



Welcome to

The Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center!



Mary Ann Picone, MD
Medical Director, MS Center

Many of you may have noticed the new name above the MS Center entrance. This is in honor of the Palestroni Foundation for its very generous donation. We are so grateful for these funds to continue improving our patient services.

It is hard to believe that it is already February and 2018 has come and gone. We've accomplished a lot, however, during the past year.

We have additional physicians who work with our MS patients:

Dr. Richard Lee, an urologist, sees patients twice a month at the MS Center. Dr. Steven Welish, a cardiologist/internist is available for general medical care, including immunizations, making it easier for patients to access care. Dr. Rosenbluth, a pain specialist and palliative care physician, is also a resource for many of our patients.

We also are excited to share the news that Holy Name now has a convenient retail pharmacy, located down the hall from the MS Center. Holy Name PharmaCare enables patients to get many prescriptions before they leave the hospital. Of note too, arrangements can be made for patients to get scooter or wheelchair evaluations at home.

In terms of MS therapies, we continue to expand our infusion services. More patients have been on higher efficacy treatments such as ocrevus, lemtrada and tysabri and we're excited about these effective therapies.

Early recognition and treatment of MS is so important in slowing disability progression, and fortunately, we now have more therapies. However, since MS is such a heterogeneous disease, no one medication works

for everyone. Follow-up monitoring is key in evaluating relapses, new MRI activity and examination changes. Clinic visits are also important for overall safety monitoring.

We continue to be involved in research studies on both current and new investigational agents to help with slowing progression and stimulating myelin repair. Anyone interested in research is encouraged to talk to a staff member.

Last April and May, we made presentations at the International Foot and Ankle Biomechanics Conference in New York City and the Consortium of MS Centers in Nashville. Looking ahead, we are planning a weight management behavioral study to help improve overall health and I have been working on a book, *MS for the Non Neurologist*, which should be out this spring.

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Stem Cells in MS

**AUTOLOGOUS HEMATOPOIETIC
STEM CELL (AHSC) THERAPY,
A PROMISING APPROACH,
BUT NOT YET READY FOR
PRIME TIME**



David B. Duncan, MD, MSCS, FAAN



Mary Ann Picone, MD
Medical Director, MS Center

Multiple sclerosis (MS) is a complex disorder of the brain and spinal cord characterized by inflammation and scarring. These scar areas represent lost myelin — the exterior coating on certain nerves — or in some cases, loss of the entire nerve.

Treatments are more successful in slowing down and for some patients, stopping the disease's progression. Still, researchers are seeking therapies with stronger results, possibly reversing the damage, a process called neuroregeneration.

One area of research on neuroregeneration that has created a great deal of interest is the potential therapy from stem cells. Studies conducted with various types of stem cells have shown that these therapies may prevent disease progression and neuroregeneration.

A promising form of stem cell therapy, known as Autologous Hematopoietic Stem Cell (AHSC) therapy, involves giving patients their own stem cells.

In patients with relapsing remitting MS who received AHSC therapy, 83 percent showed no evidence of worsening MS two years later and 67 percent had not declined in five years.

In addition, a treatment center in Canada reported 23 out of 24 MS patients remained disease-free 13 years after an AHSC procedure. This suggests a more significant result than from effective current therapies.

It is important to remember that AHSC is a complicated procedure that uses radiation or chemotherapy to eliminate or significantly suppress the immune system before transplanting a patient's own stem cells. This procedure is believed to cause a potent anti-inflammatory effect, essentially rebooting the immune system.

The difficulty in evaluating the benefit of AHSC is that the procedure was not performed uniformly or in the same kind of patients. Some were treated in later stages of their disease while others were treated early due to aggressive MS.

Another concern is safety. It was reported there was a 2.1 percent chance of death within 100 days of the stem cell procedure, though this appears to have happened less in patients who were younger and in earlier stages of the disease.

Stem cells may potentially be used to repair damaged nervous tissue. Studies suggest that stem cells found in fat, skin and bone marrow may assist in remyelination, reduction of scar formation, improved circulation, decreased inflammation and protection of the nervous system. Some initial studies have suggested administering the stem cells may be safe; however, details as to how the stem cells should be prepared and given and how often has not been determined.

One concern is that stem cell treatment may lead to genetic alterations of the stem cells. This could result in abnormal tissue formation, tumors or a malignancy following transplantation. Already, reports show spinal cord

MS Research at Holy Name

Stacy Melvin

Clinical research is essential in improving the quality of life of patients with life-changing diseases. Holy Name Medical Center remains committed to leading and participating in a number of clinical studies, especially those involving MS therapies. We continue to be at the forefront in the development of new treatments, improving current therapies and obtaining long-term safety information of approved therapies.

