



Summer/Fall 2024

# THE Motivator

Published by the Multiple Sclerosis Association of America

## Seeking Balance in MS



Join us for MSAA's 2024-25  
**Improving Lives Through Art®**  
new series – creative virtual  
fundraising events focused on  
the many benefits of art!



## Virtual Paint-Alongs

**NOVEMBER 12, 2024**

**MARCH 4, 2025**



Join artist Hannah Garrison, MSAA Art Showcase participant, as she guides you through the re-creation of one of her works of art.



## Virtual Art Tour

**FEBRUARY 11, 2025**



Joe Caliva (pictured), art expert and docent at the Barnes Foundation in Philadelphia, will return once again to lead a very special

Art Tour, focusing on African American army veteran and artist Horace Pippin. This tour will highlight the works by Pippin featured at the Barnes and from other museums as well.

Pictured on the left is "Autumn's Gaze," the featured artwork for MSAA's November paint-along virtual event.



Multiple Sclerosis  
Association of America

To purchase tickets, please visit [engage.mymsaa.org/ILTA24\\_25](https://engage.mymsaa.org/ILTA24_25)

Published by the Multiple Sclerosis Association of America

**Gina Ross Murdoch**  
President & CEO

**MSAA Board of Directors**  
**Jennifer L. Schwartz, Esq.,** Chair  
**Eric K. Bossard,** Vice Chair  
**Meryl Ravitz, CPA,** Treasurer  
**Wendy B. Scott, Esq.,** Secretary  
**Barry A. Singer, MD,** Member at Large  
**Audrey A. Allsopp**  
**Ann Baird Bishop, Esq.**  
**Julian Gamboa**  
**Michael Schoenhaut**  
**Martha Senturia, PhD**  
**Jason M. Slattery**  
**Andrew Woo, MD, PhD**

### The Motivator Staff

**Andrea L. Griffin,** Editor  
VP of Communications & Marketing  
**Susan Wells Courtney**  
Senior Writer & Creative Director  
**Barry A. Hendin, MD,** Chief Medical Officer  
**John Masino,** Advertising Manager  
Senior Director of Digital Communications

### MSAA National Headquarters

375 Kings Highway North, Suite B  
Cherry Hill, New Jersey 08034  
**(800) 532-7667**  
[mymsaa.org](http://mymsaa.org)

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



## COVER STORY

### 8 Seeking Balance in MS

*By Susan Wells Courtney and Tom Garry*

Valuable information is provided on dizziness, balance, and mobility.



## DEPARTMENTS

- 2 Up Front** *By Gina Ross Murdoch*  
MSAA's President and CEO talks about MSAA's vital programs and ways to support them.
- 26 Ask the Doctor** *By Barry A. Hendin, MD*  
MSAA's Chief Medical Officer answers questions sent in by readers.
- 28 Research News** *By Tom Garry*  
A current IV medication may now be taken subcutaneously, plus a medication for relapsing MS is studied in primary-progressive MS.
- 30 Program Notes** *By Susan Wells Courtney*  
Details are given on MSAA's resources and recent awards.
- 32 Thoughts About Giving** *By Susan Wells Courtney*  
Opportunities to support MSAA are highlighted, including volunteers who are going the distance in support of MSAA.
- 34 Stories to Inspire** *By Donna O'Daniel*  
An avid bird watcher retires from the field, but now observes from a new perspective.



Multiple Sclerosis Association of America

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

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

Copyright © Multiple Sclerosis Association of America, 2024. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without prior written permission from MSAA.



# Increasing Outreach of MSAA's Vital Programs

**By Gina Ross Murdoch**

MSAA President and CEO

As we transition into the autumn months, our work to fulfill MSAA's mission is busier than ever. The growth of our programs is essential to Improving Lives Today and serving the MS community in the best ways possible.

Examples of this growth include the ability to provide valuable support and resources to greater numbers of people through our Helpline Specialists... the dissemination of critical information on topics such as treatments, research, managing symptoms, general health and wellness strategies, and more via our educational programs, online information, plus our publications... delivering safety

and mobility products as well as cooling vests for symptom relief... the continuing expansion of our webinar, podcast, and video offerings, plus one of our newer initiatives, the Multiple Sclerosis Implementation Network™ (MSIN™). This patient-centric initiative includes the development of a practice-based research network for medical professionals to share data and experiences to improve health outcomes for people with MS.

This is just a sampling of the vital work that MSAA performs every day to fulfill our mission of Improving Lives Today for all those affected by MS. However, another crucial part of our work is to raise the money needed to keep these programs flourishing. One of our fundraising opportunities is Team MSAA's participation in the annual *runDisney* events,

---

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, Ms. Murdoch 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. She currently serves as Treasurer of the Multiple Sclerosis Coalition (MSC), a group of nine separate organizations dedicated to supporting the MS community. Ms. Murdoch has held several elected positions in her town; volunteers for her college alma mater, Drew University; and recently, earned her Master's in Business Administration from Boston University.

## In Memoriam: June Halper, MSN, APN-C, FAAN, MSCN

MSAA would like to recognize a great loss within the MS community. In July, Consortium of Multiple Sclerosis Centers' (CMSC) CEO and Founder June Halper passed away, leaving behind a legacy of incredible advancements in the field of MS and patient care over the course of her 50-year career. Her many achievements will continue to play an important role in MS care for countless years to come. Our thoughts are with June's family, our colleagues and friends at CMSC, as well as with all those who knew June and benefited from her selfless devotion to the care of others.

which include the Walt Disney World® Marathon Weekend from January 8-12, 2025, and the Disneyland® Half Marathon Weekend from January 30 - February 2, 2025.

For the past few years, I have joined more than 100 other runners, walkers, and virtual participants in raising funds for MSAA's programs and services, while also making new friends and hearing inspirational stories of challenges and personal achievements. For more information, please see our "Thoughts About Giving" column beginning on page 32.

We also have a number of other ways to support MSAA and the MS community. These include making a donation to honor or remember someone special, as well as creating your own DIY fundraiser. And finally, I want to mention that Giving Tuesday on December 3rd is an important date to show your support for MSAA and our free programs and services.

In addition, I would like to point out the significance of this issue's cover story focusing on the topics of balance, mobility, and dizziness. Difficulties in these areas are

experienced by a large percentage of individuals with MS – and learning more about these symptoms and how they may be better managed can help to improve both safety and quality of life.

Before concluding this edition of "Up Front," I want to wish all of our readers good health and happiness throughout the rest of 2024 and into the New Year. ■

## MSAA Webinars and Videos

MSAA offers a variety of educational webinars and videos covering a wide range of vital topics. Several of these are available in Spanish. Please visit [mymsaa.org/videos](https://mymsaa.org/videos) to learn more.



For people living with relapsing multiple sclerosis (RMS)

**briumvi**<sup>®</sup>  
ublituximab-xiiy 150 mg/6 mL  
injection for IV

**1-HOUR INFUSION  
TWICE PER YEAR<sup>a</sup>**

BRIUMVI is the **only B-cell therapy approved** for RMS, administered as a 1-hour infusion, twice per year<sup>a</sup>

### Well-studied clinical profile

- Tested in 2 clinical studies with more than 1,000 people, of which 543 were treated with BRIUMVI and 546 were treated with teriflunomide\*

### Proven effective in 2 clinical studies

- BRIUMVI reduced relapses by up to 59% in Study 1 (in Study 2 by 49%) compared to teriflunomide
- Significantly reduced brain lesions on magnetic resonance imaging (MRI)

– Joy, Living with RMS and taking BRIUMVI



See more study results  
at [BRIUMVI.com/results](https://BRIUMVI.com/results)

**BRIUMVI has been prescribed to  
over 5,000 people**

<sup>a</sup> Following the starting dose.

\*teriflunomide is the active ingredient in AUBAGIO<sup>®</sup>. AUBAGIO<sup>®</sup> is a registered trademark of Sanofi or an affiliate.

Data on File, TG Therapeutics 2024.

BRIUMVI Prescribing information. TG Therapeutics Inc; 2022.

#### INDICATION

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

#### IMPORTANT SAFETY INFORMATION

##### Who should not receive BRIUMVI?

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

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

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

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

**Infusion reactions:** Infusion reactions are one of the most common side effects of BRIUMVI, which can be serious and may require you to be hospitalized. You will be monitored during your infusion and may be monitored after each infusion of BRIUMVI for signs and symptoms of an infusion reaction. Tell your healthcare provider if you get any of these symptoms:

fever	itchy skin	wheezing
chills	dizziness	nausea
headache	feeling faint	abdominal pain
flu-like symptoms	swelling of	throat irritation
fast heartbeat	tongue or throat	redness of the
hives	trouble breathing	face or skin

PLEASE SEE ADDITIONAL IMPORTANT SAFETY INFORMATION ON THE FOLLOWING PAGE

## IMPORTANT SAFETY INFORMATION (CONTINUED)

**These infusion reactions can happen over 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 an infusion reaction, your healthcare provider may need to stop or slow down the rate of your infusion.

### Infection:

Infections are a common side effect, and upper respiratory tract infections are one of the most common side effects of BRIUMVI. BRIUMVI increases your risk of getting infections caused by bacteria or viruses that may be life-threatening or cause death. 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 painful urination. Your healthcare provider should delay your treatment with BRIUMVI until your infection is gone.

**Hepatitis B virus (HBV) reactivation:** Before starting treatment with BRIUMVI, 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 BRIUMVI. 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 BRIUMVI.

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

**Progressive Multifocal Leukoencephalopathy (PML):** PML may happen with BRIUMVI. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These symptoms may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion, and personality changes.

**Low immunoglobulins:** BRIUMVI may cause a decrease in some types of antibodies. Your healthcare provider will do blood tests to check your blood immunoglobulin levels.

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

have or think you have an infection.  
take or plan to take medicines that affect your immune system. These medicines may increase your risk of getting an infection.

have ever had hepatitis B or are a carrier of the hepatitis B virus.  
have had a recent vaccination or are scheduled to receive any vaccinations.

**You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with BRIUMVI.** You **should not** receive 'live' or 'live-attenuated' vaccines while you are being treated with BRIUMVI and until your healthcare provider tells you that your immune system is no longer weakened.

**When possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with BRIUMVI.** If you would like to receive any non-live vaccines while you are being treated with BRIUMVI, talk to your healthcare provider.

