

FOR IMMEDIATE RELEASE:

TISCH MS RESEARCH CENTER OF NEW YORK ANNOUNCED

Leading Research Center for Multiple Sclerosis Takes Name of Benefactors

The Board of Directors of the Multiple Sclerosis Research Center of New York (MSRCNY) has announced the re-naming of the institution as the Tisch MS Research Center of New York. Representing a new model of healthcare, the research center, coupled with its clinical affiliate, the International Multiple Sclerosis Management Practice (IMSMP), is the largest MS facility in the world with over 80,000 square feet at their Manhattan location and serves patients from over forty-five countries and five continents.

The name change, which is effective immediately, is a reflection of Bonnie and Dan Tisch's long standing support for the research center and an indication of their continued philanthropy to support the Center's mission of unraveling the mysteries of MS at both the cellular and molecular level and ultimately finding a cure.

"We are truly honored and grateful for the tremendous generosity of the Tischs and this recognition of the outstanding research being conducted at our Center," stated Dr. Saud A. Sadig, Director and Senior Research Scientist. "We are confident the Tisch MS Research Center of New York will continue to perform ground-breaking experiments and provide the rapid progress we strive for in accelerating our approach to finding the cause of MS."

A new research website will also be launched at: www.tischms.org

International Multiple Sclerosis Management Practice

Saud A. Sadiq, MD Director

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Dr. Saud A. Sadiq Invited to Speak on Stem Cell Research at Landmark Event Within the Vatican

Dr. Saud A. Sadiq has accepted an invitation to participate in the Second International Adult Stem Cell Conference: Regenerative Medicine --- A Fundamental Shift in Science and Culture to be held within the Vatican, April 11-13, 2013. The invitation came directly from the renowned Vatican's Pontifical Council for Culture, NeoStem, The Stem for Life Foundation and STOQ International as these organizations continue to promote their charter of raising global awareness on adult stem cell usage.

"This invitation is a personal honor for me but more importantly brings to the forefront the discoveries and innovative research being conducted at the Tisch MS Research Center of New York," stated Dr. Sadiq. He added, "The amazing collaborative effort on the part of The Vatican's Pontifical Council for Culture, NeoStem, The Stem for Life Foundation and STOQ International exemplifies the tremendous need to explore the use of regenerative medicine via stem cell therapy and end patient suffering."

Dr. Sadiq will be participating on a "Cell Therapies for MS" panel moderated by Meredith Vieira, American journalist and National TV correspondent. The panel will explore new therapies for multiple sclerosis and Dr. Sadiq will share the wealth of clinical data the Tisch MS Research Center of New York has gathered on the use of autologous adult stem cells.

Check www.tischms.org for updates and pictures from the conference.



Scientists at our research center attended the 11th Congress of the International Society of Neuroimmunology held November 4th-8th in Boston, MA. They presented the following posters:

Andre Muller, Saud Sadiq: "Cerebrospinal fluid levels of the 'B-Cell Maturation Antigen' (BCMA, TNFSRF17) are increased in MS and correlate with B cells."

Violaine K. Harris, Kristi Clark, Saud A. Sadiq: "The role of Fetuin-A in neuroinflammatory responses in multiple sclerosis."

The team headed by Dr. Violaine Harris continued their work on the role of Fetuin-A as a biomarker for MS, with the following paper accepted for publication and in press:

Harris, V.K., Donelan, N., Yan, Q.J., Clark, K., Touray, A., Rammal, M., and Sadiq, S.A. Cerebrospinal fluid Fetuin-A is a biomarker of active multiple sclerosis. *Mult Scler J* (in press), 2013.

Laboratory Research

Dr. Massimiliano Cristofanilli, along with IMSMP naturopathic doctor, Dr. Deneb Bates, presented on the potential association between gluten intolerance and MS at the conference of the Society for Neuroscience held in New Orleans, October 13-17, 2012. Dr. Cristofanilli summarizes their preliminary work as follows:

Multiple sclerosis (MS), the most prevalent chronic neurological disease among young adults, is an autoimmune disease of the central nervous system characterized by loss of myelin and neurodegeneration. MS pathogenesis is best understood to be an autoimmune response against myelin in a genetically predisposed population that has been exposed to a currently unknown environmental trigger.

Celiac Disease is the overt gastrointestinal manifestation of an autoimmune reaction triggered by a known environmental trigger: gluten—a protein found in commonly consumed grains. Gluten can cause extraintestinal manifestations with or without gastrointestinal symptoms and elevated antitissue transglutaminase 2 (tTG2) autoantibodies.

