

NARCOMS *NOW*

SPRING 2012

www.narcoms.org

Vol. 1, Issue 1



INTRODUCING...

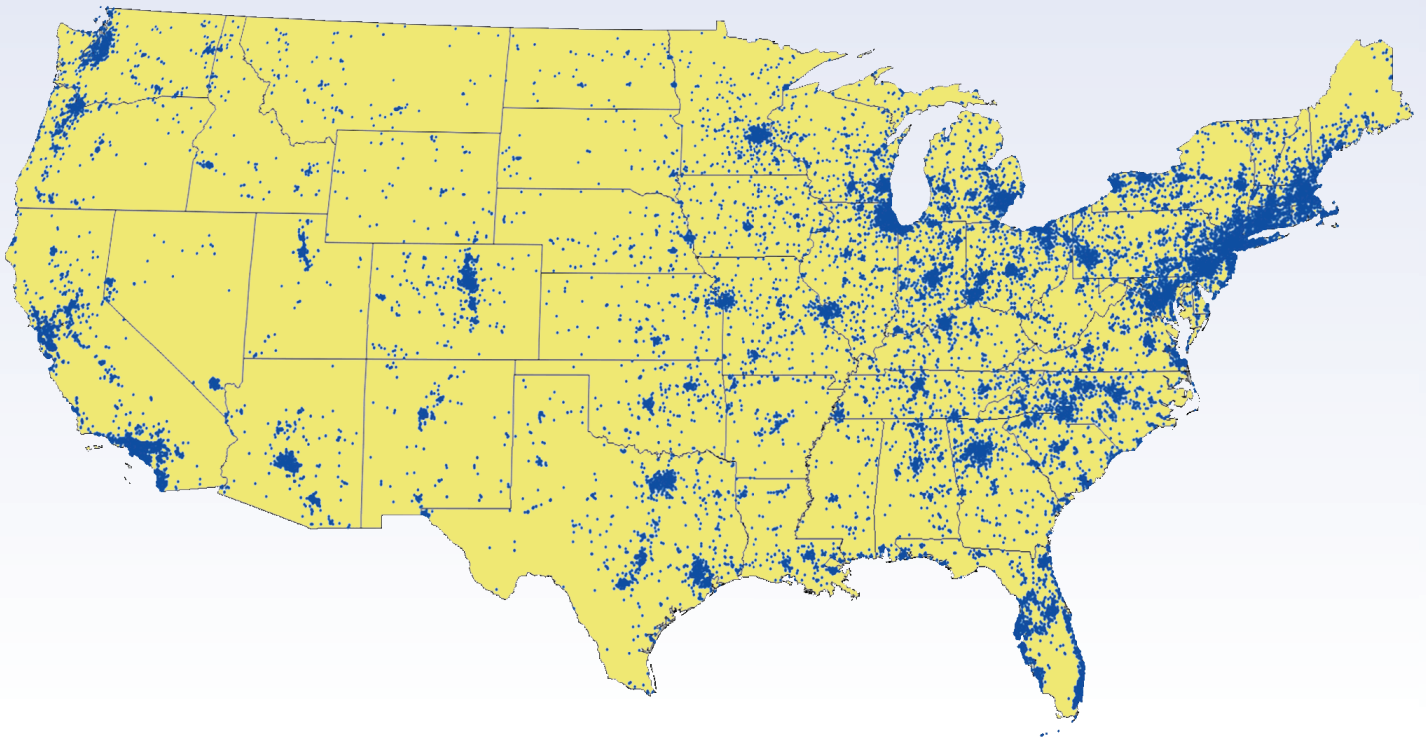
NARCOMS *NOW*

We are very excited to share our first issue with you!

We received almost **500** name suggestions and almost **3,000** votes!

The winning name, **NARCOMS NOW**,
was submitted by two participants in **Kentucky & Maine**

Coming in a very close second place and earning the title of a section in the magazine is
NARCOMS Messenger, submitted by participants in **Kentucky, Ohio, and Washington**



YOU are **NARCOMS**

PAGES & SECTIONS

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NARCOMS NOW

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Lindsey received her MS in Biostatistics in 2011 and is a Research Analyst with NARCOMS

The Spring 2012 Survey will be available in April:

On-line survey will be available on April 16 – June 29

Paper surveys will be mailed out beginning April 9th
The special section contains questions on Health Literacy:

[See Survey 101 on page 13 for more information](#)

You can review your past survey responses online at www.NARCOMS.org:

Click on the [Participant Log in Here](#) link

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

We welcome your questions, comments, & suggestions:

Call: 1-800-253-7884 (toll free US)
Email: MSRegistry@NARCOMS.org

Who you'll hear on the phone:

Chad, Chasity, Jeffry, Lindsey, or Desiree

En Español - Para acceder a nuestro sistema a línea:

www.narcoms.org/es

Nuestro sitio de web es de alta seguridad para proteger su confidencialidad. Para solicitar la envía de un cuestionario de inscripción por correo, llame al Registro NARCOMS al (800) 253-7884.

