**North Central States Chapter**
2508 S. Carolyn Avenue
Sioux Falls, SD 57106

**National Multiple Sclerosis Society**

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## 2008 Little Black Dress for MS Champagne Luncheon and Fashion Show in Des Moines, Iowa

Now is the time to get out your favorite little black dress and invite your friends to the 4th Annual Little Black Dress for MS Champagne Luncheon. Guests are encouraged to wear their little black dresses in a show of solidarity and support for all those affected by MS. Since MS affects nearly two-thirds more women than men, it is only fitting to celebrate the strength of those whose lives have been touched by MS.

Ellen Sue Stern, renowned author, lecturer, and motivational speaker, will be the guest speaker at the October 17, 2008 event, held at the West Des Moines Marriott. Known for her witty approach to the unexpected twists life can throw one's way, Ellen Sue is a Celebrity Ambassador for the National MS Society and works with individuals dealing with any number of life's "surprises." Guests will also enjoy a fashion show sponsored by Aimee, a high-end boutique in Des Moines' East Village.

Tickets for this elegant affair are $50 per person or $350 for a table of eight. Visit **www.littleblackdressforMS.org** or call 1-800-344-4867 for details.

National Multiple Sclerosis Society

# CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Sept./Oct. 2008 • Volume 3 • Issue 4 North Central States Chapter

## The Society's Promise to You

### Promise 2010 and the Research it is Funding

Finding a cure for MS is a top priority of the National MS Society. In addition to providing support and education for those living with MS, the Society funds more MS research than any other private organization in the world. By supporting research and providing the resources people with MS need to keep moving forward, the Society is fulfilling its promise to create a world free of MS.

One major research initiative is the Promise 2010 Campaign, a set of projects designed to look further into under-studied, yet promising avenues of prevention, treatment, and understanding. The North Central States Chapter has pledged $100,000 for this effort and the Society's combined investment will total $30 million to fund four major research areas: nervous system repair, pediatric MS, a long-term quality of life study, and a study on the lesion patterns of MS.

**Nervous system repair and protection**
Four teams of scientists received $15.6 million from the Society to expedite the search for a way to reverse the damage that MS causes. By bringing together four of the top research teams in this area of study, the Society is fostering collaboration and as a result, speeding the process of bringing symptom reversing drugs to market.

**Pediatric treatment centers**
Although MS is typically diagnosed in people ages 20-50, advancements in technology have led to more children being diagnosed with the disease. Right now, it is estimated that 25,000 children under the age of 18 have MS. While an early diagnosis has its benefits - such as being able to track and understand the disease better – there are scientific and medical obstacles. Many doctors have little or no experience dealing with MS in children and none of the six FDA-approved drugs for treating MS have been tested thoroughly on children.

The Society has established six centers specializing in pediatric MS. The Pediatric MS Centers of Excellence not only treat children living with MS, they also share what they learn about MS in those under 18. Learning more about the disease in its earliest stages advances the search for a cause and ultimately, a cure.

**Sonya Slifka Longitudinal Study**
Because MS affects each person differently, detecting patterns is vital for researchers to understand the disease. The Sonya Slifka Longitudinal Study was commissioned by

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MS CONNECTION

Publication of the National Multiple Sclerosis Society - North Central States Chapter

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the Society as a way to track the symptoms and lifestyle changes in a diverse population of people with MS. This project is not just aiding researchers, it is also informing policy makers about what issues affect people with MS. The study tracks volunteers who participate in a short phone survey every six months. Volunteers answer questions about their symptoms, quality of life, employment, treatment, and access to MS care.

This study is recruiting volunteers who want to help further scientists' understanding of MS. Call 1-800-305-8013 for details.

**The MS Lesion Project**
MS manifests itself in so many ways that it has caused researchers to wonder if there is a single cause and if a single therapy could be found to help all who have MS. The MS Lesion Project is a collaborative effort by scientists all over the world who are working with tissue samples from people with MS to further understand the lesion patterns.

**How can I help?**
Using donated tissue samples, scientists have found four distinct types of lesions, each of which resulted in different patterns of myelin damage (the substance that insulates nerve fibers). Further study is needed to determine if different lesion patterns result in common symptoms and could be treated by a common therapy.

The four projects that make up Promise 2010 are bringing the world closer to a cure and complete understanding of MS each day. By supporting these initiatives, the Society is working to fulfill its promise to you - that a world free of MS is not only possible, it is getting closer each day.

