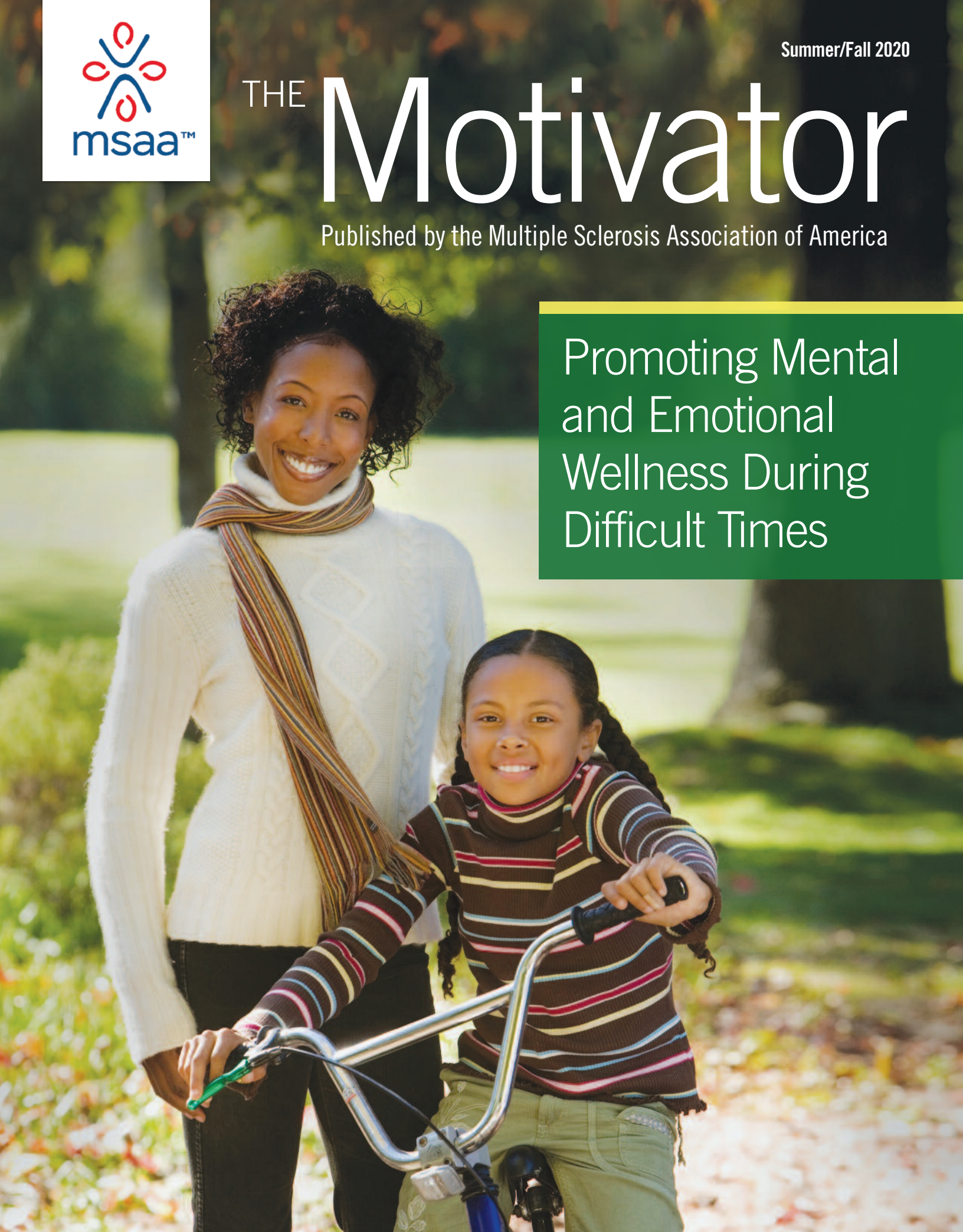
Summer/Fall 2020

msaa™

THE Motivator

Published by the Multiple Sclerosis Association of America

Promoting Mental and Emotional Wellness During Difficult Times



Make a MATCHING GIFT *before the end of the year!*

As the year begins to draw to a close, your support of MSAA's free programs and services is still greatly needed – and now your gift can be doubled or tripled! Many employers sponsor matching gift programs and will match charitable contributions or volunteer hours made by their employees, employee spouses, or retirees.

To see if your employer participates in a matching gift program, please visit
support.mymsaa.org/matching

COVID-19 and MS Pathfinder

Designed to enable easy access to your most pressing questions

MSAA, in partnership with Wondros, has launched a **free, innovative and informative online tool** to navigate through the many issues associated with the ongoing pandemic.

msaa *Improving Lives Today!™*
Multiple Sclerosis Association of America

MyMSAA.org/covid-19-and-ms-pathfinder

The COVID-19 and MS Pathfinder has been made possible through generous support from Bristol Myers Squibb, Johnson & Johnson, and Novartis.

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Published by the Multiple Sclerosis Association of America

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President & CEO

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The Motivator's purpose is to inform and educate those with MS and their families. MSAA does not endorse or recommend any specific products, services, therapies, or activities mentioned in articles or advertisements that appear in *The Motivator.* MSAA, its staff, and those affiliated with the writing of this publication cannot be held responsible for any unintentional errors.

SUMMER/FALL 2020

COVER STORY

DEPARTMENTS

Please send comments regarding *The Motivator* to **editor@mymsaa.org**

msaa *Improving Lives Today!™*
Multiple Sclerosis Association of America

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

Needs of the MS Community Are Greater than Ever

By Gina Ross Murdoch
MSAA President and CEO

In the previous issue of *The Motivator*, I talked about how life had turned upside-down for virtually everyone in the United States and for many throughout the world as a result of the pandemic. I expressed our hope that everyone is staying healthy and safe… and that our hearts go out to all those who have been directly affected by this virus. I expressed our gratitude to the medical professionals and first responders, who risk their own safety to help others… and our gratitude also went out to all of the essential workers who provide the vital products and services needed to ensure our safety and wellbeing.

While we all hoped that this wouldn't be the case, six months later, my message has not changed. Our country's activities are all still greatly restricted, as we wait for the nationwide infection rates to drop and for an approved vaccine to become available. We continue to express our wishes for good health to the MS community, and gratitude to those who are making personal sacrifices for others. And as we all try to balance family and home responsibilities, social distancing and virtual schooling, as well as financial burdens, along with so many other challenges, we know that the mental and emotional toll is significant.

Sadly, the nation's challenges reach well beyond those of the pandemic, including racial injustice, acts of violence, and senseless loss of life. Please know that MSAA advocates equally for members of the MS community, and supports peaceful efforts aimed at erasing the inequalities that exist between people of different races, religions, gender, and economic backgrounds, as well as those with disabilities. For our full statement, please visit **mymsaa.org/msaa-statement**.

I also want to acknowledge all of the losses associated with recent natural disasters, most notably severe weather and raging wildfires. Our thoughts and prayers go out to everyone

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

who has been affected by these unprecedented conditions, and we hope that these families and communities will have the ability and strength to rebuild and recover as quickly as possible.

In an effort to help our readers and as many members of the MS community as possible, this issue's cover story focuses on promoting mental and emotional wellness during these difficult times. We hope that you find this article to be beneficial, and for those who may be struggling, we hope it will provide both comfort and positive direction.

As readers can imagine, the needs of the MS community are greater than ever. Many households have seen a reduction in income, which means that purchasing much-needed equipment – for safety or symptom relief – may not be possible. Magnetic resonance imaging (MRI) is critical to patient care, and yet is often impossible for many to afford. Providing free safety and mobility equipment, as well as MRI funding, are just two of MSAA's programs that are always vitally needed. Additionally, particularly at this time of self-isolation, loneliness, and worry for the future, MSAA's Client Services Specialists are available to address callers' concerns, offer understanding, and provide vital solutions and resources. Many people may also benefit by joining My MSAA Community, a safe, peer-to-peer online forum. For more information, please visit **healthunlocked.com/msaa**.

In addition to our established programs, MSAA understands the value of providing critical, timely, and accurate information, and developed initiatives including a COVID-19 "hub" on our website, as well as a series of webinars specifically addressing the coronavirus and its impact on the MS community. In July, MSAA launched MSAA's "COVID-19 and MS Pathfinder," a digital tool for the MS community to access vital information related to the pandemic. For more information, please see "Program Notes," starting on page 34.

While we are doing our very best to meet the needs of the MS community, at the same time, we need additional contributions to keep our free programs and services running at full capacity. Support is truly appreciated and contributions may be made in several ways! To make a convenient online donation, please visit **mymsaa.org/donate**. Additionally, MSAA offers several "Shop and Support" options, in which a percentage of online purchases is donated to MSAA. Interested individuals may also enroll in a matching-gifts program through their employer, or hold a virtual fundraiser. For more information on ways to support our mission, please see "Thoughts about Giving," which starts on page 40.

The year 2020 will be remembered for COVID-19 and its impact on not only the United States, but throughout the world. However, having opened our doors in 1970, I also hope that 2020 will be remembered in recognition of MSAA's 50 years of service and its impact on people living with MS. On behalf of MSAA, I once again send our wishes of good health and safety during this challenging time. In addition, I want to express our appreciation for any support you are able to provide… and please know that your support truly Improves Lives Today for the MS community, each and every day. ■

ZEPOSIA® (ozanimod) | 0.92 mg capsules

Living with relapsing multiple sclerosis (MS)?

TAKE A LOOK

at a once-daily pill for MS

People had fewer relapses with ZEPOSIA

48%
FEWER RELAPSES

In a one-year study:
People who took ZEPOSIA had 48% fewer relapses than those who took a leading injectable medicine (Avonex).*†

38%
FEWER RELAPSES

In a separate two-year study:
People who took ZEPOSIA had 38% fewer relapses than those who took a leading injectable.†

See additional study results at **ZEPOSIA.com/results**

*Avonex (interferon beta-1a).

†One-year study: People taking ZEPOSIA had an Annualized Relapse Rate (ARR) of 0.181 vs 0.350 with a leading injectable. A total of 895 people were studied (ZEPOSIA 447, a leading injectable 448). Two-year study: 0.172 ARR with ZEPOSIA vs 0.276 with a leading injectable. A total of 874 people were studied (ZEPOSIA 433, a leading injectable 441).

