



AN IMPORTANT MESSAGE FROM YOUR NURSES INSIDE . . .

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Healing MS



NEW CLINICAL RESEARCH STUDIES GET INVOLVED!

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

MRI Suite Opens

“We have now completed the first steps in creating a state-of-the-art MS treatment and wellness center. Offering our patients these services is deeply gratifying.” Dr. Saud A. Sadiq

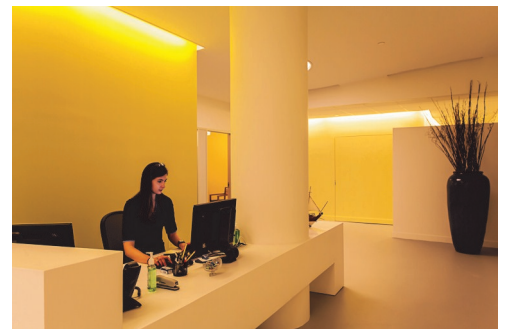
On Monday, March 27th Eve Baxley arrived at the newly renovated 3rd floor of the IMSMP. She was checked in by a patient care coordinator and had her brain MRI with contrast performed. Once the images were captured, Eve headed upstairs where she was greeted by our concierge and taken to her office visit with Dr. Sadiq. Dr. Sadiq already had Eve’s scans opened on his computer and was reviewing them as Eve took a seat. We listened to our patients state the frustrations of scheduling an MRI, attempting to have reports and discs sent to the right location and the lack of assurance that their

doctor receives these important scans in a timely fashion. “I’ve had several MRIs and never in my time of having MS have I experienced anything like this.” said Eve. “From the moment you walk in the room, the staff guides you are at ease and even played my favorite music. The high-tech machine itself is comfortable and spacious and the room was so peaceful—I almost fell asleep. I came out thinking, did I just have an MRI?”

For more on the MRI Suite turn to page 2 . . .



Above: A patient will always be greeted and escorted through the entrance of the MRI suite. Below: MRI suite main reception desk.



Saud A. Sadiq, M.D.
Director

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The MRI Suite — Specializing in MS Imaging



Continued from page 1

With a newly, well-trained staff of almost 10 healthcare professionals, led by Claudia Almodovar, RN, the MRI Suite has seen over 100 patients since opening. To schedule your next MRI, please call: 212-265-8070.

Prior to scheduling an MRI appointment . . .

- Confirm with a member of our staff that your physician has requested an MRI for your next scheduled office visit.
- Complete any blood work necessary or requested by your physician for an MRI to be performed. Allow approximately one week for results to be processed.
- Discuss all insurance and financial questions with a member of our Front Staff.
- Hydrate to enable easy placement of an IV when contrast dye is being used.
- Request any prescription medication you may need for the procedure in advance of having the MRI performed.
- Please alert a member of the MRI staff of any issues with claustrophobia, surgical implants or devices that they need to be aware of to ensure your safety.



From Your Front Staff

Reimbursement Check Advisory

IMPORTANT: When you receive a reimbursement check from your insurance company for services rendered at the MS center you must mail us the check immediately along with the explanation of benefits so that we can process your payment properly. Checks must not be cashed.

Insurance Plan/Policy Changes

If your insurance is changing, please inform the front staff. Also, anyone who makes an insurance plan change within the same insurance company must still advise the front staff of these changes. These changes may affect your yearly out of pocket responsibility if your deductible and coinsurance change especially if you are receiving an IV treatment at the center.

Address/Phone Changes

Whenever you move to a new location or change phone numbers, please make sure the front staff at the IMSMP is notified. This will avoid any confusion when returning a phone call you've made to the office and prevent you from not receiving important mail from the center.

Please Check-out

Upon leaving the IMSMP all patients must stop by the front desk to check-out. Whether you had an office visit with your MD, physical therapy, a procedure or injection by a nurse, please stop at the main reception area so our secretarial staff can ensure your account and future appointments are up-to-date.


IMSMP/MSRCNY and staff photographs
courtesy of Edward Brydon, PhD.

