



NARCOMS

North American Research Committee on Multiple Sclerosis

Happy New Year!

The Faces of NARCOMS

The following article was written for this newsletter by Leslie F., a NARCOMS participant:

As an avid cyclist, I took it in stride when I had double vision in 1998, and managed to ride in group rides focusing on only one of the multiple wheels in my line of double-vision. But I was lucky. Aside from a little tingling in my feet, it wasn't until 2004 that I had a second "visionary" event-this time it was optic neuritis during graduate school. I used an eye patch and tried to focus on what I was reading, even though I was distracted by not knowing what was happening to me. One MRI and bout of prednisone later, my vision recovered. But with it came the diagnosis of Multiple Sclerosis.

I remembered back to elementary school, when I participated in the MS Readathon to raise money for MS research. At the time, I thought it was a debilitating disease where people were immediately in wheelchairs. I know now that this is how it happens for many, but there are a wide variety of experiences. I have relapsing-remitting MS. But I am perfectly willing to have my next MRI come back with no scars and no new lesions.

**Interested in becoming
a Face of NARCOMS?**

**See page 7 for more
information on how to
contribute your story**

My personal philosophy is one that has some resistance to being labeled, and I struggle with owning this diagnosis of MS. People tell us to "fight" to "battle," to try to "win" out over MS. I think that's a lot to ask. So often, we feel our bodies are against us, that we are separate from our bodies, as they shake or betray us in ways we could never have imagined. In my world, I'm already busy fighting. I have a nervous system that is at war with my immune system, and asking me to fight the disease itself is a lot to ask. I do hope for a cure, and I want research and advocacy to help bring an end to MS.

To come into my body, I practice yoga, which helps. I want to understand the tingling, the blind spots, and the loss of balance as part of my experience. And I am perfectly willing to have improved balance and decreased symptoms with years of practice. I am housed in this body and I hope for myself to make the best of life that I can in the time that I'm here.

**Introducing
Davis Guthrie
NARCOMS staff
Role: Participant Communications Liaison**

I have grown up in Birmingham, AL and lived here all my life. I am 23 years old and graduated from the University of Alabama at Birmingham with a degree in Criminal Justice. I plan to return to school this



Davis

Fall to pursue a Nursing degree. I have been working with NARCOMS for almost a year now and enjoy working with all of the participants through emails and phone conversations.

I enjoy helping all of the participants with their questions regarding the NARCOMS MS Registry as well as trying to assist them with their general Multiple Sclerosis questions. I look forward to continuing my interactions with the participants in the future.

Toll Free Number: 1-800-253-7884

OTHER STUDIES IN PROGRESS

Be on the lookout for an additional survey sent by mail to randomly selected participants. This supplemental survey is titled "The Impact of Treatment on Mobility, Activities of Daily Living, and Quality of Life " and is different from our update surveys conducted in the Spring and Fall.

We have collaborated with ACORDA Therapeutics, Inc. to design a survey that may help answer some important questions to MS researchers. We hope you are able to take some time and participate in this on-going study.

Latino participants will be invited in February to take part in a brief telephone interview.

Look for the Spring 2010 survey in April 2010!

