

Minnesota Chapter

msconnection

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www.mssociety.org

MS Annual Convention speakers fighting MS NOW

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he Minnesota Chapter is pleased to introduce three speakers to be featured at the 2006 MS Annual Convention Nov. 9 to 12 in St. Paul. Whether it's conducting ground-breaking research for a cure, giving a voice to care partners of people with multiple sclerosis or empowering those living with the disease, each person is doing something NOW to fight MS.

Sue Thomas



During the MS Annual Convention general sessions Saturday, Nov. 11, keynote speaker Sue Thomas, who has been deaf since

childhood and was diagnosed with multiple sclerosis at the age of 51, will share a compelling story of how determination and resolve allowed her to overcome the odds she has faced as a person living with disabilities. Thomas was hired by the FBI to conduct undercover surveillance work as a lip reader in crime investigations. Thomas's critical role in high profile FBI cases inspired the original PAX television series "Sue Thomas: F.B.Eye."

In 2001, Thomas was diagnosed with MS, which affects her mobility and vision. Though MS is progressively impairing her most vital form of communication, her sight, Thomas remains positive and works to raise awareness about hearing loss and MS by speaking to people around the globe.

Dr. David Hafler



Also at the general sessions, keynote research speaker Dr. David Hafler, a well-known Harvard neurologist, will discuss his role in

mapping the genome of people with MS and offer a glimpse into the latest scientific research aimed at finding a cure for the disease.

ms connection

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Chair William T. Mac Nally

Chapter President Maureen Reeder

Newsletter Editors

Emily Wilson

Joel Ulland

E-mail editor@mssociety.org

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. Sponsorship of society programs or events does not connote that the National Multiple Sclerosis Society recognizes superiority in products or services provided by the sponsoring entity over other entities providing like or similar products or services.

To obtain an audio tape of MS Connection, call Charlene Vold at the Minnesota Chapter.

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MS Connection on the Web

Did you know you can read the MS Connection online? Visit www.mssociety.org and click on "What's new." Then follow the link to sign up to read the newsletter online, and the Minnesota Chapter will e-mail you when a new issue of the MS Connection is available to read online.

Can you help us?

The Minnesota Chapter is always looking for in-kind donations. If you are able to donate any items on the list below, please call the Minnesota Chapter.

Office supplies

- Black permanent markers
- large three-ring binders

Equipment

- dish soap
- disposable dish cloths
- extra-long handled spoons
- paper cups

- staple guns and staples
- Toolbox with basic tools

First aid supplies

- Ace wraps 4"
- Band-aids
- blister packs
- cold packs
- first-aid tape
- sunscreen

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. National MS Society medical advisors recommend that people with MS talk with their health care professional about using one of these medications and about strategies and effective treatments to manage symptoms. If you or someone you know has MS, please contact the society today at www.nationalmssociety.org or 1-800-FIGHT-MS to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.



Maureen Reeder Chapter President

Teens fight MS with courage and hope

always feel proud
when I hear about
the exciting things
teens are doing to
get involved with the
Minnesota Chapter, help
fight multiple sclerosis

and reach out to people affected by the disease. Some of these teens, while dealing with the many ups and downs of adolescence, are living with MS. Other teens are coping with MS in their families, providing care for a parent and taking on extra responsibilities at home to make things easier for a loved one. During a time when life is filled with possibility, promise and a whirlwind of activity, these young people are standing up to unexpected challenges and obstacles in a very adult way: with courage and hope.

Five teens from the Minnesota Chapter area, among 204 nationwide, were awarded National MS Society college scholarships. These young people were chosen out of nearly 1,000 applicants throughout the country and have all been touched by MS. Two of the Minnesota Chapter scholarship recipients have a parent with MS, while three are living with the disease.

These teens are active in their communities, successful in school and are doing amazing things to fight MS. I congratulate Breana Kochmann, Clarissa Longworth, Heather Rice, Bryan Rudell and Amy Trettel for being honored with this national award, and I commend them for their strength. You will learn more about these teens in the next issue of the MS Connection.

