The 27th Annual Meeting of the CMSC and the 5th Cooperative Meeting of CMSC and ACTRIMS was held May 29th through June 1st in Orlando, FL. There were 1,749 attendees this year from all over the world, with many different backgrounds!

GLOBAL ATTENDANCE

There were 26 individual countries represented with the U.S. having the most attendees (1,481).

Diverse Professional Attendance

140 Clinical and Medical Researchers
289 Other Medical Professionals
364 Physicians and Neurologists
389 Nurses and Nurse Practitioners
473 Business and Industry Representatives
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Hello,

Welcome to the Fall 2013 issue of NARCOMS Now.

In this edition we are talking about cognitive changes that can occur in individuals living with multiple sclerosis. In May, the NARCOMS Team traveled to Orlando, Florida, to attend the annual joint meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS). (Look for coverage of NARCOMS’ research presentations, videos, and other discussions on the new “In the Media” section of the NARCOMS website.) We had the opportunity to review and discuss the most recent research on multiple sclerosis with experts, practitioners, caregivers, and patients from around the globe. In coming issues of NARCOMS Now, you’ll find articles based on interviews with several of these experts. This issue touches on changes in emotional and mental health and cognitive function brought on by MS. According to the National Multiple Sclerosis Society, half of all MS patients will experience depression at some point. How patients can manage this and other mental changes that can be brought on by MS is discussed in this issue’s “Feature Focus.”

Also in this issue’s “MS Reflections,” we address sources of health information for NARCOMS patients. Nearly 9,000 of you answered questions in our 2011 survey about sources of health information on MS—thank you! Not surprisingly, most of those who responded (nearly 85%) reported using the internet as a source of MS information. See the article to learn about other often-used sources, and some frustrations reported regarding the information found online.

Also in this issue are news items regarding the death of a patient who had been taking Tecfidera (though not concurrent with her death); newly published updates on on one of the CCSVI studies funded by the National MS Society; a study on possible nerve damage repair in patients with MS; and results of a clinical trial of a cannabis substitute for treating MS.

Finally, please take note of the NARCOMS Now photo contest and submit your “MS life” story in pictures. For details see page 15.

We hope you are enjoying the incoming fall season and the transition back to school!

Sincerely,

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

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

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

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

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NARCOMS PROMISE

Your personal information is always confidential.

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

VIEW PAST SURVEYS

www.narcoms.org

**Click on:** Participant Log in Here

**Enter** your username and password. **Select** the correct picture, click **Login.** **Click** the Form Summary link.

**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.**

EN ESPAÑOL

Para acceder a nuestro sistema a línea:

www.narcoms.org/es

Nuestro sitio de web es de alto seguridad a para su confidencialidad.

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

BECOME A PART OF NARCOMS:

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

Reminder when Completing Paper Surveys:

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!
According to the National Multiple Sclerosis Society, half of all individuals living with MS will experience cognitive problems, defined as a range of brain functions, including the ability to:

- learn and remember, focus, maintain, and shift attention as needed
- organize, plan, and problem solve
- understand and use language
- accurately perceive the environment
- perform calculations

While only a minority of individuals with MS will develop severe cognitive problems as everyone knows... forgetting things or feeling fuzzy headed can be distracting, embarrassing—even dangerous.

The good news is that for most persons with MS, certain high-level cognitive functions remain intact, including reading comprehension, long-term memory, the ability to hold a conversation and general intellect. Other areas, such as short-term memory (where did I leave my keys?), attention and concentration, information processing, visual perception, and even verbal fluency (finding the “right” words) can be affected.

More good news: Today’s top MS researchers are looking into ways to recognize and treat cognitive function issues for individuals living with MS.

At this year’s Consortium of Multiple Sclerosis Centers (CMSC) and Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) joint conference in May, several researchers presented their latest work on cognitive issues in MS, and how to handle them.
**Dr. Yael Goverover**, Associate Professor of Occupational Therapy at New York University, and her colleague **Dr. Helen Genova**, Research Scientist with the Kessler Foundation—a New Jersey-based public charity dedicated to improving the lives of people with physical and cognitive disabilities caused by chronic conditions—discussed their work on how cognitive factors can moderate activity limitation and participation in MS.

