

CMSC UPDATE

► Feature Focus: An Interview with June Halper

NARCOMS **NOW**

In May/June of this year, NARCOMS researchers and staff attended the Fourth Annual Meeting of the Consortium of Multiple Sclerosis Centers (www.cmssc.org) and Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS), held in the Hilton San Diego Bayfront.

Here are a few fast numbers from this four-day event:

- 176** = Lights and 22 speakers used for the Clay Walker concert Friday night
- 3,000** = Feet of ethernet cable/extension cord/etc. used in the exhibit hall
- 142** = Hours it would take to listen to all presentations, one after the other
- 1,788** = This year's attendance; the highest ever, up from 1,544 last year



**LOOK FOR THE GLOBE THROUGHOUT
THIS ISSUE FOR MORE FAST FACTS
FROM THE FOURTH ANNUAL
MEETING OF CMSC AND ACTRIMS**

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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Hello,

Welcome to the Fall 2012 issue of *NARCOMS Now*.

In this issue you will find reports from the Consortium of Multiple Sclerosis Centers (CMSC) and Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) annual meeting. This includes a conversation with June Halper, the CMSC's executive director and founding member, and one of the visionaries behind the development of NARCOMS.

I'd like to take this opportunity to address an important topic raised by some of our readers and NARCOMS participants: Why we do not devote much attention to alternative therapies in our surveys? There are several reasons.

In the past our surveys have included detailed questions about the use of complementary and alternative therapies, and providers who recommend them. This experience told us that many people with MS use these therapies (>50%) and reinforced how difficult it is to study them, as many NARCOMS participants reported using multiple therapies. Some alternative therapies may be effective while others may not.

There is typically little or no regulatory oversight to the manufacture and sale of supplements, so the actual contents may vary dramatically from brand to brand. Most of these alternative treatments do not have patent protection. Also, the use of alternative therapy approaches changes over time, making it difficult to study their long-term impact.

NARCOMS aims to conduct research with results that will make a substantial contribution to our understanding of MS. There may be effective treatments among alternative therapies, but formal clinical trials are probably a better way to evaluate them than a NARCOMS questionnaire. Several other investigators are conducting such trials. While we are dedicated to exploring all facets of this disease, NARCOMS will continue to focus our studies where we can have the greatest impact.

We hope you will continue to join us as we work to achieve our NARCOMS mission to improve clinical care and quality of life for persons with MS and their families, through increased knowledge about MS. Please don't hesitate to let us know what you think about the magazine, and don't forget to visit us online at www.narcoms.org/narcomsnow. Tell a friend with MS about NARCOMS—we would love to bring more people into the Registry to help us better understand MS.



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.

A handwritten signature in black ink that reads "Dr. Fox".

A CONVERSATION WITH: JUNE HALPER, MSN, ANP, FAAN



June Halper is a certified adult nurse practitioner who has specialized in multiple sclerosis since 1978. The Consortium of Multiple Sclerosis Centers (CMSC), founded in 1986, is the largest organization of MS healthcare professionals in the world. Halper was president of the Consortium from 1995–1997 and has been the Executive Director since 1992.

Halper has published and lectured extensively on multiple sclerosis. She is a member of the American Academy of Nurse Practitioners, the founding director of IOMSN, the International Organization of MS Nurses, and the recipient of the IOMSN's first June Halper Award for Excellence in Nursing in Multiple Sclerosis.

She was inducted as a Fellow into the American Academy of Nursing in November 1999. In 2000, she spearheaded the establishment of the Multiple Sclerosis

International Credentialing Board, which developed the first international certification examination in multiple sclerosis nursing, offered in June 2002 and bi-annually thereafter. As Executive Director of the CMSC, she initiated the first certification examination for MS specialists in 2004.

Halper continues to be involved in clinical care as a nurse practitioner at the MS Center of the New Jersey Medical School, UMDNJ, Newark, New Jersey, and at the Bergen Volunteer Medical Initiative in Hackensack, New Jersey.

She is dedicated to the fight against multiple sclerosis through educating the next generation of healthcare professionals, as well as expanding research to promote best practices in the comprehensive management of the disease. Halper spoke with *NARCOMS Now* in summer 2012.

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NN: HOW DID YOU FIRST COME TO BE INVOLVED WITH MS NURSING?

June Halper: I went back to school when my children were young to become a registered nurse. I did not care for hospital nursing, so I went into public health. Many patients who were homebound had MS, and I became acquainted with the far end of the spectrum, the progressive form of the disease. In September of 1980 I went to work with the local chapter of the National MS Society. During that time, I became an Adult Nurse Practitioner and subsequently helped found the MS Center at Holy Name Hospital, Teaneck, NJ. I worked there until 2008.

