

Welcome

Annual
Report 2024



The **ILC** Foundation

EDS  Foundation

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Director

Mary Argent-Kawala



Director

Allan Gordon



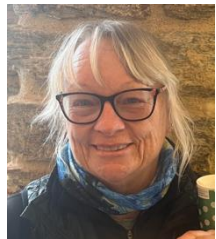
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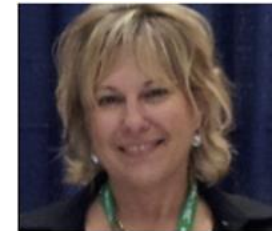
Director

Jacqueline Raposo



Director

Peter Reinhardt



President

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Secretary

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Message from Board of Directors

Dear Friends, Supporters, and Community Members,

On behalf of the Board of Directors of the EDS Canada Foundation, we are pleased to share this Executive Summary highlighting our progress, priorities, and path forward. The past year has been one of growth, resilience, and renewed commitment to our mission: to support, educate, and empower individuals and families affected by Ehlers-Danlos Syndromes and related conditions across Canada.

We have continued to expand our reach and impact through targeted education initiatives, strengthened partnerships with healthcare professionals, and advocacy for improved access to care. Our community programs have seen record engagement, and we are especially proud of the collaborative efforts that have driven forward research awareness and patient support services.

Key highlights include:

- Development and dissemination of new educational materials for both patients and practitioners;
- Launch of regional outreach initiatives to increase access to information and peer support;
- Strengthened relationships with clinical experts and researchers to inform care pathways and future studies.

None of this would be possible without the dedication of our volunteers, the trust of our community, and the generosity of our donors and partners. As we look ahead, we remain steadfast in our vision of a future where every Canadian with EDS receives timely diagnosis, informed care, and compassionate support.

Thank you for being a vital part of this journey. Together, we are creating change—one step, one voice, and one story at a time.

With gratitude,
Board of Directors
EDS Canada Foundation

Driving Change for Complex Care

Vision, Mission and Values



Our Mission

To help Canadians overcome the challenges of living with Ehlers-Danlos Syndromes and related conditions, including chronic pain through knowledge-sharing resources, awareness, education, wellness support and research to find cures.



Our Vision

To inspire hope and contribute to the health and well-being of Canadians living with Ehlers-Danlos Syndromes and related conditions including chronic pain.



Our Values

EDS Canada Foundation values are centered on collegial cohesive collaborations to improve support services for Canadians with Ehlers-Danlos Syndromes and Chronic Pain.

2024 Highlights



Enhancing Access to Knowledge Through Zotero File Management

In 2024, the EDS Canada Foundation continued to strengthen our educational and resource programs by leveraging Zotero, a powerful file management and research tool. We use Zotero to organize, maintain, and expand two critical initiatives: the **EDS Toolkit**—supporting primary care practitioners, specialist physicians, and researchers—and our **Community of Practice**—empowering service providers who directly support individuals living with Ehlers-Danlos syndromes and related conditions.



Education

By streamlining access to curated, evidence-based resources, Zotero enables us to deliver timely, relevant, and trusted information to both healthcare professionals and community advocates across Canada. This approach not only enhances the quality of care and understanding of EDS but also fosters a stronger, more informed network of support.



Resources

Impact for Our Donors:

Thanks to your generous support, we equipped practitioners and community leaders with centralized, easily accessible knowledge tools—ensuring that individuals with EDS receive better-informed care and support. Your contributions are directly advancing education, collaboration, and quality of life for the EDS and chronic diseases community.



Virtual Support Programs



Transforming Lives Through Our Wellness Program

In 2024, our Wellness Program continued to be a lifeline for individuals living with Ehlers-Danlos syndromes and related conditions. Through **virtual group sessions** and **one-on-one support**, we created safe, inclusive spaces where participants could connect, be heard, and receive guidance tailored to their lived experiences.

This program goes beyond support—it fosters resilience, reduces isolation, and builds confidence in managing complex chronic conditions. Participants report life-changing outcomes: improved mental health, stronger self-advocacy, and a renewed sense of hope and belonging.

Impact for Our Donors:

Your support made it possible for [insert number] individuals to access compassionate, personalized care when they needed it most. Because of you, people facing daily challenges with pain, mobility, and misunderstanding now feel seen, supported, and empowered to take back control of their lives. You are not just funding a program—you are changing lives.



