

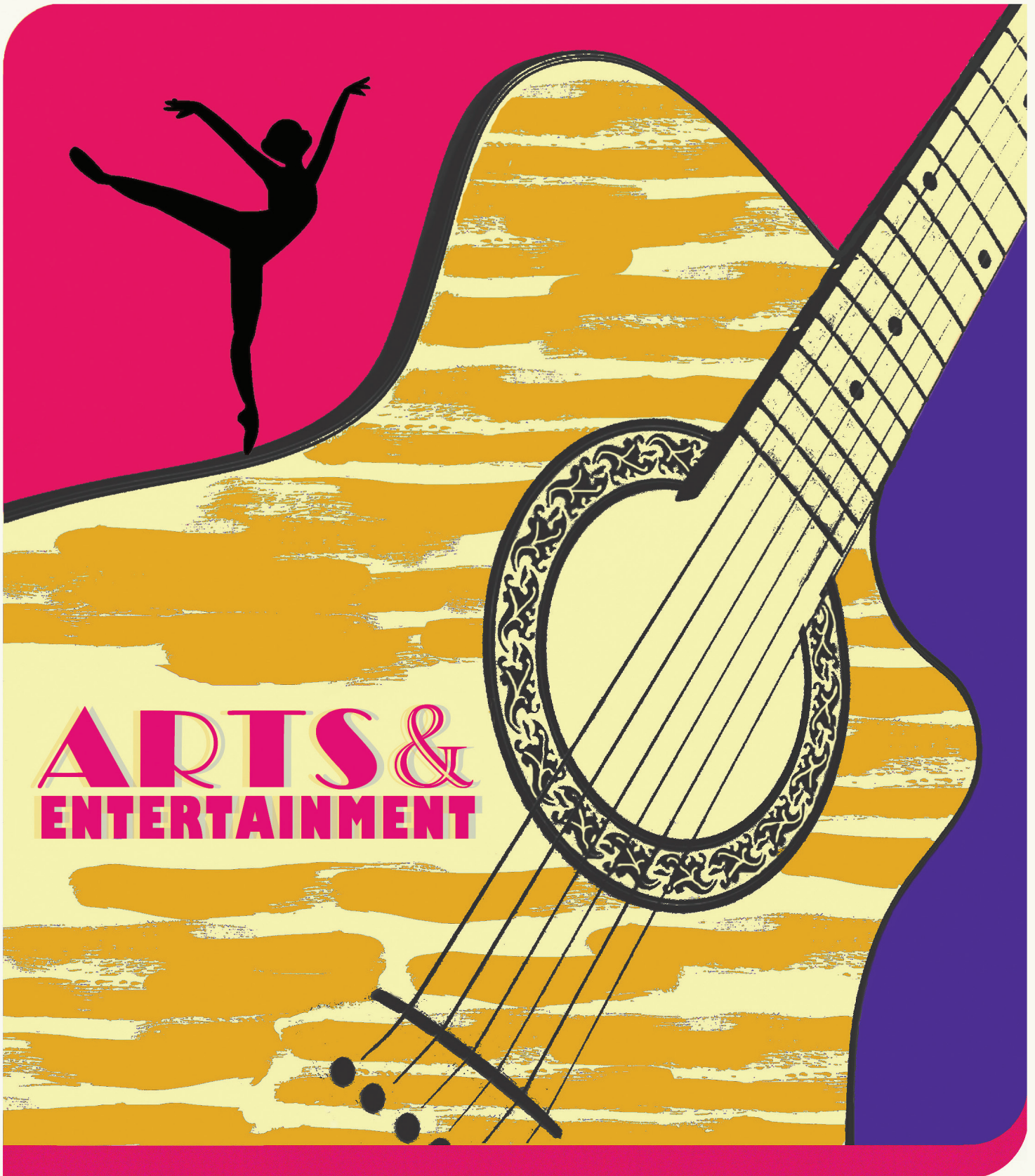
NARCOMS

SUMMER 2012

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NOW

Vol. 1, Issue 2



**ARTS &
ENTERTAINMENT**

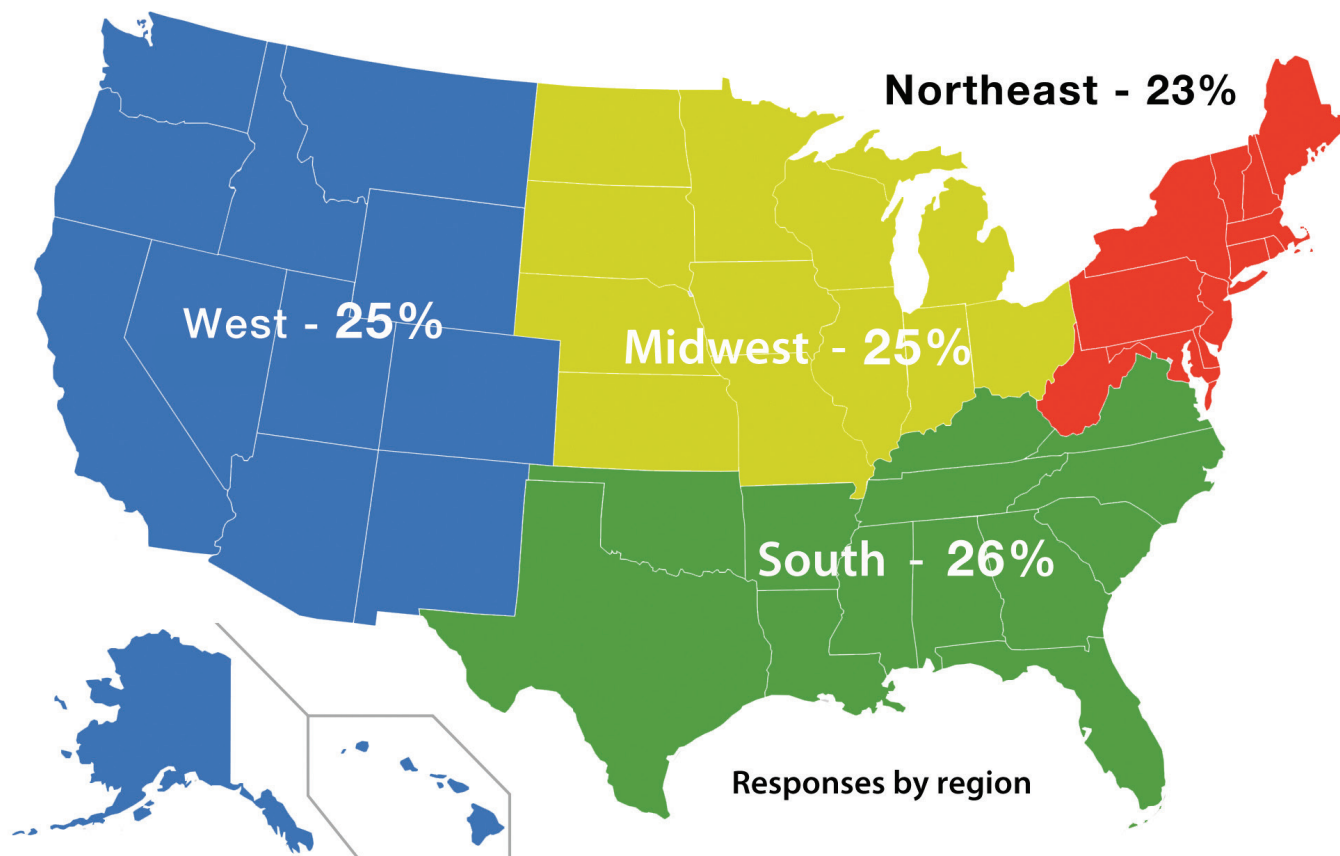
NARCOMS **NOW**

NARCOMS Now Presents: Fall 2011 Survey Roundup

Thank you for completing the Fall 2011 Survey! NARCOMS received:

- 3,012 paper surveys
- 5,865 online responses
- The response rate for the Fall 2011 Survey was 67.5%

Here's what the responses look like by region in the U.S.:



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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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.

Hello,

Welcome to Summer and to the second issue of *NARCOMS Now*.

We have devoted this issue to exploring multiple sclerosis and the arts, including a look at the potential role of music as a form of therapy. We also interview Phil Keoghan, host of television's "Amazing Race" series, who has raised more than a million dollars toward the treatment and cure of MS.

The staff of NARCOMS recently attended the Consortium of Multiple Sclerosis Centers (CMSC) and Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) annual meeting, May 30 through June 2 in San Diego. Findings from research using NARCOMS data were presented on a variety of topics, and we look forward to reporting these to you in the Fall issue of *NARCOMS Now*. These medical meetings provide important opportunities for researchers and medical practitioners to:



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.

- Share research findings
- Get feedback from others about our research
- Ask for ideas on how to tackle tough questions or understand confusing results
- Generate topics for future research

The meeting presentations are examples of the important ways in which data collected from the NARCOMS surveys can be studied to bring researchers, doctors, and caregivers closer to understanding how better to treat and, one day, cure MS. Look for news and reports from the conference in the Fall issue of *NARCOMS Now*.

We hope you will continue to join with us as we work to achieve our NARCOMS mission to improve clinical care and quality of life for persons with multiple sclerosis and their families, through increased knowledge about MS. We also hope you are enjoying the new look and feel of *NARCOMS Now*, and its accompanying website: www.narcoms.org/narcomsnow.

Please don't hesitate to let us know what you think. And tell a friend with MS about NARCOMS—we would love to bring more people into NARCOMS to help us better understand MS directly from the people it affects!

