

MS CONNECTION NEWSLETTER

GIVE THE GIFT OF MUSIC

Looking for a last minute gift? Every time you give the gift of music through MS Music Store, the Ohio Valley Chapter benefits.

Visit MS Music Store at www.MSMusicStore.com and sample any of the 600,000+ songs available from the Warner Music Group. Then, email a gift of 10 songs for just \$12.60. In most cases, that's cheaper than iTunes.

Artists include Blake Shelton, Cee-Lo Green, Jason Mraz, Zac Brown Band, The Black Keys, Flo Rida, Gym Class Heroes, Linkin Park, Kid Rock, Eric Clapton, Green Day, Michael Buble, Hunter Hayes, and thousands more!



DONATE YOUR AUTO FOR A TAX DEDUCTION

AUTOS-4-MS allows individuals and organizations to donate their unwanted vehicles to help those with multiple sclerosis.

We accept cars, trucks, boats, trailers and motorcycles. We also accept recreational vehicles upon inspection.

The National MS Society receives 100% of the proceeds from the sale of each vehicle.

Don't delay, help drive MS away by donating your vehicle today! Go to Autos4MS.org.

Fill out and submit our electronic vehicle donation form prior to January 1st, 2013 to be eligible to claim on your 2012 taxes!

If you have further questions, please phone Jim Leedy at 1-877-672-8864. Thank you!

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LIVING WITH MS

MS SYMPTOMS AND WINTER WEATHER

BY JULIE STACHOWIAK, PHD

Most of us with multiple sclerosis are heat intolerant to the point of being unable to function outside during peak summer temperatures. But when I asked people with MS on my blog at www.ms.about.com what their MS temperature “limits” were, I was surprised when several people said that the cold wasn’t so great for them, either.

Many people complained of increased spasticity in cold weather. Readers mentioned that their limbs “felt like wood” or that their joints ached during lower temperatures. A couple of people also mentioned that the MS “hug” could be intolerable in the cold. (The MS hug is the gripping feeling around the torso that is caused by a lesion in the spinal cord that results in spasms in the tiny muscles between the ribs.)

I also know that some people with MS tend to feel more fatigued in winter months. This could be an indirect result of coping with some of the symptoms mentioned above. It could also be that the shorter days and limited sunlight exacerbate depression, which can be a symptom of MS. New data is emerging all the time on the role of vitamin D in MS.

Perhaps we feel our symptoms more acutely when our vitamin D reserves are at their winter lows, although this hasn’t been confirmed yet by scientific studies.

Here are a few tips to help you enjoy the colder months if you are bothered by frigid temperatures.

- Soak up sunshine during the warmest part of a sunny winter day to help your body produce vitamin D.
- Don’t overdo the heat. When I get cold, I tend to take really hot showers. Recently, I got dangerously dizzy during one. Remember, extreme heat is not our friend, either.
- Warm yourself from the inside. Drink a hot beverage to take the chill off.

Like many other situations that we must navigate through with MS, a little strategic planning of winter activities can help you have some control over symptoms. Put some thought into what you enjoy doing in the winter, take a couple more precautions and get the most out of the cold months. ■

Diagnosed with MS in 2003, Julie Stachowiak, PhD, is the author of *The Multiple Sclerosis Manifesto*.

Originally published on www.blog.nationalMSsociety.org.



CELEBRATION 2012 ANNUAL MEETING AND AWARDS CERMONY

Walk MS 2012 Top 50 Fundraisers

Michael Barron
Carol Toschlog
Jim Bodenmiller
Susan Kahn
Lora Gary
Judy Tudor
Connie Veach
Barbara Diehl
Randy Rhodes
Dave Schwarber
Danneen Ross
Amy Vandergrift
Cliff Labbe
Amanda Feldmann
Emmy Friedenber
Amanda Glenski
Lori Gregorski

Rolf Hetico
Dawn Gast
Charline Werts
Judy Ramsey
Carol Sims
Collette Herbig
Kim Barker
Steve Kratzer
Eric Yeiser
Hayley North-Jett
Michelle Regula-Bidwell
Shalana Shreffler
Cheryl Chasteen
Holly Walters
Lori Gerring
Nancy Suer
Lori Fry

