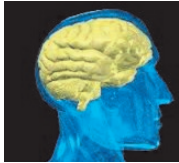




**PREGNANCY AND  
MS: EVERYTHING  
YOU NEED TO KNOW**



**HOW TO CALM  
YOUR FEAR OF  
NEEDLES**



**PUBLISHED  
RESEARCH  
HOT OFF THE PRESS**

ISSUE 16 | VOLUME 3 | SUMMER 2012

# Healing MS

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

## Register for the 15th Annual MSRCNY Patient Symposium

**"The year 2012 represents a culmination of 20 years of research and discovery in our laboratory. I strongly urge patients to attend." Dr. Saud A. Sadiq**

Many of you may remember attending the 2011 MSRCNY Patient Symposium and seeing the pictures on the right in a presentation given by Dr. Saud Sadiq. He questioned, "Are we there yet? When will the search be over?"

**How close are we to discovering the cause of multiple sclerosis?"**

The 2012 MSRCNY Patient Symposium will answer these questions and more! This year we present recent findings in our laboratory and how they translate into the lives of our patients. You *must be* in attendance for this information.

**Multiple Sclerosis Research Center of New York**

**invites you to the**

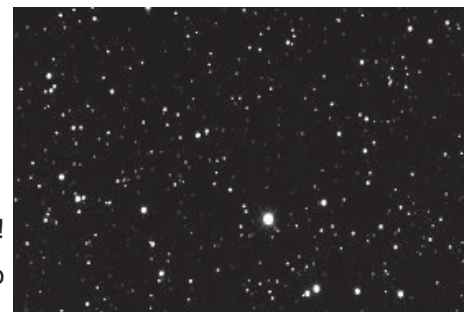
**15th Annual Free Patient Symposium**

**Sunday, October 21st, 2012 at 9:30am**

**Hilton New York**

**1335 Avenue of the Americas, (between 53rd & 54th Street)**

**Register today at [www.msrcny.org](http://www.msrcny.org) or call 646-557-3919**



**How far away are we  
from finding the answer?**



Saud A. Sadiq, MD  
Director

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## Clinical Research Review

We are currently pursuing a number of exciting clinical research projects. We have the following updates for some of our new and ongoing studies:

**Dermatopathology in MS:** Dr. Williams is continuing his study investigating microscopic immune changes in the skin of patients with typical MS, atypical demyelinating disease (people with either MS or unexplained brain demyelination who have symptoms that suggest a systemic autoimmune disease), 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 people with MS have microscopic immune changes in the skin. 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.

**Skin Biopsies for the Generation of MS-Specific Stem Cells:** We are continuing our collaborative study with the New York Stem Cell Foundation on skin cell-derived stem cells. The study aims to elucidate more about the genetic underpinnings of MS, as well as create a large bank of fibroblasts and stem cell lines for future research. We recently expanded enrollment for the study and are actively recruiting both MS patients and volunteer controls. Study involvement includes a small skin biopsy and health questionnaire.

**Accelerated Cure Project:** The Accelerated Cure Project (ACP) is a non-profit organization committed to stimulating research to find the cause and cure of MS. ACP's primary goal is to create a large-scale repository of samples and data

from MS patients, which researchers throughout the country can use to study MS. We are pleased to announce that enrollment in ACP will be re-opening shortly. Participation involves completion of a questionnaire (via interview and medical records) and a blood sample.

**Hypnosis Study:** We are continuing our collaborative study investigating hypnosis as a treatment for anxiety and side-effects associated with injection of MS medications and/or general pain.

**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. This better identifies patients at risk for developing PML, a rapid and potentially fatal inflammatory disorder of white matter in the brain. Once patients have tested positive for the antibody, they should consistently remain positive, so STRATIFY-2 recently amended its blood sample testing policy to account for this. As a result, any patients who have previously tested positive for the anti-JCV antibody and submit blood samples for the study will no longer receive test results. These additional blood samples will be stored for future research only.

Our studies on **daclizumab (DECIDE)** and **mitoxantrone (RENEW Follow-up)** have officially closed. We'd like to thank those who participated in these studies for their time and effort.

**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.**

## Published Research

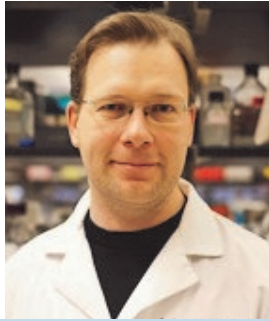
Two of the Multiple Sclerosis Research Center of New York's Principal Investigators have been lead authors on scholarly articles accepted for publication in peer-reviewed journals during the last quarter. **Dr. Violaine Harris's** article, "Characterization of Autologous Mesenchymal Stem Cell-Derived Neural Progenitors as Feasible Source of Stem Cells for Central Nervous System Applications in Multiple Sclerosis" is published in *Stem Cells Translational Medicine*.

