

# MS Links

FALL-WINTER 2024

HolyName 

The Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center

## Happy Fall!

I have always loved autumn, fall foliage, and the increased energy that we seem to feel this time of year. We have all been looking forward to cooler temperatures considering how hot and humid the summer was. For people with MS, the heat can often lead to an increase in fatigue, difficulty focusing and concentrating, and even a slower gait. As we enter the fall, I remind everyone to keep up to date with flu shots and other immunizations to help everyone stay healthy. This fall will also bring updated diagnostic criteria for MS, so stay tuned for that.



This past May, I was fortunate to attend the Consortium of Multiple Sclerosis Centers' annual meeting in Nashville. There was a great deal of optimism about how far we have come since 1993, when the first effective treatment for MS became available; now, we have over 20 disease-modifying therapies. In this newsletter we will hear from two patients who have had MS for many years and continue to do well.

The meeting featured presentations on the importance of early detection and how we are now recognizing an MS "prodrome," which can predate the first clinical episode that leads to diagnosis. In fact, we often do see MRI changes that show brain tissue damage before someone receives a diagnosis. Artificial intelligence may help us not only detect these early changes but also help radiologists better monitor how lesions evolve.

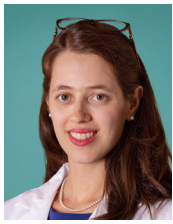
Another discussion focused on the challenges of aging with MS, and teasing out which symptoms are due to aging and which are due to MS. Some of you have been involved in the aging study conducted at Albert Einstein College of Medicine as well as various Kessler cognitive studies, which help us identify these differences and develop techniques to improve cognition and balance. Exercise is still the best medicine in this regard, as well as proper nutrition. Little changes can provide long-lasting benefits.

I hope you enjoy the contents of this newsletter. Please let us know your comments and anything else you would like to read about. All of us at the Holy Name MS Center are here to provide the best care possible and keep you doing well!

Best wishes,

*Mary Ann Picone, MD*

**Mary Ann Picone, MD**  
Medical Director, MS Center



## ASK THE EXPERT

**Asya Wallach MD**  
Neurologist, MS Center

### Do My Periods Affect My MS? And Does My MS Affect My Periods?

The menstrual cycle is a complicated interplay of rising and decreasing levels of estrogen and progesterone. In retrospective studies, up to 82% of women with MS have described premenstrual MS symptoms worsening around three days before the start of menstruation. Many cite prominent fatigue as well as other symptoms unique to the individual woman. Over-the-counter aspirin can help ameliorate these symptoms, which typically resolve by the time menstruation begins. If the symptoms are sufficiently bothersome, you may want to discuss birth control with your gynecologist.

Sometimes, patients will ask me if their MS or their MS medications influence their menstrual cycles. Several studies have attempted to answer this question, and the results are inconsistent: It may be that women with MS become more likely to develop irregular cycles or less frequent cycles after being diagnosed with MS. Beta interferons (e.g. Rebif®, Betaseron®, Avonex®, Plegridy®) may lead to spotting and light periods while long-term exposure to steroids may lead to irregular, heavy periods.



## Get Ready for Open Enrollment

Open enrollment is a set period when you can make changes to your health insurance plan. This is a good time to review your existing coverage and compare it with other available options. You should consider any changes in your health, financial situation, or anticipated needs for the coming year to help you make your decision. Here are some key things to keep in mind:

**Timing:** Open enrollment happens during a specific window each year. For employer-sponsored plans, it usually occurs in the fall. Government marketplaces like the Affordable Care Act (ACA) have their own set period this year from November 1, 2024 to January 15, 2025. The Medicare Annual Election Period runs from October 15 to December 7 every year.

**Costs:** Consider not only monthly premiums but also deductibles, co-pays, co-insurance, and out-of-pocket maximums. A lower premium may mean a higher cost when you need care.

**Benefit Changes:** Insurance providers often make changes to plan benefits, network providers, covered medications, and agreement terms. Review these changes to ensure your preferred doctors, medications, and services are still covered.

Understanding these aspects can help you make informed decisions about your healthcare coverage during open enrollment.



