

MSAA

MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA

Improving Lives Today!®

Summer/Fall 2017

THE Motivator

Published by the Multiple Sclerosis Association of America

**Home and Lifestyle
Modifications
for Safety and
Accessibility**



Announcing TEAM MSAA's Endurance Events

This year, MSAA is a charity partner for several endurance events across the nation! Please join Team MSAA in making a difference in the lives of individuals affected by multiple sclerosis.

Rock 'n' Roll Marathon Series

Events Nationwide

Tough Mudder Series

Events Nationwide

Walt Disney World® Marathon Weekend

Presented by Cigna® | January 3 – January 7, 2018 | Orlando, FL

We understand that these types of endurance events are not for everyone. If you know someone interested in marathons and other running events for charity, please be sure to share this information.

For more information, please visit
support.mymsaa.org/teamMSAA



ANY POOL, ANY TIME

*Dive into action with Swim for MS
...any season of the year!*

SWIM FOR MS is a national fundraiser in which volunteers are encouraged to create their own swim challenge to support MSAA. It's as easy as 1-2-3!

1. Create your own swim activity
2. Set a challenge goal
3. Recruit family & friends to donate!

REGISTER TODAY!

Visit SwimForMS.org or
call (800) 532-7667 ext. 157

SPONSORS: HardcoreSport • Endless Pools



Team Captain Courtney Evers and her friends on Team DragonFLY swam 4,825 laps and raised more than \$5,000 in support of the MS community!



SWIM FOR MS
ANY POOL, ANY TIME

Published by the Multiple Sclerosis Association of America

Gina Ross Murdoch
President & CEO

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COVER STORY

4 Home and Lifestyle Modifications for Safety and Accessibility

By Maryann B. Hunsberger

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MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

Improving Lives Today!®

The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.



MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

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You + MSAA = Helping People With MS

By Gina Ross Murdoch
MSAA President and CEO

Welcome to fall! As we approach the Thanksgiving season, we are more thankful than ever for the support, inspiration, and dedication of our MSAA family to continue our relentless efforts to **Improve Lives Today** and every day. So many of you have come together – care partners, volunteers, corporate partners, and others – combining your efforts and expertise with those of our staff and Board to achieve incredible growth and impact in our 2017 fiscal year.

Our Board of Directors continues to evolve and expand with the addition of two new members: Wendy Scott, Esq., who became the eighth Law Dean of the Mississippi College of Law; and Paula Nitto, CPA, CFO for Axis Technologies. We are grateful that these two dynamic leaders have joined our mission. Also in 2017, William Saunders and Timothy Garrett completed their terms on our Board.

Both served for many years and left an indelible legacy on MSAA that will serve our members for years to come. We extend our heartfelt appreciation for their time and service.

As we concluded our 2017 fiscal year in the end of June, we reached many notable goals! These include: the full restoration of our MRI program to meet the needs of a maximum number of clients; the distribution of a record number of cooling vests; the growth of our My MSAA Community forum to more than 1,500 active members; the development of our partnership with Antidote, inviting our members to take an active role in cutting-edge research; the advancement of our Navigating MS program toward the publishing of a white paper on the key results of our international risk/benefit program; and the production of our *Changing Lives Monday to Sunday* video, telling the story of MSAA to thousands across the country. Most of all, our impact on thousands of lives increased across the board.

Gina Ross Murdoch is a seasoned executive in non-profit management. Her career includes leadership positions with chapters of the Leukemia and Lymphoma Society as well as the American Diabetes Association. Earlier, she spent 14 years overseeing development activities at a large chapter of the National Multiple Sclerosis Society, leading explosive growth initiatives and ground-breaking strategic projects. An active member of the community, Ms. Murdoch has held several town positions and volunteers for her college alma mater, Drew University.

Looking ahead, our focus is to continue this building momentum of impact and innovation. As we approach MSAA's 50th anniversary in 2020, we are thinking ahead to how we can exponentially increase the ways we may better assist the entire MS community.

I would like to also acknowledge how thankful I am for the many volunteers who devote their time and talent to raise funds for MSAA and the many services we provide. Without their help, without **your** help, none of the important activities such as our MRI Access Fund, Cooling program, in-person educational programs, publications like this issue of *The Motivator*, our Helpline, and so many other services would happen. You will

see our volunteers highlighted later in this magazine in honor of their creativity, efforts, and dedication.

You too can be part of the team! Several options are available: participate in Swim for MS, join me in a half marathon, attend our Improving Lives Benefit in March 2018, and/or make a much-needed donation! At this important time of year, I ask and encourage you to be generous with your time and be generous with your support, enabling MSAA to extend that generosity of help to so many struggling with multiple sclerosis in their lives. I thank you in advance for your partnership in Improving Lives Today AND in planning for tomorrow. I wish all of you a happy and healthy holiday season. ■

**Submit Your
Best Work for
MSAA's 2018**

Art Showcases

MSAA is now accepting submissions for the **MS Ability Showcase** and **Four Seasons Showcase**!

MSAA welcomes paintings in oil, watercolor, and acrylic, as well as pastels and drawings in pencil and ink. MSAA also accepts digital artwork.

Artwork will only be accepted from individuals who have MS. Submitted pieces must be two-dimensional. Sculpture, pottery, fabric, and other types of three-dimensional works cannot be accepted to either showcase. The **MS Ability Showcase** is open to all themes; however, submitted artwork to the **Four Seasons Showcase** must depict a specific season or holiday. You may submit up to three (3) pieces of your artwork for each showcase.

Submissions will be featured on MSAA's website beginning March 2018 in recognition of MS Awareness Month. Each month we will highlight one artist and his or her work.

Submissions will be accepted until December 15, 2017. For submission guidelines, visit support.mysaa.org/artshowcase

For more information, contact:

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Email: showcase@mysaa.org
Phone: (800) 532-7667, ext. 117



**Scarecrow in
Cabbage Patch**

Karen Bloom,
Kendallville, IN



Burnt Island Light

David Desjardins, Union, ME

Home and Lifestyle Modifications for Safety and Accessibility

Written by
Maryann B. Hunsberger

Reviewed by
Jack Burks, MD
MSAA Chief Medical Consultant

Edited by
Susan Wells Courtney



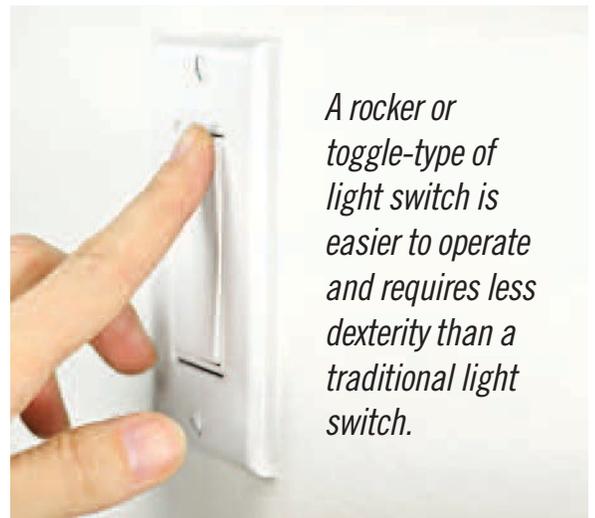
I remember skipping down the stairs and leaping over the baby gate at the bottom with my hands full of laundry. Then I'd run down another flight of steps to the basement to fill the washer before sprinting back up with the wet sheets. With one arm full of wet sheets and the other grasping my son, I'd jump down the back steps and hang the sheets on the clothesline. And that was all before breakfast.

I never dreamed that a few years later, I'd be stranded on my front landing, unable to get down the two steps without holding onto my husband. I certainly never imagined that I'd get stuck in my bathtub, unable to stand up without my husband to pull me out.

Over time, I found solutions to some of the obstacles I was experiencing. Some remedies were not difficult. For instance, I learned that showering was easier than taking a sit-down bath. When the time came that I needed to sit while bathing, I purchased a shower chair at a medical supply store. When the single railing on our inside staircase became too difficult for me to navigate, purchasing a second railing at a home-improvement store was a simple fix. And while I was fortunate enough to have my husband install the railing, for anyone without a handyman at home, accredited handymen may be located by searching on the Better Business Bureau's website at www.bbb.org.



A lever-type door handle can be operated with an elbow or a fist if needed.



A rocker or toggle-type of light switch is easier to operate and requires less dexterity than a traditional light switch.

Easy Solutions for Mobility Problems, Fatigue, and Other Impairments

Resolving an accessibility problem is often easy with just a few changes. Shelley Peterman Schwarz devised many solutions for different accessibility problems and put them into a book, *Home Accessibility: 300 Tips for Making Life Easier*. Schwarz says some of her favorite solutions are ordinary products from home-improvement stores. Door handles with a lever instead of a knob, and rocker light switches that toggle on and off, are two examples.

