



Healing MS

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

STEM CELLS — “A DREAM DEFERRED”?

The most exciting of Tisch MSRCNY's presentations at the 67th American Academy of Neurology® (AAN) Annual Meeting were the results presented during the *Multiple Sclerosis Highlights in the Field* session; namely that our Phase I trial using stem cells in the treatment of multiple sclerosis (MS) shows very encouraging results.

Interim analysis presented at the meeting showed that six of the nine patients who received at least one treatment are exhibiting increased motor strength, improved bladder function, and an enhanced quality of life – something **unprecedented and unrecorded** in previous treatments for MS, which to date only offer hope in stopping the progress of the disease and not in repairing any damage already done. Furthermore, the treatments were very well tolerated with no serious adverse events reported. Our full press release can be seen at: <http://tischms.org/news/april-23-2015-tisch-ms-research-center-new-york-reports-early-improvement-stem-cell-trial>

While patients are “now gaining sensation” that they “thought was totally lost” the Phase I study is proceeding at a slower pace than anticipated due to the lack of adequate funding. Despite our promising results, expansion to a Phase II stem cell study cannot be contemplated without expansion of our stem cell facilities. This is further compounded by the closure of our former animal facility. Our forward progress is currently halted because we need \$10 million to develop an experimental research and stem cell laboratory on the 3rd floor of the Tisch MS Research Center. The critical situation highlights the precariousness of our predicament as an independent research institution almost completely reliant upon private philanthropy to succeed. Unless we are able to receive sufficient funding, the hopes of those with MS that our stem cell treatment will continue to be researched will be quashed, and the likelihood that it will reach the market and be available to every person with MS will be minimal.

Unlike Tisch MSRCNY, pharmaceutical companies and private universities have the advantages of having billions of dollars available to spend on research and development. **We're asking all of our supporters to ensure that this study not become “a dream deferred”*, and to please make a gift in whatever amount is possible to assist our journey in bringing neural regeneration to the world!**

*“What happens to a dream deferred? Does it dry up like a raisin in the sun?”
- Langston Hughes, “A Dream Deferred”



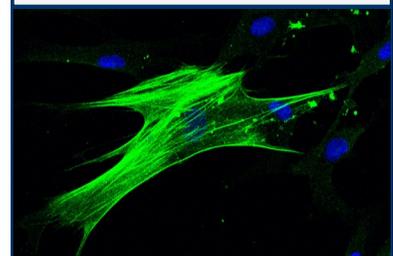
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**Tamara Vyshkina, PhD
preparing stem cells for
injection**



**Mesenchymal stem cell
harvested from the bone
marrow of a patient with MS**

INSIDE THIS ISSUE

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IMSMP staff checking in guests on mobile devices

SAVE THE DATE: OCTOBER 18TH, 2015

18th Annual MS Patient Symposium

Where: New York Hilton Midtown

When: 9:30am—1:00pm

This free educational event is open to patients, their family members and caregivers.

Registration is required.

To register early go to:

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

RESEARCH REVIEW FROM THE 2015 AMERICAN ACADEMY OF NEUROLOGY ® (AAN) ANNUAL MEETING

Tisch MSRCNY presented eight posters at the AAN Meeting in Washington, D.C. this April. Impressively, five of these posters boasted first-year research assistants as first authors and presenters:

Ruth-Anne Langan expanded on Dr. Harris's team's previous work on the biomarker Fetuin-A. Earlier research found that elevated Fetuin-A levels in the cerebrospinal fluid (CSF) correlated with increased disease activity in MS. Langan found that this biomarker is present in the structure of the brain involved in maintaining the blood brain barrier (BBB) during Experimental Autoimmune Encephalomyelitis (EAE) - the common mouse model for MS. Langan found that the presence of Fetuin-A correlated with increased expression of molecules associated with the trafficking of immune cells across the BBB. Further, in mice lacking Fetuin-A, Langan saw a reduction in BBB permeability, indicating a role for this protein in the movement of immune cells into the CNS. Her poster was titled, **Fetuin-A, a CSF Biomarker of MS Disease Activity, is Upregulated at the Blood Brain Barrier.**

