

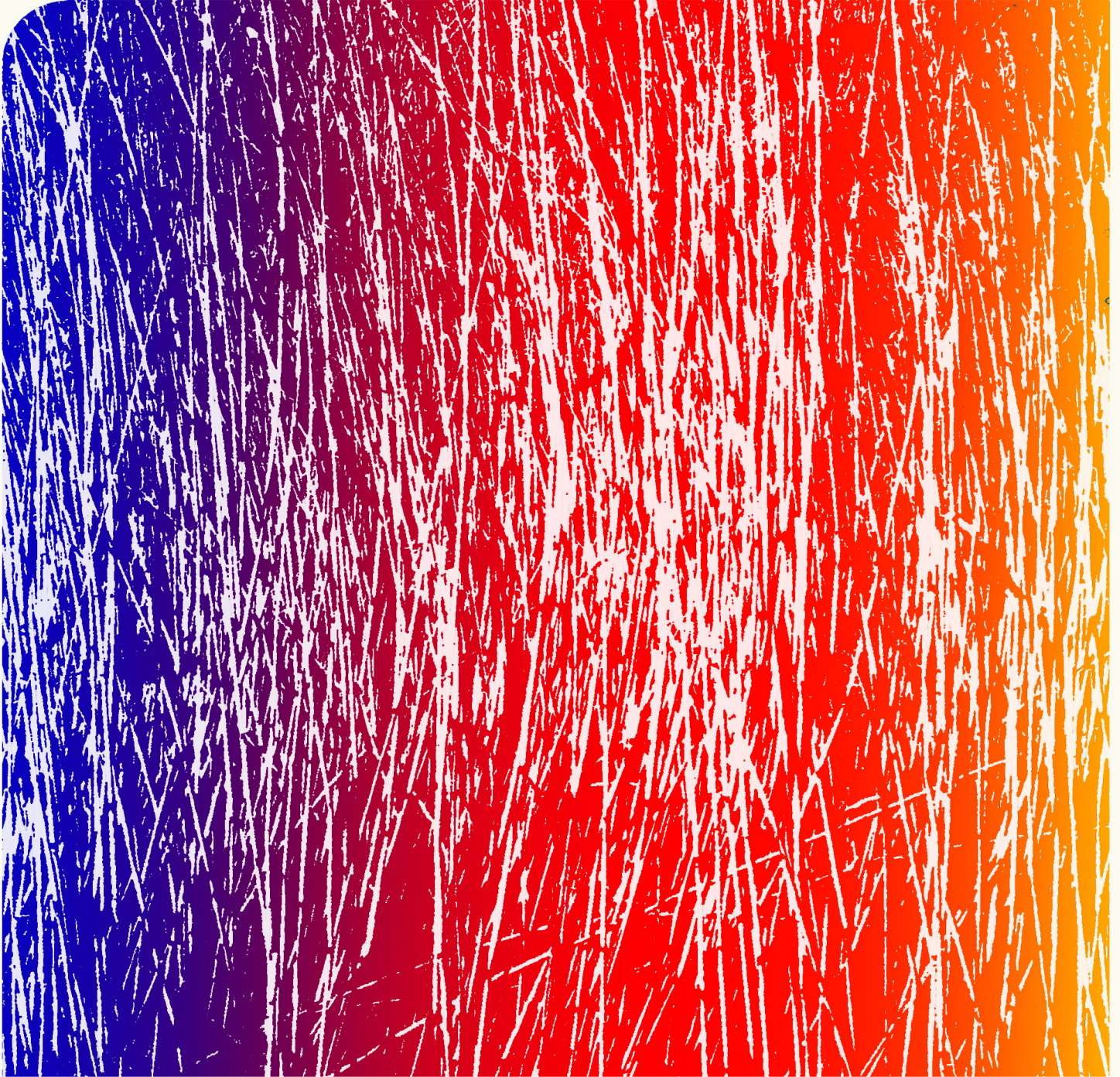
# NARCOMS

# NOW

SUMMER 2013

[www.narcoms.org](http://www.narcoms.org)

Vol. 2, Issue 3



## RISK TOLERANCE TO MS THERAPIES



## Spring Survey Thank you!

*Over 7,000 NARCOMS participants have already completed the Spring 2013 update!*

If you haven't completed your survey yet:

**Online:** The survey is open until June 30th

**Paper:** Please mail surveys by June 30th

## SPEAKING OF DATA....

The annual combined meeting of CMSC & ACTRIMS was held May 28 – June 1 in Orlando, FL.

See NARCOMS Messenger on page 18 for a preview of the topics presented at CMSC/ACTRIMS – all with information contributed by NARCOMS participants.

You can catch up on what was presented in Orlando in the Fall 2013 *NARCOMS Now* or...

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See **Q&A** on page **8** for details.



A project of the Consortium of Multiple Sclerosis Centers



THE CONSORTIUM OF  
MULTIPLE SCLEROSIS CENTERS

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# NARCOMS NOW

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**Hello,**

**Welcome to the Summer 2013 issue of *NARCOMS Now*.**

In this edition we will be talking about risk tolerance to multiple sclerosis therapies. As we mentioned in our last edition of *NARCOMS Now*, decision-making for MS is becoming more complicated. What treatment-related risks is the individual with MS willing to take? How does this “risk tolerance” depend on the potential benefits of the treatment? In this edition of *NARCOMS Now*, Dr. Sneeha Ramesh discusses the findings of a study about risk tolerance involving more than 5,000 NARCOMS participants. We found that risk tolerance differed between men and women. Risk tolerance also differed according to age, and the severity of disability due to MS. This kind of information is important for health care providers to understand, so that treatment decisions can be individualized. For all of the details please read “MS Messenger” on page 18 Thank you to those of you who participated in the risk tolerance study!

Also in this edition, our “Feature Focus” discusses health and nutrition in MS. Diet and physical activity are of steadily increasing interest in MS. For example, several recent studies suggest that being overweight or obese in late adolescence increases the risk of MS. Researchers are also beginning to realize that adipose (fat) tissue may play a role in MS. Adipose tissue secretes hormones called adipokines that play a role in inflammation and metabolism. Look for more information about this over the next year or two, reported here in *NARCOMS Now*.

Adequate vitamin D intake is important for bone health. Osteoporosis, or thinning of the bones, is more common in people with MS than in the general population. It increases the risk of fractures, so prevention is very important. Vitamin D supplementation is typically needed to achieve normal vitamin D levels. Calcium is another key ingredient in bone health. Unlike vitamin D, we have many good sources of calcium in our diets.

