



Summer/Fall 2021

# THE Motivator

Published by the Multiple Sclerosis Association of America

**PLANNING FOR  
FUTURE CARE**






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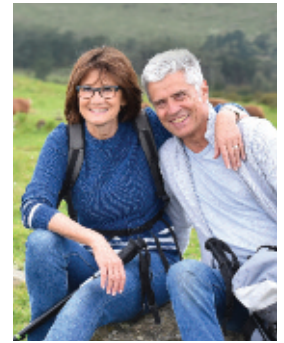


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Multiple Sclerosis  
Association of America

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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# Strengthening Our Foundational Initiatives

**By Gina Ross Murdoch**

MSAA President and CEO

At the conclusion of each fiscal year, we reflect on the past 12 months in terms of MSAA's positive impact on the MS community, ways in which we made a difference, and how we can improve on these achievements in the upcoming year. Looking back at our last fiscal year, covering July 1, 2020 through June 30, 2021, we were still deep in the pandemic at the start of the year – without a real sense of when vaccines were going to become available – and our view of the future was unclear. We continued to face a myriad of challenges, but saw signs that some light was starting to shine through.

Despite the positive steps that have taken place, we acknowledge that our world still struggles with health inequities, social injustice, economic hardships, and profound loss. The MS community has been, and continues to be, impacted by these difficult forces. However, we have not lost hope for an

end to the pandemic and look for resolutions to the many issues the MS community faces.

As we have done since the beginning of the pandemic, MSAA continued our dual efforts of focusing on our core programs and evolving into new ways of living our mission. Over the years, MSAA has built a strong foundation of partnerships throughout the MS community. In these challenging times, that foundation served as a launchpad to new collaborations and increased support for mental health and wellness awareness programs, MRI funding assistance, and outreach to underserved MS communities, just to name a few areas. We are proud that MSAA has not reduced or eliminated any of the vital and free programs the MS community depends on each and every day.

This fiscal year saw such innovations as our first virtual “Together at Home” Improving Lives Benefit, the launch of the COVID-19 and MS Pathfinder digital tool as well as a series of webinars on COVID-19 and MS, the initiation of our “Improving

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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.

Lives Through Art” series, and the conclusion of our 50th Anniversary social media campaign. In addition, we had staff representation on critical advisory boards focused on health equities, an MS Awareness Month dedicated to Improving Mental Health and Wellness, as well as an Instagram “takeover” by actress and MS community member Selma Blair.

This strengthening of foundational initiatives and the expansion of new collaborations formed the basis of our updated strategic plan covering 2021, 2022, and into 2023. The plan encompasses findings from our 2018 Needs Assessment, plus feedback from people living with MS, care partners, healthcare providers, staff, MS experts, and MSAA’s Board of Directors. All voices were critical in creating this plan and continue to be vital as we seek to respond to the drastic changes seen in 2020 and 2021

with a transformative plan for the future. You can visit our website at [mymsaa.org/strategic](https://mymsaa.org/strategic) to see the updated plan and quarterly progress reports. I encourage you to contact me at [president@mymsaa.org](mailto:president@mymsaa.org) with thoughts on this plan, how MSAA can continue Improving Lives Today, and ways in which you may want to get involved in our mission.

As we end this fiscal year and look forward to the next, there is much to be proud of, but also, much still to be done. We need to create new connections as well as build upon current partnerships. We must stay flexible in our approach and firm in our commitment to our mission of Improving Lives Today.

Together, we are charting the next chapter of support, information, innovation, care, and education for all impacted by multiple sclerosis. Thank you to all who have been part of our past, and welcome to all who will join us for our future. ■

## Latest Edition of MSAA’s MS Relapse Toolkit

MSAA recently published a second edition of the *MS Relapse Toolkit*, which provides helpful information including **common symptoms of a relapse, treatment options, and ways to plan in advance for a relapse.**

To read or order a copy of the **English version** of the *MS Relapse Toolkit*, please visit: [mymsaa.org/ms-relapse-toolkit](https://mymsaa.org/ms-relapse-toolkit)

Para leer u ordenar una copia de la **versión en español** del *Kit de instrumentos para las recaídas de la esclerosis múltiple (EM)*, visite: [mymsaa.org/ms-relapse-toolkit-espanol/](https://mymsaa.org/ms-relapse-toolkit-espanol/)

*Funding for these publications was made possible by Mallinckrodt Pharmaceuticals.*

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# PLANNING FOR FUTURE CARE

Options for future care and how to plan ahead financially

BY TOM GARRY

Edited by Susan Wells Courtney,  
MSAA Senior Writer

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

## Introduction

“I don’t want to become a burden to my family” is a frequent concern voiced by people with multiple sclerosis (MS). In addition to worries about current symptoms and the physical toll that the condition may take in the years ahead, individuals with MS can anguish over the prospect of exhausting not only the emotional reserves of their loved ones, but financial resources as well.

The concern is real, but the outcome is far from inevitable. In this article, experts outline six steps that people with MS and their families can take to establish a solid financial

foundation. However, before addressing these six steps, to follow is a brief overview of long-term care options that provide the appropriate care needed as all individuals age and may become less able to care for themselves.

## Types of Long-Term Care

As people with MS contemplate what their abilities and living situation might be in the years ahead, individuals with a chronic condition as well as those without, may have considered the possibility of needing in-home care or a nursing home at some point in their future. While engaging in financial

planning with that costly scenario in mind probably is a prudent approach, remember that the great majority of people with MS do not enter a nursing home. Rather, they have a number of options they can draw upon to meet their specific needs, should such changes be necessary. Keep in mind not everyone with MS will need any of these levels of enhanced care. These options include:

- Hiring a part-time home-health aide to come to the home to assist with dressing, eating, toileting, and other activities of daily living
- Having a full-time home-health aide – either one who works in the home for a fixed shift each day or who actually lives in the home – assist with activities of daily living
- Scheduling visiting nurses and physical therapists to come to the home to provide services; people in need of skilled nursing or physical therapy services may also qualify for at-home occupational or speech therapy
- Receiving care from a rehabilitation facility or skilled nursing facility on a short-term basis, such as while recovering from a fall, relapse, or other acute medical situation
- Moving to an assisted living facility (ALF) on an ongoing basis; these types of facilities typically require that residents have a certain degree of independence and mobility, with thresholds varying from one facility to another; in the ALF setting, there generally is a basic degree of nursing care, such as medication management

- Entering a skilled nursing facility, commonly referred to as a nursing home, on an ongoing basis

The costs of these different levels of care obviously vary greatly, as do their eligibility for coverage under private insurance and government programs. For details on costs and sample figures, please refer to “By the Numbers: The Importance of Planning Today for Tomorrow’s Needs,” found on page 12.



Disability income-replacement insurance is meant to replace a portion of a person’s lost earnings, and so does not pay for these services, per se, although a person can use money provided by disability insurance to pay for a home-health aide or other care. Long-term care (LTC) insurance, by contrast, is designed to pay specifically for the services of an aide or for a nursing home stay, but as noted later, only about eight million Americans – or just under 4% of the nation’s estimated 209 million adults – have private

LTC insurance. As a result, many people rely on their own savings and investments, and on government programs such as Social Security Disability Insurance, Medicare, and Medicaid to fund needed care. Bear in mind, however, that each government program has specific eligibility requirements and coverage provisions, as outlined in Step #4, beginning on page 15.

## The Six Steps to Planning for Long-Term Care

Thinking about the care that may be required in the years ahead, and how to fund it, can be a daunting proposition, but experts say that a proactive approach can go far toward easing current anxieties and avoiding future problems. To follow is a six-step approach to preparing for what tomorrow may hold.

### ***Step #1: Act today in anticipation of tomorrow's needs***

Martin M. Shenkman, CPA, MBA, PFS, AEP, JD, knows from personal experience how difficult it can be to focus on long-term financial matters when a diagnosis of MS has just up-ended a family's world. But he also knows from professional experience how important it is to do just that.

"In the days and weeks after you learn that you or a loved one has MS, you're processing that news, trying to learn all you can about the condition, making decisions about treatment, and dealing with a range of emotions and issues," says Shenkman, whose wife, Patti, was diagnosed with MS in 2006. While acknowledging those challenges, Shenkman knows from his work as an attorney whose practice is devoted to estate planning that it is critical for people with chronic conditions to devote time and thought in the near term to planning for the long term.