“These items aren’t made for people with disabilities, but they make life easier. A lever door handle can be opened with an elbow or a fist. It’s the same for rocker light switches – hand strength isn’t required to turn them on or off. Touch lamps, timers on lamps, and motion-activated lightbulbs can also help.”

For someone with mobility problems, moving or eliminating furniture to allow more room for a mobility device can help. Schwarz

continues, “Arrange the rooms for your convenience. Forget aesthetics and the latest decorator trends. Take throw rugs, for instance. These can be dangerous to someone with a mobility problem. It’s better to get rid of them.”

Patricia Bobryk, MHS, PT, MSCS, ATP is a physical therapist who is certified as an Assistive Technology Professional (ATP) through the Rehabilitation Engineering Society of North America (RESNA). She explains that changing thresholds can be another easy fix. “When floor surfaces change from tile to carpet, people can catch their toes on these slight changes in floor level. A flatter molding or one that is more beveled can help.” Bobryk also notes that nonskid flooring works better than carpeting for someone in a manual wheelchair. While many may be familiar with this fact, considering these types of floors when planning home improvements is important.

ABOUT THE AUTHOR

Maryann Hunsberger is a freelance writer who is familiar with mobility and accessibility issues. In this article she includes some of her own experiences with home-accessibility needs and solutions, as well as the recommendations of several experts.

Individuals with disabilities may be able to find solutions by modifying how they perform their normal activities. For example, some people might feel more stable if they hug the wall or lightly hold onto furniture when walking between rooms. One MSAA client found that she couldn't get in and out of the bathtub to bathe in the evening because of fatigue and balance issues. Changing her bathing time to the morning, when she had the most energy, made a difference. The client was then able to bathe without making changes to the bathtub.

In homes with bathrooms on the main floor, some people move their bedrooms to the first floor rather than purchasing a stair lift if needed to reach a bedroom on the second floor. Once in the bedroom, another tip is to use foot-lifter straps to help get into bed with less effort. Foot-lifter straps may also be used to lift one's legs to put on socks. And instead of straining to be heard by someone in another

room, some people install baby monitors in certain locations throughout the house so they can easily be heard from any room.

Reducing Fatigue through Energy Conservation

Fatigue is a common issue for people with MS and other disabilities. As an occupational therapist, Kathleen Zackowski, PhD, OTR is trained to help people to modify how they do things so they can conserve energy and be safe. "Energy-conservation techniques allow a person to enjoy what they are doing without using up all of their energy. Learning how to cut corners lets a person still do things without becoming exhausted."

Decreasing the total load is key to conserving energy, according to Zackowski, and this may be applied to many of one's daily activities. For instance, when cooking, she recommends using a barstool to sit on while preparing food, which saves precious energy. A good idea is to select a barstool with a back to provide lumbar support. Another option is to use a sit-stand work stool that adjusts to various counter heights.

Chopping food and making salads when seated at the table is also an easy change. Bobryk says, "Any activity you can do while sitting instead of standing saves 25 percent of the energy required. This also holds true for sitting to take a shower, and by doing so, you have more energy to do whatever is needed afterward. When cooking, a good tip is to keep a crockpot within easy reach. This is a great energy saver and you can throw all of the ingredients in at once."

continued on page 11



Preparing food while sitting is a good energy-saving strategy.

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.

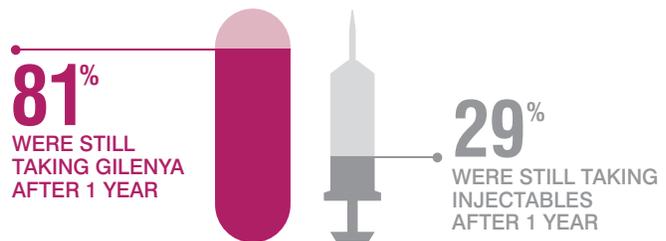


Thinking about a different treatment option?

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!"**

  [Learn more at gilenya.com](http://gilenya.com)



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'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, or by going to 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 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, or go to 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 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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Schwarz reminds people that tasks can be broken up into smaller segments. “You don’t need to do everything at the same time,” she states. “Modifying or even postponing certain tasks to conserve energy can often reduce or eliminate the need for expensive modifications.”

One of the easiest fixes in the kitchen is to have everything at eye level. Bobryk states that this can be accomplished by changing the locations of things. “Keep the things that you use frequently at arm’s reach instead of up too high or down too low.” Shelves that slide out work well, too. They can be purchased online and used in existing cabinets. Extension shelves with drop-down cabinetry can be purchased at home-improvement stores. “Reachers” or “grabbers” are inexpensive and can assist with accessing various items when not able to put everything within reach. These can be purchased at any pharmacy or medical supply store.

Using a “reacher” allows for easy access to items in hard-to-reach places, avoiding the need to ask for help or reconfigure the shelving.



Cooling accessories such as this vest provide symptom relief for heat-sensitive people. MSAA’s Cooling Distribution Program provides free vests to individuals with MS who qualify.



Easy Solutions for Temperature Sensitivity

Temperature sensitivity can be a problem for people with MS, and kitchens get hot when cooking. Wearing cooling vests and other cooling accessories can help in the kitchen. “If it’s too humid where you live, evaporative cooling accessories won’t work as well, so add ice packs in the vest,” says Bobryk.

Induction plates, which are portable cooktops with ceramic tops, keep kitchens cooler. Induction plates heat through magnetic conduction versus a heating element or a gas flame – so the surface does not get overly hot – but only certain types of cookware will work with induction plates. Larger toaster ovens and microwaves may often be used instead of the oven, and these generate less heat as well. Cooking earlier in the day can also help. “By evening, your energy is lower and you are more prone to be bothered by the heat. Preparing food in the morning when it’s cool, and reheating the food in the toaster oven or microwave at dinnertime, is a good strategy.”



Today's technology allows for individuals to control lights, temperature, security systems, and other devices through their smartphone.

Easy Solutions for Visual Impairments

The most important factor for someone with visual impairments is to have clear paths with no clutter to trip over. Colorful reference points also help. Adding a contrasting border to carpet, wood, or tile floors around the edge of the room can provide a good visual cue. A differently colored walking path can show the way from room to room. Floor colors that contrast with furniture colors are also useful. Doorways and light switch plates in contrasting colors can be effective as well. Schwarz says that an inexpensive way to show contrast is to use painter's tape. "Place it where the wall meets the floor. It's designed to come off without stripping the paint."

The use of contrasting paint on the risers of steps can make steps more visible (risers are

For the person with both temperature sensitivity and fatigue, Wi-Fi thermostats save steps by allowing for remote programming. Once a smart thermostat is synced with a Wi-Fi router, remote access is available from a computer, tablet, or smartphone app. A smart thermostat and Wi-Fi router can be found online or at home-improvement stores.

A Wi-Fi thermostat can stand alone or be part of a larger home-automation system that is run by a single app. For example, kits combining a Wi-Fi thermostat, hub, wall switches, and outlets allow lamps and appliances to be operated by a smartphone. Home-improvement stores and online vendors also carry these additional products. Some can even be interfaced with a smart-speaking device, so lowering the heat can be as simple as saying, "Lower the heat to 70 degrees."

These steps illustrate how contrasting colors on the risers and treads of a stairway help to distinguish where each stair begins.



the front panels that face you when walking up the steps). This color should contrast against the color of the top of each step, where your foot touches, and this part of the steps is referred to as the “tread.” Just be sure not to paint the tread of cement steps, since they can become slippery and dangerous.

Easy Solutions for Cognitive Impairments

Zackowski points out that many people with MS may experience cognitive changes, especially as individuals become older. Additional factors such as stress, depression, family issues, and a hectic schedule can also impact one’s memory and other cognitive functions. She advises, “Make lists instead of trying to remember everything. Doing so will become automatic after a couple months. While it takes time, having lists to refer to will make your life better.”

Smartphones and smartwatches come in handy for people with cognitive changes. With built-in timers, they can be used as reminders to take medication or to perform a necessary task. The calendars on these devices can be set for events, such as doctor appointments, and reminders will pop up on the screen or vibrate at the right time. Some smartwatches can be set to read these reminders aloud.

Certain smartwatches may also have medical alert components. At the push of a button, help is summoned. These watches come with a hub that operates by plugging it into a wall socket. These can be purchased online and at various retail stores.

MCAA’s mobile phone application, My MS Manager™, can also assist with reminders

and record-keeping. It is available free of charge to individuals with multiple sclerosis (MS) or their care partner to use on their iPhone, iPad, iPod touch, or Android mobile phone device. My MS Manager™ allows members of the MS community to track disease activity, store medical information, and generate charts and reports across various metrics such as treatments, moods, symptoms, and more. For information, please visit mymsaa.org/mobile.