“As a doctor, from the information I received at the FMF2024 conference from EDS Canada Foundation, I had a positive thumb/palm test and was able to obtain an early diagnosis of an ascending aortic aneurysm. You saved my life.” Anonymous

Partnerships





Research



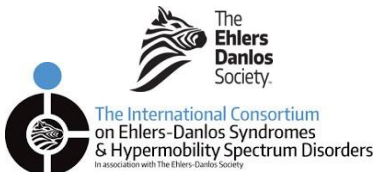
- ✓ **EDS Canada Foundation supports CanChild** as subject matter experts on an EDS & pediatric occupational therapy exploratory study to advance understanding of clinical practice for children and youth and contribute to the development of resources and inform further research.



- ✓ Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis (ICanCME) Research Network 2.0 - ME/CFS EDS/HSD+ study with co- Investigators, Alain Moreau, PhD, Director with patients as partners and leaders. The first is the Network's tradition of Patients as Partners - "Nothing about us, without us." This Network embraces the reality that those with lived experience are key to accelerating research. They have helped research teams design and implement safer, more respectful and more accurate studies. Our patient partners are recognized as leaders and experts at every stage of the work – **EDS Canada Foundation partner with \$5K in 2025 & 2026**



- ✓ **EDS Canada Foundation** membership with Research Canada (**\$1.2K annually**) to support engaging Canadians living with Ehlers-Danlos Syndromes and chronic pain in research and translating research results that will lead to the development of care pathways to help reduce the high cost of healthcare.



- ✓ **EDS Canada Foundation is an active Affiliated member and in-kind patient-engaged research partner** of the EDS Society International Consortium Allied Health Working Group.

Looking Ahead

Province Territory	Population Canada 2023	Prevalence of hEDS/HSD 1:300	Prevalence of EDS Rare Types 1:5000	Prevalence of Chronic Pain 1:5
BC	5,582,127	18,607	1,116	1,116,425
AB	4,756,408	15,855	951	951,282
SASK	1,218,976	4,063	244	243,795
MAN	1,464,440	4,881	293	292,888
ON	15,801,768	52,673	3,160	3,160,354
QC	8,948,540	29,828	1,790	1,789,708
NS	1,066,416	3,555	213	213,283
NB	842,725	2,809	169	168,545
PEI	175,853	586	35	35,171
NFLD	540,418	1,801	108	108,084
NWT	44,760	149	9	8,952
YK	45,148	150	9	9,030
NUN	40,817	136	8	8,163
TOTAL	40,528,396	135,095	8,106	8,105,679

OUR WHY

With prevalence of Hypermobile Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorder (EDS/HSD) being recognized as 1 in 300, there is a greater need to provide resources and support services.

Looking Ahead

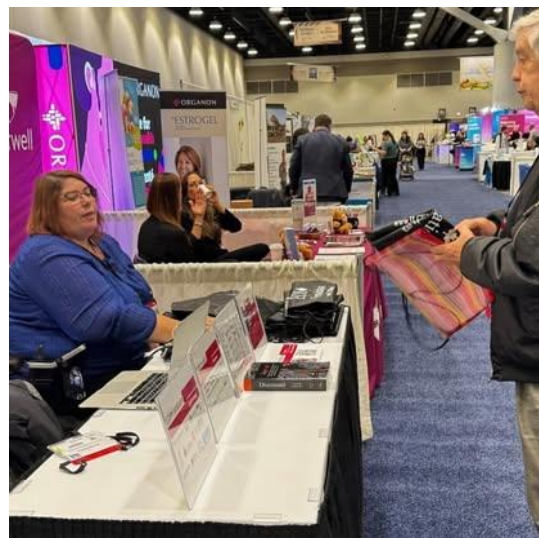
"From my doctor attending FMF2024 conference, my doctor finally connected the dots of my symptoms and finally had answers of feeling alone and undiagnosed. I have now been diagnosed with hEDS and my doctor has coordinated a multidisciplinary team for my healthcare needs. The resources I received during wellness sessions with EDS Canada Foundation, helped me manage my symptoms, and help me draft my disability tax credit forms for my doctor.." Jane (name changed for client confidentiality)

Aiming to reach population we serve through Advocacy, Education, Research, Resources, Wellness Services, and Partnerships to enhance outcomes.

