A big part of my excitement at the annual meeting of the European Committee for Treatment and Research in Multiple Sclerosis, or ECTRIMS, in October 2015 was seeing so many researchers from around the world working hard to find the best solutions for people affected by MS. I found this to be especially true in the growing area of lifestyle and wellness research — exploring diet, exercise, physical activity and other approaches — all of which people can manage themselves to improve how they feel and possibly how their MS evolves.

NUTRITION AND DIET

The idea of intermittent fasting as a way to fight inflammation is being explored by MS researchers. But anyone who’s tried it knows how challenging it can be to stick with it. That’s why I was intrigued by a small trial involving 48 people with relapsing-remitting MS done by Dr. Markus Bock and colleagues (Universitätsmedizin Berlin).

The investigators studied various diets that may affect “ketone bodies” — molecules in the liver that may protect the brain and spinal cord. Compared to participants who followed their usual diets, participants who followed either a “ketogenic diet” (a high-fat, adequate-protein, low-carbohydrate diet) or a prolonged-fasting diet (an initial seven-day fast followed by a Mediterranean diet) reported improved quality of life. These results are encouraging; hopefully we will see results in larger numbers of participants in the future.

Another interesting study reported by Dr. Aiden Haghikia (Ruhr-University Bochum, Germany) and colleagues had previously found in mice that gut bacteria giving off short-chain (versus medium- or long-chain) fatty acids could protect against the development of MS-like attacks. To translate these results to human beings, the team administered daily capsules of “propionate,” which contains short-chain fatty acids, to 18 healthy volunteers. They found no side effects, but more importantly, cells that activate immune attacks in MS were suppressed, while other cells, call Tregs, that turn off attacks, increased by 25-30 percent. This early report shows the potential of a nutritional supplement that could be tested for its benefits in people with MS.

CONTINUED ON PAGE 3
RESEARCH OPPORTUNITIES

TREATMENT CHOICES STUDY
Researchers at UMKC are investigating how MS patients make treatment choices. The study will require one two-hour visit.

PARTICIPANT CRITERIA: To qualify, you must:

- Be diagnosed with multiple sclerosis
- Be 18 years of age or older
- Speak English as your primary language

IF INTERESTED: Call 816-235-5428 or umkcmsmedfeedback@umkc.edu. Participants will be compensated $50 for their time.

MINI-BALANCE EVALUATION SYSTEMS TEST
Rockhurst University is conducting a research study to learn more about the use of a balance and walking test, the Mini-Balance Evaluation Systems Test (Mini BESTest), in people with Multiple Sclerosis. To participate in the study, you will need to complete two testing sessions on the campus of Rockhurst University in Kansas City.

Approximately one week later, you will be asked to return for the second session. Each session should take approximately 1 hour. If you would like more information or are interested in participating, please contact Kristern Potter at kirsten.potter@rockhurst.edu or 816-501-4486.

GET CONNECTED
Remember you are not alone. There is an entire MS community out there for you!

- Sign up to receive Society emails at: www.nationalMSsociety.org/signup.
- Join the MSConnection.org community: www.MSconnection.org.
- Talk to an MS Navigator. 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 or www.facebook.com/NavigatorMS
EXERCISE AND INNOVATIVE TECHNOLOGY

We are seeing more studies on the benefits of exercise and physical activity in people with MS. As research advances, we’ll share it so people with MS will have the information they need to choose what’s right for them.

Researchers are looking at how exercise may lead to changes in brain function. Dr. Francesca Tona (Sapienza University, Rome) and colleagues looked first at whether 26 people with MS with balance problems would benefit from home-based training using videogames and the Wii balance board five times a week for 30-minute sessions over 12 weeks. Many experienced improvements in their balance after the program.

Next, the researchers explored how “functional connectivity” — the connections between different areas of the brain measured using neuroimaging — changed after the 12 weeks. They found increased connectivity in several areas of the brain including the cerebellum, which controls bodily movement. This is particularly exciting because participants didn’t have to go to a gym or healthcare facility; instead, they could access the technology and complete the sessions at home. This study also provided evidence for “neuroplasticity,” the idea that the brain is capable of changing in ways that may improve people’s day-to-day function.

Meanwhile, a team from Denmark and Belgium led by Dr. Ulrik Halgas (Aarhus University) noted that people with MS tend to lose muscle mass and that they have fewer “myogenic stem cells” — cells in the body that help rebuild muscle. The team reported that after a 12-week, high-intensity training program (involving exercise machines for strengthening upper and lower body muscles), the number of myogenic stem cells more than doubled in people with MS. This kind of exercise program may not be for everyone, but it’s encouraging to know that such regrowth is possible.

