



Healing MS

THE IMSMP NEWSLETTER TO ADDRESS THE NEEDS OF OUR PATIENTS
AND KEEP YOU INFORMED OF THE LATEST RESEARCH TREATMENTS
AND WAYS TO HEAL

Global Perspectives & The IMSMP Difference

Interviews With Members of the IMSMP's International Family from Italy & Sweden

Here at the IMSMP, we take pride in being an international presence in the MS community, proudly treating patients from around the globe, totaling 55 different countries. Our neurologists, clinicians, nurses, and administrators, all take part in what we believe is the best MS patient care center in the world.

We wanted to spotlight two international patients to see what perspective we could gain from their experiences. What could we learn about our Center and our doctors from patients traveling thousands of miles for their care? How can we do better for all of our patients? We interviewed Helena Tenerz from Sweden and Alessia Albanese from Italy, to see how living with MS affects life outside the United States.

Alessia Albanese from Naples, Italy:

Living in Italy - what made you decide to travel to New York for your MS care?

When I was diagnosed 10 years ago, I spent a few days in total disorientation. I didn't know much about the disease and relied heavily on friends and family for their recommendations. After some research and discussion, I found a prestigious neurological center in Milan. I underwent a spinal tap in the hospital which left me with the definitive diagnosis of MS. When I was discharged, I was advised to get MRIs every three months and to not undergo any therapy to control my disease. My first MRI showed that I was having another relapse. It was then I realized that I needed another opinion and a different direction to follow. So, the daughter of a colleague of my husband had been to the IMSMP, had given great references, so we were wondering why not try it?

What are the differences in MS healthcare in the United States versus Italy?

In Italy, there are no highly specialized centers exclusively dedicated to the disease. The cause of and cure for MS can only mature in these patient care centers like the IMSMP and, above all, in research facilities like Tisch MS Research Center. The Italian healthcare system is often restricted in therapeutic choices by their spending limits, sometimes even behind the patients' best interest.

cont. pg 2



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**Alessia Albanese, from Italy,
with husband, Paolo &
Dr. Saud A. Sadiq**



**Helena Tenerz,
from Sweden, with
Dr. Armistead Williams**

INSIDE THIS ISSUE

- Welcome New Research Assistants
- A Letter from Dr. Sylvester
- Have you Registered for the 2017 Tisch MSRCNY Patient Symposium?
- Making Meaning With MS
- Thank You to Our Donors



Traveling from out of Town?

Check out The Fairfield Inn & Suites New York Manhattan/Central Park

538 West 58th Street between 10th and 11th Avenues, (212) 757-8550

A special rate* is available at this convenient location adjacent to our Center. Guests will need to identify themselves as: *International Multiple Sclerosis Management Practice Group Travelers* when booking a reservation, by phone.

*Rate subject to availability.

GLOBAL PERSPECTIVES CONTINUED

How does your environment impact living with MS?

I consider myself very lucky that I can actively manage my disease in my home country surrounded by my family, while having the opportunity to fly once a year to New York to receive the best medical care. At the IMSMP, I have found experts at the forefront of MS research, who not only deal with the disease, but genuinely care about their patients and treating the person behind the MS.

Anything you would like to add?

I would like to thank Dr. Sadiq, who in addition to taking care of me for the past 10 years, has always reassured me and given me the strength and the confidence that someone understands my disease. The geographical distance has never been a problem. I am sure that the happiness I have found in these years since I was diagnosed would not be possible without the medical and emotional support of Dr. Sadiq and the entire IMSMP staff.

Helena Tenerz from Uppsala, Sweden

How did you hear about our Center?

As my MS became more progressive my neurologist started me on Rituximab in August of 2015. About nine months later when my functionality began to worsen, my husband and I started researching alternative treatments. We found information about the Tisch MS Research Center and their stem cell trial, as well as the clinical care at the IMSMP and came to see Dr. Williams in June of 2016.

Living in Sweden - what made you decide to travel to New York for your MS care?

Since there are no approved treatments for progressive MS, my doctor in Sweden had no possible treatment alternatives besides Rituximab, which apparently was not helping me. Thus, he agreed it was a good idea to contact and meet Dr. Sadiq and Dr. Williams at the IMSMP. After my first meeting with Dr. Williams, he began treating me with intrathecal injections of methotrexate every eight weeks. Although New York is far from Sweden, there are direct flights.

What are the differences between healthcare in Sweden and healthcare here at the IMSMP?

