

NARCOMS

Spring 2016

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NOW

Vol. 5, Issue 2

A painting of a large, gnarled tree with thick roots in the foreground. The tree is set in a landscape with green grass and a body of water in the background. A small rabbit is visible in the middle ground, looking towards the left. The sky is a soft, hazy mix of pink and blue.

MS& Other Conditions

5 questions with ...

Gretchen Matthewson, FNP-BD, CMSN

Specialty Coordinator and Nurse Practitioner in Neurology, Corinne Goldsmith Dickinson Center for Multiple Sclerosis, Icahn School of Medicine at Mount Sinai Hospital

Gretchen Matthewson is a board certified nurse practitioner and a certified MS nurse with experience in acute and family care. She earned a master's degree in Family Practice from Columbia University and provides education, counseling, direct patient care, and follow-up for patients and their families. Ms. Matthewson is particularly interested in nutrition and exercise and their impact on mental and physical health. A regular participant of the MS Bike Ride, she encourages her patients and colleagues to join her for fun and fitness.



1. Why is nutrition so important for MS?

In order for the body to heal from the damage that can occur from MS, it must be functioning optimally. Excellent nutrition is essential because food is the fuel your body uses to support all of the many functions that are involved in healing.

2. Why are Patient Reported Outcomes important?

It is critical to understand the patient's perspective. How patients interpret their experience and incorporate it into their frame of reference will determine the decisions they make about their treatment in the future.

3. What other area of research needs more attention?

There are so many! Conditioned immune response is intriguing. Training our bodies into thinking we've had medicine even when we haven't, thereby reducing the amount of actual medicine needed, potential side effects, and cost. Research along these lines was initially done with MS patients in 1996—this area warrants another look.

4. What do you think will be the next breakthrough?

Using sound frequency to speed recovery time and improve health. (NARCOMS Note: for results from a recent study on this topic see <http://www.ncbi.nlm.nih.gov/pubmed/25257616>)

5. What is your “MS Tip” to managing a life with MS?

Keep a broad perspective. Look around you. Disabilities are often invisible. Many of the people you observe and encounter who appear to be well are often fighting silent battles. Be kind to each other, we all have obstacles to overcome.

A project of the Consortium of Multiple Sclerosis Centers



THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS

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NARCOMS NOW

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A Letter from the Director - Spring 2016

Greetings,

Welcome to our spring issue of *NARCOMS Now*. We hope the groundhog's prediction came true in your area and you'll soon be seeing signs of spring. You may have noticed the cover art for this issue, the first from our NARCOMS Cover Art Contest, by artist Debbie Casteel. Her piece is titled "Hare by the Roots," and embodies the hope of new things to come in spring.

In this issue we feature the complicated topic of comorbidities in MS—how they are recognized and diagnosed; which are most prevalent with MS; and how are they treated? Interviews with three experts in research on MS and comorbidities reveal what they find most intriguing in recent studies, and agree that while patterns are emerging, there is room for additional investigation.

"Snapshot" takes a look at what you, our NARCOMS participants, have told us about your general wellness and nutrition.

"MS News" this issue touches on a variety of recent MS news, including the recent FDA announcement that it has granted breakthrough therapy status to the drug ocrelizumab for primary progressive MS (read more about it on page 20). Other recent news includes a study on the potential value of high-dose vitamin D for MS patients. Additional research examines the previously understudied "taste dysfunction" many individuals with MS experience, in addition to other sensory changes.

We hope you'll consider our "Clinical Trials" listings this issue, both of which are telemedicine-based interventions, in which participants execute treatment routines at home and record the results. Our highlighted "MS Apps & Blogs" this issue are those which aim to help learn more about our own well-being by tracking such lifestyle habits as sleep, calorie consumption, exercise frequency and intensity. We would love to hear from you on your personal favorites, as these technological tracking programs continue to proliferate and evolve.

As this issue goes to press, we're heading to the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Congress 2016 in New Orleans, with a theme of progressive MS. We look forward to sharing some of the latest research in this important area with you in upcoming issues of *NARCOMS Now*.

Happy Spring,



Dr. Robert Fox
Managing Director, NARCOMS



Dr. Robert Fox is the Managing Director of NARCOMS, the Medical Director at the Mellen Center for Multiple Sclerosis and a practicing neurologist at the Cleveland Clinic in Ohio.

NARCOMS INFORMATION CORNER



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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.



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Reminder When Completing Paper Surveys:



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!

MS & Other Conditions

Living with multiple sclerosis can be a challenge. Living with MS plus another condition can add a layer of complexity to treating MS — not only for the person him or herself, but for caregivers as well. Which condition do you treat first? Which condition do you treat most aggressively? When does the treatment of one condition outweigh treatment of the others?

The condition of having more than one disease at a time is referred to in medical terms as comorbidity (see sidebar, page 9, for a history of the term). The concept of comorbidity is relatively new—it was not defined until the 1970s—so methods for coping with comorbidities are also still evolving.

Research on comorbidities in MS has increased in the last few years, largely through the efforts of investigators such as Ruth Ann Marrie, MD, PhD, Professor in the Departments of Internal Medicine and Community Health Sciences at the University of Manitoba, and Director of the Multiple Sclerosis Clinic at the Winnipeg Health Sciences Centre. Dr. Marrie is also the Scientific Director of NARCOMS.

In 2015 Marrie and her collaborators published a special issue of the *Multiple Sclerosis Journal* featuring the results of their systematic review of the literature on the incidence and prevalence of comorbidities with MS. (<http://tinyurl.com/jp662o3>)

The study was part of an international initiative, called the MS Comorbidities Project, to understand how common it is for people with MS to have other medical conditions, and how those conditions may affect the course and treatment of an individual's MS. The literature review was the first phase of the project, which resulted in seven papers in the *MS Journal*.



Dr. Ruth Ann Marrie

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

“We were trying to clearly establish what the existing knowledge was about the frequency of comorbidity with MS,” Marrie says, “as a foundational piece for future studies trying to understand what the effect of those conditions would be on MS. We looked at what do we know about the basics, which in turn allows us to plan how to move forward.”

Marrie has published frequently on the topic of comorbidities in MS, often using NARCOMS data; with studies on specific topics such as vascular comorbidity (e.g. high blood pressure, diabetes) as it relates to disability progression in MS; depression and anxiety in MS versus the general population; the effect of comorbidity on survival in MS; and pain-related activity limitations associated with comorbidities in MS, to name a few.

“I started working on this topic 10 years ago, after recognizing when I was seeing people in clinic that sometimes the individuals were more limited by other health conditions than by their MS,” she recalls Marrie says she went to read about comorbidities and how to manage them in MS, and realized there was very little material available..

The recent literature review focused on 249 studies conducted between 1905 and 2012. Conducting the review took 14 months from approval to completion, and revealed several patterns about comorbidities and MS:

- The **five most common conditions** along with MS were: depression, anxiety, high blood pressure, high cholesterol, and chronic lung disease
- The **most common autoimmune diseases** were: thyroid disease and psoriasis
- The **types of cancer occurring most often** in those with MS were cervical, breast, and digestive system cancers. The risks of urinary system cancers and meningiomas were higher than expected while the risks of ovarian, pancreatic, prostate and testicular cancer were lower than in the general population.