Physical activity has many potential benefits in MS. Regular aerobic (oxygen-burning) exercise may reduce fatigue. Regular stretching may help with spasticity. Exercise can also improve strength and quality of life. A particularly exciting possibility is that regular aerobic exercise may improve cognitive function.

Also in this issue are news items regarding the passing of Annette Funicello; the most recently approved therapy for MS, Tecfidera; and updates from the first annual meeting of the Multiple Sclerosis Outcome Assessments Consortium (MSOAC). Finally, you will read more about NARCOMS presentations at the recent joint Consortium of Multiple Sclerosis Centers (CMSC)/Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) meeting in Orlando, Florida.



**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.

**Enjoy the summer!**

Sincerely,



# NARCOMS INFORMATION CORNER



## HAVE AN IDEA?

We would love to hear from you!  
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comments & suggestions.

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## NARCOMS PROMISE

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



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**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.*



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**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!**

## Weighty Matters: Diet and Exercise in MS

Most of us strive for yet struggle to maintain a healthy, well-balanced diet. But for those living with MS, nutrition can take on a heightened importance. From fad diets to special supplements, it can be difficult to wade through the constant stream of information about what works and what doesn't. As MS research has progressed in the last several years, however, certain dietary practices have proven effective.

### SALT: TOO MUCH / TOO LITTLE

It is widely known that most Americans consume far higher than the recommended levels of daily sodium intake. However, it can be difficult to know how much salt is too much, *and* how much is enough.

Recent studies suggest that consuming too much salt may trigger MS or another autoimmune disease. In March, the journal *Nature* published three studies by collaborators at Yale, Harvard, and MIT-Broad Institute showing that eating too much salt may put you at risk of developing an autoimmune disease. These initial results may provide new insights on immune system activity involved in MS.

David Hafler MD, a neurologist and immunobiologist at Yale University, and his team report on salt's ability to increase activity of immune cells called helper T cells, both in lab dishes and in an MS-like disease in mice. The team found that mice fed a diet high in sodium produced a flood of inflammatory infection-fighting helper T cells, a type of cell implicated in autoimmune disease. The mice then developed autoimmune encephalomyelitis, an animal version of multiple sclerosis.

In the second and third studies, Vijay Kuchroo and Aviv Regev and colleagues worked with scientists from the Broad Institute in Boston to explore molecular pathways for the production of the specific T

cell involved, Th17. Halfler, Kuchroo, and Regev got the idea for the inter-related studies from a prior study that discovered a rise in inflammatory cells among people who regularly ate fast food. The next step in this research is to extend it into humans, before any clinical applications can be made.

Meanwhile in May, the Institute of Medicine announced results of a report showing it is unclear whether following a low-salt diet offers benefits, even though national guidelines urge that certain high-risk patients do just that. In fact, ultra-low sodium diets may do more harm than good the report by this agency, which advises the federal government about health, concluded.

According to a May 14 article by the Associate Press, "the average American consumes more than 3,400 mg of sodium a day, equivalent to 1½ teaspoons. Current U.S. dietary guidelines say most people should limit that to 2,300 mg a day, while certain people—those older than 50, African-Americans, and people with high blood pressure, diabetes or chronic kidney disease—should aim for just 1,500 mg."

The conclusion at this point seems to be that more research is needed to determine exactly how much salt consumption is appropriate, for healthy populations and more specifically for those with chronic illnesses like autoimmune diseases.

## Weighty Matters: Diet and Exercise in MS

### OBESITY: A WEIGHTY MATTER

We all know being overweight—and even obese—is not healthy, but it may have even previously unimagined risks. Several recent studies have shown that obesity in late adolescence is associated with an increased risk of MS. A study published in the journal *Neurology* in April showed body size in childhood is also associated with MS risk; specifically, obese children and teenaged girls may be at increased risk for developing multiple sclerosis or clinically isolated syndrome (CIS). The association was not found for boys, however.

“Over the last 30 years, childhood obesity has tripled,” study researcher Annette Langer-Gould, MD, PhD, of the department of research and evaluation at Kaiser Permanente Southern California and a member of the American Academy of Neurology, said in a press release. “In our study, the risk of pediatric MS was highest among moderately and extremely obese teenage girls, suggesting that the rate of pediatric MS cases is likely to increase as the childhood obesity epidemic continues.”

Fifteen percent of all US children were considered to be overweight (having a BMI between the 85th to <95th percentile) and 16% were considered to be obese (BMI: ≥95th percentile). Langer-Gould and colleagues identified 75 children and adolescents aged 2 to 18 years diagnosed with pediatric MS and compared them with 913,097 children without MS, according to the release. Researchers obtained BMI data from before symptoms appeared. All participants were grouped according to weight class: normal weight, overweight, moderate obesity and extreme obesity.

One-half of children with MS (50.6%) were overweight or obese versus 36.6% of those without MS. The researchers behind the study suggest that parents and caregivers of children who are overweight or obese give particular care to reports of numbness, tingling, or limb weakness and bring them to a doctor’s attention.

*“ Obese children and teenage girls may be at increased risk for developing multiple sclerosis or clinically isolated syndrome (CIS). ”*

Researchers are also beginning to discover that adipose (fat) tissue may play a role in MS. Adipose tissue secretes hormones called adipokines that play a role in inflammation and metabolism.

In a very small study that took place in 2009, three patients with MS who received infusions of cells from their own adipose tissue—which contains a type of stem cells called mesenchymal stem cells—all had improvements in their conditions. The study was published by Boris Minev, M.D., of the University of California San Diego, and his colleagues, online in the *Journal of Translational Medicine*. Clinical trials are ongoing to evaluate the safety and feasibility of therapies involving doses of autologous mesenchymal stem cells, specifically in patients with secondary progressive multiple sclerosis who do not respond to treatment.

### VITAMIN D & CALCIUM: TO SUPPLEMENT OR NOT TO SUPPLEMENT?

Adequate vitamin D and calcium intake is important for everyone's bone health. Osteoporosis, or thinning of the bones, is more common in people with MS than in the general population. Osteoporosis increases the risk of fractures, so prevention is very important. Most people require vitamin D supplementation to maintain normal vitamin D levels. Calcium—commonly sufficient in our diets—is another key ingredient in bone health. When combined, calcium and vitamin D regimens may provide an important boost to the body's immune system to help mitigate nerve tissue damage and bone loss associated with MS.

