Loeys Dietz Syndrome Foundation Canada Annual Impact Report 2025

2025: AN INFLECTION POINT FOR LOEYS-DIETZ SYNDROME IN CANADA

Fondation du syndrome Loeys • Dietz Syndrome Foundation · Canada

Table of Contents

1. Message from Leadership

Jida El Hijjar, Executive Director (Left), Joseph Galli, Chair (Right)

There are moments in the life of an organization when you can feel something shift. There are years when the work begins to speak for itself, not because the work is finished, and not because the challenges have disappeared, but because the foundation that has been carefully built, year after year, begins to show its strength.

For Loeys-Dietz Syndrome Foundation Canada, 2025 was one of those years.

It was an inflection point.

For many years, we have been building with purpose: listening to families, learning from clinicians, convening researchers, supporting patients, and asking what it would take to create a stronger, more connected system for people living with Loeys-Dietz syndrome and heritable thoracic aortic disorders in Canada.

1. Message from Leadership

Rare disease work requires patience. It requires persistence. It requires courage to build before the path is fully visible. And it requires the belief that even when a condition affects too few people to attract the attention it deserves, those lives are no less urgent, no less complex, and no less worthy of coordinated care, research, and hope.

In 2025, that path became clearer.

This was the year our cornerstone initiative, the CAN-ACT Registry, moved from planning into action. Patient recruitment and data collection officially began, with 96 patients enrolled by the end of 2025 and continued growth into 2026. After years of protocol development, partnership-building, ethics submissions, site engagement, and national coordination, Canada is now beginning to generate the kind of data our community has long needed.

That milestone represents far more than a technical achievement. It represents a belief that Canadian patients deserve to be seen in Canadian data. Because data is not just numbers. Data is how we make people visible. It is how we begin to understand patient journeys, gaps in care, outcomes, and opportunities to do better. Through CAN-ACT, we are helping build the evidence needed to improve care, guide research, inform policy, and advocate for stronger systems for years to come.

At the same time, the needs of patients and families became more visible than ever. In 2025, LDSF Canada received a record-breaking number of patient and family requests: 131 compared to 69 the previous year. Almost twice as many people reached out for information, guidance, reassurance, connection, research access, support in finding clinicians, and help navigating difficult moments.

1. Message from Leadership

Behind every request is a story: a parent trying to understand a child's diagnosis, an adult patient looking for the right specialist, a family preparing for surgery, someone newly diagnosed and wondering what their future will look like. These requests remind us why we exist. They remind us that our work is not abstract. It is deeply human.

They also tell us something important: people are finding us. They are trusting us. And they are increasingly seeing LDSF Canada as a place where they can be heard, supported, and guided. To meet this growing need, we strengthened our patient support capacity, including through the addition of genetic counselling expertise, and continued expanding our resource directory, clinic directory, and educational supports.

This year also showed us that our reach is growing. Across our digital platforms, LDSF Canada saw record engagement: 126,800 Facebook views, 27,900 Instagram views, more than 2 million LinkedIn impressions, continued growth on YouTube, and more than 111,000 website page views. These numbers are not simply communications metrics. They are signs that awareness is expanding, that our educational content is reaching people, and that the Foundation's voice is becoming more visible across Canada and beyond.

More and more, LDSF Canada is being recognized not only as a rare disease charity, but as a credible national partner in research, education, advocacy, and system-building.

1. Message from Leadership

But growth, for us, has never been about visibility for its own sake. Growth is responsibility. In 2025, that responsibility was reflected across every part of our work. Through GRIP, our Global Research and Insights Platform, we continued organizing and analyzing the global body of Loeys-Dietz syndrome research, helping identify where the science has advanced and where knowledge gaps remain. Through our research partnerships, we supported innovation in diagnosis, screening, oral health, family screening, 3D facial imaging, quality of life, and patient learning pathways. Through our education initiatives, including the AORTA App, new patient guides, and our first LDS Patient Education and Imaging Day in London, Ontario, we continued turning knowledge into practical tools for patients, families, and clinicians. Through advocacy and awareness, we brought the LDS and HTAD community into more rooms where decisions are made.

All of this reflects why our model matters.

LDSF Canada is not a traditional foundation that simply funds work from a distance. We are builders. We are conveners. We are partners. We invest financial resources, but we also invest human resources, in-kind expertise, strategic leadership, project management, and countless hours of coordination. We sit on committees. We join task forces. We bring the patient voice into rooms where decisions are made. We help turn ideas into programs, and programs into impact.

In 2025, we saw what happens when a patient foundation is not only a source of support, but a true system partner.

1. Message from Leadership

The momentum of 2025 gives us hope. More importantly, it gives us direction. It tells us that the foundation we have been building is strong. It tells us that our community is ready. And it tells us that when patients, families, clinicians, researchers, volunteers, donors, policymakers, and partners come together around a shared purpose, we can begin to change systems that once felt immovable.

To the patients and families who trusted us this year: thank you. Your courage continues to guide us.

To the clinicians, researchers, allied health professionals, volunteers, donors, and partners who walked beside us: thank you. Your commitment is helping shape a better future.

2025 was an inflection point.

Now, together, we move forward with purpose and determination.

With gratitude and determination,

Jida El Hajjar
Executive Director, Loeys-Dietz Canada

Joseph Galli
Chair, Loeys-Dietz Canada

2. Research and Innovation

a. CAN-ACT Registry

The CANadian Aortopathy and Connective Tissue Disorders (CAN-ACT) Registry is the first pediatric registry of its kind in Canada, dedicated to individuals affected by Heritable Thoracic Aortic Diseases (HTAD), including Loeys-Dietz Syndrome (LDS), Marfan Syndrome (MFS), vascular Ehlers-Danlos (vEDS) and other rarer connective tissue conditions. For the first phase of development of the Registry, LDSF Canada committed a total amount of 221,000$ over 4 years to fund CAN-ACT in partnership with the Canadian Congenital and Pediatric Cardiology Research Network (CCPCRN) and with leading Canadian researchers, clinicians, and patient partners. The future commitments of LDSF Canada will be determinedbased on patient recruitment and the data results of the first phase.

CAN-ACT Registry

CANadian Aortopathy and Connective Tissue Disorders Registry
Registre CANadien des Aortopathies et Maladies Congénitales du Tissu Conjonctif

What Is the CAN-ACT Registry?

The CAN-ACT Registry is a secure, centralized, and ethically governed national database that captures both genotypic and phenotypic information from children and youth diagnosed with Heritable Thoracic Aortic Disease (HTAD) across Canada. This includes data on symptoms, genetic mutations, diagnostic imaging, treatment strategies, lifestyle and exercise, quality of life, and long-term outcomes. By systematically collecting and harmonizing data across institutions, the registry serves as a robust evidence platform that:

- Informs and improves clinical decision-making
- Guides the development of care standards
- Catalyzes research on rare aortic conditions

2. Research and Innovation

a. CAN-ACT Registry

Study Design

The CAN-ACT Registry is structured as a prospective, pan-Canadian observational cohort study. It includes pediatric and adolescent HTAD patients currently followed at participating institutions.

Consented Participants: For patients who provide informed consent, the study collects retrospective medical history from birth to the date of consent, and prospectively gathers clinical and patient-reported data at enrollment (Year 0), Year 3, and Year 5.

Waiver of Consent Participants: For patients who do not respond and cannot be reached, a waiver of consent permits the collection of retrospective clinical data through chart review at Year 0, with an update at Year 3 if contact remainsunsuccessful.

Clinical and Patient Data Collected

The CAN-ACT Registry will generate national descriptive statistics on:

- Epidemiology:
  - Prevalence of HTAD in Canada, using national population as denominator
  - Distribution of genetic mutations across HTAD subtypes
  - Incidence and prevalence of clinical features, complications, and comorbidities
  - Survival rates

- Health Services Use:
  - Diagnostic imaging utilization
  - Cardiovascular intervention rates

2. Research and Innovation

a. CAN-ACT Registry

Clinical and Patient Data Collected

- Demographics:
  - Sex at birth, gender identity, ethnicity, education level, and employment status

- Symptoms and Patient-Reported Outcomes:
  - Symptom prevalence at enrollment and incidence over time
  - Quality of life trends using diagnosis-specific instruments
  - Physical activity levels and their evolution over time, benchmarked against normative data

Why it Matters?

