



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

Tisch MS Research Center of New York's Priorities, Direction & Investigations for 2018-2021

In 2001, our research center led by Dr. Saud A. Sadiq began an initiative to develop a reparative therapy for MS patients with established disability. Following several years of laboratory-based research developing a cell therapy and establishing efficacy in animal-based models of the disease, we were able to get FDA-approval for a Phase I clinical trial. Our Phase I trial was completed in 2017 and the results that were published earlier this year showed safety and tolerability, as well as encouraging efficacy trends. At Tisch MSRCNY, a commitment was made to invest in this novel treatment with the goal of bringing this therapy into clinical practice. A \$5 million state-of-the-art Regenerative Medicine Laboratory was completed in March 2018 and we are now ready to embark on a landmark three-year Phase II clinical trial to hopefully establish the effectiveness of our stem cell treatment.

Moving forward we have established the following three projects as priorities for the upcoming years.

To better understand and treat coordination and balance difficulties in patients with MS. In some people with MS, the major reason for disability is a lack of coordination with their limb function. These patients have great difficulty with daily activities, including writing and walking. The area of the brain that is responsible for coordination is a cauliflower-like structure found at the base of the brain called the cerebellum. Unfortunately, this phenomenon does not respond to currently available medications and physical therapy has limited benefits. Dr. Anna Iacoangeli and her team are creating experimental models of the disease to identify the factors that lead to cerebellar dysfunction. In addition, her team is also investigating if there are unique molecular or protein signatures in the blood or cerebrospinal fluid (CSF) of patients that develop cerebellar disease. We hope that in the next three years we will translate what we learn from our experiments to develop rational therapeutic strategies. Finally, we hope to also initiate clinical trials later this year using novel approaches to better treat patients with balance difficulties.

To create an experimental model of progressive MS that will enable us to better understand and treat patients with secondary progressive MS (SPMS) and primary progressive MS (PPMS). In preliminary work, Dr. Jamie Wong and her research team have made some remarkable progress. Injecting minute quantities of CSF derived from PPMS patients directly into the CSF of the cervical spine of mice results in weakness of the limbs and demyelination.

(continued on next page)



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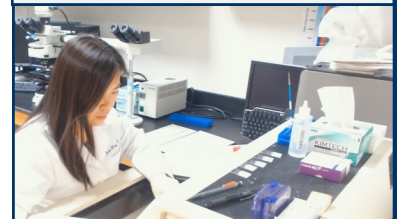
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Jerry Lin



**Dr. Anna Iacoangeli (L) with
Natalie Favret**



Dr. Jamie Wong

INSIDE THIS ISSUE

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- Thank You to Our Donors

TISCH MS LABORATORY RESEARCH

(continued from cover)

Validation of this work is currently underway. These studies should allow our scientists to map the factors that lead to disease progression and also to develop new treatment strategies. The hope is that disease progression can be arrested in SPMS/PPMS patients so that repair strategies, such as our stem cell treatment, can be optimally effective. One approach that is being investigated is to cleanse out the damaging factors in CSF by a process of “pheresis.”

Finally, and perhaps most importantly, we need to identify the initial trigger(s) that cause MS. This has been a central goal of the Tisch MS Research Center of New York since its inception. This work has recently been boosted due to a grant from the Emerald Foundation. Jerry Lin and associates have made immense strides in elucidating the CSF antibody response in patients with MS over the past decade. We have

studied several thousand single antibody-producing cells (B-cells and plasma cells) and have tried to determine if they react with a number of myelin targets found in the human brain. We are also investigating the link with the Epstein-Barr virus to establish how the immune system in patients with MS escapes self-tolerance and becomes autoimmune. In some patients, we have found environmental trigger factors and are currently working on animal models to firmly establish these findings.

These priorities require additional funding and establishment of an experimental disease laboratory that we are planning to build adjacent to our recently completed Regenerative Medicine Laboratory. We are excited by the tremendous progress of our research in the past decade and are dedicated to finding the elusive cause of this disease and pave the path to an eventual cure.

