

momentum®

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SUMMER 2020

A handle on pain

New approaches mean more people with MS are taking control and getting their lives back.

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I'M READY

**FOR AN MS TREATMENT THAT'S
NOT AN INFUSION, NOT AN INJECTION, NOT A DAILY PILL.**

MAVENCLAD is the first and only short-course oral therapy with no more than 10 treatment days a year over 2 years.*

Talk to your healthcare provider to find out if MAVENCLAD is right for you, and visit mavenclad.com for more information.

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

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

MAVENCLAD may cause serious side effects.

Treatment with MAVENCLAD may increase your risk of developing cancer. You should follow healthcare provider instructions about screening for cancer. Because of the risk of fetal harm, do not take MAVENCLAD if you are pregnant or of childbearing potential and not using effective birth control.

Your healthcare provider will monitor your health before you begin treatment, and during your 2 yearly treatment courses. You will continue to be monitored for at least another 2 years, during which you do not need to take MAVENCLAD. Your healthcare provider may also delay or completely stop treatment if you have severe side effects. It is not known if it is safe and effective for people to restart MAVENCLAD after the full 4-year period.

*Depending on your weight.

Please see Important Information, including **serious side effects**, on the following pages.

IMPORTANT INFORMATION ABOUT MAVENCLAD® (cladribine) tablets, for oral use

Read this information carefully before using MAVENCLAD and each time you get a refill, as there may be new information. This information does not take the place of talking with your healthcare provider (HCP).

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

MAVENCLAD can cause serious side effects, including:

- **Risk of cancer (malignancies).** Treatment with MAVENCLAD may increase your risk of developing cancer. Talk to your healthcare provider about your risk of developing cancer if you receive MAVENCLAD. You should follow your healthcare provider instructions about screening for cancer.
- **MAVENCLAD may cause birth defects if used during pregnancy. Females must not be pregnant when they start treatment with MAVENCLAD or become pregnant during MAVENCLAD dosing and within 6 months after the last dose of each yearly treatment course. Stop your treatment with MAVENCLAD and call your healthcare provider right away if you become pregnant during treatment with MAVENCLAD.**
 - For females who are able to become pregnant:
 - Your healthcare provider should order a pregnancy test for you before you begin your first and second yearly treatment course of MAVENCLAD to make sure that you are not pregnant. Your healthcare provider will decide when to do the test.
 - Use effective birth control (contraception) on the days on which you take MAVENCLAD and for at least 6 months after the last dose of each yearly treatment course.
 - Talk to your healthcare provider if you use oral contraceptives (the “pill”).
 - You should use a second method of birth control on the days on which you take MAVENCLAD and for at least 4 weeks after your last dose of each yearly treatment course.
 - For males with female partners who are able to become pregnant:
 - Use effective birth control (contraception) during the days on which you take MAVENCLAD and for at least 6 months after the last dose of each yearly treatment course.

What is MAVENCLAD?

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

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

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

Do not take MAVENCLAD if you:

- have cancer (malignancy).
- are pregnant, plan to become pregnant, or are a woman of childbearing age or a man able to father a child and you are not using birth control. See **“What is the most important information I should know about MAVENCLAD?”**
- are human immunodeficiency virus (HIV) positive.
- have active infections, including tuberculosis (TB), hepatitis B or C.
- are allergic to cladribine.
- are breastfeeding. See **“Before you take MAVENCLAD, tell your healthcare provider about all of your medical conditions, including if you:”**

Before you take MAVENCLAD, tell your healthcare provider about all of your medical conditions, including if you:

- think you have an infection.
- have heart failure.
- have liver or kidney problems.
- have taken, take, or plan to take medicines that affect your immune system or your blood cells, or other treatments for MS. Certain medicines can increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations. You should not receive live or live-attenuated vaccines within the 4 to 6 weeks preceding your treatment with MAVENCLAD. You should not receive these types of vaccines during your treatment with MAVENCLAD and until your healthcare provider tells you that your immune system is no longer weakened.
- have or have had cancer.
- are breastfeeding or plan to breastfeed. It is not known if MAVENCLAD passes into your breast milk. Do not breastfeed on the days on which you take MAVENCLAD, and for 10 days after the last dose. See **“Do not** take MAVENCLAD if you:”

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

How should I take MAVENCLAD?

- Limit contact with your skin. Avoid touching your nose, eyes and other parts of the body. If you get MAVENCLAD on your skin or on any surface, wash it right away with water.
- Take MAVENCLAD at least 3 hours apart from other medicines taken by mouth during the 4- to 5-day MAVENCLAD treatment week.

- o If you miss a dose, take it as soon as you remember on the same day. If the whole day passes before you remember, take your missed dose the next day. **Do not take 2 doses at the same time.** Instead, you will extend the number of days in that treatment week.

Your healthcare provider will continue to monitor your health during the 2 yearly treatment courses, and for at least another 2 years during which you do not need to take MAVENCLAD. It is not known if MAVENCLAD is safe and effective in people who restart MAVENCLAD treatment more than 2 years after completing 2 yearly treatment courses.

What are the possible side effects of MAVENCLAD?

MAVENCLAD can cause serious side effects, including:

- o See **"What is the most important information I should know about MAVENCLAD?"**

- o **low blood cell counts.** Low blood cell counts have happened and can increase your risk of infections during your treatment with MAVENCLAD. Your healthcare provider will do blood tests before you start treatment with MAVENCLAD, during your treatment with MAVENCLAD, and afterward, as needed.

- o **serious infections such as:**

- **TB, hepatitis B or C, and shingles (herpes zoster).**

Fatal cases of TB and hepatitis have happened with cladribine during clinical studies. Tell your healthcare provider right away if you get any symptoms of the following infection related problems or if any of the symptoms get worse, including:

- fever
- aching painful muscles
- headache
- feeling of being generally unwell
- loss of appetite
- burning, tingling, numbness or itchiness of the skin in the affected area
- skin blotches, blistered rash and severe pain

- **progressive multifocal leukoencephalopathy (PML).**

PML is a rare brain infection that usually leads to death or severe disability. Although PML has not been seen in MS patients taking MAVENCLAD, it may happen in people with weakened immune systems. Symptoms of PML get worse over days to weeks. Call your healthcare provider right away if you have any new or worsening neurologic signs or symptoms of PML, that have lasted several days, including:

- weakness on 1 side of your body
- loss of coordination in your arms and legs

- decreased strength
- problems with balance
- changes in your vision
- changes in your thinking or memory
- confusion
- changes in your personality

- o **liver problems.** MAVENCLAD may cause liver problems. Your healthcare provider should do blood tests to check your liver before you start taking MAVENCLAD. Call your healthcare provider right away if you have any of the following symptoms of liver problems:

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

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

- o **heart failure.** MAVENCLAD may cause heart failure, which means your heart may not pump as well as it should. Call your healthcare provider or go to the closest emergency room for medical help right away if you have any signs or symptoms such as shortness of breath, a fast or irregular heart beat, or unusual swelling in your body. Your healthcare provider may delay or completely stop treatment with MAVENCLAD if you have severe side effects.

The most common side effects of MAVENCLAD include:

- o upper respiratory infection
- o headache
- o low white blood cell counts

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

Distributed by: EMD Serono, Inc., Rockland, MA 02370

MAVENCLAD is a registered trademark of Merck KGaA, Darmstadt, Germany.

For more information, call toll-free 1-877-447-3243 or go to www.mavenclad.com



momentum

Momentum is published quarterly by
the National Multiple Sclerosis Society

Vol. 13, No. 4

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ISSN 1940-3410

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



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



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



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



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We plan for many contingencies, but we did not plan for a pandemic. And we were not alone. It seems the world was unprepared. However, the MS movement is resilient. We are resilient.

We are a movement, by and for people affected by MS. And because of the strength that we gain from each other, we will absorb the blow of this pandemic, and we will persevere to ensure people can live their best lives as we pursue pathways to a cure.

When the pandemic hit, the National Multiple Sclerosis Society moved swiftly in response. We activated disaster recovery and crisis response teams, closed our offices to shelter in place and maintained business continuity. We launched a COVID-19 web page and held weekly webinars for people affected by MS. We provided MS healthcare providers COVID-19 and MS webinars in conjunction with the Consortium of MS Centers. We launched a data-sharing initiative to contribute to COVID-19 and MS research. MS Navigator services were uninterrupted. Many self-help group leaders shifted to virtual meetings.

No one should face MS alone — we are here.

The long-term implications of this pandemic remain unclear. Here is what we know: The viability of large, event-based fundraising is uncertain, at best. When and how we may be able to bring groups of people together for a shared in-person experience is unknown. As a result, our fundraising took a hit. We will continue to make changes to live within our means and, for some time, the National MS Society will be a smaller organization in revenue and staff. We will continue publishing Momentum magazine. However, the local MS Connection newsletter, which was mailed alongside Momentum magazine, will be discontinued.

Some things have changed fundamentally. But our commitment to people affected by MS has not.

We will ensure that people living with MS have current, accurate and comprehensive information on MS. We will innovate — increase virtual opportunities to connect and learn and fundraise. We will continuously improve MS Navigator services, so everyone can connect with a supportive partner to overcome MS challenges.

Visit our website at **nationalmssociety.org** to get up-to-date and reliable information about the coronavirus and search for ways to connect with others. You can contact an MS Navigator by calling 1-800-344-4867, emailing **ContactUsNMSS@nmss.org**, or visiting us online at **nationalMSSociety.org/navigator**.

Now more than ever, it is vital that we stay connected.

How are you holding up? Please share your stories of or your need for resilience. As always, I would love to hear from you. ■



Let me know
your thoughts.
Email me at
cyndi@nmss.org.

Cyndi Zagieboyle

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

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on the cover

Tra, diagnosed in 2010, is among the 80% of people living with MS who have also experienced pain related to their disease.



PHOTO BY KEITH CARLSEN

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PHOTO COURTESY OF DAVE BEXFIELD

Dave Bexfield, who has traveled to many national parks, has some tips for others with MS.

Look for these icons throughout **Momentum**.



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

Everybody is different

I feel that it is as much my responsibility as **Momentum's** to reach a balance in article content and tone. I read only what appeals to and informs me in **Momentum**, as well as four other MS magazines and one spinal cord injury magazine. After 20 years with MS, I am challenged to complete a 3-mile MS Walk with mobility aids, but I have friends that can manage the 50-mile Challenge Walk and a 60-year-old friend who died from her MS a couple of years ago. We are all different, and no one magazine can be everything to everyone.

Heather Mansfield, Virginia

Real facts of life

Thank you for the "Fired up" article by Nicole Bradley-Bernard (Fall 2019) — real facts of life with MS. We do need to be more prepared by doctors about how this can and does affect us daily. We fight a daily battle with an enemy that is silent in attacks and strikes at any time. Add in the roller coaster of emotions, and the picture becomes much clearer on dealing with MS. Hearing about how unkind MS can be is a hard thing to hear, but knowing is much better than being in the dark. You can prepare yourself with a backup of friends and family to be there for support. Sometimes, the only question they need to ask you is, "How can I help you deal with this?"

L. Taylor Paris, Tennessee

More than nicknames

After reading the Spring 2020 Letters in **Momentum**, I want to talk about MS devices — a word I find offensive, by the way. In my experience — three power

chairs in the last 20 years — adapting to a device can be very frustrating. Although these chairs are lifesavers, they present many new challenges. It takes acceptance, adjustments and determination to master these functions when you have MS, not just affectionate nicknames. With respect for this struggle, let's tell it like it is.

Mary Stella Lamont, Florida

A voice for us all

Kimberlee Zabawa's voice is heard by all of us, to perfectly describe our "slow processing" incidents ("Still Unshakable," Spring 2020). I love, love, love this story. It reinforces our feelings that we are OK, just please have patience with us.

Annemarie Rainka, Massachusetts

State of limbo

I just read "State of Limbo" (Summer 2019). I thought I was the only one! I do not feel so lonely and depressed after reading this article. I have been in a state of limbo since 1990, when my first neurologist diagnosed probable MS. Over 15 years, he would always order an MRI and it always came back negative. At least the physician I saw for a second opinion suggested medicine to relieve my pain. I am now seeing another neurologist annually, but all he can do is treat my symptoms. I wish I had been able to take one of the MS medications to see if that would have had an effect. Thank you for this article! This is why I am so happy to receive **Momentum**. ■

Janet, Massachusetts

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



Email us at editor@nmss.org.



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



Tag your thoughts @mssociety using #Momentum.



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

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WITH RELAPSING MS YOUR GOAL IS

TO FIND A WAY TO KEEP

Whether you're new to treatment or ready for a change,

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

SEE WHAT ONE PILL  ONCE A DAY CAN DO

INDICATION

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

IMPORTANT SAFETY INFORMATION

DO NOT TAKE AUBAGIO IF YOU:

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

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

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

SANOFI GENZYME 

MOVING FORWARD*

talk to your doctor about once-daily AUBAGIO



Patient Portrayal



Visit myAUBAGIO.com or scan here to learn more

- Have had an allergic reaction to AUBAGIO or a medicine called leflunomide.
- Take a medicine called leflunomide for rheumatoid arthritis.

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

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

AUBAGIO may cause serious side effects, including: reduced white blood cell count — this may cause you to have more infections; numbness or tingling in your hands or feet that is different from your MS symptoms; allergic reactions, including serious skin problems;

breathing problems (new or worsening); and high blood pressure. Patients with low white blood cell count should not receive certain vaccinations during AUBAGIO treatment and 6 months after.

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

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

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

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

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



PILL ACTUAL SIZE

Once-daily
AUBAGIO[®]
(teriflunomide) 14mg tablets

AUBAGIO is available in 14 mg and 7 mg tablets.

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

Rx Only

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

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

AUBAGIO may cause serious side effects, including:

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

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

What is AUBAGIO?

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

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

Who should not take AUBAGIO?

Do not take AUBAGIO if you:

- have had an allergic reaction to AUBAGIO or a medicine called leflunomide
- have severe liver problems

- are pregnant or are of childbearing age and not using effective birth control
- take a medicine called leflunomide

What should I tell my doctor before taking AUBAGIO?

Before you take AUBAGIO, tell your doctor if you:

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

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

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

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

How should I take AUBAGIO?

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

What are possible side effects of AUBAGIO?

AUBAGIO may cause serious side effects, including:

- See "What is the most important information I should know about AUBAGIO?"
- **decreases in your white blood cell count.** Your white blood cell counts should be checked before you start taking AUBAGIO. When you have a low white blood cell count you:
 - **may have more frequent infections.** You should have a skin test for TB (tuberculosis) before you start taking AUBAGIO. Tell your doctor if you have any of these symptoms of an infection:
 - fever
 - tiredness
 - body aches
 - chills
 - nausea
 - vomiting
 - **should not receive certain vaccinations during your treatment** with AUBAGIO and for 6 months after your treatment with AUBAGIO ends.
- **numbness or tingling in your hands or feet that is different from your MS symptoms.** You have a greater chance of getting peripheral neuropathy if you:
 - are over 60 years of age
 - take certain medicines that affect your nervous system
 - have diabetesTell your doctor if you have numbness or tingling in your hands or feet that is different from your MS.
- **Allergic reactions, including serious skin problems.** Tell your doctor if you have difficulty breathing, itching, swelling on any part of your body including in your lips, eyes, throat or tongue, or any skin problems such as rash or redness and peeling.
- **new or worsening breathing problems.** Tell your doctor if you have shortness of breath or coughing with or without fever.
- **high blood pressure.** Your doctor should check your blood pressure before you start taking AUBAGIO and while you are taking AUBAGIO.

The most common side effects of AUBAGIO include:

- headache
- diarrhea

ADVERTISEMENT

- nausea
 - hair thinning or loss (alopecia)
 - increases in the results of blood tests to check your liver function
- Tell your doctor if you have any side effect that bothers you or that does not go away.

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

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

How should I store AUBAGIO?

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

General information about the safe and effective use of AUBAGIO.

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

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

For more information, go to www.aubagio.com or call Genzyme Medical Information Services at 1-800-745-4447, option 2.

What are the ingredients in AUBAGIO?

Active ingredient: teriflunomide

Inactive ingredients in 7 mg and 14 mg tablets: lactose monohydrate, corn starch, hydroxypropyl cellulose, microcrystalline cellulose, sodium starch glycolate, magnesium stearate, hypromellose, titanium dioxide, talc, polyethylene glycol and indigo carmine aluminum lake.

