Good companions
Pets can enrich the lives of people living with MS.

56
MAVENCLAD®
(cladribine) tablets 10 mg

I'M READY
FOR AN MS TREATMENT THAT’S
NOT AN INFUSION, NOT AN INJECTION, NOT A DAILY PILL.*

*Not taken every day of the year.

MAVENCLAD is the first and only short-course oral therapy with no more than 10 treatment days a year over 2 years.

Talk to your healthcare provider to find out if MAVENCLAD is right for you, and visit mavenclad.com for more information.

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).

MAVENCLAD may cause serious side effects.

Treatment with MAVENCLAD may increase your risk of developing cancer. You should follow healthcare provider instructions about screening for cancer. Because of the risk of fetal harm, do not take MAVENCLAD if you are pregnant or of childbearing potential and not using effective birth control.

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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IMPORTANT INFORMATION ABOUT MAVENCLAD® (cladribine) tablets, for oral use

Read this information carefully before using MAVENCLAD and each time you get a refill, as there may be new information. This information does not take the place of talking with your healthcare provider (HCP).

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

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”).
    - You should use a second method of birth control on the days on which you take MAVENCLAD and for at least 4 weeks after your last dose of each yearly treatment course.
    - 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.

- Take MAVENCLAD at least 3 hours apart from other treatments for MS. Certain medicines can increase your risk of getting an infection.
- Take MAVENCLAD if you:
  - have cancer (malignancy).
  - 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 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.
- MAVENCLAD is not recommended for use in people with clinically isolated syndrome (CIS).
• 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:

• See “What is the most important information I should know about MAVENCLAD?”

• 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.

• 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 have 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 blotsches, 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
  • 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
  • allergic reactions (hypersensitivities). MAVENCLAD can cause serious allergic reactions. Start 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.

• 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:

• upper respiratory infection
• headache
• 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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For more information, call toll-free 1-877-447-3243 or go to www.mavenclad.com

Address drop, add or change Email: mailinglist@nmss.org Call 1-844-675-4787

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.

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This October, we will launch our fiscal year 2022-2024 Strategic Plan. The plan declares the impact we are working toward as we pursue our updated mission: We will cure multiple sclerosis while empowering people affected by MS to live their best lives.

This strategic plan addresses the unique experiences of all people affected by MS and our role in reaching a better future while highlighting our firmly held belief that together we are stronger.

In developing the plan, the Strategic Plan Development Advisory Committee first learned as much as we could about the unique experiences of everyone living with MS. The effects of MS on people’s lives can be determined primarily by whether they were diagnosed before there were any disease-modifying therapies (DMTs) or when early drug therapies became available. Today, people get diagnosed faster and have many more therapy options.

We also envisioned the future for people who have yet to be diagnosed with MS. Many weighed in with perspectives and ideas. Perhaps you were one of them.

Building on 75 years of progress, we are accelerating toward a world free of MS. The focus of our strategic plan is on four impact areas:

1. Accelerate cures through global leadership
2. Improve access to personalized, affordable, high-quality MS healthcare
3. Strengthen the MS movement through more and deeper connections
4. Empower people affected by MS to solve everyday challenges

The full plan can be found online: ntlms.org/strategicplan.

Mike Pongon, chair of the Strategic Plan Development Advisory Committee, sums it up: “This plan unleashes our entire organization to move the needle for people with MS. It will take all of us with our unique talents working together to accomplish this ambitious plan, but I know we can do it!”

I agree. This plan provides us the direction and focus needed to accelerate progress while ensuring we can take advantage of opportunities that arise and effectively pivot when needed.

Do you see yourself and your priorities in the strategic plan? As always, I’d love to hear your ideas.

Let’s keep in touch!
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From pigs to parrots, pets can enrich the lives of people living with MS. 56

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  Inspiration through art

Kate Perkins was diagnosed with MS in 2010. Her labrador, Belle, has helped her stay active, relieve stress and boost her confidence.

Sarah Judson’s MS journey led her to pursue art.

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

Your article on managing foot drop (“5 tips for managing foot drop,” Spring 2021) gave me more information on the subject than any doctor has in 10 years. I take care of my son who was diagnosed with MS in 2003. Thank you for your detailed explanation of foot drop and your recommendations. I often read all your articles in Momentum and feel that they are very informative.

Rosa Sanchez, New York

First MRI an ordeal

I read “7 tips for getting through an MRI” in the Summer 2021 issue. My first MRI, in 1986, was a horrible ordeal. Luckily, my husband was allowed to stay in the room with me. He held onto my foot, and that helped me relax. I have “dog ears,” so the music was too loud and hurt my ears. I ended up just counting the “knocks.” I am now lucky to have access to an open MRI machine, so I feel less claustrophobic. There are more and more of these around the country. Thanks for your knowledgeable and supportive magazine and organization.

Elisa Linderman, California

Heartfelt look

I very much appreciated and was inspired by Aaron Freedman’s article, “A small window,” in the Summer 2021 issue. Mr. Freedman provided a heartfelt look at depression and anxiety that many people living with MS experience. He did so with a poetic use of language. Thank you.

Mary Sheeran, Minnesota

Offering optimism

Thank you to Aaron Freedman for his willingness to share his experience, perspective and insights (“A small window,” Summer 2021). He is younger than me and his MS is more debilitating than mine, yet he offers an optimism without it sounding or feeling like “disability porn.” I spend long hours in bed, though I can still struggle to get myself up and out if there is a place to take my failing body that could make that painful effort worth the while. I have the fortune of a window view — trees, a couple of Japanese maples and several evergreens. Together they attract bird life — crows, a family of doves, scrub jays, magpies and hummingbirds. Once or twice a year, perhaps, a family of wild turkeys sits at the fence line. All of this to comfort and distract me does not help me understand the being that I am. I break her into separate pieces — mind, brain, body, energy and emotion. Each blaming and/or apologizing to the other for its responsibility/complicity in the progression of this malady. It is in me and of me. Was it birthed with me? Did it arrive later, now fully integrated into the being of this woman? Some days I am articulate and hopeful as I probe and ponder. Those days are rare. I am a slow learner, and while I don’t know what this is or where it originates, I believe it contains lessons I need to know. And once I know them, I, and not the disease, will progress.

Suzanne, Oregon

Readers relate to Aaron Freedman’s story about mindfulness and his MS.

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

Email us at editor@nmss.org. Like and comment on our page at facebook.com/nationalMSsociety. Tag your thoughts @mssociety @momentum.

Share your #MSAffirmation with the #Momentum community.
Tag @mssociety on Twitter or Facebook.

I AM ABLE TO WALK ON MY PATH WITH PEACE AND COURAGE!
Andrew Forsdick, diagnosed with MS in 2013

You are what you think.

Living with multiple sclerosis can feel unpredictable. Manage your stress with positive self-talk or perspective-taking. Affirmations can help set the tone for your day and pave the way for better sleep, nutrition and exercise — key pillars of building stronger immunity. Ahead are tips on boosting your health and immune system.

PHOTO: KEITH CARLSEN
Finding gratitude

by Robert LeRose

Despite the challenges of MS, there are ways to be thankful.

The pandemic, widespread unemployment, racism, political turmoil — the last few years have been a catalog of hard times. But there’s almost always something to be thankful for, no matter how small. How can people with multiple sclerosis find ways to be grateful during dark days?

Finding gratitude

Despite the challenges of MS, there are ways to be thankful.

“Many folks with MS experience unique challenges that can increase stress or cause frustration,” says Derek Anderson, PhD, a clinical psychologist at VA Puget Sound Health Care System. “But research has shown that by focusing on gratitude and appreciation, we can improve our well-being, happiness and life satisfaction,” says Anderson, who provides psychotherapy for individuals with MS. “Gratitude is also associated with greater resilience, which is a key factor that can help individuals overcome adversity and manage health complications.”

To cultivate gratitude, Anderson offers these suggestions:

- Writing or voice-recording “three good things” every day in a journal can lead to greater well-being.
- Sending a letter to someone you’re grateful for can improve happiness and reduce depression.
- Listening to gratitude meditation recordings can guide you toward reflection and help you focus on gratitude across many different areas of life. Being grateful can take many forms, as these portraits of people with MS illustrate.

Jerrod Harris
Age: 43
Diagnosed in 2008

Harris served two tours in Iraq in 1999 and 2000 as a corporal with the 35th Signal Brigade. Returning home, he worked as an outside technician for Verizon, raised a family (now totaling five kids) and ran up to five miles a day when he started having double vision and getting dizzy. After his MS diagnosis, he withdrew from people and had a “pity party and didn’t want to invite anybody.”

He stopped working in 2011, and today, his MS makes his arms and legs feel as if they’re asleep. He got COVID-19 in February 2021 and says feeling each breath made him want to cry. But it’s little things that Harris is thankful for and that keep him motivated and focused, like being able to hug his 4-year-old son and talk with him before daycare or having a warm home on a cold, rainy day.

Harris is grateful for every experience he has. He says he doesn’t have bad days, just some that aren’t as good. “I’ve definitely served with people who had bad days. After that bad day, they had no more days. That’s a bad day,” he says. “To be around my family and friends, whether in a wheelchair or on a cane, is such a blessing. It’s not going to help me to be negative or feel sorry for myself. Sometimes, we don’t understand the power we have in how we think. What you focus on is what you choose to be.”

Dee DiFatta focuses her energy on positivity. Naming her wheelchair Proud Mary helped her feel in charge of her MS.

PHOTO: SANDRA COSTELLO PHOTOGRAPHY

PHOTO: SANDRA COSTELLO PHOTOGRAPHY
Dee DiFatta
Age: 49
Diagnosed in 1993

In a way, DiFatta became her authentic self and found her true calling in life because of her MS diagnosis. She had always put up a positive front to the world but was really angry and frustrated inside. Telling people that she had MS was unconsciously having a negative influence on her. "I gave my power away to the disease and allowed other people and circumstances to define me," she says.

To rethink her condition and reclaim power, she came up with variations for the initials MS. She began defining them as "Modified Swagger" (because she walked differently), "Motivational Spitfire" and "Magnificent Strength." She defiantly named her walker Diva and her wheelchair Proud Mary and felt in charge for the first time. During this self-discovery, she met a master of reiki — a form of spiritual healing using life-force energy — who taught her the power that words, thoughts and actions can exert on the body.

DiFatta found the confidence and courage to quit her insurance job on Feb. 14, 2020. She wrote a book, "Your Daily Dose of PositiviDee," and focused her energies on being a positivity coach, inspirational speaker, author and educator. "I'm truly grateful when I get up in the morning, and I'm still alive and can take a breath. I love my life for the first time, love what I do, love who I am. I'm so excited to share my wisdom and knowledge and major revelations with others, so they can find their way out of the dark and into the light. Everybody gets labeled and stuffed in a box at some point, but I decided to throw the box away and allow myself to be authentically me."

