

## 8 steps to fiscal fitness

Pursue a clean “bill” of health with these financial planning tips.

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# 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.**

Give today at  
[nationalMSSociety.org/  
COVID19ResponseFund](https://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](https://nationalMSSociety.org). Text STOP to 68686 to stop. Text HELP to 68686 for help.



National  
Multiple Sclerosis  
Society



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DIAGNOSED IN 2012

# momentum

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

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



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



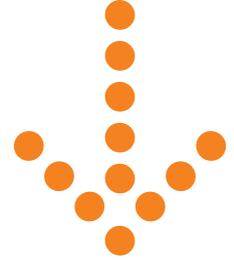
Momentum's Winter 2018-2019 issue received a 2019 Finalist Award in the category "Nonprofit Publication"

#### Corrections:

The image on pages 48-49 of the Summer 2020 issue of **Momentum** incorrectly identified the fish pictured as a zebrafish. It is a lionfish. A zebrafish is pictured here. We regret the error.



The Summer 2020 issue of Momentum listed an incorrect issue number. It should be Volume 14 Issue 3.



The old saying “necessity is the mother of invention” has played out during this COVID-19 pandemic.

Knowing that people affected by multiple sclerosis might be isolated from family and friends, it was urgent that we find new ways to connect people to the MS movement. Staying connected has never been more important.

In the beginning of our Walk MS season, we had to halt in-person events by the hundreds. Walk MS is for fundraising, first and foremost. It is also a community rallying point — a place where people in the MS movement come together and make their feelings and commitment known. We decided we needed a virtual place, so we pivoted and created that space.

Jennifer Lee, executive vice president of fundraising events, laments, “We were so excited to kick off a record-breaking Walk MS campaign. However, time could not be wasted commiserating because we knew our walkers were feeling disappointed as well. They have always been our most connected fundraisers, coming together because they have MS or care about someone with MS.” Lee learned that in the process of going virtual, “I came to appreciate we can still engage people in our work, deepen existing relationships and bring new people into the MS movement — even when we cannot get together in person.”

In addition to Walk MS and other fundraising events, we had to shut down all in-person education and connection programs. This is a big concern. Many rely on in-person programs to connect with people who understand what they are going through. Feelings of isolation and anxiety increase when we are apart. We need more and better ways to connect virtually, especially when virtually is the only option.

Many self-help groups started meeting online during the pandemic. Yolanda Treiguts, a 30-plus-year leader of the South Cook group in Illinois, decided to go virtual when she heard from members who were isolated. Treiguts says, “I felt digitally unqualified and very nervous that the meeting would not go well.” But after an amazing virtual meeting, Treiguts says, “It is a powerful good feeling to learn new skills and keep the group going.”

Karen Hooper, vice president of program development and engagement, video conferences with self-help group leaders once a week to share ideas and learn together. “Isolation is not new to the MS community,” Hooper says. “Volunteer leaders are getting creative to ensure that members can support each other virtually.” To find a group, visit [nationalmssociety.org/Resources-Support/Find-Support/Join-a-Local-Support-Group](https://nationalmssociety.org/Resources-Support/Find-Support/Join-a-Local-Support-Group). To learn more about starting a group, email [peerconnections@nmss.org](mailto:peerconnections@nmss.org). If you prefer the phone, call an MS Navigator at 1-800-344-4867.

We’ve made big strides in our virtual presence. In the short term, we had to. We will use what we learned to expand opportunities and to enhance in-person experiences when we can be together again.

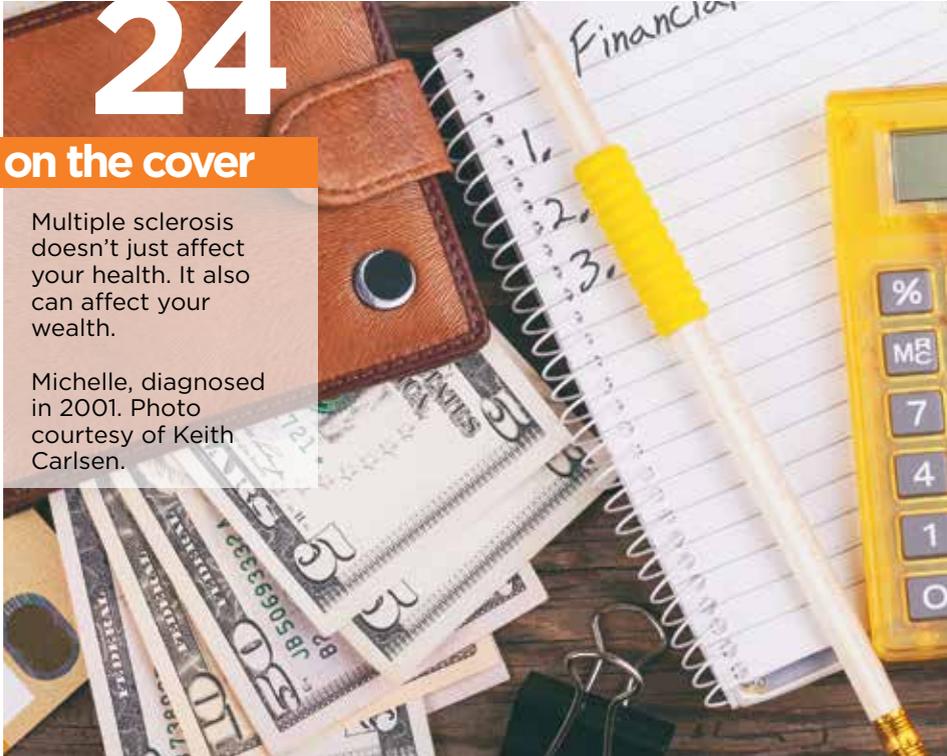
Where are you in this new virtual world? What’s holding you back? I’d love to hear from you. Let’s stay connected! ■



Let me know your thoughts.  
Email me at [cyndi@nmss.org](mailto:cyndi@nmss.org).

*Cyndi Zagieboyo*

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).



# 24

## on the cover

Multiple sclerosis doesn't just affect your health. It also can affect your wealth.

Michelle, diagnosed in 2001. Photo courtesy of Keith Carlsen.

ISTOCK

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## ■ thrive

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PHOTO COURTESY OF ASHLEY SUVANTO

Ashley Suvanto's MS diagnosis led her to a new calling.

Look for these icons throughout **Momentum**.



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# more stories

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## Contact Momentum

 [nationalMSsociety.org/momentum](http://nationalMSsociety.org/momentum)



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

## 'The bouncer' hit home

I really enjoyed the article by Jessie Ace in the Fired Up section of the Summer 2020 issue titled, "The bouncer." What a horrible experience for her. Unfortunately, people don't understand invisible illnesses, are quick to judge and so rude at times. I have multiple sclerosis and colitis and have had 13 surgeries on both ankles. I was diagnosed with MS in 2003. I use a cane on bad days. Even on good days, I will take it with me if I get a scooter in a store just so people see I am disabled and not just faking it. It's not fair to be judged, feel guilty or feel the need to apologize/explain because of invisible illnesses.

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Becky Myers, Ohio

## Those good Samaritan sharks

"Tell it like it is" (Spring 2020): What a fantastic article. I had no idea I wasn't the only who had a problem with "good samaritan sharks." Admittedly, I usually think of them more as vultures than sharks. What's worse is that I'm married to one. How can it be that being disabled lessens my rights as a fellow human being? I can and do accept help graciously, but I don't want it when I'm forced to accept it. You know, don't grab me underneath my armpits and hoist me upwards when I'm still grappling with the pain of having smacked onto the ground. The article — actually the whole magazine, was perfectly timed. Thank you.

---

Lori Murphy, Washington

## Not so accessible

I have a problem with accessibility to concert theaters. I've had multiple sclerosis since 1978, and now that I'm in my 70s, and living in Florida, I'm using my motorized wheelchair more and more and finding wheelchair accessibility is lacking in the Tampa Bay area. For instance, my favorite musical group was playing in Tampa, and I had tickets. I hired someone to drive me, because I knew the handicapped parking was on a first-come, first-served basis, and I didn't want to arrive two hours before the concert started. The wheelchair-"accessible" restroom was a joke. Don't people realize that just because we are handicapped, doesn't mean we shouldn't be able to attend concerts? We aren't dead. We just cannot walk. I called the theater to complain, but according to Florida laws, they qualify as handicapped accessible. Why, oh why, don't they hire handicapped designers? Or listen to their customers?

---

Lois Underwood, Florida

## Using the same tricks

I sit here and cry as I reread "Still unshakable" (Spring 2020). I reread because I forgot that I had read it. It touches me so closely. I imagine that this is me and my daughter in a few years. I am a lot like the mom in this article. I will not get a handicap placard or use a cane yet either. I don't need it. I will wait. I don't use the words handicapped or disabled because I don't need them yet. I do often have to ask people to repeat things so that I can process what they say. Like the mom in this article, I choose only to tell my husband and daughter when I want to, so they don't worry. This article hit home. I am glad to know that there is someone else who uses the same "tricks" as I do. Thanks for the smile. ■

---

Michele Frank, Pennsylvania

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



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

SEE WHAT ONE PILL  ONCE A DAY CAN DO

## INDICATION

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

## IMPORTANT SAFETY INFORMATION

### DO NOT TAKE AUBAGIO IF YOU:

- **Have severe liver problems. AUBAGIO may cause serious liver problems, 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.

SANOFI GENZYME 

# MOVING FORWARD\*

talk to your doctor about once-daily AUBAGIO



Patient Portrayal



Visit [myAUBAGIO.com](https://myAUBAGIO.com) or scan here to learn more

- **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](https://www.aubagio.com).**



PILL ACTUAL SIZE

Once-daily  
**AUBAGIO**<sup>®</sup>  
(teriflunomide) 14mg tablets

AUBAGIO is available in 14 mg and 7 mg tablets.

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

**Rx Only**

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

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

**AUBAGIO may cause serious side effects, including:**

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

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

**What is AUBAGIO?**

AUBAGIO is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), 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 diabetesTell 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

## ADVERTISEMENT

- 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](http://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

# SEE WHAT ONE PILL, ONCE A DAY CAN DO FOR YOUR RELAPSING MS

LEARN MORE AT [MYAUBAGIO.COM](http://MYAUBAGIO.COM)



**AUBAGIO**  
(teriflunomide) 14mg  
tablets

## Tips for living a more sustainable life

Trying to be more environmentally friendly doesn't mean going without. Rather, living sustainably means being aware of your resource and energy consumption. If you're looking to change your habits and reduce your impact on the environment, here are some simple ideas to get started.



Use energy-efficient LED light bulbs and turn off lights when you leave the room.



Buy loose fruits and vegetables rather than packaged produce.



Invest in a pressure cooker to reduce cooking time and energy.

### Around the house:

- Unplug devices at night, including your WiFi router and computer.
- Transform old clothes into cleaning rags.
- Not every city recycles the same way. Research what types of plastics are recyclable where you live.

### When shopping:

- Ask for digital receipts rather than printed.
- Try to buy products packaged in glass or paper rather than plastic.
- Support brands that are environmentally conscious.

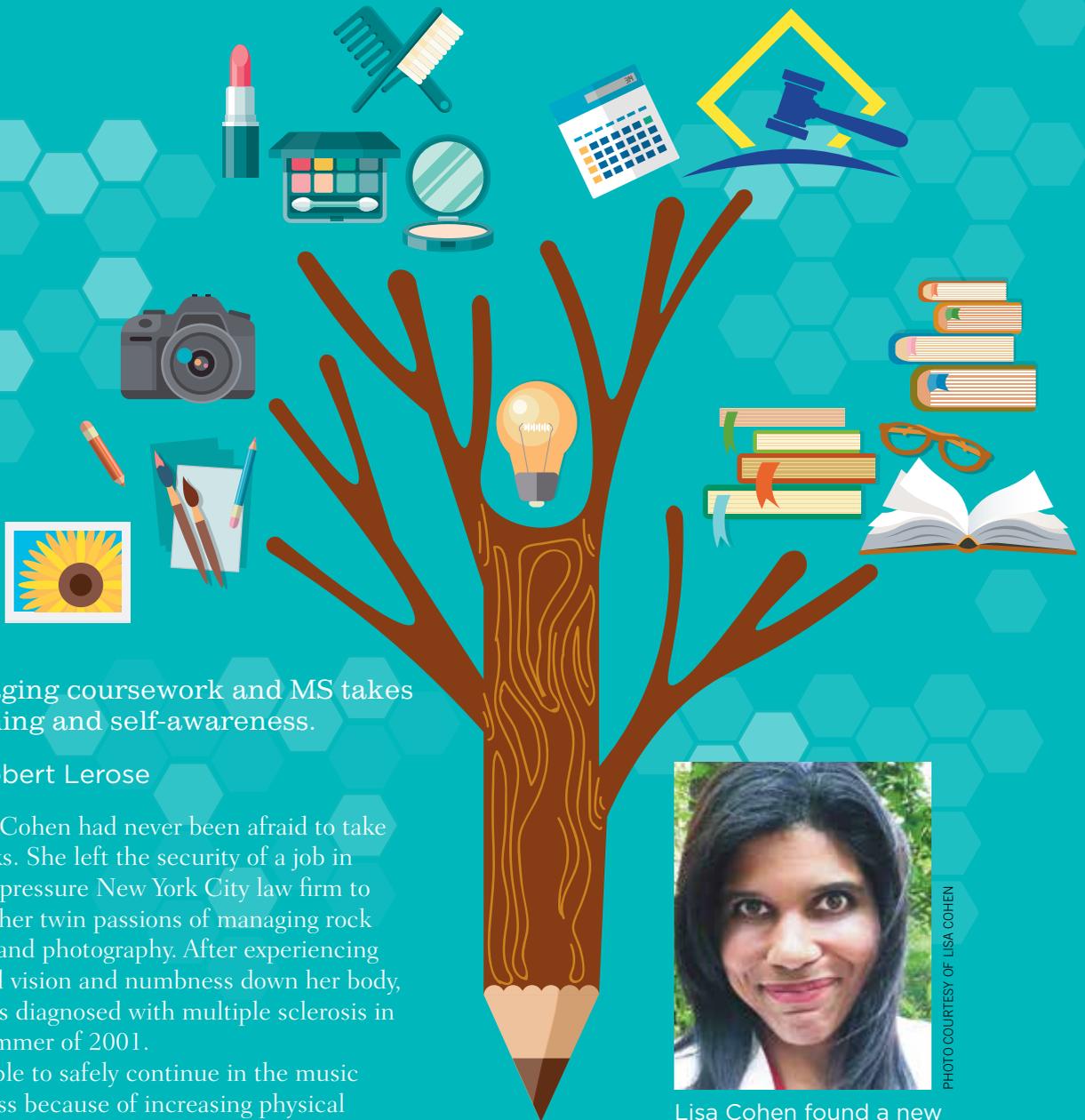
### In the kitchen:

- Use a water filter for your sink or fridge — don't buy plastic water bottles.
- Use washable dishes, utensils and straws rather than disposables.
- Make your own coffee instead of buying takeaway cups.
- Use a dishwasher instead of washing dishes by hand if possible.
- Use a cloth or sponge to clean instead of paper towels.

Practical ideas  
for living well  
with MS

# in the know

# School days



Managing coursework and MS takes planning and self-awareness.

by Robert Lerosé

**L**isa Cohen had never been afraid to take risks. She left the security of a job in a high-pressure New York City law firm to follow her twin passions of managing rock bands and photography. After experiencing blurred vision and numbness down her body, she was diagnosed with multiple sclerosis in the summer of 2001.

Unable to safely continue in the music business because of increasing physical limitations, she eventually co-founded Makeover Your MS, a nonprofit that addresses



Lisa Cohen found a new career path after going back to school.

PHOTO COURTESY OF LISA COHEN

ISTOCK.COM: MATRIYOSHKHA, BORTONIA, RUNEER, MAULANA AHSAN

the makeup and grooming issues of women with MS, and found a new purpose in her life. “I wanted to have some type of component to help them with their day-to-day [challenges]. That’s what made me interested in going to school for life coaching,” Cohen says.

Returning to school can be both daunting and exciting. For some, like 50-year-old Cohen, it’s a chance to start a new career. For others, it’s a way to sharpen existing skills, stay mentally active or just enjoy the companionship of fellow learners. Managing MS while staying on top of your studies starts with some self-evaluation.

