In Tune With MS
Congratulations to NARCOMS Now Photo Contest
Summer 2014 Winner
Joe M. — Columbus, OH

“The Beat Goes On”

What does the photo represent in your “MS Life”? 
“Live your passion.”

— Joe M.
Letter from the Director: Summer’s Here with Country Music All-Stars

NARCOMS Info Corner

Feature Focus: Musicians Julie Roberts and Clay Walker

Survey 101: MS and Marijuana - A New Survey

MS Reflections: Complementary and Alternative Medicine (CAM)

NARCOMS Messenger: World MS Day 2014 & NN Photo Contest

NARCOMS Snapshot: Early MS Symptoms

MS News: Medical Marijuana & MS, Birth Control Pills & Obesity

Q&A: NARCOMS results & “Old” Language on Surveys

New MS Apps & Blogs Feature

Play: Find the following words...

Faces of NARCOMS: Balancing the Tilt

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Hello,

Welcome to the Summer 2014 edition of NARCOMS Now.

It is our pleasure to share with you in this issue our conversations with two country music stars who live, work, and thrive with multiple sclerosis. Julie Roberts is an up-and-comer who recently signed the first record deal in 40 years with Sun Records, the Nashville-based label that played home to such stars as Roy Orbison, Neil Young, and Elvis Presley. Roberts shares her candid story about how she survived an epic flood and a diagnosis of MS, forging ahead in her music career to release her latest album, “Good Wine and Bad Decisions.”

Clay Walker is a multi-platinum country singer who graces the stage at the annual joint meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS). We got the chance to talk with him prior to the conference and his concert, about his life with MS and his non-profit organization, Band Against MS.

Also in this issue’s “MS Reflections,” I’ve summarized the American Academy of Neurology’s (AAN) new guidelines on complementary and alternative medicines for the treatment of MS. As more and more individuals are considering the use of these various therapies—ranging from medical marijuana to acupuncture and beyond—clinicians need a guideline to help determine whether and how to work them into patients’ treatment regimens.

“MS News” of late includes the AAN’s guidelines on the use of marijuana to treat some MS symptoms. Also of note, drug-maker Genzyme announced it will resubmit its application to the U.S. Food and Drug Administration for its once-a-year drug to treat multiple sclerosis, Lemtrada (alemtuzumab).

Finally, our third NARCOMS Now photo contest winner of the year is featured inside the magazine’s front cover. The Fall 2014 issue will be our final issue to include the photos, so please submit your “MS life” story in pictures. For details see page 14.

Enjoy your start to summer, and look forward to articles and coverage of the CMSC/ACTRIMS meeting in our next issue.

Sincerely,

Robert Fox
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
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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.

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Go to: www.narcoms.org
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Choose the survey you would like to view from the drop down menus and click the View Summary link. Print like you would any document.

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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!
Like many living with multiple sclerosis, singer-songwriter Julie Roberts did not know much about MS prior to her own diagnosis in 2006. It was her early memories of volunteering in a nursing home—and a resident named Carol—that she recalled upon hearing her doctor utter the two words that would change her life.

“When I was first diagnosed Carol was the first person I thought of,” Roberts recalls. “I thought, ‘I met her for a reason, and we connected for a reason—now I know why.’”

Roberts says she has always loved playing music and singing, which she did regularly at a nursing home in her hometown of Lancaster, South Carolina. One resident named Carol, she recalls, seemed rather young to be living in an assisted living facility.

“Carol was in a wheelchair and she was really young,” Roberts says. “She’d always come in the room when I’d sing country and gospel music, and she’d always ask me to sing, ‘What Part of No’ by Lorrie Morgan. I connected with her; she was so happy and so excited for me to sing that one song for her. I asked my mama, ‘Mama why is she in a nursing home, she’s so young?’ Mama finally asked, and Carol said she had MS.”

When Roberts, who is 35, learned she had the same disease decades later, Carol came to mind.

“Carol was my only introduction to MS at that time, Roberts says. “This is a part of my path and I hope God uses me to help people like I did Carol. It kind of makes me tear up to talk about—it’s like coming full circle.”
Roberts is the beautiful blue-eyed, blonde-haired country music singer whose debut single “Break Down Here” was a Top 20 hit on the Billboard Hot Country Singles and Tracks (now “Hot Country Songs”). It was the first track from her self-titled debut album.

