



# NARCOMS

North American Research Committee on Multiple Sclerosis

## Inquiring Minds Want to Know!!!

### Important News!!!

NARCOMS has relocated to the University of Alabama at Birmingham (UAB) in Birmingham, AL.

We are expanding the project. Be on the lookout for this periodic newsletter. It will inform you about the growing number of registry activities and the increasingly important role the registry plays in the field of MS care and MS research.

### Introduction of Our Staff

We would like to introduce you to Davis Guthrie and Desiree Mitchell. They will be assisting you with any questions or concerns. They can be reached by phone (1-800-253-7884) – 8am to 5pm (Central Time) or by email ([MSRegistry@narcoms.org](mailto:MSRegistry@narcoms.org)).

### NARCOMS is trying to GO GREEN!!!!

For those participants who receive paper surveys and have supplied an e-mail address we ask that you help us by receiving our newsletters and similar items via e-mail. You can do this by sending us an e-mail or calling the toll free number listed in the paragraph above to let us know you would like to change your contact information. You will continue to receive your update surveys by mail.

### With Your Help!!!

The NARCOMS registry has become a major resource for MS research and clinical trials for new treatments!

We want to thank ALL of you for helping us build the registry. The time you take out of your busy schedules to complete the surveys has made us what we are today. We appreciate your continued and dedicated participation in the NARCOMS MS Registry.

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.

## About NARCOMS

North American Research Committee on Multiple Sclerosis (NARCOMS) is a project of the Consortium of Multiple Sclerosis Centers (CMSC), a not-for-profit professional organization for MS healthcare providers and researchers involving 198 participating centers of the MS Treatment and research community. The data coordinating center, located at University of Alabama at Birmingham (UAB), maintains NARCOMS, the largest voluntary, patient-driven Multiple Sclerosis (MS) registry in the world. The registry involves personnel from at least three more sites in the US and Canada (the University of Colorado Health Science Center in Denver, Barrows Neurological Institute in Phoenix, and the University of Manitoba in Canada). Over the past 10 years more than 34,000 people with MS, including over 4,000 Veterans, have participated in the registry by submitting their health-related data by mail or online via the internet. Registry data have been featured in 34 peer-reviewed journal articles and more than 80 scientific posters and presentations. These reports provided information to guide new research. They also provide evidence supporting the approval of new drugs in the fight against MS.

## Purpose of the Registry

The purpose of the registry is two-fold: First of all, de-identified datasets are used to investigate important aspects of MS, such as the natural course of the disease, patterns of care, outcomes research, long-term effects of treatment, and factors affecting the quality of life of patients. Secondly, the registry expedites recruitment of MS patients for clinical trials across the country and reduces the cost associated with the process.

The project provides a unique opportunity for all MS patients to facilitate and support MS research. All adults with MS are invited to join in this long-term research study by first enrolling in the registry and filling out our baseline questionnaire and then completing an update questionnaire twice a year, either by mail or conveniently online ([www.narcoms.org](http://www.narcoms.org)). The questionnaires are available in English or Spanish. All information gathered is strictly confidential and used for statistical analyses only. Any opportunities to participate in research studies are presented to you for you to choose whether you want to participate. Research results are published in scientific journals, and shared with the participants in an informative quarterly publication, Multiple Sclerosis Quarterly Report, which is mailed to all registry participants free of charge. For more information or to request enrollment forms or other material, please call 1-800-253-7884 or contact us at [MSregistry@narcoms.org](mailto:MSregistry@narcoms.org).

We also are interested in pursuing issues that are important to you. We invite suggestions from you the participants.



## Plans for the Future

We aim to provide communicate with you more often, via this newsletter. Several other goals for this registry are as follows:

- requesting recruitment assistance from participants to ensure we represent all MS patients in all forms and stages of their disease process
- international expansion to enable experiences and advances worldwide to be shared
- expanding further to the Spanish speaking population, a growing segment of the US population and share experiences with the large world of Spanish speaking countries
- gathering information regarding other demyelinating diseases often confused with MS
- creating pediatric cohorts to better understand the earliest manifestations of the disease
- enrolling more newly diagnosed patients to ensure that issues in the early stages of disease are represented along with issues important to other MS patients.

### NARCOMS Tip of the Month

Exercise has been suggested in scientific studies to improve most symptoms of MS by inducing reparative processes in the brain!!!

