

the MS CHRONICLE®

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June/July 2026

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

A Message from the Executive Director:

Greetings everyone! Happy Summer, I think! As I sit here working on this newsletter, it looks and feels more like a day from April, 64 degrees and raining buck-ets! However, I am sure summer days will be right around the corner.

As we approach July and August, we will be experiencing hot and humid days. Did you know about 60 to 80% of people diagnosed with MS experience issues with heat sensitivity? Are you one off them? For information, look for the article on "Heat Sensitivity in this newsletter.

Spring was busy with service programs and health fairs. Thank you to all who attended service programs and a special thanks to those of you that stopped at our Health Fair booths to say hello!

We are in the planning stages for Fall programs and will notify you of them when they become available.

We have special events coming up. See info on them in this newsletter. Your help in promoting them to get the word out would be greatly appreciated. If you have questions, don't hesitate to give us a call at the MS Office at 315-438-4790.

Heads-up. We are moving our office sometime during the middle to end of July. Same location, just moving to another area in the building. We may be without internet and phone service for a day or two while the move is taking

place. Just letting you know, if you happen to call or email us and we do not get back to you in a timely manner, it is because we have no access to our phones and computers. Just try us again!

Take care and enjoy your Summer!

Jessa

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

Support Group meetings are for sharing experiences and gathering information about Multiple Sclerosis. These groups are open to persons with MS, family members and friends.

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

Syracuse Support Group

NO MEETING IN JULY OR AUGUST

2nd Tuesday of the month
Denny's Restaurant - Carrier Circle
6591 Thompson Road, Syracuse 13206
6:00PM – 8:00 PM
In Private Meeting Room

Contact:

MS Resources – 315-438-4790

Madison County Area Support Group

1st Monday of the month
First Presbyterian Church of Chittenango
118 Arch St. Chittenango, NY 13037

**Enter the building off Russell
Street, the door closest to the play
area**

2:00 - 4:00 PM

Contact:

Dianne Murray – 315-480-0007

Binghamton Area MS Breakfast Buddies

This group meets in the Binghamton area. Times and locations vary. Please contact Sue for information and details.

Contact:

Sue Maston – (570) 623-2302

MS Social Group

This group meets monthly at various locations. Lunch is on your own. It is strictly social to interact with other clients. To receive information on dates and locations, you must contact Annette at the MS Resources Office. Provide your phone number and email address to be notified of dates, location and time.

Contact:

Annette by phone or email.
MS Resources - 315- 438-4790

Email: msrofcny@msrofcny.org

Keep us Informed!

**Please notify MS Resources if you
have moved, changed your phone
number or changed your Email
Address.....**

If you have moved, changed your phone number or changed your email address, please remember to let us know. You can simply call the MS Resources Office at 315-438-4790 or Email us at:

msrofcny@msrofcny.org

Please include your old address, changes to your mailing address, home phone and or cell phone numbers. Thank you.

MS Resources – Phone System



Phone Number: **315-438-4790**

Press 1 – To hear about services

Press 2 – To speak to Annette

Press 3 – To speak to Jessa

If we are not available, leave a message – we will get back to you ASAP.

Special Thanks...

To: Dr. Angela Applebee, Dr. Erica Parrotta and Carol Sames, PhD for speaking at our “Empowering Women with MS” seminar in April.

To: TG Therapeutics, Amgen, Horizon Infusions, Genentech, Bristol Myers Squibb and Vanda Pharmaceuticals for their support in sponsoring the seminar.

To: All our clients that attended the seminar that day.

It was “empowering,” informative and beneficial for all!

What exactly is NMOSD?

At the “Empowering Women With MS” educational program on April 18th, representatives from Amgen, a sponsor of the seminar, were there. There were several questions as to what, the condition

NMOSD, how they treat it and its similarities to MS.

The regional account manager from Amgen came into our office and provided us with numerous handouts and information on NMOSD. Here is an explanation of it.

NMOSD stands for Neuromyelitis optica spectrum disorder, a rare autoimmune disease that causes inflammation in the central nervous system, which is made up of the optic nerve, brain stem and spinal cord. It is often mistaken for MS, however, specific testing can lead to an accurate diagnosis.

The median age of onset is 40 years, but it can occur at any age, Women may be 9x more likely to be impacted versus men and there is a 2-3 fold higher prevalence in Asian and African American populations. About 22,000 people live with this condition.

