

the MS CHRONICLE®

Volume 19, Issue 3

June 2017

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

Message from the Executive Director:

Wow! The walks are in the rear-view mirror along with the MS Dinner of Hope and I can hardly believe that we are 6 months into 2017. Where does the time go??? We are getting all our planning done for the Golf Events and a new event that will be introduced inside the newsletter.

Congratulations again to our honorees at the MS Dinner of Hope. We had a very successful dinner and auction. Thank you again to our sponsors, attendees and donors.

For summer support group meetings, please check with your group facilitator to see if you are going to meet. Definitely there will be no meetings at Lincoln Jr-Sr. High School in Syracuse in July and August. The school is closed for summer vacation and we do not meet. Meetings will then resume in September. Annette had a meeting in Oneida with a few people about starting a group in that area, stay tuned for further information about this.

We will be launching a new website very soon and we encourage you all to visit it and gives us some feedback on it. We are working with a few people to get it completed, up-to-date and more modern. Just to remind you all again, we do have an extensive lending library available to you and if you would like the listing of books,

etc, visit the website and click the library icon. Books, etc can be loaned for a month at a time.

Have a great summer, stay cool, Happy Graduation to any new graduates and we hope to see you at one of the many summer events.

Look inside for:

- ▶ General Tips for Making Life Easier
- ▶ Voices Heard
- ▶ Support Group Info
- ▶ Smile.Amazon.com Info
- ▶ Romano's Point of View
- ▶ "Cruisin' for a Cause"

General Tips for Making Life Easier

Life with MS can often times get complicated. There is a great book entitled, “300 Tips for Making Life with MS Easier” and we have several in our lending library. Feel free to check it out from the library and read it over and take notes, it is a great read. Here are a few tips that can make life much simpler.

> Keep balance in your life. Prioritize, eliminate, consolidate and streamline activities in all aspects of your life.

> Pace your activities and rest before you become exhausted. Try to break down a given activity into a series of smaller tasks or if need be, enlist the help of others.

> Arrange your home for your convenience. Sometimes this means placing furniture in strategic locations to help you walk from room to room or placing a chair halfway down a long hallway so you can stop to rest. Sometimes it means purchasing duplicate cleaning supplies for the upstairs rooms and downstairs rooms. (Then you do not need to carry them up and down a set of stairs and potentially fall or drop them all over)

> When shopping, pushing a grocery cart may give you added stability as you walk. Some department stores have carts also and a number of stores and malls have battery powered scooters for patrons who tire easily or have issues with walking. You may need to call ahead (as in the case at Destiny USA in Syracuse and reserve one) and check on the availability for the day whenever you decide to do your outing.

> In your home replace traditional light switches with rocker-panel switches that

require less fine motor control. They can be turned on or off by pressing with an arm, elbow or palm of the hand and are available lighted or not. Hardware stores and home-building supply stores have them for sale.

> Before installing grab bars, determine where they would provide the most help. A space the width of a clenched fist should exist between the grab bar and the wall. Then be sure to anchor the grab bar to the studs in the wall so they can withstand the pressure and weight when being used. Vinyl-covered hand grab rails are better for grip and absorb less heat.

“300 Tips for Making Life with Multiple Sclerosis Easier.” Schwarz, Shelley Peterman. Demos Education 1999.

Interested in making life a little easier-

27 year old responsible male looking to assist an MS client in Onondaga County with light yard work and housework and/or companion care. Fee is negotiable, contact Annette at the MS Resources Office – (315) 438-4790.



Make life simpler, call Annette today and discuss your needs and see if this young man can assist.

Sometimes Our Voices are Heard

One of our clients, who is in a wheelchair along with a spouse who is also in a wheelchair attended a show at the Crouse Hinds Theater at the Civic Center. At intermission the male client attempted to use the men's room and discovered there was not an accessible one to use. He wrote a letter to the County Executive and recently received a letter back from the Executive Director of the Human Rights Commission for Onondaga County/Syracuse. They acknowledged the problem and implemented the following steps:

Constructed a new ADA men's bathroom on the mezzanine level, installed a new ADA stall in the existing bathroom on the orchestra level and constructed a new ADA unisex single occupant bathroom in the lobby level. In addition, they implemented a signage program in the Civic Center lobby and in the elevators indicating where the ADA bathrooms are located.



Same program implemented at the County Office Building on State St.

MS Resources 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

1613 James St. Syracuse NY 13203

6:30PM-8:00PM School Cafeteria

Contact: Angela McBride- (315) 876-2614

Madison County Area-

1st Monday of the month

Chittenango Center, Russell Street,

Chittenango – Conference Room

2:00PM-4:00PM Contact: Donna Denison
for more info at (315) 655-3517

Auburn/Cayuga County Area-

4th Tuesday of the month

Finger Lakes Mall, Rts. 5 & 20

Auburn, Community Room

Enter at Mall Entrance by Penney's. 7PM

Contact Susan Rusinko (315) 255-0982 or
Bernie Caruana at (315) 252-1183

Liverpool Group –

3rd Tuesday of the month

United Church of Christ Church (UCC) in

Bayberry, 215 Blackberry Rd. 6PM – 8 PM

in Fellowship Hall, follow the signs to the

meeting room. Contact: Carolyn Vickery –

(315) 409-9692 or Pat Apicella – (315) 720-
7141 or (315) 303-5648

Broome County Group –

4th Thursday of the month

Vestal Library, 320 Vestal Pkwy. Vestal NY

6:30PM Conference Rooms

Contact: Steve Yeager – (607) 785-7703 or

Rick Fiori – (607) 321-1489

MS Breakfast Buddies –

Meeting in the Binghamton area:

Contact Sue Maston: (570) 623-2302 for

times and locations.

