

## ACCELERATING DISCOVERY:

An Interview with Ann Romney



## Congratulations to our **NARCOMS NOW Photo Contest Winner**



### **"HIKING THE WAVE"** BY STEVE W. OF SCHAUMBURG, IL

Congratulations to the overall winner of our *NARCOMS Now* photo contest. Steve W.'s "Hiking the Wave" image of him hiking in the Vermillion Cliffs wilderness area is an inspiration. He said, "Hiking to remote and unique places keeps me motivated to remain active and strong, and photography exercises my creative side and keeps my mind sharp." We can see the results, and they are spectacular!

Thanks to all who participated by sending your photos and voting.

A project of the Consortium of Multiple Sclerosis Centers



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MULTIPLE SCLEROSIS CENTERS

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## NARCOMS NOW

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# A Letter from the Director - Spring 2015

## Greetings,

Spring is upon us—even if the weather says otherwise. March is MS Awareness Month, and we're pleased to continue to be an ongoing, crucial contributor to multiple sclerosis research by providing data. We can't say it enough: Thank you for your ongoing participation in NARCOMS. We hope this month you'll consider telling someone you know about NARCOMS, and perhaps they will consider participating too.

To highlight the importance of MS research, we had the privilege of speaking with **Ann Romney**, former first lady of Massachusetts and, importantly, namesake sponsor of the **Ann Romney Center for Neurological Diseases**. The center, located at Brigham and Women's Hospital in Boston, aims to fund research to study five neurologic diseases under one roof: multiple sclerosis, ALS, or Lou Gehrig's, Alzheimer's, brain tumors, and Parkinson's. Romney spoke frankly about her journey from diagnosis to where she is today—in remission and proudly speaking out about the importance of research to find a cure for these neurologic diseases. As she so strongly stated, "In 20 years, I don't want to be talking about neurologic diseases because I want them to be cured."



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

"**MS News**" this issue focuses on advances in placental cell research in MS; on the effects of switching from an injectable to an oral drug over switching to another injectable; on first results of the National Multiple Sclerosis Society Comorbidities Project; and on a latest publication using NARCOMS data, on the prevalence and characteristics of tremor. We're also launching a section on clinical trials in MS. "**MS Apps**" is also back in this issue, highlighting apps designed for use by clinicians and their patients.

"**Snapshot**" this issue highlights some of the early results of the "NARCOMS Survey on Marijuana and MS," distributed in August 2014. The full results will be available later this year, but take a peek at some of the numbers now. In "**MS Reflections**," **Dr. Stacey Cofield** addresses revisions recently made to definitions of the disease course in MS. The last time the definitions were revised was in 1996. Several changes have been made which are worth noting and worth asking your care provider about.

Finally, we are looking forward to presenting NARCOMS research at both the upcoming American Academy of Neurology and Consortium of Multiple Sclerosis Centers meetings. Look for stories to come from those important research forums, in future issues of *NARCOMS Now*.

Best,



**Dr. Ruth Ann Marrie**  
Managing Director, NARCOMS



# NARCOMS INFORMATION CORNER



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## ACCELERATING DISCOVERY: An Interview with Ann Romney

Looking at the smiling faces radiating from her family photos, it's easy to imagine there is nothing ailing Ann Romney. But Romney, like so many people living with multiple sclerosis, faces challenges each and every day.

"It's a daily struggle, not just something you overcome," Romney says. "It's something you work on every day."

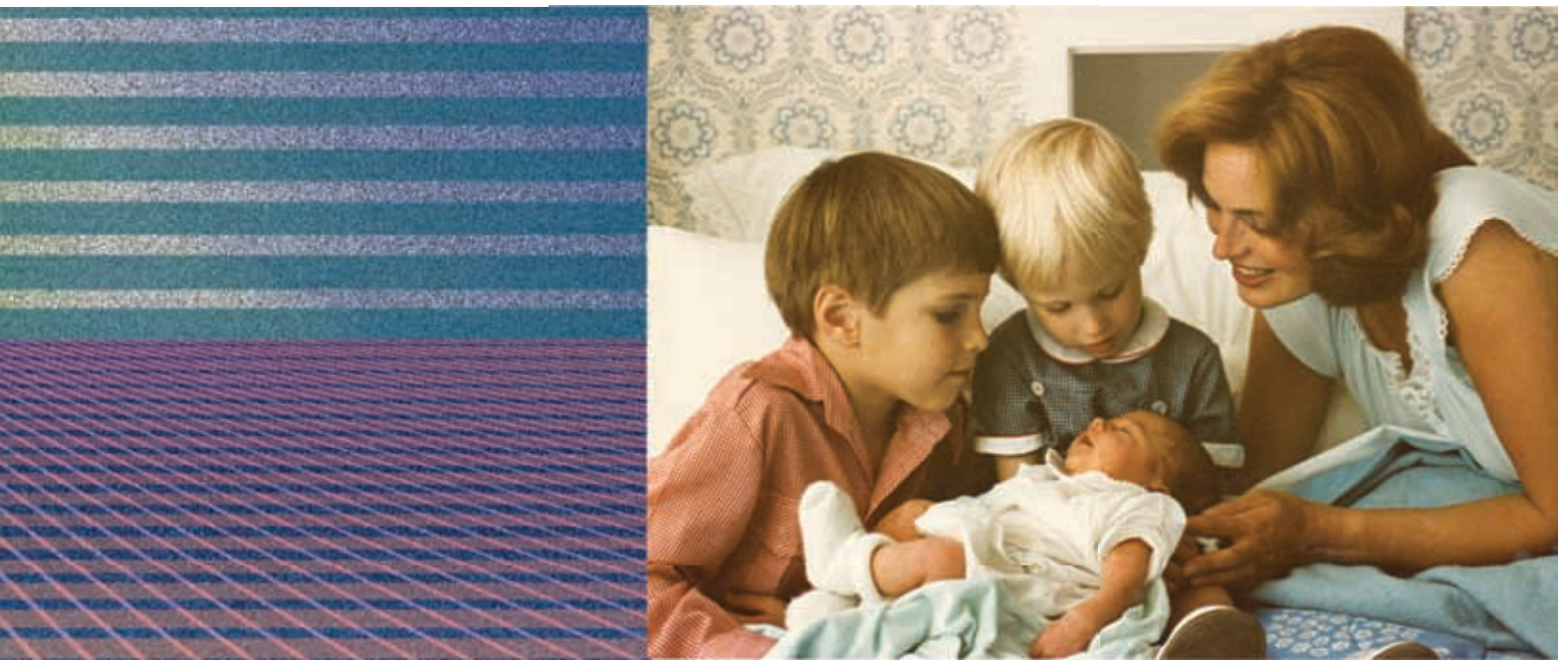
As former first lady of Massachusetts and wife of 2012 Republican presidential candidate Governor Mitt Romney, Romney recognizes she is in a position to make a difference. In October 2014 she announced the opening of the Ann Romney Center for Neurologic Diseases at Brigham and Women's Hospital in Boston, her hometown for forty years. The center will fund research in five of the world's most complex neurologic diseases: MS, Alzheimer's, Parkinson's, brain tumors, and ALS or Lou Gehrig's disease.

