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MS CHRONICLE®

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

A Message from the Executive Director:

Summer is flying by and before you know it, fall will be upon us. We are concentrating our efforts on 4 events for the fall to raise money for our agency. Our Annual Poker Walk to be held at Bridie Manor on October 8, 2022, The Little Big Smoke Event to be held at Barbagallo’s Restaurant on October 13, 2022, Our Annual Direct Mail Appeal which takes place in early November and finally our Annual MS On-Line Auction. The auction has been very well received and a great fund raising opportunity that grew out of the covid pandemic. Look for additional information inside the newsletter with ways you can assist us with these events.

Many of the support groups will be re-starting in September so please take note of new times and new locations for some of the meetings. If you have any questions or concerns, please feel free to contact the office. We have had a few calls about a “care-givers” only group. As of this publication, we have not formalized any specific meetings, but it is something that we are looking into. All care-givers are welcome to attend any of the support groups with or without the client. We encourage active participation by all who attend these meetings and look for the exchange of ideas and support. It is very important for all

involved with a loved one with MS to understand the disease, the disease process and put strategies and coping skills in place. For any concerns that you may have, give the office a call and we will do our best to assist you.

The Great New York State Fair will be starting soon and our advice is to bring cooling items to help you beat the heat and most importantly remember to drink lots of cool drinks to stay hydrated so you can enjoy all the Fair offers. Check out the buildings which are air conditioned and plan your day accordingly.

Jessa

Look Inside for:

- ◆ **Support Groups**
- ◆ **Calendar of Events**
- ◆ **Epstein Barr & MS**
- ◆ **Annette’s Corner**
- ◆ **MS On-Line Auction**

Multiple Sclerosis Resources of Central New York, Inc. ® Support Group Meetings

Support Group meetings are for sharing experiences and gathering information about MS with family and friends.

Support group meetings are now meeting in person. For information and details on each support group look below.

Please note changes in location and dates. Check with Support Group leaders as to special meeting restrictions.

If you have any questions or concerns, regarding support groups or are in need of any additional information, call the contact leaders or the Multiple Sclerosis Resources of Central New York, Inc. ® Office at 315-438-4790.

Syracuse Group

NEW LOCATION **STARTS IN SEPTEMBER**

2nd Tuesday of the month
Denny's Restaurant - Carrier Circle
6591 Thompson Road, Syracuse 13206
6:30 – 8 PM
In Private Meeting Room

Contact:
MS Resources – 315-438-4790

Liverpool Group

3rd Wednesday of the month
United Church of Christ (UCC)
215 Blackberry Road Liverpool 13090
6 - 8 PM
Fellowship Hall – Follow signs to meeting room

Contact:
Carolyn Vickery –(315) 409-9692

Fairmount/Camillus Area

MEETING IN SEPTEMBER

1st Wednesday of the month
Fairmount Community Library
406 Chapel Dr. Fairmount NY 13219
1:30 - 3:00PM
Community Room

Contact:
Kim DeStefano – (315) 569-2636

Madison County Area

1st Monday of the month
First Presbyterian Church of Chittenango
118 Arch St. Chittenango, NY 13037
2:00 - 4:00 PM

Contact:
Donna Denison - (315) 655-3517

Auburn/Cayuga County Area

LOOKING FOR A NEW LOCATION

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

Broome County Group

4th Thursday of the month
Dunkin
216 Reynolds Road, Johnson City 13790
6:30 – 8 P.M.
Community Room

Contacts:
Steve Yeager – (607) 785-7703 or
Rick Fiori – (607) 321-1489

MS Breakfast Buddies

Meets in the Binghamton area
Times and locations vary

Contact:
Sue Maston – (570) 623-2302

Is there a link between the Epstein – Barr Virus and MS

Article featured in: *Brain and Life*, July 2022. Written by Alberto Ascherio, MD, PhD.

Yes, there is a link, according to a study published in *Science* in January 2022.

