

June 2016 Newsletter

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

Indiana Support Group Meeting Dates

Evansville, IN support group will meet Saturday, June 11th, at 10:00 a.m. at the TSMSA Office, 971-C S. Kenmore Drive. **Speaker**: **Gayle Golike** E-RYT 200, RCYT became a certified Forrest Yoga teacher in 2004. She has continued to do numerous teacher trainings with an emphasis on anatomy and alignment.

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

Princeton, IN support group will meet Saturday, June 25th, at 10:00 a.m. at Gibson General Hospital, 5th floor, first room on right. Join us for an open discussion and refreshments. **Contact:** TSMSA Office 1-866-514-4312.

<u>Tell City, IN</u> support group will meet Tuesday, June 14th, at 11:00 a.m. at Mary Ann Weatherholt's camp for a "Summer Picnic". We will provide the meat, drinks, and paper products. Please join us and bring your favorite dish to share. Call Terri for directions! Contacts: Terri Hasty / 812-649-4013 or Gayle Taylor / 812-719-2417.

Washington, IN support group will meet Saturday, June 18th, at 10:00 a.m. at Daviess Community Hospital. Join us for an open discussion and refreshments. Contacts: Cindy Kalberer / 812-254-6735 or Fran Neal / 812-259-1565.

Kentucky Support Group Meeting Dates

Henderson, KY support group will meet Saturday, June 4th, at 10:00 a.m. at Calvary Missionary Baptist Church, 2360 Green River Road, Henderson, KY. Contacts: Meg Burnley / 270-826-9507 or Debbie Whittington / 270-827-8298.

<u>Owensboro, KY</u> support group will meet Monday, June 13th, at 6:00 p.m. at HealthPark -Owensboro Health, 1006 Ford Ave, Owensboro, KY. **Contact:** Susan Reynolds / 812-228-6100.

Illinois Support Group Meeting Dates

Fairfield, IL support group will meet Saturday, June 4th, at 11:00 a.m. at Fairfield Memorial Hospital in the Board Room of Horizon Clinic. Join us for an open discussion. **Contacts:** Kathie Hill / 618-847-8452 or TSMSA / 1-866-514-4312.

ST.MARY'S

We would like to sincerely thank St. Mary's Health System for their continued support of the Tri-State MS Association's monthly newsletter.

Shared Solutions: 1-800-887-8100 www.copaxone.com/shared-solutions *Thank you to Teva Neurosciences for sponsoring our monthly newsletter*



	June 6, Monday, The Ted Donosky MS Golf ScrambleLocation: Rolling Hills Country Club, Newburgh, INSingle and foursomes available. See website for sponsorship opportunities!www.tristatems.orgCall TSMSA for more information!
	June 8 – July 17, Holy Hoops H.O.R.S.E. Shootout for Multiple Sclerosis Come play basketball for a cause! Sign up to play H.O.R.S.E. during select dates and times, June 8 th thru July 17 th at Wesselman Park or American Baptist East by calling Jay Stockman: 812-774-3963. Visit www.holyhoops4ms.com for a list of available times and prizes! All participants will receive a prize! Participants of all ages are welcome, excluding individuals who have signed to play collegiate basketball. Make a tax-deductible donation of \$20 to play, and an additional \$10 to re-enter if you have been knocked out. All donations will benefit TSMSA! Tell your family and friends, and sign up today!
	June 9, Thursday, Mallinkcrodt (Acthar) Educational Program Speaker: Dr. Kristi Nord, Neurologist, Memorial Hospital, Jasper, IN <u>Time</u> : 6:00 p.m. Location: The Log Inn, 12491 County Road 200E, Haubstadt, IN 47639 <u>RSVP</u> : You and 1 (one) guest: 812-423-5943 or 1-866-514-4312
TEXAS ROADHOUSE	June 12, Sunday, Texas Roadhouse Give Back Fundraiser Present the enclosed flyer to your server at Texas Roadhouse (7900 Eagle Crest Blvd, Evansville), and Holy Hoops H.O.R.S.E. Shootout will give back 10% of sales to TSMSA!
	June 13, Monday, Teva (Copaxone) Educational Program Speaker: Dr. Rod Warren, Neurologist, Evansville, IN <u>Time</u> : Registration 5:30 p.m.; Program 6:00 p.m. Location: Biaggi's Ristorante Italiano, 6401 E Lloyd Exp, Evansville, IN <u>RSVP</u> : You and 1 (one) guest: Shared Solutions 1-800-887-8100
NEWS	June 16, Thursday, Monthly Newsletter Stuffing <u>Time</u> : 11:30 a.m. <u>Location</u> : TSMSA Office – Come help, while you make new friends!
HAPPY FATHER'S DAYI	June 19, Sunday, Happy Father's Day! Celebrate the special dads in our lives!