If you have a baby and you received BRIUMVI during your pregnancy, it is important to tell your baby's healthcare provider about receiving BRIUMVI so they can decide when your baby should be vaccinated.

are pregnant, think that you might be pregnant, or plan to become pregnant. BRIUMVI may harm your unborn baby. You should use birth control (contraception) during treatment with BRIUMVI and for at least 6 months after your last infusion of BRIUMVI. Talk with your healthcare provider about what birth control method is right for you during this time.

are breastfeeding or plan to breastfeed. It is not known if BRIUMVI passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take BRIUMVI.

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

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

**The most common side effects of BRIUMVI include:**

Infusion reactions, upper and lower respiratory tract infections, herpes infections, extremity pain, insomnia, and fatigue.

These are not all the possible side effects of BRIUMVI. Call your doctor for medical advice about side effects. You may report side effects to FDA at **1-800-FDA-1088**. You may also report side effects to TG Therapeutics at **1-877-TGTXINC (1-877-848-9462)**.

For more important information, go to [www.briumvi.com](http://www.briumvi.com) or call **1-833-BRIUMVI (1-833-274-8684)**.

**PLEASE SEE FULL PRESCRIBING INFORMATION AT [WWW.BRIUMVIPI.COM](http://WWW.BRIUMVIPI.COM) AND BRIEF SUMMARY ON FOLLOWING PAGES**



© 2024 TG Therapeutics, Inc. All rights reserved.  
BRIUMVI® is a registered trademark of TG Therapeutics, Inc. US-BR-2300193v2 07/2024



## **Consumer Brief Summary**

### **BRIUMVI® (bree-UM-vee) (ublituximab-xiiy) injection, for intravenous use**

**IMPORTANT FACTS:** This is a brief summary of important information regarding BRIUMVI and does not replace talking to your healthcare provider about your condition.

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

##### **BRIUMVI can cause serious side effects, including:**

**Infusion reactions.** Infusion reactions are one of the most common side effects of BRIUMVI. Infusion reactions can be serious and may require you to be hospitalized. You will be monitored during your infusion and may be monitored after each infusion of BRIUMVI for signs and symptoms of an infusion reaction. Tell your healthcare provider if you get any of these symptoms: fever, chills, headache, flu-like symptoms, fast heartbeat, hives, itchy skin, dizziness, feeling faint, swelling of tongue or throat, trouble breathing, wheezing, nausea, abdominal pain, throat irritation, or redness of the face or skin.

**These infusion reactions can happen over 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 an infusion reaction, your healthcare provider may need to stop or slow down the rate of your infusion.

**Infections.** Infections are a common side effect, and upper respiratory tract infections are one of the most common side effects of BRIUMVI. BRIUMVI increases your risk of getting infections caused by bacteria or viruses that may be life-threatening or cause death. 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 painful urination. Your healthcare provider should delay your treatment with BRIUMVI until your infection is gone.

**Hepatitis B virus (HBV) reactivation:** Before starting treatment with BRIUMVI, 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 BRIUMVI. 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 BRIUMVI.

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

**Progressive Multifocal Leukoencephalopathy (PML):** PML may happen with BRIUMVI. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These symptoms may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion, and personality changes.

**Low immunoglobulins:** BRIUMVI may cause a decrease in some types of antibodies. Your healthcare provider will do blood tests to check your blood immunoglobulin levels.

#### **What is BRIUMVI?**

BRIUMVI is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS), including:  
clinically isolated syndrome  
relapsing-remitting disease  
active secondary progressive disease

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

#### **Do not receive BRIUMVI if you:**

- have active hepatitis B virus (HBV) infection.
- have had a life-threatening allergic reaction to BRIUMVI. Tell your healthcare provider if you have had an allergic reaction to BRIUMVI. See **“What are the ingredients in BRIUMVI?”** for a complete list of ingredients in BRIUMVI.

#### **Before receiving BRIUMVI, 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 BRIUMVI?”**



take or plan to take medicines that affect your immune system. These medicines may increase your risk of getting an infection.  
have ever had hepatitis B or are a carrier of the hepatitis B virus.  
have had a recent vaccination or are scheduled to receive any vaccinations.

**You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with BRIUMVI.** You **should not receive** 'live' or 'live-attenuated' vaccines while you are being treated with BRIUMVI and until your healthcare provider tells you that your immune system is no longer weakened.

**When possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with BRIUMVI.** If you would like to receive any non-live vaccines while you are being treated with BRIUMVI, talk to your healthcare provider.

If you have a baby and you received BRIUMVI during your pregnancy, it is important to tell your baby's healthcare provider about receiving BRIUMVI so they can decide when your baby should be vaccinated.

are pregnant, think that you might be pregnant, or plan to become pregnant. BRIUMVI may harm your unborn baby. You should use birth control (contraception) during treatment with BRIUMVI and for at least 6 months after your last infusion of BRIUMVI. Talk with your healthcare provider about what birth control method is right for you during this time.

are breastfeeding or plan to breastfeed. It is not known if BRIUMVI passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take BRIUMVI.

**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 BRIUMVI?**

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

Your healthcare provider may do a pregnancy test before each infusion of BRIUMVI.

Before treatment with BRIUMVI, you will receive a corticosteroid and an antihistamine medicine to help reduce the risk of infusion reactions by making them less frequent and less severe. You may also receive other medicines to help reduce the risk of an infusion reaction. See **"What is the most important information I should know about BRIUMVI?"**

Your first dose of BRIUMVI will last about 4 hours.

Your second dose of BRIUMVI will be given 2 weeks after your first dose. This infusion will last about 1 hour.

Your next doses of BRIUMVI will be given as 1 infusion every 24 weeks. These infusions will last about 1 hour.

### **What are the possible side effects of BRIUMVI?**

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

#### **The most common side effects of BRIUMVI include:**

Infusion reactions, upper and lower respiratory tract infections, herpes infections, extremity pain, insomnia, and fatigue. See **"What is the most important information I should know about BRIUMVI?"**

These are not all the possible side effects of BRIUMVI. 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 BRIUMVI.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your pharmacist or healthcare provider for information about BRIUMVI that is written for health professionals.

### **What are the ingredients in BRIUMVI?**

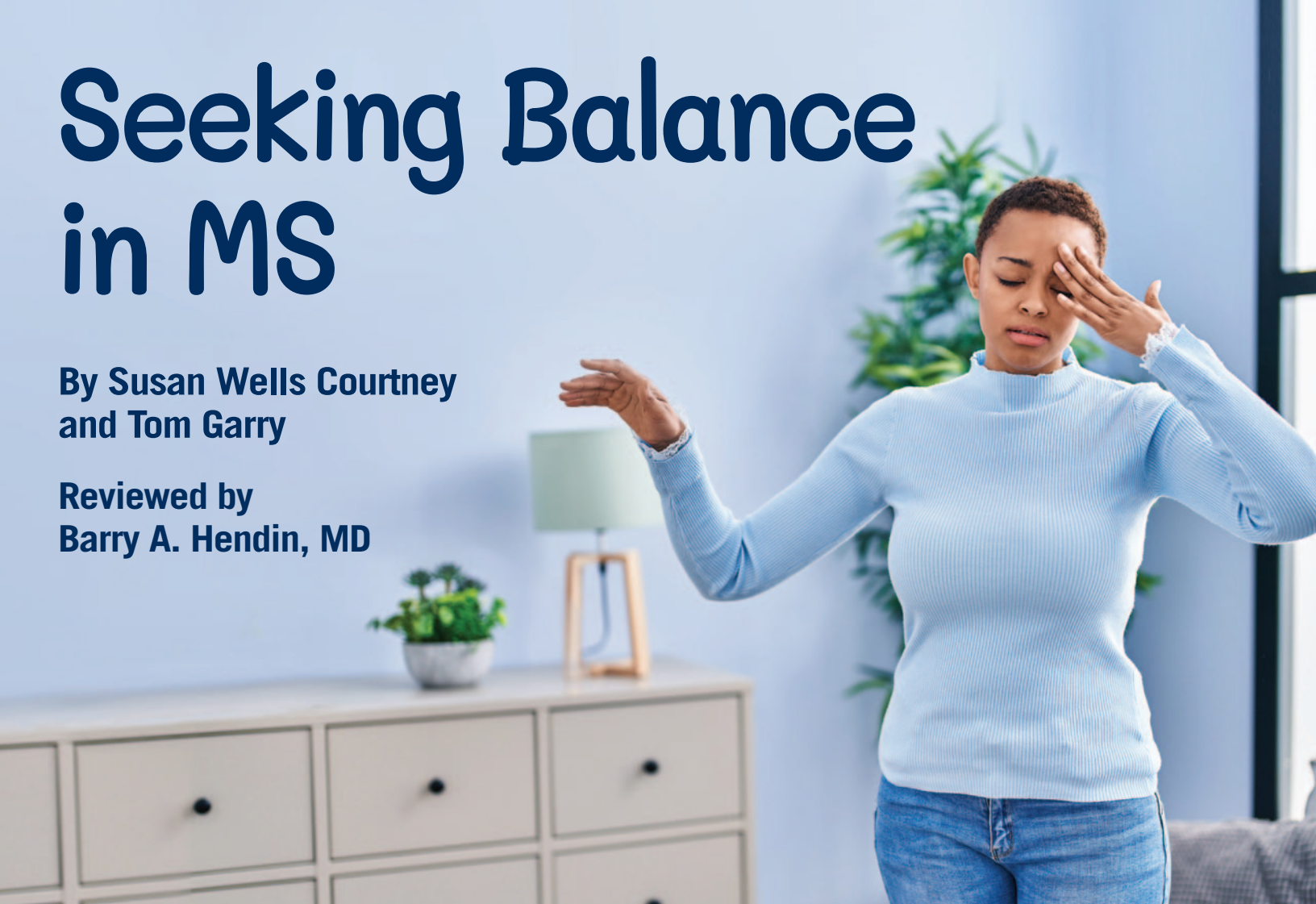
**Active ingredient:** ublituximab-xiiy.

**Inactive ingredients:** hydrochloric acid, polysorbate 80, sodium chloride, sodium citrate, Water for Injection, USP.

# Seeking Balance in MS

By Susan Wells Courtney  
and Tom Garry

Reviewed by  
Barry A. Hendin, MD



**Do you ever feel dizzy? If so, please know that you are not alone. Many others – both with and without MS – experience this uncomfortable sensation.**

Between 15% to 35% of the general population experiences dizziness at some point in their lives. This percentage increases to roughly half (49% to 59%) of individuals with MS reporting dizziness. In the United States, an estimated 7.5 million people seek medical attention for dizziness each year, making it one of the most common complaints seen by doctors and emergency departments.<sup>1</sup>

Dizziness can present in varying degrees and types, including vertigo, which is the

sensation of spinning or movement around you. Naturally, dizziness and vertigo greatly affect balance and mobility. In addition, these types of challenges not only add to fatigue – a common symptom experienced by more than 70% of the MS population – but are also worsened by fatigue. Given these facts, it should come as no surprise that balance disorders are seen in 75% to 82% of people with MS who have mild to moderate disability.<sup>1</sup>

In this issue's cover story, we examine both dizziness and vertigo, as well as balance and mobility, in two separate sections. As you will see, the physical or psychological issues behind one's dizziness can vary greatly, and once the exact cause is determined, effective treatments are available.

