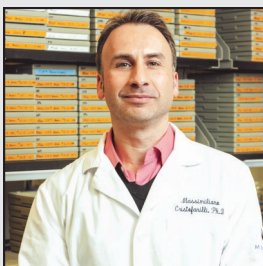




# Healing MS

THE IMSMP NEWSLETTER ADDRESSING THE NEEDS OF OUR PATIENTS AND KEEPING YOU INFORMED OF THE LATEST RESEARCH TREATMENT AND WAYS TO HEAL

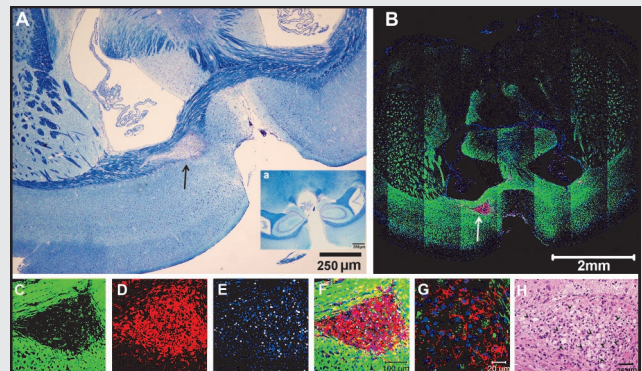
## Tisch MSRCNY Publishes Landmark Paper in Experimental Neurology



**Massimiliano Cristofanilli, PhD**

The Tisch MS Research Center is excited to announce that a team led by **Dr. Massimiliano Cristofanilli** has succeeded in a three year effort to create a model of progressive multiple sclerosis. Currently the widely used experimental model of multiple sclerosis known as Experimental Autoimmune Encephalomyelitis (EAE) best mimics relapsing-remitting MS (RRMS). Use of the EAE model has resulted in many

breakthroughs in MS, but most of these do not apply to progressive disease. Perhaps because of this there is a relative lack of understanding of the mechanisms underlying disease progression in MS and few effective treatments for progressive disease. Availability of a disease model for progressive MS would help change this dismal outlook for patients with secondary and primary progressive MS. In a **landmark** study supported in part by funding from the **Emerald Foundation** the research team from Tisch MSRCNY created a new model of progressive MS. The study entitled **“Progressive multiple sclerosis cerebrospinal fluid induces inflammatory demyelination, axonal loss, and astrogliosis in mice,”** authored by Dr. Cristofanilli along with his research team of Hannah Rosenthal, Barbara Cymring, Daniel Gratch, Benjamin Pagano, Boxun Xie, MS, under the overall supervision of Saud A. Sadiq, MD was published in the journal *Experimental Neurology*. The model was created by directly injecting human cerebrospinal fluid (CSF) derived from patients with progressive MS into the



{Adapted from Cristofanilli et al., *Experimental Neurology* (in press)}

**Images representing immune-mediated demyelination in a mouse brain injected with CSF from a progressive MS patient.**

CSF “pockets” of a mouse’s brain. This resulted in typical lesions of MS forming in the animal brain’s immune cells, loss of myelin and nerve damage. This unique model may now be employed to discover the underlying events that lead to these pathological changes and thus better understand disease activity and progression. In addition, this model can be used to evaluate MS patient treatment outcomes in mice and to guide customized therapeutic regimens, which may ultimately lead to the development of specific therapies targeting PPMS and SPMS.

**Lab Research continued on next page**

### International Multiple Sclerosis Management Practice

**Saud A. Sadiq, MD, FAAN**  
Director

#### CLINICAL

Raheela Asifuddin, BS, R.T.  
(N)(CT)(MR)(AART)  
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Merry Davidson, RN  
Beth DiBiase, LCSW  
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Dawn Jones, RN  
Stephen Kanter, PT, DPT  
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Dorothy Kurdyla, RN, MSN  
Yadira LaMazza, MSW  
Marlon Lasa, RN, BSN  
Beth Levine, RN, BSN

Rebecca Lizarraga, NP  
Whitney Mallis, BSN  
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Rusudan Siriya-Gleyzer, BS,  
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Armistead Williams III, MD

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Sharmilee Roy  
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Ruth-Anne Langan, BA  
Jerry Lin, BS  
Xinhe Liu, MEd  
Ying Liu, PhD  
Indira Londono, MS  
Kelsey McDermott, BA  
Fozia Mir, PhD  
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Tamara Vyshkina, PhD  
Boxun Xie, MS

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# Tisch MS Research Center of New York 17<sup>th</sup> Annual MS Patient Symposium

Join us on Sunday, October 19<sup>th</sup>, 2014 at the New York Hilton in Midtown

This year's topics will include: **Alternative Approaches** with presentations from the IMSMP Wellness Team; **Neurology Roundtable Discussion: Traditional Care** with a review of new medications and feedback on existing therapies from the IMSMP neurologists; **Future Treatments & Stem Cell Update** with presentations by Dr. Saud A. Sadiq and Dr. Violaine Harris on research breakthroughs and the status of our FDA-approved Phase I Clinical Stem Cell Trial.

