

MS CONNECTION NEWSLETTER

LIVING WITH MS

MAKE MODIFICATIONS - STAY ACTIVE

Judy Braudmeier loves the outdoors. She enjoys fishing, deer hunting, camping and of course, going to her grandchildren's games. Living with MS can make that a challenge.

"I just have different ways of doing things," Judy said. "If there are things you really want to do you have to change your habits and rest up. I might rest up for two days for something I really want to do that is an all day thing."

To make sure she can stay as active as possible outdoors, Judy tries to be as active as possible indoors. Whenever she goes up stairs she stretches out her calf muscles by putting her toes on the bottom step and dropping her heels to the floor. Judy also keeps a stretch board that her husband made. Several times a day Judy will stretch for 5-10 minutes.

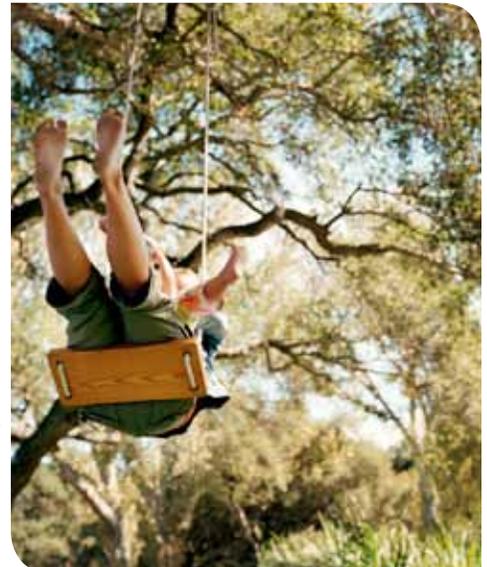
"It keeps my legs more limber," she said. "I still have weakness sometimes, but I'm trying to do what I can."

At the recommendation of one of her doctors, Judy also purchased a Nintendo Wii video game. It gives her a chance to get up off the couch, get a bit of exercise, and play with her grandchildren from the comfort of her own home.

"You have the games to help keep you moving and you have the balance exercises to help as well," Judy said. "My grandkids think it's great I'm playing with them and I'm getting some

exercise. It's in an open room so if I fall I won't hurt myself."

When Judy does venture outside she plans ahead. Her husband and son even modified their deer hunting stand so she can climb it easier.



"If we're going to go out fishing, especially in the summer, I have a cool-down vest and we go out early in the morning," she said. "If it's real hot when camping, I'll stay in the camper and then go out in the evening."

Judy also takes every opportunity she can to learn about MS as she is very active in the Wood River Talk MS Group.

"I joined the group because I wanted to learn about what was going on because I wasn't understanding a whole lot of it," Judy said. "What I was reading at the time scared me to death. I ended up with a great bunch of people. We share things just like one big family. If we're having bad days we know we can contact each other." ■

INSIDE

4

DOC TALK

5

2015 PROGRAMS

6-7

RESEARCH

10-11

ADVOCACY



**National
Multiple Sclerosis
Society**

Mid America Chapter
7611 State Line Rd., Ste. 100
Kansas City, MO 64114
1-800-344-4867

Chairman: John Snyder
Chapter President: Tami Greenberg

© 2015 National Multiple Sclerosis Society, Mid America Chapter
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 Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.



FROM THE PRESIDENT

HOPE SPRINGS ETERNAL

Dear friends,

Spring is my favorite season. As the trees bud and flowers bloom, I am reminded of hope. And we know that, in our movement to end MS, there is more hope than ever before!

The work that we are engaged in, together, is fueling our progress towards a world free of MS. And it's making a difference! You are an important part of this movement, and together we are changing the world for people affected by MS.

There are several ways you can help propel our shared fight against MS:

- Tell your story! Whether you share your MS journey with a friend, through social media, or with a legislator, it helps bring more people to this work. It also helps remind you that you are not facing MS alone.
- Get some family and friends together and register for Walk MS! You can show up in person at one of our events, or you can participate online. We need your help, your presence, and your fundraising. It makes a difference, and it's a great way to connect with the MS community.
- Make ending MS part of your legacy! You can make a deferred gift to the National MS Society through a will, trust, or estate plan. This offers a lasting legacy of support to people affected by MS. Call us at 1-800-344-4867 and ask about the Lawry Circle.