A handwritten signature in black ink that reads "Dr. Fox". The signature is stylized and cursive.

Q: Why is NARCOMS asking me about my “worst hand”?

A: The “worst hand” question has to do with hand function, where participants self-report symptoms and disability in their hands. The Hand Function Performance Scale has a mild relationship to the Nine Hole Peg Test, which uses the average speed of both hands.

While it is tempting to describe each hand individually, especially when there are differences in disability when one hand is compared to the other, the instructions ask for you to describe the condition of your worst hand function condition for two important reasons:

1) **Consistency:** All participants in NARCOMS are being compared in the same manner since everyone is being compared based on the condition of his or her worst hand function.

2) **Comparability:** When answers are given in a uniform way over time, then hand function is always based on the worst functioning.

Dr. John Rinker, UAB, recently began investigating the effect of tremor in both hands. For more on this story see [MS Reflections](#) on page 14.

Q: Why haven’t I been asked to participate in any other research projects through NARCOMS?

A: Additional research projects that NARCOMS assists or conducts are targeted to the specific persons of interest for that specific study. You may not have received an offer as part of our efforts not to waste your time in a study that you more than likely won’t meet the criteria to enter.

1) Using **existing** NARCOMS data. The questions a researcher is interested in may already be included in regular NARCOMS updates. This is why it is so important that we hear from you every Spring and Fall.

2) Including **special** questions in a regular update. Researchers with a small number of short questions may include them as part of a regular update. Any new or special questions will be highlighted at the start of every regular update and explained here in [Survey 101](#). See page 17.

3) A **project** outside of a regular update. Most of the time, these projects are based on a very specific question and invitations are sent only to participants that have indicated on a regular update that they have a certain condition or a certain level of disability (such as Dr. Rinker’s project on page 14).

It is important that you continue to fill out regular update surveys. For more research using NARCOMS data, see [NARCOMS Messenger](#), page 16.