Robbie Nash
Jennie Ward
Deborah Beegle
Stephanie Magrisso
Penny Ake
Lori Whittenberger
Bonnie McCarthy
Donna Wagner
Allison Schmidt
Madeline Williams
Tricia Smith
Shirley Link
Stephanie Pastura
Matt Feldmann
Elissa Miller
Kiley Kinnison

Bike MS 2012 Top 50 Fundraisers

Michael Rath sack
Victor Voegele
Carol Heitzer
Frederick Ferguson
Michael Esselman
David Roediger
Eric Josvanger
Samuel Powel
Bill Goetz
Roger Messenger
James Singler
Jeff Sutherland
Rick Burdick
Stephen O'Neill
Eric Deel
Dave Wall
Jim Lewis

Bob Bloom
Ginger Kubala
Bob Wanat
Jim Murphy
Mike Johnson
Dave Foster
Danielle Yarber
Donald Garrison
Renee Wieman
Lee Robinson
Lori Oppt
Paul Sudkamp
Eric Burgmann
Shari Heinrich
John Chester
Tom Moffitt
Bill Kilduff

Avi Bahir
Jim Schult
Randy Nickum
Kelly Knox
Rick McKenzie
Valarie Ervin
Dan Klocke
Ken Miller
Vicki Klocke
Charles Baker
Elisa Nickum
Red Jentz
Jeff Wiles
Don Boyle
Bill Frost
Patricia Knight-Lutz



ADVOCACY

WHERE WE ARE: HEALTH INSURANCE EXCHANGES

BY MARCELLA DURAND

If you had to create a way for millions of people to learn everything they need to know about health insurance, so that they could choose a policy that's right for them and get properly enrolled with top-notch customer support, how would you do it?

That's the question state lawmakers are facing as they consider how to organize their state's health insurance exchange, a major component of the ACA (Affordable Care Act) due to begin operation by 2014.

CHOOSE A POLICY THAT'S RIGHT FOR YOU.



WHAT THEY ARE

Health insurance exchanges are web-based “marketplaces” where individuals and small businesses can compare and purchase affordable and qualified health benefit plans. Existing models have been compared to websites like www.travelocity.com or Consumer Reports’ product ratings that offer consumers a choice of options, based on their needs and preferences.

In addition to information about the price of various plans, the exchanges will be able to tell people if they qualify for tax credits provided in advance to make the plans affordable.

Exchanges also increase competition among insurance companies, which should bring down costs. Members of Congress and other federal employees currently get their health insurance from exchanges — an indication that exchanges will stay good resources for finding quality affordable coverage with good benefits and protections for **everyone**.

HEALTH INSURANCE EXCHANGES ARE WEB-BASED ‘MARKETPLACES’ WHERE INDIVIDUALS AND SMALL BUSINESSES CAN COMPARE AND PURCHASE AFFORDABLE AND QUALIFIED HEALTH BENEFIT PLANS.

The ACA has established standards that exchanges **must** meet, but most of the planning and implementation will take place at the state level.

State lawmakers can either establish their state's own exchange through legislation, or allow their eligible residents to use an exchange run by the federal government. Many exchanges are still "under construction" as states across the nation debate what will work best for them.

WHAT'S INCLUDED

Some important features of exchanges that will help people with MS and others when they go shopping for health coverage include:

- **User-friendly application and enrollment processes.** A single, standardized application form and a "no wrong door" approach determine which programs people are eligible for and direct them through the process with a minimum of red tape.
- **Security.** For many people, if they lose their job, they lose their insurance, too. Exchanges guarantee a secure place where anyone who's not already covered through an employer plan or Medicare can obtain insurance. Moreover, by law, insurance plans offered through exchanges will not be able to deny coverage because of pre-existing conditions like MS.
- **Accessibility.** Help with selecting and enrolling in a plan will be available to consumers over the phone, online through the exchange's website, and in person through specially trained "navigators." Traditional insurance brokers and agents will continue to play a role by helping business owners and other customers purchase health coverage, too.

All services of the exchange should be available to all persons eligible for its products, regardless of any disabling condition. That includes overcoming barriers due to language, as well as physical or cognitive disabilities.