**Dr. Andre Mueller's** article, "Inhibition of SLPI Ameliorates Disease Activity in Experimental Autoimmune Encephalitis" is in print in *BMC Neuroscience* and is available at <http://www.biomedcentral.com/1471-2202/13/30/abstract>. Full publication information is as follows:

- Harris VK, Faroqui R, Vyshkina T, and Sadiq SA. *Stem Cells Translational Medicine* 1:536-547, 2012.
- Mueller AM, Jun E, Conlon H, Sadiq SA. *BMC Neuroscience* 13:30, 2012.



## Spotlight on Dr. Andre Mueller, Ph.D.



**Andre Mueller, Ph.D.**

Dr. Andre Mueller's group recently published a paper from their ongoing work on the protease inhibitor SLPI, a molecule that prevents enzymes from breaking down proteins in the body. SLPI is of potential interest to MS because it inhibits the activity of pathogenic proteases and the activation of immune cells known to contribute to tissue damage in the central nervous system (CNS). Dr. Mueller's published study focused on whether SLPI modifies the disease course of a mouse model of MS, commonly known by the acronym EAE (experimental autoimmune encephalomyelitis). To do this Dr. Mueller's group vaccinated mice with SLPI protein, inducing the production of neutralizing antibodies that inhibit the activity of SLPI. They then initiated EAE in SLPI-vaccinated mice compared to control mice that were vaccinated with an unrelated protein, to see how the disease was influenced. SLPI-vaccinated mice developed a significantly milder form of the disease compared to control mice, suggesting that neutralization of SLPI may have therapeutic value in MS.

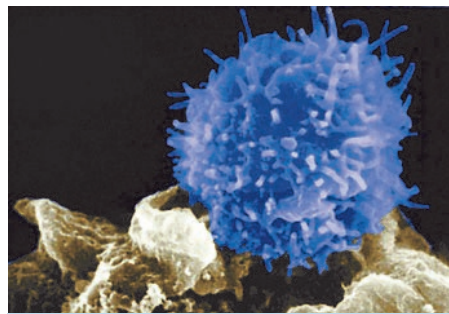
To understand how SLPI might play a role in the disease process, Dr. Mueller looked for factors known to be associated with EAE improvement. They found an increase in the number of T-regulatory cells, which are a key anti-inflammatory cell of the immune system. Subsequent experiments using human T cells isolated from the blood suggested that in the presence of SLPI, fewer T-regulatory cells are produced. Fewer T-regulatory cells could mean that there is reduced regulation of a pro-inflammatory immune state, such as one responsible for autoimmune responses in MS.

Dr. Mueller concluded that, at least in an animal model of MS, SLPI exerts potent pro-inflammatory actions by modulation of T cell activity and its neutralization may be beneficial for the disease. Dr. Mueller's group is continuing their studies in order to define SLPI's role within CNS autoimmunity.

You can access the paper online for free at the Open Access journal BMC Neuroscience using the link below.

Inhibition of SLPI ameliorates disease activity in experimental autoimmune encephalomyelitis Andre M Mueller, Esther Jun, Hana Conlon and Saud A Sadiq BMC Neuroscience 2012, 13:30doi:10.1186/1471-2202-13-30. Full online access at: <http://www.biomedcentral.com/1471-2202/13/30>

In a second project Dr. Mueller is investigating whether cells in the cerebrospinal fluid (CSF) are derived from inflammatory CNS lesions.



**Activated Human T-Cell**

These CSF cells are of high interest because they may reflect on disease activity in the CNS.

At MSRCNY, we have the unique opportunity to study these CSF cells. In a large-scale approach, profiles of CSF cells isolated from controls, patients with relapsing-remitting MS, and patients with progressive MS are compared with each other by microarray analysis. The microarray measures the abundance of all messenger RNA "transcripts," the nucleic acid intermediate that tells the cell how to make a protein from its DNA gene. This study aims to link certain patterns of CSF cells with specific disease types and identify new therapeutic targets. One interesting finding that has come from this second study and will be published soon is that patients with MS were found to have reduced Hepatocyte Growth Factor (HGF) in both the cells found within the CSF as well as the CSF itself, but not in blood plasma. HGF is a pleiotropic cytokine with anti-inflammatory and neuroprotective properties as well as the ability to stimulate cells in the CNS. When delving further into the role of HGF in MS they found that patients with active disease had lower levels than patients with inactive disease, suggesting HGF could be an important biomarker for

disease activity. Indeed, when they looked in a cohort of patients undergoing treatment with natalizumab they found that successful treatment correlated with increased levels of HGF compared to those patients not on natalizumab. Although this study does not shed any light on the mechanisms of progressive MS it does represent a step forward in the search to find reliable biomarkers for disease activity in MS. This paper has been accepted for publication and should appear shortly so look for the announcement on our website when the paper is released.

