MS Links

Spring-Summer 2026

HolyName

The Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center

Letter from the Medical Director

Welcome to the spring-summer issue of MS Links. We all deserve congratulations for having made it through a long winter!

News from the Consortium of Multiple Sclerosis Centers Annual Meeting (CMSC)

- Dana Jones, our nurse practitioner, spearheaded a study with our nurses to detect urinary tract infections in patients on B-cell-depleting therapies. Dana presented this research at CMSC in Charlotte, N.C., in May. Infections can be more common with certain therapies, so it's very important to let us know if you are not feeling well. **Read more about the study on p. 5**.
- Data on fenebrutinib were also presented at CMSC. This BTK inhibitor is a new class of drugs being studied for both relapsing and progressive patients. It may reduce annualized relapse rates compared with teriflunomide.

Other News in This Issue...

- Cognitive changes, such as short-term memory loss, word-finding difficulties, and information-processing difficulties, are among the memory problems that accompany MS. They are often invisible symptoms because someone may appear physically fine but still have these underlying problems. These symptoms can appear early in the disease course. We are fortunate to have neuropsychologists Drs. Portnoy and Fechter, who evaluate patients for any of these changes and can discuss ways to help compensate for cognitive difficulties (**Learn more on p. 6**). In January, the MS Center will work with NYU occupational therapy students to develop a cognitive rehabilitation program at Holy Name.
- Diome Kramer, the research coordinator nurse for our MS clinical trials, discusses a study underway comparing ocrelizumab to the investigational BTK inhibitor remibrutinib. The new drug shows potential for slowing MS progression. **Learn more on p. 11**
- In addition to new therapies being studied here at the MS Center, we are also working on strategies to help improve function and quality of life for patients. The Bioness walking aid can improve walking ability in people with foot drop. There are monthly evaluation sessions for patients interested in testing this device. **Learn more on p. 10**.
- Maintaining your overall health is of utmost importance. Many patients don't have a primary care physician for yearly checkups. **Visit p. 5 to find a physician**.
- While not covered in this issue, we wanted to share that ENABLE, a study we participated in involving Briumvi, showed that 99.4% of patients remained relapse-free and reported benefits in convenience and tolerability after switching from other anti-CD20 therapies.

As always, our goal is to provide compassionate care using the latest treatment strategies. We are here for you. Enjoy this newsletter, and please reach out to suggest topics for future newsletters.

Mary Ann Picone, MD

Mary Ann Picone, MD, Medical Director, MS Center

ASK THE EXPERT

Is MS Hereditary?

Mary Ann Picone, MD

Medical Director, MS Center

The short answer is that genetics can raise your chance of getting MS, but they do not decide your future. Most people with MS have many small genetic differences plus environmental triggers.

MS is not caused by one single "MS gene." Instead, MS risk is largely polygenic, meaning many common genetic variants each add a small amount of risk. Researchers have identified more than 230 genetic variants linked to MS susceptibility, most of which are associated with immune system pathways. A gene region called HLA-DRB1*15:01 is one of the strongest genetic links to MS, but having it does not guarantee MS.

If your parent, child, or sibling has MS, your chance of getting MS is higher than the general public — about 7 to 8%, according to the National Multiple Sclerosis Society. Even identical twins (who share the same genes) don't always both get MS.

What Genes Can't Tell Us

Right now, genetic tests can't determine for sure who will get MS. Polygenic risk scores can indicate higher or lower genetic risk, but they are not precise enough to predict disease on their own. Some genes affect whether someone gets MS, while others may affect how the disease progresses. Scientists are still studying this.