Really, it comes down to YOU. We need your help to fuel progress. And this Spring, there are many aspects of our movement to end MS that give me hope: the extraordinary progress being made in MS research; the connections being made in homes, online, and across our territory; the walkers, and cyclists, and online fundraisers who help fuel the mission; and the brave and authentic people who tell their MS story. Because of you, I have hope.

All my very best,



TAMI GREENBERG
CHAPTER PRESIDENT

LIVING WITH MS**IMPACT STATEMENTS FROM 2014**

In 2014, the Mid America Chapter offered an array of programs and services to address financial need, facilitate connections to others impacted by MS, to take charge of their lives through information about MS and disease management and to influence policies that drive research, enhance care, improve quality of life and help others live with dignity now. 1,225 persons participated in Traveling Turkeys, Family Getaway Days and Socials, TREND Symposium, Talk MS, Couples Retreat, and Financial Assistance. 30% of these participants responded to questionnaires to evaluate the impact of their participation.

ADDRESS FINANCIAL NEED

76% Immediate financial needs were met

87% The assistance improved the quality of life

CONNECT WITH OTHERS**IMPACTED BY MS**

81% Felt less isolated in coping with the disease

84% Felt connected to others

96% Knew other people with MS and their families

INCREASE KNOWLEDGE OF**RESOURCES AVAILABLE**

89% Knew how to access resources in their community that may assist in their efforts to be as independent as possible

92% Knew how to request assistance from the NMSS for MS-related issues

LEARN TOOLS FOR DEVELOPING RELATIONSHIPS

80% Learned at least one new thing about NMSS programs and services

100% Learned at least one new positive coping strategy from other people with MS and their families

IMPROVE FAMILY RELATIONSHIPS

87% Felt their relationship with spouse/family/children improved

93% Were able to spend more time with family/friends celebrating Thanksgiving

EMPOWERED TO MANAGE THE SYMPTOMS OF THE DISEASE

95% Had a better understanding of the disease

79% Knew at least two strategies to help me to deal with or cope better with MS

KNOW MS TREATMENTS

50% Planned to discuss (or have discussed) different MS treatment modalities with health care provider

UNDERSTAND RESOURCES**AVAILABLE**

88% Learned at least one new thing about NMSS programs and services

90% Knew how to request assistance from the NMSS for MS-related issues

CALLED TO ACTION

100% Had a better understanding of issues important to people with MS

BECOME ACTIVISTS

93% Were more likely to reach out to elected officials on MS matters

100% Will encourage others to become activists

88% Intend to use at least one of the tools learned in future advocacy

4 docTALK

WELLNESS

LET'S GET MOVING

BY SHARON LYNCH, MD

When I was first involved in MS care in the 1980's, it was common for neurologists to counsel their patients to reduce their activity levels, rest a lot, and not to exercise. Because of the effects of heat and the increased weakness people with MS experienced when they were fatigued, it was thought that people should give in to this and limit their activities so that they wouldn't get weaker.

One of my mentors at the University of Utah, Dr. Jack Petajan, was one of the first big proponents of exercise in MS. He worked with the Jimmy Heuga Center and wrote papers on the beneficial effects of exercise in MS. As time has gone on, we in the MS care community have become more and more aware of the benefits of exercise in MS. By the 1990's, we began recommending that people with MS exercise regularly to reduce fatigue and build stamina. There is now even research that aerobic exercise and fitness may improve cognition in other neurological diseases. This could also be true for MS.

