



National
Multiple Sclerosis
Society
Ohio Valley
Chapter

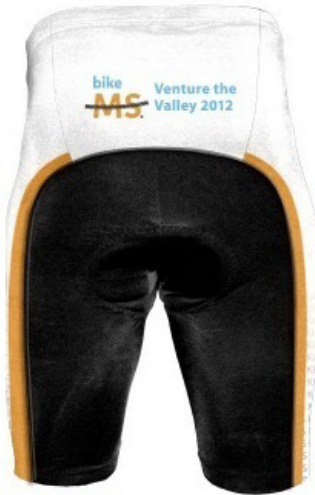
CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Special Edition: Bike MS



Official Bike MS Venture the Valley 2012 Jersey



Official Bike MS 2012 shorts



Bike MS socks



Official Bike MS Venture the Valley 2012 Top Banana Jersey

These are the official jerseys, shorts and socks for Bike MS: Venture the Valley 2012! How can you get them? Check our blog, FightMSblog.org, or call Steve Niemann at 513-769-4400.

Presented by



KROGER BRAND



FUNdraise WITH CITY BBQ

Raise money for your team while sharing the love of City Barbeque!

Now you can enjoy great barbeque and raise money for your Bike MS team at the same time.

Just pick a day and invite your friends, family, neighbors, and associates to your favorite City Barbeque location, and City Barbeque will donate 25 percent of the sales from your group to your team!



City Barbeque will provide you with a flyer to reproduce and share with as many people as you can*. You'll definitely want to spread the word because City Barbeque will keep track of all sales related to your group on that day. Then, they will gladly write you a check for 25 percent of the sales from your group!

Check out our blog, FightMSblog.org, for more information!

GET A BIKE MS CABIN

Camp Kern cabins are now available to rent for Bike MS weekend (August 25 & 26). Cabins are priced at \$32 per bed for the entire weekend (Friday and Saturday nights).

Available Camp Kern cabins include:

MAIN CAMP – Cabin #'s 1-4 & 20 (Sleep 14)

MAIN CAMP – Cabin #'s 5-19 (Sleep 12)

Obviously, prices vary based on number of beds per cabin. For more information, or to reserve a cabin, please phone Rebekah Schraer at 513-769-4400.

Think of the fun your group can have decorating a cabin, and sitting around your private campfire.



IN NEED OF HOME MODIFICATIONS FOR ACCESSIBILITY?

Are you in need of home modifications for accessibility?

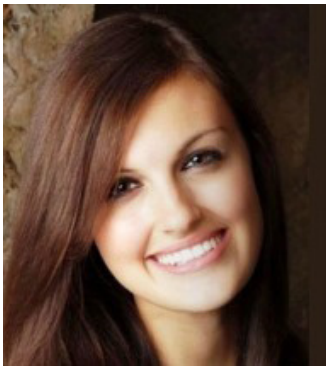
You may be able to qualify for a special grant that is being offered for a limited time through the Federal Home Loan Bank for this purpose.

You may qualify if you are:

- a homeowner living with MS in the Ohio Valley Chapter (Cincinnati/Dayton/Northern Kentucky area), and
 - in need of accessibility modifications to your home
- For full details (or to apply), please phone Amanda Gelter at 513-769-4400.



2013 SCHOLARSHIP PROGRAM



Do you know a student living with MS? Or maybe you know a student who has a parent living with MS?

The Ohio Valley Chapter of the National MS Society wants to help that student achieve his or her goal of attending college. Each year, we award one \$1,000 scholarship.

2013 scholarship application opens October 1st. More information at NationalMSSociety.org.

NATIONAL MS SOCIETY DAY AT THE REDS



The Cincinnati Reds have invited us to National MS Society Day at The Cincinnati Reds, September 25, 2012. The Milwaukee Brewers visit Great American Ball Park to take on the Reds at 7:10pm. It should be a great game, as Sports Illustrated has predicted, "The Reds will win the World Series."

If you are a team captain, this has tremendous fundraising potential for you.

Team captains can participate in this great opportunity. Let us know how many tickets your team would like to sell for National MS Society Day at The Cincinnati Reds, September 25, 2012. The National MS Society will provide the tickets. You and your team sell the tickets for \$18 (Mezzanine face value is \$24). Eight dollars from each ticket your team sells benefits your team's fundraising. For more information, call Steve Niemann at 513-769-4400 or visit FightMSblog.org.