*"It has been a year of groundbreaking research and discoveries at Tisch MSRCNY. Everyday we learn from our brave patients as we continue to translate findings from the lab into treatments. We look forward to sharing this knowledge and discussing the future of multiple sclerosis therapies with all of you."* Saud A. Sadiq, MD, FAAN

The day of the event, check-in will begin at 8:30am.  
The program will run from 9:30am-1:00pm.

**REGISTER TODAY at: [www.tischms.org](http://www.tischms.org)**  
Or call (646) 557-3919

\*For guests traveling from out of town, please see the back cover for information on the hotel.

## Lab Research cont'd

In another outstanding research development, the journal *Neurology Neuroimmunology and Neuroinflammation* has accepted a paper by lead author Dr. Fozia Mir entitled "Cerebrospinal fluid isoprostane levels are a biomarker of oxidative stress in multiple sclerosis." The paper authored by Dr. Mir, Donald Lee, Hetal Ray, and Saud A. Sadiq, MD identified a lipid, 8-iso prostaglandinF2 $\alpha$  (8-iso-PGF2 $\alpha$ ), as a biomarker for disease activity and oxidative stress in the CSF of multiple sclerosis patients. Levels of this biomarker in 231 MS patients (including RR, PP, and SP subtypes) were found elevated compared to controls with the most striking values in a subgroup of SPMS patients. This is an important new area of research because it provides an objective measure to test for oxidative stress in MS patients and allows for the response of these levels to therapeutic intervention to be tested.

**Drs. Harris and Sadiq** also coauthored a review entitled "Biomarkers of Therapeutic Response in Multiple Sclerosis: Current Status," which was accepted for publication in the journal *Molecular Diagnosis and Therapy*.

Finally **Dr. Andre Mueller** together with Bo Hyung Yoon and Saud A. Sadiq, MD published a paper entitled "Inhibition of Hyaluronan (HA) synthesis protects against CNS autoimmunity and increases CXCL 12 expression in the inflamed CNS," in the *Journal of Biological Chemistry*. The authors investigated the effect of neutralizing a key component of scar formation, hyaluronan, and showed that doing so results in decreasing the severity of experimental MS.

### Abstracts

We are also pleased to share that a number of abstracts from our laboratory have been accepted to two fall conferences. At the Society for Neuroscience (SfN) meeting in Washington, DC, the work of Massimiliano Cristofanilli, PhD, Daniel Gratch, Benjamin Pagano, Deneb Bates, ND and Saud A. Sadiq, MD entitled "TGM6 is a potential biomarker in MS and its expression by reactive astrocytes in the murine spinal cord during EAE correlates with disease course," has been selected for a platform presentation. This work has also been accepted to MSBoston2014 (Joint ACTRIMS-ECTRIMS Meeting), where the researchers

will present a poster entitled "TGM6 is highly expressed by reactive astrocytes in the murine spinal cord during EAE and its levels correlate with the disease course."

Dr. Cristofanilli stated, "I am very excited about our new data suggesting the involvement of TGM6, a transglutaminase protein expressed in the CNS, in the pathophysiology of EAE and MS. We recently obtained evidence suggesting that MS patient CSF levels of TGM6 protein and antibodies against it could be useful biomarkers to diagnose MS vs. other neurological conditions, differentiate between MS subtypes and predict disease activity and progression."

Abstracts authored by Fozia Mir, PhD and her team of Donald Lee, Hetal Ray, and Saud A. Sadiq, MD have also been accepted to both fall conferences. To describe her work, Dr. Mir stated, "We are using a metabolomics screen to identify new potential therapeutic targets in progressive MS. Metabolomics is the study of all the chemical end product in our bodies and can identify the unique fingerprint that disease processes leave behind."

## Lab Research cont'd



Fozia Mir, PhD

At the SFN meeting, Dr. Mir will give a platform presentation on her abstract entitled "**Metabolomics of cerebrospinal fluid reveals differential signatures of progressive multiple sclerosis.**" In addition, Dr. Mir's abstract, "**Metabolomics of cerebrospinal fluid from progressive MS patients,**" has been accepted for presentation as a poster at the Joint ACTRIMS-ECTRIMS Meeting.

Marwan Alahiri, MD, Shivani Agarwal, Ying Liu, PhD and Saud A. Sadiq, MD's, abstract entitled "**The protection of A2aR on BBB permeability from Th1 cytokines in MS,**" also has been accepted to the Joint ACTRIMS-ECTRIMS Meeting.

