



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

Tisch MSRCNY Presents Its' Latest Work at the 2017 American Academy of Neurology (AAN) Annual Meeting.

In April, the dedicated team of scientists and research assistants from the Tisch MSRCNY laboratory attended the world's largest gathering of neurologists, at the AAN Annual Meeting held this year in Boston, Massachusetts. The event brings together more than 10,000 neurology professionals from across the globe to network, discuss cutting-edge research, and take part in top-rated education programming across a wide variety of topics. Once again, abstracts presented by our Tisch MS researchers were extremely well-received.

Jerry Lin's group presented two abstracts, "Comprehensive Analysis of the Intrathecal B-cell Response in Patients with Multiple Sclerosis" and "Cerebrospinal Fluid (CSF) Cellular Analysis of Patients with Multiple Sclerosis (MS) Treated with Anti B-cell Therapy – Correlated with Treatment Response."

Research from the first abstract analyzed the CSF of ten patients with the most robust B-cell response to better understand the role of B-cells in the pathogenesis of MS. The group found that the mechanism of the B-cell response in the CSF may depend on the type of B-cell (either the IgG or IgM B-cell type), due to the correlation of certain CSF molecular factors with specific B-cell types.

Research from the second abstract analyzed the CSF of thirty-six patients, treated with Rituximab, to determine the CSF composition of non-responders. The group demonstrated that anti B-cell treatment failure is characterized by persistence of B-cells, plasmablasts (another cell type in the B-cell family) and plasma cells in CSF.

The abstract, "Increased Methionine Sulfoxide Levels in the CSF of Multiple Sclerosis Patients," was presented by Dr. Fozia Mir's group. This abstract focused on the effect of the metabolism of methionine on the pathology of MS. Methionine is an essential amino acid (building block of protein) needed for many critical functions in our body. We found that there are disturbances/ changes in its' pathway and hence its' levels in the CSF of MS patients. This change in the levels of methionine can contribute to disease symptoms.

Continued on page 2 . . .

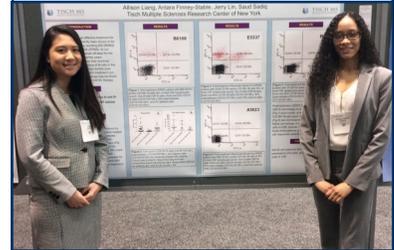


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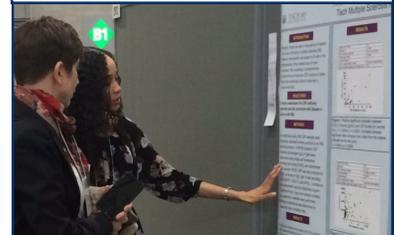
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Research Assistants, Allison Liang and Antara Finney-Stable, presenting at the 2017 AAN Annual Meeting



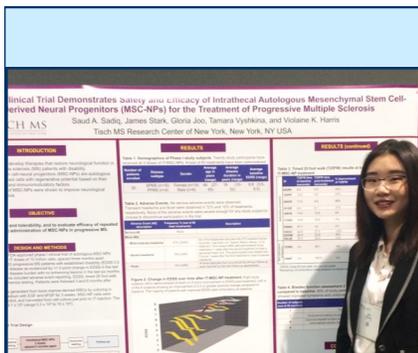
Research Assistant, Antara Finney-Stable, discussing the abstract with an attendee

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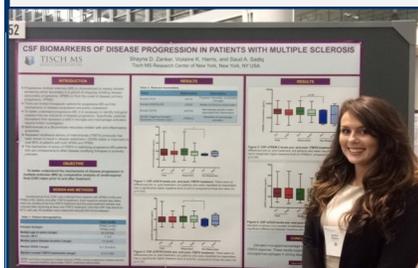
- Tisch MS Researchers present their work at the 2017 AAN Annual Meeting
- Welcome 2 New Nurses
- Registration is open for the 2017 Tisch MSRCNY Patient Symposium
- What is the MIND Diet?
- Thank You to Our Donors

TISCH MS LABORATORY RESEARCH

Research Presented at the 2017 American Academy of Neurology® (AAN) Annual Meeting (continued from cover)



Research Assistant, Gloria Joo, presented an abstract



“The AAN Annual Meeting was the first conference I participated in, as an academic. I learned about novel research in the field of neurology, and was able to envision what my future will be like as a physician.” - Shayna Zanker, Research Assistant

Dr. Violaine Harris’ group presented two research abstracts entitled, “Cerebrospinal Fluid Biomarkers Associated with the Reparative Effects of Intrathecal MSC-NP Treatment in Patients with Progressive Multiple Sclerosis,” and, “CSF Biomarkers of Disease Progression in Patients with Multiple Sclerosis.” The first abstract focused on identifying biomarkers of MS patient responsiveness to intrathecally-delivered autologous bone marrow mesenchymal stem cell-derived neural progenitors (MSC-NP). Through CSF analysis, altered levels of specific biomarkers were identified in these patients. The second abstract also identified biomarkers but investigated variations in their levels before and after treatment with intrathecal methotrexate (ITMTX). The changes in biomarkers that were observed could be indicative of disease stabilization from treatment with ITMTX.

