



New International Survey Finds MS Patients and Neurologists View Communication Positively, Yet Struggle to Discuss Key MS Symptoms

September 10, 2014

- *Neurologists Underestimate Patient Discomfort with Discussing More Typical Symptoms* –
- *Patients Most Uncomfortable Engaging in Candid Dialogue about More Private Symptoms* –
- *Patients and Physicians Not Always Aligned on Most Helpful Disease Resources* –

CAMBRIDGE, Mass.--([BUSINESS WIRE](#))--Findings from an international survey show differences in the perceptions of people living with multiple sclerosis (MS) and neurologists when discussing MS symptoms, including those that are personal and sensitive. While the results generally suggest a positive assessment of current practice in MS, important gaps were identified that could potentially impact disease management and patient quality of life. These findings will be presented this week at the Sixth Triennial Joint Meeting of the Americas Committee for Treatment and Research in Multiple Sclerosis and the European Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS-ECTRIMS) in Boston.

The survey, commissioned by Biogen Idec (NASDAQ: BIIB) and conducted online by Harris Poll, was developed in partnership with the State of MS Consortium, an international steering committee of treating neurologists from five countries and representatives from patient advocacy groups. The survey involved MS patients and neurologists who treat the disease in Germany, Italy, Spain, the United Kingdom (UK) and United States (U.S.) and aimed to understand the current experiences of those living with and treating the disease, including communication between MS patients and their physicians.

"There are a variety of symptoms a person living with MS can experience, and as physicians we need to constantly evaluate the most effective strategies to address all of our patients' needs," said Mar Tintore, M.D., Ph.D., senior consultant neurologist, Neurology-Neuroimmunology Department, MS Centre of Catalonia, Hospital Vall d'Hebron, Barcelona, Spain. "This survey illustrates that while there is a high degree of satisfaction with overall physician-patient communication, disconnects between patients and physicians mean some symptoms could be under-managed."

Despite Open Communication, Discomfort Remains in Discussing Typical Symptoms, Including Those That Are Private and Sensitive

More than eight in ten patients (83 percent) say they feel comfortable talking about their MS with their neurologists, noting their neurologist provides them with helpful information (81 percent). Moreover, 85 percent of patients characterize their neurologist as honest in setting their expectations for therapy success. Similarly, nearly all neurologists (96 percent) feel they have an open dialogue in which their patients can ask any question they want, and 90 percent indicate they have a good understanding of all aspects of their patients' disease. Yet a divide exists specifically around communication about certain MS symptoms.

Neurologists tend to underestimate their patients' discomfort talking about MS symptoms often associated with the disease, while overestimating patient discomfort discussing other, more private symptoms. Nearly one in five patients who experience MS symptoms report being uncomfortable speaking with their neurologist about their difficulty walking (19 percent), tremors (19 percent) and muscle spasms (18 percent), but only two to three percent of neurologists identify these symptoms as uncomfortable topics for their patients to discuss with them. Conversely, neurologists are in alignment with patients when identifying the most difficult topics for patients to discuss, and tend to expect a higher level of discomfort than what is expressed by patients. The sensitive symptoms that emerged as the most uncomfortable for patients to discuss were sexual difficulties (54 percent of patients, with 87 percent of neurologists perceiving this as being uncomfortable for patients) bladder or bowel problems (28 percent; 54 percent), mood swings (26 percent; 37 percent) and cognitive/memory issues (21 percent; 37 percent).

What can Hinder Communication?

Not surprisingly, time constraints are cited as the greatest barrier by neurologists (47 percent) when it comes to patient communication. For patients, however, not wanting to be perceived as being "difficult" was cited as the barrier that most interfered with communication with their physicians (24 percent), followed by time constraints (21 percent).

"The discomfort reported by both people living with MS and treating physicians suggests that important conversations about all of the symptoms associated with MS may not be happening," said Maggie Alexander, chief executive, European Multiple Sclerosis Platform (EMSP). "People with MS and their physicians should be empowered and equipped to discuss all aspects of the disease. This open and honest dialogue is critical to achieving improved quality of life and better long-term outcomes."

Information is Accessible, but More is Needed

While the survey shows communication gaps between patients and neurologists exist, findings also demonstrate respondents are seeking information about the disease:

- Sixty-three percent of physicians recommend materials available at their office to their patients, while only 19 percent of patients cite these materials as most helpful;
- Seventy-two percent of patients find online and social media resources most helpful for finding information about MS; these resources are also recommended by 73 percent of physicians to their patients;
- Many neurologists indicate a desire for additional resources to provide to their MS patients, including information on maintaining cognitive function (49 percent), managing the emotional challenges of having MS (45 percent) and being sexually active (43 percent).