In Sweden I'm being treated at a big University hospital setting, which is different, compared to the IMSMP. In Sweden most healthcare is public and not private. My doctor in Sweden is researching hematopoietic stem cell transplantation, which he also uses to treat patients. The environment at Uppsala University hospital is not as personal as the care I receive at the IMSMP. Dr. Williams and the entire staff at the IMSMP are always so friendly and make my time in New York a pleasure.

Do you find other differences with living with MS in the United States versus outside the US?

I try to live as unaffected as possible however, in bigger cities like New York I am unable to walk for long distances. In Sweden, I am able to bicycle for daily exercise as well as for my commute to work.

The IMSMP would like to thank all of our patients who travel from near and far for their care at the International Multiple Sclerosis Management Practice.

BEST OF LUCK TO THE CLASS OF 2017 TISCH MSRCNY RESEARCH ASSISTANTS AS THEIR JOURNEY CONTINUES

Tisch MSRCNY is Thrilled to Announce that All of our Second Year Research Assistants will be Matriculating to Medical Schools and Graduate Programs this Fall!

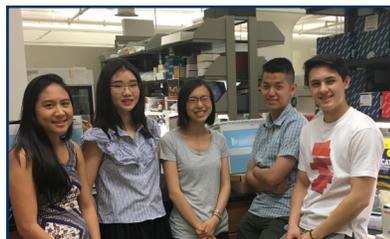
Allison Liang will be attending Rutgers Robert Wood Johnson Medical School for a Masters in Biomedical Science (MBS). Allison worked with Dr. Sadiq and Jerry Lin on their B-cell pathology related to MS. Allison felt that working at Tisch MSRCNY for the last two years has increased her confidence in how to critically analyze experimental results and present them in a scientific field to her peers.

Gloria Joo will be attending Rosalind Franklin University's Chicago Medical School in the fall. Gloria worked on our Phase I stem cell trial with Dr. Sadiq

and Dr. Harris. Gloria enjoyed the opportunity to work closely with the 20 study participants and all of our researchers for the last two years.

Jesse Huang will be attending SUNY Downstate in their medical program. Jesse worked with Dr. Wong and Dr. Cristofanilli on neurodegeneration in mice models. Jesse worked on genetics in her undergrad and found it very rewarding to translate her studies into tangible science.

Jeffrey Jian will be attending Vanderbilt University's doctoral program in biomedical sciences and will be a part of their Pathology, Microbiology and Immunology Department. Jeffrey worked with Dr. Cristofanilli's group, helping to publish their paper on the role of transglutaminase-6 in astrogliosis and is the most proud of the work he did with mouse models in MS.



From L to R: Allison Liang, Gloria Joo, Jesse Huang, Jeffrey Jian and John Tuddenham

John Tuddenham will be attending Columbia's MD/PhD program in the fall with the hopes to enter their neuroscience PhD program. John worked with Dr. Harris and enjoyed learning more about translational science and addressing the needs of patients through laboratory innovation. He feels his time at Tisch MSRCNY will help him in his career with neurodegenerative diseases.

Tisch MS Research Center of New York is delighted to welcome a new class of Research Assistants to work in our laboratory.



Gillian Carling (Columbia University) will join the team of Dr. Violaine Harris.



Natalie Favret (Wesleyan University) will be working with Dr. Anna Iacoangeli.



Matthew Mendelsohn (Emory University) will have Dr. Fozia Mir as his Principal Investigator.



Serena Shimshak (Wesleyan University) will work with Dr. Jamie Wong.



Alexandra Tse (Cornell University) will join Jerry Lin's team.



Sophia Yang (Cornell University) a Clinical Research Assistant, will work with Dr. Sadiq and Dr. Harris.

THE REGENERATIVE MEDICINE LABORATORY

Personnel Update

Tisch MSRCNY Welcomes 2 New Team Members



Bhaumik Shukla

Cell Culture Specialist

Bhaumik graduated from Rutgers University with a Bachelor of Science in Biology with Honors. His previous employer was RTI Surgical.



Jennifer Francis

Quality Assurance Associate

Jennifer has a Bachelor of Science in Chemistry from Temple University, and she joins us from NCM USA Radiopharmaceuticals.



Construction continues on the 3rd floor of our Regenerative Medicine Laboratory. The walls are up and there is a light at the end of the tunnel!

For more photos, visit:
www.facebook.com/TischMSRCNY/

A NOTE FROM THE NURSES

When Traveling, What to Know Before You Go!

