

Winter/Spring 2021



THE Motivator

Published by the Multiple Sclerosis Association of America



Finding Purpose in Life



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



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.

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

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Recounting the Past, Looking to the Future



By Gina Ross Murdoch
MSAA President and CEO

For the past two issues of MSAA's magazine, our "Up Front" column has been devoted to the growing challenges we have been experiencing as a nation, and worldwide. These challenges ranged from the COVID-19 pandemic surging out of control, along with the resulting loss of life, jobs, businesses, and vital food and supplies... to unspeakable racial injustice, devastating wildfires, and life-threatening weather conditions.

We continue to express our heartfelt gratitude to the healthcare community, emergency personnel, caring agencies, and volunteers who have all worked bravely and tirelessly to help heal our nation. While we continue to be challenged by these issues, some are showing positive signs – particularly with the approval of COVID-19 vaccines and tens of millions of individuals inoculated

throughout the United States. But even as the herd immunity strengthens, businesses reopen, and people return to jobs, we cannot let our guard down. Yes, this is a time to acknowledge and celebrate each individual victory, but at the same time, we need to be aware, remain vigilant, and stay informed. At MSAA, our focus continues to be on providing innovative programs and unwavering support for the multiple sclerosis community. We remain fiercely committed to addressing health inequities as well as providing key educational information on topics including emotional and mental wellness.

Our hope for our readers, and the entire MS community – including people diagnosed with MS, care partners, family members, and medical professionals – is that their lives are moving ahead. We hope that people are able to look forward to the future once again. With the arrival of spring last month, we all can anticipate the renewal of the many things we value in our lives.

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.

Where Do We Go from Here?

We may now want to ask, “Where do we go from here?” At MSAA, we have a number of encouraging programs and initiatives, either in progress or poised to launch.

One vital initiative to mention is our annual MS Awareness Month campaign, whose theme for 2021 was, “Improving Mental Health and Wellness.” This topic is particularly important given these challenging circumstances just discussed. And although March has passed, all of the information is still available. Our digital programs and resources from our MS Awareness Month activities have been archived on our MS Awareness Month website hub. Please refer to “Program Notes” beginning on page 35 for more information on these resources as well as upcoming programs.

Adding to the support that we are providing to the MS community is our cover story in this issue of *The Motivator*. Beginning on page 4, this informative and inspiring article defines and explains the life-enhancing and life-extending benefits of having a clear Purpose in Life. Identifying and immersing yourself in an activity in which you are completely passionate about and find rewarding may provide great emotional and physical benefits, including a strengthened immune system and a healthier heart, lowered blood pressure, and more.

And finally, MSAA’s upcoming Virtual Improving Lives Benefit, “Together at Home,” takes place on Thursday, May 13th. Since this event is virtual, tickets are open to everyone nationwide! Our first-ever virtual gala,

“Together at Home” will be hosted by MS advocate Tyler Campbell and will provide attendees with a dynamic and uplifting live program highlighting MSAA’s impact on the MS community.

This virtual event will feature inspiring stories highlighting our honorees, key insights into resources for the MS community, and a silent auction. We are pleased to recognize our corporate honoree – longstanding MSAA partner – Medscape as well as this year’s mission honorees, Ángel Chinaea, MD, Medical Director of the San Juan Multiple Sclerosis Center; Lourdes Fernández Trujillo, Executive Director of the Puerto Rico Multiple Sclerosis Foundation; and the MS community in Puerto Rico. For more information, please see page 38. I hope to “see” everyone at our Virtual Improving Lives Benefit on May 13th! ■

Check out MSAA’s PODCAST

Listen to episodes covering topics such as relationships and MS, care partner needs, diversity and MS, and nutrition. Please visit MSAA’s website at mymsaa.org/podcasts to listen to our podcast, which is also available on all of the major podcast directories and networks.

Finding Purpose in Life

By Laura Bradford

Reviewed by Barry A. Hendin, MD

Edited by Susan Courtney



What is My Purpose in Life?

That's a question many of us have likely pondered at some point, especially when standing at one of life's many crossroads. It is, after all, natural to question your direction, your goals, your hopes, and a desire to help others. But did you know that finding and embracing that purpose may actually play a part in your physical and mental health? Additionally, some data suggest that the risk of developing certain autoimmune diseases may possibly be reduced.

To see how and why, let's take it back to the beginning and Viktor Frankl, the Viennese neurologist and psychiatrist credited with introducing Purpose in Life to medicine for the first time. A holocaust survivor, Frankl credited his ability to survive his time in concentration camps to what was,

essentially, his purpose in life (PIL) – to bring attention to PIL's place in the medical world.

He shared his thoughts on PIL and how it helped him to survive those dark years in his book, *A Man's Search for Meaning*. In a nutshell, Frankl believed that we are instinctively wired to have a purpose in life, and that having one, and pursuing one, will keep us healthy. This purpose, he says, differs from person to person as everyone has his or her own individual mission.

Unfortunately, as often happens in a world where everything – ideas, studies, technology – is ever changing, Frankl's push to get PIL the attention it deserved met with some resistance. After all, how can one truly define, measure, and study a person's perception of purpose?

Well, James Crumbaugh and Leonard Maholick, two of PIL's earliest researchers, sought to do just that in 1964 when they created a scale to evaluate PIL. Comprised of 20 statements, they would ask patients to rate from 1 (low) to 7 (high). The scale sought to explore Frankl's belief in a person's will to find meaning in one's life.

The pair crafted their statements to look, specifically, at the three areas Frankl identified as key components – meaning in existence, freedom to create meaning in life, and the will to find meaning in future challenges. The final score of the scale determined whether a person's PIL was high or low.

Frankl's Key Dimensions

In the first of Frankl's key dimensions (determining meaning in existence), participants were asked to rate their answers to the following statements on that 1-to-7 scale, with a "4" being considered neutral.

- I am usually: completely bored (1), to, exuberant/enthusiastic (7).
- In life I have: no goals or aims at all (1), to, very clear goals and aims (7).
- In achieving life goals, I have: made no progress whatsoever (1), to, progressed to complete fulfillment (7).

In the second of Frankl's key dimensions (freedom to create meaning in daily life), statements included such items as:

- I regard my ability to find a meaning, purpose, or mission in life as: very great (7), to, practically none (1).
- My life is: in my hands and I am in control of it (7), to, out of my hands and controlled by external forces (1).
- Facing my daily tasks is: a source of pleasure and satisfaction (7), to, a painful and boring experience (1).

For the third of Frankl's key dimensions (will to find meaning in future challenges), statements included such items as:

- Life to me seems: always exciting (7), to, completely routine (1).
- Every day is: constantly new and different (7), to, exactly the same (1).
- After retiring, I would: do some of the exciting things I have always wanted to do (7), to, loaf completely the rest of my life (1).

Once all 20 statements were rated by a participant, the final score was tallied. The higher the score, the higher a person's PIL, and, thus, the heightened motivational force for survival Frankl had described.

Despite Crumbaugh and Maholick's efforts to quiet the skepticism surrounding PIL and its place in a person's overall health with their scale, though, the subject faded into the background.

Until about a Decade Ago...

Now, thanks to a preponderance of data, talk of PIL in relation to health is not only back, but it's getting noticed for all the right reasons, according to Adam Kaplin, MD, PhD, former 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.



“The data is showing us that one’s purpose needs to be in helping others,” Kaplin explains. “Just wanting more money or other hedonistic pursuits aren’t enough. Helping others is intrinsically rewarding in and of itself in a way that is very different than buying a car or a house.”

So What is Purpose in Life, Exactly? And How Does it Impact Health?

Purpose is what guides our decisions, shapes our goals, defines our path, affects our choices, and helps us establish our life’s meaning. What each individual person’s purpose is, depends in part, on whether he or she tends to be more intrinsically or extrinsically motivated. Those who lean more toward being intrinsically motivated derive pleasure and/or purpose from helping others, while those who tend to be extrinsically motivated are driven more by tangibles (such as a hands-on project).

