

June 2015 Newsletter

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

Indiana Support Group Meeting Dates

Evansville, IN support group will meet Saturday June 13th, at 10:00 a.m. at the TSMSA Office, 971-C S. Kenmore Drive. **Speaker: Kay Hummel, Dr. of Natural Medicine HHP, CR, Reiki Practitioner II, AADP** (more information on Dr. Hummel included in newsletter) **Contacts:** Nita Ruxer / 812-479-3544 or Sharon Omer / 270-333-4701.

Princeton, IN support group will meet Saturday, June 27th, at 10:00 a.m. at Gibson General Hospital, 5th floor, first room on right. Join us for an open discussion and refreshments. **Contact:** Alice Burkhart / 812-782-3735.

<u>Tell City, IN</u> support group will meet Tuesday, June 9th, at 11:00 a.m. at the Twilight Towers, 1648 10th Street, in the cafeteria. Join us for an open discussion and refreshments. Contacts: Terri Hasty / 812-649-4013 or Gayle Taylor / 812-719-2417.

Washington, IN support group will meet Saturday, June 20th, 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 6th, 10:00 a.m. Calvary Missionary Baptist Church, 2360 Green River Road in Henderson. <u>Speaker</u>: Susan Reynolds, RN, MSCN, will discuss "Good Information for Newly Diagnosed MS Patients." Contacts: Meg Burnley / 270-826-9507 or Debbie Whittington / 270-827-8298.

<u>Owensboro, KY</u> support group will meet Monday, June 8th, at 6:00 p.m. at HealthPark - Owensboro Health, 1006 Ford Ave., The topic will be "Depression and MS." Contact: Susan Reynolds / 812-228-6100.

Illinois Support Group Meeting Dates

Fairfield, IL support group will meet Saturday, June 6th, at <u>11:00 a.m.</u> at Fairfield Memorial Hospital conference room. Join us for an open discussion. **Contacts:** Carol Anne Greenwood / 618-847-8364 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.



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



June Calendar of Events













June 1, Monday, The Ted Donosky MS Golf Scramble Location: Rolling Hills Country Club Save the Date! Sponsorships available!

Call TSMSA for more information!

June 15, Monday, Teva (Copaxone) Educational Program Speaker: Dr. Randy Cox, Neurologist, Owensboro, KY Time: 6:00 p.m. Location: Moonlite Bar-B-Q, Owensboro, KY RSVP: You and 1 (one) guest, Shared Solutions 1-800-887-8100

June 18, Thursday, Monthly Newsletter Stuffing <u>Time</u>: 11:30 a.m. <u>Location</u>: TSMSA Office – Come help, while you make new friends!

June 20, Saturday, Car Wash Fundraiser at Lucas Oil Center

<u>Time</u>: 7:00 a.m. to 4:00 p.m.! <u>**Location**</u>: Lucas Oil Center, 2650 N. Green River Rd, Evansville, IN Come support TSMSA and get your car washed! All money raised will benefit the TSMSA! Surprise Dad with a shiny clean car for Father's Day!

June 21, Sunday, Father's Day! Remember all the Special Dads in our lives today! Call him, send a card or flowers, serve him breakfast in bed or take him out to eat, spend some time relaxing with him. He would love to see or hear from you!!

June 25, Thursday, Tad-Pole Cruise IN

<u>Time</u>: 6:00 p.m. to 8:00 p.m. (Awards at 9:00 p.m.) **<u>Location</u>**: Jake's Wayback Burgers, 115 Cross Pointe Blvd, Evansville, IN. \$5.00 entry fee. Dash plaques, trophies and more.

YOU and 1 (one) Guest



The Tri-State MS Association is proud to support Pharmaceutical Companies with the many educational programs generously underwritten in the tri-state. These programs provide the most up-to-date information on current medications for individuals living with multiple sclerosis. It is important to note these programs are designed for individuals living with MS and their immediate family members. While we want to have a great turn out, reservations should be limited to YOU and 1 (one) guest. When bringing additional friends, you may be knocking another MS individual out of attending due to limited seating or budget restrictions for the program. If there are additional openings, we will send out an e-mail with that information! I am still focusing on articles for the newly diagnosed MS patient. The classic newly diagnosed MS patient is a woman of childbearing age. I was diagnosed with MS when I was thirty years old. I had all three of my children after I was diagnosed. At that time, some of the disease modifying MS therapies had just come out, and the thought was that you waited until your MS progressed before you started taking a disease modifying therapy. I started my first disease modifying therapy 16 years ago, after my last child was born. I have had MS for 25 years now!

Helpful pre-pregnancy information:

MS does not affect the ability to get pregnant. MS is not inherited. There are some genetic factors, but environment and immune factors also play a role. The general population has a 0.13% chance of getting MS, and children of parents with MS have a 2% to 2.5% chance of getting MS. The risk of getting MS if you have a sibling with MS is slightly higher, suggesting that environment plays a strong role. Pregnancy has no negative long term effect on MS. Usually, MS disease activity decreases during pregnancy because a pregnant woman's immune system has to change in order to allow the pregnancy to continue. Estriol, which is produced during pregnancy, is now being studied as a treatment for MS.

