

# CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Winter 2008-2009

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Minnesota Chapter

## Create change through activism

Every year Minnesotans come together to speak with lawmakers about issues affecting people with multiple sclerosis at the National MS Society, Minnesota Chapter Capitol Conference. This year, MS activists will focus on two issues: a bill to cap prescription co-payments for MS disease-modifying drugs and a tax credit for family caregivers (see Page 18 for a breakdown of these issues).

The 2008 Capitol Conference, Tuesday, Feb. 3, at the state Capitol in St. Paul, Minn., is for anyone who wants to speak up for people living with MS. Group leaders guide participants throughout the day. Before visiting the Capitol, activists participate in one teleconference training and one in-person training. New this year, the chapter offers three options for both trainings.

### MS activist training schedule

Conference participants must complete one teleconference training and one in-person

training. At the trainings, participants receive tips for meeting with legislators and an overview of this year's hot issues.

### Teleconference trainings

Wednesday, Jan. 21, 4–5 p.m.

Thursday, Jan. 22, 7–8 p.m.

Friday, Jan. 23, 10–11 a.m.

### In-person training sessions

Saturday, Jan. 31, 2–4 p.m., Bloomington

Monday, Feb. 2, 2–4 p.m. or 7–9 p.m., St. Paul

### Register

There is no cost to attend. Transportation and lodging is provided to people traveling from greater Minnesota or outside the Metro Mobility service area. To register, contact Kari Harju at 800-582-5296 or [kharju@mssociety.org](mailto:kharju@mssociety.org). Learn more at [www.MSsociety.org](http://www.MSsociety.org).

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**move it.**

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March 2-8, 2009



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To obtain an audio tape of MS Connection, call Timothy Holtz at the Minnesota Chapter.

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## 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 chapter.

### Office supplies

- banker boxes
- binders (various sizes)
- black permanent markers
- envelopes (various sizes needed)
- file folders
- school supplies
- white boards
- gift baskets for men/women
- kitchen supplies
- Metro Mobility tickets
- otoscope (for checking ears)
- pill boxes (four times per day)
- restaurant/store gift certificates/prizes
- Rubbermaid® containers (large)

### Other supplies

- 5 megapixel or greater digital cameras
- CDs and DVDs
- DVD player
- external DVD burner
- fishing gear
- first aid supplies
- themed decorations (Valentine's Day, big city and baseball)
- toiletries (call for details)
- trophies (old)
- turning sheets
- umbrellas that attach to wheelchairs

*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 contact the society at [www.nationalmssociety.org](http://www.nationalmssociety.org) or 1-800-582-5296 to learn more.*

# Note from the board



**Karen Larson**  
Board Chair

## We are all in this together

**O**ver the past year, we've seen many great strides in the movement to end multiple sclerosis. Research continued to progress at a remarkable rate, with breakthrough studies that may lead us to develop ways to restore myelin and neurological function as well as predict MS disease activity and progression.

Right here in Minnesota, we worked to make sure families living with MS had the information, resources and support they need to live well in spite of this disease and adapt to its challenges. We created new programs, forged new collaborations, and launched special advisory groups to better meet the needs of people touched by the disease.

MS activists rallied for change and helped to pass an important bill to improve transit services for people with disabilities, and volunteers logged an astounding 40,000 hours to help improve the lives of people with MS and move closer to a cure.

And while year's end is often a time to look back on the things we've accomplished — it's also a time to look ahead, to the things yet to be done.

In 2009, the Minnesota Chapter will find new ways to move the lives forward of people with MS — including new educational

opportunities, networking gatherings, programs for people who are newly diagnosed with MS, and smoking cessation and financial planning programs.

We will create new opportunities for people with MS statewide to drive change through advocacy. And we will continue to advocate on issues affecting quality of life for Minnesotans with the disease — like the 1,200 percent increase in co-payments for MS prescription drugs under some health insurance plans.

In 2009, anyone who wants to do something about MS now will have exciting opportunities to use their skills, knowledge and passion as part of the Programs Volunteer Leadership Task Force and Movement Ambassador program.

And the Minnesota Chapter will boldly ask for support from our fundraisers, donors and corporations so we can continue our relentless pursuit for prevention, treatment and a cure.

Sometimes, as a new year approaches, goals for the coming year can seem daunting. But as the saying goes, "Many hands make light work." That's what is so great about the MS movement — all of us are in it together. If each of us contributes in whatever way we can, our movement will grow bigger and stronger.

