

the MS CHRONICLE®

Volume 12, Issue 3

June 2010

A Publication of Multiple Sclerosis Resources of Central New York, Inc.®

Message from the Executive Director:

*Just when I thought there was no more confusion about MS Resources and other agencies, I was wrong. I guess there is still some confusion about us and other like sounding non-profits. So let me reiterate here, we are a **one-of-kind, local, non-profit agency in East Syracuse. We are not part of any other Multiple Sclerosis agency.** We do not share events, programs or services. We have worked very hard over the past twelve years to establish our own individual identity and create our own inroads in the realm of MS. Should you still not understand the difference, please call us or send us an email and we will clear it up for you. We are a local agency and everything we do benefits local clients. That goes for programs, services and dollars. We spend 90 cents out of every dollar raised right here in CNY to support client programs, etc. Keep that in mind when you are getting ready to make a donation of some sort and question whether or not the agency that you are thinking about donating to can make that claim?*

If you have big summer plans, be sure that you stay cool and well hydrated. You want to have a good time at graduation parties, family gatherings and picnics, so it is important to keep your body temperature cool and keep fluids close by. We do have some good information on beating the heat and if you are interested, please contact the Office and we will get it out to you.

You can check out MS Resources on Facebook now. We are in the creating phase and hope to get all events, programs and services posted. You can join and be a friend, meet other people with MS and share experiences.

I hope to see many of you at the Client Indoor Picnic scheduled for later this summer. Details will be sent soon. Have a safe and enjoyable summer.

Look inside for:

- ▶ Vertigo and MS
- ▶ What exactly is CCSVI?
- ▶ Romano's Point of View
- ▶ Utica Walk Wrap - Up
- ▶ Support Group Meetings

Vertigo and MS

Vertigo is a common symptom of MS, occurring in about 20% of people with MS at some point. It is an acute, uncomfortable sensation, making those who are already a little unsteady, even more nervous about moving around. Fortunately, it is not a permanent symptom, and may not even indicate a new lesion or inflammation, as vertigo can have non-MS causes. Though it can be caused by lesions in the cerebellum or the nerves that control the vestibular functions of the ear in the brain stem, it appears that a very common cause in people with MS is something called benign paroxysmal positioning vertigo, rather than demyelination, and is in no way related to MS. Vertigo can also be made worse by some of the drugs prescribed for MS symptoms, such as tricyclic antidepressants.

Vertigo is a sensation of spinning, whether it feels like you are spinning or your surroundings are rotating around you. It can feel like the ground is suddenly rushing upwards or that the room is moving continuously or only seems to rotate part of the way. Vertigo episodes rarely last for a long time, but they can recur for weeks, going away gradually. Vertigo can cause people to be very nervous about going out, so they limit their activities, as they are afraid of having an attack. It can be a very powerful feeling of movement and can cause nausea or vomiting. At its worst, it can cause difficulty standing or walking and even leads to falls.

Consult your neurologist or an ENT if you experience symptoms of vertigo. There are medications such as antivert (meclizine) which can help.

MS Manifesto-Demos 2010

MS LifeLines

Who are they: MS LifeLines is a free support service designed to help those starting and staying on Rebif therapy today and every step of the way.

Customer Support Specialists:

When you contact the MS LifeLines Call Center, you'll reach one of their caring and knowledgeable Customer Support Specialists. Their job is to get you the support you need when you need it. These Specialists will connect you with the appropriate person for your needs within the MS LifeLines network. Available to you-Monday through Friday, 8AM – 8PM EST.

Nurse Support Specialists:

The Nurse Support Specialists receive extensive training and are certified in MS management. They can answer questions you may have about relapsing MS and Rebif. No question is ever too big or too small. Available through MS LifeLines Call Center, Monday through Friday, 8AM – 10PM EST. A health care professional can still be reached even after these hours.

