



National
Multiple Sclerosis
Society
Central North Carolina Chapter
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**COMING SOON!!
WILD, FANTASTIC & AMAZING :
WALK MS 2013**

Keep an eye on
www.WalkMSncc.org!
Registration will open
this fall!



SAVE THE DATES!

March 23, 2013
WILD North Carolina Zoo Walk
NC Zoo, Asheboro, NC

April 13, 2013
FANTASTIC Rockingham County Walk
The Penn House, Reidsville, NC

April 20, 2013
AMAZING Piedmont Triad Walk
Fourth of July Park, Kernersville, NC

CENTRAL NORTH CAROLINA CHAPTER
MSCONNECTION

MOVING TOWARD A WORLD FREE OF MS | FALL 2012

Blast off to a World Free of MS! Annual Meeting and Awards Party

Thursday, November 1st

New format! New excitement! Dinner!



This year we will celebrate our successes and, importantly, learn what's happened over the past year to move us closer to our goals to STOP progression of MS, REPAIR damage caused by MS and CURE MS.

how she met Phil Keoghan of the Amazing Race television show; and how she now participates in bike rides throughout the country with Phil. As Regina says, "This is an incredible journey for me personally, but I hope to bring inspiration to others living with MS and to encourage them to be strong, keep moving and live to fill their aspirations!"

Nearly 20 years ago there was only one drug available to treat the underlying course of MS. Now the pace of new drugs that are available to treat MS and to help manage symptoms is accelerating. Today there are more options than ever before with many other potential therapies in the pipeline. Dr. Emily Pharr, Director, Wake Forest Baptist Health Multiple Sclerosis Clinic, will share with us "What's New in MS?"

Then it will be time to celebrate! Literally hundreds of cyclists, walkers, Dinner of Champion participants and Women on the Move luncheon participants will raise over \$1,500,000 to support research and local programs and services. Contributing to our success are also hundreds of volunteers who devote countless hours to make our events safe and fun. We'll take time to recognize people who are making a difference right here in our chapter.

Regina Lyalls has a unique story about her experiences while living with MS. Hear as she tells her personal journey with MS. Learn

Watch your mail for your invitation!

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If You or Someone You Know Has MS

Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis. Talk to your health care professional or contact the National MS Society at www.nationalmssociety.org or 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

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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.

We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

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Central North Carolina Chapter

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SAVE MONEY AND GO GREEN

If you would prefer to receive your chapter newsletter by email rather than regular mail, simply call the office or email bonnie.nevin@nmss.org.

CYCLISTS SHARE WHAT BIKE MS: TOUR TO TANGLEWOOD MEANS TO THEM

Last year, with nearly 1,700 cyclists and more than 500 volunteers raising over \$1 million, Bike MS: VF Corporation and Wrangler Tour to Tanglewood was a huge hit. This year on September 15-16, 2012 at Tanglewood Park in Clemmons, we're hoping for another successful campaign but we can't do it alone and hope you will make plans to join us. Proceeds from the event help to fund local programs and services as well as MS research.



For Clara Vann, the Tour to Tanglewood has become a second family. When Clara Vann first started cycling, she felt that four miles was a great accomplishment. When her chiropractor invited her to join his team, Spare Tires, last year, she was a little intimidated by the distance of the ride. After deciding to attempt it, she found out that Tour to Tanglewood benefitted the MS Society. Having a good friend with the disease gave her an even bigger incentive to ride. "By fundraising, riding and volunteering at MS events, it is the one thing I can do to help find a cure for the disease," Vann says. "I knew that Bike MS is where I was supposed to be and it was confirmed with the tremendous amount

of support I got from volunteers, staff, BRT's and several cycling groups." For Tina Kimball, team captain of Team BB&T, the Tour to Tanglewood is a fun way to get to know co-workers outside of the office for a great cause.



Kimball says, "I am looking forward to having our own Team BB&T tent set up at Tanglewood this year and meeting lots of people including my co-workers." The event is a great cause to bring co-workers together. The environment is very community based with everyone working towards a common goal: blasting off to a world free of MS. "Just seeing so many people coming together raising money and working on this event is truly amazing," Kimball says.

For Greg Kiser, the Tour to Tanglewood is a personal quest. In 2003, Greg's mother was diagnosed with multiple sclerosis. Within a two year period Kiser saw his mother accept early retirement as a special needs teacher, lose her ability to drive and take care of her dream house, and take on a life in assisted living. As a loving son, Greg stays well involved in his mother's everyday life and has to face the enduring effects of MS on their relationship.

