

MS Links

MULTIPLE SCLEROSIS



EXPANDING OUR MS CENTER

Mary Ann Picone, MD

Medical Director, MS Center

This past year we received funding for a study we called Prescription for Wellness, which incorporates an individualized exercise program, nutrition counseling, sleep evaluation, and behavioral therapy at the Holy Name Fitness Center in Oradell. We were able to offer the program to 20 patients and are looking for ways to expand it.

Exercise of any kind is key to helping to promote neural repair and improving cognition and fatigue. Even if you may think you are too tired to exercise, it often makes you feel more awake — just the opposite!

News from ECTRIMS

GFAP, NFL, PIRA, BTKI: These initials may seem like a jumbled word salad, but at the recent ECTRIMS international MS meeting in Milan this past October, they were the hot topic of presentations.

GFAP: GFAP stands for “glial fibrillary acidic protein.” This is a biomarker for myelin and axonal loss in the normal-appearing white matter in MS. It has potential for helping us better track, and possibly predict, MS disease progression. Clinical trials are utilizing GFAP to assess the impact of therapies on disease progression. GFAP can be detected by a simple blood test.

NFL: Neurofilament light protein (NfL), which Dr. Wallach elaborates on in this newsletter, is another biomarker that can help us assess inflammation within the central nervous system. We presented a poster on results of some of our MS Center data at the ECTRIMS meeting.

PIRA: PIRA stands for “progression independent of relapses.” This can start early after diagnosis and may be the main reason why we may not always see changes on MRI or clinical relapse, but there can still be some progression of disease activity noted in walking difficulty or worsening of fatigue or cognition. It is related to compartmentalized inflammation in the central nervous system.

Welcome Spring!
By this time of
the year most
of us are looking
forward to longer
days and more
time outdoors.



ASK THE EXPERT



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

Can I get pregnant if I have MS?

Multiple sclerosis does not impact fertility or a woman's ability to conceive. Women with MS can generally have successful pregnancies, but the influence of MS on pregnancy varies among individuals. Routine follow-ups with neurologists and obstetricians is crucial for managing the condition and ensuring a healthy pregnancy.

The impact of MS on pregnancy depends on disease activity; some women experience symptom reduction during pregnancy, particularly in the second and third trimesters. However, there is an elevated risk of relapse in the postpartum period. Medication management is essential, and adjustments to disease-modifying therapies (DMTs) may be necessary during pregnancy due to potential risks to the fetus.

Will my baby get MS?

Multiple sclerosis has a multifaceted origin involving both genetic and environmental factors. Although MS is not directly inherited through a single gene, there is evidence supporting a genetic influence. People with a first-degree relative (parent, sibling, or child) affected by MS have a slightly increased risk of developing the condition compared to the general population. However, the absolute risk remains relatively low, and the majority of individuals with a close relative with MS do not develop the disease themselves.

EXPANDING OUR MS CENTER

Continued from page 1



BTKI: BTKI stands for "bruton tyrosine kinase inhibitors." Currently being studied in clinical trials, these are oral therapies that are designed to directly modulate the functions of both B cells and myeloid cells (including microglia and macrophages) in the CNS. They offer a novel mechanism of action to target both inflammatory and degenerative processes of MS. The goal of future therapies in MS is to better target the degenerative aspect of the disease. Although

one early trial did not meet its desired outcome, several others are still in late-phase studies and we await their results this year.

There were also many presentations at the meeting on the benefits of anti-CD20 therapies such as Ocrevus® and the recently approved Briumvi®. The earlier MS is recognized and treated, the better patients do. Our goal is to keep you as stable as possible. These are highly effective therapies and have made significant impacts in the lives of patients.

This year, we were very fortunate to expand our MS Infusion Suite for the comfort of our patients and their caregivers. Many patients have already been infused in the new space and the feedback has been very positive. We also expanded our neuropsychological and social work services both for evaluations and counseling. You will hear more from one of our neuropsychologists, Dr. Jeffrey Portnoy, in this newsletter. In addition, we recently welcomed a psychiatrist, Dr. Leonid Begun, who is able to see patients in his Teaneck office.