Hello All -

It is with great excitement that I welcome you to our new publication, *NARCOMS NOW*. In the last year we have set many goals for *NARCOMS*; one of these goals is in your hand (or on your computer screen) right now - a magazine for you, our *NARCOMS* participant.

We deeply value your contribution to our research efforts, and want to provide this magazine as a small “thank you” for your participation.

NARCOMS NOW will include:

- summaries of recent research surveys
- publications & presentations using *NARCOMS* data
- an introduction to upcoming surveys
- a section for MS news from around the world



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

We want you to feel more connected to what we learn through *NARCOMS*. We hope you will find this magazine valuable, and invite your comments and feedback to help make it better. In fact, you already contributed to naming it: from almost 500 names submitted, *NARCOMS NOW* won the final vote.

Finally, I want to thank each of you for participating in *NARCOMS*.

It is only through your generous gift of time filling out each of our surveys, that *NARCOMS* has become the powerful research tool that it is today. We know the surveys can be tedious and the questions occasionally odd or deeply personal. But your data on these surveys is the cornerstone from which all of our research arises. Without you, we can't do anything. 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 multiple sclerosis and their families through increased knowledge about MS.

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

Q: I'm concerned NARCOMS is going to use my personal information to sell my name to advertisers?

A: First, NARCOMS does not sell or share your personal information to anyone outside of NARCOMS. We do not release personal information to any outside group. This is why all invitations to participate in other research studies are sent directly by us and not the outside researcher.

Second, NARCOMS is a non-profit, free registry, sponsored by the Consortium of MS Centers. Any information provided to researchers using data collected through NARCOMS is de-identified (does not include your name or personal contact information). All data are secure and access to even de-identified data sets is provided only under binding legal agreements.

Finally, your personal information is always kept confidential. The Data Coordinating Center is under the observation of its Institutional Review Board (IRB), which approves any and all questionnaires before we can send them to you.

The IRB also reviews the entire project, and our approaches to protecting the privacy of data, at least once every year.

Q: Why did NARCOMS recently ask me about my internet habits and where I get my medical information?

A: That set of questions is from a national survey called Health Information National Trends Survey (HINTS) developed by the National Institutes of Health. The purpose was to provide insight into health information-gathering in general, and specifically relating to MS. Little is known about MS information preferences and the availability of information on MS.

Asking about where you get your medical information tells us about your access to online resources for MS and will help us serve NARCOMS participants more effectively.

Q: Why do you ask about lifestyle choices that don't seem to be related to my MS, such as smoking & drinking alcohol?

A: We ask about lifestyle choices to determine how these factors may be associated with MS and the severity or progression of the disease.

See “MS Reflections” on Page 8 for information about smoking & MS.

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.

MOVING FORWARD WITH MS: Mobility Issues & Answers

Whether you were recently diagnosed with MS and experience no mobility issues; received your MS diagnosis as a result of an incidence of limb weakness; or have experienced increasing difficulty with movement as your MS progresses, mobility issues may come with the territory when it comes to MS.

A neurodegenerative disease, MS affects the central nervous system and often results in a loss of balance and muscle control. Loss of mobility can affect not only physical health but mental health as well, including your mood, the ability to work, and to complete daily tasks. MS can greatly increase fatigue, which in turn can affect mobility and balance. Muscle spasms and tightness (which make insomnia a common problem) can be disruptive and painful.

The symptoms of MS may threaten to slow you down, but there are many ways to manage mobility issues caused by the disease. Exercises, particularly those that build leg, back, and core strength, have been shown to aid mobility and in some cases slow the progression of mobility symptoms. Remember to always talk to your doctor before starting any new exercise regimen. With the help of options such as assistive devices, adapted motor vehicles, and physical therapy, many MS patients learn to manage and even minimize symptoms affecting their movement.

Many MS patients learn to manage and even minimize symptoms affecting their movement.



LET'S GET PHYSICAL

Physical therapy (PT) may come as a welcome prescription for MS patients. While PT cannot cure MS, it can help ease symptoms such as tremors, tingling, numbness, paralysis, and loss of balance. Physical therapists teach exercises and stretches that can help patients compensate for impairments brought about by MS.

Often the exercises, once learned, can be performed at home. Many physical therapists can also perform “functional capacity evaluations,” which provide information for disability claims based on physical performance.

“The overall goal of physical therapy is to improve movement and function, and to relieve pain,” says Dr. Cecilia Graham, associate professor in the University of Alabama at Birmingham’s department of physical therapy. “In turn, this improves patients’ overall quality of life and increases independence.”



