INTERNATIONAL MULTIPLE SCLEROSIS
Management Practice

Winter 2014
Volume 3, Issue 26

Healing MS

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

TISCH MSRCNY FACES FUNDING CRISIS FOR EXPERIMENTAL RESEARCH FACILITY

We are currently the only center in the United States that is conducting an FDA approved clinical trial using stem cells in patients with MS. The goal of the Phase I trial is to determine whether or not the therapy is safe and effective. We hope that this will lead to additional future trials and that with our concurrent research, the reversal of disability will become a realistic therapeutic objective.

Achieving our goals requires us to overcome two immediate hurdles. The first is the closure of the animal research facility which we are currently using, scheduled to occur on May 31st, 2015. This facility is located less than a block away at Roosevelt Hospital, and its closure is a result of Mt. Sinai's recent acquisition of St. Luke's Roosevelt Hospital Center. Unfortunately, it could not come at a worse time for us as animal research is a critical component of all of the work at the Center, and especially of our stem cell program. The second critical issue is the need to expand our regenerative disease program, in particular, our stem cell facility.

Having previously anticipated our needs, we have 10,000 square feet of undeveloped space on the third floor of the Tisch MS Center slated to be an expanded research facility. This new site will be designated as the Institute for Experimental and Stem Cell Research at the Tisch MS Research Center of New York. The cost of the project is roughly $10 million, and construction is expected to take 16 weeks and will commence as soon as funding is secured.

In order to continue our trend of surpassing our academic goals, Tisch MSRCNY urgently needs to begin the rapid development of the area on the third floor in order to ensure that our studies carry on without devastating interruptions or delays. We are asking all of our friends, family, advocates, donors, and supporters to please consider making a gift so we can move ahead with our research plans.

Thank you for your consideration.

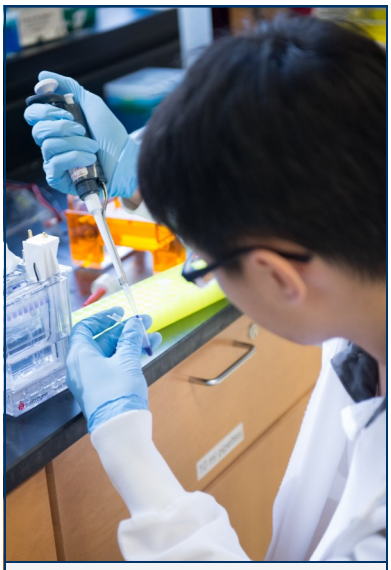
TISCH MS
RESEARCH CENTER OF NEW YORK

FOLLOW US ON FACEBOOK

SHARE OUR NEWSLETTER

DONATE TO RESEARCH

INSIDE THIS ISSUE



Pak Ho Au, Research Assistant

CLINICAL RESEARCH

The IMSMP is now providing information for iConquerMS™, a program associated with the Accelerated Cure Project. iConquerMS™ allows patients to independently enter their health information into a secure online database, where it will be analyzed in conjunction with that of thousands of others living with MS. In their words:

"iConquerMS™ is a novel way to fight multiple sclerosis, empowering people living with MS to securely contribute their health data and ideas to advance research. iConquerMS™ is part of a national research network, called PCORnet, that will enable collaborative partnerships to improve healthcare and advance medical knowledge in ways never before possible in the United States."

Pick up a flyer at the front desk or in the infusion suite, or visit the website: www.iConquerMS.org to learn more. Any questions or concerns should be directed to the iConquerMS™ group, reachable via e-mail: iConquerMS@acceleratedcure.org and phone: (844) 897-1211.

Tisch MSRCNY is currently the only research laboratory in the United States conducting an FDA-Approved Phase I Clinical Stem Cell Trial for MS

pictured above: some of your IMSMP Nurses

* Our nursing team suggests that you take prescriptions for blood work and/or urinalysis and urine cultures to your local Quest Diagnostics or LabCorp if possible. By using these laboratories, we are able to access your test results easily so that we can quickly provide more efficient quality care.

* When calling the nursing phone line, please indicate whether or not it is okay for us to leave a detailed message on your voicemail, or if you would prefer that we simply state that we are returning a call from your doctor's office.

