

INTERNATIONAL MULTIPLE SCLEROSIS Management Practice

Summer 2015 Volume 3, Issue 28

# Healing MS

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

# Innovative Therapies, World Class Healthcare

The International Multiple Sclerosis Management Practice (IMSMP) serves MS patients from almost every state and from countries all over the world. This reputation stems from the fact that all aspects of healthcare delivery are constantly reviewed and improved so that the patient is always assured of receiving the best care possible. However, in the final analysis the discerning and demanding patient ultimately seeks the latest and best "doctor" care. Physicians past and present at the IMSMP (and its predecessors) have delivered innovative therapies and established trends for others to follow.

In early 1992, we initiated intrathecal (within the spinal canal) baclofen therapy in patients with spasticity becoming the first center in New York to introduce this therapy, later on becoming the first in the world to publish the use of this therapy in ambulatory patients. In 1995, faced with patients with intractable pain syndromes and spasticity, we successfully combined intrathecal morphine and baclofen therapy. Based on this success over several years we published these findings as well as being the first to introduce intrathecal clonidine for MS patients with spasticity and pain. At the same time we used 4 aminopyridine to help patients with ambulation at least 15 years before it was approved by the FDA as Ampyra® . One of our greatest innovations was the introduction of intrathecal methotrexate as a therapy for progressive MS patients in 2001; introduced after several years of research conducted at Tisch MSRCNY and has since been successfully and safely used in hundreds of our patients. Our biomarker development program initiated in 2001 has over the past 14 years matured to the point that almost all progressive disease patients are now managed optimally based on the patient's spinal fluid characteristics. Currently, we are conducting the only FDA-approved stem cell trial in MS in this country and our exciting preliminary results suggest that this will potentially be the first reparative therapy for MS patients with disability. Our goal is always to lead in MS care, that is why patients from 50 countries come for their care to the IMSMP - to get the best treatment anywhere.

Visit www.tischms.org to read our published research.



- Neuroscience conference
- Traveling with MS helpful tips to know!
- Have you registered for the 2015 MS Patient Symposium?
- Please support Team Tisch MS!
- Thank you to our donors!



# 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. Ying Liu, the work entitled, **"Vitamin C facilitates pluripotent stem cell maintenance of MSCs and promotes its neurotrophic functions"** has been accepted. Previous publications indicate that high doses of Vitamin C may increase growth and decrease cell death of pluripotent stem cells. The initial results from Dr. Liu's group indicate that Vitamin C may have beneficial effects when administered simultaneously with mesenchymal stem cells.

The abstract, **"Single cell analysis of MS CSF B Cells shows predominant IgM response in some MS patients"** was accepted from the group led by Jerry Lin. Recent publications indicate that the presence of IgM, a type of antibody, in the cerebrospinal fluid (CSF) may be involved in more aggressive forms of MS, or may be a predictor of future conversion to clinically definite MS. The results of the Lin group suggest IgM levels do not appear to correlate with disease type, phase and/or duration. However, CSF taken from the same patients over time indicate that levels of IgM are consistent and specific to that patient. Further study will be needed to learn more about the activity of IgM in MS.

From the group led by Dr. Massimiliano Cristofanilli comes the project, "CSF from progressive MS patients stimulates microglial activation pathways in vitro and in vivo." In this study, the team investigated the effect of CSF on microglial activation (one of the inflammatory responses thought to be involved in MS) using their recently-published mouse model of progressive MS. The group found that CSF from progressive MS patients who were clinically stable following treatment had greatly diminished capacity to activate this inflammatory pathway compared to untreated samples from the same patients. This finding suggests that treatment, particularly methotrexate, may target this inflammatory response in MS.

#### **Grants & Awards**

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

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

#### **Personnel Update**



John Tuddenham (Columbia University) will be working under the supervision of Dr. Violaine Harris.





Jessie Huang (Cornell University) will have Dr. Massimiliano Cristofanilli as her Principal Investigator.

Allison Liang (Cornell University) will join Jerry Lin's team.





Jeffrey Jian (Cornell University) will work with Dr. Massimiliano Cristofanilli.

Gloria Joo,

Sadiq.

(Williams College),

a Clinical Research

Assistant, will work

with Dr. Saud A.