Thank you for all the great things you did in 2008. Please join us again in 2009 so we can keep moving forward, together.

## MS Connection goes quarterly, online news center launched

The National MS Society, Minnesota Chapter announces that as of the current issue, the MS Connection newsletter is now a quarterly publication. Instead of six bimonthly issues, readers receive four seasonal issues of the print edition. With this change comes a new, online hub for all your MS Society news. MS Connection Online keeps you informed about up-to-date news stories — so you

don't have to wait until the print edition arrives in your mailbox to learn about the latest developments in research or other breaking stories. Online, readers can access stories that appeared in recent print editions, but also special, Web-only feature stories, profiles and much more. Visit the brand new Web page at [www.MSsociety.org](http://www.MSsociety.org) and click on MS Connection Online.

### What's on MS Connection Online right now?

- Chasing the blues away: managing MS-related depression
- Mpls.St.Paul Magazine honors MS Society volunteer Bill MacNally
- What's your financial I.Q.?

**+ ONLINE** When you see this icon, it means there's expanded coverage of this topic on MS Connection Online. To check out the new Web page, visit [www.MSsociety.org](http://www.MSsociety.org) and click on MS Connection Online.

### Apply for 2009 scholarships

The deadline to apply for a 2009 National MS Society scholarship is Jan. 15, 2009. High school seniors with a parent who has multiple sclerosis, high school seniors with MS and high school (or G.E.D.) graduates of any age who have MS may apply for a scholarship if they plan to attend an accredited post-secondary school for the

first time. To learn more and download an application, visit the Client Programs page at [www.MSsociety.org](http://www.MSsociety.org) and click on family, care partner and youth programs.

#### → QUESTIONS?

Contact Megan at 612-335-7955 or [mspark@MSsociety.org](mailto:mspark@MSsociety.org).

## KARE 11 honors MS Society volunteer

Longtime Minnesota Chapter volunteer David Chaikin was honored this September as a 2008 Eleven Who Care award recipient. Chaikin, diagnosed with multiple sclerosis in 1992, is dedicated to raising awareness about MS and helping others affected by the disease. His volunteer activities with the chapter include the long-term housing, scholarship review, development and public outreach advisory committees; board of trustees; and Mentor, Bike MS Champions, Capitol Conference and Movement Ambassador programs. Chaikin also is a chapter speakers bureau member and Community Health Charities Ambassador.

Eleven Who Care — which recognizes the contributions of grassroots volunteers and promotes the spirit of volunteerism — celebrated its 25th anniversary with a



*David Chaikin with Minnesota Chapter President Maureen Reeder at the 2008 Eleven Who Care Awards.*

90-minute live telecast honoring the 2008 winners and past recipients. Chaikin received a \$1,100 donation, which he directed to the Minnesota Chapter Scholarship Program.

## New volunteer leadership program for people with MS

The Minnesota Chapter presents an exciting volunteer opportunity for people with MS to use their creativity and innovation to recruit and engage more volunteers in the MS movement. The Programs Volunteer Leadership Task Force offers three ways to get involved.

**Take on an ongoing office position.** Help connect people affected by MS to chapter programs as a volunteer programs assistant.

**Become a programs volunteer recruiter.** Engage more volunteers in the MS movement by using your expertise of chapter programs and connections to people affected by MS.

**Launch your own unique program.** Do you have special talents or a unique idea for a program for people affected by MS? Tell us your idea and you may have the opportunity to execute your own program.

### → LEARN MORE

Contact Timothy Holtz at 612-335-7930 or [tholtz@mssociety.org](mailto:tholtz@mssociety.org) or visit the [volunteer page at www.MSsociety.org](http://www.MSsociety.org) and click on Programs.

## Call for board candidates

The chapter governance committee is considering candidates to serve on the board of trustees. To propose a candidate, write to Susan A. Hagstrum, Ph.D., chair of the governance committee, by April 1. Mail nominations to 200 12 th Ave. S.,

Minneapolis, MN 55415. The committee will select the best-qualified candidates and present a slate of nominees at the MS Annual Convention. Nominees will not be taken at the meeting. Learn more about newly-elected board members on Page 17.

