

the MS CHRONICLE®

Volume 22, Issue 2

April 2020

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

Message from the Executive Director:

Hello Everyone,

*I hope you are staying safe! As you know, people with underlying health conditions are more vulnerable during this pandemic, which means persons diagnosed with Multiple Sclerosis are more vulnerable. **So please, stay in! If you must go out, keep your trips to a minimum, wear a mask and abide by social distancing regulations.***

*Our physical office is presently closed, but Annette, Tammy and I are working from our homes. You can contact us via phone or email. Messages are checked several times during the day, so call **315-438-4790** or email us **msrofcny@msrofcny.org***

*Many clients prefer to receive our newsletter via regular mail, but for this edition it will not be possible. I am asking a favor of all of you. If you talk to your MS Friends, ask how they receive our newsletter. If they get it mailed, you can forward it on to them, have them email us and we can email it to them or instruct them how to go to our website to read it. **www.msresources.org** Thank you for your help.*

Multiple Sclerosis Resources is here to help our clients to the best of our ability and our means. If you have questions, if you are in need of anything or if you just want to talk – call or email us, remember we are only a phone call or email away –we will do our best to help you.

Presently, all of our fundraisers through the end of May have been postponed, in hopes they will take place later in the year. At the end of May, we will revisit the current situation of the pandemic and determine what lies ahead for our postponed events, as well as our June and July events. We will keep you posted. Please look inside our newsletter regarding information on the Mission Steps Walks, which took place in March.

This pandemic has affected our community and will affect us as an agency, if we are unable to host all of our annual scheduled events. If you have any creative ideas to raise funds to help us support our mission, call or send us an email! We are always open to suggestions!

This a difficult time for everyone, but we are strong and we will get through this!

Stay Safe!

Jessa

Look inside for:

- ▶ Drip or Skip?
- ▶ Myo Wearable Sensor Captures Subtle Movement Problems in MS
- ▶ What is Tele Medicine????
- ▶ Support Groups
- ▶ Events
- ▶ Smile.Amazon.com

Drip or Skip?

IV treatments are a hot wellness trend. Here's what you need to know.

At “drip bars” across the country, you can now get IV infusions of vitamins and minerals that supposedly treat everything from stress to jet lag. But that doesn't necessarily mean you should. “IVs allow medications and supplements to go directly into your bloodstream,” says Nada Milosavljevic, MD founder of the integrative health program at Massachusetts General Hospital. “However, there's limited research on vitamin infusion therapy, and an improperly administered IV can be dangerous.” If you're determined to do a drip, you can lower your risk by heeding Milosavljevic's advice:

Vet Your Tech - Confirm that the clinician is a board-certified nurse or doctor-look them up on your state's medical board site - and ask about their IV training (programs often require up to 48 hours). “though uncommon, infections can occur with an inexperienced technician, as can clots and air embolisms, both of which could travel to your brain, lungs, or heart and cause a heart attack or a stroke,” says Milosavljevic.

Inquire About Ingredients – “Find out which ones will be used in your IV cocktail and check with your primary doctor to make sure they target your concern, Milosavljevic says. For example, some clinics offer vitamin B12 to help combat fatigue in the short term. “You should also ask which pharmacy the ingredients are sourced from and then contact the state medical board to ensure it's credentialed”, she says.

Get Personal – Disclose any medications you're on or health conditions you have, in case they could make IV therapy unsafe (for

instance, excess fluid can send already – high blood pressure higher), “The provider should also review your medical history, take your vitals before the session, and monitor your throughout,” she says. Speaking of providers, IV therapy is not a substitute for regular doctor visits or treatment plans prescribed by a physician, so consult yours before you even consider going with the flow. – **Angela Mats. 2019 Oprah Magazine.**

Myo Wearable Sensor Captures Subtle Movement Problems in MS

By: Patricia Inacio, Ph.D

A multi-sensor band worn on the arm or leg, called Myo, can capture and relay difficulties with limb movement due to MS with an accuracy that mirrors gold standard measures of disability, like the Expanded Disability Status Scale, a study reports.

These findings support the device's potential to more easily and quickly assess physical impairment in MS by detecting subtle changes in movement.

The study “Novel MS vital sign: multi-sensor captures upper and lower limb dysfunction” was published in the journal *Annals of Clinical and Translational Neurology*.

MS progression and clinical outcomes are usually evaluated at periodic exams. However, this approach offers only a single snapshot of the patient's performance, and is informative only over time through continuous examinations. Tools able to evaluate less evident changes taking place at shorter intervals are needed. “We currently lack reliable measures of subtle MS disability progression over short-time intervals,” Jennifer Graves, MD, PhD, a neurologist at

University of California San Diego Health and the study's lead author, said in a press release.

