

the MS CHRONICLE®

Volume 11, Issue 3

June 2009

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

Message from the Executive Director:

*Many of you may still be confused about who we are – MS Resources of CNY, that is! We **are not**, I repeat, **not** a part of any other large, Nationally based non-profit organization. We have no affiliations with any other organization, no joint programming, no collaborative ventures at all. We have worked very hard over the last 10 years to establish our agency as a local, grass roots, non-profit agency dedicated to helping local clients affected by MS meet their everyday needs. When you make a contribution to MS Resources, it stays right here in Central New York. Actually, 90cents out of every dollar raised goes right back to client services!!!!*

We do many things at MS Resources such as host free educational programs, provide free medical transportation for neurology visits, provide scholarship dollars for aqua therapy and land exercise programs at the IHP, offer support groups, free newsletters, information, referrals, advocacy and much more. In order to do these things we need to raise revenue and we do that through our Walks, Dinner, Bowling event, Golf Tournaments, and various other small fundraisers.

I hope this clears up any confusion you may have about the difference between us and other like sounding organizations and we hope that you will continue to embrace us in

our 11th year and support us through your attendance at our many service related programs or participation in our special events. If you have questions, please call us, we want to be sure that everyone understands who we are, what we do and what makes us different.

Know of someone newly diagnosed? Please pass along our contact information.

Look inside for:

- ▶ Financial Matters – Shared Solutions
- ▶ MS on the Mind
- ▶ MS LifeLines Nurses
- ▶ Walk-Wrap Up - Utica
- ▶ Romano's Point of View
- ▶ Support Group Meetings

FP 88 Vaccine for MS and Other Autoimmune Diseases

There has been some news lately about a vaccine for MS and I was recently sent a link to the East Carolina University website where this information was posted:

East Carolina University seeks a collaborative partner to develop a new advancement in the treatment and prevention of autoimmune diseases-especially multiple sclerosis.

MS afflicts more than 2.5 million people worldwide. In the US alone, 400,000 people suffer from the disorder at an annual cost to the economy of about \$20 billion. MS is an autoimmune disease that affects the central nervous system, and more particularly, the myelin material that surrounds and protects individual nerve fibers. The body's own immune system attacks the myelin, leaving behind lesions and scarring that interrupt electric impulses traveling to and from the brain. Symptoms of MS include fatigue, bladder and bowel dysfunction, difficulty in walking, reduced cognitive function, dizziness, depression, pain, visual impairment, sexual dysfunction and other symptoms. No cure exists for MS, but various treatments are available to improve the quality of life for those living with the disease. The global market for these treatments is currently estimated at \$4.9 billion.

Technology: Mark D/ Mannie, PhD, of the Department of Microbiology and Immunology at the Brody School of Medicine at East Carolina University, recently developed a unique fusion protein that, when tested in the rat model of experimental autoimmune encephalomyelitis (EAE), produced a dramatic tolerogenic effect. Rats, whether pre-treated or treated following exposure to EAE

stimulating agent, exhibited decreased incidence, reduced symptoms and delayed onset of attack.

Dr. Mannie is currently planning studies in other mammalian models that will eventually lead to clinical trials in humans.

Advantages: *Strong market need for products with improved efficacy and simpler modes of delivery

*Technology may be applied to other autoimmune disorders

*Fusion protein is selective and does not hinder normal T cell activity in the immune system.

Other Applications: Diabetes Type 1, Rheumatoid Arthritis, Crohn's Disease, Lupus, Hyperthyroidism & Hypothyroidism & other autoimmune disorders

About the Inventor:

Mark D. Mannie, Professor, Dept. of Microbiology and Immunology, The Brody School of Medicine, Greenville NC

For more information: www.ecu.edu/cs-dhs/microbiology/mannie.cfm.

When more information becomes available on this topic, I will do my best to relay it to you.

Financial Matters - Shared Solutions

From affordable access to continuing coverage-Here's what matters:

Shared Solutions can help new clients and existing Copaxone clients with:

Questions about coverage
Assistance for out-of-pocket costs once insurance is applied
Choosing Medicare Part D programs

Financial assistance with the donut hole
Referrals for free product for uninsured
and underinsured clients

Shared Solutions will do what it takes to
find personalized solutions-here's the proof:

For Copaxone clients who received
assistance with their co-pays*¹:

The average co-pay is less than
\$20

Per month as of April 8, 2009

More than two-thirds of clients pay
\$0

Nothing at all!!

