

# *the* MS CHRONICLE®

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## Message from the Executive Director:

*Another year has begun and that always means the planning of all the spring events including the 3 walks. The walks are truly our largest events and the best way to educate everyone on MS as a health concern.*

*we hope that we can get hundreds of people to join us for this twist on BINGO.*

*A few months ago a study by the BlueCross/Blue Shield Association showed the highest amount of medical claims by persons with MS in our area. This gave us pause for a moment as the report mentioned that Syracuse was the area with the highest amount of MS. Annette did several radio, television and newspaper interviews concerning this news. There were also several students at the S. I. Newhouse School of Public Communication at Syracuse University that focused on this data as well and called the office for more conversations and more information regarding the incidence of MS in the Syracuse area. This has certainly helped keep the MS Resources name in the media and we are grateful for the time and reporting done concerning this report.*

*We hope to see you at one of our upcoming walk events. Details are inside the newsletter or call the office at 315-438-4790 for more information.*

*Get more information on our newest event, Music Bingo. This is going to be a blast and*

### Look inside for:

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## Use of DMTs Changing ‘Natural History’ of Relapsing MS, Study Says – Consortium of MS Centers

Thursday, January 2, 2020

Posted by: Elizabeth Porco

People with relapsing multiple sclerosis (MS) have a better prognosis and a slower progression to disability since the introduction of disease-modifying treatments (DMTs) some 20 years ago, according to a retrospective study.

The study, “Outcomes in a Modern Cohort of Treated Multiple Sclerosis Patients Followed from Diagnosis Up to 15 Years,” was published in the *International Journal of MS Care*.

“Before disease-modifying therapies (DMTs) were available, the natural history of MS with regard to attainment of accepted disability milestones was reported with a fairly wide variance comparing outcomes across studies,” its researchers wrote.

But all “share an overall precarious picture of the prognosis for newly diagnosed patients,” they added, noting “[m]ore recent data sets drawn from patients in the ‘treatment era’ may provide a different conclusion.”

A team led by researchers with the Allegheny Health Network (AHN) Neuroscience Institute, at Allegheny General Hospital (AGH) in Pittsburgh, assessed the influence of DMTs on clinical outcomes, namely disability milestones, by conducting one of the longest running and most detailed studies of its type. It followed people diagnosed with MS for up to 15 years after symptom onset.

“In the field of MS research, the most widely

cited natural history studies involve the pre-treatment era of a patient’s journey,” Thomas Scott, MD, a neurologist at AHN and the study’s senior author, said in a press release. “The publication of our work is an exciting advancement in the world of MS care, as it provides insight into better outcomes over the past few decades.”

Researchers reviewed all the available disability data collected routinely on 184 newly diagnosed relapsing MS patients seen at their clinic from 1989 through 2006. Patients’ mean age at symptom onset was 35.4.

Most (76%) were examined at least once a year after an initial diagnosis, and followed for an average of 13 years. Outcomes were evaluated based on the expanded disability status scale (EDSS), which ranged from 0 (no disability) through 6, which is defined as ‘the use of a walking aid such as a cane or crutch to walk roughly 100 meters.’

Results indicated that 25% of these patients took 10.7 years to reach EDSS 3.0 (moderate disability), and 25% took 16.3 years to reach an EDSS of 6.0.

Among the group followed for 15 years after symptom onset, 19% reached an EDSS of 6.0.

“For patients who were observed throughout the duration of the study, we looked at them until they reached about 50 years old. At that time, just under 20 percent had become cane dependent needing support to walk more than one or two blocks,” Scott said.

“When we examine our outcomes data along with some of the most recent reports of other MS treatment centers we note that overall the

trends suggest potentially better outcomes compared to natural history studies,” the researchers wrote.

Overall, “it looks like general progression of the disease has slowed, and far few patients are ever disabled, thanks to advances in clinical therapies, education and resources,” Scott added.

In the study, patients were typically treated with DMTs within two years of diagnosis, with the majority (98%) receiving either interferons (brand names include Avonex and Betaseron) or glatiramer (sold as Copaxone, Glatopa and other generics), with only a small group (22%) given Tysabri (natalizumab), usually after reaching an EDSS of 4.0.

Based on their findings, the team concluded that with the wide availability of DMTs, and their potential to improve a person’s quality of life and slow disease progression, the prognosis of relapsing MS is now much more favorable than previously reported.

However, measures of the long-term impact of DMT use in future studies are needed.

“The long term impact of DMTs may now be coming into focus, as a new prognosis for RMS is unfolding,” the researchers concluded. “Though our results seem favorable, measurement of the long term impact of new treatments on the moving target of long term prognosis still represents a daunting challenge. The availability of highly efficacious treatments will hopefully make this easier.”

