



FALL 2012
UPPER MIDWEST CHAPTER

MS CONNECTION NEWSLETTER

MS KILLS CONNECTION



CONNECTION KILLS MS



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\$110,000
AWARDED IN MS
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NEW FINDINGS
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MEETING

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 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. To see the full in-kind list, visit MSSociety.org and click "Donate."

- Electronic readers (Kindle, Nook)
- Power pallet jack
- File folders
- 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

200 12th Ave. S.
Minneapolis, MN 55415
800-582-5296

Board chair: Carol Houghtby
Chapter president: Holly Anderson
Editor: Maggie Flanagan
Design: Sue Schweitzer

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Upper Midwest Chapter

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LETTER FROM THE BOARD CHAIR

RAISING FUNDS TO FIND A CURE

The first year after officially becoming the new Upper Midwest Chapter presented some challenges for staff, but it was full of triumphs and unexpected cause for celebration, too. We saw growth in many of our fundraising events, including an increase in programs and services throughout the entire chapter area.

In the winter of 2012, three leadership events were hosted in Iowa and North Dakota. Little Black Dress for MS in Fargo, N.D., and Iowa City, Iowa, and Taste of Generosity in Des Moines, Iowa, brought in a combined \$105,000.

Walk MS generated more than \$2 million, about a half-million below our goal. However, Bike MS: Cruise the Cornfields hosted 70 more participants and raised \$20,000 more in revenue than last year.

And, our biggest cycling event, Bike MS: C.H. Robinson Worldwide MS 150 Ride, raised a whopping \$3.2 million!

Money raised through these events helps fund NOW: No Opportunity Wasted Research Revolution. With the help of Phil Keoghan from “The Amazing Race,” the Society has committed to raising \$250 million by 2015 in support of MS research.

NOW is focused on three key areas: to **STOP MS** in its tracks, to **RESTORE** what’s been lost and to **END MS** forever.

I invite you to partner with us in our campaign to end multiple sclerosis NOW. Visit MSSociety.org to learn more about fundraising events in your area, and sign up! Also, you can become an MS Research Champion today! Visit tinyurl.com/MSResearchChampion to get started.

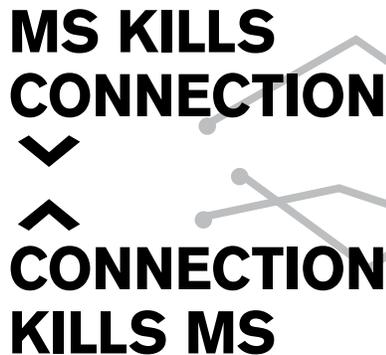
CHAPTER TO HOST FOUR MS ANNUAL CONFERENCES

What if everyone affected by MS — people living with the disease, their family and friends, health care professionals, care providers and community members — could connect with one another in one place? What if we could defy this disease with the very thing it seeks to destroy: connections? And what if, by connecting our knowledge, our hope and our experiences, we could gain a new understanding of how to move forward?

Connect with other families affected by MS at an Upper Midwest Chapter MS Annual Conference, to be held this fall and winter near Des Moines, Iowa; Minneapolis, Minn.; Fargo, N.D.; and Sioux Falls, S.D.

- Learn more about the National MS Society, the progress we've made and what's in store for the future.
- Hear from MS experts about groundbreaking research, recently approved therapies and what's in the pipeline.

**MS KILLS
CONNECTION**
▼
▲
**CONNECTION
KILLS MS**



MARK YOUR CALENDARS

MS Annual Conference, Fargo, ND

Saturday, Nov. 3, 2012, 10:30 a.m. – 2 p.m.
Ramada Plaza Suites and Conference Center

MS Annual Conference, Altoona, IA

Saturday, Nov. 17, 2012, 10:30 a.m. – 2 p.m.
Prairie Meadows Events and Conference Center

MS Annual Conference, Minneapolis, MN

Saturday, Jan. 26, 2013, time TBD
Hyatt Regency Minneapolis

MS Annual Conference, Sioux Falls, SD

Saturday, Feb. 9, 2013, 10:30 a.m. – 2 p.m.
Location TBD

- Meet Chapter President Holly Anderson and board members, and discuss accomplishments and highlights from the past year with Society staff.
- Young people ages 13–18 can meet other teens who are affected by the disease at the Teen Summit, where they'll provide input on how the chapter can better support them, learn more about how they can get involved and have fun!