Latanya Brooks
Age: 51
Diagnosed in 2002

On the list of things that Brooks is thankful for is the intervention of a persuasive gentleman — a stranger to her — in helping her choose a course of treatment. As a mental health technician in the Air Force for 10 years, Brooks thought that she could tough out MS after her medical discharge from the service. "I had already told myself that I was a soldier, didn't need any medication and could beat this MS stuff," she says. But a hospital administrator at Johns Hopkins Community Physicians, Brooks is still hestet with fatigue and short-term memory loss today. She has learned to accept it, trust in God, pray a lot and surround herself with positive people, from her understanding husband to her 3-year-old grandson.

"I tell people [with MS] all the time: You didn't cause this to happen. It's something that happened to you. You've just got to embrace it and learn to live a happy and healthy life — and you can."

Jimetris Parnell
Age: 48
Diagnosed in 1995

Parnell was a sergeant in military intelligence, planning to make it her career, when numbness in her feet and chronic fatigue led to her MS diagnosis and discharge from the service. Today, she uses a wheelchair and is legally blind, but her vision and spirit are untrammeled as she reflects on her accomplishments and maintains her optimism.

After her stint in the Army, she became fascinated by computers and got a bachelor's degree in computer science. She was working with larger-scale computer systems and networking, getting regular promotions, raising two kids, and going for her master's in software engineering at night when she began falling at work. The stress of her commitments on her body forced her to give up working and a six-figure salary in 2014.

"But in my short-lived career, I was able to accomplish things that even people who don't have MS haven't been able to accomplish yet," she says.

Parnell is grateful for friends and family who don't have MS haven't been able to accomplish yet," she says.

Robert LeRose is a Long Island, New York-based writer.
COVID-19 taught people to treasure toilet paper, live music, indoor dining and hugs. For many, it led them to appreciate good health — the foundation of which is a strong immune system.

A healthy immune system is especially vital for people with autoimmune diseases like multiple sclerosis, according to MS immunology researcher Jeri-Anne Lyons. Lyons says the immune system in people with MS attacks the central nervous system, damaging the protective myelin sheaths that insulate healthy nerves.

"The immune system is a balancing act between a pro-inflammatory response and an anti-inflammatory response," explains Lyons, associate vice president for research and dean of the Graduate School at the University of Northern Colorado. "A small amount of inflammation is good. It’s what clears infections. The damaging immune response in multiple sclerosis results from chronic inflammation, which happens in part when the immune system’s anti-inflammatory mechanisms are faulty."

It’s like a faucet: The pro-inflammatory response that destroys infections is like a hot-water tap that will scald you if it’s left running. The immune system has a counteractive anti-inflammatory reaction that acts like a cold-water tap to moderate the temperature.

"Some researchers theorize that MS attacks happen when protective immunity drops," says Lyons, who points to evidence that bacterial and viral infections may trigger MS exacerbations by riling up the immune system. "For example, urinary tract infections often will predispose a relapse."

Underscoring the importance of immunity in the MS community are some disease-modifying therapies (DMTs), which may further compromise the immune systems of people with MS and leave them susceptible to dangerous infections.

"If someone’s on an immunosuppressive drug, that puts their immune system at a deficit, which means they need to bring their immune system back up to a normal, healthy baseline to fight off infections."

**4 TIPS to boost immunity**

A healthy immune system is essential — especially when you have MS.

by Matt Alderton

**EXERCISE**

**SLEEP**

**STRESS MANAGEMENT**

**DIET**

**PHOTOS: ISTOCK/ FIZKES, PIXELSEFFECT, YULKA3IC, RATSANAI**

in the know
and diseases,” explains MS researcher Alexander Ng, a professor of exercise science at Marquette University. “You need a healthy immune system in case you step on a rusty nail and to protect you from colds and flus. It’s central for survival.”

Fortunately, the immune system is equipped with at least four levers you can pull to maintain its balance: exercise, diet, sleep and stress.

1 Exercise

You already know that exercise is good for your heart. What you might not realize, however, is that it’s also good for your immune system. “The evidence is clear,” Ng says. He says the body interprets physical activity as stress, and its response is to flood the bloodstream with disease-fighting white blood cells.

The response is as manual as it is chemical, according to Lyons, who cites the role of lymph — the fluid that circulates white blood cells through the body. “Our lymph vessels help regulate the immune response, but they don’t have the same pumping action that our blood does,” she explains. “They’re not pumped by the heart. They’re pumped by movement. So, when we exercise, we’re forcing lymph to circulate through the body. The more lymph that circulates, the more opportunity it has to encounter and destroy infectious agents.”

Research indicates that exercise might even promote the growth of helpful gut bacteria. That’s particularly interesting in the context of a November 2020 study, funded in part by the National Multiple Sclerosis Society, which found evidence of immune cells that react to specific gut bacteria in people with MS; during MS relapses, they travel from the gut to the brain to reduce inflammation.

Be careful, though. Evidence suggests that too much exercise, especially without adequate rest, may hurt instead of help the immune system. “Again, exercise is a type of stress. And when we’re stressed, we release stress hormones like cortisol that can depress the immune system,” explains Ng, who says the secret to getting a positive instead of negative immune response is to focus on exercising at a moderate instead of vigorous intensity. On a scale of zero to 10, where zero is being sedentary, and 10 is sprinting at full speed up a hill, he says you should be at a three or four — just starting to break a sweat. “Anything more vigorous could trigger cortisol production.”

Exercise duration is as important as the intensity. You should get at least 150 minutes of physical activity per week, broken up into increments of anywhere from 10 to 90 minutes at a time. Exercise sessions that are longer might depress immunity, according to Ng, who says you can further mitigate the hormonal effects of exercise with a post-workout snack.

“Exercise can produce chemicals that have a beneficial anti-inflammatory effect. However, exercise can also deplete glucose from muscle or blood that contributes to a stress response,” Ng says. “It’s advised that after vigorous or prolonged exercise you consume carbohydrates immediately, which replenishes blood glucose and can blunt the body’s physiological stress response,” he adds.

2 Diet

Diet is an important immune system lever, according to neurologist Vijayshree Yadav, MD, director of Oregon Health & Science University’s Multiple Sclerosis Center. Yadav says the best thing you can do for your immune system is maintain a fit and well-nourished body and healthy weight. “When you eat poorly, you can become overweight or obese. And when you’re overweight or obese, you can be at risk for many problems and diseases,” she says. People affected by obesity are more likely to develop bacterial and viral infections, according to the Obesity Action Coalition, which cites as a possible culprit chronic inflammation from excess fat, which makes it harder for the body to battle microbes.

“Especially for people with MS who may not be able to do as much exercise because of disability or fatigue, the best way to achieve weight reduction is by a supervised nutrition program and caloric restriction,” says Yadav, who emphasizes that there’s no “right” diet. “Any diet that can give you a good cardiovascular profile in the long term can help you achieve that goal as long as you’re paying attention to the quantity and the quality of the calories and nutrients you’re consuming.”

Concerning immunity, foods that can alleviate inflammation should be the primary source of high-quality calories. For example, research suggests that green leafy vegetables, olive oil, berries, nuts, fish and tomatoes may reduce inflammation. In contrast, red meat, dairy, gluten, fried foods and processed sugars may cause it.

To get their anti-inflammatory effects, you generally have to eat whole foods. However, there is at least one dietary supplement that’s worth taking: vitamin D.

“Vitamin D is critical for a whole host of reasons,” Lyons says. “It helps regulate calcium absorption, which is important for bone health, but it also helps regulate the immune response.”

Its immune-modulating properties make vitamin D especially important for people with autoimmune diseases, including MS. “Data shows that low vitamin D levels can increase disease activity in MS and may impact disease progression,” Yadav says. Although the body produces its own vitamin D from sunlight — it can take as little as 10 minutes of direct sunlight on the arms and legs to get your daily recommended allowance of vitamin D — most people are deficient. Supplementation is therefore helpful. “It’s one of the few supplements you can take that makes a difference,” Lyons says.

Vitamin D helps regulate calcium absorption and the immune response.”

— Jeri-Anne Lyons, immunology researcher
Sleep can have downstream effects on the immune system, according to Abbey Hughes, a rehabilitation psychologist at Johns Hopkins University School of Medicine. “There have been lots of studies showing that when one is not getting enough sleep — or enough good-quality sleep — they are more vulnerable to getting the flu or seasonal colds,” says Hughes, whose specialties include MS and sleep disturbances. “For people who are immune-compromised, like people with MS, that underscores the importance of getting regular sleep to protect your immune system.”

According to Hughes, minor adjustments at bedtime can make a big difference for people who have occasional and mild sleeplessness. She suggests turning off screens an hour before bed and abstaining from alcohol late in the evening. Blue light from phone and computer screens inhibits the sleep hormone melatonin. Alcohol becomes a stimulant as it’s metabolized, causing wakefulness in the middle of the night. Having a dark, quiet and cool bedroom also is helpful. If necessary, use an eye mask, earplugs and a fan.

People who suffer from chronic sleeplessness, including those with sleep disorders like insomnia, might need to reprogram their brain. “The key to treating insomnia usually is managing your brain’s association with the bed, so you’re not equating it with frustration around sleep,” explains Hughes, who suggests maintaining a consistent bedtime. Over time, it may be easier to fall asleep by setting the body’s internal clock. “People who aren’t getting enough sleep often try to go to bed earlier. But if sleep doesn’t come easily, you might want to make your bedtime later. People who delay their bedtime until they’re sleepy are more likely to fall asleep sooner and to sleep through the night.”

That could mean initially getting only four or five hours of sleep a night instead of eight. Once you’ve established a routine that works, however, you can gradually dial back your bedtime. The worst thing you can do is lie in bed awake. “The natural reaction is to lie there trying to will yourself to sleep. But if you’re not falling asleep after about 10 minutes, you should get out of bed and go do some other low-key, relaxing activity for maybe 20 minutes, then try again,” Hughes says. “When you spend time lying in bed, you train your brain that it’s OK to be awake in bed. You don’t want to make that association.”

Stress management
Even if you’re getting optimal exercise, nutrition and sleep, stress can sabotage your immune system. “Chronic stress can make you more vulnerable to infection and potentially to MS relapse, so it’s very important to manage it effectively,” Hughes says. As Ng previously explained about exercise, the problem with stress is the body’s hormonal reaction to it, which creates inflammation. You can neutralize that response by engaging in activities like yoga, tai chi and meditation, all of which have been shown to reduce the stress hormone cortisol.

Even something as simple as deep breathing can be effective. “If you have an Apple Watch, use the breathing app,” Lyons suggests. “Stopping to focus on your breath for even a minute when you’re stressed can help bring down your stress levels.”

