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February 2020 Newsletter

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

Indiana Support Group Meeting Dates

Evansville, IN support group will **NOT** meet until March.

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

Tell City, IN support group will **NOT** meet until March.

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

Washington, IN support group will meet Saturday, February 15th, 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 Monday, February 10th, at 3:30 p.m. at *Seventh Street Baptist Church, 627 Short 7th Street, Henderson, KY*. Join us in the Dr. A. M. Brooks Family Life Center to discuss future meetings.

Contacts: Cheryl Walker / 270-823-4752 or Gayla Gilbert / 270-860-7689

Owensboro, KY support group will **NOT** meet until March.

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

Illinois Support Group Meeting Dates

Fairfield, IL support group will meet Saturday, February 1st, 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><u>February 10, Monday, Genentech (Ocrevus) Educational Lunch Program</u> <u>Speaker:</u> Dr. Nicole Everman, St. Joseph’s Neurology, Lexington, KY <u>Time:</u> 12:00 p.m. (noon) <u>Location:</u> Moonlight Bar-B-Q Inn; Owensboro, KY <u>RSVP:</u> You and 1 (one) guest: 1-844-627-3887 or Ocrevus.com/events</p>
	<p><u>February 10, Monday, Genentech (Ocrevus) Educational Dinner Program</u> <u>Speaker:</u> Dr. Nicole Everman, St. Joseph’s Neurology, Lexington, KY <u>Time:</u> 6:00 p.m. <u>Location:</u> Biaggi’s, 6401 E. Lloyd Expwy; Evansville, IN <u>RSVP:</u> You and 1 (one) guest: 1-844-627-3887 or Ocrevus.com/events</p>
	<p><u>February 20, Thursday, Monthly Newsletter Folding</u> <u>Time:</u> 11:30 a.m. <u>Location:</u> TMSMA Office</p>

Upcoming Events

	<p><u>March 3, Tuesday, Biogen (Tecfidera) Educational Dinner Program</u> <u>Speaker:</u> Dr. Kristi Nord, Memorial Neurology, Jasper, IN <u>Time:</u> 6:00 p.m. <u>Location:</u> The Patio Steak House, Tell City, IN <u>RSVP:</u> You and 1 (one) guest: Navigating-MS.com or 1-866-955-9999</p>
	<p><u>April 7, Tuesday, Biogen (Tecfidera) Educational Dinner Program</u> <u>Speaker:</u> Dr. Kristi Nord, Memorial Neurology, Jasper, IN <u>Time:</u> 6:00 p.m. <i>Eastern Time</i> <u>Location:</u> The Schnitzelbank Restaurant, Jasper, IN <u>RSVP:</u> You and 1 (one) guest: Navigating-MS.com or 1-866-955-9999</p>



Beginning in February, AARP Foundation Tax-Aide will offer free tax preparation for low- to moderate-income taxpayers, especially those 50 and older. Services will be offered at several locations in the tri-state area. For scheduled dates and times, visit www.aarp.org/taxaide and search for locations by zip code. Or you can call AARP toll-free at 1-866-448-3618.

When you go to a Tax-Aide location, don’t forget to take your important documents, including your previous year’s tax return, your Driver’s License (or government issued ID), and your bank account information (if you want to direct deposit any refunds due), and all tax documents that you received in the mail or online.

PLEASE NOTE: The hours at each location are subject to change on a weekly basis. So call the location the day before you plan to go to confirm the AARP Tax-Aide hours.

Getting the Most Out of Your Appointment with Your Neurologist

Susan Reynolds, RN, MSCN

Your neurologist is your greatest ally in your treatment of multiple sclerosis. MS is a condition you will need to manage for the rest of your life, so it is important to develop an open line of communication with your neurologist. Use your time with your neurologist to get answers to your questions. Don't feel rushed or worry about asking silly questions. The more information you can give your doctor about symptoms, flare-ups, or general health, the better equipped he or she will be to help treat your MS.

Write down your questions. Before your appointment write down your questions, starting with the most important ones. Prioritize. Don't wait until the end of the appointment when the doctor is going out the door to bring up your problems or questions.

Take someone with you. Consider asking a friend or family member to go with you so you can get help remembering what was said at the appointment. One of you should take notes at the appointment or even record what the doctor says, with the doctor's permission of course.

