

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:

<https://www.theilcfoundation.org/member-support-program/>

Contact Us:

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Charity No.: 809911068RR0001

***The ILC Foundation** is a longstanding Canadian charity that supports people living with complex health issues from Ehlers-Danlos Syndromes, hypermobility and chronic pain. We support the community to make meaningful connections and share stories, resources and research to mobilize knowledge and improve health and wellness.*

Chronic Pain never takes a holiday: give a gift today

If you missed GivingTuesday on November 28th, please consider giving back this holiday season with a year-end donation to The ILC. A tax-deductible gift would greatly support our 2024 advocacy, education and wellness programs. You will assist us in finding necessary answers for the one-in-five-hundred Canadians living with Ehlers-Danlos Syndromes, and the one-in-five Canadians living with Chronic Pain, including children and youth. Your generosity will help transform the health of the population we serve to ensure a proper care pathway for the holidays and into the future: <https://www.theilcfoundation.org/donate/>



The Canadian Ehlers-Danlos Syndromes Conference 2023 - The Lurking Symptomology took place on Saturday, November 4th

(To view these presentations please join The ILC as a member: <https://www.theilcfoundation.org/member-support-program/>)

DR. SATISH R. RAJ

EHRLERS-DANLOS SYNDROME AND DYSAUTONOMIA



Dr. Raj shared the importance for a proper diagnosis concerning POTS and the relevance of receiving a POTS plus diagnosis in individuals, primarily women, with multiple comorbidities, like HEDS/HSD, ME, to name a few, and these people are five times more likely to also have MCAS than those without the HEDS/HSD comorbidity. He highlighted a recent study of EDS-POTS vs. POTS only patients, that there are longer diagnostic delays, challenges and a younger onset. As with our other speakers, Dr. Raj discussed pharmacological and non-pharmacological treatments for POTS, reinforcing that the condition is chronic with no cure but can be treated and managed for a better quality of life.

DR. CLAIR FRANCOMANO

A DEEPER DIVE INTO THE MANAGEMENT AND DIAGNOSIS OF EDS



Dr. Francomano's presentation highlighted the complexity of HEDS and HSD and how they affect various organ systems. She shared that the primary focus of managing musculoskeletal symptoms involves muscle relaxation and physical and aquatic therapy, which will benefit joint laxity. She described different methods for pain management and how to manage cardiovascular symptoms, hypotension, and other related syndromes. Dr. Francomano believes, as many would agree, that understanding the underlying causes of symptoms and tailoring treatments based on an individual's condition, along with regular exercise and coping strategies, is the key to managing HEDS and HSD.

DR. LINDA BLUESTEIN

AN INTEGRATIVE MEDICINE APPROACH TO CARE IN EDS/HSD



Dr. Bluestein's presentation highlighted how an integrated approach for treating hypermobility is best practice and will ensure preventative health. She described the challenge with this diagnosis and shared the flexibility concerns, symptoms, and treatment. We couldn't agree more with Dr. Bluestein that individuals must document their unique challenges and empower themselves so they can direct their care and educate their healthcare professional(s) in a respectful partnership to live well.

DR. BRAYDEN YELLMAN

IT'S NOT JUST HYPERMOBILITY: THE INTERPLAY OF COMORBIDITIES



Dr. Yellman, presented on the many comorbidities of EDS patients and shared interesting overlapping symptom factors. The fact that nearly 1 in 3 patients with MCAS had a comorbid diagnosis of hEDS in a large patient sample is a striking statistic, highlighting the need for a better understanding of the overlap of these conditions. Concerning CCI/AAI, upright imaging is preferable over supine imaging, and it is challenging to find experienced professionals to aid in the imaging, diagnoses, management and treatment of these conditions. He explained that surgical interventions are a last resort, but are sometimes warranted. When reviewing Small Fibre Polyneuropathy, he shared that both quantitative sensory testing and skin biopsy evaluation have indicated a high incidence in hEDS patients. Concerning Median Arcuate Ligament Syndrome, it most often occurs in females in their fourth decade of life, there is a possible pathophysiological relationship in patients with POTS and/or hEDS and surgical treatment has a 70%-80% success rate in reducing abdominal pain.