Mental strategies can work as well as physical ones. Yadav, for example, suggests positive self-talk — especially for people with MS. “Having MS itself is extremely scary, but accepting the disease and adapting to it are really important,” she says. “Teaching yourself to have a positive attitude can help you cope with the stress of your perceived deficits.”

Deficits can be physical, in the case of MS, but also financial, spiritual or relational. “For relationships, improving your communication skills might help. ‘Because relationships can be a big source of stress, improving how you interact with your family, your partner or your friends can be a really great stress-management technique,’” explains Hughes. One strategy she often promotes is “perspective-taking.” “If we feel that our point of view is being threatened, that will often increase our stress response. One way to reduce that when you’re having a conversation is taking the other person’s perspective to understand where they’re coming from. It sounds basic, but it really can help when you’re having a disagreement.”

Strategies like perspective-taking can reduce conflict, but they can’t eliminate it. No matter what you do, you’ll still experience stress — not to mention inadequate sleep, nutrition and exercise. And that’s OK.
Discover VUMERITY® (diroximel fumarate)—an oral treatment for relapsing MS. Together, let’s celebrate what makes you truly you.

What is VUMERITY® (diroximel fumarate)?
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.

Important Safety Information

Do not take VUMERITY if you:
- have had an allergic reaction (such as hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to diroximel fumarate, dimethyl fumarate, or any of the ingredients in VUMERITY
- are taking dimethyl fumarate

Before taking and while you take VUMERITY, tell your healthcare provider 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 healthcare provider about all the medicines you take including prescription and over-the-counter medicines, vitamins, and herbal supplements.

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 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:
  - severe tiredness
  - loss of appetite
  - pain on the right side of your stomach
  - yellowing of your skin or the white part of your eyes
  - personable changes
  - vision problems
  - changes in thinking and memory
  - confusion
  - numbness or weakness on one side of your body
  - changes in balance
  - trouble speaking or swallowing
  - weakness or numbness in your arms or legs
  - break in your skin with blisters, and itchy, scaly rash
  - new or worsening eye problems
  - changes in thinking or behavior
  - changes in the way your body uses food

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 healthcare provider if you have any of these symptoms and they bother you or do not go away.

Ask your healthcare provider if taking aspirin before taking VUMERITY may reduce flushing.

Call your healthcare provider 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

These are not all the possible side effects of VUMERITY. Please see Patient Information on the following page and full Prescribing Information at VUMERITY.com.

For help with financial, insurance, or treatment education, call 1-800-456-2255 Monday-Friday from 8:30 am to 8 pm ET. Hablamos español.

VUMERITY comes with support
For help with financial, insurance, or treatment education, call 1-800-456-2255 Monday-Friday from 8:30 am to 8 pm ET. Hablamos español.

Ask your healthcare provider or get more details at KnowVUMERITY.com
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 hives, rashes, 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.
• You can take VUMERITY with or without food. If you experience flushing, you may take VUMERITY with food (avoid high-fat, high-calorie meal or snack) to help reduce flushing. Call your doctor if you have any of these symptoms of flushing:
  o weakness on one side of the body that gets worse.
  o changes in thinking and memory.
  o memory loss.
  o pain on the right side of your stomach.
  o yellowing of your skin or the white part of your eyes.
  o dark or brown (tea color) urine.
  o loss of appetite.
  o confusion.
  o numbness in your arms or legs.
  o vision problems.
  o personality changes.

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.
• Do not drink alcohol at the time you take a VUMERITY dose.
As a salt-lover, Meredith O'Brien used to eat Ritz crackers upside down to savor the salt crystals dissolving on her tongue. But one day, two years into her diagnosis of multiple sclerosis, those same crackers tasted like plain paste. The next morning, her coffee tasted burnt. Red wine at dinner tasted sour. When O’Brien, who is based in the Boston area, brought up the issue to her neurologist, he said he’d never heard of such a thing.

“Taste alterations are a primary MS symptom that has flown largely under the radar,” confirms Mona Bostick, a dietitian-nutritionist in Greensboro, North Carolina, who also lives with MS. A 2016 study in the Journal of Neurology suggested that 15% to 32% of people with MS may experience taste deficits. A 2019 study in the Journal of Community Dentistry and Oral Epidemiology puts that number closer to 40%. The latter study also found that 68.4% of survey respondents complained of dry mouth, which further dampens flavor, as saliva helps taste buds do their job.

While a paler palate may not seem as troubling as MS symptoms such as bladder issues, spasticity or muscle weakness, it’s more than a mere inconvenience. If left untreated, loss of taste can lead to a host of severe health problems, Bostick warns, from decreased appetite and weight loss to malnutrition and depression. What’s worse: If you compensate by oversalting or oversweetening your food, that could lead to or exacerbate conditions such as hypertension and diabetes.

If flavor doesn’t deliver, there are ways to wake up your taste buds.

by Aviva Patz
Why loss of taste happens in MS

As with most things related to MS, experts aren’t 100% sure exactly how the loss of taste happens, but it comes back to myelin, the fatty sheath that protects neurons and is damaged in MS. “Change in taste has been shown in research to be related to how the disease affects myelin-related brain lesions,” explains Susan Barker, director of Rehabilitation Services at Norton Women’s & Children’s Hospital and the Norton Specialty Rehabilitation Center at St. Matthews in Louisville, Kentucky. In the study mentioned earlier, MRI scans corroborated reported deficits in taste, 22% lost sour taste and 15% were missing bitter taste when compared with controls.

While taste changes may come and go over weeks or months, as happens to O’Brien, there’s no direct evidence that they signal a worsening of your MS, according to Barker.

Factors contributing to a loss of taste

If your food seems “odd” or “off,” talk to your healthcare provider about whether it could be a side effect of a medication you’re taking, suggests Alex Burnham, director of TBH Institute and Rehabilitation Services at the Boston Home, where he works with people with MS. “If you can correlate it with the start of a medication — for MS or something else you’re using for symptom management — see if taking a lower dose or stopping the medication resolves the symptoms.” Of course, you need to do a risk-benefit analysis first, he adds. Be sure to have any changes in your medication regimen approved by your healthcare provider.

Bostick names at least five medications you may be taking for primary MS symptoms that could alter taste sensations and contribute to dry mouth:

- The disease-modifying therapies (DMTs) Lemtrada, Aubagio and Copaxone
- Medications such as oxybutynin, often prescribed for bladder control issues
- The muscle relaxants and spasticity medications Baclofen and Dantrolene
- Antidepressant medications
- Diuretics
- Antihistamines for allergy symptoms
- Antihypertensives (blood pressure medications)
- Cannabinoids
- Diuretics
- Gout medications
- Lipid-lowering agents
- Opioid pain relievers
- Psychiatric medications

Lastly, comorbid conditions may be directly associated with dry mouth. Conditions include:

- Cystic fibrosis
- Diabetes
- Hormonal imbalances
- Hypothyroidism
- Lupus
- Removal of the salivary glands
- Rheumatoid arthritis
- Sjogren’s syndrome
- Sleep apnea

What ‘taste loss’ is really like

In MS, taste loss doesn’t mean zero taste. That’s because taste is a symphony of sensations involving not just your ability to detect salty, sweet, sour, bitter and umami (savory) flavors, but also food texture, color and temperature, as well as your sense of smell. “What we experience as flavor is all of these senses working together,” Bostick says.

Fortunately, there are ways to maximize your senses of taste and smell and once again enjoy salted pretzels, sour pickles, bitter coffee, sweet cookies and your favorite linguini alfredo without putting your health at risk. Here’s what you need to know.

Taste is linked to the brain through food texture, color and temperature as well as the sense of smell and olfactory nerves.
Spice it up

Trust chef Trevis Gleason, who lives with MS, to boost flavor.

His first tip: Add MSG. “A lot of people will freak out when I say monosodium glutamate, but glutamate is a molecular structure that occurs naturally in a lot of foods known to be high in umami, like seaweed,” he says. MSG, available in shakers at supermarkets and online, is usually made by fermenting starch, sugar beets, sugar cane or molasses. Some versions, such as Accent, have added sodium.

If you’re sensitive to MSG (some people claim it causes side effects), try incorporating more foods that are naturally high in glutamate: tomatoes, open-gill mushrooms, rinds of hard cheeses like Parmesan and Pecorino, certain seaweeds, anchovies, soy sauce and miso paste. “If you’re cooking a rich stew, add a handful of oyster mushrooms and a cheese rind,” Gleason says. “MSG doesn’t add taste — it just opens the taste buds, so you can taste more of what’s already there.”

Gleason’s weapon of choice is a spice blend of his invention that he calls the “umami bomb.” “People love it because you put half a teaspoon into sauce, soup and gravy, and it just explodes things,” he says. Gleason markets the “umami bomb” in Ireland, but you can make your own with this flexible recipe:

**Umami bomb**
- Red miso powder
- Tomato powder
- Wild mushroom powder blend
- Dried seaweed

Use equal amounts of each ingredient (e.g., 1 tablespoon each, etc.), and grind them into a fine powder. Add to sauces, soups, stews or any foods that need a pop of flavor. Freshly ground, it keeps for up to one year in an airtight jar.

**How to preserve or improve your sense of taste**

Although there are no known medical treatments for lost taste, the issue can resolve on its own, often when an exacerbation subsides. If it doesn’t, you may see some improvement with these techniques.

- **Explore the spice cabinet.** “Diversify the flavors in your diet,” Burnham suggests, adding that many people get stuck in a rut of the same old herb blend. “If you’ve never tried a Middle Eastern za’atar mix — it’s both savory and a bit sour — it adds a different dimension,” he says. Experiment with marinades and condiments such as horseradish, mustard, balsamic vinegar reduction, salsa and hot sauce. O’Brien says sriracha and spicy chipotle mayo are her new go-to condiments, and Bostick swears by the sodium-free herb blend Mrs. Dash (she is not affiliated with the brand).

- **Marinate meats.** Proteins such as red meat, poultry and seafood often taste “off” for people with MS experiencing taste issues. “Try marinating meats in sweet or acidic juices like orange or lemon juice (plus herbs), or a spicy salad dressing, to “elevate the positive and offset the less pleasant flavors,” Bostick says.

- **Add tart foods.** Acidic fruits and drinks — including oranges, grapefruits, lemonade and grapefruit juice — can stimulate saliva production, which will enhance your ability to taste, according to Bostick. O’Brien eats citrus fruits because they’re the one food that still “explodes with flavor.”

- **Engage all of the various senses related to taste.** Barker recommends eating foods with new textures to “stimulate the tongue and mouth and heighten the senses” and changing the temperature of foods — warm tastes stronger than cold because it’s more aromatic, engaging your sense of smell.

- **Ban things known to dull taste.** Bostick says smoking has a significant negative impact on the capacity to both smell and taste, which is yet another reason to quit the habit. Alcohol can worsen dry mouth, which hampers taste, so try drinking in moderation or abstaining. That goes for any mouthwash that contains alcohol, too. To make your own alcohol-free version, add ¼ teaspoon baking soda and ¼ teaspoon salt to 1 cup warm water, then rinse with plain water afterward.

