



**UPDATES ON  
MEDICARE FROM  
YOUR SOCIAL WORK TEAM**

ISSUE 22 | VOLUME 3 | Winter 2013



**GET INVOLVED IN A  
CLINICAL RESEARCH STUDY**

# Healing MS

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



**VITAMINS:  
WHAT'S IN IT FOR ME?**

**Tisch MS Research Center of New York produced twelve abstracts accepted for presentation at the 66<sup>th</sup> American Academy of Neurology (AAN) Annual Meeting**

The American Academy of Neurology meeting is the world's largest gathering of neurologists featuring breakthrough scientific research. It's to be held between April 26th and May 3rd, 2014, in Philadelphia, PA. **"Twelve accepted submissions at the AAN is a record for Tisch MS in its nearly 10 years as an independent research institution, and serves as both a confirmation and reflection of the dedication of our scientists and support staff to discovering the cause of and cure for multiple sclerosis,"** said **Dr. Saud A. Sadiq.**

Here is a brief overview of the research being presented through our abstracts. Two accepted studies continue our important work on Fetuin-A as a biomarker of MS disease activity, as well as new research on Fetuin-A in grey matter. Other research involves mesenchymal stem-cell derived neural progenitor cells (MSCNPs)— the type of cell we will be using in our upcoming clinical trial – in a variety of applications. Another interesting abstract is on immune reactivity to certain viral antigens in the central nervous system, as part of our ongoing research into the cause of MS. We will also be presenting abstracts on biomarkers of aggressive vs. benign disease, animal models of progressive disease, and possible neurological worsening in response to the drug Tecfidera.

In addition to preparing for the annual conference, Tisch MSRCNY researchers have more exciting news. The work of the research team headed by Andre Mueller, PhD., culminated in the publication of an article in *Frontiers in Molecular Neuroscience* and the work of the research team headed by Massimiliano Cristofanilli PhD., culminated in the publication of an article in *Neuroscience*. Summaries of these publications can be found in [Lab Research](#) continued on page 2.



#### International Multiple Sclerosis Management Practice

**Saud A. Sadiq, MD**  
Director

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Lee J. Seidler

## Thank you, Lee Seidler

In 2005, Dr. Sadiq shared with Lee his vision of building an independent research center in concert with a world class medical practice. Lee agreed to guide his mission by offering his over forty years of experience in corporate finance, financial analysis, accounting and taxation. He spearheaded the effort by the Board of Directors, obtained the necessary funds to open the Center in 2006 and worked with attorneys to establish it as a Sec. 501(c)(3) not for profit organization.

With the Center fully operational, Lee's significant contributions continued as he worked tirelessly to bring resources to the Center, raise its public profile, build and expand its Board, provide financial advice and guidance, work with auditors, and manage board matters, in addition to donating over \$2.5 million to keeping the facility financially viable. Under his leadership, and because of his generosity, the Center has become part of the largest MS research and treatment center in the world.

In November of 2013, the Tisch MS Research Center of New York announced that the Center's Chairman of the Board of Directors, Lee J. Seidler, stepped down after eight years of service and will continue to serve as Chairman Emeritus. David Greenstein has taken over as Board Chairman.

Lee and Dr. Sadiq have known each other for sixteen years. Lee met Dr. Sadiq in 1998 at St. Luke's Roosevelt Hospital Center, when his wife Lynn became a patient. Lynn passed away in 2004, from causes other than MS.



Lee J. Seidler with co-founding Board members Bill and Betty Ruder

"Lee has been a tremendous leader and friend without whom many of our research endeavors wouldn't have been possible. He has selflessly given of his time and sacrificed countless weekends working on our behalf. He recruited to the Board, several of our current members. We look forward to his continued advice, support and participation on our Board in his new role as Chairman Emeritus," said Dr. Saud A. Sadiq.

## Clinical Research

### Stem Cell Trial Update

Following FDA approval for the enrollment of twenty patients with a confirmed diagnosis of primary or secondary progressive MS this past August, Tisch MS Research Center of New York is moving forward with the Phase I safety and tolerability clinical trial of intrathecal administration of mesenchymal stem cell-derived neural progenitor cells. Patient enrollment began in January 2014 and will continue at a steady pace until all twenty subjects have been enrolled. There is no formal application or pre-enrollment process for inclusion in the study; positions in the study will be offered to IMSMP patients on the basis of a consensus decision by our neurologists, and those selected will be notified as soon as an enrollment date is chosen for them. As we lack the output capacity of a commercial pharmaceutical laboratory, we ask for selected subjects' continued patience as we proceed to enroll and treat patients as quickly as possible. Further updates to the status of the trial will be promptly reported at [www.tischms.org](http://www.tischms.org).

