

# MS CONNECTION NEWSLETTER



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LEARN MORE  
ABOUT HIGH-  
DEDUCTIBLE  
HEALTH PLANS

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. The National MS Society's medical advisors recommend that people with MS talk with their health care professionals about using these medications and about effective strategies and treatments to manage symptoms. If you or someone you know has MS, please visit [nationalMSSociety.org](http://nationalMSSociety.org) or call 800-582-5296 to learn more.

## CAN YOU HELP US?

If you're able to make an in-kind donation to the Upper Midwest Chapter, contact Lindsay at 612-335-7976, 800-582-5296 (option 2) or [lindsay.anderson@nmss.org](mailto:lindsay.anderson@nmss.org). To see the full in-kind list, visit [MSSociety.org](http://MSSociety.org) and click "Donate."

- Electronic readers (Kindle, Nook)
- Power pallet jack
- Bike rack
- Digital photo printer
- Gift cards (restaurants, convenience stores, etc.)
- Concert and event tickets
- Jump drives (portable storage devices)
- Lanyards and clear name badges
- Gift basket items for silent auctions
- Dry-erase board

## NATIONAL MULTIPLE SCLEROSIS SOCIETY

### Upper Midwest Chapter

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If you wish to receive **MSConnection** via email, please let us know at [editor@MSSociety.org](mailto:editor@MSSociety.org).

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[editor@MSSociety.org](mailto:editor@MSSociety.org)



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## LETTER FROM THE PRESIDENT

# ANCHORS AWEIGH

Last summer, my family purchased a boat — more specifically a boat that doesn't float. It's become a playground for neighborhood kids. Sometimes they are explorers; other times they are princesses; but most often, they are pirates.

Not long after the boat arrived, my six-year-old daughter, Adeyla, turned in her princess dress for pirate garb and led us on a voyage to the pirate exhibit at the St. Paul, Minn., Science Museum. Most interesting to me was learning the two most important roles on a ship — the doctor and the carpenter. For your ship to run well, the people working on it need to be well. You also need the boat to stay afloat.

I've been thinking about this on my land voyages throughout our large chapter territory, and I have come to realize all of us are doctors or carpenters in the MS movement. Some of us are both.

There are the literal health care providers who are so vital to our movement. But there are also social workers, caregivers, club and group leaders, camp counselors and more who work to make sure families affected by MS are living well day by day. You are the doctors of this MS movement, and we can't move forward without you.

And then there are Walk MS coordinators, fundraisers, donors, volunteers and staff members who help ensure we have a sound foundation, can stay afloat and move at record speed. You are funding research with no opportunity wasted and are ensuring programs and services are provided across the chapter territory. You are the carpenters of this MS movement, and without you, our ship would sink.

So mateys, as we embark on our second year in this new Upper Midwest Chapter, join me with your tool belt and your stethoscope to journey toward the ultimate treasure — a world free of MS! ■

## NEWS

# NEW ORAL THERAPY AUBAGIO AVAILABLE FOR RELAPSING FORMS OF MS



The U.S. Food and Drug Administration (FDA) approved Aubagio® (clinical name teriflunomide), a once-daily pill from Genzyme, to treat relapsing forms of multiple sclerosis in September 2012. Aubagio (pronounced oh-BAH-gee-oh) is the second oral disease-modifying therapy approved for the treatment of MS.

“We are greatly encouraged to see a new oral therapeutic option become available to people

living with MS,” said Bruce A. Cohen, M.D., professor, Davee Department of Neurology and Clinical Neurosciences at Northwestern University’s Feinberg School of Medicine, and incoming chair of the National MS Society’s National Medical Advisory Committee. “As with any new therapy, the long-term safety of Aubagio will need to be carefully monitored,” he added. Dr. Timothy Coetzee, chief research officer at the National MS Society, agreed. “With the collaborative research underway around the world today, this is an extremely hopeful time for anyone who is diagnosed with MS.”

## HOW AUBAGIO WORKS

Multiple sclerosis involves immune system attacks on the brain and spinal cord. Aubagio is a novel oral compound that inhibits the function of specific immune cells that have been implicated in MS. It’s related to leflunomide, a drug used to treat arthritis. Aubagio can inhibit a key enzyme required by white blood cells (lymphocytes), reducing the reproduction of certain immune cells active in MS.