Field Nurses:

A dedicated team of MS-certified Nurse Specialists is available in many areas across the US to help you get started on Rebif. In the comfort of your own home, they can”

- >Show you proper injection technique
- >Share tips for reducing certain side effects
- >Answer questions you may have

Reimbursement Specialists:

The Reimbursement Specialists are there to help you get the best possible coverage under your insurance plan. If you do not have insurance, or if your insurance will not cover your treatment, the Reimbursement Specialists will help you get connected with

the appropriate assistance programs. They are available Monday through Friday, 8AM – 8PM EST.

2008 EMD Serono pamphlet.

What is CCSVI???????

There is still a lot of discussion going on about CCSVI. Here is some information of what CCSVI is all about.

CCSVI – Chronic Cerebrospinal Venous Insufficiency is a chronic condition if left untreated, which causes blood from the brain and spine to be slowed or stopped in an attempt to flow back to the heart.

The condition is caused by stenosis, a narrowing of the veins that are primarily used to drain a human's blood from the spine and brain. This usually occurs in the jugular and azygos veins. When these veins become narrowed blood takes longer to get back to the heart and in time, causes the blood to reflux. Reflux is a term given to blood being forced back into the brain or spine. If this occurs, leakage of red blood cells and other fluids can flow into the tissue of the brain and spine, at times crossing the crucial blood brain barrier. If blood stays in the brain for a prolonged period a slowed perfusion may occur. This is the delay of deoxygenated blood leaving the head. This causes a lack of oxygen or what is known as hypoxia in the brain and has been linked to fatigue in MS.

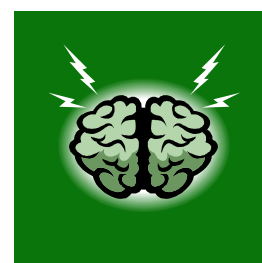
CCSVI and its relation to MS- A leading surgeon named Dr. Paolo Zamboni from Italy completed a preliminary study using ultrasound and MRV (magnetic resonance venography) to examine the blood vessels leading in and out of the brain of hundreds of patients and ordinary healthy controls.

Dr. Zamboni discovered that the majority of the patients with MS including one of which happened to be his wife, had jugular and azygos veins which drain blood from the brain distorted or blocked. In healthy controls without MS, the veins or vessels were not.

The Buffalo University CCSVI Study- More than 55% of MS patients participating in the initial phase of the first randomized clinical study to determine if persons with MS exhibit narrowing of the extracranial veins, causing restriction of normal outflow of blood from the brain, were found to have the abnormality.

When the 10.2% of subjects in which the results were border line were excluded, the percentage of affected MS patients rose to 62.5%, preliminary results show, compared to 25.9% of healthy controls. These preliminary results are based on the first 500 participants in the Combined Transcranial and Extracranial Venous Doppler Evaluation study, which began at UB in April 2009.

There are numerous studies being conducted currently. For more information, please consult with your own neurologist. At the time of the printing of this newsletter, we have heard from many clients stating that they have had a difficult time finding a physician who will test for CCSVI unless they were prone to strokes. If we learn of any new details, we will certainly pass those along to you.



What Should Others Know About MS?

It is important for your family, friends and coworkers to understand MS. Initially you may feel that you do not want anyone to know that you have MS. That is certainly understandable, but it is essential to tell the people you love and others when necessary, so that they can understand and help you deal with the disease. Most people are pleased and surprised at how supportive and understanding others are when they are informed. Many people may have guessed that something was wrong but did not know what to do or say. Until they know the truth, employers may not understand your need to take time off or to rest, and they may think you are not working well. Decisions to inform should be made on an individual basis, but in general, disclosure is a good idea. Once family and friends are aware of your diagnosis, they might benefit from literature that would allow them to better understand MS. In particular, your family should understand your symptoms and problems so they can be helpful and supportive. This is not possible if they are unaware of your MS and how it makes you feel.

MS Resources offers educational programs, support groups and literature. We can even add any family members/friends to this newsletter mailing list. We know how important support is to every client and want to be sure that your support system is well informed.