WHEN DID YOU BEGIN WORKING WITH THE CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS?

I have belonged to the CMSC since its founding in 1986. In the late 1980s the Consortium director, Dr. Jack Conomy, asked me to join the board—it wasn't a nonprofit organization at the time—it was a tiny organization with approximately 10 member centers. Subsequently, I was asked to work as part-time Executive Director in 1992. I assumed full-time responsibilities in 2008.

WHAT INSPIRED YOUR WORK AND DEDICATION TO MULTIPLE SCLEROSIS?

MS comprehensive care can be all consuming. There's so much to do; there is so much potential in this disease; there is so much that needs to be done. I think the turning point for the organization and for me personally was in 1992 when we held a conference called "*What Do We Know About Multiple Sclerosis.*"

Dr. [Thomas John] "Jock" Murray developed a model of "what we know"—which was tiny—"how we practice, and what we don't know."

We published an entire issue of a journal, *Journal of Neurologic Rehabilitation*, from this meeting, in 1994. We organized groups—one from a neurologic perspective, a nurses' group, a rehab group, speech and language, and a counseling section. Dr. Aaron Miller named NARCOMS during this meeting. Dr. Tim Vollmer, who was a member of one group, took on the task of organizing NARCOMS, which became a database.

The turning point of our organization was when our members took a look at what, why, and how we were doing things. We got to really know each other and our annual meeting started getting bigger and our activities started growing. We became a nonprofit organization during that time.

"There's so much to do; there is so much potential in this disease; there is so much that needs to be done."

WHAT ARE SOME OF THE BIGGEST CHANGES YOU'VE SEEN IN MS CARE IN YOUR CAREER?

Disease modifying therapies [DMT]—and the fact that we can do something about the disease course was a major turning point. We can offer patients something more than "you have your diagnosis, now go home," or what Labe Scheinberg defined as, "Diagnose and adios," or "MRI and goodbye."

Now we have the MRI, which provides imaging to see and monitor the course of the disease, and new information about immunology, genetics, and epidemiology.

CMSC TIME LINE

1986	-	1 st CMSC Organizational Meeting in Cleveland, OH (www.ms-care.org)
1987	-	1 st Annual CMSC Meeting in Minneapolis, MN
1992	-	June Halper named Executive Director
1993	-	NARCOMS founded (www.narcoms.org)
1995	-	June Halper named CMSC President (until 1997)
1996	-	10 th Annual CMSC Meeting in Atlanta, GA
1997	-	International Organization of MS Nurses founded (IOMSN, www.iomsn.org)
1999	-	1 st Issue of the <i>International Journal of MS Care</i> (IJMSC, www.ijmsc.org)
2006	-	20 th Annual CMSC Meeting in Orlando, FL
2007	-	1 st Cooperative Meeting with ACTRIMS in Washington, DC (www.actrims.org)
2011	-	25 th Annual CMSC Meeting in Montreal, Canada
2012	-	CMSC reaches over 200 centers in the US & Canada with over 4,000 health care professionals

We must let our members know this is their registry, their dollars are supporting it and they have an obligation to take part. Part of their CMSC membership is to get all MS specialists to participate—so we must get that message to every member.

We also have the comprehensive care approach—which includes various specialties such as rehabilitation. When we first started out in the mid 1980s, rehab was the big focus; then it petered out in mid 1990s with DMTs; and now it is in the forefront of care and research. Today we are able to provide cognitive rehabilitation, physical therapy, occupational, and speech therapy.

CAN YOU PROVIDE SOME RECENT EXAMPLES OF MS RESEARCH THAT YOU ARE EXCITED ABOUT?

A lot of it is emanating from the NARCOMS registry—I think there is a lot of information coming out of our database. NARCOMS contains a huge pool of data that we need to continue to tap into on a regular basis because it really shows what MS is doing to people on a day-to-day basis.

We can never forget this is a person behind this diagnosis. It does shorten the life span in some people and we must make every effort to make life easier for all those affected by MS.

I think the most urgent message I can spread is to ask that every center and member of the Consortium encourage their patients to register in NARCOMS. We need people when they're newly diagnosed—young children, adolescents, pregnant women. I think that registry is going to yield a wealth of information.

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WHAT ARE SOME OF THE INITIATIVES YOU'VE BEEN MOST PROUD OF IN YOUR TIME WORKING WITH MS?

We [the CMSC] started out with just me and a bookkeeper, and now have a full-time staff of 10. I am proud of the increase in our membership, attendance at our meetings, and of NARCOMS. I think we are making a difference in MS care; that would be the thing we would be most proud of.

I am thrilled we have an MS Coalition where all the organizations band together to advocate for all those affected by MS. People are proud to belong to our organization. One dream I have is to have every person with MS enroll in the NARCOMS registry.