Goverover earned a Ph.D. in occupational therapy but completed post-doctoral work in neuropsychology after working with patients. “I came to learn that cognitive impairments are very limiting,” she says. “I wanted to look at how better participation in the activities of daily life can improve cognitive function,” she says. “We are looking more at cognitive effects than emotions, to determine what promotes or restricts activity, and see whether we might target a rehabilitation program to enhance these factors in patients’ lives.”

Utilizing a large data set designed for another study—looking at information about ability to complete such tasks as cooking breakfast and the frequency with which it was done—Goverover and Genova compared that data to employment information, and examined whether there were similarities. “We found that processing speed is the most important cognitive factor for both of these activities—that people who have slower cognitive speed tend to cook less and be unemployed,” Goverover says. “This relates to memory and executive function, and we wanted to see what other variables are very important for participation in daily activities.”

Genova, whose career up to now has involved research looking at cognition and depression in MS, is now focused on emotional processing issues—how individuals perceive the emotions of others. Her current research started in 2009 and was recently funded by the CMSC. It involves examining the three main areas of facial affect: recognition; procity (voice conveying information); and theory of mind (understanding someone who may have beliefs different than your own).
What she found was that people with MS are often impaired in all three areas. In addition, she says, “people with MS tend to have problems with anger, fear and shame.”

Genova and Goverover are co-principal investigators on the research, which involves a computerized program that takes images of faces and breaks down their basic facial features.

What does all this mean in the day-to-day life of someone with MS?

“It really affects the global aspect of participation in daily life—it’s really part of life to be able to identify and be able to react,” Goverover says. Genova adds that, “without social support, individuals tend to participate less in the activities of daily life.”

“How can we bridge between the lab to everyday life,” Goverover asks. “This is an important goal in our research.”

“We are looking more at cognitive effects than emotions, to determine what promotes or restricts activity, and see whether we might target a rehabilitation program to enhance these factors in patients’ lives.” — Dr. Yael Goverover

FROM COGNITIVE TO EMOTIONAL: MIND OVER MATTER?

In an effort to emphasize mental health issues in the treatment of multiple sclerosis, Drs. Rosalind Kalb and David Rintell hosted a panel discussion at the CMSC event on interdisciplinary teamwork to manage the complex patient. Their goal was to expand the discussion beyond the clinical and neurological to the emotional and psychological aspects of care.

The panel, which included a neurologist and a physical therapist among other professionals, discussed four challenging cases and how they might address them as caregivers working in the same clinic.
“What people experience as they participate is that when disciplines work together it not only helps the patient who has a chronic disease that requires input from all, but also helps the clinicians, because no one can work in isolation,” says Kalb, Vice President, Professional Resource Center at the National MS Society in New York. “It also provides the opportunity for mutual support among clinicians—they see what that can feel like. Those not working in a comprehensive MS center can feel as if they’re acting in isolation.”

Rintell, a psychologist at Partners MS Center at the Brigham and Women’s Hospital in Boston, describes a case from his center in which a patient displayed “definite functional symptoms not caused by a neurological deficit,” he says. She had concerns about being able to walk down the aisle for her wedding. Utilizing a team approach, with both physical and mental health therapy, she was able to do so, he says. “It was a successful demonstration of the need to address not only the medical but the emotional, as the two often go hand in hand.”

The key message Kalb says she hopes participants in the panel take away is that caregivers have to “meet patients where they are, and keep them engaged.” She suggests, for example, that an idea or option presented by a physical therapist may not seem as intimidating as if it were suggested by a neurologist, or vice versa.

Both doctors say there is a great need for mental health professionals with expertise in treating patients with MS and other chronic illnesses. “Over half of individuals with MS will have a major depressive disorder,” Rintell says.

Kalb points out the importance of mental health treatment for patients with MS goes beyond pain or discomfort.