Newsletter Editors:
Pamela Levin, RN, Umar Sadiq



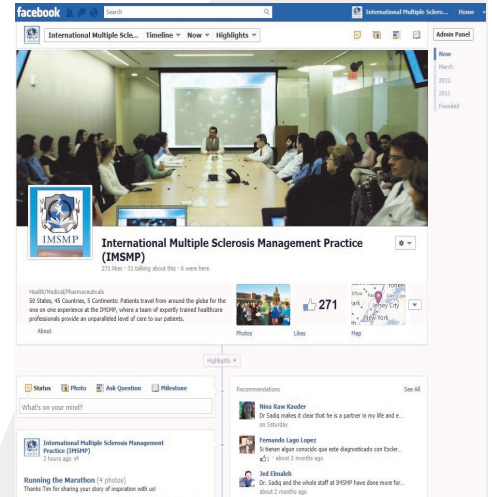
Like us on Facebook

www.Facebook.com/IMSMP

The International Multiple Sclerosis Management Practice is now on Facebook. If you have a Facebook account, log onto www.Facebook.com/IMSMP. When you click on the “Like” symbol,  you will immediately start receiving the latest updates on your MS center. This page will provide information on MS research happening at the Multiple Sclerosis Research Center of New York, and tips on how to optimize your health including diet and nutrition advice from our

naturopathic doctor, Dr. Deneb Bates. This will also provide you with an inside look at the new and exciting things taking place at the clinical practice such as our expansion and recent opening of our MRI Suite. Most importantly, the IMSMP Facebook page will feature Profiles of Courage of our patients. We hope this site helps our patients to stay informed, stay connected and belong to a community of caring.

www.Facebook.com/IMSMP



Profiles of Courage: The Patients of IMSMP



Donnie Loughran, Jr.



Profiles of Courage: Charles “Donnie” Loughran, Jr.

With the launch of our new IMSMP Facebook page comes an opportunity for our patients to share their lives with others. We have always known our patients are fearless and dynamic. Our patients take on a lifelong diagnosis and don't let it stop them from living life to the fullest. Profiles of Courage allow patients to share their accomplishments and successes. Whether it's traveling to a new place, participating in a special event or finding beauty in your everyday life, we want to know. Please help us provide an environment of support and encouragement to our patients. We would like to thank Donnie Loughran, Jr. for sending us his pictures titled “They Will Surf Again.” Don's inspirational story and day at the beach can be viewed at www.Facebook.com/IMSMP. If you have a story to share, please write to newsletter@imsmp.org or message us on Facebook. We would love to hear from you!

Maintain A Healthy Mouth A Message From Your Nursing Staff . . .

More than just a pretty smile, maintaining optimal oral health is essential for staying healthy. The oral cavity has a unique composition of healthy bacteria and yeasts commonly called “normal flora.” The balance of organisms can easily be altered by systemic illness, treatments, or poor oral hygiene. Even individuals with ideal physical and mental health can be challenged in their pursuit of optimal oral health. People with complicated medical and/or mental health problems have a greater incidence of oral health problems because many are unable to perform the basic tasks necessary for fundamental oral hygiene. This is compounded by the fact that some systemic diseases and medications used in their treatment compound the risk of oral problems such as gum disease, infections or tooth decay. Medications that cause immunosuppression (suppression of the body’s immune system) can allow normal flora in the saliva and oral cavity to grow beyond the typical range thus causing infections. Bacteria from the mouth can also enter the bloodstream through the gums which can become a serious medical problem. For these reasons, the medical staff here at the IMSMP urges their patients to take care of their teeth and gums. The American Dental Association (ADA) recommends the following for good oral hygiene:

- Brush your teeth twice a day with ADA-accepted fluoride toothpaste.
- Replace your toothbrush every three or four months or sooner if the bristles are frayed. A worn toothbrush won't do a good job of cleaning your teeth.
- Clean between teeth daily with floss or an interdental cleaner. Tooth decay-causing bacteria still lingers between teeth where toothbrush bristles can't reach. This helps remove the sticky film on teeth called plaque and food particles from between the teeth and under the gum line.
- Eat a balanced diet and limit between-meal snacks.
- Visit your dentist regularly for professional cleanings and oral exams.



Safe Needle Disposal



As many of our patients are on injectable therapies, it is important that we inform you on the proper disposal of these household sharps. Household sharps include syringes with needles attached, pen needles, or lancets. Needles attached to syringes should never be detached but rather disposed of as one piece. Used needles should never be recapped, and sharps should be disposed of immediately after use. Patients with multiple sclerosis may require medication therapies which are delivered through self-injection and thus require proper disposal afterwards. Household sharps disposal guidelines vary state-to-state, so it is important that you know how to safely and properly dispose of such items according to your state laws. In NY state there are over 80 sharps collection sites, which mostly consist of hospitals or nursing homes. To find your nearest sharps collection site, visit <http://www.health.ny.gov> or your state’s department of health website. All sharps containers should be kept in a safe place away from children or pets and can be purchased at your local medical supply store or pharmacy. Sharps may also be sealed in a puncture-resistant laundry detergent or bleach bottle, labeled “home sharps.” Prior to bringing your sharps to a collection site please make sure they are safely sealed in a sharps container. If you are coming into the center for an office visit, please feel free to bring us your sharps safely sealed and we will gladly dispose of them for you. Proper handling of household sharps is an important safety concern which will keep you and your family safe.