Added Scott: “Through these findings, we begin to open a larger window of opportunities

for clinicians to better understand and treat patients. ... I think we’re also shedding more light on the disease which in turn can lend to a healthier peace of mind and hope for a promising future” for patients and their families.

By: Idra Mumal, MSc

Multiple Sclerosis News Today

*CMSC Disclaimer*

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### **MS: Common Herpesvirus Variant Raises Risk**

New research distinguishes between two similar variants of the human herpesvirus 6 and finds that one variant significantly increases the risk of developing MS.

MS is an autoimmune condition affecting hundreds of thousands of people in the US. The condition affects the central nervous

## Herpesvirus Cont'd

system, “tricking” the immune system into attacking the protective myelin sheath that surrounds the nerve.

The medical community has not yet identified the cause of MS. Many health professionals believe that genetic predisposition plays a role, with environmental factors such as smoking and viral infections potentially triggering MS risk genes.



Of all the viruses that may play a role in the development of MS, the Epstein Barr virus (EBV) which causes mononucleosis has received the most attention from researchers. EBV, also known as human herpesvirus 4, is part of the herpesvirus family. A significant number of epidemiological studies have pointed to EBV infection, as well as a number of other environmental factors, as potential causes of MS. In addition, recent research has suggested that EBV can activate risk genes for other autoimmune conditions such as lupus.

Scientists have also associated human herpesvirus 6 with MS. However, previous studies linking HHV-6 and MS were not able to differentiate between herpesvirus 6A and herpesvirus 6B.

So, new research, which appears in the journal *Frontiers in Immunology*-aimed to make this distinction and examine the associations with MS.

Anna Fogdell – Hahn, an associate professor in the Department of Clinical Neuroscience at the Karolinska Institute in Sweden is one of the senior investigators and the corresponding author of the new study. Fogdell – Hahn and team examined the anti-bodies in the blood of 8,742 people with MS and 7,215 matched controls. They then did the same in a pre-MS cohort of 478 people and 476 matched controls.

In the MS cohort, the participants were matched for age at diagnosis, sex and residency, while in the pre-MS cohort, they were matched for biobank, sex, date of blood sampling and the date of birth.

Researchers examined the antibodies against two proteins that differ the most between Herpesvirus 6A and 6B, thus distinguishing between the two forms of the virus.

The research concluded that participants with MS were 55% more likely to have antibodies against the HHV-6A protein than the controls. In the pre-MS group, people with a 6A viral infection were more than twice as likely to go on to develop MS than the controls. By contrast, HHV – 6B was not associated with MS. Also, the earlier in life the discovery of the virus, the higher the person’s likelihood of developing MS. The scientists also found that people who had EBV in addition to HHV -6A had an even higher risk of developing MS.

“This is a big breakthrough for both the MS and herpesvirus research,” says Fogdell – Hahn. “Both HHV 6A and 6B can infect our brain cells, she adds, but they do it in slightly different ways. Therefore, it is now interesting to go forward and attempt to map out exactly how the viruses could affect the onset of MS.”

Medical News Today, January 2020

## **MS Resources Support Group Information**

Interested in sharing experiences about MS, come with family/friends to a meeting. Should the weather be inclement on the day or night of a support group meeting, please use your best judgment before venturing out.

You can check with the office or your group's leader to see if a meeting has been canceled. Thank you.

### **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  
Onondaga Center, Russell Street,  
Chittenango – Conference Room  
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 –**

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  
**\*\*\*No Meeting In February\*\*\***

### **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: 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.

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

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



We will receive .5% of your overall sales  
when you select us. 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.

## Save the Dates & Participate

### Note: New Location

#### Fish Bowl

Saturday, March 28, 2020 at Flamingo Bowl, 7239 Oswego Rd. Liverpool NY. Cost to bowl \$30. Lunch Only - \$20 Registration at 12Noon, tournament starts at 12:30PM. For more information or if you would like to donate a door prize, please contact the Office at (315) 438-4790.

#### Walks 2020

The Annual Mission Steps Walks and MS Awareness Days have been scheduled for 2020 as follows: All sites begin with registration at 9:30AM. You can visit the vendor displays set up adjacent to the registration area. T-shirts, snacks and lunch will be provided to all participants who are participating.

Sunday, March 1, 2020 – Syracuse Walk  
Destiny USA, Canyon Area

Sunday, March 15, 2020 – Binghamton Walk,  
Oakdale Mall, Center Court

Sunday, March 29, 2020 – Utica Walk  
Sangertown Square, Target Hall area

You can visit the website at [www.msresources.org](http://www.msresources.org) and click on the special events icon. Look for the Walk information and you can register, etc right on-line. Want to sponsor yourself or another walker? – you can do that too! Read the forms, fill out the information and submit! Questions or Concerns, please call the Office at (315) 438-4790. We look forward to seeing you at one of the Walk Events.