The reviewers also concluded that little is known about comorbidities with MS in Asia, Central or South America, as most of the studies done up to now have been conducted in North America and Europe. The quality of the studies was also so variable, the reviewers concluded, that it was difficult to compare results.

The findings raised other questions, Marrie says: “Is it true that so-called benign brain tumors are more common in those with MS,” she asks, “or is it just because people with MS get MRIs more often than the general population and therefore have a higher detection rate?” This speaks to another issue of comorbidities and MS—which comes first, which should be treated, when, and how?

“As long as the treatments for the two conditions don’t worsen one another, or have significant interactions, you can treat and move forward,” Marrie says. “It’s a question of evaluating the priority—quality of life, greatest long-term risk, and so on. It remains an ongoing challenge to try and coordinate multiple aspects of care.”

Marrie says next steps include trying to understand how comorbidities affect people with MS, “not just day-to-day symptoms and disease progression, but also responses to treatment. No one healthcare provider can be good at everything and we need to involve other providers when it’s appropriate.”

Marrie has several ongoing projects in this area, including one looking at the frequency of comorbidity in people with MS in four Canadian provinces, how having a comorbidity affects the use of a disease-modifying therapy (DMT), their choice of DMT, and how rapidly their MS progresses. Another project aims to understand the effect of anxiety and depression on people with MS as opposed to those with inflammatory conditions such as rheumatoid arthritis and inflammatory bowel disease, to “find better ways to diagnose and provide better information to individuals with those conditions, their families and their healthcare providers,” she says.

Marrie says one of her first studies on comorbidities in MS, using the NARCOMS database, inspired her to continue to study this area. A recent study in this area, published in *Neurology* in May 2015, looked at mortality in MS and found that “people with MS are living longer than they used to,” she says. “The bad news is there is still a survival disadvantage, but there was good news. My initial hypothesis was that if you had a comorbidity it would be much worse if you also had MS—but the good news is, that was not the case.”

Dr. Helen Tremlett has also conducted several studies on comorbidities in MS. She says she was first drawn to studying MS while in pharmacy school because of its unknowns.

“As an undergraduate student at that time, I felt that in many other diseases—hypertension or diabetes, for example—we were clearly told, here’s the test, here’s the disease, here’s the drug, and here are the measurable outcomes. And then we got to MS, and we had none of those things,” Tremlett says. “I thought that was so such an eye-opener, it just captivated me. When I had the opportunity to do a PhD, I chose to focus on MS because I thought there was a real need and opportunity to make a contribution.”

Dr. Tremlett, PhD, is a Canada Research Chair in Neuroepidemiology and MS, and Professor at the University of British Columbia, Vancouver, Canada. She has collaborated with Dr. Marrie on several comorbidity studies in MS. One of Tremlett’s earlier studies linked data from the British Columbia Cancer Agency with MS-related data and found that people with MS had a reduced risk of cancer.

NARCOMS is important because “you’re accessing people who don’t necessarily go to an MS clinic”

- Dr. Helen Tremlett

“When we broke down the data into individual cancers, we found that across the board there was a reduced risk of most cancers,” she says. “Brain cancers were a little higher than you

would expect but that was in the first five years after MS diagnosis, when MRIs are more frequent.”

Tremlett’s research team decided to dig deeper and obtained information about tumor size from the BC Cancer Agency to see if, when MS patients are diagnosed with cancer, their tumor sizes were any different than expected in the general population.

“We found that tumor size in MS patients at the time of diagnosis was a little larger than you would expect,” she says. “That could suggest that maybe some of the cancers are being overlooked in these patients. While we do not know this for sure, perhaps it is possible that when an MS patient tells their doctor they are tired or have other related symptoms, the doctor might attribute these to the MS, rather than testing for other things.”

Another interesting finding included the discovery that “neurology has probably underestimated comorbidities because historically, many studies gathered information primarily from people who come to MS clinics,” she says.

She explains that they assumed people with MS who were sicker were more likely to come to a MS clinic, but their research found the opposite—people with MS who did not come to an MS clinic had a higher burden of comorbidities.

“This means that those studies which have relied on data only from people coming to MS clinics may not give the whole picture. Many studies may have previously underestimated the burden and impact of comorbidities in MS.”



Tremlett suggests this is why participation in registries such as NARCOMS is so important to offering real insight to comorbidities in MS, because “you’re accessing people who don’t necessarily go to an MS clinic.”

A study conducted by Drs. Tremlett and Marrie found that the presence of a comorbidity affects a patient’s likelihood of starting an MS drug. As the number of comorbidities increases, the likelihood for the patient receiving MS drugs is reduced. This is particularly true for the presence of anxiety, she says.

“The issue of comorbidities in MS has only recently come on the radar,” Tremlett says. “One question we are looking at now is, if you have a comorbidity, does that mean your MS will do worse in terms of progression? And if you treat that comorbidity, would you therefore make that MS progression better?”

Helen Tremlett, PhD

Canada Research Chair in Neuroepidemiology and Multiple Sclerosis and Professor at the University of British Columbia, Vancouver, Canada in the Faculty of Medicine, Division of Neurology. Previously funded as a Michael Smith Foundation for Health Research Scholar and a MS Society of Canada’s Don Paty Career Development Award. Also holds operating grants from the Canadian Institutes of Health Research (CIHR), the US National MS Society and the UK MS Trust. Trained in pharmacoepidemiology/ multiple sclerosis with a PhD from Cardiff University, UK. Heads the ‘Pharmacoepidemiology in MS (PiMS) Research group.’ Research interests include: the natural history of MS; prognosis and predictors of disease progression in MS; mortality; effectiveness of the immunomodulatory drugs (IMDs) for MS; adverse effects of the MS IMDs; pharmacogenomics; MS epidemiology; comorbidities and MS; pregnancy and MS; impact of parental MS on childhood developmental outcomes; the gut microbiome and MS.

These are just some of many unanswered questions in the area of comorbidities and MS. Researcher and clinician John Fisk's work focuses on cognitive problems in MS and their impact on the health-related quality of life.

Dr. Fisk, PhD, a Clinical Neuropsychologist with the Nova Scotia Health Authority and an Associate Professor in the Department of Psychiatry at Dalhousie University, Nova Scotia, says his interest in mental health comorbidities in MS developed from his work with Dr. Thomas "Jock" Murray—"a giant in the field of MS care" (see the *NARCOMS Now* interview with Dr. Murray in the Fall 2014 issue). Murray encouraged Fisk to examine mental health issues, cognitive problems and a variety of other disabling MS symptoms that weren't widely recognized in MS at that time.

Fisk's research focuses on issues including: cognition, anxiety, depression, pain, and fatigue and how they all fit into MS care and overall quality of life. Cognition issues with MS typically represent the widely distributed nature of MS changes throughout the brain, he says.

People can do remarkably well despite an underlying neurologic condition if you really optimize their medical management.

