

# momentum®

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

FALL 2018

## Keeping MS in check

Former pro hockey player  
**Bryan Bickell and family**  
bring a positive outlook  
to living with MS.

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National  
Multiple Sclerosis  
Society

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## ADVERTISEMENT

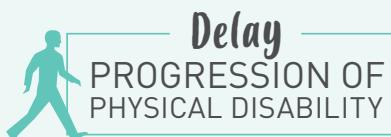


Laura S., living with relapsing MS



### Say yes to TECFIDERA—a pill that can **cut MS relapses in half.**

TECFIDERA is a twice-daily pill proven to **work against relapsing multiple sclerosis (MS)** in **3 important ways**. TECFIDERA can:



In a 2-year study, **TECFIDERA reduced risk of relapse by 49%** compared with placebo.  
People were also **38% less likely to experience physical disability progression**.

#### What is TECFIDERA?

Tecfidera® (dimethyl fumarate) is a prescription medicine used to treat people with relapsing forms of multiple sclerosis.

#### Important Safety Information

Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients.

Before taking and while you take TECFIDERA, tell your doctor about any low white blood cell counts or infections or any other medical conditions.

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

TECFIDERA may cause serious side effects including:

- **Allergic reactions**
- **PML, which is a rare brain infection that usually leads to death or severe disability.**
- **Decreases in your white blood cell count.** Your doctor should check your white blood cell count before you take TECFIDERA and from time to time during treatment
- **Liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed.

# opens up possibilities

Tell your doctor right away if you get any symptoms of a liver problem during treatment, including:

- severe tiredness
- loss of appetite
- pain on the right side of your stomach
- dark or brown (tea color) urine
- yellowing of your skin or the white part of your eyes

**The most common side effects of TECFIDERA include** flushing and stomach problems. These can happen especially at the start of treatment and may decrease over time. Taking TECFIDERA with food may help reduce flushing. Call your doctor if these symptoms bother you or do not go away. Ask your doctor if taking aspirin before taking TECFIDERA may reduce flushing.

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

**Are you ready to say yes to the possibility of fewer relapses?**  
Visit [yestoTEC.com](http://yestoTEC.com) or call 1-844-TalkTec (1-844-825-5832).

**Tell your doctor** if you are pregnant or plan to become pregnant, or breastfeeding or plan to breastfeed. It is not known if TECFIDERA will harm your unborn baby or if it passes into your breast milk. Also tell your doctor if you are taking prescription or over-the-counter medicines, vitamins, or herbal supplements. If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

**For additional Important Safety Information, please see Patient Information on the following page.**

This is not intended to replace discussions with your doctor.

\$0  
CO PAY

**yes** to finding support

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

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



**Patient Information**  
**TECFIDERA® (tek" fi de' rah)**  
**(dimethyl fumarate) delayed-release capsules**

**What is TECFIDERA?**

- TECFIDERA is a prescription medicine used to treat people with relapsing forms of multiple sclerosis (MS)
- It is not known if TECFIDERA is safe and effective in children under 18 years of age

**Who should not take TECFIDERA?**

- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients. See below for a complete list of ingredients.

**Before taking and while you take TECFIDERA, tell your doctor if you have or have had:**

- low white blood cell counts or an infection
- any other medical conditions

**Tell your doctor if you are:**

- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby.
  - If you become pregnant while taking TECFIDERA, talk to your doctor about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting [www.tecfiderapregnancyregistry.com](http://www.tecfiderapregnancyregistry.com). The purpose of this registry is to monitor the health of you and your baby.
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your doctor should decide if you will take TECFIDERA or breastfeed.
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

**How should I take TECFIDERA?**

- Take TECFIDERA exactly as your doctor tells you to take it
- The recommended starting dose is one 120 mg capsule taken by mouth 2 times a day for 7 days
- The recommended dose after 7 days is one 240 mg capsule taken by mouth 2 times a day
- TECFIDERA can be taken with or without food
- Swallow TECFIDERA whole. Do not crush, chew, or sprinkle capsule contents on food.
- Protect TECFIDERA from light. You can do this by storing the capsules in their original container.
- If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

**What are the possible side effects of TECFIDERA?****TECFIDERA may cause serious side effects including:**

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)
- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your doctor should do a blood test before you start treatment with TECFIDERA and while on therapy.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your doctor right away if you get any of these symptoms of a liver problem during treatment.
  - severe tiredness
  - loss of appetite
  - pain on the right side of your stomach
  - have dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes

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

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

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

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

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

**What are the ingredients in TECFIDERA?**

**Active ingredient:** dimethyl fumarate

**Inactive ingredients:** microcrystalline cellulose, silicified microcrystalline cellulose, croscarmellose sodium, talc, silica colloidal silicon dioxide, magnesium stearate, triethyl citrate, methacrylic acid copolymer - Type A, methacrylic acid copolymer dispersion, simethicone (30% emulsion), sodium lauryl sulphate, and polysorbate 80.

**Capsule Shell:** gelatin, titanium dioxide, FD&C blue 1; brilliant blue FCF, yellow iron oxide and black iron oxide.

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

This Patient Information has been approved by the U.S. Food and Drug Administration. Revised: 1/2017

## How did you find the resources you needed after you were diagnosed with multiple sclerosis?

Did you find reliable information and the right support?

We want people to be able to get what they need when they need it—especially at diagnosis.

Fortunately, resources and information are more accessible and easier to find in today's world.

More than 720,000 people visit **nationalMSSociety.org** each month to learn about MS and the latest advances in MS research. They use it to find information on MS symptoms and treatments, and for tools, resources and wellness strategies to help them live their best lives. And they connect with others affected by MS through our online community at **MSconnection.org**.

Whether you or a loved one is newly diagnosed or have lived with MS for many years and need something new, information on these sites is available to support you. And if you can't find what you're looking for, if you have a complex issue like finances or housing needs or you want to talk to someone, you can connect with a highly trained MS Navigator by online chat, on the Society's website or at 1-800-344-4867.

You can come in and out of the website as much or as little as you need. We are here! The



**Cyndi Zagleboyo**

sooner you plug into these resources, the more information and support you know you have access to. It can be a powerful tool.

Says Kate Tomlinson, the Society's vice president of digital marketing: "Our website is often the first interaction and sometimes the

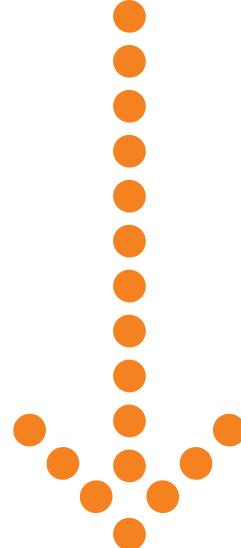
preferred way for a person affected by MS to connect with the Society. We want that connection to be easy and the information to be valuable. Feedback from site visits helps us continually improve the topics that are covered and the way information is organized. Our goal is to have you leave the site feeling more informed and better equipped to answer the everyday challenges of living with MS."

The saying is true: Knowledge is power. We want to empower people affected by MS to solve everyday challenges. We want to connect people to information, resources and communities of support so they can be more powerful than the challenges of MS.

What are your thoughts about the website? How do you use it? And how can we make it better? ■



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



Let me know your thoughts.  
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Tag your thoughts @mssociety  
using #Momentum.



Join discussions  
at [MSconnection.org](http://MSconnection.org).

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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  
Summer 2017 issue,  
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gatherMS

Living with MS can be unpredictable.

Finding the right support  
shouldn't be.

Navigate MS with  
a site dedicated to  
connecting people  
to the resources  
they need.

gatherMS.com

Genentech



FALL 2018

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## on the cover

Bryan Bickell's MS diagnosis changed his life and career, but that hasn't stopped him from keeping a positive attitude.

PHOTO COURTESY OF BRYAN BICKELL

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PHOTO COURTESY OF LIN SHANTI GOODMAN

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COVER PHOTO IS COURTESY OF BRYAN BICKELL

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Lin Shanti Goodman creates paper-mache animals for inspiration.

Look for these icons throughout Momentum.



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### **IN THE NEXT ISSUE**

How people cope with a change in diagnosis from relapsing-remitting MS to secondary-progressive MS.

**Plus:** Stories about the women of WeAreILLmatic, your relationship with your assistive devices and new treatment guidelines for MS.

## Contact Momentum

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

Address drop, add or change  
Email: [mailinglist@nmss.org](mailto:mailinglist@nmss.org)  
Telephone: 1-844-675-4787

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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.



## What a cure means to me

### A world without MS

A cure for MS would be half my dream (Forward, Summer 2018). The first half is a world without MS. No more devastation and destruction to those diagnosed and their families. No more lives robbed of what could have been. Step one: Cure and stop MS. Hooray for that day! Countless people will be spared the horrors that too many have and are now suffering. My other wish is to fix the damage MS has already done. In the end, all I can say is stay active, stay positive and stay hopeful.

---

Kenneth Swiderski, Oregon

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### No discomfort

As a 62-year-old woman diagnosed in my early 30s, I believe a cure will only be a cure when it doesn't inflict any discomfort. In the medical community today, there are healthcare professionals treating conditions of all sorts, but if these treatments even appear worse than the conditions they were designed to treat, they will not be used to their greatest abilities. Every time I read about new testing for MS, it sounds more and more as though researchers see people with MS as guinea pigs. We are not. It is high time to be looking not only for more effective testing, treatments and cures, but people-friendly ones as well.

---

Renee Ducker, Montclair, New Jersey

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### Stop it from getting worse

When I was diagnosed about 45 years ago, I was a healthy and active 23-year-old, and my doctor advised me to go on with my life, and I would probably live to the age of 55. Well, trick's on him: I am now 71 and still active with five grandchildren. My doctors now identify my situation as progressive MS. My idea of a cure is "first things first." Whether it is relapsing, progressive or whatever, just stop it from getting worse. With the new diagnostic procedures, MS can and should be identified relatively early. My idea of a realistic "cure" for the next few years is to "stop the bleeding"—not a real cure, but "do not let me get any worse."

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Rand Garrett, Virginia

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### To live a normal life

To me, a cure means I can walk, run, skip and jump again. I can think of what to say. I will feel alive, play with my granddaughter. My feet, legs and hands won't be numb anymore. It means to live a normal life. It has been my dream since 1991—when I was diagnosed with MS—to be able to walk next to my husband, have friends and go out for lunch and shopping again just like I used to. Thank you for searching for a cure for all of us with MS.

---

Jayne Almonrode, Tennessee

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

Email us at  
[editor@nmss.org](mailto:editor@nmss.org)



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discussions  
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## Attention to research

The article about Robin Franklin, PhD, and his award-winning research into myelin generation clarified my understanding about how regeneration sometimes works and sometimes doesn't ("Beautiful melody," Summer 2018). The broad focus—across articles—about specific research projects and about the broader strategic approach that the MS Society is crafting was very helpful. The articles about research focused on cognitive function and everyday stress in its various manifestations gave interesting information and specific ideas that you could use in this very moment. I especially appreciated hearing about the different ways people think about a cure. Thank you for the description of the process behind research decisions. I applaud the broad circle of stakeholders who inform the research process. It's not an easy task when trying to balance a broad set of needs with both short- and long-term horizons.

---

Dan Hammang, California

## Less alone

The article "Out-stressing stress" (Summer 2018) really hit home. I know my own thoughts of defeat are what cause much of my anxiety and stress. I know I just need to calm down, reassess the situation and start again after relaxing and taking in a deep breath. I need to give myself credit for what I have accomplished, which makes my list a little less daunting, or just put the list out of sight and go with the flow of the day. That being said, I also can accomplish so many of my day-to-day tasks and still feel that I did not get anything done unless I do something creative, such as sending a greeting card, thanking someone who has helped make my life easier, watering my tomatoes, or just relaxing and breathe nature in. Then, I feel like I have not wasted the day. Thank you, Aviva Patz, and all the people she interviewed for their stories, especially Clarisa Walcott. Thanks for sharing the beautiful photo in your yoga pose. I feel less alone in this mean disease by reading **Momentum**.

---

Darla Petersen, Utah



## The fun grandma

I was diagnosed with MS in 1980 and have experienced just about everything that Donna Rice has ("Outward appearances," Summer 2018), especially her fears about grandchildren. I have four grandchildren ranging in ages from 13 to 21. I was there when each of them was born, and in May 2018, I was there for my granddaughter's college graduation. Over the years, I have found ways to be a "fun grandma." The grandchildren couldn't wait to be able to sit on my lap and "drive" my scooter or to be tall enough to push my wheelchair. They grew up with a handicapped grandmother and have learned to appreciate people with disabilities. I send them text messages that say, "Have a good day" or "Love you and miss you." They always respond. Being smart, determined and stubborn, you will find a way to be the grandma that you want them to see and love.

---

Barbara Fratamico, Smithtown, New York

## Determined as ever

Thank you, Scott Rice, for writing about your wife, Donna, ("Outward appearances," Summer 2018) and thank you, **Momentum**, for publishing it. My wife, Natalie, was diagnosed with MS in 1964 at the age of 28. She remains determined as ever, remaking herself as MS slowly progresses. Neither employers nor our social contacts had any clue what it took at home for Natalie to meet those commitments. She often states how fortunate she feels to have "pulled it off" as well as she has over such a length of time. The phrase, "Well, you don't look like you have MS," resonated with Natalie. The other is, "I just can't see what that dog does for you," about her three service dogs. Some family members still believe Natalie is either mentally ill or is "malingering," and that I do too much for her. Others said they were no longer including us because Natalie probably couldn't come anyway, or they didn't want to be around to see Natalie "go downhill and die." Natalie is now 82 years old. ■

---

James Rowe, Oregon

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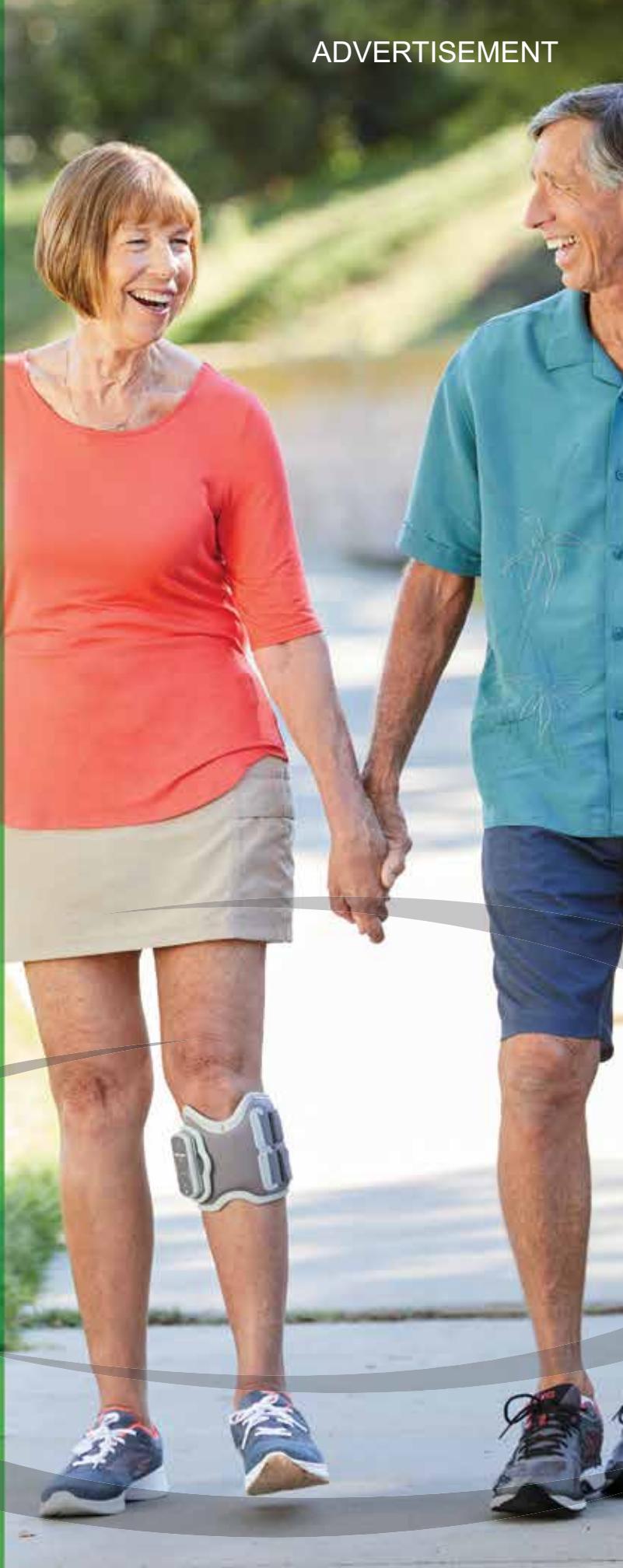


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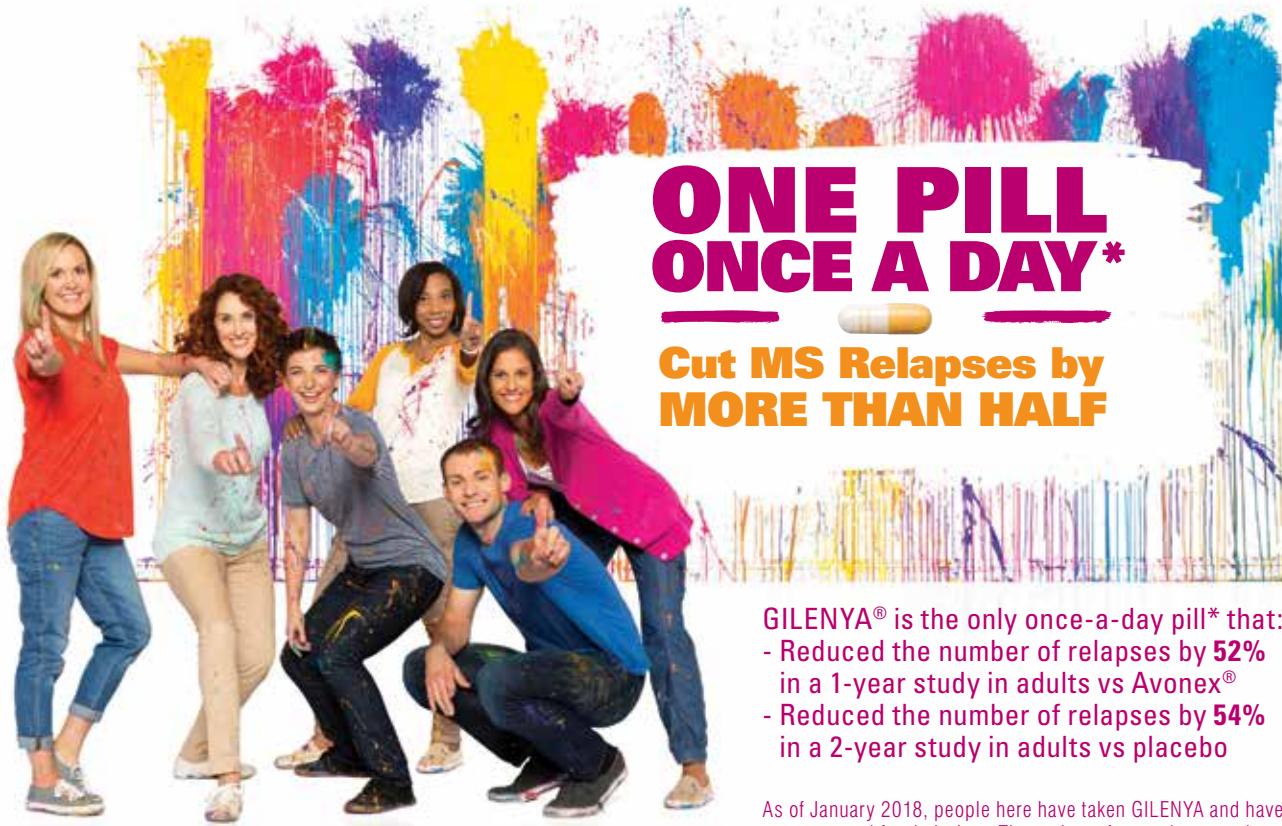
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FOR RELAPSING FORMS OF MULTIPLE SCLEROSIS (MS)



## ONE PILL ONCE A DAY\*



**Cut MS Relapses by  
MORE THAN HALF**

GILENYA® is the only once-a-day pill\* that:

- Reduced the number of relapses by **52%** in a 1-year study in adults vs Avonex®
- Reduced the number of relapses by **54%** in a 2-year study in adults vs placebo

As of January 2018, people here have taken GILENYA and have been compensated for their time. The patients featured may no longer be taking GILENYA today.

More than **230,000** people have been treated with GILENYA worldwide. This includes people in clinical trials and those prescribed GILENYA—join them and say, **"HEY MS, Take This!"**

**INDICATION** GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults and children 10 years of age and older.

as seen on an ECG, or if you take medicines that change your heart rhythm. Do not take GILENYA if you are allergic to fingolimod or any of the other ingredients.

**IMPORTANT SAFETY INFORMATION** You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure. Do not take GILENYA if you have an irregular or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT

\*GILENYA can result in a slow heart rate when first taken. You will be observed by a health care professional for at least 6 hours after you take your first dose. You may need to repeat this monitoring if you miss a dose or are a child who is moving to 0.5 mg from the 0.25 mg dose.

Please see additional Important Safety Information on the next page and Brief Summary of Important Product Information on the following pages.



Talk to your health care professional to see if GILENYA is right for you.



Visit [gilenya.com](http://gilenya.com) to learn more.

## IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

- Slow heart rate, especially after first dose. Adults and children will be monitored by a health care professional for at least 6 hours after the first dose or after a child takes the first dose of 0.5mg of GILENYA when switching from 0.25mg daily dose. Your pulse and blood pressure will be checked hourly. You'll get an ECG before and 6 hours after your first dose. If any heart problems arise or your heart rate is still low, you'll continue to be monitored. If you have any serious side effects, especially those that require treatment with other medicines, or if you have certain types of heart problems, or if you're taking medicines that can affect your heart, you'll be watched overnight. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor, or seek immediate medical attention if you have any symptoms of slow heart rate, such as dizziness, tiredness, feeling like your heart is beating slowly or skipping beats, or chest pain. Symptoms can happen up to 24 hours after the first dose. Do not stop taking GILENYA without consulting with your doctor. Call your doctor if you miss 1 or more doses of GILENYA—you may need to repeat the 6-hour monitoring.
- Increased risk of serious infections, some of which could be life threatening and cause death. You should not receive live vaccines during treatment with GILENYA and for 2 months after you stop taking GILENYA. Vaccines may not work as well when given during treatment with GILENYA. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test to check your white blood cells before you start GILENYA. Call your doctor right away if, while taking GILENYA or for 2 months after your last dose, you have fever, tiredness, body aches, chills, nausea, vomiting, or headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion. These may be symptoms of meningitis.
- Progressive multifocal leukoencephalopathy (PML). PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems. Call your doctor right away if you have any new or worsening symptoms of PML that have lasted several days, including changes in your thinking or memory, changes in your vision, decreased strength, problems with balance, weakness on 1 side of your body, loss of coordination in your arms and legs, confusion or changes in your personality.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. If it happens, macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Swelling and narrowing of the blood vessels in your brain. A condition called PRES (posterior reversible encephalopathy syndrome) has happened rarely in adults taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you experience any symptoms, such as sudden severe headache, sudden confusion, seizures, or sudden loss of vision.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Liver problems. Your doctor should do blood tests to check your

liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.

- Increases in blood pressure (BP). BP should be monitored during treatment.
- Skin cancers including basal and Merkel cell carcinoma and melanoma. Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, new darkened area in your skin, a sore that does not heal, or growths on your skin such as a bump that may be shiny, pearly white, skin colored, or pink. While taking GILENYA, limit the amount of time you spend in sunlight and ultraviolet (UV) light as well as use sunscreen with a high sun protection factor and wear protective clothing.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. It is not known if GILENYA passes into breast milk. Talk to your doctor about the best way to feed your baby if you take GILENYA. A pregnancy registry is available for women who become pregnant during GILENYA treatment. For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by e-mailing gpr@quintiles.com, or by going to [www.gilenyapregnancyregistry.com](http://www.gilenyapregnancyregistry.com).

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; stroke or mini-stroke; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections due to a disease or are taking medicines that lower your immune system, including corticosteroids, or have taken them in the past; eye problems; diabetes; breathing or liver problems; or uncontrolled high blood pressure. Also tell your doctor if you have had chicken pox or have received the chicken pox vaccine. Your doctor may test for the chicken pox virus, and you may need to get the full course of the chicken pox vaccine and wait 1 month before starting GILENYA. Children 10 years and older should complete their vaccination schedule before starting GILENYA.

If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.

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

The most common side effects with GILENYA were headache, abnormal liver tests, diarrhea, cough, flu, sinusitis, back pain, abdominal pain, and pain in arms or legs.

In the pediatric study:

- The safety in children 10 years and older receiving GILENYA was similar to that seen in adults.
- The rate of seizures was higher in GILENYA-treated patients compared to that of a leading injectable.

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

**Please see additional Important Safety Information on previous page.**



**Please see Brief Summary of Important Product Information on next pages.**

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T-GYA-1359199

## BRIEF SUMMARY

### IMPORTANT FACTS ABOUT GILENYA® (fingolimod) capsules

The risk information provided here is not comprehensive. If you are the parent of a child who is being treated with GILENYA, the following information applies to your child. This information does not take the place of talking to your doctor about your medical condition or your treatment.

To learn more about GILENYA, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-800-GILENYA (1-800-445-3692) or visit [www.GILENYA.com](http://www.GILENYA.com).

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

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

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

**All adults and children will be observed by a health care professional for at least 6 hours after taking their first dose of GILENYA. Children should also be observed by a health care professional for at least 6 hours after taking their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose.**

After you take your first dose of GILENYA and after a child takes their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose:

- Your pulse and blood pressure should be checked every hour
- You should be observed by a health care professional to see if you have any serious side effects. If your heart rate slows down too much, you may have symptoms such as:
  - dizziness
  - tiredness
  - feeling like your heart is beating slowly or skipping beats
  - chest pain
- If you have any of the symptoms of slow heart rate, they will usually happen during the first 6 hours after your first dose of GILENYA. Symptoms can happen up to 24 hours after you take your first GILENYA dose
- 6 hours after you take your first dose of GILENYA you will have another ECG. If your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be observed
- If you have any serious side effects after your first dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. You will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA the next day
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight after you take your first dose of GILENYA.

Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA. Call your doctor or go to the nearest hospital emergency room right away if you have any symptoms of a slow heart rate.

**If you miss 1 or more doses of GILENYA,** you may need to be observed by a health care professional when you take your next dose.

Call your doctor if you miss a dose of GILENYA. See "How should I take GILENYA?"

- 2. Infections.** GILENYA can increase your risk of serious infections that can be life-threatening and cause death. You should not receive **live** vaccines during treatment with GILENYA and for 2 months after you stop taking GILENYA. Talk to your doctor before you receive a vaccine during treatment and for 2 months after treatment with GILENYA. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with GILENYA.

GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test to check your white blood cells before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection during treatment with GILENYA and for 2 months after your last dose of GILENYA:

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

**3. Progressive multifocal leukoencephalopathy (PML).** PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems. Symptoms of PML get worse over days to weeks. Call your doctor right away if you have any new or worsening symptoms of PML, that have lasted several days, including:

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

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

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

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

### What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults and children 10 years of age and older.

It is not known if GILENYA is safe and effective in children under 10 years of age.

### Who should not take GILENYA?

#### Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or mini-stroke (transient ischemic attack or TIA) or certain types of heart failure in the last 6 months.
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA.
- are taking certain medicines that change your heart rhythm.
- are allergic to fingolimod or any of the ingredients in GILENYA. See the end of this leaflet for a complete list of ingredients in GILENYA. Symptoms of an allergic reaction may include: rash, itchy hives, or swelling of the lips, tongue or face.

Talk to your doctor before taking GILENYA if you have any of these conditions or do not know if you have any of these conditions.

### What should I tell my doctor before taking GILENYA?

**Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:**

- an irregular or abnormal heartbeat (arrhythmia).
- a history of stroke or mini-stroke.
- heart problems, including heart attack or angina.
- a history of repeated fainting (syncope).
- a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.
- recently received a vaccine or are scheduled to receive a vaccine.
- chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the full course of the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- your child has completed his or her vaccination schedule. Your child needs to have completed his or her vaccination schedule before starting treatment with GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes.
- breathing problems, including during your sleep.
- liver problems.
- high blood pressure.
- types of skin cancer called basal cell carcinoma (BCC) or melanoma.
- are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.

- Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
- If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

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

For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by sending an email to [gpr@quintiles.com](mailto:gpr@quintiles.com), or go to [www.gilenyapregnancyregistry.com](http://www.gilenyapregnancyregistry.com).

- are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. Talk to your doctor about the best way to feed your baby if you take GILENYA.

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

Especially tell your doctor if you take medicines that affect your immune system, including corticosteroids, or have taken them in the past.

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

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

#### How should I take GILENYA?

- Adults and children will be observed by a health care professional for at least 6 hours after taking their first dose of GILENYA.
- Children should also be observed by a health care professional for at least 6 hours after taking their first dose of 0.5 mg of GILENYA when switching from the 0.25 mg dose. See "What is the most important information I should know about GILENYA?"**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- Call your doctor right away if you miss a dose of GILENYA. You may need to be observed by a health care professional for at least 6 hours when you take your next dose. If you need to be observed by a health care professional when you take your next dose of GILENYA you will have:
  - an ECG before you take your dose
  - hourly pulse and blood pressure measurements after you take the dose
  - an ECG 6 hours after your dose
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight by a health care professional in a medical facility after you take your dose of GILENYA.
- If you have serious side effects after taking a dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. If you were observed overnight, you will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA. See "What is the most important information I should know about GILENYA?"

#### What are possible side effects of GILENYA?

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

- See "What is the most important information I should know about GILENYA?"
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened rarely in adults taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you have any of the following symptoms:

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

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

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

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

**• increased blood pressure.** Your doctor should check your blood pressure during treatment with GILENYA.

**• types of skin cancer called basal cell carcinoma (BCC) and melanoma.** Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, a new darkened area on your skin, a sore that does not heal, or growths on your skin such as a bump that may be shiny, pearly white, skin-colored, or pink. Your doctor should check your skin for any changes during treatment with GILENYA. Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear protective clothing and use a sunscreen with a high sun protection factor.

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

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

- |                        |   |
|------------------------|---|
| • headache             | • inflammation of the sinuses (sinusitis) |
| • abnormal liver tests | • back pain                               |
| • diarrhea             | • stomach-area (abdominal) pain           |
| • cough                | • pain in arms or legs                    |
| • flu                  |   |

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

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

#### Keep GILENYA and all medicines out of the reach of children.

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

Medicines are sometimes prescribed for purposes other than those listed here. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms that you have. It may harm them. This document summarizes the most important information about GILENYA. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about GILENYA that is written for health professionals.

#### What are the ingredients in GILENYA?

##### 0.25 mg capsules

**Active ingredient:** fingolimod

**Inactive ingredients:** mannitol, hydroxypropyl cellulose, hydroxypropyl betadex, magnesium stearate, gelatin, titanium dioxide, yellow iron oxide.

##### 0.5 mg capsules

**Active ingredient:** fingolimod hydrochloride

**Inactive ingredients:** mannitol, magnesium stearate, gelatin, titanium dioxide, yellow iron oxide.

GILENYA is a registered trademark of Novartis AG.

Manufactured by: Novartis Pharma Stein AG, Stein, Switzerland

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

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

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## Prep now, eat later

This fall, save time and eat healthfully by washing, chopping and preparing most of your food for the week and storing it in containers or jars. You'll be more likely to eat more vegetables during the week if they're cut and ready to go. This fall-inspired salad with maple cider vinaigrette developed by nutritionist Megan Gilmore can be made in advance, making healthy eating a breeze throughout the week. Turn the page to learn more about how to incorporate healthier foods into your diet.

For the recipe complete with ingredients and instructions, visit [detoxinista.com/fall-mason-jar-salad-with-maple-cider-vinaigrette](http://detoxinista.com/fall-mason-jar-salad-with-maple-cider-vinaigrette).

PHOTO COURTESY OF MEGAN GILMORE

# in the know

Eating well  
could be a big  
step toward  
feeling well.

by Matt Alderton

**Y**our mother was right: You really are what you eat—especially if you have multiple sclerosis, which could be helped or hindered by your diet.

“While at this point we don’t have evidence that any diet out there can cure or prevent MS, good nutrition is still important for people with MS because it can lower the risk of developing other diseases and disorders,” explains Holly Prehn, a registered dietitian at UCHealth, an Aurora, Colorado-based health care system. UCHealth is working with the Rocky Mountain MS Center’s Wellness Pilot Program, which promotes whole-body and lifestyle wellness in people with MS. “Vascular disease risk factors such as obesity, hypertension, hyperlipidemia, heart disease and diabetes are common in people with MS and may have negative effects on disability progression in MS,” Prehn says. “Following a healthy diet can help reduce the risk of developing these vascular disease risk factors.”

Alongside the disease-modifying therapies, a healthy diet may also reduce the inflammation associated with some MS symptoms.

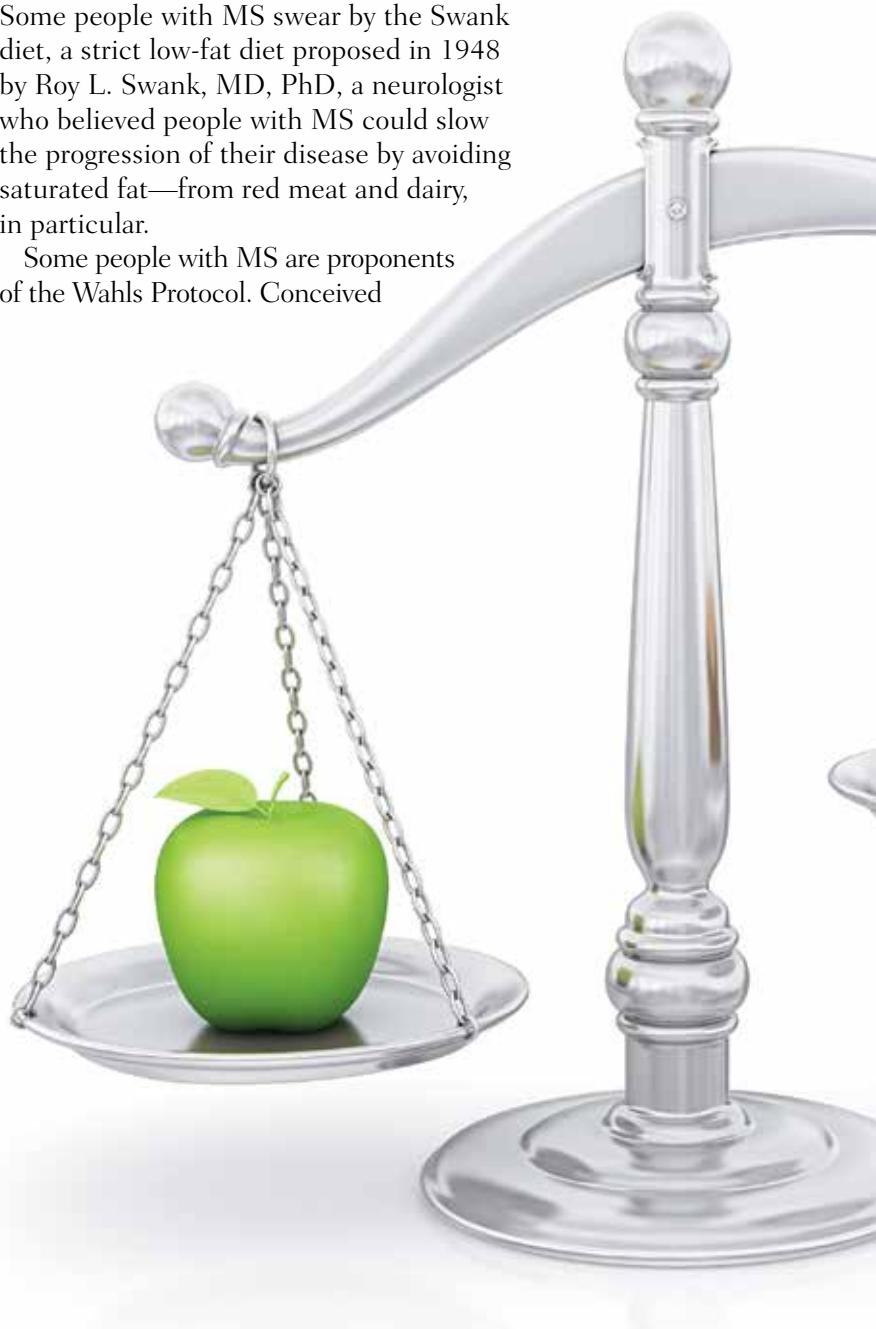
“We want to avoid putting anything in the body that could cause inflammation,” says Kristin Kirkpatrick, lead dietitian and manager of wellness nutrition services at the Cleveland Clinic Wellness Institute in Cleveland, Ohio. “It’s about trying to keep the body in a state of homeostasis as much as possible to avoid flare-ups and live a happy, normal life.”

# Weighing a

## What is a ‘healthy’ diet?

Some people with MS swear by the Swank diet, a strict low-fat diet proposed in 1948 by Roy L. Swank, MD, PhD, a neurologist who believed people with MS could slow the progression of their disease by avoiding saturated fat—from red meat and dairy, in particular.

Some people with MS are proponents of the Wahls Protocol. Conceived



# healthy diet

by Terry Wahls, MD, who was diagnosed with MS in 2000, the Wahls Protocol is a take on the Paleo diet that consists of foods that were consumed by ancient humans, such as meat, fish and leafy green vegetables, while



**The underlying idea  
is simple: Good  
food in, good  
health out.**

avoiding foods that weren't, such as dairy, grains and legumes.

Although devotees of both have reported positive results, neither diet has been sufficiently substantiated by scientific research. "We need more evidence, for sure," Kirkpatrick says.

## Eating well

Unlike some conditions—like cardiovascular disease, for which doctors may prescribe the DASH (Dietary Approaches to Stop Hypertension) diet—the absence of evidence means there is no specific diet “prescription” for MS. Both Prehn and Kirkpatrick, however, are advocates of the Mediterranean diet, which embraces the traditional eating patterns of countries bordering the Mediterranean Sea.

The Mediterranean diet has “consistently been demonstrated to provide a degree of protection against major chronic degenerative disease,” Prehn says. “While there is not one definition of a Mediterranean diet, the overall way of eating is characterized by a high intake of vegetables, fruits, legumes, nuts and seeds, unrefined grains and olive oil; a moderate intake of fish; a low to moderate intake of poultry and dairy products, generally in the form of cheese and yogurt; [and] a low intake of red meat.”

The underlying idea is simple: Good food in, good health out.

“I like to think of food as fuel for what you want to do in your day,” Prehn says. “If you fuel your body well with healthful foods to provide you with energy and the vitamins and minerals that you need, then you can optimize how your body and mind function.”

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Matt Alderton is a Chicago-based writer and editor.

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

Good sources of healthy fat are olive oil and oily fish like mackerel, lake trout, herring, sardines, tuna, halibut, grouper and salmon, which are chock-full of omega-3s.

Include protein-rich nuts, chia seeds and flax seeds in your diet. Although they are high in fat, most of it is monounsaturated and polyunsaturated fat, which is associated with good cardiovascular health.

Whole grains provide fiber, which promotes gut and heart health. Smart choices include whole-grain bread, brown rice, oatmeal and quinoa.

Fruits and vegetables supply important vitamins and minerals—including antioxidants that can prevent or delay some types of cell damage.

Added sugar—in desserts, beverages, etc.—has been linked to obesity, heart disease, diabetes, cancer, tooth decay and inflammation.

Refined grains like white rice, white bread and baked pastries have been stripped of their fiber and many of their vitamins, making them void of nutrition.

Red meat is high in saturated fat, which raises your cholesterol and may lead to heart disease. Avoid processed meats like hot dogs and sausages.

Gluten is a general name for the proteins found in wheat. Although there's no evidence that gluten causes MS, some studies have shown that people with MS report gluten intolerance in greater numbers than the general population.

Healthy fats

Nuts and seeds

Whole grains

Fruits and vegetables

Added sugar

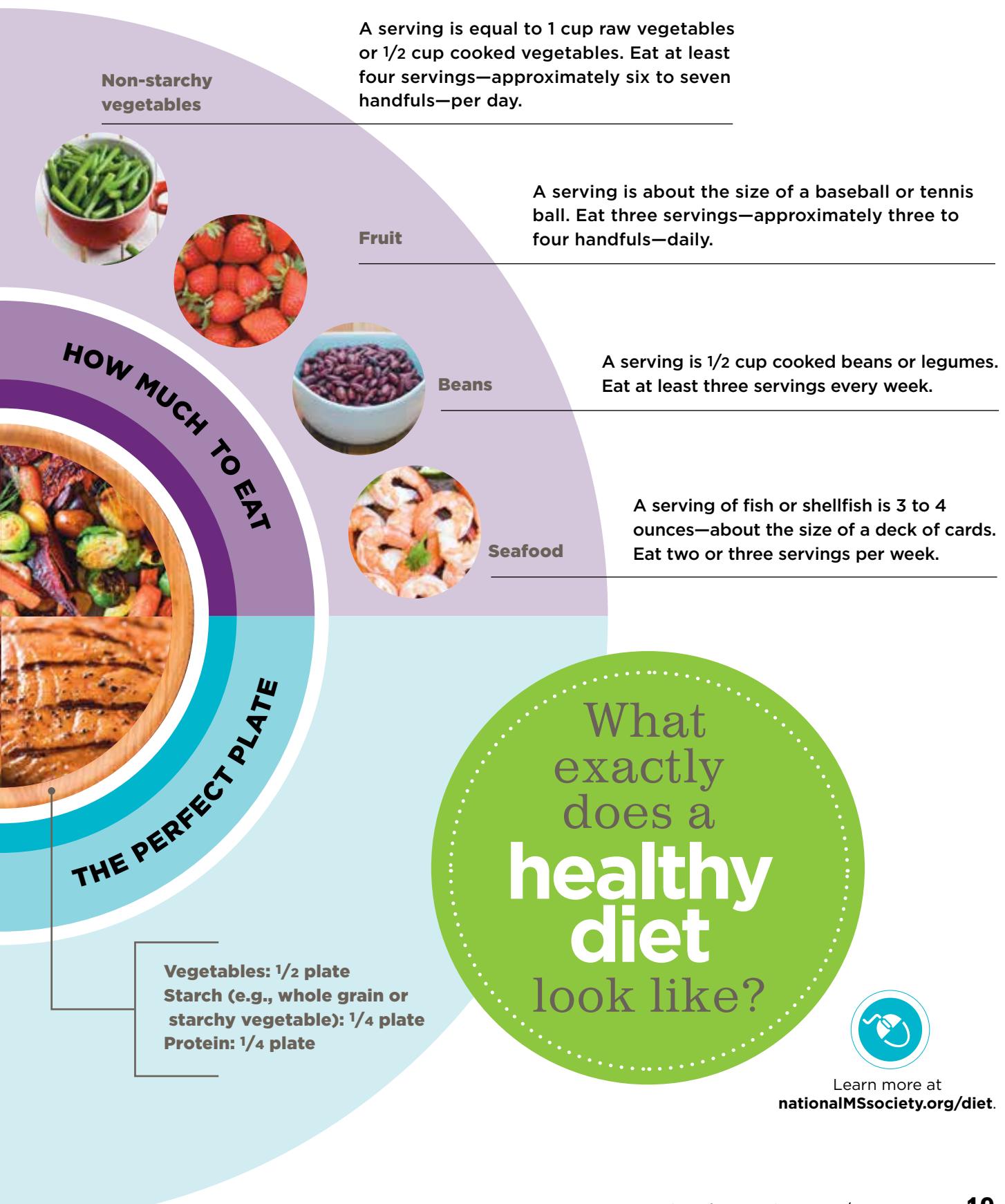
Refined grains

Processed meats

WHAT TO EAT

WHAT TO AVOID





## Get more done, one thing at a time.

When you're feeling fatigued, it's not always possible to do everything. Sure, there may be a dozen things on your to-do list, but sometimes it's better just to pick one or two to tackle rather than trying to do it all. Researchers at Harvard University found that the most productive people change focus relatively few times, compared to those who are more frenetic, changing focus up to 500 times a day.

