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Winter/Spring 2025

THE Motivator

Published by the Multiple Sclerosis Association of America

The Benefits of Physical, Speech, and Occupational Therapies

11TH

Improving Lives Benefit

msaa *Improving Lives Today!®*
Multiple Sclerosis
Association of America

WEDNESDAY, MAY 14, 2025

MSAA is proud to announce our 11th Improving Lives Benefit at the **BARNES FOUNDATION** in **PHILADELPHIA, PA.** In addition, MSAA will be livestreaming the event, giving the MS community across the country the opportunity to view the event from the comfort of their homes!

Mission Honoree:
Barry A. Singer, MD
Director and Founder, The MS Center for Innovations in Care at the Missouri Baptist Medical Center;
Member, MSAA Board of Directors

Host:
Tyler Campbell
MS Advocate and
Motivational Speaker

Corporate Honoree:
Cionic
A medical technology company building bionic clothing to improve walking and strength

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WINTER/SPRING 2025

COVER STORY

DEPARTMENTS

msaa *Improving Lives Today!®*
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.

Notable Programs, Resources, and Events

By Gina Ross Murdoch
MSAA President and CEO

Happy spring! I'm pleased to share a few exciting updates. One of our programmatic highlights is a comprehensive, nationwide initiative aimed at better understanding how MSAA and other patient advocates can effectively close gaps in care for underserved communities. Titled "MS Ecosystem Framework," this project involved a national needs assessment survey and roundtable discussions, with the goal of personalized and targeted interventions for individuals living with MS. For more information, please see our "Program Notes" column beginning on page 28.

I would also like to remind our readers about our upcoming 11th Improving Lives Benefit, taking place on Wednesday, May 14th, at the Barnes Foundation in Philadelphia. This is MSAA's most significant fundraiser of the year and excitement is building as we continue to prepare for this important event. We are pleased to once again offer a livestreaming option for all those interested in attending this event virtually, from the comfort of their home.

Each year at our Improving Lives Benefit, we recognize two very special honorees who have made vital contributions to the care and well-being of individuals with MS. This year, our Mission Honoree is Barry A. Singer, MD. Dr. Singer is the Director and Founder of The MS Center for Innovations in Care at the Missouri Baptist Medical Center and has been an integral part of MSAA's mission. In addition to our Mission Honoree,

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Gina Ross Murdoch is a seasoned executive in non-profit management. Her career includes leadership positions with chapters of the Leukemia and Lymphoma Society as well as the American Diabetes Association. Earlier, 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.

we are also recognizing Cionic as our Corporate Honoree. Cionic is a medical technology company that develops bionic clothing to help improve walking and strength.

MS advocate and motivational speaker Tyler Campbell will once again be hosting our Improving Lives Benefit. His energy brings excitement to the room as he inspires all who attend with his heartfelt stories of overcoming challenges and embracing future aspirations. If you would like to join us at this uplifting event – either in person or virtually via livestreaming – please see our "Thoughts About Giving" column beginning on page 31.

Of course, our Improving Lives Benefit is just one piece of our fundraising efforts to further develop and grow MSAA's urgently needed programs and services. Another very special fundraising initiative is Team MSAA's participation in the annual *run*Disney events. This year, people living with MS and their family members joined together as Team MSAA to support MSAA's mission of Improving Lives Today. As always, these events were a great success and I want to express my sincere appreciation to everyone who participated.

I would also like to highlight the success of this year's MS Awareness Month, which took place in March. Our theme, "Empowered from the Start with MSAA," focused on education and support for individuals who are newly diagnosed with multiple sclerosis. In addition to the newly diagnosed population, the entire MS community may benefit from these resources as well, which may be accessed by visiting **mymsaa.org/awarenessmonth**.

One of many programs featured during MS Awareness Month in March was the launch of our 2025-2026 Art Showcase on MSAA's website. Each year, we add another collection of amazing art pieces to our online gallery. All artwork is created by individuals with MS and is accompanied by each artist's inspiring story. To view this year's Art Showcase, please visit **mymsaa.org/artshowcase2025**.

In addition, I would like to emphasize the importance of this edition's cover story, which highlights the different types of therapy that are critical to the care and well-being of individuals with MS. Encompassing physical, speech, and occupational therapies, this article features three experts in the field, each providing detailed explanations on how these therapies can benefit those experiencing the different symptoms of MS, while also increasing strength, function, and overall safety.

And finally, I would like to conclude with a message about spring, which is a time of awakening and starting anew. I hope that all of our readers may experience their own forms of renewal this spring season – whether improving physical and emotional health, expanding interests, or developing new skills. Whatever your goals are, please know that we are always here to support you. ■

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> - *Melanie*

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[a] Following the starting dose.

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INDICATION

BRIUMVI is indicated for the treatment of relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.

IMPORTANT FACTS

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
  - 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
  - redness of the face or skin

PLEASE SEE ADDITIONAL IMPORTANT FACTS ON THE FOLLOWING PAGE

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** or call **1-833-BRIUMVI (1-833-274-8684)**.

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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.

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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.
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- 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.

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For more information, go to www.briumvi.com or call 1-877-848-9462.

The Benefits of Physical, Speech, and Occupational Therapies

By Tom Garry

Reviewed by
Barry A. Hendin, MD

Multiple sclerosis has a highly individualized, sometimes life-altering impact on each person it affects. Fortunately, the same can be true of physical therapy, speech therapy, and occupational therapy when people with MS partner with therapists in those professions.

"There is *always* something you can do," says physical therapist **Mandy Rohrig, DPT, MSCS**, and member of MSAA's Healthcare Advisory Council (HAC). She explains that no matter the nature of a person's MS, working with a therapist can identify ways to adapt to the condition and live your best possible life. This article will examine what physical therapy (PT), speech therapy (ST), and occupational therapy (OT) entail, the role they play in the management of MS, and how people with MS can make effective use of the therapies to enhance their quality of life.

Please note that while mental health counseling or therapy can also offer considerable benefits, it is not addressed in this article, which focuses on therapies that address the physical manifestations of multiple sclerosis. For information on mental wellness, please visit **mymsaa.org** for webinars, podcasts, and articles on this topic.