In 2018, we continued with studies that improve current treatments while embarking on remyelinating efforts, drugs which were in early development. Although some approved therapies are effective in “arresting” the underlying disease action in Relapsing Remitting MS and in primary progressive MS, it is vital for further exploration of repairing damaged myelin. Information from these studies is being collected and the results are not yet available.

Great strides have been made also in developing a number of therapies for those with active relapse activity. However, effective treatments for secondary progressive MS are desperately needed and the MS Center will be partnering to investigate such therapies.

RESEARCH CANNOT BE SUCCESSFUL WITHOUT VOLUNTEERS

Research cannot be successful without volunteers, and opportunities to participate are constantly available. Participation is voluntary and patients can withdraw at any time. Our studies are highly controlled, carefully monitored, and give access to medications or therapies patients might not otherwise be prescribed. Volunteers receive study-related medical evaluations and the trial drug/placebo at no cost. Compensation for travel may be provided. Some studies may not involve pharmaceuticals, instead focusing on improving health and wellness. They may address fatigue, pain, depression, stress, and weight management.

If you are interested in participating in studies that are currently accepting patients or would like to be added to a data base for future efforts, please speak to your physician or another member of the staff.

tumors in patients receiving cells in their spinal column.

Unfortunately, news of the popularity of stem cell research has also produced unsavory business practices, leading to some clinics offering direct-to-consumer stem cell treatments. This involves removing stem cells from bone marrow, skin, or fat followed by unproven methods of stem cell processing and replacement. Such procedures are unlikely to have positive results and can cost from \$5,000 to \$50,000.

Today, stem cell therapies in MS management offer a promising approach for possible immunomodulation, neuro-protection and repair of nervous system damage; however, they are not yet ready for prime time and are not considered standard of care.



Honoring Her Son Despite MS

Cheryl Dotz

When Cheryl Dotz finally learned she had multiple sclerosis, she felt a wave of relief. Her symptoms had triggered a menu of tests and led her neurologist to offer some pretty grim possibilities — amyotrophic lateral sclerosis (Lou Gehrig’s disease) or a brain tumor.

“I can live with MS,” Cheryl remembers responding to her neurologist. “It’s better than these other diseases you mentioned.”

Her diagnosis came when she was already under a tremendous amount of stress — just two weeks earlier her son Ryan deployed to Iraq. He was in the National Guard and volunteered to go

overseas so another guardsman didn’t have to leave his family. Cheryl’s symptoms, vague and persistent for years, escalated immediately after Ryan left, and her physician said Cheryl’s stress over Ryan’s deployment probably caused her symptoms to flare.

“I was 57 and probably had MS for many years without anyone knowing,” Cheryl said. “I had a lot of tingling in my legs but most of my symptoms were only on the left side. I was very tired and dragged my foot sometimes.”

Her doctor told Cheryl he didn’t think she had MS largely because her symptoms only affected one side. And her

fatigue could be attributed to her busy life — a job as a teacher, and raising three children.

Once she was diagnosed, Cheryl went to a large academic medical center in New York City for treatment. She received a medication regimen that helped only slightly. She still felt tired, had difficulty walking and numbness.

Two months after he deployed Ryan was killed. Cheryl, still struggling with her disease, mourned with her family for some time before they turned their grief into action. In honor of Ryan, they created the Sgt. Ryan E. Doltz Foundation, which gives scholarships to local high school seniors and helps families of deployed soldiers.

The years passed and Cheryl was still fighting the progression of MS. Her doctors told her she was doing well but, “I didn’t feel well,” she said.

Finally, someone near her home in Mine Hill, N.J., recommended Dr. Picone, who Cheryl has been seeing now for 10 years, despite the long drive. “The commute is definitely worth it,” she said.

Dr. Picone started Cheryl on new medications and her overall well-being improved dramatically. Her strength returned and her symptoms decreased significantly.

“Now, I can walk long distances — I just use a cane so I don’t look like I’m wobbling, as my daughter calls it,” Cheryl said. “But I am able to do so much — I can walk through the mall and went into the city to see a Broadway show. I feel so much better.”

Switching Medication?

It may affect your insurance coverage.

Juliana Avalo

Most pharmaceutical companies offer financial assistance for different medications, enabling some patients to get prescriptions free of charge. Not all medications are given financial aid.