“A lot of people think they have to just live with the symptoms they have. But [PTs] can help a lot.”

—Dr. Cecilia Graham, UAB

To find a physical therapist, ask your doctor about outpatient PT services. (Your insurance company might require a referral for PT treatments.) Duration and frequency of treatments will vary by patient, but Graham, who has MS, says many patients are surprised by what PT entails.

“Physical therapy is not necessarily a big time or money commitment,” Graham says. “There are a lot of things that physical therapists can do to just help people function better. Don’t be afraid to ask your doctor whether you might need a referral for physical therapy. A lot of people think they have to just live with the symptoms they have. But we can help a lot.”



KEEP ON MOVING

A wide range of devices exist that can help manage the physical symptoms of MS. These so-called “assistive tools” make particular functions easier to perform, and can be prescribed by occupational or physical therapists. Check with your health insurance provider to see what physical and/or occupational therapy treatments it covers.

Some examples of mobility aids include:

Orthotics—lightweight inserts worn in shoes; increase stability and decrease fatigue

Canes—most useful when one leg is weaker than the other; should be held on the body’s stronger side

Walking Aids—these medical devices leverages functional electrical stimulation (FES) to improve the walking ability of people living with foot drop

Walkers—can provide support for maintaining balance, especially in the presence of significant leg weakness

Wheelchairs/Scooters—often recommended when patients suffer from falls; electronic scooters are often available at grocery stores, airports, and other large buildings, making for a less physically taxing shopping or travel experience

ON THE ROAD AGAIN

Being in a wheelchair or scooter full time does not necessarily end the ability to drive. The technology for adapting vehicles to be driven by those with physical disabilities continues to evolve. Often automobile manufacturers will assist with the cost to convert a vehicle and make it more adaptable for those with physical impairments.

The National Highway Safety Traffic Administration (NHTSA) has developed a process, based on the experience of driver rehabilitation specialists, to help avoid potentially expensive mistakes when buying and modifying a vehicle with adaptive equipment. These include evaluating your needs, selecting the right vehicle, choosing a qualified dealer to modify your vehicle, being trained on the equipment, and maintaining your vehicle.

Costs for modifying a vehicle can range greatly, but are often covered in part or in full by private health insurance. Your state's vocational services agency may also be able to provide some funding. For more information, see the NHSTA's brochure at www.nhtsa.gov/cars/rules/adaptive/brochure/brochure.html.

Physical therapy can help ease symptoms such as tremors, tingling, numbness, paralysis, and loss of balance.

Keep in mind that you may be required to obtain an on-the-road evaluation, performed by a driver rehabilitation specialist, who will generate a report containing specific recommendations on driving requirements or restrictions, and a list of recommended vehicle modifications. Contact the Association for Driver Rehabilitation Specialists (ADED; www.aded.net) to locate a qualified evaluator in your area.

A STEP FORWARD

One of the common traits of MS is that it has no single set of symptoms, or course of progression. The symptoms of MS are as variable as the individuals who have the disease. Knowing about the available options for making movement with MS easier can provide the opportunity to move forward each day with the disease.

As new drugs, therapies, and treatments are tested and improved, life with MS moves forward, and with the help of a variety of aids, MS patients can too.

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.

Your personal information is always confidential.



DOES SMOKING INCREASE THE RISK OF CO-EXISTING AUTOIMMUNE DISEASES IN MS?

INTRODUCTION

Some studies have reported that persons with MS are more likely to have other autoimmune diseases (AD) than persons in the general population, but some studies have not.^{1,2} When two diseases occur together more often than expected, researchers consider why.

One possible explanation is that the causes of the two diseases are the same.

This means that comparing people with both diseases to people with only one of the diseases may help to identify the cause of those diseases.

Smoking is a possible risk factor for MS and for autoimmune diseases including rheumatoid arthritis, inflammatory bowel disease (such as Crohn's disease), and possibly uveitis (swelling in the eye).^{3,4,5} We looked at whether smokers with MS were more likely to have a co-existing AD than non-smokers with MS.

THE QUESTIONS

In the Fall 2006 update questionnaire we asked NARCOMS participants whether they had other health problem in addition to MS.⁶ For each condition we asked what year the condition was diagnosed, and whether participants were receiving any treatment for the condition. The list of AD we asked about is here (Table 1).



Dr. Ruth Ann Marrie

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 and will be sharing her knowledge with NARCOMS participants throughout the year.

“Smoking was associated with a 43% increased risk of rheumatoid arthritis and 38% increased risk of uveitis”

Most NARCOMS surveys contain some question about smoking status, but in Fall 2006 more in-depth questions were asked and then we classified each participant

as “Ever Smoked” if they had indicated smoking 100 or more cigarettes or “Never Smoked” if they had smoked less than 100 cigarettes total.

