NARCOMS NOW

Spring 2017

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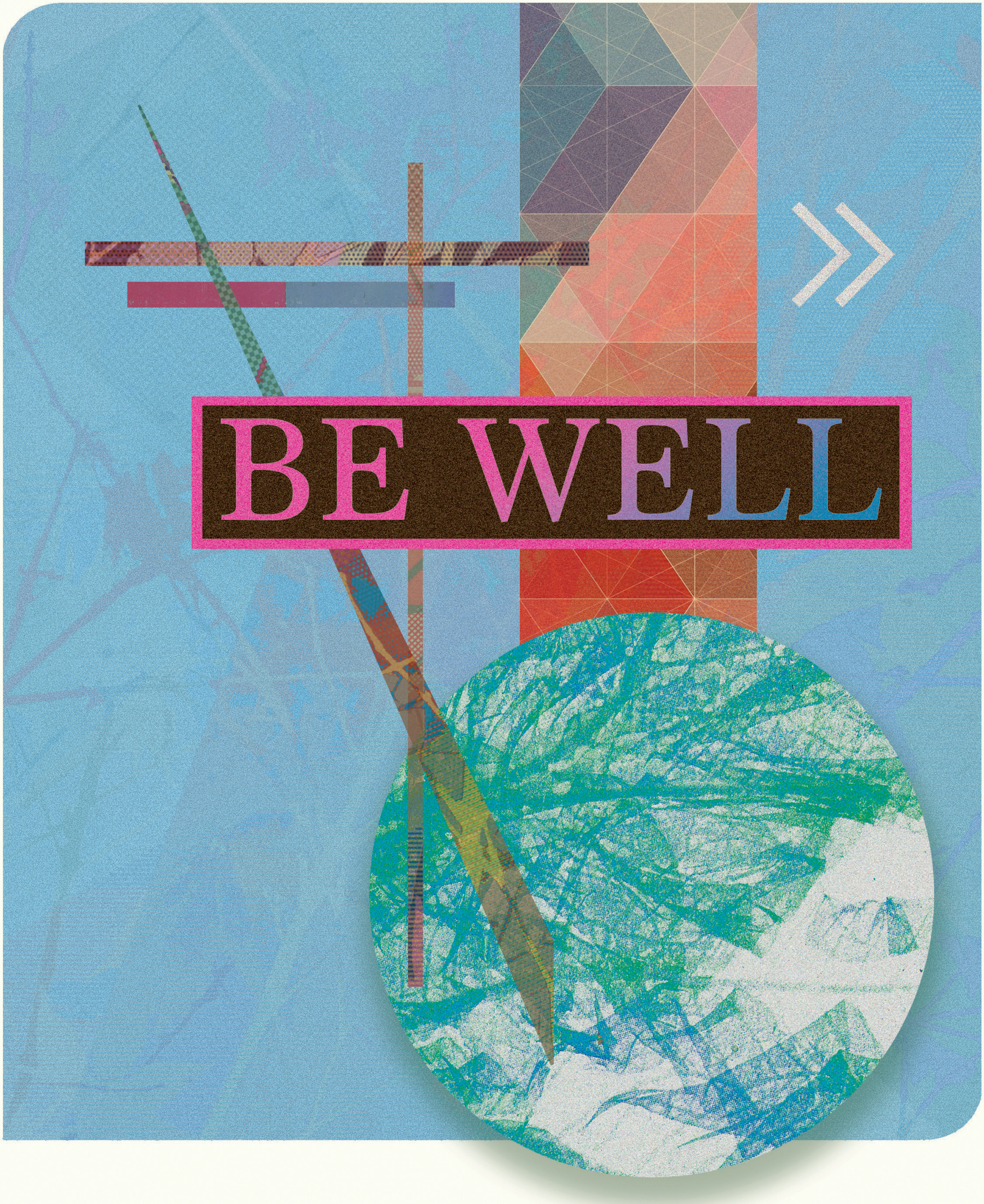
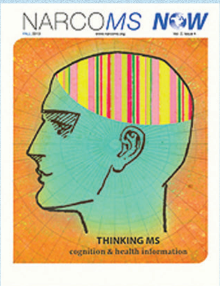
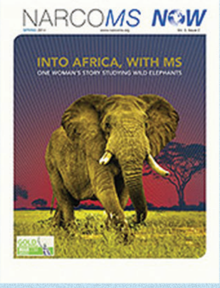


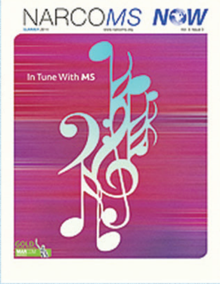
NARCOMS Now celebrates 5 Years!

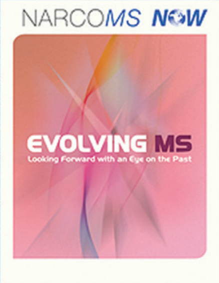
Thank you for taking this journey with us, and please continue to share your thoughts and sentiments: narcomsnow@narcoms.org.

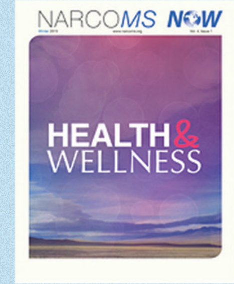
Here's a look back at all of our covers!

