

MSAA

MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA

Improving Lives Today!®

Winter/Spring 2019

THE Motivator

Published by the Multiple Sclerosis Association of America

A man and a woman are looking at a tablet together. The man is on the left, wearing a grey sweater, and the woman is on the right, wearing a white shirt. They are both looking down at the tablet with focused expressions. The background is a blurred bookshelf filled with books.

Planning
for Your **Future**

Ensuring that you and your loved ones are protected through careful legal and financial planning.

Honor Someone Special



Whether acknowledging a special occasion, celebrating a birthday, or honoring a loved one, making a donation to MSAA in someone's name will allow **MSAA to send one of four beautiful cards** to the individual being honored or to his or her family. Each card features original artwork by a person with MS, along with the artist's inspirational story.

Please call (800) 532-7667 ext. 110 to make a donation in honor or in memory of someone.

**Announcing
TEAM MSAA's**

Endurance Events

MSAA is offering a wide range of endurance events during our 2019 season! Throughout the year, we invite you to make a difference in the lives of those affected by multiple sclerosis by participating in a **running or cycling event** in support of MSAA's free programs and services.

**We can make a difference
with every mile!**

To see the full list of endurance events MSAA is offering this year, please visit **support.mymsaa.org/teamMSAA**

Please note: We understand that these types of endurance events are not for everyone. If you know someone interested in participating in endurance events for charity, please encourage them to visit our website for more information.



Published by the Multiple Sclerosis Association of America

Gina Ross Murdoch
President & CEO

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



COVER STORY

4 Planning for Your Future

By Susan Wells Courtney

This article defines the legal and financial decisions and documents that need to be considered when planning for the future.



DEPARTMENTS

2 Up Front *By Gina Ross Murdoch*

MSAA's President and CEO provides highlights from MSAA's new strategic plan.

25 Ask the Doctor *By Jack Burks, MD*

MSAA's chief medical consultant answers questions sent in by readers.

30 Research News *By Susan Wells Courtney and Tom Garry*

Two new treatments approved; new MS population estimate given.

32 Program Notes *By Peter Damiri*

A recap of MS Awareness Month and new resources are featured.

34 Thoughts about Giving

By Erich Fasnacht and Kaitlyn Gallagher

Vital fundraising initiatives and opportunities are highlighted.

38 Stories to Inspire *By Jo Ann Maxwell and Judy Heilpern Eror*

In this special two-part edition, one reader discusses driving challenges, while the other talks about a daughter's determination.

44 Spread the Word

Three books from MSAA's free Lending Library are featured.

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



**MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA**

Improving Lives Today!®

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



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

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A Five-Year Strategic Plan for Progress



By Gina Ross Murdoch
MSAA President and CEO

Now that spring has arrived, this is a time to look ahead and experience exciting new beginnings. The same is true for MSAA, where we've made significant recent progress as we plan for the future.

One of the most exciting advances is the approval of our new five-year strategic plan. The creation of this plan, which will serve as a roadmap for increasing our service to the MS community, incorporated feedback from our staff, Board of Directors, Healthcare Advisory Council, national needs assessment survey results, and an analysis of the entire MS community. To follow are the values that continue to be a foundation of our organization:

- MSAA is passionately committed to identifying, evaluating, providing, and addressing the needs of everyone affected by multiple sclerosis (MS).

- MSAA will always remain a credible, unbiased organization that prioritizes serving the needs of individuals living with multiple sclerosis, their families, and the multiple sclerosis medical community.
- MSAA focuses on improving health outcomes and quality of life for individuals with MS by providing a wide array of free supportive programs and services to MS clients and their families.
- Through collaborations, MSAA seeks to develop and deliver innovative educational resources and materials that are responsive to the needs of the MS community.
- MSAA recognizes and celebrates the diversity of the MS population by providing culturally appropriate and relevant programming and materials to meet the needs of all people in the MS community.

The overall vision of this plan aims to strengthen the impact of our vital signature programs. It also aims to increase awareness – both within and outside of the MS

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.

community – of how MSAA can help and actively engage everyone affected by MS in identifying and addressing their ever-changing and critical needs.

We will be posting more detailed information associated with each area on our website shortly. We will also review our progress regularly to ensure we are achieving our goals for YOU. I welcome your active participation in accomplishing these goals.

The focus of this issue of our magazine is already in line with our strategic plan to raise awareness about a critical topic: planning ahead for your medical, financial, and legal needs. This is a sensitive and important subject that virtually all families must face, regardless of whether or not MS is involved.

Additionally, in our “Thoughts about

Giving” column, you will read about fellow supporters of MSAA who are engaging their local communities and raising funds for programs, services, and outreach. We are grateful and inspired by the efforts of these Champions, adding their personal touch to help increase our impact. On behalf of MSAA and the MS community, we say, “Thank you!” If you would like to join these meaningful efforts, please visit MSAA’s website at **mymsaa.org** for fundraising and volunteer opportunities, or call **(800) 532-7667**.

Most of all, we thank you for your partnership with MSAA. We have tremendous goals to reach and so many people to help. Together, we are able to fulfill our vital mission of Improving Lives Today – and strive to improve MORE lives today and every day! ■

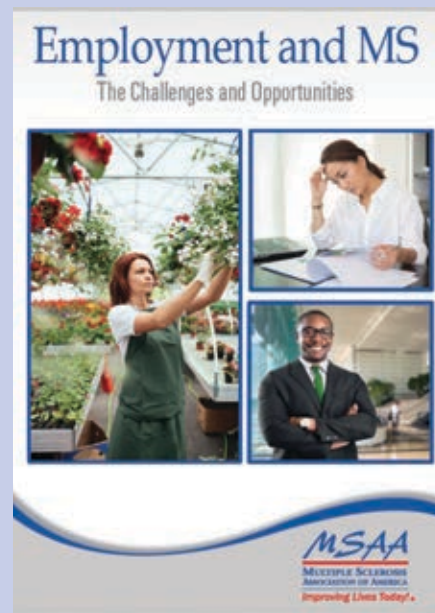
Employment and MS: The Challenges and Opportunities

In this brand-new publication, MSAA provides a comprehensive overview of the many factors involved with staying in the workforce and making the most of one’s career choices, including:

- *Cultural expectations and norms in the workplace*
- *One’s personal work identity*
- *MS symptoms and their potential impact at work*
- *Information to record and discuss with the neurologist*
- *Americans with Disabilities Act*
- *Social Security benefits while working*

Funds for this booklet have been generously provided through an educational grant from Genentech.

To download or order copies, please visit **mymsaa.org/publications** or call **(800) 532-7667**.



Planning for Your Future

Ensuring that you and your loved ones are protected through careful legal and financial planning.

By Susan Wells Courtney

Reviewed and edited by
Martin M. Shenkman, CPA, MBA, PFS, AEP, JD

Introduction

This article provides an overview of some of the most important topics to consider when planning for one's future. Legally, everyone should have specific documents in place that will appoint selected individuals to make medical decisions and handle personal as well as financial matters, should the need arise. These individuals assigned to handle another's business also need legal permission to access financial and medical records, along with discussing these matters with the different legal, financial, and healthcare professionals. Healthcare preferences must also be communicated in advance, put in writing, and perhaps given to physicians to add to your medical records.

Financial planning is critical to making sure that property and investments are properly invested, insured, and managed for an individual's future as well as his or her family's future. In terms of health care, people need to be assured that they will have access to medical care as they age, as well as funding for various levels of assisted care and skilled nursing care residences, if and when the time arises.

Many of us don't realize the importance of planning in advance, at least not to this degree. And no one enjoys dealing with planning for unpleasant events like health challenges or death, but not dealing with them will almost assure you and your loved ones a more difficult time.

However, when a



medical emergency arises or some other life-changing event occurs, having all of the right planning, documentation, information, and instructions in place can mean the difference between everything running smoothly according to one's wishes... and avoiding loss of control of legal, financial, and medical decisions and desires. Ultimately, planning ahead can more likely ensure a secure and stable future, whereas insufficient planning puts decisions and even financial assets in the hands of strangers – and could leave an individual, as well as his or her family, without control and in financial trouble.

Planning Ahead for Individuals with a Chronic Illness

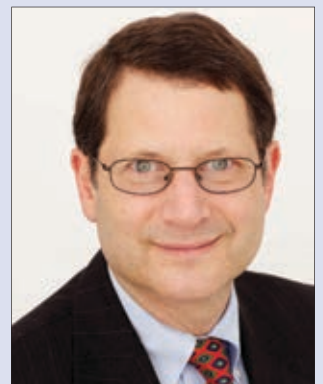
For individuals with a chronic illness, or those with a family member with a chronic illness, advance planning becomes even more vital and more specified. Extra attention needs to be given to the typical symptoms and progression of one's disease. As most of our readers know, multiple sclerosis (MS) is

unpredictable. With relapsing forms of MS, it can flare up and leave someone unable to function for weeks or months at a time. Often, but not always, the relapse may remit and allow the individual to return to his or her full activities. For individuals with progressive forms of MS, one's disease may advance at a slow pace, without flare ups, while others may experience a more aggressive form of the disease. Additionally, the symptoms of MS vary greatly, from numbness, visual changes, reduced mobility, and pain, to depression, cognitive problems, and overwhelming fatigue.

As noted throughout this article, these specific symptoms and anticipated disease progression will need to be taken into consideration when creating important legal documents that serve to: specify medical directives; appoint people to handle one's legal, financial, and medical decisions; allocate how one's estate is to be distributed, having family or other benefactors who may bequeath you money include a special needs or so-called supplemental needs trust for oneself;

MSAA would like to thank Attorney **Martin M. Shenkman**, CPA, MBA, PFS, AEP, JD, for his invaluable assistance with this important article. Shenkman is the founder of Shenkman Law, located in New Jersey and New York, and specializes in estate and tax planning, planning for closely held businesses, and estate administration. In addition to serving on several editorial boards for tax, estate, and real estate publications, Shenkman has written 44 books and more than 1,200 articles. A recipient of many awards for his work in writing, education, and legal matters, Shenkman has been a frequent source for numerous national publications and a guest expert appearing on television and radio shows. Active in a number of charitable and community causes and organizations, Shenkman is currently developing a new website,

ChronicIllnessPlanning.org, dedicated to educating professional advisers on planning for clients with chronic illness and disability. Shenkman received a Bachelor of Science degree from Wharton School, an MBA from the University of Michigan, and a law degree from Fordham University School of Law.



and even provide emergency medical information as well as temporary guardianship of a minor in the absence or temporary disability of a parent.