Any doubts he had about participating in the

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NEW FINDINGS AT AAN MEETING

BY MARCELLA DURAND

In April, over 12,000 neurologists and researchers gathered in New Orleans to present the latest research in multiple sclerosis at the American Academy of Neurology's annual meeting. Here are some highlights.

STOPPING MS

A phase III trial of experimental oral therapy BG-12 found that the average annual relapses over two years in 1,430 people with relapsing-remitting MS was reduced by 44 to 51 percent over placebo. Disability progression was not reduced significantly. The most common adverse events reported were gastrointestinal events and reddening; a small study in 56 people taking BG-12 found that pretreatment with aspirin reduced the latter. However, whether long-term use of aspirin in combination with BG-12 is effective and well-tolerated has yet to be determined. Biogen Idec applied to the FDA in February 2012 for marketing approval of BG-12 to treat MS.

In a phase III trial that compared intravenous alemtuzumab against standard dosing of Rebif (interferon beta-1a), the relapse rate in 840 people with relapsing-remitting MS was reduced by 49 percent or the risk of disability progression reduced by 42 percent. Genzyme plans to file for FDA approval of alemtuzumab for MS in the second quarter of 2012.

Results of a phase III trial of Gilenya (fingolimod) indicated that a daily dose reduced the relapse rate by 48 percent compared with placebo in 778 people with relapsing-remitting MS. Gilenya is the first oral disease modifier for MS to be approved by the FDA.

First results from a clinical trial testing a combination of Copaxone and Avonex showed some evidence that they were better together than either therapy alone. However, the combination was not superior in reducing relapses or progression of the disease.



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LIVING WITH MS GIVING CARE

BY TERRI KUCZYNSKI, M.DIV., CT

All of us give care throughout our lives, whether it is through holding a hand or helping with daily needs from transportation to bathing. We give care when we listen to another's sadness and when we fix a meal. We give care when we send a card or manage medication.

Giving care to a loved one with MS can be very rewarding and at the same time unbelievably challenging. In some ways being a caregiver is like using a battery-powered drill. At first the drill is fully charged and the task at hand seems to be manageable. As the charge dies down, the task becomes more difficult until the drill just can't continue. The only way to go on is to recharge the drill. If the caregiver does not recharge over time, even the smallest task becomes overwhelming.

Rick, diagnosed in 1991



SOME WAYS TO RECHARGE ARE TO:

- 01 Ask for help. Even simple things such as getting a gallon of milk for you or providing respite care so you can take a walk around the block can make a big difference.
- 02 Join a support group or an Internet chat room set up for carepartners. (See 'Carepartners Connect' on page 7).
- 03 Take care of your body with proper nutrition, exercise and sleep.
- 04 Do something — call a friend, write a letter, read — that gives you a daily break from the caregiving role.
- 05 Stay connected with community — don't become isolated.
- 06 Laugh. Watch funny movies or TV programs.

IF A CAREGIVER DOES NOT RECHARGE OVER TIME, EVEN THE SMALLEST TASK BECOMES OVERWHELMING.

Just recently I visited a friend who was caring for her husband. We talked about the many difficulties of caregiving. She talked about her feelings of helplessness and shared that at times she felt a lot of anger, which in turn made her feel guilty. She went on to tell me that her husband's physical care could be overwhelming, but keeping track of all the day-to-day activities of life sometimes seemed crushing. She felt weary and alone in this role that she was so

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SELF-HELP GROUPS

Burlington
2nd Thursday of the month, 10 a.m.
Alamance Regional Medical Center
Annie 336-226-7712

Davie County
2nd Monday of the month, 6 p.m.
Davie County Hospital
Jackie 336-909-5877

Elkin / Tri-County
Sharing the Journey
1st Monday of the month, 10 a.m.
Unihealth Post-Acute Care
Deb 336-835-8419

Greensboro

Aquatics Exercise Group
M-W-F, 11 a.m.
Spears YMCA
Wyn 336-852-2182

Greensboro H.O.P.E.
Helping Other People Endure Multiple Sclerosis
4th Tuesday of the month, 11 a.m.
Montgomery's at 623
Robin: 336-697-2445
Birdie: 336-229-7916

Men's Group - Greensboro
Every Wednesday of the month, 8:30 a.m.
St. Francis Episcopal Church
St. Mike's House
John 336-545-0100

The Overcomers - Greensboro
3rd Tuesday of the month, 11:30 a.m.
Kathleen Clay Edwards Greensboro Library
Jackline 336-681-4025

Women Let's Talk - Greensboro
1st Wednesday of the month, 10:30 a.m.
St. Francis Episcopal Church
St. Mike's House
Call chapter at 336-299-4136 for information.