To start, it's important to understand that physical therapy, speech therapy, and occupational therapy are distinct healthcare professions, each with a well-defined role in patient care and stringent educational requirements for its practitioners. At the same time, the three professions often complement one another in the comprehensive management of multiple sclerosis. To follow are details on the specific roles and requirements for each of these three types of therapies.

Physical Therapy

The American Physical Therapy Association (APTA) explains, "Physical therapy is treatment provided by a physical therapist or physical therapist assistant that helps people improve their movement and physical function, manage pain and other chronic conditions, and recover from and prevent injury and chronic disease." APTA adds that physical therapists "examine, diagnose, and treat movement dysfunction."[1]

After earning a bachelor's degree, a person aspiring to a career in the profession must complete a Doctor of Physical Therapy (DPT) program accredited by the Commission on Accreditation in Physical Therapy Education and pass a state licensure exam. DPT programs typically are three years in length.[2] Some physical therapists – particularly those who have been practicing for many years – do not have a doctoral degree, but meet their state's licensing requirements for the profession.[3]

The physical therapist's role in treating a person with MS depends on the challenges the person is facing, but Dr. Rohrig notes that walking difficulties and balance issues are two of the main reasons people with MS receive physical therapy.

Speech Therapy

Turning to speech therapy, the American Speech-Language-Hearing Association notes, "Speech-language pathologists (SLPs) work to prevent, assess, diagnose, and treat speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults."[4] Those specialists, often referred to as speech therapists, must earn a master's degree from a program accredited by the Council on Academic Accreditation in Audiology and Speech-Language Pathology, complete a clinical fellowship,[5] and meet their state's licensure requirements.

Sherry Perucho, DHA, MA, CCC-SLP, CBIST, says that communication and swallowing challenges are among the main reasons people with MS seek care from her fellow speech-language pathologists.

Occupational Therapy

The American Occupational Therapy Association (AOTA) states, "Occupational therapy enables people of all ages to participate in daily living," adding that occupational therapists "focus on the things you want and need to do in your daily life. Occupational therapy intervention uses everyday life activities (occupations) to promote health, well-being, and your ability to participate in the important activities in your life."[6] A master's or doctoral degree is required to practice as an occupational therapist,[7] and state licensure is also required.

Shaina Meyer, MS, EdD, MSCS, is an occupational therapist with extensive clinical experience in MS and a member of MSAA's Healthcare Advisory Council (HAC). She explains that people with multiple sclerosis receive OT for issues ranging from fine motor skills to fatigue management.

How Therapy Can Make a Real Difference: The Story of One Young Woman with MS

A high school student had recently been diagnosed with MS. Her parents did not speak English and had difficulty understanding the diagnosis and how to best support their daughter.

"Our team, including physical therapy, occupational therapy, and nursing, stepped in to help the family navigate this challenging and new situation," recalls Sherry Perucho, DHA, MA, CCC-SLP, CBIST. The speech-language pathologist adds, "When she first came to us, she was dealing with several challenges, including poor balance, difficulty with writing and fine motor skills, low vocal intensity, and getting tired quickly when speaking. She also struggled with schoolwork due to attention issues and occasional difficulty expressing her thoughts, both verbally and in writing. The fatigue she experienced was also a major barrier to her daily tasks."

Dr. Perucho continues, "Through skilled speech therapy interventions, we were able to address her communication challenges, which were particularly important before her return to school. We helped her improve her ability to organize her thoughts, communicate more clearly, and use strategies to manage cognitive fatigue and the academic demands she faced."

While other members of the care team focused on various aspects of the young woman's MS-related needs, speech therapists helped her develop the skills needed to navigate rigorous academic expectations, such as using memory aids and developing effective study strategies.

Dr. Perucho explains, "This was crucial for her success in school, as it allowed her to not only keep up with her studies, but to engage more confidently with her peers and teachers as well. We also assisted her in getting the proper accommodations she needed upon return to school."

The speech-language pathologist notes, "By addressing these cognitive-communication challenges, we empowered her to return to school with greater independence and confidence, ensuring that she could meet both her educational and personal goals. The improvements in her communication and cognitive function were essential to her overall recovery and helped her successfully finish the school year and graduate."

While this story of struggle and success focused on enabling a student to obtain her diploma, Dr. Perucho said that its lessons are equally applicable to people with MS facing challenges in the workplace, at home, in their relationships, and in their daily lives.

She explains, "Interdisciplinary care is so important. Neurologists, nurses, physical therapists, occupational therapists, speech-language pathologists, and other clinicians must work together to provide person-centered care." ■

Get Ready, Get Set, and Go to Therapy!

A common theme voiced by the experts interviewed for this article is that earlier interaction with a therapist, typically translates into greater benefits for a person with MS.

"Many people with MS wait until they experience significant difficulties before they seek speech therapy support. Ideally, I'd like to see individuals proactively, even before noticeable speech or swallowing changes occur," says Dr. Perucho, a speech-language pathologist and clinical manager at the Nevada Community Enrichment Center, a comprehensive rehabilitation center for people with neurological conditions, located in Las Vegas, Nevada.

She continues, "Clinicians and patients should be aware of early signs, such as increased effort to speak clearly or be understood, subtle voice fatigue or changes in volume, mild coughing or throat clearing during meals, and difficulty with multitasking or processing conversations. Identifying these issues early allows for preventative strategies that help individuals maintain their function longer and adapt to changes more effectively." Dr. Perucho notes that she is seeing a welcome trend toward earlier referral as the multidisciplinary model of comprehensive care becomes more widely adopted by MS providers.

> "People with MS should know they have options. They don't have to struggle alone."
>
> – Sherry Perucho, DHA, MA, CCC-SLP, CBIST

Even with a referral, however, some people with MS can be reluctant to make an appointment with a therapist for a very understandable reason, according to Dr. Rohrig. She states, "Often times, particularly in those first weeks and months after receiving a diagnosis of MS, people are faced with a lot of decisions related to medications, related to employment, related to their social relationships and overall life, and I think physical therapy and other types of therapy can become de-prioritized when dealing with that lengthy to-do list."

