



# 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

## Annual Future Without MS Gala Raises a Record \$3 Million for Research at the American Museum of Natural History

Our deepest gratitude to all of our supporters, including Academy Award winner F. Murray Abraham who graciously emceed the Tisch MS Research Center of New York's annual *Future Without MS* Gala. The evening was a huge success raising critical funds needed for the groundbreaking research happening in the Tisch MS Laboratory. Mr. Abraham set the tone for the evening when welcoming the audience to the ballroom. "Don't tell me we can't beat MS," Abraham declared. "We can beat MS but it takes a lot of money ... One day my wife, Kate, like so many of you, will stand before us and say, 'I am completely cured.'"

Four hundred guests attended the gala at the New York City landmark American Museum of Natural History on October 17, 2019. Cocktails and hors d'oeuvres were enjoyed among the iconic dinosaur skeletons in the museum's Rotunda. Dinner was served beneath the colossal sperm whale in the Hall of Science, with musical performances before Auctioneer Pat Tully took the stage and entertained guests while they bid on fabulous prizes.

After one of the most successful live auctions to date, guests watched an emotional video presentation featuring IMSMP patients and highlighting the work of principal investigators Dr. Jamie Wong and Dr. Anna Iacoangeli. In the video, patients shared what a world without MS would look like to them. For Dr. Sadiq, given his lifelong quest to find the cause and one day a cure for MS, a world without the disease would look like "destiny fulfilled."

The night concluded with Dr. Sadiq, joined by F. Murray Abraham, announcing this year's gala was the most successful ever, raising a record \$3 million.



Four hundred guests filled the Hall of Science at the American Museum of Natural History

## Winter 2019 Volume 3, Issue 45



F. Murray Abraham and Dr. Saud A. Sadiq at the *Future Without MS* Gala



Tisch MSRCNY Board Members David and Jeanette Rosenblum



IMSMP and Tisch MSRCNY Staff ready to check-in guests in the Rotunda

### INSIDE THIS ISSUE

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## TISCH MS LABORATORY RESEARCH

### Tisch MSRCNY Presented Research at the Society for Neuroscience

Tisch MSRCNY is proud to announce that six posters were presented at the Society for Neuroscience (SfN) Annual Meeting in Chicago, Illinois on October 19-23, 2019. Jerry Lin, BA, Jamie Wong, PhD, Anna Iacoangeli, PhD, Nicolas Daviaud, PhD, and research assistants Clara Arndsten, BA, and Jacelyn Greenwald, BA attended the conference. Here are the posters:

#### **Metabotropic glutamate receptors are implicated in cerebellar dysfunction in multiple sclerosis**

*Clara Arndsten, Natalie Favret, Anna Iacoangeli, Saud A. Sadiq*

Cerebellar dysfunction (CD) is a difficult to treat symptom of multiple sclerosis because the mechanisms of CD are not fully understood. Dr. Iacoangeli and her team developed a mouse model of cerebellar dysfunction in order to better understand the disease. From this model, they learned that a group of glutamate receptors, group 1, may be involved in CD and should be investigated further.

#### **Expression profile of neural, trophic, and immunomodulatory genes in multiple sclerosis donor-derived mesenchymal stem cell-neural progenitors**

*Jacelyn Greenwald, Saud A. Sadiq, Violaine K. Harris*

Mesenchymal stem cell-neural progenitors are currently being studied in our Phase II trial as a potential treatment for progressive MS. While the treatment effect of the stem cells has been demonstrated, we want to fully understand their molecular characteristics. Through this study, Dr. Harris and her team investigated the genetic profile of these stem cells. Preliminary results have identified potential pathways that are responsible for the therapeutic mechanisms of these cells.

#### **CNS pathology and motor deficits observed following injection of multiple sclerosis CSF derived recombinant antibodies is limited to primary progressive MS**

*Francesca Cali, Alexandra Tse, Jamie Wong, Jerry Lin, Saud A. Sadiq*

Previous research at our center has demonstrated that injection of primary progressive MS (PPMS) cerebrospinal fluid (CSF) in mice results in motor deficits. Jerry's team, with the help of Dr. Wong, hoped to identify the molecular cause of these motor deficits. Their results indicated that

antibodies derived from PPMS CSF likely contribute to the motor deficits seen in mice and further research should be done to understand the role of CSF antibodies in MS.