Historically, Canada has lacked a unified resource to track and study rare aortic diseases in children and adults. This has created significant gaps in care, diagnosis, and also research as concluded by our GRIP analysis.

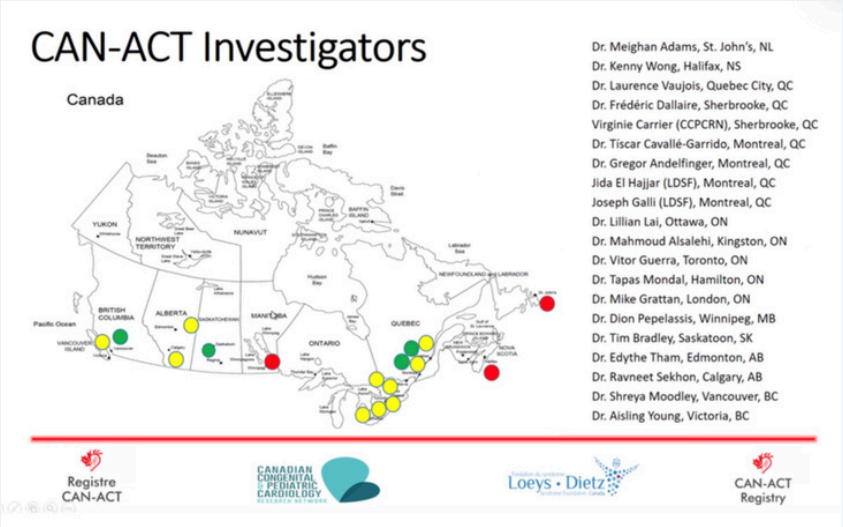
- CAN-ACT aims to determine:
  - How many children in Canada are being followed for Heritable Thoracic Aortic Disease?
  - What are their genetic diagnoses and clinical features?
  - How and where are they being treated?
  - What is the impact of these diseases on their quality of life and physical activity?
  - How can we better advocate for these children to improve their health care and quality of life?

2. Research and Innovation

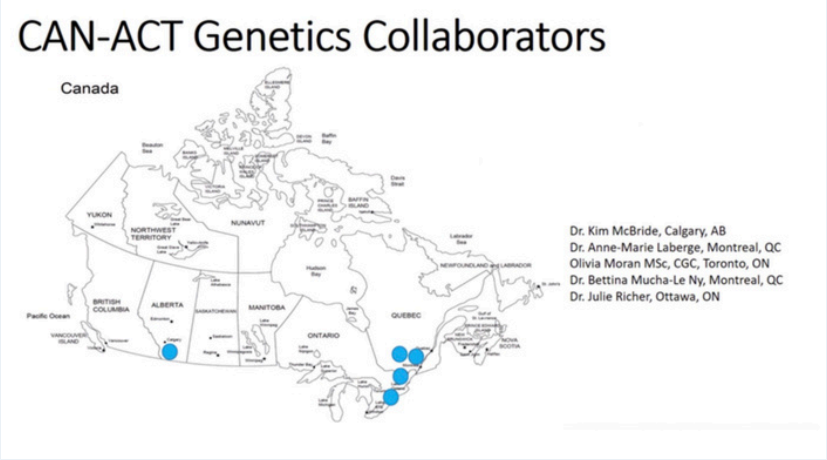
a. CAN-ACT Registry

CAN-ACT Investigators and Collaborators

We are honoured to have 18 researchers, 1 patient-partner, and 5 geneticists from coast to coast that are contributing to the registry.



CAN-ACT Investigators across Canada



CAN-ACT Genetic Collaborators across Canada

2. Research and Innovation

a. CAN-ACT Registry

CAN-ACT Investigators and Collaborators

CAN-ACT Steering Committee

From left to right: Dr. Tíscar Cavallé-Garrido (co-Chair), Dr. Gregor Andelfinger, Joseph Galli, Dr. Frédéric Dallaire (CCPCRN), Jida El Hajjar, Dr. Tim Bradley (co-Chair).

The responsibilities of the steering committee are to:

- Review progress and engagement of participating sites- monthly meetings
- Annual steering committee/advocacy committee meetings to assess data quality and review data/update goals and priorities
- Biannual steering committee meeting with all CAN-ACT participants to review individual study progress and review pending collaboration proposals
- Support the Principal Investigators in related research grant applications

2. Research and Innovation

a. CAN-ACT Registry

Key Highlights of 2025

- We hosted an in-person Investigators Meeting at Vascular 2025 in Québec City (October 2025) to continue strengthening national coordination and patient-partnered research.

CAN-ACT members at Investigators Meeting at Vascular 2025

- The CAN-ACT website was launched to support participant recruitment, data access, and public engagement: can-act.org
- CAN-ACT produced a short YouTube video featuring Co-Chair Dr. Tiscar Cavallé-Garrido, Pediatric Cardiologist and Director of the Aortopathy Clinic at the Montreal Children's Hospital. In the video, Dr. Cavallé-Garrido discusses the importance of the CAN-ACT Registry and how it will support clinical care and research by improving our understanding of heritable thoracic aortic disease across Canada: https://www.youtube.com/watch?v=pt8d1r-Hglw

2. Research and Innovation

a. CAN-ACT Registry

Key Highlights of 2025

- We enrolled first cohort of 96 patients, marking a major milestone in national data generation for heritable aortopathies.

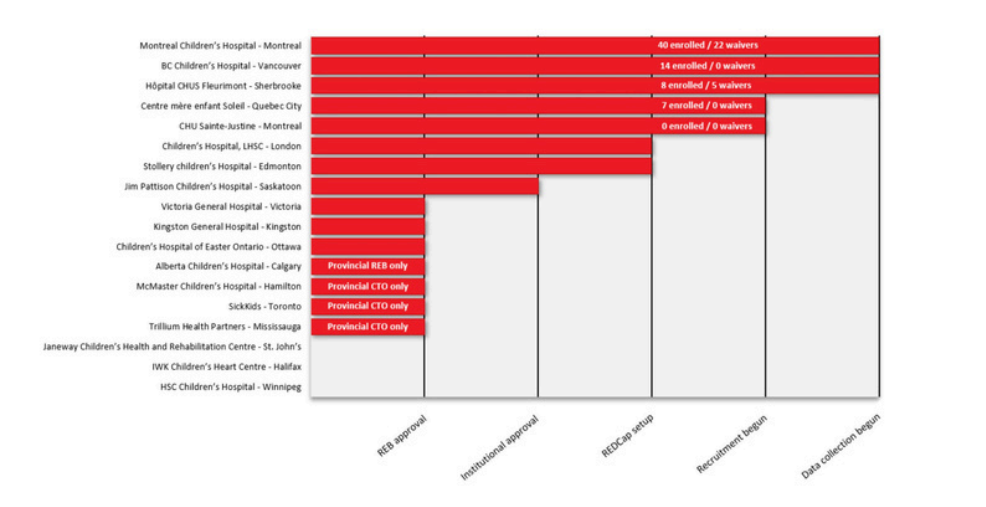


Figure 1: Cohort of patients enrolled across sites

- Steering Committee Engagement: We held 12 monthly steering committee meetings to maintain the momentum on CAN-ACT activities.
- CAN-ACT Consortium: Through in-kind and financial support, LDSF Canada has helped initiate several consortium research projects across Canada. These studies, described in Section C, are now underway at participating sites.
- Ethics Approvals: Achieved research ethics board (REB) approvals at 8 of 18 participating sites, with additional submissions in progress.
- LDSF Canada Disbursement: In 2025, LDSF Canada disbursed 105,000$ to CCPCRN (hosting institution of CAN-ACT at CIUSSS Estrie-CHU de Sherbrooke Hospital-Dr. Frédéric Dallaire account) and 21,201$ to Montreal Children's Hospital(Dr. Tiscar Cavalle-Garrido account) in direct support of the registry's development and operations.

2. Research and Innovation

a. CAN-ACT Registry

Future Directions

- Beyond clinical care, CAN-ACT will generate Canadian-specific evidence to inform regulatory, health policy, and health technology assessment (HTA) decisions—addressing a major data gap in rare aortic conditions. Importantly, the registry is designed to be interoperable with global initiatives, enabling international collaboration and data sharing, including future alignment with international registries such as CLARITY: https://clarityregistry.com

- The CAN-ACT Registry will also equip researchers with high-quality, real-world data to better understand disease patterns, severity, and variability across the Canadian HTAD population.