Fairmount/Camillus Area -

1st Wednesday of the month

Fairmount Community Library

Chapel Dr. Fairmount NY 13219

1:30PM – 2:30PM Community Room (time
change)

Contact: Ericka Braundel- (315) 391-6912

Amazon.com Offers Incentives to Charity

For all of you who purchase items through Amazon.com, we have news for you. If you search Smile.Amazon.com and enter Multiple Sclerosis in the Charity section, we will receive .5% of your overall sale. Simple, it sure is! Log onto the computer and remember MS Resources as you make your purchases, but it must be entered through Smile.Amazon.com. Questions, call Jessa at (315) 438-4790. We know that there are many people who shop on-line so spread the word and don't forget us during your Christmas preparations too!

Post on your face-book page so your family, friends and all your contacts will know about it. Paste it, share it, Use it!

- Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to the charitable organization of your choice.
- AmazonSmile is the same Amazon you know. Same products, same prices, same service.
- Support your charitable organization by starting your shopping at **Smile.Amazon.com.**



BE Sure you...

Select a Charity (This is where you would type in Multiple Sclerosis Resources of Central New York, Inc.)

Walk 2017 Results

Syracuse-

- 1st Matt Deno
- 2nd Kimberly Berger
- 3rd Susan Rusinko
- 4th Donna Denison
- 5th Ann Marie Fleet
- 6th Trisha Evans
- 7th Sue Dahl
- 8th Angela Easterly
- 9th Mike Fabery
- 10th Barb Conrad

Binghamton -

- 1st Betty Calkins
- 2nd Vicki Haus
- 3rd Robin Holcomb

Utica –

- 1st Mary Collis
- 2nd John Finch
- 3rd Jean Finch

Watertown –

- 1st Kelly Balcom

Thank you to everyone who came out and supported these events. Because of the lack of interest in the Watertown area walk, we will disband it for 2018. We hope you will join us in one of the other Walks. Just another quick reminder, if you still have outstanding pledge money, please remit to the Office as soon as possible.

We look forward to the 2018 Mission Steps Walks. The 2018 event will be the 20th Annual Mission Steps Walk in Syracuse, a true milestone...please join us in celebrating this event.

Golf Event

Jackson – Roy Memorial – “Tee off Against MS” – Monday, July 24th at Tuscarora Golf Club. Price is \$160 pp. Golf Packages and sponsorships are available. Call the office at (315) 438-4790 for more information and to sign up your foursome. Other tournaments are also scheduled so please inquire by contacting Jessa at MS Resources.

New Event

“Cruisin’ for a Cause”

Do you like Classic Cars, Food Trucks, Live Entertainment? Do you ride a motorcycle or know someone who does? We have a perfect event for you this summer – “Cruisin’ for a Cause” is just that and we hope a whole lot more...

MS Resources along with Syracuse Fence bring this first time event to Kegs Canalside on N. Hamilton Street in Elbridge NY on Saturday, August 12th, from 1PM – 7PM. There will be a motorcycle ride for anyone interested in that coordinated by the Teamster Horsemen. Back at Kegs, we will have raffles, auctions, music and more. \$10 admission benefits the programs and services of MS Resources.



Don't miss out, save the date. Event held Rain or Shine. We know you will have a great time.....

Romano's Point of View

Radical Self-Care

I have been trying to practice things that don't come easily to me, and in this case, I'm talking specifically about doing what I know is best for me, despite it being the opposite of what I want to do. This battle in me is constant because I am childish and just don't want to place boundary lines on my antics. My body, however, is screaming, "Well, you need to!", and I am forced to comply. It's a diametric dance that I have been compelled to participate in.

Today this dancer is bone-tired and therefore ready to practice some radical self-care. I am accepting my limitations today (brain fog, fatigue, pain) and I am using some already-written pieces to fill out my article this time around. The writings are from my old blog that hardly anyone ever read, so there is barely a chance that these little stories are familiar to you.

