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## January 2018 Newsletter

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

### Indiana Support Group Meeting Dates

**Evansville, IN** support group will **NOT** meet in January. See you in February!!

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

**Tell City, IN** support group will **NOT** meet in January. Stay Warm!!

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

**Washington, IN** support group will meet Saturday, January 20<sup>th</sup>, 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 meet Saturday, January 6<sup>th</sup> at 10:00 a.m. at Calvary Missionary Baptist Church, 2360 Green River Road, Henderson, KY. Join us for an open discussion.

**Contacts:** Cheryl Walker / 270-823-4752 or Debbie Whittington / 270-827-8298.

**Owensboro, KY** support group will meet **NOT** meet in January. See you in February!!

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

### Illinois Support Group Meeting Dates

**Fairfield, IL** support group will meet Saturday, January 6<sup>th</sup> 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.*

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*Thank you to Teva Neurosciences for sponsoring our monthly newsletter!*



## Calendar of Events

	<b><u>January 1, 2018 Happy New Year!!</u></b>
	<p><b><u>January 18, Thursday, Monthly Newsletter Folding</u></b>  <b><u>Time:</u></b> 11:30 a.m.  <b><u>Location:</u></b> TSMSA Office – Come help, while you make new friends!</p>
	<p><b><u>January 31, Wednesday, Biogen Idec (Tysabri) Educational Dinner Program</u></b>  <b><u>Speaker:</u></b> Dr. Kristi Nord, Neurologist, Memorial Hospital, Jasper, IN  <b><u>Time:</u></b> 6:00 p.m.  <b><u>Location:</u></b> Biaggi's Ristorante Italiano, 6401 E Lloyd Exp, Evansville, IN  <b><u>RSVP:</u></b> You and 1 (one) guest: Active Source 1-866-955-9999</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	Mary Rueger	Open Door UU Church
Michael Clauson	Regina Dillworth	David Titus
Kanesta Downs	Rhonda Lamping	Mr. & Mrs. David Whittington
Marcia Augustus	First Advantage Realty	Mr. & Mrs. Rick Seibert

#### **In Memory of Joni Gentry**

Bruce Adler

#### **In Memory of Douglas Boyer**

Mr. & Mrs. Sheldon Hauge  
 Mr. & Mrs. Marc Fishback

#### **In Honor of Kathy Keach**

Mr. & Mrs. Michael Keach

#### **In Honor of Diana Sanner**

Mr. & Mrs. Robert Kassenbrock

#### **In Honor of Debbie Hebbeler**

Mr. & Mrs. Roy Freudenberg  
 Mr. & Mrs. Larry Sims

#### **In Honor of Mr. Paul Mayer**

Mr. & Mrs. Harry Simon



### **Happy Birthday To You!**

Brenda Kozil	Diana Michael	Debbie Whittington
Carmen Dill	Rachel Zerby	Sarah Russell

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.

Finding the right Disease Modifying Therapy (DMT) and staying with the medication are the most important things for a patient with MS. Staying on your DMT maximizes your chances of doing well in the future. Many resources are available to patients taking a DMT. Each drug company that sells DMTs has support programs to help patients who are taking DMTs. Each support program has nurses available by telephone to advise MS patients regarding problems with their DMTs. The nurses can help you manage injection site reactions and side effects of the medications.

Despite the fact that early treatment for MS is vital, only 60% of patients with relapsing remitting MS are using DMTs. According to the NARCOMS patient registry study data, an average of 50% of MS patients discontinue using their DMTs.

**The main reasons for not taking DMTs were:**

- Dislike of needles
- Not being sick enough
- Fear of side effects
- Cost vs. benefit
- Discouragement from physicians who don't strongly support early treatment.

**Additional reasons for non-adherence to DMTs, according to NARCOMS include:**

- Increase in MS signs and symptoms
- Lack of obvious benefit
- Flu-like signs and symptoms
- Skin reactions
- Depression

Realistic expectations play a big part in adherence to a DMT. It is important that each patient understands that the DMTs usually do not make you feel better. They may make you feel worse at first, and often you can't tell whether or not they are working. The differences can only be seen with long-term use of DMTs. Patients who stay on DMTs long-term typically do quite well. These patients have less disability and longer periods without disease flare-ups.