The registry will serve as a platform for multicentre consortium-initiated research projects, with an initial portfolio of studies outlined in Section C of this report. These projects will enable investigators to address priority research questions, support trainee-led initiatives, and foster collaborations across participating centres. Clinicians will be able to identify high-risk patients earlier and develop more personalized treatment plans based on genotype-phenotype correlations and long-term outcomes.

2. Research and Innovation

a. CAN-ACT Registry

Looking Ahead to 2026

- Our CAN-ACT website will be continuously updated with enrollment updates including consent Tracking, data entry completion status, data validation status for all contributing sites.
- We anticipate enrolling our first cohort of 500 patients, marking a major milestone in national data generation for heritable aortopathies. As of May 2026, we have enrolled 222 patients across 18 sites.

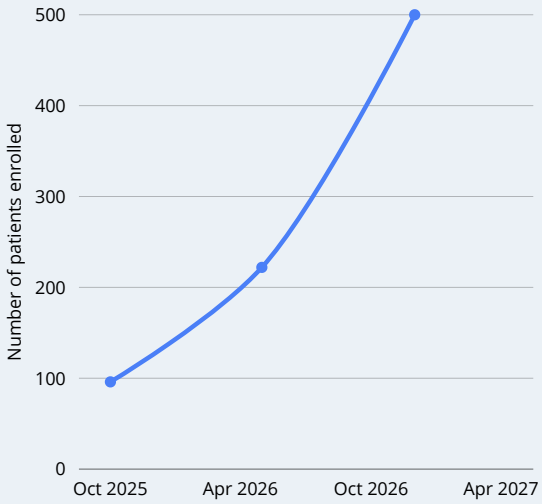


Figure 2: Anticipated cohort of patients to be enrolled

SAH HAD
SYMPOSIUM SUR LES AORTOPATHIES HÉRÉDITAIRES
HERITABLE AORTIC DISORDERS SYMPOSIUM

- We will present study findings at 4th International Symposium on Heritable Disorders of the Aorta (HAD4), highlighting key insights from the growing CAN-ACT cohort, including recruitment progress, and preliminary analyses that demonstrate the value of a coordinated national registry for advancing research in heritable aortopathies in Canada.

- We will prepare and disseminate an interim data report summarizing enrollment trends, data quality metrics, site participation, and early research findings. This report will provide participating centres, patient partners, funders, and collaborators with an overview of network progress and emerging opportunities for future research and knowledge translation.

2. Research and Innovation

b. Innovation in Diagnosis and Screening

Comprehensive Access to Rare-disease Expertise in Oral Health

LDSF Canada is supporting the development of the CARE Network (Comprehensive Access to Rare-disease Expertise in Oral Health), a national initiative led by Dr. Daniel Graf, Professor in the Faculty of Dentistry at the University of British Columbia and Director of the Craniofacial, Oral, Dental Disorders (CODED) Research Cluster. The network brings together dental specialists, medical geneticists, researchers, educators, and patient partners to address critical gaps in oral health care for individuals living with rare diseases.

Through a national workshop and ongoing collaboration, CARE will identify educational and clinical practice gaps, improve awareness of oral and craniofacial manifestations of rare diseases, and develop recommendations to support earlier diagnosis and more coordinated, patient-centred care. The initiative is particularly relevant to conditions such as Loeys-Dietz syndrome, where dental and craniofacial features may contribute to earlier recognition and timely access to specialized care. To date, support has been provided in-kind through the coordination of the first in-person CARE Network meeting and workshop, held in Vancouver, BC, in 2026.

UBC

CARE Network
COMPREHENSIVE ACCESS TO RARE-DISEASE EXPERTISE

Craniofacial Features

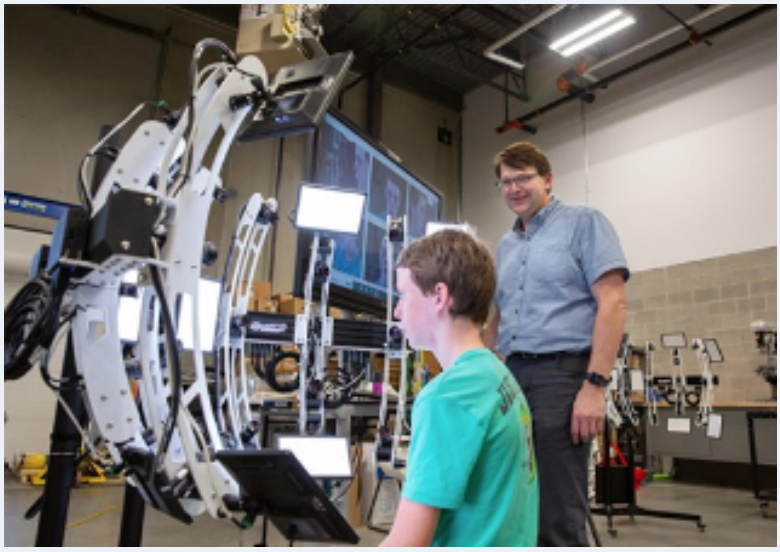
2. Research and Innovation

b. Innovation in Diagnosis and Screening

Using 3D Facial Imaging and Genetics to Predict HTAD Severity

LDSF Canada is supporting a research project led by Dr. Benedikt Hallgrímsson and his team at the University of Calgary that aims to investigate whether subtle craniofacial features can serve as biomarkers of aortopathy severity. By combining advanced facial phenotyping, genetic analyses, and animal models, the research team will examine how facial shape variation correlates with aortic disease progression and clinical outcomes in both syndromic and non-syndromic HTAD.

The study will also identify genetic factors associated with more severe disease, with the goal of developing new tools for earlier diagnosis, improved risk stratification, and more personalized care. This innovative research highlights the potential of artificial intelligence and precision medicine to transform the care of individuals living with rare genetic disorders and heritable aortic disease. To date, our contribution has been provided in-kind through project direction, knowledge mobilization, and logistical planning for the London, Ontario event (Section 5b), which was delivered with a budget of approximately $25,000.



Dr. Benedikt imaging a child

2. Research and Innovation

b. Innovation in Diagnosis and Screening

Patient-Initiated Family Screening for Genetic Aortopathy

LDSF Canada is supporting a research project led by Dr. Gabrielle Horne at the Maritime Connective Tissue Clinic to better understand how individuals with genetic aortopathies can encourage at-risk family members to undergo screening. Through a contribution of $12,480, LDSF Canada is helping advance research that aims to improve family screening uptake and the early identification of individuals at risk of hereditary aortic disease. Family screening is critical for identifying relatives who may be at risk of life-threatening aortic complications before symptoms occur.

Building on more than 15 years of experience with a patient-initiated family screening model, Dr. Horne's team found that while nearly one-third of screened relatives were identified as having a genetic aortopathy, fewer than half of patients successfully initiated screening within their families. Through interviews with patients who were highly successful, moderately successful, or unsuccessful in engaging relatives, this qualitative study will identify barriers, facilitators, and best practices for family outreach.

The findings will help inform strategies to improve early detection, increase family screening uptake, and ultimately prevent avoidable aortic dissections and sudden deaths.

2. Research and Innovation

b. Innovation in Diagnosis and Screening

Advancing Quality of Life Research in Loeys-Dietz Syndrome

Recognizing the importance of understanding the day-to-day experiences of individuals living with Loeys-Dietz syndrome (LDS), LDSF Canada initiated the coordination of a new research project in collaboration with Dr. Julie Richer, Medical Geneticist at the Children's Hospital of Eastern Ontario (CHEO).

People living with LDS often experience symptoms that extend beyond the heart and blood vessels, including pain, fatigue, sleep disturbances, headaches or migraines, anxiety, and challenges with exercise. Although these symptoms can significantly affect day-to-day life, little research has explored their prevalence, severity, and how they are interconnected. This study, led from the CHEO Research Institute and supported by LDSF Canada, aims to better understand these experiences through a series of short online surveys completed by adults with LDS.