Hope is a Huge Word

“Hope has two beautiful daughters – their names are anger and courage; anger at the way things are, and courage to see that they do not remain the way they are.” ~ St. Augustine. The other day when my cousins came into town from Virginia, we made a stop at the Christmas Tree Shop and then went to lunch at Heid's so they could get their coney fix. While at Heid's, I saw a father, a short, stocky guy in a white golf shirt, get angry at his pre-teen daughter for not moving through the mustard area fast enough. (If you've been to Heid's you know that there's always a traffic jam at the corner of Cashier and Mustard.) This father grabbed the little girl's arm and pushed her against the windows, growling at her to move out of the way. He did this in a low tone with a clenched jaw, as if it were a scene replayed often. I was immobilized by the sight of his hairy hand

Romano Cont'd

squeezing her arm and wanted to call him out right there. But he and his daughters moved outside quickly while I made my way to an inside table. I got up a few minutes later to peer out the window and saw the little family eating right below me; they seemed to be eating their lunch as if nothing had happened. At the very end of our meal, they came inside for a rest room break. I was holding my last french fry when I saw him, and that fry seemed like a perfect item to catapult ten feet to the back of his white shirt. And as I went through the ramifications of launching it, I dipped it in ketchup. I came to my senses and ate it quickly so I wouldn't be tempted to release it. But my anger over his hurtful actions caused me to LOUDLY discuss the horrible way some fathers treat their children, touching them and hurting them because of their own anger issues. I punctuated some of the dissertation with a word unfit to print, and he turned around to look my way. His daughter looked embarrassed; he didn't.

I'm sure Hope's daughter, Courage, would've handled the whole scene differently. But for that part of that day, I became Hope's other daughter. It just doesn't feel like enough.

Thank You, Sylvia, Wherever You Are

Last evening I went to a local funeral home for the calling hours of my Uncle Al. He wasn't my uncle at all, but a nephew of my father's which made him a second cousin to me. I guess because he was thirty years older than me I always called him uncle. Not that you needed to know any of that, but still.

It was a normal evening at a wake...offering condolences, trying to recognize faces and stopping to chat here and there. I came across a woman and I was positive I knew who she was. Using my often-faulty memory, I said hello to her and called her Ida. She told me that Ida was her sister who has been dead for

18 years; she was Sylvia. After my profuse apologies, she told me she was going on 89 years old; the offering of her age so easily at the beginning of our conversation was quite endearing to me (since I've never been a fan of the secrecy-of-age conspiracies). Sylvia wore a gorgeous black and white chiffon top with linen pants and a modernized string of pearls, stood tall and straight and spoke with my sisters and me for a bit. When we asked her where she was living, she paused and said, "I know where, just not at this moment." With her index finger pointed, she asked us to give her a minute. We watched as she walked over to a relative of hers, whisper a bit and return to us. She was smiling as she told us the name of her street and said, "I'm sorry about that. Sometimes I have a senior moment." And she laughed! A soft, genuine, "I'm-not-gone-yet" laugh that gave me a great big dose of hope.

One of My Favorite Quotes

I just watched the movie *Akeela and the Bee* and want to share this fabulous quote:

"Our deepest fear is not that we are inadequate. Our deepest fear is that we are powerful beyond measure. We ask ourselves, Who am I to be brilliant, gorgeous, talented, fabulous? Actually, who are you not to be? We were born to make manifest the glory of God that is within us. And as we let our own light shine, we unconsciously give other people permission to do the same."

That's the end of the "stolen" writings and I feel better already. As we head into the various enjoyments (and challenges) of spring and summer, follow the advice of Dory in *Finding Nemo*, "Just keep swimming...swimming, swimming, swimming. What do we do? We swim, swim." Because sometimes, that is all we can do.

For Sale

Merits Bariatric Heavy Duty Transport Chair (22" seat size) Brand new in the box – comes with stationary leg rest. Also has additional elevating leg rests, safety flag, side pouch, cup holder, detachable arm rests and hand brakes

Joerns House Journey 340 patient lift (lifts up to 340 lbs) Only used for 4 months

Joerns Deluxe Standing Sling (medium)

Non-tilt overbed table by Drive Medical

Heavy Duty Bariatric Commode by Drive Medical

1 Folding Walker & 1 Non Folding Walker

Call Yvonne at (315) 765-9952 for more info.

Webinar

The Importance of Staying on Therapy
(concerning Tysabri)

Thursday, July 13, 2017 8PM EST
To register: visit, MSwebseries.com or call 1-866-955-9999.
Biogen 2016.

Walmart Grocery

Walmart has begun a new pickup and delivery service. Take advantage of Walmart's everyday low prices and save time by shopping online. Simply place an order on-line at walmart.com/grocery, choose a timeslot, and your order will be loaded directly into your car at your local

Walmart, or in some markets, you can have our order delivered to your home.

Find out if Walmart grocery is available in your neighborhood by entering your zip code on the walmart home page. For more information, contact your Walmart store by phone.

Newsletter is written and edited by:

Annette Simiele

Call (315) 438-4790/1-800-975-2404

Fax (315) 438-4704

E-mail msrofcny@msrofcny.org

Website - www.msresources.org

Call us if you need us.....

Multiple Sclerosis Resources of CNY, 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.

Dates to Save-

6th Annual Poker Walk – Oswego -9/9/17
Mens Retreat – Hamiton 9/22-9/24/17
Syracuse Comedy Night – 10/20/17
MS Health & Wellness Expo –
Syracuse 10/24/17

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