



## **NARCOMS (North American Research Committee On MS)**

**OUR VISION:** The Vision of the NARCOMS/Global Patient Registry is to facilitate multi-center research in the field of multiple sclerosis (MS). We strive to develop collaboration between centers of excellence in MS throughout the world to increase knowledge, leading to improved clinical care and quality of life for MS patients.

### **OUR GOALS:**

Facilitate a confidential way for patients to supply valuable information to researchers about their course of disease that may lead to more effective treatments and care for people living with MS, while reducing the time and cost of conducting studies.

Provide a worldwide research resource for people living with multiple sclerosis so they can provide information about themselves and their course of disease.

Develop new collaborations between researchers, patients, and healthcare providers to:

- Increase knowledge of effective treatments
- Increase high quality healthcare services
- Raise awareness of MS
- Promote greater understanding about MS
- Increase peer reviewed publications

The NARCOMS Registry is an active database of over 34,000 individuals who have MS. It was developed in 1993 by the Consortium of Multiple Sclerosis Centers (CMSC) to provide a way for individuals with MS to confidentially provide detailed information on their course of disease as well as their treatment. We are seeking to raise awareness about MS and increase the enrollment numbers in the Registry to help us further research efforts and eventually find the cure.

### **Patient Registry Purpose**

The purpose of the Registry is to speed the development of new therapies and healthcare services by facilitating research in these areas and reducing the time and cost of research studies. Individuals with Multiple Sclerosis are invited to enroll in the Registry through direct mailings, MS centers, support groups, and the NARCOMS Registry webpage. Enrollment involves filling out a questionnaire and mailing it or submitting it online to the Registry Administration Office. Participants are assured that strict confidentiality will be maintained and that their names will not

be given to anyone without their permission. The questions asked are regarding demographic information, MS-related medical history, immunologic and symptomatic therapies, health care services used, and a series of patient-assessed performance scales that reflect disability in eight domains of function.

### **Benefits of Participation**

- You are helping to provide the information needed to learn about the variations of MS in a very large group of patients and to monitor the progression of the disease
- You help us monitor the effects of various treatments. Your information may be providing ideas for future research
- You will be receiving the printed version of the MSQR free of charge
- You will be informed of recent studies and their results
- You will be notified of clinical trials in which you may be eligible to participate

### **Contact Information:**

Website: <http://www.cmscnarcoms.org>  
Enroll online: <http://www.cmscnarcoms.org/enroll>  
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