Although not everyone can afford to hire professionals when creating these documents and making vital decisions for one's future, it is strongly advised if it is at all feasible. Not only are such professionals recommended, ideally, these professionals should be experienced in assisting individuals with disabilities and must be aware of the many factors involved with long-term planning for one's specific illness. Additionally, when consulting with a professional, individuals need to be realistic



about their prognosis and be able to communicate their special needs – including those they currently have and those that they anticipate in the future.

You should also never suspend common sense and the knowledge that you have. Not

every professional will understand the enigmatic (or difficult to understand) nature of your disease course or how your planning may need to be tailored. So whatever option you take – whether hiring an attorney and other adviser or endeavoring to do the planning and documents on your own – you would be well-advised to educate yourself and stay proactive. If something doesn't make sense to you, ask questions and get a resolution.

In his book, *Estate Planning: For People with a Chronic Condition or Disability*, Attorney Martin M. Shenkman explains, “If you or a loved one has a chronic illness, estate planning takes on greater importance and requires modifications from what is typically done for those who don't have a chronic illness. Too often estate planning is viewed as merely signing ‘standard,’ or what lawyers affectionately call ‘boilerplate,’ forms. While this is dangerous for even the average person, it can be catastrophic for those with chronic illness and their loved ones. ‘Standard’ forms just won't work for you.”

The KEY point is that you must redefine “estate planning.” Most people equate estate planning with planning for death and signing a will. That might be an important part of the process, but if you are perhaps at the age of 50, you might have another 40 years of life expectancy, even with MS, and estate planning should be more about protecting you and your loved ones for that next 40 years. Be sure to focus on a broad and holistic perspective of what estate planning is really about.

Anyone with a chronic illness should not feel that he or she is alone in this situation.

According to a 2014 report issued by the National Health Council in Washington, DC, “Chronic diseases affect approximately 133 million Americans, representing more than 40% of the total population of this country. By 2020, that number is projected to grow to an estimated 157 million, with 81 million having multiple conditions... More and more people are living with not just one chronic illness, such as diabetes, heart disease, or depression, but with two or more conditions. Almost a third of the population is now living with multiple chronic conditions.”

Shenkman continues with this key note, “You need to be proactive. Don’t assume that your advisers (attorney, accountant, financial planner, etc.) understand the nuances of your illness or how planning and documents need to be modified for you. You have to inform them. If you’re uncomfortable discussing your illness and its potential consequences, bear in mind that if you don’t make sure the people advising you really understand, you won’t have the protections you or your loved ones need. However difficult, you’ll benefit by being forthright, clear, and very specific.”



Step 1: Organize emergency information

If something happened to you, or if you were to experience a major flare-up, would your loved ones know where to find important information, such as legal, tax, and financial records? Would they know where your bank accounts are located and what insurance policies you have? How about your specific doctors, their contact information, and medications you are taking? You may also care for young children, and instructions for who is to take over in your absence needs to be clearly noted, plus you may have pets that require attention. These are all critical items that your loved ones will need to access quickly if you were to have a medical emergency and were not available to provide this type of information yourself. Shenkman advises to take the time to make sure such information is “organized, available, and simple.” If it is a password-protected computer, will someone know the password and where to find it?

Organizing emergency information is particularly important for individuals with a

Seven Steps of Estate Planning

In *Estate Planning: For People with a Chronic Condition or Disability*, Shenkman divides estate planning into seven vital steps. To follow is a listing of these seven steps, along with a description of each. Additional information is given to explain how these steps may be modified if someone is living with a chronic illness.

For people with relapsing or primary progressive forms of multiple sclerosis (MS)



MS
shouldn't
make you
question
your plans

What is OCREVUS?

OCREVUS is a prescription medicine used to treat adults with relapsing or primary progressive forms of multiple sclerosis.

It is not known if OCREVUS is safe or effective in children.

Who should not receive OCREVUS?

Do not receive OCREVUS if you have an active hepatitis B virus (HBV) infection.

Do not receive OCREVUS if you have had a life threatening allergic reaction to OCREVUS. Tell your healthcare provider if you have had an allergic reaction to OCREVUS or any of its ingredients in the past.

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

OCREVUS can cause serious side effects, including:

- **Infusion reactions:** OCREVUS can cause infusion reactions that can be serious and require you to be hospitalized. You will be monitored during your infusion and for at least 1 hour after each infusion of OCREVUS for signs and symptoms of an infusion reaction. Tell your healthcare provider or nurse if you get any symptoms (see accompanying Patient Information).

These infusion reactions can happen for up to 24 hours after your infusion. It is important that you call

your healthcare provider right away if you get any of the signs or symptoms listed in the accompanying Patient Information.

If you get infusion reactions, your healthcare provider may need to stop or slow down the rate of your infusion.

• Infection:

- o OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any signs of infection (see accompanying Patient Information). These signs can happen during treatment or after you have received your last dose of OCREVUS. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.
- o **Progressive Multifocal Leukoencephalopathy (PML):** Although no cases have been seen with OCREVUS treatment in clinical trials, PML may happen with OCREVUS. PML is a rare brain infection that usually leads to death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness



In **relapsing MS**, OCREVUS demonstrated†:

- **Reduction** of relapses
- **Slowing** of disability progression
- **Significant impact** on brain lesions

In **primary progressive MS**, OCREVUS is the first and only FDA-approved treatment.

Have Fewer Maybes With OCREVUS

TALK TO YOUR DOCTOR TODAY

on 1 side of your body, strength, or using your arms or legs (see accompanying Patient Information).

- o **Hepatitis B virus (HBV) reactivation:** Before starting treatment with OCREVUS, your healthcare provider will do blood tests to check for hepatitis B viral infection. If you have ever had hepatitis B virus infection, the hepatitis B virus may become active again during or after treatment with OCREVUS. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. Your healthcare provider will monitor you if you are at risk for hepatitis B virus reactivation during treatment and after you stop receiving OCREVUS.
- o **Weakened immune system:** OCREVUS taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

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

What are the possible side effects of OCREVUS?

OCREVUS may cause serious side effects, including:

- **Risk of cancers (malignancies) including breast cancer.** Follow your healthcare provider's instructions about standard screening guidelines for breast cancer.

Most common side effects include infusion reactions and infections.

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

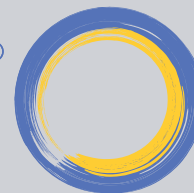
For additional Important Safety Information, please see the accompanying Patient Information.

*First dose of OCREVUS is split—given as 2 separate infusions 2 weeks apart.

†In two 2-year clinical studies vs REBIF.‡

‡REBIF® is a registered trademark of EMD Serono, Inc.

OCREVUS®
ocrelizumab 300MG/10ML
INJECTION FOR IV



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

PATIENT INFORMATION

OCREVUS® (oak-rev-us)
(ocrelizumab)
injection, for intravenous use

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

OCREVUS can cause serious side effects, including:

- **Infusion reactions:** OCREVUS can cause infusion reactions that can be serious and require you to be hospitalized. You will be monitored during your infusion and for at least 1 hour after each infusion of OCREVUS for signs and symptoms of an infusion reaction. Tell your healthcare provider or nurse if you get any of these symptoms:

- | | |
|-----------------------------|-----------------------------------|
| ◦ itchy skin | ◦ redness on your face (flushing) |
| ◦ rash | ◦ nausea |
| ◦ hives | ◦ headache |
| ◦ tiredness | ◦ swelling of the throat |
| ◦ coughing or wheezing | ◦ dizziness |
| ◦ trouble breathing | ◦ shortness of breath |
| ◦ throat irritation or pain | ◦ fatigue |
| ◦ feeling faint | ◦ fast heart beat |
| ◦ fever | |

These infusion reactions can happen for up to 24 hours after your infusion. It is important that you call your healthcare provider right away if you get any of the signs or symptoms listed above after each infusion.

If you get infusion reactions, your healthcare provider may need to stop or slow down the rate of your infusion.

• Infection:

- OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any of the following signs of infection including fever, chills, a cough that does not go away, or signs of herpes (such as cold sores, shingles, or genital sores). These signs can happen during treatment or after you have received your last dose of OCREVUS. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.
- **Progressive Multifocal Leukoencephalopathy (PML):** Although no cases have been seen with OCREVUS treatment in clinical trials, PML may happen with OCREVUS. PML is a rare brain infection that usually leads to death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include problems with thinking, balance, eyesight, weakness on 1 side of your body, strength, or using your arms or legs.
- **Hepatitis B virus (HBV) reactivation:** Before starting treatment with OCREVUS, your healthcare provider will do blood tests to check for hepatitis B viral infection. If you have ever had hepatitis B virus infection, the hepatitis B virus may become active again during or after treatment with OCREVUS. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. Your healthcare provider will monitor you if you are at risk for hepatitis B virus reactivation during treatment and after you stop receiving OCREVUS.

- **Weakened immune system:** OCREVUS taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

What is OCREVUS?

OCREVUS is a prescription medicine used to treat adults with relapsing or primary progressive forms of multiple sclerosis.

It is not known if OCREVUS is safe or effective in children.

Who should not receive OCREVUS?

- **Do not** receive OCREVUS if you have an active hepatitis B virus (HBV) infection.
- **Do not** receive OCREVUS if you have had a life threatening allergic reaction to OCREVUS. Tell your healthcare provider if you have had an allergic reaction to OCREVUS or any of its ingredients in the past. See "**What are the ingredients in OCREVUS?**" for a complete list of ingredients in OCREVUS.

Before receiving OCREVUS, tell your healthcare provider about all of your medical conditions, including if you:

- have or think you have an infection. See "**What is the most important information I should know about OCREVUS?**"
- have ever taken, take, or plan to take medicines that affect your immune system, or other treatments for MS. These medicines could increase your risk of getting an infection.
- have ever had hepatitis B or are a carrier of the hepatitis B virus.
- have had a recent vaccination or are scheduled to receive any vaccinations.
 - **You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with OCREVUS.** You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with OCREVUS and until your healthcare provider tells you that your immune system is no longer weakened.
 - **When possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with OCREVUS.** If you would like to receive any non-live (inactivated) vaccines, including the seasonal flu vaccine, while you are being treated with OCREVUS, talk to your healthcare provider.
 - If you are pregnant or planning to become pregnant talk to your doctor about vaccinations for your baby, as some precautions may be needed.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if OCREVUS will harm your unborn baby. You should use birth control (contraception) during treatment with OCREVUS and for 6 months after your last infusion of OCREVUS.
- are breastfeeding or plan to breastfeed. It is not known if OCREVUS passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take OCREVUS.

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

How will I receive OCREVUS?