SOCIETY WORKSHOPS A POINT OF CONNECTION

BY HELEN RUSSON



Nadja (middle), diagnosed in 2008

From the moment the doctor told me, “You have MS,” everything changed. I felt a wide range of emotions: relief (because I didn’t have a brain tumor), anger (although I wasn’t sure who to be angry at) and fear of the future. What **was** this disease, and how would it impact me and the people who were important to me? I had no idea what my new life would be like, or how to get started on it.

Like many people, I first turned to research. This was in 1997, before the Internet was in full swing (at least at my house). So I went to the library, trying to learn about MS. I had heard about the National MS Society, but for days I was hesitant to call the number. Finally, I made the call, which led to my second-most important discovery of the year: my chapter was about to begin a series of in-person workshops for people who had just been diagnosed with MS.

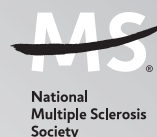
Each workshop featured a different guest speaker. On the first evening, a neurologist spoke in practical terms about the disease. Her

presentation included a slideshow illustrating how white blood cells inexplicably start attacking the protective coating of the nerves (myelin sheaths). She had actually brought a ruptured electrical cord, exposing the frayed wires underneath. That simple prop was probably the most effective tool of my MS education. It helped me realize that if I’m having a hard time lifting my leg, it’s not because I’m lazy or weak-willed. It’s because of those well-meaning (but very misguided) white blood cells.

Afterward, the neurologist answered our questions about the day-to-day realities of living with MS. She also talked about some ongoing clinical trial studies and invited us to learn more about them. (I ended up participating in several such studies, all of which were very rewarding.)



Knowledge Is Power is a six-week, free, at-home educational program for people who are newly diagnosed. Mail or email formats. To register, call 1-800-344-4867, or visit www.nationalMSsociety.org/knowledge.



JOIN THE MOVEMENT®



An in-person workshop at the Central North Carolina Chapter

Each workshop was similarly organized. A speaker would give a presentation and then answer questions. We were introduced to experts in

medicine, mental health, yoga and nutrition. At some point each evening, we broke into small groups to discuss what we had learned. I remember that one of the most fun and empowering activities was learning how to get a good workout while sitting down. (Who knew?)

Throughout these programs, chapter staff told us about their services and resources, which included numerous opportunities to volunteer. I soon started volunteering and I haven't stopped yet!

New frontiers

Of course, things have changed since 1997. While many chapters continue to offer in-person workshops similar to what I experienced, they have also begun exploring additional ways to help people newly diagnosed with MS connect to the Society—and to each other.

"Almost every home now has access to the Internet and that seems to be a primary source for information, especially for tech-savvy people," noted Mary Roberts, associate vice president of the South Central Region. "So we are doing our research to find new and creative ways to reach people."

Teleconferencing, videoconferencing and webcasts are a few options. "We plan to have a program in one site and broadcast that program to other sites across our region," said Roberts. Some chapters are also trying out new formats for workshops, such as offering quarterly workshops with a nurse, or teaming up with an area MS center or university to provide workshops led by doctors.

Peer support programs are another way to connect. Anyone newly diagnosed can call 1-866-673-7436 to have a confidential telephone conversation with a peer with MS through the Society's MSFriends program. Or they can visit www.nationalMSSociety.org/onlinepeerconnections to search through online profiles of trained peer support volunteers. Once matched, participants can connect confidentially and one-on-one via telephone or email. To discover the full spectrum of resources that the Society offers, call us or 1-800-344-4867 to be connected to an MS Navigator®.

MS is not a virtual disease, and the computer isn't a substitute for personal connection, but we are working to combine the best of both worlds, looking for ways to embrace the information age and to continue to provide the healing power of human contact.



Helen Russon is a volunteer at the Oregon chapter.

THE DIRT ON ADAPTIVE



Staci, diagnosed in 1985

GARDENING

Gardening is one of the most popular hobbies in the United States, one that can benefit people both mentally and physically, as well as provide fresh and healthy food. “Gardening gives me control over something in a situation where I don’t always have control,” says Laurie Reiser, diagnosed with MS in 2003. “No matter where you live, or who you are, you can garden.”