More Complex Solutions Involving Steps, Ramps, or Railings

One accessibility problem that stumped me was entering and leaving my home. Through connections I made with the disability community in my state, I was able to find a local Assistive Technology Professional (ATP). The ATP came to my home and spoke with me, asking me what I was having the most trouble with. I told him I couldn’t take my children to school, since I couldn’t climb down the front steps.

Since this individual was certified by the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), he was qualified to assess my situation and offer suggestions to keep me safe while providing independence. He told me that the dilemma with my front steps was partly caused by the steps not being made to state code, which has a maximum height of 7.75 inches. Two of my steps were 10 inches high. The step leading into the front door had an 11-inch rise, forcing me to hang onto the storm door closer (pneumatic cylinder) to pull myself into the house.



Landscape ramps such as this one are both functional and attractive.

The ATP explained that he sometimes recommends wooden ramps for problems like these. Depending on the situation, he may recommend modular ramps, which are steel structures that, although not portable, are not permanent structures. These can be moved to a new home or can be placed inside garages, so the house won't have a visible front ramp. The ATP noted that modular ramps also hold up to the elements better than wooden ramps. In other situations, he may recommend landscape ramps, which are made of cement and blend beautifully into the scenery. People who don't want a ramp-like structure in front of their homes often prefer this solution.

When a house is too high for a ramp or has no room for one, the ATP sometimes suggests vertical platform lifts, either for outside or inside a garage. These lift a person in his or her wheelchair or scooter right up to the door.

Since I'm able to walk to my car, the ATP didn't recommend a ramp. He explained that for every inch of rise, a foot of ramp is required to be compliant with the Americans with Disabilities Act (ADA). For instance, with a 7-inch-high rise, you need a 7-foot ramp. If you have a 21-inch rise, you will need a 21-foot ramp. This means that the ramp may need to wind around. Above 30 inches requires a landing. The landing needs to be big enough – 5 feet x 5 feet – to turn a wheelchair or scooter onto. Since my steps were 31 inches high, a 31-foot ramp with a landing would be required. Not only was that too much walking for me, but I didn't want such a large structure in my front yard.

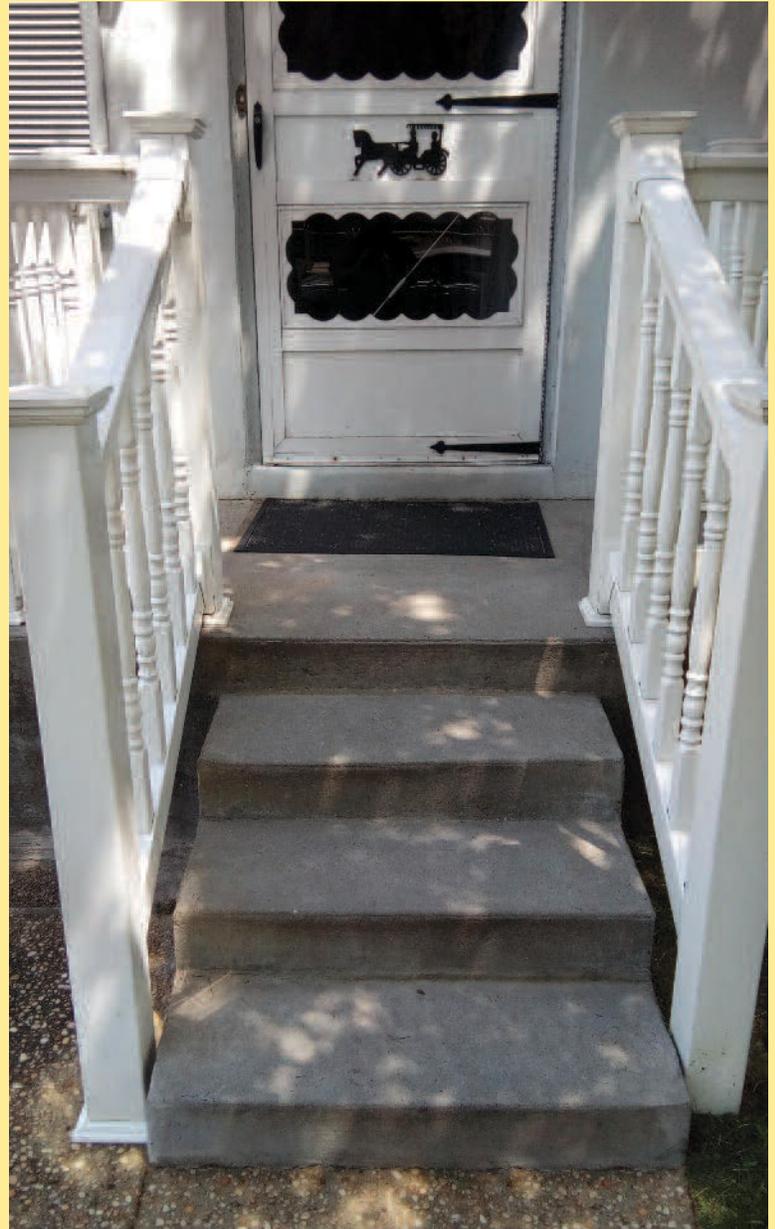
Instead, the ATP recommended low-rise steps with two railings. He suggested that I walk up and down some curbs to determine the height I'd be able to handle alone. I found that I was fine with a 5-inch-high curb, so I

knew my steps should be that height. He also recommended railings on both sides of the steps. He said a handrail should be included, which is a separate rail that is usually attached to the inside of a railing. It is inset from the larger outside rails and provides a rail for holding onto that is typically lower, thinner, and easier to grasp. However, I ended up not getting these handrails added, although these could have been helpful.

The ATP explained that he sometimes recommends widening entry doorways for wheelchairs or scooters to go through. In my case, he recommended simply adding a 5-inch vertical grab bar between my front door and my storm door so I wouldn't need to hang onto the storm door closer anymore. This small modification has made such a difference in my ease of entering as well as my feeling of safety.

I didn't know how to find a contractor who was familiar with disability accommodations. Instead, I just chose the contractor who gave me the best price, which is not always the best plan. Since he was not familiar with disability accommodations, I needed to explain to the contractor what low-rise steps were. Even at that, he inexplicably thought I also wanted the stair treads to be small and wanted the steps to be narrow. The steps he began to construct looked like they were for toddlers. I had to remind him that I wanted wider steps with a normal stair tread (10-½ to 11 inches) so adults could use the steps.

continued on page 19



This article's author was able to resolve her accessibility problems at her own home by replacing her tall steps with low-rise steps (above) and a double railing.

A 5-inch vertical grab bar (right) was added to the doorway, which is very useful to help her to enter her home and feel safe.



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. 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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H.P. **Acthar**[®] 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. You may also report side effects by calling 1-800-778-7898.



A handrail connected to the main railing is often recommended for easier gripping.

In looking back, I found that I did some things right, such as hiring a RESNA-certified ATP to assess my situation and give me recommendations, and requiring the contractor to correct the stair width and tread size. However, I did some things wrong, such as hiring a contractor with no knowledge of disability accommodations and not insisting that handrails be added to the railing.

As my experience shows, finding a competent contractor is important. The Better Business Bureau's website is a good resource for finding contractors who are licensed, insured, and experienced. At the same time, finding a contractor who knows about disability modifications is crucial. Bobryk suggests looking for a CAPS-certified (Certified Aging in Place Specialist) contractor. The website for the National Association of Home Builders (NAHB) at www.nahb.org provides a great deal of information on buying, maintaining, and remodeling homes. It also gives a list of CAPS-certified contractors on their website.

Bobryk also suggests interviewing contractors. "Ask how many accessibility designs they have done. Ask for pictures.

Ask for certification in either accessible design or universal design. Universal design means the design will work for everyone, with or without disabilities."

Modifications inside the Home

If wheelchairs are needed, front entries are only part of the more costly solutions people with MS may need. For example, kitchens are fraught with obstacles. Bobryk suggests starting small. "You can do things piece by piece. Maybe start by lowering light switches and raising electrical outlets to wheelchair height."

She says an existing sink can be made wheelchair accessible by removing the cabinet under the sink and leaving it open. The same can be accomplished with a stove by switching to a cooktop with an open space under it.



Removing cabinets from under a counter, sink, or cooktop can allow individuals to have easy access with a wheelchair.



An example of universal design, a two-tiered countertop allows a person in a wheelchair to sit alongside the lower counter, while an ambulatory person can stand or sit at the higher counter.

“Make sure the cooktop knobs are in front. And switch to sink faucets that can be turned on by touching or waving.” Also, side-hinged wall ovens open like a regular door and allow for easier sliding in and out of food. Drawer dishwashers are easier to load and empty.

