



**CHECK OUT  
THE LATEST NEWS  
FROM YOUR NURSES**



**SAVE THE DATE: 10/19/14  
2014 MS PATIENT SYMPOSIUM**



**ALTERNATIVE  
WAYS TO TREAT  
YOUR MS**

ISSUE 23 | VOLUME 3 | Spring 2014

# Healing MS

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

## FDA-Approved Phase I Clinical Stem Cell Trial Begins at Tisch MS Research Center

### Stem Cell Trial Update

Tisch MS Research Center of New York is delighted to report that all of the regulatory approvals for our Phase I safety and tolerability clinical trial of the intrathecal administration of Mesenchymal Stem Cell-Derived Neural Progenitors (MSC-NPs) have been obtained, and that the study is officially underway. Patient enrollment is nearly complete, and those selected will be notified as soon as an enrollment date is chosen for them. To enroll, patients have to meet all of the inclusion criteria including having established disability without recent relapses or disease worsening. Enrolled patients will undergo extensive baseline testing including a neurological exam, an MRI, measurement of nerve conduction and bladder function, and an assessment of overall baseline health. All of these tests will be repeated after the treatment in order to assess any changes in neurological or overall health that might be related to the stem cells.

As we lack the infrastructure of a commercial pharmaceutical laboratory, we ask for selected subjects' continued patience as we proceed to enroll and treat patients as quickly as possible. Anyone who has expressed his/her interest in participating in the trial will be put on the waitlist while we actively pursue ways to expedite the initial phase of the study. Further updates on the status of the trial will be promptly reported at [www.tischms.org](http://www.tischms.org).



**Dr. Gabriel Sara extracting bone marrow**



**Stem cells to be harvested and expanded**

#### International Multiple Sclerosis Management Practice

**Saud A. Sadiq, MD  
Director**

#### CLINICAL

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Lisa Dabney, MD  
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R.T. (MR)(CNMT)  
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## Clinical Research

### Control Volunteers Needed!

Tisch MSRCNY is hard at work on several important research projects requiring donation of biological materials from both MS patients and control subjects (people without MS). MS patients have already generously provided most of the material necessary for research, but in order to move forward, we need the help of our patients' friends and family.

### Skin Biopsies for the Generation of MS-Specific Stem Cells/Skin Biopsies for the Study of Dermatopathology in MS:

Tisch MSRCNY is continuing work on two studies involving the collection of skin biopsies. One is a collaborative effort with the New York

Stem Cell Foundation (NYSCF) to generate induced pluripotent stem cells (iPSCs) from adult skin cells in order to study the genetic underpinnings of MS.

The other is Dr. Williams' investigation of microscopic immune changes in the skin of patients with typical MS, atypical demyelinating disease, and healthy controls. The study aims to improve methods of differentiating MS from diseases that mimic it, and to determine whether MS is associated with microscopic immune changes in the skin. Healthy control subjects, as well as additional MS patients, are needed for both studies. Participation involves the collection of a single skin biopsy and completion of a health questionnaire in the case of the NYSCF study, and two small skin biopsies and a blood draw in the case of Dr. Williams' study. Risks in both cases

include formation of a scar smaller than a pencil eraser at the biopsy site, and a very small chance of infection. Any infection, while highly unlikely, would be treatable.

**Tisch MS Research Center of New York is on Twitter:** For fast-breaking updates to research, and media coverage of our discoveries, investigations, and clinical trials, please follow @Tisch\_MS at: [www.twitter.com](http://www.twitter.com).

**If you are interested in any of our clinical research studies, please contact our Clinical Research Assistants Daniel Koffler and/or Sydney Chirls at (646) 557-3852 and (646) 557-3860 respectively.**

## Important Billing Update

**Due to insurance restrictions our office will only be able to obtain Rituxan authorizations for those patients infusing at the International Multiple Sclerosis Management Practice.**

## Tisch MSRCNY Welcomes New Chairman

In November of 2013, the Board of Directors of the Tisch MSRCNY elected David G. Greenstein, CPA as its new Chairman. David joined the Board of Directors in 2009 and served on the Finance Committee for two years. A patient of Dr. Sadiq since 2004, he and his family have made significant contributions to the Center over the years that have made a tremendous impact on the growth of the organization.