Three large clinical trials of Aubagio have been completed, and at least two more are ongoing. In the phase III TEMSO study and phase III TOWER study, Aubagio reduced the average number of MS relapses and disease activity more than an inactive placebo in a combined 1,965 people. Of two different doses tested during the TOWER trial, the higher dose also slowed progression of disability.

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**“WITH THE COLLABORATIVE RESEARCH UNDERWAY AROUND THE WORLD TODAY, THIS IS AN EXTREMELY HOPEFUL TIME FOR ANYONE WHO IS DIAGNOSED WITH MS.”**

— Dr. Timothy Coetzee, National MS Society chief research officer

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In another study, called TENERE, Aubagio was compared with Rebif® (interferon beta-1a, EMD Serono and Pfizer) in relapsing MS, and didn't reach its primary endpoint — the “risk of failure,” meaning the first occurrence of a relapse, or permanent discontinuation of the study treatment, whichever came first.

To learn more about clinical trials, how they work, and how you can participate, visit [nationalMSSociety.org](http://nationalMSSociety.org) and search “clinical trials.”

## **OTHER ORAL DISEASE-MODIFYING THERAPIES**

Other oral therapies to treat MS are now available or in development. Gilenya™, approved by the FDA in September 2010, is an oral therapy approved for relapsing forms of MS to reduce the frequency of clinical relapses and to delay the accumulation of physical disability. Oral BG12 (sponsored by Biogen Idec), for relapsing MS, is currently being reviewed by the FDA for marketing approval and laquinimod (sponsored by Teva Pharmaceutical Industries) is in later stages of development for relapsing MS.

Aubagio isn't being tested in progressive MS. However, there are large clinical trials being conducted to test the effects of Tysabri®, Gilenya®, Ocrelizumab and Masitinib in progressive MS.

## **POTENTIAL RISKS**

In trials to date, Aubagio was generally safe and well tolerated. The most common side effects experienced by participants in clinical trials include diarrhea, abnormal liver tests, nausea, flu and hair thinning.

Taking a disease-modifying therapy is currently the best way to reduce MS disease activity and future deterioration. Selecting an MS therapy should be done by people with MS in collaboration with their MS doctors.

Physicians and people with MS can contact Genzyme for information about Aubagio and patient support programs by calling 855-676-6326 or visiting [MSOnetoOne.com](http://MSOnetoOne.com). ■

## LIVING WITH MS

# MS SYMPTOMS AND WINTER WEATHER

BY JULIE STACHOWIAK, PH.D.

Most people 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, [ms.about.com](http://ms.about.com), what their MS temperature “limits” were, I was surprised when several people said the cold wasn’t so great for them, either.

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



Some people with MS also tend to feel more fatigued in winter months. This could be an indirect result of coping with some of the symptoms mentioned above. It might also be attributed to the shorter days and limited sunlight, which can exacerbate depression, a common symptom of MS.

New data on the role of vitamin D in MS continues to emerge. Perhaps MS symptoms are more acutely felt when 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 frigid temperatures affect your MS-related symptoms.

- Soak up sunshine during the warmest part of a sunny, winter day to help your body produce vitamin D.
- Don’t overdo the heat by taking really hot showers or spending too much time in front of a fire or space heater. Remember, extreme heat can be bad for MS, too.
- Warm yourself from the inside. Drink a hot beverage to take the chill off.

Like many other situations people with MS must navigate, a little strategic planning of winter activities can give you more 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. ■

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Diagnosed with MS in 2003, Julie Stachowiak, Ph.D., is the author of “The Multiple Sclerosis Manifesto.”

**VOLUNTEER**

**THREE CHAPTER VOLUNTEERS RECEIVE HALL OF FAME AWARD**

Three extraordinary leaders from the Upper Midwest Chapter were named 2012 National MS Society Volunteer Hall of Fame award winners. This prestigious honor is given to the most esteemed and select group of the nation's Society volunteers.



Dr. Gary Birnbaum — recipient of the Volunteer Hall of Fame Lifetime Achievement award — is a driving force in the movement to create an MS-free world. Throughout his 35 years of service, he's enhanced the lives of people with MS, not only in the Upper Midwest, but around the world. Dr. Birnbaum is a neurologist at the Minneapolis Clinic of Neurology and director of the MS Treatment and Research Center. Birnbaum has served on the chapter's Board of Trustees since 1978 and serves on the Clinical Advisory Committee. He's also a tireless Research Advocate and donates his time and talent nationally, serving on the National

MS Society Medical Advisory Board and Clinical Care Committee. He's spent years educating future generations of MS clinicians and researchers as a University of Minnesota faculty member. He also regularly speaks at Society client and professional education programs.



