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June 2020 Newsletter

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

All Indiana, Illinois and Kentucky Support Group Meetings are Canceled for the Summer!

All Newsletter Folding for the Summer is Canceled!

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 still 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. Please stay home, stay safe and stay well!

***Please send your email address to officemanager@tristatems.org to receive newsletters and the latest program updates.**

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
 Ms. Stacy Little
 Ms. Nancy Arapios

Mr. & Mrs. Steve Sanner
 Ms. Denise Orrick
 Network For Good

In Honor Of Connie Romain

Ms. Janice Davies

In Memory of

Anna Mae Fehrenbacher

Mr. & Mrs. Robert Fehrenbacher

In Memory of John Hegeman

Mr. & Mrs. Alan Shovers

In Memory of Leon Soriano

Mr. & Mrs. Alan Shovers



Happy Birthday To You!

Kathy Knight	John Wick	Tiffany Stepto
Jeff Elpers	Scott Berry	Gayle Taylor
Billie Jo Winder	Lori Gray	Donna Cooper
Alice Burkhardt	Joyce Elpers	John Wick
Andrea Slack	Becki Unfried	Windy Whitacker
Jon Perryman	Ethel Schuster	Susie Sims
Carolyn Herron	Kurt Tretter	Paula Elpers

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.

I hope everyone is staying at home and staying safe during the coronavirus pandemic. Staying at home can be tough and with most of our daily movement restricted during the coronavirus pandemic, it can be difficult to keep up an exercise routine. If you enjoy fitness or yoga classes, you're probably missing the atmosphere of the gym or the ability to swim or aquacise in the pool. But now, more than ever, exercise is important. It can have a huge impact on anxiety you're feeling due to coronavirus and help ease stress and depression.

It's normal to feel stir crazy, but also less motivated to exercise since your routine has been turned upside down. Even a small amount of movement, like stretching or a walk around the block, can make a difference in how you feel. Historically exercise was something to be avoided by people with MS. Doctors advised against exercise because of the problems MSer's have with fatigue and overheating. As a result, generations of MS patients became de-conditioned due to inactivity.

A now classic 1996 study of people with mild to moderate disability from MS, conducted under the supervision of Jack Petajan, MD, PhD, an MS specialist formerly at the University of Utah, demonstrated the benefit of exercise with MS patients. Regular aerobic exercise — vigorous enough to raise the pulse and respiration rate — increased fitness, arm and leg strength, and workout capacity, and improved the participants' bowel and bladder control.

People in the study also reported reduced depression, fatigue and anger. Studies have also shown exercise can combat the loss of fitness caused by a sedentary lifestyle and be therapeutic for such MS-related problems as spasticity and poor balance.

Don't go out and start a difficult exercise program but do try some things and fit some movement into your routine every day. Warm-up, stretch, and get your heart rate up. Every MSer has a different level of ability. I have found many videos on YouTube to that are made specifically for people with MS from wheelchair to ambulatory patients. The best videos I have found are made by MS Workouts, MS Gym and MS Trust. My neurologist at Vanderbilt MS Clinic stresses how important exercises that target core strength are for people with MS. Your core muscles are the muscles in your trunk that hold you up and help you maintain your balance.

Be sure to stay hydrated and cool while you move. Try bringing a fan into the room where you exercise and turn it directly on you while you are moving. Warm up with stretching before you get started. Get someone else at home to exercise with you. Start slow and gradually increase your time and intensity. You will feel better when you do!

Team Rubicon and Patient Advocate Foundation - APPLY FOR ASSISTANCE:

During this time of the COVID-19 crisis, many people are unable to access, and afford, their most basic needs, including food. Team Rubicon and Patient Advocate Foundation have partnered to provide emergency food assistance to those who have cancer, Multiple Sclerosis or Rheumatoid Arthritis, and have been affected by COVID-19. Patient Advocate Foundation is providing a one-time \$500 financial assistance grant to those in need of financial assistance to purchase food.

The COVID-19 Emergency Food Assistance Program is powered by the generous support of Bristol Myers Squibb Foundation. <https://teamrubiconusa.org/applynow/>

U.S. Food and Drug Administration Approves Bristol Myers Squibb's ZEPOSIA® (ozanimod), a New Oral Treatment for Relapsing Forms of Multiple Sclerosis

In clinical trials, ZEPOSIA demonstrated efficacy on a key clinical marker of disease activity annualized relapse rate (ARR) – as compared to AVONEX® (interferon beta-1a)^{1,2,3}

ZEPOSIA is a sphingosine-1-phosphate (S1P) receptor modulator that requires no label-based first dose observation¹

ZEPOSIA adds to Bristol Myers Squibb's legacy immunology franchise and marks the first FDA approved New Drug Application since the Celgene acquisition

Approval date: March 25, 2020

What is the drug for?