However, while people may have a

“Just wanting more money or other hedonistic pursuits aren’t enough. Helping others is intrinsically rewarding in and of itself in a way that is very different than buying a car or a house.”

predilection for being intrinsically or extrinsically motivated, an individual who tends to be extrinsically motivated is able to look within him or herself and ultimately choose a purpose that helps others – should he or she wish to do so – and still derive health benefits from it. Only purposes that help others appear to positively affect health.

Dementia/Alzheimer’s Disease: Dementia occurs when brain cells (neurons) are damaged and no longer work properly. The type of dementia is characterized by the nature and location of the cell damage. The most common form of dementia is Alzheimer’s disease.

In “New Movement in Neuroscience: A Purpose-Driven Life,” published in the May-June 2015 issue of *Cerebrum*, co-authors Kaplin and Laura Anzaldi explain that “among the neurons most affected in Alzheimer’s, are those found in the hippocampus region of the brain (associated with short-term memory). Proteins called beta-amyloid and tau accumulate in neurons and lead to cell death and improper functioning. The damage in Alzheimer’s primarily manifests itself in memory loss.”

Until fairly recently, the only real advice given as to ways to potentially combat the development of Alzheimer’s has been to eat



healthy, exercise, and keep your brain stimulated. But now, thanks to work by Patricia Boyle and colleagues at the Rush Alzheimer's Disease Center, there is reason to believe PIL could help reduce the risk of developing Alzheimer's.

The study itself looked at more than 900 seniors with the same burden of plaques in their brain over a six-year time period. What researchers found is that those with a low PIL were 2.4-times more likely to progress to Alzheimer's than those with a high PIL.

According to Kaplin and Anzaldi's paper, that study, among others done by Boyle's group, "suggest that PIL may have a protective effect on what is known as cognitive reserve and that people with a greater reserve can withstand more brain injury before developing neurologic symptoms."

Risk of Stroke: The fifth leading cause of death in the United States, strokes occur when blood vessels fail to provide blood to oxygenate

brain tissue. Strokes can run the gamut from brief, reversible transient ischemic attacks (TIAs), to massive, deadly attacks.

In 2013, scientist Dr. Eric S. Kim and his colleagues published a study that looked at PIL in relation to stroke in older adults. He and his team followed almost 7,000 participants, who had never had a stroke, over a four-year time period. They found that as the subjects' PIL scores improved, the risk of stroke went down by as much as 22 percent.

Risk of Heart Attack: Turning to the leading cause of death in the United States, Kim and his team followed 1,500 subjects with cardiovascular disease for two years. What they found was that a higher baseline PIL was linked to a lower risk of heart attack. In fact, each unit increase of that baseline PIL on a six-point scale was associated with a 27-percent decreased risk of heart attack within two years.

What about Autoimmune Diseases (Such as MS) that Affect the Central Nervous System? Can PIL Play a Part in That, as Well?

To answer that, we must first differentiate between acute stress and chronic stress and their unique impacts on the body. Acute stress occurs over a short period of time, helping to initiate the body's "fight or flight" response in the presence of something potentially harmful. Chronic stress occurs over a longer period of time.

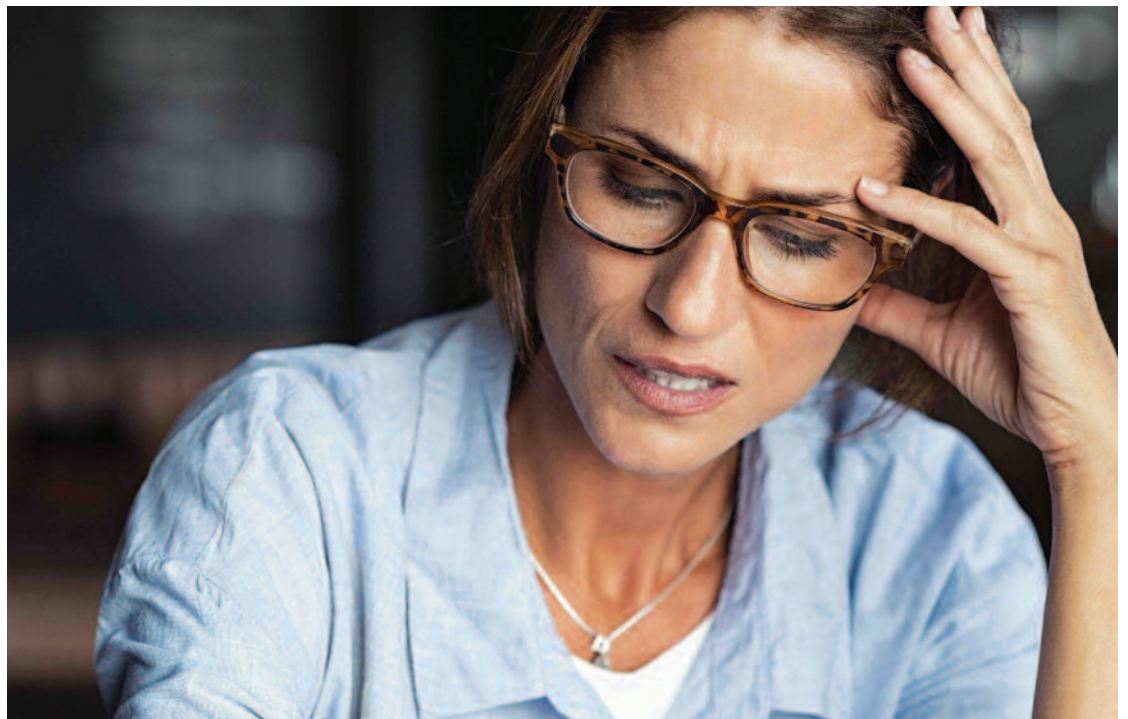
When you experience stress, your brain releases a hormone into the bloodstream which further stimulates your adrenal glands to release the stress hormone known as cortisol. Cortisol has many positive benefits or tasks. For starters, it stimulates your body to metabolize molecules that increase energy production in your cells so your body can

better handle the stressful situation.

Cortisol also has an effect on the immune system. When released into your bloodstream, it stimulates your immune cells to produce anti-inflammatory cytokines and inhibits your immune cells from producing pro-inflammatory cytokines. Or, in other words, the cortisol helps to temporarily block the body's inflammatory response so it can better function during the stressful situation.

During chronic stress (that which is more sustained due to stressors such as a difficult job or home situation), cortisol levels remain higher than normal for prolonged periods of time. When this happens for any hormone in the body, the body can desensitize to that hormone. In regards to the immune system, the regulation of the inflammatory response will be thrown off, thereby increasing inflammation in the body. It can also have a negative effect on your immune system's

When you experience stress, your brain releases a hormone into the bloodstream which further stimulates your adrenal glands to release the stress hormone known as cortisol.



I'M READY

**FOR AN MS TREATMENT THAT'S
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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 continue to monitor your health during the 2 yearly treatment courses, as well as between treatment courses and for at least another 2 years, during which you do not need to take MAVENCLAD. Your healthcare provider may delay or completely stop treatment with MAVENCLAD 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.

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ability to respond appropriately when it is needed, or even not needed.

Inappropriate immune system activity, Kaplin and Anzaldi's article points out, is thought to be a contributing factor in many central nervous system conditions including Parkinson's disease, Alzheimer's disease, and multiple sclerosis.

How PIL Specifically Affects the Body

"Studies have shown that having a high purpose in life lowers resting cortisol," says Kaplin. "Even if the participants were stressed, they were more likely to get their cortisol lower if they had a high PIL."

Kaplin went on to explain that it's when cortisol rises and stays high that the body's immune system stops responding, thus having an effect similar to driving a car with the emergency brake on, so that in an emergency it no longer provides any assistance.

One example of PIL and a link to positive, objective changes in inflammatory response is interleukin 6 (IL-6), a cytokine that is important in the pro-inflammatory response of the immune system to a myriad of general stimuli, including bacterial and viral exposure. Since the dysregulation of IL-6 has been implicated in multiple central nervous system diseases, an experiment was conducted and published in *Health Psychology* in 2007 that looked at the blood levels of IL-6 and its receptor in a population of women. According to Kaplin and Anzaldi's article, researchers found that higher PIL scores were associated with lower levels of the IL-6 receptor, implying

less IL-6-mediated inflammatory activity. The relationship held when researchers controlled for sociodemographic and health factors, suggesting that PIL may be associated with a chronic calming effect on the immune system activity.

