



# 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

## BREAKING NEWS

### Tisch MS Research Center of New York Awarded \$1 Million National MS Society Grant for Phase II Stem Cell Research

*"We are deeply appreciative for this support from the National MS Society as we initiate Phase II of this study to hopefully establish the effectiveness of our stem cell treatment. Together, we are on the forefront in forming the therapeutic basis of reversing disability in people with MS."* - [Dr. Saud A. Sadiq](#), Director and Chief Research Scientist at Tisch MSRCNY

[Tisch MS Research Center of New York \(Tisch MSRCNY\)](#) recently announced that it has been awarded a \$1 million research grant from the National MS Society to support Phase II of their FDA-Approved Stem Cell Clinical Trial for MS.

Phase I of this trial was completed in 2017 with [published results in EBiomedicine](#) showing safety and tolerability. This landmark study witnessed stem cell treatment recipients take steps without their cane and experience a reversal of disability.

*"There is an urgent need for more effective treatments for MS, particularly for those with more progressive forms of the disease,"* said Dr. Bruce Bebo, National MS Society Executive Vice President, Research. *"We believe that the potential of all types of cell therapies must be explored, and we are pleased to be a part of this clinical trial."*

The Phase II trial is a randomized, placebo-controlled, double-blind study testing the efficacy of multiple intrathecal injections of autologous bone marrow-derived mesenchymal stem cell neural progenitors (MSC-NP) in 50 patients with progressive MS. Additional funding needs to be secured to ensure completion of the 3-year study.

Scientists recruited from around the world work at Tisch MSRCNY to accelerate patient-based research which translates into the lives of those suffering from multiple sclerosis. They continue to investigate and discover biomarkers of disease activity and mechanisms of disease progression and each day are one step closer to their ultimate goal – to discover the cause of multiple sclerosis and lead to a future without MS.

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[WWW.TISCHMS.ORG](http://WWW.TISCHMS.ORG)

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National  
Multiple Sclerosis  
Society



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## SOCIAL WORK NEWS

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



**Joao Goncalves racing for TTMS at the 2018 TCS New York City Marathon**

Team Tisch MS (TTMS), founded in 2015, is a team of runners, bikers, swimmers, and triathletes, who compete in races and other events to raise money for the Tisch MS Research Center of New York. These funds help advance research to find the cause of and cure for multiple sclerosis. Joao Goncalves, TTMS member and long-time patient of Dr. Sadiq at the IMSMP, took on and successfully completed the 2018 TCS New York City Marathon on November 4<sup>th</sup>. He traveled all the way from Spain to run alongside fellow TTMS members in this 26.2-mile race. Here, he shares his uplifting story in an interview...

**Congratulations on completing the 2018 TCS New York City Marathon! As a person with MS, there's no doubt that you are an inspiration. What made you decide to sign up for a marathon in the first place?**

Thank you so much! The thought first landed in my mind a couple years ago, inspired by other Team Tisch MS runners. I got a lot of inspiration from Mireya Montalvan-Panzer, a 2016 Team Tisch MS runner, who has been extremely supportive of my efforts.

**Why did you choose to run for Team Tisch MS?**

As an MS patient, I could not think of a more noble purpose than to raise funds to support research done at Tisch MSRCNY.

*A Future Without MS* really resonates with me. Fundraising for Tisch MSRCNY was very engaging and I also connected it with an important milestone in my journey with multiple sclerosis, the 20<sup>th</sup> anniversary of my diagnosis. I was also inspired by people who fought very hard against MS (and other life-threatening conditions), some of them, unfortunately, who didn't win despite their brave efforts. Paying a tribute to their heroic fight also became part of the purpose.

**Not only did you run 26.2 miles, but you flew all the way from Spain to do so! What made you decide to run specifically in New York?**

I wanted to be part of Team Tisch MS and run with the group in NYC. For me, New York has a very special place in my heart. It represents hope and resilience. I visited Dr. Sadiq at the IMSMP for the first time in 2008 after my worst MS relapse since being diagnosed in 1998. Both my wife Inés and I were very worried and anxious. It seemed like MS was finally starting to win. After a few visits I felt I was regaining control with the help of Dr. Sadiq, and finally, in 2012, I started feeling much better and relapse-free. For us, this is a strong motive to celebrate, and I could not think of a better place to do that than NYC! Confirmation came from the cheering on the streets from the great people of New York and the thousands of committed volunteers that helped us during the race. It really made our celebration a unique experience.