As a result, patients need to understand their pharmacy benefits in case they need to switch to a drug that isn’t free or offered at a discount. In addition, regulations governing how much financial assistance can be offered are constantly changing, which affects pharmacy benefits.

Also keep in mind that infusion therapy adds costs, which can vary depending on where patients get their infusions. For some sites, patients will need to use pharmacy and medical benefits while at other locations they may use medical benefits to cover an administration charge. It’s important that all patients understand both medical and pharmacy benefits.

The Alfiero & Lucia Palestroni Foundation Multiple Sclerosis Center!

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On another note, it is important to keep current on vaccinations, particularly the flu vaccine. Also, if you haven’t seen it, Holy Name has a new ad campaign, which features two of our patients. Read their stories on [ThisPlaceisDifferent.org](https://www.thisplaceisdifferent.org).

All of us here at the MS Center are dedicated to improving patients’ quality of life. MS can be difficult and challenging but together we can make a positive difference. The MS Center is here for you.

Nicholas Urbina

From Thoughts of Death to a Normal Life



Nicholas Urbina was a high school senior when he thought he was going to die, probably soon. He had been sick for months – with numbness, double vision, vomiting and vertigo – and he was so weak he couldn’t get out of bed.

“I was definitely scared,” Nicholas said. “I couldn’t put into words what was going on but I definitely thought it was the end for me, and I could see my parents were really scared.”

Nicholas landed in several hospitals, often drifting in and out of consciousness. He couldn’t go to school – he needed help from his mother, father or brother just to get out of bed. Finally, a spinal tap revealed Nicholas had multiple sclerosis.

“The diagnosis didn’t scare me – I was glad and relieved they pinpointed what was wrong with me,” he said. “But it was still a slow road to recovery.”

Nicholas’ brother heard about Holy Name’s MS Center and Nicolas started seeing Dr. Picone. Slowly, his strength returned as his symptoms subsided. The day he went back to school for the first time – it was his birthday, February 24, 2010. He was in a wheelchair but happy to be back.

“It was a huge flood of emotions – I hadn’t seen anyone in months,” he said. “I also went to my prom and my graduation in a wheelchair. It was my way of saying hey, I’m fine. I’m here.”

Still, Nicholas had his dark days. There was a point when he told his father, “I’m never going to get out of this chair. I’ll never walk again.”

But after three years in a wheelchair, Nicholas did walk again. He still needed an injection every three days and

**“IT WAS A HUGE FLOOD
OF EMOTIONS...
I HADN’T SEEN
ANYONE IN MONTHS”**

since a family member administered it, he felt trapped and couldn’t travel. Yet he could feel his body recovering. Then in early 2017, Dr. Picone put Nicholas on ocrevus. Only one infusion every six months was monumental and gave him his freedom.

“I wouldn’t be where I am today if not for Dr. Picone and the staff at Holy Name,” Nicholas said. “I’m not just some guy showing up — we’ve built a relationship. Overall, I feel great. I’m not your typical 26-year-old, running and jumping but between 1 and 100, I’m a solid 90. I walk every day, hang out with my friends.”

Nicholas also works as a physical therapy aide. After receiving so much care and attention for years, he wanted to work in a field where he could give back.

“Some patients feel so down and I tell them that I was in a lot worse condition but look at me now,” he said. “I can be part of a support system for them and I know how important that is.”

Nicholas still goes for his own physical therapy. Balance is an issue, and it probably always will be. “But from everything I’ve experienced, I’m fine with that. I live a pretty normal life right now, especially considering what I went through.”

The Americans with Disabilities Act: What You Need to Know

Dorothy Northrop

When former President George H.W. Bush passed away in December, much time was spent reviewing the accomplishments of his administration. Probably one of his most important achievements was signing the American with Disabilities Act (ADA) in 1990.

Its importance was noted when so many people with disabilities honored him following his death. Passage of that legislation opened doors and provided protections that had not been previously available. Along with later amendments, it gave civil rights protections to individuals with disabilities similar to those provided to people based on race, color, sex, national origin, age and religion. It guaranteed equal opportunity in public accommodations, employment, transportation and state and local government services.

Significant progress has been made as a result of the ADA, enabling people with disabilities to become more engaged in their communities, broaden their employment opportunities and become more independent through accessible transportation. But more work needs to be done. It is important that everyone be vigilant about their rights and hold accountable those who would deny access and opportunities protected by the ADA.

