

**MSAA**

MULTIPLE SCLEROSIS  
ASSOCIATION OF AMERICA

*Improving Lives Today!®*

Winter/Spring 2018

# THE Motivator

Published by the Multiple Sclerosis Association of America

A photograph of a Black couple standing in a garden filled with colorful flowers. The woman, on the left, is wearing a magenta top and blue jeans, and is holding a small potted plant with yellow flowers. The man, on the right, is wearing a dark blue striped shirt and is smiling at her. The background is a lush garden with various flowers and greenery.

**FINDING  
DIRECTION**

**WHEN NEWLY DIAGNOSED**



# Announcing TEAM MSAA's Endurance Events

This year, MSAA is a charity partner for several endurance events across the nation! Please join Team MSAA in making a difference in the lives of individuals affected by multiple sclerosis.

## Tough Mudder Series

Events Nationwide

## Rock 'n' Roll Marathon Series

Events Nationwide

## Marine Corps Marathon

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## Disney Princess Half Marathon Weekend

Presented by Children's Miracle Network Hospitals®

Held at Walt Disney World Resort®

February 21 - February 24, 2019 | Orlando, FL



For more information, please visit

**[support.mysaa.org/teamMSAA](http://support.mysaa.org/teamMSAA)**

## ANY POOL, ANY TIME

*Dive into action with Swim for MS  
...any season of the year!*

**SWIM FOR MS** is a national fundraiser in which volunteers are encouraged to create their own swim challenge to support MSAA. It's as easy as 1-2-3!

1. Create your own swim activity
2. Set a challenge goal
3. Recruit family & friends to donate!

## REGISTER TODAY!

Visit **[SwimForMS.org](http://SwimForMS.org)** or  
call (800) 532-7667 ext. 157

**SPONSORS:** HardcoreSport • Endless Pools



13-year-old Walker is swimming laps in honor of his mom who has MS. Walker has pledged to swim laps for one minute for each dollar donated during his second Swim for MS challenge!



**SWIM FOR MS**  
ANY POOL, ANY TIME

Published by the Multiple Sclerosis Association of America

**Gina Ross Murdoch**  
President & CEO

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**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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# Accepting the “New Normal” for Life with Multiple Sclerosis



**By Gina Ross Murdoch**  
MSAA President and CEO

You hear the news, “You have multiple sclerosis,” and wonder what is next and how you will handle this news. This edition of *The Motivator* focuses on how you and those around you may best begin and continue your MS journey, once you have become “newly diagnosed.” For readers who may not be “newly diagnosed,” you’ll find some interesting information in our cover story as well.

As many of you will recall, prior to your diagnosis, you may have been searching for a reason for your symptoms without solid answers. Now that you have received that answer, you will probably have a myriad of questions about treatment decisions, employment, wellness, daily life, family, and so much more. While this can be an exceedingly challenging time, MSAA is here for all individuals affected by multiple

sclerosis, with a wide array of vital services for the entire family.

All people diagnosed with MS come to accept their “new normal” in their own way and time. Do you want to attend an in-person program, or are you more comfortable learning about key information at home – through MSAA’s website, publications, videos, webinars, or by speaking with one of our Helpline specialists? There is no right way to begin your life with multiple sclerosis, either as the person living with MS or the family around him or her. Everyone approaches this differently. As you read our cover story, you will see that you are not alone on your journey and that MSAA is ready to offer support, resources, and connections, all free of charge to the MS community.

In our “Thoughts about Giving” column, you will read inspiring stories of perseverance and determination by our Team MSAA endurance participants. This group of amazing volunteers committed to run or

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



walk anywhere from a local 5K event to the Walt Disney World® Dopey Challenge of 48.6 miles! They participated in Rock n' Roll events, Tough Mudders, and the Walt Disney World® Marathon Weekend presented by Cigna®.

I was among the runners who laced up and took off in support of MSAA. I joined Team MSAA as a full participant raising funds and completing a half marathon. I was running in honor of so many living with MS, who inspired me to keep going throughout the race. Their strength in facing the challenge of MS every day helped me cross the finish line along with the rest of the Disney team.

You will learn the heartwarming story of Bekah and Rachael who took on the Dopey Challenge (48.6 miles) on behalf of their father, Dan Scharett, who is living with MS. I had the pleasure and honor of meeting Dan at our Team MSAA breakfast. I was moved by his determination to live life to the fullest – no matter what MS threw his way!

I hope you enjoy this issue and find it informative and inspiring. Most of all, I hope



*(From left to right) Dan Scharett is joined by MSAA President & CEO Gina Ross Murdoch, along with Dan's wife Elizabeth Scharett, race participant Katie Kern, and Dan's daughters (and race participants) Rachael Scharett and Bekah Ware, for an enjoyable breakfast before the weekend races in Walt Disney World®.*

you see that MSAA is truly here by your side for the MS community, whether you are newly diagnosed, taking on the challenge of an endurance event, searching for critical resources, or needing to talk to one of our Helpline specialists. We are here to Improve Lives Today! ■

## NEW MSAA PUBLICATION AVAILABLE

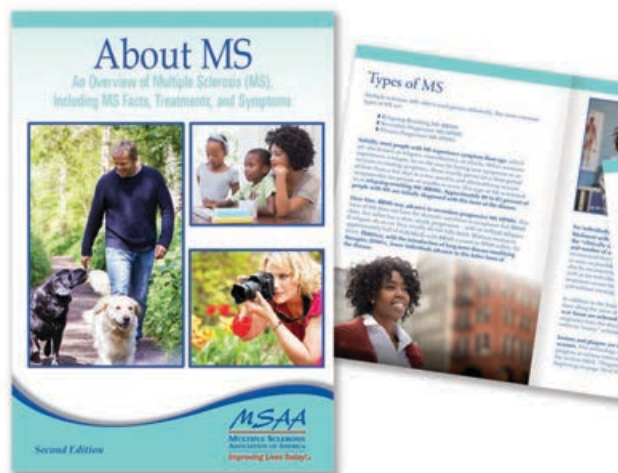
### **About MS** *Second Edition*

#### ***An Overview of Multiple Sclerosis (MS)***

*Including MS Facts, Treatments, and Symptoms*

To download or order *About MS*, please visit

**[mymsaa.org/about-ms](http://mymsaa.org/about-ms)**



# FINDING DIRECTION

## WHEN NEWLY DIAGNOSED

An overview of the many factors involved with a diagnosis of MS and information to help with making choices



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By **Susan Wells Courtney**

**M**ost individuals who have been diagnosed with MS often talk about the confusion around their initial symptoms, and the long period of waiting for an answer. Once the diagnosis of MS is confirmed, this typically creates more confusion... and countless questions. The purpose of this issue's cover story is to explain the basics behind MS, as well as treatment options, details on some of the more challenging symptoms, employment issues, and government programs. At the end of the article, readers will find a list of resources for more information.

Although many readers of *The Motivator* may no longer be considered newly diagnosed, and much of the information may not be new to them, they may find that certain details are of help, including the employment or government program information, as well as the list of resources. Additionally, this article is a good reference for people to share with relatives and friends who may be unfamiliar with MS – and much of the information may help those relatives and friends to better understand the difficult challenges faced by individuals with MS.

# THE BASICS

## What is MS?

**Multiple sclerosis (MS) is a disease of the central nervous system (CNS)**, consisting of the brain, optic nerves, and spinal cord. With MS, areas of the CNS become inflamed, damaging the protective covering (known as “myelin”) that surrounds and insulates the nerves (known as “axons”). In addition to the myelin, over time, the axons and nerve cells (neurons) within the CNS may also become damaged. **MS is thought to be an autoimmune disease**, where the body’s own white blood cells become misdirected and attack the body’s myelin and axons.

## Who gets MS?

**Most people with MS experience their first symptoms and are diagnosed between the ages of 15 and 50**, although individuals of any age, including children, may be diagnosed with MS. Women are three times more likely than men to develop a relapsing form of MS. Geographically, people who live farther from the equator (in more temperate climates) have a higher risk of developing MS than people living in hotter areas near the equator, or in very cold areas near the north or south poles. The degree of risk associated with where someone lives as a child will remain throughout his or her life. More prevalent among those of northern European or Scandinavian ancestry, Caucasians have a higher incidence than those of African or Hispanic heritage to develop MS.

## Is MS Contagious?

**MS is not contagious, nor is it hereditary.**

However, MS susceptibility is increased if a family member (blood relative) has MS. The average risk of developing MS in the United States is one in 1,000, or one-tenth of one percent. For first-degree relatives (such as a child or sibling), the risk increases to three or four percent. This is not true for adopted children or half siblings (who do not share the same parent who has MS), whose risk is the same as unrelated individuals. With identical twins, if one twin has MS, the other’s risk is about 30 percent; non-identical twins’ risk is equal to other siblings.

## What are the Possible Causes of MS?

**Researchers have studied a variety of possible causes for multiple sclerosis (MS), and a combination of factors appears to be involved.** A popular theory looks at commonly known slow-acting viruses (one that could remain dormant for many years), such as measles, herpes, human T-cell lymphoma, and Epstein-Barr.

Genes have some role in susceptibility to MS, but the exact mechanisms remain unclear. Additional theories include nutritional factors (such as fat intake as well as deficiencies in fish oil and Vitamin D), cigarette smoking (increasing MS risk and worsening disease activity), and the interactions of bacteria that live in the intestines (referred to as “gut microbiota”), among others. Certain parasites may be a possible risk-reduction factor in the development and severity of MS.



## How is MS Diagnosed and Disease Activity Evaluated?

**Diagnosing and evaluating MS disease activity is most reliably done by neurologists through a neurological history and examination.** Tests that can indicate MS and rule out “MS mimickers” (other diseases that resemble MS but have other causes) are also performed. **Lesions (areas of inflammation and myelin damage in the brain and/or spine) may be viewed on a magnetic resonance imaging**

**(MRI) scan.** Inflammation can be better evaluated with gadolinium (or contrast) enhancement – a type of dye given to the patient via injection prior to the procedure. Test results can also help determine the effectiveness of a disease-modifying therapy (DMT), or to get an “inside view” of a patient’s disease status. Other tools sometimes used for an MS diagnosis are lumbar puncture (spinal tap) and evoked potential (EP) tests, measuring nerve response.