**Tell us about your training regimen and how MS impacted your training.**

I am optimistic. Yet, when I decided to engage in this challenge, I assumed I would face some "bumps" during my preparation or even on race day. Indeed, I faced some episodes of fatigue, especially during the hotter days of Madrid's summer. My response was to allow myself to deviate from the training plan and build some extra rest. Obviously, this brought some pressure on the scaling up of miles and eventually, I became somewhat concerned. Fortunately, I had enough support from my cheerful wife, family, and friends, including Mireya, that helped me stay strong and

focus on the progress rather than on the speed of the progress. I'm sure many non-MS patients also go through similar concerns and mood changes when training for a marathon.

**It was so nice to have you and your family with us at the TTMS Post-Marathon party. What did it mean to have them join you on this incredible journey and end the day surrounded by family dancing at the party?**

Thank you, we really appreciated the invitation and the warm welcome. I was extremely happy to be able to celebrate this incredible journey with my wife and children. My wife Inés is the most generous person you will ever meet and she has been dealing with my MS for 14 years. She suffered with me, assisted me when I most needed it, cheered my efforts and recoveries, and finally, she supported me when I had the crazy idea of running a marathon. My two children Pedro (11) and Helena (9) were also exposed to my MS, although for a long time they didn't quite understand why daddy sometimes would not play outside with them. Celebrating together was as important as finishing the marathon, it really meant a lot to all of us.

**You ran a really successful fundraising campaign. Can you speak about your experience soliciting for a cause so close to home?**

A few years ago, Dr. Sadiq told me that his mission was to find a cure and treatment to reverse disability from MS, and together with his team he would accomplish it. He told me this in a very inspiring way and if you know Dr. Sadiq, you know what I mean. Fundraising was harder than I anticipated, but I would always remember Dr. Sadiq's words and that kept me telling my story and engaging people in my network. Besides sharing my story, I started using other examples. I found out that some people in my network had a close tie to MS mainly through a family member. Contributors also appreciated my training efforts for the marathon, so clearly connecting a personal commitment to the fundraising campaign helped me be more effective.

## SOCIAL WORK NEWS

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

**What words of advice would you give to anyone with MS who wants to train for an endurance race like the TCS New York City Marathon?**

I am happy to share a few things that worked well for me. First, be sure about the purpose. I wanted to raise funds for MS research, celebrate 20 years fighting with MS, and pay tribute to people that fought MS very hard. Having a meaningful purpose helped me keep the energy levels high during the long preparation. Then I chose a challenging, yet realistic goal. To make sure it was realistic I consulted with my doctor to check for any concerns with my overall health condition.

My family and friends were the supportive networks that I involved since the beginning. I shared my purpose, my goal, and why it was important to me. They kept cheering me on, training with me at times and holding me accountable for progress. The actual training program is also very important. There's lots of literature available but I strongly recommend finding professional support or a running club. I feel very fortunate to have finished a marathon on my first attempt, but I also know that something could have happened on race day, so from the beginning, I just thought that the true failure was not to try it at all.



## A NOTE FROM THE NURSES

### Symptom Management



One of the best ways you can take control of your healthcare is to be vigilant of any medical symptoms you might be experiencing. Being aware and in tune with your body is a great way to stay on top of your health. If you begin to notice any new MS symptoms or any changes to your recurrent MS symptoms, please give a call to the nurses' station. We can help you sift through what is MS related and what is not. Additionally, keeping a diary to track any patterns is also a helpful tool. If after discussing all of this with a nurse there is still more to address, you can schedule a focused nursing symptom management appointment to help you further. At these visits, a nurse can perform a detailed assessment and thoroughly review

symptoms with you to coordinate a care plan with your attending physician. Some MS symptoms that we provide focused assessments for include: fatigue, bladder, bowel, pain, headaches, and spasticity. We are continuing to grow this aspect of our nursing services in 2019, so please stay tuned!



22<sup>nd</sup> Annual Tisch MS Research Center Patient Symposium  
**Sunday, October 6, 2019**  
 New York Hilton Midtown

## FROM THE FRONT DESK

The IMSMP kindly requests that patients do not hold on to insurance checks.

Please send the checks in a timely manner, and keep them in good condition by not folding them.