## PART I: DIZZINESS AND VERTIGO

### Initial Exam, Types, and Pathologies

As noted in the introduction, dizziness is a very common symptom among both individuals with MS as well as members of the general population. However, the type of dizziness someone experiences (vertigo is one type of dizziness), as well as the cause of that dizziness, varies greatly between different people. In order to identify the type of dizziness and its cause, the workup may include the following:

- Positional testing to see how the dizziness changes between different positions and also to observe eye movements when the head is turned certain ways
- A detailed history that includes duration of the dizziness and if it is continuous or episodic
- Discussion of possible triggers
- A magnetic resonance imaging (MRI) scan when the central nervous system (CNS) is involved
- Additional testing, as needed

Once the specific cause is determined, a treatment plan may be implemented. Members of the MS community should keep in mind that when experiencing dizziness, just because someone has MS, does not necessarily mean that the dizziness is a result of disease activity. While a new lesion, inflammation, or an exacerbation may cause dizziness, at the same time, a different, non-MS-related issue may be to blame.

**Dizziness** is divided into four types:

- Vertigo (the sensation of spinning or your surroundings moving around you; it can be accompanied by nausea, vomiting, and hearing loss)
- Disequilibrium without vertigo (the sensation of falling)
- Presyncope (feeling close to fainting)
- Psychophysiological dizziness (light-headedness resulting from anxiety or panic)

**Vertigo** is divided into two main categories:

- Dysfunction or disease within the **central nervous system**, originating from pathology in the cerebellum or brain stem
- Dysfunction or disease within the **peripheral nervous system**, originating from the inner ear or vestibular nerve

### Diagnosis

The first step in diagnosis is to determine the type of dizziness someone is experiencing. The next step is to distinguish between dysfunction within the central nervous system (relating to the cerebellum or brain stem) and the peripheral nervous system (involving the inner ear or vestibular nerve).

Identifying which nervous system is involved in the dizziness or vertigo is critical for the appropriate treatment of one's specific cause of dizziness and vertigo. The "HINTS" examinations, which stands for Head Impulse (for maintaining fixation), Nystagmus (fast and involuntary eye movement), and Test of Skew

(measuring uneven or oblique eye movement), is a quick, bedside method to distinguish between these two types of pathology.<sup>2</sup>

The HINTS examinations are performed by one's doctor and consist of different exercises: fixating eyes on the doctor's nose while the patient's head is turned, looking side-to-side, and having one eye covered while fixating on the doctor's nose. The resulting eye movements (maintaining or not maintaining fixation, slow versus fast nystagmus in different directions, and downward versus upward eye movement during fixation with one eye covered) indicate if the dizziness and vertigo are of central or peripheral origin, as well as which side is affected in vestibular neuritis.

In addition to learning what type of dizziness one is experiencing (vertigo, disequilibrium, or presyncope) and performing the HINTS examinations, the duration of vertigo and its trigger(s) are also important for an accurate diagnosis. The physician must also ask about the presence of headaches, tinnitus (ringing in the ears), hearing loss, and other neurologic deficits, to better identify the cause.

Some individuals experience chronic dizziness, which can result from different causes, particularly if an accurate diagnosis has not been made (often despite one or more doctor visits) and an appropriate treatment plan has not been implemented. In addition, some may also experience what is called "visual vertigo," where "visually busy" surroundings can cause their symptoms to worsen. Examples of "visually busy" surroundings include large stores with rows of shelves, bright or moving lights, and traffic.

## Central Nervous System Pathology

Vertigo that is caused by dysfunction within the central nervous system, relating to the cerebellum or brain stem, could indicate one of the following conditions:

- Stroke
- Tumor
- Hemorrhage
- Multiple sclerosis

When the central nervous system is involved, other neurological symptoms are often present, such as weakness, sensory changes, or confusion. For individuals with MS, vertigo and any concurrent increase in symptoms can be signs of inflammation from MS and possibly signs of a relapse. When a problem within the central nervous system is suspected, a magnetic resonance imaging (MRI) scan is performed.

## Peripheral Nervous System Pathology

Peripheral pathology refers to disorders of the peripheral nervous system, involving the inner ear or vestibular nerve, and are frequently associated with vertigo, but are often benign and easier to treat. These include:

- Benign paroxysmal positional vertigo (BPPV)
- Vestibular neuritis
- Vestibular migraine (VM)
- Ménière's disease (MD)
- Cervical vertigo

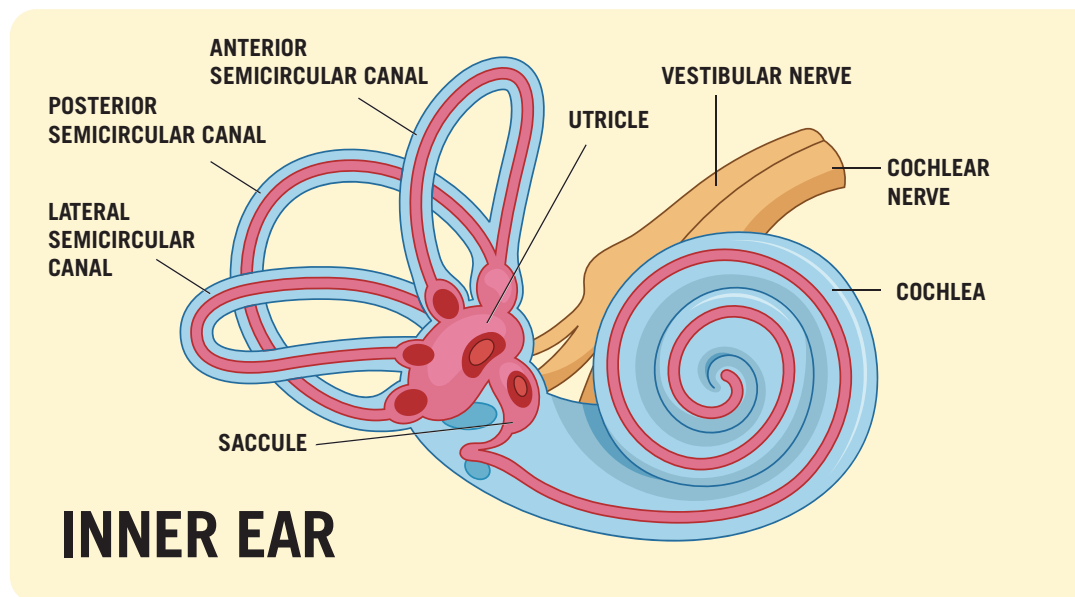
## Benign Paroxysmal Positional Vertigo

Benign paroxysmal positional vertigo (BPPV) is the most common cause of “positional vertigo,” which is when someone changes position – possibly lying back or sitting up – and experiences vertigo. It is also the most successfully treated type of vertigo. BPPV may also cause nausea, visual issues, and nystagmus.

The mechanisms behind BPPV are well-defined. Otoconia, also known as “ear stones,” are small calcium crystals found in two organs of your vestibular system called the saccule (sensitive to vertical acceleration) and the utricle (sensitive to horizontal acceleration); both are located in the inner ear. Hairlike cells within these organs are stimulated by the otoconia to tell the brain that the body is accelerating, which is a vital component to balance.<sup>3</sup>

Other important components to balance include three semicircular canals found in the inner ear region of both ears, and each is paired with the corresponding one on the opposite side. These canals are lined with cilia (microscopic hairs) and filled with a liquid substance, signaling the brain as to which direction the head is tilting. The three canals are anterior (detecting forward and back “nodding of head” movement), posterior (detecting a tilt-like head movement), and lateral (for side-to-side head movement).<sup>3</sup>

Through different positional testing, such as the “Dix-Hallpike” and “Roll” tests, doctors may determine which ear canal has been affected, and on which side, according to the movement of the eyes during these tests. Vertigo triggers and duration differ slightly between these canals as well.



## INNER EAR

BPPV occurs when otoconia is dislodged from the utricle and enters one of the ear canals. Age, head trauma, inner ear disease, vestibular neuronitis, osteoporosis, and inner ear surgery, are among the causes of otoconia becoming dislodged.<sup>2</sup> With BPPV, when the head is moved, these misplaced calcium crystals improperly stimulate the cilia within the affected canal, sending false movement signals to the brain that are not in agreement with those signals from the corresponding canal, causing the individual to have the spinning sensation known as vertigo.

BPPV can be treated through different maneuvers performed by a doctor, while the

patient is in lying and sitting positions, and having their head turned in certain directions. Examples of these maneuvers to reposition the calcium crystals include the “Epley maneuver,” the “Barbecue maneuver,” and the “Semont maneuver,” depending on which canal is affected.

According to an article on a holistic approach to dizziness, the authors note that treatments may be used for more severe symptoms of BBPV. They explain that antihistamines and anticholinergic drugs may be used to relieve nausea, vomiting, and vertigo during the acute phase of BBPV. Examples of these medications include dimenhydrinate, diphenhydramine, and metoclopramide. However, vestibular suppressants, which are medications used to suppress nystagmus (abnormal eye movement) and reduce motion sickness, cannot be used during treatment with one of the maneuvers mentioned previously; nor can these types of medicines be used for a prolonged period of time without the risk of developing chronic dizziness.<sup>2</sup>

## **Vestibular Neuritis**

Vestibular neuritis is a disorder causing the vestibulocochlear nerve, which is located in the inner ear, to become inflamed. Thought to be caused by a viral infection, this affects balance and can cause dizziness and vertigo. Treatments for vestibular neuritis include medications such as antivirals and those used to treat nausea, dizziness, and inflammation. Physical therapy with specific exercises can also help reduce the symptoms.<sup>4</sup>

## **Vestibular Migraine**

Vestibular migraine (VM) is a neurological condition and is the second most common cause of vertigo. Symptoms include sudden attacks of vertigo, along with migraine symptoms that are experienced with at least half of these attacks. Vestibular migraine symptoms include: headache; sensitivity to light, sound, and/or touch; nausea and vomiting; and migraine aura.