Social Work Section



The IMSMP Social Work Team
L to R: Shelly White, LMSW; Beth DiBiase, LCSW; Yadira Ovalles-LaMazza, MSW

Support Groups

Coping with MS is easier when you are less alone. We are recruiting people with MS and spouses/partners of people with MS to join these new support groups:

Newly Diagnosed Group

for people who have been diagnosed with MS for approximately three or fewer years.

Professional Women's Group

for working women with MS.

Men's Coping and Connections Group

for men with MS who are no longer working.

Due to popular demand, a new

Spouses'/Partners' Group has been added in addition to the one that has been meeting for the last four years.

SUPPORT



GROUPS

If you are interested in joining any of these groups, please contact the social work department at: 212-265-8070.

“Thank You For Holding”

Thank You Brandt & Sons Marketing Group

In 2006, the IMSMP completed an online request form searching for a company to produce our “On Hold” recordings. Immediately, Brandt & Sons Marketing Group responded offering their services FOR FREE. They have been providing the music, voiceover talent and updated recordings continuously throughout the year for the past 6 years. Our recordings are produced in honor of Cameo Philips, a member of the Brandt Family who battled MS for 10 years. For more information on Brandt & Sons Marketing Group and the services they provide, log onto: www.brandtsons.com



Jury Duty Letters

The social work department handles letters excusing patients from jury duty. Your doctors will be happy to provide these letters to patients who are disabled, meaning that they are unable to work full-time. Letters may also be given to the family members who are primary caregivers of patients who are disabled and need continuous care at home. Thank you for understanding these conditions.

Long Term Care Insurance Tips

The social work department believes that everyone, people with MS or not, should have long term care insurance. Long term care insurance pays for the cost of home care, assisted living, or nursing home care for people who are unable to care for themselves in the future, due to disability or age. Once a person has a pre-existing condition like MS, though, it is difficult to impossible to get the insurance. Here are some ways to get it:

Pay into a group policy through your or your spouse's employer or another large organization (some professional and civic organizations offer insurance) that offers long term care insurance without medical underwriting. Large companies cannot scrutinize the medical history of every employee who applies for group insurance, so people with pre-existing conditions can slip by the medical underwriting process that would normally disqualify them.

Apply if you live outside of New York State. Companies outside of New York, like Penn Treaty 800-362-0700 <https://www.pennetreaty.com/index.asp> have been known to offer policies to people with MS who are asymptomatic or are not disabled.

Social Security Disability

People who are unable to work because of MS can collect Social Security Disability benefits if they have worked and paid taxes long enough, and if they have worked five out of the last ten years. In other words, if you are disabled and have not applied for Social Security Disability, you may lose your benefits by waiting too long to apply. Call the social work department with any questions you may have.



Clinical Research Review

The Clinical Research Team has been busy with several exciting projects. We have the following updates for some of our new and ongoing studies:

Update on the Stem Cell Study: MSRCNY received IRB approval from the International Cellular Medicine Society on Nov. 21, 2011, to undertake a 20 subject clinical trial of mesenchymal stem cell-derived neural progenitors (MSC-NPs) in the treatment of progressive MS, and recruitment from the IMSMP patient population began in January. Patient interest in the study far exceeded the initially approved 20 places, and we will shortly seek approval of an expansion to 40 or 60 study subjects. Patients interested in information or participation in the trial can contact the Clinical Research Assistants at the numbers listed below. Informational brochures and informed consent forms outlining the procedure, timeline, inclusion and exclusion criteria, and risks involved in participation are available to all IMSMP patients.

Update on the Intrathecal Methotrexate Biomarker Study:

Intrathecal methotrexate is a therapy that can slow or stabilize the progression of MS. The goal of the Intrathecal Methotrexate Biomarker Study is to discover cerebrospinal fluid (CSF) biomarkers that can identify which patients are responding to the methotrexate treatment. Patients enrolled in the study will have CSF samples taken before initiation of the treatment and at the time of each treatment. CSF samples then undergo tests at the MSRCNY aimed at the identification and validation of protein biomarkers. The findings from this project will not only give us a better understanding of how methotrexate works, but will also help scientists identify the underlying process that drives progressive MS.