We enjoy hearing from you. If you have a question or comment, please email MSregistry@narcoms.org or call toll free at 1-800-253-7884.

MUSIC THERAPY AND MS



Music Therapist Angela Howard, MT-BC

Everybody likes some type of music. For someone dealing with a chronic illness, bursting out in song might not be the first impulse. But music has healing qualities that can alleviate stress, anxiety, and even pain. Music therapy is a health care discipline used worldwide as a treatment for all sorts of illnesses, and its benefits can be seen in those living with multiple sclerosis.

The broad definition of music therapy is using music to address a nonmusical goal. This can include physical and emotional health goals, and even academic or educational goals. In a clinical or hospital setting, music therapists tend to focus on three things: reducing anxiety, depression, and the perception of pain. According to the American Musical Therapy Association, “research results and clinical experiences attest to the viability of music therapy even in those patients resistant to other treatment approaches.”

Libby Stephens, Music Therapist–Board Certified, at the University of Alabama at Birmingham, conducts music therapy sessions in acute care, palliative care, and intensive care settings. “We see that it helps the patients relax, and it helps them cope and express their feelings about what they’re going through,” Stephens says.

“I certainly think that every institution should have its music therapy and its music therapists.”
—*Oliver Sacks, MD, neurologist*

“Sometimes we refer to the music almost as a third party—it’s often easier for someone to say, ‘That song reminds me of when this happened in my life,’ or, ‘This song makes me think about what I’m going through,’ when they’re listening to or playing music.”

A NEW WAY TO TREAT PATIENTS

As a formal discipline, music therapy is relatively new to American medicine. The first music therapy college training programs were established in the U.S. in the 1940s. It became an organized profession in 1950, with the establishment of the National Association for Music Therapy, which began publishing its own periodical—the *Journal of Music Therapy*—in 1970.

Today licensed music therapists must be board certified, a process that includes completing a bachelor's degree and a six-month internship, then passing a board exam. Music therapists are generally trained in voice, piano, and guitar.

Music therapists work largely on referrals and orders from pastoral care, social workers, doctors, and nurses. At UAB they respond within 24 hours of being contacted by doing an initial assessment, to evaluate the patient's needs and set a goal for their treatment.

A music therapy session often consists of the therapists playing live music to the patient—the patient's preferred type of music, as self-identified or suggested by a family member or caregiver. Vital signs and other physical symptoms are monitored before, during, and after the sessions, and breathing rates, pulse, and blood pressure often decrease.

"I can't put into words how beneficial music therapy is for families and patients for anxiety, stress, and existential suffering," says Dr. Kellie Flood, Medical Director of the Acute Care for Elders Unit in the Division of Gerontology, Geriatrics, and Palliative Care at the University of Alabama at Birmingham's Department of Medicine.

***"We teach music lessons in a therapeutic way, which can be a really valuable coping skill when they get home."
— Libby Stephens, Music Therapist***

Music therapists can play at the bedside for anywhere from 20 to 60 minutes, but they also employ other techniques to introduce patients to the concept and help calm them down. "We often do songwriting, and it's a great way for patients to help cope with and process their feelings," Stephens says. "Some are able to sit down and do it right away with us, while others take it a few words at a time."

Music therapists sometimes ask patients to play instruments to help with movement issues or to strengthen a specific muscle or motion. In addition, they recommend coping mechanisms that patients can use outside of a clinical setting, including deep breathing and progressive muscle relaxation. "We teach music lessons in a therapeutic way," Stephens says, "which can be a really valuable coping skill when they get home."

In addition to participating in research presentations and educational networking opportunities taking place at the **CMSC** event in San Diego, meeting attendees had the chance to hear country music artist **Clay Walker** perform at the meeting's conclusion. Walker was diagnosed with MS in 1996.



Live music is more effective than playing recorded music for several reasons, Stephens explains. “The main difference is there is a person there to share in the process, making it a kind of removed way to start processing feelings and talking about what’s going on. The other part is we can tailor the music to their needs with the rhythm and the wording we use.”

Stephens says that overall what she has seen in patients responding to music therapy is that “it really helps decrease the anxiety that comes along with being diagnosed with something completely new, or with being in the hospital. It humanizes the hospital experience, and normalizes the environment. Once that anxiety level comes down it’s easier for people to listen and start processing what’s going on.”

“I can’t put into words how beneficial music therapy is for families and patients for anxiety, stress, and existential suffering.”
— Dr. Kellie Flood, UAB

Music therapists work in an interdisciplinary way with a team, talking with social workers, doctors, nurses, and family members in addition to the patients themselves, to complement what they do. “We have found time and time again that when patients and families are facing chronic, life-changing illnesses, there is also personal, emotional, and spiritual suffering, and music therapy has a dramatic impact in these areas,” says Flood. “A lot of times distraction alone for pain management makes a huge difference.”

And the benefits of music therapy often go beyond the patients and their families, Flood says. “It has been the best thing for our staff, whose morale has gone up 200% since we brought music therapy in,” Flood says. “I’ve not found any patient who wouldn’t benefit from music therapy. There’s something about music that just brings joy.”

FOR MORE INFORMATION ABOUT MUSIC THERAPY:

The Society for the Arts in Healthcare: www.thesah.org

“**Music Therapy with MS**,” an article by Concetta M. Tomaino, D.A. MT-BC, LCAT, Executive Director, Institute for Music and Neurologic Function, and Senior Vice President, Music Therapy Services, Beth Abraham Family of Health Services, New York. Posted online by the Multiple Sclerosis International Federation: <http://tinyurl.com/6qpo3cm>

The Certification Board for Music Therapists: www.cbmt.org

American Music Therapy Association: www.musictherapy.org





THE “AMAZING RACE” TO END MS

Phil Keoghan is best known for his role as host of television’s reality show “The Amazing Race,” which has won 12 Emmy Awards, and concluded its 20th season in May. But Keoghan has also dedicated a great deal of time and energy—both physical and mental—on raising awareness of, and funding for, multiple sclerosis. “MS affects people in so many different ways, but I like the idea that because it is a disease that takes movement away from people, we encourage people to move and to fight back, whether it’s creating awareness, raising funds, or taking a stand,” he says.