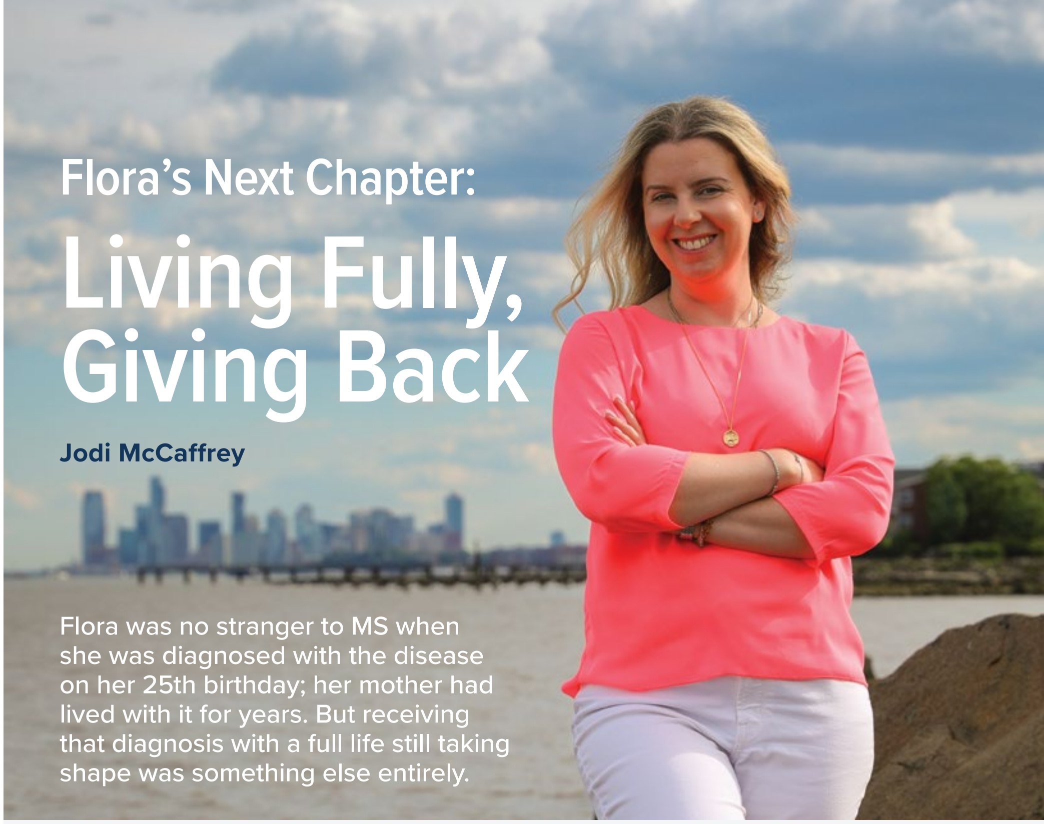
If you are concerned about passing down MS to your children:

- Talk with your neurologist about your specific situation.
- Consider genetic counseling if you want to learn more about testing and what results might mean for your family.

If someone is concerned that they are at increased risk of developing MS, they should:

- Avoid smoking.
- Get enough vitamin D through safe sun exposure, eating foods like fatty fish, egg yolks, and fortified foods, or taking a supplement.
- Follow medical advice.

These steps can lower risk or help health even when genes raise risk.



Flora's Next Chapter:

Living Fully, Giving Back

Jodi McCaffrey

Flora was no stranger to MS when she was diagnosed with the disease on her 25th birthday; her mother had lived with it for years. But receiving that diagnosis with a full life still taking shape was something else entirely.

"Having watched my mom navigate MS, I already had some understanding of what it meant," says Flora, who lives in Franklin Lakes. "But there's a difference between knowing about something and living it. I had a choice in how I was going to show up for myself every day, and I chose positivity."

Like her mother, Flora turned to Mary Ann Picone, MD, medical director of Holy Name's MS Center. After experiencing vision issues that led to her diagnosis, she tried a series of injectables and oral medications before finding Ocrevus, the infusion therapy she remains on today.

"I've tried not to let MS affect me physically, emotionally, or mentally," she says. "It's something that I have, but it doesn't define who I am. Medicine can only do so much. The rest is about controlling your mindset, and choosing, every single day, to focus on what's good."

That mindset extends to the practicalities of treatment, too. The busy mother of three has found an unexpected silver lining in her infusion schedule. "I have a 15-year-old, a three-year-old, and a one-year-old. I work full-time, so I kind of look forward to it because it's a nice break," Flora says.

Building a Family and a Community

Today, Flora's vision issues are gone, and she feels great. She loves to travel and cook, walk the dog, practice Pilates, and chase two toddlers. But what energizes her most is the community she's building for others who are just starting their MS journey.

Flora plans to launch Pour It Out, a support community built around honest conversations about life with MS. The format is intentionally informal: one-on-one coffee meetups or small group gatherings, each week centered on a new topic, from navigating newly diagnosed life to managing relationships, staying active, and starting a family with MS. "I was very fortunate to have an incredible network of doctors who helped me not only manage MS, but build my family through IVF [in vitro fertilization]," she explains. "I know how overwhelming it can feel when you're newly diagnosed and trying to figure out what your life looks like now. I want to be the person in someone's corner who has actually been through it."

Pour It Out draws on the relationships and expertise Flora has cultivated over nearly 15 years with MS. Whether someone needs a one-on-one conversation or wants the energy of a group, she wants to meet them where they are.