“It’s just really understanding how MS impacts you and knowing that it may not be a straight four-year shot or a two-year shot. You may need to take longer to do that, and that’s OK,” says Nancy Lowenstein, a clinical associate professor of occupational therapy at Sargent College of Health & Rehabilitation Sciences.

### Key points to keep in mind

In balancing your MS and school work, Lowenstein says to keep three things in mind: physical status (such as walking and muscle strength), cognitive abilities (the times that you function best mentally) and fatigue.

For example, if you have to attend a physical campus, consider whether it has elevators, ramps and curb cuts. Is it accessible to scooters, walkers or canes? What is the distance between your classes? How long will you have to get from one class to another?

For cognitive challenges, Lowenstein recommends talking to the school’s disability office. Sometimes the school may provide devices to help you take notes if you have trouble writing. You can also get permission from the professor to record the lectures or ask fellow students to share their notes with you.

### Planning and transparency

Many schools offer online classes and degree programs, and some institutions began online programs instead of in-person classes as a result of COVID-19. Be sure to check.

Taking classes online eliminates many of the obstacles that traditional classrooms pose, giving you more flexibility, freedom, comfort and control. Often, classes are recorded automatically to accommodate fluctuating schedules, allowing you to access them at your convenience or when you’re most refreshed.

Another alternative is the so-called university without walls, where students work with advisers to create their own curriculum. At Northeastern Illinois University, for example, students are evaluated on their core competencies and not on how many credit hours they earn.

Managing your time and knowing what you can handle are key. “I encourage my patients to do an analysis of themselves and their time,” says Tracy Carrasco, an occupational therapist at the Orlando Health MS Comprehensive Care Center. Patients fill out an hour-by-hour chart of everything they need to do the next day, then write down what actually happens that day. This self-assessment allows them to see what changes can be made to improve their time management. “It gives them first-hand information rather than me telling them what would be beneficial for them,” Carrasco says.

Students with MS should factor in any additional medical costs. Depending on their situation, Lowenstein says that they may need to start at lower-tuition community or state schools, and then transfer.

PHOTO COURTESY OF NANCY LOWENSTEIN



Nancy Lowenstein specializes in occupational therapy and advises people with MS to balance their workloads with school.

PHOTO COURTESY OF TRACY CARRASCO



Occupational therapist Tracy Carrasco says a self-assessment test can highlight necessary changes for better time management.

Whether to disclose your MS diagnosis to your instructor or the school will likely not be an issue if you take online courses, but what about courses where you have to show up?

For the most part, it's up to the student to decide whether they want to say anything, but telling the school ahead of time could work in your favor. Lowenstein says to discuss your situation with the school's disability office to see if you need any special accommodations and what the school might be able to provide. Typically, the office will give you a letter for your instructors saying, for example, that you will be recording the lectures, you might need extra time for test taking, or you might miss classes — but the letter won't specify your diagnosis and professors can't ask you about it. "If you talk really honestly with the disability office, then you can iron out all these things with them, and they'll help you with the professor," Lowenstein says.

### Going for the positive

Although Cohen could fulfill most of her program's requirements online, she did have to attend some all-day workshops in person. One exercise required her to close her eyes and walk across a large room — a big problem that was mitigated because she already told them about her MS. "My classmates were very good about keeping me safe physically. It wasn't easy and maybe took me a little longer, but it was doable," she says.

Hannah Garrison, 30, was struggling to make a career as an artist when she was diagnosed with MS in June 2017. Like Cohen, the diagnosis is leading her back to the classroom. In May 2019, Garrison became an arts instructor at Hearts Need Art, a San Antonio-based organization that uses the arts to give emotional support and relief to patients with life-altering illnesses. "It was a way to bring humanity back into their lives. Even if I only spent an hour with them once a week or once a month, it was still such a good thing for me to see what it does for people," she says. Garrison hopes to go back to school in 2020 to get her master's degree in counseling/art therapy. Because of the physical complications of her MS (dizziness, heat intolerance and neuropathy) and financial considerations, she is leaning toward an online degree



PHOTO COURTESY OF HANNAH GARRISON

Hannah Garrison, diagnosed with MS in 2017, is pursuing a master's degree in counseling/art therapy.

program or a hybrid teaching arrangement, giving her more control over her situation.

"Having a goal and pursuing something is incredibly helpful to keep your mind off your diagnosis and the negative things happening in your life," Garrison says. ■

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

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

# Moves you can use



Functional exercise can help make everyday tasks easier.

by Brandie Jefferson

If you want to run a six-minute mile, how do you get there? To many people the answer is clear: Hop on the treadmill or hit the streets and run. Practice until you reach your goal.

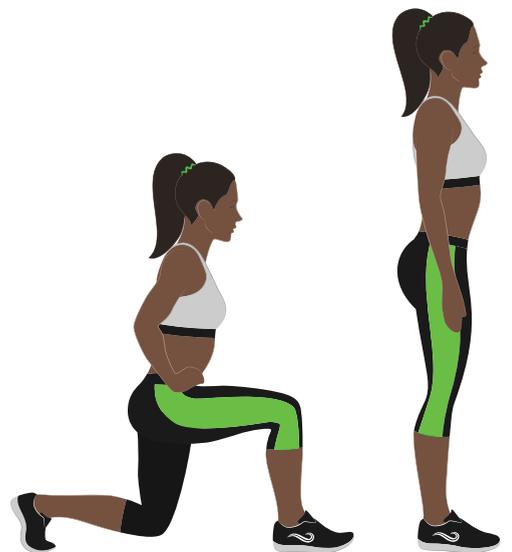
But what if your goal is to be able to stand confidently from a seated position? Is there an exercise routine for that?

The answer lies in what's known as functional exercise. Though precise definitions vary, in essence, functional exercise has a purpose beyond improving performance of a particular exercise or improving general fitness. It is used to help people perform everyday tasks that they are having trouble with because of their multiple sclerosis. These tasks are referred to as functional tasks.

"The first part of any evaluation is to ask, 'What is the task you want help with?'" says Herb Karpatkin, a physical therapist and associate professor of physical therapy at Hunter College in New York City. "It could be walking. It could be reaching. It could be rolling over in bed."

Karpatkin has specialized in physical therapy for people with MS since 1995.

**Squats may help improve the strength and balance needed to get into or out of a chair.**



**Lunges may help improve the functional task of getting on and off the floor.**

Once he knows a person's goal, he reverse-engineers a regimen. "We figure out what components of strength or coordination go into the task. Then I work on specific exercises or stretches to improve those components. And we try the task again."

And, in some cases, again... and again ... and again. "The path has never been straightforward," says New York resident Merrill Hesch, 64. Hesch was diagnosed with MS in 2011 and began working with Karpatkin shortly after her diagnosis. When they first met, she couldn't stay seated — she kept sliding out of her chairs. She could walk down a flight of stairs, but when she tried to walk up, she would "crumble into a mess." When she stood, she placed all her weight on one leg. She calls it her "flamingo pose." She had trouble walking any distance at all.

One day, Karpatkin noticed that after she did the "grapevine" — walking sideways, crossing one foot over the other quickly, an exercise given to her by a previous physical therapist — she could walk a short distance without problems. "When Herb saw that, he said, 'Do it again!' Then, 'Again!'"

He determined she had been dealing with abdominal dystonia, involuntary muscle movements that can outwardly reveal themselves in subtle, and sometimes not so subtle, ways.

"That was when we realized that the only way to help would be to go through a range of therapy that was very task-specific in order to make significant improvements in all aspects of my life," Hesch says.

### Common exercises can help

There are some well-known exercises that are commonly recognized as serving a specific function.

For example, according to Mandy Rohrig, a physical therapist and senior programs consultant with Can Do Multiple Sclerosis in Avon, Colorado, "Squats may help someone improve the strength and balance needed to get into or out of a chair more easily."

Lunges are another example of a functional exercise. "They would help someone improve the functional task of getting on and off the floor," she says.

Squats and lunges may be a common move in any given exercise routine, but they can just as easily be a



PHOTO COURTESY OF MERRILL HESCH

Merrill Hesch, diagnosed with MS in 2011, discovered that functional exercise helped her regain strength.

functional exercise when they serve as a means to a specific end, Rohrig says.

The rewards of functional exercise can be seen in the short term, but they also compound over time. Getting out of a chair, for example, is just one of the little things many people do every day that can help facilitate a healthy level of physical activity.

Kathleen Zackowski, PhD, is the senior director of Patient Management, Care and Rehabilitation Research for the National Multiple Sclerosis Society. She works on the research portfolio that focuses on wellness and rehabilitation.

Lifestyle physical activity is one area of wellness that is being studied. This type of activity includes cleaning the house or preparing a meal, things we all do to keep active throughout the day.

"Lifestyle physical activity includes activities that are planned and unplanned leisure, occupational and household tasks," Zackowski says.

### Physical activity benefits quality of life

Research shows that maintaining a healthy baseline of activity has benefits for people's quality of life. "It's really critical to protect our ability to stay active," Zackowski says. From walking, to standing with or without assistance, to feeding oneself, "It doesn't matter what level of ability one has, everyone should work to participate in some level of activity."

Functional exercise can help enhance participation in lifestyle physical activities, Zackowski says. For example, preparing a meal might require a lot of walking back and forth around a kitchen. One form of exercise that might help in that case could be walking in a swimming pool. "Some people enjoy this form of exercise most because they can stand and walk with less assistance, using the resistance of the water to support them as they walk," she says.

Walking in a pool could also allow a person to push themselves harder than they might otherwise because the cool water can mitigate the discomfort that many



people experience when they become overheated.

Zackowski notes that heat sensitivity, along with fatigue, can be potential barriers to any kind of exercise, including functional exercise, for people with MS. The freedom that comes with a routine that can be done at home on your own time can be particularly helpful in that respect, she says. "Symptoms of MS often fluctuate. Participating in a functional exercise program at home gives a person the flexibility to do one activity one day, and another the next."

Knowing which exercises to do isn't always as easy as squats for sitting, or practicing rolling over to get better at rolling over in the bed. Exercises should focus on strengthening the muscle groups required to perform certain activities.

"If an individual uses a transfer or sliding board to transfer from a wheelchair to another chair, they would require good shoulder blade and tricep muscle strength to push off," Rohrig says. "The functional exercise that may be helpful would be triceps strengthening, such as tricep dips."

To address foot drop, a person might benefit from shin-strengthening exercises. Improving balance might mean standing with one's feet

**Lifestyle physical activity is one area of wellness that is being studied. This type of activity includes cleaning the house or preparing a meal, things we all do to keep active throughout the day.**

progressively closer together. It might not always be obvious which functional exercises address certain conditions. For that reason, Rohrig says seeking professional help is a good move.

### Take symptoms into account

“I think it’s important for people with MS to consider a consultation with a physical therapist to help prioritize the exercises that can optimize individual function while taking into consideration MS symptoms,” she says.

**Preparing a meal might require a lot of walking back and forth around a kitchen.**



ISTOCK.COM/DMYTRO BOCHKOV

## Functional exercises that help daily living

### Carrying a child

Lifting weights from the floor to the chest may translate into improved ability to lift a child.

### Bringing bags of groceries from your car to the kitchen in one trip

Carrying kettlebells in one or both hands while walking can simulate carrying bags of groceries.

### Sitting without support or positioning yourself in bed

Core strengthening may help with bed mobility or sitting balance.

### Operating a manual wheelchair

Try a tricep extension: Strengthen your shoulder extensors by holding a light dumbbell in one hand. Bend forward in your chair until your chest hits your knees, holding the dumbbell toward the floor. Keeping the arm straight, pull it back, behind you. Return to the starting position.

### Improving posture when seated in your wheelchair

Try a dumbbell row: Strengthen your scapular retractors by holding a light dumbbell in one hand. Bend forward in your chair until your chest hits your knee, holding the dumbbell toward the floor. Pull your shoulder blades together and bend your elbow to bring the weight up toward your chest.

## in the know

That advice rings true for Hesch.

From day one, she wanted to be able to walk unassisted. But the exercise that she thought would help — walking slowly on a treadmill — was a no-go for her. “Every now and then I would try it at the gym,” she says, but it didn’t help. “The path was never that straightforward.” In the end, what helped with her gait? “Biking,” she says without hesitation. “The more I bike, the better I walk.”

Over a 15-month period, Karpatkin was able to help Hesch walk without the crutches she had been using. She now uses Nordic walking sticks to help combat her fatigue.

For someone who uses a wheelchair, Karpatkin says, the issue is the same: “What is the function they want to carry out? What do they want to do that they cannot do?” he asks. “It’s an issue of determining that task, asking what limitations MS has imposed and how we can address those limitations.”

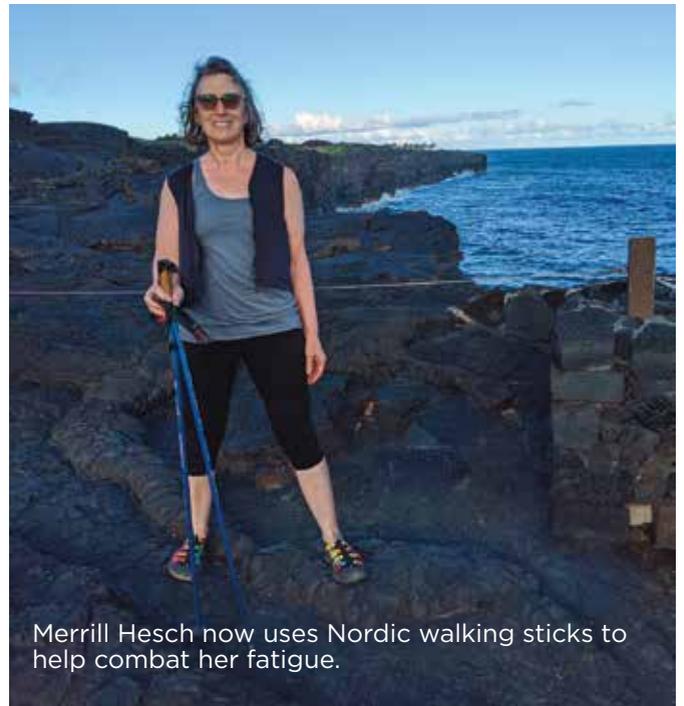
To help transfer from a wheelchair to a seat, exercises that strengthen certain shoulder muscles are helpful. For example, try holding onto your wheelchair’s armrests or push rims and lifting your bottom off of the seat.

But for people Karpatkin sees who primarily use devices to help get around, he asks one important question first: Have you tried physical therapy before turning to an assistive device?

“I see it all the time,” he says. “Someone with MS goes to a doctor and, instead of prescribing physical therapy, the doctor says, ‘Here’s a cane,’ or ‘Here’s a brace.’ And that can make things worse,” Karpatkin says. “Rather than trying exercise to improve or compensate for limitations, the cane or the brace can make them walk less.” And the less someone walks, the weaker the muscles needed to perform that specific task become.

“It’s something I’m very passionate about,” Karpatkin says. “There are a large number of underserved patients who have no problem getting the medication they need, but the physical therapy is rarely prescribed.

Whether it’s running a six-minute mile or standing unassisted for a few moments, exercise can be hard, but ultimately, it’s worth the effort.



Merrill Hesch now uses Nordic walking sticks to help combat her fatigue.

PHOTO COURTESY OF MERRILL HESCH

“Keep a positive attitude,” Zackowski says. “Maintain a certain level of activity so you’re not going through weeks when you’re not active, but be kind to yourself,” she adds. “Life is complicated, and this is an important part of life.” ■

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

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Learn more about the benefits of exercise at [ntlms.org/Exercise](https://ntlms.org/Exercise).