By examining multiple domains together, this study will help identify patterns that may inform future clinical care, patient education, and supportive interventions. The findings will provide valuable insights into the lived experiences of people with LDS and help guide future research priorities identified by the community. This initiative represents an important step toward addressing a significant gap in the current understanding of how LDS affects individuals beyond clinical outcomes. The project will explore key dimensions of quality of life through patient-reported outcomes, including physical health, emotional well-being, social participation, healthcare experiences, and the broader impact of living with a rare genetic condition. By gathering insights directly from patients and families, the study aims to capture the realities of navigating LDS across different stages of life and identify areas where additional support, resources, and interventions may be needed.

b. Innovation in Diagnosis and Screening

Advancing Quality of Life Research in Loeys-Dietz Syndrome

As a patient-driven organization, LDSF Canada is playing a central role in helping to shape the study design, ensuring that the research reflects the priorities and concerns of the LDS community. The findings are expected to provide valuable evidence that can inform future clinical care, patient support programs, advocacy efforts, and research priorities. Currently in the development phase, the study is scheduled to launch in 2026. Once underway, it will represent one of the first dedicated efforts in Canada to systematically examine quality of life among individuals living with LDS, helping to build a more comprehensive understanding of the patient experience and ultimately improve care and outcomes for the community.

To date, LDSF Canada has contributed approximately $4,300 in in-kind support through the time and expertise of Sally Al Mutfy, Patient Education Consultant, who has supported project development, planning, and patient engagement activities.

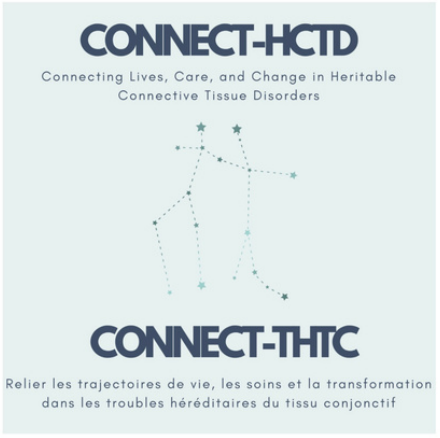
2. Research and Innovation

b. Innovation in Diagnosis and Screening

CONNECT-HCTD: Connecting Lives, Care and Change in Heritable Connective Tissue Disorders

LDSF Canada is supporting CONNECT, a research project led by Dr. Gabrielle Pagé at the Université de Montréal and coordinated by Catherine Côté, a doctoral student in clinical psychology. The project aims to better understand the life trajectories, care pathways, and lived experiences of people living with heritable connective tissue disorders (HCTDs), including Ehlers-Danlos syndromes, Marfan syndrome, and Loeys-Dietz syndrome.
A key component of the project is the development of a Patient Learning Pathway (PLP), an interactive roadmap designed to help individuals and families navigate life with an HCTD. Co-developed with people living with these conditions, caregivers, healthcare professionals, and community organizations, the PLP will bring together reliable information, practical resources, and guidance tailored to different life stages and care needs.

By integrating clinical recommendations with lived experience perspectives, the pathway aims to support self-management, facilitate access to appropriate care and services, strengthen patient empowerment, and reduce the challenges associated with navigating complex and often fragmented healthcare systems. LDSF Canada has committed $20,000 in funding to support this initiative, in addition to providing in-kind contributions through project direction, promotion, and knowledge mobilization activities.



2. Research and Innovation

c. Patient Voices Driving Research and Change

LDSF Canada continues to champion patient-centered research that advances understanding of the lived experiences of individuals and families affected by Loeys-Dietz syndrome (LDS). In 2025, we supported a study exploring patient perspectives on the LDS diagnostic journey, led by Sally Al-Mufty as part of her Master of Science graduate research project and co-authored by LDSFC's Research and Patient Support Officer.
The study, “From Lived Experiences to Systemic Change: Patient Perspectives on the Diagnostic Journey of Loeys-Dietz Syndrome," was published in CJC Open, an international, peer-reviewed, open-access journal dedicated to advancing knowledge in cardiology and cardiovascular science. Through interviews and patient experiences, the research sheds light on the challenges individuals face in obtaining an accurate and timely diagnosis, including delays in recognition, barriers to specialist care, and the emotional impact of navigating a rare disease.

The significance of this work was further recognized when it received the Outstanding CAGC Trainee Poster Award at the 2025 Joint Conference of the Canadian Association of Genetic Counsellors (CAGC) and the Canadian College of Medical Geneticists (CCMG).
By amplifying patient voices, this research contributes valuable evidence that can inform clinical practice, improve diagnostic pathways, and guide future national initiatives aimed at enhancing care for individuals living with LDS. It reflects LDSF Canada's commitment to ensuring that patient experiences remain at the center of research, advocacy, and healthcare system improvement.

CJC Open Article Publication

2. Research and Innovation

d. Global Research and Insights Platform (GRIP)

The Global Research and Insights Platform (GRIP) is an innovative, living repository of scientific literature related to Loeys-Dietz syndrome (LDS). Developed and curated by LDSF Canada, GRIP is the only centralized database in the world dedicated exclusively to collecting, organizing, and analyzing LDS research across genetics, clinical manifestations, diagnostics, surgical outcomes, and emerging therapies. The platform serves clinicians, researchers, patients, and advocates by improving access to evidence and supporting knowledge translation across the global LDS community.

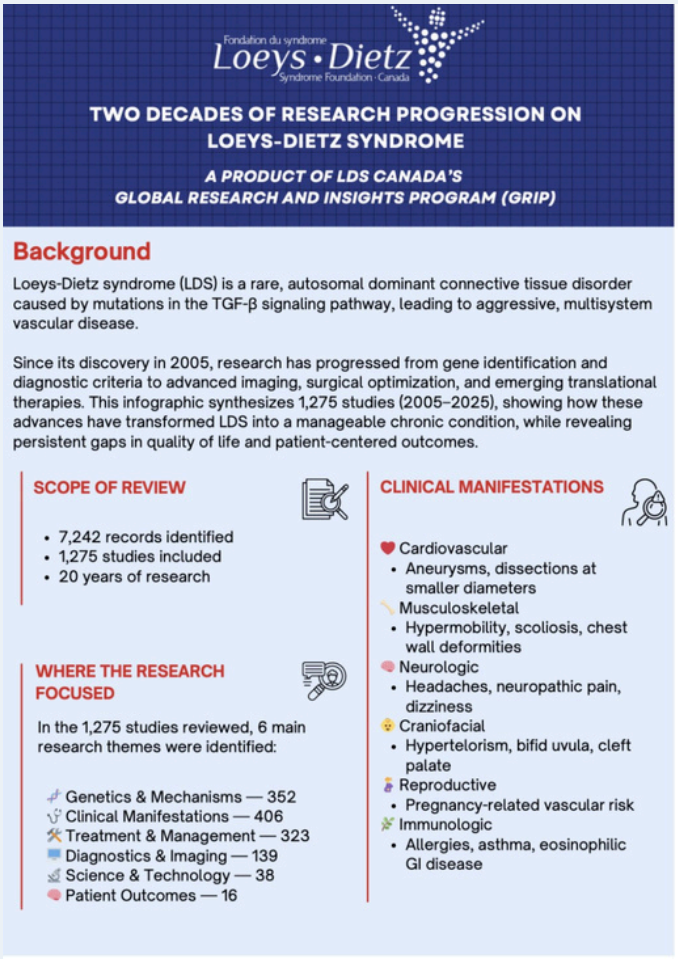
As of December 31, 2025, GRIP contained 1,762 publications, making it the most comprehensive and up-to-date collection of LDS research available. Of these, 1,275 articles were directly related to LDS and formed the basis of a systematic review examining the first 20 years of Loeys-Dietz syndrome research. This analysis demonstrated how the field has evolved from genetic discovery and diagnostic clarification (2005–2010), to diagnostic imaging and phenotype expansion (2010–2015), surgical optimization and improved survival (2015–2020), and more recently, genetic screening and translational therapies (2020–2025). While these advances have transformed LDS from a newly described condition into a more manageable chronic disease, important gaps remain in understanding patient-reported outcomes, quality of life, and psychosocial impacts.

2. Research and Innovation

d. Global Research and Insights Platform (GRIP)

By consolidating global research into a single searchable platform, GRIP helps clinicians stay current on evolving best practices, supports researchers in identifying knowledge gaps and developing new studies, strengthens evidence-based advocacy efforts, and improves access to scientific information for patients and families.