"You're going to have really bad days, and then you're going to have really awesome ones. It's all of the wonderful, small moments on those good days that make up the bigger picture of who you are," she says. "You need an incredible support system, and if you don't have one, I'm happy to be that for you."

Flora can be reached at flora.pinskiy@gmail.com.

Patients Put Their Best Feet Forward at Spring Fashion Show

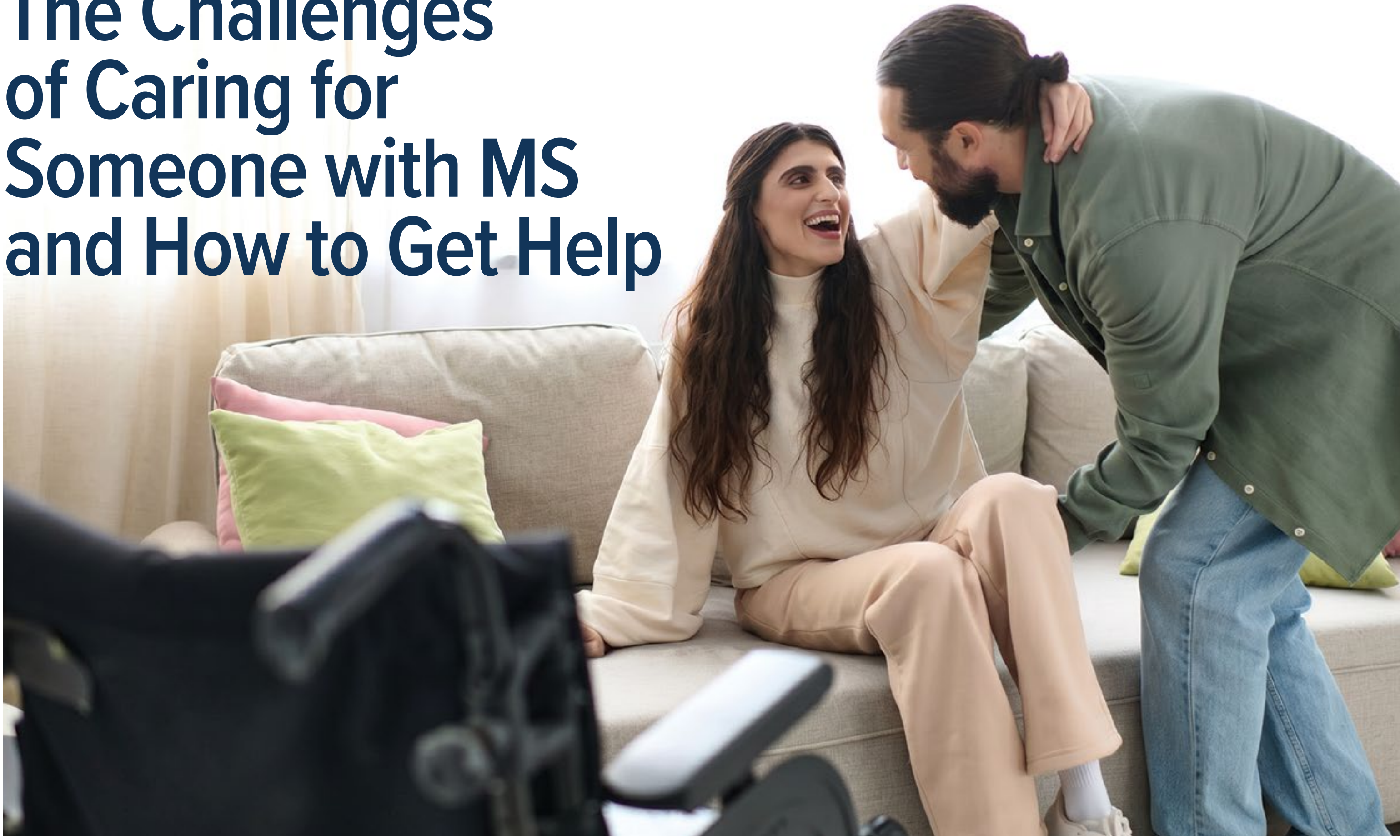
The Teaneck Marriott at Glenpointe hosted more than 400 guests on April 26 for Holy Name Foundation's 26th Annual Spring Fashion Show for MS. Patients, staff, friends, and supporters worked the runway to show off the season's latest looks. The event benefited the Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center at Holy Name.