"The sooner you start, the better, even though it's hard," says the attorney, who practices in New York City. Shenkman adds that while focusing on financial planning is critical for everyone, the need is significantly heightened for people with MS because they may face the potential for both reduced lifetime earnings due to a shortened or otherwise limited work span and a greater need for medical and related care.

"One of the first steps people should take is to evaluate their spending. The day before receiving a diagnosis of MS, you may have had certain aspirations about what you would





be earning in the future and about the lifestyle those earnings would support. Learning that you have MS is cause to reexamine all of that, and to make adjustments now – not at some point down the road. Cutting back on expenditures can help fund savings and investments. You don't have to go crazy and immediately make drastic reductions, but you also can't pretend that nothing has changed," says Shenkman, adding that people should also consider questions such as whether converting term insurance to permanent coverage, refinancing their mortgage, paying off credit cards, or evaluating their investments, may make sense.

The attorney notes that a diagnosis of MS is also reason to ensure that basic documents that all people should have – including a will, a power of attorney form, and a healthcare proxy document – are in place and up-to-date. In addition, people need to consider whether they should establish a trust. For details, please see "A Matter of Trusts: Exploring approaches to setting aside money for future use," found on page 26.

While taking a clear look at the range of future scenarios is essential, the attorney adds that people should not make rash decisions out of fear. "For example, I have seen people cancel life insurance policies to save on paying the premiums, when those policies could have been sold in the secondary market," he said,

referencing the market in which previously issued policies are bought and sold. Shenkman adds that in other cases, younger adults newly diagnosed with MS have switched their investment strategies to extremely conservative approaches that may give them a sense of security in the near-term, but may not serve them well over the long-run.

Shenkman says the key is to navigate between avoidance and denial on the one hand, and over-reaction and ill-advised moves on the other. And that, adds the CPA and attorney, is why the next step is critical.

**Step #2: Assemble a team of trusted advisors**

People with MS need to draw upon the expertise of at least four different professionals in planning to finance their future care needs, says Shenkman. "You want an accountant, a financial planner, an attorney who specializes in estate planning, and a social worker," he explains. But



recognizing that not everyone can afford all these professionals, you still need to obtain the guidance that each of these disciplines can provide.

The attorney adds that it is essential to identify and start working with those professionals now, not when an urgent need arises. “You want time to find the people who are right for you, to develop a level of comfort and rapport with them, and to enable them to become familiar with you and your specific circumstances.”

Shenkman notes that while it’s obviously preferable to connect with legal and financial professionals who have experience with multiple sclerosis, or chronic illnesses generally, that should not be the top consideration. “First and foremost, you want to make sure that they are really good at what they do. You need them to be the experts in taxes, investments, or setting up a trust. *You*, with the guidance of your healthcare professionals, are the expert on your MS and your overall situation. Just as they will educate and guide you in their areas of

expertise, you need to educate and guide them about how MS affects you, and about your hopes, concerns, plans, and preferences.”

Meanwhile, says Shenkman, a social worker can help identify issues to discuss with the financial and legal members of the team. He or she can be an invaluable resource in addressing workplace issues, navigating the healthcare and health-insurance systems, and understanding and dealing with the eligibility documentation requirements for government programs, and designing a care program if needed.

### ***Step #3: Understand your current benefits***

“People newly diagnosed with multiple sclerosis often don’t realize that the insurance coverage they have may not cover all aspects of their care, or the full cost of those services that are covered,” notes Angel Blair, MA, Manager of Mission Delivery – Client Services for the Multiple Sclerosis Association of America (MSAA). “Becoming educated on what your various insurance

plans cover – including health, disability, and others – is an important initial step following a diagnosis of MS,” Blair says in relaying advice that she regularly shares with people who call the MSAA Helpline at **(800) 532-7667, extension 154**.

Shenkman wholeheartedly agrees. “People tend to focus on their health insurance coverage



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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.

<sup>†</sup>Depending on your weight.

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

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

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

#### MAVENCLAD can cause serious side effects, including:

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

### What is MAVENCLAD?

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

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

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

**Do not** take MAVENCLAD if you:

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

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

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

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

### How should I take MAVENCLAD?

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

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

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

### What are the possible side effects of MAVENCLAD?

#### MAVENCLAD can cause serious side effects, including:

- o See **"What is the most important information I should know about MAVENCLAD?"**
- o **low blood cell counts.** Low blood cell counts have happened and can increase your risk of infections during your treatment with MAVENCLAD. Your healthcare provider will do blood tests before you start treatment with MAVENCLAD, during your treatment with MAVENCLAD, and afterward, as needed.
- o **serious infections such as:**
  - **TB, hepatitis B or C, and shingles (herpes zoster).** Fatal cases of TB and hepatitis have happened with cladribine during clinical studies. Tell your healthcare provider right away if you get any symptoms of the following infection related problems or if any of the symptoms get worse, including:
    - fever
    - aching painful muscles
    - headache
    - feeling of being generally unwell
    - loss of appetite
    - burning, tingling, numbness or itchiness of the skin in the affected area
    - skin blotches, blistered rash and severe pain
  - **progressive multifocal leukoencephalopathy (PML).** PML is a rare brain infection that usually leads to death or severe disability. Although PML has not been seen in MS patients taking MAVENCLAD, it may happen in people with weakened immune systems. Symptoms of PML get worse over days to weeks. Call your healthcare provider right away if you have any new or worsening neurologic signs or symptoms of PML, that have lasted several days, including:
    - weakness on 1 side of your body
    - loss of coordination in your arms and legs

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

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

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

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

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

#### The most common side effects of MAVENCLAD include:

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

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

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# Planning Today For Tomorrow's Needs

A few statistics highlight the importance of taking a prudent approach to anticipating how MS may affect long-term earnings and expenses:

**62**  
percent

of working-age people with MS reported that multiple sclerosis had affected their employment. [Marck]

**\$4,385**

average monthly cost of a home health aide in 2019. [Genworth]

**5 to 14**  
percent

of people with MS eventually will need nursing home care. [Finalyson 2019; Marrie 2014]

**64**  
percent

of people with MS reported they do not have long-term disability insurance. [Planchon]

**66**  
percent

of people filing for bankruptcy cited medical costs as a direct or indirect reason for their financial problems. [Himmelstein]

**\$7,513**

average monthly cost of a semi-private room in a nursing home in 2019. [Genworth]

**90**  
percent

of people with MS reported having no long-term care insurance, which helps pay for in-home, community-based, and nursing home care. [Planchon]

**19.7**  
percent

of working-age people with MS reported they had retired due to disability. [Marck]

# Going the distance to educate people with MS on financial planning

Martin Shenkman, CPA, MBA, PFS, AEP, JD, and his wife, Patti Klein, MD, log not only hundreds of hours but also thousands of miles in educating people with MS and other chronic conditions about the importance of making wise financial decisions.

When Dr. Klein, an anesthesiologist, was diagnosed with MS in 2006, her husband was shocked to learn how little financial information was tailored specifically to the needs of people with multiple sclerosis or, for that matter, other chronic illnesses. An attorney specializing in estate planning who also is licensed as a certified public accountant, Shenkman set out to fill that void.

One approach was writing. Drawing on his professional expertise, Shenkman has written several books and numerous articles on the subject, including *Estate Planning for People with a Chronic Condition or Disability*, Demos Health, 2009.

The other route – literally – that he and his wife decided to pursue was to travel

across the country, speaking about financial planning as volunteers. When Dr. Klein's condition made air travel too difficult, the couple purchased a recreational vehicle and started driving cross-country for a total of up to two months each year, conducting free workshops on financial planning for people with disabilities and their families, as well as educating professional advisers on helping clients living with chronic illness.

“Just as a diagnosis of MS or a similar condition requires a person to make informed decisions about treatment, there's a pressing need to understand – and address – the financial implications involved. By providing this education, and delivering it from the perspective of people who understand what it's like to deal with MS, we hope to provide people with the information and motivation needed to be well prepared for whatever the future may hold,” Shenkman says.