Make sure you understand. Repeat what the doctor told you in your own words to make sure you understand. Most doctor's offices print on paper changes in your medications and treatment, along with the date and time of any scheduled tests. Keep this paper for your reference. If they don't give you a paper with this information, ask them to do this for you.

Make a list of your meds. Always prepare a list of all medications you are currently taking, including strength and dosing schedule. Take the list to your doctor appointment.

Keep a list of symptoms. Keep a list of all the symptoms you have had since your last neurologist visit. Note when the symptoms started and what you did to treat them. It is important to discuss symptoms that are related to your MS.

Discuss your symptoms. Discuss any symptoms about depression, memory loss, trouble concentrating, vision problems, sexual issues, bowel and bladder problems, fatigue, numbness and tingling, muscle stiffness, and pain. Many medications are available to treat MS symptoms. These can be added to your MS treatment along with your disease modifying therapy.

Complementary or alternative therapies. Don't be afraid to ask your neurologist about complementary or alternative therapies you may be considering. Always tell your neurologist if you are going to try a complementary or alternative therapy. Your neurologist can tell you if the therapy is safe to combine with the other medications you are taking. Many neurologists are open to their patients' trying supplements, herbs, massage, yoga, reflexology, acupuncture, chiropractic, and many other things. They should also be able to tell you which complementary therapies have some medical research to back them up.

Be honest about your lifestyle. Always be honest about your lifestyle habits that may affect your MS. Diet, smoking, physical activity, alcohol or drug use, and sexual history. Not sharing information like this can be harmful. Always tell your neurologist if you are pregnant or intend to become pregnant. All of the MS disease modifying therapies are not recommended to be taken while pregnant. You should also not be taking MS disease modifying therapies while you are trying to get pregnant.

Ask about new meds. Don't be afraid to ask your neurologist about any new drugs for the treatment of MS or symptoms of MS. You can ask your neurologist to help you understand information you have learned elsewhere. If you have been to an educational program or heard an MS expert speak recently, in person or on the internet, you can ask your neurologist for his or her expertise. Ask how the information applies to you.

Don't be afraid to talk. Don't let the doctor do all of the talking. Sometimes people just let doctors keep talking and talking even though they don't understand a thing. You have to stop them and say "I'm sorry, I don't understand you. Can you explain it to me in words that I can understand?"

Make decisions together. Share decision-making is when you work with, and are supported by, health professionals to make decision about your treatment based on the best possible information. Most neurologists are willing to debate the best course of action, some will leave the choice entirely to you, but others prefer to give clear-cut advice about what they think is the most appropriate.

Find out what to do during an exacerbation. Always find out from your neurologist the appropriate action to take when you think you are having an MS exacerbation. Your doctor may have a 24-hour on call phone number or he/she may prefer you go directly to the emergency room for corticosteroids or other treatments.

Find the right neurologist for you. As a patient you have the right to have your questions answered. You also have the right to request a referral to a new neurologist if you feel your current neurologist is not giving your condition the kind of attention required to correctly treat it. Look for neurologists who specialize in the treatment of MS. MS specialists are usually found at an MS Clinic. The Consortium of MS Centers (CMSC) has a nationwide list of MS Clinics on their website. At the Tri State MS Association office, we have a list of MS clinics that are within driving distance of the tri-state area.

The Art of Getting a Good Second Opinion

Facing important medical decisions can be difficult. You owe it to yourself to examine all options for treatment. Getting a second opinion is good medical practice. The December 2019 / January 2020 edition of AARP Magazine has a great article: "The Art of Getting a Good Second Opinion. Know what to ask and when to ask it". To read this article, visit aarp.org and search for 'The Art of Getting a Good Second Opinion.'





In Memory 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.....

In Honor of Tri-State MS Association

Dr. Rick Yeager
Ms. Mildred Connaway
Mr. Mike Clauson
Mr. Marc Fine
Ms. Pamela Gray
Mr. David Titus
Ms. Gwendolyn Brewer
Ms. Leta Kelly

Dr. Kristi Nord
Mr. Myron Yeager
Ms. Alison Steckler
Mr. & Mrs. James Alka
Mr. & Mrs. Charles Bledsoe
Mr. & Mrs. Brad Voyles

Mr. & Mrs. Taylor Payne
Mr. & Mrs. John McNaughton
Mr. & Mrs. Scott Alford
United Leasing, Inc.
Open Door UU Church
Network For Good

In Memory of Joni Gentry

Bruce Adler

In Memory of Frank Wiegand

Mr. & Mrs. Jack Snurpus



Happy Birthday To You!

