



National
Multiple Sclerosis
Society

Central North Carolina Chapter
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CENTRAL NORTH CAROLINA CHAPTER MS CONNECTION

MOVING TOWARD A WORLD FREE OF MS | SPRING 2013

MS AWARENESS WEEK MARCH 11-17

No matter where you live, what you do and who you are, there are lots of ways to participate in MS Awareness Week, March 11 to 17. We've collected ideas nationwide to share what people have done to raise awareness of multiple sclerosis, but MS Awareness Week is also about expressing your own unique experience of the disease. Connect with others to raise awareness at www.MSconnection.org or call us at 1-800-344-4867. Here are some ways to get involved.

SPREAD AWARENESS

- Share your story with everyone you know during MS Awareness Week at www.MSconnection.org.
- Raise MS aWEARness by wearing orange. Need something new? Visit www.nationalMSsociety.org and click "Store" in the top navigation bar.

JOIN AN EVENT

- Learn about Bike MS, register to ride or start a team at www.BikeMS.org.
- Learn about Walk MS and find a team or event at www.walkMS.org.
- Or visit www.DoItYourselfMS.org to find out how to create your own DIY event.

TAKE ACTION

- Join the MS Activist Network to contact your legislators and urge them to support issues of importance to you and the MS community. Sign up at www.nationalMSsociety.org/MSActivist.
- Contact us to connect and find out what activities are being planned in our area. Call (336) 299-4136 or go to www.nationalMSsociety.org/ncc.
- Join the online MS community at www.MSconnection.org.
- Sign up for our monthly MS eNEWS at www.nationalMSsociety.org/signup for the latest on research, legislation and more that impacts people living with MS.

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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.

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

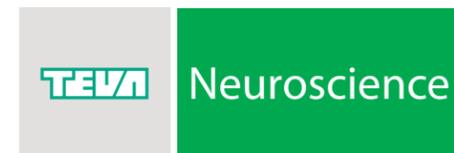
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Central North Carolina Chapter

HOW TO CONTACT US

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This newsletter is partially funded by
Teva Neuroscience.

SAVE MONEY AND GO GREEN

If you would like to receive your chapter newsletter by email rather than regular mail, email mark.scheerer@nmss.org with your request.

VICTORY IN MEDICARE SETTLEMENT

BY MARCELLA DURAND

A settlement to end Medicare's so-called "Improvement Standard," which denied coverage of certain treatment services to people with multiple sclerosis and other diseases, was officially approved January 24th by Chief Judge Christina Reiss of the U.S. District Court in Vermont.

The settlement to end the standard was reached in a nationwide lawsuit in which the National MS Society was a plaintiff. The Society had joined other organizations including the Parkinson's Action Network, the Alzheimer's Association, United Cerebral Palsy and Paralyzed Veterans of America in a class-action suit to challenge the Centers for Medicare and Medicaid Services (CMS) over the standard.

The standard had denied Medicare coverage for services such as skilled nursing facilities, home health and outpatient therapy benefits like physical or occupational therapy to Medicare beneficiaries living with MS if they did not show improvement. However, these often-expensive services can be critical to prevent decline or maximize independence.



MS ACTIVISTS MAKE CHANGE HAPPEN

The settlement's approval effectively means that any denial citing the "improvement standard" can be appealed moving forward and even dating back to Jan 18, 2011 (the date the case was filed). CMS is now tasked with revising its Medicare Benefit Policy Manual and other policies, guidelines and instructions to ensure that Medicare coverage is available for skilled services in home health, nursing home and outpatient settings. CMS must also develop and implement a nationwide education campaign to ensure beneficiaries with chronic conditions are not denied coverage for critical services.

Visit www.MSActivist.org for more info.

Marcella Durand is the content planning and development manager for the Society.

Programs and Services calendar

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

March

Wednesday, March 13, 7:00 p.m.
Employment Teleconference Series: The Impact of Health Insurance on Career Decisions

Wednesday, March 27, 7:00 p.m.
Employment Teleconference Series: How to Talk About MS to Your Employer

All calls from this series will be available online.