TIPS FROM THE NURSING TEAM

At our Center, ongoing routine blood work is required before starting and while taking various medications in order to properly monitor patients and to ensure their safety. With Tecfidera, an oral medication which was FDA approved in 2013 for the treatment of multiple sclerosis, our doctors require each patient to have a liver function test and complete blood count to screen for lymphopenia (a low lymphocyte count which can be an adverse reaction to the medication). This should be done prior to starting treatment and repeated every 2 months for the first 6 months of treatment and every 6 months thereafter. Our nursing team keeps track of when each patient is due and we ask that upon receiving a blood work prescription in the mail, that you have this done in a timely fashion. For your safety, it is very important to have up-to-date blood work in order for us to continue prescribing your medication.

Aubagio is another FDA approved oral medication for the treatment of multiple sclerosis. Since Aubagio inhibits the replication of rapidly dividing cells, including immune cells, our office requires that patients have a TB skin test done prior to starting this medication, unless otherwise indicated by your doctor. Additionally, our office requires liver function tests and complete blood counts to be done before beginning this therapy as well. We are now requiring that this be done monthly for the first 6 months of therapy. After 6 months, this blood work will be required intermittently.

In addition, it is important to be aware that Aubagio has been classified as a pregnancy category X medication meaning that it is extremely toxic to a fetus. It is imperative that responsible birth control measures must be taken while on this medication. If you are on Aubagio, and family planning is in your near future, male or female, please call our nursing line and inform your doctor.

Our nursing team is always here to assist you in any way that we can!

WHAT IS LEMTRADA ?
BY DR. ANDREW SYLVESTER

Alemtuzumab, or Lemtrada, was approved for use in multiple sclerosis in November of 2014. Lemtrada has an extremely robust benefit for multiple sclerosis and is administered intravenously as one course per year, but is limited by the frequent occurrence of substantial side effects. Lemtrada is not a new drug, as it has been used as a cancer treatment for more than 10 years for chronic lymphocytic leukemia, T-cell lymphoma, and cutaneous T-cell lymphoma under the trade names Campath, Campath-1H, and MabCampath. It is comprised of one type of unique antibody (monoclonal) which is designed to attach to and destroy major components of the immune system called lymphocytes. Types of lymphocytes include B-cells and T-cells. Other treatments for MS are known to impact B-cells, T-cells, or both. Lemtrada eliminates both types of cells from the body and has a prolonged effect. The treatment protocol is to infuse Lemtrada once daily for 5 consecutive days, and then to repeat each year with 3 consecutive days of infusions. Even though the medication course is administered annually, the duration of the effect on the immune system is typically prolonged, sometimes more than 2 years.

The benefits of Lemtrada are impressive. In two 2-year studies in which Lemtrada was compared to Rebif, relapse rates were decreased by an average of 50% compared with Rebif, and more than half of the patients were relapse-free. In one trial, disability was improved by 42% for Lemtrada patients while worsening occurred in Rebif patients. MRI measurements on new lesions were also impressive. Thus, Lemtrada has an efficacy seen only with the most beneficial therapies.

Side effects with Lemtrada were significant and concerning. Most patients experience at least one adverse event. Reactions during the infusions were common and included low blood pressure, shortness of breath, chills, rashes, fevers, and itching. Infections were more common and there is potential for serious infections such as herpes simplex and zoster (shingles). Most concerning was an alarming rate of autoimmune diseases caused by Lemtrada. Roughly 34% of patients developed autoimmune thyroid disorders including hypothyroidism, hyperthyroidism, and Grave's disease. The majority of those who developed these conditions ultimately required chronic medical therapy, while some also required surgical intervention. Other rare autoimmune conditions included glomerular nephropathies (a kidney disorder) and immune thrombocytopenia or low platelets (a component of blood involved in clotting). There is also a concern for the occurrence of certain forms of cancer. The risk of serious side effects over several years necessitates close and diligent monitoring of blood and urine measurements for 48 months after a patient's last Lemtrada infusion.

