We Are Here for You!

Mary Ann Picone, MD
Medical Director, MS Center

Happy New Year!
If you’re wondering whether people with MS are more susceptible to COVID — read on. There’s some good news.

As you might know, Holy Name Medical Center was initially at New Jersey’s epicenter of the COVID outbreak and I was so impressed by Holy Name’s teamwork and response. Everyone at that time and continuing today, goes above and beyond to treat patients with the most advanced care and to keep everyone safe.

Throughout this pandemic, the The Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center has been open and ready to take care of patients. It is important to continue to take your MS therapies and do necessary monitoring blood work. Since your safety is our number one concern, we’ve implemented a number of precautions to help prevent the spread of COVID.

Early in the pandemic, we changed office visits, other than infusion therapies, to televisits. Now we use a mix of televisits and in-person, while maintaining social distancing by limiting the number of patients in the center. Most people wait in their cars, no one is allowed in the waiting room. Those getting infusion therapies are met by their nurse and personally brought into the infusion center. Everyone is screened for COVID symptoms prior to their visit, masks must be worn and temperatures checked before entering. All rooms and surfaces are disinfected between visits.

Most importantly, many are asking if MS patients have an increased risk from COVID. They are not, in general, immunocompromised, so unless there are other medical problems such as asthma, they are not at an increased risk either of contracting or recuperating from COVID. It is also recommended that patients continue their disease-modifying therapies because the risk of disease progression increases if medications are stopped.

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Neuromyelitis optica spectrum disorder, NMOSD for short, is a rare relapsing remitting disorder of the brain and spine. Historically, it was considered a subtype of MS, but it often leads to catastrophic attacks of blindness and weakness, with much worse chances for recovery than MS.

In 2004, the antibody responsible for this illness (in most cases), AQP4, was discovered by Dr. Vanda Lennon at the Mayo Clinic. Since then, NMOSD, which affects nearly 17,000 people in the U.S., has been transformed from a very rare diagnosis with no proven treatment and a very poor prognosis to a treatable condition with an improved prognosis. (See the article, Blind with 20/20 Vision.)

To date, five high quality, randomized, trials have been completed. The results support the ongoing use of two medications traditionally used by Holy Name MS Center neurologists to treat this condition. Three new medications were also studied and did so well that they were awarded FDA approval for the treatment of NMOSD. The three medications, in order of approval date, are briefly discussed below.

**Soliris** was tested in adults with NMOSD who had the AQP4 antibody. Patients received an infusion weekly for 4 weeks, followed by a larger infusion or placebo every other week. Patients were allowed to stay on their prior NMO treatment (as long as it wasn’t Rituxan). Only 3% of patients who got Soliris had a relapse verses 43% of those not on the study drug. This drug places patients at risk for meningococcal infection, therefore vaccination is required prior to starting treatment.

**Uplizna** was tested in adults with NMOSD. Most had the AQP4 antibody, but since about 10% of patients with NMOSD do not have this antibody, patients without it were also included. Some patients also had worse disability in this trial than in the Soliris trial. The medication was administered as two half doses by infusion, and then a full dose or a placebo six months later. At the conclusion of the study, 12% of Uplizna patients had another relapse, compared to 39% of the placebo group. This medication is similar to Rituxan but its effects on the immune system are a little bit broader.

**Enspryng** was tested in adults (and several children) with NMOSD, with and without the AQP4 antibody. Enrolled patients were slightly less disabled than in the other two trials. In one study, patients were only treated with Enspryng or a placebo; in another study, Enspryng was allowed to be combined with the patient’s pre-existing NMO treatment. Enspryng is administered under the skin every 2 weeks for the first month and then monthly. The results of these two studies found that Enspryng was very effective, similarly to Uplizna and Soliris. Only 11% of patients treated with Enspryng suffered a relapse compared to 34% who were treated with a placebo. The drug had better efficacy in patients who were positive for the AQP4 antibody. This drug is similar to Actemra, a rheumatoid arthritis drug that is used off label in NMO (and outperformed Imuran for NMO in a comparison trial also completed this year).

Given all of these recent advances in the field of NMO, 2019 – 2020 has been called the year of NMO! We are thrilled to share these and other advances with you. They would not be possible without brave patients agreeing to participate in clinical research trials.
Pipeline Medications

**Elezanumab** — is in trials currently. It’s being studied as both an immunomodulation therapy and a neuro-repair therapy.