Dr. Mueller was assisted in these studies by research assistants Hana Conlon and Esther Jun, who have both since gone on to start their graduate studies in nursing (Columbia University) and medicine (University of California, Irvine) respectively. Dr. Mueller studied Technical Biology at the University of Stuttgart in Germany and graduated with a diploma in biological process engineering. In both his graduate work and postdoctoral training, Dr. Mueller evaluated the role of probable MS-causing factors within animal models of MS and identified new molecular targets for future treatment, including SLPI. Dr. Mueller is currently assisted by Bo Hyung Kathy Yoon, BS, and Eva Franzova, BS, both graduates of Cornell University.



**Hana Conlon**



**Esther Jun**



# Comprehensive Care Column: PREGNANCY AND MS

This month's Comprehensive Care Column features Director of Social Work, Beth DiBiase, LCSW and Assistant Nurse Manager, Theresa Lee RN, providing everything you need to know about:

## PREGNANCY AND MS

### Does an MS diagnosis affect my family planning?

When a person is diagnosed with MS, he or she may initially question plans for the future. The clinicians at the IMSMP believe that a diagnosis of MS does not necessarily have to alter life plans, and many people with MS go on to have children. There is less than a 3% chance of the child of someone with MS being diagnosed with MS. When considering starting a family, people with MS do often consider their energy level, potential for future disability impacting upon child rearing and earning income, and the impacts of chronic stress on MS. Meeting with a social worker at the IMSMP is a smart way to talk through family planning questions in light of an MS diagnosis.

### Can any MS treatments affect my fertility?

The most commonly prescribed MS treatments typically do not affect your fertility. If at any point you are uncertain about your treatment's effect on fertility, please discuss your concerns with your doctor.

### Do I need to go off all of my MS meds if I am planning to become pregnant?

Once you and your partner decide to start trying to become pregnant, there should also be a discussion between you and your doctor in order to determine a plan of action. Some MS treatments are safe in pregnancy, while others are not. Please speak with your doctor to find out about your specific medications.



### What if I become pregnant accidentally while I am on MS medications?

If you should become pregnant unintentionally while on treatment, please call your doctor's office immediately so he is aware and can further advise on your next step.

### Can the labor and delivery process affect my MS?

MS specifically does not usually cause problems during labor and delivery. The incidence of obstetric complications for those with MS remains unchanged. Each person is unique so the labor and delivery experience will vary.

### I have heard that women with MS are prone to exacerbations after delivery. What should I watch out for after delivery?

Women with MS are usually "protected" during pregnancy due to the elevated hormone levels. With that said, as the hormone levels return to normal after delivery, the risk of relapse increases. Your post-delivery appointment with your doctor is very important for this reason. At this visit, you will be examined by your doctor and there will be a discussion regarding your treatment plan.

### What do I need to know about breastfeeding and MS?

Breastfeeding is a viable option for women with MS. The only time that it may be discouraged is if your doctor feels that you need to restart your treatment to reduce your risk of relapse. While some medications can be safe during breastfeeding, most are not. You may also need an MRI. You will receive instructions on how to incorporate an MRI with breastfeeding. These are things that can be discussed during your post-delivery visit.

### What can I do to adjust my life to a new baby in order to cope with stress?

This is a great time to solicit some help. In fact, your partner may want to help out in some way in order to feel useful during such an important time, when much of the responsibility for infant care falls on the mother. The need to set priorities is essential because of the extra demands a baby will place on energy levels. It is important to have a routine with your baby that is flexible while still providing the structure that will bring comfort to both of you. Keeping yourself from expecting perfection can be a good way of lessening unnecessary stress.

### The following helpful tips will allow you to maximize your energy level with your newborn child.

A co-sleeper bassinet promotes bonding and enables parents and infant to sleep better. Sleeping within arm's reach makes night feedings easier and helps to conserve energy as you can reach your baby from your bed without getting up.

Slings are available in mesh and other fabric, and can be worn at the front or the back. Slings worn on the back are only appropriate for an ambulant parent with good balance and upper extremity strength. A baby could be supported by the sling while lying or sitting on the parent's knee, thus freeing the parent's hands.

There are practical advantages of breast feeding for women with MS who may experience more fatigue than other new mothers. You can conserve energy since the milk does not have to be prepared and bottles do not have to be washed. A baby can be breast fed in a number of ways: Nursing pillows are available which can cradle the baby in the mother's lap. A sling worn on the front may be used to hold the baby close to the breast. Sometimes the easiest and least tiring technique is to feed the baby while lying on the side facing the baby. If you bottle feed, position the baby in any of the ways described for breast feeding.

