

INTERNATIONAL MULTIPLE SCLEROSIS Management Practice

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Healing MS

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

IMSMP & TISCH MSRCNY CELEBRATE 10 YEAR ANNIVERSARY!



On March 6th, 2006, the elevator opened on to the 4th floor at 521 West 57th Street and a doctor's office like no other came to be. A calming, tranquil environment welcomed patients with soft colors on the walls still smelling of fresh paint. A crew was hard at work buffing floors and the concierge could be heard saying, "Please pardon our appearance, we are still moving in!"

Dr. Saud A. Sadiq's vision of seamless interaction between clinicians and researchers all working to better the lives of those suffering from MS became a reality on that day in March. It is now 10 years later and we celebrate just how far the International Multiple Sclerosis Management Practice (IMSMP) and the Tisch MS Research Center of New York (Tisch MSRCNY) have come!

"We are thrilled to reach this important milestone as we continue our mission to discover the cause of and cure for multiple sclerosis." - Dr. Saud A. Sadiq

The IMSMP has become a destination MS center and is one of the best MS facilities in the world with some of the highest rated neurologists, offering personalized medicine. It is a center of excellence dedicated to comprehensive healthcare.

Tisch MSRCNY has become a recognized leader in MS research with hundreds of publications and abstracts presented at various conferences over the past decade in addition to being the only center in the U.S. to conduct an FDA approved clinical stem cell trial for MS. Visit **www.tischms.org** for more.

As we continue to expand and innovate, our gratitude is with our patients as we reflect on the inspiration, strength and support they have provided us since the day our doors opened!



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A Decade Of Dedication



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LABORATORY RESEARCH

Research to be Presented and Highlighted at the 2016 American Academy of Neurology ® (AAN) ANNUAL MEETING

Tisch MSRCNY is proud to announce that all eight of the research abstracts submitted to the AAN were approved for poster presentations for the 2016 AAN Annual Meeting in Vancouver, BC, Canada this April.

Dr. Saud A. Sadiq's "Multiple **Intrathecal Dosing of Neural Progenitors Administered to Progressive MS Patients with Disability is Safe and Improves** Disability Scores," which addresses the ongoing results from the Center's Phase I stem cell trial, was accepted for dual presentation, both as a talk at the "Remyelination and Repair in Multiple Sclerosis" Data Blitz Presentation and as a poster presentation during the "MS and CNS Inflammatory Disease: Clinical Trials" session. Dr. Sadiq's abstract documents the neurological improvements of patients in bladder function, 9 Hole Peg Test, and Expanded Disability Status Score (EDSS), and concludes that the treatment is safe and well tolerated, and proposes that the efficacy trends warrant a Phase II trial.

Leslie Blackshear, one of our clinical research assistants, authored "Long-Term Clinical Stability in a Subset of MS Patients with **Minimal Therapeutic Interven**tion." This study documents the existence of a group of MS patients with little to no discernible evidence of disease activity or progression 10 to 20 years following diagnosis, despite having received minimal or no long-term treatment.

Danielle Blemur, a research assistant under Dr. Mir's supervision, investigated blood and CSF levels of a specific metabolite, CMPF and the role it could play in the pathogenesis of MS, in "Elevated levels of the furan fatty acid metabolite,

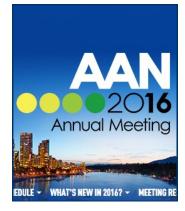
3-carboxy-4-methyl-5-propyl-2furanpropanoic acid (CMPF) in the serum of multiple sclerosis patients."

"Intrathecal autologous mesenchymal stem cell-derived neural progenitors (MSC-NPs) for the treatment of progressive multiple sclerosis: safety and preliminary efficacy data from a Phase I trial." In this work, Dr. Violaine Harris evaluates the safety, tolerability, and preliminary efficacy of three intrathecal (IT) administrations of autologous MSC-NPs in progressive MS. The study found this treatment to be safe in all 20 study patients with no major adverse events. Ruth-Anne Langan expanded on Dr. Harris's team's previous research on the Fetuin-A biomarker. In her abstract, "Fetuin-A, a CSF Biomarker of **Multiple Sclerosis Disease** Activity, is Upregulated at the Blood-CSF Barrier,"

Langan discusses the possible role of Fetuin-A in blood-CSF immune cell trafficking and how further research is needed to better understand the mechanism of disease activity.