Misdiagnosis:

NMOSD – A single attack can cause disability, Attacks are usually more severe and can result in permanent disability and AQP4 antibody positive in blood test.

MS – Several individual attacks typically cause disability over time, Attacks are typically less severe and can result in better recovery and AQP4 antibody negative in blood test.

For more information, please contact the Office at (315) 438-4790 or visit NMOSDWontstopme.com

A preclinical study from Mass General Brigham found evidence that irisin could offer a potential target for future MS therapies

Scientists identified that the exercise hormone irisin binds to spinal cord neurons in a mouse model of multiple sclerosis (MS). In MS, neurons and synapses in the spinal cord are lost. Irisin treatment reduces the loss of neurons and synapses.

A new study offers clues as to why exercise can improve neurological symptoms in people with multiple sclerosis (MS). The study, led by investigators from Mass General Brigham and University Medical Center Hamburg-Eppendorf (UKE), examined levels of the exercise hormone irisin in a mouse model of multiple sclerosis. Researchers found that irisin reduced both clinical symptoms and the loss of neurons in the experimental model. Additionally, when irisin was removed, the protective effects of exercise disappeared. Taken together, the researchers' findings suggest that irisin can protect neurons from inflammation-driven neuro-degeneration, offering a potential target for future MS therapies. Results are published in [Nature Metabolism](#).

"We are optimistic that our study will open up further developments of irisin as a therapeutic for, in particular, progressive MS," said senior and corresponding author [Christiane D. Wrann, DVM, PhD](#), a neuroscientist and leader of the Program in Neuroprotection in Exercise at [Mass General Brigham Neuroscience Institute](#) and the [McCance Center for Brain Health](#) at Massachusetts General Hospital. "Our findings strengthen the argument that irisin can help protect

neurons in the context of multiple types of neurodegenerative diseases." MS is a chronic, autoimmune-mediated neurodegenerative disease in which the immune system attacks the myelin sheaths that swath neurons in the brain and spinal cord. Current therapies for MS reduce inflammation but do not adequately prevent neurodegeneration. Research from other groups has shown that aerobic exercise can improve MS symptoms, but the exact mechanisms have been unknown. Wrann and colleagues have previously shown that the hormone irisin, produced by muscles during exercise, [can improve cognitive function and neuroinflammation in mouse models of Alzheimer's disease](#). In their new federally funded study of MS, researchers also found evidence of neuroprotective effects. In the MS model, deleting irisin canceled out the protective effects of exercise while adding irisin back rescued neurons and improved disease outcomes. Irisin reduced neuronal loss in three central nervous system compartments: spinal cord, hippocampus, and retina, reduced loss of synapses and restored a neuroprotective gene program.

"What we find particularly exciting is that an exercise-induced molecule can directly protect neurons in a mouse model of multiple sclerosis, revealing a fundamentally new mechanism by which exercise can influence neurodegeneration in MS," said Sina C. Rosenkranz, MD, first author and head of the Behavioral Interventions group at the Institute for Neuroimmunology and Multiple Sclerosis (INIMS) at UKE. Rosenkranz is a former postdoctoral fellow in the Wrann lab.

"Interestingly, in the current study we did not find a direct suppressive effect of irisin on peripheral immunity, but rather direct neuroprotective effects," said

[Ruxandra F. Sîrbulescu, PhD](#), co-senior author on the study, a neuroimmunologist at Mass General Brigham Neuroscience Institute and leader of the Regenerative Medicine program at the [Vaccine and Immunotherapy Center](#).

The authors note that more research is needed to understand how irisin's protective mechanism works. They also note that it's important to remember that the benefits of exercise in multiple sclerosis are complex and likely involve multiple factors, not just irisin alone. The team plans to continue investigating the hormone's effects and mechanisms in future studies.

Authorship: In addition to Wrann, Rosenkranz, and Sîrbulescu, co-authors include Joana F. da Rocha, Luis Moreira, Pius Schlachter, Jasmina Bier, Kaela Healy, Daniela Neves Silva, Mohamed Ariff Iqbal, Marjan Gharagozloo, Yueyue Xiong, Matthew A. Murphy, Helena C. Lichtenfeld, Lukas Raich, Michaela Schweizer, Asude Ertaş, Marcel S. Woo, Vanessa Vieira, Samuel E. Honeycutt, James P. White, Gregory A. Wyant, Manuel A. Friese, and Peter A. Calabresi.

