

# *the* MS CHRONICLE®

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## Message from the Executive Director:

*A new year began and unfortunately we are still coping with COVID-19. It has been a long haul and so many things have changed and happened in our lives, but we are a resilient crew and we shall overcome this huge cloud hanging over our heads. I sincerely hope by Summer we will be able to resume to normal or close to normal activities.*

*As you know, the vaccine for COVID-19 is out, if you have any questions or concerns regarding it, please consult your neurologist or primary care physician. Unfortunately, we are not health care professionals, so we cannot answer any direct questions you may have.*

*Regrettably, many of our Spring programs and fund raising events are still on hold, but we will be ready to forge ahead as soon as we get the green light, so be on the look-out for news on them.*

*At this time, I would like to send out a special thanks to all of our supporters for their very generous donations to our year end mail appeal. We were overwhelmed with your generosity. You stepped up to support our agency during these rough times and we are so very grateful. It is truly evident, that you believe in our agency, that you want to support our mission and that you want to assist us in serving the MS persons in the areas we cover.*

*In November, our agency began our 23rd year of providing client services to MS clients. We are proud of what we have accomplished over the years and we promise to continue to do our best to support our mission and to service our MS clients. Remember, our office continues to operate on a daily basis and we are only an email message or phone call away.*

*Take care....continue to wear your masks, wash your hand, keep your distance and stay safe!!*

*Jessa*

### Look Inside for:

- ◆ Support Groups
- ◆ Long Term DMT Use
- ◆ Walks Postponed
- ◆ Annette's Corner
- ◆ Amazon Smile!

## **NO IN PERSON SUPPORTS GROUPS ARE BEING HELD**

**The Liverpool Support Group is doing Zoom meetings. If you are interested in participating in that group, you must contact Carolyn Vickery (number below) and provide her with your email address. She will then add you to her list and email you the information prior to the meeting.**

**If you have any questions or concerns, please call the contact leaders or the MS Office.**

### **MS Resources Support Groups**

For sharing experiences about MS with family and friends join a meeting.

#### **Syracuse Area-**

2<sup>nd</sup> 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-**

1<sup>st</sup> Monday of the month

First Presbyterian Church of Chittenango –

118 Arch St. Chittenango 2:00PM-4:00PM

Contact: Donna Denison for more info at (315) 655-3517

#### **Auburn/Cayuga County Area-**

4<sup>th</sup> 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 – ZOOM**

3<sup>rd</sup> Tuesday of the month

United Church of Christ (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

#### **Broome County Group –**

4<sup>th</sup> Thursday of the month

Dunkin Donuts on Reynolds Rd. Johnson

City in the Community Room 6:30PM –

8:00PM 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 -**

1<sup>st</sup> Tuesday of the month

Fairmount Community Library

Chapel Dr. Fairmount NY 13219

1:30PM – 3:00PM Community Room

Contact: Kim DeStefano – (315) 569-2636

### **Staying In Touch**

The pandemic made us realize how important it is for us to be able to contact you via email. There are still many clients that have not shared their email with us. If you know of any clients who are not getting emails from us, please have them call the MS Office or email us so we can get them on our list. It is so very important for us to be connected. We encourage you to get our newsletter via email rather than regular mail, but if you want to receive it by mail, you certainly can. [msrofcny@msrofcny.org](mailto:msrofcny@msrofcny.org)

### **Virtual Service Programs are still Virtual**

Pharmaceutical companies are conducting service programs virtually. As we receive information on them, we will forward you the information on them via email. To participate in the programs you must make reservations by calling or emailing them. The instructions are in the flyers we send to you. Please take advantage of these most informative programs.

## **Amazon.com Offers Incentives to Charity**

Are you an Amazon-aholic...if so...help support MS Resources through your purchases. We will receive .5% of your overall sales when you select us as your charity of choice. Here is the link:

Amazon.com, we have news for you.