**Ublituximab** — is a monthly rapid infusion that is engineered to be delivered faster than Rituxan and Ocrevus, without the infusion reactions. Phase 2 trials are completed, with results showing 74% of participants had no evidence of disease activity at 48 weeks.

**Ponesimod** — has finished Phase 2 trials, with three different doses. All showed significant reduction in new enhancing lesions and a 42% maximum in annualized relapse reduction. Ponesimod is also being studied in other trials as a combination therapy with dimethyl fumarate.

**Brutons Tyrosine Kinase Inhibitors (BTK)** — is a new class of medication that has not yet been used in MS. The mechanism of action (MOA), which means how it affects the specific target in a cell, is different from anything we have used in the past.

**Evobrutinib** — has completed Phase 2.

**SAR442168** — has completed Phase 2, with trials that included both relapsing remitting and primary progressive MS participants.

New Medications

**Kesimpta (Ofatumumab)** — is a monthly subcutaneous injection, released in September 2020. Clinical trials showed that in the first year 5 out of 10 patients achieved no disease activity followed by 9 out of 10 in the second year.

**Zeposia (Ozanimod)** — is a daily oral therapy released in June 2020. Clinical trials showed that 76% of patients were relapse free at year 2.

Stem Cell Therapy

Research on stem cell therapy continues. Autologous Hematopoietic Stem Cell Transplant (AHSCT) uses the patient’s own stem cells and is generally an early treatment option for those who have failed other treatments. An ongoing 6-year study shows that at year 4 and 5, only 5% of the 156 patients had disability worsening compared to 66% of patients treated with a disease modifying therapy, including Tysabri, Ocrevus, Lemtrada, or Rituxan. Despite this and other stem cells studies, we still don’t have enough data to conclude its efficacy as an MS treatment. We continue to caution patients about Stem Cell Tourism, seeking stem cell transplants abroad. A warning — a visiting male patient in Panama developed a tumor with someone else’s DNA in his spine after treatment.

**The Pandemic/Depression**

The coronavirus has produced depression/anxiety in many people. The MS population is 3 to 4 times more likely to experience depression and nearly 55% of MS patients will have depression throughout their disease. Depression may be a symptom of MS and not just a reaction to having the disease. If the pandemic has worsened your depression or anxiety, talk to your provider; we are here to help.

Stress Management

As we know, stress can play a role in MS. A 2012 study put 11 MS patients in a treatment or control group. The treatment group, given skills to better manage stress, had fewer brain lesions compared to the control group. However, new lesions were detected in the treatment group post therapy. It’s important — try to find ways to reduce your stress, including meditation, diaphragmatic breathing, yoga, getting enough sleep, reconnecting with loved ones, and taking breaks from social media.
Due to the COVID pandemic, we are now providing our neuropsychological assessments and counseling services virtually, over the internet.

Neuropsychological testing is important to detect possible cognitive changes in MS (e.g. changes in concentration, attention, memory, or problem-solving abilities). Cognitive changes occur in approximately 50% of people with MS. Although they tend to be mild or moderate — unlike Alzheimer’s Disease which causes severe cognitive losses — they can interfere with work or other valued activities.

This assessment is utilized to develop a rehabilitation plan for patients with cognitive changes to help improve their function. Neuropsychological assessments are important to document work-related cognitive disabilities.

We are also offering internet-based psychotherapy and counseling to our patients. Concerns we typically address include COVID stress, depression, anxiety, and adjustments to MS-related changes. We are also providing limited cognitive rehabilitation to some patients. For those we are not able to treat, we will evaluate the patient’s insurance to help them select providers that meet their needs.

Keep in mind, all of these services are offered free of charge to our patients.

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Dr. Fred Foley
Director of Neuropsychology
at Holy Name

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Dr. Picone — ACP Fellowship!

Congratulations to Dr. Mary Ann Picone for her elected fellowship with the American College of Physicians. The ACP Fellowship is a distinction awarded by fellow physicians who recognize the accomplishments and achievements of the recipient, both to medicine and the broader community. The entire staff of Holy Name is proud of Dr. Picone and this well-deserved recognition.
Keeping your immune system healthy is especially important during these tough times and the coming change of seasons. Considering the fact that we all need to consume food throughout the day, there are so many chances to optimize the immune supporting nutrients in the foods we choose.

There are two main nutrients the body needs. Macronutrients, which your body requires in large quantities, and micronutrients, which are needed in smaller quantities.