At the MS Center, our mission is to be a comprehensive resource for all your healthcare needs, ensuring seamless access to quality care. Please feel free to reach out to us for guidance.

**Juliana Avalo** Administrative Director, MS Center  
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## LUNCH & LEARN

We hope you've been enjoying the monthly Lunch and Learn sessions designed for you and your families to better understand MS and manage common symptoms. Stay tuned for more informative sessions this year! We welcome your feedback and topic suggestions at [mcenter@holynome.org](mailto:mcenter@holynome.org). Thank you for participating!



# People with MS in the Workplace

This summer, there were two back-to-back articles published in prestigious MS scientific journals about people with MS in the workplace.

One article, published in the *Multiple Sclerosis Journal*, looked at 755 patients with MS across various Italian MS centers. Patients at every stage of MS were studied and all or many were affected by the disease for an average of nearly 35 years. Only half of them were employed, despite 78% having at least a high school diploma. Of the 460 patients in the study who filled out a questionnaire to assess for job difficulties, 19% reported opting for early retirement (before age 65). These people tended to be more likely to have additional comorbidities beyond MS, including high blood pressure (20%), depression (17%), anxiety (12.5%), other autoimmune diseases (10%), and high cholesterol (8%). People with these additional

conditions were also more likely to report “some” or “extreme” problems on multiple quality-of-life metrics such as mobility, difficulty with usual activities, and pain. This study underscores the importance of maintaining a relationship with your primary care physician and actively practicing preventive medicine, making time for exercise, cancer screenings, and vaccinations against preventable diseases.

Another article, published in *Multiple Sclerosis and Related Disorders*, explored workplace factors that influence employment outcomes for people with MS. The research took place in Australia with the hope of guiding ergonomic strategies that keep more people with MS in the workforce. Of the 1,577 people with MS who responded to the survey, 662 were employed, but 128 felt they were at risk of becoming unemployed. Of

the 915 unemployed, half believed they were unemployed due to their MS, citing inflexible work conditions, transportation issues, architectural barriers, requirements to stand for long periods of time, and difficult-to-use equipment.

If you feel that you are at risk for becoming unemployed, please talk to your MS team or your manager. Many employers are willing to work with you by offering modifications such as cooling units, work-from-home days, and flexible hours. Prior studies have shown that continued employment is associated with better quality of life and mood of the individual, and also has societal benefits. We want to support you as much as possible! If employment is definitely not possible, we can support you in applying for disability. The National MS Society Employment Guide is a great resource to review for more information.

-Asya Wallach, MD



## ASK THE EXPERT

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

### How Does MS Impact Cognitive Function?

MS can have a significant impact on cognitive function. Up to 50% of patients may experience mild to severe cognitive changes, which can affect daily functioning. Common areas impacted include:

- short-term memory: problems retaining new information
- attention and concentration: challenges with focusing on tasks or maintaining attention for extended periods
- processing speed: delays in the ability to think through information or respond to questions
- problem-solving: difficulties in planning, organizing, and completing tasks
- language: challenges with word-finding or organizing thoughts verbally

Neuropsychological testing can help assess the extent of cognitive impairment. Healthcare professionals can use these assessments to tailor treatment plans. Sometimes, cognitive rehabilitation is recommended to improve cognitive function. Lifestyle modifications, such as regular exercise, adequate sleep, a healthy diet, and stress management, can also support cognitive health.

While cognitive function can be affected by MS, many strategies and resources are available to help people manage these challenges effectively. Regular communication with your healthcare team can provide ongoing support and adaptation to any changing needs.

### Kent Manno: Managing Multiple Sclerosis through Fishing Trips

Living with MS doesn't have to stop you from enjoying your favorite pastimes. Just ask 63-year-old Kent Manno.

Despite MS limiting the use of his legs, Kent has found ways to keep fishing, an activity he loves dearly. Having MS creates daily challenges, but Kent has found options to keep the fishing rod in hand and the joy alive. His story is a testament to resilience.



"MS doesn't have to slow you down or stop your days of fishing or enjoying a boat trip with your friends and family," he said. "The key is to find ways to continue doing what you love without compromising health, safety, or comfort."