Given the high risk-high reward nature of Lemtrada, the availability of other treatments for MS, and the expected FDA-approvals of other impressive and safe options for MS in the near future (Ocrelizumab and Daclizumab), it is the opinion of the doctors at the IMSMP that the use of Lemtrada will be limited to patients with extremely aggressive multiple sclerosis who are experiencing rapidly advancing disability and do not have other treatment options available. Our approach will be to administer one course of Lemtrada to get the disease under control reasonably quickly and serve as a bridge treatment as we then switch to another that is safer in the long term. We anticipate prescribing Lemtrada for only a handful of patients in the manner described above.

For patients interested in learning more about Lemtrada, we encourage you to ask your neurologist at your next appointment. We also plan to discuss Lemtrada at our next MS patient symposium on October 18th, 2015.

Andrew Sylvester, MD

*Due to Lemtrada's prolonged effect on the immune system, it can potentially limit the options available to use in the future with additional treatments for multiple sclerosis, cancer, or other immune diseases that may arise. Meaning, if Lemtrada is not working adequately in a given patient, or a patient develops other medical conditions that require intervention of medications that affect the immune system (such as cancer), the safety of adding other treatments may be limited due to an interaction with Lemtrada. Also, Lemtrada is not safe in pregnancy.

Evelyn Schroeder, RN

A NOTE FROM EVELYN . . .

To all our wonderful patients, I want to let you all know that I have retired as of 12/31/14. I am sorry I wasn't able to tell each of you personally. Please know that I leave with a heavy heart as I have been honored to be a part of your lives for the past 13 years. I have been blessed to be allowed to share your joys, triumphs, heartache and heartbreak with all of you. You have all taught me so much. I truly admire your positive spirit, your inquiring minds and your willingness to keep moving forward trying new treatments and medications. Your families have taught me how to over-come adversity with love and to always see beyond the disease to the person inside. I leave you with your excellent physicians and a great team of nurses. They will all continue to take great care of you. I will miss you all.

Love,
Evelyn

SOCIAL WORK NEWS

Resource Manual Coming Soon!

The social workers at the IMSMP have a collective 27 years of experience amassing knowledge about living with MS. They have been collecting and organizing all of the resources they have found over the last 12 years into a comprehensive *MS Resource Manual* for the patients and families of our Center.

The full resource manual is expected to be ready for your use in Spring of 2015, and will be available on our web-site. We will also mail, e-mail or hand you chapters on specific subjects of interest to you as a supplement to your meeting or phone consultation with one of our social workers. From our website as your home base, you will also be able to navigate quickly and easily to recommended websites and download necessary forms to apply for resources and benefits.

Since the information and resources are always changing, the primarily web-based content of our manual will enable it to be updated frequently to remain current.

Some topics that are included in the manual are:

- Insurance
- Housing
- Accessible travel
- Attorneys with MS experience
- Disability

Check our website and Facebook page regularly to download the manual when it launches!

FROM THE MRI SUITE

Did you know the MRI suite is open on Saturdays?

Our state-of-the-art MRI department has been accommodating patients on Saturdays as part of its commitment to unparalleled healthcare.

Our facility is equipped with two 3 Tesla MRI scanners, along with special features in MRI rooms, such as the music of your choice and a soothing atmosphere.

The IMSMP has made it even more convenient for our patients who are unable to have their MRIs performed during the week to now secure an appointment on a Saturday. Please be sure to speak with a member of our courteous and experienced MRI staff about your insurance before scheduling your visit. They can also assist with any special needs you have. Schedule your MRI by calling (212) 265-8070.

FOLLOW US AT FACEBOOK.COM/IMSMP

INFUSION SUITE REMINDERS

When receiving an intravenous treatment at the IMSMP Infusion Suite, please only bring one family member or friend to accompany you. We are extremely busy and cannot accommodate more than one additional person per patient.

If your infusion is more than 3 hours long, we recommend bringing lunch with you. The clinical staff in the infusion suite must be available to patients infusing at all times and therefore cannot order meals or leave the suite to pick up deliveries.