#### **Expression profiles of noncoding RNAs in the CSF of PPMS and RRMS patients**

*Anna Iacoangeli, Natalie Favret, Clara Arndsten, Saud A. Sadiq*

Previous studies of the expression profiles of noncoding RNAs (ncRNAs) have been useful in understanding and diagnosing several diseases. Dr. Iacoangeli's team hoped to identify markers in PPMS and RRMS patients that may provide diagnostic and molecular information about MS. From their work, they discovered that there were many ncRNAs that were different in PPMS vs. RRMS, in particular vault RNAs. Further research should be done to understand the functional meaning of these RNAs in PPMS.

#### **Experimental evidence that disease pathogenesis in sporadic ALS is unique and distinct from that seen in familial ALS**

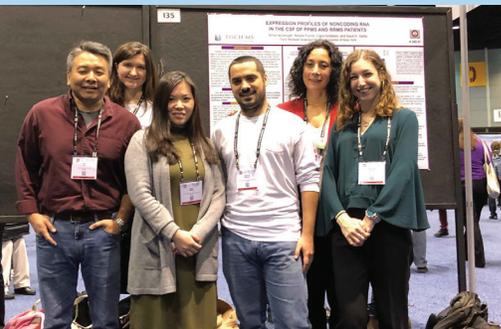
*Anna Roselle, Serena Shimshak, Jamie Wong, Saud A. Sadiq*

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disorder characterized by motor neuron death. There are two types of ALS, sporadic, which is the most common, and familial, which is associated with a genetic mutation. Dr. Wong's team hoped to understand if the mechanisms of disease in these two types were the same. They studied the effect of cerebrospinal fluid from ALS patients on mice and their findings suggest that the disease mechanisms for sporadic ALS and familial ALS are distinct.

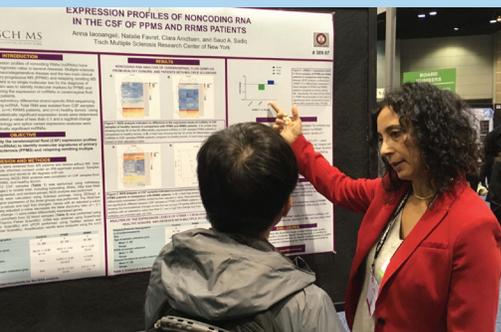
#### **Cerebrospinal fluid pheresis may have therapeutic value in primary progressive multiple sclerosis**

*Jamie Wong, Anna Roselle, Serena Shimshak, Laura Zitella Verbick, Natalie Nazarian, Aaron McCabe, Saud A. Sadiq*

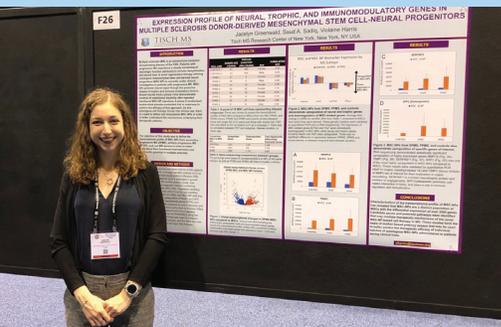
Previous research by Dr. Wong's team demonstrated that when PPMS CSF is injected into mice, it induces motor deficits. In this study, they hoped to evaluate if filtering the CSF would remove the molecules that induced the motor deficits. They used a filter developed by Minnetronix and their results indicated that the filtered CSF did not cause motor deficits in mice. Further research needs to be done to understand the treatment implications in MS patients.



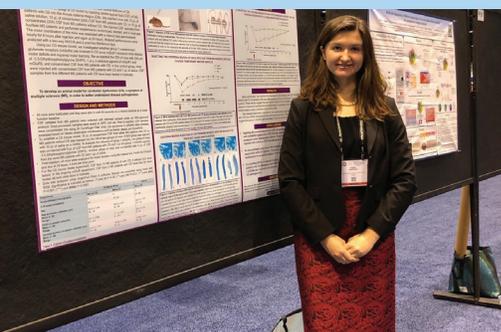
Members of the Tisch MSRCNY team at the Society for Neuroscience (SfN) Annual Meeting in Chicago



Dr. Anna Iacoangeli explains her research



Research Assistant Jacelyn Greenwald with her abstract poster



Research Assistant Clara Arndsten with her abstract poster

## 22<sup>nd</sup> ANNUAL TISCH MS RESEARCH CENTER PATIENT SYMPOSIUM

### Thank You For Attending!



**Dr. Saud A. Sadiq presenting at the Symposium**

Tisch MSRCNY and the IMSMP would like to thank everyone who attended the Tisch MS Research Center of New York’s 22<sup>nd</sup> Annual Patient Education Symposium. This year, we were honored to host guests from Ireland, Madrid, Canada, Connecticut, Delaware, Florida, Kansas, Maryland, Missouri, New Jersey, North Carolina, Oregon, Pennsylvania, Texas, and Virginia, to name a few! Over 400 guests gathered in the grand ballroom of the New York Hilton Midtown to watch

presentations focused on treatment algorithms, lifestyles that promote wellness, and breakthroughs in MS research.