Dr. Rohrig is a physical therapist and Certified Multiple Sclerosis Specialist, serving as Senior Programs Consultant for Can Do MS. She notes that insurance coverage and financial considerations can also be barriers. Dr. Rohrig adds that scheduling an appointment with a therapist should not become an obligation for people with MS, but rather should be seen as a service available to them once they are ready for it.

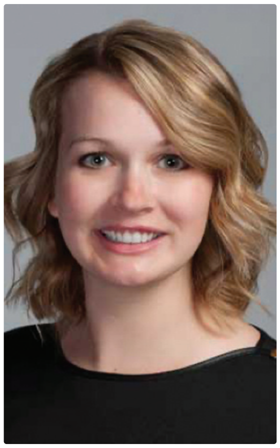
Ms. Meyer is an occupational therapist and Certified Multiple Sclerosis Specialist who teaches occupational therapy and health policy as a clinical instructor at the University of Arkansas. She says that when ready to work with a therapist, taking some time before the first meeting to think about the challenges one is experiencing in the course of daily life, along with one's specific goals of therapy, can be very helpful.

Ms. Meyer explains, "When we meet with a person with MS, we want to know, 'What is most impactful to you?' We're going to focus our attention on that issue or activity, looking at underlying causes, contributing factors, and potential strategies to address it."

While sooner is better than later, and taking time to prepare beforehand, can make for a more productive intake session, the most important step people with MS can take with regard to therapy is the *first* step: making and going to that initial appointment.

What Happens at the First Session?

Ms. Meyer explains that when she was in clinical practice, her typical intake visit for a person with MS was one-hour long. "The first 15 minutes were devoted to reviewing what I had learned about the person from the medical information I had received prior to the meeting and asking clarifying questions to dig deeper into some details I needed about their routines or the roles they might fulfill in their day, like being a mother or a full-time office worker or somebody who plays pickleball twice a week.



> "When we meet with a person with MS, we want to know, 'What is most impactful to you?' We're going to focus our attention on that issue or activity, looking at underlying causes, contributing factors, and potential strategies to address it."
>
> – Shaina Meyer, MS, EdD, MSCS

"The next 30 minutes or so would involve assessments. During that time, I would assess skills that may be impacting function, including physical factors (such as strength), cognitive factors (like attention), and psychosocial factors (such as anxiety), while also considering how other variables, like fatigue and sensory changes, might complicate these skills. We would spend the last 10 to 15 minutes with me providing a summary of what I had observed and obtaining the person's feedback or questions. Most importantly, we'd look at the person's goals."

She continues, "When I meet with people for an evaluation, the questions I ask include, 'What matters most to you? When you think about your day and your roles, what motivates you? What inspires you to get up in the morning?' It's important to get those answers because they speak to the core of the person. From there, we can figure out together how to help them continue being successful in those areas."

Dr. Rohrig and Dr. Perucho explain that the initial physical therapy and speech-

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pathology sessions for a patient with MS are similarly wide-ranging and focused on the patient's priorities.

As with occupational therapy, the assessments performed during a physical therapy intake session focus on balance, strength, and range of motion, in addition to mobility, Dr. Rohrig says. She adds, "The first visit includes discussion of why the person has come to physical therapy and what they want to achieve from the time we spend together."

In terms of speech therapy, Dr. Perucho says, "A comprehensive initial assessment includes a detailed evaluation of speech, swallowing, and cognitive-communication abilities. Speech assessment focuses on articulation, volume, breath support, and overall intelligibility. Swallowing evaluation involves observing the person while eating and drinking, and in some cases, instrumental studies like a Videofluoroscopic Swallow Study (VFSS) or Fiberoptic Endoscopic Evaluation of Swallowing (FEES) may be recommended." She adds that speech-pathology therapists receive extensive training in performing these safe, painless procedures.

Dr. Perucho continues, "Cognitive-communication assessment examines attention, memory, executive function skills, language, and processing speed to identify any challenges affecting daily interactions.

Additionally, we discuss the functional

Securing Insurance Coverage

When it comes to insurers covering therapy related to MS, the news is neither all good nor all bad, according to the three experts interviewed for this article. They noted:

1. While there is wide variance in what insurers will and will not cover, **obtaining approval for an initial assessment typically is relatively easy.** Securing approval for ongoing therapy can be more challenging.

2. When deciding whether to approve therapy services for a person with MS, **insurers want to know specific needs, goals, and potential benefits** – to the patient and to the healthcare system. The more information that a clinician can provide when referring for therapy, the better. Similarly, the more documentation the therapist can provide about how the treatment regimen relates to the patient's goals and offers benefits, such as reducing the risk of a fall or other problem that could lead to a costly hospitalization, the more likely an insurer may be to continue covering care.

3. Demonstrating progress is vital. Just as you don't want to spend your time pursuing therapy that isn't yielding results, insurers don't want to spend their money paying for such therapy. Conversely, providing objective evidence of progress may prompt approval for continued sessions.

impact of these symptoms, exploring how they affect the person's daily life. Based on the assessment, we set personalized goals tailored to what matters most to the individual, whether that's improving speech clarity for work, ensuring safer swallowing, or developing strategies to manage cognitive fatigue."

The information gathered at the intake sessions often provides clues to underlying problems that would not be immediately apparent without this clinical equivalent of detective work. Ms. Meyer explains, "Let's say a woman tells me, 'When I'm cooking a meal, I'm dropping lots of things.' She assumes that this is because she is having sensory changes or hand weakness. However, the evaluation may show that there is not a sensory problem and that her grip strength is good.

"Further assessment may reveal cognitive changes. If so, one of the things we're going to explore is whether doing too many things at once – having a conversation with someone or listening to the radio while she's trying to cook – is putting too much demand on her brain, and that's why she is dropping things. If that is the case, then the strategy isn't to perform exercises to enhance grip strength, it's to change how she completes that task and build skills to make her more successful at multi-tasking. However, that wouldn't have been apparent if we had not thoroughly explored the situation."

In keeping with that example, she explains that a therapist's role involves formulating strategies and fashioning

4. Draw on the expertise of the clinic's staff. Office personnel often are well-versed in the nuances of different payers' policies and frequently have good rapport with the people who assess claims at the insurance companies. Don't be shy about asking for help if needed. It's also important to feel comfortable discussing any financial concerns about co-pays and deductibles with your therapist.