MSF: MSF is taking applications for cooling products through June 1st. You may apply online or print an application at www.msfocus.org or you may call 1-888-673-6287.

MSAA: You may download an application for a cooling vest from MSAA at www.mymsaa.org. Complete the application and mail it to the address on the form. Or you may call 1-800-532-7667.

<u>Calendar of Events</u> (cont'd)



Upcoming July Event



July 12, Tuesday, Teva (Copaxone) Educational Program Speaker: Dr. Randy Cox, Neurologist, Tell City, IN / Hardinsburg, KY <u>Time</u>: 12:00 p.m. (noon) Location: Moonlite Bar-B-Q, Owensboro, KY RSVP: You and 1 (one) guest: Shared Solutions 1-800-887-8100

Nuedexta: Medication to Treat Uncontrolled Crying or Laughing

Susan Reynolds RN, MSCN

A medication has been approved for a symptom of MS that is not commonly talked about. The medication is called Nuedexta, and it is marketed by Avanir Pharmaceuticals. Nuedexta is supposed to treat pseudobulbar affect (PBA) or Involuntary Emotional Expression Disorder (IEED). It is characterized by uncontrolled or exaggerated episodes of crying, laughing, or other emotional displays occurring with minimal or no stimulation to provoke such a response. Studies show that up to 50 percent of MS patients experience PBA. People who have the condition usually have some type of neurologic disorder, typically MS, Amyotropic Lateral Sclerosis, Parkinson's disease, dementia, traumatic brain injury, or stroke.

Nuedexta contains dextromethorphan hydrobromide, 20 mg and quinidine sulfate, 10 mg. A few years ago the medication was almost approved by the FDA under the name Zenvia, but the FDA sent the company back to the drawing board, citing concerns over heart rhythm safety. The main concern was whether quinidine caused QT prolongation (a heart rhythm abnormality that can cause a heart attack). The amount of quinidine was decreased by one-third, and more clinical trials were done. The new formulation will be sold under the name Nuedexta.

Nuedexta is first in its class of medications, thought to affect the neurotransmitter glutamate, although the exact mechanism by which Nuedexta works is unknown. Nuedexta was tested at two strengths: 30 mg dextromethorphan hbr with 10 mg quinidine, and 20 mg dextromethorphan with 10 mg quinidine. Each reduced the PBA rate by 46.9% and 49% respectively, relative to a placebo.

Patients with PBA typically experience embarrassment because of their unpredictable emotional outbursts leading to disruptions of their relationships with family and friends. This can lead to social isolation. It is thought that PBA is a disconnection syndrome that results when regulation of higher centers of the brain associated with emotions are impaired due to disease or injury. Physicians sometimes treat the signs and symptoms of PBA with anti-depressants called serotonin reuptake inhibitors, e.g. fluoxatine, citalopram, paroxetine, and sertraline. The trade names are: Prozac, Celexa, Paxil, and Zoloft. These can significantly reduce the frequency of emotional outbursts, but they can also cause unwanted side effects.

Patients with PBA are frequently misdiagnosed with depression, bipolar disorder, personality disorder and sometimes even epilepsy. One difference is that the previously mentioned disorders have sustained emotional states over long periods of time.

PBA's emotional episodes are relatively short in duration. Usually the patient is laughing or crying, and it is not congruent with what the patient is feeling. A test most commonly used by doctors to diagnose PBA is the Center for Neurologic Study Lability Scale (CNS –LS), a short seven item questionnaire completed by the patient. Another test performed is the Pathological Laughing and Crying Scale (PLACS) which is based on an interview between the patient and the clinician.

Nuedexta is taken once a day for the first week, then two times a day starting on the eighth day. Side effects can be diarrhea, dizziness, cough, vomiting, weakness, peripheral edema, and flatulence. The FDA cautions that quinidine is linked to a risk for severe and potentially fatal immune-related thrombocytopenia (decreased platelets that can lead to bleeding) that can be preceeded by such nonspecific signs and symptoms as lightheadedness, chills, fever, nausea, and vomiting. Treatment should be permanently discontinued if thrombocytopenia develops.