Dr. Jamie Wong’s group presented the abstract, “Intrathecal Delivery of Primary Progressive MS Cerebrospinal

Fluid Induces Behavioral Deficits and Spinal Cord Pathology in Mice.” Since there is no animal model for primary progressive multiple sclerosis (PPMS), this group looked into developing such a model to better understand disease pathogenesis of PPMS. By intrathecally injecting CSF of PPMS patients into mice, they observed motor weakness, reactive astrogliosis, and axonal damage, which may help to reveal the mechanism of PPMS.

On the clinical side, Dr. Saud A. Sadiq and Dr. Violaine Harris presented the abstract, “Phase I Clinical Trial Demonstrates Safety and Efficacy of Intrathecal Autologous Mesenchymal Stem Cell-Derived Neural Progenitors (MSC-NPs) for the treatment of progressive multiple sclerosis.” This poster detailed the latest safety and efficacy data of the Phase I stem cell trial. Thus far, no serious adverse events were observed in any of the 20 study patients, and neurological improvements of varying degrees were observed in the majority of these patients.

To learn more about our state-of-the-art stem cell research lab dedicated to MS

or

to make a donation to help fund this initiative, please contact the Tisch MSRCNY development office:

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(646) 557-3900

LAYING THE GROUNDWORK AT THE INSTITUTE FOR EXPERIMENTAL & STEM CELL RESEARCH



CLINICAL RESEARCH

OCRELIZUMAB (OCREVUS™) FDA Approved Treatment of MS

Ocrelizumab (OCREVUS™), an anti-B cell therapy has been approved by the FDA as of March 28th 2017, for the treatment of relapsing remitting multiple sclerosis (RRMS) and primary progressive multiple sclerosis (PPMS). This treatment is highly effective for RRMS, based on the data from the Phase III clinical studies. It is also the first drug approved for use in PPMS. At the IMSMP, we have used Rituximab, a similar anti-B cell treatment, for the past 16 years with great success. It is because of the effectiveness of this therapy (Rituximab) we were able to persuade Medicare to cover the costs of this therapy in New York.

Rituximab, however, is NOT approved by the FDA for use in MS. At our Center we use it as an off-label drug. This unfortunately can require several weeks to obtain approval from insurance carriers and often approval may be denied.

Therefore, the approval by the FDA of Ocrelizumab, which should have almost identical anti-B cell activity

to Rituximab, appears to be good news for MS patients. However, there are some serious concerns with Ocrelizumab that patients need to be made aware before they consider this therapy.

First, in the RRMS trial, there were 9 patients who developed various malignancies within three years of taking Ocrelizumab (4 patients within the first 2 years and 5 patients in the following year). This is alarmingly high considering that these patients were mostly in their third decade of life and had no previous history of cancer. In the trial for PPMS patients, 13 patients developed cancer within the three years of taking Ocrelizumab (11 in the first two years and 2 additional cases in the following year).

This means that more than 1 in 50 patients developed cancer within three years of taking Ocrelizumab among the PPMS patients. These risks of malignancy associated with Ocrelizumab are not seen with Rituximab (more than a thousand patients just at our center since 2001 and several hundred thousand

worldwide). This risk of cancer with Ocrelizumab is not explained at present and the magnitude of the problem cannot be defined, as the medication has not been given for a period longer than 3 years.

There are also additional concerns with Ocrelizumab, such as the risk of life threatening infections which caused the trials in patients with rheumatoid arthritis and systemic lupus erythematosus (SLE) to be halted in 2010.

Although, it is indeed progress that the first medication for PPMS has been approved, the patients should be fully informed of its' potential risks. For patients who can obtain Rituximab, it would be safer to continue with this therapy, until with time, we are better able to advise patients about the risks associated with Ocrelizumab.



A NOTE FROM THE NURSES

Welcome Valentina & Tessa!