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*continued from page 8*

following a diagnosis of MS, because they want to understand to what extent tests, treatments, and visits to various healthcare professionals are covered. All of that is very important. In addition, you also need to have someone with expertise examine the specifics of your life insurance policy and any employer-based or private disability coverage you may have,” says the attorney. Shenkman notes, for example, that some term life insurance policies have provisions that allow for their conversion to whole life insurance, which may be advantageous after an MS diagnosis.

In other cases, life insurance policies have provisions that allow for people with a terminal illness or a permanently disabling condition to receive some portion of the policy’s value on a tax-free basis while still alive.<sup>1</sup> This early payment obviously reduces the amount that the policy’s beneficiaries will receive after the insured person’s death, and sometimes is capped at a certain percentage of the death benefit. Further, these provisions – often called accelerated death benefits – more often apply to people with a terminal illness rather than to those with a chronic illness with a modest or minimal impact on life expectancy, such as MS.

Other life insurance policies are hybrid products that also encompass paying for long-term care. As the government’s Administration on Aging explains, “The idea is that policy benefits will always be paid, in one form or another [either after or before

death]. These products are relatively new and the features are changing as the product evolves. The amount of the long-term care benefit is often expressed in terms of a percentage of the life insurance benefit.”<sup>1</sup>

Please note that early-payment provisions are not included in all life insurance policies, and combination life and long-term care insurance policies are relatively new and not common. Life insurance policies should be thoroughly reviewed for these and other provisions and features.

Turning to disability insurance, Shenkman notes that people need to understand how an insurer defines “total disability” vs. “partial disability,” and what notifications and documentation are required – and in what timeframe – to demonstrate disability. You don’t want to violate a requirement of the policy and risk jeopardizing your coverage. Another consideration, the attorney adds, is whether the disability insurance will pay out if a person can no longer work in his or her own occupation or whether it has a more-stringent requirement that the person not be able to work in any occupation.

“These policies can be quite complex, and you want someone who is familiar with their provisions to examine them closely before you take any action,” says Shenkman. Additionally, homeowners should review their mortgage paperwork to see whether they purchased, and may have forgotten, insurance that provides for their home payments to be made should they become disabled. Experts add that it is important for people to realize that long-term disability



***Beyond insurance policies and other financial products and plans already in place, people with MS should become familiar with funding and care sources they may need to draw upon in the future.***



policies are not designed to match the full amount of money a person had been earning, and often provide only 40% to 60% of a person's prior income.

One of the best forms of insurance for meeting future needs related to MS is long-term care (LTC) insurance, which typically covers personal care in the home, the community setting, and nursing homes. However, only about 8.1 million Americans have purchased LTC coverage.<sup>2</sup> A recent survey of 2,507 people with MS conducted by researchers at the Cleveland Clinic's Mellen Center for Multiple Sclerosis Treatment and Research in Cleveland, Ohio, found that just 9.7% of respondents had long-term care insurance.<sup>3</sup> If you are among that minority of people who had the foresight to purchase LTC insurance, Shenkman explains that it is particularly important to review the terms of that policy.

Selena Fisher, MA, Manager of Mission Delivery – MRI for MSAA, notes that people should also explore the benefits offered at the

state level and by their county Disabilities Services Office or similar agency.

#### ***Step #4: Understand your future options for financing care***

Beyond insurance policies and other financial products and plans already in place, people with MS should become familiar with funding and care sources they may need to draw upon in the future. These include government programs such as:

- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- Medicare
- Medicaid
- Veterans Benefits

The **Social Security Disability Insurance (SSDI)** program provides monthly payments to people who are disabled and who have a “qualifying work history” of their own or of a spouse or parent, meaning that work-related taxes were paid into Social Security. SSDI is available only to people who are deemed

totally disabled; people with partial or short-term disabilities are not eligible. The Social Security Administration applies a strict definition when assessing disability. Three key provisions include:

- The person cannot do work that he or she did previously
- The person cannot adjust to other work because of his or her medical condition, and
- The disability has lasted or is expected to last for at least one year or to result in death.<sup>4</sup>

The monthly amount paid is based on earnings over a person's career. For 2021, the average amount for all qualifying people with disabilities is \$1,277, with that average rising to \$2,224 for a qualifying worker with a disability who has a spouse and one or more dependent children.<sup>4,5</sup> With a few exceptions, people who qualify for SSDI payments must wait five months after approval to start receiving payments.

### **Supplemental Security Income (SSI):**

This program is also operated by the Social Security Administration. Unlike SSDI, however, eligibility is not based on a person's work history. Rather, the program provides basic financial assistance to people with disabilities and older people with limited or no income and assets. The financial requirements are quite stringent, with individuals required to have savings and/or other assets of \$2,000 or less, and married couples living together having resources, savings, and/or other assets of \$3,000 or less. Homes that people live in are not counted toward the valuation of their assets. The value of their cars typically is excluded as well. The monthly payment to individuals is \$783, while that for couples is \$1,175. Most states provide an additional stipend to SSI beneficiaries and automatically qualify these people for Medicaid.<sup>5,6</sup> **Medicare** pays for healthcare for people aged 65 years and older, and for people younger than 65 who are receiving Social Security Disability benefits.<sup>1</sup>

**Medicare** primarily covers doctor visits, medications, and hospital stays, and does not pay for most long-term care or personal care. There are some exceptions, however. If a person has had an inpatient hospital admission of at least three days and then is admitted to a Medicare-certified nursing facility within 30 days of that hospital stay



and needs skilled care, Medicare will pay a portion of the costs for up to 100 days of each benefit period. For the first 20 days, Medicare pays the full cost of care, while patients are responsible for a co-pay for days 21 to 100, at which point Medicare stops covering long-term care. Medicare Advantage plans follow the same approach, but the co-pay costs to patients may vary from those of the traditional Medicare program.<sup>1</sup>

Medicare will also pay for part-time or intermittent skilled nursing care when a physician deems it medically necessary, as well as physical therapy, occupational therapy, and speech therapy provided by a Medicare-certified home health agency. Additionally, Medicare will cover 80% of the cost of durable medical equipment, such as wheelchairs or walkers, with the Medicare beneficiary being responsible for the other 20%.<sup>1</sup>

**Medicaid** is a joint federal-state program, so it is important to keep in mind that eligibility requirements and covered services vary considerably from state to state.

Medicaid differs from Medicare in important ways. On the plus side, Medicaid will cover ongoing long-term care services, whether delivered at home, in the community, or in a nursing home. On the negative side, eligibility is based on financial and other requirements, meaning that if you earn or have too much money, you will not be eligible. As a result, many nursing home residents have to first exhaust their personal funds to become eligible for the Medicaid program.

Further, when Medicaid covers long-term care services, federal law mandates that states attempt to recover the amount Medicaid spent on a person's behalf from his or her estate following the person's death. This requirement can involve assets such as the person's home and property, although estates are exempt from this recovery while a Medicaid recipient's spouse is still alive.<sup>1</sup> Given the complexity of getting into the Medicaid program, and of trying to keep any assets out of Medicaid recovery after death, obtaining guidance from an elder law attorney or other professional well-versed in how the program works can be very advantageous both for people with MS and their families.

**Veterans' benefits.** People who served in the military may qualify for a range of nursing home, assisted living, and home healthcare services provided by the United States Department of Veterans Affairs. Information on these services is available at <https://www.va.gov/health-care/about-va-health-benefits/long-term-care/>.

In addition to government programs, many people with MS draw on their assets to fund care in their own home, an assisted living facility, or a nursing home. Beyond savings and investments, those assets can include the value of their home or life insurance policy.

For example, a reverse mortgage is a type of home equity loan that provides people with either a lump-sum payment or a line of credit they can draw upon as needed. In either case, the money can be spent for any purpose the person chooses, including

paying for long-term care. You continue to live in your home and retain the title to the home, and do not have to repay the loan so long as you live in the home. Further, so long as you spend the money in the month it is received, the money is not taxable, does not affect Social Security or Medicare benefits, and is not taken into consideration when determining eligibility for Medicaid.<sup>1</sup>

For all of those attractive features of a reverse mortgage, several other factors must be considered. First, the home must be your primary residence, and you must continue to live in it and to pay all property taxes and maintenance costs. Any existing mortgages or other debt tied to the home must be paid before the money can be used for other purposes, and the company providing the reverse mortgage can also stipulate that money be spent to make specific repairs that affect the value of the home. People generally have to be age 62 or older to qualify for a reverse mortgage, and meet with a counselor to examine whether a reverse mortgage makes sense for them. Payment of the amount borrowed and interest accrued is due when the last borrower, which typically is the remaining spouse, sells or moves out of the house, or dies. If heirs want to retain ownership of the home, they can repay the reverse mortgage. Alternatively, they can sell the house and keep the difference if the sale price is higher than the amount due on the mortgage.<sup>1</sup> The complexity and potential pitfalls of reverse mortgages argue for close consultation with an attorney.

