



**National
Multiple Sclerosis
Society**
Central North Carolina Chapter
2211 West Meadowview Road
Suite 30
Greensboro NC 27407

NON-PROFIT
ORGANIZATION
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410

Save the Dates

Walk MS: Modern Automotive 2010!

NC Zoo Walk: Asheboro

March 27th

Rockingham County Walk: Reidsville

April 10th

Triad Walk: Kernersville

April 24th

600 Walks. One Destination. A World Free of MS.

Registration opens October 1st

www.walkmsncc.org or call 336-299-4136

CENTRAL NORTH CAROLINA CHAPTER MS CONNECTION

MOVING TOWARD A WORLD FREE OF MS | OCTOBER- DECEMBER 2009

Another Successful Bike MS: BB&T Tour to Tanglewood!

The 24th annual Bike MS: BB&T Tour to Tanglewood was held on September 26th & 27th. Over 2000 cyclists and volunteers participated to make it another successful year for the chapter's premier fundraising event.

While, the 90-mile two-day adventure is not an easy task, it was easy for hundreds of participants, volunteers and spectators to celebrate at the new finish line. The new finish line, valued at \$65,000, was made possible by the collaboration of Vulcan Materials Company, Larco Construction, Thompson-Arthur Paving and Construction and other community partners. The ride was a success because of the more than 90 team captains and 1200 team members. In addition, the over 250 VIBE (Very Important Biking Entrepreneurs) continue to play a vital role in our fundraising efforts, raising on average \$2000 each.

Continued on next page

Annual Meeting: Quest for a Cure

The leaves are changing color, the air is cooler and the Central NC Chapter Annual Meeting is right around the corner. We hope you will join us for Annual Meeting: Quest for a Cure on Friday, October 23, 2009. For those of you who have attended Annual Meeting in the past, this year will be a different format as the chapter is continuing to watch our expenses where possible while still offering the highest quality of programs.

Check-in/exhibits will run from 6:00pm – 7:00pm. The program portion will begin at 7:00pm. This year our featured speaker is Dr. Patricia O'Looney, Vice President of Biomedical Research at the National Multiple Sclerosis Society in New York, NY. She spoke at the chapter's "Research Evening" in 2005 and we are so excited to have her back. She will be discussing emerging MS therapies and the "quest for the cure." She has recently been featured in Web MS, Health-Day News and Plus Model Magazine.

Light refreshments will be served. The cost is \$5 per person. Fee waivers are available. Call 1-800-FIGHT-MS or visit our website at www.nationalmssociety.org/ncc to register.

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**National
Multiple Sclerosis
Society**

Publication of the National Multiple Sclerosis Society Central North Carolina Chapter

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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.

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

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 National Multiple Sclerosis Society is dedicated to ending the devastating effects of MS.

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Central North Carolina Chapter

Thank you again to everyone who donated their time and energy making this event one of the best and well run bike rides in the south-east.

FOLLOW US ONLINE!



Become a fan of the chapter at
www.facebook.com/nmssncc



Follow us on Twitter at <http://twitter.com/nmssncc>



Check out chapter videos at www.youtube.com/NationalMSSocietyNCC

HOW TO CONTACT US

National Multiple Sclerosis Society
Central North Carolina Chapter
2211 West Meadowview Road, Suite 30
Greensboro, NC 27407
336-299-4136
1-800-FIGHT-MS

National Multiple Sclerosis Society
www.nationalmssociety.org
Email: nat@nmss.org

Central North Carolina Chapter
www.nationalmssociety.org/ncc
Email: ncc@nmss.org

Chapter Podcast and Blog
www.cncmschapternews.com

Detecting Nervous System Protection & Repair

Imagine this: a new therapy works to protect brain cells from the damage caused by MS and possibly even repairs them. But there's no way to tell when it is actually working.

Nearly 60 scientists discussed the problem at a workshop held last summer in Amsterdam by the National MS Society's International Advisory Committee on Clinical Trials. Findings were published in *Nature Reviews Neurology* 5, 256-266, and is available free at nature.com/nrneurol/journal/v5/n5/pdf/nrneurol.2009.41.pdf.

The scientists assessed emerging and current imaging technologies, rating qualities such as how well results corresponded to clinical symptoms. Three technologies stood out:

- Optical coherence tomography (OCT) uses infrared light to measure the thickness of the nerve fiber layer of the retina at the back of the eye.

