



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

STEM CELLS AND THE CAUSE OF MS WHERE ARE WE TODAY?

The Tisch Multiple Sclerosis Research Center of New York recently marked its' ten year anniversary. Undoubtedly, our greatest achievement to date has been our stem cell research. Beginning with laboratory studies even before the Tisch Center was founded, research moved from bench to pre-clinical studies and pilot clinical work. In September 2016, the last of 20 patients completed the treatment phase of the Phase I clinical trial establishing safety and tolerability of our approach. Our research team headed by Drs. Sadiq and Harris is now ready to build on our observations and experiences and establish efficacy of our stem cells in patients with multiple sclerosis. Based on improvement in motor function noted in several patients with disability in our Phase I trial, a controlled and double blind study involving 50 patients with MS is now in its' formative planning phase. In August 2016 our clinical protocol was approved by the FDA for a Phase II study, the first "repair" therapy to reach this stage in the United States. This cumulative work represents 15 years of research at a cost of over \$10 million dollars. Funding is now being actively sought for the Phase II efficacy trial, which we hope will begin this landmark two year study in early 2017.

Our other major research endeavor is to find the cause of MS based on molecular analysis of the immune cells in the cerebrospinal fluid (CSF) of MS patients. Currently, partially funded by a grant from the Emerald Foundation, this research led by the team of Jerry Lin, has made some remarkable progress. However, identification of the initial trigger remains elusive. The focus now is on investigating CSF taken from select high yield groups, such as new disease onset patients, discordant identical twins, and families with multiple affected members. Research on this project began years ago in 1994 and the goal of finding the cause of MS represents the "mission" of the professional life of Dr. Sadiq. The pace of this research as with all such work is again hugely dependent on the amount of available funding.

At the Tisch Center, our research is done to better the lives of MS patients. We have high goals such as establishing a regenerative therapy for disabled patients, and finding the cause of MS so that a rational path to a cure may be found. In the interim, at our affiliated clinical entity the IMSMP, we will always continue to provide the highest standards of innovative individualized clinical care for all of our patients worldwide. Together, we relentlessly strive toward, "A Future without MS."



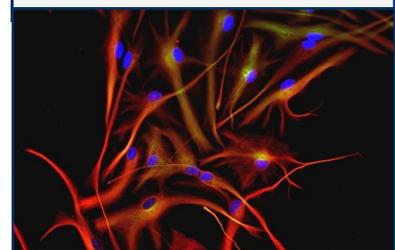
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**Stem Cell Research Scientists,
Dr. Saud A. Sadiq and
Dr. Violaine Harris**



**Patient stem cells
harvested and cultured at
the Tisch MS Laboratory**

INSIDE THIS ISSUE

- Welcome New Tisch MSRCNY Research Assistants!
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NEWS FROM THE TISCH MS LABORATORY

The Tisch MS Research Center is proud to announce that a number of abstracts from our laboratory have been accepted to the Society for Neuroscience (SFN) conference to be held in Chicago, Illinois this fall.

From the group led by Dr. Violaine Harris, the abstract written by research assistant John Tuddenham, **“Correlating biomarker levels with disease subtypes in multiple sclerosis,”** was accepted. Recent publications proposed several biomarkers to identify patients with multiple sclerosis.

The results from Dr. Harris’ group distinguish ITM2B and Angiotensinogen as prospective biomarkers of treatment response. Further study will be needed to determine whether potential biomarkers SOD1, SOD2, Contactin-1, and Kallikrein-6 reflect levels of inflammation or oxidative stress in MS patients.

The abstract, **“Intrathecal delivery of primary progressive MS cerebrospinal fluid induces behavioral deficits and spinal cord pathology in mice,”** was accepted from Dr. Jamie Wong. Previous publications indicate that primary progressive MS (PPMS) patients exhibit less inflammation

than relapsing-remitting MS (RRMS) patients. Dr. Wong tried to create an animal model of PPMS in mice using intrathecal injections of cerebrospinal fluid (CSF). The results of her research suggest that astrogliosis was responsible for the behavioral deficits and spinal cord pathology observed in the mice after the administration of intrathecal PPMS CSF injections.