5. Check if your insurer has a chronic care case manager who can be assigned to work with you. Many insurers employ nurses or other healthcare professionals to coordinate the care of people living with ongoing conditions or illnesses. The payers want their plan members to be well, and they don't want to spend money on expensive healthcare services that perhaps can be avoided with a modest investment upfront. Think, for example, of the difference in cost between a flu shot and an emergency room visit for the flu. While case managers work for the insurer, they generally will be strong in-house advocates for services that promise to benefit both the patient and the insurer.

6. Be an advocate – for yourself and for other people with MS. Persistence often pays off in today's healthcare system. So, if your request for therapy services is denied, speak with your therapist and medical provider for assistance in resubmitting the request, possibly with stronger evidence. ■

workarounds (strategies for managing a problem without fully resolving it) as well as having a patient perform specific exercises. "It's more than just remediating or fixing something. It's about changing habits and behaviors and routines," Ms. Meyer adds.

Two Keys to Success: Realistic Expectations and Real Effort

An avid runner came to see Dr. Rohrig not long after being diagnosed with primary-progressive MS. "So much of his identity, his view of himself, was wrapped up in running," she recalls. Now, the man who was accustomed to logging many miles over the road each week, had reached a figurative crossroads. "Like many people with MS, he had to decide whether he would stop pursuing an activity that he loved because he could no longer engage in it the way that he had before his symptoms emerged, or whether he would make adaptations that would allow him to continue running, albeit in a different way."

Exemplifying the grit of a long-distance runner, the man decided to keep going. "He knew that not only his identity but also his mental health and his physical well-being were related to running, and so he fit his routine to his abilities. He would run for a bit and then walk for a bit. It took more time, but he still got his miles in. To my mind, a 'ralk star' (run-walk star)," the physical therapist says.

> "Regardless of your level of ability, move to the extent that you can, and use that movement to find joy in your life."
>
> – Mandy Rohrig, DPT, MSCS

Dr. Rohrig says that the man's story is a testament not only to the strength and resilience of so many people with MS, but also to the importance of bringing realistic expectations to any form of therapy.

In some cases, the experts interviewed for this article say, patients come to therapy expecting a "cure" – the total elimination of a symptom or limitation – and view anything short of that as unacceptable and not worth the effort. Although therapists pursue remediation whenever possible, a patient's condition often means that the goal of therapy is not so much to restore function to a pre-diagnosis state, as it is to achieve incremental improvement or stop or slow further decline.

They add that while therapists owe patients their best assessment of what's realistic, patients owe it to themselves to embrace what's realistic and to make a real effort to pursue it as best they can.

According to Ms. Meyer, that pursuit of what's possible needs to take place outside of therapy appointments as well as during those sessions. She explains that when she was providing patient care, "I felt very strongly about not seeing people for extended periods of time, because a big part of our model was building self-determination and self-advocacy with our interventions – teaching and training people how to do things themselves, rather than me just doing things to them or for them."

The occupational therapist adds that while it can be challenging to find the right balance between direct care and patient education, some people may struggle to engage with exercises or strategies on their own, leading to reliance on the therapist and viewing therapy as just attending appointments. Recognizing each person's unique circumstances can help create a more collaborative approach where clients feel supported in taking charge of their progress. "We should be supporting people so that they are able to do [exercises] on their own. We should be removing barriers. So, if I'm

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Just What the Physical Therapist Ordered: Four Activities for People with MS

While individualization is key when it comes to designing physical therapy regimens for people with MS, Mandy Rohrig, DPT, MSCS, says there are four types of activities that – with their healthcare provider's approval and appropriate assistance, if needed – can benefit virtually all people living with MS. Dr. Rohrig explains that those activities involve:

1. **Posture awareness.** "Shoulder blade squeezes and chin tucks can be performed sitting or standing," the physical therapist notes.

2. **Sit-to-stand exercises.** "I'm a huge proponent of supporting the ability to get in and out of a chair, even if you do require assistance. It's really important to keep the muscles involved active," she adds. For these and other types of exercises, readers may visit **cando-ms.org/exercises** to access a series of "MS Moves" videos.

3. **Calf stretches.** "For people who are ambulatory, calf tightness can cause balance issues and shuffling when walking, both of which increase fall risk. People who use wheelchairs can experience calf tightening because they aren't using their legs to walk, but they too, can do simple calf stretches a few times a day."

4. **Deep breathing.** "This one is beneficial for all people," Dr. Rohrig says, explaining that taking time each day to engage in deep breathing can preserve lung capacity and help with energy management. ■

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.

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MS, multiple sclerosis; RMS, relapsing multiple sclerosis.

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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.

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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, 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.

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, or go to www.mothertobaby.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.

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teaching someone about an exercise program, I want to make sure that they can follow it with or without me, and that they have the tools and home or community environment they need to do it."

Closing Thoughts from the Experts

While physical, speech, and occupational therapists are experts in their respective disciplines and can recommend interventions tailored to an individual's specific needs, they can also develop an important perspective on "the big picture" by virtue of seeing many people with MS over the years. The three MS clinicians interviewed for this article drew on that perspective to offer some final thoughts to readers living with MS.

Dr. Rohrig says, "Keep moving! Movement gives people confidence and enables them to live their best life. So many people come to physical therapy thinking of all the things they can't do. And whether they are walking or are using a wheelchair, they often are surprised to discover all of the things they can do. So regardless of your level of ability, move to the extent that you can, and use that movement to find joy in your life."

Ms. Meyer offers, "I believe that everyone deserves to prioritize their health and wellness, but I understand that it can be challenging for different people based on their unique circumstances. It's not about striving for perfection in diet, exercise, or sleep. Rather, it's about making small, mindful choices that support our well-being, whether that's nourishing our bodies, moving in ways that feel good, or finding moments of rest. Each of us is on our own journey, and every choice we make impacts our overall health, including our ability to cope with stress and anxiety. It's all connected, and even small steps can lead to meaningful improvements."

And Dr. Perucho concludes, "Remember that speech therapy and other forms of therapy aren't just about fixing problems. With speech therapy, it's about preserving communication, swallowing safety, and quality of life for as long as possible. Comparable goals apply in other forms of therapy, and the earlier we start, the more options we have. Above all, people with MS should know they have options. They don't have to struggle alone." ■

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Questions from Our Readers

By Dr. Barry Hendin
MSAA's Chief Medical Officer

Q: What types of mental health issues occur with MS, and can they be successfully treated?

