, an important area of the brain related to memory and learning,” Kalron says.

The **hippocampus** is a small, curved organ found deep in the brain's temporal lobe that plays a critical role in memory. It is involved in functions including:

- **Spatial memory**, which allows you to do things like navigating mazes and parallel parking.
- **Memory consolidation**, which impacts the process of locking in memories during sleep.
- **Memory transfer**, which involves moving memories from a sort of holding area into long-term storage in the brain.

The hippocampus also helps encode emotions into memories. For example, when you hear a song from your high school days, it may bring up warm, giddy feelings tied to the memory of your first kiss or sadness related to a lost game.

Advancing what we know

While a large body of research already shows that exercise boosts the brain, this is the first to pin down the brain's specific area responsible for those improvements. “The way we analyze the MRI data — we compared it to normative values [standard measurements in a healthy population] — it's a more statistical way to understand the benefits of regular exercise on people living with MS,” Kalron says. “We strengthened the findings of some of the earlier studies and also made it more specific.”

Exercise is vital

Regular exercise joins a healthy diet and good sleep hygiene as pillars of general health and well-being. Getting moving is especially critical for people with MS because it can help manage symptoms. Studies show that aerobic exercise programs can help improve cardiovascular fitness, strength, bone density and flexibility for people living with MS. Exercise may also improve MS symptoms involving bladder and bowel function, fatigue, cognitive function and mood.

It's important to note that the researchers saw a brain benefit with even lighter forms of physical activity. "You don't have to train for a marathon," Kalron says. "Even moderate-level walking is enough to maintain brain capabilities." He adds that the key is to do it regularly, ideally three times a week for a half-hour at a time.

Suggested forms of physical activity for people living with MS include swimming, gardening, household chores, cooking, walking the dog and taking the stairs instead of the elevator.

Slowing MS progression

More than just easing MS symptoms, regular exercise has the power to "actually slow progression of the disease." As Kalron says, "it gets the neurovascular system working more optimally in general." That means smoother, faster, more efficient communication between the nerves in the brain and the spinal cord. Improving this system is critical for people living with MS, as lesions that develop along these structures as the disease progresses can interfere with essential signaling, causing symptoms ranging from lack of bladder control to spasticity to brain fog.

"Regardless of disability or cognitive level, exercise helps you maintain a larger



PHOTO: ISTOCK/BENJAVISA



You don't have to train for a marathon. Even moderate-level walking is enough to maintain brain capabilities."

— ALON KALRON, PhD

hippocampus at any stage of the disease," Kalron adds. Knowing that regular exercise can minimize symptoms and preserve brainpower should help more people living with MS take control of their disease.

New exercise guidelines

The message from the last decade is that physical activity is important in MS, according to Kalron, so much so that the National MS Society has issued new physical activity recommendations for healthcare providers to share.

The recommendations — developed by a group of experts in the fields of MS, exercise, rehabilitation and physical activity published in the April 2020 issue of *MS Journal* — lay out examples of activity suitable for all disability levels, from people with mild impairment and people whose walking is limited to people who use a wheelchair or are confined to a bed or chair.



PHOTO: ISTOCK/BENJAVISA

Further research

Kalron and his team plan to continue investigating the impact of physical activity on brain structures. “We want to keep asking the important question: How much exercise do you need to change areas of the brain to reverse degeneration?” he says. “Now we can focus on specific areas to help answer that question.” ■

Aviva Patz is a writer in Montclair, New Jersey.

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

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Novel approaches

Scientists are exploring innovative new approaches to treating MS.

by Mary E. King, PhD

Scientists are exploring a variety of approaches to treat MS, including pharmaceutical to diet-altering gut bacteria and stem cell work. **Momentum** talked to two experts about innovative pharmaceutical and cell therapy approaches: Dr. Daniel Ontaneda, MD, PhD, from the Mellen Center for MS at the Cleveland Clinic in Cleveland, and Dr. Michael D. Kornberg, MD, PhD, from the department of neurology at Johns Hopkins University School of Medicine in Baltimore.

Target MS progression

Evobrutinib is a type of protein that can be given orally instead of by injection or infusion. It targets specific immune cells that play an essential role in the progression of MS. It primarily blocks B cells, reducing their activity and inhibiting other immune cells (myeloid cells), which may have additional roles in MS. Evobrutinib targets immune cells differently from ocrelizumab (Ocrevus), which is already on the

market. Blocking B cells is a new approach to treating MS and could help individuals not helped by Ocrevus. Evobrutinib had positive results in a phase 2 trial. Importantly, it reduced the number of active brain lesions in MRI scans of the participants compared to those who received a placebo, and it was fairly well tolerated. Phase 3 trials are underway in participants with relapsing-remitting MS (RRMS).

“[Evobrutinib] will likely have a place in treating RRMS, due to its fast on/off mechanism of action and its safety profile,” Kornberg says. “However, what is most exciting about this new class of drugs is that, unlike those currently available, they target cells that are thought to play a primary role in progressive MS. This creates hope that they may provide benefit in progressive MS.”

While the new class of drugs may be available for RRMS within the next few years, data about its effectiveness in progressive MS will take longer, Kornberg says.

According to Ontaneda, phase 2 results are promising, but he adds, “This therapy will need to be tested in larger phase 3 studies to

determine efficacy as compared to other MS disease-modifying therapies.”

Reboot the immune system

Scientists are also studying a type of stem cell transplant (aHSCT) that “reboots” the immune system using cells taken from an individual’s bone marrow. (See page 48.)

“aHSCT has the potential to ‘cure’ MS if given early in the course of the disease, but it carries substantial safety concerns, and whether it’s more effective than other highly effective MS therapies remains unknown,” says Kornberg.

Ontaneda says that while aHSCT is a promising therapy, it is commonly reserved for the most aggressive forms of RRMS.

The BEAT-MS trial is a large phase 3 trial recruiting 156 people with RRMS at 19 sites across the U.S. to study aHSCT. Learn more about the study site at beat-ms.org.

“This will be the first trial to directly compare the efficacy and safety of aHSCT to other highly effective therapies and will likely determine whether aHSCT becomes





PHOTO: ISTOCK/ DRAGONIMAGES, THE-LIGHTWRITER

a standard part of MS treatment,” Kornberg says.

“The safety of aH SCT has been improving over time, as experience with different regimens and protocols have been tested, which make the trial results very important. The trial is testing aH SCT against the current best available medical therapy for MS,” Ontaneda says.

Repair existing damage to nerve cells

Researchers also want to find a way to reverse nerve damage. In laboratory studies, another agent, eleanumab, does just that: It helps repair nerve cells and the myelin that coats them. Research is now underway in people with MS.

The first study, a small phase 1 trial, demonstrated that eleanumab is safe in individuals with either secondary progressive MS or RRMS. It is being tested for how well it works in two double-blind studies, one with 123 individuals with primary progressive MS and one with 208 people with RRMS. Participants will receive either this experimental agent or a placebo in addition to their usual MS therapies.

Ontaneda says eleanumab targets a specific protein active in MS that blocks nerve growth and nerve repair. “This is a relatively new approach in MS, and it holds promise as a potential therapy to reverse the damage. It is also being studied in stroke and spinal cord injury,” he says.

“Unlike currently available drugs, the hope is it will repair prior damage and improve disability rather than simply prevent new lesions from forming,” says Kornberg. “Therapies that lead to the recovery of neurologic function are a major unmet need for MS patients.” Because eleanumab is in such early stages of research, its success is still very uncertain.

In an approach involving stem cells — NurOwn (MSC-NTF) cells — researchers are removing a specific type of cell from an individual’s bone marrow and treating these cells so they will secrete natural chemicals that stimulate nerve growth. The cells are reinfused into the individual. Scientists hope this therapy will protect nerves from further damage and boost myelin repair in damaged nerves. It is being tested in 20 people with progressive MS.

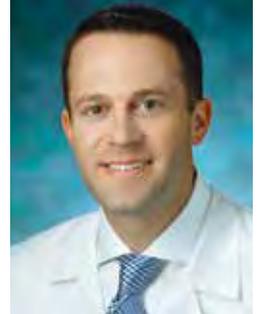
Types of therapies and trials

Two significant approaches underlie most of these new therapies. One is the use of monoclonal antibodies, which are special proteins carefully designed in the laboratory to bind only to certain molecules. A monoclonal antibody gives researchers a way to carefully target and block a specific action or cell type, like the multiplication of a type of immune cell called a B cell that plays a crucial role in MS. The novel antibodies discussed here are evobrutinib, elezanumab and temelimab.

Another hot topic in biomedical research, including in MS, is the use of cell therapy. Stem cells are found in both embryos and adults. Two new therapies use adult stem cells. One is called autologous stem cell transplantation (aHSCT), a complex procedure that “reboots” the immune system. Doctors must

destroy a person’s immune system using chemotherapy, then regrow it using the individual’s own stem cells (autologous) taken from bone marrow before administering chemotherapy. This course is risky because the person won’t have a working immune system to fight off infection while new immune cells are being made. Another approach using stem cells — NurOwn (MSC-NTF) cells — removes a specific type of stem cell from bone marrow, treats the cells to stimulate nerve growth and returns them to the patients. The immune system is not “rebooted” in this procedure.