CONTINUED ON PAGE 7

NEWS

**MORE THAN
\$110,000
AWARDED IN MS
SCHOLARSHIPS**



In 2012, the National MS Society, Upper Midwest Chapter awarded 72 scholarships, totaling \$117,000, to college-bound students affected by MS. Nationally, the Society granted more than \$1 million to 646 students across the country.

Created in 2003, the MS Scholarship Program helps students affected by MS move their lives forward to achieve their post-secondary education goals in spite of the many financial challenges the disease can present.

MEET JUST A FEW OF OUR NEW SCHOLARS



Jessica Blosberg of Shoreview, Minn., is one of the 2012 National Top Scholars. She will attend the University of Minnesota – Twin Cities and plans to receive a degree in animal sciences or agriculture. She’s been a member of the National Future Farmers of America for four years, serving most recently as vice president. Blosberg is a National MS Society volunteer and special event participant and has volunteered more than 700 hours since she was six years old. Both her father and her younger sister live with MS. She said, “MS has definitely challenged our family, but I know I am blessed.”



Also a National Top Scholar, Mara Klecker of Sioux Falls, S.D., whose mother lives with MS, will study journalism and mass communications at the University of Nebraska – Lincoln. A leader of the Serve and Learn Student Association, a member of the Youth Action Council, a Camp Courage counselor, a Muscular Dystrophy Camp volunteer and much more, its clear community service is incredibly important to Klecker. She said, “Through my experiences with the disease, I have learned patience and the joy of helping others.”

Jenna Dominquez, a 2012 Brittany Groess Scholar from Maplewood, Minn., was

CONTINUED ON PAGE 15

VOLUNTEER

VOLUNTEER
SPOTLIGHT

JANET NURNBERG

Janet Nurnberg is a National MS Society all-star. Not only has she been a volunteer with the Upper Midwest Chapter for more than six years — serving as a youth camp counselor, special event volunteer and member of the 20s and 30s Advisory Group — she's committed to participating in every fundraising event in Minnesota in 2012.

Janet's mother was diagnosed with MS more than 20 years ago. Her sister also lives with the disease. "I started volunteering because that was one thing I could easily do to help end MS."

Aside from raising a total of \$5,000 for her 2012 event participation, Janet is focusing closely on recruiting people in their 20s and 30s to join the 20s and 30s Crew, a volunteer group for young adults. "I think it's important to give people an avenue to get involved, and working with a fun and inspiring group of peers can be the best avenue there is." The 20s and 30s Crew has a presence at all Minnesota fundraising events. If you're interested in joining, contact Janet at janet.nurnberg@gmail.com.

Meet other Society volunteers at tinyurl.com/EverydayHeroes. ■

VOLUNTEER
OPPORTUNITIES

The National MS Society, Upper Midwest Chapter is always looking for volunteers with a variety of skill sets. Volunteers help stretch donor dollars and build a stronger organization. Volunteer and move us closer to a world free of MS!

Run to Stop MS — Oct. 7, Minneapolis, MN; Oct. 21, Des Moines, IA

Volunteers are needed to help cheer on runners along the course.

Care Partner Appreciation Dinner — November, Twin Cities and Des Moines, IA

Help us recognize and celebrate MS care partners. Work at registration and check-in at the beginning of the event.

MS Annual Conference — Nov. 3, Fargo, ND; Nov. 17, Des Moines, IA; Jan. 26, Minneapolis, MN; Feb. 9, Sioux Falls, SD

Help with check-in and the Teen Summit.

There are so many ways to get involved no matter where you live. For more information about volunteering or to sign up today, please call 800-582-5296 (option 2). ■

EVENTS

MS LEADERS
RECOGNIZED



golden
CIRCLE

This spring, the Upper Midwest Chapter hosted two events in conjunction with research symposiums in Johnston, Iowa, and Grand Forks, N.D. These

events were held to recognize and honor a select group of MS leaders, volunteers and Golden Circle* members. The receptions provided guests the opportunity to personally meet and speak with the presenting neurologist and others who share a similar passion: to find a cure for MS.