If you would like to contribute to the Society's progress toward a world free of MS, please contact Cal McKeown, Senior Manager of Donor Relations at 1-800-344-4867. One of the most effective ways to create a world free of MS is to support the Society's research initiatives. ■



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# President's Message

Growing up in small-town South Dakota, I learned early on that a person is only as good as the promises they keep. To this day, I measure my own success by how well I fulfill my promises. We at the Society have promised you a world free of multiple sclerosis and we absolutely won't quit until we have delivered on that promise.

It's a big promise, a world free of MS, and it's one that I don't take lightly because I know that none of our members do either. Traveling around our chapter, I meet people every day who need us to deliver on our promise: 40-year-old women living in nursing homes with 80- and 90-year-olds because their symptoms don't allow them to live at home; families who don't know from one day to the next if Dad will make it to work because of his MS; college students who have trouble walking to class because of the fatigue caused by MS.

In this issue of the *MSConnection* and online at **myMSsociety.org**, the chapter is asking you to tell us **how** we can fulfill our promise to you. With your help, advocacy and research are moving steadily ahead, and the future is looking brighter than ever. But there are things we are doing now to keep people affected by MS moving forward. Our programs and services department offers wellness programs, services, financial assistance and grants, educational tools, and support. But, we know we can do more; we want to offer a menu of programs and services that will meet more of your needs.

Please take a few minutes and share your thoughts on the survey in this newsletter or on our website. The feedback you provide us will allow us to serve you better and fulfill our promise to create a world free of MS.

With my appreciation and commitment,

Jennifer

Jennifer Kline, Chapter President

## Don't Miss the Annual Meetings

Starting later this month, the chapter will begin its series of Annual Meetings. Three identical meetings in Fargo, Sioux Falls, and Des Moines will give members the chance to hear about the chapter's goals for the next year, vote on the Board of Trustees, and hear the stories of the Chapter Award winners. To nominate someone for a Chapter Award or the Board of Trustees, call 1-800-344-4867 or e-mail nth@nmss.org.

Fargo, North Dakota on September 22, 2008
Des Moines, Iowa on September 27, 2008
Sioux Falls, South Dakota on October 6, 2008

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 MS. Talk to your health care professional and contact the National MS Society at **www.nationalMSsociety.org** or 1-800-344-4867 to learn about ways to help manage MS and about current research that may one day reveal a cure.



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# Chapter Calendar

For details on these and other upcoming events, please call 1-800-344-4867 or visit **www.myMSsociety.org**.

## September

| Date | Event | Location |
|---|---|---|
| Sept. 1 | Labor Day | Nationwide |
| *Local Society offices are closed.* | | |
| Sept. 5 | Makes Sense! Lunch and Learn | Des Moines, IA |
| *Call 1-800-344-4867 to reserve your space at this monthly program.* | | |
| Sept. 5 | Federal Focus | Chapter-wide |
| *Watch your e-mail inbox for information on the Society's federal advocacy. Not getting these e-mails? Visit **www.nationalMSsociety.org/advocacy** to join the MS Action Network.* | | |
| Sept. 13-14 | bike MS: Weekend Ride Around the Hills | Black Hills, SD |
| *Cycle 150 miles in two days or cheer on riders as they cross the finish line. Visit **www.myMSbike.org**.* | | |
| Sept. 15 | Chapter Award nominations due | Chapter-wide |
| *Make sure you have nominated someone who inspires you for a North Central States Chapter Award.* | | |
| Sept. 15 | Board of Trustees nominations due | Chapter-wide |
| *Board of Trustees nominations are due today. Learn more by calling 1-800-344-4867.* | | |
| Sept. 15 | Guy Talk | Teleconference |
| *At 7:00 p.m. CST, call 1-800-514-2821 and use code 565525# to join the guys and talk about MS.* | | |
| Sept. 16 | Real Talk. Real Answers. | Teleconference |
| *Join young adults living with MS nationwide for Real Talk. Real Answers. Living with MS in Your 20s and 30s. Learn more at **www.realtalkrealanswers.com**.* | | |
| Sept. 22 | Annual Meeting | Fargo, ND |
| *Learn about the chapter's accomplishments and goals at this annual event.* | | |
| Sept. 27 | Annual Meeting | Des Moines, IA |
| *Learn about the chapter's accomplishments and goals at this annual event.* | | |
| Sept. 27-28 | Newly Diagnosed Retreat | Oacoma, SD |
| *Join the Society for this educational weekend at the Cedar Shore Resort.* | | |
| Sept. 30 | Wide Horizons Family Grant Program Deadline | Chapter-wide |
| *Today is the last day to apply for the family grant this quarter.* | | |