- John Fisk, PhD

"Slowed speed of information processing is a predominant problem for a lot of MS patients—seen in most tasks that require the integration of information from a variety of sources. With memory tests, for example, you need more opportunities to learn, and perhaps additional help with retrieval."

Fisk says the range of estimates for how many people with MS are affected by cognitive impairment is broad—from 30 to 70 percent— and that

determining whether it's truly cognitive versus sensory or motor functions that can affect performance of a particular task, "can be a challenge."

Whatever the exact figure, Fisk stresses the importance of recognizing that issues such as mental health and cognitive concerns contribute in large part to the overall morbidity and reduced quality of life in MS.

"For many these issues can be among the most significant disabling features of the disease," he says. "The more effective we are at managing neurologic disability, the more we have to acknowledge, account for, and try to better manage the other problems, in terms of preserving function."

So what can someone with MS and a coexisting disease do to be as healthy as possible? All of our experts agree: general wellness practices, such as quitting smoking, healthy eating, maintaining a healthy weight, and managing stress, all contribute to better health outcomes.

From one patient population to another, there is increasing evidence of how good heart health is going to be beneficial in other disorders, including MS.

Fisk emphasizes that focusing on the positive things individuals with MS can do to achieve wellness can be powerful. "People can do remarkably well despite an underlying neurologic condition if you really optimize their medical management otherwise," he says, "and maximize their ability to do other things in their lives, such as exercise or staying engaged socially. If we start to pay attention to these other comorbidities and deal with them as part of the MS, then that will really start to help."

Managing expectations of energy and time are also important, Fisk says. "You have to set priorities on what's meaningful for you, and focus on those—which is very easy for someone like me to say, but it is not an easy thing to do. But when you're faced with a chronic neurologic condition, it's all the more important—this is something you *have* to do."



John Fisk, PhD

Dr. John Fisk completed his PhD in Psychology at the University of Western Ontario and a postdoctoral fellowship at Brandeis University.

Dr. Fisk provides a clinical neuropsychological service specializing in neurodegenerative disorders at the QEII Health Sciences Centre in Halifax, Nova Scotia. He is an Associate Professor in the Department of Psychiatry at Dalhousie University and holds additional appointments in the Departments of Medicine and Psychology & Neuroscience.

Dr. Fisk's research has focused on neurodegenerative disorders, primarily multiple sclerosis, dementia and systemic lupus erythematosus.

His research examines the epidemiology of these disorders and their associated symptoms, early signs of cognitive problems, and the impact of these disorders on health-related quality of life.

Where Did The Term “Comorbidity” Originate?

Comorbidity is a medical term indicating the presence of one or more additional disorders or diseases co-occurring with a primary disease or disorder. The additional disorder can be a behavioral or mental disorder. Its literal translation is “co,” meaning “along with,” and “morbidity” meaning “diseased condition.”

Prior to the 1970s, there was no term to describe patients with multiple disorders or diseases. The term “comorbidity” was introduced in medicine in the late 1970s by American epidemiologist and researcher A.R. Feinstein, who devised the term while studying clinical diagnosis and methods used in clinical epidemiology.

The question was then, and remains now, how to evaluate the whole state of a patient who suffers from a number of diseases simultaneously, where to start, and which disease do you treat first, second, and so on?

The three experts interviewed for this article tended to agree: “comorbidities” sounds a bit, well, morbid, and may not be the most accurate description of what’s going on in a patient’s life.

“These things are often all related—for example, fatigue is an end product of a lot of things. Pain—where does that come from? Weakness? Neuropathy? Disentangling all of these things is a challenge, and often it’s the whole package. It’s a constellation of issues and problems,” says John Fisk, PhD. “Using the term comorbidity implies that they are distinct—I don’t think all of these things are something else, they’re all related. Depression, fatigue, anxiety—they don’t have to be thought of as separate disorders.”

SURVEY 101

Spring 2016

In the US, there are five states in which adults with a life-threatening (terminal) illness can seek physician-assisted death (see sidebar). In February 2015, the Supreme Court of Canada ruled that adults with grievous (severe) medical conditions (which would include MS) are entitled to physician-assisted death, even if their illness is not life-threatening. This is more liberal than US laws.

The most recent study regarding thoughts and attitudes of those with MS was done in 1999. “The Attitudes toward physician-assisted suicide among persons with multiple sclerosis” found that almost one third of people living with MS had thought about assisted suicide as an option for themselves (<http://tinyurl.com/jamywx>).

To update this research, in the Spring 2016 Update there will be a short section with hypothetical questions about Physician-Assisted Death. We recognize that this is a sensitive topic. But we think that your opinions about this are important and will help doctors and other healthcare providers who are asked about this by their patients to better understand what people with MS think about this. Thank you in advance for answering these questions honestly.

Current Physician-assisted Death Laws in the United States

Oregon: 1997

The first such law in the US, the Oregon Death with Dignity Act allows Oregonians who have a terminal illness such as cancer or Lou Gehrig’s disease to end their lives by voluntarily taking lethal medications prescribed by a doctor.

Washington State: 2008

Washington Death with Dignity Act

Montana: 2009

Trial court ruling *Baxter v. Montana*

Vermont: 2013

Patient Choice and Control at End of Life Act

California: 2016

via the California End of Life Option Act, effective some time in 2016.

**If you ever have questions about survey topics,
please do not hesitate to contact us.**

MS APPS (& BLOGS)

Sleep Cycle (Free for iOS)

This app uses an iPhone's microphone or accelerometer to monitor sleep movements using sound or vibration analysis to record your sleeping habits, and uses "sleep cycle theory" to wake you after you've received an optimal night's rest—a feature called a "smart alarm." Users set a window of time when the alarm should go off, and the app rings gently to wake you when it judges your sleep movement is "on target." The app's designers claim "waking up like this makes you rested and relaxed." Sleep Cycle also records sleep habits to track sleep quality over time.

The app is integrated with Apple Health and exchanges sleep analysis and heart rate. Just for fun, you can compare your sleep with everyone else using the app (worldwide!). You can also export sleep data to Excel for detailed analysis. With a premium account (\$4.99/year, \$2,99/3 mos., \$1.99/1 mo.), you can track how events such as drinking coffee or eating too much—or even changes in the weather—affect your sleep quality. Use of the app requires the phone sitting next to your bed or on the floor, and it must be fully charged.

SleepBot (Free for Android or iOS)

SleepBot works similarly to Sleep Cycle using the phone's accelerometer to track your sleep activity and "wake you at just the right time." It can be set to record sounds, in case you're worried about sleep apnea, for example. Its smart alarm sets a time range to be woken up, and triggers the alarm at the optimal time in that range.

Simply Being – Guided Meditation by Meditation Oasis (\$1.99 for Apple)

Never meditated before, and worried you might not be "doing it right"? This app offers a mix of soft music and gentle guidance that leads even the novice—or the experienced—meditator into a calm state. Choose from several sound options and time limits, so you can try it for a full half hour, or simply to reboot for five minutes.

