

MS CONNECTION MAGAZINE

BE INSPIRED.
GET CONNECTED.
WALK MS.

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WALK MS.
SEE PAGE 7.



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LETTER FROM THE PRESIDENT

As I write this we celebrate MS Awareness Week. In fact, this morning my daughters were decorating cupcakes in preparation for an MS Awareness presentation at their school. Last night one of my daughters was doodling before bedtime in anticipation of tomorrow's presentation and she created an MS badge to wear. I thought to myself, we're doing a great job with our branding! And then I thought about how far this movement has come as the Gateway Area Chapter celebrates 60 years in 2015!



REBECCA FEHLIG
CHAPTER PRESIDENT

- 60 years ago we had no unified brand for MS. Today my daughters are making orange and black cupcakes; This week MS was featured on the Today Show, plus 2 local stories in Southern Illinois.
- 60 years ago we had no symptom modifying treatments for MS. Last week Dr. Mark Tullman treated his first patient on the newly released infusion treatment, Lemtrada (the 12th approved).
- 60 years ago individuals with progressive forms of MS had little hope. Today the international community has joined to invest resources through the International Progressive MS Alliance.
- 60 years ago if you were diagnosed with MS, you did not know where to turn. Today we offer online, telephone and in person support around the country.
- 60 years ago there was no focus on rehabilitative therapy. This week our Challenge Walkers shared stories with each other of why they joined the MS Movement as they train for their 50 mile journey this May; participants in Talk MS Groups, fitness classes, Chamber of Commerce and even the annual Olney, IL Fish Fry, have gathered to share stories and connect about MS.

There is more to come in the coming weeks! 325 MS activists will be on Capitol Hill in March to educate Congress and urge their support of 2015 advocacy priorities for people living with MS. Over 50 local professionals will gather to Kick Off our 20th Anniversary Corporate Achiever's Campaign in March. On April 19, we will welcome David Osmand to join us at Walk MS in Forest Park

As we celebrate 60 this year, I would love to hear from each of you on what you are doing to make an impact for individuals living with MS.

With gratitude,

WOMEN ON THE MOVE

COUNTRY STAR TO SPEAK AT LUNCHEON

Being diagnosed with MS when she was 27 was just the first in a series of challenges that country music star Julie Roberts has faced over the last seven years. While working on the release of her second album, *Men and Mascara* (2006), the follow-up to her critically acclaimed debut *Julie Roberts* (2004), the singer lost the backing of her record label, despite universal acclaim of her work, including an array of music award nominations and performances on NBC's *The Tonight Show*, ABC's *Good Morning America* and an *In the Moment* feature on CMT. Less than four years later, Roberts watched the 2010 Tennessee floods destroy her home and car. On top of that, she was injured leaping from the roof of her two-story house into a rescue boat.

None of this, however, could keep Roberts down — or away from her fans. She stayed close to them via social media sites like Facebook and Twitter and created her own label, *Ain't Skeerd*, to release her third album, *Alive*, in 2011. In the title song she wears her philosophy proudly on her sleeve:

I fall sometimes
I crawl sometimes
Lose it all sometimes
It makes me stronger

The years of struggle — and of rising to the

challenges her life has thrown her — have paid off big. In 2013 Roberts released her fourth, career-defining album, *Good Wine and Bad*



COUNTRY SINGER JULIE ROBERTS WILL BE THE FEATURED SPEAKER AT THE WOMEN ON THE MOVE LUNCHEON APRIL 30.

Decisions, on the legendary Sun Records

“I feel like I’ve finally found a place to be,” she says. “Where my music really fits. I’m really excited about that. It doesn’t seem real in a way. Maybe when I see the actual record with the Sun label on it.”

“I want people to know that I can still do whatever I want,” she says, when asked if she’s up to the hectic schedule. “It’d be way more stressful for me to not be doing what I love. I would worry more for my health sitting home than playing shows every night. That’s where I love to be.”

Connect with Julie Roberts and get her tour schedule at JulieRoberts.com

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! ■

WELLNESS

ADAPTING YOGA TO FIT THOSE LIVING WITH MS

For everyone, particularly people living with Multiple Sclerosis, it's vital to keep moving.

“Human beings have evolved to move,” said Iyengar Yoga certified instructor Robert Gadon. “When we aren't moving our systems, the circulatory systems, blood system, lymphatic system don't get used, the body stagnates. Anything you can do to get people moving is a good thing.”

Robert holds a weekly yoga class for people living with MS who struggle to move.

“They come in scooters or wheelchairs and some can stand up,” Robert said.

So how do they do yoga? Robert helps them and they do whatever portion of the pose they can.

“We adapt the way we do the pose. Instead of doing a complete posture, we'll work on a piece of the pose,” Robert said. “If the pose involves extending the leg, lifting the trunk and extending the arms, maybe they can't do all three at once, so we break it down and people can get benefit from that modified pose. What I focus on is extension in the legs, arms and trunk.”

Staying active and doing adaptive yoga poses not only benefits the participants physically,



THERE ARE MANY BENEFITS TO YOGA, PHYSICALLY, MENTALLY AND SOCIALLY.

but mentally and socially as well.