Our patient profile panel, hosted by Yadira LaMazza, the Director of Social Services at the IMSMP, illustrated that while MS is one disease, everyone’s MS story is different. In this inspiring segment, a few patients shared their journey and how they are “Making Meaning with an MS diagnosis.”

Later in the day, Dr. Sadiq addressed new research happening in the Tisch MSRCNY Lab and illustrated the advancements we are making in understanding progressive disease.

In response to the multiple requests for the information that was presented, we have posted the majority of the PowerPoint slides on [www.tischms.org](http://www.tischms.org). They may also be found on our Facebook page at [www.facebook.com/TischMSRCNY/](https://www.facebook.com/TischMSRCNY/).

We would like to thank all of those who took a moment to complete our survey and offered feedback on ways to improve upon next year’s event. Plans are already in the works. We hope to see you there on **Sunday, September 13, 2020!**



**Dr. James Stark discussed the concept of NEDA (No Evidence of Disease Activity), how patients are evaluated for NEDA, and the important differences between a relapse and pseudorelapse**



**In his talk, Dr. Armistead Williams spoke about the process involved in overcoming challenges**



**Dr. Deneb Bates discussed how we can “Do Better” by managing stress, minimizing exposures, and understanding the role of food to make better choices**



**In this inspiring segment, Yadira LaMazza spoke with a patient panel to find out how they are making meaning with their MS diagnosis**

## 22<sup>nd</sup> ANNUAL TISCH MS RESEARCH CENTER PATIENT SYMPOSIUM

### How Do You Make Meaning?



23<sup>rd</sup> Annual Tisch MS Research Center Patient Symposium  
Sunday, September 13, 2020  
New York Hilton Midtown

## NEW PERSONNEL

### Welcome to the Team!

Please join us in welcoming three great additions to the Center. Courtney McKoan joins our nursing team, Alifiya Tahir is our Clinical Trials Manager, and Balram Boodhram is our new Bookkeeper.



Courtney McKoan, RN, BSN

Please join us in welcoming our new nurse, Courtney McKoan, RN, BSN. Courtney started at the IMSMP on August 26, 2019. Courtney graduated from the College of New Rochelle in 2017 and began her nursing career at Mount Sinai Hospital in their Neurology and Neurosurgery unit. In her time working at Mount Sinai she gained valuable experience about MS care and is excited to have the opportunity to work with our patients here at the IMSMP.



Alifiya Tahir, BDS, MPH

Alifiya Tahir received her training in dentistry from India. She further pursued a Master's in Public Health with a concentration in Epidemiology and Biostatistics from Rutgers University. Alifiya began working at Tisch MSRCNY in May 2019. Alifiya coordinates and implements the processes and protocols of the phase II stem cell trial for MS. Prior to joining Tisch MSRCNY, she worked as a Clinical Research Scientist at a specialty pharmaceutical company. She helped design and run clinical trials in pediatric ophthalmology, and acute pain. Alifiya has published scientific research papers, a book chapter in emergency medicine, and a poetry book. She is excited to be a part of Tisch MS Research Center of New York and looks forward to working with the clinical trial patients.



Balram Boodhram, AAS

Balram Boodhram joins us from Queens, New York. Prior to starting at the IMSMP, he worked as an accountant at Selfhelp Community Services, Inc., a social service company as part of the Department for the Aging. Balram graduated from the University of Guyana with a degree in Accounting and later with an associate degree in Accounting from Queens Borough Community College. He is thrilled to join the accounting team at the IMSMP and looks forward to making a difference in the lives of people with MS.