Macronutrients are derived from proteins, carbohydrates, fats, and water and can be found in:

- Lean meats like chicken, fish, and turkey
- Whole grains like brown rice, quinoa, buckwheat, and barley
- Healthy fats like fatty fish (salmon, halibut, mackerel), avocado, nuts, and seeds

Micronutrients are composed of vitamins, minerals, trace elements, antioxidants, and phytochemicals. Lower quantities are generally needed but they are equally important. Some of the more researched micronutrients:

Vitamin C — helps to protect against infections caused by viruses and bacteria, and has been shown to decrease the duration of colds. Easily incorporate it in your diet by eating oranges, kiwi, bell peppers, strawberries, and broccoli, to name a few.

Vitamin D — Numerous studies have shown the importance of vitamin D to the immune system. Recent small studies also show a healthy range of vitamin D can decrease the severity and possibly reduce the chances of contracting COVID-19. The sun is the best source, it’s possible to get a good dose depending on the location and season. It is often difficult to get recommended doses from your diet but a few good sources are salmon, mushrooms, fortified milks, tuna, and eggs. Supplements are usually recommended for most people.

Vitamin A — has been shown to help fight respiratory infections. Food sources are easy to spot by looking for the color orange, found in sweet potatoes, pumpkins, carrots, and butternut squash.

Zinc — provides a significant role in boosting immunity. Recent small studies have shown it could block the replication of the COVID-19 virus. Food sources are meats, firm tofu, lentils, yogurt, oatmeal, pumpkin and sunflower seeds.

Selenium — is a powerful antioxidant that boosts immune function. One of the best sources is Brazil nuts, about 2–3 nuts provide 200 mcg. Avoid large amounts of these nuts to prevent toxic levels of selenium from forming. In this example, more is not necessarily better.

A plant-based diet will ensure you have enough macronutrients and micronutrients to maintain a strong and healthy immune system. At each meal try to make half of your plate from plants.
Cori Noble remembers the exact moment he lost his sight. He was 30 years old and just woke up from a nap.

His wife and 18-month-old son were there and he asked why they were sitting in the dark. She told him it was 3 pm and the sun was shining through the windows. The room was awash in light yet Cori couldn’t see a thing.

“I knew then the grayish fog that was blocking everything except for shapes had gotten worse and now it was a black fog that never lifted,” Cori said. “Darkness came and caused a major shift in the way I knew life. I was tested beyond anything I had known. At that point I was in a wheelchair and blind, which was just awful. I worked hard to get back on my feet.”

Cori has neuromyelitis optica spectrum disorder, NMOSD, a rare relapsing remitting disorder of the brain and spine. Historically, it was considered a subtype of MS, but it is typically more severe and until recently, had no effective treatments. (See Dr. Wallach’s article on NMOSD.)

Like MS, the symptoms from NMOSD were strange and sporadic. Starting just two months after getting married in 2010, Cori noticed he had spasticity in his legs that would leave them numb and he was unable to walk for a time. Gradually, he lost the ability to walk completely. His bladder and kidneys weren’t working properly either and he had the hiccups for a month. As he put it, “his body was going haywire.”

A series of hospital stays and doctor appointments led to a MS diagnosis. One neurologist wasn’t sure that was accurate and recommended Cori see Dr. Mary Ann Picone, Medical Director of the MS Center at Holy Name Medical Center.

Dr. Picone admitted Cori and ran tests that found he had an infection, causing a very high fever. She also discovered he had NMOSD, not MS, and started treatment immediately, for his disease and the infection.

“My fever was so high I was basically cooking from the inside,” Cori said. “But the care at Holy Name was amazing. My infection
was affecting different parts of my body and I thought I was dying. But I could feel the love and compassion from everyone. I think if I had gone to another hospital, I would be dead.”

At that point, Cori was still able to see, though it seemed as if he were looking through a gray veil. Once his infections cleared, he went to a rehabilitation facility to work on regaining the use of his legs. It was when he was in that facility that he woke up with his wife there and realized he was in total darkness.

This was the start of an arduous journey for Cori. He was angry and scared. His would no longer be able to keep his job at a printing company. He was also a tattoo artist and a licensed barber — all skills he couldn’t use without his sight.

“I could deal with not being able to walk but my eyes were everything,” he said.

But once he realized that for the time being at least — he still believes one day he will see again — his sight wasn’t returning soon, he focused hard are getting out of his wheelchair. He also went on to get his associate’s degree and is working on starting a career as a social worker. He learned braille and enrolled in a vocation school for the blind to learn how to do the basics of daily living such as cooking and laundry.

