

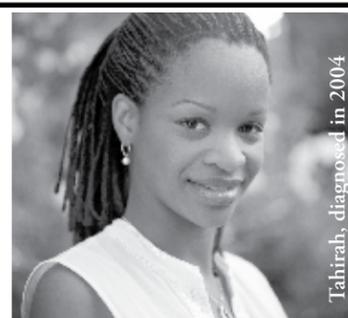


**National
Multiple Sclerosis
Society**
Central North Carolina Chapter
2211 West Meadowview Road
Suite 30
Greensboro NC 27407

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
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410

Self-Help Groups Provide Positive Support

Our self-help groups are more than monthly get-togethers involving sitting in a circle. The positive environment of a self-help group will help you learn new information and strategies for living with MS while finding support through a sharing of common life experiences. Whether you have multiple sclerosis or are a family member of someone with MS look for a group in your area (see page 6) and call the leader for more information about their next meeting.



Tahirah, diagnosed in 2004

KNOWLEDGE is **POWER**

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

CENTRAL NORTH CAROLINA CHAPTER MS CONNECTION

MOVING TOWARD A WORLD FREE OF MS | FALL 2010

Join Us for an Especially "Super" Year Celebrating the 25th Annual Tour to Tanglewood

The 25th Annual Bike MS VF Corporation and Wrangler Tour to Tanglewood is presented by Wachovia, a Wells Fargo Company and will take place September 25-26, 2010 at Tanglewood Park in Clemmons. Since the event's inception twenty-five years ago, it has grown from 32 participants raising about \$7,000 to about 1600 cyclists raising a million dollars. Our goal for this year is to have 2,000 cyclists and volunteers raising over one million dollars and we need your help. We are seeking riders, volunteers, virtual cyclists (people who fund-raise, but don't ride in the event) and Linking Lives partners for cyclists who request them (Linking Lives is a program that pairs a person living with MS with a cyclist).

Our theme for this year is super heroes to acknowledge those who have embraced the tour and helped it become the event it is today and what its success means—more inroads to a world free for MS. By supporting the Tour to

Continued on the next page



Chapter Annual Meeting set for Saturday, November 6th

Join us on November 6th for an informative, entertaining Annual Meeting. The meeting will be held, once again, at the Embassy Suites in Greensboro beginning with light refreshments. Douglas Jeffery, MD will provide the latest information about MS and exciting progress that is being made to treat it. Following a short business meeting and recognition of key volunteers, Dr. Paige Greason, a mental health counselor at the University of North Carolina School of the Arts who lives with MS, will discuss how to transform our relationship with MS and use the diagnosis as an ally to live more fully in the present moment.

Watch your mail for more information!

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**National
Multiple Sclerosis
Society**

Publication of the National Multiple Sclerosis Society Central North Carolina Chapter

Chair
Kevin Beeson

Vice Chair
Debbie Marshall

Chapter Programs Chair
Chip Harris

Chapter President
Elizabeth Green

Chapter Programs and Services Director
Mark Scheerer

Chapter Development Director
Emily Conner

Newsletter Editor
Bonnie Nevin

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

HOW TO CONTACT US

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

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

Continued from Cover

Tanglewood, you will get a chance to be a hero on a mission to better the lives of those living with multiple sclerosis. Monies raised will support important research and local programs and services that enhance the quality of life for thousands people with MS.

Some highlights of this year's ride include a new route, a silent auction, more entertainment and more opportunities for supporters to cheer on the participants in the event. This year we are changing the route to create one central rallying point for all cyclists, skaters, volunteers and spectators to join in the celebration. The new route will start AND end at Tanglewood Park, spanning over four counties. Day one offers routes ranging from 20-100 miles and travels over the roads that mark the best of the old route. Day two routes range from 30-70 miles and will explore new roads in the scenic Yadkin Valley Wine Region. Visit www.tourtotanglewood.org to view photos, route maps and more.

Get involved today by visiting www.bikeMSncc.org or calling 336.299-4136. Cyclists must be at least 12 years old by September 25, 2010 to participate. The registration fee is \$40 and participants commit to raising a minimum of \$200 to ride.