These potential therapies are in various stages of research, from smaller, earlier phase 1 or phase 2 trials that can give early signals of success to larger, later-stage phase 3 studies designed to rigorously test safety and efficacy.



Dr. Michael D. Kornberg, MD, PhD, leads an MS research team at Johns Hopkins University School of Medicine.



A different tactic to help protect nerves and increase myelin repair involves an experimental therapy using extremely tiny crystals of gold (biocatalytic nanocrystalline gold (CNM-Au8)). In laboratory experiments, these specially designed crystals boost the energy-producing steps that occur naturally inside cells.

The therapy helps brain cells, which need a lot of energy to repair myelin. CNM-Au8 also seems to help protect nerve cells against further damage. Scientists are now testing CNM-Au8 in 150 people with MS in a phase 2 trial to determine whether it is effective in promoting myelin repair and protecting nerve cells.

Targeting viruses linked to MS

Previous infection with Epstein-Barr virus (EBV) has been linked to the risk of developing MS. ATA188 is a therapy that uses immune T cells from healthy donors. When given to people infected with EBV, these cells will specifically attack certain immune cells infected with EBV. Researchers are studying ATA188 in a phase 1 trial in 97 individuals who live with progressive MS.

Kornberg says, "There is a clear, consistent association between EBV infection and

risk of MS. One hypothesis is that persistent EBV infection of immune cells continues to drive disease throughout a patient's life. If this hypothesis is correct, ATA188 could eliminate the ongoing trigger for the disease. However, there is no definitive evidence yet supporting the hypothesis that persistent EBV infection is a cause of MS."

Temelimab is an agent that targets another class of viruses called human endogenous retroviruses (HERVs). The science is relatively complex,

but what's important is that HERVs produce a protein that researchers have found inside active MS lesions. In lab experiments, the protein seems to promote unwanted inflammation and hinder the repair of myelin. The hope is that by blocking HERVs, temelimab will help repair myelin and slow or stop MS progression. It's being studied for safety and to see how it acts in humans in a phase 2 study of 40 people with RRMS. ■

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

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

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What is MAYZENT® (siponimod) tablets?

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

IMPORTANT SAFETY INFORMATION

Do not take MAYZENT if you:

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

MAYZENT may cause serious side effects, including:

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

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

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

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

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

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

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

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

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

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

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

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

MAYZENT may cause possible side effects, including:

- **increased blood pressure.** Your health care provider should check your blood pressure during treatment with MAYZENT.
- **liver problems.** MAYZENT may cause liver problems. Your health care

provider should do blood tests to check your liver before you start taking MAYZENT. Call your health care provider right away if you have any of the following symptoms of liver problems:

- nausea
- vomiting
- stomach pain
- tiredness
- loss of appetite
- your skin or the whites of your eyes turn yellow
- dark urine

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

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

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

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

Please see Consumer Brief Summary on following pages.

CONSUMER BRIEF SUMMARY

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

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

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

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

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

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

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

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

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

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

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

See “**What are the possible side effects of MAYZENT?**” for more information about side effects.

What is MAYZENT?

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

Who should not take MAYZENT?

Do not take MAYZENT if you:

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

What should I tell my healthcare provider before taking MAYZENT?

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

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

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

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

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

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

How should I take MAYZENT® (siponimod) tablets?

The daily maintenance dose of MAYZENT is either 1 mg or 2 mg, depending on your CYP2C9 genotype. Ask your healthcare provider if you are not sure about your daily maintenance dose.

Do not split, crush, or chew MAYZENT tablets; take tablets whole.

Start your treatment with MAYZENT using the following titration schedule:

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

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

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

What are the possible side effects of MAYZENT?

MAYZENT may cause serious side effects, including:

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

- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping MAYZENT.

The most common side effects of MAYZENT include:

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

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

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

How should I store MAYZENT?

Unopened Containers

MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. If you need to store MAYZENT tablets for more than 3 months, containers should remain unopened and stored in a refrigerator between 36°F to 46°F (2°C to 8°C) until use.

Opened Containers

Bottles

MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. Do not refrigerate after opening.

Starter Pack/Blister Card

MAYZENT 0.25 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. Do not refrigerate after opening. Store in original calendarized blister wallet container.

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

General information about the safe and effective use of MAYZENT

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

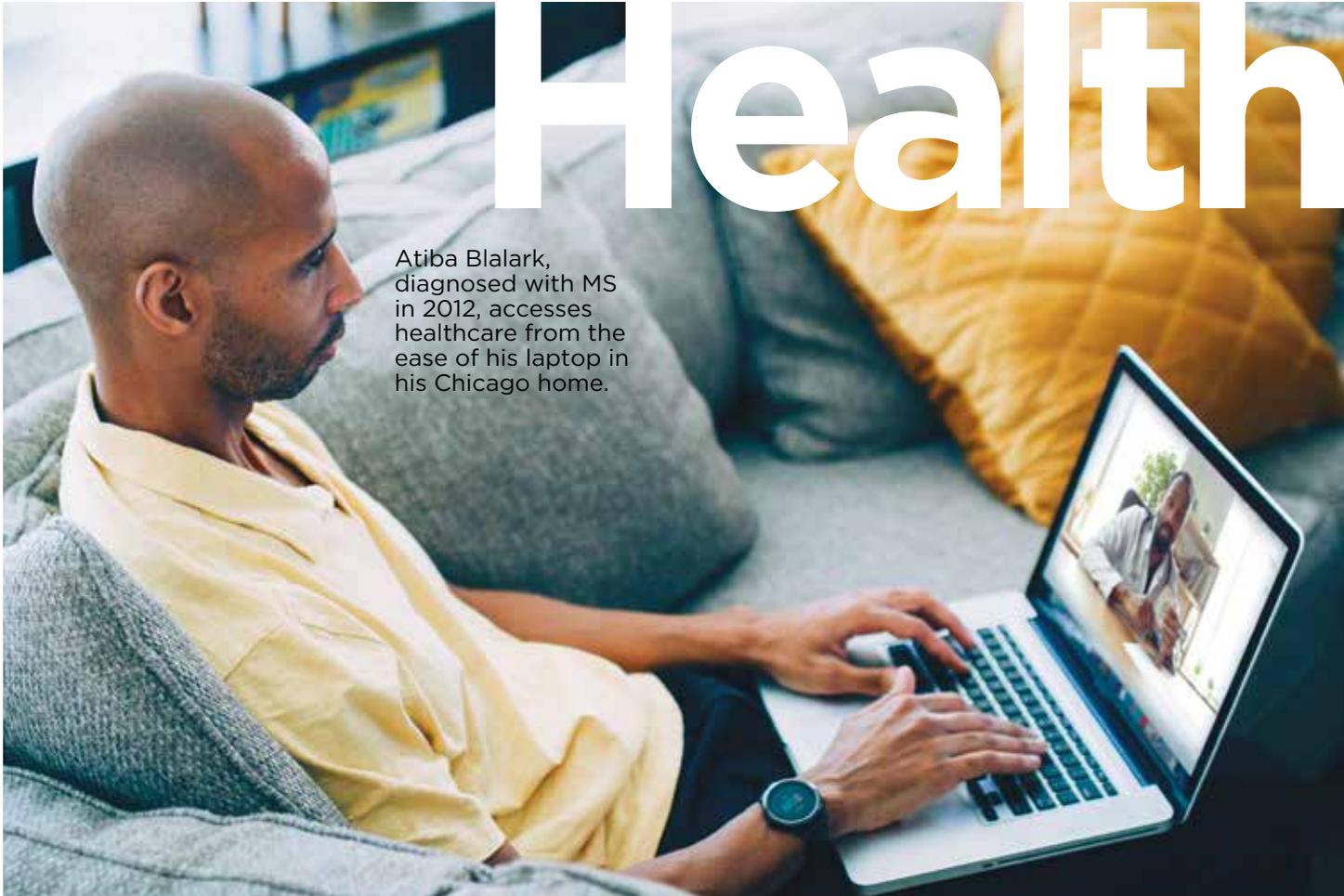
What are the ingredients in MAYZENT?

Active ingredient: siponimod

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

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Atiba Blalark, diagnosed with MS in 2012, accesses healthcare from the ease of his laptop in his Chicago home.

PHOTO: JACKIE QUEJANO

Health from home

Spurred by the pandemic, virtual doctor visits save time and trouble.

by Matt Alderton

Going to the doctor was always an ordeal for 63-year-old Deborah Miller, who has lived with MS for 23 years. Miller relies on her sister to take her to appointments and uses a manual wheelchair to get to and from the car. It's time-consuming and exhausting. In spring 2020, however, she discovered a new way to see her doctor: Instead of waiting for her sister to pick her up, Miller logs onto the internet from her computer and speaks with her neurologist via video chat.

Virtually seeing her neurologist saves time, helps Miller conserve energy and reduces her dependence on others. “That’s important because I’m fiercely independent, and I only have a window of about six hours during the day where I can be physically put to my limits,”

says Miller, who lives in St. Charles, Missouri. “After that, I can’t think clearly, and my legs don’t bend because I’m overtired, which is a whole other fiasco.”

