PRESS RELEASE

New surveys show over 80% of patients with spasticity and cervical dystonia treated with botulinum toxin-A experience debilitating symptom recurrence

- *Over 400 patients with spasticity or cervical dystonia responded to online surveys evaluating the disease burden and the impact on their personal and professional lives*
- *Results reveal the need for longer-lasting symptoms control to improve patients' perceived quality of life*
- *The results of the two surveys will be presented during the 6th Congress of the European Academy of Neurology*

PARIS, FRANCE, 23 May 2020 - Ipsen (Euronext: IPN; ADR: IPSEY) today presents the results of two patient surveys. The surveys involved over 400 respondents from five countries, living with spasticity or cervical dystonia and receiving botulinum neurotoxin type A (BoNT-A) injections. The results show that over 80% of respondents experienced debilitating symptom recurrence, and revealed that a lack of long-lasting symptom control between injections has a profound impact on the personal and professional lives of patients.[1-4]

"The results from these two important patient surveys provide significant insight into the real-life burden of the two conditions; however, they also highlight a worrying disconnect between patients' treatment expectations and their actual experience. The findings, which build on our growing understanding of spasticity and cervical dystonia, provide us with the potential to unlock meaningful changes in clinical practice," said Dr Alberto Esquenazi, Department of Physical Medicine and Rehabilitation, Gait and Motion Analysis Laboratory, MossRehab and Albert Einstein Medical Centre, U.S. and lead investigator on the spasticity survey.

The first survey[1,2] investigated the burden of spasticity on patients' lives. Of the 210 respondents from France, Germany, Italy, the U.K., and the U.S., 83% reported that symptoms of spasticity returned between two sessions of BoNT-A, with 59% of these patients experiencing that return within three months of their last treatment. Symptom recurrence significantly impacted patients' quality of life, including sleep, relationships, performance of daily tasks and working lives. In addition, 47% of working patients reported being unable to work when symptoms re-emerge and 45% of working patients felt less efficient at work than before.[1,2]

The second survey[3,4] adopted a similar approach, analyzing data from 209 respondents with cervical dystonia from across France, Germany, Italy, the U.K., and the U.S. Of the respondents, 88% reported the reappearance of pre-existing symptoms between BoNT-A injections. The majority of working respondents reported a significant impact on their professional life, with 66% stating that they did not feel comfortable at work and 66% did not feel as efficient at work as usual. Patients' personal lives were also significantly compromised by their symptom recurrence, with an impact on their ability to socialize, sleep well, drive, or perform daily tasks.[3,4]

In both surveys, over 70% of patients said they would like longer lasting benefits from their treatment.[1-4]

The Carenity 2 surveys reveal the debilitating impact that symptom recurrence can have across every aspect of life for patients with spasticity and cervical dystonia, indicating that more needs to be done to relieve the burden of symptoms for patients suffering from these neurological conditions.[1-4]

Full results of the Carenity 2 survey in spasticity were published in Frontiers in Neurology on 07 May 2020.[1]

Antony Fulford-Smith, Vice President, Global Medical Affairs, Ipsen, commented: *"*Spasticity and cervical dystonia have a devastating effect on patients' lives, seriously affecting their mobility, employment and quality of life. At Ipsen, we are constantly searching for ways to improve disease management and comprehensive care with a patient-centered approach. It's clear from these surveys that more can be done to relieve the burden of these challenging diseases on patients' day-to-day lives."

Spasticity and cervical dystonia are distinct neurological conditions, though they share the characteristics of poor muscle control and spasms and are routinely treated with BoNT-A injections.[3,5,6] Spasticity affects more than 12 million people worldwide[7] and is generally caused by damage to the area of the brain and spinal cord responsible for controlling muscle and stretch reflexes due to stroke, traumatic brain and spinal cord injury, multiple sclerosis and cerebral palsy.[5] Cervical dystonia is a rare disorder of unknown origin in most of the primary cases, characterized by involuntary contractions of the neck muscles.[6]

About the Carenity 2 surveys
The two patient surveys, commissioned by Ipsen, were conducted between May to September 2019 by Carenity, an online patient community. A total of 419 respondents from France, Germany, Italy, the U.K and the U.S responded to the surveys via the online platform Carenity. Eligible participants were over 18 years old and had (or cared for someone with) spasticity or cervical dystonia (CD) treated with BoNT-A for at least one year. To assess burden of spasticity or CD for patients and their caregivers, the Carenity 2 surveys explored the impact of symptom re-emergence on quality of life.[1-4]

Ipsen has an ongoing partnership with Carenity, a social media platform for people living with chronic diseases and presented findings from the first Carenity international survey which focused on spasticity at TOXINS 2019.[8]

About spasticity
Spasticity is estimated to affect more than 12 million people worldwide.[7] It is a condition in which certain muscles are continuously contracted causing stiffness or tightness of the muscles, which can interfere with normal movement, gait and speech.[5] Spasticity is usually caused by damage to the parts of the brain or spinal cord that control voluntary movement,[5,9] leading to a change in the balance of signals between the nervous system and the muscles which leads to increased activity in the muscles.[5] Spinal cord injury, multiple sclerosis, cerebral palsy, stroke, brain or head trauma and metabolic diseases can all cause spasticity.[9] Spasticity is experienced by 34% of stroke survivors within 18 months following a stroke.[10]

About cervical dystonia
Cervical dystonia (CD), also known as spasmodic torticollis, is a movement disorder in which involuntary muscular contractions occur primarily in the neck muscles.[6,11] This can cause the head to turn to one side or to be pulled backward or forward.[6,12] CD is relatively uncommon, affecting 57 to 280 people per million.[13] It can occur at any age, although symptoms generally appear in middle age, often beginning slowly and usually reaching a plateau over a few months or years.[14] The degeneration of the spine, irritation of nerve roots or frequent headaches can make CD particularly painful.[14] In most cases the cause is unknown and no cure exists.[13]

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