Organ-specific gluten reaction involves immune response toward other transglutaminase (TG) isoforms including tTG3 (expressed in the skin, leading to dermatitis herpetiformis) and tTG6 (expressed in the brain, causing gluten ataxia and possibly correlated with Schizophrenia).

A number of studies have shown increased rates of celiac antibodies associated with different autoimmune diseases, including type 1 diabetes, thyroid disorders, and MS. One study found 10% of MS patients to have positive celiac antibodies compared to 2.4 % of the control group. Although there are conflicting studies showing no increase in celiac antibodies in MS, one aspect of the conflicting results may be the inconsistency of the type of antibodies measured as well as differing thresholds for positive test results.

In this study we investigated the serum levels of tTG6 antibodies in MS patients, which have never been studied before. Using a commercially available ELISA kit, we found a higher prevalence of tTG6 antibodies (either IgA or IgG) in MS patients compared to healthy control individuals. Our results indicate that serum levels of tTG6 antibodies may represent a biomarker useful to identify MS patients who would benefit from a gluten-free diet.



Clinical Research Review

Control Volunteers Needed!

Tisch MS Research is hard at work on several important research projects requiring donation of biological materials from both MS patients and non-MS patients (control subjects). 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 members.

Control Cerebrospinal Fluid (CSF) Collection:

The Tisch MS Research team investigating the cause of MS, headed by Jerry Lin and Dr. Sadiq, is analyzing samples of cerebrospinal fluid from MS patients and may be on the verge of a breakthrough in the search for the cause of MS. To continue their work, however, they will need to analyze cerebrospinal fluid from non-MS control subjects, with which the CSF of MS patients can be compared. Control CSF is hard to come by in general, and control CSF extracted freshly enough to allow important proteins to be analyzed prior to degradation is almost impossible to acquire at present. For friends and family of MS patients, a donation of cerebrospinal fluid may be the most important step to take to advance MS research. We are currently looking for CSF samples to be obtained by a lumbar puncture (also known as a spinal tap) performed by an IMSMP neurologist.

Skin Biopsies for the Generation of MS-Specific Stem Cells/ Skin Biopsies for the Study of Dermatopathology in MS: Tisch MS Research is continuing work on two studies involving the collection of skin biopsies. One is a collaborative effort with the New York Stem Cell Foundation to generate induced pluripotent stem cells (iPS) from adult skin cells in order to study the genetic underpinnings of MS. The other is Dr. Williams's investigation of microscopic immune changes in the skin of patients with typical MS, atypical demyelinating disease, and healthy controls. Healthy control subjects, as well as additional MS patients, are needed for both studies.

If you are interested in any of our clinical research studies and would like to learn more, please contact our Clinical Research Assistants Deirdre Dulak or Daniel Koffler at (646) 557-3860 and (646) 557-3852 respectively.

A Note from the Nurses What is a lumbar puncture?

A lumbar puncture (or spinal tap) is performed in your lower back, in the lumbar region below your spinal cord. The procedure is done in a simple seated position with your forearms resting on your lap. Once your lower back is assessed and the area is cleansed, a numbing medicine called lidocaine is injected to minimize discomfort. A long thin needle is then inserted between two lumbar bones (vertebrae) to remove a sample of cerebrospinal fluid. This is the fluid that surrounds your brain and spinal cord to protect them from injury and provide transport for necessary nutrients. This procedure is generally painless although patients have reported a slight sensation of pressure. A lumbar puncture can help diagnose disorders of the central nervous system such as multiple sclerosis. Components of cerebrospinal fluid, such as certain proteins or immune cells, can be separated in our lab and further analyzed. Sometimes our physicians use lumbar punctures to inject certain medications or chemotherapy drugs into the cerebrospinal fluid as a treatment measure.

From the Front Desk

New Concierge Service at IMSMP

The IMSMP is proud to introduce a new concierge service to our patients. If you visit the center on a regular basis for various appointments or routine procedures, you may now request a personal concierge to coordinate all of your scheduling, present and future. This person will be able to help you plan appointments in a consistent and efficient manner. They will be your main contact at the front desk to alleviate any confusion when booking your appointments. These visits include: pump refills, intrathecal methotrexate treatments, physical therapy, social work appointments or routine infusions. You may request any member of our front desk staff.

Call today at (212) 265-8070 and they will be happy to get you started!

Newsletter Editors: Pamela Levin, RN, Umar Sadiq

Comprehensive Care Column: Cognition and Exercise



Joanne Festa, Ph.D.

"What can I do to improve my memory?" In the last issue of Healing MS, we stated there's emerging research demonstrating that aerobic exercise, can produce the brain boost many people are looking for. Cognitive functioning begins to decline, in part, because the brain slowly shrinks from loss of neurons, a process known as atrophy. Identifying methods of slowing or reversing this process seen in normal aging has become a new focus of research.