Reiser is a Colorado Master Gardener who teaches adaptive gardening in the western part of the state through the local extension office of Colorado State University. “Adaptive gardening is simply about creating your own space,” she emphasizes. “There are lots of reasons to adapt.

You can put a garden at your height—on a patio, balcony, railing, steps, cinder blocks, window ledge or tabletop you can roll up to.”

Reiser points out that people need little more than a patch of ground to get started—and that patch of ground can even be in a container. Nowadays, there are few limits to what can be grown in pots. “Breeders have come up with plants that are compact—and containers need less weeding,” Reiser points out.

A garden open to all

Enabling Gardens in Angleton, Texas, south of Houston, focuses on containers and raised beds, according to Cynthia Leonard, one of two dozen active volunteers. “We welcome groups and individuals, anyone who wants to learn how to do accessible gardening,” she says.

Participants learn how to use rain barrels and raised beds, and to garden most suitably for their climate. The garden has 18 planter boxes of different sizes, some of which “have a horizontal board across the top where people can sit and



Lettuce at Enabling Gardens

work on the



Laurie Reiser (left) and volunteers transfer plants to a raised bed.

It also features an A-frame trellis called a “cattle panel” that vines, squash and cucumbers grow on. “Someone in a wheelchair can roll under it and reach right up and pick fruits and vegetables,” says Leonard, who was diagnosed with MS in 1997.

Leonard’s been gardening for seven or eight years, starting with flowers in pots, then moving on to tomatoes. She and her husband “picked beets and mustard greens in January, and we had fresh tomatoes for Christmas dinner,” she says. “It sure is nice to be able to step outside and get good fresh vegetables. I know how they’ve been grown and what’s been put on the soil. Gardening gives me a sense of peace and well-being.”

Get prepared

Gardening is a “hot” activity in more ways than one. To beat the sun, do outdoor work early or late in the day. Set up a shady rest area with

a stool or folding chair on a deck, or under a tree, umbrella or arbor. Wear a hat, gloves and a cooling vest, or carry a spray bottle filled with cool water. (Call 1-800-344-4867 for information about cooling resources or visit www.msassociation.org/programs/cooling.) Set a timer to remind you when to take a break.

Ergonomic gardening tools, such as add-on handles for trowels or extendable hoes, can help make gardening tasks easier. Go to www.abledata.com and search for “garden tools” to get an idea of what’s available.

Reiser suggests enlisting a buddy, such as a friend or volunteer from a Scout troop or 4-H club, to help with tasks like hauling bags of potting soil. Local community gardens, botanical gardens or garden clubs may also offer communal space and resources. Search online for barrier-free, adaptive or accessible gardening or ask your public library if they have any books on the topic to get an idea of what’s possible. And then in a few months, enjoy the fruits—literally—of your labors!



THANKS FOR HANGING WITH US AT MUCKRUCKUS MS



Thank you for your participation in Muckruckus MS Ohio Valley 2012. Close to 800 participants and volunteers worked hard to raise much needed funds for the nearly 6,000 people in this area living with MS!

Please keep up the hard work. There's still time to become a VIP Muckety Muck! All donations are due by Tuesday, July 31st to be eligible for fundraising prizes.

See and share more photos at [MicroMoments.net!](http://MicroMoments.net)



BLOG OPENS DOORS FOR MS COMMUNITY



Society blogger Nicole Lemelle

Fatigue, isolation, doctor's visits—and yes, sex with MS—are just a few of the topics covered in the Society's new blog at blog.nationalMSSociety.org.

Not much is off-limits to Society bloggers and commenters. Instead, people with MS and MS specialists dig into very personal issues—and universal ones. "In these cyber pages, we intend to open up the doors which have long been closed (by society, by our families and—quite frankly— by many of us living with MS) to discussion," wrote blogger Trevis Gleason on January 4. "To that end, I'd like to take this opportunity to ask you—the readers of The Unspeakable Bits —what topics you think are under discussed if not just plain ignored by the MS 'authorities' out there?"

Join in the conversation at blog.nationalMSSociety.org.

Café con Leche

Invitamos a las personas hispanas/latinas con esclerosis múltiple a participar una vez al mes en un grupo telefónico gratis totalmente en español. Para más información o para inscribirse llame al 1-800-344-4867, opción 3. (Hispanic /Latino people with MS can participate by phone in a free monthly Spanish-language support group. For more information, call 1-800-344-4867 and press 3.)