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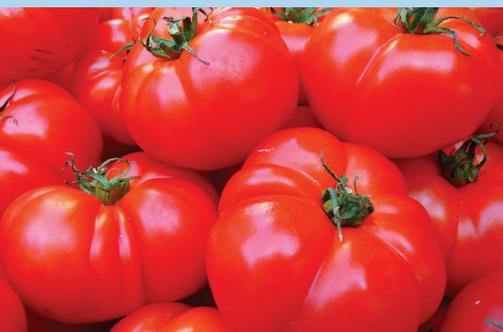


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## NEWS ON NATUROPATHY

### Diet and Multiple Sclerosis



If you feel confused about what's the best diet for MS, there's a good reason! You may have noticed that suggestions, made by various "experts" over the years, have swung so wildly that some of the diets advised for MS are actually opposites of each other. Examples include the Paleo Diet (a modern approximation of the diet our Paleolithic ancestors ate) with an emphasis on meat, vegetables, fruits and nuts, versus the McDougall Program—a vegan approach that excludes all animal products but focuses on a high starch diet from whole grains and beans. For decades, Dr. Roy Swank promoted a very lean approach, studying an extremely low-fat diet for people with MS. But in the last few years, the Ketogenic Diet, in which fat makes up 75% of dietary calories, has received a lot of attention.

Some diet choices, like the Mediterranean Diet or a vegetable-focused Paleo plan, tend to have side benefits that can improve health for anyone, whether or not you may have MS. More extreme diets, like the high-fat Ketogenic Diet, have potential for harm if not undertaken carefully with medical monitoring.

Dr. Bates, the IMSMP's naturopathic doctor, is here to help. She works with people who have MS to optimize their food and lifestyle to create the best environment for body and brain repair. While there's no perfect one-size-fits-all plan, here are some tips that apply to everyone:

1. Stay away from foods with trans fats, also known as partially hydrogenated vegetable oils. Trans fats are formed through an industrial process and can be found in snack foods, baked goods, fried foods, and margarine. These chemically altered fats are some of the very worst for human health.
2. Fish: while one of the best sources of protein, it's critical that you avoid fish that is high in mercury, a known neurotoxin. The four fish you should never eat because of high mercury include: swordfish, shark, tile-fish, and king mackerel.
3. Don't smoke! Cigarettes have been shown to increase the risk of developing MS as well as progression of the disease.
4. Eat more fresh food and less processed food. The human food supply has changed dramatically over the last few decades as autoimmune diseases have become more prevalent. Processed foods are more likely to contain ingredients (such as salt, sugar, gluten, emulsifiers, organic solvents, and nanoparticles) that are suspected to contribute to the rising incidence of autoimmune diseases. Fruits and vegetables are naturally low in salt and sugar and high in fiber and antioxidants, the right balance to benefit people with MS.



## TEAM TISCH MS NEWS

### Team Tisch MS Update

Team Tisch MS (TTMS) has tripled the number of racers who joined the team in the first two months of 2019. Racers will be participating in running, cycling, swimming, walking, Tough Mudder, and Spartan events throughout the country. Our goal is to have over 100 racers representing TTMS in over 100 racing events. If you know someone who participates in any local, national, or international events, share the news that wearing the TTMS jersey when racing can help make a difference in Tisch MSRCNY's efforts to find a cause and cure for multiple sclerosis. To become a TTMS racer, please visit: [www.teamtischms.org](http://www.teamtischms.org).

The Team Tisch MS program is a great way to get friends and family involved in supporting the cutting-edge research taking place at Tisch MSRCNY. Whether it is donating to a racer or putting together a team to participate in a local 5K, the opportunity for you to be part of TTMS is a click away. Please visit [www.teamtischms.org](http://www.teamtischms.org), where you will find all of our racers and can easily contribute to help them reach their fundraising goal. Follow TTMS on Instagram [@teamtischms](https://www.instagram.com/teamtischms) and show your support by using the hashtag #TTMS!



TTMS Member Laura Cariello

## TISCH MSRCNY'S NEW CHAIRMAN OF THE BOARD

### Congratulations, Philip Weisberg!



**Philip Weisberg, CFA**

In December 2018, the Tisch MS Research Center of New York announced that the Center's Chairman of the Board of Directors, David G. Greenstein, stepped down after four years of dedicated service. He will continue to serve on the Board of Directors. "David has been a tremendous leader and friend without whom many of our research endeavors wouldn't have been possible. We appreciate his devotion to our work, his guidance and years of unwavering support. We look forward to his continued advice, and participation on our Board," said Dr. Saud A. Sadiq.

Philip Weisberg has been elected the new Board Chairman. Phil is a Financial Executive who has led companies through successful stages of corporate development including start-up ideation, attracting strategic investors, capital raising from the private equity community, acquisitions, public offering, company sale, merger integration, and turn around.

Phil joined the Tisch MS Research Center of New York's Board of Directors in 2012 and has served as Treasurer for the past two years. In his new role, Phil states, "We should focus on building on the many successes to date and accelerating our efforts by continuing to innovate to break down the barriers that stand between patients and a cure."

He received a Bachelor's of Electrical Engineering from The Cooper Union and an MBA in Finance and International Business from NYU.