Thank you to our generous sponsors and donors, including:

- Honorary Co-Chair Larry R. Inserra, Jr., the Inserra family and ShopRite Supermarkets, Inc.
- Honorary Co-Chair Joseph M. Sanzari
- Chairperson Susan Zurndorfer
- Lisa Ani Garapedian and Glenn Boyd
- TG Therapeutics

Asya Wallach, MD (middle), with a few of her patients: (left to right) Patricia A. Korshalla, Veronica F. Sherman, Natalie Caez, and Katie McCarten.

The Challenges of Caring for Someone with MS and How to Get Help



Asya Wallach, MD - *Neurologist, MS Center*

Multiple sclerosis is often described as a journey, and the people who come along for the ride – usually spouses or life partners, sometimes siblings, parents, or adult children – have an important role. We call them caregivers, and they deserve our gratitude.

Early on, during the scary period of first learning about the diagnosis and adjusting to living with the disease, the caregiver may share many of the same worries as the patient: What will their future look like? What can we expect? How do we adjust to this new normal?

Watching a loved one cope with fatigue, pain, new physical limitations, or cognitive changes can be heartbreaking. Many caregivers experience anxiety about the future, feelings of helplessness, social isolation, sleep problems, and chronic stress. Mental health counseling geared toward caregivers, either in groups or individually, may be helpful, as well as occasionally taking time "off" to avoid burnout.

There are financial stressors involved with caring for a loved one with a chronic illness, too. Some caregivers find that they have to take time off from work, use paid family leave, or switch jobs entirely to provide adequate care. Sometimes, expenses – including medical treatments that aren't covered fully by insurance and home modifications – can add up, putting a strain on the family's nest egg.

Caring for a Spouse with MS

Finally, I'd like to mention the elephant in the room: the relationship between spouses may shift from a romantic, loving partnership to a patient-caregiver dynamic. This may be troubling to both parties. While the patient may need assistance with some things, they still will want to maintain some degree of independence. At times, being "overly cared for" can feel just as bad as being "under cared for."

Patients tell me they wait all day for help until their spouses come home, but help doesn't always arrive when they want it. Unfortunately, when your partner works outside the home, it's challenging for them to come home to a "second shift". It's important to continually communicate your needs, wants, and negotiables.

Getting Help

If you are caring for someone with MS, you are not alone. If possible, ask another family member to pitch in, or consider hiring outside help. The following resources may be helpful:

- National MS Society
- MS Association of America
- Single Parents with MS
- *The Selfish Pig's Guide to Caring* by Hugh Marriott

Making Your MS Infusions Safer: Our Recent Study

Dana Jones,
MSN, AGPC NP-C, CCRN - Nurse Practitioner, MS Center

We recently conducted a four-month study of 354 infusion visits to make your MS treatments safer. Because MS can reduce bladder sensation, many patients develop “silent” urinary tract infections (UTIs) without feeling sick. To catch these, we tested a new three-step safety protocol:

1. **A two-week lab check**
2. **A day-before phone screening**
3. **A mandatory day-of urine test (using convenient home-collection kits to make providing a sample easier).**

The results were remarkable: We caught 50 active infections before treatment. Crucially, 40 percent of these were completely “silent” and were only discovered because of the day-of urine test!

By catching these hidden infections before you sit in the chair, we prevent severe illness and ensure your body is strong enough to receive your MS therapy

ASK THE EXPERT

Dana Jones, MSN, AGPC NP-C, CCRN
Nurse Practitioner, MS Center

How Do NPs and Physicians Work Together?

As a nurse practitioner (NP) in an MS practice, I am here to partner with you in managing your health and well-being.

My role includes conducting thorough assessments to understand your unique experience with MS and monitoring how the disease is affecting you. I collaborate closely with your physician to develop individualized treatment plans that may include prescribing disease-modifying therapies and medications to help manage specific symptoms, such as pain, fatigue, or spasticity. I can also renew those prescriptions as needed.

During daunting times — such as when you’re considering changing therapies or navigating a recent relapse — I’m here to provide the education and support you need. I believe that patient education is key, so I’m dedicated to answering your questions and providing information about your diagnosis and treatment options. My goal is to ensure you feel supported and empowered as we work together to navigate the challenges of living with MS, ultimately improving your quality of life along the way.

Your health and comfort are my top priorities, and I’m committed to walking this journey with you.

Do You Have a Primary Care Physician?

A strong relationship with a primary care physician – such as a doctor who specializes in family medicine, internal medicine, or OB/GYN – is especially important when you’re living with MS.