MS ACTIVISTS HELP ADD MS TO COMPASSIONATE ALLOWANCES LIST

Thanks to hard work by Society activists, an aggressive form of MS now qualifies for the Compassionate Allowances Program, which expedites the review of Social Security Disability Insurance (SSDI) applications at the Social Security Administration. Thanks to passionate and articulate testimony by MS Activists Dr. John Booss and Yvonne Brown at a March 2011 Autoimmune Hearing held by the Social Security Administration, "malignant MS" was added to the Compassionate Allowances List, allowing people with more aggressive forms of the disease to qualify for SSDI more quickly.

SURVEY SAYS WALKING ISSUES IMPORTANT TO ADDRESS



Susan Cohn-Child, diagnosed in 1995, walks with son Zach

Seventy percent of people with MS who have difficulty walking see that as the most challenging aspect of managing their disease, according to a recent survey sponsored by the National MS Society and Acorda Therapeutics, maker of Ampyra, a drug intended to improve walking.

Respondents to the survey reported that problems with mobility restrict their daily activities and affect their emotional and financial well-being. Some 60% of adults with MS who experience difficulty walking have fallen; for a third of them, a fall resulted in an injury.

While 65% of those surveyed reported walking difficulties or trouble with balance, 40% “rarely or never” discussed the issues with their doctor.

“Clearly we need to encourage and empower people with MS to discuss walking impairment with their doctor, including newly diagnosed patients who may be experiencing only mild problems with walking or balance difficulties,” said Nicholas LaRocca, PhD, vice president for Health Care Delivery and Policy Research at the Society.

RESULTS IN FOR POTENTIAL MS THERAPIES

- In a two-year Phase III trial, the oral MS therapy **BG-12** significantly reduced—by up to 51%—the average number of annual MS relapses. More than 1,400 people with relapsing-remitting MS participated in the study. BG-12 is thought to inhibit the immune cells and molecules that are involved in MS attacks on the brain and spinal cord. This study should help to define further the safety and promise of BG-12 as a potential therapy for relapsing MS.
- The experimental intravenous MS therapy **alemtuzumab** significantly reduced relapse rates and the worsening of disability in a two-year Phase III study that compared alemtuzumab to Rebif. The study, called CARE-MS II, involved 840 people with relapsing-remitting MS. The FDA has fast-tracked alemtuzumab, which should speed up future review.
- A study of 324 patients comparing the MS oral therapy **teriflunomide** with Rebif found no significant difference in the numbers of participants in each group who experienced events defined as treatment failure. Teriflunomide is thought to prevent damage to the nervous system by immune cells. A previous phase III trial was more successful and three others are ongoing. The FDA is reviewing an application for marketing approval of teriflunomide.

To stay current on MS therapies in the pipeline for FDA approval, sign up for MS eNEWS at www.nationalMSSociety.org/signup.

DO IT YOURSELF FUNDRAISING GETS BOOST



DIY event, MS Cup Race, Minnesota Chapter

A family in Florida who says they like to “eat, drink and throw a good party” hosts a casino night on behalf of the National MS Society. A fellow in Minnesota sponsors an annual four-day event for four-wheeling enthusiasts to ride on trails in the middle of the woods. Other folks have hosted golf tournaments, sailing races, dinner parties, bake sales, hoops for hope basketball and even a strongman competition, a bike ride in high heels and a tabletop decorating contest. A Wall Street–based poker tournament raised over \$850,000, but a \$200 bake sale is equally appreciated.

Diverse as they are, these events are all Do It Yourself (DIY) Fundraising, where people committed to raising awareness and money for the MS movement are limited only by their imagination. DIY fundraising has been going on a long time, but what’s new is an online tool at www.doityourselfms.org, “which gives the same resources as we give to Bike MS and Walk

MS participants,” according to Rachael Nuwash, DIY project manager for the Society.

These resources include a comprehensive toolkit that covers everything someone who is organizing a DIY event needs to know: establishing a timeline, budgeting, how to make an event memorable, where to hold it, publicity, finding sponsors and volunteers, tips for the day of the event, FAQs and much, much more.

People can find out what lessons others have learned and how to create a committee—a core group that will support the effort and whose talents can be utilized. (For example, a friend who’s a graphic designer can design the invitation.) The toolkit also includes flyers, badges and email signature images to download. “The online tools are very intuitive,” said Nuwash, so organizers can easily and quickly reach out to friends, family members and co-workers.