INDICATION

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

IMPORTANT SAFETY INFORMATION

Do not take ZEPOSIA if you:

- have had a heart attack, chest pain (unstable angina), stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have or have had a history of certain types of an irregular or abnormal heartbeat (arrhythmia) that is not corrected by a pacemaker
- have untreated, severe breathing problems during your sleep (sleep apnea)
- take certain medicines called monoamine oxidase (MAO) inhibitors

Talk to your healthcare provider before taking ZEPOSIA if you have any of these conditions or do not know if you have any of these conditions.

ZEPOSIA may cause serious side effects, including:

- **Infections.** ZEPOSIA can increase your risk of serious infections that can be life-threatening and cause death. ZEPOSIA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 months of stopping treatment. Your healthcare provider may do a blood test of your white blood cells before you start taking ZEPOSIA.

  Call your healthcare provider right away if you have any of these symptoms of an infection during treatment with ZEPOSIA and for 3 months after your last dose of ZEPOSIA:
  - fever
  - feeling very tired
  - flu-like symptoms
  - cough
  - painful and frequent urination (signs of a urinary tract infection)
  - rash

IMPORTANT SAFETY INFORMATION (cont'd)

ZEPOSIA may cause serious side effects, including (cont'd):

- headache with fever, neck stiffness, sensitivity to light, nausea, or confusion (symptoms of meningitis, an infection of the lining around your brain and spine)

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

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

  Call your healthcare provider if you experience the following symptoms of slow heart rate:
  - dizziness
  - lightheadedness
  - feeling like your heart is beating slowly or skipping beats
  - shortness of breath
  - confusion
  - chest pain
  - tiredness

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

Continue reading for additional possible serious side effects of ZEPOSIA.

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

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

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

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

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

ZEPOSIA can cause serious side effects, including:

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

The most common side effects of ZEPOSIA can include:

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

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

Call your healthcare provider for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.FDA.gov/medwatch or call 1-800-FDA-1088.

Please see Brief Summary of Information on next page.

Bristol Myers Squibb™

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

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

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

ZEPOSIA may cause serious side effects, including:

1. **Infections.** ZEPOSIA can increase your risk of serious infections that can be life-threatening and cause death. ZEPOSIA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 months of stopping treatment. Your healthcare provider may do a blood test of your white blood cells before you start taking ZEPOSIA.
   Call your healthcare provider right away if you have any of the following symptoms of an infection during treatment with ZEPOSIA and for 3 months after your last dose of ZEPOSIA:
   - fever
   - feeling very tired
   - flu-like symptoms
   - cough
   - painful and frequent urination (signs of a urinary tract infection)
   - rash
   - headache with fever, neck stiffness, sensitivity to light, nausea or confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

   Your healthcare provider may delay starting or may stop your ZEPOSIA treatment if you have an infection.
2. **Slow heart rate (also known as bradyarrhythmia) when you start taking ZEPOSIA.** ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days that you take ZEPOSIA. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heart rate:
   - dizziness
   - lightheadedness
   - feeling like your heart is beating slowly or skipping beats
   - shortness of breath
   - confusion
   - chest pain
   - tiredness

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

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

What is ZEPOSIA?

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

Do not take ZEPOSIA if you:

- have had a heart attack, chest pain (unstable angina), stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months.
- have or have had a history of certain types of an irregular or abnormal heartbeat (arrhythmia) that is not corrected by a pacemaker.
- have untreated, severe breathing problems during your sleep (sleep apnea).
- take certain medicines called monoamine oxidase (MAO) inhibitors (e.g., selegiline, phenelzine, linezolid).

Talk to your healthcare provider before taking ZEPOSIA if you have any of these conditions or do not know if you have any of these conditions.

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

- have a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.
- received a vaccine in the past 30 days or are scheduled to receive a vaccine. ZEPOSIA may cause vaccines to be less effective.
- Before you start treatment with ZEPOSIA, your healthcare provider may give you a chicken pox (Varicella Zoster Virus) vaccine if you have not had one before.
- have had chickenpox or have received the vaccine for chickenpox. Your healthcare provider may do a blood test for the chickenpox virus. You may need to get the full course of the vaccine for chickenpox and then wait 1 month before you start taking ZEPOSIA.
- have a slow heart rate.
- have an irregular or abnormal heartbeat (arrhythmia).
- have a history of a stroke.
- have heart problems, including a heart attack or chest pain.
- have high blood pressure.
- have liver problems.
- have breathing problems, including during your sleep.
- have eye problems, especially an inflammation of the eye called uveitis.
- have diabetes.
- are pregnant or plan to become pregnant. ZEPOSIA may harm your unborn baby. Talk with your healthcare provider if you are pregnant or plan to become pregnant. If you are a female who can become pregnant, you should use effective birth control during your treatment with ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Talk with your healthcare provider about what birth control method is right for you during this time. Tell your healthcare provider right away if you become pregnant while taking ZEPOSIA or if you become pregnant within 3 months after you stop taking ZEPOSIA.
- are breastfeeding or plan to breastfeed. It is not known if ZEPOSIA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ZEPOSIA.

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

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

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

You should not receive **live** vaccines during treatment with ZEPOSIA, for at least 1 month before taking ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Vaccines may not work as well when given during treatment with ZEPOSIA. Talk with your healthcare provider if you are not sure if you take any of these medicines.

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

How should I take ZEPOSIA?

You will receive a 7-day starter pack. You must start ZEPOSIA by slowly increasing doses over the first week. Follow the dose schedule in the table below. This may reduce the risk of slowing of the heart rate.

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

- Take ZEPOSIA exactly as your healthcare provider tells you to take it.
- Take ZEPOSIA 1 time each day.
- Swallow ZEPOSIA capsules whole.
- Take ZEPOSIA with or without food.
- Avoid certain foods that are high (over 150 mg) in tyramine such as aged, fermented, cured, smoked and pickled foods. Eating these foods while taking ZEPOSIA may increase your blood pressure.
- Do not stop taking ZEPOSIA without talking with your healthcare provider first.
- Do not skip a dose.
- Start taking ZEPOSIA with a 7-day starter pack.
- If you miss 1 or more days of your ZEPOSIA dose during the first 14 days of treatment, talk to your healthcare provider. You will need to begin with another ZEPOSIA 7-day starter pack.
- If you miss a dose of ZEPOSIA after the first 14 days of treatment, take the next scheduled dose the following day.

What are the possible side effects of ZEPOSIA?

ZEPOSIA can cause serious side effects, including:

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

The most common side effects of ZEPOSIA can include:

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

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

General information about the safe and effective use of ZEPOSIA.

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

Manufactured for: Celgene Corporation, Summit, NJ 07901

Patent: www.celgene.com/therapies

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Promoting Mental and Emotional Wellness During Difficult Times

By Susan Wells Courtney
MSAA Senior Writer

Reviewed by Barry A. Hendin, MD
MSAA Chief Medical Officer

Introduction

Who could imagine that the lives of so many in our nation could be uprooted so dramatically and for so long, from a pandemic we had never even heard of less than a year ago. And as discussed in our "Up Front" column, we are also facing some significant and heartbreaking challenges, including racial injustice, acts of violence, severe weather, and raging wildfires.

"Feeling anxious? You are not alone. This is a common reaction to an uncommonly stressful time." This is according to Adam Kaplin, MD, PhD, chief psychiatric consultant to the Johns Hopkins Multiple Sclerosis and Transverse Myelitis Centers, and clinician-researcher in the departments of psychiatry and neurology at Johns Hopkins Hospital in Baltimore, Maryland.

Dr. Kaplin continues, "Compared to the same time last year, we are seeing a 400-percent increase in depression and anxiety among Americans. We are also seeing significant increases in trauma and stressor-related disorder, self-medicating through the use of alcohol or drugs, plus suicidal ideation and attempts."

Readers should note that depression and anxiety are not limited to just those with multiple sclerosis or other chronic illnesses; this increase in depression, anxiety, and other emotional issues applies to virtually all populations living in our country, and similar mental health problems are being observed around the world.

In this article, we will examine the symptoms of depression and anxiety, as well as other effects of the pandemic, more closely. We will explain which populations are at the greatest risk and how these types of symptoms can affect not only overall health, but notably, the immune system. We will also

provide strategies and resources aimed at improving overall mood and wellbeing, and through studies on something called "Purpose in Life," explain how the mind-body connection can dramatically affect one's emotional, mental, and physical health.

Dr. Kaplin has a great interest in "Purpose in Life," or "PIL," and has published research findings that support its effectiveness for individuals with chronic illness, including MS and Alzheimer's disease. In addition to the positive effects on one's mental and emotional health, PIL has also been shown to significantly support the central nervous system, cardiovascular health, and even the immune system – reducing inflammation and calming overactive immune-system activity. More information is provided on this exciting research appearing later in this cover story, found on pages 20 and 21.

Background

MSAA's Winter/Spring 2020 issue of *The Motivator* featured the cover story, "Coping with the Emotional, Physical, and Mental Effects of a Pandemic." However, due to the start of the pandemic, this particular issue of our magazine was not printed. It was only available on our website in digital formats.

"Coping with the Emotional, Physical, and Mental Effects of a Pandemic" gave important details on COVID-19 and pandemics, how to limit exposure, common reactions to (and strategies to cope with) disease outbreaks and social isolation, additional wellness information, children's responses to the pandemic, plus a collection of helpful resources and articles. If you have not seen this issue and would like to read the entire cover story or any of the other sections, please visit **mymsaa.org/motws20**.

Additionally, MSAA provides a wealth of information on symptoms and symptom management on our website at **mymsaa.org/symptoms**. Much of the information on depression and anxiety from our website has been summarized for this article. This information was originally written by Miriam Franco, PsyD MSCS, who has been an esteemed member of MSAA's Healthcare Advisory Council for many years. Dr. Franco is a psychotherapist and psychoanalyst who specializes in helping individuals cope with chronic illness and has a private practice in the Philadelphia area. Dr. Franco's observations on the pandemic and its effects on the MS community are provided in a sidebar on page 19.