Your PCP helps you stay on track with routine visits, medications, screenings, and the everyday management that supports your long-term health. Finding the right doctor can take time. You want someone you connect with and whose approach fits your needs and goals. Visit holyname.org/physician for a list of physicians in the Holy Name network.

Why Neuropsychological Evaluations are Important

By Jeffrey Portnoy, PhD, and Brad Fechter, PsyD, Clinical Neuropsychologists

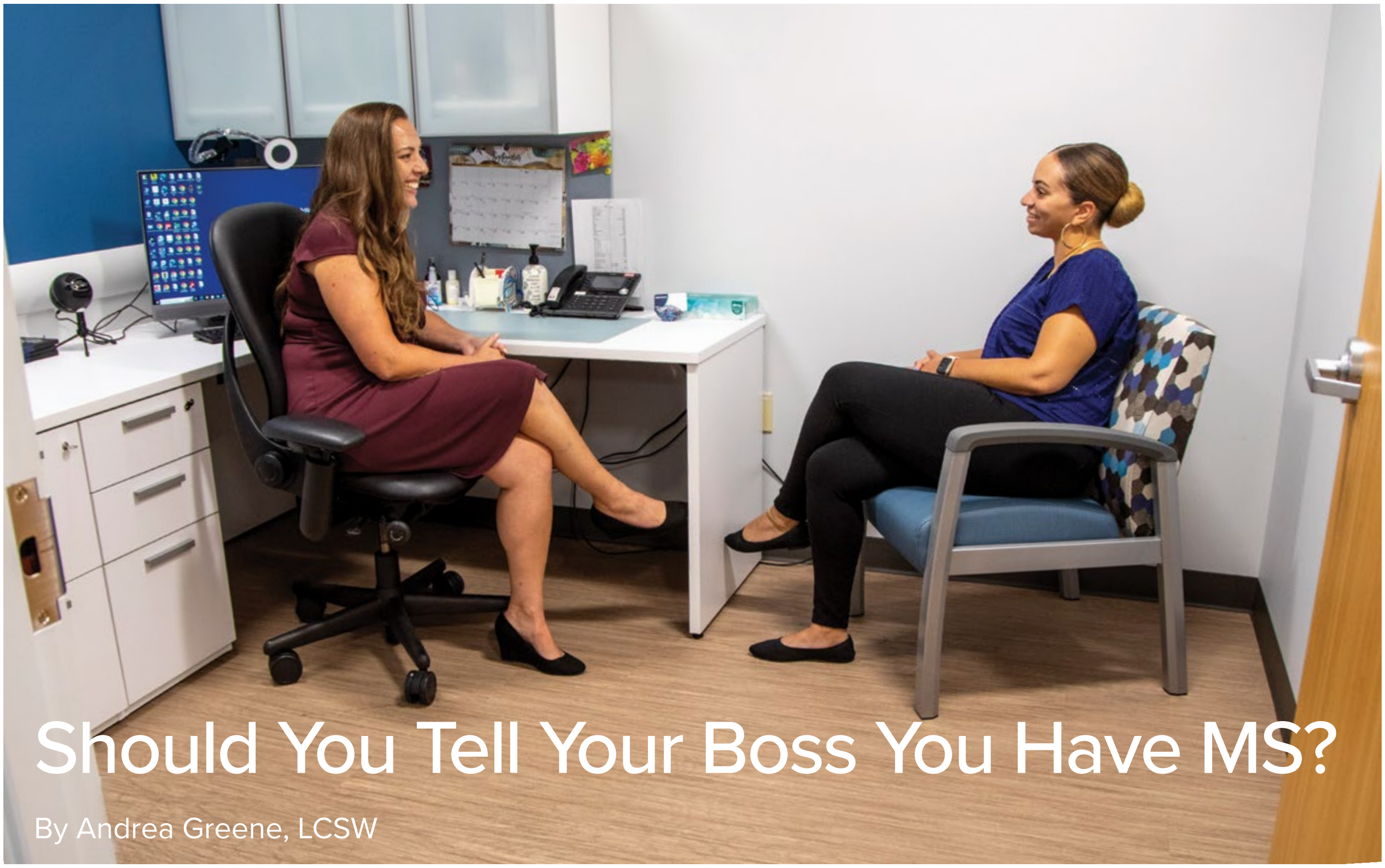
Tracking changes in balance, walking, and vision is an important part of caring for people with MS. But MS can also affect memory, attention, thinking speed, and mood. Because these are important indicators of your overall health, having regular neuropsychological evaluations is an important part of long-term care.