Finally, the ACTRIMS-ECTRIMS abstract submitted by Violaine Harris, PhD, Tamara Vyshkina, PhD, Sydney Chirls, and Saud A. Sadiq, MD entitled "**Intrathecal Administration of Mesenchymal Stem Cell-Neural Progenitors in Multiple Sclerosis: An Interim Analysis of a Phase I Clinical Trial,**" was chosen as a platform presentation to be delivered during a session focused on cell-based therapies. Two abstracts from Dr. Harris' team have been accepted as poster presentations, the first entitled "**Exosomes released by Mesenchymal Stem Cell Populations Promote Differentiation and Maturation of Oligodendrocytes,**" authored by Mark Landy, Violaine Harris, PhD, and Saud A. Sadiq, MD; the second entitled "**CSF Fetuin-A is a Biomarker of Subclinical Disease Activity in Progressive MS,**" authored by Violaine Harris, PhD, Mark Landy, Sydney Chirls, Indira Londono, MS, and Saud A. Sadiq, MD.

## Grants & Awards

Congratulations to our Research Assistant, Marwan Alahiri, MD on his **Educational Grant awarded by the ACTRIMS-ECTRIMS Meeting Steering Committee and Meeting Scientific Committee** for his abstract listed above. The prize includes complimentary meeting registration and \$500. Cheers!

## Clinical Research

### Stem Cell Trial Update

Tisch MS Research Center of New York is delighted to report that all regulatory approvals for our Phase I safety and tolerability clinical trial of intrathecal administration of Mesenchymal Stem Cell-Derived Neural Progenitor Cells (MSC-NPs) remain in place and the study is underway. Patient treatments have begun and enrollment will continue at a steady pace until all twenty study participants have been enrolled. There is no formal application or pre-enrollment process for inclusion in the study; positions in the trial will be offered to IMSMP patients on the basis of a consensus by our neurologists, and those selected will be notified as soon as an enrollment date is chosen for them. As we lack the output capacity of a commercial pharmaceutical laboratory, we are in the process of acquiring new laboratory incubators in order to increase the number of patients

that can be treated each month. We ask for selected subjects' continued patience as we proceed to enroll and treat patients as quickly as possible. Further updates to the status of the trial will be promptly reported at [www.tischms.org](http://www.tischms.org).

### New Projects

In addition to the project outlined above, two new clinical research studies are currently underway:

**A multicenter, retrospective, observational study evaluating real-world clinical outcomes in relapsing-remitting multiple sclerosis patients who transition from Tysabri® (natalizumab) to Tecfidera® (dimethyl fumarate):**

This study hopes to establish the optimal length of the washout period between stopping Tysabri and starting Tecfidera - a switch found in routine clinical practice since the release of Tecfidera® in March 2013. Research will be conducted through

a confidential chart review of pre-existing clinical records of eligible RRMS patients.

**Long Term Use of Intrathecal Methotrexate in Progressive Multiple Sclerosis:** Intrathecal Methotrexate (ITMTX) is of particular interest at our Center as it was discovered at Tisch MSRCNY and is one of the few treatments shown to have an effect in patients with progressive forms of MS. This project focuses on patients who have received treatments of ITMTX for at least three years and will elucidate the safety and effectiveness of these treatments. Participants will complete a questionnaire indicating their medication satisfaction and the perceived efficacy of ITMTX.

If you are interested in any of our clinical research studies, please contact our Clinical Research Assistants Leslie Blackshear and/or Sydney Chirls at (646) 557-3852 and (646) 557-3860 respectively.

Dr. Massimiliano Cristofanilli's **Emerald Foundation Grant**, awarding him \$75,000 per year, was renewed for its second year. The grant lasts for three years and supports the establishment of an animal model of progressive MS.

## Personnel Update

Tisch MS Research Center of New York is delighted to welcome a new class of Research Assistants to work in our Laboratory: Ruth-Anne Langan (Cornell University) will be working under the supervision of Dr. Harris. Danielle Blemur (Cornell University) will work with Dr. Mir. Pak Ho Au (Rensselaer Polytechnic Institute) will join Jerry Lin's team. Kelsey McDermott (Williams College) will have Dr. Cristofanilli as her Principal Investigator. Leslie Blackshear (Williams College), a Clinical Research Assistant, will work with Dr. Sadiq.



Five of our Research Assistants left the center in 2014 to begin medical school. Donald Lee, who worked with Dr. Mir, will matriculate at Hofstra University. Bo Hyung Yoon, formerly with Dr. Andre Mueller's team, will attend Jefferson University. Lena Bell, who worked under Dr. Harris, will begin at Drexel University. Hetal Ray, formerly a member of Dr. Mir's team, will attend Robert Wood Johnson Medical School and Daniel Koffler, a Clinical Research Assistant who worked with Dr. Sadiq, will matriculate at SUNY Downstate College of Medicine.