Phil resides in New York with Alla his wife and his two children Mike and Hannah.

## NEW PERSONNEL

### Welcome to the Team!

Please join us in welcoming three great additions to the Center.



#### **Sharon Brenner, Laboratory Manager**

Sharon Brenner joined Tisch MSRCNY as Laboratory Manager in November 2018, after graduating from Hunter College with degrees in Biology and Psychology. While at Hunter college, she completed her undergraduate thesis on the effects of depression on social behaviors and neuronal firing in the ventral tegmental area (VTA) of mice. She brings her research and office administrative skills to her laboratory managerial position. She was drawn to Tisch MSRCNY because of the dual dedication in clinically aiding patients and in making enormous strides in research on MS.



#### **Allison Hodgkins, Human Resources Coordinator**

Allison Hodgkins graduated from SUNY Cortland in 2010 with a BS in Sports Management after finishing her senior internship in Manhattan. After graduation, Allison remained in New York City and began her work at Sportime Randall's Island/John McEnroe Tennis Academy, where she held various positions, ultimately leaving in 2017 to pursue a new career in Human Resources. She began her role as HR Coordinator at the IMSMP in November of 2018. Allison is originally from Saratoga Springs, NY where she often spends summer weekends at her parent's house and camp on Lake George.



#### **Amanda Kinge, Cell Culture Specialist**

Amanda received her undergraduate degree at Stockton University in Biochemistry and Molecular Biology. She joined Tisch MSRCNY to work on the stem cell clinical trial as a Cell Culture Specialist. Before starting here, she worked at Novartis Pharmaceuticals and Bristol Myers Squibb as a Cell Processing Specialist. At Novartis, Amanda worked on their commercial Car-T therapy for leukemia patients. She is excited to work at the Tisch MS Research Center of New York and hopes that the stem cell clinical trial can help better the quality of life for all MS patients.

## PHYSICAL THERAPY & REHABILITATION

### The Benefit of a PT in Your Wellness Program



Many people with multiple sclerosis are motivated to start an exercise program to combat the potential impairments that are commonly associated with the disease. While many patients will see a physical therapist (PT), some will choose to work with wellness professionals instead of/or in addition to a PT. When it comes to exercise programs for people with MS, a neurologic physical therapist should ALWAYS be involved.

Nationally, there are relatively few physical therapists who work primarily with people who have MS, however there are thousands of PTs who are able to provide a quality evaluation and treatment plan for people with MS.

Regardless of your past experiences with therapy, patients with MS should see a PT at least one or two times per year, and not just when something “big” happens. This may be the difference in an impairment becoming a disability or a weakness resulting in a fall.

Impairments from MS such as fatigue, balance dysfunction, or joint tightness are directly linked to the disease. There are additional issues that are directly caused by MS, but may result in various levels of disability. Examples of this include posture related pain, muscle overuse injuries that can present as weakness, and overall physical deconditioning which can result in fatigue and depression. All of these can be screened out by a PT, and your exercise program can be adjusted accordingly.

The decision to work with a wellness professional such as a personal trainer, pilates professional, or yoga instructor, is generally a very good decision because the patient will exercise regularly. However, beware of programs or exercises described as “specific to MS.”

There is no such thing as an “MS Exercise.” Often, these programs will focus on being exceedingly careful not to “over-fatigue” or “overheat.” In many cases, these patients are under exercising. Instead, we recommend that your PT and wellness professional collaborate on creating an overall program designed specifically for you.

Now is the time to reset your goals. Be proactive in developing a physical wellness team who can help you for years to come.

To schedule an assessment with an IMSMP physical therapist, please call (212) 265-8070.

## DEVELOPMENT DEPARTMENT NEWS

### Cards for a Cure Texas Hold ‘Em Poker Tournament



Joey Renda with his friends and family

Once again, “Friends of Joey Renda” hosted Cards for a Cure Texas Hold ‘Em Poker Tournament in support of Tisch MSRCNY’s research. The annual event held on October 20, 2018, at the Flemington Elks in Flemington, NJ was another great evening and even greater fundraising success. More than 100 people came out to see friends, enjoy fabulous entertainment, share a delicious meal, and play a few hands of Texas hold ‘em. As always, Joey and his friends made Tisch MSRCNY the big winner for the night by raising over \$27,000.

Joey Renda proved that his friends know when to hold ‘em for a cause. From their first event in 2012, Joey, along with his incredible and generous friends and family, have raised nearly \$190,000 for Tisch MSRCNY’s research. Thanks “Friends of Joey Renda” for helping Tisch MSRCNY win the big pot!

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