Apps for FitBit, Jawbone, Garmin, other Wearables

The biggest change in wrist-worn fitness trackers in the last few months is arguably the addition of continuous heart-rate monitoring. One large drawback that seems under development is the capability to be worn in water, such as while swimming. Battery life is another common issue—when GPS and other continuous tracking modes are on, many of these devices require a recharge after fewer than 12 hours. There is no consensus as of yet as to which of these is preferred—it may be a highly personal preference—but we will report back in a future issue of MS Apps & Blogs.

MyFitnessPal (free for iOS and Android)

This free app is a calorie-counting and food-tracking app that includes features such as message boards for users and a "HelloHealthy" blog. It claims to be the "world's largest health and fitness community with over 65 million users worldwide." You can track your weight, exercise (including how many calories you've burned), and the foods you eat regularly, so completing calorie counts becomes simpler over time.

Do you have a favorite? Email us at: narcomsnow@narcoms.org. Today it seems nearly every other person you see is wearing some sort of tracking device on her wrist. Now that corresponding apps have been available for several years, which are most useful?

NARCOMS

As you know, at the end of every NARCOMS update survey, you can enter any comments, questions or suggestions you have about NARCOMS. Here are a few of your recent questions:

Q: Why don't you ask about our intake of vitamin D3? Since I've started vitamins D3 it's like my MS has been "squashed." It's wonderful!!

A: It is wonderful that you are feeling wonderful! NARCOMS does ask about Vitamin D and other supplements in some updates, most recently in Spring 2015. A study was published in 2009 regarding bone health (<http://tinyurl.com/hprxahl>). NARCOMS will continue to ask about supplements and vitamin D as it applies to specific research questions in the future.

Q: The nutrition section needs to also look at food cost availability of food, banks, food stamps and the inability to buy medications and food.

A: These are very important topics. In 2010 we did ask about costs of many aspects of living with MS and in Fall 2014 we specifically asked about costs of medications. The results of both of these research projects are being prepared for publication. We'll let you know when the results are available.

Q: I can't remember but if you haven't asked before, please do a questionnaire on spirituality?

A: What a great idea! So great, in fact, the we will be asking about spirituality, religion, and other sources of emotional support in the Spring 2016 update. There has been some prior research about spirituality and how people with chronic disease cope emotionally. The most recent research directly related to MS and religion and spirituality have been outside the US or have been more related to the practice of yoga and the effects on MS.

In this Spring update, you will be asked general questions about your religious beliefs and practice. In addition, there will be questions about the ways you find emotional support, including attending support groups. We appreciate your honesty and time in answering these questions. For more on the Spring 2016 update, see "Survey 101" on page 10.

You also had some questions about other conditions and MS, which are asked every Spring and will be asked again in the Spring 2016 update:

Q: Why don't you ask about other medical conditions a person may get which are related to MS? Do you ask about other new autoimmune diseases that have surfaced along with the MS? What about arthritis or other skeletal diseases?

A: The update list has about 20 common or related conditions but if you have a condition that is not on the list, please write the condition in the comments at the end of the update survey. Select "other" and write in the condition.

Q: You asked about diets in the Fall 2015 update, do you ask about GI issues affecting the diet and/or weight?

A: We ask about weight in every update and there has been published NARCOMS research on GI and weight-related issues and MS. Two examples are "Cumulative Impact of Comorbidity on Quality of Life in MS" (<http://tinyurl.com/znoqh54>) and "High frequency of adverse health behaviors in MS" (<http://tinyurl.com/n3gddfj>).

Q: Thank you for your work on behalf of those affected by MS!!

A: Well that isn't a question but we really want to say THANK YOU! Without you and your continued dedication this research would not be possible.

For more about MS and Other Conditions, see "Feature Focus" on page 4 and for more about NARCOMS and Other Conditions see "MS Reflections" on page 16.

MS MESSENGER

NARCOMS Now Cover Art Contest

The *NARCOMS Now* cover art contest continues—we've received some great pieces so far, and look forward to showcasing them on our cover for the remaining 2016 issues, as well as online.

This issue's cover is by artist Debbie Casteel, a resident of Washington state whose medium is oil paints. This painting's title is "*Hare by the Roots*," chosen to match an art contest theme at her local library, which was "hair."

"I was working on this painting of the roots of a tree, and so went to my thesaurus and chose 'hare' instead," she says.

Casteel says she inherited a love of art and painting from her father, but quit practicing herself for several years after her MS diagnosis. "Then seven years ago a man in my church encouraged me to pick it back up again," she says. "I went to an oil painting class, and it has turned into a kind of therapy. I enjoy oil paint because once you jump in it's fun and forgiving—it gives you time to look at what you've done and make changes."

To submit your original artwork, email a high-resolution photo to: msregistry@narcoms.org. Tell us about the piece, including a title and what inspired the work, and about yourself as an artist. One piece will be featured on each remaining cover for 2016 and all submissions will be shown online at: www.narcoms.org/narcomsnow.

Thank you to our generous sponsors

NARCOMS would like to acknowledge the Brodsky Family for its generous, continued support of the registry. This family foundation has provided financial donations to NARCOMS since 2004. Thank you to the Brodsky Family for this crucial backing—your generosity allows us to continue the work we do to further research every day.

NARCOMS Celebrates 20 Years

It's hard to believe but this year marks the 20th Anniversary of NARCOMS data collection and the 5th year of *NARCOMS Now*! You may have noticed we're celebrating by rolling out Tweets and posts on Instagram using the hashtags: #NARCOMS20years #NARCOMSfacts. If you are one of the individuals who has participated in NARCOMS for 20 years, we can't express significant gratitude for the contributions you have made to MS research.

Any and all surveys you have completed as a NARCOMS participant is so valuable to the body of data used to conduct the latest MS research. Thank you! Look to our Summer issue to learn more about the 20th anniversary of research at NARCOMS, and the 30th anniversary of the Consortium of Multiple Sclerosis Centers (CMSC).



NARCOMS Now

2016 Cover Art Contest!

This year marks the 20th Anniversary NARCOMS data collection and the 5th year of *NARCOMS Now*!

We want to celebrate by including YOUR art on the 2016 NARCOMS Now covers for Spring, Summer, and Fall!

To submit your original artwork, email a high resolution photo to: msregistry@narcoms.org

One piece will be featured on each remaining cover for 2016 and all submissions will be shown online at www.narcoms.org/narcomsnow



The artist allowed NARCOMS to reimagine the original painting, as seen above, to convey a sense of renewal for our spring cover.

Spring 2016 Cover Image: Hare by the Roots
Artist: Debbie Casteel

NARCOMS and Comorbidities Research

Since the start of NARCOMS enrollment in 1996, NARCOMS has asked about other diseases and conditions in an attempt to understand if and how they may be related to MS. In the recently published “A systematic review of the incidence and prevalence of comorbidity in multiple sclerosis” (also see Feature Focus page 4), six NARCOMS research papers were cited as contributing to the current understanding about MS and comorbidities. These papers talked about visual disorders, diabetes, and vascular disease (see next page). NARCOMS has also contributed research in other conditions and the relationship of these conditions to MS.