**\*\*\*\*\*News Flash\*\*\*\*\***

**For a direct link to MS Resources  
use: [smile.amazon.com/ch/16-1558498](https://smile.amazon.com/ch/16-1558498)**

**YOU MUST ENTER THROUGH  
Smile.Amazon.com**

### **Save Around Books Are Here!**

Filled with great discounts and savings we are pleased to once again be selling the Save Around Books. The Book is \$25 and we can mail it to you for an additional \$8 for postage or you can make arrangements to pick it up at the Office in E. Syracuse. They make great gifts for family, friends, neighbors or yourself.

Call today and we will reserve one for you.

### **Spring Walks are Postponed**

We were hopeful that things were going to get back to “normal” but it does not seem that way just yet. We can't hold events with large groups of individuals, so at this time we must postpone our walk events which take place in March. We are keeping our fingers crossed that we may be able to host them later in the year. Stay tuned for more info.

## **Annette's Corner**

It is with extreme sadness that I notify you all of the passing of my sweet, kind and loving mother, Rosita Simiele. Mom suffered a major stroke on Christmas Eve and passed on December 28, 2020 with me by her side. She was very peaceful and for that I am grateful. Her stroke was severe and survival would have been difficult. My mom loved attending many MS events with me and I truly cherish every memory I have. Mom and I spent a great deal of time together after her retirement and though the past few years she experienced failing health, she was a joy to be around. I found comfort in her presence and remember most nights of watching television, holding each others hands. We always told each other how much we loved one another and I am eternally thankful for having such wonderful parents, who now are reunited along with my brother Frank and grandparents.

I am overwhelmed with the support from many of you, our MS clients and friends. Thank you and please take time to let your loved ones know how you feel about them. Never go to bed angry and love with all your heart as I did my mom. May she Rest in Peace! My Rosebud...



## Long Term Use of DMT's

Long-term use of disease-modifying therapies (DMTs) in people with [relapsing-remitting multiple sclerosis \(RRMS\)](#) has a beneficial cumulative effect compared to shorter treatments, delaying the development of irreversible disability and conversion to [secondary progressive MS \(SPMS\)](#), a recent study shows. The study, "[Cumulative effects of therapies on disability in relapsing multiple sclerosis](#)," was published in the *Multiple Sclerosis Journal*. The short-term efficacy of DMTs in MS has been demonstrated in clinical trials; yet their long-term impact is less well-established. Extension trials are a common strategy for long-term analysis, but are limited by selection bias because most clinical trial participants who respond to treatment are more likely to enter an extension trial, thus leading to an overestimation of effectiveness. Recently, statistical methods have been developed to control some of these biases. However, most studies used conventional statistical approaches and overlooked the cumulative impact of DMT exposure over time on current disability. This led to the development of a statistical model to assess current risk, regardless of treatment or combination of treatments in the past. The model includes DMT exposure, dose, and timing of past exposure to generate a value called a weighted cumulative exposure (WCE) metric. Researchers in France now used the WCE metric to analyze the medical records of 2,285 adult patients with [RRMS](#) to estimate associations between exposure to DMT over time, and the current risk of irreversible disability and conversion to [SPMS](#). Notably, most people with RRMS eventually develop SPMS. Participants' mean age was 33.4, including 75% women with a median follow-up of 14.9 years. Most patients (78.6%)

were exposed to at least one DMT during follow-up, while 57.5% received two or more DMTs, and 40.2% three or more DMTs. The analysis focused on DMTs received three to 20 years before.

Results showed that past DMT use longer than five years was associated with a cumulative protective effect over time. The effect was most prominent between five and 10 years prior. If a patient started DMTs 15 years ago, 10 years of treatment led to a 36% decrease in the current risk of developing an irreversible disability, as defined by an expanded disability status scale (EDSS) of four (i.e., significant disability, able to walk without aid or rest for 500 meters, or 546 yards), compared to two years of treatment started at the same time. The results suggested that "long-term DMT is, therefore, more beneficial than DMT prescribed at the same time for a short period," the researchers wrote. Also, the risk of irreversible disability decreased by 26% for continuous DMT use of 15 years starting 20 years ago compared to five-years beginning 10 years ago, and 38% lower than those who had two years of continuous exposure starting seven years ago.