WHAT DO YOU SEE AS THE CMSC'S ROLE IN THE FUTURE OF MS RESEARCH AND TREATMENT?

I don't think we will have a cure for MS very soon but we do now have effective treatments based on our model. Years ago it took months and years to get people into a good care system based on how long it took to be diagnosed. Today, there's a new concept called the medical home model, which is being employed in many chronic illnesses.

I think the fact that we're treating people earlier means we're going to be with them throughout their lifetimes—as they have children, age, and go through transitions.

That is where our work with the MS Coalition can make a difference—a comprehensive model for services outside the scope of treatment centers—for services such as counseling. We have to be able to offer resources throughout a lifetime with MS.

WHAT WILL WE SEE THAT'S DIFFERENT AT CMSC/ACTRIMS 2013?

We had several focus groups at the Consortium and the clear message that emerged was that the providers want more time for networking; they want more opportunity to interact on a one-to-one level with experts.

“I think the most urgent message I can spread is to ask that every center and member of the Consortium encourage their patients to register in NARCOMS.”

WHAT MESSAGE WOULD YOU LIKE TO GIVE TO NARCOMS PARTICIPANTS WHO WILL READ THIS ARTICLE?

I would say that I thank them—they are absolutely the reason we do what we do. I would like them to try to help us expand the registry, and encourage people to join NARCOMS. We know the medical and nursing and rehabilitation aspects of MS, but we really need to learn from them the meaning of their disease. It's so important to us. It's like they're part of the team. We need them—it's their registry, not ours. ●



CMSC FAST FACTS » 24% of CMSC attendees were nurses or nurse practitioners; 23% physicians or neurologists

Q: Why can't I find the listing of clinical trials I used to see in the MSQR in *NARCOMS Now*?

A: The MSQR was published in collaboration with United Spinal Association (<http://www.unitedspinal.org/>) and supported by advertisements and subscription fees. Still in its inaugural year, *NARCOMS Now* has no external funding and is compelled to limit the number of pages to manage cost.

Also, maintaining an accurate and current print-based listing is a challenge, due to the ever-increasing number of studies.

However, we plan to provide online research listings later this year at www.narcoms.org/narcomsnow. In the meantime you can find clinical trials information in several ways:

- The National MS Society provides a listing of open clinical trials (search by your state): www.nationalmssociety.org/research/clinical-trials/participate-in-clinical-trials/index.aspx
- www.clinicaltrials.gov also lists open research studies (search for MS)
- Ask your doctor about local studies, or visit your neurologist's office website to see if there are research projects in your area
- NARCOMS continues to notify qualifying candidates about research projects that have requested recruitment assistance

Editor's Note:

We have received lots of feedback from NARCOMS participants about *NARCOMS Now*—thank you! We really appreciate hearing from you and look forward to incorporating some of your suggestions in future issues.

We received several great emails about the summer issue interview with Phil Keoghan, host of "The Amazing Race" about his bike ride across America and the film *The Ride*. Still, other readers wondered what happened to the scientific articles.

The main focus for *NARCOMS Now* is, indeed, research—both NARCOMS research and MS research worldwide. However, we aim to balance the research findings presented in "MS Reflections" and "Snapshot" with MS lifestyle and news pieces, like those in "Faces of NARCOMS" and "MS News." "Feature Focus" and "NARCOMS Messenger" will feature both research-related articles and MS interest articles such as "Music Therapy and MS," depending upon what is current news in the MS world and in NARCOMS research.

We strive to have our magazine content reflect the interests of everyone who participates in NARCOMS.

We enthusiastically welcome all your comments and suggestions as we move into the second year of *NARCOMS Now*.

—**Stacey Cofield**, Executive Editor

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.

PELVIC FLOOR DISORDERS AND MULTIPLE SCLEROSIS: ARE PATIENTS SATISFIED WITH THEIR CARE?

—Dr. Sangeeta Tina Mahajan

INTRODUCTION

Adverse effects of multiple sclerosis (MS) on the pelvic floor functions, including bowel, bladder, and sexual function, are common, but can be embarrassing to discuss. Urinary problems occur in 50 to 80% of patients during their disease course, ranging from urinary retention to incontinence.¹ Overactive bladder symptoms—including frequent urination, strong urgency to urinate with or without leakage, and nighttime voiding—occur more frequently in MS patients, affecting 41% of neurologically normal women versus 75% of patients with MS.^{2,3} Additionally, a significant number of MS patients report bowel and sexual dysfunction, including severe constipation and decreased sexual sensation.⁴

Due to the prevalence of these conditions, MS care providers have recently made significant efforts to address the importance of evaluating and treating pelvic floor dysfunction. Recently the Consortium of Multiple Sclerosis Centers convened a consensus forum to establish recommendations for the evaluation and treatment of bowel and bladder complaints in MS patients, drafting simple flow charts and an informative publication.⁵ The goal was to ensure continued attention to pelvic floor disorders in the care of patients with MS.

