TRI-STATE MULTIPLE SCLEROSIS ASSOCIATION

971-C S. Kenmore Drive
Evansville, IN 47714
Phone: 812-423-5943 Toll-Free: 1-866-514-4312
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May 2019 Newsletter

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

Indiana Support Group Meeting Dates

Evansville, IN support group will meet Saturday, May11th, at 10:00 a.m. at the TSMSA office, 971-C S. Kenmore Drive. Join us for an open discussion.

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

Tell City, IN support group will meet Tuesday, May 14th, at 11:00 a.m. at Twilight Towers, 1648 10th Street, in the cafeteria. Join us for an open discussion.

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

Washington, IN support group will meet Saturday, May 18th, at 10:00 a.m. at Daviess Community Hospital. Join us for an open discussion.

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 Debbie Whittington / 270-827-8298.

Owensboro, KY support group will meet Saturday, May 11th, at 11:00 a.m. at HealthPark - Owensboro Health, 1006 Ford Ave, Owensboro, KY. Join us for an open discussion and refreshments.

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

Illinois Support Group Meeting Dates

Fairfield, IL support group will meet Saturday, May 4th, at 11:00 a.m. at Fairfield Memorial Hospital in the Board Room of Horizon Clinic. Join us for an open discussion.

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

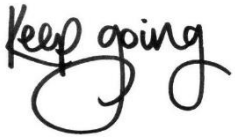
	**May 1 thru May 20, Holy Hoops for MS Fundraiser & Restaurant Giveback Nights** **Location:** American Baptist East gymnasium, 6300 Washington Ave, Evansville, IN Deadline to pay $20 entry fee: Wednesday, May 1 Restaurant giveback nights throughout May. (*See details in this newsletter*.) For more information: www.holyhoops4ms.com
	**May 9, Thursday, Genzyme (Lemtrada) Educational Lunch Program** **Speaker:** Dr. James Winkley, Baptist Neurology Center, Nicholasville, KY **Time:** 12:00 p.m. (noon) **Location:** Moonlite Bar-B-Q, Owensboro, KY **RSVP:** You and 1 (one) guest: 1-877-895-1136 or Lemtrada.com
	**May 9, Thursday, Genzyme (Lemtrada) Educational Dinner Program** **Speaker:** Dr. James Winkley, Baptist Neurology Center, Nicholasville, KY **Time:** 6:00 p.m. **Location:** Biaggi's Ristorante Italiano, 6401 E Lloyd Exp, Evansville, IN **RSVP:** You and 1 (one) guest: 1-877-895-1136 or Lemtrada.com
	**May 16, Thursday, Monthly Newsletter Folding** **Time:** 11:30 a.m. **Location:** TSMSA Office – Come help, while you make new friends!

Upcoming June Events

	**June 3, Monday, Ted Donosky MS Golf Scramble** **Location:** Rolling Hills Country Club *Individual entry fee*: $125.00; *Foursome*: $500; *Dinner only*: $30 Sponsorship opportunities available. For details, visit tristatems.org or call TSMSA: 812-423-5943
NewMed 	**June 4, Tuesday, EMD Serono (Mavenclade) Educational Dinner Program** **Speaker:** *To be announced* **Time:** 6:00 p.m. **Location:** Biaggi's Ristorante Italiano, 6401 E Lloyd Exp, Evansville, IN **RSVP:** You and 1 (one) guest: 1-877-969-1722 or mslifelines.com/liveevents
	**June 25, Tuesday, Biogen Idec (Tysabri) Educational Dinner Program** **Speaker:** Dr. Kristi Nord, Neurologist, Memorial Hospital, Jasper, IN **Time:** 6 p.m. EST (5 p.m. Central Time) **Location:** Schnitzelbank Restaurant, 393 Third Ave, Jasper, IN **RSVP:** You and 1 (one) guest: Navigating-MS.com or 1-866-955-9999

Don't watch the clock.
Do what it does.
Keep going!

~ Sam Levenson



Novartis receives FDA approval for Mayzent® (siponimod), the first oral drug to treat secondary progressive MS with active disease

*Mayzent® (siponimod) is the first and only treatment specifically approved for patients with active secondary progressive multiple sclerosis (SPMS) in over 15 years.

