



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

The IMSMP Rededicates Itself to Patient Care Management

“Nursing at the IMSMP means challenging ourselves so we can provide excellent care to our patients. We do this because, not only do our patients inspire us, they deserve it.”

- Jamie Weinstein, RN, BSN Director, Nursing & Clinical Services

With March being MS awareness month, Dr. Sadiq and his team would like to focus on how we can make your quality of life with MS better today. MS can affect all body systems resulting in debilitating symptoms, ranging from ambulation, fatigue, depression and bladder dysfunction. At the IMSMP, we want to reinvigorate our patient management program, by providing our patients with the option to have a scheduled symptom management visit with one of our MS specialty trained nurses with input from your neurologist.

What does this mean for you as our patient? During your next scheduled office visit, your neurologist will assess the need for a nursing symptom management referral. During this appointment, you will review your current symptoms, with the end goal of you leaving the Center with an individualized treatment plan. Our nursing department is dedicated to empowering you with the knowledge and tools to take control of your MS symptoms.

Your symptom management visit will build upon the IMSMP's comprehensive care model. Patients will be able to discuss their current medication regimen, which medications they have tried, which medications seem to be improving their health, their dosages, drug interactions, and any other concerns. The nurse will be your advocate by communicating your specific needs with your neurologist.

MS is different for everyone, which means every patient has specific needs and deserves targeted, tailor-made treatment plans. Our goal for your symptom management visit is for you to leave the Center feeling empowered with a definitive treatment plan. We encourage and want to remind our patients to take a proactive approach to their disease.

Let our staff continue to help change any challenges you face into successes. We are at the forefront of medical knowledge and patient care in MS, take advantage of our entire team and let us fight this together.



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Nurses and all IMSMP clinicians meet each morning to discuss patient visits that day and how they can provide the best comprehensive care



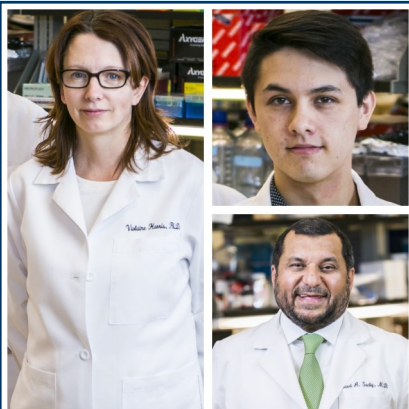
**Whitney Mallis, RN with
Paula McCurchin**

INSIDE THIS ISSUE

- Published Research from the Tisch MS Laboratory
- March is MS Awareness Month
- Save the Date Symposium 2017
- Join Team Tisch MS!
- Thank You to Our Donors

TISCH MS LABORATORY RESEARCH

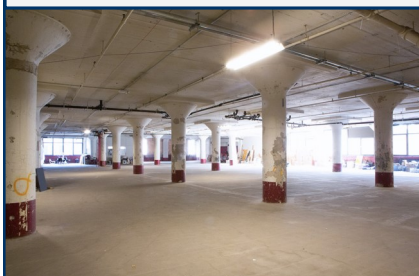
Tisch MSRCNY is proud to announce that two papers from our laboratory were recently published:



Dr. Violaine Harris pictured with John Tuddenham and Dr. Saud A. Sadiq

The paper authored by Dr. Massimiliano Cristofanilli's group, **"Transglutaminase-6 is an auto-antigen in progressive multiple sclerosis and is upregulated in reactive astrocytes,"** was published in the, *Multiple Sclerosis Journal*, on December 22, 2016. This work investigated the role of the transglutaminase-6 (TGM6) enzyme in the central nervous system of patients with multiple sclerosis. The results of the study showed that antibody levels against TGM6 (TGM6-IgG) were significantly higher in progressive MS patients with clinically active disease, and suggest TGM6-IgG could serve as a potential cerebrospinal fluid biomarker to monitor MS disease activity.