Update on the Stratify-2 Study: Many IMSMP patients are enrolled in the Stratify-2 study, which tests for the presence of antibodies to the JC virus in Tysabri patients to better identify patients at risk for developing Progressive Multifocal Leukoencephalopathy (PML), a rapid and potentially fatal inflammatory disorder of white matter in the brain. Stratify-2 recently underwent an amendment expanding the timeframe of the study by an additional two years and establishing a Focused Sampling Group in which patients who are JCV positive, have had at least 12 Tysabri treatments, and have a prior history of certain immunosuppressive drugs, may choose to enroll. The purpose of the Focused Sampling Group is to provide a more detailed understanding of the mechanisms by which PML develops and how to identify risk factors for PML more precisely than a simple blood antibody test.

Update on the Hypnosis Study: We are still actively recruiting for a study on the use of hypnosis to treat anxiety and side-effects associated with injection of MS medications and/or general pain. This project is a collaborative study with a licensed clinical social worker at the NYU Silver School of Social Work.

Update on the Accelerated Cure Project (ACP): Enrollment in the Accelerated Cure Project remains closed except for patients with Neuromyelitis Optica (NMO). ACP is a long term study attempting to assist research into the cause of MS by establishing a large database of biological samples and medical histories of patients with autoimmune demyelinating diseases of the CNS. We expect that general enrollment for MS patients as well as a family of related neurodegenerative diseases will reopen in the near future.

DECIDE: Enrollment in DECIDE, a Biogen Idec-sponsored clinical trial of Daclizumab to test its effectiveness against that of Avonex for patients with Relapsing-Remitting MS, has closed.

RENEW Follow-up Study: The MSRCNY has largely completed work on the RENEW Follow-up Study with EMD Serono, Registrat-Mapi, and MediciGlobal. The study was a follow-up with patients who received Mitoxantrone in the past to further evaluate the drug. We'd like to thank all who participated in this study for their time and assistance.

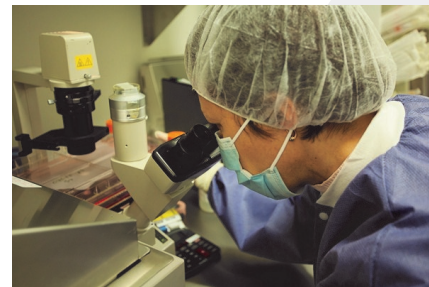
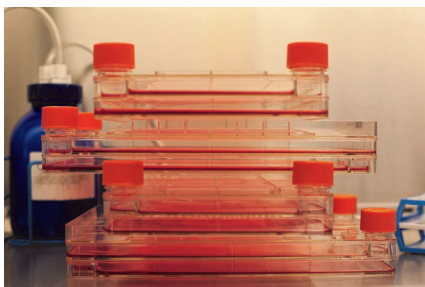
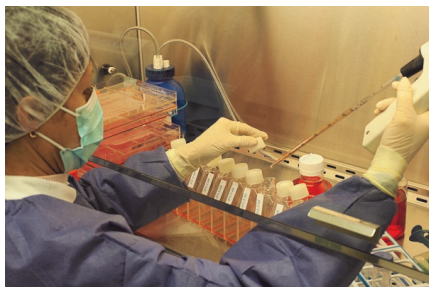
Research Skin Deep

Introducing the NYSCF Skin Biopsy Stem Cell Study: MSRCNY received IRB approval on Jan. 25, 2012 to begin a study, in conjunction with the New York Stem Cell Foundation, of skin cell-derived pluripotent stem cells obtained from skin biopsies of MS patients as well as (ideally, blood-related) control subjects. The purpose of the research is to identify the genetic underpinnings of diseases like MS and to better understand the genetic component of disease mechanisms. In addition, NYSCF scientists will establish a permanent bank of fibroblasts and stem cell lines for future research.

Introducing the Dermatopathology in MS Skin Biopsy Study: We are currently recruiting for an additional skin biopsy study. The study aims to evaluate for microscopic immune changes in the skin of patients with typical MS, atypical demyelinating disease (not confirmed MS), and healthy controls. The project has two goals: to look for a better method of differentiating MS from diseases that mimic it and to determine if the skin can show us something about the MS immune response. We are looking to enroll patients with MS, patients with atypical demyelinating disease, and any friends or family as controls. Participation in the study involves a routine skin biopsy of the thigh and forearm, as well as a blood draw of two tubes.

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 and Daniel Koffler at 646-557-3860 and 646-557-3852, respectively.

