

the MS CHRONICLE ®

Volume 13, Issue 6

December 2011/January 2012

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

Message from the Executive Director:

I hope everyone had a wonderful holiday season and a blessed new year.

I am proud to say that MS Resources is into its 14th year of service to those with Multiple Sclerosis in Central New York and surrounding areas. We continue to provide the most up-to-date information via this newsletter, educational programs and tele-conferences. We are also so thankful to all of you for supporting the agency in many different capacities.

As we approach winter, I will reiterate my winter notes to you:

**Please call the office on the day/night of a support group meeting if the weather is inclement to see if anything has been cancelled.*

**If you feel unsafe driving yourself to an MS medical appointment, please call the office at least 24 hours in advance and we will provide transportation for you.*

**Please be sure that your walkways/ramps are clear of snow and are not slippery, the last thing you need is a fall.*

**If you are apprehensive about getting out to the grocery store, contact a few of the local supermarkets to see if they will shop and deliver your groceries to you (a few stores do this such as Dominick's Market on*

Lodi Street in the city of Syracuse and Nichols in Liverpool.)

There will be several spring educational programs and we hope to see you there.

Questions or Concerns, please contact us. We are eager to assist you in your everyday needs.

Look inside for:

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- ▶ Dumb Things Smart People Say to Folks with MS
- ▶ Time to Prepare for Mission Steps 2012
- ▶ Romano's Point of View
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Acknowledging MS Cognitive Challenges

*Slow down and absorb details. Avoid the compulsion to fill all of your free time with activity. Rest your mind between activities. Take a rest or nap for 15-30 minutes to recharge your mental energy, but avoid sleeping longer periods during the day, because this can leave you drowsy and irritable.

*Reduce or eliminate distractions during conversations and while performing tasks. Turn off the television or radio unless it is useful as background noise.

*Ignore the telephone's ring and call-waiting feature. Return calls when you can concentrate.

*Have conversations in physical environments where distractions can be kept to a minimum.

*Complete one task at a time. A home repair, returning telephone calls, reading and physical/occupational therapy exercises can all be accomplished in one day; but allow each task adequate spacing so that two or more activities are not left uncompleted at any one time.

*Schedule the most fatiguing work during the times of your highest stamina.

*Avoid pushing yourself to the point of fatigue. Step back, take a break, and allow yourself the opportunity to return to the project later, refreshed and more aware of the details involved.

*Explain to your immediate family and close friends the ways in which you need to limit your activities. Provide them with a specific schedule as to when you will be available. Sometimes operating with MS

limits can be planned; at other times, changes may be dictated by stress and fatigue. Be aware of how your body might malfunction under these circumstances and be prepared to back off from commitments.

*Allow family and friends to assist you with endeavors that may unduly tax the limits of your mind and body. Let them know what would be helpful and when you need help. Be honest with yourself and them, permitting yourself to ask for and receive assistance.

* Learn to recognize and understand your own anger-not only what situations can light your fuse, but also how to manage MS obstacles so that others do not bear the aftershock of your frustration. Anger about MS is normal, but properly dealing with the effects of MS is the patient's responsibility. Seek professional counseling before it becomes critically necessary.

*Remain open to constructive comments and suggestions.

*Keep in mind that denying your emotions and avoiding potentially useful changes in your life may be counterproductive.

These highlights were taken from the 2nd Edition of "Facing the Cognitive Challenges of Multiple Sclerosis" by Jeffrey Gingold. This book is new to the Lending Library.

Dumb Things Smart People Say to Folks with MS

We have all heard it before, people saying the dumbest things to people with MS. Now we have a new paperback book in the Lending Library which we are sure you will get a chuckle out of at the very least. Remember you can borrow any of these

books for a month or more if you would like to read them. Here are a few of those famous sayings:

Are you drunk?

But you look so good, how could you be sick?

Must be nice to sleep all day...I wish I could take a nap in the middle of the day.

Your MS isn't that bad!

You are too young or too old to have MS!

Are you one of Jerry's Kids????

How long do you have before you end up in a wheelchair?

It's probably not MS, you are just getting older.

Dee Kite, the author of the book, "The Dumbest Things Smart People Say...To Folks with MS," has lived with MS for more than 23 years. As a Personal Life Coach, she helps adults with MS thrive, not just survive. Dee lives in San Antonio with her husband, Scott and their two dogs, Trixie and Coconina. To learn more about Dee visit: MyMSCoach.com or CoachKite.com. Order the book today from Amazon.com, it will make a great addition to your library, or borrow it from the Lending Library.

Inflammatory Cortical Demyelination in Early Multiple Sclerosis

(From the New England Journal of Medicine)

Background: Cortical disease has emerged as a critical aspect of the pathogenesis of MS, being associated with disease

progression and cognitive impairment. Most studies of cortical lesions have focused on autopsy findings in patients with long-standing, chronic, progressive MS, and the non-inflammatory nature of these lesions has been emphasized. MRI studies indicate that cortical damage occurs early in the disease.