Disclosures: Wrann holds a patent related to irisin (WO2015051007A1). Wrann is an academic co-founder and consultant for Aevum Therapeutics. Wrann has a financial interest in Aevum Therapeutics, a company developing drugs which harness the protective molecular mechanisms of exercise to treat neurodegenerative and neuromuscular disorders. Wrann received honoraria from Novartis outside the scope of this

work. Wrann's interests were reviewed and are managed by Massachusetts General Hospital and Mass General Brigham in accordance with their conflict of interest policies. Rosenkranz has received speaker honoraria from Merck, Roche and Sanofi, all outside of this work. Calabresi has received consulting fees from Lilly and Novartis and is PI on a grant to JHU from Genentech. Woo received honoraria from Lilly and Eisai outside the scope of this work.

Funding: This work was supported in part by the National Institutes of Health (NS117694, AG062904, AG064580, AG072054, NS117598, NS041435, R56AG056664, T32AG07057); the Cure Alzheimer's Fund; a SPARC Award from the McCance Center for Brain Health; the Hassenfeld Clinical Scholar Award; the Claflin Distinguished Scholar Award; the Boehringer Ingelheim Fonds travel grant; the Advanced Clinician–Scientist Fellowship from the Federal Ministry of Education and Research, Germany (iSTAR 01EO2106); the Gemeinnützige Hertie-Stiftung (P1200012, P1250014); the Deutsche Forschungsgemeinschaft (DFG, German Research Foundation—project 523862973); a National MS Society Career Transition Grant (TA-2104-37423); and the Else-Kröner-Fresenius-Foundation.

Paper cited: Rosenkranz SC *et al.* “The exercise hormone irisin has neuroprotective effects in a mouse model of multiple sclerosis” *Nature Metabolism* DOI: 10.1038/s42255-026-01527-7

Decoding Hospital Diets for Patients with Neurological Diseases

This is great Information for you or a loved one and should be implemented when needed. Not every hospital stay may require you to have a special diet, but there are instances where it is vitally important. Dieticians or speech-language pathologists will evaluate patients with neurological conditions or any type of swallowing issue shortly after admission.



These professionals are key members of the hospital care team. It is always important to let the dietician determine an individualized meal plan for such things as calorie intake, heart health, low sodium, diabetes and other factors. The speech-language pathologist can check for such things as coughing while eating or drinking and other potential choking risks. Sometimes a barium swallow test may be ordered for the patient to make further assessments on their issues. If it is determined that safety is a concern, alternative feeding options may need to be put in place.

At a recent support group meeting in Syracuse, we had a speech language pathologist discuss these key elements to good swallowing practices, etc. For information on State of Mind Speech and

Swallowing, please call the MS Resources office at (315) 438-4790 or email us at msrofcny@msrofcny.org for more information.

If it has been determined that there exists trouble when swallowing, a meal plan can be adjusted to modify foods.

If you are admitted to the hospital, remember to keep your meal times and diet very similar to what you do at home. This will give added stability to your hospital stay and so many hospitals supply you with menus from the kitchen, so that you can take a bit of extra time and really plan out the days meal options.

Heat Sensitivity Management

If you are bothered by heat sensitivity, especially during the hot summer months, it is very important for you to manage it. The hot summer days are not the only factors that can contribute to heat sensitivity, but some individuals are more prone to it at this time of year. Other issues causing heat sensitivity can be fevers, extensive exercise and taking extremely hot baths or showers. You need to be aware of this to prevent your core body temperatures from rising too quickly, as it can temporarily worsen MS symptoms.



Cooling tips:

- Wearing a cooling vest, it can help keep your core body temperature from rising
- Use neck wraps or cooling towels when you are outside. Put them in the freezer or run them under cold water
- Use fans or air conditioning when you are indoors
- Take cool showers or baths to cool down.
- Avoid being outside during the hottest part of the day
- Wear lightweight, loose-fitting clothing
- Sip on ice-cold water during the day
- Eat popsicles – check the sugar content or try sugar free ones. Make your own freeze pops: kool-aid, lemonade, juices – watch the sugar content
- Eat foods with a high water content – ie. watermelon, cantaloupe, strawberries, iceberg or romaine lettuce, celery, zucchini
- There are medications that can help too! Consult your neurologist

Exciting News from CNY Neurological Consulting

We are pleased to share an important update for our MS community. CNY Neurological Consulting is opening our **new Infusion Suite**, designed to provide a comfortable, convenient, and patient-centered experience for individuals receiving MS infusion therapies.

