

Fall 2017 Volume 3, Issue 37

# Healing MS

THE IMSMP NEWSLETTER TO ADDRESS THE NEEDS OF OUR PATIENTS AND KEEP YOU INFORMED OF THE LATEST RESEARCH TREATMENTS AND WAYS TO HEAL

## OVER \$2.5 MILLION RAISED FOR MULTIPLE SCLEROSIS RESEARCH AT THE 2017 FUTURE WITHOUT MS GALA

## Senator Schumer Cuts the Ribbon for State-Of-The-Art Regenerative Medicine Laboratory

More than 350 guests enjoyed a beautiful evening at the stunning Gotham Hall ballroom in New York City on November 9<sup>th</sup>, 2017. The evening included: cocktails, dinner, musical performances, and guest speaker, U.S. Senator Charles E. Schumer. After a live auction, guests watched a very special video presentation featuring the new Regenerative Medicine Laboratory, built to support the upcoming Phase II stem cell trial.

After a brief introduction from Emcee, Barry Weintraub, the dinner began with a personal welcome speech about the fight required of those who live with MS from Hillary Mandel, wife of Tisch MSRCNY Chairman of the Board, David Greenstein. Auctioneer Pat Tully entertained while guests bid on fabulous once-in-a-lifetime experiences including; a trip to the Super Bowl and up-close and personal seats to the sold-out, "Springsteen on Broadway."

Next, Senator Schumer took the stage. "The Tisch MS Research Center is the ONLY place in the country with an FDA-approved Phase II stem cell clinical trial for MS," said Senator Schumer. "The innovative research that Dr. Sadiq and his team do, brings us every day more hopeful that we will find a cure."

The evening culminated with a ribbon cutting, commemorating the build-out of the Regenerative Medicine Laboratory. "My deepest gratitude to Senator Schumer and all of our supporters," said Dr. Saud A. Sadiq. "After the success of our Phase I stem cell trial, I look forward to embarking on Phase II and developing a repair therapy to reverse disability in MS and hopefully other neurological diseases."

It's the incredible generosity and commitment of our contributors that inspires our research team to continue their work and lead us down the path to a *Future Without MS*.

More Gala photos on page 11



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Hillary Mandel welcomes the crowd at beautiful Gotham Hall



Senator Chuck Schumer accompanied by Dr. Saud A. Sadiq & Chairman Emeritus, Lee Seidler

## **INSIDE THIS ISSUE**

- Tisch MS researchers present their work in Paris
- Inspiration from the 2017 symposium
- A special message from Shelly White
- Thank you to our donors

## TISCH MS LABORATORY RESEARCH

Tisch MSRCNY Presented Multiple Research Abstracts at MSParis2017, 7th Joint ECTRIMS-ACTRIMS Meeting in Paris, France

Dr. Anna Iacoangeli presented the research abstract, "Novel molecular markers associated with cognitive dysfunction in multiple sclerosis." It is known that a majority of MS patients eventually develop cognitive dysfunction, characterized by loss of memory and motor function. Iacoangeli et al. has identified molecular markers for severe cognitive dysfunction (SCD) in MS patients, including two proteins (Parkin and deglycase DJ-1) previously linked to other neurodegenerative disorders such as Parkinson's and Alzheimer's diseases. Dr. Iacoangeli presented preliminary results which indicate that levels of Parkin and DJ-1 are decreased in CSF samples of MS patients with cognitive dysfunction compared to control groups.

Dr. Violaine Harris presented two research abstracts, the first of which is entitled, "Phase I/II clinical trials testing multiple dosing of intrathecal mesenchymal stem cell-derived neural progenitors in patients with progressive MS." This abstract focused on the progress of the clinical trials testing multiple dosing of intrathecal mesenchymal stem cell-derived neural progenitors in MS patients. Since proving safety in Phase I of the clinical study, the team is now setting up the Phase II trial, which will assess efficacy of IT-MSC-NP treatment compared to a placebo sham-IT control.

The second abstract presented by Dr. Harris was entitled,
"Intrathecal autologous cell

"Intrathecal autologous cell therapy is associated with changes in cerebrospinal fluid biomarkers in patients with progressive multiple sclerosis," highlighted results from the recently completed Phase I clinical trial. This trial studied intrathecal autologous cell therapy. One focus was to identify novel biomarkers of clinical response to the MSC-NP treatment in patients with progressive MS. Findings include noticeable differences in the expression levels of cerebrospinal biomarkers like certain trophic/immunomodulatory factors in MS patients who responded effectively to the reparative cell therapy strategy.