Cognitive dysfunction in individuals with MS can be the result of whole-brain atrophy: that process of neuronal cell loss similar to what is seen in older adults.

One intervention that shows promise in preserving and improving cognitive functioning in MS is physical exercise. In addition to the often mentioned physical benefits of exercise, studies have shown improvements in other areas of functioning. such as emotional well-being. The beneficial effects of exercise on cognition have been demonstrated in both animal and human studies. Almost 30 years ago, Dustman et al. compared the cognitive performances of three groups of patients: aerobically-trained subjects, strength and flexibility trained subjects, and those not engaged in exercise. The aerobicallytrained subjects showed greater improvement on a cognitive evaluation than the other two groups on working memory, processing speed, and executive function.

In several research studies of older adults, exercise has been associated with increases in brain volumes. In a study conducted by Colcombe et al. (2006), older adults were randomly assigned to an aerobic exercise training group and a non-aerobic (stretching and toning) training group. Participants in both groups participated in a program consisting of one hour sessions, three times a week, for a six month period. Results demonstrated significant brain volume increases and less age-related brain volume decreases in areas of the cortex associated with memory and attention among those in the aerobic training group.

This month's Comprehensive Care Column features Director of Neuropsychology, Joanne Festa, Ph.D. and Supervisor of Rehab Services, Stephen Kanter, PT, DPT providing everything you need to know about: Cognition and Exercise

Prakash et al. (2010) conducted a study assessing aerobic fitness and its relationship with gray matter volume and white matter integrity in participants diagnosed with MS. They found a positive a relationship between aerobic fitness and the brain.

The results indicated that increased aerobic fitness is associated with lower white matter lesion load and greater volume in areas of the brain associated with processing speed. Increased aerobic fitness, measured by oxygen uptake during aerobic exercise such as walking, swimming, and cycling, has been shown to improve cognitive functioning, particularly producing improvements in memory and executive functioning.

In a small cross-sectional study of 33 participants with multiple sclerosis, Motl et al. (2011) assessed the relationship between physical activity and performance on several cognitive tests. Physical activity was measured by the number of steps walked, using an accelerometer over a seven day period. Cognitive processing speed, learning, and memory were assessed with neuropsychological measures. The analysis showed a significant relationship between higher physical activity and greater cognitive processing speed, after controlling for variables of age, gender, and education. This study illustrated a positive relationship between physical activity and cognitive functioning in participants with multiple sclerosis and underscored the need for larger scale research examining this relationship.

Research suggests that exercise may increase brain tissue volume or decrease brain tissue loss by facilitating greater blood flow and oxygen uptake to the brain consistently and over a prolonged period of time (Dustman et al, 1983). Colcombe et al. also cites animal studies that suggest increased aerobic fitness may be associated with increased gray matter as a result of such mechanisms as growth of capillary beds, increase of connections between neurons, and increases in brain cell growth.

Cognitive dysfunction is a prevalent symptom among individuals with MS. It may be present even in the absence of physical symptoms and can influence many aspects of daily living. Although issues of symptom exacerbation, fatigue, and possible

physical limitations in multiple sclerosis can create challenges to getting regular exercise, given the potential benefits, adding exercise to your daily health routine must be considered as a first line treatment.





Stephen Kanter, PT, DPT

Regardless of physical status, all people with multiple sclerosis can engage in a daily exercise program. In many cases, equipment is not needed. A walk outdoors can prove to be one of the most beneficial parts of a daily program to help improve MS related symptoms including fatigue, strength, and balance, while at the same time decreasing levels of depression and social disconnect. On days where walking outside is not possible, a standing program can serve to be an effective substitute. A standing program can include 5 minutes of standing every waking hour.

In addition, during standing time, balance exercises and aerobic activities can be incorporated. For example, dancing in place, shadow boxing or other arm exercise component, tai chi, and/or yoga can be included, based on your physical therapist's recommendations. The key component to a good physical wellness program is being consistent by performing structured physical activities every day. On days when you feel your worst physically and cognitively, it is exercise which makes you feel better that day and beyond!

For a cognition or P.T, assessment, please schedule an appointment by calling (212) 265-8070.