A: Mental health issues are more common in people with multiple sclerosis. Approximately 50% of people with MS experience depression at some point in their life. We believe that much of this is biological in origin and associated with brain inflammation, rather than just situational problems.

There is also an increase in anxiety, and at least one-third of people with MS will experience significant anxiety. Of course, people living with MS must cope with all of the ordinary stressors of life, in addition to the challenges that MS presents. Navigating one's job, personal relationships, and physical functions are often more complex for members of the MS community.

Fortunately, these and other mental health issues can be treated and managed. Psychologists, counselors, and psychiatrists have specialized skills in addressing depression, anxiety, and situational stressors. Often one's neurologist or primary care physician can help with the more common mental health issues.

Several different types of medications are available to treat depression and anxiety, and as with most medications, the degree of effectiveness versus the potential side effects needs to be discussed with one's doctor. Please note that many antidepressants may require several weeks before the full benefit is reached, and some require regular blood work.

In addition to medications for depression and anxiety, non-pharmacologic interventions can be very helpful. People experiencing depression and anxiety often benefit from a self-directed approach to wellness, including regular exercise, healthy eating, getting adequate sleep, and maintaining their social connections.

A variety of therapeutic approaches may also be used during the counseling process. Examples include: "talk therapy," which helps a person gain insight and resolve problems through discussions with a therapist; "interpersonal therapy," which focuses on issues arising in relationships; and "cognitive/behavioral therapy," which works to change negative ways of thinking into more positive approaches. In addition, family or couples therapy, as well as support groups and peer counseling, can be particularly helpful for members of the MS community. Phone therapy and virtual online sessions have become good options for individuals who may have trouble accessing these types of services from their location.

Taking medication while participating in psychological therapy appears to be the most effective means of treatment for depression and/or anxiety. But regardless of what type of treatment you select, if you are experiencing depression, anxiety, or any other type of mental issue, please see a medical professional and begin your treatment plan as soon as possible, before symptoms worsen.

Q: What are your thoughts on BTK inhibitors, and how might their effectiveness and side effects/risk factors compare to the currently approved disease-modifying therapies? Also, how soon could these types of medications be approved?

A: Bruton tyrosine kinase (BTK) inhibitors represent real hope for people living with MS. Over the years, we have been more and more successful in reducing the likelihood of relapses. However, we have not been equally successful at reducing the progression that occurs independent of relapses. We define that progression using different terms, including "non-active secondary progression" and "PIRA" (progression independent of relapse activity).

BTK inhibitors have features different from our current medications. One significant difference is that BTK inhibitors are small molecules, which enable them to penetrate the brain and reach areas of smoldering inflammation. Smoldering inflammation may be the cause of this kind of progression that occurs independent of relapses. Conversely, our current disease-modifying therapies are large molecules, so they have a difficult time penetrating the brain.

Another important difference is the type of immune system that BTK inhibitors affect, versus the type of immune system that our current disease-modifying therapies affect. The two main types of immunity are "innate" and "adaptive." On the one hand, innate immunity is nonspecific to different antigens. A person is born with this type of protection and it responds quickly to almost any foreign organism (or "microbe") to prevent infection. On the other hand, adaptive immunity, also known as "acquired immunity," takes several days to develop and reacts to a specific antigen.

BTK inhibitors work on both the innate and adaptive immune systems, while our currently approved medications work primarily on the adaptive immune system. The fact that BTK inhibitors affect both types of immune systems may well provide an advantage over the current treatments that largely only affect the one type.

The first successful trial of a BTK inhibitor was announced in September 2024 at the ECTRIMS annual meeting held in Copenhagen, Denmark. The molecule, tolebrutinib, reduced progression by 31% compared to placebo. It also showed risk for liver toxicity in a small group of patients. We expect that when it is approved, there will be a risk mitigation program (REMS) to manage that risk.

In December 2024, the United States Food and Drug Administration (FDA) designated tolebrutinib as a Breakthrough Therapy for the treatment of adults with non-relapsing secondary-progressive multiple sclerosis (nrSPMS). For more information about this designation, please see page 26 of "Research News."

It is still speculative as to when we will see BTK inhibitors available commercially. But I am looking forward to being able to use these agents for the unmet needs associated with non-active secondary progression. ■

Please email questions for
Ask the Doctor to **askdr@mymsaa.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

By Tom Garry

Reviewed by Dr. Barry A. Hendin
MSAA's Chief Medical Officer

FDA designates tolebrutinib as a Breakthrough Therapy

In December 2024, the Food and Drug Administration (FDA) granted Breakthrough Therapy designation to tolebrutinib, an investigational, oral medication being studied for the treatment of non-relapsing secondary-progressive multiple sclerosis (nrSPMS).[1] The FDA designation is designed to expedite the development and review of medicines that target serious or life-threatening conditions.

While more than 20 disease-modifying therapies (DMTs) are approved for use in various forms of relapsing MS, none are specifically approved for nrSPMS, a condition in which people initially diagnosed with relapsing-remitting MS (RRMS) experience a steady progression without relapses. The Breakthrough Therapy designation was based on positive results from the Phase III HERCULES study involving more than 1,100 people with nrSPMS. The study found that tolebrutinib delayed the time to the onset of six-month confirmed disability progression (CDP) by 31% compared to placebo. Further, 10% of study participants receiving tolebrutinib experienced confirmed disability improvement, compared to 5% of those receiving placebo.

Tolebrutinib belongs to a class of medications known as Bruton's tyrosine kinase (BTK) inhibitors. For more information on how BTK inhibitors work, please see pages 24 and 25 of our "Ask the Doctor" column. ■

Shorter Transition Beneficial when Switching from Tysabri® to an anti-CD20 therapy

When switching from Tysabri® (natalizumab) to an anti-CD20 monoclonal antibody such as Ocrevus® (ocrelizumab), Kesimpta® (ofatumumab), or Briumvi® (ublituximab), a shorter transition period appears to offer a reduced risk of relapse compared to a longer transition, according to a European study.[2]

The study involved 139 people with relapsing forms of multiple sclerosis receiving care at one of eight MS centers in Austria, Switzerland, and Germany. All study participants had received Tysabri or a biosimilar version of the medication for a median time of 4.4 years. During one year of follow-up, 16.1% of patients who had a transition period of 45 days or more experienced a relapse. By contrast, 11.1% of those whose transition lasted 30 to 44 days had a relapse, and no patients who made the switch in less than 30 days experienced a relapse.

