

Chronic Pain Connector



Become a member

The Member Benefit Support Program provides educational resources to help individuals balance school, work, self-care and leisure activities. Living with Ehlers-Danlos Syndromes and its related conditions, including chronic pain can be isolating and difficult to manage. Email:

info@TheILCFoundation.org for membership information.

Contact Us:

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Charity No.: 809911068RR0001

The ILC Foundation is a longstanding Canadian charity that organizes and funds programs to support its strategy to raise awareness and provide resources about Ehlers-Danlos Syndromes (EDS), which affects 1 in 300 Canadians, and 1 in 5 live with chronic pain: children are not spared. The ILC's long-term goals are to break down the barriers to timely care and support and increase resources for individuals in their communities.

New Board Directors

The ILC recently welcomed two new Board members. Fatima Abrar, CPA, MHA (CC) joined at the end of 2023, bringing financial expertise. Annie Parry, RN, PhD joined early in the new year, bringing her nursing experience and, like Fatima, a dedicated passion for closing the healthcare gap for those living with EDS, Hypermobility Spectrum Disorders (HSD) and chronic pain. We welcome their expertise, time, and energy to our cause.

STAY TUNED FOR OUR NEW LOOK!

The new ILC website will launch in the coming weeks and will include the 2023 Conference presentations.

National Volunteer Week - April 14 - 20, 2024



This year's theme for National Volunteer Week is **Every Moment Matters**. The ILC wants to highlight the importance of each one of our volunteers and their contribution to the EDS/HSD and chronic pain communities when they need support more than ever. Sharing time, skills, empathy, and creativity is vital to our communities' inclusivity, strength, and well-being.

Our Volunteers are fundamental to completing our mission. Their time and energy significantly help us move towards a more accessible healthcare pathway for those with EDS/HSD and chronic pain. By coming together, committing to support, and increasing our collective efforts and impact, we contribute to improving the community's quality of life.

When we work together and forge meaningful relationships across communities, The ILC's purpose is greater, and so is the sense of belonging. By connecting and engaging with the community, we know our importance—volunteering matters. When we share these connective moments, we co-create the neighbourhoods, culture, and society we want to live in.

Right now, whatever we can contribute is needed and valued. From assisting Canadians to navigate the healthcare system, providing valuable resources, engaging in Peer Wellness programs that support physical and mental health to research and advocacy efforts, and implementing our annual education events to increase awareness and mobilize knowledge of the challenges those living with heritable connective tissue disorders face, it is in these moments we can move collectively from surviving to thriving again.

This year, let's come together to recognize and celebrate the importance of every ILC volunteer's impact from coast to coast to coast. Now more than ever, **Every Moment Matters**.

A large graphic featuring a smiling woman in a crowd, overlaid with colorful geometric shapes (green, yellow, purple) and the text "YOU MATTER TO US" in white. The background is a photograph of a diverse group of people, with the woman in the foreground being the central focus.

YOU MATTER TO US

EVERY MOMENT MATTERS

 **VOLUNTEER BÉNÉVOLES CANADA**

NATIONAL VOLUNTEER WEEK
APRIL 14 - 20, 2024

#NVW2024 #EveryMomentMatters

The **ILC** FOUNDATION

ILC EDS 



Walk'n Wheel-a-thon

May is EDS Awareness Month

Join The ILC at our Ontario Walk'n Wheel-a-thons to raise awareness and funds. Walks will take place on the following dates and locations:

May 25th: 12:30 pm in Midland @ Town Dock

**May 25th: 12:30 pm in Ottawa, Queen Elizabeth
Driveway @ City Hall**

**May 26th: 12:30 pm in Burlington @ Hidden Valley
Park**

**June 2nd: 9:30 am in Toronto @ Palais Royale on
Lakeshore Road**

[Information & Registration](#)

The Canadian Ehlers-Danlos Syndromes Conference takes place on November 2, 2024

The ILC Planning Committees have begun discussions for this year's event. The theme is to educate physicians and primary care providers on EDS/HSD and provide them with tools to make care timely and practical by helping them identify related comorbid conditions.

*** DETAILS COMING SOON ***

The **ILC** FOUNDATION

2024

THE CANADIAN EHLERS-DANLOS SYNDROMES CONFERENCE



EDUCATIONAL
FOCUS IS
CENTERED ON
CURRENT BEST
EVIDENCE FROM
LEADING
CANADIAN AND
INTERNATIONAL
SPECIALISTS
WHILE
PROVIDING
HEALTHCARE
PROFESSIONALS
AND PATIENTS
RESOURCES TO
MANAGE
SYMPTOMS AND
IMPROVE
QUALITY OF LIFE.