It was Keoghan’s lifelong passion for cycling that led to his interest in MS. He and his wife Louise, who live in Los Angeles, were asked to sponsor a local cycling team in Santa Monica that happened to be supported by the National MS Society. Part of that team’s mission was to ride in the Bike MS ride in Ventura, California, every year to raise money for MS. “Up to that point, I really did not know much about MS at all,” Keoghan says. “I had heard of MS but my understanding of the disease was very limited.” That was back in 2005.

By 2009, Keoghan had committed to biking 3,500 miles from Los Angeles to New York—a trip chronicled in the documentary film, *The Ride*, which raised more than half a million dollars toward finding a cure for MS. So what happened between those two points in time?

A LIFE-CHANGING BIKE RIDE

“I took part in my first MS ride, and really was hooked to continue doing it because of the people I met who live with the disease,” Keoghan recalls. “My understanding of MS increased tremendously. I got to understand how complicated a disease it is, and how differently it affects each person.” The MS rides in particular, he says, captured some of the daredevil streak for which Keoghan is known.

At the age of 40 he co-wrote a book called *NOW: No Opportunity Wasted*, about creating a sort of extreme bucket list of activities to do before you die, such as dining atop an active volcano or renewing wedding vows underwater (both of which Keoghan has done).



“I got to understand how complicated a disease it is, and how differently it affects each person.”
— Phil Keoghan

“What appealed to me about cycling in Bike MS rides was that you were doing something for yourself by staying fit and being active, but also doing it for someone else by raising funds,” he says. “That’s really what got me hooked. In 2009, when I was deciding to take on the biggest physical and mental challenge of my life turning 40, I thought, ‘I really need to do this ride for a reason other than just turning 40.’ I decided to do it for my chosen charity, raising money for MS.”

During that 40-day, 3,500-mile ride, Keoghan and his team aired daily video blogs which, along with footage of the journey, he then turned into the film, *The Ride*. He and his wife decided to donate all proceeds from the documentary to the National MS Society. In February 2012, the Showtime channel aired the film nearly daily for a month, and its licensing fee pushed the total sum Keoghan and his team had raised for MS to more than \$1 million.

“Various chapters of MS organizations have used the film as a way to motivate their team members to get out and take part in these Bike

MS rides,” he says. “There are 100 Bike MS rides across the country with 110,000 riders, so it’s a tremendous amount of potential energy out there to create MS awareness.”



Regina Lyalls and Phil Keoghan

TACKLING MS IN TANDEM

Keoghan's most recent MS endeavor is embarking on a second year of the "Together in MS" campaign, sponsored by Novartis (www.togetherinms.com). The campaign partners Keoghan and a team of professional women cyclists with people living with MS to ride tandem bicycles in National MS Society Bike MS events across the country.

“ I would like to encourage people to find a way to continue to live their life in a way they want to—not to let MS define who they are. ”
—Regina Lyalls

“Because the Bike MS rides are so successful, because I love bicycles so much, and because MS predominantly affects women, I thought, ‘Wouldn't it be great if we had some incredible kinetic energy in the form of a women's team who rode in all the big races across the country, who were ambassadors for MS in their own way, who could ride with people who have MS,’” Keoghan explains.

“We take a professional rider—or in my case, me—and ride in a tandem bicycle with somebody who has MS. What a powerful thing to do together.”

The Together in MS tandem cycling tour began May 12 near Minneapolis-St. Paul and continues in five other cities nationwide. Regina Lyalls, a Winston-Salem, NC, mother living with MS, will ride in tandem with Keoghan in a total of four races.

Lyalls, 45, says of living with MS, “there's always a bright side—it's not always doom and gloom.” Lyalls' first Bike MS ride a year ago had no personal significance when she first registered. “I had signed up where I work to take part in a local Bike MS event,” she recalls.

“The day I got my registration packet in the mail was the day my doctor told me I had MS. That day became very personal for me and took on a whole new meaning.”

Lyalls says that before she received her diagnosis she had heard about MS but didn't know much about it.



« Keoghan with members of the Together in MS team.

She emphasizes, for those who were recently diagnosed or who have been living with the disease for a while, the importance of speaking with a doctor to get the information to make an informed decision. “I would like to encourage people to find a way to continue to live their life in a way they want to—not to let MS define who they are,” she says. “MS is what I have, it is not who I am.”

For Jessica Tajima, who rode tandem with the Together in MS team recently in Minnesota’s Sam’s Club Twin Cities race, her MS diagnosis in 2006 was an emotional blow from which it took her years to recover.

“In the beginning, I continued to live the way I always had,” she says. “But eventually because I hadn’t dealt with the diagnosis, I became really depressed and gained a lot of weight. That made my symptoms worse, and I became depressed about my body image. Sometimes I feel like the hardest part is you don’t know what is going to happen, and no one can tell you because it’s different for everybody.”

Tajima says her life literally changed because of an infomercial—her husband

was in Iraq with the military, she was home alone and up late one night, and saw an advertisement for a workout DVD.

“It came in the mail two days later and I’m like, ‘Ok, this is day one of the rest of my life. I’m going to start this, do it, and push through this,’” Tajima recalls. “I did exactly that, started working out, became much more in tune with my body, and my symptoms started getting better as I was shedding pounds and being more active. That was a year and a half ago. I changed the way I was eating, from a bunch of junk food and fast food to healthier food. I saw a lot of changes with my disease progression.”