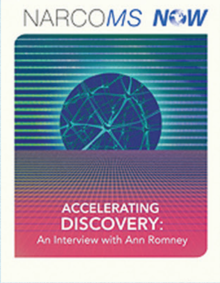


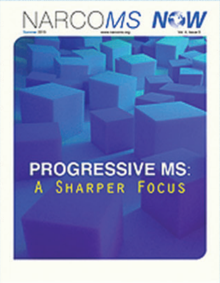












Credit for their design goes to our talented creative director Shawn Avery Stokes—and to a few to you from our art contest. Thanks for making us look so good! Let us know which one is your favorite and why: narcomsnow@narcoms.org.

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NARCOMS *MS* **NOW**

STAFF

Robert Fox, MD
Managing Director

Ruth Ann Marrie, MD, PhD
Scientific Director

Gary R Cutter, PhD
Coordinating Center Director

Stacey S Cofield, PhD
Executive Editor

Christina Crowe, MA
Managing Editor & Media Specialist

Shawn Avery Stokes
Creative Director

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For any questions regarding *NARCOMS Now* funding please call 1-800-253-7884.

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A Letter from the Director - *Spring 2017*

Welcome,

Dr. Ruth Ann Marrie is a Don Paty Career Scientist, practicing neurologist and Director of MS Clinic at University of Manitoba Health Sciences Center in Winnipeg, Canada.

Just like clockwork, it's spring once again. Welcome back to *NARCOMS Now*— this issue marks the fifth anniversary of our magazine's first issue, in Spring 2012. So many research advances in understanding and treating multiple sclerosis (MS) have come about in the past five years. We are proud to have been a part of those advances based on the information you so graciously share with us in our surveys. Thank you for taking part in our Spring Survey, ongoing now.

With this five-year anniversary comes a shift for the NARCOMS Registry in the location of our coordinating center, database, and staff. We outline this change in "Messenger" (p. 8). Please remember you can always contact us with any questions at our toll-free number, 1-800-253-7884, or by email, MSRegistry@narcoms.org.

On our inside front cover we celebrate *NARCOMS Now* cover art since the magazine started, when you picked the name! This edition of the magazine tackles the important issue of wellness when living with MS or supporting someone who has this chronic illness. Wellness can span a broad range of topics, but we focus on exercise, nutrition, and emotional well-being (see "Feature Focus," page 4).

"MS Reflections," (p. 10) reviews some NARCOMS research about wellness. We are excited that this area is the focus of more research now, and that this will lead to better recommendations for people living with MS.

"MS News," (p. 12) reports on some research advances related to the diagnosis and treatment of MS, including the use of stem-cell transplants to induce long-term remission of MS. "MS Apps & Blogs," (p. 16) touches on blogs and websites describing resources for MS in mental health and wellness. As we welcome spring, we thank you again for completing our Spring Survey. We are grateful for your continued participation in NARCOMS. Don't forget to send us your own MS stories for our "Faces of NARCOMS" feature in each issue.

Sincerely,

Ruth Ann Marrie

Dr. Ruth Ann Marrie
Scientific Director, NARCOMS

NARCOMS INFORMATION CORNER

Have an idea?

We would love to hear from you! Send us your questions, comments & suggestions.

Call: **1-800-253-7884** (toll-free US)

Email: narcomsnow@narcoms.org
Online: www.narcoms.org/contact

Who you'll hear on the phone:

Michele

Coordinating Center

As the NARCOMS Coordinating Center moves to Washington University in St. Louis, MO, *NARCOMS Now* would like to thank **Chad** & **Chasity** for their dedication to the NARCOMS registry.

They have been answering the phone and emails for almost 8 years. We wish them well!

NARCOMS Promise

Your personal information is always confidential.

The NARCOMS Global MS Patient Registry facilitates multi-center research on multiple sclerosis, developing collaboration between MS centers of excellence throughout the world to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.

En Español

Para accender a nuestro sistema a línea:

www.narcoms.org/es
Nuestro sitio de web es de alto seguridad a para su confidencialidad.

Para solicitar la envía de un cuestionario de inscripción por correo, llame al Registro NARCOMS al (800) 253-7884.

Become a part of NARCOMS:

WWW.NARCOMS.ORG / 1-800-253-7884

Reminder When Completing Paper Surveys:

If possible, please use pen rather than pencil when filling out NARCOMS paper surveys. Responses are scanned to electronic files for data capture and pen is easier to read. Thanks!

FEATURE FOCUS

Health and Wellness in MS

Rob Motl, PhD

Amy Sullivan, PsyD, ABPP

Lynne Shinto, PhD

The word wellness can encompass many aspects of health, including both physical and mental well-being. While decades ago "wellness" may not have been considered attainable for individuals with a chronic illness, today we can define wellness as living your best life. This of course may take different forms for each individual, and include factors ranging from exercise to employment, insurance to accessibility, and much more. Where once the concept of wellness may have been considered among researchers and clinicians as a form of alternative therapy, today wellness is on the forefront of MS research and concepts of care.