Any person who has experienced decreased mobility—particularly a loss of weight-bearing activity (such as using a wheelchair or staying in bed most of the time)—should be concerned about osteoporosis. The prolonged or excessive use of corticosteroids (to treat MS relapses) also can lead to loss of bone density. Studies have shown that people with MS are two to three times more likely to fracture bones than healthy individuals. Talk to your physician about your risk for osteoporosis and whether they advise establishing a baseline and periodic follow-up evaluations to determine your bone health.

The National Institutes of Health's daily calcium requirements suggest 1,000 mg per day for adults 25 to 65 years old, and 1,500 mg per day for postmenopausal women. For the best absorption of calcium, it is important to obtain 400-800 IU of vitamin D from the foods you eat or from a dietary supplement. Dairy products (especially milk) often include

vitamin D. Studies suggest that in the MS population higher doses of vitamin D may be needed to achieve sufficient levels of vitamin D. Please talk to your doctor about how much supplementation you need. You can also get it by spending a brief time in the sun during the summer months (in case you were looking for an excuse to do so).



Weight-bearing exercises are another way to enhance bone strength. Speak with your doctor about introducing strength-training exercises or physical therapy to your routine.

*“Studies have shown that people with MS are two to three times more likely to fracture bones than healthy individuals.”*

If you have concerns about your dietary needs and are interested in speaking with a registered nutritionist or dietician, visit the Academy of Nutrition and Dietetics at [www.eatright.org](http://www.eatright.org) to find one near you.



## Weighty Matters: Diet and Exercise in MS

### GETTING PHYSICAL

Physical activity has many potential benefits for those living with MS. In 1996, researchers at the University of Utah published the first study demonstrating clearly the benefits of exercise for people with MS. It showed that those patients who participated in an aerobic exercise program had better cardiovascular fitness, improved strength, better bladder and bowel function, less fatigue and depression, a more positive attitude, and increased participation in social activities. Since 1996, several additional studies have confirmed the benefits of exercise in MS.

The benefits of exercise for those with MS—and the general population—cannot be ignored. It can strengthen muscle and bones, relieve stress, improve cardiovascular function and flexibility, and maybe even make you smarter. Aerobic (oxygen-burning) exercise done regularly may reduce fatigue—ongoing studies are recruiting participants to learn more. Similarly, stretching may help with spasticity. Exercise can also improve strength and quality of life. A particularly exciting possibility is that regular aerobic exercise may improve cognitive function. Of course you should avoid exercising in the heat of summer, and prevent excessive fatigue.

Walking, swimming, and dancing are examples of exercises that can work well for those with MS. Some adaptive exercises, such as yoga, water aerobics, and tai chi, may work particularly well for those with MS. Ask your doctor or physical therapist about an exercise program that is appropriate for you.

*“The benefits of exercise for those with MS—and the general population—cannot be ignored. It can strengthen muscle and bones, relieve stress, improve cardiovascular function and flexibility, and maybe even make you smarter.”*

Although living with MS can present many challenges, care and attention given to diet, exercise, and weight management can help alleviate some symptoms—and have added benefits of boosting mood and self-confidence. Finding the right exercise and nutrition formula for you may take some time, but it is almost guaranteed to pay off if maintained. Consider it part of your regimen in treating your MS, and keep up the hard work!



**Q:** Does NARCOMS plan to have a Facebook, Twitter or other social media page?

**A:** We do plan on it, In fact, NARCOMS recently started a Twitter feed!  
You can find us on Twitter @NARCOMS.

Not familiar with Twitter? Twitter is an online social networking service where users can to send and read messages of up to 140 characters with links to other websites and pictures – these are called “Tweets.” You can follow @NARCOMS just to read tweets about NARCOMS and MS-related news.

## Don't have Twitter? Here's how you can follow @NARCOMS:

- » To join go to: <https://twitter.com/signup>
- » You'll need to enter some limited information, including:  
**Name > Email address > Create a username > Create a password**
- » Once you have an account, type @NARCOMS into the search window



- » Go to our Twitter page and click on “Follow”
- » Go to <https://support.twitter.com/> for more information on using Twitter

## Twitter Privacy Tips:

- » Don't use your NARCOMS username and password for your Twitter account
- » Don't share any personal information on Twitter
- » For Twitter's privacy information: [www.twitter.com/privacy](http://www.twitter.com/privacy)

The followers of @NARCOMS may not be NARCOMS participants.  
For the complete NARCOMS Twitter privacy statement, go to: [www.narcoms.org/twitterpolicy](http://www.narcoms.org/twitterpolicy).

**As always, we will never share your personal information!**

## Do you ever wonder what happens to the special surveys you complete?

*NARCOMS would like to thank everyone who participated in the Acorda study! The first part of the results of this multi-part project have just been released and it is because of your participation that this project was completed.*

### ACORDA THERAPEUTICS ANNOUNCES PUBLICATION OF NEW DATA ON IMPACT OF MOBILITY IMPAIRMENT DUE TO MULTIPLE SCLEROSIS

The Acorda-sponsored study was conducted in collaboration with NARCOMS and responses from more than 3,000 participants, who reported they did not use a scooter or wheelchair and had at least some walking ability.

This project focused on estimating the costs of lost productivity due to missed work or school, and on patient-reported perceived health status. The researchers estimated that the total costs of this lost productivity exceed \$30,000 per person with MS, per year.

The study also found that lost productivity due to MS-related mobility complications was high, with an average work reduction of nine hours a week, and eight days every six months.

The study was a joint effort by Acorda and the University of Connecticut. Dr. Craig Coleman, Associate Professor in the School of Pharmacy at the University of Connecticut: "We found that

indirect costs increased and patient perception of their own health declined as mobility impairment worsened. This research builds on earlier findings that mobility loss adversely affects activities of daily living, and emphasizes the need to address mobility loss due to MS."

These analyses were based on some of the data collected over a three-year period. Additional analyses of the data are under way; look for updates in future issues of *NARCOMS Now*.

### UPCOMING RESEARCH:

We continue to facilitate MS research by providing recruitment assistance for IRB-approved research studies. In June some of you will be receiving invitations from NARCOMS to participate in a survey or clinical study focusing on a variety of topics such as spasticity, physical activity, MRI, SPMS, and PPMS.

**The results were published in *PlosOne* and can be found online, free of charge, at <http://dx.plos.org/10.1371/journal.pone.0054756>.**

If you have any questions about how these updated survey questions apply to you, don't hesitate to call us at 1-800-253-7884 (toll-free US) or emailing [MSregistry@narcoms.org](mailto:MSregistry@narcoms.org).