Our hope is to accomplish three objectives with this article. Our first objective is to explain the different types and symptoms of both depression and anxiety, so individuals may recognize if they or a loved one may be suffering from a form of one or both disorders. Our second objective is to provide emergency contacts, resources, and strategies for mental and emotional wellness. And finally, we hope that by raising awareness, those experiencing such symptoms will consult with their family doctor, neurologist, or mental-health professional for both a diagnosis and a treatment plan – one which may involve talk therapy, medication, and/or changes in lifestyle.

Depression in MS and Types of Depression

Researchers believe that the high rate of major depressive disorder, dysthymia (a chronic type of depression), and bipolar disorder with MS, is a result of the disease process or the etiology of the disease itself. In other words, the damage to the nerves within certain areas of the brain is believed to increase the chance of greater depressive reactions. Depressive reactions are not to be confused with sadness or fatigue.

Sadness is a feeling in response to disappointments and losses; it is experienced directly in relation to one of these triggers. Experiencing sadness helps us to mourn and move through an experience of pain or loss. It typically does not last long, and once expressed, is relieved.

Fatigue, the most common symptom of MS, occurs in response to having the disease and is greater at certain times of the day. It may not be eliminated, but can be reduced by periods of rest and appropriate planning and pacing of your activities.

A depressive mood typically lasts longer and is not associated with one trigger alone. Moods, by definition, have strong intensity and long duration. Shifting or distracting yourself from your mood is difficult.

Major Depressive Disorder

With this most-common type of depression, you can have one major episode or experience recurring episodes over time. To be considered to have major depressive disorder, you typically experience a depressed mood most of the day, nearly every day, and you would also have some or all of the following symptoms:

- have a loss of pleasure in most if not all activities that usually give you pleasure
- experience a significant change in weight (loss or gain)
- either have difficulty falling asleep or sleeping too much
- feel a loss of energy and motivation
- likely have feelings of worthlessness, low self-esteem, or major guilt
- have difficulty concentrating or making decisions

Additionally, you may:

- have recurrent thoughts of harming yourself, possibly have thoughts of suicide
- lose interest in keeping up your appearance
- have aches and pains that physicians can't explain
- have mood lability, which means you can cry or become angry easily over things that typically would not draw that kind of reaction from you

Dysthymia

This type of depression is very similar to major depression, except that the symptoms may not be as severe and you may not experience as many of them. The key feature to dysthymia is that it is felt to be a chronic mood, something you have had for at least two years. This form of depression is not episodic; it's not characterized by a sudden episode or outburst. Rather, it is more like a

slow malaise that starts to be associated with your normal mood. Dysthymia is typically experienced with long-standing insomnia, poor appetite or overeating, poor concentration, and poor self-esteem.

Bipolar Disorder (or Manic Depressive Disorder)

This type of disorder is highly genetic in that it often runs in families and is sometimes referred to as manic depressive disorder. You can have a mild or more severe form. If you have a sibling, parent, or close relative who has been diagnosed with this disorder, and you are experiencing any signs of depression, it is a good idea to have this checked by a mental-health professional. With this disorder, episodes of low mood and depression are interspersed with periods of euphoria or heightened activity and agitation. You must have at least a single episode of mania or heightened activity, agitation, and euphoria, to warrant this diagnosis.

Assessing the Symptoms of Depression

In all types of depression, activities of daily living can feel overwhelming and there is a tendency to believe you will never change. Several symptoms of depression are common ones of MS, such as fatigue, trouble sleeping, cognitive difficulties – especially being unable to focus and concentrate – and feeling slowed down. These similarities can, however, be distinguished by a mental-health specialist who has experience with MS, such as a social worker, psychologist, or psychiatrist, who is specialized or certified in this area.

Gender Differences

Women are not only more likely to have MS, but they are also more likely to experience depression. It is not known if this is attributable to hormonal factors and fluctuations caused by pregnancy, menopause, and/or menstrual changes. Additionally, women tend to have multiple care-related responsibilities, are under major stress, and are constantly multi-tasking. While women may be more inclined to seek help, men are more likely to self-medicate with drugs and alcohol, as well as take prescribed antidepressants.

Often, depression may present itself first with some men as increased irritability. And those who have been vulnerable to depression prior to having MS will likely have a higher risk for depression during the course of MS. Other risk factors include a lack of or low social support and isolation, substance dependency and abuse, or presence of another medical condition.

Specific Effects of Depression on Quality of Life (QOL)

Depression is Still Highly Untreated in MS

In one study of people with MS who experienced thoughts of suicide, one-third had not received any psychological help, and two-thirds had not received any anti-depressant medication. This may be largely due to the fact that such problems are not always communicated to the doctor.

Given the wide range of physical symptoms experienced by individuals with MS, physicians tend to spend most of the limited appointment time on the physical course of the disease. Often the patient with MS is the one to bring up the issue of emotional disturbances or mood in order to have them addressed. People with MS, their care partners, and their physicians, all need to be aware of these symptoms that can arise with MS, and be sure to inquire about any emotional issues that could be present.

Suicide Risk

Untreated high rates of depression and anxiety increase suicide risk in MS. Also, severe depression, abuse of alcohol, and social isolation (living alone) can increase the risk of suicide as well. Anyone experiencing these types of thoughts, or care partners who might suspect this of their loved one with MS, should immediately contact their physician, therapist, or the National Suicide Prevention Lifeline. Trained counselors are available 24 hours per day, seven days per week, at **(800) 273-TALK (8255)**.

Strained Family Relationships

For family members, understanding the physical symptoms of MS is often easier than understanding the emotional ones. When depressed, becoming passive, exhibiting a negative mood, and experiencing low motivation are common; some may even withdraw from others. This may irritate family members, causing them to be critical or expecting you to do one thing that will snap you out of your mood. They may feel at a loss encountering your helpless mood.

If you become withdrawn, family members may withdraw too, as they may not fully understand what is needed. A loss of sexual interest or libido is also common and this too can have a negative impact on couples. Depression is not overcome by the power of positive thinking. Family members should

IMPORTANT RESOURCES

National Suicide Prevention Lifeline
English: **(800) 273-TALK (8255)**
Español: **(888) 628-9454**
TTY: **Dial 711 then (800) 273-TALK (8255)**
suicidepreventionlifeline.org

Substance Abuse and Mental Health Services Administration (SAMHSA) Disaster Distress Helpline: (800) 985-5990
This helpline provides free and immediate counseling to anyone in need of help coping mentally or emotionally with the pandemic or any current crisis or disaster.

SAMHSA National Helpline
(800) 662-HELP (4357)
samhsa.gov

avoid giving advice. Instead, a referral to a skilled mental-health professional can be of great benefit, ideally someone who specializes in MS, can work with both the individual and/or family, and can prescribe a specific antidepressant medication if needed.

Coping with Depression

Depression is treatable and needs the time and attention it deserves, like any other condition. Expecting someone to "just get over it" or "just put up with it" won't help. Many become depressed following the diagnosis of MS because time is needed to adjust to what the diagnosis means, as well as any potential losses in one's quality of life that may be anticipated.

Individuals who do not cope well, whose coping skills are highly emotionally centered and involve reacting by escape or avoidance, may experience a worsening of their depression. It is natural to be upset and struggle with the uncertainty and loss that surrounds the course of living with MS, yet constructive problem-solving and psychological counseling can be extremely beneficial. Getting help with focusing on what you can control, and learning to respond – not just react – to your experience, will help over time.

Treatment Options

Participating in psychological therapy and taking a medication for depression appear to be the most effective means of treating depression. Treating depression with a medication or a drug alone does not address the underlying causes. This is because communicating and sharing your experiences with others and with a mental-health professional has been shown to improve one's ability to cope and to continue to find meaning in one's life. Consistent exercise has also been shown to improve depression.

Many types of psychotherapies may be effective in treating depressive disorders. These include cognitive behavioral therapy (CBT), psychotherapy, problem-focused supportive-group therapy, and telephone-administered CBT for individuals with MS who experience significant levels of depression.

For treatment with medications, consulting a psychiatrist, if possible, may be of greater benefit. Many managed-care and insurance plans have psychiatrists available for medication management. Your therapist can also aid you in this referral process. Consulting a psychiatrist is important because general practitioners (GPs) or family physicians may not be as familiar with the range of antidepressant medications available, versus someone who specializes in this field.

Medications That Can Trigger Depressive Responses

Steroid use is known to induce depressive reactions or exacerbate bipolar reactions in individuals. Additional medications, such as those used to treat urinary incontinence or spasticity, can also affect mood. If you are taking one or more of these medications, check with your physician to see if they in any way could be lowering your mood.

I WON'T LET RELAPSING MS DEFINE MY LOOK

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

VUMERITY MAY WORK AGAINST RELAPSING MS IN THREE WAYS:

RELAPSES

PHYSICAL DISABILITY

BRAIN LESIONS

What is VUMERITY® (diroximel fumarate)?

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

Important Safety Information

Do not take VUMERITY if you:

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

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

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

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

What should I avoid while taking VUMERITY?

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

What are the possible side effects of VUMERITY?

VUMERITY may cause serious side effects including:

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

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

The most common side effects of VUMERITY include:

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

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

Please see Patient Information on the following page and full Prescribing Information at VUMERITY.com.

BIOGEN SUPPORT SERVICES
FOR PEOPLE WITH RELAPSING MS

VUMERITY comes with support

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

ASK YOUR HEALTHCARE PROVIDER

or get more details at **KnowVUMERITY.com**

VUMERITY®
(diroximel fumarate) delayed-release capsules 231 mg

Biogen

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

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

Do not take VUMERITY if you:
- have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to diroximel fumarate, dimethyl fumarate, or any of the ingredients in VUMERITY. See **"What are the ingredients in VUMERITY?"** below for a complete list of ingredients.
- are taking dimethyl fumarate.

Before taking and while you take VUMERITY, tell your doctor about all of your medical conditions, including if you:
- have liver problems.
- have kidney problems.
- have or have had low white blood cell counts or an infection.
- are pregnant or plan to become pregnant. It is not known if VUMERITY will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if VUMERITY passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while using VUMERITY.

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

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

What should I avoid while taking VUMERITY?
- Do not drink alcohol at the time you take a VUMERITY dose.