In its second year, the Minnesota Chapter Teen Council continues to draw teens throughout the chapter to raise awareness about MS, meet other teens affected by MS and volunteer at chapter programs and events. Teen Council members Lexi Moser and Michaela Janssen, whose mothers both have MS, presented information about MS to their peers at Kennedy High School this past spring. They asked their fellow students to sit on their hands for one minute to simulate numbness, a common MS symptom. These young women are taking a unique approach to educating their peers and helping them understand the importance of joining the fight against MS. Lexi and Michaela recruited 80 students from their school to participate in the 2006 Christopher & Banks MS Walk.

At this year's MS Youth Camp, nearly 100 youth ages 9 to 17, whose lives have been affected by MS, had the chance to connect with other young people who share their experiences, fears and concerns about the disease, and also to just be kids. Many teens at this year's camp commented that the group has become like a family to them. By sharing the common bond of growing up in a family affected by MS, these teens provide support and friendship to one another. The education they receive at camp and the skills they develop by connecting with other teens will arm them with the resources and dedication to continue the fight against this disease.

It's important to remember that MS touches people of all ages. I'm truly inspired to see young people taking an adult approach in confronting the obstacles that come with an MS diagnosis.

Chapter introduces programs for care partners

or nearly every person with multiple sclerosis, there is someone in his or her life providing support and care as he or she faces the emotional and physical challenges of the disease. These are important people who partner with their loved ones in response to the many demands of MS, and the Minnesota Chapter calls them care partners.

Though many care partners are spouses, they can also be a parent, sibling, close friend, partner, or child. A care partner's role can range from providing occasional help or emotional support to more intensive assistance with daily tasks and can change throughout the course of the disease.

The Minnesota Chapter has long recognized the importance of care partners by providing educational programs about issues such as coping with the changes MS brings, as well as social programs that offer time to relax, socialize and connect with others. This fall the Minnesota Chapter will offer several new programs to better meet the needs of care partners.

A bimonthly e-newsletter, Care Partner Connections, will include helpful information, stories, tips and resources. Care partners will also be invited to submit their personal stories, photos and questions to the e-newsletter. The e-newsletter will also be available in hard copy.

The chapter will offer more direct support and referral services for care partners. Starting this October, care partners seeking information, support services or simply someone to talk to can contact Nancy Dawn Van Beest, M.S., at the chapter office during regular business hours and Thursday evenings until 8 p.m.



The chapter will offer more educational and recreational programs for care partners of people with MS, including the care partner getaway Jan. 26 to 28 in Plymouth, Minn.

A new mentoring program will match care partners with others who have experience as a care partner and can offer insight, support and friendship.

To celebrate National Family Caregivers Month this November, the Minnesota Chapter will host its first-ever "Caregiver Appreciation Dinner" Thursday, Nov. 9, in conjunction with the 2006 MS Annual Convention. The dinner will feature keynote speaker Suzanne Mintz, president of the National Family Caregivers Association. Mintz has been a care partner for her husband, who has been living with MS for more than 30 years. The dinner is open to all care partners, and the Minnesota Chapter will help provide respite services for care partners attending the dinner.

The chapter will also host a care partner getaway Jan. 26 to 28 at the Plymouth Radisson Convention Center in Plymouth, Minn. Last year one care partner who attended the getaway said, "It has been many years since I have felt so cared for and so special. Everything possible was included to benefit us this past weekend."

For more information about care partner programs and services, contact Nancy Dawn Van Beest, family support coordinator, at 612-335-7936 or ndvanbeest@mssociety.org.

Programs help you take charge

he Minnesota Chapter's Take
Charge education programs
provide strategies for dealing with
the major life changes that multiple
sclerosis may bring. Based on the feedback you
provided at education programs during the
past year, the Minnesota Chapter developed
four different Take Charge educational
series to provide you with knowledge and
strategies for coping with major life changes
and managing MS symptoms.

Take Charge education programs will focus on balance and fall prevention, family relationships and intimacy, stress management and evaluating your response to disease-modifying therapies, and vision problems associated with MS. Each program focusing on these issues will be presented at eight different locations in the chapter area.

With these programs, the Minnesota Chapter hopes to provide you and your loved ones with the resources and information you need to manage major life changes and maintain your quality of life. Experts in each of the topic areas will offer you tools and strategies to deal with these key issues.