“The yoga postures have become a means for penetrating into the mind,” Robert said. “If you have a lot of things you're thinking about, it's very hard to sit still with a very active mind. The postures help to bring the mind into focus. It gets the mind settled. It's a way of practicing meditation in action.”

As the class has progressed, Robert has pushed its participants to do more.

“I've gotten to know the group, and I know what they are capable of and I'm always experimenting to see what else they can do,” Robert said.

Doing yoga also gives participants a good feeling about themselves.

“It gives them confidence,” Robert said. “It changes the perspective they have of themselves and they learn that they can do more than they thought they could. That's important. Another benefit is, it provides companionship. To live with MS is hard and people are social. If you can't get out and engage with other people you can get depressed. I think for some people in the group this is something they look forward to as getting out, socializing, moving a bit and seeing their friends.” ■

LIVING WITH MS

FROM WHEELCHAIR TO GOLF COURSE

Richard Nelson is no stranger to the hardships of living with multiple sclerosis. Diagnosed in 1996, Richard's life quickly took a different path than he had imagined.

"I had returned from the Peace Corps, started a family and I had a great deal of my life left to live," Richard said. "I was an avid runner and very in-tune with my body so, I knew something was off. I went to the doctor for some flu medicine and was diagnosed with MS shortly after."

Like most young people receiving the diagnosis, Richard had no idea what MS was.

"I had never heard of it," Richard said. "I had to do a lot of research and read about it. At the time, it felt like a death sentence."

After struggling with the disease and some complacency, Richard decided it was time to take control.

"I was really dependent on my wheel chair," Richard said. "I could do things around the house but the wheel chair became who I was. Last summer, I decided that if I could swing a golf club, I could play."

Today, Richard is no longer dependent on his chair. He cites a change of attitude as the best medicine.

MY GOAL IN LIFE IS TO HELP PEOPLE UNDERSTAND THAT LIFE IS FRAGILE. I HAVE MS. BUT, MS DOESN'T HAVE ME. NOW I DON'T TAKE LIFE FOR GRANTED. IT'S CHANGED EVERYTHING ABOUT ME

- RICHARD NELSON

"Setting my mind on this goal, it changed so much. It became really therapeutic to me. I was really suffering from depression but this gave me will-power," he said. "It gave me confidence. Golf really changed my life. I am able to golf every single day. I have the support of my family and make it a priority because it is what I have to do."

Richard is realistic about his future but refuses to let MS be who he is.

"I know I will have good days and bad days," Richard said. "My goal in life is to help people understand that life is fragile. Yes, I have MS. But, MS doesn't have me. Now, I don't take life for granted. It's changed everything about me."

Richard plans to host a golf tournament benefiting the National MS Society on July 18. For more information on this event, visit gatewaymssociety.org. ■

DEVELOPMENT

WELLNESS VILLAGE COMING TO WALK MS

Walk MS connects people living with MS and those who care about them. It is a day when we come together to show the power of our connections.

NEW THIS YEAR! We are showcasing some of our health and wellness partners who will be located in the NEW MS Wellness Village!

What you can expect...

- Warm up exercise before start time
- Occupational & physical therapists from your community rehab centers
- Local Talk MS group leaders
- Medical equipment companies
- Accessible van demonstration
- Information on disease modifying drugs from pharmaceutical company representatives
- and more

BE INSPIRED. GET CONNECTED. WALK MS.



- | | |
|-----------|--|
| April 11 | East Central Missouri
East Central College |
| April 12 | Mid Missouri
Ashland City Park |
| April 18 | Southern Illinois
SIUC Student Center W. Patio |
| April 18 | St. Charles County, MO
370 Lakeside Park |
| April 19 | Southeast Missouri
Capaha Park |
| April 19 | Forest Park, MO
Upper Muny Parking Lot |
| April 25 | Millstadt, IL
Millstadt City Park |
| April 26 | Edwardsville, IL
Township Park |
| May 9 | Illinois Riverbend Area (Godfrey)
Glazebrook Park |
| August 15 | O'Fallon, IL
Community Park |
| Sept 19 | Mt. Vernon, IL
Veterans Memorial Park |

walk
MS

REGISTER TODAY!

gatewaymswalk.org
1.855.372.1331

MS PSYCHO-EDUCATIONAL SUPPORT GROUP

Creve Coeur Community Counseling & the Gateway Area Chapter of the National MS Society presents "Multiple Sclerosis Psycho-Educational Support Group" on 8 consecutive Sundays from 1-3 p.m.

Discussions and educational topics to include but not limited to:

- Receiving diagnosis and navigation of the medical system
- Processing your fear of the unknown
- Managing your energy with healthy lifestyle choices
- Managing family and work relationships
- Learning how to find meaning in life and live with a purpose!

Cost for all 8 sessions: \$30/person, scholarships available, applications required.

Location: Creve Coeur Counseling, 10176 Corporate Square Drive Suite 100S, St. Louis, MO 63132

Contact: Joe Applebaum at Creve Coeur Community Counseling at 314-991-0100 ext. 716 for more information or to register.

• PAID ADVERTISEMENT •

**Get inspired. Meeting medical specialists. Connect with others.
All at a Novartis MS Education Link Event.**

Mark Tullman, MD is talking multiple sclerosis (MS) and treatment.

