

Position Statement

Canadians with Ehlers-Danlos Syndromes, Heritable Connective Tissue Disorders and Chronic Pain in Canada being denied access to critical neurological, neuroradiological and neurosurgical healthcare.

“The Canada Health Act sets out the objective of Canadian health care policy to protect, promote and restore the physical and mental well-being of Canadians and to facilitate reasonable access to health services without financial or other barriers”¹

All Canadians living with Ehlers-Danlos Syndromes (EDS), Heritable Connective Tissue Disorders (HCTD) and Chronic Pain, should have equitable and timely access to care in the primary, acute, mental health, chronic and palliative physician care to protect, promote and restore their physical and mental health well-being.

Terms:

Connective Tissue supports many parts of the body (skin, eyes, heart, etc.) Think of it as the “cellular glue”.²

Ehlers-Danlos Syndromes are a group of connective tissue disorders that can be inherited and are varied both in how they affect the body and in their genetic causes.^{3 4}

Heritable Connective Tissue Disorder is an umbrella term for inherited illnesses affecting connective tissue in the body. Some types include EDS, Marfan Syndrome, Loey-Dietz Syndrome (LDS) and Osteogenesis Imperfecta.

Chronic Pain is pain that continues beyond three months.

The ILC Foundation is a registered charity that has been in operation for almost 10 years. The ILC advocate for all stakeholders: patients, caregivers and health care professionals alike, focusing on improving the lives of those living with EDS, HCTD’s and Chronic Pain.

Background Information:

¹ <https://www.canada.ca/en/health-canada/services/health-care-system/canada-health-care-system-medicare/canada-health-act.html>

² http://www.niams.nih.gov/sites/default/files/catalog/files/connective_tissue_ff.pdf

³ <https://www.ncbi.nlm.nih.gov/pubmed/27824552>

⁴ [American Journal of Medical Genetics Part C: Seminars in Medical Genetics Supplement to the American Journal of Genetics Volume 175C, Number1, March 2017\(Pages 1-2\)](#)

According to the World Health Organization's ranking of the world's health systems, Canada ranks 30th - better than the United States at 37th but worse than the United Kingdom at 18th.⁵ Canadians receive high quality medical care in areas where the conditions are well known and can be supported by the basic tenets of universality, portability, comprehensiveness, accessibility and public administration. One in five Canadians live with under-serviced Chronic Pain.⁶ Within this population, are those with EDS/HCTDs, who do not have access to neurology, neuroradiology and neurosurgery.

On October 28, 2015, The ILC Foundation joined the Crawford family in presenting an 8,000-signature petition to the Legislative Assembly of Ontario.⁷ The Minister of Health, Eric Hoskins stated, *"People living with Ehlers-Danlos Syndrome and other rare diseases face enough challenges on a daily basis that finding the right care and support in Ontario shouldn't be one of them. The new initiatives our government is pursuing will help people living with Ehlers-Danlos Syndrome and other rare diseases access the supports they need so they can receive the highest quality of care close to home."*⁸ Nonetheless, three years later, desperate patients and their families are continuing to jeopardize their own financial security by travelling out of country to access healthcare by EDS/HCTD knowledgeable doctors in the United States.⁹

One of the recommendations of the Ontario EDS Expert Panel Report, dated December 3, 2015 was, *"Given the limited available information regarding best practices, neurosurgeons and other specialists providing care for EDS patients in Ontario will continue to liaise with specialists in other jurisdictions, and to attend specific conferences about this rare disease to support knowledge creation, translation and adaption in Ontario."*¹⁰ The ILC has educated both medical professionals and patients at annual conferences for seven years, six with CME accreditation,¹¹ yet a very low number of doctors attend. Similarly, The ILC is involved in organizing an International Medical Scientific meeting for health care professionals.¹² Currently, there is only one Ontario neurosurgeon speaking and one attending.

In 2014, for a duration of approximately 2 years, Ontario had a neurosurgeon who cared for EDS patients and a number of surgeries were completed. Collaborations had begun with the International EDS Consortium Neurology Working Group and \$25,000 from The ILC Foundation was allocated to support this research. With the neurosurgeon no longer practicing medicine, the following initiatives are no longer being worked on:

- a. The ILC, in collaboration with the neurosurgeon, was working on an educational presentation that would be rolled out to the Ontario Spine Program.
- b. Patients that were operated on, are not being followed. They are not part of a post-operative study that includes imaging to capture risk/benefit data to further understand surgeries in this population. The failure to gather this critical information, further impedes the MOH in effectively caring for these patients. Without interdisciplinary care that include neurology, neuroradiology and neurosurgery, patients continue to bog down emergency departments, have countless ineffective and at times damaging diagnostics and endless referrals.

