

MS CONNECTION NEWSLETTER



PICTURED LEFT TO RIGHT: REED BOYLAN, SARA BOYLAN, AND LESLIE DONHOFF OF TEAM "STYLIN' FOR MYELIN" AT WALK MS LOUISVILLE 2012

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LETTER FROM THE PRESIDENT



STACY FUNK, CHAPTER PRESIDENT

CONNECT WITH US ONLINE:

Kentucky-Southeast Indiana Chapter

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kyw@nmss.org

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Connect with us:

www.msconnection.org

Dear Friends,

The leaves are drifting off the trees and a cool breeze is blowing in as the seasons change here in Kentucky and Southeast Indiana. We are drawing to the end of our fiscal year, proud of our successful fundraising events and programs and services.

It is now the season for giving and being thankful for family and friends. As Chapter President, I have been profoundly affected by the families I have met. The way in which I have seen families join together and support each other is inspiring. Many families have touched me at a very deep level and changed my perspective on life. I am thankful for good health, value my relationships more, and truly live each day to the fullest.

Whether or not you participated in Walk MS, Bike MS, the Best of Louisville Bash, or Crystal Boots and Silver Spurs, we are grateful for your support and involvement. These funds support the 4,800 people in our chapter who are living with Multiple Sclerosis. Join us on November 17, 2012 at our Annual Meeting as we look back on the year and give thanks to our devoted friends and supporters (see page 9 for more information).

Thank you for a wonderful year and for your continued support.

Sincerely,

Stacy Funk, Chapter President

NOMINATIONS FOR THE KENTUCKY-SOUTHEAST INDIANA CHAPTER'S BOARD OF TRUSTEES

If you would like to nominate someone for the Chapter's Board of Trustees for the 2012-2013 Chapter term, please contact Chapter President, Stacy Funk at stacy.funk@nmss.org or at 502-526-5301 by Friday, October 12 by close of business. All nominees will be considered by the Chapter's Governance Committee. Nominees that are approved by the committee will then be voted on by the entire membership at the Annual Meeting on November 17.

Don't just ride, Bike MS

BE A PART OF SOMETHING EXTRAORDINARY!
BIKE MS: KENTUCKY-SOUTHEAST INDIANA
COMING TO YOU *REFRESHED* IN 2013!

MS KILLS CONNECTION CONNECTION KILLS MS

Come connect with us in 2013 and experience a fresh, exciting, and most of all, memorable weekend.

With a choice of more than 100 extraordinary rides, the Bike MS experience is the ride of your life.

Registration opens November 1, 2012. Free registration for the first 2 weeks!

Registration Code: BikeMSKentucky

For more information contact Stacy Funk at stacy.funk@nmss.org or 502-526-5301

www.bikeMSky.org



NATIONAL MULTIPLE SCLEROSIS SOCIETY

Kentucky-Southeast Indiana Chapter

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

Chairman: Jeff Hamilton

Vice Chair: Chris Bingaman, Michelle Husted

Treasurer: Dennis Dirksen

Secretary: Debbie Nelson

Chapter President: Stacy Funk

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Kentucky-Southeast Indiana Chapter

Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.

RAY, DIAGNOSED IN 2003



MONEY MATTERS

WHAT ARE JOB ACCOMMODATIONS AND HOW DO I GET ONE?

BY KRIS GRAHAM

At the Society's Information Resource Center, where people with multiple sclerosis and their families can call an MS Navigator® at 1-800-344-4867 for help on a range of topics, we recently received a question about how to obtain accommodations when multiple sclerosis starts to get in the way of doing your job. So here's what I told our caller.

First, I explained what accommodations are. They can be things like new equipment or changes to existing equipment. Another type of accommodation may be a change to your work routine, such as hours worked. (Read a

few real-world examples of accommodations that have worked for people with MS at www.askjan.org/soar/MS/MSex.html.)

I then pointed out two things to remember about accommodations:

- 01 You must be able to perform the essential functions of your job. The ADA (Americans with Disabilities Act) does not require employers to reduce essential job functions, but you can ask to change how you perform an essential job function. Usually employers decide which job functions are essential.
- 02 Your employer does not have to provide you with your first choice in accommodations. The employer has to provide an accommodation that is reasonable and effective, if available — so be ready to discuss alternatives.

Next, we discussed whether or not the ADA applied to the caller's situation. People can request reasonable accommodations under the ADA if:

- They work for an ADA-covered employer;
- They are “qualified” to do the job; AND
- They are a person with a disability as defined by the ADA.

ADA-covered employers include private employers with 15 or more employees, all state and local governments, employment agencies and labor unions. If you're not sure whether your employer is covered by the ADA, contact your regional ADA Center (look up your region at www.adata.org) or visit JAN (the Job Accommodation Network) at www.askjan.org. Both organizations are free and confidential resources. If your employer

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is not covered by the ADA, contact an MS Navigator® at 1-800-344-4867 for assistance in exploring other possible legislation that may protect you.