- **Address dry mouth directly.** Stay hydrated, even if it means more bathroom breaks. “Bladder issues may lead to avoiding fluids to prevent accidents, but doing so may contribute to dehydration,” Bostick says. She suggests trying artificial saliva, a combination of ingredients designed to mimic the stuff produced naturally by our glands. It comes in over-the-counter sprays, rinses, gels, swabs and dissolving tablets and can help lubricate the mouth and enhance taste. Try rinsing before meals. Bostick says it may improve the flavor of foods.

- **Slow down.** “Eat mindfully,” Bostick advises. “Take small bites, chew slowly, and move food around your mouth to stimulate all of your taste and sensory receptors.”

Aviva Patz is a writer in Montclair, New Jersey.
• Are pregnant. AUBAGIO may harm an unborn baby. DO NOT TAKE AUBAGIO IF YOU:

• Have severe liver problems. AUBAGIO may cause and active secondary progressive disease, in adults. clinically isolated syndrome, relapsing-remitting disease, to treat relapsing forms of multiple sclerosis (MS), to include AUBAGIO "INDICATION levels monthly for the fi rst 6 months.

Your healthcare provider will run certain tests before you start treatment. • Your risk may be higher if you already have liver

problems or take other medicines that affect your liver. It is not known if AUBAGIO passes into breast milk.

• Are of childbearing potential and not using effective

birth control. AUBAGIO may stay in your blood for up to 2 years

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. 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.

Your healthcare provider will run certain tests before you start treatment. You should have a pregnancy test before 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. 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. 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. 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. 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.
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 complete list of ingredients in AUBAGIO.

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 starting AUBAGIO
  - every 3 months after you start taking AUBAGIO

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

• nausea
• vomiting
• stomach pain
• loss of appetite
• tiredness
• yellowing of 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.
  - If after stopping AUBAGIO, you 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 it, tell 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 not do both.
  - 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 are the possible side effects of AUBAGIO?

AUBAGIO may cause serious side effects, including:

• nausea
• body aches
• vomiting

• skin reactions that may lead to death. Stop taking AUBAGIO and call your doctor right away if you have any of the following symptoms of an infection:
  - fever
  - rash
  - blood in your urine

If your female partner plans to become pregnant, you should not receive certain vaccinations during treatment with AUBAGIO and for 6 months after your treatment with AUBAGIO ends.

allergic reactions. Stop taking AUBAGIO and call your doctor right away or get emergency medical help if you have difficulty breathing, hives, swelling on any part of your body including in your lips, eyes, throat, or tongue.

• severe 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 of an infection:
  - rash
  - severe skin reactions.

Some skin reactions may be serious and may 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
• photosensitivity
• 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, tacc, 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

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

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Debi Capwell thinks she began having multiple sclerosis symptoms as a teenager. But she wasn’t diagnosed until she was in her early 40s, after her foot drop became so severe that she was afraid she wouldn’t be able to walk well enough to continue her career as a home-health nurse.

“I wanted to find ways to improve my foot drop and keep my job,” she says. “After 27 years as a nurse, I felt like without a job, I would feel useless. And I feel better if I go into work because I know I’ll have things to do, and I’ll be up on my feet and walking. When I’m at home, I’m tired, and I just want to sit on the couch.”

Capwell tried physical therapy, but it had little effect on her foot drop. She researched and decided that a functional electrical stimulator (FES) device was her best option. But with a $7,500 price tag, the device was out of reach for her budget.

Then, one of Capwell’s patients suggested she look into vocational rehabilitation. It is most certainly not a new concept. But for Capwell, it was a new path to follow.

You might not have to quit your job after all. Vocational rehabilitation helps people with MS explore their employment options.
rehabilitation services. Capwell, who lives near Scranton, Pennsylvania, applied to the state’s office of vocational rehabilitation. After meeting with a counselor and providing some basic information about her disability, living situation, income and career interests, Capwell acquired an FES device free of charge.

“It was a pretty smooth process and only took about a month,” she says. “Now, my foot drop is much better, and I get to keep my job.”

Help explore your options
People living with MS might give up their jobs without fully exploring how they could continue working. Vocational rehabilitation services can help you explore your options — and maybe stay employed.

A few years ago, a pair of university professors set out to produce a thorough employment and MS assessment. They surveyed nearly 2,000 American adults living with MS and discovered some alarming statistics.

At the time of their diagnosis, 82% of people with MS had a paying job. Five years after their diagnosis, only about 40% were employed.

Many of these people — 75% — left their jobs voluntarily, but 80% felt they still could work.

About 75% of the study participants wanted to go back to work. “They quit while they could still work and ended up regretting that decision,” says Phillip Rumrill, PhD, professor of counselor education and director of research and training in the Human Development Institute at the University of Kentucky. Rumrill and Malachy Bishop, PhD, a professor in the Rehabilitation Psychology and Special Education Department at the University of Wisconsin-Madison, conducted the study published in 2015 in the journal Work.

The number of people with MS who wish they were still in the workforce is so high that Rumrill and Bishop believe it’s a public health issue.

“Employment is an important part of life for most people,” Bishop says. “It contributes to our identity and income, and it provides benefits like health insurance, the opportunity to interact with others socially and a way to be productive and contribute to our community.”

Rumrill says research shows that many people with MS are well-educated and highly trained in their jobs. “Society is losing out on the really valuable resource of workers with MS,” he says. “We all benefit when people with MS work as long as they want to.”

Bishop cites a study he, Rumrill and others conducted that was published in 2019 in the Journal of Vocational Rehabilitation.

“We found that employment was one of the top contributors to quality of life for people with MS,” Bishop says. “Researchers are increasingly looking at the relationship between work and health and finding that work is an important contributor to health as well.

“But for too many people living with MS, the loss of employment is an unnecessary result of the diagnosis.”

Rumrill points out that when people are newly diagnosed, they might juggle a lot of emotion, information and advice from friends and family. “Sometimes people think quitting work is the easiest choice,” he says.

But hasty decisions are a big reason why so many people with MS who leave their jobs later have regrets. It’s why Bishop and Rumrill are evangelists about ensuring that

Joe Stuckey, a rehabilitation counselor, says it’s natural for people with MS to deny work challenges.

Laura B. Biddle, a graduate student, says it’s natural for people with MS to deny work challenges.
people with MS know all of their options before making employment choices. “If you choose to stay working, we want to help you. If you choose to stop working, we want to help you,” Rumrill says. “And we believe the best way to do all of that is through vocational rehabilitation services.”

Lack of an exit strategy Many people with MS leave their jobs because of physical, mental or emotional symptoms. In their 2015 study, Bishop and Rumrill cited data showing that almost 50% of people with MS who quit their jobs did so because of ambulatory issues. Between 30% and 59% said fatigue was the most critical factor. People with cognitive impairments were four times more likely to be unemployed. Depression and anxiety were also factors.

Rumrill and Bishop’s research shows that people with lower incomes and levels of education may have jobs that require more physical exertion and thus feel more pressure to quit before their physiological symptoms worsen. People who have a spouse who’s working tend to leave their jobs more often than those who don’t.

Meanwhile, people higher up on the job scale may have the flexibility and authority to adjust their schedules to accommodate their symptoms — and keep their jobs. “The reasons people with MS stop working vary widely and are personal and individual, but the barriers they face to continue employment can often be addressed,” Bishop says. “I have spoken with many people with MS over the years who found that stopping working was the right choice for them. But unfortunately, many people with MS decide to stop working without access to the information they need to plan for their futures.”

That’s where vocational rehabilitation comes in.

Services that help The U.S. Vocational Rehabilitation (VR) Program dates back to 1920 and is funded through a partnership between federal and state governments. Today, every state has a vocational rehab agency, often with multiple offices. The agencies may have different names in different states, like the Office of Vocational Rehabilitation or the Department of Vocational Rehabilitation, but they all fall under the same umbrella.

The VR Program is designed to help people with disabilities or chronic illnesses keep their jobs or find new jobs. Its services are extensive, and many are free. If you’re debating whether to continue working, your local VR office can help you with long-term planning. It can provide financial and benefits counseling and help you evaluate the psychological and social aspects of keeping or quitting your job.

VR can offer specialized tests and assessments that identify workplace accommodations you may need for your specific MS symptoms now or later if you want to continue working. A counselor can work with your employer to implement those accommodations. If you haven’t revealed your diagnosis to your employer, VR programs can supply you with assistive technology, devices, tutors or other aids to reduce work barriers on your own.

VR also can provide services like work transportation or housing modifications that allow you to work at home.

If you’re thinking about changing careers to a less-demanding job, VR can help you identify transferrable skills. It offers job counseling, tests and guidance. It can hook you up with vocational training and education and help you identify and apply for a new job.

And if you choose to stop working, VR can help with volunteer opportunities or finding new activities and hobbies.

Health status can change very quickly when you have MS, which can lead to employment emergencies that vocational rehabilitation can address.”

— JOE STUCKEY, REHABILITATION COUNSELOR

“There are a lot of potential benefits to reaching out to VR, but I think the biggest benefit people with MS can get is the ability to make the most informed decision possible about their future and their careers,” Bishop says.

How to get in the door Essentially, anyone who has a physical or mental impairment that causes problems with working may be eligible for VR services. Requirements vary by state, but all you may need is a doctor’s letter stating your impairment. People receiving Social Security income or disability insurance qualify automatically. Still, they need to show documentation of three limitations to be eligible for this category of disability.

Sharon Silverman, vocational rehabilitation supervisor for Pennsylvania’s Office of Vocational Rehabilitation, says MS symptoms can be very specific to the individual and lead to different limitations for different people. VR offers forms that health providers can complete.

Along with stating the diagnosis and the prognosis, the provider is asked questions like how long their patient can sit, stand or walk; what type of work tasks the patient can or can’t do; and whether the patient may have difficulty working more than 20 hours a week.

Once the Pennsylvania office of VR has that documentation and determines eligibility and where the individual falls in their order of selection, a counselor meets with the new client and maps out a vocational rehabilitation plan. Bishop says the vast majority of VR counselors have master’s degrees and all are trained in vocational and career planning and medical and psychosocial aspects of disability and chronic illness.

Despite the relative ease of applying for VR programs, Rumrill says people with MS tend not to use VR services — or even know they can.

The hidden resource One of the biggest reasons why people with MS aren’t VR customers is because they don’t view themselves as disabled — especially in the early stages of their disease. “You may need a little healthy denial to get through this illness,” Rumrill says.

Another issue is that doctors who work with people with MS may not know about VR services or recommend them. According to Rumrill, the No. 1 answer given when people with MS are asked why they quit their jobs is their doctor recommended it. “Your neurologist may say you need to quit working because of the stress,” he says. “But most neurologists are unacquainted with the stress of being unemployed.”