Named the Volunteer Hall of Fame Health Care Professional, Dr. Bruce Hughes has nearly 20 years of experience in the field of MS care and research. Hughes is currently director of the MS Center at Ruan Neurology Clinic and Research Center; Director of Specialty Medicine at Mercy Hospital in Des Moines, Iowa; and an associate professor at Des Moines University College of Medicine. He has a long history of speaking at both client and professional education programs throughout the chapter area. Hughes is also a longtime volunteer Research Advocate and has served a remarkable 17 years on the chapter's Clinical Advisory Committee — a committee he's chaired since 1998. In addition to his long history as a dedicated MS care provider, researcher and educator, Hughes has played a pivotal role in the success of the chapter's A Taste of Generosity event since 1996.



Daniel Rude of Oakdale, Minn., received the Hall of Fame award for Programs and Services. Rude has been volunteering for the Society for 10 years, logging nearly

CONTINUED ON PAGE 8

## CONTINUED FROM PAGE 7 (VOLUNTEER)

2,000 hours of service. Beyond providing support to his wife, who lives with MS, he's a successful MS group leader and mentor, a five-year member of the chapter's Care Partner Advisory Group and a spokesperson and advocate for people with MS and their care partners. Dan shared his story at the federal level to help secure funds for the Lifespan Respite

Care Act and continues to raise awareness locally by reaching out to elected officials.

Congratulations, Hall of Fame award recipients! The Upper Midwest Chapter is extremely proud and even more grateful for all your years of service to people with MS and the Society. ■

## VOLUNTEER SPOTLIGHT

### MEET CHELSEA CARON



Chelsea commits 10-20 hours per week as the Grand Forks, N.D., Walk MS 2013 coordinator, her newest role at the National MS Society. Walk MS coordinators plan event logistics, secure local sponsors and raise awareness in their communities. Without them, Walk MS would be impossible.

"I decided to become a Walk MS coordinator because I wanted to bring awareness to multiple sclerosis and the events that fund the mission to end the disease. There are so many individuals who don't know what MS is and there are people with MS who don't know how much

support and assistance is out there for them. But mostly, I did it for my mom and other family members who have been diagnosed with MS."

Caron's mom was diagnosed with MS more than 30 years ago. "She's been such an inspiration in my life because no matter how tough one day may be, she continues to keep moving forward knowing tomorrow is a new day," she said.

Though this is Caron's second year as a coordinator, she's been connected to the National MS Society for more than five years. She was first introduced to the Society after being awarded an MS scholarship to help with college tuition. Caron is active in the MS One-to-One Program (formerly known as the Mentor Program). She's also added event participant to her resume, riding in Bike MS: TRAM, a five-day cycling vacation in Minnesota.

Thank you, Chelsea, for all you do to move us closer to a world free of MS! ■

## EVENTS

# ENJOY FOOD, WINE, INSPIRATION AND MORE



The National MS Society, Upper Midwest Chapter will host three unique events this winter to increase MS awareness and generate funds for cutting-edge research, as well as programs and services that improve the lives of people affected by the disease.

A Taste of Generosity, to be held Saturday evening, Feb. 16, 2013, in Des Moines, Iowa, provides people who are passionate about the MS movement an opportunity to sample extraordinary wines from all around the world, enjoy gourmet food and experience the excitement of a silent and live auction.

To purchase a seat for A Taste of Generosity 2013, visit [tinyurl.com/ATasteofGenerosity](http://tinyurl.com/ATasteofGenerosity) or call 800-582-5296 (option 2). ■

## SAVE THE DATES

On the Move events feature a keynote speaker, a silent and live auction, delicious food and the company of other people who are passionate about ending MS forever.

### On the Move Little Black Dress Luncheon

Thursday, Feb. 28, 2013

Hilton Garden Inn, Fargo, ND

### On the Move Little Black Dress Brunch

Saturday, March 2, 2013

Brown Deer Golf Club, Iowa City, Iowa

### On the Move Luncheon

August 2013

Minneapolis, MN

To learn more about chapter brunch, luncheon and wine-tasting events, visit [MSsociety.org](http://MSsociety.org) and choose “Fundraising Events” in the left-hand navigation.