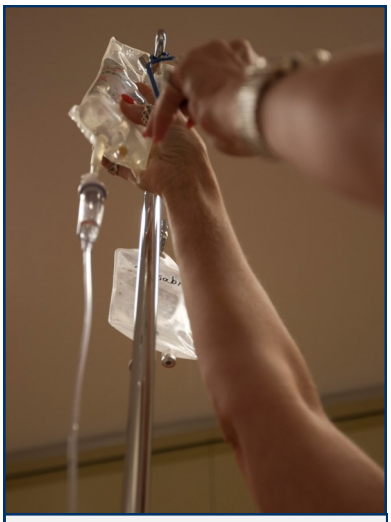


photo courtesy of Alden Reiss

FROM YOUR PHYSICAL THERAPISTS

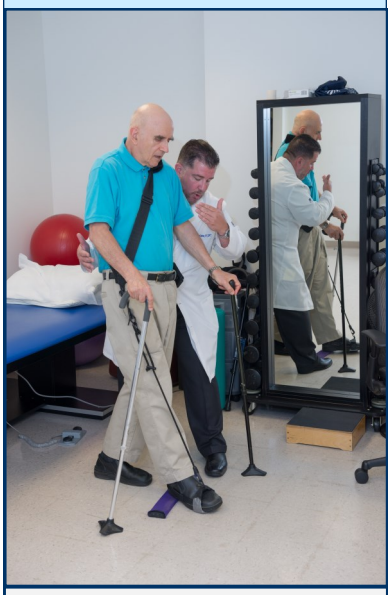
In the context of physical therapy and wellness at the IMSMP, we take a multi-faceted approach in treating each individual who enters our department. As most of the patients who have worked with Dr. Kanter and/or Dr. Woods have come to realize, the PT evaluation and re-evaluation visits act as a new beginning toward developing real and meaningful goals for the individual. Physical therapists are educated to determine levels of physical impairment and how they limit activity and independence.

Activity and participation are key components to what disability means for a person with any impairment, regardless of the reason. The focus of a physical therapy and wellness program for people with MS includes a pre-habilitation component (addressing the potential impairments that can be caused by MS) and a re-habilitation component (addressing recent worsening of symptoms or impairments with efforts to recover function). These components can and should be implemented simultaneously by a therapist willing to listen and work toward your functional goals.

The easier part of a physical therapy program is identifying exercises and activities to maximize independent and safe function. The hard part is for patients with MS to recognize how they can optimize their potential to reach maximal independence and safe function. At times, the "how" part refers to use of assistive devices such as canes or a walker. In some cases, the use of these devices is not necessary for everyday life, but is important to maximize function and to reach personal goals.

When it comes to physical disability, the definition does not state that you are not permitted to use assistive mobility devices. It does, however, refer to decreasing involvement in "the external world" and decreasing social interaction. You may realize now that there is an intimate link between your personal behaviors and desires and the definition of disability.

A case example I commonly share with patients is the person with MS who uses a walker or scooter for mobility, depending on situation, who goes to events that take place with family and friends and travels the world with other people who use walkers and scooters. Then I ask whether this person is more or less disabled than another person with MS who has difficulty walking and has fatigue with walking who refuses to use any assistive devices and chooses to avoid activities that require walking and, thereby, does not go on desired trips or social functions. Who do you think is the one more impacted by his/her disability?



Dr. Stephen Kanter performs a neurorehabilitation technique with patient, Harvey Geisler

Durable Medical Equipment

YOUR CHOICE IN WHEELCHAIR VENDORS

Over the past several years, the process for a patient to get a new wheelchair, scooter, or other equipment – referred to as Durable Medical Equipment (DME) has become more challenging in many ways. A simple letter or note from your physician or physical therapist is no longer acceptable. There are strict criteria for eligibility, which has resulted in the process becoming a lengthy one.

The IMSMP wants to remind you that we have no affiliation with any wheelchair clinic or DME vendor that you work with during this process. It is your choice who you want to work with. While our staff will offer the options of potential vendors to use, it is important that you choose a quality vendor that will work with you about your DME eligibility and is able communicate with our office about what is needed to process your order.

If there are documentation needs and/or you are having issues with getting needed DME, it is recommended that you contact the IMSMP to speak with one of our physical therapists. In some cases, you will also need to come into the IMSMP for a clinical visit to meet the eligibility requirements for your DME order. Please help us to help you in getting your equipment as quickly as possible.

The IMSMP offers a Naturopathic Doctor on staff as part of our holistic approach

A child playing in dirt illustrates the Hygiene Hypothesis

NEWS IN NATUROPATHY

Does living environment increase the risk of autoimmune diseases?