Thus, "the earlier and the longer the use of DMT, the lower the risk of reaching an irreversible EDSS 4," the researchers wrote. Also, compared to untreated patients, there was a 24% decrease in the current risk of permanent disability for those who were treated continuously for five years, starting 10 years ago. A statistical analysis found the risk factors significantly associated with irreversible disability were sex, current age, irreversible EDSS score at the beginning of the study, inclusion period of treatment, and the cumulative number of relapses during follow-up. For every one-year increase of

age, the risk of irreversible EDSS 4 also increased in patients who experienced relapses.

Regarding progressing to SPMS, past DMT use over five years before had a significant protective and cumulative effect on risk. Here, the risk of developing SPMS was 45% lower for participants who were treated continuously for 10 years starting 15 years ago compared to those treated for two years, starting at the same time. Again, “longer duration of DMT had a beneficial cumulative effect on the current risk,” the scientists wrote.

When the team combined early treatment data with treatment duration, there was a 34% reduction in SPMS risk for those treated for 15 years starting 20 years ago, than it was for five years beginning 10 years ago. Compared to untreated patients, later or long-term DMT treatment also significantly affected the current risk with a 31% decrease in those given DMTs for five years starting 10 years ago, and 54% lower risk for treatment beginning 15 years ago.

“In conclusion, the results stress that a long-term use of DMT is associated with a stronger beneficial cumulative impact over time than only early use on the current risk of disability or occurrence of secondary progression in RRMS,” the team wrote.

#### [Steve Bryson PhD](#)

Steve holds a PhD in Biochemistry from the Faculty of Medicine at the University of Toronto, Canada. He worked as a medical scientist for 18 years, within both industry and academia, where his research focused on the discovery of new medicines to treat inflammatory disorders and infectious diseases. Steve recently stepped away from

the lab and into science communications, where he’s helping make medical science information more accessible for everyone.

Fact Checked By:

[Patricia Silva, PhD](#)

Patrícia holds her PhD in Medical Microbiology and Infectious Diseases from the Leiden University Medical Center in Leiden, The Netherlands. She has studied Applied Biology at Universidade do Minho and was a postdoctoral research fellow at Instituto de Medicina Molecular in Lisbon, Portugal. Her work has been focused on molecular genetic traits of infectious agents such as viruses and parasites.

MS News Today; January 8, 2021.

### **For Sale**

Bariatric Wheelchair – 6 yrs old

Wheelchair – approx. 20 yrs old, but functions well

Price is negotiable on both items

For more information: Call – Rosemary at (315) 455-8540

### **Free**

**Hitch Mount Aluminum Mobility Wheelchair /Scooter Carrier Ramp**

**Arrangements must be made for pickup**

**First Come First Serve**

**Call MS Resources – 315-438-4790**

**See Details Below**



**Hitch Mount Aluminum Mobility  
Wheelchair /Scooter Carrier Ramp  
by Haul Master**

Comes with Owner's Manual and Safety  
Instructions

Load Capacity: 500lbs.

Vehicle Hitch Receiver Size: 2" , Class 3 or  
better hitches

Inside Platform: 47" L x 27-5/8" W x 7-1/2"  
H

Exterior Platform: 49-7/8" L x 29-1/2" W x  
8-1/2" H

Removable Ramp: 41-1/2" L x 27-3/4" W x  
1-1/2" H

Overall Dimensions w/ramp up: 50" L x 40-  
1/2" W x 43-1/2" H

Hitches uses/ has: 4 tie down locks, 2 R-  
pins, 2 lock pins

Serial number: 67599

Newsletter is written and edited by:

**Annette Simiele**

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