Her second album, Men & Mascara, followed in 2006. In 2013 Roberts signed with Sun Records, a Nashville label known for producing albums for such legendary stars as Johnny Cash and Elvis Presley. Her first single from the album, “Good Wine and Bad Decisions,” was released October 29, 2013, and was the label’s first full release in 40 years. But like any good country music ballad, Roberts’ story hit some bumps along the road to success.

Road To Stardom

Roberts says she always knew she wanted to become a country music star. From the time she was little, she and her two sisters would sing in church and at events like pageants around town. “They didn’t like it as much as I did,” she says. “Mama would tell you I used to say I wanted to be Barbara Mandrell when I grew up.”

Roberts says she modeled her education and early career after Trisha Yearwood, another of her favorite country singers. She, like Yearwood, moved to Nashville, Tennessee, to study the music business at Belmont University. As a student in America’s country music capitol, Roberts performed in local clubs and restaurants. When she graduated she took a job as an intern and then a receptionist at Mercury Nashville Records. While there, she recorded a demo tape with producer Brent Rowan.

“If you work for a record label and you’re a singer, you work on your stuff after hours, which is what we did,” she says. After playing Roberts’ demo around town, Rowan asked her if he could take it to their boss, label head Luke Lewis. “I said, ‘Only if you don’t tell him it’s me.’ Brent took it into Luke’s office and I could hear it playing through the walls. Then I heard it playing again.”

Ultimately Roberts signed on with Universal Group Nashville’s Mercury Nashville division.

Onset of MS

It was between the release of her first and second albums, in 2004 and 2006, respectively, that Roberts began noticing odd physical symptoms. She was living her dream, traveling and playing shows nearly every night. During a show one night Roberts’ hands went numb as she held the microphone.

“My hands just quit, and my vision was getting blurry,” she says. “I’d be signing [autographs] at the merchandise table and of course I knew how to write my name, but my vision was so blurry I couldn’t see what I was writing. I never let on what was going on.”

It took feeling a sensation “like a shock going through my spine” to send Roberts to the doctor (a symptom known to MS patients as Lhermitte’s sign). He referred her to a neurologist, who scheduled her for an MRI and spinal tap. When her doctor called back with the results, Roberts purposely did not answer. Instead she asked her mother to call the doctor for her.
“I really was afraid for the worst. I remember where I was when she called me, driving on I-65 north from south of Franklin, Tennessee, back to where we lived. She called and said, ‘You don’t have a brain tumor but they’ve diagnosed you with MS.’ The first person I thought about was Carol.”

Roberts went in to see her doctor and was handed a stack of literature on MS, a disease she knew little about. At first, she maintained her life and schedule as she always had, working in annual MRIs with her neurologist, which showed limited change. Exercise—which was also a fairly new addition to her lifestyle, helped her maintain the energy she needed to perform, she says.

“When I got my record deal they put me into exercise boot camp. It taught me how to exercise and I came to love it, and do it every day. It’s like an escape for me.”

Then Came The Flood

With her MS seemingly under control and her career on an upswing, Roberts soon had to learn to cope through another major life event. On May 2, 2010, heavy rains caused unprecedented flooding in the city of Nashville. The townhome Roberts shared with her mother, her sister, and their four dogs was overtaken with water, as were their cars. The family had to sit and wait, watching the water rise, to be rescued by boat.

“It totally changed my perspective in life to see that things you take for granted can be taken away from you just like that,” she says.

“Who would ever think that the little creek that runs behind your condo complex would rise up. Everybody around us lost their homes and nobody had flood insurance. You learn how your family and those closest to you really are all that is important in those moments.”

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“She is so inspiring,” Roberts says of Unruh. “She has had MS for a long time but has lived an awesome life and had all of her dreams come true. It was just inspiring to see someone who is so strong. She’s now on the National MS Society Board of Directors. She just never gave in. I love that. I want to be like Jeannie is to me for other people, when they’re first diagnosed or just living with MS.”

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Roberts continues to exercise and combines that love with fundraising for MS awareness by taking part in MS walks. Earlier this year she completed a 50-mile fundraising walk with her mom in Charleston, South Carolina. By sticking with her health regimen and keeping family close, she says, Roberts is feeling great.