- **Reassurance.** Exchanges will offer plans that allow people to keep their current healthcare providers. This is important to people with MS or other chronic conditions, who often have established a solid relationship with their doctor, nurse or therapist.
- **Transparency.** By law, details about all plan options and covered benefits, including out-of-pocket costs and benefit exclusions, must be made clear. Greater transparency in coverage will help consumers make "apples to apples" comparisons between options from insurers competing on a level playing field.

WHERE WE ARE NOW

To find out more about our state's plans for establishing a health insurance exchange, visit the Kaiser Family Foundation's interactive website at www.statehealthfacts.org, or www.healthcare.gov/news/factsheets/2010/07/esthealthinsur_exch.html (click the "state-by-state" link). The Society has also set up a Web page devoted to ACA FAQs (Frequently Asked Questions) at www.nationalMSSociety.org/ACAFAQS. ■

Marcella Durand is the associate editor of *Momentum*, the Society's national magazine. Go to www.nationalMSSociety.org/Momentum.



AWARENESS

NATIONAL MS SOCIETY BOW TIE

The National MS Society Bow Tie was unveiled at the Ohio Valley Chapter's Dinner of Champions.

The colors are silver and orange. Orange is the official color of the National MS Society. Silver is in honor of Local 12 television Vice President, Les Vann. He is the 2012 Silver Hope Award winner.

The dots on the tie are depictions of a healthy myelin sheath, making this tie truly connected to the mission of the National MS Society.

A few of these limited edition ties are available for just \$57 each. All proceeds benefit the Ohio Valley Chapter of the National MS Society. To purchase, please email mary.wright@nmss.org or phone Mary Wright at 513-769-4400.



KEN ROSENTHAL (WITH TODD FRAZIER OF THE CINCINNATI REDS) WEARS THE NATIONAL MS SOCIETY BOW TIE. HE ALSO WORE THE TIE DURING GAME 2 OF THE 2012 WORLD SERIES



CHRIS WELSH (WITH THOM BRENNAMAN) OF FOX SPORTS OHIO WEARS THE NATIONAL MS SOCIETY BOW TIE.

Special Thanks to Dhani Jones and Chad Williamson of Bow Tie Cause for their dedication to this project.

CLASSIFIEDS FOR SALE

SCOOTER

2004 Golden COMPANION II, 2004 model, new \$2,335. New batteries 5/13 \$240. Basket, horn, lights. \$750 firm.



And aspirator, sterile tubing. \$50.

Connie
(513) 519-7059.

MEDICAL SUPPLIES

Hill-Rom Total Care Sp02RT Bed Advanced wound care mattress. Lateral Rotation. Percussion and Vibration pulmonary functions. Full chair positioning. Excellent condition - used 3 months - original owner.

Permobil M300 Electric Wheelchair Fully equipped. Seat-tilt and full back recline features. High profile Roho seat cushion included.

Respironics Cough Assist

Invacare 5 Oxygen Concentrator

Please call Kevin at 513-226-0493 for additional information.

BUYER BEWARE: Classified transactions are not a program of the National MS Society. Transactions are made solely by the buyer/seller/trader/recipient. These transactions are not reviewed, approved or endorsed by the National MS Society. The National MS Society is not responsible for the quality of any items, and will not participate in any transaction or recourse. We did, however, want to inform you of this opportunity as a service/courtesy to our members. Proceeds do not benefit the Ohio Valley Chapter of the National MS Society.

2012 Golden Circle

THANKS TO THE GENEROSITY OF DONORS IN THE OHIO VALLEY, NEARLY \$65,000 WAS RAISED DURING THE 2012 CAMPAIGN AND MORE THAN \$165,000 SINCE 2010.

2012

Paul and Cindy Barnhart	Lindsay Mowery
Connie Barr	Gerald Mushaben
Casey and Rachel Boland	Jeffrey Nielson
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Kent Holwadel	Mark and Beth Townsend
Omar and Carol Johnson	Andy and Debbie Walter
Susan Kahn	Steven and Carolyn Wenstrup
Christina Kohnen	Andrew and Cheryl Winans
Kuhns Brothers Company Foundation	Sidney Wittenberg
Marvin and Peggy Lewis	Bob and Kit Wylly
David and Joann Lindner	Eric Yeiser
Glenn and Lauren Marino	

THE GOLDEN CIRCLE COMMITTEE GRATEFULLY ACKNOWLEDGES ALL THE DONORS WHO CONTRIBUTED TO THE GOLDEN CIRCLE 2012 CAMPAIGN WITH GIFTS OF \$1,000 OR MORE — THANK YOU!