Treatments can include lifestyle changes to reduce stress and fatigue, watching for dietary sensitivities, and rehabilitation exercises to help with balance issues. Medications may be given to help prevent vestibular migraine, such as tricyclic antidepressants, calcium channel blockers, antiseizure medication, and beta-blockers. Nonsteroidal anti-inflammatory drugs (NSAIDs), motion-sickness medications, and antipsychotic medication may be used to help reduce the symptoms.<sup>5</sup>

## **Ménière's Disease (MD)**

Ménière's disease (MD) is a rare disorder of the inner ear, affecting balance as well as hearing, and causing other symptoms such as vertigo and tinnitus (ringing in the ears). When someone is diagnosed with Ménière's disease (MD), symptoms may come and go with this condition.<sup>6</sup>

MD cannot be cured, but treatments are available to help with symptoms. Treatments include vertigo medications and vestibular rehabilitation (exercises to help with balance). In more severe cases, middle-ear injections or surgery may be considered.<sup>7</sup>



# STAY COOL WITH POLAR PRODUCTS!



## INTRODUCING THE COOL58® COOLING ACCESSORY KIT – NOW AVAILABLE THROUGH THE MSAA COOLING PROGRAM!



### KIT INCLUDES THE FOLLOWING COOLING PRODUCTS:

- **Cool58® Hat:** your choice of ball cap or bucket hat
- **Cool58® Deluxe Neck & Head Wrap**
- **Cool58® Performance Cooling Wrist Wraps**
- **Cool58® Bra, Under Arm & Groin Cooler:** two packs with covers, plus a complete extra set



### WHY CHOOSE US?

- **40 Years of Excellence:** Leading provider of MS cooling products.
- **20 Years with MSAA:** Proud supplier for the MSAA Cooling Program.



Experience targeted cooling with gentle 58° packs. Use accessories separately or together for maximum benefit!



### ALSO AVAILABLE:

**COOLFIT® KIT (OPTION B):** Secrets Torso Wrap with Kool Max® Packs, Kool Max® Deluxe Neck Wrap, Pair of Kool Max® Ankle Wraps, Pair of Kool Max® Wrist Wraps, and an extra set of Kool Max® cooling packs for each product.

**KOOL MAX® ZIPPER FRONT VEST KIT (OPTION C):** Kool Max® Zipper Front Vest, Kool Max® Deluxe Neck Wrap, and an extra set of Kool Max® cooling packs for each product.

### DISCOVER YOUR PERFECT COOLING SOLUTION TODAY!

**OUR TEAM IS READY TO HELP YOU FIND THE IDEAL COOLING PRODUCTS TAILORED TO YOUR UNIQUE NEEDS.**

**800.763.8423**  
**polar@polarproducts.com**



**polarproducts.com**

## Cervical Vertigo

Cervical vertigo is a condition where dizziness or vertigo (often more of a “floating sensation” versus spinning) is associated with neck pain. It may result from an injury to the neck, often occurring months or years earlier, or it may result from inflammation or arthritis within the cervical spine (neck) area. In addition to neck pain, dizziness, and a “floating” type of vertigo, symptoms can include balance problems and headache. Visual symptoms, such as rapid eye movement and visual fatigue, can also occur.

Cervical vertigo is treated by first addressing the problem causing neck pain, which might involve medications, physical therapy, and vestibular rehabilitation. Medications may include those that reduce inflammation and reduce dizziness, as well as muscle relaxants and pain relievers.<sup>8</sup>

## Psychophysiological Dizziness

Looking at psychophysiological dizziness, differentiating between neurologic manifestations versus a psychogenic origin can be complicated. In other words, determining which is the cause and which is the effect can be confounding. While anxiety and depression are strongly associated with dizziness, the unpleasant sensations of dizziness and vertigo, along with the fear of falling and injury, can create a great deal of anxiety. Additionally, this type of dizziness may be provoked by external influences, such as being in a crowd, driving, or feeling confined.

Psychophysiological dizziness tends to last for months or longer, and may have periodic flare-ups and possibly presyncope (feeling close to fainting) resulting from hyperventilation. However, anxiety and depression frequently occur in combination with Ménière’s disease and Vestibular migraine (VM) as well, so determining the origin of dizziness and vertigo that are accompanied by anxiety and depression requires specialized and ongoing evaluation and treatment.

Antidepressants and anxiolytic medications may be given to help reduce the lightheadedness or vertigo associated with psychophysiological dizziness. Cognitive behavioral modification techniques with desensitization for situational anxiety may also be of benefit.<sup>9</sup>





## Medication Side Effects

Another cause of dizziness that should not be overlooked is the use of certain medications. Frequently prescribed in older people or individuals with certain medical conditions, common medications that can cause dizziness include antiarrhythmics, antiepileptics, narcotics, muscle relaxants, and antiparkinsonian agents.<sup>2</sup> If a certain medication is suspected to be causing dizziness or vertigo, one's physician may be able to make adjustments to a prescribed medication.

## Closing Notes

According to MSAA Chief Medical Officer Dr. Barry Hendin, "The symptoms of dizziness and vertigo are experienced by a large portion

of not only the MS community, but the general population as well. As this article illustrates, these symptoms may be caused by any number of disorders – some serious, some benign and easy to treat.

"I would like to emphasize that new onset dizziness, vertigo, and imbalance, may indicate a relapse in someone with MS, but other causes are possible. When symptoms are new and persistent, prolonged, or severe, this warrants an evaluation by a clinician. In most instances, while concerning to the person experiencing these symptoms, such episodes do not pose any danger to the individual, other than the need to take the necessary precautions to reduce the risk of falling."

## References

1. García-Muñoz C, Cortés-Vega MD, Heredia-Rizo AM, et al. Effectiveness of Vestibular Training for Balance and Dizziness Rehabilitation in People with Multiple Sclerosis: A Systematic Review and Meta-Analysis. *J Clin Med*. 2020 Feb 21;9(2):590.
2. Koukoulithras I, Drousia G, Kolokotsios S, Plexousakis M, Stamouli A, Roussos C, Xanthi E. A Holistic Approach to a Dizzy Patient: A Practical Update. *Cureus*. 2022 Aug 4;14(8):e27681.
3. Yetman D. What Are Ear Stones, Also Known as Otoconia? Published by Healthline. October 7, 2022. Accessed at <https://www.healthline.com/health/ear-stones>
4. Vestibular Neuritis. Cleveland Clinic. Accessed August 2024 at <https://my.clevelandclinic.org/health/diseases/15227-vestibular-neuritis>
5. Vestibular Migraine. Cleveland Clinic. Accessed August 2024 at <https://my.clevelandclinic.org/health/diseases/25217-vestibular-migraine>
6. Ménière's Disease. Cleveland Clinic. Accessed August 2024 at <https://my.clevelandclinic.org/health/diseases/15167-menieres-disease>
7. Ménière's Disease. Mayo Clinic. Accessed August 2024 at <https://www.mayoclinic.org/diseases-conditions/menieres-disease/diagnosis-treatment/drc-20374916>
8. Cervical Vertigo. Cleveland Clinic. Accessed August 2024 at <https://my.clevelandclinic.org/health/diseases/23174-cervical-vertigo>
9. Lanska DJ. Psychophysiological dizziness. Published by MedLink Neurology. Updated 05.20.2024; originally released 10.22.2003. Accessed at <https://www.medlink.com/articles/psychophysiological-dizziness>

## PART II: BALANCE

### Keeping Your Balance – Literally – with MS

Remember the old adage, “It’s not what you say, it’s what you do”? That’s not entirely true when it comes to balance issues and – particularly – falls in people with MS, says Michelle H. Cameron, MD, PT, MCR.

“The most important thing you can do is to tell your provider if you’re falling or fearful of falling,” says Dr. Cameron, a neurologist and physical therapist. She explains that “saying something” is a prerequisite to “doing something” in terms of working with your clinician to develop an individualized plan to enhance balance and reduce the risk of falls.

Too often, she says, “People don’t tell us about falling because they don’t think there is anything that can be done. While we may not get to zero falls, we usually can reduce the number of falls, the severity of falls, and their consequences. As with so many of the challenges posed by MS, we as clinicians do not have a magic wand that can make the problem go away, but there are many steps we can take, and we can make it a lot better.”

Providers’ ability to manage balance problems stems in part from how frequently they see them. Dr. Cameron explains that 50% to 80% of people with MS have balance and gait dysfunction.<sup>1</sup> She adds that about half of people with MS fall at least once in a three-to-six-month period, with 30% falling more than once in that interval.<sup>2</sup>

While the prevalence of balance problems in MS is well documented, Mandy Rohrig,



DPT, MSCS, says that the profound impact of those challenges is not always fully appreciated, even by the people experiencing them.

“Balance affects so many aspects of life for a person with MS, from obvious things like mobility, exercise, and risk of falling, to issues that may be less apparent but that are very important, such as self-image, socialization, and relationships with loved ones,” says Dr. Rohrig, a physical therapist, Multiple Sclerosis Certified Specialist, and member of MSAA’s Healthcare Advisory Council.

Indeed, a study of 75 people with MS who were ambulatory and who had a recent fall or near fall found that greater confidence in one’s balance was associated with both greater social satisfaction and greater social engagement.<sup>3</sup> By contrast, Dr. Rohrig says,

reduced confidence about balance can mean reduced social interaction. “If a couple is not going out because one of them is worried about falling, their world gets smaller and smaller, and it can negatively affect not only their relationships with other people, but also with one another.”

## The Importance of an Individualized Approach

Dr. Rohrig explains that obtaining a thorough history is the first step in developing a plan tailored to a person’s specific balance challenges and needs.

“I partner with the person with MS and the care partner – if that person is involved and with my patient’s permission – to explore the circumstances when they have experienced imbalance, are concerned about falling, or had a fall. We do this investigative detective work together. This essential conversation helps to guide me in terms of how to best conduct the physical examination and overall assessment, and to then provide recommendations for interventions to improve balance and reduce fall risk. The interventions must address what is meaningful to the person,” says Dr. Rohrig, who has more than 14 years of experience practicing in a rehabilitation organization’s MS and vestibular/balance rehabilitation programs.

Her evaluation, she explains, includes looking at functional movements, such as sitting, standing, and walking, and assessment of strength, range of motion, spasticity, vision, and vestibular function. In terms of strength, a focus on the legs and core is particularly important, says Dr. Rohrig, who serves as

Senior Programs Consultant for Can Do MS (at [cando-ms.org](http://cando-ms.org)), a national non-profit organization that delivers health and wellness education programs to people with MS and their families.