<u>My Story</u> by Susan Putman

I was diagnosed with MS in 1992. I had been a triathlete, bi-athlete and a marathon runner so the news that my left leg drag would prohibit me from running was very upsetting to me. MS, like any type of illness whether chronic or not, causes us to want to "fight" the disease. Our instinct leads us right to anger and the desire to be "tougher" and "bigger" than the illness. However, it took me 16 years to figure out that, at least with a chronic illness, the key to success is NOT to "fight" the illness. It took me that long to realize and accept the fact that the illness is bigger than me. I learned that the key to success was to learn to LIVE with the illness, to get along, to embrace it in a way. That I could take all the energy that I was spending on being angry and fighting and find ways to spend that energy in a positive way.



From L to R: Grace, Claire, James and Susan Putman

Since the beginning, my doctors had suggested that I swim. However, I resisted the idea until our family moved to a new town in 2008. The local YMCA was such a beautiful facility and the pools seemed inviting enough for me to give it a try. Swimming at the Y has truly changed my life. Not only does it allow me to exercise physically but it provides time for me to have mental peace; to listen to music, think clear thoughts, exercise my brain as well as my body.

Recently, I had an exacerbation with my MS and I was unable to swim for 6 months. Under the watchful eyes of Dr. Sylvester and a lot of patience and faith in our current protocol, I was finally able to return a few weeks ago. How great did it make me feel to walk into the pool, see the lifeguards smile at my return and like old friends, wave hello. It felt like I was back home again. And then to jump into the pool and get back into my regular routine, in my regular time slot, was the most amazing feeling of success. I had made it back from a truly low period of my 21 years of existing with MS. Swimming at the Y had been my light at the end of the tunnel and now I was back. Thank goodness the IMSMP held my hand and walked me through this trying time. Thank goodness this beautiful place was right here, waiting for me when I was ready to return.

> Submit Your Story to: newsletter@imsmp.org

Social Work News Hope for Medicare Home Care and Rehabilitation

On January 24, 2013, a Federal Judge approved a settlement in the Medicare Improvement Standard case, *Jimmo vs. Sebelius*. This settlement clarifies that Medicare rules **DO** allow for ongoing physical and occupational therapy and home health aide services even when there is no objective improvement in the patient's health or functioning.

For years, Medicare has denied coverage of PT, OT and home health aide services once the patient's improvement had "plateaued." The National MS Society was a plaintiff in this case and sees this development as a critical step forward for thousands of people with MS nationwide. The IMSMP's social workers and physical therapist have been following this case for months, in the hope that our patients will benefit from more ongoing services in outpatient settings, in home care, and in nursing homes.

If you are told by your outpatient physical therapy or home care provider that Medicare is going to stop your services, here is what you can do:

- 1. Ask why.
 - * Rehabilitation (PT/OT) still has an annual dollar amount cap on services. Although, there are some possible exemptions.
 - * Services must, as always, be medically necessary and be considered a skilled service.
 - * But if you are told that your services are being cut because you are not improving, you can fight.
- 2. Ask the agency or rehab center to submit a claim to Medicare for a "formal Medicare coverage determination." In home care cases, you may have to pay for your home care while Medicare decides to continue your services, and then be reimbursed after their decision.
- 3. Call IMSMP to ask your MS doctor to write a letter in support of your agency's or PT's Medicare claim, stating that your services are medically necessary and require skilled services to prevent deterioration of your MS related condition.

Only the agency or center that is providing the services can appeal to Medicare to continue them. IMSMP staff cannot, so your first step is to talk to your rehab or home care provider. We are happy to provide you with a letter of support. Please check out the information under <u>Social Work Resources</u> at our website: **www.imsmp.org/services/social-work** for further information and to read the Self-Help packets to help you advocate for yourself!



News on Naturopathy

Luteolin: Nutrient Found in Common Vegetables that Reduces Harmful Immune Cell Activation in the Brain

Microglia are cells that serve as a part of the immunological function of the central nervous system (CNS). These cells patrol the brain and spinal cord, protecting them from infections and other injuries while removing dead and dying cells. While they are generally beneficial, microglia can also be associated with CNS diseases. Specifically, persistent over-activation of microglia is harmful and linked to high levels of oxidative stress, inflammation and demyelination, which are hallmarks of neurological damage in multiple sclerosis (MS).

Notably, there are natural compounds including those found in common vegetables that can affect the functioning of microglia. For example, emerging research shows that a molecule called luteolin calms over-active microglia, switching them to their neuroprotective state and decreasing levels of oxidative damage and inflammation. These studies suggest, in turn, that luteolin might potentially decrease MS disease progression, by reducing the immune response that contributes to demyelination and neurodegeneration.

The effects of luteolin on MS, in people, have not been studied. But, there's no reason to wait to consume these healthy, luteolin rich foods.

