

MS CONNECTION NEWSLETTER



WE ARE GEARING UP FOR BIKE MS:
BLUEGRASS, BIKES, & BOURBON ON
JUNE 22-23, 2013! FIND OUT MORE
ABOUT RIDING OR VOLUNTEERING AT
WWW.BIKEMSKY.ORG (PAGE 4).



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GROUP IN YOUR
COMMUNITY**



BRITTANY SHEPPARD,
UNIVERSITY OF LOUISVILLE



MADISON RAY,
ST. CATHARINE COLLEGE

CONNECT WITH US ONLINE:

**Kentucky-Southeast
Indiana Chapter**

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SCHOLARSHIP ANNOUNCEMENT

The Chapter is excited to announce this year's recipients of its annual Scholarship Program: Madison Ray and Brittany Sheppard.

The program helps students affected by MS pursue a college education. It is open to high school seniors who live with MS or have a parent who does; or anybody living with MS who has not yet been to a post-secondary school.

“For the Ray and Sheppard families and the hundreds of thousands diagnosed with MS across the country, there are very few known sources of scholarship assistance specially targeted for these families,” said Stacy Funk, Chapter President. “MS shouldn’t stand in the way of an education, and we are hopeful this program will give families some relief.”

Information about scholarships for 2014-15 will be available on the National MS Society website on October 1st. For more information, call 1-800-344-4867.

FIRST WALK OF THE SEASON A SUCCESS!

WWW.WALKMSKY.ORG

Thank you and congratulations to Bell County for hosting their First Annual Walk/Run MS raising \$17,000 to benefit the National MS Society – Kentucky Southeast Indiana Chapter. Walk/Run MS Bell County was held on April 20 at Middlesboro High School with over 200 participants and volunteers in attendance. Thank you to everyone who helped make this event possible and a special thank you to our Walk/Run MS Bell County Committee Chair, Ashley Cambron.

And thank you to our sponsors: Leadership Bell County, Home Federal Bank, Wal-Mart (Store #739), Lincoln Memorial University, Middlesboro ARH Hospital, Associates in Neurology Research, Teva Pharmaceuticals, Superior Van & Mobility and Genzyme.

Walk MS: Central Kentucky
Saturday, September 7, 2013
Freeman Lake - Elizabethtown

Walk MS: Bowling Green
Saturday, September 14, 2013
Preston Miller Park

Walk MS: Madisonville
Saturday, September 21, 2013
Madisonville City Park

Walk MS: Paducah
Saturday, September 28, 2013
Noble Park

For more information contact Mary Carabella at 502-526-5303 or mary.carabella@nms.org.

Walk MS: Lexington
Saturday, September 14, 2013
RJ Corman - Nicholasville

Walk MS: Pulaski County
Saturday, September 21, 2013
Pulaski County High School

For more information contact Tiffany Smith at 859-294-7060 or tiffany.smith@nms.org.

NATIONAL MULTIPLE SCLEROSIS SOCIETY

Kentucky-Southeast Indiana Chapter

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

Chair: Michelle Husted

Treasurer: Dennis Dirksen

Secretary: Debbie Nelson

Chapter President: Stacy Funk

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Kentucky-Southeast Indiana Chapter

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BIKE MS

BLUEGRASS, BIKES, & BOURBON JUNE 22 - 23, 2013

New name, new routes, new venue = an AMAZING adventure! Don't miss out on Bike MS: Bluegrass, Bikes & Bourbon!

Join us for an unbelievable two day journey through the heart of Kentucky's Bourbon Country! Saturday will start in Shelbyville, KY, with a finish line party at Four Roses distillery and overnight in Lawrenceburg, KY. Ride back to Shelbyville on Sunday and celebrate with your friends and family at Gallrein Farms. 35, 65, & 100 mile route options.

Visit www.bikeMSky.org for more information. Can't join us for the ride? Consider being a Virtual Cyclist and still help raise funds to create a world free of MS!

