



# CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Winter 2012

Mid America Chapter

## KEEP MOVING to maintain your health

Staying fit is tough to do under the best of circumstances. Throw MS into the mix and it can be even more challenging. But the benefits you can gain from a fitness routine are worth the effort. A study published by researchers at the University of Utah in 1996 was the first to demonstrate clearly the benefits of exercise for people with MS. Those patients who participated in an aerobic exercise program had better cardiovascular fitness, improved strength, better bladder and bowel function, less fatigue and depression, a more positive attitude, and increased participation in social activities. Since 1996, several additional studies have confirmed the benefits of exercise.

In addition to being essential to general health and well-being, exercise is helpful in managing many MS symptoms. Inactivity in people with or without MS can result in numerous risk factors associated with coronary heart disease. It

can also lead to weakness of muscles, decreased bone density with an increased risk of fracture, and shallow, inefficient breathing.

As winter approaches finding ways to stay fit takes a lot of creativity, but the benefits are worthwhile. Think about the activities you do every day and figure out ways to incorporate movement into them. Do leg lifts while sitting at your desk or arm lifts while brushing your teeth. Take the longer route to your desk in the morning. Take advantage of the times of the day when you have the most energy, but don't overdo it. Learn your body and how much you can do without leading to a backlash of fatigue. Often short bursts of activity throughout the day can work better than one chunk of exercise. Spend 10 minutes three times each day and you will be getting 30 minutes of exercise without the major fatigue that would come from a 30 minute workout.

*Story continues on page 3*

THIS ISSUE:



AND MORE!

CONNECTIONS  
PAGES 4-5

DOC TALK  
PAGES 6-7

MS ACTIVISM  
PAGES 12-13

VOLUNTEERS  
PAGE 14

**1-800-344-4867**

Publication of the  
National Multiple Sclerosis Society  
Mid America Chapter  
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Kansas City, MO 64114

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**If You or Someone You Know Has MS** 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. Talk to your health care professional or contact the National MS Society at [www.nationalmssociety.org](http://www.nationalmssociety.org) or 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

The National Multiple Sclerosis Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The National Multiple Sclerosis Society assumes no liability for the use of contents of any product or service mentioned.

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 mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

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Mid America Chapter

Due to our Chapter's expansion as well as the ongoing economic challenges, we continue to focus on managing costs and increasing program impact. As such, **we will be consolidating our St. Joseph operations into our Kansas City office.** Our current St. Joseph office staff person, Erica Kiehnhoff, will now be based in our KC office and will continue to partner with others in the KC office as well as volunteers in St. Joseph and surrounding communities in NW Missouri to provide support to those affected by MS. We welcome your feedback. For questions, please call 816-396-0320 or e-mail [midamericachapter@nmss.org](mailto:midamericachapter@nmss.org).

**Facebook**



Want more contact with other people living with MS? The National MS Society's Mid America Chapter is on Facebook (where you'll find discussion threads, links and more). Interact with other people in the community with MS! Like us at [facebook.com/MSmidamerica](https://facebook.com/MSmidamerica).

**Twitter**



Get the inside scoop on the latest about our top fundraising events. Follow the Mid America Chapter on Twitter for all things related to Walk MS chapter-wide and Bike MS in Kansas City, Nebraska and Ozarks. Join the movement at [twitter.com/WalkMSkmo](https://twitter.com/WalkMSkmo) and [twitter.com/BikeMSkc](https://twitter.com/BikeMSkc), [twitter.com/BikeMSoz](https://twitter.com/BikeMSoz) and [twitter.com/BikeMSne](https://twitter.com/BikeMSne).



It's all about adapting what you do to meet your current situation.

It can be frustrating when an activity you used to enjoy, becomes too much to do, but finding a way to adapt that activity you love is empowering. **Keep focused on what you loved about the activity;** camaraderie with friends, brisk air, the challenge. Look for ways to incorporate those aspects into what you can do. There is a plethora of adaptive equipment available; search the Internet for "disabled recreation activities" to find ones in your area.