Over the past year, the physical therapy department has expanded to provide more opportunities for evaluation and treatment not only in physical therapy but also vestibular and occupational therapy. We also offer speech and language services and pelvic floor rehabilitation exercises for patients with overactive bladders. Group exercise classes have begun again and we are opening them to more people to allow for greater accessibility for all.

As always, all of us at the Holy Name MS Center are here for you. Stay positive, stay active, and let us know how we can better assist you!



NFL MARKERS: A POTENTIAL MVP EMERGES THAT MAY HELP FLAG INCOMING FLARE-UPS

Asya Wallach, MD
Neurologist, MS Center

As a leader in MS care, we continue to participate in new diagnostics and treatments for the condition. Over the past year, you might have noticed a new measurement in your bloodwork: NfL. Aside from the National Football League, NfL also stands for neurofilament light chain, a section of a protein found in neurons.

When neurons are damaged, NfL will leak out. Originally, this biomarker was identified in the spinal fluid, but now, research has shown that we can reliably measure it in blood as well. In patients with MS, an elevated NfL may indicate that new

inflammatory MS activity is about to occur, is occurring, or is resolving. An elevated NfL number may influence your neurologist to consider doing an earlier MRI with gadolinium contrast. Starting a disease-modifying treatment or switching to a higher efficacy treatment may also be warranted.

We realize we need to be cautious when interpreting the results of elevated NfL as this test is not specific to MS. This biomarker may be elevated due to nervous system damage from other causes, including infection, trauma, and dementia in the central nervous system. It could also be elevated due to nerve damage outside of the central nervous system (e.g. peripheral neuropathy), kidney disease, being underweight, and smoking.

Keeping in mind the previously listed caveats, a potential future use of NfL may be in determining MS stability after medication discontinuation.

In October 2023, our work related to NfL measurements was recognized by international specialists when it was presented at ECTRIMS, an international MS conference in Milan.

We're looking forward to learning more about NfL and incorporating other biomarkers into our practice as they become available, so we can continue to provide the best care for our patients.



ALL ABOUT NEUROPSYCHOLOGY AT HOLY NAME

Jeffrey Portnoy, MD

Neuropsychologist, MS Center



Dr. Jeffrey Portnoy is a clinical neuropsychologist who specializes in caring for adults with cognitive and behavioral changes related to neurological and psychiatric disorders like MS. Neurological conditions are frequently associated with cognitive changes; between

40% and 65% of MS patients are thought to have difficulty with memory, word-finding, comprehension, or other thinking abilities. Mental health conditions are also common in this population, with nearly half of MS patients experiencing clinically significant depression or anxiety during their lifetime. Left untreated, cognitive and emotional challenges can greatly affect patients' social functioning, ability to maintain employment, and overall quality of life.

The neuropsychologists at Holy Name offer comprehensive evaluations, during which the patient undergoes a series of tests

used to map the capacities of different structures and pathways in the brain. The results provide valuable information about how MS has affected a patient's thinking abilities, whether other medical conditions are affecting brain health, and if the patient's symptoms may be partially or fully reversible. Findings also reveal a personalized baseline, which allows for precise monitoring of each patient's neurocognitive health over time.

Dr. Portnoy also provides cognitive rehabilitation to MS patients. Unlike similar programs that teach compensatory strategies for cognitive problems, the rehabilitation services at Holy Name are geared toward modifying the reversible factors that can provoke or worsen cognitive deficits. Each patient's neuropsychological exam results help guide effective treatment of issues that can interfere with cognitive performance, such as disordered sleep and emotional difficulties. The goal is to help patients to feel as much like their old selves as possible and attain significant improvement in their quality of life.