“The work of other members of the caregiving team cannot move forward if emotional or psychosocial issues are taking over,” she says. “I want to keep reminding that that information is not just for the mental health professional—whether it’s a physical therapist, nurse, occupational therapist, or family member.”
Q: When I log into NARCOMS to complete my survey, I see a “Preferences” option. What can I do with that—change from a paper survey to an online survey? Can I change my email or mailing address?

A: Yes! You can do all of these things, and we encourage you to review your preferences each time you log in. Here is how to make changes to your NARCOMS account:

• Go to www.NARCOMS.org and click on »

• Login using your username and password »

• Click on “Forgot Password?” if you need a reminder sent to your email, or call 1-800-253-7884 »

• Once you are logged in, click on “My Settings” and you can change your mailing address, email address, contact preferences, NARCOMS Now preferences, and your security settings (including changing your password) »
Lean over and pick up a pen; hug your loved one; open a door. We use our hands and arms every day without paying any attention to it — until we have trouble performing these activities. With the increased use of computers, smartphones, and tablets, tasks such as typing have become how we communicate with each other. Limited function of the upper extremities can clearly change how we are able to interact with those around us.

Every NARCOMS update survey includes general questions about how MS symptoms affect your daily life, and one specific question about your overall hand function. However, as many of you have pointed out, these routine questions do not provide specific information about how the functioning of each of your upper extremities (hand and arm) may affect or alter your daily life.

In the upcoming Fall 2013 Survey you will find specific questions about upper limb function, to assess how MS currently affects your ability to do common daily activities. This new section contains questions in four topic areas:

1. General questions about your upper extremities, including which is your dominant hand. This is the hand you use to do most single-hand activities, such as writing, opening a door, or picking up an item. Please choose left, right, or if you use both hands equally, choose ambidextrous.


3. Specific activities that would usually be done with both hands. Please answer these questions on your ability to perform each function listed, even if it is not a function you need to perform often.

4. Recent activities: Your ability to perform the listed activities in the 2 weeks prior to the survey.

When answering these questions, keep in mind that there is no correct answer. Answering as honestly and accurately as possible will help us evaluate how upper extremity function affects various aspects of living with MS. We will share a summary of the results with you in a future issue of NARCOMS Now.

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 email MSregistry@narcoms.org.

Have an idea for Survey 101?

Please contact us via telephone, email or online at www.narcoms.org.
INTRODUCTION

In 2003, the National Cancer Institute supported the development of the Health Information National Trends Survey (HINTS). HINTS was developed to assess several issues. First, HINTS aimed to assess changing trends in health communication. Second, access to and use of cancer information was of interest. Finally, HINTS also assessed perception of cancer risk and health behaviors. Based on their findings, we were interested in assessing use of health information about multiple sclerosis (MS) by NARCOMS participants.

In recent issues of NARCOMS Now we have talked about the increasing complexity of decision-making in MS. Informed decision-making requires timely access to quality information. However, we do not know very much about the information sources used by people with MS. We aimed to look at the sources of health information used by NARCOMS participants and their trust in those information sources.

THE QUESTIONS

In the Fall 2011 update questionnaire we asked participants to tell us about their use of health information sources. Specifically, we asked where participants went for health information during their most recent search for health information. We asked about what kinds of information they were searching for. Finally we asked about their trust in the information sources they used. To do this, we adapted the 2007 HINTS survey. We replaced MS for cancer in the HINTS questions. We also substituted MS organizations (such as the National Multiple Sclerosis Society [NMSS] and CMSC) for cancer organizations.

We grouped information sources into two categories. The first category was interpersonal sources including family, health care providers, friends, and patient advocacy organizations. The second category was mass media sources including books, newspapers, brochures, libraries, magazines, and the internet.

Study Participants

A total of 8,586 NARCOMS participants were included in the study. Of these 22.4% were men and 77.6% were women. Ninety-five percent were whites, while 4.5% reported another race. The average age was 56.6 years. Sixty-five percent of participants completed the questionnaire online.