STUDY PARTICIPANTS

A total of 8,983 NARCOMS participants were included in the study.⁶ Of these 24% were men and 76% were women. Ninety-four percent were white, 2.4% were African American, and 3.3% reported another race. The average age of the responders was 52.7 years and 54% of them reported having smoked at some point.

Table 1. Co-existing Autoimmune Diseases

Autoimmune Disease	Percent (%) Affected
Thyroid disease	10.0
Rheumatoid arthritis	3.6
Inflammatory bowel disease	3.5
Uveitis	3.3
Systemic lupus erythematosus	1.1
Sjogren's syndrome	0.6

CO-EXISTING AUTOIMMUNE DISEASE

Overall, 1,649 (18.5%) reported at least one AD, the most commonly reported was thyroid disease. The frequency of AD increased with age (Figure 1). Nearly 5% of participants (410) reported a pre-existing autoimmune disease when their MS symptoms first started.

Of the 8,929 participants who answered the smoking questions, 99% (8,875) also answered the questions about co-existing AD. Of these, 4,834 participants had ever smoked. Among those who had ever smoked, 10.7% reported at least one AD. Among nonsmokers, 7.8% reported at least one AD. Ever smokers were 22% more likely to report an autoimmune disease than nonsmokers.

Among those participants who did not have an AD when their MS symptoms first started, smokers were 23% more likely to develop an AD than non-smokers. Female smokers had a 29% increased risk of developing a co-existing AD but male smokers did not have an increased risk of developing a co-existing AD.

Smoking was associated with a 43% increased risk of rheumatoid arthritis and 38% increased risk of uveitis. These findings suggest that further research is needed into the effects of smoking in persons with MS. Other researchers will need to see if they can reproduce these findings.

NARCOMS, SMOKING STATUS AND FUTURE RESEARCH

We will continue to ask about smoking status to see if these relationships change over time and we have added questions

“Women smokers had a 29% increased risk of developing a co-existing autoimmune disease”

about exposure to secondhand smoke to determine if there are similar relationships between exposure to someone else's smoke and AD in persons with MS.

Responses to these question will be very important and we truly appreciate your taking the time to complete each update survey.

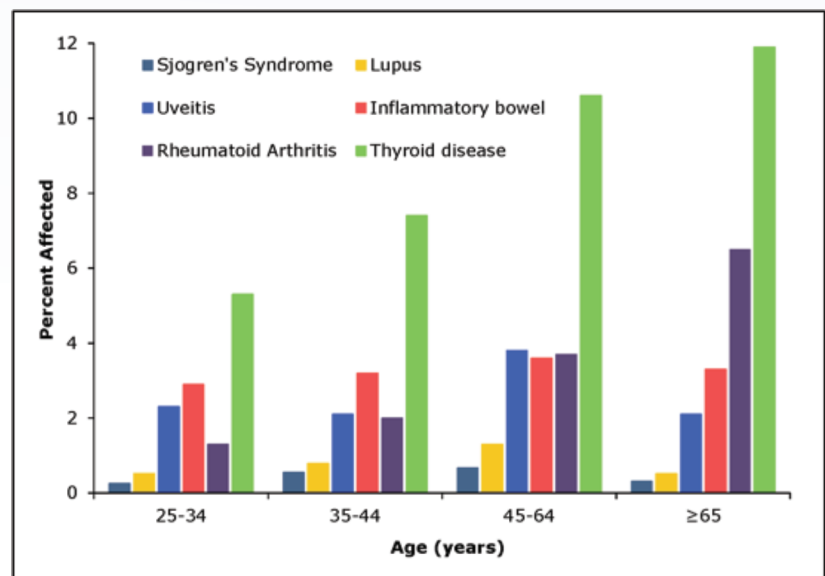
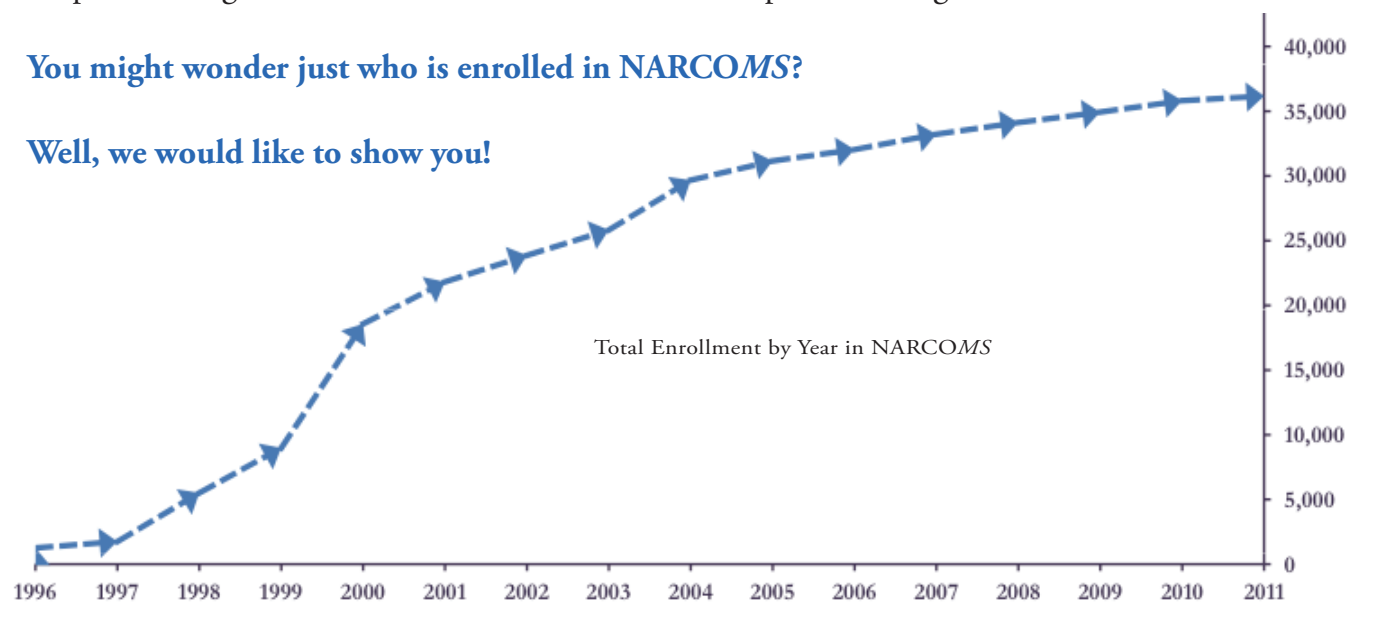