Tysabri and the various anti-CD20 monoclonal antibodies are considered highefficacy disease-modifying therapies (DMTs). Since 2017, when Ocrevus became the first anti-CD20 therapy approved for use in MS in the United States, many clinicians have sought to shift their patients with MS from Tysabri to another high-potency DMT because of concerns about progressive multifocal leukoencephalopathy (PML), a rare but often fatal opportunistic infection of the brain.

While cases of PML have occurred in patients taking anti-CD20 therapy as well as in those receiving Tysabri, the duration of Tysabri use has been identified as a risk factor for the condition, prompting many clinicians to try to limit their patients' time on the medication. ■

FDA issues anaphylaxis warning for Copaxone® and Glatopa®

Earlier this year, the FDA issued a warning about the risk of anaphylaxis, a rare but serious allergic reaction, with use of the disease-modifying therapy (DMT) glatiramer acetate.[3] This medication is marketed as Copaxone® and Glatopa®. The reaction can occur at any time while on treatment, ranging from after the first dose to after doses administered years later. For most patients, the symptoms appeared within one hour of injection.

Although hundreds of thousands of people with relapsing forms of MS have used glatiramer acetate since its approval in 1996, anaphylaxis associated with this medication has only been reported in 82 patients worldwide. While this number is extremely low, individuals taking this medication should be aware of this potential danger and watch for signs of an allergic reaction.

Symptoms of anaphylaxis include wheezing, difficulty breathing, swelling of the face, lips, or throat, and hives. The FDA notes that the early symptoms of anaphylaxis can be similar to a temporary reaction that sometimes happens within minutes after an injection of glatiramer acetate. Involving symptoms such as flushing, chest pain, palpitations, anxiety, shortness of breath, rash, or hives, this post-injection reaction usually goes away on its own within 15-30 minutes.

Readers are advised to contact their prescribing doctor if they experience any of these immediate post-injection reactions, and not to take any additional doses until getting permission from their doctor. If symptoms worsen or do not improve, individuals should seek immediate medical attention by going to an emergency room or calling 911. ■

References

1. Sanofi-Aventis Groupe. Tolebrutinib designated Break-through Therapy by the FDA for non-relapsing secondary progressive multiple sclerosis. December 13, 2024.

2. Bsteh G, Hoepner R, Gernert JA, et al. Switching from natalizumab to antiCD20 monoclonal antibodies: Short transition interval is associated with improved outcome. *Eur J Neurol.* 2025 Jan;32(1):e16587. doi: 10.1111/ene.16587.

3. Food and Drug Administration. FDA Drug Safety Communication. FDA adds Boxed Warning about a rare but serious allergic reaction called anaphylaxis with the multiple sclerosis medicine glatiramer acetate (Copaxone, Glatopa). January 22, 2025.

MS Ecosystem Framework Initiative

By Susan Wells Courtney

With our mission of Improving Lives Today, MSAA is continually striving to evaluate and meet the ever-changing needs and challenges of the MS community. Recognizing that important changes are necessary to meet the needs of underserved communities, MSAA has set out to: (1) identify and assess these needs, (2) gather vital input from individuals living with MS as well as healthcare professionals, and (3) develop personalized and targeted interventions for the MS community. These three phases make up the design of MSAA's MS Ecosystem Framework initiative.

Phase 1: Conduct a National Needs Assessment Survey

Phase 1 began in October 2023 when MSAA conducted a national **"Survey of Equity and Unmet Needs,"** in both English and Spanish. The ecosystems considered included: (1) geographic regions where respondents reside, (2) how far respondents are from an MS center, (3) respondents who are unable to see an MS expert, and (4) respondents experiencing barriers related to affordability, MRIs, and other comprehensive care.

According to the survey's results, the **barriers to care** that were reported the most often are as follows:

- Affording medical care and MRIs (34%)
- Finding MS care in one's community (34%)
- Finding doctors to coordinate one's MS care with other needed care (31%)
- No health insurance or high insurance-related costs, including deductibles and co-pays (21%)
- Finding accessible transportation to medical appointments (18%)
- Finding accessible medical facilities (8%)
- Lack of culturally relevant care (4%)

In this first phase, **"cultural humility"** was highlighted. According to the study, "Cultural humility involves an ongoing process of self-exploration and self-critique combined with a willingness to learn from others. It means entering a relationship with another person with the intention of honoring their beliefs, customs, and values."

With respect to the different cultures, people with different ethnic backgrounds reported higher percentages of those experiencing the barriers to care noted above. For example:

- 75% of American Indian or Alaska Native respondents and 54% of Hispanic, Latinx, or Spanish-origin respondents found affording medical care and MRIs to be a barrier to care (versus 34% of the entire group of survey respondents)

- 44% of Asian respondents had trouble finding doctors to coordinate their MS care with other needed care (versus 31%)
- 27% of Black or African American respondents experienced a lack of culturally relevant care as a barrier of care (versus 4%)

While the majority of these respondents did not feel that race or ethnicity played a role in their MS journey, the numbers of those who did think it played a role were still significant. More than 10% of Hispanic, Latinx, or Spanish-origin respondents; more than 20% of American Indians or Alaska Natives; more than 30% of Asians; and close to 40% of Black or African Americans, felt that race or ethnicity played a role in their MS journey.

Phase 2: Conduct Regional Roundtable Discussions

The second phase of MSAA's MS Ecosystem Framework has been titled, "Living with Multiple Sclerosis." This is defined as "A qualitative research project to understand the needs, challenges, and barriers of people living with multiple sclerosis in Inland Empire, California; Central Texas; Atlanta, Georgia; and Upstate New York." These four locations were selected according to the most respondents with the greatest needs, along with representing different regions of the country.