Dr. Fozia Mir presented the research abstract, "Metabolomic screening of cerebrospinal fluid from multiple sclerosis patients reveals a distinct signature." Mir et al. investigated the biochemical and cellular changes in the pathological process of MS. Her team performed a mass spectrometricbased assay to identify and quantify metabolites including amino acids from the CSF of MS patients and controls. Dr. Mir's results show significantly altered metabolite ratios in the MS population and that the changes correlated with disease subtype and activity. The measured change in the metabolic pathway helps to identify the pathophysiology of multiple sclerosis.

Dr. Jamie Wong presented the abstract, "Differential effects of primary and secondary progressive MS cerebrospinal fluid on motor function and spinal cord pathology," which focuses on her team's work to understand differences in the pathological mechanisms underlying primary progressive multiple sclerosis (PPMS) and secondary progressive multiple sclerosis (SPMS).

Mice were injected with cerebrospinal fluid from PPMS and SPMS patients and differences were observed in the disabilities of these two experimental groups. The experiment suggests that there may be a difference in the makeup of PPMS and SPMS CSF and in the mode of progression for the subtypes.

Jerry Lin's group presented two abstracts on the role of B-cells in MS, the first of which is entitled. "The anti-myelin antibody response in MS is primarily directed against myelin oligodendrocyte glycoprotein." Their research analyzed the types of B-cells in the MS CSF, the types of antibodies they produce, and the factors that govern B-cell stimulation and mobility. They found that CXCL13 may have a role in attracting B-cells into the CNS, more specifically, the ones that make IgG oligoclonal bands. In addition, two factors that govern B-cell stimulation and survival (BAFF and APRIL), may be involved in an interdependent way in recruiting IgM producing B-cells.

The second abstract by Lin's group, "Comprehensive analysis of the intrathecal B-cell response in patients with MS," highlighted that most of the antibodies in the CSF of MS patients (65%) may be directed against the myelin protein MOG via Western blot, one of the techniques used. However, using another major technique in the lab, ELISA, only a small percentage (4%) of these antibodies reacted with MOG. More research is needed to clear up this discrepancy and to determine the main targets of MS antibodies in the CNS.

## A NOTE FROM THE NURSES

## Friendly Reminders from Your Nursing Team

With the holiday season here, please be mindful of any prescriptions that you may need to renew. Many pharmacies close for the holidays and we want to make sure your prescriptions are filled on time. This is especially important to keep in mind if you are expecting a script from a mail order pharmacy.

With the beginning of a new year, oftentimes insurance plans and policies change. As this can be a trying process, please be proactive about it. Anytime there is a change to your insurance, please remember to fax us a copy of your new insurance card (front and back) to (212) 265-8194. Simply calling and leaving your new insurance information on our prescription line limits our ability to help get your medications covered in a timely fashion. Speak with your new insurance plan about any medications you are currently taking to find out if they are preferred. Please let the office know of any non-preferred medications, this will help to alleviate lengthy appeal times.

During each office visit please bring a list of any medications you are currently taking. This will help the nurses update your chart accordingly, and allow for more time to discuss any medical issues you may be having.

We frequently get asked by our patients if it is okay to receive the flu vaccine. As a Center wide policy, if you are over 65 years old, our doctors agree that it is okay to get the flu vaccine, unless contraindicated for medical reasons. For anyone under 65, please give us a call on the nursing line to discuss if the flu vaccine is recommended for you. Additionally, if you have questions about other vaccines, please call the nurses' phone line so they can discuss this directly with your physician.

Please keep in mind the importance of seeing a primary care physician yearly. Many patients have either not had a physical in a few years or have no primary care physician at all. Having a good relationship with a PCP will assist us in giving you the most comprehensive care possible. With cold and flu season here, if you are experiencing any symptoms of a cold or possible flu, please reach out to your PCP. They will be able to guide you in how best to proceed.

Paying extra attention to your handwashing technique can help reduce the spreading of germs. A helpful tip is humming the "Happy Birthday" song from beginning to end twice while washing your hands with warm water and soap.

As a reminder we are not a commercial lab, and cannot run blood work for other doctors' offices. If you are written a prescription for blood work from another doctor's office, please consult the ordering physician for any and all questions.



## Don't Forget To ...

Bring an up-to-date list of any medications you are currently taking with you to every office visit. This will help the nurses update your chart accordingly, and allow for more time to discuss any medical issues you may be having.