Your first evaluation gives your care team a “baseline” snapshot of how your brain is working at one point in time. Repeat testing every one to two years helps us see whether things are remaining stable or changing over time. Sometimes testing shows small changes that may not yet be obvious in daily life. Other times, it provides reassurance that your thinking and memory remain strong.

Repeat evaluations can also help identify the cause of new cognitive symptoms. MS is not always the reason for memory or attention problems. Stress, anxiety, depression, fatigue, poor sleep, and some medications can also affect thinking abilities. Many of these issues can improve with treatment or changes in lifestyle or medication, making it important to identify them early.

Today, people with MS are living longer and healthier lives thanks to advances in treatment. As people age, it can become difficult to tell the difference between normal aging, MS-related cognitive changes, and other conditions that affect memory. Regular evaluations help your care team better understand these changes over time.

Regular neuropsychological testing is a practical way to monitor brain health, guide treatment decisions, and support quality of life. With this detailed information, we can help you confidently navigate changes and keep your health on the right track.



Should You Tell Your Boss You Have MS?

By Andrea Greene, LCSW

Being diagnosed with MS can affect many parts of your life, including your emotional well-being. One of the most difficult decisions is whether to tell your employer about your diagnosis.

Some people choose to disclose their MS diagnosis right away because they need workplace accommodations. Others wait until symptoms begin affecting their job duties. Some employees don't share their diagnosis at all. These choices can be emotional and stressful. You may worry about being judged, treated differently, losing promotions, or even losing your job. These fears can lead to emotional exhaustion and increased anxiety and stress, especially when trying to manage your symptoms quietly.

For some, keeping an MS diagnosis private helps them feel independent and in control. However, hiding symptoms or avoiding conversations can also create emotional strain. Constantly worrying about fatigue, mobility issues, memory problems, or unexpected flare-ups may increase anxiety over time. You might begin to feel isolated or disconnected from coworkers because of this secret you are carrying.

Questions to Consider

Before telling your boss, it can help to think through possible outcomes. Ask yourself:

- Do I need accommodations right now?
- Do I trust my manager?
- How supportive is my workplace culture?

Talking with a therapist, support group, or trusted family member can also help reduce anxiety and build confidence before having the conversation.

What the Law Says

Employees with MS also have legal protections under the Americans with Disabilities Act (ADA). The ADA protects qualified employees from disability discrimination and allows workers to request reasonable accommodations. These accommodations may include:

- Flexible schedules
- Remote work
- Extra breaks
- Modified duties
- Assistive technology
- Changes to the workspace

Employers must also keep medical information confidential.

Deciding whether to disclose an MS diagnosis at work is not only a career decision but also a mental health decision. Take time to consider your physical and emotional needs, workplace culture, and legal rights to help you make choices that support both your health and your future.

The MS Center offers short-term psychotherapy. If you are interested, call the MS Center at 201-837-0727. The MS Center also offers 30 minutes of monthly meditation in our Mindfulness Mondays series.

I Think I’m Having an MS Flare, but My Doctor Says It’s Only a Pseudo-Flare. What’s the Difference?

ASK THE EXPERT

Asya Wallach, MD
Neurologist, MS Center

You’re likely already familiar with MS flares. Also called relapses or exacerbations, flares are new neurologic symptoms or worsening of prior symptoms for at least 24 hours. During a flare, there is no fever or infection. These episodes are a sign of new inflammatory damage due to loss of the myelin sheath, the protective coating around nerve fibers. Often, new lesions appear on an MRI in the context of a flare.

What Is a Pseudo-Flare

A pseudo-flare (or pseudo-exacerbation) is a temporary return or worsening of old neurologic symptoms, even though there is no new disease activity happening in the body. These episodes happen when something puts extra stress on the nervous system, making it harder for signals to travel through areas that were damaged in the past.

Common triggers of pseudo-flares:

- Infections
- Hot weather
- Emotional stress
- Dehydration
- Being overly tired

During a pseudo-flare, symptoms usually look like earlier problems you’ve had, or a milder version of a past attack. They tend to be short-lived—often lasting only a few hours—and they are not associated with new changes on an MRI.

How to Tell the Difference

Knowing whether you’re having a new MS flare or a pseudo-flare is very important. A true flare means new inflammation is happening, and your doctor may talk with you about treatments like steroids to help you recover more quickly. You might also discuss whether your current long-term MS medication is still the best fit or if it should be changed. It is important to reach out to your MS team if you believe you may be having an MS flare.

With a pseudo-flare, those conversations aren’t usually helpful because there is no new disease activity. Instead, the focus should be on finding and treating whatever is stressing your body—such as an infection, heat, or another trigger—since that is what’s causing the temporary symptoms.