## TYPES OF MS

Multiple sclerosis (MS) affects each person differently. The most common types of MS are:

- Relapsing-Remitting MS (RRMS)
- Secondary-Progressive MS (SPMS)
- Primary-Progressive MS (PPMS)

**Initially, most people with MS experience symptom flare-ups**, which are also known as relapses, exacerbations, or attacks. When someone experiences a relapse, he or she may be having new symptoms or an increase in existing symptoms. These usually persist for a short period of time (from a few days to a few months) and afterward the person may remain symptom-free for periods of months or years. This type of MS is referred to as relapsing-remitting MS (RRMS). Approximately 80 to 85 percent of people with MS are initially diagnosed with this form of the disease.

**Over time, RRMS may advance to secondary-progressive MS (SPMS).** This form of MS does not have the dramatic variations in

symptoms that RRMS does, but rather has a slow, steady progression – with or without relapses. If relapses do occur, they usually do not fully remit. Without treatment, approximately half of individuals with RRMS convert to SPMS within 10 years. However, with the introduction of long-term disease-modifying therapies (DMTs), fewer individuals advance to this latter form of the disease.

Individuals who are not initially diagnosed with RRMS may be experiencing a more steady disease progression. **Approximately 10 percent of the MS population is diagnosed with primary-progressive MS (PPMS)**, where individuals experience a steady worsening of symptoms from the start, and do not have periodic relapses and remissions. This form is usually diagnosed in older people.

**A small percentage of individuals are diagnosed with less-common forms of MS.** While some disagreement exists regarding the terminology, these less-common forms include progressive-relapsing MS, fulminate MS, benign MS, and burned-out MS.





opens up possibilities

Laura S., living with relapsing MS

## 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](http://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](http://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](http://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](http://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](http://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



# RELAPSES

## What is a Relapse?

Relapses, also referred to as exacerbations, attacks, flare-ups, episodes, or bouts, are initially experienced by most people diagnosed with multiple sclerosis (MS). Relapses occur with relapsing-remitting and sometimes secondary-progressive forms of MS, in which case both are considered “relapsing forms of MS.” Relapses do not occur with primary-progressive MS (PPMS), although people with PPMS may experience day-to-day fluctuations.

**During a relapse, inflammation is occurring along the nerves and the myelin, causing people with MS to have a temporary worsening or recurrence of existing symptoms and/or the appearance of new symptoms.**

This can range from a few days in duration to a few months, followed by a complete or partial recovery (remission). Acute physical symptoms and neurological signs must be present for at least 24 to 48 hours, without any signs of infection or fever, before the treating physician may consider this type of flare-up to be a true relapse.

**A pseudoexacerbation is a temporary worsening of symptoms without actual myelin inflammation or damage,** brought on by other influences. Examples include other illnesses or infection, exercise, a warm environment, depression, exhaustion, and stress. When symptoms flare, checking for a fever is important, since even a minor infection and slight increase in temperature can cause symptoms to appear.

## RELAPSE FACTS

- ✓ Inflammation along nerves and myelin
- ✓ New or worsening symptoms
- ✓ Symptoms must be present for at least 24 to 48 hours, without a fever
- ✓ Duration of a few days to a few months



## PSEUDOEXACERBATION FACTS

- ✓ Not caused by new damage
- ✓ Brought on by other influences
- ✓ Urinary tract infection is most common cause
- ✓ Usually subsides within 24 hours



## How Are Relapses Managed?

Relapses are usually treated with a **high-dose course of powerful corticosteroids** (a type of steroid) over a period of three to five days. These are given by intravenous (IV) infusion, administering the drug directly into the bloodstream for a quicker response. Some doctors prescribe oral steroids after the high-dose treatment, to ease the patient off of the medication. **Another FDA-approved option** is Acthar® Gel, which contains a highly purified form of the hormone **adrenocorticotropin (ACTH)**. It is given once daily for two to three weeks and is injected either into the muscle or under the skin.

# TREATMENTS

## The Importance of Long-Term Treatment

**Treatment with a long-term disease-modifying therapy (DMT) is crucial for most people with relapsing MS, as well as for some individuals with primary-progressive MS (PPMS),** since disease activity and damage usually continue within the CNS even when no new symptoms are present. When a person begins a treatment regimen early in his or her disease course, disease activity is slowed for most individuals. This not only reduces the number and severity of symptom flare-ups, but also reduces the number of active lesions that appear on an MRI, as well as delays the progression of the disease (possibly delaying any related disability). Getting early treatment and staying on a DMT for MS may also delay the rate of conversion from relapsing-remitting MS (RRMS) to secondary-progressive MS (SPMS).

## The FDA-Approved Treatments for MS

The chart shown on page 11 includes the 15 DMTs currently approved by the Food and Drug Administration (FDA) for the long-term treatment of MS. Additional DMTs are likely to be approved by the FDA in the near future. All of these DMTs are approved for treating either relapsing-remitting MS (RRMS) or all relapsing forms of MS, which includes secondary-progressive MS with relapses. Ocrevus™ is the exception, which is also approved for primary-progressive MS. In addition, some of the DMTs have been

approved for “clinically isolated syndrome” (CIS), which refers to a patient reporting one or more symptoms prior to a diagnosis of MS.

## Talking to One’s Neurologist about Treatments and What to Ask

MSAA’s S.E.A.R.C.H.™ program is just one of several programs designed as tools for individuals with MS and their families to play a more active role in the successful management of their MS. Among the numerous questions to consider include: What are the therapies? Am I a candidate? What should I know about each one? How will my body react to taking one of these medications? How are the different medications administered? What about the costs or insurance? Once I have begun taking a DMT, how do I know if the one I am prescribed is working?

Another tool developed by MSAA is My MS Manager™, a free application for iOS and Android mobile phones and devices. This app helps individuals to track and record their medications, symptoms, and side effects, as well as create reports for their healthcare professionals.

## Remaining Adherent

Once a DMT is initiated, evidence has shown that treatment needs to be ongoing for benefits to persist. Non-adherence and gaps in treatment have been associated with an increased rate of relapses and progression of disability. Helpful strategies include: managing the side effects of the medications; understanding expectations of the DMTs by



allowing six months to one year to see the effects; adjusting to a treatment by consulting an MS nurse or other healthcare professional with questions; and staying on schedule by

setting reminders and keeping track of treatments through a written journal, electronic calendar, or phone app.

MEDICATION	ADMINISTRATION	ASSISTANCE PROGRAMS
<i>The following medications are given at one's home via subcutaneous (under-the-skin) self-injection, with the exception of Avonex®, which is given via intramuscular (deeper in the tissue) self-injection:</i>		
<b>Avonex®</b> (interferon beta-1a)	Given once weekly	<b>Above MS</b> (800) 456-2255 / <a href="http://www.avonex.com">www.avonex.com</a>
<b>Betaseron®</b> (interferon beta-1b)	Given every other day	<b>BetaPlus</b> (844) 788-1470 / <a href="http://www.betaseron.com">www.betaseron.com</a>
<b>Copaxone®</b> (glatiramer acetate)	Given daily or three-times weekly	<b>Shared Solutions</b> (800) 887-8100 / <a href="http://www.copaxone.com">www.copaxone.com</a>
<b>Extavia®</b> (interferon beta-1b)	Given every other day	<b>Patient Services Program</b> (866) 398-2842 / <a href="http://www.extavia.com">www.extavia.com</a>
<b>Glatopa®</b> (glatiramer acetate)	Given daily or three-times weekly	<b>GlatopaCare</b> (855) 452-8672 / <a href="http://www.glatopa.com">www.glatopa.com</a>
<b>Generic Glatiramer Acetate Injection</b> (glatiramer acetate)	Given daily or three-times weekly	<b>Mylan MS Advocate Program</b> (844) 695-2667 / <a href="http://www.glatirameracetate.com">www.glatirameracetate.com</a>
<b>Plegridy®</b> (peginterferon beta-1a)	Given once every two weeks	<b>Above MS</b> (800) 456-2255 / <a href="http://www.plegridy.com">www.plegridy.com</a>
<b>Rebif®</b> (interferon beta-1a)	Given three-times weekly	<b>MS Lifelines</b> (877) 447-3243 / <a href="http://www.rebif.com">www.rebif.com</a>
<i>Given via intravenous (IV) infusion, usually at a hospital or infusion center:</i>		
<b>Lemtrada®</b> (alemtuzumab)	Given for a course of five days, with a three-day course one year later	<b>MS One to One</b> (855) 676-6326 / <a href="http://www.lemtrada.com">www.lemtrada.com</a>
<b>Novantrone®</b> (mitoxantrone)	Given every three months; seldom prescribed due to serious health risks	N/A
<b>Ocrevus™</b> (ocrelizumab)	Given every six months, with the initial dose given in two half-doses	<b>OCREVUS Access Solutions</b> (866) 422-2377 / <a href="http://www.Genentech-Access.com/patient.html">www.Genentech-Access.com/patient.html</a>
<b>Tysabri®</b> (natalizumab)	Given every four weeks	<b>Above MS</b> (800) 456-2255 / <a href="http://www.tysabri.com">www.tysabri.com</a>
<i>Taken orally at one's home:</i>		
<b>Aubagio®</b> (teriflunomide)	One tablet taken daily	<b>MS One to One</b> (855) 676-6326 / <a href="http://www.aubagio.com">www.aubagio.com</a>
<b>Gilenya®</b> (fingolimod)	One capsule taken daily	<b>Patient Services Program</b> (800) 445-3692 / <a href="http://www.gilenya.com">www.gilenya.com</a>
<b>Tecfidera™</b> (dimethyl fumarate)	One tablet taken twice daily	<b>Above MS</b> (800) 456-2255 / <a href="http://www.tecfidera.com">www.tecfidera.com</a>

# SYMPTOMS

**MS has the potential to cause several different symptoms and the specific symptoms each person experiences vary greatly.** When experiencing one or more of these symptoms, individuals should consult their physician. Medications are available to treat many MS symptoms, which include over-the-counter drugs as well as prescribed medications. Diet, exercise, counseling, and lifestyle/wellness therapies, may also be helpful with managing certain symptoms.