Once the evaluation is completed, Dr. Rohrig shares her recommendations with the person. “I spend a lot of time educating people about how balance works and then personalizing that information to their unique situation. Education facilitates a deeper understanding of the ‘why,’ which makes my recommendations – the ‘how’ – more meaningful to them.” (See “The Basics of Balance,” page 24.) Dr. Rohrig says those recommendations typically cover three categories: exercise, environment, and, as indicated, use of adaptive devices.

**Exercises** generally focus on enhancing strength, range of motion, balance, and vestibular function, and often involve practicing going from sitting to standing and – in a safe corner – shifting one’s weight forward and backward and from side to side. The key, Dr. Rohrig adds, is for a professional to identify which exercises are appropriate for a person’s physical condition and functional needs. “I don’t want people using valuable energy and time on exercises that are not addressing a meaningful function for them,” she explains.

**Environmental considerations** include attention to maintaining balance on different types of interior and exterior surfaces, negotiating ramps and stairs, and maintaining balance in dynamic situations, such as a sidewalk crowded with people hurrying past.

*continued on page 22*

WITH KESIMPTA FOR RMS,  
"I CAN FILL  
*My* TIME  
MY WAY."

—JAMIE-LYNN SIGLER

Mom, Actor, MS Advocate  
Switched to KESIMPTA in 2023

Jamie-Lynn takes KESIMPTA® for her RMS in less than 1 minute a month,\* when ready. Whether she's at home with the kids or on the go for work, it fits into her busy schedule—which is just one of the reasons she switched to KESIMPTA.

Scan to learn  
more about taking  
KESIMPTA



MS, multiple sclerosis; RMS, relapsing multiple sclerosis.

\*After 3 weekly starter doses; typical administration time when ready to inject.

 **Kesimpta**®  
(ofatumumab) 20 mg  
injection

## Indication

### What is KESIMPTA (ofatumumab) injection?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including clinically isolated syndrome (CIS), relapsing-remitting disease, and active secondary progressive disease.

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

## Important Safety Information

### Who should not take KESIMPTA?

Do NOT take KESIMPTA if you:

- have an active hepatitis B virus (HBV) infection.
- have had an allergic reaction to ofatumumab or life-threatening injection-related reaction to KESIMPTA.

 **NOVARTIS**

**Novartis Pharmaceuticals Corporation**  
East Hanover, New Jersey 07936-1080

## Important Safety Information (cont)

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

KESIMPTA can cause serious side effects such as:

- **Infections.** Serious infections, which can be life-threatening or cause death, can happen during treatment with KESIMPTA. If you have an active infection, your health care provider (HCP) should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections. Tell your HCP right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.
- **HBV reactivation.** If you have ever had HBV infection, it may become active again during or after treatment with KESIMPTA (reactivation). If this happens, it may cause serious liver problems including liver failure or death. Before starting KESIMPTA, your HCP will do a blood test to check for HBV. They will also continue to monitor you during and after treatment with KESIMPTA for HBV. Tell your HCP right away if you get worsening tiredness or yellowing of your skin or the white part of your eyes.
- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your HCP right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory, which may lead to confusion and personality changes.
- **Weakened immune system.** KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

### Before you take KESIMPTA, tell your HCP about all your medical conditions, including if you:

- Have or think you have an infection including HBV or PML.
- Have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- Have had a recent vaccination or are scheduled to receive any vaccinations.
  - You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA. You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your HCP tells you that your immune system is no longer weakened.
  - Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.
  - Talk to your HCP about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- Are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control

(contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your HCP about what birth control method is right for you during this time.

- Are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your HCP about the best way to feed your baby if you take KESIMPTA.

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

### How should I use KESIMPTA?

**See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready pens or prefilled syringes.**

- Use KESIMPTA exactly as your HCP tells you to use it.
- Your HCP will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars, or stretch marks.

### KESIMPTA may cause serious side effects including:

- **Injection-related reactions.** Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. There are two kinds of reactions:
  - **at or near the injection site:** redness of the skin, swelling, itching, and pain. Talk to your HCP if you have any of these signs and symptoms.
  - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, tiredness, rash, hives, trouble breathing, swelling of the face, eyelids, lips, mouth, tongue and throat, and feeling faint, or chest tightness. Contact your HCP right away if you experience any of these signs and symptoms, especially if they become worse or you have new severe signs of reactions after subsequent injections. It could be a sign of an allergic reaction, which can be serious.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your HCP will do blood tests to check your blood immunoglobulin levels.

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

- Upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache.
- Headache.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Please see accompanying Consumer Brief Summary on the following page.**

## Consumer Brief Summary

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

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

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

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

**Infections.** Serious infections, which can be life-threatening or cause death, can happen during treatment with KESIMPTA. If you have an active infection, your health care provider should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections.

Tell your health care provider right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.

- **Hepatitis B virus (HBV) reactivation.** Before starting treatment with KESIMPTA, your health care provider will do blood tests to check for HBV. If you have ever had HBV infection, the HBV may become active again during or after treatment with KESIMPTA. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. You should not receive KESIMPTA if you have active hepatitis B liver disease. Your health care provider will monitor you for HBV infection during and after you stop using KESIMPTA. Tell your health care provider right away if you get worsening tiredness or yellowing of your skin or white part of your eyes during treatment with KESIMPTA.
- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your health care provider right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion and personality changes.
- **Weakened immune system.** KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

#### What is KESIMPTA?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including:

- clinically isolated syndrome
- relapsing-remitting disease
- active secondary progressive disease

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

#### Do not use KESIMPTA if you:

- have active hepatitis B virus infection.
- have had an allergic reaction to ofatumumab or life-threatening injection-related reaction to KESIMPTA.

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

- have or think you have an infection, including HBV or PML. See **"What is the most important information I should know about KESIMPTA?"**
- have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations.
  - **You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA.** You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your health care provider tells you that your immune system is no longer weakened.
  - **Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.**
  - Talk to your health care provider about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your health care provider about what birth control method is right for you during this time.
  - **Pregnancy Registry:** There is a registry for women who become pregnant during treatment with KESIMPTA. If you become pregnant while taking KESIMPTA, tell your health care provider right away. Talk to your health care provider about registering with the MotherToBaby Pregnancy Study in Multiple Sclerosis. The purpose of the registry is to collect information about your health and your baby's health. For more information or to register, contact MotherToBaby by calling 1-877-311-8972, by sending an email to [MotherToBaby@health.ucsd.edu](mailto:MotherToBaby@health.ucsd.edu), or go to [www.mothersbaby.org/join-study](http://www.mothersbaby.org/join-study).
- are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your health care provider about the best way to feed your baby if you take KESIMPTA.

**Tell your health care provider about all the medicines you take,** including prescription and over-the-counter

medicines, vitamins, and herbal supplements.

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

### How should I use KESIMPTA?

**See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready® pens or prefilled syringes.**

- Use KESIMPTA exactly as your health care provider tells you to use it.
- KESIMPTA is given as an injection under your skin (subcutaneous injection), in your thigh or stomach-area (abdomen) by you or a caregiver. A caregiver may also give you an injection of KESIMPTA in your upper outer arm.
- Your health care provider will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars or stretch marks.
- The initial dosing is 20 mg of KESIMPTA given by subcutaneous injection at Weeks 0, 1, and 2. There is no injection at Week 3. Starting at Week 4 and then every month, the recommended dose is 20 mg of KESIMPTA administered by subcutaneous injection.

If you miss an injection of KESIMPTA at Week 0, 1, or 2, talk to your health care provider. If you miss a monthly injection, give it as soon as possible without waiting until the next scheduled dose. After that, give your KESIMPTA injections a month apart.

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

**KESIMPTA may cause serious side effects, including:**

See **“What is the most important information I should know about KESIMPTA?”**

- **Injection-related reactions.** Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. There are two kinds of reactions:
  - **at or near the injection site:** redness of the skin, swelling, itching and pain. Talk with your health care provider if you have any of these signs or symptoms.
  - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, tiredness, rash, hives, trouble breathing, swelling of the face, eyelids, lips, mouth, tongue and throat, and feeling faint, or chest tightness. Contact your health care provider right away if you experience any of these signs or symptoms, especially if they

become worse or you have new severe signs of reactions after subsequent injections. It could be a sign of an allergic reaction, which can be serious.

- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your health care provider will do blood tests to check your blood immunoglobulin levels.

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

- upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache. (See **“What is the most important information I should know about KESIMPTA?”**)
- headache.

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

You may report side effects to FDA at 1-800-FDA-1088.

### How should I store KESIMPTA?

- Store KESIMPTA in a refrigerator between 36°F to 46°F (2°C to 8°C).
- Keep KESIMPTA in the original carton until ready for use to protect from light.
- If needed, KESIMPTA may be stored for up to 7 days at room temperature, up to 86°F (30°C).
- Write the date taken out of the refrigerator in the space provided on the carton.
- If stored below 86°F (30°C), unused KESIMPTA may be returned to the refrigerator and must be used within the next 7 days. If this KESIMPTA is not used within those 7 days, then discard the medicine.
- Do not freeze KESIMPTA.
- Do not shake KESIMPTA.

**Keep KESIMPTA and all medicines out of the reach of children.**

### General information about the safe and effective use of KESIMPTA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use KESIMPTA for a condition for which it was not prescribed. Do not give KESIMPTA to other people, even if they have the same symptoms that you have. It may harm them.

You can ask your pharmacist or health care provider for information about KESIMPTA that is written for health professionals.

### What are the ingredients in KESIMPTA?

**Active ingredient:** ofatumumab

**Inactive ingredients: Sensoready pen and prefilled syringe:** arginine, disodium edetate, polysorbate 80, sodium acetate trihydrate, sodium chloride, and Water for Injection. Hydrochloric acid may be added.

*continued from page 17*

Within a house, she adds, particular vigilance is needed in the kitchen and the bathroom, the two rooms in the home where people tend to be most active and face the most hazards, such as stepping into and out of a shower or tub, or moving from one workstation to another during meal preparation. She notes that the kitchen and bathroom also can be the hottest rooms in a home, whether due to a pot steaming on the stovetop or the warm mists generated by a long shower, which can be problematic for people with the heat sensitivity frequently seen in MS.

With respect to **adaptive devices**, Dr. Rohrig says that practical, individualized strategies can help people with MS maintain balance and reduce fall risk. She cites wearing firm-soled shoes and equipping bathrooms with bath chairs, tub benches, grab bars, and raised toilet seats or commodes.

## **Falls: Recognizing the Risk Factors**

Much of what we know about the risk for falls comes from studies of older people in the general population and so is not necessarily applicable to people with MS, says Dr. Cameron. This neurologist has worked to remedy that shortcoming over the course of her career by conducting extensive research into fall risk and risk reduction specifically in the context of multiple sclerosis.