Joe Stuckey, a rehabilitation counselor at the University of Washington Medical Center in Seattle, says it’s a natural coping strategy for people with MS to deny or minimize their work challenges. “Folks have a lot of fear and uncertainty about the impact of MS on their work, but
They may assume their work difficulties to their healthcare provider. They want to rejoin the workforce. While it’s a good idea to access VR services while you’re still working, VR also can help people who want to rejoin the workforce.

The benefits of early admission
A study published in 2015 in Rehabilitation Research, Policy, and Education reported that about 70% of people with MS weren’t working when they applied to a VR program. But those who utilized VR while they still had a job saw increases in their average weekly earnings and average number of hours worked.

“About 70% of clients in this group were able to retain their jobs or find new jobs after receiving VR services,” Bishop says. “Unfortunately, for several reasons, the numbers are somewhat lower for people who have stopped working.”

Rumrill says one of those reasons is that “every day someone’s disengaged from the workforce, they feel more disconnected, both mentally and physically. Job retention works best sooner in the disease process, when people still are relatively healthy and still think of themselves as workers. Once you get on disability or Social Security income, you don’t tend to go back.”

Another reason is universal and doesn’t apply only to people with MS. It’s easier to help someone keep their job than to help them restart their career. But as any mother who re-enters the workforce after taking time off to raise a child knows, it’s not impossible.

Still, there can be red tape and delays with government-run VR services. Rumrill says it can take as long as six to eight weeks for a VR office to determine whether an applicant is eligible for services. That’s why some people opt for VR programs at universities and clinics financed by health insurance.

Some large healthcare facilities with MS programs provide VR services as part of their overall rehabilitation services.

NYU Langone Health is a major academic medical center that offers VR services through its Rusk Rehabilitation Program. Vocational Rehabilitation Director Robert Lindsey says the department is a private nonprofit partially funded by the state VR agency. People who want to use NYU VR services need a referral from their doctor, the state VR agency and the Department of Veterans Affairs. Individuals are accepted on a case-by-case basis. “But I’ve never seen anyone with an MS diagnosis turned down for an initial assessment,” Lindsey says.

Online options
You can find a VR program in your state by visiting askjan.org and searching “state vocational rehabilitation agencies.”

The National Multiple Sclerosis Society has MS Navigators who can also help find programs near you. You can reach them by calling 1-800-344-4867 or online at nationalMSsociety.org/Navigator.

There are MS Navigators who specialize in benefits, employment and health insurance-related needs. The Society has information related to employment needs on its website, including a brochure “The Win-Win Approach to Reasonable Accommodations.”

For more information, please visit nationalMSsociety.org/employment.

VR counselors are also big fans of the Job Accommodation Network (JAN), a free online service for anyone with a disability. You can find it at askjan.org.

“JAN is our federal government’s most successful vocational rehabilitation network,” says Phillip Rumrill, PhD, a professor of counselor education at the University of Kentucky. “You can talk to vocational rehab counselors by online chat, email or phone. You can search for general MS topics or by specific symptoms.”

A search for “multiple sclerosis” on askjan.org gives information on how the Americans With Disabilities Act applies to MS, along with lists of specific job accommodations for common symptoms. For instance, “decreased stamina and fatigue” turns up 26 solutions ranging from anti-fatigue matting to low-task chairs to work site redesign.

There are resources for job seekers and people who want to start their own businesses. You can search by disability, limitation, work-related function or accommodation needed. You can also create your own portal to keep all of your JAN information in one place.

Whether you opt for an in-person or virtual VR counselor or a public or private VR program, employment experts say you can gain valuable tools to help make the best choices about your work life now and in the future.

“MS changes the level of control you have over your health, so why not take steps to control your career?” says Phillip Rumrill, PhD.
High-tech walking help

Exercise rehabilitation with help from a robotic exoskeleton might benefit people with multiple sclerosis. In a pilot study of 10 people with MS who had difficulty walking, a robotic exoskeleton was used to help them walk.

The four-week exercise and rehabilitation program using a wearable robotic exoskeleton resulted in:

+ Improved brain connectivity
+ Improved information-processing speed
+ Improved walking ability

In this section, Momentum explores research to help people affected by MS live their best lives.

For more information on the robotic exoskeleton exercise research study, visit ntlms.org/roboticexercise

Vicky Uhland is a writer and editor in Lafayette, Colorado.
The expression “You’re born with all of the brain cells you’ll ever have” might have been a fairly common assumption. That is until Dwight Bergles, PhD, professor at the Solomon H. Snyder Department of Neuroscience at Johns Hopkins University, noticed some mysterious cells getting in the way of his postdoctoral research.

The 2021 winner of the Barancik Prize for Innovation in Multiple Sclerosis, Bergles has made several discoveries and innovations that may do more than usher in a new era of myelin-regeneration therapies. His lab’s findings have upended some of the most common assumptions about what happens in the brain.

New tools for research

“In addition to the major contributions Bergles and his team have made to advance myelin repair research, he and his lab have also developed advanced research tools,” says Bruce Bebo, PhD, executive vice president of research at the National Multiple Sclerosis Society, which administers the award. “These tools have made it possible to answer critical research questions that advance strategies to restore function and improve quality of life in people with MS.”

Bergles didn’t start his career thinking about MS, but he had been researching the brain as a graduate student at Stanford University and then as a postdoctoral fellow at Oregon Health and Science University, where he used glass electrodes to record the electrical activity of individual cells.

“Occasionally, we encountered these mysterious cells,” Bergles says. “At the time, we didn’t know about the existence of these cells. We didn’t realize what they were, their properties or where they were found.”

An important discovery

The cells were oligodendrocyte progenitor cells (also known as oligodendrocyte precursor cells or OPCs). They make up 5% of all the cells in the nervous system. They are of particular interest to MS research because of what they turn into. As their name suggests, these cells can mature into oligodendrocytes, which make myelin that wraps around axons, the major neuronal communication pathways, insulating and sustaining them in the brain and spinal cord.

OPCs kick into action when myelin has been damaged during the course of MS. And Bergles discovered that they form connections with neurons through synapses — points of contact that scientists previously believed were only for neuron-to-neuron communication.

“This was a very striking observation to many people in the field,” Bergles says.

A look inside

Jonah Chan, PhD, the Debbie and Andy Rachleff professor of Neurology at University of California San Francisco School of Medicine, wrote in his nomination letter for Bergles that the discovery led to “a paradigm shift in our understanding of what neuron-glial (other cells in the brain) interactions truly represent.”

Since his paradigm-shifting discovery, Bergles has remained at the forefront of research and technological advancements. One of his innovations sounds straight
out of a science fiction tale: “We have a window into their brains,” Bergles says.

He developed a line of mice with a fluorescent protein built into their OPCs. Then researchers removed a tiny piece of the mouse skull and replaced it with a tiny piece of glass.

That allowed Bergles and his colleagues to watch the movement of a single progenitor cell through the living brain. Using a high-resolution imaging technique, they can now watch these cells move through space in real time—over several months—as they form synapses with neurons, and they can see their transformation into oligodendrocytes unfold “like a caterpillar becoming a butterfly,” Bergles says. They have also used the technology to look at the oligodendrocytes.

“The imaging mode we use allows us to see individual oligodendrocytes and every single myelin sheath that each one of those cells forms,” Bergles says. “The incredibly high-resolution allows us to watch where and when new sheaths are formed and follow the dynamics of individual myelin sheaths.” They can also watch them regenerate myelin after damage, mimicking what happens in MS.

Yes, regenerate

“This is one place where OPCs break all the rules,” according to Bergles. While most nervous system development and refinement is complete in early life, OPCs stick around and are able to change throughout a lifespan, turning into myelin-making oligodendrocytes in response to injury.

Something about that process is disrupted in MS. But the field is in a place where it may soon understand more fully why OPCs sometimes transform, leading to remyelination, while other times, they do not, thanks to work by Bergles and researchers he has trained and worked with over the years.

Teacher and leader

“If I train an army of individuals who are gifted, extremely committed and highly skilled, then they are the ones who are going to solve this problem,” Bergles says. “They will get us to cures for MS. And the National Multiple Sclerosis Society has been crucial because they’ve provided fellowships for a number of researchers in my lab.”

The fellowships allow researchers to earn a living wage while working in Bergles’ lab.

“Most came to this lab and weren’t thinking about oligodendrocyte progenitor cells or demyelination, but together we’ve been able to make substantial discoveries,” Bergles says. He could be talking about himself. After all, he had little knowledge about myelin or MS when he started, but he followed his curiosity and ultimately changed our understanding of the human brain. Now he watches the future take shape in his lab.

“It is certainly one of, if not the most, valuable things for me to experience that sense of discovery from the trainees in the lab,” he says. “When they are the ones saying, ‘Look what I found!’ … For them to have that sense of ability and confidence, and then continue to do amazing things in their own labs, is incredibly rewarding.

“I can only do so much, myself. They are the ones who are going to solve this problem.”

Searching for solutions

Bergles foresees the solution to the problems of MS as twofold: a continuation of the therapeutics in use now to suppress the immune system, coupled with the regeneration of myelin spurred, perhaps, by drugs that may be similar to the ones his lab is examining.

Using the imaging platform developed in his lab, combined with therapies designed to push OPCs to transform, Bergles has been tracing the arc of myelin recovery. “Some things are very effective,” he says, “but it is not at all a panacea.” In some regions, remyelination occurs. In others, it does not.

Bergles suspects other factors can inhibit the transformation of OPCs, and his next goal is to determine what they are, bringing science closer to reversing MS damage. But OPCs may hold the key to understanding more than myelination in the brain. “We have the ability to create new oligodendrocytes,” he says, “that may be one way in which the nervous system can adapt to different conditions. It may be a way that brain plasticity works.”

When it comes to the mechanisms at work directing these OPCs and how we might harness them for therapeutics to reverse the damage done to the myelin of people with MS, there is still a lot of work to be done. There are so many questions yet to be answered. Or, for a more positive perspective, Bergles offers: “There is so much left to be discovered.”

Brandie Jefferson is a writer in St. Louis, Missouri. She was diagnosed with MS in 2005.
International collaboration accelerates the development of effective treatments for progressive MS.

by Lori De Milto

Nearly half of all people with multiple sclerosis have or will develop progressive MS. Yet researchers have struggled to understand and develop treatments for this form of the disease.

The FDA has approved only one medication for treating primary progressive MS and has provided retroactive approvals for all relapsing MS drugs to include secondary progressive MS with disease activity (clinical relapses or new lesions on MRI). No treatments are approved for secondary progressive MS without disease activity. Even so, additional treatment options are needed for progressive forms of the disease.

“Unmet needs in progressive MS are a bigger problem than a single MS organization can grapple with. The Alliance has brought together the best people from around the world to tackle this challenge,” Fox says.