Symposium guest speaker Dr. Todd Janus, director of research at Iowa Health and director

for the Program on Multiple Sclerosis at Iowa Health Physicians, attended the reception in Johnston, Iowa, May 23. Golden Circle members and MS leaders in attendance also had the chance to meet Upper Midwest Chapter President Holly Anderson and Board of Trustees member Mike Whitmer. In addition, attendees heard from Mike and Megan Antenucci about their life with MS and Velo, Mike’s service dog.

In Grand Forks, N.D., June 6, supporters met and heard from Dr. Matthew Roller, neurologist and member of the board of directors for Altru Health System, as well as Upper Midwest Chapter Board of Trustees member, Steve Dirksen.

Special thanks to our guest speakers and MS experts for sharing their knowledge with some of the most passionate and dedicated leaders in the MS movement!

*National MS Society donors who make annual gifts of \$1,000 or more ■

CONTINUED FROM PAGE 4 (MS ANNUAL CONFERENCES)

Plus, help us recognize volunteers, fundraisers, donors and other extraordinary leaders in the MS movement.

When you get down to it, it’s pretty simple. MS kills connections. But it’s connections that will kill MS.

For more information or to RSVP, visit MSsociety.org or contact Ann at 800-582-5296 (option 2) or specialevents@MSsociety.org. ■

WHO SHOULD ATTEND

- People living with MS, their care partners and family members
- Upper Midwest Chapter Board of Trustees members
- Health care professionals
- Corporate partners, donors and volunteers
- Event participants and team captains

NEWLY DIAGNOSED

THE GATHERING
TABLE

BY RONDA GIANGRECO



On July 26, 2008, I was a 53-year-old woman who considered herself very fortunate. I was just back from my latest adventure at a cooking school in Italy. My husband, Michael, and I had spent the day wine tasting in Napa with friends. Life was good.

One day later, I was a disabled woman.

Learning your wife has been diagnosed with multiple sclerosis would be difficult for any man to accept, but for my husband it was a particularly cruel twist of fate. The disease had entered Michael's life when he was just a child; his mother died from complications due to MS when he was just 16 years old. Now it was back for his wife.

Worried that I might not be able to walk for much longer, I asked myself the question, "To where should I walk now?"

My answer: To the kitchen! An avowed foodie, I've always loved to cook. My kitchen is my sanctuary, a place where I can dispense with aggravations while surrounded by the aroma of bubbling soups and the comforting familiarity of my pots and pans. What better place to face the fear gnawing at my gut? It might not have been a conventional treatment plan, but why not attempt to triumph over MS with steaming plates of pasta?

When I made the audacious vow to my husband that I would host a dinner party every Sunday night for an entire year as a means of warding off this disease, he thought I had lost my mind. One would have to be a bit certifiable to think about cooking 52 dinners while living with a neurological condition, but a discussion about parties would be immensely more entertaining than one about motorized wheelchairs. I would stare down MS with spatula in hand.

We began by inviting every friend we knew. The first six who accepted the invitation would join us at our home in Sonoma, Calif., for an evening of laughter, good food and plenty of great wine. Throughout the year, we added people we had met at events, through friends and even a woman I had struck up a conversation with in a grocery store aisle. Eventually, more than 130 people received our email invitation each week.

As we sat around our big, square dining table — referred to in the furniture industry as a "gathering table" — we heard stories that made

us weak with laughter and others that brought tears to our eyes. We were given fresh insights into the people we thought we knew well, while we also formed dozens of new friendships.

I LEARNED FROM THE STORIES OF OTHERS THAT THE CHALLENGES WE FACE HELP FORM THE CORE OF WHO WE ARE AND GIVE US INSIGHT INTO THE STRENGTH WITHIN.

There was the sweet, older neighbor who joined us for dinner one night and informed us that he had been Bozo the Clown in his younger days. The entire table was awestruck when he burst into character. We discovered one of our friends had helped make The Allman Brothers famous. Another had been on a plane with the terrorists a week before 9/11.