### Control Volunteers Needed!

Tisch MSRCNY 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. Please contact our Clinical Research Assistants Daniel Koffler or Sydney Chirls at (646) 557-3852 and (646) 557-3860, to get involved.

## Lab Research cont'd

Mueller A.M., Nassery A., Conlon H., Liu X., Jun E., Yoon B., Cristofanilli M., and Sadiq S.A. Effects of intraventricular methotrexate administration on Cuprizone-induced demyelination in mice. *Frontiers in Molecular Neuroscience* 6(34): 1-10, 2013.

**Summary:** In general MS patients with progressive disease respond poorly to anti-inflammatory therapies. In order to better understand the mechanism by which methotrexate is protective in progressive MS, Dr. Mueller and his team analyzed its impact on an animal model in which CNS demyelination occurs in the absence of inflammation. Methotrexate reduced the development of CNS damages and interfered with processes leading to scar formation in MS patients without affecting repair processes.

These findings suggest that methotrexate interrupts non-inflammatory pathological processes within the CNS.

Cristofanilli M., Cymring B., Lu A., Rosenthal H, Sadiq S.A. Cerebrospinal fluid derived from progressive multiple sclerosis patients promotes neuronal and oligodendroglial differentiation of human neural precursor cells *in vitro*. *Neuroscience* (2013) DOI: 10.1016.

**Summary:** This paper found that cerebrospinal fluid (CSF) from multiple sclerosis patients has the important capacity to influence neural precursor cell (NPC) fate. NPCs exist naturally in the brain and they have the capacity to self-renew and differentiate into neurons, oligodendrocytes, and astrocytes. This ability is thought to be essential to promote CNS repair after injury.

Dr. Cristofanilli's research revealed that *in vitro* CSF from progressive MS patients reduce the proliferation of NPCs and increase their differentiation towards neuronal and oligodendroglial cell fates. These findings suggest that the CNS of progressive MS patients is geared towards regeneration and repair, although it is not yet evident which factor(s) are preventing these regenerative mechanisms from overcoming the disease.



## A Note from the Nurses: Prescriptions

Here at the IMSMP we try to make prescription refills as easy as possible but we know there can still be a lot of questions. Here is a quick guide to how different types of prescriptions are processed:

### Refills of non-controlled substances

Requests are called in by the patient to the prescription line or called/faxed in by the pharmacy. The request will be filled the same day if submitted by 3pm. The prescriptions are processed through the pharmacy and through your insurance. Your insurance may require a prior authorization at this time.

### Refills of controlled substances

Requests are called in to the prescription line by the patient or the pharmacy. The prescription is then written on the prescription pad (per Federal Law) and mailed to either the patient or the pharmacy. Please allow one business week for delivery.

### New medications or a change in dose

Requests must be called in to the nurses' phone line by the patient. The nurse then speaks to the doctor regarding the need for new medication or a change in medication. If the prescription is deemed medically

necessary by the doctor it is called into the pharmacy or mailed if a controlled substance.

### Disease modifying therapies

These prescriptions usually have a few more steps involved. For most, there is a start-up form that the patient and doctor must sign. This is then processed by the drug manufacturer and sent to the appropriate mail order pharmacy after investigating the patient's insurance. Once the pharmacy receives the prescription they must then determine if an authorization is needed and contact us.

This process can take a few weeks or longer depending on the insurance.

### Specialty medications

These medications are generally filled by a mail order pharmacy and require prior authorization. Make sure you request refills about 2 weeks prior to running out to allow time for shipping and prior authorizations if needed.

### Infusions

Beginning a new infusion medication can take some time. Certain medications are not initially covered by insurance and require not just a prior authorization but also a number of appeals. With some medications,



such as Rituxan, this process can take months. Please be patient. Our hands are often tied because we must wait for the insurance company to issue the denial in writing before we can appeal. Authorizations for Rituxan can only be done by our office if you are infusing at the IMSMP.