- Magnetic transfer ratio (MTR) measures how much energy is transferred or absorbed by protons in the brain.

- Whole brain volume measurement, which is done with a series of MRIs, has excellent sensitivity to disease changes, researchers noted, but does not distinguish well between types of tissue damage.

The researchers concluded that a combination of these technologies appears to be best to determine if a new therapy is working to protect brain cells. But they also agreed that it is much harder to detect whether a therapy is working to repair brain cells. You may hear about fMRI, an imaging technology that measures the amount of oxygen used by different areas of the brain, as a way to detect repair as scientists conduct more studies.



Breastfeeding & MS

Breastfeeding may benefit women with MS, a recent study suggests. In the study, only 36% of women with MS who breastfed exclusively for at least two months after birth experienced an exacerbation, as compared to 87% who did not breastfeed or who supplemented with formula.

While the study was small, the results question the benefit of forgoing breastfeeding in order to resume MS treatment after birth. The study was published online in the *Archives of Neurology* in June 2009.

Not breastfeeding reactivates the ovaries, said lead researcher Dr. Annette Langer-Gould, a process that may be the reason MS exacerbations typically increase after birth.

The researchers will be conducting a larger study to confirm the findings and possibly identify the immunosuppressive factor in breastfeeding.

Listen to a Teleconference This Month!

Teleconferences are a great way for you to learn about different topics relating to multiple sclerosis without ever having to leave your house! Make plans to listen to at least one teleconference in the upcoming months to see how easy it is and how much information you can get! All teleconferences have question-and-answer sessions so come prepared with your questions!



Tuesday, October 13, 2009

MS Care

Learn how to be the decision maker in your life regarding your MS. A board certified adult nurse practitioner and board certified multiple sclerosis nurse will discuss how to improve your health and well-being so that you can live the most optimal and rewarding life while living with your MS.

Tuesday, November 10, 2009

Accessible Travel

The President/CEO of Accessible Journeys will talk about vacation and travel planning for people with disabilities.

Tuesday, December 8, 2009

Accessible Design

An occupational therapist will discuss possibilities and resources available for modifying your home to better fit your needs.

Call 1-800-FIGHT-MS to register or visit our website!



**2nd Annual Holiday Party
Watch your mailbox for an
invitation!**

When a Medication is Off Label

Almost every medication used to treat a symptom of MS is prescribed off label. This means that the U.S. Food & Drug Administration ruled the drug safe and effective for another medical condition, but did not specifically approve it for use with MS. For instance, beta blockers are approved for treatment of high blood pressure and migraines, but they also help to reduce some tremors. Doctors often use these medicines "off label" to treat tremors in MS. Generic forms are available, so they are often covered by insurance companies.

In the case of medications that do not have generic forms (such as Provigil for fatigue), insurance providers may not cover their use. "It comes down to how expensive a medication is," said Dr. George Garmany of Associated Neurologists of Boulder, Colo. "It's usually not an issue when there is a generic equivalent for a drug."

The expense factor

But why are so many medications that are effective for MS symptoms not approved for that use?

"It costs a lot of money for drug

companies to do the studies," Dr. Garmany explained. "Once the drug is approved for its primary use, the company may not wish to cover the additional expense of trials to show that it is effective in MS."

The right diagnosis

Some symptoms of MS, such as depression, may allow for on-label use. "Depression is depression," Dr. Garmany said. "The fact that someone has MS only modifies the way the depression is expressed. And if a patient has a legitimate diagnosis that would allow for on-label use, the doctor is best off using that."

Covering your costs

1 Ask your healthcare provider if there is a generic equivalent.



2 If there isn't one, or your healthcare provider feels the off-label drug is best for you, file an appeal if insurance won't cover it. "Every insurance plan must provide for an appeal of any 'adverse determination' made by the plan, including at least two levels of appeal," said Kim Calder, director of Insurance Initiatives for the Society. The Society can help. Visit nationalMSSociety.org/insuranceappeals.

We also have a toolkit of appeal letters for doctors that relate to commonly prescribed off-label treatments for MS. Visit nationalMSSociety.org/appealtoolkit.