MAJOR GIFTS

Make a gift every payday

payroll deduction through your workplace giving campaign to the National Multiple Sclerosis Society, Minnesota Chapter is a simple way to make a difference in the fight against MS. A few dollars every paycheck will help support programs and services for people living with MS in Minnesota and western Wisconsin and vital MS research.

If your workplace participates in a Community Health Charities campaign, we invite you to select the National Multiple Sclerosis Society, Minnesota Chapter to receive your gift. Or if you participate in a United Way campaign, simply write in a designation to the National MS Society, Minnesota Chapter. For help setting up a payroll deduction through your workplace giving campaign, you can consult your campaign coordinator.



A workplace giving campaign is a simple way to support the Minnesota Chapter.

For more information on how to support the Minnesota Chapter through workplace giving, please contact Rachel Hughes, gift planning manager, at 612-335-7965 or rhughes@mssociety.org.

People with MS take charge of major life changes

hen someone is diagnosed with multiple sclerosis, the person may have to make certain changes in his or her life to adapt to the physical and emotional effects of the disease. Though major life changes following an MS diagnosis can be difficult and overwhelming, finding positive ways to adapt to these changes can make the process easier. Nancy Jaffee-Shiff and Tom Blyton have developed ways to take charge of their MS and encourage others who are living with the disease to do the same.

Nancy Jaffee-Shiff of Hopkins, Minn., has multiple sclerosis and hopes there will be a cure for the disease in her lifetime. Until that happens, Jaffee-Shiff said she's finding ways to take charge of her disease.

Jaffee-Shiff's husband built a swimming pool at their Hopkins home five years ago, and she found the water to be therapeutic for her MS symptoms. Every year since, between May and October, she goes on a "summer break." According to Jaffee-Shiff, being in her pool is like "a little slice of heaven" and added that she "practically lives in the water." The pool has also been a great way for Jaffee-Shiff to exercise and socialize with friends who join her regularly for aqua-jogging sessions. When the weather turns cold, Jaffee-Shiff misses spending time in the pool, but water-aerobics classes at the Jewish Community Center have allowed her to enjoy the benefits of swimming through the winter months.

Jaffee-Shiff said she has coped with her disease by staying positive and having a

good sense of humor. She has also made friends with other people who are going through similar life changes. Jaffee-Shiff tries to stay connected with friends, family and her community and stay physically active. When she is not in her pool, she spends time volunteering at the Minnesota Chapter. Managing life changes is all about "keeping my cup half full," said Jaffee-Shiff.

Tom Blyton of St. Paul has been living with MS for two decades. Six years ago, progressing symptoms of his MS caused him to quit working. Blyton said that after he stopped working, he did a lot of "sitting around and moping." That's when Blyton got involved with the Minnesota Chapter. He began attending chapter programs and volunteering at the MS Society office. Blyton said this helped him to learn new ways to manage the disease and connect with others who are also living with MS.

He became a chat host for msworld.org, a collaborative partner of the National MS Society that was created to help people with MS network with others whose lives are affected by the disease.

According to Blyton, an MS diagnosis changes your life, but doesn't have to ruin it. "This disease is not the end of your life," said Blyton. "Basically, you can do anything." He credits chapter programs for helping him to adapt to the changes in his life since his diagnosis. This fall, Blyton will spend several months vacationing on the East Coast and plans to stay connected with the MS Society by volunteering at the West Virginia Chapter in Charleston, W.Va.

ADVOCACY msconnection

MS Society continues fight for research funding

espite recent setbacks, the National MS Society continues to aggressively pursue a 5 percent federal funding increase for the National Institutes of Health in fiscal year 2007 as Congress will attempt to finish the appropriations process by October 2006.

Recently, the appropriations committees charged with allocating annual funding for the NIH passed their appropriations bills, but funding proposals in both the U.S. House of Representatives and Senate were too low for the NIH to be able to keep up with inflation or make modest investments in new research. Lack of federal funding could have a significant impact on biomedical research aimed at finding a cause of and cure for MS and other chronic diseases, as the majority of MS-related research is conducted and funded by the NIH.