What are the possible side effects of VUMERITY?
VUMERITY may cause serious side effects including:
- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing). Stop taking VUMERITY and get emergency medical help right away if you get any of these symptoms.
- **PML (progressive multifocal leukoencephalopathy)** a rare brain infection that usually leads to death or severe disability over a period of weeks or months. Tell your doctor right away if you get any of these symptoms of PML:
  - weakness on one side of the body that gets worse
  - vision problems
  - confusion
  - clumsiness in your arms or legs
  - changes in thinking and memory
  - personality changes
- **herpes zoster infections (shingles),** including central nervous system infections.
- **other serious infections**
- **decreases in your white blood cell count.** Your doctor should do a blood test to check your white blood cell count before you start treatment with VUMERITY and while you are on therapy. You should have blood tests after 6 months of treatment and every 6 to 12 months after that.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking VUMERITY and during treatment if needed. Tell your doctor right away if you get any of these symptoms of a liver problem during treatment.
  - severe tiredness
  - loss of appetite
  - pain on the right side of your stomach
  - have dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes

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

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

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

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

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

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

This Patient Information has been approved by the U.S. Food and Drug Administration. Revised: 03/2020

Anxiety in MS: Frequently Overlooked and Undetected

Anxiety is perhaps the most taxing and under-treated psychological effect of living with MS. It does not appear to result from the physical disease process of MS, but rather stems from the realities of living with MS. Individuals living with MS know that it's the unpredictability, and therefore the difficulty, in planning and preparing for the effects of MS on your life, that drives one's anxiety. Anxiety disorders are estimated to affect 43 percent of those with MS, and are also more common among women.

The scientific literature suggests that anxiety levels are higher at the onset of the disease and when it co-exists with moderate to severe depression. Tragically, the combination of untreated, sustained depression along with anxiety can produce higher rates of suicide among people with MS. Limited social support and higher rates of alcohol consumption also elevate anxiety disorders in MS.

Anxiety disorders are frequently overlooked and often undetected. As a result, they can worsen one's quality of life and greatly reduce treatment adherence. Research suggests that approximately half of those with MS who have a diagnosable anxiety disorder are not receiving an anti-anxiety medication and/or psychotherapy. This is important to consider, because if an anxiety disorder co-exists with a depressive disorder, adequate treatment may require higher doses of an antidepressant medication for a longer period of time. This is something that many healthcare professionals may not be implementing if they are not well-versed in this area of treatment.

The Symptoms of Anxiety

The spectrum of anxiety disorders includes panic attacks, phobias, obsessive-compulsive disorder (OCD), and generalized anxiety disorder (GAD). GAD is more prevalent in MS, followed by panic disorder and OCD. Those at higher risk are women, particularly those with a prior history of depression, excess drinking, and the presence of high social stressors. To be considered to have an anxiety disorder, a patient would present physiological and/or psychological symptoms.

Examples of physiological symptoms:

- Trembling
- Increased heart rate or heart palpitations
- Dry mouth
- Shortness of breath
- Nausea
- Hot or cold sensations
- Tingling in fingers or toes
- Lightheadedness
- Faintness/fatigue
- Muscular tension
- Restlessness
- Insomnia, specifically difficulty falling asleep
- Frequent urination

Examples of psychological symptoms:

- Chronic unhappiness
- Worry, guilt, or feeling out of control
- Indecisiveness
- Feelings of inadequacy, feeling criticized, or easily embarrassed
- Rigidity, which is to be inflexible and less willing to make changes
- Hostility, feeling anger toward others
- Repeating certain behaviors or ruminative thoughts (pondering something repeatedly)
- Over-anticipating things
- Excessive concern with physical health
- Negative thinking about the future
- Racing thoughts

Lowering anxiety requires many steps that include learning stress-reduction techniques. These techniques include:

- Interrupting and changing both "all or nothing" types of thinking, as well as catastrophic thinking, where an individual dwells on the worst possible outcomes
- Incorporating exercise into lifestyle
- Breaking down fearful concerns into manageable, "present-oriented" solutions, aimed at resolving the issues at hand
- Problem-solving one step at a time
- Allowing and normalizing feelings of loss of control, while allowing the effect of any losses to be grieved and expressed

Learning to control your reactions and quiet yourself can allow you to feel anxiety when needed to problem-solve, but not to become so overwhelmed by it. Increasing the areas of where you can have control and prioritizing activities can also help. Developing a more spiritual, entrusting attitude has also been found to be helpful to many.

Psychotherapy, either psychodynamic or cognitive/behavioral, includes stress-reduction techniques such as guided imagery, biofeedback (a technique that teaches individuals how to control their body's responses), and meditation. These can be very helpful to reduce anxiety. Medication management is also available.

Dr. Kaplin notes, "Surprisingly, during this pandemic, people under 25 are at the greatest risk for worsening anxiety. Many are stuck living with older family members versus being out on their own, possibly attending college or starting their careers, and enjoying their independence.

"Another high-risk group are the healthcare professionals who work at the hospitals. They care for patients with COVID-19 every day – some of whom never recover – and often don't seek help for themselves if and when they need it."

Dr. Kaplin adds that mindfulness can be helpful to reduce symptoms of depression and anxiety. He explains, "Mindfulness gives people the opportunity to take a break, to 'check out' from the stressors, and then 'check in' with themselves. It's particularly useful when life is too busy."

For more information on mindfulness, please see MSAA's archived webinar, "Keeping it Simple: Everyday Mindfulness for People Living with MS." This may be found by going to **mymsaa.org/videos/everyday-mindfulness-for-people-living-with-ms/**

The Effects of the Pandemic on Individuals with MS

By Miriam Franco, PsyD MSCS
Psychotherapist and Psychoanalyst

An esteemed member of MSAA's Healthcare Advisory Council for many years, Dr. Miriam Franco is a psychotherapist and psychoanalyst who specializes in helping individuals cope with chronic illness. She has a private practice in the Philadelphia area.

"In my practice, I have observed particular reactions to the COVID-19 pandemic among my MS clients. These individuals have certainly experienced sharp increases in anxiety as well as a heightened sense of vulnerability and exposure to risk during the onset of the viral spread and the start of lockdown and social distancing.

"However, as time passed and we learned somewhat more about COVID as a disease, I found that reactivity to the effects of COVID – isolation, children out of school, access to healthcare, lack of adequate testing resources, financial concerns, etc. – were generally similar to the concerns others felt and experienced who do not have MS. Naturally, individual variables are most relevant here, such as where in the United States one lives and the rate of COVID spread, whether one has social supports nearby, access to healthcare, and how flexible work options are regarding where and when one works. These factors appeared to be more significant than having MS itself. Of course, any one of these factors, if present, is challenging when one is concerned about their higher-risk status in terms of comorbidities, should he or she come down with the virus.

"Some common themes specific to having MS and coping with the aftermath of COVID did emerge. Those who had engaged in intensive physical therapy to gain or sustain balance, mobility, or pain relief, went on to experience profound frustration, worry, and loss because physical therapy treatment was not available for four-to-six months. This interruption of therapy appears to have created a serious setback and current challenge.

"On the other hand, many have marveled at how much better their virtual appointments with their neurologists have been because they're typically longer online and more relaxed, given the increased convenience for both parties. Initially, in the Philadelphia area, patients expressed increased fear and concern regarding safety and viral risk while obtaining infusion treatment at major centers. This has since decreased as local facilities have gotten savvy about how to set up, prepare, protect, and educate those receiving infusions.

"The simultaneous effect of the current political climate and COVID spread was and continues to be an identified source of angst, concern, and anxiety for my clients, with or without MS. For individuals with MS, having a therapist knowledgeable about MS and health concerns related to COVID is an advantage in that they feel they have a professional who can understand their concerns, connect them to organizations or resources to clarify issues, and respond to their needs. This creates a sense of safety and connection, while decreasing one's sense of isolation, which is felt by so many of us during this time."

Purpose in Life and its Impact on Mental and Physical Health

What is Purpose in Life?

"New Movement in Neuroscience: A Purpose-Driven Life," published in the May-June 2015 issue of *Cerebrum*, is an informative and thought-provoking article co-authored by Adam Kaplin, MD, PhD and Laura Anzaldi. In this writing, the concept of "Purpose in Life" is explored and study data are provided to support its many proposed health benefits.

The Editor's Note from this article explains, "Purpose in Life (PIL) is a research area that focuses on the interactions between mind and body and the powerful ways in which emotional, mental, social, and spiritual factors can directly affect health. It links the belief that your life has meaning and purpose to a robust and persistently improved physiological health outcome."

PIL was first introduced to psychiatry in the 1940s by the Jewish physician, Viktor Frankl, who was trained in both psychiatry and neurology. He was practicing in Austria during World War II, and survived three years in different concentration camps, including Auschwitz. According to Frankl, "Man's main concern is not to gain pleasure or to avoid pain but rather to see a meaning in his life. That is why man is even ready to suffer, on the condition, to be sure, that his suffering has meaning."

In 1964, researchers James Crumbaugh and Leonard Maholick created a twenty-question scale to measure PIL. This was in response to those who challenged the ability to assess PIL and the validity of those studies. According to Kaplin and Anzaldi's article, "Other researchers have sought to characterize the nuances of PIL. The general consensus is that PIL includes dimensions such as (1) believing that life has meaning or purpose, (2) upholding a personal value system, and (3) having the motivation and ability to achieve future goals and overcome future challenges."

What are the Potential Health Benefits Related to Purpose in Life?

In terms of cognitive decline and dementia – which encompasses difficulties with memory, cognition, and communication – Purpose in Life (PIL) appears to have significant effects in delaying and possibly preventing these types of disorders. According to work done by Patricia Boyle and colleagues at the Rush Alzheimer's Disease Center, PIL may be neuroprotective, helping to protect the nerves of the brain.

Looking at more than 900 seniors who were at risk for dementia and following them for seven years, the investigators found that those with high PIL were 50% less likely to develop Alzheimer's disease and 30% less likely to experience mild cognitive impairment. Even those without Alzheimer's disease showed a slowing of age-related cognitive decline.

In terms of cardiovascular benefits, higher levels of PIL have been shown to reduce the risk of stroke and heart attacks. In a study that followed a group of men for 13 years,

investigators found a 72% lower rate of death from stroke, a 44% lower rate of death from cardiovascular disease, and a 48% lower rate of death from any cause, among those with a strong sense of purpose.

