



BIKE MS: VENTURE THE VALLEY 2011

Presented by Kroger Brand

August 27-28, 2011
Camp Kern, Oregonia, Ohio

Join the Movement. Three ways to Get Involved:

- 1** Form a TEAM.....Starting a team is a great way to participate in Bike MS with family, friends, coworkers or a community group. Register your team, set a challenging, yet attainable fundraising goal and join Bike MS: Venture the Valley 2011 for a fun, rewarding and inspirational ride!
- 2** Volunteer.....Volunteers are vital to the success of Bike MS. Whether you choose to help with rest stops, registration, set-up, clean-up or cheering at the finish line, you become an integral part of the movement. Ask friends, family, neighbors, faith or civic groups and others you know to support the movement by volunteering at Bike MS: Venture the Valley 2011.
- 3** Donate.....By making a donation, you help fund relentless research to find a cure for multiple sclerosis and help the chapter provide programs and services that empower the nearly 6,000 people living with MS in 24 Ohio Counties and the three Northern Kentucky Counties of Boone, Kenton and Campbell.

We look forward to your participation in Bike MS! For more details contact: Steven.Niemann@nmss.org or call 800.344.4867.

Publication of the National Multiple Sclerosis Society, Ohio Valley Chapter
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MS stops people from moving. We exist to make sure it doesn't.

SOCIETY'S CHIEF RESEARCH OFFICER NAMED

Dr. Timothy Coetzee is the Society's new chief research officer, effective January 1, 2011. Dr. Coetzee has researched MS his entire career. Most recently, he was instrumental in founding Fast Forward, the research subsidiary of the National MS Society that focuses on speeding new treatments to market, and served as its president from 2006 to 2010. He received his PhD in microbiology and immunology from Albany Medical College, N.Y., in 1993, and in 1995, received the Society's Advanced Postdoctoral Fellowship to support his research on the structure and function of myelin. He joined the Society's Research Department in 2000, where, among other accomplishments, he helped establish the Translational Research Partnerships in Nervous System Repair and Protection in MS, a five-year commitment to fund four large collaborative research teams focused on developing tools and strategies to promote nervous system repair and protection in MS.

MAY 25 IS WORLD MS DAY



More than two million people in the world live with MS. To raise awareness of the global scope of the disease, and to strengthen the worldwide network of people living with MS, the Multiple Sclerosis International Federation started World MS Day two years ago. More than 200 events in 60-plus countries will address this year's theme of employment and access to appropriate work. Take a survey about work or sign a petition urging leaders and employers to protect the rights of people with MS to work at worldMSday.org

CONNECT WITH AN MSFRIEND



No matter how wonderful friends and family can be, there are times when people want to talk to someone who understands exactly what they are going through—someone who has MS, too.

That's where **MSFriends** come in. Volunteers with MS connect with callers to share how they live with MS and to help with problem-solving or challenges people with MS face in relationships. They may also help with symptom management. People can call to speak to an MSFriend at **866-673-7436**, 7 a.m. until midnight, Eastern Time. Or they can leave a message and get a call back the next day.

The program got its start in 2005 under the umbrella of the VisionWorks Foundation, but is now being administered directly by the Society. "This allows us to expand the ways people living with MS can connect," said Kimberly Koch, MPA, Associate Vice President, Family and Support Programs for the Society. "It's nationwide, so people can get involved even if their chapter doesn't have a peer support program."

There are currently about 40 volunteers. Koch hopes to expand this to about 100. All have MS themselves, but in the future, other family members or care partners may be recruited. The main difference between the Society's MS Navigator® program and MSFriends

is that the Navigators' primary job is to get people referred and connected to resources, while the Friends' job is to listen and provide emotional support. If you'd like to be an MSFriend, call us about training.

MSFriends averages 9,000 calls a year, and they are completely confidential. "MSFriends allows people to connect when they feel like it, unlike self-help groups, which meet at a specific time," said Koch. "If your question comes up at an odd hour, there's a place to reach out for support."