Because heat is a major trigger, people often notice more pseudo-flares during the summer. If you know that the heat brings out your MS symptoms, it’s important to think about how you will stay cool during the summer. Many patients find ice packs, cooling vests/scarves, fans, and staying indoors or by a body of water helpful.

Staying Positive Despite the Challenges of MS

By Jodi McCaffrey

For years, Yassette Morales struggled with fatigue, and for years, doctors chalked it up to the typical exhaustion that a mother of three boys under age 8 would feel. She had bouts of numbness and blurred vision, but still couldn't get a diagnosis. Then, while at the lake with her boys 18 years ago, the Lodi resident began to experience tingling and numbness. When she felt even worse the next day, she headed to the nearest emergency department.

"I woke up, and half of my body was numb," Yassette, now 45, recalls. "I was crying because I thought I had a stroke."

At the hospital, she was diagnosed with both MS and lupus. However, further testing ruled out lupus as the cause of her symptoms. She contacted the MS Society to find a doctor and was referred to the MS Center at Holy Name.

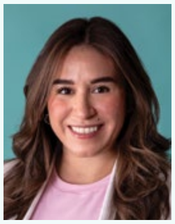
"I've received the best care at Holy Name, especially when I was so scared and confused about my diagnosis," says Yassette, a patient representative at another hospital. Knowing she had support helped her feel understood and cared for during a difficult time.

It took some trial and error to find the right treatment for Yassette's symptoms. Now under the care of neurologist Asya Wallach, MD, she is on Ocrevus and feeling good. "It's been a journey, but I'm doing really well now. I haven't had any new lesions in a long time," Yassette says.

Putting on a Positive Spin

Since her diagnosis, Yassette finished her bachelor's degree with the help of a friend who drove her to class when MS affected her vision. She recently added a master's degree to her list of accomplishments. Her sons are now 20, 21, and 26, and she has two granddaughters through her stepson. She enjoys craft projects and making treats for family and friends. And while she experiences occasional fatigue, migraines, and pain, she keeps looking forward.

"Even though some people would say I got the short end of the stick, I've always tried to stay positive," she explains. "That's the first battle. If you give in to all those negative thoughts, you're done. Always stay positive."



Understanding Your Insurance Benefits

Juliana Avalo, *Administrative Director, MS Center*

Understanding your insurance benefits can help you avoid unexpected costs and make your healthcare experience smoother. Every insurance plan is different, so it is important to review your coverage at the beginning of each year, especially since many benefits reset annually.

Key Terms to Know

- A **deductible** is the amount you must pay before insurance begins covering services.
- **Copays** are fixed amounts due at the time of a visit.
- **Coinsurance** is a percentage of the cost you may owe after the deductible is met.
- Your **out-of-pocket maximum** is the highest amount you are responsible for paying during the plan year.

Patients should also confirm whether providers, laboratories, imaging centers, and infusion services are considered in-network, as out-of-network services often result in higher costs. Prior authorizations may also be required for certain medications, procedures, or imaging studies, and approval times can vary by insurance carrier.

We encourage all patients to review their insurance cards, understand referral requirements, and contact their insurance provider with any coverage questions before appointments or treatments. Being informed about your benefits helps reduce delays, improve access to care, and enable our team to better coordinate your healthcare needs.

Always feel free to contact our office at 201-837-0727 for assistance or email mscenter@holyname.org.

What is Foot Drop, and Can Functional Electrical Stimulation Help?

Amy Shames, PT - *Home Care Rehabilitation Coordinator*

Foot drop is a common symptom in patients with neurological conditions like MS. When muscles in the foot or ankle become weakened, lifting the front of the foot or toes can become more difficult, causing the foot to drag. Foot drop can make walking more difficult and can increase the risk of trips and falls. Fortunately, there are some interventions — including functional electrical stimulation (FES) — that can help.

Is FES Right for You?