### ***Have an idea for Survey 101?***

Please contact us, via telephone, email or online at [www.narcoms.org](http://www.narcoms.org).

## THIRD ORAL DISEASE-MODIFYING MS THERAPY APPROVED

The U.S. Food and Drug Administration in April 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.

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%.

The drug's active ingredient is dimethyl fumarate (DMF), a derivative of fumaric acid—a naturally occurring substance that can be found in mushrooms, lichens, and moss. DMF was first used for medicinal purposes in a highly effective anti-psoriasis drug called Fumaderm, which has been marketed in Germany since 1994.

*The New England Journal of Medicine* in late April published two case reports detailing instances of a rare brain infection in patients taking a therapy that included fumaric acid, the active ingredient found in Tecfidera. The studies were published just three weeks after the drug, made by Biogen Idec Inc., received FDA approval.

The incidents, which were not in Tecfidera patients, had been previously disclosed to investors and U.S. and European.

“This is information that has been out in the public domain for some time,” said Doug Williams, Biogen executive vice president for research and development. “The regulators at the FDA and the European Medicines Agency have been aware of these cases all through the review process for Tecfidera.”

Tecfidera's safety label recommends that patients have their blood cells counted within six months of first receiving the therapy and then once annually thereafter. Before approval, however, some physicians had called for patients receiving the drug to have more regular blood testing to catch signs of PML early.

In a response also published in *The New England Journal of Medicine*, Biogen noted that one case in the Netherlands involved a compound pharmacy's version of Fumaderm, which is considered off-label use, and that the Germany case involved a chemically differentiated drug than Tecfidera and involved a patient who hadn't been diagnosed with multiple sclerosis.

In clinical trials of Tecfidera involving more than 3,600 patients, no cases of PML have been diagnosed.

## MEETING OF MS CONSORTIUM AND FDA CLEARS WAY FOR NEW TOOL FOR CLINICAL TRIALS IN MS

The National MS Society-funded **MS Outcome Assessments Consortium** (MSOAC) ([www.c-path.org/msoac.cfm](http://www.c-path.org/msoac.cfm)) held its first annual meeting with the U.S. Food and Drug Administration on April 1–2 to discuss steps needed to “qualify” a new measure of MS disability that will be recognized by the FDA and the European Medicines Agency to speed new therapies for MS—particularly progressive forms of the disease.

The consortium was launched in Fall 2012 and is co-directed by Richard Rudick, MD (Vice Chairman, R&D, Neurological Institute and Director, Mellen Center, Cleveland Clinic Foundation), Nicholas LaRocca, PhD (Vice President, Health Care Delivery and Policy Research, National MS Society), and Lynn Hudson, PhD (Chief Science Officer, Critical Path Institute).

The meeting included international representatives from 16 academic institutions and nine pharmaceutical companies. Gary Cutter, PhD, NARCOMS' Coordinating Center Director, noted that mobile devices such as smartphones offer the opportunity to collect real-time activity readouts from people in their own environment. He also cautioned about the need to consider other aspects of a person's health, such as other disorders (called co-morbidities), which may complicate the interpretation of outcomes.

An annual meeting will be held with the FDA; look for periodic updates from the National MS Society and in future issues of *NARCOMS Now*.

Funicello first noticed her MS symptoms while losing her footing on the sand filming a spoof of "Beach Party." She waited several years before going public with news of her diagnosis—to counter rumors of alcoholism as she increasingly lost her balance. In 1993 she opened the Annette Funicello Fund for Neurological Disorders at the California Community Foundation.

According to an article on the National MS Society's website, Funicello once said, "When the stories about my MS came out, everyone gave me their love and their prayers. I'm human, and sometimes I can't help but ask, 'Why me?' But I believe everything happens for a reason, and I know now that my mission is to help others raise funds for MS. The more I read about MS, the more encouraged I am. When I wake up in the morning, I like to imagine, this is the day I'm going to hear about an MS cure on the news."

**NARCOMS REMEMBERS: ANNETTE FUNICELLO**

"M-I-C-K-E-Y..."

If you're of a certain age, you will remember that song, and one of its most revered singers. She is perhaps best remembered as one of the original Disney Mouseketeers on "The Original Mickey Mouse Club," and a star on the often-imitated film "Beach Party." Annette Funicello was a respected multiple sclerosis activist since her diagnosis in 1987. She died April 8 at the age of 70 from complications from multiple sclerosis.



Annette Funicello in 1963

## PATIENT PREFERENCES FOR RISKS ASSOCIATED WITH MS THERAPIES

By Sneha Ramesh, PhD, CCRP

### *Have you ever wondered how other persons with MS make their treatment choice or what might make people choose a riskier treatment?*

Until a few years ago, the choice of treatment options was limited to two injection therapies: glatiramer acetate or interferon-beta treatments, each of which reduces MS relapses by 30%. Both of these options required self-injections and carried manageable risks of flu-like symptoms or skin-site reactions. A newer drug, natalizumab (Tysabri), was introduced less than a decade ago and was found to be about twice as effective in reducing relapse rate, but also carried a risk of progressive multifocal leukoencephalopathy (PML), an often fatal brain infection. Other newer disease-modifying therapies that are now available—for example fingolimod (Gilenya)—or being explored for MS treatment appear to have good efficacy but frequently pose greater risks. Whether you have been newly diagnosed with MS or need to switch to another MS therapy, you are likely to face the challenge of choosing a treatment option that will benefit you the most while accepting the risks associated with your choice.

Robert Fox, MD, Managing Director of NARCOMS, was also interested to know more about treatment decisions made by persons with MS. As a result, NARCOMS participants were invited to participate in a survey to better understand the risk-taking attitude of the MS population. NARCOMS offered this survey twice, first in the fall of 2010, and a second time in the fall of 2011. Two of the treatment options offered in the surveys were: 1) a hypothetical curing of MS (named CureMS),

with a complete and permanent reversal of all MS symptoms but a risk of immediate painless death in sleep and 2) natalizumab (NAT) with benefits that include reduction of MS relapses by 68%, but a risk of PML. In addition, we also asked several questions about disease status, risk-taking attitude, literacy and information-seeking behavior. Thank you to those of you who participated—We'd like to share our findings with all NARCOMS participants.