Despite these efforts, the outcomes of provider education—as gauged by patient satisfaction and improvement in quality of life associated with pelvic floor complaints—have not yet been assessed. It remains unclear if our increased efforts are giving patients a satisfactory level of care for these private issues.

THE QUESTION

How satisfied are MS patients with the care they receive for pelvic floor complaints, including bowel, bladder, and sexual dysfunction symptoms, and have these evaluations and treatments impacted their quality of life?

RESULTS

In the fall of 2010, the bi-annual NARCOMS questionnaire was delivered to 16,000 participants, of which 9,397 (59%) responses were returned.

A large number of respondents reported significant pelvic floor complaints, including 41% with moderate to severe bladder symptoms, 30% with moderate to severe bowel symptoms, and 42% with moderate to severe sexual complaints.

Increased disability as gauged by the Patient-Determined Disease Steps (PDDS) was correlated with the presence of any pelvic floor symptoms ($p < 0.001$). Sixty-one percent of respondents reported being asked by their MS care provider about bladder dysfunction in the last year, while only 50% had been asked about bowel problems, and 20% about sexual dysfunction.

Despite only moderate-to-low rates of questioning regarding pelvic floor issues, patients were relatively satisfied with the evaluation and treatment they had received for bladder and bowel complaints, but less so with the care of sexual dysfunction issues. In general, most patients with moderate-to-severe pelvic floor symptoms reported improvement (28% of respondents) to no significant change (30% of respondents) in their quality of life with treatment of their pelvic floor complaints.

SUMMARY

Despite extensive education efforts to MS care providers, only approximately half of the patients most affected by bowel and bladder complaints have been evaluated for these symptoms in the previous year. Even fewer patients report evaluation of sexual dysfunction issues. Despite these poor statistics, the patients who do receive evaluation and treatment for these issues are generally satisfied with their care, although effects on quality of life range broadly, from positive to no effect. ●

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CMSC FAST FACTS » 230 = Total number of posters displayed; 11 were related to the NARCOMS data



Dr. Sangeeta Tina Mahajan

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Dr. Mahajan presented this article as a poster at CMSC 2012

RECENT NEWS ON INTERFERON- β AND EMERGING MS DRUGS

• NEW STUDY RESULTS ON INTERFERON- β

A study published in the July 18 issue of the *Journal of the American Medical Association* concludes that **interferon beta**, a widely used multiple sclerosis (MS) treatment, does not stave off the time to disability. Interferon beta does reduce MS relapses, however, so patients should continue taking it, researchers concluded.

The study included data on nearly 2,700 MS patients from British Columbia, Canada, with relapsing-remitting MS who were followed for 4 to 11 years. About one-third of the patients were treated with interferon beta after it became available in the early 1990s, and one-third were not treated with interferon beta. Data were also examined from a third group of MS patients who were diagnosed and followed before interferon beta was a treatment option.

The investigators found no statistically significant difference in how long it took for patients prescribed interferon beta to become disabled, defined as needing a cane to walk 330 feet.

“We were not able to find a significant association between interferon beta exposure and progression to disability,” said Helen Tremlett, an associate professor of neurology at the University of British Columbia.

Several other studies have suggested that interferon beta, by reducing relapses, could also prolong progression to disability, Tremlett said. Still other research has found that brain scans (MRIs) of people taking interferon beta show less damage. About 85 percent of those with MS start with a relapsing-remitting course, in which relapses are followed by partial or total recovery, according to the National Multiple Sclerosis Society.

In related news about the drug, a research presentation at the CMSC/ACTRIMS meeting in May showed that, at 21 years, treatment with interferon beta-1b reduced the risk of death by approximately 47%, compared with placebo, for patients with MS.

Anthony Reder, MD, Professor of Neurology at the University of Chicago Medical Center, and colleagues (including Gary Cutter, PhD, NARCOMS' Coordinating Center Director) presented the data, which reflect the longest period of follow-up for a treatment-exposed MS population.

Look for a full interview with several of the authors of this study, published in the April 24, 2012, issue of *Neurology*, in our winter issue.