## CAUTION

Flu & COLD SEASON AHEAD



## THANK YOU FOR ATTENDING THE 2017 SYMPOSIUM



Dr. Saud A. Sadiq speaks with guests after his research presentation

Tisch MSRCNY & the IMSMP would like to thank everyone who attended the Tisch MS Research Center of New York's 20th Annual Patient Symposium. This year, over 700 guests filled the grand ballroom of the New York Hilton Midtown.

Each year we strive to bring new information on MS research, symptom management and nutrition and wellness to all who attend. This year's event featured guest speaker, Dr. Amy Stein, a pelvic floor therapist who discussed pelvic pain in people with MS. Dr. Deneb Bates invited us into her kitchen to cook a brain healthy dish and Dr. Saud A. Sadiq addressed research happening in the Tisch MS lab and around the world.

We would also like to thank all of those who took a moment to complete our survey and offered feedback on ways to improve upon next year's event. Plans are already in the works. We hope to see you there!

SAVE THE DATE: 10.14.18 21st Annual Tisch MSRCNY Symposium

## 2017 Symposium Patient Profiles ~ A Presentation of Courage



## Discovering What Can Happen When You Put Your Mind To It & Never Give Up

The most inspirational part of the day during the 2017 symposium came from our patient profiles featuring, Willem VanDooijeweert and Jesse Eisenstodt.

Willem shared his story of being diagnosed with MS after the appearance of brain and spine lesions on an MRI. He began injections to halt progression but never truly felt well. Willem made the decision to take diet and exercise to unprecedented levels. He investigated an anti-inflammatory diet and perfected it. Today, Willem is living his best life and even competing in professional volleyball tournaments around the country!



You may remember Jesse from his *Healing MS* newsletter article, "Making Meaning with an MS Diagnosis." Jesse illustrated what you can come back from when you make changes in life, seek the help you need and find your inner strength. After a hospitalization and an exacerbation that left him with difficulty walking, Jesse refused to let his MS define him. He began speaking with a therapist, practicing mindful meditation and even changed careers. Jesse left the finance world to work at a school for the developmentally disabled.

"Working with the developmentally disabled, gave me a new perspective and allowed me to give something back after all of the help I've received over the years."

Thank you to Willem & Jesse for the inspiration!

## WHAT INSPIRES YOU?

During the 2017 Tisch MS Research Center Symposium, We Asked People With MS, What Inspires You?

Here's What They Told Us...

























Our sincere appreciation to all who participated and provided such inspirational images!

To view the full photo album, please visit our Facebook page at:

https://www.facebook.com/TischMSRCNY/



## FROM THE FRONT DESK

Making any changes? As soon as your insurance plan, home address or telephone numbers change, please do not hesitate to contact the office and give them the new information.

This will allow us to keep our files up to date and we can better serve our patients when we have all the correct information to work with. Thank you!



21st Annual Tisch MSRCNY Symposium 10/14/18

## SOCIAL WORK NEWS

#### Goodbye from Shelly White, LCSW



For the past seven years, I have had the privilege of working with amazing people at the IMSMP, including patients, staff, and families. It is now time for me to move on to my next chapter as a psychotherapist. I do this with excitement, but also sadness as I say a heartfelt goodbye to the many people here who have touched my life over the years.

Thank you to the patients and their families who have taught me the meaning of strength, courage, and determination. It is an honor to have been trusted with your deepest emotions and your greatest accomplishments. You face challenges every day that others take for granted, both visible and invisible. You continue to maintain meaning and hope in the face of adversity. I am grateful for all you have given to me.

Thank you to the wonderful staff members who put their heart and soul into caring for our patients every day. I could not be prouder to have been a part of your team. I will miss the camaraderie and support that carried me through my introduction to life as a social worker. I wish all of you the best.

Thank you Dr. Sadiq, for everything you taught me and for creating a place where people feel so cared for. I pray you will find the cure for MS.

## **IMSMP PERSONNEL NEWS**

Welcome Molly Eisenhardt, LMSW



Molly Eisenhardt received her undergraduate degree from The College of New Jersey. She then attended Fordham University where she earned her Master's in Social Work. Previously, Molly worked at The Alzheimer's Foundation of America as their education program coordinator.

"I knew the IMSMP was a good fit on the first day I walked in! Everyone was extremely caring and I could see how that attitude is reflected in direct practice. I love being a part of a unique center and multidisciplinary team whose goal is to best fit the need of our patients. Thank you to the patients and staff for welcoming me to the IMSMP," says Molly.

