





971-C S. Kenmore Drive
Evansville, IN 47714
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April 2019 Newsletter

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

Indiana Support Group Meeting Dates

Evansville, IN support group will meet Saturday, April 13th, 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, April 9th, 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, April 20th, 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, April 13th, 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, April 6th, 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

  <p>Gehlhausen</p>	<p><u>April 16, Tuesday, Celebrating Easter Spring Fashion & Floral Event</u> Time: 6:00 to 8:00 p.m. Location: Gehlhausen Floral, 735 S. Green River Rd, Evansville, IN Tickets: In Advance: \$15; At the Door: \$20 (<i>All ticket proceeds benefit TSMSA.</i>) 5% GiveBack to TSMSA 20% Off Entire Purchase Fashions by: Gehlhausen Floral</p> <p>Fun, Fashions, Refreshments, Door Prizes, and a chance to win a Golden Egg Spring Package</p>	
	<p><u>April 18, Thursday, Monthly Newsletter Folding</u> Time: 11:30 a.m. Location: TSMSA Office – Come help, while you make new friends!</p>	

Upcoming Events

	<p><u>May 1 thru May 20, Holy Hoops for MS Fundraiser & Restaurant Giveback Nights</u> Location: American Baptist East gymnasium, 6300 Washington Ave, Evansville, IN Deadline to pay \$20 entry fee: Wednesday, May 1 Restaurant giveback nights throughout May. (<i>See details in this newsletter.</i>) For more information: www.holyhoops4ms.com</p>	
	<p><u>May 9, Thursday, Genzyme (Lemtrada) Educational Lunch Program</u> 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</p>	
	<p><u>May 9, Thursday, Genzyme (Lemtrada) Educational Dinner Program</u> 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</p>	



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
Jeffrey Curtis
Stacy Little

Nancy Arapios
Mike Cherry
Denise Love

Open Door UU Church
Schwan's Home Service
Diamond Galleria

In Memory of Joni Gentry

Bruce Adler

In Memory of Brenda Kozil

Debbie Hebbeler
Linda Mattingly

Have you ever thought about participating in a clinical trial for a new MS drug? Clinical trials help determine whether a drug is safe and effective for MS. Without patients who are willing to be volunteers in these studies, we could not have new and better therapies. The goal of clinical trials is to determine if a new test or treatment works and is safe. Clinical trials can also look at other aspects of care, such as improving the quality of life for people with MS.

The Federal Government has established strict regulations and guidelines for clinical research to protect participants from unreasonable risks. However, all risks cannot be completely eliminated, so it is important to know the process and the risks that may be involved.

Here is an outline of the process:

1. **Pre-Clinical Trials:** Potential therapies are tested in the laboratory and on animals to determine toxicity and side effects. The sponsor meets with the FDA after each stage to figure out their next steps and establish parameters for future trials.
2. **Clinical Evaluation:** An application for an investigational new drug is filed with the FDA. The results of the pre-clinical studies are a part of the application.
3. **Phase I - Safety:** Dosing for the future trials is assessed. Small numbers of healthy volunteers (usually 20-30 people) are given the drug in gradually larger doses to test for tolerability, side effects, or complications. This is done to determine what a safe dose would be.
4. **Phase II - Safety and Efficacy:** Studies in this phase are done to determine therapeutic effect, as well as safety. These trials usually have 40 to 300 participants. Several studies may be done in this phase on a variety of patient populations. The study is controlled, which means the drug is compared with the standard treatment or an inactive placebo. Studies in this phase will determine if a larger more definitive phase III trial is worth the money.
5. **Phase III- Controlled Safety and Efficacy:** Larger populations (hundreds to thousands of people) are used to confirm the beneficial effect from phase II trials and continue to monitor side effects. These multi-center trials can span several years and countries.
6. **Regulatory Filing:** The sponsor submits an application for marketing approval along with all the data collected in the trials. The FDA final approval process can take up to two years.
7. **Phase IV- FDA Approval and Post Approval Monitoring:** Post approval marketing studies might be done to assess long-term safety and effectiveness. The sponsor must continue to monitor any adverse side effects and report them to the FDA.
8. **Manufacturing:** The FDA regulates the manufacturing of drugs by testing several lots of drugs prior to marketing. They also inspect manufacturing facilities and require companies to keep manufacturing records.