**Plan your activity, including breaks, ahead of time.** If you are going to a fitness facility it's a good idea to visit the location ahead of time so you know what to expect for temperature, where the restrooms are located and the overall accessibility of the facility. It's a good idea to meet the instructor ahead of time and see what they know about MS. You can get brochures from the MS Society to share with the instructor or even suggest specialized training available through the Society. Doing this leg work ahead of time will allow you to focus on getting a great workout.

**Find a buddy to get fit with.** Working out with a friend provides encouragement, support and most importantly accountability. Pick an activity you both enjoy or alternate between a couple different ones. Be sure to schedule a regular time on your calendar. You will be more consistent and have the added benefit of spending time with a friend.

**Challenge yourself to do what you can** when you can. Exercise may be different when you have MS, but it can still be an integral part of your life. And the benefits are huge.

**RESOURCES TO HELP KEEP YOU FIT**

- Brochures like Stretching for People with MS, Stretching with a Partner and Exercise and MS are available by calling the MS Society.
- Momentum Magazine Fall 2012 includes a great article about exercise and MS and what current research tells us.
- Midwest Teleconference November 2012 was on Exercise and MS and reviews current research findings. Listen to the recording on our website.
- MS Navigators can help you find resources for fitness. Can help you find programs in your area, connect you to local resources. Financial assistance program can help with the financing adaptive equipment or a membership to a fitness program.
- MSmidamerica.org has volumes of information about developing an exercise routine. Just type exercise in the search box in the upper right-hand corner.

Exercise programs are available throughout our chapter including:

**AQUATICS:**

Omaha & Springfield

**MS FORWARD GYM:**

Omaha and coming soon to Kansas City

**YOGA IN CHAIRS:**

Kansas City

**YMCAS:**

Wichita

# WE ARE ALL CONNECTED

GET CONNECTED IN YOUR AREA

MS Connection Groups bring together people who share a common life experience, for support, education and mutual aid. Members of Connection Groups share a belief that positive personal change happens through individual efforts with the support of others. Find new power and confidence in facing the challenges of living with MS while learning new information for managing your MS. Get connected to a group in your area today!

## Chapterwide

Name	Location	Contact
Hope From Home MS Group	Via Telephone	Karen 402-486-1885

## Kansas East:

Name	Location	Contact
Manhattan Area Self-Help Group	Manhattan, KS	Mary: 785-539-1339
Positive Living	Topeka, KS	Merica: 785-273-2173
Sabetha Self-Help Group	Sabetha, KS	Debbie: 785-284-2612, JoAnn: 785-736-2730

## Kansas Central:

Name	Location	Contact
Salina Self-Help Group	Salina, KS	Susan: 785-823-1954
Life's Journey	McPherson, KS	Tim: 316-804-4332
Butler County MS Support Group	El Dorado, KS	Janice: 316-320-9025
Asbury MS Group	Wichita, KS	Karen: 316-942-5919
HuSHMS	Hutchinson, KS	Ruth: 620-662-3584

## Kansas West

Name	Location	Contact
Great Bend Self-Help Group	Great Bend, KS	Marian: 620-639-4500

## KC Metro:

Name	Location	Contact
Blue Springs Self-Help Group	Blue Springs, MO	Dixie: 816-229-2851
Midtown Strivers	Kansas City, MO	Helen: 816-761-3296
Johnson County Heroes	Shawnee Mission, KS	Sharon: 913-631-3495
20s & 30s MS Connection Group	Leawood, KS	Jennifer: 913-339-8839
Northland MS Connection Group	Kansas City, MO	Dorthey: 816-741-2833, Linda: 816-741-7404

## Missouri Central:

Name	Location	Contact
Cass County Self-Help Group	Belton, MO	Jean: 816-779-6933
Warrensburg Self-Help Group	Warrensburg, MO	Karen: 660-827-1112, Reva: 660-747-3870
Bates County Self-Help Group	Butler, MO	Mary: 660-679-5749, Cheryl: 660-200-7046