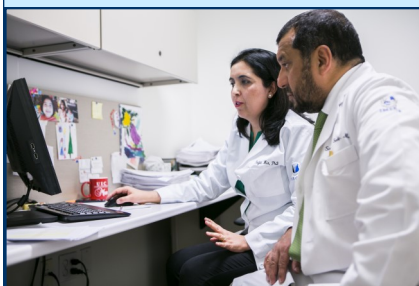
The paper authored by Dr. Violaine Harris' group, **"Biomarkers of multiple sclerosis: current findings,"** was published in, *Degenerative Neurological and Neuromuscular Disease* on January 12, 2017. This paper discussed recent advances in the research of cerebrospinal fluid biomarkers, such as neurofilament chains and oligoclonal IgM antibodies. This paper also highlights the need for further research to better verify the utility of the biomarkers discussed, as well as the importance of investigating new biomarkers.



Future home of state-of-the-art stem cell lab on the 3rd floor

Construction has begun on the largest stem cell research laboratory dedicated to MS Research. Watch us grow . . .

CLINICAL RESEARCH



Dr. Fozia Mir and Dr. Saud A. Sadiq

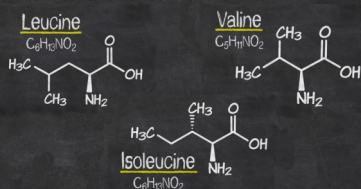
Dr. Fozia Mir and Dr. Saud A. Sadiq are currently developing a study to investigate the relationship between MS and fatigue. Fatigue is a common symptom of multiple sclerosis and can significantly interfere with a patient's ability to function. The cause of MS fatigue is currently unknown, and there is no objective way to test or measure it. Our investigators are interested in understanding the mechanisms behind MS fatigue and developing a potential biomarker for assessing it.

Our researchers' recent metabolomic screening of MS patients' CSF has revealed significantly lower levels of branched chain amino acids (BCAAs) in MS patients as compared to healthy controls. They hypothesize that decreased BCAA levels in the CSF will have various physiological effects in patients with multiple sclerosis and may lead to increased fatigue.

In order to study this further, the team will look at patient CSF and blood samples, as well as observed and reported fatigue symptoms. They will also investigate the value of BCAA supplementation to alleviate MS fatigue.

It is important to note that BCAAs are used as supplements to prevent fatigue in athletes and an ongoing clinical trial is examining their effect on traumatic brain injury.

Branched Chain Amino Acids



NEWS ON NATUROPATHY

Another Good Reason to Eat Organic

Environmental influences are suspected to play a role in neurodegenerative diseases such as multiple sclerosis, Parkinson's, and Alzheimer's Disease. Certain environmental toxins known as "neurotoxins," including: heavy metals, solvents and pesticides are known to be harmful to the brain. According to the Society of Toxicology in the paper, *The Role of Environmental Exposures in Neurodegeneration and Neurodegenerative Diseases*, "Major mechanisms are shared between virtually all neurodegenerative diseases. Blood brain barrier disruption, protein aggregation, oxidative stress, and mitochondrial dysfunction are major shared pathogenic processes. Neurotoxins may either initiate or potentiate such processes, ultimately leading to neurodegeneration."

How can you minimize your risk from neurotoxins?

Think about your personal exposures. Depending on your job or your environment, you may have more or fewer exposures than an average person. A common route of exposure is through food and water. Filtering your drinking water, choosing organic meats and dairy products, and following the Environmental Working Group's (EWG) guidelines for avoiding the fruits and vegetables most contaminated with pesticides is a great place to start.



The EWG publishes a handy guide every year, outlining the "Dirty Dozen"—12 foods most contaminated with pesticides (the ones you should make an effort to buy organic) as well as the "Clean 15"—foods with hardly any pesticide residue.

The most recent Dirty Dozen and Clean 15:

Dirty Dozen: Strawberries, apples, nectarines, peaches, celery, grapes, cherries, spinach, tomatoes, sweet peppers, cherry tomatoes, and cucumbers.

Clean 15: Avocados, sweet corn, pineapples, cabbage, sweet peas, onions, asparagus, mangos, papayas, kiwi, eggplant, honeydew, grapefruit, cantaloupe, and cauliflower.

For more information, see EWG.org, or schedule an appointment with Dr. Deneb Bates, the IMSMP's Naturopathic Doctor, for personalized recommendations.



Don Loughran adaptive surfing

MARCH IS MS AWARENESS MONTH

We are looking for patient stories to post on social media throughout the month of March and all year round! Please share with us what keeps you motivated, how you achieve your goals and triumphs along the way. The IMSMP is inspired every day by our patients.