## October

| | | |
|---|---|---|
| Oct. 3 | Makes Sense! Lunch and Learn | Des Moines, IA |
| *Call 1-800-344-4867 to reserve your space at this program on symptom management.* | | |

For more upcoming programs, events, and important dates, visit **www.myMSsociety.org**.



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# How We Joined the Movement

The MS movement is made up of people who are passionate about creating a world free of MS. Your neighbors, friends, colleagues, and family are all a part of this movement. There is still time to nominate the leaders of the MS movement for the North Central States Chapter Awards. Submissions are due by September 15, 2008. You can nominate someone online at **www.myMSsociety.org**.

**Amber Spicher, Cedar Rapids, Iowa**
Last summer, Amber was looking for a way to make a difference. She chose to volunteer at the Society in honor of her friend from college who was diagnosed with MS.

Amber is currently a member of the Bike MS committee and also assists with fundraising and other events as needed. "I like feeling like I am part of something positive and feeling like what I do makes a difference to people," she said.

My Horse
By Carolyn J. Paulsen

He strides past me,
His streaming flanks shining like molten copper
In the early morning sun.
How he loves his workout!

I watch the routine,
With longing, the rider no more.
I sigh with the memories
Of mornings like this.

Power in motion,
So beautiful to watch is this horse of mine.
Would that his strength
Could pass down to me.

I will ride no more
My wheelchair is now my saddle.
Memories will sustain me
Along with the tears.

**Carolyn J. Paulsen, Sioux Falls, South Dakota**
Joining the MS movement for Carolyn meant sharing her story of MS with others. Last spring, Carolyn contacted the Society wondering if there was room in the *MSConnection* for her to share a poem she had written. After living with MS for 54 years, Carolyn now lives in a long-term care facility and had been talking to one of the nurse's aides about riding horseback. Although Carolyn had only ridden a horse once, she appreciated their beauty and freedom. That conversation inspired her to put pen to paper and describe her own feelings.

Although each person with MS experiences different physical symptoms, many of the emotional conflicts are the same. Carolyn's poem highlights how difficult adapting can be. "I typed this one letter at a time with a pencil eraser," Carolyn explained. "It works."

**Sheri Paulson, Fargo, North Dakota**
Sheri was diagnosed with MS in 2001 and despite her initial fears that MS would change her life for the worse she has done anything but slow down. She has completed two marathons, seven half marathons, a sprint triathlon, and numerous other running events.

For Sheri, a diagnosis of MS became to appreciate life and make big goals. Sheri has consistently been a top fundraiser at Walk MS the last few years and has been a wonderful ambassador for the National MS Society. "I want to offer hope for other people with MS, that things will be OK and their lives are not over," she has said.

This year, she took on both a new physical and fundraising challenge – she rode in the two-day Bike MS: Ride the Wind event in North Dakota and had a goal of individually raising $5000.



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# Needs Assessment

The North Central States Chapter of the National MS Society exists to end MS. To ensure that the chapter is meeting your needs, please take a few minutes and let the chapter know what services you use, what programs you enjoy, and what new opportunities you'd like to see.

Complete this survey by October 1, 2008 and return to:

8187 University Blvd., Suite B
Clive, Iowa 50325

Or, complete the survey online at **www.myMSsociety.org**.