While many of us look forward to getting out of town, there are certain things to consider in preparation for traveling. The nursing team has put together a few friendly reminders to help ease the travel process, which can often become stressful.

A few tips to stay ahead of the game:

* A month in advance of your planned trip date, take inventory of any prescription medications or supplements you may be running low on. Also, please note if you are on your last refill, this is the time to reach out to the nursing prescription line, as it will give the nurses enough time to obtain prior authorization for any medications that may require it. Additionally, if a vacation override is required, this will give the nursing staff enough time to make sure all appropriate paperwork is in order.

* If you take any supplements through Dr. Bates, and are running low, please contact the front desk about ordering more. If you are taking any over the counter medications, please make note of these too, and allow yourself enough time to pick up anything you may need at your local pharmacy.

If you are traveling anywhere that recommends or requires vaccinations, please call our nursing line as soon as possible so that we can consult with your attending neurologist on how to address this. This will leave ample time to complete any paperwork, or write any letters that may be required.

* On that topic, please be mindful of any travel letters you may need, as there is a 5-7 business day window allotted for staff completion of these letters (i.e. traveling with injectable medications, hotel accommodations, etc.).

* If you are traveling within the United States, you may want to make note of the closest pharmacy to where you are staying in case of any emergencies. If you are traveling abroad, you may want to look into local medical support in the area.

* If you use any assisted devices or durable medical equipment, please be sure to check in advance if there are any special arrangements that may need to be made with your mode of transportation or hotel to accommodate them.

* Take time to do some research on the climate and environment of where you'll be traveling. This information will help you determine if there are any specific accommodations that need to be made due to the surrounding location. This will make packing and planning activities easier.

As always, if you ever have any questions or concerns, please contact the dedicated nurses line (212) 265-8070.

A LETTER FROM DR. ANDREW SYLVESTER

To All of the Incredible Patients at the IMSMP,

After 18 years in the IMSMP family, I will be moving to St. Barnabas Health Center in Livingston, New Jersey, to become the Medical Director of the Multiple Sclerosis Comprehensive Care Center.



Andrew Sylvester, MD

I want to thank every one of my patients and those of Dr. Sadiq, Dr. Williams, and Dr. Stark, with whom I have had the pleasure of serving. It is your perseverant attitudes and positive outlooks that inspire my work and the reason I have dedicated my life to being an MS specialist. I only wish that I had the opportunity to say goodbye to each one of you personally and tell you how much you have meant to me and how I hope I have been able to make a significant difference in your lives.

I also would like to thank the outstanding staff at the IMSMP; all the nurses, administrators, fellow neurologists, and our entire Tisch MS Research Center from the past and current times. I am sincerely grateful to Dr. Sadiq for his guidance and support. I have had the tremendous opportunity to work for one of the best patient care centers in the world and a lab at the forefront of MS ingenuity.

My priority is to ensure that you continue to receive the same level of care without disruption.

There are 2 options going forward:

1. You are welcome to elect to remain my patient at the Multiple Sclerosis Comprehensive Care Center at the Saint Barnabas Medical Center. The IMSMP can transfer all of your pertinent records to Saint Barnabas Medical Center in Livingston, New Jersey, effective September 1st, 2017.

OR

2. You may choose to continue your care with the IMSMP. If you wish to continue with the IMSMP, please call the Center at (212) 265-8070 at your earliest convenience and an appointment will be made with either Dr. Williams or Dr. Stark.

My Warmest Regards,

Andrew Sylvester, MD

NEWS ON NATUROPATHY

Research supporting the connection between gut health and brain health is getting stronger. Short Chain Fatty Acids (SCFAs) are a link between your diet, the gut, the immune system and the brain. SCFAs are produced by gut bacteria from dietary fiber. Recent studies have shown that SCFAs modulate the immune system in a way that is beneficial for MS, and may alter gene expression in the brain to prevent neurodegeneration and promote regeneration. Oat bran is one of the best types of dietary fiber to increase butyrate, a neuroprotective SCFA.

Gene Expression Altering Cookies

These almost-but-not-too-healthy cookies are an easy way to increase dietary fiber. Try coconut sugar for its lower glycemic index.

- 1 cup nut/seed butter (almond, peanut, tahini, cashew or a combination)
- 2 eggs
- 1 tsp vanilla
- 1/2 cup coconut sugar (or brown sugar)
- 2/3 cup gluten free oats
- 1/2 cup unsweetened coconut flakes
- 1 tsp baking soda
- Handful of dark chocolate chips
- Handful of dried fruit (try cranberries or chopped apricots)

Preheat oven to 350.