Help us share that inspiration!

To be a part of these special posts,

email: plevin@imsmp.org



10.22.17

20th Annual Tisch MSRCNY
Patient Symposium



FOLLOW UP QUESTIONS

If you see one of our clinic MD's and have follow up questions regarding your appointment, please reach out to their offices directly.

Dr. Lisa Dabney: (212) 523-3348

Dr. Neil Grafstein: (212) 241-4812



Members share experiences at an IMSMP support group

SUPPORT GROUPS AT OUR CENTER

Caregivers - 2nd and 4th
Thursday 6:15 pm – 7:30pm
monthly

Coed Coping with MS -
Thursday 11:30am – 1:00pm
weekly

Women Coping with MS -
Wednesday 11:30am – 1:00pm
weekly

Telephone Coping with MS -
1st Wednesday 2pm - 3pm
monthly

Newly Diagnosed - 1st
Thursday 6pm – 7:30pm monthly
for 6 months

A NOTE FROM THE NURSES

Dr. James Stark now has nursing coverage for prescription refills and renewals. If you call before 3pm, the prescription will be handled the same day. However, if you have any medical questions or concerns and you are a patient of Dr. Stark's, please leave a message for him, as he is still handling medical issues directly.

When having blood work done, please give us a courtesy call 7-10 days later to go over the results. This will ensure that the documents have arrived at our office and have been reviewed by your neurologist. Whenever possible, please try to use Quest Diagnostics or LabCorp, as these results come directly to our office. You can check with your insurance company to see which lab is in network.

When considering vaccinations, always call the nurses line, to confirm that in fact, the vaccine is truly necessary.

If you are ever hesitant about whether or not to go to the Emergency Room, please call us on the nurses' line so that we can appropriately advise you on how to proceed.

Flu Season: The importance of a primary care physician (PCP) is imperative,



especially during flu season which peaks December—March and can last as late as May. If you call the nurses' line with symptoms of the flu, please be aware that we will likely redirect you to your PCP.

With the beginning of a new year, oftentimes insurance plans and policies change. As this can be a trying process, please try to be proactive about it. Anytime there is a change to your insurance, please remember to fax us a copy of your new insurance card (front and back). Simply calling and leaving the new insurance information on our prescription line limits our ability to help get your medications covered in a timely fashion. Please speak with your new plan about any medications you are currently taking to find out if they are preferred. If they are non-preferred medications, alerting us to this knowledge will help alleviate lengthy appeal times.

SOCIAL WORK NEWS

WHY JOIN A CAREGIVER SUPPORT GROUP?



Why should I join a support group? "I don't like hearing other's sob stories," "I'm shy," "I don't like speaking in groups," "I don't have time." Can you relate? I am sure every person who belongs to a support group had one or more of these thoughts before they took the plunge.

Caring for anyone with a chronic illness can be a loving, noble task but it is not easy physically or emotionally and, "nobody seems to really understand what it is like," except someone else who is going through it.

The main purpose of a support group is for members to feel **heard, understood and cared for**. Members' feedback validates emotional reactions — even through laughter, when frustrations or anecdotes strike a chord (laughter is a great tension reliever). Sharing useful information and advocating for one another helps caregivers to know they are not alone.

Please contact the Social Work department at (212) 265-8070, for more information about any of our support groups listed on the left.

PHYSICAL THERAPY & REHABILITATION

Stand Up Now or Else . . .

For people with MS, fatigue and weakness are two reasons why sitting may be a preferred position throughout the course of one's day. Sitting, a body position which multiple joints are in a bent position, allows the effects of gravity to cause joint, muscle, and nerve problems. Also sitting is a common cause of posture abnormalities, muscle weakness, decreased endurance and, in many cases, increased aches and pain.

So, what can be done? Stand more often. When patients are asked about their daily activities, it is common that over 90% of their waking hours are spent in a sitting position.

The benefits of standing are extensive to keep people healthy, as well as to improve one's overall health. Whereas, one may not have a direct physiologic control of their MS, that same person can decrease or eliminate symptoms associated with MS. Standing activities have been reported to improve muscular strength and endurance, joint flexibility, posture, bowel and bladder function, respiration efficiency and overall feeling of wellness. Improved bone density, circulation, lymphatic return, and improved balance are all benefits for

patients with MS, including those who are not able to walk. This is essential since continued sitting can lead to further decline.