We had staunch conservatives sitting across from diehard liberals. We hosted Christian fundamentalists at the same table as a lesbian couple. And everyone learned there is more uniting than separating us.

By the time week 52 arrived, I had made gallons of marinara sauce, scores of ravioli and mountains of gelato. In doing so, I was able to conquer my fear of the future. I learned from the stories of others that the challenges we face help form the core of who we are and give us insight into the strength within.

The icing on the cake ... I was still on my feet. MS didn't win. I did.

I could never stomach my story being touted as yet another example of how just thinking positively can change the course of your life, though. Anyone who has spent time in a hospital bed looking up at grim faces knows there are some hurdles you cannot clear just by employing a perky disposition. The last thing I want to do is add to anyone's burden by suggesting otherwise. My tale is not about bucking up.

Simply put, it is a story about learning that I had more grit and resolve than I had imagined. I found that good friends are a powerful therapy, and I discovered even though fate may shove you in a direction you don't want to go, you can still find a means of traveling the road on your terms.



Ronda Giangreco has written a book about her year-long adventure called **The Gathering Table — Defying Multiple Sclerosis with a Year of Pasta, Wine & Friends** available at [amazon.com](https://www.amazon.com). Sign up for her free monthly newsletter at thegatheringtable.net. ■

ADVOCACY

MAKE YOUR VOICE COUNT

BY RENEE VANDLIK

Election Day 2012 is on the horizon! Get ready to cast your vote for who best represents the issues you care about. Here's what you need to know to vote in the elections Nov. 6.

THE BIG PICTURE

This fall, Americans will cast votes for the presidency, every member of the U.S. House of Representatives and one-third of the U.S. Senate. What's different? Since the 2010 census, 15 million Americans became eligible to vote and an anticipated 50 million more will vote this November due to stronger engagement in national campaigns. However, people with disabilities register to vote at a 16 percent lower rate than other Americans; and with one in 10 eligible voters having a disability, that's a lot of people whose voices



aren't being heard. Make sure yours is. National Voter Registration Day is Sept. 25, 2012. Register yourself and learn how you can register others at usa.gov/Citizen/Topics/Voting/Register.shtml.

PREPARE TO VOTE

This year, citizens in 30 states will have to comply with voter identification laws. Contact your local polling precinct ahead of time to find out what you'll need. Also, ask about accessibility: you don't want to show up to find out you can't get in the door. Since 2005, the Help America Vote Act requires every precinct in the country to have at least one voting machine or system accessible to persons with disabilities, including those with vision impairments. Learn more at aapd.com/what-we-do/voting.

If you find it's too difficult to vote in-person, plan to vote absentee. Learn more about absentee voting at longdistancevoter.org.

THE INFORMED VOTER

To learn more about issues that affect people with MS, such as health care, accessibility and medical research, visit nationalMSsociety.org/advocacy. Then, find out where the candidates stand on those issues — yourcandidatesyourhealth.org is one place to start.

LOCAL RESOURCES

Each state has different rules about voting. For example, North Dakota doesn't require voters to register, while Minnesota, Iowa and South

Dakota require voters to pre-register or register at the polls.

To get your voting and candidate questions answered, check out these local resources:

- National MS Society, Upper Midwest Chapter: tinyurl.com/MSsocietyVote
- Your local Secretary of State's office
- League of Women Voters: lww.org
- Nonprofit Vote: nonprofitvote.org

If you're interested in helping with the chapter's voter outreach efforts or have questions, contact Jenna at 612-335-7981, 800-582-5296 (option 2) or jenna.washnieski@nmss.org. ■

Renee Vandlik is the Society's director of state government and local government relations.

GIVING

MAKE A GIFT THROUGH PAYROLL DEDUCTION



WORKING FOR A HEALTHY AMERICA

Participating in a workplace giving program is an easy way to support the MS movement. Many companies offer these programs, and it's easy to sign up! Find out if your company has a giving campaign, and consider using automatic payroll deduction to make regular gifts to the National MS Society, Upper Midwest Chapter.

If your workplace participates in the Community Health Charities campaign, you can choose the Society as your gift recipient. You can also register through United Way if your company's a member. It's as simple as writing in a designation to the chapter. Your company's campaign coordinator can help you through the process.

