ANNUAL MEETING & RESEARCH UPDATE

Join us for the 2015 Annual Meeting & Research Update program on Saturday morning, December 5, at the DoubleTree by Hilton Portland. The morning begins at 9 AM with a vendor coffee hour and brunch buffet, followed by Annual Meeting remarks and the Research Update presentations 10 AM – 12 PM.

We are fortunate to have two outstanding National MS Society-funded researchers to share their expertise with us, Sergio Baranzini, PhD, University of California at San Francisco and Ben Emery, PhD, Oregon Health & Science University.

Dr. Baranzini is the recent recipient of the National MS Society Stephen C. Reingold Award for the most outstanding research proposal to investigate the microbiome.

continued on page 5
In my role at the Oregon Chapter, I see firsthand how lives are affected by MS. It’s what drives me to do this world-changing work. Which is why I’m so thrilled at the progress being made right here in Oregon and all across the globe.

For instance, we have accelerated research breakthroughs. We are successfully completing the largest fundraising campaign for MS research in history — 250 million dollars — funds for 818 research projects to Stop MS in its tracks, Restore what has been lost and End MS forever. We are recognized as the catalyst for all major advancements in MS research, connected with all available MS treatments with five therapies approved during these past five years alone.

Funding research to make these advances comes from diverse sources — through events like Walk MS, Bike MS, bequests, and through the generosity of people like Don Tykeson who told us, “We all have a limited amount of time on this earth, and we all have a role to play.”

Our role is to help you live your best life. If there’s anything we can do for you, please reach out anytime.

Sincerely,
Lisa Roth
Chapter President

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 MS 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. © 2015 National Multiple Sclerosis Society, Oregon Chapter
2015 & 2016 — SAVE the DATES
EVENTS & PROGRAMS

NATIONAL MS SOCIETY
1-800-344-4867 option 1 • defeatMS.com

■ Giving Tuesday (#Giving Tuesday)
  Tuesday, December 1

■ Annual Meeting & Research Update
  Portland, OR • Saturday, December 5

Café con Leche: Conversation & support in Spanish for people living with MS
  • 11 AM-12:30 PM PST on all dates
  • Tuesday, December 8
  • Tuesday, January 12
  • Tuesday, February 9
Details: 1-800-344-4867, option 3
Call-in Number: 1-888-262-0101

OHSU MS CENTER
Brown Bag Lunch Programs
2nd Fridays • 503-494-7661
www.ohsu.edu/msbrownbag

■ Topics TBA • Portland, OR
  • Friday, January 8 • 11:30 AM-1 PM
  • Friday, February 12 • 11:30 AM-1 PM

CAN DO MS WEBINARS • 2nd Tuesdays
  online at www.mscando.org/webinar

■ Invisible Symptoms & Managing Pain in MS
  • Tuesday, December 8 • 5-6:15 PM PST

■ Topics TBA • 5-6:15 PM PST
  • Tuesday, January 12
  • Tuesday, February 9

National MS Society Research Webcast
Living Your Best Life with MS in 2016 & Beyond
Tuesday, Dec. 15, 2015 • 11 AM-12 PM PST
Learn about the exciting progress and incredible momentum being made in research by joining a live webcast with MS experts as they discuss symptom management, promising treatments, and encouraging research on the horizon; wellness strategies and exercise tools to enhance quality of life; emotional well-being, depression, and strategies for living your best life after an MS diagnosis. A recording will also be available 48-72 hours after it occurs on the National MS Society Webcast Archive.

Please register for this webcast at:
www.nationalmssociety.org

RESEARCH STUDIES & CLINICAL TRIALS

NATIONAL INSTITUTES OF HEALTH
www.clinicaltrials.gov and type in search bar: “MS Oregon” or “MS Washington”

NATIONAL MULTIPLE SCLEROSIS SOCIETY
www.nationalmssociety.org/Research/Participate-in-Research-Studies

NORTH AMERICAN RESEARCH COMMITTEE ON MS
www.narcoms.org

PACIFIC NW MS REGISTRY
www.pacificnwms.org
Connection groups are for people with MS and family members. Join others to share experiences and offer information and resources.