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

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

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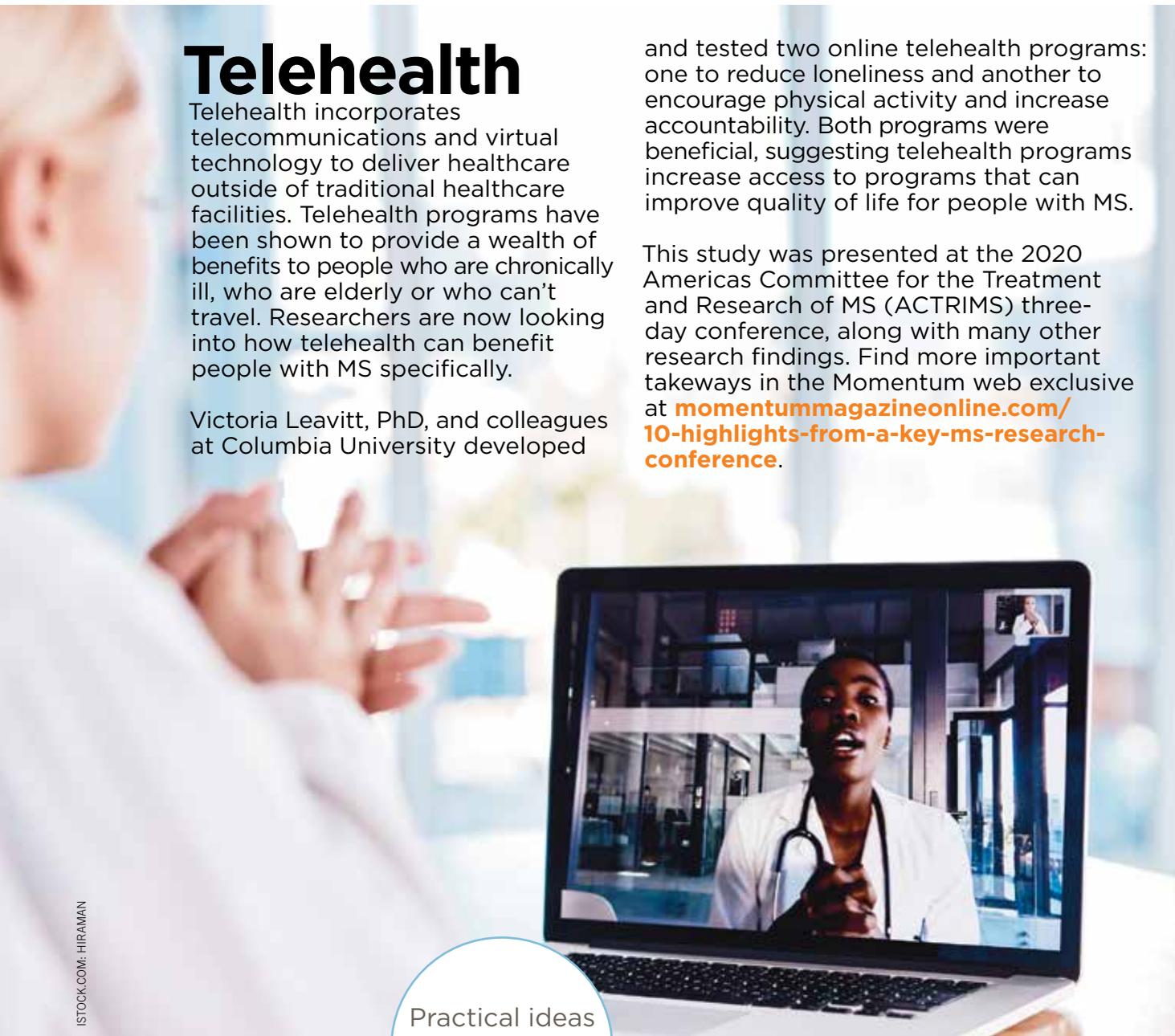
Telehealth

Telehealth incorporates telecommunications and virtual technology to deliver healthcare outside of traditional healthcare facilities. Telehealth programs have been shown to provide a wealth of benefits to people who are chronically ill, who are elderly or who can't travel. Researchers are now looking into how telehealth can benefit people with MS specifically.

Victoria Leavitt, PhD, and colleagues at Columbia University developed

and tested two online telehealth programs: one to reduce loneliness and another to encourage physical activity and increase accountability. Both programs were beneficial, suggesting telehealth programs increase access to programs that can improve quality of life for people with MS.

This study was presented at the 2020 Americas Committee for the Treatment and Research of MS (ACTRIMS) three-day conference, along with many other research findings. Find more important takeaways in the Momentum web exclusive at momentummagazineonline.com/10-highlights-from-a-key-ms-research-conference.



Practical ideas
for living well
with MS

in the know

 in the know

Making life

easier in the kitchen

'Chopped' winner offers practical tips — and a recipe — for cooking with MS.

PHOTO COURTESY OF

in the know

Chris Holland went from paralegal to restaurant chef and three-time winner of the cooking competition show “Chopped” in the span of about a decade. And he credits it all to multiple sclerosis.

Holland, who was diagnosed with MS in 2004, says his life “fell apart when I got sick.” But he put his life back together and, with encouragement from his wife, Marge, decided there was no better time to pursue his lifelong dream of becoming a chef. Today, he’s chef and part owner at DVine Bar in Rockland County, New York, where he specializes in what he likes to call “eclectic, weird fine-dining.” He concocts menu items that run the gamut from duck fat potato chips with cipollini onion crema to seared tuna and chanterelles.

“I love it there,” Holland says. “I have a great boss who really understands about my MS.”

Holland figures he applied to be on “Chopped” about 10 times before he got the call. Since then, he’s had an impressive run. He notched his third championship in November 2019, donating the \$10,000 prize money to the National Multiple Sclerosis Society as a way to give back to an organization that he says has given so much to him and others. He’s also had a great response to his appearances on the show. He’s particularly happy when he hears from “the young people who were diagnosed. They say it’s so nice to see somebody who’s able to do something like I do.”

It’s not always easy. Standing for long hours in a hot kitchen, wielding knives and other cooking utensils while whipping up that cipollini crema can take its toll on somebody with MS. So, who better to offer a variety of practical tips for making life easier in the kitchen?

Here are chef Holland’s tips, along with a bonus recipe you can make while dreaming about being a “Chopped” chef yourself:

Get a Microplane grater

This grater is one of the most important tools in my kitchen and the best \$15 you could ever spend. In addition to providing the delicious zest from a citrus fruit, it has other uses for the quick processing of ginger or garlic. Simply grate the ginger or garlic and avoid the tedious task of chopping these aromatics. You don’t even have to peel them.

Get some help from the supermarket

While I encourage everyone to cook your food rather than buy it, there is nothing wrong with using precooked foods for a head start. Rotisserie chickens are available in most supermarkets and are very affordable. Use them in anything that calls for cooked chicken as an ingredient and save those bones for a stock. Check the salad bar for ready-to-go ingredients that you can use in your own culinary creations.



Slow cookers are your friend

Slow cookers are a great way to stay out of a hot kitchen and avoid spending time on your feet. Many recipes call for 15–20 minutes of prep time, then set it and forget it. Just remember to start cooking early, as many recipes take hours to finish cooking. Slow cookers are also great for soups.



The microwave is not just for reheating coffee and for frozen dinners

This much-maligned kitchen tool does impressive work with vegetables. Hearty greens such as broccoli, green beans and carrots cook beautifully in a microwave. Just wash the vegetables (do not dry) and place them on a ceramic plate and cover with plastic wrap. Microwave on high for three minutes. Check for the desired doneness and add more time as needed. Season afterward with olive oil, lemon, and salt and pepper.



A salad doesn’t have to just be lettuce

A salad is an easy vehicle for incorporating foods beneficial to those living with MS, such as avocado, whole grains such as quinoa or chia seeds (high in fiber), fatty fish such as salmon, trout and tuna (omega 3s), walnuts (omega 3s), and lean proteins such as chicken, turkey and pork tenderloin. ■



Mediterranean chicken tacos

Cook Time: 15 minutes

Servings: 4

Ingredients:

1 small rotisserie chicken

3 cloves of fresh garlic (grated with a Microplane)

½ teaspoon dried oregano

½ teaspoon ground cumin

Pinch chili flakes (optional)

½ cup extra virgin olive oil plus 3 tablespoons

Juice of half a lemon

Zest of 1 lemon

1 English cucumber (diced)

½ red onion (diced)

2 tablespoons fresh dill (chopped)

1 tablespoon red wine vinegar

½ cup Greek yogurt

Salt and pepper

8 flour tortillas (6-inch)

Directions:

1. Pull the meat off of the chicken and shred into a large bowl.
2. In a medium sauté pan, heat the olive oil over medium heat. Check the heat by putting one piece of the diced onion into the pan. It should sizzle immediately upon hitting the oil.
3. Once the oil is at the correct temperature, turn off the heat, and add the garlic, oregano, cumin and chili flakes. Stir the oil for one minute or until the pan stops sizzling.
4. Add this oil mixture (reserving 3 tablespoons) along with the lemon juice to the shredded chicken. Season with salt and pepper to taste.
5. In a separate bowl, add:
 - Diced cucumber
 - Diced red onion
 - Reserved olive oil
 - Chopped dill
 - Red wine vinegar
 - Salt and pepper to taste
6. In a separate bowl, add:
 - Greek yogurt
 - Lemon zest
 - Salt and pepper to taste
7. In a small sauté pan, toast flour tortillas.
8. To assemble, spread one side of tortilla with the yogurt mixture. Top with chicken and the cucumber “salsa.”

For the leftovers, consider adding shredded mozzarella and making a Greek chicken quesadilla served with lemon yogurt and cucumber salsa.



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Directing your life

Wellness coaches can help people with MS get on the right track.

by Matt Alderton

If life were a movie, multiple sclerosis might feel like an unwelcome plot twist. It certainly did for 33-year-old Lauren of Washington, D.C. When she was diagnosed with relapsing-remitting MS in 2017, Lauren, who asked that her last name be withheld to protect her privacy, had a hard time coping. So she did what smart thespians do when they need help playing a new part: She sought direction from behind the camera.

“If I’m the actress, Kate is the director,” Lauren says of her adviser, health and wellness coach Kate Costello of Wildcrafted Wellness in Washington, D.C., and Bethesda, Maryland. “I’m the performer, but she helps me get on the right track.”

Costello agrees. “A good director helps an actor actualize their role. I don’t tell Lauren what to do, exactly; I help her be the best actress she can be in the role that she’s playing.”

“**I don’t tell Lauren what to do, exactly; I help her be the best actress she can be in the role that she’s playing.”**

—KATE COSTELLO

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PHOTO COURTESY OF KATE COSTELLO



Kate Costello, health and wellness coach at Wildcrafted Wellness



Of course, MS isn't a role at all. It's a reality. And with the help of a wellness coach, people with MS can learn tools and techniques that help them manage it.

What is a wellness coach?

Wellness coaches, also known as health or life coaches, help clients create a vision for their wellness, develop personalized strategies to create healthier habits and support them during each step of their journey.

"Coaching is about helping someone be their best self," says wellness coach Barbara B. Appelbaum of Appelbaum Wellness in Deerfield, Illinois. "A coach doesn't tell a person what to do or how to do it. Instead, a coach asks powerful open-ended questions to help a



A coach is an accountability partner."

—BARBARA B. APPELBAUM



PHOTO COURTESY OF BARBARA B. APPELBAUM

Barbara B. Appelbaum, wellness coach at Appelbaum Wellness

person figure out what it is they truly want and how they want to get there.”

In that way, a coach differs from other professionals who might be part of a person’s wellness team. A doctor might prescribe medication. A nutritionist recommends a food plan. A physical trainer sets up an exercise routine. A wellness coach, on the other hand, “plays on the same field as the individual,” Costello explains. “It’s not about the coach’s plan; the client directs the whole thing. It’s completely collaborative.”

Appelbaum agrees.

“A coach is an accountability partner,” she says. “Because it’s much easier to achieve your goals if you have someone helping and championing you along the way.”

Another important distinction is wellness coaches’ focus on holistic health and well-being. A wellness coach is trained to combine all the myriad aspects of one’s well-being — physical, mental and emotional health, for example, as well as social and even professional wellness — in order to create a larger picture. This can be especially meaningful for people with MS, says Mindy Couture, an MS Navigator with the National Multiple Sclerosis Society and owner of Courageous Heart Life Coaching, a coaching practice based in Littleton, Colorado.

“MS, of course, is a big part of somebody’s life. But it’s just a part. The role of a coach is helping you think about your whole health — the other hopes, dreams and desires you have,” Couture says. “I hear from people all the time who say they have trouble moving on after their diagnosis. They get stuck. A coach’s role is to help them get unstuck and keep moving forward.”

““

Before you invest in a coach, you need to be in a place where you’re ready to be coached.”

—MINDY COUTURE

Managing MS

Because wellness can be physical, mental, emotional or even social, anyone can benefit from wellness coaching, proponents say. But for exactly the reasons Couture describes, people with MS often find it especially advantageous. After she was diagnosed with MS, for example, Lauren felt angry, depressed and dispirited. Over time, coaching helped her feel whole again.

“In a situation that feels so out-of-control, having someone who can keep you grounded is vital,” explains Lauren, whose coaching sessions with Costello focus on, among other things, overcoming negative belief patterns — separating Lauren from her disease — and correcting negative self-talk. This includes learning to have compassion for herself by reframing internal dialogue around optimism instead of pessimism. “I take a disease-



PHOTO COURTESY OF MINDY COUTURE

Mindy Couture, MS Navigator with the National Multiple Sclerosis Society and owner of Courageous Heart Life Coaching

modifying therapy (DMT), for example. Instead of thinking about it negatively, I've learned to think about it as me doing something good for myself."

By thinking positive thoughts, Lauren has discovered that she can manifest positive feelings. "I do regress at times," she admits, "but through this process, I've realized that I am not MS. I have some MS symptoms, but MS isn't me. I'm still Lauren, and I can do anything."

Negativity can come just as quickly from external sources as from internal ones, says Appelbaum, who was diagnosed with MS in 2006. When they get together virtually or in person, she says, people with MS sometimes end up in a negative feedback loop that's fueled by a sense of shared suffering. When that happens, a coach can be a voice of positive dissent.

"There's a tendency in the MS community to want to jump in and say, 'Yeah, it sucks. I'm suffering, too,'" Appelbaum says. "A wellness coach can break that cycle by saying, 'It's OK. Vent for a minute. But after that, let's do something about it.'"

Although people with MS should seek medical advice only from their healthcare providers, a wellness coach can help them execute their provider's advice. In that way, coaching can support physical as well as mental wellness. If someone with gait issues has been prescribed stretching exercises or walking, for example, a wellness coach may be able to help them establish routines, incentives and behaviors that help them achieve their physical therapy objectives.

"Whatever your goals are, a coach can help by providing motivation and accountability, and by helping you find ways to make the work fun," Couture says.

Are you ready for change?

A coach can help you set goals. It's important to realize, however, that it ultimately is up to you to achieve them.

"I believe that coaching is an amazing, important investment in yourself, your health and your quality of life. Before you invest in a coach, however, you need to be in a place where you're ready to be coached," Couture says. "Just showing up for coaching doesn't improve your life. You have to be committed to yourself, committed to your goals and committed to making the changes you want to see in your life."

Because changes won't happen overnight, expect to work with a coach for anywhere from several months to a year. After that, you should feel empowered enough to be your own coach.

"After coaching, you should have a newfound ability to handle on your own whatever the next issue is that you encounter in your life," Costello says. "The end goal is to have the capacity to be your own change master." ■

Matt Alderton is a Chicago-based writer and editor.



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4 questions to ask your coach

Because the client-coach relationship can be extremely intimate, it's important to find a coach with whom you're comfortable.

"It's important to interview a few people before you decide on a coach because you're going to have to be vulnerable with that person," says 33-year-old Lauren of Washington, D.C., who asked that her last name be withheld to protect her privacy. "It's like finding a doctor. You've got to see who you connect with."

Asking the following questions can help you narrow down your choices based on budget, style and experience:

1. What are your fees?

Coaches typically charge by the hour, and their rates can vary dramatically depending on their location and experience, says wellness coach Barbara B. Appelbaum of Appelbaum Wellness in Deerfield, Illinois, who adds that coaches who are just starting out might charge \$75 per hour. MS Navigator Mindy Couture, owner of Courageous Heart Life Coaching in Littleton, Colorado, estimates that the average is closer to \$100 per hour. However, the top coaches can earn up to \$500 per hour or more. All coaches, Appelbaum says, should be willing to offer the first session free so you can

assess whether you're a match.

If \$100 per hour is too steep, there are a few ways you might be able to save money. For example, Appelbaum says some coaches offer services on a sliding scale for low-income clients, and most sell packages — a bundle of 10 sessions, for instance — at a discounted rate. Some coaches even offer group coaching, says Couture, who adds that a group setting allows coaches to provide services at a lower cost.

Although insurance and health savings accounts typically do not cover coaching, some employers might subsidize it as part of their wellness benefits, says health and wellness coach Kate Costello of Wildcrafted Wellness in Washington, D.C., and Bethesda, Maryland.

2. Where will we meet, and how often?

Coaching may take place in person but often is offered virtually. Although arrangements vary, Appelbaum says formal sessions typically last for 45 minutes to an hour and take

place once per week, with an allowance of shorter communications by text message and email. Remote sessions can take place by phone or video chat.

3. What are your qualifications?

Not all coaches are created equal. To ensure a coach is the real deal, look for either a degree or a professional certification — or both. Some wellness coaches, for example, have a master's degree in health and wellness coaching from an accredited university. Others are graduates of various coaching academies and workshops. The gold standard, Appelbaum says, is a credential from the International Coach Federation (ICF), which certifies professional coaches and offers a searchable directory of ICF-credentialed coaches on its website. If your coach is not ICF-certified, ask where they were trained and take the initiative to look up the program. When you do, you can see what was required — an hour-long internet course,

for example, or a year of dedicated training — and judge for yourself whether the coach has adequate experience.

4. Do you have experience with chronic illness?

Costello, Appelbaum and Couture agree: If you have

MS, it would be nice to work with a coach who has experience with chronic illness generally or multiple sclerosis specifically — but it isn't necessarily required. On the one hand, a good coach should be able to help virtually any client with virtually any problem. On

the other hand, a coach who's versed in MS is likely to have more empathy for their client. If your goals are specific to MS, consider a coach who specializes in clients with chronic disease. If your goals are external to your illness, that experience may be less important.

Wellness coaching 101

A coach DOES ...	A coach DOES NOT ...
Help you set goals	Prescribe solutions
Hold you accountable	Punish mistakes
Focus on the present	Care about the past or worry about the future
Facilitate behavior change	Dictate behavior change
Ask insightful questions that help you discover your own answers	Provide “expert” answers or advice
Integrate physical, mental, emotional and social health	Isolate physical, mental, emotional and social health
Motivate you	Manage you
Listen to your hopes, needs and desires	Judge your negative feelings and behaviors

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Laura S., living with relapsing MS

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- It is not known if TECFIDERA is safe and effective in children under 18 years of age

Important Safety Information

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

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TECFIDERA may cause serious side effects, including:

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- **PML** a rare brain infection that usually leads to death or severe disability
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 - pain on the right side of your stomach
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 - yellowing of your skin or the white part of your eyes
- **herpes zoster infections (shingles)**, including central nervous system infections
- **other serious infections**

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 healthcare provider if you have any of these symptoms and they bother you or do not go away. Ask your healthcare provider if taking aspirin before taking TECFIDERA may reduce flushing

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

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 - 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.
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What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

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- **other serious infections**

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General Information about the safe and effective use of TECFIDERA

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- 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.

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Manufactured for: Biogen Inc., Cambridge, MA 02142, www.TECFIDERA.com or call 1-800-456-2255

Tips for consuming more water

It's important to stay hydrated, especially in the heat of summer. On average, men need about 15 cups of fluid a day and women need about 11 to stay adequately hydrated, with water being the most important fluid source. Here are a few tips to help you drink more water:

1. Make it easily accessible.

Always keep a glass of water near you so it's in easy reach. If getting up to refill your glass is a deterrent, opt for a larger, reusable bottle. Some people also find themselves drinking more water when using a straw; an eco-friendly option would be a reusable glass or silicone straw, or a bottle with one built in.