## A Note from the Nurses:

### Welcome Whitney!

Please join us in welcoming our new nurse, Whitney Mallis, RN, BSN. Whitney started at the IMSMP on April 21<sup>st</sup>, 2014 and we are thrilled to have her on our team. She graduated from SUNY Downstate in December 2013 with her bachelor of science in nursing and came to us with great clinical experiences from institutes like Stamford Hospital and Greenwich Hospital. Prior to joining our nursing team, Whitney was a private duty nurse who provided total patient care to a young girl suffering from a spinal cord injury. Her compassion, skills, and knowledge are what make her a great asset to the IMSMP.



Whitney Mallis

### Help us, help you

Here are a few tips from the nursing team that will assist us in providing you with faster and more efficient care:

- When having lab work done, whether it is blood work or a urine test, please make sure to use our requisition or order form. It would be ideal if you use a Quest Diagnostics or a LabCorp whenever possible, as these results come directly to our office. When you use a local laboratory or local primary care office many times the results do not come to our office. Prior to choosing a Quest Diagnostics or a LabCorp, please check with your insurance to see which lab is in network.
- As there are many departments at the IMSMP, whenever a nurse leaves a patient a message, we always leave our name on the voicemail. Please listen to your voicemail prior to calling us back so we can direct your call efficiently.
- For controlled substances, like Ambien, Klonopin, Provigil, etc., please call the prescription line at least one week before you run out of medication. This allows us to mail your prescription to your home or pharmacy in time.
- If you have seen one of our specialty doctors, like the urologist, pain doctor, or gynecologist and have a question or need a prescription refilled, please call our office directly and we will help facilitate your need.
- When calling the office, please make sure to specify if you are calling regarding a clinical matter or if you need a refill for an established medication. Please keep in mind, to change treatments or if you are interested in starting a new medication, that request has to first be discussed with your MS specialist and you will need to be transferred to the phone nurse.

**The nursing team is here to help make your lives easier, so please let us know how we can help!**

## Billing Reminder

The IMSMP kindly requests patients not to hold onto insurance checks. In addition, checks should not be cashed and should be sent along with the explanation of benefits so that the payment is applied properly.

## Congratulations!

The Center would like to welcome back employee Sherly Sylvia after the birth of her baby boy, David who was born on Mother's Day just under 6 pounds!

## Friendly New Faces at the Front Desk

Please welcome the following professionals who joined our front desk staff during the past year: Sylvia Ciapinska, AA Science, Leslie Hannan, BA English, Suzanne Murphy, BS Retail and Service Management, Ariana Nowicki, AD Liberal Arts, RMA Certified, Brooke Racho, MEd and Kristyn Rosetty, BS Microbiology/Genetics.



Brooke Racho



Sylvia Ciapinska



Leslie Hannan



Suzanne Murphy



Ariana Nowicki



Kristyn Rosetty

## New Scale for all IMSMP Patients now Available

### A Comprehensive Care Column by Dr. Deneb Bates and Dr. Stephen Kanter

#### Call For a “Midyear Resolution” to Set Weight Management Goals

At the IMSMP, our goal is to provide the best care in the world for people with multiple sclerosis while maximizing one's overall health and wellbeing. This includes optimizing diet, helping you move better, supporting your mental and emotional health, and guiding your vitamin and supplement program; all in integration with your MS medications and management. One important part of wellness is weight management.

For people with reduced mobility, weight management can be especially challenging for several reasons. The lack of opportunity for aerobic exercise often leads to weight gain. Less standing and lifting contributes to muscle loss and reduced bone density. An important factor in weight management is taking routine measurements on an accurate scale.

There are many people who choose not to weigh themselves. People who are not able to stand easily may not have access to a scale which can provide an accurate measurement. Many people who use wheelchairs or scooters may not have measured their weight in years. Thanks to a generous donation from the Peller family, the IMSMP now has a new scale that is available for our patients.

This scale allows people who are unable to stand (or need to hold onto something when standing) to get an accurate weight measurement. Usually, these patients will receive skewed measurements on a standard scale due to holding on to their walker, cane or support from another



**Dr. Kanter weighing a patient on the new IMSMP scale**

person. For those patients who haven't been weighed in a while, take the opportunity next time you are at the IMSMP to try our scale. The clinical staff will now be measuring weights during selected office visits. Patients who cannot use a standard scale and want to be measured can request this if you are at the center for any service.

If a patient wants to use the scale during his/her visit to the IMSMP, we ask that he/she contact the office to request this service at least 4 days prior to your appointment. As the use of the scale requires a member of the clinical staff to be involved, we ask for you to help by contacting us prior to being at the Center so you can be scheduled accordingly.

Having a baseline weight is an important measure of your health, and helps to

identify risk factors for other diseases, like metabolic syndrome and cardiovascular disease, as well as muscle wasting and osteoporosis, all of which can be modifiable complicating factors for people with MS. Obtaining an accurate weight also helps with motivation and is essential to monitor your progress when you make diet and lifestyle changes for the better.

