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April / May 2020 Newsletter

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

Indiana Support Group Meeting Dates

Evansville, IN support group will **Not** meet until further notice.

Contacts: Nita Ruxer / 812-479-3544 or Sharon Omer / 270-333-4701.

Tell City, IN support group will **Not** meet until further notice.

Contacts: Terri Hasty / 812-649-4013 or Mary Ann Weatherholt / 812-719-2666.

Washington, IN support group will **Not** meet until further notice.

Contacts: Fran Neal / 812-259-1565 or TSMSA / 1-866-514-4312.

Kentucky Support Group Meeting Dates

Henderson, KY support group will **Not** meet until further notice.

Contacts: Cheryl Walker / 270-823-4752 or Gayla Gilbert / 270-860-7689

Owensboro, KY support group will **Not** meet until further notice.

Contacts: Susan Reynolds / 812-228-6100 or TSMSA / 1-866-514-5312.




Illinois Support Group Meeting Dates

Fairfield, IL support group will **Not** meet until further notice.

Contacts: Carol Anne Greenwood / 618-558-1045 or TSMSA / 1-866-514-4312.

*The Mission of the Tri-State Multiple Sclerosis Association
is to enhance the quality of life for individuals living
with multiple sclerosis and their families in
Southern Indiana, Southern Illinois, and Western Kentucky.*

Calendar of Events

	<p><u>April 7, Tuesday, Biogen (Tecfidera) Educational Dinner Program</u> <u>Speaker:</u> Dr. Kristi Nord, Memorial Neurology, Jasper, IN <u>Time:</u> 6:00 p.m. <i>Eastern Time</i> <u>Location:</u> The Schmitzbank; Jasper, IN <u>RSVP:</u> You and 1 (one Restaurant) guest: Navigating-MS.com or 1-866-955-9999</p>
	<p><u>April 19, Thursday, Monthly Newsletter Folding and Guest Speaker:</u> <u>Time:</u> 11:30 a.m. <u>Location:</u> TSMSA Office</p>
<p>SAVE <i>the</i> DATE</p>	<p><u>April 23, Thursday, EMD Serono (MAVENCLAD) Educational Dinner Program</u> <u>Speaker:</u> To be announced <u>Time:</u> 6:00 p.m. <u>Location:</u> Moonlite Bar-B-Q Inn; Owensboro, KY <u>RSVP:</u> You and 1 (one) guest: MAVENCLAD.com or 1-877-969-1722</p>
	<p><i>All educational programs, support groups, and office meetings have been canceled until further notice. We will continue to update you on facebook and the on our web site (tristatems.org). If you need us, please call the office. We check the calls many times during the day and will do our best to get you the services you need. 812-423-5943 or toll free 866-514-4312 www.tristatems.org</i></p>

For the latest up to date recommendations about MS and COVID-19 check out these channels on Youtube.

Disclaimer: To get the best advice related to Coronavirus and your MS disease Modifying therapy, please **talk to your Neurologist** if you have questions about the therapy you are taking.

I have found several excellent webcasts from neurologists who are MS experts. You can access these webcasts on YouTube. www.youtube.com

* Go to the search box on YouTube and search for **Aaron Boster COVID-19 Multiple Sclerosis Drugs and Health Risk.**

*From the YouTube search box search for: **MSAA What you need to know about COVID-19 and MS**

*From the YouTube search box search for: **Ask an Expert: COVID-19 and MS treatments.**

If you want to be continuously updated with more of the latest news about COVID-19 and MS or about MS in general you can subscribe to these channels on YouTube.

You can listen to audio broadcasts well:

***Realtalkms.com** has a podcast you can listen to from an app on your phone or at their site on your computer. Episodes 132-136 relate to the Coronavirus and MS. There will be more episodes by the time you get this newsletter.

Soundcloud.com has an audio teleconference you can listen to on your computer. It is about COVID-19 and MS and is done by Ben Thrower MD, an MS expert in Atlanta.

In the search box on the Soundcloud site search for:

COVID-19 teleconference #1 Ben Thrower, MD, March 2020 and COVID-19 teleconference #2 Ben Thrower, MD, March 202

Susan M. Reynolds RN, MSCN

Hello Everyone!