*Up to 80% of patients with relapsing remitting MS (RRMS) will develop SPMS; Mayzent addresses a critical unmet need for RRMS patients in transition and those with active SPMS who have transitioned.

*Approval is based on the Phase III EXPAND trial, the largest controlled clinical study of SPMS patients, showing Mayzent significantly reduced the risk of disease progression, including impact on physical disability and cognitive decline.

*Mayzent is approved across the MS spectrum for clinically isolated syndrome (CIS), RRMS and active SPMS, with most patients not requiring a first dose observation.

Novartis today (March 27, 2019) announced that the US Food and Drug Administration (FDA) has approved Mayzent® (siponimod) for the treatment of adults with relapsing forms of MS, including secondary progressive multiple sclerosis (SPMS) with active disease, relapsing remitting multiple sclerosis (RRMS) and clinically isolated syndrome (CIS)*. SPMS is a debilitating form of MS characterized by progressive and irreversible neurological disability. Patients will not require a first dose observation unless they have certain pre-existing cardiac conditions.

"One of the most important aims of MS treatment is delaying disability progression and preserving cognition," said Paul Hudson, Chief Executive Officer, Novartis Pharmaceuticals. "With Mayzent, SPMS patients with active disease will have access to the first effective oral therapy directed towards disease progression, even when MS transitions to a stage where deterioration is less dependent on the usual relapse activity. Mayzent is a testament to the Novartis mission to reimagine medicine. We are delighted that our ongoing commitment to stop MS has led to a much-awaited treatment for these patients in need." Most patients transition from RRMS to SPMS over time. Therefore, starting therapy early is critical for patients to help slow the rate of disability progression. Disability progression most frequently includes - but is not limited to - an impact on ambulation, which could lead to patients needing a walking aid or a wheelchair, bladder dysfunction and cognitive decline.

The approval of Mayzent is based on groundbreaking data from the Phase III EXPAND study, a randomized, double-blind, placebo-controlled study, comparing the efficacy and safety of Mayzent versus placebo in people living with SPMS. Patients enrolled in EXPAND were representative of a typical SPMS population: at study initiation, patients had a mean age of 48 years, had been living with MS for approximately 16 years and more than 50% had a median Expanded Disability Status Scale (EDSS) score of 6.0 and relied on a walking aid. Mayzent significantly reduced the risk of three-month confirmed disability progression (CDP) (primary endpoint; 21% reduction versus placebo, p=0.013; 33% reduction versus placebo in patients with relapse activity in the two years prior to screening, p=0.0100). Additionally, Mayzent meaningfully delayed the risk of six-month CDP (clinical disability progression), (26% versus placebo, p=0.0058) and reduced the annualized relapse rate (ARR) by 55%. Furthermore, EXPAND showed significant favorable outcomes in other relevant measures of MS disease activity, including cognition, MRI disease activity and brain volume loss (brain shrinkage).
Most common adverse reactions (incidence greater than 10%) were headache, hypertension, and transaminase increase.

*Clinically isolated syndrome (CIS) is defined as a first episode of neurologic symptoms that lasts at least 24 hours and is caused by inflammation or demyelination in the central nervous system.

About Mayzent® (siponimod). Mayzent is a next generation, selective sphingosine 1-phosphate receptor modulator indicated for the treatment of relapsing forms of multiple sclerosis (RMS), to include clinically isolated syndrome (CIS), relapsing remitting disease, and active secondary progressive disease, in adults.

Mayzent selectively binds to S1P1 and S1P5 receptors. In relation to the S1P1 receptor, it prevents the lymphocytes from egressing the lymph nodes and as a consequence, from entering the CNS of patients with MS. This leads to the anti-inflammatory effects of Mayzent. Mayzent also enters the CNS and directly binds to the S1P5 and S1P1 sub-receptors on specific cells in the CNS (oligodendrocytes and astrocytes) to promote re-myelination and prevent inflammation.