**Tip:** Instead of multitasking, try clustertasking. Choose an activity that you do often, such as checking emails, and cluster the task into two or three designated sessions a day rather than constantly checking messages throughout the day, advises Devora Zack, productivity expert and author of "Singletasking."

In this section, people with MS share their stories and tips on how they juggle life and fatigue.



# thrive

Forging a path  
to your best life

Inside this section: MS fatigue 21//At the front 30

# MS fatigue

It's the most common symptom of the disease, but there are ways to manage it.

by Vicky Uhland

**E**very day, Donna Rice wakes up in her Issaquah, Washington, home around 9 a.m. For the next hour, she lies in a fetal position, mustering the strength to get out of bed. "The best way I can describe it to others is that my body aches all over, like when you have the flu," says Rice, who was diagnosed with multiple sclerosis in 2004 at age 43.

Once she's finally on her feet, Rice eats breakfast. She rests for an hour and then showers. From about 11 a.m. to 3 p.m.—what she calls her prime time—she visits her doctors, runs errands, socializes with friends and tries to get in a daily walk. By 5 p.m., she's exhausted and ready to settle in for the evening.

PHOTO COURTESY OF DONNA RICE



With planning, Donna Rice is able to get what she needs done by 5 p.m. so that she can settle in for the evening.



PHOTO COURTESY OF DONNA RICE

Donna Rice's daughter, Kaela Graham (right), organized a team of her sorority sisters to participate in Walk MS in Clarkston, Washington.

Farther south along the Pacific Coast, Cheryl Hile begins most of her days by strapping on the ankle-foot orthotic that helps prevent foot drop and then heads out for a 3-mile run through her San Diego neighborhood. Hile, who was diagnosed with MS in 2006 when she was 32, believes this exercise regimen improves her mood and fights muscle atrophy, but she must do it first thing in the morning because of afternoon fatigue. Her fatigue also heightens the cognitive deficiencies that forced her to leave her job as an accountant in 2017.

"As the day progresses, it's harder for me to find words, pay attention and focus on people," Hile says. Even math-related tasks she's an expert in, like balancing her checkbook or doing the family taxes, are more difficult in the afternoon, when fatigue makes the mistakes creep in. "It's like when you have an allergy and you're on Benadryl—that kind of brain fog," she says. "Sometimes I tell people it's like being jet-lagged."

Although Rice and Hile's fatigue and their solutions for dealing with it take different forms, their symptoms are familiar to nearly everyone who has been diagnosed with MS. A variety of studies show that a majority of people with MS experience fatigue, which a 2017 research review defined as "extreme and persistent mental and/or physical tiredness, weakness or exhaustion."

MS fatigue cuts across age, gender and ethnicity, and can occur at any stage of the disease. Fatigue levels frequently vary, making it difficult to predict how you'll feel on any given day—and when you'll hit a wall. And unlike typical feelings of tiredness, MS-related fatigue can have an enormous impact on how you function in every aspect of your life, playing havoc with relationships, jobs, hobbies and even simple, everyday tasks like getting dressed or cooking dinner.

While living with MS fatigue can be a challenge, a variety of therapies, strategies and tools can help you identify the types of fatigue you have and how to manage more effectively. Here's how to ensure you have enough energy for the things that matter most in your life.

## The two types of fatigue

Like MS itself, the cause of fatigue in MS is unknown. But researchers do know there are two types of MS-related fatigue: primary and secondary.

**Primary fatigue** is related directly to the disease of MS. John Schafer, MD, founder and director of Mercy MS Center in Sacramento, California, says research shows this type of fatigue may be due to several causes.

One potential culprit is immune-system hormones called cytokines, which are released as part of the inflammatory process in MS. Cytokines are what make you feel weak and exhausted when you have the flu or an infection, and Dr. Schafer says there is some evidence they may contribute to MS fatigue. Demyelination and the subsequent decline in nerve conduction may also lead to a gradual erosion of muscle strength and endurance.

Another suspected cause of fatigue has to do with how MS interrupts nerve pathways in the brain. As a result, the brain may have to enlist more regions to do

Cheryl Hile says that exercise helps improve her mood and fights muscle atrophy. She runs three miles most mornings because fatigue sets in during the afternoons.

a task that one region could normally do on its own. Some research shows this may cause wear and tear on brain circuits, contributing to cognitive fatigue.

"Think of your brain like a computer. If you try to work on various programs simultaneously the computer's processing speed is going to be slower," says Augusto Miravalle, MD, chief of the Multiple Sclerosis Division at the University of Florida College of Medicine. "There are neural structures by which MS patients use networks not normally used by individuals with intact brains in order to compensate for brain damage. MS can require your brain to recruit other areas to do a simple task, which slows down your mental processing speed."

**Secondary fatigue** is usually due to MS symptoms. For instance, Dr. Miravalle notes that depression is a common symptom of MS, and fatigue is a frequent symptom of depression. Bladder issues that force you to wake up throughout the night and interrupt sleep can worsen fatigue. So can muscle spasms and pain. MS-related heat sensitivity can worsen the typical fatigue many people feel when temperatures soar. And some medications may contribute to fatigue (see sidebar on page 25).

Chronic stress can also be a cause of fatigue, although once again, researchers aren't sure how. There could be a biological correlation in people with MS, Dr. Miravalle says.

"We do know that the younger the patient is, the more likely that external factors like medications, depression and stress are factors in fatigue," he says. "These are people whose muscles may not be tired, but who still crash at 2 p.m."

The complicated causes and treatment of MS fatigue led Dr. Miravalle to open the University of Florida College of Medicine's Multidisciplinary Comprehensive Fatigue Clinic in early 2017. This one-stop shop includes an occupational therapist who can help with energy-conservation solutions at work and home, and a physical therapist who designs personalized exercises to improve muscle strength and mood. A neuropsychologist addresses the mental and emotional aspects of fatigue. And a doctor and nurse practitioner evaluate patients for secondary causes of

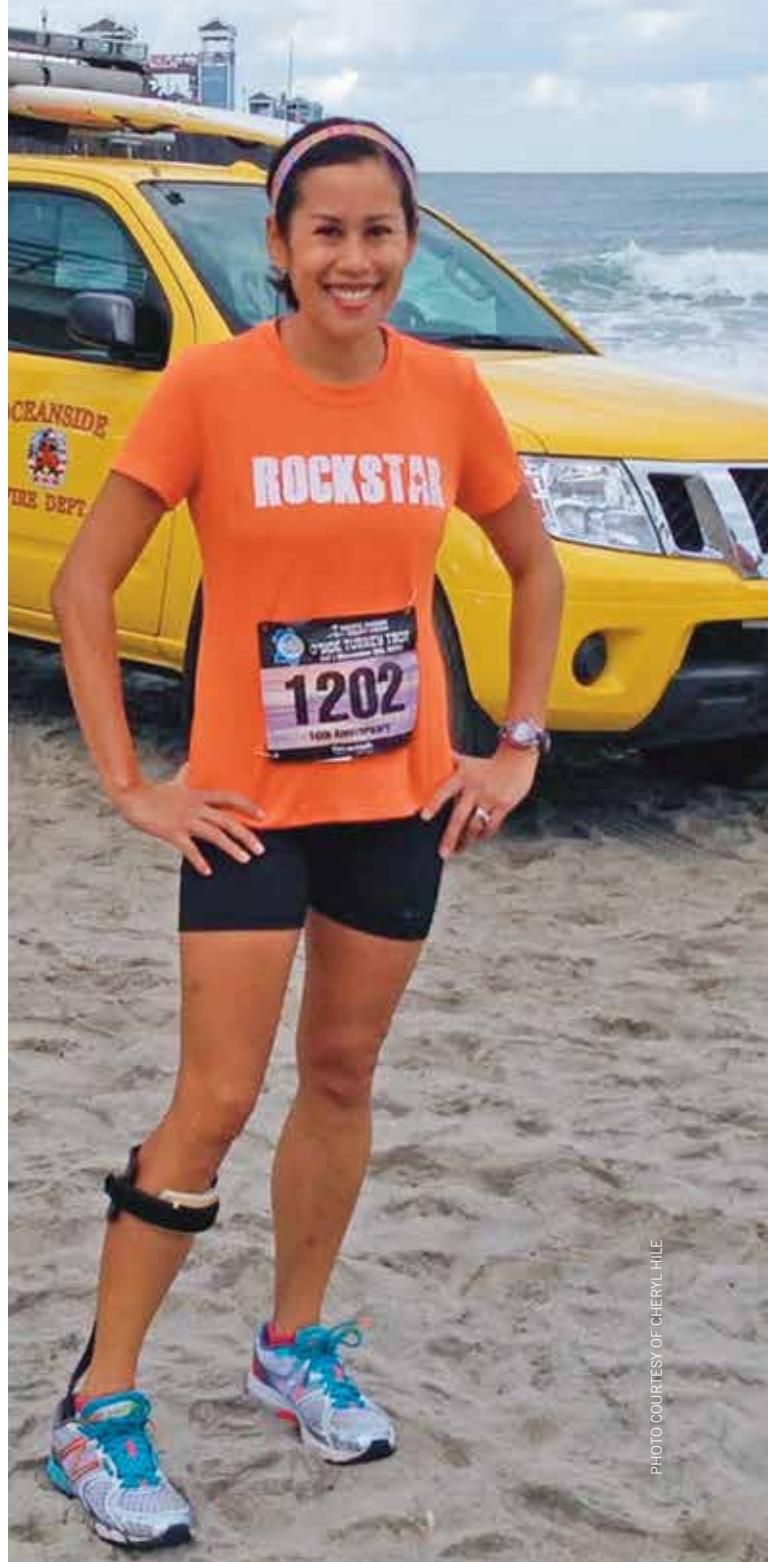


PHOTO COURTESY OF CHERYL HILE

fatigue, making referrals to specialists like urologists or psychiatrists who can address those root issues.

If you don't have a similar resource nearby, you can still consult with each of these types of practitioners. There are also quite a few steps you can take on your own to help manage your fatigue.

### Defining your fatigue

It's difficult to deal with your particular type of fatigue if you don't know how it manifests, says Abbey Hughes, PhD, assistant professor in the Division of Rehabilitation Psychology and Neuropsychology at Johns Hopkins University School of Medicine. Hughes recommends her patients start by keeping a diary of their fatigue, tracking what points in the day they feel tired and what they were doing, or what was happening around them at the time. While fatigue levels can vary from day to day, this can help you determine a pattern of when you tend to feel most exhausted and what may exacerbate it.



John Quarles, a computer science professor, manages his fatigue by being selective about how he spends his time and energy.

PHOTO COURTESY OF JOHN QUARLES

Many people find that fatigue is associated with constants in their life, including work, family, friends and other relationships, and responsibilities at home. While it may be impossible to jettison some or any of these factors, there are ways to modify how you deal with the people and things in your life to help reduce fatigue.

Hughes recommends the spoon theory to help determine what's truly important to you—and what you can let go. Start by imagining you have 10 spoons to use throughout the day. When you're confronted with an activity or obligation, ask yourself, "Is this something I want to spend my spoon on?" Hughes says.

People who don't understand your fatigue may feel like you're lazy or inconsiderate if you don't want to devote a spoon to their needs or desires. Depending on how important they are to you, Hughes says there are different ways to address this.

For close family or friends, Hughes recommends describing your fatigue to them so they don't confuse it with the tiredness that everyone feels at one point or another. "You could talk to them about how it's like pain—ask them to imagine they have a chronic knee problem and then say, 'That's my fatigue. It can overtake my attention and physical function for a period of time, go away and then come back,'" she says.

John Quarles, a San Antonio, Texas, computer science professor who was diagnosed with MS in 2005 at age 24 and began using a wheelchair in 2009 mainly due to his fatigue, prefers an exercise analogy. "I tell people: 'You know how when you go to the gym and work out too much, and your legs feel like jelly? That's how I feel all the time.'"

Quarles has developed his own version of the spoon theory. "I find I'm constantly doing a cost-benefit ratio in my head. I'll think, 'How much energy am I going to expend to go out to lunch with my friends? Will it seem more like work than fun?'" he says. "I've always been reclusive, but I'm probably even more now because of my fatigue."

For casual acquaintances, work colleagues or others with whom you don't want to discuss your disease, Hughes suggests telling them that you have a health condition that causes a lot of fatigue, and here's what you need to do—work at your son's school fair in the

## A pharmaceutical approach to fatigue

Some medications can directly influence fatigue levels, so it's important to discuss your options with your healthcare providers and tell them about all the medications you are taking, including any over-the-counter medications.

Many treatments for pain, spasticity or bladder overactivity can have sedating side effects and so can compound the effect of fatigue. Whether such medications can actually cause MS fatigue is not clear.

Some MS disease-modifying therapies (DMTs) can make primary fatigue worse and may also contribute to depression-related fatigue, says Augusto Miravalle, MD, chief of the Multiple Sclerosis Division at the University of Florida College of Medicine. On the other hand, research shows that other DMTs can reduce symptoms of fatigue and depression.

One study of 164 people with MS, published in 2015 in *Frontiers in Neurology*, found that after a year of taking natalizumab (Tysabri), 92 percent of the participants had either stable or improved fatigue symptoms.

John Schafer, MD, founder and director of Mercy MS Center in Sacramento, California, says some pain medications and antidepressants can cause or aggravate fatigue, so ask your doctor about side effects if you take these types of drugs.

There are medications specifically for fatigue, but Dr. Schafer says their effects vary. Amantadine has been helpful for some people with MS, he says. He has had more success with Provigil and Nuvigil, which are stimulants originally designed to treat narcolepsy. "Many patients report that they feel more energized and have more mental focus with these medications," he says.

On the minus side, Provigil and Nuvigil are expensive and may make people feel "wired," Dr. Schafer says, but reducing the dosage may help with both of these factors. Stimulants like Dexedrine, Ritalin and Adderall are cheaper, but they can create the same jittery feelings, are more likely to be abused, and have been linked to cardiac and thyroid issues, he says.

morning rather than the afternoon, skip the company softball team, go out to lunch rather than dinner or take some other specific solution.

### The psychology of fatigue

One key point to consider when defining your fatigue is that it may not just be physical or cognitive. There are also emotional aspects that can influence how your fatigue manifests.

For instance, Hughes says someone might feel so overwhelmed by his disease that he can't get out of bed. Another person might have difficulty paying attention for long periods of time, which makes her upset and exhausted. And mental or emotional fatigue might make people with MS feel less motivated to do anything that requires physical effort.

Jagriti "Jackie" Bhattacharai, PhD, an MS rehabilitation postdoctoral fellow at the Johns Hopkins University School of Medicine, is working on a new study that shows, among other things, that people with fatigue are more likely to rate their cognitive or physical function as worse than it actually is.

"When you feel fatigue, you may not have the resources to make yourself feel as capable as you really are," Bhattacharai says. "Because people limit their activities based on their fatigue, they may feel like they're not functioning well even though they actually are."

Bhattacharai and Hughes both note that cognitive behavioral therapy (CBT) can be effective in combatting these perceptions of fatigue. For example, maybe you feel like you're a bad mother or not a team player because you can't do a four-hour shift at your

daughter's school bake sale. But this guilt is actually zapping energy that you could be spending on the things that really matter to you.

The key to CBT for fatigue is to create goals that are reasonable and achievable based on your values, and then examine how your thoughts and feelings work with those goals. A therapist or psychologist can help you with this.

Above all, CBT involves giving yourself a break. "None of us can do everything we want all of the day, all of the time," Hughes says. "And for individuals with MS, that is even more apparent."

Hughes says a CBT skill called behavioral action (BA) can be particularly helpful for people struggling with fatigue associated with depression. Basically, BA is "pleasant activity scheduling," or purposely making time for activities you like or that help reduce depression. This could include yoga, progressive muscle relaxation or something as simple as a five-minute meditative break every hour to pace yourself and help conserve energy.

## Working through fatigue

Along with dealing with the psychological aspects of fatigue, there are specific steps you can take to physically reduce your fatigue—or work around it.

"Rehabilitation professionals often talk about the four P's of fatigue or energy management: planning, positioning, prioritizing and pacing," says Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska.

Planning refers to organizing your day in ways that optimize your energy. Say, for instance, your fatigue diary shows your workload or activity peaks in mid-morning and then about half an hour later, you feel fatigued. You can counter that by spreading your high-stress tasks throughout the day.



PHOTO COURTESY OF MARIO MARTINEZ

Mario Martinez decided to cut back on his work hours to better manage his fatigue.

Or, like Mario Martinez, who was diagnosed with MS in 1996 at age 26, you might need to cut back your work schedule to deal with your fatigue.

Martinez feels so drained by factors like the afternoon heat and humidity in his Mexican border town of Weslaco, Texas, that he can no longer work full time in his job at an independent living center. "I only work 8 to 12, then sometimes go straight home and take a nap. I get so fatigued I probably couldn't drive myself home if I worked in the afternoon," says Martinez, who uses a wheelchair and drives with hand controls.

The second "P" of energy management, positioning, refers to how you physically move around. "For example, standing uses more energy than sitting, so activities such as meal preparation and grooming, if completed in a seated position, will cumulatively conserve energy for later in the day," Rohrig says.

Tracy Carrasco, an occupational therapist with the MS Comprehensive Care Center at Orlando Health in Orlando, Florida, points out that sitting in an



Ronith Dunn, a mother of two girls, has learned to balance her energy levels with her family life.

PHOTO BY RIKU FOTO



PHOTO BY RIKU FOTO

Ronith Dunn and her daughter enjoy staying fit together. Dunn exercises for at least an hour every morning to help reduce her fatigue.

“

**Rehabilitation professionals often talk about the four Ps of fatigue or energy management: planning, positioning, prioritizing and pacing.”**

—Amanda Rohrig, PT

ergonomic chair that encourages proper posture can reduce your daily energy expenditure by as much as 25 percent. “Good posture encourages good respiration and helps ensure you’re not working one set of muscles more than another,” she says.

Calm colors and cool temperatures in your home or office can also reduce the external factors that help create fatigue, as can appropriate lighting. “Overhead lights can be fatiguing,” Carrasco says. “Use close, soft light like lamps.” And in areas like the office or kitchen, organize your space so you don’t have to make multiple trips around the room to do simple tasks. Another option is to prepare meals during the weekend, freeze them and then reheat on evenings when you feel too fatigued to cook.

The final “Ps” of fatigue management, prioritizing and pacing, can also be thought of as proactive resting. “Often in the clinic, I hear of people ‘feeling good’ on a given day, so they do everything on their to-do list,” Rohrig says. “By the end of the day, the client is exhausted and it may take two to three days to recover.”

She suggests pacing yourself by scheduling rest breaks throughout the day—even if you feel like you don't need them.

Occupational therapists who understand MS can help you figure out how to order and prioritize your day, week or month to help you successfully manage your fatigue as well as help others understand your abilities. This can include making a family calendar so everyone knows when important events are coming up and that you need to rest in advance, or explaining to children that mommy is tired when she gets home from work so she needs to lie down before helping with homework.

“

**A common thing I hear from people  
who have fatigue is they don't exercise...  
[but] It helps me focus, get my day  
started and strengthen my legs.”**

—Ronith Dunn

## Forging a relationship with fatigue

Baltimore resident Ronith Dunn was diagnosed with MS at age 23, a few years before her first child was born. For the last decade, she's been a single mother to two girls, now ages 19 and 14, along with a pair of family dogs. MS fatigue definitely affects the family dynamic, but Dunn has learned how to not only manage it, but also explain to her daughters how it affects her—and them.

“I'm able to work a full day, but when I'm done, I'm done. When the fatigue hits, I feel

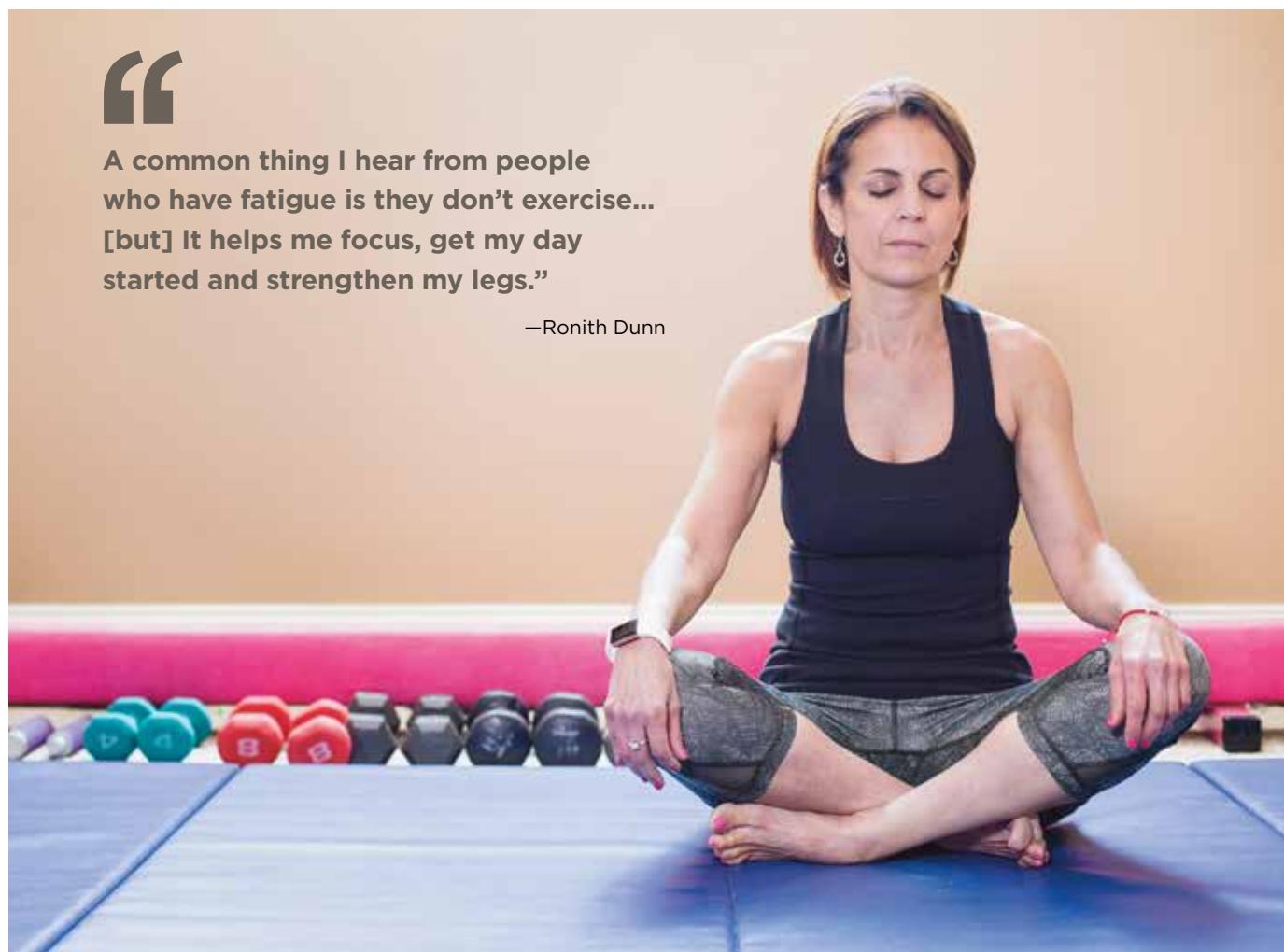


PHOTO BY RIKU FOTO

## Exercise and fatigue

It seems counterintuitive to exercise when you're tired. But people with MS who work out regularly say it can substantially reduce their fatigue.

