MS KILLS CONNECTION ❯ ❮ CONNECTION KILLS MS

National Multiple Sclerosis Society

During **MS Awareness Week March 11 to 17**, hundreds of thousands of people across the country will work to increase awareness and understanding about multiple sclerosis — a chronic disease of the central nervous system, for which there is no cure. MS interrupts the flow of information within the brain and between the brain and the rest of the body. Thanks to growing collaboration around the world, however, there are improved treatments leading to enhanced quality of life for people living with MS.

MS divides minds from bodies, pulls people from their lives and away from one another. MS is a destroyer of connection. But it is possible to build connections that MS cannot destroy. Every connection we make is a small victory and, together, our small victories create larger ones that will help end MS forever. Every connection counts.

We need your help to connect people with information about MS and ways to join the movement to create a world free of this disease. In this media kit, you'll find profiles of people affected by MS in Iowa, as well as information about Walk MS events near you, the latest in MS research, resources available for people affected by the disease and more.

If you have any questions or would like more information, don't hesitate to contact me at 612-335-7933 or michelle.leppert@nmss.org.

Thank you for moving us toward a world free of MS.

Sincerely,

Michelle Leppert
Marketing and Public Relations Coordinator
National MS Society, Upper Midwest Chapter

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National Multiple Sclerosis Society

FOR IMMEDIATE RELEASE

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MS Awareness Week March 11 – 17, 2013

DES MOINES, March 6, 2013 — Multiple sclerosis is a life altering disease that affects each person in a unique and different way. MS kills connection — divides minds from bodies, pulls people from their lives and away from one another. But it is possible to build connections that MS cannot destroy. Our connections raise questions, find answers, bring knowledge and provide hope to the millions of people affected by MS worldwide. The National Multiple Sclerosis Society and those living with MS across the state of Iowa are connecting with people across the nation during MS Awareness Week, March 11 to 17.

Every connection we make is a small victory, and together, our small victories will create larger ones that will help end MS forever. The National MS Society, Upper Midwest Chapter encourages Iowans to get involved during MS Awareness Week and throughout the year. Below are just a few ways to join the MS movement. Learn other ways to get involved, such as volunteering, giving, advocating, fundraising and more, at MSsociety.org.

- **Every Connection Counts:** Share your story and connect at www.MSconnection.org. Learn about MS, upload your own photo and connection to share with others and download tools to spread awareness.
- **MS Day at the Capitol, March 12:** People affected by MS are invited to visit the Iowa State Capitol to share their stories with legislators and raise MS awareness. Click here or contact Jenna at jenna.washnieski@nmss.org.
- **MS Women's Conference, March 16:** Join us for an event specifically designed for women living with MS and their family and friends in Coralville, Iowa. Click here for more information or to register.
- **Walk MS Iowa, May 18:** Walk MS is the rallying point of the MS movement. In 2013, Walk MS events will be held in Cedar Falls/Waterloo, Cedar Rapids, Des Moines, Dubuque, Mason City and the Quad Cities on May 18, and in Sioux City on May 4. Learn more at myMSwalk.org.
- **Bike MS: Cruise the Cornfields, June 22-23:** Bike MS: Cruise the Cornfields takes cyclists on a scenic tour through central Iowa, with a festive overnight in Ames. The Upper Midwest Chapter boasts five other extraordinary rides. Learn more at myMSbike.org.

INTERVIEW OPPORTUNITIES: This year's Walk MS Iowa ambassadors are working to raise awareness and rally others to join them for Walk MS. See below to arrange interviews with the 2013 Walk MS ambassadors:

Emily Britt, Iowa City, IA, diagnosed in 2010**:**
Click here to read Emily's story
Contact: 214-592-6282 or mrsemilybritt@gmail.com

Angela Baker, Moline, IL (Quad Cities Walk Ambassador), diagnosed in 2002**: Click here to read Angela's story**
Contact: 309-792-2063 or rnabaker4@mchsi.com

Melissa Shelabarger, Des Moines, IA, diagnosed in 2009**: Click here to read Melissa's story**
Contact: 515-803-7228 or melks.1984@yahoo.com

Jeana & Jacquelyn Arbegast, Sheffield, IA, Jeana diagnosed in 2002: **Click for Jeana & Jacquelyn's story**
Contact: 641-892-4325 or jarbegast@frontier.com

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About multiple sclerosis
Multiple sclerosis, an unpredictable, often disabling disease of the central nervous system, interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. MS affects more than 17,000 people here in the Upper Midwest Chapter area, and more than 2.1 million people worldwide.

