

## Globe trotting

With some planning, people with MS can travel anywhere in the world.

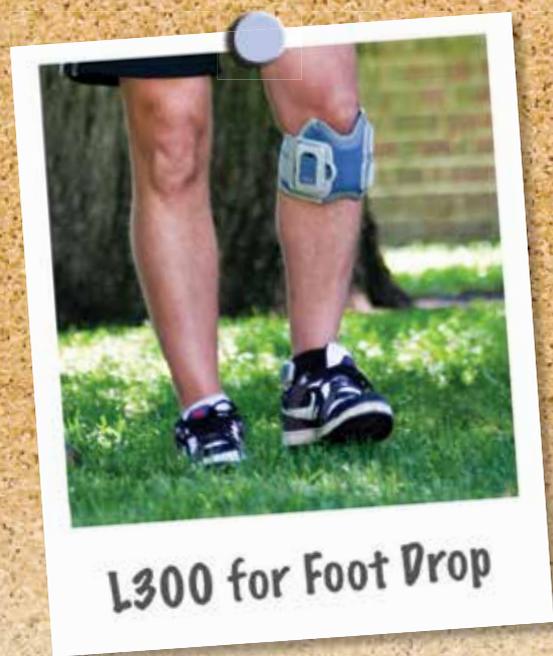
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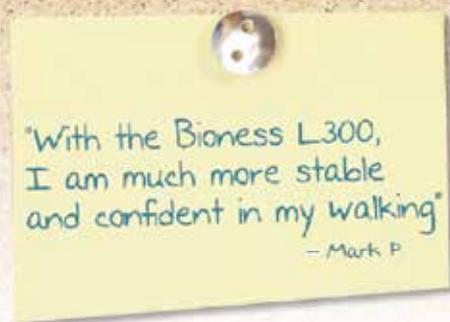


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Mark P.

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**Be Bold. Be True. Be You.**

It's your future.

Talk to your doctor about the clinically proven results of **3-times-a-week COPAXONE® (glatiramer acetate injection) 40 mg for relapsing MS**

Turn the page to learn more about Teva's COPAXONE®.

## Use

COPAXONE® is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS).

## Important Safety Information

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

Some patients report a short-term reaction right after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, 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.

**Please see additional Important Safety Information and brief summary of full Prescribing Information on the following pages.**

**COPAXONE®**  
(glatiramer acetate injection)

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support. knowledge. answers.

Arrange your treatment around your life—  
not your life around your treatment

Talk to your doctor about how **3-times-a-week COPAXONE® (glatiramer acetate injection) 40 mg** can help you manage your relapsing MS:

- Injections must be at least 48 hours apart
- Proven clinically effective<sup>1</sup>
- Demonstrated safety and tolerability profile<sup>1</sup>
- The financial support, training and nurse support, and educational resources of Teva's **Shared Solutions®**

### Important Safety Information (cont'd)

Chest pain may occur either as part of the immediate postinjection 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.

**Please see additional Important Safety Information and brief summary of full Prescribing Information on the following pages.**

**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 right 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.

- **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
  - itching
  - lumps
- 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.

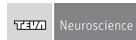
This Patient Information Leaflet summarizes the most important information about COPAXONE. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about COPAXONE that is written for health professionals.

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: August 2016.

COP-44042

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3-times-a-week COPAXONE<sup>®</sup> (glatiramer acetate injection) 40 mg—the # 1 prescribed therapy for relapsing MS in the US<sup>2\*</sup>

Ask your doctor today about Teva's COPAXONE<sup>®</sup>.  
Visit [www.copaxone.com/Teva40](http://www.copaxone.com/Teva40) to learn more.

### Important Safety Information (cont'd)

The most common side effects in studies of COPAXONE<sup>®</sup> are 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<sup>®</sup>. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking COPAXONE<sup>®</sup>.

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 and brief summary of full Prescribing Information on the previous pages.**

\*Based on total number of prescriptions for relapsing forms of MS (IMS National Rx Audit, March 2017). All Rights Reserved by IMS.

**References:** 1. COPAXONE<sup>®</sup> (glatiramer acetate injection) prescribing information. Rev. 8/2016. Teva Neuroscience, Inc. 2. IMS Health National Prescription Audit, March 2017. Data proprietary to IMS Health.

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**COPAXONE<sup>®</sup>**  
(glatiramer acetate injection)

**shared solutions<sup>®</sup>**  
support. knowledge. answers.



**Cyndi Zagieboylo**

**E**very day we wake up to the realities of a rapidly changing world.

The National MS Society is changing, too. This past year we've gone through critical organizational changes that affect everyone in the MS movement, especially our volunteers, staff and people living with MS. We are excited to share these changes with you!

Over several years—even decades—we examined the

Society's structure. We wanted to ensure that we remain relevant and always improve our effectiveness, now and into the future. Along the way, we listened, we learned, we watched other nonprofit organizations re-structure, and we refined our approach to focus on being the best National MS Society possible.

We want to provide life-changing services with demonstrated impact nationwide. We want to increase the number of community leadership volunteers and provide talented employees with a rewarding career. We want to produce the most engaging event experiences for all participants. We want to invest more in MS research and solutions so people with MS can live powerfully. Our ability to do all of this at even higher levels is now possible because we have an aligned nationwide staff team with the expertise to continually increase effectiveness and impact.

So, let's get to the question I bet is on your mind, "What does this mean for me?" Well, you might know Society staff members who have moved into a different role. Or you may be missing staff members who are no longer with the organization. To some people, that can feel like missing a friend who's moved away. To others, it may feel like the Society is not as closely connected with your neighborhood. Changes like these can be difficult.

I want to assure you that the Society is here to be your supportive partner in navigating life with MS—no matter where you live. While our staff structure has changed, our commitment to address the needs of people affected by MS hasn't.

That's why we are reviewing each and every program to make sure it's the most effective use of resources and has an important impact on people's lives. At the same time, we are assessing what can be expanded and delivered throughout the country using a variety of formats—online, in person or over the phone. The way we implement services and conduct events may look different, but we now are positioned to reach more people, facilitate more connections and collaborate with more like-minded organizations—not just in some places, but across the entire country.

Although we can't have an office and staff in every town, we are developing community councils to engage volunteers wherever there is interest to help you connect with other people who share your concerns and passions. We expanded our volunteer advisory committees, both local and national, to include a broader variety of perspectives to ensure that many viewpoints are considered as we make important decisions. We expanded volunteer event committees to drive participation and fundraising, and to produce memorable event experiences. There are other ways for volunteers to create impact in their communities—through Do-It-Yourself events, self-help groups or as MS Activists. It takes all of us to create meaningful change.

We remain focused on our vision of a world free of MS, and together we've made remarkable progress. The Society funded the foundational research that led to a breakthrough progressive MS therapy, Ocrevus®, and, through Society fellowships, we launched the careers of scientists who conducted this research. Also, Edward M. Dowd donated \$3 million over three years to establish the Edward M. Dowd Personal Advocate Program—a nationwide support service to address the most challenging problems that MS causes. Today, MS Navigators work as an integrated team to partner with and find solutions for everyone who calls, emails or writes to the Society with questions, concerns or needs. This program was not feasible in our prior structure when staff worked in separate units rather than as one nationwide team, and the quality of service depended on which part of the country someone lived.

These organizational changes better position us to accomplish our strategic plan to ensure both life-changing

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## on the cover

**Travel agency owner Tarita Davenock advises people who are hesitant about traveling to take small trips at first.**



PHOTO BY RIKU PHOTO

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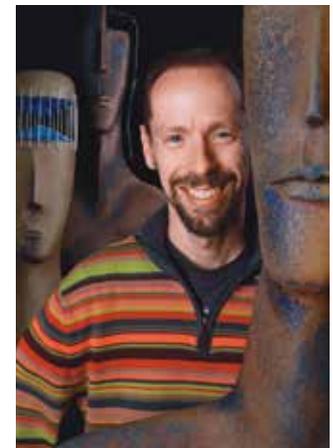


PHOTO COURTESY OF RYAN MOFFETT

Sculptor Ryan Moffett lends his experience with MS to his work.

Look for these icons throughout **Momentum**.



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**Hispanic people with MS:** Studies show an increase in the number of Hispanic and Latino people who are living with MS. **Plus:** Stories on new Social Security Disability Insurance guidelines, how voice command devices make tasks easier, and strategies beyond disease-modifying therapy to take care of yourself—from yoga to changes in your diet.



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



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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.

## IMPORTANT SAFETY INFORMATION

### 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.
- **Infection:** OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.

### 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 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 safety information, please see the accompanying Patient Information.**

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

**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.
- **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 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.

Manufactured by: Genentech, Inc.,  
A Member of the Roche Group,  
1 DNA Way,  
South San Francisco, CA 94080-4990  
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For more information, go to [www.OCREVUS.com](http://www.OCREVUS.com) or call 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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# momentum

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Cyndi Zagieboylo

**Editor**  
Jane Hoback

**Advertising Sales**  
Elisa N. Beerbohm  
303-698-6100 x15204  
elisa.beerbohm@nmss.org

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733 Third Ave., Third Floor  
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1-800-344-4867

@ [editor@nmss.org](mailto:editor@nmss.org)

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Continued from page 3

breakthroughs that enable people to live their best lives today as well as research breakthroughs that will ultimately end MS forever.

We will continue to improve and evolve to keep up with the changing world, and we will always strive to create the greatest impact.

I'm a finisher. I want to end MS, and I know you do, too. Together we are stronger! Let's continue to work together toward a world free of MS.

I welcome your thoughts. Keep in touch! ■

*Cyndi Zagieboya*

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



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



## Never feel ashamed

I just wanted to comment on the "Owning my MS" article by Debbie Moyes (Summer 2017). Great article, and very similar to what I have been going through with my MS. I love how she wrote that I should have never acted ashamed, that I haven't done anything wrong and I sure as heck am not a bad or tainted person.

I was diagnosed with MS in January of 2000. I tell people that's when my warranty was up. It's extremely important to keep one's sense of humor. Over the years I went through vision, hearing and numbness problems. Now I have leg weakness, primarily the right leg. I can get around with a walker for short distances, but I need a scooter or wheelchair for longer distances. I was just diagnosed from relapsing/remitting to progressive MS.

Debbie Moyes, thank you for such a good article.

---

Victor Campbell, Arizona

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## Interesting, educating articles

Thanks so much for the Summer 2017 issue of **Momentum**. I usually read every issue cover to cover soon after I receive them in the mail. However, this particular issue really captivated my attention. From the start to the end, there were very interesting as well as educating articles, and I loved the article on "glamping."

Keep up the good journalism, and I look forward to more interesting issues of **Momentum**.

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Teresa C. May, Virginia

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PHOTO COURTESY OF JAMIE-LYNN SIGLER

## Thanks to Jamie-Lynn Sigler

Please express my heartfelt appreciation to writer Stephanie Stephens and especially Jamie-Lynn Sigler (“Getting real about MS,” Summer 2017) for sharing this personal account with others with MS. I am a bit older than Jamie-Lynn, and certainly not as famous, but I have traveled much of the same challenging road with her.

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Sid Burwell, California



PHOTO COURTESY OF JOE SHYMANSKI

## Use data wisely

My sincere gratitude and congratulations to all the folks that contributed to the passage of the 21st Century Cures Act (“A game-changing act,” Summer 2017). The overwhelming bipartisan support of the bill was an eye-popper.

I also believe that the collection of good data can contribute to our understanding of how the brain works and how we might prevent and cure diseases like MS. And just as important is the need to protect individual health information. It is imperative that effective firewalls be in place. For that reason I cringe at the name they chose: The National Neurological Conditions Surveillance System. I hope that doesn’t mean what it seems to imply, surveillance by the government of a health database. Surveillance is a term usually associated with policing. Surveillance has a legitimate use in the protection of our communities, but it doesn’t belong in our collection of data on health conditions.

Nonetheless, I laud this step toward the effective use of data on a national scale to help us understand the brain, the human genome and our health.

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Dan Hammang, California

## Male support

I really liked the article titled “A man thing” in the last **Momentum** magazine (Summer 2017). I really believe men should get together to share their MS experiences. ■

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Rick Rayer, Ohio

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



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



Like and comment on our page at [facebook.com/nationalMSSociety](https://www.facebook.com/nationalMSSociety).



Tag your thoughts @mssociety using #Momentum.



Join discussions at [MSconnection.org](https://www.msconnection.org).

## Cost of care

Considering long-term care but concerned about the expense? It's worth it to know your options. For example, it may not be too late to invest in long-term care insurance, which can help pay for both skilled and non-skilled care. Policies, which vary widely, may include coverage for a whole range of services, like adult day care, assisted living, medical equipment and informal home care. If you plan to receive care at home, borrowing through a reverse mortgage also might be a good option for you. It allows you to use the equity from your home to increase your cash flow. Learn more about nursing home care on **p. 17**.

Practical ideas  
for living well  
with MS

# in the know

# Documenting for dollars

Keeping a diary of symptoms and responses to treatments can help get insurance claims paid.

by Jane Hoback

**F**iling a health insurance claim can be challenging for even the most straightforward issue. But getting coverage for medications and equipment to treat multiple sclerosis—particularly if treatments are for new or exacerbated symptoms—can introduce a whole new level of complexity.