CMSC FAST FACTS » 45 = The number of exhibitors; running 10.5 hours of exhibition time

RECENT NEWS ON INTERFERON β AND EMERGING MS DRUGS

NARCOMS DATA AND INTERFERON- β

Data collected in the NARCOMS registry have been studied and results published or presented regularly on the use of interferon beta to treat symptoms of MS. Some examples include:

- Fatigue characteristics in multiple sclerosis: the North American Research Committee on Multiple Sclerosis (NARCOMS) survey, *Health Qual Life Outcomes*. 2008 Nov 14;6:100.
- Natural history of MS among patients treated with IM interferon β -1a. Poster S85, presented at the CMSC conference in Denver, May 2008. (Abstract published in *International Journal of MS Care*, 10, S1, 37–38.)
- Why are eligible patients with multiple sclerosis not on treatment with interferon beta or glatiramer acetate: Risk factors for non-treatment. Presented at American Neurological Association 124th Annual Meeting in Seattle, WA. (Abstract published in *Annals of the 124th Annual Meeting of the American Neurological Association*, 1999, p. 35.)



As with any treatment, you should discuss with your doctor if any of these therapies would be appropriate for you and your MS.



CMSC FAST FACTS » 42 = The number of meeting spaces used for the meeting, plus an outdoor venue and exhibit hall

RECENT NEWS ON INTERFERON- β AND EMERGING MS DRUGS

• EARLY BUZZ OVER EMERGING MS DRUGS

It's no secret that the "injection" part of "injectable therapies" is no fun. But for those who dread their shots or are experiencing troublesome side effects, new treatment options may be just around the corner.

Teriflunomide (Aubagio) is a once-daily oral therapy being developed by Genzyme (a subsidiary of Sanofi) that is thought to alter the immune system by blocking the synthesis of DNA. Two Phase 3 clinical trials (the last stage of clinical trials before submission for regulatory approval) in relapsing remitting MS showed that teriflunomide reduces the frequency of relapses and the number of new lesions on MRI. One of the two trials also found that teriflunomide slowed the progression of disability.

Teriflunomide was generally well tolerated, but had side effects including diarrhea, nausea, and hair thinning. In addition, teriflunomide has also been shown to increase the rate of birth defects in offspring of both male and female animals treated with the drug. It has been submitted to the both the U.S. FDA and European regulators for approval, with a decision expected by the end of 2012.

Dimethyl fumarate (BG-12) is a twice-a-day oral drug therapy being developed by Biogen Idec. How exactly dimethyl fumarate works is not clear, but it may involve the activation of a cellular pathway involved in cellular protection and anti-inflammation. In two Phase 3 clinical trials in relapsing-remitting MS, dimethyl fumarate showed a reduction in the frequency of relapses and new lesions on MRI. Like teriflunomide, one of the two trials also found that dimethyl fumarate slowed the progression of disability.

The main side effects of dimethyl fumarate include skin flushing and gastrointestinal symptoms, such as cramps, abdominal pain, and diarrhea, which improved after the first few weeks. Dimethyl fumarate also has been submitted to the U.S. FDA and European regulators for approval, with a decision expected by the end of 2012.

Teriflunomide and dimethyl fumarate would join fingolimod (Gilenya; made by Novartis) as oral treatment options for relapsing-remitting MS. As with any new treatment, the long-term risks of these two new therapies are not well understood. It will require many years of observation to know if their safety profiles match the excellent long-term safety profile of the injectable therapies (interferon- β 1 and glatiramer acetate). ●



CMSC FAST FACTS » 34,122 = Square feet of conference space used to accommodate registrants

The Fall 2012 NARCOMS survey will include two new sets of questions. Following is some information on why we are asking these questions.

MARRIAGE & COHABITATION

Family and social supports are important in adjusting to daily life with MS, both in the early years following diagnosis and later, as disability progresses. Coping with MS can strain close personal relationships, especially marriages and committed relationships. Several studies have evaluated the stability of marriage and long-term relationships as it relates to life with MS, but these studies have mostly been carried out in Europe. To compare the impact of MS on these types of social support in NARCOMS participants with the types of social support described in European studies, we are asking you to give a detailed history of your experience with marriage and cohabitation, and to indicate whether there have been any children born or adopted during these relationships.

Completing this section will help us determine how MS affects long-term personal relationships in the NARCOMS cohort. We hope that you will complete it, however, we understand that this information is rather personal. You may opt to skip these questions—simply indicate that you do not wish to answer, and complete the remainder of the survey.

SPECIAL TOPIC SECTION – PSEUDOBULBAR AFFECT (PBA)

As part of ongoing research about MS and other neurological disorders, there is a special section in the Fall survey about Pseudobulbar affect, or PBA. PBA is a neurologic disorder characterized by episodes of involuntary or uncontrollable crying and/or laughing, or other emotional displays. It occurs more often in people with MS than in the general population.

Persons with Pseudobulbar affect may find they cry uncontrollably even when something is only moderately sad. They may also be unable to stop crying for several minutes. Also, the emotional reaction may seem inappropriate for the situation, such as laughing uncontrollably when angry or frustrated.