Laboratory Research



Scientists at MSRCNY have been busy presenting their work at conferences around the world. **Dr. Andre Mueller** presented his poster "Analysis of the CSF Cell Transcriptome of Multiple Sclerosis Patients," at the EMBL Conference: Omics and Personalised Health in Heidelberg, Germany on February 16-18, 2012.

Dr. Fozia Mir presented "Lipid Peroxidation Products as Novel Biomarkers in the Cerebrospinal Fluid of Multiple Sclerosis Patients," at the 43rd American Society for Neurochemistry in Baltimore, Maryland on March 3-7, 2012. In addition, the following five posters from MSRCNY were presented at the 64th American Academy of Neurology (AAN) meeting on April 21-28, 2012 in New Orleans, Louisiana:

"Cerebrospinal Fluid Derived from Progressive Multiple Sclerosis Patients Promotes Neuronal and Oligodendroglial Differentiation of Human Neural Precursor Cells In Vitro." [Authors: Massimiliano Cristofanilli, Barbara Cymring, Amy Lu, Hannah Rosenthal, and Saud A. Sadiq].

Dr. Cristofanilli was selected to present this study during a special 'Poster Rounds' presentation at the AAN.

"Accurate Risk Assessment for the Development of PML in Natalizumab Treated MS Patients Requires CSF Analysis." [Authors: Margaret Bettin, Jerry Lin, and Saud A. Sadiq].

"Do Immunological Profiles of the Cerebrospinal Fluid Correlate with Disease Severity in Multiple Sclerosis?" [Authors: Edward Brydon, Emma Marszal, and Saud A. Sadiq].

"Neuroketals in the Cerebrospinal Fluid of Multiple Sclerosis Patients." [Authors: Donald Lee, Fozia Mir and Saud A. Sadiq].

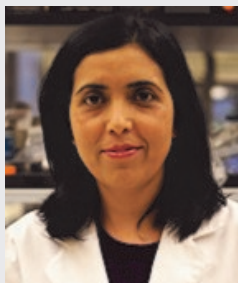
"Long-Term Safety of Intrathecal Methotrexate in Progressive Forms of MS." [Authors: James W. Stark and Saud A. Sadiq].

Copies of these abstracts can be found on our website: www.MSRCNY.org

Congratulations! Many of our research assistants who joined in June 2010 will be leaving MSRCNY this summer to pursue their medical educations. Many of them were accepted into top medical schools, including Columbia University, University of California Irvine, University of Florida, and Ross University. We want to thank and congratulate **Peggy Bettin, Hana Conlon, Raihan Faroqui, Esther Jun, Emma Marszal, Hannah Rosenthal** and **Amir Touray** for all their achievements and hard work at MSRCNY.

The MSRCNY internship program is pleased to welcome our new summer interns for this year: **Brittany Arditi, Matthew Baker, Charalambia Lauka**. They will be doing an 8 week internship in our laboratory. The MSRCNY internship program offers exciting opportunities for college level students to gain valuable experience doing multiple sclerosis research.

Spotlight on Dr. Fozia Mir, PhD



Fozia Mir, PhD

Dr. Fozia Mir joined MSRCNY in March 2011, and is investigating oxidative stress and lipid peroxidation in multiple sclerosis. There is growing evidence of the involvement of oxidative stress to brain damage in multiple sclerosis (MS). Lipids (fats) are the most abundant component of the brain and comprise about

70 to 85% of the dry mass of the myelin. Under conditions of oxidative stress, free radical production is increased which leads to lipid peroxidation – breakdown of the lipids. This brain is very vulnerable to this kind of damage (ROS) as it has very low levels of anti-oxidants which are our defense against oxidative stress. There is currently no biomarker for measuring oxidative stress in the brain.

Dr. Mir is investigating the ROS generated lipid peroxidation products in the brain and if their levels increase with disease severity in the cerebrospinal fluid (CSF) of MS patients. Her initial results

from this study demonstrate elevated levels of these lipid peroxidation markers and increase oxidative stress in MS patients. These lipid peroxidation products can thus serve as biomarkers for oxidative stress in MS. Therefore, they can be used to monitor the effectiveness of the upcoming new therapies in MS which target oxidative stress like BG-12 and laquinimod. It also will help select patients who are likely to benefit most from these medications

In addition to exploring oxidative stress biomarkers, Dr. Mir has a longstanding interest in elucidating the role of lipids like thromboxane A2, in regulating brain cell function

and viability in the brain under normal and stress/disease states. Dr. Mir is currently utilizing a mouse model to investigate the role played by thromboxane A2 in the maintenance and elaboration of myelin during MS.

