

the MS CHRONICLE®

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Message from the Executive Director:

Heat, Heat and still more Heat, that seems to be the word for summer 2010. I can't really remember a summer in many years with so many days in the 90's. I hope that many of you who are adversely affected by the heat are doing your best to stay cool and everyone needs to stay well hydrated. We have a pamphlet on Heat Sensitivity if anyone is interested in reading it.

It was really fun to see so many people at the Client Indoor Picnic at the Empire Room. We enjoyed great food and fun! Congratulations to all the door prize winners and to Pat Kelly from CNY Sedan Services for winning the handmade quilt. Many thanks to those who brought in canned goods for our Holiday Baskets! We appreciate your thoughtfulness.

This summer we have had many third-party events where MS Resources has been the chosen recipient of the proceeds. Thanks so much to each and every one of you for your support and interest. We know the amount of time it takes to put an event together and we so appreciate all your hard-work and dedication.

Don't forget about Pig-A-Palooza if you are participating. I know Annette has been working diligently on securing door prizes and creating really fun games. Be sure to RSVP for the PIGNic. Check your last flyer

for all the details and join us. We really would like to have at least 100 people there so we can continue this next year.

Special thanks to Joanne Catanzarita and Cindi Segovis for once again being our assistants at the Women's Weekend. We are excited for next years weekend and have already begun planning!

The calendar is getting filled with educational programs, fund raising events and much more.

I hope that the rest of your summer is cool and safe!

Look inside for:

- ▶ Numbness & Tingling/Cold Feet
- ▶ Motorcycle Ride – Watertown
- ▶ Romano's Point of View
- ▶ Men's Weekend Get-Away
- ▶ Support Group Meetings

Numbness & Tingling

Numbness and tingling are among the most common complaints in MS. They usually are an annoyance rather than a truly disabling symptom. They occur when the nerves that transmit sensation do not conduct information properly, so that one is unable to feel sensation from that area.

Little can be done to treat numbness and, because it usually is a harmless symptom, there is no real need to do so. In some cases steroids may improve sensation by decreasing inflammation, but their use is reserved for instances of real need. Neurontin and Elavil may be administered with an occasional decrease in feelings of numbness.

Focusing on numbness may magnify the problem and make it especially bothersome. The best approach is to realize that it is only an annoyance and does not imply a worsening of the disease. A more aggressive approach with cortisone therapy may be considered if the numbness involves the hands, impairing fine movements, or the genitalia, making sexual relations difficult. Unfortunately, no medication specifically treats numbness. If the numbness gets in the way of function, a course of corticosteroids may be necessary.

Cold Feet-

The complaint of cold feet is common in MS, even in the milder forms of the disease. The maintenance of skin temperature is an “involuntary” process under the control of that portion of the nervous system referred to as “autonomic”, which controls functions such as heart rate, sweating and pupil dilation. Short-circuiting in the interconnections that control the diameter of blood vessels and those nerves that sense

temperature appears to be responsible for the perception of cold feet.

This symptom may be annoying, but it usually is innocuous. There is nothing wrong with the blood vessels themselves in the legs or feet, and there is nothing dangerous in the slight drop in temperature that produces this sensation. It should be emphasized that cold feet do not signify a general circulatory problem. Most people who have this symptom are young and have normal blood vessels. Although they are not protected from vascular disease by MS, they are no more likely to have it than are others of a similar age. Nonetheless, if the problem is severe it should be checked out by a physician.

The best way to manage the problem of cold feet is with warm socks, an electric blanket and similar local treatments. Occasionally, niacin or medications that dilate blood vessels may be used to alleviate this symptom when it is particularly annoying.

“Managing the Symptoms of Multiple Sclerosis”, Schapiro, Randall T., MD., Demos 2007.

Betaseron’s “Your Guide to Decide”

Find the information you need now- The interactive “*Your Guide to Decide*” is as close as the nearest computer. This is a new stick that you plug into the USB port to learn about Betaseron.

Betaseron is clinically proven to delay progression from CIS to RRMS

BETAPLUS is exclusive support when you need it

BETAPLUS can help make your treatment affordable, \$0 monthly co-pay (some restrictions do apply)

The office has a few computer sticks if you are interested in learning more about Betaseron. Call today and we will send the packet to you.

Support Group Information

Interested in sharing experiences about MS, come with family/friends to a meeting.