NARCOMS Wellness Tip

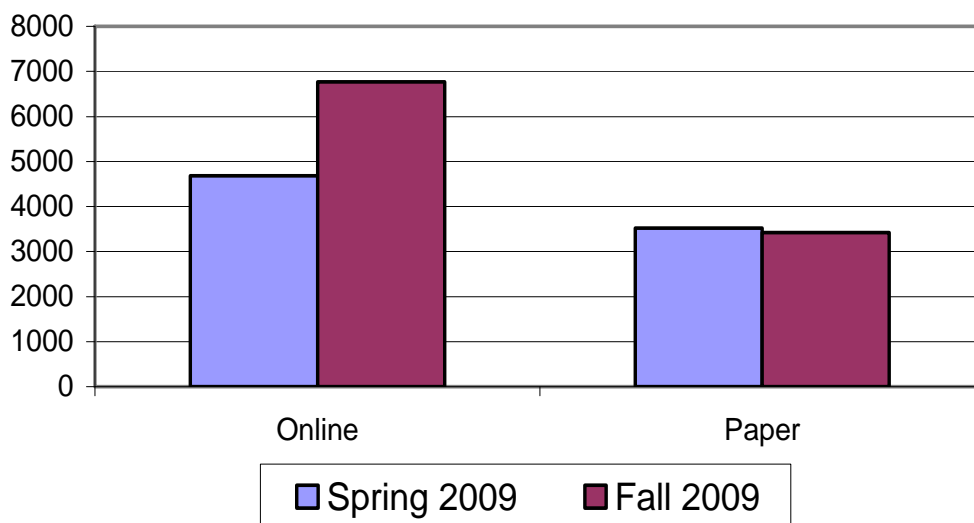
A regular, full-body exercise program is not only healthy but may help the brain in MS patients repair itself by inducing increased cortical plasticity. This may lead to more effective cortical remodeling, which is the main way the brain and spinal cord recover function after injury.

There is increasing literature on this, and clinical trials have definitively proven exercise can improve most symptoms of MS. There is no single best exercise program, so patients can determine with their care providers what works best for them.

Timothy L. Vollmer, MD, FAAN

Survey Updates, Spring and Fall, 2009

Our sincerest thanks to all who participated in our paper and online survey updates in the Spring and Fall of 2009. As displayed below, we had a dramatic increase in responses for the Fall update compared to last Spring. NARCOMS participants completed 10,194 surveys in the Fall of 2009 - almost 2000 more than were completed in the Spring of 2009 !!! We couldn't do this research without you, thanks!



Summaries of recently-published papers on MS-related health issues

Co-morbidities and their effect on disability with resultant recommendations for managing MS

Depression in multiple sclerosis (MS) may be due to several factors, including the presence of physical comorbidities such as hypertension, cancer (breast, lung, colon, rectal, skin), diabetes, heart disease and several others. This study compared the risk of depression between MS patients with physical comorbidities and MS patients without physical comorbidities. Information was gathered through questionnaires distributed to NARCOMS Registry volunteers. The responders also completed the Center for Epidemiologic Studies Depression Scale (CESD) for information on depression.

This study correlated levels of depression on CESD with occurrence of physical comorbidities in the responding population. Analysis included patients aged 16 to 50. Respondents tended to be white, female and of higher educational level and socioeconomic status than non-responders. All comorbidities were associated with higher risk of depression except kidney disease, which was associated with decreased levels of depression.

This paper concludes that Patients with MS and physical comorbidities are at increased risk of depression, but they are more likely to be diagnosed and treated than MS patients without other chronic conditions. The authors caution that the findings should be confirmed in a population-based cohort study. It warns that providers must be aware of the high risk of depression in MS and must develop consistent approaches to identifying and treating it.

From the Article: **Effect of Physical Comorbidities on Risk of Depression in Multiple Sclerosis**, found in the International Journal of MS Care, Volume 11, pages 161-165, 2009.

Website: <http://www.ms-care.org/cmsc/Journal-of-MS-Care.html>

Bone Health in MS

Although osteoporosis is considered common in multiple sclerosis (MS) and it is an important risk factor for fragility fractures, few studies have focused on fractures in MS. This paper analyzes data collected through questionnaires voluntarily completed by MS patients in the NARCOMS Registry on frequency of osteoporosis, fractures and clinical risk factors for fracture in MS.

Each patient reported history of osteoporosis or osteopenia (low bone mass), sedentary level of physical activity, falls in the previous year, current smoking status, family history of osteoporosis, and impaired mobility. 27.2% of responders reported low bone mass and over 15% reported a history of fracture after age 13. Among those reporting fractures, 46.2% reported multiple fractures.