Continued on next page . . .



## PREGNANCY AND MS continued

### **What do I need to know about postpartum depression?**

It is common and normal for healthy women to feel depressed and/or anxious after giving birth because of the intense hormonal fluctuations as well as the major life changes involved with being a new mother. This is often called "baby blues" or "postpartum blues." Women who experience the baby blues might feel teary, emotional, moody, have difficulty sleeping, appetite disturbance, anxiety, or irritability. These are all normal feelings and should improve with a little time and with the help of your support system.

Postpartum depression (PPD) is a more serious problem that involves ongoing symptoms like those above, which last for more than a couple of weeks, and/or are accompanied by disturbing thoughts. Women who are concerned that they have PPD should consult their OB/GYN or midwife.

Having MS can be an additional component in the baby blues. One reason for this is that some women may have an MS exacerbation after delivery, which can cause additional stress and the need for medical attention. This post-delivery experience being outside of the norm for new motherhood can be especially upsetting, as the new mother may fear it's encroaching upon bonding with her baby.

Even mothers with MS who do not have a flare-up may experience the baby blues with an added layer of worry. In their new role as a mother, they may worry about the future and their ability to care for this new life. The support of a spouse, partner, family and friends is especially important during this time, and new mothers with MS are encouraged to seek short term counseling to help cope with the changes in their bodies and lives. The social work department at the IMSMP or your OB/GYN or midwife are good resources for support.

## Social Work Section

### **Health Insurance Open Enrollment**

The final quarter of the year is when Medicare and many employers allow for changes to be made to health insurance coverage, often called *open enrollment*. Preparing in advance for open enrollment will ease the process by allowing you to consult with insurance brokers, human resources, and our social work department with plenty of time to spare.

*Group health insurance* through employers may allow you to change your level of coverage between individual and family, or change your carrier altogether during this time.

When comparing plans, pay close attention to annual deductibles, out-of-pocket maximum, coverage caps, and out-of-network benefits.



Medicare's open enrollment period is from October 15<sup>th</sup> through December 7<sup>th</sup>. During this time you can:

- Convert from a Medicare Advantage Plan back to original Medicare
- Switch between different Medicare Advantage Plans
- Join a Medicare Prescription Drug Plan
- Switch between different Medicare Prescription Drug Plans
- Drop your Medicare Prescription Drug coverage completely

Between January 1<sup>st</sup> and February 14<sup>th</sup>, Medicare allows the following changes:

- Convert from a Medicare Advantage Plan back to original Medicare
- Join a Medicare Prescription Drug plan IF you just switched back to original Medicare



## **SUPPORT GROUPS**

The social work department is pleased to offer a second *Spouses' and Partners' Support Group* because of the popularity and demand for a forum in which spouses/partners of people with MS can share experiences and support each other.

We are also seeking more participants for the following support groups:

- Professional Men's Group - men who are working despite physical impairment.
- Newly Diagnosed Group - people who have been diagnosed with MS in the last 3 years.
- Skype Group - for people who cannot travel to the center and want to connect with others.

**For questions regarding insurance selection or any of the support groups listed above, please call the social work department at 212-265-8070.**

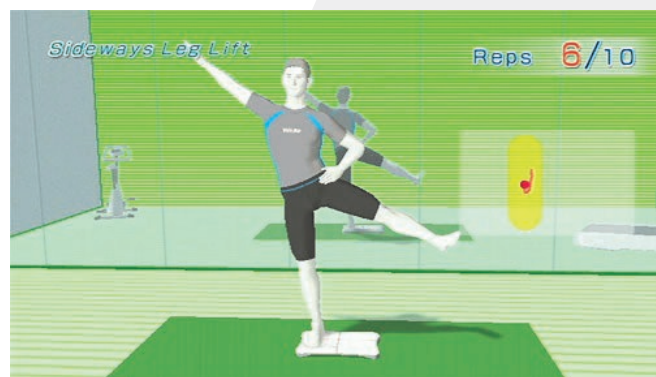
# P.T. News



**Dr. Stephen Kanter**

## **Virtual Reality and Other Advancements in Rehabilitation in 2012**

Virtual Reality (VR) interventions have become an increasingly common and popular treatment option for people with balance, strength, and flexibility limitations. VR interventions included “lower tech” systems such as Wii® and X-Box®, both of which are used at the IMSMP by Dr. Kanter. The benefits of VR for people with MS include the immediate feedback patients get while performing variety of movements, many which are not usually performed as part of a traditional home exercise program. The public availability of Wii® and X-Box® makes the potential for advancing a physical therapy exercise program to a level which can promote neuroplasticity and allow for adjustments to keep a home exercise program from becoming boring (a very common reason people stop performing their daily exercises). An additional benefit of these VR systems is the ability to