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

# Finally... a better mobility solution than Scooters or Power Chairs.

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

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

After just one trip around your home in the Zoomer, you'll marvel at how easy it is to navigate. It is designed to maneuver in tight spaces like doorways, between furniture, and around corners. It can go over thresholds and works great on any kind of floor or carpet. It's not bulky or cumbersome, so it can roll right up to a table or desk- there's no need to transfer to a chair. Its sturdy yet lightweight aluminum frame makes it durable and comfortable. Its dual motors power it at up to 3.7 miles per hour and its automatic electromagnetic brakes stop on a dime. The rechargeable battery powers it for up to

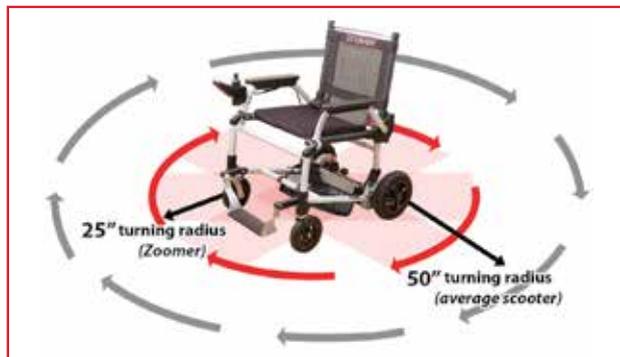


8 miles on a single charge. Plus, its exclusive foldable design enables you to transport it easily and even store it in a closet or under a bed when it's not in use.

Why spend another day letting mobility issues hamper your lifestyle? Call now and find out how you can have your very own Zoomer.

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The secret to the Zoomer is its simple steering system. You operate it with a simple-to-use joystick, giving you precision maneuverability and the ability to navigate tight spaces easily with a 25" turning radius. It is designed to let you pull right up to a table or desk. You no longer have to move to another chair to work or eat at your table



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Please mention code 113135 when ordering.



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## ADVERTISEMENT

I WON'T LET RELAPSING MS DEFINE

# MY LOOK

Discover VUMERITY® (diroximel fumarate)—an oral treatment for relapsing MS. **Together, let's celebrate what makes you truly you.**



### VUMERITY MAY WORK AGAINST RELAPSING MS IN THREE WAYS:



### What is VUMERITY® (diroximel fumarate)?

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

### Important Safety Information

#### Do not take VUMERITY if you:

- have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to diroximel fumarate, dimethyl fumarate, or any of the ingredients in VUMERITY
- are taking dimethyl fumarate

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

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

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

#### What should I avoid while taking VUMERITY?

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

#### What are the possible side effects of VUMERITY?

#### VUMERITY may cause serious side effects including:

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing). Stop taking VUMERITY and get emergency medical help right away if you get any of these symptoms
- **PML (progressive multifocal leukoencephalopathy)** a rare brain infection that usually leads to death or severe disability over a period of weeks or months. Tell your healthcare provider right away if you get any of these symptoms of PML:
  - weakness on one side of the body that gets worse
  - clumsiness in your arms or legs
  - vision problems
  - changes in thinking and memory
  - confusion
  - personality changes



- **herpes zoster infections (shingles)**, including central nervous system infections
- **other serious infections**
- **decreases in your white blood cell count** Your healthcare provider should do a blood test to check your white blood cell count before you start treatment with VUMERITY and while you are on therapy. You should have blood tests after 6 months of treatment and every 6 to 12 months after that
- **liver problems.** Your healthcare provider should do blood tests to check your liver function before you start taking VUMERITY and during treatment if needed. Tell your healthcare provider right away if you get any of these symptoms of a liver problem during treatment
  - severe tiredness
  - loss of appetite
  - pain on the right side of your stomach
  - have dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes

**The most common side effects of VUMERITY include:**

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

These are not all the possible side effects of VUMERITY. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. **For more information go to [dailymed.nlm.nih.gov](http://dailymed.nlm.nih.gov)**

**Please see Patient Information on the following page and full Prescribing Information at [VUMERITY.com](http://VUMERITY.com).**



**VUMERITY comes with support**

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

**ASK YOUR HEALTHCARE PROVIDER** or get more details at **[KnowVUMERITY.com](http://KnowVUMERITY.com)**

 **VUMERITY**<sup>®</sup>  
(diroximel fumarate) delayed-release capsules 231 mg

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

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- are taking dimethyl fumarate.

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

**How should I take VUMERITY?**

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

**What should I avoid while taking VUMERITY?**

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

**What are the possible side effects of VUMERITY?**

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**For more information go to [dailymed.nlm.nih.gov](http://dailymed.nlm.nih.gov)**

**How should I store VUMERITY?**

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

**General Information about the safe and effective use of VUMERITY**

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

**What are the ingredients in VUMERITY?**

**Active ingredient:** diroximel fumarate

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

Manufactured for: Biogen Inc., Cambridge, MA 02142, [www.VUMERITY.com](http://www.VUMERITY.com) or call 1-800-456-2255

## 5 tips to save on prescriptions

Cost can be a real barrier to being able to buy the medications you need. If you are struggling to afford your medications or just want to save money, the following tips might help.

1

**Flexible Spending Accounts.** People who have a health insurance plan through their jobs can use a flexible spending account (FSA) to pay for copayments and deductibles, some prescription and over-the-counter medications, certain medical equipment and supplies, and some other healthcare costs. FSAs usually are accepted at large retailers like Target, Walmart and Amazon; pharmacy chains like CVS and Walgreens; and even your local pharmacy under certain conditions.

2

**Charitable programs.** National charitable relief programs such as NeedyMeds, the Patient Advocate Foundation Co-Pay Relief Program and PhRMA's Medicine Assistance Tool offer assistance to people who meet eligibility requirements. For information about prescription assistance, go to [ntlms.org/PAP](https://ntlms.org/PAP).

3

**Coupons.** Websites like GoodRx can help you compare generic and brand-name drug prices at nearby pharmacies and offer coupons for additional savings.

4

**Mail-order services.** Using your insurance company's mail-order service might be more cost-effective than filling a prescription at your local pharmacy.

5

**Manufacturer savings programs.** Some pharmaceutical manufacturers have their own programs to help people save money on their medications. Check to see if the makers of any name-brand medications you take offer assistance.



# thrive

Forging a path  
to your best life

Inside this section: 8 steps to fiscal freedom 24 // When MS isn't your only disease 32



ISTOCK.COM/ELLJASENOVA

# **8** steps to **fiscal**

Pursue a clean 'bill' of health with these financial planning tips.

by Matt Alderton



**M**ultiple sclerosis doesn't just affect your health. It also can affect your wealth.

Just ask Angela Bradford of Edmonton, Alberta. On July 1, 2018, she was out socializing with friends when she suddenly lost the ability to walk. Nearly a year and countless stumbles later, she found out why: She has MS.

Even though she has insurance to cover her care and treatment, she's been seeing dollar signs ever since. Because she's more vigilant about her health, for example, she's spending more on groceries and fitness classes in pursuit of better nutrition and more exercise. Every time she goes to the doctor, she has to pay for parking. And if her illness progresses, someday she might not be able to work.

"The financial ramifications of a chronic illness can be crazy," says Bradford, 37, whose saving grace was her profession: Four years ago, she became an independent financial broker who assists individuals, families and businesses with financial planning. Because she practices what she preaches, she had ample resources to counter any financial issues.

Not everyone is so lucky: According to the Federal Reserve, 25% of Americans are "just getting by" or worse, and 4 in 10 do not have enough cash, savings or credit to cover an emergency expense of \$400. And chronic illness costs a lot more than \$400: Research shows that the average American with one or two



PHOTO COURTESY OF ANGELA BRADFORD

Angela Bradford, who has MS, helps others with financial planning.

**25%**  
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**emergency expense**  
**of \$400.**

# fitness



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chronic illnesses pays approximately \$4,000 per year in out-of-pocket healthcare costs, and that the onset of a chronic disease reduces one’s wages by 18%.

“I would be hard-pressed to find anyone whose illness hasn’t affected their financial well-being,” says

Annelise Bretthauer, a certified financial planner who used

her own experience with chronic illness — she was diagnosed with Crohn’s disease in 2017 — to establish Rise Up Financial, a Hillsboro, Oregon-based practice that specializes in financial planning for individuals with chronic disease.

According to Bretthauer, health and money are inextricably linked. “I think it’s really important that people take ownership of their health,” she says. “Financial planning is part of that.”



Annelise Bretthauer specializes in financial planning for those with chronic illnesses.

PHOTO COURTESY OF ANNELISE BRETTHAUER

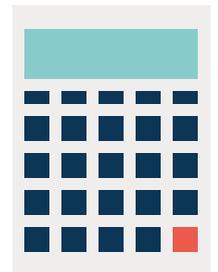
Although fiscal health is as individual as physical health, a strong financial plan is universally helpful. It starts with the following steps:

**1 Take a financial inventory.**

Financial planning starts with two fundamental questions: How much money do you need, and how much do you have?

Certified financial planner Dick Bell likens it to a shopping-mall directory. “Let’s presume we’re at the Mall of America ... and we want to find a particular store,” explains Bell, owner of Bell Financial in Calabasas, California. “We could wander around all day until we find it, or we can go to the directory, which tells us not only where it is, but more important, our starting point.”

You can define your financial destination by calculating your current and future living expenses — how much money you require for housing, food and other expenses, including healthcare. The latter can be especially difficult to define for people with MS



because they can fluctuate widely based on disease progression. Your doctor's administrative staff, however, may be able to help you estimate based on potential scenarios, Bretthauer says.

Once you have an understanding of what you need, you must assess what you have, including income sources such as employment, Social Security, assets (your home, savings, retirement funds, investments) and liabilities (debt).

"You can't plan unless you know what you're dealing with," Bell says.

## 2 Eliminate credit card debt.

If what you need is greater than what you have, you must fill the gap, which is impossible when you have credit card debt, the interest on which can wreak havoc on your wallet.



Although there are numerous debt-reduction methods, Bell is partial to the avalanche and snowball methods. With the former, you focus on paying off the credit card with the highest interest rate first, which can help you get out of debt more quickly. With the latter, you focus on paying off the credit card with the lowest balance first, which gives you a quick win that can keep you motivated.

However you approach it, debt reduction likely will require sacrifices — putting the money you spend on new clothes or lattes, for example, toward debt repayment. "You should have more money coming in every month than you have going out," Bell says. "If you don't, you have to cut back on spending."

## 3 Step up your savings.

Just as important as reducing debt is increasing savings.

"If I'm driving to work and get a flat tire, it's going to cost \$200. For somebody who doesn't have \$200, that's a real problem," Bell says. "So, it's important to build up a pot of money for a rainy day."



Bell recommends stockpiling at least three months of living expenses; once you reach that goal, he says, aim for six months.

"If you have trouble saving, have money automatically put into a savings account," continues Bell, who says many banks and credit unions allow you to do this by setting up automatic withdrawals from your paycheck.

Supplemental income also can help with savings. You could take on a roommate and collect rent, for example, or start a home-based business — as long as you're careful not to jeopardize needed public assistance by exceeding associated income limits.

"In today's world, 'work' means a lot of different things. Even if you have a disability that keeps you out of the traditional workforce, there might be other ways you can earn income," explains Bretthauer, who recommends a "bucket" approach to saving: Divide savings into separate accounts earmarked for specific purposes.

For people with MS, one of those buckets should be for healthcare. "I recommend looking at your health insurance to see what your out-of-pocket maximum is and having at least that much money set aside in a healthcare emergency fund," Bretthauer says.

## 4 Exercise your insurance options.

Speaking of insurance: Because it can keep financial crises at bay, it's a critical piece of everyone's financial plan.



"An ounce of prevention is worth a pound of cure," says certified financial planner Nilay Gandhi with Vanguard Personal Advisor Services, who recommends conducting an insurance review to determine what policies you have, what your premiums and copays are, and whether there are any exclusions or elimination periods (the amount of time before you begin receiving benefits).

Along with health insurance, people with MS should consider disability and life insurance. Because both can be prohibitive to obtain with a chronic illness, those who work should take advantage of group policies when their employers offer them.

"Having group coverage means you don't have to go through the underwriting process," Bretthauer says. "That can be vital to getting covered when you have a chronic illness."

Group disability policies typically replace a portion of your income (50–60%) during a finite benefit period. Because they have value in the eyes of the IRS, such policies are taxable if the benefit is paid for by your employer, although employers typically let you decide whether you want to pay taxes on the value of the benefit now or be taxed if you develop a disability later.

People with MS should pay them now, says Ben Soccodato, a certified financial planner and chartered special-needs consultant at Barnum Financial Group in Westchester, New York. The reason is simple: If you pay taxes now, you'll be taxed on the value of the premiums, which in most cases is less than \$1,500 per year. If you pay taxes later, you'll be taxed on the value of the benefit you receive.

"A couple hundred dollars of additional tax money upfront could provide you tens of thousands of dollars in extra income if you actually become disabled," Soccodato says.

If you have dependents, sign up for group life insurance, suggests Soccodato, who says employers typically offer an optional supplemental benefit people



Nilay Gandhi recommends insurance reviews.



The timing of your tax payments can make a difference in your savings, says Ben Soccodato.

PHOTO COURTESY OF NILAY GANDHI

PHOTO COURTESY OF BEN SOCCODATO



**A couple hundred dollars of additional tax money upfront could provide you tens of thousands of dollars in extra income if you actually become disabled."**

—BEN SOCCODATO

with MS and their spouses should take advantage of. "The employer plan may only give you \$50,000 of coverage, but you can elect another \$100,000 or \$200,000 in coverage without going through medical underwriting," Soccodato explains.

**5 Home in on your home.**

Because it's probably your biggest investment, your home is low-hanging fruit if you need to improve cash flow in the face of chronic illness.



"The home is close to the heart.

To reduce its effect on your finances, work with your lender to see if there are actions you can take to mitigate the impact of your mortgage," advises Gandhi, who says you may be able to lower your monthly payments by refinancing, which can lighten your financial load and help you avoid or delay foreclosure if money gets tight.

Although a low mortgage payment can help your short-term finances, what's best for your long-term finances is having no mortgage payment at all, according to Bell, who recommends applying extra cash when you have it toward your mortgage principal. Doing so, he says, will help you pay off your loan sooner so you can retire debt-free. That will help you feel emotionally secure in your home, allow you to direct money toward other financial goals and give you a nest egg in the form of home equity.

Whether you need it for retirement or long-term care, you can access that equity by selling your home or securing a reverse mortgage. "I look at the home as a last-resort place to take money from," Bell says. "But if your house is paid off and you start to accumulate

medical or other bills you can't handle, a reverse mortgage might make sense in order to generate extra income."

## 6 Redefine retirement.

Retirement planning is especially important for people with MS because they might have a shorter working life.

"When I talk to the average person about retirement, we're usually planning on a time horizon of 30 years. But when you have a chronic illness, you might need that money in three years," Bradford says.

That uncertainty requires thinking differently about retirement, according to Bretthauer, who says people with MS should still save for retirement but should invest their retirement savings differently. For example, whereas a typical person in their 30s or 40s may invest aggressively in stocks — which can lose significant value overnight as a result of market fluctuations — people with MS should think about investing more conservatively to ensure funds are available when they're needed.



An employer-sponsored 401(k) plan is the best retirement savings vehicle, according to Bell, who suggests putting as much money as possible into your 401(k) so as to take advantage of employer matches. "The more you can put into your retirement plan, and the earlier, the better," he says.

## 7 Fast-track legal planning.

Financial planning goes hand-in-hand with legal and estate planning — especially for people with MS.

"Being prepared for death is necessary for everybody, but when you have a chronic illness it brings it to the forefront," explains Bradford, who says everyone should have the following estate-planning documents:



- A will, which sets forth how and to whom you wish your property to be distributed.
- An advance directive, which describes what medical

treatments you want if you're dying, permanently unconscious or otherwise unable to make medical decisions.

- Durable financial and healthcare powers of attorney, which name proxies to make financial and healthcare decisions for you, respectively, if you're incapacitated.

If you have wealth that you want to pass on to your heirs, an estate-planning attorney also can help you set up a trust, which can be a tax-efficient and probate-resistant means of bequeathing assets.

Certain types of trusts can even benefit you while you're living, according to Soccodato, who recommends that people with MS ask an elder-law attorney about Medicaid asset protection trusts and special needs trusts, both of which can help you qualify for Medicaid and/or Supplemental Security Income (SSI) by putting your assets into the hands of a third party who can distribute them to you for certain allowable living expenses.

## 8 Plan with a professional.

Find a financial professional to help you navigate all these issues.

Although there are many types of financial professionals, Bretthauer says "fee-only financial planners" are ideal because they give independent, objective



advice and do not make income from commissions on financial products. You can find one near you by consulting the National Association of Personal Financial Advisors (NAPFA), which has a "find an advisor" tool on its website.