- In large bowl, combine nut butter, eggs, vanilla and coconut sugar. Beat with a mixer until smooth.
- Combine oats, coconut flakes and baking soda in a small bowl. Stir together, add to the wet ingredients, and mix to combine.
- Stir in chocolate chips/dried fruit.
- Bake on a parchment lined baking sheet for 10-14 minutes.

For more ideas on diet and MS, please schedule to see our naturopathic doctor, Dr. Deneb Bates.

Don't miss Dr. Bates at the 2017 Tisch MS Research Center Patient Symposium where she will present and prepare a brain healthy dish!

Register today at www.tischms.org



Deneb Bates, ND

SPOTLIGHT ON DR. JAMES STARK

The Scope of Dr. Stark's Role

Dr. James William Stark is a board-certified MS specialist that has been with the IMSMP since 2008. Dr. Stark was born and raised in New York City but moved to Boston briefly during college to attend Boston University. After graduating, he came back to New York to attend the Albert Einstein College of Medicine, at which time he already knew he wanted to pursue a career in neurology. After medical school, Dr. Stark completed his neurology residency training at Montefiore Medical Center/Einstein and served as Chief Resident in his final year. He then completed a two-year neuroimmunology fellowship with Dr. Sadiq and was invited to join the practice immediately after. He has been with the IMSMP ever since.

Aside from his clinical practice, seeing patients with MS and related neurological disorders, Dr. Stark has a number of other roles at the Center. He is heavily involved in clinical research, including the evaluations in our Phase I stem cell trial and planning for Phase II. He serves as the Center's Director of Clinical Trials and has presented his research at MS conferences eight times in the last nine years. Dr. Stark has a number of administrative duties as well, including Director of the Residency and Fellowship Program, Grand Rounds coordinator, and member of our gala committee. He regularly gives MS lectures to neurology residents and other health professionals at institutions around the city and has contributed



Dr. Stark reviews an MRI with nurse manager, Samantha McKillip

to media presentations on healthgrades.com and everydayhealth.com, among others. Additionally, Dr. Stark was named a, "New York Rising Star," on Superdoctors.com in 2016 and again in 2017.

Dr. Stark is an avid cook and, yes, as a Stark, of course he watches and reads the, "Game of Thrones" series! His favorite thing to do is explore the wonderful sights and tastes of New York City, especially with his 2-year-old rescue Boston Terrier, Jack.



Jack

FRONT DESK NEWS



Aleksandra Wawryzniak

Welcome Front Desk Team Member, Aleksandra

Aleksandra graduated from Berkeley College with her Bachelor's degree in International Business. She previously worked as a billing coordinator for Starcom USA. Aleksandra came to the IMSMP with the hopes of working with a team that has a positive impact on people's lives.

MAKING MEANING IN YOUR LIFE WITH AN MS DIAGNOSIS

This month the social work department would like to feature Herminia Roman's story. She has been a patient at the IMSMP since January 2010. Herminia wanted to share how she is Making Meaning...



**Herminia Roman
with pup, Buffy**

Seven years ago when I was diagnosed with MS I never realized how much my life would change. I convinced myself that I had been misdiagnosed and that I did not have MS. My denial was not without justification, since I was asymptomatic and would not begin a medication regimen for 6 months after I was diagnosed. This denial lasted for 3 years, when my first exacerbation slapped me in the face with reality and I finally began my journey of accepting and living with MS.

As with all journeys, who you choose to bring along determines the success of the mission. My team included; my family, especially my wife, my friends and the members of the IMSMP. These would be the people I would rely on to help me transition from my normal life that I was used to, to the life that awaited me with MS my, "new normal."

As depression began to take over my life, I decided I needed to seek out professional help. I made an important call to the social work department at the IMSMP and scheduled my first appointment with Yadira LaMazza. My conversations with Yadira helped my reality journey take form. We discussed being diagnosed with MS, and the emotions that surrounded my diagnosis, my denial and my resistance to accepting the changes that were taking place in my body and mind. Yadira not only helped with the emotional component of my life, but she also guided me to seek out assistance with the physical challenges and suggested I start physical therapy (PT), the next stop on my journey.

One of the biggest challenges I faced was the physical component. From getting out of bed, to getting dressed and doing my own hair, these simple tasks became my greatest challenges which caused me the largest amount of frustration.