Assessment Questions on the CNS-LS Scale:

- 1. There are times when I feel fine one minute, and then I'll become tearful the next minute over something small or for no reason at all.
- 2. Others have told me that I seem to become amused very easily or that I seem to become amused about things that really aren't funny.
- 3. I find myself crying very easily.
- 4. I find that even when I try to control my laugher, I am often unable to do so.
- 5. There are times when I won't be thinking of anything happy or funny at all, but then I'll suddenly be overcome by funny or happy thoughts.
- 6. I find that even when I try to control my crying, I am often unable to do so.
- 7. I find that I am easily overcome by laughter.

Instructions for filling out CNS-LS: Write answers, using a scale between 1 and 5, with 1 being "never," and 5 being "most of the time." Write down the number that describes the degree to which each item applies to you DURING THE PAST WEEK. Write only 1 number for each item.

If you score 13 or higher, you may be having PBA symptoms. You should discuss with your doctor.

Sources: Nuedexta.com; Avanir Pharm. press release, Avanir Pharm. patient advertising brochure



Schwan's Cares Fundraiser

Giving back to the Tri-State MS Association never tasted so delicious! We will have a Schwan's Cares fundraiser thru July 7, 2016. Go to Schwans-Cares.com to order from Schwan's Home Delivery and help our organization meet its fundraising goals.

When you order thru July 7th, 20% of all product sales and 40% of eGift Card sales will go back to TSMSA! Schwan's Home Delivery offers over 350 delicious foods, flash-frozen at the peak of freshness! You will find the perfect meal ideas for parties and events, all delivered right to your door! There are two ways to support us:

Order Online:

- 1. Visit http://www.schwans-cares.com/c/26514
- 2. Click "Shop to Give"
- 3. Start shopping!

Existing Schwan's customers need to follow one of the ordering steps above to create your fundraising affiliation and have your order contribute to our campaign. Your order will be delivered on your existing route day. New customers need to choose a delivery date & time during checkout.



Lucas Oil - Father's Day Gift Ideas

Lucas Oil Diamond Discount Cards: Purchase a discount card from the TSMSA office or Lucas Oil Center for \$10.00 to receive discounts from many local businesses. Proceeds benefit TSMSA.

Lucas Oil Discount Football: Purchase a football (7" diameter) from the TSMSA office or Lucas Oil Center for \$10 to receive \$5.00 off a car wash or oil change at Lucas Oil Center *every time* you show the football.

Order by Phone:

1. Call 1-855-870-7208 and provide Campaign ID: 26514





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 Stacy Little	Open Door UU Fellowship Denise Love Orrick	Professional Transportation Daniel McCarty
Nancy Arapios	Carl Brown	Trevor Hoehn
Nancy Arapios		
<u>In Memory of Joni Gentry</u>	<u>In Memory of Von Sloan</u>	<u>In Memory of Richard Gooch</u>
Bruce Adler	Laura Weibush	Ethel Taylor
	Vonda Templeton	Robyn Gunnip
In Memory of Don Harris	In Memory of Mary Kay Thomas	In Memory of Sheila Overton
Ms. Iona Wildt	Connie Romain	Allison Spaeth
Robert Mangiarelli	Debbie Hebbeler	
Scott Smith	Sharon Omer	
	Linda Mattingly	



HAPPY BIRTHDAY TO YOU!!				
Kathy Knight	John Wick	Betty Tharp		
Tiffany Stepto	Jeff Elpers	Scott Berry		
Gayle Taylor	Billie Jo Winder	Lori Gray		
Donna Cooper	Alice Burkhart	Joyce Elpers		

<u>If you would like to have your birthday included in our newsletter</u>, please send a note that includes <u>your name</u>, your <u>date of birth</u>, and your <u>signed permission</u> for us to print it in our newsletter. Our mailing address is 971-C S. Kenmore Drive, Evansville, IN 47714.



Thank you to **Jason's Deli** for hosting a give back night for TSMSA. We appreciate the support!!

Thank you

Thank you **Kight Lumber**, **Sherwin-Williams Paint**, and **Danny Hirsch** for making our second craft event a huge success! Thank you to all those that came and made a flag or flower! They were all so unique and beautiful! Check out all the pictures on Tri-State MS Association's Facebook page!

Evening of Excellence

Congratulations to Spirit Award Recipients: Mary Jane Miles and Beckie Dennis!