## Missouri Northwest:

Name	Location	Contact
Chillicothe MS Connection Group	Chillicothe, MO	Stacy: 660-646-1303
Support Positive	St. Joseph, MO	Nancy: 816-223-5607
MS Piggies	St. Joseph, MO	Janet: 816-233-4180
Northwest Missouri Self-Help Group	Maryville, MO	Annette: 660-725-4103

## Missouri Southwest:

Name	Location	Contact
Branson MS Connection Group	Branson, MO	Jennifer: 417-593-0236, Tenya: 417-559-6075
Springfield Connection MS Group	Springfield, MO	Mary: 417-895-8228, Heather: 417-887-0170

## Eastern Nebraska/Western Iowa

Name	Location	Contact
Council Bluffs MS Group	Council Bluffs, IA	Jerry: 712-366-9569, Donna: 712-642-4711

## Nebraska East:

Name	Location	Contact
Beatrice MS Group	Beatrice, NE	Emmett: 402-228-3585
Columbus MS Group	Columbus, NE	Robbin: 402-270-3305
Norfolk MS Group	Norfolk, NE	Ken: 402-379-3629
Lincoln MS Fellowship Group	Lincoln, NE	Karen: 402-486-1885, Linda: 402-202-9820
NW Lincoln MS Connection Group	Lincoln, NE	Ruth: 402-261-8050
Nebraska City MS Connection Group	Nebraska City, NE	Lisa: 402-873-3414
Positively Moving Forward	Omaha, NE	Mary Jo: 402-330-1983

## Nebraska Central

Name	Location	Contact
Grand Island MS Support Group	Grand Island, NE	Jayne: 308-382-1883, Dixie: 402-834-0075
Lexington Area MS Self-Help Group	Lexington, NE	Anita: 308-324-4406

## Nebraska West:

Name	Location	Contact
McCook MS Self-Help Group	McCook, NE	Joann : 308-345-6816, John: 308-278-2165
North Platte Area MS Support Group	North Platte, NE	Alicia: 308-520-0351, Kathy: 308-534-3548
Panhandle MS Support Group	Scottsbluff, NE	Beth: 308-632-0918



Living with MS can sometimes mean seeing several healthcare professionals throughout the year. Getting to know your healthcare professionals beyond the exam room can make the process more manageable. The article below is written by Joan McMahon, MSA, BSN, CRRN. Joan has been involved with the Mid America Chapter of the MS Society in various roles for over 20 years. She is currently a member of the Clinical Advisory Committee. Joan is the Spinal Cord Injury Program Coordinator at the University of Kansas Hospital. In addition, she is active nationally in the Association of Rehabilitation Nurses and the Academy of Spinal Cord Injury Professionals.

## Health Care Self Advocacy

by Joan McMahon, MSA, BSN, CRRN

Everyone should advocate for themselves when it comes to health care...especially those with a chronic disease such as MS.

### SO WHAT DOES SELF-ADVOCACY MEAN?

It means:

- Speaking up for yourself.
- Representing yourself as interested in your own health care and not as a passive recipient of care.
- Making informed decisions about your health care.
- Taking actions to make sure that your choices are included in your health plan of care.
- And by doing this assuming some control

of your life circumstances.

### HOW DOES A PERSON ADVOCATE FOR THEMSELVES:

#### Become informed

- Read about MS.
- Keep up regarding research.
- Ask questions and then clarify further until you understand.
- Get connected to the MS Society.



Joan McMahon,  
MSA, BSN, CRRN

### Communicate completely and assertively

#### Overall

- Exhibit self-confidence. Speak with conviction.
- Describe what your unique needs are.
- Be concise.
- Indicate what you perceive will meet your needs.
- Anticipate the reaction to your request... and try to understand their reply.
- Listen to others views.
- Be organized in your approach.

#### With your physician

- Choose a physician who you are comfortable speaking with. It is OK to change your health care provider, if you do not feel comfortable.