In 2014 the National Multiple Sclerosis Society convened a group of individuals with MS, healthcare professionals, researchers and Society staff to review the then-current knowledge in the areas of diet, exercise and emotional wellness; identify gaps in knowledge in these areas; and suggest educational resources and support programs in these areas to better meet the needs and interests of people living with MS. At that time, the three priority areas were defined as diet, exercise, and emotional wellness.

Last fall the NMSS convened a second Wellness Research Work Group, made up of experts in their respective fields, and in February 2017 the group published an article on gaps and priorities in MS wellness research. The Group's primary goals are stated as seeking, "scientific evidence supporting the application of lifestyle, behavioral, and psychosocial approaches for promoting optimal health of mind, body, and spirit (in other words, wellness) in people with MS as well as managing the disease and its consequences."

Outside of disease management through medication and other clinical tools, the group focused, as before, on diet, exercise, and emotional wellness. They published a report in the *MS Journal* (online, January 12, 2017) revisiting these priority areas in wellness research in MS. Some of the findings include questions they encourage current and future researchers to answer.

Exercise in MS

Rob Motl, PhD, is a professor at the University of Alabama at Birmingham School of Health Professions who serves on the Work Group. Motl's expertise is in exercise clinical trials for individuals with MS. He hopes the work this group is doing will result in high-quality clinical trials relating to wellness in treating people with MS, he says.

"We probably know the most about exercise and its benefits, and the least about diet and emotional wellness," Motl says. "We need to improve the rigor of our clinical trials in these areas."

Studies have established that exercise can help prevent cognitive decline and improve mood, and the extent of the benefits is still being examined. The Work Group suggests researchers focus on answering the following questions for exercise and MS:

- What are the optimal ways to promote exercise and physical activity?
- What safety issues are involved?
- What are the best approaches to exercise and physical activity for people with MS, including those with more advanced disease?
- What are the best methods for translating findings from exercise and physical activity research to the daily life of people with MS?
- How can we increase participation in physical activity among people with MS?
- And ultimately, to what extent does exercise and physical activity affect emotional health, physical health, quality of life, and the course of MS?

Motl's research has helped confirm that individuals living with MS should do aerobic exercise and resistance training twice a week for 30 minutes each. Identifying similar prescriptions for diet and emotional well-being are the next frontiers in wellness with MS, Motl says. In addition to enhancing clinical trials in this area, Motl says training and mentoring future scientists and clinicians to focus on wellness is important.

"Guidelines are one thing, but how to implement them is the next step," he says. "We need to develop strategies, tools, and resources to do so, and the NMSS will focus on these next."

Another area of importance is providing increased options for "self-regulation," Motl says. "People with MS are looking for ways to live a better life and be empowered. This research effort shows that we are listening to them, and to the scientific community, and now we need to prioritize these research efforts. We want to create programs that can turn around and benefit the patients."

Emotional Well-Being in MS

Mental health is of key importance when living with a condition like MS. According to Amy Sullivan, PsyD, ABPP, staff clinical psychologist at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic, depression is common among MS patients—up to 50% may have it at some point in time—nearly three to four times as common as in the general population.

While emotional wellness is recognized as a prominent issue in MS, many questions about emotional wellness remain. The NMSS Work Group identified the following:

To what extent do the following affect emotional health and the course of MS?

- **Resilience:** The capacity to recover quickly from difficulties
- **Positive psychology**: The scientific study of the strengths that enable individuals and communities to thrive
- **Stress management:** Techniques intended to equip a person with effective coping mechanisms for dealing with psychological stress
- **Problem solving:** The process of finding solutions to difficult or complex issues

What are optimal ways to promote these strategies?

Sullivan, who also serves on the NMSS Work Group, points out the importance of differentiating between stress and mental illness, and describes how the Mellen Center developed a process for helping patients cope with stress that is short-term and shows tangible results.

“We teach our patients about the body’s physiological response to stress, with the goal of decreasing the fight-or-flight response and increasing the rest and relax,” she says. “We teach patients the diaphragmatic breath and use some biofeedback tools so they’re able to tangibly see physiological responses to increasing relaxation, such as decreasing heart rate. There is no cookie-cutter response—we teach a variety of skills so each person can utilize what is the most effective skill for them.”

Sullivan emphasizes how emotional health is not a single event to be addressed and moved past, but rather it may recur in different ways and require ongoing strategies for management. She argues the importance of establishing a long-term relationship with a mental health professional, and with that provider at least yearly in the form of a mental health check-up, rather than waiting for a crisis to occur before finding help. This can be a psychologist, social worker, counselor, or even a nurse practitioner.

Sullivan will give a presentation at the 2017 Consortium of Multiple Sclerosis Centers annual meeting on behavioral medicine. Other wellness topics presented at CMSC will touch on suicide and nutrition. “In addition to psychologists or psychiatrists, this is a disease that is manageable, and it is so important to combine physical and emotional health, because taking care of one helps the other. MS can take a lot from you but the last thing I want it to take is your joy,” she says.

Nutrition in MS

Although no single diet has been shown to be best for everyone with MS, a healthy diet has been shown to improve well-being. Research continues to examine the effects of vitamin D, sodium, links between the gut bacteria and MS (if any), and more.