The abstract, **“Thromboxane A₂ levels are increased in the cerebrospinal fluid of active multiple sclerosis patients,”** authored by Fozia Mir, Danielle Blemur and Saud A. Sadiq has also been accepted.

This study by Dr. Mir’s group investigated the involvement of the pro-inflammatory lipid thromboxane A₂ in multiple sclerosis and its’ animal model experimental autoimmune encephalomyelitis (EAE). Results show that thromboxane A₂ levels are significantly increased in the CSF of multiple sclerosis patients. In the EAE study, the expression levels of the thromboxane A₂ receptors in the mouse’s brain and spinal cord were also found to be upregulated during active disease. Further studies are underway to investigate its’ potential involvement in the pathophysiology of multiple sclerosis.

Dr. Violaine Harris’ group presented an abstract entitled, **“Reparative effects of intrathecal MSC-NP cells in patients with multiple sclerosis mediated by trophic and immunomodulatory factors,”** at the International Society for Stem Cell Research Conference in San Francisco, California. Prior research has established differences in gene expression between mesenchymal stem cells (MSC) and the neural progenitor variants (MSC-NP) currently being used to treat patients in the stem cell trial. Preliminary results from Dr. Harris’ group indicate that a number of proteins that affect tissue repair were produced in elevated quantities by MSC-NPs versus MSCs. These proteins and other markers of disease activity were also detected in the CSF of patients enrolled in the stem cell trial. Moreover, CSF levels of several of these markers correlated with treatment response.

Grants and Awards

Dr. Saud A. Sadiq received funding from the Emerald Foundation for the, “Distinguished Investigator Award,” to identify the cause of MS. The grant was awarded effective July 1st, 2016.

Tisch MS Research Center of New York is delighted to welcome a new class of Research Assistants to work in our laboratory.

PERSONNEL UPDATE



Zerina Balic (New York University) will work with Dr. Fozia Mir.



Antara Finney-Stable (Cornell University) will join Jerry Lin’s research team.



Lena Josephs (Vassar College), a Clinical Research Assistant, will work with Dr. Saud A. Sadiq.



Nathan Kung (Columbia University) will have Dr. Jamie Wong as his principal investigator.



Shayna Zanker (University of Massachusetts Boston) will work under the supervision of Dr. Violaine Harris.

Tisch MS Research Center of New York 19th Annual MS Patient Symposium



The Tisch MS Research Center of New York will hold the LARGEST patient education symposium in the U.S. at the New York Hilton Midtown.

People with multiple sclerosis, their family members and caregivers are all welcome to attend for FREE!

Come and learn from nationally recognized MS clinicians and Tisch MS researchers as they discuss, **"Complete Control of Your Multiple Sclerosis."**

OCTOBER 2016

16
SUNDAY

9:30AM - 1:00PM

New York Hilton Midtown
1335 Avenue of the Americas
(between 53rd & 54th Street)

REGISTRATION IS REQUIRED. SPACE IS LIMITED. REGISTER TODAY AT:

www.tischms.org
or call (646) 557-3919



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IMSMP CLINICAL NEWS



Neil H. Grafstein, MD

We are pleased to welcome Neil H Grafstein, MD to the IMSMP. Dr. Grafstein is a board certified Urologist with expertise in both neurourological and non-neurogenic voiding dysfunction. He is the only Urologist at Mt. Sinai certified in female pelvic medicine and reconstruction. Dr. Grafstein attended State University of New York (S.U.N.Y) Health Science Center - College of Medicine and completed his Residency in Urology at S.U.N.Y Downstate Medical Center. He also completed a fellowship in Reconstructive Urology at Duke University. Patients can schedule an appointment to see Dr. Grafstein by calling (212) 265-8070.