Gianvito Martino, MD, the principal investigator of the Alliance’s BRAVEinMS collaborative drug discovery network, agrees. “Based on advances in science and technology, it is impossible to have everything state-of-the-art in each single institution. By bringing together experts from different institutions, we can get a better view of what is going on with progressive MS,” says Martino, a professor of experimental biology and vice rector for research at San Raffaele University in Milan, Italy.

BRAVEinMS is one of two international drug discovery collaborative research networks funded by the Alliance, where leading MS researchers from multiple countries have been working together since 2017 to understand, prevent and reverse the progression of progressive MS. BRAVEinMS focuses on finding compounds that can protect and repair the brain. Compounds are substances that could be made into medications. The other drug discovery network focuses on preventing brain damage in progressive MS by understanding how the immune process affects disease progression and identifying compounds that use this understanding to treat progressive MS.

“We didn’t quit during the COVID-19 pandemic. We continued to work, taking advantage of bioinformatics tools, so we could work remotely during the lockdown,” Martino says.
The Alliance is also supporting the creation of tools to speed up and improve clinical trials, so more treatments can be studied faster and at less cost. For example, researchers are studying biomarkers that can identify changes in the brain if a treatment is effective and potentially predict the course of the disease. A biomarker is a characteristic of the body that can be measured to show how the body is doing. A protein from a blood test can be used to diagnose a heart attack, for example. In clinical trials, biomarkers are often used to measure the effects on people of the drug being tested.

International drug discovery networks

BRAVeInMS comprises 13 investigators from Italy, France, Germany, Europe, Canada and the U.S. The team is identifying compounds that may protect nerve cells and promote myelin repair. Protecting nerve cells would prevent further damage and disability from progressive MS while repairing myelin would allow people with progressive MS to recover some function. The BRAVeInMS team started with more than 1,500 compounds. Using sophisticated bioinformatics tools, the researchers created a virtual model of MS. They then screened these compounds for their ability to protect nerve cells or promote myelin repair in laboratory tests. Results of many laboratory tests led to seven compounds that could potentially become drugs, two of which appear to be the most promising, according to Martino.

“We are confident these two compounds will be the right ones to progress to clinical trials if they are effective in the animal models,” Martino says. Testing of progressive MS in animal models began in March 2021. Martino hopes to have the results of the testing by the end of 2021. If the compounds work in animal models, the next step would be clinical trials in people.

The role of the immune system

Francisco Quintana, PhD, professor of neurology at Brigham and Women’s Hospital, Harvard Medical School, is leading the network focused on developing a drug discovery pipeline for progressive MS. He and his team of eight investigators from the U.S., Canada, Israel and Sanofi Genzyme are studying the immune system’s role in the central nervous system to find effective treatments for progressive MS. While the immune system normally protects the body from infections, Quintana and other researchers have previously found that immune cells in the central nervous system may promote disease activity in MS and other diseases.

Quintana’s team has identified biological pathways that control the immune response in MS. They also found that manipulating the biological pathways using genetics can stop nerve damage and alter disease progression in animal models.

Next, the team found a type of brain cells called astrocytes that can turn off inflammation based on signals emanating from bacteria in the gut. They are studying how the anti-inflammatory functions of astrocytes could be harnessed to develop new treatments for progressive MS, such as customized probiotics to alter the balance of gut bacteria to turn on the anti-inflammatory activity.

Compounds are screened for their ability to protect nerve cells or promote myelin repair.

“Both networks have identified candidate molecules that look promising for application to progressive MS. They are finishing the validation stage. The next steps will be to take these molecules into clinical trials,” Fox says.

The Alliance is funding projects to improve clinical trials and speed the development of new treatments. These include developing a routine blood test that could predict and measure disease progression. Other projects include creating tools that use MRI images as a biomarker of disability progression for use in clinical trials. The blood test project explores whether the protein Serum Neurofilament light chain (NFL) can function as a biomarker, help predict the future course of progressive MS and show whether a treatment is preventing nerve damage.

Neurofilaments are structural proteins in nerve cells in the central nervous system. NFL is a type of neurofilament released when there is damage to the brain that occurs in MS. NFL then passes into the blood where it can be measured with a blood test.

Scientists have found that NFL in the blood is a plausible marker for measuring damage to the brain. More work is needed before an NFL blood test can be used routinely for personalized medicine, including developing standard procedures for collecting and analyzing blood samples. An Alliance expert panel is developing recommendations for using an NFL blood test as a biomarker in clinical trials. The panel will be working with regulators to address challenges to doing this. Fox and Kathryn E. Smith have been leading this panel.

The MRI network is developing imaging tools and computer programs to predict changes in the brain as MS progresses. These tools could be used in clinical trials as biomarkers to measure if a treatment is slowing or stopping disease progression.

This network is led by Douglas Arnold, MD, professor and neurologist at McGill University in Canada, in collaboration with investigators from the Netherlands, U.K., U.S. and Switzerland. The team uses cutting-edge advances in artificial intelligence and machine learning to develop imaging tools and computer programs. So far, they have processed and analyzed more than 72,000 MRI scans from 13,500 people.

MRI biomarkers of disease progression would reduce the time and cost of developing new treatments. Researchers would know much sooner whether a prospective treatment is working and need far fewer patients to participate in clinical trials.

Working to improve quality of life

Current treatments for many of the worst symptoms of progressive MS are insufficient, and people affected by these symptoms experience diminished quality of life.
The Alliance focuses efforts to jumpstart research on several key symptoms: fatigue, impairment of mobility and upper limb function, pain and cognitive impairment. An expert panel published a paper outlining critical knowledge gaps and research priorities for these symptoms. Priorities include the need for better ways to measure symptom severity, best treat these symptoms, and sustain the benefits of treatments to provide relief and improve function for people with progressive MS. "The International Progressive MS Alliance provides hope for a pathway forward in accelerating the development of treatments to stop progressive MS and improve the lives of those affected," Fox says.

The National Multiple Sclerosis Society is a leading agency for The International Progressive MS Alliance, providing financial support, operational management and scientific staff support. Cyndi Zagieboylo, the Society’s president and CEO, serves as chair of the Alliance’s executive committee, its decision-making body. As an original member of the scientific steering committee, Robert Fox, MD, helped set the research agenda for the Alliance and was the Society’s first scientific representative to the Alliance before becoming the steering committee’s vice chair earlier this year.

The Zoomer’s versatile design and 1-touch joystick operation brings mobility and independence to those who need it most.

If you have mobility issues, or know someone who does, then you’ve experienced the difficulties faced by millions of Americans. Once simple tasks like getting from the bedroom to the kitchen can become a time-consuming and potentially dangerous ordeal. You may have tried to solve the problem with a power chair or a scooter but neither is ideal. Power chairs are bulky and look like a medical device. Scooters are either unstable or hard to maneuver. Now, there’s a better alternative... the Zoomer.

My Zoomer is a delight to ride! It has increased my mobility in my apartment, my opportunities to enjoy the-out-of-doors, and enabled me to visit the homes of my children for longer periods of time. The various speeds of it match my need for safety, it is easy to turn, and I am most pleased with the freedom of movement it gives me. Sincerely, A. Macon, Williamsburg, VA

After just one trip around your home in the Zoomer, you’ll marvel at how easy it is to navigate. It is designed to maneuver in tight spaces like doorways, between furniture, and around corners. It can go over thresholds and works great on any kind of floor or carpet. It’s not bulky or cumbersome, so it can roll right up to a table or desk- there’s noneed to transfer to a chair. Its sturdy yet lightweight aluminum frame makes it durable and comfortable. It’s dual motors power it at up to 3.7 miles per hour and its automatic electromagnetic brakes stop on a dime. The rechargeable battery powers it for up to 8 miles on a single charge. Plus, it’s exclusive foldable design enables you to transport it easily and even store it in a closet or under a bed when it’s not in use. Why spend another day letting mobility issues hamper your lifestyle? Call now and find out how you can have your very own Zoomer.

Finally... a better mobility solution than Scooters or Power Chairs.
ZEPOSIA is a prescription medicine used to treat adults with relapsing multiple sclerosis (MS) who have eye problems, especially an inflammation of the eye called uveitis.

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 uncontrolled, severe breathing problems.
- have or have had a history of certain medicines to control your heart rhythm (antiarrhythmics), or heart beat that is too slow (bradycardia), or pauses in your heartbeat (arrhythmia) that is not corrected by a pacemaker.
- have had chickenpox or have received the vaccine for chickenpox. You must 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, or treat Parkinson's disease.
- 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 baby.
- are nursing or plan to breastfeed. It is not known if ZEPOSIA passes into your breast milk.

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

Do not skip a dose.
- If you miss 1 or more days of your ZEPOSIA dose during the first 14 days of treatment, take 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.

The most common side effects of ZEPOSIA can include:
- headache
- rash
- pain and/or redness in the eyes
- sudden severe headache
- worsened symptoms of MS

BE READY FOR WHAT'S NEXT

In a ONE-YEAR study:
People who took ZEPOSIA (ozanimod) had 48% fewer relapses than a leading injectable medicine (Avonex).†

In a separate TWO-YEAR study:
People who took ZEPOSIA had 38% fewer relapses than a leading injectable.‡

ZEPOSIA may cause serious side effects, including:
- 1. Infections: ZEPOSIA may 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 after you stop taking ZEPOSIA. Your healthcare provider may give you a blood test to check the number of your white blood cells before you start taking ZEPOSIA.
- 2. Slow heart rate (also known as bradycardia) when you start taking ZEPOSIA. ZEPOSIA may slow 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:
- dizziness
- light-headedness
- confusion
- feeling like your heart is beating slowly or skipping beats
- shortness of breath
- chest pain
- sudden severe headache
- unusual tiredness
- enlarged liver
- heart rhythm problems

Talk with your healthcare provider if you have any of the following symptoms:
- slowed heart rate
- difficulties breathing
- worsening breathing problems.

Call your healthcare provider right away if you have any of the following symptoms:
- unusual tiredness
- sudden severe headache
- unusual color vision
- sensitivity to light
- a blind spot in the center of your vision
- sudden vision loss of one or both of your eyes
- vision changes in your eyes
- deafness
- unusual taste
- worsening breathing problems
- swelling of blood vessels in your brain.

What are possible side effects of ZEPOSIA (ozanimod)?

ZEPOSIA may cause serious side effects, including:

1. Liver problems. ZEPOSIA may cause liver problems. Your healthcare provider will do a blood test to check your liver before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
- increased pain in your abdomen
- yellowing of the whites of your eyes
- 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. See "How should I take ZEPOSIA?" section for more information.