## FROM THE FRONT DESK

### Please Be Advised:

**If you receive an insurance check for services rendered at the IMSMP or MRI center, that check MUST be mailed to:**

**International MS Management Practice  
521 West 57<sup>th</sup> Street, 4<sup>th</sup> floor  
New York NY 10019**

**Checks do NOT need to be endorsed. Patients should NOT be cashing checks to pay with a credit card.**



## SOCIAL WORK NEWS

### Making Meaning in Your Life with an MS Diagnosis



**Eve Budkins with her children**

I was a wife, an orthopedic physical therapist in a busy practice, and I had a 2-year-old and a 6-month-old at home. I was nursing my 6-month-old when I noticed my entire left arm was numb and my hand was not working well. I also realized the left side of my face and my left leg didn't feel right. Must be the long hours of caring for a baby while in uncomfortable positions, right? Nope, not right! I had multiple sclerosis! The diagnosis came quickly and with the force of a freight train. I was knocked down, to say the least. I was so overwhelmed with the diagnosis that I couldn't eat, I couldn't sleep, I couldn't think straight. I could not function as a wife or a mother, and I certainly could not return to work and take care of patients.

I was fortunate to have a mother-in-law who was familiar with the IMSMP and I was able to consult quickly with Dr. James Stark. Upon meeting Dr. Stark I let out a huge sigh of relief that I didn't even realize I was holding in. His initial words to me were, "You will be ok!" Simple words, but mind-altering for me. Of course Dr. Stark delved into the diagnosis, the anatomy, and the treatments available, but he also spoke to me as a person and not just a patient. He knew my mind had gone off the rails and he knew just what to say to bring it back. He also recognized that I felt alone and he made sure I understood that I was not. He soon referred me to his associate, Yadira LaMazza, Director of Social Work Services, and the IMSMP support group that she ran. I remember meeting with Yadira thinking, "I am not one to share thoughts and feelings" and that this would not be "my thing." After a few minutes with Yadira I couldn't stop talking. I had held so much

in since the diagnosis and I didn't even realize it needed to come out. I started meeting with the support group once a month, under Yadira's guidance, and my world began to change. I was able to sit in a room with others who knew exactly how I felt. Even though each one of us had a different presentation of the disease, we all understood the language we were speaking. We could "describe the indescribable" symptoms of MS and we all understood. My family is amazing and could not be more supportive. However, they do not have MS. Those without multiple sclerosis listen and support, but can't truly understand. That is why the support group was critical for me. After each meeting with the group I always felt better and it was mostly because I realized I was not alone.

I was also encouraged to meet with the naturopathic doctor, Dr. Deneb Bates through my support group. Dr. Bates had helped many from the group and I wanted in! Soon after meeting with Dr. Bates I was taking vitamins and considering food in a way I never had before. Through blood work, she could confirm that my anxiety and lack of energy was real. It wasn't just "all in my head!" That was also comforting and helped me push forward. Six months after my diagnosis I was on the right medication, I was talking freely about my diagnosis, I was living with my symptoms, and I was no longer deathly afraid. I was taking control of my life again and not letting MS define me. It was a struggle but I literally peeled myself off of the couch and forced myself to live. I returned to work and was present for my family. Focusing my attention elsewhere took my concentration off of my diagnosis. Not thinking about MS helped me deal with MS. The mind is a powerful force and I needed to learn how to positively channel my thoughts and energy. Yes, the possibility of the next MS flare is always lurking in the background but I don't let the thought of it take center stage for too long.

I keep busy with work, family, friends, and I even find myself at the support group helping others cope and "not feel alone." I needed to accept the diagnosis, understand

the diagnosis, and talk about it. I might have multiple sclerosis, but I am NOT multiple sclerosis. I am so thankful to have been directed to the IMSMP. The doctors and clinicians there have helped me redirect my thoughts and ultimately my life. Help is available in many different forms at the IMSMP and it is there for the taking!

To learn more about the social work services and support groups available at the IMSMP, please call (212) 265-8070.

## NEWS ON NATUROPATHY

## Fasting and Multiple Sclerosis

Fasting is a hot topic in neurological disease research, and for good reason. Strategies that alternate fasting and feeding, which we've mentioned previously as "Cyclic Calorie Restriction," prevent and treat neurological disorders in animal models of diseases, including the animal model of multiple sclerosis. Modified fasting in the animal model of MS reduces autoimmunity, enhances regeneration of myelin making cells, and improves repair in areas of the brain damaged by the disease[1]. New research continues to show that by reversing age-related changes in stem cells, fasting restores the regenerative capacity of aged cells and promotes formation and function of myelin making cells, which improves remyelination[2].