Kelsey McDermott, a member of Dr. Cristofanilli's team, presented research on Transglutaminase 6 (TGM6), an enzyme relevant to other autoimmune

diseases. Active MS patients were found to have elevated levels of antibodies against TGM6 in their CSF suggesting that TGM6 is a potential target during active disease. McDermott and her team looked at both MS and EAE lesions and found TGM6 to correlate with scar formation (sclerosis). Her poster was titled **Transglutaminase 6 is a biomarker of disease activity and astrocytic proliferation in MS.**

Bianca Ulloa, part of Dr. Liu's group, identified and characterized the expression of another potential biomarker of disease activity in the CSF: the protein Haptoglobin (Hp). Ulloa found that CSF Hp concentration was higher in progressive MS patients compared to patients with relapsing-remitting MS. This increase correlated with the Expanded Disability Status Scale (EDSS) of the disease. Her poster was titled **Cerebrospinal fluid haptoglobin (Hp) levels are elevated in MS patients with progressive disease.**

Pak Ho Au, part of Jerry Lin's group, continued the study to identify a molecule targeted by antibodies in MS patients focusing on two potential human myelin protein targets, MOG and MBP. Results found that 50% of patients show reactivity against MOG, while none display reactivity towards

MBP. The substantial percentage of patients with this MOG reactivity may imply a role for the molecule in the pathogenesis of MS. His poster was titled **Myelin Oligodendrocyte Glycoprotein is the Primary Myelin Protein Target of CSF B-cell Antibodies in MS.**

Danielle Blemur, a member of Dr. Mir's group, investigated the presence of biochemical metabolites (small molecules involved in metabolism) in human CSF. Blemur has begun to identify differences between the metabolite profiles of progressive MS patients and healthy controls. Further study aims to validate the results and characterize the differences in metabolites amongst MS subtypes. Her poster was titled **Metabolite profiling of cerebrospinal fluid derived from MS patients.**

Additionally, Dr. Marwan Alahiri authored the poster **The protection of A2aR on BBB permeability from Th1 cytokines**, and Mark Landy authored the poster **Fetuin-A Correlates with Cortical Demyelination and is a CSF Biomarker of Disease Activity in Progressive MS.** Dr. Violaine Harris presented **Interim results of the Phase I Clinical Stem Cell Trial (see cover story).** For more info go to: www.tischms.org

BENEFITS FROM BIOTIN? A COMPREHENSIVE CARE COLUMN BY DR. ARMISTEAD WILLIAMS & DR. DENEBA BATES

Research presented at the 2015 AAN Annual Meeting suggests that high dose biotin (vitamin B7) may be helpful for some people with progressive MS. The Phase III trial, led by French researcher Prof. Ayman Tourbah, showed a meaningful improvement in some patients.

The rationale for trying biotin is to address two injuries of MS, namely that a demyelinated nerve is less efficient at conducting signals, so the nerve must work harder, and that MS can damage the mitochondria or “energy factories” of cells, which produce the basic cellular energy called ATP. The combination of increasing energy demands and reduced supply is an unmet need in MS.

Here is where biotin comes in. As a coenzyme, a nutrient necessary for enzyme function, biotin is involved in the production of energy and the creation of ATP. It is also necessary for a potentially rate limiting step in the creation of fatty acids, which are needed in the formation of myelin. People with MS do not have biotin deficiency, but the researchers postulated that extremely high doses might help improve the function of one or both of these pathways.

In this Phase III trial, people with PPMS or SPMS were randomized to receive either biotin (300mg/day) or placebo for one year. The patients were on a stable drug regimen with no evidence

of a recent relapse. One hundred and three patients received biotin and 51 received placebo. The primary endpoint of the trial was a 20% improvement in 25 foot walking speed or an improvement in EDSS. To reduce the likelihood of fluctuation, two baseline measures were taken a month apart and the improvement had to be noted at both 9 and 12 months. Thirteen patients (15% of the people who completed the study) had a significant improvement in one or the other measure.

This is an interesting study with modest but important benefits for a group of patients with progressive MS, as it not only showed an improvement in function, but also revealed a new potential pathway for enhancing treatment in PPMS.

So you may ask: “Should I take biotin on my own?”

This study used 1,000 times the normal recommended daily dose of biotin. While no serious toxicity was noted in the trial, at this dose the drug does interfere with some lab tests, including Thyroid-Stimulating Hormone (TSH). As this is a dose not encountered in nature and it can affect the interpretation of laboratory tests, we recommend that you consult with your IMSMP neurologist or Dr. Bates prior to starting a regimen.