Valentina Assenova has been with the IMSMP since January of 2017. In her 5 years as a registered nurse, she has worked in almost every aspect of medical surgical nursing, with a specialty in Oncology. She brings a skill set that is truly unique, as her IV skills are outstanding. Her experience in a busy oncology unit was the foundation to her expertise in obtaining peripheral vascular access. Valentina earned her Bachelor's degree at the College of Staten Island, NY.

Please join us in welcoming our new clinical nurse, **Tessa Grant**. Tessa started at the IMSMP in November 2016 and has been an excellent addition to our team. Her enthusiasm and exceptional interaction with patients makes her a natural fit for our Center. Tessa previously worked with Dr. Douglas Schottenstein at New York Spine Medicine and graduated from Wagner College's nursing program in 2015.



Valentina Assenova, RN



Tessa Grant, RN

TIME
IS
PRECIOUS

FROM THE RECEPTION DESK



Sara Endy

Please Help Us Welcome A New Member to the Reception Staff

Sara Endy graduated from Indiana University of Pennsylvania with a Bachelor's in Anthropology and a minor in Spanish. She worked previously as a personal trainer which included clients with MS and taught group fitness classes specifically for people with Parkinson's disease.

REHABILITATION NEWS

Taking Control of Time – From a Physical Therapist's Perspective

While people with multiple sclerosis navigate the ways one can live a, 'more normal' life, a common obstacle is waiting to get better. The variability of the disease, the hope that the effects of the disease will disappear, the efforts made to find the perfect medication are all reasons why a person with MS may put their life on hold. During this time, life continues and the need to maintain overall health, both physical and psychological, also continues. However, in many cases, activities needed to maintain or improve physical health are eliminated. This not only includes standard physical exercises to improve strength and flexibility, or specialized exercises to improve balance or endurance, but life activities as well.

Over the course of one's life, there is one thing that can be lost forever. That is time. Time to participate in

activities with family, time to be with friends, time to do something good for oneself. In the field of physical rehabilitation, the psychology of rehabilitation can be more relevant than the actual exercises that are prescribed. Lost time being sedentary, lost time not participating in family activities is time that cannot be recovered with any medicine or physical therapy.

Physical therapy goals for people with MS must start with safe mobility and participating in desired activities. Accomplishing these goals can happen multiple ways such as, temporary use of a mobility device like a cane or wheelchair. Satisfying the overarching functional goals does not mean that other goals, such as increasing strength, balance, and independent walking can't also be worked on. Time should be used wisely when considering one's physical abilities. That is, don't let perceived inabilities steal that time to live life.

NEWS ON NATUROPATHY

The MIND Diet is an easy to follow food plan that combines two heart healthy dietary strategies, (the DASH diet and the Mediterranean diet), with preliminary results showing it may help to prevent cognitive decline. The benefits of the MIND diet are likely through the combination of brain supporting foods, along with improvement of blood flow to the brain. While this diet is not designed specifically for people with MS, it offers a simple starting place for anyone who wants to eat to support their brain health.

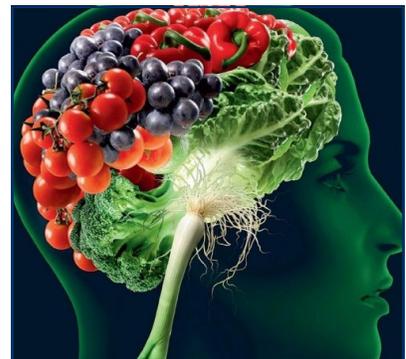
Include these foods:

Daily: green leafy vegetables, other vegetables, nuts, whole grains, olive oil, up to 1 glass of wine

Every other day: beans

Twice per week: berries, poultry

At least once per week: fish



Limit these foods:

Red meat, butter and margarine, cheese, pastries and sweets, fried or fast food.

To develop a personalized diet strategy for your particular health needs, see Dr. Bates, the naturopathic doctor at the IMSMP.

MAKING MEANING IN YOUR LIFE WITH AN MS DIAGNOSIS

The Department of Social Work would like to introduce a new feature in our newsletter, “Making Meaning.” To, ‘make meaning’ in one’s life when faced with adversity, as part of a therapeutic method, was identified and explained by famous psychiatrist, Viktor Frankl in his book, Man’s Search For Meaning. At the IMSMP, we want to feature patient’s stories of how they have made meaning in their life, while facing MS difficulties. Here is how Jesse Eisenstodt is making meaning:



Jesse Eisenstodt

I was diagnosed with MS eight years ago, and my strength to battle, cope, and come to terms with my life now, has changed over time. What I’ve learned through it all, is that it doesn’t matter if you get your ability to cope from external influences like doctors, medication, support groups and therapy including, occupational, physical, or speech (I’ve had to take part in all three) and of course friends and family.