If you're unable to make a gift through a workplace giving campaign, you can also set up a sustaining gift at MSsociety.org. For more information, contact Lindsay at 612-335-7976, 800-582-5296 (option 2) or lindsay.anderson@nmss.org. ■

RESEARCH

RESEARCH TIDBITS
FROM RECENT AAN
MEETING

BY MARCELLA DURAND



In April, more than 12,000 neurologists and researchers gathered in New Orleans to present the latest research in multiple sclerosis at the American Academy of Neurology's (AAN) annual meeting. Read about some of the highlights that came from this meeting of minds.

**STOPPING MS**

More than 1,400 people with relapsing-remitting MS participated in a phase III trial of an experimental oral therapy called BG-12. The participants had up to 51 percent fewer relapses over two years compared to those taking a placebo. Although relapses decreased, disability progression was not reduced significantly. The most common adverse events reported were stomach irritation and reddening, though aspirin was shown to reduce the reddening. Biogen Idec applied to the FDA in February, 2012, for marketing approval of BG-12 to treat MS.

Intravenous alemtuzumab was compared against Rebif in a recent phase III trial. For the 840 people in the study with relapsing-remitting MS, relapse rate was reduced by 49 percent and the risk of disability progression reduced by 42 percent. Genzyme has filed for FDA approval and is awaiting results.

Gilenya was introduced to the market two years ago as the first oral disease modifier for MS to be approved by the FDA. Results of a phase III trial indicated that a daily dose of Gilenya (fingolimod) reduced the relapse rate by 48 percent compared with placebo in 778 people with relapsing-remitting MS.

Results from a clinical trial testing a combination of Copaxone and Avonex, two existing disease modifying therapies, showed some evidence they were better together than either therapy alone. However, the combination was not superior in reducing relapses or progression of the disease.

In a separate study, researchers were able to identify gene signals that could predict a high response to therapy in people who used Copaxone. This may point the way for future research on optimizing MS treatment choices.

A study of a green tea extract called Polyphenon E given to 10 people with relapsing- or secondary-progressive MS found a 13 percent increase in average levels of a molecule that reflects nerve tissue health. The researchers are now conducting a phase II study to determine safety and neuro-protective effects in 48 people.



RESTORING WHAT'S LOST

Researchers have found that blocking LINGO-1, a nervous system molecule, increases myelin repair in mice. The first human trial evaluated the safety of the approach in 42 people with relapsing or secondary-progressive MS. Researchers reported no serious effects and support moving this repair strategy to a phase II clinical trial.

After a prominent food and wine critic with MS developed a decrease in taste, researchers at the Mount Sinai School of Medicine looked further into this lesser known symptom of MS, called dysgeusia. In seven people with MS experiencing dysgeusia, MRI revealed lesions in the same area of the brain stem. In some cases, loss of taste had been the first MS symptom, making it an important clue.



ENDING MS FOREVER

In a study of 500 people with MS, researchers found that men with low vitamin D levels may be more susceptible to disability, while women with low levels of the vitamin had more brain lesions if they had a genetic marker common in people with MS. The study points to possible gene and gender influences in vitamin D levels and the risk of developing MS.

For more AAN news, visit nationalMSSociety.org/research.

NEW STUDY ON MARIJUANA

A clinical trial of 37 people with MS with spasticity resistant to standard medications found that half who smoked marijuana once a day experienced significant improvement in symptoms compared to placebo. However, the researchers also found participants showed significantly reduced thinking ability after smoking marijuana. The Society is currently supporting a clinical trial of different forms of cannabis products to test their ability to relieve MS-related spasticity.

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

CORPORATE SPOTLIGHT

PRIME THERAPEUTICS HELPS CLEAN UP THE MUCK



The National MS Society thanks Prime Therapeutics for supporting this year's MuckRuckus MS™ Twin Cities sponsored by Subaru, which took place Aug. 11, at Trollhaugen in Dresser, Wis. Prime Therapeutics is a thought leader in pharmacy benefit management. They stopped by the event site with mini towels for participants to clean off all the muck after crossing the finish line! Prime Therapeutics had a MuckRuckus MS™ team, Prime PBM, which was captained by Sally Reigel, a passionate advocate for the National MS Society. She also participated in both a Walk MS and Bike MS event this year. Thank you, Sally, and Prime Therapeutics for getting dirty for a great cause!