The Society Responds to CCSVI Findings



On April 14, at a Web forum jointly sponsored by the Society and the American Academy of Neurology, four experts discussed recent findings that suggest chronic cerebrospinal venous insufficiency, or CCSVI, a blockage in blood drainage from the brain and spinal cord, may contribute to nervous system damage in MS.

Dr. Robert Zivadinov of the University at Buffalo, State University of New York, stressed the need for further clinical studies to confirm that CCSVI is associated with MS and to understand how it might be involved.

Dr. Paolo Zamboni of the University of Ferrara in Italy, who initiated the CCSVI hypothesis with a small study in 2009, also recommended controlled studies to

determine the role of CCSVI in MS, and whether it can be safely and effectively treated with an endovascular surgical procedure.

Other participants included Dr. Andrew Common, radiologist in chief at St. Michael's Hospital, University of Toronto, and Dr. Aaron Miller, medical director of the MS Center at Mount Sinai Medical Center and chief medical officer for the Society.

The Society is funding expanded research on CCSVI in MS. Visit nationalMSSociety.org/ccsvi to learn about new CCSVI research projects announced on June 11.

What's New in MS Research and Treatment

In a special webcast, MS experts discussed the latest in MS research and treatment at nationalMSSociety.org/june30webcast.

The Society's Dr. Patricia O'Looney led a discussion with leading researchers on new oral treatments, infrequent-dose therapies, and current research in nervous system repair and protection and chronic cerebrospinal venous insufficiency (CCSVI).

ADA Celebrates 20

The Americans with Disabilities Act (ADA), signed into law in July 1990, promised to change the landscape for citizens with disabilities. "But the ADA's promise will be reached only if we remain committed to full implementation," said David Chatel, the Society's executive vice president of Advocacy.

"We can best celebrate our progress by reaffirming our principles of equality and inclusion," said Joyce Nelson, the Society's president and CEO.

Learn more! Visit nationalMSSociety.org/ADA.



Welcomes Your Work

MSWorld, the Society's online partner, invites you to share your stories, poems and artwork, and to meet your peers through message boards and chat rooms. Membership in this global online community is free and confidential. Join today at msworld.org.

Programs and Services calendar

For more information about the chapter's upcoming programs and services, please call 1-800-344-4867 or visit www.nationalmssociety.org/ncc.

August

Exploring Your Employment Options

August 10, 7:30 pm

Learn about innovative community employment and training opportunities available for persons with MS.

Get Out! A Social Group for people living with MS in their 20s and 30s

August 12, 6:30 pm

Arigato Japanese Steak and Seafood House
1200 S Holden Rd. Greensboro

No registration required.

Email nmssgetoutgroup@gmail.com with ?S

** Everyone is in charge of their own food and drink

September

Coping with the Invisible Symptoms of MS

September 14, 7:30 pm

This program will address those problems and concerns and help you to find ways to cope with invisible symptoms.

Bike MS: Tour to Tanglewood

September 25 and 26

October

Newly Diagnosed Teleconference

October 5, 7:00 pm

This program will discuss many challenges including depression, telling others about having MS and understanding the impact that MS may have on career choices.

November

Annual Meeting

November 6

See cover for description.

Walking Towards a Cure!



With three locations, sunny skies, immense volunteer support and numerous sponsors later, the Walk MS: Modern Automotive 2010 attracted more than 2,000 participants in support of the cause! Collectively the Walks held at the NC Zoo in Asheboro, The Penn House in Reidsville and Fourth of July Park in Kernersville raised over \$240,000 and brings us that much closer to creating a world free of MS. These fundraising efforts help researchers discover treatments and continue the search for a cure, provide self-help groups and counseling for local people with MS, education and exercise programs, and financial assistance for medical equipment purchases and emergencies to name a few.