April 14, 2015 at 6:00PM

Hunan Restaurant, 710 East Main Street, Carbondale, IL 62901

Save a seat for a friend. Accessible to folks in wheelchairs or who need assistance. Light meal served. Validated parking. Space is limited. **Please RSVP by calling 866-682-7491**

Catch a Web event from home at ms-web-events.com

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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 really hot when we are 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." ■

ADVOCACY

WHEN YOU HAVE MS, ARE UNINSURED & YOUNG

BY MARCELINE 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 go to the clinic doctor on 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.

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.



**MARCELINE DOVER AND
DR. STEVEN MILLER**

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? Multiple Sclerosis, 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. ■

ADVOCACY

WANTED: DISTRICT ACTIVIST LEADERS

Lead the way in your community by becoming a volunteer District Activist Leader. As a District Activist Leader, you will build and foster critical relationships with the elected officials in your area. You will serve as a liaison between these officials and the Society, helping to develop a reliable grassroots movement across the state and the country.

ILLINOIS:

Please contact Suzanne at 314-446-4169 or Suzanne.carron@nmss.org

MISSOURI:

Please contact Sarah at 314-446-4193 or sarah.gentry@nmss.org

TAX TIME REMINDERS

Don't forget! You can help end MS forever by donating to the National MS Society through the **Multiple Sclerosis Fund on the Missouri State Income Tax Form**. This tax check-off program allows taxpayers to designate a \$1-\$200 donation. Money contributed will be subtracted from any income tax refund owed to the individual by the state or would be added to the income tax the individual owes the state. If you made any accessibility modifications (such as installing ramps or grab bars) to your home this year, you might also be eligible for the **Home Access Tax Credit**. For Missourians with incomes up to \$30,000, the tax credit pays 100% of the cost of home modifications, up to \$2,500. For Missourians with incomes between \$30,000 and \$60,000 the credit covers 50% of modification costs, up to \$2,500. For more information, visit dor.mo.gov.

CAREPARTNER SUPPORT RESOURCES

NATIONAL SERVICES

CARE CALL

CareCall is a branch of MS Friends that is specifically for CarePartners. Leave a message with the volunteer who answers, and a trained CarePartner who has experience with loved ones with MS will return your call to answer questions and offer support. The number of volunteers is limited, but you can expect a callback within 48 hours.

Phone: 1-866-673-7436
Website: nationalmssociety.org/MSFriends



MS CONNECTIONS

Connect with others who live with MS through one-on-one connection or support groups. The number of CarePartners who volunteer is limited, but there are some available. Contact: For more information, contact the National MS Society or your local chapter
Website: msconnection.org/Find-Support/One-on-One-Peer-Connections

MS WORLD

MS World collaborates with the National MS Society and works to reach people with MS, family members, and friends. MS World hosts many online chats and message boards to offer the latest information. The site is designed to be “patients helping patients.” Post your questions to have other members share their insights with you, and have a chance to share your expertise by responding to others’ posts. MS World also provides a weekly newsletter, educational teleconferences, free webcasts, and various chat room topics such as Laughter is the Best Medicine, Primary Progressive MS/Secondary Progressive MS, Caregivers Chat, Newly Diagnosed, Family and Friends, and Parents with MS.

Website: msworld.org

CAN DO MS

Can Do MS offers a variety of lifestyle empowerment programs for people living with MS and their CarePartners. With a very holistic view of people with MS and their community, Can Do MS programs aim to expand knowledge, skills, tools, and confidence to empower people living with MS to live their best lives. This foundation recognizes that MS is a family disease, and specializes in a wide range of programs to address the needs, goals, and concerns of CarePartners and family members.

Phone: 1-800-367-3101
Email: info@mscando.org
Website: mscando.org

CHAPTER SERVICES

CAREPARTNER AND FAMILY GROUP

This group covers a series of topics important to CarePartners or to anyone who provides care for a loved one with MS. It meets at the David C. Pratt Cancer Center in St. Louis, MO on the first Tuesday of the Month at 6:00 pm. It is facilitated by Karen Tripp, Marriage and Family Counselor. Please RSVP.

Phone: 1-800-344-4867
Email: stacey.cameron@nmss.org
Website: <http://bit.ly/talkmsgroups>

MS TOGETHER

This couples’ social group provides an informal social opportunity to meet and talk. Events are organized by the couples themselves and they include potlucks and ball games. Expect to actively participate in planning and organizing, as well as having fun! This group meets quarterly. The location changes, but is generally in the St. Louis area.

Email: jsalacki2@gmail.com
Website: <http://bit.ly/talkmsgroups>

LENDING LIBRARY

In support of our mission, the Multiple Sclerosis Association of America (MSAA) provides free access to accurate, current, and comprehensive information to people with MS, those who care for them, and health professionals through our lending library. Books, DVDs, and CDs are available on a variety of topics including symptom management, emotional health, exercise, family support, disease information, and more.