The amount and type of exercise someone with MS should be doing is still under study. I think it will always vary a lot with the individual, and there will never be a "one size fits all" in exercise for MS. In general, active aerobic exercises such as swimming, exercise bikes, elliptical machines, Nu-steps, and treadmills are useful forms of exercise. The safety of these types of exercises depends on the severity of the person's MS, (a person who trips easily should probably not use a



THERE IS NOW RESEARCH THAT AEROBIC EXERCISE MAY IMPROVE COGNITION IN NEUROLOGICAL DISEASES.

treadmill), and the length of the exercise depends on the strength and fitness of the individual. Sometimes, only a few minutes a day is the best a person can do. People who can only walk a few steps can sometimes use walking in their home with a walker as their exercise of the day.

We also recommend various types of stretching and balance exercises. Many people love Yoga, Tai Chi, or other stretching and balance programs. Traditional stretching can also be very helpful, and a good physical therapist can guide a person with MS on an individualized stretching and strengthening program.

I currently help to run the Mid-America MS Achievement Center. It is a program designed to work with people with more severe MS to do therapy and exercise services on a weekly basis. We hope to expand this program in the next few years, and over time we hope to serve people at all disability levels.

The most exciting thing about exercise is that it helps almost everyone. From the people with mild MS who run marathons or ride the Bike MS to those with severe MS and are wheelchair bound, exercise can help to improve and maintain their ability to live the best life they can! ■

INDEPENDENT EXERCISE PROGRAMS OFFERED IN THE MID AMERICA CHAPTER

Mid America MS Achievement Center

Kirmayer Fitness Center
University of Kansas Medical Center
3901 Rainbow Blvd
Kansas City, KS 66160
913-588-8668
Jmarkwardt-oberheu@kumc.edu
www.msachievement.org

Excel Program at the Rehabilitation Institute of Kansas City

3011 Baltimore Avenue
Kansas City, MO 64108
816-751-7914
Monday, Wednesday, and Thursday from
4-6 p.m. \$20/month

University of Nebraska Medical Center

Engage Center for Successful Aging
730 South 38th Street Omaha, Nebraska
Contact Jeanne Hannan at 402-552-7227
or jeannie.hannan@unmc.edu
Combo class including stretching aerobic
and resistance training
Monday and Wednesday 5:30 to 6:15 pm

MS Forward Gym

www.msforward.org
8802 S. 135th St. #300
Omaha, NE 68138
402-330-6292
Monthly Fees / No Membership Required
*Now offering online exercise videos at
www.powerforward.tv for \$9.95 a month

*Please let us know if there is an exercise program in
your community that would be good for people with
MS. Contact Jean Long at 816.448.2180 or
jean.long@nmss.org*

LIVING WITH MS

2015 PROGRAMS

Consider participating in one of these
upcoming programs to connect with others
impacted by MS and take charge of your life
through information.

JUNE 6

Family Get Away Day
Joslyn Art Museum
Omaha, Nebraska
*Registration opens
April 1*

JULY 25-26

Couples Retreat
Branson, Missouri
*Registration opens
June 15*

JUNE 27

TREND Symposium
University of Kansas
Regents Center in
Overland Park, Kan-
sas and online
*Registration opens
May 1*

Call 1-800-344-
4867 to register.
Please review the
program page at
msmidamerica.org. If
you want to receive
a monthly notice of
programs call 1-800-
344-4867 to provide
your e-mail address.

NATIONAL

TELECONFERENCE

nationalMSsociety.org/telelearning

MS FRIENDS

1-866-673-7436.

MSCONNECTION.ORG

MSconnection.org

VOLUNTEER- DRIVEN PROGRAMS

Contact Jean Long at 816.448.2180 or
jean.long@nmss.org. ■

RESEARCH

UNDERSTANDING MS GENETICS RESEARCH

BY CLAUDE SCHOFIELD, PHD

People affected by multiple sclerosis sometimes ask me: “It’s great that they found another gene that is linked to MS, but what does it mean for me?” Well, the genetics research presented at the annual meeting of the Americas and European Committees for Treatment and Research in MS (ACTRIMS-ECTRIMS), held in Boston this past September, has given me great answers.