Of the \$4.1 billion increase in fiscal year 2006 that the House designated for Labor, Health and Human Services appropriations,

none was allocated to the NIH. Of the \$7.1 billion Labor-HHS budget increase that the society successfully supported, and the Senate overwhelmingly approved earlier this year, only a 0.8 percent increase (\$220 million) was included for the NIH in fiscal year 2007, a figure disappointingly lower than the society expected.

At the National MS Society's Public Policy Conference in May 2006, and throughout the legislative year, the society joined the patient community and medical research organizations in a collective request to Congress for a 5 percent funding increase for the NIH in fiscal year 2007. This modest increase is essential for the NIH to sustain ongoing work in vital MS research.

To join the Minnesota Chapter's Action Alert list and stay updated about this and other legislative issues, visit our Web site and click on Advocacy under Client Programs or contact Joel Ulland, Minnesota Chapter vice president of public affairs, at 612-335-7933 or julland@mssociety.org.

CHAPTER NEWS

Chapter to extend office hours starting this fall

he Minnesota Chapter has announced that starting this fall, an advocacy and information staff member will be available every Tuesday from 5 to 7:30 p.m. to take your phone calls. Heather Svenson, Sarah Danen, or Sheila Hall can connect you to information or resources and answer your questions about living with multiple sclerosis, housing options, Social Security, and more. Advocacy and information staff will still be available during the day, but

will offer extended hours for those who aren't able to call during regular business hours. If you are calling from the Twin Cities metro area, call 612-335-7987 to reach a staff member directly. If you are calling from a greater Minnesota community, call the Minnesota Chapter's main office number at 1-800-582-5296, and dial extension number 7987 when you hear the automated recording listing chapter hours.

Society to fund MS rehabilitation research program

The National MS Society has launched a funding program for MS rehabilitation research. The mentor-based postdoctoral fellowship program will provide support for mentors and institutions that train postdoctoral fellows in research applied to MS and similar disorders.

The society aims for the program to recruit and train clinician-scientists in rehabilitation research specific to MS and ultimately, find the best methods for people with MS to optimize their physical and cognitive capabilities. For more information on this training program, visit http://www.nationalmssociety.org/research-rehabfellow.asp.

Oral teriflunomide shown effective in reducing lesions

Teriflunomide (Sanofi-Aventis), an experimental oral drug being tested for safety and efficacy in relapsing forms of MS, was shown to significantly reduce MRI-detected disease activity in a 36-week, Phase II clinical trial involving 179 people with relapsing forms of MS. Teriflunomide is an agent that may modulate T cells, which drive the immune attack in MS. Dr. Paul O'Connor from the University of Toronto, Ontario, and colleagues originally reported these results at the 2004 Congress of the European Committee for Treatment and Research in MS, and have now published the findings in the March 28 issue of Neurology.

In the study, 157 people with relapsingremitting MS and 22 people with secondary-progressive MS with relapses were randomly assigned to receive inactive placebo, or one of two doses (7 mg or 14 mg) of teriflunomide once daily for 36 weeks. The primary objective of the study was to determine the effect of treatment on the average number of active areas of disease activity, or lesions, observed on MRI scans taken every six weeks. Secondary objectives included frequency of relapses and any increase in disability as measured by the Expanded Disability Status Scale (EDSS).

Both treatment doses were associated with reduced numbers of active lesions compared with placebo. Significantly fewer people taking the higher dose showed an increase in the EDSS than those in the placebo group. The drug was well tolerated; adverse events included headache and upper respiratory tract infection, and were similar among all three groups.

A larger study of teriflunomide is underway in people with relapsing-remitting MS in North America and Europe. For more information, visit www.clinicaltrials.gov/ct/show/NCT00134563.

Embryonic stem cells restore nerve function in rats

In a first, researchers report that nerve cells derived from mouse embryonic stem cells that were transplanted into rats with spinal cord injury were able to connect with muscles and partially restore function. Dr. Douglas Kerr and colleagues from The Johns Hopkins University School of Medicine in Baltimore report their results in the Annals of Neurology, online edition, June 26. While this work was done in a model of virus-induced spinal cord injury, it bears some relevance to the potential use

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PROFILE msconnection

"Blogger" shares stories about life with MS

ary Weinand of Maple Grove, Minn., has experienced many life changes since she was diagnosed with multiple sclerosis. Her teaching career was cut short due to her progressing MS symptoms, and last fall, Weinand began training with a service dog to help her with the daily tasks that had become difficult because of her disease.

