



# MS CONNECTION NEWSLETTER



## Walk MS

Spring Walk MS event information on page 7

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## MEET OUR STAFF

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## WELCOME SUZANNE



It is our pleasure to introduce Suzanne, Thompson, our new Development Manager. Suzanne comes to us with 23 years of fundraising and special event experience, with eleven of those years running her own production company in Indianapolis. She has already making huge strides for this years Bike MS: Bluegrass, Bikes, Bourbon & BBQ and Suzanne will also be the chapters liasion for Crystal Boots and Silver Spurs. It's not often you find someone with both bike and gala experience so we are thrilled to have her with us! Suzanne also she has two beautiful sons, one fantastic daughter in law and a dog named Sonny. Recently, she moved back to her hometown of Louisville after having been away for nearly 30 years and is thrilled to be a part of the National MS Society.

## BOARD OF TRUSTEES OFFICERS

Diana Quesada - *Chairman*

Nick Papachristou - *Hilliard Lyons  
Vice-Chairman*

Bob Montgomery - *Dean Dorton Allen Ford  
PLLC Treasurer*

Emily Witt - *Trilogy Health Services  
Secretary*

Keith Johnson - *Robbins Enterprises  
Audit Chair*

John Sheller - *Stoll Keenon Odgen, PLLC  
Governance Chair*

## BOARD OF TRUSTEES MEMBERS

Jessica Tretter - *AFB Wealth Management*

Eben Hollingsworth - *Xerox*

Michelle M. (Husted) Baugh - *USI*

Ramsey Carpenter - *The Providence School*

Brett Corbin - *Raymond James & Associates*

Todd DeYoung - *Humana*

Dr. Stephen Kirzinger - *Quintiles Clinical  
Research Organization*

Walter "Dub" Newell - *FirstLight HomeCare*

Dan Rattner - *Rattner Bloodstock*

Sam Rock - *Rock Law Group PLC*

Rick Sexton - *New Life Industries*

Tracy Shelby - *Harper Industries Inc.*

James W. Shircliff - *Raymond James &  
Associates*

Dr. Cary Twyman - *KentuckyOne Health*

Jason Waters - *ARGI Financial Group*

Julie Garrison - *Baptist Health Louisville*

Jeff Hamilton - *Reed Weickamp Schell & Vice*

## CONNECT WITH US ONLINE!

### KENTUCKY-SOUTHEAST INDIANA CHAPTER



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Follow us:

[nationalmssocietyky](https://www.instagram.com/nationalmssocietyky)

## CHAPTER WISHLIST

We work diligently to be good stewards of money raised for the National MS Society. In doing so, we ask all year round for In-Kind donations to help us reduce costs at our events. Below is a wish list of items needed for upcoming 2016 events. If you would like to purchase any of the items below, please contact *Maci Baurle* at 502-526-4031 or [maci.baurle@nmss.org](mailto:maci.baurle@nmss.org). Thank You!

1. Large & Small Trash Bags
2. Clorox Wipes (10 Containers)
3. Large & Small Aluminum Trays (Need 20 small and 20 large)
4. Zip Lock Bags (All Sizes)
5. Bug Spray (Need 20 bottles)
6. Dixie Cups
7. Sun Screen (Need 20 spray cans)
8. Baby Wipes (Need 10 containers)
9. Paper Towels (Need 20 rolls)
10. Paring Knives (Need 10)
11. Bottle Openers
12. Packing Tape
13. Duct Tape
14. Heavy Duty Clear Medium and Large Storage Bins (Need 20)
15. Very Long-Handled Spoons (Need 10)
16. Markers/Sharpies (Thick And Fine)
17. Large Oversized Coolers (100 Quart or Larger, need 4)
18. Pop Up Tents (10X10, need 6)
19. Large Heavy Duty Zip Ties
20. Powdered Gatorade
21. Plain Orange Containers (Small – To Hold Raffle Tickets, Bracelets, Etc...)
22. Decorative Containers
23. Plastic Knives, Forks, Spoons
24. Wireless Speaker Boxes



## GET TO KNOW THE BOARD MEMBERS

Name: **Brett Corbin**

*Company:* The Corbin Financial Group of Raymond James

*Job Title:* Financial Advisor, Investments

*Family Members:* Samantha (wife), Jack (stepson, 8) and Ella (stepdaughter, 11)

*Hobbies:* Golf, Swimming, and Travel

**MS Connection:** My wife's side has been affected, but there has not been much on my side of the family. I joined the local board because I found it to be a great group of folks and felt like I could lend a hand to help further the cause.