"The Ann Romney Center for Neurologic Diseases will accelerate global innovation and

discovery, leading to faster treatments and preventions for these diseases," Romney says. "My wish is that this center will give a voice to those [with] neurologic diseases and restore a culture of hope for those in need."

The idea for the center came during a visit with her neurologist, Dr. Howard Weiner, she says. Dr. Weiner is the Robert L. Kroc Professor of Neurology at the Harvard Medical School, Director and Founder of the Partners Multiple Sclerosis Center and Co-Director of the Center for Neurologic Diseases at the Brigham and Women's Hospital. He has been Romney's neurologist for nearly 20 years.

"Every time I'd have my appointments over the years, I'd be curious about the research advancing in the lab," she says. "As I thought through the initiatives that I wanted to champion if I became first lady [of the United States], a center to advance neurologic research seemed a natural fit. When Mitt lost I thought, 'Why not do it, still?' And then Weiner said his MS research is resulting in advances in other brain diseases as well."



Studying several neurological diseases under one roof seemed like a clear way to potentially accelerate the research, Romney says. “It became an important topic for me not only studying the other diseases together in the lab, but also to foster collaborations. We’ve got to bring our collective knowledge together. That is the objective of the Ann Romney Center—not only to study MS but ALS, Parkinson’s, brain tumors, and Alzheimer’s.”

## CHALLENGE LEADS TO REWARD

Romney, 65, was diagnosed with MS 17 years ago. She was living in Boston at the time, but in 1999 moved to Salt Lake City, Utah, with her husband Mitt. Mitt was president and CEO of the Salt Lake Organizing Committee for the 2002 Winter Olympics (a position that led to his successful 2002 election as governor of Massachusetts). The move to Utah was a tough one for Ann, she recalls.

“I knew nobody in Salt Lake—I had lived in Boston my entire adult life, and my doctors were there,” she says. “It was an important time for me because I was really, really sick. In Boston, people would see me and I’d still look like I was fine, but it was very hard for me to keep up with all the boards I was on, my involvement with the church—all these different things I had always done,” she says. “I was really struggling and could barely take care of myself.”

Romney recalls that despite being challenging, relocating proved valuable in unexpected ways.

“For me to walk away and say goodbye to everybody—it was so hard but also allowed me to say, ‘I can’t do anything because I’m moving.’ It was in a way a relief to not have to admit that I just don’t have the energy to be productive.’ Relocating to Salt Lake City forced me to make time to take care of myself—realizing, at that time, that was my most important job.”



## FEATURE FOCUS

Romney emphasizes how important that recognition is with the diagnosis of a chronic disease like multiple sclerosis, and understanding what that means for each individual.

“It’s a tough thing newly diagnosed patients have to deal with—how to figure out how to communicate to everyone around us. Not accepting extra responsibilities, sitting down with family, friends, and coworkers and saying, ‘I have limited energy and I need to save it and not do everything I was able to do before.’”

In Salt Lake, Romney continued taking steroids intravenously on a monthly basis, but also began trying new activities to boost her energy and maintain or improve her fitness. “I tried reflexology and acupuncture, and began just pushing myself a little more, being outdoors, trying things that gave me more energy. After three years I continued to slowly—and I mean slowly—improve my energy.”

It was her love of more than 30 years, her husband Mitt (the Romneys were married in 1969 and have five sons together), who suggested Ann carry the Olympic torch in the 2002 Olympics.

Ann, who says she “had a hard time walking up a flight of stairs when I got to Salt Lake,” was convinced when Mitt told her all of the torch runners were appointed as heroes in others’ lives. “He turned to me and said, ‘You are a hero in my life, I want to nominate you.’ I was so stunned, I decided I had to do it.” She started jogging slowly to train for the 1/8th mile run. During the event, Mitt handed her the torch and ran alongside her, she recalls. “A few of my children were there running next to me for support. I looked around and everyone was crying—they knew what this meant and how significant it was. I took off, and Mitt’s like, ‘What the heck?!’ I had a burst of energy and ran that eighth of a mile at a pretty quick clip. What a miracle and wonder that I was able to overcome the disease in that moment. I really appreciated my husband sticking with me.”

Being in Salt Lake also provided Romney a chance to engage in an activity she hadn’t enjoyed since she was a child—horseback riding. She credits riding with helping her stay active with her MS. As a child she had horses she says were her best friends.





When she was diagnosed with MS, she says, she asked herself, “‘What do I have in my life that I really love that I want to do before I get too sick to do it?’ It was horses. I instantly thought, ‘I’m going to start riding again.’”

In Salt Lake the Romneys bought Western trail horses and on weekends loaded them into trailers, drove to the mountains, and rode in what Ann calls, “complete wilderness. The second we’d get in the saddle, Mitt would start to sing, and that’s what happens when you ride, your soul starts to sing. You forget everything, all your problems, you have more energy, just by getting on the back of the horse. I call them my partners in therapy.”

Romney says the ability to ride is motivation for her to stay in shape, because horseback riding requires her to be fit. “I am still riding and loving it and loving my horses—it’s something that is just for me. I have 23 grandchildren, 10 children—5 sons and 5 daughters-in-law—and a very busy husband, all with busy lives and this is just for me. This is my thing and my joy. It’s wonderful to have that in my life.”

## AMBASSADOR FOR MS

Romney says today she is thrilled at the possibilities the Ann Romney Center for Neurologic Diseases poses for advancing neurological research. And as she copes with her MS on a daily basis, as a public figure, she says she feels “blessed and happy to be an ambassador for MS.”

“It’s time for me to give back. People suffering with these diseases have touched me in such a personal way; I see their struggle, I know their struggle, because I’ve been there. I feel so overjoyed when people with MS come to events and show up for me. It’s time for me to show up for them now and do whatever I can to give them hope.”

Romney commends those who participate in research studies and clinical trials to find cures for neurological diseases. “The more we can raise awareness, and let people know what’s happening out there, the more people are going to want to help and get on the bandwagon,” she says. “I applaud those who go into your study [NARCOMS] and register—that’s a lot of work to do that, that’s a commitment. It’s so important. Collectively we can do so much.”



