In the beginning

What it’s like when you’re first diagnosed with MS.
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.
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.

What is MAVENCLAD?

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

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

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

Do not take MAVENCLAD if you:

- 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 not receive these types of vaccines during your treatment with MAVENCLAD and until your healthcare provider tells you that your immune system is no longer weakened.
- have or have had cancer.
- are breastfeeding or plan to breastfeed. It is not known if MAVENCLAD passes into your breast milk. Do not breastfeed on the days on which you take MAVENCLAD, and for 10 days after the last dose. See “Do not take MAVENCLAD if you:”

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

How should I take MAVENCLAD?

- Limit contact with your skin. Avoid touching your nose, eyes and other parts of the body. If you get MAVENCLAD on your skin or on any surface, wash it right away with water.
- Take MAVENCLAD at least 3 hours apart from other medicines taken by mouth during the 4- to 5-day MAVENCLAD treatment week.
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 get any symptoms of the following infection related problems or if any of the symptoms get worse, including:
    - fever
    - aching painful muscles
    - headache
    - feeling of being generally unwell
    - loss of appetite
    - burning, tingling, numbness or itchiness of the skin in the affected area
    - skin blotches, blistered rash and severe pain
  - progressive multifocal leukoencephalopathy (PML). PML is a rare brain infection that usually leads to death or severe disability. Although PML has not been seen in MS patients taking MAVENCLAD, it may happen in people with weakened immune systems. Symptoms of PML get worse over days to weeks. Call your healthcare provider right away if you have any new or worsening neurologic signs or symptoms of PML, that have lasted several days, including:
    - weakness on 1 side of your body
    - loss of coordination in your arms and legs

- **Decreased strength**
- **Problems with balance**
- **Changes in your vision**
- **Changes in your thinking or memory**
- **Confusion**
- **Changes in your personality**

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

- **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

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CORRECTION
The article “When MS isn’t your only disease” in the Fall 2020 issue included an incorrect number of Americans with MS. Current estimates show that 1 million people live with MS in the U.S. The paragraph in the article should read: “A 2018 retrospective analysis of 5 million Americans found that the most common comorbidities were high blood pressure and high cholesterol (26% to 30% of all people analyzed), gastrointestinal disease (18% to 21%) and thyroid disease (13% to 17%).” We regret the error.
Wherever you live, we strive to be a place where you can connect for the most comprehensive multiple sclerosis information and available resources. We want to be a place where you feel welcome and at home — among friends, able to be yourself, comfortable, accepted for who you are.

This is thanks to a nationwide network with 800 leadership volunteers, 1,200 self-help group leaders, 34,000 MS activists, including 312 District Activist Leaders, plus hundreds of thousands of event participants. As a result, we have built a movement that includes close to 550,000 of the estimated 914,000 people who have been diagnosed with MS. Where are the other 364,000? How do we reach them to make sure they know that we have their back? No one should live with MS alone.

Most would agree that we are doing well with outreach, that knowing and engaging 60% of people with MS is good. I think we can do better. I know some of you who take it upon yourselves to be a “go-to resource” in your local community. Or maybe you just fell into that influential position. There are more people out there who are inspiring, welcoming and inviting, and creating space for people to plug in and take part in the MS movement.

We are formalizing the name, MS Ambassador, but many serve in this role without a title. Magnetic, easily approachable people who view people they don’t know as future friends, not strangers. They are people like Diane Kramer from State College, Pennsylvania, who is featured in a story about our Virtual State Action Days. After she was diagnosed with MS in 2010, Diane contacted the Society. She started a self-help group. She took it upon herself to visit local neurologists’ offices to deliver up-to-date information about the Society. People in Diane’s community know they can count on her to make connections. Her engagement led to her nomination to the Society’s national board of directors. She started her term in November. Like so many other volunteers across the country, Diane doesn’t just represent the National MS Society. She IS the National MS Society in her community.

And there are others, like Micah Love from Houston. Micah didn’t plug in at his first opportunity, or even his second. When a friend let Micah know he would ride Bike MS in his honor, Micah decided to plug in. As he puts it, “For me, the MS Society is a refuge, a safe haven. I can be myself and belong — it’s not overbearing. And before I knew it, I became the connection point for others. I hear from people who are newly diagnosed. I get to share my experience and let them know that the MS Society is a good place to plug in.”

Lauren Spero, vice president, volunteer and community engagement, leads our efforts to uncover and inspire more MS Ambassadors. She says: “We need people everywhere who want to BE the MS Society in their communities, like Diane and Micah. People who have that warm, open, accepting personality that others gravitate to. We need their help, so people feel comfortable and confident connecting with us. At the Society, we strive to be a place for anyone affected by MS to connect, be empowered, lift others up and belong. There is no doubt that together we are stronger. MS Ambassadors are proof of that.”

We know people who thrive are connected. That’s not going to be the same for each person, and it’s likely to change over time. How do you want to plug in? Could you be an MS Ambassador? Let’s keep in touch!
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People of color with MS face unique challenges and inequities living with their disease. PLUS: Virtual doctor visits, gardening with MS and five tips for how to manage foot drop.

Contact Momentum

nationalMSsociety.org/momentum

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

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

editor@nmss.org

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.
Good advice on wellness coaches
Thank you for the article “Directing your life” in the Summer 2020 issue. I have been thinking about getting a wellness coach, but really didn’t know what to look for or what questions to ask. I’ve had MS for 10 years, and I’m still trying to process this. I think a coach will help. I love how the article made what to look for simple. I know that I am the director of my life, but it’s good to have a partner as a coach who will hold you accountable. I have to be ready to accept the change, and I think that has been my problem over the years. I know that I need to set goals to get me through my milestones throughout this disease. This is great motivation, and I really appreciate Momentum sharing this information.

Elisha Banks, California

Two great articles
Thank you for two great articles in the Fall 2020 issue. “MS as a cure for mediocrity” is quite inspiring and made me realize that I need to keep pursuing my first love, the piano. “Jewelry with a hidden meaning” was also excellent.

Marie Powers, Illinois

Impossible to separate symptoms
The article “When MS isn’t your only disease” (Fall 2020) hit home. In addition to my MS, I have rheumatoid arthritis, restless leg syndrome, shortness of breath, high blood pressure, high cholesterol and degenerative scoliosis (with two major back surgeries), to name a few. When I go to one of my specialists and they want to know how whatever they are treating me for is doing, I am at a loss how to answer. My symptoms are so intertwined. They are nearly impossible to separate.

Donna Schneider, Washington

Physical therapy helps
I just sat down on my front porch to read my Fall 2020 issue of Momentum magazine. I’ve been reading it for 20 years and have never written but felt compelled to write today. In the article “Moves you can use,” the question, “Have you tried physical therapy before turning to an assistive device?” really hit home. Until this summer, I’d never considered physical therapy, but my daughter-in-law suggested it after she heard I’d fallen six times in five weeks on the same silly step in our home. It took me weeks to find a PT who would serve me, as I am a part of a healthcare sharing ministry, but I found an excellent therapist. After only two sessions, I am more stable than I’ve been in a while. I still use my cane, but I’m steadier and using it more effectively, and I haven’t fallen since I met with the PT. Best $200 that I’ve spent in a while. Thank you, Momentum.

Cindy Woodcock, Texas

Revelation
As a person with MS since 1985, I thought the account in the Fall 2020 issue about Ian Duncan, PhD, concerning his research into remyelination (“Repair work”) was quite positive news.

G. L. Welch, Georgia
Research and human interest
I always enjoy reading Momentum. Thank you for the scientifically in-depth research articles and inspirational human impact stories. Well done.

Pam Lyons, Arizona

A surprised poet
I totally agree with what Amy Black stated: “An incurable disease is a stellar excuse to craft a mission statement and live it out” (“MS as a cure for mediocrity,” Fall 2020). I have lived with MS for 50-plus years now. This year, I found I’ve become a poet. Who, me? I’ve penned more than 16 poems now; my first, “Chair on Wheels,” was published in our local newspaper. I’m 72 and writing poems has totally surprised me. I even wrote a poem on becoming a poet, “Who me?”

Sandy Crabtree, Idaho

Research offers hope
I have struggled with MS for 46 years. My first attack was thought to be a brain tumor. Thankfully, I recovered fully. One year later, I had my second exacerbation. I’m 76 and only recently have had to use a wheelchair or walker. I took Avonex once a week for 16 years until 2016, when my neurologist suggested I stop as I now have progressive MS. I am so happy to see that Ian Duncan, PhD, (“Repair work,” Fall 2020) has used his talents on remyelination, as I feel this will change the future for people dealing with this disease. Hope is all that we have.

Jim O’Brien, Rhode Island

Bring problems to light
I felt terrible for Lois Underwood, as I completely understand when things are not as accessible as they should be (“Not accessible,” @Momentum, Fall 2020). A while ago, my son played high school football at a stadium, and I (as well as others) could not get down the stairs of the stadium without something to hold onto, like a railing. I started writing letters to the city. Not just from a disgruntled mother, but for the disabled and elderly people of my city, too. I didn’t say that I was the only one having the problem. I received a response within months. So, Lois, try writing letters to your city to get things changed, not just for you, but also for others in your community. Someone else is thinking the same way you are, and it only takes a couple of complaints to get the things we need done. I love your statement, “We are not dead!” This is true. Accessibility most times is a joke at a lot of places, but until it is brought to light by a few of us, nothing much will happen.

Denise Hobbs, Washington

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

Color therapy (or chromotherapy) is an alternative remedy that may help improve mental and physical health. Different colors affect our mood and emotions. While more studies are needed to confirm the benefits of color therapy, color psychology suggests that specific colors can be calming, balancing or stimulating, and these mental effects can affect how we feel physically.

Since winter can sometimes leave us feeling depressed or more down than usual, try incorporating warm colors — red, orange and yellow — to boost your mood because they are commonly associated with energy and happiness. Green is also a good option because it can promote healing.

Incorporate color therapy into your home, such as painting the walls in your bedroom. Mindfully use color during art therapy, which is another form of therapy where people express themselves through creative processes such as drawing or painting.

Practice color yoga and meditation at a color-lit studio or by wearing glasses with colored lenses while you exercise.
New guidelines highlight the benefits of exercise for all people with MS — regardless of ability.

by Matt Alderton

Exercise is the golden rule of health and wellness and has been for millennia. Nearly 3,000 years ago, for example, the ancient Indian physician Sushruta became the first doctor to recommend moderate daily exercise, which he believed could provide resistance to disease and “physical decay.” Just a few centuries later, the ancient Greek physician Hippocrates of Kos became the first physician to give a written exercise prescription, which he gave to a patient suffering from consumption. Since then, everyone from Jane Fonda and Richard Simmons to Bruce Springsteen and Michelle Obama has hailed the benefits of physical activity.

If there’s one person who hasn’t always been on the exercise bandwagon, however, it might have been your neurologist. That’s because, for a very long time, doctors advised against exercise for people with multiple sclerosis.

“Until fairly recently, the conventional wisdom was that people with MS shouldn’t exert themselves,” says MS specialist Barbara Giesser, MD, a neurologist at the Pacific Neuroscience Institute in Santa Monica, California. “This may have stemmed from the observation that when somebody with MS exercises and gets overheated, they can have a temporary worsening of symptoms.”
“The problem with MS, of course, is that the nerves are scarred. They don’t conduct electricity properly. If you take a damaged nerve and heat it, you get a temporary conduction block. The heat temporarily impedes the nerve’s ability to function, but it doesn’t cause more damage,” Giesser says.

In fact, not only does exercise fail to make MS worse, it actually might make it better. In 2019, the National Multiple Sclerosis Society convened an international and interdisciplinary group of MS experts, researchers and clinicians, including Giesser, to create a new set of exercise and physical activity guidelines for people with MS. Published in April 2020 in the Multiple Sclerosis Journal, its work breaks new ground by making physical fitness accessible and attainable for all people with MS.

The merits of movement
Exercise physiologist Robert Motl, PhD, calls exercise a “potent stimulus” that has “clear pleiotropic effects.”

“That means it has effects on nearly every single system within the human body,” says Motl, a physical therapy professor at the University of Alabama at Birmingham and one of the coauthors behind the Society’s new exercise guidelines. “When you look at MS specifically, exercise can affect the expression and degree of inflammatory immune cells. For example, exercise can decrease pro-inflammatory immune cells and increase anti-inflammatory immune cells. Exercise also is known to stimulate nerve growth factors, which can help reduce damage within the brain caused by multiple sclerosis.”

Exercise is especially stimulating to the hippocampus and thalamus, areas of the brain with critical roles in memory and learning, and speech processing and motor function, respectively.

“Exercise has cellular-level effects … that translate into changes in brain structure and function, which in turn translates into other benefits like reducing fatigue,
improving cognition, improving walking and, ultimately, improving quality of life by enabling people to be employed and engage in social activities,” Motl says.