April

Saturday, April 6, 9:00 a.m.
MS Adventures at the NC Zoo

Tuesday, April 9, 7:30 p.m.
Managing the Symptoms of MS
Teleconference with David Scagelli, MD

Wednesday, April 17, 6:30 p.m.
Below The Belt: Bladder and Bowel Issues in MS Conference Call

May

Thursday, May 9, 6:30 p.m.
Multiple Sclerosis, Sex and Intimacy Teleconference with Pamela S. Boyle, MS, FAACS

Wednesday, May 29 World MS Day

June

Wednesday, June 12, 6:30 p.m.
Improving Independence in Progressive MS Teleconference with June Halper, MSN, ANP, FAAN

AUGUST

Coming in August... Women with MS: Embrace the Whole You Retreat

MS Adventures at the NC Zoo

Join the National MS Society as we visit the NC Zoo in Asheboro for a day of family fun on Saturday, April 6, 2013!

- Open to people living with MS and their immediate family members (spouse/partner and children living in the home)
- Cost of the program is \$3 per person. This includes full-day admission and a \$5.00 meal ticket redeemable inside the zoo.
- Space is limited - register now! Visit www.nationalMSSociety.org/ncc or call 1-800-344-4867.

Managing the Symptoms of MS Teleconference

Tuesday, April 9th from 7:30 - 8:30 p.m.

Join us for our teleconference "Managing the Symptoms of MS." Dr. Scagnelli specializes in Multiple Sclerosis and Adult Neurology at Raleigh Neurology's Durham and Raleigh offices.

Learn more and register for these teleconferences at nationalmssociety.org/ncc.

Employment Teleconference Series

Each teleconference is accessible via a toll-free number. Participate in several calls or just the one that interests you. You will need to register individually for each call you wish to attend.

If you didn't have a chance to participate, there's still a chance for you to listen to each call. Simply go to our website and look for 2013 Employment Teleconference Series. From there you will find a link that will take you right to the page where you can listen to the calls as well as download any handouts that were available for the programs.

Multiple Sclerosis, Sex and Intimacy Teleconference

Thursday, May 9, 6:30 - 7:30 p.m.

Pamela S. Boyle, MS, FAACS

Join us for an open and honest discussion about the personal and intimate side of living with MS. This presentation provides opportunities for participants to explore concepts of intimacy, challenge their communication skills and explore a range of sexual expressions to awaken or enhance the sexual connection.

Improving Independence in Progressive MS Teleconference

Wednesday, June 12, 6:30 - 7:30 p.m.

June Halper, MSN, ANP, FAAN

Sometimes MS symptoms can progress to the point that they significantly interfere with daily activities. Maintaining control and independence in everyday life doesn't necessarily mean doing everything the same way you did it before. This call will discuss how to navigate the world of assistive technology and suggest ways to modify your environment at home and at work to optimize control and independence.

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
Christal 336-501-7045

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
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

CAMERON HARRIS - DIRECTOR, DEVELOPMENT AND OPERATIONS



The Central North Carolina Chapter is thrilled to announce that Cameron Harris has been promoted to the role of Director, Development and Operations.

Joining the staff in 2008 as Special Events Manager, Cameron cultivated and grew signature leadership campaigns including the Dinner of Champions series and Winston-Salem and Greensboro MS Luncheons. In her new role, Cameron will continue to oversee these campaigns as well as all day-to-day chapter operations. Additionally, she will manage the financial, data and donor stewardship staff.

“Cameron is a strong leader and I am excited for her to embrace this role,” says Jennifer Lee, Regional Vice President of the Southeast Region of the National MS Society. “She is committed to addressing the challenges of everyone affected by MS.”

Cameron is a native of High Point and resides in Greensboro with her husband, Tim. She is a graduate of the University of North Carolina at Chapel Hill. She can be reached at Cameron.Harris@nmss.org or 336-299-4136 x49204.

Equipment Loan Help

As you may well know, for years the chapter has provided short and long-term medical equipment loans to persons living with MS in our chapter territory. Unfortunately, due to the increase needs in medical equipment our loan closet supplies are almost depleted. If you or anyone you know has any medical equipment (scooters, manual wheelchairs or rolling walkers) that has been gently used and in good condition please contact Gordon Miller at 336-299-4136 or gordon.miller@nmss.org. The donation of medical equipment would be greatly appreciated and can assist those persons living with MS to have a continued level of independence they may not otherwise have without your donation.