**MS symptoms are often compounded by extreme fatigue, which may be worse in the afternoon, sometimes relating to a rise in body temperature.** Some symptoms may be temporarily increased by heat intolerance – a classic MS tendency – where a rise in temperature (internally or externally) causes a person to feel much worse. Energy, cognition, and strength can be particularly affected. Keeping cool through air-conditioning or various devices, including cooling apparel, is

often helpful for people with heat-sensitive MS. Cooling accessories are available through MSAA’s **Cooling Distribution Program** to those who qualify, or these may be purchased through outside vendors.

**When recovering from a symptom flare-up or learning to cope with a change in mobility, rehabilitation through physical therapy and occupational therapy can be of great value.** Speech therapy, therapeutic exercise, and certain medical devices may also be useful in dealing with the symptoms of MS. Some of those who have a physically demanding or highly stressful job may choose to make a career change, in which case vocational training is helpful. Stress-management strategies can also assist.

When a family member is diagnosed with MS, **participating in some type of counseling program is often of benefit to everyone involved.** Individuals may be affected in different ways, both physically and emotionally. Seeking professional assistance can help.

## Common Symptoms of MS

Listed alphabetically in categories below

### PHYSICAL SYMPTOMS

balance problems  
bladder dysfunction  
bowel problems  
muscle spasticity (stiffness)  
sexual dysfunction  
speech difficulties  
swallowing disorders  
tremor  
walking and mobility issues



### EMOTIONAL, COGNITIVE, AND PSYCHOLOGICAL SYMPTOMS

anxiety  
cognitive changes  
depression  
pseudobulbar affect (PBA – a neurologic effect characterized by sudden, uncontrollable expressions of laughter or crying without an apparent trigger)



### “INVISIBLE” SYMPTOMS

dizziness/vertigo  
fatigue  
numbness  
pain  
sleep issues  
Uhthoff’s syndrome (the temporary appearance of symptoms resulting from heat stress)  
visual disorders  
weakness





## A Discussion of the Emotional, Cognitive, and Psychological Symptoms of MS

While the physical symptoms of MS – such as changes in bladder function, spasticity, and mobility, for example – are greatly important and can impact one's daily activities and lifestyle, these types of symptoms are more apparent, more relatable, and more tangible to care partners. Most physical symptoms have a variety of treatment options available, and for the most part, can be monitored and measured.

The emotional, cognitive, and psychological symptoms of MS, on the other hand, are not only quite challenging for both people with MS and those close to them, but they can also be very confusing for everyone involved. A variety of issues are possible, but some of the more common symptoms include anxiety, cognitive changes, depression, and pseudobulbar affect (PBA). Again, as a reminder, individuals with MS experience a variety of symptoms – and not everyone will experience these types of emotional, cognitive, and psychological changes.

Readers should keep in mind that everyone experiences changes in emotions at one time or another, as well as the typical “ups and downs” of everyday life. A tragic event may cause someone to feel sadness for an extended period of time, and stressful events can cause great anxiety until the problems are resolved. These are normal reactions from which most people recover and eventually return to their usual, healthy outlook on life. However, when someone experiences severe and/or prolonged depression or anxiety, possibly not related to

any specific event or issue, professional help may be needed.

With MS, the rate of depression is three-times higher than the general population and it is also higher than with other chronic illnesses. Anxiety, too, is estimated to affect almost half of individuals living with MS and is typically undetected and untreated – more so than depression. The combination of heightened levels of depression and anxiety, if untreated, can even pose a risk of suicide in MS.

Pseudobulbar affect (PBA) occurs in 10 percent of people with MS, although some research suggests that a much larger number may be affected. It is characterized by sudden, uncontrollable expressions of laughter or crying without an apparent trigger, and also occurs in other chronic, neurological conditions. Fortunately, the medication Nuedexta® has been developed specifically to treat PBA.

While depression can result from the physical effects of MS within the nerves of the brain, or as with anxiety, it can be a natural byproduct of living with the disease, PBA is typically caused by physical changes in the brain. It is crucial to understand that individuals are not able to control such emotions and they should never feel ashamed or judged for experiencing them. The good news is that these symptoms are all highly treatable.

Emotional disturbances can cause significant pain and suffering, and lead to disruptions in family, work, and social life. Emotional disturbances can also impact roles and relationships, sexual function, and one's self-image. Physicians, nurses, psychologists, and social workers who can identify, diagnose,

treat, and manage these disturbances effectively are vitally important. These professionals can help their patients and family members talk about the emotional symptoms of MS – not just the physical ones. They encourage patients and family members to seek psychiatric and psychological treatment, which can have a dramatic, positive impact on the quality of their patients' lives.

Cognitive changes with multiple sclerosis (MS) are also fairly common. Most studies state that approximately 50 percent of individuals with MS may have some type of cognitive dysfunction. Individuals with MS who experience cognitive issues may have trouble with functions such as attention, information-processing speed, executive functions (decision making), episodic memory, and visuospatial abilities. These deficits can affect several activities of daily living, including employment, driving, social integration, and adherence to medication regimens. Problems with concentration and the ability to shift attention are other examples of cognition impairments observed with MS.

Other MS symptoms can affect one's cognition, including fatigue, problems in sleep management, and depression. The side effects of medication can also have an impact on cognition. Additional factors include anemia, infection, and thyroid problems. Various medications, including those used to treat Alzheimer's disease, are being studied in MS, but so far, these have not shown dramatic results. Cognitive rehabilitation and retraining, as well as exercise, have shown to have a positive effect on cognition in MS.

## **A Discussion of the Invisible Symptoms of MS**

Similar to the emotional, cognitive, and psychological symptoms of MS, the “invisible” symptoms of MS can be challenging and confusing to both individuals with MS as well as those close to them. Recognizing these symptoms, seeking treatment, and practicing effective strategies are key to coping well with these types of issues. To follow is a brief discussion of two of the more challenging invisible symptoms: MS fatigue and MS pain.

### **Coping with MS Fatigue**

Fatigue has been described as an “overwhelming sense of tiredness.” Up to 80 percent of people with MS experience the disabling effects of fatigue and this can occur any time in the course of MS. Many people with MS find that fatigue increases as the day goes on, and worsens with a rise in body temperature, which might be caused by hot and humid weather.

As noted earlier, cooling technology can be very helpful to combat MS fatigue and other symptoms associated with an increase in temperature. However, cooling someone too quickly – such as taking cold baths or sitting close to the air conditioner – can cause shivering and vasoconstriction. This reaction does not help to alleviate MS symptoms. By slowly cooling down the body, which can be achieved through passive cooling garments, fatigue can be significantly reduced, helping a person with MS perform his or her daily activities.

Fatigue can be difficult for family members and friends to understand, because it is invisible to others. If fatigue is poorly understood, a person with MS who is experiencing fatigue might be characterized as “lazy.” Educating family, friends, and partners about MS fatigue is very important.

People with MS who experience fatigue often feel as though their “batteries have run low” after doing some of their daily activities. A brief rest often serves to recharge the batteries, so it’s possible to finish the task. Planning one’s activities in advance can help, such as trying not to go up and down the stairs more often than necessary, preparing meals in advance and freezing them for future use, sitting while performing household duties, and other types of energy conservation can help. Listing activities in their order of importance enables a person to see clearly what needs to be done first and what can wait until another day.

### Coping with MS Pain

More than 50 percent of individuals with MS identify pain as a significant symptom. MS pain is mixed and may be divided into two different types. Pain from MS can be a direct result of damage to the nerves and is referred to as **neurogenic**. This type of pain may be intermittent or steady; spontaneous or evoked. Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen usually won’t work well on this type of pain. The over-stimulated nerves need to be calmed, and this may best be accomplished with anti-epileptic drugs, tricyclic antidepressants, and anti-spasticity

drugs, to treat painful spasticity and spasms. Topical medications such as lidocaine gel or Zostrix® (capsaicin topical analgesic) may help reduce the burning and tingling.

A second type of pain is associated with living with disability and its effects. This is referred to as **nociceptive**. Caused by any mechanism that stimulates a pain response, it can be mechanical, thermal, chemical, or electrical. Examples of this type of pain include musculoskeletal pain, lower-back pain, painful spasms, pain related to urinary-tract infection, pain of pressure sores, and even pain associated with disease-modifying drugs.

Unlike neurogenic pain, nociceptive pain may respond to NSAIDs, which includes ibuprofen (Advil® and Motrin®). Tylenol® (acetaminophen) may help with this type of discomfort too. Antidepressants are sometimes effective and their function is twofold: they may help to shift the perception of pain, while also elevating one’s mood. Anti-spasticity medications may be used if spasticity and/or spasms are contributing to one’s discomfort.

Non-pharmaceutical approaches to pain include acupuncture, massage, tai chi, yoga, meditation, aquatic therapy, and physical therapy, among others. A physical therapist experienced with MS can be particularly useful in returning balance and good posture back to one’s movement. Warm compresses can sometimes loosen a tight muscle or reduce lower back pain, while an ice pack is normally prescribed for a recent muscle injury or injection-site reactions.



# AFTER THE DIAGNOSIS

## Initial Reactions

Miriam Franco, PsyD, MSCS, is a psychotherapist and psychoanalyst who specializes in working with individuals coping with chronic illness. She recently developed an app that focuses on relaxation and guided meditations for coping with the challenges of MS.