Dr. Mary Ann Picone, Kent's physician and the Medical Director of Holy Name's MS Center, knows how hard it can be for people like Kent to participate in the activities they love. "Patients with MS are faced with a variety of challenges," she said. "It is often difficult to maintain a fitness program or other pastimes when you are also dealing with fatigue, which can be debilitating. Coordination problems, muscle stiffness, and weakness can also increase the risk for falls and contribute to feelings of anxiety and depression."

But Dr. Picone has encouraging advice: "I tell all my patients that there are modifications to help you look and feel your best in the face of some of these difficulties."

He still relishes being outdoors and fishing and now just sticks to the shorelines of rivers, ponds, and lakes. After facing a heart attack and now MS, Kent can attest to the positive power of fishing on one's psyche. "Fishing can be a way to handle stress-related life events," he said.

Kent is grateful to keep doing what he loves. For him, the thrill lies in the challenge, not just in catching fish. It's about the quality time spent outside with loved ones and the life lessons he learns along the way.

### Dr. Picone Quoted in U.S. News & World Report

Dr. Mary Ann Picone, Medical Director of the MS Center at Holy Name, was recently tapped by *U.S. News & World Report* for her expert commentary on spinal stenosis, a condition that affects some people with MS. Here's everything you need to know.



# Closing the Gap: Holy Name's Commitment to Inclusive, Accessible, and Compassionate Care

Delivering high-quality healthcare isn't one-size-fits-all. It doesn't always meet diverse needs, especially in historically disadvantaged communities that encounter barriers to care.



Health disparities are negative differences in health outcomes due to social, economic, and environmental factors, affecting even neurologic disorders. These disparities are often attributed to determinants like race, culture, health literacy, and biological factors.

As a result, policies and programs aimed at reducing health disparities by focusing on lifestyle changes and natural bodily functions often overlook the underlying social and economic factors that contribute to these disparities.

People with chronic illnesses like MS face significant challenges, including high healthcare costs, productivity loss, home modifications, long-distance travel, relationship issues, and reduced community involvement. Responses to these challenges can vary, and stigma, especially for those in disadvantaged groups, can exacerbate these difficulties. These stressors can manifest in the body in ailments such as cardiovascular disease, mental health challenges, and increased blood pressure. As expected, these issues can negatively impact MS. It is crucial for those living with MS to address these factors with a multidisciplinary team to overcome these obstacles.

At Holy Name, we understand the unique needs of our community and know that our patients come from different backgrounds. We continuously educate ourselves as MS providers to ensure we have the appropriate tools and resources to offer the best care possible. We strive to meet the diverse needs of all patients from all backgrounds, and we will continue to provide and expand on resources we offer, such as no-cost transportation, free drug programs offered by pharmaceutical companies, mental health services, and financial assistance to individuals in need.

This is our pledge to you, our patients.

***-Dana Jones, MSN, AGPC NP-C, CCRN***



## REMEMBERING June Halper

It is with sadness that I share the recent passing of June Halper, who founded the MS Center at Holy Name in 1985. At that time, we did not have our current therapies to treat MS and patients experienced greater levels of disability.

June was a pioneer in developing comprehensive care models for MS. She was a tireless advocate for patients and their families who was dedicated to improving their lives. She was also committed to advancing education and served as the Executive Director of the Consortium of MS Centers, where she established certification exams for standards of care.

I first met June in 1993, when she needed a medical director for what was then the Gimbel MS Center. I had just finished my residency and fellowship at UMDNJ and was pregnant with my first child. June was my mentor and guide; I learned more from her about the physical and emotional care of patients and their families than I ever could from any textbook. She would not rest — or let others rest! — if a patient needed help. I recall getting a phone call from her regarding a patient in need as I was in the recovery room after delivery. She pushed all those who came in contact with her to do their best.

June was a champion for improving MS care and patient outcomes. Many longstanding Holy Name MS Center patients will remember her energy, passion, humor, and endless compassion. She was truly a force of nature. It is said that life is measured by the good that you do and the lives that you touch. June went above and beyond. She will be missed by many, but most of all, I will miss her as my dear friend.