With regard to inflammation, Kaplin and Anzaldi explain how inflammation is a factor in the development and worsening of central nervous system (CNS) disorders, which include MS, as well as neurodegenerative diseases, such as Alzheimer's and Parkinson's diseases. Inflammation in certain areas of the brain can also cause cognitive impairment and depression. While the body's immune system produces inflammation to fight infection and heal injuries, when it becomes overly active, it can damage tissues and cause disease. Psychosocial stress can also contribute to inappropriate immune system activity.

PIL may have a calming effect on immune system activity. For example, blood tests show lower levels of the pro-inflammatory cytokine interleukin-6 (IL-6) for individuals with higher PIL scores. Interestingly, researchers have found that those who sought to experience happiness for immediate gratification – without a long-term purpose – actually had higher amounts of pro-inflammatory genes compared with those who were striving for a purpose. Given these findings, the authors conclude, "This correlation implies that seeking purpose helps avoid a pro-inflammatory state, a positive step in fighting neurological diseases."

How Purpose in Life May Impact Depression

In Crumbaugh and Maholick's original paper, they noted that the patients they studied who were significantly depressed exhibited a "clearly observable loss of life purpose and meaning," than those who were not depressed. However, they also commented, "It may be difficult to untangle whether depression decreases PIL or low PIL leads to depression."

Additionally, Kaplin and Anzaldi "drew some parallels between meaningfulness and peaceful feelings that religion can bring." They stated, "Many people experiencing a tragedy or crisis turn to faith to find comfort, support, and answers. It is possible to endure almost anything as long as we can identify a greater purpose, and for some, religious doctrines and beliefs provide reasons and reassurances for suffering." However, they also note that "how clearly and confidently an individual holds to their self-concepts of the world and their place in it" determines the degree of PIL, indicating to the authors that while having some similarities, "PIL and religion are separate and independent phenomena."

In summary, Kaplin and Anzaldi state, "Identifying a purpose to life can have profound implications in overall life satisfaction and health, as it motivates and drives us even in the face of difficulties and hardships. PIL appears to be biologically wired into our thinking and necessary for optimal health."

Source: Kaplin A, Anzaldi L. New Movement in Neuroscience: A Purpose-Driven Life. *Cerebrum*. May-June 2015:7.

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 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 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:

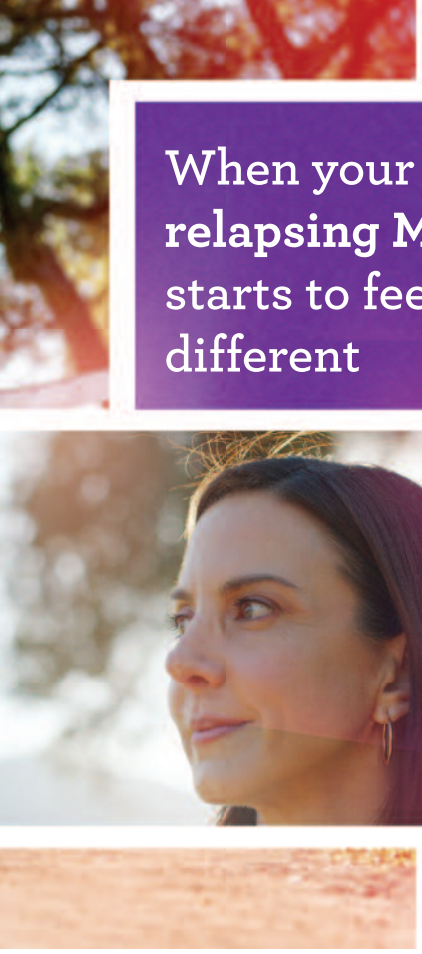
   - fever
   - tiredness
   - body aches
   - chills
   - nausea
   - vomiting
   - headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

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



When your relapsing MS starts to feel different

it may be time for MAYZENT®

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

In the overall study, nearly **3 out of 4 people taking MAYZENT®** showed no 3-month confirmed disability progression.*

Talk to your doctor about MAYZENT.
Visit **mayzent.com** to learn more.

MAYZENT®
(siponimod) tablets
0.25 mg • 2 mg

*74% of people taking MAYZENT, compared to 68% of people taking placebo.

The effect of MAYZENT was significant in people who had a relapse in the 2 years before the study, but not considered significant in people who did not.

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

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

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

MAYZENT may cause possible side effects, including:

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

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

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

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

Please see Consumer Brief Summary on following pages.

NOVARTIS

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080

3/20

T-MZT-1386689

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
   - 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 your 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:
  - 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 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:
  - o sudden severe headache
  - o sudden confusion
  - o sudden loss of vision or other changes in your vision
  - o 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.

Dr. Adam Kaplin's

ABC's for Good Mental and Emotional Health

A = Ask for Assistance

- Knowing when and how to ask for help is far more important than knowing how to silently endure being in pain. It actually takes more strength to request a helping hand.
- Asking for help gives others the chance to feel good about helping.
- All of us together are smarter than any one of us alone.
- Be mindful of the need to check in with your support system and be proactive.

B = Breaks

- Give yourself a break from worry. These are not normal circumstances and you should not expect yourself to always behave normally.
- Take a break to breathe. Notice how you feel. Be grateful for the good things, and stay grounded in the present when problem-solving.

C = Communicate

- Social isolation & quarantine is like being in a life raft together with your loved ones.
- Communicate directly; don't assume others know what you are thinking or feeling.
- What isn't said is still communicated, but you don't know what it is the other person is hearing.

D = Don't Do Things that will Make the Situation Worse

- Don't self-medicate with alcohol or drugs.
- Don't take your frustration out on others.
- Don't watch too much news, particularly alarmist news.
- If you wouldn't do it pre- and post-COVID, don't do it now.

E = Exercise, Eat, and Sleep

- Routine is the way you keep yourself steady in unpredictable times.
- Taking care of yourself through moderate exercise, eating good foods, and getting enough quality sleep, will minimize any unexpected health issues.

F = Find Your Purpose in Life

- As described on pages 20 and 21, having a strong Purpose in Life can provide a number of physical, mental, and emotional benefits. This is good advice to follow!
- Need help in finding your purpose? Go to **psychologytoday.com** and search for "purpose in life."
- A blog post on the Psychology Today website gives five tips for finding purpose:
  - Step 1: Find out what drives you.
  - Step 2: Find out what energizes you.
  - Step 3: Find out what you are willing to sacrifice for.
  - Step 4: Find out whom you want to help.
  - Step 5: Find out how you want to help.

- For more details, please see the following blog post: "Five Steps to Finding Your Life Purpose." *Psychology Today*. Written by Tchiki Davis, PhD and posted on December 12, 2017. This article may be accessed at **psychologytoday.com/us/blog/click-here-happiness/201712/five-steps-finding-your-life-purpose**
- You will find that by helping others, you are also helping yourself!

G = Gratitude

- Find something to be grateful for every day.
- You will often find that you are grateful for other people, and recognizing this will bring you closer to them.

H = Have Fun!

- Spend time doing things you enjoy!
- Losing yourself in a fun activity provides many health benefits and can help relieve stress.

I = Identify Quick Resources for Wellness

- Having a mental-health crisis or feel you just need to talk to someone? **Crisis Text Line (CTL)** is a 24/7 free service where you can connect via text with a live, trained Crisis Counselor anytime for confidential and personal discussions. **Text HOME to 741741** to start.
- A great number of apps are available to promote mental wellness. Many are free and others have fairly low costs – but always check in advance to be sure you know what you are accessing and what the cost will be. Some popular free apps, as listed by PsyCom, include:
  - **MoodTools:** Designed to support people with clinical depression by aiding the path to recovery.
  - **MindShift:** Designed specifically for teens and young adults with anxiety.
  - **Self-Help for Anxiety Management (SAM):** Self-help if meditation "isn't your thing."
  - **Quit That!** Helps users beat their habits or addictions.
  - **eMoods:** A mood-tracking app designed specifically for people with bipolar disorder.
  - **Happify:** This mood-training program is your fast-track to a good mood.
  - **Recovery Record:** App for anyone recovering from an eating disorder and wanting to develop a more positive body image.

For more apps, please see "Top 25 Mental Health Apps: An Effective Alternative for When You Can't Afford Therapy?" written by Jessica Truschel and posted on the PsyCom website at **https://www.psycom.net/25-best-mental-health-apps**

For general information or to speak with a trained Client Services Specialist, please call MSAA's Helpline at **(800) 532-7667, extension 154**. Questions to MSAA's Client Services department may also be emailed to **MSquestions@mymsaa.org**.

ASK THE DOCTOR

Viruses and Antibodies

By Dr. Barry Hendin
MSAA's Chief Medical Officer

Q: There is a lot of talk about antibodies for COVID-19 after a person has already contracted the coronavirus. I've heard that the COVID-19 antibodies don't stay in the body indefinitely. Why then do the JC virus antibodies stay with us indefinitely once we have them? Also, do the coronavirus and JC virus interact?

A: We are still early in our understanding of this novel coronavirus and its consequence, COVID-19. It's important to remember that we have only been investigating this new coronavirus since December 2019. We are learning more, but our knowledge is still incomplete. Questions remain regarding the level and the duration of immunity from COVID-19. We have a fuller understanding of the JC virus, which causes progressive multifocal leukoencephalopathy (PML), a serious brain infection. Currently, there is no evidence of an interaction between the JC virus and the virus that causes COVID-19.

JC virus levels can change. A small percentage of JC virus-negative people become positive each year. People with positive JC virus assays may have their level of positivity vary over time. And a small number of people who were designated JC virus-positive, have a drop in their JC virus assay levels and are then designated JC virus-negative. In this case, the virus hasn't actually disappeared, but the reaction to the virus has diminished.

Q: I would like to know more about contrast agents. Last year, I found that the hospital I went to for a brain MRI no longer uses gadolinium as the contrast agent. Instead, the hospital uses Dotarem, which does not require a blood test beforehand.

Since that time, I started with a new neurologist and a different hospital, and this one only uses gadolinium and thus requires a blood test. I have read some interesting articles about using gadolinium and that its agents can be deposited in the brain for an indeterminate time or maybe forever, and its use is somewhat controversial.