The most common flu-like symptoms from interferons are: Muscle aches, headache, nausea, chills, fatigue, and fever. These typically resolve after the first 24 hours of injection, but may persist up to three months following the initiation of therapy. Dose titration is helpful in minimizing the side effects of interferons. Dose titration means the patient starts the injections at 25-50% of the maximum dose for 3 to 4 weeks, increasing gradually until they get to the maximum dose. Most people take their shots at night before going to bed. Take acetaminophen or naproxen (Aleve) one hour before taking the injection.

There are ways to manage some of the problems that occur when using DMTs. One of the problems is skin reactions. The most common skin reactions are swelling, bruising, redness, induration (hardening of the skin and tissue), and necrosis (tissue death). To keep reactions to a minimum you must rotate sites meticulously, insert the needles at a 90 degree angle, insert the needle deeply enough into the skin, avoid sun exposure, and adequately warm the injectable solution.

Treating depression improves adherence to DMTs. Studies have shown that patients who are depressed do not do very well in adhering to their DMTs. MS patients should be monitored for depression. Family members and MS patients taking DMTs should report signs and symptoms of depression to their neurologist. Family support is very important to MS patients, especially if there are cognitive issues. With permission from the MS patient, family should be included in any education done about the DMTs. Social support is also very important in helping MS patients stay on their DMT.

MS experts recommend that anyone who has been diagnosed with a relapsing form of MS should consider beginning treatment as soon as possible. Because of their associated risks, Lemtrada and Zinbryta are usually reserved for people who have already tried and failed two other DMTs. If you have been diagnosed with a clinically-isolated syndrome (CIS - a first episode of neurologic damage), you may benefit from taking a DMT as well.

**The possible benefits of these medications include:**

- Reduction in numbers of new lesions as shown on magnetic resonance imaging (MRI)
- Reduction in the number of exacerbations (also called relapses, attacks, flare-ups)
- Reduction in progression of disability
- Probable reduction in future disease activity, and improvement in quality of life.

Patients who are diagnosed with primary progressive MS should talk with their healthcare provider about starting treatment with Ocrevus. Ocrevus is the only medication approved by the U.S. Food & Drug Administration (FDA) for the treatment of primary progressive MS.

All of the available DMTs are more effective early, when the disease is more active and inflammatory, than later when the disease is generally more progressive and neurodegenerative.

If you are not insured or are underinsured, there are patient assistance programs to help you pay for DMTs. All of the drug companies have patient assistance plans to help you cover the cost of your therapy. Keep in mind that the application process for some of these assistance programs can be very slow. If your insurance is changing, or you may lose your insurance, please apply to the patient assistance plan without delay. This may prevent a gap in coverage of your DMT.

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**Equipment Closet:** If you need durable medical equipment, check our equipment closet before you make the purchase. If we have what you need, we would love for you to have it and save your money! The items available include:

- ✓ Wheelchairs (including one with a manual reclining / tilting seat)
- ✓ Walkers (including one with a forearm attachment)
- ✓ Shower chairs
- ✓ Bedside commodes
- ✓ Canes
- ✓ An exercise bicycle



## Disease Modifying Therapies for MS

The following are the Disease Modifying Medications currently available in the US. Do you have questions about any of these medications, or do you need financial assistance? Help is just a click or a phone call away. Visit the websites or call the numbers listed below.

<b>Aubagio</b> (by Genzyme)	Once a day pill	<a href="http://www.msonetoone.com">www.msonetoone.com</a> 1-855-676-6326
<b>Avonex</b> (by Biogen)	Once a week injection (intramuscular)	<a href="http://www.abovems.com">www.abovems.com</a> 1-800-456-2255
<b>Betaseron</b> (by Bayer)	Every other day injection (subcutaneous)	<a href="http://www.betaseron.com/betaplus/affordability">www.betaseron.com/betaplus/affordability</a> 1-800-788-1467
<b>Copaxone</b> (by Teva)	Three days / week injection (subcutaneous)	<a href="http://www.sharedsolutions.com">www.sharedsolutions.com</a> 1-800-887-8100
<b>Extavia</b> (by Novartis)	Every other day injection (subcutaneous)	<a href="http://www.extavia.com">www.extavia.com</a> 1-866-925-2333
<b>Gilenya</b> (by Novartis)	Once a day pill	<a href="http://www.gilenya.com/c/ms-pill/go-program">www.gilenya.com/c/ms-pill/go-program</a> 1-800-445-3692
<b>Glatopa</b> (by Sandoz) Generic for Copaxone	Daily injection (subcutaneous)	<a href="http://www.glatopa.com">www.glatopa.com</a> 1-855-452-8672
<b>Lemtrada</b> (by Genzyme)	<i>1st treatment:</i> 12 mg/day on 5 days. <i>2nd treatment:</i> 12 mg/day on 3 consecutive days administered 12 mo after 1st treatment course	<a href="http://www.msonetoone.com">www.msonetoone.com</a> 1-855-676-6326
<b>Ocrevus</b> (by Genentech)	IV infusion therapy	<a href="http://www.ocrevus.com">www.ocrevus.com</a> 1-844-672-6729
<b>Plegridy</b> (by Biogen)	Bi-weekly injection (subcutaneous)	<a href="http://www.abovems.com">www.abovems.com</a> 1-800-456-2255
<b>Rebif</b> (by EMD Serono)	Three days / week injection (subcutaneous)	<a href="http://www.mslifelines.com">www.mslifelines.com</a> 1-877-447-3243
<b>Tecfidera</b> (by Biogen)	Once a day pill	<a href="http://www.abovems.com">www.abovems.com</a> 1-800-456-2255
<b>Tysabri</b> (by Biogen)	IV infusion therapy given once every four weeks	<a href="http://www.abovems.com">www.abovems.com</a> 1-800-456-2255



