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March 2021 Newsletter

Offering support, care, and hope...*right here at home!*

All Support Group Meetings and Newsletter Folding are Cancelled Until Further Notice!

We are continuing to work behind the scenes to make sure the telephone calls, emails, and office needs are being handled. It is important to us that we provide up-to-date information on our website and Facebook page for you. Please stay home, stay safe, and stay well!

Send your email address to officemanager@tristatems.org to receive newsletters and programs!

The Mission of the Tri-State Multiple Sclerosis Association is to enhance the quality of life for individuals living with MS & their families in Southern IN, Southern IL & Western KY

Having MS Does Not Mean You Are More Susceptible to MS /Susan Reynolds RN, MSCN

Very early in the pandemic there were some confusing international guidelines out about MS treatments, and many people thought they needed to go off medications.

The MS community didn't know a lot about COVID in the beginning, but they wanted to make recommendations to MS patients based on data—not conjecture. The MS community around the world came together to share information in a powerful way. They are now able to provide more specific, less scary information because of that.

According to Robert Fox MD, at the Mellen MS Clinic in Cleveland Ohio, “Because we’re altering the immune system (with MS disease modifying therapies) patients have an increased risk for some infections with some of these therapies, it has made us worry that patients could have increased risk for COVID-19,” Dr Fox Says. However, on April 30, doctors in Italy published a paper in *The Lancet Neurology* on their initial experience of patients with MS and COVID-19. “Of the 232 people with MS who were reported as contracting COVID-19, the severity, rate of complications, and the fatality rate were quite similar to what we see in the general population who don’t have MS,” Fox says.

Current evidence says that MS patients aren't more or less likely to get infected and don't seem to get a worse case if they do get COVID. People who are on treatment for MS and have gotten COVID haven't had worse outcomes. MS practitioners want patients to know they are not at extra risk due to their MS, and it's not practical or appropriate to stop taking their medications.

There is reason to think MS patients with higher disability may be at greater risk for a more severe infection, says Fox. “People who are wheelchair- or bed-bound have a harder time with respiratory infections in general. It’s more difficult for them to cough and clear respiratory secretions.”

Based on available data, MS experts recommend MS patients get vaccinated as soon as the vaccine is offered. Disease modifying therapies (DMTs) are not expected to interfere with the vaccine, *but patients should consult with their physicians to consider timing the vaccine around treatments. However, because COVID-19 poses serious health risks, and supplies are still limited, getting the vaccine as soon as possible may be more important than timing it around treatment.*

If you have MS and you get COVID, please report it to the [CoViMS Registry](#) for those with MS, and other CNS demyelinating diseases (Neuromyelitis Optica Spectrum Disease, or MOG antibody disease) who have developed COVID-19. Go to [Covims.org](#) to report it yourself, or ask your physician to do it for you.

Are There Changes to Formal MS Treatment Guidelines to Follow?

A variety of medical organizations have made recommendations on MS therapies and whether patients should hold, change, or extend the dosing interval for their medications, says Fox.

The [Multiple Sclerosis International Federation](#) recommends the following guidelines:

- People currently taking disease-modifying therapies (DMTs) should continue their treatment.
- People who develop symptoms of COVID-19 or test positive for the infection should discuss their MS therapies with their healthcare provider.
- Before starting on any new DMT, the risk of COVID-19 and the individual's disease course should be considered.
- Those who are due to start on a DMT but haven't yet, should consider selecting a treatment that does not reduce specific immune cells (lymphocytes). Examples include: Avonex and Rebif (interferon beta 1a) and Betaseron and Extavia (interferon beta-1b), Copaxone (glatiramer acetate) or Glatopa (glatiramer acetate), and Tysabri (natalizumab).

Medications that reduce lymphocytes over longer intervals include: Lemtrada (alemtuzumab), Mavenclad (cladribine), Ocrevus (ocrelizumab), and Rituxan (rituximab).

The following oral DMTs may reduce the ability of the immune system to respond to an infection: Gilenya (fingolimod), Tecfidera (dimethyl fumarate), Aubagio (teriflunomide), and Mayzent (siponimod). **The risks and benefits of initiating these treatments during the COVID-19 pandemic should be carefully reviewed.**

People with MS who are currently taking alemtuzumab, cladribine, ocrelizumab, rituximab, fingolimod, dimethyl fumarate, teriflunomide, or siponimod and are living in a community with a COVID outbreak should isolate themselves as much as possible to reduce their risk of infection.