“Sleep is just good in general, but for me—Mama has said since I’ve been little that I need a lot of sleep,” she says. “Also, just trying to be happy and not being stressed—being positive and expecting the best helps. I read books about positive thinking, and also my faith helps me a lot. And family—Mama and I are very close, we live together; we’ve always been very close. She’s my other half.” Roberts’ latest album, “Good Wine & Bad Decisions” is available online her website, julieroberts.com.
Musician Clay Walker is a multi-platinum country music star who has been living—and performing—with MS since 1996.

Walker will entertain the crowd at this year’s CMSC/ACTRIMS conference with a concert, as he has done for many years.

NARCOMS Now had the chance to talk with Walker about his life with MS.

How many years have you been performing at the CMSC conferences?

I probably couldn’t count them all. The reason I do it is to keep me involved with patients who have MS, but I also like being around nurses and doctors and other people who really know what’s going on, so I can share pertinent information.

My job is performing. My first job is staying healthy. I feel pretty blessed that I’ve been able to do that. If you had asked me 18 years ago when I was diagnosed if I thought I’d be walking, I would have said no. The first doctor who diagnosed me gave me a grim outlook. That really shocked me into learning what MS was.

You were diagnosed in 1996—did you tell friends and family about the diagnosis right away?

It took me a while to tell—I didn’t really know how I was going to deal with it. When I was diagnosed there weren’t very many medications at that time. None of them were really proven all that effective. Fortunately when I met Dr. Jerry Wolinsky [Walker’s neurologist] he got me started on a different medication than what I was on in the beginning. For 16 years I’ve been on one single medication—and have had no relapses in 16 years. I take the medication just three times a week—it’s much easier now than it was before.

What made you decide to start your nonprofit organization “Band Against MS” in 2003?

For people who’ve done well there has to be the expectation to give back and to do what we can. The charity I started has evolved over the past 10 or so years into a very helpful tool, I believe, for a lot of people who have MS. What we don’t know, we try to direct people through our website, to places where they can find information (www.bandagainstms.org).
Tell us what you know about NARCOMS, and why it’s important for people to participate?

I know you collect data and information from people who have MS, and that patients sharing this information is important. We want people to know what is the best way to find out how to treat or manage MS. If nobody knows what causes MS and nobody knows the cure for MS, who’s to say it’s not lying in the midst of all of us who are living with it?

What messages would you share with those living with MS or those who know and love someone living with MS?

It’s a very personal disease. Formulating a game plan with a neurologist who you trust and very expressing yourself to that neurologist is really important—they can get a feel for what’s going to work for you and what you’re going to stick with. People are creatures of habit and a lot of us are lazy! So you know somebody who doesn’t exercise at all, a one-hour-a-day, five-times-a-week exercise program isn’t going to be something they’re jumping for joy to do. It is important to formulate a plan that is achievable and attainable—especially if you’re going to take one of the conventional therapies out there. It becomes a very personal decision—you have to be sure it’s something you feel like you can stick with. It’s important to take that step and not procrastinate about it, even if you’re doing fine. You’ve got to stay committed.

There’s no way that I would have the kind of health that I have right now if I was not able to formulate that game plan with my neurologist and stick with it. No way—whether it’s riding horses, playing golf, or having three kids under the age of 5!
MS and Marijuana – a New Survey in August!

As reports of the use of marijuana for medical purposes rise (see side bar), researchers are increasingly interested in how patients are using marijuana’s main therapeutic component, cannabidiols, to treat symptoms of MS. In fact, the American Academy of Neurology (AAN) just released their report on guidelines for MS and marijuana (you can read more in “MS News” on page 16). In Great Britain a medication called Sativex is now approved to alleviate MS symptoms, and some states in the U.S. allow for medical marijuana use. Many NARCOMS participants have asked us why NARCOMS does not ask about marijuana use, so in August we will, with a new survey.

Because this survey asks about use of a drug that is not legal everywhere, we understand that you might be uncomfortable if the answers were in any way linked to your NARCOMS information, so they won’t be—this short survey will be completely anonymous. It has only 25 questions and will not collect any personal or identifying information about you.

Recent Headlines:

- AAN finds that medical marijuana may alleviate certain MS symptoms
- The Boston Globe reports marijuana can alleviate MS symptoms
- The Calgary Herald reports studies find marijuana lessens painful spasms of multiple sclerosis
- Reuters reports Britain approves GW Pharma’s cannabis drug Sativex for MS
- The Daily News reports that Marijuana-based drug

Have an idea for Survey 101?