Take advantage of the wellness services we offer, which are specifically tailored for people living with MS. In regard to weight management, Dr. Kanter and Dr. Woods, the IMSMP Physical Therapists, are prepared to evaluate your exercise program. In many ways, efforts to manage weight will improve overall physical abilities of patients with MS including improving balance and functional strength, while decreasing risk of falls, fatigue and the risk of orthopedic injuries.

Dr. Bates, our Naturopathic Doctor, can help you optimize your diet, vitamins, and supplements for your specific health needs and goals. This includes individualized plans to help with weight management, which can help maintain bone and muscle health, and is a first step in addressing metabolic syndrome and cardiovascular comorbidities. Now with the new scale, all patients seen at the IMSMP can work toward a measureable goal when it comes to managing your weight.

If you have any questions about the procedure and scheduling related to using this new scale, feel free to contact Dr. Bates or Dr. Kanter at (212) 265-8070.

### **Calling all Bioness users!**

It is with great appreciation that we thank Cynthia Brodsky for her donation of the Bioness L300 Plus Clinician's Programmer to the Physical Therapy Department at the IMSMP. This system will allow all of our patients who currently own the Bioness L300 or L300 Plus device to have any adjustments needed done at the Center.

The Bioness L300 is a lower leg orthotic that uses electrical stimulation to activate the muscles that lift the foot during walking. It is an alternative to an ankle foot orthotic (AFO), which is typically prescribed to people who walk with foot drop in order to prevent tripping and falls. The Physical Therapy Department holds Bioness Clinic trial days once per month to allow appropriate candidates to trial the device.

If you currently own or are in a trial rental of the Bioness L300 or L300 Plus device and have questions or concerns about how the device is working or are not wearing the device due to poor fit, discomfort or for any other reason, you can contact the Center and make an appointment with Elizabeth Woods, DPT. Dr. Woods is a specialist in using the device and trained in fully fitting and adjusting both placement and setting options for the device. Now, with the addition of the programmer to the Center, both Dr. Woods and Dr. Kanter have the ability to promptly assist with any changes necessary to improve your satisfaction and safety with using your Bioness L300 or L300 Plus. The IMSMP physical therapists are here to help you and welcome any questions you may have. Please contact the Physical Therapy Department with your questions or concerns about your Bioness or contact the Center to schedule an appointment for consultation with one of our physical therapists.

## Social Work News

### Update on the Affordable Care Act

The Affordable Care Act (ACA), also known as Obamacare, went into effect in January 2014 and we have been monitoring its effects on our patients ever since. The information below refers to New York State as every state has implemented the ACA in its own way.

- Many of our patients with individual or family health insurance policies have had their policies cancelled and have had to purchase new policies on the Health Insurance Exchange.
- Purchasing a policy through the exchange is the only way an individual or family can obtain his or her own insurance outside of being covered by a group policy, such as through an employer.
- As we reported in the winter newsletter, none of the individual plans on the New York State exchange offer out of network benefits (PPO's), making these plans impractical for many of the procedures and IV treatments at the IMSMP.



- After being lobbied by consumer advocacy groups, New York State considered requiring insurance companies to offer PPO plans with out of network benefits to individuals and families beginning in 2015, but ultimately decided to allow insurance companies to restrict access to out of network care. Insurance companies may opt to offer PPO plans next year if they choose.
- New York is one of three states throughout the country that does not require insurance companies to offer PPO options. However, we have learned, that other states, including NJ, PA and CT, are offering PPO options.

If you have any questions about this topic, please contact the Social Work Department at the IMSMP at (212) 265-8070.

## Out and Expressed with my MS

### An article by Dara Ramboyoung

Having been diagnosed with MS 10 years ago and in remission for 7 of them, I lived the first 8 long years in my head worried about being judged. I worried what others would think. Could they relate? Do they have the right amount of life experience and perspective to even remotely understand what's happened to me? This was exhausting because I was constantly in a state of evaluating others' ability to understand me. I was utterly exhausted. Utterly in my head. Constantly assigning one's worthiness to whether or not they could relate to a diagnosis. I worked tirelessly on getting out of my head and becoming fully expressed in this area of my life.

I had now been in remission and truly figured out a management system if you will, that worked for me when various things crept up: fatigue, stress, depression (still harder for me to manage than my MS), diet and exercise. I wasn't sharing this with anyone and the fact that I got something and wasn't sharing...was the point I was missing. It's not about me. I wasn't able to connect with people about something that had already happened. It wasn't a choice, it was pure circumstance. I came out of the closet. I started to post

on Facebook, tell my taxi drivers, friends, acquaintances, whomever might benefit in a relatable conversation to this one point: it's not whether or not something happens in life...it's what you do when it does. I had a story and if something, anything, resonated with whomever I was speaking to, inspired them or motivated them to take a different course of action around whatever they happened to relate to about my story, then mission accomplished. I stopped telling myself that people would judge me and I stopped making up stories in my head about what this person or that person would think or do around MY fact; I was diagnosed with MS. The rest is mine. I own it. No one else. I get the power around sharing what it's been like for me. The thoughts or judgments or whatever else shows up for someone are theirs.