"At Biogen Idec, we believe that successful MS treatment extends beyond medication. Our goal with this survey was to better understand the needs of the patient and the physician, and through that understanding bring a new awareness to the importance of a comprehensive dialogue about MS," said

Gilmore O'Neill, vice president, Multiple Sclerosis Research and Development, Biogen Idec. "Our alliance with the State of MS Consortium will ultimately help us work with the MS community to address these issues and continue to improve care."

In collaboration with the State of MS Consortium, an in-depth report of these findings and perspectives from the committee members is currently under development, and will be available to the MS community by the end of the year. As part of its ongoing commitment, Biogen Idec continues to evaluate the results of this survey and work with the community to identify new and innovative solutions to improve care for MS patients. For more information about the State of MS, visit BiogenMS.com.

About the Survey

Harris Poll, on behalf of Biogen Idec, surveyed 982 adults diagnosed with multiple sclerosis ("MS patients") and 900 neurologists who treat MS patients ("neurologists") within Germany, Italy, Spain, the UK, and the U.S. between March 18 and April 25, 2014. Within the U.S., MS patient responses were weighted for gender, age, region, race/ethnicity, education and income where necessary to align with actual proportions in the U.S. MS patient population; U.S. neurologist results were weighted for gender, region, and years in practice where necessary to align with actual proportions in the U.S. neurologist population. A global post-weight analysis was applied to the total data in order to give each country equal weight.

About the State of MS Consortium

The survey was led by the State of MS Consortium, an international steering committee of treating neurologists and representatives from patient advocacy organizations across five countries: the U.S., UK, Spain, Germany and Italy. The steering committee members, who were involved in the development of the survey, include:

- Maggie Alexander, chief executive, European Multiple Sclerosis Platform, representing 39 MS societies from 34 European countries
- Martin Duddy, M.D., consultant neurologist, department of Neurology, Royal Victoria Infirmary, Newcastle upon Tyne, UK
- David E. Jones, M.D., assistant professor, University of Virginia Health System, Charlottesville, VA, U.S.
- Nancy Law, executive vice president, National Multiple Sclerosis Society, U.S.
- Mar Tintore, M.D., Ph.D., senior consultant neurologist, Neurology-Neuroimmunology Department, MS Centre of Catalonia, Hospital Vall d'Hebron, Spain
- Antonio Uccelli, M.D., associate professor of Neurology and head of MS Clinic and Neuroimmunology Unit, University of Genoa, Italy
- Robert Weissert, M.D., Ph.D., senior physician and researcher, university professor of Clinical Neurobiology, University of Regensburg, Germany
- Sibyl Wray, M.D., director, Hope Neurology MS Center, Knoxville, Tenn., U.S.

About Multiple Sclerosis

Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system, which is made up of the brain, spinal cord and optic nerves. Symptoms may be mild or severe, ranging from numbness in the limbs to paralysis or loss of vision. The progression, severity and specific symptoms of MS are unpredictable and vary from one person to another. MS affects more than 2.3 million people worldwide,¹ with more than 500,000 sufferers in the European Union² and 400,000 in the United States.³ Relapsing forms of MS include: relapsing-remitting MS (RRMS), the most common form of the disease accounting for 85 percent of cases, which is characterized by clearly defined acute attacks with full recovery or with residual deficit upon recovery;⁴ and progressive-relapsing MS, which affects 5 percent of people with MS and is characterized by steadily worsening disease from the beginning with occasional acute attacks like those experienced by people with RRMS.⁵

About Biogen Idec

Through cutting-edge science and medicine, Biogen Idec discovers, develops and delivers to patients worldwide innovative therapies for the treatment of neurodegenerative diseases, hemophilia and autoimmune disorders. Founded in 1978, Biogen Idec is the world's oldest independent biotechnology company. Patients worldwide benefit from its leading multiple sclerosis therapies. For product labeling, press releases and additional information about the Company, please visit www.biogenidec.com.

¹ Multiple Sclerosis International Federation, Atlas of MS 2013. *Epidemiology of MS*. Page 8. Date Accessed: July 9, 2014. http://www.msif.org/includes/documents/cm_docs/2013/m/msif-atlas-of-ms-2013-report.pdf?f=1

² Multiple Sclerosis International Federation. Atlas of MS 2013. *Epidemiology of MS*. Date Accessed: July 9, 2014. <http://www.atlasofms.org/query.aspx>

³ NMSS. *MS Prevalence*. Date Accessed: July 9, 2014. <http://www.nationalmssociety.org/about-the-society/ms-prevalence/index.aspx>

⁴ NMSS. Relapsing-Remitting MS. Date accessed: March 17, 2014. <http://www.nationalmssociety.org/What-is-MS/Types-of-MS/Relapsing-remitting-MS>

⁵ NMSS. Progressive-Relapsing MS. Date accessed: March 17, 2014. <http://www.nationalmssociety.org/What-is-MS/Types-of-MS/Progressive-relapsing-MS>

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