PLEASE READ



E-mails & Social Media

A statement from IMSMP, MSMPNY & Tisch MSRCNY regarding our online policy:

At the International Multiple Sclerosis Management Practice (IMSMP), the Multiple Sclerosis Management Practice of New York (MSMPNY) and the Tisch MS Research Center of New York, it is our policy that no staff members participate in any online conversation with patients, patients' families or others regarding patients of the Center. This includes requesting or accepting a "friend" invitation on any social media platform. **Involvement in any type of social media between patients and staff members puts the Center at risk of violating HIPAA regulations.** In addition, questions should only be asked via telephone or in person. IMSMP, MSMPNY and Tisch MSRCNY will do everything possible to not compromise the privacy or security of protected health information.

Thank you for understanding.



CLINICAL RESEARCH

We are excited to announce that Beth Levine has accepted the position of Clinical Research Nurse Coordinator at The Tisch MS Research Center of New York. Beth's extensive background in a clinical research setting along with her many years as an RN at the IMSMP, makes her the perfect candidate working to support the Phase I/II clinical trials. Beth will be managing and implementing clinical research protocols, assuring efficiency, compliance, and the safety and well-being of all trial participants. Congratulations, Beth!

A REQUEST FROM IMSMP BILLING

When using a personal check at the IMSMP, you MUST write your name or account # on the check. Many checks have been received without the patient's name on it, causing difficulty in identifying who the check belongs to and where funds should be credited.

Also, we kindly request all insurance checks be forwarded rather than cashed and that the explanation of benefits accompany these checks when sent in.

A NOTE FROM THE NURSES

Here are a few facts about the once-a-day oral medication, Aubagio. Aubagio is the second FDA-approved oral medication used for relapsing remitting multiple sclerosis. Aubagio works by inhibiting replication of rapidly dividing immune cells. Similar to Cellcept, which is another medication used off-label for MS, Aubagio can be considered a, "mild chemotherapy."

The most common side effects seen with Aubagio are gastrointestinal issues and hair loss. If you do experience hair loss, it should only be mild and temporary. If this occurs, we recommend an over-the-counter supplement such as biotin for hair strengthening.

In addition, Aubagio is a pregnancy

category X drug, meaning this medication is toxic to a fetus. Anyone on this medication should take strict and effective birth control measures. This applies to both men and women taking Aubagio. Please make sure to inform your doctor if you are considering Aubagio and thinking about family planning.

If your doctor decides that Aubagio is the appropriate medication choice, you will receive blood work prescriptions for a liver function test and complete blood count. This blood work will need to be completed prior to starting the medication and will also be required monthly for the first six months on Aubagio. At the IMSMP, we monitor your blood work very carefully to ensure your safety!

SOCIAL WORK NEWS



For people living with multiple sclerosis, travel can be more difficult, no matter what the season. The social work department can assist patients in applying for accessible transportation, driving permits and private transportation companies to help you get to work, appointments or social events a lot easier. Below are resources for these services. Feel free to call the social work department with any questions you may have.

Access a Ride- New York City

The service is shared-ride, door-to-door or feeder service. When applying for Access-A-Ride (AAR) or recertifying you must go to their office to be approved. AAR will pick you up and take you to the scheduled appointment.

More information about the application process, scheduling trips, fares, traveling with a companion, etc. can be found on the Access-a-Ride website: <http://web.mta.info/nyc/paratran/guide.htm>

Accessible NYC Taxi Service

The New York City Taxi and Limousine Commission manages a program that provides wheelchair-accessible yellow taxi dispatching services. Wheelchair-accessible yellow taxis will respond to trips originating in Manhattan and ending anywhere in the five boroughs, Westchester and Nassau counties, and the three regional airports. Passengers pay the normal metered taxi fare in New York City from the point of pick-up to destination. There are no extra costs to passengers. There are five ways to request a New York City wheelchair-accessible taxi:

- Call 311
- Call the dispatch center directly: (646) 500-9999
- Text a request to: (646) 400-0789
- Use the mobile app "Wheels on Wheels" (WOW), powered by Taxi Magic and available free at the Apple iTunes Store
- Order online at

www.nycaccessibledispatch.org

Customers living in the Bronx, Brooklyn, northern Manhattan, Queens, and Staten Island can call the Boro Taxi car services (also known as Street Livery bases) listed in this website to order a wheelchair accessible taxi to the outer boroughs:

<http://www.nyc.gov/html/tlc/html/passenger/accessible.shtml>

PHYSICAL THERAPY & REHABILITATION

A Two Part Article from Dr. Stephen Kanter, Supervisor of Rehabilitation Services.