Kelsey McDermott in Dr. Massimiliano Cristofanilli's group authored **"CSF from Progressive-MS** Patients stimulates microglial activation pathways in vivo and in vitro," in which she investigates the activation of microglia (resident immune cells in the brain) in an effort and consistency of MSC-NPs derived to further understand the different subtypes of MS. The activation of microglia was found in PPMS CSF, which reduced with treatment.

Dr. Fozia Mir authored "Thromboxane A2 Levels are Increased in the CSF of Active Multiple Sclerosis Patients," which discusses her investigation



of the metabolite thromboxane A2 and its potential role in the pathophysiology of MS.

John Tuddenham, one of Dr. Harris's research assistants, authored "Effects of Intrathecal MSC-**Derived Neural Progenitors** (MSC-NP) Treatment on **Biomarker Levels in the CSF** in Patients with Progressive Multiple Sclerosis." This study investigated whether the repair of neurons in MS could be detected by CSF biomarker analysis, which measures the CSF concentrations of specific proteins. The CSF levels of the proteins of interest, Hepatocyte Growth Factor (HGF) and Neurofilament light (NF-L), were increased in patients after treatment.

Dr. Tamara Vyshkina authored "Quality Control of Autologous **Bone Marrow Mesenchymal Stem Cell-Derived Neural Progenitors from Patients with Multiple Sclerosis Prior to** Intrathecal Injection. This abstract looked at the quality from the bone marrow of MS patients for stem cell therapy. Laboratory testing of these mesenchymal stem cells showed low frequency of abnormalities, and confirmed the safety of this therapy.

For more information regarding research, please visit: www.tischms.org

CLINICAL RESEARCH

Phase II Stem Cell Trial

Encouraging results from the ongoing Phase I stem cell trial have propelled Tisch MS to move on to Phase II, which is expected to launch this summer. While Phase I has primarily focused on the safety of this treatment, Phase II will test the efficacy of stem cells in a double-blind, placebo-controlled, randomized trial consisting of forty patients.

The need for funding is critical, as patient recruitment and the commencement of Phase II cannot occur without sufficient financial support. Tisch MSRCNY is in the process of applying for grants from the National Institutes of Health (NIH), the National MS Society and various other charitable organizations.

FROM THE FRONT DESK

Safety first:

Dedication to our patients has always been our priority, and we remain committed to giving the best care to everyone we serve. At this time, we would like to address safety.

If you don't feel well, it is important that you keep your visit with your doctor, and inform our staff if you are having a bad day with walking, or feel that your balance is off. We understand that our facility is large and would like to make sure our patients are aware of what safety precautions are in place.

On the 4th floor, we have a wheelchair and a walker at the front concierge area that is available for patients to use in the center on the day of their appointments.

If you don't feel well, but are still able to walk, an IMSMP medical staff member can assist you throughout the center. If you are experiencing an exacerbation or have a history of falls, the doctor may require that you are escorted throughout the center with the use of a wheelchair or walker.

Appointments are confirmed 48 hours in advance, so if you are having difficulty walking, you have the opportunity to let our staff know at that time so we can have a wheelchair ready for your use in the center or have someone assigned to assist you on the day of your visit.

Creating a safe environment is something we take very seriously.

A NOTE FROM THE NURSES

The clinical nursing department would like to welcome two new RNs!







Jessica Keaney joined our team from The Neonatal Intensive Care Unit at Mt. Sinai Hospital. Jessica is originally from Tennessee where she received her Bachelors of Science in Nursing at Tennessee Wesleyan University.

Jaclyn Trezza joined our team from The Cardiothoracic Step Down Unit at Columbia University Presbyterian Hospital. Jaclyn is originally from New York where she received her Bachelors in Nursing at Molloy College.

They are a great addition to our nursing team. Jessica and Jaclyn are excited to get to know our wonderful patients.



Tisch MSRCNY Stem **Cell Trial Welcomes** Judith Jaffe Multiple Sclerosis Center

The Judith Jaffe Multiple Sclerosis Center at Weill **Cornell Medical College** will be the other leading MS center to join the Tisch MS **Research Center clinical** stem cell trial for MS. The Judith Jaffe Center will participate in patient recruitment and data collection. All costs and expenses related to the Phase II study are solely the responsibility of Tisch MSRCNY.



IMSMP Payments by Check

Patients mailing in checks must also send along the explanation of benefits that comes from your insurance carrier.

Please do not fold checks as they are processed through a scanner and may not be read correctly.