## Events raise more than \$6.7 million in 2008



*Challenge Walk MS participants arrived at the James J. Hill House before the final victory march to the state Capitol in St. Paul, Minn.*

The Minnesota Chapter's 2008 event season came to a close with the MS River Road Run Motorcycle Tour, Women Against MS benefit luncheon and Challenge Walk MS: Twin Cities. The MS River Road Run raised approximately \$125,000, the Women Against MS luncheon, with nearly 450 attendees, raised more than \$115,000, and more than 200 people took on the three-day, 50-mile Challenge Walk MS: Twin Cities, raising more than \$500,000. In 2008, chapter events raised more than \$6.7 million total to help fund MS research projects and programs for people affected by the disease in Minnesota and western Wisconsin.

## Chapter awards \$3,000 grant to local MS clinic

The Minnesota Chapter recently awarded a \$3,000 grant to the Multiple Sclerosis Treatment and Research Center of the Minneapolis Clinic of Neurology in Golden Valley, Minn., to support professional education for MS-certified nurses. The Community Grant Program seeks to address the needs of people with MS at a grassroots level through collaboration

with other nonprofit organizations and affiliated clinics. Grant proposals are reviewed quarterly and grants are awarded based on the needs of people with MS and compliance with approved terms and conditions.

**→ LEARN MORE**

Contact Linda Munson at 612-335-7953  
or [lmunson@MSsociety.org](mailto:lmunson@MSsociety.org).

## How will you *Move it.* during MS Awareness Week?

**W**ithout you, there wouldn't be an MS movement. Your story, your enthusiasm and your passion for a world free of multiple sclerosis invigorate our movement every day.

This is why we are counting on you to engage new people in our work to end MS during MS Awareness Week 2009, March 2 to 8.

This year we want everyone to "move it" by doing at least one thing to demonstrate their commitment to a world free of MS.

This year's theme, *Move it.*, encourages everyone to move the message forward in their unique way. Whether you volunteer, walk, bike, advocate, donate or educate people about MS, you are making your mark and building on the already powerful movement.

There are countless things you can do to *Move it.* During MS Awareness Week, the Minnesota Chapter offers exciting opportunities to volunteer on street teams, advocate for people living with MS, register for Walk MS and Bike MS events, raise awareness in your communities and more.

It may seem small, but simply talking to people about your involvement with the MS Society is one of the easiest, yet most powerful, things you can do during MS Awareness Week. Sharing your story helps people understand



this complicated disease and gives them a personal connection to the cause.

The Minnesota Chapter recently launched the Movement Ambassador program as a way to help you tell your story. Movement Ambassadors do little things to engage others in the MS movement and are crucial in our work to end MS. For example, have you ever worn an MS Society T-shirt and had someone approach you to talk about MS? When you share your story with that person, you engage them in the movement. Learn how to become a Movement Ambassador below.

**+ ONLINE** Visit *MS Connection Online* in early 2009 to get an online toolkit full of excellent tools, resources and ideas.

## Become a Movement Ambassador

As a Movement Ambassador, you receive exclusive Web access to training videos, manuals, opportunities to share your story and fun online tools. Plus, you'll receive a monthly

e-mail with simple ideas to engage people, success stories from ambassadors, contests and more. Register at [MSsociety.org](http://MSsociety.org) or call Jenna at 612-335-7981.

## Outstanding care partners, health care professional recognized

Family care partners and health care professionals are essential to providing support and care to people living with multiple sclerosis. The National MS Society, Minnesota Chapter called for nominations for those who go above and beyond in caring for people with the disease. The recipients of the Care Partner of the Year Luminary Awards and Health Care Professional of the Year Starfish Award were recognized at the third annual Care Partner Appreciation Dinner, Nov. 21.

### Care Partner of the Year Luminary Awards



**Chuck Grui**  
— adult category

Chuck Grui has been a care partner to his wife, Christine, for 13 years, and his enthusiasm for learning about the disease allows him to be

patient, understanding and aware of the unique challenges of MS.

“He loves to come up with ideas that make my life easier at home and out in the community,” Christine said, adding that Chuck goes out of his way to provide support to her friends living with MS, too.

Christine said Chuck’s positive attitude helps her cope with the disease. Chuck often changes his work schedule so he can accompany her to programs, doctor appointments and physical therapy. “He doesn’t complain about having to work extra hours to pay for my medication or equipment, and he gives up his weekends to volunteer for MS Society fundraisers to make sure the programs I need continue to be available,” Christine said.