About the National Multiple Sclerosis Society
The National MS Society addresses the challenges of each person affected by MS. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move forward with their lives. In 2012 alone, the Society invested $43 million to support 350 research projects around the world while providing programs and services that assisted more than one million people. The Society is dedicated to achieving a world free of MS. The Upper Midwest Chapter represents more than 17,000 people with MS in Iowa, Minnesota, North Dakota, South Dakota and several counties in western Wisconsin and Nebraska. Join the movement at www.nationalMSsociety.org.

Early and ongoing treatment with an FDA-approved therapy can make a difference for many people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSsociety.org or 800-FIGHT-MS (344-4867).

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Fact sheet: Upper Midwest Chapter

The National MS Society, Upper Midwest Chapter represents more than 17,000 people with MS in Iowa, Minnesota, North Dakota, South Dakota and several counties in western Wisconsin and Nebraska. We provide resources for people living with MS and their families, friends and care partners, including:

- Four licensed social workers, who connect people with MS to resources and assist them in working with insurance companies, applying for programs, locating appropriate housing, discovering ways to manage the disease, finding solutions to family and employment issues, learning about Social Security, and more;
- More than 100 MS clubs and groups across the chapter area;
- More than 30 exercise and wellness programs;
- Independent Living Grants, which provide financial assistance to families in the purchase of products and services such as medical equipment, aids for daily living, home and auto modification, chore services and respite care;
- Emergency financial assistance to help steer families out of crisis by helping to pay for things like utility bills and mortgages;
- Educational programs about MS research, treatments and symptom management;
- Getaways and camps for fun, relaxation and friendship;
- Programs for youth and teens who have a parent or close relative with MS;
- Scholarships for students who live with MS or have a parent or guardian with MS;
- Community grants for local MS partner clinics;
- Social and educational opportunities and support for care partners, friends and families of people with MS; and
- Advocacy efforts for MS-related issues, working to minimize budget cuts that would hurt people with MS and other disabilities; and training and mobilizing its network of grassroots activists to raise awareness, share their stories and make changes for people with MS.

Fact sheet: multiple sclerosis

What's multiple sclerosis? Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain and between the brain and the body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person can't yet be predicted, but advances in research and treatment are moving us closer to a world free of MS.

Who gets MS? Most people with MS are diagnosed between the ages of 20 and 50, and at least two to three times more women than men. There are an estimated 10,000 children under the age of 18 who also live with MS. Studies suggest genetic factors make certain individuals more susceptible to the disease, but there's no evidence MS is directly inherited. It occurs more commonly among Caucasians, especially those of northern European ancestry, but people of African, Asian and Hispanic backgrounds aren't immune.

How many people have MS? There are more than 17,000 people living with MS in the Upper Midwest Chapter territory — Iowa, Minnesota, North Dakota, South Dakota and counties in western Wisconsin and Nebraska — and 2.1 million worldwide.

What are the typical symptoms of MS? Symptoms of MS are unpredictable and vary greatly from person to person and from time to time in the same person. For example, one person with MS may experience abnormal fatigue and another may have vision problems. While one person with MS may experience a loss of balance, muscle coordination or tremors — making walking and everyday tasks difficult to perform — another may have slurred speech and memory issues.

What causes the symptoms of MS? In MS, symptoms result when inflammation and breakdown occur in myelin, the protective insulation surrounding the nerve fibers of the central nervous system, which is comprised of the brain, spinal cord and optic nerve. Myelin is destroyed and replaced by scars of hardened "sclerotic" patches of tissue. Such lesions are called "plaques" and appear in "multiple" places within the central nervous system. This can be compared to a loss of insulating material around an electrical wire, which interferes with the transmission of signals.