Miller is one of millions of Americans who has discovered telehealth — many for the first time during the COVID-19 pandemic. Although healthcare professionals have long recognized the potential benefits of virtual doctor visits, neither the Centers for Medicare & Medicaid Services (CMS) nor private insurers previously reimbursed them. That changed in March 2020, when CMS announced it was expanding access to telehealth on a temporary and emergency basis so Medicare beneficiaries who were at risk of contracting the coronavirus could receive a range of services without having to visit a healthcare facility.

But even before the pandemic, telehealth has offered solutions for people like Miller who face challenges when scheduling healthcare visits.

The virtues of virtual

Because telehealth visits were so few before the COVID-19 pandemic, data about their effectiveness is scarce, particularly among people with MS. Still, what limited data exists is promising.

One piece of research, in particular, sheds some light: In 2018, the U.S. Department of Veterans Affairs (VA) Multiple Sclerosis Center of Excellence conducted a systematic review of 28 different studies into the efficacy of telehealth. The studies, spanning nearly two decades, produced “a range of outcomes with variable quality.” Overall, the studies demonstrated that telehealth is “beneficial, cost-effective and satisfactory for patients and providers,” according to the review.

For practitioners, the most substantial evidence so far is what they’ve witnessed firsthand since telehealth’s

PHOTO: ISTOCK/ALT IMAGES



Before COVID-19: 14,000
Medicare beneficiaries received
a telehealth service per week.

tipping point in spring 2020. Specifically, providers say they’ve noticed several benefits, the most significant of which is increased access to care.

“We in the MS community have always felt that telehealth is something that would make a lot of sense for our patients — especially patients who have

mobility issues or who live far away,” says Dr. Nancy Sicotte, MD, chair of the Department of Neurology at Cedars-Sinai Medical Center in Los Angeles. “I have one patient who lives in Bakersfield, California, which is two hours away. He works full time and would have to take a whole day off from work every six to nine months to drive down and see me. Now he can turn on his tablet from his office, talk to me for 25 minutes, then turn around and go back to work.”

Making visits easier

It’s more than convenience. Some patients can’t afford time off work, not to mention transportation and parking costs. Others, like Miller, are easily fatigued and have difficulty finding transportation, though she emphasizes that her appointments with her neurologist are well worth the effort she makes. Still, others live in areas that are prone to extreme weather, where driving on any given day might be dangerous.

Faced with many obstacles, some people with MS will opt to skip healthcare appointments altogether, forfeiting the positive health outcomes routine care might otherwise yield. This is especially true in specialties that require frequent visits. While a person with MS might see a neurologist only once or twice a year, for example, they might see a physical therapist or psychologist once or twice a month or even weekly. That can compound obstacles and increase the number of missed appointments.

“If you live with MS and have fatigue, you may wake up one morning and find that your body is not moving very well. Are you feeling able and motivated to get dressed and take transportation to come to see me in my office? It’s not likely,” says Kimberly McGuire, PhD, a clinical psychologist at the Kessler Institute

for Rehabilitation in West Orange, New Jersey. “But if you’re not feeling well, can you make it over to the phone or the computer? It’s a lot more likely, and you’ll get the support you need on a day when you probably need it most.”

Access to care is even more critical for those who live in small cities or rural towns away from MS centers of excellence. “It’s an equity issue,” Sicotte says. “We have some effective therapies for MS, but they require subspecialty expertise and have significant risks associated with them. [Telehealth] could help us address health disparities and ensure the best possible outcomes for people in places where there is a relative shortage of MS specialists.”

Along with its apparent benefits, telehealth has some unexpected advantages. One, for example, is the ability to interact with a person’s family member or friend.

“The most important part of an exam is taking a patient’s history, and we can do that just as well during a telehealth visit as we can in person — sometimes even a little better,” says Dr. Aaron Miller, MD, medical director of the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Hospital in New York. “That’s because there’s often a spouse or significant other at home who might or might not have been present at an in-person visit, and they can sometimes add useful information to the conversation.”

Telehealth also offers a unique window into a person’s environment and routine, allowing providers to tailor care to real-life circumstances. “As a physical therapist, patients will sometimes tell me, ‘I’m having trouble getting in and out of my bathroom’ or ‘I’m having trouble reaching this one cabinet where I store things,’” says Meredith Drake, a neurological physical therapist at Johns Hopkins Hospital in Baltimore. “With telehealth, I can actually see the weird stair they’ve been having trouble climbing and help them maneuver it.”

Cyber shortcomings

For all its benefits, telehealth also has its warts, according to Beverly Betz-Zachery of Crofton, Maryland, diagnosed with MS in 2010. When the pandemic began, she started virtually seeing her counselor every other week. When it came to her neurologist,

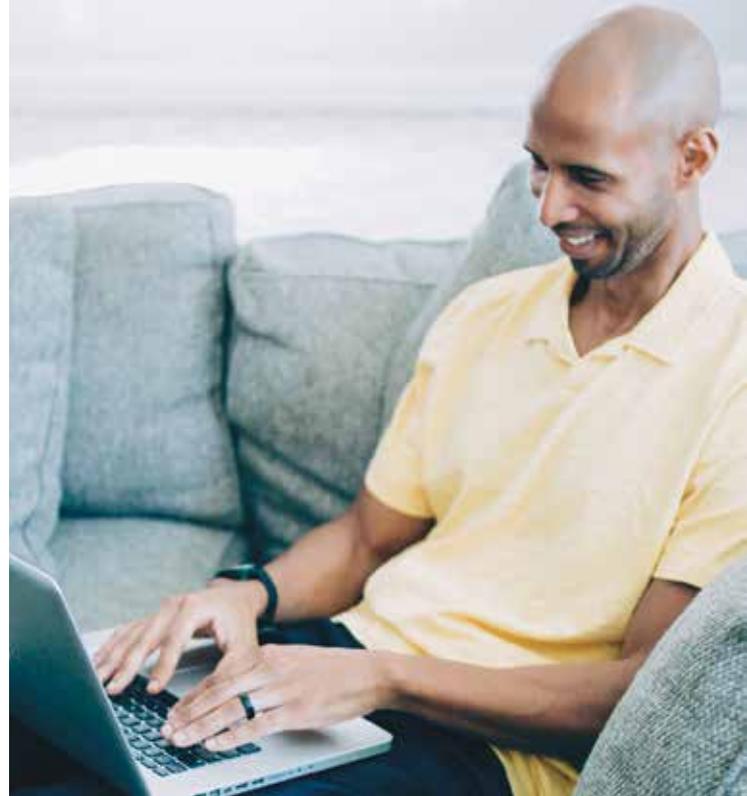


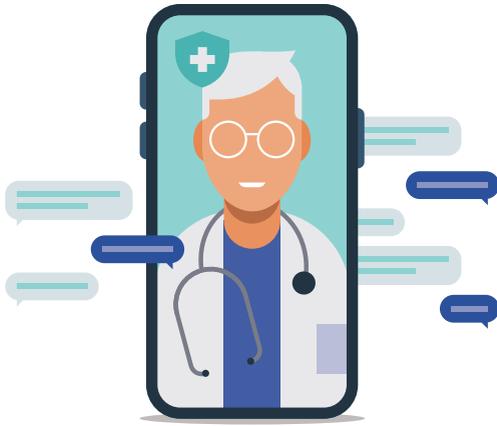
PHOTO: JACKIE QUEJANO

however, telehealth didn’t seem like enough. “When I’m seeing the psychologist, it’s great. We’re just talking, so it works out fine,” says Betz-Zachery, 69. “However, my virtual appointments with the neurologist and other specialist seemed incomplete without the ability of the doctors to observe my issues with my drop foot and other mobility concerns.”

Some healthcare professionals share Betz-Zachery’s trepidation. “When you do exams remotely, it’s not as thorough as in-office exams because of limitations,” says Dr. Barry Singer, MD, director of the MS Center for Innovations in Care at Missouri Baptist Medical Center in St. Louis. “In the office, you can very easily check vision, sensation, reflexes and strength of different muscle groups. All of those things are harder or impossible to check remotely.”

Cognitive impairments can be challenging to address, as well. “You have to be able to figure out how to manipulate the technology to participate in a video visit, and that can be an issue for folks who are cognitively impaired,” Sicotte explains.

Pain management is yet another thorn, observes Jodie Haselkorn, MD, a psychiatrist and MS specialist at the VA Puget Sound Health Care System in Seattle. “What’s really difficult is doing hand or small-joint therapy, or addressing acute pain that requires specific modalities and skilled hands,” she says.



**Between mid-March
through early July 2020:
More than
10.1 million
Medicare beneficiaries
received a
telehealth service.**

PHOTO: ISTOCK/RLT IMAGES

Though it works well for Betz-Zachery, even virtual psychotherapy has limitations. “When you see someone on video, for the most part, it’s like a school portrait: from the mid-chest up,” McGuire says. “As a mental health practitioner, when you’re sitting in a room with somebody, you see all their nonverbal cues — what they’re doing with their hands, how much they’re shifting in their seat, whether they are crossing their legs. Body language can be useful in helping a therapist establish an emotional and therapeutic connection with the client, and this is missing with a video session.”