“His attitude is always positive and he has a good sense of humor in looking at the

many life changes we have had to make along the way.”



**Amirah Muwahid**  
— youth category

When a parent is diagnosed with a chronic illness, children often take on the role of a care partner.

Amirah Muwahid

was just 10 years old when she began providing care to her mother, Mary, who lives with MS. Because the disease makes it difficult for Mary to do household chores, Amirah, now 17, takes on jobs her mom can’t handle. Amirah also regularly gives her mom injections for disease-modifying treatments.

“With her help, and the distraction of her giggles and laughter, we get it done,” Mary said. “I am very grateful to my daughter that she has taken on these responsibilities with such love, grace and maturity.”

### Health Care Professional of the Year Starfish Award

#### Megan Frost

Megan Frost is a physical therapist and co-owner of STEP Physical Therapy — a center that uses specialized equipment



and knowledge to help people achieve physical wellness and manage pain. Megan recently launched an exercise program specifically for people with MS.

Many participants say the program has been extremely beneficial thanks to Megan's positive, uplifting attitude and deep understanding of how MS affects the body.

**+ ONLINE** *Read more about this year's winners at MS Connection Online.*

"Megan is always eager to learn more about MS by meeting with neurologists and rehabilitation doctors. She has invested a lot of herself and her finances in developing a program to treat people with MS at all stages of their disease."

"Megan's positive attitude rubs off on everyone around her and the exercise and therapy programs speed by without feeling like 'work.'"

"She understands multiple sclerosis, how to help us gain strength and overcome our disabilities."

— Testimonies from participants in the MS exercise program at STEP Physical Therapy

## Chapter names Olseen and Madore legislators of the year

The Minnesota Chapter honored Sen. Rick Olseen, Harris, Minn., and Rep. Shelley Madore, Apple Valley, Minn., as 2008 legislators of the year for their leadership and support in improving transit services for people with disabilities in Minnesota.



**Sen. Rick Olseen**

Olseen and Madore introduced Senate File 2695 and House File 2943 — legislation requiring enhanced planning for transit services for seniors and people with disabilities.

Olseen and Madore supported the transit legislation through negotiations, amendments and committee hearings and worked with the Metropolitan Council and Minnesota Department of Transportation to come up



**Rep. Shelley Madore**

with a plan all sides could agree to. Thanks to their unwavering support and dedication, this important legislation was passed as part of the Omnibus Transportation Policy Bill during the 2008 legislative session.

As state legislators, Olseen and Madore — both elected in 2006 — showed their commitment to improving the lives of Minnesotans. Olseen introduced a variety of legislation on transportation and education issues, and Madore was a champion of disability issues, introducing more than 20 separate bills to enhance quality of life for Minnesotans with disabilities.

## 2009 EVENTS

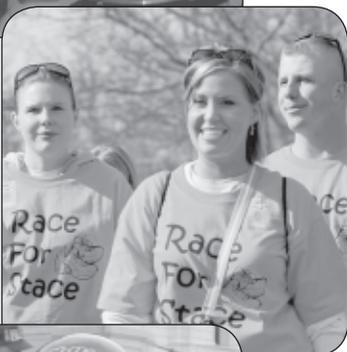
When you join a Walk MS, Bike MS, motorsport or luncheon event, you become a part of a powerful movement to create a world free of MS.



### **MS Sno Rally Snowmobile Tour**

**Feb. 5–8, 2009**

*An all-inclusive, three-day snowmobile event in Grand Rapids*



### **Walk MS: Christopher & Banks Walk presented by Anchor Bank**

**May 3, 2009**

*Walks held in 17 cities throughout Minnesota and western Wisconsin*



### **Bike MS: Allianz Twin Cities Ride**

**May 9, 2009**

*Choose a 30- or 60-mile route featuring the Gateway trail*

### **Bike MS: Larkin Hoffman MS 150 Ride**

**June 12–14, 2009**

*A two-day, 150-mile bike ride from Duluth to the Twin Cities*

### **Bike MS: Star Tribune The Ride Across Minnesota**

**July 26–31, 2009**

*A five-day cycling vacation across Minnesota*



### **On the Move Luncheon**

**August 2009**

*A benefit luncheon and silent auction in Minneapolis*



### **MS River Road Run Motorcycle Tour**

**Aug. 15–16, 2009**

*A weekend motorcycle tour*

### **Challenge Walk MS: Twin Cities**

**Sept. 11–13, 2009**

*A three-day, 50-mile walk in the Twin Cities*

## Community rallies to send area resident to MS Camp

**M**ultiple sclerosis self-help group leaders help connect people with MS to one another in a group setting, provide support, facilitate thoughtful discussion and share information about the disease. Above all, these trained volunteers are there to listen, but sometimes, hearing the unique challenges of group members compels self-help group leaders to do much more by taking action.