I started to give back responsibility to everyone else and solely take responsibility for myself and an unusual thing started to occur for me. People started to become inspired by what I had to share. They didn't judge or think less of me. I showed up as someone living with a disease, not defined by it. People responded to this and not only that, but started to connect me with others living

with MS who needed support, better doctors, or something different to help navigate through this maze. I realized while I was living in my head, I was robbed of living for the greater cause.

We all have something that has happened and to not share that may be a missed opportunity to connect, help, or reach out to someone in need. It all gave me the confidence to continue talking to people and commit myself to sharing my journey with MS and rid myself of the attachment of being judged. This is how it showed up for me and to be able to share this with my MS community will hopefully inspire someone, maybe not to "come out of the closet," but rather think differently about what has already happened. The past is in the past and we can only push onward and upward...with a little help and encouragement, it always feels better.



**Dara Ramboyoung pictured above with her two sons**

## The 17<sup>th</sup> Annual Tisch MSRCNY Patient Symposium needs your questions for our Neurology Roundtable Discussion



The 2013 Symposium Q&A session

This year's Patient Symposium offers attendees the opportunity to submit their questions in advance to our panel of neurologists, specializing in multiple sclerosis. We are currently looking for questions pertaining to either current FDA-approved therapies or new treatments that you may have heard about.

Drs. Andrew Sylvester, Armistead Williams III and James Stark will be discussing traditional MS care as well as future treatments in the pipeline.

**To submit a question, email us at: [newsletter@imsmp.org](mailto:newsletter@imsmp.org).  
In the subject line, please type: Symposium Question**

We look forward to answering your inquiries on Sunday, October 19<sup>th</sup>, 2014 during the Tisch MSRCNY Patient Symposium at the New York Hilton Midtown.

**Register for the 2014 Symposium at: [www.tischms.org](http://www.tischms.org)**

## Worsening in MS: Relapse or Pseudorelapse?

**By Dr. James W. Stark**

Patients with multiple sclerosis can exhibit worsened symptoms for a few different reasons. As physicians, we use certain terms differently from how they are used in regular speech and this can generate some confusion. For example, we reserve the term "relapse" for new or worsened symptoms, which are due to **new inflammatory MS activity** in the brain or spinal cord. Usually in a true "relapse," the new symptoms manifest over a few hours or days, plateau over a few days to weeks and then slowly improve over weeks to months. Steroids will often more rapidly improve this kind of worsening but steroids are actually not always necessary. Additionally, the vast majority of the time, this kind of worsening is associated with a change on your MRI scan.

Another way MS patients can experience worsening is called a pseudorelapse. When physicians use this term, we are also referring to worsened neurologic symptoms; however the underlying cause of the worsening is not from new immune system activity or inflammation, but rather from the damage that has occurred from previous inflammation. This is very important because the treatment of this is generally not intravenous steroids, but determining what could be affecting the body to bring out "old" symptoms. There are a number of stressors that can affect the body and MS in this manner. These include increased body temperature (from a fever, over-exercising, hot tub/sauna...), infection even in the absence of fever (the flu, urinary tract, sinus, and skin), trauma, surgery, new medications, other medical conditions (high blood sugar in diabetics) and psychological stress to name a few. A pseudorelapse is not associated with an active MS lesion on an MRI result.

There are a variety of clues to help differentiate between a relapse and a pseudorelapse. Occasionally, it can be difficult to distinguish and further ancillary testing, such as an MRI, is required. Here are some quick tips to try to differentiate

between the two. (NOTE: call the office if you're having new symptoms, this article is meant to be an educational tool only!)

1. **Timing:** If the worsened symptoms fluctuate, and especially if they resolve completely and then return, that is a good sign you may be experiencing a pseudorelapse. This is one of the reasons that we rarely treat an MS relapse within 24 hours of symptom onset. Unlike a stroke, there is no evidence that rapid initiation of steroids is better and we want to judge whether symptoms may improve on their own.
2. **Old symptoms:** The recurrence of old symptoms is more common in a pseudorelapse. Generally, MS does not result in repeated inflammation in the exact same part of the brain, so it is unlikely that patients will experience another true relapse in the exact same manner as their previous relapses.
3. **Localization:** Localization is the term in neurology for identifying the location of the lesion within the brain or spinal cord based on the pattern of symptoms. Occasionally, neurologists can say that a specific location of a lesion in the central nervous system cannot cause all of the current symptoms. This would indicate to us that another process (like infection, medication, stress) may be going on, which is causing the generalized worsening, rather than a new, active MS lesion.
4. **Types of symptoms:** Some worsened symptoms are much more likely to be a pseudorelapse than a relapse. These include sudden worsening of spasticity and pain, which are certainly seen in MS, but are rarely due to an acute relapse.