VOLUNTEERS NEEDED

Help us to make Bike MS a huge success! Each volunteer's contribution, large or small is critical to the success of the event. There are a variety of volunteer opportunities available: Rest Stops, Registration/Package Pick-up, Site Set Up & Tear Down, Bike Check-in/Check-out, HAM Radio Operators, SAG Drivers, etc. Volunteers provide key support to Bike MS and we couldn't do it without you!

Register to be a Bike MS volunteer by emailing jerika.amos@nmss.org or call 502-526-4031 for more information.



CONGRATULATIONS TO DENNIS DIRKSEN (CENTER), LOYAL CHAPTER BOARD MEMBER AND VOLUNTEER, ON HIS RECENT RETIREMENT!

UPCOMING EVENTS

BEST OF LOUISVILLE BASH

July 25, 2013

Churchill Downs, Louisville
Tickets \$50 and Tables \$750

For more information go to
www.bestoflouisvillebash.com or call
Mary Carabella at 502-526-5303.

CRYSTAL BOOTS & SILVER SPURS - LEXINGTON

August 17, 2013 - Spindletop Hall

For more information contact Tiffany Smith at
859-294-7060 or tiffany.smith@nmss.org.

CRYSTAL BOOTS & SILVER SPURS - SOUTHERN INDIANA

September 28, 2013 - Floyds Knobs, IN

For more information go to
www.crystalboots.com. For tables and tickets
contact Maria Wheatley at 502-648-2283 or
mariau@maconstruction.com.

EMPLOYEE SPOTLIGHT

ALL ABOUT MARY

Name: Mary Carabella

Position: Development Manager since February of 2011

Degree: Art History – I started out at the University of Cincinnati, transferred to Borough of Manhattan Community College in NYC, then to Hunter College on the upper east side of NYC, and finally transferred to the University of Louisville from where I graduated with an Art History Degree.

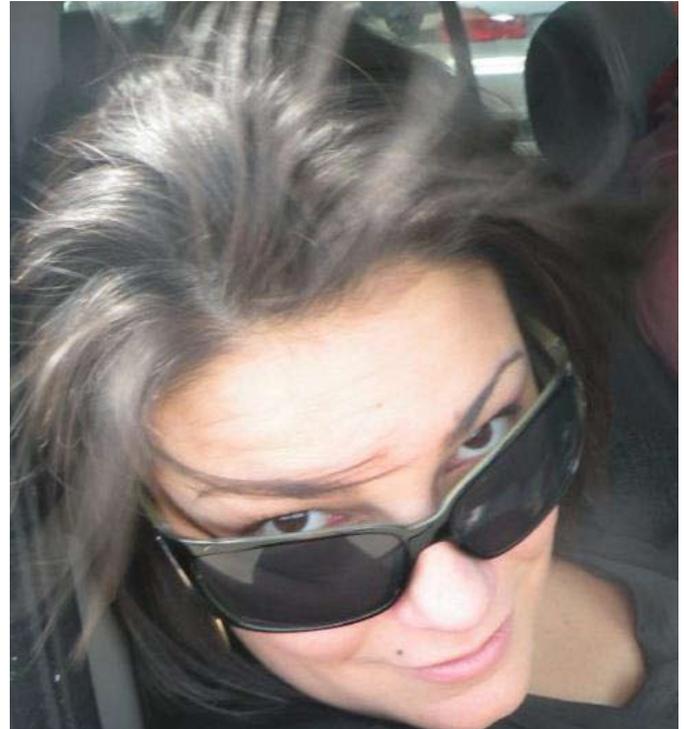
Previous work experience: Barista (at the first ever Starbucks in Cincinnati), Bartender, Server, Cocktail Waitress, Weight Room Attendant, Museum of Modern Art in NYC, Trucking Dispatcher, Retail Associate, Asst. Special Event Manager at the Speed Art Museum, Foundation Coordinator at the Greater Louisville Medical Society Foundation, Party and Liquor Store Manager, VP of Marketing at New Age Communications.

Places lived: Ohio, California, Illinois, Maine, New York, and Kentucky

Hobbies: Painting and re-painting. I like to paint canvas too and dabble in photography. I recently started a blog as well that tells bits of my life. I try to find the humor in most things and I've had some really funny stories and unbelievable moments.