Exercise also is beneficial for its impact on other illnesses that can exacerbate MS, according to occupational therapist and guidelines coauthor Kathleen Zackowski, PhD, the Society’s senior director of patient management, care and rehabilitation research. “When someone who has a chronic neurological disease isn’t active enough, they can develop comorbidities like diabetes and obesity, which can be very impactful not only to the person’s life but also to the progression of MS,” she says.

Exercise even has mental and emotional benefits. “We know that mood is significantly impacted in people with MS and that staying active helps mood,” says clinical psychologist and guidelines coauthor Rosalind Kalb, PhD, a consultant to the Society as well as to the MS education organization Can Do Multiple Sclerosis. “People who exercise feel better, and people who feel better manage their symptoms more effectively.”

**Making activity attainable**

Exercise is healthy. The problem is: Many people with MS don’t know how to fit it into their lives.

“People with MS often know that exercise and physical activity are important and beneficial for their disease and their overall health,” says guidelines coauthor Amanda Rohrig, a physical therapist at Horizon Rehabilitation Centers and senior programs consultant at Can Do Multiple Sclerosis. The challenge occurs when movement becomes more difficult or feels unfamiliar because of MS, to the extent that participation in exercise and physical activity declines, Rohrig explains. “Previous forms of exercise and physical activity become challenging, unsafe or unenjoyable, so people significantly reduce or stop participating.”

The Society’s new exercise guidelines were born of that realization, according to coauthor Kathleen Costello, the Society’s associate vice president for healthcare access, who conceived the guidelines with Kalb, Motl and Zackowski. “What we needed and did not have was one place where a person with MS or their healthcare professional could go to see what types of things we’re talking about when we say exercise is good,” says Costello, a nurse practitioner specializing in MS care. “I was looking for something incredibly practical that synthesized the research and put it into a format that people could use. That’s what we as an organization developed.”

Based on current evidence and expert opinion, the new guidelines — which have been endorsed by the Consortium of Multiple Sclerosis Centers — are tailored by disability level using the Kurtzke Expanded Disability Status Scale (EDSS), a method of measuring neurologic disability in MS. The scale ranges from EDSS 0 (no disability) to EDSS 9.0 (confined to a bed). Wherever they fall on the EDSS, people
with MS can participate in some form of exercise or physical activity. The guidelines recommend completing at least 150 minutes per week of exercise and/or 150 minutes per week of lifestyle physical activity.

The distinction is essential. “Exercise is doing something repetitive over a period of time and with a specific objective (for example, higher intensity) whereas lifestyle physical activity can be accumulated as part of your daily activities, including work, household or leisure time,” Zackowski says.

In other words, exercise is structured and prescriptive, while lifestyle physical activity tends to be unstructured and spontaneous. Exercise for people with mild impairment, for example, might include running, walking, weight training and yoga. Exercise for wheelchair users might consist of strengthening the lungs using a spirometer or strengthening the arms by way of arm cycling. Lifestyle physical activity, on the other hand, might include gardening, cleaning, or pushing a grocery cart for people with mild impairment, and folding clothes, seated dancing or manual propulsion for wheelchair users.

Although exercise typically is more effective than lifestyle physical activity at building aerobic capacity, muscle strength and balance, each yield similar benefits for people with MS with regards to symptom management and disease progression, according to Motl, who stresses the guidelines’ flexibility. Individuals don’t have to accumulate 150 minutes of exercise and 150 minutes of lifestyle physical activity. They don’t have to accumulate it all in one bout or session. Instead, they can do a mix of exercise and lifestyle physical activity that they accumulate in small increments.

“Start slowly and listen to your body,” Motl advises. “If you’re not used to being active, don’t immediately try to do 30 minutes of walking five days a week at a moderate intensity. That’s going to do more harm than good. Instead, start with just 5 minutes two or three days a week.”

Rohrig agrees and suggests consulting a health professional before escalating your physical activity. “Specifically, physical therapists and exercise specialists can help guide people safely toward this recommendation,” she says.

**Doctor’s orders**
The authors wrote the guidelines as much for clinicians as they did for people with MS. “The key is educating both the healthcare provider and the patient that exercise and physical activity are an integral part of their treatment plan, just like taking medicine is,” explains Giesser, who says providers — including neurologists — can use the guidelines as an icebreaker. “A neurologist isn’t necessarily the person who can prescribe a comprehensive exercise regimen, but a neurologist can certainly start the conversation.”

Zackowski agrees. “I would love to see physicians, including neurologists, make a point of asking their MS patients how active they’ve been — and if they’re
not active, what the barriers are that they’re facing.”

As the authors acknowledge in the guidelines, barriers can be:

- Physical (e.g., rural vs. urban environments, unsuitable home environment, lack of community facilities or transportation)
- Social (e.g., limited support, dependence, cultural factors)
- Medical (e.g., fatigue, fitness level, symptom fluctuation, comorbidities, treatments and medications)
- Financial (e.g., gym membership, equipment costs, childcare fees)

Some of the most common barriers, however, are emotional, according to Kalb, who says people with MS often experience fear, anxiety and apathy about exercise.

“We call all the negative messages that people with MS send themselves ‘brain chatter,’” Kalb explains. “When you work with a specialist, you can negate some of that brain chatter by learning different ways to adapt.”

For example, providers can give someone concerned about exacerbating their MS symptoms strategies for managing them — anti-spasticity medications can help with muscle spasms, for example, a cane with ambulation issues and a cooling vest with heat sensitivity.

“Ideally, physicians would make it clear to their patients that activity is important,” Zackowski says. “It would then be great if the physician could talk to other patient providers such as a nurse or physical therapist, who can help the patient find resources that help them safely increase their activity and exercise.”

Resources might include:
- Starting a take-home exercise program with resistance bands and other equipment
- Getting a referral to a physical or occupational therapist
- Calling an MS Navigator (1-800-344-4867), emailing ContactUsNMSS@nmss.org or visiting nationalMSsociety.org/navigator.

“Watching online videos that the Society has created to demonstrate stretching, aerobic and breathing exercises for people with MS at all ability levels. Whatever resources their providers share, the message the guidelines’ authors most want people with MS to receive is that everyone should exercise — and that everyone can.

“All people with MS, regardless of ability level, can participate in exercise and lifestyle physical activity,” concludes Rohrig, who reiterates that all movement, such as folding clothes, picking up kids’ toys, working in the garden, doing yoga, riding a bike, counts. “In the simplest terms: People with MS should try to move as much as they can, as often as they safely can.”

Matt Alderton is a Chicago-based writer and editor.

Learn more about the new exercise and physical activity guidelines and watch demonstration videos at ntlms.org/ExerciseRecommendations.
Get moving

The National MS Society recommends that all people with MS get 150 minutes per week of exercise and/or 150 minutes per week of lifestyle physical activity.

People with MS who have a mild impairment ranging from no restrictions to limited endurance, unsteadiness, and impaired information processing and memory:

- Aerobic exercise such as walking, rowing, running, jogging, swimming or stair climbing.
- Resistance/strength training using weight machines, free weights, resistance bands or body weight exercises.
- Flexibility training encompassing standard stretching or yoga.
- Neuromotor activities, such as Pilates, dance, yoga, Tai chi or equine-assisted therapy. Examples include walking, gardening, road cycling, hiking with poles, individual and team sports, and dancing.

People with MS who have restricted ambulation, including people who have limited walking ability, people who are prone to falls and people who use mobility aids:

- Exercise your core by doing seated isometric ab exercises, and/or moving or stationary seated balance and posture exercises. Examples include walking as able, manual wheelchair propulsion, power-assist cycling, swimming, water therapy, adaptive sports, seated dancing, yoga, boxing and active weight shifting.
- Breathing exercises using a resistive breathing apparatus, such as a spirometer.
- Flexibility training via stretching.
- Work out upper extremities using weights or resistance bands, or by doing arm cycling.
- Exercise lower extremities by walking with a walker, doing sit-to-stand exercises, doing power-assist cycling or doing body weight treadmill training.

People with MS who use wheelchairs:

- Breathing exercises using a resistive breathing apparatus, such as a spirometer.
- Flexibility training wherein you stretch all affected upper and lower extremity joints, with assistance if needed.
- Work out upper extremities using weights or resistance bands, or by doing arm cycling.
- Exercise lower extremities by standing with support and using a standing frame.
- Exercise your core by doing seated isometric ab exercises, moving or stationary seated balance and/or posture exercises. Examples include activities of daily living (e.g., cleaning, grooming, laundry, shopping), water activities, bed mobility exercises and pressure relief (e.g., front/lateral press-ups).

People with MS who are confined to a bed or chair:

- Breathing exercises using a resistive breathing apparatus, such as a spirometer.
- Flexibility training via a passive or active range of motion of all joints, as able.

Care to comment? Email us at editor@nmss.org.
WITH RELAPSING MS YOUR GOAL IS TO FIND A WAY TO KEEP Whether you’re new to treatment or ready for a change,

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

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

IMPORTANT SAFETY INFORMATION
DO NOT TAKE AUBAGIO IF YOU:
• Have severe liver problems. AUBAGIO may cause serious liver problems, which can be life-threatening. Your risk may be higher if you take other medicines that affect your liver. Your healthcare provider should do blood tests to check your liver within 6 months before you start AUBAGIO and monthly for 6 months after starting AUBAGIO. Tell your healthcare provider right away if you develop any of these symptoms of liver problems: nausea, vomiting, stomach pain, loss of appetite, tiredness, yellowing of your skin or whites of your eyes, or dark urine.

• Are pregnant. AUBAGIO may harm an unborn baby. You should have a pregnancy test before starting AUBAGIO. After stopping AUBAGIO, continue to use effective birth control until you have made sure your blood levels of AUBAGIO are lowered. If you become pregnant while taking AUBAGIO or within 2 years after stopping, tell your healthcare provider right away and enroll in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2.

• Are of childbearing potential and not using effective birth control.

It is not known if AUBAGIO passes into breast milk. Your healthcare provider can help you decide if you should take AUBAGIO or breastfeed — you should not do both at the same time.

If you are a man whose partner plans to become pregnant, you should stop taking AUBAGIO and talk with your healthcare provider about reducing the levels of AUBAGIO in your blood. If your partner does not plan to become pregnant, use effective birth control while taking AUBAGIO.

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

Your healthcare provider will run certain tests before you start treatment. Once on AUBAGIO, your healthcare provider will monitor your liver enzyme levels monthly for the first 6 months.
• Have had an allergic reaction to AUBAGIO or a medicine called leflunomide.
• Take a medicine called leflunomide for rheumatoid arthritis.

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

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

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

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

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

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

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

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

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

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

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

AUBAGIO may cause serious side effects, including:

- **Liver problems:** AUBAGIO may cause serious liver problems that may lead to death. Your risk of liver problems may be higher if you take other medicines that also affect your liver. Your doctor should do blood tests to check your liver:
  - within 6 months before you start taking AUBAGIO
  - 1 time a month for 6 months after you start taking 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
- 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.
  - After stopping AUBAGIO, continue using effective birth control until your blood levels of AUBAGIO are low enough. If you become pregnant while taking AUBAGIO or within 2 years after you stop taking it, tell your doctor right away.

- **AUBAGIO Pregnancy Registry:** If you become pregnant while taking AUBAGIO or during the 2 years after you stop taking AUBAGIO, talk to your doctor about enrolling in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2. The purpose of this registry is to collect information about your health and your baby’s health.

- **For men taking AUBAGIO:**
  - If your female partner plans to become pregnant, you should stop taking AUBAGIO and ask your doctor how to quickly lower the levels of AUBAGIO in your blood.
  - If your female partner does not plan to become pregnant, you and your female partner should use effective birth control during your treatment with AUBAGIO. AUBAGIO remains in your blood after you stop taking it, so continue using effective birth control until AUBAGIO blood levels have been checked and they are low enough.

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

What is AUBAGIO?

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

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

Who should not take AUBAGIO?

Do not take AUBAGIO if you:

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

What should I tell my doctor before taking AUBAGIO?

Before you take AUBAGIO, tell your doctor if you:

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

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal supplements. Using AUBAGIO and other medicines may affect each other causing serious side effects. AUBAGIO may affect the way other medicines work, and other medicines may affect how AUBAGIO works. Especially tell your doctor if you take medicines that could raise your chance of getting infections, including medicines used to treat cancer or to control your immune system.

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

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

How should I take AUBAGIO?

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

What are possible side effects of AUBAGIO?

AUBAGIO may cause serious side effects, including:

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

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

- Allergic reactions, including serious skin problems. Tell your doctor if you have difficulty breathing, itching, swelling on any part of your body including in your lips, eyes, throat or tongue, or any skin problems such as rash or redness and peeling.
- new or worsening breathing problems. Tell your doctor if you have shortness of breath or coughing with or without fever.

- high blood pressure. Your doctor should check your blood pressure before you start taking AUBAGIO and while you are taking AUBAGIO.

The most common side effects of AUBAGIO include:

- headache
- diarrhea
• nausea
• hair thinning or loss (alopecia)
• increases in the results of blood tests to check your liver function
Tell your doctor if you have any side effect that bothers you or that does not go away.
These are not all the possible side effects of AUBAGIO. For more information, ask your doctor or pharmacist.
Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-332-1088.