This special section in the Fall survey asks about these types of emotional outbursts, and if you have ever been diagnosed with PBA. Please think about the specific situations and answer if you have experienced any of them in the prior week only. We are not asking if you have ever experienced them, just if you have experienced them in the prior week.

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. (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.



FROM CALIFORNIA TO FRANCE

The Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) meeting was this past June in San Diego, California, in conjunction with the Consortium of Multiple Sclerosis Centers meeting.

The European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) annual meeting will be held in October in Lyon, France.

NARCOMS researchers will be presenting several posters at the ECTRIMS meeting, on research based on data collected from the NARCOMS registry. They include:

- Do patient-reported symptom changes indicate increased odds for a future relapse in MS?
- How do MS patients in the NARCOMS registry navigate their treatment options beyond first-line therapies?
- Comparative effectiveness of long-term users of disease-modifying therapies

Look to future issues of *NARCOMS Now* for articles about the published results of this and other research based on data from NARCOMS.

STRENGTH IN NUMBERS

Hopefully you've noticed with the NARCOMS presence and national and international meetings that the NARCOMS registry has become a major resource for MS research! This is entirely due to your participation and we would love for you to spread the word about NARCOMS:

- If you know of anyone with MS, please encourage them to visit our website or give them our phone number to speak with us directly.
- If you visit MS support groups, please let us know—we are happy to provide you or your group with NARCOMS brochures & some additional copies of *NARCOMS NOW* to give out.

The information you and others provide is extremely valuable. It may lead to improved care, and evidence for insurers to support the benefit of treatment, and create ideas for researchers to develop new treatments or approaches to care.

BECOME AN ONLINE PARTICIPANT

In an effort to focus more of our budget on research and less on printing costs, please consider becoming an online participant. Give us a call at 800-253-7884 and we'll get you set up!



CMSC FAST FACTS » Top four countries represented at the conference: USA (80.7%); Canada (6.6%); Germany (3.9%); UK (3.7%)

SHORTER SURVEYS

You may notice that the Fall 2012 survey is shorter than the Spring survey! In fact, the printed survey used to be 24 pages and has been trimmed to 20 pages. Excluding the cover and instructions, the questions now make up 16 pages.

With nearly 20 years of data, we have been able to determine that some of the questions we had been asking every 6 months don't actually need to be asked that often.

The biggest change you'll notice this time is the 7-question Health Survey is not included in the Fall Survey. You will see these questions again but not necessarily every year.

We have also tried to limit the special sections that contain new questions to only 2 pages moving forward into 2013.

Thank you for completing the Fall 2012 survey and we hope you will continue to participate in NARCOMS so even as our surveys shrink, our knowledge about MS will grow!

DON'T LET US WIND UP AS SPAM

To our online participants:

Please remember that our survey invitations will be sent to you via email. It is possible for our invitation emails to get caught in your spam filter. Try these steps to make sure you get NARCOMS emails:

- ✓ Add our email address to your contact list:
MSregistry@narcoms.org
- ✓ Check your email spam, trash or junk folder. We recommend scanning your spam folder every once in a while to see if any important messages are there.
- ✓ Do not open any emails from an email address or contact you do not recognize—these messages could contain viruses.

As always, if you have any questions about anything you receive from NARCOMS, please feel free to give us a call: 800-253-7884



Please Recycle!

All paper and printed materials you receive from NARCOMS, including surveys, letters to participate in other projects, and *NARCOMS Now* can be recycled. Let us know if you no longer wish to receive printed materials—everything is available online or via email!

NARCOMS & EDUCATION

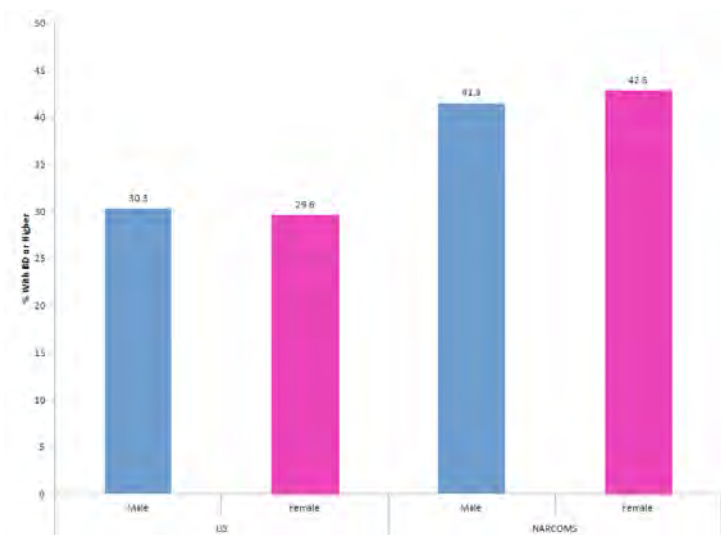
Every year, fall signals the start of school for students nationwide. The recently released 2010 U.S. Census data include updated statistics on education levels in the general population. In general, persons with MS have higher levels of education when compared to the overall population—but how do those in the NARCOMS Registry compare to national averages?