Findings

Participants reported using a variety of interpersonal and mass media information sources (Figure 1). The most common source used was the internet, followed by health care providers and the National Multiple Sclerosis Society. Overall, 68.3% of participants used mass media as their first information source.

As compared to participants who were over age 60 years, those aged 35—49 years were twice as likely to report using mass media sources than interpersonal sources of information. Participants aged 18—34 and 50—59 years were also more likely to use mass media sources. Participants reporting a higher annual household income were more likely to use mass media sources than those with a lower income. Participants with less disability, as measured using Patient Determined Disease Steps, were more likely to use mass media than participants reporting severe disability.
Figure 1. The first source for health information, the last time it was sought (n = 7,376 responding)

Participants sought a wide range of information regarding MS. For example, participants looked for information about MS in general, treatment, and access to health care (Table 1).

Table 1. Type of health information sought about multiple sclerosis (MS) at the time of the most recent search.

<table>
<thead>
<tr>
<th>TYPE OF HEALTH INFORMATION SOUGHT</th>
<th>PERCENT SEEKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment for MS</td>
<td>78.9%</td>
</tr>
<tr>
<td>General information about MS</td>
<td>62.5%</td>
</tr>
<tr>
<td>Symptoms of MS</td>
<td>55.8%</td>
</tr>
<tr>
<td>Coping with MS</td>
<td>55.1%</td>
</tr>
<tr>
<td>Complementary and alternative therapies</td>
<td>46.2%</td>
</tr>
<tr>
<td>MS organizations</td>
<td>42.5%</td>
</tr>
<tr>
<td>Cause of MS</td>
<td>40.4%</td>
</tr>
<tr>
<td>Prognosis</td>
<td>36.9%</td>
</tr>
<tr>
<td>Paying for medical care</td>
<td>24.5%</td>
</tr>
<tr>
<td>Insurance</td>
<td>22.9%</td>
</tr>
<tr>
<td>Where to get medical care</td>
<td>18.4%</td>
</tr>
<tr>
<td>Diagnosis of MS</td>
<td>19.1%</td>
</tr>
<tr>
<td>Other information</td>
<td>26.0%</td>
</tr>
</tbody>
</table>
Many study participants found it hard to get the information they wanted (2,131; 28.2%) or were frustrated by their search (2,120; 28.1%). Nearly 40 percent of participants had concerns about the quality of the information they found. Twenty-one percent of participants found the information hard to understand. Trust in information sources varied greatly, with physicians reported as the most trusted information source. (Figure 2).

**Figure 2.** Degree of trust in various information sources (n = 7,267)

More than 85% of participants used the internet or email (n = 7,292). In addition to looking for health information online, participants reported several other online activities. Some of these activities included social networking (61.2%), looking for a health care provider (34.5%), buying medications or vitamins (34.3%), communicating with a physician (32.0%), seeking advice about lifestyle activities (31.9%), using online support groups for people with MS (20.7%) and blogging (7.8%).

**Summary**

The internet is the first source of health information for NARCOMS participants. This is similar to the general population where the internet is the first source of cancer information. Participants had varied information needs, and had some concerns about the quality of the information they found. Continued work is clearly needed to provide persons with MS with access to high quality health information.

“MS Reflections” is excerpted from this article.


NARCOMS ON SOCIAL MEDIA

TWITTER UPDATE:

In the Summer issue we told you about @NARCOMS on Twitter. We are nearing 100 followers and growing every day! If you are new to social media, Twitter is an easy place to start, and a great way to keep up with MS- and NARCOMS-related news. Visit www.twitter.com to join and find us @NARCOMS.

LINKEDIN:

We have had a number of email requests to connect with users on LinkedIn, a social media website for “Professional Networking.” While we appreciate your invitation to join, LinkedIn is a place for individuals to make business connections, and as a small non-profit organization we have not yet found a place for NARCOMS on a site like LinkedIn. We’ll keep you posted if that changes.