Dr. Franco explains, “First reactions can range from shock, disbelief, and anger, to fear and denial. These are all adaptive and predictable responses that you may experience initially. If you had to wait months or years for a definitive diagnosis after living with puzzling, unexplained symptoms, or if you doubted your perceptions, the diagnosis can bring some relief. This is especially true if you’ve been told ‘this is all in your head.’

“Most MS doctors are aware that individuals need time to grasp what is happening, to learn and understand what may be involved, and to find out about what treatment options are available. Time is needed to not only build a treatment plan, but to also develop trust and a supportive relationship with healthcare practitioners.”

Your family will need time as well to adjust to the diagnosis and people react to a diagnosis in different ways. Some want to learn everything they can about MS as soon as possible. Education can come in many forms, from informative websites, publications, and

videos, to support groups, educational programs, and one-on-one discussions with your healthcare professionals. Be sure that you are keeping the amount of information at a reasonable level and are consulting reliable resources, such as MSAA or other major MS organizations.

While some want to get information, others may become upset and “turn off” at the idea of learning more about the disease. They know that getting MS is not fair, that it is not anyone’s fault, but they may still ask, “Why me?” Other common reactions are great concern and over-protectiveness. A spouse or parents (including a parent of an adult with MS) can often feel this way, and in their worry for your safety and

health, may infringe upon your independence. Learning about the disease and having open communication about your symptoms, along with the precautions you are taking, can greatly help to reduce the anxiety that your spouse, parents, or others close to you may be experiencing.

Dr. Franco continues, “It’s important to keep in mind that if any of your initial reactions to having MS become unmanageable or too uncomfortable, you’ll find that much support is available. Major MS organizations such as MSAA provide resources for support, including helplines, educational videos and publications, and assistance with locating psychologists and social workers, who can help people cope with the emotions and stress of MS. Support groups can also be very helpful.”



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## Making Adjustments

Kathleen A. Taylor, PhD is a Professor in the Psychology Department and Chair of the Women and Gender Studies Department at the Sierra College in Rocklin, California. She is also a member of MSAA's Healthcare Advisory Council.

Because MS has so many symptoms that may not be visible to another person, people tend to think that you don't look sick, even when experiencing difficult symptoms. Often someone with MS may look fine, but he or she is unable to participate in everyday activities. Those around you may not understand or believe how ill you may be feeling and some may even feel resentful or angry that you are not doing your fair share of work around the house or on the job.

Dr. Taylor explains, "This can be particularly difficult for women due to gender stereotypes about women as non-rational or prone to hysteria. The very nature of MS in terms of ambiguity of early symptoms may play into these gender-biased notions about women's 'inherent' emotionality, leading to the assumption that they are unreliable reporters of their own experience. Combine this with the tendency for women to emotionally take care of their loved ones, and this can become a significant issue.

It is essential to be frank about your symptoms and clearly define limitations. This can be difficult, but also expressing when one is having a 'good day' versus bad helps people understand that not all MS days are

experienced in the same way."

Particularly when not having a good day, or when experiencing a flare-up of symptoms, having plans in place for redistributing household duties is always a good idea. Knowing that your spouse and older children can pitch in with making a meal, shopping, laundry, and other responsibilities can help to

provide some peace of mind. While care must be taken not to ask too much of your children, learning to help someone in need teaches children the importance of having empathy for others and looking beyond their own needs and wants.

In the book, *Multiple Sclerosis: The Questions You Have, The Answers You Need* (Demos Health, 2012), author Rosalind C. Kalb,

PhD, points out, "As you confront the challenges of everyday life with MS and learn alternative ways to do things, you will begin to identify strengths and talents you never knew you had." She suggests that as you give up an activity, experiment with others that may turn out to be equally satisfying.

Most importantly, find an aspect of yourself that MS is unable to touch, such as your sense of humor, religious beliefs, or love of music. This "MS-free zone" will help you to retain a sense of who you are, and can also be an important source of emotional energy. When feeling drained or overwhelmed by the challenges of everyday life, you can refuel by tapping into the things you enjoy through your MS-free zone.





## Getting Help and Support

Kimberly Castelo, MS, LMFT, CST, CIIP is a Licensed Marriage and Family Therapist, Certified AASECT Sex Therapist, Certified Emotion Focused Couples Therapist, and Certified Integrated Intimacy Professional in Seattle, Washington. She is also an inspiring speaker at MSAA's educational programs.

Ms. Castelo explains, “Individuals need to welcome any feelings that come. It is normal to feel like your emotions are on a roller coaster and you need to allow these feelings to surface. You also need to allow space for family members to be worried and concerned – they too need to adjust to the diagnosis. Family and individual counseling can be very helpful during this initial period. Individuals should also talk to their neurologist about fears, treatment plans, and even quality-of-life concerns.

“Do not isolate yourself... And don't feel that you need to tell everyone about your diagnosis. Take your time sharing only with those you choose to tell. Be sure to set boundaries and to say ‘no’ when you find you are doing too much. You need to care for yourself, rest, or do things that are life-giving for you.”

Individuals also need to ask for help. Ms. Castelo inquires, “Why is asking for help so hard to do? Is it because we are told never to show weakness? Is it because we are having a hard time accepting help, and if so, why?” Take time to reevaluate what is stopping you

from asking for help. Find that asking for help – even from people who you do not know well – is a strength! It is also a way to allow yourself to feel loved and cared for.

Ms. Castelo continues, “Withdrawing is very common when we are feeling overwhelmed. However, reaching out to others helps with our mood and outlook on life. While our tendency might be to withdraw, the goal would be to fight that urge and try something new. You'll find that staying involved with others can add more happiness to your life. Try doing the kinds of things that you used to enjoy, such as going to a movie, or getting together with an old friend.

“Support groups are great! They help us feel like we are not alone.

We can also learn about new ways of coping with MS that we hadn't thought of before. In addition, we can meet new friends who we can connect with and expand our network of people with whom we can engage and share our thoughts.

“Look for a group where your voice can be heard and where you can learn from the others. Hopefully being heard and learning new ideas is what you can expect from every group. Take some time to decide if a group is right for you... because as with all relationships, getting to know the other members takes time. Give some time to find the rhythm of the group and how you might add to that rhythm.”



## EMPLOYMENT AND MS

After diagnosis, many may question if they will be able to stay at their job – and some might immediately assume that they will need to discontinue their career. However, no one knows the course his or her MS will take, and particularly with today's treatment options, many are experiencing fewer and less-severe relapses. Many find that they are able to stay at their job.

If and when symptoms interfere with one's ability to perform a job, accommodations can frequently be made. These may include easy changes such as getting a closer parking spot or modifying one's office space, or more significant modifications, such as changing one's job duties and schedule. Various types of assistive technology are also available. However, accommodations must be reasonable, and not cause undue hardship to the employer.

The big question that individuals with MS are faced with is whether or not to divulge that they have MS to their employer and coworkers. They may feel that doing so will impact their relationships at the office. Fears may be that coworkers will treat them differently, that they may miss out on promotions, or that they may even lose their job.

The Americans with Disabilities Act (ADA) has been protecting individuals with disabilities from discrimination since 1990, and this has served to prevent people from wrongfully losing their job, being demoted, or taking a cut



in pay. This law, which applies to employers of 15 or more people, also specifies that reasonable accommodations be made to modify one's position, schedule, or work environment, to enable a person with a disability to continue his or her employment. Please note that state or local laws may apply to smaller companies, helping to prevent discrimination and allow for reasonable accommodations in those circumstances.

Under the ADA, people do not need to divulge their specific diagnosis. However, if an accommodation is needed, one needs to establish that he or she has a disability. A disability is an impairment that affects one or more major life functions such as sight, hearing, mobility, etc. If an accommodation is requested, the employer must determine whether or not the individual has a disability that would affect his or her ability to perform the job and requires some type of modification.

Sometimes medical documentation is needed for the employer if one's disability is not obvious. While people do not need to divulge a specific diagnosis, they do need to give some type of reason for their disability if requesting an accommodation. Saying they have a "neurological condition" may be adequate – and this can be stated in their medical documentation from their doctor as well, rather than specifically saying that they have MS, should anyone prefer to keep his or her diagnosis private.

Individuals may feel the need to divulge that they have MS, or some type of disability, when their symptoms may be easily observed and can no longer be hidden – such as when experiencing changes in mobility. They may also want to tell their employer when having to take extra days off from work and are having trouble keeping up with their duties. Another reason may be to request modifications to their work environment, job description, or schedule. Examples of schedule changes may include such options as flexible hours, job-sharing, changing from full-time to part-time hours, and working from home.

In regard to interviewing for a new job, potential employers are not allowed to ask whether or not an applicant has a disability. However, they may ask applicants if they have any concerns with their ability to be proficient at the job. If a medical exam is required, it must be one that is required for all individuals applying for similar positions and must also be

related to the work at that company.

Clinical Instructor/  
Social Worker Kara  
Barton, MSW, LCSW,  
from the Keck Medical  
Center of the University  
of Southern California,  
has served as a speaker

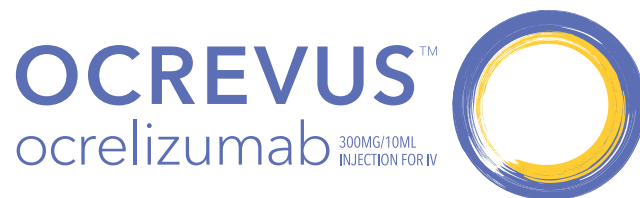


for MSAA's educational programs, providing important details on employment and MS. Ms. Barton explains, "I have worked with people living with MS and other neurological diagnoses for more than a decade. I recognize that existing laws do not help to reduce the fear and worry that arise when a diagnosis could change one's work and potential earnings.

"However, I know that such changes may be seen as an opportunity for people to reassess their values and needs. This becomes a sort of personal reflection that redirects the focus from one of fear, to a path of hope, building a new way of living. When this focus has been redirected, one is not a victim, but rather an agent overseeing the changes in his or her own life. I encourage people to identify and take advantage of the many resources available for individuals who are changing directions or careers in their lives. Doing so will help to avoid isolation and lack of motivation. Building strong support can be key to sustaining professional longevity and a high quality of life."