Cori and his wife recently celebrated their 10th Wedding Anniversary and have been there for each other as they both battled health problems while raising their two sons.

“I talk to my sons about not being able to see,” Cori said. “I let them know that daddy can’t see but I can hear and I’m still here. I tell them that no matter what happens during their lives, it’s never over until the end. There is a quote, ‘The only thing worse than being blind is having sight without vision.’ I’m not sighted but I have 20/20 vision.”

It is with great sadness that I am writing to inform you of the passing of Stacy Melvin, who was very dear to all of us here at the MS Center for many years. Stacy was our research coordinator and lost her struggle with breast cancer in August.

Stacy started at the MS Center in 1990 as the neuro-rehab nurse coordinating discharge planning for MS patients. She was one of the first people I met when I started here at Holy Name. She always had a smile on her face and a word of encouragement. She touched the lives of so many patients who were involved in MS clinical trials. She was a cheerleader, a teacher, and an inspiration.

Many patients told me how Stacy not only cared for them as a nurse, but also as a friend, and they will always remember her smile, her intelligence, and her good humor. They learned about Stacy’s children, who were the light of her life.

All of us here at the MS Center will remember her incredible strength, bravery, and perseverance as she battled breast cancer. Her spirit will live on in our memories and our good works. Stacy’s Fund, a resource to help provide a nursing scholarship on an annual basis, has been set up in her memory.

— Dr. Mary Ann Picone

Donations to may be sent to
Holy Name Medical Center Foundation
718 Teaneck Road, Teaneck NJ 07666
(indicate “Stacy’s Fund” on the memo line)

Or you may wish to contribute at
holynamo.org/Foundation
(Indicate “Stacy’s Fund” in a note to the Foundation)
Mary Ann Duffy thinks her form of multiple sclerosis is so atypical that she questions whether she really has the disease. After all, since 2003 she has donned her overalls every Thanksgiving morning and walked 43 blocks holding a thick rope tethered to one of the giant balloons during the Macy’s parade. “It’s a long morning but I love it,” she said.

She walks unimpeded, not needing the help of a walker or cane. “Can someone with MS really do that?” she often wonders. “So many people I know with MS are in wheelchairs.”

But the reality is, she does get confused, finds it hard to sit or stand in one place for a long time, and lately, has been short on patience. She has also left the oven and stove on and suffers with vertigo at times.

Mary Ann, 56, has been on medication for MS since 2005, after her second relapse. Her first experience was in 1997, when she was hospitalized due to a severe case of double vision, but she denied the diagnosis. She thought she was too young to have MS and refused any medication to address the disease.

“I had my two daughters by then and a very stressful job working in a bank call-in center where customers were always upset about their accounts — usually overdraft fees,” Mary Ann said. “I thought my symptoms were a result of nerves and stress.”

When she had her second relapse, she was suffering with double vision and became extremely clumsy at her job.
This time, her co-workers noticed. Her doctor just gave her a lot of information on MS treatments and told her to pick which one she wanted. She was overwhelmed and desperately needed a new doctor.

She found Dr. Mary Ann Picone, Medical Director of the MS Center at Holy Name.

“Dr. Picone is so knowledgeable and always answers all my questions,” Mary Ann said. “I feel like she really understands this disease and the best medications to address your symptoms. Since I’ve been seeing her I haven’t had a relapse.”

Dr. Picone gave her a disease-modifying drug that required her to inject the medication each week. “I called it the macarena drug — once a week in different muscles, the leg, the arm, the butt,” Mary Ann said with a laugh.

“That made such a difference,” Mary Ann said. “The people there, like at Holy Name, were wonderful. They helped me build the strength I needed to move better so I wouldn’t fall, and so I would be able to do things like open jars easier.”

The testing with Dr. Foley showed MS was affecting the part of her brain that had to do with cognition, which is why she can walk and talk without any difficulty, she said.

Since then, Mary Ann left her job and spends a good part of her day helping her two daughters and four grandchildren. She has helped pick the kids up from school, and performs other daily activities to keep her house running such as cooking, cleaning, and laundry. She is sitting out the parade this year but has all intentions of taking hold of that rope in 2021.