The NMSS Work Group has suggested answering the following questions in future research on diet and nutrition:

- What are the optimal ways to help people with MS adopt or maintain specific dietary regimens?
- What are the most valid and reliable nutrient biomarkers to utilize in studies of diet?
- What role do gut bacteria play in the course of MS?
- Using small trials, to what extent do specific comprehensive diets, balanced diets, good nutrition, and specific nutrients affect physical health and the course of MS?

Lynne Shinto, PhD, is an Associate Professor in the Department of Neurology at Oregon Health Sciences University, who studies nutrition in chronic illnesses.

In addition to her research Shinto, who serves on the NMSS Work Group, works in an integrated medicine clinic seeing MS patients. She says the most frequently asked question she gets is what diet to adhere to for MS.

> *“MS can take a lot from you but the last thing I want it to take is your joy.”*
> - Amy Sullivan, PsyD, ABPP

"The Work Group decided there probably is no 'MS diet,' just like there's no Type 2 Diabetes diet or only one specific diet for anyone," Shinto says. "It would be a good idea to look at different types of diets and if they show benefits, then offer choices from those. Whatever healthy diet people will stick with is what I recommend. When people have choices, they are more likely to stick to it."

Similar to exercise and mental well-being, nutrition and diet research studies in MS are traditionally small and difficult to administer, requiring participants to come to a clinic site and eat prescribed foods. The Work Group aims to help change that by offering guidelines for efficacy in these trials.

"In trials studying diet, if researched in a well-designed way, do we see objective differences or improvements in participants?" Shinto asks. "That is what we are aiming for, to find a way to validate these studies which are not drug interventions." Next steps include sharing the information, she says, and garnering interest among researchers to tackle these topics in future trials.

"One of our priorities is to get people interested and trained well in methodologies that would help them evaluate whether these studies are effective," she says. "This may mean pulling in people who may have experience in this research to partner with people who are already doing MS research, maybe not in lifestyle or wellness, to create collaborative efforts in designing these studies." Shinto recommends that MS patients ask their doctors about wellness issues. As with any modifiable lifestyle factors, including diet, exercise, meditation, yoga, and other practices, you should speak with your healthcare provider before starting a new regimen.

NARCOMS Now featured an interview with NMSS nutritionist Denise Womack in our Winter 2015 issue, available online here: www.narcoms.org/narcomsnow/pdfs/NARCOMSNowWinter2015.pdf

Overall Health

So many factors can be considered under the umbrella of "wellness," including symptom management, quitting smoking, sufficient sleep, and more.

The Wellness Research Work Group will present a workshop at the 2017 Annual Meeting of the Consortium of MS Centers, "Wellness in MS: Methodology for Clinical Studies," to educate attendees about how to maintain quality in clinical trials of wellness approaches.

The Work Group also has developed a plan for reviewing, updating, and adding to the Society's wellness materials, so that these materials can be used for continuing medical education for healthcare providers.

This research group and the NMSS say they hope this work will attract new research and improve clinical practice in wellness in MS. *NARCOMS Now* will continue to report on these advances in methods to improve the lives of those with MS.

For a list of clinical trials on wellness in MS currently recruiting participants, see page 14. For a list of wellness-related resources available online, visit "MS Apps & Blogs," page 18. For NARCOMS wellness research see "MS Reflections," page 10.

MS Messenger

Thank you to the registry participants who have contacted us and given us feedback about the NARCOMS Registry. Your continued support and feedback help us to improve the survey content and how the online users interact with the updates. The recent relocation of the NARCOMS Coordinating Center means a few changes to the NARCOMS Update surveys. Here's a preview of what will be a bit different.

How will you get the survey?

- **Paper Updates:** You will continue to receive the paper survey via the US Postal Service. The only change you will notice is the new return address that appears on the survey and the return envelope. The surveys will now be mailed back to St. Louis, Missouri.

- **Online Updates:** The survey invitation you usually receive by email will now contain a direct link to your individual survey. All you need to do is click on the link, and it will take you directly to your survey. You will fill out the survey like you normally do, click submit, and your survey will be complete.

What is new online? For those of you that complete the updates online, we are happy to announce some new and exciting changes! We think they will make the survey easier to access and easier to complete:

- **No more login or password!** You will no longer need to remember a login name or a password. Your survey and link are unique to you. They will be accessed through a secure, individualized link emailed to you.

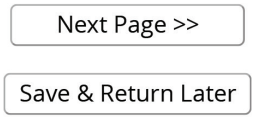
- **Updating your contact information:** If you need to update your contact information, you can easily do that within the survey. Outside of survey time, you can report address changes to MSRegistry@narcoms.org or call 1-800-253-7884 (toll free US).

- **How to Take a Break:** If you need to take a break while filling out your survey, you will be given a code so you can pick back up where you left off. All you have to do is click "Save & Return" at the bottom of each screen, and your return code will appear (see box).

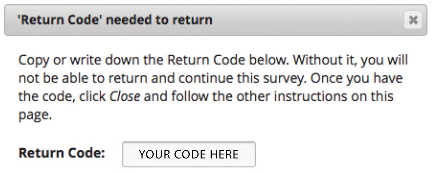
- **Remember:** The code to return to the survey will not be in the email (to protect your privacy) – you will need to record the code to use later.