"A common thing I hear from people who have fatigue is they don't exercise," says Ronith Dunn, who has lived with MS for 23 years. Dunn does weight training, spinning, yoga or another form of exercise at least an hour each morning.

"It helps me focus, get my day started and strengthen my legs," she says.

John Quarles, who was diagnosed with MS in 2005, says "warming up his legs" through walking on a treadmill, doing squats or other exercises helps him sleep better and improves his mood, which in turn reduces fatigue.

Because fatigue is individualized and can

change in a matter of minutes, it's a good idea to learn a few different workouts from a physical therapist. "Have exercises that can be completed when fatigue is minimal or moderate, as well as exercise options when fatigue is terrible and overwhelming," says Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska.

For example, if you feel so tired you can't get out of bed, something as simple as deep, diaphragmatic breathing exercises or a few simple stretches may help energize you.

"I do not want people wasting valuable energy on exercises that are not encouraging function or helping them work towards a goal they wish to achieve," Rohrig says.

like I've been run over by a train, and then I start to have elevated MS symptoms—pain in my hips, numbness in my arms," Dunn says. "At nighttime when I'm tired, I tell my daughters my MS is bothering me, and they understand. I'm usually in bed by 8:30 or 9."

Carrasco says reframing the situation can help when you feel like you're failing the people around you because of your fatigue. For instance, rather than being burdened, children who do extra chores can learn independence and feel proud to help. And delegating duties can encourage teamwork and help your colleagues or friends develop new skills.

Dunn learned that lesson seven years ago, when an MS exacerbation had a major impact on the attention she could devote to her daughters. "I started to feel terrible I couldn't do stuff," she says. "And then I thought, 'There are a lot of moms who don't do a quarter of what I do, and they don't have MS.' I've learned to keep my mental health by never thinking

there's anything wrong with me—including my fatigue."

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



Learn more about MS fatigue at [nationalMSSociety.org/fatigue](http://nationalMSSociety.org/fatigue).

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

# At the front

60,000 U.S. military veterans live with MS.

by Aaron Dalton

The men and women of the U.S. military serve in many ways and on many different fronts. And thousands of these veterans also face a unique challenge: multiple sclerosis.

An estimated 60,000 U.S. military veterans live with MS. The Veterans Health Administration (VHA) provides care to more than 20,000 of them annually. Many receive care and treatment at the VHA-affiliated MS Centers of Excellence (MSCoE), a network with dozens of clinics across the country that offer comprehensive care to veterans with MS. This care is provided by a highly trained team of specialists that includes neurologists, psychiatrists, psychologists, physical therapists, occupational therapists, speech-language pathologists, nurses and social workers.

"Some veterans living with MS get treated in the private sector without realizing the fabulous benefits they may be able to access at the VHA," says Jodie Haselkorn, MD, director of the MSCoE-West, located jointly in Seattle and in Portland, Oregon. "The VHA has access to all the FDA-approved disease-modifying therapies (DMTs) for MS. That's not always the case in the private sector, and it enables us to make sure that veterans living with MS get on a safe, appropriate treatment that will have the most benefits."

The centers coordinate and provide clinical care, rehabilitation services, education and information processing, and telehealth services. To gain a better understanding of MS, the centers conduct laboratory, clinical, epidemiological and health services research.

To help prevent burnout among caregivers, the Department of Veterans Affairs (VA) provides respite care services for eligible veterans whose caregivers need some relief. Home health aides, adult day health centers and community living centers are available. The services show that "the VHA recognizes how important

caregivers are in helping veterans to manage living with MS," Dr. Haselkorn says.

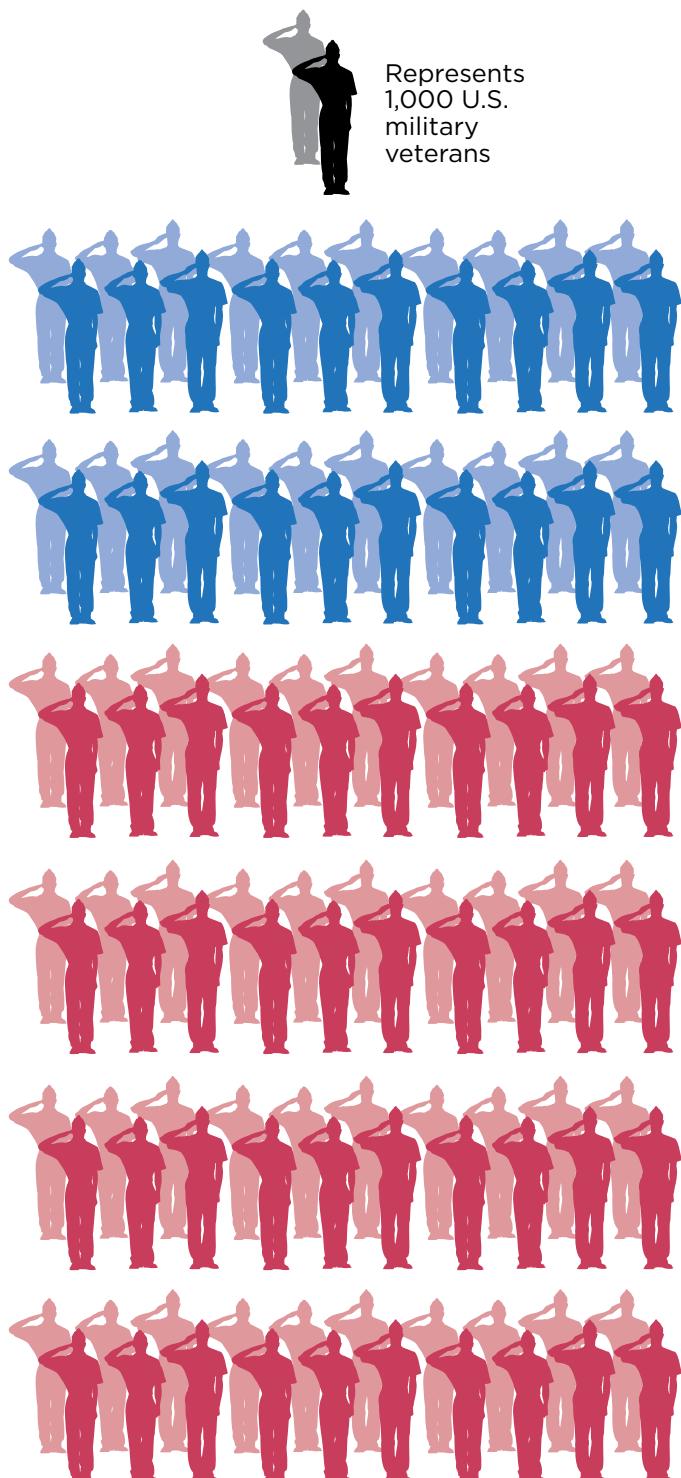
One ongoing research initiative at the VA—the Million Veteran Program ([www.research.va.gov/mvp](http://www.research.va.gov/mvp))—seeks to collect and perform whole genome screening on 1 million veterans as part of an effort to help untangle links between genes and MS. "MS is a complex disorder with a genetic component, but it's unclear how much of an effect each gene has on the disease," says Mitch Wallin, MD, director of the MSCoE-East in Baltimore, Maryland, and Washington, D.C. "We can only hope to sort out these connections if we can analyze a large number of genomes, so I would encourage any veteran with MS to sign up for the program."

While MS is more prevalent among women in the general population, the military is still a male-dominated profession, so most veterans with MS are men. This demographic characteristic of the U.S. military allows the centers to better understand how MS affects men. "The disease is worse in men, especially among non-Caucasians," Dr. Haselkorn says.

## Service-connected status

Veterans who have experienced a disability from an injury or disease that was incurred or aggravated during active military service can get what is known as service-connected (SC) status.

Service-connected status plays an important role in determining a veteran's priority group rating with the VHA. Veterans with a higher priority group rating may have access to more health care benefits at lower or no cost in the VHA system. Other factors such as financial resources, wartime service and honors also play a role in determining a veteran's priority group status and access to the VA's health system.



**An estimated 60,000 U.S.  
military veterans live with MS.  
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Since MS can be difficult to diagnose promptly, the VHA generally presumes veterans are eligible for SC status if they are diagnosed with MS while on active duty or within seven years after an honorable discharge.

Dr. Wallin notes that veterans who are diagnosed with MS more than seven years after they have been discharged may still be able to obtain SC status if they can show evidence that their MS symptoms occurred during active duty or within seven years after they were honorably discharged.

Service-connected veterans also may be eligible to receive disability compensation from the VA. There are many factors that can affect the amount of compensation the VA pays to disabled veterans. To learn more, visit [va.gov](http://va.gov) and click on “Benefits, then Disability Compensation.”

To learn about the full range of services the VHA offers to SC and non-SC veterans living with MS, visit [va.gov/MS/Veterans/Benefits/What\\_Are\\_My\\_VA\\_Benefits\\_for\\_Multiple\\_Sclerosis.asp](http://va.gov/MS/Veterans/Benefits/What_Are_My_VA_Benefits_for_Multiple_Sclerosis.asp).

While some veterans living with MS opt for private care, Dr. Haselkorn says there are other good reasons for them to seek treatment at a VHA facility. “At the VHA, we’re accustomed to dealing with veterans living with MS. We appreciate and honor their service,” she says. “I believe many of our patients benefit from the camaraderie they find at the VHA. When they roll or walk into one of our facilities, they find a group of people who really understand them, where they have been and what they are going through now.”

### Veterans' stories

Each veteran takes his or her own path to diagnosis, treatment and living with MS. Here are six of their stories:

#### **Garvis Leak**

Garvis Leak, 56, retired from the Air Force in 2011 as a decorated combat veteran, had served 26 years in the personnel career field at bases around the U.S. as well as in Germany, Japan and Turkey.

By 2012 he was having problems with low energy, fatigue and recurring migraine headaches. An MRI revealed Leak had MS. “I had actually experienced these same sorts of symptoms on several occasions while on active duty, but at the time I attributed

them wrongly to stress and the tempo of operations associated with my job," he says.

As a result of his service-connected status, Leak can get treated for MS at his local VA medical center in Dayton, Ohio, without paying any out-of-pocket fees. He sees a neurologist there every three months.

"When I go the VA, I feel like they are family," Leak says. "You meet other people there who have served in the military and are now living with MS. The shared experiences create a sense of comfort. It's a great support system to talk and share our stories."

While Leak previously received physical therapy at the VA, these days he exercises independently at a gym at least three days a week and participates in Bike MS rides and Disabled American Veterans walks. Drawing on his own experiences overcoming the challenges associated with his diagnosis, Leak operates his own business as a life coach and financial wellness adviser.

### Deanna Deschenes

The youngest of 10 children, Deanna Deschenes joined the Navy in 1989. "My decision may or may not have been influenced by [the movie] 'Top Gun,'" she jokingly admits.

On active duty in Virginia and Florida for eight years, she worked in aviation structural mechanics and safety equipment—ejection seats, air-conditioning systems, liquid oxygen and pressurization. She retired in August 1996, two days after giving birth to a daughter.

Although she experienced some visual problems and dizziness during her years of active service, it was only in December 2004 that she suddenly experienced optic neuritis, losing half her vision in both eyes. This led to her MS diagnosis in January 2005.

Now 48, Deschenes, who lives in Birmingham, Alabama, has received her MS treatment from private providers for more than a dozen years. But she has decided to apply for service-connected status in hopes of obtaining MS care through the VHA system.

"I think the VA offers a high standard of care and great neurologists," Deschenes says. "If I'm able to obtain service-connected status, I could get care at the VA without any out-of-pocket payments, which would be helpful."

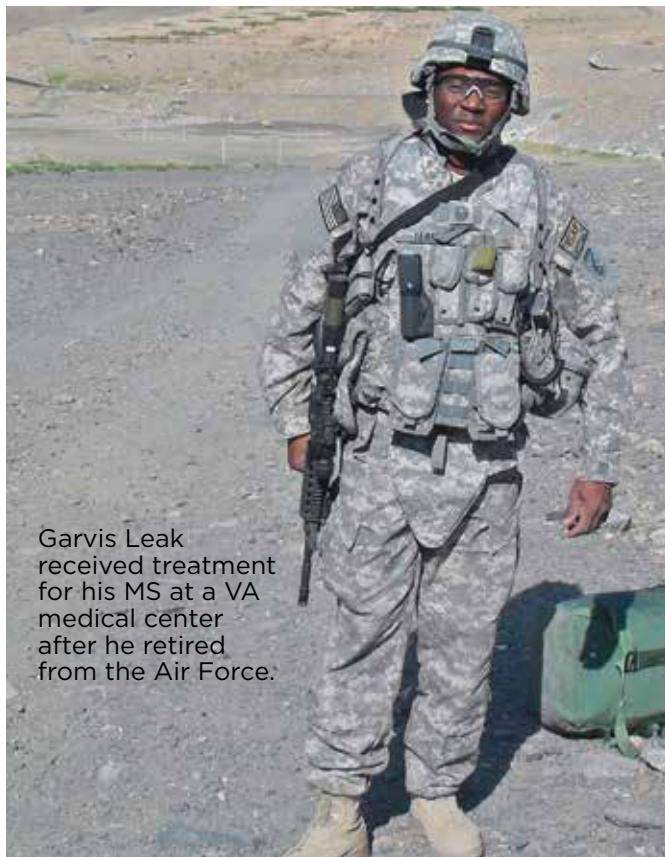
### How can veterans living with MS apply for service-connected status?

Online, through the mail or in-person at a VA regional office, independently or with the assistance of an attorney, claims agent or Veterans Services Organization (VSO) representative.

Veterans can strengthen their application for service-connected status by having accurate and detailed documentation of all relevant neurological symptoms and any MS-related medical visits.



To find out more about enrollment and eligibility for VA services, veterans can visit [vets.gov](http://vets.gov).



Garvis Leak received treatment for his MS at a VA medical center after he retired from the Air Force.



PHOTO COURTESY OF DEANNA DESCHENES

## Robert Taylor

Robert Taylor, 58, was born and raised in Detroit, then spent 20 years in the Army. He served as a courier carrying special classified messages, mail and news in Operation Desert Shield and Desert Storm in Saudi Arabia. He was a drill sergeant and non-commissioned officer.

He left the military in 1997 and went to work in human resources for the South Carolina Department of Social Services. Around that time, Taylor started to experience tremors, temporary vision loss and problems with bladder control. He would get into an elevator for a meeting on another floor of his office building and find himself frozen on the spot. Unable to exit the elevator, he would sometimes ride up and down for 30 minutes before he could take a step forward to get out. In 2012, he was diagnosed with MS.

Taylor receives ongoing care through the VA that includes tests and appointments with occupational therapists and physical therapists.

Taylor realizes now that his symptoms began before he retired from the Army. "Looking back through my record, I can see that I started having symptoms during my active service immediately after I returned from a stint in Saudi Arabia. Suddenly, I was falling down on physical training runs. I had scuff marks on the toes of my shoes from foot drop. At the time, nobody ever told me that these could be signs of MS."

Taylor is involved with the Society and serves as a District Activist Leader in South Carolina, where he lives today. He volunteers at health fairs to hand out information on MS and has twice attended public policy conferences in Washington, D.C., to speak with legislators about obtaining funding for MS research.

## Tom Unrath

Tom Unrath spent 20 years traveling the world with his family as an Air Force chaplain. He first experienced MS symptoms in 2001 while stationed at Grand Forks Air Force Base in North Dakota. A primary care manager at the base clinic began running tests to see whether Unrath might have MS.

Deanna Deschenes (right), a former Navy engineer, was diagnosed with MS nearly nine years after her retirement from the Navy. She lives with her family in Birmingham, Alabama.

Unrath had not yet received a definitive diagnosis when he was transferred to Patrick Air Force Base in Florida. In 2003, he met with the chief of neurology at the University of Florida Health Shands Hospital in Gainesville, who diagnosed Unrath with MS.

"At that time, with a disease like MS, I was required to participate in a medical review board to see whether I was fit to remain on active duty," Unrath says. "That was a bit nerve-wracking, as I did not want to be suddenly kicked out of the military. I had pledged to serve for a full 20-year career. I had been trained, at great cost to the taxpayer, to fulfill this profession for which I was highly qualified, and which I felt called by God to do. Also, while a medical retirement would have allowed me to receive full benefits, it would have reduced my retirement pay."

The review board allowed Unrath to stay on active duty, although he no longer qualified for international deployments.

Unrath retired from the military in 2007. After serving as an interim pastor for several congregations, he became part-time pastor at Messiah Lutheran Church in Cocoa, Florida, in 2010, and now serves there as quarter-time pastor.

Today, Unrath, 62, copes with fatigue, mobility problems and trigeminal neuralgia that can flare up

Robert Taylor experienced MS symptoms while he was in the military. Today he receives ongoing care through the VA.

PHOTO COURTESY OF ROBERT TAYLOR



Tom Unrath first experienced MS symptoms while he was an Air Force chaplain. He says that MS has played a role in helping him become a better pastor.

to the point where he cannot eat, drink or even speak. Nonetheless, he says that his MS has played a role in helping him to become a better pastor.

"There have been several things in my life that have allowed me to become more empathetic to the difficulties that other people face," Unrath says. "Eleven days before I received my final MS diagnosis, my daughter was killed in a car accident. It was a double blow. But since then, I have helped lead support groups, both for people with MS and for parents whose children have died. These experiences have given me a greater understanding of the challenges that other people are going through."

Unrath participates in MS activism with the Society in Florida and on Capitol Hill in Washington, D.C. He is also a peer reviewer for the Department of Defense's MS Research Program and part of the Society's Activism Advisory Committee. "Research toward a cure and ensuring that costs for MS medications are kept at a reasonable level where they are accessible to everyone who needs them—those are my top two priorities as an advocate," Unrath says.

### Kenneth Johnson

Kenneth Johnson grew up in Los Angeles and joined the Army. The military deployed him to Asia and the Middle East, where he fought in Operation Desert Shield and Desert Storm.

After his deployment, Johnson was participating in a field training exercise in Arizona when he suffered a spinal cord injury that ultimately led to his discharge after eight years of service.

After working at a sheriff's department and a police department, he was a federal special agent and criminal investigator for more than seven years.

During his time as a special agent, Johnson began experiencing problems navigating stairs, walking long distances or standing for extended periods of time.

He was diagnosed with MS in 2014. "I didn't know what to do at first," Johnson says. "It took me about a year to figure out that if I didn't do anything, this disease would eat me up. I started experiencing muscle

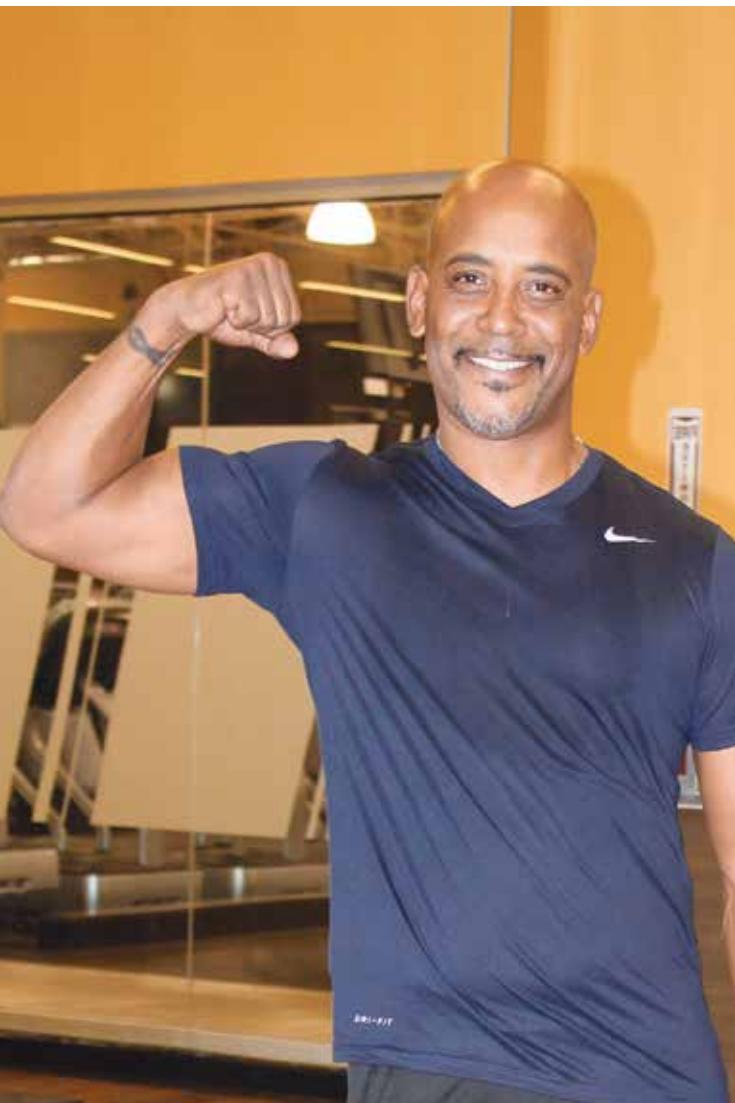


PHOTO COURTESY OF KENNETH JOHNSON

Kenneth Johnson makes exercising a priority to help manage his MS symptoms.

degeneration and lots of pain that made it difficult for me to rest."