I hope you are all safe at home during this Covid-19 pandemic. This is a very stressful time for people with MS. Isolation is already a consideration for some MS patients and now everyone must stay at home in order to stop the spread of Covid-19, so people with MS will be getting fewer visits from family members and hopefully, not going out to socialize.

Older adults and people with pre-existing mental health conditions, have an increased risk of experiencing mental distress with social distancing, quarantine or isolation. People with disabilities, such as people with MS, who require specialized diets, medical supplies, assistance from caregivers and other accommodations are also at risk for mental stress during a pandemic because of the increased difficulties in receiving the care they require.

Below is some advice from the American Psychological Association to help you cope with the isolation that comes from being in quarantine.

Limit news consumption to reliable sources

It's important to obtain accurate and timely public health information regarding COVID-19, but too much exposure to media coverage of the virus can lead to increased feelings of fear and anxiety. Psychologists recommend balancing time spent on news and social media with other activities unrelated to quarantine or isolation, such as reading, listening to music or learning a new language. Trusted organizations — including the U.S. Centers for Disease Control and Prevention, the U.S. Substance Abuse and Mental Health Services Administration and the World Health Organization — are ideal sources of information on the virus.

Create and follow a daily routine

Maintaining a daily routine can help both adults and children preserve a sense of order and purpose in their lives despite the unfamiliarity of isolation and quarantine. Try to include regular daily activities, such as work, exercise or learning, even if they must be executed remotely. Integrate other healthy pastimes as needed.

Stay virtually connected with others

Your face-to-face interactions may be limited, but psychologists suggest using phone calls, text messages, video chat and social media to access social support networks. If you're feeling sad or anxious, use these conversations as an opportunity to discuss your experience and associated emotions. Reach out to those you know who are in a similar situation. Facebook groups have already formed to facilitate communication and support among individuals asked to quarantine. Relying on pets for emotional support is another way to stay connected. However, the Centers for Disease Control and Prevention recommend restricting contact with pets if you contract COVID-19 until the risks of transmission between humans and animals are better understood.

Maintain a healthy lifestyle

Get enough sleep, eat well and exercise in your home when you are physically capable of doing so. Going outside is very important while you are at home under quarantine. Take a chair and sit in your yard or go for walks in your neighborhood, while maintaining social distancing.

If you can't get outside because of physical restrictions you should sit close to an open, sunny window to enjoy the sunshine and spring breeze. Have someone put a birdfeeder outside of the window. Try to avoid using alcohol or drugs as a way to cope with the stresses of isolation and quarantine. If needed, consider telehealth options for psychotherapy. If you already have a psychologist, contact them ahead of a potential quarantine to see if they can continue your sessions using phone-based or online delivery.

Use psychological strategies to manage stress and stay positive

Examine your worries and aim to be realistic in your assessment of the actual concern as well as your ability to cope. Focus on what you can do and accept the things you can't change. One way to do this is to keep a daily gratitude journal. You may also choose to download smartphone applications that deliver mindfulness and relaxation exercises. Focusing on the altruistic reasons for social distancing, quarantine or isolation can also help mitigate psychological distress. Remember that by taking such measures, you are reducing the possibility of transmitting COVID-19 and protecting those who are most vulnerable.

(This one was added by me.)

Express your creative side

Did you play a band instrument in high school? Were you once interested in painting or drawing or photography? Do you have stacks of vacation photos you once promised yourself you'd put in a scrapbook? Is there a recipe you've always wanted to try but never had the time?

Use your time in isolation to reconnect with creative activities that you've had to put on hold because life got too busy. Spending time on creative activities keeps your brain busy.

Keeping your mind occupied and engaged may help ward off feelings of boredom or restlessness and make the time pass more quickly.

There are many online options for people with MS and everyone else to connect to others, my own church is having online church services during the pandemic quarantine. Our church is also having a Wednesday night discussion and social hour online, using "Zoom". You can connect to any number of free exercise classes, yoga classes, meditation and discussion groups. I have been posting information about educational webinars about MS on our Facebook page. I will continue to do this during the quarantine. I will post some Webinars that are coming up this month and next month at the end of this article.