DIY event, Kids for a Cure, New Jersey Metro Chapter

“The people who like to organize do-it-yourself events are going to do it no matter what,” Nuwash noted. “Their commitment, creativity and intense connection to the Society are like no other. In turn, we’re committed to supporting people who want to do something **now**.”



bike to create a world free of MS

bike MS: Venture the Valley 2012 Rider Registration August 25 & 26 2012

OFFICE USE ONLY

Date Received:

Date Entered:

PLEASE PRINT CLEARLY.

Mr. Mrs. Ms. Miss Dr. Please circle: **MALE** **FEMALE**

First Name _____ Last Name _____

Preferred Email Address _____

I would NOT like to receive email updates about Bike MS from the National MS Society.

Street Address _____

City _____ State _____ ZIP _____

Preferred Phone Number _____ DOB _____

Emergency Contact information: Name _____

Contact number day of event: _____

Are you riding with a team? YES NO

If yes, what is the name of your team? _____

REGISTRATION FEE SCHEDULE (* DOES NOT INCLUDE LODGING FEE)

Through April 13: \$30*

April 14-July 20: \$40*

July 21-August 20: \$50*

Pre-registration closes August 19 and reopens on August 24 at Camp Kern

August 24-August 26: \$60

\$32 Camp Kern Bed Camping Hotel Other Accommodations

TOTAL: _____

Registration Form Continued on Reverse Side



Would you like to receive important messages (weather, safety, fundraising, etc.) by text?
 If yes, please provide your mobile phone number _____

Please tell us your connection to multiple sclerosis?

- I have MS
- I have a Friend or Co-worker with MS
- Relative: Child of a person with MS
- Relative: Parent of a person with MS
- Relative: Sibling of a person with MS
- Relative: Spouse of a person with MS
- Relative: Other
- Other

Why do you participate in Bike MS?

- I have a connection to MS
- I wanted to experience and conquer the physical challenge of the ride
- I registered primarily for the experience and fun of it
- I am an avid cyclist and riding enthusiast

Which of the following route options will you choose for Bike MS 2012?

- 25 mile route
- 50 mile route
- 75 mile route

Which of the following days will you be participating in Bike MS 2012?

- Saturday
- Sunday
- Saturday & Sunday

What is your T-shirt size?

- Small
- Medium
- Large
- X Large
- XX Large

What is your jersey size?

- Small
- Medium
- Large
- X Large
- XX Large
- XXX Large

Not including this year, how many years have you participated in this event? _____

What is your fundraising goal? _____

All riders must raise a minimum of \$300 by the day of the event: August 25-26, 2012

Would you like to start your fundraising efforts with a self pledge? YES \$ _____

TOTAL AMOUNT PAID: \$ _____

- CASH
- CHECK # _____
- CREDIT CARD # _____

Card Type _____ **Authorization Code** _____ **Expiration Date** ____/____

Name on Credit Card _____

I understand that participating in Walk MS/Bike MS 2012 can potentially be a hazardous activity presenting risk. For consideration of participation in the event, I freely accept and voluntarily assume the risks of personal injury or property damage that may result. I, and anyone entitled to act on my behalf, waive and release from all claims and liabilities of any kind arising out of my participation, even though that liability may arise out of negligence or carelessness on my part. I agree to hold harmless the National MS Society, corporate sponsors, volunteers, cooperating organizations and all parties connected with this event from any liability as a result of my participation. I will permit emergency treatment in the event of injury or illness while participating and give permission to use my name and any photos and videos taken of me during the event in any promotional materials, publications or websites.

I understand that the National Multiple Sclerosis Society reserves the right to dismiss anyone that may cause disturbance or otherwise jeopardize the safety of him/herself, participants, volunteers or staff.

I CERTIFY THAT I HAVE READ THIS WAIVER AND RELEASE AND THAT I UNDERSTAND THE SIGNIFICANCE OF ITS INTENT.

Print Name: _____ **Signature:** _____

Parent/Guardian Signature (if under 18): _____ **Date:** _____





**National
Multiple Sclerosis
Society**
Ohio Valley
Chapter

4440 Lake Forest Drive, Suite 120
Cincinnati, OH 45242
513-769-4400
fightMStoday.org

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