NEW MS LEARN ONLINES

Recent and upcoming MS Learn Online videos include swallowing difficulties (now up), mood changes (now up), MS and the African American community (now up), searching for the cause of MS (two-part series, May 5 and 19), and more. New Learn Onlines in Spanish will debut March 3. View them any time, night or day, at

nationalMSsociety.org/mslearnonline, where you can also sign up to receive an e-mail when a new webcast debuts. Transcripts (.pdf format) and podcasts (.mp3 audio format) are available for most programs.

PREVENTION COUNTS

Although managing MS can feel like a fulltime job, it's important to pay attention to general health, too. People with MS face the same risks of cancer, heart disease and stroke as everyone else. For a list of screening and vaccinations recommended for your age group, download the **preventive care recommendations** brochure at **nationalMSsociety.org** or call us for a copy.

CREATE A FUNDRAISER TO REMEMBER



Did you know there are literally thousands of ways you can help? People who want to contribute to the mission to end MS are invited to dream up and produce original events that raise money for research and care.

Every year, all over the country, volunteers organize and host golf, billiards and bowling tournaments, auctions and raffles, dinners, concerts, rummage sales, wine tastings,



barbeques, motorcycle fun rides, skiing days and dances. Other events include a trap and skeet fun shoot, a bratwurst and

bake sale, a boat show and a car show. A sailing party in Minnesota and the 7th Annual Bell Family Rabbit Hunt in Wisconsin each raised thousands of dollars. Holiday themes are also popular, such as Easter egg hunts or Halloween parties with a pay-to-enter costume contest. The types of benefits to create are



Development.

These events may raise anything from a few hundred to tens of thousands of dollars. There's no minimum required and certainly no maximum, Ross said. And you don't even have to create a brand-new event, she added. You



can add a fundraising element to pretty much any existing occasion.

How much time it takes to prepare depends on how elaborate the plans are. They can be as simple as asking friends to pay a few dollars at the door to attend a private party. On the other hand, a large-scale gala might take four to six months, or even longer, to plan.

"We have a lot of cool Society events, but people have their own interests," said Ross. "Community events reflect how you want to be involved."

Have a great idea? Call us and ask for the Community Event Organizer Guidelines and the Community Event Information Form, or enter as a search term at **nationalMSSociety.org**.

THE CANE MUTINY

BY SISTER KAREN ZIELINSKI, OSF



Was I imagining eyes on me as I crossed the room? No. They were watching me. It seemed like hours to walk across the dining room to the cafeteria line the first time I used my cane. I was

embarrassed and self-conscious. I was not yet 40 years old; it was the 16th year of my MS diagnosis. My physical therapist suggested I use a cane to get around since my balance was off and my legs were weak. She told me a cane would give me more support and stability, and keep me from falling and breaking a bone. It would also signal others to be careful around me, to give me a little more space. It made good sense—but it made me feel like a nerd.

People had known for years that I had MS; now messages filtered back to me via friends that “Karen’s MS is really bad. She is walking with a cane now!” There are many invisible MS symptoms, but using a cane is a dead giveaway of weakness in my body and the progression of the disease.

In a world where physical appearance and independence are so highly valued, walking

with a cane through a public place was not easy. I was proud. The cane showed my physical weakness. I felt like I was the entertainment of the day.

After a few weeks, I just accepted it as part of the many losses of living with MS. If someone stared at me, I stared back at them and asked “What?!” I told them I used a cane for safety.

The irony was that as much I tried to fight the emotional stigma of using a cane, I came to appreciate how much better I walked with one. Eventually, I realized the cane was part of accepting reality—acknowledging that I had a chronic disease and needed a walking aid.

I swallowed my pride in two ways: I reminded myself that I could still walk, although in a limited way, and I remembered that nobody’s perfect.