The Society also can help: Its Financial Education Partners (FEP) program, led by Bell, provides pro bono financial planning and education to individuals with special health or financial circumstances. You can be screened for a financial planning referral by contacting an MS Navigator at 1-800-344-4867, emailing **ContactUsNMSS@nmss.org** or going online at **nationalMSsociety.org/navigator**.

Whoever you choose, it's important to make sure they have not only the right credentials — a certified

## Planning and progression

Multiple sclerosis symptoms can change. Your financial needs and objectives should therefore evolve as your illness progresses, suggests Annelise Bretthauer, owner of Rise Up Financial in Hillsboro, Oregon.

Based on her own experience — she has Crohn’s disease — Bretthauer says people with chronic illness typically fall into one of two financial planning groups, the first being the newly diagnosed.

“There is so much to learn about your disease when you are first diagnosed, and money is a big part of that,” Bretthauer says. “To take care of your health, you need money, and to make money, you need your health. It’s a very emotional cycle that impacts a family from every angle.” Bretthauer says people who are newly diagnosed with MS should ask the following questions when doing their financial planning:

- What medications will I need, and how much will they cost?
- Are there other lifestyle changes I need to make— for example, to diet, exercise or sleep — that will cost money?
- What benefits are available to me through my employer or the government?
- Do I have insurance? Am I still insurable?
- Do I need to change my spending habits in response to increased medical expenses?

After they live with their illness for a while, people eventually graduate to a new, more mature stage of financial planning that is less reactive and more proactive.

“Chronic illnesses can be unpredictable. We need to prepare financially for that unpredictability,” Bretthauer says. “It’s a balance between finding small, easy financial adjustments you can make today and planning ahead for the bigger adjustments you may need to make tomorrow.”

Bretthauer says individuals who are more mature in their illness should ask the following questions:

- What steps can I take to slow or stop the progression of my disease, and will those cost money?
- If I cannot stop the progression, how do I want to continue living my life and what resources will that require?
- Is my family set up financially if something were to happen to me?
- Have I completed my estate plan?

Whatever stage of illness you’re in, it’s important to remember that financial wellness often hinges on mental wellness.

Concludes Bretthauer, “Having a chronic illness can be overwhelming. If you get your mind in the right space, doing what you need to do financially is a lot easier.”

financial planner (CFP) designation is the gold standard — but also the right chemistry.

“It’s important to find someone who fits well with who you are,” Bretthauer concludes. “Otherwise, it can be very hard to want to implement their recommendations.” ■

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Matt Alderton is a Chicago-based writer and editor.



Learn more about financial planning, resources and how to find the right professional at [ntlms.org/financialplanning](https://ntlms.org/financialplanning).

The Financial Planning for a Life with MS brochure is available at [ntlms.org/planningpdf](https://ntlms.org/planningpdf).

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

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**JOSEPH**  
**DIAGNOSED IN 2008**

# When MS isn't your only disease

Other chronic health conditions may be common —  
and connected.

by Vicky Uhland

**F**or much of her life, Lorrie Bortner has dealt with an irritable bowel and lactose intolerance. About a decade ago, her cholesterol levels began to spike. And last year, she had surgery for endometrial cancer.

In 2016, at age 62, Bortner was diagnosed with primary progressive multiple sclerosis. She experienced symptoms for at least five years before her diagnosis, and her husband thinks she may have had the disease for many years before that.

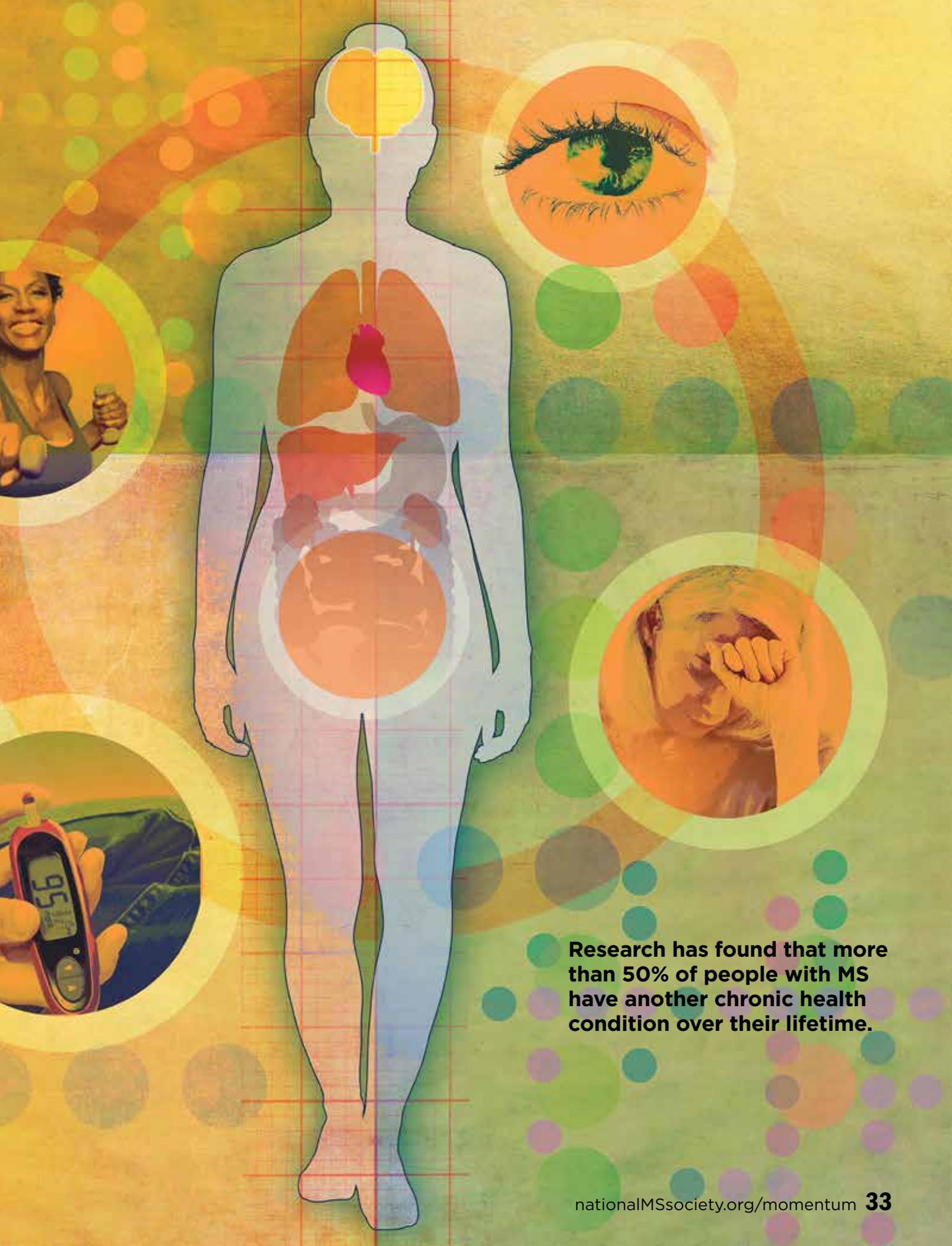
Bortner says her doctors have looked at each of her health conditions as separate incidences with different causes. But over the years, she's wondered if her various health issues are somehow related. Could her MS be a factor in her other diseases, and vice versa?

Increasingly, researchers are discovering this may very well be the case. In the past decade, there have been dozens of studies on the association between MS and coexisting health conditions, known as comorbidities. And the results have been eye-opening.

“Our research has found that more than 50% of people with MS have another chronic health condition over their lifetime,” says Ruth Ann Marrie, MD, PhD, professor of medicine and community health sciences at the University of Manitoba, Canada, and director of the Multiple Sclerosis Clinic at the Health Sciences Centre in Winnipeg.

In Bortner's case, high cholesterol and irritable bowel are common

ILLUSTRATIONS BY ROY SCOTT



**Research has found that more than 50% of people with MS have another chronic health condition over their lifetime.**

MS comorbidities — and may have even delayed her MS diagnosis. As with many factors associated with MS, researchers aren't sure why Bortner and others living with MS can also have seemingly unrelated health conditions. But studies have revealed some causes and consequences of these dual diagnoses.

### Key characteristics of comorbidities

Age is an important factor in MS comorbidities. Your likelihood of developing another disease increases with age, Marrie says. This is particularly true if the comorbidity is vascular, such as heart disease, diabetes, high blood pressure or high cholesterol.

Like MS, vascular diseases are related to inflammation, says Tingting Zhang, MD, PhD, assistant professor at Brown University School of Public Health's Center for Gerontology and Health Care Research. These diseases also share common risk factors with MS, such as smoking and obesity.

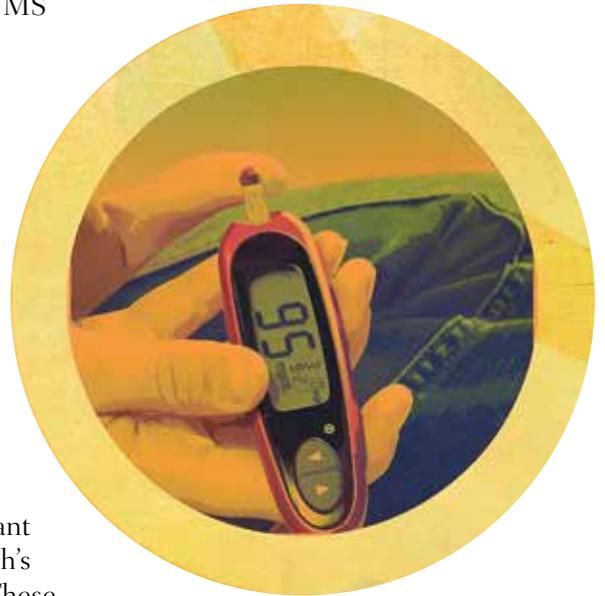
In addition, vascular diseases may have symptoms similar to MS, particularly fatigue. Healthcare providers can focus on treating those conditions and might not do tests to see if their patient also has another disease like MS. Consequently, people with cardiovascular disease are more likely to have a MS diagnosis delay, Zhang says. "And that delay can be up to 10 years."

Other health conditions that share symptoms with MS — particularly depression and anxiety — can delay MS diagnosis as well, Zhang says. And, in a Catch-22, having a higher number of comorbidities can also increase MS symptoms.

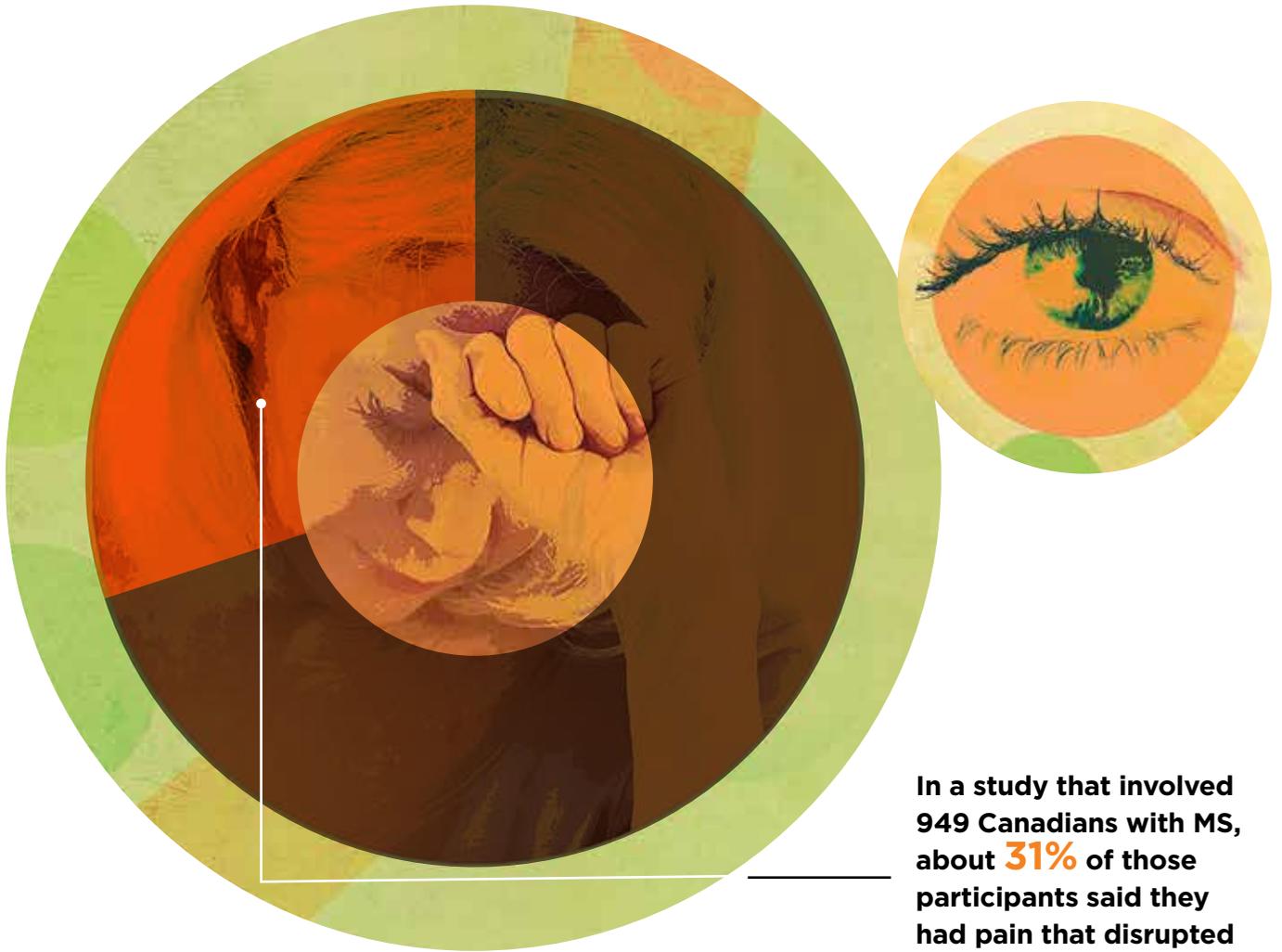
"For instance, if someone has fatigue and MS and diabetes and depression, that can affect physical and cognitive impairment," Marrie says. "And the more comorbidities you have, often the more fatigue and pain issues."

One of her studies on this subject, published in 2015 in *Multiple Sclerosis and Related Disorders*, involved 949 Canadians with MS. About 31% of the study participants said they had pain that disrupted their lives.

In particular, the comorbidities of fibromyalgia, rheumatoid arthritis, irritable bowel syndrome, migraine, chronic lung disease, depression, anxiety, high blood pressure and high cholesterol were associated with disruptive pain. And people with chronic obstructive pulmonary disease, anxiety and thyroid disease reported worsening pain during the course of the two-year study.



**If someone has fatigue, MS, diabetes and depression, that can affect physical and cognitive impairment.**



**In a study that involved 949 Canadians with MS, about 31% of those participants said they had pain that disrupted their lives.**

### **How comorbidities affect MS progression**

Several studies show that vascular comorbidities may be associated with a quicker progression of MS-related disability. But Marrie points out that cardiovascular disease and diabetes are often age-related and can also occur at the age when someone's MS transitions from relapsing-remitting to progressive. Therefore, the disease progression/comorbidity link may very well be a complex scenario.

Marrie says researchers don't know yet whether other types of comorbidities contribute to MS progression, or whether controlling these health conditions can slow progression. However, one of her studies, published in 2017 in *Neurology*, showed that people with MS who were also diagnosed with migraines or high cholesterol, or who had three or more comorbidities, had more relapses over a two-year period than people with MS who did not have those comorbidities.



Living with relapsing multiple sclerosis (MS)?

# TAKE A LOOK

at a once-daily pill for MS

## People had fewer relapses with ZEPOSIA

↓ **48%**

**FEWER RELAPSES**

### In a one-year study:

People who took ZEPOSIA had 48% fewer relapses than those who took a leading injectable medicine (Avonex).<sup>\*†</sup>

↓ **38%**

**FEWER RELAPSES**

### In a separate two-year study:

People who took ZEPOSIA had 38% fewer relapses than those who took a leading injectable.<sup>†</sup>

See additional study results at [ZEPOSIA.com/results](https://www.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).

### 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

**IMPORTANT SAFETY INFORMATION (cont'd)****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)

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

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

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

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

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

Continue reading for additional possible serious side effects of ZEPOSIA.