“Qualified” to do the job means that someone has the “skills, experience, education, or other requirements” of the position, and “can perform the essential functions of the position with or without reasonable accommodation.” (For more information, download the Disability Law Handbook — Employment and the ADA for free at www.swdbtac.org/html/publications/dlh/employment.html.)

The ADA’s definition of a “person with a disability” now includes most people with MS, thanks to the passage of the ADA Amendments Act and updated Equal Employment Opportunity Commission regulations. Although people with MS do not necessarily have to disclose their diagnosis, they must provide enough information for the employer to understand that they are a person with a disability. For more about workplace disclosure and a helpful worksheet, visit www.nationalMSSociety.org/disclosure.

My next advice to the caller was to be prepared! Before you request accommodations, make sure you can answer all of the following questions:

- How is MS affecting your job, potential job, or application process?
- Why are you requesting accommodations?
- What information will you need to provide to your employer (or potential employer) to clarify the impairment affecting your work and the accommodation that will remedy

the situation?

- What accommodations or changes to your work will be effective?
- When should you speak with your employer (or potential employer)?
- Who should you involve in the conversation?
- How should you follow up on your request?
- What are your rights if things go wrong?

Finally, I told the caller that if she had additional questions, an MS Navigator would be standing ready for her call. ■

THESE RESOURCES CAN PROVIDE MORE HELP AND INFORMATION

The Win-Win Approach to Reasonable Accommodations, available at www.nationalMSSociety.org/accommodations.

ADA — Your Employment Rights as an Individual With a Disability, available at the U.S. Equal Employment Opportunity Commission’s website at www.eeoc.gov/facts/ada18.html.

Employees’ Practical Guide to Negotiating and Requesting Reasonable Accommodations under the Americans with Disabilities Act, available at www.askjan.org/EeGuide.

JAN’s Searchable Online Accommodation Resource (SOAR) at www.askjan.org/soar/index.htm.

NEWLY DIAGNOSED

HOW I COMMUNICATE ABOUT MS WITH MY CHILDREN

BY JULIE STACHOWIAK, PHD

I have twin girls who are now six years old. I was diagnosed with multiple sclerosis a couple of years before they were born, so it has always been present in our little family. I guess there was never a question about whether or not to share my MS status with them — it was too big to hide.

One of my first memories of the girls really understanding that I wasn't entirely well was when I had been reduced to tears by some incident.



JULIE STACHOWIAK WITH HER TWO DAUGHTERS

One of my small daughters came to where I was sitting on the ground with my head in my hands and adjusted my collar, saying, “Here you go, Mommy. I’ll take care of you.”

The experts will tell you (and I can confirm) that young children pick up when a parent is not feeling well. Child psychologists will tell you that this can manifest as increased clinginess, regression in terms of speech or potty-training progress, or reversion to younger behavior (such as needing a pacifier). Older children may get worried that something terrible is happening — that their parent will die, that they will die, that they did something bad and whatever is going on is all their fault. This may turn into sleeping issues or nightmares, withdrawing emotionally, or acting out at school.

Those same experts say that we should answer all questions about our MS honestly and directly, adjusting information as they get older. That might, or might not, work for you. I know that some people choose to keep their MS from their children until they reach a certain age or something happens where it must be revealed. These parents may feel they are protecting their children from the pervasive worry of having a sick parent.

I think that it is an individual choice. We all have to make our own way as parents. I can't tell you what to do — I cannot tell you that you must be open about your MS with your children.

The only thing I can tell you with 100 percent clarity is that it is impossible to show your children too much love.

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As far as my situation goes, I have chosen to be very open with my daughters (in an age-appropriate way). I tell them when I am tired and I tell them when I feel better and I make sure that we do something fun and active during those times. We discuss MS and I have tried to explain to them what is happening in my brain. They know that I don't like it when music is too loud or when we've been outside in the sun for too long.

AS FAR AS MY SITUATION GOES, I HAVE CHOSEN TO BE VERY OPEN WITH MY DAUGHTERS ... I TELL THEM WHEN I FEEL BETTER AND I MAKE SURE THAT WE DO SOMETHING FUN AND ACTIVE DURING THOSE TIMES.

I won't say that I have handled it perfectly. I have seen one of my daughters looking at me with a furrowed brow too many times, while the other one may come into my bedroom with "nightmares," when I suspect she really just wants to check on me. However, I do think that they are considerate, gentle and compassionate. They seem slightly less self-centered than some of their classmates. They are not afraid of people who are different — we have friends with Down syndrome, who use wheelchairs and who are hooked up to oxygen. My girls don't seem to see any of it, just the person whom they want to tell about their Halloween costume or their newest toy. I'm proud of that. ■

SOCIETY RESOURCES FOR FAMILIES

The Society's "Family Matters" Web page at www.nationalMSSociety.org/FamilyMatters contains links to helpful brochures, programs and resources.