Karen Zielinski is a Franciscan nun and director of the Canticle Studio for the Sisters of St. Francis of Sylvania, Ohio. She is a freelance writer and former Board chair of the Northwestern Ohio Chapter.

There’s more to this!

Go to **Walking (Gait), Balance & Coordination Problems** at nationalMSSociety.org/walking_gait_problems for an overview of resources and a list of articles, brochures and videos exploring what can be done for walking problems. Or call us for help!
1.800.344.4867.

RESEARCH NEXT STEPS



The turn of the year saw MS researchers assessing their progress in a number of areas. A think tank on progressive MS brought together MS investigators, research funding agencies and industry representatives. And, in January, Dr. Timothy Coetzee, chief research officer of the Society (see News), moderated a panel of MS researchers in a live webcast, “Repairing the Nervous System in MS: Progress and Next Steps.”

How does MS progress?

At the think tank, which was hosted by the Society and its commercial drug development entity Fast Forward last December in Boston, Society President and CEO Joyce Nelson pointed out that progressive MS is the centerpiece of the Society’s Strategic Response for the next five years, with a focus on:

- Researching what leads to disease progression,

- Finding ways to repair damage to the nervous system.
- Accelerating the development of new therapies.

Better identification faster

Finding ways to more quickly identify progressive MS based on biology rather than on symptoms would mean therapies could be tested earlier in the course of the disease and possibly protect the nervous system from injury.

Some evidence indicates that nerve degeneration occurs independently of inflammatory events, but there is other evidence that degeneration stops when inflammation subsides. Therefore, more research is needed to understand the cause of underlying nerve damage in progressive MS and to identify new targets for therapies. Participants also discussed the need for biomarkers—“footprints” that could help identify or predict MS progression. Think tank participants reported that steady progress is being made in finding noninvasive ways of detecting nervous system damage and whether protection or repair are taking place.

Additional issues

The participants discussed other important issues, as well. Many clinical trials do not run long enough to make clear whether there is an effect against slow progression. The traditional measurement of disability progression, the EDSS scale, is not sensitive to subtle change, which poses a problem in monitoring progressive MS.

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And, some previous trials used a mixed population of people with primary progressive MS and secondary progressive MS. Since it's not clear that all types of progressive MS would respond the same way, mixing participants may be one reason that some past trials were not successful. For a complete wrap-up of the meeting and a webcast featuring a panel of several participants, visit nationalMSSociety.org/thinktank.

Repairing the nervous System

On January 11, Dr. Coetzee, chief research officer of the National MS Society, was joined by Drs. Peter Calabresi, Ian D. Duncan, Charles ffrench-Constant and Gavin Giovannoni for the webcast, "Repairing the Nervous System in MS: Progress and Next Steps." The four researchers recently served as leaders of four international teams in the National MS Society's Nervous System Repair and Protection Initiative, funded through the Promise: 2010 campaign.

The investigators discussed research on the ways that nerve fibers, or axons, and their protective myelin coatings are damaged. Certain drugs the experts have studied seem to prevent nerve cells from dying in an animal model. Since some of these drugs are commercially available right now for other

diseases, they are good candidates for future clinical trials.

New drugs emerging

The researchers also talked about repairing the nervous system by stimulating the body's own repair cells to be more active or by trying several types of stem cells to repair myelin. Part of the conversation included how newer approved treatments may help in the battle to protect the nervous system in

people with MS.

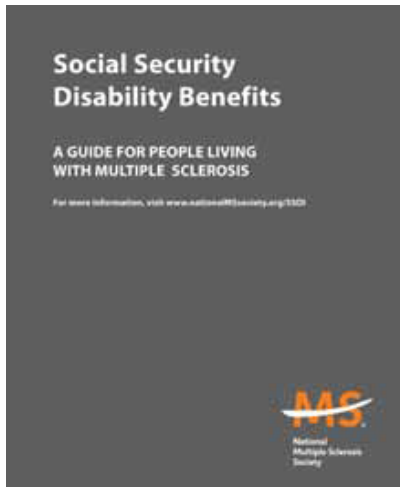
"For the first time we're really starting to see the emergence of very, very effective drugs for treating inflammation," Dr. Giovannoni said, noting that these therapies might also help to stave off nervous system damage and allow natural repair processes to work, although this has not yet been proven. "We've seen people who have highly active disease going on these drugs and improving," he said. For a full report or to read a transcript of the webcast, visit nationalMSSociety.org/webcasts.