⁵ <http://thepatientfactor.com/canadian-health-care-information/world-health-organizations-ranking-of-the-worlds-health-systems/>

⁶ https://cdn.ymaws.com/www.canadianpainsociety.ca/resource/resmgr/docs/pain_fact_sheet_en.pdf

⁷ https://www.youtube.com/watch?v=I80HZZrq2w8&ab_channel=MichaelHarris

⁸ <https://www.theilcfoundation.org/eds-division-history/>

⁹ <https://www.theilcfoundation.org/wp-content/uploads/2015/07/Provide-out-of-country-treatments-to-Ehlers-Danlos-Patients.pdf>

¹⁰ http://www.health.gov.on.ca/en/common/ministry/publications/reports/eds/eds_expert_panel_report_en.pdf

¹¹ <https://www.theilcfoundation.org/annual-conference/>

¹² <https://csfflowsatniagarafalls.org/>

The healthcare landscape for this patient population shifted precipitously. In 2016 the lead neurosurgeon who followed the majority of this patient population, lost hospital privileges.

Following the loss of the Ontario neurosurgeon, The ILC was asked to endorse and circulate a letter to the patient population. The purpose of the letter was to reassure EDS patients that they would continue to receive care.¹³ This care has not materialized. The ILC continues to be inundated with communications from patients and their advocates needing help with their neurological symptoms.^{14 15}

In 2018, The ILC conducted an unprecedented survey, *“Understanding healthcare barriers for patients with Ehlers Danlos Syndrome, hereditary connective tissue disorders and complex chronic pain in Canada.”*¹⁶ More analysis of the data from the 454 respondents needs to be completed but an early report speaks to the magnitude of challenges these individuals face without access to care.

The ILC consistently hears from healthcare professionals that EDS/HCTD patients are complex. Patients are often thwarted from accessing appropriate care and are incorrectly labeled with mental health issues. This incorrect labelling is not only traumatizing but impacts all future healthcare interactions for these patients. Another statistic from the previously mentioned survey, finds that out of 228 Ontario respondents, most patients (89%) were formally diagnosed with EDS/HCTD, and the prevalence of neurological symptoms in our Ontario sample was 79% (167/215). Almost all respondents (96% or 160/167) reported significant disability imposed by neurological symptoms, with 46% reporting prior serious consideration for suicide because of the burden of this symptomatology.

As EDS and HCTDs are complex diseases, in that the connective tissue does not hold joints in place, the most accurate imaging is while load bearing (being upright). Imaging such as digital motion fluoroscopy (DMX) and upright MRIs accomplish this, but they are not available in Canada. Other testing often required, such as flexion extension CT scans, evoke potential and urodynamic studies are also not readily available.

Solutions:

1. MOH to fund a neurosurgeon with an interest in the EDS/HCTD population, who will receive additional training and research funding.
2. Until such time as there are trained neurosurgeons who are able to do shunts, Chiari, decompressions, tethered cord detethering surgeries, cranio-cervical instability and stabilization surgeries in EDS and HCTD patients, out-of-country requests for funding are approved.
3. Add the following resources to the EDS clinic: neurosurgeon, neurologist, neuroradiologist, TMJ cranial cervical specialist, bracing/orthotist, neuro-ophthalmologist. As this knowledge increases, the EDS clinic to facilitate outreach education via the existing Ontario-based project ECHO.
4. Ministry of Health to procure upright MRI and DMX imaging machines. Canadian neuroradiologists provided education, allowing them to properly read the imaging of EDS/HCTD patients. *“Diagnosis is important to ensure that harm is not caused by doing too much of the wrong thing and not enough of the right thing.”* Dr. Norm Buckley, Chair, Anesthesia, Hamilton, ON.

¹³ <https://www.theilcfoundation.org/news-release/>

¹⁴ <https://www.theilcfoundation.org/patient-stories/>

¹⁵ <https://www.theilcfoundation.org/category/knowledge-base/patient-stories/>

¹⁶ <https://www.theilcfoundation.org/survey-understanding-healthcare-barriers-for-patients-with-ehlers-danlos-syndrome-hereditary-connective-tissue-disorders-and-complex-chronic-pain-in-canada/>

5. The Ontario Medical Association (OMA) and the Ontario Ministry of Health (appropriate provincial equivalents, Canada wide) to generate a billing code for EDS/HCTDs and Chronic Pain Management to support:
 - a. appropriate doctor remuneration to conduct proper assessments
 - b. on-going care effective data collection to forecast health service requirements.

6. All levels of government to support a national pain strategy.¹⁷ Dr. Bruce Dick, Clinical Psychologist from Edmonton stated *"We owe The ILC and EDS a debt of gratitude to helping us recognize the need to look more closely at connective tissue disorders to understand chronic pain.*

The ILC is committed to being part of the solutions in support of the needs in this marginalized population. Each time we receive the very poor mental health anguished calls from individuals or parents, on failed healthcare and worse, on the death or attempted suicide, we are heartbroken. The layers of loss in the EDS population are so multilayered, and for the individuals' that have lost their life as a direct result of the lack of timely and knowledgeable neurosurgical care due to Ehlers Danlos Syndromes (EDS) with the comorbid conditions there are not words that can adequately express the degree of sadness and anger felt and feel we must all take responsibility for in the respective roles of stakeholders.

The ILC is in communication with its medical advisers and the MOH to ensure that the lack of access to timely and knowledgeable neurosurgical and interdisciplinary care will be addressed.

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¹⁷ <https://www.mcmasterforum.org/find-evidence/products/project/developing-a-national-pain-strategy-for-canada>