- OCREVUS is given through a needle placed in your vein (intravenous infusion) in your arm.

- Before treatment with OCREVUS, your healthcare provider will give you a corticosteroid medicine and an antihistamine to help reduce infusion reactions (make them less frequent and less severe). You may also receive other medicines to help reduce infusion reactions. See **"What is the most important information I should know about OCREVUS?"**
- Your first full dose of OCREVUS will be given as 2 separate infusions, 2 weeks apart. Each infusion will last about 2 hours and 30 minutes.
- Your next doses of OCREVUS will be given as one infusion every 6 months. These infusions will last about 3 hours and 30 minutes.

What are the possible side effects of OCREVUS?

OCREVUS may cause serious side effects, including:

- See **"What is the most important information I should know about OCREVUS?"**
- **Risk of cancers (malignancies) including breast cancer.** Follow your healthcare provider's instructions about standard screening guidelines for breast cancer.

Most common side effects include infusion reactions and infections.

See **"What is the most important information I should know about OCREVUS?"**

These are not all the possible side effects of OCREVUS.

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

General information about the safe and effective use of OCREVUS.

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

What are the ingredients in OCREVUS?

Active ingredient: ocrelizumab

Inactive ingredients: glacial acetic acid, polysorbate 20, sodium acetate trihydrate, trehalose dihydrate.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.OCREVUS.com or call 1-844-627-3887.

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

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chronic illness such as MS where cognitive issues can be a symptom. Cognitive symptoms can affect information-processing skills, reducing one's ability to focus, maintain, and shift attention from one thing to another. These symptoms can also make performing simple and complex math skills more difficult, as well as impact executive function, which are involved with overseeing and coordinating tasks such as organization, planning, sequencing, problem solving, and judgment. This adds to the challenge of staying on top of financial, legal, and medical decisions and obligations, particularly during flare-ups.

By having emergency information well-organized in advance, Shenkman points out that this can become a “tool” to assist with keeping up with these types of obligations. Not only can it help people with MS to stay current with bills, taxes, insurance, bank accounts, etc., but it also can help these individuals to maintain control of their business dealings for a longer period of time. He also explains that while estate and financial-planning books provide forms to organize information, this isn't enough for someone coping with a chronic illness. Techniques are needed to organize financial and other information so that the individual with MS may continue to use and update his or her records, keeping everything current in case of an emergency.

Step 2: Designate a person to handle financial and legal issues


Through a legal document known as a “**power of attorney**,” you are able to appoint an individual to help with your legal and financial

matters during a time when you are not able to do everything for yourself. This might include activities such as making deposits, paying bills, and handling other business tasks. For individuals with MS, a power of attorney may need to step in and handle business dealings during an MS exacerbation. Once the relapse has remitted, the individual may be able to resume the control of his or her affairs.

With a chronic illness such as MS, which typically has a long disease course, help may be needed for several years. Members of the MS community may choose to name three or more people as alternates to serve as their power of attorney to ensure they have protection in the distant future. Readers should note that the rules for power of attorney vary by state, and some states limit those you may name as power of attorney to certain close relatives. Individuals should consult an attorney in their state when creating a power of attorney.

Additionally, individuals with MS need to be certain that their power of attorney is “**durable**.” Without being designated as durable, power of attorney becomes invalid when someone becomes disabled. Minimally, a statement such as, “This power of attorney will remain in force and effect even if I'm disabled,” needs to be included in the document. But be careful as the required language will vary by state. Be sure to use the right terminology required by your state's laws.

While a power of attorney allows a trusted person (aka “**agent**”) to be selected to handle or assist with your financial and legal matters when help is needed, and a durable power of



Whoever is chosen to be your agent in your healthcare proxy should understand MS and how you are affected by this chronic condition.

attorney continues regardless of disability, other options for power of attorney exist. These include: “**general power of attorney**,” giving the person you select permission to handle all financial, legal, and other matters; “**special power of attorney**,” limiting the person you select to certain transactions; a “**business power of attorney**,” to handle affairs if you own or operate a business; and “**springing power of attorney**” (not recognized by all states), which only allows the person you have selected to handle your affairs when you are disabled and not before, often adding the obligation of having to prove that you are officially disabled – and possibly delaying when the person you have selected may take over your affairs.

For the reason just mentioned, the option of springing power of attorney is often not appropriate for someone with MS, who would need immediate assistance with their personal affairs when experiencing a sudden relapse. By the time disability can be proven for the agent to take over, a person with MS could have already recovered from the relapse. On the other hand, if an individual with MS gives an agent general power of attorney so that

business dealings such as physically going to the bank may be handled by the agent prior to any significant disability, the person with MS may be giving up more control than he or she wishes at this point in time. Also, please keep in mind that some states will not recognize or accept a springing power.

Shenkman suggests that a “hybrid approach” may be best for some chronic illnesses, combining different types of power of attorney and including details that are specific to your situation. This is particularly helpful if a power of attorney is needed only for limited duties, such as going to the bank when fatigue and mobility are an issue... or when disease flare-ups are possible, at which time a power of attorney would be needed to step in temporarily, but then give control back to the individual once his or her flare-up has subsided. This hybrid approach is a creative and flexible method of tailoring your power of attorney form to best fit your specific situation.


Step 3: Designate a person to make healthcare decisions and access medical records

Through a legal document known as a “**healthcare proxy**,” you are able to appoint an

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individual – often a relative or a friend – to make medical decisions for you if you are not able to do so yourself. This would typically be at a time of a medical emergency or if someone is ill or disabled and not able to communicate or make decisions on his or her own.

The person who is appointed by a healthcare proxy (known as the “**agent**”) would help make decisions to ensure that your healthcare wishes are followed. Without a healthcare proxy agent, no one else has the right to make such decisions for another individual. This agent can also help to monitor how you are being cared for, even if you are able to make the bigger decisions on your own. Please note that you will need to complete a special authorization for your healthcare proxy

agent to have access to your medical records, and this authorization must follow the requirements listed in the Health Insurance Portability and Accountability Act (HIPAA).

Whoever is chosen to be your agent in your healthcare proxy should understand MS and how you are affected by this chronic condition. You should openly discuss the form of MS that you have – explaining whether you have a relapsing form that will flare up and then subside, or if you have a progressive form that slowly worsens without remissions. Possible symptoms should also be discussed, so your proxy is familiar with what you may be experiencing and how your symptoms are often treated.

If you do not have someone to name as a healthcare proxy agent, about 20 states permit a different approach called a Physician Order for Life Sustaining Treatment, or “POLST.” Some states use different terminology. Where permitted, you can complete a form that your physician can put into your medical records and then your physicians will be authorized to make decisions if necessary.

Step 4: Communicate your healthcare wishes

A legal document known as a “**living will**” provides your healthcare wishes in the event of an emergency or other healthcare situation when your proxy may not be available or may be too upset emotionally to assist. This document will often address such topics as which life-saving procedures someone wishes to have performed depending upon his or her prognosis. Whenever going through a medical procedure, the hospital and attending doctors

may keep your living will on file should it ever be needed in an emergency.

While the healthcare proxy that appoints an agent to make healthcare decisions for you is integrally connected with one's living will, since the agent may ultimately need to make the choices that are specified in the living will, the two documents are prepared and processed independently of one another. And while some hospitals and medical facilities require a living will for their files, some states do not recognize a living will. In these states, only the healthcare proxy carries any legal importance.

Regardless of whether or not a state recognizes a living will, it still provides critical insight into your healthcare wishes, which can be invaluable to your healthcare proxy agent, family members, and others involved in your healthcare. It needs to present "clear and convincing" proof of what you do and do not want performed. Particularly in light of having a chronic illness, you'll want to add your individual wishes to the standard language, specifying in greater detail your preferences and values. Simply signing a standard form just prior to a medical procedure or using a generic form from the internet is risky and may not result in the preferences you have specified.

Some of the decisions noted in a living will include: whether to take no heroic measures or to take all measures to preserve your life; if artificial nutrition and hydration may be discontinued at any time; quality-of-life statements; religious convictions; guardian designation; pain-relief measures; organ donations; and burial instructions.

While these topics are not pleasant to think about, having such directives in place will help ensure that the correct actions are taken if and when the time arises. It also helps to take some of the pressure off of loved ones who may be too emotionally involved to make difficult decisions regarding your final wishes.

Step 5: Protect your minor child with an emergency child medical form

If your child is temporarily in someone else's care – possibly because you are away on vacation or in the hospital with a medical situation, for example – an **emergency child medical form** is vital should he or she become ill or have any type of a medical emergency. A completed and signed form providing important information is enormously helpful to your child's caretakers and medical professionals. This form includes health-



related details such as any health conditions, medications, allergies (including allergies to medications and materials), health-insurance information, and special instructions for his or her care.

A guardian appointment stated in a will does not come into effect until the parents have died. If one or both parents are not available and the child is temporarily in someone else's care at a time when a medical emergency arises, hopefully someone else close to the child can help to make medical decisions. However, while an emergency child medical form may not be considered as a legal document, it can provide critical information to the doctor and medical facility. This document should include the following information:

- The name of the person who is caring for your child or children while you are absent
- Contact information for you, your close relatives, your child's pediatrician, and any other relevant individuals
- Your child's medical insurance information
- Your child's current conditions and medications
- Your child's blood type, allergies, and any other unique medical situation
- Your child's medical history
- Religious restrictions

After signing this form, the original should go to the person caring for your child, and copies should go to his or her pediatrician and another to be filed at your home. If traveling and if you don't have all of the specifics memorized, you may want to take a copy with you as well.

Step 6: Sign a will

A **will** is a legal document that provides instructions on how one's assets are to be distributed after he or she is no longer living. If children under the age of 18 are involved, the will should also include the name(s) of those who will become the guardians of the minor children.

In his book, *Estate Planning: For People with a Chronic Condition or Disability*, Shenkman notes, "While your will is an essential part of your estate plan, and possibly the key document governing the distribution of your assets on death and the appointment of a guardian if you have minor children, it is not much different from wills executed by people who do not have to contend with a chronic illness." For this reason, he refers readers to publications written for the general public, which address wills in greater detail.

Shenkman explains that a will, or Last Will and Testament, may not be as important as a funded revocable living trust in regard to one's assets. (Details on this type of trust are given in the next section.) However, when properly prepared and executed, your will can protect your loved ones and ensure that your wishes are carried out. He notes that individuals with a chronic illness may want to consider donating to one or more charitable organizations that serve others with the same condition. Assets not affected by a will include IRAs and retirement plans, life insurance policies, jointly owned assets, as well as certain bank and other accounts, depending on how they are transferred after one's death.