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

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

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

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

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

**ZEPOSIA can cause serious side effects, including:**

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

**The most common side effects of ZEPOSIA can include:**

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

These are not all of the possible side effects of ZEPOSIA. For more information, ask your healthcare provider or pharmacist. Call your healthcare provider for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.FDA.gov/medwatch](http://www.FDA.gov/medwatch) or call 1-800-FDA-1088.

**Please see Brief Summary of Information on next page.**

This information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have any questions about ZEPOSIA® (ozanimod), ask your healthcare provider. Only your healthcare provider can determine if ZEPOSIA is right for you.

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

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

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

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

**What is ZEPOSIA?**

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- have or have had a history of certain types of an irregular or abnormal heartbeat (arrhythmia) that is not corrected by a pacemaker.
- have untreated, severe breathing problems during your sleep (sleep apnea).

- take certain medicines called monoamine oxidase (MAO) inhibitors (e.g., selegiline, phenelzine, linezolid). Talk to your healthcare provider before taking ZEPOSIA if you have any of these conditions or do not know if you have any of these conditions.

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

- have a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.
- received a vaccine in the past 30 days or are scheduled to receive a vaccine. ZEPOSIA may cause vaccines to be less effective.
- Before you start treatment with ZEPOSIA, your healthcare provider may give you a chicken pox (Varicella Zoster Virus) vaccine if you have not had one before.
- have had chickenpox or have received the vaccine for chickenpox. Your healthcare provider may do a blood test for the chickenpox virus. You may need to get the full course of the vaccine for chickenpox and then wait 1 month before you start taking ZEPOSIA.
- 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 alemtuzumab
- medicines to control your heart rhythm (antiarrhythmics), or heart beat
- strong CYP2C8 inhibitors such as gemfibrozil or clopidogrel
- medicines that inhibit breast cancer resistance protein transporters, such as cyclosporine and eltrombopag
- CYP2C8 inducers such as rifampin
- opioids (pain medicine)
- medicines to treat depression
- medicines to treat Parkinson’s disease

## Brief Summary of Information About ZEPOSIA® (zeh-poe'-see-ah) (ozanimod) capsules

Rx Only

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

Talk with 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 in the table below. This may reduce the risk of slowing of the heart rate.**

Days 1-4	Take 0.23 mg (capsule in light grey color) 1 time a day
Days 5-7	Take 0.46 mg (capsule in half-light grey and half-orange color) 1 time a day
Days 8 and thereafter	Take 0.92 mg (capsule in orange color) 1 time a day

- 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?

**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 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. See “**How should I take ZEPOSIA?**” section for more information.
- **breathing problems.** Some people who take ZEPOSIA have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems.

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

- blurriness or shadows in the center of your vision
- a blind spot in the center of your 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 with drugs in the same class. Symptoms of PRES usually get better when you stop taking ZEPOSIA. If left untreated, it may lead to a stroke. Your healthcare provider will do a test if you have any symptoms of PRES. Call your healthcare provider right away if you have any of the following symptoms:

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

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

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

### The most common side effects of ZEPOSIA can include:

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

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

### General information about the safe and effective use of ZEPOSIA.

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

Manufactured for: Celgene Corporation, Summit, NJ 07901

Patent: [www.celgene.com/therapies](http://www.celgene.com/therapies)

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The type of comorbidity may also determine whether someone is initially diagnosed with the relapsing-remitting or progressive forms of MS.

In a study published in 2011 in *Acta Neurologica Scandinavica*, Marrie and her fellow researchers found that in women, gastrointestinal comorbidities and obesity were more associated with a diagnosis of relapsing-remitting MS. And the same was true for both women and men with mental comorbidities like depression and anxiety.

“The questions about why MS and comorbidities travel together are important questions we need to pursue,” she says. “I don’t think we can give one explanation for all comorbidities.”

Research reveals some comorbidities have shared genetic factors, Marrie says. For instance, inflammatory bowel disease and MS have some shared genes.

### Common comorbidities

A variety of studies have found that along with vascular diseases, depression and anxiety are the most common MS comorbidities.

“Some studies say up to half of people with MS may experience depression in their lifetimes, and a third of people may experience anxiety,” Marrie says. “Structural and functional changes in the brain due to MS may play a role in depression and anxiety, along with inflammation.” And, as with the general population, genetic risk and stressful events are also relevant risk factors for anxiety and depression.

Other comorbidities associated with MS include:

- **Autoimmune diseases** like psoriasis
- **Gastrointestinal issues** like inflammatory bowel disease and irritable bowel syndrome
- **Chronic lung diseases** like asthma
- **Vision issues** like cataracts, glaucoma and uveitis (eye inflammation)
- **Some cancers**, like bladder cancer and meningiomas (brain tumors)

Research also reveals the following about comorbidity prevalence:

- In a 2008 questionnaire involving nearly 9,000 people with MS, Marrie and her team found that men were more likely to have a comorbidity than women.
- A 2018 retrospective analysis of 5 million Americans

### The most common comorbidities of Americans with MS

**High blood pressure and high cholesterol**  
(26% to 30% of all people analyzed)



with MS 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%).

- In a 2015 review of 118 studies, Marrie and her team found that along with depression and anxiety, other psychiatric comorbidities are common in people with MS. Nearly 15% abuse alcohol, 6% have bipolar disorder, 4% have psychosis and 3% abuse substances.
- A 2019 study of nearly 57 million Americans with and without MS found that asthma was a whopping three times more common in people with MS. The greatest prevalence of asthma in people with MS was in those younger than age 30 and those older than age 80.

### Diagnosing a comorbidity

Before being diagnosed with endometrial cancer, Bortner knew something was wrong with her body and that it wasn’t MS-related.

“I had some weird symptoms like bleeding, so I knew it was gynecological,” she says. “But with other symptoms, sometimes I can’t tell if they’re due to MS or something else.”

Bortner has heard about MS comorbidities, but not from her doctors. Part of that, she believes, is because she lives in Taos, New Mexico, a small town with no

**Gastrointestinal disease**  
(18% to 21%)



**Thyroid disease**  
(13% to 17%)



neurologists. Her primary care doctor helps her manage her high cholesterol, but she worries he’s not educated enough about MS to also know things like what types of vaccines she should get. “After my first shot for shingles, I was paralyzed from the waist down for eight hours,” she says. “I don’t know if that had to do with my MS, so I didn’t get the second shot.”

Zhang says there’s plenty of research on MS comorbidities; it is expected that the majority of neurologists should be familiar with them, even if they don’t specialize in MS. But other healthcare professionals might not be as knowledgeable about these complex issues. Here’s what Zhang and Marrie say you can do to help with this problem.

### Coordinating your care

Zhang recommends asking your primary care doctor for cholesterol, blood glucose and other tests to detect common vascular comorbidities. And Marrie suggests giving every healthcare professional you visit a list of your health conditions and medications. Keep the list on your smartphone as well, so you always have it available.

If you have a new symptom or health concern, make sure to consult with your neurologist. “A non-MS provider may mistakenly say, ‘It’s your MS,’ while a neurologist comfortable with MS may consider other possibilities,” Marrie says.

It’s also important to note that medications for other health conditions could interfere with your MS

medications, and vice versa. For instance, Marrie says, fingolimod (Gilenya) can slow your heart rate, so it isn’t advisable to take if you have certain vascular issues or are taking some medications to manage high blood pressure or heart disease.

But whatever you do, don’t take your medications into your own hands. “People with comorbidities may take many medications, so they can feel overwhelmed and choose which medications to take,” Zhang says. “Patients may need to work with their primary physicians and MS specialists together to decide the most appropriate medications they should take,” she says.

Consider asking one healthcare professional — maybe your primary care provider if you see him or her most frequently — to be a coordinator for your various health treatments and medications. And look into using a single pharmacy for all of your medications, as its prescription software will likely flag any drug interactions.

### DIY comorbidity prevention

While your MS diagnosis might make you more susceptible to some other health conditions, that doesn’t mean you’re helpless. Many of the steps you can take to reduce the severity of MS symptoms can also lower your risk of developing comorbidities.

In particular, research shows the following strategies are effective:

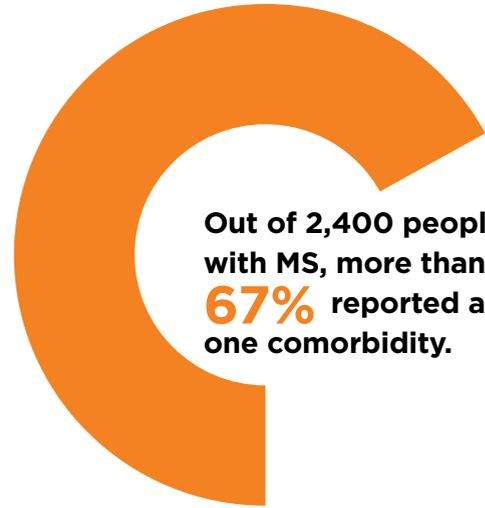
- **Watch your weight.** A survey of nearly 2,400 people with MS, published in 2016 in PLoS One, found that 23% of the participants were overweight and 19% were obese. More than 67% reported at least one comorbidity, including back pain (36%), depression (32%), anxiety (29%) and arthritis (14%). “Being overweight, obese, or a former or current smoker was associated with an increase in the number of comorbidities; while healthy diet, physical activity ... and moderate alcohol consumption were associated with decreased number of comorbidities,” the researchers concluded.
- **Exercise.** A 2018 review of 34 studies, published in Multiple Sclerosis and Related Disorders, found that physical activity reduced the risk factors for vascular comorbidities. Unfortunately, the review didn’t note what type of physical activity and for how long. But plenty of research shows that even a little bit of movement each day can be beneficial for both MS symptoms and vascular disease risk.
- **Incorporate wellness strategies.** A 2017 paper published in Neurotherapeutics notes that there’s a “growing appreciation of the role of certain comorbidities and lifestyle factors on [MS] disease activity, disability, mortality and overall quality of life.”

The authors say there’s evidence that exercise; a plant-based, anti-inflammatory diet; vitamin D supplementation; smoking cessation; and cognitive behavioral therapy can improve physical and mental health in people living with MS and comorbidities.

Finally, if you’re feeling overwhelmed about dealing with your MS and other health conditions, National MS Society MS Navigators can help. Call 1-800-344-4867, email [ContactUSNMSS@nmss.org](mailto:ContactUSNMSS@nmss.org) or go online at [nationalMSSociety.org/navigator](http://nationalMSSociety.org/navigator) for help and support. ■

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



**Out of 2,400 people with MS, more than 67% reported at least one comorbidity.**

**Research shows that even a little bit of movement each day can be beneficial for both MS symptoms and vascular disease risk.**



Learn more about managing multiple diagnoses at [ntlms.org/multipliadiagnoses](http://ntlms.org/multipliadiagnoses).

**Care to comment?** Email us at [editor@nmss.org](mailto:editor@nmss.org).



CARLOS (CENTER), DIAGNOSED IN 2001

# Find Doctors & Resources Tool

The National MS Society strives to put solutions in the hands of those who need it most. The Find Doctors & Resources tool on our website empowers people affected by MS to access a directory of healthcare professionals, tools and resources through our website. This online tool is easy to use and available 24/7.

## What is Available on Find Doctors and Resources

Through Find Doctors & Resources, visitors can search a comprehensive list of credible doctors and resources near them to help address MS-specific needs. These providers and resources include, but are not limited to: neurologists, rehabilitation centers, psychologists, disability attorneys, mental health professionals, home modification financing, adaptive vehicles and modifications, long-term care facilities, centers for independent living, equipment loan programs and more.

Start using the Find Doctors  
& Resources tool today at  
[nationalMSSociety.org/FDR](https://nationalMSSociety.org/FDR)



 Momentum exclusive

Mary Rouvelas (seated) goes scuba diving with her husband and children to stay active.



# Changing the world

Mary Rouvelas uses her expertise to help others with MS.  
by Kimberly Kishpaugh

**M**ary Rouvelas challenges the social barriers that leave people affected by multiple sclerosis feeling lonely and socially isolated by advocating for better services, celebrating support networks and championing self-care.

She has firsthand experience with those issues. Shortly after graduating from law school, Rouvelas was diagnosed with MS. Despite initial tingling in her left foot and temporary vision loss, she experienced only mild symptoms throughout the first few years. “For a good six or seven years, it was more scary and threatening, but it really didn’t impact my day-to-day life,” Rouvelas recalls.

But in 2006, she started to have mobility issues, which have steadily worsened. Rouvelas now uses a scooter to get around. “You don’t realize the world is essentially built for mobile people until you’re not one, and then you realize there are just a lot of places you really need to plan for,” Rouvelas says. “There are places we no longer go because they are not friendly [to people with disabilities].”

She has taken up therapeutic horseback riding and adaptive scuba diving to stay active and connect with her family. “My husband and I were scuba divers before I was diagnosed with MS,” she says. “Now, our children are certified, so we can all go as a family, so that’s been really fun.”

Rouvelas acknowledges that while there is a heavy focus on the medical aspect of the disease when someone is first diagnosed, the psychological and emotional effects are often overlooked.

“There is a large percentage of people with MS who have depression and anxiety, and I don’t think it’s a coincidence — it’s a reflection of how difficult it can be to have this disease,” Rouvelas says. “That’s actually where I think the National MS Society can be really

wonderful. It really fills the need for people to have information, outreach, programs and a sense of family that improve the quality of life for people living with MS.”

Rouvelas began advocating for the Society in 2014 when she was doing public policy work for the American Cancer Society Cancer Action Network in connection with challenges to the Affordable Care Act. “I felt the National MS Society should have the

chance to be represented in the work I was doing as well,” she recalls. “I wanted to represent MS patients in court battles about the Affordable Care Act, so I reached out to the Advocacy team at the Society.”

Today, Rouvelas is senior counsel for the American Cancer Society Cancer Action Network and the in-house coordinator for 20 different patient groups, including the Society, which filed a brief with the U.S. Supreme Court in May 2020 urging the high court

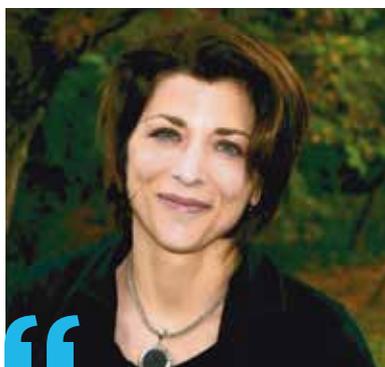
to uphold the Affordable Care Act.

The brief cites the devastating and lasting effects people would face if the Affordable Care Act is struck down. It provides extensive scientific data showing that access to health insurance improves medical outcomes for a wide range of conditions and studies showing that

the health law has made a measurable difference in prevention and care.

“My particular area of expertise is public policy and advocacy,” Rouvelas says, “and if I can do some good for people with MS in that arena, I want to do as much as I possibly can.”