A study done by N. Rohleder in 2014 examined the impact on the inflammatory stress response. Higher levels of IL-6 were detected in the bloodstream of participants with low PIL scores in each subsequent stressful exposure.

Another study, this one from 2013, looked more generally at stress-related "transcriptomes" (a collection of all of the genes that are expressed in a specific system). Researchers wanted to explore which genes were active in immune cells in people with hedonic or eudaimonic wellbeing.

Hedonic wellbeing is based on the notion that increased pleasure and decreased pain leads to happiness. Eudaimonic wellbeing is based on the concept that people feel happy if they experience purpose and growth from challenges.

The study showed that the immune cells in people with hedonic wellbeing expressed more pro-inflammatory genes than did those with eudaimonic wellbeing. The correlation, according to Kaplin and Anzaldi's article, therefore seems to imply that seeking purpose helps avoid a pro-inflammatory state, providing helpful information in the fight against neurological diseases such as multiple sclerosis.

"I think the inflammatory system is key here," Kaplin says. "People with a higher PIL

are less stressed because their purpose helps ground them, and when they are less stressed, they tend to handle neurological disease better.”

Stress, Kaplin is quick to point out, isn't necessarily bad in and of itself. Everyone has it at some point. But how it's interpreted can make the difference between its positive and negative effects.

Impossible to Ignore...

In light of the positive research surrounding PIL, many doctors have turned to it as a matter of course in treating their patients. Do you remember that 20-question scale Crumbaugh and Maholick created in

1964 to assess PIL? That scale is still used today by many in the medical community, including Kaplin.

“It gives me an important idea of whether the patient has a high or low PIL – both because of the implications of this score for overall health outcome long-term, but also because it alerts me to the fact that I may need to focus on PIL if the individual has none,” Kaplin says.

“Conversely, if a patient has a high PIL despite experiencing depression, for example, I know where to focus my efforts and that the patient will likely do well if I can help to remove the impediment of his or her mood disorder.”

Although studies with PIL have only included helping other people, and have never examined the care of animals, one might speculate that providing service to animals might also qualify as an intrinsic PIL. This would not include those being paid to care for an animal, but rather, those who have formed a close bond with their pets or other animals, and then provide urgent care so they may be safe, well-fed, and comfortable.



Getting from A to B (Finding Your PIL)



Aside from the studies with PIL, intuitively, it makes sense that having a purpose keeps us looking forward instead of backward. But finding that purpose, and sometimes having to adapt that purpose to reflect changes in physical ability, isn't always an easy task and multiple factors can come into play, according to Amy Sullivan, PsyD, ABPP, clinical health psychologist at the Mellen Center for MS Treatment at the Cleveland Clinic.

“We must understand that everyone’s life is driven by a multitude of things: responsibilities of work, caring for family members, et cetera,” says Sullivan. “That’s why, when looking for purpose, it’s important

to look at the larger picture.”

To that end, when helping patients find purpose, Sullivan first seeks to help them understand what brings them joy and holds their interest, or more importantly, the things they feel passionate about and the things that give meaning to their life. She encourages them to process those things with a family member who truly knows them. Meditation and journaling can also help lead to finding one’s purpose.

It’s important to note here that being happy and having a purpose in life do not always go hand in hand. While happiness can have its positive impact on the body in terms of less stress, one’s happiness is often rooted in the moment. Meaningfulness, on the other hand, is more enduring and, as Frankl believed, can be the key component in helping a person survive great stress and suffering, as it did for him.





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One thing Kaplin suggests to his patients who are looking for their PIL, is to think back on crucible moments in life, i.e., those moments that were extremely challenging. How did you overcome it? What did you do? It is in those actions that he believes many people will find their true PIL.

In the writing, “Finding Power and Purpose in Your Crucible Moment,” by Warwick Fairfax (found at crucibleleadership.com/2019/04/finding-power-purpose-in-your-crucible-moment/), the importance of a crucible moment is explained. “I have found that when you use a crucible moment to help others, it can be very healing. When we take the focus off ourselves

and try to use what we have been through to help others, it can make a huge difference in our spirit and our lives. Living such a life – using the pain of a crucible experience to help others – is what leading a life of significance is all about.”

Still unsure of your true PIL? Then consider looking back on goals you had when you were younger, or look to the stories of others to see if they resonate. Read inspirational books, or attend lectures. Stories that inspire make us dig deeper, Kaplin says. “We learn by example.”

However, of greatest importance in the search for one’s PIL, is that it’s your own, Kaplin cautions. “It has to be your belief,

what you find rewarding in order for it to instill mental and physical health.”

For patients in Sullivan’s care, what brings joy and excitement to one’s life becomes obvious over time. And when they find their PIL, a decrease in depression is notable in both objective and subjective ways, she says.

“When working with MS patients to help them to find their PIL, I look at where they are in life,” Sullivan says. “For those who are newly diagnosed or in a new phase or change of function, it’s important for patients

to have some space to grieve, and then to help them adapt to what comes next.”

For some, knowing their PIL isn’t the problem. Rather, it’s finding a way to pursue it within the framework of their physical abilities. The key is being open to tweaks and adjustments as they can often bring about PILs that are every bit as rewarding as the original version, something Kaplin has witnessed firsthand with patients.

“I had one patient who wanted to coach his child’s softball team but didn’t think he could, given his condition. I said, ‘Why not? Go show them that when you get knocked down, you get back up.’ And he did. And he ended up teaching the kids on that team about life as much as he did softball.”

Another patient had spent years dreaming about the traveling she wanted to do upon retirement. But, when the time came, her condition made it so she didn’t think she could still travel. Eventually, over time and with encouragement, she found destinations that could accommodate her desire to travel. Now, she maintains a travel log for people with disabilities.

“A lot of times, you have to give something up to find your purpose,”





Whether caring for someone out of choice or necessity, care partners are in a unique situation, one where, very often, their own needs – physical and mental – are secondary to that of the person they are caring for.

Kaplin says. “Old goals can be changed and adapted to where you are now.”

PILs and Care Partners

One thing both Kaplin and Sullivan are quick to say, is that having a Purpose in Life is important for care partners as well. Whether caring for someone out of choice or necessity, care partners are in a unique situation, one where, very often, their own needs – physical and mental – are secondary to that of the person they are caring for. As a result, Kaplin says, rates of depression in care partners tend to be high, making them prime for diseases, too.

While noble in many ways, it is important for these care partners to realize that they can better manage the impact of stress on their own bodies by taking care of themselves and finding

their own PIL.

“It’s like that announcement on an airplane when they tell you that if the cabin suddenly loses pressure during the flight and the oxygen masks come down, you should put it on yourself first before helping a child,” Sullivan says. “You have to breathe so you can help your child in that situation. The same holds true for care partners and the person they’re caring for, as well.”

PILs are Different for Everyone...

As Kaplin suggests above, looking to the stories of others can inspire and often help you to step back, dig deep, and maybe even help lead you to finding your own PIL.

For Gary Heimbach, of Broken Arrow, Oklahoma, who was diagnosed with multiple

sclerosis in 1999, finding his purpose in life was a game-changer. “Before I was diagnosed, I was a workaholic climbing the corporate ladder,” Heimbach says.

“But with my diagnosis, I realized that my life purpose is not just about me, but more my relationship with my family, friends, and others. It made me realign and focus my priorities in life.”

Heimbach has come to embrace the notion that we “exist, live, or survive not to be takers but to give. Givers of time, values, and of our love.”

David Desjardins of Union, Maine – an MSAA Art Showcase participant – points to his determination to stay active and vital as his purpose in life. For him, the ways in which he accomplishes that goal have become more

limited as his life progresses, but the determination to find a way remains.

“I think it’s human nature when faced with accepting loss and changes to one’s life to want to retreat and sit in a corner mourning that loss,” Desjardins says. “The challenge we all have is to overcome those feelings and find something on which to focus that gives satisfaction and draws attention away from the problems we are facing.”