You can register with NARCOMS, a registry for MS patients and MS Research at: www.narcoms.org or 1-800-253-7884.

- You will be notified of clinical trials and other studies for which you may be eligible to participate.
- They will keep you updated on findings that might be of current or future interest through their quarterly magazine NARCOMS NOW.
- You will be contributing to the knowledge base that can lead to improved treatments and quality of life for you and future people with MS.

There is no cost for your participation. NARCOMS is a project of the Consortium of Multiple Sclerosis Centers. Additional support over 20-plus years of data collection is provided by grants and in-kind services from United Spinal Association, Paralyzed Veterans Association (PVA), the National MS Society, researchers and industry collaborators, as well as the following pharmaceutical companies: Berlex, Biogen, Genentech, Sanofi Aventis, Serono, and Teva Neuroscience.

Benefits to participating in a clinical trial:

1. You can gain access to new treatments before they become widely available.
2. You will be closely monitored and receive high quality medical care.
3. You will be helping others by contributing to medical research.

Risks to participating in a clinical trial:

1. There may be unpleasant or serious side effects.
2. The treatment may not be effective, or it may not work for you.
3. You may receive a placebo.
4. Participating may take more time than a normal treatment regimen.
5. You may have to undergo more treatments and tests and see the doctor more frequently.
6. You may have to change doctors.

How Participants Are Protected: Most clinical research is federally regulated with built in safety guards to protect the patient. The trials have carefully controlled protocol. An independent data and safety monitoring board follows the study closely for side effects and any unexpected outcomes.

Informed Consent and Costs: Before you participate in a clinical trial you will be asked to understand and sign an informed consent. The sponsor must follow the informed consent in order protect the participants in a trial. All of the key facts concerning the trial must be described to the volunteer within the informed consent documents. This should be studied carefully by the patient, and any questions should be answered before a decision is made to participate in a trial. The informed consent should outline any costs that will be billed to you. In most cases, the research will cover the costs of the study drug and any medical care performed to fulfill the study's goals. You should contact your insurer about the trial and the informed consent to find out how it will affect your insurance benefits and if it will pay for expenses that may not be covered in the clinical trial.

Several MS Centers close to the tri-state area participate in clinical trials on a regular basis:

- * University of Louisville MS Center - University of Louisville, Louisville, KY; Phone: 502-561-7400
- * Vanderbilt Multiple Sclerosis Clinic - Nashville, TN; Phone: 615-936-0060
- * Norton Neuroscience Institute - Louisville, KY; Phone: 502-629-1234, option 3.
- * Indiana University MS Center - Indianapolis, IN; Phone: 317-948-5450
- * Advanced Neurosciences Institute - Franklin, TN; Phone: 615-791-5470

Most centers require you to be a patient at that MS center before participating in a clinical trial.

Websites: Center Watch: www.centerwatch.com; CISCRP - The Center for Information and Study on Clinical Research Participation: www.ciscrp.org; and www.clinicaltrials.gov

Sources:

Participating in Clinical Trials, A Guide for People with MS. A brochure from National MS Society. MS in Focus, Issue 17, Introduction to Research in MS.

Participating in a Clinical Trial, by Margot Russell with Allen C Bowling M.D. Ph.D.



Thank you to The Diamond Galleria for your support during 2018!

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

HOLY HOOPS

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

MAY 4: FIRST ROUND OF SINGLE-ELIMINATION TOURNAMENT

MAY 6: RESTAURANT GIVEBACK AT BOSTON'S PIZZA (11 A.M.-11 P.M.)

MAY 7: RESTAURANT GIVEBACK AT WAYBACK BURGERS (4-8 P.M.)