An entrepreneur, financial expert, philanthropist and avid hand cyclist, David has been the VP and a Partner of Lakin Tire, a company engaged in recycling tires on a national level, since 2001, after selling US Tire Recycling, a tire company he founded in 2000. He received his BS/BA in Accounting from Boston University and lives in Manhattan with his wife, Hillary Mandel, an executive at IMG Worldwide. David also serves on the Board of Achilles International and the New York City Chapter of the National MS Society. He has two children and participates in marathons throughout the world.

"I am excited to lead the Center during this exciting time in its history and look forward to working with the Board and staff on continuing its growth," stated David.

"The Center is very fortunate that David has accepted the role of Chairman of the Board. His expertise in business and natural

charisma made him a unanimous nominee. He is universally well liked and his even temperament will enable him to lead Tisch MS Research Center to even greater heights. He is totally committed to the neural regeneration project as well as to help discover the cause of multiple sclerosis. The research staff and Board of Directors of Tisch MSRCNY firmly believe that David will be an inspirational and exemplary leader," said Dr. Saud A. Sadiq, Director and Chief Research Scientist at Tisch MSRCNY.



**David Greenstein recently participated in the St. Anthony Marathon in Padua, Italy**

**SAVE the DATE: Sunday, October 19<sup>th</sup>, 2014**  
**17<sup>th</sup> Annual Tisch MSRCNY MS Patient Symposium**  
**Space is limited. Register early at [www.tischms.org](http://www.tischms.org)**

**See Back Cover For More Details**



## A Note from the Nurses:

Dr. Armistead Williams now has nursing coverage for prescription refills and renewals. He also has nursing coverage for any clinical questions you may have for him. For prescriptions, if you call before 3pm the prescription will be handled the same day and for clinical calls we always return your call the same day.

If you are a patient with an intrathecal pump for spasticity or pain management, please remember that for your safety you must come in for your refill of medication at least 2 weeks prior to your alarm date. We purposefully schedule patients at least 2 weeks ahead of time to account for patients that become ill and need to re-schedule, inclement weather, unexpected hospitalizations, etc.. Please keep this in mind when making your appointments.

The IMSMP urges all patients to have a primary care physician (PCP). As your MS management team, we treat and manage MS symptoms and many times will help treat infections that affect your MS. However, all patients should have a primary care physician to manage common illnesses and medical conditions that are separate from your MS. Medical conditions such as hypertension, high cholesterol, and diabetes, just to name a few, should all be managed by your PCP. Any new medical conditions or medications should be brought to our attention at your next office visit or you can call us with a medical update.

Please join us in welcoming our new nurse, Samantha McKillip, RN, BSN. Samantha started at the IMSMP on

December 2<sup>nd</sup>, 2013 and has been a perfect fit from the start. Her eagerness to learn and her outstanding interaction with patients make her an ideal nurse for our Center. Samantha previously worked at Mount Sinai Roosevelt Hospital in their Oncology unit and graduated from Villanova University's nursing program in 2010.



**Samantha McKillip**

## Social Work News

### **Employment with MS: Knowing Your Rights and Staying in the Workforce**

Knowing your employment rights, as a person with MS, is essential even for people who are newly-diagnosed with no visible symptoms. We know that satisfying work contributes to quality of life and we believe that people with MS who continue to work as long as possible feel better, longer. This column is meant to educate everyone with MS about your employment rights and how to remain working for as long as it makes sense.