SELF-HELP GROUPS

New Self-help Group Announcement A Family Affair: Living Beyond MS

Monday, October 5th, 6:00 PM
Evangelical Methodist Church
411 Bethel St Gibsonville, NC
Family members are welcome!
For more information call Paula at
336-375-0713

Burlington

2nd Thursday of the month, 10:00 AM
Alamance Regional Medical Center
Harriet 336-538-1143
Carolyn 336-584-6888

Davie County

2nd Monday of the month, 6:00 PM
Davie County Hospital
Carolyn 336-998-6398
Kathy 336-940-5256

Elkin / Tri-County

4th Monday of the month, 11:00 AM
Hugh Chatham Memorial Hospital, Elkin
The Synergy room
Deb 336-835-8419

Greensboro

Aquatics Exercise Group
M-W-F, 11:00 AM
Spears YMCA
Denise 336-643-3648

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

The Enforcers - Greensboro
3rd Tuesday of the month, 11:30 AM
Calvary Christian Center
Jackline 336-681-4025

Women Let's Talk - Greensboro
1st Wednesday of the month, 10:30 AM
St. Francis Episcopal Church
St. Mike's House

Sharon 336-254-3531
Susan 336-697-9150

High Point/Jamestown

But You Look So Good
2nd Saturday of the month, 11:00 AM
Poblanos Mexican Restaurant
Lisa 336-454-6785

King

MS P.A.L.S.
2nd Tuesday of the month, 6:30 PM
First Baptist Church
Candy 336-985-5636

Rockingham County

Reidsville

Friends with a Purpose
4th Tuesday of the month, 6:00 PM
Annie Penn Hospital
Ana 336-616-1001

Let's Talk MS

Call for information
Debbie 336-623-5098
Jan 336-589-1489

Winston-Salem

Leaps and Bounds
2nd and 4th Monday, 10:00 AM
Ardmore Baptist Church
Theresa 336-924-2707

You, Me and the Lord, too!
Every Tuesday of the month, 10:00 AM
Cornerstone Baptist Church
Dolores 336-784-8460

Wilkesboro

2nd Thursday of the month, 6:00 PM
Woodhaven Restaurant
Wanda 336-667-1889
Kent 336-903-1539

Get out! Social Group for People with MS in their 20s and 30s - Let's go bowling!

Where: AMF All Star Lanes
910 South Holden
Road, Greensboro

When: Thursday,
October 8
6:30pm - 8:30pm



What: Time for meeting, eating and
greeting! **\$5 per person** which in-
cludes bowling, shoe rental, and pizza.

Call 1-800-FIGHT-MS to register or visit
our chapter's website calendar. **Hope to
see you there!**

**Mark your calendar for December
10th for the next Get Out!**

The Affordable Access to Prescription Medications Act (S.1630)

Senator John Rockefeller (WV) has introduced the Affordable Access to Prescription Medications Act (S. 1630). This act will:

-Establish a cap on prescription drug costs. The bill establishes a \$200 cap on the amount a person could be charged for any one prescription, and a \$500 cap on the total amount an individual could be charged for all prescriptions in any given month. These caps apply to all public and private insurance coverage, including Medicare prescription drug plans.

-Create an exceptions process for specialty drugs. The most expensive prescription drugs in the Medicare prescription drug program that are on specialty tiers are not subject to beneficiary exemption requests. For all other Medicare-covered prescription drugs, a beneficiary can request an exemption to allow them access to needed drugs. High-cost, specialty drugs can be difficult to access, and this bill will allow any beneficiary to request any necessary prescription drug through the exemption process.

-Require MedPAC studies on discrimination and cost-sharing. The first study will review Medicare prescription drug policies (under Medicare Parts B, C, and D) to make sure they do not violate non-discrimination rules. The second study will examine the impact of prescription drug cost-sharing on beneficiaries and their health.

Get Involved

Join the movement at nationalMSsociety.org/advocacy

PROGRAMS

Equipment Loan Closet Wish List: Manual Wheelchairs

Our chapter offers a short-term and a long-term equipment loan program. These items are available to clients who do not have the resources to obtain much-needed equipment. Right now, we are in need of more manual wheelchairs for our closet. If you have a manual wheelchair in good condition, please consider making a donation to our equipment loan closet. Contact Jessica Thomas, Program and Services Manager at 336-299-4136 or jessica.thomas@ncc.nmss.org to get more information.

