

Spring 2016 Volume 3, Issue 31

Healing MS

THE IMSMP NEWSLETTER TO ADDRESS THE NEEDS OF OUR PATIENTS AND KEEP YOU INFORMED OF THE LATEST RESEARCH TREATMENTS AND WAYS TO HEAL

CONTROVERSIES IN MS

by Dr. Deneb Bates







Many patients come to see us at the IMSMP with questions about how they could proactively manage their MS with life changes such as; altering their diet, or by taking nontraditional medication. Dr. Deneb Bates, a naturopathic doctor who specializes in a holistic approach in treating MS patients, offers her thoughts on the most up to date research. The following nontraditional treatment options are most commonly brought up by our patients:

Medical Marijuana

As various states legalize the medical use of marijuana for certain patient populations, it has become a popular topic as a treatment option for MS symptoms. Although medical marijuana has some potential benefits, it has some detriments as well. The benefits of medical marijuana in MS include; pain relief and patient perceived level of spasticity. It also may be mildly helpful for bladder frequency. Because it is sedating and induces hunger, it can also be helpful for sleep and for people who need to gain weight. The risks of marijuana use include; balance issues and negative impact on cognitive function. These risks have increased significance in the MS population. It also can exacerbate fatigue and contribute to weight gain. The psychotrophic (mind altering) effects of marijuana are considered a positive aspect by some and a negative aspect by others. Like every other treatment option, it's important to weigh the risks and the benefits of this controversial herb. For most people with MS, other available medications can better treat the symptoms without some of the troublesome side effects caused by marijuana.

Tobacco

Tobacco is one of the few known environmental risk factors contributing to the onset and progression of MS. If you are a smoker and you have MS, you have so much to gain by quitting, including protecting your neurological health. Dr. Bates offers a 6 week program for smoking cessation which has helped many of our patients quit.



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Dr. Deneb Bates, IMSMP Naturopathic Doctor

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CONTROVERSIES IN MS

Cover story cont'd

Low Salt Diet

Animal studies show that an extremely high salt diet increases Th17 cells, the part of the immune system that aggravates MS. Human studies have shown that people with MS with the highest salt excretion in their urine have the most severe disease course. Salting your food at the table may not be the real problem though. Packaged and processed foods are by far the biggest source of salt in the human diet. Fruits and vegetables are naturally low sodium foods. One of the best take-away messages from these studies is to focus on a fresh, plant-based diet, and reduce consumption of lowquality high-sodium packaged foods.

Gluten-Free Diet

Gluten has become a popular dietary enemy. Does a gluten-free diet really make a difference in people with MS? The answer is...maybe. But it seems to be individual. Celiac disease is one of the few autoimmune diseases with an identifiable and removable triggergluten! In all diseases, it is ideal to find the causative factor, because then we have the potential to remove it, and essentially cure the disease. It's exciting to identify a trigger of an autoimmune disease that can be entirely controlled by removing it from the diet. In recent years, gluten has become a suspect food for people with all types of autoimmunity. The idea is that eating gluten containing foods increases the susceptibility to autoimmunity beyond celiac disease, and that eating a gluten-free diet will reduce any added stress on the immune system for people with gluten sensitivity. Some studies have shown an increase in gluten sensitivity in people with MS, but it is still a small percentage of the total MS population. People with gluten sensitivity often feel noticeably better on a gluten-free

diet, and people with true celiac disease must avoid gluten 100% to control their disease. Because celiac disease can be an MS mimic, Dr. Bates believes that everyone with MS or similar neurological symptoms should be tested for celiac disease so that we never miss a treatable problem. Gluten sensitivity is harder to quantify than celiac disease because there aren't perfect lab tests to identify it. Dr. Bates works with the patients at the IMSMP to identify any food sensitivities, including but not limited to gluten, to maximize their health.