NARCOMS SAYS Farewell

It is with some sadness that we are wishing a very fond farewell to Desiree (Desi) Mitchell, the NARCOMS Project Manager in the Coordinating Center at UAB. Desi has been an integral part of NARCOMS since the coordinating center moved to UAB. She will be greatly missed by our staff and by many of you with whom she spoke about NARCOMS over the years.

We wish her well on her journey and look forward to seeing where it takes her. Thank you Desi!
NARCOMS PHOTO CONTEST

NARCOMS is launching a “Living with MS” photo contest for NARCOMS participants! We would like to see and show how you live with MS every day. We are accepting email submissions of digital photographs depicting your “MS life,” to be featured in NARCOMS Now in 2014. We look forward to seeing your photos and sharing your picture and story of living with MS. Here are the guidelines:

- Submit high-resolution photos at: www.narcoms.org/narcomsnow/photocontest.
- Include a title for each photo submitted, as well as a short (250 words or less) description that tells us what the photograph represents in your “MS life.”
- One photo will be featured in each issue of NARCOMS Now in 2014; additional submissions may be featured on the website at www.narcoms.org/narcomsnow.
- A 2014 photo contest winner will be chosen online from the 4 featured photos by NARCOMS participants. An online winner will also be selected from photos not featured in the magazine.
- The 2014 winner and online winner will both receive a NARCOMS Now prize pack.
- NARCOMS reserves the right to use the submitted photos and the artist’s biographical statement at its discretion in printed and online material including NARCOMS publications, cards and calendars, and materials that pertain to NARCOMS and NARCOMS Now.
- For contest information and the required release statement please visit: www.narcoms.org/narcomsnow/photocontest.

**Remember:** You can also submit the story of your MS journey to “Faces of NARCOMS” by sending us your 1-page entry to: narcomsnow@narcoms.org.

Don’t forget to complete your Fall NARCOMS Survey! You should receive your survey online or by mail in October. Thank you to all our wonderful NARCOMS participants!
BIOGEN IDEC INVESTIGATING DEATH OF WOMAN TAKING TECFIDERA

The Wall Street Journal on July 22, 2013, reported that Biogen Idec, maker of the MS drug Tecfidera, is investigating the cause of death of a 59-year-old woman who had taken Tecfidera, but was not on the medication when she died.

In March the FDA approved Tecfidera capsules (dimethyl fumarate—formerly known as BG-12) as a first-line disease-modifying therapy for people with relapsing forms of MS. It is the third oral therapy approved for MS, and the tenth disease-modifying treatment available in the U.S. Tecfidera joins Gilenya and Aubagio as the only MS treatments currently in pill form.

According to the article, the unidentified woman had been taking Tecfidera for her MS for 5½ weeks. She stopped taking it after experiencing severe side effects including vomiting, diarrhea and nausea. Two and a half weeks after she stopped taking the drug, she developed a severe type of pneumonia that occurs more frequently in MS patients, and died. A spokeswoman from Biogen said the woman had a history of irritable bowel disease and recurring infections including bronchitis.

Any link between the woman’s death and the use of Tecfidera looks “unlikely,” the spokeswoman said, but the company’s investigation is ongoing. “Biogen Idec is committed to patient safety, and it continues to be our first priority,” the spokeswoman said.

Tecfidera is thought to inhibit immune cells and molecules, and may have anti-oxidant properties that could be protective against damage to the brain and spinal cord—though its exact mechanism of action isn’t known.

In two large-scale studies, called DEFINE and CONFIRM, Tecfidera reduced relapse rates by approximately 50% over placebo, and reduced the progression of disability by about 30%.

STUDY SHOWS HOPE THAT NERVE DAMAGE IN MS COULD BE REPAIRED

A new study published in Nature Neuroscience sheds light on how cells regenerate the myelin sheath surrounding nerve fibers in the brain. Researchers hope this discovery may help lead to the development of treatments that could repair nerve damage and restore lost function in patients with MS.

In individuals with multiple sclerosis, the immune system attacks and destroys myelin, a protein that insulates nerves in the brain, spinal cord, and optic nerve. As that myelin is destroyed, patients experience symptoms ranging from vision problems, to numbness, to paralysis.

