

# MS CONNECTION NEWSLETTER



Photo by Mark Kiryluk

**INSIDE  
THIS  
ISSUE**

**04**

IS IT HARDER  
TO WORK  
WITH MS?

**06**

EVERY  
CONNECTION  
COUNTS

**08**

RESEARCH:  
PROGRESS ON  
THERAPIES

**14**

EDUCATIONAL  
TELECONFERENCE  
SERIES

## BE ORANGE...GO GREEN

### Blue Ridge Chapter

In order to make better use of our resources, the Blue Ridge Chapter is using email to keep our members up-to-date. To receive future program announcements and be orange while going green, please call 800.344.4867 to share or update your email address.

## CONNECT WITH US ONLINE:

### Blue Ridge Chapter

[www.nationalMSSociety.org/vab](http://www.nationalMSSociety.org/vab)



### Like us:

[www.facebook.com/nmssblueridge](http://www.facebook.com/nmssblueridge)

[www.facebook.com/walkMSblueridge](http://www.facebook.com/walkMSblueridge)

[www.facebook.com/CountryRoadsRide](http://www.facebook.com/CountryRoadsRide)

[www.facebook.com/TourDeVine](http://www.facebook.com/TourDeVine)



### Follow us:

[@MSBlueRidge](https://twitter.com/MSBlueRidge)

## 2013 ACTION DAY

# PICTURE SUCCESS



MS Activists gather after meeting with Virginia Assembly members to show support of bills to increase access to prescription medications and expand the state's Medicaid program.



MS Activists in West Virginia meet with Governor Earl Ray Tomblin after visiting Assembly members to promote MS awareness.

## ADVOCACY

# 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.

For more information, visit [www.MSActivist.org](http://www.MSActivist.org).

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

## NEWLY DIAGNOSED IS IT HARDER TO WORK WITH MS?

JULIE STACHOWIAK, PhD

Many people with multiple sclerosis find it difficult to continue working, even in the early years of the disease. Tasks that seemed challenging before MS can become seemingly insurmountable afterward. The fluctuation of daily symptoms and unknown levels of future disability make mapping out a strategic career path a challenge, to say the least. We simply do not know what the future holds around our ability to perform a job.

**“I AM ABLE TO WORK MORE WHEN I FEEL GOOD, LESS WHEN I FEEL BAD, AND TAKE A QUICK NAP IF NEEDED.”**

I am lucky enough to be able to work from home. I am able to work more when I feel good, less when I feel bad, and take a quick nap if needed. There are days when I can work a full day, but there are many days when I do not feel productive at all — when even looking at the computer screen feels like torture.

### MEMORY ISSUES MAY IMPACT EMPLOYMENT



I know that as each year has gone on, the problems that I have had in trying to work efficiently seem to get worse. However, recent research indicates that some people who are newly diagnosed or have had an episode of a clinically isolated syndrome may already need to adjust their time at work.

Researchers in the Netherlands wanted to look at how MS-related cognitive dysfunction affected work in people who are recently diagnosed with MS. In the Cognition and Socio-Economics (COGNISEC) study, the researchers studied 45 people who had been diagnosed with MS or had a clinically isolated syndrome within the past two years and have been on disease-modifying therapy for less than six months or not at all.

### WHAT THEY FOUND:

- People with higher levels of fatigue and disability all decreased their working hours within 12 months following diagnosis.

- Lower long-term memory scores correlated with a lower number of hours and days spent working during the week.
- People who scored lower on “focused attention” and “speed of memory” were more likely to say they “wished to work less.”
- Scores on tests assessing depression (Beck Depression Inventory) did not correlate at all with quantity of working hours.

While its findings need to be replicated in larger studies, so far this research shows that cognitive dysfunction can negatively impact the capacity to work, even in the very early stages of MS.

### WORKING A BALANCE

What does this mean? Let’s face it, even jobs that we love can lose some of their luster when we have to negotiate symptoms that add to our physical disability. While it is tempting to keep pushing ourselves to do more and overcome some of these challenges, it is important to remind ourselves that we may have very real cognitive symptoms related to our MS that are impacting our abilities to work the same way we did in the past.

**“... SO FAR THIS RESEARCH SHOWS THAT COGNITIVE DYSFUNCTION CAN NEGATIVELY IMPACT THE CAPACITY TO WORK, EVEN IN THE VERY EARLY STAGES OF MS.”**

On the other hand, many people with MS continue working long after their diagnosis. Disease-modifying therapies, new technologies, better symptom management, legal employment protections and community resources can help you remain in the workforce — and education and preparation can be your most powerful tools for success.