Get Out! A social group for people in their 20s and 30s with MS
Email nmssgetoutgroup@gmail.com to get on the list to receive notifications.

High Point/Jamestown
But You Look So Good
2nd Saturday of the month, 11 a.m.
Poblanos Mexican Restaurant
Lisa 336-454-6785

Kernersville - NEW
Newly Diagnosed and Minimally Affected
4th Wednesday of the month, 6 p.m.
Main Street United Methodist Church
Sherri 336-992-2134
Matt 336-750-0732

King
MS P.A.L.S.
2nd Tuesday of the month, 6:30 p.m.
First Baptist Church
Martha 336-983-0170

Winston-Salem
You, Me and the Lord, too!
2nd and 4th Tuesday, 10 a.m.
Cornerstone Baptist Church
Dolores 336-784-8460

Wilkesboro
2nd Thursday of the month, 6 p.m.
Woodhaven Restaurant
Wanda 336-667-1889
Kent 336-903-1539

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unprepared for. After we talked, I walked out of the room and, when I turned to say goodbye, I saw her struggling to help her husband transfer from the sofa to a wheelchair. I then witnessed the true meaning of giving care. In the middle of the transfer, I saw them share a loving embrace. It was very brief, but very intentional. At that moment I could not tell who was caring for whom. I saw two people caring for each other. What a great way for both to re-

charge.



Terri Kuczynski, M.Div., CT, is a patient/family counselor at the Rex Cancer Center in Raleigh, N.C.

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CAREPARTNERS CONNECT

There is a wealth of ways for carepartners to connect online. Here are a few of them.

Those caring for someone with MS can create their own website or visit another's at www.CaringBridge.org. Here, carepartners can keep an online journal and photo gallery, ask for help with tasks, and post updates for friends and family who in turn can post messages of support.

Today's Caregiver at www.caregiver.com includes a map, clickable by state, of area support groups, and a special section where caregivers can post their tips for others. It also offers articles and information on everything from nutrition tips to long-distance care.

The Well Spouse Association at www.wellspouse.org is a nonprofit membership organization that offers peer-to-peer support and educates healthcare professionals and the general public about the unique challenges that "well" spouses face every day.

The National Family Caregivers Association at www.thefamilycaregiver.org provides an online forum for caregivers to post questions or talk to others in similar situations.

The Society's online community at www.MSconnection.org offers a secure place for carepartners to connect. Members can create a personal profile to share posts, updates, blogs, photos, videos and links, and search for other members by demographics, shared interests and more. The Society also offers a page for carepartners at www.nationalMSsociety.org/carepartners with information and resources on accessible housing, hiring home help and more. Carepartners can also participate in the Society's Online Peer Connections program, www.nationalMSsociety.org/onlinepeerconnections. Here they select a peer support volunteer from an online database and arrange to speak one-or-one via email or telephone on an agreed-upon topic. All conversations are confidential.

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 \$1,500 to support a cause close to your heart. It is joining a family of people that 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 lives of 400,000 living with multiple sclerosis.

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.

Why did you participate in the Challenge Walk?

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

Tell me a little bit about your experience there.

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.

What was the most memorable part of the experience?

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

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

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 fundraising effort will be.

Join Dennis and accept the challenge March 1 -3, 2013. 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.



Dennis Dirksen and Tiffany Smith

In a separate study, researchers were able to identify gene signals in people who had participated in a clinical trial of Copaxone that could predict a high response from the therapy. This may point the way for future research on optimizing MS treatment choices.

A study of a green tea extract called Polyphenon E given to 10 people with relapsing-remitting or secondary progressive MS found a 13 percent increase in average levels of a molecule that reflects nerve tissue integrity. The researchers are now conducting a phase II study to determine safety and neuroprotective effects in 48 people.

RESTORING WHAT'S LOST

Researchers have found that blocking LINGO-1, a nervous system molecule, increases myelin repair in mice. The first human trial evaluated the safety of the approach in 42 people with relapsing or secondary-progressive MS. Researchers reported no serious adverse events and support moving this repair strategy to a phase II clinical trial.