PRESCRIPTION FOR WELLNESS

Asya Wallach, MD

Neurologist, MS Center



Whenever I meet a newly diagnosed MS patient, our conversation undoubtedly turns to, "What can I do, Doctor?" I see this question in a positive light, because it underlines that we don't have to take this disease lying down. People with MS can play an active role in their treatment. For example, we've

known for years that a healthy diet and exercise routine are beneficial for people with conditions such as heart disease, diabetes, depression, and osteoporosis. There is also significant evidence that adopting a healthy lifestyle is very beneficial to people with MS.

Here at Holy Name, we have created a multidisciplinary pilot program called "Prescription for Wellness." It unites the MS Center, HNH Fitness Center, registered dietitians, sleep coaches, and the neuropsychology team to develop and evaluate

an intensive 3-month exercise program for patients. The program includes two 30-minute supervised personal exercise sessions per week, a nutrition consultation, sleep coaching, and motivational visits. Patients receive a Fitbit to track their behaviors as well as a complimentary membership to HNH Fitness. I presented on the program at last year's Consortium of MS Centers conference in Denver, Colorado. Research is ongoing, and results are expected later this year.

While the research continues, I implore you to not sit back: Put on your sneakers, get a bottle of water, and start moving! The goal is to challenge yourself a little — maybe break a sweat — to build muscle and improve bone health and coordination. I suggest my patients avoid exercise that is so intense they are out of commission for hours or days afterwards.

This program is supported by generous grants from The O'Shea Foundation and Bristol Myers Squibb.



KEY REASONS WHY YOU SHOULD KEEP YOUR APPOINTMENTS

Juliana Avalo

Administrative Director, MS Center

An appointment gives you the opportunity to express your concerns and share updates with your provider, who will then perform a physical exam. Then, the two of you can work together to establish or refine a plan for treatment. Keeping your scheduled appointments also provides:

1. **Continuity of care:** Regular appointments help establish a consistent relationship with your doctor. This enables them to understand your medical history, track your health progress, and provide appropriate and personalized care.
2. **Early detection and prevention:** Regular check-ups allow your doctor to monitor your health status and identify any potential health issues at an early stage. Early detection often leads to more effective treatment and better outcomes.
3. **Medication management:** Doctors can monitor your response to medications, adjust dosages, or switch medications if necessary. This helps ensure that your medications are managing your health conditions and not causing adverse effects.
4. **Emergency preparedness:** Your doctor will have a better understanding of your health status if they see you regularly. This can be crucial in the event of a medical emergency, as they'll have accurate and up-to-date information to guide your care.

5. **Trust-building:** Consistently attending appointments builds trust between you and your doctor. This can facilitate open communication, making it more likely that you'll share important health information and follow medical advice.

Most importantly, with a chronic disease like MS, consistent appointments are crucial for managing your condition and adjusting treatment plans as needed.

Remember, skipping appointments can lead to missed opportunities for early intervention and effective treatment. If you need to reschedule an appointment, it's important to do so as soon as possible by calling the office at 201-837-0727 or emailing mscenter@holyname.org. Open communication with your health-care provider is key to maintaining your health and well-being.





STRESSED? GIVE MINDFULNESS A TRY

Andrea Greene, LCSW

Clinical Social Worker, MS Center



Andrea Greene, LCSW, joined Holy Name in 2021 and has been offering short-term (12 week) psychotherapy to patients who are experiencing difficulty adjusting to a new MS diagnosis, a new stage of progression, or limitations. Here, she shares how mindfulness can help people living with MS.

When we talk about MS, it is difficult to ignore the link between stress and MS symptoms. There are many studies on the importance of stress management in people with MS.

Research from Johns Hopkins Medicine suggests that depression and anxiety can occur three times more often in people with MS than in the general population. In order to address symptoms of depression or anxiety, it is important to first notice them. Mindfulness exercises can teach people how to regulate their emotions and give voice to their experiences. They can also help with stress relief and even pain tolerance.