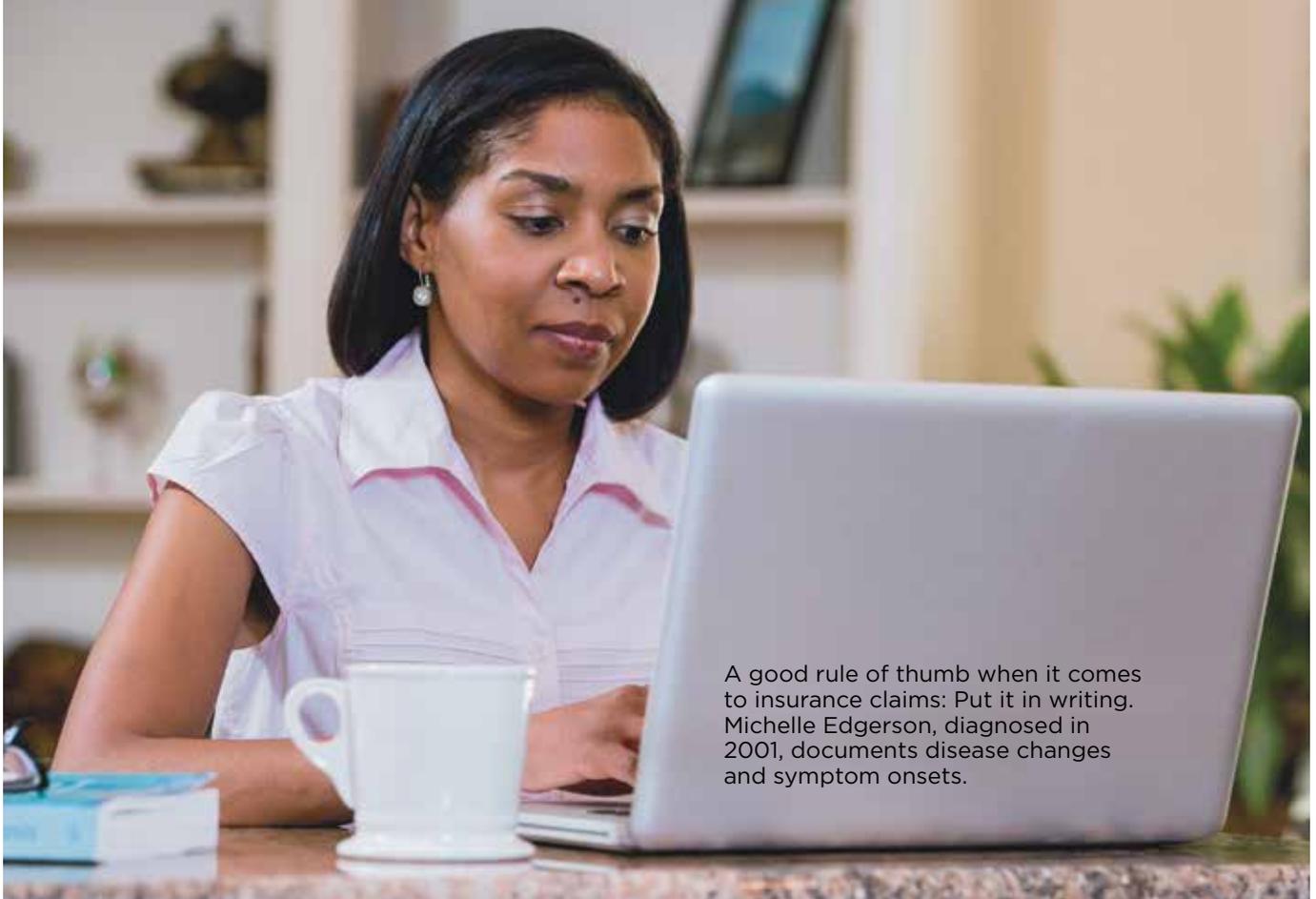
However, certain approaches can make a big difference. Keeping a detailed, accurate diary of your symptoms and responses to treatments may help get a claim paid or a denial reversed. And in this new world of patient responsibility and evidence-based medicine, doing so could be critical.

Many medications and durable medical equipment for MS require prior authorization from the insurance company, and much of the burden falls on healthcare providers to submit medical information [to the insurance company] to support that, says Kathy Costello, MS-certified nurse practitioner and member of the National MS Society's healthcare access team.

“Healthcare providers must provide documentation that includes the diagnosis, the need—particularly for durable medical equipment—what has already been tried, what happened, and the reasons if they need to change to something else,” she says. “So it’s important to make sure you’ve told your provider very specifically what your



Lynda Hartley's notes in her day planner detail her MS symptoms and medication side effects.



A good rule of thumb when it comes to insurance claims: Put it in writing. Michelle Edgerson, diagnosed in 2001, documents disease changes and symptom onsets.

symptoms are and how they're affecting your daily life," Costello says. A good way to do that is to keep a detailed written log that you can bring to your medical appointments.

### The diary details

Lynda Hartley of Boise, Idaho, spent 33 years working in the claims department at Blue Cross of Idaho Health Services before she retired. She was also diagnosed with MS in April 2015 at age 69, so she has seen the process from both sides.

Hartley had been reading through template letters that the Society provides healthcare professionals and people with MS for preauthorization requests and appeals of denials to insurers when she spotted a preauthorization request for a motorized wheelchair or scooter. She noted that the letter contained a comment about the patient "having some good days."

"That could be a red flag for many insurance companies," Hartley says, because the phrase is vague. The comment possibly implies that the person can walk,



PHOTO COURTESY OF LYNDA HARTLEY

Lynda Hartley

and leads an insurance reviewer to think a walker would be better and less expensive than a motorized scooter, resulting in a denial. "The patient needs to be specific," Hartley emphasizes. For example, if a person tells her doctor she had such intense pain that she couldn't walk for a certain number of hours on specific days, "those are the notes that the doctor [should be] sending to the insurance company," Hartley says.

Hartley began to write down her own treatments and symptoms. She now keeps track of her injections and makes notes of any symptoms or side effects

she experiences. She also keeps records throughout the week about symptoms like fatigue or pain. "I write down little notes in my day planner about how I was feeling, and what I was doing at the time, and bring them to my doctor," she says.

Logs might include specific symptoms, time and date, duration, severity, stress level, energy level, physical activity, food intake and other issues or observations. It's particularly important to keep track of any new symptoms

that last 24 to 48 hours, how the symptoms affect you and what they prevent you from doing, Costello says.

Such logs can take a variety of formats. Some people use existing paper-based journals or diaries, while others download symptom trackers from the internet (for example, [nationalMSSociety.org/symptomtracker](http://nationalMSSociety.org/symptomtracker)) or use apps on their phones or tablets. Some, such as MS Self for iPhone, let you track symptoms and medications as well as factors like mood and energy. Others, like My MS Manager for both iPhone and Android, track symptoms and medications, and store medical information. Visit the Apple or Google Play store to review and download these and other apps—and find what’s right for you.

## Dealing with denials

Keeping good records becomes even more important if you are appealing a denial of coverage by your health insurer, particularly if a company denies coverage for a more expensive medication in favor of a cheaper one, says Jennifer Obenchain, clinical team lead, patient services division, at the Hampton, Virginia-based Patient Advocate Foundation.

“You have to have documentation: The patient can’t take this medication for these reasons,” Obenchain says. “The more information healthcare providers can give, the easier it is for the insurance company to understand what’s going on and why they’re asking for this,” she adds.

Kim Calder, director, Health Policy, at the National MS Society, recalls a case where an individual had been taking an injectable disease-modifying treatment for a number of years, ultimately developing injection fatigue. The man’s skin also was scarred and bruised from the injections. “So he just basically stopped. Then his MS started getting worse.” The man’s doctor prescribed an oral medication to replace the injectable, but the insurance company refused to cover it. The man appealed the decision, using photos he had taken to document his damaged skin. The result: “It worked,” Calder says.

His use of the oral medication was approved.

## Medical equipment details

Documentation is perhaps more important now than ever before, Calder says, because in today’s healthcare climate, most insurers pay only for proven strategies. Medications

must be approved by the Food and Drug Administration. That approval, in turn, occurs only when scientific evidence from clinical trials shows that the medication is helpful.

But when it comes to durable medical equipment (DME), comparable studies may not exist. “If you want to argue that Mrs. Jones needs this hospital bed because she can’t get out of bed herself, I don’t know if there are studies for that, so it’s difficult to make the case that it should be paid for,” Calder says. “That’s when it’s very helpful to have accurate information about an individual’s symptoms.”

While these concerns arise whether someone has commercial insurance or Medicare, “the rules are much stricter for Medicare, especially for DME,” Costello says. “If someone needs some type of wheeled mobility, Medicare wants to know if the person needs it in the home as well as in the community. It’s very important to submit medical documentation that supports that need.”

Keeping track of symptoms can also be helpful if you need to support requests for job accommodations, file a private disability claim or file for Social Security Disability Insurance.

Hartley notes that even if it doesn’t ultimately get her insurance to cover DME or other needs, she values her log anyway. “I like to keep track of my symptoms because I’m new to MS and am not sure I’d recognize a relapse,” Hartley says. “When I go to see the doctor, I can take my notes in and we can talk about what’s really happening with my disease.” ■

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Jane Hoback is the new editor of **Momentum** magazine.

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For more information, visit [nationalMSSociety.org/healthinsurance](http://nationalMSSociety.org/healthinsurance) and [nationalMSSociety.org/healthinsuranceappeals](http://nationalMSSociety.org/healthinsuranceappeals).



The Patient Advocate Foundation also offers free assistance at [patientadvocate.org](http://patientadvocate.org).

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

# Finding care away from home

Considering your needs, options and goals can help you outline your choices—and reduce anxiety.

by Lori De Milto

Judy Youngclaus didn't want to leave her home. But when her multiple sclerosis got worse and she needed help with things like transferring from her wheelchair to the bed or toilet, Youngclaus knew it was time to think about moving to a nursing home. "I was no longer able to do the things I used to do, and I needed a lot more help," she says.

Youngclaus, who was diagnosed with MS in her 30s and is now 70, moved to the Boston Home, a National MS Society Center of Excellence in Long-term Care, in 2011. Now, Youngclaus participates in a writing group and a book club, plays cribbage and other games, and goes on trips to Red Sox games, plays and restaurants. "After a week or two, I thought that this was the best place I could ever be," she says.

The Boston Home is one of a handful of nursing homes nationwide that specializes in caring for adults with MS. Most people with severe MS who need assistance with activities of daily living move to a regular nursing home, where they are younger and



PHOTO COURTESY OF JUDY YOUNGCLAUS

Judy Youngclaus



PHOTO COURTESY OF INGLIS HOUSE

Resident Nicholas "Ty" Klug paints at Inglis House in Philadelphia, a nursing home that is geared to people with MS and other disabilities.



PHOTOS COURTESY OF INGLIS HOUSE

Sisters Ashley Murphy-Moore, left, and Ebony Moore are residents at Inglis Gardens at Belmont, an independent living community.

Inglis House holds the Keen Games, its version of the Olympics. Each year, more than 150 residents compete in a variety of games, such as wheelchair slalom, precision throw, bowling and more.



For advanced care information, visit [nationalMSSociety.org/advancedcareneeds](http://nationalMSSociety.org/advancedcareneeds) or connect with an MS Navigator at [nationalMSSociety.org/navigator](http://nationalMSSociety.org/navigator).

more active mentally than most residents. Staff members at many nursing homes don't have experience providing the more specialized care that people living with MS need, but some are willing to learn.

### Challenges of independent living

When MS progresses, family members can't always provide the physical help needed for independent living at home. While assisted living is occasionally an option, some people need more help than assisted living provides, such as skilled nursing care.

Staff members in nursing homes have the training and experience to help people transfer safely from a wheelchair to the bed, toilet or shower, and help with activities like dressing and eating. Plus, they're available 24/7. Nursing homes also offer a variety of rehabilitation and recreational therapies.

Relief from isolation is another reason to make the move. "It can be very isolating at home if you can't get out, and your spouse or caregiver is only there part time," says Marva Serotkin, CEO of The Boston Home.

Progressed MS can cause swallowing problems, breathing problems, skin breakdown (including pressure sores caused by sitting or lying most of the day), urinary tract infections and other health problems that require professional care, which a nursing home can provide.

Linda Litton, 56, moved to Inglis House in Philadelphia in 2015 after repeated falls. "In the beginning, I could crawl to something, lean on it and get up. Over time, I would just lie on the ground and wait for my neighbor or my husband, and if they weren't available, the fire department," says Litton, who has been living with MS since she was 39. Inglis House is also one of the few nursing homes in the U.S. for people with MS and other disabilities, and another MS Society Center of Excellence in Long-term Care.

Thinking about moving to a nursing home can seem scary and stressful. But the time to do it is before you have to move. "Once you have a plan that gives you choices down the road, it's a whole lot easier to function and cope," says Gavin Kerr, president and CEO of Inglis.



PHOTO COURTESY OF LINDA LITTON

Linda Litton, who has been living with MS for more than 15 years, decided to move into Inglis House after repeated falls and challenges getting back up.



Mary Czyzyk uses her iPad in her room at Inglis House.

## Checklist for MS care and activities at nursing homes

- Are there younger residents?
- Are there other people with MS?
- Do residents seem to be happy and well cared for?
- Do staff members seem to enjoy spending time with and caring for residents?
- Are staff members willing to learn more about caring for people with MS?
- What activities are available?
- Is transportation available to go into the community (e.g., for shopping and events)?
- What opportunities are available to stay engaged in the community?
- Is the physical facility clean, pleasant and accessible to power wheelchairs and other mobility equipment?

Youngclaus first met with the staff from The Boston Home a few years before she moved there. At that time, she was using a walker and lived independently. When Youngclaus needed more help, she went to another nursing home for about seven months before a spot in the Boston Home opened up. That's common, especially if you have Medicaid, as many people living with MS in nursing homes do. Some people have long-term care insurance.

While it's never an easy decision, most people adjust to life in a nursing home, especially if the facility "pays attention to your unique needs and provides a socially rich environment," says Debra Frankel, a National MS Society staff member who specializes in healthcare access initiatives. Frankel also notes that family relationships may improve when family members no longer are primary caregivers. Without the stress on the caregiver to be constantly available and do very physical work, and without the person with MS having to depend on the family member, they can go back to a more normal family relationship.

"My stay at Inglis House is fulfilling," says Litton. "I like to be as independent as I can, but I can also get the extra help that I need." If Litton drops or can't reach something, for example, or she needs assistance setting up her computer or using the toilet, someone is available to help her, and she has access to nurses 24/7. She also likes being able to have physical therapy right at Inglis House. Litton has made many friends there and participates in activities like trivia, word games, a weaving class, and trips to stores and restaurants.

### Age-appropriate care

Some 88 percent of nursing home residents are 65 or older, and 45 percent are 85 or older, according to the AARP Public Policy Institute. In contrast, the average age of residents is 54 at Inglis House and 57 at The Boston Home. People with MS who are living in nursing homes need interesting activities and access to transportation so they can get out into the community. But they also need more specialized clinical care, such as help managing spasticity and cognitive issues that are quite different

## 5 keys to independent living

1. Safe, affordable, accessible housing
2. Access to healthcare by professionals who understand the needs of people with MS
3. Support for daily living (from family and friends or paid caregivers)
4. Engagement in life
5. Access to transportation



PHOTO COURTESY OF INGLIS

The Inglis Resident Council is composed of (from left) Nicholas “Ty” Klug, Linda Litton, Susan Ginyard-Loving and Mary Czyzyk. All have MS. They are shown with John Scott (standing) of the National MS Society during Inglis’ 140th anniversary celebration in May.

from dementia, which staff members at many nursing homes don’t have experience providing. “Finding age-appropriate care and people who understand MS is a challenge,” says Frankel. “Visit several nursing homes, and ask a lot of questions.”