The **Family Medical Leave Act of 1993 (FMLA)** and the **Americans with Disabilities Act of 1990 (ADA)** are the two pieces of legislation that help people with MS remain employed. The FMLA entitles people to take up to 12 weeks of medical leave per year for their own medical condition or to care for a family member with a medical condition, and return to their own job without fear of reprisal. The time off can be either paid or unpaid, depending on the laws in individual states. People with MS use FMLA typically if they take a day off of work because of MS symptoms or to come to a doctor's visit. People who take a period of short term disability would also be covered by FMLA. It is important to note that FMLA refers to *time*, not to *money*.

You may use your FMLA time while being paid by a short term disability policy. You do not necessarily have to disclose your

MS to your employer in order to use FMLA time, but you do have to submit medical information stating that you have a serious medical condition.

The **Americans with Disabilities Act** includes many provisions for people with disabilities, one of which is the right to "reasonable accommodations." According to the U.S. Department of Labor, a reasonable accommodation is any modification or adjustment to a job or work environment that enables a person with a disability to perform a job. The inclusion of the word *reasonable*, though, means that the employer must make provisions to help the employee do his or her job without sacrificing getting the job done properly. For instance, working from home may be a reasonable accommodation only if it does not inhibit the work of the company. The person with the disability must be able to perform all of the functions of the job for which he or she was hired, with the use of the accommodation.

The most important takeaway from this article is that if you are going to use FMLA time or ask for a reasonable accommodation, you should get advice specific to your situation. Call the social work department at the IMSMP with any questions, especially about disclosure and negotiating for reasonable accommodations.

## From the Front Desk



**Erica Peskin**



**Raheela Asifuddin**

### **We are happy to announce growth within our IMSMP staff.**

Erica Peskin, BA has been with the IMSMP for over 5 years. She is a dedicated medical secretary that is an essential part of our team. Erica has been promoted to Front Staff Manager. We are very happy for her and wish her success.

Raheela Asifuddin, BS, R.T. (N)(CT)(MR)(AART) joined the MRI Suite as an MRI Technologist in April of 2012. She has over 25 years of experience in most Radiology fields. We are excited to announce that she has been promoted to MRI Manager. She has been an important part of the MRI team and we wish her all the best.





## News on Naturopathy

### Evidence Based Guidelines for Using Complementary and Alternative Medicine in MS Published by the American Academy of Neurology

Practicing medicine requires a thoughtful evaluation of data emerging from a plethora of sources in order to provide the most safe, effective, and individualized care for each person. The gold standard for determining whether a specific treatment is effective is a randomized double-blinded placebo controlled trial performed utilizing a large population with well-defined outcome measures. Not all studies meet this standard. The art of medicine is therefore in applying the results of studies of various types to patients in the "real world." Professional organizations offer guidance in this regard, by reviewing existing evidence and providing general recommendations on important topics.

One area that has received a great deal of interest is the use of complementary and alternative medicine (CAM). This term refers to a very broad range of "unconventional" treatments that people might use in addition to, or instead of, standard medical therapies. These can include diet and lifestyle interventions, vitamins and supplements, and traditional healing systems such as acupuncture or Ayurvedic medicine. People with MS often use CAM for managing symptoms and/or drug side effects, attempting to control disease progression, and/or improving their overall health. In fact, it is estimated that up to 80% of people with MS use some form of CAM (either with, or without, the guidance of a knowledgeable practitioner).

As such, the American Academy of Neurology (AAN) recently published its report on the current evidence for using CAM in MS [Yadav et al, Summary of evidence-based guideline: Complementary and alternative medicine in multiple sclerosis: Report of the Guideline Development Subcommittee of the American Academy of Neurology. *Neurology*. 2014 Mar 25;82:1083-92.].

**First and foremost, the AAN concluded that adequate evidence exists to make recommendations for the following therapies:**

- \* Medical cannabinoid derivatives show efficacy for symptoms of spasticity and some types of pain, but not for objective measures of spasticity. Evidence also shows they may improve urinary frequency but not urinary incontinence. They were found to be not helpful for tremors. Evidence for smoked cannabis is insufficient to recommend for spasticity, pain, balance, posture or cognition.
- \* Ginkgo is possibly effective for fatigue, but not for cognitive dysfunction.
- \* Reflexology may be helpful for paresthesias.
- \* Magnet therapy may be effective for fatigue but not for depression.