## THE ANN ROMNEY CENTER FOR NEUROLOGIC DISEASES

Ann Romney has set a one-year goal of raising \$50 million to support the center, which is co-directed by Dr. Howard Weiner and Dr. Dennis Selkoe.

“I set the one-year goal for myself,” Romney says. “I know it is ambitious but there is so much work to be done. The faster we can fund the research the faster we can find treatments and cures.”

“Through innovative research and treatment, Dr. Weiner and the incredible team at Brigham and Women’s have given me the gift of enduring hope, and that is what this Center is really about. It’s about improving and saving the lives of countless patients and families facing a heartbreaking diagnosis.”

Weiner says the Romney center has three goals: to break down silos and foster collaboration within institutions and between institutions; “drilling for oil,” or funding “the type of work NIH would never fund—where we try to open up new areas;” and “shots on goal,” a sports term, which means “driving the research so we are always testing a new drug or treatment in these diseases.”

Weiner uses the examples of several concepts in development, including a nasal vaccine for Alzheimer’s disease; special antibodies for brain tumors; and new treatments for progressive MS—and discusses trying to move each of these into initial phase clinical trials.

“We want to treat people, and if you don’t get compounds into people, you’re not treating them,” he says. “We have to be continually driving toward these, then keep building the pipeline.”



The Center’s bi-partisan advisory board includes such notable members as Neil Cavuto (anchor, “Your World with Neil Cavuto” and Fox Business News and fellow MS patient), Congressman Joseph Kennedy III, Montel Williams, Marc Mezvinsky (husband of Chelsea Clinton), and the former governor himself.

In 2016, the Ann Romney Center for Neurologic Diseases will move to a new location, the Brigham Building of the Future (BBF). The BBF will be “one of the most technologically sophisticated patient care and research facilities in the country,” Romney says.

“It’s humbling to think about this, but I want the Ann Romney Center to go down in history as the place where the best treatments for MS, Alzheimer’s, ALS, Parkinson’s, and brain tumors were first discovered,” Romney says. “In 20 years, I don’t want to be talking about neurologic diseases because I want them to be cured.”



# MS APPS (& BLOGS)

This installment of MS-related apps focuses on apps designed for patients and clinicians. NARCOMS and *NARCOMS Now* do not endorse the use of any particular tools or treatments for multiple sclerosis.

Have a favorite app or blog that makes your “MS Life” easier? LEmail us at [narcomsnow@narcoms.org](mailto:narcomsnow@narcoms.org). All of the apps featured below are available for download, free, on iTunes or Google Play.

These apps have not been evaluated for medical accuracy by *NARCOMS Now* and unless otherwise indicated, have not been approved by the U.S. Food and Drug Administration (FDA).

## **My MS Conversations** (By Syandus Inc. for the CMSC)

The Consortium of Multiple Sclerosis Centers has developed a free app called “My MS Conversations,” for use as an interactive group session featuring animated participants serving as “experienced virtual patients.” The characters can share their stories of coping with MS, and respond to input as the user drives the conversation to topics of his or her interest. It is designed for use by anyone affected by MS, including patients, their families, and professionals, and touches on topics ranging from the basic (“What is MS and why do I need treatment?”) to more in-depth conversations regarding adherence, pitfalls in self-management, the long-term nature of MS and gender-specific concerns.

## **EDSS Calculator** (Developed at Sunnybrook Health Sciences Centre in Toronto, Canada) (Note: Costs \$0.99 to download)

The Toronto EDSS Calculator helps healthcare professionals and researchers compute the Expanded Disability Severity Score (EDSS) for patients with Multiple Sclerosis, using Kurtzke’s algorithm. It includes instructions and videos to help grade each functional system accurately.

A screen summarizes all functional systems along with the EDSS, which can be saved as a picture or printed and added to a chart.

## **Multiple Sclerosis Diagnosis & Management** (By Börm Bruckmeier Publishing LLC for the NMSS)

This is an app designed for practicing neurologists, resident physicians, and other healthcare professionals involved in the management of patients with MS. The Multiple Sclerosis - Clinical Care App contains current information on the diagnosis, classification, and management of multiple sclerosis (MS), concisely presented for use at the point of care. The content has been developed by Borm Bruckmeier Publishing in collaboration with the National MS Society.

### **Highlights include:**

- Signs and symptoms characteristic of MS
- Common clinically-isolated syndrome presentations
- National MS Society resources for clinicians and their patients

## **Multiple Sclerosis-MedImage Cases** (by @Point of Care)

This new “eTextbook” is a series of 26 biweekly MRI case presentations, providing audio commentary from MS experts of the MRI. It is designed to be used as a tool to measure disease activity, disease progression, and response to therapy, and to guide practical therapeutic approaches. Each case is peer-reviewed and offers CME/CE credit.

Wow—that Fall 2014 update sure was a doozy! Thank you for completing all those questions about treatment history; we know the survey was long and at times a bit confusing. We always try to make the questions as clear as we can, but some topics are hard to ask about in an easy and straightforward manner. Thanks again for your answers, and your patience!

The new questions in the Spring 2015 update are simpler and easier to answer. We will ask about how active you are at home and at work (if you work), and how much time you spend doing different levels of physical activity, including walking and sitting.

In addition, you'll be asked if you have had any accidental falls and whether you use any assistive devices to help with your mobility, such as an ankle support, a scooter or a cane.

It is important to find out how active people living with MS actually are in their daily lives and in different stages of the disease. Prior research has shown that staying physically active can help you feel better overall—both mind and body. The information we gather can provide guidelines for healthcare providers to better assist you with improving your activity level and adjusting your daily activities to fit your MS life. Thank you in advance for completing this short special section.



**The Foundation of the Consortium of Multiple Sclerosis Centers  
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## HELP US WRITE THE NEXT CHAPTER...



- Opportunities to improve patient care through medical student research projects, rehabilitation trainees and resident scholarships
- Fellowships in MS-related research and clinical care
- Opportunities for CMSC Pilot Research Grants and patient registry efforts

**The Opportunities to Improve Patient Care in the Future Are Many –  
Limited Only by Our Resources**

Visit our website for more information on scholarships, fellowships and awards: [www.cmscfoundation.org](http://www.cmscfoundation.org)



## NARCOMS at the American Academy of Neurology and CMSC Annual Meetings

Two posters highlighting findings based on NARCOMS research will be featured at the **American Academy of Neurology (AAN) 67th Annual Meeting**, April 18 to April 25, at the Walter E. Washington Convention Center, in Washington, DC.