In some kitchens, a two-tiered countertop, where one counter is above the other, can be helpful. This example of universal design allows a person in a wheelchair to sit at the lower counter, while an ambulatory person can stand at the higher counter. This functions well for center islands. It also works well for people who fatigue too easily to stand while preparing food.

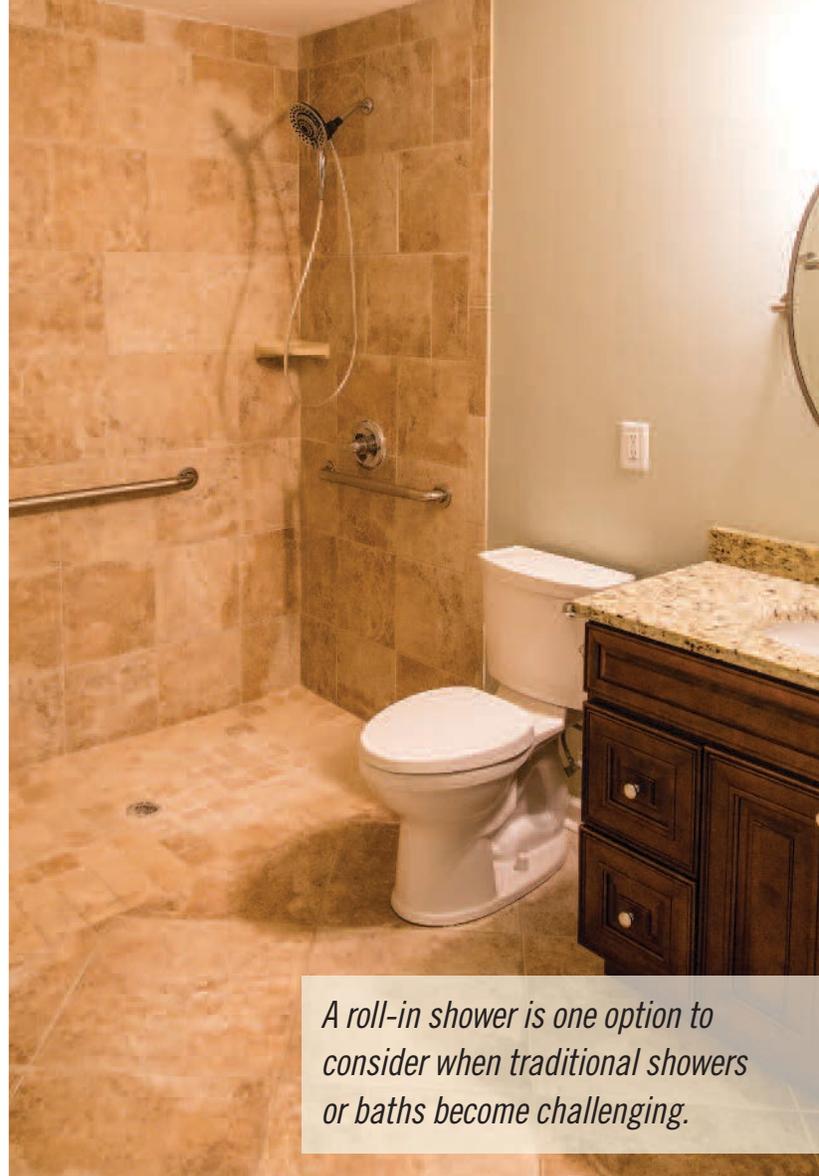
Bathrooms are the other inaccessible hot spot in most homes. Bobryk says, “The bathroom is a big issue that doesn’t always have an easy fix. If someone can’t access the bathroom, we need to call in professionals. But, ask the builder for pictures of other accessible bathrooms he or she built. Wheelchair users might need to lower towel bar height and buy a bathroom sink that is lower. Roll-in showers, walk-in tubs, and hydraulic lift tubs are options to consider.”

Grab bars are important to help steady someone with balance problems. Bobryk notes, “They make them way more stylish now. The grab bar functions the same but doesn’t look like it’s for a disability. Home-improvement stores carry these more stylish grab bars.” Individuals may also go online to shop for aesthetic grab bars. Some websites will recommend local installers, and they may show diagrams and instructions for ADA grab bar requirements for shower stalls, bath tubs, and toilet stalls. Grab Bar Specialists is an online company that offers this type of information, which you can find on their website at www.grabbarspecialists.com.

Widening the bathroom doorway isn’t always necessary. Doors can be reversed to open out, giving more space to enter the bathroom. Regular doors can sometimes be switched to pocket doors that slide inside the walls. And offset hinges can be used to create more space. Bobryk says, “It’s an easy fix that lets the doors swing open behind the door jamb. It can allow for an extra 1-½ or 2 inches of space.”

Many interior doors, such as those used for a bathroom, are only 24 inches wide. When widening a doorway is necessary, if the approach is straight, you will minimally need a 32-inch opening to accommodate a wheelchair. If the door is connected to a hallway and a turn is needed, a 36-inch opening is required. According to Adaptive Access, a national supplier of home-modification equipment and local contractor in Houston, Texas (www.adaptiveaccess.com), a number of steps are necessary to widen a doorway. These include removing the old door and trim; possibly moving a light switch; and cutting the wallboard and studs. Once the opening has been prepared, the new door and trim may be installed. These will need to be painted and the flooring at the base of the doorway will need to be repaired – so you'll need flooring that matches the existing floor. They estimate that two experienced carpenters will take about eight hours to complete the job.

Sometimes the cost of modifying the entry to the house, the kitchen, and the bathroom is far too great. Schwarz says this might mean it's time to move. "It's important that one's home not make them feel trapped or unable to function. When a person feels unsafe in their house, when they can't leave the house safely, when they can't bathe safely, when they are becoming a recluse, it's time to think about doing something different. When thinking about major remodeling, ask yourself if it's smart or if it would be easier finding a more accessible place. Accessible homes and apartments are much easier to find today than 20 years ago."

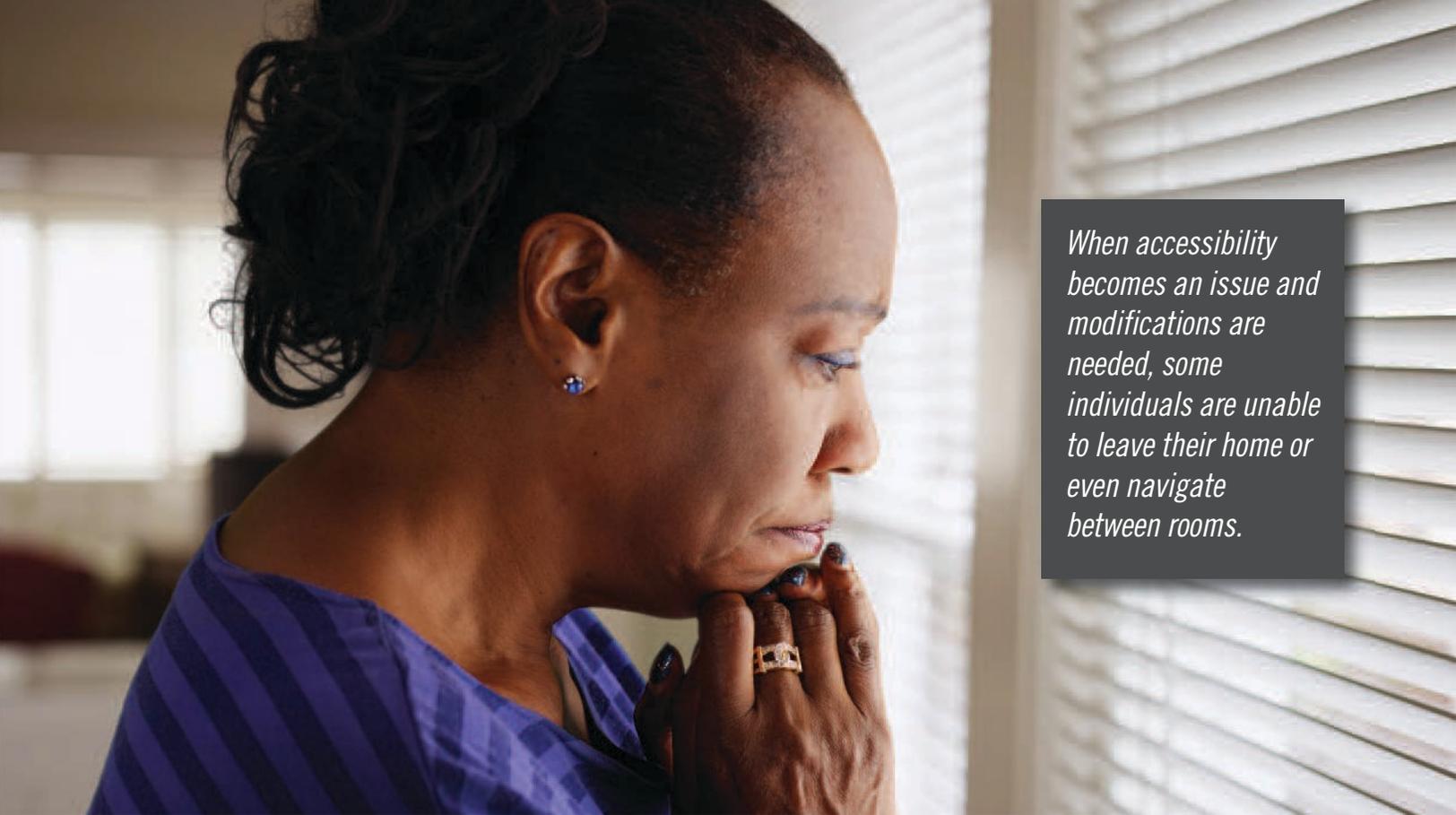


A roll-in shower is one option to consider when traditional showers or baths become challenging.