While there are only a few nursing homes like The Boston Home and Inglis House nationwide, other nursing homes may have units or programs for younger adults with chronic conditions or disabilities. An MS Navigator—an information, referral and support service from the Society—can help you learn about options in your community.

“Have an open mind. If there is a nursing home administrator and nursing director who are open to learning more about how to take care of people with MS and helping you find age-appropriate activities, that nursing home may be an option. The National MS Society can provide training and materials for nursing home staff,” says Frankel.

Serotkin suggests talking to the director of nursing and notes that even at The Boston Home, staff members continue to learn a lot from residents about their needs. She also suggests chatting with other people living with MS about their experiences in nursing homes. “Find the best place where you’ll be able to have a satisfying life,” says Litton. ■

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

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To find and compare nursing homes and get information about inspections, staff and quality measures, visit [medicare.gov/nursinghomecompare/search.html](https://www.medicare.gov/nursinghomecompare/search.html).



Your Guide to Choosing a Nursing Home or Other Long-Term Care, Centers for Medicare & Medicaid Services, includes a nursing home checklist on pages 26–32. Learn more at [medicare.gov/Pubs/pdf/02174-Nursing-Home-Other-Long-Term-Services.pdf](https://www.medicare.gov/Pubs/pdf/02174-Nursing-Home-Other-Long-Term-Services.pdf).

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

FOR RELAPSING FORMS OF MULTIPLE SCLEROSIS (MS)

**HEY MS,  
WE'D RATHER  
CALL THE SHOTS,  
NOT TAKE THEM.**



GILENYA Guides are people with experience fighting back against relapsing MS with GILENYA. They have been compensated for their time.



**Thinking about a different treatment option?**

Think about this: GILENYA® is the only once-a-day\* pill proven to cut relapses by more than half. In a 1-year study, it reduced the number of relapses by 52% vs a leading injectable and, in a 2-year study, by 54% vs placebo.

**Here's another reason to consider GILENYA:**

**More people who started on GILENYA stayed on GILENYA** compared to people taking injectables†



In a separate study, 352 people out of 433 (81%) who started GILENYA were still taking it 1 year later, but only 125 people out of 428 (29%) who started on an injectable were still sticking with it. At the start of the study, everyone was taking either GILENYA or an injectable MS therapy.

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

**IMPORTANT SAFETY INFORMATION** You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, 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 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.

\*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.

†Interferon beta or glatiramer acetate.

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

Connect with the community and tell your MS to **"Take This!"**

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## IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

- Slow heart rate, especially after first dose. You will be monitored by a health care professional for at least 6 hours after your first 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 feeling dizzy or tired or feeling like your heart is beating slowly or skipping beats. 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. 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 before you start GILENYA. GILENYA may decrease the way vaccines work in your body, especially the chicken pox vaccine. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if 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. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with thinking, eyesight, strength, balance, weakness on 1 side of your body, or using your arms and legs.
- 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 may be 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 occurred rarely in patients 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 headache, confusion, seizures, loss of vision, or weakness.
- 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.
- A type of skin cancer called basal cell carcinoma (BCC). Talk to your doctor if you notice any skin nodules (shiny, pearly nodules), patches or open sores that do not heal within weeks. These may be signs of BCC.

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. Women who take GILENYA should not breastfeed, as it is not known if GILENYA passes into breast milk. 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](mailto: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; 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.

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. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while taking GILENYA and for at least 2 months after stopping GILENYA treatment.

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.

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.**



**BRIEF SUMMARY**  
**GILENYA® (je-LEN-yah)**  
**(fingolimod)**  
**capsules**

Read the Medication Guide before you start using GILENYA 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 health problem or treatment.

**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 (ECG) before you take your first dose of GILENYA.

**You will be observed by a healthcare professional for at least 6 hours after you take your first dose of GILENYA.**

After you take your first dose of GILENYA:

- Your pulse and blood pressure should be checked every hour.
- You should be observed by a healthcare 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
- 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 healthcare 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 and decrease the way vaccines work in your body to prevent certain diseases, especially the chicken pox vaccine. 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 before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:

- fever
- tiredness
- body aches
- chills
- nausea
- vomiting
- headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion (these may be symptoms of meningitis)

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. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with:

- thinking
- eyesight
- strength
- balance
- weakness on 1 side of your body
- using your arms and legs

4. **A problem with your vision called macular edema.** Macular edema can cause some of the same vision symptoms as an 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 may be 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. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

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

**Who should not take GILENYA?**

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or warning stroke 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 (hypersensitive) to fingolimod or any of the other ingredients of GILENYA listed at the end of this medication guide. Allergic reactions, which could include symptoms of rash or itchy hives, swelling of lips, tongue or face, are more likely to occur on the day you start GILENYA treatment but may occur later. If you think you may be allergic, ask your doctor for advice.

If any of the above situations apply to you, tell your doctor.

**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 warning 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 taking medicines that lower your immune system. Tell your doctor if you have had 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.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure
- a type of skin cancer called basal cell carcinoma (BCC).
- 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. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

**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.

Especially tell your doctor if you take vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.

#### How should I take GILENYA?

- You will be observed by a healthcare professional for at least 6 hours after your first dose of GILENYA. 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 healthcare professional for at least 6 hours when you take your next dose. If you need to be observed by a healthcare 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 healthcare 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.

See “**What is the most important information I should know about GILENYA?**”

Serious side effects include:

- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients 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 headache
  - confusion
  - seizures
  - loss of vision
  - weakness
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.

- **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
  - vomiting
  - stomach pain
  - loss of appetite
  - tiredness
  - your skin or the whites of your eyes turn yellow
  - dark urine
- **a type of skin cancer called basal cell carcinoma (BCC).** Talk to your doctor if you notice any skin nodules (e.g., shiny pearly nodules), patches or open sores that do not heal within weeks (these may be signs of BCC).

The most common side effects of GILENYA include:

- headache
- abnormal liver tests
- diarrhea
- cough
- flu
- sinusitis
- back pain
- abdominal pain
- pain in arms or legs

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.

#### General information about GILENYA

Medicines are sometimes prescribed for purposes other than those listed in a Brief Summary. 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 you have. It may harm them.

This Brief Summary contains 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 healthcare professionals.

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

#### What are the ingredients in GILENYA?

**Active ingredient:** fingolimod

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

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## Beauty for all to behold

The awe-inspiring national parks do not disappoint. Thankfully, for nature lovers, the most famous ones—Grand Canyon, Rocky Mountain, Yellowstone and Yosemite—are “user-friendly” to wheelchair and scooter users. All have accessible trails, as do many other national preserves, recreation areas, lake shores, scenic trails and forests. The National Park Service offers an “Access Pass” for people with permanent disabilities and their families. Visit [nps.gov](https://www.nps.gov) for details on how to apply. Learn more about traveling with MS on **p. 26**.

# thrive

Forging a path  
to your best life

Inside this section: Globe trotting 26 // No shame 34

# Globe



# trotting

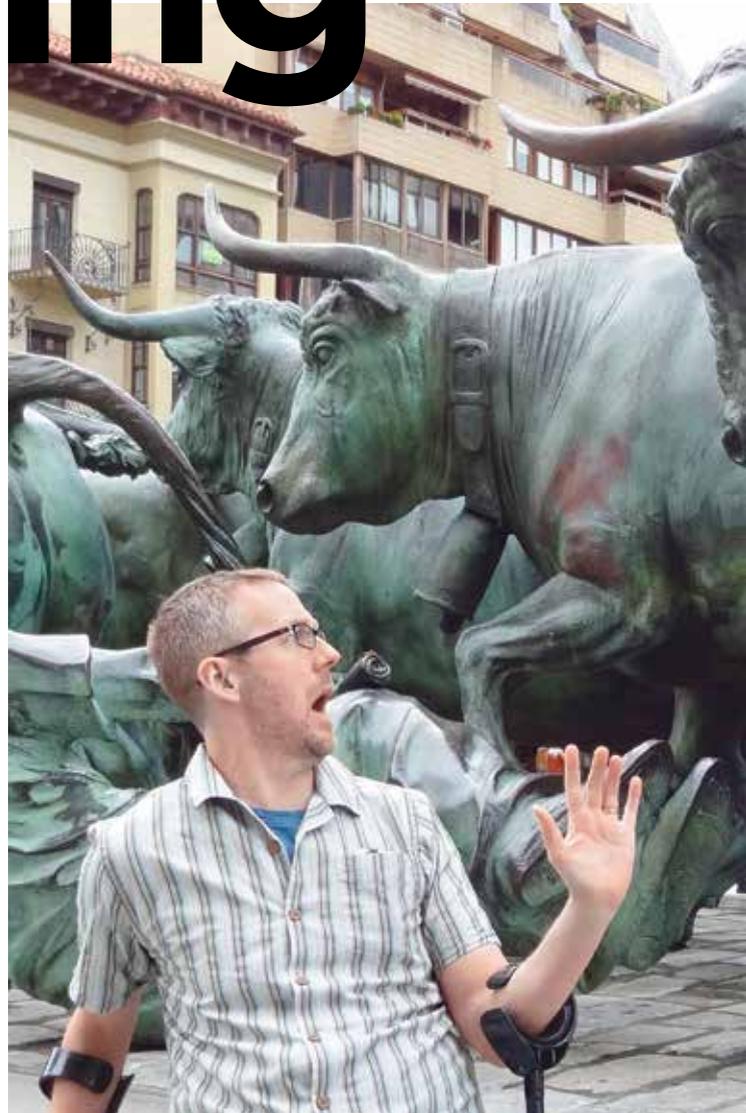
With some planning, people with MS can travel anywhere in the world.

by Vicky Uhland

**B**y any standard, Dave Bexfield's globe-trotting résumé is impressive. The 49-year-old Albuquerque, New Mexico-based founder of the nonprofit website **ActiveMSers.org** has traveled to more than 50 countries—30 of them since he was diagnosed with multiple sclerosis in 2006. In fact, in the seven years since his disease has progressed to the point where he regularly uses a wheelchair, Bexfield and his wife, Laura, have visited 17 countries, including places like Peru, Turkey and Russia that aren't known for their accessibility.

Along with the usual travel woes like misplaced hotel reservations and flight cancellations, Bexfield has experienced an MS flare-up while on the road. In 2009, when he and Laura were in Venice, Italy, an exacerbation left Bexfield's legs so weak that he was unable to walk. He immediately called his neurologist and swapped his sightseeing plans for time spent relaxing in his hotel's garden, watching the gondolas go by. When Bexfield regained some mobility, his travel agent called the Italian MS Society, which arranged to lend him a wheelchair. With a few tweaks to their plans, Dave and Laura were able to continue—and enjoy—the rest of their three-week trip throughout Italy.

"I've learned that I can manage to go to any place on this planet—it just might take more planning and flexibility," Bexfield says.



PHOTOS COURTESY OF DAVE BEXFIELD



But even an experienced traveler like Bexfield recognizes the potential perils of leaving home with MS—whether to a destination 10 or 10,000 miles away. “The night before I go on a trip, I’m always a ball of nerves, with all kinds of ideas about what can go wrong,” he says. “But I’ve realized that not only can I travel with MS, there are even some advantages.” For instance, because he was using a wheelchair after his 2009 exacerbation in Italy, he and his wife were given free tickets to the Vatican—entry fees to tourist sites are often waived for people with disabilities—and whisked in through a VIP entrance. They arrived at the Sistine Chapel before it opened to the rest of the public, and viewed Michelangelo’s masterpiece all by themselves.

Bexfield came up with his travel motto that day: *carpe diem*, or seize the day. Here’s what he, other travelers living with MS, travel agents who specialize in trips for people with disabilities, and healthcare professionals advise that people with MS do to successfully seize their own travel moments.

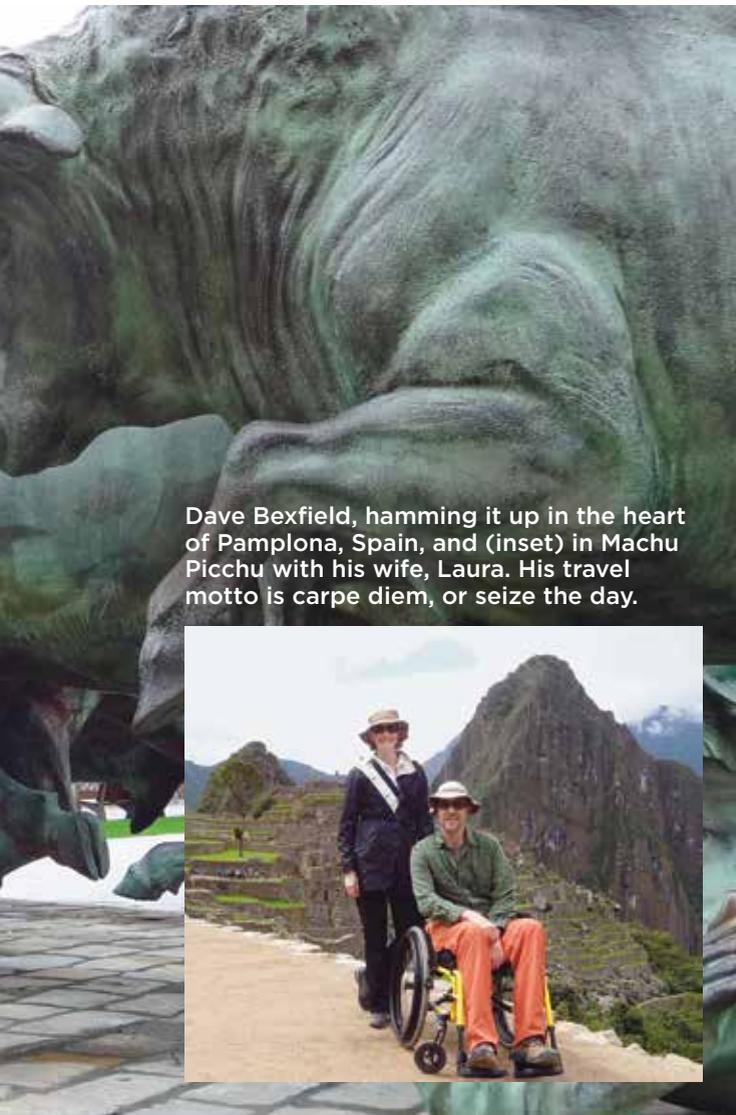
### Start small

Tarita Davenock, who was diagnosed with MS in 1995 and later founded Travel For All, an agency in British Columbia, Canada, specializing in accessible travel, says it’s possible for people with MS to travel almost anywhere in the world.