WHY DO I NEED A COGNITIVE ASSESSMENT? BY DR. JOANNE FESTA

After all, the examination takes several hours and there may be an out of pocket cost to the patient, so why should they spend the time or money? There are numerous benefits of undergoing a cognitive assessment.

People with MS may be referred for a cognitive assessment for several reasons. They may report that they are having problems with their memory, concentration, word-finding or difficulty keeping up at work. In some cases, a patient’s neurologist or family member may notice changes in cognitive functioning. Alternatively, a newly diagnosed patient without cognitive complaints or physical symptoms can be referred for a baseline examination. Cont’d p. 4



Armistead D. Williams III, MD



Deneba Bates, ND



Any medical questions should be directly communicated by phone. We kindly ask you do not text your neurologist. Thank you.

More on Cognition

* Neuropsychological assessment has long been a part of the comprehensive, multi-disciplinary care at the IMSMP, similar to other MS monitoring techniques such as an MRI. The evaluation will give your neurologist quantitative information about your current cognitive functioning. It can assist your neurologist in determining if there has been disease stability or progression, and may inform treatment decisions. The evaluation will also help the patient and their families better cope with this key aspect of neurological functioning. There are emerging techniques to improve cognitive functioning via rehabilitation and only an evaluation can help determine if you qualify as a candidate.



Allergy Meds & Testing

* If you are affected by seasonal allergies, there are several over the counter medications that are available. These include: Claritin, Allegra, Zyrtec, along with Claritin-D, Allegra-D or alternatives containing pseudoephedrine if you suffer from more severe nasal congestion. Please note that most allergy medications can cause sedation. If you suffer from fatigue and/or take other medication that cause similar side effects, please be cautious.

COGNITION CONT'D

For patients or family members who are *reporting difficulties with cognition* an evaluation will help to determine if there is an issue. The evaluation will describe the areas of dysfunction and the severity of the problem. Cognitive difficulties can be caused by factors other than MS and those factors are explored in your evaluation. These other factors may become potential treatment targets, (e.g. depression or a sleep disorder). An evaluation will help facilitate the treatment of those problems.

For patients who are *experiencing difficulties functioning at work*, the evaluation can help determine the underlying cause of those issues. Treatments may be available to address the causes of cognitive dysfunction. The evaluation will determine your cognitive strengths and weaknesses, from which, an individual rehabilitation plan can be established. Your results will also inform decisions about your current capacity to work or go to school and help identify potential opportunities or challenges in those settings. For example, workplace accommodations may help you function better at work. The evaluation may also be helpful in deciding whether or not you can apply for disability.

Baseline evaluations are often performed after being newly diagnosed. Even in the context of minimal physical disability, cognitive dysfunction may be present and detectable by testing shortly after being diagnosed. Although this dysfunction may be mild and go unnoticed by the patient, it is important to document. Early identification is increasingly important in the context of new disease modifying therapies. For those patients whose exam suggests stable cognitive functioning, the evaluation establishes a baseline in case changes are suspected in the future. In all cases, baseline evaluation is essential to long-term disease monitoring, which also informs your overall MS treatment. At the IMSMP, our goal is to provide comprehensive care for MS: this means attending to all aspects of the patient - including your cognitive functioning!

TIPS FROM THE NURSING TEAM

Warmer weather is here and many with MS experience heat sensitivity. Heat sensitivity can be caused by a rise in body temperature from exercise, staying outside in high humidity, or taking a hot bath or shower. This can exacerbate MS symptoms, which we call a pseudorelapse.

It is very important to remember that these potential symptoms caused by heat and humidity are not harmful and are also temporary. Symptoms related to heat sensitivity usually reverse once the source of heat is removed. Here are some helpful tips to decrease negative effects from heat:

Wear loose, lightweight clothing. Fabrics such as cotton or linen are ideal. Synthetic fabrics such as polyesters or spandex should be avoided as they can contribute to rising body temperatures.

Additionally, darker fabrics can also absorb heat and should be avoided on very hot days.

Products such as cooling vests are very helpful to decrease heat sensitivity.