perform exercises with a family member or friend which can make an exercise program more enjoyable. The key with any exercise program for people with MS is safety and consistency. The environment which the VR system is used should be safe, clear of floor clutter, but having something to hold on (e.g. cane or walker) is acceptable to ensure safe performance. Consistency cannot be overemphasized. Unless an exercise program is incorporated into your daily routine, the benefit of exercise will be limited. Questions regarding your home exercise program can be discussed during your next visit with Dr. Kanter, or with your local physical therapist.

## **Dr. Kanter Presents at Major MS Conference About Orthopedic Issues in MS**

Dr. Stephen Kanter, the Physical Therapist and Supervisor of Rehabilitation Services at the IMSMP, presented to the IOMSRT members at a national conference in San Diego last June regarding Orthopedic Issues in multiple sclerosis. The IOMSRT is the International Organization of Multiple Sclerosis Rehabilitation Therapists, the only organization in the United States in which PTs, OTs, and Speech Pathologists are members who treat a high percentage of patients with MS in their daily practice. Dr. Kanter is one of fewer than 20 therapists in the NYC Metropolitan area who is a member.

During his presentation, Dr. Kanter explained that orthopedic issues can compound the impairments caused by MS and should be recognized and treated promptly to minimize the potential for long term disability. A key difference between orthopedic problems and those caused by MS is the orthopedic conditions are usually very treatable and, many times, reversible.

Dr. Kanter, who is also a Board Certified Athletic Trainer, has over 15 years of experience in treating orthopedic conditions. He works with Dr. Allan Inglis, an Attending Orthopedist, at the monthly Orthopedic Clinic at the IMSMP. During the orthopedic clinic, Dr. Kanter and Dr. Inglis will consider the effect of the orthopedic condition on any MS related mobility problems and determine orthopedic treatment options, while always keeping in mind a patient's MS status and medications being taken.

## **From Your Front Staff**

The Front Desk would like to remind patients: if you choose to cash your reimbursement check from your insurance company and prefer to pay an invoice from the IMSMP by credit card, you will be responsible for the 3% credit card fee. Your credit card will be charged accordingly.

Due to lack of storage space, Dr. Sadiq is requesting that patients kindly take back their MRI films. If you feel you do not have a need for the films, please call the office and give permission for them to be discarded. You will be asked to sign a release in order to have them disposed of. If you do wish to pick them up, kindly bring something to carry the films in. If we don't hear from you within 6 months we will assume you don't have a need for them and they will be destroyed.

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

**Newsletter Editors:  
Pamela Levin, RN, Umar Sadiq**



## News on Naturopathy

### **This Simple Naturopathic Tip Can Decrease Anxiety and Pain from your Injectable MS Medication**



Do you dread your injection? Although most people with MS eventually get used to their injectable MS medications, some people never quite get over their fear of needles, or are simply annoyed by the literal pain from injecting on a regular basis. Natural medicine has a simple and lovely solution to help with both injection pain and needle anxiety: **lavender oil** aromatherapy. A study published in 2011 (by S. Kim et al) showed that smelling lavender oil before an injection reduced the stress level of the volunteers as well as their perception of pain intensity. The calming and pain reducing effects of lavender lasted for about 20 minutes after inhaling the oil.

To improve your experience with your own injections, consider trying these ideas:

- Buy a small bottle of lavender (*Lavandula angustifolia*) essential oil (available from natural food stores and well stocked pharmacies).
- Before your next injection, place 1-2 drops of the lavender oil on a cotton ball. Take a few minutes to relax and breathe in the aroma from the oil before you proceed with your injection.
- Another option is to make a lavender room spray. Fill a clean spray bottle with distilled water, leaving a little room at the top. Add 10 drops of lavender essential oil and a tablespoon of vodka. Screw on the spray top and shake it gently. Spray the air in the room before your next injection to benefit from the relaxing and pain reducing properties of this aromatic medicinal plant.