DR. SVETLANA BLITSHTEYN

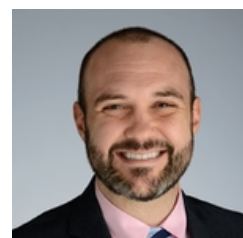
DYSAUTONOMIA, HEADACHE AND HYPERMOBILITY SPECTRUM DISORDERS



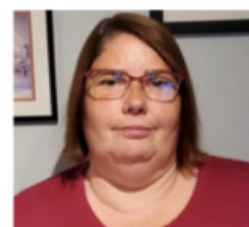
Dr. Blitshteyn, highlighted understanding the association between dysautonomia, HSD and MCAS as a triad of migraine comorbidities commonly seen in clinical practice, all three of which need to be diagnosed and treated to achieve any degree of effective migraine management. She shared that autonomic neuropathy is a dysfunction of peripheral autonomic nerves and how it differs from dysautonomia. She shared critical information on POTS: it is about symptoms, not just vital signs; the most disabling and treatment-resistant symptoms are fatigue, dizziness and cognitive dysfunction (brain fog); and comorbid conditions, such as migraine, neuropathic pain, insomnia and joint pain, all of which are prevalent in HSD, should be treated. Dr. Blitshteyn shared that EDS as a comorbid condition is missed by many pain and headache clinics/practitioners and discussed the many neurological manifestations of EDS.

June 27th Webinar: Fitting the Pieces Together and the 10% Rule

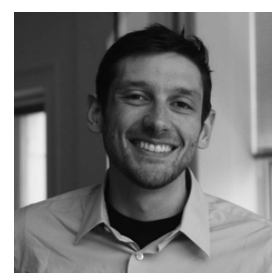
Dr. William Black and Dr. Jordan Jones shared their 2021 provider survey results in the presentation Establishing a Road Map to Overcome Barriers to Ehlers-Danlos Syndromes Care. They highlighted how practitioners in Kansas City report discomfort and decreased confidence with diagnosing EDS and are more comfortable co-managing care with specialists rather than developing care plans for EDS patients. The need to create additional education and access to patient care and diagnostics and the importance of multidisciplinary clinics where patients can have all of their health issues addressed more timely and efficiently under one roof are ways that will significantly benefit EDS patients and practitioners and offer much hope for the future.



Tammy Stadt highlighted the importance of planning and provided tips on what works best to plan and mitigate the challenges of living with EDS and Chronic Pain. Having a personal arsenal of coping strategies and, even more importantly, a supportive, understanding and compassionate caregiver of one's needs is vital. This wealth of knowledge from her lived experience benefits The ILC community and our Foundation in her Director and Wellness Support roles.



Gabi Schaffzin detailed the history of pain scales and how this tool was initially designed to monitor the workplace rather than better understand and manage pain. This explanation helps us understand many of today's challenges with its usage and how biases have come into play. Understanding the historical flaws in these diagrams and how the doctor is seen as the expert, not the patient with pain, is constructive. This presentation allowed us to see that pain scales are necessary evils versus practical tools, and we hope that this research contributes to newer advances that will lead to a better pain tool that assesses a patient appropriately and compassionately, without judgement and bias, that we have seen since inception.



Click here to see the presentations:

<https://www.theilcfoundation.org/the-ilc-eds-2023-virtual-conference-series-june-27th-webinar/>

Thanks to all our 2023 Conference series presenters for understanding the EDS community's challenges and recognizing the benefits collaborative and respectful partnerships in care will bring to population health and the healthcare sector. These factors inspire hope and contribute to the health and well-being of individuals living with Ehlers-Danlos Syndromes and chronic pain diseases: our vision for the community.

Virtual Support Groups

The ILC offers Support Groups for people living in Canada with EDS/HSD. Each group requires advance registration, with maximum participation at 18. These professionally-facilitated groups are scheduled on the 1st and 3rd Monday at 1:00 pm, and links to register will be shared one week prior to each session. Go to: <https://www.theilcfoundation.org/virtual-support-groups/> for more information.