Figure 1. Autoimmune Diseases by Age Group

NARCOMS started in the 1990s with almost 9,000 participants by the end of that decade. While there have been some organizational changes, enrollment has grown every year. With over 35,000 participants enrolled in NARCOMS by 2010 and surveys completed by almost 10,000 active participants every Spring and Fall, you have provided a great deal of information about MS and persons living with MS.

You might wonder just who is enrolled in NARCOMS?

Well, we would like to show you!

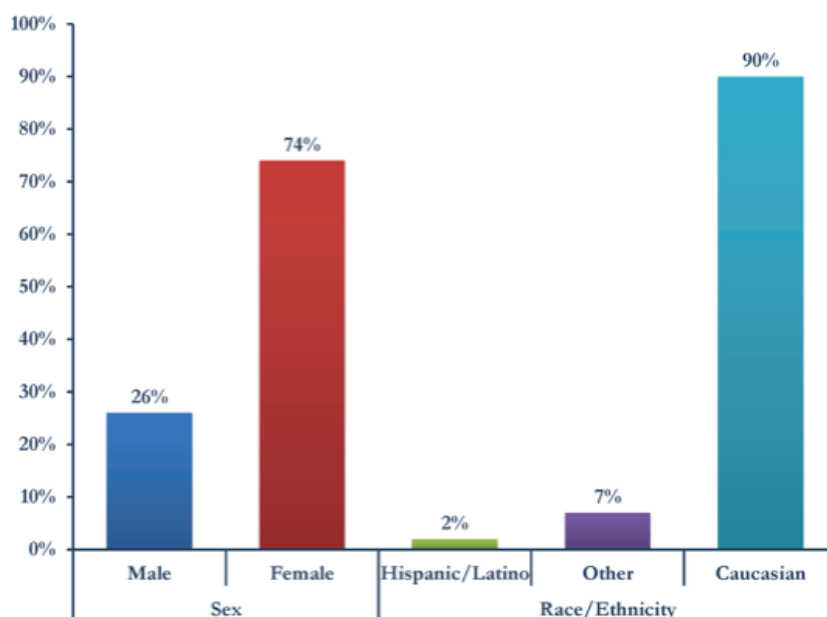


Participants by Location: Most of our participants lived in the US when they enrolled (about 95%) with more than 400 enrolled living in Canada, 60 in England, and 34 down under in Australia. Within the US, the highest state enrollment is for California, closely followed by New York. We even have about 50 enrollees from Hawaii and more than 60 in Alaska!