One of the first research papers from NARCOMS published in 2002 noted differences in treatment of depression depending upon location of treatment for veterans. Numerous other research projects have followed. Most of these projects have considered comorbidities in some way. Below are some of the highlights of these publications as NARCOMS celebrates 20 years of patient-centered research in 2016– thanks to your contributions.

A History of NARCOMS Publications

1996	→	NARCOMS begins data collection
1999	→	The first publication about the registry The NARCOMS Patient Registry: A Resource for Investigators
2000	→	NARCOMS begins longitudinal follow up with the first update in Spring 2000
2002	→	Disability and treatment patterns of MS patients in United States: a comparison of veterans and nonveterans
2008	→	Use of single screening question from NARCOMS to detect severe depression in MS → Comorbidity, socioeconomic status, and multiple sclerosis → Fatigue characteristics in multiple sclerosis: NARCOMS survey → Comorbidity delays diagnosis and increases disability at diagnosis in MS
2009	→	Effect of physical comorbidities on risk of depression in MS
2010	→	The under treatment of overactive bladder symptoms in MS: An ancillary analysis of the NARCOMS patient registry → Vascular comorbidity is associated with more rapid disability progression in MS
2011	→	Cumulative Impact of Comorbidity on Quality of Life in MS → Smokers with MS are more likely to report comorbid autoimmune diseases → Association between comorbidity and clinical characteristics of MS → Substantial adverse association of visual and vascular comorbidities on visual disability in MS
2012	→	Substantial burden of dizziness in MS
2013	→	"Seeing" in NARCOMS: A look at vision-related quality of life in the NARCOMS registry
2015	→	Causes of death among persons with MS

For links to freely available results from these papers visit: www.narcoms.org/narcomsnow

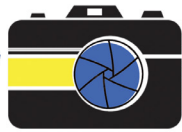
So what did the systematic review find?

- The five most common comorbidities in MS were: depression, anxiety, hypertension (high blood pressure), hypercholesterolemia (high cholesterol) and chronic lung disease.
- Thyroid disease and psoriasis were the most common autoimmune diseases.

How did NARCOMS research contribute to the systematic review?

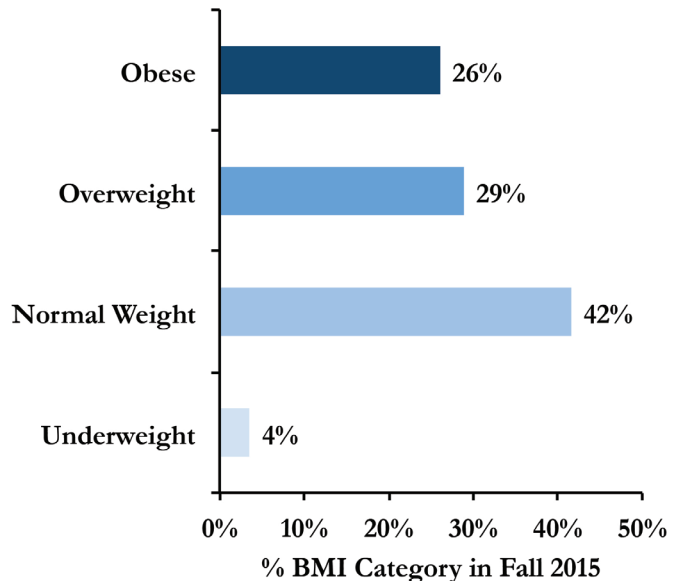
Paper Title	Conclusions from the Research
Comorbidity delays diagnosis and increases disability at diagnosis in MS	In general: It takes longer to diagnosis MS if you already have another health condition. Persons with comorbidities have more disability at the time MS is diagnosed than those who do not. Cited in the review: As foundational research for the review.
Association between comorbidity and clinical characteristics of MS	In general: Comorbidity is frequently present at onset of MS and is associated with differences in clinical characteristics. Cited in the review: Provided estimation of rates of diabetes, cataracts and glaucoma in a self-reported MS population.
Substantial adverse association with visual and vascular comorbidities on visual disability in MS	In general: Visual and vascular comorbidities are associated with worsening of visual disability. Cited in the review: As foundational research for the comparison of “peripheral vascular disease in the MS and general populations” and visual comorbidities being “associated with greater vision associated disability.”
“Seeing” in NARCOMS: A Look at Vision Quality of Life in the NARCOMS Registry	In general: Visual comorbidities were associated with lower vision-related quality of life. Cited in the review: For showing that “the prevalence of cataracts and glaucoma increased with age.”
Vascular comorbidity is associated with more rapid disability progression in MS	In general: Vascular comorbidities are associated with a substantially increased risk of disability progression in MS, regardless of when the vascular disease is diagnosed. Cited in the review: As one of “several studies suggest that vascular comorbidities including hypertension, hyperlipidemia, and heart disease may adversely influence disability progression.”
Comorbidity, socioeconomic status and MS	In general: Lower incomes are associated with higher rates of comorbidities. Cited in the review: For research on hypertension, and peripheral vascular disease.
Smokers with MS are more likely to report comorbid autoimmune diseases	In general: Smokers had an increased risk of developing any autoimmune disease. Cited in the review: Showing that smoking was associated with a much higher risk of rheumatoid arthritis and uveitis (eye inflammation) and that “the risks of these diseases may reflect shared genetic susceptibility, shared environmental exposures such as smoking, or both”

An overview of the six systematic review papers can be found for free at: <http://tinyurl.com/jp662o3>. See Snapshot in the Fall 2015 Issue to see a report on other conditions reported by NARCOMS participants: <http://tinyurl.com/zwbj6rs>.