Many are wondering how to safely shop, order, and prepare food to minimize transmission of the novel coronavirus. The virus causing COVID-19 can survive on surfaces and objects for up to 3 days. This is the reason that we are strongly encouraged to wash our hands regularly, especially after touching frequently handled objects such as door knobs or handles along with maintaining important social distancing practices. The primary method of transmitting COVID-19 is droplets spread from being close to an infected person (who may have no symptoms), thus social distancing is the most important way to reduce risk to you and others.

Please try to order your groceries online and then go pick them up or have them delivered. Give yourself 3-4 days before you run out of food to do this. Wipe down your food cans and boxes in your garage and wash your fresh food under running water using a brush before you cook them.

Because of the limited ability of coronavirus to survive on surfaces, the easiest way to minimize risk of infection from foods purchased at a store or delivered to your home is just let it sit in an out-of-the way place for three days. Of course, this won't work for foods that need immediate refrigeration or freezing. COVID-19 is an "enveloped virus," meaning that it is covered in an oily membrane. Fortunately, plain soap is very effective at disrupting the oil on surfaces, and water is effective at removing and rinsing away the virus.

For fresh produce that will not be cooked before eating, wash thoroughly under running water. If desired, use a vegetable scrub brush and scrub the surface vigorously with a small amount of soap and water (be gentle with softer produce). This method is effective at removing pathogens on the surface. Wash the scrub brush with additional soap and water after each use. Other popular rinses such as vinegar are not known to be effective at killing viruses.

For other perishables that need to be immediately frozen or refrigerated (especially frequently touched items like milk containers) it may also be a reasonable precaution to wash the container surface with a small amount of soap and water. Be sure to wash your hands again after doing so.

When a food budget is limited, try using a slow cooker to prepare soups and stews. These are forgiving in flavor when not using the freshest ingredients (like when your greens become slightly wilted), and can stretch out a few ingredients into several portions. They also freeze well for up to 2-3 months when stored in an airtight container.

Food service establishments and delivery services should be following local health departments' guidelines on food safety and regular screening of employees for COVID-19 symptoms. Many establishments now offer food deliveries with minimal or no contact, such as prepaying with a credit card over the phone, food being carried to a car for pickup, or food being left on the doorstep. Because COVID-19 can remain on cardboard surfaces for up to 24 hours, discarding cardboard food packaging is suggested. Once receiving the meal, transfer the meal from its packaging onto a plate, discard the packaging, and wash hands thoroughly with soap and water.

GUIDANCE FOR THE USE OF DISEASE MODIFYING THERAPIES

DURING THE COVID-19 PANDEMIC

**THIS ARTICLE WAS COPIED FROM THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTER'S WEBSITE
MSCARE.ORG**

People with MS have asked for guidance on the use of Disease Modifying Therapies (DMTs) during the COVID-19 pandemic. There are numerous recommendations circulating that attempt to provide clarity and guidance, however, differences among the recommendations have created confusion. DMT decision making varies significantly from country to country, ranging from highly provider-directed to a collaborative decision-making model.

The National MS Society's National Medical Advisory Committee believes DMT decisions should be individualized and made collaboratively between the person with MS and his/her healthcare provider. Based on their expert advice, the Society recommends:

1. People with MS should follow [CDC guidelines](#) and these [additional recommendations for people at higher risk](#) for serious illnesses from COVID-19.
2. People with MS should continue disease modifying therapies (DMTs) and discuss specific risks with their MS healthcare provider prior to stopping a DMT.
3. Before starting a cell depleting DMT* or a DMT that carries warnings of potentially severe increase in disability after stopping**, people with MS and their MS healthcare providers should consider specific risks (e.g. age, comorbid health conditions, location) and benefits.

These recommendations have been endorsed by the Consortium of Multiple Sclerosis Centers (CMSC) and all other members of the MS Coalition***.

In addition to the above guidance, the MS International Federation (MSIF) provides [global advice](#) on DMT use during the COVID-19 pandemic. Their recommendations provide more detailed guidance for the initiation and continuation of DMTs and are endorsed by the National MS Society and the MS Coalition. With both the MSIF and the Society's recommendations, decisions regarding DMT use should be individualized and made by the person with MS and his/her healthcare provider.