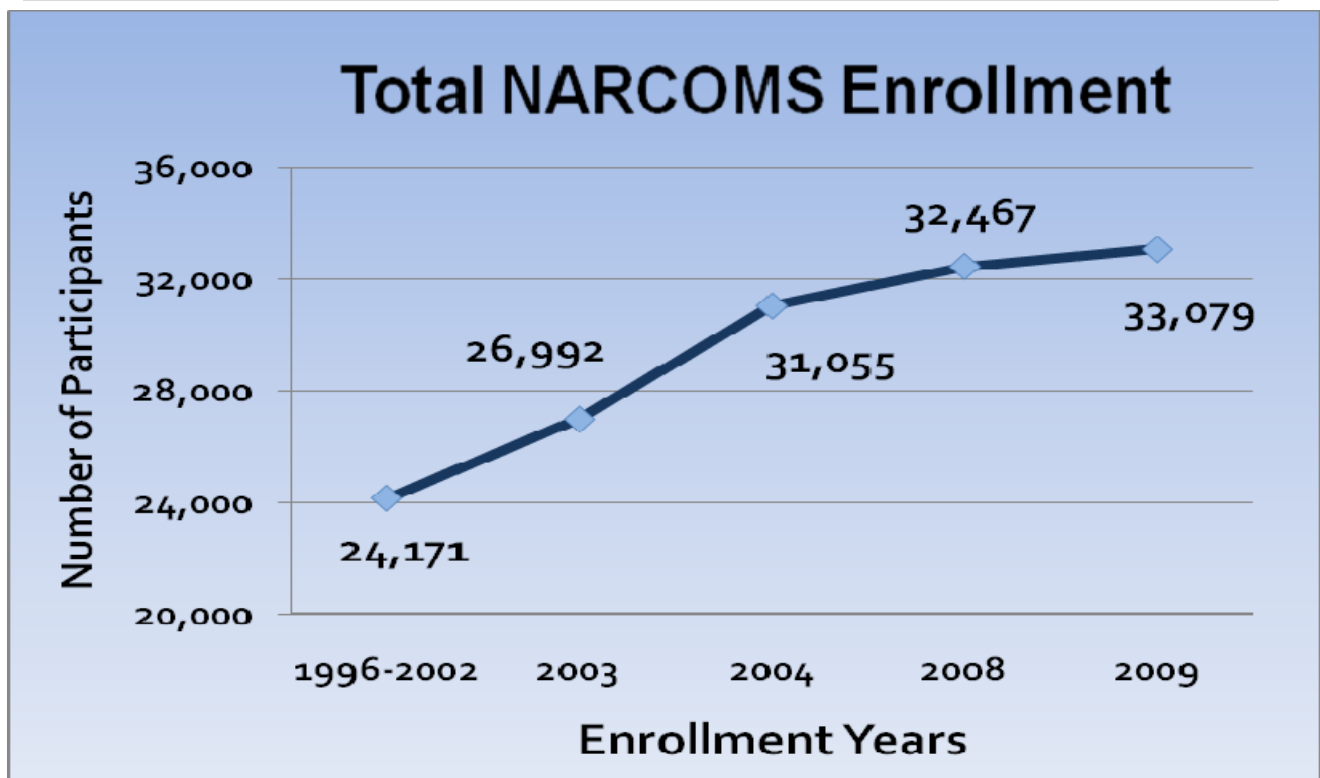


### What's on the web in MS?

Vitamin D and Statins have been in the news lately regarding their association with MS. Click on the links below for more information.

- [Learn more about Vitamin D](#) (click on the Summer 2009 link)
- [Vitamin D Levels and MS](#)
- [Vitamin D3](#)
- [Statins Show Potential as Immune Modulators in MS](#) (scroll down to page 10 for Statin use information)

Clinical Trials are being planned worldwide to assess whether increasing vitamin D and/or treatment with Statins truly improve MS patients. Vitamin D levels clearly appear lower in MS patients. What needs to be shown is that increasing Vitamin D can improve the prognosis or status of MS patients.



### IMPORTANT REMINDERS

- Please keep your username and password written down in a safe place
- **If username and password are forgotten you will need to call 1-800-253-7884.**
- Help us by using pen instead of pencil when completing surveys.
- Please help us expand the registry. When you speak with other MS patients tell them about NARCOMS.