Dr. Stacey Cofield, NARCOMS Deputy Director, will present a poster entitled, “Marijuana Usage and Disability in MS in the NARCOMS Registry” as poster P1.140 during poster session P1, taking place on April 20 from 2–6:30pm.

Amber Salter, NARCOMS researcher, will present a poster entitled, “Characteristics of Switchers to Newer Therapies in the NARCOMS Registry” as poster number P3.282 during poster session P3, taking place on April 21, from 2–6:30pm.

Look to future issues of *NARCOMS Now* for information on this research.

NARCOMS is proud to be hosting a booth at the **Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting** in Indianapolis, Indiana, May 27–30, 2015.

This includes two posters, on patient perspectives in insurance changes and therapy decisions; and disease modifying therapies and the decision-making process, as well as a platform presentation on marijuana usage in NARCOMS registry.

For more information on the meeting visit: [www.annualmeeting.ms-care.org](http://www.annualmeeting.ms-care.org).

## In Memory: Joseph Herbert, MD, NYU Langone MS Comprehensive Care Center Founder



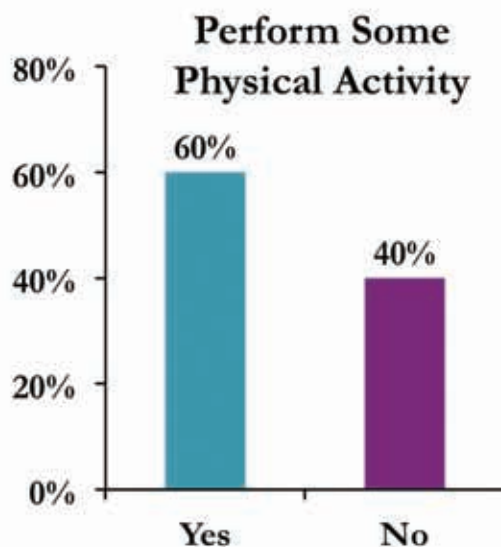
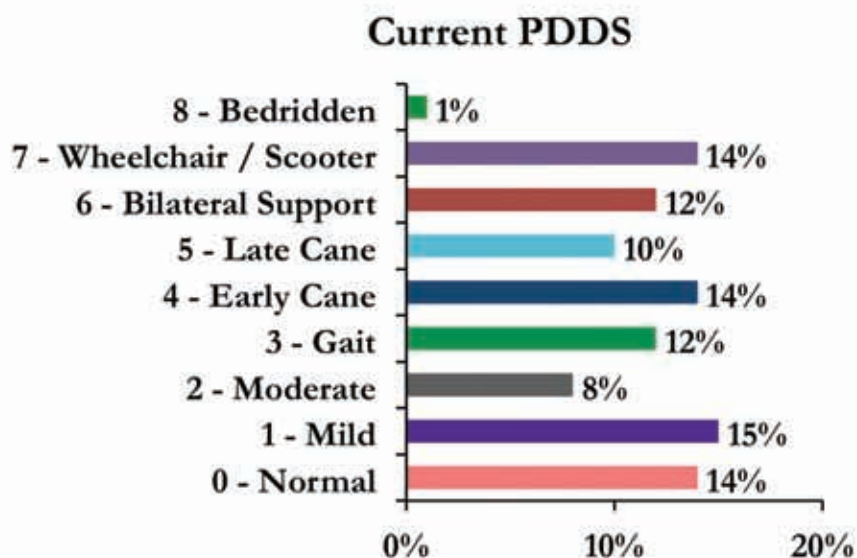
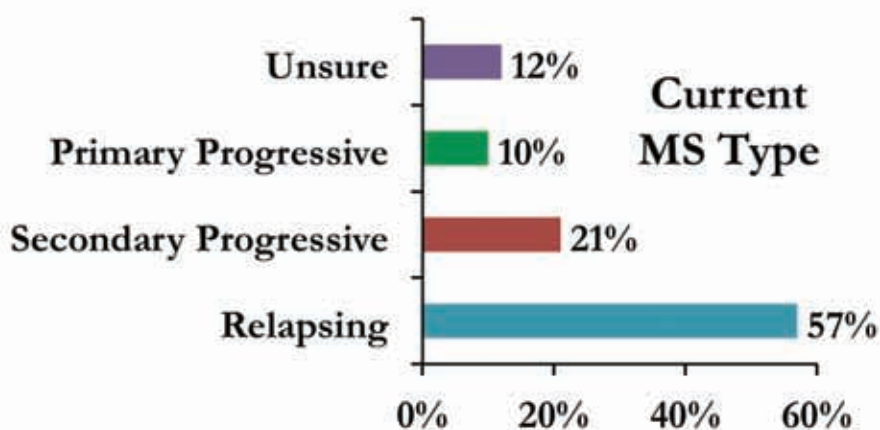
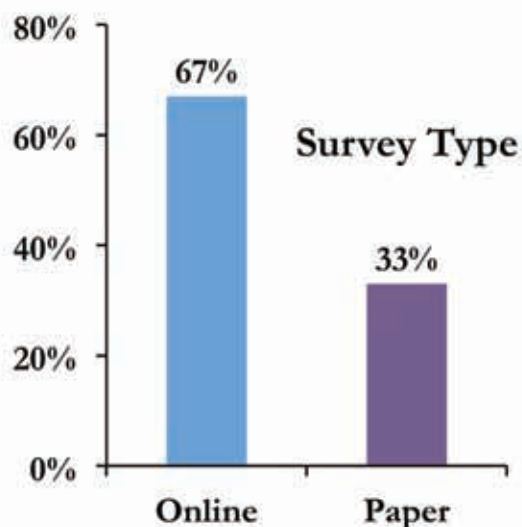
Dr. Joseph Herbert (MD), founder of one of the world’s first comprehensive MS centers at NYU Langone Medical Center, died January 2, 2015, of cancer. Dr. Herbert was professor of neurology and director of the NYU Langone Medical Center’s Multiple Sclerosis Comprehensive Care Center. The Center is internationally recognized for its quality of care and active MS research program.

“Joe Herbert was a great friend of NARCOMS,” said Gary Cutter, PhD, NARCOMS Coordinating Center Director. “He continually stimulated us to figure out ways that clinicians could use patient-reported data to improve their care.”

Renowned for his research, Herbert recently he worked in implementing the MS Severity Score as a clinical tool; the investigation of ethnic variability among people with MS; and development of a new bedside disability scoring system for MS. In 2013, he co-authored two NARCOMS papers. Herbert was a founding member of the New York State MS Consortium Database, as well as MS Base, an ongoing, longitudinal, strictly observational database open to practicing neurologists worldwide.