Perhaps you get your strength from within, both mind and body. The important thing is that you do something to help yourself and not focus on, “why me?” Feeling sorry for yourself, and the depression that often follows, are totally natural reactions and absolutely have their place in your journey. Here are a few of the tools that I’ve used that have helped me limit, to steal from the Star Wars universe, that, “dark side.”

Eight years ago, I thought what I’m about to say was complete, “bull.” Then I started meeting with Shelly White in the Social Work Department of IMSMP, and TALKING. Talking about your feelings, about your MS and starting a journey of self -discovery and learning to get to the bottom of why you’re feeling the way you do, becomes a major source of strength. That knowledge is power, and is able to give you back some desperately needed control. Let’s face it, at least for myself, the thought of not having control of my life anymore is what’s led to most, if not all of my emotional and mental struggles. Talking though this with someone helps, and even though I don’t meet with Shelly anymore, I have been in therapy ever since and am a big proponent of it.

Another tool that has helped me was being introduced to the practice of mindfulness, and mindful meditation. This was also an idea, that years ago, I would have laughed at. It’s basically the practice of being able to stay in the moment. It’s helped me focus on what’s, “real” and not the crazy or bad thoughts that can creep into our heads when we’re not paying attention. Especially with MS, if you can’t anchor yourself to real life, in the moment, you can really drive yourself mad with depressing thoughts about what your life may become and what the future holds. I recommend it for anyone that can get too much in their own heads. I know I can, and to be honest, I’d much rather remain positive. Mindfulness helps me do that.

The last thing I did is leave my career in finance to pursue something more rewarding. Now, I work at a school for the developmentally disabled. This has done two things that I feel have helped me. First of all, working helps me to feel that I am still a functioning member of society and does a lot for my feeling of self-worth. Too many people with MS feel they can’t work. This can lead to feeling ostracized and isolated from the rest of the world. I’m not saying everyone with MS can and should work. I’m saying if you can’t work, find something you feel passionate about and do it. Maybe it’s selling things over the internet, maybe it’s joining your local Italian American Club, or maybe it’s writing a blog about your experience with MS, like I am now. Secondly, reality is just the lens you choose to see your life through, and when you look at it through the lens of others less fortunate, you just might gain a new perspective. 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.

These are some of the tools I’ve used that have become my strength over these last seven years to help me cope with MS. I hope it helps you do the same.

*The Social Work Team would like to thank Jesse Eisenstodt and invite other patients to tell their story of, “making meaning.” This is not necessarily about how you got back to where you were before MS, but how you are finding meaning in your life in spite of whatever MS has handed you. To share your story, please contact the social work department at (212) 265-8070.

DEVELOPMENT DEPARTMENT NEWS

Inspiring Events by Patients & Friends



**Karen & Keith Kaplan with
Dr. Saud A. Sadiq**



**The Kaplan Family (L to R):
Keith, Karen, Cameron,
Jamie, Harrison**

Changing the Odds Against MS

Hundreds turned up to the inaugural Changing the Odds Against MS event in Charlotte, NC on March 31st. Keith and Karen Kaplan, along with an amazing and tireless event committee, put together a fun night of casino entertainment, jazz, food - and a whole lot of fundraising for the Tisch MS Center. The event, hosted at CenterStage@ NoDa, raised OVER **\$200,000!** Thank you to the Kaplan family (and their friends, colleagues and community) for the hard work and for raising the bar for fundraising events sky high.

“Karen and I were overwhelmed and deeply moved by the way our community came together to support our family and the groundbreaking research underway at the Tisch MS Center,” Kaplan shared. “Thank you to all who sponsored the event, donated their time, money and services, and to all who joined us to Change The Odds Against MS.”

A Delicious Fundraiser

Julia Weiss, age 15, and Danielle Heller, age 12, once again, partnered together to raise money in support of the research at Tisch MSRCNY. They sold bagels, muffins, and cream cheese in fun flavors from The Bagel Nook in Freehold, New Jersey, raising over **\$400** in support of our research. Thank you, Julia and Danielle, for your hard work and creative effort!



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*This list includes donors of \$500 or more received between February 1st and April 30th, 2017. 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.



SAVE THE DATE

10.22.17

20th Annual Tisch MS Research Center Patient Symposium

Sunday, October 22, 2017

**New York Hilton Midtown
1335 Avenue of the Americas, NY, NY 10019
9:30am – 1:00pm**

For More Information & To Register

visit: www.tischms.org/events

Or call (646) 557-3919

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