Before joining the MSRCNY research team, Dr. Mir worked as a Research Assistant Professor in the Department of Pharmacology at the University of Illinois, Chicago. She received her Ph.D. in Laboratory Medicine from the All India Institute of Medical Sciences, New Delhi, India and did her postdoctoral training at the University of Illinois, Chicago.



Comprehensive Care Column: Summer Strategies

IMSMP is proud to introduce their Comprehensive Care Column. Two specialists at your MS center have come together and written an article bringing you tips and suggestions from their areas of expertise. With summer just around the corner, this issue features naturopathic doctor, Dr. Deneb Bates and physical therapist, Dr. Stephen Kanter with ways to:

BEAT THE HEAT!

Have you ever let your work-out routine lapse for a few weeks and you find it much harder to get going again?

Staying active year round is essential to staying in shape and preventing deconditioning. For people with multiple sclerosis, the most common neurological disease diagnosed in young adults, staying active in the heat and humidity of summertime is both especially challenging and especially important. People with MS become deconditioned faster than an average person, and because of neurological damage, they can have a harder time getting function back again. Unfortunately, nerve conduction over damaged nerves slows in heat and humidity of summer, making it especially hard for a person with MS to maintain even daily activities, let alone a work-out routine.

Whether you have MS or you just want the best strategies to keep your fitness routine going through the hot and humid months, take a few tips from the Wellness experts from the IMSMP to learn some strategies to Beat the Heat and stay active and in top condition all summer:

Prehydrate and Rehydrate:

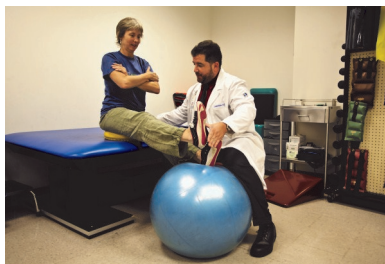
Drink plenty of water before engaging in physical activity in the heat so that you have reserves built up before the sweating kicks in. Include some electrolyte rich beverages too, such as plain or flavored coconut water or electrolyte rich water (like smartwater™) to help with cellular hydration.



Consider a Cooling Vest: If you are someone who melts at the idea of working out in the heat, or if you have MS and know you won't move as well once your body temperature rises, consider a cooling vest. These vests are beneficial for many people with MS, who are thermosensitive, while participating in basic physical activities. A more preferred and sometimes more effective strategy is "pre-cooling," wearing the cooling vest before initiating an activity or work out. This pre-cooling, in conjunction with drinking smoothies (as will be discussed below) can allow for an overall greater output of physical work with decreased side effects including, but not limited to, heat illness/heat exhaustion. "Post-cooling" with the vest or taking a cool shower after an exercise session can enhance physical recovery. Be sure, however, not to elicit any shivering with a cool shower or a cooling vest since this suggests your body's core temperature is not in normal range.

Swimming: When the effects of gravity cause problems for people with severe joint pains and/or muscle weakness, swimming is a good option as part of a physical wellness program. Swimming activities are great for increasing strength, improving joint flexibility, enhancing circulation, and improving cardiopulmonary endurance.

Aqua therapy: Water exercises (other than swimming) are a great option for people to improve strength, flexibility, and balance. Use of "water weights," "water sneakers," and various other aqua therapy specific equipment can make water exercises enjoyable and challenging. Depending on the depth of water and intensity of waves, a water program can be used, like swimming, to minimize forces on joints, while also eliciting powerful muscle contractions needed for strength, growth and balance improvement.



Top: Dr. Stephen Kanter
Left: Dr. Deneb Bates

Take a Cue from Ancient Wisdom: Ayurvedic medicine, an ancient Indian system of diet and lifestyle for different body types, gives ideas for how to cool down a Pitta-type person who is aggravated by heat. Cooling foods that balance Pitta include watermelon, fresh salads, and cool mint tea.

Blend these Ideas: Sports nutrition suggests following intense exercise with a combination of protein and carbs that will build muscle and replace glycogen stores so that your future exercise performances are well fueled. Many specialists suggest people with MS drink icees or slushies to help cool their core during summer exercise. Blend these ideas with a nutritionally packed smoothie. With ingredients that provide extra muscle and neuro-protection to a person with MS, this is also a great easy recipe for anyone who wants some cooling nutrition to keep them active and fit all summer.