2. 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 if 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:
- warning symptoms such as blurred vision, flashes of light, floaters, blind spot, loss of vision,
- decreased vision,
- unusual color vision
- sensitivity to light
- a blind spot in the center of your vision
- unusual color vision
- eye pain
- swelling or bulging of blood vessels in your brain, in a condition called PRES (Posterior Reversible Encephalopathy Syndrome) is a rare condition that can occur with ZEPOSIA and with drugs like it 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:
- sudden severe headache
- sudden vision loss of one or both of your eyes
- unusual changes in your vision
- seizures
- severe worsening of multiple sclerosis (MS) after stopping ZEPOSIA.

If you stop taking ZEPOSIA, your risk for worsening 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.

The most common side effects of ZEPOSIA can include:

1. Upper respiratory tract infection.
2. Elevated liver enzymes.
3. Low blood pressure if you have any of the following symptoms:
- sudden severe headache
- death
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- unusual color vision
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From pigs to parrots, pets can enrich the lives of people living with MS.

By Shara Rutberg

Kate Perkins had tried everything — from medication to warm wheat bags — to relieve the multiple sclerosis pain wracking the right side of her body. Defeated, exhausted and overwhelmed, she knelt in front of her sofa, head pressed into the blue fabric in a position that sometimes helped and cried until she felt a soft, warm pressure on the top of her head. Belle, her yellow Labrador, had silently crept up alongside her and rested her chin on Perkins’ bowed head. Belle breathed deeply. Perkins breathed deeply. She focused on their breaths and the warm, soft weight of the dog’s head. She knew then “that it was going to be all right.”

“I remember that day vividly,” says the 47-year-old mother of two from her home in the U.K. “It was amazing.”

Perkins was diagnosed in 2010. She adopted Belle as a 12-week-old puppy from a local shelter in 2014. Perkins was just beginning to process the impact the disease would have on her life. “I was lonely and isolated,” she says. “I’d lost my confidence. I lost myself.” She credits the Lab, a breed famous for fetching tennis balls, with retrieving her life.

Animal helpers

Cave paintings dating back to the first century show dogs guiding people. Animals have been helping us navigate life, at least since then. The Americans with Disabilities Act (ADA) defines service animals as “trained to do work or perform tasks for people with disabilities,” including “physical, sensory, psychiatric, intellectual or other mental disability.” Emotional support animals also provide therapeutic benefits to people with medically diagnosed disabilities.

People living with MS attest that animals don’t need official certifications to enhance their lives. “Animals enrich our lives in so many ways. It’s hard even to verbalize it,” says Tenley Diaz, 30, a veterinarian diagnosed with MS in 2012. In those measures of wealth, she may be in the 1% with her menagerie: two dogs, a cat, three beta fish, two snakes and an axolotl, a type of salamander. “It’s truly pure joy they bring me,” she says.

What’s the best pet for someone living with MS? “The ideal animal is different for everybody, depending on their physical abilities,” Diaz says.

Fun, love and laughs

Cathy Wilkinson Barash relishes the nightly ritual she shares with her cats Pause, a tiger cat, and Itty Bitty Kitty, a small Maine Coon of 18 pounds. (Maine Coons can get up to 30 pounds.) Barash will get in bed and read to Pause, who snuggles next to her, while Itty Bitty Kitty lays on her lap, completing the kitty cocoon. “Cat purring is healing energy,” says the 71-year-old who was diagnosed with MS in 1984. “They are my little healers. My god, if I didn’t have them in my life, I don’t think I would be living.”

One of Cathy Wilkinson Barash’s cats is a Maine Coon named Itty Bitty Kitty.
them, it would be horrible. They’re my family. They’re just not tax-deductible,” she says with a laugh. They provide fun, comic relief and unconditional love — all of which she’s especially treasured while living alone during the pandemic.

“Pets give you a purpose,” she says. “They’re the reason you get up in the morning. You need to care for them, and in turn, they give you so much back.”

Margo Williamson, 35, agrees. Her furry family member, Gizmo, a hamster, is only about the size of her hand. “I love her more than anything,” says Williamson, who was diagnosed in 2016. “She is a sweet, loving, little thing that brings so much joy to my life. I live alone and don’t have any family, just friends, and having someone, even if they’re tiny, that loves you does help. And I know she does.”

Pets help with all the “good chemical feelings,” Williamson says. “They make you happy. Often with MS, you’re in your own body too much, focused on yourself. Focusing on someone else helps greatly. When I’m taking care of her, I’m taking care of me.”

For Stephanie Faris, Phoenix, her cockatiel, is a critical part of the environment she’s created to keep her well since her 2012 diagnosis. “He makes me smile and laugh all day long,” says Faris of the gray bird with a yellow head, rosy cheek circles and mohawk-like crest that extends and lowers with his mood like a feathery exclamation point. Phoenix spends most of the day perched on Faris’ shoulder — accompanying her to work as a special events DJ, where he “dances and sings along.”

“He’s my best friend,” she says, and the perfect pet for her, as she’s home most of the time, which gives him the interaction she says birds require. “With him, I never feel lonely.” The opinionated bird even makes sure Faris takes her afternoon rest to help manage her fatigue. “When I lie down, if I don’t stay still, he gives me little pecks to remind me to stay still. He knows the difference now between my MS shakes/tremors or me just restlessly moving and only pecks me when it’s tremors.”

Tenley Diaz, a veterinarian diagnosed with MS in 2012, has two dogs, a cat, three beta fish, two snakes and a salamander.
Pets help reduce stress. “And as everyone with MS knows, stress makes symptoms worse,” Smolinski says. “My dogs are my little anti-stress balls.”

Animals are “mood lifters,” agrees Sarah Mathis Henderson, 38, whose mood is constantly lifted by Hamilton, her mini pig — whom she calls Hammy and who weighs close to 200 pounds. “He just cracks me up, watching him wallow in the mud or listening to him smacking his food — even though I can’t stand it when my kids do that!” says Henderson, who was diagnosed in 2016. Hammy, who is litter box trained, spends most of his day outside and sleeps on his blanket in a closet in the bedroom Henderson also shares with her husband. While Henderson adores Hammy, she doesn’t recommend pigs, in general, for people with MS, due to their size. “It doesn’t bother us to have him in the house, but for some people, that’s not OK,” she says, laughing.

What to consider

The full-grown size of your potential pet is just one crucial factor to consider when thinking about adding an animal to your family, says Diaz. “I have tiny dogs,” Alisha Crawford’s dogs Kali, a collie-shepherd, and Jynx, a Labradoodle, make sure she gets out of the house every day to walk them to the dog park. “If I didn’t have the pups, I don’t know if I’d leave the house much, and fresh air and movement are so important with MS,” says the 40-year-old, who was diagnosed three years ago. At the dog park, where they can run amuck without her having to worry about keeping up with them, she savors simply “hanging out with them, trying to enjoy the moment and not take time for granted.”

“I feel like they can read me and sense how I’m feeling, which is just fantastic,” she says. They’ll snuggle up when she needs comfort, walk slowly and lean into her, “helping” her up the stairs when her symptoms slow her down.

Stress relievers

AJ and Paulie, Mary Ellen Smolinski’s Maltese dogs, read her as well — though they’re just about 11 pounds each, says the 68-year-old, who was diagnosed in 2015. “When I’m down, they sense it and try to stay near me,” she says. Fortunately, they both fit in her lap at once.

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What to consider

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Consider the breed, energy levels, and typical breed personalities and training requirements, then research which might best fit your lifestyle and physical environment. Keep in mind that senior animals may take less energy to care for. Remember that even small animals need care that takes energy. “Think carefully about what will be required physically, emotionally and financially,” Diaz says.

People with MS must plan for future possibilities, too. “I know it’s hard to think about, but I may not be at the same level of physical ability later on,” Diaz says. “You need to have a plan about who will care for the animals if, after a relapse, you don’t come out with the same abilities.” The pet owners we spoke with emphasized having care plans — help lined up — during times they are unable to care for their animals.

“Get pet insurance,” Perkins says. “There can be quite a financial investment, as well as an emotional one.” However, the return on the investment is beyond calculation, she says. “Belle just makes all of us so happy physically, mentally and emotionally. If she charged for her service, we’d be paying a lot!”

With a chronic condition, you’re so often worried about the future. Belle helps me live life in the present. Looking after her, even just stroking her, helps me release the stress and anxiety of living with MS. She helped me grow my confidence. After my diagnosis, I was scared of doing things. She made me walk, and I found that walking helps manage my pain and mental health.” It also helped her connect with other dog walkers.

MS can be an invisible disease, she says. “Often, people can’t see your symptoms. You have to put on a brave front. You don’t have to do that with a pet. I never thought I’d come such a long way, but since I’ve had Belle, I’ve even been looking into working again. She’s helped me find myself again — a different version of the old me. Maybe a better version.”

Shara Rutberg is a writer in Evergreen, Colorado.

Care to comment? Email us at editor@nmsso.org.
2. Infections.

- have certain types of heart block or irregular or abnormal heartbeat

IMPORTANT SAFETY INFORMATION

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

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to delay disability progression.

What is MAYZENT® (siponimod) tablets?

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to delay disability progression.

- have eye problems, especially an inflammation of the eye called uveitis
- have a fever or infection, or you are unable to fight infections due to a weakened immune system
- have breathing problems, including during your sleep
- have a history of stroke or other diseases related to blood vessels in your brain;

Tell your health care provider if you have had chickenpox or have 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:

- a type of skin cancer called basal cell carcinoma (BCC), melanoma, or squamous cell carcinoma

- had or now have a type of skin cancer called basal cell carcinoma (BCC), melanoma, or squamous cell carcinoma
- 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
- 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 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:

- 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
- 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 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.

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

- body aches
- sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

MAYZENT causes certain side effects in adults. It is not known if these side effects occur in children.

MAYZENT may cause side effects in adults. It is not known if these side effects occur in children.
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 bradycardythmia) 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.

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 in your blood. This may 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.

3. 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, unusual tiredness, rash, sore throat, swollen lymph nodes.
Every year, National Multiple Sclerosis Society volunteers visit their congressional representatives on Capitol Hill as part of the Society’s Public Policy Conference to advocate for policies aimed at improving the lives of people with multiple sclerosis. “People with MS have always been advocates, and in fact, the Society’s first Washington, D.C., conference closely coincides with the Americans with Disabilities Act becoming law,” says Abby Carter Emanuelson, associate vice president for advocacy and activist engagement with the Society.

In 2021, the pandemic forced activists to attend the conference and lobby Congress virtually. But the change turned out to be a success. “We really saw a surge of interest in attending the conference due to virtual communication,” says Bari Talente, executive vice president for advocacy and healthcare access. “Before the pandemic, only about 300 people could attend in person. This time, meeting virtually, nearly 900 people participated over two days from their homes across the country, and content from the conference is available for the rest of the year.”