“I’ve sent people who use a wheelchair to Nepal,” she says. “I tell them don’t let the fear of potentially having a new symptom or an exacerbation when you’re away from home stop you from traveling.”

That said, Davenock admits it’s “still a little bit scary for me to travel,” primarily because of mobility issues—she uses a wheelchair—and occasional brain fog. But she believes one of the best ways to help reduce travel fears is to start small. While Machu Picchu or the Great Wall of China may be on your bucket list, you will feel more confident if you work your way up to challenging destinations.

“Try starting out with a weekend trip like a wine tour,” Davenock says. “That gets you used to not sleeping in your own bed or having your home bathroom.” Then consider a longer vacation in the U.S. or Canada, where the healthcare professionals speak your language and accessibility is less of an issue. In the U.S., the



Dave Bexfield, hamming it up in the heart of Pamplona, Spain, and (inset) in Machu Picchu with his wife, Laura. His travel motto is *carpe diem*, or seize the day.





Tarita Davenock, with her husband, James, by the marina in Nanaimo, a city on Vancouver Island in British Columbia. She owns a travel agency specializing in accessible travel.

PHOTOS BY RIKU PHOTO

Americans with Disabilities Act guarantees equal access to transportation like Amtrak and public city buses, while the Air Carrier Access Act governs the rights of people with disabilities when it comes to air travel.

John Sage, who founded Houston-based Sage Traveling after he suffered a spinal cord injury in 2001 and began using a wheelchair, says when you're ready to go abroad, a Caribbean cruise can be a good first trip. The plane trip to your embarkation destination doesn't take long, cruise ships have accessible staterooms and elevators, they're relatively easy to navigate if you have cognitive or vision issues, there's a doctor on board, and if you're feeling fatigued, you can skip the shore excursions. A magnetic wristband or medication to prevent motion sickness can address minor vertigo.

If you prefer to be on land rather than the sea, Bexfield recommends taking one of your first voyages to a city that has hosted the Paralympics. "Places like London, Barcelona, even Rio, are going to have a lot of accessibility features," he says.

Bexfield tends to avoid group tours—even ones that specialize in disabilities—because of the unique nature of MS symptoms. "MS is such a funky disease. Some people do fantastic in the mornings but they crash in the afternoon, or vice versa," he says. "A tour may not be set up to accommodate that." One option is tours for seniors, which usually go at a slower pace. Sage and Davenock say they can also tailor tours to one's specific MS symptoms.

Travel agents can be a good resource if something goes wrong. After Bexfield's exacerbation in Italy, his travel agent called the hotel the Bexfields were planning to stay

at in southern Tuscany, and the innkeeper went down to city hall to get a temporary handicapped parking pass so they could park virtually anywhere inside the walls of the hill town.

Travel agents can also advise you about the best trip cancellation or travel insurance should a medical issue keep you from going on your journey. They can help you find a healthcare professional at your destination or, worst-case scenario, get you airlifted home. If you don't use a travel agent, find out before you leave home if the country you're visiting has an MS organization that can provide assistance—most European and South American countries do. And if you're in a real pinch, you can always contact the American consulate in any country.

While people with MS may have reservations about the demands of group tours, when you're visiting a new city, Sage recommends booking a private guided tour the first day. Not only will you get an overview of the area, but you can also ask the guide questions about things like public restroom locations; accessibility of monuments, museums or restaurants; or even the best place to cool off on a hot day.

### Healthcare on the go

When it comes to medical issues, a little preplanning can save a lot of potential hassle during your trip. Barbara Giesser, MD, medical director at UCLA's Marilyn Hilton MS Achievement Center, says it's best to inform your healthcare providers before you hit the road. If you're traveling by plane, ask for a note from your doctor stating that you have MS and will have medication and injection

supplies in your carry-on bag. It's not a good idea to pack medications in bags you plan to check, in case your luggage is lost.

If you're traveling to a region where you need a vaccination, it's important to ask your doctor if your medications will interfere with the effectiveness of the vaccine. "In general, people with MS are advised to avoid live vaccines," Dr. Giesser says. This may include vaccines for tuberculosis, measles or yellow fever.

Your doctor may give you a prescription for extra medication in case you lose some on the road or if your trip is extended. And Dr. Giesser says if you'll be traveling in a remote region where healthcare isn't readily accessible, some neurologists will give you a prescription for oral steroids in case you have an exacerbation.

You should also ask your doctor if any of your medications need to be refrigerated during your trip. Bexfield advises putting temperature-sensitive medications in a small soft-sided cooler that contains a gel ice pack. He recommends packing a few digital thermometers as well, to check the temperature in your hotel refrigerator or minibar so you don't inadvertently freeze your meds. Don't have a fridge? Bexfield says most hotels will deliver a portable one to your room if you ask.

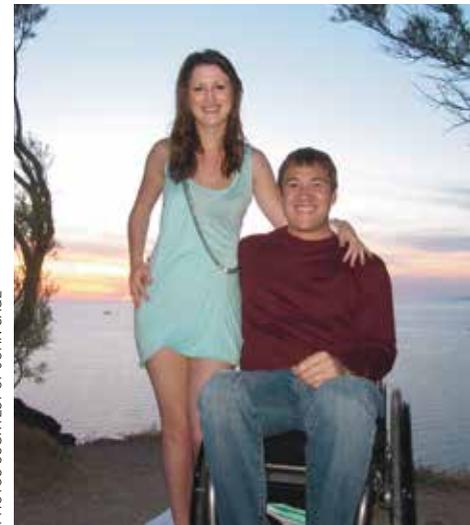
If you have limited balance, strength or endurance, Amanda Rohrig, a physical therapist (PT) with Horizon Rehabilitation Centers in Omaha, Nebraska, recommends consulting with a PT prior to your trip. "A physical therapist who understands MS will help you to strategize—not dread—travel opportunities," she says.

And don't forget to make sure your health insurance has reciprocity in other states or countries, says Laura Kingston, an occupational therapist at Providence St. Vincent Medical Center in Portland, Oregon. If it doesn't, she recommends buying travel insurance from a reputable company like AAA. Bexfield is a fan of AIG Travel Guard. In fact, he had travel insurance during his exacerbation in Italy. "Calling my neurologist immediately after it happened turned out to be important to get reimbursed by my travel insurance," he says. "They needed confirmation that it was a medical emergency and not just a change of heart or oversleeping."

### Travel hacks for specific symptoms

Because people with MS have varying symptoms, there are no one-size-fits-all travel recommendations. Instead,

John Sage, founder of Sage Traveling, believes any travel is possible with preparation. Here he is (clockwise from left) with his wife, Tiffany, in Santorini, a Greek island, where they got engaged in 2010; in Tuscany, Italy; and snorkeling in the Caribbean, near the island of Bonaire, in 2014.



PHOTOS COURTESY OF JOHN SAGE

it's best to plan your trip to accommodate your main symptoms. Here's what experts suggest.

**Fatigue or pain.** When Pam Woods was diagnosed with MS in 2003 at age 38, she refused to let her disease interfere with her travel plans. "I truly believe wanderlust is part of my genetics," she says. So she and her husband, Darren, continued to travel around the U.S. and Europe despite weakness in her left leg, foot drop, fatigue and bladder issues. But in 2012, she had a big flare-up and went on disability. "I started thinking what happens if I'm in my 60s or 70s, and my MS gets worse and I can't travel?" she says. So she and Darren sold their house and traveled in Europe for a year.

Woods calls their journey, which was designed to accommodate her fatigue and mobility issues, "slow travel." She and Darren would pick a city they wanted to stay in and rent a place for a month through Airbnb or another vacation-home site. Then they would take day trips to nearby destinations. "By forcing me to slow down, MS allowed me to experience a place like a local," Woods says. She could also come home for naps and cook her own healthy meals.

Even when she's on a short vacation, Woods is still a fan of slow travel, although she admits it takes some mental adjustments. "I have to let go of my expectations that I need to see or do everything," she says. Instead, she will take a rest day while her husband goes sightseeing. "It gives him a break from being a caregiver and lets him go at his own pace. While being left behind



is hard, I enjoy hearing Darren's stories of what he saw."

Woods also uses her rest days to plan her sightseeing expeditions. For instance, she knows museums can be fatiguing, so she prioritizes what she wants to see. Many national and international museums have free wheelchairs for patrons, but Woods cautions that they're usually first-come, first-served, so it's best to arrive early.

Woods likes to build in rest days before and after long travel days. Kingston also advises setting aside a few hours each day to rest, particularly during hot afternoons. And if personal grooming or bathing is fatiguing, Kingston suggests showering at night. "This helps you conserve some energy in the morning for other activities," she says. Or consider scheduling sightseeing trips only in the afternoon, to allow you to recuperate from morning ablutions.

If your destination requires a long plane, train or car trip, Davenock suggests breaking it up into less-tiring



chunks when possible. Fly for a few hours, for instance, and then stay overnight in a hotel before continuing on.

**Mobility issues.** Sage, who has navigated hundreds of miles of European cobblestone streets in his wheelchair, says virtually anywhere can be accessible if you do your homework. "To help alleviate anxiety, plan a trip that meets

your highest level of accessibility needs," he says. That includes scouting out transportation, hotels, restaurants, museums and other sights before you leave home. But because people have different definitions of "accessible," ask for photos or, ideally, a video of hotel rooms, bathrooms, elevators and building entrances. A travel agent or tour guide that specializes in disabilities can also provide this information.

And don't forget to research whether a hotel is in an accessible, centrally located part of town. Sage suggests

using Google Maps' Street View to see whether a property is surrounded by hills, stairs or other accessibility nightmares. Also consider choosing a hotel with room service for times you're too fatigued to go out to a restaurant.

Once you find an acceptable hotel, Sage recommends booking it as much as six months in advance, especially if your trip is during the high season. "A lot of hotels in Europe have only one or two accessible rooms, and they get reserved quickly," he says.

Rohrig says even if you don't use a cane or walker at home, consider taking them with you on your travels. "They may be helpful in unfamiliar circumstances, and they can improve your ease, safety and mobility so you can concentrate on enjoying your experience."

Bexfield likes to bring multiple walking aids in case he loses one or finds that it doesn't work well on certain terrain. He's also a fan of foldable wheelchairs for their portability. And don't forget a bungee cord to secure the chair on public transportation such as a bus or train. If you need to navigate rough surfaces throughout your trip, Bexfield suggests all-terrain wheelchairs equipped with off-road tires and even shock absorbers. If you prefer a scooter, Sage says they're usually easy to rent in advance through Special Needs Group ([specialneedsatsea.com](http://specialneedsatsea.com)), which delivers and picks them up at your destination in the U.S. or abroad.

Above all, Bexfield says, check your ego along with your luggage. "I've taken a cab ride for 100 meters because I was just too fatigued to walk," he says. "I've hired porters to carry me at Machu Picchu. Is someone staring? Who bloody cares!"

**Bladder or bowel issues.** Woods and Bexfield agree that wearing protective undergarments and carrying an extra change of lightweight clothing are key when you're on the road. Smartphone or tablet apps like Flushd, SitOrSquat and Airpnp will tell you where the nearest restroom is. Sage has also been known to make a quick detour into an American fast-food restaurant, which will usually have an accessible restroom no matter which country it's located in.

For future trips, Woods is considering an RV because she would always have a bathroom with her. But for now, when nature calls and there's no public restroom nearby,



PHOTOS COURTESY OF PAM WOODS

she depends on the kindness of strangers. "I've found that in almost any place, if you appear desperate, they'll rush you to the bathroom even if it's not public," she says.

**Heat sensitivity.** This is one of Bexfield's main symptoms, so he's done quite a bit of research on cooling vests that perform well on the road. His favorite travel vests are those that recharge in an ice-filled cooler (Glacier Tek: [glaciertek.com](http://glaciertek.com) or ThermApparel: [thermapparel.net](http://thermapparel.net)) or at room temperature (First Line Technology: [firstlinetech.com](http://firstlinetech.com)).

Bexfield also likes to travel during the fall or spring because temperatures are cooler. If he does travel in the summer, he packs a sun-safe travel umbrella to provide shade and relief from the heat. (Gustbuster umbrellas are his favorite: [innovagolf.com](http://innovagolf.com).)

And, of course, always look for hotels with air conditioning or, at the least, windows that open.

**Cognitive issues.** Whether you're traveling with others or alone, Davenock recommends making a copy of your itinerary and contact information, and putting it in a secure pocket in your clothing in case you get lost or forget where you're going. Taking photos of your hotel address, room number, street signs or other landmarks can

Pam Woods takes time to enjoy the places she visits, calling it “slow travel.” She and her husband, Darren, took a detour from their trip along Route 66 (inset) to spend a few days at the Grand Canyon in Arizona.



also be a good memory aid. And Sage recommends having a backup plan in case something goes wrong. Hotel construction, train strikes or inclement weather can mean your original plan needs quick modification.

While it’s helpful to know the language of the country you’re visiting, English is so universal that even in the hinterlands you’ll likely find someone who can speak enough to help you. Another option is to use a translation app like Google Translate or iTranslate.

Museums and other tourist attractions can be loud and overwhelming to the senses. Bexfield recommends visiting early, when most tourists are sleeping in, and only staying for a couple of hours. In fact, consider planning your trip during the offseason, when there will be fewer tourists overall.

And finally, think positively. “What I would have loved to have heard when I was first injured was about all of the places that are possible, rather than impossible, for people with disabilities,” Sage says. “There are tons of places that someone with MS can visit.” ■



Visit **nationalMSsociety.org/travel** for more tips and information.

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

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

# No shame

MS symptoms can be embarrassing sometimes, but there are positive ways to cope.

by Olivia Cole

**W**hen Lisa Kemppainen, a psychotherapist in Colorado Springs, Colorado, meets with new clients, she tells them she has multiple sclerosis. That way, if they see her struggling to climb stairs or veering down a hallway like she's drunk, they'll understand why. And she lets them know she might have to abruptly interrupt them during a session and make a quick trip to the bathroom.