MAY 8: RESTAURANT GIVEBACK AT THREE AZZIP PIZZA LOCATIONS (11-9)

MAY 11: FINAL ROUNDS OF SINGLE-ELIMINATION TOURNAMENT

MAY 13: RESTAURANT GIVEBACK AT BOSTON'S PIZZA (11 A.M.-11 P.M.)

MAY 14: HOLY HOOPS FOR M.S. AUCTION

MAY 20: RESTAURANT GIVEBACK AT BOSTON'S PIZZA (11 A.M.-11 P.M.)

MAY 1-MAY 20
2019



FOR MORE INFORMATION VISIT
WWW.HOLYHOOPS4MS.COM



Games to Challenge Your Brain



Many MS patients struggle with cognitive issues. Those issues may include memory, word finding, attention span, planning, decision making, understanding, and concentration. Below are some games that may help strengthen brain function.

Jigsaw Puzzles – Retail stores offer a variety of choices in jigsaw puzzles. Sizes range from jumbo to very small pieces, and from few to thousands of pieces. They’re made for everyone!

Search & Find Games – These games include hidden pictures, word search puzzles, and mazes.

Scrabble – In this game, players calculate their scores by using simple math, and of course, they are challenged to come up with words to add to the board.

Checkers – This game challenges players to perform strategic moves.

Battleship – Players use planning and strategy to sink the opponent’s ships.

Uno – Each player uses strategic planning to be the first person to have only one card remaining.

Solitaire – In this single player card game, concentration and strategy skills are challenged.



Happy Birthday To You!

Peggy Wade Sue Hartig
Kristi Stewart Williams

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.



REHAB FOR LIFE & TRI-STATE MS ASSOCIATION

April Strengthening & Balance Workshops

Here's a look at our upcoming workshops! Remember that this class is \$5 per person, per class to be paid that day and ANYONE is welcome. The following classes will be held at Rehab for Life's

NEW LOCATION (6215 East Florida St, Evansville):

- Tuesday, 4/2: 12-1 PM
- Tuesday, 4/9: 12-1 PM
- Tuesday, 4/16: 12-1 PM
- Tuesday, 4/23: 12-1 PM
- Tuesday, 4/30: 12-1 PM

RSVP to Tri-State MS: (812) 423-5943



Check out the Facebook page of one of our supporters, David. He created the “Run to Smash MS” page to raise money for the Tri-State MS Association and to allow others to follow his journey running races to bring awareness for MS in our tri-state area. You can find him on Facebook by searching for @runtosMaSh. Share his message and help him get donations for our nonprofit!



Summer Cooling Products

It's not too soon to start thinking about cooling off during hot weather. The Multiple Sclerosis Foundation (MSF) and Multiple Sclerosis Association of America (MSAA) are taking applications for cooling products for income eligible individuals.

MSF: MSF is taking applications through June 1st for cooling products, including cooling vests, neck wraps, wristbands, and hats. You may apply online or print an application at www.msfocus.org, or you may call MSF at 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.

Vectren Weatherization Program



Vectren offers a free weatherization program for low income households. If you meet income guidelines and if your home is more than 5 years old, you can receive an in-home energy assessment through the weatherization program.

During the assessment, an energy advisor will perform a walkthrough to understand how your home and appliances use energy. Upon completion of the assessment, the advisor will provide a report with an action plan for additional energy-saving efforts for your home. For more information, go to www.vectren.com or call 1-800-227-1376.



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Join us at our Spring Fashion & Floral Event

Fun, Fashions, Refreshments, Door Prizes, and a chance to win a Golden Egg Spring Package

Celebrating Easter

Spring Fashion & Floral Event

Tuesday, April 16th, 6:00 pm - 8:00 pm
Gehlhausen Floral, 735 S. Green River Road

Fashions by Gehlhausen Floral
Door prizes ~ Light refreshments

Advanced tickets: \$15
At the door: \$20

All ticket proceeds will benefit the
Tri-State MS Association
tristatems.org
(812) 423-5943 or 1-866-514-4312

Chance to Win Golden Egg Spring Package

5% Give Back to TMSA

20% Off Entire Purchase


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Gehlhausen