Each issue of **Keep S'myelin** has fun, engaging activities to help parents and children learn about and discuss MS together. Go to www.nationalMSSociety.org/keepsmyelin for back issues and subscription information.

Search for and download Society brochures **Plaintalk — A Booklet about MS for Families** for information on talking about MS with family members and **Someone You Know Has MS** for children at www.nationalMSSociety.org.

Join the online "Family Matters" community at www.MSconnection.org.

Watch the Society video "Parenting with MS" at www.youtube.com/watch?v=V93TG_0LJiA.



Diagnosed with MS in 2003, Julie Stachowiak, PhD, is the author of **The Multiple Sclerosis Manifesto** and www.ms.about.com.

Originally published at www.blog.nationalMSSociety.org.

WAYS TO GIVE

WALK WITH
PURPOSE

EACH STEP BRINGS US CLOSER TO THE CURE

Challenge Walk MS: Charleston Challenge is many things. It is a collaborative event among nine chapters of the National MS Society in the Southeast. It is walking 50 miles in 3 days and raising more than \$1500 to support a cause close to your heart. It is joining a family of people who care about the same mission. It is seeing the historical city of Charleston, South Carolina by foot and staying at the beautiful Wild Dunes Resort on Isle of Palms. Most importantly, it is taking on a challenge that perhaps you wouldn't think you could do but finding the inner strength to make a difference in the lives of 400,000 living with multiple sclerosis.



DENNIS DIRKSEN, BOARD TREASURER, WALKING FOR HIS FAMILY IN THE 2012 CHALLENGE WALK MS: CHARLESTON CHALLENGE

Dennis Dirksen from the Kentucky Southeast Indiana Chapter participated for the first time in 2012 and raised over \$14,000! We asked him to share a little bit about his journey.

Q: Why did you participate in the Challenge Walk?

A: It was the cause and the physical challenge that sparked my interest.

Q: Tell me a little bit about your experience there.

A: It was an exceptional experience—it was not only challenging, but was also inspirational and motivational for me. It also reinforced that my family and I are not alone in our quest for a cure—seeing 300 other individuals, determined to cover 50 miles in 3 days for the cause was further reinforcement that others are there alongside you, dedicated to helping find a cure for multiple sclerosis. Many times you feel like you are alone in this quest, so the exposure to all of the other determined and dedicated individuals was inspirational and reassuring.

Q: What was the most memorable part of the experience?

A: I enjoyed every part of it immensely; the Saturday evening candle-light ceremony was very touching.

Q: What kind of fundraising advice can you give to those who want to participate next year?

A: It must be very personal so that it touches the emotions of those who you are asking to donate to the cause. The more personal you

can make the story, the more effective the fund-raising effort will be.

Join Dennis and accept the challenge March 1-3, 2013. The entire staff of the Kentucky-Southeast Indiana Chapter did! We are dedicated to raising critical funds for MS research, programs, and services for our local families affected by MS. To join TEAM KENTUCKY or to donate go to <http://main.nationalmssociety.org/goto/teamkentucky>.

If you are interested in attending an “Explore the Challenge” meeting or have any questions about this unique event, please contact Bonnie Nevin at 336-299-4136 or bonnie.nevin@nmss.org. Visit challengems.org for more event information. ■

ACCEPT THE CHALLENGE
A WORLD FREE OF MULTIPLE SCLEROSIS
MARCH 1-3, 2013 ■ WALK 50 MILES IN 3 DAYS
RAISE \$1,500 FOR THE NATIONAL MS SOCIETY



LEARN MORE OR REGISTER TODAY:
WWW.CHALLENGEMS.ORG OR 1-800-344-4867



WE ARE LOOKING FOR FRIENDS!
LIKE US ON FACEBOOK:
WWW.FACEBOOK.COM/KYNMSS

CALENDER EVENTS

GAINING MOMENTUM: ANNUAL MEETING & MS RESEARCH UPDATE Saturday, November 17, 2012

Join us as we take a look back on 2012. You won't want to miss out on the complimentary pancake breakfast, volunteer appreciation awards, and research discussion. Breakfast begins at 9:30 AM. We are also happy to welcome Dawne Gee of Wave 3 as our Mistress of Ceremonies.

Program features Dr. Malachy Bishop, Professor of Rehabilitation Counseling and Rehabilitation Counseling Doctoral Program Coordinator with the University of Kentucky. Dr. Bishop will speak about his current research, “Specialized Housing and Housing Issues for People with MS: A national analysis and its local implications; funded by the National MS Society.”

St. Joseph Catholic Church, 1406 East Washington Street, Louisville, KY 40206.