But despite these precautions, Kemppainen has defecated in her pants during sessions with clients. "Lots of times I have no warning it's coming, and then it really comes out," she says. "And when I try to change my clothes in the restroom, I'm unstable so I get

poop on my hands, on the floor, on my clothes. It couldn't be more embarrassing."

But Kemppainen, who was diagnosed with MS in 1998, refuses to succumb to shame. "When something embarrassing happens, I have compassion for myself. And I tell myself it's not my fault," she says. "I'm completely the victim of my MS. People don't like to use the word 'victim,' but in this case it's true."

She's seconded by Ann Marie Johnson, a human services professional in Brooklyn, New York, who was diagnosed with MS in 2002. Along with depression, bladder issues and problems with fine motor skills, Johnson has tingling in her upper body that makes her feel like things are crawling on her skin.

"I have long nails that look nice, but aren't so great when I'm scratching intensely. I have scratch marks on my neck and chest that look like I was attacked by a wild animal," she says. "It's so involuntary that I don't notice the type of harm I'm doing to myself."

Johnson was embarrassed about how she looked until she realized that wasn't productive. "I told myself those crawling sensations weren't going away, so I needed to learn how to handle the scratching. I can't control my MS, but I can control how I handle my symptoms."

Unlike more hidden symptoms like fatigue or heat intolerance, "bowel and bladder issues, cognitive changes, and problems with balance and walking can draw attention to you when you don't necessarily want it," says Peggy Crawford, PhD, a clinical psychologist in Cleveland. "They can take away the 'invisibility' of MS." These symptoms also create a Catch-22. "They can be so embarrassing that people don't even bring them up to





Lisa Kemppainen, here on the peninsula in Long Beach, California, and with her son, Isaac, on the adjacent page, sometimes has bathroom accidents as a result of her MS, but it does not prevent her from getting out and enjoying life.

PHOTOS COURTESY OF LISA KEMPPAINEN



Ann Marie Johnson, traveling in India on a birthday trip last year, acknowledges she has bladder issues, and tingling that makes her scratch her skin. She has found ways to manage both problems.

their physician or nurse practitioner, who may actually be able to help them improve those symptoms,” she says.

Here’s how healthcare professionals and people living with MS suggest you not only cope with embarrassing symptoms, but also reframe them so they become less mentally and emotionally distressing.

### Identifying the source

Basically, says Dr. Crawford, embarrassment is a form of anxiety. You may be anxious that people who don’t know that you have MS will jump to the wrong conclusions or judge you. “For instance, people who have problems walking may be accused of using alcohol or drugs,” she says. And then there’s the anxiety that people who know you have MS may give you unwanted advice after they see a symptom that makes you—or them—uncomfortable.

Ironically, being anxious about something can actually increase the likelihood that it will happen, says Deborah Miller, PhD, associate professor of medicine at the Cleveland Clinic’s Mellen Center for Multiple Sclerosis. That’s why she recommends a three-step process to help alleviate that anxiety and embarrassment: Identify the issue, share it with others and work on problem-solving strategies.

Identifying the issue includes not only acknowledging your symptoms, but also examining how you react to them.



PHOTO COURTESY OF GLENN DOMILICI

Glenn Domilici, with his wife, Rhondell, in the Cayman Islands, is less embarrassed than he used to be by some of his MS symptoms, such as memory problems, because he knows he cannot control them.

“Ask yourself, ‘What’s the worst thing that could happen if X, Y or Z symptom occurs? Has that ever happened? Do you know anyone that’s happened to? What are the likely consequences if it does happen—someone makes fun of you at a party? Calls the boss?’” Dr. Miller says. “By thinking of the worst-case scenario and what you would do, you can make a plan that will help alleviate your anxiety. You might even start laughing at what you’re imagining. After all, nobody has ever died of embarrassment.”

Kemppainen says if she feels embarrassed to use a mobility aid like a cane or a scooter, she creates a positive scenario in her mind. “Rather than thinking of strangers judging me, I visualize getting out of my car and walking to my office, and how my friends are walking by and looking at me with a lot of compassion, and celebrating how brave I am.”

Glenn Domilici, a New York City resident who was diagnosed with MS in 2005, has memory issues that sometimes make him lose his train of thought and appear as though he’s not paying attention to the person he’s talking to. But he’s learned to think of this and other symptoms as more frustrating than embarrassing.

“If I’m underdressed at a formal affair and I’m embarrassed, that’s my fault,” he says. “But with MS I have no control over whether my right hand works well, or if I stutter sometimes while I’m talking or if I have to go to the bathroom more often. These things are unavoidable, so it serves no purpose for me to be embarrassed.”

### Acknowledging the issues

The next step is deciding when to discuss your symptoms with others, and how much you want to reveal. “It really depends on whether and how it’s intruding in your life—

like if you dread going to work because you're afraid people are noticing your bladder issues," Dr. Crawford says. "And if other people are changing their behavior toward you, or if a symptom creates a safety issue—like cognitive difficulties that affect your driving ability—then maybe you should disclose."

Kemppainen says there can be unexpected benefits from revealing your embarrassing symptoms. "I've found that people are really empathetic, and it builds trust with them."

But that doesn't mean you need to invade your own privacy, especially with someone who doesn't know you have MS. "When people are embarrassed, they feel like they need to give a full-blown explanation, but they don't really," Dr. Miller says. "Don't lie, but don't feel like you need to go into detail. You can address the symptom, not the diagnosis."

For instance, Drs. Crawford and Miller suggest using phrases like "I've lost my train of thought," or "I have a weak bladder" or "I have a strained knee" or "My stomach hasn't been right all day long."

Or you can use humor, like, "Isn't that amazing, someone my age wetting their pants," Dr. Miller says. "Humor can reduce the other person's anxiety of not knowing what to say."

## Overcoming the embarrassment

"It's too simplistic to say 'don't be embarrassed' when something embarrassing happens," Dr. Crawford says. "But if you practice coping strategies, you can feel more in control of the situation. And you'll feel less embarrassed if you know several options are available to you."

She also advises to not let embarrassment prevent you from talking with your healthcare providers, who often can help manage your symptoms.

For instance, a physical therapist can help with gait or balance issues. Behavioral therapists can give you tools to deal with cognitive issues, like always putting your keys in the same place or developing a shorthand with your spouse when you need help finding a word you've forgotten. Bowel problems, including constipation, can often be treated medically.

Johnson says for bladder issues, she's learned to drink a glass of water or a cup of coffee relatively quickly, rather than taking occasional sips. That way, she stays hydrated

but finds she has to visit the restroom less frequently. "Figure out how soon after you drink something that you have to go," she says. "And then make sure you're near a bathroom during that time period."

For her scratching issues, Johnson has discovered that cutting her nails and carrying lotion that she can rub on the itchy spot can help. And, although it can be challenging to treat these kinds of sensory symptoms, it's a good idea to discuss them with your neurologist. Johnson also shared her problem with her boyfriend, who has learned to take her hand when she tries to scratch, and rub the area himself.

"I had to let go of my ego and ask for help," Johnson says. "I've realized there are so many people who want to be on my journey with me, so I shouldn't be afraid to be vulnerable with them."

Johnson admits this wasn't easy in the beginning. Setting boundaries and maintaining dignity while asking for help with intimate issues can be challenging. "But if you don't tell people in advance what you truly need and instead leave it up to them to choose how to assist you, they may do it in a way you don't want," Dr. Crawford says. For instance, if you need assistance with going to the bathroom, but you don't actually need someone to stay in the stall with you, tell the person that.

Kemppainen has found that her close friends and family like being told how or when they can help. "There's so much guessing with MS that a lot of times people don't know what to do," she says. "I say something like, 'This is one of those moments that I dread. And I'm so sad that I need to ask you this, but can you help me?' And then I tell them what I need. If the person doesn't respond with compassion, you probably should get them out of your life."

The bottom line is that while experiencing a bladder, bowel, balance, gait or cognitive issue in public may never be easy, it doesn't have to be shameful either.

"One of the gifts of MS is that it has taught me that sometimes I just have to get over myself," Kemppainen says. "Nobody really cares if I'm peeing or pooping my pants. What they really care about is me." ■

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Olivia Cole is a writer in Denver.

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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**<sup>®</sup>  
(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)  
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42



# solve

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



## A FISHY SITUATION

The freshwater zebrafish, known for its ability to regenerate fins, skin and even the brain during the larval stages, has proven to be an ideal subject of myelin research. Kelly Monk, PhD, a 2016 National MS Society Harry Weaver Neuroscience Scholar, might agree. She has identified several gene mutations—changes in molecular instructions—that cause specific defects in node structure. Her research could suggest a therapeutic strategy to restore normal myelin function in people with MS. Learn more about how women are making an impact on MS research on [p. 43](#).

# Women at the forefront

Scientists are making remarkable headway in MS research.

by Susan Worley



Dr. Claudia Lucchinetti, who researches the pathology of MS lesions, won the John Dystel Prize for Multiple Sclerosis Research last year.

**R**esearch in multiple sclerosis continues to move forward at a rapid pace, and women are at the forefront of scientific progress in many areas. With few well-defined career paths to follow, they are discovering their own keys to success.

“It’s incredibly rewarding to contribute to the effort being invested in improving treatments for MS, especially when the science is evolving so rapidly,” says Dr. Jiwon Oh, assistant professor of medicine in the Division of Neurology at the University of Toronto and a practicing neurologist at St. Michael’s Hospital in Toronto.

Inspired by personal experiences and encouraged by generous mentors, these four trailblazers are doing cutting-edge research, exploring areas ranging from advanced imaging of lesions to neuroprotection and myelin repair.

## Making things happen

In 2016, Dr. Claudia Lucchinetti became the first woman to receive the prestigious John Dystel Prize for Multiple Sclerosis Research, awarded jointly by the National MS Society and the American Academy of Neurology (AAN). The prize acknowledged her many years of exceptional contributions to the field, particularly with regard to

PHOTO COURTESY OF THE MAYO CLINIC

advancing our understanding of the neuropathology of MS and improving the care of people with MS.

Dr. Lucchinetti was honored by the prize and grateful for the “great teachers and wonderful mentors and colleagues” who played important roles in her career.

But she also notes a critical way she contributed to her own success.

“I really never waited for things to happen in my career,” Dr. Lucchinetti says. “I’ve learned that there isn’t anything passive about pursuing a career in research. To move forward in the field, it’s important not only to be

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**To move forward in the field, it’s important not only to be passionate and take advantage of opportunities placed in front of you, but also to reach out and make new contacts and investigate new possibilities.”**

—DR. CLAUDIA LUCCHINETTI

passionate and take advantage of opportunities placed in front of you, but also to reach out and make new contacts and investigate new possibilities. One factor that consistently shaped my career over the years was my tendency to be proactive and make things happen.”

Excited by a course on antibodies and immunological disorders in college, she sent letters to investigators at the Mayo Clinic in Minnesota, inquiring about opportunities to work in their labs. One letter was addressed to Dr. Vanda Lennon, a pioneer in autoimmune neurology research

Dr. Jiwon Oh, a neurologist, uses advanced MRI techniques to identify markers that may be used as outcome measures in clinical trials of MS treatments.



PHOTO COURTESY OF DR. JIWON OH

and immunology. Dr. Lennon became an important career-long mentor and colleague. In 1983, Dr. Lennon helped arrange a summer research opportunity for Dr. Lucchinetti in the lab of Dr. Moses Rodriguez at the Mayo Clinic.

“While studying a mouse model of MS that first summer, I realized I could combine my interest in clinical neurology with my interest in basic science,” Dr. Lucchinetti says. “I also was lucky that Dr. Rodriguez gave me a good balance of freedom and supervision.”

After graduating from medical school, she returned to the Mayo Clinic as a resident in neurology. Then, in 1994, while she was chief resident, she had a life-altering encounter with a young mother who had a very rare and terminal type of MS known as Marburg’s Variant MS.

“Although she was quite ill during that time, I connected with her on a very personal level,” Dr. Lucchinetti recalls. “I committed myself to studying the pathology of MS lesions (areas of damage in the brain or spinal cord) with the hope of finding effective treatments for all forms of the disease.”

Dr. Lucchinetti recognized another potential research opportunity during her residency while studying biopsied tissues from people with MS that Dr. Rodriguez had collected over the years. After reading about the research of Dr. Hans Lassmann in Vienna, a world leader in

experimental neuropathology, she wrote to him, thus beginning a fruitful collaboration that would help shape her career.

In 2000, Dr. Lucchinetti, Dr. Lassmann and another colleague in Germany, Dr. Wolfgang Brück, published a landmark paper that, for the first time, described four types of lesions, or distinct patterns of myelin destruction, in people with MS. These different patterns of damage to myelin—the material that surrounds and protects nerve fibers in the brain and spinal cord, and which aids in the transmission of nerve signals—were discovered by the team after detailed analysis of tissues from both biopsies and autopsies.

“This had important implications because previously we always treated MS lesions similarly, as if they were all formed the same way,” Dr. Lucchinetti says. “Our work suggested that perhaps there are different mechanisms of injury that warrant different individualized or personalized approaches to treatment.”

Their findings led to the launch of the MS Lesion Project, an international collaborative initiative jointly funded by the Society and the National Institutes of Health. The project brought together a wide range of experts—including pathologists, immunologists and radiologists—with the aim of better understanding the MS lesion and, in turn, improving

treatment of the disease.

The researchers amassed an unprecedented collection of tissue samples from more than 1,000 people with MS, and discovered that unique antibody patterns were associated with different lesion patterns, information that could facilitate some treatment decisions. Dr. Lucchinetti’s work today continues to build on her early studies of MS lesions, as well as another groundbreaking study, which showed that the cerebral cortex, or outermost layer of the brain, is targeted early in the MS disease process.

And with a Collaborative MS Research Center award from the Society, which is supported by The Donald C. McGraw Foundation, Dr. Lucchinetti, together with Dr. Chuck Howe, is now leading a team at Mayo Clinic that is studying nerve cells and possible ways to protect them from MS injury. One approach is to reprogram skin cells from people with MS and turn them into stem cells, then grow them in lab dishes to see if they display abnormal energy processes. This would create “MS in a dish,” enabling close study of the abnormalities and the ability to test therapies aimed at the problem.

### **Drawing inspiration from personal experience**

Dr. Oh was first drawn to the field of neurology for very personal reasons.