HOW GENES INTERACT

Dr. David Hafler (Yale University) launched the discussion about genes and MS when he delivered the keynote lecture during the opening ceremony. He was the founder, with other researchers, of the International MS Genetics Consortium, a team that has turned MS genetics on its ear. “Virtually every MS geneticist on earth is working together,” he declared and spoke eloquently about where we are in the search for MS genes. He noted that there will likely be hundreds of MS risk genes uncovered eventually. “Each [gene] by itself has a small effect on disease risk; but each interacts



with the environment,” he noted. “These are not bad genes, and it’s not a bad environment – it’s a bad interaction.”

MAPPING MS SUSCEPTIBILITY

Dr. Philip De Jager (Harvard), recipient of the 2014 Barancik Prize for Innovation in Research, presented the Consortium’s latest findings – a replication of its pivotal genetics study, published in **Nature Genetics** (online, September 29, 2013), that identified 48 new genetic variants associated with MS based on data gathered from 30,000 people with MS and more than 50,000 controls without MS. Gene research is grueling – data from thousands of people with and without MS need to be gathered in massive numbers, and then all those data must be replicated. Dr. De Jager announced that after studies involving over 80,000 people, they now have identified more than 159 genetic variations

related to MS, and more importantly, have begun to identify the specific immune cells and proteins involved, and how much weight each one carries. “We have created a reference map of MS susceptibility,” said Dr. De Jager. “Now we turn to the task of understanding the biology of MS susceptibility.”

EXPLORING DIFFERENCES

Dr. Noriko Isobe (University of California, San Francisco) and the Consortium reported on how genes differ between African Americans and Caucasians with MS, following up on a 2013 study published in **Neurology** (online, June 14, 2013). Eight novel genes were identified among African Americans with MS that were not uncovered in the larger gene scans. We’ve seen that the experience of African Americans with MS is different from that of Caucasians, and this study is putting us on the road to finding out why.

GENES AND VITAMIN D

Dr. Jennifer Graves (University of California, San Francisco) and the Network of Pediatric MS Centers reported on findings from an ongoing study led by investigators nationwide of what triggers MS in children. They showed that vitamin D status, which has been linked to MS risk, was associated with MS relapses only if children have a specific immune gene. The original study included 185 kids, and this group is collecting data on hundreds more. Trials of vitamin D supplementation are ongoing, so

I’m hopeful that future findings will show who may be helped most by this strategy.

TRANSLATING THE DATA

Taking a big step toward translating all of this gene data, Dr. Nikolaos Patsopoulos (Brigham and Women’s Hospital) and colleagues from a range of institutions in Boston examined which proteins interact with the 159 genes that have been pinpointed by the Consortium. Then they cross-linked this information with the “druggable genome” —a data set on how existing therapeutics interact with the genome—and identified more than 2,000 possible therapeutic interactions.

Genetics research is a huge part of our efforts to end MS forever because by understanding factors that may cause MS, we’re better able to target research of solutions to those specific factors. This meeting has given me a lot of hope that we are on the right path to doing just that. ■

Dr. Claude Schofield is the director of Discovery Research at the National MS Society.

Originally published on MSconnection.org/blog.

To follow the latest MS research, visit www.nationalMSSociety.org/research, or sign up for MS eNEWS at www.nationalMSSociety.org/signup.

LIVING WITH MS

CONNECTIONS THROUGH EDUCATION

For those living with MS, education can include learning about the disease and treatment options, keeping up on the latest MS research, and staying informed about advocacy efforts to shape public policy. Because you are empowered to live well with MS when you have information, the National MS Society develops or promotes education programs like this year's North American Education Program (NAEP) focusing on **“Mood and Cognition in MS: What You can Do.”** This program package includes a facilitator's guide, video and participant handbook.

The Mid America Chapter is providing three opportunities to explore this education program, learn more about how MS affects mood and cognition, and connect with others living with MS.

- **Connection Groups:** Connection groups are support groups for people living with MS. There are over 30 connection groups throughout the Mid America Chapter that you can join, or you can start one in your community. Connection Group leaders have access to educational programs developed by the National MS Society and its partners and often choose to use these programs as content for connection group meetings.
- **Community-Driven Events:** The chapter is looking for individuals who have a passion for planning social or educational events.