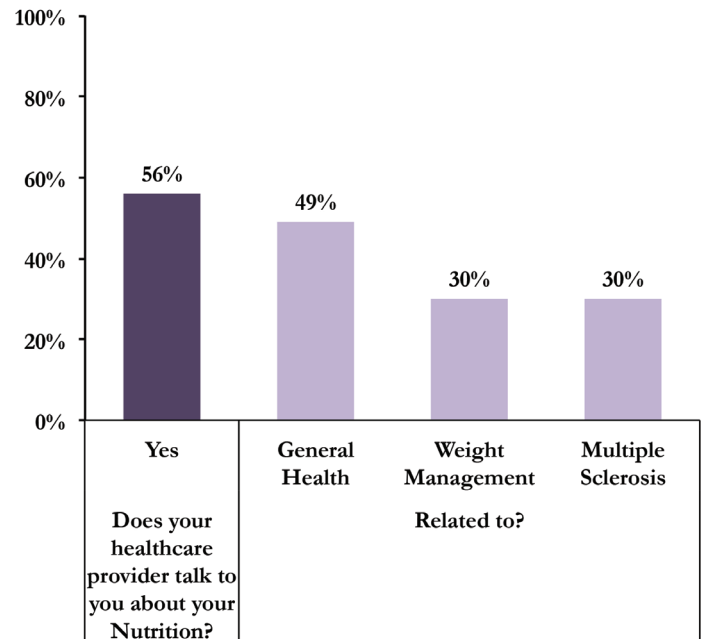
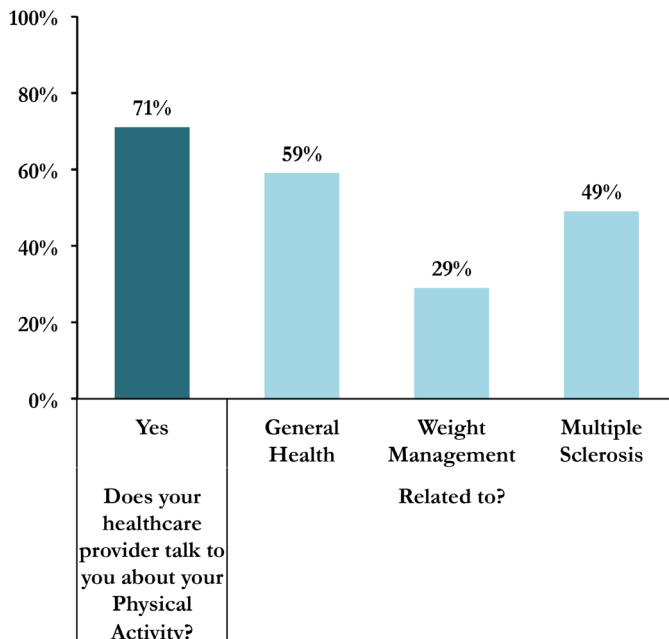


Thanks to you, Fall 2015 was another successful update survey, with over 7,600 responses! The special section focused on Nutrition and Wellness, including whether you discuss your nutrition and physical activity with your healthcare provider and what, if any, diets you have tried. In “Feature Focus”, (page 4) all of the experts agreed that “general wellness practices, such as ... healthy eating, maintaining a healthy weight ... contribute to better health outcomes.” So what does NARCOMS look like in terms of nutrition and wellness?

Healthy Weight: Body mass index (BMI) is used as a measure of body fat based on height and weight. From your responses in the Fall 2015 update, 46% of participants would be categorized as “Normal Weight” or “Underweight” with a BMI less than 25. For more on BMI and maintaining a healthy weight, talk with your healthcare provider or visit the National Heart, Lung and Blood Institute’s *Aim for a Healthy Weight* website for additional information (<http://tinyurl.com/mk7hc75>).

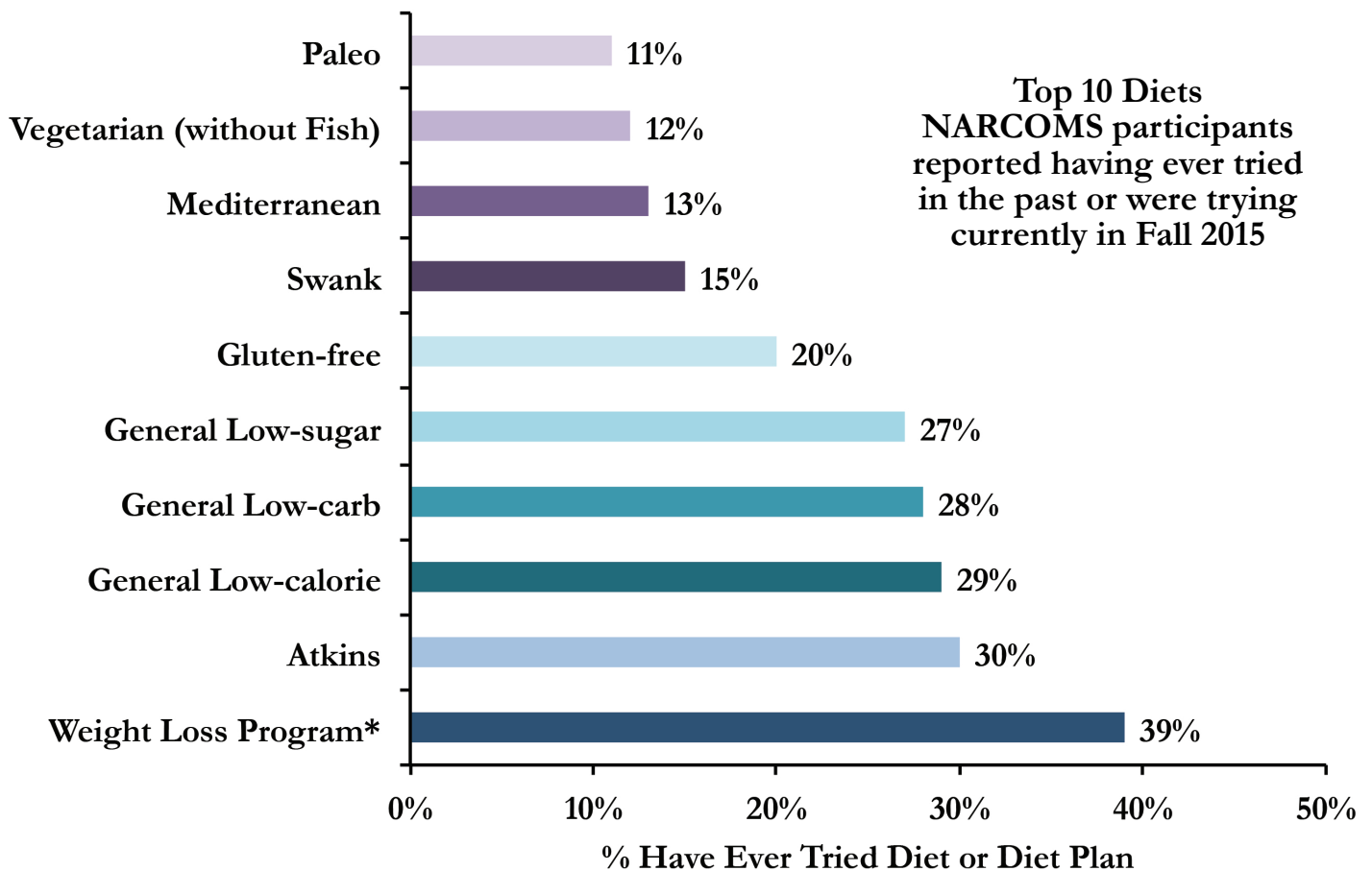


General Wellness, Diets and Nutrition: The majority of you reported that you have discussed physical activity and nutrition with your doctor or healthcare professional. The biggest reason for talking about both was General Health; talking about MS was more common when talking about Physical Activity than when discussing Nutrition.



Diets: In addition to asking you about physical activity and nutrition, we also asked you what diets you have tried in the past or might be currently following, and why. The majority of you reported that you have tried at least one of the diets listed in the past (45%), with 27% of you currently following at least 1 diet plan. Most have tried these diets for general health reasons (63%), followed by 58% for weight control, and/or 43% for reasons related to MS.

From the list of 19 diets, 39% reported having tried a “Weight loss program,” for example *Jenny Craig®, *Weight Watchers®, or *Nutrisystem®. One-third of you who currently are following a diet reported following a “General Low-sugar” plan, and the most common combination of diet plan being followed was “General Low-sugar” plus “General Low-carb” (10.1% of those following at least 2 plans currently).