Beyond hybrid life/long-term care policies

and accelerated death benefits, there are other ways life insurance policies can provide a source of income to pay for long-term care needs. One such approach is known as a viatical settlement. In this arrangement, a company buys the life insurance policy for a percentage of its value. The seller designates the company as the policy's beneficiary, and in return gets cash. The company continues making payments on the policy, so that it receives the full value of the policy when the person dies. In most cases, a person must be terminally ill, with a life expectancy of two years or less, to enter into a viatical settlement. However, some states allow people who are chronically ill to sell their life insurance policy in this manner. The payment is tax-free, but in the case of a chronically ill person expected to live for at least two years, may represent only 50% of the policy's total value.<sup>1</sup> Again, consultation with an attorney is imperative.

Experts say that while a diagnosis of multiple sclerosis essentially precludes people from obtaining long-term care insurance, it does not necessarily prevent them from obtaining life insurance and even, in some cases, long-term disability insurance, although MS-related disability may be excluded from the scope of the policy's coverage. Similarly, with life insurance, the amount of coverage available may be limited, and companies may choose to defer issuing policies to recently diagnosed people, preferring to see how their disease course unfolds over subsequent months or even years. Whether with life or disability



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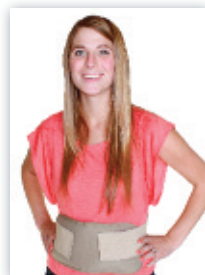
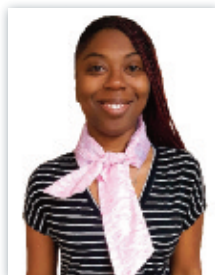
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insurance, however, people with MS should expect to pay higher-than-average premiums that reflect the risk associated with their condition. For a fuller discussion of obtaining life insurance following a diagnosis of MS, please see the article “Life Insurance with Multiple Sclerosis” by Jeff Rose, CFP® at <https://www.goodfinancialcents.com/life-insurance-multiple-sclerosis>.

Other options for funding care include retirement savings and annuities. In most cases, if an individual withdraws money from a 401(k) retirement plan or Individual Retirement Account (IRA) before reaching age 59½, he or she must pay a 10% early withdrawal tax, in addition to any other taxes. This 10% tax is waived for people documented to have a total and permanent disability.<sup>7</sup> However, people contemplating such early withdrawals should consider the long-term impact of dipping into their retirement savings sooner than expected, and discuss the ideas with a financial

planner or other professional.

Meanwhile, annuities are contracts between a person and an insurance company. The person pays the insurance company “up front,” in a single large payment or a series of payments, in return for the insurance company providing subsequent periodic payments. There are several forms of annuities, including a deferred long-term care annuity that generally is available to people up to age 85.<sup>1</sup> As with reverse mortgages and other financial instruments, the calculations and considerations entailed in determining whether an annuity makes sense for you can be quite involved, and merit discussion with a financial planner, estate planning attorney, or other professional.

### ***Step #5: Optimize your work situation***

People with MS may believe that their financial interests are always best served by working as long as possible, even if that means switching from full-time to part-time

employment, to keep a paycheck coming in. It’s a natural assumption, but one that can have unintended negative consequences, says Deborah Miller, PhD, a social worker at the Cleveland Clinic’s Mellen Center for Multiple Sclerosis Treatment and Research.

“All too often, I see people with MS who have continued working well beyond the point when they really should have



stopped given their degree of disability,” says Dr. Miller. Besides the negative impact on their health, this approach can be detrimental in two ways, she explains.

“If people have taken a lower-paying job because it entails work they can do more easily than their former, better-paying job, or if they switch from full-time to part-time work, they may be adversely affecting the amount of their Social Security Disability Income payment because the government considers their earnings history in determining the benefit amount,” she explains.

Similarly, people who are experiencing MS-related difficulties doing their work, but who are reluctant to seek reasonable workplace accommodations under the Americans with Disabilities Act (ADA), are taking a considerable risk, Dr. Miller noted. “I can’t count the number of people who worked until they were fired because of performance issues, and then they got nothing. Had they disclosed the challenges they were facing, they could have had accommodations made, or perhaps gone out on short-term disability through their employer’s plan.”

Dr. Miller cites the case of a data analyst who doesn’t want her employer to know about the cognitive issues being caused by her MS. However, the employer has noted repeated problems with her “number crunching” and has put a corrective action plan in place – a step that could result in her being fired in the absence of improved performance. “So now she’s staying two-to-three hours after regular working hours every

night to check and re-check her numbers, and is exhausting herself, which is not good for her health or, ultimately, her job performance,” Dr. Miller notes.

“I understand the reluctance to raise these issues with an employer, and the determination to keep working is admirable, but it is really important to step back and focus on the long-term impact of these decisions,” says Dr. Miller.

Dr. Miller adds that while some people with MS are hesitant to invoke the provisions of the ADA, others have an exaggerated view of the protections the law provides.

As detailed in MSAA’s publication, *Employment and MS: The Challenges and Opportunities*, (available online at [mymsaa.org/employment-and-ms](http://mymsaa.org/employment-and-ms)) the 1990 law does not mandate that an employer keep an employee with a disability in his or her job no matter what. Rather, it requires that companies with 15 or more employees make “reasonable accommodations” to enable an employee to perform his or her duties. At the same time, the employer does not have to make changes that would represent an “undue hardship” for the company.

The law specifies that it is the employee’s responsibility to seek an accommodation, rather than the company’s obligation to proactively offer to make adjustments. And this, says Dr. Miller, can be a stumbling block for many people with MS. “Often, people won’t want to disclose to their employer that they have multiple sclerosis, whether out of a

*continued on page 27*

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**I'M AT MY BEST WHEN MY  
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#### What is MAYZENT® (siponimod) tablets?

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

#### IMPORTANT SAFETY INFORMATION

##### Do not take MAYZENT if you:

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

##### MAYZENT may cause serious side effects, including:

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

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

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

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

weeks after your last dose of MAYZENT:

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

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

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

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

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





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

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- had or now have a type of skin cancer called basal cell carcinoma (BCC), melanoma, or squamous cell carcinoma
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your health care provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
  - If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your health care provider about the best way to feed your baby if you take MAYZENT.

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

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

**MAYZENT may cause possible side effects, including:**

- **increased blood pressure.** Your health care provider should check your blood pressure during treatment with MAYZENT.
- **liver problems.** MAYZENT may cause liver problems. Your health care provider should do blood tests to check your liver before you start taking MAYZENT. Call your health care provider right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - tiredness
  - loss of appetite
  - your skin or the whites of your eyes turn yellow
  - dark urine

- **breathing problems.** Some people who take MAYZENT have shortness of breath. Call your health care provider right away if you have new or worsening breathing problems.
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your health care provider right away if you have any of the following symptoms: sudden severe headache, sudden confusion, sudden loss of vision or other changes in vision, or seizure.
- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your health care provider if you have worsening symptoms of MS after stopping MAYZENT.
- **a type of skin cancer called basal cell carcinoma (BCC), melanoma, and squamous cell carcinoma.** Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, a new darkened area on your skin, a sore that does not heal, or growths on your skin, such as a bump that may be shiny, pearly white, skin-colored, or pink. Your doctor should check your skin for any changes during treatment with MAYZENT. Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear protective clothing and use a sunscreen with a high sun protection factor.

**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](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

**Please see Consumer Brief Summary on following pages.**

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## CONSUMER BRIEF SUMMARY

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

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

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

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

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

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

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- fever
- vomiting
- tiredness
- headache with fever, neck stiffness,
- body aches
- sensitivity to light, nausea, confusion (these
- chills
- may be symptoms of meningitis, an infection
- nausea
- 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.