As a way to deal with new obstacles in her life, Weinand began writing a blog. A blog, short for Web log, is a self-published online journal that provides commentary on any number of subjects from politics to scrapbooks to pop culture.

Weinand learned about blogs from her four children, all in their 20s, and got the idea to start one herself during a journaling workshop held at last year's MS Camp. Weinand was skeptical at first about sharing her life on the Internet. "I had always kept a journal," she said. "But I had never put it out there for everyone to see."

But Weinand said her children encouraged her to start the blog. One of her children once told her that "it would be so cool to have a mom who blogs." In talking with her children, Weinand learned that they, too, were "bloggers."

In October of 2005, while training with her service dog, Emma, Weinand began writing her blog, titled "Life with a Service Dog." Her entries discuss the ins and outs of living with Emma, the daily struggles of MS and other stories.

Weinand said the blog has helped her in dealing with both the physical and emotional aspects of living with a chronic



To date, more than 7,000 people have visited Weinand's blog, and on some occasions she has received more than 100 hits in one day.

illness. Reflecting on the day's activities when writing her blog entries improves her cognition and is also therapeutic in coping with the disease. "It allows me to see all the positive things in my life," she said. "It helps me focus on what I can do, rather than what I can't."

"Blogging" has also allowed Weinand to connect with other people with MS and people living with service dogs, including a reader from Australia. An acquaintance once told Weinand, "Your blog is the first thing I read in the morning."

"I have met so many people with MS through this blog," Weinand said. "Sharing my life with other people helps me deal with my MS and has made me realize that I'm not alone."

To visit Weinand's blog, go to http://servicedoglady.blogstream.com/.

CLINICAL TRIALS IN THE **CHAPTER** AREA

CURRENT Name of study: Preventing **Neutralizing Antibody Formation in Multiple Sclerosis Patients Treated** with Subcutaneous Interferon Beta-1a (Rebif).

> Name of physician conducting study: Dr. Gary Beaver.

Purpose of study: This trial will study whether methylprednisolone reduces neutralizing antibodies

formation compared to placebo. Inclusion criteria for participants: Must have relapsing-remitting multiple sclerosis and be taking Rebif for less than three months.

This study is: Open.

Contact: Laurie Athmann, M.A., R.N., at the St. Mary's Duluth Clinic Health System in Duluth, 218-786-3863.

Name of study: CombiRX.

Name of physician conducting study: Dr. B. Mark Keegan.

Purpose of study: Comparing the combined use of interferon beta 1-a (Avonex) and glatiramer acetate (Copaxone) to the use of either agent alone. The goal of the study is to identify which medications are most beneficial in treating relapsingremitting MS. Inclusion criteria for participants: 18-60 years old, diagnosis of relapsing-remitting MS and at least two attacks during the

preceding three years. Exclusion criteria: Prior use of any interferon beta, glatiramer acetate, acute exacerbation within 30 days of screening, chronic systemic steroid use, use of immuno-suppressive or chemotherapeutic agents or IVIG, pregnancy or plan to become pregnant.

This study is: Open.

Contact: Darcy Rauchwarter, R.N., at the Mayo Clinic in Rochester, 507-284-9360.

Name of study: ASSERT.

Name of physician conducting **study:** Dr. Gareth Parry.

Purpose of study: The University of Minnesota is conducting a research study to determine whether the combination of an FDA-approved medication for MS and an oral steroid is an effective therapy for relapsing-remitting multiple

sclerosis. You may be eligible if you have been diagnosed with relapsingremitting multiple sclerosis, have had at least one relapse in the past year, and are age 18 to 50.

This study is: Open.

Contact: Clinical Neuroscience Research Unit at the University of Minnesota in Minneapolis, 612-624-6145.

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CLINICAL TRIALS

Name of study: CombiRx.

Name of physician conducting study: Dr. Susan Scarberry.