Could you tell me if one contrast agent is preferred over the other, and if one is thought to be safer? Also, can contrast agents increase the risk of blood clots, or could they pose any threat if blood clots are present when administered?

A: Gadolinium has been widely and safely used in patients for many years, however, it does carry increased risks in patients with kidney disease or allergies to gadolinium. Approximately 15 years ago, reports began to appear that a tiny amount of gadolinium could be retained in the brain, particularly in patients who had multiple gadolinium infusions.

Although no evidence has been found to suggest that the tiny amount of retained gadolinium could produce disease or injury, the finding led to the wider use of newer, structurally different forms of gadolinium, such as Dotarem® (gadoterate meglumine), which is not associated with significant retention in the brain. Many MS neurologists have also reduced their gadolinium use for routine follow-up exams.

Regarding blood clots, in general, gadolinium is not associated with an increase in blood clots and has not been shown to worsen existing blood clots. However, as in any medical situation, rare exceptions could possibly occur.

Q: Have you heard about treatments by a Texas group that use stem cells from umbilical cords? They cannot do the procedure in the United States because the FDA has not approved it. Their procedure is done in Panama.

According to testimonials, they have had great success with MS patients. Why can't these types of trials be approved and started in our own country? The cost is approximately

$25,000 and includes treatment, care, hotel, and airfare. Considering the price of MS medications in this country, this treatment is very inexpensive.

A: Stem cell treatments are an interesting and often beneficial intervention for highly active MS that is not currently controlled by approved disease-modifying therapies. Stem cell therapies (SCT) are still investigational in nature and are most safely performed in experienced academic centers with rigorous protocols. These may be performed at an investigational protocol without cost – and in some instances – in North America.

Experimental medications and therapies in this country are tested through the different clinical trial phases as approved and overseen by the United States Food and Drug Administration (FDA). Performing trials under strict supervision ensures the safety of the participants. For more information on FDA-approved SCT trials for the treatment of MS (and possible participation), readers may visit the Clinical Trials Search section of MSAA's website at **mymsaa.org/clinicaltrials**.

In your question, you mention using stem cells from umbilical cords. Stem cells may be derived from different sources, including: embryonic, amniotic, or umbilical cells; genetically altered adult cells; and adult cells from fat or marrow. With SCT, participants are typically given strong immunosuppressant chemotherapy and/or radiation prior to receiving the stem cells (either taken from the participant or from a donor). All of the steps involved in SCT involve risks to the patient, some of which may be severe and even life-threatening. In unregulated centers, the risks can be significant and the benefits uncertain. Ultimately, cost is not the issue… safety is.

MSAA's website and publications offer information about stem cell therapy (SCT) for the experimental treatment of MS. Details on some of the newer studies on SCT are featured in the recent editions of MSAA's *MS Research Update*, and may be found by going to the Publications section of MSAA's website at **mymsaa.org/publications**, and scroll down to select one of the two most recent editions of the *MS Research Update*. ■

Please submit questions for Ask the Doctor via email to ***askdr@mymsaa.org***

Barry A. Hendin, MD, is a highly accomplished neurologist who specializes in MS. He is the chief medical officer for the Multiple Sclerosis Association of America (MSAA) and has spoken at several of MSAA's educational programs. After 45 years as a neurologist with Phoenix Neurological Associates, Ltd., Dr. Hendin is now director of the newly created Multiple Sclerosis Center of Arizona. He is also director of the Multiple Sclerosis Clinic at Banner University Medical Center and clinical professor of neurology at the University of Arizona Medical School.

FDA Approves Kesimpta® (Ofatumumab) for Relapsing Forms of MS

On August 20, 2020, Novartis announced that the United States Food and Drug Administration (FDA) approved Kesimpta® (ofatumumab) for adults with relapsing forms of multiple sclerosis (RMS), which includes clinically isolated syndrome, relapsing-remitting disease, and active secondary-progressive disease. Kesimpta is a B-cell therapy, which binds to and depletes B-cells shown to be associated with disease activity in MS. Typically this type of therapy is only available via infusion at a hospital or infusion center; however, Kesimpta is the first self-administered B-cell therapy for MS. It is given monthly via subcutaneous injection at one's home, providing individuals with MS a new and convenient option for treating their MS.

Kesimpta is a monoclonal antibody, which is a laboratory-produced molecule that fulfills the same functions as the body's naturally produced antibodies. Antibodies are key components of the immune system that recognize, bind to, and combat cells that can cause harm. Kesimpta is a fully human antibody, meaning that it was developed from human cells, whereas other (nonhuman) monoclonal antibodies are developed from animal cells. This newly approved medication targets CD20, a protein found on the surface of B cells, which are immune system cells believed to contribute to the development of MS.

The approval of Kesimpta is based on results from the Phase III ASCLEPIOS I and II studies, in which Kesimpta demonstrated superiority over Aubagio® (oral teriflunomide) in significantly reducing the annualized relapse rate (ARR), three-month confirmed disability progression (CDP), and the number of gadolinium-enhancing (Gd+) T1 and new or enlarging T2 lesions. These trials examined the efficacy and safety of Kesimpta relative to Aubagio in more than 1,800 people with relapsing-remitting MS (RRMS).

Results of the ASCLEPIOS I and II studies found that compared with Aubagio, Kesimpta demonstrated a significant reduction in ARR by 51% and 59% (respectively) and a relative risk reduction in three-month CDP of 34.4%. In addition, Kesimpta significantly reduced the mean number of both Gd+ T1 lesions (98% and 94% relative reduction, respectively) and new or enlarging T2 lesions (82% and 85%).

The most common side effects of Kesimpta include upper respiratory tract infection (URTI), with symptoms that include sore throat, runny nose, and headache, as well as headache not related to a URTI. Serious but less-common side effects include infections and injection-related reactions.

Novartis is offering "Alongside Kesimpta®," a program that provides education and resources to individuals who are taking Kesimpta. For more information, please call **1-855-KESIMPTA (855-537-4678)** or visit **kesimpta.com**. ■

FDA Approves Generic Version of Tecfidera®, Taken Orally for MS

On August 17, 2020, the United States Food and Drug Administration (FDA) awarded early approval of Mylan's generic version of Biogen's Tecfidera® (dimethyl fumarate), an oral medication approved in 2013 for relapsing forms of MS in adults. Mylan announced the launch of this generic medication on August 19, 2020, noting that this is the first generic of any MS oral treatment available to individuals in the United States. In late 2019, the FDA approved three generic versions of Gilenya® (fingolimod) oral capsules for the treatment of relapsing forms of multiple sclerosis (MS), but these are not yet commercially available.

Generic treatments have the same active ingredients and carry the same benefits and risks of the initially approved (brand-name) medication. Inactive ingredients can differ with generic medications, and generic treatments are not required to conduct the same degree of rigorous clinical trials prior to approval. As a result, generic medications are normally offered at a lower cost to the patient.

Clinical trials with Tecfidera showed a reduction in relapse rate, a delay in progression of physical disability, and a slowing in the development of brain lesions, as compared to placebo. The most commonly reported side effects are flushing and gastrointestinal events.

For more information, please call Mylan's customer service number at **(800) 796-9526**.

Bafiertam™ Oral Capsules Approved by the FDA for Relapsing Forms of MS

On April 30, 2020, Banner Life Sciences LLC (Banner), a privately held specialty pharmaceutical company, announced the United States Food and Drug Administration (FDA) approval of Bafiertam™ (monomethyl fumarate) delayed-release oral capsules to treat relapsing forms of multiple sclerosis (MS). This approval includes the treatment of clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), and active secondary-progressive MS (SPMS). Banner has not yet announced when the medication will be available.

Bafiertam is a "bioequivalent alternative" to Biogen's Tecfidera® (dimethyl fumarate), which means that the active ingredient and site of action do not differ significantly between the two medications. The therapeutic effect is assumed to be equivalent. Since a lower dose of Bafiertam is equivalent to Tecfidera, this may potentially lead to a reduction in gastrointestinal (GI) side effects, such as diarrhea, nausea, vomiting, and abdominal pain. However, these side effects have not been evaluated in clinical trials in people with relapsing forms of MS.

For information about Bafiertam and its assistance program, Banner Patient Support, please visit **Bafiertam.com** or call **855-3BANNER (855-322-6637)**. ■

Launch of Zeposia® Announced

The commercial launch and availability of Zeposia® (ozanimod) for the treatment of adults with relapsing forms of multiple sclerosis (RMS) was officially announced on June 1, 2020. Initially approved by the United States Food and Drug Administration (FDA) on March 25, 2020, the makers of Zeposia, Bristol Myers Squibb, made the decision to delay its launch in light of the COVID-19 pandemic and the tremendous burden on the country's healthcare system.

Given once daily as a 0.92 mg oral pill, Zeposia's approval includes the treatment of clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), and active secondary-progressive MS (SPMS). Compared to Avonex® (interferon beta-1a) in clinical trials, Zeposia reduced the annual relapse rate (ARR), demonstrated a relative reduction in brain lesions, delayed confirmed disability progression, and may prevent or delay cognitive deficits.

For information about Zeposia and the ZEPOSIA 360 Support™ Program, please visit **Zeposia.com** or call **(833) ZEPOSIA** or **(833-937-6742)**. ■

For More Information

To read MSAA's full articles on these updates, please visit **mymsaa.org/news**. For general information or to speak with a trained Client Services Specialist, please call MSAA's Helpline at **(800) 532-7667**, **extension 154**. Questions to MSAA's Client Services department may also be emailed to **MSquestions@mymsaa.org**.

Written by Susan Wells Courtney
MSAA Senior Writer

Portions written by Tom Garry
Medical Writer

Reviewed by Dr. Barry A. Hendin
MSAA Chief Medical Officer

COMING SOON:

Vaccination Safety in MS

MSAA is pleased to announce its newest brochure, *Vaccination Safety in MS*. Please visit the publications section of our website to view or order a copy:

mymsaa.org/publications

MSAA Expands Services and Support to Meet Client Needs During the Pandemic

By Peter Damiri

Expanded Core Services

As you may have read in previous online announcements, MSAA made several revisions to our core signature services in response to the coronavirus pandemic and its impact on the MS community. Most notably, **we added a COVID-19 economic hardship waiver to the Equipment and Cooling Distribution Programs and the MRI Access Fund** so families experiencing financial crisis due to the pandemic can select this option to qualify if they would otherwise not meet annual income guidelines.