Second, some therapies have been proven ineffective for treating disability and MS disease activity. These include the Carl Loder regimen, bee venom therapy, and a low-fat diet.

Finally, for many CAM therapies, although some smaller studies do exist, the existing data is not strong enough to conclude whether or not they provide benefits (see table for examples).

Mind-Body Practices	Biological Substances	Physical Practices
Biofeedback Music therapy Mindfulness training Hypnosis	Padma 28 Linoleic acid Acetyl-L-carnitine Low Dose Naltrexone	Hippotherapy Yoga Massage Acupuncture

#### **"Absence of Evidence is Not Evidence of Absence" \***

Just because a therapy hasn't been adequately studied doesn't mean that it isn't helpful. The evidence to support CAM in MS will continue to evolve, however, some CAM therapies may never be studied in a way that shows conclusive evidence of efficacy. CAM can be difficult to study, impossible to double-blind, or the studies may be too expensive. Nevertheless, many people have success with CAM treatments and use them as part of an integrative approach to help manage their disease. Like all medical decisions, the use of CAM as part of your overall treatment plan requires thoughtful analysis of the risks, benefits and costs of each particular therapy in the context of your individual health and circumstances.

The IMSMP's Naturopathic Doctor, Deneb Bates, works with patients and their neurologists to provide guidance on the use of CAM as a part of an integrative strategy to provide optimal individualized care for people with MS. \* quote by Carl Sagan

## Physical Therapy

### Don't Lose Faith

Many patients with multiple sclerosis have experienced a time when their physical therapy programs did not provide the benefits that they hoped for. A reason why patients become more frustrated with "ineffective physical therapy," as compared to "ineffective medicine" is physical therapy requires one to work and be actively engaged. When a physical wellness program (physical therapy, gym exercises, pilates/yoga/tai-chi, etc) doesn't result in major benefits, patients sometimes lose faith. In many cases, patients will say to themselves that "it is not worth the effort." Unfortunately, in the great majority of cases, regardless of the medication that one is taking, withdrawing from a physical wellness program will result in greater disability with an earlier onset. At some point, the patient (with urging from a family member or their neurologist) will restart their physical wellness program to limit the physical deterioration and attempt to reverse disability and develop a higher level of independence. **(physical therapy continues on next page)**

## Physical Therapy cont'd

To achieve the highest level of functional independence, a patient (with help from their family and others who provide support), must be an active participant in their physical wellness program. This starts with a commitment to work with a physical therapist on a regular basis AND perform regular activities that are prescribed. Some patients have accomplished this by seeing a physical therapist as few as 2-4 times per year. These patients are very successful with performing their home exercise/activities every day. Patients who are actively engaged in their physical wellness program will include various activities. An example of a good physical wellness program may include, 1-2 days of swimming, 1-2 days of pilates/yoga/tai-chi, and 1 day at the gym using machines. Remember, these all revolve around a daily stretching regimen.

One may believe that while exercise must be performed for a certain amount of time to be "worthwhile," the key is performing exercises daily. Unlike physical exercise programs for orthopedic issues like sprained ankles, or training programs such as those done by performing artists or professional athletes, a daily exercise program including stretches, standing exercises and activities, and specifically prescribed functional exercises is appropriate for most people with multiple sclerosis. Days off from exercises and stretches have an effect on all people and, for people with multiple sclerosis, may be the main reason for not finding benefits or reaching one's goals.



Don Loughran stays active in the ocean

Remember, to consider your functional goals when starting your wellness program. Whether they are to manage your garden, get to the beach, go to a ball game with your family or friends, or just to get outside of your home every day, you should find a physical wellness professional who can help guide your exercise program so you will move toward your goals. Even if you have thought of tasks as no longer being possible, be open to trying again. You never know your full potential until you try to expose it.