Low Dose Naltrexone (LDN)

Naltrexone is an FDA-approved medication that blocks opiate receptors and can prevent opiate overdose when used in emergency situations. Low Dose Naltrexone uses a fraction of this dose for off-label uses. LDN has caused much confusion and controversy among patients and neurologists. Probably the biggest confusion is the idea that LDN can replace FDA-approved medications as a disease modifying medication. This unproven use causes doctors concern that their patients are risking preventable disability by using LDN in place of the disease modifying therapies for MS. Understanding the way LDN works can help both patients and doctors put it to use in the most appropriate way.

Our bodies produce natural opiates (endorphins) throughout the day. They help us feel good and are natural pain relieving substances. As a miniscule dose, LDN blocks opiate receptors for a short period of time (several hours). When LDN is dosed at bedtime, this short-term blockage of opiate receptors makes the body experience a relative shortage, to which it responds by

increasing natural endorphin production. After a few hours, around the time of awakening, the activity of LDN wears off, and the open receptors are flooded with the body's own natural "feel good" molecules. This boost in endogenous endorphins can help people get through the day, feeling better.

While some patients feel benefits from LDN, there has been no proven benefit for the disease course of MS. Dr. Bates cautions that it should not be used by people on opiate pain medications, or for anyone who has trouble sleeping because of pain at night.

Supplements Instead of Medications

Taking an integrative approach to your treatment is the optimal way to care for MS. However, all the tools available to manage MS have their strengths and weaknesses. While approaches with diet and supplements can reduce inflammation and calm the immune system, FDA-approved MS medications are the best treatments available for controlling disease activity. No supplement can stop relapses or disease activity the way a well-prescribed medication, carefully considered by an MS neurologist, can. However, medications that stop disease activity don't have the ability to repair damage or rebuild brain function. Only a healthy body, armed with the right nutrients, can help to heal the brain. It is within every person's control to be as healthy as possible and to create an internal environment that helps their bodies and brains to heal. Don't wait for the future. Start today by giving your body everything it needs to regenerate and repair to the best of its ability.

LAB RESEARCH

Research Review from the 2016 American Academy of Neurology® (AAN) Annual Meeting

Tisch MSRNCY presented multiple research abstracts at the 2016 AAN Annual Meeting in Vancouver, BC, Canada:

From the clinical end, Dr. James Stark, Dr. Armistead Williams, and Dr. Saud A. Sadiq presented the abstract, "Evaluating the Safety and Efficacy of Transitioning MS Patients from Natalizumab to Rituximab." This research looked at a cohort of MS patients transitioning from Natalizumab, an effective treatment for relapsing forms of MS, to Rituximab, a different treatment that benefits both refractory relapsing and progressive forms of MS, in order to evaluate the incidence of Progressive Multifocal Leukoencephalopathy (PML) in this patient group. The results showed that there were no observed cases of PML or immune reconstitution inflammatory syndrome (IRIS). The results also showed that patients whose MS had been well controlled on Natalizumab maintained equivalent disease stability when transitioned to Rituximab.

Dr. Sadiq's abstract, "Multiple Intrathecal Dosing of Neural Progenitors Administered to Progressive MS Patients with Disability is Safe and Improves Disability Scores," was accepted for dual presentation, both as a talk at the Remyelination and Repair in Multiple Sclerosis Data Blitz Presentation and as a poster presentation. Dr. Sadiq presented data from the Phase I trial showing that the novel stem cell treatment was safe and well-tolerated with no serious adverse events reported.

For more information regarding the abstracts published and presented by Tisch MSRCNY, please look at our Winter 2015/2016 edition of our Healing MS Newsletter.

CONGRATULATIONS TISCH MSRCNY RESEARCH ASSISTANTS!

Tisch MSRCNY is thrilled to announce that all 6 of our secondyear research assistants will be matriculating to medical schools and graduate schools:

Pak Ho Au, who has worked with Jerry Lin, will be pursuing an MD at Robert Wood Johnson Medical School, part of Rutgers University.

Leslie Blackshear, who has worked with Dr. Saud A. Sadiq, will be pursuing an MD at Emory University School of Medicine.