Theresa Ladd Nita Ruxer Diana Helfrich
Bruce Houpp Terry Shanks JaVan Cook

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.



IMPORTANT: Confirm Before Switching



Physicians / Pharmacies

Every year, many MS patients receive notifications that their physician's office and/or pharmacies are in the process of negotiating with medical insurance companies. If negotiations do not come to a satisfactory conclusion, then the physician's office and/or pharmacy will no longer be a participating provider in that network during the following year. *Before you switch doctors or pharmacies* check to see if negotiations were settled successfully. Many times, doctors and pharmacies notify patients of pending negotiations as a courtesy to the patients. But they are able to reach an agreement before the end of the year.

Disease Modifying Therapies

Every year, many MS patients receive notifications that their disease modifying therapies (DMTs) may not be covered by their medical insurance plan. *Never quit taking your DMT* because coverage of your DMT is in negotiation. Call your physician or your medical insurance company to see if negotiations were settled successfully. Many times, insurance companies notify patients of pending negotiations as a courtesy to the patients. But they are able to reach an agreement before the end of the year. If an agreement has not been met, contact your physician for assistance in deciding what to do.

Disease Modifying Therapies: Patient Information and Financial Assistance

AUBAGIO

MS One to One
855-676-6326
aubagio.com/cost

AVONEX

MS ActiveSource
800-456-2255
avonex.com or aboveMS.com

BETASERON® and BETAPLUS®

800-788-1467
betaseron.com

COPAXONE

Shared Solutions
800-887-8100
copaxone.com

EXTAVIA®

Extavia Go Program
866-398-2842
extavia.com
Patient Assistance NOW
800-245-5356
patientassistancenow.com

GILENYA®

Gilenya Go Program
800-445-3692
gilenya.com
Patient Assistance NOW
800-245-5356
patientassistancenow.com

GLATOPA

GlatopaCare
855-452-8672
glatopa.com/glatopa_care

GLATIRAMER ACETATE

Mylan Support Program
844-695-2667
glatirameracetate.com/en/patient-support

LEMTRADA

MS One to One
855-676-6326
lemtrada.com

MAVENCLAD

MS LifeLines®
877-447-3243
ntlms.org/mavencladresources

MAYZENT

Novartis Patient Assistance Foundation
800-277-2254
ntlms.org/novartisassistance

NOVANTRONE

No patient support program at this time

OCREVUS

Genentech Access Solutions
844-627-3887 or 866-422-2377
Genentech-Access.com

PLEGRIDY

MS ActiveSource
800-456-2255
plegridy.com or aboveMS.com

REBIF

MS LifeLines
877-447-3243
rebif.com or mslifelines.com

TECFIDERA

MS ActiveSource
800-456-2255
tecfidera.com or aboveMS.com

TYSABRI®

MS ActiveSource
800-456-2255
tysabri.com or aboveMS.com

VUMERITY

800-456-2255
aboveMS.com



 **Acts of Kindness** 

“We are made kind by being kind.” ~Eric Hoffer



A special *thank you* to CEO and President Ron Romain and United Companies employees for your very generous donation of \$19,652 to TSMSA. We are truly blessed by your kindness and dedication to our organization. We appreciate your continued support and generosity.

Thank you to Molly, Rick and Janice Jillson for the awesome “Strike Out MS” softball tournament. This first time event raised over \$8,000. They are busy planning next year’s event that will be even bigger!



Thank you to Mike Kishline, The Rug Gallery of Newburgh, for his generous donation. Mike did a fundraiser on Facebook in honor of his birthday, and raised over \$1,000.

And *thank you* to Mr. and Mrs. Scott Alford for your continued donation of cornhole boards. Check out the Alford’s newest venture at: <https://www.facebook.com/wildwoodquilts2019>

Thank you also to *everyone* who supports TSMSA with donations throughout the year. We sincerely appreciate your generosity. It’s with your support that we are able to continuously provide support....*right here at home.*