ADVOCACY

The 2009 National MS Society Greensboro Dinner of Champions

The 2009 National MS Society Greensboro Dinner of Champions honoring Coach Butch Davis, head football coach of the University of North Carolina, was held on Thursday, June 4th at the Koury Convention Center in Greensboro. Co-chairs were Gray McCaskill, Dwight Stone, and Tommy Watkins. Mike Hogewood served as master of ceremonies. The event raised approximately \$90,000 for the Central NC Chapter through participant patronage, sponsorships and the silent auction.

Thank you to the more than 530 individuals who attended the dinner, the members of the dinner committee and others who made contributions to make this event such a success. We would also like to say a special thank you to Coach Butch Davis for serving as our dinner honoree and for making keynote remarks. In addition, we would like to thank our Benefactor Sponsors, International Textile Group and Lincoln Financial Group.

The 2010 Greensboro dinner will be held in late spring or early summer. More information will be posted in future MS Connection issues and on our website at www.nationalmssociety.org/ncc.



Coach Butch Davis

NEWLY DIAGNOSED

For People New to MS

Possible MS? Diagnosis can be tricky. It is reasonable to seek a second opinion when the diagnosis is uncertain. Call us for referrals to experienced neurologists in this area.

Last year, the Society convened an international task force to create guidelines that can help neurologists distinguish MS from its look-alikes. The paper, published in *Multiple Sclerosis* (2008 Nov;14[9]: 1157–74), is free to practitioners, who may download it at msj.sagepub.com/cgi/content/abstract/14/9/1157.

- A diagnosis of MS is a personal and family crisis in anyone's terms. Now, finding good professional support for emotional health has just become a bit easier. The Society is partnering with HelpPRO, a referral service for people seeking a qualified professional provider. Visit helppro.com for information about who practices in our area.
- "Tome control de su Esclerosis Múltiple." Designed for the Hispanic family living with MS, the information kit provides resources on how to maintain quality of life, navigate the healthcare system, and more. Please explore nationalMSSociety.org/tomecontrol.



Nutrition SOS

by Denise Nowack, RD

It's summertime when storms, fires or power shortages might strike. Experts recommend being prepared with a 3-day supply of food and water.

What does a 3-day supply look like?

Let the Food Pyramid be your guide.

- Bread, cereals, grains: Pretzels, ready-to-eat cereals, granola bars, rice or popcorn cakes, boxed couscous, noodles in a cup or packaged ramen.
- Fruits: Canned fruit, fruit roll-ups, applesauce, dried fruits, bottled fruit juices, powdered juice drinks.
- Vegetables: Canned vegetables and soups, bottled vegetable juice,

instant potatoes.

- Meat, poultry, fish, dry beans, nuts: Canned meats, tuna lunch packets, canned lentil/bean soups, chili or stews, sardines, canned beans, dried jerky, peanut butter, canned nuts.
- Milk, cheese, dairy: Powdered or canned evaporated milk, boxed soy milk, process cheese, snack cup puddings.

Choosing the right foods

- 1 Look for foods you like to eat! Familiar foods will provide a sense of comfort in stressful times.
- 2 Look for foods that are "shelf stable." These include cans, dried mixes and items that require no refrigeration. Seal cookies and crackers in a plastic bag or container.
- 3 Should you lose power, you'll need items that are ready to eat. Canned foods don't really require cooking even if they'd taste better hot. Consider small cans that provide just the amount you might consume at one time.

If the power goes out

A charcoal or propane grill or camp stove can be used for emergency cooking

but be sure to use these outdoors. Candle warmers, chafing dishes, and fondue pots can also heat foods. If you do not have an alternative way to heat water, don't include instant foods in your supplies.

Storage tips

Pack your foods in a container that can be carried easily out of your home in an emergency. Store in a cool, dry place and date with a marker. Rotate with a fresh supply every 6–12 months.

Remember water

Store at least one gallon per person per day for drinking, food prep and hygiene. Date and rotate water supplies every 6 months.

And essential supplies

Manual can /bottle opener, resealable plastic bags, paper plates, disposable eating utensils, trash bags, and matches in a waterproof container.

Don't forget pets!

They need 3 days of food and water too.