An Important Message from the Infusion Suite

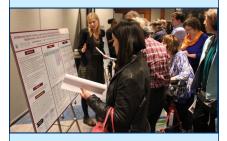
At the IMSMP, it is our number one priority to make sure all care and treatments take place in a calm and therapeutic environment. We kindly ask that you please do not bring young children or more than one guest when visiting the infusion suite.

Our goal is to provide excellent service in a relaxing atmosphere with respect to all of those around.

Thank you for understanding.

SAVE THE DATE October 16th, 2016

Tisch MSRCNY Patient Symposium



9:30am - 1:00pm New York Hilton Midtown

A free educational event for MS patients, their families and caregivers. Join us!

Registration & more info coming soon!

NEWS ON NATUROPATHY

Learning Complex New Activities may Help Support New Myelin Formation into Adulthood

Myelin was once considered to be an inert element in the nervous system. Today, thanks to newer scientific approaches and powerful tools, myelin is being recognized as a highly dynamic and metabolically active tissue, essential to the execution of the brain's most complex functions, and a key modulator of plasticity (changes in the brain brought about by experiences). Although the majority of myelin development happens in childhood and adolescence, recent studies have shown that production of new myelin can continue to happen, even in adult brains.

In a paper written by Tomassy et al, "Diversity Matters: A Revised Guide to Myelination," they recognize that myelin production is regulated by brain activity, and that our behaviors influence the development of new myelin throughout adulthood. "Once myelination of all brain regions is completed, **production of new myelin is still possible; adults who actively learn complex tasks such as studying a second language, juggling, or pianoplaying show increased myelination in specific regions of the brain**. These observations suggest that brain activity can impact the production of new myelin, even in adulthood." Learning new things, engaging in meaningful work and enjoying novel activities are all strategies that have been recognized to promote brain health and memory. It's exciting to see that these activities may even help stimulate the growth of new myelin. What new thing will you learn next?

SOCIAL WORK NEWS

The IMSMP Social Work Department continues to offer support groups for our patients, as well as for their spouses/partners, which help to bring people to-gether who share common life experiences. To quote a long time group member:

"To be given an opportunity to voice everyday concerns, good and bad, is so relieving. We have fun in the group, get a sense of community and an arena to articulate how our lives are affected."

The following groups continue to meet at the IMSMP, and are often open to new members:

-Women's Coping and Connection Group

-Professional Men's Group

-Spouse/Partner Group

As of January 2016 Shelly White, LMSW,



is leading a new support group for men and women with disabilities who are available to meet every Thursday from 11:30am to 1:00pm at the IMSMP. It is a great opportunity to meet new people, share common experiences, learn from one another, support one another, share other interests and socialize. If you are interested, please call (212) 265-8070 and ask for Shelly White.

There will also be a Newly Diagnosed Group starting March 2016 at the IMSMP. This group is for patients who have been diagnosed within the last 3 years. If you are interested, please contact the Social Work Department at the number above.

PHYSICAL THERAPY & REHABILITATION

Maximizing Health of a Muscle in People with MS

For people with multiple sclerosis, weakness is a common symptom. The terms "weakness," as well as "strength," are sometimes miscommunicated when determining physical wellness goals. Weakness can be due to many factors other than a true decrease in muscle strength. Weakness in MS often suggests difficulty in moving, which can be caused by fatigue, overheating, poor nutrition, spasticity, poor core stability and/or poor balance. In many cases, increasing the strength of a muscle will not completely eliminate the sense of weakness.

Getting stronger is commonly simplified to a person's ability to exercise with heavier weights or greater tension on resistance bands. Strength is much more complicated than that. For some, the changes in strength over the course of the day cause issues in walking or other activities. These changes create a unique frustration in people with MS trying to live their lives.

Let's examine some factors which must be considered regarding strength, weakness and how to maximize the health of a muscle for people with MS.

1) Muscles create and also control movement!

A muscle that is unable to perform its "control function" usually results in decreased balance and falls. Exercises for muscles must include those which work on the "control function" of a muscle. An example of this would be reverse sit ups or very slow squats.

2) A muscle needs to be a certain length in order to work properly.

Joints that have limited movement

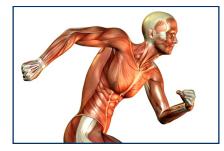
will result in muscles that shorten. Stretching a muscle is an exercise that must be done by everyone with MS several times throughout the day; correct joint positioning is essential as well. Full body posture training and use of bracing may be the most important parts of keeping a muscle at its necessary length.