“My mother had a stroke while she was in her mid-30s,” she says. “Watching her cope with a chronic neurologic disease at a young age was a formative experience for me. It showed me how a neurologic disorder can completely change the trajectory of a young woman’s life.”

As a young neurology resident, Dr. Oh investigated a number of different neurological subspecialties, including stroke neurology and neuro-oncology, but found she was particularly interested in individuals with MS.

“I met many young women affected by MS, and the challenges they faced really resonated with me,” she says. “In part, that’s because I was a young woman facing challenges related to balancing a career and family, and I recognized how difficult it would be to also have to cope with a chronic neurologic disorder such as MS, and the future repercussions related to a diagnosis of MS.”

As a neurology resident at the University of Toronto, she had exposure to the MS Clinic at St. Michael’s Hospital, one of the largest MS clinics in Canada. She says she was impressed by the rapid changes in MS research.

“MS is one area of neurology in which the field is so dynamic you can actually see it changing right in front of you,” Dr. Oh says. “The management of MS is dramatically different now, compared with when

I was a resident.”

During a clinical and research fellowship in neuroimmunology and neurological infections at the Johns Hopkins School of Medicine, Dr. Oh explored the use of magnetic resonance imaging (MRI) technologies under the mentorship of imaging experts Dr. Peter Calabresi and Dr. Daniel Reich. During this time, while also completing her doctorate at the Johns Hopkins School of Public Health, Dr. Oh developed a particular interest in imaging of the spinal cord.

“The spinal cord is commonly affected in MS and is the source of a lot of clinical disability,” she says. “The spinal cord basically is much like a highway, in that it is a conduit for all of the motor and sensory fibers that extend to your arms and legs and torso. It’s an important structure, and yet it is tiny and very difficult to image accurately, so in the past it was largely ignored. Until recently, the brain was the primary focus of MS research.”

The optic nerve, another structure commonly affected by MS, also was inordinately difficult to image until researchers, such as her mentor Dr. Calabresi, were able to use a technique known as optical coherence tomography (OCT). OCT allows experts to examine the layers of the back of the eye (retina) as they shrink or atrophy when affected by MS.

During her work with Dr. Calabresi, Dr. Oh became curious about the relationship



PHOTO COURTESY OF DR. JIWON OH

Dr. Jiwon Oh is a co-leader of North American Imaging in Multiple Sclerosis Cooperative.

“

**MS is one area of neurology in which the field is so dynamic you can actually see it changing right in front of you. The management of MS is dramatically different now, compared with when I was a resident.”**

—DR. JIWON OH

between motor (such as walking problems) and sensory (such as numbness) deficits revealed by imaging of the spinal cord and the optic nerve, and became the primary driver behind a study comparing these, which was published in *Neurology* in 2015.

“My colleagues and I found that measures derived from the spinal cord and optic nerve provide a much better understanding of disability caused by MS,” Dr. Oh says. “Whether the focus is general disability or disability in a specific area—for example, vision, or sensation, or weakness in the legs—measures of the retina and spinal cord are actually more relevant to explaining disability than measures of the brain alone. You can’t just have tunnel vision and focus on the brain. You really need to sample all areas of the nervous system that MS affects.”

Dr. Oh is a co-leader of North American Imaging in Multiple Sclerosis Cooperative (NAIMS), a collaborative group of imaging research centers with expertise in MS. Serving as secretary of NAIMS as well as a steering committee chair, she and colleagues in the U.S. and Canada are beginning large-scale studies to develop reliable image-based markers of disease progression and treatment, and improve our biological understanding of MS.

Splitting her time between St. Michael’s hospital in Toronto and Johns Hopkins, Dr. Oh

continues to use advanced MRI techniques to identify markers that may be used as outcome measures in clinical trials of MS treatments. She also is trying to gain a better understanding of radiologically isolated syndrome (RIS), abnormal MS-like brain findings identified during the diagnosis of an unrelated condition (such as migraine), which in some cases eventually lead to the development of MS symptoms. And, with funding from the National MS Society, she has launched a new imaging study with mentor Dr. Reich.

### **Finding your passion**

Dr. Ilana Katz Sand, an attending physician at the Corinne Goldsmith Dickinson Center for Multiple Sclerosis in New York, joined the center in 2011 under a fellowship funded by a Sylvia Lawry Physician Fellowship from the Society. An assistant professor of neurology at the Icahn School of Medicine at Mount Sinai in New York, Dr. Katz Sand treats people with MS and other autoimmune diseases that affect the central nervous system, while conducting several MS research studies.

Dr. Katz Sand credits her father, a neurologist, with encouraging her interest in the field at an early age. When she was in high school, she often accompanied her father to see patients. Her interest in MS deepened during her neurology residency.

“I related well to patients with MS, many of whom are young women,” she recalls. “Also, because MS is a chronic disease, neurologists typically treat patients for a long period of time. The idea of meeting a new patient and carrying that person through potentially difficult years—including reproductive years and early efforts to start a career—and helping the person over time particularly appealed to me.”

Near the end of her fellowship at Mt. Sinai, Dr. Katz Sand was introduced to MS research by her mentor Dr. Patrizia Casaccia, chief of the Center of Excellence for Myelin Repair at Mount Sinai. Dr. Katz Sand credits Dr. Casaccia, a basic scientist and physician and an expert on myelin repair, with shaping her identity as a research scientist and encouraging her interest in translational research, which focuses on the practical application of scientific discoveries.

In one current project, with Dr. Casaccia and colleague Dr. Matilde Inglese, Dr. Katz Sand is examining the potential link between progressive MS and the dysfunction of mitochondria, the structures inside cells that are responsible for producing energy.

“If a cell is not producing enough energy, it will get sick and may die,” says Dr. Katz Sand, co-author of a 2015 article on this topic in the journal *Brain*. “Our research suggests that this may be a contributing factor in



Dr. Ilana Katz Sand, who is leading a pilot study on the impact of a special plant-based diet on women with MS, discusses the study with patient Jessica Hamilton.

“

**The idea of meeting a new patient and carrying that patient through potentially difficult years ... and helping that person over time particularly appealed to me.”**

—DR. ILANA KATZ SAND

PHOTO COURTESY OF MOUNT SINAI HEALTH SYSTEM

the clinical symptoms that we see in our patients with MS.”

Another early project under Dr. Casaccia’s mentorship involved examination of the role that bacteria in the gut—or microbiota—may play in the development of MS. Dr. Katz Sand became particularly enthusiastic about this project because of questions from her patients, who wanted to know if they could improve their MS symptoms by changing their diet.

“Questions regarding diet come up all the time, and because there has not been rigorous research in this area, my colleagues and I really have had no way to answer any of those questions.”

Dr. Katz Sand received funding from the Society for a pilot study of 30 women with MS to examine the impact of a diet high in polyunsaturated fatty acids and polyphenols (antioxidants found primarily in plants).

“The diet includes foods that, based on our research, we think may be anti-inflammatory and therefore neuroprotective (protective of nerves at risk for damage from MS). It encourages foods such as fish, fresh fruits and vegetables, and whole grains. It doesn’t permit meat other than fish, and it limits salt intake,” says Dr. Katz Sand, who designed the study.

She hopes the results will contribute to the development

of clinical trials, which may ultimately lead to non-pharmaceutical therapies for MS.

### Following an unexpected path

When Meredith Hartley, PhD, was completing her doctoral dissertation on the biochemistry of bacteria at the Massachusetts Institute of Technology in Cambridge, she had no idea she would end up pursuing a career in MS research. While searching for postdoctoral research opportunities, she felt particularly drawn to research on a disease known as X-linked adrenoleukodystrophy (X-ALD) led by Thomas S. Scanlan, PhD, now her adviser at Oregon

Health & Science University (OHSU), in Portland, Oregon.

“X-ALD is a disease that is somewhat similar to MS,” says Dr. Hartley, since, like MS, it damages nerve-insulating myelin in the brain and spinal cord. “It’s a rare genetic disease. One severe form primarily affects young boys, who often survive fewer than three years after onset of symptoms. A genetic mutation causes the build-up of toxic fatty acids that result in a number of abnormalities, including [the destruction of myelin] in the brain.”

Dr. Scanlan was interested in looking at the role of a drug called sobetirome in the treatment of this rare disease. During her postdoctoral fellowship at OHSU, sponsored by a grant from the Society, Dr. Hartley examined the effect of sobetirome on mouse models of X-ALD. Sobetirome is very close in structure to the natural thyroid hormone that all people with a normal thyroid gland have.

“Thyroid hormone plays an important role during development because it tells the brain to produce myelin. The hope is that sobetirome can promote repair in places where myelin has been destroyed in individuals with X-ALD and MS,” she says.

In a study published by the Endocrine Society in the journal *Endocrinology* in 2017, Dr. Hartley and her colleagues showed that sobetirome does indeed help to lower the toxic levels of fatty acids that cause

PHOTO COURTESY OF MEREDITH HARTLEY, PHD



Meredith Hartley, PhD, has been researching the role of the drug sobetirome in the treatment of a rare genetic disease. She is now examining the effect of the drug on mouse models of MS.

demyelination in X-ALD.

“What’s especially exciting is that we are seeing lowering of these fatty acids in the brain as well, so the drug is working in the brain. No one has ever demonstrated this activity in the brain setting before, so we are pretty excited about the promise of this drug,” says Dr. Hartley.

Dr. Hartley and her colleagues are now examining the effect of sobetirome on mouse models of MS, with a Society grant that is supported in part by the Dave Tomlinson Research Fund.

“Our ultimate goal is clinical trials in MS,” says Dr. Hartley, “We hope that upcoming testing in clinical trials for X-ALD will possibly smooth the pathway to clinical trials for MS.” ■

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Susan Worley is a freelance medical writer in Bryn Mawr, Pennsylvania.

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**What’s especially exciting is that we are seeing lowering of these fatty acids in the brain as well, so the drug is working on the brain.”**

—MEREDITH HARTLEY, PhD



To learn more about MS research, visit [nationalMSSociety.org/Research](https://www.nationalMSSociety.org/Research).

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



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

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.

- 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
- chest pain
- trouble breathing
- fast, slow, or irregular heartbeat
- rash

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

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

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
- unexplained weight loss
- eye swelling
- nervousness
- fast heartbeat
- unexplained weight gain
- feeling cold
- 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
- chest pain
- yellowing of the skin or whites of the eyes (jaundice)
- dark urine
- 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.

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.

**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
- coughing up blood
- cough
- chest pain or tightness

**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](http://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

SANOI GENZYME 

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GZUS.LEMT.15.07.1872(1)b December 2016

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

**MEDICATION GUIDE**  
**LEMTRADA® (Iem-TRA-da)**  
**(alemtuzumab)**

**Rx Only**

**Injection for intravenous infusion**

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:

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

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.

- 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 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.

## 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.**

- o **listeria.** People who receive LEMTRADA have an increased chance of getting an infection caused by the bacteria, listeria. Avoid foods that may be a source for listeria (for example, deli meat, unpasteurized milk and cheese products, 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.

- **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:
  - o shortness of breath
  - o chest pain or tightness
  - o cough
  - o coughing up blood
  - o 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 healthcare provider 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-FPLR-SL-JUL16

Rx Only

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

SANOFI GENZYME 



The pros and cons of disclosing your MS to family and friends

by Aviva Patz

# To tell or not to tell

In 1993, British expat Rachel Padgett landed in the hospital with crippling joint pain stemming from a relapse of her multiple sclerosis, diagnosed four years earlier when she was 18. But for some reason the hospital tests didn't attribute her knee pain to MS. So Padgett's roommates concluded she had been faking her illness.

Instead of being supportive, they ostracized her, making her feel miserable. "So at age 22, I decided to stop telling people," says Padgett, who's now 46, happily married and living in Seattle. For 25 years, she hid her MS, blaming old injuries and weird viruses for symptoms that cropped up in public.

"I thought no good would come from telling anyone."

Padgett's initial experience with disclosure illustrates a conundrum for people with MS. To tell or not to tell family and friends is a deeply personal decision with many social and emotional considerations. Neuropsychologist Paul Wicks, PhD, of **PatientsLikeMe.com**, a free website where people share their health information, has found that MS, ALS (amyotrophic lateral sclerosis) and epilepsy rank highest on conditions people tend to disclose. If you're weighing the risks and benefits of sharing your MS with your social circle, here are some things to consider.

## The downsides to disclosure

In our social media age, where even personal details are shared in tweets and posts, it can be tough to know when and where to reveal your MS. Certainly, there can be downsides, according to Peggy Crawford, PhD, a clinical psychologist who has worked with people with MS for decades. These are the most common:

**Disbelief:** Your news may be met with shock or even skepticism. “It’s not unusual for people who have no outward symptoms to hear, ‘Oh, but you look so good. Are you sure they made the right diagnosis?’” Dr. Crawford says. Padgett’s roommates didn’t believe she had MS and attributed her disclosure to just wanting attention.

**Unsolicited advice:** Your disclosure may seem like an open invitation for feedback. Dr. Crawford says that while the tips may be well-intentioned, it’s easy to perceive them as a criticism of your decisions—about where to go for care, for example, or which neurologist to see. Often, people think they’re doing you a favor by forwarding articles about new or complementary therapies.

**Different attitudes:** People may make assumptions about who you are and what you can and can’t do. Olivia Eveland, who was diagnosed with MS in 2015, has kept the news from others because, in the past, people who learned she had MS began looking at her as if she was fragile or needed special attention. “They stop inviting you to things because they think you can’t go, or they change plans when you’re involved because they don’t want you to



Learn more about disclosing your MS at [nationalMSSociety.org/Disclosure](http://nationalMSSociety.org/Disclosure).



Rachel Padgett felt a renewed sense of freedom when she disclosed that she has MS.

PHOTO BY EUGENIA GORDIENKO PHOTOGRAPHY

feel left out,” she says. “They ask how you’re feeling 50 times a day and whether you need anything, forgetting that you’re still the same person you were before MS, just a little slower or a little weaker.” The upside to not disclosing, is that she’s treated like everyone else, says Eveland, who blogs about her MS at [CloudyWithaChanceofPolkaDots.Wordpress.com](http://CloudyWithaChanceofPolkaDots.Wordpress.com). The downside: “When I’m having a bad vertigo or fatigue day, it’s difficult to pretend I’m OK.”

**Relationship challenges:** MS can present a challenge to some relationships. “There’s some risk that the other person will feel unable to cope, especially with the disease’s unpredictability and potential for disability,” Dr. Crawford says. Keep in mind, however, that secrecy is not a good foundation for a relationship, so if MS sends your date packing, he or she probably wouldn’t have made the best companion in the long term.