Don't lose faith. Being an active part in your physical wellness program will help you reach your goals.

## Tisch MSRCNY Development Department News

### Patient Fundraising Events

*Thank you and congratulations to our patients who create ingenious ways to raise money for the Center and work so hard to make them successful.*

#### **Makin' Moves for MS: Hope Matters & Swim for Success with Danielle Bacigalupo**

Inspired by watching her mother's battle with MS since she was a young girl, Danielle took matters into her own hands to help with fundraising for the FDA-Approved Phase I Clinical Stem Cell Trial. On Saturday, April 5<sup>th</sup>, approximately 100 people turned out at the Regina Pacis Youth Center in Brooklyn for her *Makin' Moves for MS Zumba Party*, which also featured a silent auction and raffle. Danielle also organized a swim-a-thon with the help of her close friend Gina Sulpizio, whose swim team got involved and swam up to 200 laps to *Swim for Success!* Danielle had help from her family members, partner, and many friends - especially Natalie Russell, to raise \$25,000 for the stem cell clinical trial.

#### **Dawn Madell, Celebrating Anniversaries!**

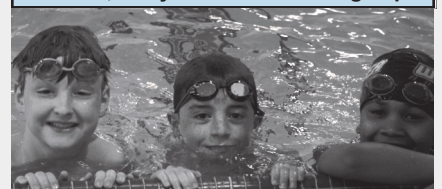
IMSMP patient Dawn Madell went the extra kilometer to raise money for research at Tisch MSRCNY this spring when she traveled to Durham, NC to participate in Merge Record's 25K race for charity. Merge Records celebrated their 25<sup>th</sup> anniversary with the run on Saturday, March 22<sup>nd</sup>. When asked about the run Dawn said, "I am a music supervisor, and celebrating this label's anniversary was super special to me. It just so happened it was also the anniversary of my diagnosis. So I decided I would run the race, and also raise money for Tisch MS Research Center." Dawn's efforts raised \$4,937 for research.

#### **The Millburn Rockets Take Off for MS Research**

Pingry School student Henry Graff and his 12 and under boys soccer team wanted to support their coach who lost his father to MS. They collected \$215 for Tisch MSRCNY.



Danielle, Patty and Michael Bacigalupo



Swim-a-thon participants



Dawn Madell (right) with her running partner



## Tisch MSRCNY Development Department News cont'd

### Calling All Golf Fans!

Michael Bucceri is organizing a golf outing on Monday, June 30<sup>th</sup> at the Crystal Springs Resort in Hamburg, NJ to raise funds for the Center's FDA-Approved Phase I Clinical Stem Cell Trial. It includes a cookout luncheon, shotgun start, cocktail reception, buffet dinner, silent auction and 50/50 raffle. Non-golfers can enjoy the day at the pool and spa.

Individual golfer tickets are \$300 and non-golfer tickets are \$150. Contact Kimberly Woodward at (646) 557-3863 or [kwoodward@tischms.org](mailto:kwoodward@tischms.org) for more information or visit the event page at [tischms.org](http://tischms.org).



### Please Help Support the Center's Mission While Shopping on Amazon.com

The Amazon Smile program will donate 0.5% of the price of your eligible purchases to the Center by logging on to [smile.amazon.com](http://smile.amazon.com) and entering Tisch Multiple Sclerosis Research Center or going directly to: <https://smile.amazon.com/ch/25-1922851>.



### Indiegogo Social Media Fundraising Campaign for Stem Cell Trial Exceeds Goal

On Friday, March 14<sup>th</sup>, the Tisch MS Research Center of New York launched a four week social media fundraising campaign on Indiegogo.com to raise funds for its FDA-Approved Phase I Clinical Stem Cell Trial. The Center chose Indiegogo as a fundraising platform since it has not received federal, state, or corporate funding to cover costs of the stem cell study. The crowdsourcing website heightened awareness of the study, introduced new donors to the Center and, within 23 days, the \$300,000 goal was exceeded. A total of \$317,540 was raised by almost 1,000 generous people. Funding will be directly applied to the study and stem cell research at Tisch MSRCNY.