3) There are different "types" of muscles within each muscle.

Each individual muscle is made up of many muscle fibers. Generally, a skeletal muscle is composed of two fiber types. One type functions to work hard and quickly, and then needs to recover. Let's call these the "sprinter muscles." The second type works steadily over a long period of time. Let's call these the "marathon muscles." Exercises using the sprinter muscles should focus on generating power quickly to create as well as control movement. A high percentage of routine activities only need sprinter muscles. In people with MS, the marathon muscles may not be used enough to keep them functional. Specific endurance programs that incorporate rest periods are important to strengthen this aspect of a muscle. Please note: improving skeletal muscle endurance is not the same as improving cardiovascular endurance through "standard aerobic" exercises.

 Nerve conduction and connection to the muscle cannot be achieved through inactivity and sitting.

Improving nerve conduction is complicated since MS decreases the speed at which a signal can move within an affected nerve. There are some prescription medicines that can be discussed with your neurologist to improve nerve conduction



and make sure that it does not worsen. Physical activities are necessary to make any functional changes in the nervous system to improve muscle contractions and overall muscle health, regardless of MS type.

5) Functional strength is more important than getting stronger muscles.

Having a stronger (and bigger) individual muscle may not allow people to stand, transfer or walk on their own. The muscle needs to be worked in a way that replicates the task it needs to perform. Training a muscle to create movement when sitting will not necessarily carry over to using a muscle to control a movement while standing. For neuroplastic changes to result in functional improvement, specificity in movement is required.

6) Pain must be controlled for muscles to work effectively.

Hopefully, you can use this knowledge of improving the health of your muscles to start or restart the next phase of your physical wellness program. A daily program is essential to be able to safely and most effectively perform the activities you want this spring and summer. Working with a physical therapist or other rehabilitation professional can help maximize your physical independence. People with MS should review and update your physical wellness plan every year with a licensed physical therapist.

THE MOLLIE AND PHILIP ROSENBERG Rehabilitation Suite



Christian Woods and Shelly Ferrell



L to R: Tom Livezey, Chris Nemec, Ray Nash, and Joseph Renda



Susan Jakubowski, Julia Jakubowski & John Kissane

TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

Announcing The Mollie and Philip Rosenberg Rehabilitation Suite

Anyone who has been a patient at the International Multiple Sclerosis Management Practice knows that treating the whole person (not just the symptoms of MS), has been in its DNA from the start. This past spring, a special donor with a longstanding history at the Center, stepped forward to recognize this tradition by making a very generous contribution to name the rehabilitation unit The Mollie and Philip Rosenberg Rehabilitation Suite.

Dr. Sadiq, the IMSMP and Tisch MS Research Center of New York have all been near and dear to Mrs. Sandra Kanter and her family for nearly two decades. Her late husband, Allen Kanter, was a patient of Dr. Sadiq, and years later her son, Dr. Stephen Kanter, joined Dr. Sadiq to grow the physical therapy department into a vital center of activity that keeps MS patients as active, healthy and as happy as possible. In tribute to her legacy and generosity, the Center designated the rehabilitation unit according to Sandra's wishes to honor her parents, Mollie and Philip Rosenberg.

Inspiring Events by Patients & Friends

9/19 - Shelly Ferrell and Christian Wood's Timmer's Way Annual Music Festival at O'Neil's Pub & Restaurant (Norwalk, CT) - \$20,000

10/17 - 4th Annual Friends of Joey Renda Texas Hold'em Poker Tournament at the Flemington Elk's Club (Flemington, NJ) - \$28,000

11/09 - Julia Jakubowski's 5K for Tisch MS Research Center of New York's Stem Cell Research Study at Trump National Golf Club Charlotte in honor of John Kissane (Mooresville, NC) - \$5,500

11/27 - Ugo Vincenzini's Run the Research for MS (Manama, Bahrain) - \$1,300





Team Tisch MS is back !

Calling all walkers, runners, iron (men/women) and adrenaline lovers; are you interested in racing to repair MS? Come join our team and help us fundraise and raise awareness.

For more information contact us at: <u>ttms@tischms.org</u>.

DEVELOPMENT DEPARTMENT NEWS CONT'D

WITH SINCERE APPRECIATION, WE HONOR & RECOGNIZE OUR DONORS*

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<u>\$1,000 +</u>

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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 November 1st, 2015 and January 31st, 2016. 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 Kimberly Woodward,

kwoodward@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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