Syracuse Area-

2nd Tuesday of the month
Lincoln Middle School, James Street
7PM-8:30PM School Cafeteria

****Meetings resume in September.**

Madison County Area-

1st Monday of the month
Stonehedge Nursing Facility
Russell Street, Chittenango
2:30PM-4:00PM Dining Room

Auburn/Cayuga County Area-

4th Tuesday of the month
Denny's Restaurant
Grant Ave, Auburn
7PM Coffee, etc. on your own.

Syracuse Area Social Gathering-

Contact: Dottie Robertson for more information @ 672-8129.

Oswego County Area-

1st Wednesday of the month
Seneca Hill Manor
20 Manor Drive, Oswego
2PM First Floor Dining Room

Liverpool Group –

3rd Thursday of the month
United Church of Christ Church (UCC) in Bayberry, 215 Blackberry Rd. 6:00PM – 8PM in Freedom Hall, follow the signs to the meeting room.

Contact: Carolyn Vickery – 409-9692 or Pat Apicella – 727-7140

Words to Know

Metabolism-Energy changes that occur within the cells of the body.

Olfactory-The sensation involved with smell.

Paraplegia-A weakness of both legs

Plasmapheresis-The removal of plasma with replacement by an appropriate fluid; removes impurities in the plasma.

Protein-A class of chemicals naturally occurring in plants and animals composed of nitrogen and amino acids.

Remission-A lessening in the severity of symptoms or their temporary disappearance during the course of the illness.

Spinal Cord-The part of the Central Nervous System (CNS) that connects the brain and its related structures to the peripheral nervous system.

Shared Solutions TeleConference Schedule

Bladder & Bowel Issues in MS-

Bladder and bowel function can be embarrassing topics, but they are critical to your health and quality of life. We'll discuss why it's important to report concerns to your physician and share approaches that can help you manage symptoms.

August 10th 8PM ET

August 11th 9PM ET

Christopher LaGanke, MD

President, N. Central Neurology Associates

Schedule Cont'd
Director, JoAnne P. LaGanke MS Center,
Cullman, AL

Michelle T., MS Peer

Immune Smart: Making RRMS Treatment Choices for the Future-

With new options on the horizon, there are new considerations when making a treatment decision. Hear more about the different ways that therapy can impact immune function.

September 29th 8PM ET
September 30th 9PM ET

Gabriel Pardo, MD
Medical Director, Multiple Sclerosis Center
of Oklahoma, Mercy Neuroscience Institute,
Oklahoma City, OK

Terrie P., MS Peer

***It's easy to participate! No RSVP required.
One number for all: 1-800-823-1880. Call
today to set up a reminder call so you don't
miss the teleconference. Or simply call in
on your choice of teleconference nights to
participate.***

Frequently Asked Questions Regarding CCSVI

- Q. What does CCSVI stand for?
A. Chronic Cerebral Spinal Venous Insufficiency.
- Q. What is the difference between an ultrasound and an MRI for the jugular veins?
A. Ultrasound can image the vessel and flow in real time. As such, it can monitor the motion or lack of motion of a valve throughout the cardiac

cycle. However, Ultrasound does not have the full scope of 3D coverage that MRI does nor the in-plane resolution although through plane resolution can be quite high for the vessel wall.

- Q. Does having a cardiovascular problem and MS relate to CCSVI?
A. At this time, we do not know
- Q. Does an MR scan affect iron in the brain?
A. An MRI would have no effect on iron in the brain that we know of.

www.ms-mri.com

Romano's Point of View *The Spirit of July*

July is one of those rare months that is colored a certain way in my mind. Just as October is orange and golden yellow, July is always red, white and blue. Draped on porches or flying on staffs, those colors remind me to pause and think about the freedoms I enjoy but usually take for granted. With you, I have the **freedom to** speak, write, vote, assemble, practice my religion, and own a firearm, among many other valuable liberties.

In the MS community there is also talk about freedom. It all began with Dr. Zamboni's research done in Italy last year. He reported that there was evidence that a percentage of people with MS had problems with blockages in the veins of their neck or other places. Patients from all over the world have been clamoring to be tested and treated for their possibly narrowed or twisted veins. The treatment phase of the condition known as CCSVI (Chronic Cerebrospinal Venous Insufficiency) is known as the "Liberation Treatment". Ever since I first heard that

term, I've been enthralled with the concept. I'm gaga over the thought of liberation!