Name: **Jim Shircliff**

*Company:* Raymond James and Associates

*Job Title:* Financial Associate

*Family Members:* Jenny (wife), Corey (daughter), and Audrey (daughter)

*Hobbies:* Science (particularly astronomy) and coin collecting

**MS Connection:** I was diagnosed with MS in 2005 and have led a MS Walk team for several years.



## GET TO KNOW THE BOARD MEMBERS

Name: **Julie Garrison**

*Company:* Baptist Health

*Job Title:* Regional Marketing Manager

*Family Members:* Brooke (daughter, 21) and Taylor (daughter, 17)

*Hobbies:* Reading, snow skiing, and spending time with friends and family

**MS Connection:** My mom was diagnosed with MS when I was a junior in high school.



Name: **Kenny Jewell**

*Company:* Hertiage Electric Inc.

*Job Title:* President

*Family Members:* Denise (wife), Logan (son), Garrett (son), Amber (daughter), and Brandon (son).

*Hobbies:* Playing music, construction and building, and crafting with my wife

**MS Connection:** My MS connection is my wife, diagnosed in December of 2006 with relapsing/remitting MS. She is my rock, my life, my best friend.

## COMMUNITY

# WALK MS REGISTRATION IS OPEN!

Register today online at [walkms.org](http://walkms.org) or contact our Fundraising Support Center at [fundraisingsupport@nmss.org](mailto:fundraisingsupport@nmss.org) or (855) 372-1331.

Walk MS has become a rallying point of the MS movement, creating a community of shared commitment determined to end MS. Last year Walk MS raised nearly \$50 million. With our chapter hosting eight walks, raising nearly \$400,000 and welcoming almost 4,000 participants!

### Walk MS Louisville Kick off and Donute Building Contest!

- Saturday, April 30
- Goodwood Brewery  
636 E Main St. Louisville, KY 40202
- Opens: 9:00AM
- Contest Begins: 10:00AM



RSVP online at [www.nationalmssociety.org/KYW](http://www.nationalmssociety.org/KYW) or 502-526-5303

### Walk MS Lexington

Saturday, April 9, 2016  
*Masterson Station Park*

### Walk MS Perry County

Saturday, April 16, 2016  
*Perry County Park*

### Walk MS Pulaski County

Saturday, April 23, 2016  
*Shopville Community Park*

### Walk MS Louisville

Saturday, May 21, 2016  
*Louisville Water Tower Park*

### Walk MS Central Kentucky

Saturday, September 10, 2016  
*Freeman Lake-Williams Pavilion*

### Walk MS Columbia

Saturday, September 2016  
*Lindsey Wilson College*

### Walk MS Bowling Green

Saturday, September 17, 2016  
*Preston Miller Park*

### Walk MS Western Kentucky

(Formerly Walk MS Paducah)  
Saturday, September 24, 2016  
*Noble Park*



*It's a personal challenge.*

*It's a weekend experience.*

*It's an extraordinary achievement.*

*It's Bike MS.*

- Saturday and Sunday *June 25 and 26, 2016*
- Louisville Water Tower Park
- Registration Fee: \$50
- Register online at [bikemsky.org](http://bikemsky.org) or contact the Fundraising Support Center at [fundraisingsupport@nmss.org](mailto:fundraisingsupport@nmss.org) or (855) 372-1331.

On June 25-26, 2016, Bike MS will take cyclists on a grand Kentucky experience featuring historic landmarks, the banks of the Ohio River, and the beauty of our Olmsted Park System. Cyclists will begin and end at the Louisville Water Tower Park. Several route options will be available ranging from 25-100 miles.

- Bike MS is a fully supported ride with rest stops every 10-15 miles providing cyclists food, beverages, and a break in the shade. In addition, we provide support and gear vehicles, bike mechanics, medical staff, and helpful volunteers.