### FALL 2014 UPDATE

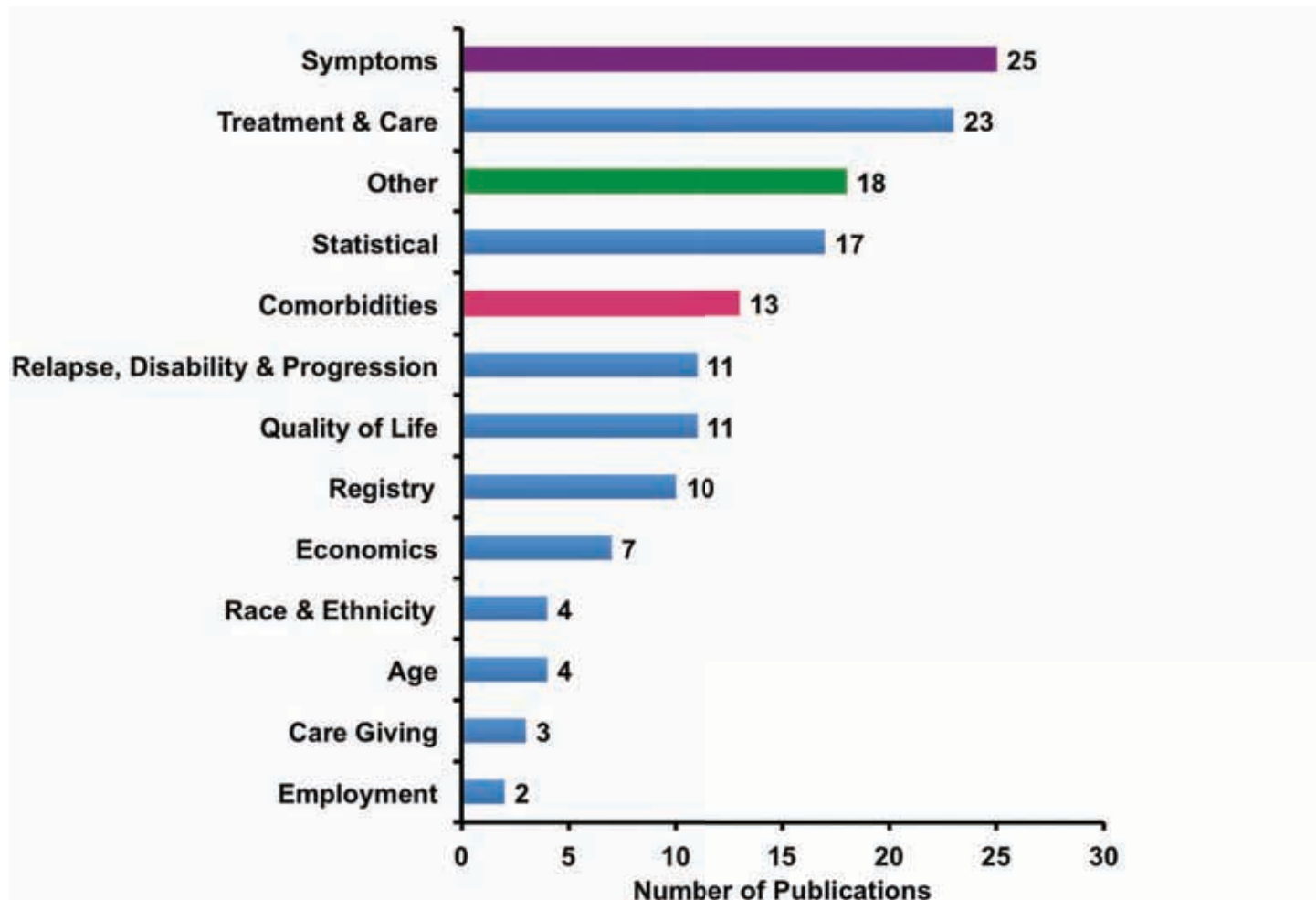
Thank you for participating in the Fall 2014 update! If we had the space, we would say thank you 7,601 times over—that is how many people participated in the Fall Survey. Here is a look at who participated and what you've told us about your MS (% of participants shown).





## NARCOMS PUBLICATION UPDATE

Since 1999, NARCOMS has published 80 papers with research results utilizing data that you have provided—thank you! Four papers were published in 2014 and two already in 2015, covering topics such as quality of life, disease progression, and treatment.



➤ **Symptoms include:** Bowel & Bladder, Cognitive, Depression, Disability, Dizziness, Fatigue, Mobility, Pain, Sensory, Sexual Dysfunction, Spasticity, Vision

➤ **Comorbidities include:** Visual, Cancer, Fibromyalgia, Depression, Anxiety, Vascular

➤ **Other topic areas:** Diagnosis, Health Information, Reproductive Health, Sexual Intimacy, Smoking, Veterans

## REVISED DEFINITIONS RELEASED FOR MS DISEASE COURSE

**Stacey Cofield, PhD**, NARCOMS Coordinating Center Deputy Director  
University of Alabama at Birmingham

### INTRODUCTION

If you have seen your MS healthcare provider recently, they may have mentioned to you that the way we describe the course or type of MS has changed. A group of MS experts has looked at what has been learned in the last two decades about the disease course and updated the classification of MS based on what actually happens to you, the patient.

Prior to this, the most recent update to the definitions of the clinical course of MS was in 1996. Starting in 2011, the International Advisory Committee on Clinical Trials of MS re-examined MS types. To do this they looked at clinical, imaging, and genetic advances through meetings and reviews of publications and research results. The work was jointly sponsored by NMSS and The European Committee for Treatment and Research in MS. By 2013, the Committee and other experts (The MS Phenotype Group) completed their work. They recommended that most of the original clinical courses should be kept. However, they added some other categories, and also suggested adding greater detail, to better describe people with MS. What does that mean?

**Here are the basics** (see Table 1, next page):

**A type of “possible MS” has been officially defined:**

1. Clinically Isolated Syndrome (CIS): accepted as the first clinical presentation of the disease (like a single relapse) but the patient has not yet met the definition of MS. Patients in this group may never be diagnosed with MS, although many will be.

**One MS definition has been “retired”:**

1. Primary Relapsing (PR): the Committee felt that PR overlapped with other clinical courses and should no longer be used as an MS type.

**The two main courses of disease, Relapsing and Progressive, remain but have changed slightly:**

1. Patients are defined as having Primary (PPMS) or Secondary (SPMS) and then

2. Further classified in 2 ways: (i) active or not active; and (ii) stable or progressing based on examination by an MS healthcare provider at least once a year.