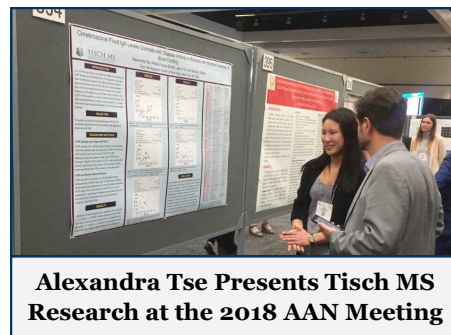
Research Presented at the 2018 American Academy of Neurology® (AAN)

Annual Meeting

On April 21st-27th, 2018, Dr. Sadiq, Dr. Williams, Dr. Bates, and six members from the Tisch MSRCNY lab attended the 70th Annual American Academy of Neurology conference in Los Angeles, California. Our team presented four posters and spent the week immersed in the latest research and treatment innovations in the field of neurology. Our team presented, “Effects of MS Donor-Derived Mesenchymal Stem Cell-Neural Progenitors (MSC-NP) on Microglial Polarization,” “Cerebrospinal Fluid S-Adenosyl Methionine Levels are Decreased in Multiple Sclerosis Patients,” “Cerebrospinal Fluid Derived from Primary Progressive MS Delays Remyelination After Lysolecithin-Induced Demyelination,” and “Cerebrospinal Fluid IgA Levels Correlate with Disease Activity in Patients with Multiple Sclerosis, A Novel Finding.”

For many of the research assistants, it was their first opportunity to attend a professional medical conference where they were able to interact with their peers and leaders in the field of neurology, as well as present the work being done at Tisch MSRCNY.

“I found my first trip to the American Academy of Neurology conference very rewarding because I was not only able to present the research I have been working on but was also able to see and



Alexandra Tse Presents Tisch MS Research at the 2018 AAN Meeting

discuss the work of established neurologists from around the world,” said Alexandra Tse, a first-year Tisch MSRCNY research assistant.

Our team was particularly excited about some of the recent advancements in medical technologies aimed at improving the monitoring of MS symptoms at home. These exist in the forms of mobile apps and biosensor devices. The use of these devices enables a novel approach to study the day-to-day physiological changes in patients with MS. Physicians are also using AI (Artificial Intelligence) and machine learning technologies to integrate data gathered from these devices with electronic medical records to produce a more comprehensive medical platform, which will improve clinical research and patient care.

A NOTE FROM THE NURSES

Taking Accountability is Taking Control

One of the most empowering actions a patient can do for his or herself is to take personal accountability. Staying on top of your healthcare plan is a way to prevent a delay in treatment, which could lead to a worsening of your disease.

When on an MS disease-modifying agent, one of the most important things you can do for yourself is to make sure you are fully educated on your medication. Whether it is an oral agent, an injectable, or an infusion, knowing the potential side effects, correct dosing, safety bloodwork monitoring involved, the frequency of doses, or when prescription refills are needed, are all ways of taking ownership.

One MS treatment in particular that requires important follow up is Rituxan®. Since Rituxan usually involves infusions only twice yearly, we ask our patients to take accountability for their continuity of care. Here are a few tips on how to take action:

1) Document your completed infusion(s) in your calendar, appointment book, mobile phone, or any other device you use to track your appointments. Please call us to let us know your infusion dates, so that we can update it in our system as well.



2) Place a reminder for four to five months from those dates to call the Center and tell us when you will be due for your next infusion(s). Our volume of Rituxan patients is so large, that this will only help us, as nurses, to take accountability as well.

3) Please keep in mind that bloodwork is medically necessary prior to every infusion. By calling our Center to remind us that you are due, we can prepare and send your bloodwork prescription to initiate your next infusion(s).

4) Keep in mind that the approval process for Rituxan can be quite lengthy due to the insurance companies. Please be patient as the Rituxan team will do our best to prevent delays.