# CLINICAL RESEARCH CONTINUES TO GAIN INTERNATIONAL RECOGNITION

This June, Dr. Sadiq delivered more promising results from Tisch MS Research Center of New York's (Tisch MSRCNY) FDA-approved Phase I stem cell trial at the International Society for Stem Cell Research's Annual Meeting in Stockholm, Sweden.

The Tisch MSRCNY research report presented interim analysis of the first ten patients treated, all of whom had zero adverse effects or safety concerns. The report went on to show that seven of the ten patients state improved muscle strength in their lower limbs and most remarkably, a patient who was wheelchair-bound for over one year is now able to use a walker. A second patient, who would walk with assistance but fell frequently due to weakness and instability, has not fallen in over three months due to improved balance and is regaining normal strength in her lower limbs. She is now transitioning from walking with assistance to ambulating unaided. A third patient, who had lower right limb weakness, now has normal strength in his leg. In addition, of the nine patients with bladder dysfunction, five have reported noticeable improvement in this troubling area.

Dr. Sadiq while pleased by these positive efficacy trends cautions, however, that this is an interim analysis and the study will have to be completed before definitive conclusions can be drawn.



TISCH MSRCNY CORDIALLY INVITES PATIENTS, THEIR FAMILIES AND CAREGIVERS TO THE 18<sup>TH</sup> ANNUAL MS PATIENT SYMPOSIUM

#### Sunday, October 18th, 2015 9:30am – 1:00pm

**New York Hilton Midtown** 1335 Avenue of the Americas (between 53<sup>rd</sup> and 54<sup>th</sup> streets)

This year's topics include: ways to battle depression, fatigue and cognitive issues, naturopathy & MS, radical new treatments for multiple sclerosis and you'll hear from patients improving in our FDA-approved stem cell trial. Space is limited. Registration is required.

# Register today at: www.tischms.org or call (646) 557-3919



# **Rituxan**" Rituximab

#### **Attention Rituxan Patients**

For any IMSMP patients currently receiving their Rituxan at Beth Israel Infusion Center, here are some important facts that you should know:

Beth Israel Infusion Center is located at 325 West 15<sup>th</sup> Street New York, New York 10011 Between 8<sup>th</sup> and 9<sup>th</sup> Avenue.

If you need to schedule an appointment, you can contact Terrell at (212) 604-6030. She will be able to answer any questions that you may have.

#### Important information from the IMSMP Billing Department

#### **Explanation of Benefits**

Please send the explanation of benefits you receive from the insurance company along with your payment to the IMSMP.

#### **Online Banking Payment**

When paying through online banking (also called "bill pay"), some checks do not list the patient's name or account number. This becomes a challenge and is time consuming as the staff attempts to figure out who the patient is so we can apply the payment to the correct account. Please indicate your name and account number through your online banking system. This option should be available or can be added to the memo section.

# FROM THE NURSING TEAM

At the IMSMP, the nurses on the prescription line are available to help with refill requests, prior authorizations and any questions that you may have. Our goal is to make life as easy as possible! Here are several tips from your nursing staff to ensure that prescription requests and questions are addressed quickly and efficiently.

When leaving a message on the prescription line (and nurse triage phone line) please:

1. State your name and date of birth clearly.

2. Leave a phone number and let us know when you will be available for any questions before 5:00pm.

3. Let us know if we can leave a detailed message if you are unavailable, or indicate if you prefer that we only leave a brief message with our name and call back number.

4. Make sure your voicemail box is not full if we do need to leave a message.

Please be aware that controlled substances, by federal law, typically have to be mailed to your pharmacy. This process, unlike other prescriptions, can take up to 1 week. Please allow for ample time in between to ensure that you get your medication before you need it. We will no longer be able to call in emergency supplies of medication for controlled substances.

When calling in with a request for a specialty medication prescription refill or prior authorization, please be aware that the process of going through your specialty pharmacy or insurance company can take time. Please allow up to 1 week for specialty pharmacy medication refill requests in addition to 1 week for prior authorization requests.

If your insurance is changing let us know what your new insurance will be, in addition to providing us with your new identification number and provider phone number. Please either fax or mail a copy of your new insurance card (front and back) so that we can have this on file. Please also indicate which specialty pharmacy you will be using with your new insurance.

If you would like to pick up a prescription from our office, please allow at least 1 business day for processing.