### NARCOMS and the International Advisory Committee on Clinical Trials of MS

Both Dr. Robert Fox (MD), NARCOMS Managing Director; and Dr. Gary Cutter (PhD), NARCOMS Coordinating Center Director, served on the Committee and are listed as co-authors on the *Neurology* paper that outlined the new definitions.



1996

2013

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### Clinically Isolated Syndrome (CIS):

- No CIS definition
- Not Active: only one MS-like issue
  - Active: once there is more than one issue, CIS becomes RRMS
- 

### Relapsing Remitting MS (RRMS):

- Relapses with full recovery
  - Relapses without full recovery
  - Active: clinical relapses and/or MRI activity
  - Not Active: no relapses or MRI activity
- 

### Progressive Disease:

Progression should be measured by your MS healthcare provider at least 1 time per year

- |                              |   |
|------------------------------|---|
| • Primary Progressive (PP)   | • PP: increase in disability from diagnosis   |
| • Secondary Progressive (SP) | • SP: started with RRMS but developed gradually increasing disability even between relapses |
| • Progressive Relapsing (PR) | • No longer using PRMS as a definition  |

### **Both PPMS and SPMS are classified as:**

- Active with progression
  - Active but without progression in the last year
  - Not active but with progression
  - Stable disease (not active and without progression)
- 

## **WHAT DOES THIS MEAN FOR NARCOMS?**

NARCOMS will begin asking participants about the new courses or types of MS in the Fall 2015 update survey. Since not all participants have seen their MS healthcare provider since these definitions were released in July 2014, we wanted to allow enough time to see your doctor and discuss these new courses.

# Comorbidities, Resources, and Support

**Update Survey Comments** – Every NARCOMS update includes a space for you to include comments, questions, or suggestions. With 7,000+ participants responding to each update, we can't respond to every comment—but we do read them, and read them all. Comments usually fall into two categories:

– **Help with serious medical or mental health issues:** While NARCOMS does not provide healthcare, we do care about your well-being and will try to provide information when we can. We contact the person directly with information on where to get help with their current situation, like resources and support groups.

– **Comments or suggestions:** We thank you for these—they are forwarded to the research team or *NARCOMS Now* staff for use in future research and/or answered in the magazine. Here are a few of the questions we received after the Fall 2014 update:

**Q:** Is attention paid to the answers that I submit to these questionnaires? Does it just float into ether? What are the results of the survey used for?

**A:** Great attention is paid to your answers. It takes about two months after each update to get the data ready for analysis and go through the comments. Some of the survey questions are part of one-time research projects (like the special sections) and results of these special projects are usually published within 2 years. Other questions, like the PDDS are used to help describe the course of the MS disease over time. See Snapshot for the publication update from 2014 (page 12).

**Q:** Do the physicians that treat MS receive results or just researchers or drug companies?

**A:** *NARCOMS Now* is sent to the member sites of the Consortium of MS Centers and all published results are available not only to MS physicians and health care providers, but to anyone that wants to read them! Full results may be restricted by subscription to the journal but summary results (called abstracts) can often be found online using a free service called PubMed ([www.ncbi.nlm.nih.gov/pubmed/](http://www.ncbi.nlm.nih.gov/pubmed/)). Keep in mind that though a drug company may sponsor a specific NARCOMS research project, the drug companies never get your personal information. NARCOMS collaborates with many types of researchers and we strive to share all results in *NARCOMS Now*, at scientific meetings, and in publications. For recent publications, go to [www.NARCOMS.org/publications](http://www.NARCOMS.org/publications).



**Q:** Why do you need to know what other conditions or diseases that I have? Why do you only ask about them every other year?

**A:** Other conditions or diseases, also called comorbidities, affect your overall health and can affect how your MS changes or is treated. You tell us about your health when you enroll in NARCOMS but it is important to know if you are diagnosed with any new conditions since enrollment:

- **Acute:** a condition that develops quickly without a long prior history of episodes or related conditions. Acute conditions are sudden and often require immediate medical attention. Broken bones, asthma attacks, and heart attacks are examples.
- **Chronic:** diseases that last for a longer period of time and need consistent medical treatment, though there can be acute flares (like an asthma attack).

NARCOMS collects information on both acute and chronic conditions. Acute conditions are usually asked in the special sections (you'll be asked about recent falls and broken bones in the Spring 2015 update). Chronic conditions are collected every two years, since by definition, they are longer-term issues and will not change as frequently (you'll see the "Other Conditions" section in the Spring, too). For more information on how comorbidities relate to MS, see "MS News" page 19.

**Q:** Can I compare one year of my answers to another year of my answers?

**A:** Yes you can! You will need to log into the NARCOMS website; once there, click on "Form Summary" and you can see past answers. If you need help logging in, contact NARCOMS. You can call us at: 1-800-253-7884, or email us at: [narcomsnow@narcoms.org](mailto:narcomsnow@narcoms.org).

To submit a question for Q&A please email  
**[narcomsnow@narcoms.org](mailto:narcomsnow@narcoms.org)**



## NMSS Releases First Results from Comorbidities Project

Individuals living with MS often face other co-existing medical conditions, known as comorbidities. The National MS Society in January 2015 reported results of the first stage of a project the supported designed, to study how common it is for people with MS to have other conditions, and how those impact the course and treatment of their MS.

The publication comes in advance of an international scientific workshop jointly supported by the National MS Society and the European Committee for Treatment and Research in MS (ECTRIMS) to focus attention on comorbidities and determine next steps to finding solutions for people with MS.

Doctors now recognize that comorbidities may affect the course of a disease like MS, from delays in diagnosis, to influencing disease progression, and issues of wellness and quality of life. The MS Comorbidities Project seeks to characterize the types and frequencies of comorbidities in MS. The International Advisory Committee on Clinical Trials in MS, comprised of international leaders in MS research and clinical care and jointly supported by the National MS Society and ECTRIMS, is undertaking this project. Its members include Ruth Ann Marrie, MD, PhD, Scientific Director of NARCOMS, and Gary Cutter, PhD, NARCOMS Coordinating Center Director.

The project's first phase included a systematic review of existing published studies related to specific medical conditions in people with MS. The results are reported in seven papers published in the *MS Journal*.