If you have any questions about how these updated survey questions apply to you, don’t hesitate to call us at 1-800-253-7884.
How Will I Get the Survey?

This online survey will be conducted separately from the regular Fall update, outside of the NARCOMS data collection website.

- Online participants will receive an email with a link to answer the questions.
- Other registry participants will get a postcard in the mail with the link to type into an internet browser. We apologize but you will not be able to complete this survey on paper.

What Kinds of Questions Will Be on the Survey?

There will be three sets of questions on this survey:

1. Questions about marijuana: Whether you have ever used it, if you have used it specifically for your MS, and if you think it should be legal in the United States for treatment of MS.

2. Questions about other health-related habits like cigarette smoking and alcohol consumption. These questions will help us better understand your overall health habits to compare to the population in the U.S.

3. Questions about you and your MS status. Because the survey is totally anonymous, you will be asked to answer a few questions that you may have recently answered in the NARCOMS Update Survey such as: age, gender, and current PDDS score. We appreciate you taking the time to answer those few questions again.

How Long Will the Survey Be Available?

The survey will be open for the entire month of August and will close Friday, August 29th. Look for your email or postcard in early August! We look forward to your opinions on this topic, and thanks for contributing to this survey and all NARCOMS research.
CAM Guidelines For MS
By Dr. Robert J. Fox, MD, FAAN, Director of NARCOMS

The American Academy of Neurology (AAN) (www.aan.com) in March published a new guideline for the use of complementary and alternative medicine (CAM) for Multiple Sclerosis. The AAN is an association of neurologists and neuroscientists dedicated to promoting high-quality care for people with nervous system disorders. The organization stated it felt a need for evidence-based guidelines for CAM therapies to treat MS and its symptoms because their use has become increasingly prevalent.

What is Complementary and Alternative Medicine?

CAM refers to health care options developed outside of conventional, mainstream medicine.

CAM therapies can range from various forms of exercise, to mindfulness meditation, to marijuana, to acupuncture, to name a few. Complementary medicine generally refers to using a nonmainstream approach along with conventional medicine—it “complements” traditional therapies. Alternative medicine refers to using nonmainstream approaches in place of conventional medicine. Most CAM therapies are not FDA regulated, so their purity and quality can vary significantly.

Why Develop Guidelines for CAM in MS?

MS currently has no cure, and often causes uncomfortable symptoms that can be a challenge to manage. Research shows many people look to CAM therapies to treat MS and its symptoms: up to 80% of people with MS report the use of CAM therapy. With so many of their patients using CAM therapies, clinicians need to understand the evidence supporting their use.

Table 1. Evidence of CAM Benefit
What Did the AAN Experts Find About CAM Treatments in MS?

The AAN panel found evidence to support the effectiveness of cannabinoids against some MS symptoms, including spasticity and pain from spasticity. Cannabinoids are a group of chemicals related to the active ingredient in cannabis (marijuana). They also found that ginkgo biloba, reflexology, and magnetic therapy may be effective against fatigue and paresthesias (a “pins and needles” sensation). They found that several CAM therapies are either possibly or probably ineffective for treating MS disease activity and a variety of MS symptoms (Table 1). Twenty-two therapies had insufficient evidence to determine whether they were effective or not (Table 2).

(For the full text of the article, visit: neurology.org/content/82/12/1083.full).

What Does This Mean for People With MS?

People with chronic diseases like MS, which has no cure, are often attracted to CAM therapies to treat the disease or relieve symptoms. CAM treatments range widely in effectiveness, cost, and intrusion—from exercise regimens, to diets—to invasive surgical procedures. Some approaches may be relatively harmless, but others may have side effects, significant risks, steep financial costs, or interact dangerously with conventional medications. When considering the use of any CAM therapy, always ask your clinician first.
Celebrate World MS Day 2014

All around the world on Wednesday, May 28, it’s World MS Day! NARCOMS will be celebrating by capturing images of attendees at the Consortium of Multiple Sclerosis Centers/Americas Committee for Treatment and Research in Multiple Sclerosis (CMSC/ACTRIMS) annual meeting in Dallas.