For more information contact Bailey Preston at bailey.preston@nmss.org or 502-526-5061.

CALENDAR PROGRAMS

Join us at one of our three locations for our Healthy Steps Lunch Bunch series! Participate in an educational and support program from 11:00 AM to 12:30 PM. Bring your caregivers, family, and friends and enjoy a FREE lunch. Space is limited, so please RSVP by calling 1-800-344-4867 option 1 or visit our website at www.nationalmssociety.org/kyw.

ELIZABETHTOWN LUNCH BUNCH

November 1 and January 3, 2013

First Thursday of the month bi-monthly at First Federal Savings Bank on 2323 Ring Road in Elizabethtown.

LEXINGTON LUNCH BUNCH

October 29 and November 26

December meeting cancelled due to holiday

Last Monday of the month at Cardinal Hill in the Center of Learning Room 3, on 2050 Versailles Road in Lexington.

LOUISVILLE LUNCH BUNCH

October 2, November 6, and December 4

January meeting cancelled due to holiday

First Tuesday of the month at Kosair Charities in the Community Room at 982 Eastern Parkway in Louisville.

WALK MS PADUCAH APPRECIATION PARTY

Tuesday, November 6, 2012

Doors Open: 6:30 PM CDT

Appreciation Awards: 6:45 PM

Dinner: 7:15 PM

Program: 7:30pm – 8:30 PM

Program features a presentation by Dr. Sarah Shelton, Licensed Clinical Health Psychologist and Kentucky Multiple Sclerosis Certified Specialist.

Lourdes Hospital Community Room at 1530 Lone Oak Road in Paducah.

STAY TUNED FOR A BOWLING GREEN AND ELIZABETHTOWN APPRECIATION PARTY!

Fear.

Hope.

MS KILLS CONNECTION
CONNECTION KILLS MS

**Give What You Know at
MSconnection.org**

SELF HELP GROUP MEETINGS

BOWLING GREEN

Contact Tim at (270) 535-9161
6:00 PM, Sky Rehab Clinic
2nd Tuesday of each month

ELIZABETHTOWN

Contact Tom at (270) 230-8145
2:00 PM, Republic Bank Ring Rd.
4th Tuesday of each month

FRANKFORT

Contact Michelle at (502) 803-6239
6:30 PM, Frankfort Regional Medical Pavilion
2nd Floor Conference Room
2nd Friday of each month

LEXINGTON

Contact Penni at (859) 536-3350
11:30 AM, Location TBA
For more information, go to
www.nationalmssociety.org/kyw
1st Wednesday of each month

MADISONVILLE

Contact Dan or Carolyn at (270) 639-5679
6:00 PM, Trover Clinic 8th Floor
4th Monday of each month

NEW ALBANY

Contact Michael at (812) 944-0279
6:00 PM, Floyd Memorial Hospital
Paris Education Wing
4th Monday of each month

PADUCAH

Contact Teresa at (270) 554-5603
6:30 PM, Lourdes Hospital
Marshall Nemer Pavilion, Borders Room
1st Tuesday of each month

OHIO COUNTY

Contact Tim at (270) 535-9161
6:30 PM, Ohio County Wellness Center
1st Tuesday of each month

WINCHESTER

Contact Carolyn at (859) 749-6442
5:00 PM, Gaunce's Deli & Cafe
1st Thursday of each month

DID YOU KNOW?

MS Navigators are the first people you should call! They can provide you with the latest information about MS and locate resources when you need it. **Call an MS Navigator today! Monday through Friday, 1-800-FIGHT-MS (344-4867) Option 1, 9:00 AM to 7:00 PM EDT, Monday through Friday.**



**National
Multiple Sclerosis
Society**

1201 Story Avenue
Suite 200
Louisville, KY 40206

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VOLUNTEER SPOTLIGHT

TERESA GUESS

Teresa Guess was diagnosed with Multiple Sclerosis eleven years ago. She is a Registered Nurse with twenty years experience and a Multiple Sclerosis Certified Nurse since 2008. She works PRN as a Nurse Educator teaching MS patients injection training.

Teresa has been the Self-Help Group Leader in Paducah for three years. She wants to make sure no one with MS feels as though they are fighting their MS battle alone. She makes sure her support group has a positive, uplifting atmosphere and always says she wants, “our members and guests to feel better when they leave than they did when they came!” Teresa loves being a volunteer with the National MS Society and truly appreciates the resources and help from the Chapter. She believes that together we will make a difference in the lives of many families and individuals.

“I’ve been truly blessed to meet so many special people through my volunteer work. I strongly urge everyone to attend National MS Society sponsored events and programs. Stay positive! Get active! Get involved! We can and will be better by working together! ■



RENA HOLMES, MARY CARABELLA, AND TERESA GUESS (LEFT TO RIGHT)