Partners in Care

We are excited to announce the launch of a web search capability for Partners in MS Care. Anyone can now search for Partners in MS Care by state, distance from a zip code, or by category. This new service increases the Society's ability to connect people living with MS and their families to qualified providers of MS care. In our chapter area we currently have two Partners in Care with more to be added throughout the next year. Wake Forest Baptist Health Multiple Sclerosis Center under the direction of Dr. Emily Pharr, has been designated a Center for Comprehensive MS Care. The Treatment Network / Jessica Thomas, MSW, LCSW, has been designated a Partner in Care in the area of mental health. For more information about each of our Partners and more detailed information about the program please visit www.nationalmssociety.org/partners-in-ms-care/index.aspx

A PLACE FOR EVERYONE AT WALK MS

In spring 2011, then 93-year-old Rose Hill embarked upon her third Walk MS in honor of her son Michael, who lives with multiple sclerosis. She wanted to do something to help Michael, and so many others who are affected by the disease, live better lives.

To get in shape for the big day, Rose walked laps around her retirement home, determined to be ready for the four-mile Walk MS route. On the day of the event, Rose made it halfway before she started to feel tired. Her family asked if she wanted a ride to the end and her reply was, "No way!" Grandchildren, children and friends held onto her arms and together they trekked toward the finish line. The next year, at 94, Rose registered for Walk 2012 as co-captain for her team, A Rose for a Cure.

There is a place for everyone at Walk MS. Family members from grandparents to tiny toddlers, people newly diagnosed with MS, people with progressive MS, friends, coworkers and more all take part in Walk MS events across the nation. Walk MS is for anyone who wants to do something about MS now.

Whatever your experience is with MS, we invite you to join us. Be a part of the Walk MS community. Start a team, join a team, volunteer or be there cheering participants along to the finish line.

ROSE HILL WITH HER TWO SONS, MICHAEL, AT LEFT, WHO LIVES WITH MS, AND LARRY



LOCAL WALK DATES

Walk MS connects people living with MS and those who care about them. It is a day we come together to show the power of our connections.

Find a Walk and start fundraising today. Because the money we raise at Walk MS speeds new treatments for people with MS, ensures financial support for people dealing with the havoc MS causes and supports local programs.

Whether you want to walk or volunteer, we need your help. Visit www.walkMSncc.org or call 336-299-4136 to register. We hope to see you at Walk MS 2013 sponsored by Modern Automotive.

March 23
North Carolina Zoo, Asheboro

April 13
Rockingham County - Penn House, Reidsville

April 20
Piedmont Triad - 4th of July Park, Kernersville

SARA ROWE AND HER TEAM "STEPPING WITH SARA"



CLIMB MS RAISES \$12,000

Climb MS: Power up the Tower, was held on Saturday, February 2nd, at the Winston Tower in downtown Winston-Salem. The event hosted 230 climbers participated in an effort to create a world free of MS. The event raised \$12,000.

Sara Rowe was the top fundraiser with \$1,695. Her team, "Stepping with Sara" was both the largest and top fundraising team with 27 climbers raising \$2,300!

The fastest climber was Luke Holman with a time of three minutes eighteen seconds. David Ochoa (3:52) and Alex Langevin (3:54) also placed in the top overall male category. Justin Rawkey (4:44), Dena Harris (5:02), and Emily Davis (5:05) were the top overall female finishers. Twelve firefighters also climbed to the top wearing full gear!

This year's event was sponsored by Fleet Feet Sports in Winston-Salem. Prior to the climb, Fleet Feet held a training event at Forsyth Country Day in January to help participants prepare to 'Power Up the Tower.' For more information, visit www.climbmsncc.org.



Bike MS: Gears and Cheers May 4, 2013

On May 4, Bike MS: Gears and Cheers will feature scenic routes through Guilford and Rockingham counties. The post-ride celebration at Grove Winery will include lunch, a commemorative wine glass and an afternoon in the vineyards with live music. Register to ride or volunteer at www.gearsandcheers.org.

Bike MS: Tour to Tanglewood September 28 & 29, 2013

Save the date for the 28th Annual Bike MS: Tour to Tanglewood on September 28 & 29. This cycling event features two full days of riding through the Yadkin Valley and the party of the year at the Tanglewood Park amphitheater.