THE BASICS:

- The U.S. Census education statistics are based on responses from 199,928 people, and 29.9% of them reported having earned a bachelor's degree or higher.
- The NARCOMS sample has 17,908 people that reported sex, region where they live, employment status, and were at least 25 years old, as well as giving their education level at the time they joined NARCOMS. Compared with the general population, more NARCOMS participants reported having at least a bachelor's degree (42.5%).

BY SEX:

- In the U.S. Census, slightly more men (30.3%) than women (29.6%) have earned at least a bachelor's degree
- While in NARCOMS both men and women report more than 40% with at least a bachelor's degree: 41.5% for men and 42.8% for women

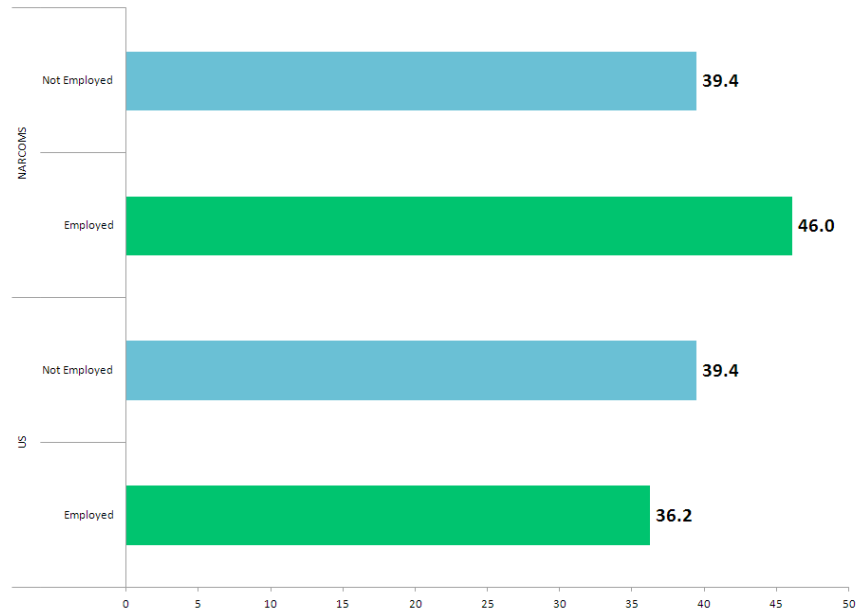


BY AGE:

- In the U.S., those with a bachelor's degree or higher ranged from just below 20% for the oldest age group (>75) up to 33.1% for 35-44 year-olds
- In NARCOMS, more than 35% of all age groups have at least a bachelor's degree, with the 25-34 year-olds having the highest level, at 48.3%

BY EMPLOYMENT STATUS:

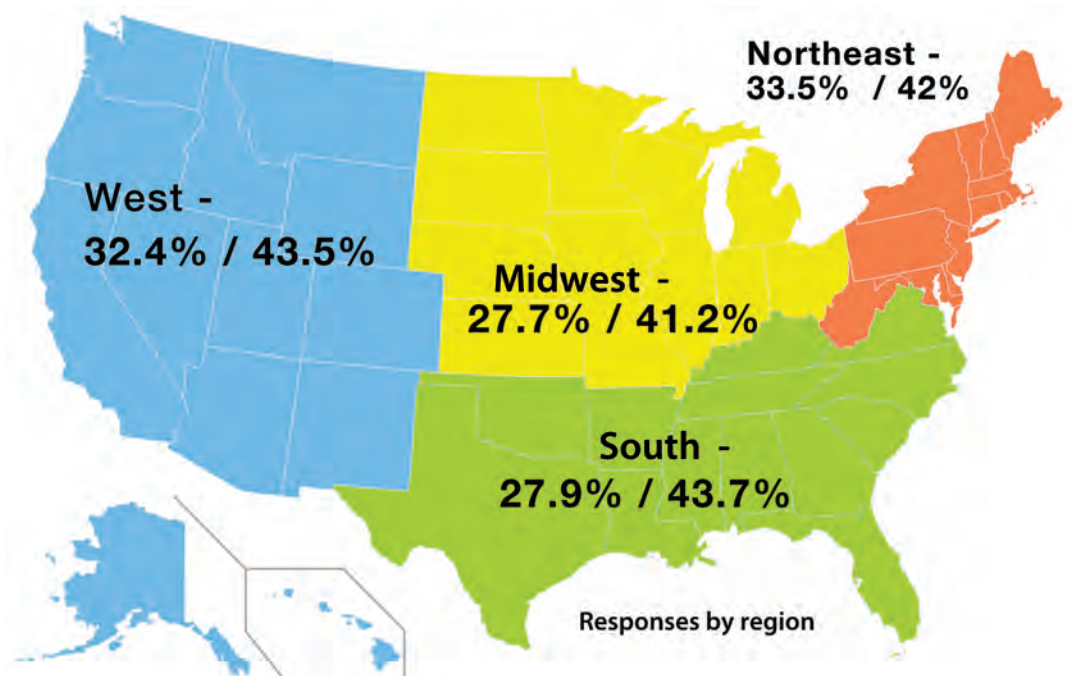
- 36.2% of those currently employed in the U.S. report having earned at least a bachelor's degree
- 46% of those employed full-time at enrollment had at least a bachelor's degree
- The rates for those unemployed or retired is similar in the U.S. and NARCOMS, at 39.4% in both groups