### What is MAYZENT?

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

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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
- had or now have a type of skin cancer called basal cell carcinoma (BCC), melanoma, or squamous cell carcinoma
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your healthcare provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
  - If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take MAYZENT.

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

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

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

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

#### How should I take MAYZENT® (siponimod) tablets?

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

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

- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping MAYZENT.
- **a type of skin cancer called basal cell carcinoma (BCC), melanoma, and squamous cell carcinoma.** Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, a new darkened area on your skin, a sore that does not heal, or growths on your skin, such as a bump that may be shiny, pearly white, skin-colored, or pink. Your doctor should check your skin for any changes during treatment with MAYZENT. Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear protective clothing and use a sunscreen with a high sun protection factor.

#### 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](http://www.novartis.us) or call 1-888-669-6682.

# A MATTER OF TRUSTS

## Exploring approaches to setting aside money for future use

Trusts are legal arrangements that, in simplest terms, allow a person (known as the trustee) to hold and expend funds on behalf of another person, the beneficiary. You can be your own initial trustee and name a successor to take over if you can no longer serve. For some living with MS, naming a co-trustee to help you with the tasks, from inception, may be a better option. People considering establishing a trust need to consult an attorney with expertise in estate planning. Trusts that might be appropriate for a person with MS include:

### **Revocable living trust**

*This document directs where and how a person's assets will be transferred while he or she is living, and also prevents those assets from being subject to probate proceedings in court following the person's death.*

### **Special needs trust (including Medicaid disability trusts)**

*These trusts can be established to pay for items that a person with a disability may need but that aren't covered by government programs such as Medicaid. A special needs trust can either be funded by the beneficiary himself (a first-person trust) from sources other than income, such as a settlement or inheritance, or funded by a family member or other person (a third-party trust).*

*One of the main advantages of a special needs trust is that the assets in the trust are not taken into account when determining a person's financial eligibility for Medicaid or Supplemental Security Income, so long as the trust is properly established and operated. It is important to note, however, that if a person established a first-person trust, Medicaid will seek to recover any assets remaining in the trust at the time of his or her death. Medicaid does not seek to recover funds from third-party trusts.*

*If a person is receiving Supplemental Security Income, special needs trusts generally cannot pay for basic items, such as groceries or rent. The laws governing special needs trusts are complicated, and vary considerably from one state to another. Further, there are important tax implications with this form of trust and other trusts, all making an attorney's guidance essential.*

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In addition to trusts, people with disabilities may also want to explore setting up an ABL (Achieve a Better Life Experience Act) bank account. People can save up to \$100,000 in these accounts without those deposits affecting their eligibility for Medicaid or SSI.

*continued from page 21*

desire to preserve their privacy or for fear that they will be stigmatized. However, they needn't disclose the diagnosis of MS itself. Rather, they can just talk about the particular issue that is making it difficult for them to do their job. So if a woman with MS is having visual issues, she can disclose that problem and ask for a larger computer monitor without explaining that the visual issue is caused by MS. The physician note supporting that request need document only the visual problems, not the underlying diagnosis."

### **Step #6: Optimize your health**

A growing body of evidence suggests that as people with MS seek to secure their financial future, the best investment they can make may be in their own health.

For example, a study that followed more than 1,200 working-age people with MS for two-and-a-half years found that a higher level of disability at baseline predicted loss of employment at follow-up.<sup>8</sup> This finding reinforces the common-sense idea that the less disability a person with MS experiences, the greater ability he or she has to remain in the workforce and continue earning a paycheck. While people do not have the power to fully dictate the course of their MS,

## Track MS symptoms in real-time with **My MS Manager™**

***A convenient and effective tool to help manage multiple sclerosis through a mobile device.***

- *User-friendly navigation, making it easy to effectively manage the ever-changing course of one's MS.*
- *Expanded treatments section allowing users to track and store more medication information with ease.*
- *Measure how fatigue, cognition, bladder control, and depression affect quality of life.*
- *Care Team feature helps users connect with their physician to share progress and reports securely.*

### **Download My MS Manager™ today**

and join the thousands of people already using the app to help stay on top of their MS symptoms.

powered by:



steps such as taking their medications regularly and adopting a healthy lifestyle can have a major impact.

Meanwhile, a Canadian study compared 226 people with MS who were admitted to a nursing home from 2005 to 2013 with almost 900 other people with MS not admitted to nursing homes during that period. The researchers found that the people who entered nursing homes had more comorbidities – conditions in addition

to MS, such as diabetes, heart disease, chronic lung disease, and depression – than their counterparts, while the people who continued to live in the community had more office visits to their clinicians. The investigators noted, “These visits may provide greater opportunities for regular health monitoring and preventive care, thereby reducing the risk of [nursing home] entry.”

Taken as a whole, these and other studies suggest that when people take steps to control their MS, its symptoms, and comorbid conditions such as diabetes and high blood pressure, that proactivity is likely to yield long-term benefits in terms of their financial as well as their physical health.

### **In Summary**

People living with MS have never had greater cause for optimism. Medical therapies and other interventions are improving outcomes and enhancing quality of life, and still more advances are on the near horizon.

At the same time, people with MS always need to look realistically at what issues may arise in the future. As people age, the passage of time reduces capabilities for everyone – it’s just the natural progression of the body after reaching one’s prime. However, the nature of MS means that those living with the condition need to be prepared for the possibility of an earlier and potentially greater degree of disability than the average person. Should this occur, individuals may benefit by planning in advance for an increased need for care.



***Taking steps to control one’s MS, its symptoms, and conditions such as diabetes and high blood pressure is likely to yield long-term benefits in both physical and financial health.***

Just as a proactive approach to medical care and a healthy lifestyle can enhance long-term health, addressing financial planning today – rather than waiting until critical decisions loom – can provide a solid foundation for meeting future needs. ■

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Administration on Aging. U.S. Department of Health and Human Services. Using life insurance to pay for long-term care. Available at <https://acl.gov/ltc/costs-and-who-pays/who-pays-long-term-care/using-life-insurance-to-pay-for-long-term-care> Accessed August 31, 2021.

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# HELPFUL RESOURCES

A sampling of organizations, websites, and other resources offering valuable information on planning and paying for potential future care needs

## ORGANIZATIONS AND AGENCIES

**Multiple Sclerosis Association of America (MSAA):** MSAA's toll-free Helpline can provide people with MS and their family members with a variety of resources and guidance. The Helpline can be reached at **(800) 532-7667, extension 154**. Helpline hours are Monday through Thursday, 8:30 am to 8:00 pm, EST, and Friday, 8:30 am to 5:00 pm, EST. Additionally, people can email MSAA at **MSquestions@mymsaa.org** or chat through the online MS Chat feature at **mymsaa.org/chat**.

**AARP:** The organization's "Aging in Place" initiative offers guidance and resources for people who want to continue living in their own homes despite the challenges posed by advanced age or disability. Information is available at **aarp.org/livable-communities**; while there, website visitors may also search for "age-friendly states" and select the first option for a newly updated state-by-state listing.

**Administration for Community Living::** This agency of the U.S. Department of Health and Human Services helps connect people with disabilities with resources for community living, offers information on advocating for yourself or a loved one with a disability, and also supports employment initiatives for people with disabilities. For more information please go to **acl.gov/programs**.

## WEBSITES

**Social Security Administration "Benefits for People with Disabilities" webpage:** This resource provides information on both Social Security Disability Insurance and Social Security Income. For more information please visit **ssa.gov/disability**.

**LongTermCare.gov:** This U.S. Department of Health and Human Services website provides guidance on how to meet the costs of long-term care. It details what various types of private insurance policies cover, and also outlines the role that different government-benefits programs may play.

**Medicare.gov:** This government website's nursing home comparison section, found at **medicare.gov/nursinghomecompare/search.html**, has a search function to locate nursing homes in your area, and then provides ratings of each facility's staffing, quality measures, health inspections, and other factors. It also has an extensive "Tools and Tips" section.



## PUBLICATIONS AND ARTICLES

### ***The Motivator, Winter/Spring 2019***

The cover story in this issue of MSAA's flagship publication features Martin Shenkman, CPA, MBA, PFS, AEP, JD, and other experts discussing legal and financial planning for people with MS. The article is available at [mymsaa.org/planning-for-your-future](http://mymsaa.org/planning-for-your-future).