The incidence of autoimmune diseases, such as multiple sclerosis, is rising, and some studies suggest the *"Hygiene Hypothesis"* could be one explanation for this.

The Hygiene Hypothesis refers to the idea that early childhood exposures to foreign microorganisms, including infectious bacteria and parasites as well as those that are beneficial (like probiotics), educate our developing immune systems. It is believed that having this "immune tolerance" makes us less susceptible to both allergic and autoimmune diseases. Thus, adults in industrialized societies might have a greater risk of developing autoimmune diseases as a consequence of being exposed to fewer microorganisms during childhood, because of access to cleaner food, water, and living environments.

A recent study published in the *Journal of Neurology, Neurosurgery, and Psychiatry* supports the relevance of the Hygiene Hypothesis in MS. This study found that women who tested positive for antibodies against *H. pylori* bacteria had a decreased risk of MS. *H. pylori* infection is often acquired during childhood, can be involved in the formation of stomach ulcers, and is found more commonly in developing countries. The authors propose that, while *H. pylori* might specifically be protective against developing MS, *H. pylori* is more likely to be a marker for exposure to a variety of bacteria in childhood; providing evidence for the Hygiene Hypothesis.

The Hygiene Hypothesis and the resulting microbiome (bacteria that share our body space) are particularly exciting topics in research, because they are modifiable through environmental changes, diet, supplements, antibiotics and probiotics. These interventions offer the potential to influence the immune response in people with autoimmune diseases.

To learn more, schedule an appointment with Dr. Bates, IMSMP's Naturopathic Doctor, who works with patients to investigate and balance the microbiome as well as other aspects of health.

TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

Patient Event Highlight:
Harrison Kaplan's Bake Sale

Patient Keith Kaplan shared the following story:

"My 12-year-old son, Harrison (unbeknownst to me) made a presentation to his middle school Student Council requesting that they do a fundraiser to raise money for the Tisch MS Research Center. The Student Council and their advisor decided to hold a bake sale.

During an assembly, the bake sale was announced to the 300 middle school children. They were told that it was Harrison's idea and that the money would go toward Tisch MSRCNY. They also received a brief explanation of MS. The bake sale was January 27th and the results far exceeded my expectations: $300!"

Congratulations to Harrison Kaplan and his successful effort to raise money for the Center and awareness about MS.

THANK YOU TO OUR GENEROUS DONORS*

$50,000 +
Emerald Foundation, Inc.
Noel & Edward Foley

$25,000 +
Arnone, Lowth, Wilson, Leibowitz, Andriano & Greco
Epstein Teicher Philanthropies
Kathy & David Ferguson
Genzyme, A Sanofi Company
Lynn & Paul Lattanzio
Joe Renda, Family, and Friends
Town Fair Tire Foundation
Cara Wagner

$10,000 +
Anonymous
Theodora & Irwin Balaban
Dorothy Berwin
Cynthia Brodsky
Linda Feinberg
David Greenstein & Hillary Mandel
Kimberly Griffiths & Paul Broder
The Howard and Betty Halff Fund of the San Antonio Area Foundation
Harold I. and Faye B. Liss Foundation
Mark Lessing
Helene & Joseph Massimino
McNamara Purcell Foundation
Mellen Foundation, Inc.
The New York Community Trust
Srinivasan Ramiah
Cheryl & Steven Schwartz
Bonnie H. Silverman
Connie Steensma & Richard Prins
Aduke Thelwell
Susan & Stanley Trotman
WebMD Health
Hope & Alan Winters

$5,000 +
Anonymous (2)
Debbie & Glenn August
Cauldwell Wingate Company, LLC
Betsy & John Crosby
Howard & Margaret Goldberg
Gordon Family Charitable Foundation
Colleen & Phil Hempleman
Michael Hirschberg
Jill C. Howard, PhD
Fredy Hunziker
Florence & Michael Mandel, in honor of Steven Mandel
MS Hope for a Cure
Rubenah & Farouk Sadiq
Nancy & Arthur Seter
United States Flavor Corp/ Florence & Michael Mandel
Patty & Russell Wolff