## The upsides to disclosure

Your experience with disclosing MS will be as individual as you are. There’s simply no one-size-fits-all when it comes to how people will react. That said, these are some of the benefits that people may experience if they decide to open up.

**Burden lifted:** Keeping secrets is exhausting. “Disclosure can reduce this stress and lift some weight from your shoulders,” Dr. Crawford says. When Padgett finally decided to reveal her MS, she says “I felt a freedom I never felt before.” She stopped worrying that if she went to a party she wouldn’t be able to say she was tired and leave. She stopped fretting about not finding a parking spot—because she got a handicap sticker. She doesn’t worry about going down a flight of stairs because she’s free to cling to the banister or enlist friends’ support. “I didn’t know I was carrying around so much guilt

about potentially inconveniencing everybody with my illness,” she says. “But I was also internalizing the shame of lying every single day to cover my condition.”

Shauna Longmire, of Helena, Montana, disclosed her MS following her diagnosis in 2006. “When you keep MS a secret, it’s like you’re ashamed. But you haven’t done anything wrong. When you don’t admit to something, you let it control you,” she says. “I have MS. It doesn’t have me.”

**Emotional and social support:**

When friends know you have MS, it’s easier to ask for help—and get it. “Many people want to help, but don’t know what you need and, consequently, don’t offer, or offer too much, too little, or something that’s not even on your radar,” Dr. Crawford says. Padgett says disclosing her MS has helped her build an authentic support system. “Knowing you have a safe place to land at the end of the day—with a dear friend or a spouse who can be there for you unconditionally—is really important,” she says. “MS can be a lonely journey, and it can help to have people to hold your hand.”

**Corrected assumptions:** Odds are that people have observed some of your symptoms and made guesses about what’s up. Padgett’s coworkers thought she had cancer because she was always tired and often going to the hospital. In some cases, people assume symptoms like imbalance and gait issues are related to being drunk.

**Strengthened relationships:** When you share your MS diagnosis with someone, it shows your trust in them. Longmire says her disclosure helped her relate to other people who have disabilities, which she believes is pretty much everyone. “Some are just more noticeable than others,” she says.

**Better understanding:** Telling immediate family, close friends and extended family about your diagnosis can prompt them to “learn more about the disease so they can try and gain some understanding and empathy,” Dr. Wicks says. Better understanding what you need could also help expand the care they might be able to provide.



**I didn’t know I was carrying around so much guilt about potentially inconveniencing everybody with my illness. But I was also internalizing the shame of lying every single day to cover my condition.”**

—RACHEL PADGETT

**Decisions about disclosure**

Disclosure doesn’t have to be all or nothing. “Not everyone needs to know,” Dr. Crawford says. “Start with people you already trust, with whom you already have mutual respect and empathy, or people with whom you have the most contact or the most fun. If a relationship feels like it’s worth pursuing, it’s probably worth disclosing.”

Consider your motivation for disclosure when planning what you’ll say. Is it to share personal information with an important person in your life? To explain recent physical or emotional changes? To rally assistance and

support? Once you know why you’re telling, you’ll be better able to shape your message, whether it’s how MS affects you day to day, the fact that it’s not contagious, or perhaps just that it can be unpredictable. Whatever your rationale for sharing, be prepared for a variety of reactions.

“Most everyone has been kind, supportive and has said things like, ‘Now I just think you’re even more amazing,’ and ‘What can I do? How can I help? What do you need?’ and ‘Thank you for telling me your story,’” Padgett says. After guarding her secret for years, she now happily tells strangers about her condition, saying things like, “I have bad balance because I have MS. I’ve had it for 25 years. What do you want to know?” Being so open has been life-changing,” she adds. “It has turned my life around in an amazing way.” ■

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Aviva Patz is a freelance writer in Montclair, New Jersey.

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

Imagine another  
**PERSPECTIVE**  
 on relapsing MS

TECFIDERA is the

**PRESCRIBED PILL**

for relapsing MS in the US since September 2013.\*

Consider **TECFIDERA**—a pill that has the strength to cut relapses in half.

TECFIDERA is a twice-daily pill for relapsing multiple sclerosis (MS) that has been shown to cut relapses in half. During a 2-year study, TECFIDERA reduced risk of relapse by 49% compared with placebo. TECFIDERA is also proven to slow the development of brain lesions and delay the progression of physical disability.

Over 230,000 people around the world have taken TECFIDERA.† Ask your doctor if you should too.

**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. 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

**Important Safety Information (continued)**

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 [daily.med.nlm.nih.gov](http://daily.med.nlm.nih.gov).**

**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.**

\*Based on number of prescriptions from IMS NPA™ Weekly Data (September 27, 2013 – January 13, 2017). †Biogen data on file.

 **Tecfidera**®  
 (dimethyl fumarate) delayed-release capsules 240 mg



Visit [TecPerspective.com](http://TecPerspective.com) or call  
**1-844-TalkTec (1-844-825-5832)**

**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

# Changing



Michigan couple gets a taste for a new MS fundraiser.

by James Townsend

**B**ack in the 1990s, Scott and Ruth Crichton of Commerce Township, Michigan, learned that Scott's niece had been diagnosed with multiple sclerosis. "She didn't really need any financial help at the time," Scott says. "But we wanted to do something supportive, so we decided to go after the disease itself." Since then, he says, two more of their friends and relatives have been diagnosed with MS.

So, in 2002, the couple came up with the idea of hosting a fundraiser at a golf course in Commerce Township, about 40 miles north of Detroit—and the Hacker Scramble was born. The name came from Scott's brother-in-law, whose nickname for Scott was "Hacker," a teasing dig about his less-than-sterling abilities on the golf course.

"We had a lot of fun with it," Scott says. "We came up with silly games, like seeing how far you could drive a marshmallow,

and trying for a 40-foot putt using a hockey stick, charging \$5 for each try." In addition to charging \$100 to participate in the challenge, the Crichtons incorporated silent auctions and enlisted their company's vendors for sponsorships and prizes. They are partners in Cul-Mac Industries, supplying chemicals to the automotive industry in Detroit.

"Over the years we've learned a lot," Scott says. "We tried all sorts of things in the beginning. For instance, early on we decided everyone would get a door prize, and we got lots donated, like samples from our vendors. But gathering all the items and moving them was a lot of work. We finally realized that people didn't come to get a \$5 gift." Other ideas, though, like the silent auction, were easier to organize and raised nearly \$2,000 every year.

"Also, at first we tried to invite the world by getting news outlets

interested and such, but we never got much traction there," Scott says. "Turns out it was better to just recruit people with whom we had some affiliation, like co-workers and friends. When people asked us what they could do to help, we told them bring the people you work with. Bring two other people to make a foursome. That was far more effective.

"That first year we raised about \$5,000, and we were thrilled," Scott says. The amount increased each year, and attendance averaged more than 100 people. "Last year the event raised almost \$30,000, bringing the total over the past 14 years to more than \$250,000."

## A new direction

As successful as the event was, the couple decided to change course in 2017. "When the Hacker Scramble was first conceived, there were only one or two golf charity outings at play.

# course



PHOTO COURTESY OF SCOTT AND RUTH CRICHTON

Scott and Ruth Crichton are trying a new type of fundraiser this year. It will pair small plates of food with wine and beer.

Now there are many more—memorials and charities for one disease or another, and we felt we were having to compete with them,” Scott says. In addition, many of their older regular attendees were not golfing anymore, and the young people

who had first been involved were grown and raising families. “Plus, we were constantly worried that we’d be rained out. It never happened, but there were some very close calls,” he adds. “We’re determined to keep it going, but we always said that when we reached that target goal of \$250,000, we wanted to try something different.”

So, this year the couple is planning a November event that will pair small plates of food with wine and beer. “It’s another excuse for people to get together and do something meaningful and fun,” Scott says. “And it’s something universal. Everyone eats and drinks, and now we don’t care what the weather will be.”

Asked if they have any experience in wine and beer tasting, Scott chuckles. “Well, we’re experienced in drinking it.” They expect to host the event at a local brewery or meeting hall, or even at the golf course clubhouse, hiring a local chef or caterer to provide the food and a microbrew expert or sommelier for the pairings.

“We’re sure it will be well-attended,” Scott says. “We expect about 100 people. We have a very loyal core of attendees. Many have been to all 14 events we’ve hosted.”

And what will they call the new event? “Well, for sure it’s going to be the Hacker something ... We haven’t decided yet,” Scott says. “This is really an experiment. If it doesn’t work as well as we hope, we’ll try something different—maybe a chili cook-off or a rib roast. But we love doing this, and we’ve never considered not doing it again.” ■

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James Townsend is a freelance writer in Boulder, Colorado.

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With Do It Yourself (DIY) Fundraising MS, your talents and hobbies can become a fundraising event of your own. For details on how to kick-start your DIY fundraiser, visit [diyMS.org](http://diyMS.org).

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

## ADVERTISEMENT

# WHEN MS RELAPSE INTERFERES, TAKE ACTION.

Ask your doctor about Acthar, a prescription treatment option that has been shown to speed relief of multiple sclerosis (MS) relapse.



Acthar may work by helping the body produce natural steroid hormones and also by affecting immune cells that may impact inflammation.\*



It can be self-administered whenever and wherever it's right for you, per your doctor's prescription.



The Acthar Support & Access Program (A.S.A.P.) provides comprehensive support—in-home injection training, finding co-pay assistance, and more.

\*While the exact way that Acthar works in the body is unknown, further studies are being conducted. This information is based on laboratory data, and how it relates to patient benefits is unknown.

### H.P. Acthar® Gel

(repository corticotropin injection) [H P AK-thar jel]

#### What is H.P. Acthar Gel?

Treatment for adults with acute relapses or flares of multiple sclerosis (MS). Studies have shown H.P. Acthar Gel to be effective in speeding recovery from an MS relapse. However, there is no evidence that Acthar affects the ultimate outcome or natural history of the disease.

Acthar is injected beneath the skin or into the muscle.

#### IMPORTANT SAFETY INFORMATION

You should NOT take Acthar before talking to your doctor if you have any of these conditions: A skin condition called scleroderma, bone density loss, any infections, herpes simplex of the eye, had recent surgery, stomach ulcers or history of stomach ulcers, heart failure, uncontrolled high blood pressure, have been given, or are about to receive, a live or live attenuated vaccine, or have allergies to pig-derived protein. Tell your doctor if you are pregnant or plan on becoming pregnant.

Acthar is injected beneath the skin or into the muscle. It should never be injected into a vein.

Acthar can cause side effects similar to those with steroid treatments. It can cause adrenal gland changes which may cause symptoms of Cushing's syndrome.

People on steroids or with Cushing's syndrome may experience: increased risk of infections; an increase in upper body fat, rounded "moon" face, bruising easily, or muscle weakness; increased blood pressure, body salt, and fluid; unpredictable response to vaccines; stomach or intestinal

Actor portrayal.



TO LEARN HOW ACTUAL  
PATIENTS WITH MS RELAPSE ARE  
TAKING ACTION WITH ACTHAR, VISIT

**ACTHARMSRELAPSE.COM/ACT**

problems; changes in mood or behavior; worsening of other medical conditions; eye problems; or allergic reactions. Tell your doctor if you experience any of the above symptoms. Also tell your doctor about any other health problems you have and about all medicines you are taking.

Taking Acthar may mask symptoms of other diseases and may cause bone density loss at any age.

The most common side effects include: Fluid retention, changes in blood sugar, increased blood pressure, behavior and mood changes, and changes in appetite and weight.

Specific side effects in children under 2 years of age include: Increased risk of infections, increased blood pressure, irritability, symptoms of Cushing's syndrome, cardiac hypertrophy (thickening of the heart muscle) and weight gain.

The above side effects may also be seen in adults and children over 2 years of age.

These are not all of the possible side effects of Acthar.

Tell your doctor about any side effect that bothers you, or that does not go away. Call your doctor or pharmacist for medical advice about side effects. You may report side effects to the FDA. Call 1.800.FDA.1088 or visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects by calling 1.800.778.7898.

**Please see Brief Summary of Information on the following page.**

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February 2017 Printed in USA.

H.P. **Acthar**<sup>®</sup> GEL  
(repository corticotropin injection) 80 U/mL

For MS  
Relapse  
In Adults

### IMPORTANT FACTS ABOUT H.P. Acthar Gel

Please read this summary carefully and ask your doctor about Acthar. No advertisement can provide all the information needed to determine if a drug is right for you or take the place of careful discussions with your healthcare provider.

#### What is H.P. Acthar Gel used for?

Acthar is a prescription medicine used to treat acute relapses or flares of multiple sclerosis (MS) in adults. Studies have shown H.P. Acthar Gel to be effective in speeding recovery from an MS relapse. However, there is no evidence that Acthar affects the ultimate outcome or natural history of the disease.

Acthar is injected beneath the skin or into the muscle. Acthar should NEVER be injected directly into a vein.

#### When should I not take H.P. Acthar Gel?

DO NOT take Acthar until you have talked to your doctor if you have any of the following conditions:

- A skin condition called scleroderma
- Bone density loss or osteoporosis
- Any infections, including fungal, bacterial or viral
- Eye infections such as ocular herpes simplex
- Had recent surgery
- Stomach ulcers or a history of stomach ulcers
- Heart failure
- Uncontrolled high blood pressure
- Allergies to pig-derived proteins
- Have been given or are about to receive a live or live attenuated vaccine
- Suspected congenital infections (in children under 2 years of age)
- Cushing's syndrome or Addison's disease

#### What warnings should I know about H.P. Acthar Gel?

**Infections:** You may be more likely to get new infections. Also, old infections may become active. Tell your doctor if you see any signs of an infection or at the first sign of an infection or fever. Signs of infection are fever, cough, vomiting, or diarrhea. Other signs may be flu or any open cuts or sores.

**Cushing's syndrome or adrenal insufficiency:** When taking Acthar long term, your adrenal gland may produce too much of a hormone called cortisol. This can result in symptoms of Cushing's syndrome including increased upper body fat, a rounded "moon" face, bruising easily and muscle weakness. Adrenal insufficiency may occur after you stop taking Acthar. Signs of adrenal insufficiency include weakness, patches of darker skin, weight loss, low blood pressure and belly pain. Recovery from adrenal insufficiency may take from days to months. Your doctor may prescribe steroids during this period. You should not stop taking Acthar suddenly. Follow your doctor's instructions when stopping Acthar treatment.