2. Add flavor.

You can zest up water in a variety of ways, including adding slices of fruit or muddled herbs, infusing water with fruits or vegetables, or freezing fruit or herbs into your ice cubes.

3. Create a habit.

Whether you decide to take sips of water between tasks at work or during commercials while you watch TV, forming a habit can increase the likelihood you'll drink more water each day.

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Forging a path
to your best life

Inside this section: A handle on pain 26 // Trails well-traveled 32

A handle

Up to 80% of people living with MS will have a painful condition during the course of their illness



PHOTO BY KEITH CARLSEN

on pain

by Aviva Patz

New approaches mean more people with MS are taking control and getting their lives back.

After a relapse of her multiple sclerosis in 2016, Gina Gentry was in such agonizing pain that she'd curl up in a ball on the couch and cry. "It felt like the bones in my mid-back to my knees were in a vice that kept getting tighter — it was a pressure and a throbbing pain," she says. The 30-year-old from Minneapolis started taking medication and was up to nine pills a day without much relief when she began discovering a handful of effective treatments — an anti-depressant, medical cannabis, physical activity and a healthy diet. "I do feel pain every day, but I get through it," says Gentry, who works full time as an MS Navigator with the National Multiple Sclerosis Society.

Up to 80% of people living with MS will have a painful condition during the course of their illness, according to a 2013 article in the journal *Pain*. "A lot of people with MS have mixed types of pain — some neuropathic pain, like achy legs or tingling, discomfort or burning, and also some musculoskeletal pain, like back pain, hip or knee pain," explains Dawn Ehde, PhD, Nancy & Buster Alvord Endowed Professor in Multiple Sclerosis Research at the University of Washington School of Medicine.

The pain can be significantly disabling, potentially leading to social isolation, mood disorders, mobility problems, loss of employment, and even increased pain and a worsening of other MS symptoms, according to the Society. It can be incredibly challenging to treat because neuropathic pain, caused by damage to the central nervous system that's a hallmark of MS, doesn't respond to traditional painkillers.



Watch a video on managing pain and sleep at [nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Pain](https://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Pain).

Tra, diagnosed in 2010, manages her symptoms by taking everything day by day. Playing rugby and staying active, resting when she needs to, and dealing with stress right away also help.

The U.S. Food and Drug Administration has approved exactly zero medications for MS pain, and the ones prescribed off-label can have unpleasant side effects. The good news: Fresh research and treatment approaches are offering new hope. “We don’t have a cure for chronic pain,” Ehde says, “but there are a lot of things people can do that will be helpful.”

Defining pain in MS

There are two main types of pain in MS:

- Neuropathic, from the damage caused in the central nervous system from MS
- Musculoskeletal, from disability caused by the disease

“If it’s central nervous system pain, we look for qualities associated with that — burning, tingling, prickling, pins and needles, pain with touch, electrical shocks,” says John Rose, MD, Chief of the Division of Neuroimmunology at the University of Utah. Rose notes that the pain can be intense, and that people may have more than one type of pain and in more than one part of their body.

Musculoskeletal pain usually involves dull throbbing or aching. It can come from muscle weakness, extra

stress on bones and joints, changing one’s gait, or from health issues that affect the general population and could be unrelated to a person’s MS, Rose says. He tells the story of a 67-year-old man with MS who had pain while raising his leg. It turned out that he had nerve compression and needed hip surgery — neither problem was related to his MS. When both of those issues were addressed, his pain went away.

The experience of pain in MS

Julie Fiol, director of MS Information and Resources at the Society, says the types of pain people living with MS may typically experience include:

- Headache
- Burning, prickling, stabbing, ice cold or electrical sensations in the extremities
- Trigeminal neuralgia (a stabbing pain in the face or jaw area)
- Lhermitte’s sign (a brief, stabbing, electric shock-like sensation that runs from the back of the head down the spine and often into the arms or legs when the neck is bent forward)
- Spasticity (muscle stiffness and involuntary spasms)
- Squeezing or tightness around the torso (the MS hug)
- Itching without a rash or other skin issue

Chronic pain in MS can be life-altering. Barbara Reed, 51, of Fishers, Indiana, had to quit her job and go on disability in 2010 because the pain from her MS was so crippling.

“I was heartbroken,” Reed says. “I loved my job.”

Reed says her pain “feels like being stabbed or having constant muscle spasms or charley horses. Then there is the deep aching, tingling, numbness, touch sensitivity, temperature sensitivity, not to mention the tremors.”

Reed has to decide every day whether it’s worth the pain and effort to get up and try to do something. And she says people aren’t always sympathetic. She has a friend who “doesn’t understand the effort it takes just to get ready, and then the effort it takes to do whatever when we are out. I think this is one of those things that can’t be judged by anyone other than a person with MS.”



PHOTO COURTESY OF BARBARA REED

Chronic pain from her MS affects Barbara Reed each day.

Diagnosing pain in MS

There is a formal pain scale on which people rate their pain from 0 to 10, and your healthcare provider will ask questions and do exams to look for signs that align with the sensations you describe, Rose explains. But he and his team are working on developing a pain reporting tool that would be more detailed and specific. “It’s opened our eyes to the fact that these patients are putting up with pain we need to know about,” he says. “Seven on a pain scale regularly? That’s too high to be tolerating.”

Revelations from the latest research

Medications can be helpful, including anti-seizure and certain anti-depressant medications prescribed off label. However, results are limited. One study found that on average people living with MS and pain use nine different strategies to manage their pain, “with very few reporting effective relief of that pain despite those strategies,” Fiol says. One of the remedies reported to be most effective in that study was hypnosis.

Newer approaches to treatment

Hypnosis is just one of the mind-body therapies getting more attention and research dollars. “They used to be looked at as strange, but now they’re considered a best practice,” says Pearl B. Werfel, PhD, Chair of the California Psychological Association CARE Program. Besides not having negative side effects, psychological interventions give people a sense of control. “That’s what people want, because it’s scary to be in pain,” says Werfel, who is lead author of the book, “Multiple Sclerosis: Advances in psychotherapy, evidence-based practice.”

“You don’t know how or when it’s going to end,” Werfel adds. “It’s easy to think, ‘I’m in pain, I’m always going to be in pain.’ But that panic actually makes the pain and inflammation worse.”

Mind-body interventions work because damage in the body is only one piece of the puzzle when it comes to the amount of pain people experience. “Think of it like the volume on a stereo: Some thoughts, feelings and actions can turn the volume up on pain and lead to more danger signals being processed,” Ehde explains.

“There are other thoughts, feelings and actions that can turn down the volume on pain, reducing the number of pain signals processed in the brain and the amount of pain you feel.”

Treatments beyond medication

Here are some approaches to reducing pain for people with MS that don’t involve taking medication, according to the experts:

- Physical activity, whether it includes formal physical therapy or a home or community exercise program, is “somewhat of a panacea,” Ehde says. “It may modulate how pain is processed in the brain, and it makes you feel good because it gets you out and around other people, so there’s the social connection and feeling of self-efficacy.”

The movement also conditions your muscles to support your back and joints, which helps prevent discomfort and musculoskeletal pain. Gentry bikes every day, works out with resistance bands and a kettlebell every other day, and also practices yoga a few times a week. “If I don’t keep moving, my pain gets so much worse,” she says. “If I miss just two days, the pain comes back, and it comes back strong.”

- Relaxation training, which could involve breathing, imagery and progressive muscle relaxation, can bring on the body’s natural relaxation response — a combination of slower breathing, lower blood pressure and a feeling of increased well-being, according to the National Institutes of Health. “Strategies like relaxation cause changes in the brain that dampen or decrease pain sensations as well as our emotional, physical and cognitive experience of pain,” Ehde says.

Relaxation is immensely helpful for people who live with chronic pain, whose brains are almost “too good” at processing pain and need to be desensitized. Werfel has seen great success with imagery, in which a focus on pleasant images replaces negative or stressful feelings. She tells the story of one woman who would wrap a patterned scarf around her leg where she had shooting pain. “When she’d get into the intricacies of how beautiful the scarf was, she would relax and have less of the signal pain,” Werfel says.

Pacing helps reduce pain

Pacing or energy management helps you more evenly plan your days to avoid the cycle of overdoing it and then needing to recover from increased pain. A 2015 clinical trial showed that among people taught “pacing” skills by telephone over eight sessions, about 50% had a meaningful reduction in pain and fatigue.

Cognitive behavioral therapy (CBT) changes the automatic thought process that can ramp up pain. Although it’s reasonable to think the pain is “terrible, I can’t stand it, I don’t know what to do,” Ehde explains, “you can learn ways to reframe those thoughts. We’re not saying be a Pollyanna — ‘everything is amazing!’ — but how can you develop an alternative thought?”

For example, you might think: “I’ve gotten through this before. I can practice my meditation, my relaxation. I have things I can do to feel better. This doesn’t mean my MS is getting worse.” In an eight-week study for those newly diagnosed with MS, published in 2016 in BMC Psychiatry, CBT helped drastically reduce the

high levels of depression and anxiety that we know to heighten the experience of pain.

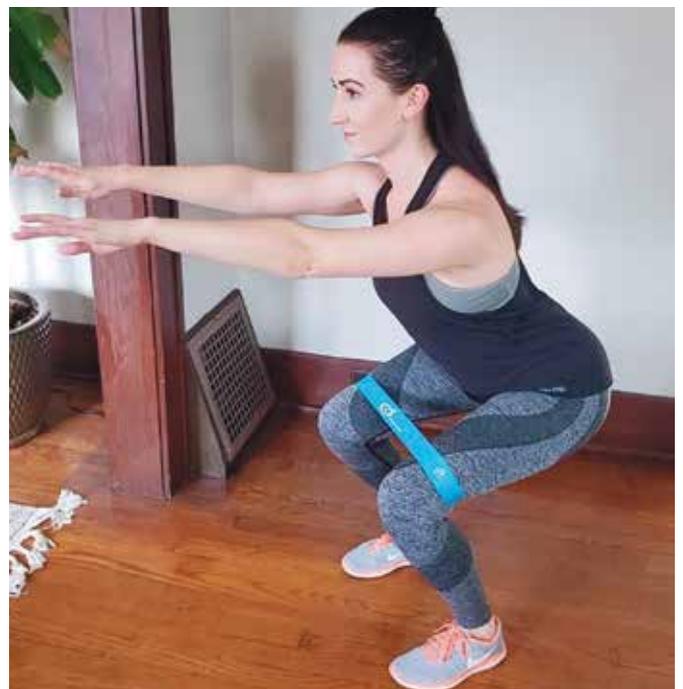
Mindfulness meditation teaches you to become aware of pain and view it differently, and it’s very effective. A 2018 study in the International Journal of MS Care shows a “strong and significant association between greater mindfulness and lower levels of pain interference.” In a 2019 study in the journal Pain Reports, MRI scans show precisely how the practice alters brain function to reduce the experience of pain. Earlier studies show that it can also reduce measures of depression, pain-related anxiety and physical disability.

Self-hypnosis can change response

Self-hypnosis training helps you take advantage of the power of your mind to control how you feel in your body. Ehde says it can change the way your brain responds to pain signals, so you feel less pain all the time. It also teaches you how to enter a state of relaxation when you need it. “Most patients report that



PHOTOS COURTESY OF GINA GENTRY



Gina Gentry tries to fit movement into her daily schedule to treat her MS pain. She bikes every day, works out with resistance bands and a kettlebell every other day, and practices yoga a few times a week.

when they learn to do this, they feel immediate pain relief, and that this relief can last for hours or longer,” she says. In a 2014 study in *American Psychologist*, hypnosis not only effectively reduced chronic pain but also had “clear effects on the brain and spinal-cord functioning.” Werfel confirms that after an online self-hypnosis program she conducted with the Society, participants reported taking much less pain medication and even seemed more clear-headed over time.

Somatic experiencing was initially used for trauma because it can work with the autonomic nervous system to decrease inflammation, which decreases pain, Werfel says. Here’s how it works: Find a place in your body that’s comfortable and focus on that, even if it’s your hair or the tip of your nose. “Make the brain aware that there’s a part of your body that’s comfortable,” she explains. For a second, pay light attention to the uncomfortable spot, then switch back. “People can begin to notice the discomfort without triggering a stressful reaction that increases inflammation,” Werfel says. “The goal is to have pain not interfere as much with what you’re doing, bringing it to a point where it’s tolerable enough so you can go about your day.”

Diet could be a powerful weapon against pain. Several studies show an association between pain and healthy lifestyle habits including diet quality, says Dr. Ilana Katz Sand, MD, Associate Director of the Corinne Goldsmith Dickinson Center for MS at Mount Sinai Medical Center. The center is conducting studies on diet and MS, and hopes to develop dietary guidelines in the future. In the meantime, it can’t hurt, and it may help, to eat cleaner. “A big part of what inspired me to pursue research on diet in MS was my observation that my patients who followed a healthy diet seemed to fare better than those who did not,” Katz Sand says.

Gentry sticks to a plant-based diet with lots of fruits and vegetables, nuts and seeds, and some fish for the omega-3 fatty acids. She avoids dairy, meat, gluten, added sugar, saturated fats and foods high in omega-6 fatty acids, such as that from canola oil. “I’ve come to a point where I see food as medicine,” Gentry says. “What I put in my body is either going to help or hinder me.”

Working with your healthcare professional

Besides experimenting with medication, one of the first steps to reducing pain is understanding the role the brain plays. “Sometimes people think pain is physical, so why are we talking about my thoughts?” Ehde says. But they’re connected. “Thoughts influence feelings, which influence behavior, which influences physical pain.”

Ehde’s first line of defense is mindfulness meditation or relaxation because it delivers the most benefit early in the treatment. Then, she might explore ways to boost physical activity and improve sleep and teach some cognitive behavior therapy skills, all while having people track their symptoms. “They start to notice patterns of how they respond to pain — what makes it worse, what makes it better — and use that information to create a toolkit,” Ehde says.

Concerns about treatments

With all medications, there are risks of unpleasant side effects, Rose says, including cloudy cognition, fatigue and balance issues. Some anti-depressants might cause irregular heartbeat; others pose a risk of swelling of the limbs and depression. Another issue is that a medication might not reach its full dosage for a few weeks, and meanwhile, people get frustrated and stop taking it. Neurologists tend to avoid opioids because of the risk of addiction, though they might help some people and can be convenient and inexpensive in small doses. And CBD (cannabidiol, a non-intoxicating chemical compound found in cannabis), while anecdotally helpful, is still largely unstudied and unregulated. Gentry swears by the sublingual cannabis spray she’s used for two years. However, more work needs to be done to establish its safety and efficacy, Fiol cautions.

Physical activity, energy pacing and the mind-body interventions appear to be universally safe, though there’s some trial and error involved as you discover what works for you. As Gentry tells the newly diagnosed, “This is your body, your disease, and you can make the choices that will make you feel better.” ■

Aviva Patz is a writer in Montclair, New Jersey.

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

Trails well- traveled

MS doesn't have to be a barrier to exploring national parks.

by Vicky Uhland



PHOTO COURTESY OF DAVE BEXFIELD



Dave Bexfield
at Grand Teton
National Park in
Wyoming

There are few things more uniquely American than our national park system. For more than 100 years, we've been able to explore saguaros and sequoias, glaciers and geysers, caves and canyons. We can travel from the heights — Denali National Park in Alaska — to the depths — Death Valley National Park in California and Nevada — of our country's remarkable geography.

We can wade in the Atlantic and Pacific oceans and the Niobrara and Congaree

ivers. And we can learn about our culture and history at parks like Mesa Verde in Colorado, Valley Forge in Pennsylvania and Kaloko-Honokohau in Hawaii.

With this avalanche of experiences outside our back doors, it's no wonder that nearly 320 million people a year visit the 419 parks, battlefields, historic sites, memorials, monuments, recreation areas and waterways that make up the U.S. National Park System (NPS).

"National parks are the best idea we ever had. Absolutely American, absolutely democratic, they reflect us at our best rather than our worst," said writer, environmentalist and historian Wallace Stegner in 1983.

But for many people living with multiple sclerosis, national parks don't seem like the best idea — or even a good idea. Mobility issues, fatigue, heat sensitivity, cognitive issues, vision problems, or bowel and bladder concerns can make a visit to a national park feel off-limits.

And yet, that doesn't have to be the case. An NPS initiative, "All In!" prioritizes accessibility throughout the park system. National park visitors with MS say the initiative, which began in 2015 and ends in 2020, has made an impact in terms of more accessible trails, facilities and, most important, park rangers who have been trained to understand the needs of people with disabilities.

"It's a move away from the mindset of 'accessibility is this extra thing you do' to 'accessibility is a fundamental thing you do,'" says Jeremy Buzzell, chief of service-wide housing and accessibility program support in the Park Facilities Management Division of the NPS.

Of course, there's only so much that can be done to make the great outdoors accessible. But travel experts say there are plenty of steps people with MS can take



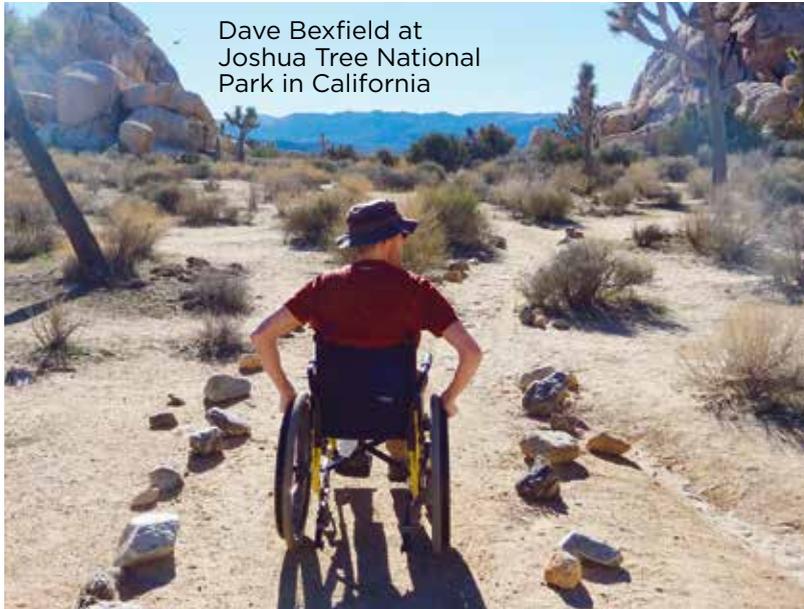
Jodi Johnson at the Sabino Canyon Recreation Area in Arizona

PHOTO COURTESY OF JODI JOHNSON



Greg Lais, executive director at Wilderness Inquiry

PHOTO COURTESY OF GREG LAIS



Dave Bexfield at Joshua Tree National Park in California

PHOTO COURTESY OF DAVE BEXFIELD

in tarmac trails, flat boardwalks and accessible bathrooms in the front country areas. Many parks also have roads that lead to scenic overlooks, making it easy to experience a park's grandeur without leaving the car or park shuttle. And some parks let you check out all-terrain wheelchairs and other accessibility equipment.

