

NARCOMS: Researchers need YOU

To really understand multiple sclerosis, you have to talk to people who have it. Researchers who are tackling difficult questions about the disease are no different—except they need to talk to thousands of people about it. In 1993, the Consortium of Multiple Sclerosis Centers (CMSC) recognized this need and created a registry called NARCOMS (the North American Research Committee on Multiple Sclerosis), to capture the experiences of people living with MS.

In the 20 years since NARCOMS' inception, more than 36,000 people have joined the registry. But more participants are needed right now to help it grow and become even more representative of people with MS. In 2012 alone, researchers used data from the registry participants to report on mobility impairment, walking speed, quality of life, disease progression, genetics, overactive bladder, vertigo and many other topics to help express the MS experience.

NARCOMS studies risk tolerance

In just one example of the research that NARCOMS is facilitating, Dr. Robert Fox—the current managing director of NARCOMS and medical director at the Cleveland Clinic's

Mellen Center for Multiple Sclerosis—received funding from the National MS Society to look at people's views on the risks involved in newer MS therapies, such as the possibility of developing the brain disease PML from using Tysabri.

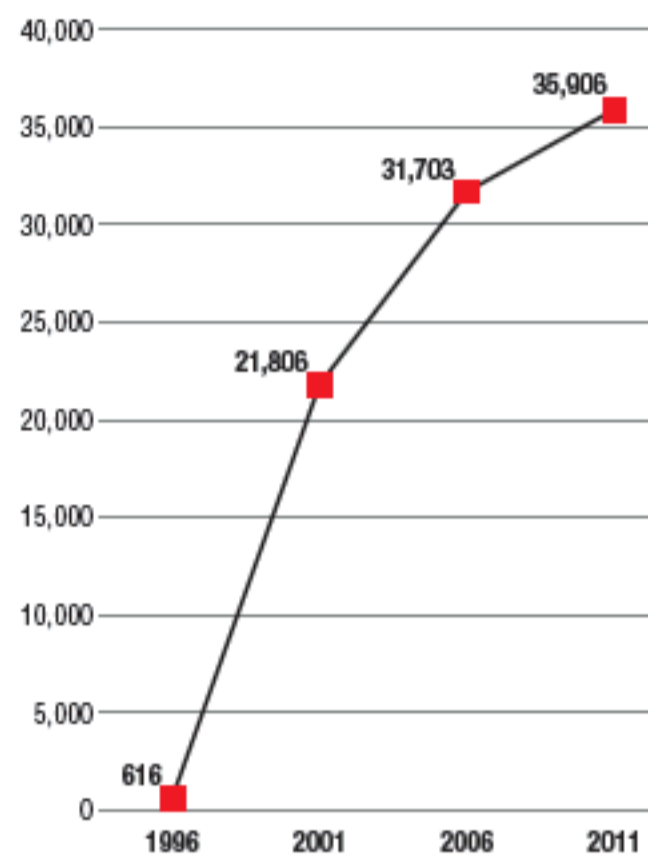
Dr. Fox and his colleagues administered a survey on the topic to 5,446 people from the NARCOMS registry and then repeated the survey one year later. Team members have found, not surprisingly, that people who are more severely disabled by MS are willing to take higher risks with therapies. Interestingly, tolerance to risk shifted over time, with more than one-fifth of respondents becoming less willing to tolerate risks over the one-year period. These results suggest that patients' acceptance of the risk of MS therapies is subject to change and may require ongoing discussions with healthcare providers.

This study and many others using data from NARCOMS are being used to improve our understanding of life with MS (Abstract #P986,ECTRIMS 2012).

How do you sign up?

Anyone with a diagnosis of MS can participate in NARCOMS and contribute to research studies. Participants are asked

Total enrollment in NARCOMS from 1996 to 2011



to complete an enrollment questionnaire, and then update surveys twice a year. Surveys take about 45 minutes to complete and can be filled out online or in print.

NARCOMS conducts other studies beyond the biannual surveys, and provides recruitment assistance to other MS researchers, but participation in those is completely optional. Although NARCOMS builds collaborations with other investigators to further our understanding of MS, it does not sell or share personal information; what's more, all analyses are conducted with data that cannot personally identify any participant.

To enroll, call 800-253-7884 (toll free) from 8 a.m. to 5 p.m. Central Time, Monday through Friday, or visit the website at narcoms.org. ■