Advocacy Committee

Our new volunteers have successfully supported the development of the recent community survey. In this healthcare journey survey, **75.6%** of respondents agreed that having access to a healthcare team to navigate the system in their province would be beneficial, and **41.5%** do not have financial support available when required, with **85.4%** sharing these include barriers to other regular health treatments, such as Physiotherapy or Occupational Therapy; **61%** cannot access adaptive equipment or orthotic braces; and **56.1%** cannot access health supplements or over the counter medications.

We hope that by sharing these results The ILC can increase advocacy and awareness for the community and assist with implementing necessary future programming and support.

The Canadian EDS 2023 Conference Committee

Thank you to our outstanding committee members Tanya, Ilana, Sandy (X2), and Claudine for their excellent contribution to planning and organizing the 2023 EDS Conference Series. Discussions began a year ago to successfully run two educational webinars and the full-day annual Conference on November 4th, significantly increasing registration and participation in this event from previous years. We are incredibly grateful for your continued time and energy and look forward to planning for 2024. Please share your skills and experience at Jacqueline@TheILCFoundation.org if you want to support this event next year.

Communications & Wellness/Peer Support Committees

Our ongoing academic partnership with McMaster University will engage our Communications and Wellness/Peer Support Committees. A fall educational placement has the Occupational Therapy (OTP I) students reviewing and updating The ILC community of knowledge and research, and preparing the Provider survey shared by our Kansas City colleagues, Dr. Jones and Dr. Black — to be sent nationwide to gauge Canadian Provider knowledge and awareness of EDS. In winter 2024, The OTP III students will review these survey results and provide occupational therapy support in the Wellness Support Sessions. This role-emerging placement continues to support the community in Wellness Sessions with daily living activities, health resources and navigation to find appropriate services. We cannot state how much we appreciate the dedicated and experienced Client Navigators (ILC Ambassadors) for their time and resources to this program.

Research Committee

This summer, we shared Western University's and UHN's request for community input to collect population data to improve health interventions, management and accessibility. **CANSpine and SPINA** have the first international registry focused on rehabilitation for musculoskeletal and spinal problems, which are problems of the neck, mid back, or lower back. **UHN**, through its **Anthropometrics Project** sought people who use wheeled devices to participate in a research study to learn how to improve the dimensions of spaces to make public spaces more accessible to navigate. The findings from this study will develop building policy and design guides to improve accessibility in public areas for Canadians who use wheeled mobility devices.

Generous Donors

On August 31st, The ILC Foundation's Treasurer, Roger Lapworth and Executive Director, Jacqueline Raposo, were invited to meet Shawn Alam, Peter Reinhard (ILC Founding Board member) and Emma Friend at **Leggat Cadillac Burlington** for their generous cheque presentation of **\$1,500** (corrected). Thank you for supporting our ongoing advocacy efforts to improve care, increase education and mobilize knowledge for better population health.



Peter, Roger, Jacqueline, Shawn

The ILC is very grateful for the generous donations received from our compassionate supporters. These ongoing contributions allow our volunteers to provide the hope and necessary care deserved to the EDS community: Thank you for your support!

Thought Provoking Views

- Above and Beyond - The Accessibility & Inclusion Podcast
- This Might Hurt:
<https://www.thismighthurtfilm.com>

Controversial Read

The Way Out: A Revolutionary, Scientifically Proven Approach to Healing Chronic Pain by Alan Gordon and Alon Ziv.

Chronic Pain Awareness Month



Each September, Pain Awareness Month allows us to reflect on the needs of the many people living with chronic pain and the research that we hope will treat it and offer prevention for life.

In Canada, there are eight million people living with chronic pain, affecting physical and mental health aspects and inhibiting work, play, relationships, and overall quality of life. As with many health issues, individuals living with pain often experience health equity issues: Pain disproportionately affects those living in poverty, with mental health conditions, the Indigenous, racialized, and LGBTQ2S communities, those with disabilities, and women, to name a few (Pain Canada, 2023).

About. Pain Canada. (2023).

<https://www.paincanada.ca/about#pain-canada>

The 2023 En Flque Women's Outdoor Soccer Team from Burlington, Ontario



Thank you, ladies, for supporting The ILC cause and highlighting EDS, its related conditions and chronic pain in the Burlington Women's Soccer League.



HAPPY HOLIDAYS

WE ARE TRULY
GRATEFUL FOR

your continued support