\*Some of the employment information is from: *The Everything Health Guide to Multiple Sclerosis* (Adams Media, 2009), written by Margot Russell with Allen C. Bowling, MD, PhD.





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## 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.

## IMPORTANT SAFETY INFORMATION

### 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.
- **Infection:** OCREVUS increases your risk of getting upper respiratory tract infections, lower respiratory tract infections, skin infections, and herpes infections. If you have an active infection, your healthcare provider should delay your treatment with OCREVUS until your infection is gone.

### 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 safety information, please see the accompanying Patient Information.**

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

**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.

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**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 vaccines at least 6 weeks before you start treatment with OCREVUS.** You should **not** receive certain vaccines (called '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.
- 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.,  
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1 DNA Way,  
South San Francisco, CA 94080-4990  
U.S. License No. 1048

For more information, go to [www.OCREVUS.com](http://www.OCREVUS.com) or call 1-844-627-3887.

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

Issued: 3/2017

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## GOVERNMENT PROGRAMS

Attorney and Counselor at Law Jamie R. Hall specializes in Social Security Disability and Long-Term Disability. He has handled hundreds of disability cases nationwide from his practice in Kennett Square, Pennsylvania. In this section on government disability programs, Mr. Hall answers some commonly asked questions about applying for disability benefits.

**When someone with MS experiences worsening symptoms that interfere with his or her ability to work, what government programs are available?**

The number of government programs available to assist individuals with MS is markedly limited. The three primary programs that support those who have left work due to MS are: Social Security Disability Insurance (SSDI); Supplemental Security Income (SSI); and state-based, short-term disability benefits.

**How do these programs differ in terms of benefits?**

**Social Security Disability Insurance (SSDI)** is the best of the three programs, as it pays a benefit for the disabled individual, his or her minor children, and does permit limited, part-time work. It also provides access to Medicare after a waiting period. Unfortunately, the process of applying for this benefit can take up to three years, depending on whether

the claimant must appeal the matter at the hearing level. The program also has a five-month waiting period before any benefits are payable.

SSDI has a number of requirements, including the number of years worked – both in terms of lifetime work and recent work; the latter requires someone to have worked at least five of the past 10 years prior to disability. These types of issues can become complicated for people who haven't worked for the past five-plus years, possibly while staying home to care for children, and then finding that they are unable to return to the workforce due to worsening

symptoms. Additionally, age is another factor, where one's ability to perform certain full-time jobs when younger than 50, or older than 50, is taken into consideration.

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

benefits are limited to individuals with minimal assets and low family income, and the program provides only a small payment. It permits almost no earnings and provides only access to Medicaid.

**State-based benefits** are only available in a minority of states – such as California and New Jersey – and typically cover only a short period of time. For those living in these states, it can provide a financial bridge to cover the period it takes for the **Social Security Administration (SSA)** to make a decision on an SSDI or SSI claim.



### How does someone go about applying for these programs, and should people do anything to prepare in advance?

I generally recommend that people apply through an attorney from the start. If pursuing a claim on their own, however, they should file online at **ssa.gov**. The SSA's online portal allows individuals to save their claim and complete the filing over several sittings if necessary. For claimants with fatigue and focus issues, applying online is a good method to file a well thought-out claim at their own pace. Although claims can also be filed through SSA representatives on the phone or in person, the quality of such claims varies with the skill level of the representative, time allotted, and the quality of information provided by the claimant.

In terms of preparation, reviewing one's medical records in advance – to make sure nothing is incorrect or missing – is a good plan. Medical records are not limited to those from the neurologist; the SSA now considers reports from neuropsychologists, physical therapists, nurses, and other members of the healthcare team.

Individuals may also benefit from keeping a journal of symptoms, relapses, medications, and other relevant details; such records can be helpful in supporting how one's condition has worsened over time. Phone apps, such as MSAA's My MS Manager™ (at **mymsaa.org/mobile**), can assist with doctor reports and keeping information organized and current. As of 2016, the SSA put new "listings" into effect, specifically to help determine the impact of one's MS symptoms.

### If denied, should individuals request an appeal or reapply?

As to appeals, my thought has always been that if a claim is good enough to file, it's good enough to appeal through the hearing level. Reapplying, which means giving up on the current claim and filing a new claim, presents three problems. First, there is little reason to believe a different decision will be reached on another application. Second, the best chance of approval in the whole process is through an appeal at the hearing level. And third, SSDI eligibility can expire, and failing to appeal may forfeit valuable rights.

### When should a lawyer be consulted?

An attorney can be very helpful with the initial filing. The information that the lawyer can provide to the SSA for a disability claim may help to avoid an initial denial. Although an initial decision may take only four months, if denied, the next step is for an appeal, which requires a hearing – potentially adding another two years to the application process. If an application is denied, I strongly recommend having an attorney for the appeal and hearing. At this stage, the claimant has unsuccessfully pursued the claim on his or her own, and further attempts to represent oneself can result in irreparable harm to the claim. The hearing simply moves too quickly in the courtroom and is too complex to represent oneself.

### What is the best way to find a lawyer?

MS claims are different than the vast majority of claims. Proving fatigue, cognitive slowing, bladder issues, and many of the other



typical MS symptoms requires knowledge of the condition as well as the SSDI claims process.

One way to inquire about an attorney is through one's neurologist, who may be familiar with lawyers who are experienced with filing disability claims for individuals with MS. Other ways to locate a lawyer may be through internet forums and internet searches for lawyers experienced in MS. Additionally, one's lawyer does not need to be local to the claimant. Disability cases are frequently handled long-distance through phone, mail, and email communications. When handling cases across the country, with many of my clients, I only meet them in-person if a claim goes to a hearing.

### What are the misconceptions that people have about these types of programs?

Some people believe that everyone is denied SSDI benefits at the initial level. We have found that well-supported claims filed by MS patients, particularly if aged 50 or older, have a reasonable success rate. That being said, applicants should always assume that they will have to go to a hearing to be approved.

Many people are concerned they cannot afford an attorney. With the contingent fee structure, an attorney is only paid if the claim is approved, and is paid a portion of the past-due benefit. These fees are set by statute and are uniform across the industry: the attorney receives 25 percent of the past-due amount, with a maximum payment of \$6,000. Additionally, claimants are permitted to change attorneys if they see fit. If a claimant

has private long-term disability insurance and been approved for disability benefits, the insurance company will almost always pay for the SSDI attorney's fee. Furthermore, the claimant can choose any attorney as their representative, and is not limited to the entity provided by the insurer.

Individuals applying for disability benefits often are not aware that they can work part time, both while applying as well as after benefits have been approved. This part-time work should be discussed with your attorney, but can be used at the hearing level as proof of one's work ethic, as well as to show the impact of only a few hours at work on a person's fatigue and function.

### Do you have any resources for more information?

People can find a great amount of information on the SSA's website at **ssa.gov**, including a wide variety of publications as well as explanations and instructions for applying for disability benefits. **MSWorld.org** has a good deal of patient-driven information in their forums, including a forum specifically discussing the disability claim process. I also worked with Can Do MS last fall to provide an hour-long presentation (with Q&A) on the Social Security Disability claim process. This webinar has been archived on their website at **cando-ms.org**. MSAA also has an online video, *A Closer Look at Disability Benefits*, at **mymsaa.org/videos/closerlook-disability**. Additionally, social workers at larger neurology offices are a great and under-utilized resource.

## IN CLOSING

We hope that readers find the information in this article to be helpful. MSAA's Helpline callers often tell our Client Services Specialists of the challenges to being newly diagnosed. In addition to adjusting to the diagnosis and addressing symptoms, other challenges include: the issues with family members and friends who don't understand the disease and some of its symptoms; the variety of disease-modifying therapies and questions to ask the doctor; avoiding depression and isolation; employment issues and potentially a need to change careers; and the process of applying for Social Security Disability Insurance. This article may be helpful to keep on hand for future reference, or to show a loved one to help him or her get a better understanding of what someone with MS is experiencing.

Stephen Krieger, MD, FAAN, is the Associate Professor of Neurology at the Corinne Goldsmith Dickinson Center for MS, Icahn School of Medicine at Mount Sinai. Dr. Krieger explains, "I realize that being diagnosed with MS is like being invited into a club no one ever wished to join. But once the shock or frustration begins to wear off, I encourage anyone diagnosed with MS to look around and realize that this is a field of medicine marked by incredible scientific progress, a community of patients and advocates defined by their optimism and resilience, and a specialty of neurology filled with people who have devoted their careers to steering people with MS toward the best possible outcomes, for years and decades to come."

Indeed, the medical community is more optimistic than ever about the future of disease-modifying therapies for MS and their potential to one day not only stop the progression of MS, but even return function to people whose MS is more advanced. In addition, many individuals with MS are benefiting from wellness strategies, such as eating a healthy diet, making positive lifestyle changes, and finding encouragement and camaraderie through support groups and internet forums. MSAA offers My MSAA Community, a peer-to-peer online forum (hosted by HealthUnlocked.com) where participants can share information and their experiences with multiple sclerosis. Individuals are also benefiting from physical and stress-reducing activities such as aquatic exercise, yoga, tai chi, mindfulness, and guided imagery.

In conclusion, Michelle T. Fabian, MD, who is the Assistant Professor at Corinne Goldsmith Dickinson Center for Multiple Sclerosis, Mount Sinai Hospital, provides her perspective on a diagnosis of MS. "For most, the diagnosis of MS is unexpected and life-altering. Early on, an approach to wellness is critical. I encourage my patients to focus on good nutrition, exercise, sleep, and strategies that will support emotional stability. I also encourage them to learn about the disease through reputable organizations such as MSAA, to cultivate healthy relationships, and to recognize that one can still enjoy an active lifestyle. Although it may be hard to believe at the time of a new diagnosis, many of my patients say that post-diagnosis, they feel healthier than ever before."

