

# MS CONNECTION

MOVING TOWARD A WORLD FREE OF MS | SPRING 2012

## MS NOW AN MS RESEARCH REVOLUTION

The Society recently launched a research revolution, MS NOW (No Opportunity Wasted), as a comprehensive approach to propel knowledge forward. Over the next five years, the Society will devote \$250 million to move MS research farther and faster than ever before. Our commitment is a broad strategy focused on three distinct results:

- STOPPING THE DISEASE
- RESTORING WHAT FUNCTION HAS BEEN LOST
- ENDING MS FOREVER

MS NOW includes all Society research – Fast Forward and commercial discovery and development, health care policy, scientific fellowships, rapid response funding, targeted research initiatives, basic and laboratory

discovery, and international consortiums and collaborations.

Your support helps fund groundbreaking research all over the world . . . and right here in Northern California. For example, in the area of **Restoring Function**, Dr. David Rowitch from the University of California, San Francisco was awarded a three-year grant for “APC gene function in oligodendrocyte development and myelin regeneration.” Dr. Rowitch is studying the role of a gene that may be important for myelin repair in MS.

Another three-year grant was awarded to Dr. Jeffrey Bluestone, also from UCSF, to focus on **Stopping the Disease**, by studying “CD4+ FoxP3 lineage cells in CNS autoimmune disease and therapy.” Dr. Bluestone is looking for ways to use the immune system’s regulatory mechanisms to stop immune attacks in MS.

Please join us in our mission to achieve a world free of multiple sclerosis. To make a gift or to learn more about MS NOW please contact Don Hall, Director of Donor Relations, at 415-230-6678 ext. 73015 or [Don.Hall@nmss.org](mailto:Don.Hall@nmss.org).



**National  
Multiple Sclerosis  
Society**

### WALK MS: NORTHERN CALIFORNIA 2012

12 walk sites. One destination. A world free of MS. Visit [www.walkmsnorcal.org](http://www.walkmsnorcal.org) to register as a walker or volunteer, form a team, make a donation, or be an event sponsor. Step by step, dollar by dollar, Walk MS is changing lives. Look inside to learn more about Walk MS.

## MS CONNECTION SPRING 2012

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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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## KEEPING UP WITH HEALTH REFORM

BY KIMBERLY CALDER

With various provisions of the Affordable Care Act (ACA) kicking in and legislative challenges to the ACA, it can be hard to keep up—particularly on the state level. Here are some Society-vetted sources for reliable and up-to-date information about the impact of the ACA in our area.

**The National Conference of State Legislatures** at [www.ncsl.org](http://www.ncsl.org) has a whole section on Health Reform that includes a series of brief reports on a variety of ACA-related topics. The site also includes a searchable database, updated every Tuesday, of state legislation related to the ACA. Search 2012 legislation by state, topic, keyword, status or primary sponsor.

**The National Academy for State Health Policy** at [www.statereform.org](http://www.statereform.org) offers an online network called State Refor(u)m, which enables direct connection and information-sharing between policymakers, activists and others working on health reform implementation.

The federal government's official site on the ACA at [www.healthcare.gov](http://www.healthcare.gov) is the best source for hard numbers on the ACA. Click on "The Healthcare Law and You," then "Implementation Resources" to view an interactive map of the U.S. Here you can click to see, for example, how many young adults are now insured in each state, the number of residents who no longer face a lifetime limit on their insurance coverage, the amount of new funds for community health centers and more.

To follow changes in ACA legislation and other public policy issues that specifically affect people

with MS, check in with Society MS Activists at Twitter [@MSActivist](https://twitter.com/MSActivist) and visit [www.MSactivist.blogspot.com](http://www.MSactivist.blogspot.com). The Society also regularly updates Frequently Asked Questions on its website at [www.nationalMSsociety.org/ACAFAQ](http://www.nationalMSsociety.org/ACAFAQ), as more is understood about how the law could impact people with MS.

*Kimberly Calder is the Society's director of Federal Health Affairs and Insurance Policy.*

In Northern California, there is an established **Health Benefits Exchange Board** charged with implementing Health Care Reform. The exchange board is meeting regularly and the Northern California Chapter, as an advocacy organization, is monitoring its activities, attending its meetings and providing input into key discussions. Specifically, we have made recommendations that the essential health benefits offered to Californians include:

- Meaningful habilitation and rehabilitation benefits, including appropriate and medically necessary durable medical equipment.
- Insurance coverage be comprehensive enough to protect persons with chronic conditions from less-than-optimal health or financial hardship.
- An end to the practice of "specialty tier" drugs where people with high cost drug needs are discriminated against by making them pay more out of pocket than other people.

To learn more about the implementation of health care reform in California and the Health Benefit Exchange please access this website: [www.healthexchange.ca.gov/](http://www.healthexchange.ca.gov/)

## A TRIBUTE GIFT TOUCHES MANY LIVES



**“I want to do something to honor my sister... to help her and the many others who are affected by the disease ... and help find a cure, even if it takes longer than my lifetime.”**

We all know someone special: someone we admire, respect, and love. Our relationships with these individuals are priceless, and honoring the people who make them possible can be especially gratifying. A Tribute gift is a meaningful way to express your appreciation for that person.

Celebrate special occasions such as birthdays, anniversaries, weddings or simply extend gratitude by creating a card unique to the event you wish to commemorate.

Monica’s giving to the National MS Society is a perfect example. Since 2004 she has been giving a monthly gift to the National MS Society in honor of her sister who is living with MS. Her reason for giving is simple; “I want to do something to honor my sister ... to help her and the many others who are affected by the disease ... and help find a cure, even if it takes longer than my lifetime.”