“There is nothing I want more than to use my expertise to help other people with MS.” ■



**There is nothing I want more than to use my expertise to help other people with MS.”**

—MARY ROUVELAS

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

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# solve

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

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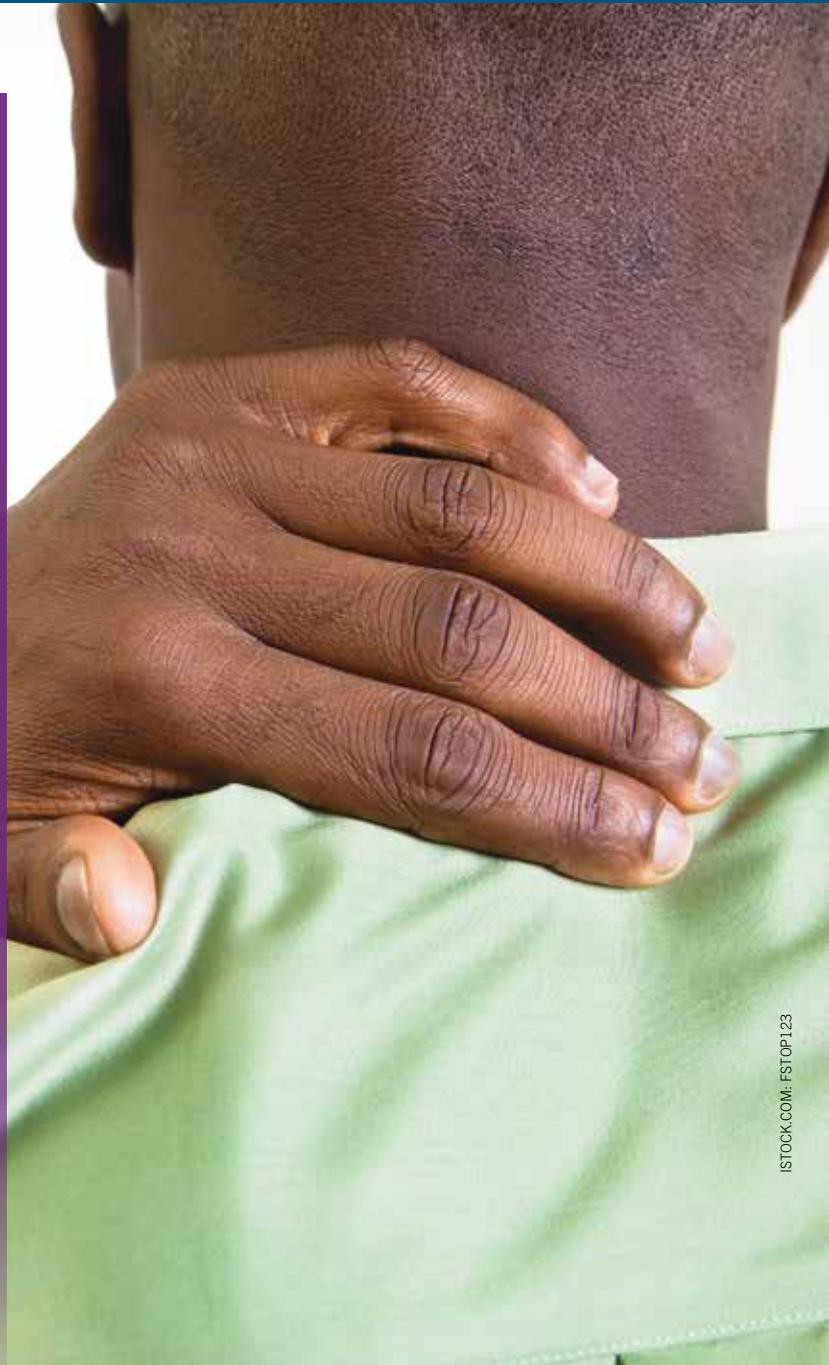
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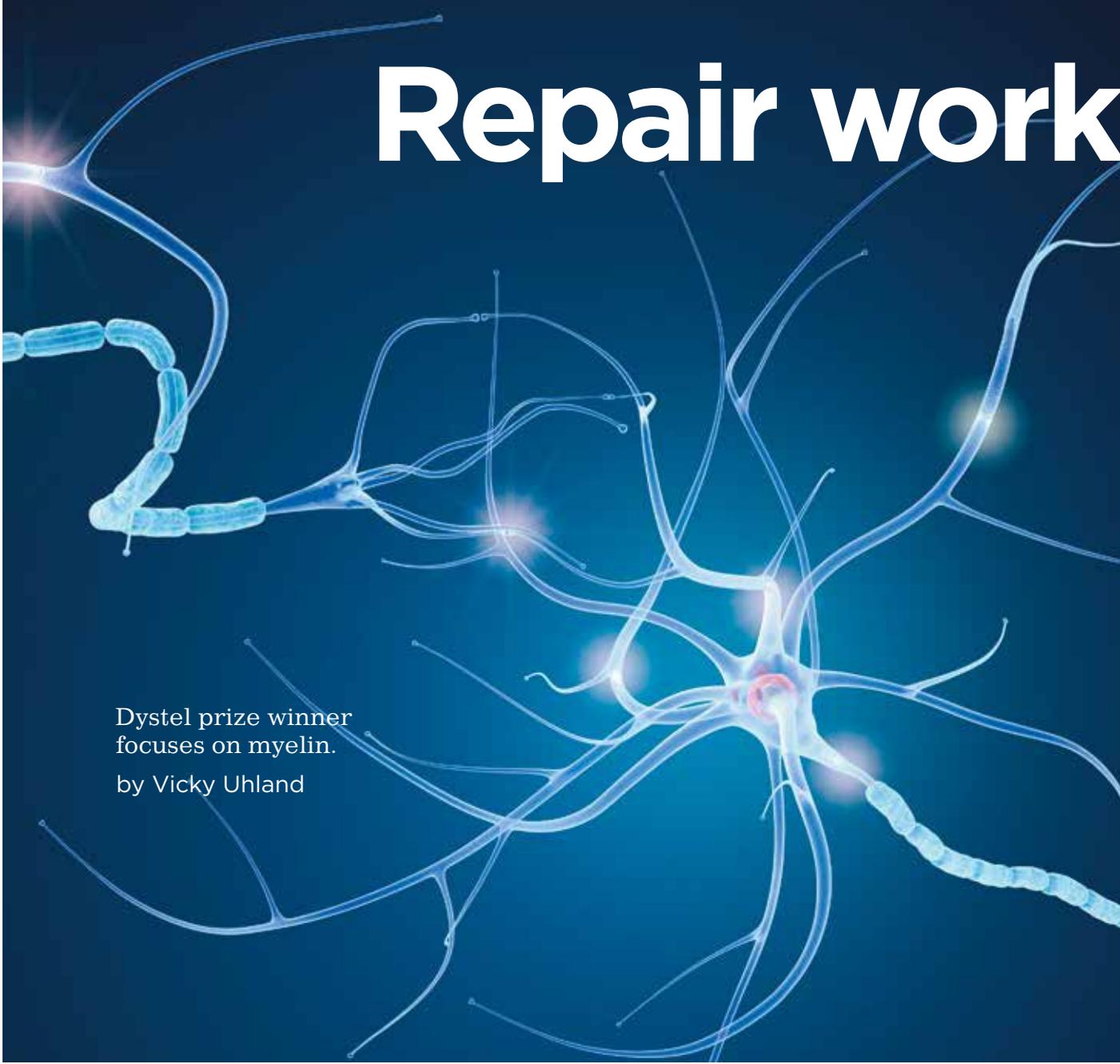
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### TECH NECK

Electronic devices are a big part of our lives, and many of us spend time hunched over a computer or staring down at a smartphone or tablet. Repeatedly looking up and down at a screen puts excess pressure on the bones and muscles in our neck and shoulders, giving us what's known as "tech neck." This can cause strain in the neck, stiffness in the shoulders, headaches and possibly damage to the spine. Here are some ways to prevent tech neck:

- 1. Take breaks.** If you work in front of a computer, take frequent breaks to move around. Set reminders to take breaks away from them throughout the day.
- 2. Change how you hold your phone.** Bring the screen to eye level when you need to use your phone, so your head isn't slouched forward or craning too high.
- 3. Do yoga.** If you're able, performing certain yoga poses can help alleviate pain from tech neck. Helpful poses include baby cobra, cat-cow and downward facing dog.





# Repair work

Dystel prize winner  
focuses on myelin.

by Vicky Uhland

**M**any people yearn for a cure for multiple sclerosis. It's the focus for hundreds of scientists and millions of dollars in research funding. However, what if it were possible to develop a treatment that improves function and eradicates the symptoms of MS? For the nearly 1 million people living with the disease in the U.S., that may be just as relevant as a cure.

Clinical trials of drugs that potentially promote myelin repair have already been carried out thanks to the pioneering research of Ian Duncan, PhD. For decades, Duncan has investigated how to repair myelin, the insulating and protective coating of nerve fibers in the central nervous system. MS attacks and erodes myelin, leading to the symptoms associated with the disease.

The development of myelin and how to repair the myelin sheath is growing area of MS research.

Duncan has been awarded the 2020 John Dystel Prize for Multiple Sclerosis Research for his groundbreaking work on remyelination.

The annual prize, which is awarded by the National Multiple Sclerosis Society and the American Academy of Neurology, recognizes an outstanding researcher who is helping to advance the understanding, treatment or prevention of MS. The late Society National Board member Oscar Dystel and his late wife, Marion, established the prize in 1994 in honor of their son John Jay, an attorney whose promising career was cut short by progressive disability from MS. John died of complications of the disease in June 2003.

“Dr. Duncan was one of the earliest investigators to tackle central nervous system repair in demyelinating disease and to uncover leads as to how to best achieve this,” wrote Stanford University professor Lawrence Steinman, MD, in a letter nominating Duncan for the Dystel Prize. “This work began before we had any approved treatments for MS and considerably before relative stabilization of the disease was achieved with our current armamentarium of therapies, which have subsequently provided the cornerstone for the now-more-accepted belief that central nervous system repair is an important next step to achieve.”

Like previous Dystel Prize winners, Duncan has devoted his professional life to research on MS and other myelin disorders. But Duncan has taken a different route than many of his peers.

### From horses to humans

Duncan grew up in Scotland and graduated from Glasgow University’s School of Veterinary Medicine in 1971. Four years later, he earned his PhD with a thesis on



**Dr. Duncan was one of the earliest investigators to tackle central nervous system repair in demyelinating disease.”**

— LAWRENCE STEINMAN, MD

experimental neuropathology in horses.

Until his third year as an undergraduate, Duncan intended to be a practicing veterinarian. However, after spending a summer in a lab he realized that he was more interested in neuroscience and exploring mechanisms of disease, and so he opted for a research career.

Shortly after Duncan earned his PhD, he became a postdoctoral fellow in the Department of Neurology at McGill University in Montreal, Quebec, Canada. With Albert Aguayo, MD, and Garth Bray, MD, Duncan conducted research into experimental cellular interactions in the central nervous system, supported by the MS Society of Canada.

Animals don’t get MS, so it may seem like Duncan made quite a leap from veterinary school to his research into remyelination. But it’s not as unusual as it sounds.

“The field of remyelination has been significantly represented by people with veterinary training,” Duncan says. “I think it’s because research on remyelination often involves animals, and of course we have the right background to work with animal models.”

### Remyelination revelations

At McGill University, Duncan discovered that myelinating cells could be taken from the peripheral nervous system of mice and transplanted into their central nervous systems where they made small areas of myelin. That gave him the idea that maybe those cells could be used clinically in demyelinating disorders, if larger areas could be remyelinated.

In 1982, Duncan moved to the University of Wisconsin to research this idea further. “That was the time when I really became totally enamored with all things myelin — both the development of myelin and how to repair the myelin sheath,” he says. “My lab



PHOTO COURTESY OF IAN DUNCAN, PHD

Ian Duncan, PhD, led a team that researched how human stem cells could repair myelin loss and reduce MS symptoms.

became immersed in how to restore myelin in genetic myelin disorders and MS.”

Duncan and his team of researchers were the first to show that transplanting cells into a canine model that lacked myelin throughout the central nervous system could result in myelination of areas close in size to some MS plaques.

But the challenge was to discover how a similar transplantation approach could be carried out in people. One of Duncan’s focuses was to determine which developmental stage of oligodendrocytes — the cells in the human body that produce the myelin sheath — would be best for transplanting into the central nervous system and rebuilding missing myelin.

It took several phases of research to accomplish this. Duncan and Joe Hammang, PhD, and Su-Chun Zhang, PhD, were the

first to demonstrate that transplanting animal neural stem cells into the central nervous system could generate oligodendrocytes and initiate remyelination. Then with Oliver Brustle, PhD, they showed that human embryonic stem cells could also give rise to neural stem cells. This paved the way for research into using human stem cells in MS that could potentially repair focal myelin loss and reduce or even eradicate MS symptoms.

### ‘Functional recovery’ in MS

Duncan moved away from cell transplantation and switched his attention to studying remyelination by enhancing the resident cells of the nervous system as the source of new myelin following demyelination. Using an enigmatic model in the cat, he has re-examined fundamental questions relating to myelin repair. In this model, cats fed irradiated food develop profound demyelination that results in a progressive neurologic disease. Return to a normal diet leads to remyelination and neurologic recovery.

While it had been proposed that remyelination in MS and animal models results in neurologic recovery, definitive proof had been lacking until Duncan’s demonstration in the feline model. He and colleagues then showed that surviving adult oligodendrocytes could participate in remyelination; this had previously been thought unlikely and identified this cell as an additional target for future remyelinating drugs.

“In a complex war, the more diversified soldiers you have, the better chance you have for winning, if I can make that analogy,” Duncan says. “The final cure in MS will probably not be a single treatment, but rather a multi-treatment solution.”

While current disease-modifying treatments are effective in many patients in reducing relapses and severity of disease,

Outside the lab, Ian Duncan, PhD, contributes to MS as a Bike MS fundraiser.





none of these drugs has been proven to promote myelin restoration.

“People with MS are looking for a number of things. They want to stop ongoing disease, that’s for sure,” Duncan says. “But almost equally, they’d like to have some improvement. They would like to be less tired, they’d like to be more mobile, have better balance and see normally. So we can’t just stop the disease. We need to actually improve people’s function.”

### Drug trials underway

There have been two recent clinical trials on remyelinating drugs. One trial was unsuccessful and one had mild success, though measuring their effect and clinical benefit was difficult. But Duncan’s recent work with cats has revealed a better way to measure if a drug is actually doing its remyelinating job — and potentially stopping MS symptoms.

“The field is challenged by the lack of primary outcome measures that reliably identify remyelination,” wrote Bruce D. Trapp, PhD, chairman of the Cleveland Clinic’s Department of Neurosciences, in his letter nominating Duncan for the Dystel Prize. “[Duncan’s] studies have important implications for future clinical trials of remyelinating therapies in multiple sclerosis patients.”

Evaluating drug-induced remyelination by MRI has proven difficult. However, Duncan’s research found that a type of test called visual evoked potentials can measure whether the optic nerve in a cat has become demyelinated, and then whether a drug or other treatment has actually remyelinated the nerve.

Duncan says there is currently a human clinical trial planned in the United Kingdom for a drug that promotes remyelination that will use the visual evoked potential as an outcome measure, and it is likely that

this test will be included in future trials of remyelinating drugs.

### A fundraising prizewinner

The scientists who nominated Duncan for the Dystel Prize noted that his dedication to MS research extends outside the laboratory.

Duncan has participated in Bike MS fundraisers and has also raised money for the Society through the American Birkebeiner cross-country ski race. His efforts have been so successful that he’s been elected to the Society’s Volunteer Hall of Fame in both the Professional and Outstanding Fundraiser categories.

Duncan also co-produced a PBS documentary with Steinar Hybertsen, “Multiple Sclerosis, The Vikings and Nordic Skiing,” that discusses the value of active lifestyles for people with MS. And he’s even had a Hollywood moment, as a character in the movie “Lorenzo’s Oil,” which deals with healing myelin damage in a young boy with a genetic myelin disorder.

Trapp also notes that “Dr. Duncan has had a stellar career as an academic educator and mentor of young scientists.” Duncan is a frequent lecturer at medical and research institutes around the world and has served on many study and advisory boards in the U.S., Canada and Norway.

### The future

With the identification of a model to test new remyelinating drugs, Duncan plans to collaborate with a biotech company to test a new molecule and determine whether it correlates with myelin repair. He also plans to explore the reasons irradiation of food results in demyelination in cat models. ■

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

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).



For adults.  
Not an actual patient.

### What is MAYZENT® (siponimod) tablets?

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

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

### IMPORTANT SAFETY INFORMATION

#### Do not take MAYZENT if you:

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

#### MAYZENT may cause serious side effects, including:

- 1. Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT.** MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of MAYZENT.  
During the initial up dosing period (4 days for the 1-mg daily dose or 5 days for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the up dosing. Call your health care provider if you miss a dose of MAYZENT.
- 2. Infections.** MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your health care provider should review a recent blood test of your white blood cells before you start taking MAYZENT.  
Call your health care provider right away if you have any of these

symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:

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

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

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

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

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

## ADVERTISEMENT

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A once-daily pill that can significantly slow down disability progression in people whose RMS is progressing.

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(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.

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

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

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

**MAYZENT may cause possible side effects, including:**

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

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

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

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

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

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

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

**Please see Consumer Brief Summary on following pages.**

MAYZENT and the MAYZENT logo are registered trademarks of Novartis AG.