<u>Top Food Sources of Luteolin</u>: Celery and celery seed Sage, Thyme, Oregano (especially Mexican oregano) Peppermint Parsley (fresh or dried) Artichokes Peppers (both hot and sweet) Radicchio

For individualized dietary and supplement strategies, schedule a visit to see Dr. Deneb Bates, the IMSMP's Naturopathic Doctor.

A Delicious Way to Enjoy Luteolin



Healing MS would like to introduce Nina Kauder:

"I learned from my chemist dad and foodiecentric European family, that magic could happen when foods were mixed properly and I began cooking, in earnest. I channeled my passions into a culinary career, graduating from the famed Culinary Institute of America. I was diagnosed with various food allergies & sensitivities and ultimately, relapsing-remitting Multiple

Sclerosis after 15 years as a professional chef. I left the industry overnight, to regroup and start anew with access to proper TLC (healthcare benefits) for what was becoming my failing body.

Fast-forward to now, a full 20 years later. I've come full circle, once again a chef, with a "Peak - Performance" fueled approach to my creations in concert WITH my managed illness, a positive outlook and a healthier-than-ever-body."

After meeting with Dr. Bates and discussing the importance of Luteolin, I want to provide you with a way to enjoy a healthy dose!

Here's a Parsley Pesto Recipe to get you started.

3 cloves of garlic

zest of one lemon

1 large bunch of rinsed parsley (while all varieties are high in luteolin, flat leaf has more flavor – let your flavor preference and availability guide you)

1/2 cup cold-pressed olive oil (Olive is higher in luteolin than other heart-healthy oils)

1 cup raw walnuts, sunflower or pumpkin seeds

 $\frac{3}{4}$ teaspoon Himalayan or other quality salt – I also like sea salts $\frac{1}{2}$ teaspoon freshly ground black pepper or 1/4 tsp of a hotter style of pepper for a slight, healthy burn in your food.

Method: Place the peeled garlic cloves in a food processor fit with the S-blade. Process to chop. Add the lemon zest and parsley and process again. You may need to add the parsley a bit at a time depending on the capacity of your food processor. Process all the remaining ingredients till all the nuts have been finely chopped and everything is well combined. Serve garnished with a drizzle of olive oil to keep that vibrant green surface from browning. Present with a wedge of lemon!

Hint: Dig in AND check your smile for errant green bits in your teeth after enjoying this!

For more recipes from Nina Kauder, visit her blog at: www.rawsomeeats.com or visit www.facebook.com/RawsomeEats

Tisch MS Research Development Department News

We extend our deep appreciation to Joe Renda and his family and friends for organizing a very successful *Cards for a Cure Texas Hold'em* Fundraiser at the American Legion in Whitehouse Station, NJ on October 13, 2012. The event raised a whopping \$15,130 for MS research. Dr. Andrew Sylvester attended the event along with a large group of supporters enthusiastic about supporting our mission and Joe.

Patient Fundraising Campaigns and Events

Thank you and Congratulations to our patients who create ingenious ways to raise money!



Many Thanks to . . .

Board Member **Meredith Berlin's** new passion is designing and creating jewelry. On October 14th, Guilded Lynx in Ridgefield, CT hosted her first trunk show. 50% of all proceeds of Meredith's jewelry sales were directed to her other passion— Tisch MS Research. She raised \$1,660 from this initiative.

On Sunday, November 18th, 2012 **Dawn Madell** ran the Philadelphia Marathon and donated the entire \$2,481 that she raised to Tisch MS Research.

Also in November, **Michelle Rafanelli** hosted an Open House in her home in Rockaway, NJ that raised \$1,078. We are grateful for the following thoughtful and dedicated individuals who took the initiative to raise money for the Center in 2012 through their own fundraising campaigns:

Noel Charbonneau Jennifer Cott Sheryl David Allison Laidlaw Paul Lattanzio Bernadette Mariani Elizabeth Maslow Montesano Susan Putman Jack Rubin Betty Ruder Greta Rubin Schwartz Mindy Silverman Carol Swidler

Shop Online for Tisch MS Research: Gifts that Give

Giftsthatgive.com is a shopping website that will give 20% of purchases to your designated cause. Just type "TISCHMS" in the search box on the home page and shop away! Other shopping sites on which Tisch MS Research is registered include: igive.com and givebackamerica.com.

COCKTAILS FOR A CURE SAVE THE DATE!

Greenwich Village Country Club Friday, April 26, 2013 at 6:30pm Buy your ticket today at: Cocktailsforacure2013.eventbrite.com

The Tisch MS Research Center of New York recognizes its contributors for their generous support that allows its research to make a significant impact on the field of MS.

\$10,000 +

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The Development Office can be reached by calling Kimberly Woodward, Development Manager at (646) 557-3863/kwoodward@tischms.org





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