If you experience a violation of the ADA and would like to report it, go to www.ada.gov and click on the box **“File an ADA Complaint.”**

MS Center: A Pharmacist's Perspective

Vincent DeFedele, RPh, PRS

Taking care of patients has been my passion for 37 years. My one-on-one with patients enables me to inform them about their medications, potential side effects, possible drug interactions, and teach them how and when to properly take their medications for the best results.

Pharmacists' intervention in patient care increases compliancy and makes patients more comfortable and at ease when taking medications. Studies have shown a decrease in hospital re-admittance when a pharmacist explains the importance of taking medications as prescribed by their physicians.

As the number of new treatments for MS continues to grow, it is important

that patients starting new protocols are educated about all aspects of their treatment. I communicate daily with the MS infusion center and counsel patients about changes in treatment so they understand the purpose of the medication, precautions they may need to take and possible side effects.

I've found that talking with patients has made a positive impact on how they understand their treatments. Answering their questions about medications and explaining what they need to know has been a positive influence and helps them understand and increase compliancy.

Another aspect of my job is creating a medication record of all drugs and nutritional supplements patients take

so I can check for possible drug interactions, making sure they are taking the prescribed medications properly and offer suggestions if needed. As an added bonus, I have had the privilege of working with clinical research that has produced drug treatments for MS.

My involvement with the MS center has been rewarding, professionally and personally. I would like to thank Dr. Picone and all the MS staff for welcoming me to their patient care team. I thoroughly enjoy working with such a talented, dedicated group of people and have established a good relationship with very special patients.



Having a positive
influence helps
increase compliancy

Annual MS Awards Dinner



The 2018 MS Awards Reception, hosted by the Holy Name Medical Center Foundation, was a tremendous success, raising \$260,000 for the MS Center. Nearly 600 guests attended the event, held on October 23 at The Venetian in Garfield, NJ.

This year, the Foundation honored Joseph M. Sanzari with the Lawrence R. Inserra Leadership Award for his philanthropic leadership and commitment to the MS community. Thanks to Mr. Sanzari and all those who so generously support Holy Name's MS Center, we are able to continue providing unparalleled patient care and access to innovative clinical research to thousands of patients and families throughout the tri-state region.

All of the funds raised from this event directly benefit MS patient care and research.



▲ MS Staff at the Awards Dinner.

◀ Kristine Sayrafe and Lucia Palestroni of The Alfiero & Lucia Palestroni Foundation with Michael Maron at the MS Awards reception.

Cognitive Issues in People with MS

Frederick W. Foley, PhD, Director of Neuropsychology

Cognitive problems are common in people with MS, affecting approximately 45 to 60 percent of patients. The most common issue is slowed processing speed (slowed thinking), followed by problems with memory, attention, visual judgement and problem solving.

The good news is that often, these cognitive issues tend to be mild to moderate and severe issues are relatively rare. Cognitive rehabilitation (exercises in attention, memory, and thinking) is often helpful, as is regular aerobic exercise. If you have concerns about your attention, concentration or memory, your neurologist may recommend neuropsychological testing to provide a profile of your cognitive strengths and weaknesses.

This is the first step to remediate cognitive problems.

We have an active research program on cognitive problems at the MS Center. Our studies have found that anxiety worsens cognitive issues, so treatment for anxiety may help. We also found that verbal memory problems indicate an increased risk of falling, which suggests that treatment for patients who fall should include a cognitive assessment.

Further, we have an early intervention program for employed women to see if we can remediate factors related to losing their job, such as fatigue, depression and cognitive problems. We hope that early screening and

improving these issues will prevent job loss. Another study found that starting treatment very early with a disease-modifying therapy is associated with stable cognitive functioning over an 11-year period. We are very appreciative of our patients who volunteer to participate in these studies, which enable us to make more discoveries about cognition and MS.

In addition, the Holy Name MS Center received a Mental Health Mini-Mentorship grant from the Consortium of MS Centers to train licensed mental health providers to recognize the unique mental health challenges faced by people with MS. They will also teach best practices for assessment and intervention.

Occupational Therapy for Individuals with MS

Christine Smith, OTR/L, MSCS

Many people with MS are afraid of losing the ability to perform daily tasks.

Occupational therapy can alleviate those fears by helping maintain the skills needed for independent living and productivity at home or work.

Occupational therapy focuses on activities that address many MS symptoms. You can do exercises to strengthen and stretch your upper body, improve your coordination and learn other skills tailored to your level of functioning. Occupational therapists work with you by incorporating:

- Fatigue management
- Cognitive rehabilitation
- Home modifications
- Workplace adaptations including computer modifications
- Introduction and education regarding adaptive equipment

You need a prescription from your physician to begin occupational therapy. Often, MS patients don't start therapy until a doctor or patient recognizes the need for intervention.