Marrie and her co-authors identified more than 7,000 studies on a variety of comorbidities and MS and narrowed these down, completing a full-text review of 249 studies conducted between 1905 and 2012, including NARCOMS research. Most were conducted in North America or Europe, leading the authors to comment that little is known about comorbidities that occur with MS in Central or South America, Asia or Africa. Also, the studies' design and quality varied so greatly that it was difficult to compare their results. However, the review showed that:

- » The five most common disorders occurring alongside MS were: depression, anxiety, high blood pressure, high cholesterol, and chronic lung disease.
- » The most common autoimmune diseases occurring with MS were thyroid disease and psoriasis.
- » The types of cancer that occurred most often in people with MS were cervical, breast, and digestive system cancers. There appeared to be a higher than expected risk of meningiomas and urinary system cancers, and a lower than expected risk of pancreatic, ovarian, prostate and testicular cancer, compared to the general population.
- » Some disorders were found more often than expected, such as heart disease, congestive heart failure, stroke, arthritis, inflammatory bowel disease, irritable bowel syndrome, seizure disorders, bipolar disorder, sleep disorders, and alcohol abuse.

The authors suggest further work is needed to develop data sources to examine MS comorbidities worldwide, and to account for differences in gender, age, and ethnicity. They also suggest that efforts should be coordinated so that methodologies are similar and results can be compared.

This spring, the International Advisory Committee on Clinical Trials in MS and other experts in MS research will meet to discuss next research steps, such as available data that may facilitate further research, and which comorbidities demand more immediate focus. The Spring 2015 update will ask about your comorbidities (see page 10).

### Brotsky Foundation Funding

NARCOMS would like to acknowledge the Brotsky Family for its generous, continued support of the registry. This family foundation has provided financial donations to NARCOMS since 2004. Thank you to the Brotsky Family for this crucial backing—your generosity allows us to continue the work we do to further research every day.

### Prevalence of Tremor in NARCOMS Participants

Tremor is common among NARCOMS registrants and severely disabling for some, according to research by John Rinker II, MD, University of Alabama at Birmingham, recently published in *BMJ Open* (*BMJ Open* 2015;5:e006714 doi:10.1136/bmjopen-2014-006714).

Rinker and his team, including NARCOMS researchers Dr. Gary Cutter and Amber Salter, asked a subset of NARCOMS participants to take part in a supplemental survey on tremor. As part of the tremor severity assessments respondents also drew Archimedes' spirals with each hand, using a pen provided with the survey.

Of that subset of 552 individuals, the prevalence of tremor in NARCOMS participants ranged from 45–46.8%, with severe tremor affecting 5.5–5.9% of respondents. The survey showed those diagnosed with MS at a younger age and tremor onset had mild tremor severity, compared with those with moderate or severe tremor. Rates of unemployment, disability and symptomatic medication use increased with tremor severity, but were high even among those with mild tremor.



These data reinforce previous smaller studies describing the disproportionate effect of tremor on employment, function and overall quality of life for patients affected with MS, Rinker says.

“Tremor can be a disabling symptom affecting many aspects of life,” Rinker says. “This study reinforces the need to further research for treatments to ameliorate symptoms of tremor in patients with MS.”

Click here for a video of Dr. John Rinker discussing tremor and ataxia in NARCOMS participants with Dr. Daniel Kantor:  
[www.narcoms.com/multimedia/drrinker](http://www.narcoms.com/multimedia/drrinker)

## Switching from Injectable to Oral Drug More Effective than Switching to Another Injectable

Patients who switched from an injectable treatment to an oral treatment (fingolimod; Gilenya) had fewer relapses compared to patients who switched to a different injectable treatment, researchers found in an article recently published online in *JAMA Neurology*.

The observational study followed patients who switched medications following clinical relapse or disability progression while on either interferons or glatiramer acetate (Copaxone). Those who switched to fingolimod had a significantly lower mean annualized relapse rate than those who changed to another injectable immunomodulator, according to Tomas Kalincik, MD, PhD, of Royal Melbourne Hospital in Australia, and colleagues.

In an editorial accompanying the article, Olaf Stuve, MD, PhD, of the University of Texas, and Diego Centonze, MD, PhD, of To Vergata University and Hospital in Rome, said the study adds to growing evidence that switching to newer agents like natalizumab (Tysabri) or fingolimod may be more effective.

Kalincik and colleagues conducted their analysis of data from MSBase, which collects observational data on MS patients in routine clinical care, from July 1996 to April 2014.

Patients with relapsing-remitting MS had been on a beta-interferon drug or glatiramer acetate for at least six months before changing to another injectable (beta-interferon or glatiramer acetate) or to fingolimod because of clinical disease activity. They were then observed on the new medication for at least three months.

Kalincik and colleagues found that patients who switched to fingolimod had both a lower relapse rate and a lower risk of relapse than those who switched to another injectable immunomodulator.

Those who switched to the oral drug also showed a lower risk of disability progression and a higher rate of disability regression, they reported. They also had a lower rate of stopping treatment at 2 years.

In their editorial, Stuve and Centonze agreed that the quality of observational data in their study can provide “crucial information to support decision-making relevant for MS management in real-world practice.”

The results are in line with studies such as TRANSFORMS, one of the clinical trials leading up to fingolimod’s approval, which found patients with active disease activity despite immunomodulatory therapy, “may still have optimal disease control after switching to fingolimod.”

The study, which was funded by fingolimod’s manufacturer, Novartis, did not examine switches to natalizumab or newer oral agents.

They concluded that evidence has accumulated that, “escalating to the more effective medications natalizumab or fingolimod should be an early consideration for most patients with breakthrough disease.”



## Cells From Placenta Safe for MS Patients, Study Shows

Patients with MS were able to safely tolerate cells cultured from human placental tissue, according to a study published in *Multiple Sclerosis and Related Disorders*.

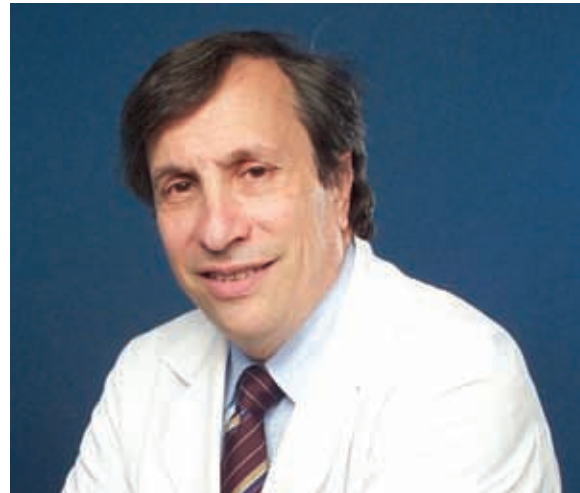
“This is the first time placenta-derived cells have been tested as a possible therapy for multiple sclerosis,” said Fred Lublin, MD, Professor of Neurology, Icahn School of Medicine at Mount Sinai and principle author on the study, “Human Placenta-Derived Cells (PDA-001) for the Treatment of Adults With Multiple Sclerosis: A Randomized, Placebo-Controlled, Multiple-Dose Study.”