Demographics:

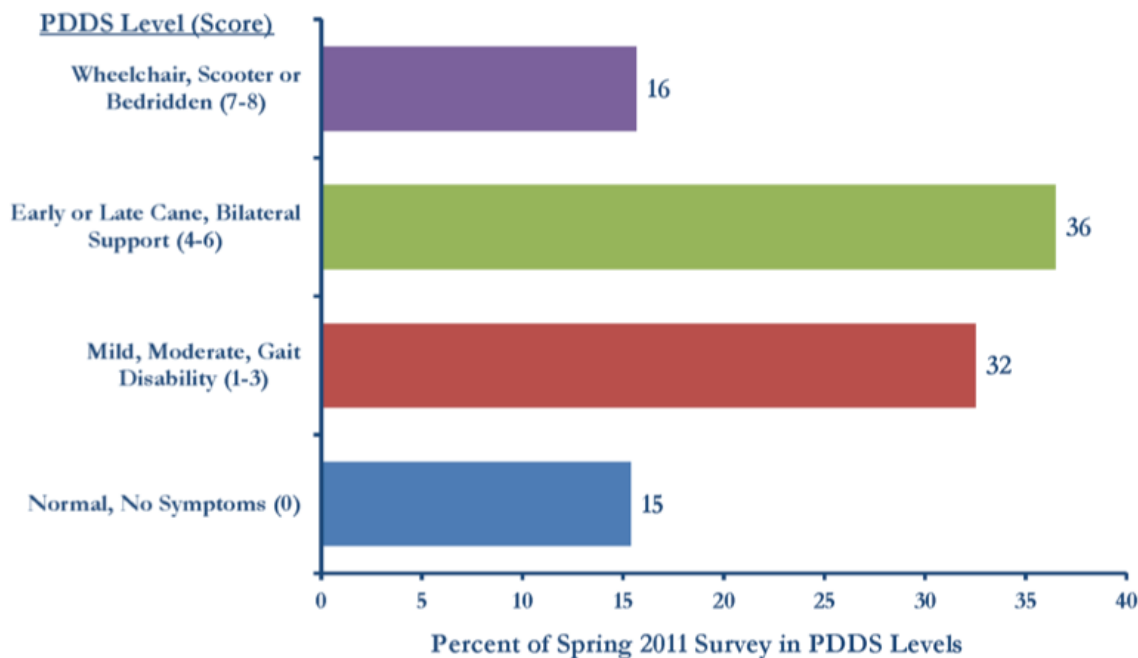
Not surprisingly, almost $\frac{3}{4}$ of the participants are Female and 90% identify themselves as White/Caucasian, though 2% are of Hispanic/Latino Ethnicity.

On average, participants reported being 38 years old at disease onset.

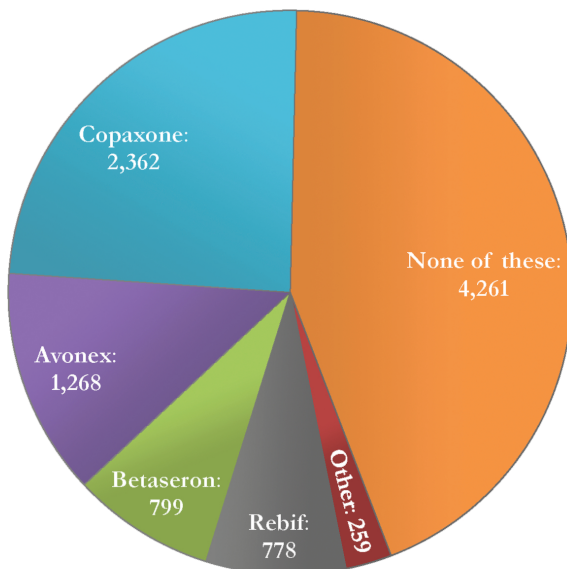


Disease Status – Years of MS & Patient Determined Disease Steps (PDDS):

As of June 2011, NARCOMS participants on average have been living with MS for 19 years, though this ranges from the newly diagnosed to persons with more than a 30 year history of MS symptoms. Almost half (47%) of participants are still relatively mobile, with a PDDS in the range of Normal (0) to a Gait Disability (3). For more on Mobility & MS see **Feature Focus** on page 5.



■ Other ■ Rebif ■ Betaseron ■ Avonex ■ Copaxone ■ None of these



Treatment:

Most participants, 55%, had used a disease modifying therapy in the six months prior to the Spring 2011 survey; with most taking a form of interferon-beta (Avonex, Betaseron or Rebif) or Glatiramer Acetate (Copaxone).



This last year was a year of transition at NARCOMS, with new leadership and some new directions for NARCOMS. As many of you already know, Dr. Timothy Vollmer stepped down at the end of 2010 after leading NARCOMS since its original inception. His bold vision for NARCOMS and passion in engaging persons with MS in their own research gave rise to what is now the largest voluntary MS registry in the world. To better manage such a large registry and focus on more research projects, the director role was divided into two – Scientific Director and Managing Director.