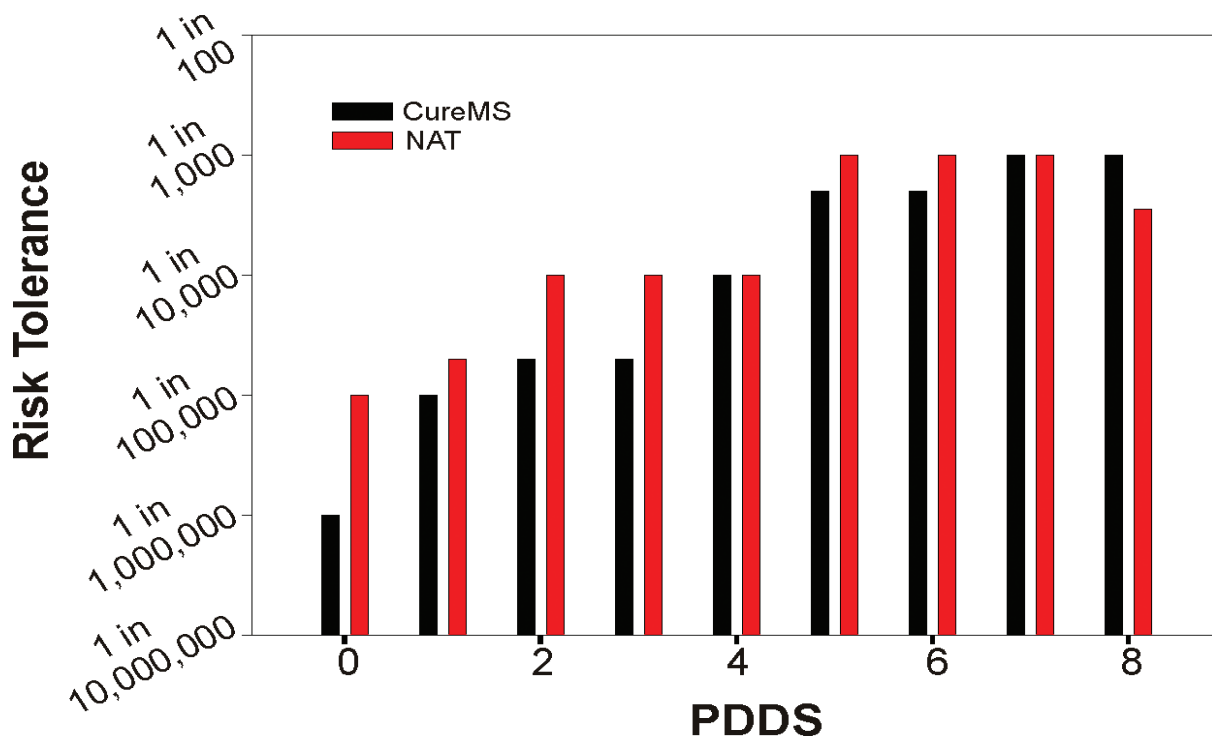
The survey was completed by 5,446 NARCOMS participants. The median risk tolerance for both scenarios was 1:10,000, which means that half (50%) of the survey participants were willing to take a risk if the chance of risk occurrence was 1 in 10,000. We found some interesting characteristics associated with risk acceptance:

- On average, males had greater risk tolerance than females for risks associated with both treatment scenarios (although there was great variation among both men and women).
- Participants with greater disability were willing to take more risks for the two treatment scenarios. This might be explained because people with increasing disability are in a greater need for relief from their MS symptoms and therefore might accept greater risks, if a treatment has a good chance of making the disease more manageable.

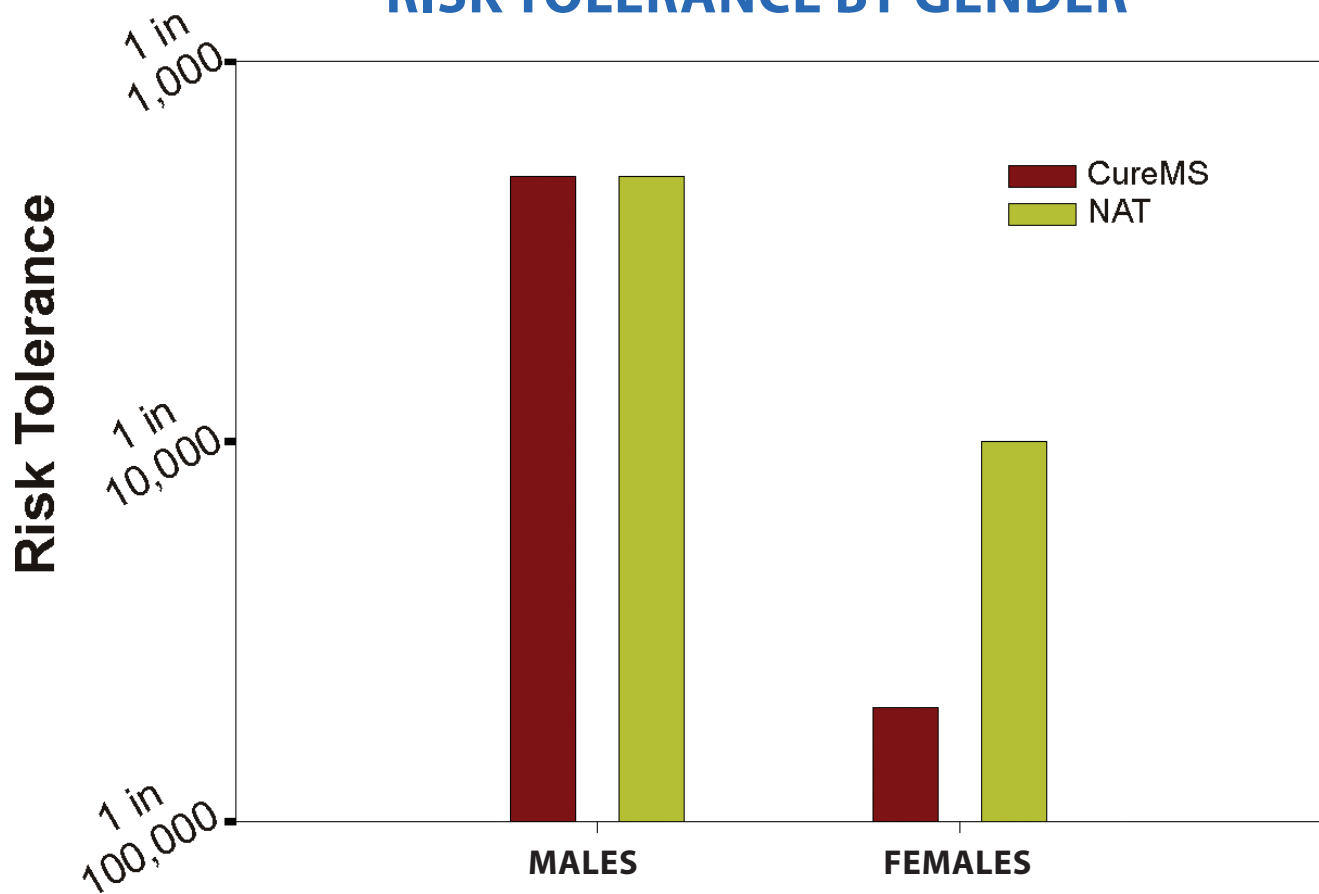
- Participants who were taking Tysabri at the time of this survey showed at least a 10-fold greater tolerance to risks associated with either scenario. Tysabri users are informed of the risk of PML before starting treatment, yet they choose to risk PML because of the benefits offered by Tysabri. Therefore, this group may in general be willing to take more risk to help them manage their MS.
- Those who had MS for a longer duration had a modestly greater risk tolerance than those who had MS for a shorter duration. With time, it is likely that MS symptoms have worsened, and when faced with the prospect of greater disability and no effective therapies, participants may be willing to take greater risk in their treatments.