On behalf of the Central NC Chapter and the 2000+ participants in addition to all of those living with MS, we extend our utmost appreciation and thanks to Modern Automotive Network, our title sponsor. We also thank all of you for your dedica-

tion and fundraising efforts. Without the ongoing support of all of the event participants, donors, volunteers and irreplaceable sponsors, none of this would have been possible. Their continued enthusiasm and commitment is invaluable in our efforts to find a cure. Together we will continue our mission to "Mobilize people and resources to drive research for a cure and to address the challenge of everyone affected by MS."

Make sure you catch us next year as we continue to not only fundraise but to rally around the cause and raise awareness for Walk MS: 2011!

ADVOCACY

Self-Advocate Toward a Better Life

What does self-advocacy mean? In short, it means speaking up for yourself. It also means making informed decisions and taking responsibility for them. The Society's Self-Advocacy Toolkit at nationalMSSociety.org/selfadvocacy can help you advocate for a better life: in the family, at work, in your community, at the doctor's office and for health insurance.

The right tools for the job

The toolkit helps clarify what questions to ask and offers a framework for answering them. What should you do about a sudden increase in the co-pay for your medication? Should you disclose your MS to your employer? How can you improve communication with your spouse and children? For example, how can you get your kids talking to you after you tell them your diagnosis?

"The Self-Advocacy Toolkit is 'one-stop shopping' for techniques to assess your situation,

Continued on page 9

SELF-HELP GROUPS

Burlington
2nd Thursday of the month, 10:00 AM
Alamance Regional Medical Center
Annie: 336-226-7712

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

Gibsonville
A Family Affair: Living Beyond MS
Group is not meeting at this time, call for information.
Paula: 336-375-0713

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
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

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.

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

Lewisville
Group is not meeting at this time, call for information.
Karyn: 336-775-6683

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
On hiatus, meetings resume on 9/13/10
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

RESEARCH

Study May Lead to Individualized Treatment

For unclear reasons, a significant number of people with MS do not benefit from interferon therapy, but it can take months or even years to discover this. Since earlier treatment has been linked to better outcomes, being able to predict whether someone will respond to interferon could avert useless treatment and potentially improve results.

A study published in *Nature Medicine* (March 28, 2010) points the way to an answer why some respond to treatment and others don't. Dr. Lawrence Steinman of Stanford University and Dr. Chander Raman, of the University of Alabama at Birmingham tested in mice their idea that response to interferon might depend on which types of cytokines (immune messengers) were leading immune attacks. They found that interferon reduced MS-like symptoms in mice whose experimental disease had been produced by T helper 1 cells, but worsened disease when it was caused by T helper 17 cells.

The team then checked blood samples of 26 people with MS and found they could differentiate between those who did and didn't respond to interferon, based on patterns of cytokines.

Larger studies will be needed to confirm the study's findings before they will be useful in the clinic. "The data provides a strong

"Being able to predict whether someone will respond to interferon could avert useless treatment and potentially improve results"

foundation for the possibility that we will be able to tell someone before starting treatment if it will work," said Dr. Steinman.

The study was funded in part by the National MS Society.

Low-dose Naltrexone May Improve Quality of Life

Most people with MS experience stress, at least sometimes. A recent pilot clinical trial found that low-dose Naltrexone (LDN) may help. LDN is FDA-approved to treat opioid and alcohol addiction. At significantly lower doses, it has been prescribed as a treatment for certain diseases, including MS.

Up until now, there has been very little clinical study of LDN's usefulness for people with MS. Dr. Bruce Cree, Dr. Douglas Goodin, and colleagues at the MS Center, University of California at San Francisco, conducted a study of 60 people with MS. Participants received LDN for eight weeks and inactive placebos for eight weeks with one week free of treatment in between.

The investigators found that LDN significantly improved some measures of quality of life—specifically, mental health, pain and self-reported cognitive function. However, they found no impact on symptoms such as fatigue, bowel and bladder control, sexual satisfaction or visual function.

Continued on page 8

The investigators emphasized that the results did not support the use of LDN instead of proven MS treatments, but they do suggest that it may relieve certain MS symptoms, and that larger studies may be warranted.

What comes first— Epstein-Barr or MS?