In addition to organizing the NARCOMS leadership and personnel, NARCOMS has developed a strategic plan with specific initiatives to help refine our Vision, Mission, and Goals for NARCOMS.

ORGANIZATION OF NARCOMS

Dr. Ruth Ann Marrie

Scientific Director

A clinical neurologist and epidemiologist from the University of Manitoba (Canada), Dr. Marrie oversees the scientific direction of NARCOMS. This includes topics for update surveys, research priorities, analysis of the data collected, and review of results that come out of NARCOMS projects.

Dr. Robert Fox

Managing Director

Dr. Fox, also a clinical neurologist, will provide administrative oversight for NARCOMS. Including interactions with external collaborators, management of ongoing NARCOMS projects, fiscal oversight, and reporting to our parent organization the Consortium of MS Centers.

Dr. Gary Cutter

Coordinating Center Director

Dr. Cutter (PhD), a Biostatistician and MS Researcher at the University of Alabama at Birmingham, coordinates and manages all research projects and oversees the NARCOMS staff at UAB to ensure the day-to-day operations flow smoothly.

NARCOMS MISSION STATEMENT

NARCOMS VISION

To improve clinical care and quality of life for persons with multiple sclerosis and their families through increased knowledge about MS.

NARCOMS MISSION

To conduct epidemiological and health services research in multiple sclerosis. To support new investigators and facilitate exploration of emerging research areas, as well as collaborative multi-center research focused on multiple sclerosis, its treatment and prevention.

NARCOMS GOALS

Patient: Increase understanding of MS from the perspective of the person with MS

Disease Management: Assess knowledge of treatment and healthcare services, including expected and unexpected consequences thereof

Knowledge Transfer: Disseminate knowledge and increase awareness of MS and its management to patients, their families, care providers, researchers, advocacy groups and policymakers

Understanding the NARCOMS Update Surveys – Why we ask what we ask

Did you know that 45% of NARCOMS participants have completed college? On average, persons with MS are more highly educated than the general US population (26% completed college according to the 2010 US Census). However, being educated does not necessarily mean that you can easily understand medical information, or use that information to make an informed health decision. The Spring 2012 Update Survey, which will be released online and mailed out in mid-April, will include new questions on a topic called “Health Literacy.”

LITERACY VS. HEALTH LITERACY

In general, literacy is a set of reading, writing, basic math, speech, and comprehension skills. We use these skills to function in society each day. When we apply these skills to a health context, such as reading a label on a prescription bottle or a nutrition label, or understanding self-care instructions, it is called health literacy. Your health literacy influences your health care decisions. Lower health literacy can make understanding health and treatment options more difficult.

Why is it important to know about the health literacy of the NARCOMS population? You may recall we also recently asked about where you obtain your health information. This, together with knowing the level of health literacy, will allow us to:

- Adjust the way we present information to NARCOMS participants, online, in print, and in the surveys
- Compare the NARCOMS results with similar research in other populations and other diseases.

Research Definition: Validated Questionnaire

A validated set of questions is one that has gone through testing procedures to show that it measures what it was designed to measure no matter:

- who responds
- when they respond
- who asks the question

The same set of questions is used, in the same order and will give reliable and dependable results that can be applied to a general population.

THE QUESTIONS

We have chosen a set of questions on this topic to compare the results with similar surveys already conducted in other populations. (See the sidebar for a definition of a validated questionnaire we use.) In the three short sections, you’ll see a series of questions that assess health literacy as it relates to reading medical terms; how much you use the internet to access health information; determine what you think about the information you find online; and determine how well you can interpret health information that uses numbers.

THE ANSWERS

These questions are not a test and it's not about how well you score. Some of the questions may not have "correct" answers. Here are some things to keep in mind while answering the questions:

Section A: You will be asked to look at a list of words that may or may not be real words. Simply place an "X" next to the words you think are real words.

Section B: This section will focus on how you use the internet to obtain health information. It is ok if you do not use the internet, simply check the box indicating this and skip to the next section. Please as honest as you can about using the internet to obtain health information. Many doctors and clinics now use the internet as a resource for patients, and it will be useful to know how NARCOMS participants in world's largest MS registry use the internet for health information.

Section C: You will be looking at an example of a nutritional label, similar to those found on almost every pre-packaged food item you buy and answer a few questions about what is on the label.

OUR GOAL

With these questions, we hope to capture how various people use medical information, and to improve how such information is presented to you and others with MS in the future. We understand that new sections add to the time it takes to complete the survey and we thank you for taking the time to complete these new questions.