### A note about prior authorizations (PAs)

PAs are required by insurances for many drugs including specialty medications and those not on the preferred drug lists. The process for PAs is as follows: the nurses are informed by the pharmacy that a PA is needed; the nurse calls the insurance and requests a PA form be faxed to our office; the form is then filled out, signed by the doctor at the end of the day, and faxed back to the insurance company. The insurance can then take up to 72 hours to process the request and issue their decision. IMSMP policy is that PAs are always done via fax in order to ensure that all questions are addressed appropriately and thoroughly.



## Should I Take Vitamins?

Several recent studies, including those published in the high-profile medical journal, the *Annals of Internal Medicine*, have sparked a discussion about the value of taking vitamin and mineral supplements. In summary, these studies showed that, for **healthy adults** without any **known nutrient deficiencies**, supplementation did not seem to increase lifespan or prevent heart attacks strokes

## News on Naturopathy

or cognitive decline. However, a mild but statistically significant reduction in cancer risk was observed for men.

An editorial entitled "Enough Is Enough: Stop Wasting Money on Vitamin and Mineral Supplements" was published in the same issue of this medical journal. While these studies and the editorial do raise valid concerns, the headline grabbing title fails to convey the nuances of vitamin and mineral supplementation, including the range of risks and benefits for real people.

Here are some important points for discussion:

- Medical study design and data interpretation are complex topics. Studying a population of well-nourished

adults does not necessarily allow us to draw conclusions about vitamin and mineral supplementation for everyone, certainly not for people with specific health issues or those with less than healthy diets.

- A healthy and balanced diet is the best source of nutrients. A pill that includes a selection of synthetic nutrients will never replace the nutritional complexity of real food. Vitamins and minerals in food are coupled with other dietary components like fat, fiber, protein, and numerous other biologically and medicinally active molecules that may have synergistic value.

[Continued on next page](#)



### Should I Take Vitamins cont'd

- Multivitamins are not necessary for everyone. The purpose of supplementation is to fill in nutritional gaps. Certain dietary restrictions and health conditions increase the potential benefits of supplementation for individuals.
- Not all supplements are created equal. The dose, formulation, bioavailability, and purity of different brands are highly variable. High quality supplements used in appropriate doses provide optimal benefit.

While vitamin supplements, used appropriately and tailored to the individual, can contribute to improving wellness and managing diseases, including multiple sclerosis, taking vitamins in lieu of other treatments is far from ideal care. In the case of MS, this choice could lead to disability that would have been preventable with appropriate medications.

At the IMSMP, our Center's philosophy is that integrative care is the best approach to managing MS. This includes using appropriate medications along with holistic approaches like diet, supplements, and lifestyle modifications (such as sleep and stress management) to provide our patients with the best care possible for living well with MS.

In conclusion, if you are interested in taking vitamin and mineral supplements, consult with a professional trained in nutritional medicine to individualize and optimize your supplement program, and coordinate it with your medical care. Naturopathic Doctors are the professional experts in nutritional medicine, requiring four years of medical training in order to use supplements, along with diet and medications, to benefit patients' overall health and treat disease. At the IMSMP, our Naturopathic Doctor, Deneb Bates, partners with the MS neurologists to provide holistic integrative care for people with MS.

Do you want to receive emails about the latest research, treatment and ways to heal? Please help us in our effort to collect email addresses and alert our patients, friends and supporters of everything happening at Tisch MSRCNY. Send your name and email address to: [newsletter@imsmp.org](mailto:newsletter@imsmp.org)



## Social Work News

Do not let these important opportunities pass you by



If you are no longer working because you are disabled from MS, you should apply for **Social Security Disability (SSD)** before it is too late. In order to be approved, you must show that you have worked for 5 out of the last 10 years, AND are completely unable to work because of your MS. If you miss that window, you may not be entitled to Social Security or Medicare until you are of retirement age.

When you first become eligible for Medicare, you have 6 months to apply for a **Medigap/Medicare supplement** insurance plan. These are the plans that pay the 20% that Medicare does not. After these 6 months, in most cases, you no longer have a right to buy these plans which can be very valuable in your MS care.

### Affordable Care Act Update

As we reported in the last newsletter, the Affordable Care Act (ACA) began enrolling members in insurance plans in October, with coverage beginning as of January 1<sup>st</sup>. The social work department remains engaged in learning about the plans and the effects they may have on the care of people with MS around the country.