For example, a patient may say that they can no longer play piano, but our 150 year old bedside neurological exam technique can't quantify this. In a standard clinical trial, this patient would be rated stable and not progressing," Graves added.

A tool able to capture disease progression – like difficulties in moving the limbs properly – “within six to twelve months instead of three to five years” could “drive faster drug development for the most disabling forms of MS,” she said. A team led by researchers at UC San Diego evaluated whether the commercially available Myo gesture control armband, developed by Thalmic Labs, could be a robust tool to measure changes in limb function in MS patients.

A multi-sensor device, the Myo band includes an accelerometer, (which measures acceleration) a gyroscope (measures orientation and angular velocity) and a surface electromyography (which measures nerve electrical impulses). It can be used in the forearm or calf and it connects to a computer via Wi-Fi.

“The use of multi-sensors allows for use of complementary data types that can be employed for a more comprehensive view of the movement,” Graves said. “The types of sensors used are widely available. A product that could be purchased from Amazon, which was originally used for gaming and other gesture control tasks was used. The critical steps in the work involved the data processing and analyses, including use of artificial intelligence approaches” she added.

A total of 117 people with MS (mean age, 47) and 30 healthy people serving as controls (mean age, 39.7) were part of the study.

Those using the Myo band were asked to complete 20 finger or foot taps, on each of their four limbs, with data downloaded to a computer. An analysis showed that MS clients took longer to complete the taps, 1.65 seconds longer for finger tap and 1.82 seconds longer for foot taps, than did the control group.



(Myo Armband)

Overall, the findings suggested that the Myo band is a reliable tool for measuring neurological outcomes by detecting limb function changes.

Future studies and validation of the device are needed, however, this can be a great tool to be used. Possibly in our very near future this device will become main-stream in the MS arena. Stay tuned for what could be a real innovative tool to be used.

[Smile.Amazon.com](https://smile.amazon.com)

Purchase items through Amazon.com – and **support Multiple Sclerosis Resources**, especially now – when you're staying in. Amazon will donate .5% percentage of your total order to our agency, a very simple task, no cost to you and we benefit!, Just type the link below in your browser:

Direct MS Resources Link:

smile.amazon.com/ch/16-1558498

Questions...just call the office – 438-4790

MS Resources Support Group

DURING THIS COVID-19 PANDEMIC, ALL OF THE MS RESOURCES SUPPORT GROUPS HAVE BEEN CANCELLED UNTIL FURTHER NOTICE.

PLEASE BE ADVISED YOU ARE STILL ABLE TO CALL SUPPORT GROUP LEADERS FOR INFORMATION, QUESTIONS, OR SIMPLY TO TALK.

WE WILL NOTIFY YOU AS SOON AS POSSIBLE, WHEN SUPPORT GROUPS WILL BE ABLE TO BE REINSTATED.

PLEASE STAY SAFE!!

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
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-

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 (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 –

4th 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 -

1st Tuesday of the month
Fairmount Community Library
Chapel Dr. Fairmount NY 13219
1:30PM – 3:00PM Community Room
Contact: Kim DeStefano –(315) 569-2636

Everything You Need to Know About Telemedicine

Telemedicine has become increasingly integrated into the medical field, especially in recent years with access to rapid communications everyday life. Telemedicine has plenty of benefits: it's highly accessible, cost-effective, and lends itself to quick and efficient information transfer between patient and doctor. Telemedicine has actually been in use since the 1950s, but it is now experiencing an especially significant usage boom due to new technologies.

Telemedicine Defined

So what is telemedicine? Telemedicine, put simply, is healthcare administered remotely through available communication technologies to reach patients who are not able to easily access those services in person.

Telemedicine Through Time -

Telemedicine, as we mentioned earlier, has been in use since the 1950's, but truly started to gain traction in the 1960's, when it was put into practice to better reach individuals who needed psychological evaluations at Norfolk State Hospital. This was done through a closed-circuit TV system, with the evaluator over 100 miles away!

While Telemedicine was initially created with rural communities living outside of easily accessible health care networks in mind, it became apparent that health care was also difficult to access even in urban settings for some communities. It was upon this realization that the investment and planning structure of what telemedicine could be changed; the United States government got increasingly more involved in investing in this technology, with government departments from Health and Human Services to NASA investing in research.