Reference: www.census.gov/newsroom/releases/archives/education/cb11-72.html



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

SAFETY AND TREATMENT NEWS

First Test Approved to Help Detect Risk of Rare Brain Infection

On January 20, 2012, the FDA issued a press release that reads in part: “the U.S. Food and Drug Administration allowed marketing of the first test to help determine the risk for a rare brain infection called progressive multifocal leukoencephalopathy (PML) in people using the drug Tysabri (natalizumab) to treat multiple sclerosis (MS) or Crohn’s disease (CD).”

The virus is present in about ½ of all US adults, but usually doesn’t cause symptoms or any problem. In MS patients taking natalizumab and carrying the virus, the virus can go to the brain and cause a serious brain infection. The overall risk for developing PML is believed to be about 2 in 1,000 and this blood test along with other risk factors, including duration of treatment with Tysabri and previous treatment with other drugs that suppress the immune system, can help identify who is at a higher risk for this serious complication. It is important to note that this new test does not test for the brain infection itself, but rather identifies who has been exposed to the virus that causes PML.

RESEARCH NEWS

Stem Cell Study shows Promising Safety Results in Progressive MS

A recent article published in *Lancet Neurology* reported that stem cells from a person’s own bone marrow (called autologous mesenchymal stem cells) were safely given to patients with secondary progressive multiple sclerosis. The study was conducted

in Europe and involved 10 people with secondary progressive MS who received an intravenous infusion of the stem cells.

The participants were followed for 10 months after the infusion for any adverse reactions. One patient developed a rash and two developed bacterial infections but the researchers did not find any serious adverse events in the 10 months following the infusion. In addition, the researchers also found some evidence of improved vision. Additional research is ongoing and will need to be conducted in many more patients but the procedure was well tolerated in this group.

OTHER NEWS

The 4th Cooperative Meeting of the Consortium of MS Centers (CMSC) and Americas Committee for Treatment and Research in MS (ACTRIMS) will take place May 30 - June 2, 2012 in San Diego, CA. The meeting is for MS healthcare professionals and researchers and focuses on a wide range of clinical and research areas, from Basic Science and Environmental Factors to Disease and Symptomatic Management.

If you are attending, please visit us at our NARCOMS booth. NARCOMS Now will be covering the CMSC Annual Meeting with live blog posts and stories in future issues of this magazine. For more information on the meeting, visit www.cm-sc-actrims.org, and watch for the blog posts on www.narcoms.org/narcoms_now

For more information on all of these stories visit www.narcoms.org/narcoms_now/MS_News

play

Find These Words: advance, confident, change, encourage, fly, breakthrough,
jump, excel, communication, inspiring, current, present, evolve,
accomplish, dashing, bold, herald, network, ally, scout



As someone who has had MS for 36 years, (diagnosed 35 years ago), I offer my experience hoping it might be helpful to people with more recent diagnoses. When I first found out that I had MS, I read up about the disease. I'd barely heard of it. I knew what might be coming.

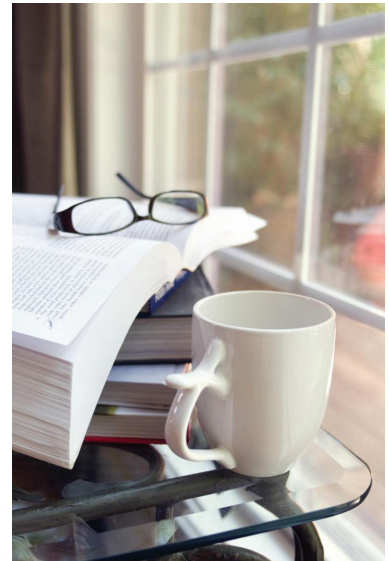
For the first 18 years where I only had brief 2 week relapses every 2 years, I was extremely grateful. But I never thought that I could "beat it." When I began to have extreme fatigue and difficulty walking, I wasn't surprised or shocked. I had no control over the disease, but at least I wanted control over my mental health. Not wringing my hands and accepting possible reality helped me face the future calmly.

In 2000, my neurologist suggested that I give a new injection a try for my fatigue. After 8 months of receiving an injection once every 3 months, my fatigue became manageable. I stayed on it for 3 ½ years (longer would have hurt my heart) and the fatigue hasn't returned.

I am prepared that the fatigue might return at any time.

Again, I won't be shocked. I can no longer drive. I am what is called "wheelchair bound". But I use a scooter, go to the library, scooter to the neighborhood coffee shop for lunch with friends, and ride to the river to read a book. Adult refugee students come to my home for English-as-a-Second-Language lessons.

I don't fool myself that this plateau will last forever, but until the fatigue returns or other dastardly MS symptoms arise, I say, "Enjoy your life. If you don't who will?"



Acceptance and moving forward has worked for me. Best of luck to all of us!

Melinda F.

Have a story for Faces of NARCOMS? Email MSRegistry@narcoms.org

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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