A company called Celgene developed cell lines from placenta, which is readily available, and which has stem cell-like features, meaning they can potentially enhance repair. This eliminates the problem of deriving stem cells from an individual. Also, because placenta cells are primitive, the body does not reject them.

“The idea was to see if you can develop strategies that will alter the course of the disease,” said Lublin. “The next step will be to study larger numbers of MS patients to assess efficacy of the cells, but we could be looking at a new frontier in treatment for the disease.”

This safety study was conducted on 16 MS patients (10 with relapsing-remitting MS and 6 with secondary progressive MS) between the ages of 18 and 65. Six patients were given a high dose of the placental cells, another six were given a lower dose, and four patients were given a placebo. All participants were given monthly brain scans over a six-month period to ensure they did not acquire any new or enlarging brain

lesions, which would indicate a worsening of MS activity. No participants showed any unexpected worsening on MRI and after one year. Most had stable or improved levels of disability.



**Fred Lublin, MD, Professor of Neurology,**  
Icahn School of Medicine at Mount Sinai

“We’re hoping to learn more about how placental stromal cells contribute to myelin repair,” said Lublin. “We suspect they either convert to a myelin-making cell, or they enhance the environment of the area where the damage is to allow for natural repair. Our long-term goal is to develop strategies to facilitate repair of the damaged nervous system.”

“The hope is that these cells will go to where the damage is and enhance repair—that is what has happened in animal models,” said Lublin. Continued safety testing is underway by Celgene, and the research will then progress to larger trials. “It’s worth moving forward,” he said. Any time the immune system is altered, for example by an experimental treatment, there is always a risk for MS to worsen, Lublin noted. “The important thing here in this and a few other studies is that these are carefully done, early phase studies—it’s not yet ready for prime time. No one has a stem cell program that works, yet.”

## MS Walks in Full Stride



The National MS Society kicks off its season of MS Walks in spring. Make sure to connect with your local chapter to see how you can get involved—as a walker, fundraiser, volunteer, or just spreading the word. Visit [www.nationalmssociety.org](http://www.nationalmssociety.org) to find dates for events in your area. It's a great way to get out and meet others living with and caring for people with MS. The walks started in 1988 and to date have raised more than \$870 million to support programs and research.

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## CLINICAL TRIALS IN MS

As loyal NARCOMS participants we know you are interested in MS research, and we welcome you to a new section of MS News: Clinical Trials in MS. NARCOMS is a participant registry, which means you provide us with your information, so what is different about clinical research?

Clinical research involves at least one visit to a clinic, doctor's office or hospital. According to the National Institutes of Health (NIH): "People volunteer to participate in carefully conducted investigations that ultimately uncover better ways to treat, prevent, diagnose, and understand human disease. Clinical research includes trials that test new treatments and long-term natural history studies, which provide valuable information about how disease and health progress."

Here we'll discuss MS clinical trials in process, their results, and opportunities for involvement. Since *NARCOMS Now* is published four times per year, we will not be able to list all current and past trials in each issue. Between issues, you can find clinical trials information in many places:

- » NIH maintains ClinicalTrials.gov, which is required for all federally sponsored clinical trials.
- » CenterWatch.com is a Boston-based commercial system that provides international clinical trials information for both professionals and patients.
- » The EU Clinical Trials Register lists clinical trials for the European Union.
- » ResearchMatch, funded by the NIH and the National Center for Advancing Translational Sciences (NCATS), asks you to answer a few questions about yourself—creating a profile—and ResearchMatch contacts you with potential opportunities for involvement.

## FOR MS-SPECIFIC CLINICAL TRIALS:

- The National Multiple Sclerosis Society's Research page lists new and ongoing clinical trials, and also offers an "MS Trial Alert" page with the latest updates in MS trials.
- Multiple Sclerosis Discovery Forum (MSDF) offers a dynamic graphic depicting ongoing clinical trials in MS, where you can search by the medication, the type of trial and even who is sponsoring the trial. (available at: <http://www.msdiscovery.org/ongoing-clinical-trials-in-MS>). Also available on MSDF is a searchable drug-development pipeline, which provides key information about compounds under investigation for therapeutic use. It is curated by the MSDF editorial staff, who welcome additional input from users, as well as feedback on which compounds you would like to see next.





## *Find the following hidden words:*

awareness, care, mindful, insight, energy, power,  
knowledge, planning, activism, rally, progress, connection,  
change, passion, movement, thoughtful

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

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# FACES *of* NARCOMS

## Relief in a Diagnosis: Never Give Up

My name is Nancy and I live in Northwestern Vermont. We Vermonters are known for being strong, independent and self-reliant folks. That is all that my mom, who passed away when I was 19, ever wanted for me—to be self-sufficient.

Not diagnosed until my late twenties, I began having “invisible” difficulties since I was ten years old. The only one who understood that something was seriously wrong was my mom. She frequently brought me to the local health care clinic, where I was received as a small, pale weakling who was always tired and sickly. A nurse would place a thermometer in my mouth, draw some blood, and pop her head back in to declare, once again, that I was not anemic—that in fact my iron levels were very high. The doctor would promptly excuse himself, like some great mystery had just been solved. This scenario played out for several years; each time I was too sick to go to school.

For 19 years, these same people did this to me. At one visit one of the practice’s three doctors told me I was young and healthy, and recommended I go home and exercise for as long as I could, then take the hottest bath I could stand. By then I was 28 years old, the mother of two wee ones, and going through a bad divorce. I went to my apartment and followed his orders; while in the bath, I suddenly went totally numb down my whole right side (this persisted for over six weeks).

When I visited their office, I had another difficult experience. The doctor said I “should” be numb from the waist down, or the neck down, not from the mid-chest down to my toes. Thank goodness a medical student was shadowing him that day. On a small piece of paper, the young lady wrote “M.S.?” This got me an MRI and an appointment with a neurologist, which revealed I had a clear case of RRMS, with damage to the C3 spine on the left side, which controlled my body from mid-chest down on the right side.

In my life I’d been dizzy, tired, clumsy, weak, forgetful, irrational, difficult, and in pain. Each time I caught a cold or virus, I’d wind up bedridden. Now I had a diagnosis. It was a place to start, a place to mourn my losses, and to try to get well. Now I am 47 and know for sure that true family, caring friends, and alleged “social support,” are hard to come by. But I keep plugging along. The very few people who do know me see me as one of the strongest people they have ever met. Never, never, never give up; and, if you can, get a dog.

— Nancy W., Bakersfield, VT

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