Dr. Kanter's knowledge of PT and the needs of MS patients was a great help to me. We not only worked on the challenges I was having, but he always sent me home with exercises that have become part of my daily routine. With his help I found a new love for PT. It is extremely beneficial in helping me overcome my daily physical challenges.

I have been fortunate in my life to be surrounded by a loving family and amazing friends that have always been there during all my endeavors. It was difficult to tell them about my MS because I was the protector, the comedian, and at times, caregiver. The last thing I wanted was to let them see me suffer but in reality I needed to let them in, so that they could give me

love, strength and a reason to live. As I became comfortable with my MS, they began to realize that I was still me. This journey would never be complete without them.

According to Webster's dictionary a, "caregiver," is a person who cares for someone who is sick or disabled.

What this definition does not tell us is that a caregiver usually puts their life aside in order to provide someone with love and assistance. My caregiver, is my biggest cheerleader, she is the one that guides me toward clarity and is the one that has never turned her back on me from the day I was diagnosed. She attends all my appointments, all my infusions, and e-mails doctors. She advocates for me on a daily basis. She is always trying to help me understand my, "new normal." This person is my wife. Everyone needs a caregiver and usually that falls on the shoulders of our spouse, children and parents, but through our journey we must remember that they too are going through this and that some days are just as difficult for them as they are for us.

Well this is my journey, I call it my, "new normal." It is my life with MS. It has taught me that no matter how hard things get having the proper support in place will allow you to live life to its fullest. This journey is never ending and I hope the team players I have chosen will continue to play their roles and that the new members I incorporate will continue to help me battle new levels of living with MS.

If you would like to share how you are Making Meaning in Your Life with an MS Diagnosis, please contact the IMSMP social work department at (212) 265-8070.

COMPREHENSIVE CARE COLUMN

Filling in the Gaps in Managing MS: For Patients, Their Families and Caregivers

By: Yadira LaMazza, Supervisor of Social Services and Dr. Stephen Kanter, Supervisor of Rehabilitation Services

For people with MS, the impairments that result from the disease can have mild to severe effects on one's physical, emotional and/or cognitive health. Along with seeing a neurologist who specializes in multiple sclerosis, a patient will often work with other healthcare professionals to manage MS related symptoms. It is common to work with a physical therapist (PT) and occupational therapist (OT) to work on physical impairments that limit independence. A speech language pathologist (SLP) may also be seen to address issues with speaking, such as low volume or endurance, and/or difficulty with drinking fluids or eating food without coughing. An OT or SLP, can also help with cognitive rehabilitation.



Physical Therapist, Dr. Elizabeth Woods with Cynthia Brodsky

The collaborative efforts of a PT to improve physical functions such as transfers, balance and walking, along with an OT and SLP, provides for a good foundation toward managing activities of daily living. This is a reason why living environments and determining one's specific functional goals are so important when seeing a rehabilitation professional. Often, for optimal care and management of one's MS, consulting with a social worker to review personal factors that can have a direct influence on the ability to be productive in life while managing MS is as important, or even more so, than just trying to rehabilitate physically.

The social work department at the IMSMP provides basic care management. We have one-on-one meetings with our patients that are no longer able to work, as well as assist in navigating the private, group and Social Security Disability application process. We help review



**Yadira LaMazza, MSW &
Stephen Kanter, DPT**

insurance plan options (including Medicare) and important questions to ask the carrier before choosing a plan. The social workers can also provide information on government programs, attorneys who specialize in the Medicaid process, and assessment and referrals to agencies that offer services, such as home health aides.

The reason why advanced care management may be needed to supplement basic IMSMP social work services for people with MS, is that a care management agency can provide ongoing support on a regular basis. This can alleviate the burden on family members and the patient.

Yadira and Dr. Kanter, frequently meet and work with professionals and companies that provide advanced care management. Based on their discussions, they can provide the services needed for people who feel overwhelmed managing their insurance benefits and/or personal finances. In addition, they can help to determine ways to stretch your money to cover treatment while maintaining a desired life style. Advanced care managers can serve as your medical project managers so you can focus on staying healthy and enjoying life.

In some cases, care management services are covered by long term care insurance policies. For more information, please contact the IMSMP social work department for an appointment. The social workers will then collaborate with an IMSMP physical therapist to consider the best options for your situation.

The importance of advanced care management may be the difference between a person being able to live in their home or needing to move out. Additionally, advanced care management can help families of patients with MS to ensure finances are managed in a way to provide appropriate care with access to the right equipment to ensure the safety and well-being of the patient and all caregivers.