*Please see page 33 for References and Resources*

# Treatment Questions and Diagnostic Issues

**By Dr. Jack Burks**

MSAA's Chief Medical Consultant



**Q:** If someone has lesions on his or her spine, can Tysabri possibly help with relapsing-remitting MS? I have read that Tysabri only helps to combat brain inflammation. Please let me know your opinion.

**A:** Fortunately, this information you read is not accurate. Tysabri® (natalizumab) works well throughout the brain and spine to help reduce inflammation. Its mechanism of action is to reduce the ability of destructive (pro-inflammatory) lymphocytes from crossing the blood-brain barrier into the brain and spinal cord, where they become misdirected and attack healthy myelin and nerves. Lymphocytes are a type of white blood cell found in the immune system, whose job is usually to help fight diseases. However, in MS and other autoimmune diseases, they may cause damage.

Tysabri is one of several approved disease-modifying therapies (DMTs). Having an in-depth discussion with your neurologist or MS specialist about DMTs and their benefits and risks will help you to decide what option might be the best treatment for you. For information on all of the approved DMTs, please visit MSAA's website at [mymsaa.org](http://mymsaa.org) and select "Treatments" under "MS Information."

**Q:** I have had relapsing-remitting MS for nine years now. I've tried a few of the DMTs and am doing well. In addition to MS, I have had type 1 diabetes for 51 years. Although I'd like my blood sugar to be lower, I am doing okay and I walk daily. My questions are: (1) do many people with MS also have diabetes, and (2), do you have any special recommendations for people such as me who have both conditions?

**A:** The chance for type I diabetes is increased three-times in individuals with MS, according to a recent Danish study. Both illnesses are related to lymphocytes in the immune system targeting an individual's own body – specifically the pancreas and the brain, in this case. My recommendations for you are to keep up with a good diet, exercise regularly, and continue the efforts you are making to lower your blood sugar. Good health strategies help both diseases.

As you have experienced, DMTs can be very helpful for your MS. While older individuals with MS may be more inclined to have type II diabetes, many younger, type I diabetic patients are now living long lives with MS. An area of future research is to better understand the



incidence as well as the most effective combined treatments for both conditions.

**Q: If my spinal tap is normal, does that mean I don't have MS?**

**A:** Some individuals with MS may have a normal spinal tap. In those situations, neurologists usually rely on the neurological history and examination as well as the MRI and other tests. For example, one test (evoked potentials) measures the speed of myelin function in the eye, brain, and spinal cord. If doubts remain, going to an MS center for a second opinion is an option.

**Q: I was diagnosed in 1998 with relapsing-remitting MS. I was prescribed double-dose Betaseron and have been on this medication for 20 years. Now I'm 66-years old and my doctor wants me to discontinue my treatment. Reason: I have not had any relapses in the past 10 years, although my MRI does show some new lesions. He feels it's not doing anything for me now and claims there is a greater possibility of my getting cancer at my age. I feel it's doing what it was supposed to do! I welcome your opinion or thoughts.**

**A:** I am so pleased that you have had no MS relapses for more than 10 years while on Betaseron® (interferon beta-1b). More good news is the fact that studies of patients on Betaseron for more than 20 years have not shown an increased risk of cancer. Nonetheless, some neurologists believe that having no relapses for several years indicates

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that the treatment (to quote your question) “is not doing anything.”

The risk of stopping Betaseron is that your MS may get more severe. New MRI lesions may indicate that you continue to experience some ongoing MS damage. You need to compare the potential risks of stopping your therapy versus the risk of cancer. The research does not demonstrate an increased cancer risk with Betaseron, but everyone must face the risk of cancer as we age, even if we take no medications.

In general, I encourage everyone to get the recommended testing for cancer as they age, but as noted, Betaseron has not been shown to increase one’s risk of cancer. In addition, I personally do not recommend discontinuing MS disease-modifying therapy, especially if there is MRI evidence of new MS activity. However, the final decision is between you and your neurologist.

**Q: I am 64-years old. My doctor recently changed my medication from Gilenya to Ocrevus. I have heard that the trials for Ocrevus indicated reduced efficacy in patients older than 55 years of age. Is this true?**

**A:** The clinical trials with Ocrevus™ (ocrelizumab) did not include patients older than 55. Therefore, no data are available to know if someone 64 years of age would respond better or worse than the studied patients who were 55 or younger.

Your neurologist likely reviewed your specific risk and benefit profile before switching from Gilenya® (fingolimod) to Ocrevus. The FDA prescribing information says Ocrevus is “indicated for treatment of adult patients with relapsing or primary-progressive MS.” Since no data are available on patients older than 55, beware of rumors. Ask specific questions to your neurologist. If still concerned, consider a second opinion at an MS center.

**Q: I was interested in the question that you received regarding sudden falls published in the Summer/Fall 2017 issue of *The Motivator*. I have had that experience and discovered that falls were likely to occur when I wasn’t paying attention. If I become distracted from paying attention to walking, I seem to lose contact with my position in space, similar to closing my eyes during a balance test.**

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.

**A:** Thank you for sharing your personal experiences. I agree – paying attention and not getting distracted while walking, especially at night, is critical for individuals with MS and for those who have experienced falls or losing their “position in space.” Good lighting and removing obstacles in the house that may inadvertently cause someone to trip is critically needed. Individuals with MS and their families should “fall-proof” their home as much as possible. ■

#### 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](mailto:askdr@mymsaa.org).  
Please include “Ask the Doctor” in the subject line.

**STRESS-LESS WITH MS!**

Introducing **IMAGERYWORK** for iPhone and Android.

Designed by Dr. Miriam Franco, this new app focuses on relaxation and guided meditations for coping with challenges of living with MS. Also includes Relieve Caregiver Stress track.

Download on the App Store

GET IT ON Google Play

Learn more at [ImageryWork.com](http://ImageryWork.com)

Cover Story: Finding Direction When Newly Diagnosed

*continued from page 29*

## REFERENCES AND RESOURCES

### Articles appearing previously in *The Motivator*:

- “Cognitive Issues with MS: Research, Strategies, and Support,” Winter/Spring 2015
- “Disease Effects and Needs of Minority Populations with MS,” Winter/Spring 2017
- “Making the Most of Our Relationships,” Winter/Spring 2016
- “Managing the Physical Symptoms of MS,” Summer/Fall 2013
- “The Emotional and Psychological Symptoms of MS,” Winter/Spring 2014
- “The Hidden Symptoms of MS,” Winter/Spring 2013
- “Wellness in MS,” Summer/Fall 2015

### MSAA Booklets:

- About MS*
- Aquatic Exercise and Multiple Sclerosis: A Guide for Patients*
- How to S.E.A.R.C.H.™ for the Right MS Therapy for You!*
- MS Relapse Toolkit*
- Understanding Progression in MS*

See more information and links to the resources listed above at [mymsaa.org/ws18-resources](http://mymsaa.org/ws18-resources)



# Stem Cell Transplantation

In an online report from BBC News appearing in March 2018, results of an international trial using hematopoietic stem cell transplantation (HSCT) were given. They state that more than 100 individuals with relapsing-remitting MS (RRMS) participated in this trial, which took place in hospitals located in the United States, England, Sweden, and Brazil. HSCT involves collecting stem stems from a patient's own blood, "wiping out" (or "resetting") the individual's immune system with high-dose chemotherapy, and then returning the preserved stem cells back to the patient.

According to the report, only one relapse occurred among the stem cell group after one year, compared with 39 in the group given a "drug treatment." After an average follow-up of three years, the stem cell transplant had failed in three out of 52 patients (6 percent), compared with 30 of 50 (60 percent) in the control group. The report also stated that individuals who received the HSCT experienced a reduction in disability, while individuals in the drug group experienced worsening symptoms.

In February 2018, the results of a study using autologous mesenchymal stem cell-derived neural progenitors (MSC-NPs) were published in EBioMedicine. The study took place at Tisch MS Research Center of New York, where they found evidence that a stem cell-based treatment may reverse disability in progressive multiple sclerosis (MS). This type

of stem cell is derived from the patient's own bone marrow, and with this form of stem cell transplant, chemotherapy is not used to reset the immune system. Instead, these cells are returned to the individual via intrathecal (into the spinal canal) injection, with the aim to potentially repair damaged nerves and improve function.

Twenty individuals with progressive MS took part in this study. As determined by improvements on the expanded disability status scale (EDSS), the participants demonstrated an improvement in disability. In addition, 70 percent of the participants saw an improvement in muscle strength, and 50 percent experienced improved bladder function. The report also states that all 20 participants completed the 60 scheduled treatments without any serious adverse effects; minor adverse events included transient fever and mild headaches.

MSAA's Chief Medical Consultant Dr. Jack Burks explains, "Each year we learn of new trials with stem cells and many successful patient stories. The fact that many scientists from many countries are working together is fabulous. I am excited with these pilot studies, however, some deaths occur – too often without appropriate medical caution. We need to find more uniform scientific protocols that reduce adverse events – and we are getting there. While I consider it to be very promising research, stem cell transplant should not be considered as the standard first line of care."

## Siponimod Reduces Disability Progression in SPMS

In March 2018, Novartis announced the results of the Phase III Expand study, which compared the safety and effectiveness of siponimod to placebo in patients with secondary-progressive multiple sclerosis (SPMS). Siponimod is an investigational, selective modulator of specific subtypes of the S1P receptor, which prevents certain damaging immune-system cells from entering the central nervous system and leads to anti-inflammatory effects. It also has the potential to modulate damaging cell activity and reduce the loss of neurological function.

Taken orally once per day, siponimod showed significant reductions in the risk for disability at three and six months, and also reduced annual relapse rates (in those still experiencing relapses) and disease activity as shown on MRI – including a reduction in brain-volume loss. The Expand study had 1,651 participants from 31 countries, all with SPMS. Novartis plans to submit siponimod in 2018 to the United States Food and Drug Administration (FDA) for approval as the first disease-modifying therapy to delay disability progression in SPMS.