### ***Employment and MS: The Challenges and Opportunities***

Written by Kara Barton, MSW, LCSW, this MSAA publication addresses topics including the Americans with Disabilities Act (ACA), reasonable workplace accommodations, and the circumstances in which people with disabilities may receive Social Security benefits while working. This publication is available at [mymsaa.org/employment-and-ms](http://mymsaa.org/employment-and-ms).

### ***Estate Planning for People with a Chronic Condition or Disability***

By Martin Shenkman, CPA, MBA, JD. Demos Health. 2009. This book provides comprehensive yet readily understood guidance on financial and legal planning for people with chronic conditions such as MS.

### ***Private Disability Insurance Claims: A Guide for People with MS and their Healthcare Providers***

Published by the National Multiple Sclerosis Society (NMSS), this publication offers a wealth of practical information on how to obtain disability insurance benefits. The guidebook is available at [nationalmssociety.org](http://nationalmssociety.org) by searching for "Private Disability Insurance Claims."

### ***Applying for Social Security Disability Benefits: A Guidebook for People with MS and their Healthcare Providers***

Another comprehensive guidebook from the NMSS, this one is focused on Social Security and is available at [nationalmssociety.org](http://nationalmssociety.org) by searching for "Applying for Social Security Disability Benefits."

### ***"Life Insurance with Multiple Sclerosis"***

This detailed online article from Jeff Rose, CFP® is available at [goodfinancialcents.com/life-insurance-multiple-sclerosis](http://goodfinancialcents.com/life-insurance-multiple-sclerosis).

### ***Your Money, Your Goals: Focus on People with Disabilities***

A helpful guide from the federal government's Consumer Financial Protection Bureau, which is available at [files.consumerfinance.gov/f/documents/cfpb\\_ymyg\\_focus-on-people-with-disabilities.pdf](http://files.consumerfinance.gov/f/documents/cfpb_ymyg_focus-on-people-with-disabilities.pdf).

BE READY FOR WHAT'S NEXT

I take **ZEPOSIA**, a once-daily pill.  
And I take on **GOALZ** that matter to me.  
Ask your MS healthcare team about **ZEPOSIA** today.

## ZEPOSIA is scientifically proven to reduce MS relapses

**48%** FEWER RELAPSES

### In a ONE-YEAR study:

People who took ZEPOSIA<sup>®</sup> (ozanimod) had 48% fewer relapses than a leading injectable medicine (Avonex).<sup>\*†</sup>

**38%** FEWER RELAPSES

### In a separate TWO-YEAR study:

People who took ZEPOSIA had 38% fewer relapses than a leading injectable.<sup>†</sup>



### See the full study results

Scan this code with your phone's camera or visit [ZEPOSIA.com/results](https://ZEPOSIA.com/results)

\*Avonex (interferon beta-1a).

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

#### 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<sup>®</sup> (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:

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

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

#### 2. Slow heart rate (also known as bradyarrhythmia) when you start taking ZEPOSIA.

ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days that you take ZEPOSIA. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heart rate:

- dizziness
- lightheadedness
- feeling like your heart is beating slowly or skipping beats
- shortness of breath
- confusion
- chest pain
- tiredness

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

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

#### What is ZEPOSIA?

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

## IMPORTANT FACTS (CONT'D)

### 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
- CYP2C8 inducers such as rifampin
- CYP2C8 inhibitors such as gemfibrozil (medicine to treat high fat in your blood)
- opioids (pain medicine)
- medicines to treat depression
- medicines to treat Parkinson's disease
- medicines to control your heart rate and blood pressure (beta blocker medicines and calcium channel blocker medicines)

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.

### 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
- headache

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.

This is a brief summary of the most important information about ZEPOSIA.

# Questions from Our Readers



**By Dr. Barry Hendin**

MSAA's Chief Medical Officer

**Q: Do you feel that the COVID-19 vaccine is safe for someone who has had MS for many years?**

**A:** As we have come to realize, COVID-19 infections are potentially dangerous and sometimes fatal. This is especially true for older individuals and for people with medical comorbidities. Although MS itself does not increase the risk of getting COVID-19 or the risk of a bad outcome, risk is heightened in older people with MS, especially when this is associated with increased disability and medical comorbidities.

MSAA recommends COVID-19 vaccination after appropriate discussion with your clinician. I strongly recommend vaccination for my MS patients, with rare exceptions.

With some immunosuppressive therapies such as B-cell depleting therapies, I recommend vaccination prior to initiating treatment, but I don't try to time vaccinations in patients who are already on disease-modifying therapies. Examples of these types of B-cell depleting therapies include Kesimpta® (ofatumumab), Lemtrada®

(alemtuzumab), Ocrevus™ (ocrelizumab), and the experimental medication, Rituxan® (rituximab). Provided your clinician agrees, my recommendation has generally been to roll up your sleeve and get your vaccination as soon as it's available for you.

**Q: I am a young 81-year-old woman and a retired marketing executive. At 36, my first symptom of MS was numbness in my legs causing falls. After decades of various symptoms that would come and go – including numbness and loss of bowel and bladder control – I was finally diagnosed with MS at the age of 70.**

**Since my diagnosis, I have taken a total of three disease-modifying therapies approved for MS. My advancing symptoms include worsening gait/balance issues and visual problems. I've had to give up tennis and golf, and I now use a walker; I've also had physical therapy over the years. I've been diagnosed with secondary-progressive MS, but my neurologist is hesitant to prescribe another disease-modifying therapy for me at my age, due to potential side effects.**

**My concern is how rapidly I am declining and what's next. Any recommendations would be appreciated.**



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**A:** Progressive problems with MS are discouraging no matter when in the course of your MS they occur. I certainly understand your concerns. We have improved our ability to reduce injury in the inflammatory stage of MS, but are far less advanced in treating progression. Part of the problem is that the worsening in MS can be due to MS progression or alternatively to medical issues and aging. In the case of worsening, we should first be sure that we have not neglected simple considerations such as exercise and diet and mental health as part of a wellness routine. It's a time to look at medications to be sure that they are not adding to symptomatology.

The FDA has recommended use of most medications for relapsing forms of MS when

there is still evidence of active inflammation, such as a relapse or new MRI lesion in the past year. In situations where there is no evidence of active inflammation or active disease, there are still medications that improve quality of life. We have symptomatic therapies for bladder problems and walking problems and mood problems. We also have supportive therapies such as physical therapy or occupational therapy or speech therapy which can make a real difference in improving function. This may be a time to consider changing strategies with an emphasis on wellness, symptomatic treatments, and physical therapies.

**Q: I am an MD (medical doctor) with MS. I take the immunosuppressant Gilenya, and I wanted to ask if you recommend testing for antibodies to confirm seroconversion.**

**A:** For our readers, I will explain that seroconversion occurs when an individual develops antibodies to a foreign (or disease-causing) substance, known as a pathogen, as part of its immune defense. When testing for these antibodies, we are able to see if a virus or other pathogen is currently active within the body – and this includes herpes as well as the JC virus – both of which are described below.

Many of the immunosuppressive disease-modifying therapies, including Gilenya® (fingolimod), increase the risk of herpes reactivation (including the varicella virus, which is the cause of shingles and chickenpox). I generally test for varicella before starting immunosuppressive therapies

including Gilenya and vaccinate if the titers are low or absent. I wait approximately four weeks thereafter to start treatment. I don't test to reassess seroconversion.

However, I suspect that the seroconversion to which you are referring is the conversion from JC virus negative to JC virus positive status. I do not check for seroconversion with JC virus for patients on Gilenya. Progressive multifocal leukoencephalopathy (PML) risk assessments for JC virus status have been worked out for patients taking Tysabri® (natalizumab), but not for patients taking Gilenya. The risk factors for PML and Gilenya appear to be related more to age (over 50) and duration of therapy.

**Q: Your website is very helpful. I am 59 years old and I'm having right-sided facial and leg pain. I also feel the need to empty my bladder all of the time. Does MS present at my age, and are these common symptoms?**

**A:** I'm glad to hear that you find our website to be very helpful! Thank you for letting us know.

With regard to your question, MS generally occurs in a young-adult population between 20 and 45 years. But MS can occur in the pediatric population (including young children and adolescents) and also in people at the

age of 59 and beyond. There is no age that confers absolute protection from MS. As people age, however, we tend to look for other explanations rather than MS because of the decreased risk in an older population. Please note that in the second question of this column, the writer had experienced symptoms since she was 36, but was not diagnosed until she was 70.