**EUGENE MS SELF-HELP GROUP**
- Day: Fourth Saturday of the month
- Time: 11:30 AM
- Location: Countryside Pizza
  645 River Road, Eugene, OR 97404
- For more information contact:
  Christie at 541-912-7288
  or cwells0625@gmail.com,
  or Mitza at 541-221-1889 or
  maritzalanderos@gmail.com

**LINCOLN CITY MS SELF-HELP GROUP**
- Day: Second Tuesday of the month
- Time: 11:00 AM
- Location: The Moose Lodge
  1350 SE Oar, Lincoln City, OR 97367
  (behind the Lincoln City Outlet Mall)
- For more information contact:
  Alethea at 541-921-8149
  or lafrenzamj@yahoo.com

**ONLINE SUPPORT GROUPS**
Search [www.MSconnection.org/groups](http://www.MSconnection.org/groups) for one that meets your needs, if you would like to take part in an online group. There are groups for people who are newly diagnosed, specific interest groups, and groups for family members and carepartners.

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While MS does not affect intelligence, long-term memory, conversational skills or reading comprehension, it can affect a range of cognitive functions. These include the ability to learn or retain new information, concentration and attention, planning and prioritizing, and verbal fluency.

But there are ways to manage MS-related cognitive changes.

To learn more about cognition and MS, visit [www.nationalMSsociety.org/cognition](http://www.nationalMSsociety.org/cognition).

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**PORTLAND MS BUSINESS & PROFESSIONAL DISCUSSION GROUP**
— STARTING JANUARY 2016
- Evening: Second Tuesday of the month
- Time: 5:30-8:00 PM
- Location:
  Water Tower Conference Room
  (3rd Floor), 5331 SW Macadam Avenue
  Portland, OR 97239
- For more information contact:
  Barbara at barbaraosbo@gmail.com
  or 503-313-6677
Dr. Sergio Baranzini will present *Bringing together genes and environment to better understand MS*. In the past 10 years, enormous progress has been made in deciphering the genetic factors contributing to the risk of developing MS. Recent advances in DNA sequencing technology have enabled the analysis of bacterial communities in and around us to be described with great accuracy. Paradoxically, the genetic study of some of these bacteria may be useful in informing us about the critical environmental triggers that when combined with previously identified genetic risk can result in MS. A better understanding of the factors that contribute to developing MS will be crucial for the development of safer and more effective therapies for people with this disease.

Dr. Ben Emery will present *A Transcriptional Approach to Myelin Repair*. The Emery Lab at OHSU is testing a strategy for increasing myelin repair in MS by manipulating a major gene in myelin formation. The body’s ability to repair myelin by itself is incomplete. Myelin formation is genetically controlled and a gene called myelin regulatory factor (Myrf) appears to play a critical role in that process. Myrf works in the oligodendrocyte cells that make myelin in the brain. Therapies that increase Myrf activity may ultimately be used to increase natural myelin repair.

To register for the Annual Meeting & Research Update, visit www.defeatMS.com or call 1-800-344-4867, option 1.
Melissa Martin can personally attest to the incredible impact that MS research can have on a person’s life.

Diagnosed in 2009 with secondary-progressive multiple sclerosis, Martin joined a double-blind clinical study co-funded by the National MS Society and the National Institutes of Health for a promising new medication in 2014.

“My hopes weren’t very high that the study would do anything for my symptoms,” says Martin, whose mobility issues and fatigue became so severe that she had to leave her home and husband to live with her parents. “I was falling all the time, bumping into walls, sleeping 16 hours a day. I wasn’t able to bathe or dress myself,” she remembers.

“Mainly what I was hoping for was that the research could be used to help other people,” she says. But to her surprise, the research had a personal impact. “Now, I can do everything but drive. And I’ve moved back home with my husband.” While not every study has such a dramatic personal effect, many lead to a deeper understanding of the disease and make progress toward stopping MS in its tracks, restoring function and ending MS forever.

Life-Changing Impact

Incredible research advances have changed the landscape of MS treatments and strategies for living one’s best life with the disease. Take Nancy Speer, diagnosed with MS in 1993 — before the first disease-modifying therapies (DMTs) were introduced. “For the first five or six years after my diagnosis, there wasn’t any kind of treatment,” she remembers. “The only thing my doctors could recommend was a vitamin and mineral regimen.” When DMTs became available, Speer was ecstatic. However, she found that the side effects that she experienced were a major drawback.