**Neil Dohlmann**

Neil Dohlmann has helped lead the MS self-help group in Luverne, Minn., since 1996. Last spring, he learned that group member Dan Brower, of Hills, Minn., wanted to attend MS Camp — the National MS Society, Minnesota Chapter’s weeklong program for adults living with MS.



*Dan Brower, pictured at MS Camp last August.*

Brower, diagnosed in 1993, lives in a local nursing home, where he is the youngest resident. He thought camp would be a great

opportunity to meet other people his age who live with MS and spend quality time outdoors.

In order to get to camp, Brower needed a wheelchair accessible van with a lift, which costs \$1,500 roundtrip. Brower’s place of residence couldn’t assist in paying for a van and the Minnesota Chapter could not cover the full balance. Dohlmann understood how important it was that Brower be able to participate, and he had a feeling people in the community would feel the same. He was right.

Dohlmann shared Brower’s story with local newspapers and set up a donation fund at an area bank. The Rock County Star Herald, Hills Crescent and Worthington Daily Globe ran articles encouraging readers to make donations, and in just one month, residents raised enough money to pay for Brower’s ride to camp.

For Dohlmann, going the extra mile is part of the job. “You do what you have to do,” he said. Dohlmann, Brower and fellow group members are grateful to local newspapers and the community for their support. The group dedicated one of its regular meetings to writing thank-you notes.

**→ MS CAMP 2009**

MS Camp 2009 will be held May 3 to 8 and Aug. 23 to 27. Learn more at [www.MSsociety.org](http://www.MSsociety.org).

## Volunteers recognized at annual Sylvies awards show

As a volunteer-driven organization, the National MS Society, Minnesota Chapter depends on thousands of passionate volunteers each year to help make its programs, services and events a reality. In 2008, volunteers dedicated more than 40,000 hours of their time to the chapter. To recognize those extraordinary volunteers, the Minnesota Chapter hosts the Sylvies — an annual awards dinner named in honor of National MS Society founder Sylvia Lawry.



*“When you volunteer, you become part of a family.”*  
— Wally Kirchoff, Norman Cohn Hope Award recipient



*“Meeting so many amazing people who are involved with this fight, makes it so easy to continue giving all we’ve got.”*  
— Corry Fredrickson, Chapter Volunteer All-Star



*“To see the movement progress and develop has been very rewarding, mentally and physically.”*  
— Pat Budnik, Chapter Volunteer All-Star



*“Everyone shares a common and determined objective of education and support for people affected by MS. And just as importantly, everyone shares the dream of eradicating the disease.”*  
— Dale Kivimaki, Chapter Volunteer All-Star

## Volunteer opportunities

### **May 3, Walk MS: Christopher & Banks Walk presented by Anchor Bank**

Walks held in 17 sites throughout Minnesota and western Wisconsin.

### **May 3-8 and Aug. 23-28, MS Camp**

Weeklong program in Maple Lake, Minn. Nurses and cabin assistants needed.

### **May 9, Bike MS: Allianz Twin Cities Ride**

One-day bike ride in Maplewood, Minn.

## 2008 Sylvies recipients

### **Norman Cohn Hope Award**

Wally Kirchoff

### **Chapter Volunteer All-Stars**

Pat Budnik

Corry Fredrickson

Dale Kivimaki

### **Group Volunteer All-Stars**

Miller-Dwan Regional Rehabilitation Center of Duluth

Scholarship Review Committee

Transport America

### **Leadership Volunteer All-stars**

Bill Cook

Larry Schmid

Jeff Olsen

### **Office Volunteer All-Stars**

Bob Matchinsky

Susan Stellmacher

### **Programs Volunteer All-Stars**

Katie Cerney

Edward Gillespie

Jennifer Johnson

### **Rookie Volunteer All-Stars**

Antonio Collodoro

Gary Helm

Barb Thornton

### **Special Events Volunteer All-Stars**

Dave Britz

Gordy Hanson

Brandon Jutz

### **Youth Volunteer All-Stars**

Kelsy Krueger

Team of the Future

### **June 12-14, Bike MS: Larkin Hoffman MS 150 Ride**

Two-day, 150-mile bike ride from Proctor to the Twin Cities with an overnight at Grand Casino Hinckley.