IMPROVING COGNITIVE FUNCTION

Finally, I am encouraged to see more studies that show how cognitive rehabilitation can improve learning and memory in people with MS. After all, cognition is an important part of what makes us feel well.

A team from Italy and the United Kingdom, led by Dr. Micaela Mitolo, tested an intensive program designed to target multiple areas of the brain and thus multiple cognitive problems. Among the 15 people who underwent one-hour rehab sessions for five days a week for four weeks, cognitive function improved, even in areas not specifically involved in the training. Brain imaging also showed that compared to the participants who did not undergo the program, those who did experienced increased functional connectivity.

To learn more, visit [www.nationalMSsociety.org/research](http://www.nationalMSsociety.org/research).

Nicholas LaRocca, PhD, is vice president of Health Care Delivery and Policy Research at the National MS Society.
LIVING WITH MS

UPCOMING PROGRAMS

TREND SYMPOSIUM
JUNE 18, 9 A.M. - 2 P.M.
BEST Conference Center, University of Kansas, Edwards Campus, Overland Park, KS
Featured Topic: Celebrating the Last 30 Years!
The progress made in MS treatments in the last 30 years and what is on the horizon!

TREND brings together people living with MS and those who care about them for a day of education and networking.

Keynote speakers: Dr. Sharon Lynch, Neurologist, Clinical Focus on Multiple Sclerosis, University of Kansas, and Dr. Scott Belliston, a MS Society-funded Clinical Fellow, University of Kansas.

For those unable to attend in person, a live stream link is available. Register for the online only TREND Symposium event.


COUPLES RETREAT
JULY 16-17
The Sheraton
Overland Park
Hotel, 6100
College Boulevard,
Overland Park, KS

This dynamic program will help you learn to:

• Break patterns that prevent effective communication
• Apply problem solving techniques
• Manage MS as a team
• Develop skills for life, and
• Help your partnership thrive!

$100 per couple

Couples Therapy Testimonials:

“If I would have known this 20 years ago, I would have been a better partner and dealt with this better.”

“I found this weekend helpful for me dealing with my wife’s MS. I like the analogy that MS is a visitor to our home and we have to deal with it as a family.”

HOW TO SIGN UP
Call 1-800-344-4867 to register or view the calendar at www.msmidamerica.org.
LIVING WITH MS

ONLINE LEARNING OPPORTUNITIES

NATIONAL TELELEARNING SERIES
The 2016 Webinar & Telelearning Series brings together a collaboration of MS experts — to help you learn strategies to live your best life with MS. Each free webinar & telelearning program features two presenters with time for Q&A. To register go to http://bit.ly/nmsstelelearning

Traveling with MS, June 14, 7 p.m.
Author and accessible travel expert Candy Harrington will share tips, resources and hard-to-find information about the logistics of accessible travel planning; while world traveler Lisa Kemppainen will recount her globetrotting escapades in this informative webinar. Topics covered will include air travel, TSA screening, finding accessible lodging and dealing with fatigue and temperature sensitivity on the road. Candy and Lisa will also share some of their favorite accessible travel finds.

Understanding and Managing Your Spasticity, July 12, 7 p.m.
Spasticity is a condition in which certain muscles continuously and uncontrollably contract, causing stiffness and tightness of the muscles. Starting with an overview of the central nervous system and why spasticity occurs, Gail Hartley (Nurse Practitioner) and Kathy SanMartino (Physical Therapist) will help you understand and manage this complex symptom.

Workout Your Worries: Anxiety and Exercise in MS, August 9, 7 p.m.
If you live with MS, you are twice as likely to experience anxiety and mood disorders. In fact, up to 60% of people with MS experience low mood or depression, and up to 40% experience anxiety. Mood issues can be caused by the disease process itself or by the challenges and stressors that arise from managing a chronic condition. While medications and talk therapy are important strategies, emerging evidence suggests that exercise may be equally as effective. Aerobic exercise such as cycling and walking, as well as stretching activities such as yoga, may help to manage mood.

Please join psychologist Meghan Beier, Ph.D., and a physical therapist Mandy Rohrig, PT, DPT, for an honest, interactive conversation about recognition of mood changes and ways to manage mood with physical activity.

Health Insurance: What Everyone Needs to Know MS, September 13, 7 p.m.
This webinar will provide a basic overview of the different ways people with MS and their families can get and keep health insurance, how to plan for transitions (such as moving from employer-based coverage to Medicare), and what to expect as an enrollee in a private or public health insurance plan.
POSITIVE PSYCHOLOGY

Positive psychology focuses on growth and well-being. While other branches of psychology tend to focus on dysfunction and abnormal behavior, positive psychology is centered on helping people thrive and become happier and more productive. Positive psychology does precisely the opposite of traditional modern psychology – it focuses on what an individual is rather than what he or she isn’t.

