

## TWO WOMEN RIDE TO BEAT MS

THOUSANDS OF MILES SEPARATE THESE TWO WOMEN LIVING WITH MS. BUT THEY SHARE A PASSION: BIKE MS

Photo: Jeanine Lunsford



**Christina Hake**

It's Lisa Disbrow's first Bike MS event and Christina Hake's second. Neither had been much of a cyclist until they were diagnosed and then got involved with Bike MS.

"I was a complete novice," Christina said. "Then someone loaned me a very, very nice road bike." Friends and family helped Christina create the Smyelin' As We Ride team, and they won Most Spirited Team last year in the Northern California Chapter's Waves to Wine ride. "We have a joke in our family that we're all going to live longer because I got this disease," she laughed.

Lisa is busy training with her team, named after her clothing boutique, Scout & Molly's, for the Eastern North Carolina Chapter's September Bike MS event. "I haven't ridden a bike since I was 10 years old—this will be my first real cycling event," she said. While she's hit a couple

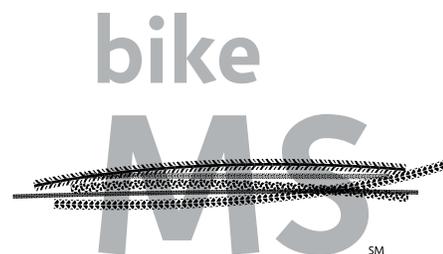
Photo: Ashley Jones



**Lisa Disbrow**

bumps along the way—once literally a tree root—she's climbed right back on the saddle. "I was a little banged up, but recovered just fine," she said.

The Society provides all participants in Bike MS events with information about essential gear, cycling techniques, sports nutrition and safety. Support continues on the weekend of the ride with fully stocked rest stops, support vehicles, and enthusiastic volunteers and staff to cheer everyone on. For information on how to get involved here, visit [bikems.org](http://bikems.org) or call us.



## FOR PEOPLE NEW TO MS

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

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

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

## CONGRESS MOVES ON HEALTH-CARE REFORM

In June Congress introduced two health-care reform proposals, both of which include provisions important to people with MS.

The Senate Health, Education, Labor and Pensions Committee (HELP), led by Sens. Chris Dodd (D-Conn.) and Ted Kennedy (D-Mass.), introduced the "Affordable Health Choices Act," which prohibits insurers from denying coverage based on pre-existing conditions and includes caps on out-of-pocket spending, support for long-term care and subsidized premiums for low- and middle-class families.

The Energy and Commerce, Ways and Means, and Education and Labor Committees also

released a draft bill with similar provisions.

Both drafts are expected to be debated in the House and Senate before Congress recesses this August.

### ADD YOUR VOICE

As legislators prepare to make this bold move, the National MS Society encourages people living with MS to help influence the health-care reform debate by sharing the Society's National Health Care Reform Principles ([nationalMSsociety.org/reformprinciples](http://nationalMSsociety.org/reformprinciples)) with members of Congress and their staff.

### GET INVOLVED

Join the movement at [nationalMSsociety.org/advocacy](http://nationalMSsociety.org/advocacy).

## WHEN A MEDICATION IS OFF LABEL

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

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

### THE EXPENSE FACTOR

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



David Borchart

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

### THE RIGHT DIAGNOSIS

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

### COVERING YOUR COSTS

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

- 2 If there isn’t one, or your health-care provider feels the off-label drug is best for you, file an appeal if insurance won’t cover it. “Every insurance plan must provide for an appeal of any ‘adverse determination’ made by the plan, including at least **two levels of appeal**,” said Kim Calder, director of Insurance Initiatives for the Society. The Society can help. Visit [nationalMSsociety.org/insuranceappeals](https://nationalMSsociety.org/insuranceappeals).

We also have a toolkit of appeal letters for doctors that relate to commonly prescribed off-label treatments for MS. Visit [nationalMSsociety.org/appealtoolkit](https://nationalMSsociety.org/appealtoolkit) or contact us.



## NUTRITION SOS

BY DENISE NOWAK, RD

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

### WHAT DOES A 3-DAY SUPPLY LOOK LIKE?

Let the Food Pyramid be your guide.

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

bottled vegetable juice, instant potatoes.

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

### CHOOSING THE RIGHT FOODS

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

### IF THE POWER GOES OUT

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

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

### STORAGE TIPS

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

### REMEMBER WATER

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

### AND ESSENTIAL SUPPLIES

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

### DON'T FORGET PETS!

They need 3 days of food and water too.

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

## DETECTING NERVOUS SYSTEM PROTECTION & REPAIR

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

Nearly 60 scientists discussed the problem at a workshop held last summer in Amsterdam by the National MS Society's International Advisory Committee on Clinical Trials.

Findings were published in **Nature Reviews Neurology** 5, 256-266, and is available free at [nature.com/nrneurol/journal/v5/n5/pdf/nrneurol.2009.41.pdf](http://nature.com/nrneurol/journal/v5/n5/pdf/nrneurol.2009.41.pdf).