Johnson realized he could only deal with his MS by strengthening his body. He eliminated processed foods from his diet and adopted a rigorous exercise routine that includes running, weight lifting and swimming. "Today, I make that one of my main priorities—to exercise every day for three hours per day," he says.

Now 49 and living in Los Angeles, Johnson volunteers with the Society, helping wherever he is needed. Johnson serves as leader of a monthly MS support group that meets at the VA West Los Angeles Medical Center. He also attends classes on living with MS.

## High-risk, high-reward research

Congress passed legislation creating the MS Research Program (MSRP) in 2008.

Funded through the Department of Defense, the MSRP seeks to fund high-risk, high-reward research that has the potential to have a major impact on knowledge and treatment of MS.

MSRP is a peer-reviewed program in which the people making funding decisions include not just scientists, but also consumer reviewers—people living with MS or caring for those living with MS. Since the program is administered through the Department of Defense, many of these consumer reviewers are veterans or spouses of veterans.

Over the past decade, the MSRP has distributed more than \$46 million in grant money. Much of this funding has been devoted to researching MS detection and diagnosis, clinical and experimental therapeutics, and the pathobiology of the disease.

Johnson has service-connected status for his spinal cord injuries. But he also hopes to get service-connected status for his MS. Looking back, he believes he experienced MS symptoms during his military service. Pointing to the larger picture of military veterans living with MS, he says that connecting his MS to his time in the military is important for accurate documentation.

He makes regular visits to his local VA clinic to see his primary care physician and neurologist, while receiving physical therapy at a private facility in Pasadena, which is covered as a VA benefit. "The VA has taken really good care of me," Johnson says.

## Kevin Byrne

Kevin Byrne grew up in the Bronx, attended the U.S. Military Academy at West Point, graduated from the aviation branch and ended up piloting Apache attack helicopters.

In September 2000, he was serving as a troop commander in Korea, in charge of approximately 120 soldiers in an air cavalry troop, when he began to experience numbness and tingling in his fingers and toes.

At first, he shrugged off the symptoms. "When you are a pilot, you generally don't go to see a doctor for things like that, because you don't want to get grounded," he says. "But when the tingling spread into my neck and then started to affect my vision, I went to a general physician, who sent me to a neurologist. Within a couple of weeks, I had a diagnosis of MS."

Although Byrne could no longer fly helicopters, he persuaded his commanding officers to let him stay in Korea to command an aircraft maintenance group. Nine months later, his symptoms had worsened and he was forced to return to the U.S. After additional testing at Walter Reed Medical Center, he received an honorable discharge from the military and a referral to the VHA.

"I've had a good experience with the VA," Byrne says. "At the time, I was living in Pittsburgh, so I went to the VA hospital there. I had no idea what to expect, but I just walked up to the help desk and handed my records to the gentleman volunteering there. He looked them over, looked at me and said, 'Welcome home, Captain Byrne.' From that point on, they've really taken care of me."

In the years after his diagnosis, Byrne built a career in the logistics and supply chain field. He got married, moved to Oregon and became a father to a girl named

Kevin Byrne says his military training helped him cope with MS.



PHOTO BY KEITH CARLSEN

## Possible links between military service and MS

Recent research conducted by Mitch Wallin, MD, and others shows that the annual rate of new MS cases diagnosed in the U.S. military from 1990 to 2007 was 9.6 per 100,000 individuals. This is significantly higher than the annual MS incidence rate of 4.2 per 100,000 for the total U.S. population reported in the 1970s.

Dr. Wallin notes that some of the variation between MS incidence rates inside and outside the military may be due to differences in access to health insurance. Since all active duty U.S. military members and their immediate family members have access to health insurance through the military, they may be more likely to seek medical care for neurologic symptoms that can lead to an MS diagnosis. By contrast, uninsured or underinsured Americans outside the military might ignore or downplay such symptoms, meaning they might delay diagnosis or not get diagnosed even if they do have MS.

Dr. Wallin, Dr. Haselkorn and colleagues also published a study on veterans of the 1990–91 Gulf War that found the risk of developing MS was actually lower in U.S. military personnel who deployed to the Gulf War than among those who stayed behind on the home front.

“Whether deployment to other wars can increase the risk for MS is not clear and deserves further study,” Dr. Wallin says.

Eleanor. He subsequently wrote a children’s picture book called “My MS and E” about how he and his daughter grow, learn and celebrate life together despite Byrne’s MS.

“My background was math, science and engineering,” Byrne recalls. “I had no interest in any of the literary arts or things of that nature, so it’s kind of funny that writing has become one of the things that I enjoy so much.” All the profits Byrne earns from the book are donated to the MS Society.

By 2016, Byrne’s symptoms were worsening. He experienced increasing weakness along the left side of his body and numbness throughout his right side. “I also have issues with vision, fatigue and incontinence, but the loss of [feeling in] my limbs is the big issue,” Byrne explains. “That’s what led me to my disability retirement.”

Now 46, Byrne publishes [neverstopneverquit.com](http://neverstopneverquit.com), a blog that focuses on living with MS, and he has participated in Bike MS events since 2003.

Today, Byrne is focusing on his rehabilitation and volunteering with the Society in Oregon, where he serves on the board of trustees.

Byrne is convinced that his military training has helped him cope with MS. “In the military, you learn to work and succeed with the resources that you have,” he says. “Instead of lamenting the fact that I have MS, I focus on the things I can do in spite of my limitations. At West Point, I learned that the only way to win against a fierce and determined enemy was to never stop and never quit. That has become my mindset. My MS will never quit until it is defeated, so therefore I will never quit until I manage to defeat MS.” ■

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Aaron Dalton is a freelance writer in Nashville, Tennessee.

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For more information, visit  
[va.gov/ms](http://va.gov/ms), [dav.org](http://dav.org) and [pva.org](http://pva.org).

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## ADVERTISEMENT



### What is OCREVUS?

OCREVUS is a prescription medicine used to treat adults with relapsing or primary progressive forms of multiple sclerosis.

It is not known if OCREVUS is safe or effective in children.

### Who should not receive OCREVUS?

**Do not** receive OCREVUS if you have an active hepatitis B virus (HBV) infection.

**Do not** receive OCREVUS if you have had a life threatening allergic reaction to OCREVUS. Tell your healthcare provider if you have had an allergic reaction to OCREVUS or any of its ingredients in the past.

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

#### OCREVUS can cause serious side effects, including:

- Infusion-related reactions:** OCREVUS can cause infusion-related reactions that can be serious and require you to be hospitalized. You will be monitored during your infusion and for at least 1 hour after each infusion of OCREVUS for signs and symptoms of an infusion-related reaction. Tell your healthcare provider or nurse if you have any symptoms (see accompanying Patient Information).

**These infusion-related reactions can happen for up to 24 hours after your infusion.** It is important that you call your healthcare provider right away if you have any of the signs or symptoms listed in the accompanying Patient Information.

If you get infusion-related reactions, your healthcare provider may need to stop or slow down the rate of your infusion.

#### • Infection:

- OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any signs of infection (see accompanying Patient Information). These signs can happen during treatment or after you have received your last dose of OCREVUS. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.

- **Progressive Multifocal Leukoencephalopathy (PML):** Although no cases have been seen with OCREVUS treatment in clinical trials, PML may happen with OCREVUS. PML is a rare brain infection that usually leads to death or severe disability. Tell your healthcare

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MS



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**Ask your healthcare provider about OCREVUS.**

provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness on 1 side of your body, strength, or using your arms or legs (see accompanying Patient Information).

○ **Hepatitis B virus (HBV) reactivation:** Before starting treatment with OCREVUS, your healthcare provider will do blood tests to check for hepatitis B viral infection. If you have ever had hepatitis B virus infection, the hepatitis B virus may become active again during or after treatment with OCREVUS. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. Your healthcare provider will monitor you if you are at risk for hepatitis B virus reactivation during treatment and after you stop receiving OCREVUS.

○ **Weakened immune system:** OCREVUS taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

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

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

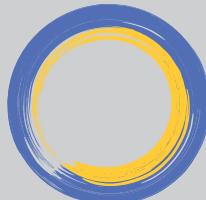
- **Risk of cancers (malignancies) including breast cancer.** Follow your healthcare provider's instructions about standard screening guidelines for breast cancer.

Most common side effects include infusion-related reactions and infections.

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

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

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† REBIF® is a registered trademark of EMD Serono, Inc.

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

## PATIENT INFORMATION

OCREVUS™ (oak-rev-us)

(ocrelizumab)

injection, for intravenous use

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

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

- **Infusion reactions:** OCREVUS can cause infusion reactions that can be serious and require you to be hospitalized. You will be monitored during your infusion and for at least 1 hour after each infusion of OCREVUS for signs and symptoms of an infusion reaction. Tell your healthcare provider or nurse if you get any of these symptoms:

- |                             |                                   |
|-----------------------------|-----------------------------------|
| ◦ itchy skin                | ◦ redness on your face (flushing) |
| ◦ rash                      | ◦ nausea                          |
| ◦ hives                     | ◦ headache                        |
| ◦ tiredness                 | ◦ swelling of the throat          |
| ◦ coughing or wheezing      | ◦ dizziness                       |
| ◦ trouble breathing         | ◦ shortness of breath             |
| ◦ throat irritation or pain | ◦ fatigue                         |
| ◦ feeling faint             | ◦ fast heartbeat                  |
| ◦ fever                     |                                   |

**These infusion reactions can happen for up to 24 hours after your infusion.** It is important that you call your healthcare provider right away if you get any of the signs or symptoms listed above after each infusion. If you get infusion reactions, your healthcare provider may need to stop or slow down the rate of your infusion.

- **Infection:**

- OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any of the following signs of infection including fever, chills, a cough that does not go away, or signs of herpes (such as cold sores, shingles, or genital sores). These signs can happen during treatment or after you have received your last dose of OCREVUS. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.

- **Progressive Multifocal Leukoencephalopathy (PML):** Although no cases have been seen with OCREVUS treatment in clinical trials, PML may happen with OCREVUS. PML is a rare brain infection that usually leads to death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness on 1 side of your body, strength, or using your arms or legs.

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- **Weakened immune system:** OCREVUS taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

## What is OCREVUS?

OCREVUS is a prescription medicine used to treat adults with relapsing or primary progressive forms of multiple sclerosis.

It is not known if OCREVUS is safe or effective in children.

## Who should not receive OCREVUS?

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

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

- have or think you have an infection. See "**What is the most important information I should know about OCREVUS?**"
- have ever taken, take, or plan to take medicines that affect your immune system, or other treatments for MS. These medicines could increase your risk of getting an infection.
- have ever had hepatitis B or are a carrier of the hepatitis B virus.
- have had a recent vaccination or are scheduled to receive any vaccinations. **You should receive any required vaccines at least 6 weeks before you start treatment with OCREVUS. You should not receive** certain vaccines (called 'live' or 'live attenuated' vaccines) while you are being treated with OCREVUS and until your healthcare provider tells you that your immune system is no longer weakened.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if OCREVUS will harm your unborn baby. You should use birth control (contraception) during treatment with OCREVUS and for 6 months after your last infusion of OCREVUS.
- are breastfeeding or plan to breastfeed. It is not known if OCREVUS passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take OCREVUS.

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

## How will I receive OCREVUS?

- OCREVUS is given through a needle placed in your vein (intravenous infusion) in your arm.
- Before treatment with OCREVUS, your healthcare provider will give you a corticosteroid medicine and an antihistamine to help reduce infusion reactions (make them less frequent and less severe). You may also receive other medicines to help reduce infusion reactions. See "**What is the most important information I should know about OCREVUS?**"
- Your first full dose of OCREVUS will be given as 2 separate infusions, 2 weeks apart. Each infusion will last about 2 hours and 30 minutes.
- Your next doses of OCREVUS will be given as one infusion every 6 months. These infusions will last about 3 hours and 30 minutes.

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

OCREVUS may cause serious side effects, including:

- See "What is the most important information I should know about OCREVUS?"
- **Risk of cancers (malignancies) including breast cancer.** Follow your healthcare provider's instructions about standard screening guidelines for breast cancer.

Most common side effects include infusion reactions and infections.

See "What is the most important information I should know about OCREVUS?"

These are not all the possible side effects of OCREVUS.

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

**General information about the safe and effective use of OCREVUS.**

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

**What are the ingredients in OCREVUS?**

**Active ingredient:** ocrelizumab

**Inactive ingredients:** glacial acetic acid, polysorbate 20, sodium acetate trihydrate, trehalose dihydrate.

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1-844-627-3887.

This Medication Guide has been approved by the U.S. Food and  
Drug Administration  
Issued: 3/2017

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# solve

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

## Inside this section

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### GOT 3 MINUTES? TRY THIS QUICK BODY SCAN MEDITATION

The unpredictable symptoms of MS can be physically and emotionally draining. Evidence is beginning to show that mind-body work is effective in improving depression, anxiety, fatigue and balance in individuals with MS. When people meditate, they feel centered, calm and energized. So what are you waiting for? If you're facing symptoms such as fatigue, give the meditation exercise below a try. In this issue's Solve section, you'll learn more about research being done to help alleviate fatigue in MS.

Sit comfortably in a chair or on the floor.

Close your eyes if you like.

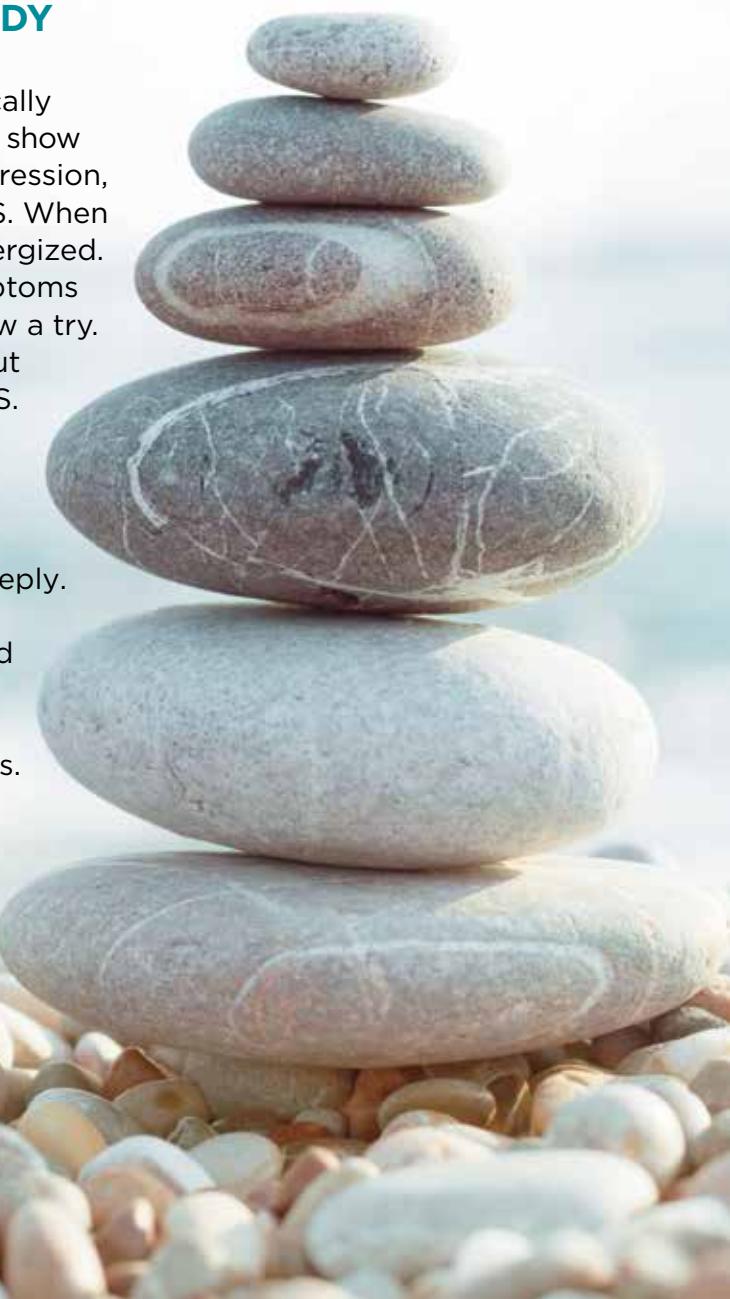
Take a few slow deep breaths.

As you exhale, have a sense of relaxing more deeply.

Notice the parts of your body—feet, legs, back, stomach, hands, arms, shoulders, neck, face—and relax each of them.

Notice your whole body together.

Take a few last deep breaths and open your eyes.



Research studies are targeting the most common MS symptom.

# Focus on fatigue

by Lori De Milto

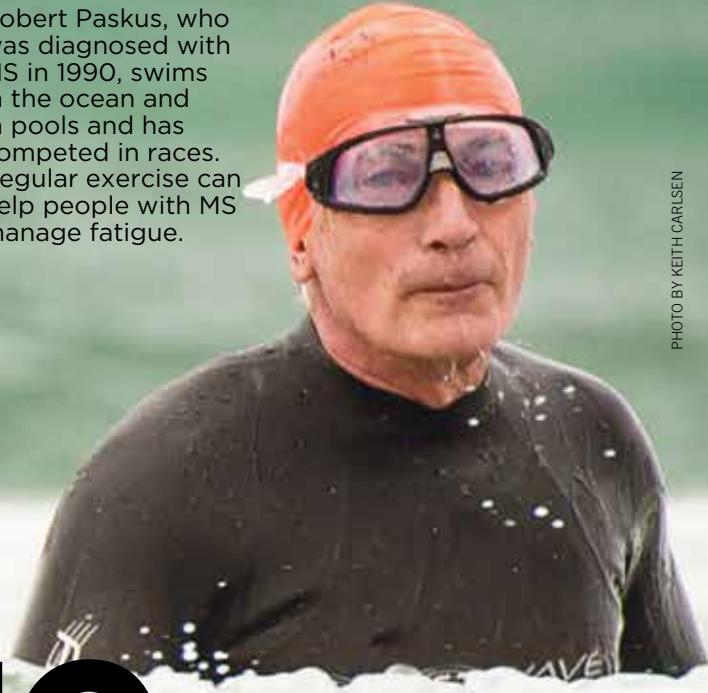
**M**ost people with multiple sclerosis experience fatigue, one of the most common—and most difficult—MS symptoms to treat. This makes fatigue an important target for research studies. Among a range of scientific projects on the topic, researchers are studying the link between higher body temperature and fatigue, ways to help people with MS exercise and whether too much iron in the brain contributes to cognitive fatigue.

## Helping people with MS exercise

Exercise may help people with MS manage fatigue, but exercising can be difficult. “Many people with MS would like to exercise and can exercise, but are worried due to fear of exhaustion,” says Victoria M. Leavitt, PhD.

Leavitt and Deborah Backus, PhD, are both studying ways to help people with MS exercise. Leavitt is an assistant professor of neuropsychology (in neurology) and director of the Multiple Sclerosis Cognitive Neuroscience Laboratory at Columbia University in New York City. Backus, who is a physical therapist is director of MS Research at the Shepherd Center in Atlanta.

Robert Paskus, who was diagnosed with MS in 1990, swims in the ocean and in pools and has competed in races. Regular exercise can help people with MS manage fatigue.



## Taking aspirin to relieve exercise-related fatigue

After learning that higher body temperatures are linked to more fatigue in people with relapsing-remitting MS, Leavitt and colleagues studied whether taking aspirin, which cools the body, before exercising could help people exercise longer without being exhausted.

**The first two studies showed that people with relapsing-remitting MS (94 people) had higher body temperatures than people with secondary-progressive MS (22 people) and people who don't have MS (84 people). The National Institutes of Health and the Kessler Foundation provided partial funding for one study.**

Next, Leavitt and colleagues compared taking aspirin to taking a placebo before exercising on a stationary bike. Participants were able to exercise longer after taking aspirin. The eight participants who were sensitive to heat when they exercised reduced the increase in their body temperature after exercise by

## More research on MS fatigue

**STUDY:** An interactive, self-directed MS fatigue management website is being tested to let people with MS monitor, communicate about and get help managing fatigue.

**RESEARCHER:** Marcia Finlayson, PhD, is studying how well the site works. Finlayson is vice dean (Health Sciences), professor and director at the School of Rehabilitation Therapy, Queen's University in Canada.

**STUDY:** Ruth Ann Marrie, MD, PhD, and colleagues studied how having MS along with other conditions affected fatigue in 949 people with MS. Participants completed a fatigue questionnaire and reported their other conditions. Participants who were older and had more disability were more likely to report fatigue. Depression, irritable bowel syndrome, migraines and anxiety were associated with persistent fatigue over two years.

**RESEARCHER:** Dr. Marrie is a professor of internal medicine (neurology) and community health sciences, and director of the Multiple Sclerosis Clinic at the University of Manitoba.

Dr. Marrie published results in the International Journal of MS Care.

**STUDY:** Dawn M. Ehde, PhD, and colleagues compared self-management to symptom education in 163 people with MS. Both groups had eight weekly 45- to 60-minute telephone sessions led by a therapist plus two 15-minute follow-up calls. The self-management group learned proven cognitive-behavioral strategies for managing symptoms, while the symptom education group only received information. Both groups had meaningful improvements in fatigue, pain and mood. Half of the participants who reported severe fatigue at the start of the study had a major, lasting reduction in fatigue.

**RESEARCHER:** Ehde is a clinical psychologist at the University of Washington School of Medicine Department of Rehabilitation Medicine. The study was published in Archives of Physical Medicine and Rehabilitation, 2015.

PHOTO COURTESY OF VICTORIA M. LEAVITT, PHD



Victoria M. Leavitt,  
PhD

56 percent when they took aspirin first. The National Multiple Sclerosis Society provided partial support for this study.

"Aspirin works on many levels," Leavitt says. "It reduces temperature, relieves pain and relieves inflammation." Leavitt hopes to do larger studies to confirm these results. If these new studies confirm her results, she says aspirin "would be the first symptomatic treatment for MS that's available over the counter and is not prohibitively expensive."