## Dear MS,

Sixteen years...I can hardly believe it's been that long! And yet not a moment goes by when I don't think about you, and how you suddenly, unexpectedly crashed into my life like a baseball through a living room window! I never asked you to come. I barely knew you existed, but you came anyway. You came quietly at first and then you slowly, slyly, snuck into my body and devastated what was vital to me. First you got my vision, my precious vision that let me clearly see everything around me, like the electric blue sky that you turned into a dreary grey, and the actors on stage in the theatre, and the musicians at Symphony Hall, whose images you blurred. HOW DARE YOU DO THAT TO ME! But when you took away my ability to walk independently, I think that was the worst. I BET YOU THOUGHT YOU GOT ME THEN, and maybe you did, when at first I threw the cane in the back seat of my car, and said, 'FINE...I'll use that cane if I have to!' but then found that I needed it...a little at the beginning, and then all the time. AND I BET YOU THOUGHT YOU GOT ME when you took away my ability to paint with my left hand. Maybe you did at first when I got discouraged when my beautiful handwriting turned into scribble, and I BET YOU THOUGHT YOU GOT ME when I finally had to give in to crippling waves of fatigue. WELL, MS, I HAVE NEWS FOR YOU! I use a crutch and hold an arm if it's offered, BUT I GET TO WHERE I NEED TO GO! AND, MS, I HAVE MORE NEWS FOR YOU! I've been practicing painting with my right hand, and have actually come to love the looser images I create. Last summer an art gallery even exhibited my work! AND ONE MORE PIECE OF NEWS FOR YOU, MS, you will never break me down. I'll fight you to the end. You won't weaken my spirit, or diminish my optimism. I may not walk well. My vision is far from perfect, and I can't hand-write a thank you note anymore, BUT I'M STILL ME!!! I'm proud of who I am, and I wouldn't want to be anyone else.

Unfortunately MS, I know you'll stay in touch.

Leslie



**By Leslie Simmons**





By Robin K. Crickmore

In the early eighties, a band of fearless committed young men and women joined with the federal government to fashion legislation to support the rights of the disabled population. July 26, 1990 represents Independence Day for all disabled citizens; it is the day the now famous **Americans with Disabilities Act (ADA)** became law. At that time, I was working at the American Foundation for AIDS Research (AmFAR) and several of my co-workers partnered with Ted Kennedy to get this law on the books. One of them is permanently and post humorously recognized as a coauthor of the Bill. Amidst the cheering celebration in my workplace, I had no idea what a personal impact the law would have on my own life. I was not yet diagnosed with MS. I was not yet disabled.

## Knowing Your Rights Will Change Your World

The ADA protects your rights under the law; providing equal access to employment, travel, events and your home, among other things. The ADA is only effective to the exact degree you are willing to first know, and then voice, and finally to fight for your rights. Think about the words; *equal access under the law*. These are powerful words, fighting words. They represent freedom, independence, and empowerment. These words can give you back your life. The ADA changed our world.

In many cases, access is established and you need only be aware of the proactive reasonable accommodations already in place. For example, I am an opera lover, I travel by scooter and I have a licensed, trained, "certified for public access", Service Dog. The Metropolitan Opera assigns me an aisle seat in the top row of the balcony so my dog can lie beside me. In addition the Met assigns me a Safety Man who escorts me to my seat and exits with me. Traveling by plane is made easy; airline personnel are trained to accommodate both the scooter and the Service Dog. Recently, on a fully booked flight to San Francisco, extending an unusual kindness, the airlines blocked off a seat for my pup, a large labrador retriever named Dirk.

In other cases, enlightenment and willingness to change comes more slowly. When it became necessary for me to travel by scooter as I could only walk a half a block with difficulty, the Co-op where I lived refused to put in a one step ramp. Even though the Commission For Human Rights in the City of New York had taken the case as a clear violation of my rights, it took 10 months of determined resolve to win. Today, I am prepared to defend my right of access to a public pool, as swimming is an essential part of my health care regime. No one says it is easy to be a front-runner, a whistle blower, a behind the scenes fighter. It is anything but easy; I believe it is our obligation.

The road to freedom and equality begins with education. Begin by knowing your rights under the law; be prepared to defend those rights. There are countless people who simply do not know they have rights and are unprepared to stand up for what they need. To quote Norman Cousins, "In a democracy, the individual not only enjoys the ultimate power, but carries the ultimate responsibility."

Thank you to Leslie Simmons and Robin K. Crickmore.  
Please send us your story at [newsletter@imsmp.org](mailto:newsletter@imsmp.org)

## Nursing Staff Update

**Please help us welcome Tracey Eaton to the IMSMP nursing staff!**

Tracey Eaton recently graduated Pace University with her BSN in Nursing. She already holds a BA in Psychology from San Diego State University. Prior to starting a career in nursing, Tracey was a Health Volunteer in The Gambia, West Africa with the Peace Corps. She began working at the IMSMP in January.



Tracey Eaton, RN, BSN



For more MS tips and updates, don't forget to:



At [www.facebook.com/IMSMP](http://www.facebook.com/IMSMP) Here's some of what you'll find:

### Summer Sensitivity

The IMSMP would like to remind its patients to be extra careful in the sun when on an antibiotic. Some medications have a photosensitivity side effect and exposure to the sun may result in bad sunburns.