Additionally, certain application documents are now optional if individuals cannot connect with their physician due to concerns or limitations in traveling to medical appointments. All three programs now offer **online applications** (new for the MRI Access Fund) and the option of downloading the forms from our website to mail or fax to MSAA.

We are pleased to report these changes have resulted in continued program expansion and added support to the MS community. Many clients have shared with us their heartbreaking struggles as a result of this ongoing crisis, but also some wonderful words of appreciation for our programmatic changes. In a recent email sent to MSAA, Sarali A. of Georgia wrote, "*I wanted to take a moment and thank you for the cooling vest you sent. My husband and I are both unemployed right now with little chance for work on the horizon. Your generosity is uplifting.*"

MSAA greatly appreciates these kind sentiments from Sarali and many others. We encourage anyone in need of our core services to apply online at **mymsaa.org** or call our Helpline for assistance at **(800) 532-7667, ext. 154**. Also, as a friendly reminder, the MSAA toll-free Helpline has expanded its hours to 8:00 PM Eastern from Mondays through Thursdays. Our trained and experienced Client Services Specialists are here to answer your questions, provide resources, and lend a calm and reassuring voice to people living with MS and their care partners. You can also contact the Helpline Specialists by emailing **MSquestions@mymsaa.org** or sending a chat question via **mymsaa.org/chat**.

MSAA would like to thank our supporters who enable us to maintain and expand these vital core services, especially in this urgent time of need. The MSAA Cooling and Equipment Programs are made possible, in part, with support from Biogen, Mallinckrodt, Mylan, and the Virginia T. Dashiell Foundation. The MRI Access Fund is supported by Biogen and Sanofi Genzyme, and the Helpline is funded, in part, by Biogen, Bristol Myers Squibb, and Sanofi Genzyme.

African American Advisory Board Update

MSAA's African American Advisory Board is comprised of several healthcare professionals, individuals with MS, and care partners. As a result of the meeting in 2019, MSAA compiled the feedback from the members and produced a publication titled *Multiple Sclerosis and the African American Experience*. This publication, along with the list of advisory board members, can be accessed by visiting **mymsaa.org/african-american-advisory-board**.

The second annual African American Advisory Board meeting includes the healthcare professionals from the advisory board and will be conducted as a virtual meeting this month (October). This meeting focuses on a multifaceted approach to improving the overall care experience of African Americans living with MS, led by the African American MS Work Group.

Content direction and specific recommendations for the proposed interventions will be provided by the African American MS Work Group. This initiative is in partnership with Impact Education.

Outcomes from these meetings will continue to help guide MSAA's programmatic offerings specific to the African American MS community.

COVID-19 and MS Pathfinder Tool

To help the MS community stay as informed and updated as possible on the coronavirus and its impact on MS, MSAA launched an innovative and informative online tool to navigate through the many issues associated with the ongoing pandemic. Developed in partnership with Wondros, the **COVID-19 and MS Pathfinder** is designed to enable easy access to your most pressing questions, including:

- What are the facts about COVID-19?
- What if I need to stay at home?
- How do I get what I need?
- How do I stay safe?
- How do I stay healthy?

Updated weekly based on the world's most authoritative sources on COVID-19, this free online tool provides details on research into treatments and vaccinations, potential long-term effects of the virus, symptoms, emergency care, and more. The COVID-19 and MS Pathfinder

online tool offers a unique and user-friendly design to access the various topics, while featuring clear and concise explanations of what to be aware of, how to prepare, and whom to contact to ensure your safety and wellbeing. We invite you to explore this amazing new tool by visiting our website at **mymsaa.org** or you can access it through our free mobile phone app, My MS Manager.

The COVID-19 and MS Pathfinder has been made possible through generous support from Bristol Myers Squibb, Johnson & Johnson, and Novartis.

Wealth of Informative Webinars

Starting at the beginning of the pandemic and continuing for as long as needed, MSAA has launched a series of live, national webinars titled: "**What You Need to Know about COVID-19 and MS**," featuring our Chief Medical Officer Dr. Barry Hendin and the Chair of MSAA's Healthcare Advisory Council Dr. Carrie Hersh. Presented in a very conversational, town-hall style with ample time for audience Q & A, this webinar series is now approaching its seventh live program, scheduled for Monday, October 19th at 8:00 PM Eastern. The previous six programs are archived on our website along with a related MSAA program from June titled "**Understanding the COVID-19 Impact on MS in People of Color**," presented by MS expert neurologist Dr. Mitzi Joi Williams.

To date, the COVID-19 and MS webinars have generated more than 5,000 live and archived views with many positive comments from the audience. One such note of appreciation expressed during the exit survey of Program 6 stated: "*Learned a lot tonight about risk factors of COVID with various co-morbidities. Appreciate the presenters' knowledge as well as their very realistic and honest answers about what is known and not known about COVID. Thankful for these great webinars.*"

If you have not watched these programs, we invite you visit **mymsaa.org/videos** to view the archived recordings.

Additionally, MSAA has been actively converting many of our previously scheduled, in-person educational programs, into live, national webinars. **Upcoming programs slated for this fall into winter will explore topics that address: being newly diagnosed with MS; how parents can discuss MS with their children; the Hispanic-American MS patient experience**; and many other important issues. You can register for these free, live programs by visiting our calendar of events at **mymsaa.org/calendar**. Also, please know that previous webinars that were broadcast during the summer on topics such as wellness, the African American experience with MS, understanding brain health, and more, are now available for on-demand viewing on the MSi video website page at **mymsaa.org/videos**.

MSAA strives to keep you as informed, updated, and prepared as possible to manage the ongoing challenges of living with MS, especially during these unpredictable and challenging times. We are thinking of you and your family and are here to help any way we can. Please stay safe and be well! ■

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.

- 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:

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

- upper respiratory infection
- headache
- 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

EMD SERONO

MAVENCLAD®
(cladribine) tablets 10 mg

US/CLA/0619/0371 Printed in USA 07/19

You Can Support MSAA While Shopping from Home

Fundraising Profiles by Kaitlyn Gallagher

During these uncertain times, many people have turned to online shopping to meet their family needs. Whether shopping online for everyday items or gifts, please be sure to include MSAA in your plans as well as encourage your friends, relatives, and community contacts to do the same! **Proceeds from your online shopping help MSAA continue to provide FREE programs and services.**

Opportunities to support MSAA through online shopping are outlined below and can be accessed by visiting **support.mymsaa.org/ShopAndSupport**

- **Shop AmazonSmile** and select MSAA as your designated charity. Amazon will donate 0.5% of the price of your eligible purchases to MSAA.
- **Purchase a PopSocket**, the easy-grip accessory for your mobile phone! The Poptivism campaign will donate 50% of your purchase to MSAA. You can order various designs, including MSAA's logo as well as featured artwork from MSAA's Art Showcase contributors.
- **Get your swag on** with an MSAA Swim for MS swimsuit or towel, along with Team MSAA shirts, hat, bag cinch, and more. Twenty percent of your purchase goes back to MSAA.
- **Glam up for MS!** Katie's Cottage Barn, a jewelry boutique in New Jersey, is selling awareness bracelets and donating 25% of the proceeds to MSAA.

If you have any questions or need more details about these or other opportunities to support MSAA, please call **(800) 532-7667, ext. 161**. We greatly thank you for your support! ■

Victoria Rafferty crosses the finish line after completing her first marathon during the Walt Disney World® Marathon Weekend with Team MSAA in January 2020.

Popular Twitch streamer Bonks snaps a selfie to promote one of her recent charity gaming streams.

RUNNING VIRTUALLY WITH VICTORIA

Team MSAA participant **Victoria Rafferty** completed her first marathon during the Walt Disney World® Marathon Weekend in January 2020, a challenge she always dreamed of accomplishing. In addition to completing the marathon, Victoria raised more than $2,000 for MSAA's free programs and services! This year, Victoria has (virtually) returned to Team MSAA to participate in the Disney Virtual Wine & Dine Half Marathon Weekend Powered by AfterShokz this November 2020 and has again set a goal of $2,000!

To get in shape for the virtual race weekend, Victoria is committed to keeping with her regular training routine. She works out five days a week and will be focusing on running longer distances and lifting weights as the race weekend approaches.

While Victoria was excited by the prospect of racing in Disney amongst some of her favorite Disney villains, she has decided to make the best of the virtual race weekend by going somewhere outside that is scenic and new to her to complete her race challenge. Her advice to aspiring Team MSAA participants? "Get out there and run, enjoy the nice weather, fall is here – outdoor runs are the best during the fall season." To read more about Victoria and support her fundraising goal, please visit **support.mymsaa.org/goto/vicki**. ■

GAMING FOR GOOD WITH ONLINE STREAMING EVENTS

Over the past few months, some incredible gamers have streamed on Twitch, a popular streaming platform, in support of our free programs and services for the MS community!

MSAA Twitch charity streamer, **Bonks**, was inspired to start fundraising for MSAA after watching charity streams from one of her favorite fellow Twitch streamers. Choosing MSAA as her beneficiary was an obvious choice – several people close to her are living with MS. "Knowing what they're going through makes me want to do everything in my power to help," says Bonks. "I believe that as independent content creators, we have to be willing to use our voices to help those in need."

Bonks explains that it is quite easy to start streaming for your favorite causes! "When you're doing a charity stream, you have an automatic link that people can donate directly to, to help you reach your goal." (Bonks reached her goal of $800 for her MSAA charity stream!) "Most streamers doing fundraiser events will have a reward for donating, usually involving themselves doing something," says Bonks. "For example, I had a reward system where every person who donated $1 or more would get their name written on my arm with a Sharpie. It's a fun way to give someone a reason to donate."