Mindfulness teaches us how to be in the moment, without any judgment or evaluation. This creates a distance between the stressor and the opportunity to respond. Here is where we find our power.

In his book *Man's Search for Meaning*, Austrian psychiatrist and Holocaust survivor Viktor Frankl writes, "Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom."

This year, we've implemented monthly mindfulness sessions for our patients. Mindful Mondays typically take place the first Monday of the month from 12:30 to 1:00 p.m. You are invited to join us every month; look out for emails from Holy Name on how to register.

This year, we also welcomed a social work intern, Margit Malacrida, who is a candidate for her Master's Degree in Counseling at Montclair State University. With her help, we've been able to start a short-term support group for caregivers. This group meets for seven sessions and moves in a cycle, so please contact us if you are interested in joining.

Having MS does not mean depression or anxiety disorders are inevitable. However, if you feel like you might need support, we are here to help you.

Andrea has 15 years of experience providing individual and group psychotherapy. In addition to working at the MS Center at Holy Name Medical Center, Andrea has a private practice in Teaneck. Outside of work, Andrea practices mindfulness to care for her three kids and new pup, Lily.



ASK THE EXPERT

Asya Wallach, MD
Neurologist, MS Center

Can I stop my MS medication?

This is a very hot topic right now, with multiple studies attempting to answer this very question. The DISCO-MS study, which recently published results, involved adults ages 55 and above. These participants were already using FDA-approved medications for MS regularly and had been clinically stable for at least five years. The participants were split into two groups; one group was asked to discontinue their MS disease-modifying treatment and the other group was asked to keep it going. There were 259 people who completed this study, most of whom were taking platform injectable therapy (interferons or glatiramer), and yet, the authors couldn't statistically determine if continuing or not continuing would be the better option. While there was a numerical difference in the amount of participants in the "discontinue" group versus the "continue treatment" group who suffered a clinical relapse (3 vs. 1) and those who suffered a new MRI lesion (14 vs. 5), there was no difference between the two groups in terms of disease progression or performance on cognitive testing.

Other large trials that are still underway include DOT-MS, which asks a similar question to DISCO-MS but looks at all adults regardless of age, and STOP-I-SEP, for patients over 50 with stable secondary progressive MS.

In my practice, I always strive to balance safety, efficacy, and patient preference. Sometimes, this means suggesting that we stop a medication due to the emergence of some safety concerns. Or it could be the opposite and we continue the medication if a patient has been tolerating it very well, to reduce the chance of a relapse or disease progression. Many times, we may choose to de-escalate disease-modifying treatment rather than stop it altogether. This may mean decreasing the dosing frequency of an infusion medication, or switching from a high efficacy infusion to a pill or injection with a better safety profile.



I feel well. Do I even need to take my MS medication?

YES! Please don't stop your medication without talking to your doctor first! MS disease-modifying treatments are meant to be taken consistently as prescribed, not in response to how you feel. In the case of relapsing MS, we prescribe these medications to prevent new clinical relapses and MRI lesions from occurring. We also prescribe them to slow the progression

of the disease. We don't truly know how any one individual patient will do at the time of diagnosis, but we know on average, the quality of life of people with MS has drastically improved over the last quarter century

since these drugs have been developed. More people are living longer, staying employed, and walking for more years after diagnosis now than they used to.

If you have a hard time taking your MS medication, please talk to your doctor, as there are likely other options. Some people do well with daily or weekly medications. Others do better with monthly or biannual medications. Others really don't like the idea of being on medication indefinitely and switch to induction medications such as cladribine and alemtuzumab, which are taken for a short period of time but have very long lasting effects on the immune system.