Because coverage issues should not impact
therapy decisions or outcomes...Make
Shared Solutions the first call for infor-
mation. Call them at 1-800-887-8100.

Shared Solutions – Focus on Benefits

Resources - When health care insurance
providers, including Medicare Part D, are
about to hold their annual enrollments pro-
cess many questions arise and a great deal of
confusion ensues. The Benefits Inves-
tigation Team at Shared Solutions is avail-
able to help simplify the process. Call
Shared Solutions at 1-800-887-8100 for the
following:

***Help with the enrollment process for Medicare Part D-**

Medicare automatically sends information to
the newly eligible, identified through the
Social Security database

Those already covered by Medicare will be
contacted about the open enrollment period
and informed of any changes that may affect
them

Shared Solutions can help with the enroll-
ment process for Medicare Part D,(when
calling, be sure to have your Medicare and
Insurance cards handy and a list of all medi-
cations that you are taking)

***Benefits Investigation-**

Assistance re-verifying coverage with
other insurers or when switching providers
at any point in their therapy experience

***Co-Pay Assistance-**

For clients taking Copaxone, a co-pay
assistance program is available through
Shared Solutions for those who qualify

**For more information about any of the
programs or services offered by Shared
Solutions, call them at 1-800-887-8100
and press 2 for the health care provider
line.**



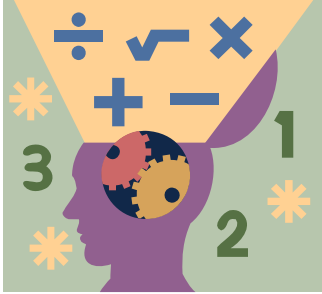
2008 Teva Neuroscience, Inc. Focus Issue 3.

MS on the Mind

Delicate, difficult, taboo. Due to stigmas
and fears, that's how the subject of cognitive
problems in MS used to be viewed by both
people with MS and their doctors.
However, research in the last 20 years has
opened a window on MS and the mind, and
the changes in thinking, memory and
emotions people with MS encounter are em-
erging from the shadows to be discussed and
managed rather than ignored.

Mind Cont'd

Cognition refer to the high-level operations of the human brain, which include our abilities to learn and remember information, pay attention, solve problems, speak fluently and think quickly.



We now know that at least some decline in cognition occurs in about 50% of people with MS and that cognitive decline does not correlate with physical decline. Only 5% to 10% of people with MS have cognitive problems that seriously disrupt their daily living. In other words, 9 out of 10 people with MS are free of severe cognitive problems. That does not mean that changes that are annoying rather than disruptive should be ignored.

How MS Affects the Brain - Stress, depression and fatigue – all common in MS – can each disturb memory and attention. Natural aging and some medicines can also be blamed. Cognitive problems due to MS, on the other hand, come from direct damage to brain tissues.

MS attacks myelin, the tissue covering nerves in the brain and spinal cord. The lesions (scars) left behind can stop or slow nerve impulses and cause both the physical and the cognitive deficits of MS. Studies using magnetic resonance imaging (MRI) in people with MS have shown that having a large number of lesions in the cerebral hemispheres of the brain, where the more complex brain functions take place, is strongly related to cognitive problems. Cognitive problems are also strongly related

to brain atrophy, which results when nerve tissue is lost.

People with MS who experience forgetfulness may fear that their symptoms are a sign of Alzheimer's disease. Such fears are unfounded. MS and Alzheimer's disease are 2 different diseases that affect the brain differently. The effects of Alzheimer's are more severe, rapid and widespread in the brain and the disease always progresses, disrupting moment-to-moment memory, use of language and eventually self-awareness. In contrast, MS-related deficits may stabilize at any time, and the people experiencing them are usually able to compensate with use of reminders and thinking aids. MS tends not to affect general intellectual ability, long-term memory or reading comprehension.