Nevertheless, doctors can accomplish an impressive amount remotely. For example, Sicotte says she can easily review MRI scans and lab results with her telehealth patients, and she can look for signs of cranial nerve damage by examining facial asymmetry, listening for speech slurring and conducting basic eye movement tests. Miller likewise tests his patients’ coordination by asking them to put their finger to their nose, perform rapid alternating hand movements and sometimes slide their heel down their shin.

Singer has fine-tuned his virtual gait exams by asking patients to prop their phone against the wall on the floor, so he can observe their legs while they walk, including heel to toe. Even physical therapy can be effective from home, according to Drake. In the absence of specialized equipment, she has her patients do strength-building exercises with soup cans,

milk jugs and other household items, as well as complementary resistance bands that her practice mails to their homes.

“We can’t do a full physical exam, but there’s a lot we can do,” says Patricia Melville, a nurse practitioner at the Stony Brook University Neurosciences Institute in Stony Brook, New York. “When a patient comes in for a follow-up, I may spend 20 or 30 minutes with them and spend only five



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minutes doing a neurological exam. I spend the rest of the time talking about their symptoms, strategizing ways to help ameliorate them and answering questions about new treatments or therapies. All of that can be discussed virtually.”

‘Here to stay’

Its limitations mean telehealth isn’t for all. Still, its benefits mean it’s definitely for some, according to Drake, who says people with MS who are stable and know their bodies can thrive in virtual environments. At the same time, those who are newly diagnosed or coping with new or worsening symptoms might prefer hands-on care.

That resonates with Jennifer Stuart of St. Louis, who’s had MS since she was 17. So far, she’s had two telehealth visits with her neurologist. “I wouldn’t mind continuing to do telehealth visits going forward for regular checkups, but if there were something I was more concerned about, I would probably want to go into the office,” says Stuart, 34. “I definitely like it, though. You’re at home, and there’s no waiting at all, which is really convenient.”

Still, doctors need to see their patients in person eventually. In the future, Melville foresees a hybrid care model. “At some point,” she says, “I think patients will come in annually for an in-person visit, so we can do a full, thorough neurological exam with blood work and an MRI. And those who want to will then be able to do their follow-up visits via telehealth.”

From an insurer standpoint, prospects look bright so far: Although CMS began widely reimbursing telehealth only on an emergency basis because of COVID-19, it has since proposed changes to permanently expand telehealth coverage.

Concludes Sicotte, “It’s going to evolve. I think we’re going to see more regulations and requirements around what makes sense to do virtually and what doesn’t. I think telehealth is here to stay.” ■

Matt Alderton is a Chicago-based writer and editor.

How to prepare for a telehealth visit

A successful telehealth visit is as dependent on the patient as it is on the provider. Here are healthcare professionals’ top tips for preparing:

- **Check your internet connection.** The most critical thing in telehealth is a reliable internet connection, says Patricia Melville, a nurse practitioner at the Stony Brook University Neurosciences Institute.
- **Make sure other programs on your computer are closed.** Free up bandwidth by exiting unused programs.
- **Do a technology test run.** Different healthcare providers use different platforms for telehealth. Some may use consumer platforms like Zoom or FaceTime, while others may use proprietary solutions. Likewise, some may allow you to connect via your smartphone, while others might require a computer. Find out ahead of time what your provider uses, then take it for a test run before your appointment, Melville advises. If your provider uses Zoom, try doing a Zoom call with a friend or family member beforehand to ensure you’re familiar with the technology and don’t waste precious appointment time learning it. If you’re not comfortable with technology, it’s a good idea to have available someone who is — a spouse, a friend or a child, for example — so they can help troubleshoot any glitches.
- **Make sure you’re visible.** When you do your test run, be sure to check your camera angle, cautions Meredith Drake, a neurological physical therapist at The Johns Hopkins Hospital. Your provider may want to see your full body, not just your face, so learn ahead of time to position your phone or computer appropriately. Also, she says, be mindful of

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

Telehealth claims by privately insured people increased by 8,336% in April 2020 compared to April 2019, according to the healthcare nonprofit FAIR Health.

lighting; if you do your telehealth visit in front of a bright window with a lot of glare or a dim room with little light, your provider won't be able to see you adequately.

- **Create a safe, private, well-lit and quiet space.** If your telehealth visit will have a physical component — if you're doing virtual rehab, for example, or even a virtual neurological exam — ensure that you can do it safely in your home or office, or wherever you're conducting your telehealth visit. If you're at risk of falling from balance issues, for example, it's a good idea to have a chair or walker available to lean on and to have someone nearby who can help you if you need it, says Drake. If required, you also should clear space ahead of time where you can do physical therapy exercises.
- **Provide your location and phone number to the provider.**
- **Set goals.** Finally, you should prepare not only your space but also your plan, according to Jodie Haselkorn, MD, MPH, a physiatrist and MS specialist for the VA MS Center of Excellence and the VA Puget Sound Health Care System in Seattle. It's easy to get lost in a teleconference by distractions when you're connecting from home, she says, so it's a good idea for patients and caregivers to write down essential objectives and questions ahead of time. When preparing your plan, remember the top three or so issues of personal concern are more likely to be discussed thoroughly in one visit rather than a large number of problems. Multiple large concerns may need additional visits.



PHOTO: ISTOCK/RLT IMAGES

In July 2020, CMS reported a 4,300% increase in telehealth visits compared to pre-pandemic levels, from 0.1% of Medicare primary care visits in February 2020 to 43.5% in April 2020.



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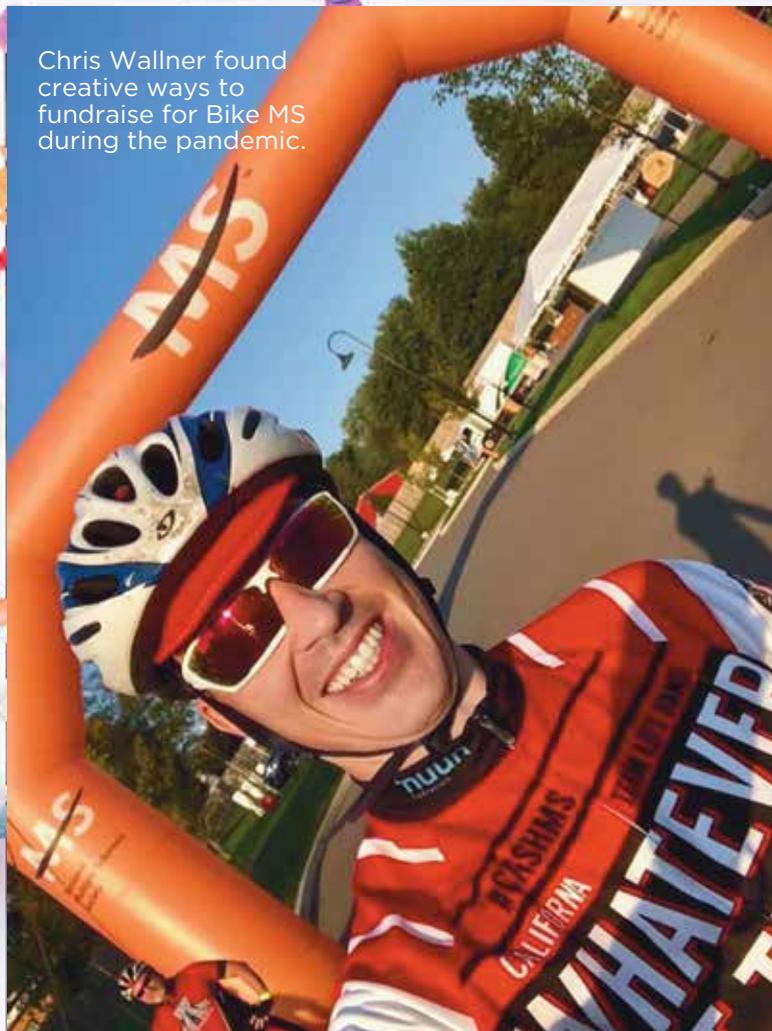
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move

The MS movement in action

Chris Wallner found creative ways to fundraise for Bike MS during the pandemic.



Going virtual

The pandemic prompted new ways to bike, walk and climb for MS.

by Shara Rutberg

As Leigh Krauss climbed the last of the 1,215 stairs to the 70th floor of 30 Rockefeller Center in New York City during the 2019 Climb to the Top, she was surrounded by more than 50 friends and family members in matching team shirts, cheering, clapping — and huffing and puffing.

Krauss, a physical therapist living with multiple sclerosis, had just completed her sixth Climb, a fundraiser for the National Multiple Sclerosis Society. She completed the first one just a few months after her MS diagnosis. Suffering from debilitating quad pain and fatigue, she climbed, hanging onto her father's shoulder for the last 10 flights, barely finishing. For six years in a row, she's fought through symptoms to reach the top of the Rock. Her team has raised over \$300,000.