Disease modifying therapies (DMT's) pre-pregnancy:

Before you try to become pregnant, there is usually a 3-month period of washout recommended with all of the disease modifying therapies except for Copaxone. But most doctors also advise a 3-month wash out with Copaxone, to be safe. ("Washout" means doctors want you to be off of the drug for three months before you start trying to get pregnant.) It is advised that all women of childbearing age use contraception while on a disease modifying therapy. Teriflunomide (Aubagio) has a black box warning for teratogenicity (birth defects) and will not be prescribed unless you are on birth control. You will be given a pregnancy test (among other tests) before it is prescribed if you are of childbearing age. If you are going through in vitro fertilization, it has been shown that GnRH (gonadotropin releasing hormone) agonists that are given can increase the risk of MS relapses. This is not a contraindication against in vitro fertilization, but it should be discussed with your Neurologist.

During pregnancy:

Having MS does not make a pregnancy high risk, unless the mother has Progressive MS with disability. A relapse during pregnancy can be treated with IV steroids, as long as the mother is in the 2nd or 3rd trimester. It is advised that the mother minimize or stop taking all drugs to treat the symptoms of MS. No disease modifying therapies can be taken during pregnancy.

Copaxone has been used during pregnancy, Betaseron, Rebif and Avonex have been studied, and all of these drugs have had pregnancy registries. There are even some examples of natilizumab (Tysabri) being used during pregnancy. The newer MS DMT's (Aubagio, Gilenya, Tecfidera) have active registries where the outcomes of accidental pregnancies are monitored. If you become pregnant and have taken one of the disease modifying therapies within a week of becoming pregnant, the FDA advises that you register your pregnancy with the registry that is set up for the drug you are taking. This can be discussed with your OB/GYN and your Neurologist. The purpose of the registry is to identify the outcomes of these pregnancies, including miscarriages and birth defects.

Anesthesia: Women with MS can safely have an epidural during labor.

Postpartum (after delivery):

There is a decreased risk of MS relapse during the third trimester of pregnancy. A recent study showed that, during the first 3 months postpartum, 14% of women have an MS relapse. A very recent study has shown that if a disease modifying therapy (DMT) has been used any time in the 2 years before you become pregnant, there is a significant decrease in the probability of having a postpartum relapse. This study is causing some neurologists to advise women of child bearing age to get on a disease modifying therapy for 2 years before attempting to become pregnant.

Breastfeeding:

It is not advisable to take a DMT while you are breastfeeding. You must discuss with your Neurologist and OB/GYN how progressive is your disease, and make the decision with them as to whether you want to breast feed and for how long. It is advised that a person with very active disease should start a DMT immediately after they deliver and forgo breastfeeding.

If you become pregnant while taking a DMT there is a 'Mother to Baby' study for women with autoimmune diseases. The study will monitor you throughout your pregnancy: The Phone number is: 1-877-311-8972.

MS Pregnancy registries phone numbers are below:

Avonex: Registry and study is completed Betaseron: Registry and study is completed Rebif: Registry and study is completed Tysabri: Registry and study is completed Aubagio: 1-800-745-4447 option 2 Gilenya: 1-877-598-7237 or register via Gilenya's website: www.gilenyapregnancyregistry.com Tecfidera: 1-800-456-2255

The above information came from a recent CEU class I took that was led by Patricia Coyle MD, Professor and Vice Chair of Clinical Affairs Director, MS Stony Brook University, Stony Brook, NY. Another panelist in the presentation was Jacqueline Bernard MD, Assistant Professor of Neurology, University of Chicago Medical Center, Chicago, IL. The MS pregnancy registry info came from each drug's website.

Other sources:

<u>Confavreux C¹, Hutchinson M, Hours MM, Cortinovis-Tourniaire P, Moreau T</u>. Rate of pregnancy-related relapse in multiple sclerosis. Pregnancy in Multiple Sclerosis Group. <u>N Engl J</u> <u>Med.</u> 1998 Jul 30;339(5):285-91.

Hughes SE, Spelman T, Gray OM; MSBase study group. Predictors and dynamics of postpartum relapses in women with multiple sclerosis. *Mult Scler*. 2014;20(6):739-746.



The MSAA Cooling Program offers cooling vests and accessories for adults with multiple sclerosis as well as children diagnosed with pediatric MS. MSAA encourages you to consider your cooling needs and make your selection carefully as there are no returns or exchanges. If you have any questions, please call MSAA at (800) 532-7667 or email: clientservices@mymsaa.org

(In May's newsletter we provided you with the MS Foundation's cooling vest program info.)

MORE Cooling Products:

To make your own cooling vest go to: www.p2designs.com/pdfs/SoldiersVest.pdf

www.mscooling.com: cooling vests, neck coolers, hats, wrist coolers and cooling scarves

www.cool-off.com: Misting Fans. You can also get them at Walmart, Target or sporting goods stores.

www.silvereagleoutfitters.com: vests, cooling blankets and headwear

www.polarproducts.com

www.stacoolvest.com



Each year the Multiple Sclerosis Foundation makes dreams come true for individuals with multiple sclerosis across the country through the Brighter Tomorrow grant.