### **June 13-19, Youth Camp**

Weeklong camp at Wolf Ridge Environmental Learning Center for youth affected by MS. Counselors, especially males, and nurses needed.

## Study shows nerve regeneration in MS lesions

A study of brain tissue obtained from people with multiple sclerosis indicates that while many areas of damage show expected loss of myelin and nerve cells, a few older lesions show a 72 percent increase in nerve cells when compared with neighboring brain regions. Findings support the possibility that nerve cells in the white matter of the brain can be replaced after they are destroyed by MS.

## Study to explore physical activity reduction in MS: participants needed

Investigators seek people with relapsing-remitting MS to participate in a study exploring whether frequency and severity of MS-related symptoms influence physical activity. The study could improve our understanding of factors that reduce physical activity in MS, and help design programs to increase it. To learn more, contact Elise McAuley at 888-796-7966 or [symptomstudy@gmail.com](mailto:symptomstudy@gmail.com).

## FDA agrees to fast review of MS drug

Drug maker BiMS Medical Corp. announced the FDA has designated dirucotide as a "Fast Track Product," which should expedite its future FDA review after results of current trials are submitted. Dirucotide is a synthetic fragment of myelin basic protein (MBP), which reduces the production of spinal fluid antibodies that react against MBP during the immune attack on the brain and spinal cord in MS.

**+ ONLINE** *Ever wonder how clinical trials work? What happens in each phase? How do I get involved? Visit the research page at MS Connection Online to find out.*

## \$5 million awarded to new MS research program

Thanks to the work of MS activists nationwide, \$5 million was awarded for a historic MS research project within the Congressionally Directed Medical Research Programs (CDMRP) to study the potential link between MS and military service. This is the first time MS has ever received its own line item allocation under CDMRP, a program funded through the Defense Department.

## No overall link found between hepatitis B vaccine and MS

A study evaluating the potential that hepatitis B vaccination increases the risk of developing MS found no general increase in risk from exposure to the vaccine. However, the investigators did find a possible hint that a specific brand of the vaccine may increase the risk of MS, but that finding requires confirmation.

**+ ONLINE** *Read the full report on these and other studies at MS Connection Online.*



## Research pipeline



**Isobel Scarisbrick,  
Ph.D.**

Isobel Scarisbrick, Ph.D., a researcher and professor at Mayo Clinic in Rochester, Minn., is leading a team that is investigating a family of enzymes responsible for damaging myelin. In an interview with the

Minnesota Chapter, Scarisbrick explains these enzymes, progressive MS and promising news on the horizon.

### What is an enzyme?

Body tissue such as myelin contains unique types of proteins. An enzyme breaks down proteins into smaller units. A family of enzymes called kallikreins may help us understand damage caused by MS and other diseases.

### What is so special about kallikreins?

Kallikreins (KLK) are the largest family of serine-type enzymes in the body. The presence of certain kallikreins in blood or tissue is associated with various diseases. For example, KLK6 is elevated in brain lesions of people with MS.

### How did you learn about the association between MS and KLK6?

We found KLK6 was densely expressed in neurons in the brain and also in oligodendrocytes, or myelin-making cells. When we blocked the enzyme activity of KLK6 in an animal model of MS we saw delayed onset and progression of disease.

### What research have you done to further investigate these enzymes?

We looked at the levels of five different kallikreins in the blood of people with MS

and found elevated levels of both KLK1 and KLK6. The interesting aspect was when we broke it down into people with relapsing-remitting or secondary-progressive MS we found the elevated levels occurred mostly in people with secondary-progressive MS. In fact, this elevation seemed to distinguish the relapsing-remitting from the progressive patients.

### What does this mean for the future of progressive MS?

It is possible that kallikreins 1 and 6 contribute to neurodegeneration known to occur in the progressive phases of MS. We are excited to target these enzymes to see if we can slow some of the damage. We would also like to know whether these enzymes may serve as biomarkers of secondary progressive MS.