If you’re interested in donating an auction item or volunteering at one of these unique events, contact Lindsay at [lindsay.anderson@nmss.org](mailto:lindsay.anderson@nmss.org), 612-335-7976 or 800-582-5296 (option 2).

## ADVOCACY

# MAKE A DIFFERENCE AT YOUR STATE CAPITOL



Now that elections are over, new legislators are in office and ready to represent you during the upcoming legislative session. Many elected officials have limited knowledge of the nature and impact of multiple sclerosis. As a constituent, you have the opportunity to share your story with the people who represent you and help them understand the needs of people affected by MS in your community.

**THE NATIONAL MS SOCIETY, UPPER MIDWEST CHAPTER NEEDS YOUR HELP REACHING OUT TO LEGISLATORS AND EDUCATING THEM ABOUT MS AND THE ISSUES THAT AFFECT PEOPLE LIVING WITH THE DISEASE.**

One of the most meaningful ways to make your voice heard is to participate in your local MS Day at the Capitol. This is an opportunity to connect with your legislators, meet others who are passionate about MS-related policy issues and raise awareness about MS at your state capitol.

For more information or to register, contact Jenna at 612-335-7981, 800-582-5296 (option 2) or [jenna.washnieski@nmss.org](mailto:jenna.washnieski@nmss.org).

- St. Paul, MN: Wednesday, Feb. 6, 8:30 a.m. – noon
- Pierre, SD: Wednesday, Feb. 13
- Bismarck, ND: Thursday, Feb. 21
- Des Moines, Iowa: Tuesday, March 12, 10 a.m. – 1 p.m.

**SAVE THE DATE**  
**MS AWARENESS WEEK IS**  
**MARCH 11–17, 2013.**

Visit [MSsociety.org](http://MSsociety.org) in February to learn more about how you can get involved.

GIVING

# YOUR YEAR-END GIFTS

This December, please consider the National MS Society when making your charitable, year-end, tax-deductible gifts. Your donation will continue to accelerate promising new research leads, fund life-changing programs and provide financial assistance for people with MS.

Making a gift in the name of a friend or family member is a meaningful way to honor a special person during the holidays. When you make an honorary holiday contribution, we'll send a greeting card to your friend or family member. Please be sure to let us know your gift is a holiday contribution and provide us with the name and address of the person you're honoring.

Visit **MSsociety.org** to make your tax-deductible gift today, or contact Jane at 612-335-7969 or [jane.piotrowski@nmss.org](mailto:jane.piotrowski@nmss.org). ■

# MS SCHOLARSHIP APPLICATIONS AVAILABLE ONLINE

The National MS Society offers scholarships to support college-bound students with MS or who have a parent or guardian with MS. Scholarships are awarded to first-time college freshmen of any age. Applications for those entering college in the fall of 2013 are now available online and are due Jan. 15, 2013.

For more information about the MS Scholarship Program, visit **MSsociety.org** and search "scholarships," or contact Bethany

at 612-335-7954, 800-582-5296 (option 2) or [bethany.hansen@nmss.org](mailto:bethany.hansen@nmss.org).

To make a donation to the MS Scholarship Program, contact Shannon at 612-335-7928, 800-582-5296 (option 2) or [shannon.wolkerstorfer@nmss.org](mailto:shannon.wolkerstorfer@nmss.org). ■

The Jumpstart MS Scholarship Program, sponsored by Best Buy, is designed to encourage teens affected by MS to stay on track toward post-secondary education and remain active in school and their community.

One \$1,500 Jumpstart Scholarship is awarded annually to a ninth-grade student living in the Upper Midwest Chapter area. Applications will be available online December 2012.

**MONEY MATTERS****HANDLING A  
HIGH-DEDUCTIBLE  
PLAN**

BY MARCELLA DURAND



In a trend that seems to be increasing, many employers will be offering high-deductible health plans to their employees in 2013. A Kaiser Family Foundation 2011 employer survey reported a jump to 17 percent of covered workers enrolled in a high-deductible plan, compared to just 8 percent in 2009.