## 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](http://www.mayzent.com).

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

#### 1. MAYZENT may cause serious side effects, including: Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT.

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

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

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

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

- fever
- vomiting
- tiredness
- headache with fever, neck stiffness, 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

#### 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 healthcare provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

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

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

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

#### What is MAYZENT?

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

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

#### Who should not take MAYZENT?

##### Do not take MAYZENT if you:

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

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

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

- have an irregular or abnormal heartbeat
- a history of stroke or other diseases related to blood vessels in the brain
- breathing problems, including during your sleep
- a fever or infection, or you are unable to fight infections due to a disease or taking medicines that lower your immune system. Tell your healthcare provider if you have had 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:

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

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

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

### What are the possible side effects of MAYZENT?

MAYZENT may cause serious side effects, including:

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

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

### • severe worsening of multiple sclerosis after stopping

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

### The most common side effects of MAYZENT include:

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

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

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

### How should I store MAYZENT?

#### 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.

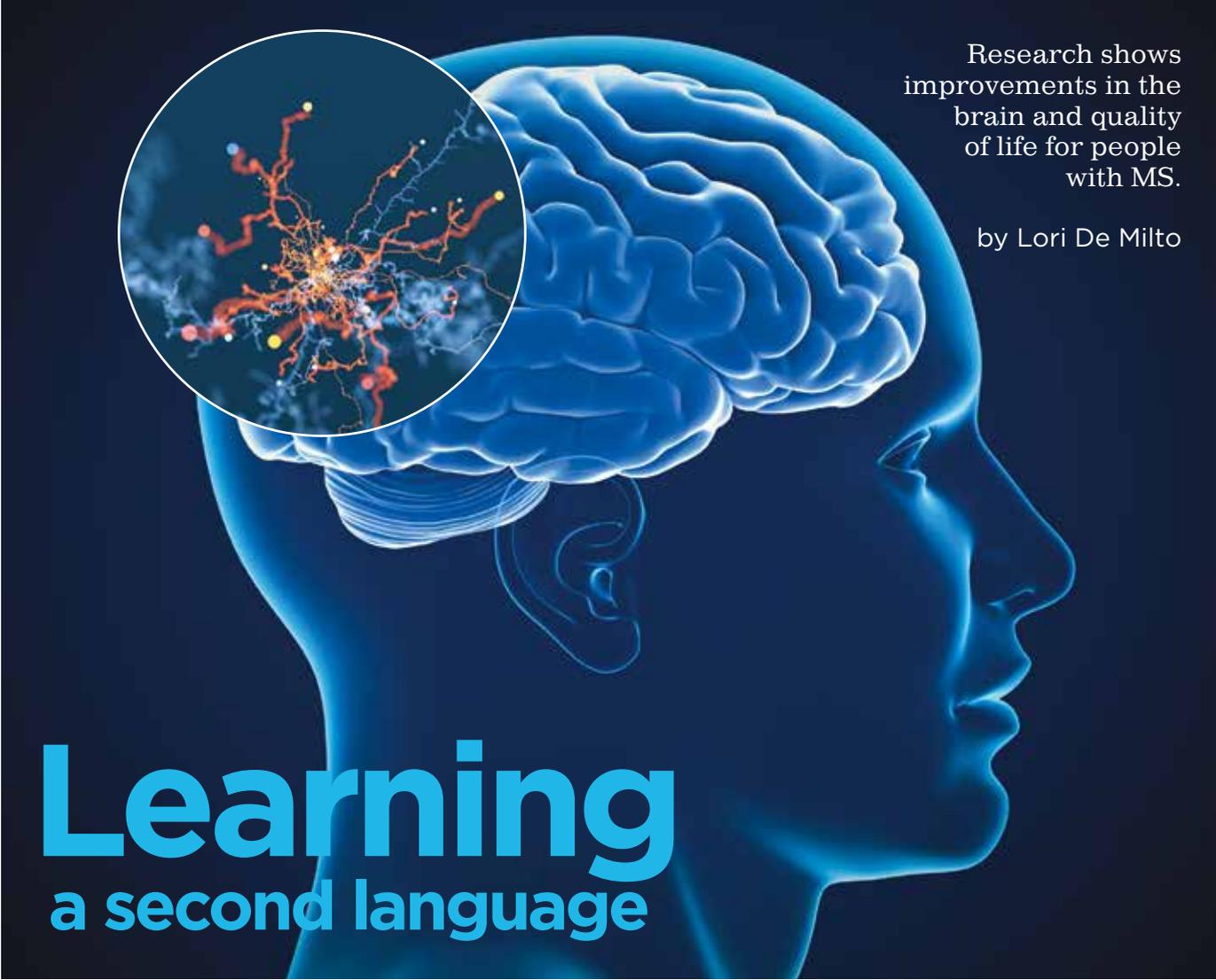
### What are the ingredients in MAYZENT?

**Active ingredient:** siponimod

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

Distributed by: Novartis Pharmaceuticals Corporation, East Hanover, New Jersey 07936

For more information, go to [www.pharma.us.novartis.com](http://www.pharma.us.novartis.com) or call 1-888-669-6682.



Research shows improvements in the brain and quality of life for people with MS.

by Lori De Milto

# Learning a second language

**P**eople living with multiple sclerosis who learn a second language might be able to function better and feel better, according to a study by researchers in Austria.

The study, led by Rainer Ehling, MD, at the Medical University of Innsbruck, showed that learning a second language can expand some areas of the brain that were damaged by MS. The results were published in an article in PLOS One (December 2019).

Early in MS, the brain's gray matter may be damaged, causing cognitive symptoms, such as problems remembering things, finding the right word and processing information. Many people with MS will experience some changes in cognitive functioning during the course of their disease.

Changes in cognitive function make it harder for people living with MS to function physically, mentally, emotionally and socially. This is called health-related

## Study participants

- **Ages 18–50**
- **People with MS:**
  - »Patients at Medical University of Innsbruck
  - »Had relapsing-remitting MS for less than 10 years
- **People without MS:**
  - »Similar to people with MS in age, sex, education and English proficiency
  - »Relatives or friends of people with MS in the study and people who responded to ads at the Medical University of Innsbruck.

quality of life. Things like whether you feel sick or sad, or are in pain, and your energy level and mood are all part of health-related quality of life. Not feeling well physically and/or emotionally can interfere with your work, social activities and other regular daily activities. The impact of poor health-related quality of life on your ability to do the things you usually do can range from slight to extreme.

### English language training program

Some studies have found an increase in gray matter volume and cognitive improvements after healthy adults learned a second language. The brain is made up of gray matter and white matter. The gray matter includes the nerve cells and several associated structures. The white matter consists of nerve fibers — which transmit messages to, from and throughout the

brain — and myelin. Myelin is the fatty substance that surrounds and protects nerve fibers.

Ehling and his research team wanted to see if learning a second language could lead to similar changes in people with MS. The researchers work at the Medical University of Innsbruck, the University of Innsbruck, the Clinic for Rehabilitation Münster and the Karl Landsteiner Institut für Interdisziplinäre Forschungam Reha Zentrum Münster.

In this small study, 11 adults with MS and 12 adults who did not have MS and whose native language was German participated in an eight-week English language training program at the Medical University of Innsbruck. They spent three hours each week in a classroom. At home, they worked on vocabulary lists and extra listening and speaking activities.

Before and after the training program, the researchers measured the participants' gray matter and health-related quality of life. The researchers used magnetic resonance imaging (MRI) brain scans to measure gray matter and had participants complete a health-related quality of life survey called the 36-Item Short Form Health Survey.

### More brain volume and function

At the beginning of the study, participants with MS had less gray matter in their brains than participants without MS. Despite this, participants with MS “were as successful in learning a [second language] in terms of listening comprehension, speaking fluency and vocabulary scores as their healthy counterparts,” say the study authors. Both groups had significant improvements in these areas.



**The study ‘provides evidence for significant gray matter volume increases in people with MS.’ ”**

—RAINER EHLING, MD

## Other ways to maintain and improve cognitive function

Learning a second language is only one way to engage your mind and optimize your cognitive function. Other useful activities include:

- Reading
- Creative writing
- Journaling
- Handiwork
- Board or card games
- Drawing or painting
- Crossword or jigsaw puzzles
- Learning to play an instrument

Social activities, such as participating in a support group, book club, or meetings at your church or synagogue, also help you engage your mind. Optimizing your cognitive health also helps you feel better in general.



After the English language training program, participants with MS had significantly more gray matter in areas of the brain related to short-term memory, learning and environment recognition. The researchers believe that the areas of the brain used in learning a second language can help people with early MS maintain cognitive function and may trigger neuroplasticity.

Neuroplasticity is the brain's ability to adapt to new experiences and rewire itself after being damaged to preserve function. Functional MRI studies show that activities designed to improve higher-level language processes increase brain activity and stimulate neuroplasticity. These activities also help people improve their cognitive function.

### Better quality of life

Learning a second language also led to significant increases in health-related quality of life.

Before the training program, participants with MS had much lower scores for mental health than participants without MS. Their mental health was much better after the training program. People without MS had about the same mental health scores before and after the training program. Physical health was the same before and after the training program for both groups.

The researchers concluded that the study “provides evidence for significant gray matter volume increases in people with MS and age- and sex-matched health controls following a short training in different language-related brain regions. These encouraging results prompt further investigation of the effectiveness of (second-language) learning on the improvement of distinct cognitive impairments in people with MS.”

### More research is needed

This was a small study and the participants with MS had mild disabilities. More research is needed to find out how learning a second language might help relieve cognitive problems in MS. ■

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

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).



ISTOCK.COM: COMICSANS

It's a part of life when you have MS, but there are ways to make it easier.

by Shara Rutberg

# no

**I**t was Wednesday evening when Michael O'Grady's 14-year-old daughter hit him with a teenage emergency. The shoes she was planning to wear to Friday's semi-formal dance no longer fit.

"Dad," she asked, "can you just take me to the mall for new ones after school tomorrow?"

O'Grady, 52, was diagnosed with multiple sclerosis in 2012. Since then, he's learned how to manage his daily energy. He's learned how

his cognitive and physical abilities shift during the day. "I know my own body and how my day goes," he says. "And I know I can't go anywhere at night. I'm pretty much shut down by that time." Another critical thing the Lincroft, New Jersey, father of three has learned since his diagnosis? How to say "no."

"There are times when I can do things and there are times when physically, it's not going to be safe,"

Michael O'Grady (bottom right) was diagnosed with multiple sclerosis in 2012. He's learned how to manage his daily energy to balance life as a father.



PHOTO COURTESY OF MICHAEL O'GRADY

he says. He had to turn his daughter down.

"That hurt," he says. "I'm her father, I should be able to do simple things like that."

Predictable — and unpredictable — symptoms make saying "no" part of life with MS. Experts and people living with the disease share strategies for turning down requests and dealing with the guilt and other feelings when you have to decline invitations or cancel plans.

### Have a standard line ready

"Having a standard line, like an elevator pitch, that you know in advance can make it easier to respond," says Paige Bentley, a North Carolina mental health professional who was diagnosed with MS in 2007. Amy Clark, diagnosed with MS in 2002, agrees. Her line, "Please understand I live with a chronic disease and there's going to be times and days when I just can't do what I want to

do. People were generally pretty understanding," says the California resident.

She also suggests adding a caveat to responses if you think you might be able to take part but aren't sure. She would say: "My intent right now is to be there, but you need to know that I might wake up on that day and not be able to." Bentley suggests using a "soft RSVP," like, "I'd love to come, but would it be OK to let you know the day of?"

Suggest people make contingency plans, says Deborah Mandelbaum, who practices in Maplewood, New Jersey, and New York City, and works with many clients who have MS or have a family member with MS. For example, “if it’s being the class mom in school, have a backup to call if you’re not up to it. If it’s leading a big meeting at work, have a second-in-command ready.” Practically speaking, it lets things get done. But beyond that, she says, “it gives people the message that you take this seriously but may not be able to do it. It also takes the pressure off you.”

### **It’s OK to say no**

When a hard no is required, give yourself permission to give it, says Tracy Clafin, 63, who has relapsing-remitting MS, and has led MS self-help groups in Chico, California. “It’s really hard at first, but be honest and give yourself permission to say ‘no.’”

When you do turn down an invite, or cancel plans, how much do you need to explain? “Educate,” says Mandelbaum. “Explain that MS can change from day to day. Fatigue is an issue. It’s nothing personal against the person doing the inviting, but there’s a lack of predictability and a lack of control with this disease.”

How much to explain depends on each person, she says. “Some people are openly

curious, others aren’t going to want to know at all.”

Having invisible symptoms can make things harder. “I don’t wear my MS,” says Ann Marie Johnson, who was diagnosed in 2002 and has been an MS peer counselor, self-help group leader and has served on the National MS Multicultural Advisory Committee. “But I tell people all the time, ‘there are many faces to MS.’ Just because a person is walking, it doesn’t mean there’s not invisible stuff going on.”

You might lose some friends. Some people will understand. Some won’t. “That’s the reality of life with any illness — cancer, or MS or diabetes,” Mandelbaum says. “There are some losses of friendship and relationships. But you can’t change or control others, you can only try to be positive and offer information.”

“Your real friends are understanding,” says Johnson, who lives in Brooklyn, New York. “Other friendships have to be redefined.” Other relationships, she says, need to end.

She had one friend who not only failed to understand why she couldn’t do things the way she used to, that friend actually “made me feel bad about being sick,” Johnson said. That woman is no longer in her life.

“MS teaches you what real friendship truly is — and that’s about being honest about who I am and what the ‘new Ann



PHOTO COURTESY OF DEBORAH MANDELBAUM

Deborah Mandelbaum says a contingency plan can help take the pressure off when you have to say “no.”

Marie’ (post-diagnosis) can and can’t do,” she says. “This woman just kept longing for the old Ann Marie. It’s enough that I’m longing for the old Ann Marie. I don’t need friends longing for her, too.” Choosing who you keep in your life is “about who’s going to be in that journey with you,” she says.

That longing for the pre-diagnosis self is normal, experts say. “It’s a larger part of acceptance,” Mandelbaum says. Guilty feelings that may arise after declining invitations or canceling plans become more about sadness and loss, she says. “Acceptance is something we deal with a lot in therapy, going through the Kubler Ross stages of grief (denial, anger, bargaining, depression and acceptance).” What makes it even more challenging with MS, is that the loss is constantly



**Shift your mindset so you don't think you can't do something. Instead think now you have to do it in a different way."**

—ANN MARIE JOHNSON

changing. "What you might have done six months ago, you might not be able to do now," says Mandelbaum. This makes it harder for people living with MS to deal with and it can make it harder for other people to understand. "Friends may wonder, 'Why six months ago were you able to go on that hike and you can't now, even though you don't look any different?'" she says.

### **Suggest alternatives**

Another approach to making plans is to give a response that's not a "yes" or a "no," but rather is a "yes, in a different

way." Accept the invitation to spend time with someone but present a way to do so that you can handle. Offer an alternative, says Mandelbaum. "For example, I can't come over Saturday night, but I'd love to catch up — can we Skype? I can't make a New Year's Eve party, can we do lunch New Year's Day? That way the message is 'it isn't that I'm not interested in you, it's that I can't do the requirements of getting there.'"

"Shift your mindset so you don't think you can't do something. Instead think now you have to do it in a different

Ann Marie Johnson, diagnosed with MS in 2002, is an MS peer counselor.



PHOTO COURTESY OF ANN MARIE JOHNSON

way,” says Johnson. Consider whether “the moment, or the memory” is more important. Is it more important that you go on a long walk with friends or that you get to spend quality time with them? “For me, it’s more important to be with my friends,” she says. “And I had to let them know that.”

Bentley encourages the people she counsels to shift from FOMO — the fear of missing out — to SHOMO — show up more. “Show up more for the things that are important,” she says. “It gives us the opportunity to say ‘no’ when we have to and a really strong ‘yes’ to things we can do.” In that way, she says, MS can help us see things more clearly, and “bring some clarity and purpose into the day-to-day.”

### Step by step

Bentley suggests following these steps when making or canceling plans:

Step one: self-acceptance. You might say, “Yes, I do have this limitation in my life that means I’m going to have to pay more attention to my needs and ask for help.”

Step two: self-compassion. Acknowledge your feelings. “Name the feeling that you’re feeling, like sad or guilty. And remember you’re not alone — there are other people who need to cancel plans, too. Everybody has something. It just might be more frequent for people with MS.”

Step three: self-trust. “Remind ourselves that we can trust ourselves to still do the things that are important to us, to stay connected with the people who are important to us and really show up for those opportunities.”