For now, the liberation I'm referring to is not *necessarily* the liberation from CCSVI. I'm referring to the secret desire I harbor to be ***freed from*** all the restraints that MS has put on my life. I've been compiling a huge unwritten list during my journey---it could be called the "I-Want-Freedom-From-Database".

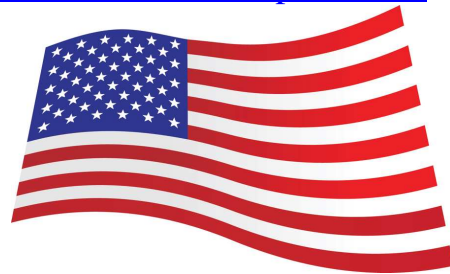
Part of my ***freedom from*** entries are straightforward. I want ***freedom from*** brain fog. I'd like ***freedom from*** ugly shoes without sacrificing my safety. How about a dose of ***freedom from*** heat intolerance so I can go to the beach or pool and make it to the water and back without an ambulance being called to the scene? Daily shots, buzzing arms, double vision--- I want ***freedom from*** those too.

The majority of my virtual listings is broad in scope, however. For example, I want ***freedom from*** having to choose. Right now, I can't say, "I'll do one thing AND then I'll do another". Instead I have to plan and say, "I'll do this thing OR that thing, but not both." Well, I don't want to choose; I want to do both! (The word *both* is punctuated with a foot stomp.) Each situation, chore, activity or event must be processed and categorized in terms of energy expenditure (EE), with a careful consideration of other criteria that impacts the EE. The processing and choosing is complex. For instance, an activity or chore done today will affect all activities done tomorrow. Generous amounts of time for recuperation in between activities must be allotted to build-up my supply of energy units (EU). Before long, the chores I need to do and the activities I want to do stack up, and a backlog of commitments-to-be-repaid grows by the day. This backlog is accompanied by a huge side order of guilt from not repaying those commitments and becomes an extra stress of its own. Another

twist: doctors' appointments and tests supercede most other activities or chores, which means that an activity that I want to do will drop off my list completely. Hopes and dreams? Those are all archived in dusty, inaccessible places. There's no time (or EU) for dreaming, let alone fulfilling those dreams. There's only time for choosing.

Despite it all--- the daily struggles of balancing and selection and the oppressive heat---July will remain a special month to me. My heritage of existing liberties (***freedoms to***) has enabled me to dare to dream about the liberties that don't exist yet. (***freedoms from***). In this great nation of ours, there are excellent possibilities ahead for us. I believe that so strongly that I'm willing to bet my precious red, white and blue flag tiara on it.

P.S. Readers wanted at my blog:
www.donna55.wordpress.com.



Men's Weekend Get Away

The Annual Men's Weekend Get Away is scheduled for September 17-19, 2010 at the White Eagle Conference Center in Hamilton NY. The Weekend is a great time to meet up with old friends, meet new ones, share stories, listen to a medical professional, play games and activities and win lots of prizes. There is also ample free time to explore the grounds of the conference center, rest and enjoy all the amenities offered. The entire weekend is only \$125 and scholarship dollars are available.

Weekend Cont'd

For an application, please call the Office at (315)438-4790. We really would love to have at least 15 men in attendance. Once you come the first time, you will wonder why you never came in the past. Call today, we promise you will have a great time and eat very well also.

Please consider attending the weekend this year and if you would like to speak with a past participant, we can have someone call you. Space is limited, so call today.

MS in the News MS in the News

Active Mind May Protect MS Patients

June 2010-A small study of MS patients shows that maintaining an intellectually active lifestyle can help preserve learning and memory, even among patients with a high degree of damage.

Although there's no indication that being mentally engaged protects against damage itself, the findings do suggest that an active mind may be better equipped to retain its functions even in the event of damage.

MS is a neurodegenerative disease that causes inflammation to the central nervous system, which can lead to damage. Loss of cognitive function, including memory and learning capabilities, is common among persons with MS.

Protecting the Mind-
Researchers at the Kessler Foundation Research Center in West Orange, NJ, studied 39 women and 5 men around age 45 who had MS for an average of 11 years and who did not have any history of mental illness, learning disabilities or substance abuse.

The investigators measured the patient's mental activity by having them complete verbal and memory tests and by evaluating their vocabulary—often considered a marker for intellectual enrichment. The patients also underwent MRI's to assess any damage.

Overall, patients who had lived a mentally active lifestyle, one that was filled with education, reading and other mentally engaging activities, showed a greater buffer against mental decline, even if they had extensive damage.