- Be prepared for the visit. Bring everything you are asked to bring. Make a list of all of your questions and bring it with you. If you have had previous testing, bring the results with you. This will help prevent wasting your time and the physicians.
- Be honest in reporting your medication regime. Do you really take a medication twice a day...or do you often only take it once? Has something changed since your last visit? Your medication list should include over the counter vitamins, pain meds and other supplements that you use.
- Ask questions, if the physician is ordering a new medication. What is it for? Does it replace one of your other medications... or is it additional? What are the potential side effects? Is it an expensive medication that you cannot afford? If so, is there a substitute?
- Be honest in communicating those items that your health care provider will disapprove of (smoking, excessive alcohol, weight gain or other poor life style choices).
- Keep a journal of symptoms and bring it with you so you remember the details.
- Ask questions about treatments suggested, warning signs. If you do not understand, ask the physician or physician extender to explain again.
- After a test, be sure to schedule an appointment to get the results.
- Be respectful, but firm with your needs. Do not be intimidated.
- Take notes. You can then refer back to them if you have forgotten the details.

#### With your personal care providers/ PCAs

- Communicate clearly what you would like to happen.
- Communicate your appreciation of good

- care received.
- Keep good records of care received, not received, denied.
- Understand and report to the authorities verbal and/or physical abuse.

### Health Insurance

- Keep informed of changes in health care legislation.

#### If you have it:

- Learn what your policy does and does not cover.
- If you believe they have made an error, question it.
- Document any and all interactions with your insurer.
- Have you physician's office check to be sure that tests ordered and referrals are covered by your insurance and are in network.

#### If you do not have health insurance:

- Contact the MS society for names of programs or clinics in your area.
- See if you would qualify for Medicaid or Medicare.
- Contact your local health department for referral to free care.

#### Consider your eligibility for Social Security

- Research what is needed.
- Collect all the facts you need.
- Talk with you PCP or neurologist concerning your eligibility.
- Be aware that there is a tight window to reply to queries or you must start over.

Articles written by columnists are featured solely because they are considered valuable information and you may find them beneficial. Information is not necessarily endorsed by the MS Society.



You don't even have to leave your home to participate in this FREE teleconference series! Get the most up to date information on a variety of topics the second Monday of every month. Teleconferences are free, but registration is required. You can register for one or two programs or all 12. We will send call-in information and handouts the week prior to the call and you will receive a reminder the day before the call.

**African Americans Get MS Too**  
**January 14, 2013 at 7 p.m.**

**Presenter: Adil Javed, MD, PhD, The University of Chicago Medicine**

- Understand the prevalence of MS in the African American community.
- Learn how the disease affects African Americans differently.
- Explore resources available from the MS Society.

**What's Happening NOW - MS Research**  
**February 11, 2013 at 7 p.m.**

**Presenter: Dr. Bruce Bebo, AVP, Discovery Research, National MS Society**

- Learn how the MS Society supports MS research.
- Hear about Society funded research projects.
- Receive the latest information about what is hot in MS research.

**Don't Fall for It - Keep Your Balance**  
**March 11, 2013 at 7 p.m.**

**Presenters: Becky Anderson, OT, Fairview**

**MS Achievement Center & Megan Frost, PT, STEP Physical Therapy**

- Understand the common causes for MS imbalance and falls.
- Learn how to minimize your risk of falling.
- Gain practical tips and strategies for making your environment safer.

**Calm Before the Storm**  
**April 8, 2013 at 7 p.m.**

**Presenter: Elena Sabin, American Red Cross**

- Learn what you need to do to plan for a natural disaster.
- Gain insight about special considerations for people with disabilities.
- Explore community resources to help after the disaster.

**It's Not Just In Your Head**  
**May 13, 2013 at 7 p.m.**

**Presenter: Dr. Julie Bobholz, PhD, Clinical neuropsychologist at Aurora BayCare Clinic and Froedtert Hospital/Medical College of Wisconsin**

- Learn the prevalence of common MS symptoms of anxiety, depression and mood swings.
- Understand the physiological and psychosocial causes of these symptoms.
- Explore strategies for facing these symptoms.

**My Family has MS**

**June 10, 2013 at 7 p.m.**  
**Presenter: Rosalind Kalb, PhD,**

**Vice President of the NMSS Professional Resource Center**

- Learn how MS impacts all family members.
- Explore effective communication methods for the whole family.
- Gain strategies for dealing with the challenges MS can bring to family life.