AGING AND MS STUDY

Frederick W. Foley, PhD

Psychologist, MS Center



Very little is known about the aging brain in people with MS. Dr. Roee Holtzer of the Albert Einstein College of Medicine has partnered with the Holy Name MS Center on a National Institutes of Health-funded research project investigating cognitive

function, mobility, and falls in people with MS 60 and older. For this study, patients walk on an electronic mat while the frontal part of the brain's function is imaged in real time. People are also given a cognitive task to see how the brain responds to

both motor and cognitive demands. This project will help us learn more about the aging brain in people with MS, which may lead to better rehabilitation approaches for mobility and cognitive function. The MS Center is still recruiting for this study. If you would like more information, please contact Dr. Foley at f Foley@holyname.org.



ASK THE EXPERT

Mary Ann Picone, MD

Medical Director, MS Center

Will getting regular vaccines cause my MS to worsen?



Getting vaccinated plays an important role in preventing communicable illnesses, and the benefits of long-term preventive immunity outweigh risks associated with vaccines. The main concerns regarding immunizations and MS are if the immune system can tolerate the vaccine, and the potential for relapse in symptoms.

It is important to keep in mind that infections of any kind, whether viral or bacterial, and particularly those associated with fever, can worsen MS symptoms, so vaccinations can help in the prevention of pseudo-relapses.

A study on vaccines and MS that utilized a large European database did not show any increased relapse risk following vaccines that do not contain live viruses, such as those for tetanus and hepatitis B. Guidelines from the National MS Society and American Academy of Neurology do recommend inactivated vaccines, which also

include the flu, COVID-19, and shingles vaccines. Anyone who has gotten the flu knows how debilitating it can be.

Live-attenuated vaccines, such as those for measles, mumps, rubella, and varicella (the virus that causes chicken pox), contain a weakened version of a live virus. We usually recommend these vaccines be given prior to starting treatment if blood viral antibody levels are found to be low. An example of a live vaccine is the yellow fever vaccine, which fortunately is not generally recommended unless you are traveling to an area where there is high risk.

Patients who are on medications that can deplete B cells may have a decreased vaccine immune response, so we usually need to adjust the timing of their infusions. Interferon treatments and Copaxone® do not affect vaccine response. We have seen good vaccine responses in patients receiving most oral treatments and Tysabri®.

In general, people with MS should schedule vaccines approximately a week apart. For example, if you are getting the flu shot, wait a week before getting another vaccine to help minimize risk of any reaction. Staying well hydrated and taking Tylenol or Advil can reduce vaccine side effects.

Always speak with your doctor or nurse at the MS Center about your individual circumstances — your care team is here to help you understand which vaccines you may need and when.

RESEARCH UPDATE

Mary Ann Picone, MD

Medical Director, MS Center



Diana Naylor, MSN, RN, CCRP, is our new research coordinator, overseeing the clinical research team working on multiple sclerosis clinical trials.

The goal in MS research is to find new therapies that target cells in the central nervous system that may

help slow degeneration and promote repair. Another goal is to further our understanding of the disease and how we can better improve quality of life for all patients.

We continue to participate in collaboration with the Albert Einstein College of Medicine on evaluating aging in MS and the cognitive and gait changes involved. This may help us better understand what cognitive effects might be due to aging and narrow down what is due to MS. We also collaborate with the Kessler Institute for Rehabilitation on studies about exercise and its effects on improving cognition.

Our Prescription for Wellness pilot study, which began last year at the Holy Name Fitness Center, is a 12-week program incorporating exercise, nutrition, a sleep evaluation, and behavioral therapy. We hope to expand this study as we receive more funding.



In my welcome letter I mentioned BTK inhibitors as the new wave of therapies being studied in MS, both in relapsing and progressive disease. We are participating in clinical trials involving this class of oral medications that we are hopeful will offer added benefit in slowing disease progression.

We encourage patients who are interested in clinical research to reach out to either me, Dr. Wallach, or Dr. Jones. Many patients throughout the years have benefited from their involvement in our studies.