A variety of parks also have interactive or interpretive programs that are helpful for people with vision or cognitive issues. For example, Buzzell says the new museum at Gateway Arch National Park in Missouri has tactile representations of artifacts that are under glass, including 3-D models of maps. And at Grand Teton National Park in Wyoming, the visitor's center has

to not only enjoy national park outings but also feel confident about doing so. Here's what they recommend.

Don't presuppose

You'd think a small park surrounding the deepest lake in the United States wouldn't be a great choice if you have mobility issues. But Crater Lake National Park in Oregon has done a "really fantastic job with access," says Lynn Anderson, director of the Inclusive Recreation Resource Center at the State University of New York College at Cortland.

The key, Anderson says, is how accessible the "front country" of the park is. She says most visitors only see about 5% to 10% of a park — the famous front country scenery like the geysers at Yellowstone National Park in Wyoming or the dunes at White Sands National Park in New Mexico. These are the areas that have benefited most from the "All In!" program.

It may be impossible to pave the wilderness, but it is possible to put



Lynn Anderson at Crater Lake National Park in Oregon

PHOTO COURTESY OF LYNN ANDERSON

a room devoted solely to nature sounds like waterfalls and geysers.

There are also tours for people who want to visit the more rugged, backcountry portions of parks. “Most parks have accessible routes and tours,” says Tarita Davenock, who was diagnosed with MS in 1995 and later founded Travel for All, an agency in British Columbia, Canada, specializing in accessible travel.

For instance, NPS-authorized companies operate accessible boat, raft, kayak or canoe tours in Voyageurs National Park in Minnesota and Glen Canyon National Recreation Area in Utah and Nevada. Or you can take a hand-bike tour of backcountry trails in parks like Grand Teton in Wyoming.

You can Google the name of the park and “adaptive programs” or “adaptive tours” to find these excursions, or ask at the park visitor center — just make sure to talk with the tour operator before you go to ensure they can accommodate your needs.

Another option is to arrange a tour through a travel agency that specializes in inclusive adventures — like Travel For All or Minneapolis-based Wilderness Inquiry.

“There’s a fear of the physicality of national parks,” says Wilderness Inquiry Executive Director Greg Lais, whose sister has MS. “Can I make it on that trail, or walk that loop? This is very common, and not just limited to people with MS. A lot of people use our trips to prove to themselves that they can do more than they thought they could.”

Know before you go

Many people with MS are used to researching activities beforehand to avoid surprises. That goes double with national parks.

Start with the park’s website. You can find a list of all 419 national parks on the NPS website, [nps.gov](https://www.nps.gov). All but a handful of the parks have websites. Choose the park you want, click on its website, find the “Plan Your Visit” tab, then click on “Accessibility” to learn about accessibility features at the park.

But just as some parks are more accessible than others, some park websites have more accessibility information than others. For instance, Yosemite National Park’s website only lists “deaf services” under its accessibility tab. Grand Canyon has an eight-page “Accessibility Guide” PDF that includes everything from accessible ATMs to average daily temperatures.

These dichotomies are why savvy national park visitors like Dave Bexfield and Jodi Johnson recommend checking out a variety



To find a list of all 419 national parks on the National Park Service website, visit [nps.gov](https://www.nps.gov). Most parks have their own websites. Choose the park you want, click on its website, find the “Plan Your Visit” tab, and then click on “Accessibility.” The link will list accessibility features at the park. Due to COVID-19, some national parks might be closed or partially open. Be sure to check before you visit.



of resources before visiting a national park.

Bexfield, who operates the **ActiveMSers.org** website out of his Albuquerque, New Mexico, home, estimates that he's been to about a dozen national parks since he was diagnosed with MS in 2006. He currently uses a manual wheelchair to get around, and in the past has used forearm crutches and trekking poles.

Bexfield checks out a park's accessibility via its website, but also through independent websites like **spintheglobe.net** and **barrierfreetravels.com**. Even if you don't use a wheelchair, Googling the name of the park plus "wheelchair" can help you find firsthand accessibility info from people with mobility issues.

Anderson also recommends the AllTrails app to research specific trails in a park.

Johnson, a Darnestown, Maryland, resident who was diagnosed with MS in 2008 and uses a yellow scooter she's nicknamed Bumblebee, checks out Google Maps to zero in on whether a trail is packed dirt, gravel or other accessible material. And she Googles "accessible activities" at parks she's interested in visiting. "I also try calling the park, although it can be hard to reach rangers by phone," she says.

But you can almost always find a ranger in person at park visitor centers, and they can be a wealth of information. Most parks have maps or brochures of accessible trails and bathrooms, and rangers can tell you if a path is under repair, has stairs, or has exposed tree roots, mud, mulch or other accessibility nightmares. They can also point you to the most accessible scenic



PHOTO COURTESY OF DAVE BEXFIELD

overlooks and park shuttles that can get you there.

The key, though, is to ask specific questions for your individual needs. "What rangers think is accessible is not necessarily accessible," Bexfield says. Adds Buzzell: "The NPS' goal is not to say 'x' trail is accessible or not accessible. Instead, we describe the trail, like the average rise and run, the average cross slope and whether it's dirt or rock."

At the same time, unmarked areas may be navigable for people with mobility issues if the surface is packed and relatively even. For example, Johnson found that the supposedly accessible ramps at San Juan National Historic Site in Puerto Rico were too steep for her scooter to descend, but the "non-accessible" lawn in front was perfectly accessible.

"When they take the care to manicure a lawn like that so you can get your scooter

Dave Bexfield has been to about a dozen national parks since he was diagnosed with MS in 2006.



ISTOCK.COM: LOSTINBIDS



What rangers think is accessible is not necessarily accessible.”

—DAVE BEXFIELD

across it, it makes you feel just like a normal visitor,” Johnson says.

When nature calls

Concerns about fatigue, heat sensitivity and accessible bathrooms can also scare people away from national parks. What happens if you hit a wall in the middle of a trail and can't go any further? Or what if you have to “go” and there's no bathroom nearby?

Bexfield and Johnson have some answers.

First of all, they note that it's important to schedule your visits when crowds and temperatures are at their lowest. That usually means avoiding the summer months and the midday hours. Instead, try to visit national parks in the late spring or early fall, and in the morning or late afternoon.

“You see more wildlife then and can Instagram out the wazoo, whether you're exploring from a trail or a vehicle,” Bexfield says. “Don't forget that you can do a lot from the comfort of your car.”

He also recommends taking a mobility device that's one level up from what you usually use. For instance, if you use a cane, bring trekking poles or arm crutches as well for added stability and safety. And when he wasn't using a wheelchair, Bexfield carried a portable, lightweight camp stool in his backpack for times when fatigue hit, and there wasn't a nearby place to sit.

He also packs a portable bedside commode in his car when he visits national parks. “It's a little security blanket so I can go into the back of a parking lot and use the ‘facilities’ if I have to.”

While all national parks are required to have accessible bathrooms, that doesn't

Take a hike — for free

U.S. citizens or permanent residents who have disabilities can get a free lifetime Access Pass for any national park, wildlife refuge, forest or other federal recreation land.

You'll need either a letter from a doctor stating that you have a “permanent physical, mental or sensory impairment that substantially limits one or more major life activities,” or proof of Social Security Disability Income or Supplemental Security Income.

You'll also need documentation of citizenship or permanent residency, such as a state driver's license or ID, birth certificate, passport or Green Card.

Once you've got all of that in hand, you can apply for an Access Pass either in person at a national park or by mailing in a form from this website: store.usgs.gov/s3fs-public/access_pass_application.pdf. There's a \$10 processing fee if you apply by mail; in-person applications are free.



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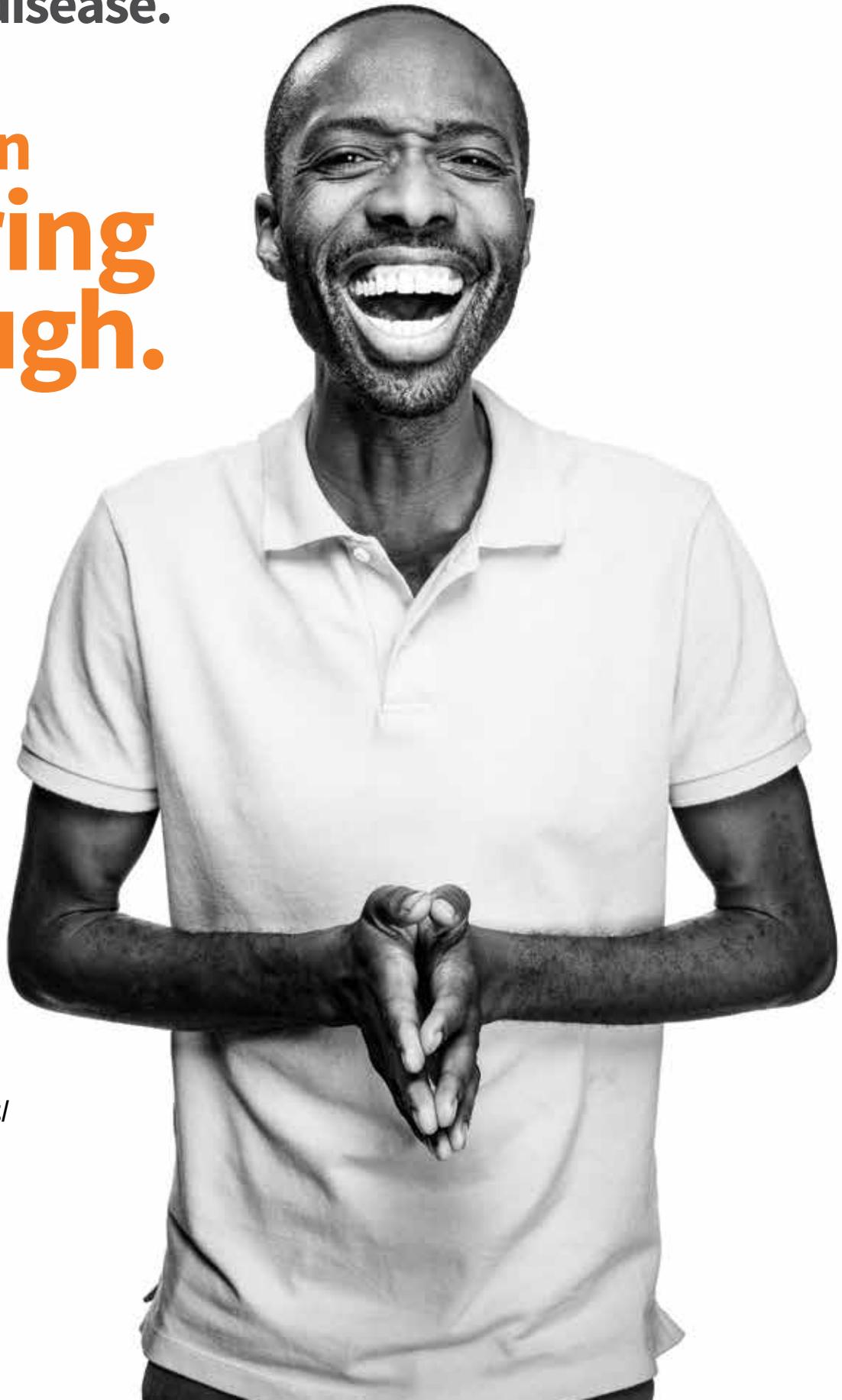
necessarily mean an outhouse or portable toilet is maneuverable for someone with a scooter or other mobility device, or that the pathway to the bathroom isn't too steep or rocky.

But Bexfield has found that, in general, national park bathrooms are quite accessible, especially if you check out the signs and pictures on the door saying what type of toilet it is — like a squatty potty or wheelchair-friendly.

Another reason to avoid peak times at parks is that there can be lines for the toilets. That's why Bexfield recommends taking the opportunity to visit any bathroom you pass that doesn't have people waiting.

MS is an
isolating disease.

I focus on
sharing
a laugh.



Damian

Vlogger. Actor.
Diagnosed in 2015.

Hear Damian's story at
[nationalMSSociety.org/
damian](http://nationalMSSociety.org/damian)



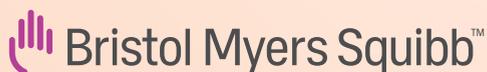
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MS doesn't stop, and neither will we.

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

Support the Society COVID-19 Response Fund

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

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

Give today at
[nationalMSSociety.org/
COVID19ResponseFund](https://nationalMSSociety.org/COVID19ResponseFund)
or text **GIVE** to 68686*



ANQUETTE,
DIAGNOSED IN 2013

Here's what we're doing, and how you can help.

Providing support through resources and information

Answers to pressing questions

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

A partner to navigate challenges

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

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

Virtual programming and events to reduce isolation and maintain wellness

Expanded virtual events and programs help keep our movement connected and provide relevant information so people with MS can manage physical and emotional challenges. Current offerings include:

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

*Msg. and data rates may apply. Max. 15 msgs/mo. Terms and conditions and privacy policy at nationalMSSociety.org. Text STOP to 68686 to stop. Text HELP to 68686 for help.

A healthcare community better equipped to deliver care

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

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

Amplifying the voices of the MS movement to address urgent needs

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

Fueling MS research

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

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



**National
Multiple Sclerosis
Society**

10 accessible national parks in the U.S.

Buddy system

Bexfield’s and Johnson’s final piece of advice is always to visit national parks with at least one other person.

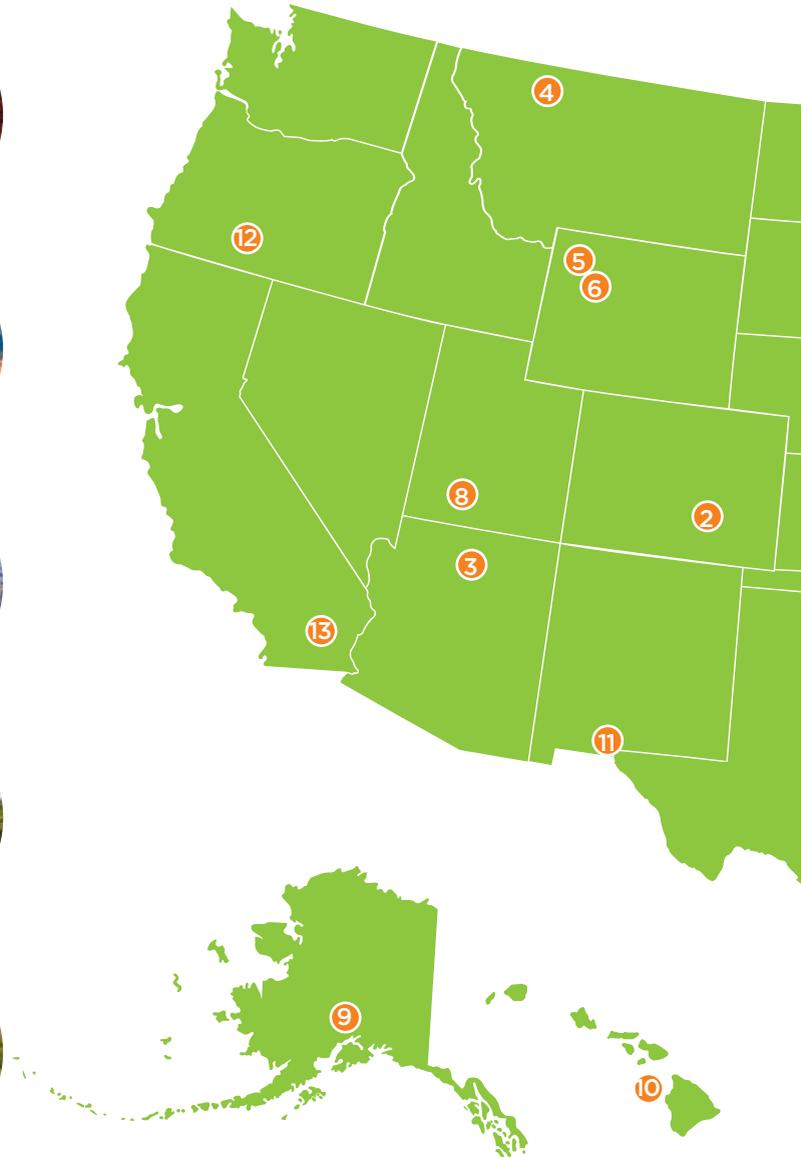
This is important for everyone, not just people with MS. While solitary rambles through the wilderness sound romantic, the harsh reality is that there are too many opportunities to get lost or injured. A buddy not only helps keep you safe but can have other benefits.

For instance, Bexfield’s wife, Laura, will go ahead on trails and check whether they’re muddy, damaged or otherwise inaccessible. Buddies can also scope out a restroom to make sure you can access it. And they can help you feel empowered to keep on trekking.