How should I store AUBAGIO?
• Store AUBAGIO at room temperature between 68°F to 77°F (20°C to 25°C).
• Keep AUBAGIO and all medicines out of reach of children.

General information about the safe and effective use of AUBAGIO.
Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AUBAGIO for a condition for which it was not prescribed. Do not give AUBAGIO to other people, even if they have the same symptoms you have. It may harm them.
This Medication Guide summarizes the most important information about AUBAGIO. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about AUBAGIO that is written for healthcare professionals.
For more information, go to www.aubagio.com or call Genzyme Medical Information Services at 1-800-745-4447, option 2.

What are the ingredients in AUBAGIO?
Active ingredient: teriflunomide
Inactive ingredients in 7 mg and 14 mg tablets: lactose monohydrate, corn starch, hydroxypropyl cellulose, microcrystalline cellulose, sodium starch glycolate, magnesium stearate, hypromellose, titanium dioxide, talc, polyethylene glycol and indigo carmine aluminum lake.
In addition, the 7 mg tablets also contain iron oxide yellow.
This Medication Guide has been approved by the U.S. Food and Drug Administration.

Genzyme Corporation
Cambridge, MA 02142
A SANOFI COMPANY

Revised: September 2019
TER-MG-SL-SEP19
MS is an isolating disease.

I focus on sharing a laugh.

Damian

Hear Damian’s story at nationalMSsociety.org/damian
From Zoom to FaceTime, there are plenty of ways to stay in touch virtually with friends and family when getting together in person might not be ideal or easy. Whether you’re facing inclement weather, a new diagnosis (page 28), or mobility challenges (wheelchair transition tips on page 22), here are some ways to make the most of your video chats.

- **Do a fun activity together.** Is there an interest you share with your friends or family members? Plan an activity around it. Are you amateur chefs? Cook and eat a meal together. Avid readers? Get together for a virtual book club. In need of some exercise? Follow a fitness video together, such as Zumba or light yoga.

- **Show up in style.** Put on the silliest hat or tie you own, most extravagant gown or that costume you still have from last Halloween. These fashion statements will surely bring some laughs, and maybe a story or two.

- **Play a game.** Break out a multiplayer card or board game or play a video game together via online play. There are also plenty of gaming resources online, from BINGO cards to trivia questions, so don’t worry if not everyone owns the same game. Or, create your own game of charades by writing down prompts and sharing them.
Everyday should have been fine.

It was late in the afternoon, the end of the day at the medical facility where I had undergone diagnostic breathing tests. I was recovering from aspiration pneumonia courtesy of my multiple sclerosis-weakened respiratory system.

With my tests completed, my wife, Michelle, and I boarded an empty elevator.

Large medical facilities often mean parking garages, long hallways and lots of walking — walking I could no longer do, even with a rollator and multiple rests.

Today, we’d decided to incorporate my new wheelchair into the trip. Though getting in and out of the men’s room took some doing, it worked out pretty well and reinforced my decision not just to use the chair that day but to get it in the first place.

We boarded the elevator, turned around to face the door and pushed the button for the first floor. Then we moved back a couple of feet and waited for other passengers to get on.

We hadn’t noticed another door behind us until it opened, and people began filing in. We turned to face...
Roll with it
the “correct” entry, with all those people now crowded into a packed elevator standing in front of us. Michelle stared at the backs of a bunch of heads and necks. Me? I had a different view. I was sitting in my chair “cheek to cheek” with my fellow passengers. And while the elevator hadn’t yet moved an inch, I had clearly reached the “bottom” floor.

Life is different in a wheelchair. From opening doors to navigating bathroom stalls to transporting the chair to and from your destination, it can be challenging, chaotic and frustrating. The unpredictability of MS and its symptoms only adds to that mix. On top of that, there’s all the emotional baggage that comes with it.

A wheelchair can get you from point A to point B a lot easier, which means less energy spent on the journey and more spent enjoying the destination, even if it’s simply going to the kitchen to grab a snack before settling in for a Netflix binge. You don’t have to worry about tripping and falling and the awkward, tension-filled drama that accompanies your every step with a cane or walker. And, like much of life itself, it gets a little easier with experience.

As with all things MS, getting the right chair for your needs, and learning how to live in — and with — it requires time, energy and patience. I asked mobility experts and MS-wheelchair users for insights, tricks, tips and advice that can help get you rolling faster and easier.

Chair today, tool tomorrow
The decision to transition to a wheelchair can be an emotional one. It a milestone that marks the loss of a core function as well as the challenge of learning to live life forever strapped into a piece of equipment that announces your disability wherever you go. It also represents a piece of ground forever lost to MS — a disease bent on painting those who have it into ever-smaller corners.

Justin Kimrey is a mobility and seating specialist at Stalls Medical in North Carolina. He is also a certified assistive technology professional (ATP) who analyzes the needs of customers with disabilities, helps them select the appropriate technology for their needs and then trains them in how to use their devices. Kimrey says emotional turmoil often hinders our acceptance of transitioning into a chair and influences our decision-making later in the process, too.

Kimrey, who began using a wheelchair after an automobile accident left him unable to walk, says there’s a somewhat definable path users with MS take to a wheelchair. First, the cane-walker-rollator combo stops working for them. They frequently choose a scooter next, not because it’s the best choice for their mobility needs, but because it’s easier for them to accept.

Kimrey says many of his customers have MS. “They prefer to be in a scooter because it’s less ‘visually’ disabling in our society,” he says. Consequently, they
often choose a manual chair
over a power chair, and also
because it doesn’t require
a conversion van to haul it
around and because they can
get some exercise by pushing
themselves in it.

Rick Ebner followed much of
that path himself. Diagnosed
with MS in 1995, the 57-year-
old is a former Division
II collegiate athlete and
traveling salesman from the
Bloomington, Minnesota, area
and is now on Social Security
Disability Insurance. A broken
arm suffered while using a cane
convinced him to try a scooter.
The decision was not without
its costs. “I had a lot of holes
in the doors and the walls,” he
says. “There’s a learning curve
with this whole thing.”

A driver’s assessment gone
wrong sped his transition to a
power chair. “I was driving [for
the assessment],” he says. “I
was lifting my right leg [with
my hand] from the gas to the
brake, and as soon as he [the
assessor] saw me do that, he
said, ‘You’re done.’”

“I started crying,” Ebner says.
“My independence was now
being threatened. It brought
tears to my eyes.”

It got harder. Affable by nature,
Ebner began losing his temper
with his daughters, something
he rarely did. He decided to
make an appointment with a
therapist for help.

“I remember going in to
meet with [the therapist], and
I remember the chair was by
her desk, but I specifically
remember seeing a box of
Kleenex and I’m thinking to
myself, ‘What is that there for?’”
he says. “And by the end of my
meeting, I was using that box
of Kleenex. She told me I was
almost clinically depressed. I had
no idea.”

Ebner was prescribed an
antidepressant that “took
the edge off and made a big
difference in my outlook.”

Ebner works out regularly on
adaptive exercise equipment
at the Courage Kenny
Rehabilitation Institute in
nearby Golden Valley. Sharing
his story with friends at the
Institute, he learned more
about power chairs, adaptive
hand controls that might make
it possible for him to drive
again, and about conversion
vans he could wheel right into
and … go.

See and be seen

Ebner decided to get a power
chair. While being measured
for it, he began to see things
differently. “The people that
were fitting me to the chair
told me, ‘Rick, now people can
see you. It’s all you. It’s not the
steering column in front of your
scooter. They see you,’” he says.

“And I never thought about that.
That helped me in my mindset.
That gave me hope.”

Not long after he received his
chair, Ebner began volunteering
at a senior home. “I needed to
stop focusing on myself and to
give back and to serve others,” he
says. “And that’s what I did, and
that’s what helped me climb out
of it. Today, Ebner credits his
power chair for getting him “back
in the game.”

Alicia Vanek, an occupational
therapist at the Fairview
Achievement Center in St. Paul,
Minnesota, says much of her job
is educating patients about what
a wheelchair can do for them
and findings ways to incorporate
it into their lives.

“My job is to help people realize
that a wheelchair is another tool
in their life that can increase
independence versus increasing
disability,” she says. “A lot of
people see a wheelchair as
increasing their disability or that
it looks bad,” Vanek notes. “A lot
of it honestly is that education
piece and trying to just get
people open to the idea of a
wheelchair and what it could do
for them.”

Chair-curious but not sure
where to turn? Chances are
good your neurologist, physiatrist,
primary care physician or
physical therapist has noticed
your diminishing abilities.

Ask for help. You may be able
to find an assistive technology
resource near you that will
let you test drive a wheelchair
before buying one.

Some home health equipment
companies rent them. You might
know someone who has a chair
you can try, or talk to about their
life in a wheelchair. Getting
a wheelchair may be a tough
decision to make, but it’s an
important one.
Choose your seat wisely

Your healthcare insurance policy likely covers some of the cost of a new wheelchair. Check with your provider to learn more. You will need a physician’s order documenting what type of chair you need to receive coverage. Though that order typically comes from your neurologist or physiatrist, your primary care physician can write one, too. Your physical therapist may help your physician write the order for a wheelchair before it’s submitted to your seating specialist.

But choosing the type of chair you want can get tricky, warns Meredith Linden, a clinical specialist at the International Center for Spinal Cord Injury at Kennedy Krieger Institute in Baltimore, Maryland. She understands some people’s reluctance to choose a power chair due to social stigma.

Many insurance programs, including Medicare and Medicaid, she says, will only pay for a new chair every five to seven years — unless your diagnosis changes. So, choosing a manual chair for appearances’ sake may come back to haunt you should you need the benefits of a power chair before five years has passed. Kimrey says a typical power chair costs about $30,000 without insurance.

Though a manual wheelchair may be easier to embrace emotionally, a power chair may be a better long-term option, especially for people with MS battling fatigue and upper-body weakness, Linden says. However, that’s often not what people want to hear. “It’s tough for them to admit that they need to make the transition,” Linden says. “And then to see the big picture from an insurance perspective and get the power chair is a challenging process and decision for them.”

The best seat in the house

Almost as important as getting your chair is making sure your home will accommodate it. From ensuring doorways are wide enough to installing grab bars where needed to identifying potential trouble spots — steps, room dividers, accessing closets, etc. — they all play a role in everyday life in a wheelchair.

It is a potentially long list. Arranging for a home visit from an occupational therapist or your seating specialist can help (though your seating specialist may also offer to sell home aid products to you). If you know someone in a wheelchair, you might consider asking that person for help, too.
Or you can be like Mary Lamont and take matters into your own hands. Diagnosed with MS in 1981, Lamont lives near Fort Lauderdale, Florida, and has used a power chair for the past 20 years. Though she was offered a package of lessons when she received her first chair, she did the unthinkable and read the manuals that came with it instead.

Today she knows where everything in her home belongs. Or doesn’t. “All the furniture in my house, there is a certain place where I have room to get by the chair, or past the couch or TV or something,” Lamont says. “I have it all situated where it’s not in the way.” She has also had three doorways widened, and she plans to have three doors removed, too.

Even with all the modifications, Lamont says using her chair remains a work in progress. “I’m still running into walls, and it’s hard going around some corners in the house, but I’m doing the best I can,” she says. She offers this piece of advice to new users: “They should not be discouraged when they get the wheelchair, because it can be very, very frustrating. You think, ‘I’ll never be able to master this chair, it’s hopeless.’ But you find that as you use it, within a few weeks, it’s just routine.”

**Oh, the places you’ll go!**

Before you hit the open sidewalk, path or mall, it’s essential to understand that using a wheelchair of any type isn’t without its challenges. There are plenty of ways you can learn how to use your chair, including clinics and lessons at facilities like those where Vanek and Linden work and that Ebner attends. Linden recommends that if possible, new users should try to find such a place. (Search keywords “neurorehabilitation clinic/institute” or “adaptive/assistive technology clinic/institute.”) Your doctors and therapists may be able to help, and your seating specialist may offer training lessons, though there may be a fee.

No matter who is giving you the lesson, if there are specific activities you need help with, such as getting...
in and out of the restroom, opening doors to that restroom, getting over curbs, or taking mass transit, don’t just settle for practice in the clinic. Take a trip to a reasonably quiet coffee shop together and practice; real-world situations and conditions are always harder.

There are several videos on YouTube that you also might find helpful. Or you can do as Ebner did. Before he took his power chair with him and his family on vacation in early 2020, he asked other wheelchair users for advice.

“I talked to other people at Courage who travel and they’re in chairs,” Ebner says. “They traveled everywhere, and they came over to my house, and we talked about it. So I got the inside scoop on what I should do.” Besides learning to let airlines know about his disability and power chair when purchasing his tickets, his friends also explained how to best tag and prepare his chair to minimize damage to it during flights.

Vanek recommends trying online resources if you don’t have access to other wheelchair users in person. (See links at the end of this article.)