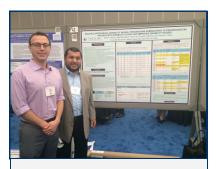
Danielle Blemur, who has worked with Dr. Fozia Mir, will also be pursuing an MD at Emory University School of Medicine.



Ruth-Anne Langan, who has worked with Dr. Violaine Harris, will be pursuing a PhD in Immunology at the University of Pennsylvania.

Kelsey McDermott, who has worked with Dr. Massimiliano Cristofanilli, will be pursuing a PhD in Neuroscience at Albert Einstein College of Medicine.

Bianca Ulloa, who has worked with Dr. Violaine Harris and Dr. Ying Liu, will be pursuing an MD/PhD at Albert Einstein College of Medicine.



Dr. James Stark & Dr. Saud A. Sadiq present research at the 2016 AAN Annual Meeting



Pak Ho Au



Leslie Blackshear



Danielle Blemur



Kelsey McDermott



Ruth-Anne Langan



Bianca Ulloa





What is Team Tisch MS?

Team Tisch MS, also known as TTMS, is the team of runners, bikers, swimmers, triathletes, and ironmen/ironwomen who are competing in races and other events, raising money to donate to the Tisch Multiple Sclerosis Research Center of New York to advance research and help find a cause and cure for multiple sclerosis.

Announcement: Last Call to secure your spot for the 2016 TCS NYC Marathon!!

Run the world's most famous race and support an important cause. For more information visit:

http://tischms.org/teamtisch-ms

A NOTE FROM THE NURSES

Nursing Educational Seminars Coming Soon ...

We are excited to announce that our nursing team will be starting two seminars with the goal of providing a support system as well as a source of educational information for our patient community.

There are so many questions that our patients frequently ask about multiple sclerosis. Why does the heat affect me? What do I need to know about vaccinations? Why do my symptoms worsen with an infection? What side effects might I experience with different medications? The list can go on and on and your nursing team is here to help!

Although our phone line is always available to assist with more urgent issues, we are happy to announce this new nursing forum project to provide an educational, interactive experience.

During these seminars, which will be held at our center, as well as broadcast live through a webinar, we will discuss current research updates, focus on various topics of interest, and provide an environment for discussion. We will also solicit suggestions from our community so that we can cover those topics that are most relevant to you.

We will also be starting separate educational seminars designed specifically for newly diagnosed patients. These will be held at 5pm on the first Wednesday of each month and they will present an overview of the nursing services that we provide at the IMSMP, in addition to discussing issues pertinent to newly diagnosed patients.

We are looking forward to these new projects and will provide further updates in the coming weeks!



Save the Date Sunday, October 16th, 2016

Tisch MS Research Center of New York 19th Annual MS Patient Symposium

New York Hilton Midtown ~ 9:30am - 1:00pm

Register Today at: www.tischms.org

Or call (646) 557-3919

PHYSICAL THERAPY & REHABILITATION

Finding Your Physical Therapy Team

For people who have multiple sclerosis, a common question asked is, "Where do I find the right physical therapist for someone like me?" In many cases, the patient or their caregivers are looking for a physical therapist who specializes in multiple sclerosis. The fact is, there are few physical therapists who primarily treat people with MS. The MSCS (Multiple Sclerosis Certified Specialist) credential may be seen after the name for a PT who commonly works with people with MS. There are, however, many physical therapists who are great at treating the symptoms commonly found in people with MS.

For people who have balance and gait dysfunction, a neurologic PT is ideal, but many good orthopedic and sports PTs are able to create a quality functional mobility and fall prevention therapy program as well. Many neurologic PTs can recommend appropriate bracing for foot drop or spasticity management. A neurologic PT may have the NCS (Neurologic Certified Specialist) credential.

Orthopedic PTs are the most common in the field. In many cases, orthopedic specialists are best able to manage the symptom of pain, since most pain is due to orthopedic (specifically joint) dysfunction.