Anyone wishing to try this approach should ask their doctors about whether there are any medical concerns for them if they were to take two aspirin before a

PHOTO COURTESY OF BING YAO, PHD



Bing Yao, PhD

workout – the regimen Leavitt recommends to her patients. She recommends exercise for 30 minutes three times a week. Aerobic exercise is best, but stretching and yoga are helpful, too. “Start with one day a week, and do something you enjoy,” she says.

### Cycling for strength, endurance and less fatigue

Supported by a grant from the Society, Backus and colleagues studied whether functional electrical stimulation (FES) cycling relieved fatigue in people with moderate to severe MS who use wheelchairs. Done on a stationary bike, FES uses low-level electrical impulses to stimulate the leg muscles. “We think FES

exercise may make it easier for people with MS to use the muscles for other tasks so they experience less physical fatigue,” Backus says.

Fourteen participants completed the study, cycling for 30 minutes three times a week for one month. An exercise specialist documented each participant’s fatigue, pain and spasticity, and monitored symptoms. Overall, 86 percent of the participants improved their performance on the FES cycle, either by cycling longer or with more resistance. The impact of FES cycling on fatigue wasn’t as strong as the impact on performance, but the majority of participants said they felt less tired. Researchers concluded that FES cycling may be a safe and viable option for exercise for people with MS

A photograph of Brian Thompson, a man with MS, riding a hand cycle on a beach at sunset. He is wearing a light blue long-sleeved shirt, dark pants, and a white helmet. He is smiling and looking towards the camera. The background shows a colorful sunset over the ocean. The photo is taken from a slightly low angle, showing the front of the hand cycle and the rider's upper body.

Brian Thompson, diagnosed with MS in 2012, exercises on a hand cycle at Venice Beach, California. He cycles in the early morning or late evenings because his fatigue is worsened by heat intolerance.

who use wheelchairs. The study was published in the International Journal of MS Care.

Backus is now doing more research on FES in people with MS who use wheelchairs and also in people who don't. Early results suggest that both groups can build stronger muscles and increase their endurance using FES. "I hope we demonstrate that people have more capacity for change and improvement, even if they have severe MS, and that FES might be a good tool for them. Then we can develop programs so they can get access to FES cycles," says Backus. While people can buy FES cycles, they're very expensive and are usually only available at MS centers or rehabilitation institutes.

### **Looking for the cause of cognitive fatigue**

Iron in the brain is important, but too much iron in a part of the brain called the basal ganglia may be linked to cognitive fatigue in people with MS. Cognitive fatigue affects your ability to learn and remember information, organize, plan and solve problems, focus and other aspects of thinking.

Under a grant from the Society, Bing Yao, PhD, is studying the link between iron in the brain and cognitive fatigue. Yao is senior physicist and manager of the Rocco Ortenzio Neuroimaging Center at the Kessler Foundation and an assistant professor in the Department of Physical Medicine and Rehabilitation at Rutgers University, both in New Jersey.

The study will include about 120 people: 80 with relapsing-remitting MS and 40 people who don't have MS. At one study visit, participants will complete questionnaires about and take tests related to cognitive function. They'll also have an MRI scan while doing a cognitive test. The impact of iron will be measured using an advanced MRI technology called Susceptibility Contrast Imaging.

During the cognitive test, participants will look at images on a screen on the back of the scanner and respond to what they see by pushing buttons on a box they hold. The images are in different colors and shown at different speeds. An eye-tracking system is available for participants who can't move their fingers quickly.



Taking two aspirin before exercise may help people with MS exercise longer.

PHOTO BY KEITH CARLSEN

Yao will measure the difference in iron and the severity of cognitive fatigue between the two groups. "The findings will greatly improve our knowledge of fatigue mechanisms in MS," says Yao. "This may lead to effective treatments such as medication that reduces the concentration of iron in certain regions of the brain."

As of April 2018, the study was still enrolling participants. For more information about the study, contact the Research Recruitment Specialist at **researchstudies@kesslerfoundation.org**.

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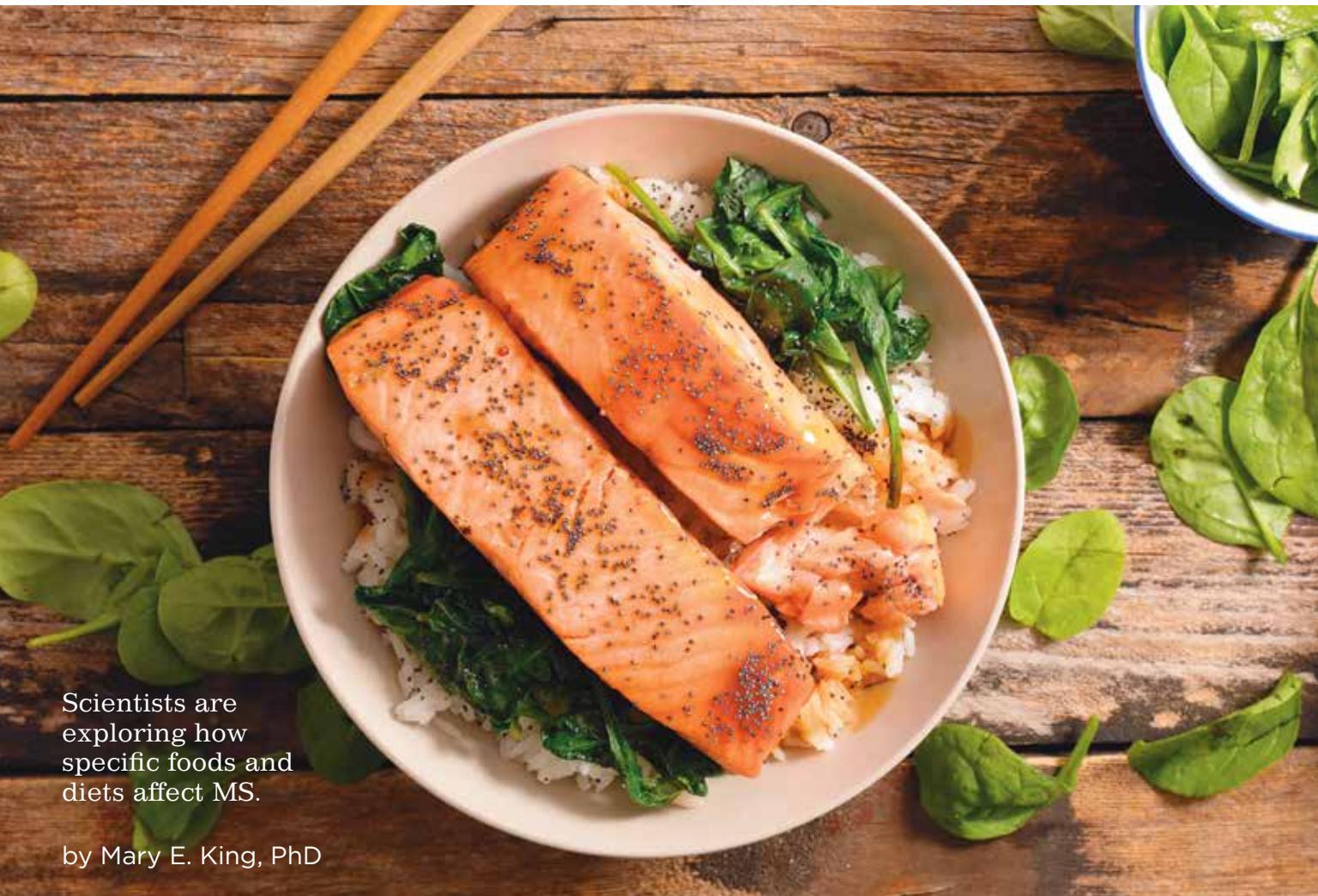
Lori De Milto is a Sicklerville, New Jersey-based freelance writer.

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To learn more about MS research, visit **nationalMSSociety.org/Research**.

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



Scientists are exploring how specific foods and diets affect MS.

by Mary E. King, PhD

# Eating habits

We know what we eat affects our health. But does diet also influence multiple sclerosis? There is currently no single dietary guideline recommended for people with MS, but these three researchers are investigating overall eating habits and specific foods, looking for possible impacts on MS.

## How what we eat might affect MS

Pavan Bhargava, MD, assistant professor of neurology at Johns Hopkins School of Medicine, has reviewed the available scientific evidence about five popular “diets”—or eating plans—in MS. He summarized available research on:

- the Paleolithic, or “paleo,” diet (emphasis on protein, more polyunsaturated fat, no dairy/eggs/gluten)
  - the Mediterranean diet (emphasis on whole grains, vegetables, fruits, legumes, olive oil and fish)
  - the McDougall diet (low-fat, high-carbohydrate, vegaan and gluten-free)
  - the Swank diet (low saturated and unsaturated fat)
- Dr. Bhargava points out that diet may affect MS in at least three different ways.

### 1. Direct effects on the immune system.

For example, some immune cells interact directly with specific dietary components like vitamin D or fatty acids. A higher intake of polyunsaturated fats has been linked to less inflammation, while eating saturated fats has been linked to greater inflammation.



### 2. Indirect effects on the bacteria in our intestines—the gut “microbiome.”

Changes in diet affect the numbers and types of bacteria in the gut, which can shift the immune system to be more or less inflammatory.

### 3. Protective effects on neurons and myelin-making cells and other cells in the brain.

Foods rich in biotin, or vitamin B-7, may have a direct effect on brain cells, he says.

“There is, unfortunately, a real lack of evidence currently to say that any one diet has a significant impact on the course of MS, and, therefore, to recommend for people with MS,” Dr. Bhargava emphasizes. He also found that three of these eating plans—paleo, McDougall and Swank—could lead to significant dietary deficiencies in such things as folic acid; vitamins D, B6, or B12; calcium; iron; or omega-3 fatty acids, depending on the specific dietary restrictions. “It is important to talk with your doctors before adopting a new eating plan,” Dr. Bhargava says.

However, Dr. Bhargava does recommend some general dietary steps that are linked to good health overall. “Eat fresh food, predominantly plant-based food and avoid highly processed foods and those that are high in saturated fat,” he tells his patients.

## Healthier eating—less disability and depression?

Kathryn C. Fitzgerald, ScD, postdoctoral research fellow at Johns Hopkins School of Medicine in Baltimore, administered a dietary screening questionnaire to participants in the North American Research Committee on MS (NARCOMS) Registry and received a total of 6,989 responses. “We developed a dietary quality score from each individual’s responses. Higher scores were given for high intakes of fruits, vegetables and whole grains, and lower intakes of red and processed meats and lower added sugar,” she explains.

“We found that individuals with higher-quality diets had lower levels of MS disability relative to those with lower-quality diets. We also found that people with higher-quality diets had less severe depression relative to those with lower-quality diets.”

Because previous studies have shown that people with MS have an increased risk of several other heart or metabolic health conditions (like high blood pressure and high cholesterol) that can adversely affect MS outcomes, “It is possible that a healthy diet may impact MS disability through its beneficial effects



Pavan Bhargava,  
MD



Anette Langer-  
Gould, MD, PhD



Kathryn C.  
Fitzgerald, ScD

on cardio-metabolic risk," Fitzgerald says. "We can't say for certain from this study alone how diet impacts MS disability—only that there appears to be an association," Fitzgerald says. One factor that might confuse the results, she adds, is that it is possible that more severe disease can affect an individual's ability to engage in a healthy diet. "We're currently working on a follow-up to this study looking at if diet can impact future disability to address this potential pitfall," Fitzgerald says. "There is a lot of anecdotal evidence about diet in MS, but scientific evidence investigating diet in MS is pretty sparse, so there's a lot of room for this field to grow."

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### **Does more seafood lower risk of having MS/CIS?**

Annette Langer-Gould, MD, PhD, neurologist and MS regional lead, Kaiser Permanente Southern California, Los Angeles, found an association between eating more fish and a lower risk of having MS or clinically isolated syndrome (CIS) using

data about the eating habits of 1,153 people. About half of the study participants had been diagnosed with MS or CIS, and about half were healthy control subjects. "We defined a high fish intake as either eating one serving of fish per week or eating one to three servings per month in addition to taking daily fish oil supplements," she explains.

The researchers defined "low intake" as eating fish less than once a month and not taking fish oil supplements. "We compared the risk of having MS in participants who said they had a high fish intake compared with those who reported a low fish intake," she says. Dr. Langer-Gould discovered that study participants with a high fish intake had a 45 percent reduced risk of having MS or CIS diagnoses when compared with the ones with a low fish intake.

"We know from other studies that being a good source of omega-3 polyunsaturated fatty acids is one way that fish is protective in MS," Dr. Langer-Gould says. "These results add more evidence that a diet rich in fish may reduce the risk of developing MS," she adds. However, Dr. Langer-Gould emphasizes that this study shows an association, not cause and effect. She points out that more research is needed to confirm these results and to further pinpoint the way in which omega-3 fatty acids act to reduce risk of developing MS, possibly on inflammation, metabolism or nerve function.

Dr. Langer-Gould adds that most of her patients change their diet after receiving a diagnosis of MS, and that she recommends increasing their fish consumption (especially salmon, sardines, lake trout and albacore tuna) or adding fish oil supplements, as well as eating more plant-based foods. She also cautions, "What you are not eating is also important. So, for example, perhaps reducing saturated fat from meat, which also occurs naturally when you eat more fish instead of red meat, is another factor."

---

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



Learn more about healthy eating at  
[nationalMSSociety.org/diet](http://nationalMSSociety.org/diet).

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

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### Important Safety Information

Do not take COPAXONE® if you are allergic to glatiramer acetate or mannitol.

Some patients report a short-term reaction within minutes after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain, fast heart beat, anxiety, and trouble breathing. These symptoms generally appear within minutes of an injection, last about 15 minutes, and do not require specific treatment. During the postmarketing period, there have been reports of patients with similar symptoms who received emergency medical care. **If symptoms become severe, call the emergency phone number in your area.** Call your doctor right away if you develop hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the injection site. If any of the above occurs, do not give yourself any more injections until your doctor tells you to begin again.

Chest pain may occur either as part of the post-injection reaction or on its own. This pain should only last a few minutes. You may experience more than one such episode, usually beginning at least one month after starting treatment. Tell your doctor if you experience chest pain that lasts for a long time or feels very intense.

A permanent indentation under the skin (lipoatrophy or, rarely, necrosis) at the injection site may occur, due to local destruction of fat tissue. Be sure to follow proper injection technique and inform your doctor of any skin changes.

The most common side effects of COPAXONE® include redness, pain, swelling, itching, or a lump at the site of injection, flushing, rash, shortness of breath, and chest pain. These are not all of the possible side effects of COPAXONE®. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking COPAXONE®.

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 full Prescribing Information on the adjacent page.**



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COP-45352 June 2018

**COPAXONE**  
(glatiramer acetate injection)

**shared solutions**  
support. knowledge. answers.

## Patient Information

### COPAXONE® (co-PAX-own) (glatiramer acetate injection) for subcutaneous use

Read this Patient Information before you start using COPAXONE 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 COPAXONE?

COPAXONE is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS). It is not known if COPAXONE is safe and effective in children under 18 years of age.

#### Who should not use COPAXONE?

- Do not use COPAXONE if you are allergic to glatiramer acetate, mannitol or any of the ingredients in COPAXONE. See the end of this leaflet for a complete list of the ingredients in COPAXONE.

#### What should I tell my doctor before using COPAXONE?

##### Before you use COPAXONE, tell your doctor if you:

- are pregnant or plan to become pregnant. It is not known if COPAXONE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if COPAXONE passes into your breast milk. Talk to your doctor about the best way to feed your baby while using COPAXONE.

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

COPAXONE may affect the way other medicines work, and other medicines may affect how COPAXONE works.

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

#### How should I use COPAXONE?

- For detailed instructions, see the **full Prescribing Information** for complete information on how to use COPAXONE.
- Your doctor will tell you how much COPAXONE to use and when to use it.
- COPAXONE is given by injection under your skin (subcutaneously).
- Use COPAXONE exactly as your doctor tells you to use it.
- Since every body type is different, talk with your doctor about the injection areas that are best for you.
- You should receive your first dose of COPAXONE with a doctor or nurse present. This might be at your doctor's office or with a visiting home health nurse who will teach you how to give your COPAXONE injections.

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

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

- **Post-Injection Reactions.** Serious side effects may happen within minutes after you inject COPAXONE at any time during your course of treatment. Call your doctor right away if you have any of these post-injection reaction symptoms including:

- redness to your cheeks or other parts of the body (flushing)
- chest pain
- fast heart beat
- anxiety
- breathing problems or tightness in your throat
- swelling, rash, hives, or itching

If you have symptoms of a post-injection reaction, do not give yourself more injections until a doctor tells you to.

- **Chest Pain.** You can have chest pain as part of a post-injection reaction or by itself. This type of chest pain usually lasts a few minutes and can begin around 1 month after you start using COPAXONE. Call your doctor right away if you have chest pain while using COPAXONE.

### COPAXONE® (glatiramer acetate injection)

• **Damage to your skin.** Damage to the fatty tissue just under your skin's surface (lipoatrophy) and, rarely, death of your skin tissue (necrosis) can happen when you use COPAXONE. Damage to the fatty tissue under your skin can cause a "dent" at the injection site that may not go away. You can reduce your chance of developing these problems by:

- following your doctor's instructions for how to use COPAXONE
- choosing a different injection area each time you use COPAXONE. See Step 4 in the Instructions for Use, "Choose your injection area".

The most common side effects of COPAXONE include:

- skin problems at your injection site including:
  - redness
  - pain
  - swelling
  - rash
  - shortness of breath
  - flushing (vasodilation)

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 COPAXONE. For more information, ask your doctor or pharmacist.

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

#### How should I store COPAXONE?

- Store COPAXONE in the refrigerator between 36°F to 46°F (2°C to 8°C).
- When you are not able to refrigerate COPAXONE, you may store it for up to 1 month at room temperature between 59°F to 86°F (15°C to 30°C).
- Protect COPAXONE from light or high temperature.
- Do not freeze COPAXONE syringes. If a syringe freezes, throw it away in a sharps disposal container. See Step 13 in the Instructions for Use, "Dispose of your needles and syringes".

**Keep COPAXONE and all medicines out of the reach of children.**  
**General information about the safe and effective use of COPAXONE.**

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information Leaflet. Do not use COPAXONE for a condition for which it was not prescribed. Do not give COPAXONE to other people, even if they have the same symptoms as you have. It may harm them.

This Patient Information Leaflet summarizes the most important information about COPAXONE. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about COPAXONE that is written for health professionals.

For more information, go to [www.copaxone.com](http://www.copaxone.com) or call 1-800-887-8100.

#### What are the ingredients in COPAXONE?

**Active ingredient:** glatiramer acetate

**Inactive ingredients:** mannitol



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Product of Israel

This brief summary is based on COPAXONE FDA-approved patient labeling, revised: January 2018.

COP-45346



# connect

Building relationships

## Power of connection

Support groups offer  
a sense of community  
for people with MS.

by Shara Rutberg

**W**hen Chloe Cohen met Laura Wieden in 2005, “it was one of the most amazing moments of my life,” she recalls. Cohen had been diagnosed with multiple sclerosis in 1998 at age 20. The two met at the National Multiple Sclerosis Society’s Portland, Oregon, office after Cohen had asked if anyone at the Society knew of any recently diagnosed people her age.

“It was pretty awesome,” says Cohen, now 40. “Finally, we could share our experiences.”

The two women formed a support group for young people. Today, 13 years later, the group is still going strong.

### Sense of connection

Across the country, more than 900 MS-specific groups meet to offer that sense of connection, says Monica Aden, manager of program development for the Society. There are groups based on region, age, shared interest and demographics. Some are just for people with MS, others also welcome family members, others are just for family and friends. Members determine how often, where and how long groups meet.

“It’s amazing the connections that are made, they’re just so powerful,” Cohen says. “Especially when you’re first diagnosed. You don’t know what your future’s going to hold.” For Cohen and Wieden, the fact that they were both young was critical. They had both gone to other groups but hadn’t found the right fit so they started their own.

Their group discussed topics specific to being young and living with MS, like handling the stress of college,

when stress can be a trigger for the disease. More powerful than information around particular topics, Cohen says, was the feeling of not being alone, of connecting with other like-minded people with MS.

### Supporting one another

Because the disease is different for each person, “with MS, you don’t get it unless you got it,” says Jim Fairchild, 48, of Vancouver, Washington, who has been a member of a group in Portland for 10 years. “It’s nice to be around positive people who get it.”

“You can feel so isolated,” says Revella Levin. And she should know. The 91-year-old psychotherapist underwent 50 years of stigma, misdiagnosed by 26 neurologists, feeling contempt from her family who believed she had hysteria. When she was finally diagnosed with MS in 2008 and found a group for women over 40 nearby in Queens, New York, she began attending and has been a regular member for years. “I’d absolutely encourage others to go,” says Levin, who has found “great comfort” in the meetings.

“There’s a sense of relief that you know there’s a place you can go regularly and where you know you’re going to talk with people who truly understand what you’re going through,” says Fairchild, who sometimes feels himself holding certain things in until the group’s monthly meeting. “You get asked ‘how’re you doing’ all the time,” he says. “And you say ‘OK’ or ‘fine.’ How often do you really get to answer



Jim Fairchild and Chloe Cohen are both members of the Society’s Portland, Oregon, support group.

PHOTO COURTESY OF CHLOE COHEN AND JIM FAIRCHILD

that question? This group is people who really care. They've got your back. You're not alone. The biggest thing for me through the years has been that connection, just knowing there are people there I care about who care about me." That feeling of connection can help grow confidence, says Karen Johnson, who leads a group for African-Americans in Oakland, California.

Members can find inspiration at groups, especially during dark times. Cohen, who says she turned her life around with "luck, hard work and a different drug," went from not being able to move the left side of her body and feeling like she was 80 when she was 20, to feeling at 40, like she's 30—maybe 25. When she was first diagnosed she "never heard positive stories, it was always stories of people getting worse. She says sharing her story throughout the community has positively impacted hundreds and hundreds of people with MS.

Levin also finds inspiration in her group, especially in the example of how another member, who uses a wheelchair, lives her life. "She handles it so magnificently," says Levin, who notes that the woman, a photographer, still gets out with help to take pictures.