Calvin Stroud turned to his twin brother, Alvin, for help. Alvin, who also has MS and uses a power chair, was diagnosed a few years earlier than Calvin, who was diagnosed in 1999. His brother’s MS has been more aggressive, which gave Calvin a sense of what might be on his horizon. “I kind of had a built-in roadmap, because I was able to go off of my brother’s experiences,” he says.

Using his power chair, Stroud can reach kitchen counters and pots and pans, which lets him do some cooking, and though the sidewalks aren’t in the best shape in his neighborhood, he’s able to navigate them while walking his beagle terrier, Simpson. Like Ebner, he purchased a conversion van and still drives. Stroud and his wife, Kim, are also fans of portable ramps, installing a series of them around their Washington, D.C., area home so he can go in and out and roll onto their deck.

They’ve learned to call ahead before going out to ensure their destination is accessible and to carry extra ramps with them — just in case. “You never know how accessible places are,” Stroud says. “You ask them if their restaurant is accessible and they say it is, but then there’s a two-inch, three-inch step up that you have to navigate somehow,” he says.

Like Stroud, I’ve learned contacting the venue ahead of time is critical to minimizing frustration, which makes everything so much more fun. But there’s more to it than that. My wife and I love music, and we tend to enjoy bands that play smaller venues. We also like to dine out at independent, locally owned restaurants that are often in older urban locations. All are often barely accessible.

I’ve taken to emailing ahead, explaining my needs, and I can tell everyone is eager to help. I ask if there is a table that I can roll right up to in my chair. There always is, and everyone who helps us is always wearing the biggest smile — just like we are.

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

What it’s like when you’re first diagnosed with MS.

by Vicky Uhland

On the surface, Jennifer Ellinger, Bob Hermanson, Emily Reilly and Nicole White don’t have much in common. They are different ages, genders and ethnicities. They live thousands of miles apart and have diverse lifestyles.

What they do have in common is their multiple sclerosis diagnosis. And whether that diagnosis was more than a decade ago, in Ellinger’s and Reilly’s cases, or fewer than two years ago, in White’s and Hermanson’s cases, they all vividly recall what it was like their first year of living with MS.

They remember how they felt physically, emotionally and mentally. They remember the confusion and fear and depression. They remember when they finally realized that they had MS, but MS didn’t have them.

“When I made it to the one-year mark, and I got my MRI results back and everything was stable, I thought, ‘Wow, I think I’ve got it. I think I’ve got control of this,”’ Ellinger says.

People living with MS, healthcare professionals and support teams agree that the first year after an MS diagnosis can be one of the most challenging. Adjusting to the “new normal” of living with a chronic disease varies from person to person, but there are some concerns that tend to be universal.
Nicole White, diagnosed with MS in 2019, connected with others with MS on social media.

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MS specialists and people living with MS identified the most common questions people ask in their first year after diagnosis. Although they approached the issues from different perspectives, they agreed on many things as well. Here’s their advice for people grappling with a new MS diagnosis.

“I relate to sunflowers because they are big, strong and independent. They do their part to make the world brighter and then they go inward and close to rejuvenate, repair and restore (while still standing) to only then open up again bursting with color and excitement.”

— Nicole White
People living with MS
Jennifer Ellinger, 46, diagnosed with MS in 2009, Huntsville, Alabama
Bob Hermanson, 46, diagnosed with MS in 2018, Boulder, Colorado
Emily Reilly, 32, diagnosed with MS in 2005, Alexandria, Virginia
Nicole White, 43, diagnosed with MS in 2019, Chicago

MS healthcare specialists
Luydmila Jovine, licensed clinical social worker and psychotherapist who specializes in chronic illness, New York
Jacqueline Nicholas, MD, OhioHealth System Medical Chief of Multiple Sclerosis and Neuroimmunology, Columbus, Ohio
Susan Stuart, nurse practitioner and nursing director, Georgetown Multiple Sclerosis and Neuroimmunology Patient-Centered Specialty Practice, Georgetown University Hospital Department of Neurology, Washington, D.C.

National Multiple Sclerosis Society
Chrissie Griffin, MS navigator and licensed clinical social worker, Raleigh, North Carolina
Steven Nissen, director, MS Navigator Services Delivery, Washington, D.C.

How do I get the best information about my disease? Should I just Google “multiple sclerosis?”

Google is a great way to find reputable resources, such as the National MS Society. However, don’t rely solely on “Dr. Google” for diagnosis or prognosis of your disease.

Hermanson: “I admit I spent too much time on Google after I was diagnosed. There’s just so much gibberish. People were talking about their own experiences that may or may not have anything to do with me.”

Hermanson said he found some valuable, science-based information by doing searches on phrases like “cell depletion” and Rituximab, the disease-modifying therapy (DMT) he takes.

Griffin: Call the Society to speak to an MS Navigator like herself and connect via live chat, email, social media or through the Society website (nationalMSsociety.org).

“Newly diagnosed calls are my favorite because I’m able to provide people with the information and materials when they have the most impact. We have so much information to give and can tailor it to their individual needs.”

The Society also offers a wide variety of information and resources, including how to find local support groups, on its website.

Nicholas, MD: Make a list of questions for your healthcare providers. “Some patients don’t want to feel overwhelmed with too much information on the internet and the challenges of knowing what is accurate, so they prefer to get information on MS when they visit their neurologists/MS doctors. That’s appropriate, too.”

Bob Hermanson, diagnosed with MS in 2018, discussed disease-modifying therapies (DMT) with his doctor and opted for infusions.
**Nicholas:** “If you don’t feel you are getting the best care or answers to your questions, patients shouldn’t be afraid to get a second opinion for MS care.”

It’s important to feel comfortable with your providers, including their level of experience and bedside manner.

She recommends visiting a specialized MS center if one is convenient for you. These centers, which are usually offered through university hospitals or large healthcare systems, have MS fellowship-trained neurologists, physical therapists, urologists, psychologists, social workers and other clinicians trained in MS.

“Not all neurologists are familiar with these centers, so you may need to suggest it,” Nicholas says.

Another option is to consult with an MS specialist. Doctors at specialized centers have completed a four-year medical residency in neurology, and then an MS and neuroimmunology fellowship that lasts between one to three years. Ask your neurologist if there’s an MS specialist near you. If there isn’t, one option is to travel to visit a specialist annually or communicate through telemedicine.

**Ellinger:** She learned about MS when she was studying to be a registered nurse in the mid-1990s. “The picture of MS at that time was bleak. That was before DMTs, and it was almost labeled a death sentence. I had a lot of fear when I learned I had MS.”

Ellinger countered that fear by doing research. She looked at the MS Society website, analyzed statistics and figures on disease progression, and learned about the various MS medications.

“I was looking for a flowchart — your MS is going to go to this, then this, then this. I wanted to be able to look at somebody with MS and say: ‘I’m going to be just like that.’ I found that no two of us are alike.”

**Jovine:** “Every time the feet are numb, the migraine won’t go away, the vision is blurred, the thought is always creeping in that ‘this is it. Here’s that moment. I thought I was doing well, but it’s just a matter of when.’ We are primed to prioritize the negatives of life as a survival tactic. So it’s crucial to check in with yourself as often as possible and see if your beliefs about the future are accurate. Catastrophizing is a barrier to healthy living as opposed to a resource.”

**Disease progression** is one of the most common topics people ask about when they call an MS Navigator.

**Griffin:** “They have gone to Google, and they have read about people being in wheelchairs within six months after their diagnosis. I always tell them that people can live long, happy lives with MS.”

When Jennifer Ellinger was diagnosed with MS in 2009, she tried to learn all that she could by researching the disease.
Hermanson: His mother was diagnosed with MS when he was in fourth grade, and now, three decades later, she's in hospice care. As a former physiology and anatomy instructor at the University of Colorado, he's done plenty of research into his mother's disease. “I always told myself MS wasn't hereditary, so there's no way I would get it.” When his right arm went numb, he ignored it. When he had balance issues, he blamed it on getting older. But the symptoms persisted, and he finally had a brain MRI. “When I was told I had a demyelinating disease of the CNS (central nervous system) and 30 active lesions, my [jaw] just dropped.” But after quizzing his doctor about DMTs, he learned that the drugs could make his prognosis much better than his mother's. He opted for Rituximab. “When I got my first MRI after my first infusion, it showed that I had no more active lesions. I was encouraged that maybe we can just hold it here.”

Nicholas: One of the keys to MS care is not to delay treatment. “When somebody is newly diagnosed, research shows that treating the disease effectively early has the greatest impact on how you will do throughout your life with MS. DMTs are an investment to protect your physical and cognitive health in the long term.”

It’s common for people who are newly diagnosed not to want to take a DMT. Often, they’re worried about the potential side effects, risks or insurance coverage. The key to choosing a DMT is identifying one that will be effective enough for your MS and that fits into your lifestyle. “I work with patients to find out what DMT options we believe will be effective for them and then to select one that they feel comfortable taking and one that is an acceptable mode of administration for them. Sometimes, insurers will ask us to use an alternative DMT first, but often with appropriate documentation, we can get the DMT that both we as the MS specialist and the patient feel is the best approved.”

But DMT approval is not an exact science, and sometimes she has to appeal an insurer's decision. “This is where it’s important to have a physician who’s invested in fighting for what their patients need.”

Nissen: With many DMTs costing tens of thousands of dollars a year, financial considerations are a top concern. “MS Navigators get many calls from people concerned about copays. They may be embarrassed to talk to their doctor about it or feel uncomfortable reaching out for help.”

For people who have private health insurance, pharmaceutical companies have patient-assistant programs that may help with drug costs. For those on government insurance, such as Medicare, some nonprofits may offer assistance with DMTs, but they can quickly run out of funds. MS Navigators can provide referrals to programs that might be available.
How do I find support groups or individuals? Whom should I talk to about my disease?

White: As an African-American, she had particular trouble finding support groups in the months after her diagnosis, and that contributed to her fear and depression.

“The one person I knew who had MS died from it at an early age. I could not find representation of anyone who looked like me who battled with MS. Where was the group for people who are 42, professional and African-American?”

White loathed asking for help. “I was independent to a fault. I had to exercise my ability to be vulnerable with my family and friends. This is not a disease you want to manage by yourself. I had to understand that allowing your loved ones to help and support you makes you more able to do the things you want and need to do. Support is a lifeline.”

A friend who researched support groups and resources on her behalf reached out to White. While the resources were helpful, White longed for building a connection with a support group. Eight months into her diagnosis, White joined the Facebook group We Are ILLmatic, an African-American support group for MS warriors.

Hermanson: He found some useful Facebook groups that suit his irreverent approach to the disease, including “The MS-kateers: A Band of MiSfit MSers.”

Other options include groups and support offered through MS organizations like the National MS Society, the Multiple Sclerosis Foundation (msfocus.org) and the MS Association of America (mymsaa.org).

Stuart: When deciding to join a support group, it is important to choose a group that will meet your needs, whether you are newly diagnosed, have had MS for years, or if you experience some level of disability. “Some people need time to accept and understand their diagnosis and MS treatment.”

Jovine: The way you tend to cope with life, in general, is how you will approach dealing with and communicating about your diagnosis. “The last time you had a cold, what was that like? Did you lock the door, go under the sheets and stay there; did you take a lot of medicine and go to work, or did you ask people to take care of you? Do you reach out to everyone you know when you’ve lost a job, a relationship or a pet? Or do you get stronger by going inward?”

It’s important to honor your communication style. But at the same time, if you have trouble accepting help, you might need to work on that and accept that some things will simply be beyond your ability due to your disease.

“As you discover what works for you and your MS, share that with people close to you. People think that others will just intuit what they need, but that’s not the case. It’s helpful to have another perspective to see the big picture, to invite other opinions and thoughts. Maybe with some support and resources, the burden can be lightened.”
Thrive

Q Should I quit my job? Should I tell my employer I have MS?

Nissen: “Sometimes (with people who are newly diagnosed) their healthcare provider or their loved ones say: ‘You’re going through so much stress, you should just quit your job and go on disability.’”

Nissen generally encourages newly diagnosed people to “breathe and take a step back. Don’t make rash decisions without thinking about the long-term consequences. In addition to a paycheck, there are benefits to working, including contributing to society and having positive self-worth.”

Of course, not everyone can continue their job or perform it as they did before their MS diagnosis. MS Navigators help people understand their legal rights and responsibilities that apply to employment, including disclosure and accommodations that can be requested under the Americans with Disabilities Act (ADA).

Jovine: There are psychological issues that may need to be addressed as well. “Ask yourself, ‘Is it time to start thinking about your job right now? Are you making a decision based on fear?’”

Q How do I handle the mental and emotional aspects of my disease?

White: For eight to 10 years before her MS diagnosis in February 2019, she suffered from chest tightness, numbness in her legs for weeks at a time, paralysis in her face and optic neuritis.

“Over and over, I was told that the reason I was having all of these issues was that I was obese.”

Another reason was that she is Black. “No one ever talked to me about MS being a possibility, not even the neurosurgeon. I was never tested for it, and it was never considered. So, when I got diagnosed with MS, I had no reference or preparation, and I thought my life was over. I went into a severe depression. I had no clue about MS, and I didn’t want to fight. I felt that if God gave it to me, then this is what I’m supposed to have.”