Phone: 1-800-532-7667 ext. 154
Website: www.mymsaa.org/mssa-help/lending-library

CAREGIVER SUPPORT SERVICES

ABLEDATA

AbleData is a database that provides access to over 29,000 assistive technology and rehabilitation equipment products. The site provides its consumers with descriptive and objective information about products to help you make the most educated decisions for your needs or the needs of your loved ones.
Phone: 1-800-227-0216
Website: abledata.com

AGIS

This site is dedicated to eldercare to help you make educated caregiving decisions. AGIS provides access to information, checklists, and articles from unbiased sources.
Phone: 1-866-511-9186
Website: agis.com

CAREGIVER.COM

Caregiver.com provides numerous resources for caregivers, including a national network of support groups and access to financial assistance. This website focuses on providing support specific to both urban and rural residents across the U.S. Caregiver.com also features a bi-monthly magazine.
Phone: 1-800-829-2734
Website: caregiver.com

CAREGIVER ACTION NETWORK

This organization aims to advocate on behalf of a wide range of caregivers as well as providing resources to help educate and give support to caregivers. Some of their services include: an online family caregiver support forum; e-newsletters with tips for caregivers; and a network of volunteers who are or have previously been

caregivers.

Phone: 1-800-896-3650
Website: caregiveraction.org

CARING BRIDGE

CaringBridge is an online network that aims to help people stay connected and facilitate communication about health conditions. The use of a personalized website allows you to post comments about needs or updates on health status. This way, friends and family know how best to be supportive.
Website: <http://www.caringbridge.com/nationalmssociety>

CARING TODAY

Caring Today works to provide you access to advice from experts in a variety of fields, resources for caregivers, support from other caregivers, and help you manage day-to-day stress associated with caring for a loved one with a chronic health condition. This is done through online resources and a quarterly national magazine.
Phone: 203-542-7200
Website: caringtoday.com

FAMILY CAREGIVER ALLIANCE

Through a tool called the Family Care Navigator, the Family Caregiver Alliance helps to support and educate caregivers. This tool is used to help caregivers better understand and navigate programs that affect or may help their loved one. These programs include government, nonprofit, and private assistance programs.
Phone: 1-800-445-8106
Website: caregiver.org

MS FOUNDATION

The MS Foundation focuses on the impact of MS on

the people diagnosed, as well as their families. They offer numerous programs, including a Homecare Assistance Grant program that can help provide temporary support for access to home care, therapy visits, respite care, and transitions.
Phone: 1-888-673-6287
Website: <http://www.msfocus.org/homecare-grant-program.aspx>

MSWORLD®

A chat and message board site for people with MS, family members, and friends. It provides a safe and comfortable environment, offering the latest information and referrals. The website is moderated by people with MS who understand what it means to live with this disease. MSWorld also provides educational teleconferences, free webcasts, and various chat room topics such as Laughter is the Best Medicine, Primary Progressive MS / Secondary Progressive MS, Caregivers Chat, Newly Diagnosed, Family and Friends, Parents with MS.
Website: msworld.org

NATIONAL CAREGIVERS LIBRARY

The library provides free access to hundreds of useful resources for caregivers, including: articles, forms, checklists, and links to external sources. It is one of the largest sources of information and tools for caregivers.
Phone: 804-327-1111
Website: caregiverslibrary.org

NATIONAL COUNCIL ON INDEPENDENT LIVING

NCIL refers callers to local centers of independent living

and offers publications and advice related to disability issues.
Phone: 1-877-525-3400
Website: ncil.org

NEXT STEP IN CARE

Next Step in Care focuses on transitions associated with chronic health conditions. The website contains guides to help family members understand and plan for smooth transitions in care. Focus for safe and smooth transitions is placed on careful planning, clear communication, and ongoing coordination.
Website: nextstepincare.org

STRENGTH FOR CARING

Strength for Caring is a website created for family caregivers that features a resource center with access to information regarding health conditions and message boards for advice and support. It also provides daily inspiration and articles on caring for yourself while caring for others.
Phone: 1-866-466-3458
Website: strengthforcaring.com

WELL SPOUSE ASSOCIATION

The WSA focuses on support and education for spouses and partners of people living with chronic illnesses. The website provides access to a national network of support groups, a mentor program, letter writing groups, respite weekends, continuing support for members whose spouses have died, and a newsletter and e-newsletter.
Phone: 1-800-838-0879
Website: wellspouse.org

PUBLICATIONS

Caring for Loved Ones with Advanced MS: A Guide for Families
Dorothy E. Northrop, MSW, ACSW, and Debra Frankel, MS, OTR, ed. 2007. 112 pp. Available in print or online from the National MS Society.

Adapting: Financial Planning for a Life with MS
National Endowment for Financial Education, 2003. 72 pp. Available in print or online from the National MS Society.

Maximizing Independence: A Guide to Planning for Changing MS Care Needs
The Multiple Sclerosis Association of America, The Multiple Sclerosis Foundation, and the National Multiple Sclerosis Society, 40 pp.

A Guide for Caregivers
Tanya Radford, ed. 2011. 29 pp. Available in print or online from the National MS Society.

When a Parent Has MS: A Teenager's Guide
Dianne O'Connell, ed. 2009. 25 pp. Available in print or online from the National MS Society.

OTHER PUBLICATIONS: BOOKS

Multiple Sclerosis: A Guide for Families
Rosalind C. Kalb, PhD, ed. Demos Health, (3rd Ed.), 2006. 256 pp.

Multiple Sclerosis: The Questions You Have, the Answers You Need
Rosalind C. Kalb, PhD, ed. Demos Health, (5th Ed.), 2011. 448 pp.