The cause of MS is unknown, but the Epstein-Barr virus, a herpes virus that can cause mononucleosis and is spread through bodily fluids like saliva, has long been thought to be a likely suspect. Establishing a causal relationship, however, has been difficult because Epstein-Barr infects about 95% of adults in the US while MS affects 0.2% of the population. In addition, MS symptoms don't usually appear until 10 years after an Epstein-Barr infection.

To find out if there is a link, researchers at the Harvard T.H. Chan School of Public Health analyzed data from more than 10 million military recruits over 20 years. Every two years, the scientists took blood samples to see whether the soldiers had been infected with the Epstein-Barr virus and to assess the relationship between that infection and MS onset during the period of active duty.

They discovered that the risk of MS increased 32-fold after infection with Epstein-Barr but was unchanged after infection with other viruses. Levels of a certain biomarker associated with nerve degeneration typical in MS increased only after an Epstein-Barr infection. These findings cannot be explained by any known risk factor for MS and suggest that the Epstein-Barr virus is the leading cause of MS, the researchers wrote.

The delay between infection with Epstein-Barr and the start of MS may be partially due to MS symptoms being undetected during the earliest stages; it also may be partially due to the relationship between the Epstein-Barr virus and the immune system, which is repeatedly stimulated whenever the virus reactivates.

The mechanism by which Epstein-Barr is linked to MS is unknown, but there are at least two theories. One is that the virus, which causes a lifelong infection in memory B cells, reactivates in the brain, triggering an immune and inflammatory response and damaging the surrounding tissue. The other is that the similarity between Epstein-Barr proteins and the host's proteins causes the immune system to attack healthy tissue.

An Epstein-Barr infection, which is nearly impossible to prevent without an effective vaccine, is confirmed through a blood test that detects antibodies. Nearly all adults in the US have antibodies that reflect a current or past infection. At the moment, there is no cure, but targeting the virus with specific antiviral drugs or creating a vaccine for it could ultimately prevent or cure MS, according to researchers.

Dr. Asherio is professor of epidemiology and nutrition at the Harvard T.H.Chan School of Public Health and professor of medicine at Harvard Medical School in Boston. He was the lead author of the study on Epstein-Barr and MS published in Science.

Drug Therapies

A complete list of all drug therapies is listed on our website:

<http://msrofcny.org/education/understanding-medications-to-help-treat-your-ms/>

By clicking the links, you will be brought directly to the pharmaceutical company's website for information. Check them out if you're interested!

In addition, the pharmaceutical companies do list any virtual or live seminars on their web sites. When we receive information on the seminars from them, we also list them on our website.

Annette's Corner

It is high school reunion time around the Syracuse area. I have seen lots of posts from family and friends that they have attended or will be attending their high school reunion. I will be attending mine at the end of August, and I am excited to get together with so many former classmates. I am intrigued by the word reunion, a return to a union we once had. When I think of MS Resources and all we have had to go through with covid, I am drawn to a "reunion" of the agency. Both Jessa and myself have missed not only doing events, but service programs as well and seeing so many of you at them. We need to reunite as one force again in this battle against MS. People that we saw or spoke with frequently have faded into infrequent chats.

Events have been scheduled and support groups are meeting and these are great initial steps in our MS Reunion stage. Many of you will have attended some of

the summer events or will be planning to and we are so anxious to see you and hear how you are doing.

Please do as much as you are comfortable doing and if it means simply checking in via a phone call, we would love to talk with you. It is through each one of you that we can reunite and reignite the passions of fighting MS as one entity. We become whole as we gather as individuals in a common goal.

I will love my high school reunion and taking that stroll down memory lane, but I assure you, however, my heart will be full and we will feel the energy when MS Resources has been reunified!

REUNION
2022



Are you an Amazon-aholic.....

if so...help support Multiple Sclerosis Resources of Central New York, Inc. ® through your purchases. We receive .5% of your overall sales on each and every purchase you make, when you select us as your charity of choice. It's simple and easy. Here is the direct link:

<http://smile.amazon.com/ch/16-1558498>

Special thanks to all of you participating in this program. We are now averaging about \$ 1,500 per year!