Purpose of study: Comparing the combined use of interferon beta 1-a (Avonex) and glatiramer acetate (Copaxone) to the use of either agent alone. The goal of the study is to identify which medications are most beneficial in treating relapsing-remitting MS. Inclusion criteria for participants: 18-60 years old, diagnosis of relapsing-remitting MS and at least two attacks during the preceding three years.

Exclusion criteria: Prior use of any interferon beta, glatiramer acetate, acute exacerbation within 40 days of screening, chronic systemic steroid use, use of immuno-suppressive or chemotherapeutic agents or IVIG, pregnancy or plan to become pregnant.

Contact: Tish Skarloken, at the MeritCare MS Center in Fargo, N.D., 701-234-4091.

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of cell replacement to repair damage in multiple sclerosis. Dr. Kerr's expertise is being tapped by the National MS Society's Promise: 2010 Nervous System Repair and Protection team led by Dr. Peter Calabresi.

The researchers caution that the safety and effectiveness of this strategy must be confirmed in larger, longer studies, to determine if function can be restored over longer distances, as another step toward its possible application in humans.

Cell-based therapies are also under study for MS. In a report published in 2003, Dr. Gianvito Martino of Fondazione Centro San Raffaele in Milano, Italy and colleagues showed that adult mouse neural stem cells, or neurospheres, injected into the blood or brain cavities of mice with MS-like diseases can move through the brain and spinal cord to sites of tissue damage, promote repair of nerve-insulating myelin, decrease damage to nerve fibers, and reverse clinical disease. Dr. Martino is among Society-

funded researchers investigating the potential of cell transplantation in MS.

Tetanus vaccination may lower risk of MS

A study published by Harvard researchers reported that people who had received tetanus vaccine were one-third less likely to develop MS than those who had not been vaccinated. The pooled analysis, by Dr. Miguel Hernán and colleagues from Harvard School of Public Health, was published in Neurology (July 25, 2006). The studies compared the cases of 963 people who had MS with 3,126 "controls" who were friends or relatives or who had other neurological disorders, or who were from the general population. The controls were more likely to have had a history of tetanus vaccine than those in the MS group, suggesting that something about tetanus vaccination may be protective against MS. As this was a retrospective study no firm conclusions as to cause and effect can be drawn.

MS doesn't keep team captains from the finish line

MS 150 Bike Tour Team Captain Rick Ebner

Last winter, a physical therapist told Rick Ebner, team captain of the MS 150 Bike Tour team the Moving Violations, that completing the 150-mile ride June 9 to 11 would be nearly impossible. Ebner, who was diagnosed with multiple sclerosis in 1995, was "devastated."

But Ebner rode anyway and completed the ride having only sat out a few miles along the route, an accomplishment he credits to the encouragement he received from his teammates and the strength he found in himself.

The Moving Violations, made up of Ebner's friends and family, brought 13 riders to this year's MS 150 Bike Tour presented by GMAC-RFC and raised more than \$11,000 to help fight MS.

Ebner said his teammates rode alongside him during the tour offering support and encouraging words. "The enthusiasm my teammates brought really carried me through the ride – it propelled me to keep going," Ebner said. "When I finished I realized that though my disease is strong, my mind and my heart are strong, too."



Rick Ebner, front center, and his MS 150 Bike Tour team the Moving Violations.



Team Victory at the 2006 Christopher & Banks MS Walk presented by Serono/Pfizer.

Christopher & Banks MS Walk Team Captain Chris Anderson

Chris Anderson, team captain of the Christopher & Banks MS Walk team Victory, was diagnosed with MS in September 2004. He organized a team for the 2005 MS Walk and recruited 34 people. This year, the team brought 51 people to the event and raised more than \$11,800.

Anderson had no intention of finishing the walk this year because of his MS, but something his mom told him the day he was diagnosed helped him to complete the eight-mile walk. "She said that I can have MS, but MS can't have me," Anderson said. The sight of his 50 teammates, all wearing T-shirts with red "V"s for victory on the front, and their praise also helped Anderson to stay motivated throughout the walk.