## Zinbryta® Withdrawn from Marketplace

On March 2, 2018, Biogen and AbbVie announced the voluntary withdrawal of their MS medication, Zinbryta® (daclizumab), due to new safety concerns. At least 12 cases of inflammatory encephalitis and meningoencephalitis – both forms of brain inflammation – have been reported in Europe.

Earlier issues with liver failure have also played a role in the decision. People who are currently taking this medication should contact their healthcare provider as soon as possible to discuss discontinuing the medication and to learn about different treatment options. Anyone with questions or concerns about the withdrawal should contact Biogen's service center at **(800) 456-2255** or their website at **[www.zinbryta.com](http://www.zinbryta.com)**. For additional research news items, please visit **[mymsaa.org](http://mymsaa.org)**. ■

*Written by Susan Wells Courtney,  
MSAA Senior Writer*

*Reviewed by Dr. Jack Burks,  
MSAA Chief Medical Consultant*



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# Spring Forward, Cool Ahead

**By Peter Damiri**

Vice President of Programs and Services

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

*"Due to my MS, I have been unable to work for the past couple of years. It's beyond a huge*

*adjustment to go from enjoying years of employment and independence to being unable to work. With no income and having to rely on family to help with insurance, it makes what everyone at MSAA does that much more appreciated. This cooling vest is not just an article of clothing. It has the ability to keep me from feeling worse. Thank you so much!"*

MSAA greatly appreciates this wonderful note from Nikki and the opportunity to offer our cooling program to the MS community. To learn more about qualifying for a free cooling vest through MSAA, please visit **[mymsaa.org/cooling](https://mymsaa.org/cooling)** or call **(800) 532-7667, ext. 154. ■**

## MRI Access Fund Recently Expanded

To help meet the continuously escalating demand for MRI assistance, MSAA recently announced new program changes to the MRI Access Fund that will increase our ability to serve more clients than ever before. In case you were not aware of the update, please know that qualified clients can now receive two MRI scans (brain and c-spine) per application or reimbursement support for previous MRI scans.

Under the reimbursement option, applicants must still apply to the MRI Access Fund, provide required documentation, and

meet income eligibility requirements. For qualified clients who have had a cranial and/or c-spine MRI with a date of service from July 1, 2017 to present, MSAA will pay the remaining costs up to a maximum of \$600 per MRI. MSAA will pay the billing facility directly; we will not reimburse individual clients. Also, please know the 24-month wait period to reapply for MRI assistance is still in effect. To learn more and apply, please visit **[mymsaa.org/mri](https://mymsaa.org/mri)** or call **(800) 532-7667, ext. 120. ■**



## MSAA Invites You to Join Our Community

With more than 2,500 active and engaged members, MSAA's online peer-to-peer forum, My MSAA Community, continues to gain interest and help make a positive impact for people living with MS and their care partners. Launched in the summer of 2016 and powered by HealthUnlocked, My MSAA Community is a safe and friendly online environment where members can share information and experiences, connect with others and contribute to ongoing conversations about everyday life with MS.

Helping to guide conversations when needed and maintain the forum's respectful rules of engagement are several MSAA volunteer community ambassadors, including the three quoted on this page! Each of these friendly volunteer community ambassadors actively posts and responds to ongoing conversations on a regular basis.

If you are interested in joining the 2,500-plus active and engaged members on My MSAA Community, please visit **[healthunlocked.com/msaa](http://healthunlocked.com/msaa)**.

Please note that when you visit My MSAA Community, you will not be on MSAA's website. The online community is accessed through a separate site hosted by HealthUnlocked.com. ■

"I stumbled upon the MSAA chat room when I was at my lowest of low points in dealing with my MS. I was disabled and feeling totally worthless and useless. Once I joined the chat room it took me only a matter of weeks to figure out that by helping others in the chat room and sharing common experiences, I not only helped others but I helped myself as well. I found a new purpose in life. The MSAA chat room saved me."

**- Fancy1959 (Joined August 2016)**

"I found My MSAA Community, soon after dx. I was so angry! And lost! Here I found others that understood, and didn't judge me. Here We Are All The Same."

**- Jesmcd2 (Joined August 2016)**

"When I found this site, I felt I had joined arms with hundreds who were there to buoy me up and lead me through the maze of emotions and overload of information. I can't imagine how I'd feel today without the people of this group who have been there along the way. Thank you all!"

**- Greaterexp (Joined September 2016)**

# Give Monthly... Improve Lives Today, and Every Day!

by Angel Serrano, CFRE and Kaitlyn Gallagher

Living with multiple sclerosis can be overwhelming, affecting individuals physically, emotionally, and psychologically. If you or someone you care about has MS, you know that this is a disease of uncertainty. Symptoms, such as fatigue, numbness, anxiety, and difficulty walking, vary with each person – and day-to-day. With the help of caring, generous people like you, there are ways to help empower those who are living with this disease.

By becoming a monthly donor, you can provide

ongoing support to ensure that MSAA is there to provide valuable

information and resources, mobility equipment, cooling accessories for heat-sensitive individuals, nationwide educational programs, MRI assistance, and more.

Every day, MSAA receives calls and letters from people we are able to help, because of YOU! Julie, Travis, and Gerri are just a few of the more than 400,000 Americans currently living with MS. Each week another 200 or more are diagnosed. Every day can be a struggle – and every donation helps improve their quality of life.

Monthly Giving is a convenient way to spread out your gift to MSAA over time with automatic, recurring contributions. Your monthly gift creates a reliable source of funding year-round to help provide assistance, information, and emotional support to the entire MS community. For only \$10 per month, you will join a special community of monthly donors who are committed to improving the safety, mobility, and independence of individuals affected by MS through vital services and support.

Please visit [support.mysaa.org/sustainer](http://support.mysaa.org/sustainer) or call (800) 532-7667, ext. 146 to become a monthly donor. ■

"I cannot thank you enough for providing these items (equipment) as well as all the information you make available for us MS'ers to try to lead lives rich with ability and possibility rather than being crippled by this debilitating disease. Thank you, thank you, thank you."

– Julie M.

"I would like to thank the MSAA for all the help and encouragement that they gave me. They helped get me through the toughest part of my life I've ever had."

– Travis S.

"Thanks to the resources from MSAA, I now have a walker and some great eating utensils. I refuse to become immobile and this helps tremendously on achieving just that. Faith slowly restored."

– Gerri G.

## How You Can Make a Difference

**\$10**  
per month  
(\$120/year)

a shower chair, bathtub safety rail, and grab bar for one individual with MS

**\$15**  
per month  
(\$180/year)

a four-wheel walker and quad cane for one individual with MS

**\$25**  
per month  
(\$300/year)

cooling vests for two individuals with MS

**\$50**  
per month  
(\$600/year)

a wheelchair for one individual with MS

**\$60**  
per month  
(\$720/year)

an MRI exam of the brain for one individual with MS



## GINA AND MSAA'S MISSION WITH THE MOUSE

MSAA's President & CEO, Gina Ross Murdoch, traveled down to Walt Disney World® in Orlando, Florida shortly after New Year's Day 2018 to participate in the Walt Disney World® Marathon Weekend presented by Cigna® as a dedicated member of #TeamMSAA! After months of training and fundraising, Gina crossed the finish line of the 13.1-mile half marathon on Saturday, January 6th. Gina was able to raise more than \$3,000 for the MS community! During her race, Gina donned the names of people with MS on her Team MSAA singlet as a way to recognize the challenges faced by those in the MS community on a daily basis.

Gina stated, "Those living with multiple sclerosis, those caring for a loved one with multiple sclerosis, and the entire medical community that has dedicated their lives to research and care, propelled me through to cross the finish line!" ■

*MSAA President & CEO Gina Ross Murdoch shows off her strength and team spirit while wearing a tutu for the Walt Disney World® Marathon Weekend presented by Cigna®.*

## DOPEY CHALLENGE FOR DADDY, PART II

In the Summer/Fall 2017 issue of *The Motivator*, we shared the story of Rachael Scharett, the young woman who decided to run in the four-day, 48.6-mile Dopey Challenge through Walt Disney World® in Orlando, Florida. She took this challenge in honor of her father, Dan Scharett, who has lived with MS for 25 years. Since our last issue, Rachael's sister, Bekah Ware, joined the Dopey Challenge journey. Together, Rachael and Bekah successfully completed the full race during the first week of January 2018, and raised more than \$7,000 for MSAA's free programs and services!

Rachael says about her father, "It was his motivation and drive that inspired me to run the Dopey Challenge. Seeing him fight to live a fulfilled life despite his MS motivates me to do things I normally consider too hard to do." ■



*Dan Scharett's daughters Bekah (left) and Rachael (right) celebrate after completing the 48.6-mile Dopey Challenge.*



## Create Your Own Event

Each year, individuals and groups turn their passions and interests into unique fundraisers to raise thousands of dollars for MSAA. Simple ideas could include a bake sale, “Dress-Down Day” at the office, a coin toss, a bingo party, “Strike MS” bowling competition, or joining Team MSAA in various endurance events.

Other exciting ideas include a car wash, a polar plunge, or a sporting event such as a golf, soccer, tennis, or basketball tournament. If you enjoy swimming, you can also create your own Swim for MS challenge – check out **SwimForMS.org** for more information.

If interested in creating your own fundraisers, please visit **support.mymsaa.org/create** or email us at **events@mysmsaa.org**.

To follow are just a few examples of inspirational individuals and groups who have gone above and beyond to improve the lives of those affected by MS.