**WAKE UP!**

**July 8, 2013 at 7 p.m.**

**Presenter: Doug Schell, APRN, MSCN, MidAmerica Neuroscience Institute**

- Learn why fatigue and sleep disturbance are two of the most common and debilitating symptoms in MS.
- Explore medical treatments available for fatigue management and sleep aids.

- Gain strategies and behavioral changes for improving sleep and minimizing fatigue.

**MISSED A CALL?**

All calls are recorded and made available on our website and through our Lending Library about two weeks after each call.

**Probiotics and MS**

**August 12, 2013 at 7 p.m.**  
**Presenter: Dr. Loren Rolak, MD Director of the Marshfield Clinic MS Center**

- Understand probiotic as treatment options.
- Learn about the hygiene hypothesis and what is has to do with MS.

- Hear about research projects in MS based on the hygiene hypothesis.

To register for a teleconference or to learn more about the Midwest Teleconference Series, call 1-800-344-4867 and press 1 or go online to [MSmidamerica.org](http://MSmidamerica.org) or e-mail [midamericachapter@nmss.org](mailto:midamericachapter@nmss.org).



National Multiple Sclerosis Society



Whether you are newly diagnosed or looking to connect with others, join us for an informal conversation about MS AND YOU!

**POSSIBLE TOPICS:**

- Just the basics – the disease modifying therapies
- Sharing your diagnosis with family and friends
- Understanding your diagnosis
- Finding support
- Q&A with a healthcare professional

CHECK YOUR E-MAIL FOR LOCAL DATES & TIMES

A LIGHT DINNER WILL BE SERVED

**LOCATIONS INCLUDE:**

KANSAS CITY, OMAHA, SPRINGFIELD, WICHITA & EXPANDING TO MORE LOCATIONS!

Registration is free, but required.

**1-800-344-4867, PRESS 2 MS MIDAMERICA.ORG**



# A RESEARCH REVOLUTION: WHERE YOUR DOLLARS GO

The National MS Society connects people to find solutions. The Society is driving promising research for everyone with MS; our commitment is not just to some people with certain forms of disease or experiences. We committed to solutions for all, and ultimately an end to MS.

The Society's No Opportunity Wasted (NOW) campaign committed to invest \$250,000,000 in promising MS Research by the end of 2015.



### RESEARCH THAT WILL STOP MS IN ITS TRACKS.



### RESEARCH THAT WILL RESTORE WHAT'S BEEN LOST.



### RESEARCH THAT WILL END MS FOREVER.

The Society supports and funds research activities spanning all research stages, including early discovery research, translational research that brings promising ideas forward into actual therapeutic solutions for testing, and clinical trials. We drive all types of promising research that can impact those living with MS.

### FUNDRAISING DOLLARS AT WORK:

Local research studies are direct examples of where Walk MS, Bike MS and other event fundraising directly goes. Our Chapter has recently partnered with the University of Missouri - Kansas City and the University of Kansas Medical Center to pursue a research study that illustrates our commitment to the

National NOW research campaign made possible by fundraising efforts.

The chapterwide research study is looking for participants living with relapsing-remitting MS who are choosing not to take medication to prevent flare-ups. Participants are not required to take disease-modifying treatments to be part of this study. Instead, researchers are interested in learning about reactions to the telephone counseling you will receive. It is hoped that this research will help us improve MS care and better understand reasons some patients with MS choose not to take medication.

### STUDY REQUIREMENTS:

- 1 1/2 hour appointment prior to start of telephone counseling.
- Four 20 minute telephone conversations about MS medications.
- Completion of questionnaires at home.

### CRITERIA:

- Diagnosed with a relapsing form of MS.
- Discontinued taking a disease modifying medication.
- Do not currently have plans to begin taking MS medications.

If you are interested in participating and meet the above criteria, please contact: Jared Bruce, Ph.D., at 816-235-5428 ext. 1, or via e-mail at [mmedfeedback@umkc.edu](mailto:mmedfeedback@umkc.edu).