In New York, none of the individual plans offer out of network benefits, making these plans impractical for much of the care at the IMSMP. We have learned, that other states, including NJ, PA, CT and NC, are offering PPO options, which do offer out of network benefits. We do not yet know, however, how well these plans are working for patients, as they have only been in effect for a short period of time. We will continue to monitor the ACA and make information available to our patients as it becomes available.

If you have any questions about any of the information in this column, please feel free to call the social work department at any time at: (212) 265-8070.

## PT: Addressing Rehab Needs in 2014. It's not "just exercise."

As research progresses in finding the cause of and cure for multiple sclerosis, it is as important as ever for patients with MS to review and update their physical wellness program. In some cases, patients who have a regular routine should have a physical or occupational therapist (PT or OT) determine how it can be upgraded to allow for greater neuromuscular benefit. In other cases, patients who have stopped or slowed in their exercise program need to re-dedicate themselves to a program that is structured for their specific needs.

Movement and exercise can be described by patients as "hard" or "fatiguing," but it must be understood that immobility or only moving when absolutely necessary can be as debilitating as the disease itself. A great start for a physical wellness program can include only a few stretches, standing for periods of time, and/or walking outdoors for a couple of minutes every day.

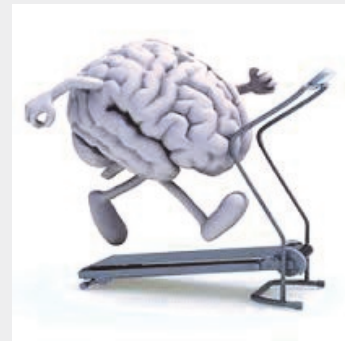
A program must include activities that are done every day. On the days when you work with a physical therapist or trainer, the activities can and SHOULD be at a higher level of challenge that you would not be able to perform on your own. If you are only being put on machines, it may be beneficial to look for a PT who will focus more on neuromuscular exercises. As a service to our patients, the IMSMP physical therapists are available to speak with your local PT or OT regarding optimal exercises and plans of care.

Since most patients will not be eligible for having therapy covered year round, it is important to schedule therapy sessions in a manner that will not result in you "running out" of PT by the summer.

Medicare beneficiaries should be aware that there are a finite number of sessions that therapists will be able to provide during a year.

Along with performing a formal and focused physical activity program every day, patients who have needs for assistive devices such as canes, crutches, and walkers and are Medicare beneficiaries should be aware of the new policies in place regarding securing these devices. Now in 2014, Medicare beneficiaries (as well as some patients who have commercial insurance) can no longer get their walking device from any surgical supply store or vendor; these devices must be processed from specific companies for them to be eligible for coverage. This is also true for patients who would benefit from a scooter, but may not be true for customized power wheelchairs. To best determine which walking device, scooter or wheelchair is appropriate and to upgrade or restart your physical wellness program, schedule an appointment to see Dr. Kanter or Dr. Woods.

It should be understood, that being on the right medical treatment is only one part of the overall care for MS. Exercise is an integral component not only for being able to move as safely and independently as possible, maximize your quality of life, but also for cognitive wellness.



## More News on Exercise and Cognitive Functioning

You may recall the article in last winter's issue, that evidence from several studies illustrated that exercise shows promise in preserving and improving cognitive functioning. Physical activity also has been shown to provide benefits in the quality of sleep and emotional well being in older adults. We've written about a study that demonstrated exercise is associated with increases in brain volumes, particularly in the areas associated with memory.

A recent publication in the *Journal of Neurology* (Sandroff et al., 2013) adds to the evidence on exercise and improved cognitive functioning. A randomized controlled study of 82 participants compared two groups of patients, those in the walking/exercise group versus those on a wait list (the control group), all having mild to moderate disability. The researchers examined the effects of an internet based, one-on-one video chat/coaching session for behavior change to increase physical activity over six months. All participants completed a baseline and 6-month evaluation of cognitive processing speed and the 6-minute walk test as well as self-report measures of physical activity and disability status.

All participants could walk either with or without an assistive device and at baseline were getting under 60 minutes of physical activity per week.

**Effect of exercise:** As expected, participants in the exercise group, all having the individualized internet sessions, demonstrated an increase in physical activity after six months. Consistent with other studies, some of the participants in the wait list group showed a decrease in physical activity over the same six months.

**Effect on cognitive processing speed:** After six months of increased exercise, participants with mild disability demonstrated a moderate increase in cognitive processing speed (CPS). Those with moderate disability and all those in the control condition showed minimal change in CPS.