Our team will now be offering infusions for several key MS medications, including **Ocrevus (ocrelizumab)**, **Briumvi**,

and **Tysabri**. By bringing these services in-house, we aim to make treatment more accessible, streamlined, and supportive for our patients.

We look forward to welcoming you into our new space and continuing to provide the highest level of neurological care.



There are always things happening around us that make us smile, increase our belief in humanity and help move the world a little bit more in the direction of positivity. I recently saw a short expose about a young girl, maybe 10 or 11 who attended work with her mother on the weekends at a local nursing home in their community. The mother is a visiting nurse who takes vitals from the residents and checks on meds while her daughter engages in discussions with the residents. She walked around the facility with pen and paper in hand and asked a very simple question, “if you could have 3 wishes what would they be? She was anticipating answers like new homes or cars, however, the answers she received were things like: cheese, stationery, stamps, fresh fruit, visiting pets, etc. She was amazed that nothing was extravagant but simple things that could be readily supplied to these residents. She took the bull by the horns and started a small non-profit and raised funds to get these little wishes to be fulfilled. To me this was an awe-inspiring story where a very simple request could be so easily satisfied, but more importantly it was one young girl, looking

to fulfill a simple wish, who let her creativity take over.

I hope that you are also inspired by this little girl and her desire to fulfill 3 wishes for the residents of this nursing facility. Maybe you could ask your children, parents or neighbors what would their 3 wishes be. It could be fun to hear what the responses might be. Also share your 3 wishes, maybe, just maybe they will be fulfilled.

I am really going to ponder long and hard what my 3 wishes might be!



chcanys.org

The Federal 340B Drug Pricing Program

Established by Congress in 1992, the federal 340B Drug Pricing Program allows “covered entities,” like community health centers (CHCs), to purchase discounted pharmaceutical drugs to “stretch scarce federal resources” at no cost to taxpayers. CHCs are required to reinvest 340B savings into patient care and do so by expanding access, strengthening services, and providing discounts to patients.

340B Savings Improve Access to Care

CHCs rely on 340B to support and expand essential services, including subsidized medications for uninsured and underinsured patients; dental and behavioral health access; school-based health centers; and critical supports like housing, transportation, and food assistance. The services are made possible by pharmaceutical manufacturer discounts required under the 340B program.

Although New York’s 2023 transition to a fee-for-service Medicaid pharmacy model under the Department of Health (DOH) ended 340B savings for most Medicaid drugs, savings remain for commercial insurance, Medicare, and clinic-dispensed Medicaid drugs, allowing CHCs to continue to rely on 340B savings to support their programs.

Erosion of 340B and Restrictive Industry Practices

Since 2020, pharmaceutical manufacturers have restricted or denied access to 340B pricing, reducing the savings CHCs depend on to support patient care. Many manufacturers now prohibit 340B pricing at contract pharmacies, limiting patients’ ability to access affordable medications close to home. In NY, 95% of CHCs rely on contract pharmacies, partnering with an average of 20 pharmacies to serve their communities.

At the same time, pharmacy benefit managers (PBMs) are imposing restrictive 340B- only contracting terms that are taking away savings from safety-net providers and lining their own pockets. Together, these actions undermine the 340B program and jeopardize care in medically underserved communities.

New York must pass the 340B Prescription Drug Anti-Discrimination Act (A.6222 Paulin/S.1913 Rivera) to protect the integrity of the 340B program and fortify CHCs' access to critical savings.

The bill prohibits discriminatory practices that limit access to 340B-priced drugs, requires pharmaceutical manufacturers to honor 340B-priced drugs at contract pharmacies, and authorizes DOH to enforce compliance through monetary penalties. Similar laws in Arkansas and Louisiana have withstood legal challenges and successfully restored 340B access by compelling manufacturers to lift harmful restrictions in those states.

This is about patient care. Protecting 340B savings ensures CHCs can continue delivering care to the communities that rely on them.

They count on us, can we count on you?

Two Sides of a Prescription: How 340B Makes a Difference

Imagine at your local CHC, 2 patients need the same heart medication.