- **Sterling High School in New Jersey** raised \$297 by holding a car wash to raise awareness in their community.
- **Great Southern Bank in Missouri** held their Community Matters Casual Day to benefit MSAA and raised \$2,079 by asking employees for a donation to wear jeans to work.
- **Crossfit Accolade in Virginia** held a burpee fundraiser in their community and raised \$350. For anyone not familiar, a burpee is a type of aerobic or strength-training exercise, also known as a squat thrust. In this type of an event, participants might raise money by doing a certain number of burpees within a specific amount of time.
- **The City of Durham Inspection Department in North Carolina** raised \$1,592 as part of their “7 Stars” employee-giving campaign kick-off celebration.
- **Nana’s Cookies 11th Annual Bake Sale in Pennsylvania**, organized by Alyssa, Lynne, and Linda, raised \$3,800 to support MSAA’s programs and services.

Additionally, a family in California has held an annual Christmas dinner for the past 20 years. Instead of exchanging gifts with one another, members of the family donate to support a different charity each year. For 2017, they chose MSAA as their charity, to honor a relative who was recently diagnosed with MS. Raising \$700, a family member wrote to MSAA, “We chose MSAA because your organization provides very practical items. Whether it is financial assistance [for an MRI], cooling vests and other physical aid items, or education for families and recently diagnosed persons, these items provide real concrete help for people diagnosed with MS.” ■



*Walker is participating in his second Swim for MS fundraiser in honor of his mother.*

## Swim for MS

Swim for MS is a national fundraiser in which volunteers are encouraged to create their own swim challenge to support MSAA.

Walker first discovered our Swim for MS fundraising campaign in 2017, where volunteers can create their own swim activity, set a challenge goal, and collect pledges from family and friends to help support MSAA's free programs and services. Walker not only reached, but exceeded his goal in 2017, raising more than \$1,800 to help support the MS community.

This year is Walker's second Swim for MS fundraiser in honor of his mother, Shana, who

has had MS since 1999. On his fundraising page, Walker states, "My goal is to raise \$2,500, which is almost \$150 for each year my mom has struggled with MS." Walker says, "Lots of people don't 'get' she's not well or unable to do things at times because her symptoms are invisible. I hope to help raise awareness about what the reality of living with MS is truly like."

Swimming 1,600 minutes so far, Walker has already raised \$2,037! To read more or to help him reach his goal of raising \$2,500, please visit [support.mymsaa.org/Walker](https://support.mymsaa.org/Walker). ■

## Make a TRIBUTE Gift



Through MSAA's **Tribute Gift program**, a gift can be given as a lasting remembrance to memorialize a loved one, honor a friend or celebrate a birthday, holiday, anniversary, or unique accomplishment.

Your generous donation will help ensure more people get the assistance they are seeking – cooling vests, wheelchairs, informational resources, vital MRIs and much, much more.

To make a tribute gift, please visit [support.mymsaa.org/tribute](https://support.mymsaa.org/tribute)

# Finding Happiness after an MS Diagnosis

Photo: Matt D'Avella

## By Courtney Carver

In the spring of 2006, I was training for a cycling event in Salt Lake City, Utah, to raise funds for MS research. The owner of the company I worked for had multiple sclerosis and inspired me to raise money for this cause. He was in a wheelchair and I was going to ride for him.

Things were crazy-busy at work that spring and I wasn't feeling well. After coming home from a trip to Europe, what I thought was a little jet lag turned into a lot of vertigo. I had experienced vertigo before and I figured it was just some type of ear infection. My doctor thought the same thing. As the weeks progressed, I couldn't walk a straight line, let alone ride a bike. Along with vertigo came fatigue. One side of my face and my hands were tingling. None of these symptoms were brand new, but I had never had them all at once or this severe. Two months later, I still felt like I was stumbling out of a bar whenever I

*Courtney Carver, above, making notes while enjoying the outdoors. The author found happiness by removing the overwhelming stress and clutter from her life. Following her diagnosis, Courtney simplified her life and wrote a book about the process, titled *Soulful Simplicity*. This book is featured in our "Spread the Word" column on page 44.*

stood up. I had missed the bike ride and was diagnosed with MS.

My diagnosis wasn't as tidy as I just noted. Instead of a few sentences, it was days and weeks of fatigue, vertigo, and uncertainty. It was MRIs with gadolinium-contrast agents delivered via IV that made me want to throw up, eye tests, blood work, ultrasounds of my heart to rule out mini strokes, balance and neuro exams. And the cherry on top ... a blood patch to stop the debilitating headache caused by the leaking fluid in my spinal cord after a lumbar puncture.

By the time I called for my test results, I was vulnerable, scared, sick and tired. Here is how the conversation went:



- Me:** Hi, I'm calling for test results from my lumbar puncture.
- Them:** Yes, we have them right here. You don't have MS.
- Me:** Thank you so much!
- Them:** I can't believe you didn't know. We got your results back last week.
- Me:** That's not possible. My lumbar puncture was this week.
- Them:** (big, painful pause) We'll call you back.

*Next call:*

- Them:** Hi Courtney, Sorry about that. You do have MS.
- Me:** What? (Thinking to myself: did you just diagnose me with MS over the phone?) What should I do now?
- Them:** Come pick up some brochures and choose a drug.
- Me:** OK (Thinking ... I'm supposed to pick my own drug? This is not okay. Nothing will ever be okay again.)

I left the cubicle at my office and cried all the way home. I thought my life was over. I was afraid that MS would take over and ruin my health, my family, my work, and everything I cared about.

And then, inch by inch, I changed my life. I changed what I ate, what I owned, what I owed, where I worked, and how I loved. I changed all of it. Today, 12 years later, I am practically symptom free. I haven't had a relapse in more than 10 years and recent

MRIs show no new lesions or MS progression. I moved from powerless victim to the hero of my own story. I realized I have choices. I didn't choose MS, but I do choose what foods I put in my body, what treatments I take, who I spend time with, who is on my medical team, and how I view my life and the world.

I didn't want MS, and I don't wish it on anyone else, but it has been a blessing in my life. Dealing with the uncertainty of MS helped me to become more comfortable with uncertainty in other situations. I am more concerned with what's happening today versus what's happening next week, or next year. Working through the fear of an unpredictable diagnosis reminded me that fear is only what I think, and not what is. That gave me confidence to make big changes, and take risks that I would have walked away from before. Ignoring the people who told me not to share my diagnosis with co-workers, my daughter, and other people, taught me that showing up and being honest about who I am and what I'm going through isn't a sign of weakness. Honesty and vulnerability may repel some people, but it attracts the right people.

The unexpected diagnosis helped me to worry less as I realized that the things we worry about and stress over every day are typically not the things that actually happen. My busy life may not have been the cause of MS, but I had overlooked the damage that chronic busyness was doing to my health and relationships for years. MS gave me permission to listen to my body, and to create a life with time and space for what really matters to me. ■

# MSAA's Lending Library Selections

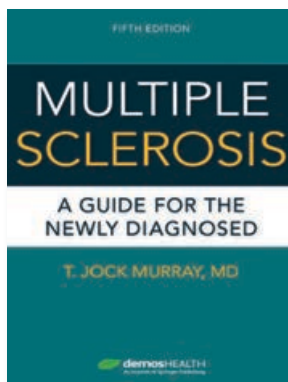
## Multiple Sclerosis: A Guide for the Newly Diagnosed (fifth edition)

by T. Jock Murray, MD

Demos Health | MSAA Book #316

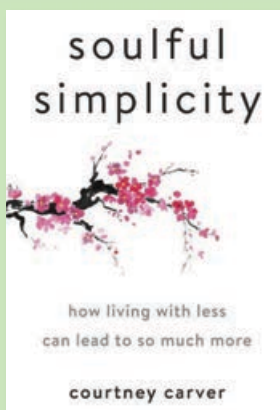
Author Thomas John “Jock” Murray, MD has been a big part of the MS community for more than half of a century. Among his many contributions as an MS neurologist, educator, researcher, and writer, he was also the founder and past president of the Consortium of MS Centers.

In this fifth edition, Dr. Jock Murray addresses the history of MS and explains what MS is, how it is diagnosed, and its possible causes. He describes treatment options and touches on practical guidelines for living and coping with the disease. He provides important information on employment, financial and life planning, as well as details on research and clinical trials. Helpful references such as a glossary, additional reading, and resources are also included in this informative publication.



## MSAA's Lending Library

To borrow books featured in this column or any other book in MSAA's Lending Library, please visit [mymsaa.org/library](http://mymsaa.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.**



## Soulful Simplicity by Courtney Carver

TarcherPerigee | MSAA Book #389

Many short and quick chapters make up this very insightful publication – which is indicative of the book's main message – to simplify one's life! The author, Courtney Carver, tells the story of her life prior to and after her diagnosis of MS, and then goes on to explain how she was able to find happiness by removing the overwhelming stress and clutter from her life. In the process, she talks about family, work, and lifestyle – coming to many conclusions about what was wrong and why her life was so challenging.

Courtney's book includes several short lists of questions and action steps. Recognizing one's wake-up call, practicing healthy routines, reducing stress by learning to say no, simplifying through clearing debt and clutter, as well as developing positive relationships, are among the many topics addressed.



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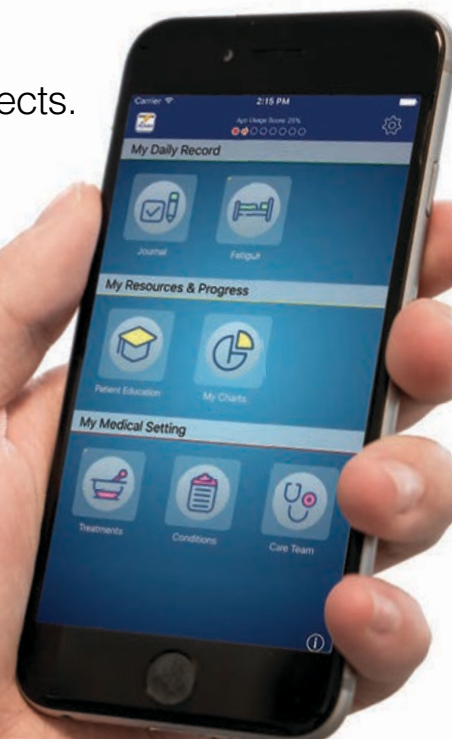
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