But newly available infusion-based and oral MS medications became available, making a major difference in Speer’s life. “It’s absolutely amazing,” she says. So, she and her husband Ray Anderson are devoted to ensuring that other people with MS will benefit from research as much as she has. Toward that goal, they are dedicated donors to the Society’s No
Opportunity Wasted (NOW) MS Research campaign, which has funded Society research initiatives to stop MS, restore function and end MS since 2011, and is now drawing to an end.

UNPRECEDENTED PROGRESS

In just five years, the NOW campaign is responsible for more than a quarter of the nearly $900 million the Society has raised for MS research since the Society was founded in 1946. As a result, the promise of MS research is more apparent than ever, with three potential myelin repair treatments now in clinical trials and more potential treatments for MS — including progressive MS — in the pipeline than at any other time in history. Our understanding of the causes of the disease has also deepened significantly, with more than 100 genetic variants identified and several risk factors for developing MS confirmed. In addition, five new treatments became available, dramatically increasing the range of options for people with MS.

Since the NOW campaign’s start, the Society has launched 779 cutting-edge research projects that include:

• 71 clinical trials;
• 137 grants to train promising MS researchers;
• 132 projects to test rehabilitation and wellness approaches; and
• 25 commercial research partnerships aimed at overcoming any barriers to developing promising new therapies.

In partnership with MS Societies of Italy, the United Kingdom, the Netherlands, Canada and the MS International Federation, the Society founded the International Progressive MS Alliance, which brings together a growing number of MS organizations and international experts to hone in on the causes and treatments of progressive MS. The Alliance has thus far awarded 33 grants to MS researchers and developed a global MS research portfolio to understand where research is most needed.

“One thing I like about the NOW campaign,” says Lisa Sailor, a mother of three diagnosed with MS in 1993, “is that it helps people like me who live with a progressive form of MS. It’s exciting to live in this time because I think we will soon see some major breakthroughs in MS research. There’s hope on the horizon and that in itself is huge.”

LASTING IMPACT

Make a lasting impact and celebrate our achievements over the last five years by helping us reach the $250 million NOW Campaign goal by December 31, 2015, to accelerate breakthroughs that will change lives and end MS forever.

• Make a NOW gift today
• Share your story on the impact that MS research has had on your own life
• Ask friends, family, coworkers and other members of your community to give

Together, we can stop progression of MS, restore lost function and end MS forever. Visit www.nationalMSsociety.org/NOW.
RESEARCH

NEW FINDINGS on VITAMIN D

The results from a large-scale study have added to increasing evidence of a possible link between low vitamin D levels and the risk of developing multiple sclerosis.

Researchers at McGill University looked at genetic factors that cause vitamin D deficiency and their impact on people’s risks of developing MS. The study, which was published August in PLOS Medicine, confirms that people with gene variations linked to low vitamin D had increased chances of getting MS. The researchers used data from close to 15,000 people with MS and 24,000 healthy controls drawn from the International Multiple Sclerosis Genetics Consortium study, a global effort that, thanks to the help of more than 80,000 participants, has thus far identified more than 159 genetic variations related to MS.

Previous studies have pinpointed low levels of vitamin D as one of the factors that increases an individual’s chance of getting MS. However, it is not known yet whether taking vitamin D supplements can reduce the risk of developing MS, or help treat people who already have the disease. Researchers at John Hopkins University and other centers that are funded by the National MS Society are recruiting participants to compare the effectiveness of the recommended amount of vitamin D supplementation to high-dose vitamin D supplementation in reducing MS disease activity when added to standard therapy with glatiramer acetate (Copaxone®). For more information about this study, visit www.clinicaltrials.gov/ct2/show/NCT01490502.

In another study, researchers from the University of Minnesota and the National Cancer Institute are comparing UVB exposure (a form of ultraviolet radiation that increases vitamin D production in the body) in approximately 350 people with MS and 700 people without MS.

A third study conducted at the Harvard School of Public Health is following up on previous findings that higher vitamin D intake and high blood levels of vitamin D are associated with a significantly lower risk of developing MS, and that smoking and elevated levels of antibodies to Epstein-Barr virus, or EBV, are associated with increased risk of developing MS. The researchers are evaluating blood samples and data from more than 1600 people at high risk for developing MS to identify and examine links to early MS progression from vitamin D levels, EBV infection and smoking.