**1. What is your connection to MS?**

- ☐ I have MS or possibly have MS
- ☐ I have a friend with MS
- ☐ My parent has MS
- ☐ My child has MS
- ☐ My sibling has MS
- ☐ My spouse has MS
- ☐ Other _____

**2. Which fundraising events have you participated in?**

- ☐ Walk MS ☐ Bike MS
- ☐ Little Black Dress for MS
- ☐ A Taste of Generosity
- ☐ Other _____

*If you do not have MS or a possible diagnosis of MS, please skip to question 12.*

**3. What is your marital status?**

- ☐ Single, never married
- ☐ Married
- ☐ Divorced
- ☐ Widowed

**Would you be interested in a program or service related to MS and marital status?**

☐ Yes ☐ No

**4. Do you have children under the age of 18?**

☐ Yes ☐ No

**Would you be interested in a program or service related to MS and children?**

☐ Yes ☐ No

**5. What is your housing situation?**

- ☐ Live with family
- ☐ Live alone
- ☐ Live with care taker or aide
- ☐ Live in a long-term care facility

**Would you be interested in a program or service related to MS and housing?**

☐ Yes ☐ No

**6. How long have you been diagnosed with MS?**

- ☐ I have not been diagnosed
- ☐ Less than one year
- ☐ One to three years
- ☐ Three to five years
- ☐ More than five years

**Would you be interested in a program or service related to MS and how long you have been diagnosed?**

☐ Yes ☐ No

**7. What type of MS have you been diagnosed with?**

- ☐ I have not officially been diagnosed
- ☐ Relapsing-remitting
- ☐ Primary progressive
- ☐ Secondary progressive
- ☐ Progressive-relapsing

**Would you be interested in a program or service related to types of MS?**

☐ Yes ☐ No

**8. Have transportation issues prevented you from attending a medical appointment or Society event in the past year?**

☐ Yes ☐ No

**9. Which type of insurance do you have?**

- ☐ Private insurance
- ☐ Champus/Tricare
- ☐ Veterans' coverage
- ☐ Medicaid or state equivalent
- ☐ Medicare
- ☐ I am not insured

**Would you be interested in a program or service related to MS and insurance?**

☐ Yes ☐ No



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**10. What type of doctor do you see most often for MS care?**

- ☐ Family doctor/primary care physician
- ☐ Neurologist
- ☐ Ophthalmologist
- ☐ Rehabilitation medicine specialist/ physiatrist
- ☐ Physical/occupational therapist
- ☐ Alternative therapy specialist
- ☐ I do not currently see anyone

**11. How often do you see a neurologist?**

- ☐ Regularly, about once a year
- ☐ Frequently, more than once a year
- ☐ Occasionally, only during flare-ups
- ☐ Rarely, almost never

**12. Are you a member of a self help group?**

☐ Yes ☐ No

**13. What is your gender?**

☐ Male ☐ Female

**14. What is your birthday?**

_____(MM/DD/YYYY)

**15. Do you have internet access at home?**

☐ Yes ☐ No

**16. Do you receive chapter newsletters?**

☐ Yes ☐ No

**17. What is your favorite aspect of the newsletters?**

- ☐ Calendar of events
- ☐ Letter from the president or director
- ☐ Research update
- ☐ Programs and services details
- ☐ Fundraising details
- ☐ Self help group stories and listings
- ☐ "How We Joined the Movement" stories
- ☐ I do not read the newsletters
- ☐ Other:_____

**18. Would you be interested in receiving e-newsletters, if offered?**

☐ Yes ☐ No

**19. Have you attended a program (i.e. a workshop or self help group meeting) in the past three months?**

☐ Yes ☐ No

If no, why not?_____

**20. Have you used a service (i.e. direct financial assistance or 1-800-344-4867) in the past three months?**

☐ Yes ☐ No

If no, why not?_____

**21. How do you learn about the chapter's resources right now?**

- ☐ By reading the *MSMovement* (blue)
- ☐ By reading the *MSConnection* (orange)
- ☐ By visiting **www.myMSsociety.org**
- ☐ By calling 1-800-344-4867
- ☐ From local mailings
- ☐ From a friend
- ☐ Other:_____

**22. What area needs a new program/ service?**

_____

**23. Please rate your feelings on the following (1-Very Satisfied, 2-Satisfied, 3-Not Satisfied, 4-Very Dissatisfied):**

Frequency of chapter communications
1 2 3 4

Quality of chapter communications
1 2 3 4

Current programs available in your area
1 2 3 4

Current services available to you
1 2 3 4

**24. What is your occupation?**

- ☐ Professional or technical
- ☐ Management
- ☐ Sales
- ☐ Clerical
- ☐ Military
- ☐ Laborer
- ☐ Retired
- ☐ Not working (not retired)
- ☐ Other:_____

**Would you be interested in learning ways the Society could use your skills?**

☐ Yes ☐ No

**25. What else would you like to share?**

_____

_____



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