High-deductible plans (HDHPs) include a minimum deductible starting at \$1,250 for an individual to \$2,500 for a family. The maximum out-of-pocket amount, which includes the deductible and any coinsurance or copays a member pays in 2013, is \$6,050 for an individual and \$12,100 for a family.

If your employer is transitioning to one of these plans this fall, here are some things a person with MS or their spouse or partner might need to know.

**THE MORE YOU KNOW**

“Get all the information you can about the HDHP your employer is offering,” recommended Kris Erickson, senior health insurance manager at the National MS Society. “Find out what the deductible amount is and find out what the benefits are after the deductible is met.”

Most qualified high-deductible plans, meaning they meet government requirements, are accompanied by Health Savings Accounts (HSAs). HSAs allow people to pay for or reimburse themselves for medical services with pretax dollars and often include a contribution by the employer. “These are tax free, so contribute as much as possible,” said Erickson. In 2013, the annual maximum contributions are \$3,250 for an individual and \$6,450 for a family. Individuals who are at least 55 years of age can also contribute a \$1,000 “catch-up” contribution.

**HSA VS. FSA**

HSAs are not the same as Health Flexible Savings Accounts (FSAs). The law requires the entire annual FSA election amount be available to an employee up front, but HSA funds are only available as deposits are made to the account. However, it’s possible to reimburse yourself for a claim later in the year once more funds have accumulated in your HSA.

The maximum annual contributions to an FSA are also different. In 2013, IRS rules will limit them to \$2,500 for an individual and \$5,000 for a family. In addition, unlike FSAs, there is no “use it or lose it” forfeiture on an HSA, and if someone leaves their job, they can take their HSA with them. HSAs also can earn interest.

For a full list of the “qualified medical expenses” for which money stored in your HSA can be used, visit [irs.gov/publications/p502/index.html](http://irs.gov/publications/p502/index.html).

## PREVENTIVE CARE

Under the Affordable Care Act (ACA), private health insurance plans must cover certain preventive health services. (For more information on what’s covered, visit [healthcare.gov/prevention](http://healthcare.gov/prevention).) If someone’s enrolling in a high-deductible plan, it’s important to know annual physicals and preventive screenings are covered. For added motivation, medical costs are less expensive if a problem is caught earlier. In addition, vaccinations and checkups for children under a high-deductible family plan are also considered preventive.

## MS TREATMENT & CARE

Much of MS treatment and care isn’t considered preventive. For instance, MRIs are not considered as such, and the cost of having one will not be covered until one’s deductible is reached.

A person with MS who has a high-deductible plan may be hit hardest by prescription drug

costs. With qualified, high-deductible family coverage, the deductible for the family has to be reached before any non-preventive medical expenses or prescription drugs are covered. In other words, even if only one person is incurring medical expenses, the full family’s deductible must be met by that individual before the insurance will pay for expenses.

In these cases, Erickson recommended looking into patient assistance programs. “If you qualify for assistance, it can make your medication affordable.” For more information, visit [nationalMSsociety.org/PAPs](http://nationalMSsociety.org/PAPs), or call an MS Navigator® at 800-344-4867.

On the plus side, with traditional coverage, deductibles may or may not apply to the out-of-pocket maximum and copays never do. Knowing the true out-of-pocket maximum could be an improvement over traditional plans.

## THE WAY FORWARD

The main reason employers are switching to high-deductible plans is lower premiums. “One improvement is that high-deductible plans are less expensive,” said Erickson, and sometimes these savings may be passed on to employees. While not every employer will be switching to a high-deductible plan, it’s a trend to keep an eye on. ■

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Marcella Durand is on the staff of **Momentum**, the Society’s national magazine.

## CORPORATE SPOTLIGHT

SAM'S CLUB WINS  
CORPORATE STAR  
AWARD

Congratulations to Sam's Club for winning the Upper Midwest Chapter's 2012 Corporate Star award! Sam's Club has helped raise MS awareness and a

significant amount of money to fund research, programs and services through grassroots efforts, such as donation jars, popcorn, caramel apple and hot chocolate sales; MS bracelet

and sneaker sales to employees and customers; and break room activities like bake sales, chili cook-offs and more.

The Sam's Club Fridley, Minn., store has propelled the MS movement forward by raising the most money out of all locations in the Midwest. Additional funds — totaling \$22,000 — also came from a program called "Volunteerism Always Pays," where employees could submit National MS Society volunteer hours for additional cash support for the chapter. At Bike MS: SAM'S CLUB Twin Cities Ride, employees volunteered and provided snacks for participants.