Core Cooling Anti-Oxidant Smoothie:

- ½ frozen banana. Peel and half bananas and keep in a container in the freezer. Banana provides the sugar and starch to refuel muscles after exercise. Freezing them first makes them the perfect substitute for higher sugar icees.
- ½ cup frozen blueberries. Blueberries are Brain Berries! Their dark purple-blue color hints to their high concentration of anthocyanadins, an antioxidant known to cross the blood brain barrier and help prevent oxidative damage.
- 20 grams of whey protein. Whey is a superior protein for helping to build lean muscle mass. In addition, it is a precursor for your body to make glutathione, one of the best natural antioxidants for helping to quell oxidative damage that is a major factor in neurodegenerative disease.
- 1 cup of unsweetened almond or soy milk.

Combine all ingredients in a blender and blend until smooth. Use this as a pre or post work-out drink to cool the core and provide the perfect nutrients to build lean muscle, replace body stores of energy, and give an anti-oxidant boost to protect brain and cellular function!

IMSMP Salutes its Patients . . .

Congratulations to Tim Burke! At 44 years old, Tim ran his first marathon after being diagnosed with MS thirteen years ago. He went through the emotional ups and downs after hearing the news, "Why me? It's not fair! I'll do anything to be able to walk and not become disabled." "I was weak," he said. "My foot dropped. Fatigue was severe. My eyesight was affected, and I just felt like MS was going to win. Then something amazing happened," he said. "I accepted that I have MS, and decided that as my own best advocate, I wasn't going to live with MS. It was going to have to live with me." After seeing several neurologists, he arrived at the IMSMP and met Dr. Sylvester, an MD who he says treats his disease, not just the symptoms. In an effort to take control of his MS, Tim began running, "I found that running seemed to make me feel good," he said, "and I could do it around my schedule, and my fatigue level." Tim has been symptom-free now for four years. "And for four years now," he says, "MS hasn't been able to catch me."

Read more of Tim's story at [Facebook.com/IMSMP](https://www.facebook.com/IMSMP)



Tim Burke

My Story . . .



By Miriam Harris-Kaplan

I was diagnosed in 1999 but suspect I have had MS since 1991. Strange symptoms from those years like weakness and tingling finally made sense. In 1999 my right hand became numb. I thought it was a repetitive strain injury from my work as a licensed massage therapist, but then the numbness spread to my entire right side. In its own strange way, my diagnosis brought relief. After being tested for cancer, lupus, diabetes, and ALS, as well as being asked if I "would like some pills for your nerves dear." it was a relief not to be crazy.

A month later, I met the man I would marry. George and I met at a sabbath dinner. I told him about the MS that night. I felt that if it was a deal breaker I needed to know. He was unfazed. He has been my biggest ally. He has put up with several rounds of steroids, which I do not tolerate well. I get so labile he calls me the werewolf when I take them. I kept biting his head off but he kept growing new ones.

We married in 2001 and I danced at our wedding. Our first dance was "Embraceable You" by Gershwin followed by "Your Feet's Too Big" by Fats Waller. (Never tell your hubby your shoe size!) I also sang "I Love You For Sentimental Reasons" to him. I was able to work as a massage therapist until 2002 when I began to use a cane.

I joined a gym and treated it as my "job." I discovered Nia dance. It is a fusion of dance, healing arts and martial arts which helps me with balance and coordination and just plain feels good. My vision is to put together a Nia class for MS which could be adapted to standing and sitting positions. George and I adopted a shelter cat and named her (you guessed it) Nia. With 2 broken legs prior to her adoption, she has overcome adversity and is doing just fine. She keeps me inspired. Throughout the week I do pilates, Nia and body sculpt. I also have been exploring chi gung. The instructors have been great at teaching me modifications. I swim often in the summer, less so in colder months. I am not sensitive at all to heat, but oddly enough, am sensitive to cold. I find the balance between appropriate exercise and appropriate rest is a delicate one, which I constantly have to fine tune. I use a scooter to get around the city and a walker at home. I was uneasy about getting a scooter as I was afraid I would gain weight and stop moving. The opposite has happened and I have lost weight. I think of the scooter as something I USE, not something I AM IN. It is a tool, not a state of being. While I do not have formal training, singing is an important part of my life.

While I have lost certain functions, I celebrate those that I still have. I sing in my synagogue. I sang at my wedding. I have sung several times for a friend who was hospitalized. The legs don't work so well, but the voice is still there.

How did I get to IMSMP?