To learn more and follow the research on vitamin D and MS, visit: www.nationalMSsociety.org/vitaminD
ATTENTION SCHOLARS

MARK YOUR CALENDARS!

The National MS Society Scholarship Program is open to take applications for the 2016 academic year. Students can apply online now through January 15, 2016. The Scholarship Program is competitive in nature. Finalists will be selected on the basis of demonstrated financial need, academic record, leadership and participating in school or community activities, work experience, an outside appraisal, goals, aspirations, special circumstances and an essay written by the applicant regarding the impact of MS on their life.

LEARN MORE & APPLY

Don't miss out! Each applicant must meet the basic eligibility criteria, complete the online application at: www.nationalMSsociety.org/scholarship and mail supporting documents by the January 15, 2016 deadline.

GET CONNECTED

Sign up to receive Society emails: www.nationalMSsociety.org/signup

Join the MSConnection.org community: www.MSconnection.org

MS NAVIGATORS

Ask an MS Navigator for help to navigate the challenges of MS. Find personalized answers to your unique needs, up-to-date information, referrals and practical resources.

Call 1-800-344-4867
contactus@nmss.org
www.facebook.com/NavigatorMS

BECOME AN MS ACTIVIST TODAY

Are you an MS Activist? The National MS Society, Oregon Chapter is issuing a challenge for 100% participation in the MS Activist Network, and we need you. MS Activists receive National MS Society email messages to affect important policies and priorities, and engage key decision-makers.

▶ View what it means to be an MS Activist and move toward a world free of MS at: www.nationalMSsociety.org/activistvideo
▶ Follow @MSActivist for federal updates.
▶ Take action and Join the National MS Society MS Activist network today at: www.nationalMSsociety.org/MSActivist
When Dr. Frank Bittner realized that the field of multiple sclerosis tied together his interests in both conventional medicine and evidence-based alternatives related to diet, exercise, and supplements, he wanted to further his training where there was an active and diverse training program. OHSU was the place he found that was leading the way in new trials for complementary and alternative interventions for MS and translating them to the clinic. Dr. Bittner was awarded an MS and Neuroimmunology Fellowship, to work at the OHSU MS Center and the VA MS Center of Excellence-West with renowned experts in MS neurology and research.

Originally from Cleveland, Ohio, he went to medical school at Ohio University Osteopathic School, and completed his neurology residency in Morgantown, West Virginia. “I wanted to sub-specialize in an area where patients are highly motivated to learn about their illness and work to get well and maintain wellness with conventional and alternative medicine.”

Dr. Meredith Frederick is a Neuroimmunology Fellow, and a National MS Society Sylvia Lawry Fellow. She received her medical degree from University of Colorado School of Medicine, and completed her general neurology residency at OHSU.

The National MS Society awarded the three-year Sylvia Lawry Physician Fellowship to Dr. Frederick this year for MS clinical research. She will develop the skills involved in the design, implementation, and analysis of clinical trials in MS. She also has a grant from the Foundation for the Consortium of MS Centers to fund her research.

Dr. Frederick chose MS as a subspecialty because of all of the wonderful people she’s met in her
I got my life back... Thanks to my self-help group I found a support network and understand what to expect living with MS. My bequest to the National MS Society is like a gift of love to my family. And it helps the MS community move forward.

Contact the Society and ask how you can help others with MS through your will or trust. Join the movement in a powerful way.

1-800-344-4867
nationalMSsociety.org

Do it yourself fundraising is an opportunity for people in our Chapter area with a deep commitment to the MS cause, to raise awareness and critical funds for the MS movement in new and creative ways.

For more information, contact:
Dana Voelker, Director of Development
503-445-8358 • Dana.Voelker@nmss.org
www.defeatMS.com, click on: “Fundraising Events”

Dr. Meena Kannan

Dr. Meena Kannan is the third local neurology MS Fellow at present. She completed undergraduate training at Georgetown University, medical school at University of Alabama-Birmingham, and her neurology residency at Emory University School of Medicine. Dr. Kannan began her MS and Neuroimmunology Fellowship at OHSU in 2015.