ZEPOSIA is a drug used for the treatment of adults with relapsing forms of multiple sclerosis (RMS) including:

- clinically isolated syndrome,
- relapsing-remitting disease, and
- active secondary progressive disease.

In RMS, patients have episodes of worsening function (relapses) followed by recovery periods. Patients can also experience an increase in the underlying disability, particularly as the disease progresses.

How is this drug used?

ZEPOSIA is a capsule taken by mouth once daily. ZEPOSIA is initially started at a low dose and then slowly increased over the first week.

What are the benefits of this drug?

ZEPOSIA was better in reducing the risk of disease relapse in comparison to interferon β1a, a product approved for the treatment of relapsing forms of MS.

Were there any differences in how well the drug worked in clinical trials among sex, race and age?

- **Sex:** ZEPOSIA worked similarly in men and women.
- **Race:** The majority of patients were White. The number of patients in other races was limited; therefore, differences in how well ZEPOSIA worked among races could not be determined.
- **Age:** ZEPOSIA worked similarly in patients younger and older than 40 years of age.

What are the possible side effects?

ZEPOSIA may cause serious side effects including life threatening infections, decreased heart rate, liver injury, increased blood pressure, decreased lung function, and build-up of fluid in the back of the eye (macular edema).

The most common side effects of ZEPOSIA are upper respiratory infections, increased liver enzymes, blood pressure drop upon standing, urinary tract infection, back pain and high blood pressure.

Were there any differences in side effects among sex, race and age?

- **Sex:** The occurrence of side effects was similar in men and women.
- **Race:** The majority of patients were White. The number of patients in other races was limited; therefore, differences in the occurrence of side effects among races could not be determined.
- **Age:** The occurrence of side effects was similar in patients younger and older than 40 years.

WHO WAS IN THE CLINICAL TRIALS?

Who participated in the trials?

The FDA approved ZEPOSIA based on evidence from two clinical trials (Trial 1/NCT 02294058 and Trial 2/ NCT02047734) of 1767 patients with RMS. The trials were conducted at 173 centers in the United States, Belarus, Poland, Russia and Ukraine.

How were the trials designed?

The benefits and side effects of ZEPOSIA were evaluated in two clinical trials of patients with relapsing forms of MS. Patients received ZEPOSIA or comparator (interferon β 1a, a product approved for the treatment of relapsing forms of MS) for up to one year (in Trial 1) or up to 2 years (in Trial 2). Neither the patients nor the health care providers knew which treatment was being given until the trials were completed.

The benefit of ZEPOSIA was evaluated based on the percentage of patients who experienced reduction in disease relapse in comparison to patients treated with interferon β 1a.

Bristol Myers Squibb announced it will delay commercialization of the drug as the US healthcare system continues to deal with the COVID-19 pandemic.

"The company made the decision based on what's in the best health interest of our patients, customers, and employees. Bristol Myers Squibb will continue to monitor the environment and will partner with the neurology community to inform launch timing," they note in a [press release](#) announcing the approval.

Information on Zeposia from www.fda.gov

MONTHLY WEBINAR SERIES: from Can Do Multiple Sclerosis in Colorado.

Go to www.cando-ms.org to register for these webinars. On the second Tuesday of every month at 8pm ET, join our free live webinars to learn about various aspects of living with MS and how to manage common symptoms and challenges. Register today, hear from MS experts, and ask your own questions! **Register once for the entire series!**

JUNE 9th, 2020 @ 7:00pm - 8:15pm US/Central Symptom Management: Motor Component

Learn about the impact of MS on motor function. Together, we'll discuss common challenges caused by weakness, spasticity, and tremors while exploring practical management strategies.

MS Beacon/MS Views and News Webinars: To receive email notifications of these events, You need to be registered with MS Views and News. If not receiving our e-Newsletters, you therefore are not registered with us. To register go here: <http://www.msviews.org/msviewsandnews4/>

JUNE 4th MS VIEWS LIVE VIRTUAL EVENT @ 7pm ET Rick Harris PsyD – Psychology

Webinar Management of stress and anxiety during uncertain times. Family dynamics and management techniques while facing changes in our community.

JUNE 25th MS VIEWS NOW / Interview Posting Dawn Morgan & Daana Townsend, Patient Leaders and Cohosts of Myelin & Melanin Podcast – Being African American and Living with MS - A patient's perspective today

JUNE 18th Let's Talk Relapsing MS - Webinar from Biogen

Let's Talk Relapsing MS Eating Well, Register today at TalkRMS.com or 1-866-955-9999

Date: Thursday, June 18, 2020, Time: 5:45 PM CST

Healthcare Professional Speaker: Emily Evans, MD, Mercy MS Care, Town and Country, MO

Patient Speaker: Philip W.