- Only 2% of the participants indicated not using a seatbelt while driving, and that small group reported a 10-fold greater risk tolerance for the two scenarios than those who always used seatbelts.
- Those who care for dependents at home (i.e. children or elderly) had lower tolerance for risks associated only with the CureMS scenario. This group may view treatment-associated risks as interfering with their responsibilities at home and therefore are not willing to accept increased risks of treatment.
- Those who reported one or more relapses in the last 12 months showed a 5-fold greater risk tolerance to the CureMS scenario than those with no reported relapses. Symptom worsening during a relapse may motivate a person to take greater risks with their MS treatment.

## RISK TOLERANCE BY DISABILITY STATUS



## RISK TOLERANCE BY GENDER



## GENDER

This study has increased our knowledge about risk acceptance in MS patients. Based on the data collected, we can appreciate that males would accept greater risks, although also recognize that there is a significant range of tolerated risk. Those who accepted one risky treatment (e.g. Tysabri) may be more willing

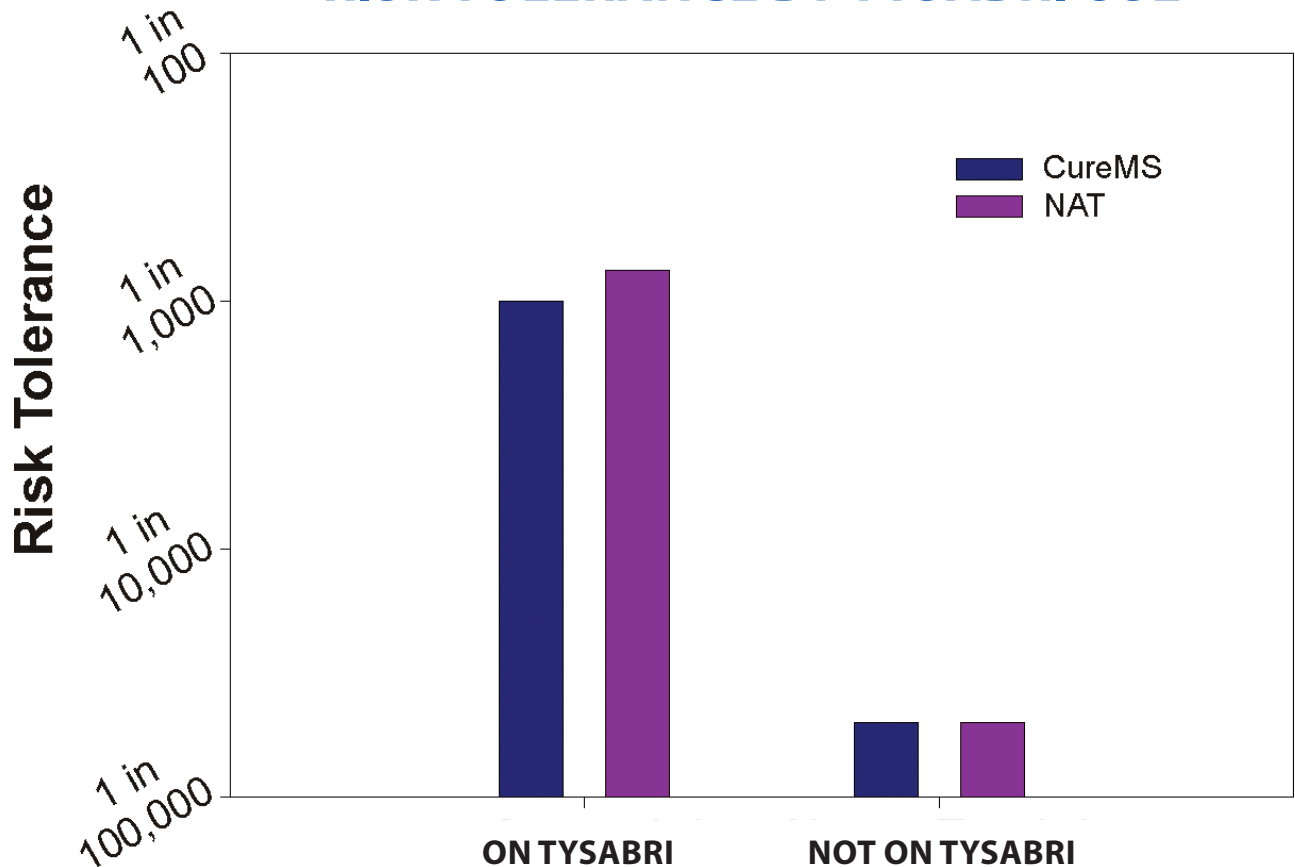
to accept another risky treatment. Those with increasing disability or those who have had MS for a longer duration may also be more willing to accept a risky treatment. We hope our findings will help neurologists treating MS to better guide their patients in making decisions about MS treatment.