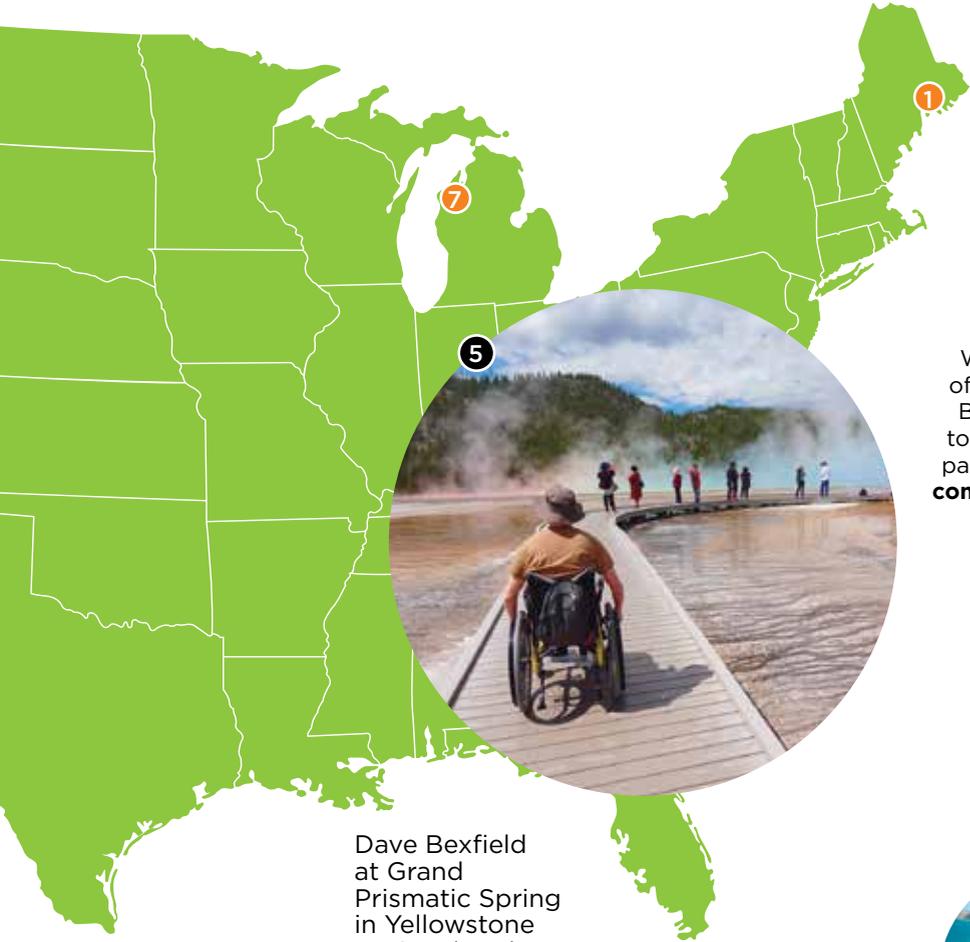
Of course, no matter how much you plan or anticipate, a visit to a national park can be full of adventure — both good and bad. But that’s OK, Johnson and Bexfield say.

“People underestimate what they can do. If I can explore the world with abandon — and not hurt myself, at least not usually — you can push your personal boundaries and make new discoveries on your own,” Bexfield says. “It starts with just opening your front door.” ■

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



1. Acadia National Park, Maine
2. Great Sand Dunes National Park and Preserve, Colorado
3. Grand Canyon National Park, Arizona
4. Glacier National Park, Montana
5. Yellowstone National Park, Wyoming
6. Grand Teton National Park, Wyoming



Dave Bexfield at Grand Prismatic Spring in Yellowstone National Park



Watch a video of some of Dave Bexfield's trips to these national parks at [youtube.com/watch?v=Q4_S2tzDOSs](https://www.youtube.com/watch?v=Q4_S2tzDOSs).



7. Sleeping Bear Dunes National Lakeshore, Michigan

8. Sunrise and Sunset Points, Bryce Canyon National Park, Utah

9. McKinley Station Trail, Denali National Park, Alaska

10. Kaloko-Honokōhau National Historical Park, Hawaii

11. White Sands National Park, New Mexico

12. Crater Lake National Park, Oregon

13. Joshua Tree National Park, California

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



solve

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

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Games and puzzles can boost cognitive health

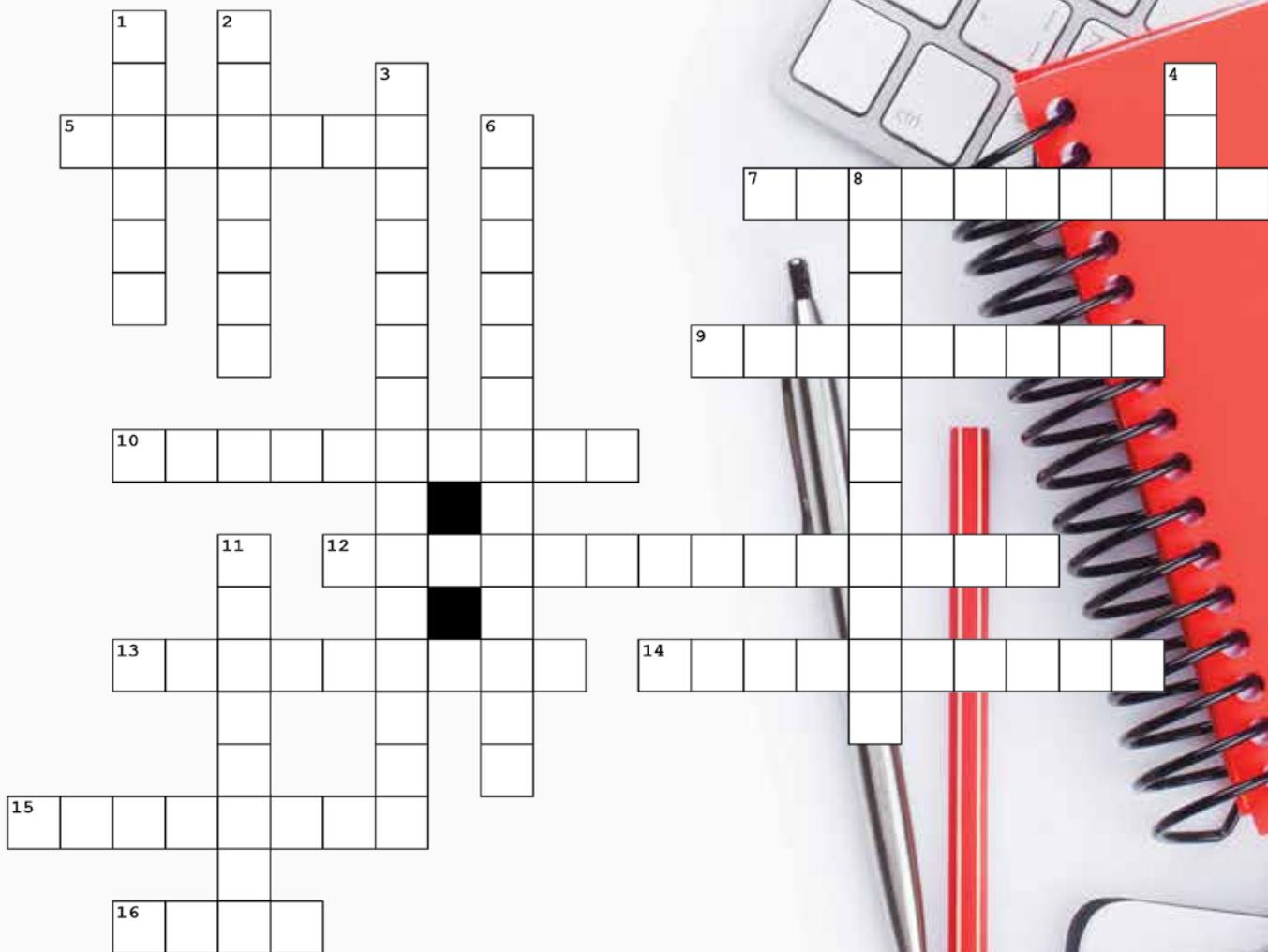
We know cognitive challenges are a common multiple sclerosis symptom, but did you know that puzzles and games might help improve your cognitive health? Taking time each day to work on crossword puzzles or play video games or brain-training apps like Lumosity, Fit Brains Trainer and CogniFit could help improve memory, concentration and even relieve anxiety. Plus, puzzle and brain-training apps are easily accessible from your phone and can be played any time — while you're waiting for a doctor's appointment, on a commute or at home.

More research is needed to find out the full benefits of brain training and how games specifically affect cognitive health, but current studies show that long-term play can have positive results. Try solving the following crossword puzzle to get started.

Words and clues for the puzzle:

ACROSS

5. Feeling off-balance, lightheaded or like your surroundings are spinning
7. Feelings of stiffness or having involuntary muscle spasms
9. Another word for swallowing problems
10. One of the most common symptoms of MS; persistent feelings of sadness, irritability or hopelessness
12. Programs designed to help you improve or maintain function
13. A type of speech problem that includes loss of volume
14. A type of speech problem that includes slurring
15. Altered, diminished or lost sensation
16. Treating MS should include a comprehensive care _____.



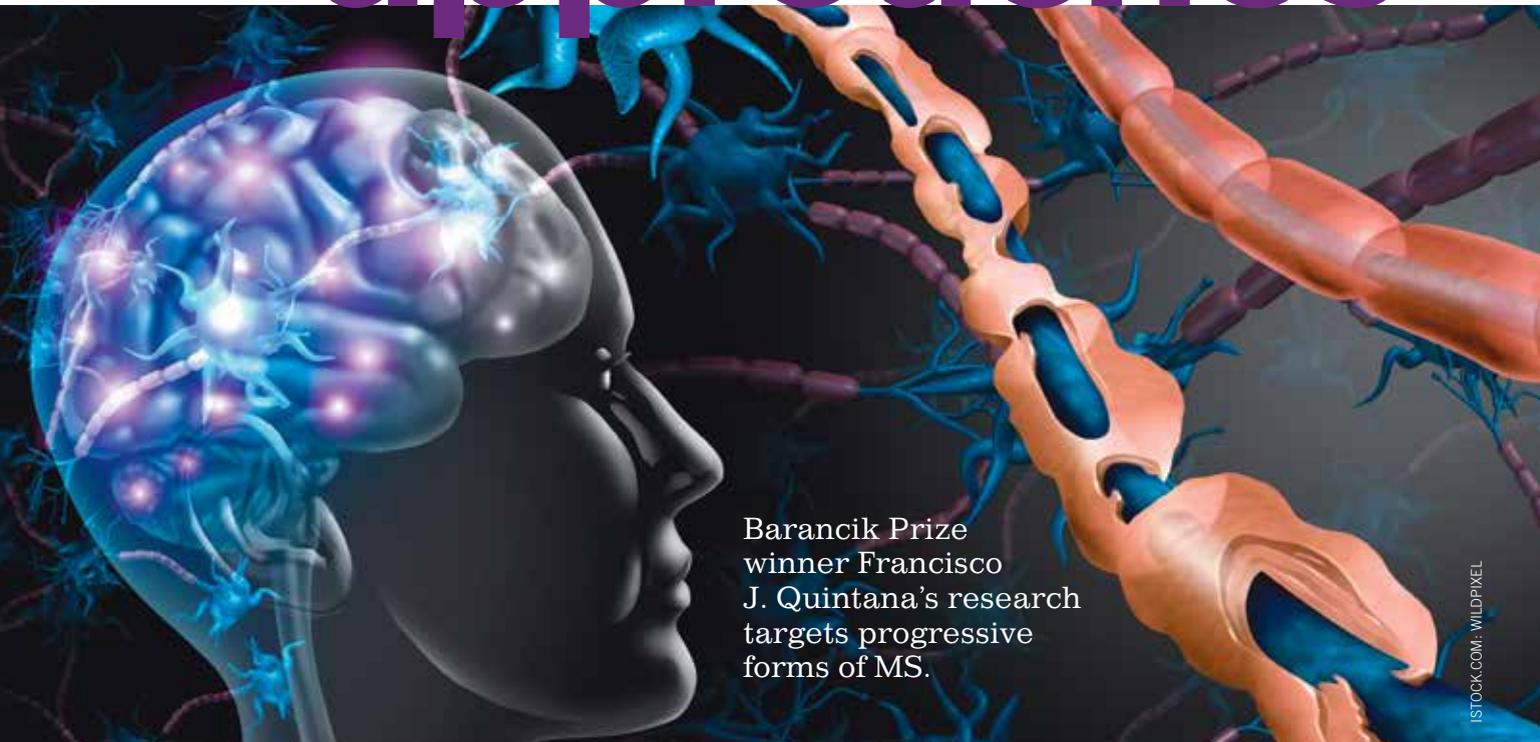
DOWN

- 1. Another word for uncontrollable shaking
- 2. Occurs in about 80% of people with MS; can significantly interfere with ability to function at home or work
- 3. Hormones that can be used to treat severe MS exacerbations
- 4. Abbreviation for a type of talk therapy that helps manage negative thoughts or behaviors
- 6. Damage to the protective covering that surrounds nerve fibers in your brain, optic nerves and spinal cord
- 8. Alternative therapy that may benefit a wide range of symptoms, such as pain or gait issues
- 11. A type of sleep disturbance that can be caused by MS symptoms, medications or the disease itself

- ANSWERS:**
- Across:**
 5. Vertigo
 7. Spasticity
 9. Dysphagia
 10. Depression
 12. Rehabilitation
 13. Dysphonia
 14. Dysarthria
 15. Numbness
 16. Team
- Down:**
 1. Tremor
 2. Fatigue
 3. Corticosteroids
 4. CBT
 6. Demyelination
 8. Acupuncture
 11. Insomnia

ISTOCK.COM: KARANDAEV

Creative approaches



Barancik Prize winner Francisco J. Quintana's research targets progressive forms of MS.

ISTOCK.COM: WILDPXEL

By Mary E. King, PhD

Francisco J. Quintana is a professor of neurology at the Ann Romney Center for Neurologic Diseases at Brigham and Women's Hospital, Harvard Medical School. He created a new model for studying MS, developed two types of therapies that are entering clinical trials, identified new types of cells that are important in MS, and is advancing our understanding of how cells inside the

brain that are involved in MS autoimmune processes talk to each other.

"Professor Quintana collaborates on a global scale to apply creative approaches to very complex questions about what triggers brain inflammation in multiple sclerosis and to find ways to stop it," says Bruce Bebo, PhD, executive vice president at the National Multiple Sclerosis Society, which administers the award. "He has earned the

Francisco J. Quintana, PhD, is the 2020 recipient of the Barancik Prize for Innovation in MS Research for his groundbreaking work that could lead to new treatments for people with progressive forms of multiple sclerosis.



PHOTO COURTESY OF FRANCISCO J. QUINTANA

Barancik Prize for being highly resourceful in applying advanced technologies to make progress toward developing new treatment approaches, especially for progressive forms of MS.”

Two leading MS researchers who supported Quintana’s nomination also praised his work.

Quintana is “an incredibly talented young scientist whose highly significant

contributions have already generated novel hypotheses, identified important immunoregulatory mechanisms and opened new areas of research in MS,” says Howard L. Weiner, MD, co-director at the Ann Romney Center for Neurologic Disease at Brigham and Women’s Hospital and the Robert L. Kroc professor of neurology at Harvard Medical School.

Dr. Lawrence Steinman, MD, Zimmermann professor of pediatrics, neurology and neurological sciences at Stanford University, says that Quintana’s findings “have important implications for our understanding of the pathogenesis of MS and other neurologic disorders, while they also identify candidate targets for therapeutic intervention.”

“I’m humbled, honored and happily surprised,” Quintana says. “It is one of the biggest awards you can dream of as a scientist working in MS. I couldn’t be more thankful.”

Quintana adds: “While it is great that I got this prize, the biggest accomplishment I can dream of is if anything we are doing ends up improving the lives of patients with MS.” Quintana also credits the extremely supportive environment at his institution. “I have been lucky to be surrounded and mentored by people who are so passionate about MS. I am very thankful about receiving this prize, but the real prize will be helping patients.”

Roots of research interest

Quintana points to his grandfather as a key reason for the direction his research has taken. “Growing up, one of my role models was my grandpa, the father of my mom,” he says. “I was very close to him, but

eventually, he came down with a neurologic disease. It was very sad for me because he went from being this very big, strong, tall energetic man into someone who was completely lost. Although he didn't have MS, this experience pushed me toward the world of neurologic diseases, including MS, as I began my research."

Quintana emphasizes that the National Multiple Sclerosis Society has played a central role at multiple stages of his career. "The very first grant I got as a principal investigator was from the Society. It allowed me to start my laboratory and form my research group," he says. "Later, they awarded me the Harvey Weaver Scholar award faculty grant, which allowed me to put resources and lots of thought into new areas of research in MS."

Outstanding research contributions

Quintana says his research group's efforts are focused on mechanisms of MS disease and its treatment. One major project, he explains, began with basic science investigations of an important protein called aryl hydrocarbon receptor (AHR). This protein is involved in many important cell functions. When specific small molecules bind to it (a process called activation), AHR travels to the nucleus of the cell, where the DNA that makes up our genes resides. AHR can alter how DNA is read in the nucleus, changing how genes behave.

Quintana says that AHR interested him in part because the types of small molecules that can activate it come from a number of sources. The sources include bacteria in our guts, the food we eat and even pollutants, all factors that are of increasing interest to researchers wondering about their impacts on MS.

Quintana's wide-ranging work in this area demonstrates his unique talents for investigating basic science questions. He broadens the work to multiple avenues of research that may produce real clinical impact for people with MS. His research has resulted in groundbreaking publications in some of the foremost science journals, including *Cell*, *Nature* and *Nature Medicine*.

Quintana's research showed that genetic changes produced by AHR include significant effects on T cells. AHR can reduce the activity of a particular type of disease-promoting T cells while making another type of T cell, one that is helpful in immune diseases, more active.

Quintana is interested in how AHR can affect autoimmune diseases like MS and diabetes. His investigations led to the development of very tiny, synthetic spheres called nanoparticles as a potential therapeutic agent. These tiny particles have been designed to trigger AHR's positive effects in autoimmune diseases. The nanoparticles have been licensed by a pharmaceutical company that will begin clinical trials, first in people with type 1 diabetes, by the end of 2020. (The exact composition of these nanoparticles is proprietary information, but other types of nanoparticles have been made out of metals like gold or types of fats. They have been used to deliver medicine to tumor cells as one example of their increasing use in medicine.)

His team is also developing probiotics, which we all carry in our intestines — the live yeasts in yogurt, for example. For this research, however, the probiotics developed by Quintana's team suppress inflammation. The hope is to create a therapeutic probiotic that will be helpful in MS. However, the research is still in the early phases and is further away from reaching clinical trials.

“

I am very thankful about receiving this prize, but the real prize will be helping patients.”

—FRANCISCO J. QUINTANA

Quintana is using zebrafish to study how different environmental chemicals impact neurodegeneration.



