

North American Research Committee on Multiple Sclerosis

Denise I. Campagnolo, MD, MS

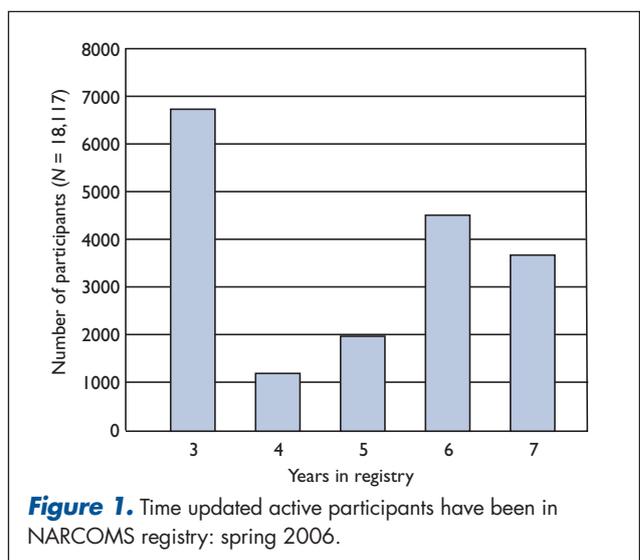
The Consortium of Multiple Sclerosis Centers (CMSC) established the NARCOMS project in 1993 to develop a registry of patients with multiple sclerosis (MS) to help facilitate multicenter research in the field of MS. Initially, NARCOMS was the acronym for North American Research Consortium on Multiple Sclerosis. In 1999, the word *Consortium* was changed to *Committee*. The registry is a relatively comprehensive database consisting of easily accessible data used by investigators to develop research strategies and survey MS-related issues. In 1996, Timothy Vollmer, MD, was appointed the director by the board of CMSC. The registry project was initially operating at the Yale University Multiple Sclerosis Research Center, of which Dr. Vollmer was also director at the time, and the US Department of Veterans Affairs (VA) Connecticut Healthcare System West Haven campus.

Enrollment in the NARCOMS patient registry was initiated in 1996 through various recruitment strategies, and self-reported disease-specific data have subsequently been collected through enrollment and follow-up questionnaires. Recruitment started slowly because of insufficient funds and a lack of awareness of the registry's function and potential value, but it improved greatly with time. As the registry grew, pharmaceutical companies started offering unrestricted grants, which further increased enrollment. When the registry reached 3000 participants, a collaboration was established with the leadership of the Eastern Paralyzed Veterans Association (EPVA, a chapter of the Paralyzed Veterans of America [now the United Spinal Association]), to enroll veterans with MS in the registry. A large advertising campaign through the various VA magazines and postcard mailings through the VA database resulted in enrollment of >2000 veterans with MS. In addition, when Dr. Vollmer became the editor of *Multiple Sclerosis Quarterly Report (MSQR)* in mid-1999, the cost of printing and mailing the publication to all NARCOMS registry participants was taken on by EPVA. The strong partnership between NARCOMS and the United Spinal

Association continues to offer *MSQR* free to all active registry participants.

The first major use of the registry's database occurred in 1998, when Serono Laboratories funded a survey of the registrants to evaluate the reasons for nonadherence to immunotherapies. The results of that survey were presented in conferences and demonstrated one of the practical uses of the database.

The NARCOMS registry is currently considered a valuable resource for surveying people with MS and for recruiting participants for particular clinical trials. As registry data accumulate and its potential achieves prominence, it is positioned to play a leadership role in establishing an international registry that would enable cooperative, comparative studies. As of spring 2006, close to 32,000 individuals with MS were enrolled in the NARCOMS registry, and >18,000 active participants recently updated information (Figure 1). Twice a year, all active registry participants receive an update questionnaire seeking current demographic, health care delivery, disease status, and treatment information. These updates, together with the baseline survey at enrollment, are referred to as the NARCOMS long-term epidemiological study of people with MS.



Dr. Campagnolo is Medical Director—NARCOMS, Director of Clinical Multiple Sclerosis Research, Barrows Neurological Institute, Phoenix, AZ, USA

The following types of data are requested from NARCOMS participants:

- Demographic and socioeconomic characteristics—sex, age, race/ethnicity, education, employment, insurance, marital status, residence
- Diagnosis and history—age at diagnosis, age at symptom onset, blood relatives with MS, twin, magnetic resonance imaging
- Disease characteristics—relapse rate, solumedrol-treated relapses, symptom stability/worsening
- Treatment—disease-modifying agents and other immunotherapies, symptomatic, alternative
- Health care utilization—providers, emergency room visits, overnight stays, and reasons
- Functional domains and quality of life—patient-determined disease steps, performance scales, SF-12 health survey.

Participants may enroll in the registry, update their contact information, and respond to the most recent questionnaire online via a secure website. NARCOMS also has an actively used generic email address (narcoms@chw.edu). More than 60% of registry participants prefer to complete the surveys online.

In 2003, NARCOMS moved to Barrow Neurological Institute in Phoenix, Arizona. In this location, the database is

hosted by Emerge.MD, a company specializing in designing and maintaining research databases. Enhanced data access and management capabilities through a proprietary PHI editor have streamlined routine operations and further increased and enhanced online participation. In 2005, I became the medical director for the project. With my medical leadership and the extraordinary efforts of Project Manager Tuula Tyry, PhD, the database has continued to grow during the transition.

Today, the registry is involved with nine research studies, including recent explorations of fatigue, pain, care-partner issues, and sexuality, and has eight projects in the pipeline. Results from these and future studies are and will be reported in *MSQR* to further motivate and encourage registry participants in their commitment to MS research. The NARCOMS administrative team works simultaneously with many investigators in MS, exploring uses of the data to answer research questions and conducting focused surveys. The enrollment and update questionnaires will soon be available in Spanish, with availability in other languages to follow. We hope that clinicians caring for people with MS will make their patients aware of this valuable database and encourage them to submit their information. Enrollment can be accomplished online at www.narcoms.org/enrollment, or a paper survey (United States only) can be obtained by sending an e-mail to narcoms@chw.edu or calling 1-800-253-7884. □