After a prominent food and wine critic with MS developed a decrease in taste, researchers at the Mount Sinai School of Medicine looked further into this lesser-known symptom of MS, called dysgeusia. In seven case reports of people with MS with dysgeusia, MRI revealed lesions in a small area of the brain stem. In some cases, loss of

taste had been the first MS symptom, meaning it may be an important signal.

ENDING MS FOREVER

In a study of 500 people with MS, researchers found that men with low vitamin D may be more susceptible to disability, while women with low levels of the vitamin had more brain lesions if they had a genetic marker common to people with MS. The study points to possible gene and gender influences in vitamin D levels and the risk of developing MS.

For more AAN news, visit www.nationalMSSociety.org/research.

Marcella Durand is on the staff of Momentum, the Society's national magazine.

NEW STUDY ON MARIJUANA

A clinical trial of 37 people with MS with spasticity resistant to standard medications found that the half who smoked marijuana once a day experienced significant improvement compared to placebo. However, the researchers also found that participants showed significantly reduced thinking ability after smoking marijuana. The Society is currently supporting a clinical trial of different forms of cannabis products to test their ability to relieve MS-related spasticity.



MAKE YOUR VOTE COUNT

BY RENEE VANDLIK

Election Day 2012 is on the horizon, so get ready to cast your vote for who best represents the issues you care about. Here's what you need to know to vote in the elections on November 6.

THE BIG PICTURE

This fall, Americans will cast votes for the presidency, every member of the U.S. House of Representatives and one-third of the U.S. Senate. What's different? Since the 2010 census, 15 million Americans became eligible to vote and an anticipated 50 million more will vote this November due to stronger engagement in national campaigns. However, people with disabilities register to vote at a 16 percent lower rate than other Americans. And with 1 in 10 eligible voters having a disability, that's a lot of people whose voices aren't being heard. Make sure yours is. National Voter Reg-

istration Day is September 25, 2012. Register yourself and learn how you can register others at www.usa.gov/Citizen/Topics/Voting/Register.shtml.

PREPARE TO VOTE

This year, citizens in 30 states will have to comply with voter identification laws. Contact your local polling precinct ahead of time to find out what you'll need.

Also ask about accessibility: you don't want to show up, only to find out you can't get in the door. Since 2005, The Help America Vote Act requires every precinct in the country to have at least one voting machine or system accessible to persons with disabilities, including those with vision impairments. Learn more at www.aapd.com/what-we-do/voting/.

If it's difficult to vote in-person, plan to vote absentee. Learn more at www.longdistancevoter.org.

THE INFORMED VOTER

Go to www.nationalMSsociety.org/advocacy to learn more about issues important to people with MS, such as health care, accessibility and medical research. Then find out where the candidates stand on those issues—www.yourcandidatesyourhealth.org is one place to start.

Renee Vandlik is the Society's director of State Government and Local Government Relations.

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Tour quickly vanished as his mother suggested he embrace the challenge and Kiser couldn't find any reason to say no. Now entering his second year with the event, Kiser has set a high philanthropic and physical bar for himself—he plans to raise over \$1000 and is training to ride 165 miles in total. He knows the distance will be a strenuous challenge, but knowing the pain his mom struggles through everyday due to MS, he is ready to bike through the pain for her.

Join Clara, Tina, Greg and more this September 15-16 in the Bike MS: Tour to Tanglewood. For those of you contemplating over whether to participating in the Bike MS: Tour to Tanglewood event or not, Kiser has some advice: "Do it! Just get on your bike, raise a little money and ride. I've seen all different speed groups represented, and really anyone can ride in this event. It is a great motivator to get in shape and drop a few pounds while really making a difference for those with MS, and those that might have it in the future." So come join us this year as cyclist, volunteer or sponsor!

For more information please visit www.bikeMSncc.org or call 336-299-4136.



Greensboro MS Dinner of Champions

Honoring Wes Miller

Head Basketball Coach, UNCG

Thursday, September 6, 2012

Greensboro Country Club

Honorary Chair: Freddy Johnson

Co-Chairs: Mike Godwin, George Hoyle & Kurt Kronenfeld



Winston-Salem MS Dinner of Champions

Honoring Murray Greason

Wednesday, September 26, 2012

Bridger Field House at BB&T Field

Honorary Chairs: Dr. Nathan and Julie Hatch