It is with great gratitude that we begin 2018. The support that YOU have shown us throughout 2017, and all the way back to our beginning in 2001, is greatly appreciated! The Tri-State Multiple Sclerosis Association, YOUR association, would not be in the community without your help!

Recently, I was reminded about our humble beginning by one of our founders, Suzy Sims. She shared with me the prayer she has been praying since 2000:

“I pray for the success of the Tri-State Multiple Sclerosis Association. Please guide the Staff, Board of Directors and Volunteers. Help us to recruit responsible, productive Board Members, accountable for the administration of the Association. Let us all follow the agenda that is most important for those suffering from MS, their families, and caregivers. Guide us to formulate a clear vision of their future needs so we can prepare to meet those needs. Amen” ~*Suzy Sims*

That group of volunteers: Suzy and Larry Sims, Alan Shovers, Connie Romain, Sharon Kennedy, Charlie and Sharon Omer, Connie Kirwer, Liz Kalb, Linda Alvey, Meg Burley, Susan Reynolds, and I, came together in September of 2000. We went on to establish the Tri-State MS Association in 2001, declaring to keep all monies raised local to be used toward an MS Clinic. We have never wavered from the dream of a local MS Clinic! However, we recognized the many unmet needs of individuals living with MS and their family members, and knew we needed to help with those important services.

**With YOUR help, are we able to provide free services to 1,350 local individuals!**

- ✓ An average of 300 calls and 100 individuals reach out to TSMSA each month for help and resources;
- ✓ 6 monthly Support Group Meetings in Indiana, Kentucky and Illinois;
- ✓ An MS Certified Nurse (the only one local) providing education and symptom management;
- ✓ A monthly newsletter (We mailed 16,200 newsletters in 2017);
- ✓ Social events: a day for adults focused on health; a Family Day at GattiTown; a cookout in Tell City; Breakfast with Santa; and several holiday parties;
- ✓ Financial and medical assistance;
- ✓ 64 MS therapy educational programs, coordinated with pharmaceutical companies locally.

As we begin 2018, we once again ask for you to stand beside us on this journey! We recognize that we had the dream, but it was *your* donations in the past and today that keep us here locally providing help!

Please consider donating today! If you are not able to today, then maybe tomorrow or next month.

Most importantly, Suzy and TSMSA ask you to keep us in your prayers; and we will keep you and your family in our prayers.

Sincerely,

*Debbie Hebbeler*  
Executive Director



## Winter Weather: Coping With the Challenges



Cold weather can aggravate fatigue, spasticity, and pain for some people with MS. The following are a few tips for you to consider as you cope with the challenges of the winter weather.

**Keep your hands and feet warm.** The fingers can overreact to cold temperatures, causing pain in the fingernails and toenails. So wear socks and gloves.

**Allow extra time.** Plan ahead so that you can walk slowly to prevent falls. If you are running errands or going in and out of the cold, take your time while indoors. Try to allow your body to warm up fully before you go back outside.

**Lift your feet.** Be aware of the need to lift your feet higher when walking in snowy conditions.

**Winterize your “wheels.”** Have the tire pressure, wheel balance, nuts, and bolts of your wheelchair checked. Also, purchase ice grips for your cane or walker to make moving along the ice safer.

**Warm yourself from the core.** Drink warm beverages to take the chill off a little faster. Hot chocolate, or warm tea or coffee (decaffeinated) can warm you from the inside out.