“I know I have the symptoms of MS but there are still days that I question whether I have the disease,” Mary Ann said. “I have learned so much — I realize now that everyone has such different symptoms. The one thing anyone with MS needs to understand — stress is our kryptonite. You have to learn how to manage stress and that’s what I do now. And I would tell anyone — if you have MS, see Dr. Picone or the other specialists at the MS Center.”

While the drug kept the double vision at bay, Mary Ann did notice that she was experiencing some cognitive issues. She was getting confused and started feeling some aches and pains. Overall, she was having a hard time doing her job.

Dr. Picone sent Mary Ann for cognitive testing by Frederick W. Foley, PhD, Director of Neuropsychology, at Holy Name. She also recommended occupational and physical therapy at HNH Fitness, a medically-based center in Oradell operated by Holy Name.

Dr. Picone uses a number of neurological tests to provide personalized care for each patient.
Many thanks to Itamar and Rachel Carmi, the Teaneck couple who owns Bernie Mev shoes, for donating 200 pairs to the MS Center and other areas of Holy Name Medical Center during the COVID-19 pandemic. Employees in nursing, environmental services, food and nutrition, physical therapy, pharmacy, laboratory, cardiology, radiology, and the Cancer Center enjoyed the comfort and support of the well-made footwear.

Bernie Mev Shoes Donation

Celebrating 35 years of advanced, personal care at the MS Center, the Holy Name Medical Center Foundation published Dress the Heroes, a 60-page publication honoring our healthcare workers. The pages are filled with patients conquering MS, staff and friends of the MS Center, and the healthcare heroes who provide such compassionate skilled care.

DRESS THE HEROES

If you would like to receive a copy of Dress the Heroes, contact Lisa Futterman at foundation@holiname.org or call 201-833-3000, ext. 3899.
Welcome Jason Yin!

Jason Yin is a new member of the MS Center team, serving as the research coordinator for MS clinical trials. Jason is a native of Michigan and earned his B.S. in Biopsychology, Cognition, and Neuroscience. He received his Master’s from the New York University Graduate School of Arts and Sciences. Jason has worked as a research assistant and is fluent in Mandarin Chinese.

As new generic medications become available, especially Copaxone and Tecfidera, many people are asking if they will be able to stay on their BRAND name medication. Most major commercial insurers will cover BRAND medications if they have an approved authorization, but the drugs fall under higher TIERs so they are more expensive. Remember, there are still copay assistance programs through the manufacturers, but the coverage is limited.

For patients with an insurer that does not cover BRAND medications even when generics are tried and there is an adverse reaction, an authorization can be submitted since it would meet medical necessity criteria for BRAND. Always remember, it is very important to check with your medical provider before making any changes to medications.

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Mary Ann Picone, MD
Medical Director, MS Center

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susceptible to the virus have generally not been seen. This is an evolving situation and we continue to gain better understanding about the virus and how it can affect MS patients. If new information suggests different protocols, we will make changes accordingly.

As vaccines become available, there is no contra indication to getting the Pfizer and Moderna vaccines. Patients on infusion therapies should discuss the timing of the vaccine with their doctor. We encourage everyone to get one.

The mRNA vaccine technology is also showing promise in recent research studies as a possible treatment for MS. It is currently being tested in mice and hopefully will show benefits in humans as studies progress.

In Other News at Our MS Center:

• Dr. Foley and his staff are providing virtual counseling for anyone experiencing anxiety and depression from dealing with COVID.
• New therapies for relapsing MS and for a variant of MS, neuromyelitis optica, have been approved by the FDA.
• We have a higher-strength 3 Tesla MRI machine and our physical therapy department is open and ready to treat patients.

During the pandemic, it’s very important that you don’t neglect tests and treatments. Although there has been a lot of change this year, what remains the same is our commitment to you. Reach out with any concerns and know that you are our number one priority!

Juliana Avalo
Administrative Director, MS Center

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Charitable Giving

Your support helps us to continue providing compassionate, comprehensive care that includes accurate diagnostics and emerging therapies to patients 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:  holynamed.org/Foundation
Send:  Holy Name Medical Center Foundation
       718 Teaneck Road
       Teaneck, NJ 07666
Contact:  foundation@holynamed.org
          201-833-3187
          201-833-3708 (fax)

Thank You for Your Support!

Holy Name PharmaCare

Holy Name Medical Center 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.

Conveniently located next to the MS Center, PharmaCare is open
   Monday through Friday, 7:30 am – 6:00 pm
   Saturday, 9:00 am – 3:00 pm

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