More on General Wellness: If you are interested, the National MS Society has a Wellness Discussion Guide for People with MS and their Healthcare Providers, with worksheets to help prepare questions for your healthcare provider for discussion (<http://tinyurl.com/gp2h3vf>). And, for some recent research about MS & general well being, see the current issue of the *International Journal of MS Care* (<http://ijmsc.org/toc/ijmc/18/1>). As always, talk to your doctor or healthcare provider before you start any exercise program or diet.

FDA Grants “Breakthrough Therapy” Status to Ocrelizumab for PPMS



The U.S. Food and Drug Administration (FDA) on February 17, 2016 granted breakthrough therapy designation for ocrelizumab (OCREVUS—Roche) for treating people with primary progressive multiple sclerosis (PPMS).

There are currently no approved treatments for PPMS, which affects around 15 percent of MS patients.

“Roche plans to pursue marketing authorization for both PPMS and relapsing multiple sclerosis (RMS), a more common form of the disease, and will submit data from three pivotal Phase III studies to global regulatory authorities in the first half of 2016,” the company said in a statement.

Breakthrough therapy designation speeds up the development and review of medicines intended to treat serious or life-threatening diseases. Ocrelizumab is the first investigational medicine for MS to win the designation by the FDA, Roche said.

Clinical trial results released in October 2015 at theECTRIMS meeting showed ocrelizumab cut multiple sclerosis relapses by nearly half compared with the older product Rebif. Ocrelizumab also cut clinical disability by nearly a quarter in a separate study of people with PPMS.

Taste Dysfunction More Prevalent than Thought in Multiple Sclerosis

Taste is just one the five senses which can be affected by multiple sclerosis, however it may be more greatly impacted than originally believed, and may correlate with lesions on the brain. A new study from the University of Pennsylvania’s Smell and Taste Center and Department of Radiology found that the more lesions spotted on an MRI, the worse the patient’s taste function. The results were published in January 2016 in the *Journal of Neurology*.

The researchers administered a taste test for salty, sweet, bitter, and sour tastes to 73 MS patients and 73 control subjects, along with MRI of 52 regions known to be impacted by MS in both groups.

The team, led by author Richard Doty, PhD, director of Penn’s Smell and Taste Center, found that MS “significantly impacted the ability to identify tastes, especially salty and sweet,” according to a press release. A range of 15 to 32 percent of MS patients scored below the 5th percentile for controls on taste levels—a finding nearly twice as high as previous studies. In addition, taste scores were lower the higher the amount and size of lesions in the brain’s frontal and temporal lobes.

“This study represents the most comprehensive study performed to date on the influences of MS on the ability to taste,” Doty said in the release. “It appears that a sizable number of these patients exhibit taste deficits, more so than originally thought. This suggests that altered taste function, though less noticeable than changes in vision, is a relatively common feature in MS. These findings give us a better insight about that relationship, as well as the areas of the brain that are more likely to impact the dysfunction when scarred from the disease.”

The association between MS, lesions, and taste up to now had not been studied closely, nor had the correlation between taste dysfunction and nerve damage from the disease been understood.

Women outperformed men on taste measures, regardless of subject group, which mirrors what previous taste studies have found. It is likely due to the fact that women have more taste papillae and taste buds than men, the researchers note.

“Future studies investigating the relationship between taste and MS may help better diagnose and understand the disease, as well as better manage symptoms,” Doty said.

Potential Stem Cell Therapy for MS Moves into Phase-2 Trial in U.S.

A stem cell-based therapy being studied by the Tisch MS Research Center of New York (MSRCNY) as a potential treatment for MS will move into Phase 2 clinical testing following encouraging results in a Phase 1 trial. The Phase 2 study was advised by the U.S. Food and Drug Administration and is the first time a potential stem cell treatment for MS has advanced to this stage of clinical testing in the U.S.

The Phase 1 study of the treatment showed no adverse effects. The Phase 2 clinical trial will be a placebo-controlled, double-blind randomized study with 40 patients in a crossover design, in which stem cells taken from the patients’ bone marrow will be processed to become brain-like neural cells in a method developed by Tisch MSRCNY.

“Our unprecedented Phase I results have propelled us into the next phase of research,” said Saud A. Sadiq, MD, the study’s lead investigator and Tisch MSRCNY’s chief research scientist, in a center news release. “No treatment has shown reversal of established disability until now. The objective

improvement experienced in bladder function, vision and walking speed in both secondary and primary progressive MS is remarkable. We now plan to establish efficacy of stem cells as a reparative therapy in Phase II.”

Tisch MSRCNY is seeking financial support to start recruiting patients for the trial, which is expected to launch in summer 2016.

For more information on the upcoming Phase 2 clinical trial, visit Tisch MSRCNY’s Research Division’s website: <http://tinyurl.com/jdnzbpw>

Taking Vitamin D May Benefit People with Multiple Sclerosis

High doses of vitamin D3 are safe and may be beneficial for people with MS, according to study results published in *Neurology* in January 2016. “These results are exciting, as vitamin D has the potential to be an inexpensive, safe and convenient treatment for people with MS,” says study author Peter Calabresi, MD, director, Johns Hopkins Multiple Sclerosis Center and professor of neurology at Johns Hopkins University School of Medicine. “More research is needed to confirm these findings with larger groups of people and to help us understand the mechanisms for these effects, but the results are promising.”

For the pilot study, conducted by Johns Hopkins University, 40 people with relapsing-remitting MS received either 10,400 international units or 800 international units of vitamin D3 supplements per day for six months. The current recommended daily allowance of vitamin D3 is 600 international units. Blood tests at the start of the study and again at three and six months measured the amount of vitamin D in the blood and the response in the immune system’s T cells, which play a key role in MS. Patients with severe vitamin D deficiency were not included in the study.

MS NEWS

Low levels of vitamin D in the blood are tied to an increased risk of developing MS. Those with MS who have low levels of vitamin D are more likely to have greater disability and increased disease activity, according to a press release from Johns Hopkins.

Participants taking the high dose of vitamin D reached blood levels within the proposed target of 40 to 60 nanograms per millileter. Those taking the low dose did not. One person in each group, high and low doses, relapsed.

Those in the high dose group had a reduction in percentage of inflammatory T cells related to MS severity (IL-17+CD4 and CD161+CD4 cells).

“We hope that these changes in inflammatory T cell responses translate to a reduced severity of disease,” says Calabresi. “Other clinical trials are underway to determine if that is the case.”

Additional authors on the study include Elias Sotirchos, Pavan Bhargava, Moira Baynes, Achilles Ntranos, Anne Gocke and Ellen Mowry of Johns Hopkins Medicine; Christopher Eckstein of Duke University; and Keith Van Haren and Lawrence Steinman of Stanford University.

The study was supported by the Kenneth and Claudia Silverman Family Foundation, the Montel Williams Foundation, and the National Multiple Sclerosis Society.