The goal of the grant is to provide individuals with MS with goods or services (valued at up to \$1000 per recipient) to improve their quality of life by enhancing safety, self-sufficiency, comfort, or well-being.

Recipients of the Multiple Sclerosis Foundation's Brighter Tomorrow grant have received appliances, televisions, furniture, hobby supplies, retreats, and various home modifications. To qualify, a person must be 18 years of age or older and diagnosed with MS, or the parent of a minor child diagnosed with MS, and be a permanent U.S. resident. They must not have any other means of fulfilling the need they express.

Applicants are asked to provide basic personal and financial information, and to write a brief essay of 100 words or less to describe how the grant would help them have A Brighter Tomorrow.

If you would like to apply for a Brighter Tomorrow grant, simply fill out their online application, print an application, or call 888-673-6287 to receive an application by mail. Applications are accepted from June 1 to September 1 of each year.

For further information on the *Brighter Tomorrow* grant, call the Program Services Department at **888-MSFOCUS** or you can contact us by email: support@msfocus.org.



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

Deryl Killian	Nita & Lee Ruxer	Mary Rueger
Dr. Rick Yeager	Mr. & Mrs. Kelly Martin	Mr. & Mrs. Steve Sanner
United Way Gibson County	Zeidler Floral Co.	Teva Pharmaceuticals
Open Door U.U. Fellowship In Honor of Von Sloan	Toyota Motor Engineering & Manufacturing North Americ Employee Giving	Indiana State Employee Giving a
Laura Weibush	Vonda Templeton	Marquarita Prior

<u>In Memory of Joni Gentry</u> Bruce Adler

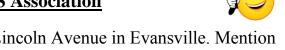


HAPPY BIRTHDAY TO YOU!!Betty TharpKathy KnightJohn WickTiffany SteptoJeff ElpersScott BerryGayle TaylorBillie Jo WinderLori GrayDonna CooperAlice BurkhardtJoyce Elpers

<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



Ways to Help the Tri-State MS Association



<u>Penny John's Gift Baskets</u>: Visit Penny John's at 1116 Lincoln Avenue in Evansville. Mention TSMSA, and 30% of profits will benefit TSMSA

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

Zeidler's: Call Zeidler's or order online. Select TSMS, and TSMSA will receive a donation.

<u>Schnucks</u>: Pick up a FREE escrip card at Schnucks. Register your card. Have your card scanned every time you check out at Schnucks. TSMSA will receive a donation.

Purchase TSMSA items at the TSMSA office: Cookbooks, T-shirts, Fans, and Bracelets.

Evansville Support Group Speaker Information:

Dr. Hummel's services are designed to help individuals move into a better state of overall wellness. From her diverse background in Complementary Medicine, Kay understands the value keeping the body at ease so that it can enjoy life to its fullest. Core to her services is Reflexology. The reflex response provided by Reflexology to the nervous system, allows the body to release the tension blocking the flow of communication to internal glands and organs. This in turn, allows for better internal performance of the glands and organs.

Reflexology helps to strengthen the body's ability to repair and rejuvenate by reducing the internal tension. This helps food, water and air to be used to heal and repair while cellular waste is efficiently removed. The body is an eco-system designed to do its job.



LOL (Laugh Out Loud)

Charlie Omer, one of the Founders of the TSMSA, loved to make us laugh by telling a joke. So in memory of Charlie, here are a few jokes provided by Sharon, his widow who continues to volunteer and serve on the TSMSA Board of Directors. *Laughter is the best medicine!*

THE PROSPECTIVE FATHER-IN-LAW ASKED, "YOUNG MAN, CAN YOU SUPPORT A FAMILY?" THE SURPRISED GROOM-TO-BE REPLIED, "WELL, NO. I WAS JUST PLANNING TO SUPPORT YOUR DAUGHTER. THE REST OF YOU WILL HAVE TO FEND FOR YOURSELVES."

WHEN MY THREE-YEAR-OLD SON OPENED THE BIRTHDAY GIFT FROM HIS GRANDMOTHER, HE DISCOVERED A WATER PISTOL... HE SQUEALED WITH DELIGHT AND HEADED FOR THE NEAREST SINK. I WAS NOT SO PLEASED. I TURNED TO MOM AND SAID, "I'M SURPRISED AT YOU. DON'T YOU REMEMBER HOW WE USED TO DRIVE YOU CRAZY WITH WATER GUNS?"

MOM SMILED AND THEN REPLIED "I REMEMBER!!"

LITTLE JOHNNY ASKED HIS GRANDMA HOW OLD SHE WAS. GRANDMA ANSWERED, "39 AND HOLDING." JOHNNY THOUGHT FOR A MOMENT, AND THEN SAID, "AND HOW OLD WOULD YOU BE IF YOU LET GO?"

Chank You

Thank you to Teva Neurosciences for sponsoring our June newsletter.

Shared Solutions: 1-800-887-8100 TTTT www.copaxone.com/shared-solutions