## **NEWS ON NATUROPATHY**

## Cyclic Calorie Restriction May Benefit People with MS

Cyclic calorie restriction involves a very low-calorie diet for several days per month, followed by re-feeding with healthy foods. While fasting for health is not a new idea, and humans undoubtedly experienced periods of low calorie intake throughout evolution, there is recent research exploring the ways that calorie restriction may be beneficial for multiple sclerosis.

Research has shown, in the animal model of MS, cycles of modified fasting suppress self-reactive immune cells, reduce disease severity and demyelination, as well as increase the formation of myelin making cells and accelerate remyelination.

Accumulating evidence shows that energy metabolism is essential to the life-long function of stem cells. Excess nutrients, over time, may deplete our natural stem cell populations. When constantly overfed, they become prematurely exhausted. Cyclic calorie restriction may



help to promote stem cell self-renewal, resting them and reactivating them with re-feeding, to encourage life-long tissue repair.

If you are interested in nutritional approaches for MS, please schedule an appointment with Dr. Deneb Bates, the IMSMP's naturopathic doctor. References for research studies available upon request.

## PHYSICAL THERAPY & REHABILITATION

## **Knowledge is Power**

Success in physical therapy for people with MS can occur for many reasons. The motivation and consistency of a patient attending PT sessions and performing home therapy activities is the main reason. The skill of the physical therapist also plays a role. There are also many times where patients share with us a physical rehabilitation and wellness product that they have learned about. The physical therapists at the IMSMP pride themselves in engaging with patients and their families about new ideas to improve the mobility and well-being for people with MS and their caregivers. Often, ideas are not simply about an exercise option, but about a product that facilitates better mobility or safer functioning.

Several products that the IMSMP has integrated into PT programs such as the Dorsi Lite<sup>TM</sup> (a foot drop brace), the Alinker<sup>TM</sup> (walking fitness 'bike'), and the Musmate<sup>TM</sup> (a hip flexor assist device), were all discovered by inquiries from patients. Many lives were changed with these products, including many people who improved their walking abilities when these were integrated into the PT plan of care.

Patients also help other patients in rehabilitation, with the recommendations of local physical and occupational therapists. All IMSMP patients can benefit from seeing Dr. Stephen Kanter or Dr. Elizabeth Woods at least once per year, however, finding a local therapist convenient to your home or office is recommended. We encourage patients to share the names and locations of the local therapists during their visit at the IMSMP, so that others can experience their services as well.

At your next PT visit, if you are happy with your local PT or OT, let Dr. Kanter or Dr. Woods know. Or if there is a product on the market that you think can benefit you, bring that information as well.

At the IMSMP, the time and attention provided to patients and their families for physical therapy is necessary in order for patients to reach their highest potential in physical and overall wellness. With a continual dialogue and collaboration between the patient, caregiver(s), IMSMP PT, and local therapists, successfully managing physical concerns for everyone with MS can be optimized.

## TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

## TEAM TISCH MS & THE TCS NYC MARATHON Over \$100,000 Raised for MS Research at Tisch MSRCNY



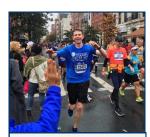
Congratulations Team Tisch MS for supporting our research with their incredible fundraising efforts! For the third consecutive year, the team has raised over \$100,000... and counting... (you can make donations to the team until the end of the year on our **Crowdrise.com** page, then search Tisch MS).

As a TCS community charity partner, Team Tisch MS has bibs for ten runners. They were joined by six additional athletes who won lottery spots in the race, making our group 16 strong this year. While most of the team is local to NYC, some of the runners came from well beyond the five boroughs with members flying in for the race from places as far as Abu Dhabi, and closer to home, Raleigh, NC.

Many team members, family and friends joined our post-race celebration directly after crossing the finish line at the Park Avenue Tavern near Grand Central Terminal. Thanks to all who supported our team with your generous donations and your cheers for our Team Tisch blue shieldwearing runners along the route!

Everyone is welcome to run, ride, walk, swim, or just cheer with Team Tisch MS. Check out **Tischms.org/join-ttms** for learn more.