**High blood pressure:** You might develop high blood pressure or retain too much fluid. As a result of this your doctor may recommend some changes to your diet, such as eating less salt and taking certain supplements.

**Vaccination:** Vaccines may not work well when you are on Acthar. Talk to your doctor about which vaccines are safe to use when you are taking Acthar.

**Hiding symptoms of other diseases:** Acthar may hide symptoms of other diseases without changing the course of the other disease. You should be monitored during and for a while

after you stop taking Acthar for signs of infection, abnormal heart function, high blood pressure, high blood sugar, change in weight and bloody or black stools.

**Stomach or intestinal problems:** Acthar may increase the risk of bleeding stomach ulcers. Tell your doctor if you have stomach pains, bloody vomit, bloody or black stools, excessive tiredness, increased thirst, difficulty breathing or increased heart rate.

**Changes in mood or behavior:** Taking Acthar can make you feel irritable or depressed. You may also have mood swings, trouble sleeping or personality changes. Also, existing emotional instability may be worsened.

**Worsening of pre-existing conditions:** If you have other conditions, such as diabetes or muscle weakness, you may find they get worse.

**Eye conditions:** You might develop certain eye conditions, such as cataracts, glaucoma or optic nerve damage.

**Allergies to Acthar:** Long-term use may increase the risk of developing an allergic reaction to Acthar. Signs of allergic reaction include: skin rash and itching; swelling of the face, tongue, lips or throat, trouble breathing.

**Weak bones:** Acthar may cause osteoporosis at any age. Post-menopausal women are at increased risk of osteoporosis and bone density should be monitored before starting Acthar and during long-term therapy on Acthar.

#### Are there special considerations for certain groups of people taking Acthar?

**Use in pregnancy:** Acthar might harm an unborn baby. Tell your doctor if you are pregnant or plan on becoming pregnant.

**Nursing mothers:** You and your doctor should decide whether to discontinue nursing or discontinue Acthar, considering the risk to the nursing infant and the benefit to the mother.

**Children:** Long-term use of Acthar can affect growth and physical development in children and should be carefully monitored. This can be reversed when Acthar is no longer needed.

#### What are the most common side effects of Acthar?

The most common side effects of Acthar are similar to those of steroids, including: fluid retention, high blood sugar, high blood pressure, behavior and mood changes, changes in appetite and weight.

Specific side effects in children under 2 years of age include: increased risk of infections, high blood pressure, irritability, symptoms of Cushing's syndrome, thickening of the heart muscle (cardiac hypertrophy) and weight gain.

The above side effects may also be seen in adults and children over 2 years of age.

#### These are not all of the possible side effects of Acthar.

Tell your doctor about any side effect that bothers you, or that does not go away. Call your doctor or pharmacist for medical advice about side effects. You may report side effects to the FDA. Call 1-800-FDA-1088 or visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects by calling 1-800-778-7898.

# Help wanted

I'm learning to let others lend me a hand.

by Mike Knight

It was a perfect sunny August day. My wife, Michelle, and I had joined friends to watch a soccer game, and in single file we were climbing the steep, narrow steps of an older stadium in Indianapolis.

I had yet to be diagnosed with multiple sclerosis. But it was getting harder for me to lift my right foot off the ground when I walked, and the problems that was causing were growing more apparent.

A month before the soccer game, during the Fourth of July holiday, my right leg had temporarily quit on me, making it impossible to get up from the chair I was sitting on. Over the years, I'd seen four or five neurologists as well as other specialists for seemingly disparate problems, including thyroid issues, sleeplessness and restless legs, and what we all thought were back and gait problems caused by running 30 to 50 miles a week. But my difficulty on the stadium steps made it obvious that something was seriously wrong, something far beyond



Mike Knight, with his wife, Michelle, has discovered the value in giving and receiving help.

a sore back or an unbalanced gait.

The old stadium steps had no railings. Trailing Michelle and our friends up the crowded staircase, I suddenly could no longer climb the stairs. I was stuck, alone and helpless.

Everything seemed to be happening in

slow motion. What was likely only two or three seconds felt like much longer. I looked from side to side, meeting faces that recognized that something serious was happening to me. I could see that they were confused and maybe even scared—exactly how I felt. Michelle, realizing I was no longer with the group, turned back to find me. When our eyes met, I saw the shock on her face.

## A helping hand

Suddenly, I felt someone take hold of my arm and gently but surely help me climb the stairs until I was in my seat. It was a beer vendor, a younger guy probably in his late 20s or early 30s. I tried to thank him, but he just shook

PHOTO COURTESY OF MIKE KNIGHT

## fired up

his head and brushed it off. And then he gave me a beer.

That was in 2013, the year I was diagnosed with MS. Since then, MS has progressed slowly up the right side of my body. Now I need a cane, and my right hand barely works. My declining capacity has presented innumerable opportunities for friends, family, co-workers and complete strangers to help me. And more and more, I am not just looking for that help, I'm embracing it.

I am now 57 years old. I have held a job since I was 12 years old, missing barely more than a couple months of work in all that time—until April 2016, when I left my job to go on disability. Men my age were taught to fend for ourselves, to be self-sufficient and independent. In many ways, a man's self-reliance is a measure of his success—or lack thereof.

At first I struggled to admit to myself that I was disabled, that there were things I couldn't do any longer. Household chores and yard work, having the energy necessary to manage an incredibly demanding job, simply going shopping with my wife—all had become significantly harder. MS forced me to re-examine what self-reliance means to me.

I don't ever want to see the look of fear in Michelle's eyes again, so I've made it my "job" to figure out how to manage my life and my disease. Accepting my limitations and knowing that I may need to ask someone for help as part of my daily life has simply become a part of that job.

And in a funny way, I've learned that I'm part of a bigger, perhaps more important social contract, one in which I can play a pivotal role even while I'm its beneficiary.

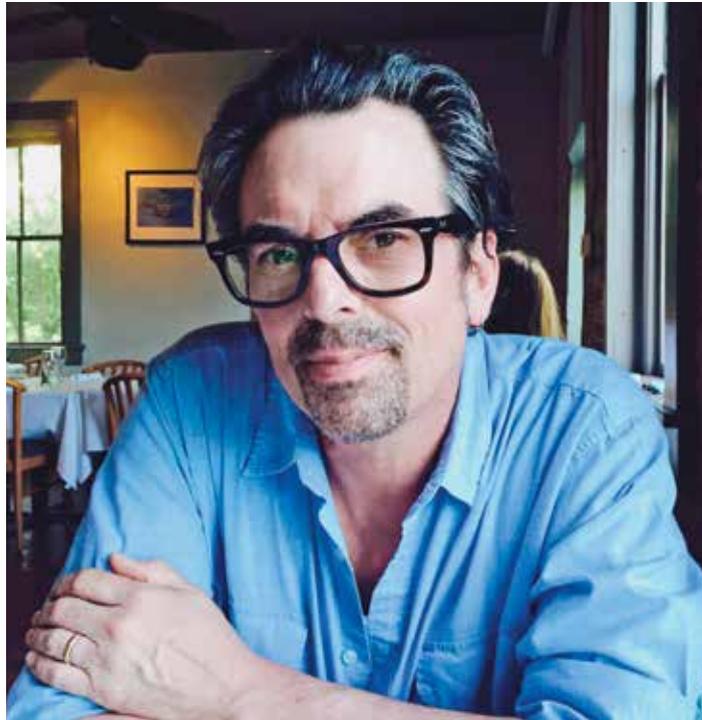


PHOTO COURTESY OF MIKE KNIGHT

According to Psychology Today, helping others gives us a "helper's high" and increases our sense of self-worth while delivering many other physiological benefits, too.

I've come to realize that by seeking and accepting help, I'm fulfilling my side of this contract: I'm available to be helped. My benefactors get a good feeling from helping me. Me? I get people who open doors when I can't, who grab too-full coffee cups from me before I spill them, who clear plates for me before I try to do it myself and before I stubbornly

perform an awkward dance while they watch, breath held, to see what accident I'm about to cause.

If not for MS, I'm not sure I'd be aware enough to recognize this powerful social contract we share, let alone its beauty. Whether we're the helper or the helped, the world is a significantly better place when we accept it, engage in it and celebrate it. Who knows? There might even be a free beer in it for you. And that's certainly worth celebrating, too! ■



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

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Learn from others how they've embraced their MS. Start or join a conversation on [MSconnection.org](https://www.msconnection.org).

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



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“**C**ONTEST! HOLY FOOM!!!! Create a super hero or villain in the Mighty Marvel manner ... and contribute your own talent to the wildest wackiest comics company since the invention of the printing press.”

When comics-crazed 16-year-old Andy Olsen saw this call for entries in Marvel Comics' FOOM (Friends of 'Ol Marvel) magazine in 1973, deciding to enter was a no-brainer. Olsen regularly blew his meager allowance on comic books at the local Jiffy Mart. He and his friends would race to the racks as soon as they'd heard that the newest issue in their favorite series hit the stands.

“Me and my buddies would have a grand old time discussing

Andy Olsen made this comic strip especially for **Momentum** magazine.

ARTWORK BY ANDY OLSEN

# Fighting a supervillain

A love of comic books offers surprising lessons in living with MS.

by Shara Rutberg

**“Me and my buddies would have a grand old time discussing plot lines. Thor. Captain America. Fantastic Four. We didn’t have computers or video games. It was different back then. It was all about ink on paper.”**

—ANDY OLSEN

plot lines,” Olsen says. “Thor. Captain America. Fantastic Four. We didn’t have computers or video games. It was different back then. It was all about ink on paper.”

Olsen grew up in Merritt Island, Florida, home to NASA’s Kennedy Space Center, where his dad worked as an engineer. With America’s space program in the neighborhood sending rockets to the moon, a world with heroes who could shoot lasers from their fingers and fly might not have seemed much of a leap to a kid with a good imagination.

Olsen and his pals spent hours debating critical issues like who would win in a battle between Superman and Hulk. When he wasn’t reading or talking about comic book characters, he was drawing them. “I was a sketching fiend,” he says. So when he saw Marvel’s contest, he got to work. After all, supposedly none other than Stan Lee himself, comic book creator and publisher who made Marvel a household name—and Olsen’s idol—would pick the winners. “Just the idea of The Man actually seeing my work was too exciting to pass up.”

Olsen sent in as his submission a cyborg hero named Wolverine. Marvel picked it as a runner-up and printed it in the magazine. Olsen was thrilled.

Some time later, Marvel debuted its X-Men: Wolverine comic, the same name as Olsen’s hero, but with a very different character design and different superhero traits.

After college, Olsen turned his love for drawing comics into a career as a graphic designer. Today, he applies his skills as a Florida defense contractor.

## A new villain

In 2010, at the age of 55, Olsen faced a villain more evil than anything he’d encountered in Marvel’s world. He was diagnosed with multiple sclerosis after experiencing what he calls a “total meltdown” that included numbness and weakness in his left hand as well as from the waist down. “I went from bulletproof to a wreck within days,” Olsen recalls. He spent a month in the hospital, where he had to relearn how to walk and use his left hand.

If life were a comic book, Olsen could have accessed one of Wolverine’s powers: a “healing factor” that allows the character to recover from bodily injury or disease at a superhuman rate. In reality, Olsen had to draw on his own internal, and very human, powers.

Living with MS is different than superheroes fighting bad guys, he says. “I’m fighting something I can’t defeat. This is not some person or monster. It’s something you have to reach down and find the mental discipline every single day to just keep fighting.”

A black belt in karate, Olsen says the focus and mental discipline he developed over his 35 years of martial arts training have been critical. He occasionally needs a cane to walk. He experiences fatigue as well as tingling and numbness. He drives himself to work three days a week and works from home the other two.

The challenge of living with MS is something you can’t really explain to people who don’t have the disease, he says. With superheroes, the struggle is easy to see—they head out to fight crime and save the world. “This a lot more personal,” Olsen says. The power of determination is not always visible and does not always create dramatic results. “There are times when my wife, Yijuan, will come up and give me a big hug, and tell me how proud and grateful she is that I’m still working, that I’m still getting a paycheck, that I’m still keeping us going.”

And as it turns out, Wolverine is not the superhero Olsen would choose to be. That would be Iron Man. After an explosion left shrapnel lodged close to Tony Stark’s (aka Iron Man) heart, he worked with a genius physicist to design special magnetized body armor to keep him alive—and help him fight the bad guys. “He had an affliction and had to deal with it, turn it around and make it into something positive,” says Olsen. “I admire that.” ■

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Shara Rutberg is a freelance writer in Evergreen, Colorado.

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Meditative sculptures include deteriorated, frayed or unplugged cords symbolizing the degenerative nature of MS.

# Form fired with meaning

by Ryan Moffett

In January 2013, I was diagnosed with multiple sclerosis after experiencing extreme fatigue, numbness in my feet and legs, and problems with balance. These symptoms, and my fears about them, prompted me to create my current body of work. My work is mainly constructed with high-fired stoneware using the coil method, where clay is rolled into ropes, called coils, and layered one upon another. After the clay sculptures are fired, I add electrical hardware, lights and found objects to finish the pieces. The large-scale sculptures, inspired by ancient Cycladic stone sculptures originating from the Greek islands in the Aegean Sea between 3300 and 1100 B.C., express a meditative state, making the pieces contemplative and spiritual. The inclusion of deteriorated, frayed or unplugged cords symbolizes the degenerative nature of MS, and how the signals to and from the brain can be weakened. The heart may have deep desires to do one thing, but the brain may send messages of fatigue, doubt, fear or conflicting logic.

My wife and I live in Clearfield, Utah, and we have four daughters. I have been teaching ceramics, sculpture and video production at Murray High School for 20 years. Sharing my love for the arts has always been my passion and source of great joy. I have noticed that since my diagnosis and subsequent sculptures, students as well as others in the community see the value and purpose of the arts on a much higher level. They have watched as my artwork evolved from beautiful forms to beautiful forms with deep personal meaning. ■

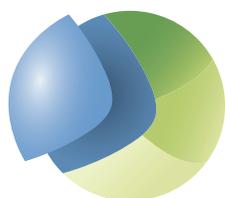


Artist Ryan Moffett's sculptures combine classical form with modern elements. The inclusion of faulty and unplugged cords, in part, represents the weakening of signals to and from the brain, he says.

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