After several years in another practice, I felt a need for a 2nd opinion. I liked Dr. Williams immediately. He was patient, smart, kind and returned calls quickly. He knew I was terrified of a spinal tap. He could not have been more supportive (of course having permission to curse helped too!) Dr. Williams has been there for me through various ups and downs. He is always honest and always kind. I've also started PT with Dr. Kanter, who is brilliant. He really "gets it" about MS. Rather than trying to "beat a dead horse" by trying to get a dead muscle to work, we focus on finding other ways to get the job done. Would my story have been different had I come to IMSMP in 1999? Who knows...but that is not something I worry about. I feel very blessed to be here and feel I am getting the best care possible. After almost 13 years since diagnosis and possibly 20 years since onset, and my MS having morphed into the land of secondary progressive, I lead a very full, active life. Are there things I wish were different? Sure (I would not say no to a functioning left leg). But I still have a great deal to celebrate. I have an amazing husband, great friends, support from my spiritual community, fabulous gym instructors, and the cuddliest cat in the world. Yes there is life after MS, which I am living to the fullest.

Thank you to Miriam Harris-Kaplan and Tim Burke.
Please send us your story at newsletter@imsmp.org

MSRCNY Development Department News

Research Laboratory Naming Reiss Family Research Laboratory

Brad and Kammi Reiss, long-time supporters of MSRCNY and Dr. Sadiq, know how to make an impact on the Center's research. MS is a mystery to most of us, and in order to understand how to ultimately cure this disease, one must first understand it intimately. MSRCNY is dedicated to finding the cause of MS in order to develop effective therapies to control and one day cure it. Through their generous support over the years, MSRCNY is pleased to announce that the Central Research Laboratory has been named in honor of the Reiss family for their loyal support and dedication to helping us find the cure.



Kammi and Brad Reiss

MSRCNY on Wall St. FXall IPO Benefits MSRCNY

On the morning of February 9th, Board Member Phil Weisberg, CEO of FXall, celebrated the launch of his company's IPO with his colleagues, investors, family and MSRCNY at the New York Stock Exchange. MSRCNY was a proud and grateful recipient of the first 1,800 shares of FXall's stock.

Thank you Phil and the Weisberg family for your thoughtful gift and promotion of MSRCNY at this high profile event, and congratulations on your company's success!



Pictured center is Phil Weisberg along with his executive team at FXall.

One Smart Shopper

Teen "Shops smart, and does good!" with Lord & Taylor

For her Bat Mitzvah, Jaclyn Tommer wanted nothing more than to raise money to support MSRCNY's Stem Cell Study. Since she loves to shop, she registered the Center as a beneficiary of Lord & Taylor's "Shop Smart. Do Good!" fundraising shopping event on April 25th at the Manhasset store. Her hard work, including reaching out to Bat Mitzvah guests, friends, family members and school mates, paid off. As a result of her efforts, MSRCNY won top online ticket-selling organization and a bonus donation. MSRCNY received a grant of over \$1,500.00 from the philanthropic retailer. Kudos to Jaclyn!



Jaclyn at Lord & Taylor with the team from Centron Advertising Agency
L to R: Nick Rodriguez, Jaclyn Tommer, Anne Giaquinto, Joe Madsen



MSRCNY

If you are interested in making a gift to MSRCNY to help sustain the promising research initiatives underway, please donate online at: www.msrcny.org
or call the Development office at: 646-557-3861

Cocktails for a Cure

Annual Benefit for MS Research a Huge Success

The Cocktails for a Cure 2012 fundraiser, held on April 27th, was a rousing evening of fun and entertainment. Its move to the larger venue, Greenwich Village Country Club, drew its largest crowd yet of over 500 people who enjoyed the evening's playground offerings including an open bar, unique silent auction, fabulous raffle prizes, nine-hole miniature golf, and favorites like air hockey, foosball, and pool. Former Major League baseball pitcher, Dwight "Doc" Goodin, made a crowd-pleasing appearance. Designed, planned and executed by dedicated volunteers Dana Schwartz and Ryan Cohen, the event successfully raised over \$25,000—100% of which will support research.



Top L to R: Ryan Cohen, Dana Schwartz, Dwight "Doc" Goodin, Rizwana Sadiq & Dr. Saud Sadiq.

Below: Dana & Ryan announce raffle winners!



MSRCNY Would Like to Thank . . .

MSRCNY recognizes its generous donors who make life-changing research possible. *

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You must be in attendance to learn about this year's topics
as they will ONLY be discussed at this event:**

**STEM CELL TRIAL—Preliminary Results
A Day In the Life of a Stem Cell Recipient**

A Breakthrough in the Cause of MS

To register log onto: www.msrcny.org or call Jill Hughes at: 212-265-8070