**Stay tuned for Saturday's new route!**





## WEBINAR & TELELEARNING SERIES



## Building Your Wellness Strategies

A collaboration of MS experts will help you build strategies to live your best life with MS. Each free program features two presenters with time for Q&A.

Join us online or by phone on topics including:

- Exercise & Cognition
- Employment (4 different topics)
- Treatment Decisions
- Research Updates
- Traveling with MS
- Stress & Relaxation
- Managing Spasticity
- Mood
- Health Insurance
- Tips for Support Partners & Families
- Diet & Nutrition
- Sleep

**Calls are held on the second Tuesday of each month from 8 to 9:15 p.m. ET**

All calls are recorded and available for playback.

Register at [nationalMSSociety.org/telelearning](https://nationalMSSociety.org/telelearning) or call 1-800-344-4867.



## RESEARCH

## ON THE HORIZON

BY MARK ALLEGRETTA

There was a lot of excitement at the annual meeting of the European Committee for Treatment and Research in Multiple Sclerosis, orECTRIMS, in October 2015, about the emergence of new treatment approaches for all forms of MS — including progressive MS.

## MAKING A BUZZ

Perhaps the biggest “buzz” was around results presented on studies of the monoclonal antibody ocrelizumab in relapsing-remitting and progressive MS. Ocrelizumab targets a protein that appears on immune B cells during specific stages of their life cycle. B cells make antibodies to help fight infection and perform other functions to stimulate the immune system. Scientists believe ocrelizumab destroys the group of B cells that include those that contribute to MS, but leaves other B cells intact that are fighting infections or are prepared to fight new ones.

A highly anticipated presentation described the results of a clinical trial of ocrelizumab involving 732 people with primary-progressive MS. Participants were given either ocrelizumab or placebo by in-vein infusions



RESEARCHERS EXPLORE NEW APPROACHES TO STOPPING MS.

about every six months. Results showed that compared to placebo, ocrelizumab significantly reduced the risk of progression of clinical disability by 24 percent, and had other positive outcomes. The main side effects were reactions to the infusions, and the incidence of serious infections was relatively low. This is the first large-scale clinical trial to show positive results in people with primary-progressive MS.

In addition, results were presented from two phase III trials of ocrelizumab in relapsing MS. In both trials, the treatment performed very well against Rebif in people who had never been on any MS therapy, as well as those who had tried other therapies. The reported results showed that ocrelizumab reduced the risk of relapse by 46 to 47 percent compared to Rebif, reduced the risk of disease progression by 40 percent, and had other positive outcomes. The sponsor, Genentech (a member of the Roche Group), stated that it plans to apply for marketing approval from the FDA in early 2016.

## A GENERIC POSSIBILITY

Another intriguing trial result came from a group of investigators led by Dr. Luanne Metz (University of Calgary) who conducted a Phase III trial of a relatively inexpensive oral antibiotic called minocycline. Minocycline has been on the market for decades and is often prescribed to treat acne, and in addition to its bacteria-killing action, it reduces inflammation.

The trial tested minocycline against placebo in 144 people across Canada who had clinically isolated syndrome (CIS) — which means they have early possible signs of MS but haven't yet shown enough signs or symptoms to be diagnosed with definite MS. The goal was to determine if minocycline, taken orally at a dose of 100 mg twice a day, could reduce the proportion of participants with CIS who converted to MS over a six-month follow-up period.

The secondary objective was to determine whether the effect could last up to two years. Their results showed that over six months, those taking twice daily minocycline had a 44.6 percent reduced risk of developing definite MS, compared to those taking placebo. There were no unexpected side effects reported from the trial — the most common include potential for diarrhea, dizziness or light-headedness, grey discoloration of the skin or tissue in the mouth or teeth, sun

sensitivity, and secondary infection due to fungi.

These results bring up a lot of questions, such as: What are the longer-term benefits or side effects? Would this help people who already have MS? Would regulators approve a generic drug like this? Would its price alone influence doctors to prescribe it?

## MORE TO COME

These are only a few of many new approaches being explored to stop the MS process and restore function. If you are interested in these and the many other reports from ECTRIMS, visit [www.ectrims-congress.eu](http://www.ectrims-congress.eu) to browse hundreds of abstracts to get an idea of what solutions are on the horizon for people with MS. One important caveat — everything presented at a meeting such as ECTRIMS is considered preliminary until it has been thoroughly peer-reviewed for publication in a respected journal — so the information shared here is based only on the information we've heard so far.