Diagnosed with MS in 2003, Julie Stachowiak, PhD, is the author of **The Multiple Sclerosis Manifesto** and [www.ms.about.com](http://www.ms.about.com). Originally posted at [blog.nationalMSSociety.org](http://blog.nationalMSSociety.org)

### TOOLS TO WORK

If you’re struggling to keep up at work, but aren’t ready to throw in the towel just yet, visit [www.nationalMSSociety.org/employment](http://www.nationalMSSociety.org/employment) or call an MS Navigator at 1-800-344-4867 to learn more about your options and get connected with employment resources in your area.

The Job Accommodation Network at [www.askjan.org](http://www.askjan.org) also offers information on a range of subjects for working people with disabilities.

MS AWARENESS

# EVERY CONNECTION COUNTS

Multiple sclerosis is a life-altering disease that affects each person in a unique and different way. MS destroys connections, divides minds from bodies and pulls people from their lives and away from one another. Millions of people are affected by MS worldwide.

There is no cure. Therefore, it's only fitting that connections would be its greatest enemy. As more connections are formed, more knowledge is shared, more questions are asked, more resources are gathered and more hope is provided to help people living with MS move their lives forward. Every connection counts.

People impacted by MS connected across the nation during Multiple Sclerosis Awareness

Week March 11-17. They continue to make connections throughout the year to combine efforts, knowledge and hope in order to move us closer to a world free of multiple sclerosis.

## MAKE A CONNECTION

Share your story and connect with others at MSconnection.org. You can learn more about MS, upload your own photo and connection to share with others, download tools to spread MS awareness or register for Walk MS or Bike MS in your community. Whether you volunteer, bike, walk, advocate, educate or support, every connection you create moves us closer to a world free of MS and shows your commitment to the MS movement.



A woman tells her support group in California about sharing her MS-related fears with her daughter for the first time.



A group member blogs about it, inspiring a woman in Dallas to reconnect with her own family.

MS KILLS CONNECTION > < CONNECTION KILLS MS



## Can Do Multiple Sclerosis | TWO DAY TAKE CHARGE™ PROGRAM

A new two-day wellness weekend for people living with MS and their support partners. Join us as we explore an interactive and multi-disciplinary approach to MS care management. Learn the individualized skills and mindset to **take charge** of your health and your life with MS.

- EDUCATIONAL LECTURES
- INTERACTIVE WORKSHOPS
- ACCESS TO MS EXPERTS

Managing MS  
Eating Well, Eating Easy  
Learning to Cope  
Communication  
Goal Setting

Mood & Cognition  
Exercise, Strength & Balance  
Travel & Recreation  
Fatigue  
Support Partner

Nurse Practitioner  
Occupational Therapist  
Physical Therapist  
Psychologist  
Dietician

JUNE 21-23, 2013

**WHEN**..... 5:00pm Friday, (6/21) - 3:00pm Sunday, (6/23)  
**WHERE**..... Embassy Suites Charleston Hotel – 300 Court St. Charleston, West Virginia 25301  
**FREE**..... \$50 application fee includes all meals, hotel accommodations, lectures and workshops for the weekend program.

Please note participants and their support partner will be responsible for travel fees to/from the program location.

In collaboration with the National MS Society, Blue Ridge Chapter.

Apply Today!

Online  
[www.msando.org/takecharge](http://www.msando.org/takecharge)

Call or Email  
800.367.3101  
[programs@mscando.org](mailto:programs@mscando.org)



This program is made possible from the generous support of



## 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](http://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 into 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 re-submit 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](http://www.nationalMSSociety.org/signup), or visit [www.nationalMSSociety.org/research](http://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.

## Bike MS: Tour De Vine

presented by Stop In Food Stores

**25th Anniversary Celebration!**

JUNE 8-9, 2013 » 2 DAY FESTIVAL  
25, 50, 75 & 100 MILE ROUTE OPTIONS

The excitement is building for the 25th Anniversary Bike MS: Tour De Vine, set for June 8-9, 2013 at Pollak Vineyards. The fun-filled event will feature live music, an engaging program, special anniversary activities and catered meals. A very special celebration dinner will be served amongst the grapevines with award winning varietals from Pollak Vineyards.

“The setting at Pollak vineyards is a perfect location to showcase the beauty of Central Virginia and celebrate both our riding and fundraising efforts for the National MS Society,” shared Nikki Hastings, co-captain with Megan Buschi of Team ACAC. “All of our team is already looking forward to the new routes, which will bring renewed excitement to the ride this year.”

### UPDATED ROUTES

Oh, yes, the routes! Participants will cycle through Central Virginia’s scenic wine country! This year’s event will feature new 25, 50, 75 and 100 mile routes to challenge every skill level.

“We wanted to mix it up a little this year. Cyclists will head south on Saturday and north on Sunday,” says Lenny Vincent, a longtime



Bike MS volunteer who develops the routes. “As always, the ride will be well-supported with SAGs (“support and gear vans) and first aid personnel along the route and rest stops every 8-12 miles.”