"Climb to the Top has really changed my life," Krauss says. "It transferred the impetus from, 'Why did this happen to me?' to 'Here's a way I can do the most with the cards I've been dealt.'"

In 2020, she and her husband, Dan, were in their new San Francisco home preparing for their New York trip for her seventh Climb. Then, COVID-19 hit.

But thanks to passion and hard work, Climb to the Top, along with the Society's other major fundraising events — Walk MS, Challenge Walk MS and Bike MS — went on. They just looked a little different.

In normal years, the Society hosts three Climb to the Top events in different cities. On March 7, 2020, in Boston, almost 600 participants ran, jogged and walked, in waves, up the 1,200 steps of 200 Clarendon Tower, raising \$360,000.

When the pandemic halted in-person events, organizers combined the next two Climbs, one in New York and another in San Francisco, into one virtual Coast to Coast Climb on August 15, 2020. Participants could "virtually" climb any of the buildings in the series or complete a trifecta of all three — Boston, New York and San Francisco.

A central online event hub live-streamed an opening ceremony and delivered all kinds of support, from a program to design and print Climb bibs to social media fundraising tools. Participants could climb stairs wherever they liked, inside or out, tracking their progress through the Charity Miles app, which provided a customized

virtual experience themed to New York, Boston or San Francisco and the buildings that would have been climbed. People climbed everywhere from the “Rocky Stairs” of the Philadelphia Museum of Art to the stone stairs at Red Rocks Amphitheater in Colorado, says Michele Ludlow, senior director, emerging events for the Society.

The Climb events raised \$1.23 million, just shy of their \$1.3 million original budget. Participants climbed in all 50 states. The virtual platform allowed people who would not have been able to travel to the original host cities to participate, engaging a new audience and generating new revenue.

Bike MS

How do you turn pickle juice and PB&Js at rest stops into a virtual experience? That was just a tiny taste of the challenge the Bike MS team faced turning the country’s largest bicycle fundraising series into a virtual experience.

“We had to completely reimagine the event,” says Kris Rauh, associate vice president, Bike MS Experience. Instead of dozens of in-person rides in locations across the country, two virtual rides were held in September and October 2020. Bike MS: Inside Out participants chose their own route and tracked outdoor miles through the Strava app and indoor, stationary bike miles through Zwift, or without any technology at all. Participants were flooded with online support throughout the rides, from a live-streamed opening ceremony to virtual rest stops, scavenger hunts with riders posting their finds on social media, fundraising challenges and live voting for the best jersey. Social media posts show Strava route maps everywhere from London to Polynesian islands and photos of cornfields and mountain passes.

“Even though how we ride is different, the why we ride is still the same — people with MS need us more than ever,” says Rauh. “We definitely saw the same spirit, passion and camaraderie on the day of the virtual event as on past events.”

Even though they had to pack their own pickle juice, Bike MS participants raised over \$8 million.

For Bike MS veteran Chris Wallner, 37, of Denver, who has completed 25 events across the country, fundraising started slowly after COVID hit.

“There was the fear of the unknown — how to ask for money when you don’t know where people are in life,” he

Over 40,000 supporters tuned into the September virtual experience.



says. “But like the Society says, multiple sclerosis doesn’t stop because of the pandemic, so neither will we.”

Wallner usually hosts a big fundraiser at a brewery, along with email and social media efforts. This year, most things went online, and he tried to find fun, unique ways to raise funds and awareness for those living with MS. He held “Five Dollar Fridays,” asking friends to donate money they would have spent in a bar. He made Bike MS beer glasses and sold hundreds over social media. Wallner, who did his ride as an indoor/outdoor century ride (102.5 miles to be exact), raised even more money this year than he did last year.

“Over 40,000 supporters tuned into the September virtual experience,” says Rauh. “Usually, Bike MS has 60,000–70,000 participants over the whole year, so we’re pretty proud of 40,000 viewers in a single day.”

Walk MS and Challenge Walk MS

There were 355 Walk MS events slated for 2020. When the pandemic hit, only 13 in-person events had occurred. The program switched to virtual within days.

“It came down to doing the walk where you were — in your neighborhood, in your backyard or your home — and posting on social media,” says Cindy Yomantas, associate vice president, Walk MS Experience.

Fundraising in the early days of the pandemic and amid lockdowns was a big unknown. Society staff debated whether it was appropriate to ask participants

#VIRTUALWALKMS

Challenge Walk usually occurs over three different weekends in three separate locations, with participants walking 50 miles over three days. One Walk occurred before the pandemic hit. Two became virtual events. Society staff members worked tirelessly to create a digital experience to match the in-person event. After an inspiring virtual opening ceremony, virtual rest stops, social media and virtual bingo, participants attended a moving Saturday night program via Zoom.

Individual walkers did what they could to make their weekends special. Hodge's mother, Julie Tucker, of Westminster, Massachusetts, went above and beyond. "That weekend is my favorite weekend of the year," says Hodge, who was diagnosed with MS in 2015 and lives in Leominster, Massachusetts. "Everyone knows what you're going through. You don't have to explain yourself."

As soon as Tucker learned the Walk would be virtual, she got busy. She arranged for nearly 50 (socially distanced) friends and family members to join her and her daughter for the final quarter mile — led by a parade of local police and fire department vehicles along Westminster's main drag.

Just keep climbing

Krauss felt the same way at the end of her event. Instead of the rowdy crowd that usually surrounds her at the top of the Rock, it was quiet when she reached the top of San Francisco's 16th Avenue mosaic steps — for the eighth time. Only her husband was waiting for her. "I still felt my team around me, climbing virtually all over the country in this fight to end MS," Krauss says. She plans to climb next year, too, regardless of the event format. "I'll be climbing every year until there's a cure," she says. ■

Shara Rutberg is a writer in Evergreen, Colorado.



Learn about details of 2021 events at
bikeMS.org
walkMS.org
challengewalkms.org
ntlms.org/climb

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



Katie Hodge (center) raised more than \$3,000 for Walk MS in 2020.

to fundraise during a pandemic. Feedback from team captains revealed that "while it's going to be hard, Walk MS participants are up for the challenge. They told us, 'That's what we're here for,'" Yomantas says.

After receiving that green light, fundraising grew stronger every weekend. New virtual team captains' meetings attracted 1,500 [participants] and were "gold mines" for sharing fundraising and celebration ideas, Yomantas says. Frequent Facebook Live sessions featuring participants telling their Walk MS stories also inspired walkers.

"Community is the core of Walk MS, and these unique virtual ways to gather gave people a chance to feel a bit of the joy of what Walk MS means — to receive a virtual Walk MS hug — and be reinvigorated," Yomantas says. The 2020 Walk MS campaign raised more than \$24 million.

Katie Hodge, a Challenge Walk MS participant, raised more money than ever in 2020, over \$3,000. "Ninety percent was Facebook. This year, I felt super bad asking for money," says the 25-year-old, who had been laid off from her job. "It was easier to just share my story with a link that said, 'Click if you're willing to donate, or share.'"

H.E.R.T.'s so good

Lifelong friends keep biking to fight MS.

by Mike Knight

Recently divorced after a 25-year marriage, Bruce Ungar was at a loss. His teenage daughter had just moved in with him, and Ungar wanted — needed — to find a way to spend their newfound time together.

Then in his 40s at the time, Ungar was stumped. “Finding connections, a way to spend time together with a 16-, 17-year-old daughter, can be sort of a challenge for a middle-aged guy,” he says.

A casual bike rider at best, Ungar decided to bring his daughter along with him to a downtown bike shop in Mount Lebanon, Pennsylvania, where they lived, to pick up a new tire for his bike. After grabbing the tire, they decided to poke around the shop for a few minutes. He didn’t know it at the time, but Ungar had stumbled onto just what he was looking for.

“I saw a brochure about our local MS Society’s supported ride called the Escape to the Lake. I approached my daughter and said, ‘Hey, is this something that you think we might do together?’”

She was athletic and in good shape, playing high school field hockey and lacrosse. On top of that, Ungar says she had “game.”

“She said, ‘Yeah, let’s do it,’” he says. “I bought her a bicycle, and we started to ride together.”

Escape to the Lake is a 150-mile fundraising ride supporting the National Multiple Sclerosis Society. Known by the local cycling community for its impeccable execution, the two-day ride begins just north of Pittsburgh. The ride then snakes its way to Lake Erie, traveling through beautiful countryside, small towns and long, spiteful hills. Created in 1985, the event hosts approximately 50 teams annually and has raised more than \$15 million since its inception,

according to Anne Mageras, president of the Society’s Pennsylvania Keystone Chapter.

Ungar and his daughter asked friends and family to donate funds to support their ride, then began to train, at first riding around their neighborhood, then taking increasingly longer rides on the converted “rails to trails” in their area.

Ungar is blunt in his assessment of their training regimen. “We were woefully unprepared,” he says.

The pair finished the ride — even if the ride nearly finished them. “We got beat up pretty badly,” he says. “We stopped on the way home to get something to eat, and we couldn’t hold our forks. Our hands were numb and feet sore. We were dehydrated and sunburned.”