Thank you, Sam's Club for being a title sponsor of a Bike MS event and a top corporate contributor!

SPECIAL THANKS  
TO TARGET

Bike MS: C.H. Robinson Worldwide MS 150 Ride is one of the Upper Midwest Chapter's biggest fundraising events, bringing in more than \$2.5 million in 2012.

Special thanks to Target for creating such a tremendous and memorable finish line experience at the event, where friends and family could watch cyclists roll in after completing 150 miles in just two days. Participants and spectators also loved taking photos with Bullseye, the Target mascot! Team Target boasted 92 participants and raised more than \$49,000 for people living with MS. Thank you, Target!

# CHAPTER PARTNERS WITH CARINGBRIDGE

The National MS Society welcomes CaringBridge as a new partner in the movement to end MS. CaringBridge is a social network that provides a forum where people can post health updates, and family and friends can stay connected and leave supportive messages during a health event, big or small, acute or long term.

If you or someone you love is newly diagnosed or experiencing a serious MS exacerbation, CaringBridge is a great way to keep your network knowledgeable about health-related challenges and progress.

## START A CARINGBRIDGE SITE

To start a CaringBridge Site, visit **CaringBridge.org** and follow a few simple steps, which include setting personalization and privacy options. Access to a CaringBridge site requires that visitors know the exact name of the site they're trying to reach, usually provided by a family member or friend. CaringBridge users have complete control

of the privacy settings and can modify them at any time. Services are available online to anyone, anywhere at no cost.

## START A SUPPORTPLANNER

The SupportPlanner helps families and friends coordinate care and organize helpful tasks, such as bringing a meal, taking care of pets and more. Visit **supportplanner.caringbridge.org** and follow the steps to set up a planner, complete with personalization and privacy options. Add helpful tasks for family and friends and ask them to join your SupportPlanner. People can sign up for specific tasks and show their support.

Thank you, CaringBridge, for supporting families affected by multiple sclerosis and helping the Society move closer to a world free of MS. ■

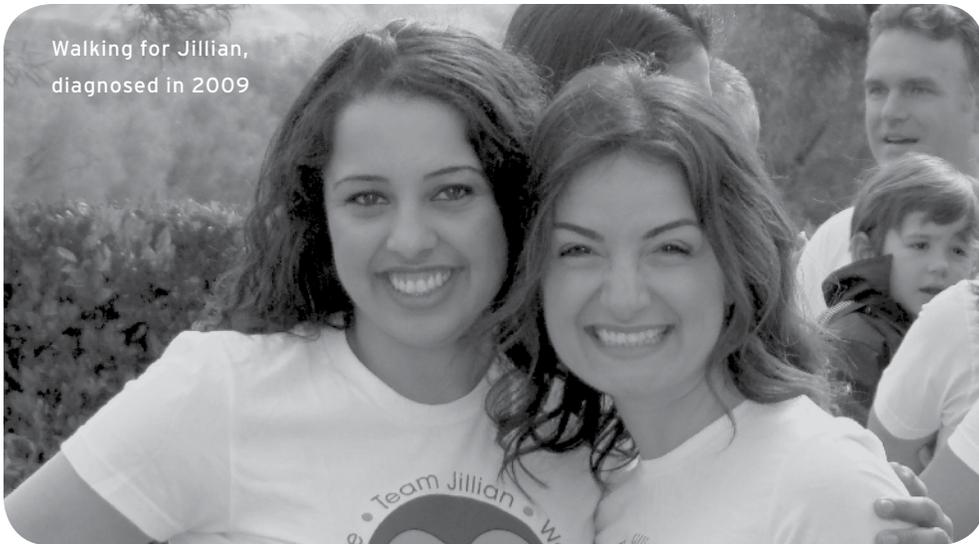




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## CALENDAR

**MS ANNUAL CONFERENCE,  
MINNEAPOLIS, MN**

Jan. 26

**MS ANNUAL CONFERENCE,  
SIOUX FALLS, SD**

Feb. 9

**WOMEN'S CONFERENCE,  
VADNAIS HEIGHTS, MN**

Feb. 23

**COUPLES SOCIAL,  
FARGO, ND**

Feb. 15

Visit the Chapter Calendar  
at **MSsociety.org** for  
more programs.