As an elementary school principal, White is dedicated to serving others. “I had nurtured a life where people depended on me for support, and I was very concerned about being less-abled because of my MS. I thought: ‘How can I serve people if I can’t even serve myself?’”

It took White five months to admit to her doctor that she was depressed and to begin medications for depression. But it wasn’t until she had a relapse in October 2019 that sent her to the hospital for 15 days that she addressed her other thoughts and feelings. “I finally understood that I was heartbroken and that I needed to mourn the life I had lost.”

In rehab after her hospital stay, White began physical, psychological, occupation, vocational and speech therapy. “I had thought, ‘I don’t need to go to therapy. I’m not that sick.’ But all those forms of therapy changed my life. It got me to realize I can manage this disease, that I have some control over this thing.”

Jovine: For people who aren’t used to self-reflection, “take note of the natural resources in your life: family, a dear friend, a good neighbor, a pet, a beautiful garden, a houseplant, a great song or painting, a book that really speaks to you.”

Yoga and Pilates are good self-reflective options for people who prefer more active pursuits. She also recommends journaling, including writing down your symptoms throughout the day. “Then you can look back and see patterns. It creates a grounding experience, helps you feel more empowered and gives a little bit of predictability.”
How can I live well with MS and manage the disease, so it doesn’t become my sole identity?

Reilly: She was 17 years old when she was diagnosed with MS, only a month after she had signed a scholarship to play soccer at Dallas Baptist University. “When my parents came to me with the results of my MRI, I experienced all of these emotions all at once — fear, anger, frustration, denial. I was so afraid that my MS would keep me from accomplishing things in life — playing soccer, finding a husband, having kids. To accept the fact that there’s not a cure for what I have was hard.”

She learned how to manage her disease with a combination of knowledge and faith. She visited an MS specialist in Arizona who helped her take ownership of her diagnosis and be an active participant in her treatment. With the combination of having a teammate with MS and a coach who was willing to learn and help modify her training to accommodate her MS, Reilly was able to learn how to listen to her body and manage her energy levels. Reilly learned those lessons so well that she became an All-American goalkeeper at Dallas Baptist.

“Faith also played a huge part in my journey. I’ve learned to be grateful for the little things, to give myself a lot of grace, keep moving and celebrate the little victories.”

Diet, exercise, stress management and self-care are all part of managing MS as well. Resources are available on the Society website.

Jovine: MS as an unwanted partner you need to figure out how to live with.

“It’s important to become more curious and aware of your habits, and that might help with managing and mastering this unwelcome intrusion that is MS. Give yourself a year to know your MS and what it means in your life.”

Find resources and information about MS on the National MS Society website at nationalMSSociety.org.

Contact an MS Navigator by calling 1-800-344-4867, emailing ContactUsNMSS@nmss.org, or visiting nationalMSSociety.org/navigator.

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

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

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

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

Call your healthcare provider right away if you have any of these symptoms of an infection during treatment with ZEPOSIA and for 3 months after your last dose of ZEPOSIA:
• fever
• feeling very tired
• flu-like symptoms
• cough
• painful and frequent urination (signs of a urinary tract infection)
• rash

People had fewer relapses with ZEPOSIA

In a one-year study:
People who took ZEPOSIA had 48% fewer relapses than those who took a leading injectable medicine (Avonex).**

In a separate two-year study:
People who took ZEPOSIA had 38% fewer relapses than those who took a leading injectable.†

See additional study results at ZEPOSIA.com/results

*Avonex (interferon beta-1a).
†One-year study: People taking ZEPOSIA had an Annualized Relapse Rate (ARR) of 0.181 vs 0.350 with a leading injectable. A total of 895 people were studied (ZEPOSIA 447, a leading injectable 448). Two-year study: 0.172 ARR with ZEPOSIA vs 0.276 with a leading injectable. A total of 874 people were studied (ZEPOSIA 433, a leading injectable 441).

TAKE A LOOK
at a once-daily pill for MS
ZEPOSIA may cause serious side effects, including (cont’d):
- headache with fever, neck stiffness, sensitivity to light, nausea, or confusion (symptoms of meningitis, an infection of the lining around your brain and spine)
- slow heart rate (also known as bradyarrhythmia) when breathing problems.
- allergic reactions.
- a problem with your vision called macular edema.
- decreased vision.
- shortness of breath.
- confusion.
- chest pain.
- tiredness.

Call your healthcare provider if you experience the following symptoms of slow heart rate:
- dizziness.
- lightheadedness.
- feeling like your heart is beating slowly or skipping beats.

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

Continue reading for additional possible serious side effects of ZEPOSIA.

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

Tell your healthcare provider about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Using ZEPOSIA with other medicines can cause serious side effects. Especially tell your healthcare provider if you take or have taken:
- medicines that affect your immune system, such as alemtuzumab.
- medicines to control your heart rhythm (antiarrhythmics) or heartbeats.
- strong CYP2C8 inhibitors such as gemfibrozil or clopidogrel.
- medicines that inhibit breast cancer resistance protein transporters, such as cyclosporine and etrombopag.
- CYP2C8 inducers such as rifampin.
- opioids (pain medicine), medicines to treat depression, and medicines to treat Parkinson’s disease.

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

ZEPOSIA can cause serious side effects, including:
- liver problems. Your healthcare provider will do blood tests to check your liver before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
  - unexplained nausea
  - vomiting
  - stomach area (abdominal) pain
  - tiredness
  - loss of appetite
  - yellowing of the whites of your eyes or skin
  - dark-colored urine

- increased blood pressure. Your healthcare provider should check your blood pressure during treatment with ZEPOSIA. A sudden, severe increase in blood pressure (hypertensive crisis) can happen when you eat certain foods that contain high levels of tyramine.

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

- a problem with your vision called macular edema. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis. Your healthcare provider should test your vision before you start taking ZEPOSIA if you are at higher risk for macular edema or any time you notice vision changes during treatment with ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
  - blurriness or shadows in the center of your vision.
  - sensitivity to light.
  - a blind spot in the center of your vision.
  - unusually colored vision.

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

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

- allergic reactions. Call your healthcare provider if you have symptoms of an allergic reaction, including a rash, itchiness, or swelling of the lips, tongue, or face.

The most common side effects of ZEPOSIA can include:
- upper respiratory tract infections
- elevated liver enzymes
- low blood pressure when you stand up (orthostatic hypotension)
- painful and frequent urination (signs of urinary tract infection)
- back pain
- high blood pressure

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

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

Please see the Important Facts on the next page.
What is the most important information I should know about ZEPOSIA (ozanimod)?

ZEPOSIA may cause serious side effects, including:

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

2. Slow heart rate (also known as bradycardia/bradynhythmia) when you start taking ZEPOSIA. ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days that you take ZEPOSIA. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heart rate:
   - dizziness
   - lightheadedness
   - feeling like your heart is beating slowly or skipping beats

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

What is ZEPOSIA?

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

• It is not known if ZEPOSIA is safe and effective in children.

Do not take ZEPOSIA if:

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

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

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

• have a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.
• received a vaccine in the past 30 days or are scheduled to receive a vaccine. ZEPOSIA may cause vaccines to be less effective.

• Before you start treatment with ZEPOSIA, your healthcare provider may give you a chicken pox (Varicella Zoster Virus) vaccine if you have not had one before.

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

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

• medicines that affect your immune system, such as alentuzumab
• medicines to control your heart rhythm (antiarrhythmics), or heart block.
• strong CYP2C8 inhibitors such as gemfibrozil or clopidogrel
• medicines that inhibit breast cancer resistance protein transporters, such as cyclosporine and etrolodipine
• CYP2C8 inducers such as rifampicin
• opioids (pain medicine)
• medicines to treat depression
• medicines to treat Parkinson’s disease

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

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

How should I take ZEPOSIA?

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

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

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

ZEPOSIA can cause serious side effects, including:

• See “What is the most important information I should know about ZEPOSIA?”
• liver problems. ZEPOSIA may cause liver problems. Your healthcare provider will do blood tests to check your liver before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
  - unexplained nausea
  - loss of appetite
  - vomiting
  - yellowing of the whites of your eyes or skin
  - fatigue
  - liver problems

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

• breathing problems. People who take ZEPOSIA have shown signs of breathing problems. Your healthcare provider should test your vision before you start taking ZEPOSIA if you are at higher risk for macular edema or at any time you notice vision changes during treatment with ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
  - blurriness or shadows in the vision
  - sensitivity to light
  - unusually colored vision
  - swelling and narrowing of blood vessels in your brain.

A condition called PRES (Posterior Reversible Encephalopathy Syndrome) is a rare condition that has happened with ZEPOSIA and both drugs in the same class. Symptoms of PRES usually get better when you stop taking ZEPOSIA. If left untreated, it may lead to a stroke. Your healthcare provider will do a test if you have any symptoms of PRES. Call your healthcare provider right away if you have any of the following symptoms:
  - sudden headache
  - sudden loss of vision or other sensations
  - confusion changes in your vision
  - seizure

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

• allergic reactions. Call your healthcare provider if you have any of these symptoms, including a rash, itchy hives, or swelling of the lips, tongue or face.

The most common side effects of ZEPOSIA can include:

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

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

General information about the safe and effective use of ZEPOSIA. Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use ZEPOSIA for conditions for which it was not prescribed. Call your healthcare provider or other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for information about ZEPOSIA that is written for health professionals. For more information, call 1-833-ZEPOSA (1-833-937-6424) or go to ZEPOSA.com. 

Manufactured for: Celgene Corporation, Summit, NJ 07901 
Patent: www.celgene.com/therapies
The National MS Society’s PROFESSIONAL RESOURCE CENTER

- **Healthcare professional webinars** — provided by leading MS clinicians and researchers on topics ranging from COVID-19 to MS biomarkers
- **COViMS** — a North American registry for providers to enter cases of people with MS and COVID-19
- **ECHO-MS** — a telelearning initiative to improve expertise through facilitated case-based learning

**Must-have Resources for Healthcare Professionals:**

- **Updated MS App for Healthcare Providers:** MS diagnosis, disease and symptom management tools. Search “Multiple Sclerosis Dx & Mgmt.” in the app store
- **MS Coalition Consensus on Disease-Modifying Therapy:** nationalMSsociety.org/DMTconsensus

nationalMSsociety.org/PRC
WHAT IS MEDITATION?

Meditation is stilling your mind and quieting your thoughts — taking notice of them without being distracted by them. Practicing meditation regularly can benefit your mental and physical health by relieving stress and anxiety and increasing mindfulness as well as possibly reducing pain.

There is no one way to meditate. You can incorporate it into your yoga practice or other daily activities, such as walking, or you can practice guided meditation. Guided meditation is led by a teacher or narrator in person or via audio or video. They can help you focus on specific imagery, walk you through breathing exercises or suggest a mantra to repeat while you meditate. Try guided meditation if you're just getting started with a regular meditation practice.

To learn more about how mindfulness meditation can benefit people with MS, turn to page 42.
Atiba Blalark and his wife, Ingrid Vargas-Blalark, live in Chicago and practice meditation any chance they get. Atiba was diagnosed with MS in 2012.
By the time Sarah Hamilton, of Washington, Connecticut, was diagnosed with multiple sclerosis in 2002, she’d been practicing a type of mindfulness meditation for over a decade. And it was that training that kept her from freaking out. “I was able to see it as more of a revelation,” says Hamilton, a certified life coach. “I could breathe, take a step back, and not drown in the emotion, the fear, the trauma. I could stay tuned into what was actually going on at that time.”

Hamilton’s experience illustrates some of the potential benefits of mindfulness meditation now being explored for people living with MS. A recent pilot study of
people with MS, conducted at Ohio State University, compared the results of a four-week, mindfulness meditation-based attention training program with a type of cognitive training as well as a control group. The results are “very encouraging and could improve mood and cognition for people with MS,” says Ruchika Prakash, PhD, co-author of the study and Ohio State University associate professor of psychology. The National Multiple Sclerosis Society funded the research.

**What is mindfulness?**

According to John Kabat-Zinn, a pioneer in bringing mindfulness-based stress reduction to the mainstream, mindfulness involves “paying attention on purpose, without judgment, in the present moment and with a kind and compassionate awareness.”

For Prakash, that means cultivating focused attention. “Intention is really important,” she says. “When you focus on the present moment, sometimes it isn’t good — especially for people with MS who may be working with all sorts of limitations,” she says. It’s also essential to cultivate an attitude of acceptance, non-judgment and being patient with yourself. For example, if a doctor gives you bad news, and then your brain goes off imagining worst-case scenarios, you can
no longer focus. “With mindfulness training, you can say, ‘Yes, it’s bad news, but I need to hear what my neurologist is saying,’” Prakash says.