### RIDING FOR RESEARCH:

Research studies like this are made possible through funds designated to research through

Bike MS and Walk MS. Raising money for the Society is more than just a passing act of kindness for many Walk MS or Bike MS teams. Their passion for a world free of MS leads them to unlimited, meaningful opportunities to connect and support the Society.

Teams such as Research Rough Riders restrict their Bike MS funds for the sole purpose of research. Team Captain, Dr. Ted Higgins, motivates his team by matching the pledges of all team members dollar for dollar in an effort to help stop MS, to restore the effects of MS and to end MS forever. He continually strives to encourage fellow team members to set and reach high fundraising goals as he works to educate them on the disease and the need for a cure.

Through his contributions, Dr. Higgins established the Dave Tomlinson Research Fund in conjunction with the Mid America Chapter,

which has helped fund The Role of Gamma Amino Butyric Acid in EAE and MS done by Dr. Ropa Phat of Stanford University. Because of Dr. Higgins' determination to the NOW campaign and the fundraising success of his team, his teammates and others around him are better educated and inspired by the cause.

People everywhere, and in every way imaginable, are raising money to end MS. Those with family and friends living with MS are devoting their time, talent and resources to fundraising efforts starting with a simple request of co-workers and neighbors to donate to a Walk MS or Bike MS team.

NOW is the time to become a champion for MS research and help lead the effort to create a world free of MS. Visit [nationalMSSociety.org/research](http://nationalMSSociety.org/research) to become a leader in the MS Research Revolution.

## RESOURCE: ENERGY ASSISTANCE PROGRAM

The Low Income Energy Assistance Program (LIEAP) is a federally funded program that helps eligible households pay a portion of their home energy costs by providing a stipend to help with the cost of heating and cooling. Eligibility guidelines differ in each state. Additionally, cooling and crisis benefits may also be available.

**KANSAS:** Online applications for energy assistance will be available the second week in January 2013 - March 31, 2013.

**MISSOURI:** LIEAP is managed by community action agencies. To see your county's eligibility guidelines please visit, [MSmidamerica.org](http://MSmidamerica.org).

**Energy Assistance Period:**

- Oct. 1 - March 31, 2013 (Physically Disabled/Elderly),

- Nov. 1 - March 31, 2013 (Everyone Else)
- Energy Crisis Program:**
- Oct. 1 - March 31, 2013
- All contingent upon when funds are depleted.

**NEBRASKA:** Please contact Nebraska Department of Health & Human Services in your county. Clients must fill out the entire FA application that is for all services, including LIHEAP.

**Energy Assistance Period:**

- Oct. 1 - March 31, 2013
- Energy Crisis Program:**
- All year, 1 crisis per year, up to an additional \$500.

To find out more about your state's energy assistance programs please visit the Programs & Services section at [MSmidamerica.org](http://MSmidamerica.org) or call 1-800-344-4867.

## CELEBRATING MS ACTIVISM AT WORK

On Sept. 12, the National Capital Chapter in the Washington, D.C. metropolitan area kicked-off the fall season with the 34th Annual Ambassadors Ball. This year's meaningful ball raised more than \$850,000, contributing to the nearly \$17 million that event has raised over its history. The event, which took place at The Ritz-Carlton in Washington D.C., has a rich history with many traditions. One such tradition is event co-chairs, the wives of Congressmen, are introduced by their husbands.

This year's Ambassadors Ball honored the Mid America's very own Representative Lee Terry. The Congressman, from the 2nd Congressional District of Nebraska, was honored for his support of MS research initiatives. Congress-

man Terry is a member of the Congressional MS Caucus and a supporter of the Lifespan Respite Care Program. He is also a co-sponsor of the National Neurological Diseases Surveillance System Act. The Congressman shared his personal story of a lifelong friend who is living with MS and how he has seen it affect her, her family and her community. When asked to comment on his experience at the Ambassadors Ball, Congressman Terry stated: "I want to thank the MS Society for the honor and for the wonderful experience at the Ambassador's Ball. The MS Society is an exceptional organization that has worked hard to shed light on a misunderstood neurological disease. This is made possible by dedication and perseverance by groups like the MS Society."