The symptoms that you are experiencing have all occurred in people with MS, but they are not specific to MS. The most common symptom of MS is fatigue. The most common first or presenting symptoms are painful loss of vision (optic neuritis), numbness and/ or weakness in the trunk and limbs (partial transverse myelitis), and double vision with incoordination due to a brain stem or cerebellar lesion.

My recommendation is to seek a good general medical or neurological evaluation that might include an MRI brain scan. This should clarify the origin of your symptoms. ■

*Please submit questions  
for Ask the Doctor via  
email to [askdr@mymsaa.org](mailto:askdr@mymsaa.org)*

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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.

# COVID-19 Vaccination

## Introduction

As noted in Ask the Doctor on page 34, MSAA recommends COVID-19 vaccination in coordination with one's healthcare provider. While new findings, recommendations, and approvals are ongoing, the facts listed below may give individuals a greater understanding of COVID-19 vaccinations and the research behind them. The majority of this information may be found on the Food and Drug Administration's (FDA's) website at **FDA.gov**. Website visitors may click on "COVID-19 Information" to learn about the latest developments. Please note that the information to follow was current at the time of publication.

## The Three COVID-19 Vaccines and How They Work

As of September 2021, three vaccines are available for the prevention of coronavirus disease 2019 (COVID-19) caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The **Pfizer-BioNTech COVID-19 Vaccine** is FDA-approved for individuals 16 years of age and older, and under the FDA-issued emergency use authorization (EUA), the vaccine may also be given to adolescents age 12 through 15. The **Moderna COVID-19 Vaccine** and **Johnson & Johnson's Janssen COVID-19 Vaccine** have both been issued the

By Susan Wells Courtney and Tom Garry

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

FDA's EUA and may be given to individuals 18 years of age and older.

Given in two doses and stored at very cold temperatures, both the Pfizer-BioNTech and Moderna vaccines contain a synthetic piece of mRNA (a genetic material) that instructs cells in the body to make the distinctive "spike" protein of the SARS-CoV-2 virus. When vaccinated, the body produces copies of the spike protein, and the immune system learns to launch an immune response against SARS-CoV-2.

The mRNA in these vaccines is only present in the body for a short time and is not incorporated into, nor does it alter, an individual's genetic material. Very rare adverse events with the Pfizer-BioNTech and the Moderna Vaccines include myocarditis (inflammation of the heart muscle) and pericarditis (inflammation of the tissue surrounding the heart). Both vaccines are approximately 95% effective in preventing moderate to serious illness five-to-six weeks after the first dose.

Given in one dose and stored at refrigerator temperatures, the Janssen vaccine is more like a flu vaccine and uses a disabled adenovirus to deliver the instructions rather than mRNA. This adenovirus is different from the coronavirus, but is able to deliver instructions on how to protect against the coronavirus.

A serious type of blood clot has been reported as a rare adverse event. The vaccine is approximately 66% effective in preventing moderate to severe illness, and 85% effective in preventing just severe illness, two weeks after the single dose.

## COVID-19 FAQs

**Do I need a vaccine if I've already had COVID-19?** Available data suggest that previously infected individuals can still be at risk of being reinfected with COVID-19 and could benefit from vaccination.

**Does vaccination prevent those from spreading the virus to others?** Most vaccines that protect from viral illnesses also reduce transmission of the virus by those who are vaccinated. While it is hoped this will be the case, this has yet to be proven.

**Can the COVID-19 vaccine cause infertility, and is vaccination safe for women who are pregnant or breastfeeding?** No scientific evidence suggests that the vaccine could cause infertility in women and there is no contraindication for pregnant or breastfeeding women to receive the vaccine.

Pregnant or breastfeeding women should discuss potential benefits and risks of vaccination with their healthcare provider.

## What's the difference between an additional dose and a booster shot?

According to the Centers for Disease Control and Prevention (CDC) at [CDC.gov](https://www.cdc.gov), sometimes people who are moderately to severely immunocompromised do not build enough protection when they first receive the two-dose vaccination. When this happens, getting another dose of the vaccine can sometimes help them build more protection against the disease. Individuals with MS who are taking certain disease-modifying therapies (DMTs) that suppress or block the immune system may be immunocompromised, and their physician may recommend receiving this additional (third) vaccine.

In contrast, a “booster dose” (or “booster shot”) refers to another dose of a vaccine that is given to someone who has built enough protection after vaccination, but then that protection has decreased over time. This is called “waning immunity.” ■

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## Two Experimental Medications for MS Show Encouraging Results

Findings from a Phase II study of the investigational medication **tolebrutinib** support conducting Phase III trials to further evaluate its efficacy and safety in people with relapsing-remitting multiple sclerosis (RRMS). Tolebrutinib inhibits Bruton's tyrosine kinase, or BTK. BTK is an enzyme expressed in B

cells and myeloid cells, which are components of the body's innate immune system, and in microglia, which are innate immune cells in the central nervous system. B cells, myeloid cells, and microglia all are believed to play a role in the inflammation seen in MS.

The Phase II study involved 130 people



ages 18 to 55 years who had been diagnosed with RRMS. The research examined how four different doses of tolebrutinib affected the number of new gadolinium-enhancing lesions seen on magnetic resonance imaging (MRI) after 12 weeks of treatment with the oral medication. The investigators found a dose-dependent reduction in the number of new lesions seen per patient.

Taken by infusion every six months, 1,000 people with relapsing forms of MS (RMS) participated in two studies with the investigational medication **ublituximab**. Researchers found that the annualized relapse rates (ARRs) were 50% to 60% lower than those of study subjects taking the disease-

modifying therapy Aubagio® (teriflunomide). Like Ocrevus™ (ocrelizumab), Rituxan® (rituximab), and Kesimpta® (ofatumumab), ublituximab targets the CD20 molecule to deplete B cells.

### 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@mymsaa.org** ■

Submit Your Best Work for MSAA's 2022-2023

# Art Showcase



Lily Pad  
Janet Chojnacki

Submissions will be accepted until December 13, 2021.

For guidelines, visit [support.mymsaa.org/artshowcase](https://support.mymsaa.org/artshowcase)

## NOW ACCEPTING SUBMISSIONS

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

MSAA will accept **3 pieces** of artwork per artist. Artwork will only be accepted from individuals who have MS and are 18 years of age or older. Sculpture, pottery, and other types of three-dimensional works cannot be accepted.

Submissions will be featured on MSAA's website beginning March 2022 in recognition of MS Awareness Month. Each month we will highlight one artist and their work.

For more information, contact:

Email: [showcase@mymsaa.org](mailto:showcase@mymsaa.org)

Phone: (800) 532-7667, ext. 117

# Information, Equipment, and Support for the MS Community

By Susan Wells Courtney

## MSAA's Informative Webinars

MSAA continues to produce live webinars on a host of vital topics! Presented in a very conversational, town-hall style with ample time for audience Q & A, the upcoming webinars provide a wealth of information to all who listen in. The following webinar topics are scheduled for the upcoming months:

- December 2021: What's for Dinner? Let's Talk about Nutrition!
- January 2022: Research Update
- February 2022: Program in Recognition of Black History Month
- March 2022: MS Awareness Month with Special Featured Topics

You can register for these free, live programs by visiting our calendar of events at [mymsaa.org/calendar](https://mymsaa.org/calendar). Also, previous webinars on topics such as wellness, the African American experience with MS, understanding brain health, and more, are now available for on-demand viewing on the MSi video website page at [mymsaa.org/videos](https://mymsaa.org/videos).

## MSAA's Helpline Offers Timely Information, Supportive Resources, and Needed Reassurance

During these anxious and uncertain times, MSAA would like to remind everyone that help is just a phone call or email away. MSAA's trained

and experienced Client Services Specialists are here to answer your questions, offer helpful resources, and provide a sense of comfort and reassurance with whatever challenges or concerns you may be experiencing.

Helpline hours are Monday through Thursday, 8:30 AM to 8:00 PM (ET), and Friday 8:30 AM to 5:00 PM (ET). We invite you to call our toll-free number at **(800) 532-7667, ext. 154** for helpful information and resources. You can also connect with our Helpline Specialists through email at [MSQuestions@mymsaa.org](mailto:MSQuestions@mymsaa.org).