Painting is one way he does that. “For me, painting regularly helps keep me feeling positive on many levels: when I first get an idea for a painting, I am looking forward to starting it and trying out my ideas; then when the painting is underway – and hopefully going well – I feel very positive and pleased; and when the painting is finished, a feeling of



Glad (left) and *A Day at the Beach* (right) by David Desjardins, Union, ME

satisfaction and accomplishment takes over.”

For Maureen Whetstone of Hummelstown, Pennsylvania, her purpose in life had always been her role as a mother. But that purpose took on a new facet when, after first her daughter and then her son were diagnosed with multiple sclerosis, Whetstone ended up being diagnosed as well. “My diagnosis gave me clarity into what they were dealing with and feeling about their diagnoses. I saw how they were just going on with life, not letting it change their activities or steal their happiness. Their determination drives me to be stronger and braver and to set an example. Always.”

As part of that example, Whetstone continued working as a para professional at a nearby school district in the area of special

education for many years. But as can be the case for someone living with MS, time to make a change for health reasons came. She took advantage of the pandemic to reassess her physical health in conjunction with her job and decided a change was needed. Now, she watches her youngest granddaughter every day. She says she still has purpose to wake up and get dressed every day. She misses her school life and helping the students who were in her care, but she’s at peace with her new job and treasures her new motivation to keep moving.

Kim Standard, of Douglasville, Georgia, another MSAA Art Showcase participant, found her purpose to be family – having and raising children – and maintaining a positive perspective for herself and others.



Smoky Mountain Scenery (left) and *Family Time Sunset* (right) by Kim Standard, Douglassville, GA

“I was raised with an aunt who was bedridden over thirty years with rheumatoid arthritis. Therefore, I saw a power chair as freedom to get around.”

Along the way, Standard started a blog. She saw it as a way to both work from home and get her message out regarding thankfulness, even in the face of adversity. She says she isn’t a writer but enjoyed the interaction between bloggers early on. Today, she spends some of her time painting – a skill she first tried in high school – only to revisit nearly 40 years later via an art class at her local senior center.

It’s Still Early, but...

According to Kaplin and Anzaldi’s article, “While research has suggested significant relationships between PIL and positive health outcomes, we cannot yet make any sweeping declarations about PIL being responsible for these actions. This is primarily because PIL studies that prove causation are difficult to design.”

But, they go on to write, “Identifying a Purpose in 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.” ■

Editor’s Note: Please see the **sidebar on pages 26-27** for helpful strategies in identifying your own Purpose in Life.

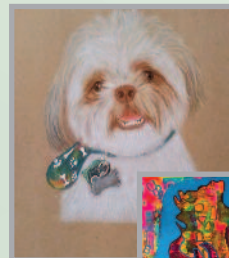
MSAA is very
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2021-2022

ART SHOWCASE

Each year, MSAA features the work of artists affected by multiple sclerosis in the annual **MSAA ART SHOWCASE**, highlighting one artist each month as our Artist of the Month.

We received many wonderful submissions from across the country and are delighted to share the work of more than 50 artists and their inspiring stories with you!

You can view the complete online gallery by visiting mymsaa.org/artshowcase2021



How I Found My PIL

By Laura Bradford

I was ten years old when I decided I wanted to be a writer. I wanted to see my name on the spine of a book. I wanted to know that something I wrote would put a smile on someone's face or help them escape for a little while just as so many authors had done for me.

It was my dream, my passion.

Years later, after working as a journalist and then having children, it was finally my time to chase that dream. I wrote, and I wrote, and I wrote. And, eventually, I landed my first three-book contract with a small publisher.

I was on my way...

I was doing it...

My first book released in June, 2005.

My second book released in March, 2006.

And then, while writing the third book in July of 2006 – when my daughters were just 7 and 11 – I was diagnosed with MS; the same disease I'd been watching my then mother-in-law battle for the past two decades.

Needless to say, finishing that third book was a struggle. And when I exhibited a brief slurring of my speech at a reader event, I wondered if my lifelong dream was over before it ever truly got off the ground.

But then I looked at my daughters, and I imagined what I'd want for them if they were in my position.



I'd want them to keep going.

I'd want them to believe in themselves.

I'd want them to keep reaching for their dreams.

And that's when I found my purpose in life. To show my girls that life's many obstacles are just that – obstacles. You may have to adjust, you may have to zigzag, but you always, always keep going.

I'm proud to say that later this year, my 36th and 37th books will be released. All but those first three pre-diagnosis books have been with major New York publishers. And my girls? They're not only watching and seeing, they're reaching for their dreams now, too.



For changing RMS
I'M AT MY BEST WHEN MY

MIND



BODY

ARE IN BALANCE

What is MAYZENT® (siponimod) tablets?

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

IMPORTANT SAFETY INFORMATION

Do not take MAYZENT if you:

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

MAYZENT may cause serious side effects, including:

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

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

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

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

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

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

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

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

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

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+ **MAYZENT, a once-daily pill, was proven to delay disability progression in people with relapsing MS**

+ *Disability progression was measured by the EDSS through a combined clinical assessment including physical and cognitive function*

+ *MAYZENT is the first and only pill studied and proven in people with RMS that's progressing*

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EDSS=Expanded Disability Status Scale; MS=multiple sclerosis; RMS=relapsing MS.

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- 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 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.
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- 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.

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.

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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.

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- vomiting
- tiredness
- headache with fever, neck stiffness,
- body aches
- sensitivity to light,
- chills
- nausea, confusion (these may be symptoms of
- nausea
- 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 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 the possible side effects of MAYZENT?**” for more information about side effects.

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- 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 chickenpox or have received the vaccine for chickenpox. Your healthcare 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
- 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.
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- 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.

Do not split, crush, or chew MAYZENT tablets; take tablets whole.

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:
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 - your skin or the whites of your eyes turn yellow
 - dark urine
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- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your healthcare provider right away if you have any of the following symptoms:
 - sudden severe headache
 - sudden confusion
 - sudden loss of vision or other changes in your vision
 - seizure

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

The most common side effects of MAYZENT include:

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

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

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

How should I store MAYZENT?

Unopened Containers

MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. If you need to store MAYZENT tablets for more than 3 months, containers should remain unopened and stored in a refrigerator between 36°F to 46°F (2°C to 8°C) until use.

Opened Containers

Bottles

MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. Do not refrigerate after opening.

Starter Pack/Blister Card

MAYZENT 0.25 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. Do not refrigerate after opening. Store in original calendarized blister wallet container.

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.novartis.us or call 1-888-669-6682.

Some How-To Steps for Finding Your Purpose in Life

By Laura Bradford

Finding a Purpose in Life is a deeply personal thing. For it to have optimal impact, it must be something that resonates for you – something that reflects your beliefs, your interests, and your goals. The key is knowing how to unearth it under the trials and tribulations of everyday life.

1 Make a list and check it twice.

Actually, make several lists...

- *What makes you happy?*
- *What are your talents?*
- *What can people learn from you?*
- *What calls you to action?*

Spend time with your answers.

Perhaps your purpose in life is on one – or more – of your lists.

2 Thank-you notes.

Grab a pen and a piece of paper and write thank-you notes to the people who have made a difference in your life. Sometimes, in acknowledging those people and the impact they had on our lives, we find a desire to do the same for others.

3 Look to those who know you best.

Taking time to see yourself through the eyes of loved ones can often reignite long dormant passions. Hearing how something you've done or said may have positively affected the life of another person is motivating. Feel that. Let it fuel you.

4 Become inspired by the stories of others.

Very often, when listening to another person's trials (via a speech, or a book, or a podcast, or a television program), we find a commonality that speaks to us. We may not have experienced the exact same thing, but we may connect over a shared feeling. How did this other person handle their obstacle? What was their motivation to turn the corner, to keep going? Did something they say resonate with you? Did it spark a desire within you? Look at that.

5

Do for others.

In a study published in *The Journal of Positive Psychology* in 2016, Daryl R. Van Tongeren and his team, said, “A central feature of meaning in life is a consideration of more than oneself. We extend this logic to suggest that altruistically motivated prosociality – acting in ways that benefit others – is a self-transcending action that may provide meaning in life.”

