

Pacific Northwest MS Registry update

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Pacific Northwest MS Registry

Multiple sclerosis is an autoimmune disease that damages the brain or spinal cord. The disease has been reported as the most common cause of neurological disability among young and middle-aged adults. Statistics show that MS is more likely to affect women and to be diagnosed during young adulthood between ages 20 and 50. The disease also is more common among people of northern and central European ancestry, and people who lived in the high latitudes during childhood.

Accurate and up-to-date measures of MS prevalence in Oregon are unavailable due to the lack of patient registries. The National MS Society estimates that more than 7,000 people in Oregon live with multiple sclerosis; however, early results from our registry indicate that this might be an underestimate by 40 percent. Further, there is an ongoing shortage of neurologists in the state who are specifically trained and willing to focus on treating this disease. The problem is particularly acute in remote, rural areas.

To respond to these challenges, the Providence Brain Institute, in collaboration with the National MS Society Oregon Chapter, developed the Pacific Northwest MS Registry and Network in October 2007. The goals are to accurately estimate the prevalence and geographic distribution of MS patients, to create a database for ongoing epidemiological and health services research in MS, and to develop an interactive MS network to provide training and improve access to specialized MS care.

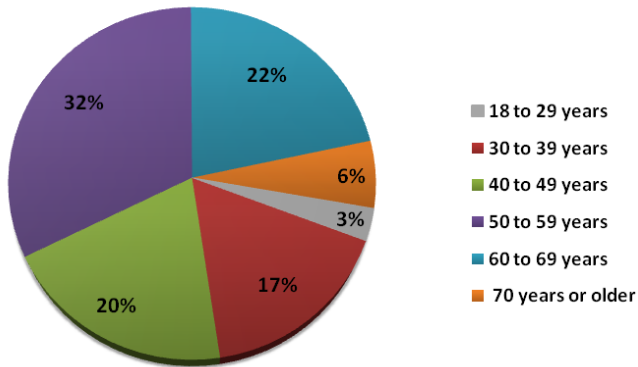
Subject recruitment sources include the National MS Society Oregon Chapter, several MS centers and neurology specialty clinics in Oregon, and online registration on the program [Web site](#). More than 3,200 people have joined the registry, and have provided demographic and health information through confidential surveys. A sub-study is in progress to investigate the prevalence and severity of depression and fatigue and their association with physical impairment on a cohort of 500 patients with clinically definite MS, based on the Revised McDonald Criteria.

The preliminary results show the majority of the current participants are Caucasian (96 percent), female (80 percent), and diagnosed with relapsing remitting form of MS (56 percent). Mean age at survey and at diagnosis were 51 and 39, respectively. Eighty-six percent had visited a neurologist within the past year, and 66 percent reported receiving FDA-approved, disease-modifying treatments.

MS registry demographic details

	N	%
Race and ethnicity		
Hispanic or Latino (of any race)	44	1.6
African-American	25	0.9
White	2,554	94.6
Asian	12	0.4
American Indian/ Alaskan Native	64	2.4
Native Hawaiian/Other Pacific Islander	1	0
Sex		
Female	2,482	80.0
Male	618	20.0
Disease pattern		
Clinically isolated syndrome	178	7.1
Relapsing remitting MS	1,401	55.7
Primary progressive MS	289	11.5
Secondary progressive MS	512	20.3
Relapsing progressive MS	137	5.4

Age of participants



Of those using a disease-modifying therapy, 25.3 percent reported missing one to two doses in the last six months; 17.5 percent missed three or more doses. The most commonly reported reason for missing a dose was that the participant forgot (40.4 percent).

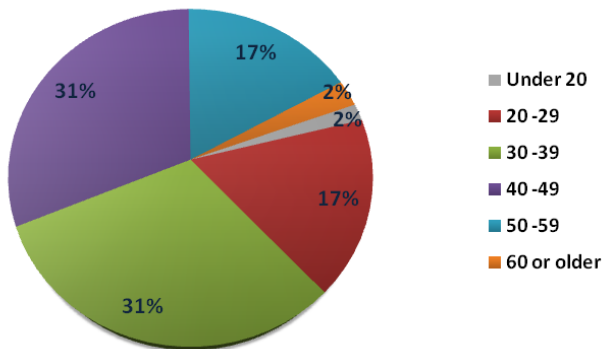
Other common reasons were because the participants were too sick (11.6 percent), or because they ran out of medication (9.1 percent).

Eighteen percent of participants report using some type of alternative or complementary therapy.

Thirty-seven percent of participants reported that they are currently employed; 28.1 percent reported that they are employed 30 or more hours per week. The majority of those surveyed, 56.8 percent, reported a change in their work status due to their MS.

Fourteen percent of surveyed participants reported that they do not see a neurologist for treatment of their MS. Of those who do see a neurologist, many report traveling long distances: 8 percent travel 51 to 100 miles, 7.1 percent travel 100 miles or farther.

Age at diagnosis



The Pacific Northwest MS Registry and Network is in process of constructing an online resource for health care providers and people living with MS. This comprehensive Web site will provide detailed information on disease patterns and treatments, therapy for various symptoms, and upcoming research. The site will be available to the public in the spring of 2010.

To learn more about the Pacific Northwest MS Registry, visit our [Web site](#) or call the project staff at 503-216-1022.