Where to Begin?

Julie Fiol, BSN, MSW, a senior research nurse at Johns Hopkins MS Center, says speaking to a professional is a crucial first step. That usually means asking a physician for a prescription to see an occupational therapist (OT). In Fiol's position, she is often the first professional who patients talk to about their need for home modifications. Sometimes, though, she is the one to suggest to patients that they need to make some changes.

"The information might come out when we see that patients are isolated, stuck in the house, injuring themselves or having bladder incontinence because their home is not accessible. We found that one patient spent all



When accessibility becomes an issue and modifications are needed, some individuals are unable to leave their home or even navigate between rooms.

day in her room because the rest of the house wasn't accessible. She couldn't get up or down stairs without someone helping her."

Fiol says she doesn't necessarily know the solutions, but she can help identify the need and make the right referral. "When we have a safety concern, we try to have a home safety evaluation done by an OT." If insurance won't pay for the evaluation, Fiol will send a physical therapist (PT) or a nurse to the house to determine if occupational therapy is needed. "At that point, insurance companies usually pay for the OT to go to the house."

Not all OTs do in-home accessibility evaluations, but most OTs can refer a patient to someone who is qualified. If a person doesn't have an OT to ask, they can start by asking their family doctor or neurologist for a referral. Often, a Physical Medicine and Rehabilitation (PM&R) physician, also known as a physiatrist, is more knowledgeable in this area and can refer someone to a qualified OT.

Fiol says most states have at least one MS center, and most know qualified OTs. If none are available, Fiol suggests contacting the home health department at a local hospital or the local Centers for Independent Living (CILs). Each state has several CILs. "These places can help with where to find an OT, what types of modifications to get or where to find funding sources." The RESNA website, at www.resna.org, has a list of RESNA-certified ATPs who can do these assessments.

Some of these modifications – or moving to a new home – can be a considerable financial burden. If friends, family members and places of worship are unable to help defray the costs, seek out solutions through local nonprofit or civic organizations and online fundraising sites. Social media can be a great advantage in this area. And if the modifications are necessary for a person's job, the State Division of Vocational Rehabilitation (DVRS) can assist with funding.

Closing Notes

I hope the information presented in this article can be useful and supportive in your efforts to improve your safety, mobility, independence, and quality of life. I especially would like to reinforce the suggestion of consulting your doctor and other healthcare professionals, including occupational and physical therapists, as a first step in this process.

In speaking with many MS clients over the years, I have learned first-hand about the positive benefits that often result from making simple lifestyle adjustments as well as using low-cost assistive devices. Unfortunately, I have also heard too many heartbreaking stories about rushed decisions to undertake expensive home modifications that proved ineffective and dangerous in some cases. Having a qualified healthcare professional evaluate your personal abilities, areas of need, and your home and work environments, can lead to a clear and effective plan with important cost-saving measures and better outcomes for you and your family.

Peter Damiri

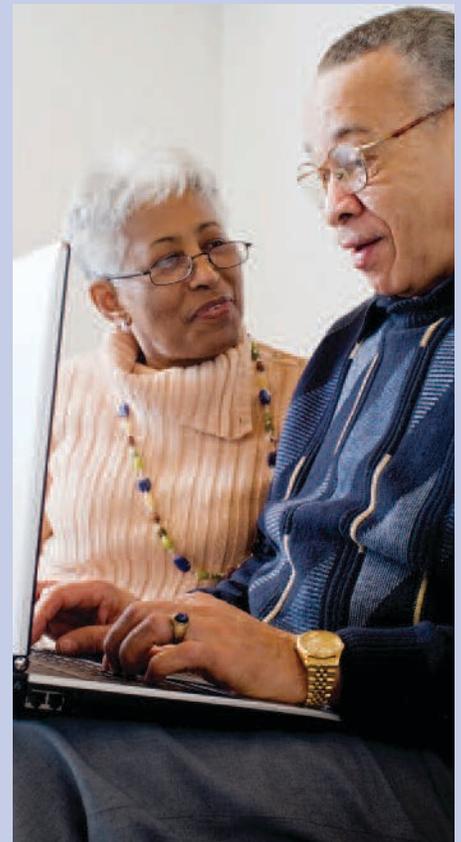
MSAA Vice President of Programs and Services

MSAA's Equipment Distribution Program

As mentioned in the article, the use of durable medical equipment and daily living aides can greatly improve a person's safety, dignity, mobility, and independence. MSAA's longstanding and popular Equipment Distribution Program offers a selection of safety and mobility items free of charge to qualified applicants who have a diagnosis of multiple sclerosis. Due to costs and other variables, MSAA's Equipment Distribution Program provides the following listed items only:

- Bathtub safety rail
- Easy-grip utensil set
- Grab bar
- Hand safety rail
- Leg lift
- Manual wheelchair
- Quad cane
- Shower chair
- Walker with seat and four wheels

If interested in applying to the Equipment Distribution Program, please visit mymsaa.org/equipment or call **(800) 532-7667, ext. 154**.



continued on page 28

OCREVUS™
ocrelizumab 300MG/10ML
INJECTION FOR IV



FDA APPROVED

**for Relapsing Multiple Sclerosis &
Primary Progressive Multiple Sclerosis**

Visit OCREVUS.com/MS or call 1-844-627-3887 to learn more

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 heart beat

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
U.S. License No. 1048

For more information, go to 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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OCR/090116/0278a Printed in USA. 3/17

Vehicle Modifications

By Maryann B. Hunsberger

As the author of the cover story, readers may have noted that I am personally familiar with mobility and accessibility issues – and necessary modifications not only apply to one’s home, but to one’s vehicle as well. I needed a way to lift my scooter into my SUV, so I attended the Abilities Expo in my state and sought information. I learned that a ramp-equipped van wasn’t right for me. I wanted to sit in the car’s seat, not in my scooter, while I rode in my car. I learned that lifts are available specifically for SUVs. I paid a vehicle modification company to come out and measure my SUV to determine which lift would work for me. I bought a

particular lift and paid the vehicle modification company to install it.

The lift reaches down to my scooter, hooks on, and pulls it right into my SUV. I had to be firm with the dealer about what I wanted, as they tried to sell me an expensive ramp-equipped van. It’s important for people to research and know what they want before approaching a vehicle modification company.

Occupational therapist (OT), Kathleen Zackowski, PhD, OTR, explains that OTs can recommend vehicle modifications. “These modifications are amazing now. They don’t cost an arm and a leg because they can be added to an existing car. A person can change from a foot pedal to hand controls. They can add different types of steps to get into a vehicle. They can add a ramp. An OT can recommend equipment that can lift a wheelchair into the trunk of their car. And an OT can explain how to get back to the front seat and be independent.”

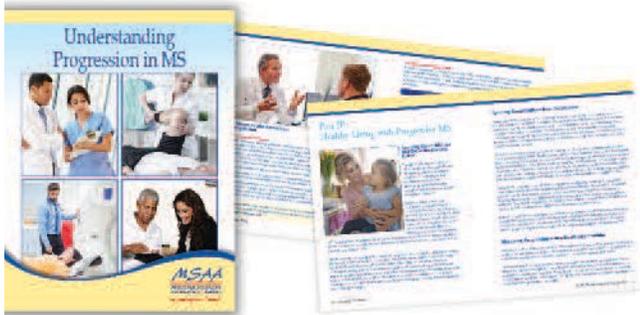
Car transfer aids also make using a car easier. Swivel seats, swivel seat cushions, auto grab bars, transfer boards, and more are available for purchase. For instance, valet seats are installed in place of regular front seats. They swivel around and lower the person to standing height in higher vehicles.