Yet Ungar says it was everything he hoped for that day in the bike shop. “We spent all this extra time together, and we had long conversations on the trail,” he says. “It was a growth experience for both of us.”

It was also 1998 and the birth of the Hungarian ExCycled Racing Team (H.E.R.T.), an ever-changing group of riders that has raised more than \$300,000 via the event over the last 22 years to help fight multiple sclerosis. It was almost the team’s birth, but not quite.

Bruce and Alan’s excellent adventures

Though Ungar and his daughter rode in the following year’s Escape, it would be their last as she went to college. Now without a partner, Ungar was stumped.

“I was looking for somebody to do [the ride] with,” he says. But who? “There’s just not so many people

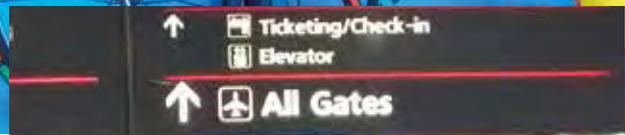


Peter Oleinick, Bruce Ungar and Alan Iszauk (left to right) of the Hungarian ExCycled Racing Team (H.E.R.T.) participate in the 2019 Bike MS Escape to the Lake Ride in western Pennsylvania.

that you can approach to say, ‘Hey, how would you like to take a 150-mile bike ride with me?’”

Enter his childhood friend, Alan Iszauk (pronounced Iz-shock). Like Ungar, Iszauk grew up in nearby McKeesport, a city of 19,000 people not far from Pittsburgh. Born just a few months apart in 1952, the two became practically inseparable. “From the time we were 4 years old, we were pretty much together. Our parents went to the same congregation,” Ungar says. “We were in Sunday school and grade school together. We were in Boy Scouts together. We went to different universities but visited each other at university.”

Ungar knew he was asking a lot. “It’s one thing if it’s a three- or four-day gig, and you stay in a bed-and-breakfast along the way,” he says. “This is 150 miles in two days, rain or shine, plus you have to raise money to



Alan Iszauk and Bruce Ungar bike to the airport.

do it.” But Iszauk, Ungar remembered, also had game. So he asked him anyway.

Then in his early 50s, Iszauk liked bicycling, but a 25-mile ride was a big deal for him. He told Ungar he’d do it anyway. “I thought he was crazy,” Iszauk says. “But I figured if Bruce could do it, I could do it.”

The two set their sights on the ride. They began a training program much like Ungar had done with his daughter. “We didn’t have road bikes and the kind of spandex stuff that you wear, didn’t really understand the whole gig,” Ungar recalls. “We just pedaled and had a good time.”

“Once again,” Ungar says, “we came out woefully unprepared.”

That’s not all they weren’t ready for, Iszauk says, remembering the last few miles of his first Escape ride. “It was a very hot day, and I didn’t think I could even get off my bike and walk,” he says. “And a woman came up to me and said, ‘I want to thank you for what you do.’”

Woozy from the grueling ride, Iszauk struggled to make sense of what she was getting at. “All I wanted to do was take a shower and go to bed, and she kept thanking me, and I just wasn’t computing,” he says.

She told Iszauk that she, too, had once participated in the ride but no longer could. “She pointed over at a wheelchair,” Iszauk says, “and it dawned on me what she was trying to communicate. Once that connected, she threw her arms around me, we embraced, I’m in tears, and no matter how much I was hurting at that moment, I was thankful that I was able to do it. She made a difference in my life.”

Iszauk vowed to return the following year to fight MS. “I said to Bruce, ‘Next year, if we do this again, let’s get

serious about raising some money. We’ve been a top fundraising team ever since.”

The first order of business was coming up with a team name. “In order to form a team [for the event], we needed a team name,” Iszauk says. “We were brainstorming and we were working with the idea of the pain we experienced by our lack of proper training. The word ‘hurt’ kept coming up in phrases, like ‘I hurt,’ ‘We hurt,’ and ‘I can’t think because I hurt.’” Trying hard to shoehorn the acronym into life, Iszauk remembered McKeesport’s heavy Hungarian population (Iszauk

and Ungar are both of Hungarian heritage), settling on the Hungarian ExCycled Racing Team. ExCycled? “We couldn’t come up with a good ‘U’ word,” Iszauk says.

Over the years, the team has sharpened its approach to distance biking, upgrading their bikes and gear, and studying how to ride more comfortably and safely. H.E.R.T.



Bruce Ungar, Gary Dubin, Alan Iszauk and Larry Sachs (left to right) pedal to Pittsburgh’s Mount Washington.

has grown from Ungar and Iszauk (now team co-captains) to some 50 members, recruited in its typical freewheeling fashion. “As we’re riding down the trails, we meet people on the trail and engage them in conversation and invite them to join us,” Ungar says. “When I’m riding around my neighborhood, when I see people who are riding along, I’ll try to catch up with them, ride with them and encourage them to join us. I invite people to come with me on a life-changing adventure.”

Iszauk is even less discerning, subjecting unsuspecting friends, family, colleagues and acquaintances to on-the-spot interviews. “I will ask anybody, ‘Do you ride a bike? Have you ever been on a bike ride longer than 25 miles? Would you like to join us? Come on for a ride with us,’” he says.

Iszauk is an equally zealous fundraiser. “He and I are both shameless about getting people as a part of the team,” Ungar says. “But he’s a shameless fundraiser. It’s positively amazing to watch.”

One particularly brazen example stands out in Ungar’s mind. Traveling past a scenic vista while on a training ride, the team happened upon a young bride and groom having their photos taken at the overlook. The unwitting young couple was unprepared for what was about to hit them.

“We, of course, congratulated them,” Ungar says. “But they engaged us in conversation, and it wasn’t five minutes before Alan was hitting up the groom for a donation to MS. We were a good-sized group, and I have to say the rest of the riders were agog.”

The long-running team, Ungar says, “is the oldest and the heaviest, that’s for sure.” Ungar was in his 40s when he took his first Escape ride over two decades ago. He turned 68 in September 2020. Iszauk will turn 69 in June 2021. The passage of time, says Ungar, has taken its toll on the team. “I’ve been doing this long enough that members of my team, good guys, have passed already,” he says. “We’ve actually taken rides to go visit their graves.”

Riding the storm out

The coronavirus shut down countless activities and events across the United States in 2020. The Society’s fundraising walks and rides, including Escape to the Lake, was among them, although many events transformed into virtual events.

Not content to sit idly by, the Hungarians organized three self-supported “replacement” fundraising rides in the event’s absence. The second ride in July was nearly 50 miles long. The ride featured a 4,300-foot vertical climb with temperatures in the mid-90s and took the team from Laurel Hill State Park, 65 miles south of Pittsburgh, to the Flight 93 National Memorial near Shanksville, Pennsylvania.

Both Iszauk and Ungar like writing “travelogue” emails, filling them with photos of the wildlife, scenery, quaint towns and architecture they pass along the way. They send their writing to

ever-growing lists of family and friends, colleagues, plus would-be team members and donors.

“Yesterday was a day of superlatives...,” wrote Iszauk in one email dated July 20, 2020, one day after finishing the ride. “...The toughest bike ride I have ever participated in, the best peanut butter and jelly sandwich I ever ate, the hottest bike ride that I can remember, the most grateful I can be for the support, love and friendship of so many ... the list goes on.” Iszauk says the team raised more than \$65,000 in 2020.

Chris Pfeiffer, Bike MS manager, says he’s come to expect the team’s dedication to raising money to beat MS. “The Hungarians represent a commitment to the cause and continue to increase fundraising year to year. They bring others along and have a fun time doing it,” he says. “The spirit of Alan and Bruce drives the team. They are the backbone of our wonderful events.” ■

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



Bruce Ungar (left) and Alan Iszauk are co-captains of the Hungarian Ex-Cycled Racing Team.

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



Living with relapsing multiple sclerosis (MS)?

TAKE A LOOK

at a once-daily pill
for relapsing MS

Ask your healthcare professional about
ZEPOSIA at your next appointment.

People had fewer relapses with ZEPOSIA

↓ **48%** **FEWER RELAPSES**

In a one-year study:

People who took ZEPOSIA had 48% fewer relapses than those who took a leading injectable medicine (Avonex).^{*†}

↓ **38%** **FEWER RELAPSES**

In a separate two-year study:

People who took ZEPOSIA had 38% fewer relapses than those who took a leading injectable.[†]

To learn more, visit ZEPOSIA.com/results or scan this QR code.



*Avonex (interferon beta-1a).

†One-year study: People taking ZEPOSIA had an Annualized Relapse Rate (ARR) of 0.181 vs 0.350 with a leading injectable. A total of 895 people were studied (ZEPOSIA 447, a leading injectable 448). Two-year study: 0.172 ARR with ZEPOSIA vs 0.276 with a leading injectable. A total of 874 people were studied (ZEPOSIA 433, a leading injectable 441).

INDICATION

ZEPOSIA[®] (ozanimod) is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults. It is not known if ZEPOSIA is safe and effective in children.