Mavenclad (cladribine) for Relapsing Remitting Multiple Sclerosis

The U.S. Food and Drug Administration today (March 29, 2019) approved Mavenclad (cladribine) tablets to treat relapsing forms of multiple sclerosis (MS) in adults, to include relapsing-remitting disease and active secondary progressive disease. Mavenclad is not recommended for MS patients with clinically isolated syndrome. Because of its safety profile, the use of Mavenclad is generally recommended for patients who have had an inadequate response to, or are unable to tolerate, an alternate drug indicated for the treatment of MS.

The FDA granted approval of Mavenclad to EMD Serono, Inc. The FDA approval of Mavenclad is excellent news for people living with RRMS and active SPMS. Mavenclad offers a new and effective option for some of those patients with an oral dosing schedule unlike any other treatment currently available," said June Halper, CEO of the Consortium of MS Centers. "People living with MS should have the ability to work with their clinician to choose a treatment with a dosing schedule that supports their lifestyle. CMSC congratulates Merck KGaA, Darmstadt, Germany, for their dedication to bring Mavenclad to the US as the first short-course oral treatment option for the community."

In the clinical trial program, 1,976 patients received therapy for a total of 9,509 patient years, of which the mean time on study including follow-up was approximately 4.8 years and 24% of the follow-up was for eight years. Mavenclad demonstrated clinical efficacy across key measures of disease activity, such as annualized relapse rate, disability progression, and magnetic resonance imaging (MRI) activity:

*Patients experienced a 58% relative reduction in the annualized relapse rate with Mavenclad compared to placebo (0.14 vs 0.33, $p<0.001$).

*81% of patients were free of relapses after two years of short-course oral treatment with Mavenclad, compared to 63% of patients who received placebo ($p<0.05$).

*Patients treated with Mavenclad had a 33% reduction in risk of 3-month confirmed disability progression as measured by Expanded Disability Status Scale (EDSS) compared to placebo ($p<0.05$).

*Patients taking Mavenclad experienced a lower median number of T1-weighted gadolinium-enhanced brain lesions and new or enlarging T2 brain lesions compared to patients with placebo (0 vs 0.33 and 0 vs 0.67) $p<0.001$).

The most common (> 20%) adverse reactions reported in the pivotal phase III study, CLARITY were upper respiratory tract infection, headache, and lymphopenia. Serious adverse reactions reported in the clinical program included malignancies (0.27 events per 100 patient-years) in Mavenclad treatment arms, compared to placebo patients (0.13 events per 100 patient-years), and herpes zoster infections (2.0% vs. 0.2%) and oral herpes (2.6% vs. 1.2%).

Following the administration of two treatment courses, additional courses of Mavenclad are not to be administered. Re-treatment with Mavenclad during years three and four may further increase the risk of malignancy. The safety and efficacy of reinitiating Mavenclad more than two years after completing two treatment courses has not been studied.

Mavenclad must be dispensed with a patient Medication Guide that describes important information about the drug's uses and risks. Mavenclad has a Boxed Warning for an increased risk of malignancy and fetal harm. Mavenclad is not to be used in patients with current malignancy. In patients with prior malignancy or with increased risk of malignancy, health care professionals should evaluate the benefits and risks of the use of Mavenclad on an individual patient basis.

Health care professionals should follow standard cancer screening guidelines in patients treated with Mavenclad. The drug should not be used by pregnant women or by women and men who are potentially fertile and for six months after the course of therapy because of the potential for fetal harm. Mavenclad should be stopped if the patient becomes pregnant.

Other warnings include the risk of decreased lymphocyte (white blood cell) counts; lymphocyte counts should be monitored before, during and after treatment. Mavenclad may increase the risk of infections; health care professionals should screen patients for infections and treatment with Mavenclad should be delayed if necessary. Mavenclad may cause hematologic toxicity and bone marrow suppression so health care professionals should measure a patient's complete blood counts before, during and after therapy. The drug has been associated with graft-versus-host-disease following blood transfusions with non-irradiated blood. Mavenclad may cause liver injury and treatment should be interrupted or discontinued, as appropriate, if clinically significant liver injury is suspected.