This is the Central NC Chapter's largest fundraising event, raising \$1 million annually. Register to ride, volunteer, become a virtual cyclist, or participate in Linking Lives at www.bikemsncc.org.

RESEARCH

PROGRESS ON MS THERAPIES

BY MEGAN WEIGEL, CNP, ARNP-C, MSCN

In 1993, Betaseron was released to market as the first disease-modifying therapy for multiple sclerosis. With the approval of oral teriflunomide (brand name Aubagio®) by the FDA in October, 2012, we now have nine disease-modifying therapies to treat relapsing forms of MS—and more on the horizon. The **MS Emerging Therapies Collaborative**, which includes the Society, provides downloadable information sheets at www.ms-coalition.org/emergingtherapies to facilitate communication between doctors and people with MS about newly approved treatments.

Research on potential treatments for progressive forms of MS is also underway and the **International Progressive MS Collaborative**, of which the Society is a member, plans to do all it can to speed the development of those treatments.

Here are the therapies to keep an eye on as we move forward in 2013.

BG-12 is an oral fumarate that has been used in Europe for over a decade to treat psoriasis. Although its exact mechanism of action is not known, it is thought to inhibit immune cells active in MS and may even be protective against damage to the brain and spinal cord.



Two large phase III studies (the DEFINE trial and the CONFIRM trial, respectively) found that BG-12 significantly reduced relapses and disease activity as detected by MRI. The most common side effects were flushing of the skin and gastrointestinal upset. In 2012, Biogen Idec applied to the FDA for approval of BG-12 to treat relapsing MS, and the review process is now underway, with the FDA's decision expected within the year.

Alemtuzumab, a monoclonal antibody that depletes circulating immune (T and B) cells thought to be responsible for MS attacks, would be administered by IV infusion for five days and then for three days one year later.

Genzyme applied to the FDA for approval of alemtuzumab to treat relapsing MS, based on positive results from several clinical trials, including one that showed a 55% decrease in relapses compared to interferon beta 1a (Rebif); however, the FDA asked the company to resubmit its application, so a timeline has not yet been established. While this therapy is powerful against MS, there is concern regarding adverse events, such as immune thrombocytopenic purpura (ITP, a bleeding disorder), and autoimmune thyroid disorders.

Laquinimod is a once-daily oral immune modulator that proved in phase III studies to statistically significantly decrease relapse rates, though not as robustly as investigators had hoped. This drug is about to be tested in another phase III study in 1,800 people with relapsing-remitting MS.

Daclizumab and **ocrelizumab** are two other monoclonal antibodies currently under study, with favorable results thus far. A highly concentrated liquid formulation of daclizumab is under study in relapsing-remitting MS. Experimental ocrelizumab, given intravenously, significantly reduced disease activity on MRI scans in a study of 218 people with relapsing-remitting MS. One person died due to brain edema; however, the relation of this death to the medication is unclear. Additional research, now going on in primary-progressive MS and relapsing-remitting MS, is needed to further determine ocrelizumab's safety and benefits.

Clinical trials of treatments for **progressive forms of MS** are currently underway: these include **natalizumab (Tysabri)**, **fingolimod (Gilenya)** and **ocrelizumab**.

MAKING CHOICES

When we consider treatment now, in particular the possibility of switching therapies, we weigh the safety and efficacy of our older, injectable disease-modifying agents against the seeming convenience and perhaps superior efficacy of newer agents. The sequencing of therapies is a new consideration, as well, as the effects of medications like natalizumab and fingolimod on the immune system may be prolonged.

Questions about new therapies may mean longer or more frequent appointments with neurologists to discuss their risk-benefit ratios.

Additionally, people with MS may choose to see an MS specialist, or be referred to one by a general neurologist, for treatment recommendations.

However, the most encouraging part, in addition to the fact that treatments for MS may be getting more effective, of course, is that the research pipeline is full. Thanks to those who are committed to research funding, science is able to continue searching for the cure, and on that search, discover medications that will keep this disease as quiet as possible.

To follow progress on potential MS therapies, sign up for MS eNEWS at www.nationalMSsociety.org/signup, or visit www.nationalMSsociety.org/research.

Megan Weigel is a Doctor of Nursing Practice and MS Certified Nurse who has been caring for people with MS for 12 years.

This article was originally published in the North Florida Chapter's **MSConnection** newsletter.