In MS, the immune system gradually destroys the myelin, but also a natural repair process called “remyelination” fails.

This latest study, led by researchers at the Universities of Edinburgh and Cambridge in the United Kingdom, describes how they studied immune cells called macrophages—known to be involved in remyelination—and found two important features that could lead to new therapies that promote myelin regeneration:

1. For remyelination to proceed, macrophages have to become anti-inflammatory

2. Macrophages release a protein called activin-A that actively encourages remyelination.
“Approved therapies for multiple sclerosis work by reducing the initial myelin injury—they do not promote myelin regeneration,” says first author Dr. Veronique Miron of the Medical Council Centre for Regenerative Medicine at the University of Edinburgh. “This study could help find new drug targets to enhance myelin regeneration and help to restore lost function in patients with multiple sclerosis.”

Miron and colleagues examined myelin regeneration in human tissue samples and in mice for this study. They wanted to understand what stimulates remyelination, and which factors involved in that process could serve as targets for regenerative treatments to restore lost vision, movement, and other functions.

The study suggests it may be possible to partner drugs that reduce the initial myelin damage with drugs that regenerate it in the central nervous system, and thus restore lost functions in MS patients.

The researchers have said they plan to look in greater detail at how activin-A works and whether its effects can be enhanced. The MS Society, the Wellcome Trust, and the Multiple Sclerosis Society of Canada funded the study.

**TRIAL RESULTS: NO IMPROVEMENT IN MS PROGRESSION OFFERED BY CANNABIS CONSTITUENT**

Patients using **dronabinol, a synthetic cannabis/marijuana derivative**, showed no improvement in MS progression, the results of a three-year clinical trial published early online in British medical journal *Lancet Neurology*, show.

This trial, the first large non-commercial clinical study to investigate whether the main active constituent of cannabis (tetrahydrocannabinol, or THC) is effective in slowing the course of progressive multiple sclerosis, shows there is no evidence to suggest this. Those at the lower end of the disability scale did note some benefits, however.

The basis for the trial was previous lab studies suggesting these types of “cannabinoids” may protect the nervous system. Results were announced in 2012 and published on July 13 by Dr. John Zajicek (Plymouth University Peninsula Schools of Medicine and Dentistry), and colleagues in the United Kingdom.

Dr. Zajicek and colleagues conducted the multi-center CUPID (cannabinoid use in progressive inflammatory brain disease) trial involving 498 people with primary- or secondary-progressive MS. Participants had varying degrees of gait impairment and other symptoms.

Two-thirds of the participants were administered oral dronabinol, and one-third took inactive placebo for three years to see if dronabinol could slow progression of MS.
The primary outcomes measured after three years were: Progression in the EDSS (Expanded Disability Status Scale) score, and change in a portion of the MS Impact Scale related to physical impact (MSIS-29-PHYS; self-reported by the patient). Imaging of the brain using MRI was also performed to look for shrinkage (atrophy) of the brain and to measure MS disease activity. Disease progression was checked at 3 and 6 months, and then every 6 months for 3 years.

Dronabinol was unable to stop MS disease progression or brain atrophy, and did not affect the occurrence of new areas of disease activity in the brain. Analysis of a subgroup of people in this study suggested a possible benefit from dronabinol in those who began the trial with milder disability, but not in those who began the trial with more severe disability. The observation of no effect on brain shrinking suggests that dronabinol does not protect the brain, at least in these circumstances and in this population. Whether dronabinol can protect the brain during earlier stages of MS remains to be tested.

**UPDATE: ADDITIONAL PUBLISHED RESULTS FROM CCSVI STUDY SPONSORED BY NMSS**

In an update from a National MS Society-supported study investigating CCSVI (chronic cerebrospinal venous insufficiency), researchers at the University of Texas Health Science Center at Houston have published additional results using imaging techniques to examine blood outflow from the brain.