This year's Syracuse event will be dedicated in the memory of long-time board member, advisory member, supporter and great

friend, Ron Ross of Twin Trees Too! Ron was instrumental in the formation of MS Resources and assisted in numerous capacities. He generously gave of his time, talents and financial support to get this agency moving in the right direction. There will be a banner and signage acknowledging Ron's legacy at the event.

Thank you to our Partners:

*Excellus BC/BS...Kinney Drugs Foundation  
Cerio LawOffice..Biogen..Etain...Genentech  
Michael Albino...Twin Trees Too!...  
Carl Fahrenkrug...Genzyme...Xylem Inc.  
Dannielle Simiele, ColdwellBanker  
Carrols Corp...Empower FC Union...  
Thermapparel...Woodlawn Cemetery*

### Annette's Corner

I went to a local drug store a few days ago to pick up a prescription and realized that not only was all the Christmas leftovers 75% off, but the shelves were stocked with Valentine's Day items and next to them was the Easter decorations, eggs, etc. I was astonished at how rapidly our retail outlets move from one holiday to the next. I wondered what happened to Ground Hog's Day and St. Patrick's Day, are these not worthy of one shelf way way way in the back of the store and where were the 4<sup>th</sup> of July decorations after all! As I thought about this, I realized this is really a metaphor of our lives. The constant momentum to move on to the next thing when the previous one was not even really finished can often be a precarious spot. I filled my cart with small "fir" trees now marked down from \$5.99 to about \$1.12 and I picked up a few Easter cards. I was caught in the revolving door of retail nirvana. I wondered if I did this in my life. Do I incompletely do a task and then start another? Am I a chain of unfinished

Corner Cont'd

stuff? How many books were at home half started, how many puzzles 50% finished, how much food was half eaten???? Then I took pause and reminded myself that no, I had only 1 book going, I did complete the crossword puzzles before starting the next page, maybe I was not “metaphorically” like the retail revolving door, maybe I was more focused, more of a “one thing at a time person”. It’s funny how so many parallels can be drawn connecting the tapestry of our lives to seasons, holidays, etc.

I will admit that even the thought of cracking the spine on two or more books at once would propel me back to the 1980’s and my college education. I would be to confused now to do that, however, I will admit that sometimes when I cannot find the solution to a puzzle, I may begin another one! So as you head out to purchase your Halloween spiders and fun size candy bars, don’t give a second thought to pushing the seasons ahead, wishing you all a pleasant Thanksgiving day!

## **New Event - Read All About It**

### **Music BINGO Fundraising Event**

This new event is based on the traditional game of BINGO, but you will be awarded a gift card as your BINGO prize. You will listen to a song and dab your paper if you have the song title. This event will happen on April 16 at the Press Room Pub on Herald Place, doors open at 6:30PM. The kitchen will be open for food and beverage should you want to eat before the game. The first game should start about 7PM.

**We would love your help** in a few different ways to get this event off the ground and make it a huge success. Contact the office and we can let you know how to help us.

### **Nationwide Prescription Savings!**

Save up to 75% when you use your free cards at your favorite pharmacy. To ensure maximum discounts, show the pharmacist your card every time you fill a prescription. This information is provided by searchRx.com. There are no fees to use the card and you will never be charged for it. For more information, please call 1-866-954-0668. No one can be rejected because of medical history. No US resident is excluded from this program for any reason. Call today and find out how you can get a Pharmacy Discount Card.

Newsletter is written and edited by:

**Annette Simiele**

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Website - [www.msresources.org](http://www.msresources.org)

Call us if you need us.....

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**For Rent: 2 Bedroom, accessible home for rent in the North Syracuse area. Please call Tammy at (315) 438-4790.**

**Calendar of Events**  
**Save the Dates**

**Mission Steps Walks –**

Sunday, March 1, 2020 – Syracuse

Sunday, March 15, 2020 – Binghamton

Sunday, March 29, 2020 - Utica

Entire Month of March - **Mock Shoe Sale**

Saturday, March 28, 2020 – **Fish Bowl**

Sunday, April 26, 2020 - **Music BINGO**

May 2020 – **Tee Off Against MS**

June 7, 2020 – **Team Deno's Fundraiser**

June 12, 13, 14, 2020 – **Women's Retreat**

Sunday, August 2, 2020 - **MS Clambake**

September 24 - 26, 2020 – **Men's Retreat**

October 3, 2020 – **Poker Walk Oswego**

October 8, 2020 – **MS Cigar Nite**

August 10, 2020 – **Tee off Against MS –  
Mary Jackson – Judge Roy Golf Event**