*Congressman Lee Terry shared his commitment to MS research at the Ambassadors Ball. Photo to credit: Betty Adler, National Capital Chapter.*

## MAKING MS ACTIVISM PERSONAL

*Mid America Advocacy Volunteer, Ann Reed, was asked why are you an MS Activist?*

I was diagnosed with MS in 1991 after having just completed my master's degree. I became involved with the MS Society to receive information on how the disease would affect me. From the very beginning, I was passionate about research. After diagnosis, I worked to educate myself on MS, research and medications. The first MS medication hit the market in 1993, and I started the drug in 1994. I have seen first-hand the benefits of research.

The information from the MS Society gave me hope and cause to remain positive. I learned of the Society's political support for the research and employment issues. During that time, disability communities were working on the Americans with Disabilities Act. I knew then, as I know now, that it was imperative that the MS Society, its staff, and most importantly, we volunteers, remain involved with public policy because there still remains a vast array of unmet needs for people living with MS and their families.

When I first became an MS Activist, I was nervous. My first visit with a Kansas state senator was nerve-racking. I didn't have a clue what I was supposed to say or do, but the legislators were kind and listened attentively, as I told my story about living with MS. I quickly learned that they did truly want to hear from me and to learn more about the policy needs of those of us living with MS.

I've been involved with the Mid America Chapter's Kansas Government Relations Com-

mittee for several years now, and I continue to believe that it is vital for legislators to hear from us, their constituents.

It is crucial for us to stand up as MS Activists to share our stories. I am grateful that the Mid America Chapter passes information so that I remain informed. As an MS Activist, I will continue to advocate for all of us living with MS by passing our stories, messages and concerns to our elected representatives.



*Mid America Chapter Kansas Government Relations Committee Member Ann Reed stands up for MS activism.*

**JOIN THE MOVEMENT.  
CREATE CHANGE.  
BE AN MS ACTIVIST.**

Are you interested in working with your local elected officials on critical issues that impact the lives of people living with MS? Whether you only have a few minutes or want to make a commitment, you can be an MS activist. With the help of grassroots MS activists, local policies and programs in both the public and private sectors can meet the needs of people living with MS. To become an MS Activist, please contact Susan Wallis at [Susan.Wallis@nmss.org](mailto:Susan.Wallis@nmss.org) or 402-390-6291.

## Are You Interested in Becoming a MS Activist?

Join us this February throughout the Mid America Chapter for Legislative Action Day 2012. Join those connected to MS in raising your voice to increase awareness and to learn more about the issues important to people affected by MS.

- KANSAS MS ACTION DAY: FEBRUARY 12, 2013**
- MISSOURI MS ACTION DAY: FEBRUARY 19 & 20, 2013**
- NEBRASKA MS ACTION DAY: FEBRUARY 26, 2013**

Please contact Susan Wallis at 402-390-6291 or [Susan.Wallis@nmss.org](mailto:Susan.Wallis@nmss.org) for additional information.



ADVOCACY

ADVOCACY

## A LIFETIME ACHIEVEMENT: 40 YEARS OF A SHARED PROMISE FOR THE MISSION

Each November, leaders across the MS movement gather together to celebrate progress, learn from each other and strengthen commitments to make an even greater impact in the coming year. Our movement is singular in vision, and our promise to people affected by MS is shared.

Our promise to people living with MS depends on our commitment to a shared vision, and the continued leadership development and progress necessary to deliver on the promise.

One local volunteer leader has demonstrated more than 40 years of commitment to our shared vision.

Because of her outstanding service to the National MS Society, Mary Reed Spencer was honored with the 2012 Lifetime Achievement Award. She received special recognition at the National Leadership Conference on Nov. 9, 2012 in Dallas.

Each year, local volunteers are nominated to receive national recognition for their remarkable service to the MS Society. Detailed nomination forms are submitted for each candidate to volunteer review panels from around the country, and they have the challenging job of selecting the final honorees. Lifetime Achievement Honorees are volunteers with 35 or more years of

service with the National MS Society. The Mid America Chapter is proud to have Mary Reed as one of this year's honorees.