Pictured is the author’s lift used to put her scooter in the back of her van, enabling her to ride while sitting in a passenger seat rather than her scooter.

Several types of vehicle modifications are available to enable wheelchair users to ride or drive in a van, SUV, or truck. Individuals should consult experts to learn about their options before investing in new equipment and/or a new vehicle.



MSAA Offers Two New Publications



Understanding Progression in MS



MS Relapse Toolkit

To download or order either booklet,
please visit mysaa.org/publications or call (800) 532-7667.

RESOURCES

Abilities Expo

www.abilities.com/expos

Better Business Bureau

www.bbb.org

Bruno Independent Living Aids for vertical and other types of lifts, plus vehicle seating

Visit www.bruno.com and select from the "Bruno Products" drop-down menu

Centers for Independent Living (CILs)

Visit www.ilru.org, then select "Directory of CILs and Associations" in the upper left column

Directory of MS Centers

Visit www.mscafe.org, then select "MS Centers Directory" from the "Connect" drop-down menu

Grab Bar Specialists

www.grabbarspecialists.com

Mobility Aids for home and vehicle use

www.mobility-aids.com

MobilityWorks for accessible vehicles

www.mobilityworks.com

MSAA video about home modifications

mysaa.org/videos/closerlook-work

National Association of Home Builders (NAHB) CAPS-certified contractors

www.nahb.org

RESNA-certified ATPs

www.resna.org/member-directory/individual

United Spinal Association's Spinal Cord Resource Center

Visit www.unitedspinal.org/resource-center/askus/, then scroll down menu on left and select "Home Modifications"



Reducing Relapses in Secondary-Progressive MS

By Dr. Jack Burks

MSAA's Chief Medical Consultant

Q: I was diagnosed with relapsing-remitting MS in 2005 and have since gone into secondary-progressive MS. I've tried several disease-modifying therapies. My walking is still declining to where I use a walker all of the time and a power chair when needed.

I watched a video for Lemtrada and as I understood it, Lemtrada didn't really work for progressive MS – only relapsing-remitting MS. Am I wrong? I thought of trying rituximab, which I know is not approved but may be available through some MS centers. I know rituximab is being advanced to another drug, but not sure what this is. I live in Springfield, Missouri, and I don't know of any MS centers in the area. Could you please give me your opinion on which way I should go?

A: I can understand your urgency to explore treatments for your secondary-progressive MS (SPMS). The important issue (not addressed in

your question) is whether you still have MS relapses or evidence of “active” MS inflammation on your MRI scan, i.e., if gadolinium-enhanced lesions are seen. If so, different treatments may be worth considering, including Lemtrada® (alemtuzumab) and other disease-modifying therapies (DMTs).

You should review the risks and benefits of all treatments with your doctor, ideally an MS specialist. As for Lemtrada specifically, it has been approved by the United States Food and Drug Administration (FDA) for relapsing forms of MS, which include SPMS with relapses for reducing disease activity, but it was not approved for treating progression. Although one of the two clinical trials compared to a high-dose interferon (Rebif®) did show an effect on MS progression, the FDA usually requires positive results in two separate clinical trials before a medication can be considered for approval. Nonetheless,

Jack Burks, MD is the chief medical consultant for MSAA. He is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies as well as new MS centers. He also advises patients, families, MS organizations, and healthcare groups. Dr. Burks is an adjunct professor at Nova Southeastern University and clinical professor of neurology at Florida International University. In addition, he has authored numerous textbooks, chapters, and articles on MS.

a discussion of Lemtrada and other DMTs for reducing relapses in SPMS is appropriate.

The new drug that is similar to Rituxan® (rituximab) is Ocrevus™ (ocrelizumab), which was approved by the FDA in March 2017. This is the first time that a medication was approved for the treatment of primary-progressive MS (PPMS) and relapsing forms of MS (RMS), which include SPMS with relapses. No comparative studies have been done to compare Rituxan and Ocrevus.

If you have questions, you might ask your neurologist to explain these treatments in more detail and/or refer you to one of the

major MS centers in your area for a second opinion. Many leading MS doctors are within driving distance from where you live. If you are unable to locate a center, MSAA's Helpline specialists can help you to locate a comprehensive MS center in your area. These MS centers likely have experience with both FDA-approved and experimental DMTs.

Q: I was diagnosed with MS in the summer of 1990 and am now 79 years of age. Approximately 10 years ago, I noticed a terrible burning in my lower back. My doctor prescribed Lyrica, which seemed to ease the problem some, but it caused swelling of my left foot and hand. Since the burning began,

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Reimagine myself

Jeannie Mai • Style Expert

Check out **ReimagineMySelf.com** for tips on how you can reimagine your life with relapsing MS, including helpful ideas and stories from chef Ben Ford, style expert Jeannie Mai and real people with relapsing MS.

Ben Ford • Chef

Jill K.

www.ReimagineMySelf.com

it has gradually moved through my buttock and into my thigh, which burns even more. Do you have an idea of what this may be?

A: MS damages myelin – the protective covering or “insulation” of the nerves – that helps speed messages into and out of the central nervous system. Brain cells (neurons) and the connecting wires (axons) may also be damaged. The myelin, neurons, and axons control sensation as well as strength, balance, and other bodily functions. Your burning symptoms may represent increasing MS damage, likely in the spinal cord.

MS-related burning sensations are difficult to treat, but medications such as Lyrica® (pregabalin), Neurontin® (gabapentin), Tegretol® (carbamazepine), and other anti-epileptic drugs may help. Anti-depressant medications such as tricyclic anti-depressants and others may also help. Zostrix® (capsaicin) cream and lidocaine gel are other options. Reducing stress, heat, and exertion also may help, although success may be limited.

Q: I was diagnosed with MS when I was 72, although I had symptoms 10 years earlier, which I ignored. My MS was discovered after I had a brain MRI to diagnose why I was experiencing chronic pain from shingles. I have tried a few of the DMTs, but I experienced side effects that were too severe. Because of high blood pressure and heart problems, I have rejected some of the treatment options.

My question is, have any special studies been done on elderly people who suddenly show symptoms of the disease, to find out if they are a discrete group that should be followed and treated differently? Is there a concern for the effect that these powerful drugs have on older bodies?

A: Those are great questions. MS studies on “elderly” people with MS are very limited. Unfortunately, this important area of research has not been adequately addressed. However, we are now more involved in such studies.

Many individuals with MS are living longer, well into their 70’s and beyond. MS trials with DMT treatments do not include participants at your age. The issue may be to limit the chances of comorbidities (other illnesses) from interfering with treatment effects and/or the potential for an increased risk of side effects. After FDA approval, doctors may prescribe the MS medications according to their clients’ type of MS activity and what they may safely tolerate, taking their age into consideration.

Potential risks versus benefits are very important for doctor-patient discussions, which is referred to as “shared decision-making.” The MS medication discussion becomes more complex in people with comorbidities related to aging. Your general medical condition may also be a factor in deciding the risks.

Q: I am hopeful that you will be able to help explain my troubling experience! I have had MS for more than 25 years, but I have never

experienced the event that happened recently. I was waiting to be seated at a restaurant, when I suddenly dropped... like a stone! I had no advance warning, and I didn't black-out. With assistance, I was able to rise without any further symptoms. I know that issues such as lack of sleep, too much stress, or using too much energy on daily tasks can impact how one feels – and this was certainly my experiences on the previous day. Could these have been contributing factors, or do you know of any other reason why I would drop unexpectedly?

A: I do not know the specific cause of your “drop attack,” but I recommend you see your doctor right away. Drop attacks are frightening

and may be related to many medical conditions. Drop attacks, fainting, or any other unexplained collapses need a complete evaluation. In some cases, contributing factors may be low blood pressure, low blood sugar, heartbeat irregularity, seizures, or stressful emotional distress.

Another explanation could be that your legs may be weak from MS. Sometimes people fall when their weak legs give away suddenly and they fall without losing consciousness. But regardless of the cause, all need to be evaluated fully. Again, I recommend you see your neurologist and your general medical doctor or internal medicine specialist as soon as possible. ■

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Being there makes a difference

It could be a simple trip to the mall, a ride to the movies or just a visit to a friend's home. The little things in life can make a big difference.

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be there

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 dailymed.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 – June 2, 2017). †Biogen data on file.

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



Visit 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. 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.**

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 or call 1-800-456-2255

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

Children and Adolescents with MS Experience Significant Reductions in Relapses with Gilenya® (fingolimod) in Phase III Trial

On September 5, 2017, Novartis announced that its Phase III PARADIGMS study in pediatric MS met its primary endpoint. Comparing individuals treated with Gilenya® (fingolimod), a daily oral medicine approved for relapsing forms of MS, to a control group receiving Avonex® (interferon beta-1a) via weekly injections, study participants in the treatment group experienced a significant reduction in their annual relapse rate. The participants in this study were children and adolescents who had been diagnosed with MS and were between the ages of 10 and 17.