Last book read: "Don't Say A Word"

Something few know about you: My last name is made up.



MARY CARABELLA
DEVELOPMENT MANAGER

Your favorite part of working for the chapter: It is very rare in life a person gets up every day and likes to go to work. This is more than a job. It's personal. Most people know that about me. I know in my heart someday there will be a cure for this disgusting, debilitating, heart wrenching, invisible disease that infiltrates every part of a person's life and the lives of those who love that person. So I get up every day and know I'm making a difference. I'm going to make life better.

To contact Mary, call 502-526-5303 or email mary.carabella@nmss.org.



BECOME OUR FRIEND ON FACEBOOK!
WWW.FACEBOOK.COM/KYNMSS



ADVOCACY

BE YOUR OWN BEST ADVOCATE

BY JENNIFER LARUE HUGET

Your whole life changes when you learn you have multiple sclerosis; mine sure did. In my case, those changes weren't largely physical. Rather, my diagnosis caused me to reconsider my place in the world and the way I interact with other people and institutions.

Like many others with MS, the process of learning to live with my condition opened my eyes to the necessity for me to become an advocate — for myself and, by extension, for others with MS.

I suppose I was accustomed to the concept of advocacy before I was diagnosed. As a mother I advocated for my kids, seeking the best healthcare, education opportunities and play dates possible.

But those of us with MS also have to learn to advocate for ourselves. We need to assert our

own needs and effectively communicate them to our doctors, employers, insurers, even our families and friends. But self-advocacy doesn't necessarily come naturally. I, for one, have always been a bit reticent to ask others to do things for me.

The National MS Society, recognizing that many people are in the same boat, offers helpful advice at www.nationalMSsociety.org/selfadvocacy for learning to take on the role of self-advocate in the key realms of our lives, from our workplaces and schools to our families and communities.

A recent legal settlement highlights the importance of self-advocacy for people with MS who are navigating the healthcare system. In the case of **Jimmo vs. Sebelius** (in which the Society was a plaintiff), a federal judge on January 24 approved a settlement that reaffirmed patients' access to Medicare benefits, regardless of whether their condition improves as a result of the treatment provided.

A bit of background: For decades, Medicare beneficiaries, especially those with long-term or degenerating conditions and those who needed rehabilitation services, have been denied care on the grounds that those services didn't result in improvements to their condition. For patients whose conditions remained stable or chronic, rehabilitative services were often deemed to be for "maintenance only," and thus weren't covered.

The new settlement reinforces the original intent of the law — that it's not legal for Medicare to deny coverage on that basis. The law requires the Centers for Medicare & Medicaid Services (CMS) to revise its Medicare Benefit Policy

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Manual and numerous other policies, guide lines and instructions to ensure that Medicare coverage is available for skilled maintenance services in home health, nursing home and outpatient settings.

Here's where self-advocacy kicks in. The new policy is already in force. People with MS don't have to wait until the CMS revises its documents to gain coverage for the care they need. People who are denied Medicare for skilled maintenance nursing or therapy because they are "not improving" can appeal those decisions right away. That's a very important form of self-advocacy.

To that end, another of the plaintiffs in the settlement, the Center for Medicare Advocacy, offers self-help materials at www.medicareadvocacy.org/take-action/self-help-packets-for-medicare-appeals to help people understand coverage rules and learn how to contest Medicare denials for outpatient, home health or skilled nursing facility care.

Of course, it's important to bear in mind that the settlement doesn't guarantee coverage; providers and people seeking Medicare coverage for treatments still have to demonstrate that the care is medically reasonable and necessary. Still, eliminating the standard that required patients to show improvement in their condition, not just maintenance, is a big step in the right direction — and one that we should all be aware of as we navigate the healthcare system.

The term "self-advocacy" can sound kind of daunting; when I first heard it, I thought it meant going to Washington, D.C., to lobby for funds for MS research. I have since learned that, yes, lobbying is at one end of the self-advocacy

spectrum. But at the other end of that spectrum there are many everyday opportunities for self-advocacy. Making sure you're getting the medical attention you need? That's self-advocacy. Reminding others that you can still do your job well, despite any limitations your MS places on you? That's self-advocacy.