### What is on the horizon?

While much work remains, we are excited that perhaps blocking either KLK1 or KLK6, or both, may represent a new therapeutic target for people with progressive MS. This is exciting since there aren't many therapeutic options for progressive MS. We are still far away from a clinical trial, but these enzymes are showing exciting potential.

### What do you do when you're not in the lab?

I'm a parent, which takes up quite a bit of time. Also, we enjoy taking advantage of the Minnesota outdoors and went on a canoeing trip to the Boundary Waters this summer.

**+ ONLINE** *Read the full study on the MS Connection Online research page.*

## \$50,000 grant to support planning for new MS day programs



For more than 20 years, the Fairview Multiple Sclerosis

Achievement Center has provided adults living with MS an opportunity to access physical therapy, occupational therapy, therapeutic recreation and a chance to socialize with other people with MS. In an effort to develop two additional adult day programs for people with MS by 2011, the National MS Society, Minnesota Chapter

launched a task force to review other adult day center models, best practices from around the country and potential partners in greater Minnesota.

UCare Minnesota awarded a \$50,000 grant to the Minnesota Chapter to support this project. UCare is an independent nonprofit organization offering health coverage plans in Minnesota and western Wisconsin. Created in 1984, UCare was the first health plan to offer health care programs for people with disabilities.

## Health care companies support the MS Society



### Express Scripts Foundation

Express Scripts Foundation partners with the Minnesota Chapter as a sponsor of Bike MS: Larkin Hoffman MS 150 Ride. The foundation also recruits a team to participate in the ride. As a health care organization, Express Scripts works to make a positive difference in communities where it has a presence. The Express Scripts mission is to make prescription drug use safer and more affordable for more than 50 million Americans through thousands of employers, managed care plans, governments and labor unions.



### Walgreens Specialty Pharmacy

Walgreens Specialty Pharmacy supports the Minnesota Chapter as a sponsor of the 2008 MS Annual Convention. Walgreens Specialty Pharmacy serves the needs of people living with complex health conditions, including multiple sclerosis. The Walgreens Specialty Pharmacy Care Team — including pharmacists, patient care coordinators and insurance advocates — offer support services to help people with MS better understand and manage the disease. Services provided include access to medications, confidential counseling and insurance benefit coordination.

## Three ways to make a difference this holiday season

### Tribute gifts

Honor a loved one during the holiday season with a gift that gives back. When you make a holiday contribution in honor of a loved one, we will send a greeting card letting them know about your gift. To make a holiday tribute gift, contact Jane Piotrowski at 612-335-7969.

### Stock gifts

A gift of appreciated stock at year end is an excellent way to earn tax savings while doing something about MS now. If the stock has increased in value since you purchased it, you receive a tax deduction for the current full fair market value of the stock (up to 30 percent of your adjusted gross income), rather than the purchase price. Also, by making a

gift to a nonprofit organization, you avoid paying capital gains tax on the increased value of the stock. To learn more, contact Shannon Wolkerstorfer at 612-335-7928 or [swolkerstorfer@MSSociety.org](mailto:swolkerstorfer@MSSociety.org).

### Sustaining gifts

Jump start your 2009 giving with a sustaining gift. Visit [www.MSSociety.org](http://www.MSSociety.org) to set up a monthly gift using your debit or credit card. You will make an automatic monthly donation to the National MS Society without even thinking about it. To learn more, contact Rachel Hughes at 612-335-7965 or [rhughes@MSSociety.org](mailto:rhughes@MSSociety.org).

## Chapter elects new board members

At the MS Annual Convention, Nov. 21 to 23, the Minnesota Chapter elected Dr. Gary Beaver, Dennis McGill and Brett Wing to the board of trustees. To nominate a candidate, see Page 6.



### Dr. Gary Beaver

Dr. Gary Beaver is director and section chair of the neurology department at the Duluth Comprehensive MS Center at St. Mary's Duluth Clinic. He also is chair of the chapter's Clinical Advisory Committee and a contributor to MS education programs.



### Dennis McGill

Dennis McGill, CFO of Ames Construction in Burnsville, Minn., was the

top individual fundraiser for Bike MS: Larkin Hoffman MS 150 Ride 2008, raising more than \$22,000. This year was McGill's second time participating in the ride.



