On Thursday, April 11, 2013, Meredith Vieira introduced Dr. Sadiq to 350 attendees at the Second International Adult Stem Cell Conference: Regenerative Medicine—A Fundamental Shift in Science and Culture held within Vatican City. The presentation began with background information on multiple sclerosis and the damage it can cause. As Dr. Sadiq spoke without the use of PowerPoint slides or videos he was able to effectively communicate the suffering he has witnessed firsthand of his patients and relay the critical importance of an approval for clinical trials using adult mesenchymal stem cells. “This research not only provides evidence of repair and regeneration, but more importantly, it provides hope for thousands of patients and their families affected by this disease.”

Cardinal Gianfranco Ravasi (pictured on the left in top photo) and other church and scientific leaders, policy makers, ethicists, educators and ministers of health from around the world, ambassadors to the Holy See and representatives of the stem cell therapeutic business community gathered to hear Dr. Sadiq’s talk. Sir John Gurdon, who won the Nobel Prize in 2012 for his work on stem cell research, was a keynote speaker at the three day conference.
Fetuin-A: a biomarker of active MS
In a recent study published in the Multiple Sclerosis Journal, Dr. Violaue Harris, Dr. Saud Sadiq, and their colleagues at Tisch MS Research investigated the utility of Fetuin-A as a biomarker of disease activity in MS. Fetuin-A is a protein secreted mainly from the liver that functions in a wide variety of physiological and pathological processes. Tisch MS researchers started studying Fetuin-A a few years ago when they found that it was elevated in the cerebrospinal fluid (CSF) of MS patients. In the recent study, they analyzed Fetuin-A levels in the CSF of 50 MS patients with active disease and compared that to another 50 MS patients with inactive disease. Fetuin-A was significantly increased in patients with active disease, indicating that Fetuin-A is a biomarker of disease activity in MS. Interestingly, MS patients taking natalizumab (Tysabri) had reduced Fetuin-A levels after one year compared to their Fetuin-A levels before starting the drug. These studies suggest that monitoring the levels of Fetuin-A in the CSF over time may help to determine an individual patient’s response to natalizumab treatment. Future work will look at whether the response to other MS drugs also correlates with reduced CSF Fetuin-A, and how this might correlate with other measures of disease such as an MRI. Harris et al. also examined whether Fetuin-A might be directly involved in the disease process in MS. Utilizing the EAE animal model of MS, they found that mice lacking Fetuin-A had less severe neurological symptoms compared to mice with Fetuin-A.


Clinical Research
The Accelerated Cure Project (ACP) is a national non-profit organization committed to accelerating the pace of multiple sclerosis research in hopes of finding the cause of, and eventually a cure for, MS. As such, the organization oversees, coordinates, and funds a large, multi-center clinical trial under the ACP name at a number of sites throughout the United States, including the joint IMSMP and Tisch MS Research Center. Through this initiative, data and samples are collected from a wide range of patients and submitted to a central repository. Researchers throughout the world are then able to request samples and de-identified medical information from this bio-bank, decreasing the amount of time and funds they must allocate to patient recruitment, as well as providing access to a more diverse range of samples. Since 2006, many IMSMP patients and their family members have participated in ACP, generously donating medical data, blood samples, and time to the initiative.

Combined ACP data has stimulated an impressive number of research projects and publications, many of which can be viewed on ACP’s website: http://www.acceleratedcure.org/impact/repository/studies

ACP recently announced plans to close the main ACP study and direct resources towards a new study aimed at understanding disease progression and treatment efficacy. The organization will maintain its sample lending program for researchers, so all previously contributed samples will still be utilized for research on a frequent basis.

The Tisch MS clinical research team would like to formally thank all of the patients and family members who contributed to the ACP program for researchers, so all previously requested samples and data will be maintained for research. IMSMP and Tisch MS Research Center.

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Further details on these posters can be found on our website at the following URL: http://tischms.org/news/tisch-ms-scientists-presented-aan-2013

If you would like to learn more about Tisch MS Research Center clinical studies, please contact Deirdre Dulak or Daniel Koffler at (646) 557-3860 and (646) 557-3852 respectively.

Tisch MS would like to announce that former Laboratory Manager Elaine Kwon has left the center to pursue new research opportunities. We wish Elaine the best and would like to thank her for her years of service to the Center. She will be greatly missed! In addition, we are pleased to announce that Indira Londono has joined the research team as the new Laboratory Manager. Indira graduated from Seton Hall University with a master’s degree in Neuroscience and biochemistry, microbiology, and immunology. We are looking forward to her contributions to our research. Welcome, Indira!