**Effect on six minute walk (6MW):** At baseline, there were no statistically significant differences between the exercise and control groups on distance of a 6MW. However, all participants in the exercise group showed an increase in 6MW distance, regardless of disability, while there

was a small decrease in the distance walked among the control participants.

This study is one among the emerging data on cognition and exercise specific to patients with multiple sclerosis. The results demonstrate improvements in cognitive processing speed among those with mild disability. Moreover, the increase in CPS was very significant, well above the value that indicates clinical meaningfulness in daily activity. There was also a relationship between physical activity and CPS such that greater increases in physical activity produced greater improvements in processing speed. Do not overlook the finding in this study that people in the wait-list group demonstrated a *decline* in their six minute walk over six months. Their physical activity level declined over the interval by just waiting. Overall, the evidence demonstrating the positive effects of physical activity on cognition is continuing to mount! Remember, our Director of Physical Therapy, Dr. Stephen Kanter, can develop an appropriate exercise program for any patient with MS!

## Tisch MS Development Department News

### Tisch MSRCNY Announces Indiegogo Social Media Fundraising Campaign for the Stem Cell Trial

Do you use social media? Would you like to raise money for the stem cell study? Join us! The Tisch MS Research Center has launched its first social media fundraising campaign through Indiegogo.com. This "crowdfunding" website enables people to donate to important causes via resources like email, Facebook and Twitter.

New Board Chairman David Greenstein is leading this project as his inaugural fundraising initiative to raise both funds for and awareness of the stem cell study. We hope that our patients, their family members and friends will get involved and help spread the word! If you are interested in learning more about this campaign, please contact Sophie Deprez at: [sdeprez@tischms.org](mailto:sdeprez@tischms.org) or (646)-557-3861.

### High Schoolers Work Hard to Raise Funds

*Dear Dr. Sadiq,*

*My name is Shannon Drury. I am Marybeth Schifano's niece from Long Island. I have seen my aunt struggle through the years with her MS, so the stem cell treatment clinical trial is an eye-opening breakthrough that has excited my family.*

*I attended the Symposium in October of 2013 and wanted to help my aunt and the Tisch MS Research Center raise money for the first 20 patients.*

*On December 7<sup>th</sup>, the Half Hollow Hills High School West basketball team, along with the Varsity Sports Club, held a fundraiser for Tisch MSRCNY. We raised a total of \$1,000 towards the stem cell study.*

*I would like to personally thank the Center for the many years of attention and care it has provided to my Aunt Mimi.*

*Thank you,  
Shannon Drury*

We thank Shannon for sharing her inspiring letter and for appealing to her high school basketball coach to request that proceeds from the annual Coaches for a Cure basketball tournament fundraiser be directed to Tisch MSRCNY.

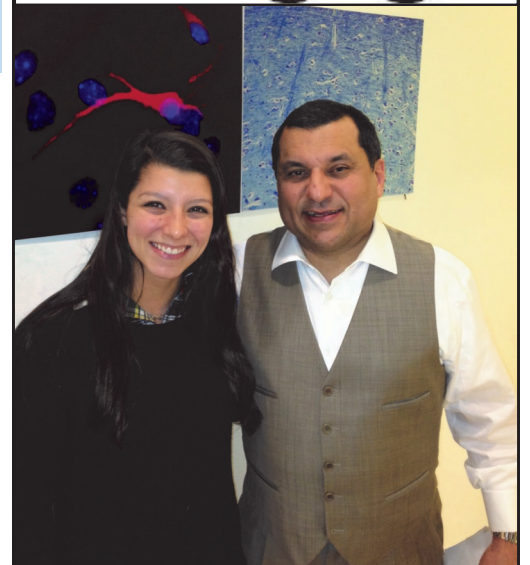
### Thank You Carly Maitlin!

Millburn High School Junior Carly Maitlin hosted an event and raised \$1,400 for the Tisch MS Research Center in honor of her friend Lauren Meisner, a patient at the Center.

The Development Department is available to provide support and resources to help you raise money for the Center. Please contact Kimberly Woodward, Development Manager, at (646)-557-3863 or [kwoodward@tischms.org](mailto:kwoodward@tischms.org) if you would like to get involved.



indiegogo



Shannon Drury with Dr. Saud Sadiq



Lauren Meisner with Carly Maitlin



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in honor of Howard Wodin  
Denise Yazdanfar

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