THE ILC FOUNDATION

Chronic Pain Ehlers Danlos HCTD

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2022 Ontario Pre-Budget Submission

Understanding Ehlers-Danlos Syndromes (EDS)

- The ILC Foundation advocates for individuals suffering from Ehlers-Danlos Syndromes (EDS) and other chronic pain diseases through public education campaigns and resources, wellness support, patient networks, government and stakeholder relations and research to find cures.
- EDS are a group of rare and inherited genetic conditions that affect connective tissue, which provide support in skin, tendons, ligaments, blood vessels, internal organs and bones.
- EDS can affect people of all ages in different ways. For some, the condition is relatively mild, while for others their symptoms can be disabling. Some of the rare, severe types can be life threatening.

EDS patients in Ontario are not looking for miracles - they're trying to improve their quality of life

- Patients with EDS experience a lifetime of physical challenges – including chronic pain, fatigue, neurological deficits like bladder control, and other related issues – which impact their mental health.
- No EDS patient experience is the same, but many face similar challenges. This includes countless visits to health care professionals, who cannot or do not recognize the symptoms of EDS or lack the expertise to treat them.
- Even after a neurosurgery referral from their family physician or specialist, many are rejected by skeptical doctors who have limited understanding of the condition and accuse them of psychological patients or only trying to access pain medication.
- Too often, those living with EDS and chronic pain are misdiagnosed or undiagnosed for years, forced to pay out of pocket for private, out-of-province health care or do not have access to the treatments they need.

Need to address a critical gap in vital EDS care in Ontario's health care system

- Ontario has a critical gap in providing the life-altering neurosurgery treatments that many EDS patients require to manage their conditions, pain and maintain their quality of life.
- Many patients in Ontario lost access to their only treatment option when a world-renowned neurosurgeon, specializing in chronic pain, relinquished his medical license after his conviction for a serious crime unrelated to his medical practice.
- As many Ontario patients with EDS are forced to seek expensive treatment options out of province, this gap in our health care system needs to be urgently addressed.
- Some patients in Ontario living with EDS have been offered medical assistance in dying instead of the care they need and deserve.
- People living with EDS should be have access to neurosurgeons, specialists and the treatments they require without having to travel out of the province or country.
- We continue to support and work alongside Ontario hospitals and neurosurgeons on the development of a proposal that envisions the creation of a provincial network of specialized treatment centres for individuals living with EDS.
- However, patients and their families are facing critical need, and we are calling on the Ontario Government to take an immediate, targeted action to address the urgent gap and ensure that they can receive the care they need in-province.

Recommendation: As a critical, immediate step, the Ontario Government to provide the necessary funding and support for the strategic recruitment and/or training of one (1) neurosurgeon with EDS and chronic pain specialization, as well as the capital investment to provide a modern surgical suite required for them to perform their highly-specialized work.