IMPORTANT SAFETY INFORMATION

Do not take ZEPOSIA if you:

- have had a heart attack, chest pain (unstable angina), stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have or have had a history of certain types of an irregular or abnormal heartbeat (arrhythmia) that is not corrected by a pacemaker
- have untreated, severe breathing problems during your sleep (sleep apnea)
- take certain medicines called monoamine oxidase (MAO) inhibitors

Talk to your healthcare provider before taking ZEPOSIA if you have any of these conditions or do not know if you have any of these conditions.

ZEPOSIA may cause serious side effects, including:

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

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

- fever
- feeling very tired
- flu-like symptoms
- cough
- painful and frequent urination (signs of a urinary tract infection)
- rash
- headache with fever, neck stiffness, sensitivity to light, nausea, or confusion (symptoms of meningitis, an infection of the lining around your brain and spine)

Your healthcare provider may delay starting or may stop your ZEPOSIA treatment if you have an infection.

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IMPORTANT SAFETY INFORMATION (cont'd)

ZEPOSIA may cause serious side effects, including (cont'd):

- **Slow heart rate (also known as bradyarrhythmia) when you start taking ZEPOSIA.** ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA.

Call your healthcare provider if you experience the following symptoms of slow heart rate:

- dizziness
- lightheadedness
- feeling like your heart is beating slowly or skipping beats
- shortness of breath
- confusion
- chest pain
- tiredness

Follow directions from your healthcare provider when starting ZEPOSIA and when you miss a dose.

Continue reading for additional possible serious side effects of ZEPOSIA.

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

- have a fever or infection, or are unable to fight infections due to a disease, or take or have taken medicines that lower your immune system
- before you start ZEPOSIA, your healthcare provider may give you a chickenpox (varicella zoster virus) vaccine if you have not had one before
- have had chickenpox or have received the vaccine for chickenpox. Your healthcare provider may do a blood test for the chickenpox virus. You may need to get the full course of the vaccine and wait 1 month before taking ZEPOSIA
- have a slow heart rate
- have an irregular or abnormal heartbeat (arrhythmia)
- have a history of stroke
- have or have had heart problems, including a heart attack or chest pain
- have high blood pressure
- have liver problems
- have breathing problems, including during your sleep
- have eye problems, especially an inflammation of the eye called uveitis
- have diabetes
- are or plan to become pregnant or if you become pregnant within 3 months after you stop taking ZEPOSIA. ZEPOSIA may harm your unborn baby. If you are a female who can become pregnant, talk to your healthcare provider about what birth control method is right for you during your treatment with ZEPOSIA and for 3 months after you stop taking ZEPOSIA
- are breastfeeding or plan to breastfeed. It is not known if ZEPOSIA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ZEPOSIA

Tell your healthcare provider about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Using ZEPOSIA with other medicines can cause serious side effects. Especially tell your healthcare provider if you take or have taken:

- medicines that affect your immune system, such as alemtuzumab
- medicines to control your heart rhythm (antiarrhythmics) or heartbeat
- strong CYP2C8 inhibitors such as gemfibrozil or clopidogrel
- medicines that inhibit breast cancer resistance protein transporters, such as cyclosporine and eltrombopag
- CYP2C8 inducers such as rifampin
- opioids (pain medicine), medicines to treat depression, and medicines to treat Parkinson's disease

You should not receive **live** vaccines during treatment with ZEPOSIA, for at least 1 month before taking ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Vaccines may not work as well when given during treatment with ZEPOSIA.

ZEPOSIA can cause serious side effects, including:

- **liver problems.** Your healthcare provider will do blood tests to check your liver before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
 - unexplained nausea
 - vomiting
 - stomach area (abdominal) pain
 - tiredness
 - loss of appetite
 - yellowing of the whites of your eyes or skin
 - dark-colored urine
- **increased blood pressure.** Your healthcare provider should check your blood pressure during treatment with ZEPOSIA. A sudden, severe increase in blood pressure (hypertensive crisis) can happen when you eat certain foods that contain high levels of tyramine
- **breathing problems.** Some people who take ZEPOSIA have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems
- **a problem with your vision called macular edema.** Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis. Your healthcare provider should test your vision before you start taking ZEPOSIA if you are at higher risk for macular edema or any time you notice vision changes during treatment with ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
 - blurriness or shadows in the center of your vision
 - sensitivity to light
 - a blind spot in the center of your vision
 - unusually colored vision
- **swelling and narrowing of the blood vessels in your brain.** Posterior Reversible Encephalopathy Syndrome (PRES) is a rare condition that has happened with ZEPOSIA and with drugs in the same class. Symptoms of PRES usually get better when you stop taking ZEPOSIA. If left untreated, it may lead to stroke. Your healthcare provider will do a test if you have any symptoms of PRES. Call your healthcare provider 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
- **severe worsening of MS after stopping ZEPOSIA.** When ZEPOSIA is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your healthcare provider before you stop taking ZEPOSIA for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping ZEPOSIA.
- **allergic reactions.** Call your healthcare provider 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 ZEPOSIA can include:

- upper respiratory tract infections
- elevated liver enzymes
- low blood pressure when you stand up (orthostatic hypotension)
- painful and frequent urination (signs of urinary tract infection)
- back pain
- high blood pressure

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

Call your healthcare provider for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see the Important Facts on the next page.

IMPORTANT FACTS

The information below does not take the place of talking with your healthcare professional. Only your healthcare professional knows the specifics of your condition and how ZEPOSIA® (ozanimod) may fit into your overall therapy. Talk to your healthcare professional if you have any questions about ZEPOSIA (pronounced zeh-poe'-see-ah).



What is the most important information I should know about ZEPOSIA (ozanimod)?

ZEPOSIA may cause serious side effects, including:

1. Infections. ZEPOSIA can increase your risk of serious infections that can be life-threatening and cause death. ZEPOSIA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 months of stopping treatment. Your healthcare provider may do a blood test of your white blood cells before you start taking ZEPOSIA.

Call your healthcare provider right away if you have any of the following symptoms of an infection during treatment with ZEPOSIA and for 3 months after your last dose of ZEPOSIA:

- o fever
- o rash
- o feeling very tired
- o 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)
- o flu-like symptoms
- o cough
- o painful and frequent urination (signs of a urinary tract infection)

Your healthcare provider may delay starting or may stop your ZEPOSIA treatment if you have an infection.

2. Slow heart rate (also known as bradyarrhythmia) when you start taking ZEPOSIA. ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days that you take ZEPOSIA. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heart rate:

- o dizziness
- o shortness of breath
- o lightheadedness
- o confusion
- o feeling like your heart is beating slowly or skipping beats
- o chest pain
- o tiredness

Follow directions from your healthcare provider when starting ZEPOSIA and when you miss a dose. See **"How should I take ZEPOSIA?"**

See **"What are the possible side effects of ZEPOSIA?"** for more information about side effects.

What is ZEPOSIA?

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

Do not take ZEPOSIA if you:

- have had a heart attack, chest pain (unstable angina), stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months.
- have or have had a history of certain types of an irregular or abnormal heartbeat (arrhythmia) that is not corrected by a pacemaker.
- have untreated, severe breathing problems during your sleep (sleep apnea).
- take certain medicines called monoamine oxidase (MAO) inhibitors (e.g., selegiline, phenelzine, linezolid).

Talk to your healthcare provider before taking ZEPOSIA if you have any of these conditions or do not know if you have any of these conditions.

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

- have 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.
- received a vaccine in the past 30 days or are scheduled to receive a vaccine. ZEPOSIA may cause vaccines to be less effective.
- Before you start treatment with ZEPOSIA, your healthcare provider may give you a chicken pox (Varicella Zoster Virus) vaccine if you have not had one before.

- have had chickenpox or have received the vaccine for chickenpox. Your healthcare provider may do a blood test for the chickenpox virus. You may need to get the full course of the vaccine for chickenpox and then wait 1 month before you start taking ZEPOSIA (ozanimod).
- have a slow heart rate.
- have an irregular or abnormal heartbeat (arrhythmia).
- have a history of a stroke.
- have heart problems, including a heart attack or chest pain.
- have high blood pressure.
- have liver problems.
- have breathing problems, including during your sleep.
- have eye problems, especially an inflammation of the eye called uveitis.
- have diabetes.
- are pregnant or plan to become pregnant. ZEPOSIA may harm your unborn baby. Talk with your healthcare provider if you are pregnant or plan to become pregnant. If you are a female who can become pregnant, you should use effective birth control during your treatment with ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Talk with your healthcare provider about what birth control method is right for you during this time. Tell your healthcare provider right away if you become pregnant while taking ZEPOSIA or if you become pregnant within 3 months after you stop taking ZEPOSIA.
- are breastfeeding or plan to breastfeed. It is not known if ZEPOSIA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ZEPOSIA.

Tell your healthcare provider about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Using ZEPOSIA with other medicines can cause serious side effects. Especially tell your healthcare provider if you take or have taken:

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- medicines to control your heart rhythm (antiarrhythmics), or heart beat
- strong CYP2C8 inhibitors such as gemfibrozil or clopidogrel
- medicines that inhibit breast cancer resistance protein transporters, such as cyclosporine and eltrombopag
- CYP2C8 inducers such as rifampin
- opioids (pain medicine)
- medicines to treat depression
- medicines to treat Parkinson's disease

You should not receive **live** vaccines during treatment with ZEPOSIA, for at least 1 month before taking ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Vaccines may not work as well when given during treatment with ZEPOSIA.