LUNCH AND LEARN

If you haven't participated in the **MS Center's virtual Lunch and Learn** series, please join us for our monthly interactive events. Dana Jones, an experienced nurse practitioner who specializes in MS care, hosts the series. The sessions focus on topics of interest related to living with MS and include guest speakers.

The events are open to anyone impacted by MS and their loved ones. They are typically held virtually one Thursday per month, from noon to 1 p.m. Registration is required. Keep an eye on your inbox for an email from the MS Center with dates and registration information.



2023 MS CENTER AWARDS DINNER

It is with much appreciation that the Holy Name Foundation thanks all who supported our 2023 MS Center Awards Dinner on November 16 at The Venetian in Garfield, NJ.

Holy Name MS Center patients and staff, health system leadership, donors, and friends enjoyed a fabulous evening together, during which we recognized two esteemed members of the MS community.



From left: Roy Putrino, RPh; Mary Ann Picone, MD; Lawrence R. Inserra, Jr.; Cathleen Davey

Dr. Mary Ann Picone, MD, Medical Director of the Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center, received the MS Center Distinguished Service Award on her 30th anniversary of providing exceptional care to Holy Name's MS patients.

Roy Putrino, RPh, Founder of Basic Home Infusion, was honored with the Lawrence R. Inserra Leadership Award for his efforts in advancing MS treatment delivery. This award recognizes individuals who have exhibited leadership in and commitment to the MS community.

Dr. Picone's vision of a one-stop MS resource has been realized at the MS Center, which offers diagnostic and treatment services, clinical trials, and a robust program of psychosocial and supportive care offerings.

All support from our events helps advance these essential services that greatly improve quality of life so that patients can work their jobs, enjoy their families, and pursue their dreams.

Your support helps us to continue providing compassionate, comprehensive care to people of all ages living with multiple sclerosis. Contributions also enable The Alfiero & Lucia Palestroni Foundation MS Center to attract top medical talent, equip them with the most advanced technology, and help fund clinical trials.



To make a gift to the MS Center please visit holyname.org/foundation or scan the QR code.

Thank you for your support!
The MS Center Staff



Dr. Picone and staff from the MS Center



SPRING FASHION SHOW FOR MS

Join us as Holy Name Celebrates our 2024 Spring Fashion Show for MS

Please join us at Holy Name's 24th Annual Spring Fashion Show for MS. This lovely afternoon event features a luncheon and auction, in addition to our celebrated fashion show featuring models from the Holy Name family of patients, staff, friends and supporters — all for the benefit of the **Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center**.

To register, visit www.HolyName.org/FashionShow

Sunday, April 21, 2024 | 11:30 am – 3:30 pm

Teaneck Marriott at Glenpointe | Teaneck, NJ

Master of Ceremonies

Chris Cimino, WPIX-TV Personality

Honorary Chairpersons

Lawrence R. Inserra, Jr., Chairman of the Board and CEO of Inserra Supermarkets, Inc.

Joseph M. Sanzari, Founder and President of Joseph M. Sanzari, Inc.

Chairperson

Susan Zurndorfer, Holy Name Foundation Board of Trustees Member

Fashions provided by





The Alfiero & Lucia Palestroni Foundation
Multiple Sclerosis Center

Holy Name Medical Center
718 Teaneck Road
Teaneck, New Jersey 07666
holyname.org/MSCenter



MS Links

MULTIPLE SCLEROSIS

SPRING 2024



HOLY NAME PHARMACARE

Holy Name now offers a full-service retail pharmacy for the public on-site in Teaneck. **Holy Name PharmaCare** operates like any free-standing pharmacy, filling 30- and 90-day prescriptions and offering select over-the-counter items. PharmaCare offers free, same-day home delivery to surrounding communities, as well as curbside pickup at the back entrance to the medical center.

PharmCare is open

Monday through Friday, 7:30 a.m. to 6:00 p.m.

Saturday, 9:00 a.m. to 3:00 p.m.

Contact PharmaCare at **201-530-7991** or
pharmacare@holyname.org