## Access More Information about Multiple Sclerosis with MSAA's Digital Educational Program Guides

MSAA has created several interactive digital guides that are now available on our website. These guides include facts, activities, resources, and more on special subject areas related to MS. Current titles include:

- It's a Generational Thing Toolkit: Creating an Understanding of MS Between Parents and Their Children
- MS on Your Mind: A Closer Look at Brain Health
- The MS and Hispanic American Experience – FAQs
- A Roadmap for the Newly Diagnosed

To learn more about MSAA's interactive digital guides, or to check out MSAA's other digital program offerings, please visit [mymsaa.org/educational](https://mymsaa.org/educational).

## Equipment Distribution Program

MSAA's Equipment Distribution Program offers products designed to improve safety, mobility, and activities of daily living, while also providing greater opportunities for exercise and wellness. MSAA distributes these products at no charge to individuals with MS who qualify for assistance, and items are shipped directly to the client.

Products provided through the program range from grab bars, shower chairs, and walkers, to wide-grip utensil sets and yoga mats. MSAA can assist in offering clients equipment products every three years. For more information, please visit [mymsaa.org/equipment](https://mymsaa.org/equipment).

## Cooling Distribution Program

Although the high summer temperatures are behind us, we still want to let our clients know that MSAA's Cooling Distribution Program provides cooling equipment all year-round. This 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.

MSAA can assist in providing clients cooling products every five years. For more information, please visit [mymsaa.org/cooling](https://mymsaa.org/cooling). ■

# Become an MSAA Monthly Improver!

***Make convenient, automatic monthly gifts using your credit card, PayPal, or checking account***

A recurring gift allows MSAA to have predictable streams of revenue to better plan for free programs and services for the MS community.

Questions? Contact the Manager of Individual Giving at (800) 532-7667, ext. 146, or [kmcguire@mymsaa.org](mailto:kmcguire@mymsaa.org)

**SIGN UP TODAY!**

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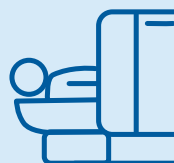
**\$10/month** provides shower chairs for two individuals with MS



**\$15/month** provides a wheelchair for an individual with MS



**\$25/month** provides a cooling vest for two individuals with MS



**\$60/month** provides an MRI exam of the brain for an individual with MS

# A New Year Means New Ways to Make a Difference

By **Rebecca Mooney**,  
**MSAA Vice President of Development**

As COVID challenges continue across the country, MSAA is working hard to maintain our nationwide virtual fundraising community, while still offering ways to give that meet the needs of all of our incredible clients, care partners, and donors so we can work together to *Improve Lives Today!*

Before the year ends, there are still ways to engage and come together with the community from your home – alone or with a group! MSAA's newest virtual series, *Improving Lives Through Art* continues with a series this

fall, as well as a planned series for both spring and fall in 2022. Consider joining us for one of our upcoming events:

- November 2nd – We will come together for one of our Paint-Alongs, again featuring one of MSAA's long-time Art Showcase contributors, Hannah Garrison. Hannah will put a spin on this event by leading the group in a card-making painting event. For more information or to register, please visit: **[ArtNov2021.givesmart.com](https://www.givesmart.com/ArtNov2021)**
- December 7th – Our veteran host, Joe Caliva, a long-time docent, will present an inspiring tour through MSAA's Art Showcase, featuring a direct look at stories from our showcase contributors and the impact art has had on them and their MS journey. For more information or to register, please visit: **[ArtDec2021.givesmart.com](https://www.givesmart.com/ArtDec2021)**



*Long-time MSAA Art Showcase contributor **Hannah Garrison** is an incredible co-host and artist who helps empower participants to make art their own during our **Improving Lives Through Art** Paint-Along events.*

In addition to our *Improving Lives Through Art* series, MSAA recently launched our brand-new Do-It-Yourself fundraising system to make it easy for you to fundraise your own way at any time. In recognition of Giving Tuesday or to capture the spirit of the Holiday Season, the end of the year is an exciting time to recognize your loved one living with MS. The new system features a wonderful opportunity to build a personal

page in honor of or in memory of your loved one, while easily sharing to encourage others to donate in their honor. Register a page today at: [mymsaa.org/DIY](https://mymsaa.org/DIY), and your personal fundraising consultant will connect with you to help make fundraising easy!

If you are not interested in events or fundraising through your personal or professional network, there are still several small ways to make an enormous difference. To learn more about these and other ways to give, please visit [mymsaa.org](https://mymsaa.org) and check out the DONATE tab or contact Kevin McGuire at [kmcguire@mymsaa.org](mailto:kmcguire@mymsaa.org). The following are just a few examples of ways to support MSAA:

- Sign on today as one of MSAA's Improvers, committing to monthly donations of any size. Being able to count on this income month after month helps MSAA plan programs and services with confidence.
- End the year right with an end-of-year donation or a gift through your advised fund. These gifts provide a tax-deduction for you while directly supporting MSAA's mission of improving lives today.
- Plan to recognize MSAA as a part of your estate? Let us know so we can add you to our Legacy Circle and keep you in the loop about how we will give purpose to these thoughtful gifts. If you are not sure how to get started, check out [freewill.com](https://freewill.com) and see if it's a good fit for your personal planning.

However you choose to give, MSAA is fortunate to have your support and we love to connect with our donors. Have new ideas for a virtual fundraiser or want to support the planning for one or more of our programs? Contact [donorrelations@mymsaa.org](mailto:donorrelations@mymsaa.org) to get involved! ■



**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!**

Please visit  
[mymsaa.org/DIY](https://mymsaa.org/DIY)



Multiple Sclerosis  
Association of America

## The Tolebrutinib Trials Find Out If You Qualify

### Actively Recruiting for Phase III Multiple Sclerosis Clinical Trials

The primary objective of these Phase III Trials is to compare the average number of relapses per year between two treatment groups, study drug vs. placebo.

See site for details, visit:  
[www.mymstrials.com/motivator](http://www.mymstrials.com/motivator)



Trial-related medication and medical care may be provided at no charge to patients who qualify. If travel is required, all travel related costs are reimbursed including meals, hotel, transportation, and even airfare.

## Tolebrutinib's Phase II Clinical Trial Results Summary:



In completed phase II study, 130 participants with relapsing-remitting MS took one of 4 doses of tolebrutinib for 12 weeks either before or after taking placebo for 4 weeks.



Compared to the placebo period treatment with the highest dose of tolebrutinib (same as used in current clinical trials) resulted in 85% to 89% relative reduction in new MS brain lesions.



The most frequently reported side effects in the phase II clinical trial were **headaches** and **flu-like symptoms**.

Online pre-qualification is **private**, and takes about **30 seconds**. See site for details, including more information about Tolebrutinib, and to learn more about MS Clinical Trial participation.



[www.mymstrials.com/motivator](http://www.mymstrials.com/motivator)

Tolebrutinib is experimental, not yet approved by health authorities, and is still under investigation for the treatment of MS.



The Tolebrutinib Trials are sponsored by Sanofi.



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Grab your Mickey ears and running shoes, because Team MSAA is going back to Walt Disney World®, with guaranteed spots for the following runDisney events. Register to run with Team MSAA for any of these events and start fundraising to Improve Lives Today for the MS community!



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November 4-7, 2021



January 5-9, 2022



February 24-27, 2022

With your commitment to fundraise, you'll receive:

- Reduced registration rates
- A personal fundraising consultant to help you coordinate your efforts
- Team MSAA swag
- The chance to earn additional incentives, including tickets to enjoy the park during your visit

*Love Disney and want to help support the MS community, but not comfortable travelling?*

Choose the **FUNDRAISING ONLY** registration option and show your support from a distance. Team MSAA virtual fundraisers will receive MSAA swag, as well as unique Disney-themed extras for meeting fundraising milestones.

Spots are limited, so sign up today at [support.mymsaa.org/teamMSAA](https://support.mymsaa.org/teamMSAA)

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# Connect with others and find support on **My MSAA Community**

Join more than 6,800 members who have similar experiences with multiple sclerosis in this online peer-to-peer forum.

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