For those who haven’t registered, it’s not too late! Registration is currently \$35 and will go up to \$40 on May 1.

### EVERYONE CAN JOIN THE FUN

Bike MS isn’t just for cyclists. Volunteers are needed now to help plan the event and to assist with phone banks and community outreach. The Society is also recruiting volunteers for the weekend of the event.

Everyone is invited out to support the riders by cheerleading at the start, on the route at rest stops and at the finish line. That extra bit of encouragement can help riders finish that last mile! For people with MS, this can be a special moment - to meet the cyclists riding to raise funds to support programs, services, advocacy and research.

To learn about the event, to register or to volunteer, visit [www.bikeMSva.org](http://www.bikeMSva.org).

## Women on the move Luncheon

Wednesday,  
May 8, 2013  
University of Virginia  
Alumni Hall

**luncheon**

11:45 a.m. - 1:00 p.m.  
Call 434.971.8010 for more  
information.

### FEATURING KEYNOTE SPEAKER

#### KRISTIE SALERNO-KENT

Writer-director-star of *The Show Must Go On*, a short movie screened at the Society’s 2007 National Conference.



## Dinner of Champions

19th Annual  
MS Dinner of Champions  
of Harrisonburg

*honoring*

**Loren Swartzendruber**

Tuesday, May 28, 2013

JMU Conference Center

Call Rebecca at 434.971.8010 for information.

22nd Annual  
MS Dinner of Champions  
of Roanoke

*honoring*

**John Williamson**

Tuesday, June 11, 2013

Hotel Roanoke

Call Rebecca at 434.971.8010 for information.

REGISTER TODAY! » [BIKEMSVA.ORG](http://BIKEMSVA.ORG) » 434.971.8010

The Annual **MS** Dinner of Champions

## WALK MS

## CONNECT IN YOUR COMMUNITY

Walk MS gives everyone an opportunity to join the movement to create a world free of MS. Whether you participate by forming a team, walking, volunteering or raising money as a "virtual walker," you are making a difference in the lives of those affected by MS.

With 22 events throughout the Blue Ridge Chapter, there's a Walk MS near you! Registration is open online at [www.walkMSblueridge.org](http://www.walkMSblueridge.org). You can sign up to walk or to volunteer. Anyone who would like to walk can also register onsite at the event.

Participants who raise \$125 or more will receive the 2013 commemorative Walk MS T-shirt. Fundraising to qualify for the shirt and other prizes continues through 30 days after the event.

To learn more about Walk MS, find out how to create a team or ways to jump start your fundraising, contact Annamarie Bonanno at 434.971.8010 or [annamarie.bonanno@nmss.org](mailto:annamarie.bonanno@nmss.org).



## Don't Just Ride. Bike MS.



### Bike MS: Country Roads Ride 2013

September 14-15, 2013

Join us for the 23rd Annual Country Roads Ride, featuring scenic road and trail routes that are challenging for the experienced rider or energetic novice! You can make a difference. Cross the finish line with us and help us finish MS!

REGISTER TODAY! » [BIKEMSWV.ORG](http://BIKEMSWV.ORG) » 304.343.5153

## SOCIAL CONNECTIONS PROGRAMS

## SELF-HELP GROUPS CONNECT FOR SUPPORT

Social connections and support groups help support people with MS and their families in adapting and coping with the changes that living with multiple sclerosis may bring. The Blue Ridge Chapter offers a variety of emotional support programs for people with MS and their families and care-partners.

One of the most popular social connections programs, self-help groups, bring people together who share a common life experience for support, education and mutual aid. Self-help groups meet across the chapter at varying times and locations. Some groups accommodate care partners as well as the person with MS. There is also a telephone self-help group to accommodate the needs of those who are unable to attend a group to distance or transportation or mobility issues. Call 800.344.4867 for information on the group closest to you.

## DIY EVENTS

## DO IT YOUR WAY

Do It Yourself Fundraising is an opportunity for people with a deep commitment to the MS cause to raise awareness and critical funds for the MS movement in new and creative ways. Your ideas are limited only by your imagination in creating a fun event! DIY events can be anything from golf tournaments to dinner parties, bake sales to endurance events - or a concert like Rock MS at The Jefferson Theater on April 13!

To make fundraising event easier, the National MS Society has developed an online fundraising tool like the one used for Walk MS and Bike MS. You can send emails to friends and family, they can make donations and you can track your efforts through social media. For more information on DIY events, visit [www.nationalMSSociety.org/vab](http://www.nationalMSSociety.org/vab) or call 800.344.4867.