The first part of the study, published early online in the *Annals of Neurology*, used Doppler ultrasound. This portion of the study focused on learning how ultrasound findings are supported by other imaging techniques. The team used magnetic resonance venography (MRV) and transluminal venography (TLV) in a subgroup of people with MS who had already undergone ultrasound vein scanning. They reported poor agreement between ultrasound and MRV. They also showed that TLV detected no pressure readings that would indicate functional vein blockages.

The study, by Stanley A. Brod, MD, Jerry S. Wolinsky, MD, and colleagues, was recently published early online in the *Multiple Sclerosis Journal*. For a full article on the study results, visit the National Multiple Sclerosis Society’s “News” page.

**LINKS:**

*Wall Street Journal*, July 22, 2013:
http://online.wsj.com/article/SB10001424127887323829104578622152746636388.html

*Biogenidec Website*: http://www.biogenidec.com

*Nature Neuroscience* article:
http://www.nature.com/neuro/journal/v16/n9/full/nn.3469.html

*Lancet Neurology* (clinical trial results):
http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(13)70159-5/abstract

*University of Texas Health Science Center at Houston*: http://www.uthouston.edu/

*Annals of Neurology* study:

*Multiple Sclerosis Journal* study:
http://msj.sagepub.com/content/early/2013/07/16/1352458513494493.abstract?papetoc

*National Multiple Sclerosis Society* article:
Thank you for your contribution to the Spring 2013 Update survey. We had 8,517 total surveys submitted, with 67.5% completed online. If you complete the survey on paper and would like to change to online—reducing both the amount of paper used and NARCOMS printing costs—please see “Q&A” on page 8.

HAND FUNCTION

In the Spring 2013 update, 99.4% of participants completed the Hand Function Performance Scale question, with 54.5% indicating Normal or Minimal Hand Disability. For more on the importance of Hand Function and MS, please see “Survey 101” on page 9.

* Preliminary results as of August 2013 — results may change
Find the following hidden words:

books, reading, classes, leaves, sweaters, apple, raincoat, football, crisp, autumn, rake, folder, chilly, pumpkin, feast, haunted, thinking, candles, abundant, baking, gather

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:
www.narcoms.org/narcomsnow/play/answers
I have a family history of multiple sclerosis, so in 1990 when a neurologist suggested an MRI showed “possible MS” (I was 38), I immediately went into denial. Cousin E. had it and was in and out of a wheelchair. I couldn’t possibly have it, could I? I had experienced foot drop since after our third son was born in 1986. “Are you limping,” people would ask. I don’t know—am I?

In 1998, I saw a new neurologist. Upon examining my MRI, he diagnosed multiple sclerosis and asked me to choose one of the three therapies. I chose Copaxone and began daily injections. My MS remained stable with the same foot drop, leg weakness, and bouts of fatigue. (I have since switched to Tysabri, then back to Copaxone, and recently started Tecfidera—no more needles!)

My older sister D. was diagnosed at roughly the same time. Her defining symptom was optic neuritis. She regained her eyesight but other issues such as imbalance and fatigue set in. She experienced depression and rapid weight loss. Doctors were consulted, medications adjusted, and she seemed better for a time. But her MS progressed rapidly. She developed antibodies to Betaseron and had to discontinue use of the drug. After four years of physical decline and dementia, her husband, daughter and I moved her from a skilled nursing facility to hospice at home. We cared for her with love and bewilderment until she peacefully passed away. A brain autopsy revealed only MS pathology. I missed my sister and worried about my own MS, but I continued to remain stable.

I have not worked for a long time, but spent many years volunteering in public schools and for nonprofits. Thankfully, my spouse has been able to support our family. Our three boys are grown now, and if you were to ask them, my MS has not overtly affected their lives. But they know not to expect me to walk long distances or invite me to events where heat could cause issues. My daily life is great, even with my limitations. Shopping, cleaning the house, and entertaining take longer and require planning ahead. I accept this and am grateful that I have a full and rich life surrounded by family, friends, some travel, and the beauty of living in the Pacific Northwest.

Lisa S.

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