ISTOCK.COM: YINYANG

Quintana's work in AHR then led his team to identify some of the specific small molecules produced by gut bacteria that also activate AHR. The team also investigated the effects of these molecules on two types of glial cells important in MS research, astrocytes and microglia. "And that led us to deeper questions about what controls these cells and how they communicate among themselves," Quintana adds.

Quintana and his group have also looked more closely at astrocytes, which were once thought to be all alike. However, they identified different types of astrocytes, including one type that may play a key role in MS progression. These discoveries led the team to think of new ways to help people with MS. One of these involves taking an existing drug for another disease and seeing if it will help treat progressive MS, an area Quintana describes as one of the biggest unmet clinical needs in MS.

In addition, Quintana has developed new models for studying MS, including using zebrafish, to screen many different kinds of environmental chemicals, like pesticides, fire retardants and preservatives, to see their impact on neurodegeneration.

Future directions

Looking to the future, Quintana says: "We are just really starting to understand to understand how the astrocytes and microglia are regulated. We want to know more about



What is the Barancik Prize?

The Barancik Prize for Innovation in Research was created in 2013 by the Charles & Margery Barancik Foundation and is administered by the National Multiple Sclerosis Society. As major supporters of MS research projects for more than 20 years, the Baranciks developed the Barancik Prize to recognize exceptional scientists who have demonstrated outstanding innovation and originality in MS research. Barancik Prize winners receive \$100,000 that can be used at their discretion. Charles and Margery Barancik passed away in 2019, and the National Multiple Sclerosis Society joins their family in mourning their loss.



ISTOCK.COM: ANTON SHAPARENKO

the different populations of these types of cells and the T cells in the brain and how they communicate — who talks to whom and which mechanisms do they use to do it. We are developing a whole new set of tools to study these interactions in human and animal cells. Understanding those cells, their diversity, how they communicate and how they are regulated is a basic and important question for neuroimmunology." ■

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

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

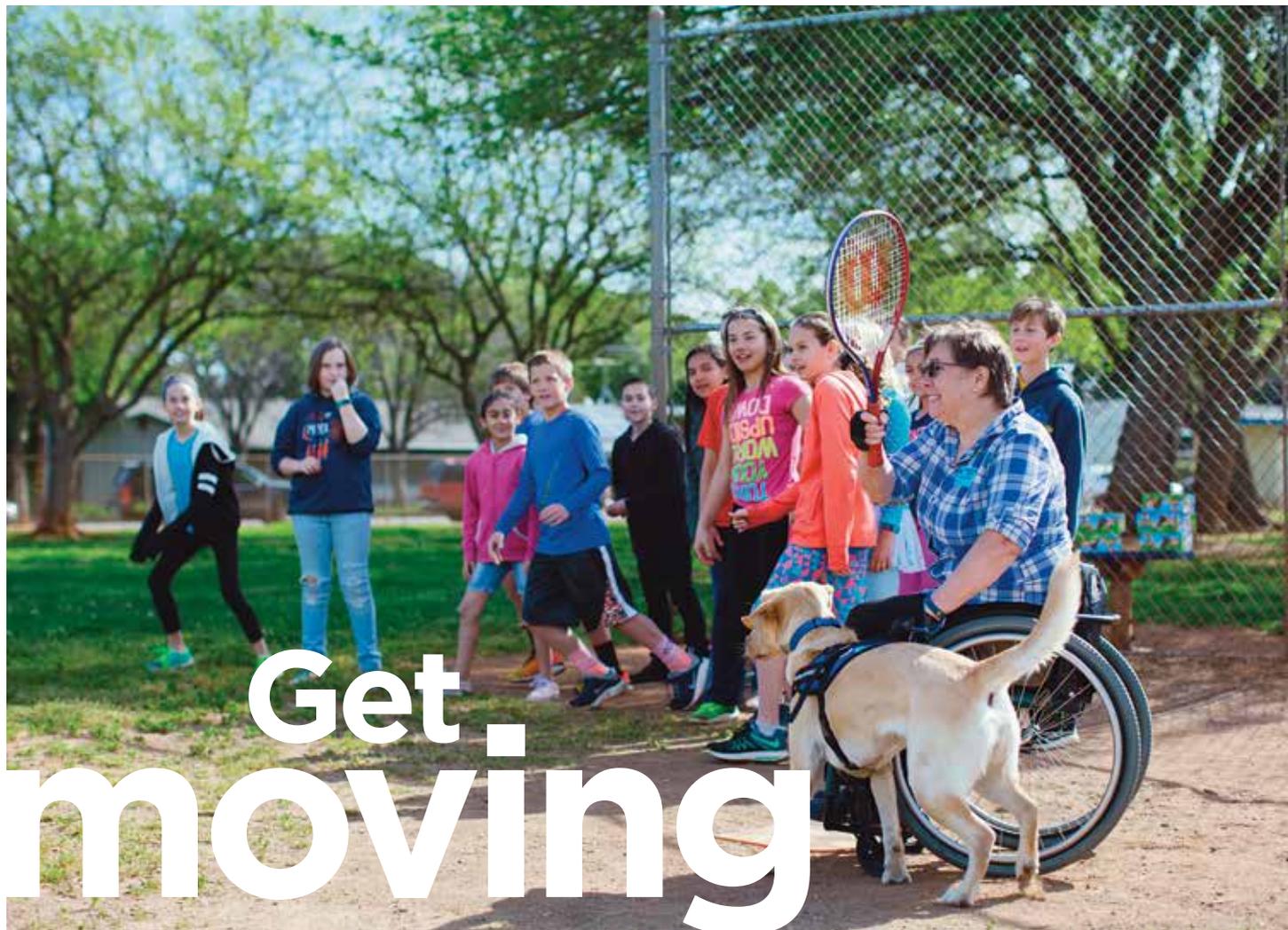


PHOTO COURTESY OF LAURIE MONSERRAT

Get. moving

People with mobility issues can benefit from exercise, too.

by Brandie Jefferson

Exercise is recommended for everyone: people with multiple sclerosis, people without, people who walk miles a day and people who use wheelchairs daily. Most people — with or without a chronic disease — don't get enough.

"Most Americans don't get enough physical activity," says Deborah Backus, PhD. And when it comes to having access and support to get in a good workout, "people with mobility limitations face much bigger barriers."

Today, healthcare professionals think differently than in the past, when exercise was not recommended for people with MS. Physical activity has been shown to have positive impacts on everything from strength and fatigue to bladder function and cognition in people with MS.

Laurie Monserrat, shown with her service dog, Tyla, tries to get exercise every day, whether it's through community sports or weightlifting with a book while reading.

Backus, the director of multiple sclerosis research at the Shepherd Center in Atlanta, is working to make exercise easier and more accessible for people with MS.

Backus leads the multisite STEP for MS trial funded by the Patient-Centered Outcomes Research Institute, with co-principal investigator and creator of the novel exercise intervention, Rob Motl, PhD, of the University of Alabama at Birmingham. Participants are put into one of two exercise groups: one randomly assigned to do exercises at a facility or from home using teleconferencing, and the other allowed to exercise wherever they want. Both groups have access to coaching.

The trial is ongoing, but Backus has already gained some insights. “Being able to exercise in a way that fits your lifestyle, just like for all of us, is going to be meaningful,” Backus says, because everyone is more likely to stick with something they enjoy.

The coaching is key. “The coaching is what’s going to probably lead to best outcomes because people need support, so they can build confidence dealing with MS,” Backus says.

Exercising with mobility aids

It can be frightening for people with MS to exercise because they might be nervous about



PHOTO COURTESY OF DEBORAH BACKUS, PHD

Deborah Backus, PhD, is leading a clinical trial that studies how exercise can be made easier and more accessible for people with MS.



PHOTO COURTESY OF STEPHANIE SILVEIRA, PHD

In her research, Stephanie Silveira, PhD, focuses on exercise adaptations for people who use wheelchairs.

experiencing a fall, fatigue or pain. A person may not know how or if they should continue a program when these issues come up. Coaches with specific knowledge of MS can help people navigate those uncertainties.

Navigating the exercise terrain can be even more

challenging for people who use wheelchairs. The first challenge is learning to use them.

“People with MS are often given wheelchairs, but they’re not taught how to use them,” says Stephanie Silveira, PhD, a postdoctoral fellow in the Exercise Neuroscience Research Lab at the University of Alabama, Birmingham. Her research focuses on exercise interventions for people with MS who use wheelchairs. Specifically, she asks, what are people interested in?

Silveira says there isn’t much research when it comes to exercise for non-ambulatory people, and much of it is developed for people in the aftermath of an injury. She and her team started by interviewing 20 people, most with primary or secondary progressive MS.

The people Silveira surveyed were most interested in cardio and strength training, but their reasons were specific to their symptoms. For instance, she says, “A few people mentioned that if they got stronger, they’d be able to stand a bit more.”

But the answer to one question, in particular, points to the differences inherent in exercise programs for people who use wheelchairs after injury versus those who have MS. And it can create problems down the line.

“When I ask, ‘How did you decide to get a wheelchair?’ some people say, ‘I just decided



PHOTOS BY KEITH CARLSEN



Above: Brian, diagnosed in 2012

Left: Michelle, diagnosed in 2001

to buy one and use it.’”

That’s just what Laurie Monserrat did.

Monserrat was diagnosed with MS nearly 30 years ago. She was getting tired throughout the day, and she had difficulty walking. At the time, she was working with people who had spinal cord injuries. “They said, ‘You’re going to fall. Get a wheelchair, save your energy, walk when you can.’” After convincing her insurance to cover one, she went to pick up her new chair.

“I just wheeled out of the place where I picked it up,” Monserrat says.

“If you don’t know how to use it, you’re going to be disinclined to exercise,” Monserrat adds. “If I’m exhausted because I don’t know how to use the chair, by the time I get to my car to go someplace to exercise, I’m done.”

Making sure she gets some exercise every day is a lesson Monserrat brought home from four days that she says changed her life. Twenty years after her MS diagnosis, she went through the Can Do MS health and wellness program (candoms.org), a retreat where she had personalized coaching and therapy for everything from

exercise to diet to mental health.

“They kept saying, ‘The answer to disability is mobility,’” Monserrat recalls. “It’s been the most impactful program I’ve done.

“I have terrible days where everything hurts, but every single day I do something,” she says. From going on a walk with crutches when she can to lifting a book up in the air after reading a page when she can’t. “Every single day.”

The National Multiple Sclerosis Society is a Can Do partner. Olympic skier Jimmie Heuga, who was diagnosed with MS in 1967, founded the organization. “Doctors



told him not to exercise,” says Kathy Zackowski, PhD, senior director, patient management, care and rehabilitation research at the Society.

Heuga began the program to help people with MS stay active. “Research shows that people with MS are far too inactive, overall,” Zackowski says. “And it’s essential to acknowledge that physical activity is different than exercise, and we need to do both.”

The benefits of staying active

Physical activity is the daily accumulation of leisure, occupational or household activities that require moderate intensity. This includes activities such as vacuuming and parking a little farther away from the store. Exercise is a form of physical activity but it is performed on a repeated basis over an extended period

of time. Think yoga, walking, or cycling. “It’s important for people to know the difference,” Zackowski says, “in part, because we need to incorporate both types of activity in our lives. And doing this is empowering.”

It’s also important to know the effects exercise can have. Research on the benefits of exercise for people with MS has borrowed from spinal cord injury therapy, as well as from stroke studies. “In a stroke, you form a lesion in your brain from a blood supply issue. In MS, the lesions in your brain or spinal cord are caused by different mechanisms,” Zackowski says, “but the symptoms people feel and their recovery from these symptoms have some similarities.”

We hear it often when it comes to stroke patients, but it’s true for people with MS as well, Zackowski says: “The brain can change over time. The idea of staying as active as you can, trying in a careful way to use a limb that isn’t working well can have benefits.”

As part of her goals leading a wellness research work group, Zackowski plans to publish guidelines and adaptations for people across the spectrum of disability. She hopes people can use it to advocate for themselves, taking the guide to a physician, physical therapist, occupational therapist or trainer and saying, “I need you to walk me through this so that

I know what I’m doing.”

People with particularly limited mobility, however, may not have that option, as spaces with adaptive machinery are few and far between.

“It’s been exciting to have an option for an exercise study that people who use wheelchairs can participate in,” said Lara Pilutti, PhD, at the University of Ottawa. She is working on a Society-funded pilot study looking at the impact and enjoyment of exercise for wheelchair users. “There’s been excitement about the adapted exercises they can do.”

Her research is in the early stages. “We’re trying to characterize responses and understand safety,” she says. “In designing the study, we’re thinking about how we can adapt certain exercises while also considering logistics,” such as specialized equipment to allow people to remain in their wheelchairs or to help people stay secure while exercising.

The trial uses tools like upper-body cycles and recumbent steppers operated by a person’s arms as well as legs. There are also high-tech interventions: functional electrical stimulation exercise, which involves mild electric stimulation, for instance, to a leg muscle while exercising that muscle using a specialized cycle.

Pilutti wants her work to have an impact beyond the participants and academic circles. “Hopefully, we can

Tips for getting more exercise

- 1. MAKE IT A HABIT.** Try to do something active every day.
- 2. LOOK INTO DIFFERENT TYPES OF EXERCISE CLASSES.** Try exercise classes designed for the elderly, which are often adapted in ways that suit people with mobility limitations.
- 3. SEE A PHYSICAL THERAPIST.** If you have insurance, make use of a physical therapist. Insurance typically pays for a limited number of sessions, says Kathy Zackowski, PhD, senior director, patient management, care and rehabilitation research at the Society. She suggests using them to learn exercises you can do at home, then checking in as insurance permits to perfect your form and learn new routines.
- 4. EDUCATE YOUR TRAINER.** Prepare to work with a trainer. Offer a potential trainer/coach the Society's "Intro to MS" for fitness and wellness professionals.
- 5. PARTICIPATE IN STEP FOR MS.** Join the STEP for MS trial if you are in one of the participating areas, or look for another study in your area. You can find some current clinical trials at nationalmssociety.org/Research/Participate-in-Research-Studies/Participate-in-Clinical-Trials.
- 6. KEEP IT LOCAL.** Visit nationalmssociety.org to find health and wellness programs in your area.

provide research that supports the use of these interventions," she says. "And it transfers to the community."

Community involvement could make all of the difference when it comes to access to exercise for all people with mobility limitations. "The equipment we use is expensive," Backus says. "For someone to have an \$18,000 bike in the home is expensive. A specialized center is expensive. How do we make this affordable?"

The Shepherd Center has collaborated with the YMCA on some adaptive programs. Backus plans to work with Motl to package the results of the

STEP trial in a way that people can use to self-advocate.

"I would like to make exercise more accessible to people with disabilities who need it the most," she says.

One thing that can change is people's attitudes.

"A shocking number of times, I've tried to go to a gym, and the trainer said, 'We can't do that,'" Monserrat says.

But self-advocacy paired with an open mind can lead to significant changes.

"I wanted to take a yoga class to help with balance," Monserrat says. She asked the

teacher if he could help. He was honest; he didn't know, but he'd try.

"He adapted poses. He does this adaptive yoga now, and it's cool. I can do some of the poses lying down. The important thing is I'm still doing something," she says. "It was a big step for me to ask, 'Can you do that? Can you help me with this?' It wasn't easy, but it paid off." ■

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

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



CARLOS (CENTER), DIAGNOSED IN 2001

Find Doctors & Resources Tool

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

What is Available on Find Doctors and Resources

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

Start using the Find Doctors
& Resources tool today at
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For adults.
Not an actual patient.

What is MAYZENT® (siponimod) tablets?

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

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

IMPORTANT SAFETY INFORMATION

Do not take MAYZENT if you:

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

MAYZENT may cause serious side effects, including:

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

During the initial up dosing period (4 days for the 1-mg daily dose or 5 days for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the up dosing. Call your health care provider if you miss a dose of MAYZENT.

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

Call your health care provider right away if you have any of these

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

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

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

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

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

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

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

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

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

MAYZENT may cause possible side effects, including:

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

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

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

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

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

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

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

Please see Consumer Brief Summary on following pages.

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CONSUMER BRIEF SUMMARY

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

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

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

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

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

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

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

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

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

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

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

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

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

What is MAYZENT?

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

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

Who should not take MAYZENT?

Do not take MAYZENT if you:

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

What should I tell my healthcare provider before taking MAYZENT?

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

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

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

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

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

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

How should I take MAYZENT® (siponimod) tablets?

The daily maintenance dose of MAYZENT is either 1 mg or 2 mg, depending on your CYP2C9 genotype. Ask your healthcare provider if you are not sure about your daily maintenance dose.

Start your treatment with MAYZENT using the following titration schedule:

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

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

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

What are the possible side effects of MAYZENT?

MAYZENT may cause serious side effects, including:

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

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

• severe worsening of multiple sclerosis after stopping

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

The most common side effects of MAYZENT include:

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

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

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

How should I store MAYZENT?

Before opening:

- MAYZENT 0.25 mg and 2 mg tablets should be stored in a refrigerator between 36°F to 46°F (2°C to 8°C).

After opening:

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

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

General information about the safe and effective use of MAYZENT

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

What are the ingredients in MAYZENT?

Active ingredient: siponimod

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

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

For more information, go to www.pharma.us.novartis.com or call 1-888-669-6682.

Gail, a 51-year-old business owner from Pennsylvania, grew up in a family where healthcare was one-sided. You went to the doctor, reported your problem and followed the doctor's instructions without question or discussion.

But when Gail was diagnosed with multiple sclerosis at age 32, she took a different approach. "I felt I needed more control over my healthcare. By trial and error, I was able to learn how to talk to my doctors. After reading articles and [considering] my own experiences, I came to shared decision-making," says Gail, who asked that her last name be withheld to protect her privacy.

Shared decision-making is a communication process where the patient and the healthcare provider work together to agree on a course of treatment. The provider supplies information to the patient on specific options, evaluating the risks and benefits of each. Then, they'll discuss what is paramount to the patient — things like values and lifestyle — before reaching a mutually satisfactory decision.



Working together

Shared decision-making gives people with MS more say in their care.

by Robert Lerosé



ISTOCK.COM/DRAFTER123

Shared decision-making helps make sure the “patient’s needs are met from a social standpoint, a health standpoint and a physiological standpoint,” says Megan Esch, MD, Gail’s neurologist at Geisinger Health System in Pennsylvania. “We [want to] ensure that we can give the best treatment possible to prevent relapses, make the patients feel good and get buy-in from both parties.”