What about **Disclosing** my Diagnosis – Disclosure about one's illness – whether to family members and friends, new acquaintances or employers and colleagues – is a significant issue for most people living with MS. Many people are uncertain how much information they want or need to disclose, especially because there often is no visible impairment and some of the sym-

ptoms caused by MS can easily be attributed to a less serious cause. Consideration about disclosure at the workplace is a whole separate issue and research should be done before disclosing at work. (MS Resources has booklets on Employment Issues should you need to read more about this)

The first and most important group or people to consider are your family members. They are the easiest to make recommendations about, but sometimes the most difficult group to tell. Close family members need to know about your MS-what to expect and what they can do to help. In general, parents, siblings and other close adult relatives should be told calmly and directly about the diagnosis. They need to begin learning what MS is and what is known about your prognosis and limitations.

Children also should be told about the diagnosis. Even very young children are aware when something is wrong and tend to imagine the worst possible scenario. They need to be given some concrete information about the disease that they can relate to and understand. They also need to be reassured that Mommy, Daddy, etc is not going to die and that they will be able to take care of them. Children need to know that, although the parent may not be able to be as physically active as before, the family will work together to solve any problems that arise. Parents should also explain that no one can “catch” MS the way a cold can be caught from another person, that the children did not cause MS, and that they have no control over making it better or worse. Parents tend to underestimate the impact of MS on their children; they are at least as affected by their parents' emotional state and the emotional climate within the household as they are by any physical limitations imposed by illness.

(MS Resources has a small booklet for children of a parent affected by MS)

Remember that:

Secrets and Half Truths do not make a firm foundation for a healthy relationship

Think about when you would like to know important health related information about other persons

Keep in mind that revealing your MS may become increasingly difficult as your investment in the relationship increases

Multiple Sclerosis – A Guide for the Newly Diagnosed. Second Edition 2002.

Spring Educational Program

June 24 – Watertown, Best Western, Washington St.
6PM Check In, 6:30PM Program

Dr. Latif, Neurologist – “Dealing with Cognitive Issues for Persons with MS”

Light refreshments will be served, RSVP mandatory by June 18th by calling:
(315) 438-4790 or 1-800-975-2404

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

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

Brain Stem – The part of the central nervous system that houses the nerve center of the head as well as the centers for respiration and heart control.

Cerebellum – A part of the brain situated above the brain stem that controls balance and coordination of movement.

Cerebrum – The large, upper part of the brain, which acts as a master control system and is responsible for initiating thought and motor activity.

Foot Drop – A condition of weakness in the muscles of the foot and ankle, caused by poor nerve conduction, which interferes with a person’s ability to flex the ankle and walk with a normal heel-toe pattern. The toes

Words Cont'd

touch the ground before the heel, causing the person to trip or lose balance.

Lumbar Puncture – A diagnostic procedure that uses a hollow needle to penetrate the spinal canal to remove cerebrospinal fluid for analysis. This procedure is used to examine the fluid for changes in composition that are characteristic of MS (elevated white cell count, elevated protein content).

Romano's Point of View

The Viral Connection

A stomach virus caught me last month. It grabbed hold of me and whipped me 'round and 'round and flung me on my bed like a lifeless rag doll. From 4:00 one morning until more than 48 hours later, I did not want to move from the fetal position lest some fluid be reminded to evacuate itself from my body. Nor did I want to drink, talk or be talked to. I slept the kind of sleep that only a fevered person sleeps--without watching the clock or hearing the neighborhood noises, and with bizarre nightmarish dreams. I experienced cycles of hot, cold, pain, sweating, and shivers and, beyond miserable, entered survival mode.

As I inched past the 2 day mark, I found the strength to reach over and grab the novel at my bedside. It was a story set in the African country of Botswana, which got me thinking about its nearby neighbor, Malawi (known to us mostly for its entanglements with Madonna's adoptions). Malawi, tucked in the southeastern part of Africa, is the impoverished place my daughter Gabrielle has gone to volunteer for the past two summers. In a few weeks she'll go back for the third time, to a small orphanage in Chitipi. I tried to imagine what it would be like to ex-

perience my virus in a place like Malawi. From the pictures I've seen and stories I've heard, it would probably be like this: I would lie in fetal position on a discarded rice sack, and, if I were lucky, I'd have a piece of cotton cloth for a blanket when the chills hit. I would hope that someone would bring me water from the local watering place, and I'd drink it no matter how filthy it was. I'd stagger outside the hut for my necessary bathroom trips, unaware of how dehydrated I was becoming. There would be no medicine to take.