Source Reference:

Louapre C, et al "Clinical characteristics and outcomes in patients with coronavirus disease 2019 and multiple sclerosis" JAMA Neurol 2020; DOI: 10.1001/jamaneurol.2020.2581.

MP Sormani, "An Italian Programme for COVID-19 infection in multiple sclerosis". Volume 19 Issue 6 P381-482, June 2020.

Multiple Sclerosis Foundation

March is MS Awareness Month

What does that mean to individuals living with multiple sclerosis and their families in the tri-state?

Since 2001 it has meant: Tri-State Multiple Sclerosis Association!

In 2001, a local non-profit was established by a dedicated group of volunteers. With support from the community and no national affiliation, they established the Tri-State Multiple Sclerosis Association. They dreamed of starting an MS Clinic, and they had a passion for providing services needed in the tri-state area. Their mission was to enhance the quality of life for individuals living with multiple sclerosis and their families throughout Southern Indiana, Western Kentucky, and Southern Illinois.

Services They Wanted to Provide:

Information on How to Manage MS: The Tri-State Multiple Sclerosis Association offers local services to over 1,350 families in our community touched by this devastating disease. Our services include: 6 local support groups, a monthly newsletter, monthly educational programs and our website: www.tristatems.org. All of these services are free!

Experts on MS: The Tri-State Multiple Sclerosis Association has an MS Nurse educator on staff. She has received her MS Certification and is one of the few MS Certified Nurses in the United States and the *only* local nurse who has earned this certification!

Guidance on MS: The Tri-State Multiple Sclerosis Association works with neurologists and pharmaceutical representatives to provide several educational programs throughout the month. These programs offer an opportunity for individuals to learn more about MS treatments to cope with this chronic illness.

A Community Team Having a Voice: All money raised by the Tri-State Multiple Sclerosis Association stays here locally! The Tri-State MS Association is independent of any national organizations, which means local money supports local services and local people!

Hope: One of the original board members, Suzy Sims, prayed the following prayer in 2001 and continues to this day. *“I pray for the success of the Tri-State MS Association. Please guide the Staff, Board of Directors, and Volunteers. Help us to recruit responsible, productive Board Members, accountable for the admiration. Let us all follow the agenda that is most important for those suffering from MS and their families and caregivers. Guide us to formulate a clear vision of their future needs so we can prepare to meet those needs. Amen.”*

In 2020, COVID-19 challenged us, as it did all non-profits! We had to adjust how we did business: working from home, no support group meetings, newsletter schedule changes, no educational luncheons or dinners, and the Board of Directors holding monthly Zoom meetings. We were sad not to be able to be there for you in person!

Fundraising events had to be put on hold for everyone’s safety! However, many of you have been able to support us with a donation! We continue to be good stewards of your gifts, making sure we are able to serve those in the tri-state living with MS and their families.

Please join us during the month of March and the coming year, in helping to bring MS awareness to the community. Let your family, friends, and co-workers know that local services are available for those living with Multiple Sclerosis and their families. And as we move forward, we know Suzy will continue to say her prayer, and the Staff and Board of Directors will be working to uphold and strengthen the Mission of the Tri-State MS Association!

***Things may look different for us, but we are here!
Offering support, care and hope...right here at home!***



AARP Foundation Tax-Aide provides in-person and remote tax assistance free of charge to anyone, with a special focus on taxpayers who are 50 or older or who have low to moderate income. This year, tax assistance is available by appointment only. Get started by booking an appointment online at taxaide.aarpfoundation.org.

Congratulations

Kathy W. was the winner of the \$500 gift card from Wayne's Appliance. Congratulations, Kathy!

THANK YOU



Thank you to the **Jillson / Hurm families** for donating holiday cheer to families living with MS.

Thank you **United Leasing** for your generous donation.

Thank you **Dean Bosler's Furniture and Mattress Showrooms** for your generous donation.

Thank you **D-Patrick Ford** for your generous donation.

Thank you **Mike Kishline** (The Rug Gallery of Newburgh) for your birthday fundraiser donation.

And thank you to *everyone* who donated to us in 2020! Your generosity was greatly appreciated.

If you are looking for some education related to your MS, you can access educational videos any time from your home computer or smart phone at the following websites:

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| www.CanDo-MS.org | Go to webinars |
| www.msviews.org | Go to Virtual Education Events |
| www.mscenter.org | Go to Educational Programs |
| www.msaa.org | Go to MS Information Video Library |
| www.bostterms.com | Go to Videos |