**Reasons for the study**
The inspiration for this study came from a casual conversation between Prakash and a person with MS about how fitness may improve processing speed for people with MS. “I was working with a woman in a wheelchair who didn’t feel she could take on an intense exercise regimen,” Prakash recalls. At the time, there were a lot of research studies coming out on mindfulness, showing promise for problems such as depression and anxiety, loneliness, inflammation, pain, lack of focus and negative moods. “Once I got my position at Ohio State, I wanted to study it more systematically,” she says, “so we started looking at mindfulness meditation and how it impacts cognitive and emotional health.”

Although symptoms can vary widely, many people with MS report emotional and cognitive difficulties, such as changes in memory and speed of thought processing. “People with MS may have a challenging time managing their emotions — 1 in 2 has some symptoms of anxiety and depression,” Prakash says. “Since emotional dysregulation — that is, patterns of emotional experience and expression that interfere with goal-directed behavior — underlies other psychiatric disorders, we wanted to identify a factor that could help people cope with both issues.”

Many people with MS also experience chronic pain, and emotional distress can compound it. “More often than not, when we experience a powerful sensation, we’re not feeling that sensation, but rather, we’re dwelling on the narrative about it,” Prakash explains. She cites the example of someone whose chronic pain was wrapped up in memories of a car accident. “He relived the trauma of the accident every time he had pain,” she says. “Once he was able to separate the pain from the narrative, he could manage it better.”

Mindfulness meditation has changed how Hamilton handles pain. “If I judge the pain to be bad, it’s worse,” she says. “Stripping out the emotional quality of the pain — the drama, the haranguing, the ‘woe is me’ — helps me get through it more easily.”

**The study**
For the study, researchers placed 61 people with MS into one of three groups: mindfulness training, adaptive cognitive training, or a control group that received no treatment until after the study. Both training groups met for two hours a week for four weeks and did an extra 40 minutes of practice at home on the other six days of the week.

The mindfulness training program involved cultivating breath awareness, engaging in mental “body scans,” a meditative practice designed to focus attention and sensory awareness of various body parts, and practicing sitting meditation, with an emphasis on thoughts, emotions and sensations.

The cognitive training program, done on a computer, involved:
- Training in processing speed (how fast you can respond to stimuli)
- Attention (ability to focus on what’s relevant to the task at hand and filter out what’s irrelevant)
- Executive function (higher-order skill that includes planning and multitasking, organizing)
- Working memory (involving the manipulation of information in the mind)
Participants filled out surveys at the beginning and end of the study asking them to rate their agreement with statements such as, “If I find myself in a chaotic situation, I can manage my emotions,” or “I experience my emotions as overwhelming and out of control.” They also did paper-and-pencil tasks assessing specific thinking skills.

**Results of the study**

After four weeks, participants in the mindfulness meditation group reported significant improvements in their ability to manage their negative emotions, compared to the other two groups.

They also reported marked improvements in processing speed — the time it takes to understand and react to information — compared to the other groups. “Processing speed or the ability to respond quickly to incoming information is one important domain impacted in people with MS,” Prakash says. “We were somewhat surprised but excited to see this training intervention that we thought would mostly impact emotion regulation also improve processing speed.”

Because it’s only a pilot study with 60 people, “we can’t say it will apply to everybody,” Prakash adds. “But the data is promising evidence that mindfulness training can help MS patients deal with their emotions more constructively and positively, and improve some elements of cognition.”

**Follow-up studies planned**

Prakash and her team are now testing ways to make the training more accessible. In the meantime, they have hosted mindfulness webinars and posted free instructional videos on a YouTube channel (bit.ly/MindBody_OSU).

“Anyone can use mindfulness — even people with limited mobility,” Prakash says, circling back to the whole reason she began the investigation.

A practice of just 15 to 20 minutes a day could change your life. “It’s the best gift I ever gave myself,” Hamilton says. “Just be patient because it doesn’t happen overnight.”

Aviva Patz is a writer in Montclair, New Jersey.

To find meditation resources, contact an MS Navigator by calling 1-800-344-4867, emailing ContactUsNMSS@nmss.org or visiting nationalMSsociety.org/navigator.

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

Halting
A new study has provided more insight into the damage to nerve cells that causes many symptoms of multiple sclerosis and has developed ways to identify therapies that could potentially halt the damage.

One of the hallmarks of MS progression is damage to nerve cells in the brain and spinal cord. Nerve cell injury causes a variety of symptoms such as numbness, tingling, difficulties walking, cognitive changes and other issues that affect overall quality of life as well as regular daily activities. While some nerve damage is caused by abnormal immune response that causes inflammation, with critical roles played by T and B immune cells, additional factors have also been implicated, particularly in progressive MS.

Katerina Akassoglou, PhD, senior investigator at Gladstone Institutes and professor of neurology at the University of California, San Francisco, and her team recently provided a better understanding of the type of cells and the cellular activities that cause this damage. The team developed a way to identify drugs that could limit or block it.

Akassoglou, Andrew S. Mendiola, PhD, a National Multiple Sclerosis Society Postdoctoral Fellow in Akassoglou’s laboratory, and colleagues described how specific immune cells that typically reside in...
the brain are activated to release reactive oxygen species (ROS), toxic substances that damage nerve cells and myelin in a process called oxidative injury. The researchers refer to these cells as “toxic immune cells.” The researchers created a directory of the toxic immune cells in the spinal cord that contribute to killing nerve cells, Akassoglou says. Then they developed laboratory procedures to help them identify known therapeutic agents that might stop or slow the process. They found that one of those agents stops immune cells from producing toxic substances and prevents nerve damage in an animal model of MS.

Like much of today’s medical research, this project involved a large number of collaborators; in this instance from the Gladstone Institutes, the UCSF Weill Institute for Neurosciences and the Small Molecule Discovery Center (SMDC) at UCSF and Baylor College of Medicine. Mendiola and Jae Kyu Ryu, PhD, assistant adjunct professor of neurology at UCSF and also a former MS Society postdoctoral fellow in Akassoglou’s laboratory, are co-lead authors of the April 2020 paper in Nature Immunology that details the procedures and results.

Mendiola explains that the researchers started with developing a new specialized technology to identify toxic immune cells that release the substances that damage nerve cells and analyze their genetic codes. They were able to determine which of the cells’ genes are “on” or “off” during this process. They hoped this process would help them identify treatments that could target these specific genes and, in this way, slow or stop the damage to nerve cells in MS.

“Surprisingly,” Mendiola emphasizes, “we discovered that only one small group of cells — one subtype of a commonly occurring brain cell called microglia — are the ‘toxic cells’ responsible for most of this damage.” The work was done initially in mouse models of MS called EAE, and it was confirmed in human brain tissue from autopsies of individuals with progressive MS.

The next step was to use a screening procedure in microglia cells in the laboratory. They checked 1,907 chemicals that researchers identified as potentially able to block the genes they think are involved in producing the harmful substances. Further testing narrowed the list to 128 promising chemicals. They honed in on one particular agent, acivicin, to test in animal models of MS. The screen was funded by a Society FastForward grant to Akassoglou and Michelle Arkin at UCSF SMDC.

“Acivicin is a drug that has been used in cancer but not MS,” Mendiola explains. “One way it may help stop the nerve damage is by interrupting the normal breakdown of the natural antioxidant glutathione that is made in the brain.” The antioxidant has chemical properties that may allow it to destroy the harmful substances released by toxic immune cells before nerve cell damage can occur.
Introducing the Human Floor Lift!

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- With the push of a button, the HFL-300 is both self and assist-operated, helping the individual back to a seated or standing position
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Ryu and his colleagues tested acivicin and were excited to discover that it prevented the development of MS-like symptoms in two different EAE mouse models. First, acivicin blocked the development of EAE in genetically predisposed mice that had not yet developed symptoms of the disease. Secondly, it also prevented relapse in another group of mice that had a chronic, longer-term form of EAE. In this experiment, the control mice, which did not get acivicin, got sicker, but the mice receiving acivicin did not.

Acivicin itself may not be a promising therapy in MS because of its known severe side effects when used as a cancer treatment. However, the work has demonstrated an exciting new target for the development of new safe therapies to preserve glutathione and block oxidative injury in MS. The team also discovered other small molecules targeting pathways relevant to MS to test in future studies. Their study also introduced a novel approach to identify agents that can protect nerve cells and could slow or stop the progression of MS.

Both scientists are excited about the possibilities of future research, including finding ways to selectively eliminate toxic immune cells from the brain and identifying safer compounds that block oxidative damage to nerve cells. Akassoglou also stresses that all of the data for genes and drugs from the recent study are available in an open-source format so that the research community as a whole can use these novel approaches to target this type of nerve damage not just in MS but in other neurodegenerative diseases as well.

Says Mendiola of their work: “I’m very passionate about this line of research. We are trying to look at this aspect of MS, the development of nerve damage in progressive disease, in a new light.”

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

Care to comment? Email us at editor@nmss.org.
MS doesn’t stop, and neither will we.

Now more than ever, people affected by MS rely on critical information, support and connection to remain strong and resilient throughout this crisis and beyond. We pivoted—swiftly—to meet the urgent needs of the MS community in this time of crisis, but now we need your help to adapt and evolve as these needs change and expand.

Support the Society
COVID-19 Response Fund

The financial toll of the COVID-19 pandemic is profound, but our commitment to people affected by MS remains. With the cancellation of hundreds of fundraising events nationwide, the National MS Society stands to lose one-third of our annual revenue—that’s more than $60 million in vital funding.

Your support ensures that we can meet the urgent and expanding needs of the MS community during this critical time.

Thank you to our lead supporter:

Genentech
A Member of the Roche Group
Here’s what we’re doing, and how you can help.

Providing support through resources and information

Answers to pressing questions
The COVID-19 and MS Resource Center, available at nationalMSsociety.org/COVID19, was developed in response to a 45% increase in Society website traffic to provide the most up-to-date information available.

A partner to navigate challenges
Every person living with MS has access to the Society’s MS Navigator Program by calling 1-800-344-4867. MS Navigators are equipped with the knowledge, tools and resources to respond to the critical needs of the MS community, including:

- Information about MS treatments and increased COVID-19 risk
- Employment concerns related to job loss and risk of continuing work
- Financial assistance to help with rent, utilities, food and other basic needs
- Emotional support due to increased isolation and anxiety

Virtual programming and events to reduce isolation and maintain wellness
Expanded virtual events and programs help keep our movement connected and provide relevant information so people with MS can manage physical and emotional challenges. Current offerings include:

- Weekly Ask an MS Expert webinars engaging over 2,000 participants
- 250 virtual Self-Help Groups
- A new partnership with Happy the App, an emotional support tool
- Weekly virtual Walk MS, Bike MS and other events

A healthcare community better equipped to deliver care
People need MS healthcare providers who understand the challenges that COVID-19 brings and can deliver vital care. We are supporting the healthcare community through:

- Bi-weekly online Healthcare Provider Discussion Forums about COVID-19 and MS, attended by over 2,000 people
- Using video technology to connect specialists from MS Comprehensive Care Centers to MS neurologists, physician assistants and nurse practitioners across the country for interactive discussions—95% of participants strongly agree that the clinics improved their knowledge of MS care during the COVID-19 pandemic.

Amplifying the voices of the MS movement to address urgent needs
MS Activists are helping policymakers understand the perspectives of people affected by MS during this crisis and are influencing future decisions as the pandemic’s impact unfolds. This includes stimulus legislation and 28 proposed COVID-19-related policies in states, 16 of which have been enacted.

Fueling MS research
With the vital funding of supporters, the Society will work to ensure that the MS research community rebounds quickly and momentum toward a cure continues.

Give today at nationalMSsociety.org/COVID19ResponseFund or text GIVE to 68686*

*Msg. and data rates may apply. Max. 15 msgs/mo. Terms and conditions and privacy policy at nationalMSsociety.org. Text STOP to 68686 to stop. Text HELP to 68686 for help.
What is MAYZENT® (siponimod) tablets?
MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.
It is not known if MAYZENT is safe and effective in children.

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

MAYZENT may cause serious side effects, including:
1. Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT. MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of MAYZENT.
   During the initial updosing period (4 days for the 1-mg daily dose or 5 days for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the updosing. Call your health care provider if you miss a dose of MAYZENT.

2. Infections. MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your health care provider should review a recent blood test of your white blood cells before you start taking MAYZENT.
   Call your health care provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:
   • fever
   • vomiting
   • headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

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

Before taking MAYZENT, tell your health care provider about all of your medical conditions, including if you:
• have an irregular or abnormal heartbeat
• have a history of stroke or other diseases related to blood vessels in the brain
• have breathing problems, including during your sleep
• have a fever or infection, or you are unable to fight infections due to a disease or are taking medicines that lower your immune system. Tell your health care provider if you have had chickenpox or have received the vaccine for chickenpox. Your health care provider may do a blood test for chickenpox virus. You may need to get the full course of vaccine for chickenpox and then wait 1 month before you start taking MAYZENT.
• have slow heart rate
• have liver problems
• have diabetes
When your relapsing MS starts to feel different, it may be time for MAYZENT®.

In the overall study, nearly 3 out of 4 people taking MAYZENT® showed no 3-month confirmed disability progression.*

Talk to your doctor about MAYZENT. Visit mayzent.com to learn more.