As for all other treatments that require refills through a pharmacy, take accountability by utilizing our prescription phone line. If you know you are running low on your medication, please call the nurses to request a refill Monday-Friday from 9am-3pm, to avoid running out of medication. Please be conscious, especially towards the end of the week, as this service is NOT available on weekends.

NEWS ON NATUROPATHY

Looking for Pain Relief? Weight Loss May Hold Unexpected Benefits

Widespread body pain often coexists with fatigue, cognitive difficulties, depression, and sleep problems. This constellation of symptoms is even more common in people dealing with obesity. Obesity is a disease of inflammation and is strongly related to the production of pro-inflammatory messengers (cytokines) in the body. Inflammation is also a component of autoimmune diseases and many of their related symptoms, including fatigue, cognitive and mood difficulties, and pain.

A recent study showed that widespread body pain, fatigue, and depression improved when study subjects committed to a calorie restricted weight loss program[1]. Participants who lost 10% or more of their body weight saw the greatest improvements. The researchers were surprised that the pain reduction was not limited to joints and weight-bearing areas, but that they found a



reduction in global pain as well. They also noted improvement in mood and fatigue and provided evidence that the benefits were through anti-inflammatory changes in the central nervous system's pain mechanisms.

Dr. Deneb Bates, the IMSMP's naturopathic doctor, is here to help you with dietary strategies to manage your weight, as well as the related symptoms of pain, fatigue, mood, and cognitive function. Contact the IMSMP to schedule an appointment.

[1] Schrepf, A., et al., Improvement in the Spatial Distribution of Pain, Somatic Symptoms, and Depression After a Weight Loss Intervention. *J Pain*, 2017. 18(12): p. 1542-1550.



**Wear Your Shirt!
Send Us a Pic!**



**2017 TTMS Racers
Tessa Grant & Whitney Mallis**

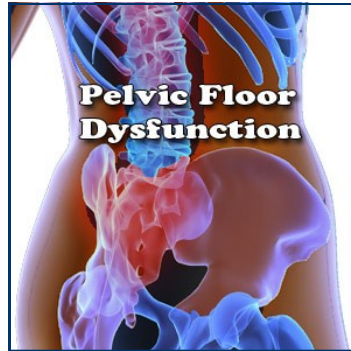
Support TTMS and get the word out by wearing your Team Tisch MS Supporter shirts proudly. Send pictures of you wearing your TTMS shirt to: ttms@tischms.org so we can show the world that we are all part of the mission to repair MS!



**2016 TTMS Racer
Mireya Montalvan-Panzer**

PHYSICAL THERAPY & REHABILITATION

Pelvic Floor Physical Therapy for Treatment of Bladder, Bowel, and Sexual Dysfunction



For people with multiple sclerosis there is a common, and often obvious, need for the use of physical therapy (PT). PT is considered a primary way for people with MS to improve their ability to walk, prevent falls, decrease spasticity, and improve overall independence in physical function. Less often thought about is the role of physical therapy to improve one's bladder, bowel, and sexual functioning.

Pelvic floor dysfunction (PFD) is not exclusive to people with neurologic conditions, such as MS, but can be something that people of all ages and abilities can experience. Simply defined, PFD is the inability to control the muscles of the pelvic floor. The muscles of the pelvic floor act like a sling for the organs that are responsible for urination, bowel movements, and sexual intercourse. When there is an issue with these muscles working together in a coordinated fashion a person may experience incontinence, urge, leakage, constipation, pain with urination, pain or pressure in the pelvic region or lower back, or sexual discomfort and difficulty. People with MS may experience these symptoms due to denervation, muscle weakness, muscle spasms or incoordination of muscle activity. If someone with MS is experiencing

any of the described PFD symptoms, in addition to seeing a urologist and/or gynecologist, a referral to a pelvic floor physical therapist can be greatly beneficial.