We are continuing to monitor this quickly evolving situation and these recommendations may be modified as data becomes available.

* Cell depleting therapies include: Lemtrada, Mavenclad, Ocrevus and Rituxan (used off-label in MS)

** DMTs with a warning of potentially severe increase in disability after stopping include: Gilenya and Tysabri

*** Members of the MS Coalition include: Accelerated Cure Project for Multiple Sclerosis, Can Do MS, Consortium of Multiple Sclerosis Centers, International Organization of Multiple Sclerosis Nurses, MS Views and News, Multiple Sclerosis Association of America, Multiple Sclerosis Foundation, National Multiple Sclerosis Society and United Spinal Association

Frequently Asked Questions about DMTs and COVID-19

1. Should I stop my DMT due to the COVID-19 pandemic?

No, you should not stop your DMT. Some websites and other MS organizations suggest that you postpone dosing of certain DMTs or switch DMTs. Based upon what is known right now, the National MS Society does not believe stopping your DMT is necessary. Stopping your DMT may place you at greater risk for new MS activity. We do recommend that you speak with your MS provide for advice about your specific situation and weigh the risks and benefits.

2. Which DMTs are immunomodulators and which are immunosuppressants?

DMTs that are immunomodulators generally do not suppress the immune system and do not place you at greater risk for infections – including COVID-19.

These include:

- glatiramer acetate (COPAXONE®, Glatopa®, Glatiramer Acetate Injection®)
- interferons (Betaseron®, Rebif®, Avonex®, Extavia®, Plegridy®)
- natalizumab (Tysabri®)

Some DMTs are immunomodulators but also restrict the ability of the immune system to respond to infection and therefore may increase your risk of infections, including COVID-19.

These include:

- dimethyl fumarate (Tecfidera®)
- siponimod (Mayzent®)
- diroximel fumarate (Vumerity®)
- teriflunomide (Aubagio®)
- fingolimod (Gilenya®)

Some DMTs deplete certain types of immune system cells known as lymphocytes and are considered immunosuppressants – and therefore may increase your risk of infections, including COVID-19. These include:

- alemtuzumab (Lemtrada®)
- ocrelizumab (Ocrevus®)
- cladribine (Mavenclad®)
- rituximab (Rituxan®)
- mitoxantrone (Novantrone)

3. I was recently diagnosed with MS and was prescribed a DMT. Should I start my DMT or should I postpone starting until after the COVID-19 crisis?

Yes, you should start your DMT.

Some DMTs may increase your risk of infections, including COVID-19. This must be weighed against other factors including your MS activity, your age, other medical conditions and other potential factors that could impact your DMT. This is a difficult decision and needs a thorough discussion with your MS provider.

4. Should I switch my DMT to one that has lower risk of my getting an infection, including COVID-19?

The guidance from the National MS Society is to discuss the risks and benefits of your DMT with your MS provider. Stopping an effective DMT may increase your risk of more MS activity – including relapses. Some DMTs may increase your risk of COVID-19 infection, but this is not a certainty. The risks and benefits need to be weighed for each individual situation.

5. Should I stay home and “quarantined” because I have MS and I am on a DMT?

People with underlying lung and heart conditions and those aged over 60 years are more likely to experience complications and become severely ill with the COVID-19 virus. This group will include many people living with MS, especially those with additional health complications, mobility issues and those taking some MS treatments. All people with MS are advised to pay attention to guidelines for reducing the risk of infection with COVID-19. Older people with MS, especially those who also have lung or heart diseases should take extra care to minimize their exposure to the virus. The World Health Organization recommendations include:

- Wash your hands frequently with soap and water or an alcohol-based hand rub
- Avoid touching your eyes, nose and mouth unless your hands are clean
- Try to keep at least 6 feet of distance between yourself and others, particularly those who are coughing and sneezing
- When coughing and sneezing, cover your mouth and nose with a flexed elbow or tissue
- Practice food safety by using different chopping boards for raw meat and cooked foods and wash your hands between handling them.