#### "Do I have an infection?"

If you think you have a urinary tract infection (UTI), please call our nursing triage phone line. We will then fax over a prescription so that you can drop off a urine sample at your local Quest or Labcorp. In order to successfully treat a UTI we need to figure out which bacteria is causing the infection. Please refrain from taking an antibiotic that you may have at home from a previous infection since this antibiotic may not be effective at treating your current infection. One of the tests that is performed when you drop off a urine sample is called a urine culture. This test identifies which bacteria is causing your infection, in addition to which antibiotic will be effective. Once your respective doctor reviews your final results, we will contact you to discuss a treatment plan.

It was a hot summer. Please remember to stay indoors during increased humidity and to drink plenty of fluids. Heat sensitivity affects many patients during this time of year. Please take necessary precautions to ensure that you are as comfortable as possible during summer months.

Your IMSMP nurses are always available to answer any questions that you may have during all business hours, so don't hesitate to give us a call!



## SOCIAL WORK NEWS

This is the time of the year that people hit the road for some well-deserved vacation and people with MS can do the same, usually with a little forethought. The following tips will help you as your plan your next trip:



# Renting Mobility Devices When Traveling

If you do not want to travel with your scooter or wheelchair, or only need one for long trips, you can rent one at your destination or for your whole trip. The following vendors can help you:

Scootaround, Inc. specializes in scooter and wheelchair rentals with over 1,500 locations around North America. They offer a 7-day a week toll-free number and a full featured website where customers can arrange rentals. Scootaround services have also extended to contracts with the major airlines in the servicing and repair of passenger mobility equipment that has been damaged in transit.

#### Phone: (888) 441-7575

#### www.scootaround.com/rent-a-scooter

#### Air Travel

This downloadable brochure is a comprehensive guide to air travel with a disability, and answers common questions about getting assistance at the airport and onboard the plane, how to fly with one's scooter or wheelchair and the rights of travelers with disabilities.

#### www.unitedspinal.org/pdf/2012accessible-air-travel-brochure.pdf

#### Hotels

These helpful tips will make choosing and staying in a hotel a less stressful experience:

If a hotel offers shuttle transportation to and from the airport, it must be wheelchair accessible. Otherwise, the hotel must provide the same service via an accessible vehicle at no charge to the person with a disability.

New Mobility magazine (www.newmobility.com), and www.wheelchairtraveling.com are good online resources for choosing accessible hotels. They suggest that the best people to ask about hotel accessibility are the housekeeping and maintenance staff as they know the rooms more intimately than anyone else on staff. www.wheelchairtraveling.com even cites a list of questions to ask before booking to ensure that your room is accessible.

If you have asked all of these questions and have requested an accessible room and you find that an appropriate room is not available when you arrive you should know that the hotel is obligated to find you another room either at that hotel or at another local hotel, at their cost, that will accommodate your needs.

IMSMP does not endorse, sponsor or recommend products, services or manufacturers. Such names appear here solely because they are considered valuable information. IMSMP assumes no liability for the use of any product, service or manufacturer mentioned. This list of resources is for your convenience only. Product and services information is the sole responsibility of each individual vendor.

#### <u>Traveling with self-injectable</u> <u>medications</u>

Many MS treatments can be carried on the plane with you. In fact, carrying on ensures that you are not separated from your medication and that you can keep it cold in a small insulated bag. Carry a note from your doctor through security attesting to the medical necessity and put your medication with your other carry-on liquids.

Your medication can be kept cool during your stay by using the small refrigerator in your hotel room or by requesting one if it is not already provided.

#### <u>Helpful Links for</u> <u>Traveling with a Disability:</u>

Emerging Horizons Guide for Travel with Disability

www.emerginghorizons.com/

Tips for getting an accessible hotel room

www.newmobility.com/2013/1 1/accessible-hotel-room/

Accessible van rentals

Fun Truck'n Mobility (New Jersey)

(973) 546-1900

www.ftmobility.com

Accessible Taxi and Limo

Twins Mobility (New York, New Jersey and Connecticut) accommodates wheelchairs and scooters with an MS knowledgeable staff.