A representative of the Together in MS program contacted Tajima about riding tandem, she says, something she had never done before. She jumped at the chance. Just before the race, she was unsure how many miles she would ride, but very excited. “I like to give myself lofty goals,” she laughed.

“I like to be active and try to inspire other people to not let MS define them. You can always overcome any kind of obstacle as long as you have the will.”



TREMOR IN MULTIPLE SCLEROSIS AS MEASURED USING THE NARCOMS TREMOR AND COORDINATION SCALE

Ruth Ann Marrie, MD, PhD

Departments of Internal Medicine and Community Health Sciences, University of Manitoba, Winnipeg, MB

INTRODUCTION

Tremor is an abnormal, involuntary movement of the body that may affect hands, arms, trunk, head, legs, or voice. It is a symptom frequently experienced by Multiple Sclerosis patients. Resting tremors are most noticeable when the muscle is relaxed, for example, when the hand is resting on the lap.

Action tremors occur when the affected body part, such as the arm, moves or is held in a specific position. Task-specific tremors only occur when very specific tasks, such as handwriting, are involved.

Some studies report that 25–58% of persons with MS have experienced tremor.^{1,2} However, less than 15% of persons with MS present with tremor or poor balance as the first symptom.³ In one study examining 100 persons with MS attending an MS clinic, 58 had tremor. Action tremor affected most often the arms (56%), followed by the legs (10%), the head (9%), and the trunk (7%).¹ None of the tremors occurred at rest.

There are multiple ways of measuring tremor. First, persons with tremor can do standardized performance tests, such as the Nine Hole Peg Test (9HPT).^{4,5} In this simple test of arm coordination, the participant is timed placing nine pegs into nine holes, then removing each peg.

The test is usually done twice with each hand. Second, rating scales that describe the location and severity of the tremor can be used.

Functional tests observe the impact of tremor on typical daily tasks, such as drinking from a full glass.^{6–8} Finally, some questionnaires assess the effect of tremor on daily activities from the patient's perspective.⁴

Several years ago, NARCOMS developed a single question in its survey, called the Tremor and Coordination Scale (TACS), to assess the impact of tremor and impaired coordination on daily activities.

In this study we compared the TACS to a standardized performance test, and looked at how often persons with MS report moderate or severe problems due to tremor.⁹

THE QUESTIONS

The participants in this study also underwent a neurological examination, and completed the Multiple Sclerosis Functional Composite (MSFC) test battery. One of the three parts of the MSFC is the Nine Hole Peg Test (9HPT) described earlier. The participants also filled out the NARCOMS TACS and Performance Scales as NARCOMS participants typically do.



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

She is a researcher and a practicing neurologist who will be sharing her knowledge with NARCOMS participants throughout the year.

Dr. Ruth Ann Marrie

STUDY PARTICIPANTS

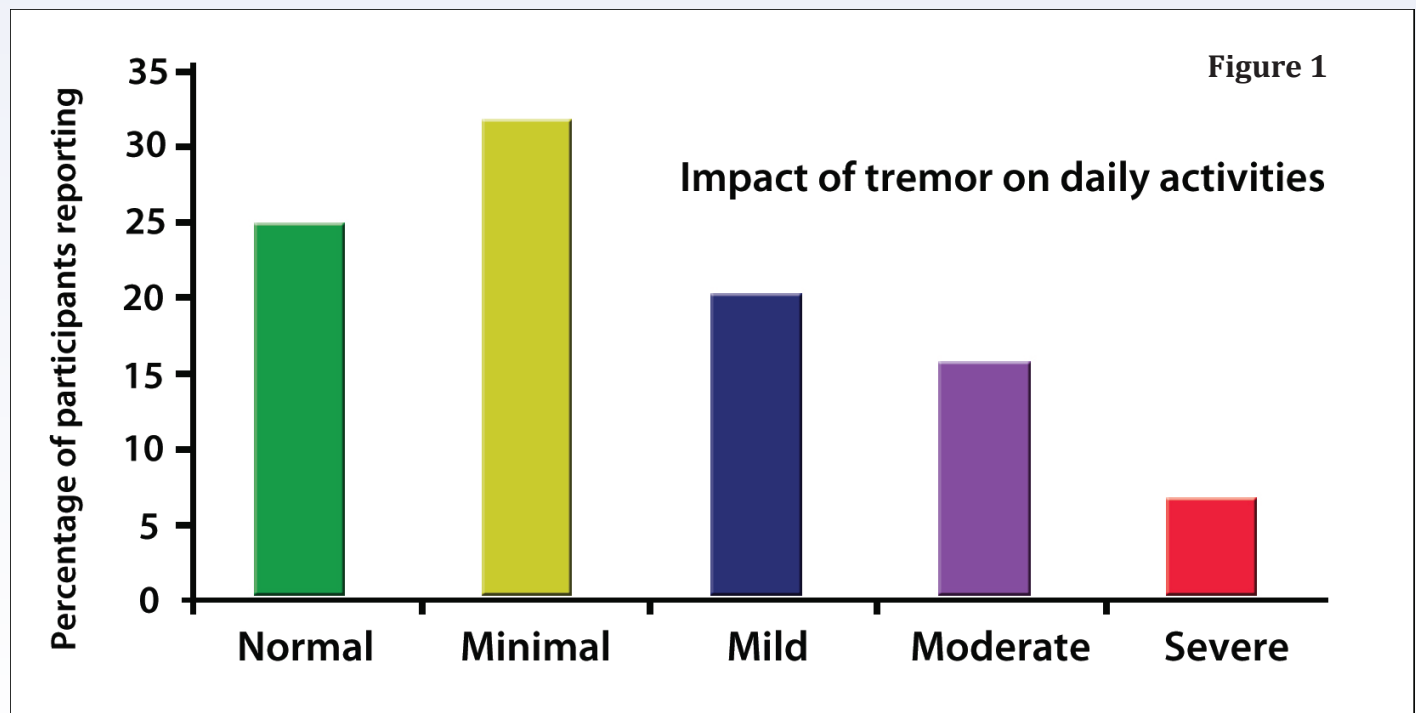
A total of 44 persons with definite MS participated in this study. Of these 79.6% were women, and 86.4% were white. The average age was 42.2 years. Most participants had a relapsing remitting course (68%), while 22.7% had secondary progressive MS, and 2.3% had primary progressive MS.