Part of the conversation included how newer approved treatments may help in the battle to protect the nervous system in people with MS.

SIGN UP FOR OUR MONTHLY MS eNEWS

Get the latest news on research in your inbox. Go to nationalMSSociety.org/signup

HOW TO GET STARTED WITH SSDI



In order to qualify for SSDI (Social Security Disability Insurance) benefits, a person needs to have paid sufficient FICA

taxes, thereby earning "work credits," in addition to having a disability that makes holding a regular job impossible. Visit ssa.gov/pubs/10029.html for an overview of eligibility requirements and work credits, which are earned each quarter of a year an individual is employed.

The SSA (Social Security Administration) recognizes MS-related difficulty with motor skills, concentration, memory, fatigue, vision or side effects of medications as among the criteria for receiving benefits. The SSA will require the following:

- The names and contact information of doctors, caseworkers, hospitals and clinics involved, the dates of visits and copies of any medical records.
- The names and dosages of all prescription medicines.

- Laboratory and test results.
- Work records from your employer. Letters from colleagues or supervisors that support the claim.

Start the process

Ask your neurologist (and occupational therapist, if relevant) to evaluate your ability to continue working. "Make sure you have your doctor's help and encouragement from the beginning," said Kris Erickson, MSCIR, MSSMC, health insurance manager of the National MS Society. "Without that, your claim may be turned down and you'll have to appeal."

"We also recommend that you journal your symptoms," Erickson added. "A description of what is happening on a day-to-day basis can make a big difference, especially if you have invisible MS symptoms. Saying 'extremely tired,' for example, is less useful than saying 'MS fatigue, four 45-minute naps a day that interfere with bathing, eating, cleaning the house.'"

You can apply online at socialsecurity.gov/applyfordisability. Or call 800.772.1213 to schedule an in-person or phone appointment. Keep copies of all the information you give to or receive from the SSA, as well as the contact information for your SSA interviewer. Be patient, persistent and punctual. "And don't be afraid to ask for help," Erickson said. An MS Navigator® can provide you with materials to help with the initial application; call 1-800-344-4867. In the event of a rejection, the Navigator will connect you with the appropriate professionals to assist in organizing an appeal. For more information, visit nationalMSSociety.org/SSDI or socialsecurity.gov/disability.