This specialty in physical therapy is relatively new. It has grown significantly since medical treatment alone may not address parts of the problem, such as the reason for the symptoms. Kegel exercises and biofeedback were common PFD treatments. Now, there are clinicians who have earned the Pelvic Rehabilitation Practitioner Certification (PRPC) and/or Woman's Certified Specialist credentials who can provide a customized evaluation and treatment plan to address PFD. PFD in MS is common in males and females, and these services are available to all patients.

Poor balance, fatigue, and trunk weakness can be linked to PFD. The IMSMP physical therapists, Dr. Stephen Kanter and, Dr. Elizabeth Woods, consider PFD during evaluations for all patients who have core weakness along with any reported bladder, bowel, or sexual dysfunction. Referrals to PFD professionals can be made and included in the overall physical therapy plan of care. Symptoms that you think may be linked to PFD should be communicated to your neurologist, nurse, and physical therapist to ensure you get treated to properly address this condition.

SOCIAL WORK NEWS

Making Meaning in Your Life with an MS Diagnosis



Chris Kaklamanakis

Chris Kaklamanakis has been a patient at the IMSMP since 2006. He has worked closely with Dr. Armistead Williams, our PT department, and Dr. Bates throughout the years. In this edition of, “Making Meaning in Your Life with an MS Diagnosis,” Chris shares how, although he struggles at times, he lives life to the fullest with MS.

“I first began experiencing symptoms of MS at the beginning of 2006. This included leg weakness, foot drop, hand weakness, and at least half a dozen more. It was

all very sudden and it had come out of nowhere. I really didn’t know what to make of it. Then one night I got out of bed and fell on the floor. I couldn’t get up on my own, I needed assistance. The next day I saw my family doctor. He sent me for an MRI and that night I ended up at Roosevelt Hospital where I spent 12 days and first met Dr. Armistead Williams. I was 39 years old and had never experienced any of these symptoms before, this was all very new and scary.

My first five years with MS were very difficult, I went through five different treatments and nothing worked. Two years after my diagnosis I began using a cane, and after four years, a wheelchair. I was sick and unhealthy, spending most of my days at home, isolating myself. I didn’t have the strength or desire to do anything meaningful. I was a mess. Things were not looking good for me and I didn’t expect them to get any better but much to my surprise, they did.

In 2011 things began looking up for me. I started Rituxan and saw Dr. Deneb Bates for my first

naturopathic consult. Dr. Bates guided me towards a healthy lifestyle for which I am eternally grateful for. While taking Rituxan and making dietary and exercise changes, I found myself feeling pretty good most of the time. I truly felt blessed, as if I was given the opportunity to start over. I joined a gym, started swimming, and began driving again after not being behind the wheel for five years. I also went back to work, selling appliances at Home Depot and I enjoy it.

Exercise, diet, and treatment, have allowed me to live an almost normal life. All these changes did not start immediately, they took time and a lot of hard work, just like anything else that is worthwhile. I still have some bad days, but now I have more good ones. At 51 years of age, this is not where I expected to be but I’m thankful for where I am. I’m working, driving, living, and I’m looking forward to seeing what tomorrow brings.

Thank you to Dr. Bates, Dr. Williams, Dr. Kanter, and Dr. Woods, I am where I am today because of them.”

The Caregivers Support Group Seeks New Members



The Caregivers Support Group has been meeting for the past eight years at the IMSMP. It is a safe place where spouses/partners can talk about and share ideas on how to cope with their loved ones living with MS. They are understood, supported, and do not feel judged, since they all are going through it together.

If you are interested in joining this group or learning about the other support groups offered at the Center, please call (212) 265-8070 and speak with the Social Work Department.