When Anderson crossed the finish line, his excitement was evident. "I finished," Anderson screamed as he spiked his water bottle on the ground. "It was an accomplishment that I'll never forget," he said.

VOLUNTEERS msconnection

Teens take the lead through Teen Council

he Minnesota Chapter's Teen
Council was established as a way
for youth to get more involved
with the chapter and connect with
other teens affected by multiple sclerosis.
Since the group was created two years ago,
the number of teens involved has doubled.

Teen Council members, ages 13 to 19, plan the teen lock-in, snow tubing outings and MS Awareness Week activities. The group helps to raise awareness about MS among their peers and get other teens involved with the chapter.

Teen Council members also volunteer as Crew members at the MS Challenge Walk, helping to unload luggage, produce a pep rally and perform spirited cheers for walkers. Erin Weber, Teen Council chair, said that participating in Teen Crew at the MS Challenge Walk is her favorite Teen Council activity. "You get to meet a lot of different people affected by MS, hear their

Volunteer opportunities

- Sept. 15 to 17: MS Challenge Walk Help with registration, pit stops, serving meals, and parking at various locations along the route.
- Various dates: Office volunteers Help staff with projects as needed or work on a regular basis and gain valuable professional experience while helping to fight MS.
- Various dates: Hospitality and registration

Help with greeting, check-in and other duties at programs statewide.



As volunteers at the MS Challenge Walk, Teen Crew members help to raise awareness and increase visibility of programs organized by the Teen Council.

stories about why they walk and you get to have fun," Weber said.

Teen Council also had a presence at this year's Christopher & Banks MS Walk presented by Serono/Pfizer. Members of the Teen Council and more than 100 teens participated in walk sites throughout the state as part of Team of the Future.

Teen Council members raise awareness about MS by educating their peers and sharing their experiences with the disease. Weber plans and facilitates Teen Council meetings and said she hopes the program will give teens an opportunity to get involved and help others affected by MS. "I like knowing that once I am older, and perhaps away at college, there will be a program in place for other kids who are dealing with something that I am all too familiar with," Weber said.

To learn more about the Teen Council, contact Nancy Dawn Van Beest, family support coordinator, at 612-335-7936 or ndvanbeest@mssociety.org.

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The MS genome project is the first-ever full genome scan of a specific human disease. If successful, the MS genome project will identify a number of specific genes that play crucial roles in MS.

Suzanne Mintz



At the Minnesota Chapter's Caregiver Appreciation Dinner, Thursday, Nov. 9, in honor of National Family Caregivers month, Suzanne Mintz, president and co-founder of the National Family Caregivers

Association (NFCA), will give the keynote address and an inspirational presentation to care partners of people living with MS

and care partners of people living with other chronic illnesses and disabilities.

Mintz is a family caregiver for her husband, Steven, who was diagnosed with MS in 1974. Her first-hand experience with caregiving led her to become a crusader for care partners of people living with chronic illnesses and disabilities, people for whom she felt deserved more recognition, training, support, assistance and public policy attention. In 1993 Mintz co-founded the NFCA, an organization that represents more than 50 million Americans who care for a chronically ill, aged, or loved one with a disability.

For more information about the MS Annual Convention, contact Emily Wilson at ewilson@mssociety.org or 612-335-7931.

MINNESOTA CHAPTER CALENDAR

Sept. 15 - 17 MS Challenge Walk

Sept. 19 Family attorney consultations

Rod Jensen, attorney at law, offers free telephone consultations.

Sept. 19 Employment consultations

Mary Harris, a disability consultant, offers free telephone consultations.

Sept. 19 Social security attorney consultations

Jennifer Mrozik, attorney at law, offers free telephone consultations.

Sept. 19 MS Basics

Winona Gain information and support.

Sept. 20 Employment consultations

Jennifer Johnson offers free consultations on interviewing, resumes and more

Sept. 20 Wednesdays with Randy

Golden Valley
Managing numbness.

Sept. 20 – Newly Diagnosed Nov. 1 Counseling Group: Moderately Affected

Bloomington Learn to navigate through a diagnosis of MS.

Sept. 21 Newly Diagnosed Education Series

Burnsville Learn to manage MS early.

Sept. 21 MS: The Genetic Connection

Detroit Lakes Learn about genetic research and MS.