At the most basic level, though, self-advocacy begins with becoming informed. As I said at the start, self-advocacy doesn't come naturally to me. But I can read and learn and discuss issues related to MS. Armed with information, I can advocate for myself with the best of 'em. ■



Jennifer LaRue Huget was diagnosed with MS in 2001. A freelance writer and children's book author, she lives in Connecticut with her husband, two teenage kids and two brown dogs.

Visit her website at www.jenniferlaruehuget.com.

Originally published at blog.nationalMSSociety.org.

COMMUNITY SPOTLIGHT

The Craig Family BBQ is set for Saturday, September 7.

We appreciate all the support we get from this family in memory of their loving mother and wife, Cathy Craig.

RESEARCH

MAKING
TREATMENT
PERSONAL

BY DR. LINDA BUCHWALD

One of the most frustrating aspects of treating multiple sclerosis, for both doctors and people with MS, is not knowing in advance how an individual will respond to a particular medication.

Our frontline disease-modifying treatments, the ones we use first in treating someone with MS, all have demonstrable benefit in clinical trials and in real practice. However, not everyone's MS responds equally to all of these medications.

Some people with MS do well with the first therapy they are prescribed in terms of how successful the drug is in reducing relapses and lessening severity of attacks. Others don't do so well and, after months or years on a particular drug, they may make the decision with their doctor to switch therapies. A new waiting period then begins to see if they will respond with fewer and less severe relapses.

Most people with relapsing-remitting MS do eventually find a therapy that works for their disease, although waiting to discover which one can be hard on them emotionally.

FINDING THE "SIGNATURE" OF MS

Currently, no doctor can predict which people will respond best to which drugs. However, if a doctor could identify which patients were more likely to respond to treatment, and if there were clues as to how active their disease will be, it would give doctors a tremendous advantage in recommending therapy. MS research now seems to be on the path to do precisely that at some point not too long from now.

A team led by Dr. Philip L. De Jager, a Harry Weaver Scholar of the National MS Society who is affiliated with Harvard Medical School and Brigham and Women's Hospital in Boston, has discovered that differences in active genes — detectable in blood samples — have the potential to be used to group people with MS into categories that may predict disease course and responses to therapy (*Science Translational Medicine*, 2012;4: 153ra131).

PERSONALIZED MEDICINE AIMS TO PREDICT
THE COURSE OF A PERSON'S DISEASE.

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The team related specific MS disease patterns to genes that were active or inactive in blood samples from 141 people who were newly diagnosed with MS and who had not yet been treated. The blood samples contained immune cells known to be important in the disease activity involved in MS. From these cells, the team extracted a type of molecule called RNA, which shows what genes were turned on in the immune cells.

IN THIS WAY, THE TEAM WAS ABLE TO FIND A “SIGNATURE” THAT COULD PREDICT, EARLY ON AT LEAST, THE LIKELIHOOD OF ACTIVE DISEASE.

Their analysis of the RNA showed that the 141 people with MS could be divided into two groups according to whether particular sets of genes involved in immune function were active or inactive. They then tested the importance of their groupings further by examining blood from 222 people who were being treated with two types of first-line therapy used in MS. The group of people with MS whose immune system genes were more active were significantly more likely to experience a relapse or show other evidence of disease activity (such as on MRI) were compared to the group whose immune system genes were less active, regardless of which treatment they were on.

A FIRST STEP PROMISES MORE

It’s very important to note that this study was a first step, and there are many more questions to answer, including whether this process can predict a shift from a relapsing form of MS to a progressive form. Further research is needed to verify and refine this approach before it becomes a tool that can benefit treatment decisions made by people with MS and their health care providers. But the study is extremely promising, and could eventually contribute towards “personalized medicine” in MS, which aims to be able to predict the course of an individual’s disease and the best treatment options to stop their type of disease activity.