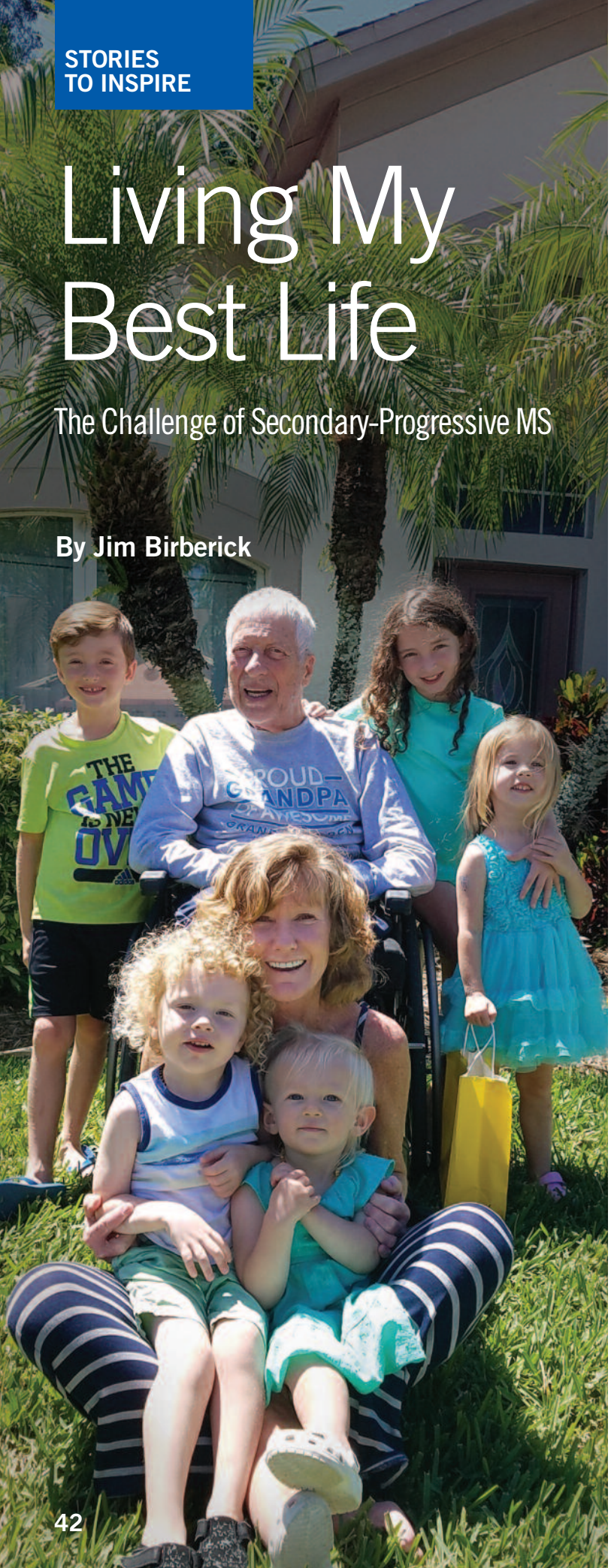
To help others understand why supporting the MS community was such an important cause for her, Bonks decided to record a video to explain the effects MS can have on a person and their loved ones. "There aren't a lot of people talking about MS, so as someone impacted, and someone who has seen first-hand how hard it is, I want people to know what it is, and what they can do to help."

To learn more, please visit **https://tiltify.com/multiple-sclerosis-association-of-america**. ■

Living My Best Life

The Challenge of Secondary-Progressive MS

By Jim Birberick



Life is good. I believe it and try to live it every day. It's not always easy. In the summer of 1989, when diagnosed with secondary-progressive multiple sclerosis (SPMS), I feared that life would never be good again. I was wrong.

I'm now 71 years old. I'm a husband, father, grandfather, and friend… and I have had MS for 30 years.

As a young man growing up in Michigan, I was an extremely active athlete. I played baseball in high school, semi-pro baseball for two years, and slow-pitch softball for many years after that. My career was going well selling clinical lab services for a well-known pharmaceutical company. They moved me to Tampa, Florida and I became the district sales manager, overseeing employees across Central and Southwest Florida. I met my wonderful wife, Jan, on a blind date and she became my world. ***Life was pretty darn good!***

We had two beautiful sons and settled into Florida living. The boys were strong, healthy, and smart. We had a lovely home on a street full of neighbors who soon became like family – and remain so, even today. We were active in our church and spent our time playing soccer and baseball with the boys, cheering them on in all they did. We were a typical suburban family. ***Life was great!***

After the initial diagnosis, I went through a period of depression, not knowing the impact it would have on me, my job, or my family. At

This 2019 photo shows "Stories to Inspire" author Jim Birberick and his wife Jan with their five grandchildren. Top, from left: Owen, 6 years; Madison, 8 years; and Ivy, 4 years. Bottom, from left: Weston, 2 years; and Cora, 1 year.

that time, there were no medications for the condition other than steroids. I entered a three-year, double-blind clinical trial, and after the drug was approved, I was injected every other day for 26 years. By this time however, I already had mobility issues and had gone from a cane to a walker to a scooter. I have been in a mobility chair full time now for the last 28 years.

I had to go on full-time disability in 1991. It was all life-changing and a constant challenge for me, my wife, and the boys as well. The doctors had me on numerous different medications and therapies, including intravenous immunoglobulin (IVIg) therapy, chemotherapy, and anything else they could think of to stop the progression. After taking my first oral medication, I ended up in the hospital for two weeks with a lumber spine infection. ***All of a sudden, life wasn't so good.***

My family experienced things I wish they never would have had to go through. My wife went back to work and kept the family together. She says it made us all stronger and brought us closer together.

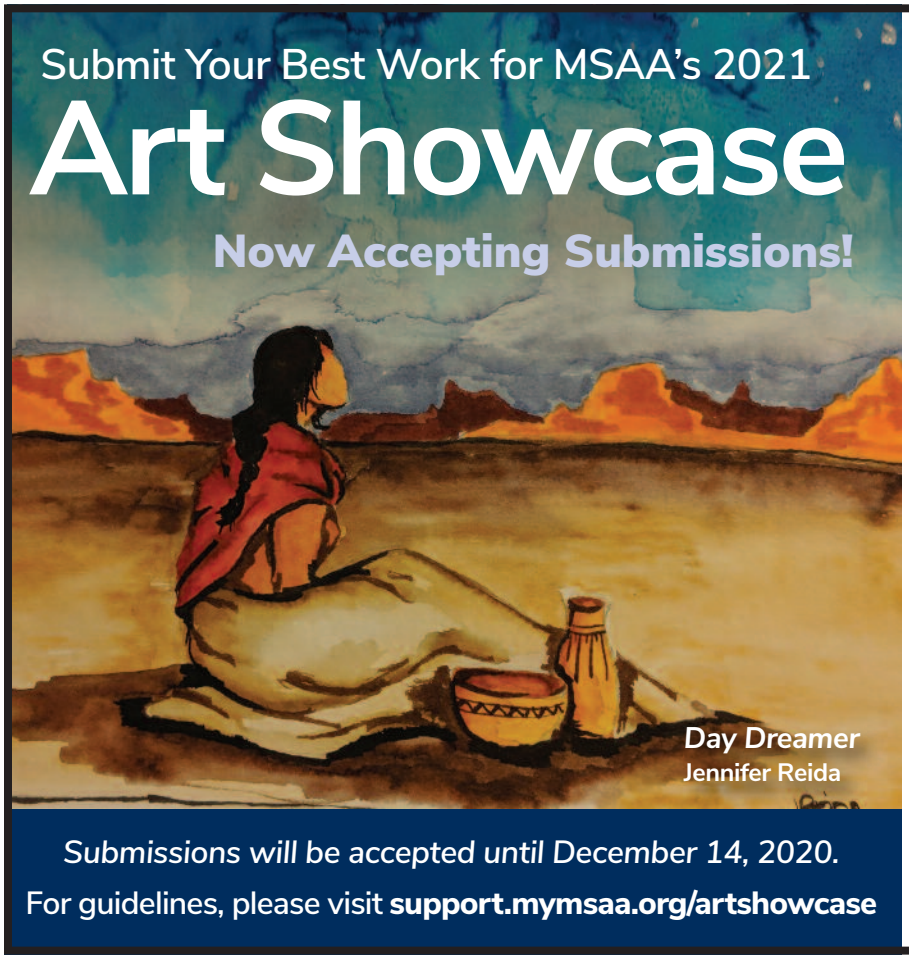
My life hasn't been easy. I have a lot of pain and sometimes it gets overwhelming. My speech is slow and my brain doesn't function as well any more. It's frustrating and embarrassing. I know that I must reach outside of myself and my own feelings. I fight every day to change from being someone who is self-absorbed into someone who leans on God for strength and understanding. I try to look at others and see their needs rather than my own.

I have adjusted to my new outlook on life and I wake up every day thinking that today will be a good day. I stretch and work out the best I can every day because I know I need to keep as much strength as I can. I focus on knowing that no matter how unfortunate having MS might be, there are people who have more difficult challenges to face. I am very fortunate to have the support of my wife, my sons, my five beautiful grandchildren, and my many friends.

I don't know what the future holds for me. None of us do, but there are so many things I can do. I choose to stay positive and focus on the things I can do versus those I cannot.

Life is truly remarkable and I'm living it the best way I can! ■

Jim poses with a new friend while on a trip to Nova Scotia.



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

NEW FOR THIS YEAR: MSAA will accept **3 pieces** of artwork per artist.

Artwork will only be accepted from individuals who have MS and are 18 years of age or older. Submitted pieces must be two-dimensional. Sculpture, pottery, fabric, and other types of three-dimensional works cannot be accepted.

Submissions will be featured on MSAA's website beginning March 2021 in recognition of MS Awareness Month. Each month we will highlight one artist and their work.

For more information, contact:
Email: **showcase@mymsaa.org**
Phone: **(800) 532-7667, ext. 117**

msaa Improving Lives Today!™
Multiple Sclerosis Association of America

Find support and share your journey on My MSAA Community

Join nearly 6,000 members who have similar experiences with multiple sclerosis in this online peer-to-peer forum.

- **Get advice and support while connecting directly with people affected by MS**
- **Feel more confident managing one's own health or family's health**
- **Solve day-to-day challenges**

msaa Improving Lives Today!™
Multiple Sclerosis Association of America

Join My MSAA Community today:
healthunlocked.com/msaa