**Sneha Ramesh, PhD, started her career in research as a cancer biologist and is now a Research Coordinator at the Mellen Center for Multiple Sclerosis, Cleveland Clinic. She coordinates several MS research studies at the Mellen Center and also provides administrative support to the NARCOMS Managing Director.**



## RISK TOLERANCE BY TYSABRI USE



## TYSABRI USE

**NARCOMS Now en Español - Bienvenidos a NARCOMS !**

**NARCOMS Ahora!** Disfrutar a [www.narcoms.org/narcomsnow/español](http://www.narcoms.org/narcomsnow/español)

**MS Reflections: EM Progresiva: La Próxima Frontera**

**Trastornos del Suelo Pélvico y la Esclerosis Múltiple:**  
¿Eastán satisfechos los pacientes con su atención?

**“La Increíble Carrera” el fin de la Esclerosis Múltiple:**  
“The Amazing Race” to End MS

**NARCOMS is available in Spanish and in English. We have a certified Spanish-language translator available to assist you.**

### Race & the U.S.

In scientific research, race and ethnicity are often used as a proxy for genetic factors but people tend to identify their race based upon cultural, language, and shared social backgrounds. Starting with the 1790 US Census, racial categories have changed and expanded to reflect the growing diversity in the United States.\* The 2000 Census was the first time people were allowed to self-report more than one race and by the 2010 Census, 2.9% of people reported two or more races, with Black and White the most commonly reported combination of race categories (Figure).

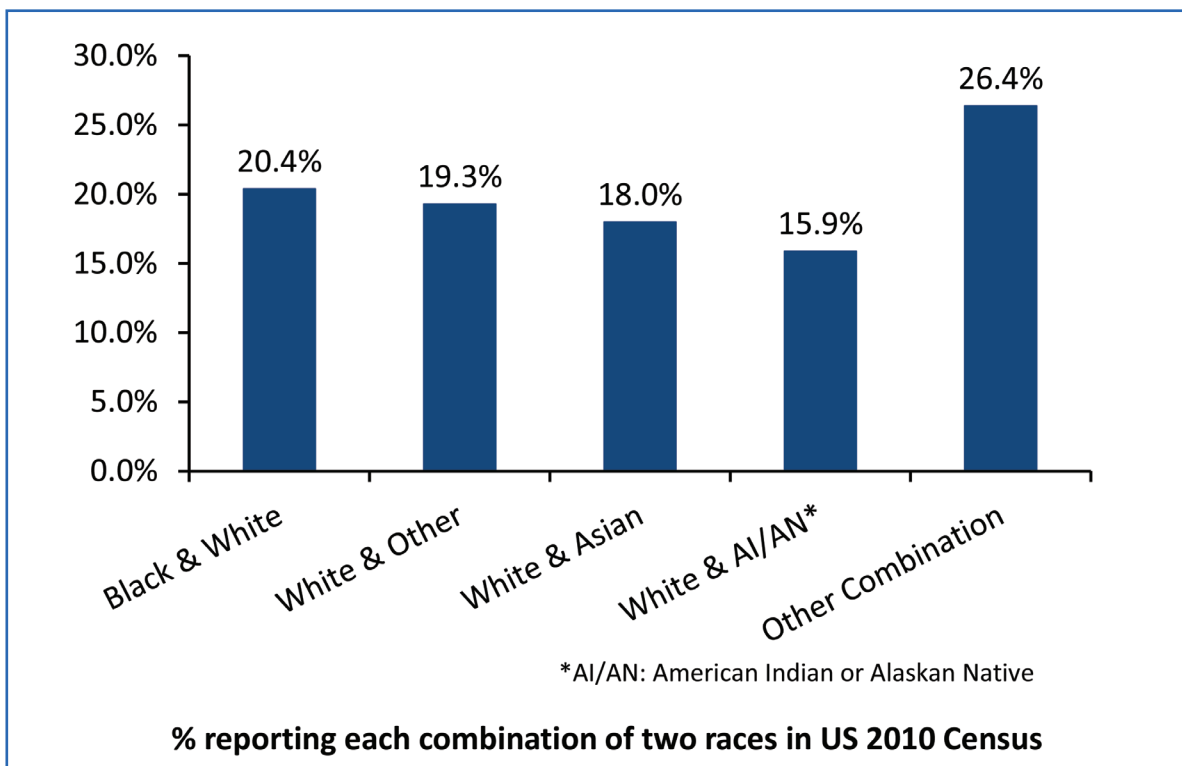
### Race & MS

Searching “Multiple Sclerosis and Race” on the National Center for Biotechnology

Information, U.S. National Library of Medicine website ([www.pubmed.com](http://www.pubmed.com)) returns 537 articles that focus on or mention the differences between racial and ethnic groups with MS. Most of MS and race research looks at differences between African American, Asian, Caucasian, and Hispanic or Latino ethnicities.

The most recent study was published in May 2013 on the “Incidence of multiple sclerosis in multiple racial and ethnic groups” in *Neurology*.\*\* While this most recent study looked at the risk of MS in different racial groups, other research investigates differences in racial groups with MS on topics including:

- rates of progression
- disability; both types and severity
- responses to treatments
- access to healthcare and utilization



## NARCOMS & Race

It is important for NARCOMS to have an accurate and up-to-date reporting of race because differences may exist between racial and ethnic groups:

- in progression and disability
- in response to medications
- in access and use of healthcare
- in other areas, and not accounting for race may result in incorrect conclusions about living with and treating MS