These community-driven events are one way to bring information and awareness about MS to a community. There have already been three successful community-driven events this year and we would like more! The NAEP Program on “Mood and Cognition” is an excellent tool to use for a community-driven education event. The content is ready to use; you just need to organize an event to make something happen in your community.

- **TREND Symposium:** The TREND Symposium is a one-day education event highlighting an area of MS research and applications for those living with MS. This year's TREND Symposium focuses on mood and cognition, “How MS Makes You Think and Feel,” and features local researchers and practitioners who will provide evidenced-based and practical information and resources. The event will be held on Saturday, June 27 at the KU Edwards Campus in the Kansas City area. For those not able to attend in person there will be an online option to watch the event.

The Mid America Chapter is committed to offering different avenues for education to all its constituents. If you are interested in any of the programs mentioned above, please contact Jean Long, Programs, Services and Connection Group Coordinator at jean.long@nmss.org or 816.448.2180. ■



THERE'S ONE NEAR YOU!

APRIL 4

Manhattan, KS
Manhattan City Park

APRIL 11

Kansas City, KS
Sporting Park

Maryville, MO
Northwest Missouri State

Omaha, NE
Stinson Park

St. Joseph, MO
Heritage Park

Topeka, KS
Lake Shawnee

APRIL 18

Hays, KS
Fort Hays State

Hiawatha, KS
Hiawatha High School

North Platte, NE
Madison Middle School

Salina, KS
Jerry Ivey Park

Springfield, MO
Mercy Eye Clinic

APRIL 25

Joplin, MO
Landreth Park

Lawrence, KS
Sunflower Elementary

Liberty, MO
Mosaic Life Center

Marshall, MO
Indian Foothills Park

O'Neill, MO
O'Neill High School

Scottsbluff, NE
YMCA

Seymour, MO
Nazarene Church

Wichita, KS
Sedgwick County Park

MAY 2

Branson, MO
Branson State Park

Grand Island, NE
Barr Middle School

Hutchinson, KS
Carey Park

MAY 3

Kearney, NE
Yanney Park

MAY 9

Gothenberg, NE
TBD

Lincoln, NE
Fallbrook Town Center

JUNE 6

McCook, NE
TBD

TBD

Neodesha, KS
TBD

REGISTER TODAY!

WALK.MSMIDAMERCIA.ORG

1-800-344-4867

ADVOCACY

WHEN YOU HAVE MS, UNINSURED & YOUNG

BY MARCILLENE DOVER

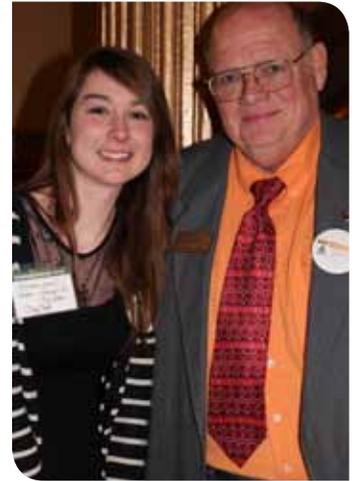
It started in early 2013. I was sitting down at work when I noticed my legs felt kind of funny. I just felt like I couldn't feel them the way I used to.

I didn't have any insurance. My mom had me on CHIP (state children's health insurance program) when I was in high school, but since I was no longer under the age of 18, I lost coverage. My mom paid for my initial doctor visit. The doctor said she would really like to do an MRI, but since I had no insurance, she was just going to go ahead and call it a pinched nerve. She prescribed six weeks of physical therapy, with no follow up appointments.

In the summer of last year, I noticed something. Walking to and from class was difficult. I stumbled a lot and even fell down, on occasion. Maybe my pinched nerve just didn't heal. That happens right? I tried not to worry and to just carry on.