The National MS Society funds the training of postdoctoral fellows in research or clinical studies related to MS, in its efforts to end MS forever. The Society’s fellowship program has trained more than 800 scientists, clinicians, and medical professionals in the field of MS research and care. This training investment has launched the careers of some of the most prominent researchers making breakthroughs today.
Donors who demonstrate their passionate commitment to achieve a world free of multiple sclerosis through an annual gift of $1,000 or more are members of the Golden Circle.

Golden Circle members stay connected to the impact of their gifts through:

- Special access to local and national leadership events, conference calls and webinars focusing on progress in MS research and the MS movement
- Breaking MS news alerts
- Connections to other Golden Circle members who share a passion for creating a world free of MS

BECOME A MEMBER:
www.deafeatMS.org
Memory challenges occur in more than half of people with multiple sclerosis, but the details on how and why have been mysterious. Microscopic connectors, or synapses, are the point of communication between individual nerve cells, and they are critically important for all functions of the nervous system, including memory. Some research has shown that synapses may be lost in some parts of the brain during the course of MS.

Now, a study published in May in *Annals of Neurology* by Drs. Iliana Michailidou, Valeria Ramaglia and colleagues in The Netherlands and Germany, has uncovered evidence that a group of immune system proteins, called “complement,” may play a role in the loss of synapses in the hippocampus, a part of the brain linked to memory.

The researchers examined samples of the hippocampus from brain tissue donated by people who had primary-progressive MS or secondary-progressive MS in their lifetimes. Compared to brain tissue donated by people without neurological disease, the investigators observed a decrease in the density of synapses in the hippocampus. Two specific types of complement proteins were increased in MS tissue at the site of synapses, compared to the other tissue samples from people of the same age. MS brains were also positive for proteins that indicate biological stress, but showed no signs of the type of complement implicated in some other diseases.

The results of the study suggest a role for specific components of complement activity in synaptic loss in the hippocampus in people with MS. In light of the important role the hippocampus plays in memory, this study also suggests that complement activity may contribute to cognitive problems experienced by people with MS. If these results are confirmed and refined through additional research, it is possible that in the future, therapies that target the complement system may be useful for preventing or treating memory problems in people with MS.

To learn more about MS-related memory issues or cognitive challenges, visit: [www.nationalMSsociety.org/cognition](http://www.nationalMSsociety.org/cognition)
Everyone with multiple sclerosis has a personal story, an experience or collection of life events and circumstances that influence who he or she is, and the unique perspectives that he or she holds. Living with MS is an integral part of that story. MS alters lives. It can transform everyday activities into challenges.

MS activists share their stories in the hope that they will inspire positive change — not just for them, but for all people living with MS. Their collective voices raise awareness about MS, educate public officials and drive change.

Their stories come in many forms. Some MS activists email their legislators when they receive MS Action Alerts, adding a personal note to share their individual perspectives. Some join their state’s Government Relations Committee to drive advocacy work in their community or become District Activist Leaders and build personal relationships with their elected officials. Others attend MS State Action Days at their state capitals, emphasizing the importance of MS advocacy priorities. And some people travel to Washington, D.C., to share their stories at the National MS Society’s annual Public Policy Conference.

—I am a man of science, a person of faith and a fourth-generation Kansan. MS has been part of my family’s story for more than 15 years. I am an MS activist because I think it matters.” — Dr. Randall Rock, Kansas

“As an MS activist, I have visited our state capital the past eight years, discussing issues with our representatives and senators. It is this goal of finding the cause and cure that keeps me going back and informing our representatives and asking for help, lending my voice to the Society and all whom we serve.” — Don Garrett, Missouri

“My mother was diagnosed with MS in 1979. I was diagnosed in 2000. Seeing the differences between the disease-modifying therapies that are available to me today, compared with the lack of any available treatment options for my mother is motivation for me to be an MS activist. There is so much exciting MS research in the pipeline; it is up to us to keep the momentum going!” — Linda Black, Nebraska

Kari Rinker is the Society’s senior manager of Programs and Advocacy, Mid America. Originally published in Mid America’s MS Connection newsletter.