"We are all overwhelmed and grateful for the generosity shown by our community of patients and friends," stated Dr. Saud A. Sadiq, Director and Chief Research Scientist and the study's Principal Investigator. He added, "Funding is like oxygen for research. Without financial support, our research into regenerative therapy cannot survive."

A hardworking group of patients, family members and friends were instrumental in helping to spread the word about the campaign and in bringing a large number of new donors to the Center. Thank you to the following people for committing themselves to the campaign's success: Stephanie Abrams, Beth Broun, Matt Cavallo, Noel Charbonneau, Ryan Cohen, Matt Danowski, Bob Dodge, the Drury Family, Jed Elmaleh, Eric Goldberg, Michelle Hires, Janis and Paul Kaiser, Karen and Keith Kaplan, Kelly Irwin, Dara Klein, Megan and Philip Reicherz, Sharyl and Gregg Reisman, Kammi and Brad Reiss, Mary Beth Schifano, Stuart Schlossman, Dana L. Schwartz, Leslie Simmons, Michelle Stack, Karen and Marc Stecker (aka Wheelchair Kamikaze), and Martin Tommer.

"The show of support has been tremendous, but our work is not done," said David Greenstein. "We hope that the success of this campaign will jump start a steady stream of donations into the Center."

We are deeply grateful to Chairman David Greenstein for spearheading the campaign with his family friend Ben Steinberg.

### Indiegogo Campaign Donors

#### **\$25,000 +**

Jeanette & David Rosenblum  
Mellen Foundation, Inc.  
Gene & Lee Seidler  
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#### **\$10,000 +**

Anonymous (2)  
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Cynthia Brodsky  
Lorraine & Frank DeCongelio  
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Doraine Schwartz  
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#### **\$1,000 +**

Anonymous (8)  
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Marlene Baldaino  
Terri & Chris Bell  
Annette & Sol Breitstein  
Nancy Brennan, in honor of Marlene Baldaino  
Lynn Lazaroff Brindell

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Felicia & William Closson, in honor of  
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Marvin & Carol Davidson, in honor of  
Tom Davidson  
Susan Dellosso, in honor of Martin Tommer  
John Drury  
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Brad Reiss  
Rosa Gonzalez, in honor of her son,  
Roland Gonzalez  
Kristen Guarneri, in honor of Keith Kaplan  
Stephen & Susan Hader  
Jacqueline Hamilton  
Linda Hirschberg, in honor of Keith Kaplan  
Terry Laudal, in honor of Kathy Blankenbiller  
Julia Mariani

Indiegogo Donors continued next page

### Indiegogo Donors cont'd

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Kyle Warendorf  
Stephanie Wolff  
Jon Yurek

This list includes donors to the Indiegogo Campaign for the FDA-Approved Phase I Clinical Stem Cell Trial of \$500 or above, received through April 30, 2014 who provided their names.

## Thank You . . .

*To our generous donors for making an impact on our progress toward a future without MS.\**

### \$1,000,000 +

Damial Foundation

### \$50,000 +

Margo & Roger Coleman  
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Kenneth Klausman  
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### \$5,000 +

Banfield Family Foundation  
Karen Jones &  
Erik Rasmussen  
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### \$2,500 +

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RESEARCH CENTER OF NEW YORK



**INTERNATIONAL MULTIPLE SCLEROSIS**  
Management Practice

521 West 57th Street, 4th Floor, New York, NY 10019

**Save the Date: 10/19/14**

## **17<sup>th</sup> Annual MS Patient Symposium**



Pictured above: Dr. Saud A. Sadiq presenting at the 2013 Symposium

**Where: New York Hilton Midtown**

**When: Sunday, October 19<sup>th</sup>, 2014, 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](http://www.tischms.org) or call (646) 557-3919**