

Child Protection in Ehlers Danlos Syndromes and Hypermobility Spectrum Disorders

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Currently, and over the past ten-years, there have been a growing number of member families that reach out to TheILC for guidance in their experiences of being diagnosed with a disorder that is not broadly believed and where child protection services become involved. These experiences have been brought forward where the most heart-wrenching and unthinkable stories demonstrate anguished parents, with adverse effect on social functioning, professional, and emotional wellbeing for the whole family.

TheILC note that Ehlers Danlos Syndromes and Hypermobility Spectrum Disorders are included as conditions that are poorly understood from a diagnostic and treatment point of view, which drives lack of care in multidisciplinary specialties and community and social services for this population.

TheILC have advocated for improved understanding in provinces where families have been impacted; and like its international counterparts, would like to understand what role charities can have to support our Canadian members. As a Canadian Global Affiliate Program Leader of the Ehlers Danlos Society, and member of the International Consortium Working Groups, we look forward to the outcomes of the roundtable expert panel discussion being organized and taking place at The Royal Society of Medicine, London, April 27, 2020, where these organizations will be sharing these experiences with the goal to identify collaborative ways forward and priorities in research.

As an organization, TheILC joins its international counterparts in the acknowledgement of the critically important work that must be done to protect these families against harm from the lack of access to care for children, adolescents and families living with these Heritable Connective Tissue Disorders. These families have a right to be heard and not live in fear when they reach out to authorities in schools, workplace, and health professionals at the risk of losing their children.

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