In 2026, LDSF Canada will continue expanding GRIP by incorporating newly published research not only on Loeys-Dietz syndrome but also on Marfan syndrome, vascular Ehlers-Danlos syndrome (vEDS), and other heritable thoracic aortic diseases (HTADs). The team also plans to disseminate findings from the 20-year LDS research review through conference presentations and scientific publications, further contributing to the advancement of knowledge in rare connective tissue and aortic disorders.



GRIP Summary Factsheet

3. Patient and Family Support

a. Support Services

Supporting individuals and families affected by Loeys-Dietz syndrome and heritable thoracic aortic diseases remains at the heart of LDSF Canada's mission.

Throughout 2025, our Patient Support Coordinator, Lindsay Parsons, provided direct support, guidance, and connections to individuals and families navigating diagnosis, treatment, and ongoing care. Through personalized support services, educational resources, peer connections, and healthcare navigation assistance, LDSF Canada helped patients and caregivers access reliable information, reduce isolation, and make informed decisions about their health and well-being.

Key Highlights of 2025

In 2025, we responded to 131 support requests, nearly doubling the 69 requests received in 2024.

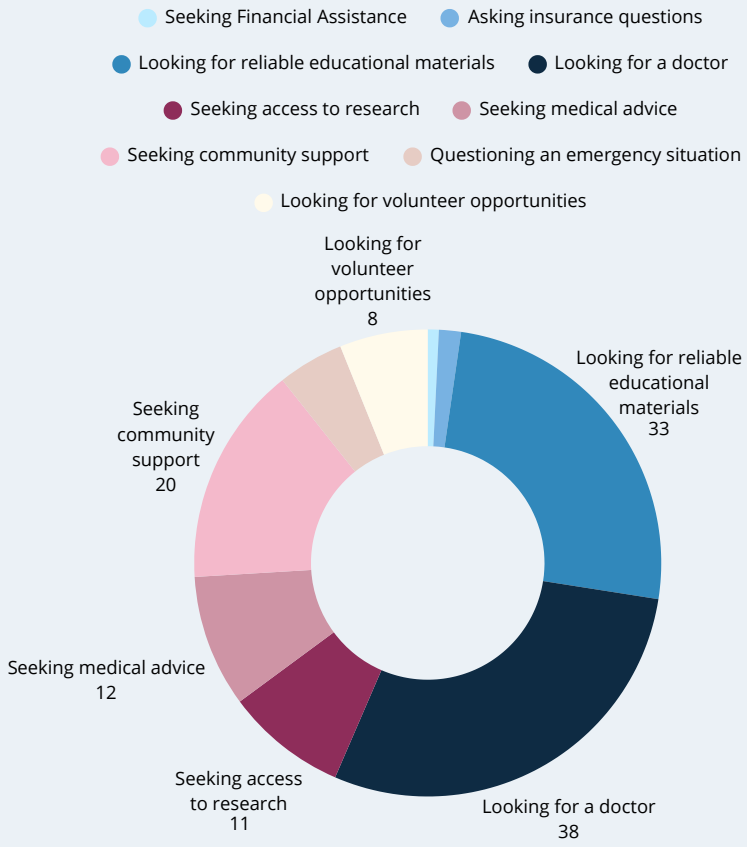


Figure 3: Reasons for Contacting LDSFC's Peer Support

3. Patient and Family Support

a. Support Services

We supported individuals and families across Canada and internationally, including in Armenia, France, Nigeria, Turkey, and the United States.

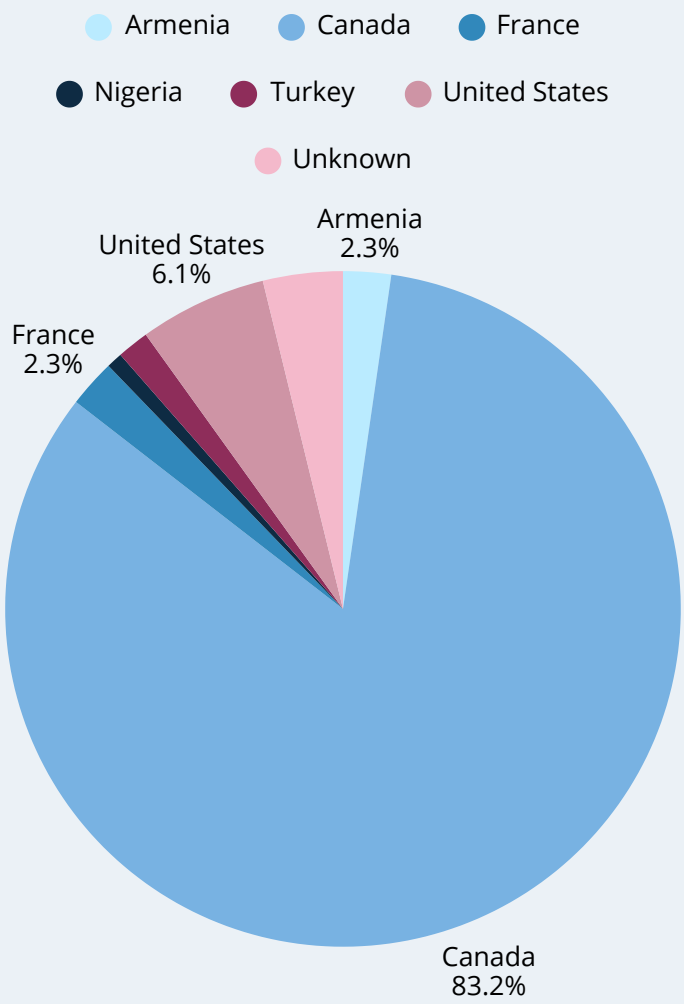


Figure 4: Countries from which Patients are Contacting LDSFC's Peer Support

3. Patient and Family Support

a. Support Services

Resource Directory:
LDSF Canada continued to expand its online Resource Directory, providing patients, families, and healthcare professionals with centralized access to trusted educational materials, support services, clinical resources, and community organizations to help navigate life with Loeys-Dietz syndrome and related heritable aortic conditions.