Seventy-five percent of participants reported at least some disability due to tremor or incoordination. 22.7% reported a moderate or severe impact of tremor (Figure 1, below).

The score on the TACS correlated with the 9HPT. The lower the 9HPT score, the higher the score on the TACS ($r = -0.51$). As the TACS score increased, quality of life decreased ($r = -0.50$).

SUMMARY

In this study, 75% of participants reported at least some disability due to tremor. Twenty-two percent of participants (more than one in five) reported moderate or severe disability due to tremor. More effective treatment of tremor in MS is clearly needed.



Around and Around and Around *Drawing Spirals to Test for Tremor in MS*



Neurologist John Rinker, MD, first learned about NARCOMS as a fellow at Washington University School of Medicine in St. Louis. When he came to the University of Alabama at Birmingham as an Assistant Professor in 2007, Rinker joined the team of neurologists making up the university's Division of Neuroimmunology and Multiple Sclerosis Center. *Continued on page 14...*

References for this article may be found at www.narcoms.org/narcomsnow

Around and Around and Around *Drawing Spirals to Test for Tremor in MS*



John Rinker, MD, received his degree from the Medical College of Georgia in Augusta, Georgia. Dr. Rinker is an Assistant Professor in the Division of Neuroimmunology and Multiple Sclerosis Center at UAB.

(Continued from page 13)

In that role, Rinker says he observed in clinic many MS patients with ataxia—a lack of voluntary coordination of muscle movements that is typically hard to treat with medications. Rinker noticed, however, that in the patients taking natalizumab, their ataxia improved. Known by its name brand Tysabri, natalizumab is a Disease Modifying Therapy (DMT) used to prevent symptoms and slow the worsening of disability in people who have relapsing forms of MS.

“Since ataxia is a notoriously difficult symptom to treat in MS, it seemed to me particularly important if one of our existing disease modifying drugs might alleviate this disabling symptom,” Rinker says. “Since the number of patients with moderate to severe ataxia who are also taking Tysabri is low in just about any given practice, NARCOMS provided a means to access a much larger group of patients with disabling ataxia to survey them about their response to Tysabri. I pitched it to the drug company folks, the makers of Tysabri, who funded the study via an investigator-initiated trial.”



In February 2012 the tremor survey was sent to 777 NARCOMS participants who met two conditions. First, they reported mild or greater tremor on the Fall 2010 NARCOMS update questionnaire. Second, they had been taking natalizumab for six months or more.

The Survey also included participants who were taking other disease modifying therapies as controls. Seventy-two percent of those surveyed responded (560). Each participant was asked to draw spirals on a page, one with each hand. Pens for drawing the spirals were supplied by NARCOMS for consistency. Neurologists specializing in tremor scored the drawings based on a 10-point scoring system (Bain and Findley, 1993). Participants also reported personal tremor history, family history of tremor, medications used to treat tremor, and demographic information.

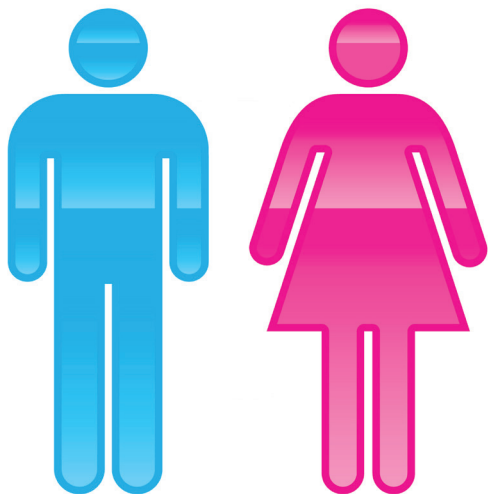
The data from the study are still being finalized. The next step, Rinker says, “will be to look at whether patients who have been on Tysabri for at least six months perceive an improvement in the severity of their ataxia or tremor, compared to patients who are taking other disease modifying drugs.”

“There are currently no treatments targeted specifically at tremor symptoms in MS,” Rinker says. “Maybe Tysabri suppresses the immune system sufficiently to help with this particular symptom, and this study sets out to take a closer look.”

Multiple Sclerosis affects women 2 to 3 times more than men, which is why so much research is done to evaluate differences between men and women living with MS. Here is a quick look at how women and men responded to the Fall 2011 survey...

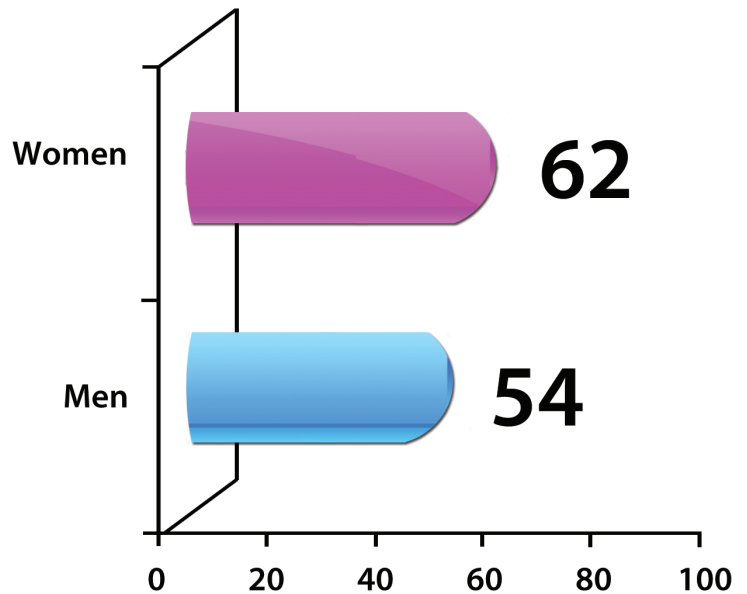
Who completed the Survey?