ADVOCACY

VICTORY IN MEDICARE SETTLEMENT

BY MARCELLA DURAND

For years, Medicare's so-called "Improvement Standard" denied coverage of certain treatment services to people with multiple sclerosis and other diseases. However, in October, a settlement to end the standard was reached in a nationwide lawsuit in which the National MS Society was a plaintiff. The Society joined other national 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 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. The standard actually violated Medicare's own official regulations, which state that "the restoration potential of a patient is not the deciding factor" for coverage. The agreement

to end the standard will vastly benefit people with MS and their families, helping place essential services back in their reach.

Once the settlement is approved by Chief Judge Christina Reiss of the U.S. District Court in Vermont, where the suit was filed, the standard's use will effectively end. CMS will revise the Medicare Benefit Policy Manual so that coverage standards will instead be based on people's need for skilled care, regardless whether they show improvement. In addition, CMS will conduct a nationwide educational campaign about the changes, which apply to Medicare and to private Medicare Advantage plans.

For more information and to follow the settlement's progress, visit www.MSActivist.org, or sign up for MS eNEWS at www.nationalMSsociety.org/signup. ■

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



MS ACTIVISTS HELP MAKE CHANGE HAPPEN.

RESEARCH

PARTNERING ON
PROGRESSIVE MS

BY MARCELLA DURAND

Treatments for relapsing-remitting multiple sclerosis have moved forward, but treatments for progressive MS have remained maddeningly elusive. A newly formed **International Progressive MS Collaborative** intends to find out why.

A far-ranging collaboration between the National MS Societies of the U.S., Canada, Italy, the Netherlands and the United Kingdom, and the Multiple Sclerosis International Federation, its mission is to speed the development of effective therapies for progressive forms of MS. “Overcoming the challenges of progressive MS is a key objective of the Society’s Strategic Response to MS,” says Timothy Coetzee, PhD, chief research officer of the Society. “This is just one of the ways we’re collaborating worldwide to speed clinical trials in progressive MS.”

The collaborative’s first step was to publish an opinion paper in **Multiple Sclerosis Journal** that outlined the challenges in developing therapies for progressive MS. It identified five key research priorities, as follows:

01 Experimental models of MS. Animal models that more closely reflect the symptoms and underlying tissue damage of progressive MS are urgently needed.

02 Identification and validation of targets and repurposing opportunities. Advances in MS genetics and the systematic re-evaluation of drugs approved for other indications may help identify new therapeutic targets in progressive MS.

03 Proof-of-concept clinical trial strategies. Lesion activity on MRI is an accepted biomarker in clinical trials for relapsing-remitting MS, but no comparable measure has been identified for progressive MS — yet.

04 Clinical outcome measures. Establishing clearer outcome measures for progressive MS will help evaluate possible therapies.

05 Symptom management therapies and rehabilitation strategies. Developing symptom management therapies and rehabilitation strategies in progressive MS may be advanced by targeted research and assessing potential treatments in rigorous, well-designed trials.

The collaborative has convened five working groups to discuss these challenges and opportunities and to make research recommendations in each of the key areas. “Tackling these issues will require an integrated, multidisciplinary approach to enable effective translation of research into therapies,” wrote the authors of the paper. [To read the paper in full, go to tinyurl.com/bdjv5ak.]

The collaborative will host an international conference in 2013 to plan how to continue moving research forward. Visit www.nationalMSSociety.org/progressiveMS for more information on progressive MS, or sign up for MS eNEWS at www.nationalMSSociety.org/signup for the latest on the collaborative’s progress. ■



**National
Multiple Sclerosis
Society**

Ohio Valley Chapter
4440 Lake Forest Drive
Cincinnati, OH 45242

WALK MS, MUCKFEST MS, AND BIKE MS ONLINE REGISTRATION NOW OPEN!



Western & Southern
Financial Group

Ohio Valley
Walk 2013

April 13th, 20th, and 27th, 2013
www.WalkMSOhioValley.org



July 27th, 2013
www.MuckFestMS.org



KROGER BRAND
Venture the
Valley 2013

August 24-25th, 2013
www.BikeMSVentureTheValley.org