Look for us at booth #127. On World MS Day we’ll be taking photos of folks describing their “MS Life” and Tweeting them @NARCOMS. For a full list of events taking place around World MS Day and a fantastic blog about folks around the world living with MS, visit their website, www.worldmsday.org.

NARCOMS Now Photo Contest Continues!

Thank you to everyone who continues to submit fantastic photos for our “Living with MS” contest! You’ll see this issue’s contest winner featured in the inside front cover of the magazine. The contest continues online, where you can vote for a winner and submit a photo of your own. Visit www.narcoms.org/narcomsnow/photocontest for guidelines, and feel free to email us your entry at: narcomsnow@narcoms.org. Fall 2014 will be our final issue of the year featuring the Photo Entries, so send in your image today!

Dr. Sanjay Gupta Follows @NARCOMS

On April 23, 2014, Dr. Robert Fox, Managing Director of NARCOMS, conducted a live Twitter chat with CNN Medical Correspondent Dr. Sanjay Gupta, a staff neurosurgeon at Emory University, on the topic of “Living Well with Multiple Sclerosis,” on @EverydayHealth. During the discussion, Dr. Fox mentioned NARCOMS (see image) and shortly thereafter Dr. Gupta became our 200th follower! You can read the full text of the chat on the EverydayHealth website. And tell your friends, caregivers, family, and colleagues to follow @NARCOMS on Twitter today!
Every person living with MS has a unique story but there are some common threads that tie each together. One of those threads is the onset of MS symptoms, including the age at which they start, and what symptoms people notice first. Singer Julie Roberts describes her first MS symptoms as numbness and vision loss (“Feature Focus,” page 4) and these are two of the most common symptoms, along with walking and balance issues.

In 2008 NARCOMS began asking new participants about their first symptoms. Since then, over 5,000 participants have completed these questions. Like Julie Roberts, the most common initial symptom reported by NARCOMS participants is numbness, followed by walking and/or balance issues. Weakness in the arms or legs, and blurry or double vision are also common. About 50% of participants report feeling these symptoms for the first time between the ages of 23 and 39 years old.

**Percent Reporting (%)**
Medical Marijuana Pills and Sprays Can Ease MS Symptoms, AAN Says

Marijuana pills and sprays may help ease spasticity and pain that can come with MS, according to a new guideline released by the Academy of American Neurology and published in its journal, Neurology. The guideline investigated complementary or alternative medicine therapies (CAM) used alongside or instead of doctor-recommended therapies to treat MS, epilepsy, and movement disorders. Read the full content of the AAN report here: goo.gl/DwDK2Q.

“This review by the world’s largest association for neurologists is intended to help neurologists and their patients understand the current research on medical marijuana for the treatment of certain brain diseases,” said review author Barbara S. Koppel, MD, of New York Medical College and Fellow of the American Academy of Neurology. “The AAN review also highlights the need for more high-quality studies of the long-term efficacy and safety of medical marijuana in the treatment of neurologic diseases.”

The AAN review concluded that certain forms of medical marijuana (in pill or oral spray form) can help treat some symptoms of MS. These include spasticity, certain types of pain (related to spasticity, including painful spasms, and painful burning and numbness) and overactive bladder.

A review by the American Academy of Neurology of available scientific research on the use of medical marijuana in brain diseases finds certain forms of medical marijuana can help treat some symptoms of multiple sclerosis (MS), but do not appear to be helpful in treating drug-induced (levodopa) movements in Parkinson’s disease. Not enough evidence was found to show if medical marijuana is helpful in treating motor problems in Huntington’s disease, tics in Tourette syndrome, cervical dystonia and seizures in epilepsy.

Neurology Now, a publication of the AAN, included an extensive article on the topic in its April/May issue, entitled, “New Guideline for Alternative and Complementary Medicine for Multiple Sclerosis.” Go to goo.gl/veNE0w to read the article in full.

Use of Birth Control Pills; Obesity May Increase Risk of MS

Findings presented at the American Academy of Neurology’s 66th Annual Meeting in Philadelphia, PA, in late April show that two new studies suggest the “obesity hormone” leptin, and hormones used in birth control pills may increase the risk of MS.

For the first study, Dr. Jorge Correale, of the Raúl Carrera Institute for Neurological Research in Buenos Aires, Argentina, and colleagues analyzed the body mass index (BMI) of 420 individuals aged 15 or 20 years. Of these participants, 210 had MS at the study’s outset while the other 210 did not.