Qualitative research took place from June to August 2024 through a series of remote, in-depth interviews and focus groups with people living with MS, patient advocates, and care team members. These were conducted in the four different locations (or "ecosystems") noted earlier. The goal of this research was to examine the range of issues in each location more closely, and then to use these results to design potential interventions.

Other important topics emerged repeatedly throughout the interviews and focus groups, regardless of where people lived. These included issues involved with delayed diagnosis, misperceptions, quality of care, mental and physical health, support groups and counseling, family and parenting, trust, and employment.

Transcripts from the interviews and focus groups were analyzed and findings were outlined and plotted on "experience maps" for each location. Using this information, the researchers created a set of actionable insights about attitudes, challenges, and needs at different stages of MS. Examples of such insights include:

- MS and its symptoms are frequently misunderstood or misinterpreted.
- Race and culture can be factors in how long it takes to get diagnosed and start treatment.
- Withdrawal, depression, and hopelessness are commonly experienced following a diagnosis.

Phase 3: Personalized and Targeted Intervention

With the actionable insights in place, several possible interventions have been recommended. These include both digital/online tools as well as awareness and educational content initiatives.

Digital tools could encompass strategies for learning about: resources and support, specific symptoms prior to a diagnosis, and insurance coverage. Awareness and educational content may include public awareness campaigns, MS-specific education for medical professionals, and guides to address other specific needs identified in the first two phases of the study.

MSAA's MS Ecosystem Framework initiative, which began with a national "Survey of Equity and Unmet Needs" in October 2023, followed by roundtable discussions through in-depth interviews and focus groups in 2024, has come full circle to identify the precise needs of a diverse community of people with MS and develop specific plans for personalized and targeted interventions. As we continue in 2025 with Phase 3 of this urgent research project, we will look for innovative ways to implement these strategies to best serve individuals with MS and help minimize the challenges they face in terms of care, treatment, and lifestyle. ■

MSAA's MS Ecosystem Framework initiative was made possible through the generous support of the following sponsors: Platinum Sponsor, Genentech; Gold Sponsor, Amgen; Silver Sponsors, Novartis, and Sanofi; and Bronze Sponsor, Biogen.

MSAA's 11th Improving Lives Benefit

Mark your calendar – MSAA's biggest event of the year is fast approaching! **On Wednesday, May 14th, MSAA will hold our 11th Improving Lives Benefit**, taking place at the Barnes Foundation in Philadelphia, and also taking place virtually for everyone to access at home! This is a very special event, as we bring together many inspirational people who play significant roles within the MS community – including healthcare professionals, individuals with MS, care partners, corporate leaders, donors, and MSAA's Board of Directors.

MSAA's Improving Lives Benefit is always an exciting time to gather and support MSAA's mission of Improving Lives Today. MS advocate and motivational speaker, Tyler Campbell, will once again join us as our emcee for this event. His energetic and upbeat personality always lifts the spirits of everyone in the room and all those tuning in via livestream.

Recognizing two very deserving honorees who have made significant contributions to the MS community will be a special part of the evening. This year's Mission Honoree is Dr. Barry A. Singer, whose work as both a physician and as a member of MSAA's Board of Directors has greatly supported our mission while helping countless people in the MS community. This year's Corporate Honoree is Cionic, a medical technology company that develops bionic clothing to improve walking and strength. Please see the following pages for more information about our honorees.

11TH Improving Lives Benefit

MSAA's Improving Lives Benefit is a very important event for MSAA, raising donations to support our vital mission. As our most impactful fundraising event of the year, MSAA depends on these funds to reach as many people across the country as possible with our urgently needed programs and services throughout the year. ■

Please join us for MSAA's 11th Improving Lives Benefit on May 14th! To purchase tickets, attend for free via livestream, or for information about our auction, sponsorship, and ad journal options, please visit mymsaa.org/benefit.

Special Thanks to the Following Sponsors for MSAA's Improving Lives Benefit:

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MSAA's Improving Lives Benefit 2025 Mission Honoree

MSAA is very proud to announce that this year's Mission Honoree is **Barry A. Singer, MD**, Director and Founder of The MS Center for Innovations in Care at the Missouri Baptist Medical Center and longtime member of MSAA's Board of Directors. Dr. Singer has made a tremendous impact on the MS community through his work as a neurologist and as a member of MSAA's Board of Directors, serving on the Executive Committee. We are truly grateful for his dedication to our mission.

Dr. Singer has served as Director of The MS Center for Innovations in Care at Missouri Baptist Medical Center since 2008. He also completed a neuroimmunology fellowship at the National Institutes of Health.

As an investigator in more than 40 multiple sclerosis trials (Phases I to III), Dr. Singer has been focused on developing new therapeutic options, including those for remyelination. He continues to publish peer-reviewed articles, present posters at national conferences, and lecture globally on MS.

Dr. Barry Singer shared, "Being selected as the 2025 Mission Honoree was surprising and deeply rewarding for me. Throughout my career, I have dedicated myself to advocating for individuals living with multiple sclerosis – whether by partnering with my individual patients, collaborating with advocacy organizations, speaking at global meetings, hosting a podcast, or sharing the latest MS updates online. Serving on MSAA's Board of Directors for the past nine years has been a true privilege, allowing me to focus on MSAA's mission of Improving Lives Today. From the MRI Access Program, which helps those unable to afford crucial MRI scans, to the Multiple Sclerosis Implementation Network, which aims to advance MS clinical care, MSAA offers vital and innovative programs that make a real difference in people's lives every day."

Dr. Singer has worked with MSAA on multiple initiatives, including webinars, videos, podcasts, and other educational programs. His expertise on MSAA's Board of Directors has provided invaluable guidance toward our organization's mission and programmatic areas. Dr. Singer's extensive work in the field of MS, his knowledge, and his optimistic outlook, together, have been a tremendous asset to MSAA and to the MS community.

MSAA is extremely pleased to recognize Dr. Singer as this year's Improving Lives Benefit Mission Honoree. His dedication shines through in all of his accomplishments, and we sincerely thank him for his many efforts in supporting MSAA's mission as well as individuals with MS, their care partners, and other healthcare professionals. ■

MSAA's Improving Lives Benefit 2025 Corporate Honoree

MSAA is very pleased to recognize Cionic as this year's Corporate Honoree. Cionic is a medical technology company that builds bionic clothing, which can specifically analyze and augment muscle activation, enabling the body to move with greater freedom and control. This technology can be extremely useful for individuals with MS who experience problems with walking and strength.