During the conference, MS activists learned to tell their stories to government officials in the format that works best for them — meetings, phone calls, emails and social media. “We use a phrase,” Talente says. “Wow, how and now’ to frame a successful outreach to policymakers. ‘Wow’ means sharing your personal story or a compelling fact. ‘How’ is how a policy or legislation will affect the MS community. ‘Now’ focuses on the specific request or legislation we want elected officials to support.”

Over the last three decades, the Society has supported activists’ involvement on Capitol Hill. Three long-time activists discuss how they became involved and what they’ve been focusing on.

Frank Austin
Since he was diagnosed with MS in May 1997, Frank Austin has become involved in advocating for dozens of pieces of legislation to benefit Americans with MS. A Navy and Vietnam veteran who spent four years teaching avionics and training other service members, Austin says, “I’ve never been a wallflower. I’ve done a lot of public speaking and don’t mind being in front of people.”

He grew up in Kansas but moved to California with his then-wife when he retired and later moved to Plainville, Kansas. On an activist trip to Washington, D.C., he visited the staff of Sen. Jerry Moran, an old school acquaintance, and then ran into him in the hall where they exchanged memories of their school days. “The older you get, the more you have experiences like this..."
Frank Austin is working to secure funding for research and care for 33,000 veterans with MS. That seem to indicate you’ve made the right choice in what you’re doing,” says Austin, now 70.

In 2000, she says, “a neurologist who specialized in MS told me, ‘We don’t have any medication that will help you. So, walk, talk and see! Go live the best life you can, and when you get another big MS attack, come back and see me.’” That gave her confidence to go ahead with all her plans. Then in 2008, reality set in again, and she spiraled into a depression for six months. “I knew then I needed a mentor, so I called the Society office in Albuquerque. They said, ‘We have the perfect member for you, a retired professor from the University of New Mexico named Caitlin Anderson.’ She told me, ‘I’m going to get you involved in volunteering with the Society’s advocacy program to help shift your negative energy into a positive mindset.’ That really helped me come out of the darkness I’d fallen into.”

Jennifer Gomez-Chavez, EdD

When Jennifer Gomez-Chavez, EdD, was first diagnosed in 1995, she was devastated. She was a young professional starting her career at the University of New Mexico and was about to be married. “I’d never heard of MS, and I didn’t want to accept myself as someone living with a disability,” she says. “I was concerned about how colleagues would perceive me and if I’d be able to have a family.”

Four years ago, Gomez-Chavez received the Society’s National Volunteer Activism Award in recognition of her extraordinary efforts. Ultimately, she says, her diagnosis led to a renewed passion for living and helping others. “Before MS, I was existing. Now I’m living. We have these things we want and our goals. When you get a diagnosis like MS, you realize ‘I’d better put this in gear today because every day matters.’ Gomez-Chavez works full time at the University of New Mexico and also is a community leader, partnering with underserved communities, listening to their needs and being a channel to bring forth their concerns. In addition, she taught the psychology of hope for 10 years at the university. “My life is all about giving people hope to live another day,” she says. “I want to tell everyone that it’s never too late to go from existing to living.”

Briana Landis

Twenty-three-year-old MS advocate Briana Landis is remarkable in many ways. First, she was diagnosed with MS at the age of 4 after having migraine headaches and blurred vision. In those days, pediatric MS was extremely rare. When she was 8 years old, she earned the Kohl’s Kids Who Care Award, which led to her being invited to appear on the “Montel Williams Show” (Williams, who lives with MS, founded the Montel Williams MS Foundation). “When I was 8, I got a letter from North Carolina Rep. Richard Hudson thanking me for appearing on Williams’ show,” Landis says. “Then years later, while attending my first Public Policy Conference, I visited Rep. Hudson’s office as an MS advocate and was surprised to see a photograph on his wall of where I did my research.”

When she was in fifth grade, the North Carolina Research Campus was built near her house. Simon Gregory, MD, began doing MS research there on genetic and environmental factors surrounding MS. Fast forward eight years, and Landis, a four-time National MS Society Scholarship winner.
recipient, earned a degree in biology, along with a two-year internship with Gregory and his fellow MS researcher Sabrina Cote, PhD.

The MS community gave Landis a way to take control of her diagnosis. She felt a connection with all the people she met and remembers one in particular. “After I gave a speech two years ago in Atlanta, I was approached by an older woman who was the coolest ever. We had a great conversation, and she told me her name was Diann Geronemus and that she'd assisted in setting up the first MS treatment center in St. Barnabas Medical Center in New York. Then she dropped this bomb — that she’d been a caregiver for the brother of Sylvia Lawry, the founder of the National MS Society. That blew me away!”

Asked about something she’s proud of, Landis says, “I’m proud of what I’ve become since my diagnosis. I lead a Walk MS team to raise funds for the Society’s mission. I’ve advocated on Capitol Hill for pediatric MS clinics, MS Research funding, more affordable MS medications and improved healthcare access. When I was diagnosed, no one knew that could happen. There wasn’t a role model to give me advice, so I’ve forged my own path. ”

The charming and upbeat Landis now lives in Greenville, North Carolina, and is planning a celebration for her 20th anniversary of having MS. “I’ve decided to celebrate instead of being afraid.”

James Townsend is a writer in Boulder, Colorado.

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**Blessings in miles and meters**

The support of my family and friends keeps me going.

by Carolyn Fisher

My story is like that of many others who live with multiple sclerosis. It was 1999, and I was getting ready for work. My makeup was the last thing to do. But when I looked in the mirror, I felt like I was looking into a kaleidoscope. I realized it was my vision. I was frightened — I didn’t know what was happening, and now I couldn’t see.

I found my way to the phone and called my husband, Jerry, who was at work. “Honey, please come home. I need you. I can’t see. Please come,” I said.

“I’m on my way. Be there as quick as I can, I love you,” Jerry said. That was exactly what I needed to hear.

When he got home a few minutes later, he led me to the car, and we were on our way to the hospital. They took me in immediately, and I had an MRI and a spinal tap. What the doctor told us was something I never expected to hear: multiple sclerosis.

It felt like a death sentence. Jerry would not want to live with an invalid, and my kids would never understand.

But I found a support group and learned much more about MS. I learned that my eyes had to be trained to see again. I wore a black patch, switching it from eye to eye. My youngest daughter and her friends were having a ball with me. My new name became the “One-eyed Mom’ster,” complete with a poem she wrote (see page 75).
The One-Eyed ‘Mom’ster’
by Jill Fisher Butler

Just call her “Patch Fisher,” they jokingly say.

“What’s on her eye? Is it here to stay?”

It appeared one day, big, bold and black.
Now it’s just fun to give her some flack.

It really is a serious phenomenon.
Which eye should she wear the patch on?

An eyeball and lashes is all that needs to be
To surprise the tie off our Pastor Anthony.

It goes back and forth; one eye to the other.
The retina sees it coming, thinking, “Oh, brother.”

Little ones see her coming, they all run and hide.
They only see a one-eyed lady, not the sweet lady inside.

We really do know it is attention she seeks.
Enough is enough! All these hours, days and weeks!

A swashbuckling pirate, her childhood dream.
But she’s gone too far, at least that’s how it seems.

Winking is prohibited, as is peek-a-boo.
So, what is this “on-the-go” woman to do?

Not allowed to drive, to compute or read a book,
The only thing left is her favorite thing. Cook!

This thrills Dad’s tummy, but a warning he must heed.
What happens when the recipe she can’t read?

But we know this never slowed her down.

If she donned the patch on her nose, she could be a clown.
But in the realms of reality, we know she’s in pain.

The mystery of health is all she wants to attain.

So, if you’re up there listening, God,
There’s a favor we’d like to foster.
Please give Mom back her eyesight.
So, she can resign from being
Our “One-Eyed Mom’ster.”

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

Fortunately, my sight returned within a few months. My husband learned to administer my disease-modifying therapy (DMT) injections weekly. He did that for 21 years and never complained. MS put me in a wheelchair for a year or so. I walked with a cane for two years. And although at 78, I have reached “elderly” now — as my daughter so eloquently reminds me — I have a very active life, and I wouldn’t want it any other way.

Six years ago, my husband was diagnosed with incurable brain cancer and given three to six months to live. Along with everything else, I wondered how I would get my injections. A nurse tried unsuccessfully to teach me.

Then, about a month before my husband went to heaven, I had an MRI. My doctor said my MS was stable and that it would be safe for now to stop the injections. This was God taking care of me, as he always had.

Although my precious husband has gone on to be with Jesus, and I miss him terribly, I’ve been blessed with a great family, many friends, a wonderful church family, and yes, I still depend on God.

My oldest daughter, Janie Morton, participates in the National Multiple Sclerosis Society’s Bike MS with her team Big Banana. She trains hard for these rides, and she puts a lot into them. I know asking for donations is not an easy task. So to all those who ride, and especially to Janie, I want to thank you. My prayer is that someday a cure will be found, so MS can be eradicated. For everyone who donates or who rides, you can look back and say you were part of it.

Carolyn Fisher lives in an apartment overlooking a lake in Winter Park, Florida, where she spends hours writing every day.
When I was 22 years old, I was diagnosed with multiple sclerosis, although doctors believe I have had MS since I was in high school. I ran track and field in high school. When I ran, I would get overheated, my left side would get weak, and I would fall to the ground. I would experience this from time to time, but I kept going and ignored it. It was not until years later when I had my daughter that the symptoms began to worsen. I woke up one morning, and the whole room was spinning. I knew something wasn’t right. An MRI showed that I had lesions on my brain, and I was diagnosed with relapsing-remitting MS. Luckily, I had a strong support system. I decided I was not going to let this disease take over my life. I had two children who needed their mom. So I kept going, pushing through the aches and pains, the fatigue, the mood swings, the depression, the vertigo, the left-side weakness — all of it. I couldn’t hold down a job or finish my college degree, but I was determined to keep going. After years of going to doctor after doctor, I finally found an MS specialist who was very upfront with me and took my concerns seriously. She prescribed a new disease-modifying therapy (DMT) that seems to be helping. I met my husband, Fred, in 2019. It was love at first sight. He is my rock, my best friend and a wonderful stepfather to my two children. Fred is my soulmate. I couldn’t decide what career I would pursue. But I found my inspiration through art. I’ve always loved art. It was a creative outlet for me, but it wasn’t until later in my life that it became my passion. My focus is resin art because resin is an innovative, creative medium. I can use different techniques that set me apart from other artists. I use my artwork to inspire other people who live with MS. I love what I do so much that I decided to start my own company, F&S Infinity Designs. I can work in the comfort of my own home doing what I love. I can rest when I need to. I can set the temperature, so I won’t get overheated. My advice to those who live with MS is to keep going, keep your head up, find what inspires you. Remember, we all are in this together. Keep fighting.

Sarah Judson lives in Dayton, Ohio, with her husband, Fred, and her two children, Caden and Brooklyn.

See Sarah Judson’s artwork at fansdesigns.com.

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