### Get out there

Stop Googling. Go to a meeting. That's Fairchild's advice on fighting the "over-Googling we all tend to do," he says. "Any time you Google, 1,000 things come up that can make you nervous. WebMD can scare the hell out of you. Talking to a person, especially a positive-minded person who has been there, is so much more helpful."

Groups also can serve as conduits for reliable information and resources.



Stephanie Pelton helps people find resources for MS as a group leader in McKinney, Texas.

PHOTO COURTESY OF STEPHANIE PELTON



Elsa Rivera leads a bilingual meeting for Spanish speakers in Oakland, California.

PHOTO COURTESY OF ELSA RIVERA

"Groups help point to so many of the resources the Society has available for us," says Stephanie Pelton, 57, a group leader in McKinney, Texas, who has also attended meetings in the Dallas-Fort Worth area.

Members learn from leaders and one another about topics ranging from navigating travel with MS to preparing for a doctor's appointment. They can also share recommendations for care.

"I found my current neurologist, whom I love, through someone at my meeting," Levin says.

Friendships that begin at group sessions often go beyond meetings, says Bruce Southwick, 62, who leads a group in Silicon Valley, California, and attends several others. Members of one group meet regularly at a rec center to work out. Others go for lunch after meetings. "We'd have 20 to 30 people at IHOP doing more talking than eating," he jokes. "The waitresses weren't thrilled." Members of the group he leads continue their discussion throughout the month via online forums. While he begins his own meetings with a presentation about an MS topic he's researched, he's seen groups splinter off based on special interests, like photography and music.

For some people with MS, talking to others of the same race and culture is key. "Culture and language can be a connector, especially among people who were not born and raised here," says Elsa Rivera, 68, who leads monthly meetings of bilingual Spanish-speakers in Oakland, California, and attends two other groups. Most of her members are native Spanish speakers, born outside the U.S. They meet at a Mexican restaurant and once a year in a member's home. Rivera, a daughter of Mexican immigrants, started

the group after spotting a flyer for a meeting for African-Americans with MS at the local Society office and asking if there was one for Latinos.

## Finding community

"I didn't feel like I identified with anybody I saw at my neurologist's office," says Cynthia Ignacio, 32, of the mostly white faces she encountered. "I hadn't seen anybody who looked like me." When she saw a notice about Rivera's group, she "mainly went to see if it was true," she says. She's been attending for several years. Besides speaking Spanish, "there are cultural things we can all relate to," she says. "Little things that help us relate, like, everyone has that one aunt that keeps giving you Mexican herbs to cure your MS."

Johnson relates. Though she now leads monthly meetings for African-Americans with MS, when she first saw a flyer about another one she was surprised that "there were even enough of us to have a meeting," she says. Though discussions can cover topics specific to her community, such as whether people feel they're getting the same treatment as people of other races, discussions often center on subjects that are not specific to African-Americans and range from sexuality and MS to alternative therapies. "I learn something every time," she says.

Not every group is right for every person, say the leaders and group members. "Go to several groups until you find one you enjoy," Rivera says.

Ask yourself how you feel when you leave the meeting, suggests Fairchild. "If you feel worse than before the meeting, that's not the group for you," he says. "Find a group where you look forward to meetings, where you want to continue conversations you started after the meeting is over."

Don't be afraid of groups. "It can be very scary," Fairchild says. "You don't know who you're going to meet." He recalls resisting going to a group when he was first diagnosed. "My biggest fear was seeing what the disease was really like. Don't let fear stop you from the growth you can find. There's a huge benefit from groups."

Core members of his group, including Cohen, have become a family over the years. When the meetings first started, it was called The Under 40 Group. "Then it became the 50-ish Group," says Fairchild with a laugh.

"Now," Cohen says, "we just call it happy hour."

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Shara Rutberg is a freelance writer in Evergreen, Colorado.

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Learn more about groups, find a group in your area or inquire about starting your own group at [nationalMSsociety.org/SHG](http://nationalMSsociety.org/SHG).

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

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Patient Portrayal

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Actual size

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

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

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

AUBAGIO is available in 14 mg and 7 mg tablets.

## INDICATION

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

## IMPORTANT SAFETY INFORMATION

### DO NOT TAKE AUBAGIO IF YOU:

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

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

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

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

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

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

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

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

**Please see Medication Guide for AUBAGIO on adjacent pages and full Prescribing Information, including boxed WARNING, available on [www.aubagio.com](http://www.aubagio.com).**

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## Medication Guide

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

Rx Only

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

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

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

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

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

#### What is AUBAGIO?

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

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

#### Who should not take AUBAGIO?

#### Do not take AUBAGIO if you:

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

#### What should I tell my doctor before taking AUBAGIO?

#### Before you take AUBAGIO, tell your doctor if you:

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

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

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

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

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

#### How should I take AUBAGIO?

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

#### What are possible side effects of AUBAGIO?

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

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

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

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

The most common side effects of AUBAGIO include:

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

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

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

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

#### **How should I store AUBAGIO?**

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

#### **General information about the safe and effective use of AUBAGIO.**

Medicines are sometimes prescribed for purposes other than those

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

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

For more information, go to [www.aubagio.com](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, hydroxypropylcellulose, microcrystalline cellulose, sodium starch glycolate, magnesium stearate, hypromellose, titanium dioxide, talc, polyethylene glycol and indigo carmine aluminum lake.

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

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

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

Please see Medication Guide for AUBAGIO and full Prescribing Information, including boxed WARNING, available on [www.aubagio.com](http://www.aubagio.com)  
SAUS.AUBA.17.05.3505

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

AUBAGIO is available in 14 mg and 7 mg tablets.

Just



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

# keep going

It's not always easy, but I'm grateful for everything I can do.

by Linda S. Bridges

I was diagnosed with multiple sclerosis in 2001 at age 45, after two exacerbations. The second relapse came after my boyfriend died. Both happened within a year during extreme hot spells in the Northeast, where I live.

Perhaps seven or eight years before those two exacerbations, I went to a neurologist because of numbness in my pelvic region. After I had an MRI and spinal tap, the doctor told me that I might have MS, but that the symptoms would probably disappear. And he said, "Don't lose any sleep over it."

After the two relapses, I was in the neurologist's office, awaiting results from my latest tests. I was sitting next to a woman about my age, in a wheelchair, bone thin, who told me, "That's what I have." Looking at her, I thought, "That is what will happen to me."

Shortly after my diagnosis, I ran into an acquaintance. He introduced me to his wife, Mary, and asked if I was OK. I told them about my MS diagnosis. Mary said very little, but shortly after the encounter, they came into my place of work. Mary told me that she, too, had MS, and that it changed her life. Here was another woman—my age, walking and talking—who gave me hope.

Mary had never told anyone about her diagnosis and was amazed that I was so open about it. She gave me her neurologist's name (and oh, what a positive change), and introduced me to another woman who was about 10 years older than I was. We had tea, and her advice was life-changing—and life-

saving. "Keep doing everything you are doing," she told me. "Walk your dog, hike, keep doing the work you are doing, keep doing your yoga. Don't stop."

That advice may well have changed the course of my life and my disease. Yoga may also have saved me. Not to mention the love, total support and encouragement of friends. I have participated in both a local Walk MS and Bike MS. That was harder! I walked four miles yesterday.

My attitude, too, has been shaped by watching friends with brain cancer, breast cancer, and many other diseases and ailments. I am alive, I am cognizant of my life, I can read, do yoga, walk miles, and I am alive!

My experience is not every woman's or every person's. Part of it may be pure luck, part may be attitude, part may be medication. I use a needle for injections and hate it, but do not dare not to. I am lucky, blessed and so very grateful to be living and independent.

Machu Picchu is on my agenda. I refuse to stop, and I will keep walking, talking and driving people crazy!

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Linda S. Bridges lives in Scarborough, Maine.



Learn from others how they embraced their MS. Start or join a conversation on **MSconnection.org**.

# A lasting legacy

“Miss Susie’s” last gift to the National MS Society capped 32 years of dedicated service.

by Laura Pemberton

**S**usan M. Collins, or “Miss Susie,” as she was affectionately known to the National Multiple Sclerosis Society, lived a quiet, humble life.

She spent her 32-year career with the Society as a receptionist, office manager, unofficial office historian and fundraising project coordinator in the Atlanta office.

“She was a woman of uncommon fortitude,” says Georgia Society President Roy Rangel. “She lived in a modest home. She didn’t drive or own a car. She walked to the bus stop and took the bus and then a train to travel the 20 miles to work every day.”

Frugal and unassuming, Miss Susie “wore the same coat the entire 13 years I knew her,” Rangel recalls. “She was just herself.”

So when Miss Susie died in 2017 at the age of 71, her \$250,000 bequest to the Society took everyone by surprise.

“We knew she didn’t spend much money, but she never talked about her financial situation. She just wanted to help people with MS in any way she could, and she continues to do that even after her life here on Earth,” Rangel says.

The Collins family was also surprised by Miss Susie’s bequest, but not by her passion for the MS movement.

“She was a very private lady,” says her brother Jeff Collins. “She was proud of her accomplishments, but she didn’t gloat about what she did.”

But Miss Susie’s bequest was far from her only contribution to the Society.

Before joining the Society staff in Atlanta, she had modeled professionally in Chicago and New York and worked for professors at Columbia University and the University of California. She attended the University of Michigan.

Miss Susie was an integral and beloved part of the Georgia staff, serving as the de facto editor and archivist.

“She was brilliant. Her intellectual capacity was amazing,” Rangel says. “She was like our Google. We could say, ‘Miss Susie, when did the Bike MS ride start?’ and she’d say, ‘Oh, 1983.’ And I never gave her anything to review that she didn’t return covered in red ink.”

## Lawry Circle

Named in honor of Sylvia Lawry, who founded the National Multiple Sclerosis Society in 1946, the Lawry Circle includes people who demonstrate their commitment to improving the lives of people affected by MS by establishing a deferred gift to the Society through their will, trust or estate plan. There are no minimum gift levels.

“A bequest to the National MS Society through your will provides continuing support for critical programs and services and furthers research for the MS community,” says Julie Upham, associate vice president of major gifts for the Society. “The process is simple to complete, and no amount is too small to leave a lasting legacy.” Upham says a gift to the Society through a will has several advantages:

Charitable gifts made through your will are 100 percent deductible for estate tax purposes

A charitable bequest may place your estate in a lower estate tax bracket

You may specify that your bequest is used for general purposes of the Society or



for a particular program of interest or earmarked solely for MS research

Your gift ensures your continued support of the Society's mission  
Establishing a deferred gift for the Society through your will, trust or estate plan entitles you to lifetime membership in the Lawry Circle

**Deferred gifts include:**

Bequest intentions in a will  
Charitable gift annuities  
Charitable trusts  
Designating the Society as beneficiary of a retirement account  
Designating the Society as beneficiary of a life insurance policy or the donation of a policy

(Please note that this information is not intended as legal, tax or investment advice. For such advice, please consult an attorney, tax professional or investment professional.)



To learn more about establishing your planned gift, visit **plannedgiving.nationalMSSociety.org**.



Susie M. Collins (bottom row, second from right) with her colleagues at the Atlanta office. Her \$250,000 bequest to the Society was far from her only contribution to the MS community.

Rangel remembers when he joined the staff in 2004, hearing a strange clicking noise coming from Miss Susie's office.

"She was in there typing acknowledgements on a typewriter," Rangel says with a laugh. He and the staff helped her learn to use a computer.

"She could do anything she put her mind to," he says. "She grew with us. She learned a lot from us, but we learned a lot from her."

"When she had something to say, everyone listened," Rangel recalls. "She didn't say much, but whatever she said we took to heart. Some passionate people are loud and aggressive. She exhibited her passion in a different way."

Rangel calls Miss Susie "a wonderful human being. I feel lucky to have known her."

Says her brother: "She was a very caring and interesting person. She was an unfailing friend."

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Laura Pemberton, based in Birmingham, Alabama, is the National Multiple Sclerosis Society's director of content. She's been with the Society since 2014.

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



## We all face the obstacles of relapsing MS the same way: with determination.

### WHAT IS LEMTRADA?

LEMTRADA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS). Because of its risks, LEMTRADA is generally used in people who have tried 2 or more MS medicines that have not worked well enough. It is not known if LEMTRADA is safe and effective for use in children under 17 years of age.

### IMPORTANT SAFETY INFORMATION

#### LEMTRADA can cause serious side effects including:

**Serious autoimmune problems:** Some people receiving LEMTRADA develop a condition where the immune cells in your body attack other cells or organs in the body (autoimmunity), which can be serious and may cause death. Serious autoimmune problems may include:

- Immune thrombocytopenia, which is when reduced platelet counts in your blood cause severe bleeding that, if not treated, may cause life-threatening problems. Call your healthcare provider right away if you have any of the following symptoms: easy bruising; bleeding from a cut that is hard to stop; heavier menstrual periods than normal; bleeding from your gums or nose that is new or takes longer than usual to stop; small, scattered spots on your skin that are red, pink, or purple
- Kidney problems called anti-glomerular basement membrane disease, which can, if untreated, lead to severe kidney damage, kidney failure that needs dialysis, a kidney transplant, or death. Call your healthcare provider right away if you have any of the following symptoms: blood in the urine (red or tea-colored urine); swelling of legs or feet; coughing up blood

It is important for you to have blood and urine tests before you receive, while you are receiving and every month, for 4 years or longer, after you receive your last LEMTRADA infusion.

**Serious infusion reactions:** LEMTRADA can cause serious infusion reactions that may cause death. Serious infusion reactions may happen while you receive, or up to 24 hours or longer after you receive LEMTRADA.



Join the many others who asked their healthcare providers about LEMTRADA. Learn more at [Lemtrada.com](http://Lemtrada.com)

- You will receive your infusion at a healthcare facility with equipment and staff trained to manage infusion reactions, including serious allergic reactions, and urgent heart or breathing problems. You will be watched while you receive, and for 2 hours or longer after you receive, LEMTRADA. If a serious infusion reaction happens while you are receiving LEMTRADA, your infusion may be stopped.

Tell your healthcare provider right away if you have any of the following symptoms of a serious infusion reaction during the infusion, and after you have left the healthcare facility:

- |                                    |            |                                      |              |
|------------------------------------|------------|--------------------------------------|--------------|
| • swelling in your mouth or throat | • weakness | • fast, slow, or irregular heartbeat | • chest pain |
| • trouble breathing                |            |                                      | • rash       |

To lower your chances of getting a serious infusion reaction, your healthcare provider will give you a medicine called corticosteroids before your first 3 infusions of a treatment course. You may also be given other medicines before or after the infusion to try to reduce your chances of having these reactions or to treat them after they happen.

**Certain cancers:** Receiving LEMTRADA may increase your chance of getting some kinds of cancers, including thyroid cancer, skin cancer (melanoma), and blood cancers called lymphoproliferative disorders and lymphoma. Call your healthcare provider if you have the following symptoms that may be a sign of thyroid cancer:

- |                         |   |                                      |
|-------------------------|---|--------------------------------------|
| • new lump              | • pain in front of neck                                 | • trouble swallowing or breathing    |
| • swelling in your neck | • hoarseness or other voice changes that do not go away | • cough that is not caused by a cold |

Please see continued Important Safety Information and Medication Guide, including serious side effects, on adjacent pages and full Prescribing Information on [Lemtrada.com](http://Lemtrada.com).

**LEMTRADA®**  
alemtuzumab<sup>12mg</sup><sub>IV</sub>

## ADVERTISEMENT

### IMPORTANT SAFETY INFORMATION (continued)

Have your skin checked before you start receiving LEMTRADA and each year while you are receiving treatment to monitor for symptoms of skin cancer.

**Because of risks of autoimmunity, infusion reactions, and some kinds of cancers, LEMTRADA is only available through a restricted program called the LEMTRADA Risk Evaluation and Mitigation Strategy (REMS) Program.**

**Do not receive LEMTRADA if you** are infected with human immunodeficiency virus (HIV).

**Thyroid problems:** Some patients taking LEMTRADA may get an overactive thyroid (hyperthyroidism) or an underactive thyroid (hypothyroidism). Call your healthcare provider if you have any of these symptoms:

- excessive sweating
- eye swelling
- unexplained weight gain
- unexplained weight loss
- nervousness
- feeling cold
- fast heartbeat
- worsening tiredness
- constipation

**Low blood counts (cytopenias):** LEMTRADA may cause a decrease in some types of blood cells. Some people with these low blood counts have increased infections. Call your doctor right away if you have symptoms of cytopenias such as:

- weakness
- yellowing of the skin or whites of the eyes (jaundice)
- dark urine
- chest pain
- fast heartbeat

**Serious infections:** LEMTRADA may cause you to have a serious infection while you receive and after receiving a course of treatment. Serious infections may include:

- **Herpes viral infections.** Some people taking LEMTRADA have an increased chance of getting herpes viral infections. Take any medicines as prescribed by your healthcare provider to reduce your chances of getting these infections.
- **Tuberculosis.** Your healthcare provider should check you for tuberculosis before you receive LEMTRADA.
- **Hepatitis.** People who are at high risk of, or are carriers of, hepatitis B (HBV) or hepatitis C (HCV) may be at risk of irreversible liver damage.
- **Listeria.** People who receive LEMTRADA have an increased chance of getting a bacterial infection called listeria, which can lead to significant complications or death. Avoid foods that may be a source of listeria or make sure foods that may contain listeria are heated well.

These are not all the possible infections that could happen while on LEMTRADA. Call your healthcare provider right away if you have symptoms of a serious infection such as fever or swollen glands. Talk to your healthcare provider before you get vaccinations after receiving LEMTRADA. Certain vaccinations may increase your chances of getting infections.

#### **Inflammation of the gallbladder without gallstones (acalculous cholecystitis):**

LEMTRADA may increase your chance of getting inflammation of the gallbladder without gallstones, a serious medical condition that can be life-threatening. Call your healthcare provider right away if you have any of the following symptoms:

- stomach pain or discomfort
- fever
- nausea or vomiting

**Swelling of lung tissue (pneumonitis):** Some people have had swelling of the lung tissue while receiving LEMTRADA. Call your healthcare provider right away if you have the following symptoms:

- shortness of breath
- wheezing
- cough
- chest pain or tightness
- coughing up blood

**Before receiving LEMTRADA, tell your healthcare provider if you:**

- are taking a medicine called Campath® (alemtuzumab)
- have bleeding, thyroid, or kidney problems
- have HIV
- have a recent history of infection
- have received a live vaccine in the past 6 weeks before receiving LEMTRADA or plan to receive any live vaccines. Ask your healthcare provider if you are not sure if your vaccine is a live vaccine
- are pregnant or plan to become pregnant. LEMTRADA may harm your unborn baby. You should use birth control while receiving LEMTRADA and for 4 months after your course of treatment
- are breastfeeding or plan to breastfeed. You and your healthcare provider should decide if you should receive LEMTRADA or breastfeed. You should not do both.

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. LEMTRADA and other medicines may affect each other, causing side effects. Especially tell your healthcare provider if you take medicines that increase your chance of getting infections, including medicines used to treat cancer or to control your immune system.

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

- |                                    |                               |                          |                             |  |
|------------------------------------|-------------------------------|--------------------------|-----------------------------|--|
| • rash                             | • nausea                      | • herpes viral infection | • pain in your arms or legs | • dizziness                              |
| • headache                         | • urinary tract infection     | • hives                  | • back pain                 | • stomach pain                           |
| • thyroid problems                 | • feeling tired               | • itching                | • diarrhea                  | • sudden redness in face, neck, or chest |
| • fever                            | • trouble sleeping            | • fungal infection       | • sinus infection           | • vomiting                               |
| • swelling of your nose and throat | • upper respiratory infection | • joint pain             | • mouth pain or sore throat |  |
|                                    |                               |                          | • tingling sensation        |  |

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of LEMTRADA.

**You are encouraged to report 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 Medication Guide, including serious side effects, on adjacent pages and full Prescribing Information on Lemtrada.com.**



Register for more information at [Lemtrada.com](http://Lemtrada.com), or speak to an MS One to One® Nurse at **1-855-676-6326**

**SANOFI GENZYME**

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GZUS.LEMT.15.07.1872(1)b(1) January 2018

**LEMTRADA**  
alemtuzumab<sup>12mg</sup>  
iv

**MEDICATION GUIDE**  
**LEMTRADA® (lem-TRA-da)**  
(alemtuzumab)  
**Injection for intravenous infusion**

**Rx Only**

Read this Medication Guide before you start receiving LEMTRADA and before you begin each treatment course. There may be new information. This information does not take the place of talking to your healthcare provider about your medical condition or treatment.

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

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

1. **Serious autoimmune problems.** Some people receiving LEMTRADA develop a condition where the immune cells in your body attack other cells or organs in the body (autoimmunity) which can be serious and may cause death. Serious autoimmune problems may include:
  - **immune thrombocytopenic purpura (ITP).** LEMTRADA may cause the number of platelets in your blood to be reduced (ITP). ITP can cause severe bleeding that, if not treated, may cause life-threatening problems. Call your healthcare provider right away if you have any of the following symptoms:
    - easy bruising
    - bleeding from a cut that is hard to stop
    - heavier menstrual periods than normal
    - bleeding from your gums or nose that is new or takes longer than usual to stop
    - small, scattered spots on your skin that are red, pink, or purple
  - **kidney problems.** LEMTRADA may cause a serious kidney problem, called anti-glomerular basement membrane disease. If this happens and you do not get treated, anti-glomerular basement membrane disease can lead to severe kidney damage, kidney failure that needs dialysis, a kidney transplant, or death. Call your healthcare provider right away if you have any of the following symptoms:
    - blood in the urine (red or tea-colored urine)
    - swelling in your legs or feet
    - coughing up blood

Side effects may happen while you receive LEMTRADA and for 4 years after you stop receiving LEMTRADA. Your healthcare provider will order blood and urine tests before you receive, while you are receiving, and every month for 4 years after you receive your last LEMTRADA infusion. You may need to continue these blood and urine tests after 4 years if you have any autoimmune signs or symptoms. The blood and urine tests will help your healthcare provider watch for signs and symptoms of serious autoimmune problems.

It is important to have your blood and urine tested, even if you are feeling well and do not have any symptoms from LEMTRADA and your multiple sclerosis. This may help your healthcare provider find any problems early and will increase your chances of getting better.