Options for Taking a Break

Anytime you need to take a break, click on the "Save and Return" button at the bottom of the page.



1. Write down the Code. You will receive an email with a new link to be used when you are ready to resume the survey. Click on the new link and enter the code.



'Return Code' needed to return

Copy or write down the Return Code below. Without it, you will not be able to return and continue this survey. Once you have the code, click *Close* and follow the other instructions on this page.

Return Code: YOUR CODE HERE

2. If you do not have a code, contact the Coordinating Center and we will send you a new link.

Are you Taking an MS Therapy?

This is the most noticeable improvement to the online survey. Thanks to you and your comments, the process is now much easier!

We will now provide you with a list of therapies, also called disease modifying therapies or DMTs, that you may have taken in the past six months.

- **What if I am NOT taking a medication?** At the bottom of the list of medications, simply check, "I have not taken any of the above therapies over the past 6 months" and press "**Next Page>>**" to go to the next question.
- **What if I am taking a medication?** Read the list of medications and select the medications you have taken in the prior 6 months and press "**Next Page>>**" then provide additional information only for those particular medications.

Do you have Other Conditions?

Just like the way you tell us about your DMTs, you'll be asked if you have any other medical conditions.

- **You have other conditions**: If you have any on the list, check "Yes" and "**Next Page>>**". You will then tell us which of the conditions you have and if you are currently being treated for them.
- **You do NOT have other conditions:** Just check "No" and press "**Next Page >>**" to go to the next question.

SURVEY 101

UPDATES TO NARCOMS

Spring 2017 Update

The Spring 2017 Update will take place in April as usual. In addition to the standard set of questions, this time the survey will ask a few questions about how you use the internet to find health-related information. It will also briefly focus on telehealth, or using technology to deliver health care, health information or health education at a distance. Telehealth is a topic that has a lot of interest from both patients and healthcare providers and your views would be very important on these matters.

Finding Health-Related Information

The internet has created new possibilities for health communication and the options continue to grow. There are an increasing variety of ways to find information and interact with your health care providers electronically. In this survey, we are interested in tools you have used to exchange medical information with health care providers. Also, we want to know your level of interest in communicating with your health care provider electronically for different types of medical information.

Questions or Comments: Please contact us by email, MSRegistry@narcoms.org, or by phone, at 1-800-253-7884 (toll free US). Our hours are 8:00 am- 5:00 pm Central Time, Monday-Friday.

NARCOMS and Wellness

Research on MS general health and wellness covers a wide range of topics. Some studies focus on emotional well-being, decreasing or managing depression, and other research is centered on things that people living with MS can do to improve wellness. This includes: changing diet, increasing physical activity, and quitting smoking. To find out if lifestyle changes have a long-term benefit for MS, studies need to follow many participants over many years. NARCOMS is well-suited to do studies on these topics, especially since from the outset, NARCOMS participants have contributed to multiple research projects about wellness and lifestyle factors. Here is a sampling of these projects.

The Impact of Exercise and Physical Activity

The first study to show the benefits of exercise for MS was in 1996, around the same NARCOMS began. The "Impact of aerobic training on fitness and quality of life in multiple sclerosis," published in the *Annals of Neurology*, showed that exercise can improve general health but also helps with MS-specific symptoms like fatigue.

In a 2008 publication, "Fatigue characteristics in multiple sclerosis: the NARCOMS survey," chronic fatigue was reported by 74% of the 9,205 NARCOMS respondents. Twenty seven percent of participants reported use of an exercise program to treat fatigue. Other treatment strategies included physical and occupational therapy and symptomatic medications. The researchers, led by Olympia Hadjimichael, PhD, suggested that "fatigue should be evaluated routinely" and that various treatments, including exercise and medication, should be considered with any MS care plan.

In a 2010 publication, "Impact of loss of mobility on instrumental activities of daily living and socioeconomic status in patients with MS," 8,180 NARCOMS participants reported an association between reduced mobility, reduced employment rates, and reduced income.

Lead author Amber Salter, PhD, and colleagues stressed, "the importance of early assessment and treatment of decreases in mobility to preserve QOL (quality of life)" and that "managed exercise, and pharmacologic therapies targeting specific factors contributing to reduced mobility, such as spasticity, fatigue and pain, may be beneficial."

Get Moving with MS

You do not have to spend hours in a gym or on a treadmill to get the benefits of exercise. Some programs to consider:

- Water aerobics or swimming
- Low-impact strength training
- Movement activities like Yoga, Tai Chi, or Pilates can all be adapted for different ability levels
- Cardio workouts can be done inside, outside, and seated

If you are affected by heat, remember to keep exercise areas cool, drink plenty of cool drinks, or break up your exercise into smaller time amounts with rest.

As always, start by consulting your healthcare provider or physical therapist to learn about what activities might be best for you. For more information visit the National MS Society webpage: https://tinyurl.com/pc3h67s

The most recent publication, in 2016, "Social Cognitive Correlates of Physical Activity in Black Individuals With Multiple Sclerosis" by Dominique Kinnett-Hopkins and Robert Motl, PhD (see "Feature Focus," p. 4) reported that research should also "consider sociodemographic and cultural differences" to improve and increase physical activity in different populations. While this study involved a relatively small number of NARCOMS participants (387), it was the first study to examine racial differences in physical activity.