Tisch MS Scientists Present at the AAN 2013: Four posters by Tisch MS scientists were presented at the American Academy of Neurology’s annual conference, held March 16-23 in San Diego, CA:

L.H. Bell, V.K. Harris, and S.A. Sadiq: "Identification of CSF biomarkers of cognitive impairment and cerebellar dysfunction in multiple sclerosis."


From your Nurses: Tecfidera (BG12) Receives Approval

The FDA has officially approved Tecfidera (dimethyl fumarate) as of March 27, 2013. Clinical trials suggest that Tecfidera may have neuroprotective properties in addition to immuno-modulatory properties by working on the NRF-2 pathway. This path is involved in cellular defense of oxidative stress, which means that the drug may protect the cell from damage caused by inflammation.

Tecfidera is an oral medication that is taken twice a day. A lower dose of 120mg twice daily will be taken for 2 weeks and then increased to the maintenance dose of 240mg twice daily. The most frequent side effects seen in trials were temporary flushing or reddening of the face and gastrointestinal side effects such as nausea, diarrhea, and abdominal cramping. If you experience any of these side effects please call the nurses’ phone line. Do not stop taking your medication.

We know many patients will be interested in switching to this drug. We welcome this as a potentially important new medication, however, a change in treatment is a significant medical decision and must be discussed with your physician. The mechanism of action is not yet fully established and once Tecfidera is used in a greater number of patients it is inevitable more adverse effects will be identified. For this reason, it is important that you meet with your physician before making any changes. The center policy for switching to Tecfidera is as follows:

1. Stable patients, who would like to change treatment, will discuss a potential change at their next office visit.
2. Patients not doing well on current treatment should contact our office and schedule an office visit with your respective doctor.
3. All patients switching to Tecfidera will be required to have baseline MRIs and baseline blood work as well as repeat blood work every 2 months for the first 6 months of treatment and then every 6 months thereafter.

From the Front Desk

Just a reminder to our patients that when calling our office for either a prescription or to speak to a nurse, it is imperative that your call be transferred to the appropriate telephone line. Due to the volume of calls we receive, we are asking that patients do not request to stay on hold until a nurse is able to speak to them. There are only so many phone lines available for incoming calls and we want all calls to have the opportunity to come through.

Prescription Line: The prescription line is a dedicated message service which allows patients to call in their requests for refills to our nurses in an efficient streamlined process. All prescription requests phoned in before 3:00pm are processed that day.

Clinical Nurses Line: The IMSMP nurses staff a phone line six days a week dedicated to answering patients’ questions and triaging which questions need to be taken directly to a doctor. Every call is returned by the end of the business day by a nurse with rich expertise in MS care.

MRI Films: Due to the lack of storage space at our center, it is necessary that we return all MRI films to our patients. Therefore, please remember to bring something to carry the films home in the next time you are here. If you choose not to take your films, you will be asked to sign a waiver giving permission for the center to discard them. Thank you for your cooperation.

Dr. Tamer Elbaz and the New IMSMP Pain Clinic

Dr. Elbaz will see patients every other Tuesday of each month from 1:00 - 4:00pm. For information on rates, insurance plans accepted and to schedule a new patient consultation, please call the IMSMP main line: (212) 265-8070

Dr. Tamer Elbaz is a board-certified interventional Pain Medicine and Anesthesiology specialist. His passion for pain medicine started when he was in medical school. He decided to pursue the necessary long steps to specialize in that field. He completed his anesthesiology training at SUNY Downstate Medical Center. He was elected to be the chief resident during his final year of training, an honor granted only to the very best. While applying for fellowship training in pain medicine, he was offered training in many places, but he choose to train at Columbia University College of Physicians and Surgeons/St. Luke’s-Roosevelt Hospital center, which offered the best training in the field in the tri-state area.

He was then elected to be the Director of the Pain Medicine Fellowship Training program at St. Luke’s-Roosevelt Hospital. He trained many physicians on various treatment modalities for pain management.

He currently holds an Assistant Clinical Professor of Anesthesiology and Pain Medicine position at Columbia University College of Physicians and Surgeons. He was appointed a NYS Pain Medicine committee member.

Dr. Elbaz has traveled the world lecturing and training pain medicine specialists on the latest techniques in the field and has presented at many conferences both nationally and internationally.