Mark Allegretta, PhD, is associate vice president at the National MS Society, leading commercial research including partnerships developed through Fast Forward. <sup>n</sup>

Originally published on:  
[www.MSconnection.org/blog](http://www.MSconnection.org/blog)

To stay up to date on MS research,  
sign up for MS eNews at  
[www.nationalMSSociety.org/signup](http://www.nationalMSSociety.org/signup).

## STATE ACTION DAY 2016

On January 14th, nine MS Activist's from around the state of Kentucky travelled to Frankfort educating and informing legislators about MS and policies that impact the MS community. We held meetings with fifteen Senators and Representatives. Thank you to Dr. Stephen Kirzinger, who chairs the Advocacy Committee. A BIG THANK YOU to MS activist, Debbie McAfee, Dinah Ward, Carl Brown, Alex Lopez, Durban Rodriguez, Kathy Meade, and Dr. Kirzinger for being a part of our State Action Day. Thank you to the Capitol Plaza Hotel in Frankfort for hosting a dinner and providing overnight accommodations.

## PUBLIC POLICY CONFERENCE

The 25th Annual Public Policy Conference was held in Washington DC on March 14-16, 2016. On March 16th over 350 MS activists visited Capitol Hill to meet with their Congressman to urge them to support priorities for people living with MS.

These priorities included:

- Co-sponsoring and passing the Advancing Research for Neurological Diseases Act (H.R. 292/S.849).
- Holding a hearing focused on patient perspective and experience with accessing MS medications.

- Funding MS research by providing at least \$34.5 billion for the National Institute of Health and \$10 million for the MS Congressionally Directed Medical Research Program (CDMRP) in Fiscal Year (FY) 2017.

For more information on becoming an MS Activist or GRC member today, please email [jinny.cornett@nmss.org](mailto:jinny.cornett@nmss.org) or 502-526-5061.



Debbie McAfee, District Activist Leader, and Dr. Stephen Kirzinger (board member) meeting with Senator Mitch McConnell's staff at Public Policy Conference in Washington DC March 16.

MS Activist's Dinah Ward, Larry Sherman Ph.D and Alicia Ray in Washington DC March 16.



## SCHOLARSHIP FY16

The Scholarship Committee is busily reviewing the 20 scholarship applications and two renewals for the Chapter we received in March. Being part of the Scholarship Committee and reviewing applicants is very rewarding and an awesome responsibility! We can't wait to announce the 2016 recipients. Thank you to all those who donated and raised money for the Scholarship Fund, it changes lives!

## NATIONAL EMPLOYMENT SURVEY

The Rehabilitation Research and Training Center (RRTC) at Virginia Commonwealth University (VCU) is conducting an employment study of adults with physical disabilities and we need your help!

- Adults with cerebral palsy, spinal cord injury, multiple sclerosis, or other physical disabilities.
- Young adults ages 18 to 24 with any type of physical disability. To be eligible to participate, you must be between the ages of 18 and 65, a U.S. citizen, be able to provide legal consent, and be a member of one of the targeted groups above.

Participants will complete an online survey requiring approximately 20 minutes. One hundred participants will be randomly selected to receive a \$25 gift card. However, there is no guarantee that everyone who

completes the survey will be selected to receive the gift card. Individuals can access the survey directly by following this link: [http://vcurrctc.org/surveys/employment\\_w\\_pd/](http://vcurrctc.org/surveys/employment_w_pd/) or by going to the MS society website <http://www.nationalmssociety.org/Research/Participate-in-Research-Studies/Surveys>.

## EVERYDAY MATTERS

Everyone has their own idea of their best life. For people living with multiple sclerosis, the idea of that "best life" can change due to the challenges of having a chronic, unpredictable and lifelong disease. To address this challenge, the Society developed this new program for people living with MS, their support partners and family members: Everyday Matters: Living Your Best Life with MS.