Thank You to Our Sponsors

Bussing-Koch Foundation Direction by Newman Edward W. Love Foundation Expressway Auto Mall FC Tucker Commercial Genzyme, a Sanofi Company

Bill & Phyllis Bussing Bonefish Grill Brinker's Jewelers Erin Grabert, Grand Hair St.

German American Bank **Koch Foundation** Kristin Dannheiser & Kyle Bernhart Marilyn O'Daniel **Old National Bank**

Pet Food Center, LLC St. Mary's Health System Steve Clark The Diamond Galleria Therapy Assoc Med Oncology **Tri-State Aero**

Tropicana Evansville United Companies WEHT 25 Local & Local 7 WTVW

Live Auction Donors

Escalade Sports Evansville Courier & Press Evansville Living Magazine French Lick Resort

Kirk & Sherry Wright Pet Food Center Robert Griffin SPHL Thunderbolts

SUV Limousine **Townsquare Media** VenuWorks / Ford Center Walt Disney World

14 WFIE Acropolis American Girl Assuage Spa Services, LLC Azzip Pizza **Basket Kases Beech Bend Park** Bella Vi Spa & Aesthetics Belle of Louisville Biaggi's Ristorante Italiano Big Splash Adv. Water Park **Casey's General Stores** Chicago Bulls Chik-fil-A Children's Museum of Indianapolis Chili's cMoe College Football Hall of Fame **Colonial Gardens** ComedySportz Indianapolis **Connie Romain** Cork 'n Cleaver Creation Museum Crystal Ball Carpet Cleaning D'Alto Studio of Perf. Arts Darrell's Photography Dean Bosler's Furniture Déjà vu Skin & Vein Center Denver Zoo

Derby Dinner Playhouse Dillard's Dr. Barry W. Rav Dr. Cindi Basinski Dr. Goodman Eastern Kentucky University Escape Evansville Evansville Archery Academy Evansville Music Academy **Evansville Otters** Evansville Phil. Orchestra Family Dentistry Flutter Newburgh Fort Wayne Children's Zoo Ganz Gatti Town GiGi's Cupcakes Grand Country Music Hall Hacienda Historic Newburgh, Inc. Holiday Inn Evansville Airport Holiday World Indiana Basketball Hall of Fame Nitro Fitness Indiana Caverns Indiana State Museum Indianapolis Colts Indianapolis Zoo J. Michael Conkright, M.D. J.E. Shekell, Inc. Jason's Deli

Silent Auction Donors Jennifer's Hallmark Joergen's Photography Johnny Cash Museum Jones Chiro. & Acupuncture Just Faux Fun Kentucky Derby Museum Kentucky Horse Park Lefler's Collision & Glass Lic's Live Well Longhorn Steakhouse Louisville Mega Caverns Louisville Zoo Mahoning Valley Scrappers Marengo Cave Mark's Mattress McAlister's Deli Mesker Park Zoo Muhammad Ali Center Naples Zoo National Corvette Museum NCAA Hall of Champions No Frye Zone Olive Garden **Oliver Winery** People's Furniture - Mattress **Portrait Innovations Red Lobster Reitz Home Museum**

Rolling Hills Country Club Science Center Shedd Aquarium Sheriff Dave Wedding Shyler's BBQ St. Louis Cardinals Stampin' Up Sugar Bakers Home Fashions Sweet Lolli Toys Swonder Ice Arena **Tennessee Smokies Baseball** TGI Friday's The Cheer Zone The Cheesecake Factory The Face Place The Galt House Hotel The Hornet's Nest The Rug Gallery of Newburgh **Tiny Prints Tri-State Athletic Club Tropicana Evansville** TSMSA Board Members University of Louisville Wild Flower Boutique WNBA Indiana Fever Working Distributors World of Coca Cola YMCA Zuki

Special Thanks to Those Who Made Our Event a Success:

Amanda Hughes Amy Higelman, Fire & Rain Angie Martin Angie Wargel

Barb Heacock Chad Schmidt CRS One Source, Alan Clark **Diane Merritt**

Donut Bank Gina Moore Jennifer Jones Jim David John Jenkins Kristin Dannheiser Linda Anslinger Monarch Beverage Pam Jutzi Sally Jochim Sandy Bitter Sassy Sweet Conf.

Schutte Printing Stacev May Stan Newman Susan Shovers **Tiffany Stepto** Trina Doepker Tropicana Evansville