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers
Maria M. Meyer with Paula Derr, RN. CareTrust Publications, (3rd Ed.), 2006. 326 pp. www.comfortofhome.com

Helping Yourself Help Others: A Book for Caregivers
Rosalyann Carter, with Susan Golant. Random House/Time Books, 1995. 288 pp.

Multiple Sclerosis: Your Legal Rights
Lanny Perkins, Esq. and Sara Perkins., Esq. Demos Health, 3rd edition, 2008. 240 pp.
Publications available through MS Association of America → Lending Library

RESPIRE SERVICES

NEXT STEP IN CARE ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER

This website has a respite locator, which is a service to help parents, family caregivers, and professionals find respite services in their area that match their specific needs. It also provides a guide to respite, The ABC's of Respite: A Consumer's Guide for Family Caregivers to help you get the most effective help.

Phone: 919-490-5577

Website: respitelocator.org

ELDERCARE LOCATOR

Eldercare Locator supplies information about numerous eldercare issues, including respite care. The website provides referrals to local respite programs and area agencies on aging.

Phone: 1-800-677-1116

Website: n4a.org

VETERANS AFFAIR MONTHLY CONFERENCE CALLS

PATIENT EDUCATION

WHEN: 2nd Monday of the Month

TIME: 7-8 p.m.

PHONE: 1-800-767-1750, access code 43157 and #

CAREGIVER SUPPORT GROUP

WHEN: 4th Monday of the Month

TIME: 1-2 p.m.

PHONE: 1-800-767-1750, access code 43157 and #

For more information go to www.va.gov/ms/

MS CLINICAL CARE NETWORK

The MS Clinical Care Network is a website that provides timely MS information and free innovative resources for health care professionals and their patients. The Clinical Care Network provides easy access to information about comprehensive, interdisciplinary MS management in a variety of formats; dynamic tools and resources for clinicians and their patients; and consultations and literature search services to support high quality clinical care.



DOWNLOAD THE FREE MOBILE APP for MS diagnosis (NMSS), disease and symptom management for iPhone, Android or Windows. Information at your fingertips about MS diagnosis, disease and symptom management.

SIGN UP FOR OUR E-NEWS FOR PROFESSIONALS - MS Clinical Care Connection - the Society's quarterly newsletter for healthcare professionals - delivers information and resources on a variety of clinical topics.

WEBSITE: nationalMSSociety.org/MSClinicalCare

EMAIL: HealthProf_Info@nmss.org

MULTIPLE SCLEROSIS COALITION CONSENSUS PAPER ON DISEASE-MODIFYING THERAPIES IS NOW AVAILABLE

A new paper entitled The Use of Disease-Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence - a consensus paper by the Multiple Sclerosis Coalition is now available. The evidence-based paper, developed and endorsed by the eight-member MS Coalition, and subsequently endorsed by Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS), will serve as an education and advocacy tool for people with MS and their healthcare providers. The purpose of the paper is to promote the importance of early and ongoing treatment and full access to all of the disease-modify therapies. **To view paper go to: <http://bit.ly/msconsensuspaper>.**



TALK MS GROUPS Talk MS Groups bring together people who share a common life experience for support, education, and mutual aid. They are led by trained volunteers.

MISSOURI			
Camdenton	9/18, 11/20 6-7 p.m.	Camden County Library 99 Rodeo Road, Camdenton, MO 65020	Christy Bays, cell (573) 480-7932 cm2owl@hotmail.com
Cape Girardeau	3rd Saturday 10 a.m.	St. Francis Health & Wellness Center, Rm. 1 150 S. Auburn, Cape Girardeau, MO 63703	Sharon (573) 332-8148
Columbia	3rd Wednesday 6-8 p.m.	Rusk Rehabilitation Center 315 Business Loop 70 West Columbia, MO 65203	Kim Williams, kimik1ster@gmail.com
Crystal City/ Festus	2nd Tuesday 1 p.m.	Disability Resource Association 420B S. Truman Bl., Crystal City, MO 63019	Marlene (636) 464-2533 Sharon webradleys@yahoo.com
Farmington	Third Thursday 6-8 p.m.	Mineral Area Hospital, Community Room 1212 Weber Road, Farmington, MO	Margaret (573) 631 7031 margaretusher2012@gmail.com
Jefferson City	3rd Monday 6 p.m., Restarting Sept. 15	Coca-Cola Bottling, Meeting Room 605 Washington, Jefferson City, MO 65109	Vickie vlueckenotte@icangels.com
Kirkville	1st Wednesday Every odd month, 6 p.m.	Annex Building 300 N. Franklin Kirkville, MO 63501	Renee 660-341-9999 or reeneadams22@hotmail.com
Moberly	3rd Thursday 6:30-7:30 p.m.	Timberlake Christian Church 1624 Gratz Brown, Moberly, MO 65270	Lynelle (660) 833-2037 or lynelle1963@gmail.com
New London	2nd Tuesday 7 p.m.	Ralls County Health Department Building 405 W. 1st Street, New London, MO 63459	Debby (573) 267-3365 mlrdsr@att.net
Rolla	Last Thursday 6:30 p.m.	Rolla Presbyterian Manor 1200 Homelife Plaza Rolla, MO 65401	Donna at (573) 263-4896 or dkreisler@centurytel.net Michelle at (573) 465-0453 or mkrrdr@gmail.com
Washington	3rd Monday 6 p.m.	St. Peter's United Church of Christ, 20 East 5th St., Washington, MO 63090	Anne (636) 359-6037
West Plains	3rd Wednesday 4:30 p.m.	Ozark Medical Ctr. Shaw Medical Bldg. 2nd Fl. 909 Kentucky St., West Plains, MO 65775	Sally (417) 469-4842 Dianna dianna.sigert@ ozarksmedicalcenter.com
ST. LOUIS METRO			
Affton	3rd Wednesday 7 p.m.	Weber Road Library 4444 Weber Rd, St. Louis, MO 63123	Tracy at (314) 353-4709 tthompson@fortdearborn.com Please leave a message
Generation OptiMiStic for people in their 20s, 30s & 40s	1st Saturday 10 a.m.	NMSS Office Gateway Area Chapter 1867 Lackland Hill Pkwy, St. Louis, MO 63146	Michelle (636) 447-5407
West County Prayer & Health	4th Wednesday 6:30-8 p.m.	Varies, contact Rose Marie	Rose Marie sqspace@sbcglobal.net