MAYZENT® (siponimod) tablets
0.25 mg • 2 mg

*74% of people taking MAYZENT, compared to 68% of people taking placebo.

The effect of MAYZENT was significant in people who had a relapse in the 2 years before the study, but not considered significant in people who did not.

** Side Effects and Precautions **

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

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

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

MAYZENT may cause possible side effects, including:

- **Increased Blood Pressure:** Your health care provider should check your blood pressure during treatment with MAYZENT.
- **Liver Problems:** MAYZENT may cause liver problems. Your health care provider should do blood tests to check your liver before you start taking MAYZENT. Call your health care provider right away if you have any of the following symptoms of liver problems:
  - Nausea
  - Loss of appetite
  - Vomiting
  - Yellow skin or the whites of your eyes turn yellow
  - Stomach pain
  - Tiredness
  - Dark urine

- **Breathing Problems:** Some people who take MAYZENT have shortness of breath. Call your health care provider right away if you have new or worsening breathing problems.

- **Swelling and Narrowing of the Blood Vessels in Your Brain:** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your health care provider right away if you have any of the following symptoms: sudden severe headache, sudden confusion, sudden loss of vision or other changes in vision, or seizure.

- **Severe Worsening of Multiple Sclerosis after Stopping MAYZENT:** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your health care provider if you have worsening symptoms of MS after stopping MAYZENT.

The most common side effects of MAYZENT include: headache, high blood pressure (hypertension), and abnormal liver tests. These are not all of the possible side effects of MAYZENT. Call your doctor for medical advice about side effects.

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

Please see Consumer Brief Summary on following pages.

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**CONSUMER BRIEF SUMMARY**

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

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

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

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

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

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

   Call your healthcare provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:
   - fever
   - vomiting
   - tiredness
   - headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)
   - body aches
   - chills
   - nausea
   - your brain and spine

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

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   - a blind spot in the center of your vision
   - sensitivity to light
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See “What are possible side effects of MAYZENT?” for more information about side effects.

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**Who should not take MAYZENT?**

**Do not take MAYZENT if you:**

- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your healthcare provider. Ask your healthcare provider if you are not sure.
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- have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

**What should I tell my healthcare provider before taking MAYZENT?**

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

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

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

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

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

Using MAYZENT and other medicines together may affect each other causing serious side effects.
How should I take MAYZENT® (siponimod) tablets?
The daily maintenance dose of MAYZENT is either 1 mg or 2 mg, depending on your CYP2C9 genotype. Ask your healthcare provider if you are not sure about your daily maintenance dose.

Start your treatment with MAYZENT using the following titration schedule:

<table>
<thead>
<tr>
<th>For the 1 mg daily maintenance dose:</th>
<th>Tablets a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 2</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 3</td>
<td>2 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 4</td>
<td>3 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 5 and every day after</td>
<td>4 x 0.25 mg tablet</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For the 2 mg daily maintenance dose, use the starter pack:</th>
<th>Tablets a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 2</td>
<td>1 x 0.25 mg tablet</td>
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<tr>
<td>Day 3</td>
<td>2 x 0.25 mg tablet</td>
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<tr>
<td>Day 4</td>
<td>3 x 0.25 mg tablet</td>
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<tr>
<td>Day 5</td>
<td>5 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 6 and every day after</td>
<td>1 x 2 mg tablet</td>
</tr>
</tbody>
</table>

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

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

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

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

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

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

How should I store MAYZENT?
Before opening:
- MAYZENT 0.25 mg and 2 mg tablets should be stored in a refrigerator between 36°F to 46°F (2°C to 8°C).

After opening:
- MAYZENT 0.25 mg tablets in the Starter Pack may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 week after opening.
- MAYZENT 0.25 mg and 2 mg tablets in bottles may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 month after opening.

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

General information about the safe and effective use of MAYZENT

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

What are the ingredients in MAYZENT?
**Active ingredient:** siponimod

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

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For more information, go to www.pharma.us.novartis.com or call 1-888-669-6682.
As days grow shorter and temperatures drop, the urge to hibernate through the winter months might seem appealing. Cultivating and maintaining social connections, however, is critical to wellness. And while a network of caring friends and family can be incredible, connecting with other people living with multiple sclerosis can enrich your life on a whole different, often more powerful level.

“It’s an isolating disease,” says Jean Petrillo, 54, who was diagnosed with MS in 2001, shortly after giving birth to twins.

“Even though your friends and family are there for you, unless you’re living with MS, it’s hard to understand — especially because so many people are living with ‘invisible’ symptoms,” says Cheryl DuFore, a social media specialist with the National Multiple Sclerosis Society. DuFore was diagnosed with MS in 1996. DuFore, who is active in social media groups and has attended in-person meetings, finds a different level of camaraderie among people who have MS.

“It’s almost an instant friend who understands what you’re going through, what you’re thinking and what you’re feeling.”

Cheryl Hile, 46, was the first person with MS to complete seven marathons on seven continents in January 2017. Cheryl holds up the custom ankle-foot orthopedic she used for the race.
Jean Petrillo organizes an MS self-help group in the Boston area. Afterward, to connect the people she met along the way, the California resident formed Run A Myelin My Shoes (RAMMS), a running and walking team. The team meets once a year to complete a running/walking event together and creates and competes in virtual events around the world year-round. Their Facebook group is extremely active.

“Relationships with other people with MS are quite different,” Hile says. “I belong to other running groups, but it’s so different when you have people who understand your disease, who live with it. They can offer a higher level of emotional support.”

“Each of us recognizes what a victory it is to be still able to run, let alone get to the finish line of a long-distance event like a marathon,” says Gary Pinder, 55, who was diagnosed in 1995 after his first symptoms emerged on his 30th birthday.

“There’s a deep, incredible appreciation of what we’re going through that others can’t relate to in quite the same way. We all understand and have this shared knowledge of what it takes to get out of bed...
in the morning,” says Pinder, a Maryland resident and RAMMS member.

RAMMS Facebook group members share typical running tips like favorite running shoes, dealing with plantar fasciitis and what to eat before a long run. But they also have MS-specific conversations about topics like the best running shoes for drop foot, dealing with spasticity in the feet and the best foods to eat to help fight MS fatigue.

Hearing stories
When people with MS get together — virtually or in-person — a range of topics tends to pop up. Brian Gorsich, 54, runs the popular MSPLC (MS Patients Leading Change) Facebook page, a virtual self-help group formed by people with MS for people with MS, from his home in Washington, Illinois. During the spring of 2020, for example, a popular topic was disease-mitigating therapies and how they might affect COVID-19. Perennial issues include different disease-modifying therapies, practical tips for dealing with symptoms (like cooling vests, kiddie pools for feet and ramps into homes), strategies to keep moving, when to consult a professional and, “what I really love,” says Gorsich, “are other people’s experiences — since they carry more weight than most articles.”

“Most people, including the newly diagnosed, are encouraged by meeting and hearing stories of those who have lived with MS for years,” says Petrillo. She started an in-person self-help group for people with MS who live south of Boston. Petrillo wanted the monthly meetings to have a wellness focus, “motivating people to live their best lives.” She finds experts to speak on topics such as exercise, yoga, meditation and sleep. Conversation flows from there.

During the pandemic, the meetings are virtual via Zoom, as are the MSPLC meetings. Petrillo finds virtual meetings so helpful that she plans to continue providing online access to the meetings.

Virtual meetings are powerful connection tools for people who are not ambulatory enough to attend in-person meetings as well as for people who don’t have meetings nearby. Denise Borkowicz, 77, lives in rural Michigan where there is no public transportation and little in terms of professional help for people with MS. Diagnosed in 1991, she runs a self-help group that meets twice monthly. The group meets once more socially for lunch, and then has an evening meeting with an educational angle, featuring speakers such as neurologists and Medicare specialists. During the pandemic, she reached out to members on the phone and hosted Zoom meetings. Connecting, especially in a rural area, she says, “helps ease the stress of the disease. People know they’re not alone, that others are going through the same thing.”

Members from around the world
Connections between people with MS stretch around the world. The MSPLC Facebook group “goes way beyond geography,” Gorsich says, with members chiming in from Ireland, England, Australia and all parts of the United States. The RAMMS group includes members from all seven continents and more than 14 countries.

One of the biggest, most internationally diverse MS social media groups is the MS Support Group on Discord (discord.gg/aQ4J2u8). Discord is a group-chatting platform initially built for gamers that has grown into a general-use platform for people who want to connect via voice and video chat. Patricia Abellanida
started the group after a disappointing search for MS chat rooms on Reddit a couple of months after her diagnosis in August 2017. The 30-year-old wanted to communicate with others with MS instantly and not wait 20 minutes, or a day, for a response on a forum or Facebook page. As a gamer, she had launched Discord sites previously, so she decided to create one for the MS community. There are about 600 members. Ninety-nine were online when we spoke. “Turns out, there were a lot more people looking for the same thing,” says the Orange County, California, resident. “People are really looking for a connection with a community that understands what we’re going through — and not everybody has local support groups in their area or can physically get to them.”

On Discord, members can designate their roles as “Have MS” or “Other,” as some channels are limited to only those with MS. Chat channels are set up to cover differing topics. One is “The Vent Chat,” where people are welcome to vent about anything. In the “Small Victories” channel, members celebrate anything from starting a new medication to the first day in a week they’ve been able to go to the bathroom consistently, according to Abellanida. The group also hosts monthly voice-chat gatherings and virtual events, such as movie and game nights.

The Discord group skews younger than most in-person groups, with most people aged 25 to 35. There’s also been an influx of teenagers that Abellanida attributes to the platform’s popularity with that particular demographic.

Websites (see suggestions at end of article) are a great place to start connecting with others who have MS, says DuFore, who lives in southeast Michigan. Also, be sure to check out Facebook and Instagram. Search Facebook groups with terms like “multiple sclerosis” and “MS.” “Once you join a group, the Facebook algorithm keeps serving you other groups that might interest you,” DuFore says. Instagram offers easy ways to connect with other individuals. “Search hashtags like #walkms or #bikems, and your feed will be populated with others who have used those hashtags and you can begin to follow one another,” she says.

You can also simply Google “multiple sclerosis” and your area or a special interest. “There is something for everybody,” says Hile. “It’s vital to find a community of people with MS that speaks to you.”

And, when the dialogue develops, it’s a powerful force. “If I don’t keep connecting, I feel at a loss, and I think I’m not alone in that feeling,” says Borkowicz. “Just the fact that you know there are other people out there like you — it’s not so scary.”

Shara Rutberg is a writer in Evergreen, Colorado.

Connect with others living with MS:
ntlms.org/peers
nationalMSsociety.org/SHG

Care to comment? Email us at editor@nmss.org.
Warren Torrence started supporting the National Multiple Sclerosis Society in 1998 when he and his father first participated in Bike MS: Breakaway to the Beach, riding 150 miles from Rockingham, North Carolina, to Myrtle Beach, South Carolina, nearly every year since.

In 2015 though, Torrence decided he wanted to try something different. “I liked doing the Breakaway, but I’m not as outdoorsy as my dad,” he says. “I thought there’s got to be another way that I can raise support.”

Torrence decided to get together with some of his online gaming friends and see if he could raise money through live streaming. The first year he raised $700. For the past two years, he’s raised more than his dad has, averaging roughly $1,200 a year. “I’m like, ‘Ha! You have to ride your bike, I get to stay at home,’” Torrence says with a chuckle.

Streaming for charity often means raising money from the comfort of your home, though not always. What is streaming and how can you raise money doing it? Those were the questions Christina Carro, senior director, Emerging Events at the Society, asked before launching Stream to End MS (nationalMSsociety.org/stream-to-end-ms) in May 2020. Carro was approached...
by streamers such as Torrence, who were already streaming to raise awareness and funds for MS and suggested that the Society launch an official campaign. “We had to look into it,” Carro says. “More people [were staying home during the COVID-19 pandemic], and we discovered that streaming is a huge and growing industry. It gives people another way to fundraise in ways they maybe hadn’t thought about.” Carro also notes that distinct from the Society’s more traditional fundraising campaigns such as Bike MS and Walk MS, Stream to End MS gives a new audience a way to participate.

Limitless possibilities
From online gaming to cooking tutorials to creating artwork, streaming possibilities are virtually limitless — that’s part of its allure. The other bonus is that you don’t have to be a tech guru to get started. “All you need a good idea and the ability to broadcast yourself,” Carro says. “On the Stream to End MS website, we’re setting up user-friendly guides so anyone — from people who are familiar with streaming to those who are interested in trying it for the first time — can get involved.” So far, more than 90 registered streamers have collectively raised more than $50,000, a number Carro...
anticipates will continue to increase given the popularity of streaming.

“It’s cool,” says Josh Conti, leader of the MS fundraising streaming group the Dadbod Squad. “To be honest, when I first found out about streaming back in 2004, I thought it was the most ridiculous thing ever, but then I saw it and my mind changed. There’s a sense of virtual community.”