Talk to your healthcare provider if you are not sure if you take any of these medicines. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I take ZEPOSIA?

You will receive a 7-day starter pack. You must start ZEPOSIA by slowly increasing doses over the first week. Follow the dose schedule of: Days 1-4: 0.23 mg 1 time a day; Days 5-7: 0.46 mg 1 time a day; Days 8 and thereafter: 0.92 mg 1 time a day. **This may reduce the risk of slowing of the heart rate.**

- Take ZEPOSIA exactly as your healthcare provider tells you to take it.
- Take ZEPOSIA 1 time each day.
- Swallow ZEPOSIA capsules whole.
- Take ZEPOSIA with or without food.
- Avoid certain foods that are high (over 150 mg) in tyramine such as aged, fermented, cured, smoked and pickled foods. Eating these foods while taking ZEPOSIA may increase your blood pressure.
- Do not stop taking ZEPOSIA without talking with your healthcare provider first.
- Do not skip a dose.
- Start taking ZEPOSIA with a 7-day starter pack.
- If you miss 1 or more days of your ZEPOSIA dose during the first 14 days of treatment, talk to your healthcare provider. You will need to begin with another ZEPOSIA 7-day starter pack.
- If you miss a dose of ZEPOSIA after the first 14 days of treatment, take the next scheduled dose the following day.

What are the possible side effects of ZEPOSIA (ozanimod)?

ZEPOSIA can cause serious side effects, including:

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

• **liver problems.** ZEPOSIA may cause liver problems. Your healthcare provider will do blood tests to check your liver before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:

- o unexplained nausea
- o loss of appetite
- o vomiting
- o yellowing of the whites of your eyes or skin
- o stomach area (abdominal) pain
- o dark colored urine
- o tiredness

• **increased blood pressure.** Your healthcare provider should check your blood pressure during treatment with ZEPOSIA. A sudden, severe increase in blood pressure (hypertensive crisis) can happen when you eat certain foods that contain high levels of tyramine. See **"How should I take ZEPOSIA?"** section for more information.

• **breathing problems.** Some people who take ZEPOSIA have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems.

• **a problem with your vision called macular edema.** Your risk for macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis. Your healthcare provider should test your vision before you start taking ZEPOSIA if you are at higher risk for macular edema or at any time you notice vision changes during treatment with ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:

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- o a blind spot in the center of your vision
- o sensitivity to light
- o unusually colored vision

• **swelling and narrowing of blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) is a rare condition that has happened with ZEPOSIA and with drugs in the same class. Symptoms of PRES usually get better when you stop taking ZEPOSIA. If left untreated, it may lead to a stroke. Your healthcare provider will do a test if you have any symptoms of PRES. Call your healthcare provider right away if you have any of the following symptoms:

- o sudden severe headache
- o sudden loss of vision or other changes in your vision
- o sudden confusion
- o seizure

• **severe worsening of multiple sclerosis (MS) after stopping ZEPOSIA.** When ZEPOSIA is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your healthcare provider before you stop taking ZEPOSIA for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping ZEPOSIA.

• **allergic reactions.** Call your healthcare provider 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 ZEPOSIA can include:

- upper respiratory tract infections
- elevated liver enzymes
- low blood pressure when you stand up (orthostatic hypotension)
- painful and frequent urination (signs of urinary tract infection)
- back pain
- high blood pressure

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

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not take ZEPOSIA for conditions for which it was not prescribed. Do not give ZEPOSIA to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for information about ZEPOSIA that is written for health professionals. For more information, call 1-833-ZEPOSIA (1-833-937-6742) or go to ZEPOSIA.com.

Manufactured for: Celgene Corporation, Summit, NJ 07901
Patent: www.celgene.com/therapies



An unforeseen challenge

My MS diagnosis taught me to embrace a whole new world.

by Lovey Ray

My entire life has been a balancing act. I've been juggling new challenges since I was a 5-year-old Black girl adopted into a Norwegian/German family, never feeling like I fit in, then abandoned at age 17. My military career was cut short because of an abusive marriage, and I became a single mom of two at a young age. I was homeless for a short time, and I dealt with several roller-coaster relationships. It all taught me that I was strong. I could overcome any obstacles thrown my way, but being diagnosed with multiple sclerosis in 2014 at age 31 was a challenge I did not see coming. It became front and center in my life.

I had just started what I thought would be my dream job when I was injured in a car accident. I started losing my vision a few weeks later. Right away, a whirlwind of tests began — in-depth vision screenings, MRIs, a spinal tap, repeatedly being asked what happened. I remember sitting in the doctor's office, being told I had MS. I didn't take it seriously until I researched the disease.

Then began the stages of grief. I was in denial — this was not going to be a big deal, and I would not make a big issue out of it.



Lovey Ray, diagnosed with MS in 2014, shares her story of strength and resilience.

I did not feel I needed to start medication right away, and I would get better. I experienced depression and anger. Being a veteran of both, I knew that if I was going to survive whatever MS had coming for me, I needed to embrace this new world and surround myself with others who were supportive and, like me, were fighting an uphill battle.

I began attending an MS group sponsored by the National Multiple Sclerosis Society. Although I was the youngest and the only female of color in the group, they accepted me. The one thing we had in common was this terrible disease. What a relief it was to hear the stories from others about symptoms that I experienced every day and how they worked through them. I started accepting that this was now a part of my life and that it was important to teach my five beautiful children that despite issues of health, race or any other curveballs that are thrown your way, you work through them. It will not be an easy climb, but you can make it.

As I adjusted to the new world I was forced into, I started reevaluating my life and removing obstacles and people who were either holding me back or holding me down. My children became front and center, and I vowed I would never miss an important day of their lives unless my health prevented me. I would focus on the here and now, not worry about the future, knowing God had it all under control and that worrying just leads to stress and anxiety. I share my story of resilience with anyone who asks, and

“

What a relief it was to hear the stories from others about symptoms that I experienced every day and how they worked through them.”

— LOVEY RAY

I try to be an example of how MS does not define who I am. Having MS led me to share my story so that others know MS does not discriminate.

Like any other disease, MS does not pick and choose who is diagnosed or tests positive. Just like so many other invisible illnesses, you never know who around you might be in pain and suffering.

The world has been thrown into chaos with different groups fighting about who is right and wrong.

They forget that everyone is different and that the color of one's skin does not make one better than another. I was raised to not “see” black or white but that we are all people who make mistakes and have a right to our own opinions. We all have feelings and pain that we hide behind.

What makes us unique is that our country is a melting pot of so many different people from different backgrounds. MS is often called the snowflake disease because no two people have precisely the same symptoms. Just as MS affects each person differently, we need to be more caring and empathetic to those around us whose opinions may not align exactly with our own. I am grateful for being unique, and while I did not ask for MS, God has allowed me to use it to encourage others, because only together can we make a difference. ■

Lovey Ray lives in Mill Creek, Washington, with her daughter and four sons. She is an Army veteran. When she is not working as a chiropractic assistant, she enjoys cooking and traveling with her family. She also leads a local MS support group in her area.

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

ART as therapy



My work became a tool to help me survive and thrive.

by Heather Wolfe

See more of Heather Wolfe's artwork:

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Heather Wolfe lives with her husband and child in East Tennessee. She's an avid gardener and loves to create bouquets for her friends and family.

When I was first diagnosed with multiple sclerosis in March 2015, I was terrified. At the time, my life was a perfect storm of stress — surviving a horrific trauma, a devastating divorce and now MS. The emotional and physical healing experience has been a long journey that I am still on today. I am grateful for my progress and for the tools that helped me survive and thrive. One of those tools was art therapy.

Having been an artist my whole life, using art as a therapy tool was a natural transition. I started my business, Heather Wolfe Art, doing custom pet portraits based on my clients' photos. The pet portraits were collages made from mixed media using handmade papers from all over the world with textures, patterns and paint. As the business grew, I was selected as a featured artist and vendor at the Westminster Dog Show in New York City and the National Dog Show in Philadelphia. This catapulted my professional career to full time, painting hundreds of portraits of champion dogs from across the world in addition to many other animals — even a therapy llama.

A few years ago, I expanded my portfolio to include live wedding paintings, where I paint the event on location as it is happening. I also do custom commission paintings of all subjects from clients' photographs of life events. I love helping my clients commemorate their celebrations of life and honor the memories with an everlasting keepsake to hang in their home. Getting to support others and show up for them in these heartfelt moments gives me a sense of purpose and joy.

My experience taught me that beauty could coexist with hardship. We cannot avoid pain, and we may not always have answers. We can let the struggle season our character instead of control our lives. I work to choose joy daily. When I suffer, I want to suffer well. Yes, I have MS, but it doesn't define me. I am so much more than that. I am an artist, an encourager, a wife and a mother of my first child. ■

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