(877) 450-4440

www.twinlimo.com/



# FROM YOUR IMSMP PHYSICAL THERAPISTS

#### You Brush Your Teeth Everyday, Don't You?

Many patients who have received physical therapy at the IMSMP have confessed to not being compliant with their physical wellness program. Often, the analogy between dental and physical health is incorporated into the clinical discussion. As we all know, not keeping up with brushing and flossing will likely result in poor oral health; the same is true about skipping on daily stretches and physical activities. Patients should understand that a daily physical wellness program is one of the expected strategies that can help manage one's effects from multiple sclerosis. The fact is, *all* people, including the family, friends and caregivers can participate in the daily wellness program (stretches and focused basic exercises) with someone with MS. A recent study published in *MS Journal* reiterates findings in many previous studies, that mood can be much improved with even small amounts of exercise. Exercising with another person may even be better for mood and increase compliance. When you start to brush your teeth, remember to think, did I do my exercises today?

## Register today for the 2015 MS Patient Symposium! Visit: www.tischms.org



# NEWS ON NATUROPATHY

#### Eat a Rainbow

Eating plenty of vegetables and fruits can support optimal health, especially if you have MS. The Centers for Disease Control and Prevention (CDC) recently found fewer than 15% of Americans met the minimal daily recommendation for fruit intake (1.5-2 cups per day), and almost 9% met the minimal recommendation for vegetable intake (2-3 cups per day). These numbers are disturbingly low, particularly because vegetables, fruits, herbs and spices are nature's richest sources of protective antioxidants, necessary vitamins, and detoxifying fiber.

Many people with MS are motivated to do everything possible to optimize their health, and this should include eating a plant-based diet. This doesn't mean a vegetarian diet, but it does mean that the majority of your food should come from nutrient dense fruits and vegetables. How many bright and colorful servings of fruits and vegetables do you eat in a day? If you are like the vast majority of Americans who eat too few, take this opportunity to become motivated to do better! The best approach to filling your body with cell protective antioxidants is to fill your plate with a variety of brightly colored vegetables and fruits. Try to eat a rainbow of colors everyday: something red, orange, yellow, green, and especially bluish-purple. Bluish-purple foods get their color from the natural pigment anthocyanin, which is an especially good antioxidant for the brain. The clue is in the color, and most bluish-purple foods are rich sources of anthocyanins. This includes blueberries, blackberries, eggplant, and even black beans and black rice.

While a plant-based diet is beneficial for almost everyone, there are a few exceptions, like people with chronic kidney disease, or those who take the medication Coumadin. Due to this and other factors, it's always best to work with a doctor who knows your personal medical history before making major dietary changes. To work with an expert on diet and multiple sclerosis, contact the IMSMP to schedule an appointment with Dr. Bates our Naturopathic Doctor.

# TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

#### Four Events, One Inspiration:

This summer, volunteers organized events to support the work at Tisch MSRCNY, specifically the stem cell program. Two walk-a-thons, a Family Day event and the second annual golf outing raised a total of of \$64,665 for MS research.

In May, Joe Revello and Emilia Strafford, his sister-in-law, organized two spring walk-a-thons where students at Corpus Cristi School and Immaculate Conception High School walked for Tisch MS Research. Together the students raised a whopping \$11,665.

On June 15<sup>th</sup>, co-organizers Michael Bucceri and Stephen Mandel hosted the 2<sup>nd</sup> Annual Take a Swing at MS Golf Outing. The day teed off with a healthy dose of sun, a buffet lunch and a grand



Joe Revello (center) surrounded by friends and supporters including Father Holmes on his right

parade of carts onto the course for a shotgun start. The event raised over \$52,500 for stem cell research in spite of the mid-afternoon storm! 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.

(Contributors appear in the donor list.)



Francouer

On June 27<sup>th</sup>, Nyika Hollis of Infusion Bakery, LLC held a Family Day event at the Holiday Inn, Midtown featuring her gourmet baked goods, face painting, and family fun for all raising \$500 for research.

#### THANK YOU TO OUR GENEROUS DONORS\*

**\$500,000 +** Anonymous Moccasin Lake Foundation/ Gaye & James Pigott

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

Allstate Giving Campaign American Express Foundation Bank of America GE Foundation Microsoft Pella Rolscreen Foundation

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

This newsletter was made possible through the generous support of Genzyme, A Sanofi Company.

\*This list includes donors of \$500 or more received between May 1<sup>st</sup> and July 31<sup>st</sup>, 2015, not including contributions supporting the 2015 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.

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Umar Sadiq, MBA Sherly Sylvia, BA Theresa Waddy Kimberly Woodward, MS

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