Dr. Elbaz has extensive knowledge and experience performing interventional pain procedures for acute and chronic pain syndromes. He is particularly interested in treating difficult and complicated cases. He is currently a member of: World Institute of Pain, American Society of Regional Anesthesia and Pain Medicine, International Spine Interventional Society, and the American Society of Anesthesiologists.
News on Naturopathy: A Comprehensive Care Column

Update on Diet and MS: New Connection between Sodium Intake and Autoimmune Disease
Written by Deneb Bates, ND, Irene Jarchum, PhD and Armistead Williams, MD

Is salt the trigger of MS? Two recent articles from the journal *Nature* suggest that sodium may cause or contribute to MS. This is interesting research, but it is premature to convict salt of causing MS. The research grabs attention because sodium would be a modifiable risk factor, it has already been "convicted" of contributing to hypertension and heart disease, and it fits in with a general idea that processed foods are a major contributor to human illness. Our take is that it is premature to convict salt of causing MS but that people should consider lowering sodium intake based on its known effects of heart disease.

To unravel the potential implications of these findings to human MS, let’s first review the background. The two articles showed that mice consuming a very high salt diet had worsened the course of experimental MS and was associated with an increase in the percentage of a special immune cell called Th17 cells known to contribute to the mouse model of MS. In MS patients, cells of the immune system enter the brain and spinal cord, where they can be found at the lesion sites. Our understanding is that many immune cells are involved in creating lesions and ultimately causing MS. One of these cell types is the T lymphocyte, also called the T cell. The normal function of T cells is to help clear infections, such as those caused by bacteria or viruses. In MS, T cells take on a different role, targeting normal cells, that protect the neurons and causing nerve damage. Scientists often study hypotheses of the causes or treatments of MS using an animal model of MS called experimental autoimmunne encephalomyelitis (EAE). Scientists trick the animal’s immune system to attack the brain and spinal cord.

In this animal model, the Th17 cell is critical for development of this MS-like disease. Mice with lower numbers of Th17 cells have lower chances of developing the symptoms of EAE. Also, in mice with fewer Th17 cells, the symptoms are milder. Conversely, mice with more Th17 cells often have worse disease. The recent studies published in *Nature*, which were carried out by two independent research groups, show that mice fed a high salt diet have an increased number of Th17 cells as compared to those fed regular mouse food. When the investigators looked at mice with EAE, they found that animals eating the high salt diet developed symptoms of the disease earlier and their symptoms were more pronounced. The scientists went further, identifying the molecule that senses salt and influences Th17 cells, called SGK1. Mice lacking SGK1 had fewer Th17 cells and milder EAE symptoms. These new findings are exciting because they provide insights into how Th17 cells develop. Also, the new research shows that, at least in mice, salt can have an important effect on the immune system and on EAE.

There are several limitations to the research. To start, EAE is an animal model and what happens in EAE may not reflect human MS. While some discoveries made in the EAE mouse model translate well to human MS, many do not. While it seems that T cells are stimulated to become Th17 cells when grown in high sodium concentrations or in mice eating excess sodium, it is not clear that Th17 cells are as important in human MS as they are in EAE. In addition, the mice were fed a diet that contained 10 times the amount of sodium as normal chow. It is unclear how that amount of salt would translate to humans. This is all interesting to scientists researching mice with experimental MS but may not apply to humans with MS.

Let’s look at salt from a general perspective. Most Americans eat far more than the recommended amount of sodium on a daily basis, on average consuming 20 times more than the body needs to function, and in most cases greatly exceeding the Tolerable Upper Intake Level of 2,300 mg per day (Tolerable Upper Intake Level is the highest amount that is likely not to cause harm to the general population). The Institute of Medicine recommends 1,500 mg of sodium per day as the Adequate Intake level for most Americans. This is considered to be a “low salt diet,” but is a good target for most people, and maybe even more so if you have an autoimmune disease like MS.

Where does this leave us? Salt is an important nutrient and flavor enhancer which we consume in excess, particularly when we eat processed foods. It may or may not contribute to MS, but we already know that it is a contributor to hypertension and heart disease, which can worsen the course of MS. This leads to a simple suggestion, consider a diet that is well established to support cardiovascular, metabolic, and overall health: a plant based diet, low in processed foods, and seasoned with herbs and spices rather than salt and sugar.

For individualized dietary and supplement strategies, schedule a visit to see Dr. Deneb Bates, the IMSMP’s Naturopathic Doctor.
Coping with MS is a very personal challenge which is as different for each person as each person’s MS is. However, there are some commonalities to the psychological challenges of living with MS. MS is a disease marked by uncertainty. Even someone with the best prognosis might worry about the future. And people with MS-related disability might struggle with anxiety and/or depression.