MINNESOTA CHAPTER CALENDAR

Sept. 27 Wednesdays with Randy Golden Valley

Cognition and its ramifications.

Sept. 30 Housing and Independence Workshop

St. Louis Park Turning the key to maximize your independence.

Sept. 30 MS and Close Relationships

Hibbing

Stay connected with family and friends.

Oct. 3 Travel Tips

Minneapolis

Gain tips for safe and fun travel.

Oct. 3 Employment consultations See Sept. 19 for details.

Oct. 4 Employment consultations See Sept. 20 for details.

Oct. 4 Wednesdays with Randy

Golden Valley
Diet and nutrition.

Oct. 5 Stress Management

Forest Lake Take charge of stress.

Oct. 7 Fall Education Conference

Proctor

Learn more about timely MS topics.

Oct. 9 Midwest Teleconference Education Series

Gain knowledge and strategies to manage MS.

Oct. 9 Financial Planning Consultations

John Robinson, CFP (R), Financial Advisor, offers free consultations on estate and financial planning.

Oct. 10 Balance and Fall Prevention

Vadnais Heights

Take charge of your balance.

Oct. 11 Wednesdays with Randy

Golden Valley

The role of an exercise program.

Oct. 13 - 15Family Getaway

Alexandria We are family.

Oct. 17 Family attorney consultations

See Sept. 19 for details.

Oct. 17 Employment consultations

See Sept. 19 for details.

Oct. 17 Social security attorney

consultations

See Sept. 19 for details.

Oct. 18 Employment consultations

See Sept. 20 for details.

Nov. 7 Employment consultations

See Sept. 19 for details.

Nov. 8 Employment consultations

See Sept. 20 for details.

Nov. 9 –12 MS Annual Convention

St. Paul

Nov. 13 Financial Planning

Consultations

See Oct. 9 for details.

For more information or to register

For more information or to register for programs, events or telephone consultations, contact the Minnesota Chapter at www.mssociety.org or 612-335-7970.

Dealing with the cognitive effects of MS

hat was the name of the actress in that movie?" Have you ever had the feeling of someone's name being on the tip of your tongue, but you weren't able to remember it? Many people with multiple sclerosis say this is what it is like to live with cognitive dysfunction.

Impaired cognitive function can make it difficult to think, reason, concentrate or remember. Fifty percent of people with multiple sclerosis experience some degree of cognitive dysfunction, but only 5 to 10 percent of people with MS develop cognitive problems severe enough to interfere with daily activities. Cognitive problems may affect people with MS in various ways, but there are several strategies for managing these symptoms.

The cognitive functions most often affected by MS include memory, speed of information processing, visual perception, problem solving and concentration. MS may affect cognitive function for several reasons. MS damages myelin and nerve cells within the brain which can compromise various brain functions. In fact, MRI studies suggest that the extent of demyelination in the brain is directly related to severity of cognitive dysfunction. MS can also affect cognition indirectly. People with MS are more likely to have depression, anxiety, stress and fatigue, all of which can result in impaired cognitive function.

While cognitive challenges are more common among people who have had MS for a long time, it can develop at any stage during the course of the disease and has even been seen as a person's first MS symptom. There is no relationship between



Memory problems are common in people with MS. Recording important information in a notebook or pocket calendar is one way to manage this symptom.

a person's level of physical disability and his or her cognitive function. Therefore a person with MS who has physical disabilities as result of the disease doesn't necessarily experience cognitive dysfunction.

How a person manages symptoms of cognitive dysfunction depends on which functions are affected. A health care professional can determine a person's cognitive deficits and strengths, and can suggest strategies for coping with these challenges. For example, suggestions for managing memory problems might be to practice memory exercises, to carry a pocket calendar or to use a notebook to store information. Disease-modifying drugs may also help cognitive dysfunction and also may reduce future damage to the brain and the nerves that affect cognition.

Cognitive dysfunction, even in mild forms, can be difficult to deal with and frustrating. People with MS should contact their health care provider if they are concerned about cognitive challenges and would like to learn strategies for managing these symptoms. To obtain a booklet on cognitive issues in MS, contact the chapter.