Modern Telemedicine - Jump to the present, and those decades of research and investment, along with significant advances in technology, have gone a long way in making telemedicine more accessible. In particular the wide-spread use of wireless tech like smartphones and tablets, and increased accessibility to wireless internet has made it possible to use telemedicine practically anywhere.

Because of this telemedicine is used for a number of different remote applications, including:

- *Managing chronic illness
- *Preventative care
- *Follow up visits
- *Supporting assisted living
- *Providing healthcare in rural areas

Because technological literacy has increased so much in the past few decades, a video call with a healthcare professional is an experience that people have become familiar with, making it an easy to understand and convenient alternative to in-person visits.

How Telemedicine Works - Telemedicine is largely used when patients have minor but urgent health issues that they want to speak to a professional about, and is typically available 24/7. Here's how it works:

Patients request care with a submission that includes the symptoms and conditions that they are experiencing, either online or over the phone. A physician, contracted by the telemedicine company, receives the patient submission. The physician assesses the patient's condition and symptoms. After the initial assessment the physician accepts or declines the visit immediately, or schedules a visit for a later date.

The Pros and Cons of Telemedicine - Telemedicine offers some significant benefits:

- Access to 24/7 care.
- Easier, more convenient access to a physician.
- Reduced costs, both for patients and facilities.
- Increased patient engagement.
- Increased access for patients with accessibility barriers to conventional care.
- Less waiting.

But naturally also has its share of challenges as well:

- Limited accessibility for physical examinations.

Lack of proper equipment at hospitals.
Technological glitches.
Assessment and diagnosis errors.
Resistance from doctors.

Telemedicine has exciting possibilities for the present and the future, although it does have some issues to work out. It cannot replace the value of an in-person visit, but as a supplement to care and a vehicle for greater accessibility, it is a technology with exciting potential!

DUE TO THE COVID-19 PANDEMIC, ALL MULTIPLE SCLEROSIS RESOURCES FUND RAISING EVENTS PLANNED THROUGH MAY 31, HAVE BEEN POSTPONED UNTIL FURTHER NOTICE. WE WILL REVISIT OUR CURRENT SITUATION AND NOTIFY YOU OF THE STATUS OF THE EVENTS.

MISSION STEPS WALKS....

❖ We would like to thank all of our Walker, volunteers and sponsors for their participation in the 3 Mission Steps Walks held in Syracuse, Binghamton and Utica.

❖ If you still have money at home to send in, please do so by converting all your cash to a check and mail it to our office:

MS Resources
P. O. Box 237
East Syracuse, New York 13057

❖ Everyone that has not received a t-shirt, will get one, once we are able to

return back to our office and resume normal operations.

❖ All top fund raisers will be notified and receive their prizes as soon as we can return to normal operations.

❖ If you have any questions on the Walks, call the MS Resources office or email us. We are all working from home and do not have access to all our records, but we will try to answer your questions with resources we have available to us.

*Special Thanks to
Our 2020 Walk Partners*

*“Your Support Has Made
A Significant Difference”*

Biogen

Sanofi Genzyme

Genentech

EMD Serono

Novartis

Excellus Blue Cross/Blue Shield

Carrol's Restaurant Group

Empower Federal Credit Union

Charles Heating Air Conditioning

Plumbing & Electrical

Kinney Drug's Foundation

Etain, LLC

Cerio Law Office

DeFrancisco & Falgiatano Law

Office

Mike & Karen Albino

Xylem Inc.

ThermApparel

Woodlawn Cemetery

Empire State CBD

Destiny USA

Oakdale Mall

Sangertown Square

PLEASE SHARE THIS NEWSLETTER WITH ALL YOUR MS FRIENDS THAT PREFER TO HAVE THEIR NEWSLETTER SENT VIA US MAIL...PRESENTLY IT CAN NOT BE MAILED.

CHECK OUT OUR WEBSITE FOR ANY UPDATES.

MOST IMPORTANTLY, PLEASE REMEMBER WE ARE HERE FOR YOU, SO CALL THE OFFICE OR EMAIL US. WE WILL GET BACK TO YOU AS SOON AS POSSIBLE!

PLEASE STAY SAFE!!

Anyone interested in helping to support the mission of Multiple Sclerosis Resources, during this difficult time, can simply write a check payable to MS Resources and mail it to:

**MS Resources
P. O. Box 237
East Syracuse, New York 13057**

Or use a credit card – type the link below in your browser:

msrofcny.org/donation/

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.

Newsletter written and edited by:

Jessa Goss & Annette Simiele

Call: (315) 438-4790 or 1-800-975-2404

E-mail: msrofcny@msrofcny.org

Website: www.msresources.org