- In addition, people with MS should:
 - Avoid public gatherings and crowds – of greater than 10 people
 - Avoid using public transport where possible
 - Where possible, use alternatives to face-to-face routine medical appointments (for example, telephone appointments).

6. Is it ok for my family members or other close contacts to go to work or other types of social gatherings?

Care partners and family members who live with, or regularly visit, a person with MS should also follow the same recommendations to reduce the chance of bringing COVID-19 infection into the home.

There is a lot still unknown about COVID-19 and risks for people living with MS. As we learn more, we will update our information and provide more detailed guidance.

**THIS ARTICLE WAS COPIED FROM THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTER’S WEBSITE MSCARE.ORG**

How To Protect Yourself In Times Of Crisis By Chris Hogan

If you're feeling panicked about money in these uncertain times,

I want you to hear me on this:

You are not alone.

You will be okay.

People all across the country are wanting to know how the COVID-19 virus will affect their finances. Here are some of the top questions I'm getting about how to handle money during this trying time.

What should I do to protect myself and my family right now?

Conserve your financial resources. This means cutting unnecessary spending, like cable television, eating out, and subscription memberships. Focus on taking care of the Four Walls. I'm talking about the absolute necessities—food, shelter, utilities, and transportation.

Should I cash out my investments or take my money out of the bank?

Absolutely not! The stock market is like a rollercoaster, and you don't jump off a rollercoaster in the middle of the ride.

If you pull your money out now, you're guaranteed a loss. But if you ride it out, you can bet the value will eventually go back up. Plus, bank deposits are insured by the FDIC and protected up to at least \$250,000.

How long will this last?

Honestly, I don't know. What I do know is the economy will recover. All you have to do is look at history as a guide. The market has always gone back up, even after the 2008 crash and other pandemics, like SARS.

How can I give myself some cushion in case of job loss?

Now is the time to build up your emergency fund. Focus on getting three to six months of expenses saved up. If you're receiving a tax refund, put that money in a savings account. If you need extra money, sell some things around the house, or look for part-time work at companies that are experiencing high demand.

Remember, control what you can control, and don't let fear dominate you. It may take a while to get through all this, but you're going to be okay!

**Chris Hogan is a two-time #1 national best-selling author, financial expert and host of The Chris Hogan Show. For more than a decade, Hogan has served at Ramsey Solutions, equipping and challenging people to take control of their money and reach their financial goals. His second book, Everyday Millionaires: How Ordinary People Built Extraordinary Wealth—And How You Can, Too, released in January 2019.*



In Memory of.....

This is a wonderful way to acknowledge those individuals in our lives that have made a difference.

Please include a note of who the donation is 'In Memory of' or 'In Honor of'.



In Honor of.....

In Honor of Tri-State MS Association

Dr. Rick Yeager
Mr. Mike Clauson
Ms. Pamela Gray
IBEW Electrical Workers

Mr. David Titus
Dr. & Mrs. Larry Sims
Network For Good

Mr. & Mrs. George Schipp
Mr. Charles D. Liech
Mr. & Mrs. Kevin Koch

In Memory of Joni Gentry

Bruce Adler



Happy Birthday To You!

Peggy Wade Sue Hartig
Kristie Stewart Williams Leta Kelly
Jim Renner Joe Randolph Stephanie Overby
Bri Dri Rhonda Grant Don Tharp
Yolanda Webb Martha Buchta Sandy Corley
Becki Richardsville Debbie Basham





Dear TSMSA Friends,

Please know that during these uncertain times of the COVID-19 virus, the TSMSA Staff and Board of Directors have you and the Association in our hearts and prayers. We are working 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.

We continue to plan for the future of the Association so when this pandemic is over, we are ready to move forward with our mission. The mission of the Tri State Multiple Sclerosis Association is to enhance the quality of life for individuals living with multiple sclerosis and their families in southern Indiana, southern Illinois, and western Kentucky. It is this mission that excited us in 2001 to start this wonderful association and it is that same mission that moves us to stay strong today!

Please stay home, stay safe and stay well!

Sincerely,

Debbie, Linda, Susan
and
Board of Directors