She explains that her research and that of other investigators has shown that among people with MS, the risk for falls tends to be greater:

- In secondary-progressive multiple sclerosis (SPMS) relative to relapsing-remitting multiple sclerosis (RRMS)
- With increasing age
- At transition points, such as when people move from RRMS to SPMS or first begin using an adaptive walking device

Dr. Cameron, a Professor in the Department of Neurology at Oregon Health & Science University, adds that the risk for falling also increases with the number of medications a person is taking.

The *nature* as well as the *number* of medications taken has an impact on fall risk she says. “Centrally acting medications, those that affect the brain, can negatively affect balance. Unfortunately, this includes many medications used to treat symptoms of MS such as spasticity and bladder control,” Dr. Cameron notes. For this reason, she adds, it is important for people with MS and their providers to carefully consider the need for each medication prescribed and to weigh the benefits and potential risks involved in its use.

One bright spot regarding medications and falls: In a study involving 248 ambulatory adults with MS, Dr. Cameron and her colleagues found that use of a disease-modifying therapy (DMT) was associated with a 48% decrease in fall risk.<sup>3</sup> Dr. Cameron explains that this risk reduction was independent of people’s disease status or age, but she stresses that the study showed a correlation rather than establishing a cause-and-effect relationship between DMT use and fewer falls.



## Putting Safety and Energy Conservation Ahead of Pride

In many cases, the risk of falling is increased not by factors beyond a person's control, but by reluctance to take steps that would reduce that risk, such as by using an adaptive walking device or switching from high-heeled shoes to equally fashionable but safer flats.

Dr. Rohrig explains, "People with multiple sclerosis may hesitate to use mobility aids because it is felt that using these devices is 'giving in' to MS. I would encourage people to instead think of mobility aids as tools. The right mobility aid will allow you to do what you're able to do more safely or allow you to do more!" She adds, "Use of mobility aids or wheeled mobility options are often considered an 'all or none' choice. In truth, it's more a matter of what makes sense in a given time and place. Certain devices may be more appropriate in certain environments, circumstances, or time of day."

Dr. Cameron agrees, saying, "Devices are there to help you to access the world, not to be seen as a sign of disability." Too often, she adds, people initially are inclined to forgo activities that give them great enjoyment rather than making necessary adaptations. When she encounters such hesitance, this neurologist and physical therapist often employs motivational interviewing to identify a person's goals and then help answer the question, "What steps can I take to keep doing what I want to do?"

Dr. Cameron adds that embracing the use of mobility aids or wheeled mobility options



can significantly enhance quality of life. "One of my patients, a woman in her thirties, reluctantly began using a wheelchair. When I saw her shortly after that decision, she told me, 'This is amazing. I wish I had done it sooner. I used to be exhausted at the end of the day. Now I have this nice, spiffy chair and I'm back to my life.' She absolutely blossomed."

Dr. Rohrig adds that the threats that balance problems pose to living a full life encompass not only falls but also the fear of falling. "Fear of falling can limit activity, and limited activity can contribute to deconditioning of muscles and balance. A person's world can gradually become smaller as people begin to limit important activities," Dr. Rohrig says. She adds that in addressing this fear, people may benefit from working with a mental health professional as well as with a neurologist and physical therapist.

Dr. Cameron agrees, noting that whether the issue is a fear of falling or actual falls, effective responses exist. By way of example, she cites research that she and her colleagues conducted with 78 people with MS who used

walking aids but who were still experiencing falls. Half of the people were assigned to participate in six weekly one-on-one virtual sessions with a physical therapist. During those sessions, the therapist focused on ensuring that the person was using the right walking aid, that the aid was the right height for the person, and that the person was using the aid correctly. The other half of study participants served as a control group.

Compared to the control group, the people who worked with a physical therapist had a greater reduction in fall rate at the end of the six-week intervention and at six months. They also had an increased level of physical activity relative to the control group at six months.<sup>4</sup> “The point is, there is a lot we can do to make things better, but it starts with a conversation about what you’re experiencing and what you’re concerned about,” Dr. Cameron says. ■

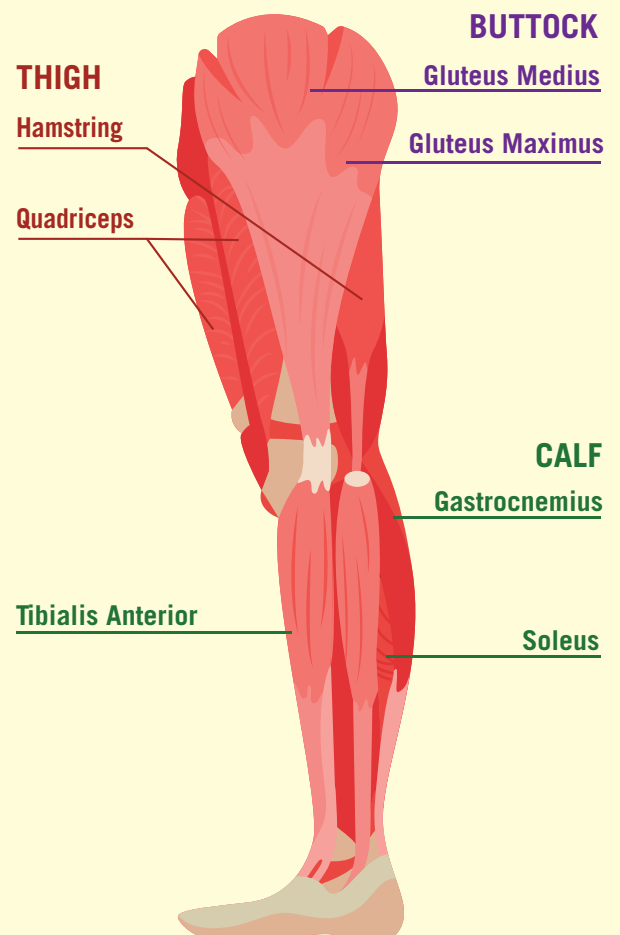
## The Basics of Balance

When Mandy Rohrig, DPT, MSCS, outlines the basics of balance to her patients with MS, she starts by explaining that two primary systems are involved – the motor system and the sensory system.

“The motor system is responsible for providing sufficient strength and range of motion to the muscles involved with balance. It also plays a role in the sequency, timing, and coordination needed for those muscles to sustain upright, balanced posture. Key muscles include the calves (gastrocnemius/soleus), lower leg (tibialis anterior), front and sides of thigh (quadriceps), back of thigh (hamstrings), buttocks (glutes), hip muscles, and abdominal muscles.”

Dr. Rohrig adds, “The sensory system involves our vision, vestibular (inner ear) system, and somatosensory input. Visual input – specifically, visual acuity – provides the nervous system with information about the environment, allowing us to anticipate or adjust to a situation. If vision is impacted by MS or other conditions, such as

## LEG MUSCLES



## References

1. Cameron MH, Nilsagard Y. Balance, gait, and falls in multiple sclerosis. Chapter 15. *Handbook Clin Neurol*. 2018;159:237-250.
2. Cameron MH, Karstens L, Hoang P, Bourdette D, Lord S. Medications are associated with falls in people with multiple sclerosis: a prospective cohort study. *Int J MS Care*. 2015;17:207–214.
3. Judd GI, Hildebrand AD, Goldman MD, Cameron MH. Relationship between balance confidence and social engagement in people with multiple sclerosis. *Mult Scler Relat Disord*. 2022 Jan;57:103440. Doi:10.1016/j.msard.2021.103440.
4. Cameron MH, Hildebrand A, Hugos C, Woolscroft L. A walking aid selection, training, and education program (ADSTEP) to prevent falls in multiple sclerosis: a randomized controlled trial. *Mult Scler J*. 2024. DOI: 10.1177/13524585241265031.

glaucoma, macular degeneration, or cataracts, balance can be impacted.”

She explains that the vestibular system of the inner ear interprets translational and rotational movements. “The inner ear has the critical role of communicating with the eye muscles through the vestibulo-ocular reflex (VOR), which keeps vision steady as the body moves or the head turns. If this reflex is not functioning properly because of a lesion or other causes, a condition called nystagmus occurs. Nystagmus is often described by people with MS as a sensation of bouncing, shaking, or difficulty focusing, which obviously can be problematic when trying to safely maintain balance in a dynamic environment.”

Dr. Rohrig continues, “Somatosensory input is a fancy way of describing the sensory input from touch, pressure, and the joints – particularly the ankles, knees, and hips – about where the body is positioned in space. If a

person with multiple sclerosis has numbness in the feet and has difficulty feeling the floor, the sensory input message from the feet to the brain is not as strong, which affects balance.”

Turning to how the two systems interact, Dr. Rohrig explains, “The body receives input from the sensory systems about its position and the environment and then communicates with the motor system about how to react to maintain safe movement and posture. The motor system in turn gives feedback to the sensory system about how to further optimize balance. The two systems and their components are at work all day every day to keep people balanced.”

While MS and its symptoms can detract from this efficient interaction, Dr. Rohrig notes that clinicians have many options for helping people meet the challenges involved. “Balance is complex” she says, adding, “but that complexity provides numerous opportunities to intervene.” ■



# Questions from Our Readers

**By Dr. Barry Hendin**

MSAA's Chief Medical Officer

**Q: I am newly diagnosed. Should I begin with a moderate or higher efficacy medication?**

**A:** A number of factors are involved in choosing your first MS medication. For primary-progressive MS, only one medication, Ocrevus® (ocrelizumab), is approved for this form of MS. For relapsing forms of MS, more than 25 disease-modifying therapies are approved for these types of MS. The best choice generally becomes clearer after a thoughtful discussion with your neurologist, based on shared decision-making.

In general, I prefer initiating therapy with a high-efficacy disease-modifying therapy, based on increasing evidence regarding the favorable benefit/risk ratio of the high-efficacy medications. However, unique circumstances, such as pregnancy, comorbidities (other existing health issues), and lifestyle choices may result in different decisions. MSAA has created the Ultimate MS Treatment Guide, a very useful online tool for navigating the current multiple sclerosis therapies. The guide may be accessed at **MStreatmentguide.org** and will help address many of the questions that you might have regarding therapies.

**Q: What sensory issues occur with MS and how are they treated?**

**A:** Sensory symptoms in MS are quite variable and can affect any part of the body. Some are more specific, including trigeminal neuralgia (a shock-like pain on one side of the face), the MS hug (typically a strong and sometimes painful squeezing around the torso), or Lhermitte's sign (an electrical sensation caused by flexing your neck).