2. **Serious infusion reactions.** LEMTRADA can cause serious infusion reactions that may cause death. Serious infusion reactions may happen while you receive, or up to 24 hours or longer after you receive LEMTRADA.

You will receive your infusion at a healthcare facility with equipment and staff trained to manage infusion reactions. You will be watched while you receive and for 2 hours after you receive LEMTRADA. **It is important** that you stay at the infusion center for 2 hours after your infusion is finished or longer if your healthcare provider decides you need to stay longer. If a serious infusion reaction happens while you are receiving LEMTRADA, your infusion may be stopped.

Tell your healthcare provider right away if you have any of the following symptoms of a serious infusion reaction during the infusion, and after you have left the healthcare facility:

- swelling in your mouth or throat
- trouble breathing
- weakness
- fast, slow, or irregular heart beat
- chest pain
- rash

To lower your chances of getting a serious infusion reaction, your healthcare provider will give you a medicine called corticosteroids before your first 3 infusions of a treatment course. You may also be given other medicines before or after the infusion to try reduce your chances of these reactions or to treat them after they happen.

3. **Certain cancers.** Receiving LEMTRADA may increase your chance of getting some kinds of cancers, including thyroid cancer, skin cancer (melanoma), and blood cancers called lymphoproliferative disorders and lymphoma. Call your healthcare provider if you have the following symptoms that may be a sign of thyroid cancer:

- |   |  |
|---|--|
| <ul style="list-style-type: none"><li>○ new lump</li><li>○ swelling in your neck</li><li>○ pain in the front of your neck</li></ul> | <ul style="list-style-type: none"><li>○ hoarseness or other voice changes that do not go away</li><li>○ trouble swallowing or breathing</li><li>○ cough that is not caused by a cold</li></ul> |
|---|--|

You should have your skin checked before you start receiving LEMTRADA and each year while you are receiving treatment to monitor symptoms of skin cancer.

**Because of your risk of autoimmunity, infusion reactions and the risk of some kinds of cancers, LEMTRADA is only available through a restricted program called the LEMTRADA Risk Evaluation and Mitigation Strategy (REMS) Program.** Call 1-855-676-6326 to enroll in the LEMTRADA REMS Program.

- You and your healthcare provider must be enrolled in the LEMTRADA REMS Program.
- LEMTRADA can only be given at a certified healthcare facility that participates in the LEMTRADA REMS Program. Your healthcare provider can give you information on how to find a certified healthcare facility.
- Read the LEMTRADA REMS "What You Need to Know About LEMTRADA Treatment: A Patient Guide" and "What you Need to Know About LEMTRADA Treatment and Infusion Reactions: A Patient Guide" after you are enrolled in the program.
- Carry your LEMTRADA REMS Patient Safety Information Card with you in case of an emergency.

**What is LEMTRADA?**

LEMTRADA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS). Because of its risks, LEMTRADA is generally used in people who have tried 2 or more MS medicines that have not worked well enough. It is not known if LEMTRADA is safe and effective for use in children under 17 years of age.

**Who should not receive LEMTRADA?**

**Do not receive LEMTRADA if you** are infected with human immunodeficiency virus (HIV).

**What should I tell my healthcare provider before receiving LEMTRADA?**

Before receiving LEMTRADA, tell your healthcare provider if you:

- are taking a medicine called Campath®. Alemtuzumab, the active ingredient in LEMTRADA, is the same drug as Campath.
- have bleeding problems
- have thyroid problems
- have kidney problems
- have a recent history of infection

- have HIV
- have received a live vaccine in the past 6 weeks before receiving LEMTRADA or plan to receive any live vaccines. Ask your healthcare provider if you are not sure if your vaccine is a live vaccine.
- are pregnant or plan to become pregnant. LEMTRADA may harm your unborn baby. You should use birth control while receiving LEMTRADA and for 4 months after your course of treatment.
- are breastfeeding or plan to breastfeed. It is not known if LEMTRADA passes into your breast milk. You and your healthcare provider should decide if you should receive LEMTRADA or breastfeed. You should not do both.

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

LEMTRADA and other medicines may affect each other causing side effects. Especially tell your healthcare provider if you take medicines that increase your chance of getting infections, including medicines used to treat cancer or to control your immune system. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

#### How will I receive LEMTRADA?

- LEMTRADA is given through a needle placed in your vein (IV infusion).
- It takes about 4 hours to receive a full dose of LEMTRADA each day.
- You will receive LEMTRADA over 2 treatment courses.
- You will receive LEMTRADA for 5 days in a row (consecutive) for the first treatment course and then for 3 days in a row (consecutive) about 1 year later for your second treatment course.

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

LEMTRADA may cause serious side effects including:

- See "What is the most important information I should know about LEMTRADA?"
- **thyroid problems.** Some people who receive LEMTRADA may get thyroid problems including an overactive thyroid (hyperthyroidism) or an underactive thyroid (hypothyroidism). Your healthcare provider will do blood tests to check how your thyroid is working. Call your healthcare provider if you have any of the symptoms of thyroid problems.

Symptoms of **hyperthyroidism** may include:

- excessive sweating                    ○ nervousness
- unexplained weight loss            ○ fast heartbeat
- eye swelling

Symptoms of **hypothyroidism** may include:

- unexplained weight gain            ○ worsening tiredness
- feeling cold                        ○ constipation

- **low blood counts (cytopenias).** LEMTRADA may cause a decrease in some types of blood cells. Some people with these low blood counts have increased infections. Symptoms of cytopenias may include:

- weakness                            ○ dark urine
- chest pain                        ○ fast heartbeat
- yellowing of the skin or
- whites of eyes  
    (jaundice)

Your healthcare provider will do blood tests to check for cytopenias. Call your healthcare provider right away if you have symptoms listed above.

• **serious infections.** LEMTRADA may cause you to have serious infections while you receive and after receiving a treatment course. Serious infections may include:

- **herpes viral infections.** Some people taking LEMTRADA have an increased chance of getting herpes viral infections. Your healthcare provider will prescribe medicines to reduce your chances of getting these infections. Take these medicines exactly as your healthcare provider tells you to.
- **human papilloma virus (HPV).** Females have an increased chance of getting a cervical HPV infection. If you are a female, you should have an HPV screening each year.
- **tuberculosis.** Your healthcare provider should check you for tuberculosis before you receive LEMTRADA.
- **fungal infections.**
- **listeria.** People who receive LEMTRADA have an increased chance of getting an infection caused by the bacteria listeria, which can lead to significant complications or death. Avoid foods that may be a source for listeria (for example, deli meat, unpasteurized milk and cheese products, soft cheeses, or undercooked meat, seafood or poultry) or make sure that the food you eat which may contain listeria is heated well if you receive treatment with LEMTRADA.

Call your healthcare provider right away if you have symptoms of a serious infection, such as fever or swollen glands. You may need to go to the hospital for treatment if you get a serious infection. It is important to tell the healthcare providers that you have received LEMTRADA.

Talk to your healthcare provider before you get vaccinations after receiving LEMTRADA. Certain vaccinations may increase your chances of getting infections.

- **Inflammation of the gallbladder without gallstones (acalculous cholecystitis).** LEMTRADA may increase your chance of getting inflammation of the gallbladder without gallstones, a serious medical condition that can be life-threatening. Call your healthcare provider right away if you have any of the following symptoms of acalculous cholecystitis, which may include:

- stomach pain or discomfort
- fever
- nausea or vomiting

- **swelling of lung tissue (pneumonitis).** Some people have had swelling of the lung tissue while receiving LEMTRADA. Call your healthcare provider right away if you have the following symptoms:

- shortness of breath                    ○ chest pain or tightness
- cough                                ○ coughing up blood
- wheezing

The most common side effects of LEMTRADA include:

- rash
- headache
- thyroid problems
- fever
- swelling of your nose and throat (nasopharyngitis)
- nausea
- urinary tract infection
- feeling tired
- trouble sleeping
- upper respiratory tract infection
- herpes viral infection
- hives
- itching
- fungal infection
- joint pain
- pain in your arms or legs
- back pain
- diarrhea
- sinus infection
- mouth pain or sore throat
- tingling sensation
- dizziness
- stomach pain
- sudden redness in face, neck, or chest
- vomiting

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

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

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

**General information about the safe and effective use of LEMTRADA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use LEMTRADA for a condition for which it was not prescribed. Do not give LEMTRADA to other people, even if they have the same symptoms that you have. It may harm them.

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

For more information, go to [www.LemtradaREMS.com](http://www.LemtradaREMS.com) or call Genzyme at 1-855-676-6326.

**What are the ingredients in LEMTRADA?**

**Active ingredient:** alemtuzumab

**Inactive ingredients:** sodium chloride, dibasic sodium phosphate, potassium chloride, potassium dihydrogen phosphate, polysorbate 80, disodium edetate dihydrate, and water for injection.

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

**Manufactured and distributed by:**

Genzyme Corporation

500 Kendall Street

Cambridge, MA 02142

US License Number: 1596

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ALE-MG-SA-DEC17



Bryan Bickell  
gives back by  
sponsoring  
service dogs for  
people with MS.

# Keeping MS in check

Former professional hockey player Bryan Bickell brings a positive outlook to living with the disease that ended his career.

by Mike Knight

**I**t was mid-November, 2016. Bryan Bickell, a professional hockey player with the Carolina Hurricanes, was at his Raleigh, North Carolina, home enjoying a rare day off with his wife, Amanda Bickell, and their two young daughters, Kinslee and Makayla. Life as a professional hockey player is lived at a breakneck pace of play, practice and travel. Time off during the season is rare, and the couple was determined to make the most of it.

But first, Bryan had to drop by his team doctor's office for what the couple assumed would be a routine visit. "We weren't really that nervous about it," Amanda remembers. After all, professional hockey players skate across the ice at speeds reaching nearly 30 mph, roughly as fast as a horse runs at top speed. Brutal collisions—into one another, into the walls around the rink—are a big part of the game. Concussions, along with head, arm and knee injuries, are common, as are MRIs and trips to the team doctor's office.

Bryan, who began his professional hockey career 12 years earlier, was no stranger to the routine.

"Honestly, I don't really understand why I decided to come with the kids," Amanda says. But Bryan had been traveling for an extended stretch, and she didn't want to waste the time together. "I thought we'll go grab lunch [afterwards] or something like that," she says. And if she didn't quite understand why she decided to go, she felt she needed to. So she loaded the girls into the car.

Soon they were in the physician's office parking lot. Bryan went in alone while Amanda waited with their daughters in the car. Ten minutes later he walked across the parking lot, eyes locked on Amanda's as he opened the car door.

"I was in the driver's seat, and he just opened the door and said, 'Can you go and talk to them?'" Amanda recalls.

Amanda was beginning to realize it was more than just a routine trip to the doctor. "I went and talked to the doctor," she says. "I just said, 'It's OK, just say it, say whatever you have to say, I just want to hear it.' And then they said, 'MS.'"

The couple had heard of the disease but knew little about it. "When I came out, he was just standing outside the car, watching me coming towards the car, waiting to see my reaction to figure out whether or not

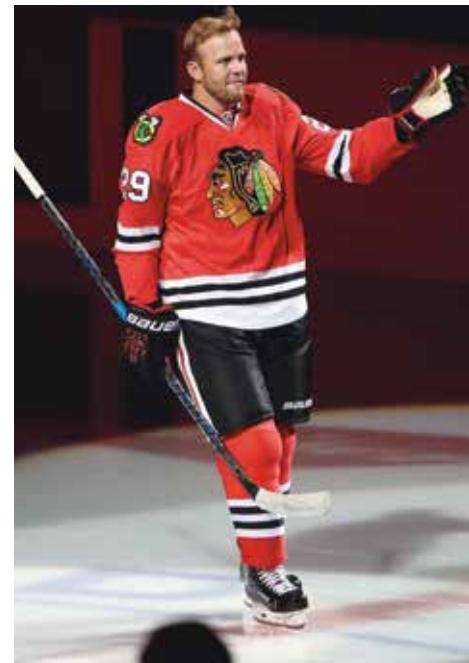
he should react and to figure out how he should be feeling in that moment," Amanda remembers. "So I just hugged him and said, 'Don't worry, it will be OK, we'll be fine.'"

### Life on the ice

Born in 1986, in Orono, Ontario, Canada, a small town of about 1,800 people, all Bryan ever wanted to do was play hockey. "When I was a kid, that was the thing that you wanted to do, you just wanted to play hockey and have fun," he says. "It was everything."

Bryan began his career playing for the Ottawa 67's, a Canadian Hockey League junior league. While traveling with the team through Ottawa he met his future bride, Amanda Caskenette. Drafted by the Chicago Blackhawks franchise in 2004, Bryan was called up to "the big leagues" in 2007, scoring a goal in his debut against the Detroit Red Wings in a 3-2 victory. At 6 feet, 4 inches tall and weighing 220 pounds, Bryan was an imposing figure on the ice, known for his physical, aggressive play. He played on three championship (the NHL's Stanley Cup) winning teams (2010, 2013 and 2015) with the Blackhawks.

In game six of 2013's Stanley Cup game against the Boston Bruins in Boston, Bryan scored a game-tying goal with less than two minutes left in the game. Seconds later, teammate Dave Bolland scored the go-ahead goal for the victory—and the Stanley Cup. In a career full of special moments, Bryan remembers that one most



Bryan Bickell was drafted by the Chicago Blackhawks franchise in 2004.



The Bryan & Amanda Bickell Foundation creates awareness about pit bulls and trains them as service dogs for people with MS.

PHOTO BY DEVIN CASKENETTE

fondly. “If I had to pick one [highlight], it was probably the tying goal in game six against Boston,” he says.

By 2015, Bryan was suffering from a string of physical issues, including dizziness, imbalance and pain and numbness in his right shoulder, arm and leg. He experienced fatigue like he’d never known. After he passed out during game five of the Western Conference finals in June 2015, he knew something was wrong. Though he saw several doctors, whatever was causing his problems remained a mystery.

The 2015-2016 season was a tough one for Bryan. The Blackhawks sent him to the minor-league American Hockey League’s Rockford, Illinois, team twice. In June 2016, he was traded to the Carolina Hurricanes.

Bryan’s health—and game—continued to decline. He played his last game of the year for the Hurricanes in October 2016, just two weeks before his MS diagnosis. He took time away from hockey to work on his health, resuming practice with the Hurricanes in January 2017.

But his return to the Hurricanes was short-lived. Bryan announced he was retiring from professional

hockey, a game that was once “everything” to him, so he could focus on his health.

### The skate beyond

At first, Bryan struggled to fill the void in his life left by the loss of his career. “I started from playing hockey when I was a kid to [receiving] the news where obviously I can’t play at the level that I used to play. And now moving on after hockey, that’s probably the scariest thing,” he says. “You know, what’s next?”

Amanda noticed her husband’s downward spiral. A previously scheduled visit from Bryan’s sister and brother-in-law not long after the diagnosis underscored his struggle. “He didn’t really want to join us in any activities,” she says. “He was pretty stressed, and I knew stress brings on symptoms. He started not being able to pick up our children and bring them up or down the stairs because he thought he was going to drop them. So right after finding out, he did go downhill.”

Amanda was determined to find the positives in their lives wherever she could. “I kind of thought that that was my job,” she says, “to stop the downward

progression and to help him the best that I could."

She scoured Bryan's daily activities, looking for ways to turn what might otherwise be negative events into positive ones. "Every chance I got, I started pointing out the good things that can come out of this," she says.

When Bryan was scheduled to go to New York for tests, she suggested she and the kids join him there for a short vacation, something they never could do while he was playing hockey.

"I had to make up a positive outcome out of a negative situation versus him just going to New York and just being all sad and depressed to get tests for MS and then fly home."

Slowly Bryan began to rebound. "We started doing things a little differently, and if I saw him being down about something, I tried to spin something in some way to find a positive about the whole situation," Amanda says. "Once we started doing that, his headaches weren't as bad, he started feeling a little bit better and started feeling like, 'OK, my life's not going to end,' and things just started to look up from then," she says. Working together with Bryan's doctor, the couple learned more about MS. Diagnosed with relapsing-remitting MS, Bryan was prescribed an infusion treatment to help slow progression of the disease. With the disease in check, he turned his attention to his family. And to giving back.

While living in Ontario, the couple adopted Bailey, a 5-week-old Staffordshire Terrier, commonly known as a pit bull. Only a few weeks later, the city banned the dogs because of their perceived violent and aggressive nature. Soon the Bickells learned that Bailey wasn't allowed in dog parks or puppy classes and couldn't even go for a walk unless she was muzzled. "I'm like, 'I don't understand. This dog's never done anything to anyone, it's just this little tiny puppy,'" Amanda remembers. After relocating to Chicago in 2012, they learned the city also was planning to ban the dogs. The



Amanda and Bryan Bickell receive a donation for their foundation from the NHL at the 2017 NHL Draft.

Bickells decided to take action through "Chicago Loves Pits." A citywide campaign meant to raise awareness about the misunderstood dogs, "Chicago Loves Pits" emphasized proper treatment and care for the dogs, and through rescue and adoption, to reduce the number of pit bulls that are abused, abandoned or euthanized. The campaign also sought to create a human-animal bond by pairing pit bull therapy dogs with children victimized by abuse and bullying.

The Bryan & Amanda Bickell Foundation sprang from the campaign. The foundation began training pit bulls as service dogs for people with MS. Based in Bowmanville, Ontario, Canada, where the Bickells live, the foundation delivered its first MS service dog to a Florida family in March 2018.

In 2017, Bryan teamed up with Biogen, maker of MS treatments, as an ambassador to share his story. When he's not chasing his daughters around the house and yard, he gets back on the ice. "I play with some friends who played at the junior level with me and some other local recreational players," he says.

No matter what, the couple stays positive in the face of an unpredictable disease. "You may not be able to control what's happening," Amanda says, "but you can control how you view it and how you react to it. I think that we've realized that, and we can apply that to many different things in life, not just MS."

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



To learn more about the Bryan & Amanda Bickell Foundation's service dog program, visit [bickellfoundation.org/msservicedogs](http://bickellfoundation.org/msservicedogs).

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

# The buddy system

by Mike Knight

Service dogs help with everyday tasks and offer companionship to people with MS.

In 1928, “Buddy,” a specially trained German Shepherd, stunned a group of reporters who had gathered to watch as he guided his blind owner, Morris Frank, across a busy New York City street, becoming the first “seeing eye” dog in the United States. Over time, the role of “service” dogs has expanded from guiding the blind to becoming active assistants capable of performing an array of tasks for people with disabilities—including people with multiple sclerosis.

## Help with everyday tasks

Specially trained to support the special needs of people with MS, service dogs can assist with all kinds of everyday tasks, including:

Helping people get in and out of chairs and beds by bracing them for balance

Assisting people to/from the bathroom and shower

Picking up items from the floor or ground



- Opening doors
- Pulling wheelchairs
- Pushing elevator buttons
- Seeking help when it is needed
- Helping people get dressed and undressed
- Turning lights on or off
- Providing support after a fall
- Fetching smaller items from other rooms
- Knowing when its owner is tiring, then nudging him or her toward a chair or a wall for support

A service dog can help with everyday tasks, such as opening a door.

First and foremost, service dogs are trained to assist and serve their owners. But in addition to the long list of tasks they help with, their unflagging companionship and love are often invaluable benefits.

**Training a service dog**  
The Americans with Disabilities Act (ADA) defines service

dogs as “dogs that are individually trained to do work or perform tasks for people with disabilities.” While there is no governing body regulating how service dogs are trained, Assistance Dogs International, Inc., (**assistancedogsinternational.org**), an international coalition with members representing assistance dog programs from around the world, offers accreditation to organizations that meet peer-reviewed operational standards of excellence.

MS service dogs may be trained by:  
The owner/trainer  
Professional trainers  
Service dog organizations

### How to find a service dog

Trained service dogs are available from a number of organizations. Though costs to recipients vary, according to Paws With A Cause, a Michigan-based not-for-profit that breeds, trains and places service dogs, “The sponsorship to breed or rescue, raise, train, place an assistance dog and provide ongoing team support exceeds \$30,000.”

If you are interested in obtaining a service dog, expect to complete a needs assessment, and, because demand is high, expect a waiting period to qualify for and

receive a trained service dog.

The following organizations are good places to start your search for a service dog:

Assistance Dogs International, Inc. (**assistancedogsinternational.org**) provides a searchable directory of accredited trainers and training programs by state, region or country.

My Assistance Dog, Inc., (**myassisteddoginc.org**), provides a list of service dog training resources.

Not-for-profit organizations and foundations, including Paws With A Cause, (**pawswithacause.org**), National Education for Assistance Dog Services, (**NEADS.org**), Canine Partners for Life, (**k94life.org**), Pet Partners, (**petpartners.org**) and Assistance Dog United Campaign, (**assistancedogunitedcampaign.org**) offer resources.

Private foundations, including the Bryan & Amanda Bickell Foundation (**bickellfoundation.org**), and the Foundation for Service Dog Support, Inc. (**servicedogsupport.org**), are among the private foundations that provide specially trained MS service dogs.

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

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# Spirituality and a giraffe

Creating paper-mache animals for inspiration.

by Lin Shanti Goodman



I am 62 years old, and I've had multiple sclerosis for 33 years. It's been quite a journey.

I've been living in an adult nursing home for the past six years. I go to physical therapy several times a week. I also go to art therapy, where I create paper-mache animals. A giraffe I created was featured in an art show at the nursing home, and the art room displays the many dogs I have made. The giraffe and an elephant share space atop my closet in my room. I've also made an owl, my spirit animal, and I plan to make a zebra and several other animals.

I'm not religious, but I consider myself a spiritual person. Peace of mind is my priority.

I've never seen myself as a victim. I've always seen myself as a fighter and that has helped get me through all these years with a positive state of mind. I live in the present moment. I hope that's an inspiration to others.

I am grateful for all the love and support I have. My father is 85, and he is an amazing, positive man. My ex-partner and I still share our love and our lives, and we recently celebrated 41 years of being a family together.

Life is good, and I am so grateful for that.

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Lin Shanti Goodman lives in Seattle, Washington.

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

MS tried to  
silence me.

But  
I won't  
let it.

**Kim**

PML survivor. Mom.  
Diagnosed in 2000.

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