As neurologists, we use all of these points to help us evaluate what is going on when a patient feels worse. We rely on your history, especially the time course and pattern of symptoms, and use laboratory testing and MRI additionally as needed.

# Tisch MSRCNY Development Department News

## Trina Hidalgo, Philanthropist Extraordinaire



Trina Hidalgo

Ninety-one year old Trina Hidalgo, a successful businesswoman who has been running her family's New York City property management and real estate development company since the age of 19, cares deeply about giving back to causes about which she is passionate. Trina has shared her wealth with many local, national, and international non-profit organizations over several decades to help sustain their important missions.

Last year, Tisch MSRCNY was an additional beneficiary of Trina's generosity when she made a \$50,000 gift in honor of her dear friend of over thirty years, IMSMP patient Phyllis Wagner. Earlier this year, after coming to a deeper understanding of the Center's work, she made a tremendous \$200,000 gift for the stem cell research program, again in honor of Phyllis, with the "deepest wish that this gift will help speed the Center in its discovery of the cause of and a cure for MS."

Dr. Saud A. Sadiq and the Tisch MSRCNY staff are inspired by Trina's gift. "We are extremely grateful for Trina's significant contribution to the Center. This made a direct impact on our stem cell research program and goes far in helping the patients who may benefit from the stem cell treatment. If it weren't for the encouragement of benefactors like Trina, we would not be able to continue pursuing our important investigations," acknowledged Dr. Sadiq.

## Events, Outreach, and Amazing Support

Tisch MSRCNY receives donations from thoughtful people near and far who create imaginative opportunities to raise money for the Center's robust research program and work hard to make them successful. They spread the word about MS, advocate for the advancement of medical research to improve the lives of patients and help the Center's vision of a future without MS. THANK YOU!



Night to Fight MS in Toronto, Canada



Team Putman

- ◆ Shane Miyama and Jason Love are two Canadians living with MS, and after learning about Tisch MSRCNY through its spring Indiegogo social media campaign, decided to organize the first annual **Night to Fight MS** that raised an amazing \$14,363 for the stem cell study. The event took place at the Beer Academy in Toronto on June 25<sup>th</sup> and was generously sponsored by Morguard Ottawa, Brokers Trust Insurance, mod Developments, Oxford Properties and Ashlar Urban and included food by Delfico Catering, beer from Creemore Springs and music by Curtis Fichtner and Matt Morgan.
- ◆ Grace and Claire Putman organized a **Spin for Susan: Pedal for a Purpose** spin class to benefit Tisch MSRCNY that took place on May 23<sup>rd</sup> at Poe Cycle in Far Hills, NJ in honor of their mother, Susan Putman. A total of \$3,150 was raised.
- ◆ Jed Elmaleh is one of the co-founders of the annual **Kayak for the Kure** event along with Kathie Livingston of Nature Adventures Outfitters. This year's fundraiser was held on May 3<sup>rd</sup> in Mt. Pleasant, SC and raised \$3,000.
- ◆ MS Views and News ([www.msviews.org](http://www.msviews.org)) hosted their annual bowl-a-thon fundraiser on April 6<sup>th</sup>, 2014 at **Strikes of Boca** in Boca Raton, FL. This year's event was to benefit MS education and stem cell research. Stuart Schlossman, President, and his Board of Directors voted to allocate \$3,000 from this fundraiser to Tisch MSRCNY's stem cell research program.
- ◆ Joe Revello and Emilia Strafford, his sister-in-law, organized the **MS School Walk for Tisch MSRCNY** at the Immaculate Conception High School (where Emilia works) in Lodi, NJ on May 21<sup>st</sup>. The students raised \$2,400 and each participant was awarded a medal by the principal.





## Tisch MSRCNY Development Department News cont'd



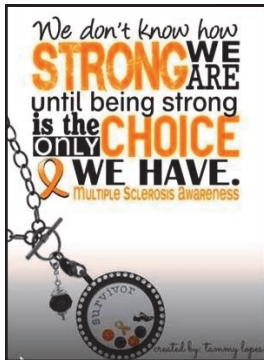
John Kissane and Jim Marasso  
of Epic Chophouse