Step 7: Create a revocable living trust

A **revocable living trust** provides instructions on where some or all of one's assets will be transferred during his or her lifetime. By having this document in place, assets won't be handled by the courts in a process called "**probate**," where assets are distributed by the courts according to your will. Also called a "living trust," "loving trust," or "revocable inter vivos trust," a revocable living trust "might be the most powerful and beneficial tool to assist you in managing assets and other matters throughout the often unpredictable course of your disease," according to Shenkman.

The benefits of a revocable living trust include being flexible, comprehensive, and detailed, enabling the owner of the trust to make specific plans with regard to one's disability. Another benefit, as mentioned, is avoiding probate in most instances after one's death. You may list yourself as the primary beneficiary of the trust, but you can also have loved ones as beneficiaries too. Living trusts are revocable, so they may be changed at any time, provided the **trustor** – the one who oversees the trust – is competent. Should the trustor at any time be deemed to not have a high enough level of competency, the living trust is no longer revocable and cannot be changed.

With MS, if you are the trustor of your living trust, you may be well-advised to have a **cotrustee** (a second **trustee**) to make decisions and handle any transactions in your place should you experience temporary



cognitive or other issues during an MS exacerbation that would put your competence in question. Having a cotrustee can allow for quicker, easier, and more effective transactions, while also keeping the living trust revocable. Unlike a power of attorney, with a revocable living trust, you may have a bank or trust company as your cotrustee if you choose. This can add integrity to the management of your trust.

However, a revocable living trust is not appropriate for everyone, particularly if money is an issue. You need to be able to afford an experienced attorney to prepare the trust, plus you also need to have significant assets to make this type of trust worthwhile. Assets such as retirement accounts and life insurance policies cannot be transferred to a trust.

Another approach that is a bit more complicated, but one that can add further safeguards, is to have a position called "**trust protector**." This is a person given limited but important powers, such as to remove and replace the trustee or to demand that the trustee account for what they have done financially.

Special Needs Trust

The brochure, *Estate Planning for Parents of Children with Disabilities* (by Special Needs Alliance), defines special needs trusts as “discretionary, spendthrift trusts created for the elderly or individuals with disabilities. They are intended to supplement, but not replace, any public benefits that the trust beneficiary receives, such as SSI, Medicaid, subsidized housing and other programs.

“The requirements and terms of the trust can vary substantially depending on the public benefits program and state... The special needs trust can be used to supplement government benefits by paying for items, services and equipment that Medicaid will not cover, such as the purchase of a home, special wheelchairs, handicap-accessible vans or mechanical beds. It will also pay for limited travel, a personal attendant, and other recreational and cultural experiences. The trust can be specifically tailored to enrich the beneficiary’s life.”

The article, “Two Different Types of Special Needs Trusts” (*The Voice* newsletter, Sept 2017, vol. 11, issue 6), describes the two types of special needs trusts (SNTs). One type is a first-party SNT, which is established and funded by the beneficiary – such as when an individual with a disability receives an inheritance or settlement and needs to save these funds for the future while keeping his or her public benefits in place. Individuals are limited to \$2,000 in assets for their government-funded benefits to stay in effect.

The other type is a third-party SNT, where someone close to the beneficiary – such as a parent or grandparent – initiates and funds the

trust. Other people may fund this trust as well. Many factors and limitations are involved with both types of SNTs, but the primary difference is that after the beneficiary dies, funds still remaining in a first-party SNT must first repay the lifetime medical benefits paid by the Medicaid programs, whereas funds still remaining in a third-party SNT are not required to repay these government programs.

According to the article, “Special Needs Trusts, How Much Trouble Are They to Manage?” (Fleming RB, Krooks C, and Krooks BA, *EP Magazine*, Mar 2015), when providing an inheritance for a child or anyone with a disability to help plan for his or her future, a special needs trust is almost always the answer. If no trust is set up, the authors point out, “The cost, loss of family control and interference by the legal system will consume a significant part of the inheritance you leave and frustrate those who are caring for [your loved one].”

The article explains that trusts are not that complicated to manage and professionals may be hired as needed to assist with details such as tax returns and accounting requirements, using funds from the trust and not as an added expense for the trustee. With regard to naming a trustee, selecting a sibling may not be the best choice. The authors state, “We frequently counsel clients to name someone else – a bank trust department, a trusted professional, or a different family member – as a trustee.” This allows a sibling, such as a sister, to do what she does best... to be a sister. If appropriate, a sibling may be named as “trust protector,” as described in the previous section.

Laura S., living with relapsing MS

opens up possibilities

Say **yes** to TECFIDERA—a pill that can **cut MS relapses in half**.

TECFIDERA is a twice-daily pill proven to work against relapsing multiple sclerosis (MS) in 3 different ways. It can **cut relapses in half**, **slow the development of brain lesions**, and **delay the progression of physical disability**. In fact, in a 2-year study, people taking TECFIDERA had a 49% lower risk of relapse and were 38% less likely to experience physical disability progression than people taking placebo.



Are you ready to say yes to fewer relapses? Visit yestoTEC.com or call 1-844-TalkTec (1-844-825-5832)

What is TECFIDERA?

Tecfidera® (dimethyl fumarate) is a prescription medicine used to treat people with relapsing forms of multiple sclerosis.

Important Safety Information

Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients.

Before taking and while you take TECFIDERA, tell your doctor about any low white blood cell counts or infections or any other medical conditions.

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

- **Allergic reactions**
- **PML, which is a rare brain infection that usually leads to death or severe disability.**
- **Decreases in your white blood cell count.** Your doctor should check your white blood cell count before you take TECFIDERA and from time to time during treatment
- **Liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your doctor right away if you get any symptoms of a liver problem during treatment, including:
 - severe tiredness
 - loss of appetite
 - pain on the right side of your stomach
 - dark or brown (tea color) urine
 - yellowing of your skin or the white part of your eyes

Important Safety Information (continued)

The most common side effects of TECFIDERA include flushing and stomach problems. These can happen especially at the start of treatment and may decrease over time. Taking TECFIDERA with food may help reduce flushing. Call your doctor if these symptoms bother you or do not go away. Ask your doctor if taking aspirin before taking TECFIDERA may reduce flushing.

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

For more information go to daily.med.nlm.nih.gov.

Tell your doctor if you are pregnant or plan to become pregnant, or breastfeeding or plan to breastfeed. It is not known if TECFIDERA will harm your unborn baby or if it passes into your breast milk. Also tell your doctor if you are taking prescription or over-the-counter medicines, vitamins, or herbal supplements. If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

For additional Important Safety Information, please see Patient Information on the following page. This is not intended to replace discussions with your doctor.

*Based on number of prescriptions from IMS NPA™ Weekly Data (September 27, 2013 – December 8, 2017).

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



Patient Information
TECFIDERA® (tek" fi de' rah)
(dimethyl fumarate) delayed-release capsules

What is TECFIDERA?

- TECFIDERA is a prescription medicine used to treat people with relapsing forms of multiple sclerosis (MS)
- It is not known if TECFIDERA is safe and effective in children under 18 years of age

Who should not take TECFIDERA?

- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients. See below for a complete list of ingredients.

Before taking and while you take TECFIDERA, tell your doctor if you have or have had:

- low white blood cell counts or an infection
- any other medical conditions

Tell your doctor if you are:

- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby.
 - If you become pregnant while taking TECFIDERA, talk to your doctor about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting www.tecfiderapregnancyregistry.com. The purpose of this registry is to monitor the health of you and your baby.
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your doctor should decide if you will take TECFIDERA or breastfeed.
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

How should I take TECFIDERA?

- Take TECFIDERA exactly as your doctor tells you to take it
- The recommended starting dose is one 120 mg capsule taken by mouth 2 times a day for 7 days
- The recommended dose after 7 days is one 240 mg capsule taken by mouth 2 times a day
- TECFIDERA can be taken with or without food
- Swallow TECFIDERA whole. Do not crush, chew, or sprinkle capsule contents on food.
- Protect TECFIDERA from light. You can do this by storing the capsules in their original container.
- If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)
- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your doctor should do a blood test before you start treatment with TECFIDERA and while on therapy.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your doctor right away if you get any of these symptoms of a liver problem during treatment.
 - severe tiredness
 - loss of appetite
 - pain on the right side of your stomach
 - have dark or brown (tea color) urine
 - yellowing of your skin or the white part of your eyes

The most common side effects of TECFIDERA include:

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

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

You may report side effects to FDA at 1-800-FDA-1088. **For more information go to dailymed.nlm.nih.gov.**

General Information about the safe and effective use of TECFIDERA

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

What are the ingredients in TECFIDERA?

Active ingredient: dimethyl fumarate

Inactive ingredients: microcrystalline cellulose, silicified microcrystalline cellulose, croscarmellose sodium, talc, silica colloidal silicon dioxide, magnesium stearate, triethyl citrate, methacrylic acid copolymer - Type A, methacrylic acid copolymer dispersion, simethicone (30% emulsion), sodium lauryl sulphate, and polysorbate 80.

Capsule Shell: gelatin, titanium dioxide, FD&C blue 1; brilliant blue FCF, yellow iron oxide and black iron oxide.

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

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

Additional Considerations

When to begin financial planning

In an interview with MSAA, Shenkman explained, “Once you're 18, you should have some minimum documents, such as a proxy and power of attorney, even if you're just a new adult. Because if you have an exacerbation and can't make medical, healthcare, or financial decisions, you need somebody to be able to act for you when you need a hand.

After you've reached the age of 18, under many state laws, your parents or whoever the responsible adult is, may not have the legal authority to act. You need to sign a document. I think that the age at which to start is far earlier than most people think about from a financial perspective and a legal perspective. Like

with so many things in life, getting a jump on it and getting it done before you need it is what you really want to do.”

MSAA also interviewed Thomas D. Foy Jr., who is the founder of IRIS Financial Services and has been providing financial planning guidance to individuals and families for more than 35 years. “For adults diagnosed with MS, there is no such thing as planning too early. As a financial advisor, I am adamant to encourage my clients to seek legal direction as quickly as

possible. Quality legal documents are a must to ensure appropriate ongoing care as well as to maximize any benefits while avoiding the potential for disqualification.”

Generic documents, state laws, and financial planning with a professional versus on your own

Foy continues, “Any qualified legal professional would agree that you get what you pay for. Although the documents that are available online may be a quick fix, you run the

risk of missing important facts that may be available when interacting with a qualified legal professional. If you are financially able to hire an attorney, be sure to ask if he or she specializes in working with families with special needs. This is a subspecialty and it is critical that your legal professional has

experience in this area.