Share your story and become an MS activist. Visit www.nationalMSsociety.org/advocacy.
FINANCIAL ASSISTANCE
HELPING to KEEP PEOPLE MOVING
BY JONATHAN BRINCKMAN

When Janiece "Hattie" Tinney could not raise money this summer to replace her disintegrating fitted braces, she thought her walking days were over.

Hattie relies on braces, which have hinged ankle supports, to prevent her feet from drooping. Without them, she is using a power chair. She received a prescription for new braces, but couldn't afford to buy them.

Medicare pays 80 percent of the cost of new braces, but there was a $350 co-pay. That is when the Oregon Chapter stepped in. Tinney applied for a grant after a friend suggested it, and received financial assistance for the co-pay.

"Oh my gosh, thank you thank you thank you. I am so glad that they helped me."

The National MS Society will make grants available to those who live with MS and have a demonstrated financial need. It is a great program, helping with everything from air conditioners and mobility equipment, to paying fees for exercise programs and more.

Tinney, who was diagnosed with MS in 2006, is now a widow, on a to-the-bones income. She does not know what she would have done if she had not received the grant. "I had a friend say, 'Call these people, that's what they're for, they're here to help you,'" Tinney said. "I'm so grateful."

Need financial support to help with mobility equipment? We may be able to assist. Contact 1-800-344-4867, option 1.

Watch MS videos at: www.youtube.com/user/NationalMSSociety
MONEY MATTERS

TRANSPORTATION OPTIONS

BY MYRA GRAY, MSW, LSW

Don’t let multiple sclerosis keep you from getting where you need to go, whether to a medical appointment, the grocery store or a restaurant for a dinner with friends. If you no longer drive because of MS symptoms such as vision issues or spasticity, there are other options for transportation if you know where to look.

REACH OUT

The first place many people with MS look for help with transportation is their own social network. Don’t be afraid to ask friends and family members for a ride: often they are happy for a chance to help out and spend time with you. And they can always say no if it’s inconvenient for them at the time. (In which case, try rescheduling!)

If an appointment is ongoing—a weekly visit to a physical therapist for instance—you might arrange a regular trip with a friend or family member. Sweeten the deal with an offer to pay or split the cost of gasoline, for instance. Even treating the driver to a cup of coffee can help.

Other opportunities to access a ride or joining a carpool may exist in your community, including places of worship, community centers and service organizations. Ask your healthcare providers if they might know of other patients who drive or a carpool that can help get you to their offices.

GO PUBLIC

Typically, the most affordable way to get around is public transportation, which can include bus routes, subways or light rail services. A good place to start exploring your city or county’s public transit system and its accessibility options is www.publictransportation.org. Here, you can search by state for what’s available near you. Or you can visit the American Public Transportation Association’s website at www.apta.com/resources/links for a list of public transit websites for all 50 states, Washington D.C., and Puerto Rico.
The Americans with Disabilities Act (ADA) requires that any transportation provided to the general public must be available to people with disabilities. The ADA also requires all public transit agencies to provide paratransit services to people who cannot use fixed-route public transportation because of their disability. The Easter Seals Project Action project, a partnership with the U.S. Department of Transportation, Federal Transit Administration, was commissioned in 1988 to improve access to public transportation for people with disabilities. Their website at www.projectaction.org offers a wealth of information on how people with disabilities can use public transit systems confidently and safely.

MORE OPTIONS

Some health insurance companies may provide transportation or cover costs of transportation to and from medical appointments. Check with your health insurance company to see what they offer. In addition, most individuals enrolled in Medicaid are eligible for transportation to and from medical care. Learn more at www.medicaid.gov.

In general, before you call to arrange transportation through your insurance company or Medicaid, follow these tips:

• Have your member ID number ready
• Have the address for pick up and the address of your destination ready
• Know the time and date of the appointment

• Specify if you will need a lift or if you need a cab
• Specify if you’re bringing someone with you

If you don’t get the answer you are looking for, ask who else you can contact. This goes for any service you’re inquiring about. Often times, agencies can offer additional information even if they can’t provide the specific service.

Visit www.disability.gov/resource/disability-govs-guide-transportation for additional transportation resources and to learn your transportation rights as a person with a disability. The National MS Society may be able to help connect you with transportation-related resources, as well. Call an MS Navigator at 1-800-344-4867.

Myra Gray, MSW, LSW, is an outreach specialist for the National MS Society.