For example, with the verbal learning and memory tests, patients were given as many as 15 tries to learn a list of 10 words and then were asked to recall those 10 words after 30 minutes. The recall decline among the more mentally active group was only 1% even among those who had high levels of damage, compared with 16% among those who led less intellectually stimulating lifestyles. People with less intellectually enriching lives had slower recall and slower learning.

“The findings suggest that enriching activities may build a person's cognitive reserve, which can be thought of as a buffer against disease related memory impairment,” says study author James Sumowski, PhD. “Differences in cognitive reserve among persons with MS may explain why some persons suffer memory problems early in the disease, while others do not develop memory problems until much later, if at all.”

The study does appear in the June 15 issue of *Neurology*.

Preventing Mental Decline-

In an accompanying editorial, Peter A. Arnett, PhD, of Penn State University in Pennsylvania called the study “provocative.” “These results open up a whole new area of inquiry in MS that could have significant impact,” he writes. “There’s the potential that people could improve their cognitive reserve to reduce or prevent cognitive problems later.”

Sumowski says people with lower than average intellectual enrichment may be at a higher risk for MS-related cognitive impairment. “Patients with lower enrichment may benefit from early intervention cognitive rehabilitation programs to reduce the risk of future impairment,” Sumowski and his team write.

The authors note that education attainment may play a role in a person’s ability to live a mentally active life. They also said their findings reflect the results of other studies, which suggested activities such as reading, crossword puzzles, and other forms of intellectual stimulation might help protect against cognitive decline in other neurodegenerative disorders, such as Alzheimer’s Disease. There is growing interest among scientists in neuroplasticity, a concept that suggests that the brain can be malleable and that mental stimulation can help keep the brain fit and supple.

WebMD 2010.

The Neuropsychological Evaluation What is it and Who does it????

A neuropsychological evaluation is a series of different test, each of which is designed to assess one or more specific cognitive changes. Evaluations can be short or long. The set of tests is often referred to as a battery. Batteries of tests may be assembled

from different sources by the examiner or purchased “off the shelf” in a pre-assembled package. In most cases, the results of the battery of tests are not combined into a single score. Instead, specific scores are generated for different functions such as verbal memory, visual memory, abstract reasoning and the like.

Because the pattern of cognitive changes in MS varies from person to person, and because the individual’s goals also vary, the evaluation must be comprehensive enough to cover a wide variety of functions and must be sensitive to the variations between individuals. Moreover, one purpose of the evaluation is to pinpoint strengths as well as weaknesses in cognitive functions, which can only be accomplished through a comprehensive evaluation.

These evaluations are generally performed by neuropsychologists. A neuropsychologist is a psychologist with a doctoral degree who has specialized training in the diagnosis and assessment of cognitive problems. A clinical psychologist may also administer neuropsychological evaluations, but clinical psychologists generally lack the specialized training needed to make the best use of these types of assessments.

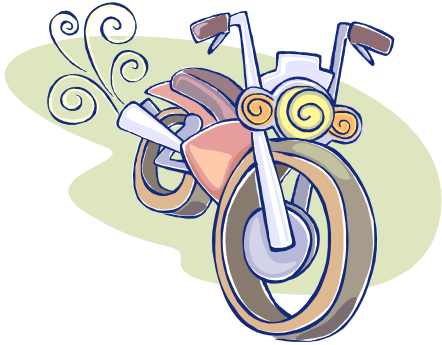
Multiple Sclerosis - Understanding the Cognitive Challenges., LaRocca, Nicholas, PhD, Kalb, Rosalind, PhD. Demos 2006

“Ride for Everyday Heroes”

The Twist of Fate Motorcycle Club in Watertown, NY will be hosting the first ride for everyday heroes with proceeds benefiting MS Resources. So if you are a motorcycle rider and want to join in this event, here are the particulars:

Ride Cont'd

Saturday, August 21, 2010 – Register at Thunderin' Cycles on Concrete Blvd., Watertown NY between 10am-11am. There is a \$15 registration fee and \$10 for a passenger. The ride leaves at 11 am sharp and stops include-Captain Jack's, Skiff's, the American Legion and finishes at the Ugly Stick in Black River. There will be a chicken BBQ, raffles and entertainment. For a flyer please contact the Office and for ride particulars, please contact:



Queen – (315) 405-2704 or visit her at www.myspace.com/twistoffatmc.com.

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