Avoid spending prolonged time outside in the heat and humidity. Instead, try to stay in an air conditioned environment during periods of extreme heat.

Avoid exercise outside in extreme heat. If you do exercise, pace yourself. Listen to your body and take breaks as needed.

Please note that extreme cold can also temporarily worsen MS symptoms. Please take necessary precautions such as dressing in warm layers and staying inside to avoid cold weather.

Allergy season is upon us. Seasonal allergies can be very bothersome. **Cont'd p. 5**

NURSING CONT'D

Here are some helpful hints from your nursing team to help diminish allergies this season:

Avoiding contact with the allergen is the most effective intervention.

To reduce contact with common allergens, such as pollen, keep doors and windows closed in the home.

Changing your clothes when you enter your home can help reduce the amount

of pollen or other allergens inside your home.

Dusting and vacuuming in your home is an effective way to get rid of lingering allergens.

Using an air-purifier is another helpful way to keep your home free of bothersome allergens.

As always, our nursing line is open to answer any questions or concerns.

P.T. FOR THE CAREGIVER

Physical therapy and wellness programs can be very beneficial for those with multiple sclerosis, but what about for the family and for caregivers?

A major area of concern related to the role of the caregiver and physical wellness is in regard to transfers and transitions. **Transfers** refer to a person moving from one position or sitting area to another location. Some examples include moving from a sitting position to standing, standing to sitting, or sitting on a wheelchair and moving directly to another sitting surface. **Transitions** refer to moving from one position to another position within the same location. Examples of a transition is to adjust the sitting position in a chair, or a person moving from lying on his or her back to lying on his/her side.

Caregivers, whether family, friends, or people who are hired to help, are often essential in providing assistance for safe and effective transfers or transitions. The concern of this process, however, is the risk to the caregiver and patient alike. These "routine" activities are commonly performed without formal training or proper preparation.

Many times, taking care of another person would not be thought to

require "formal training." However, moving anything that weighs 75 lbs or more does require training. This is true in all industries and is needed to minimize the risk of injury to all those involved.

Patient handling is one term that is most commonly used to refer to this process. **Safe lifting and moving in healthcare** is the term that the organization, "New Yorkers for Patient and Family Empowerment" uses. Regardless of the term, this process is more than just an act of love and caring for another person, it is a physical task that comes with risk. The PTs at the IMSMP offer unique services related to this for our patients and their family and/or caregivers.

Transfer training for caregivers can be incorporated into a physical therapy session upon request or when deemed necessary by a PT, RN, or MD. Most people with MS can get in and out of their bed, house and cars with the proper training, practice and equipment.

Feel free to schedule an appointment to go over options related to transfers and to discuss the schedule for transfer training that would be most appropriate to increase safety and efficiency for all involved.

Allergy Meds & Testing cont'd

* Always discuss possible allergy testing with your physician. Allergy testing, similar to vaccinations, may not be recommended as they have the potential to stimulate the immune system.

A TISCH MS RESEARCH CENTER ACHIEVEMENT

All Research Assistants
to Attend Medical
School this Fall

Congratulations to the Research Assistants from Tisch MSRCNY who have completed their two-year laboratory research academic experience. We are very proud that they have all secured places in medical school. Daniel Gratch will attend Perelman School of Medicine at the University of Pennsylvania in Philadelphia, Pennsylvania. Mark Landy will enroll in the MD-PhD program at University of Texas Southwestern Medical School in Dallas, Texas. Benjamin Pagano will attend Robert Wood Johnson Medical School in New Brunswick, New Jersey. Christopher Sears will attend Albany Medical College in Albany, New York.

We thank everyone for their dedication to MS research and wish them the best!

Important information from your IMSMP Billing Department

Patients should submit reimbursement checks to the Center upon receipt. We kindly request they be mailed directly to the office at:

IMSMP, Attention: Billing
521 West 57th Street, 4th floor
New York, NY 10019

The Billing Department would like to remind patients who prefer to pay by credit card, that you are responsible for the 3% credit card fee, and that your card will be charged accordingly.

SOCIAL WORK NEWS

Sneak Preview of Resource Manual

Coming soon on our website, you will be able to access hundreds of resources that our social workers have been collecting over the last 13 years.

The resource manual will be up and running shortly, and as a sneak preview, we want to share with you some of our favorite tips and tools for making life with MS a little easier.