YOU'RE INVITED



Tisch MS Research Center of New York 20th Annual MS Patient Education Symposium

When: Sunday, October 22nd, 2017
9:30am—1:00pm (a snack box will be provided)

Where: New York Hilton Midtown
1335 Avenue of the Americas, NY, NY 10019

Join us for the largest, FREE patient education symposium. People with MS, their family members and caregivers are all welcome to attend. Learn from leading MS clinicians and Tisch MS researchers dedicated to providing the best possible treatments, including stem cell therapy, and discovering the cause of MS.

This year's speakers include: Deneb Bates, ND, Saud A. Sadiq, MD, FAAN, James Stark, MD, and Armistead D. Williams III, MD

***Guest Speaker:** Amy Stein, DPT, BCB-PMD ~ Dr. Amy Stein, an expert in pelvic floor dysfunction (PFD) will discuss PFD in people with multiple sclerosis.

REGISTRATION IS REQUIRED. SPACE IS LIMITED.

Register Today at: www.tischms.org Or call (646) 557-3919



DEVELOPMENT DEPARTMENT NEWS

Inspiring Events by Patients & Friends

2017 Take a Swing at MS Golf Outing

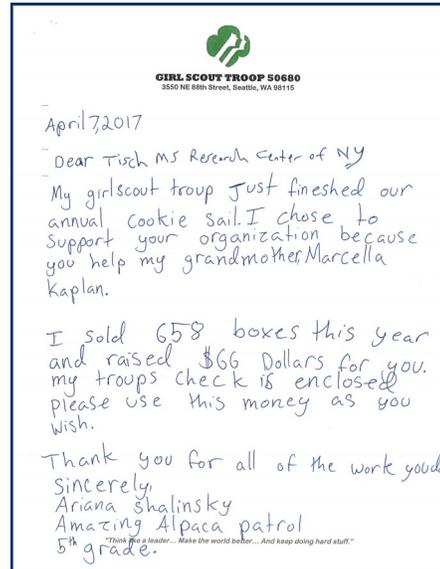
A special thank you to Michael and Gillian Bucceri, and Stephen Mandel on their 4th Annual Take a Swing at MS Golf Outing. The event, which took place Monday, June 12th at Crystal Springs Resort in Hamburg, NJ raised more than \$45,000 for our stem cell research. Thank you to all of the event sponsors, supporters, and in-kind donors who powered through the 96 degree weather to support our Center!



L to R: Ken Helman, Steve Albanese, Matt Albanese & Michael Bucceri

Big Things Come in Delicious Packages!

Thank you to Ariana Shalinsky, for supporting the Tisch MS Research Center in honor of her grandmother, Marcella Kaplan. While participating in The Girl Scout of America's annual cookie sale with her troop, Ariana raised \$66 for the Center and spread awareness about MS.



WITH SINCERE APPRECIATION, WE HONOR & RECOGNIZE OUR DONORS*

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The Tisch MS Research Center receives workplace giving funds from the United Way of New York City, United Way of Bergen County and the United Way Granite of New Hampshire. Inquire with your employer to participate.

The Tisch MS Research Center gratefully acknowledges corporate matching gifts from the following companies:

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*This list includes donors of \$500 or more received between May 1st and July 31st 2017. While every contribution is deeply appreciated, we regret that we are unable to list gifts below \$500 due to space limitations.

Every effort has been made to ensure the accuracy of this list. Please email Meaghan Browne, mbrowne@tischms.org or call (646) 557-3863 to report any errors or omissions, or if you would like to have your name removed from future listings.

IMSMP & Tisch MSRCNY
Saud A. Sadiq, MD, FAAN
Director

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Jamie Weinstein, RN, BSN
Shelly White, LMSW
Armistead Williams III, MD
Elizabeth Woods, PT, DPT, MSCS
Allan Zapanta, CNA

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Sara Endy, BA
Barbara Goldberg, MBA
Carmen Gonzalez
Galina Gurevich, BA
Leslie Hannan, BA
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Nyika Hollis
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Tammy Jordan, BS
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Sherly Sylvia, BA
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Aleksandra Wawryzniak, BA

Our Researchers

Gillian Carling, BA
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Antara Finney-Stable, BS
Jennifer Francis, BS
Violaine Harris, PhD
Anna Iacoangeli, PhD
Lena Josephs, BA
Nathan Kung, BA
Jerry Lin, BA
Matthew Mendelsohn, BA
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Jaclyn Murphy, MS
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