## EDUCATION

# TWO TELECONFERENCE SERIES ADDRESS ISSUES OF LIVING WITH MS

The Blue Ridge Chapter is pleased to present two series of teleconferences addressing a variety of topics for people with MS and their families.

**The LINKS Teleconference Series** will “link” you with the information and tips on how to maintain your quality of life in the years ahead - whether you just received a diagnosis of MS or have been living with it for a long time.

- **April 2:** How to Find the Right Care
- **April 9:** Care and Recover After a Relapse
- **April 16:** Complementary Approach to MS
- **April 23:** How to Hire Home Health Care
- **April 30:** The Hidden Effects of MS: Financial Survivability
- **May 7:** Tips & Gadgets
- **May 14:** Minimizing Your Risk of Falls
- **May 21:** Healthy Living with MS: Diet & Nutrition
- **May 28:** Clinical Trials & Progress in MS Research

**The Spectrum of MS Teleconference Series** will address some of the more challenging symptoms of MS.

- **April 17:** Below the Belt: Bladder and Bowel Issues in MS
- **May 8:** MS, Sex and Intimacy
- **June 12:** Improving Independence in Progressive MS

Call 800.344.4867 or visit [www.nationalMSSociety.org/vab](http://www.nationalMSSociety.org/vab) to register. The registration deadline is one week prior to the call. **You must register individually for each call you wish to attend.** After the calls are completed, audio recordings will be posted on our website at [www.nationalMSSociety.org/vab](http://www.nationalMSSociety.org/vab).

Check the Blue Ridge Chapter calendar for all the latest programs and events!  
Visit [www.nationalMSSociety.org/](http://www.nationalMSSociety.org/) and click Chapter Calendar on the left navigation bar.

## REGISTER NOW - MS RETREAT AT THE BREAKS

MS Retreat at the Breaks 2013 is a weekend educational retreat for people with MS and their families. We welcome singles, couples, families with children, friends and other loved ones. The retreat will provide you and yours with time to participate in activities and educational sessions throughout the weekend and discover the wonders of nature at the “Grand Canyon of the South,” Breaks Interstate Park on the Virginia-Kentucky border.



- Hotel-style Lodging (first come, first served basis)
- Wheelchair accessible overnight accommodations available
- Fully accessible park buildings
- Accessible overlooks

### Registration is OPEN!

Space is limited - register now! Call 800.344.4867 or visit [www.nationalMSSociety.org/vab](http://www.nationalMSSociety.org/vab); click on the May calendar.

### Cost

\$30 per adult, kids under 18 free

## THE MS CONNECTION IS A PUBLICATION OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

**Blue Ridge Chapter**  
1-800-344-4867  
email: [vab@nmss.org](mailto:vab@nmss.org)

**Virginia Office**  
1020 Carrington Place  
Charlottesville, VA 22901  
(434) 971-8010

**West Virginia Office**  
1700 MacCorkle Ave SE  
Suite 141  
Charleston, WV 25314  
(304) 343-5153

**Board Chairman** • Brian Mason

**Governance Vice Chair** • Ron Tweel

**Treasurer** • Meg Haymans

**Chapter President** • Fay Painter

**Secretary** • Ron Mittelman

**Editor** • Carrie Dahlquist

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 contents or use 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 mission of the National Multiple Sclerosis Society is to mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

Please consider remembering the National MS Society in your will.



**National  
Multiple Sclerosis  
Society**

Blue Ridge Chapter  
1020 Carrington Place  
Charlottesville, VA 22901

Change Service Requested

NON-PROFIT  
ORGANIZATION  
U.S. POSTAGE  
PAID  
Charlottesville, VA  
Permit No. 162

## THANK YOU TO OUR 2012 SPONSOR OF MS CONNECTION

### Sprague & Hixson LLP

**MS Connection** is sponsored by Sprague & Hixson LLP, a law firm assisting people with multiple sclerosis in Social Security disability claims.

Do you have questions about qualifying for Social Security disability benefits?  
Call us at 1-800-933-7870.

The Blue Ridge Chapter serves 6,000 people with MS in western and central Virginia, the state of West Virginia, and seven counties in Kentucky. We are a collective of passionate individuals who want to do something about MS now—to move together toward a world free of multiple sclerosis.

Contact the Blue Ridge Chapter today to learn more about all of our programs and services.

1-800-344-4867 [nationalmssociety.org/vab](http://nationalmssociety.org/vab)  
[vab@nmss.org](mailto:vab@nmss.org)

#### ***What We Offer***

Advocacy  
Community & Medical Referrals  
Educational Workshops  
Employment Resources  
Exercise Programs  
Family & Social Programs  
Financial Assistance

Free Information about MS  
Lending Library  
Newly Diagnosed Services  
Peer Supporters  
Self Help Groups  
Volunteer Opportunities  
Walk MS & Bike MS