Other sensory symptoms are less specific and described in varying terms, including tingling, pins and needles, numbness, itching, crawling, burning, and pressure or tightness. Symptoms may be a minor annoyance, or alternatively, may be perceived as painful.

Treatments vary. Many patients do not receive any treatments, particularly if they perceive the paresthesia as minor. Medications including tricyclic antidepressants, such as Elavil® (amitriptyline), Neurontin® (gabapentin), or Lyrica® (pregabalin), are often used. When symptoms interfere with quality of life, referral to a psychiatrist, a pain specialist, or a physical therapist, may be considered. Fortunately, sensory symptoms are frequently transitory and often resolve on their own.

# My MS Manager™

**A convenient and effective tool to help manage multiple sclerosis.**



User-friendly navigation, making it easy to effectively track one's MS. Features of the app include: symptom-measurement scales, educational resources, a journaling option, and more.

**Download My MS Manager™ and register your account today**



**Q: I have MS and my eyelids now spasm, leading to a diagnosis of blepharospasm. Is this related to my MS?**

**A:** Blepharospasm is a rare condition that has been associated with a number of neurological disorders, including multiple sclerosis. The term blepharospasm refers to bilateral eye twitching or spasm, or involuntary closure. This is different from benign, random unilateral eye twitching, which may occur in many people without any neurological implication, particularly during times of stress, fatigue, or overuse of caffeine or alcohol.

Although the exact cause of blepharospasm can be elusive, it is a movement disorder,

probably involving the basal ganglia and facial nerve. The basal ganglia are a cluster of cells located deep in the brain center and are primarily involved with movement functions.

Blepharospasm is generally treated by a neurologist or ophthalmologist. The most common treatment is Botox injected directly into the eyelids. This treatment is generally quite successful. Rarely, when medical treatment is unsuccessful and the condition is severe, surgery can be considered. ■

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

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

# Recent News and Study Updates in MS Research

By Tom Garry

Reviewed by Dr. Barry A. Hendin

MSAA's Chief Medical Officer

## FDA Approval of Subcutaneous Ocrevus

Approved in 2017 for both relapsing (RMS) and primary-progressive (PPMS) forms of MS, Ocrevus® (ocrelizumab) is a disease-modifying therapy (DMT) originally given only via intravenous infusion. On September 13, 2024, the US Food and Drug Administration (FDA) approved this medication to be given via subcutaneous injection – a simpler route of administration. Both given twice-yearly, the infusion takes 2 to 4 hours and the injection takes about 10 minutes. Pre- and post-treatment procedures add to these times.

Marketed as Ocrevus Zunovo™ (ocrelizumab and hyaluronidase-ocsq), this new version contains a proprietary enzyme that increases the permeability of the tissue under the skin, allowing Ocrevus to be quickly absorbed into the bloodstream. Its approval was based on the results of the Phase III OCARINA II trial, which showed blood levels of Ocrevus when given subcutaneously, as well as the safety and efficacy profile, to be comparable to the intravenous formulation in people with RMS and PPMS. Ocrevus is a humanized monoclonal antibody designed to target CD20-positive B cells, a type of immune cell thought to be involved in MS, and is the only DMT approved for PPMS.<sup>1</sup>

## MSAA Survey Defines Barriers to Care and Unmet Needs in MS

What are the biggest barriers to care faced by people with MS? MSAA recently asked that question (and others) in a nationwide survey. Of the 620 people who responded:

- 35% were unable to afford medical care
- 33% were unable to find MS care in their community
- 31% had difficulty finding doctors to coordinate their MS care
- 20% lacked health insurance
- 19% did not have access to transportation

Given those findings, it is perhaps not surprising – though still distressing – that 42% of respondents reported not seeing a multiple sclerosis specialist to manage their MS. Further, 43% said they were not able to work due to disability from MS. The survey participants were age 18 years and older, most of whom reported living with MS for 11 years or more.

In presenting these findings at the Consortium of MS Centers (CMSC) 2024 Annual Meeting, the study's authors explained, "Demographics, socio-economic status, age, race, ethnicity, and community play a significant role in the ability to access resources and healthcare." The end goal of the initiative, they added, is to "design personalized and targeted interventions to serve these MS communities."<sup>2</sup>

## Treating PPMS with Glatiramer Acetate

A Phase IIa study is assessing the efficacy and safety of 40-mg and 25-mg doses of extended-release glatiramer acetate given monthly in people with primary-progressive multiple sclerosis (PPMS).<sup>3</sup> This disease-modifying therapy (DMT) was approved by the Food and Drug Administration (FDA) in 1996 for relapsing forms of MS.

Between 10% to 15% of people with multiple sclerosis have PPMS, which is marked by a continuous decline in neurological function without early relapses or remissions. While Ocrevus® (ocrelizumab) is the only DMT currently approved by the FDA for the treatment of PPMS, several other potential therapies are in late stages of evaluation for treatment of PPMS, including extended-release glatiramer acetate. ■

1. Genentech. September 13, 2024. Accessed at <https://www.gene.com/media/press-releases>.
2. Rivera Y, Kline A, Montague A. A means to close gaps in multiple sclerosis care. CMSC 2024 Annual Meeting. Abstract QOL20.
3. Flechter S, Miller AE, Popper L. Glatiramer acetate depot (extended release) Phase IIa study in patients with primary progressive multiple sclerosis: safety and efficacy snapshot. CMSC 2024 Annual Meeting. Abstract DMT21.

# STAY CONNECTED with MSAA

Sign up for **EMAIL UPDATES** at  
[mysaa.org/email-signups](https://mysaa.org/email-signups)

Get **TEXT UPDATES**: Text MSAA to 75101

Complete Terms and Privacy Policy at [tandcs.us/msaa](https://tandcs.us/msaa)

Follow on **SOCIAL MEDIA**: @MSassociation



# Supportive and Educational Resources

By Susan Wells Courtney

## MSAA's Helpline

Regardless of where you are along your journey with multiple sclerosis... whether newly diagnosed or someone who has been living with MS for some time... information and support can be extremely helpful. If you have questions about MS, its symptoms, or available treatments... or if you need valuable resources or just looking to talk with someone who understands, our trained and experienced Client Services Specialists on MSAA's Helpline are available to provide support.

Each year, several thousand MS community members reach out to MSAA's Helpline for vital information and support. If we can assist you in any way, please contact our Client Services Specialists. Helpline hours are Monday through Friday, 8:30 AM to 8:00 PM Eastern. We invite you to call **(800) 532-7667, extension 154** or email **MSQuestions@mymsaa.org**

To reach a Spanish-speaking Client Services Specialist, please call **(800) 532-7667, extension 131**. Para comunicarse con un Especialista de Servicios al Cliente que habla español, llame al **(800) 532-7667, extensión 131** o envíe un correo electrónico a **MSQuestions@mymsaa.org**. El horario de la línea de ayuda es de lunes a viernes, de 8:30 AM a 8:00 PM, hora del este.

## Webinars

At MSAA, we are hopeful that everyone is able to take advantage of the many valuable services that MSAA provides. One exciting program that anyone can access at any time is our webinar series.

Throughout the year, MSAA offers live webinars with healthcare professionals presenting on a wide range of topics. Members of the MS community are invited to register to attend these live webinars, which are offered free of charge. In addition, anyone at any time may visit MSAA's website to access the recorded webinars. While there, you'll find that we cover a number of important topics, and we also provide several webinars in Spanish. All webinars include captioning and transcripts.

A few of the topics that MSAA will cover during upcoming webinars include:

- Sleep hygiene and MS
- Motherhood and MS
- Exercises and energy conservation during the holidays
- Keys to a Healthy Life through Nutrition, Brain Health, Exercise and Culture (in Spanish)
- Self-advocacy (in Spanish)

For more information about upcoming webinars and to register, please visit MSAA's calendar of events at **mymsaa.org/calendar**



## Recent Awards

We are honored to announce the most recent awards given to our publications and programs. Content, format, targeted audience, and overall quality are among the attributes recognized when determining these awards. Recent awards include:

- A Gold Digital Health Award for MSAA's mobile app, My MS Manager™, which provides a convenient and effective tool to manage the course of MS. For information about My MS Manager, please visit [mymsaa.org/mobile](https://mymsaa.org/mobile)
- A Merit Digital Health Award for MSAA's bimonthly "Ask the Expert" blog series, featured on our blog, MS Conversations. To access MSAA's "Ask the Expert" posts, please visit [mymsaa.org/ask-the-expert-blog](https://mymsaa.org/ask-the-expert-blog)
- A Merit Digital Health Award for MSAA's Summer/Fall 2023 edition of our magazine, *The Motivator*. This edition focused on "The Importance of Diet and Nutrition in MS." To read this award-winning edition of *The Motivator*, please visit [mymsaa.org/SF23](https://mymsaa.org/SF23)
- An APEX Award for Excellence given to the Summer/Fall 2023 issue of *The Motivator* (details noted above).
- A National Health Information Merit Award for the March 2023 edition of our bimonthly eNewsletter, *My MSAA Today*.

## MS Conversations Blog

Each month since 2012, MSAA's MS Conversations blog has featured several timely and informative posts on topics that are of great interest to people with MS and those close to them. Blog posts are written by a range of individuals associated with the MS community, including MSAA staff members and guest bloggers.

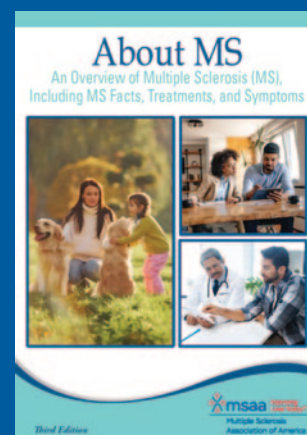
Examples of our wide array of topics include our "Ask the Expert" series, symptom management, lifestyle strategies on everything from exercise to wellness tips, along with inspirational stories. To access MS Conversations, please visit

[blog.mymsaa.org](https://blog.mymsaa.org) ■

## About MS is Available

MSAA's newest publication, *About MS, 3rd edition*, is now available. This completely updated 24-page booklet is an ideal resource for individuals who are newly diagnosed, as well as anyone interested in learning more about MS. Details include:

- The MS process, prevalence of MS, and types of MS
- Possible causes of MS
- How MS is diagnosed and monitored
- Relapse management
- Disease-modifying therapies
- Symptoms
- Wellness tips
- Plus a listing of MSAA's programs and ways to support our organization



To order a copy, please visit [mymsaa.org/about-ms](https://mymsaa.org/about-ms)

# Team MSAA Supports the MS Community

When Team MSAA participant Tiffany McCahill was first diagnosed with MS in 2017, she assumed it marked the end of her participation in endurance events. However, her desire to continue doing what she loved led her to research more about endurance athletes with MS, and she decided to continue participating in the events, while also raising funds and awareness for MS.