Is MS fatal? In rare cases, MS is so malignantly progressive, it's terminal, but most people with MS have a normal or near-normal life expectancy. Severe MS can shorten life.

Does MS always cause paralysis? No. The majority of people who live with MS don't become severely disabled. Two-thirds of people remain able to walk, though many will require an aid, such as a cane, and some will use a scooter or wheelchair to conserve energy.

Is MS contagious or inherited? No. MS is neither contagious nor directly inherited; however, studies suggest genetic factors make certain individuals more susceptible than others.

Can MS be cured? Not yet. However, advances in treating and understanding MS are achieved daily, and the progress in research to find a cure is encouraging. In addition, therapeutic and technological developments are helping people manage symptoms and lead more productive lives. Several FDA-approved medications are available and have been shown to slow the underlying course of the disease for many people with MS.

What medications and treatments are available for MS?
The National Multiple Sclerosis Society recommends people begin treatment with one of the following disease-modifying drugs — Aubagio®, Avonex®, Betaseron®, Copaxone®, Extavia®, Gilenya® or Rebif® — upon a diagnosis of a relapsing form of MS, the most common kind. These drugs help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions in the brain and may slow the progression of disability.

Novantrone® is approved for reducing disability and/or frequency of exacerbations in patients with worsening relapsing MS. This is the first therapy approved in the United States for people with secondary-progressive MS or who are experiencing a rapid worsening of the disease. In addition, approved by the FDA for return to market, is Tysabri®, which is generally recommended for patients who have had inadequate response to, or are unable to tolerate, other approved disease-modifying MS therapies for relapsing forms of MS.

Many therapies are available to treat symptoms such as spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness and cognitive issues. People should consult with a knowledgeable physician to develop a comprehensive approach to managing their MS.

Why is MS so difficult to diagnose?
In early MS, elusive symptoms that come and go might indicate any number of possible disorders. Some people have symptoms very difficult for physicians to interpret, and these people must "wait and see." While no single laboratory test is available to prove or rule out MS, magnetic resonance imaging (MRI) helps physicians reach a definitive diagnosis.

What are the different types of MS?
In an effort to develop a common language when discussing, evaluating and treating MS, the Society conducted an international survey among scientists who specialize in MS research and patient care. Analysis of the responses resulted in the following four definitions of disease categories.

- **Relapsing-remitting:** People with relapsing-remitting MS experience clearly defined flare-ups (relapses) or episodes of acute worsening of neurologic function. These are followed by partial or complete recovery periods (remissions) between attacks that are free of disease progression. Frequency: *Most common form of MS at time of initial diagnosis. Approximately 85 percent at onset.*
- **Primary-progressive**: People with primary-progressive MS experience a nearly continuous worsening of their disease from the onset, with no distinct relapses or remissions. However, there are variations in rate of progression over time, occasional plateaus and temporary minor improvements. Frequency: *Relatively rare. Approximately 10 percent at onset.*
- **Secondary-progressive**: People with secondary-progressive MS experience an initial period of relapsing-remitting disease (see above) followed by a steady worsening disease course with or without occasional flare-ups, minor remissions (recoveries) or plateaus. Frequency: *If left untreated, 50 percent of people with relapsing-remitting MS develop this form of the disease within 10 years of initial diagnosis.*
- **Progressive-relapsing**: People with progressive-relapsing MS experience a steady worsening disease from the onset but also have clear acute flare-ups (relapses), with or without recovery. In contrast to relapsing-remitting MS, the periods between relapses are characterized by continuing disease progression. Frequency: *Relatively rare. Approximately 5 percent at onset.*

Fact sheet: MS research

THE NATIONAL MS SOCIETY'S COMMITMENT TO RESEARCH

- Cumulative research funding in excess of $818 million by end of 2013
- $47.6 million to support over 350 research initiatives during 2013