Taking short breaks from regular food consumption can delay aging and prevent and treat metabolic syndrome, both risk factors in a variety of neurological diseases. Fasting has a powerful effect on cell synthesis and degradation. When we are constantly fed, our bodies are always in growth and storage mode. When energy reserves are low (which we can induce by fasting) the intracellular degradation pathway kicks in to clear misfolded proteins and damaged organelles, recycling nutrients and improving energy production[3]. Chronic food consumption without a break is like hoarding junk, while fasting gets rid of old, broken and dysfunctional cells and cellular garbage. Think of this like the Marie Kondo method for tidying up your cells. Fasting may be the equivalent of the "life-changing magic of tidying up" for body and brain, improving function of aging cells and making room for repair.

Fasting and feeding can both be good and bad - the benefits come from balancing the two. Humans are built to work like hybrid engines, alternating between using ketones and carbohydrates as fuel. During times of fasting, organisms alter their metabolism, which increases stress tolerance, conserves resources, and enhances longevity. While fasting, the body converts stored fats to ketones for fuel, and turns on mechanisms to clear damaged cells and help with brain cell survival.

When eating a diet with abundant carbohydrates, the opposite pathways engage, emphasizing remodeling and growth. It is this switching, back and forth, that creates the best circumstances for healthy brain cell metabolism. While both excessive fasting and excessive feeding can be harmful, the balance achieved by alternating between the two states seems to be optimal for brain health and longevity.

An especially compelling benefit to therapies that involve short-term food restriction is that fasting and medication-based therapies can be complementary, and do not need to be mutually exclusive. There are many different fasting regimens, and until more research is done on fasting in humans with MS, the best regimen for you depends on your body type and metabolism, as well as personal preferences and tolerance of fasting. Fasting is not for everyone, particularly anyone at risk for malnutrition, pregnant or breast-feeding women, those with type I diabetes or kidney disorders, and people over 70. Therapeutic fasting should be done in partnership with a doctor. Schedule an appointment with Dr. Bates to learn more.

1. Choi, I.Y., et al., A Diet Mimicking Fasting Promotes Regeneration and Reduces Autoimmunity and Multiple Sclerosis Symptoms. *Cell Rep*, 2016. 15(10): p. 2136-2146.
2. Neumann, B., et al., Metformin Restores CNS Remyelination Capacity by Rejuvenating Aged Stem Cells. *Cell Stem Cell*, 2019. 25(4): p. 473-485 e8.
3. Phillips, M.C.L., Fasting as a Therapy in Neurological Disease. *Nutrients*, 2019. 11(10).



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## DEPARTMENT OF REHABILITATION SERVICES

### The Role of Occupational Therapy for Patients with MS



**IMSMP Occupational Therapist Jaelyn Spechler works with a patient on ADLs**

This year, the IMSMP started offering neurologic focused occupational therapy services. This is currently available in the Department of Rehabilitation Services. Occupational therapy represents one of several new disciplines being integrated in preparation for the new wellness center scheduled to open in 2020.

Occupational Therapy (OT) is a rehabilitation specialty that focuses on every day and meaningful activities. The goal of an occupational therapist is to ensure you can do everything you want to do on a daily basis as independently and as safely as possible. Treatments that are offered can span across many different areas of one's life. Here at the IMSMP, we have focused individualized neurologic OT services. This is provided in a one-on-one environment where patients may include their family and caregivers during the OT session. Patients with multiple sclerosis have different needs, desires, and abilities. Therefore, an individualized session can address the patient's MS-related impairments, but also those beyond the MS.

During an OT session, the evaluation and treatments include addressing mobility and overall functional needs. In some ways, the session may mimic what can be done in a physical therapy session. A difference in the approach taken by an OT is the goals are more specific to succeeding at completing a desired task. For example, a physical therapist can provide treatments to train a person to safely move from the bedroom to the kitchen, but an occupational therapist will show strategies on how to perform tasks in the kitchen, such as getting food out of the refrigerator or preparing a meal. An OT can help patients learn how to get clothes from their closets and put them on and take them off more effectively. An OT uses strategies that not only incorporate strengthening and flexibility exercise but also integrate cognitive aspects of movement such as organizing tasks and managing fatigue.

OTs have a unique set of skills to consider options for how to adapt a task to make it easier or introducing tools to assist with the tasks to promote a higher level of independence. For example, if a person with MS still performs a task independently, but is starting to have more difficulty or the task is more

fatiguing, an OT treatment program may be the difference in one becoming dependent on a caregiver versus keeping that independence.