A standing program may sound easy, but can be ignored or dismissed due to its' simplicity or overall low stimulation created by the activity. For people with or without MS, a standing program can serve to significantly decrease back and leg pains associated with being in a sitting position.

This can be done as a break from TV, during commercials in television programs. Standing breaks can also be implemented in office settings with computer reminders to promote standing every 20-30 minutes. When standing, one can perform reading activities, have phone conversations or send email. There are now products on the market to make a standard desk into a standing desk with little effort.

Varidesk® is one example of a product that has been heavily marketed to promote increased standing time for people at work and at their home offices. It may take time to adjust the layout of the work station to ensure ergonomic factors are addressed. For anyone who has the ability to stand upright

with moderate to no assistance, this type of product can help with incorporating a standing program.

For people who are not able to stand without significant help, a standing frame is commonly considered at the IMSMP to start a standing program and work toward the many potential benefits of standing. A specific benefit for people who require wheeled mobility is the fact that standing can relieve pressure, which can cause wounds and poor wound healing. Spasticity and some muscle contractures can also be treated in a standing frame. The physical and psychological depression as a result of constant sitting can be improved with a standing program.

Easy Stand® is one company that makes standing frames for people who need a high level of assistance for standing. This device is the one currently used at the IMSMP for people who have initiated a standing program.

A person with MS can begin getting healthier second by the second, while being on your feet. For an appointment to start or advance your standing exercise program with Dr. Kanter or Dr. Woods, call (212) 265-8070.



Varidesk® standing desk



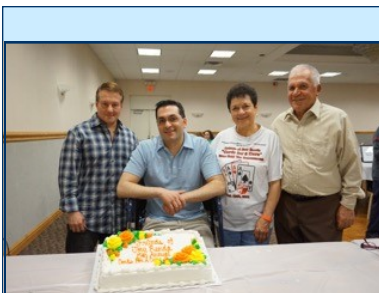
Dr. Elizabeth Woods using Easy Stand® standing frame with patient, Joanne Masor

DEVELOPMENT DEPARTMENT NEWS CONT'D

Inspiring Events by Patients & Friends

Friends of Joey Renda, Inc.

Congratulations to Joey Renda and friends for another successful Cards for a Cure Texas Hold 'Em Poker Tournament fundraiser for the Tisch MSRCNY. Over 50 players and 50+ guests packed the Flemington Elks Club in Flemington, NJ on Saturday, October 15th, for a fun filled night of food, drinks, raffles, and of course, poker! Three lucky players were awarded the tournament's top prizes, but the real winner is the Tisch MS Research Center. Thank you Joey Renda for raising **\$27,000** for our research!



**Joey Renda & his parents
with Dr. Andrew Sylvester**



**L to R: Chris Nemec—2nd
place, Fred Renda—1st place,
Joey Renda, Matt Matarazzo
—3rd place**

Welcome Lisa Mandel

Lisa Mandel joined Tisch MSRCNY in December to lead the Development Department. Lisa has worked for media and publishing companies (Simon & Schuster, Viacom, Meredith Corp) to develop audience and build revenue. Her media savvy and personal commitment to the Center makes her uniquely qualified to join Dr. Sadiq in taking on funding the very ambitious projects that are now before us - building the Institute for Experimental and Stem Cell Research, and the Phase II Stem Cell trial. "I'm thrilled to be here and I'm looking forward to meeting many of you as we work to meet and exceed our fundraising goals," Ms. Mandel said.



Lisa Mandel



2017 TCS New York City Marathon Calling All Runners!

For the 3rd year, Team Tisch MS is an official Charity Partner of the TCS NYC Marathon. We are excited to announce that we have been allotted 10 slots and are actively looking for runners! Last year's team raised over \$102,000 and we are only looking to go up from there.

If you are interested in joining our team please contact our development department at development@tischms.org or by phone at 646-557-3863.

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While every contribution is deeply appreciated, we regret that we are unable to list gifts below \$500 due to space limitations.

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

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