Methods: We evaluated the prevalence and character of demyelinating cortical lesions in patients with MS. Cortical tissues were obtained in passing during biopsy sampling of white-matter lesions. In most cases, biopsy was done with the use of stereotactic procedures to diagnose suspected tumors. Patients with sufficient cortex (138 of 563 patients screened) were evaluated for cortical demyelination. Using immunohistochemistry, we characterized cortical lesions with respect to demyelinating activity, inflammatory infiltrates, the presence of meningeal inflammation, and a topographic association between cortical demyelination and meningeal inflammation. Diagnoses were ascertained in a subgroup of 77 patients (56%) at the last follow-up visit (at a median of 3.5 years).

Results: Cortical demyelination was present in 53 patients (38%) (104 lesions and 222 tissue blocks) and was absent in 85 patients (121 tissue blocks). Twenty – five patients with cortical demyelination had definite MS (81% of 31 patients who underwent long-term follow-up), as did 33 patients without cortical demyelination (72% of 46 patients who underwent long-term follow up). In representative tissues, 58 of 71 lesions showed CD3+ T-cell infiltrates, and 32 of 78 lesions showed macrophage-associated demyelination. Meningeal inflammation was topographically associated with cortical demyelination in patients who had sufficient meningeal tissue for study.

Inflammatory Cont'd

Conclusions: In this cohort of patients with early-stage MS, cortical demyelinating lesions were frequent, inflammatory, and strongly associated with meningeal inflammation.

Lucchinetti, Dr. Claudia F. NEJM 2011.

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
6:30PM-8:00PM School Cafeteria

Madison County Area-

1st Monday of the month

Chittenango Center formerly known as:
Stonehedge Nursing Facility
Russell Street, Chittenango
2:00PM-4:00PM Conference Room

Auburn/Cayuga County Area-

4th Tuesday of the month

Finger Lakes Mall, Rts. 5 & 20
Auburn, Community Room
Enter at Theater entrance.
7:00 PM

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 – 720-7141 or 303-5648

New Books Added to the Lending Library

Books/Tapes may be loaned out for a period of 6 weeks at a time. Should you need to borrow the book or tape for a longer period of time, the office can make arrangements for you. There is no fee to check out an item, we simply ask that you request no more than 3 items at a time. Call today and request your book/tape. Check out the website for a complete list of items.

New Items include:

“The Book of Exercise and Yoga for Those with Multiple Sclerosis”

“CCSVI as the Cause of Multiple Sclerosis”

“The Dumbest Things Smart People Say to Folks With MS”

“It’s Not All in your Head” Anxiety, Depression, Mood Swings and Multiple Sclerosis

Joining the Fight Against Depression

If you can, don’t sit on the sidelines because one of the best ways to combat the depression, anxiety and mood shifts you’ll be feeling as well as the dispirited feeling you can undergo is to remain active. The less active you are, the worse you’ll feel. Go out and meet people in the organizations you like, get involved in local fund raising events, socialize as much as you feel you can, and remain involved in your life and that of others. Friends and social

connections we know are extremely helpful in terms of your mental and physical health.

All of these things help you to maintain your emotional and psychological balance, so do it. No one said you had to run a long race or stand/sit for hours manning an information table. There are lots of things to do and someone will help you find a pursuit that is within your ability level. In the process, you'll meet people who will inspire and encourage you, maybe as you've never been inspired before. You'll never know if you don't go out and meet them. You'll also never know how much you can truly do if you don't try to explore something you've never tried before. Skills that you have and of which you really weren't aware may suddenly become evident to your surprise and delight.

Helping others is also one of the ways that will build up your sense of competence again. The reward that you'll receive will be immeasurable and it can be incredibly energizing. Learn to laugh again.

Now, go out and do something today, or make a call or plan on attending one of MS Resources Support Group Meetings in January. You can call friends and family members and tell them that this year you are putting a team in the Walk. Get them to join you and make this an important task for yourself. Be sure to join us for one of our Spring educational programs. Keep your mind active and your body in the best shape you can.



Romano's Point of View Communication Breakdown

Every day with MS brings the possibility of a new surprise. I wish I could get all giddy about that, but there are hardly ever good surprises delivered by MS. Some are dropped like bombshells; others are revealed slowly, not as a shock, but as a gradual change that is realized at one particular moment in time. That moment you realize that the change has occurred is the *surprise!*

I've recently taken delivery of a surprise package filled with *wonky* hearing. By definition *wonky* means: *unreliable, not trustworthy, liable to break down*. Yes, that's it exactly! Although I've had the tendency to watch people's mouths when they speak ever since my deafness/flare-up ten years ago, now I've *realized* that I do it all the time. *Surprise!*

When I went to Syracuse Stage's production of *The Lion, the Witch, and the Wardrobe* I had a difficult time understanding what was being said on stage. I realized that I could hear the words, but I could not understand them. There was no context that I could frame them in, and I couldn't anticipate what might come next to help me along. *Surprise!* After many times of asking my sister what the actors said and trying to *really hear* their words, the effort became tiring. I concentrated on the other aspects of the play---the costumes, the set, the dancing--but not hearing well was very isolating. *Surprise!*