Shared decision-making makes me feel at ease and that my voice is being heard.”

—KERA LABONTE

For example, after a positive MRI following her first treatment with the medication Lemtrada, Gail’s second scan found additional lesions. Esch gave her the option of switching to Ocrevus. Together, they looked at recent studies of Ocrevus and discussed how it would affect Gail’s lifestyle. Gail knew what to expect with the effects of Lemtrada on her daily routines and decided to continue with it. It was a joint decision with plenty of input from both sides. “We really do have a good back and forth,” Gail says.

Open communication

When 34-year-old Kera LaBonte was diagnosed with MS at age 22, she “wanted nothing to do with it,” and went into denial. Even though she admits to being outspoken, she felt that some of her early doctors didn’t listen to what she really wanted regarding her choice of prescription medication. After learning about shared decision-making from her mother, it has become an integral part of her life.

For example, LaBonte would like to have a baby, but her current treatment could affect her chances of conceiving. Together, she and Esch looked into weaning her off the drug and switching to something that could be less problematic in a planned pregnancy.

“She listens to everything I am saying and comes up with solutions with me. I don’t feel like I have to pick what she decides. [Shared decision-making] makes me feel at ease and that my voice is being heard,” LaBonte says.

Open communication is essential in a shared decision-making relationship. Healthcare providers work to ensure that their patients have a solid understanding of the risks and benefits of any treatments, and people with MS must be honest about

their goals and fears beyond their MS — including their lifestyle, values and plans for the future — to come up with the best possible treatment plan.

“People have their own way of thinking about things,” says Matthew Carraro, MD, systemwide director of MS and neuroimmunology at Novant Health in North Carolina. “If you stop somebody’s MS, but they’re miserable all the time, what is the point? They have a horrible quality of life for a different reason. It’s really important for them to feel invested in the treatment.”

Doctors also have their own way of thinking about things, Carraro says, pointing out that there is no right way to treat MS. Healthcare providers need to explain these different factors to help their patients come to an informed decision and be honest with them about their own biases.

“I want you to be aware of where I’m coming from because I don’t know what your thoughts are for treating your condition,” Carraro says. “Being that thorough may help to dampen some of [our] biases and help patients make a choice that’s more appropriate for them, instead of a doctor saying, ‘I have this way of doing things and that’s how we’re going to do it.’ We are always influencing patients’ decisions, but when they’re informed and they’re [involved in] shared decision-making, it serves to eliminate or reduce some of that bias, which is good.”

Empowerment

For 50-year-old Jennifer Frame of Huntersville, North Carolina — who was diagnosed with MS at age 19, just as she was starting nursing school and learning to be an advocate for others — shared



PHOTO COURTESY OF KERA LABONTE

Kera LaBonte, who has MS, with her fiancé, Todd, and his son, Ayden.

decision-making can best be summed up by the idea of empowerment.

For example, she had to make several changes to her medication recently — a long, involved process. Being up-front with Carraro, her doctor, about her fears and asking him to clarify things that she read about different medications eased the burden. “It boils down to communication and being knowledgeable,” she says.

It also means recognizing that at the heart of shared decision-making is creating a safe space where no question is off-limits. Patients “should not be afraid to ask any question they have, as silly as they think it may be. We would rather that the patient ask the questions or voice the concerns, instead of harboring them, so that we can

While every person will have their own individual concerns, issues that might come up during an office visit could include:



ISTOCK.COM: EXDEZ



Jennifer Frame, who was diagnosed with MS at age 19, feels empowered when she is open and honest with her doctor, and they make decisions about her care together.



Patients should not be afraid to ask any question they have, as silly as they think it may be.

—MEGAN ESCH, MD

- Will I die from MS?
- Will my kids get MS?
- Is there an MS diet or foods/supplements that I should consider?
- Will I be able to work?
- If I can't work anymore, can you help me with applying for disability insurance?
- What are the risks of taking this medication?
- Will the medicine make me feel sick?
- Can I have kids? Do I need to stop the medicine before trying to conceive?
- What type of exercise is best?
- Can MS affect my sex life?
- I am having trouble learning new information. Is this due to my MS, or am I just getting older?
- What do you think about this information I found on the internet?

guide them in between each of their visits,” Esch says.

Esch doesn't put any limitations on how much her patients look things up on Google or Facebook, provided they discuss it with her. “I might have data to either support or refute that, and I can help them understand how it might improve the way they're feeling or how it might even harm the way they're feeling,” she says.

To make the best use of your limited appointment time with your healthcare provider, make sure to make time for conversations about shared decision-making. Here are a few suggestions:

- Open with your three most important issues and then move on to other concerns.
- Take notes or bring someone to take notes for you.
- Record the visit on your phone or digital recorder, but get your doctor's permission ahead of time.
- Before your appointment, find out what information your provider needs ahead of time, such as a CD of your MRI, films, lab test results and office notes.
- Be prepared to provide a timeline of your symptoms.
- Bring someone who knows you well — a spouse, best friend or family member — who can give the doctor a picture of you over time, describe changes in your abilities or provide other supportive history.

“Shared decision-making is critical because we need to try to hit your goals, not just ours, and that's just completely different than it was 10 years ago,” Carraro says. “You should feel inspired by where you're getting care.” ■

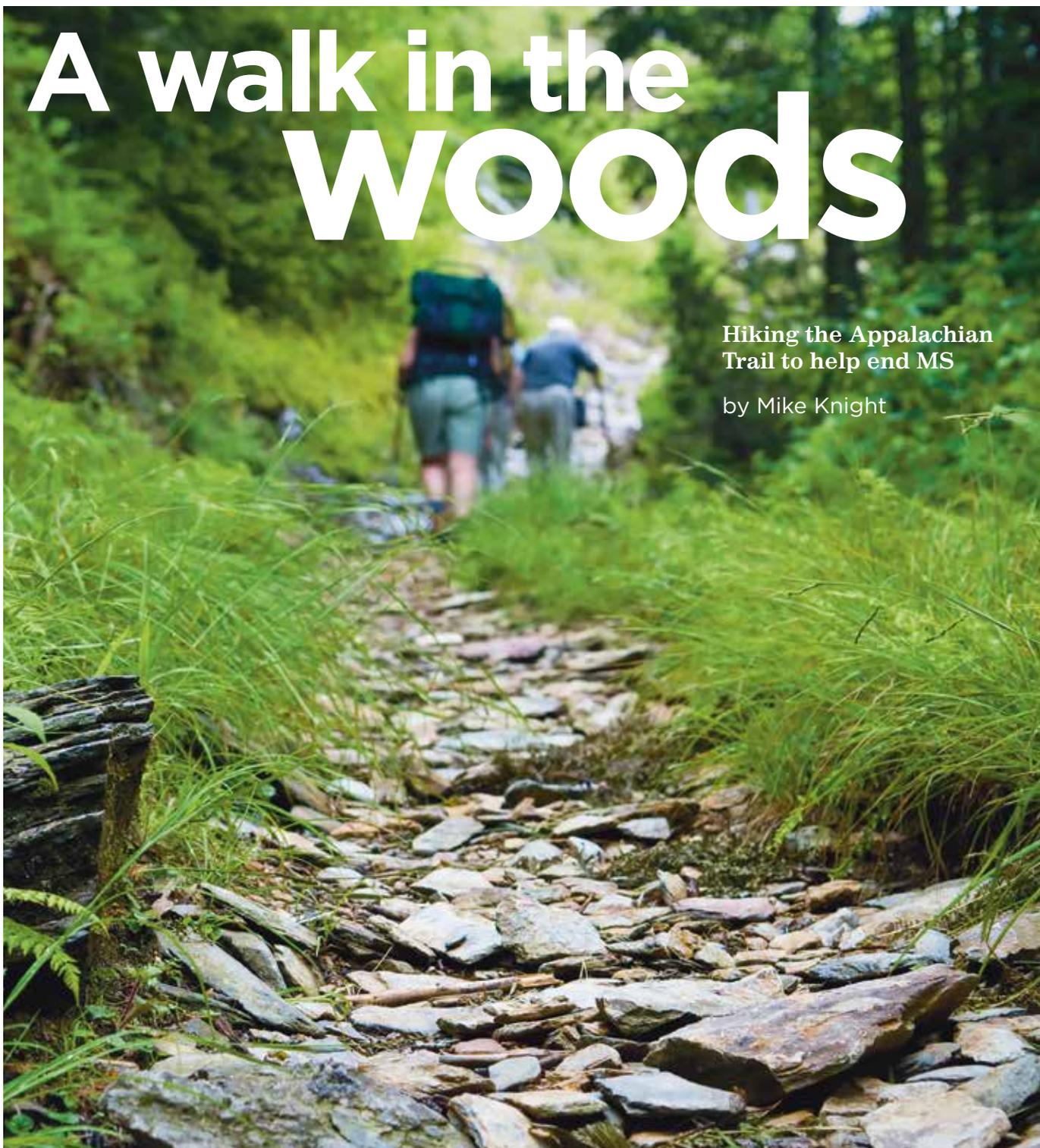
Robert Lerosé is a Long Island, New York-based writer.

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

A walk in the Woods

Hiking the Appalachian
Trail to help end MS

by Mike Knight



ISTOCK.COM: JOEL CARILLET

Stretching nearly 2,200 miles from Springer Mountain, Georgia, to Katahdin, Maine, the Appalachian National Scenic Trail is the longest hiking-only footpath in the world. More than 3 million people visit the trail annually; 3,000 of those visitors attempt a “thru-hike,” traversing the trail’s entire length through 14 states all in 12 months or less. Though flat in some areas, the trail is a continuous string of long, slow ascents and descents, and completing a thru-hike is equivalent to scaling Mount Everest — 16 times.

Two separate sets of National Multiple Sclerosis Society Do It Yourself (DIY) fundraisers chose to attempt thru-hikes on the Appalachian Trail in 2019 to help end multiple sclerosis and to show support for loved ones living with the disease.

Three friends walked onto a trail...

A 2019 graduate of the Georgia Institute of Technology (known as Georgia Tech), Daniel Oliver decided to hike the trail with his bandmate and Georgia Tech classmate Garrett Godbey and childhood friend Gabriel Foral. They did this in part because Oliver’s father, Douglas, has MS, and Oliver has other friends and family affected by the disease. Oliver and Foral had previously hiked shorter sections of the Florida National Scenic Trail and the Appalachian Trail together. They even kicked around trying an Appalachian Trail thru-hike after graduating from college.

Then, Oliver had an idea.

“We knew we wanted to hike the trail anyway and it just occurred to me one day that it would be a great idea to try to do it for charity,” he says. “I started thinking about what kinds of stuff I could do, and since I had this personal thought of my father, and my parents both donate to the Society, it just made sense.”

The three planned to complete their thru-hike via the Harpers Ferry “Flip Flop.” Rather than hiking north or southbound only, flip-flops let hikers customize routes to take advantage of milder weather, more moderate terrain and fewer crowds, making them especially popular with college students who graduate in late spring. Oliver’s group began in Harpers Ferry, West Virginia, in early June and planned to finish in late October in Springer Mountain, Georgia.



PHOTO COURTESY OF DANIEL OLIVER

From left: Bob Fesler, Garrett Godbey, Gabriel Foral and Daniel Oliver. Fesler, Oliver’s uncle, met up with the trio in Maine and hiked Katahdin with them.

A walk to remember

Colleen and Ben Gauntt of Concord, New Hampshire, wanted to do something special for their fifth wedding anniversary in 2016, something meaningful to them as a couple and as individuals — and something they’d never forget. They chose to hike a 100-mile section of the Appalachian Trail in Maine.

Hiking, Colleen says, “is something we really connect with.”

The two enjoyed their anniversary trip so much that they decided to try it again the following year and began talking about trying a trail thru-hike someday. Then Ben started to experience blurred vision and vertigo. He also started to develop foot drop while walking to work each day along with a painful, “knotty” sensation along his spine.

“

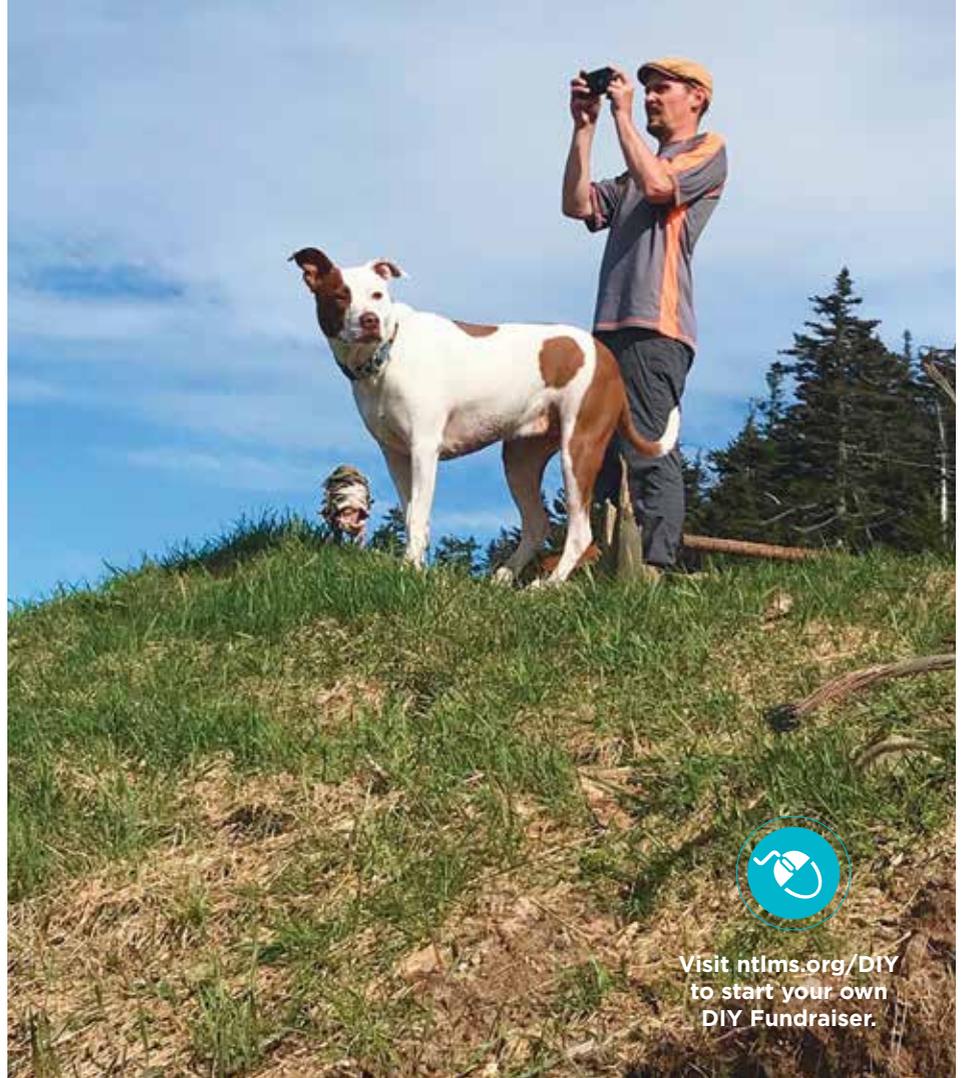
When I got on the trail, my whole mood changed. Feeling useful again was great.”

—BEN GAUNTT



In January 2018, Ben was diagnosed with relapsing-remitting MS, something neither saw coming. “When the doctor told me about the MS, I was kind of blindsided,” he says. “I was like, wait, what?” The diagnosis began what Colleen calls “an escalation of symptoms,” including mood changes and depression brought on, she believes, by stress.

The couple continued hiking as Ben’s health allowed, and if he seemed like a different man out on the trails, Ben says, that’s because he was. “When I got on the trail, my whole mood changed,” he says. The teamwork necessary to complete long hikes made him feel good. “Feeling useful again was great.”



Visit ntlms.org/DIY to start your own DIY Fundraiser.

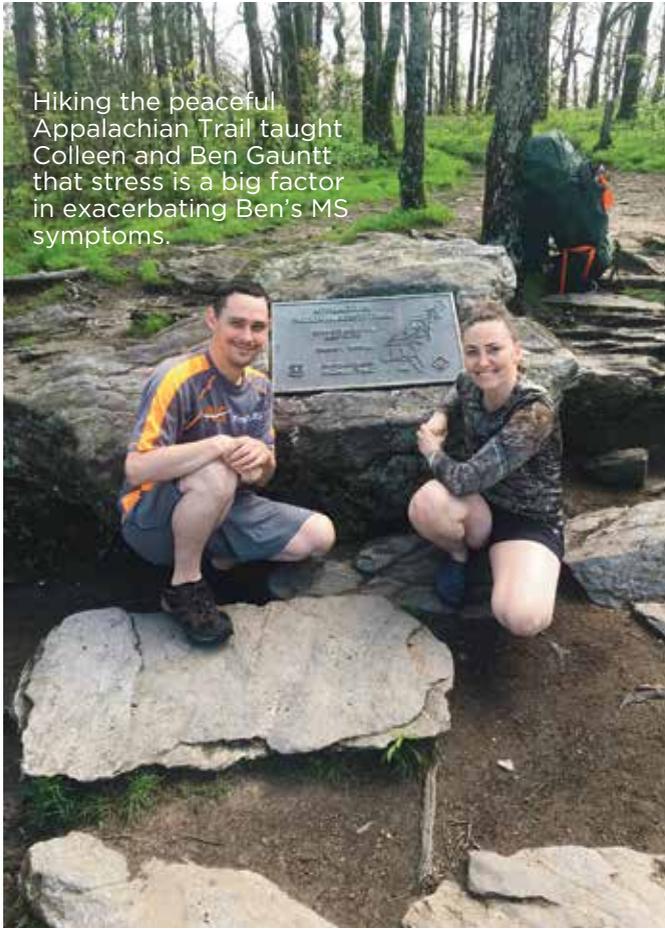
PHOTOS COURTESY OF COLLEEN AND BEN GAUNTT

Hiking is one activity that brings Colleen and Ben Gauntt closer together. Ben was diagnosed with MS in 2018, and the two still go hiking when his health allows.

In May 2018, Ben and Colleen participated in MuckFest Boston, which is a 5K fun run, obstacle course and fundraiser for MS. “It was amazing to go through and see how much money gets raised,” Colleen says.