The Impact of Mental Well-being

The 2009 publication, "The burden of mental comorbidity in multiple sclerosis: frequent, underdiagnosed, and undertreated," reported that nearly half of the almost 9,000 NARCOMS participants who responded to a special survey had at least one mental comorbidity such as depression and anxiety. Led by Ruth Ann Marrie, MD, PhD, the authors "found that the burden of mental comorbidity among patients with MS is substantial," and that depression was also underdiagnosed and undertreated. Noting that poor mental well-being can be associated with a lower quality of life, the researchers suggested that, "routine screening of mood must be part of the evaluation of MS patients by both primary care and specialty providers."

In another 2009 publication from the same survey, "Effect of Physical Comorbidities on Risk of Depression in Multiple Sclerosis," the researchers looked at whether having another co-existing health condition with MS affected the risk of depression. They found that having co-existing conditions, including diabetes, high blood pressure, high cholesterol, lung disease, as well as muscle-and-joint-related diseases, increased the risk of depression. Depression is associated with lower quality of life and a shorter lifespan, therefore it is important that depression be identified and treated.

Nutrition, Diet, & NARCOMS

The Fall 2015 Update survey included questions about diets that participants may have tried, and why they tried the diet (for general health, weight management, or for their MS).

Also, participants completed a 26-item diet questionnaire about often they ate specific food and drink items. This research is being led by the NARCOMS Research Fellow, Kathryn Fitzgerald, ScD, Johns Hopkins School of Medicine.

Fitzgerald presented the preliminary results at the 2017 ACTRIMS meeting in a poster, "Prevalence and User Characteristics of Specific Diets in People with Multiple Sclerosis,"which was awarded Best Young Investigator Poster Award. The results of this study will be presented in a future issue of *NARCOMS Now*.

What can you do?

Participating in NARCOMS helps to inform MS caregivers about the impact of lifestyle factors of those with MS. Many of these lifestyle factors are also called modifiable factors, because they can be changed. They include things like:

- Managing diet and nutrition
- Losing weight, if needed
- Stopping cigarette smoking
- Reducing alcohol consumption
- Increasing physical activity

Dr. Amber Salter's 2016 paper looking at a survey of 9,496 NARCOMS participants, "Examining the joint effect of disability, health behaviors, and comorbidity on mortality in MS," highlights the effects of other health conditions, such as diabetes, on life span in MS. Some of these conditions can be prevented through lifestyle changes.

Five-Year Study Stem Shows Cell Transplants May Induce Long-Term Remission of Multiple Sclerosis

The five-year results of the HALT-MS clinical trial looking at the effectiveness of high-dose immunosuppressive therapy and autologous hematopoietic cell transplant (HCT — see box) showed that 69% of trial participants did not experience progression of disability, relapse of MS symptoms, or new brain lesions.

"These extended findings suggest that one-time treatment with HDIT/HCT may be substantially more effective than long-term treatment with the best available medications for people with a certain type of MS," said National Institute of Allergy and Infectious Diseases (NIAID) Director Anthony Fauci, MD. "These encouraging results support the development of a large, randomized trial to directly compare HDIT/HCT to standard of care for this often-debilitating disease."

HALT-MS was sponsored by NIAID, part of the National Institutes of Health, and conducted by the NIAID-funded Immune Tolerance Network (ITN). Researchers tested the safety, efficacy (how well the treatment works) and durability (how long the results last) of HDIT/HCT in 24 volunteers aged 26 to 52 years with relapsing-remitting MS (RRMS) who, despite taking clinically available medications, experienced active inflammation, evidenced by frequent severe relapses, and worsened neurological disability.

Five years after HDIT/HCT, most trial participants had no relapses or progression, and their MS had stabilized. In addition, some participants showed improvements, such as recovery of mobility or other physical capabilities. While three participants died during the study, none of the deaths were considered related to the study treatment.

"Although further evaluation of the benefits and risks of HDIT/HCT is needed, these five-year results suggest the promise of this treatment for inducing long-term, sustained remissions of poor-prognosis relapsing-remitting MS," said Richard Nash, MD, of Colorado Blood Cancer Institute and Presbyterian-St. Luke's Hospital. Nash served as principal investigator of the HALT-MS study.

Daniel Rotrosen, MD, director of NIAID's Division of Allergy, Immunology and Transplantation says he hopes that, "if these findings are confirmed in larger studies, HDIT/HCT may become a potential therapeutic option for patients with active RRMS, particularly those who do not respond to existing therapies."

Autologous Hematopoietic Cell Transplant

The HDIT/HCT The procedure has three steps:

- **First:** Doctors collect a participant's blood-forming stem cells
- **Second:** The participant receives high-dose chemotherapy to deplete the immune system
- **Third:** The stem cells collected in step 1 are returned to the participant to rebuild the immune system.

The treatment carries some risks, and many participants experienced the expected side effects of HDIT/HCT, such as infections, pulmonary (lung), or cardiac (heart) complications.