The ways in which you can make a difference in life are endless...

- *Are you gifted in art? Is there someone who might benefit from your ability?*
- *Do you enjoy writing? Is there an organization that could benefit from your ability?*
- *Did you overcome a trial in life? Is there a group of people that might benefit from hearing of your experience?*
- *Is there an elderly person in your community who lives alone? A weekly call to say hello might be just the emotional boost they need.*
- *Are you good with animals? Perhaps you can volunteer at a shelter in some capacity.*
- *Can you stuff envelopes? Are you good with paperwork? Many organizations would value assistance in these areas.*

6

Look back on your life.

Pull out the photo albums, read an old diary, write about the best and worst parts of your life. Sometimes, in looking back, our path forward can be found.

7

Brainstorm.

It's no coincidence that professions roused in creativity place great importance on brainstorming. Very often, the best ideas are cobbled together from many people. So gather together those friends or family members you looked to for #3 (noted earlier), and start tossing out ideas of things you can do. Maybe, in the process of sharing and tweaking that comes from several minds churning a shared topic or goal, something will resonate. If it does, shift your brainstorming session to include ways in which you can set about pursuing that idea inside the parameters of your ability.

8

Reevaluate and tweak.

As life changes, so, too, can a person's PIL. If you find yourself in this situation, step back, reevaluate, and tweak as necessary. If that doesn't work, don't be afraid to go back to the drawing board in search of a brand new PIL – ones that's a better fit for where you are in life at that time.



COVID-19 Vaccine Appears Safe for People with MS

By Dr. Barry Hendin

MSAA's Chief Medical Officer

Q: Are the COVID vaccines safe for someone with MS, particularly for my type, relapsing-remitting MS? Could the vaccine cause a relapse or pseudo-relapse? Also, is one brand of vaccine safer or better than another for people with MS – and is getting the one-time vaccine an advantage over the ones that require two separate injections?

A: Given the serious nature and risks associated with COVID-19, I along with MSAA, support the MS community getting the COVID vaccine as soon as individuals are eligible, in coordination with one's healthcare provider.

The COVID vaccine appears safe for people with MS, regardless of their MS type. I do not recommend one specific vaccine; I recommend that you get the first one that you are offered. The vaccine is very unlikely to cause a relapse. A brief pseudo relapse is possible if you develop a fever, post injection, but it is unlikely.

Q: Currently I am fine and I have no problems. My question is, do I need to take medication for MS now... or because I am 60 and have remained free of symptoms for

20 years, is it safe to assume I will not have any future episodes of MS? If I do not have any serious disabling factors by now, what are the odds I would have a disabling episode in the future?

For background information, I was diagnosed with MS in 2001 and prescribed one of the disease-modifying treatments (DMTs). I stopped taking the DMT in 2006. I have not had any problems since 2001. Due to a breast cancer diagnosis in 2020, I started taking tamoxifen and I had my first ocular migraine. A CT and MRI indicated multiple TIAs. After many tests, my new neurologist decided it wasn't TIAs that caused the migraine – he thought it could be tamoxifen, MS, or cancer. We are ruling out cancer. I feel it was tamoxifen that caused the migraine. I've had no active activity on the MRI or CT – just showed scattered white spots that resembled TIAs but my doctor felt they were related to MS. My neurologist compared scans from 2001 and said that many white spots on the 2020 MRI show on the 2001 MRI.

A: I want to express my happiness regarding how well you are doing 20 years after your diagnosis of MS. There are at least two issues

for me to address. First, the diagnosis of MS sounds as if it may have been questioned initially. If there is any doubt regarding the diagnosis, this can be a good time to reassess. (If you don't have MS, of course, you won't want to be on an MS medication!)

Second, you are correct that we need to rethink the rationale for continuing DMTs as people age: the benefit of our treatments may decline and the risks may increase with aging. For people with MS in their 60's and older, the risk of relapse declines but the risk doesn't disappear entirely. I suggest a discussion with your MS clinician before making a final decision. As a side note, an important study is currently underway at the University of Colorado to address questions regarding the benefits of DMTs in MS in an aging patient population.

Q: I am 62 years old and was diagnosed with RRMS at the age of 28. I have had a few exacerbations, primarily optic neuritis three times and tingling and diminished use of my hands after my first child was born when I was 32. In the last couple of years, I have seen problems with my walking, and looking through my doctors notes from 2018 (I requested all my records), she indicated I might be starting to experience secondary-progressive MS. I had Betaseron when I was 30 years old for a year. An MRI after one year showed a new lesion and because of the stress of giving myself needles, I chose to quit treatment.

Is it realistic for me to start looking at a

DMT to slow down any potential degradation? I am very healthy. I do have some spondylitis in my hips, for which I am actively doing physiotherapy and exercise programs. I was extremely active up until two years ago, when my walking started to be affected. Since then, my physiotherapist has realigned my hips and my back, which has helped my walking by leaps and bounds.

I will be seeing my physiotherapist for my annual appointment and would like to explore a DMT that will help keep me strong and prevent my lesions from worsening. Do you have any suggestions as to what I should ask and what I should further explore?

A: During the past 28 years we have been increasingly successful at treating relapsing multiple sclerosis. Our successes have been primarily against the inflammatory aspects of MS, including relapse reduction. We have been less successful, unfortunately, in diagnosing and treating secondary progression.

Most of our DMTs are indicated for active secondary progression, which is a phase of relapsing MS in which there is still active inflammation (meaning that clinical relapses or new MRI activity are still occurring). In secondary progression without recent activity, people with MS still benefit from a general wellness program including exercise and diet. This is a good time for your physiotherapist to assess gait. Your neurologist may also want to consider a symptomatic medication for gait improvement, such as 4-amino pyridine.

Q: How do I know if I'm having an MS relapse?

A: It's not always easy to determine if symptoms that you're having are due to a relapse, but there are some rules. A relapse is defined as a new neurological deficit or a marked worsening in an old deficit, lasting at least 24 hours and separated by at least 30 days from the last event (and not better explained by something else). Brief symptoms are probably not due to a relapse.

Transient symptoms associated with overheating or a febrile illness are also unlikely to be due to a true relapse. Symptoms associated with overheating or fever are called "pseudo-relapses" and should resolve when your temperature returns to normal. These events are temperature-related and not due to a new MS attack.

An MRI scan can sometimes, but not always, help to answer the question. In the end, the determination is best assessed between you and your clinician. When in doubt, consult

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

with your clinician either by telephone or in person.

Q: Why is fatigue so common in MS and how can I manage it?

A: You are correct that the most common symptom for people with MS is fatigue. The cause is probably different from person to person. The cause of primary fatigue in MS has been debated. It may be related in part to inflammation and in part to the increased effort required to accomplish tasks for some individuals.

There is also a type of fatigue that is labeled secondary fatigue. This may be due to a number of treatable factors such as poor sleep, depression, lack of exercise, or medications. Treatment for secondary fatigue is aimed at a specific problem causing the fatigue. Your treatment would be aimed at restoring sleep, treating depression, starting an exercise program, or assessing medication.

Although a variety of medications have been used for MS fatigue, including amantadine, modafinil, and armodafinil, a general wellness program emphasizing exercise, diet, and mental health should be central to the treatment of fatigue. ■

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 Ponvory™ for the Treatment of Relapsing Forms of MS

On March 19, 2021, the Janssen Pharmaceutical Companies of Johnson & Johnson announced that the United States Food and Drug Administration (FDA) approved Ponvory™ (ponesimod) for the treatment of relapsing forms of multiple sclerosis (MS) in adults – including clinically isolated syndrome, relapsing-remitting, and active secondary-progressive forms of MS. This new disease-modifying therapy (DMT) is taken orally (by mouth) once daily and has been shown to reduce annual relapse rates and reduce disease activity as shown on magnetic resonance imaging (MRI), compared to treatment with an approved DMT, Aubagio® (teriflunomide). Ponvory should be available by prescription in April 2021.