According to the press release from Novartis, “Commonly diagnosed during adolescence, pediatric MS is associated with relapses that are more frequent and often more severe than those seen in adults with MS. Relapses negatively affect mobility, balance and cognitive function, and patients with pediatric MS are more likely to accumulate physical disability at an earlier age than those diagnosed as adults. There is currently no treatment indicated for children and adolescents living with MS, based on randomized, controlled, clinical study data.”

PARADIGMS is the first study to compare two MS therapies, approved for adults, in children and adolescents with MS. Enrolling 215 young participants with MS, PARADIGMS was a double-blind, randomized, multi-center Phase III study with a duration up to two years, followed by a five-year open-label extension phase. Side effects and adverse

events were similar to those seen in other clinical trials with adult participants.

PARADIGMS was conducted at 87 sites in more than 25 countries. Results of the Phase III study will be presented at the JointECTRIMS-ACTRIMS Meeting, which will be held in Paris, France in late October. While Gilenya is not yet approved for the treatment of pediatric MS, Novartis is continuing its analysis and is looking at next steps needed to submit this indication for approval. ■

Highlights from the AAN and CMSC 2017 Annual Meetings

Since the publication of the Winter/Spring 2017 issue of *The Motivator*, one of the online articles that MSAA published was a summary of highlights from the American Academy of Neurology (AAN) Annual Meeting in April 2017 and the Consortium of MS Centers (CMSC) Annual Meeting in May 2017.

Among the many topics was important information on MS medications, including select disease-modifying therapies and symptom-management medications. Other information was provided on a number of wellness issues, from lifestyle factors and wellness programs to mindfulness and nutrition. To view MSAA's online article, please visit mymsaa.org/aancmcs2017. ■

Mavenclad® (Cladribine Tablets) Approved by European Commission for the Treatment of Relapsing MS

On August 25, 2017, Merck announced that the 10-milligram dose of Mavenclad® (Cladribine Tablets) had been approved for marketing in 38 European countries, in addition to Norway, Liechtenstein, and Iceland. This is the first approved oral medication for MS that is given via short courses for “highly active relapsing multiple sclerosis.” This “short course” is a maximum of 20 days of oral treatment during a two-year period.

More than 2,700 patients participated in the clinical trials, some of whom were observed for up to 10 years. The Phase III clinical trials included CLARITY, CLARITY EXTENSION, and ORACLE MS. Mavenclad was shown to delay disability progression, reduce annualized relapse rate, and reduce disease activity as shown on magnetic resonance imaging (MRI). Side effects include a reduction in lymphocyte count (these are disease-fighting white blood cells), infections, and a possible increased risk of malignancy.

Although patients are given just two short annual courses of tablets within a period of two years, effectiveness can continue for an additional two years without further treatment and without the need for frequent monitoring. The pharmaceutical company plans to file for regulatory approval in other countries, including the United States. ■

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New and Expanded Educational Programs Slated for this Fall

By **Peter Damiri**

Vice President of Programs and Services

As cooler temperatures finally begin to replace the oppressive summer heat, MSAA is very excited to resume our active fall schedule of free, in-person educational programs across the country. Organized and hosted by MSAA's Regional Directors, our "fall lineup" includes several new series that will explore the areas of progression, employment, and nutrition, as well as expanded programming on popular topics that include care partnering and technology.

To begin, we are pleased to add a supportive series of educational programs around an important, and often under-discussed, topic. Titled "**Understanding MS Progression**," the series will look to help explain the meaning behind an EDSS score, the use of magnetic resonance imaging (MRI) to assess progression, how relapse rates can affect progression, effective MS-symptom management, and strategies to help slow disease progression.

Also new this fall will be a national series addressing employment issues and MS. Titled

"**Understanding Your Rights as an Employee with MS**," discussions will center on workplace accommodations and protections provided by the Americans with Disabilities Act (ADA), options related to disclosure and career changes, and details on re-entering the workforce via vocational rehabilitation and Social Security's voluntary "Ticket to Work" program.

"The information that is available at MSAA educational programs for people with MS and their spouse/caregiver is invaluable," noted MS activist Jim from Orange County, California. "As a leader of the MS Brea Connection Group, I always recommend that people attend these programs, learn from the guest speakers, and about MSAA. It's one more opportunity to get out and about, be social, ask questions, and get answers from the doctors who treat us and help us."

With a growing interest to expand wellness topics into our programming, MSAA is excited to launch a new series on nutrition and MS.

"**Nutrition and Multiple Sclerosis: The**

Connect with other people affected by MS...

...and become a part of the conversation! Visit healthunlocked.com/mymsaa to learn about **My MSAA Community**, MSAA's free peer-to-peer online forum hosted by **HealthUnlocked.com**.

Newest Information on Nutrition, and How It Can Help to Better Manage Your MS,”

will focus on the latest innovations in the field of nutrition, utilizing the most up-to-date thinking from experts in the field. A specially developed curriculum will be presented by a nutrition expert and MS neurologist. The presenting speakers will provide an overview on research demonstrating the importance of managing nutrition to achieve overall high quality of life and developing practical, workable ways to include healthy nutrition in everyday living.

Based on the popularity and success of programs conducted earlier this year, MSAA is thrilled to expand coverage around several key topic areas, including care partners as well as technology. Our expanded care-partner series, **“Taking Care of Yourself While Taking Care of Others,”** examines the challenges faced within the patient and care-partner relationship paradigm, from tackling care-partner burnout, to intimacy and social issues. Important topics presented in this program include managing stress in a changing environment, adapting new methods of time management that include personal time, understanding intimacy and progressive disability, as well as identifying resources available to the care partner.

Also this fall, MSAA looks forward to continuing another very well-received series on technology and MS titled **“What Have I Missed? The Newest Innovative Technologies, Tools, and Strategies to Help Better Manage Your MS.”** With expanded content this fall, this series will present the latest innovative, technological advances and health-management tools that can be used to

better manage MS and improve overall adherence and wellness. Topics explored include cognitive re-training tools, MS patient apps (including MSAA’s “My MS Manager™”), fitness tracking tools, assistive walking devices, and more.

While MSAA is very excited to spotlight several of these new and expanded series, please know there are many additional programs occurring throughout the year. We encourage you to visit mymsaa.org/calendar to see the full and updated listing of MSAA’s educational programs and also register to attend one or more of these insightful and worthwhile events. If you have any additional questions, please feel free to call MSAA at **(800) 532-7667, ext. 154.** ■

In Memoriam

We are sad to share the news of the passing of our dear friend and colleague, Becky Remington. Becky was MSAA’s South-Central Regional Director since 2007 and conducted countless educational programs for the MS community. Becky was greatly admired for her commitment to helping those affected by MS and served as an inspiration to many. With her positive outlook and extraordinary dedication to serving the MS community, Becky worked tirelessly to improve the lives of MS clients and their families across her vast 11-state region and beyond. Her smile and compassion will be well remembered and cherished by all.

Donate in Honor or in Memory of Someone Special

By making a tribute gift to the Multiple Sclerosis Association of America, you have the opportunity to provide a lasting remembrance to memorialize a loved one or honor a friend. You also have the opportunity to celebrate a birthday, holiday, anniversary, unique accomplishment, or special occasion – all while supporting our urgent mission.

When a tribute gift is received, MSAA will promptly send a personalized tribute or memorial card to the person or family indicated. This will notify them of your thoughtful gift, while not revealing the amount of the donation.

To make a tribute gift by mail, please send your check to:

Multiple Sclerosis Association of America
375 Kings Highway North, Cherry Hill, NJ 08034

With your donation, please include:

1. The name of the honoree
2. If the gift is in memory or in honor of someone, or if this gift is to celebrate a special occasion
3. The name and address of the recipient (if you wish us to notify them of your donation); you may also add a brief message

To make a tribute gift online, please visit support.mysaa.org/tribute.

A Special Story to Inspire

When Rose's husband Keith passed away, she knew she wanted to do something that would establish a lasting tribute to him. Keith was diagnosed with MS in 1989 and passed away due to complications of the disease. Rose created an online tribute page in memory of her husband that included a photo of Keith and allowed his friends and family to sign a guestbook. Not only did Rose help raise funds to provide free services and support to other individuals affected by MS, she was also able to share his story and memorialize her late husband.

Your generous donation will help ensure more people get the assistance they are seeking. This includes resources for the newly diagnosed – such as urgent information through MSAA's website and online videos, award-winning publications, educational programs, and vital phone consultation – as well as resources and services for those at any stage of MS, which includes cooling vests, wheelchairs, safety and mobility devices, urgently needed MRIs, and much more.