“Additionally, since each state determines the resources available and under what conditions, it is important to consider the differences based on your state of residency. Your legal professional and/or financial advisor should be equipped to discuss how things are handled in your state.”

Shenkman cautions, “I don't want to suggest that you play lawyer, doctor, or other professional on your own, but the realities are



that some people may not be able to afford more, but do your homework and make sure that the documents work for your state. If you move from one state to another, please see an attorney in the new state or update your documents if you're doing them on your own for the laws in the new state. Don't assume that the rules from the prior state will continue to apply. Some of the details are really significant and complicated. For example, if you're married and there's an issue with your marriage, and you decide to move out of state, the spousal rights under one state can be very different than another. You must see a lawyer before you go.

“Do not, and I repeat, do not, go on the internet, get a document, fill it out, sign it, and think that it's okay – unless you know it's specifically done for your state. Now, the ideal approach should be to hire an attorney in your state to help you with the state planning documents. If that's not affordable and you use something online, be certain that it conforms to your state's laws.

“I don't want to ‘nay say’ using internet documents, because many people cannot afford to go to an attorney. One of the biggest concerns I have with using internet documents, is even if the documents are robust and have lots of provisions, do you as a lay person, understand what selections you're really making? If you're going to go that route, spend some real time in advance to study and learn about each document and what you're doing, so you're at least informed. Sometimes getting together with a group of family members, friends, or other people with similar

circumstances can be of help. If doing the documents together as a group, you can ask questions of each other. Discussing a document like a healthcare proxy with a group of five or six may get you a better result than if you just try to do it on your own.

“Another concern I have with internet forms is that they are not really tailored to address your specific circumstances. So for example, and this is important, if you have MS, which is often typified by an exacerbation or an unexpected attack, and you are hospitalized for a period of time, your symptoms are worse for that period of time, but then typically subside. During this period of time, you may not be able to take care of tax, legal, and financial matters.

“With the typical legal document, once you're considered ‘incapacitated’ under the terms of the document, legally by state law, you permanently lose your position to act on this document. However, if you have a revocable living trust with a cotrustee, then you may have an agent or a successor trustee take care of things for you until you have recovered and can manage the trust yourself. This is just one way among others to ensure that you may continue to oversee your financial planning. With a disease like MS and other chronic illnesses that are typified by an attack, you need to be sure that the documents are tailored to address your specific circumstances.”

Financial planning for a child with MS

Foy points out, “If we are talking about a child with MS, parents need quality legal

advice to consider a special needs trust. These trusts are critical to outline the continuation of care in the event of a death or incapacitation of the current parents or other caregivers. These trusts will also contain the language necessary to protect federal and state benefits.”

Shenkman explains, “If you have a child with MS, you need to make sure there's financial resources for the child. Talk to an insurance consultant. Talk to a financial planner. Better off to start cutting your budget a little bit now to help protect and provide for a child. It's important to get on a financial plan, stay on a strict budget, and save for what the future may need so you can protect that child.

“You need to have an emergency document done to authorize someone to take care of the child should something happen to you, making sure that insurance and other information is available. A special needs trust, also known as a supplemental trust, is one of the documents that you may create to give your child financial security while not affecting government aid that your child is or will be receiving. Be mindful that the government aid isn't tainted or lost because money has been put in the child's own name. You really need a specialist to handle this type of a trust.

“One final point. If you're getting on in years and you have an adult child with MS, you still need to address your own care and financial stability. While you're helping your child who has health issues, you need to ensure that you are also protected. So it's really planning for both generations, your generation and that of your child.”



Closing Notes

Legal and financial planning for one's future is an extremely detailed and important responsibility, particularly when a disability or chronic illness is involved – whether it be a spouse, child, or other family member who may need care and guardianship after his or her primary care partner is gone. Readers are strongly encouraged to do their own research to learn more about the topics presented in this article. On the following page, several resources are listed, all of which provide more in-depth information on legal and financial planning.

Readers are also reminded that laws governing financial planning differ greatly depending on the state where one resides, so state resources should always be consulted. Ideally, speaking with a qualified legal or financial expert who specializes in serving the disabled or chronically ill communities will provide the best results and help ensure a positive financial future for you and your loved ones. ■

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WEBSITES

Special Needs Alliance

The Special Needs Alliance (SNA) at specialneedsalliance.org is a national organization comprised of attorneys dedicated to the practice of disability and public benefits law. This website offers a wealth of financial planning and legal information for individuals with disabilities. In addition to locating an attorney within one's state who specializes in financial planning for individuals with disabilities, visitors to the website may also find a number of informative articles, videos and podcasts, publications, and more.

Nolo Network

According to Nolo's website at nolo.com, with more than 50 web properties, the Nolo Network is one of the web's largest libraries of consumer-friendly legal information — all available for free. Although not specifically designed for individuals with disabilities, this website offers extensive legal information, a lawyer directory, a large collection of legal articles, and free legal documents, among many other resources. Nolo also publishes and sells books and software on a host of legal topics.

Academy of Special Needs Planners

Found at specialneedsanswers.com, the Academy of Special Needs Planners consists of special needs planning professionals such as attorneys, financial planners and trust officers who assist in providing the highest quality service and advice to persons with special needs and to their families. The Academy also provides direct information to persons with disabilities through a consumer website and monthly e-mail newsletter. If seeking information on a specific topic, a search on their website brings up a number of informative articles.

A Diagnosis that is Still in Question

By Dr. Jack Burks

MSAA's Chief Medical Consultant



Q: I am a 53-year-old female just recently diagnosed with CIS (clinically isolated syndrome), although I have experienced MS symptoms for many years and have been told it was fibromyalgia, EBV (Epstein Barr Virus), chronic fatigue syndrome, or similar conditions. Over the past year, I have developed numbness and tingling sensations with tremors, muscle spasms, and stabbing pain all over my body.

After seeing a new doctor in June, I was referred to a neurologist and he ordered an MRI, spinal tap, and extensive blood work. The MRI results showed evidence of lesions but very small ones. The spinal results showed high levels of protein (c-reactive, I believe) but no indication of oligoclonal bands (or “O-bands”), which puzzled him, leading to the clinically isolated syndrome (CIS) diagnosis. My MS panel blood work showed low red blood cell count and seriously depleted Vitamin B12 and D levels. While my doctor explained that the low vitamin levels are common in MS diagnoses, he also said that could be the reason for the numbness and tingling, muscle spasms, balance problems, and debilitating fatigue. I

am now receiving B12 shots and taking over-the-counter Vitamin D in high doses.

Currently I have sharp stabbing pain, lost sensation, as well as pins and needles in different places around my arm, shoulder, and hand as well as my toes and feet. I am in almost constant pain in the mid-thoracic area of my back and also in my rib area on both sides. My question is, should I have an MRI of my entire spine, or is the brain and cervical MRI sufficient, along with the CIS and vitamin-deficiency diagnosis?

A: Thank you for sharing your challenging story. In terms of what may help establish a diagnosis of MS, a spinal MRI with gadolinium (GAD) contrast certainly seems worthwhile. The complete spinal MRI may help evaluate your symptoms such as pain, tingling sensation, muscle spasms, balance problems, debilitating fatigue, and pain in the mid-thoracic area.

Was your brain MRI done with contrast? If not, a repeat brain MRI with gadolinium enhancement may also be useful. The high protein in your spinal fluid may be “gamma globulin,” which supports an MS diagnosis, even without “O-bands.”

Fortunately, you are taking Vitamin D pills and Vitamin B-12 shots. Depleted Vitamin B-12 can cause a serious “subacute combined degeneration” of the spinal cord, a disease which can mimic some MS symptoms. Vitamin D is often low in people with MS. Your diagnosis of CIS is defined as an “initial demyelinating event,” which indicates a high suspicion of MS. You apparently have had several additional events, which might be related to MS.

If uncertainty remains, your neurologist may recommend that you get a second opinion from an MS center as well. These centers can offer a comprehensive approach. Additionally, should you receive a diagnosis of MS, you may benefit from an MS disease-modifying therapy. Other treatments and other options may be discussed with your neurologist and possibly a team at an MS center. I hope you are able to identify what is causing your symptoms and find a treatment that will best address your problems.

Q: I am 41 years old and was diagnosed with MS in 2011. In November of 2017, I had a major relapse to where I had to be on short-term disability. I do not think I will be able to go back to work, even though I want to work. I'm trying to find alternatives to Ocrevus® (ocrelizumab) and Vitamin D. I have heard about coenzyme Q10 (CoQ10) and mitochondria (MitoQ®) supplements. Do you think those will help in any way to improve my walking and to use my hands and arms?

A: Coenzyme Q10 (CoQ10) and MitoQ are antioxidants, which are thought to protect the body’s cells and mitochondria from oxidative stress – a part of the aging process. Antioxidants may also play a role in metabolism and provide more energy. Proponents of these antioxidants believe that additional health benefits, such as lowering blood pressure or treating other conditions may also result, but these claims have not been proven. MitoQ is a branded version of CoQ10, and is marketed to be stronger, enhanced for greater absorption, and targeted toward protecting mitochondria.

A number of people with MS take antioxidant supplements with the hope of better long-term health. HOWEVER, no research indicates that these antioxidants are specifically helpful for MS or its damage to myelin. Antioxidant supplements are NOT an alternative to an FDA-approved, disease-modifying therapy (DMT) for MS. Individuals who may be helped through a DMT need to adhere to their treatment plan to gain the best possible results.

Although helpful, Ocrevus and Vitamin D are not your only options. If you are looking to make a change, I suggest you talk to your neurologist. He or she may want to refer you to an MS center for a second opinion. MSAA’s Helpline can assist you with locating an MS center, if needed. However, if you are not taking a DMT at this time, do not wait until your next relapse to discuss your options with your neurologist or the specialists at your closest MS center.

Q: Fourteen years ago, my daughter had trouble with her legs. After an MRI of the brain, the neurologist saw a lesion and said she had MS. She then went to another neurologist who disagreed, based on her response to some other type of test he gave her. Now 14 years later she is having pain in the legs and numbness in the feet. She has had an MRI of the spine and found to be in very good condition per the doctor. She also had an electromyography (EMG) which did not show anything. This has been going on for most of the 14 years to some extent or another. What would you recommend she do?

A: Your daughter has a 14-year history of recurring problems with her legs and feet. One MRI may have shown an MS-like brain lesion, according to one neurologist, but not to another neurologist. Her recent EMG (electromyography) is apparently normal. This test measures nerve and/or muscle health.