Patient A is uninsured and can only afford **\$10**. The medicine costs **\$100**, but through the **340B program**, the CHC buys it for **\$70**. The CHC charges the patient \$10, taking a **\$60 loss** to make sure Patient A gets the care they need.

Patient B has insurance, which pays the full **\$100**. Since the CHC paid only **\$70**, it keeps the **\$30 difference**.

That \$30 isn't profit – it's how the CHC:

- ✓ Covers losses for patients like A
- ✓ Funds dental, behavioral health, and school-based care
- ✓ Keeps care accessible for everyone in the community

This is the intent of 340B – making every dollar count for every patient.

Drug Makers Are Making It Harder to Get Your Meds

Many pharmaceutical manufacturers decided that CHCs can no longer send 340B-priced drugs to contract pharmacies.

Patient A, who lives an hour from the clinic, used to walk 15 minutes to a nearby contract pharmacy to receive their \$10 med. Now, they must travel much farther to access the discounted drug. And, without reliable transportation, they may go without their meds altogether.

Middlemen Profit, Patients Pay

CHCs use 340B savings to serve everyone – insured or not. But PBMs are finding ways to pocket those savings for themselves.

Now re-imagine **Patient B** who has insurance. Normally, the CHC is reimbursed \$100, keeping \$30 in savings thanks to 340B.

But now, PBMs are adding additional fees on CHCs for 340B-priced drugs only, chipping away at that \$30 in savings for CHCs.

That means less funding for care, more strain on CHCs, and patients are the ones who suffer.



Come join us and support

**MS Resources
Tee Off Against MS
Captain & Mate Golf Tournament**

**Sunday, July 26, 2026
Wanoa Golf Course**

**\$ 125 per person includes:
greens fees
cart fees
skins fees
prizes
chicken barbeque lunch**

Total skins payout - \$ 2,000

**1st place winners in each division
Wins - \$ 250**

\$ 500 putting contest

Limited to 128 players!

Not a golfer!

Do you know a golfer?

**Spread the word and help us make
this tournament a huge success!**

<https://msrofcny.org/events/2026/msskinstournament/>

Other ways to support it...

Buy a tee sign!

Buy raffle tickets!

Make a donation!

Tell people about it!

Ask people to buy raffle tickets!

Ask people to buy tee signs!

Tee Signs -

**Sign(s) placed on one of 18 holes on the
golf course. Display your name or your
company name on a sign**

One sign - \$ 60 2 signs - \$ 100

25/25/50 Raffle Tickets -

**\$ 5 each - 3 for \$ 10 - 8 for \$ 20
1st & 2nd place – wins 25% of money
collected & 50% for MS Resources**

Unable to participate –

Make a donation to MS Resources

**For more information:
Call MS Resources – 315-438-4790**

Or go to our website:

<https://msrofcny.org/events/2026/msskinstournament/>



We Care Wednesday At the Syracuse Mets

**MS Resources is participating in
We Care Wednesday
at the Syracuse Mets –**

Wednesday, August 19, 2026

**MS Resources will receive \$ 5
from every ticket purchased using
the following link for our agency.**

<https://www.gofevo.com/event/MSResourcesofCNY>

**Come out, support MS Resources,
come see us at our table on the
concourse and enjoy watching a
Syracuse Mets Game!**

**Remember, use that link to
purchase your tickets.
We get the credit and receive
money from each ticket you buy.**

You select where you want to sit!

**If you have any questions,
call us at 315-438-4790**

**Spread the word – tell family,
friends. neighbors, co-workers!**

**The charity with the most sales for
that evening wins some perks.
MS Resources
came in first last year –
Help us do it again!!!**



**14th Annual
Bridie Manor
Poker Walk
Saturday,
September 19, 2026**

**Bridie Manor
1830 Bridie Square, Oswego, NY**

Stroll through town, stop at various locations, pick up your playing cards, then return to Bridie Manor.

Prefer not to walk, you don't have to, you can get all your cards at Bridie Manor.

Top 5 best hands win prizes!

Entry Fee: \$ 20 per person

Includes: 7 cards to make the best 5 card poker hand, lunch at Bridie Manor, Name entered for door prizes, 5 free tickets for the Chinese Auction and loads of fun.

For details & to register click link:

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

or call MS Resources 315-438-4790

Call or Email us:

Call (315) 438-4790

E-mail - msrofcny@msrofcny.org

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 your
needs, please consult your
physician.**