Ohio Valley Chapter Life with MS Support Groups

Newly Diagnosed - 7 pm, 1st Tuesday of the month

Location varies

Contact Helen 513.226.3800

Northern KY - 1 pm, 1st Thursday of the month

Logan's Roadhouse, 6835 Houston Road, Florence, KY, 41042

Contact Debbie , 859.781.3366

College Hill - 10 am, 2nd Saturday of the month

College Hill Rec Center, 5545 Belmont Ave, Cincinnati, OH 45224

Contact Carolyn, 513.641.3156

Gallia - 6pm, 2nd Monday of the month

Holzer Medical Center, 100 Jackson Pike, Gallipolis, OH 45631

Contact Amber, 740.339.0291

Butler County - 7pm, 2nd Tuesday of the month

Berkley Square Town Hall, 100 Berkley Square, Hamilton, OH 45013

Contact Judy, 513.523.6786 / Jan 513.726.4789

Miami County - 7pm, 2nd Tuesday of the month

Robinson YMCA, 3060 S. County Road 25-A, Troy, OH 45373

Contact Sam, 937.676.5877

Fairborn - 6pm, 2nd Tuesday of the month

Fairborn Senior Center, 325 N. 3rd Street, Fairborn, OH 45324

Contact Deena, 937.559.8766

South Dayton - 6:30pm, 2nd Wednesday of the month

Charles Lathrem Senior Center, 2900 Glengarry Drive, Kettering, OH 45420

Contact Deneko, 937.270.1156

Springdale - 1pm, 3rd Thursday of the month

Springdale Community Center, 11999 Lawnview Ave., Cincinnati, OH 45246

Contact Angela. 513.236.6258

Care Partners - 7pm, 4th Wednesday of the month

Panera Community Room, 8420 Winton Road, Cincinnati, OH 45231

Contact Jody, 513.575.2660

Ross County - 3 pm, last Sunday of the month

Adena Regional West Entrance, 272 Hospital Road, Chillicothe, OH 45601

Contact Larry, 937.981.4622

Life with MS



RUN MS

Are you an enthusiastic athlete, or do you know a family member, or a colleague who is? You can help the Ohio Valley Chapter of the National MS Society by adding purpose to your passion.

Run MS is an opportunity for individuals who are avid or novice runners, walkers, cyclists and/or tri-athletes to utilize their passion for a healthy lifestyle to move toward a world free of MS. Funds raised from Run MS will be used to support the National MS Society's Ohio Valley Chapter which serves and supports over 6,000 people living with MS by running a 5K, 10K, trail race, mud run, ½ marathon or full marathon or a combination of races.

The National MS Society is a collective of passionate individuals who want to do something about MS now—to move together toward a world free of multiple sclerosis. MS stops people from moving. We exist to make sure it doesn't.

Did you know that a donation can provide the following:

- \$25.00 Provide transportation for two individuals to and from critical medical appointments.
- \$50.00 Pays for a couple living with MS to attend a Relationship Matters Program for family stability.
- \$100.00 Purchases a piece of equipment related to mobility, accessibility or safety.

- \$250.00 Purchases 10 Kroger gift cards for emergency perishable food or provides one month of comprehensive case management services for an individual with complex emotional, physical and/or economic needs.
- \$500.00 Prevents eviction, foreclosure or utility disconnections.
- \$1000.00 Provides funds for an approved, but not fully funded, research study or fellowship.

Join as an individual, join as a team or create a team and help support the fight against MS! Please go to fightmstoday.org and click on the Run MS logo to join today. For more information on Run MS contact Mary Wright at 513.956.4110 or mary.wright@nmss.org

VOLUNTEER OPPORTUNITIES

The Ohio Valley Chapter of the National MS Society depends on the commitment of volunteers as we work together to create a world free of MS. With the help of dedicated volunteers, we are able to address the challenges of each person whose life is affected by multiple sclerosis and help them stay connected to the great big moving world. Various opportunities are available for every individual and commitment level, so it's easy to become part of the movement. Sign up today to become a volunteer and be connected to the potential, the hope, the momentum of it all!

Among the volunteer opportunities available are fundraising events, advocacy, client programs, office assistance, self-help group leaders and internships. Call 1.800.344.4867 or email: ohginfo@nmss.org



Thank you to our 2011 Walk MS sponsors



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The Ohio Valley Chapter is now looking forward to exciting Walk MS 2012!

The Ohio Valley Chapter would like to congratulate the over 5,000 walkers and volunteers who joined us for an exceptional year of fundraising. Ten Walk MS events throughout the Ohio Valley region came together on April 16 and May 7 to raise funds and awareness for multiple sclerosis. Teams, big and small, joined together to share their connection and commitment to support the movement toward a world free of MS. Thanks to the dedication of the Ohio Valley Chapter's veteran teams and the leap of faith that so many new teams took with us this year. You could truly feel the energy and hope that was buzzing through the sea of orange at Walk MS.

Walk MS 2011



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Ohio Valley Chapter
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