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

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

- **Magnetic transfer ratio (MTR)** measures how much energy is transferred or absorbed by protons in the brain.
- **Whole brain volume measurement**, which is done with a series of MRIs, has excellent sensitivity to disease changes, researchers noted, but does not distinguish well between types of tissue damage.

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



## BREASTFEEDING & MS

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

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

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

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

## MS IN FOCUS EXPLORES TWO DIFFICULT SYMPTOMS

### ATAXIA & TREMOR

Did you know that in the late 1800s, doctors measured ataxia by having patients walk on long strips of paper with ink on their feet?

**MS in focus 13** includes this fact and much, much more on ataxia, otherwise known as incoordination and unsteadiness, and tremor caused by MS. This issue of the biannual magazine, which is produced by the Multiple Sclerosis International Federation, contains a range of information both practical and historical on these two difficult symptoms of MS.

No medication has thus far been shown to be consistently effective for treating tremor and ataxia in people with MS.

**MS in focus 13** explores other options, such as rehabilitation and surgery, as well as drugs in the pipeline. It also will help you understand what causes ataxia and tremor in MS, and how they are evaluated and measured by health-care providers.

**MS in focus 13** is available free of charge online at [msif.org/en](http://msif.org/en). Click the link to **MS in focus**.

## THE SOCIETY ON YOUTUBE

Check out the Society's channel on YouTube and dig into hundreds of award-winning short films, informational shorts from experts in the MS field as well as quirky and serious videos by down home vloggers who have something to say about life with MS. Some of the best are tagged by the Society as favorites, like the music video "Beautiful Day," produced by the Multiple Sclerosis International Federation and the Hertie Foundation with permission by U2.

Also cool on the Tube: the MS Society's **Move it.** videos. Check out what people around the country have done to accompany the hit from **Madagascar**. To date, the Society's snagged over 115,000 video views. Up next: a Society call for YouTube submissions and subsequent [nationalmssociety.org](http://nationalmssociety.org) site release. Go to: [youtube.com/nationalmssociety](http://youtube.com/nationalmssociety) for inspiration.

## FUELING THE MS MOVEMENT



This past May, "Amazing Race" host Phil Keoghan triumphantly crossed the finish line on his ride across America. Sponsored by GNC LiveWell, Keoghan crossed 14 states, made over 30 stops, and cycled over 3,500 miles from Los Angeles to New York City in just 40 days. In collaboration with GNC's in-store fundraising campaign his feat raised an astonishing \$500,000 for the MS movement in just six weeks.

But the excitement isn't over! The NOW One Square Meal (the meal replacement bar that fueled Phil during his ride) is giving a portion of sales back to the Society on every bar sold now through September. You can help fuel the MS movement – and yourself!

For more information visit: [nationalmssociety.org/philkeoghan](http://nationalmssociety.org/philkeoghan).



## NOT INSURED?

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

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

Click on **[nationalMSSociety.org/researchinsurance](http://nationalMSSociety.org/researchinsurance)**. And call for help from an MS Navigator at 1-800-344-4867.

## STIMULUS FUNDS HELP LAID-OFF EMPLOYEES PAY FOR COBRA

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

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

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

## ANYCATCHES?

Former employees are ineligible for COBRA if

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

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

For more information go to **[www.dol.gov/cobra](http://www.dol.gov/cobra)** or call us.

## CHARITABLE GIFT ANNUITIES DO DOUBLE DUTY

Imagine helping find a cure for multiple sclerosis while receiving lifetime payments. A charitable gift annuity or CGA is a way to accomplish both.

With a CGA, you make a gift of cash, stocks, bonds or other assets to the National MS Society. In return, you and/or someone you designate can receive regular payments starting immediately or deferred to a future time. In addition, you are eligible for a charitable income tax deduction and can potentially avoid a portion of capital gains taxes—all while helping the National MS Society fulfill its important mission.



### PROTECT YOUR FINANCIAL FUTURE

- CGA payment rates are based on the ages of the beneficiaries at the time payments begin—and increase with age. The National MS Society like most U.S. charitable organizations adopts rates suggested by the American Council on Gift Annuities.
- An annuity rate may be higher than what your current investments offer, including certificates of deposit.
- Those who are at or near retirement age find CGAs add stability to their existing financial plans.

### A CGA MAY BE APPROPRIATE IF YOU ARE CONSIDERING:

- **Creating a supplemental retirement plan**, like the couple who opened a \$10,000 charitable gift annuity with the Society, then another, and are now contemplating a third. “We were looking for someplace to put money where we could get a lifetime income stream out of it—the folks at the Society made us aware they had this program and it was a good fit for us.”
- **Providing financial assistance to a family member**, like the grandmother who found that a CGA gave her the power to support MS research and provide hope for her grandson, who lives with MS.

The minimum dollar amount required to establish a CGA with the National MS Society is \$10,000. Payment rates are slightly lower when the CGA payments benefit two people.

To find out more, please contact us, or Gillian Smith and the MS Society gift planning team at [giftplanning@nmss.org](mailto:giftplanning@nmss.org) or 800-923-7727.