At its core, positive psychology is the belief that people actively seek and inherently desire happiness. How that happiness plays out (whether through financial success, a fulfilling career, the upbringing of a family, love, stability or freedom, for example) is different from person to person. In his research, Dr. Martin Seligman, a leader in the positive psychology movement, identified the positive personal strengths that move people toward their ideals of happiness: courage, social skills, a good work ethic, honesty, optimism, perseverance and hope. Positive psychology offers strategies to help people develop and enhance these personal strengths.

RESEARCH FINDINGS IN POSITIVE PSYCHOLOGY

Some of the major findings of positive psychology include:

- People are generally happy.
- Some of the best ways to combat disappointments and setbacks include strong social relationships and character strengths.
- Work can be important to well-being, especially when people are able to engage in work that is purposeful and meaningful.
- While happiness is influenced by genetics, people can learn to be happier by developing optimism, gratitude and altruism. Money doesn’t necessarily buy well-being; but spending money on other people can make individuals happier.
EVERYDAY MATTERS

Everyday Matters is a program developed by the National MS Society to introduce and practice the concepts of Positive Psychology to promote living well with MS. Everyday Matters has two parts: the why - lays the groundwork with a discussion of the findings and tenets of positive psychology, and the how – explore how participants can apply the principles to live their best life with MS.

• Through a high-level overview and discussion, the group will begin to explore the use of the principles of positive psychology to address the everyday challenges of living with MS.
• This program is about asking all of us to change the way we look at happiness generating behaviors and habits – how to find happiness when we don’t think we can.

EVERYDAY MATTERS - WICHITA, KANSAS

Date: Wednesday, July 20th  
Time: 9:00 a.m. – 4:00 p.m.  
Location: College Hill United Methodist, 2930 E. 1st Street North, Wichita, KS  
Facilitator: Lisa Thompson  
Registration: http://ksgmain.nationalmssociety.org/site/Calendar?id=359942&view=Detail or call 1-800-344-4867.

EVERYDAY MATTERS - SPRINGFIELD, MISSOURI

Date: Thursday, July 14 and Thursday, July 21  
Time: 5:00 p.m. – 8:00 p.m.  
Location: Burrell Behavioral Health Center, 300 E Bradford Pkwy, Springfield, MO 65804  
Facilitator: Dr. Paul Tomlinson  
Registration: http://ksgmain.nationalmssociety.org/site/Calendar?id=359943&view=Detail or call 1-800-344-4867.

EVERYDAY MATTERS

TALK MS - YOUR CONNECTION TO SUPPORT AND YOUR COMMUNITY

Talk MS is a temporary support group lead by a professional counselor with experience supporting persons living with MS. The group will serve as a connector to Society resources and permanent peer-led support groups that are in development.

Meeting Location and Dates: MS Society Office, 2730 S. 114th Street, Omaha, NE 68114 June 20, July 18, August 15, September 19, 6-7:30 p.m.  
ADVOCACY

PRIORITIZING ADVOCACY EFFORTS
The National MS Society advocates for transparency and patient protections in health care insurance, particularly, access to medications, and other necessary testing and procedures. We are currently focusing our state advocacy efforts on two areas of insurance reform: prior authorization and step therapy.

PRIOR AUTHORIZATION

Prior authorization is an administrative practice used by health insurers in both public and private markets, to review the use of physician prescribed treatments and control costs. Health plans often require physicians to submit documentation justifying their recommended prescription. The insurer then determines whether the treatment is necessary to deliver quality, cost-effective care. Once request is approved, coverage is assured.

Prior authorization require healthcare providers and patients to submit significant paperwork. When coverage is denied, providers may also have to file additional paperwork to appeal the decision. These procedures may take days or weeks. Healthcare providers to dedicate substantial time and resources to the process.

Prior authorization requirements can have a negative effect on people’s lives and health outcomes. For example, a person with MS may have to delay receiving an MRI, or accessing a prescribed medication, for weeks or even months until their insurer’s forms are submitted, reviewed, and approved. People with MS may increase their risk of lapsing treatment or even worsening the course of their disease as a result of these delays.

STEP THERAPY

“Step therapy” or “first fail” are terms with which many people with MS have become all too familiar. Step therapy protocols require that patients try and fail at least one medication chosen by the insurer before they will provide coverage for the medication that was originally prescribed.