TALK MS GROUPS

ILLINOIS			
Alton/River Bend	3rd Tuesday 7-9 p.m.	The United Presbyterian Church, 2550 Rock Hill Rd., Wood River, IL 62095	Lisa (618) 258-0615
Belleville/O'Fallon	2nd Sunday 2:30 p.m.	First United Methodist Church 504 East Highway 50, O'Fallon, IL 62269	Amy (618) 235-4226
Central Illinois	4th Monday 7 p.m.	Richland Memorial Hospital 800 East Locust St., Olney IL 62450	Tony (618) 302-1333 tmadmz@frontier.com
Radiant MS Renegades	2nd Thursday 6:30 p.m.	Glen Carbon Library 198 S. Main, Glen Carbon, IL 62034	Charity (618) 420-4321 willdradiantMS@gmail.com
Herrin	Varies	Varies, contact Diane for details	Diane at dianeogden66@yahoo.com or on Facebook at MS Talk Group of Southern Illinois
Highland	1st & 3rd Wednesday 10:30 a.m.	Weinheimer Community Center 1100 Main Street Highland, IL 62249	Karen at 618-830-5681 momferguson5@gmail.com
S'myelin Gang of Litchfield	4th Tuesday 6:30 p.m.	Christian Church of Litchfield 131 Yaeger Lake Trail, Litchfield, IL 62056	Ruth (217) 999-8924 thesmyelingang@outlook.com
Metro East	4th Tuesday of even numbered months, 7 p.m.	LINC, Inc. #15 Emerald Terrace, Swansea, IL 62226	Diane (618) 235-8823 Earhart500@aol.com
SPECIALIZED GROUPS			
Couples Group	Varies, contact for information	Varies, contact for information	jsalacki2@gmail.com
Creative Art Experience	3rd Saturday 10 a.m.	NMSS Office 1867 Lackland Hill Parkway St. Louis, MO 63146	Sharon at 314-623-8528 or 4skgreene@gmail.com or Michelle at michellekeating@juno.com
MS Fun, Friends & Food	1st Tuesday in Feb., May, Aug. & Nov. 6 p.m.	David C. Pratt Cancer Center Mercy Hospital 607 S. New Ballas Rd. St. Louis, MO 63147	Michelle (314) 251-6400 Debbie (636) 579-0264 debra.morrissey2012@yahoo.com
Veterans with MS	2nd Wednesday 10 a.m.	Veterans Admin. Medical Center 1 Jefferson Barracks Dr. St. Louis, MO 63125	Lynn Seymour, DPT lynn.seymour@va.gov or 314-652-4100 ext. 64037
CarePartner and Family Group	1st Tuesday in Feb., May, Aug. & Nov. 6 p.m.	David C. Pratt Cancer Center Mercy Hospital 607 S. New Ballas Rd. St. Louis, MO 63147	Stacey (800) 344-4867 stacey.cameron@nmss.org

Learn more about MS— and its treatment.



Hear from MS experts and others living with MS. Get some answers about living with MS and information on an oral treatment for relapsing forms of MS. Then stay for a bonus session. Please join us.



Learn About MS & Parenting With Social Media

When:

Thursday, April 9, 2015
6:00 PM Central

Where:

Cannoli's Restaurant
(next to Walgreen's)
462 North Highway 67
Florissant, MO 63031

Speakers:

Kathryn Chenault, MD
Neurology of Arkansas



FYI:

Free parking or valet available.
A meal will be provided.