Ways to Help Improve Thinking -

More and more doctors and nurses regularly ask their MS clients if they're having problems with memory, thinking or emotions. If your healthcare professional does not ask, you should raise the issue yourself and describe any specific changes. Do not consider cognitive symptoms any less important to discuss than physical symptoms like spasms or a urinary tract infection. Your healthcare professional may have treatments and strategies that can improve your cognitive problems. Research on drug treatments and cognition is far from complete, but doctors today consider 3 main strategies:

1. An early start on MS disease – modifying therapy, chiefly Betaseron, Avonex, Rebif and Copaxone. The impact of these therapies on cognition is still being studied, but because they reduce the rate at which new lesions develop and accumulate in the brain, they are likely to slow cognitive decline.

2. Treat depression, fatigue and other MS symptoms that disturb thinking. Finding the right drug and dosage may take time, but be sure to discuss treatment options with your doctor to help combat these symptoms.
3. Target cognitive symptoms. There are some medications available that have been used to treat specific cognitive symptoms. Check with your own physician on traditional medications and alternative ones.

There are methods that can be used to compensate and live well in spite of cognitive changes that do not require medications. Techniques that can help with memory, attention and general thinking range from simple to sophisticated. Again, check with your neurologist on methods and tips. There are alternative ways to perform functions that have become difficult.

2009 Neur.net

MS LifeLines Nurses –

MS LifeLines is more than an educational support service-it's a community. The mission is to offer support to people with relapsing MS, people on or considering Rebif therapy, and the friends and family who support them. MS LifeLines Nurse Support Specialists are Registered Nurses who are MS-certified. Located across the country and in the MS LifeLines call center, MS LifeLines Nurse Support Specialists are available to help you with education, training and support. "We have a positive philosophy at MS LifeLines. It's a philosophy of hope: that there will someday be a cure for MS.

We encourage callers to maintain their therapy and help delay progression of this disease. Then when the cure hopefully comes, they can take advantage of it. In the meantime, we'll do everything we can to empower them and help them stay the course of therapy. Our feeling is, when you do encounter a bump in the road, call us. We're here to help. You don't have to do this alone."

Jo Scanzillo, RN MS LifeLines Nursing Manager.

2009 MS LifeLines.

MS Support Group Meetings

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

Syracuse Area-

2nd Tuesday of the month

Lincoln Middle School, James Street
7PM-8:30PM School Cafeteria

**** No Meetings in July or August, please mark this on your calendar.**

Fayetteville-Manlius Area-

3rd Tuesday of the month

East Side Manor Living Community
7164 E. Genesee St., Fayetteville
7PM-8:30PM Activities Room

**** No Meetings in July or August, please mark this on your calendar.**

Madison County Area-

1st Monday of the month

Stonehedge Nursing Facility
Russell Street, Chittenango
2:30PM-4:00PM Dining Room

Groups Cont'd

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

Walk Wrap -Up 2009

The Utica Area Walk –

Congratulations to the Utica area top individual fundraisers:

1. Brian Hull - \$2,405.51
2. Toni Biancardi - \$2,266
3. Kim Burgey - \$740
4. Betty Giruzzi - \$700
5. Albie Burgey - \$490

Top Team – The Climb for MS, Captain

Betsy Hull - \$3,560.51

Total raised at the event - \$13,000

Way to go Utica!!!!

Romano's Point of View

I have been shocked and awed, y'all! At the end of April I received the An D. Dobe Volunteer Award at the Annual MS Dinner of Hope®. It was a wonderful night that I will tell you all about, but first I want to thank each and every one of you who reads what I write. It was because you read, and because some of you say that you like what you read, that I was honored in such a beautiful way! The plaque I was given that night hangs over my desk and is my re-

minder of all the support and encouragement I have received from Jessa, Annette, countless others, and all of you. Many, many thanks.

Now, about that evening. It was a dark and stormy night...Actually I can't remember what it was like weather-wise. I was so stressed about having to give an acceptance speech, and by trying to walk in my fancy-schmancy heels, that the early part of the night was a blur. I know I got a corsage. Then my niece, bless her heart, brought me a cocktail!