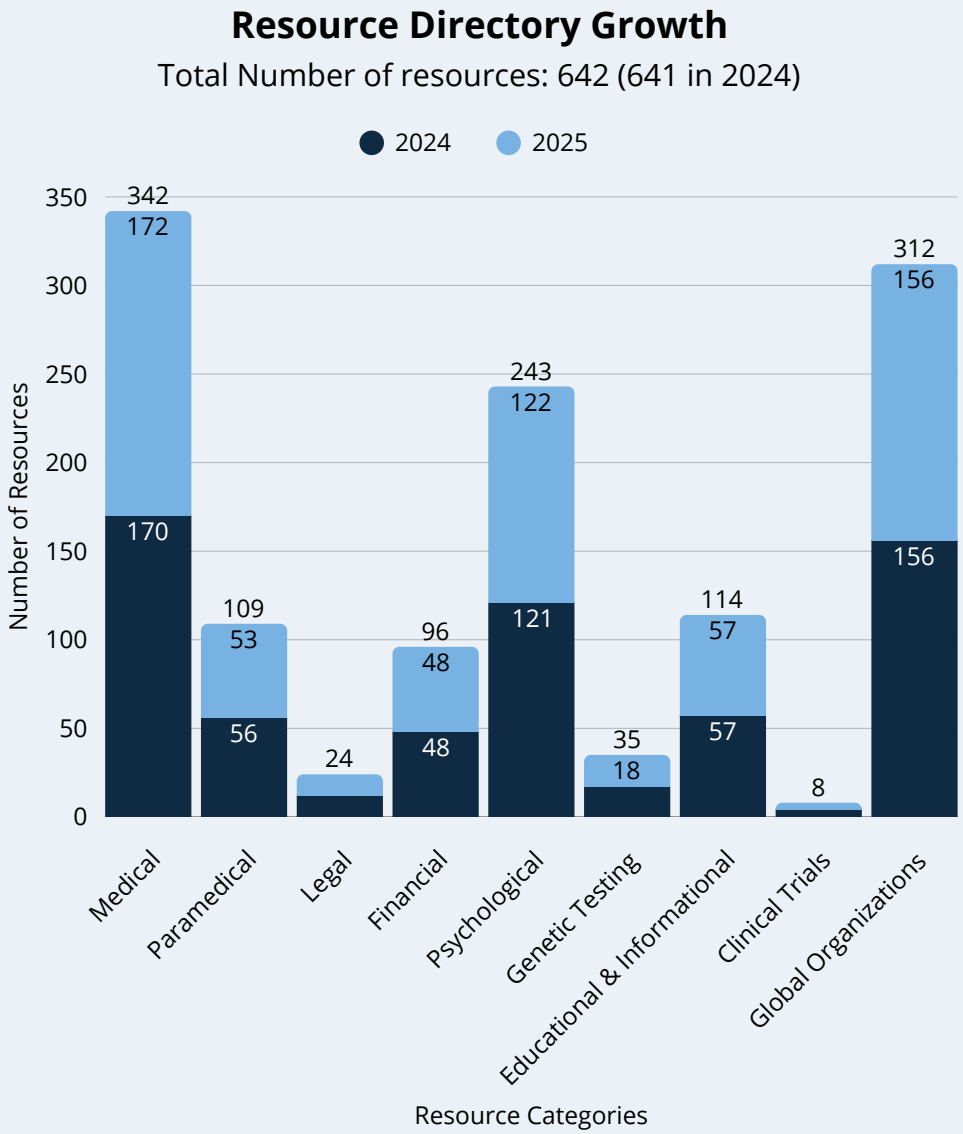


Figure 5: Resource Directory Growth from 2024-2025

3. Patient and Family Support

b. Genetic counsellor recruitment - Sally Al-Mufty

This year, LDSF Canada strengthened its capacity to support individuals and families affected by heritable aortic conditions through advancements in genetics education, research, and patient support. Team member Sally Al-Mufty became a certified genetic counsellor, further enhancing the organization's expertise in genetic counselling and rare disease care.

Sally's LDSFC-supported graduate research was recognized with the Outstanding Trainee Poster Award at the 2025 Canadian Association of Genetic Counsellors Conference. Throughout the year, LDSF Canada also advanced the development of genetics-focused educational resources, supported initiatives related to genetic testing, and integrated genetic insights more intentionally into its programs and patient support services.

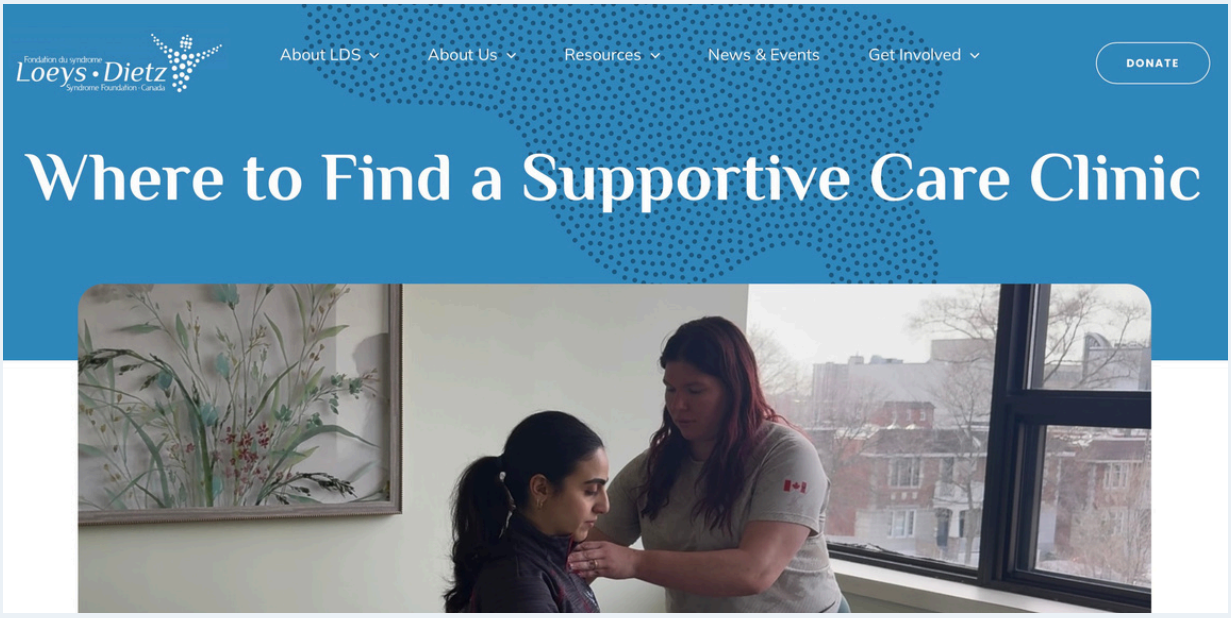
Sally Al-Mutfy
LDSFC Patient Education Consultant

3. Patient and Family Support

c. Expanding Clinic Directory

LDSF Canada continues to maintain and expand the Find a Clinic directory on its website, a growing national resource that connects individuals and families with Canadian health centres experienced in the diagnosis and management of Loeys-Dietz syndrome, related heritable aortic conditions, and genetic and cardiovascular care. Recognizing the importance of comprehensive, multidisciplinary support, LDSF Canada is broadening the directory to include allied health and quality-of-life services such as physiotherapy, mental health care, rehabilitation, and other specialized supports.

By making these resources easily accessible online, this initiative helps patients and families navigate the healthcare system more effectively and identify appropriate care and support services across Canada.



LDSFC Website - Where to Find a Supportive Clinic

4. Advocacy and Awareness

a. LDSF Canada at the 2025 Canadian Connective Tissue Conference (CCTC)

From May 26–28, 2025, LDSF Canada attended and sponsored the 29th Annual Canadian Connective Tissue Conference (CCTC) in Montreal, bringing together clinicians, researchers, trainees, and patient organizations from across Canada. The LDSFC team hosted an exhibitor booth, engaging with more than 120 attendees and sharing educational resources to increase awareness of Loeys-Dietz syndrome and other heritable connective tissue disorders.

A key highlight was a presentation by Executive Director Jida El Hajjar, titled From Rare to Recognized, which emphasized the need for earlier diagnosis, stronger research collaborations, and a coordinated national approach to supporting individuals and families affected by Loeys-Dietz syndrome and heritable thoracic aortic diseases.

Jida El Hajjar presenting at CCTC

4. Advocacy and Awareness

b. LDSF Canada at the Ehlers-Danlos Society (EDS) Conference in Toronto

LDSF Canada representatives attended The Ehlers-Danlos Society Conference in Toronto, connecting with clinicians, researchers, patient advocates, and individuals living with connective tissue disorders from across Canada and around the world. The conference provided an important opportunity to strengthen relationships within the broader heritable connective tissue disorder community, exchange knowledge and best practices, and elevate the voices and experiences of patients and families. Participation in this international gathering helped foster new collaborations and identify opportunities for future research, education, and advocacy initiatives.

Dinner with Partners at EDS Conference

Figure 9: Resource Growth from 2024 to 2025

4. Advocacy and Awareness

c. LDSF Canada at the 2025 International Congress of Oral Implantologists (ICOI) Conference

From February 20–22, 2025, LDSF Canada representatives Jida El Hajjar and Lindsay Parsons attended the International Congress of Oral Implantologists (ICOI) Conference in New Orleans as sponsors and exhibitors. LDSFC proudly sponsored Dr. Sylvia Frazier-Bowers as a keynote speaker, where she highlighted the critical role dental professionals can play in recognizing the signs of heritable aortic disorders and facilitating timely referrals for diagnosis and care. Through its exhibitor booth, LDSF Canada engaged with more than 50 conference attendees, raising awareness of Loeys-Dietz syndrome and other heritable thoracic aortic diseases, and distributing educational resources to support earlier identification and improved patient outcomes.

Lindsay Parsons and Jida El Hajjar at the LDSF Canada booth at the ICOI Conference

4. Advocacy and Awareness

d. Aortic Dissection Awareness Campaign

From September 14–20, 2025, Loeys-Dietz Syndrome Foundation Canada (LDSFC) joined Aortic Hope, the Genetic Aortic Disorders Association Canada (GADA), The John Ritter Foundation for Aortic Health, The Marfan Foundation and its divisions, Rock from the Heart, and ThinkAorta US & Canada for a joint social media campaign in recognition of Aortic Dissection Awareness Week 2025. The campaign encouraged the public and healthcare community to "Think STAT" — Suspect, Time, Aortic imaging, Talk about it — to improve recognition of aortic emergencies and promote timely, life-saving action. Through coordinated messaging, the campaign helped raise awareness of the signs and urgency of aortic dissection and reinforced the importance of early diagnosis, rapid imaging, and informed conversations about aortic health.