However, MS is a disease of myelin, the covering or insulation of the nerves (which are known as “axons”) in the brain and

PLEASE SUBMIT YOUR QUESTIONS TO:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
375 Kings Highway North
Cherry Hill, New Jersey 08034

Questions may be emailed to askdr@mymsaa.org. Please include “Ask the Doctor” in the subject line.

spinal cord. The EMG can be normal in people with MS. Her normal spine MRI does not eliminate MS or other diagnoses. The abnormal “lesion” in her brain MRI 14 years ago is worrisome. Getting a second opinion by an MS specialist at an MS center may be of benefit to you. MSAA’s Helpline Specialists may be reached at **(800) 532-7667** and can help locate a nearby MS center, if needed.

Q: My doctor wants to put me on Tecfidera® (dimethyl fumarate). My blood tests were positive for the JC virus. I also have no spleen. I am in fear of progressive multifocal leukoencephalopathy (PML). What are my chances of getting PML?

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A: Your good news is that similar to the other approved disease-modifying therapies for MS, Tecfidera is a very good treatment for MS. However, you have valid concerns about having the JC virus antibody present in your system, which may slightly increase your risk for progressive multifocal leukoencephalopathy (PML), a serious and sometimes fatal brain disease.

Overall, your risk for PML on Tecfidera is very small. Only a few PML cases have been reported in MS patients on Tecfidera. Strategies to reduce this small risk even more is to monitor your JC virus antibody regularly, get regular MRIs to check for early asymptomatic (without symptoms) PML, and to check your levels of white blood cells (lymphocytes) regularly. Low lymphocyte levels are associated with an increased risk of PML.

In addition, ANY new symptoms of brain function worsening, including psychiatric symptoms, need to be reported to your doctor quickly. Early treatment of PML is crucial to a better treatment outcome. Again, your chances of getting PML are very low, less than 1 percent, and careful monitoring that will allow for early treatment can reduce your risk of severe PML. In summary, a discussion with your doctor concerning the benefits and potential risks with

Tecfidera, as well as defining ways to further reduce your risk of PML, is very important.

Q: Would you comment on the difference between maintenance and induction therapies? This is a topic that many MS patients may not be familiar with.

A: Your question on “maintenance” versus “induction MS therapy” is a “hot topic” that is debated in MS international meetings. For those not familiar with the debates, let me explain the concepts.

In general, MS experts recommend first line “maintenance therapy” based on the potential benefits and low risks of the many older, self-injected MS therapies, such as the interferons and Copaxone® (glatiramer acetate). Patients were treated for many years with one drug as long as the results were satisfactory, and these individuals tolerated their medication well. For example, Betaseron researchers have followed individuals for more than 20 years of continuous Betaseron therapy and have found remarkable results in general on preventing disability and even death while on treatment. Many individuals taking the older medications have only experienced minor side effects and few or no adverse events.

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

However, new medications are now approved by the FDA, often with even better results than the standard MS therapies. Unfortunately, these new medications may have more serious side effects and the long-term risks are not known. For this reason, many doctors who specialize in MS start patients on the older therapies and only change treatments if a patient has deteriorated or suffered unmanageable side effects.

With the development of these newer and more powerful medications, the controversial concept of “induction therapy” has been introduced. The concept states that individuals with very active MS should be put on a stronger “induction therapy” to aggressively

stop the disease activity and transform a very aggressive MS disease course to a much more stable MS. After stabilization, the individual may be able to switch to an MS medication with fewer risks or potential side effects. Additionally, some of the highly effective treatments may not require retreatment for many years, if ever. It is too early to know. Maybe an intermittent retreatment may be repeated after several years, but only if the MS becomes active again.

The concept of induction therapy in MS is not universally accepted among MS specialists. This is because the risks versus the benefits are not clear-cut, and the long-term risks are not yet known. ■



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FDA Approves Two New Oral Treatments for Relapsing Forms of MS, Including Active SPMS

Mayzent® (Siponimod) Tablets

In a release dated March 26, 2019, the United States Food and Drug Administration (FDA) announced the approval of Mayzent® (siponimod) oral tablets to treat adults with relapsing forms of multiple sclerosis (MS). The approval includes individuals with clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), and active secondary-progressive MS (SPMS). Mayzent is the first disease-modifying therapy (DMT) to be approved in recent years for active secondary-progressive MS.

The FDA's press release explains that most people with MS start with a relapsing-remitting course of symptom flare-ups and remissions, possibly with some degree of residual disability. Over time, some patients experience an increase in disability that is independent of relapses, and this is referred to as "secondary-progressive MS."

Initially, people with this form of MS may still experience relapses, which is referred to as "active" secondary-progressive MS – the form that Mayzent is approved to treat. Without treatment, many of those with this form of MS eventually experience continued progression of disability without relapses, and this is referred to as "non-active" secondary-progressive MS. Mayzent is not approved for this latter form of the disease.

According to MSAA's *MS Research Update 2018*, siponimod is similar to Gilenya®

(fingolimod), working at the S1P receptor family to block the movement of lymph cells from lymph nodes; however, siponimod appears to interact with fewer receptors and does not stay in the body as long. Researchers hope that these small differences will minimize cardiac issues. According to Novartis, the makers of Mayzent, most patients will not require a first-dose observation (FDO) to monitor for cardiac events upon initiation.

The approval was based on the results of the EXPAND trial, a Phase III, multi-national study of siponimod involving more than 1,600 people with secondary-progressive MS. Participants were randomized to receive siponimod or placebo. The study found that, relative to placebo, siponimod reduced the risk of three and six-month confirmed disability progression events (CDP), slowed the rate of brain volume loss, and reduced the annual relapse rate. The trial also showed significant favorable outcomes in other relevant measures of MS disease activity, including cognition, reduced disease activity as shown on MRI, and reduced brain-volume loss (brain shrinkage).

According to the FDA, Mayzent must be dispensed with a patient Medication Guide, providing important information about how the medication is used as well as potential risks. Patients taking Mayzent need to be monitored for changes in vision caused by macular

edema, transient decreases in heart rate, decline in lung function, and changes in liver enzymes. Women who could become pregnant should use contraception to avoid potential risk of fetal harm. Healthcare professionals will need to monitor for other risks as well. Headache, high blood pressure, and changes in liver function tests were the most common adverse reactions reported by individuals taking Mayzent.

Mavenclad® (Cladribine) Tablets

In a release dated March 29, 2019, the United States Food and Drug Administration (FDA) announced the approval of Mavenclad® (cladribine) oral tablets to treat adults with relapsing forms of multiple sclerosis (MS). The approval is for individuals with relapsing-remitting MS (RRMS) and for individuals with active secondary-progressive MS (SPMS).

Mavenclad is not recommended for individuals with clinically isolated syndrome (CIS). According to the FDA, Mavenclad is generally recommended for patients who have had an inadequate response to, or are unable to tolerate, an alternate drug indicated for the treatment of MS.

Following the approval of Mayzent® (siponimod) oral tablets three days earlier, Mavenclad has become the second disease-modifying therapy (DMT) to be approved in recent years for active secondary-progressive MS. According to EMD Serono, the makers of Mavenclad, this medication “is the first and only FDA-approved treatment for RRMS and active SPMS that provides two years of proven efficacy with a maximum of 20 days of oral

treatment, during a two-year period.” Following these first two years, no treatment is needed for Years 3 and 4.

According to MSAA’s *MS Research Update 2018*, cladribine selectively targets the immune system’s B cells and T cells, leading to depletion of those cells. This is followed by a distinct pattern of “reconstitution,” as new B cells and T cells are produced.

The FDA’s approval of Mavenclad was based on the 96-week, Phase III CLARITY trial, where 1,326 patients with RRMS were randomized to receive one of two dose levels, or placebo. Patients receiving cladribine at either dose had annualized relapse rates that were less than half the rate of individuals receiving placebo. They also had a lower risk of sustained progression of disability and a greater reduction in the number of brain lesions identified on MRI relative to the placebo group.

The FDA explains that Mavenclad must be dispensed with a patient Medication Guide, describing important information about the drug’s uses and risks. Mavenclad has a Boxed Warning for an increased risk of malignancy (cancer) and fetal harm. Other warnings include the decreased lymphocyte (white blood cell) counts, infections, liver injury, and other health risks. The most common adverse reactions reported by patients receiving Mavenclad in the clinical trials include upper respiratory tract infections, headache, and decreased lymphocyte counts.

continued on page 40

New Resources Available from MSAA's Successful MS Awareness Month Campaign

By Peter Damiri

Vice President of Programs and Services

As you may have recently seen, MSAA focused much-needed attention, education and resources on the topic of MS and the Family during our 2019 MS Awareness Month campaign. Activities during a busy March centered around two key and significant aspects that impact families living with MS:

Relationships and **Care Partner Needs**.

Through the funding support of Sanofi Genzyme and EMD Serono, MSAA was proud to create new educational content and thoughtful conversations around helpful strategies to improve communication, strengthen relationships, accept help when needed, obtain supportive resources, and more.

For those who were able to participate in our month-long series of program activities, MSAA greatly appreciates your engagement and we hope you gained valuable insights and useful information. If you were unable to connect with MSAA during these scheduled programs or would like to revisit the information presented, we are pleased to announce that our live webinars and podcasts have been archived on our website's dedicated MS Awareness webpage for on-demand access. MSAA's Ask Me Anything programs can be read on our My MSAA Community online forum at healthunlocked.com/msaa.



*Marriage and family therapist Kimberly Castelo hosted MSAA's **Intimacy and Family Planning with MS** webinar.*

For the topic of Relationships and MS, MSAA activities included:

- **A live webinar on “*Intimacy and Family Planning with MS*”** presented by licensed marriage and family therapist Kimberly Castelo, LMFT, CST, CIIP. In this one-hour program, Ms. Castelo addresses ways to understand MS as a couple; sexual dysfunction and intimacy issues; the effects of MS on family planning and treatment options; and effective strategies to improve communication, conflict resolution, and better health outcomes.
- **MSAA's inaugural podcast, *Exploring Relationships***, presented by psychologist, social worker, certified guided imagery practitioner, and multiple sclerosis specialist Miriam Franco, MSW, PsyD, MSCS. Drawing

upon her wealth of professional expertise, Dr. Franco discusses physical and mental fatigue, depression and anxiety, and how men and women communicate differently among many additional topics. The program also provides listeners with valuable insights to help spouses and couples living with MS address these issues and grow and strengthen their loving relationship.