A week or so later, I went to a children's Christmas pageant. It's a tradition to go, and I figured the kids would be loud and I would be able to hear, but the onstage commotion made things worse. While I was focused on trying to understand the final song, the cute little sheep kept trying to sit on Mary's lap. She kept pushing him off. The baby Jesus doll fell. A black lamb flopped and hopped

Romano POV Cont'd

around the stage. The kids poked and shoved each other into position while singing. One of the kids ran off. Even though I was able to hear, my inability to focus made understanding impossible. *Surprise!*

I was happily listening to music while cooking the other day when a new-to-me song came on the radio. It had a catchy tune, and I was ready to join in the chorus, but what were they singing? Something about turkey bacon decorations? I wonder what kind of home is this that hangs turkey bacon to decorate and I imagine the limp meat draped over the Christmas tree branches when my daughter says, "Maaaaaaaa, it's not that. They're singing, 'The turkey's bakin', and decorations...!'" Oh. *Surprise!*

The thing that goes along with hearing and understanding is talking. Pretty much, I love to talk. I've had some ongoing issues with speaking--times when the right word won't come, and stuttering takes its place. Lately I've had a tendency to shorthand my words, saying the bare essentials of what I need to say.

For instance, recently I was given a box of Pepperidge Farms cookies, filled with all sorts of cookies, including a soft oval-shaped cookie called *Milano*. Because I didn't want them to tempt my husband who is starting to have blood sugar issues, I hid them. Days went by before I wanted some, and then I couldn't find them. Where in the world did I hide those cookies? I looked and fretted about my sanity and finally asked for help. (They say that's what to do when you're confused.)

I asked my husband, "*Did you eat mint Milanos?*"

He said no, and two days went by until I asked him again, "*Did you see the box of Pepperidge Farm cookies that I hid on the cupboard shelf?*"

He answered, "*Yes, I threw it out. But that was a few days ago.*"

"*Well, I asked you if you had eaten the mint Milanos and you told me no.*"

"*That's because they weren't mint, they were just plain chocolate.*"

And for some strange reason, his answer didn't *surprise* me in the least.

2012 Walks

It's easy to start thinking of the Spring Walks when there is no snow on the ground. Walks are scheduled for Sunday, March 4th at Carousel Center in Syracuse, Sunday, March 25th at Salmon Run Mall in Watertown, and Sunday, April 15 at the Sangertown Square in New Hartford.

Brochures are available by calling the Office at (315) 438-4790. Please remember that MS Resources is the only locally run, locally staffed agency for persons with MS. 90 cents from every dollar stays right here in our neighborhoods helping local families and friends with their everyday needs. Please join us at one of our three locations and show your community support. You may register individually or as part of a team. If registering as part of a team, let all team members know they must also register so we have their name, address and shirt sizes. Registering only the captain is not sufficient, all members must be registered.

Questions regarding the Walk, registration, etc, please call the Office at (315) 438-4790 so we can answer those and get you started on your recruitment and fund raising.

See you at one of the Walks....

Memorial/Honor Contributions

If you would like to make a memorial contribution to MS Resources in the name of a deceased loved one, please send in a check or money order, payable to MS Resources with the decedents name and who in their family you would like us to acknowledge.

If you would like to make an honor gift in someone names for a birthday, anniversary or for another celebration, again, make a check or money order payable to MS Resources and we will be happy to notify that special person that a gift has been made in their honor.

If you are thinking about leaving MS Resources in your will, be sure to specify that it is for Multiple Sclerosis Resources of Central New York, Inc.

We greatly appreciate these gifts and would like to thank all those persons who made these types of gifts in the past.



All contributions are tax-deductible.

General Neurology Practice Announces New Location

Dr. Susama Verma, MD PLLC is proud to announce her new location at:

**1816 Erie Blvd. East Suite B
Syracuse NY 13210
(315) 469-2700**

Dr. Verma is offering the recently FDA approved Botox treatment for Chronic Migraine as well as non pharmaceutical treatment for uncontrolled epilepsy. She is currently taking new patients. Major insurances accepted.

New Generic Medicines to Hit the Market

Consumers may see major savings as some medications go generic. Some of those include:

Lexapro – used to treat depression – available in February

Tricor – used to treat cholesterol – available in July

Provigil – used to treat sleep apnea/narcolepsy – available in April

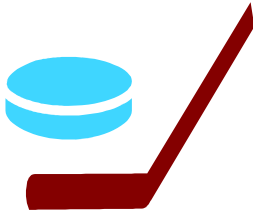
Check with your provider for details.

Syracuse Crunch Night for MS

The Syracuse Crunch is again teaming up with the B'ville Diner in support of the "Shoot to Cure" from now through February 14th. Fans that visit the B'ville Diner and make a donation for Multiple Sclerosis will receive a skate cut-out which will be displayed in the diner. In addition, beginning January 4th, fans can receive a

Crunch Cont'd

coupon valid for the purchase of a ticket to the Fan discounted rate of \$13, while supplies last. The Crunch will donate \$1 from each ticket purchased using the coupon and make a special on-ice check presentation to MS Resources of CNY at the home game on March 16th. Please patronize the B'vill Diner and show your support of the Syracuse Crunch and MS Resources!



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