*Mary Ann Picone, MD*



## ASK THE EXPERT

**Mary Ann Picone MD**  
*Medical Director, MS Center*

### How Can I Tell If I Am Having a Relapse?

Patients ask this question often, especially when first diagnosed. A good rule of thumb is that a relapse (sometimes called a flare-up, attack, or exacerbation) usually lasts at least 24 hours without fever or infection. For example — especially considering how hot it was this summer — if you are exposed to high temperatures, you may notice an increase in symptoms such as tingling or weakness, but if you cool down and symptoms improve, that is not a relapse. If you are exercising and notice an increase in body temperature or have symptoms that resolve with rest, that is not a relapse.

Sometimes it is harder to tell. If you have an infection, like a urinary tract infection or upper respiratory infection (especially with fever), you can have worsening symptoms, but these should improve once the infection is treated. In fact, sometimes patients may not realize they have a urinary tract infection and worsening symptoms can be the clue. If symptoms persist after treatment, tell your doctor because it may indicate a true relapse. Also, for example, if you wake up and notice tingling in your hand and it improves within a few minutes of movement, that is not a relapse — but if it persists or worsens over the course of the day, then you should notify us.

Steroids are still the treatment of choice in the event of a flare-up because they help decrease the inflammation that is present. We may also ask you to have an MRI done to see if there has been any new MS disease activity.

# Damian Cremisio

## 25 years of successfully managing MS

When he was first diagnosed with MS, Damian thought it would affect his ability to play and perform the saxophone. Over 25 years later, he's still making music. He credits Holy Name's Dr. Mary Ann Picone, Medical Director of the MS Center, for keeping him well.



Damian Cremisio was only 35 when he was diagnosed with multiple sclerosis in 1999. He was immediately worried about his future as a musician. "My idea of MS at that time was that you're heading straight to a wheelchair and then completely debilitated," Damian, now 60, said.

Damian became concerned about his health when he started walking with a limp. He'd had a large, benign tumor removed from his hip in his late 20s, so he thought that perhaps some scar tissue had developed. He also noticed that he began to feel dizzy when he was hot, either from being out in the sun or performing under strong stage lights. His primary care physician sent him to an ear, nose, and throat doctor who suspected a brain tumor and referred him to a neurologist. A spinal tap showed that what was actually causing him symptoms was MS.

Losing mobility would affect Damian's ability to play his saxophone and perform, impacting both his livelihood and greatest passions. He opened up about this to a doctor who was not very sympathetic, telling Damian: "You're young enough, you'll learn something."

"I have a much better doctor now," chuckles Damian, speaking about his current neurologist, Dr. Mary Ann Picone. A fellow of the American Academy of Neurology, Dr. Picone has been the Medical Director of the MS Center at Holy Name Medical Center since 1993.

Damian has been seeing Dr. Picone since he moved to New Jersey over 15 years ago. He's lived in various parts

of the country and seen multiple doctors in the years since his diagnosis, but he hasn't had the same level of trust with any other physician. Previous neurologists didn't appear to have the same level of concern and care that Damian appreciates about Dr. Picone.

"I know I can email her at any moment and I'll get a reply that day, if not within the hour," Damian said. That open line of communication alleviates some of the stress that can come with managing MS. He also appreciates the kindness he receives from everyone he encounters at Holy Name.

"I'm a patient, but they don't treat me like I'm infirm," Damian said. This level of care is what makes the long drive from where he lives in Asbury Park to Holy Name worth it.

In the years since his diagnosis, Damian hasn't seen much progression in his symptoms, despite having relapsing-remitting MS. He needs to be careful not to overheat and his limp is worse when he's tired, but he is grateful that he has never lost anything due to MS beyond his ability to run. He's still able to do the things he loves the most, like performing and traveling with his wife. Damian even wrote a song called "Believe" about living with MS, which he performs with his band, Damian and the DCQ. Believing, he said, is what has helped him live a full life with MS.

"Here I am at 60 years old, still working as a musician," Damian said. "I have my bad days and my good days, but [MS] hasn't stopped me from doing anything."



The Alfiero & Lucia Palestroni Foundation  
Multiple Sclerosis Center

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