Full HALT-MS results here:
https://tinyurl.com/zdy87n9

Blood Biomarker to Determine Types of Multiple Sclerosis Identified

Researchers in Australia have discovered the first-ever blood biomarker—a chemical identifier in the blood—to distinguish the different types of multiple sclerosis (MS). The research was published in *Nature Scientific Reports*, in the article, "Kynurenine pathway metabolomics predicts and provides mechanistic insight into multiple sclerosis progression."

MS has three clinical courses: relapsing remitting, secondary progressive, and primary progressive. Determining the MS course is traditionally a lengthy, challenging process that requires an array of tests. This breakthrough, made by Edwin Lim, PhD, and Gilles Guillemin, PhD, from Macquarie University in Sydney, may change the process.

"This significant discovery will facilitate the ability to quickly and simply diagnose the three types of MS and will allow clinicians to adapt their treatment for MS patients more accurately and more rapidly," says Guillemin.

The research was funded by the National Health and Medical Research Council and Multiple Sclerosis Research Australia. The researchers used several repositories to complete these experiments, including the Accelerated Cure Project for MS, The Human Brain and Spinal Fluid Resource Center (sponsored by the National MS Society), and the Tasmanian MS Longitudinal Study.

"We have been excited to be part of the translation of this fundamental research into a potential clinical blood test," said Dr. Matthew Miles, CEO of MS Research Australia. "This has the clear capacity to be the first-ever blood biomarker for the prognosis of MS, and in doing so will meet one of the real unmet needs in the clinical management of MS."

First Results From Phase 3 Ozanimod Trial Show Reduced Relapse Rate

The first results of a Phase 3 clinical trial of the drug ozanimod on 1,346 individuals in 20 countries with RRMS showed a reduced annualized relapse rate (ARR) while on the oral drug compared to patients taking weekly interferon (IFN) beta-1a (Avonex®).

Ozanimod (manufactured by Celgene) is thought to act by keeping certain white blood cells in the body's lymph nodes and out of the central nervous system.

Researchers compared two oral doses of ozanimod—0.5 mg and 1 mg—with the weekly injection of interferon beta-1a (Avonex) for at least 12 months. Both doses of ozanimod were more effective (showed statistically significant and clinically meaningful improvement) compared to Avonex in achieving the trial's primary objective—a lower relapse rate—and the secondary endpoint of fewer brain MRI lesions over 12 months, data showed.

"These data add to the growing body of evidence supporting the use of ozanimod as a disease-modifying therapy for relapsing MS," Bruce Cree, associate professor of neurology at the University of California, San Francisco, said in a press release. "We look forward to the continued study of ozanimod as well as presentation of the full results of the phase III trial at an upcoming international scientific meeting [ECTRIMS, Oct. 23–27, 2017]."

Clinical Trials in **MS**

These clinical trials are designed to study issues in well-being with multiple sclerosis.

Lakeshore Examination of Activity and Disability Exercise Response Study (LEADERS)

Purpose: This study will examine the effectiveness of group exercise classes on the health and functional status in inactive adults with neurological conditions including MS: Movement to Music, Adapted Yoga, or a home-based exercise intervention of either Movement to Music or Adapted Yoga.

Study Outcomes: Cardiorespiratory fitness, pain and fatigue, loneliness, limb and grip strength, balance, body measurements, physical function with mobility aids, anxiety, depression, and sleep function.

Eligibility: Age 18 to 65, with a diagnosis of MS and/or stroke; able to use arms or legs for exercise; ambulatory or use manual wheelchair.

Sponsor: Lakeshore Foundation and the University of Alabama at Birmingham

Contact: Casey Herman, MS, (205) 403-5504; caseyh@lakeshore.org; Hui-Ju Young, PhD, (205) 403-5521; hjyoung@uab.edu

More information at ClinicalTrials.gov, NCT025338822: https://tinyurl.com/jqepbvh

Additional Trials online at:
www.narcoms.org/narcomsnow/msnews/spring2017/page2

Dietary Approaches to Treat Multiple Sclerosis–Related Fatigue Study

Purpose: This study will compare the effect of the Swank Diet (low saturated fat) and the Wahls Elimination Diet (modified paleo) on fatigue levels in individuals with RRMS. Participants will follow their usual diet for 12 weeks and then be randomly assigned to follow one of the two diets for 24 weeks (36 week total on study).

Study Outcomes: Change in fatigue severity scale as measured in four-week intervals. Study activities include fasting blood draws, weighed food records, motor and cognitive testing, physical activity assessment, questionnaires, and daily diet checklists while following the study diet.

Eligibility: Age 18 to 70, with a diagnosis of RRMS. The study requires four visits to the University of Iowa Hospitals and Clinics in Iowa City, Iowa. Fatigue as documented by a fatigue severity scale score of greater than or equal to 4. Some reimbursement available.

Sponsor: University of Iowa and the National Multiple Sclerosis Society

Contact: Catherine Chenard, MS, RD, LD, (319) 384-5053; Michaella Fowler, BS, (319) 384-5002, MSDietStudy@healthcare.uiowa.edu

More information at ClinicalTrials.gov, NCT02914964: https://tinyurl.com/zwl5d4z

Looking for more information on MS trials?
Go to www.clinicaltrials.gov and search for "Multiple Sclerosis."