The investigators found that participants who were obese at age 20 were twice as likely to develop MS later in life, compared with individuals of the same age who were not obese.

The study results also revealed that participants who had a high BMI also had high levels of leptin in their blood. Leptin is a protein produced by fatty tissue that regulates fat storage in the body, as well as appetite and immune response.
Because leptin promotes inflammatory responses in the body, this could explain the association between obesity and MS, says Correale.

For the second study, researchers from Kaiser Permanente Southern California analyzed 305 women who had been diagnosed with MS or clinically isolated syndrome—a precursor to the disease.

All women were members of Kaiser Permanente Southern California 3 years prior to the development of MS symptoms. The women were assessed for their use of birth control pills and were compared with 3,050 women who were free of MS.

In the 3 years before MS symptoms began, 29% of women with MS had used hormonal contraceptives for at least 3 months, while 24% of women without MS had used birth control pills. Most of the women took pills that were a combination of estrogen and progestin.

The results of the study revealed that women who used birth control pills were 35% more likely to develop MS, compared with women who did not use them. Women who had stopped using hormonal contraceptives 1 month before MS symptoms began were 50% more likely to develop the disease. “These findings suggest that using hormonal contraceptives may be contributing at least in part to the rise in the rate of MS among women,” says Dr. Kerstin Hellwig.

Genzyme to Resubmit Lemtrada Application to FDA

Genzyme announced in April plans to resubmit its application to the U.S. Food and Drug Administration for its once-a-year drug to treat multiple sclerosis, Lemtrada (alemtuzumab). Lemtrada is approved for use in Europe, Canada, and Australia. The FDA rejected approval of Lemtrada on Dec. 27, 2013, due to disagreements over the design of the trial.

Genzyme claimed the rejection was due in part to the fact that the trials of 1,600 patients compared Lemtrada to EMD Serono’s drug, Rebif, but blinded the doctors who rated the effectiveness of the drugs, rather than the patients themselves.

Genzyme said it did this because patients would likely notice if they were given Rebif, which is taken three times a week, versus Lemtrada, taken once annually.

Patients showed strong support for Lemtrada and Genzyme in the wake of the December 2013 decision. One patient, Melissa Burdick, filed a citizen’s petition on Genzyme’s behalf in support of the drug’s approval.

Genzyme is a Cambridge, MA–based biotech firm and a subsidiary of French drug giant Sanofi.

The company vowed to appeal the decision, but said that “following constructive discussions” with the FDA, it plans to resubmit the application instead, with additional data requested by the agency.

“In light of the planned resubmission, the company does not expect to pursue an appeal at this time,” the company said in a statement.
Q: Where can I find results of the NARCOMS update surveys?

A: What a great question! One of our goals in NARCOMS is to provide the participants (that’s you!) with timely results. After data collection has closed, it can take over a year to complete the analysis of the data and publish the results in a scientific journal.

Since we know these results are important to you and the MS community, we aim to provide summary results more quickly in NARCOMS Now:

» In every issue:
  • Current registry information in Snapshot (Page 15).

» In some issues:
  • Recent published research project in MS News. The Spring 2014 issue reported on a Health Literacy project: tinyurl.com/lmlhnga
  • More detailed interviews or research results in Feature Focus or MS Reflections, such as “Dizziness in NARCOMS”: tinyurl.com/lan684q

» Online:
  • A listing of NARCOMS research available at www.narcoms.org/publications.

Q: Some of the words used in your questions seem outdated or even offensive. Why can’t you change them?

A: We understand that words like “disabled,” “wheelchair-bound” or “forced” may seem old-fashioned and imply that MS has control over you, instead of you being in control of your MS.

» Whenever we can, we will change these words to reflect a more contemporary understanding of MS.

» However, when the words are part of a validated question that is commonly used in research, we cannot make any changes. That would prevent accurate comparisons with previously collected answers in NARCOMS and other studies.

Thank you for understanding why seemingly simple changes are not always possible. Please continue to let us know where rewording may be needed and we will gladly make the changes we can!

If you ever have questions about the NARCOMS update surveys please call us and we will be happy to assist you: 1-800-253-7884 (toll free US).