**SAVE THE DATE FOR THIS
VIRTUAL ALL DAY EVENT**

NOV

2nd

2024



Welcome Ellie Sheppard: The ILC Fundraising, Grants & Donor Relations Coordinator

The ILC is excited to introduce Ellie to assist us with our advocacy and fundraising efforts. Ellie began this role in March and is the first ILC Coordinator hired in this capacity. We look forward to expanding programs with Ellie's support.

Virtual Support Groups are Ending for the Season

The ILC offers free virtual Support Groups for people living in Canada with EDS/HSD. Advance registration is required, with maximum participation at 18. Please join our last group of the season on Monday, April 15 @ 10:00 am PT and 1:00 pm ET. Register [here](#).

McMaster University's Master of Science OT students

This past winter, The ILC was supported by two energized and focused Occupational Therapy students in our fifth academic placement. Danielle and Olivia reviewed and updated our resources for the Community of Practice, provided a clinical lens to Wellness Sessions to support and empower the EDS community to live well, and created a quality improvement initiative for healthcare providers and students practicing in Canada. The aim is to better understand the healthcare community's current knowledge regarding the care of patients with Ehlers-Danlos Syndromes (EDS) in Canada. Please share the [EDS Provider Knowledge Survey](#) with your healthcare provider(s).

Spaces Shared

Do you have one of your home's 5 million empty bedrooms? Go [here](#) for more information on how to share your space with a student to help individuals live in their homes longer.



Healthy Ageing At Home

Board Directors Tammy Stadt and Annie Parry attended a Healthy Ageing at Home event in March. Dr. Alison Novak, from the KITE UHN and Parachute Program, shared that 56 million falls happen every day in Canada: 81% of falls are in the bathroom, and these injuries are 2.4 times more severe than anywhere else in the home; fear of falling is a risk factor for falling; 85% of falls require hospitalization; 61% of falls lead to death; and falls are the #1 cause of injury for seniors. Grab bars can reduce the risk of falling by 73%.

The Ontario Caregiver Association (OCO)

On Thursday, April 11th, 2024 from 12pm - 1pm ET the OCO is pleased to welcome Ontario's Patient Ombudsman, Craig Thompson to talk about what the office of the Patient Ombudsman is, what it does and what caregivers need to know about making health care complaints in Ontario.

[Register today.](#)



Network Research

The Power over Pain (POP) team at SickKids have developed an online portal to help young people manage pain. Here is a brief [informational video](#) to find out more and to see if you or a family member want to participate contact [Anya Nair](#).



Generous Donors

THE TENAQUIP FOUNDATION

In December, The Tenaquip Foundation made their year-end generous donation to The ILC. Thank you for your gift of **\$5,000** and your ongoing support of The ILC programs and inspiring hope in the Ehlers-Danlos Syndromes and chronic pain communities.



On February 29th, **Rare Disease Day 2024**, The ILC Foundation's Executive Director, Jacqueline Raposo, was presented with a generous donation of **\$3,000** from The Lions Club of Oakville. It was wonderful to meet Steve Knight, Sima Acan, Tim Carter, and Taran. Thank you for your continued support of The ILC programs to increase awareness and education, and contribute to the health and well-being of Canadians living with Ehlers-Danlos Syndromes and related conditions, including chronic pain.



Steve, Sima, Jacqueline & Tim (photo courtesy of Taran)

The ILC is very grateful for the continued monthly donations received from our compassionate supporters. Your contributions allow The ILC to develop timely programs and advocate for the proper care those with EDS deserve. Thank you for your generosity and support!

THANK YOU
Thank you
SO MUCH!

Good Reads: New & A Trusted Resource

Symptomatic - 1st Edition: The Symptom Based Handbook for Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders by Clair A. Francomano, Alan J. Hakim, Lansdale G.S. Henderson, Fraser C. Henderson Sr.

Note: The ILC and the Canadian Connective Tissue Society is listed on page 8 in the resources.

Disjoined: Navigating the Diagnosis and Management of hypermobile Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders. For Contributors click [here](#).

FAST FACTS

The ILC EDS Conference Series in 2023 showed a year-over-year growth rate of medical healthcare attendance by 100% and patient & caregiver attendance by 137%.

2023 Canada Helps monthly donations to The ILC increased by 88% from previous year!



Thank you for your skill,
expertise and
compassionate support
of the EDS/HSD and
chronic pain communities

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**National
Volunteer
Week**

April 14-20, 2024



**VOLUNTEER
BÉNÉVOLES
CANADA**