But advances in treatment have shown that it is ideal to incorporate strategies prior to having difficulties.

During your first visit, an occupational therapist will evaluate you. The focus will be on the tasks you want to continue doing or on those that you are no longer able to do but would like to again. The therapist will work with you to develop a treatment strategy.

To accomplish this, the therapist may use some of the following approaches:

- **Activity modification:** Make activities less fatiguing. For example, review a recipe before cooking and gather all of the necessary items to minimize trips back and forth to the refrigerator.
- **Adaptive equipment:** Use equipment such as a shower chair in order to help with unsteadiness and fatigue.
- **Strength, stretching or balance exercises:** Improve balance, prevent falls and build strength. Wheelchair-bound individuals may do exercises to increase trunk strength to perform mobility tasks.

In addition to improving physical dexterity, occupational therapy can also improve cognitive abilities. You can learn ways to compensate for issues with memory, concentration and organization. Some areas that may be improved:

- **Memory:** Design strategies to minimize misplacing items such as keys and glasses, forgetting names or missing appointments.
- **Attention:** Improve concentration for reading, tools to focus on conversation and ways to minimize multitasking.
- **Prioritize/organize:** Improve planning and performing activities by deciding what task to do first.
- **Problem solve/reason:** Focus on money management, budgeting and balancing a checkbook.

Occupational therapy can play a large role in overall health. Using occupational therapy strategies sooner rather than later may help you maintain independence despite changes in symptoms.



Therapy designed
to increase
trunk strength

Nurse Specializes in MS



Matthew Schiebel, RN, a MS Certified Specialist, has been working at the MS Center since 2014. He provides comprehensive care for patients receiving infusions, including individual education, care coordination and infusion treatments.

Matthew has been a registered nurse since 2009. Prior to Holy Name, he worked for five years in oncology at St. Joseph's Medical Center. Matthew earned his Bachelor's Degree in Nursing from the College of St. Elizabeth, after graduating from Bergen Community College with an Associate's Degree in Nursing.

First MS Certified Healthcare Associate



Christal Radburn has been a Registered Medical Assistant at Holy Name's MS Center since 2015. She is the first Healthcare Associate in the United States certified in multiple sclerosis (MSHA). Christal greets patients at the MS Center and performs routine tests

such as blood pressure, basic eye exam, timed walk and blood work.

Christal worked as a medical assistant in a general neurology office before joining Holy Name. She participates in various MS events, including the Spring Fling Fashion Show, the MS Society Walk and the MS Climb to the Top of the Rock.

Well-Deserved, Juliana



Congratulations to **Juliana Avalo**, who is now the Administrative Director of the MS Center. Juliana has been working at the MS Center for five years and handles the crucial day-to-day operations behind the scenes.



JOIN US FOR THE ANNUAL SPRING FASHION FLING

**Sunday, March 24, 2019
11:30 am**

Please join the Holy Name Medical Center Foundation for the 22nd Annual Spring Fashion Fling to benefit the MS Center. The afternoon event includes a luncheon and auction, as well as a fashion show provided by Lord & Taylor. Chris Cimino, WNBC-TV meteorologist, will serve as Honorary Chairperson, and Meredith Vieira will once again act as Honorary MS Ambassador.

Proceeds will benefit the MS Center's patient care and research programs.

Tickets: \$125 per person

Location: Glenpointe Marriott

100 Frank W Burr Boulevard
Teaneck NJ 07666

For more information or sponsorship and ad journal pricing, please call

Lisa Futterman at the **Foundation**
201 833-3000 ext. 3899

email Futterman@holyname.org or
visit holyname.org/Foundation.

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MS Links

MULTIPLE SCLEROSIS WINTER 2019



Yoga Classes

A new session of FREE yoga classes, geared specifically for MS patients, will be starting. The 8-class sessions are held on Thursdays, from noon to 1 p.m., in Holy Name Medical Center's Marian Hall conference rooms.

Space is limited — only 15 spots are available but sessions are ongoing so if one fills up, check back for the next session. Participants must bring their own mat and be able to attend all the classes. Unfortunately, Holy Name Medical Center transportation cannot be provided.

Call **201-837-0727** to register.

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 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

Send: Holy Name Medical Center
Foundation
718 Teaneck Road
Teaneck, NJ 07666

Contact: foundation@holyname.org
201-833-3187
201-833-3708 (fax)

THANK YOU FOR YOUR SUPPORT!