## The Fall 2012 Update on Race & Ethnicity

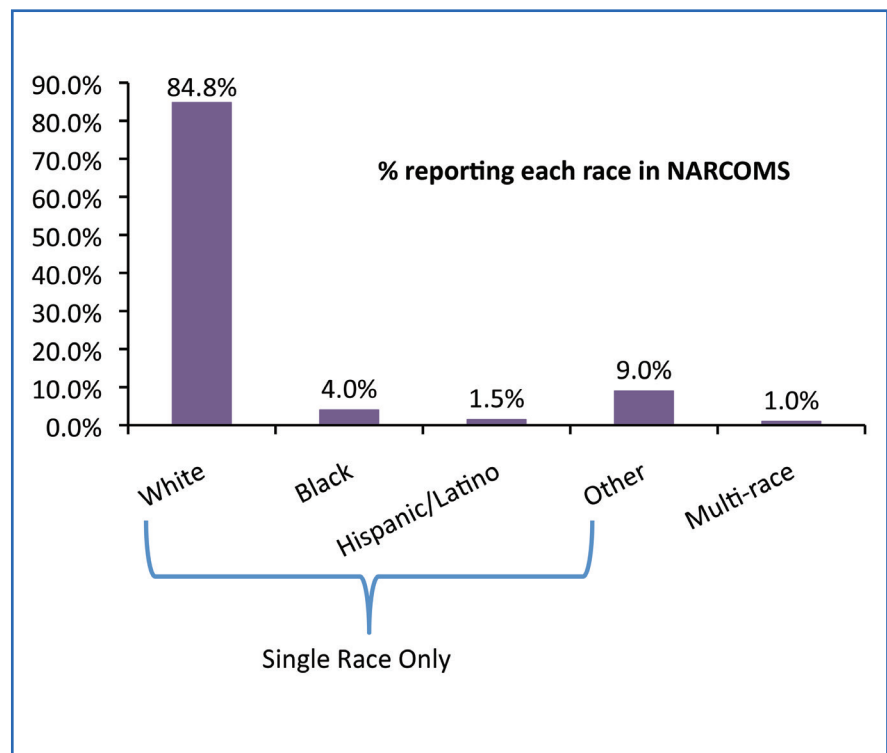
Over 7,000 participants responded to the section on race and ethnicity in the Fall 2012 survey – *thank you!* Over 1,000 participants reported race this Fall that did not have a completed race section when they enrolled. Most of NARCOMS participants report single race as White/Caucasian only but the number of people now reporting multiple races has increased to 1% of NARCOMS participants (Figure). While less than 3% of the U.S. population reporting multi-race, this is an important change in measuring the diversity of persons living with MS. For those reporting multiple races in NARCOMS, the most frequent combination was White and American Indian/Alaskan Native.

Knowing racial backgrounds of those with MS will help focus research on preventing progression, improving medications, and treating people with MS in a way that is personalized to who you are and how you live with MS.

**\*For more information on U.S. Census and Race:**

[www.census.gov/prod/cen2010/briefs/c2010br-13.pdf](http://www.census.gov/prod/cen2010/briefs/c2010br-13.pdf)

**\*\*[www.neurology.org/content/80/19/1734.long](http://www.neurology.org/content/80/19/1734.long)**



## NARCOMS AND MSAA

As some of you may know, NARCOMS recently asked 1,000 participants who are not members of the **MS Association of America**, to identify the types of services you need most, such as physical therapy, home aid, educational events, financial support, transportation, home modifications, assistive devices, and more. Thank you to all who took part. The survey was part of a partnership with the MSAA, who will collaborate with NARCOMS to analyze and report the results. Look for NARCOMS in Winter/Spring issue of the MSAA's biannual *The Motivator* magazine, published this May.

Sharing NARCOMS data results with the scientific community via a wide range of journals and conferences is an important way to both spread the knowledge and insight gained from analyzing the Registry data, and to inspire further studies in MS. It also helps practitioners get the latest information as quickly as possible, while providing a reliable source of information for health care policy and advocacy initiatives.

## NARCOMS NOW AVAILABLE EXCLUSIVELY TO NARCOMS PARTICIPANTS

Beginning with this summer issue of *NARCOMS Now*, online access to the magazine's content will be exclusively available to NARCOMS registry participants. Using your NARCOMS login and password, you can log in to read all our articles in full.

## NARCOMS EN ESPAÑOL

The NARCOMS surveys are available in Spanish, and we have a translator available to assist you with any language needs. Also, many of the *NARCOMS Now* articles are available online in Spanish. Visit [www.narcoms.org/narcomsnow/español](http://www.narcoms.org/narcomsnow/español) to access them all.

## NARCOMS @ CMSC/ACTRIMS ANNUAL MEETING

As you read this, it's likely NARCOMS researchers and staff are in Orlando, Florida, representing the organization at the annual cooperative meeting of the **Consortium of Multiple Sclerosis Centers and the Americas Committee on Research in Multiple Sclerosis**.



THE CONSORTIUM OF  
MULTIPLE SCLEROSIS CENTERS

**actrim**s

AMERICAS COMMITTEE FOR TREATMENT  
AND RESEARCH IN MULTIPLE SCLEROSIS

## CMSC/ACTRIMS ANNUAL MEETING POSTER PRESENTATIONS

NARCOMS researchers will present several posters at the meeting resulting from data provided by answers from our loyal NARCOMS participants. Thank you!

### SOME OF THE TOPICS TO BE PRESENTED ARE (BY TOPIC):

#### BASIC SCIENCE

- **Affiliation Profile of NARCOMS Registry Participants**
- **The NARCOMS Registry: Participation Review 1993–2013**
- **The NARCOMS Registry: Publication Review 1996–2012**

#### COGNITION, DEPRESSION, AND PSYCHOSOCIAL

- **Health Literacy is Associated with Health-Care Utilization in Multiple Sclerosis**

#### DISEASE MANAGEMENT, MECHANISMS AND TREATMENT

- **New Measures of Neurologic Disability Derived from NARCOMS Registry Data**

#### SYMPTOMATIC MANAGEMENT

- **Improved Tremor Outcomes in Natalizumab-Treated Multiple Sclerosis Patients**
- **Prevalence of Sleep Disturbances in the NARCOMS Registry Population**

Look to future issues of *NARCOMS Now* to learn more about publications based on this research. And visit [www.narcoms.org](http://www.narcoms.org) for video interviews with renowned MS researchers and clinicians at the conference.

Abstracts or full-length articles on most of the NARCOMS publications are readily available with search word “NARCOMS” at [www.pubmed.gov](http://www.pubmed.gov). For assistance in locating these, please contact us at 1-800-253-7884 or [MSregistry@narcoms.org](mailto:MSregistry@narcoms.org).

*Find the following hidden words:*

nutrition, diet, health, wellness, exercise, vitamins, therapy,  
movement, wellbeing, happiness, calm, peace, energy, rest, mobility

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

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:

[www.narcoms.org/narcomsnow/play/answers](http://www.narcoms.org/narcomsnow/play/answers)

# FACES OF NARCOMS



**Everyone's MS journey is unique. And every story is an inspiration. Please share your story of living with MS.**

***NARCOMS Now* is looking for your story:**

- » Your diagnosis story
- » Working with MS
- » MS and family
- » Daily life with MS
- » Your "ah ha" MS moment

**To submit a "Faces of NARCOMS" story, email: [narcomsnow@narcoms.org](mailto:narcomsnow@narcoms.org). Stories should be one page in length and may be edited for space.**

## **Coming Soon!**

- » ***NARCOMS Now* "Living with MS" photo contest!**  
**Details in the Fall 2013 issue - look for it in early October.**

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NARCOMS is a project  
of the **CMSC**. For more  
information on the **CMSC**  
visit [www.msca.org](http://www.msca.org).