Aortic Dissection Awareness Week Campaign

4. Advocacy and Awareness

e. LDSF Canada on AHTV

In May 2025, LDSF Canada participated in a live Aortic Hope TV (AHTV) question-and-answer session featuring Executive Director Jida El Hajjar and patient partner Cynthia Hamilton Urquhart, hosted by Velda Mackenzie. During the discussion, Jida highlighted the mission and key pillars of LDSF Canada while providing education on Loeys-Dietz syndrome and heritable thoracic aortic diseases (HTAD). The session addressed patient questions related to diagnosis, clinical warning signs, advocacy efforts through Canada's Rare Disease Strategy, and the critical role of research and data collection in improving outcomes for individuals and families affected by HTAD. The event provided an important platform for patient education, awareness, and community engagement.

Jida El Hajjar (bottom left) on AHTV

4. Advocacy and Awareness

f. LDSF Canada Executive Director Jida El- Hajjar Joins the Institut National d'Excellence en Sante et en Services Sociaux (INESSS) Rare Disease Committee

In 2025, LDSF Canada strengthened its role in rare disease policy and advocacy through the appointment of Executive Director Jida El Hajjar to the Institut National d'Excellence en Sante et en Services Sociaux (INESSS) Rare Disease Committee. The committee supports the evaluation of health technologies and therapies for rare diseases and contributes to improving access to specialized care across Quebec. Jida's participation ensures that the perspectives and lived experiences of individuals and families affected by rare diseases are represented in provincial decision-making processes, helping to advance more patient-centred policies and care pathways.

4. Advocacy and Awareness

g. LDSF Canada Executive Director Jida El Hajjar Appointed Chair of the Canadian Organization for Rare Disorders (CORD)

In 2025, Executive Director Jida El Hajjar was appointed Chair of the Canadian Organization for Rare Disorders (CORD), Canada's national network advocating for people living with rare diseases. Through this leadership role, Jida is helping advance the implementation of Canada's Rare Disease Strategy and strengthen national efforts to improve diagnosis, access to care, and health outcomes for individuals with rare conditions. She also represented the rare disease community at a Parliamentary Reception on Rare Disease Day, advocating for improved patient identification, earlier diagnosis, and the development of national networks of expertise to support equitable care across Canada.

Jida El Hajjar (right) speech at CORD's Parliamentary Reception on Rare Disease Day

4. Advocacy and Awareness

h. LDSF Canada Executive Director Contributing to Global Rare Disease Research Through International Rare Diseases Research Consortium (IRDiRC)

International Rare Diseases Research Consortium (IRDiRC) unites global experts to advance rare disease research. As a member of IRDiRC's Patient Advocacy Constituent Committee, Jida El Hajjar contributed to two Task Forces on measuring patient impact and developing innovative funding models for rare diseases. This work produced three peer-reviewed publications and a practical toolbox, with two articles already published and one forthcoming.

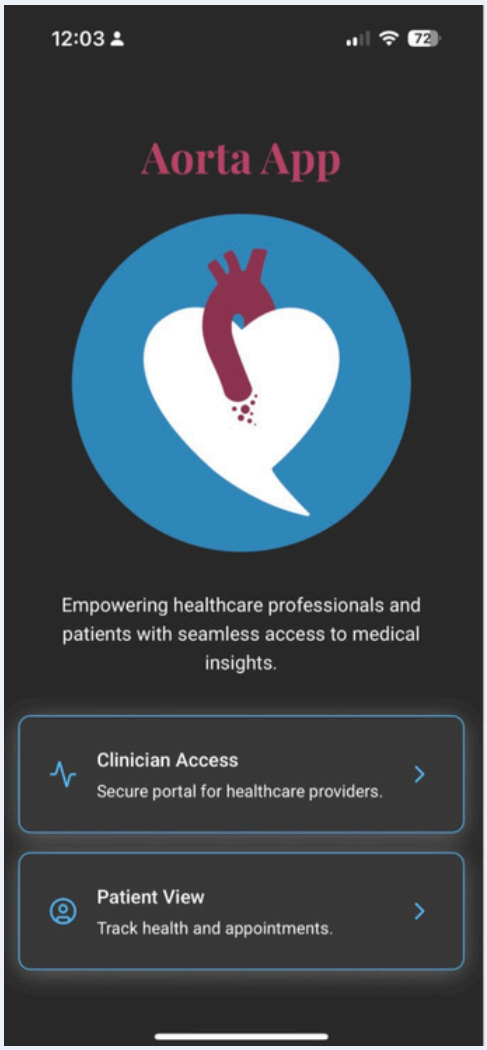
As a member of the IRDiRC Patient Advocacy Constituent Committee, Executive Director Jida El Hajjar contributed to international efforts to advance rare disease research, policy, and patient engagement. In 2025, she participated in two IRDiRC Task Forces focused on measuring patient impact and developing innovative funding models for rare disease research. This collaborative work resulted in the development of practical tools and resources for the global rare disease community, including three peer-reviewed publications, two of which have already been published, with a third forthcoming. Through this involvement, LDSF Canada continues to ensure that patient perspectives help shape international rare disease research priorities and practices.

5. Educational Initiatives

a. AORTA app

LDSF Canada collaborated with Dr. Marina Ibrahim and Andréanne Cartier at the Montreal Heart Institute, together with the digital design team at ProductShop, to develop AORTA, an evidence-based digital companion designed to support both clinicians and patients in aortic care. The platform provides clinicians with access to clinical guidelines, risk assessment and surgical threshold calculators, and referral tools to support evidence-based decision-making and standardized care. For patients and families, AORTA offers clear, accessible education on aortic conditions, genetics, and disease management, while connecting users to support resources and community networks.

By bringing together clinical and patient-facing resources in a single platform, AORTA helps improve communication, increase confidence in care decisions, and strengthen care pathways for individuals affected by heritable thoracic aortic diseases. LDSF Canada has committed $20,000 in funding to support this initiative and is providing additional in-kind contributions through project management, literature review, resource development and updates, and knowledge mobilization activities.



AORTA app

5. Educational Initiatives

b. LDS Patient Education and Imaging Day

On October 25, 2025, LDSF Canada hosted its first LDS Patient Education Day in London, Ontario, bringing together patients, families, researchers, and clinicians for a day of learning and engagement. Participants attended educational sessions led by experts and had the opportunity to contribute to research through optional advanced 3D facial imaging. The imaging initiative, led by Dr. Benedikt Hallgrímsson's team at the University of Calgary, is exploring how facial characteristics may improve the diagnosis and understanding of genetic syndromes, including Loeys-Dietz syndrome.

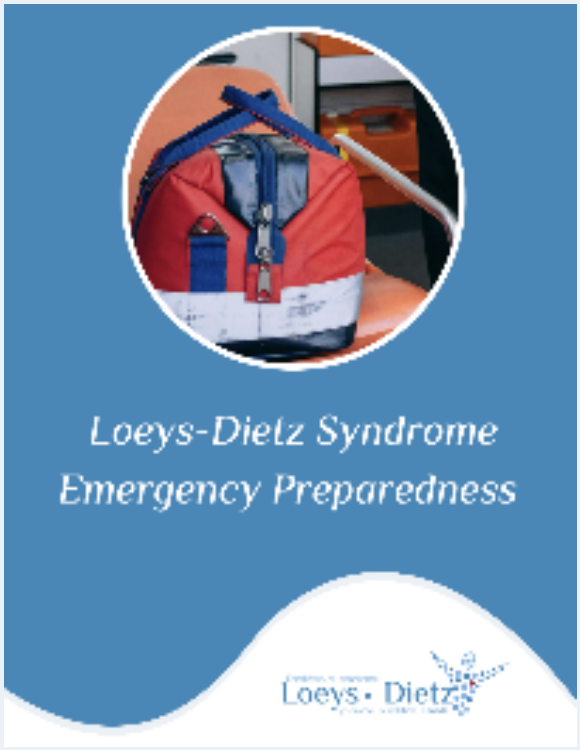
By combining medical information with 3D facial photographs from individuals and, in some cases, their relatives, the project aims to develop more accurate diagnostic tools and advance knowledge of the relationship between genetics, facial features, and disease presentation. LDSF Canada contributed approximately $25,000 in in-kind support through the logistical planning and coordination of the London, Ontario event, which enabled participant recruitment, data collection, and knowledge exchange between researchers, clinicians, and the LDS community.

