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# March 2022 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 safe and stay well!

To receive newsletters, send your email address to: officemanager@tristatems.org

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

#### **March is MS Awareness Month!**

#### Susan Reynolds RN MSCN

MS Awareness Month is a chance to bring multiple sclerosis into awareness of people in our area. The Tri-State MS Association provides information, education, and support for individuals and their family members who are living with multiple sclerosis.

MS is often an "invisible" disease. So many common symptoms can be truly life-altering to those living with them, but not always apparent to the outside world. MS is a disease of the central nervous system that disrupts communication between the brain and other parts of the body. The severity of the disease and its symptoms vary from person to person. The cause of MS is unknown; and although treatments can slow disease progression, at this time there is no known cure.

#### What is MS?

MS is a chronic disease of the brain, spinal cord, and optic nerves. Three factors appear to have an influence on developing MS: genetic predisposition; environmental factors such a geographical location; and a trigger, such as a virus.

The nerve fibers in the central nervous system are protected and made more effective by myelin, which helps the nerve fibers conduct electrical impulses to and from the brain with lightning speed. MS injures the central nervous system when the immune system mistakenly attacks myelin. Areas of myelin damage are known as plaques, or lesions, and these eventually fill in with scar tissue. The name multiple sclerosis means "many scars." MS can also cause destruction of the entire nerve. The damage from lesions disrupts the transmission of nerve impulses from the central nervous system to the rest of the body, causing a variety of symptoms.

## MS symptoms

Symptoms of MS include changes in vision, heat sensitivity, muscle weakness, problems with balance, fatigue, muscle spasms, muscle weakness, numbness and tingling, pain, emotional and cognitive difficulties, anxiety, bladder and bowel issues, depression, and more. Many MS patients experience "quiet" periods when the disease is relatively dormant, but they may still be coping with one or a number of symptoms that aren't apparent to the outside world. These patients can also have periods where the disease is quite active, known as exacerbations. During exacerbations, symptoms can be more pronounced, but usually subside and sometimes go away entirely soon after an exacerbation. Other patients may not experience dormant periods, and instead live with constant symptoms or a progressive worsening of the disease.

Every case of MS is different and every patient's experience is unique. Since no one experiences the same symptoms in the same way, MS is a difficult experience to explain or relate to others.

## Who gets MS?

Most people living with MS are diagnosed between the ages of 20 and 50, with more than twice as many women as men being diagnosed with the disease. MS is the leading cause of disability in young women and the second leading cause of disability in young men. There are an estimated 8-10,000 children under the age of 18 who also live with MS. Studies indicate that genetic factors could make certain individuals more susceptible to the disease, but there is no evidence that MS is directly inherited. It occurs more commonly among Caucasians, especially those of northern European ancestry, but people of African, Asian, and Hispanic backgrounds are not immune. A recent study showed that at least one million Americans have been diagnosed with the disease.

#### **How is MS Treated?**

Medications to treat MS have been available since 1993. Today, there are 22 FDA-approved agents for MS treatments. Research efforts to improve MS treatment are ongoing. One new frontier of MS research is exploring potential strategies for neuroprotection and neurorepair.

## Ways to stay up to date with the latest MS news:

- Accelerated Cure Project for MS. www.acceleratedcure.org
- Can Do Multiple Sclerosis. www.can-do.org
- Erase MS. www.erasems.org
- Multiple Sclerosis Association of America. www.msaa.org
- Multiple Sclerosis Foundation. www.msfocus.org
- National Multiple Sclerosis Society. www.nationalmssociety.org
- Rocky Mountain MS Center in Colorado. www.mscenter.org
- Tri-State MS Association. www.tristatems.org
- MS News Today. www.multiplesclerosisnewstoday.com
- Multiple Sclerosis International Federation. www.msif.org

Many of these organizations have grants, publications, programs, assistance or equipment for people who have MS.

#### What are the different types of MS?

- Clinically Isolated Syndrome (CIS): a first episode of neurologic symptoms caused by inflammation and demyelination in the central nervous system that may or may not go on to become MS.
- Relapsing-Remitting MS (RRMS): a disease course characterized by clearly defined flare-ups (relapses) or episodes of acute worsening of neurologic function followed by remissions (with partial or complete recovery) during which no disease progression occurs. Frequency: Approximately 85% of people are diagnosed with RRMS.
- **Primary-Progressive MS (PPMS):** a disease course characterized by nearly continuous worsening from the onset of symptoms, with or without occasional relapses. The rate or progression varies over time, with occasional plateaus. Frequency: Approximately 15% of people are diagnosed with PPMS.
- Secondary-Progressive MS (SPMS): a disease course that follows after an initial RRMS course. Following an initial period of time with RRMS, the disease becomes more steadily progressive, with or without occasional relapses.

  Frequency: If left untreated, 50% of people with relapsing-remitting MS develop this form of the disease within about 10 years of initial diagnosis.

The Tri-State Multiple Sclerosis Association provides information, education, and support for individuals and their family members who are living with multiple sclerosis. Stay updated with all of our programs by subscribing to our newsletter. Sign up for the newsletter by calling: 1-866-514-4312. We also have a website: www.tristate.org, and a Facebook page. Donations to the Tri-State MS Association assist people living with MS in the Tri-State area.

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# Evusheld from Astra Zeneca: Monoclonal antibodies for pre-exposure prevention of Covid-19

The FDA has issued an emergency use authorization for AstraZeneca's Evusheld, which is a monoclonal antibody indicated for pre-exposure prophylaxis (prevention) in individuals who are moderately or severely immuno-compromised and may not mount an adequate immune response to COVID-19 vaccination. Evusheld is **NOT A VACCINE**.

Vaccines have proven to be the best defense available against the COVID-19 complications of the SARS-CoV-2 virus and its variants. Evusheld is not a substitute for vaccination in individuals for whom vaccination is recommended. As COVID-19 variants continue to emerge, it is not yet known how effective Evusheld will be against each variant. This under investigation.

Studies of the SARS-CoV-2 vaccine responses in people living with MS have shown a reduced or absent antibody response among those who use certain disease modifying therapies (DMTs).

People with MS using the following DMTs may benefit from Evusheld:
*Sphingosine 1-phosphate receptor modulators (Gilenya, Mayzent, Zeposia, Ponvory)
*Alemtuzumab (Lemtrada) treatment within the past 24 months
*Anti-CD20 monoclonal antibodies (Ocrevus, Kesimpta, Rituxan )
Evusheld is not available for everyone. Talk to your MS healthcare provider to determine if Evusheld is right for you. Your MS provider will be able to tell you if you should take Evusheld to prevent you from getting COVID-19.
More information about the medication is available at the following link: https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-new-long-acting-monoclonal-antibodies-pre-exposure
The following pharmaceutical companies have scheduled educational dinner programs in the tristate area. For more information, visit their websites, or call them for dates and locations.
Biogen – Vumerity.com events or call 1-866-955-9999
EMD Serono – MAVENCLADevents.com or call 1-855-685-0738
We're Updating Our Mailing and Contact Lists
We need your help in updating our mailing and contact lists! If you would like to be added to or removed from our mailing list, please complete the information below. If you are currently subscribed to the newsletter, we want to know if you wish to continue receiving the newsletter.
Mail or email your response as indicated below.
New Subscriber: I would like to receive the newsletter by email
New Subscriber: I would like to receive the newsletter by US mail
Already Subscribed: I would like to continue receiving the newsletter by email
Already Subscribed: I would like to continue receiving the newsletter by US mail
Please <i>remove</i> me from the mailing list(s).
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