#### **Team Photos**



Forrest Anderson



Rami Madi (from Abu Dhabi), Jessica Keaney & Elizabeth Woods



Scarlett Fugazy & Grace Putman



L to R: Stephanie, Jason & Alex Jenny

## Special Recognition for Stephanie Brochinsky Jenny for Raising \$27,750 in Honor of Her Husband, Jason

"While MS is a part of us, it will not define us. It will not put life on hold. It will not put dreams on hold. However, if it happens to give strength unintentionally and likewise make dreams come true, so be it, and if dreaming gives strength and action to find a cure, even better. Thank you for dreaming with us, and taking action with us. Please know that Team Jenny is stronger because of your friendship, generosity & support."

#### **Check Out Our Amazing Times!**

Forrest Anderson - 4:57:47 Stephanie Brochinsky Jenny - 5:31:12 Scarlett Fugazy - 4:22:42 Tessa Grant - 4:45:06 Jessica Keaney - 6:06:12 Stacey Ketcham - 4:22:41 Rami Madi - 4:24:11

Whitney Mallis - 4:44:4 Aidan McGuilly - 5:13:17 Fiona McMahon - 3:43:02 Grace Putman - 4:22:42 Lauren Winter - 4:28:41 Elizabeth Woods - 4:06:13 Allan Zapanta - 5:55:41

## DEVELOPMENT DEPARTMENT NEWS CONT'D

## Thank You Team Tisch MS 2017 TCS NYC Marathon Sponsors













## **Inspiring Events by Patients & Friends**

### **Music for MS Research**



Over 170 guests filled the Trenton Country Club on September 30th, raising more than \$35,000 for our stem cell research. Thank you to the Renegars for reaching the high notes in support of our work.

### Learning to Help People in Need

After a discussion about helping people in need in Mrs. Stanbery's third-grade class in Fort Worth, Texas, Julia Waldvogel sprang into action. Her grandfather Phil died from MS before she was born, which motivated her to help others who struggle with the disease. "My mom says he would have liked my spunk," said Julia about her grandfather whom her mom still misses every day. We like her spunk, too! Julia approached neighbors and friends to support MS research. Thank you, Julia, for the \$70 you raised for Tisch MSRCNY. Lesson learned, Mrs. Stanbery.

## Gifts That Give Back

It's the generosity of donors like YOU that brings us closer to a Future Without MS. All donations directly fund our research and the FDA-approved stem cell clinical trial. There are several ways you can support Tisch MSRCNY this holiday season:

### **Employee Matching Gifts**

Many employers will match your personal donation. Check with your company to find out if they have a matching gift program so you can double the impact of your gift.

### Gifts of Stock

Making stock gifts can be a tax-advantaged way to support Tisch MS. Your broker can assist you in making a direct transfer of stock Shop for MS to Tisch MS as a charitable gift.

## **Planned Gifts**

You can help play an important ongoing role in sustaining Tisch MS. Planned giving can benefit you, your loved ones, and Tisch MS'

mission. Planned gifts enable charitable donations at a level that you might not have thought possible, while maximizing tax benefits for you and your family. Please contact us at (646) 557-3900 or development@tischms.org for more information.

Shop away at the following websites: AmazonSmile, iGive.com, and Goodshop. Enter Tisch MS Research Center of New York as your charity/cause.











## THANK YOU TO OUR FUTURE WITHOUT MS GALA DONORS\*

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\*Due to space limitations this list includes donors of \$1,000 or more, received as of November 9th, 2017. We sincerely appreciate contributions at all levels as they make our research possible.

## DEVELOPMENT DEPARTMENT NEWS CONT'D

## More Gala Photos



Raising a Paddle for MS Research



The Parekh Family



The Foley Family



David Rosenblum (3rd from L) with Guests



Elizabeth Maslow Montesano & Gerry Montesano with Guests

## WITH SINCERE APPRECIATION, WE HONOR & RECOGNIZE OUR DONORS\*

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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 corporatematching gifts from the following companies: Allstate Giving Campaign AmazonSmile American Express Bank of America Google JCPenny MassMutual Financial Group Microsoft Prudential Financial

\*This list includes donors of \$500 or more received between August 1st and October 31st, 2017, not including contributions supporting the 2017 Future Without MS gala. While every contribution is deeply appreciated, we regret that we are unable to list gifts below \$500 due to space limitations.

Every effort has been made to ensure the accuracy of this list. Please email Meaghan Browne,

mbrowne@tischms.org or call (646) 557-3863 to report any errors or omissions, or if you would like to have your name removed from future listings.

#### IMSMP & Tisch MSRCNY Saud A. Sadiq, MD, FAAN Director

#### **Our Clinicians**

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Allan Zapanta, CNA

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