Activities of daily living (ADLs) are the functions that OT focuses on. This includes your ability to perform feeding, grooming, bathing, toileting and dressing tasks. Another, more complex, area of OT focus is instrumental activities of daily living (IADLs). This category includes meal preparation tasks, home management tasks, caregiving (of pets, elders or children) and more. ADLs are activities that are associated with taking care of one's own body whereas IADLs are activities within the home/out in the community that supports daily life goals. Often, people with MS find ways to accomplish the tasks associated with ADLs and IADLs, but they may be unsafe and/or may be inefficient which can lead to falls and further disability. An OT program can make a significant difference with this, especially in the long term.

OT professionals are also able to assess functional cognition as well. That means they look at how ones' thinking and processing pertains to daily and meaningful activities. They then set up a plan with techniques to assist. OT and PT professionals can provide posture re-education, wheelchair screenings, balance training, brace assessments, and transfer training. The other occupational domains that can be focused specifically during an OT session are sleep preparation, education, work (including volunteer), play, leisure, and social participation. These are elements of healthcare that cannot be best provided through physical therapy alone. The OT professionals' role allows people with MS to appropriately address their impairments from all angles, rather than focusing on exercises alone.

Patients of the IMSMP can call (212) 265-8070 to schedule an appointment with Jaelyn Spechler, OTR/L for an evaluation or you can speak with your neurologist to be referred to an occupational therapist near you.

## DEVELOPMENT DEPARTMENT NEWS

### Team Tisch MS

With 14 team members running the 2019 TCS NYC Marathon, it was a busy October for Team Tisch MS! In preparation for the race, held on November 3<sup>rd</sup>, some team members held events to help reach their fundraising goals.

Molly Caughlan and Fiona McMahon, both of Beyond Basics Physical Therapy, held a running clinic on October 3<sup>rd</sup>. The event focused on improving performance and maintaining running health, two critical pieces of running a marathon!

Tisch MSRCNY's own Francesca Cali also hosted her own fundraising event on October 16<sup>th</sup> at Kettle of Fish. She held raffles for a variety of fabulous items, including SoulCycle and Flywheel classes, and a Milk Bar cake!

If planning a fundraising event wasn't enough, these runners also had to actually run the marathon. On November 3<sup>rd</sup>, Team Tisch MS hit the race course, with all participating runners finishing the race! We'd like to thank all of our marathoners for their support of Tisch MSRCNY:

- Lindsay Appel
- Morgan Appel
- Molly Caughlan
- Francesca Cali
- Brandon Hohm
- Dawn Madell
- Angela Marcucci
- Fiona McMahon
- Brenna Nelinson
- Joni Russell-Kelly
- Liz Russell-Kelly
- Danielle Small
- Kyle Smith
- Paul Smith

Tisch MSRCNY holds a special place in many of our runner's hearts. Brandon, Dawn, and Joni are all patients at the IMSMP. Danielle Small ran in honor of her cousin, Scott, another IMSMP patient; Paul Smith ran in honor of his wife, Lisa.

After the race, they headed to Park Avenue Tavern to celebrate their successes, both on and off the race track. This year's marathon team raised \$68,000, and TTMS as a whole raised \$111,000. A great time was had by all and we can't wait for next year's marathon!

If you are interested in participating in a race or obstacle course to support Tisch MSRCNY's research, please email [ttms@tischms.org](mailto:ttms@tischms.org) to get started!



Members of TTMS celebrating at the post-marathon party at Park Avenue Tavern



TTMS Member and IMSMP patient Dawn Madell completing the marathon



Angela Marcucci starting the race on the Verrazzano-Narrows Bridge



This Uncle and Nephew Duo, Paul and Kyle Smith, completed the race together



Joni and Liz Russell-Kelly training for the big day

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## DEVELOPMENT DEPARTMENT NEWS

## Deneroff Lapathon Makes Another Splash this Year



Patricia Deneroff's grandniece, Jeena

Patricia Deneroff is no stranger to diving into the deep end, whether it be in life or in the pool. She kicked off her 5<sup>th</sup> annual lapathon this past Labor Day, swimming laps in her pool to raise money for Tisch MSRCNY. Despite the rainy day, Patricia was able to complete 50 laps, with her grandniece Jeena swimming 50 additional laps the following week. The family affair raised \$15,000 for Tisch MS Research Center of New York and has raised \$86,000 since the event's inception in 2015. Thank you, Patricia, Jeena, and all of the lapathon supporters for another fantastic year!

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\*This list includes donors of \$500 or more received between August 1 & October 31, 2019, not including contributions supporting the 2019 Future Without MS Gala. While every contribution is deeply appreciated, we regret that we are unable to list gifts below \$500 due to spatial limitations.

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