OUR FUNDING HAS BEEN CRITICAL IN

- Creating tools/processes to quickly and accurately diagnose MS
- Developing most of the approved MS disease-modifying drugs
- Identifying genes that contribute to MS susceptibility
- Demonstrating a link between vitamin D and MS risk
- Recruiting, training, and retaining leading MS researchers making breakthroughs today
- Discovery of the potential for neural repair
- Getting more potential MS therapies in the pipeline than at any other time in history

SWEEPING ADVANCES MADE IN RESEARCH DURING 2012

- The approval of a second oral therapy for relapsing forms of MS and other emerging treatments progressing through the development pipeline
- The launch of the International Progressive MS Collaborative, the largest effort to date to speed research to stop progressive forms of MS
- The discovery of what could be a target of the immune attack in people with MS may lead to new understanding of the disease and new treatment strategies
- The completion of the first human trial of an experimental therapy targeting myelin repair
- Progress in restoring functions using innovative rehabilitation techniques, including memory enhancement using a technique involving stories and imagery to solidify learning, and improving balance and mobility with specific exercises
- Advances in uncovering MS triggering factors, bringing us closer to finding ways to prevent the disease; and many other advances pushing us closer to a world free of MS

OUR COMMITMENT MOVING FORWARD

We are committed to freeing the world of MS. Our global support of MS research and treatment focuses on three key areas — **STOPPING** the progression of the disease, **RESTORING** function that's been lost, and **ENDING** the disease forever. We will achieve this by pursuing all promising avenues; engaging the best and brightest minds; connecting people resources and ideas; speeding development of treatments; and identifying and filling gaps.

OUR RESEARCH FOCUS THROUGH 2015

- We better understand the scientific mechanisms that lead to disease progression and accelerate therapy development.
- We pursue new avenues to discover how nerve cells are damaged and potentially repaired.
- We pursue new rehabilitation techniques and symptomatic treatments to restore neurological function and enhance quality of life.
- We identify risk and triggering factors that cause MS, and understand the biological interactions that lead to its development so that MS can be prevented.
- We expand and strengthen the quantity and quality of MS research worldwide to accelerate new discoveries and treatments for people with MS.

2013 UPPER MIDWEST CHAPTER FUNDRAISING EVENTS

April 27	Walk MS: North Dakota, held in four North Dakota communities
May 4	Walk MS: Avera Neurosciences and Neurology Associates, held in four South Dakota communities and Sioux City, IA
May 5	Walk MS: Christopher & Banks Walk presented by Walser, MN Held in 18 communities throughout Minnesota and Western Wisconsin
May 11	Bike MS: SAM'S CLUB Twin Cities Ride One-day ride held in Maplewood, MN
May 18	Walk MS: Iowa Held in seven communities throughout Iowa.
June 7-9	Bike MS: C.H. Robinson Worldwide MS 150 Ride Two-day, 150-mile ride from Duluth to the Twin Cities
June 22-23	Bike MS: Cruise the Cornfields, IA 70- or 150-mile, two-day ride through central Iowa.
July 14-19	Bike MS: TRAM Ride (The Ride Across Minnesota) The ultimate Minnesota road trip. International Falls to Duluth, Minn.
July 27	Bike MS: Sanford Health Ride the Wind One-day scenic ride around the Fargo area
Aug. 3-4	Bike MS: Sanford Health Pedal the Plains Sioux Falls to Madison and back, South Dakota
Aug. 10	MuckFest MS Twin Cities sponsored by Subaru A fun and challenging five-mile course full of muck and crazy obstacles held at Trollhaugen Resort in Dresser, Wis.
Aug. 14	On the Move Luncheon, Minneapolis An inspiring event featuring silent and live auctions
Sept. 28-29	Challenge Walk MS: Twin Cities A 2-day, 50k journey through the best of Minneapolis
Oct. 6	Run to Stop MS, MN (Twin Cities Marathon) Run with passion. Run with heart. Run 26.2 miles closer to a cure.