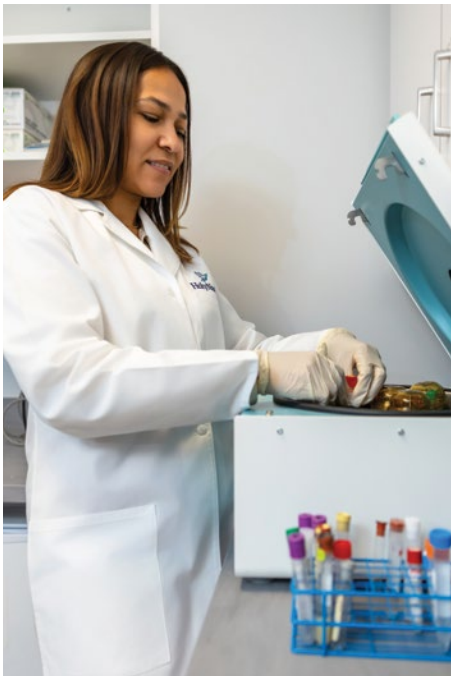
A typical physical therapy program may include stretching and strengthening exercises, balance training, gait training, and fall prevention. The physical therapist may also use FES. Through electrodes on the skin, FES uses electrical impulses to stimulate and strengthen weak muscles. The physical therapist may also recommend an external device to assist with foot drop.

- **Ankle-foot orthosis** is a lightweight brace made of carbon fiber or plastic that can be custom-made by an orthotist or purchased off the shelf. The brace fits inside the shoe, supporting the ankle and positioning the foot so users can more easily lift their toes when walking. Orthoses are easy to use and are typically covered by most insurance plans with documentation from the patient's physician.
- The **Cionic Neural Sleeve**™ is a soft fabric brace similar to a piece of clothing that fits snugly over the leg. Electrodes inside the sleeve deliver FES to the leg muscles as you walk. It can help improve strength, reduce foot drop, and improve walking ability. The Veterans Administration covers the sleeve, and Cionic is working to obtain approval from other insurance companies.
- The **Bioness 300 Go Lower Cuff** is a small cuff worn below the knee. It uses FES to help weak muscles lift the foot and leg while you walk. Because it helps lift the weaker foot, patients walk more safely and efficiently. Advocates at Bioness can help patients with payment options, including insurance coverage.

If you have foot drop, a neurologist can refer you for physical therapy. There, a physical therapist will evaluate your weaknesses and deficits to design an exercise program specific to your needs. To learn more, visit holyname.org/PhysicalTherapy.

Relapsing MS Patients on Ocrevus May Benefit from New Clinical Trial

Diome Kramer, MBA, BSN, RN - *Clinical Research Nurse Coordinator, Institute for Clinical Research at Holy Name*



If you have relapsing MS (RMS) or secondary progressive MS (SPMS), you may want to consider participating in a new clinical trial at Holy Name.

Now open, the CLOU064C12306 Study is researching if people with RMS currently on the IV drug ocrelizumab (Ocrevus) do as well if they switch to remibrutinib (RHAPSIDO), a daily pill.

- **Who may join**: Adults aged 40 to 70 with a confirmed diagnosis of RMS who have been treated with ocrelizumab at the usual dose and are neurologically stable within 30 days before joining. Doctors must agree that switching to remibrutinib is reasonable for the person. People with primary progressive MS or certain other health problems are not eligible.
- **How the study works**: About 360 people will take part. The study's core phase lasts up to 24 months. Participants who finish may join an extension phase for up to an additional 24 months.
- **What to expect if you join**: You will be randomly assigned to either switch to the daily pill or keep getting ocrelizumab. Because the study is open-label, you and your care team will know which treatment you get. The study will include clinic visits, MRI scans, and safety checks to watch for side effects and disease activity.

If you're thinking about joining, your doctor can help you weigh the possible benefits and risks. Email dkramer@holyname.org for more information.

Important Updates You Should Know

We want to keep you informed about several important updates and reminders that will help ensure a smooth visit and continued access to our programs and services.

Electronic Medical Record Transition

Thank you for your patience as our practice continues transitioning to a new electronic medical record (EMR) system. This upgrade is designed to enhance your care experience and improve communication with our team. During this transition, please allow extra time for your appointments and plan to arrive at least 15 minutes early to ensure a smooth check-in process.

For faster check-in, please complete the enrollment text/email prior to your appointment.

Learning Opportunities & Support

- **Monthly Lunch and Learn -** Open to anyone impacted by MS and their loved ones, this series is an opportunity to discuss topics related to living with MS. Held on the first Thursday of each month, and hosted by Dana Jones, NP-C.
- **Monthly Mindfulness Mondays -** In this engaging 30-minute session held on the third Monday of the month, we explore the transformative practice of mindfulness. Hosted by Andrea Greene.

We look forward to seeing you at our next event!

Stay Connected with Us

Don't miss out on updates about new services, health programs, seasonal clinics, and community events. Please make sure we have your current email address, and add us to your contact list so our messages don't go to spam. Staying connected ensures you'll always be informed about the latest opportunities to support your health and wellness.

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