Tiffany explains, “I read about many endurance athletes with MS, and it gave me hope that it was at least possible. MSAA had an opportunity to participate in the Disney Marathon events and I jumped at the chance to be able to explore what I was able to do physically while raising funds and awareness. The experience was amazing! I plan to continue participating for as long as I am able to. MSAA has supported me with hope that so much more is attainable despite the MS diagnosis.”

We thank Tiffany for being a very important part of #TeamMSAA and helping



*Completing a 10K endurance event last year, Team MSAA participant Tiffany McCahill is doing it again, but this time she's raising the bar and taking on the half marathon!*

us provide free programs and services to the MS community! To view Tiffany's fundraising page, please visit [engage.mysaa.org/PosiTiffanyMS](https://engage.mysaa.org/PosiTiffanyMS) ■

## Your Support Improves Lives Today

MSAA's free, vital programs and services are dependent upon generous donations from individuals across the country. Year-end giving is especially important for developing and providing programs for the upcoming year – programs that make a significant impact on the lives of those with MS.

Donors may choose from a number of

ways to make contributions, including one-time gifts, recurring monthly donations, and donations in honor or in memory of a loved one. Funding supports valuable services such as: the free distribution of safety and mobility equipment, plus cooling products for symptom management; informative videos, webinars, podcasts, publications, and in-

# Swimming to Raise Awareness and Donations

Parents Tejas and Sheetal Shroff have much to be proud of with their son, Ayaan, and their daughter, Aashka. Both children recognize the importance of raising awareness and donations to help individuals with disabilities.

Living in the Dallas-Fort Worth area of Texas means lots of warm weather, so MSAA's Swim for MS program was of particular interest and a natural fit for both Ayann and Aashka. Aashka is the older of the two and is currently a senior in college. Having earned the prestigious Girl Scout Gold Award for her work in helping the community, Aashka later became an active member of the Philanthropy Club in high school and went on to raise awareness and funds for MSAA through her swimming before moving on to college.

Currently a freshman in high school, Aashka's brother Ayaan was in grade school as he watched his sister participate in MSAA's Swim for MS fundraisers. This had a great influence on him and soon he was swimming

with the goal of helping others as well. Although some of his focus is on his work to become an Eagle Scout, Ayaan hasn't forgotten his strong desire to help those with disabilities and is planning an even bigger Swim for MS fundraising event from October 21st to November 5th at his local swimming pool. He plans for several of his friends to participate as well, and hopes to add some competitive fun while swimming laps as part of MSAA's Swim for MS DIY program. To donate to Ayaan's Fundraiser, visit MSAA's Facebook page and navigate to the "Fundraiser's" tab. Once there, you can search for Ayaan's fundraising page (set up by his father), as well as many other fundraisers created by our generous supporters!

Both Ayann and Aashka are interested in doing more for MSAA and to increase awareness of multiple sclerosis. We wish them both much success in their fundraisers and we thank them for their efforts in supporting MSAA and the entire MS community! ■

person educational programs; and urgently needed consultation with MSAA's Helpline Specialists.

To make a direct donation, please visit [mymsaa.org/donate](https://mymsaa.org/donate) or call **(800) 532-7667, ext. 172**. We thank all of our donors for their kind and generous contributions, which Improve Lives Today for the MS community! ■

## Create Your Own DIY Fundraiser Today!

Please visit [mymsaa.org/diy](https://mymsaa.org/diy) to access MSAA's DIY toolkit for helpful tips! Also, choose "Multiple Sclerosis Association of America" when creating a fundraiser on Facebook or Instagram!

# Birding from a Wheelchair

By Donna O'Daniel

In December of 1987, I graduated from the University of Texas with my master's degree in biological sciences. My dream of spending the rest of my life outdoors working on birds was coming true! I was 42 years old, had changed careers, and was headed for my first biology job – hiking on East and West Falkland to document their breeding birds (including five species of penguins) during their brief nesting summer. I had to be careful to avoid the mine fields that were left by the invading Argentine armies from the recent Falkland War.

Three months later, I was almost a world away in Alaska on a field camp along the Bering Sea coast with five other biologists from the Togiak National Wildlife Refuge. Our task was to monitor the northward migrating waterfowl and shorebirds on their way to their high tundra nesting grounds. Meanwhile, the daily outgoing tides from the nearby inlet were causing huge chunks of breaking ice to pile up at the narrow entrance to the Bering Sea, coming threateningly close to our tents. We scrambled to move them out of the way. Things were getting very interesting – avoiding mine fields on the southern ocean's islands, and now, avoiding huge chunks of ice in the Arctic! But I was having the time of my life!



*With binoculars in hand, Stories to Inspire author and avid bird watcher Donna O'Daniel proudly shows off a younger picture of herself, out in the field with a bird perched on her head.*

One morning I woke up in my tent and could not see out of my left eye. After six days, I had to be flown out in the refuge floatplane to see an eye doctor in Anchorage. The good news? It was optic neuritis and would resolve itself in a few weeks. The bad news? Many people with optic neuritis eventually develop MS.

But I was healthy at the time, so I just continued to my next assignment, this time at Alaska's Cape Peirce, spying on three species of seabirds (Kittiwakes, Murres, and Cormorants) nesting along the precarious, vertical cliff faces through a spotting scope to determine their nesting cycles. I had convinced my supervisor that I could do the job because I could monitor the birds with my good eye through the scope.

A year later, I was teaching biology at Chemeketa Community College in Salem, Oregon, when I awoke one morning with double vision. The diagnosis? The same as before, but the doctor told me I probably had MS already. But there were still no outward physical signs, so I just resumed my work.

Years later, in 2008, a slight weakness developed in my right leg, which over several months got progressively worse. MS had finally caught up with me. I needed a cane for stability and I needed to rest for part of the day, but by doing so, I was still able to perform volunteer bird work at national wildlife refuges in Florida and Arizona. But the big hammer came down in 2011 when my right leg ceased functioning, rest or no rest. My life changed drastically overnight. I could no longer perform volunteer bird work at national wildlife refuges or even walk.

How was I to continue my passion of observing birds? I concluded there had to be a way, even from a wheelchair, as I settled into my new home in Northern Arizona.

A sturdy electric wheelchair with large tires enables me to traverse the gravel trails at the

nearby Sedona Wetlands, where I am able to see many species of waterfowl as well as migrating and nesting perching birds utilizing the many trees lining the ponds. I also have an electric scooter in which I can zoom around my apartment complex. Binoculars at the ready, I am able to spy any winged creature in a tree, on the ground, in the water, or in the air.

I was not disappointed on my first outing using my scooter, as I saw a nesting pair of stunningly beautiful Hooded Orioles in a nearby palm tree, two strikingly patterned Gambel's Quail hesitantly walking out from the protection of a large bush, a pair of handsome Wood Ducks stealthily making their way along the water's edge of our reclamation pond, and a sprightly Black Phoebe flycatching from a pipe protruding from the pond's bank. In the sky above were the ubiquitous Common Ravens skydiving on a harried Red-tailed Hawk.

I even discovered that I can bird from my wheelchair without leaving my apartment! I have a nice view from several windows, enabling me to watch thirsty hummingbirds at my feeder, flycatchers landing on a satellite dish seven feet from my window as they hawk for flying insects, hawks and ravens perching on nearby wires, and thirsty birds that drink from my patio birdbath, six feet from my door. This past winter, I even observed a feisty Bewick's Wren scurrying about on my patio floor for insects.

I am living proof that it is still possible to enjoy a passion for birdwatching – even from a wheelchair! ■

# MSAA

TEAM  
TEAM



## Join Us at Disney in 2025!

Combine the magic of Disneyland® and Walt Disney World® with the satisfaction of making a meaningful impact for people living with MS, and you have Team MSAA! Join over 100 other runners, walkers, and virtual participants for an upcoming runDisney race!

### Walt Disney World® Marathon Weekend

January 8-12, 2025

### Disneyland® Half Marathon Weekend

January 30 - February 2, 2025

Learn More at [mymsaa.org/TeamMSAA](https://mymsaa.org/TeamMSAA)

**This holiday season,  
make one gift that will  
impact so many.**

Your gift today will improve the lives of people with multiple sclerosis across the country, not only during the holidays but all through the year.

The following are a few ways to support MSAA, and make an impact:

- Make a monthly recurring gift that supports the MS community
- Dedicate your gift in honor of or in memory of someone special
- See if your employer will match your gift

To learn more and donate, please visit  
[mymsaa.org/donate](https://mymsaa.org/donate)



# Become an MSAA Monthly Improver!

*MSAA Monthly Improvers are a generous group of donors making recurring, monthly gifts to improve the lives of people with MS.*

Recurring donations make it easy for you to support MSAA's free programs and services – while also providing MSAA with a reliable stream of revenue each month.

## Questions?

Contact Donor Relations at  
(800) 532-7667, ext. 172, or  
[MonthlyGiving@mysaa.org](mailto:MonthlyGiving@mysaa.org)



## SIGN UP TODAY!

[engage.mysaa.org/improver](https://engage.mysaa.org/improver)



**\$10/month (\$120/yr)**  
quad canes for three  
individuals with MS



**\$15/month (\$180/yr)**  
wide-grip utensil sets for  
eight individuals with MS



**\$25/month (\$300/yr)**  
cooling vests for two  
individuals with MS

Submit Your Best Work for MSAA's 2025-2026 Online

# Art Showcase



*Posing in Pink* – by Leslie Pino Durant

Submissions will be accepted until January 10, 2025.  
For guidelines, visit [mysaa.org/artshowcase](https://mysaa.org/artshowcase)

## NOW ACCEPTING SUBMISSIONS

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

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

Submissions will be featured on MSAA's website beginning March 2025, in recognition of MS Awareness Month. MSAA will highlight 12 artists and their artwork throughout the year.

For more information, please contact:  
Email: [showcase@mysaa.org](mailto:showcase@mysaa.org)  
Phone: (800) 532-7667, ext. 117

# MSAA Podcast



*Listen to episodes on a variety of topics important to the MS community, including:*

- MS and Mental Health
- Pediatric MS
- Relationships
- Care Partner Needs
- Diversity and MS
- MS Medications
- Nutrition
- and more!

Subscribe now or check out past episodes at  
**[mymsaa.org/podcasts](https://mymsaa.org/podcasts)**