BY REGION:

- In the U.S., the regions range from 28% to 34% reporting at least a bachelor's degree
- All regions in NARCOMS are above 40% Selected Characteristic: 2010

% BY REGION FOR US / NARCOMS



*U.S. Census: <http://www.census.gov/compendia/statab/cats/education.html>
231 - Educational Attainment by Selected Characteristic: 2010

Cognitive dysfunction (CD) is common in people with multiple sclerosis. Approximately 40–65% of people living with MS will experience some type of CD, including memory loss and attention and concentration issues. Research in areas of CD has shown that frequent brain exercises can help slow the changes. Try these *NARCOMS Now* brain teasers; the answers are available at www.narcoms.org/narcomsnow.

GUESS THE PHRASE

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Each number can appear only once in each row, column and region

8	1						6	5
		3	1		9	7		
				6				
3				1				9
			8	3	7			
1				5				7
				2				
		7	4		8	3		
4	5						9	6

MATCHING GAME

Connect the words that go together by drawing a line between them

dog	chair
meal	sandal
bath	puppy
couch	kitten
carpet	helicopter
cat	shower
boot	rug
airplane	snack

Did you know learning a new language is also an excellent way to “flex” your brain? Here are the words for “Hello” and “Goodbye” in some other languages:

English

Hello
Goodbye

Spanish

Hola
Adios

Italian

Ciao
Arrivederci

French

Bonjour
Au Revoir

Find These Words:

**Research, Investigate, Participate, Study, Learn, Experiment,
Therapy, Treatment, Ccience, Trials, Surveys,
Engaged, Analyze, Examine, Collaborate**



Answers to the current issue of Play can be found at:
www.narcoms.org/narcomsnow/play/fall2012/page2

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.

:) **FACES** of NARCOMS

I had to buy that mug in the gift shop at the Native American casino depicting a bit of Native American lore, “The Medicine Wheel of the Four Directions.” Above a pictorial representation of the four directions were the words, “There is more than one door.” Those words resonated with me; they summed up the attitude I was developing to deal with my MS. I was working as a realtor when I was diagnosed with secondary-progressive multiple sclerosis. My early symptoms were tripping, hand cramps, and an inability to run. As a result I could no longer fence, touch-type, or play touch football. That was just the beginning of a series of losses. Everyone’s MS symptoms are unique, but losses are the effect that each of us with MS experiences.

Loss—for me, it was gradual. Everything was getting more difficult to do: dressing, showering, gardening, and household chores. Then I couldn’t wade in a trout stream to fish. I couldn’t work anymore. Next came the wheelchair. Then I stopped driving. I wondered, “How far will this go? When will it stop?”

For me the unknown is the most devastating feature of MS. And the more I learned about MS, the more unknowns I found. I was becoming a miserable person to live with. A lesser woman would’ve walked out—my wife showed me she wasn’t in love with my earning or fishing ability; she loves me.

I saw this after heart-to-heart dialogue and some professional counseling (I strongly recommend counseling). And so I took a first step to insight, a life’s journey. I lost my ability to sell real estate, fence épée, and fly fish. The doors that opened are oil painting, cooking, contemplation, and a closer relationship with my wife.

If I had stayed focused on the closed door and what I could no longer do, I’d never have walked through the other, open doors. The most effective tool I’ve found to deal with MS is attitude. No pills, concoctions, or devices will help you as much as keeping a positive attitude and an adventurous spirit. My MS shut some doors. I want to go through the ones it opened.

—Joe C.

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NARCOMS *MS* **NOW**



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