- Conduct 2026 to 2029 strategic planning
- Expand research with our commitment to a New Frontiers grant with iCanCME, University of Montreal; CanCHILD to investigate early interventions in EDS; CanSPINE to develop research that reflects the EDS patient population and their response to physiotherapy.
- Advance the development of the Canadian Healthcare Practitioner and Physician Specialist EDS Toolkit . Focused group will be held in lieu of our annual conference to review the draft and publish in 2026.
- Advancing the Community of Practice resource library through our evidence-based project "Building Quality Improvement for Ehlers-Danlos Syndromes into a strong community of practice", done in partnership with McMaster University School of Rehabilitation Sciences Masters of Occupational Therapy.
- Advancing awareness of the EDS Canada Foundation programs and services to Primary Care Practitioners through exhibiting at medical conferences.
- Aim to expand capacity to reach population we serve with:
 - French Language services
 - Management and volunteer leadership teams

Acknowledgements

- The Value of One, The Power of Many undeniably represents our wonderful, devoted Volunteers
- With special appreciation to the Lions Club of Oakville, the Tenaquip Foundation, the Barbara and Bill Hall Foundation for their continued meaningful support.
- In 2024 our month of EDS awareness walk'n wheel-a-thons were held in Burlington, Midland and Toronto raising over \$10k

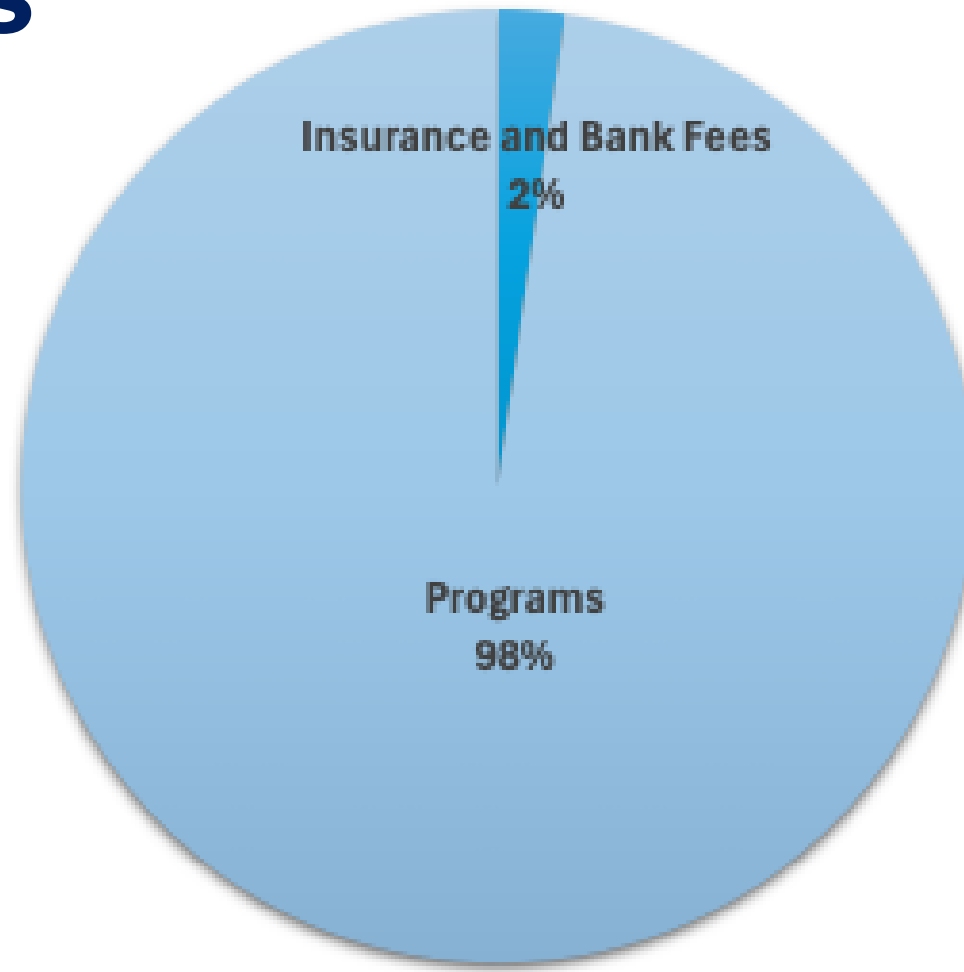


Jacqueline Raposo,
Executive Director
of The ILC

Dr. Alain Moreau,
Director of ICanCME, St
Justine, and Director of
The ILC



Financials



Where to reach us and how to get involved

Volunteer, Subscribe, Partner

www.EDSCanada.org

ContactUs@EDSCanada.org