Then one day at work, I started slurring. It lasted about 10 minutes or so, every other sentence. It didn't feel right. Then, out of nowhere, I remembered something I read on a website: slurred speech is a symptom of MS. I thought again, no way, not me. I don't have a disease. I'm 21 years old; I'm in the prime of my life. No way. I told myself that I should go get tested one day, but I wasn't thinking

seriously about it. I didn't have insurance; just to get diagnosed would be expensive. I finally decided to visit the doctor at my college campus and told him about my symptoms. I found an organization that would pay for a free MRI, should he suggest one. The doctor referred me to a neurologist, just to be safe. It's hard to get in to see a neurologist, so I had a few months to save up the \$300 it was going to cost me.



**MARCILLENE DOVER AND
DR. STEVEN MILLER**

I went to the neurology appointment, health checklist and application for an MRI in hand. I was pretty scared going in, but the doctor was really nice. He had me describe my symptoms, and then he did a physical examination. He signed off for me to get an MRI, and he seemed pretty concerned. I was in tears.

I tried to be excited, hoping to hear anything, good or bad, from my doctor. I went on with my life as usual, going to school and tutoring students. I was at lunch at the high school when I got a call. It was a nurse practitioner. She said the doctor had reviewed my MRI

results and that they showed signs consistent with MS. I couldn't help but start bawling. I told myself any news is good news; it's better than not knowing. But that's not true. Now I didn't want to know. I wanted to crawl up in a little ball and give up on life.

But that's not what I did. Instead, I had to figure out how I was going to pay for this new, very expensive part of my life. I found out about Project Access, an organization that connects uninsured people with donated specialty care. I was accepted into their program and was able to see my doctor and get more MRIs.

However, since Project Access only gives patients access to donated health care and is not actually insurance, I can only receive care as long as they are able to give it. In fact, Sedgwick County just reduced their funding. MS is so expensive, without any insurance or assistance program, my disease modifying therapy drug would cost \$2,000 to \$3,000 every month alone.

I am lucky for now to receive my medication through a patient assistance program and my neurology care through Project Access. What about other people who are living with MS and uninsured? MS, like many other diseases and cancers, could affect anyone. And not everyone is as lucky as I was; I had all the right connections this time. Many people are not so fortunate. That's why we need to expand Medicaid. No one should have to go through receiving a devastating diagnosis and then feel further devastation as they wonder how they will get the care that they need. ■

THE NATIONAL MS SOCIETY'S ACCESS TO HIGH QUALITY MS HEALTHCARE PRINCIPLES

PRINCIPLE 1: People with MS are at the center of their healthcare decision-making.

PRINCIPLE 2: People with MS have access to a comprehensive network of providers and healthcare services focused on producing the best outcomes at affordable costs.

PRINCIPLE 3: People with MS have access to comprehensive health insurance plans with affordable premiums, deductibles and other out-of-pocket costs.

PRINCIPLE 4: Healthcare providers have greater awareness, resources and tools to enable the timely diagnosis, treatment and symptom management of MS.

PRINCIPLE 5: People with MS have access to and receive high quality MS care regardless of disparities including but not limited to disease progression, level of disability, geographic location, socioeconomic status, gender, sexual orientation, race/ethnicity, cultural background, age and care setting (home- and community-based or residential).

PRINCIPLE 6: People with MS have access to high-quality long-term supports and services (including assistive technology) in settings that best meet their needs and prevent financial hardship for the individual and family.



**National
Multiple Sclerosis
Society**

7611 State Line Rd., Ste. 100
Kansas City, MO 64114

MSmidamerica.org

1-800-344-4867

midamericachapter@nmss.org

facebook.com/MSmidamerica

KANSAS AND NEBRASKA LEGISLATIVE ACTION DAYS



MS CONNECTION BEING MOVED TO E-VERSION

The September 2015 issue will only be sent electronically to your e-mail address on record. The December, March and June issues of the MS Connection will be sent hard copy and electronically to your e-mail. If you did not receive an electronic version of this MS Connection, please call the Information and Resource Center at 1-800-344-4867 to provide or update your e-mail address. If you prefer to continue receiving a hard copy of the MS Connection you must let us know, please e-mail Jean Long at jean.long@nmss.org.