Part 1: Three Important Questions to Ask Yourself . . .

“Have I stretched every day?”

Stretching is like brushing your teeth. It should be done every day and multiple times. Stretching is the most basic exercise that needs to be done by everybody, especially by people with MS who have any mobility limitations. Stretching complements all other exercises in areas such as strength training and balance. Insufficient stretching commonly leads to poor movement patterns, pain, posture dysfunction, and in some cases, worsening spasticity and decreased independence in transfers.

“Did I see a Physical Therapist at least once in the past 6 months?”

Whether it is with Dr. Kanter or Dr. Elizabeth Woods at the IMSMP or a trusted local physical therapist, the best way to prevent a pattern of physical deterioration is to schedule a physical therapy evaluation or plan of care review to update every 6

months. This session can be essential in keeping you on track by adjusting exercises that may not be beneficial or just need to be changed. Seeing a PT on a more regular basis will provide an opportunity to catch a new impairment such as weakness, tightness, or poor balance before it becomes a big problem. For people who use wheelchairs, this session can be useful in considering how the age and breakdown of the chair may be leading to new problems not directly related to MS.

“Is there anything I cannot do this year that I was able to do much better last year?”

This is possibly the most important question to reflect on. It is common to get frustrated with not being able to do an activity that you were able to do when you were “younger,” but it is the decreased abilities that occur in the short term that need to be addressed head-on since those are usually the most controllable.



**IMSMP patient,
Adriane Kufta with
Dr. Stephen Kanter**

Withdrawing from an activity that is considered harder commonly leads to additional limitations. For example, if you were not physically able to safely rake leaves during the fall this year and in 2015 you were able to, this should be addressed with your physical therapist. Returning to activities, even with modifications and/or supportive devices, as soon as possible, can decrease or halt the rate of disability.

Watch for Part 2 of this article in our fall issue of Healing MS!

NEWS ON NATUROPATHY

Fish: Super Food or Super Toxic?



Fish is both an incredible source of good nutrition and also a potential source of dietary toxins. Fish is the richest source of anti-inflammatory brain building essential fatty acids, but certain species have toxic levels of mercury, PCBs or other environmental contaminants. Mercury exposure is particularly hazardous because it crosses the blood brain barrier and is a known neurotoxin. By becoming educated in safer fish choices, it's not hard to get the benefits of fish without the risks. The benefits of eating fish clearly exceed the risks, as long as the fish consumed are mostly low in mercury.

Which fish are the best to eat and which fish should be avoided?

Best Fish Choices (high in omega 3s, low in mercury and other environmental contaminants):

*Wild Alaskan Salmon *Anchovies, Sardines, Herring
*Farmed Rainbow Trout *Farmed Striped Bass
*Farmed Sturgeon

Fish to Avoid (highest level of mercury contamination):

*King Mackerel *Tilefish
*Tuna (Bluefin, Bigeye) *Shark
*Swordfish

There are many fish in the sea (not all could be listed here)! For more information to help you make healthy choices, see the mercury calculator at www.gotmercury.org, or visit with Dr. Bates, the IMSMP's Naturopathic Doctor.

Rule of thumb:

If an entire fish, from head to tail, fits on your dinner plate, it is probably a low mercury fish.

TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

Inspiring Events by Patients & Friends

On May 25th, 2016, Immaculate Conception High School in Lodi, NJ raised **\$2,600** for the Tisch MS Research Center. Emilia Strafford has been raising money for different MS organizations for the past ten years doing walks with two different schools. She has raised over \$100,000 in her endeavors. Her brother in law, Joe Revello (a patient of Dr. Sadiq's) has secondary progressive MS. She coordinates all logistics and has brought awareness to the community.



Immaculate Conception High School Fundraisers

On June 11th, 2016, Tori Shapiro from Armonk, NY held a bake sale to raise money for Tisch MSRCNY. Tori has a family member with MS and as part of her Mitzvah project for her Bat Mitzvah, Tori and her friend Lucy Ross decided to raise money to help find a cure for multiple sclerosis. She and her family saw Dr. Sadiq speak at the 2015 MS patient symposium and were greatly affected by his passion and the promise of his work. That was when, she decided to donate the total **\$1,074** profit they made in the bake sale to the Tisch MS Research Center of New York.



Tori Shapiro (left) and Lucy Ross (right)

Are you interested in creating a fundraiser to raise money for Tisch MSRCNY? Contact Meaghan Browne: mbrowne@tischms.org to get involved!



What is Team Tisch MS?

Team Tisch MS, also known as TTMS, is the team of runners, bikers, swimmers, and triathletes, who are competing in races and other events to raise money to donate to Tisch MS Research Center of New York (Tisch MSRCNY) to advance research to help find a cause and cure for multiple sclerosis.

Can I be a part of TTMS if I do not participate in races?

Yes. You can become a supporter by recruiting potential TTMS members or you can support the fundraising efforts of current TTMS members. In addition, TTMS is always looking for sponsors to help build the program and provide mutually beneficial marketing opportunities.

When did the TTMS program start?

TTMS was founded in 2015 and, shortly afterward, was accepted as an official charity partner of the TCS New York City Marathon.

How can I help support TTMS today?

One way is to donate to TTMS and get an official TTMS T-shirt! Wear it at the TCS New York City Marathon on November 6, 2016 while cheering on the TTMS members who are running the race. Another way is to donate to help one (or more) of the runners reach their fundraising goals on our Crowdrise page: www.crowdrise.com/TischMSNYC2016

Who are the members of TTMS?

Members of TTMS can be anyone who is participating in a race (run, bike, swim, tri, etc.) and is interested in raising money to advance the research at Tisch MSRCNY.

Where can I learn more about TTMS or become a member/sponsor?

VISIT: teamtischms.org EMAIL: tms@tischms.org

CALL: (646) 557-3863 and ask for Meaghan Browne



Meaghan Browne

The Development Department would like to welcome our new Development Coordinator to the team! Meaghan Browne joins us from Boston, where she worked in loan processing for Leader Bank.

She graduated from Quinnipiac University with a focus on Donor Relations, Non-profit Fundraising and Event Planning. Meaghan is a great addition to our Development team. Welcome, Meaghan!

DEVELOPMENT DEPARTMENT NEWS CONT'D



L to R: Stephen Albanese, Ash Mitchell, Brian Kane, Michael Bucceri & Ken Helman (pictured right) tees off!

On June 6th, 2016, co-organizers Michael Bucceri and Stephen Mandel hosted the **3rd Annual Take a Swing at MS Golf Outing**. The day teed off with a windy but healthy dose of sun, a buffet lunch and a grand parade of carts onto the course. The event raised approximately **\$40,000** for stem cell research!

Special thanks to Michael and Gillian Bucceri, Stephen Mandel, and all of the event sponsors, supporters and in-kind donors who made the outing such a success. Plans are already underway for next year's event!

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The Tisch MS Research Center receives workplace giving funds from the United Way of New York City, United Way of Bergen County and the United Way Granite of New Hampshire. Inquire with your employer to participate.

The Tisch MS Research Center gratefully acknowledges corporate matching gifts from the following companies:

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*This list includes donors of \$500 or more received between May 1st and July 31, 2016, not including contributions supporting the 2016 Future Without MS Gala. 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.

IMSMP

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

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