Streaming allows streamers to broadcast content in real time. Viewers who tune in can ask the streamer questions or even take part in an online game. When streaming for charity, a streamer can include information about how to donate on the screen.

Since launching his streaming campaign in March, Conti and his squad — which includes his wife, Molly, and six friends — have raised more than $2,000. Separately and together, Conti and his crew stream themselves playing video games ranging from old-school Super Nintendo games to interactive Jackbox Party games. “Our campaign is ongoing,” Conti says. “Between everyone on our team, we stream almost every day, and our goal is just to raise as much money as we can for the National MS Society.”

The Society’s Stream to End MS campaign encourages fundraisers to be creative in designing events that suit their interests and lives. Carro and her team actively work with streamers to help bring their ideas to life. One key to creating a successful campaign is ensuring time for preplanning. “It makes a difference when a streamer has time to plan it out and promote through their networks.”

Another essential aspect for success is to make it your own, suggests Torrence, who streams under the name Timberwolf. “You have to live stream what you love,” he suggests. “Whether that’s riding your bicycle and live streaming from your handlebars or playing video games, people want to engage with you and donate because you’re sharing who you are.”

Kelsey Blackwell is a writer in Berkeley, California

Learn about Stream to End MS at nationalMSsociety.org/stream-to-end-ms.

Care to comment? Email us at editor@nmss.org.
Virtual State Action Days empowered more activists during the pandemic.

by Robert Lerose
Making things better for others is second nature for 36-year-old Diane Kramer. Growing up, she spent Thanksgiving holidays with her parents, pitching in at the USO and brightening the holidays for people who couldn’t get home. “Being of service is my love language. That’s what I do,” Kramer says.

She was working as a licensed practical nurse when she was diagnosed with multiple sclerosis in October 2010. When she started having cognition problems and became unsure of how they would affect her work, she took a medical retirement in 2017. She came up with a new way to serve: being part of the National Multiple Sclerosis Society’s MS Activist Network and attending State Action Days.

“These are days for our MS activists to go to their state capitol to engage with their lawmakers, usually on a particular issue or priority that we’re trying to keep moving in the legislature,” says Abby Emanuelson, associate vice president of advocacy and activist engagement for the Society. “It builds relationships with their state lawmakers and gives activists a sense of empowerment in the public policy-making process.”

Instead of the usual in-person meetings, activists held virtual State Action Days in 2020 because of COVID-19 restrictions. Meetings using different digital platforms were scheduled for five state legislatures still in session during the spring of 2020.

Diane Kramer, diagnosed with MS in 2010, is part of the National Multiple Sclerosis Society’s MS Activist Network and participates in State Action Days.
“It meant that I do more virtually than I ever could do physically. I could see more people and have more meaningful conversations than if I was running from one end of the capitol to the other,” Kramer says.

Kramer had already established a relationship with her legislators in Harrisburg, Pennsylvania, before her April 2020 State Action Day, so the tweets she sent throughout the day were warmly received. She also had an appointment with a staffer in her state senator’s office and used Zoom — a first for both of them that made them feel proud. The meeting went longer than usual, and Kramer was able to get real-time answers to questions, discussing such issues as access to affordable medications. “Our conversation was so productive,” Kramer says.

Father-and-son teamwork
James Dearing had his dream job as the director of marketing and health and wellness at a hospital in Illinois. It was the latest position in a career devoted to helping others, starting when he worked in a nursing home at age 15.

He was put on medical leave before being let go following his 2011 MS diagnosis. “The day I was diagnosed, all I heard was, ‘You have a disease that doesn’t have a cure.’ It was an out-of-body experience where the room got dark, and I was stuck on the freaking disease as progressive. It was a pretty stressful day,” 45-year-old Dearing says.

When he attended his first State Action Day three years ago, he brought his son Jack to show him how to talk to legislators, get his voice heard and discuss important issues. Now 13, Jack might be Dearing’s secret weapon: Legislators remember his 6-foot-1-inch son.

For the 2020 virtual State Action Day in Illinois, Dearing chose to engage with his representatives by telephone, allowing him to get his points across while working from prepared notes and without feeling rushed. Urging his state representative to co-sponsor a bill that limits out-of-pocket costs, copays and deductibles for prescription drugs was a priority. “I was a little hesitant, but it was a great experience. It was a
l little more laid back, probably because we were able to talk a little longer,” Dearing says. And Jack was at his side.

**Setting her own pace**

As a former journalist, 62-year-old Elaine Shelly knows how to cover the many sides of a story, including her own. Before her MS diagnosis in September 1991, “I was that person who wouldn’t even take an elevator. I would just run up the stairs. Now I’m a full-time wheelchair user, and just getting through the day can be challenging at times,” she says.

Shelly volunteers as a District Activist Leader for the Society, where she tracks state and federal legislation related to MS. She also became a member of the Government Relations Advisory Committee in 2020 to help the Society come up with legislative priorities. In addition, she participated in California’s State Action Day in 2020 for the first time.

Shelly used Twitter to reach out to her legislators and followed-up with a Zoom visit. “Social media is good for getting the word out about issues, but I think to be effective and impactful, you need that personal contact. I’m in the process of building relationships with staff people in my legislators’ offices,” she says.

When Shelly woke up on State Action Day, she knew it would be an “MS day.” That day, she was experiencing a lot of fatigue, and her aide had to help her complete her shower. Had there been in-person meetings in Sacramento, she wasn’t sure she would have been able to handle them, traverse the capitol and discuss protecting programs that help people with MS stay in their homes.

“But since I was at home, I was able to do things at my own pace and stop when I needed to. It made the day much more manageable for me. I think I can get my work done better online,” she says.

As of June 2020, 300 people had participated in virtual State Action Days in five states, with one more virtual event scheduled for September in New Jersey. “I see us doing more of these events. We have a whole system of low-cost tools that people can engage with [to] show their strength in numbers on issues that affect them,” Emanuelson says.

Robert Lerose is a freelance writer in New York.
Despite confusion and misperceptions about my disease, I’m showing MS who’s the boss.

by Veronica Daniels-Lewis
I was living a wonderful, busy life after college. I was in my early 20s, working toward an exciting business career in one of Texas’ largest cities. I felt like I was in charge of my destiny.

Fast-forward to my late 20s: After marriage, starting a family and working full time, I decided to become a stay-at-home mom because my husband’s job meant we moved frequently. I was a driver, teacher, cook, laundry queen, classroom room mother, coach, along with many more roles.

I was there for my family wherever and whenever they needed me.

One morning I woke up and felt strange. I had a tingling sensation, weakness in my left hand and numbness in both feet. These feelings lasted for a couple of days, so I made an appointment to see my primary care physician. I was told I was showing signs of carpal tunnel syndrome in my hand. I was given a brace and told to watch my posture and the amount of time I spent on the computer and to take frequent breaks.

After a few months, the tingling sensation got better, but I never fully recovered feeling in my left hand. I still felt constant numbness, pins and needles and pain in my feet. But no one in the medical community would validate my annoying continuous pain and take me seriously. They made me feel like my symptoms were all in my head or a product of my active, fast-paced life.

In my mid-30s, I began to experience loss of balance, tripping and falling and dropping things. Again, many of the medical professionals I visited chalked up my symptoms to my busy lifestyle and family obligations.

In 1996, after experiencing symptoms since 1988, I found a doctor who finally diagnosed my multiple sclerosis. What a relief to know someone was listening and that I was not crazy!

I was happy to finally have a name for what I was feeling, but what exactly was MS? Why did they take so long to come up with this diagnosis?

From research, along with information provided by the healthcare community, I learned that MS was a disease believed only to affect Caucasian people from Northern European ancestry and not people of color. This theory confused me.

I’m sure many people of color living with MS have similar stories of their own or have heard such stories. This always made me wonder if that’s why it took so long for me to be diagnosed.

I’ve also learned that many minorities have been diagnosed with other health issues before finally receiving a correct MS diagnosis. As a support group leader with the National Multiple Sclerosis Society, I’ve met many people of color — from those who were diagnosed years ago to those more newly diagnosed. It’s devastating to hear them describe their traumatizing journeys through a range of misdiagnoses of everything from fibromyalgia to HIV/AIDS. The signs and symptoms they reported were ignored or weren’t even considered because of these preconceived notions about them.

Today, it’s known that MS occurs in all ethnic groups, including African Americans, Asian Americans and Hispanics. Studies show higher numbers among these groups than previously thought. I’m glad to see more research, more education and information to help guide more accurate diagnosis and treatment.

I had always felt in charge of my destiny and sure of my life path, but MS, with its craziness and unpredictability, had entered my life and refused to leave. MS was trying to take control of my life.

Veronica Daniels-Lewis was diagnosed with MS in 1996.
I began to work closely with my neurologist on a healthcare plan. I was also advised to contact the Society for help, to connect with others living with MS and to get reliable information to manage my MS.

Reaching out to the Society was pivotal for me. I received the support and care for which I will be forever grateful. I am proud to say I have been involved with the Society since 1996. Reaching out also helped me make connections and adjustments to my new life.

As time passed and my kids grew up and started to create their own destinies, I decided to take on volunteer positions with the Society.

My first volunteer position was as an MS self-help group leader in my community. I could develop a safe environment for people of various backgrounds to get together to share information, thoughts and hopes. It gave me the opportunity to stand up and use my voice to lift other minorities’ voices in the web of MS uncertainties. From my own experiences, it allowed me to share information about what people of color can do to receive proper care.

When the group first started, we had five or six members in Sugar Land, Texas, a suburb of Houston. I spread the word, and we grew fast. Today we have an email list of more than 200 people living with MS of all ethnic backgrounds, from teachers to business executives, from teenagers to older adults. Parents sometimes join us because their young teenager is now living with MS and they are seeking support for them. We meet once a month, and we’re an enthusiastic group. These people are all my extended family, and they help me as much as I help them on this wild journey.

We talk about the issues we face and also invite people from the healthcare community to come in to talk with us. This led to my second position with the Society as a Community Help Relations Representative to secure guest speakers such as neurologists, primary care physicians, occupational and physical therapists, social workers and others to provide updated information on managing care when living with MS. Establishing these one-on-one relationships with the minority community was huge.

Helping the healthcare and minority community understand each other and talk about the lifestyle changes needed to live your best life with MS is crucial. We always leave the meetings feeling much more empowered.

I also am a District Activist Leader. I use my voice to inform government leaders about the legislation needed to help people living with MS and other disabilities live their best lives. I was even asked to be a member of a committee created by one of our local U.S. House of Representative offices to improve the lives of people living with disabilities in my city.

Even though MS tried to take charge of my life over 20 years ago, I am using my voice to help educate and give hope to other people living with MS. I am showing MS who is the boss. I’m staying in charge of my destiny and helping others stay in charge of theirs.

Veronica Daniels-Lewis of Missouri City, Texas, is a former independent sales consultant and new grandmother who has been living with MS since 1996.
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My art is the ultimate remedy.
by Neda Shoaei

I am Neda Shoaei, 29, a multidisciplinary artist from Iran. In 2016, I received a bachelor’s degree in English literature from the University of Tehran. I make video art and create digital collages, paint doodles and research global issues such as gender studies, human rights, silent extinction, diasporic literature and refugee crises.

When I was 17 and preparing for my university entrance exam, I was diagnosed with multiple sclerosis. The left side of my body started to feel numb, and less than 48 hours later, it was completely paralyzed. I moved to San Diego, California, to continue my treatments closer to my parents. At first, I was shocked. I vividly remember how numb I felt, both physically and emotionally. I was completely paralyzed on the left side of my body. Even my vocal cords were affected, and I couldn’t sing well for some time. And I love singing! But after a while, I started to gain hope again. I wrote short letters to my fingers, telling them how much I missed them, and I asked them to start moving again. Fortunately, they did.

Nothing helped me out of those days more than the magic of the Harry Potter novels. They helped me detach from all the harsh reality I was coping with during my MS journey. My family supported me a lot through all the hard steps I took dealing with my new life with MS. After I finally started to feel better, I returned to Tehran and entered university.
My MS is always present in my life. Gradually it became my imaginary friend. I learned to manage my MS symptoms through healthy eating habits, doing art and painting, cooking meals with different fresh vegetables and sharing new recipes with my friends. I adopted a cat. I even started playing video games. Each day, I try to realize there is nothing to be afraid of in this world. Everything can become possible for us, just in our way. My emotional attachment to giraffes started when I learned that this beautiful creature faces extinction. From then on, the giraffe has remained with me, maybe as a sign of hope. It helped me take a more in-depth look at the environmental crisis we face. By using the giraffe motif in my artwork, I began to point out concerns as a global citizen, artist and activist. I am working on a project titled “Giraffiti,” a series of digital graffiti designs. Each graffiti links to different locations around the world. The main idea of this collection is to bring people closer together and support freedom of speech for every nation, without consideration for borders. I also have been a contributor to an art residency project in Berlin since 2018, working on the refugee crisis and forced migration.

My art is the ultimate remedy for all desperate moments and short-term numbness I experience from time to time. When I start a new design, everything else just fades away. Only the giraffe remains with me.
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