People with MS often ask the social workers at the IMSMP to help them cope better with their MS. What does “coping better” mean? We think it means finding concepts and strategies to help improve your quality of life. This might mean learning over time to adapt to having MS and making choices that will help alleviate your stress.

Here are some tips that our social work department has learned from listening to our patients for years and hearing what has worked for those people who identify as having a good quality of life.

Learn what works for you- Pay attention during times of stress, MS-related or not, to what helps you calm down and feel most in control. Maybe you feel better talking to a friend or a professional; maybe you are calmed by working in your garden or writing in a journal. Whatever helps you, pay attention to it and write it down so that you can refer back to it the next time you are in a crisis, and it will help you feel more competent and in control.

Reach out: Human beings are social animals. We are the only species that speak in words and about emotions. We were not meant to struggle alone. Take inventory of those family members or friends on whom you can rely to listen without judgment when you are in emotional struggle. Call one of these reliable people in your life and share your feelings honestly. Just venting often helps. When it does not, call our social work department and we can help you find a mental health professional who can give you some help with coping. Support groups, like the ones offered by the social workers at our center, are a great resource to connect with others going through similar challenges.

Accept your feelings- There seems to be a belief in the last couple of generations that we should never feel anything “bad.” If a feeling is uncomfortable, it should be somehow eradicated, fixed or medicated away. Feelings are part of us, part of what make us human, and part of what help us to identify danger, disease, people who are not good for us, and situations that are not in our best interest. If we dull our feelings, we miss out on the ones that we seek, such as joy, love, and pleasure. Do not try to rid yourself of your feelings. Learn to remind yourself that uncomfortable feelings do eventually pass. If yours do not, reach out to a professional.

Do not let MS define you- You are a person who has MS, not an MS victim. Whether or not your MS defines you as a person is up to you. Yes, MS poses many challenges and can cause real interruption and difficulty in life. But people who define themselves by attributes outside of their MS tend to have the most satisfaction in life, no matter what their MS does. Even though you have MS, you are still someone’s son, or someone’s mother, or a sculptor, or a golfer, or an academic, or a music buff. Cultivate those talents and interests that MS cannot get too much of a hold on, and remember that you are defined as a person by who you are, not what you can do physically.

Make meaning- People who have meaning in their lives tend to cope better with MS. What is the meaning of life? We cannot tell you that. But you can figure out what the meaning of YOUR life is. People arrive at meaning by many different avenues. Some people have religious or spiritual faith beliefs that explain the meaning of life. Some people believe that authentic connection with family and friends is the meaning of life. Others believe that leaving the world a better place than we found it is the meaning of life. Explore your own beliefs and find your meaning. Some people find psychotherapy to be helpful in finding meaning. Once you do, your own struggles will make more sense to you and you will find more purpose in life.

Making Meaning
By Dave Fucio

I live in Montclair, New Jersey, and serve as the Chair of the Township’s Advisory Committee for People with Disabilities. Our Committee works with the Township on the full range of issues affecting residents and visitors: special needs students in the school system, universal housing design and zoning, access to public buildings, ADA compliance, handicapped parking, etc. In 2012, the Committee was involved in the creation and production of a 20 minute documentary.

“I Am Montclair” began as a disability awareness project for first responders. The documentary features personal interviews with members of Montclair’s famously diverse community, including people with and without disabilities, advocates, families and caregivers. At its heart, “I Am Montclair” is a community’s call to action for greater acknowledgment, acceptance and inclusion of individuals with disabilities.

The film was accepted for inclusion in the Montclair Film Festival. It was shown on Sunday, May 5th at 2pm at the Claridge Theatre on Bloomfield Avenue.

The IMSMP would like to congratulate Dave Fucio and the Montclair Advisory Committee for People with Disabilities for their outstanding accomplishment!
UPGRADING YOUR PHYSICAL WELLNESS BY GOING OUTDOORS

During the spring, summer, and early fall months, the days are longer and the opportunity for outdoor activity is at its greatest. Whereas all patients with multiple sclerosis should be engaging in a routine physical wellness program, now is the best time to start performing activities outdoors that can satisfy as “exercises” to be done to work toward your physical therapy (PT) goals. In some cases, returning to previously enjoyable activities, such as gardening, landscaping, playing ball with your family, trips to the park or beach, outings at sporting or musical events can become part of your physical therapy or occupational therapy (OT) goals.

Finding a PT or OT who is willing and able to work toward your functional goals is important for patients with MS. Simply working to “get stronger” and “more flexible” is not enough. For patients with MS, fatigue and heat sensitivity are two barriers to performing a regularly scheduled exercise program. In some cases, fatigue is directly related to intolerance to heat. For those who are not overly sensitive to heat, an outdoor exercise program is one strategy to treat fatigue. Being outdoors and getting short exposures to the sun, can help improve sleep patterns. In addition, movement outdoors (whether walking or with a mobility device), can improve the balance system in a way that cannot occur indoors.