SnapShot

NARCOMS BY THE NUMBERS:

As we say hello to the new NARCOMS Coordinating Center, we wanted to take a look back at NARCOMS overall, and since 2009 when the Coordinating Center moved to the University of Alabama at Birmingham (UAB). The first update survey that was sent from UAB was in Spring 2009 and since then the Coordinating Center has kept busy – all thanks to you!

NARCOMS

38,076
Total Participants Enrolled

29,600
With at Least 1 Update Survey

26,967
With at least 1 Year of Follow Up

15,364
With at least 5 Years of Follow Up

11,025
Active Participants

8,746
With at least 10 Years of Follow Up

7,431
Participants Enrolled since 2009 @ UAB

3,962
With at least 15 Years of Follow Up

798
Twitter Followers @NARCOMS

157
Poster or Platform Meeting Presentations

99
Total Published Research Papers

82
Poster or Platform Presentations since 2009 @ UAB

63
Research Papers since 2009 @ UAB

53
Instagram Followers @NARCOMS_Now

51
Research Projects since 2009 @ UAB

46
With at least 20 Years of Follow Up

34
Total Update Surveys

16
Update Surveys since 2009 @ UAB

4
NARCOMS Coordinating Centers

2
NARCOMS Research Fellows since 2009 @ UAB

1 You!

MS APPS (& BLOGS)

There are many health and wellness apps and websites available for your electronic devices—we covered a few in our Spring 2016 issue: http://tinyurl.com/jtlfhuc. Here we look at websites and blogs that specifically discuss wellness in living with or caring for someone who has MS.

The Bits and Bobs

http://thebitsandbobs.com

A humor blog may not be the first thing that comes to mind when considering wellness, but laughter is a means of coping with grief and all that life throws our way. Louise Bonnett-Rampersaud is the mother of two and a children's book author from Sandy Spring, Maryland. She started "The Bits and Bobs" as a means to come to terms with her husband's death from a rare disease, vascular Ehlers-Danlos syndrome, in 2014.

In 2015 another challenge came her way when she was diagnosed with MS. The blog tackles everyday moments in her short and to-the-point posts. In an interview with television's "Today" show, she discussed how she copes with MS:

> "I am doing some holistic things, like paying to attention to my diet, which have helped the inflammatory process of MS. The medications I am on can damage your liver, but my last blood work was great.
>
> I have to say, I do notice when I stick to dietary changes, I feel the difference. I am also looking into yoga….I still try to have a sense of hope and optimism. Laughter helps in any situation. Hopefully, I can touch any number of people in a bad place, who need a laugh at the end of the day."

Health Care Journey

www.healthcarejourney.com/health--wellness.html

This site features a monthly post on health and wellness topics to consider as possible methods of coping with MS symptoms. Each topic is discussed in a podcast interview with a practitioner of that treatment. Highlighting alternative therapies, topics covered on the site include: acupuncture and herbs, diet and nutrition, Reiki (a Japanese healing technique based on the principle that the therapist can channel energy into the patient by means of touch), exercise, massage, yoga, light therapy, and more.

MS Advocacy Websites

Both the National MS Society and MS Association of America have sections of their websites dedicated to overall health and wellness. The NMSS "Living Well with MS" website has monthly webinars (a collaboration with Can Do MS), a wellness workbook and expert YouTube videos. The MSAA website has resources on a range of topics in the basic categories of physical and emotional health, as well as practical topics such as insurance and legal and financial health, plus finding happiness.

NMSS: www.nationalmssociety.org/Living-Well-With-MS/Health-Wellness

MSAA: http://mymsaa.org/msaa-help/overall-wellness/

Editor's Note: *Please consult your health care provider before making any healthcare decisions or for guidance about a specific medical condition.*

Getting On With Life

Eighteen years ago I was diagnosed with Primary Progressive MS, at age 53. I was grateful that I had already had so many rich life experiences such as cross country skiing, jogging and climbing the La Luz Trail in the Sandia Mountains in Albuquerque, New Mexico.

I tried a variety of treatments and medications for my condition, with varying success. When I discontinued them I no longer had fatigue. For several years I tried every-other-week therapeutic plasma exchange infusions, with short-lived success. I even tried an autologous stem cell treatment. [For more on current research with stem cells and MS: www.nationalmssociety.org/Research/Research-News-Progress/Stem-Cells-in-MS]

In the meantime, I got on with my life! I taught a water exercise class, moderated a support group meeting, and taught yoga classes with the support of a grant provided by a pharmaceutical company. In addition, I began an adaptive ski program, joined a wheelchair basketball team, took up sled hockey, and—to celebrate my 70th birthday—went paragliding.

I have participated in fundraising activities and volunteered for several summers at a camp for children in wheelchairs. Overall, I feel I have been afforded an active, enjoyable life without wasting time whining about what I can't do. Instead, I spend my effort on finding ways to do as many enjoyable things as I can.

—Patricia M.

Editors Note: *Not all treatments work the same for every patient. Consult your healthcare provider about what treatment, if any, is right for you and your MS.*

NARCOMS Coordinating Center
The University of Alabama at Birmingham
1720 2nd Ave. South
BIRMINGHAM AL 35294-0022

twitter: @narcoms
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