In addition to its proven efficacy, Ponvory is well-tolerated and provides some additional benefits, such as its quick rate of leaving the blood system should the medication need to be stopped. The most common side effects include upper respiratory tract infections, elevated liver enzymes, and high blood pressure. Those with certain heart conditions, or women who are planning to be or are currently pregnant, should not take Ponvory.

Study Findings and How Ponvory Works

The approval of Ponvory was partly based on a two-year, head-to-head Phase III clinical

By Susan Courtney and Tom Garry

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

trial, where the efficacy, safety, and tolerability of Ponvory (20 mg taken orally, once per day) was compared to Aubagio® (teriflunomide), which was taken in oral doses of 14 mg once daily. Referred to as the OPTIMUM trial (Oral Ponesimod Versus Teriflunomide in Relapsing Multiple Sclerosis), this study included 1,133 participants and found the following results for treatment with Ponvory when compared to Aubagio:

- 30.5% lower annual relapse rate
- 71% of participants had no confirmed relapses, compared to 61% in the Aubagio group
- The number of new gadolinium-enhancing (GdE) T1 lesions and the number of new or enlarging T2 lesions were reduced by 59% and 56% respectively
- Worsening disability was prevented for most people, although the differences in rates between the two medications were not significant

Ponvory is a selective sphingosine-1-phosphate receptor (S1P) modulator that is believed to work by keeping immune cells called lymphocytes out of the blood by trapping them in the lymph nodes.

Lymphocytes that circulate in the blood and cross the blood-brain barrier to enter the central nervous system are thought to cause

the damage to nerves seen in MS. Other approved sphingosine-1-phosphate (S1P) receptor modulators for MS include Gilenya® (fingolimod), Mayzent® (siponimod), and Zeposia® (ozanimod).

Should this medication need to be stopped at any time, it leaves the blood within one week, and the effects on the immune system wear off in one to two weeks for most patients. This is of benefit for people who may be waiting to get a vaccine, who plan to become pregnant, or who need to stop the medication for any other reason.

According to Johnson & Johnson, “Ponvory does not require genetic testing or first-dose cardiac monitoring for most patients. Because initiation of Ponvory treatment results in a decrease in heart rate, first-dose monitoring is recommended in patients with certain preexisting cardiac conditions.”

Side Effects and Adverse Events

As noted earlier, the most common side effects include upper respiratory tract infections, elevated liver enzymes, and high blood pressure. Adverse effects can include more serious infections and a slowed heart rate (bradycardia or bradyarrhythmia) when starting Ponvory. To help minimize the potential for initial side effects, patients begin taking Ponvory in a titrated “starter pack” for the first 14 days. The starter pack begins with a low dose and gradually increases to the full dose approved by the FDA.

Ponvory lowers the number of white blood cells (lymphocytes) in the blood. This

medication also increases the risk of infection, including serious infection that can be life-threatening. To monitor the risk, individuals should have a recent blood test prior to starting the medication, and while taking the medication, should watch for signs of infection, such as fever, body aches, nausea, and headache, among others.

Since Ponvory can affect the heart rate, individuals need an electrocardiogram (ECG) to check the electrical activity of their heart before taking the first dose. People with certain cardiac conditions, such as those who have had a heart attack or stroke, or those experiencing angina, heart failure, or abnormal heartbeat, should not take Ponvory. Those pregnant or planning to become pregnant, or who are breastfeeding, should not take Ponvory. Individuals are advised to tell their doctor about any health condition prior to starting this medication.

For More Information

The maker of Ponvory has two programs available to the MS community. The first is Janssen CarePath, which offers support and information on insurance coverage, potential costs, and options for making treatment more affordable. The second is the Wellness Companion Program, which provides one-on-one education to help patients get started and continue treatment. For more information, please visit www.ponvory.com, or call a Janssen CarePath Care Coordinator at **877-CarePath (877-227-3728)**, Monday-Friday, 8:00 AM to 8:00 PM ET. ■

Plegridy® Now Approved for Intramuscular Injection

In February 2021, the United States Food and Drug Administration (FDA) approved a new intramuscular injection route of administration for Plegridy® (peginterferon beta-1a), a disease-modifying therapy (DMT) for relapsing forms of MS. The medication is marketed by Biogen, a Cambridge, MA-based biotechnology company.

The FDA first approved use of the interferon-based DMT in 2014. Since then, the medication has been administered subcutaneously, meaning that a short needle is used to inject the DMT into the tissue layer between the skin and the muscle.

Maha Radhakrishnan, MD, Biogen's chief medical officer, says the newly approved intramuscular route of administration "gives new and current MS patients a different delivery method that has the potential to significantly reduce injection-site reactions."

Biogen noted that the FDA's approval of the intramuscular (IM) administration of Plegridy is based on data evaluating bioequivalence and adverse reactions associated with IM administration compared to subcutaneous (SC) administration in healthy volunteers. Bioequivalence between the two dosing regimens was confirmed, and data showed that participants receiving Plegridy through IM administration experienced fewer injection-site reactions than participants receiving SC administration (14.4% vs. 32.1%). ■



Volunteer-driven fundraisers are an important part of MSAA's fundraising efforts, which help support MSAA's free programs and services.

Create your fundraiser today!
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support.mymsaa.org/DIY

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Assessing Ocrevus® in Older Adults with Progressive MS

The impact of disease-modifying therapies (DMTs) on MS often is easier to evaluate in younger adults than older people. This owes in part to the fact that younger people tend to have more inflammatory disease activity, providing a clearer baseline against which to measure the effect of a medication. Similarly, older people are less likely to have relapses, diminishing the utility of measuring changes in annual relapse rate as a marker of medication efficacy. Further, older people are likely to have more comorbid conditions – such as osteoarthritis or diabetes – making it difficult to determine whether impaired mobility, fatigue, or another symptom is due to MS or some other cause.

To better understand the impact of the DMT Ocrevus® (ocrelizumab) in older people with multiple sclerosis, researchers recently analyzed data on people with progressive forms of MS who were age 56 years and older.

Ocrevus is an anti-CD20 therapy, meaning that it exercises its effects on the CD20 molecule found on the surface of the immune system's B cells. These cells are believed to play a role in the development of MS. Ocrevus is approved by the FDA to treat both relapsing and progressive forms of MS. Clinicians also sometimes use another anti-CD20 therapy, rituximab, to treat MS. However, rituximab is not approved for use in MS, although the FDA has approved its use for a number of other diseases.

The researchers focused primarily on 24 patients for whom they had data for two years

before those people began either Ocrevus or rituximab and for two years after they started taking Ocrevus. Seventy percent of those people had been on another type of DMT before beginning anti-CD20 therapy.

After analyzing their results, the investigators reported, “We found no difference in two-year clinical endpoints for patients while on ocrelizumab [Ocrevus] compared to prior to [starting] anti-CD20 therapy, though there was a trend toward decreased CDP [confirmed disability progression] on ocrelizumab that our study was not sufficiently powered to analyze.”

While the investigators noted that larger studies are needed to examine this issue, the fact that progressive MS patients' clinical status did not worsen over roughly four years – including the last two on Ocrevus – is encouraging. ■

For More Information

For general information or to speak with a trained Client Services Specialist, please call MSAA's Helpline at **(800) 532-7667**, extension 154. Helpline hours are Monday through Thursday, 8:30 AM to 8:00 PM, Eastern Time; and Friday 8:30 AM to 5:00 PM Eastern Time. Questions to MSAA's Client Services department may also be emailed to **MSquestions@mysaa.org**

MSAA's COVID-19 "Hub" Keeps You Informed and Updated

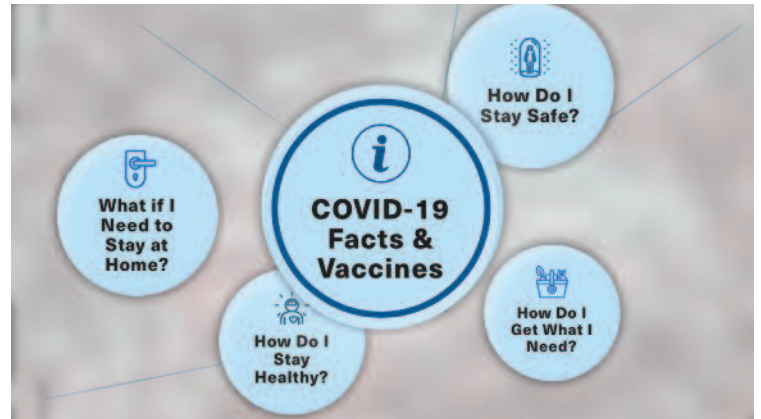
By Peter Damiri

Launched soon after the start of the pandemic in 2020, MSAA's dedicated website hub, **The Coronavirus and MS**, offers a wealth of free, educational tools and resources on COVID-19 and its impact on the MS community.