Merck KGaA, Darmstadt, Germany, is committed to helping support patients prescribed Mavenclad. Over the course of 16 years, the company`s comprehensive patient support program in the U.S., MS LifeLines®, has had over four million touchpoints with patients, care partners, health care professionals, and other stakeholders to support our goal of providing one-on-one assistance to U.S. patients prescribed a Merck KGaA, Darmstadt, Germany, MS therapy. MS LifeLines® is now expanding to help patients prescribed Mavenclad and offers personalized patient support, including assistance with navigating insurance questions and additional resources that may be able to assist patients who are uninsured or underinsured.

The U.S. approval of Mavenclad follows its approval in over 50 countries, including the European Union in August 2017.

Sources:
FDA Press releases on Mayzent and Mavenclad approval
Novartis Press release on Mayzent
EMD Serono Press release on Mavenclad

In Memory of……

In Honor 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 Tri-State MS Association

Dr. Rick Yeager	Kenny Kent	Open Door UU Church
LNB Community Bank	Old National Bank	Network for Good

In Memory of Joni Gentry

Bruce Adler

Happy Birthday To You!

Leta Kelly	James Renner	Joe Randolph
Stephanie Overby	Bri Dri	Rhonda Grant
Don Tharp	Yolanda Webb	Martha Buchta
Sandy Corley	Becki Richardville	Debbie Bashon
	Suzanne Deters	

If you would like to have your birthday included in our newsletter, please send a note that includes your *name*, *date of birth*, and *signed permission* for us to print it.

Ways to Save…… Ways to Give

Before you shop for jewelry, pick up a FREE "5+5=LOVE" card from the TSMSA office. Present your card on each visit to The Diamond Galleria. You'll receive a 5% discount, and TSMSA will receive a donation of 5% of your total purchase. It's easy!

Send Flowers! Call Zeidler's or order on line at www.zeidlers.com and select TSMS, and the Tri-State MS Association will receive a donation.

AmazonSmile. Go to smile.amazon.com and select us as your charity of choice. Amazonsmile will donate .5% of the price of your eligible purchases to TSMSA.

Upcoming Restaurant Givebacks (Sponsored by Holy Hoops 4 MS)

HOLY HOOPS

MAY 1-MAY 20

2019

FOR MORE INFORMATION VISIT WWW.HOLYHOOPS4MS.COM

MAY 1: DEADLINE TO PAY $20 TAX-DEDUCTIBLE DONATION ENTRY FEE

MAY 4: FIRST ROUND OF TOURNAMENT

MAY 6: GIVEBACK AT BOSTON'S PIZZA (11 AM-11 PM)

MAY 7: GIVEBACK AT WAYBACK BURGERS (4 PM-8 PM)

MAY 8: GIVEBACK AT AZZIP PIZZA LOCATIONS (11 AM-9 PM)

MAY 11: FINAL ROUNDS OF TOURNAMENT

MAY 13: RESTAURANT GIVEBACK AT BOSTON'S PIZZA (11 AM-11 PM)

MAY 14: HOLY HOOPS FOR M.S. AUCTION

MAY 20: RESTAURANT GIVEBACK AT BOSTON'S PIZZA (11 AM-11 PM)

Congratulations to our friends from Rehab for Life for achieving their MS Specialization Certification!

Holly Maurer, COTA

Holly is a Certified Occupational Therapy Assistant (COTA) and has been with Rehab for Life since it opened in 2007. Throughout her COTA career, she underwent additional education and training in Myofascial Release and Techniques, Vertigo treatment and management of the condition, Upper Body Rehab, Multiple Sclerosis, Dementia care, Parkinson's Disease, Kinesotaping, Mental Health, and Seating and Positioning. She earned her Multiple Sclerosis Certified Specialist (MSCS) credentials in January of 2019.

Jamie Hills, PTA

Jamie has been at Rehab for Life as a staff Physical Therapy Assistant (PTA) since its inception in 2007. Throughout her PTA career, she attended numerous continuing education courses pertaining to balance dysfunction in the elderly, strengthening, Alzheimer's and Behavioral Science, and Multiple Sclerosis. Jamie also has additional training in Myofascial Release Techniques, Kinesotaping, and earned her Multiple Sclerosis Certified Specialist (MSCS) in December of 2018.

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