Please RSVP for you and a guest at:
mslivingevents.com or call 1-866-703-6293

Event ID: TR283008 (1209557)

GZUS.MS.14.08.0005



UPCOMING PROGRAMS

TELELEARNING PROGRAM

The National MS Society telelearning program for people with multiple sclerosis and their families aims to provide information and guidance on current matters essential to living one's best life with MS. The series provides telelearning sessions for seven different topics each year. Each free telelearning will feature topic-area expert(s) by phone with online presentations, and a Q&A session. Upcoming topics include:

MS and Employment:

Supports to Help You Find Employment

Featuring Russell G. Bowe Jr., GCDF, MA, of Speer Adult Workforce Center, Samantha Mankin, MA, CRC of Division of Vocational Rehabilitation, Amira Fahmy of



GettingHired, Inc

- Thursday, March 12, 6 pm

MS and Employment:

Guide to Flexible and Home-Based Jobs

Featuring Brie Reynolds of FlexJobs.com

- Thursday, March 26, 6 pm

Managing MS Bowel and Bladder Symptoms:

Featuring Pat Kennedy, MSCN of Can Do MS,

Dr. Marlene Murphy Setzko of the Mandell MS Center

- Tuesday, March 17, 6 pm
- Thursday, March 19, 9 pm

Sex Ed for Grownups – Intimacy in MS: Featuring Dr. Timothy Hlavinka of Urology San Antonio

- Tuesday, May 19, 6 pm
- Thursday, May 21, 9 pm

Gender Differences in MS:

Featuring Dr. Barbara Giesser of UCLA

- Tuesday, July 21, 6 pm
- Thursday, July 23, 9 pm

Preparing for MS Doctor Visits:

Featuring Kathy Costello, MSCN, of the National MS Society

- Tuesday, September 15, 6 pm
- Thursday, September 17, 9 pm



Visit

nationalMSSociety.org/telelearning



or call

1-800-344-4867 to reserve your spot

STAY HEALTHY WITH MS

Studies show exercise not only improves your overall health and well-being, but also helps manage many MS symptoms. Move forward through exercise and find a program in your community or become an expert in using a healthy lifestyle to help manage MS.

*Financial assistance is available to help you pay for therapeutic recreation classes and memberships. To apply, a completed financial assistance application and confirmation of MS diagnosis from your doctor is required. Amount of financial assistance is derived from a sliding scale based on the information from the financial assistance application. Please contact the facility of choice and determine if the facility will meet your desired needs to ensure a rewarding experience. **Please note the Gateway Area Chapter makes every effort to ensure all facilities are accessible to meet the needs of people living with MS.** If you think the facility would like education on MS, please contact the Chapter office at 1-800-344-4867 option 1.*

An on-line course about MS for fitness and wellness instructors is available at bit.ly/introtofitness.

THERAPEUTIC RECREATION SITES

ST. LOUIS	ADDRESS	CONTACT	ACTIVITIES OFFERED
Bridgeton Community Center	4201 Fee Fee Road Bridgeton, MO 63044	314-739-5599	  
Carondelet Park Rec Plex	930 Holly Hills Ave St. Louis MO 63111	314-768-9622	    
Center of Clayton	50 Gay Avenue Clayton , MO 63105	314-290-8511	    
Downtown YMCA	1528 Locust Street St. Louis, MO 63103	314-436-4100	   
Edward Jones Family YMCA	12521 Marine Avenue St. Louis, MO 63146	314-439-9622	   
Emerson Family YMCA	3390 Pershall Road St. Louis, MO 63135	314-521-1822	   
JCC - Marilyn Fox Building	16801 Baxter Road Chesterfield, MO, 63005	314-442-3428	   
JCC - Staenberg Family Complex	2 Millstone Campus Drive St. Louis, MO 63146	314-432-5700	    
Kirkwood Family YMCA	325 N. Taylor St. Louis, MO 63122	314-965-9622	    
Maryland Heights Centre	2344 McKelvey Road Maryland Heights, MO 63043	314-738-2599	    
Taiwanese Church	542 Ries Road Ballwin, MO 63021	314-898-7788	



THERAPEUTIC RECREATION SITES

ST. LOUIS CONT.	ADDRESS	CONTACT	ACTIVITIES OFFERED
Mid-County YMCA	1900 Urban Drive St. Louis, MO 63144	314-962-9450	    
Mercy Medical Building	12348 Old Tesson, Suite 220 St. Louis, MO, 63128	314-729-0181	
Show Me Aquatics	2085 Bluestone Drive St. Charles, MO 63303	636-896-0999	
South City Family YMCA	3150 Sublette Avenue St. Louis, MO 63139	314-644-3100	    
South County Family YMCA	12736 Southfork Road St. Louis, MO 63128	314-849-4668	    
St. Charles County YMCA	3900 Shady Springs Lane St. Peters, MO 63376	636-928-1928	    
The Cancer Support Community	1058 Old Des Peres Rd St. Louis, MO 63131	314-238-2000	 
The Lodge in Des Peres	1050 Des Peres Road St. Louis, MO 63131	314-835-6150	   
The Pointe at Ballwin Commons	1 Ballwin Commons Circle Ballwin, MO 63021	636-227-8950	  
Riverchase	990 Horan Dr Fenton, MO 63026	618-343-0067	  
Washington Four Rivers Family YMCA	400 Grand Avenue Washington, MO 63090	636-239-5704	   
Webster Groves Family YMCA	226 East Lockwood Avenue Webster Groves, MO 63119	314-962-9622	  
Wellbridge Athletic Club	7620 Forsyth Boulevard Clayton, MO 63105	314-746-1500	   
Wellbridge Athletic Club	998 Woods Mill Road Town & Country, MO 63131	636-207-3000	   
West County Family YMCA	16464 Burkhardt Pl Chesterfield, MO 63017	636-532-3100	   
Yoga Saint Louis	3305 Jamieson Ave. St. Louis, MO 63139	314-645-9785	
Z Power Fitness	233 Lamp & Lantern Village Town & Country, MO 63017	314-378-8639	