The site's most comprehensive resource is the **COVID-19 and MS Pathfinder** tool. Developed in partnership with Wondros and **updated regularly**, this unique navigation tool allows for quick, easy access to the latest medical reports and findings addressing emerging news on:

- Vaccines and treatments
- COVID's impact on MS and disease-modifying therapies
- Ways to stay safe
- And more

In addition to this helpful tool, visitors to the website hub will find supportive resources and our growing library of on-demand COVID-19 and MS webinars. In fact, the ninth edition of our ongoing webinar series, **"What You Need to Know About COVID-19 and MS,"** is taking place on **Monday, April 26, 2021, from 8:00 PM – 9:00 PM Eastern Time**. People may sign up prior to that day and time to attend the live webinar, or view the archived video of the webinar after the event. To register for or view this latest webinar and access the MS



The COVID-19 and MS Pathfinder is one of MSAA's many supportive resources for information about the COVID-19 pandemic and multiple sclerosis.

Pathfinder tool along with additional resources, please visit mymsaa.org/covid

Digital Educational Programs and New Guide Now Available

In addition to the upcoming COVID-19 and MS program, MSAA has an active schedule of live webinars planned for the spring and early summer. **Upcoming digital programs include a series of Spanish-language presentations on MS management, a pair of webinars exploring the African American MS experience, and a host of online discussions addressing rural healthcare access and resources.**

You can register for these free, live programs by visiting our calendar of events at mymsaa.org/calendar. Also, please know that previous webinars broadcasted during the winter on topics such as how parents can

discuss MS with their children, being newly diagnosed with MS, navigating COVID-19 as a person of color, and more, are now available on the MSi video webpage at mymsaa.org/videos

Additionally, MSAA has just launched the first of several planned interactive, **digital educational guides designed to complement many of our recent webinars**. These guides include facts, activities, resources, and more on special subject areas related to MS. Debuting in April, our first digital guide, **MS on Your Mind: A Closer Look at Brain Health** is a hands-on **interactive** tool that breaks down the complexities of brain health in MS in an easy-to-read and understandable format.

As you journey through the guide, descriptive information and illustrations will help explain the impact DMTs have on overall brain health, the role of brain atrophy and brain-volume loss on the disease course, the use of MRI in measuring brain health, and more. We invite you to explore this new guide and look for additional topics coming online soon by visiting mymsaa.org/brainhealth

Spring Forward, Cool Ahead!

As we welcome the start of spring and look forward to nicer weather, this is a perfect time to remind our clients about MSAA's year-round **Cooling Distribution Program**. The MSAA Cooling Program offers a variety of free ice-pack vests and accessories to help lessen the negative effects of heat on people living with MS. Vests can be worn under or over clothing and often provide several hours of temporary cooling relief, allowing people to better manage daily life activities, as noted below by MSAA

client member, A.V. from New York.

"The cooling vest and scarf are my lifesavers! I put them on every time I go out on a hot day and it allows me to do usual things like go shopping or go for a walk without feeling completely exhausted from overheating. Thank you!"

MSAA greatly appreciates this lovely note and the opportunity to offer free cooling vests and accessories to the MS community. Additionally, MSAA provides free durable medical items including grab bars, shower chairs, walkers, exercise peddlers, and more to qualified applicants through our **Equipment Distribution Program**. As you may have previously read, MSAA continues to offer a financial hardship waiver to the cooling and equipment programs for people affected by the COVID-19 pandemic. If you are in need of free cooling or equipment items, please consider applying to these programs on the MSAA website, mymsaa.org, or by calling our **Helpline at (800) 532-7667, ext. 154**.

Resources Available on Improving Mental Health and Wellness

In addition to *The Motivator* cover story exploring the concept of Purpose in Life, MSAA also hosted a webinar on the topic of PIL with Dr. Adam Kaplin, along with other digital educational programs addressing our MS Awareness Month theme – Improving Mental Health and Wellness.

Now archived on our website for on-demand viewing, Dr. Kaplin's webinar "**Finding Purpose in Life**" provides a comprehensive look into the origins of PIL and discusses key

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- Get advice and support while connecting directly with people affected by MS
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- Solve day-to-day challenges



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study findings, which demonstrate a correlation between having meaning in life and achieving better health outcomes. The live webinar was very well attended and many viewers, including L.S. from Maryland, commented afterward on the powerful connection they felt toward the subject matter coupled with the ongoing strains of living through the pandemic.

“A seminar with Dr. Kaplin was just what I needed! These past months of life with Covid have been very difficult, causing increased depression, less activity, worsening of MS symptoms, and resulting fear. I plan to think more about my Purpose in Life and apply it to life after this pandemic.”

MSAA also enlisted the support of clinical

health psychologist Amy Sullivan, PsyD, ABPP to host a webinar on “**Managing Depression and Anxiety in MS**” and record a podcast episode on “**Caring for the Care Partner.**” Additional topics covered during the campaign included helpful strategies to address the **importance of sleep, staying connected, diet and exercise, and self-care** by top MS neurologists Annette Okai, MD and Mitzi Joi Williams, MD; along with dedicated blog posts, supportive resources, and more.

If you were unable to connect with MSAA during these scheduled programs, or would like to access the information presented, please visit our dedicated MS Awareness Month webpage at mymsaa.org/awarenessmonth. ■

MSAA's Improving Lives Benefit: Corporate Honoree

For nearly a decade, MSAA has partnered with Medscape on developing innovative educational programs for the MS community. MSAA was honored in 2016 to receive Medscape Education's "Partner in Patient Education and Health" award at their Patient Empowerment Celebration, and we are so proud to honor Medscape as MSAA's Corporate Honoree at our annual Improving Lives Benefit on May 13, 2021.

Medscape presents exceptional clinical content through creative design, aimed at promoting higher education and learning. This expertise, combined with Medscape's expansive membership of more than 200,000 primary care providers and neurologists, has enabled the delivery of quality educational programming to the healthcare professionals who are instrumental in the lives of individuals with MS.

Our joint commitment to improving care for those living with MS has served as the foundation of our relationship from the beginning, and our work together continues to meet the needs of the MS community. We are currently partnering on Medscape's "Clinical Advances in Elevating Health Equity" initiative, a new project that will explore the impact of ethnicity and race on MS care.

This past year has been challenging for all of us, with COVID-19 impacting how educational programs are developed and disseminated. MSAA launched our COVID-19 and MS Pathfinder digital tool to help provide up-to-date information about living with MS during the pandemic, and Medscape likewise developed a learning center to ensure that healthcare professionals had access to the latest information.

"At the start of the COVID-19 pandemic, we recognized the need to deliver trusted, current information and education to our global members in a timely manner," explains Douglas Kaufman, Medscape Education's Group Vice President. "As the science was rapidly evolving, we were committed to providing our members worldwide the information they needed on the front lines.

"We launched the COVID-19 Learning Center in February 2020, which has reached more than 2 million healthcare professionals worldwide with CME/education, expert insights, tools and resources to stay current during these unprecedented times. Our clinical teams across Medscape also published more than 8,000 unique informational articles and hosted many discussions with clinicians seeking information on Medscape."

In addition to developing much-needed content around best practices during the COVID-19 pandemic, Medscape also identified new ways of delivering programming to healthcare professionals. “The way we educate evolved during the COVID-19 pandemic as we saw a greater shift to digital, and a move away from live in-person education opportunities, often hosted at clinical congresses,” Mr. Kaufman shared.