Bill Jackson Slam Dunk Fundraiser

To remember and continue the legacy of Bill Jackson, President, of MS Resources who passed away in 2021, we have developed a campaign, "The Bill Jackson Slam Dunk for MS Resources." Bill dedicated his life to helping individuals with multiple sclerosis, he was an avid basketball player and he loved the sport, so what better way than to honor him, continue his legacy and raise funds to support the work of Multiple Sclerosis Resources.

For every \$10 dollars donated to this campaign, we will write your name or a message on a mini basketball and dunk it in our traveling basket! The Basket will travel with the Home Team (MS Resources) to every MS event held in 2022!



Our goal is to sink

500 basketballs

by December 31, 2022!!!

If you would like to help us reach our goal, simply mail a check to MS Resources and earmark it, "Jackson Slam Dunk." To donate by credit card, us the following link:

<http://msrofcny.org/the-jackson-slam-dunk/>

Your support in "Continuing the Legacy of Bill Jackson," a "True Hall of Fame Man," will be greatly appreciated!!!

Upcoming Events

➔ **Saturday, October 8, 2022**

Annual Bridie Manor Poker Walk

You can contact the Office for Ticket Info (315) 438-4790 or go to the following link to register:

<http://msrofcny.org/poker-walk/>

➔ **Thursday, October 13, 2022**

The Little Big Smoke

This is our annual cigar event, which we have not be able to hold in 2 years, so we are happy to be able to bring it back for our cigar friends. If you know of anyone that is an avid cigar smoker, please call us and give us their name, address and email info and we can send them information on the event.

➔ **Early November 2022**

Annual Direct Appeal

This is the one and only time of year that MS Resources sends out a direct mail appeal for donations to our agency.

➔ **November 9 - November 13, 2022**

Multiple Sclerosis Resources Annual On-Line Auction

The MS On-Line Auction has evolved into a wonderful fund raising event for MS Resources. People really enjoy this event, as they can participate right from the comforts of their own home. Last year we raised over \$ 12,000 and showcased hundreds of items.

We are already in the midst of working on this event by contacting local individuals

and businesses in our area for the donations of items.

Here's where your help helps us!!

We are looking for people to assist us with the procurement and retrieval of items for the event. Do you know someone that owns a business, or do you frequent an establishment that you could ask for gift cards or an item for the auction? We have letters in the office for soliciting, just call us and we can get them to you. We would like to know who you are going to ask for items, so we don't duplicate locations.

Three important things to know:

All items must be in our Office by Friday, October 7, 2022, so we can prepare and log it onto the website.

We need to know the retail value of the item(s) donated.

The auction runs from November 9 to 13, 2022. Anyone donating gift card(s) with an expiration date on them, must be made aware that the gift card(s) will not be distributed to winners until after November 13, 2022, so expiration dates must be taken into consideration.

What are HOT ITEMS...

Restaurant Gift Cards
Gas Gift Cards
NYS scratch of Lottery Tickets
Gift Cards to grocery stores
Gift Cards to stores (Target, Walmart, Kohl's, Christmas Tree Shops., etc.)
Signed Sports Memorabilia
Liquor and Beer Related Items
Toys
Bicycles

Kitchen Appliances (small ones)
Tickets to Sporting Events/Concerts
Hotel Overnights

Anything will work, as we combine items to make special packages.

If you would like to donate an item or items for the auction, just let us know by calling the office (315)438-4790. (Please keep in mind, all items must be new.)

Once the event is ready to go, we will send a link to the website and details on how to bid.

We use an independent vendor that is set up to conduct these types of events. We enter all the auction information onto their website and they handle all the rest and we are notified of the winners at the close of the event.

A special shout out to all of our past donors, bidders and winners and look forward to another successful year.

Thank You!



Free Wheelchair – Southern Tier Area

Silver Sport II Manual Wheelchair with leg rests, real leather, in fantastic shape was hardly used. **Contact MS Resources for further details at 315-438-4790.** You will need to make arrangements to pick up in Southern Tier area from owner.

This Newsletter is written and edited by:

Annette Simiele

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Call or Email us if you need us.....

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