Through this course, participants will:

- Increase their knowledge of the principles of positive psychology.
- Identify a challenge they would like to address, along with the positive psychology strategy(ies) they want to employ to develop an action plan.
- Participate in an interactive learning experience, deepening the classroom experience through sharing and connecting with others.

Each session's 90-minute program has two parts: a lecture component and a discussion. Program begins August 4th through September 8th, 2016 5:00- 6:00PM To register call 1800-344-4867, ext 1.

# AUTOS-4-MS

*Help drive MS away -  
donate your vehicle today!*



When you donate your car, truck, motorcycle, boat or trailer to the **National MS**

**Society**, you can feel good knowing **100% of the proceeds go directly toward benefitting people with MS**. Proceeds fund vital research into the cause, cure and treatment of MS as well as programs and services for people living with MS.

## To start the donation process:

- Call our toll-free number, 1-877-672-8864, or submit the electronic donation form found at [www.AUTOS4MS.org](http://www.AUTOS4MS.org)
- A towing company will contact you to schedule your pickup
- A receipt will be mailed to you after the completed sale transaction of the vehicle.

For answers to all your questions, please visit [www.AUTOS4MS.org](http://www.AUTOS4MS.org) or call our office at 1-877-672-8864

## NATIONAL MULTIPLE SCLEROSIS SOCIETY

### Kentucky-Southeast Indiana Chapter

1201 Story Avenue, Suite 200  
Louisville, KY 40206  
1-800-344-4867

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## SELF HELP GROUP MEETINGS:

### PADUCAH

#### West End Baptist Church

Every fourth Thursday 12 - 2 p.m.  
Call or email Alicia at **270-564-9010** or **nationalmssocietypaducah@gmail.com**

### MADISON COUNTY/RICHMOND

#### Hanger's

**2187 Lexington, Rd**  
"Myelin Matters" Every 2nd Thursday  
Contact Lisa at **606-560-9240** or **ls\_cmbs@yahoo.com**

### MADISONVILLE

#### Trover Clinic (8th floor)

Every fourth Monday 6 p.m.  
Contact Dan & Carolyn at **270-635-1178** or **dinosaur@bellsouth.net**

### LEXINGTON

#### Various locations

First Wednesday of every month at 11:30 a.m.  
Contact Leslie at **859-269-4036**

### MUHLENBERG COUNTY

#### Muhlenberg Community Hospital (Basement Conference Room)

Every third Thursday 6 - 7 p.m.  
Contact Kim at **270-315-3248** or **kmorgan123@aol.com**

### CAMPBELLSVILLE

#### Taylor County Extension Office

Every first Tuesday at 6 p.m. Contact Melissa at **mldooley@windsteam.net** or **502-507-3724**

### BOWLING GREEN

#### Sky Rehab

Second Tuesday of the month 6 p.m.  
Contact Shannon at **sgoodlesby@skyrehab.com**

### MIDDLESBORO

#### Middlesboro ARH Hospital

3600 W Cumberland Ave, Middlesboro, KY  
Contact Nina at **606-499-1987** or **nshoemaker@ymail.com**

## PARTNERS IN MS CARE

*The National MS Society takes great pride in our Partners in MS Care program. We are honored to recognize our current partners in MS Care.*

### KENTUCKYONE MULTIPLE SCLEROSIS CARE

#### Partners In MS Care- Centers

#### For Comprehensive

- Gregory Anderson, Neurologist
  - Warren Chumley, Neurologist
  - Nicole Everman, Neurologist
  - Cary Twyman, Neurologist
  - Nancy Heckler, RN, BSN MS Nurse Navigator
- 1021 Majestic Dr, Ste 200  
Lexington, Ky 40513-1867  
(859) 296-1922

### BAPTIST HEALTH REHAB

#### Partners in MS Care- Rehabilitation

#### Physical Therapy

1775 Alysheba Way, Ste 10  
Lexington, KY 40509-2479  
(859)260-4540



National  
Multiple Sclerosis  
Society

1201 Story Avenue  
Suite 200  
Louisville, KY 40206

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BLIND OR  
HANDICAPPED

**Your dollar may be the dollar that finds the cure! We continue to pave the way for MS treatments, none of which existed 20 years ago!**

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Mail to: 1201 Story Avenue, Suite 200, Louisville, Kentucky 40206

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