The authors concluded that patients with MS often have multiple risk factors for osteoporotic fractures and many are not taking supplemental calcium or vitamin D, suggesting an area with potential for improvement in care.

From the Article: **A cross-sectional study of bone health in multiple sclerosis.** Found in *Neurology*, Volume 73, pages 1394-1398, 2009.

Website: <http://www.neurology.org/>



**Yesterday's the past, tomorrow's the future, but today is a gift.
That's why it's called the present.**

MS Medications Pending FDA Approval in 2010

(based on articles from the Rocky Mountain MS Center: www.mscenter.org)

CLADRIBINE - is an FDA approved chemotherapy treatment most often used to treat leukemia and lymphoma. It provides immunomodulation through selective targeting of lymphocyte subtypes. A Phase III study reported in the New England Journal of Medicine, January 20, 2010 (www.nejm.org), showed significantly lower annualized relapse rate, higher relapse-free rate, lower risk of progression of disability and significant reduction in the brain lesion count on magnetic resonance imaging (MRI) compared to placebo.

DALFAMPRIDINE (Ampyra) – On January 22, 2010, FDA approved dalfampridine (Ampyra) a sustained-release oral tablet, to improve walking in patients with MS. Dalfampridine blocks potassium channels on the surface of nerve fibers, which may improve the conduction of nerve signals through areas of demyelination. In higher dosages, there is some risk of epileptic seizures.

<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm198463.htm>

FINGOLIMOD - is the first of a new class of potential MS medications which appear to induce immune cells to remain in the lymph nodes and spleen rather than migrating into the brain and spinal cord. Recent studies, published in the New England Journal of Medicine, January 20, 2010 (www.nejm.org), showed significantly lower annualized relapse rates compared to both intramuscular interferon beta-1a and placebo. However, at higher dosages, two fatal infections occurred. The benefit to risk factor of Fingolimod is still being researched.

LAQUINIMOD - a once-daily oral therapy, is now being studied in two Phase III clinical trials. It received *Fast Track* designation from the FDA in February, 2009. To this point, laquinimod has been well-tolerated and no severe side effects have been observed. Laquinimod may be available on the market as soon as late 2011.

TERIFLUNOMIDE - also a once-daily oral therapy, demonstrated beneficial effects in MS patients in Phase II and is now in Phase III. An immunomodulatory drug, Teriflunomide inhibits rapidly dividing cells, including activated T cells, which are thought to drive the MS disease process.

BG-12 (dimethyl fumarate) - is another emerging oral therapy for MS. BG-12 has been shown to activate the Nrf2 transcriptional pathway. This pathway is thought to defend against oxidative-stress induced neuronal death, protect the blood-brain barrier, and support maintenance of myelin integrity in the central nervous system – all key elements to treating MS. Now in Phase III clinical trials, BG-12 could soon be headed to the FDA for approval.

Please refer to your Physician for more detailed information on these drugs.

IMPORTANT REMINDERS



- Please keep your username and password written down in a safe place
- ***If username and password are forgotten please call 1-800-253-7884.***
- Please use a pen instead of pencil when completing surveys.
- Please help us expand the registry. When you speak with other MS patients tell them about NARCOMS.
- If anyone is interested in sharing their MS story in our newsletter, The Faces of NARCOMS, please write your story and send it to MSregistry@narcoms.org for consideration in a future issue or for posting on the NARCOMS website.

REMEMBER

Remember that this registry would not be possible without YOUR help!!!!

We ask your help in recruiting others to NARCOMS, especially individuals who are newly diagnosed, to provide them with companionship and information. Of course, we welcome new or returning members who have had the disease for any length of time.

If you know of anyone with MS, please encourage them to visit our website or give them our phone number to speak with us directly.

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

NARCOMS is now on the Clinical Trials Government website. You can view us at www.clinicaltrials.gov website.

For all you Word Search lovers!!!

Find these hidden words:

Determination, inspire, healing, body, mind, spirit,
fight, emotions, invincible, faith, journey, peace,
hope, strength, courage

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