DEVELOPMENT DEPARTMENT NEWS

Inspiring Events by Patients & Friends



Guests at Timmer's Way Festival



L to R: Jonathan, Lauren, Randy & Michael Belfer

Timmer's Way Festival Raises \$20,000 for MS Research

The Timmer's Way Festival is a charitable event held in memory of Timmer Wood, who was killed by a drunk driver in 2008. This festival brings together Timmer's love for music, friends, good times, and most importantly, his passion for helping others in need. The event featured entertainment, a large raffle, a silent auction, and a cornhole tournament. Timmer's cousin, Christian Wood, suffers from MS, and his family decided to send the **\$20,000** raised to the Tisch MS Research Center of New York. Thank you to the Wood family for helping us in our mission to find the cause, and one day, a cure for MS!

Fundraising Spotlight: Michael and Randy Belfer

"The only thing I want to see is a cure for MS!" Michael Belfer said. That's why he and his wife, IMSMP patient Randy Belfer, make fundraising a year-round effort that includes the whole family. The Belfer's, along with their two children, Lauren and Jonathan, shared their personal story of living with MS, along with their hope for a future without the disease, with their family, friends, and colleagues. They responded generously! Thank you to the Belfers & friends for raising over **\$22,000** to support our research.

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Every effort has been made to ensure the accuracy of this list. Please email [Lisa Mandel](mailto:lmandel@tischms.org) or call (646) 557-3893 to report any errors or omissions, or if you would like to have your name removed from future listings.

TEAM TISCH MS NEWS



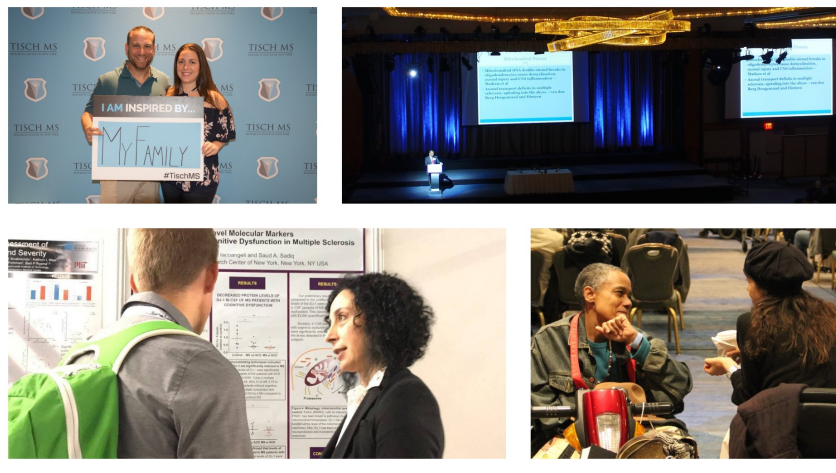
2018 TTMS Racer, Blair Schwartz, Completes the NYC Half Marathon

Off to the Races!

Team Tisch MS (TTMS) continues to grow with new racers signing up every week. Congratulations to TTMS runner, Blair Schwartz, for finishing the New York City Half Marathon this past March. She will continue her training to complete the TCS New York City Marathon this November. We would also like to congratulate the first TTMS cyclists, Stephanie DelMonte and Dr. Stephen Jones, who will be completing the Discover Hudson Valley Ride on June 24th, 2018.

TTMS welcomes our returning sponsors **Fox Rehabilitation, Outreach Rehabilitation, Beyond Basics Physical Therapy, and LymphEDIVAs**, as well as our new sponsors **CMI Compass, Metropolitan Jewish Health System, Total Health Associates, JAG Physical Therapy, and Alinker.**

To learn about all of our TTMS racers and the races they are training for, visit the TTMS website at www.teamtischms.org. Donate to their online campaign and help them reach their goal! Also, on our website, you will find information about our sponsors and how to apply to become a TTMS racer for the 2018 season.



Save the Date

Sunday, October 14, 2018

Tisch MS Research Center 21st Annual MS Patient Symposium

New York Hilton Midtown
1335 Avenue of the Americas, NY, NY 10019
9:30am – 1:00pm

For More Information & To Register
visit: www.tischms.org/events
Or call (646) 557-3919

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Allan Zapanta, CNA

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