For patients with heat sensitivity, use of a Cool-Shirt® or one of the cooling vests, along with proper nutrition (appropriate fluids and meals) can allow the majority of patients with MS to tolerate the outdoor environment for, at least a short period of time. In instances where there is high humidity, wearing the appropriate clothing to permit sweat to evaporate is very important. Ultimately, the goal is still to get outdoors, even if only for a couple of minutes.

Many patients at the IMSMP have accepted outdoor activities to be a major part of their Home Activity Program prescribed by Dr. Stephen Kanter, Physical Therapist. For example, several patients continue to routinely take their dogs out for a walk, even if the use of a scooter is needed for that task.

Walking Like a Champ

When Maryvan Pendl steps out her front door she has a new spring in her step! At Dr. Kanter’s suggestion Maryvan now brings her two year old pup, William on daily walks. However William receives all the attention. His breed, the Affenpinscher won Best in Show at this year’s Westminster Dog Show and his dad, “Banana Joe” took home top honors! “We often get stopped on the street during walks, which I enjoy,” said Maryvan. “I’m meeting more people and having more contact and interaction with neighbors. William gets me out of the house, keeps me motivated and is an excellent companion.”

Initially, Maryvan was walking just the length of her block. Dr. Kanter suggested she slowly try to increase the distance.

These days Maryvan completes the entire loop around the block with William. William was born with a minor physical imperfection and therefore deemed unable to compete and become a show dog. That’s just fine with Maryvan. William has changed her life. “He’s my Top Dog and will always be a champion in my eyes!”

Patient Fundraising Events

“Cocktails for a Cure” Benefit a Resounding Success!

The 2013 Cocktails for a Cure fundraiser, held on April 26th, was a rousing evening of entertainment. This was the second year at its new, larger venue, the Greenwich Village Country Club near Union Square, and drew a festive crowd of over 450. Event guests played nine-hole miniature golf, air hockey, foosball, and pool. They bid on items in the vast and stylish online jewelry store, through which they donated 10% of all sales between April 5th and 26th. In the final tally, over $30,000 was successfully raised to advance research at Tisch MS.

Thank You, Liberty Baptist Church

On March 10th, Tisch MS Research Center was invited to a church service at Liberty Baptist Church in Brooklyn by Crystal Bonita Windham, who has been Dr. Sylvester’s patient since 2007. During the service, Crystal’s father and Deacon of the church, Clarence Koonce, presented a check to the Center. This was followed by a lively and inspiring choir performance, directed by Crystal herself. The Tisch MS Research Center of New York is deeply touched by the generosity extended by the congregation of Liberty Baptist Church.
New Board members Dan and Bonnie Tisch were warmly welcomed to the Board of Directors at the March 27th meeting.

Left: Dr. Sadiq, Chairman of the Board Lee Seidler, and Dan Tisch stand in front of the newly renamed Tisch Research Laboratory.

Right: New signs throughout IMSMP and Tisch MS Research Center reflect its new name.

Have a Facebook account? Are you LinkedIn? With the advent of social media, it has never been easier to raise funds for Tisch MS Research Center! On Facebook’s Causes page, you can help spread the word about the Center. On LinkedIn, a simple, brief letter about the Center and a personal story that includes a link to tischms.org’s contribution page is an efficient way to bring in funds for the Center’s innovative MS research. Crowd-raising sites like firstgiving.com and crowdrise.com are great fundraising tools as well.

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

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Tisch MS Research received Corporate Matching Gift Funds from:
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Microsoft
Pfizer Foundation
Travelers Community Connections Program

*This list includes donors of $100 or more between January 1 and April 30, 2013, not including donations supporting the 2013 Path to Progress Benefit.

Tisch MS Research Center receives Workplace Giving funds from the United Way of New York City and Bergen County, NJ. Inquire with your employer to participate.

The Development Office can be reached by calling Kimberly Woodward, Development Manager at (646) 557-3863 or email: kwoodward@tischms.org
Save the Date: 10/13/13

What: Tisch MS Research Center of New York

16th Annual MS Patient Education Symposium

Where: New York Hilton Midtown

When: Sunday, October 13, 2013
9:30am-2:30pm

This FREE event is open to patients, their families and caregivers. Registration is required.

To register early go to:
www.tischms.org
Or call: (646)557-3919