THERAPEUTIC RECREATION SITES

MID-MISSOURI	ADDRESS	CONTACT	ACTIVITIES OFFERED
Columbia Activity and Rec. Center	1701 W. Ash Street Columbia, MO 65203	573-874-7700	   
Elm Street Yoga	904 Elm St. Suite 210. Columbia, MO 65201	573-441-8566	
Jefferson City YMCA	424 Stadium Boulevard Jefferson City, MO 65101	573-761-9021	   
Mexico Family YMCA	1127 Adams Street Mexico, MO 65265	573-581-1540	   
Pilates for Everybody	4818 Santana Circle Columbia, MO 65203	573-228-6389	
Pilates & Yoga at Chapel Hill	2010 Chapel Plaza Ct. Suite A Columbia, MO 65203	573-446-0224	 
ILLINOIS	ADDRESS	CONTACT	ACTIVITIES OFFERED
Edwardsville YMCA	1200 Esic Drive Edwardsville, IL 62025	618-656-0436	  
John A. Logan College	700 Logan College Road Carterville, IL 62918	618-985-3741	
Collinsville Maryville Troy YMCA	1 Town Center Drive Maryville, IL 62062	618-346-5600	  
Columbia-Monroe Physical & Sports Medicine	880 Columbia Centre Columbia, IL 62236	618-281-9699	
Mascoutah Senior Center	227 N. Market Mascoutah, IL 62258	618-566-8758	
O'Fallon Community YMCA	284 North 7 Hills Road O'Fallon, IL 62269	618-628-7701	   
One-O-One Yoga	101 S Graham Ave # 1 Carbondale, IL 62901	618-457-8186	
Sukha Yoga Center	18 South High Street Belleville, IL 62220	618-236-9642	
SOUTHEAST MISSOURI	ADDRESS	CONTACT	ACTIVITIES OFFERED
Black River Coliseum	301 South 5th Street Poplar Bluff, MO 63901	573-686-8001	  
Cape Girardeau Municipal Pool	1920 Whitener Street Cape Girardeau, MO 63701	573-335-4040	
PARC Fitness Center	2620 N. Westwood Blvd. Poplar Bluff, MO 63901	573-686-5985	
Simply Yoga	1504 Preacher Roe #2 West Plains, MO 65775	417-293-1184	
Xtreme Gymnastics Cheer and Dance	422 West Pine Street Poplar Bluff, MO 63901	573-785-3780	

Learn more about MS— and its treatment.



Hear from MS experts and others living with MS. Get some answers about living with MS and information on an oral treatment for relapsing forms of MS. Then stay for a bonus session. Please join us.



Learn About MS & Parenting with Social Media

When:

Thursday, May 14, 2015
6:30 PM Central

Where:

Gentelin's on Broadway
122 East Broadway
Alton, IL 62002



Speakers:

Mark Tullman, MD
Medical Director, The MS Center for Innovations in Care at the Missouri Baptist Medical Center

FYI:

Free parking or valet available.
A meal will be provided.

Please RSVP for you and a guest at:
mslivingevents.com or call 1-866-703-6293



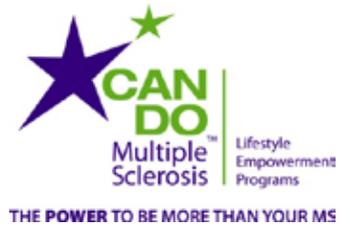
Event ID: TR283556 (1212537)

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CAN DO MS MONTHLY WEBINARS

2ND TUESDAY OF THE MONTH 7-8:15 P.M.

Can Do MS Webinar Series brings together a collaborative team of MS experts for you. 2-3 Experts Present. 1 Topic for Discussion. 0 Charge to you. Join us live from the convenience of your home or office at no charge for an in-depth discussion on topics relating to exercise, nutrition, communication, symptom management and total health. Register at mscando.org.



Update Your Outlook on Progressive MS

- April 14, 2015 7-8:15 p.m.

Language and Cognitive Issues with MS

- May 12, 2015 7-8:15 p.m.

Exercising with MS

- June 9, 2015 7-8:15 p.m.

Fatigue Management with MS

- July 14, 2015 7-8:15 p.m.

Mood and MS: Managing Depression

- August 11, 2015 7-8:15 p.m.

Preparing for MS doctor visits

- September 8, 2015 7-8:15 p.m.

DO SOMETHING ABOUT MS NOW

WWW.GATEWAYMSSOCIETY.ORG | 800 344 4867



WOMEN ON THE MOVE

mswomenonthemove.org

April 30
Clayton, MO
The Ritz-Carlton



CHALLENGE WALK MS

gatewaymschallenge.org

May 29-31
Webster Groves, MO
Webster University



MUCKFEST MS

muckfestms.com

July 11
Pevely, MO
Federated Auto Parks Raceway



BIKE MS

gatewaymsbikeride.org

Sept 12-13
Godfrey, IL
Lewis & Clark Community College