Accessible Taxi Cabs

The New York City taxi and limousine commission has begun to offer wheelchair/scooter accessible taxis that people with mobility impairment can “hail” by telephone, website, text or mobile application. Pickups must originate in Manhattan with destinations in any of the five boroughs, Westchester, Nassau County and Newark Airport in NJ.

Anyone with a mobility impairment can hail one, not just people in wheelchairs and scooters, so this is a great resource for people who walk and can travel by taxi, but may not be able to

walk the distance to the corner to hail a cab. More details are available on their website: www.accessibledispatch.com or by calling (646) 599-9999

New York City Housing Rights and Advocacy

In New York City, the Mayor’s Commission on Disabilities educates people with disabilities and advocates for them on their rights to accessible housing. The contact information below will connect you to an excellent resource for information on your rights as a person with MS in NYC:

Mayor’s Commission on Disabilities
Ted Finkelstein, Director of the Equal Access Program (212) 306-7721

Information about disabled NYC renter’s rights
www.environmentalgeriatrics.com/pdf/GEM_NYC_Accessibility_and_Creative_Design_Adaptations_for_Rental_Apt_Workshop_2012.pdf

Discover How you can Help Tisch MS Research Center by Contacting the Development Department Today!



Members of Team Tisch MS
L to R: Melissa Kanter, Allan Zapanta, Samantha McKillip, Whitney Mallis, Dr. Armistead Williams & Dr. Elizabeth Woods

TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

Support Team Tisch MS!

We are excited to announce that the Tisch MS Research Center was selected by New York Road Runners as a charity community partner of the 2015 TCS New York City Marathon taking place on Sunday, November 1st. Our dedicated team of IMSMP runners includes Dr. Armistead Williams, Dr. Elizabeth Woods, Samantha McKillip, Whitney Mallis and Allan Zapanta who have committed themselves to run the 26.2 mile race and raise awareness and critical funds for the Center’s innovative research program.

A special thanks goes to our Champion sponsors SocialFly and Series and

Bronze sponsors Beyond Basics Physical Therapy, PhaseCore Heat-Activated Personal Cooling and Fox Rehabilitation for providing a strong foundation to launch this inaugural fundraising initiative.

Please support our team by making a tax-deductible donation at: www.crowdrise.com/TischMSNYC2015/fundraiser/themultiplesclerosis or by mailing a check with “NYC Marathon” in the memo, to Tisch MSRCNY, 521 West 57th Street, 4th floor, New York, NY 10019.

You may contact Kimberly Woodward at kwoodward@tischms.org or by calling (646) 557-3861 to get involved or for more information.

TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS CONT'D

Patient Donor Highlight:

Dana Schwartz Lipsic submitted her story to employer, Zenith Optimedia, which resulted in the company donating \$5,000 to Tisch MSRCNY.

My Story....

I have been raising money for multiple sclerosis for about 10 years. MS is an autoimmune disease in which your body starts attacking the myelin sheath in your brain and central nervous system. It is most common in women during their child-bearing years and has many different possible symptoms and outcomes. The central nervous system controls everything in your body from walking to speech and vision. When your body attacks itself, scars can result and these scars can stop the signals from

going from your brain to your body.

I have many people in my life who have been diagnosed with this disease that has no cure and whose cause is unknown. Since 2005, I have done a lot to raise awareness and money for a cause I believe in. I even organized my own charity events for the past five years with my friends. We had over 500 attendees at the last event we held and donated 100% of the profits to Tisch MS Research Center of New York. The Center's mission is to find the cause of MS and it is currently the only MS center with FDA approval for a stem cell clinical trial.

This year I started a jewelry line called "my lucky stripes" to help people who need a little luck, support and comfort.



Dana Schwartz Lipsic with husband David and daughter, Blake

I donate 25% of the sales proceeds to Tisch MS Research Center.

I hope you believe in a cause that means so much to me.

THANK YOU TO OUR GENEROUS DONORS*

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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 \$250 or more received between February 1st and April 30th, 2015, and donors of \$250-\$499 received between November 1st, 2014 and January 31st, 2015 not listed in the last edition. While every contribution is deeply appreciated, we regret that we are unable to list donors below \$250 due to space limitations.

IMSMP

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