“We launched Medscape’s Virtual Symposium and Conference solutions to simulate a live education experience in a virtual space, one that still included interactivity and networking opportunities for clinicians, allowing members to still have access to the latest information in their field, within a new digital format.”

MSAA’s annual Improving Lives Benefit has been one of our signature events throughout the last decade. As we work to redesign and launch this event virtually to the entire MS community, we are honored to highlight Medscape Education and our longstanding partnership.

This vital collaboration allows us to share both our expertise and our access to providers and patients. As a result, we are able to better reach, educate, and improve clinical practice as well as the quality of life for those with MS.

This longstanding relationship and our lack of personal connection during the past year is what has Mr. Kaufman most excited about being honored at MSAA’s first virtual Improving Lives Benefit. “During this unusual year, one thing that has been missing for all of us is the opportunity to connect with our colleagues and peers in the ways that we have in the past. We are looking forward to this event to be able to engage with the MS community, to network and connect with colleagues to honor our shared commitment to improving the lives of patients with MS.”

MSAA echoes Medscape’s sentiment and we look forward to coming together in celebration of the MS community. For more details about MSAA’s Improving Lives Benefit – Together at Home, please visit: support.mymsaa.org/benefit. ■



To learn more about Medscape’s resources for both providers and clients, please visit:

Providers: medscape.org/neurology

Providers: medscape.org/shareddecisionmaking

Patients: education.webmd.com

MSAA's Improving Lives Benefit: Mission Honoree

The Multiple Sclerosis Association of America (MSAA) has a long tradition and core belief in the importance of collaboration to best meet the needs of the MS community. One of our collaborations that has truly taken on a new significance during the COVID-19 pandemic has been with the wonderful MS community in Puerto Rico.

For those living in Puerto Rico, the challenges of COVID-19 have been made more complicated by the natural disasters that they have had to endure. Those living with MS in Puerto Rico are well served by Dr. Ángel Chinaea, the medical director of the San Juan Multiple Sclerosis Center, and Lourdes Fernández Trujillo, the Executive Director of the Puerto Rico Multiple Sclerosis Foundation (FEM). MSAA is proud to recognize Dr. Chinaea, Ms. Fernández Trujillo, and the MS community in Puerto Rico as the 2021 Mission Honoree at our first virtual Improving Lives Benefit on May 13, 2021.

In early 2000, Dr. Chinaea established the first MS center in Puerto Rico and founded FEM to help meet the needs of those living with MS on the island. Dr. Chinaea serves as the Medical Director for FEM, working with Ms. Fernández Trujillo to support the MS community. While MSAA has long partnered

MSAA is proud to recognize Dr. Chinaea, Ms. Fernández Trujillo, and the MS community in Puerto Rico as the 2021 Mission Honoree at our first virtual Improving Lives Benefit on May 13, 2021.

with Dr. Chinaea and Ms. Fernández Trujillo on providing educational programming and resources to those living with MS in Puerto Rico, our collaboration has only deepened over the past year.

The COVID-19 pandemic has heavily impacted people across the United States and in Puerto Rico. In early January 2020, just prior to the COVID-19 outbreak, the citizens of Puerto Rico were rebuilding their lives while recovering from catastrophic earthquakes, leaving many people on parts of the island without power and water. To better support the ongoing efforts of Dr. Chinaea and FEM, and meet the increasing needs of the MS community in Puerto Rico, MSAA streamlined the delivery of cooling vests, providing relief from the often debilitating effects of heat.

In partnership with Ms. Fernández Trujillo and Dr. Chinaea, MSAA was able to serve more than 200 people living with MS through our Cooling Equipment program. FEM, through the

leadership of Ms. Fernández Trujillo, worked to ensure that all who needed cooling vests received them, even going so far as to hand deliver shipments to people who were unable to travel to FEM and pick up the vests themselves.

“It is with immense pleasure that we receive this year’s Mission Honoree recognition. I am truly humbled. It is an honor to accept such a distinguished award that attests to the enormous efforts we have always placed into achieving the wellbeing of our patients, as in our eyes, they will always come

first,” says Ms. Lourdes Fernández Trujillo, Executive Director of the Puerto Rico Multiple Sclerosis Foundation

Our partnership and work with Dr. Chinaea, Ms. Fernández Trujillo, and FEM exemplifies the importance of collaboration in our shared mission of meeting the needs of the MS community. We are proud to honor their dedication and the resiliency of the MS community in Puerto Rico at MSAA’s Improving Lives Benefit this year. ■



Here is what one of our clients in Puerto Rico had to say about MSAA’s Cooling program:

"Hi!! I received the cooling products. I'm thankful for these. They will be used, believe me. The cooling products will make my life easier and tolerate our beautiful weather in Puerto Rico. As an MS patient, I have postponed my beloved chore of gardening because of exposure to heat. I think I'll not only be able to garden but will enjoy the outdoors as I used to. Thanks again!!"

– M.G., Puerto Rico



Living with relapsing multiple sclerosis (MS)?

TAKE A LOOK

at a once-daily pill for relapsing MS

Ask your healthcare professional about ZEPOSIA at your next appointment.

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.[†]

To learn more, visit ZEPOSIA.com/results or scan this QR code.



*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 | • rash |
| • feeling very tired | • headache with fever, neck stiffness, sensitivity to light, nausea, or confusion (symptoms of meningitis, an infection of the lining around your brain and spine) |
| • flu-like symptoms | |
| • cough | |
| • painful and frequent urination (signs of a urinary tract infection) | |

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

IMPORTANT SAFETY INFORMATION (cont'd)

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

- **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 the Important Facts on the next page.

IMPORTANT FACTS

The information below does not take the place of talking with your healthcare professional. Only your healthcare professional knows the specifics of your condition and how ZEPOSIA® (ozanimod) may fit into your overall therapy. Talk to your healthcare professional if you have any questions about ZEPOSIA (pronounced zeh-poe'-see-ah).



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

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 bradycardia) 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 (ozanimod).
- 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

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 of: Days 1-4: 0.23 mg 1 time a day; Days 5-7: 0.46 mg 1 time a day; Days 8 and thereafter: 0.92 mg 1 time a day. **This may reduce the risk of slowing of the heart rate.**

- 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 (ozanimod)?

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 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. 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 by: Celgene Corporation, Summit, NJ 07901
Patent: www.celgene.com/therapies





ANNIVERSARY CHALLENGE

In honor of serving the MS community for more than 50 years, **Team MSAA** is bringing back the **Anniversary Challenge**. Complete your challenge during the month of June by:

- **RUNNING 6 miles**
- **WALKING 8 miles**
- **BIKING 19.70 miles**

Or take on **ALL THREE** options for the **Triple Challenge!**



Run Walk Bike
06-08-19.70

Register now and get started on your challenge at support.mymsaa.org/anniversary2021

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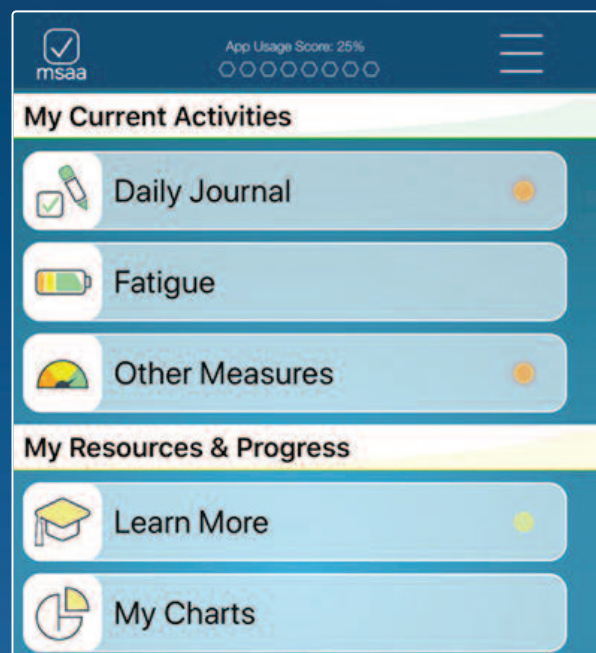
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