Monica’s gifts are received by the Chapter gratefully each month, and in turn a special Tribute card is prepared and sent to her sister,

informing her that a gift was given by her sister in her honor. Monica is pleased to say, “My sister saves every card. And each time we visit she brings them out and shows them to me. She cherishes the cards and what they represent.”

To help honor that special person or event in your life, or to memorialize the passing of a loved one, the National MS Society, Northern California Chapter will recognize each gift with a special Tribute or Memorial card.

Elizabeth Jameson, a local Bay Area artist, designed the artwork featured on the Chapter’s Tribute and Memorial cards. The cards depict images of the brain affected by MS rarely seen before. Ms. Jameson was diagnosed with MS in 1991 and is a pioneer of artwork that deals with the convergence of medical technology, neuroscience and art, reinterpreting the images to use them to explore the wonder and beauty of all brains, including those with a disease.

If you would like to make a donation in honor or memory of a loved one, please contact Don Hall, Director of Donor Relations, at 415-230-6678 ext. 73015 or **Don.Hall@nmss.org**. You can also visit our website at



**www.nationalmssociety.org/can** under the “Donate” section for more information.

**Ms. Jameson’s cards are full color, but for purposes of the MS Connection newsletter, are shown in grayscale.**

## DO IT YOURSELF FUNDRAISING GETS BOOST

A family in Florida who says they like to “eat, drink and throw a good party” hosts a casino night on behalf of the National MS Society. A fellow in Minnesota sponsors an annual four-day event for four-wheeling enthusiasts to ride on trails in the middle of the woods. Other folks have hosted golf tournaments, sailing races, dinner parties, bake sales, hoops for hope basketball and even a strongman competition, a bike ride in high heels and a tabletop decorating contest. A Wall Street–based poker tournament raised over \$850,000, but a \$200 bake sale is equally appreciated.

Diverse as they are, these events are all Do It Yourself (DIY) Fundraising, where people committed to raising awareness and money for the MS movement are limited only by their imagination. DIY fundraising has been going on a long time, but what’s new is an online tool at [www.doityourselfms.org](http://www.doityourselfms.org), “which gives the same resources as we give to Bike MS and Walk MS participants,” according to Rachael Nuwash, DIY project manager for the Society.

These resources include a comprehensive toolkit that covers everything someone who is organizing a DIY event needs to know: establishing a timeline, budgeting, how to make an event memorable, where to hold it, publicity, finding sponsors and volunteers, tips for the day of the event, FAQs and much, much more.

People can find out what lessons others have

learned and how to create a committee—a core group that will support the effort and whose talents can be utilized. (For example, a friend who’s a graphic designer can design the invitation.) The toolkit also includes flyers, badges and email signature images to download. “The online tools are very intuitive,” said Nuwash, so organizers can easily and quickly reach out to friends, family members and co-workers.

“The people who like to organize do-it-yourself events are going to do it no matter what,” Nuwash noted. “Their commitment, creativity and intense connection to the Society are like no other. In turn, we’re committed to supporting people who want to do something **now**.”

### The Beat Rolls On for MS with Chris Anthony

On February 25th, Chris Anthony set a new Guinness World Record™ for the Longest Individual Drum Roll at 8 hours, 2 minutes!

Chris turned his passion into action, and as of press time, he had already raised \$7,000 and counting! We are grateful for Chris’ leadership and are inspired by his goal of setting a new Guinness World Record™ while moving us closer to a world free of MS.

To learn more about Chris and **The Beat Rolls on for Multiple Sclerosis**, please visit [www.thebeatrollson4MS.com](http://www.thebeatrollson4MS.com).



**An in-person workshop at the Central North Carolina Chapter**

health, yoga and nutrition. At some point each evening, we broke into small groups to discuss what we had learned. I remember that one of the most fun and empowering activities was learning how to get a good workout while sitting down. (Who knew?)

Throughout these programs, chapter staff told us about their services and resources, which included numerous opportunities to volunteer. I soon started volunteering and I haven't stopped yet!

**New frontiers**

Of course, things have changed since 1997. While many chapters continue to offer in-person workshops similar to what I experienced, they have also begun exploring additional ways to help people newly diagnosed with MS connect to the Society—and to each other.

"Almost every home now has access to the Internet and that seems to be a primary source for information, especially for tech-savvy people," noted Mary Roberts, associate vice president of the South Central Region. "So we are doing our research to find new and

Each workshop was similarly organized. A speaker would give a presentation and then answer questions. We were introduced to experts in medicine, mental

creative ways to reach people."

Teleconferencing, videoconferencing and webcasts are a few options. "We plan to have a program in one site and broadcast that program to other sites across our region," said Roberts. Some chapters are also trying out new formats for workshops, such as offering quarterly workshops with a nurse, or teaming up with an area MS center or university to provide workshops led by doctors.

Peer support programs are another way to connect. Anyone newly diagnosed can call 1-866-673-7436 to have a confidential telephone conversation with a peer with MS through the Society's MSFriends program. Or they can visit [www.nationalMSSociety.org/onlinepeerconnections](http://www.nationalMSSociety.org/onlinepeerconnections) to search through online profiles of trained peer support volunteers. Once matched, participants can connect confidentially and one-on-one via telephone or email. To discover the full spectrum of resources that the Society offers, call us at 1-800-344-4867 to be connected to an MS Navigator®.

MS is not a virtual disease, and the computer isn't a substitute for personal connection, but we are working to combine the best of both worlds, looking for ways to embrace the information age and to continue to provide the



healing power of human contact.

**Helen Russon is a volunteer at the Oregon chapter.**