NORTH DAKOTA COMPANIES PROPEL THE MS MOVEMENT FORWARD



Special thanks to Dakota Supply Group (DSG), a seven-year sponsor of Bike MS: Sanford Health Ride the Wind. DSG is a full-line distributor of electrical, plumbing, HVAC, refrigeration, filtration and metering technology products and systems (and more) and is headquartered in Fargo, N.D. Thank you, DSG, for your continued support to help create a world free of MS!



Trinity Health of Minot, N.D., has supported Walk MS over the years as a corporate sponsor and encourages employees to participate or volunteer at Walk MS each May. We are grateful for their leadership in the community and for all they do to help find a cure for MS.

CONTINUED FROM PAGE 5 (MS SCHOLARSHIPS)

diagnosed with MS in 2009. She plans to attend Globe University in Minnesota to study business management and, after completing her associate's degree, to receive her bachelor's degree from a four-year college.

Rylie Murphy, a 2012 scholar from Washington, Iowa, will attend Kirkwood Community College in pursuit of a nursing degree. During high school, she devoted more than 150 hours to community service, including volunteering at Bike MS: Cruise the Cornfields, at MS Youth Camp as a counselor and at elementary schools as a mentor for children. Murphy's mother lives with MS.

While computer science does not appear to have any connection to MS, it actually does, said Alexander Larson. Alexander is a 2012 scholar from Hickson, S.D., who plans to attend North Dakota State University to study computer science. His interest came from Folding@Home, a Stanford University computer program that virtually assembles and folds proteins for scientific analysis.

Meet all 72 scholars and learn about 2013 applications at tinyurl.com/MS-scholars.

JUMPSTART MS SCHOLARSHIP

The Jumpstart MS Scholarship program, sponsored by Best Buy, is a \$1,500 scholarship designed to encourage ninth graders affected by MS to stay on track toward post-secondary education and remain active in school and their community.

This year's award winner, Jacquelyn Arbegast of Sheffield, Iowa, whose mother lives with MS, is a student government leader and is involved in cheerleading, chorus and volleyball. Her dream is to become a behavioral neuropsychologist to work with people with MS and understand how MS affects them.

Special thanks to Great River Energy for hosting the scholarship celebration July 10.

SUPPORT THE SCHOLARSHIP PROGRAM

To learn about making a donation to the MS Scholarship Program, contact Shannon at 612-335-7928 or shannon.wolkerstorfer@nmss.org.

2013 APPLICATIONS

Scholarship applications for 2013 awards will be accepted between Oct. 1, 2012, and Jan. 15, 2013. Watch for updates at tinyurl.com/MS-scholars.



**National
Multiple Sclerosis
Society**

200 12th Ave. S.
Minneapolis, MN
55415-1255

FREE MATTER
FOR THE
BLIND OR
HANDICAPPED

ATTEND THE ANNUAL MEETING BY PHONE

People affected by MS and their loved ones are invited to dial in for the Upper Midwest Chapter's annual meeting from 5:30 to 6:30 p.m. Tuesday, Nov. 13. To attend, call 888-317-4343. Please RSVP to Jane at 612-335-7969 or jane.piotrowski@nmss.org.

CALENDAR

- Oct. 7** Run to Stop MS, Minnesota
(Twin Cities Marathon)
- Oct. 21** Run to Stop MS, Iowa (Des Moines Marathon)
- Nov. 3** MS Annual Conference, Fargo, ND
- Nov. 17** MS Annual Conference, Des Moines, IA

Check out a list of upcoming community fundraising and DIY events at tinyurl.com/MS-CommunityEvents.

FOR INFORMATION OR TO REGISTER

PROGRAMS

Call 612-335-7900 or
800-582-5296 (option 1).

FUNDRAISING EVENTS

Contact Ann at
612-335-7975 or
800-582-5296 (option 2).



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Society**

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612-335-7975 or
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