To submit a question for Q&A please email narcomsnow@narcoms.org
Welcome to a new feature for NARCOMS Now. When we hear of an MS-related app or blog we think you, our readers, might enjoy, we’ll let you know about it here. Have a favorite app or blog that makes your “MS Life” easier? Let us know about it at narcomsnow@narcoms.org.

**Canstrument**

Canstrument is a motion-based musical instrument app that turns your Apple device into a musical instrument. It is designed to be used by anyone who wants to express themselves musically through motion. The app could be used by someone with limited motion in their arms, for example, by strapping an iPod Touch to the arm with a runner’s strap. When the individual moves his or her arm sideways, the app plays a scale across several octaves, imitating a variety of instruments.

This completely customizable app can be especially useful for individuals with disabilities that prevent them from playing traditional musical instruments. The app was designed by CanAssist, an organization at the University of Victoria that is dedicated both to helping those with disabilities improve their quality of life and to increasing awareness and knowledge of disability issues.

This free app is available for download at iTunes (goo.gl/uWHQ5b).

**Seeing MS**

The idea behind this app was to invite nine photographers to depict each of the most prevalent MS symptoms in a single image, inspired by stories of those touched by the disease.

Photo filters based on each symptom of MS allow users to see and share the effects of the disease using your own photos. This app, a project by Australia’s MS society, is available for free for iOS and Android devices. On their website, you can submit photos depicting one of the nine symptoms: blurred vision; pain; hot and cold, in which the nervous system cannot correctly perceive temperature; spasticity, which is the temporary loss of fine motor function; dizziness; fatigue; brain fog; loss of balance; and numbness. The nine best photos for each symptom as voted by the public, will be displayed in an exhibition alongside the nine photographers who started the Seeing MS project.
Find the following hidden words:
guitar, music, western, country, nashville, boots, spurs, 
cowboy, lasso, saloon, cattle, ballad, honkytonk, bandana, 
harmonica, hat

Find the answers to this word puzzle online:
www.narcoms.org/narcomsnow/play/answers
After my MS diagnosis in 2005 I bought a necklace with 3 silver circles engraved with the words “courage, strength,” and “spirit.” Of these, the concept I work hardest to maintain is spirit, defined as, “the principle of conscious life, or the vital principle in humans mediating between body and soul.”

As a native of the “Live Free or Die” state (New Hampshire), my independence is of great value to me. Consequently, I had to find a way to accept the medical aspects of this disease while developing the strength and courage to maintain the essential elements of myself and, my spirit.

I use strategies that are intended to keep balance in my life. My approach is to focus on aspects of a healthy lifestyle that include my body and mind. As a 50-year-old woman I realize that I resemble the 1967 Mustang I admired as a kid: I am still attractive in my own way and a unique “classic.” I need to keep rust at bay and feel the wind in my hair. I try to maintain equilibrium with my health while incorporating mind and spirit connections. For me this entails embracing intellectual, creative, and healthful pursuits.

Hearing that you have lesions on your brain can be horrifying. At the time of my diagnosis I was being tutored in Chinese, worked in healthcare research, and was on track to read 80+ books that year. I gain strength from reading about others, as well as listening to speakers like Desmond Tutu, Maya Angelou, and MS advocate Wendy Booker. I have managed to stay relapse free for over six years, and my recent neurology visit revealed that I have about 4 lesions. Keeping my MS stable represents a victory that validates the decisions I have made.

Another essential component of my life balance is creativity. For the past two years I have focused on developing my photography skills. I enjoy walking along the Maine coast in pursuit of the perfect sunset or chasing a butterfly toward a nearby flower. In 2005 I experienced a complete loss of sight in my right eye and numbness in both legs. The loss of eyesight, shock of the diagnosis and fatigue caused me to give up photography for the year it took to regain my sight. Now that I have it back, I realize what a gift it is to be able to walk and experience the wonders of nature. Capturing a stunning image and sharing it with others enriches and delights me.

Balance is always a challenge. Today I attended my weekly strength class. At the end of class I did experience the dizzy spell that I had feared. Instead of tilting I sat quietly, took a breath, and relaxed. The dizziness subsided and I was able to stand tall with the rest of the class—sweat and all! The trick of not tilting is to have the courage to accept that I have MS, the strength to continue to push myself, and the SPIRIT to relish each moment.

—Darlene G.