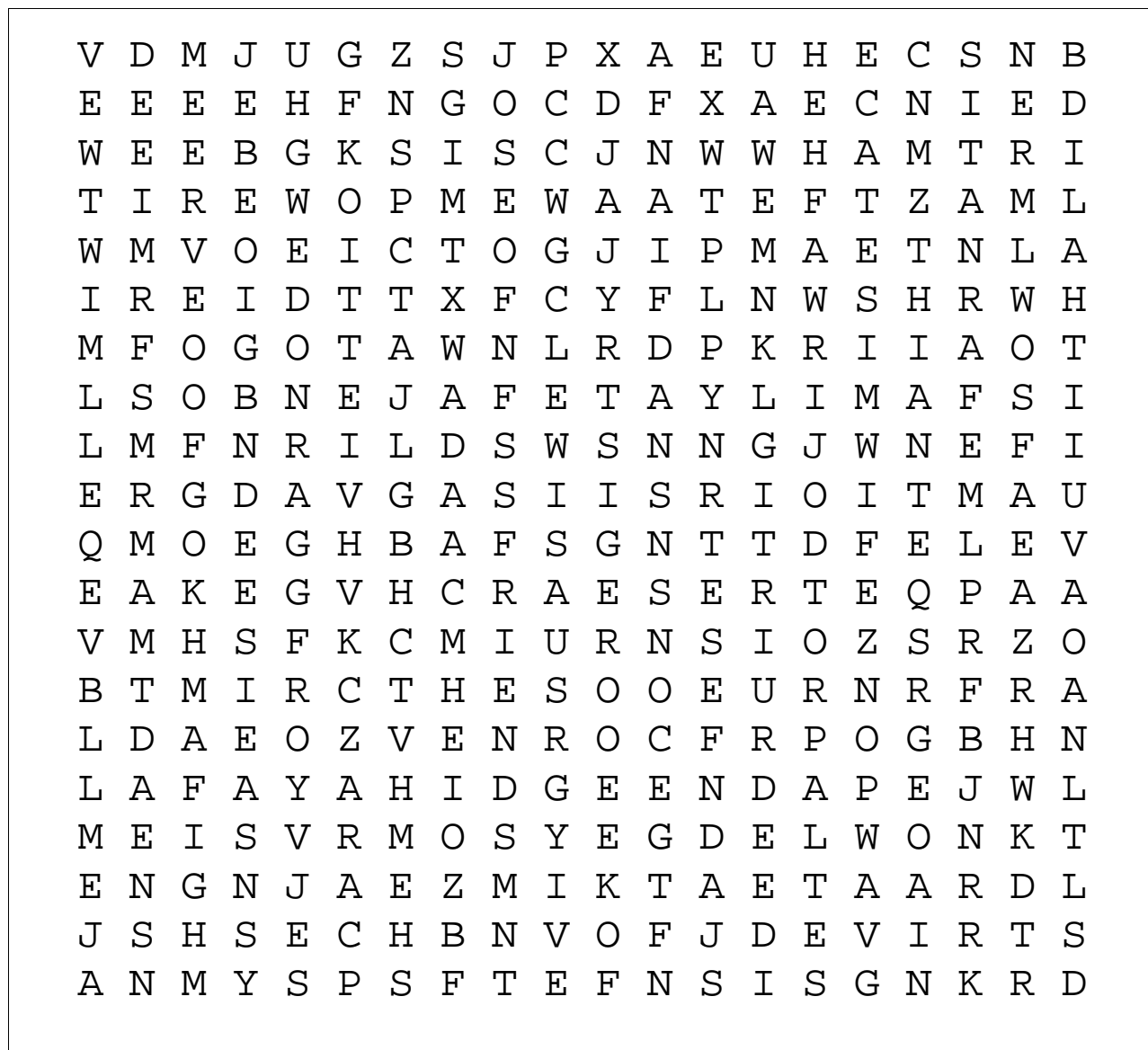
### INTERESTING RESULTS FROM YOU!!!

- Average Age at diagnosis: 37.2 years
- 73% of participants are women and 27% are men
- Average Age at NARCOMS enrollment: 47.3 years
- Average Duration of MS at enrollment: 9.9 years



*Note: We need your participation, but if you prefer not to receive any periodic newsletters from NARCOMS, simply let us know at any time by reply email or by calling us at 1-800-253-7884*

## NARCOMS Word Search Puzzle



### Find the following hidden words:

research, cmsc, narcoms, registry, empower, strong, support, friends, family, vision, knowledge, awareness, strive, encouraging