CREATE AN
**ONLINE
TRIBUTE
PAGE**
ON OUR WEBSITE

Honor a friend, remember a loved one, or celebrate a special occasion.

CREATE: Create a personal Tribute Page with your message and pictures for any occasion.

PERSONALIZE: Write a personal story, share memories, add a picture, or create a photo album.

SHARE: Email family, friends, and coworkers about your Tribute Page and ask them to support the cause or share their thoughts on your guestbook.

UPDATE: Make updates, send emails, and check the progress of your Tribute Page.

Create Your Own Fundraising Event

Each year, individuals and groups turn their passions and interests into unique fundraisers to raise thousands of dollars for MSAA. Simple ideas could include a bake sale, “Dress-Down Day” at the office, a coin toss, a bingo party, or joining Team MSAA in various endurance events. Other exciting ideas include a car show, a polar plunge, a “Strike for MS” bowling competition, or a sporting event such as a golf, soccer, tennis, or basketball tournament. If you enjoy swimming, you can also create your own Swim for MS challenge – check out SwimForMS.org for more information. If interested in creating your own fundraisers, please visit support.mymsaa.org/create or email us at events@mysaa.org.

To follow are just a few examples of inspirational individuals and groups who have gone above and beyond to improve the lives of those affected by MS.



ANNUAL COIN TOSS

The Knights of Columbus, Santa Maria Council #1443, organized their 4th Annual Coin Toss in New Jersey on March 11, 2017. Each year, volunteers are supplied with safety vests, donated lunches from Chick-fil-A, and safety assistance from local police officers. The event organizer’s wife has MS and received a shower chair, quad cane, and a cooling vest through MSAA’s Equipment and Cooling Distribution programs. This year’s event raised \$2,600 to support the MS community.

MS SPRING GOLF CLASSIC

The MS Spring Golf Classic was held in New Jersey on May 8, 2017. Nearly 180 golfers enjoyed a day of golf while raising more than \$250,000 to benefit the Multiple Sclerosis Association of America. More than 40 corporate teams from the New York City media and advertising industry participated in the MS Spring Golf Classic.



ANNUAL CAR SHOW

On July 24, 2017, 1A Auto held their 7th annual Summer Roundup Charity Car Show in Massachusetts, which included more than 200 cars – ranging from muscle cars and hotrods to rock crawlers, lowriders, imports, and exotics. The event raised \$1,500 and included a DJ, food, vendors, and raffles.





ROCK 'N' ROLL FOR TEAM MSAA

Kaitlyn Gallagher, MSAA's public relations and marketing coordinator, participated in the Rock 'n' Roll 5K in Philadelphia, Pennsylvania this past fall as a part of MSAA's endurance events initiative. Kaitlyn's grandmother lived with MS for many years and frequently participated in MSAA programs. Kaitlyn explains, "Knowing that the dollars I raise will help people with MS who are just like my grandmother gives me the motivation to cross the fundraising and race finish lines! I am honored to run in memory of my grandmother, and thank MSAA for the work that is done each and every day in the name of the MS community."

DOPEY CHALLENGE FOR DADDY

Eleven years ago, Rachael's dad, Dan, medically retired from his job because of his MS. Today, after 25 years of coping with MS, he uses a wheelchair and is unable to stand. Every day he struggles and yet every day he jokes about how "Dan-good" his life is. Rachael says, "Given how severe his condition is and how much he has struggled, I want to do the entire Dopey challenge, even though that struggle is nothing compared to his day-to-day challenges." In his honor, Rachael will be running the 48.6-mile Dopey Challenge with Team MSAA in the 2018 Walt Disney World® Marathon Weekend to raise money for individuals affected by MS. To read more of Rachael's story or to help her reach her goal of raising \$4,500, please visit support.mymsaa.org/RachaelWDW.



SWIM FOR MS

Adrienne Cornish is swimming 100 meters for every dollar donated to her Swim for MS campaign! Joining Adrienne on her Swim for MS journey is her 14-year-old daughter, Katy. Sadly, Adrienne's mother passed away due to complications from MS. She saw Swim for MS as an opportunity to honor her mother's legacy while doing what she loves most – swimming. "My daughter is named after my mother," said Adrienne. "And our Swim team name is KMCswim in honor of my mother as well. Finding Swim for MS felt like a perfect fit – I have this connection to MS, and this program offered a way for me and my daughter to swim together while supporting a cause we're passionate about." To read more of Adrienne and Katy's story, please visit support.mymsaa.org/KMCswim.

SUPPORT FOR YOUR MS IS LOOKING UP

The Above MS™ program from Biogen is here for you with tips, tools, and inspiration for your MS—and more.

There are many benefits to joining the Above MS program. As a member, you'll get extra help from those who understand MS, including:

- One-on-one MS support over the phone
- A community of peers
- Tips and education designed to help with different aspects of your life
- Information about relapsing MS treatment options from Biogen
- Insurance and financial assistance support (if you're eligible)
- 24/7 phone support from Nurse Educators
- Recommended online content based on your preferences
- MS webinars and live events in your area

Please keep in mind that your doctor is always your primary resource when it comes to your MS and your treatment.

**Get extra support from the Above MS program.
Sign up now at AboveMS.com.**

MCAA's Lending Library Selections

A Quiet Roar: Living with Multiple Sclerosis

by Heidi Redl

Caitlin Press

MCAA Book #430

Growing up on a pioneer ranch in the rough and dusty days of the late 1960s and 1970s, Heidi learned at a young age to be self-reliant and tenacious. Life as a rancher had given her the courage she would need to bravely and persistently fight back against her diagnosis of MS in 2004. This compelling and honest memoir describes her struggle living with a progressive disease, but also highlights the support and incredible friendships she found along the way.



Multiple Sclerosis... Why Not Me?

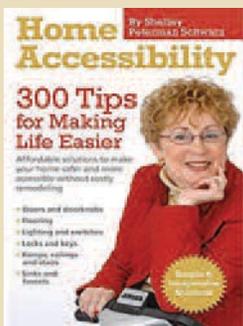
by Vincent Spoto

Dorrance Publishing Co. | MCAA Book #429

After his diagnosis, author Vincent Spoto often wondered "why me?" However, after living with MS for many years and speaking with others who courageously battle all types of life challenges, his outlook changed. In his book, Vincent recounts the adjustments he has made to better cope with MS, all while maintaining a positive attitude. He hopes his personal journey of living with MS will provide positive inspiration to others, in the same way that others have inspired him.

MCAA's Lending Library

To borrow books featured in this column or any other book in MCAA's Lending Library, please visit mymsaa.org/library to view a list of books available and to complete a form. When ordering a book, please reference the book number listed. Readers may also call MCAA at (800) 532-7667 for more information. MCAA and its clients greatly appreciate any donations made to help build the Lending Library. Please send your book donations to: **MCAA Lending Library, 375 Kings Highway North, Cherry Hill, NJ 08034.**



Home Accessibility: 300 Tips for Making Life Easier

by Shelley Peterman Schwarz

Demos Health | MCAA Book #459

Living with multiple sclerosis for more than 30 years, author Shelley Peterman Schwarz shares her vast knowledge of affordable solutions to make a home safer and more accessible without costly remodeling. Shelley takes readers on a room-by-room tour offering simple, practical, and affordable solutions that address everyday challenges and help improve safety and independence.



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EMD Serono

Teva Pharmaceuticals

Estate of Catherine A. Woodfield

VISIONARIES

(\$50,000 to \$99,999)

Acorda Therapeutics

Anonymous (2)

Mallinckrodt Pharmaceuticals

MOTIVATORS

(\$25,000 to \$49,999)

Anonymous (1)

Estate of Richard Paull

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(\$10,000 to \$24,999)

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The Foster Family Private Foundation

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Christopher Langanke

Estate of Doris Neilly

Estate of Charlotte Oliphant

Olmstead Christian Church

Santo Petroleum

Estate of Stanley Saperstein

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Marion Wowkowych



Multiple Sclerosis Association of America

375 Kings Highway North
Cherry Hill, NJ 08034 USA

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Shopping this Holiday Season?

Support MSAA every time you shop!

MSAA has partnered with several businesses who donate a portion of their proceeds back to MSAA. This is a great way to support MSAA's mission of Improving Lives Today without any added cost to you. Please register with the following businesses so a contribution can be made to MSAA whenever you make a qualifying purchase!

AmazonSmile

Here you'll find gifts for everyone, so please register MSAA as your charity

PuraVida Bracelets

For each MS awareness bracelet purchased, Pura Vida will donate 10% of the purchase price to MSAA

Yankee Candle

Support MSAA through our 6th Annual Yankee Candle Holiday Fundraiser

CafePress

Purchase customized apparel and accessories in support of the MS community

To get started, please visit
mymsaa.org/ShopAndSupport

