

First published cervical dystonia patient experience map reveals multiple barriers to optimal care at all stages, from pre-diagnosis to long-term management

- First ever patient experience map for cervical dystonia, jointly developed between Dystonia Europe, the European Reference Network for Rare Neurological Diseases (ERN–RND) and Ipsen, identifies gaps in service provision and barriers to optimal care in all five key stages of the patient journey
- Developed with personal experiences from people living with cervical dystonia from across Europe, the new map identifies the most urgent updates to service provision needed to ensure patients are accessing multi-disciplinary care: improved communication, information signposting and clear clinical pathways being central themes

Belgium, 19 May 2022 – Ipsen, Dystonia Europe and the European Reference Network for Rare Neurological Diseases announced publication of the first cervical dystonia patient journey map (CDPJM), that describes the holistic patient experience from pre-diagnosis through to long-term treatment, in the [Orphanet Journal of Rare Diseases](#).

The research found that gaps in service provision appeared immediately after symptom onset, with patients describing multiple visits to their family doctor who prescribed strong pain killers and muscle relaxants and referred their patient to up to 10 different specialists for diagnosis. Over half (53.3%) of patients had received ≥ 1 misdiagnosis.¹

Moving along the patient journey, between eventual diagnosis and initiation of treatment stages, there was a clear need for improved communication between patient and physician with patients reporting that they wanted more detailed information on the disease and on the full array of treatment options, including complementary therapies such as physiotherapy and psychosocial support.¹

The need for continued review and dialogue after a treatment plan is initiated was also evident with patients reporting a “rollercoaster” of relief associated with botulinum toxin treatment, with symptoms (and subsequent impact on daily life) returning towards the end of an injection cycle.¹

Only half (53.3%) felt their neurologist spent enough time addressing their concerns, which may contribute to the under-treatment of the condition and low numbers of patients who are currently accessing multi-disciplinary care. Indeed, the research found that people living with cervical dystonia were often left to seek complementary services themselves and reported use of a variety of alternative sources of information, including the internet (86.7%), self-help groups (66.7%) and information leaflets provided by HCPs (60.0%).¹

Monika Benson, Executive Director of Dystonia Europe, commented: “The development of the first cervical dystonia patient journey map has brought into sharp focus significant gaps in service provision, as experienced by patients themselves, and the missed opportunities to deliver multi-disciplinary care. Addressing the lack of clear clinical pathways for referrals to physiotherapists and psychologists, which was identified as a key gap in all participating countries, should be a priority. We look forward to sharing our findings and formulating an action plan with stakeholders at the DYSTONIA-DAY 2022 meeting in Copenhagen.”

Oleks Gorbenko, Global Patient Centricity Director at Ipsen, commented: “The deep experiential insights gained from this research shine a light on the many barriers to optimal management that require urgent attention, because while CD is relatively uncommon it can have a significant impact on quality of life. Changes are needed to better align with the expectations and stated needs of people living with cervical dystonia. The areas they consistently highlighted as challenges were a need for improved communication at all stages and help with signposting to information that they need. We look forward to continuing our work with Dystonia Europe and other stakeholders in these areas to drive improvements and ensure genuine shared ownership to help optimize the care experience for patients with their healthcare team.

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About the cervical dystonia patient journey map (CDPJM)

The CDPJM was developed in 2 stages: a patient survey (open questions and multichoice) of 15 patients with CD was conducted to inform the design of the CDPJM, which was then refined and validated by an expert patient focus group. The survey involved a survey of patients in France, Italy and the UK. The online

survey was conducted using LamaPoll and the structure and contents of the survey were based on a generic patient mapping survey tailored to cervical dystonia in collaboration with patient representatives from Dystonia Europe. To support the development of the CDPJM, a broad literature review was performed using PubMed and other tools to identify relevant literature.

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.^{2,3} This can cause the head to turn to one side or to be pulled backward or forward.^{2,3} CD is relatively uncommon, affecting 57 to 280 people per million.⁴ 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.³ The degeneration of the spine, irritation of nerve roots or frequent headaches can make CD particularly painful.⁵ In most cases the cause is unknown, and no cure exists.^{4,6}

About Dystonia Europe

Dystonia Europe is the umbrella organization for 22 national dystonia patient associations from 19 countries across Europe, serving the needs of everybody with an interest in the neurological movement disorder of dystonia. Founded in 1993, the vision of Dystonia Europe is to improve the quality of lives of people living with dystonia in Europe, while supporting the search for a cure. By promoting research, fostering training to support clinicians and multi-disciplinary teams improve care for patients, raising awareness of the impact of dystonia and providing the latest information and resources for our members and other stakeholders, Dystonia Europe is continuously working to improve the lives of people living with dystonia. For more information, visit <https://dystonia-europe.org/>.

About the European Reference Network for Rare Neurological Diseases

The European Reference Network for Rare Neurological Diseases (ERN-RND) is a virtual network comprised of healthcare professionals spread around Europe. The network aims to address the unmet needs of more than 500,000 people living with rare neurological diseases in Europe, 50% of whom are still undiagnosed. The network comprises more than 72 specialized healthcare providers in 25 Member States. This patient-centered network aims to address the needs of patients by implementing a care and knowledge infrastructure for diagnosis, evidence-based management, treatment and collection of patient data. For more information, visit <https://www.ern-rnd.eu/>.

Ipsen

Ipsen is a global, mid-sized biopharmaceutical company focused on transformative medicines in Oncology, Rare Disease and Neuroscience; it also has a well-established consumer healthcare business. With total sales of over €2.9bn in FY 2021, Ipsen sells more than 25 medicines in over 115 countries, with a direct commercial presence in more than 30 countries. The company's research and development efforts are focused on its innovative and differentiated technological platforms located in the heart of leading biotechnological and life-science hubs: Paris-Saclay, France; Oxford, U.K.; Cambridge, U.S.; Shanghai, China. Ipsen has c.5,700 colleagues worldwide and is listed in Paris (Euronext: IPN) and in the U.S. through a Sponsored Level I American Depositary Receipt program (ADR: IPSEY). For more information, visit ipsen.com.

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