In a disease as complicated as MS, this provides great hope to both doctors and people with MS as they work together to overcome the disease. It is also an excellent example of the growing power of MS research to employ genetic data in a treatment context. ■



Dr. Linda Buchwald is Chief of Neurology at Mount Auburn Hospital in Cambridge, Mass., and the Medical Director of the Mount Auburn Hospital Multiple Sclerosis Care Center. She is a trustee of the Society’s Greater New England Chapter and Clinical Advisory Committee member.

Originally published in the Winter 2012 issue of the Greater New England Chapter’s **MS Connection**.

CALENDAR PROGRAMS

Join us at one of our two 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.

Lexington Lunch Bunch June 24, July 29, August 26

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

Louisville Lunch Bunch August 6, September 3, October 1 *July meeting cancelled due to holiday*

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

TELECONFERENCES

Register for the upcoming teleconferences by calling 1-800-344-4867 option 1.

- **June 12** - Improving Independence in Progressive MS
- **July 9** - Riding the MS Emotional Roller Coaster
- **September 10** - Research: Where are we now? Where are we going?

BEAT THE HEAT

KEEP COOL WITH THE NATIONAL MS SOCIETY

Keep cool during this blistering hot summer with a cooling vest or neck wrap. Thanks to a generous grant from the



Honorable Order of the Kentucky Colonels, you have a chance to receive FREE cooling items to get you through the rest of this summer! In order to receive a cooling item we will need you to complete a short application and send a statement of diagnosis. If you live outside the Louisville area, please reserve yours and we'll coordinate delivery.

Items are limited, so reserve yours TODAY! Please call Bailey Preston at 502-526-5061 or email bailey.preston@nms.org to reserve your cooling product and get the application process started.

WELLNESS INCENTIVE

GET FIT AND STAY FIT

Because exercise is so important to the health of those with MS, we have introduced an incentive for everyone with MS regardless of income. The Wellness Incentive Program provides funding for up to \$150 per year to help defray the costs of joining an exercise facility or participating in recreation classes.

Contact Bailey at 502-526-5061 or email bailey.preston@nms.org to get your application today!

TALK MS 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 Friday of each month

LEXINGTON

Contact Leslie at (859) 269-4036
11:30 AM, Location TBA
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

MIDDLESBORO

Contact Nina at (606) 499-1987
6:00 PM, Middlesboro ARH
2nd Tuesday of each month

NEW ALBANY

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

PADUCAH

Contact Jessica at (270) 804-0817
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

SOMERSET

Contact Rick at (606) 872-6876
6:00 PM, Lake Cumberland Regional Hospital
3rd Thursday of each month

WINCHESTER

Contact Joy at (859) 595-7838
6:00 PM, BCTCS
1st Tuesday of each month

COMMUNITY SPOTLIGHT

A special thank you to Aaron Montgomery, drummer for V-Groove for spearheading the annual Jam for a Cure fundraiser. The event in January raised almost \$30,000 for the Chapter!





**National
Multiple Sclerosis
Society**

1201 Story Avenue
Suite 200
Louisville, KY 40206

Free Matter for
the Blind or
Handicapped



ASHLEY CAMBRON, (RIGHT) WITH
HER MOTHER, NINA SHOEMAKER

VOLUNTEER SPOTLIGHT: **ASHLEY CAMBRON**

Ashley Cambron, age 26, connected with the National MS Society when her mother was diagnosed with MS in 2004. She became actively involved with the Society three years ago when she started a Walk team for her mother. The Chapter was so impressed by Ashley and her family’s local community support, we decided to start a Walk in her hometown of Middlesboro, KY. “This experience has been the biggest reward for me and it was wonderful to see such a great outcome for the MS Walk in my hometown,” said Ashley. Walk MS: Bell County far exceeded their goal thanks to the great support from the community. This was Ashley’s first experience leading a committee and helping to plan the event. Ashley says that “it was one of the most rewarding things I have been apart of. I look forward to start planning for next year!”

MEET THE STAFF

Stacy Funk
Chapter President

Jerika Amos
Development Manager

Mary Carabella
Development Manager

Shelby Jett
Operations Manager

Cathy Kemple
Office Manager

Bailey Preston
Programs Manager

Tiffany Smith
Development Manager