Originally published in Ohio Buckeye’s MS Connection newsletter.

STAYING ON THE ROAD

If you drive, but MS symptoms are getting in the way, there are options to help keep you on the road. These include adaptive auto equipment or treatment options that may minimize troublesome symptoms. Visit www.nationalMSSociety.org and search for “driving” to learn more.
A few days ago I met Donald Tykeson. The Eugene resident calls MS “my old friend,” because it has caused him to channel his energy into what he feels is truly important. He was diagnosed shortly before his 30th birthday and was told that he would be in a wheelchair within five years. There are a number of ways that one can react to that kind of diagnosis — Mr. Tykeson responded by turning it into a life calling. “We all have a limited amount of time on this earth, and we all have a role to play,” he said. “You can stop and smell the roses, or you can get cranking and use your time in the way in which it will do the most good.”

Through a series of acquisitions in broadcast and cable TV, it took 19 years to turn his original $30,000 investment in a struggling Oregon TV station into a successful enterprise capable of launching many professional and philanthropic endeavors.

Mr. Tykeson and his wife of 65 years, Willie, have decided to use their time to help others by establishing the Tykeson MS Fellows Conference, a biannual event where fellows meet and confer with leading investigators with a common goal: stopping the progression of, and ultimately finding a cure for MS.

Since 2008, the Tykesons have provided financial support for the Tykeson MS Fellows Conference, a forum for young scientists who have been encouraged in their early careers by Society Fellowships. At the conference they meet MS researchers, share ideas, network, get advice and discuss avenues for future research. The conference and the work of these investigators is crucial to help us move closer to a cure.

Now in his 89th year, Mr. Tykeson says that although none of the disease-modifying therapies have worked for him, he has still had a “relatively smooth ride” through life. An Honorary Life Director of the Society’s National Board of Directors, he goes to work at his and his wife’s office every day — all the while staying involved in as many community activities as possible. “Maintain a positive attitude,” he says. “Don’t give up anything you don’t have to. Keep challenging yourself and give up ground slowly.”

■ Learn more about Mr. Tykeson and progress of the Tykeson MS Fellows Conference. Visit www.nmss.org > Search “Tykeson”
MEET the STAFF

I’m Janis, your new Community Engagement Manager and the person filling Wendy’s shoes at the Oregon Chapter.

I had the pleasure of working with Wendy during my internship here at the Oregon Chapter, so I know how much she meant to you, because she meant a lot to me, too. Now that I’m in Wendy’s role, I am so thrilled to meet and get to know you.

Why is my title Community Engagement Manager instead of Volunteer Manager? The Society is approaching volunteerism in an even deeper way. We will continue to work with you as Wendy so lovingly did — and potentially find ways to bring your passions and talents more greatly into the mix. Plus, I will work with our Walk and Bike teams to recruit talent for committees, specialized work groups and more.

OK. Let me tell you a little bit about myself. I’m admittedly a late bloomer and my story begins with the aforementioned internship… not quite as late as the subject in the recent DeNiro movie, The Intern, but I finally got around to completing my undergrad well into my fourth decade on this planet. This was after working for some great companies including Columbia Sportswear and Citibank.

It probably sounds corny, but from my first days interning at the Oregon Chapter, I felt this was where I belonged — there was just something special about this place and the people — something different that resonated deeply within me.

After I completed the internship and started a new job with the American Red Cross, MS and the Society had a funny way of weaving in and out of my life. I discovered that one of my oldest and dearest friends was diagnosed with MS. A co-worker from my days with Columbia Sportswear confided that she lived with the disease. My eldest daughter found out that her boyfriend’s mother lives with MS, and my youngest daughter’s close friend from high school completed her own internship at the Oregon Chapter the previous summer. It seemed like every time I turned around, MS and/or the Society was part of my conversation.

So when I heard Wendy had accepted another position, I knew the universe was telling me something. As I begin my own journey with the Society, I want you all to know how proud I am to serve with you. Please reach out and say hello. I would love to connect!

Janis Kramer
Community Engagement Manager
503-445-8356 • janis.kramer@nmss.org
National Multiple Sclerosis Society
Oregon Chapter

5331 SW Macadam Ave Ste 290
Portland, OR 97239-3847

Address or Email Change?
Call us at 1-800-344-4867