- **The return of our very popular “Ask Me Anything” (AMA) live chat program** hosted on MSAA’s online peer-to-peer forum, My MSAA Community. One week following her webinar, Ms. Castelo rejoined MSAA and continued the conversation on relationships and MS during this engaging question and answer session.

For the topic of Spotlighting Care Partner Needs, MSAA activities included:

- **“The Partnership of Care: Redefining Caregiver to Care Partner” webinar** conducted by MS nurse practitioner Megan Weigel, DNP, ARNP-c, MSCN. This well-presented webinar addresses the care partnership concept between MS couples and the family, the importance of good communication and the need to take care of yourself as a care partner.
- **Our Spotlighting Care Partner Needs podcast** presented by licensed clinical social worker, therapist, and wellness educator Lara Krawchuk, MSW, LCSW, MPH. In this easy,

*MS nurse practitioner
Megan Weigel hosted
MSAA’s **The Partnership
of Care: Redefining
Caregiver to Care
Partner** webinar.*



conversational-style program, Ms. Krawchuk discusses the challenges associated with care partnering and steps couples can take to work together as a team, understand when to ask for and accept assistance, and how to build out a wide support system.

- **A live AMA chat program to further explore care partner needs** featuring Ms. Krawchuk. This one-hour program, hosted on the My MSAA Community forum, touches on many real-life issues that impact everyone in the family.

MSAA would like to thank the above-mentioned presenters who provided a wealth of extremely helpful information and resources on these important topics, funders Sanofi Genzyme and EMD Serono, and all those who participated in the programs. We encourage everyone to view these archived programs by visiting our website at **mymsaa.org/awarenessmonth**. ■

The Golden Rule

by Erich Fasnacht, Vice President of Development
Fundraising profiles by Kaitlyn Gallagher

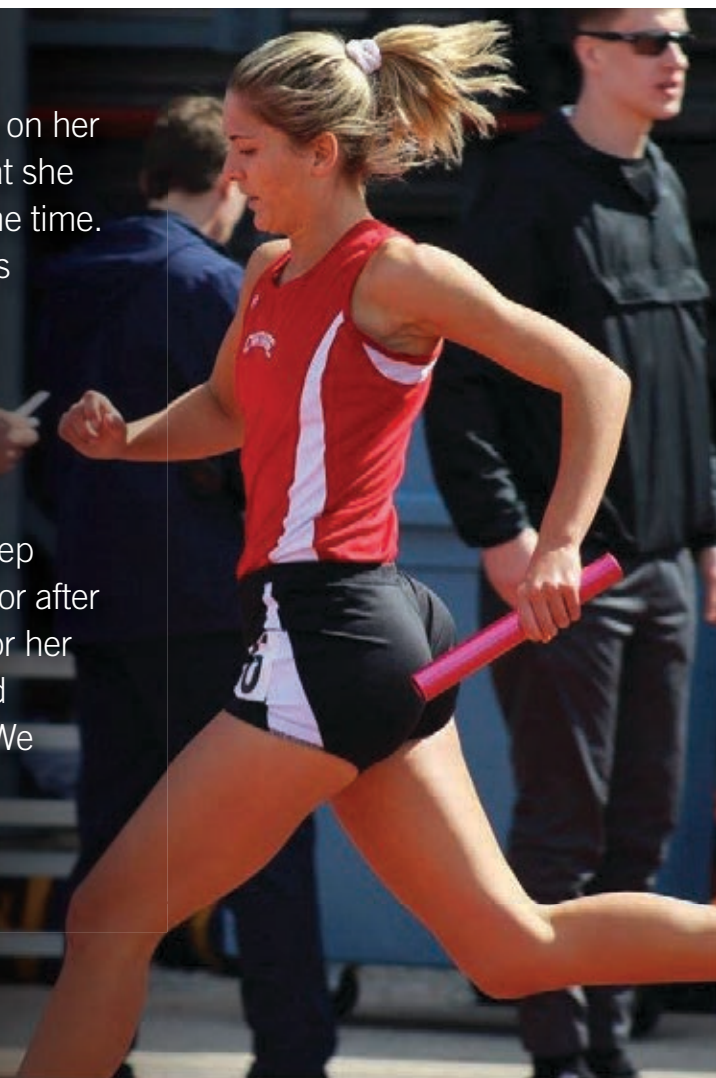
At a time and place in our country where there is so much passionate discourse, I continue to find comfort in one maxim that is shared across so many religious, political, and social texts – the Golden Rule – “do unto others as you would have them do unto you.” As simple as this is to describe and state, it’s more difficult to actually put into practice. We don’t always see how people are being treated, or what their needs may be.

But I want to think for a moment about that critical phrase that so many people in our community have heard from a doctor at some point in their lives: “You have multiple sclerosis.” From that moment on, their lives have changed. The trajectory of their hopes and dreams are altered. Their plans for physical activities may be changed. The day-to-day scheduling of doctor visits, managing symptoms, and coping with an unpredictable

13.1 MILES FOR THE MS COMMUNITY

On Sunday, July 21, 2019, runner Taylor Tenca will take on her very first half-marathon as a part of Team MSAA, a task that she has been hoping to cross off her “bucket list” for quite some time. Raising awareness for MS is a cause that is close to Taylor’s heart, which is why she’s training hard to cross the finish line at the Rock ‘n’ Roll Half Marathon in Chicago while fundraising for MSAA’s free programs and services. “My strategy is to not get burned out too early into training. Slow and steady training will get me better results,” said Taylor. “I am running with a friend of mine – we hope to keep each other on track and motivate each other to run before or after work, five days a week.” Taylor’s original fundraising goal for her half-marathon journey was \$500. To date, Taylor has raised more than \$1,000 with the help of her friends and family! We wish Taylor the best of luck as she continues to train and prepare in support of the MS community!

Taylor Tenca is a seasoned runner taking her talents to Team MSAA



MSAA is made up of people like you, working together to make sure that those who receive an MS diagnosis will also receive vital services to improve their lives.

chronic condition becomes a full-time concern. What does the Golden Rule tell us about these individuals, who have just heard this news? What would *you* have others do if you suddenly found yourself in this situation?

You would want to know that you are not alone... and that resources are available to help you. You would want to know that there is a community of people going through the same experiences... and that many donors are willing to give a helping hand.

Thank you to those individuals, from whatever your walk of life, religious background, or political persuasion, who take the Golden Rule to heart, and do unto others what you would have them do unto you. MSAA is made up of people like you working together to make sure that those who receive an MS diagnosis will also receive vital services to improve their lives – from free safety and mobility equipment, to MRI funding assistance, educational programs, Helpline support, and more!

Please contact me directly with any thoughts you have on donating to MSAA today, or making MSAA part of your legacy giving. Thank you for your support. ■

Erich Fasnacht
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Funding for this brochure was made possible by Novartis.





Lee Estep enjoys her time at the Jersey Shore while supporting MSAA.

MAKING WAVES WITH SWIM FOR MS

Swim for MS participant Lee Estep has always loved swimming. She was on the swim team in college and even taught and worked as a Waterfront Director during her time in school. Lee was diagnosed with multiple sclerosis in 2016 – as a result, she started swimming regularly to help manage her MS symptoms – she even swam in the ocean when she was at the Jersey Shore on vacation last summer! Lee is so appreciative of all the support she received from MSAA, especially the cooling vest which allowed her to enjoy the outdoors during the warmer weather. “I was thrilled with the opportunity to be able to give back by asking close friends and family members to support my Swim for MS fundraiser,” said Lee. In 2018, Lee was able to swim on a regular basis and raise more than \$500 in support of MSAA’s free programs and services! ■

FUNDRAISING MADE EASY WITH FACEBOOK

MSAA is pleased to announce two new and exciting ways to support the MS community! Facebook users are now able to create Birthday and Occasion Fundraisers in support of MSAA directly on the social media platform. Facebook Fundraising pages allow you to share your story, tell others about MSAA’s mission, and collect donations to meet your fundraising goals! They are easy to share and will provide your friends and followers with automatic notifications to remind them to contribute to your cause.

Additionally, Swim for MS and Team MSAA endurance participants are now able to connect their MSAA peer-to-peer fundraising pages to Facebook to raise money even faster! Connecting your peer-to-peer fundraiser with Facebook only takes a few clicks and all donations received through Facebook will be reflected on your personal fundraising page and your fundraising thermometer.

Ready to create or connect your fundraiser? Learn more at support.mysaa.org/fbfundraising

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Samantha Stettner's original Swim for MS goal was to raise \$1,000 while swimming 1,000 meters each day for 30 days. By the time her challenge ended in December 2018, she had raised more than \$1,700! Participating in Swim for MS gave her the confidence to join a local swim team once her challenge ended in order to continue her regular exercise!

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Driven to Succeed

By Jo Ann Maxwell

It all started when my mother was in the hospital. My niece came down from Ohio to see my mother, and she and I walked several times from my mother's room to the cafeteria. I'm sure you've been to a hospital and know how far that might be! Without me present, she mentioned to my mother that I was walking poorly and I should have hand controls in my car. That started conversations within my family that I needed to get hand controls... and needed them quickly.

I've known that I would eventually need hand controls, but I got a little upset that all of a sudden my family was pressuring me. I know they only want the best for me and want me to be safe. I guess I just didn't like the way the conversations started.

One of my good MS friends told me that I was being fearless to admit that I needed the hand controls. That really turned my attitude around! I refuse to let MS take one more thing from me! I knew that ultimately, I would gain independence through the use of hand controls.

I contacted several different organizations for assessment, training, and installation. I learned that there was an occupational therapist driving instructor in my area. I made an appointment for an assessment. I had become determined that it was time for me to make the switch.



I had my first driving training for hand controls a couple of weeks later. It was a little scary. Not only were we having a terrible rainstorm, but while my left hand was operating the brake/accelerator mechanism, my right hand and arm were having trouble with the knob on the steering wheel. We drove for more than an hour and a half, and I got very fatigued. The occupational therapist who was my driving instructor was very concerned. She wondered if I would be able to drive at all.

We tried a different knob configuration for my right hand and arm the next day. It was a disaster, turning out to be much harder than the first one we used. The instructor stopped the driving lesson after five minutes and told me that she would be writing a report to the DMV. I asked her if she thought they would pull my license after they saw that I was not successful with the training. She said they might.

She also mentioned that there could be a right installation of the brake and accelerator mechanism instead of the left. With this configuration, my left hand, which had become my dominant hand, would be on the steering wheel. She said that the dominant hand should be on the steering wheel.

Unfortunately, the local occupational therapist did not have a right-installed brake

and accelerator control. The closest certified driving instructor (another occupational therapist) with the kind of controls I needed was about four hours away. I was fortunate to find out that this second occupational therapist would soon be in my area, so she and I did some training... and I was very glad that I didn't have far to drive for my training!