Clinical Trials in MS



In this issue of Clinical Trials in MS we feature two trials that use telehealth—teleconferences and phone interviews—to monitor rehabilitation in multiple sclerosis.

Examining the Effects of a Telehealth Self-management Intervention in Multiple Sclerosis

Summary: This is a clinical trial led by investigators at Case Western Reserve University, recruiting 215 individuals across 10 U.S. states, to assess whether fatigue management and physical activity interventions often provided by rehabilitation centers can be offered by telehealth.

Sponsor: A research grant from the National MS Society, supporting lead investigator Matthew Plow, MD.

Rationale: Many people report fatigue as a main disability of MS. It can be chronic and severe, interfering with patients’ ability to maintain a job

or to engage in leisure activities. Reduced physical activity, in turn, leads to a poorer physical condition and increased fatigue levels. Dr. Plow will determine if methods of fatigue management and increasing physical activity, often conducted by on-site by medical professionals or occupational and physical therapists, can be conducted remotely. The proposed study (ClinicalTrials.gov ID: NCT01572714), investigators report, will be the largest randomized controlled trial to examine the effects of a lifestyle physical activity intervention in people with MS.

Patients will be randomly assigned to one of three activity groups, with all receiving weekly support via phone conferences: an educational program combining fatigue management with physical activity; a physical activity promotion program only, or an educational and social support group.

Over the trial's 24 weeks, changes in physical activity levels will be measured as a primary outcome, while secondary outcomes will assess fatigue levels and quality of life.

Eligibility: Participants must be ages 18 to 65, with a confirmed MS diagnosis and the ability to walk 25 feet with or without a cane. People who exercise more than 90 minutes a week, who are pregnant, who have any metabolic or cardiopulmonary disease that puts them at risk in a home exercise program, or who have had four or more falls in the past six months are not eligible to take part in the trial.

Participants must live in one of the following states: Wisconsin, West Virginia, Pennsylvania, Ohio, New York, New Jersey, Michigan, Kentucky, Indiana or Illinois.

Contact: Meghan Golding, Meghan.Golding@UHhospitals.org or (216) 368-0643. More information is also available through a National MS Society brochure.

Physical Activity in Multiple Sclerosis (MS): A Novel Approach to Study Outcomes (PHYSACTINMS)

ClinicalTrials.gov ID: NCT01572714

Sponsor: Kessler Foundation

Collaborator: University of Illinois at Urbana-Champaign

Purpose: This clinical trial focuses on exercise intervention in MS. The proposed investigation aims to: (1) Obtain objective measures of outcomes of interest (i.e., fatigue, cognition, and participation in activities of daily living, also called ADLs") and; (2) assess certain person-specific factors (e.g., personality) and other

factors that may be influenced by physical activity and indirectly result in improved outcomes (e.g., improvement in sleep and subsequent improvement in fatigue and/or cognition).

Summary: Individuals will complete a comprehensive assessment of cognition, person-specific factors, intermediary factors, physical fitness, and functional magnetic resonance imaging (fMRI) prior to and following a home-based exercise intervention.

The intervention will consist of strength training and stretching at home. Participants will be provided with elastic bands and weighted vests, and will complete a weekly log book. The study spans a four-month period.

Eligibility: Men and women ages 18-64 years with a diagnosis of MS, able to walk independently without the use of assistive devices (e.g. cane, walker, wheelchair). Must be physically able to receive regular MRI.

Exclusions: Left handedness; presence of a cardiac pace-maker, cochlear implants, or metal fragments/pieces in body; significant alcohol or drug abuse history; history of schizophrenia, bipolar disorder, or other significant psychiatric illness; history of stroke, brain injury, or neurological disease other than MS; pregnancy. Must not have had evidence of a flare-up of MS symptoms within the past month, nor administration of the following in the last month: steroids, benzodiazepines, neuroleptics or opiates (as determined by study doctor).

Contact: Angela Smith, MA, asmith@kesslerfoundation.org; (973) 324-8448 or Lauren Strober, PhD, lstrober@kesslerfoundation.org; (973) 324-8459.

play

Find the following hidden words:

Grass, growth, sunshine, renewal, earth, blossoms, green, flowers, birds, buds, sky, clouds, warmth, gardens, breeze, relaxation

Q	P	Q	E	N	C	L	K	W	P	P	O	O	Q	X	O
K	O	K	N	R	B	B	L	X	T	N	Y	V	T	Y	T
H	V	E	I	N	R	U	I	X	D	K	U	K	R	N	W
J	E	E	H	Q	O	M	D	R	S	S	D	U	O	L	C
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L	Y	H	T	A	L	V	U	M	R	W	A	V	C	F	S
A	U	M	O	D	G	F	V	S	W	R	E	C	U	X	V

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:

www.narcoms.org/narcomsnow/play/answers

FACES of NARCOMS

“MS, My Body, and Me”

It was 1974 and I was suffering from health issues I did not understand. It seemed my body was being physically attacked by some outside force and there was nothing I could do to stop it. I was experiencing symptoms like walking off balance, numbness in different parts of my body, problems with urination, and shocks up and down my spine. I visited my family physician who told me that I had Multiple Sclerosis. I walked out of his office in shock. What was MS? I had never heard of it.

After the initial shock, I set off on a quest to find the help I would need to deal with this disease. Not only was I searching for someone to help with the physical symptoms but also the emotional ones. Searching for a doctor was an experience itself. The first doctor, who diagnosed me, decided with my family doctor to give me ACTH injections three times a week. [Note: approved in 1978 by FDA as a treatment for relapse] but my symptoms just seemed to be getting worse. I saw a neurologist who told me, “You should keep working as long as you can because eventually you will end up in a wheelchair.” What bedside manner! Walking out of his office, I half-considered walking in front of an oncoming bus. I was 22 years old and this doctor just told me my life was over.

I was angry, upset and frustrated and did not know what to do. There were no medications for MS at this time except for ACTH and steroids. My thoughts were of my future and the journey I was going to take with this disease, and I must say, they did not seem promising.

My body kept telling me to keep searching for answers and not give up, and I knew it was right. I couldn't just give up—I had to find someone to help. Luckily I was not embarrassed or ashamed to tell people about the MS. A chance encounter with a woman in a client's office led me to see a new neurologist. He told me about treatments he was doing on MS patients. He said they did not work all the time, but I had good chance of success, because I was young. I took the treatments and they helped immediately. All of my symptoms were under control and stayed that way for some 35 years. I then found another doctor who started me on interferon which I have been on for 15 years.

I have suffered with symptoms for the last 40–50 years, but for the most part have been stable. I now live in Florida with my wife, have a wonderful MS neurologist as my physician, and my body and I still live to fight another day.

—Melville F. - New Port Richey, FL

Did you know? Now, in addition to emailing us at narcomsnow@narcoms.org, you can complete a submission to “Faces to NARCOMS” using our online form.

Check it out: www.narcoms.org/narcomsnow/faces-of-narcoms

*NARCOMS Now note: Not all medications will work the same for everyone.
Please consult your physician about how to treat your symptoms.*

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