### Brett Wing

Brett Wing is vice president of advertising and marketing at Cub Foods and president of Cub Cares. Wing's volunteer experience includes Taste of Many

Cultures, Cystic Fibrosis, Children's Miracle Network and the Crohn's & Colitis Foundation of America.

continued from Page 1

## Issue breakdown

### Capping co-pays for MS disease-modifying drugs

**Chief authors:** Sen. Jim Carlson and Rep. Rod Hamilton

**Overview:** In the past two years, several area health plans have increased co-payments for MS prescription drugs from \$25 for a three-month supply to \$200 for a one-month supply. This bill would cap co-pays at no more than \$50 per month for the MS disease-modifying prescription drugs.

#### Why is it important?

This disturbing trend has caused financial strain for many people with MS. For some, it has forced them to make drastic decisions about whether to pay mortgages, college tuition, utility bills and other living expenses or pay for treatment.

#### What can I do?

If you are personally affected by the co-pay increases, write a letter to your health plan expressing your concerns. Also, sign up to receive Action Alert e-mails and register for the 2009 Capitol Conference at [www.MSsociety.org](http://www.MSsociety.org).

### Family caregiver tax credit

**Overview:** If passed this legislation would provide a tax credit — up to \$2,400 per year — to family members who care for people with disabilities and/or seniors requiring assistance who are otherwise at risk of entering into a skilled nursing facility.



*Mary Springborg spoke with Rep. David Dill at the 2008 Capitol Conference.*

#### Why is it important?

Many family caregivers must cut back the amount of time spent working outside the home to provide in-home care to a loved one with a disability. Caregivers also save the government significant amounts of money by keeping their loved ones living at home and out of publicly-funded institutions.

#### Why don't family caregivers receive assistance now?

Medical Assistance currently covers care assistance for people with very low income, but many people with disabilities and seniors are not eligible for these programs and still need financial assistance.

#### Who would be eligible to receive the tax credit?

This tax credit is for individuals who provide unpaid, daily care to a family member with a disability.

#### What can I do?

Sign the Caregiver Tax Credit petition, sign up to receive Action Alert e-mails and register for the Capitol Conference at [www.MSsociety.org](http://www.MSsociety.org).

- Jan. 10** Moving Forward, Hudson, Wis.
- Jan. 15** Managing Fatigue, St. Paul
- Feb. 3** Capitol Conference, St. Paul
- Feb. 5–8** MS Sno Rally Snowmobile Tour, Grand Rapids
- Feb. 13–15** Couple’s Getaway, Alexandria
- March 2–8** MS Awareness Week

**Telephone consultations**

\* Telephone consultations are free and by appointment only

Family attorney consultations

Rod Jensen, attorney at law

**Dec. 23, Jan. 17 and Feb. 24**

Employment consultations

Jennifer Johnson, tips on interviewing, resumes and more

**Dec. 17, Jan. 21 and Feb. 17**

Employment discrimination/private disability consultations

Denise Tataryn, attorney at law

**Dec. 3, Jan. 7, Feb. 4 and March 4**

Financial planning consultations

John Robinson, C.F.P.®, financial advisor

**Dec. 15, Jan. 19 and Feb. 16**

**FOR INFORMATION OR TO REGISTER**

**Programs**

Contact registration line:  
612-335-7970

**Telephone consultations**

Contact Sarah or Heather:  
612-335-7900

**Walk MS, Bike MS and motorsport events**

Contact Cortney: 612-335-7971

## Make technology work for you



**T**echnology can help people with multiple sclerosis stay informed about the

disease, connect with others and maintain a career, but can pose challenges as well. Symptoms such as limited dexterity and vision impairment can make it difficult to type, read a computer screen or manipulate a mouse.

The National MS Society's MS Technology Collaborative maintains MyMSMyWay.com, where people with MS can access information about accessible technology, tips, monthly columns and Snapshot — a tool that

provides customized technology solutions based on a person's individual needs.

Rachel Dykoski, of Minneapolis, serves on the steering committee that oversees the collaborative. Dykoski uses technology to stay connected with friends and family and work more efficiently. "The technology adaptations I've made, such as increasing the font size or programming specific keys to reduce the amount I need to type, make it possible for me to use my computer no matter what symptoms I'm experiencing."

**+ ONLINE** *Learn more about accessible technology at MS Connection Online or visit [www.MyMSMyWay.com](http://www.MyMSMyWay.com).*



**National  
Multiple Sclerosis  
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Minnesota  
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