Virtually all people with MS are also infected with Epstein-Barr virus (EBV), but like the chicken and the egg, scientists did not know which came first. Two new studies are adding to an increasing body of evidence that shows a possible role for EBV, a herpes virus that can cause several disorders, in the development of MS.

In the first study to look at whether EBV infection preceded the clinical onset of MS, Dr. Alberto Ascherio, of the Harvard School of Public Health, and colleagues showed that in a sample of 305 people with MS found in U.S. military databases, an EBV-positive blood test came before MS diagnosis. [Annals of Neurology, January 20, 2010] “The results strongly suggest that EBV infection increases MS risk,” said Dr. Ascherio.

At the start of the study, only 5% of the participants, including the control group, tested negative for EBV. None of the people who tested negative for EBV during the follow up developed MS. In contrast, 10 people who initially tested negative for EBV, but

who acquired the virus during the follow up, developed MS. Dr. Ascherio and colleagues concluded that MS risk increases significantly following EBV infection.

“From a practical point of view, preventing EBV infection is difficult,” Dr. Ascherio said. “Most people are exposed to it in childhood. We do know that people who have a stronger immune response to EBV

“There’s pretty strong evidence that being infected with EBV in the teens or later is a risk factor for MS”

are more likely to get MS. There’s also pretty strong evidence that being infected with EBV in the teens or later is a risk factor for MS.”

The Harvard results were supported by a study

in Spain, where researchers at the Hospital Universitari Vall d’Hebron, Barcelona, reported that an immune response to a protein associated with EBV was increased in people with MS compared with siblings who did not have MS. [Multiple Sclerosis 2010: 16(3):355-358]

The study found that siblings showed signs of having been infected with a number of viruses. The only marked difference was their immune response to EBNA1, a viral protein associated with EBV. These were significantly higher in people with MS compared to their unaffected siblings.

More research is needed to find the mechanisms underlying the connection between EBV and MS, and a way to put the information to use.

MS Society Holds 2010 Winston-Salem Dinner of Champions

On Thursday, April 29, the chapter hosted the Winston Salem Dinner of Champions which honored Ron Wellman, Director of Athletics at Wake Forest University. Over 300 people attended the event at Bridger Field House at BB&T Field. The evening raised over \$66,000 to help those affected by multiple sclerosis.

Co-chairs for the event were Bob Reed and Jerry West. Cameron Kent, WXII 12 news anchor, served as the master of ceremonies. Dr. Nathan O. Hatch, president of Wake Forest University, introduced Wellman to the audience at the dinner.

“The evening was truly a meaningful experience for all of our guests who enjoyed Ron Wellman’s inspirational remarks about strength and determination,” said Elizabeth Green, Chapter President. “The MS Society is grateful to have Ron’s support in its crusade to create a world free of MS.”

Champion Sponsors for the event were BB&T and I.L. Long Construction Co., Inc. The Visionary Sponsor was Wake Forest University/Wake Forest University Baptist Medical Center. The chapter is especially grateful to these generous sponsors.



Ron Wellman

ADVOCACY CONT.

see reasonable solutions and come to a mutually agreeable result,” said Renee Vandlik, a Society senior manager for State and Local Government Relations. “It encourages individuals to identify a range of alternatives for meeting their needs.”

Working it out

The toolkit includes worksheets tailored to each significant area of life with MS: community,

family, employment, medical care, Medicare, health insurance appeals, long-term care and Social Security Disability Insurance. Each worksheet provides



a comprehensive, step-by-step approach to define the situation, consider a range of solutions and identify rights and responsibilities. The worksheets also offer sample situations and responses.

Each worksheet can be used to organize thoughts and actions around effective self-advocacy. You can keep track of tips and advice, do research on a particular issue and collect ideas for next steps. “We hope the worksheet will have a life beyond the particular issue you used it for by offering ideas for self-advocating in a range of life situations,” Vandlik said.

Get your voice heard today and visit nationalmssociety.org/selfadvocacy.

Have a Question?



Answers when you need them.

Dial 1-800-344-4867.