The insurance plan may require a patient to try a lower-cost drug for a certain period of time, before providing coverage for a more expensive option. If the health plan’s preferred treatment fails to produce the desired
outcome, the plan may authorize payment for the physician-prescribed treatment. Step therapy policies vary—for example, how many “steps” a patient must cycle through, or how long the process takes. Insurers’ exceptions procedures also vary widely in terms of how clear and accessible they are, and how often physicians’ requests are approved or denied.

People with MS and their healthcare providers have voiced concern about the effects step therapy can have on their lives and health outcomes. The process may involve significant paperwork and result in lengthy delays before people are able to receive the appropriate treatment. Prolonging ineffective treatment may result in disease progression. The initiation of treatment with an FDA-approved disease-modifying treatment is recommended as soon as possible following a diagnosis of relapsing MS.

THE ROLE OF MS ACTIVISM

As frustrating and complicated as these practices may seem, there is hope! Our MS advocacy efforts are making a difference.

• **KANSAS**: SB 341 repealed a previous protection against the use of step therapy in the state’s Medicaid program (KanCare). The National MS Society requested that patient protections be adopted as part of this process and were successful. SB 341 was passed with a physician override process (including a 72-hour response for exceptions), prohibition on “stepping” a stable patient or a patient who has tried and failed on the drug in the current or previous plan, and a 30 day window for patient “failure” specific to MS disease modifying therapy drugs.

• **MISSOURI**: HB 2029 added step therapy patient protections into private insurance plans. The National MS Society provided testimony in support of the proposed protections and were successful. HB 2029 passed, allowing access to a clear, convenient, and accessible process to request a step therapy override exception for prescription drugs. Patients will not be required to “step” if they have already tried and failed a drug on their current or previous plan. These protections will go into place in January of 2018.

Despite these successes, our efforts are not yet over. The National MS Society will continue to advocate for less cumbersome administrative practices for health care providers and more patient protections for people with MS in Kansas, Nebraska and Missouri. You can help! We need stories from people with MS who have experienced delays in their medication, forgone medication or experienced negative health outcomes due to difficulties accessing their prescribed treatments and MRIs.

Please contact kari.rinker@nmss.org or call 800-344-4867 and ask for Kari Rinker, Senior Advocacy Manager.
DEVELOPMENT

BIKE MS: IT’S MORE THAN A RIDE.

When we talk about Bike MS, we often talk about the dedicated cyclists who ride over 100 miles to raise awareness and money for the MS Society. While those cyclists are important to the MS movement, there are many ways to make a difference on or off a bicycle.

VOLUNTEERS

Volunteers make Bike MS possible. If you are interested in assisting in one of the following functions or would like to volunteer your services in an unlisted capacity, please contact Leanne at leanne.mersmann@nmss.org, call 816-448-2195, or visit bikeMS.org

BIKE MS COMMITTEE

Want to help with of all the things that make Bike MS a success? Are you good at securing donations? Do you have suggestions for signing the route? Want to promote Bike MS at different bike and wellness events? The committee needs your support.

MEDICAL/SAG/MOTORCYCLE SUPPORT

There’s a reason Pitch Magazine rated Bike MS the “Best organized bike ride” in 2015, it’s because of our on-route support. If you are first-aid certified, a motorcycle rider, or willing to spend a day on the route helping cyclists, this opportunity is for you!

REST STOP VOLUNTEERS

Rest stop volunteer: Are you a member of a civic organization that likes to give its time as a group? Volunteer to staff a rest stop along the route. All you need to do is grab your friends and show up, we will provide the materials!

START/FINISH LINE SUPPORT

Help cheer on cyclists, hand out t-shirts, set up and tear down—this position is much needed! Join the fun and lend a hand at the start and finish line (perfect for family members of cyclists to participate in while waiting for your cyclist to return!)
ADMINISTRATIVE SUPPORT

Are you willing to make phone calls to recruit past cyclists? We need your phone skills! Our most flexible volunteer opportunity, we need your help!

I RIDE WITH MS

Planning on riding in Bike MS this year? The MS Society wants to recognize all cyclists who live with MS and ride despite challenges such as fatigue or weakness. When registering for your ride, be sure to indicate that you live with MS. We will provide you with a complimentary ‘I Ride with MS’ jersey and you can enjoy some day-of event perks. Visit bikems.org for more information.

DONATE

Bike MS plays an important role in funding crucial programs and groundbreaking research. Every dollar helps. Consider supporting a Bike MS participant, or participated as a virtual rider and fundraising to support the important work the Society does every day to change the world for people living with MS.

Visit bike.msmidamerica.org for more information.
WE’RE STRONGER TOGETHER. WALK MS.

Thank you to the thousands of donors, volunteers, and participants who made Walk MS a success! Your dedication to changing the world for people affected by MS is inspiring. Together, we can end MS forever. Together, we are stronger.