In comparison, I suffered through my viral affliction with a comfortable bed, warm blankets for the chills and cool sheets for the fever. I had a caring husband who braved the germy air to bring me water, juice and soup. I had a nearby bathroom with a flushable toilet and running water, and a cabinet stocked with medicine.

Yet, despite all these comforts, I despaired at times. Even though I knew, logically, that the virus wouldn't last forever, there were many dark hours when I was convinced that I had a mutant microbe and it would continue to sicken me for the rest of my life. And so, if a short-term illness could cover me with that much hopelessness, then how could a person, perhaps my counterpart in a distant land, bear the burden of misery in a situation similar to, or worse than, this? I can generally imagine a lot of things, but I could not imagine that.

So it is, in a way, in our MS community. The disease strikes each of us differently; we see examples of a wide range of MS's effects at any of our gatherings. (and as you know, some issues remain "unseen") Each one of us has a particular set of strengths used to cope with whatever MS brings our way; these skills are the defensive tools used to keep us from despair. Because we face

continual struggles that wear us down day-by-day, MS has the potential to become a “burden of misery” that sucks the hope right out of us. We need to defend our territory and keep watch over each other, as well as ourselves, to make sure this doesn’t happen. “There is no substitute for victory.”—

Douglas MacArthur

Don’t forget to check out my blog at www.donna55.wordpress.com and leave me your ideas and comments. I’d really love to hear from you!

2010 Tickets for Charity Program

The Turning Stone Resort Championship Golf Tournament will be held August 2- 8, 2010. You may purchase from MS Resources tickets for this event and the organization will keep 100% of proceeds.

Tickets structure is:

\$25 – Good any one day

\$100 – Weekly booklet (contains 5

Good any one day tickets & 2 practice round tickets. Please call the Office at (315)438-4790 to place your order. Credit Cards may be used for purchasing tickets.

Cliptomania Hair Salon

Presents:

“The Art of Hair, Body and Canvas”

To benefit: MS Resources

On July 17, 2010 at 7PM, the Red House Theatre will be the site for the Cliptomania Hair and Fashion Show. The event will showcase local fashion designers and local hair/color stylists. There will be a silent auction with great items to bid on along with a chance to meet and greet the local talent. Tickets are \$30 and space is limited. A Special VIP reception preceding the Fashion Show will be held at 6PM and tickets are

\$50. For more information contact MS Resources or Caitlyn or Sue Dahl at the Cliptomania Hair Salon. The Red House Theatre is located at 201 S. West Street in Downtown Syracuse.

Should you be unable to attend, but would like to support this event, monetary donations will be accepted to defray event expenses. Checks may be made payable to: MS Resources and sent to: PO Box 237 East Syracuse NY 13057. If you would like to contribute an item for the silent auction, please contact us so arrangements may be made to pick up any items.

Utica Walk Wrap Up

I am making a big SHOUT OUT to all our Oneida County friends to ask for your support for the 2011 Mission Steps Walk for MS Resources. We need to grow our Walk event at Sangertown Square. This year we had about 75 people who raised over \$7,000. I thank you very much for all your efforts. Let’s get this Walk around 150 people and \$15,000. After all, the proceeds raised here, stay here!!!!

Congratulations to:

1st Place – Toni Biancardi - \$1,850

2nd Place – Kim Burgey - \$1,115

3rd Place – Brian Hull - \$473

Annual Mary Jackson

“Tee Off Against MS” Golf Tournament

July 26, 2010

Bellevue Golf & Country Club

\$225 per person

\$25 for a cart sign

\$100 for a tee sign

Call today for a golf packet

This issue of the MS Chronicle®
is paid in part through a grant from EMD
Serono®

Newsletter is written and edited by:
Annette Simiele, Associate Director.

*Happy Summer...see you at the Summer
Indoor Client Picnic!*



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