The evening's festivities were held at the NYS Fairgrounds' Empire Room. For the first part of the event, we gathered in what I call the "Silent Auction Room". Half of the room's perimeter was lined with prizes of all kinds—SU items, overflowing themed baskets, gift certificates of all kinds, autographs, even a lottery ticket tree, all waiting for new owners. On one table in the long row of prizes was something called the "Mystery Box". It was quite large, and many people seemed intrigued by it, including my sister, Joanne. She just wouldn't give up on that box!! I thought it was probably a gag box that held two dozen rolls of toilet paper, so I refused to bid on it.*

On the other side of the room was a well-attended cocktail bar. In the middle was a table that held a huge mound of steamed shrimp on ice! Other food was displayed like edible art: fruit cascading down into cheese platters, bacon-wrapped scallops, phyllo triangles...even the little hot dogs in blankets looked lovely in their silver serving

dishes. Everything was going fabulously, and then it happened.

We were shuttled away from the food and drink into the main dining room. That's when my I'm-not-prepared-to-give-a-speech anxiety started escalating. I went to the ladies room and people offered me their



advice:

Pretend that the people are on the toilet, or in their underwear, or not there, etc. My head spun after those encounters; after all, who can even conjure up such images, let alone talk at the same time? Halfway through the meal I decided that I couldn't think about it anymore. My family and friends were gathered around, laughing and having a grand time, so I decided to dispense with the drama and just say whatever came into my head when I got to the podium. That was the scariest thought of all, since my mind goes blank from time to time. But I couldn't let my apprehension affect any more of my special night—it would have to be my heart that spoke. This is just a part of what I thought, or said or wanted to say:

Eleven years ago when I received my diagnosis, the National Organization had just “left town”. As a newbie, I was filled with confusion and had questions that needed answers. (Remember, no easy internet access back then) Jessa and Annette, who are MS Resources, were a lifeline for me and my family. I began attending the many educational programs they put together and began to cope with this slithery beast of a disease. The MS Resources library books supplied me with

info, tips and even humor. (The current list is extensive; check it out.) I was extended financial help for the Vitality swimming program at the Institute for Human Performance and encouraged to attend despite my grumblings about being too tired. (By the way, the exercise really did lessen some of that fatigue.)

Swimming at the IHP also allowed me to meet some interesting people. One woman in my class was in her early thirties and had two preschool kids. She was the first person I met whose speech was affected by MS. It wasn't the slow, slurring speech, but a staccato type, like a foreign language. I learned to listen and started to understand most of what she said. I admired her spunk? She became my roommate at the first Women's Weekend I attended, and she was probably the only reason I made it through the whole three days. To tell you the truth, I was shocked by the impact progressive MS had on many of the women at the retreat. All of the walkers and wheelchairs and nursing assistants made me painfully aware of the uncertain course my disease might take. After that first night, I decided that I would call my husband and ask him to drive out to Cazenovia and “rescue” me. But at breakfast, my young roommate started to cry, and then sob, because of her speech difficulty. And so I felt compelled to stay; to help her, I thought. Yet by the end of the weekend I realized that my decision to stay helped me most of all. With laughter, tears, kindness and understanding, a bunch of differently-abled strangers gave me the strength and courage I needed to begin the task of facing my own realities of MS. It was a spring weekend that I will always remember, for it truly embodied the spirit of what we call know as “MS Resources of CNY.”

View Cont'd

*Joanne won the Mystery Box and it was filled with spa goodies, a certificate for a spa visit and a bottle of RELAX wine. No toilet paper at all.

For Sale

Mobility Scooter, 4 wheel Pride Victory 10. Less than 1 yr. old. Excellent condition, asking \$1,600 Paid \$2,200 new. Call the MS Resources office if interested.

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

**Multiple Sclerosis Resources of Central
New York, Inc. ®
PO Box 237 6743 Kinne Street
East Syracuse, New York 13057
Return Service Requested**

Call us:
(315) 438-4790

Fax us:
(315) 438-4704

E-mail us:

msrofcny@msrofcny.org

Our 800 number outside the 315
calling area:
1-800-975-2404

Website - www.msresources.org

Multiple Sclerosis Resources of Central New York, Inc. ® is a source of information concerning topics on Multiple Sclerosis. The information provided to you is derived from professionals in the field and do not represent our recommendations or opinions. We do not endorse any products, services or specific treatments. For the best advice for you, please consult your physician.