Want to stay extra hydrated this summer?  
Try some coconut water!!

Coconut water is one of the best natural sources for electrolytes, especially potassium (more than a banana and most "sports" drinks). In the past, it has even been used as IV fluid--straight from the coconut it is sterile! Enjoy!

The IMSMP hopes all of its patients had a wonderful summer.  
We look forward to seeing you on Sunday, October 21, 2012 at the MSRCNY Symposium!

## How well do you know the M.D.s at the IMSMP?

Can you match the correct MS physician to the questions below?

(A) Dr. Saud Sadiq (B) Dr. Andrew Sylvester (C) Dr. Armistead Williams (D) Dr. James Stark

1. Which doctor double majored in biology and art in college? \_\_\_\_\_
2. Which doctor has twin boys? \_\_\_\_\_
3. Which doctor has a parent from England? \_\_\_\_\_
4. Which doctor is a fan of the World Cup? \_\_\_\_\_

Answers: 1. C; 2. B; 3. D; 4. A

## A Letter from Dr. Edward Brydon:

Dear All,

I am sad to say I am leaving MSRCNY at the end of July. The two main projects I am involved in are being written-up for publication and it feels like the right time to pursue the next step in my career. I arrived at the Center in late November 2006 with a torn left ACL, the legacy of me being a rugby player, which required surgery in deep mid-winter of early 2007. I hobbled about the lab for a bit catching up on the latest MS research and formulating a plan as to what I should investigate. My background in virology and immunology dictated that one project at least would probably be on the role of Epstein-Barr virus in MS. We, like many others, have found that there is not a direct association between EBV and ongoing MS as we were unable to find the virus in the central nervous system in more than 11% of patient samples we tested. Look for the announcement on the MSRCNY website when the study is published. My other project involved looking at the difference in the CNS immune profile of patients with the least and the most severe disease. The idea was to look at the extremes of MS and see if we could pull out anything that might indicate how the autoimmune response drives the disease. We are happy to say we found something and again you should look for the announcement about that paper when it comes out. In that sense I have some completion scientifically in leaving now.

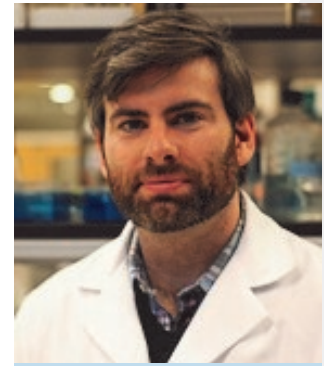
MSRCNY was an amazing place to work. The drive of Dr. Sadiq and the other staff really made it a stimulating environment. I was attracted to work here by the ease of doing what we call translational research, putting basic science into clinical practice. The fact that there is one door between the lab and the clinic emphasizes this part of the mission of MSRCNY.

In addition to the work my time at MSRCNY was punctuated with some of the happiest times of my life. I turned 30 while I worked here – that was a good party, the bar still hasn't opened since (Chumleys for those in the know). I got married, to "one of yours" shall I say (I'm British after all), in November 2008 – trust me, I am a very lucky man. In November last year, we had a baby son, Alexander. He's the happiest little fella I know. I will forever associate MSRCNY with these major events in my life. Because of that and the people I worked with I will remember it fondly. I want to thank my co-workers in the lab, especially my research assistants over the years, all the staff past and present of IMSMP, the patients and their families for whom we do this research and without whose kind consent to donate samples we couldn't do it, and finally Dr. Sadiq. There are too many words to say to fit them all here. I wish you all the best in your endeavors to find the cause and cure for MS.

Sincerely,

Ed Brydon, Ph.D.

Outgoing Assistant Research Scientist



**Edward Brydon, Ph.D.**

**Editors' Comment: Dr. Brydon is now working at Cold Spring Harbor Laboratory.**

## Research Staff Update

MSRCNY is delighted to announce that **Dr. Ying Ying Liu, MD, PhD** has accepted a position as resident neuropathologist in our laboratory. She comes to MSRCNY from a position as Associate Professor in the Department of Pathology at Shanghai Medical College of Fudan University. Dr. Liu received her medical degree from Taishan Medical College in Shangdong, China, and her doctoral degree in pathology from Shanghai Medical College.

MSRCNY is likewise delighted to announce the appointment of **Dr. Irene Jarchum, PhD** as a new Principal Investigator in the laboratory. Dr. Jarchum received her BS in Molecular and Cell Biology from the University of Connecticut, and her MS and PhD degrees in Biomedical Science from the Albert Einstein College of Medicine of Yeshiva University. She comes to MSRCNY from a post-doctoral fellowship at the Memorial Sloan-Kettering Cancer Center and is an expert in the subject of autoimmunity.