22.5% MEN 77.5% WOMEN

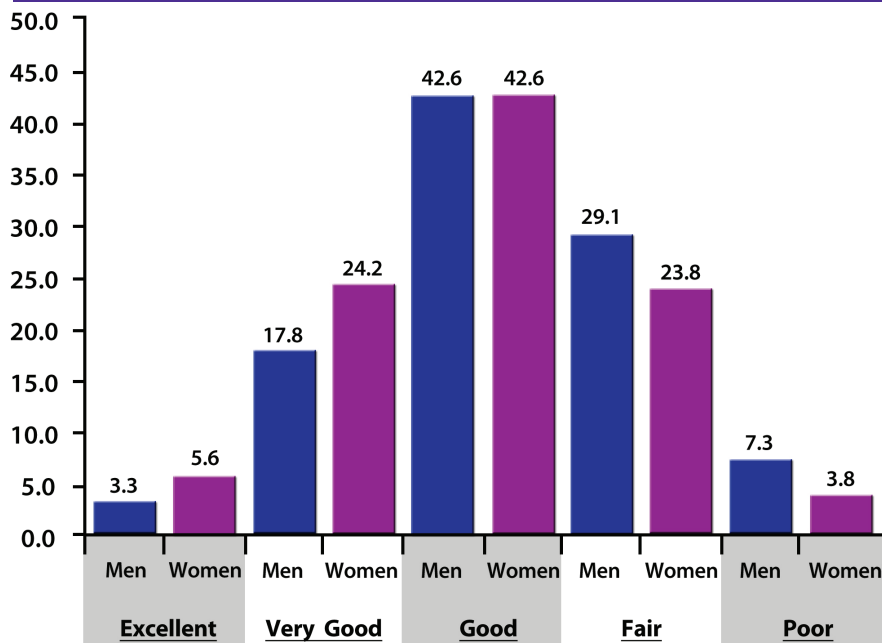


Who is currently taking medication for MS?

62% WOMEN 54% MEN



This is how men and women responded to the very first question in the Fall 2011 survey: "In general, would you say your health is..."



Great news!

Over 70% of NARCOMS participants say they are in Good or Better than Good health!

CMSC/ACTRIMS ROUNDUP: NARCOMS DATA IN ACTION

At the end of May, the NARCOMS staff attended the **Fourth Annual Meeting of the Consortium of Multiple Sclerosis Centers** (www.cmsc.org) and Americas Committee for Treatment and Research in Multiple Sclerosis (www.actrims.org). The meeting took place May 30 through June 2 in San Diego, as this

issue of *NARCOMS Now* was going to press. The goal of the CMSC meeting is to provide MS healthcare professionals with the most up-to-date information impacting patient care. NARCOMS researchers contributed in many areas, all using results from surveys to which you have contributed, including:

- Walking Speed and Health-Related Quality of Life in Multiple Sclerosis Patients
- Does Risk Tolerance to MS Therapies Change over Time? A NARCOMS Survey
- How are Relapses, Symptoms, and Disease Progression Linked in Early Multiple Sclerosis?
- NARCOMS: Simple Observation of Relapses Perceived to be Inferior to Therapy
- What Prompts a Switch to Disease-Modifying Therapy Beyond First-Line Therapies?
- Time to Disability Progression as Measured By Patient Reported Outcomes
- Item Response Theory (IRT) Methodology Can be Used to Place Common Clinical Measures of Multiple Sclerosis Progression on a Single Linear Scale of General Neurological Disability
- Pelvic Floor Disorders and Multiple Sclerosis: Are Patients Satisfied With Their Care?

REMINDER:

A Chance to Further MS Research



THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS

actrims

AMERICAS COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

Contact us at:
1-800-253-7884
and thank you!

Recently you may have received a letter notifying you of your eligibility to participate in a research study entitled, "Examining the effects of physical activity, fatigue management education, and social support using a telehealth intervention approach among adults with multiple sclerosis."

This exciting opportunity will allow you to help further the understanding of the impact that educational programs delivered over the phone have on improving health and function in adults with MS. If you're interested in participating, please call the number listed on the recruitment material sent to you, and thank you!

Look forward to full updates from the
CMSC/ACTRIMS meeting in our Fall issue, out in October!

In the Fall 2012 Survey that will be released in October, we will be asking you to update some questions you answered when you enrolled in NARCOMS. We update these questions every few years for the following reasons:

- Your answer may have changed
- The answer choices may have changed

POPULATION GROUPS

You will see two questions asking you to identify your race and ethnicity. The choices have been expanded to reflect the changes in society and in research. You can select all choices that apply to you. Answering these questions will help us determine if there are differences in the types of MS and changes in the disease over time for different races and ethnicities. **You will be asked:**

- Whether you are of Hispanic, Latino or Spanish origin, and if so, where you are from
- To select race or races that apply to you from 14 categories, or tell us another race that may not be on the list

CHILDREN, PREGNANCY AND CHILDBIRTH

There are two questions about children, childbirth, and pregnancy. We are asking you to update these questions, as your answers many have changed. **You will be asked:**

- For Men and Women: Do you have children? If you do, how many biological children and how many adopted or stepchildren do you have?
- For Women only: Have you ever been pregnant or given birth? If you have, then some information about how many pregnancies and births.