Entrepreneur Jeremiah Robison founded Cionic in 2018. Having worked in the field of wearable technology for more than 20 years, Mr. Robison looked to create innovation on a personal level. Motivated by his daughter's diagnosis of cerebral palsy, he believed that more advanced mobility solutions could be built that would adapt to individual mobility needs and retrain the connections between the brain and body.

"Cionic is deeply honored to be recognized by the Multiple Sclerosis Association of America and proud to share in their mission of Improving Lives Today," said Cionic Founder and CEO Jeremiah Robison. "Through robust clinical engagement and strong advocacy of patient voices, MSAA has been a welcome partner in our drive to bring the most advanced mobility solutions to the multiple sclerosis community. We look forward to a bright future of collaboration and continued investment in innovation."

Cionic's initial product, the Cionic Neural Sleeve, was inspired by experiences Mr. Robison saw in his daughter's mobility journey. As a young girl, she underwent a movement analysis at a gait lab, and soon after began functional electrical stimulation (FES) as part of her physical therapy. Cionic's bionic clothing combines the diagnostic power of a gait lab with the therapeutic power of FES into a comfortable, lightweight garment that can provide all-day walking assistance. Cionic also works with academic partners to conduct clinical trials and introduce new treatments to both pediatric and adult populations.

MSAA commends Cionic for its work in creating an innovative technology that can assist people – including members of the MS community – with improving mobility and strength, both of which are vitally important to one's quality of life. The Cionic Neural Sleeve is FDA cleared to improve gait and facilitate muscle re-education in individuals with multiple sclerosis.

We greatly appreciate the work that Cionic does and are pleased to recognize them as this year's Improving Lives Benefit Corporate Honoree. ■

Facing the Challenges Together

By Sharon Bosch

My story started some 25-plus years ago. I was 28 when I was officially diagnosed with multiple sclerosis in 1999. I grew up in a middle-class neighborhood in Brooklyn, and I had a very normal childhood, always outside playing, every mom knew each mom on "our block," and basically you weren't getting away with anything.

It truly was a great time to grow up. However, I was often sick as a child. For years I would have strep throat twice per month, and often, for no reason, I just didn't feel well. Finally, when I was 15, my family doctor tested me for the Epstein-Barr virus (EBV). I tested positive for having chronic and acute EBV. Studies suggest that this virus could be involved with the development of MS.

Sadly, your body begins to expect those bad days with fatigue and pain; you simply learn to press on. But I had no time to stop living. At 18, I was attending a university and busy being 18! By 22, I had graduated college, started working in the ER of a hospital, and I became engaged – everything was going so well!


Author Sharon Bosch with her companion dog, Taffy

Then, "Screech, halt, go no further, STOP! What's this? Why does my hand go numb when I'm in the shower, and why do I feel like I'm going to pass out? No. No, no, this can't be happening to me." I chalked it up to being overstressed, overworked, overtired, etc. Just a few months after getting married, my fatigue was getting worse, and I was diagnosed with Hashimoto's thyroiditis, my first autoimmune disorder.

I continued working some very stressful and long days at the ER, and I began to feel as though all of my symptoms were bursting through the flood gates. I consulted my general practitioner (GP) and explained my symptoms of fatigue, reduced arm and leg strength, gait and balance issues, difficulty finding words, and short-term memory loss. My GP referred me to a neurologist.

An MRI, a spinal tap, and a visual evoke potential (VEP) test, were ordered. My brain lit up like a Christmas tree when they added the contrast to my MRI, I had O bands in my brain stem, and was negative for the VEP. I was diagnosed within one month. Soon after, a flare-up caused a terrible case of optic neuritis. That's how quickly things can change for a person with multiple sclerosis.

No longer able to do my job effectively or safely, I had to leave a job I loved. Relapse after relapse took a significant toll on my body. Then one day, while doing my own research on new MS treatments, I came across an article about Canine Companions. I was in awe of what these highly trained service dogs can do.

I contacted Canine Companions in 2002, and after completing an application, I was accepted into a training program in 2004. My dad and I drove from Brooklyn to Farmingdale, Long Island every day for two weeks. Within a day or two, I met the dog I was going to be paired with – his name was Richie, a lab/golden retriever mix – and (lol), we didn't like each other at first.

However, I never had a dog. I didn't know that dogs pick up on our mood. If I didn't like something, Richie knew and reacted negatively. One of the trainers explained how dogs react to our feelings. Once I understood, we were able to mend our connection, and Richie and I went on to work very hard together on the commands. I would say, "side," and he would go to the right side of me, and "heel" brought him to the left side of me. I could tell him to "push" or "pull" a door, "open" a cabinet, or "get it," to retrieve anything from shoes, socks, or a basket of laundry, to keys, a pen, or even a credit card.

Richie and I graduated after passing our tests and receiving our ADI certifications. What a difference Richie made in my life! We traveled the country and used those commands daily. Richie was always there for me, always right by my side. When Richie passed at the age of 13, I was heartbroken. I mourned his death for nearly 10 years.

Then one day my son went to the car show in New York City where Canine Companions had a booth. He told me that I had mourned Richie long enough, and gave me an application to apply for a "successor dog." A year later, I was accepted into a Successor Service Dog class.

Not until I walked onto the Canine Companion Campus and spoke to others, could I finally let go of the pain I had. As soon as I met "Taffy," I knew she was my girl. As with Richie, we worked hard together to build our bond and learn the commands.

Service dogs are amazing. They are not pets, but rather an extension of our bodies. I am so grateful to everyone at Canine Companions. I've been given a new lease on life. Taffy and I are ready every day... and we face the challenges together. ■

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MSAA is very proud to present our 2025-2026

ART SHOWCASE

Each year, MSAA features the work of artists with MS in the annual MSAA Art Showcase, highlighting one artist each month as our Artist of the Month.

We received many wonderful submissions from more than 85 artists across the country and are delighted to share their work and inspiring stories!

View the complete gallery at **mymsaa.org/artshowcase2025**