Other PT specialists that should be considered for people with MS include; wheelchair specialists, pelvic floor specialists, and vestibular specialists. Wheelchair specialists are better known now as seating and mobility specialists. Many of these specialists have earned the ATP/SMS credential and are affiliated with formal wheelchair clinics. Pelvic floor physical therapy is one of the newest specialties and has been growing



Dr. Stephen Kanter

quickly to improve the physical and functional abilities for patients who have bladder and bowel dysfunction. For many people with MS, bowel and bladder dysfunction can be treated by a pelvic floor specialists. Though many pelvic floor specialists have been referred to as woman's health physical therapists, many men with bowel and bladder symptoms have successfully been treated. Vestibular physical therapists are trained in advanced examination and clinical procedures to evaluate patients with dizziness, vertigo, and related balance dysfunction. In some cases, the vestibular specialist can quickly clarify and potentially eliminate dizziness.

Finding the right PT service may best be achieved by looking for and seeing a PT specialist. If you are not sure if you need to see a PT specialist, you can be evaluated at the IMSMP by physical therapists, Dr. Stephen Kanter or Dr. Elizabeth Woods. Based on what is found during your evaluation, you may be referred to the appropriate PT specialist if necessary.

SOCIAL WORK NEWS



Emily Penn, LMSW

The Social Work Department would like to welcome our new social worker to the team!

Emily Penn, LMSW, joined our team from Overlook Medical Center in New Jersey, where she worked in an inpatient cardiac unit. Emily received her Bachelors' of Arts at Washington University in St. Louis, Missouri and her Master of Social Work at New York University in New York City.

Emily is a great addition to our social work team! Welcome Emily!

TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

Inspiring Events by Patients & Friends

Pride Cleaners MS Awareness Month (Kansas City, MO) - In honor of MS Awareness Month, this past March, every Pride Cleaners matched all customer donations made at their stores. All proceeds went to the Tisch MS Research Center of New York. Thank you to Pride Cleaners for raising \$25,200!

Middle School Girls Join Forces in the Fight Against MS

Dani Heller, age 11 and Julia Weiss, age 14, have little in common. They live in different communities, have different interests, but in March 2016 they worked together to do what they could to help the Tisch MS Research Center of New York.

The girls sold edible cookie dough from DO NYC, and developed all of their own marketing and sales strategies. They targeted other students in their schools by posting information about MS, and the delicious cookie dough that they were selling on Instagram. They also told their friends, and solicited their parents' friends as well. The girls raised \$750 that they sent to Dr. Sadiq to help him with his MS research.

Dani and Julia have been involved with the National MS Society since they were born, participating every year in the New York MS Walks from when they were in strollers. Their moms, Sherri and Lauren, have been best friends since they were in middle school together.

In 1996 Lauren's brother David Kasell (Julia's uncle) was diagnosed with MS. And then in 1999, Sherri was diagnosed with MS. Both were fortunate enough to find Dr. Sadiq to help them with their treatment.

Dani and Julia were able to raise awareness about MS, and money to support the incredible research efforts of Dr. Sadiq and the Tisch MS Research Center of New York.







TTMS Runners pictured L to R: Whitney Mallis, Stacey Ketcham, Jaclyn Trezza & Jessica Keaney



MS WALK (Long Island, NY) - April 17, 2016. Special thanks goes out to: Sandra Levine for raising \$839.74 and Christine Romano for raising \$899.05!

Team Tisch MS MORE/Shape Half Marathon

(Central Park, NYC) - April 17, 2016 . Tisch MSRCNY would like to thank our in-kind sponsor Tommy Bahama for the their support - grand total raised: \$7,871.42

DEVELOPMENT DEPARTMENT NEWS CONT'D

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The Tisch MS Research Center gratefully acknowledges corporate matching gifts from the following companies:

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*This list includes donors \$500 or more received between February 1st and April 30th, 2016. While every contribution is deeply appreciated, we regret that we are unable to list gifts below \$500 due to space limitations.

Every effort has been made to ensure the accuracy of this list. Please email Zammy Diaz Lebron, development@tischms.org, or call (646) 557-3900 to report any errors or omissions, or if you would like to have your name removed from future listings.

IMSMP Saud A. Sadiq, MD, FAAN Director

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