The role of hormones is an area of research in MS, and there may be differences in how women who have and have not been pregnant experience the disease.

If at any time during the survey you need help, feel free to ask for assistance or clarification by calling 1-800-253-7884 (toll-free US) or emailing MSregistry@narcoms.org.

Have an idea for Survey 101? Please contact us, via telephone, email or at www.narcoms.org.



AAN PRESENTATIONS ON CLINICAL TRIALS IN MS

At the recent American Academy of Neurology 64th annual meeting, held April 21–28, clinicians presented several reports on clinical trials of drugs to treat multiple sclerosis. Here are some results:

• **COMBIRX**

The CombiRx clinical trial tested a combination of Avonex (interferon beta-1a) and Copaxone (glatiramer acetate). The drug combination—when compared to the use of the individual drugs—showed some evidence from MRI that it was superior to taking either drug alone, according to Jerry Wolinsky, MD, of the University of Texas Health Science Center in Houston. However, the combination showed little benefit in terms of reducing clinical relapses when compared to the better of the two single agents, Copaxone. There was no benefit in reducing progression, as reported by Fred Lublin of Mount Sinai School of Medicine. Avonex and Copaxone have been considered the mainstays of MS treatment for several years.

The National Institutes of Health funded the CombiRx trial. Started in 2005, it enrolled a total of 1,008 patients through April 2009. Gary Cutter, MD, and Stacey Cofield, MD, both NARCOMS staff, coordinated statistical and data management for the study.

• **CONFIRM:**

SECOND POSITIVE TRIAL FOR BG-12 IN MS

Full results of a second trial of the oral BG-12 (dimethyl fumarate) in relapsing-remitting MS show that the drug significantly reduced relapse rates when compared to a placebo, and compared well with glatiramer acetate (Copaxone).

Dr. Robert Fox, medical director of the Mellen Center for MS at the Cleveland Clinic and Executive Director of NARCOMS, presented results of the Comparator and an Oral Fumarate in RRMS (CONFIRM) trial. The results are “quite consistent” with the previous phase 3 trial, Fox concluded, suggesting that, “this drug has quite robust efficacy and an acceptable safety and tolerability profile.”

Results of the Comparator and an Oral Fumarate in RRMS (CONFIRM) trial showed that the BG-12 significantly reduced the relapse rate by 44% for the twice-daily dose, and by 51% when taken 3 times a day when compared with placebo at 2 years.

New Orleans hosted the 64th Annual AAN Convention



CONTINUED...

• **CARE-MS 2:**
ALEMTUZUMAB IN MS

Full results of a second clinical trial of alemtuzumab (Lemtrada) in patients with relapsing-remitting MS who had relapsed while on previous treatment show that the treatment reduced relapse rates and disability compared with standard interferon beta-1a (Rebif).

“This study shows superior efficacy of alemtuzumab compared to interferon beta-1a across multiple outcomes, including relapses, disability (not only reduced risk of worsening but increased likelihood of improvement), and on MRI lesion activity and brain volume loss,” said Jeffrey Cohen, MD, director of experimental therapeutics, Cleveland Clinic Mellen Center for MS Treatment and Research. The CARE-MS 2 trial was funded by Genzyme.

• **UPDATE FROM OUR SPRING ISSUE:**
NEW WHEELS FOR WHEELCHAIR-BOUND

There’s a new vehicle on the market for people using wheelchairs and other mobility devices. The **MV-1 Mobility Vehicle** by Miami-based VPG Autos is the first vehicle designed specifically for those who use wheelchairs and other mobility devices. While not a high-volume car, it is a multipurpose vehicle touting the roominess of a cargo van without requiring conversion, which often results in a rescinded manufacturer’s warranty.

All MV-1 vehicles come with a factory warranty. The cars are built by AM General in the same assembly plant in Mishawaka, Ind., where the Hummer H2 is built. The MV-1 can accommodate two wheelchair-using passengers, or one wheelchair and up to five additional traditional-seated occupants. Cost: approximately \$43,000.



To learn more about the MV-1, visit: www.vpgautos.com

THE MV-1 Mobility vehicle is fully wheelchair accessible.

Find These Words:

harmony, peaceful, creative, rhythm, beat, music,
melodic, painting, sculpture, soothes, uplifting, relaxation, calming,
soaring, stomping, allegro, classical, lullabies, drawing, movement

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

:) **FACES** of NARCOMS

I am 55 years old. I was diagnosed with relapsing-remitting multiple sclerosis in 1993 when my children were small. My husband and I decided not to keep my illness from the children but to include them, so they would not be frightened for Mom. We even taught them how to help give me shots in my arms. (I think my son enjoyed that part just a little too much.)

All my life I have required a creative outlet. My earlier life was spent in the theatre as an actress where I could create roles; then as a set designer interpreting and creating sets. When MS finally crept its way becoming a roadblock to creativity in the theatre, I turned to painting. Eventually, that turned out to be too difficult for my hands.

Finally, I turned to writing as a creative outlet and have found success there. I even managed to find the energy to publish a novel with a character who is diagnosed with MS; after all, we are taught to “write what you know.” If I were asked for advice from an MS newbie, I would offer the quote by the famous German poet Goethe: “If you can dream it, begin it. Boldness has power and magic in it. Begin it now.” Don’t let your disability get in the way of doing what you love. Use your knowledge and turn it into a positive outlet for yourself and your family.

—*Lauren B.*



Each MS situation is unique—from diagnosis to treatment, from symptoms to coping mechanisms.

Do you have an MS story that you’d like to share? Your situation could enlighten someone else who is going through diagnosis; or has been living with MS for years.

Please consider sharing your story with us at:
MSregistry@NARCOMS.org.

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