$2,500 +
Anonymous
Robert & Marianne Becker
Mary Ellen & Matthew Clark
Kathy & Tim Davidson
Lisa Grunwald & Stephen Adler
Ruth & George Harms
Tamara & Dan Kilmurray
Joseph & Ann Rehs
Cynthia & Mark Ross
Janice & Barry Satine
TD Ameritrade
Beth & Charles Thoele
Robert Youdelman
Steve Zatz & Deborah Shaw

$1,000 +
Anonymous (4)
Agia Realty LLC
Lorraine Brown
Bruce W. Campbell
Case Pearlman Corporate Benefits
Sarah T. Chase
Mr. & Mrs. Adam Cohen
Cheryl Duckworth
Mike F. Egan
Therese M. Egan
Joanne & Antonio Enea
Mary & Jon Fitzgerald
Robert Gershowitz
Susan & Jonathon Held
Susan & Donald Hill
J. Weinstein Foundation, Inc.
The James O. Robbins Family Charitable Lead Annuity Trust
Jordan Family Foundation
Lawrence Golf Club, Inc.
Lynne Zoltowski Lewicki & Jonathan Lewicki
Lisa Loeffler & Ilya Kaplan
Long Island Community Foundation/NYSSCPA - Nassau Chapter
John & Kristina Macejka
Jennifer & Jay Mantz
Mitchell and Karen Kuflik Charitable Foundation
Richard & Jessica Morris
Vicki Murphy
Caryn & Ken Novick
Tasha & Brian Pannuzzo
Allyson Peltz
Hilary Peltz
Phil Perelmuter
Catherine Pihokken
Linda A. Rock, MD
Jack D. Rubin, MD
Lisa & Randy Russell
Jennifer & Patrick Ryan
Bina & Jayesh Sanghvi
Diane & Robert Sasson
Barbara & Nick Schiff
Mark & Rachel Schlau
Marcie Schultz & Stanley Schulman
Dana R. Schwartz & Joel Sauber
Linda Simon & Kyle Warendorf
Donna Squilla & Bradley Friedrich
Dr. & Mrs. Vincent D. Squilla
Sherry & Ira Stolzenberg
Joseph & Katharine Swift
Mr. & Mrs. Kenneth Weiner

$500 +
Anonymous (5)
Kate Bellucci
Benevolent, Patriotic Order of the United States
Bernard S. Berkowitz
Alan S. Berlin
Mr. & Mrs. Robert Boris
Clean Cut/ Marco
Ryan Corvaia & Maulik Pancholy
Patricia & Darrell De Nooy
Susan Doherty
Linda Donaghue
Steven & Nancy Edwards
FBI New York SWAT Team
Gail & Richard Ginsberg
Richard & Fran Hofstetter
Marilyn & Peter Klein
The Laidlaw Family
Michael Levine & Family
Anne & John Mahaney
Frances & Ivan Moradoff
The Nabama Foundation
Old Oaks Foundation
Maryann Oliver
Adeline & John O'Rourke
Pasadena Community Foundation
Roseanna & Philip Petruzzelli
PGA Tour, Inc
Joseph Piacente
Georgia B. Pollak
Michelle & Joseph Rafanelli
Mr. & Mrs. Arthur Schwartzman
Michael Silberman & Emily Eldridge
Mr. & Mrs. Erik Sorenson
Sterling Pile Fund
Sandra & Frank Stern
Wequassett Resort & Golf Club
Dr. Armistead Williams
Robert Wilmers
Justin Yoon

Matching Gifts
The Tisch MS Research Center received Corporate Matching Gift Funds from:

Allstate
American Express Foundation
Dell
Edward St. John Foundation, Inc.
GE Foundation
Microsoft
New York Life
Traveler's Foundation

The Tisch MS Research Center receives workplace giving funds from the United Way of New York City. Inquire with your employer to participate.

*This list includes donors of $500 or more received between November 1st, 2014 and January 31st, 2015. While every contribution is deeply appreciated, we were unable to list gifts below $500 in this edition due to space limitations.

TISCH MS
RESEARCH CENTER OF NEW YORK

INTERNATIONAL MULTIPLE SCLEROSIS
Management Practice

PLEASE
PLACE
STAMP
HERE

Mailing Address Line 1
Mailing Address Line 2
Mailing Address Line 3
Mailing Address Line 4
Mailing Address Line 5