In the meantime, I received a letter from the DMV saying that they had approved my medical request for specialized equipment in the car. I called them immediately and received an extension, as I needed to practice with the new controls. The person who I talked to stated that I can get an extension with a recommendation from my doctor, which I did.

I had some apprehension about the new configuration of hand controls, as I had already tried several different combinations. I had driven with my feet for 50 years, so my brain was struggling to figure out this new way. But, I had a wonderful session of driver training with the second occupational-driving instructor. We tried several configurations of a right-handed accelerator/brake. There are several ways you can use a hand control for the car. For example, you can push for the brake, and for the accelerator, you can either pull back or twist. The one that worked the best for me was the push and pull. I am also able to rest my arm on the middle console, which helps to keep my fatigue under control.

With my right hand using the hand control to brake and accelerate, my left hand – which is my stronger hand – operated the steering wheel. Using a knob that mounts on the steering wheel, we tried a less-resistant steering



For an individual who has difficulty operating a car using a standard steering wheel and foot pedals, hand controls may be installed. Shown above is a steering wheel knob on the right and a lever for accelerating and braking on the left.

using the regular steering wheel with the special knob.

The next step was to get a new quote from the installation company. I have been very blessed to receive financial assistance from a few charitable organizations. As it happens, the right controls are a little more expensive than left controls.

After 50 years of driving, I finally received my learners permit! The hand controls were installed soon afterward. I had been practicing and practicing. I really had to pay attention, especially when going from reverse to drive or vice versa. The driving test consisted of driving on a state highway, turning onto a main road,

going into a quiet neighborhood, performing a three-point turn, and backing up. Then we drove back to the DMV office. The DMV officer said I did well and I passed! Yahoo!

With this new equipment added to my car, I have also found that the extra mirrors really help. Since my two hands are busy working the brake and accelerator, it's hard to turn and look behind me. There is an added bonus as well – now that I'm driving with my hands, I can wear my ankle-foot orthotic (AFO). I couldn't drive with it before, so I very rarely used it. Now that

I can have it on all the time, I am walking so much better with it!

Even though it took six months, I'm very glad I went through with getting the hand controls for my car. It's amazing how small changes can make a big difference, and I can still drive independently. I am feeling more and more confident every day! ■

PLEASE NOTE: This issue features two reader-submitted "Stories to Inspire" articles. Please see page 42 for the second article.

Research News

continued from page 31

Analysis Shows Number of People with MS to be Much Higher than Previously Estimated

As many as 913,925 people living in the United States had multiple sclerosis (MS) in 2017, according to estimates derived from an extensive analysis of healthcare claims. That number is more than double the previous estimate of 400,000 affected people in the United States.

Researchers arrived at the higher figure by using a sophisticated algorithm (a step-by-step problem-solving process) to analyze the data found in claims from private, public, and military healthcare systems covering more than 125 million people. Investigators estimate between 851,749 people and 913,925 people are living in the United States with MS as of 2017, or from 337.9 to 362.6 cases per 100,000 people.

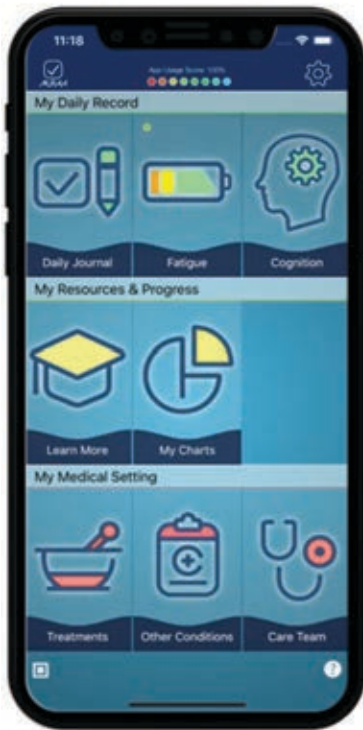
These findings suggest that there has been a steady rise in the prevalence of MS over the past five decades, the researchers noted. Correcting lower, inaccurate estimates of how many people are affected by MS is critical as the government, payers, and healthcare systems determine how to allocate resources – including research funds and patient-care staff – to address various conditions and diseases.

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

Portions written by Susan Wells Courtney, MSAA Senior Writer, and Tom Garry, Medical Writer

Reviewed by Dr. Jack Burks, MSAA Chief Medical Consultant

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Please visit mymsaa.org/mri or call (800) 532-7667, ext. 120 for more information.

MSAA's MRI Access Fund is made possible with support from Biogen and Sanofi Genzyme.



Our Family Heroine

By Judy Heilpern Eror

No one was more surprised than I was when my daughter, Catherine Garff, decided to train for the St. George Marathon. Ours is not a running family. We cycle, ski, and swim. We do not run. But Catherine is our family heroine. So she runs.

More than eight years ago, Catherine was diagnosed with multiple sclerosis. At the time, none of us knew what that meant and all of the books, pamphlets, and lectures that were recommended seemed to be full of gloom and doom. Catherine, however, is not a gloom-and-doom woman. She is amazing.

Sixteen months ago she gave birth to her youngest child – six weeks early. Catherine's blood pressure (preeclampsia) was 180 over 130. In addition to taking care of her own health issues and recovering from an emergency C-section, the baby came home with a feeding tube and an oxygen tank. If that wasn't enough, she had three other children to take care of.

Instead of feeling sorry for herself, Catherine started running. She set a goal of running the St. George Marathon – it would be her first marathon. She researched marathon training, diets, and made a plan – putting everything in a spreadsheet. And then she went to work.

Halfway through Catherine's marathon training this summer, Catherine started battling severe fatigue – a common symptom of the disease. She also began losing the feeling in

her face, arms, and legs. When she ran, she would get electric shocks down her legs. She has had MS for more than eight years, but after an MRI, it was found that Catherine's MS treatment stopped working. She had new lesions on her spine and she was in the middle of an MS relapse.

Together with a doctor, she's started a new treatment and has regained the feeling she lost in her face, arms, and legs. She has also gotten her fatigue under control, but through it all, she kept running. She will run a 13-mile training run in the morning, and go get a medication infusion at the doctor's office in the afternoon. She's been on her new treatment plan and it's working, but what is really impressive to our family is that even while going through her relapse and with all the issues she's been battling – on top of work, mothering, and typical runners' ailments – she hasn't skipped a single training run.

Catherine is more disciplined than any person I know. She has set a healthy meal plan and kept to it. She has run two half-marathons and one full one this year in preparing for St. George. Last week, on a one-day notice, she even flew to New Hampshire to join a running team who found themselves in need of a last-minute substitute.

My daughter is married to a great husband and she supports him in his career and his very active outdoor hobbies too, such as competitive bicycle racing. Catherine is the mother of four children (Daniel age 8, Catherine age 6, Duncan age 4, and Scott age 16 months). She is a successful real estate agent, and with her husband, they own a



Catherine Garff was honored to receive the Ed Wilson Special Achievement Award. This award celebrates the people who have achieved personal greatness in their lives. This award has been given to runners and wheelchair participants of all ages and circumstances – those who have gone the extra mile in overcoming adversity in their training and personal lives to run the marathon.

brokerage together. She has served as the Chairwoman of the board of the Rape Recovery Center. She has been an active volunteer at her children's school and has also served in her church. She has set an example for everyone around her.

Like I said – in our family, we don't run – we cheer. And we cheer loudly for the heroine that I am grateful to call my daughter, Catherine Elaine Eror Garff. ■

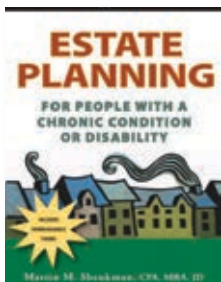
MSAA's Lending Library Selections

Estate Planning: For People with a Chronic Condition or Disability

by Martin M. Shenkman,
CPA, MBA, JD

Demos Health

MSAA Book #444



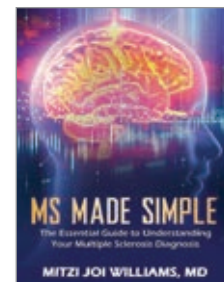
This book offers a great amount of information on financial and legal documents and considerations when chronic illness is involved. Written by a prolific lawyer who specializes in empowering people through his writing, *Estate Planning: For People with a Chronic Condition or Disability* provides vitally important details that can help individuals with MS and their families to plan for their future and financial security.

MS Made Simple: The Essential Guide to Understanding Your Multiple Sclerosis Diagnosis

by Dr. Mitzi Williams

Purposely Created Publishing Group

MSAA Book #317



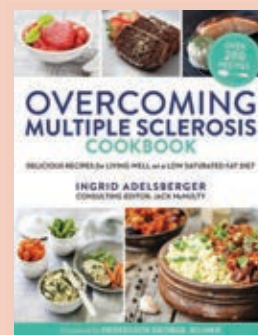
In *MS Made Simple*, Dr. Mitzi J. Williams, a neurologist and MS specialist, shares her expert knowledge of the disease. She explains basic concepts including what MS does to the body, how it's diagnosed, treatment options, and what to expect over the course of the disease. She also covers topics including MS in African Americans, the importance of research participation, and the need for collaboration with one's healthcare team.

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

Overcoming Multiple Sclerosis Cookbook: Delicious Recipes for Living Well with a Low Saturated Fat Diet

by Ingrid Adelsberger

Allen & Unwin | MSAA Book #364

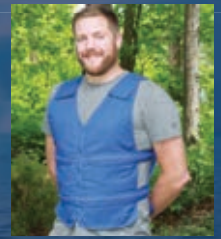
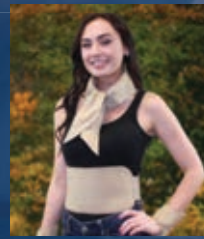


Medical research suggests that a diet very low in saturated fat may help to slow the progression and severity of MS. This cookbook gathers more than 200 favorite recipes from people with MS from around the world. The recipes include quick and easy lunches and dinners, a variety of seafood dishes, luxurious weekend breakfasts, special occasion cakes, and holiday baking. Recipes include wholefood, meat-free, dairy-free, vegan, and gluten-free options, along with a menu plan created by a nutritionist.

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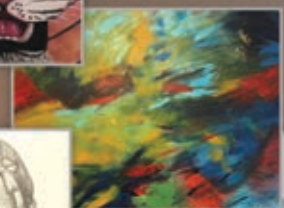
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You can view the complete online galleries by visiting
mymsaa.org/artshowcase2019





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