Ava Pampouneau

- ◆ On a very icy winter evening on January 29<sup>th</sup>, Epic Chophouse in Mooreville, NC partnered with Fisher Vineyards to host a **wine dinner** to benefit the Center's research program in honor of John Kissane that raised \$1,900.
- ◆ Mike Pitta ran a **Birthday Bash for MS Research** campaign on GoFundMe.com in honor of his godmother and aunt who suffers from MS, Janice Shewan, and directed the \$1,155 in proceeds to Tisch MSRCNY.
- ◆ In honor of her godmother, Beth Broun, eight-year-old Ava Pampouneau initiated a **read-a-thon** in Paris, France and raised a total of \$690 for the stem cell study.
- ◆ Board Member Monika Parekh hosted a **Stella & Dot Trunk Show** at her gorgeous Manhattan apartment on May 28<sup>th</sup>. Independent stylist Carla Greengrass, Monika's friend, generously donated proceeds from the sales commissions amounting to \$500.
- ◆ **Dress Down Days** were held at Solomon Page Group Healthcare and Life Sciences and the Pingry Middle School to raise money and awareness for MS. They raised \$245 and \$283 respectively.

If you have an event idea or would like more information about how you can help raise money for research, please contact the Development Department at (646) 557-3863 or via email at [development@tischms.org](mailto:development@tischms.org).



### Origami Owl Fundraiser

Patient Barbara DeRosa would like to raise awareness about MS, celebrate MS patients' strength, and generate funds for Tisch MSRCNY. Origami Owl ([origamiowl.com](http://origamiowl.com)) is a social selling jewelry business that allows people to create living lockets with custom-designed charms that tells the story of their lives. Barbara designed a special custom Origami Owl "survivor" (or in Spanish, "sobreviviente") piece and is donating proceeds of its sales to the Center.

Please contact Barbara at [glamourgirls4321@gmail.com](mailto:glamourgirls4321@gmail.com) or (848) 459-9080 for more information.

### Upcoming Fall Events

The **Third Annual Friends of Joey Renda: Cards for a Cure Tournament**, will take place on October 11<sup>th</sup> at the American Legion Hall in Whitehouse Station, NJ from 6:00pm to midnight. For more information, please visit: [friendsofjoeyrenda.com](http://friendsofjoeyrenda.com).

Stephanie Abrams, CEO of SocialFly, is organizing **MSquared Music Against Multiple Sclerosis** featuring dueling bands and comedians including Dominick Pupa, Soundmachine, Greg Cartin and Men or Myth at Session 73 in Manhattan on October 15<sup>th</sup> from 7:00pm-10:30pm. Tickets are \$25 in advance and \$35 at the door. For more information visit: [www.facebook.com/MSquaredfightsMS](http://www.facebook.com/MSquaredfightsMS).

### Get Involved!

Love comedy? Want to raise money for Tisch MSRCNY and have a great time while doing it? The co-chairs of **Multiple Laughs for Multiple Sclerosis**, taking place at the Gotham Comedy Club in early 2015, are building a committee to help with this fun fundraiser. Contact Dara Klein at (703) 928-2649 or via email at [dara@daramascara.com](mailto:dara@daramascara.com) or Michelle Stack at (917) 821-1622 or via email at [stackmich@yahoo.com](mailto:stackmich@yahoo.com).

# First Annual Golf Outing Makes a Hole in One



**Left to Right: Matthew Albanese, Ashmore Mitchell, Bryan Kane, and Michael Bucceri**

The Crystal Springs Resort in Hamburg, NJ provided a beautiful setting to host over 140 people on June 30<sup>th</sup> at the inaugural **Take a Swing at MS Golf Outing** that raised a whopping \$55,000 for the Tisch MSRCNY stem cell trial. The Outing included lunch, a round of 18 holes, cocktails and dinner featuring speeches by Drs. Saud A. Sadiq and Andrew Sylvester and a live and silent auction presented by Ryan Cohen from Grandstand Sports.

The event would not have been possible without the vision and leadership of Michael Bucceri, husband of patient Gillian, who, over a three month period, conceptualized and executed the event, even selling out the first golf course and expanding to a second. The Center is deeply grateful to the Bucceris for creating a successful event that exceeded everyone's expectations.

Plans are already underway for next year's Golf Outing taking place on Monday, June 15<sup>th</sup>, 2015. If you are interested in joining the event committee, please contact Michael Bucceri at (201) 427-0249 or via email at [buccerim@nationwide.com](mailto:buccerim@nationwide.com).

## *Thank you to all of the sponsors, donors, and friends of the Take a Swing at MS Golf Outing,*

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*to all who donated goods, services, auction and gift bag items, as well as the many volunteers who contributed hours of their time to make this event a success.*

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## Hotel rooms available for those traveling to attend the 17<sup>th</sup> Annual MS Patient Symposium



Tisch MSRCNY has secured a block of rooms at the Hilton at a discounted rate (reservations must be made prior to 09/15/14 to guarantee a room at this rate).  
Wheelchair accessible rooms are available upon request.

**To reserve a room call 1-800-HILTONS**

Request the group rate (\$359.00/night) by referencing group code: MSR  
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