Forty-two years ago, Mary Reed found her family when she joined the National MS Society. Since volunteering in 1970, her unflagging energy and commitment have inspired many others to join the movement.

Mary Reed's mother was diagnosed with MS when she was only 12 years old, the reason she continues to volunteer to this day.

She joined the Board of the Eastern Kansas Chapter and organized the first READaTHON in 1978, an effort in which she received the Bronze Hope Chest Award. She was also instrumental with realigning our chapters in 1990. Her passion for activism steered her toward leadership roles in Kansas and attendance at several Public Policy Conferences. She remains highly involved in all our events, Bike MS, Walk MS, along with numerous third party events.

Mary Reed considers the Society to be her family just as we consider her our family, a family she knows is searching for a cure, something she wants for the communities she calls home.



*Mary Reed Spencer (middle) accepts her 2012 Lifetime Achievement Award with National MS Society President and CEO Cyndi Zagieboylo (right) and National Board Chair Eli Rubenstein (left).*

Across the country people with a deep commitment to the MS cause are very successful at raising awareness and critical funds. Some fundraising efforts have grown into a community tradition while others are raising funds in new and creative ways.

DIY, or Do It Yourself fundraising is an opportunity for those living within the Mid America Chapter to raise awareness and funds for MS in unique ways. The best part of DIY fundraising is that it is completely put together by an individual or group looking to assist the Mid America Chapter's fundraising efforts. By participating in DIY fundraiser you are only limited by your creativity and eagerness to do more for the Movement.

DIY fundraisers come in all shapes and sizes and are run by corporations, individuals and families; there is no limit to how to run a DIY fundraising event.

Kathy Vandeven started Round for a Cure; a shotgun golf tournament that raises funds for MS research 17 years ago after being diagnosed with MS. Kathy was looking for a way to support MS research and ended up creating an event that has become a staple DIY fundraiser for the Mid America Chapter.

In 2011, Round for a Cure brought in \$42,000 to go directly towards MS research. Kathy solicits donations, plans for the tournament logistically and markets the event all with limited assistance from staff members at the MS Society. Round for a Cure has been met with overwhelming success, being at full capacity

at the Mozingo Lake Golf Course in Maryville, Mo.

Events such as Round for a Cure are vital to the fundraising efforts of the Mid America Chapter because they generate additional support based on creativity and personal interest. A successful fundraiser can come together using skills that you already have. Maybe you are a skilled painter, or always organize your neighborhood's garage sale; these talents can easily be transformed into an opportunity to host your very own DIY fundraiser.

It just takes one person to organize a DIY fundraiser, but can easily be a way to get your family or co-workers involved in the movement. Consider recruiting other individuals that you know who may have a tie to MS to join you. Remember to make your fundraiser personal to you, something that you will enjoy organizing and growing.

Regardless of the type of fundraising you may choose to do, the National MS Society has tools to help and support you! You'll find a DIY Fundraising Guide on *MSmidamerica.org*, which includes event planning tips, organizing suggestions, promotional tools and downloadable templates.

Share your passion for finding a cure through your own fundraising efforts and inspire your friends and family to join you in creating a world free of MS.

For additional information on Kathy Vandeven's Round for a Cure event, please visit [www.supportmsresearch.com](http://www.supportmsresearch.com).



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**National  
Multiple Sclerosis  
Society**  
Mid America  
Chapter

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The page is decorated with several clusters of stylized orange leaves or petals, scattered around the central text. The leaves are simple, teardrop-shaped with a small notch at the top, and are arranged in circular or semi-circular patterns.

# SNOWFLAKE SOCIALS

COMING JANUARY 2013...

We are more than our MS diagnosis. Connecting with others can be a powerful experience for a life with MS. Come connect and celebrate the New Year with families in your community at one of our Snowflake Socials.

Locations include Springfield, Wichita, Omaha & Kansas City.  
Dates & details coming soon.