Denise Nowack is a registered dietician and executive vice president of Chapter Programs at the Southern California Chapter.

National MS Society Scholarship Program

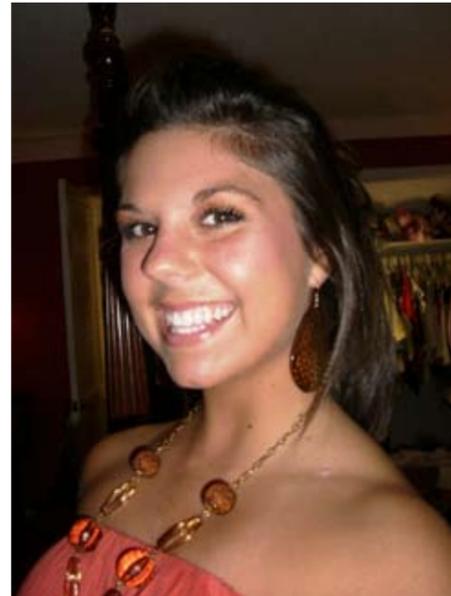
MS shouldn't stand in the way of an education. This is why the National MS Society's scholarship program exists — to help highly qualified students who have been diagnosed with MS or who have a parent with MS achieve their dreams of going to college.

Many families struggle to cope with the financial impact of MS. To assist people affected by MS, and their children, who are pursuing a post-secondary education, we provide scholarships to accredited educational programs. To be eligible, high school (or GED) graduates must be attending an accredited post secondary school for the first time (first semester). Applications are evaluated on financial need, academic record, leadership and volunteer activities, a statement of educational and career goals, and letters of recommendation. Applicants are also asked to provide a personal statement describing the impact MS has had on their life. Scholarships range from \$1,000 to \$3,000 and are for one year – non-renewable.

Scholarship applications for 2010 will be available on the National MS Society website beginning October 1, 2009. Visit www.nationalmssociety.org/scholarship or call (336) 299-4136.

The Central NC scholarship program is generously funded by Dr. and Mrs. Michael Morykwas. Over the last four years their extraordinary gift has allowed the chapter to award 19 scholarships.

Congratulations to each of the scholars! We are proud to recognize the determination and success of these special students. Meet the 2009 scholars:



Sarah Whalley Top Scholar



Austin Higgins



Amaura Moorman



Sarah Alice Murphrey



Alexander Swim

Not Insured?

The Society has posted helpful information on its website called Resources for the Uninsured and Underinsured.

Learn what to do if there's an emergency, how to get prescription drug help and explore links to the hundreds of federally funded family healthcare centers across the country that provide care even if you have no health insurance. Family healthcare centers vary significantly, but can provide services such as check-ups, immunizations, dental care, mental health services and substance abuse care. Many free family healthcare centers are also good resources for how to apply for federally sponsored programs, like Medicaid.

Click on nationalMSSociety.org/researchinsurance. And call for help from an MS Navigator at 1-800-344-4867.



Stimulus Funds Help Laid-off Employees Pay for COBRA

Anyone who loses group health insurance in a lay-off can elect to extend their coverage for up to 18 months and sometimes longer through COBRA (the Consolidated Omnibus Budget Reconciliation Act). The problem is COBRA participants typically pay 102% of the premium, making it hard to afford on unemployment insurance. Now, people who lose their health insurance when they lose their jobs may be eligible for a COBRA subsidy.

The American Recovery and Reinvestment Act—better known as the “stimulus package”—offers some relief. Eligible workers laid off between September 1, 2008 and December 31, 2009 may continue their coverage paying only 35% of the premium for up to nine months.

“Contact your former employer right away to determine whether you can opt in,” said Kim Calder, director of Insurance Initiatives for the Society. “COBRA not only provides the same coverage you had while you were working, it can help you get new insurance later on. This can be critical if you have a pre-existing condition like MS.”

Any Catches?

Former employees are ineligible for COBRA if

- The employer went out of business
- The employer terminated group coverage for all workers
- The employee was terminated for misconduct
- The employee left work voluntarily

But employees are eligible if the former employer only closed a branch or division and is still in business elsewhere. This is so even if the company offered the individual a new job in another part of the country that was not accepted.

For more information go to www.dol.gov/cobra or call 1-800-FIGHT-MS.