It’s not easy, she says. “Remember, you don’t have to struggle with this alone,” Mandelbaum says. Explore support groups and therapy. O’Grady finds strength and empathy in his support groups and “two years of therapy have helped me manage my acceptance —

and my daily energy. I’ve accepted what I can and can’t do. And I’m not afraid to say no to things.”

In the end, O’Grady’s family was able to work around his Wednesday night “no.” His wife rearranged her schedule to take their daughter to the mall. And the entire family was able to — together — enjoy how beautiful she looked in her new shoes and her semi-formal dress before she headed off to the dance. ■

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Shara Rutberg is a writer in Evergreen, Colorado.

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).



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## A challenge and a celebration to raise awareness about MS

by James Townsend

**W**alking 50 miles over a three-day weekend might not be some people's idea of a great time. But for the hundreds of participants in the National Multiple Sclerosis Society's Challenge Walk MS, the event to raise funds is a celebration and a family reunion.

Take, for instance, Anne Murphy, who has used a wheelchair for the last eight years, and her brother Paul Keohane. "I'm pretty much of a type-A person," says Murphy, who lives in Tewksbury, Massachusetts. She's not the type to lament her circumstances. She broke her back and neck in a car accident in 1985, but "just nine months later, I was doing aerobics," she recalls. "So, years later when I began limping, I thought it was something to do with the accident and that I just needed a break."

She eventually was diagnosed with primary progressive MS in 2001. "I was busy at the time studying for a master's degree in elementary education and raising my 7- and 9-year-old kids. Within nine months I had to go on disability."

Then she and Keohane found out about Challenge Walk MS: Cape Cod. Keohane, of Oxford, Massachusetts, says: "I got involved 18 years ago because someone I worked with at the time mentioned it to me. Anne had been diagnosed with MS a few years prior so I thought doing this event could be a good way for me to show my support and love for her. Anne joined

# A weekend walk

Anne Murphy, diagnosed with MS in 2001, participates in Challenge Walk MS on a three-wheeled bike with her brother Paul Keohane's help.





PHOTO COURTESY OF ANNE MURPHY

me in my third year, and I got to see first-hand how MS was affecting her. At that point I couldn't look back. As long as I was able, I was going to continue participating."

### Joining forces

Even though she was unable to walk, Murphy felt deeply that she needed to do something for the cause and to feel like she was doing something to fight back against her MS. "As my mobility was starting to go, I thought, 'This is a way for me to be mobile' — with Paul's help, of course," Murphy says. "I really didn't know what to expect or whether I'd be able to do it, but then I learned that there was going to be so much support along the way, so I decided to do it."

Keohane and Murphy joined forces for 10 years straight with Murphy sitting atop a three-wheeled bike that allowed her to pedal with her arms and Paul pushing the bike from behind over the wooded and varied terrain of the Cape Cod Rail Trail. "The pressure is all on Paul," Murphy says. "He's really been dedicated and takes on so much responsibility. He's quite an athlete and trains for hours every day leading up to this event."

They found a new three-wheeled all-terrain bike that will work better for Murphy. "It's so inspiring," Murphy says. "I love the challenge and being with all these people again that we've met over the years, seeing their smiles and talking together in the beautiful sunlight, people who either have MS or know someone who does and who know a lot about the disease. It's a really positive event with tremendous support — people cheering you on and clapping, providing water, snacks and food and places to rest along the way."

**The Challenge Walk MS event series has raised \$78 million since it began, with participants averaging \$2,200 in donations.**

**The 2019 Challenge Walk MS on Cape Cod brought in \$880,000 and 535 people participated.**

Challenge Walk MS 2020 events have been changed to virtual events because of COVID-19.

To register for any of the events or to donate, visit [challengewalkMS.org](http://challengewalkMS.org).

### Inspiring each other

Murphy says that although people remember and are inspired by her and her brother, seeing all the others participating is inspiring to them, as well. “It’s like proof of the old saying, ‘Where there’s a will, there’s a way.’”

Aileen Curran, the national director of Challenge Walk MS, says the Challenge Walk MS event series has raised \$78 million since it began, with participants averaging \$2,200 in donations. The 2019 Challenge Walk MS on Cape Cod brought in \$880,000, and 535 people participated.

There are three Challenge Walk MS events: in Cape Cod, Massachusetts; in Door County, Wisconsin; and in San Diego, California. The walks have been changed to virtual events because of COVID-19. There is an option to walk 30 miles over two days as well as the full three-day, 50-mile walk. “It’s an endurance walking event that dares us to move beyond our limits, both as individuals and as a group,” Curran says.

“I really love the last day and last hour of the Walk,” Murphy says. “Everyone changes into colored T-shirts — orange for those with MS, and blue for those who don’t have MS. Obviously everyone could see that I had MS, but when you suddenly see all the orange T-shirts and realize that



PHOTO COURTESY OF ANNE MURPHY

those people did the walk despite their MS, it’s amazing!”

When asked about one of her favorite moments over the last 10 years, without a moment’s hesitation, Murphy recalls the end of the first leg of her first Challenge Walk. “We were like at about mile 18, and I was feeling strong,” she says. “The very last part was pretty much all downhill, so I told Paul and the others, ‘I’m going to go ahead, OK? If I get tired, I’ll stop and wait for you.’ Well, there I was rolling along alone toward the finish line and all the people were cheering, thinking that I had done the whole 20 miles by myself. I was grinning from ear to ear, and I never told anyone the truth!” ■

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James Townsend is a writer in Boulder, Colorado.

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Participants at the 2019 Challenge Walk MS on Cape Cod brought in \$880,000, and 535 people participated.



Learn more about Challenge Walk MS at [challengewalkMS.org](http://challengewalkMS.org).

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

# MS researcher gets it in gear



Society fellow joins Bike MS team to raise funds for a cure.

by Mike Knight

Andrew Mendiola, PhD, received a fellowship grant for MS research.

**T**here was a problem.

It was Saturday, September 28, 2019. Andrew Mendiola, PhD, a researcher at the Gladstone Institute, an independent state-of-the-art biomedical research institution in San Francisco, straddled his bike at the starting line of the 36th annual Bike MS: Kansas City.

Part of the National Multiple Sclerosis Society's nationwide Bike MS fundraising events, the ride would take 1,500 cyclists up to 165 meandering miles via three separate routes from Olathe, Kansas (a city in the metro Kansas City area) to Lawrence, Kansas, over the next two days, with a goal of raising \$1.2 million to help end the disease. In total, Bike MS: Kansas City has raised over \$28 million since it began in 1983. In 2019, some 80,000 cyclists nationwide rode in Bike MS events, raising over \$65 million. To date, Bike MS cyclists, volunteers, and donors have raised over \$1.3 billion.

Mendiola was a "guest rider" with a local team, the Research Rough Riders, led by surgeon Ted Higgins, MD, a long-time veteran of the event. Higgins, Higgins' wife, Kim, and a group of colleagues and friends began

riding in the fundraiser in support of Higgins' friend and coworker, anesthesiologist Dave Tomlinson, MD, who had MS. Tomlinson died at the age of 52 in 2009.

"He was basically my wing-man in the operating room," Higgins says. Over time, Higgins' team merged with Biscari Brothers Bicycles bike shops in the Kansas City area. Together, the teams have about 100 riders, Higgins says. He estimates they have raised over \$1 million for MS in total.

From the beginning, Higgins and Tomlinson agreed that their financial support, which included their individual donations, as well as funds raised through Bike MS, should be directed to research focused on repairing the myelin sheath damaged by MS. The National Multiple Sclerosis Society's Postdoctoral Fellowships Grant program provided that opportunity.

Through the Society's program, Higgins and Tomlinson connected with the postdoctoral research candidates doing this work. Over the past 20 years, the funds raised have supported these researchers, and other scientists also got the chance to ride along with Higgins and the teams. It has become a unique opportunity to connect researchers and people whose

lives could be changed by the work happening in the lab.

One researcher is Mendiola, who was awarded a fellowship grant for research on blood protein fibrinogen, how it contributes to nerve degeneration in MS, and how better understanding fibrinogen might lead to reducing progression in MS.

### The wheels on the bike go 'round and 'round

While visiting his son, Eddie, who lived in San Francisco, Higgins met Mendiola for coffee and invited him to join the ride. Arriving late to Kansas City the night before the ride, Mendiola was outfitted with a 10-speed bicycle borrowed from one of Higgins' neighbors. A storm had just blown through Kansas City, pushing out the heat and humidity, and replacing it with a clear, cool weather just made for distance bike riding.

An avid runner, the 32-year-old Mendiola was confident he could complete the 120-mile route the Rough Riders would be riding over the next two days, even if he hadn't actually been on a bicycle since he was a little boy. After all, once you learn how to ride a bike you never forget.

Right?

Mendiola's legs pumped furiously as the ride began, but the other cyclists steadily began to disappear as he remained more or less in place. Mostly more. And with two days of bike riding ahead, that presented a problem.

"I get on the bike and the wheels are just spinning like crazy," Mendiola says. "I looked at Ted and said, 'Ted, I



think this bike is broken. I'm not moving!' And he's like, 'You've got to shift into gear.' And I literally looked at him and said, 'There are gears on this thing?'"

After learning how and when to shift gears, Mendiola finished the first day's ride of 78 miles with the rest of the Rough Riders. "He really tuckered himself out," Higgins says. "But then he got up the next day and we came back and did 38 miles and he was really enthusiastic about it."

Mendiola was just as enthusiastic about meeting other riders in the event, some with MS, others without, but all part of a bigger family dedicated to ending the disease. "It was amazing," Mendiola says. "You go through undergraduate, you go to grad school, you go to postdoctoral training, and you're kind of



**Left:** Andrew Mendiola (third from right), completed a 120-mile route with the Rough Riders as part of the 2019 Bike MS in Kansas City.



PHOTO COURTESY OF ANDREW MENDIOLA

**Above:** Bike MS: Kansas City has raised over \$28 million since it began in 1983. Proceeds from the fundraiser support MS research of fellows such as Andrew Mendiola (top, right).

siloes from the disease that you're working on. And so that was a unique experience because I got to hear stories and interesting things that are going on in these people's lives."

It was an experience Mendiola hadn't anticipated, and it gave his research a new and different meaning, one he'll keep with him when he needs it most. "Hearing patients tell you how impactful and meaningful your research is to them and their families is humbling, and it lit a fire in me that during those tough research days will keep me going," Mendiola says.

Especially on those days when he feels like he's standing still.

Because of COVID-19, all 2020 Bike MS events will be virtual.

To learn more about Bike MS: Inside Out, the Society's new build-your-own-adventure cycling event, visit **bikeMS.org**. ■

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

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Learn more about Bike MS at **bikeMS.org**.

**Care to comment?** Email us at [editor@nmss.org](mailto:editor@nmss.org).

# MS as a cure for mediocrity

My disease has inspired me to develop a new outlook on life.

by Amy Black

**E**verything I knew about multiple sclerosis came from “The West Wing,” a television drama about a fictional White House administration under President Jed Bartlet, played by actor Martin Sheen. When the show reveals that Bartlet has been diagnosed with MS, I remember thinking, “Poor fictional character. That must suck.” I gathered that the disease was great for ratings, but I personally couldn’t answer fundamental questions about MS. Was it even real? Contagious? Fatal?

Occasionally, this very real condition returns to the news, as it does when someone famous, such as Jack Osbourne or Selma Blair, reveals their diagnosis. Through today’s instant media, we can learn about those misfortunes seconds after disclosure, digest their personal accounts and read the attached comments from well-wishers and trolls alike.

In 2006, I squirmed before a neurologist who was not particularly gifted at dispensing bad news. I, like nearly 1 million in the U.S., now owned a fictional character’s disease.

In my low-budget, low-tech, pre-smartphone days, I did what any responsible adult would: I headed straight to the bookstore. The extent of the MS



Amy Black with her support dog named Zhavier Orion.

literature available consisted of a scientific textbook and a rather uncheerful autobiography of talk show host Montel Williams. I bought both.

I called the National Multiple Sclerosis Society and asked for every booklet, pamphlet and brochure they had. Because I’m a drill sergeant’s daughter (I make a list to organize my lists), I bought a file box and organized these printed resources alphabetically by topic.

In some ways, I envy those discovering their diagnosis in this news-in-our-palms tech age. We have

an astonishing array of immediately available sources to educate ourselves about mystery conditions. We can scour WebMD, Google every symptom and read first-person accounts no matter where we are. Few are running to a bookstore to learn more about anything anymore. However, perhaps the drawback is too much unfiltered information, which does not necessarily protect us from misunderstandings, self-diagnosis and unsafe fads.

In truth, my diagnosis didn’t hit me quite the way Selma Blair experienced. Unlike Blair, I was neither relieved to have an answer nor overcome with grief over perceived outcomes. There was no one telling me the right or wrong way to handle MS, so I simply opted not



PHOTO COURTESY OF AMY BLACK

Amy Black has a passion for documenting urban scenes.

to dwell. I didn't panic, shut down or cry. I read the brochures, filed them away and moved on. MS didn't require much personal attention for a few years, until the foot drop started. Eventually, my balance made strangers question my sobriety and my bladder turned geriatric. Outings began to require reconnaissance — how far from the parking lot, how many stairs, where are the bathrooms?

The idea that my teetering version of walking might degrade further made me reconsider my lack of a proper mission statement. Let's face it: there's nothing like an incurable disease to make you recognize a mediocre life being endured. I'd spent my 20s focused on uninspired employment and lacked significant hobbies. I did nothing exemplary. I had no backlog of exciting memories. I wasn't just vanilla... I was unflavored!

My reckoning? I ought to make use of this set of limbs while I can. My personality suits MS, a disease that prefers I follow its sometimes-isolating ideations — going nowhere, doing nothing, embodying the word "no." Inhabiting a "while I can" lifestyle means adding "yes" to my vocabulary.

Through an accidental yes, I discovered my passion: urbex photography. Urban exploration involves using my shaky, unresponsive legs to traipse and trip through

abandoned properties, creeping between rotted timbers and crawling across unstable floors to document the splendor of ancient homes, asylums and factories. This has become, for me, the definition of "alive," of "yes." And a subtle middle finger to MS, despite the host of challenges it brings to the hobby.

With 12 years behind me, I can actually say that MS is responsible for the best pieces of my current existence. Because of my limitations, I've adopted a new outlook, a new determination.

An incurable disease is a stellar excuse to craft a mission statement and then live it out. ■

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Amy Black lives in Morrisville, Pennsylvania, where her two dogs and three cats run roughshod over any hope for order.

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Amy Black's urbex photography can be found at [instagram.com/zaedah.urbex](https://www.instagram.com/zaedah.urbex). See her portraits at [instagram.com/zaedah.black](https://www.instagram.com/zaedah.black).

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# Jewelry with a hidden meaning



PHOTO COURTESY OF ASHLEY SUVANTO

My MS diagnosis led me to a new calling.

by Ashley Suvanto

**I**n 2015, I was diagnosed with multiple sclerosis. What started as a numb, heavy feeling in my foot eventually spread to the entire right side of my body. I began to wonder, was this my new normal? It was extremely difficult in the days that followed to not feel depressed and wonder why this was happening to me. I needed to be healthy to care for my 3-year-old daughter and 9-month-old son, both of whom relied on me for their every need, and to fully enjoy life with my husband, who is my best friend and biggest supporter. Thankfully, in the midst of all the chaos, God gave me an overwhelming sense of peace and strength, a newfound positivity about this life, and belief that even the simplest of moments should not be taken for granted.

I also found a new calling. While searching for some kind of outlet or purpose, I landed on simple, hand-stamped jewelry as a new creative venture. I wanted to create meaningful pieces that would inspire others in their journey with MS. Since MS poses such a unique challenge for each of us, I wanted to create a subtle way to unite us and our supporters and highlight our strength. Thirteen Nineteen (1319) stands for the thirteenth (M) and the nineteenth (S) letters of the English alphabet. My desire is for this jewelry to provide a daily reminder that we are not alone in this fight; that even on our worst days, we can find the strength to push through and not allow this disease to define us. When someone asks the meaning behind Thirteen Nineteen, it will open the door for us to spread MS awareness by sharing our story with others. We are in this together! ■

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Ashley Suvanto, 32, lives in Arizona with her husband, two kiddos and pups.

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Ashley Suvanto creates jewelry to inspire others in their MS journey.

**Care to comment?** Email us at [editor@nmss.org](mailto:editor@nmss.org).



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