A new cohort of research assistants has joined our full-time research staff. We are excited to have **Lauren Alpert** (BA, Columbia University), **Lena Bell** (BA, Columbia University), **Annabelle Chu Yan Fui** (BS, Columbia University), **Eva Franzova** (BS, Cornell University), **Hetal Ray** (BA, Williams College), **Karen Sheikh** (BA, Pace University) and **Bo Hyung Kathy Yoon** (BS, Cornell University). Research assistants work closely with our research scientists and perform a variety of experimental assays and are responsible for data management and general laboratory maintenance. Karen and Lena will be working for Violaine Harris, Kathy and Eva will be working for Andre Mueller, Lauren will be working for Massimiliano Cristofanilli, Annabelle will be working for Jerry Lin, and Hetal will be working for Fozia Mir.

The MSRCNY internship program is pleased to welcome two additional summer interns: **Charalambia Louka** (New York University) and **Brittany Arditi** (University of Pennsylvania), who will be working in 8-week rotations for Dr. Harris and Dr. Mueller, respectively. The MSRCNY internship program offers exciting opportunities for college level students to gain valuable experience doing multiple sclerosis research.

# MSRCNY Development Department News

## Patients Raise Money and Advocate for MS Research

The Development Department often receives calls from grateful IMSMP patients asking how they can help raise money for the unique and exciting research being conducted at MSRCNY. We welcome these calls and initiatives as they help to fund and accelerate research.

From tag sales, to special events, to golf outings, to appeals for donations in lieu of wedding gifts, patients create many generous and creative opportunities for their family members, friends, and business contacts to give to the center. And, in addition to raising much needed funds, these individuals also raise awareness about MS, the IMSMP, MSRCNY, and the importance of the cutting-edge research and therapies being developed in our laboratory to improve the lives of patients. Because of our minimal administrative costs, money that is raised goes directly to the laboratory, its operations and projects to further our efforts in discovering the cause of, and one day the cure for, MS.

### We would like to thank the following people for proactively supporting MSRCNY:



**Julia Mariani (center), daughter of Board Member Bernadette Mariani, with research assistants Dan Koffler (left) and Deirdre Dulak (right)**

**Julia Mariani**, the daughter of an IMSMP patient, petitioned her school to make MSRCNY the beneficiary of its annual walkathon. On May 18, she and her fellow middle school students at Friends Academy of Locust Valley walked to raise over \$31,000 for MS research—one of the largest sums to date raised at the school. A few weeks before the walk, MSRCNY research assistants Deirdre Dulak and Dan Koffler visited the students and delivered a presentation on MS, MSRCNY's research and specifically the stem cell therapy currently in development. The generous funds raised will directly impact IMSMP patients and also the hundreds of thousands diagnosed with this disease.

**Jim and Cindy Prestigiaco** and **Guy Tidisco**, who, on June 22, raised \$2,285 at a Texas Hold'em poker tournament they held in New Jersey.

**Janis Kaiser**, who announced on her Facebook page that she was holding a Tag Sale in April and giving its proceeds to MSRCNY. Several people gave an additional gift with their purchase. Janis raised \$400.

**Our sincere thanks for all of your efforts!**  
**If you have an event idea or would like more information about how you can help raise money for research please call the Development Office at 646-557-3863.**

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

Anonymous  
Albert Penick Fund  
Atlantic City Linen Supply, Inc.  
Barbara & Ken Bryfogle  
Charles and Jane Klein  
Family Fund  
Margo & Roger Coleman  
Alicia M. Conill, MD  
Mrs. Alicia Conill-DeVivo  
Lorraine & Frank DeCongelio  
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Natalie & Jerome Komisar, in memory of Allen Kanter  
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Thomas Lynch & Patricia Lynch  
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Loiza & John Paravalos  
Linda & Phil Peller  
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Robert Youdelman

\* This list includes donors of \$1,000 or more between May 1, 2012 and July 31, 2012, with the exception of *Path to Progress* 2012 donors.

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*MSRCNY receives workplace giving funds from the United Way of New York City and Bergen County, NJ. Inquire with your employer to participate.*





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# Have You Registered Yet?

## **15th Annual MSRCNY Patient Symposium**

**Over 600 people have already registered for the  
2012 MSRCNY Free Patient Symposium!**

**The MSRCNY will be pre-paying for a sit down lunch for every  
person who has registered.**

**We are happy to provide this for our guests.**

**In an effort to avoid excessive catering expenses,  
please let us know if you are unable to attend at any  
point prior to the symposium.**

**To register log onto: [www.msrcny.org](http://www.msrcny.org) or call 646-557-3919**