Some 200,000 callers a year dial this number. Regardless of why they call, they tap into a network linking them to the chapter of the National MS Society that is nearest to them (the phone company cleverly does this) and to a vast database of resources managed by our Information Resource Center, or the IRC, in Denver, Colo.

One phone number works for the entire country. If you should call after hours, you'll be asked to leave a message. But if you have an emergency, don't wait. Call 911 right away — and plan to get in touch with us as soon as the immediate problem has been resolved.

No hablan Inglés?

Choose Spanish — or other languages as needed. Vamos a encontrar a alguien que le ayude.

What happens when you dial 1-800-344-4867?

You might be calling to find out about one of our educational programs, a trip or an outing, or our Bike MS and Walk MS events. You might want to volunteer. Or you might be calling for assistance — the co-pay on a wheelchair or ways to fund

home modifications. You might need someone to talk to about the changes MS is making in your family life or you might need a referral to an MS-savvy health-care professional.

You'll get help from an MS Navigator™ — a trained human service professional, whether your call is answered here or at the national center. MS Navigators undergo comprehensive training to answer questions on just about anything you might need to know about living with MS. The central database has links to national, state and local resources, which cuts down on paper chases and endless phone calls.

More than just the facts

"The system is here to help people navigate the challenging waters of MS so they get what they need, when they need it," said Nancy Law, the Society's executive vice president of Programs and Services.

"Our mission includes emotional support," added Lisa Custy, MSCIR, associate vice president of the IRC. "We don't give information in a vacuum."

Information is a two-way street, Custy added. Chapter staff regularly update local and area resources. If you've discovered a resource that would be helpful to other people with MS, call us about it.

Sooner is usually better

"The sooner people call us when there's a problem, the more likely that it can be resolved," Law added. "Waiting until things are dire — until an eviction notice is on the door — may make it harder. But whenever you call, please know the Society is here for you."

Need Help Paying for MS Drugs?

Managing the costs of MS meds is a huge challenge, especially for people with no insurance or who are underinsured. But some help is available. Each disease-modifying drug manufacturer and many makers of medications that treat MS symptoms have Patient Assistance Programs (PAPs), which offer free or low-cost medications to those who qualify. Prescription drug discount programs can help as well. Ask your doctor if there is a generic version available for any prescription.

Patience may be needed to get benefits, however. You can get support and information from the Society too. Visit nationalMSSociety.org/underinsured or call us at 1-800-344-4867.

RESOURCE CENTERS — These centers can help with information, applications and exploring your options.

Name	Website	Phone Number
NeedyMeds	NeedyMeds.org	(online service only)
Partnership for Prescription Assistance	pparx.org	888-477-2669
RxAssist	RxAssist.org	401-729-3284

For help in purchasing disease-modifying drugs

Drug Name	Resource	Website	Phone
Avonex	MS Active Source	msactivesource.com	800-456-2255
Betaseron	BETA PLUS Patient Support Program	betaseron.com	800-788-14671
Copaxone	Shared Solutions	sharedsolutions.com	800-887-8100
Extavia	Extavia Patient Support Program	No Web site	866-925-2333
Novantrone	Novantrone Patient Assistance Program	No Web site	877-447-3243
Rebif	MS Lifelines Access Made Simple	mslifelines.com	877-447-3243
Tysabri	MS Active Source	msactivesource.com	800-456-2255

For help in purchasing drugs that address MS symptoms

Drug	Website	Phone Number
Ampyra (fampridine-SR)	No Web site at press time	888-881-1918
Baclofen (intrathecal only)	rarediseases.org/programs/medication	800-999-6673
Cymbalta (duloxetine HCl)	lillycares.com	800-545-6962
Ditropan XL (oxybutynin chloride)	jjpaf.org	800-652-6227
Neurontin (gabapentin)	pfizerhelpfulanswers.com	866-706-2400

Call an MS Navigator™ at 1-800-344-4867 about other drugs or state-supported patient assistance programs. The information here is not guaranteed to be up to date as programs may change, but we hope this helps you get started.