The experience stuck. When Ben lost his job in early 2019, the couple decided to attempt a thru-hike while he was able. Colleen applied for a Family Medical Leave Act (FMLA) accommodation to secure her job. Then, like Oliver’s trio, they decided to turn something they were passionate about doing — in their case, conquering the Appalachian Trail — into a DIY fundraiser for the Society.

Jennifer Odenice coordinates fundraising events for the Society in the New England area, including Finish MS, Jet Pull and more. Odenice helped the Gauntts launch their fundraising hike. DIY fundraising, she says, is a growing source of financial support for the Society’s vital research, services and other programs. More than 1,250 people now participate in DIY events



Hiking the peaceful Appalachian Trail taught Colleen and Ben Gauntt that stress is a big factor in exacerbating Ben's MS symptoms.

across the United States annually, raising nearly \$4 million each year to help end MS. Many are deeply linked to the cause. Of the 1,570 who participated in DIY events in 2017, roughly half had a direct connection to MS, almost 250 identified as living with the disease.

"You might not want to do a run or a walk, or Muck Fest or a Society event," Odenca says. "We give you the same tools and a fundraising page; people can fundraise with you online. You are the planner, but we are here to support you." Odenca helped the Gauntts develop and launch their fundraising campaign.

One trail, two journeys

Shortly after beginning their hike in June 2019, Colleen twisted her ankle. The couple returned to the New England area for treatment before attempting

a flip-flop from there. But Colleen's injury refused to heal, and after hiking 300 miles (and raising \$300), the Gauntts decided to put the hike on hold. But spurred by their time together on the trail, a new journey for the couple was just beginning.

Initially saddened by their inability to complete the full hike, the Gauntts began to see it instead as an opportunity in waiting. "We ended up realizing through the whole thing how much stress is such a huge indicator for Ben with his symptoms," says Colleen. "On the trail, he had so few symptoms based off of, I'm sure, the lack of stress of home life and being in nature and being active."

Not long after returning home, they decided to leave their busy lives behind and relocated to a small town in Maine. "We always wanted to move up here where life is just a little slower," Colleen says.

"We're hitting a reset button," Ben says. "We took a big jump, and it came to work out."

On Nov. 3, 2019 — nearly six months after setting foot on the trail — Daniel Oliver's group walked the last of the trail's 2,192 miles with friends and family on Springer Mountain in Northern Georgia. Existing on a daily diet featuring some combination of salami, sausages, Fritos, Cheetos, tuna packets, Oreos and Little Debbie cookies, Oliver managed to shed 45 pounds while he hiked. His group faced wind gusts over 70 miles per hour along narrow trails in the mountains and a few "sketchy people" along the way. They also encountered other hikers raising money to help end MS.

In all, Oliver's group managed to raise more than \$5,000 — their fundraising goal and an amount they found especially meaningful.

"We felt proud about the \$5,000 mark," he says, "because that's about the range of what you would expect to budget out to do the whole thing. That's the amount we would have had to raise to fund an extra hiker to come with us. So, it's kind of like [raising money for MS] was that fourth person coming with us." ■

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

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

Hilton Center's reach



by Shara Rutberg

Programs aim to empower people with multiple sclerosis.

Frank Miyamura, 73, tracks mountain lion P-61 as it crosses the 405 Freeway in Southern California. Along with nearly a dozen other members of his cognitive therapy group at the Marilyn Hilton MS Achievement Center at the University of California, Los Angeles, he's following the big cat's progress via motion-triggered camera photos and stories on an iPad. Following a discussion, the group will answer questions about the lion's journey. Then, they'll be asked to recall details in a few weeks and again in a few months. The exercise "improves our memories without feeling like we're really 'working' at it," says Miyamura, who has primary-progressive multiple sclerosis.

Cognitive therapy is just one type of session Miyamura enjoys during the day he spends at the center each week. As part of the center's flagship REACH to Achieve program, his group cycles through a schedule of cognitive, recreation, exercise, yoga, art and music therapy, as well as MS-focused educational

sessions. "This is the highlight of every week," Miyamura says of his day at the center.

The Marilyn Hilton MS Achievement Center was founded in 2001 as a collaboration between the National Multiple Sclerosis Society and the UCLA Department of Neurology to empower people with MS through educational and experiential programs.

The program is made possible through major funding by the Conrad N. Hilton Foundation. Conrad Hilton, who founded the Hilton hotel dynasty, created the foundation in 1944. The foundation made its first gift to the Society in 1957. Barron Hilton, who headed the hotel chain, made his own mark on the family foundation's focus on MS causes to honor his wife, Marilyn, who had MS.

Steve Hilton, Conrad's grandson and the son of Barron and Marilyn, is now chair of the foundation. "I think by seeing how MS affects someone you love, it opened our hearts to not just my mom's condition but



Damian Washington has benefited from the Hilton Center's Living Well Program, which is designed for people newly diagnosed with MS.

PHOTO BY KEITH CARLSEN



PHOTO COURTESY OF THE HILTON CENTER

Joan Ishihara has been coming to the Hilton Center for 13 years.

Q&A with Steve Hilton



PHOTOS COURTESY OF THE HILTON CENTER

Steve Hilton

Steve Hilton is the chair of the Conrad N. Hilton Foundation and someone profoundly affected by MS.

WHAT'S YOUR MS CONNECTION?

My mom [Marilyn] had MS. I was in my mid-30s when my mom initially had signs of MS. For her, it was a gradual decline. When it was really not possible for her to walk and she had to be helped around or in a wheelchair, that was really tough, not only for her but, obviously, for all of us in the family.

WHAT WAS YOUR MOM LIKE?

Growing up, my mom was just the best mom that anybody could hope for — vibrant, high-energy, loving, encouraging. And when I look back, I just have these memories of my mom surrounded by all of my brothers and sisters and our friends.

UCLA's famous basketball coach, John Wooden, said, "Things turn out best for those who make the best of the way things turn out." I like to use that quote to describe my mom's attitude because she was always so optimistic. Despite her disability,

anybody who has MS," Steve Hilton says.

And while the foundation supports MS research, Hilton says the foundation also sees the importance of supporting the wellness and services aspects of MS care. "Lifestyle wellness, I think, is one of the most effective things that anybody can do to improve their situation. So that's why [the achievement center] is a really great legacy for my mom," he says.

Barron Hilton's personal gifts to the Society total \$27 million. He died in 2019. Along with his gift, the Hilton Foundation has given more than \$70 million to impact MS wellness and research.



PHOTO COURTESY OF THE HILTON CENTER

which got worse over the years, she maintained a very positive attitude and all of us in the family just admired that about her.

CAN YOU TELL US ABOUT THE HILTON FOUNDATION AND HOW IT GOT STARTED?

My grandfather, Conrad Hilton, the founder of Hilton Hotels, created the Conrad N. Hilton Foundation in 1944. For many years, it was relatively small, but when he died, he left nearly his entire estate to the foundation with the mission mandate to help the most needy, impoverished and vulnerable. His legacy of philanthropy and charitable giving has permeated the Hilton family for generations.

WHAT IMPRESSED YOU AND YOUR FAMILY ABOUT THE SOCIETY?

We have a long history of giving to the Society because it is the largest funder of MS research in the world. We have been impressed with the way the Society gathers around industry-leading experts in research and is very critical in evaluating projects to invest in. There is comfort in knowing

there is strong oversight and management of our donation and that the money will go where it is needed most.

HOW DID YOUR MOM'S EXPERIENCE WITH MS HELP MOTIVATE THE HILTON FAMILY?

Our family was fortunate in that we could afford nursing care and support to help take care of my mom. But we also recognize that not all families and people affected by the disease are as fortunate. When my mom was diagnosed with MS, it really moved all of us to want to do more to help other individuals and families affected by the disease.



Read the full interview with Steve Hilton, "A Hilton Family Legacy," at nationalMSSociety.org/Momentum.



Frank Miyamura takes part in the exercise programs provided to Hilton Center members.

Elise Herlihy, executive director of the center and an MS nurse specialist, says the center offers a variety of educational and experiential programs designed for people living with MS, from those who are newly diagnosed to those who have been living with the disease for some time.

"We use a health and wellness model that complements their neurological care," she adds.

The center has a multidisciplinary team of professionals and volunteers that includes an MS nurse specialist, physical and occupational therapists, a recreation therapist and recreation instructor,

impact

a clinical exercise specialist, a dietician, a music therapist, speech and language pathologists, adaptive Iyengar yoga teachers, and mental health professionals. Sessions are all synergistic, with patients learning from the professional staff, as well as from one another.

The value of the center reaches far beyond its diverse sessions, says Medical Director Barbara Giesser, MD. “It’s a unique oasis for people with MS — a safe space, an empowering space, a nurturing space.”

The Living Well program is designed for people newly diagnosed with MS. “Most participants are young adults, just starting with their lives when they get hit with the diagnosis,” Herlihy says. “It can be paralyzing. Most don’t know anyone else with MS. The program not only provides information and strategies they can use to take charge of their lives but also provides a community of support.”

The center’s flagship program, REACH to Achieve, is an ongoing, comprehensive health and wellness program designed for people who have been living with MS for a while and are facing multiple symptom-related challenges such as mobility, ability to cope, memory changes and deconditioning. Groups meet the same day each week from 10 a.m. to 3 p.m. for sessions including exercise, recreation, emotional wellness, cognition, and nutrition and health education. Sessions are fine-tuned to meet the needs of participants, from creating exercise routines on specialized equipment to adapting recreation activities.

Damian Washington, 38, learned about the Living Well Program about a year after his diagnosis of relapsing-remitting MS. He wishes he’d found it sooner. “The long way to learning how to live with MS is to try to figure it out on your own,” he says. “The short way is doing the program, where they already have everything codified.”

“It’s comforting, it’s reaffirming and it helps steel you for the future,” Washington says. The program fits into his personal approach to life: finding the joy and leaning into it.

Center members can choose from more symptom-specific, multi-week programs as well. CogniFitness provides strategies for dealing with mild cognitive challenges that can accompany MS, including focus, memory, organization and problem-solving. Free From



PHOTO COURTESY OF THE HILTON CENTER

Program sessions at the Hilton Center are taught by a variety of health professionals and are fine-tuned to meet the needs of each participant.

Falls helps those who walk with or without a cane learn about risks for falls, how to reduce risks, and exercises to improve balance and mobility. Exercise and MS uses functional exercises to help those who are mobile improve overall wellness and help manage MS symptoms.

For those who can take advantage of the center’s programming, the benefits stretch far beyond the UCLA campus. “The warmth of the group and the comprehensive programming is just far-reaching,” says Joan Ishihara, 74, who has secondary-progressive MS and has been coming to the center for 13 years as part of the REACH program. “It keeps me going all week.”

“It takes a lot of the fear, doubt and hopelessness out of our lives,” Ishihara says. “We get to know each other and take care of each other beyond just our day at the center. It really fulfills me and makes me feel more confident about myself.”

“It extends our ability to live independently,” says Miyamura, who travels nearly two hours each way via Los Angeles’ Access transit bus to reach the center. “It provides a safe harbor for asking questions and being asked questions, getting a different perspective on how MS affects each of us. The staff go out of their way to help us live our lives the best we can at whichever stage of MS. I’m very thankful for it.” ■

Shara Rutberg is a writer in Evergreen, Colorado

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The bouncer

A bar, a band and a bathroom

by Jessie Ace

During my time living with multiple sclerosis, I've learned there can be so much judgment from the general public. I can't think of a time where I felt more judged since I was diagnosed with MS in 2013. Seriously, it happens all the time.

Don't get me wrong — I get it, OK? I look like a “normal” person. A “normal” 28-year-old woman with no apparent disability.

One particular judgment happened somewhere I never expected.

Was it a parking lot? Nope.

The supermarket? Nope.

Where, then? A bar.

Have you ever known anyone who was refused entry to a toilet in a bar? Me, neither! It was the strangest experience I've ever had.

I was in London with the UK MS Society covering a hip-hop event at a bar. It was a nice bar called The Jazz Club, and we were there to see a guy called Masta Ace, who has MS himself.

When we walked in, the vibe was calm, sophisticated. I felt hopeful it was going to be a good night.



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When nature calls

Until nature called.

Now, I'd been walking around London all day. In and out of tube stations and train stations trying to find the bar. My body was exhausted and heavy. My legs were weak, and I was tingling all over. I was struggling even to stand, leaning heavily on a nearby table for support.

When I learned the main toilets were downstairs, anxiety set in.

"There's no way I can get back up those stairs!" I said in a panic to a friend, who was standing next to me. "I'll seriously collapse and make a fool of myself. What am I going to do?"

"There is a disabled toilet on the other side of the bar, Jess, just use that," my friend suggested.

Off I staggered to find the disabled loo. All the while, I was thinking, "Thank goodness this is here. I've never felt so grateful for an accessible loo."

As I approached, a bouncer greeted me at the door of a toilet for people with disabilities. That was a first for me.

Standoff with a bouncer

As I walked closer, I had images of being in a Wild West stand-off. The bouncer, who had no intention of letting me use the loo, fired questions at me. He told me I didn't look disabled enough to use the accessible loo and directed me to the toilets downstairs.

I calmly explained why I couldn't and started to tell him about MS.

He made it clear he thought I was lying and that I just couldn't be bothered to walk downstairs.

Seriously? Why would I fake a disability to get out of walking down a staircase?

It became an even more tense debate when he simply ignored what I was saying, looking me up and down and shaking his head.

Finally, I'd had enough. "Look," I said loudly. "What do you want from me? Do you want to see my disabled permit? My MRI scans? What?! Because I am now desperate for the loo, and you are denying someone with a disability usage of the disabled bathroom."

He cocked his head to the side, squinted his eyes, pursed his lips and took a deep breath. Then, he made a statement that filled me with anger.

"OK, miss, I'll let you in this time, but next time I might not be so nice."

I shook my head, rolled my eyes and pushed past him to use the bathroom.

Shocking encounter

I got back to my table and explained what had happened to my friends, who were all rightly shocked.

How different could that situation have been? What would have happened if my MS were more severe and I didn't have control over my bladder? What would have happened if I had an invisible inflammatory bowel disease like Crohn's disease or colitis?

After my encounter at the bar, I honestly felt like a fraud. I'd never been treated this way by anybody, let alone a person with a heightened sense of self who was the bouncer of a toilet.

It's times like this that I feel so grateful to have interviewed so many people on my podcast — the "DISabled to ENabled" podcast — with different invisible illnesses, so I have more understanding of other people's difficulties. It has been my mission ever since to educate the general public on invisible illnesses.

It is so important to raise awareness of chronic invisible conditions to the general public, especially when, for some people, a common recognizable sign of disability is still a wheelchair.

Have you had any experiences like this? Contact me in the ENabled Warriors Facebook group and let me know. It makes me wonder what other strange judgments people living with MS experience. ■

Jessie Ace is the host of the "DISabled to ENabled" podcast and lives in Swadlincote, Derbyshire, in the middle of England, with her husband and her fur baby, Lucy.



Music prevails

Finding harmony within multiple sclerosis

by Steven Riccio

The dream of my youth was to explore the realms of music. When I was 13 years old, I picked up my father's dusty, red-and-white Squire Stratocaster guitar and taught myself how to play it. After a couple years developing my musicianship, I began to compose and produce my own music.

When I was 19, I was diagnosed with multiple sclerosis after an isolated case of optic neuritis, where parts of my vision became faded and discolored. Experiencing this sensation was surreal and frightening. It could have easily crippled my passion for music, but I decided I would never let it define me.

I merged my devotion for music and my ambition to improve my health by evolving my proficiency in performing on the drums. Enhancing my coordination, strength and endurance helped me to combat the debilitating symptoms of MS while further crafting my musicianship.

I graduated magna cum laude from the University of Bridgeport in 2016. I earned a bachelor's degree in music with a minor in English, while building my music and fashion company, Horriblyright. I composed, performed, produced and engineered our music, while creating our imagery through photography, video and web design. I also developed our live performances, featuring a programmed light show, choreographed to our instruments and sound effects.

My dream became a reality thanks to my proactive mentality. Multiple sclerosis will never define me. ■

Steven Riccio lives in Philadelphia.

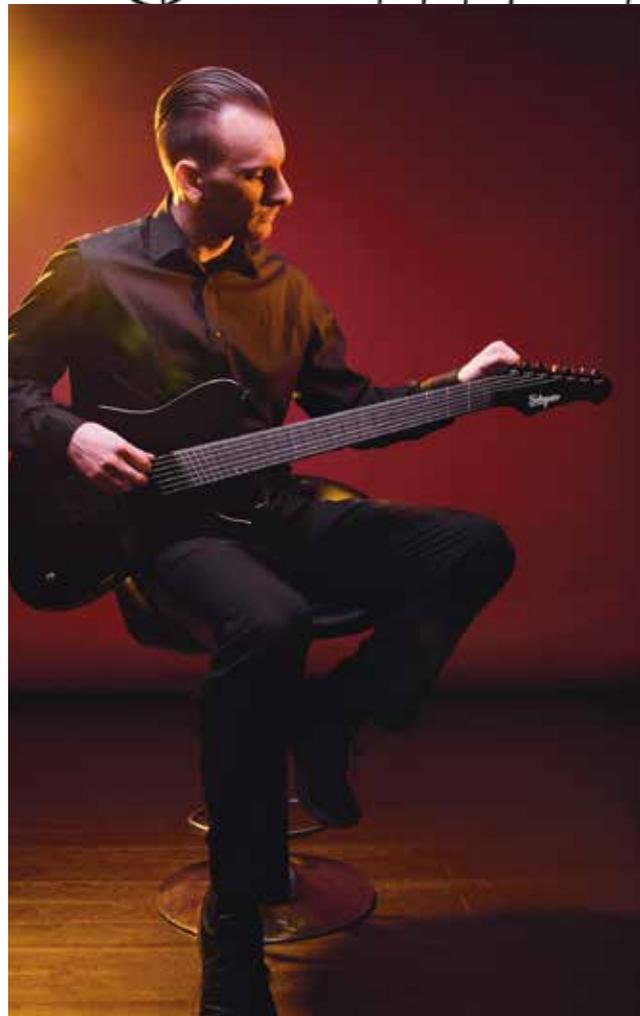


PHOTO COURTESY OF STEVEN RICCIO

Steven Riccio finds that performing music enhances his coordination, strength and endurance, all of which are affected by his MS.



See more of Steven's music and other works at stevenriccio.com.



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