Dr. Benedikt presenting his research at LDS Patient and Imaging Day

5. Educational Initiatives

c. New Educational Resources

LDSF Canada continues to expand its library of educational resources to support patients, families, and healthcare professionals with reliable, evidence-based information on Loeys-Dietz syndrome and heritable thoracic aortic diseases. In 2025, the organization developed two new educational guides: Cardiovascular Complications & Preparing for Surgery, which helps individuals better understand cardiovascular risks and prepare for surgical interventions, and Emergency Preparedness for Loeys-Dietz Syndrome, which provides practical guidance for managing medical emergencies and communicating critical health information to healthcare providers.



LDSF Canada resource - LDS Emergency Preparedeness Booklet

LDSF Canada resource - LDS: Cardiovascular Complications and Preparing for Surgery Guide

6. Social Media and Digital Awareness

Throughout 2025, LDSF Canada used social media to raise awareness of Loeys-Dietz syndrome and heritable thoracic aortic diseases, share educational resources, promote research initiatives, and connect with patients, families, healthcare professionals, and researchers. Our digital platforms helped expand the reach of advocacy campaigns, patient stories, educational content, and community events across Canada and beyond.

a. Instagram and Facebook

Facebook:

- Views: 126.8K
- Content interactions: 822, up 614.8% from 2024
- Link clicks: 385, up 940.5% from 2024
- Visits: 4.3K, up 201% from 2024
- Follows: 1,142 (970 in 2024)

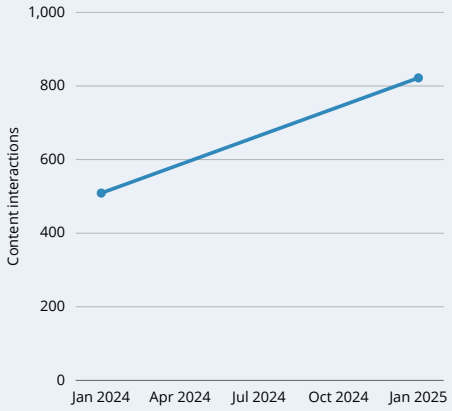


Figure 6: Facebook Content Interactions 2024-2025

Instagram:

- Views: 27.9K
- Reach: 5.4K, up 332.5% from 2024
- Content interactions: 738, up 100% from 2024
- Link clicks: 46, up 187.5% from 2024
- Visits: 1.2K, up 364.6% from 2024
- Follows: 518 (352 in 2024)

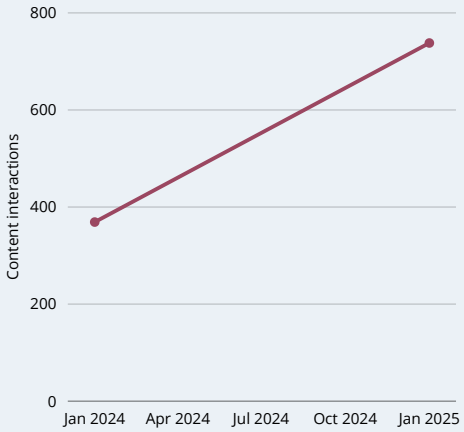


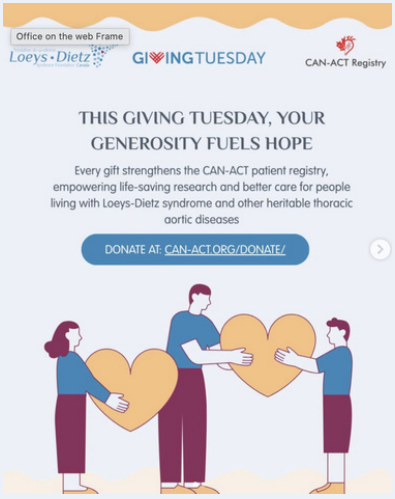
Figure 7: Instagram Content Interactions 2024-2025

6. Social Media and Digital Awareness

a. Instagram and Facebook

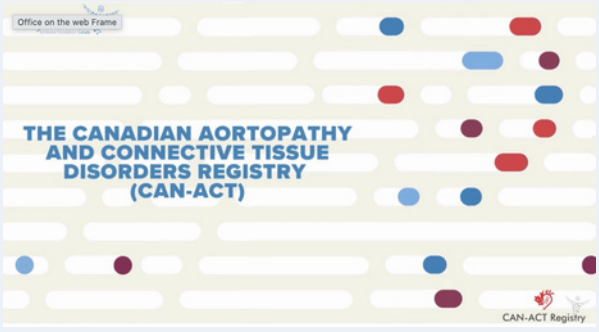
Top posts:

1. "Your Gift Helps Save Lives This #GivingTuesday, your donation directly supports the CAN-ACT patient registry"



- Views: 67,691
- Reach: 39,767
- Interactions: 203
- Likes and interactions: 196
- Link clicks: 29

2. "Hear directly from our CAN-ACT investigators about why this national registry is essential for advancing HTAD and Loeys-Dietz syndrome"



- Views: 24,796
- Reach: 14,439
- Interactions: 13
- Likes and interactions: 11
- Link clicks: 6

6. Social Media and Digital Awareness

b. X

- Views (Impressions): Average ~22 per post
- Engagement Rate ≈ 0–5%
- Followers: 124 (112 in 2024)

Top post:
HAD 2023 Conference Recap (June 25, 2023)
Engagement: 6 likes, 2 reposts, 2 replies, 949 views

Second top post:
HAD 2023 Patient Perspective Thank You (June 24, 2023)
Engagement: 5 likes, 1 reply, 330 views

c. Linkedin

- Follows: 446 (277 in 2024)
- Page views: 605
- Unique visitors: 328
- Impressions: 2,197,007

Top post:
“Hear directly from our CAN-ACT investigators about why this national registry is essential for advancing HTAD and Loeys-Dietz syndrome research in Canada”

- Views: 3,691
- Clicks: 741

6. Social Media and Digital Awareness

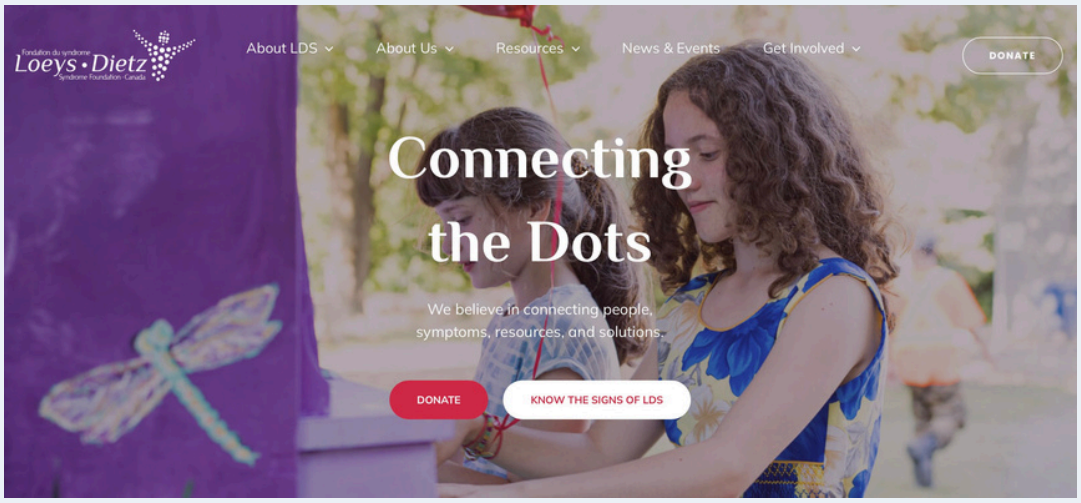
d. Youtube

- Views: 970, 17% more than 2024
- Watch time (hours): 58.2
- Subscribers 129 (116 in 2024)
- Impressions: 20.5k, up 29% from 2024

Top post:
LDSF Canada Donation Program

- Views: 229

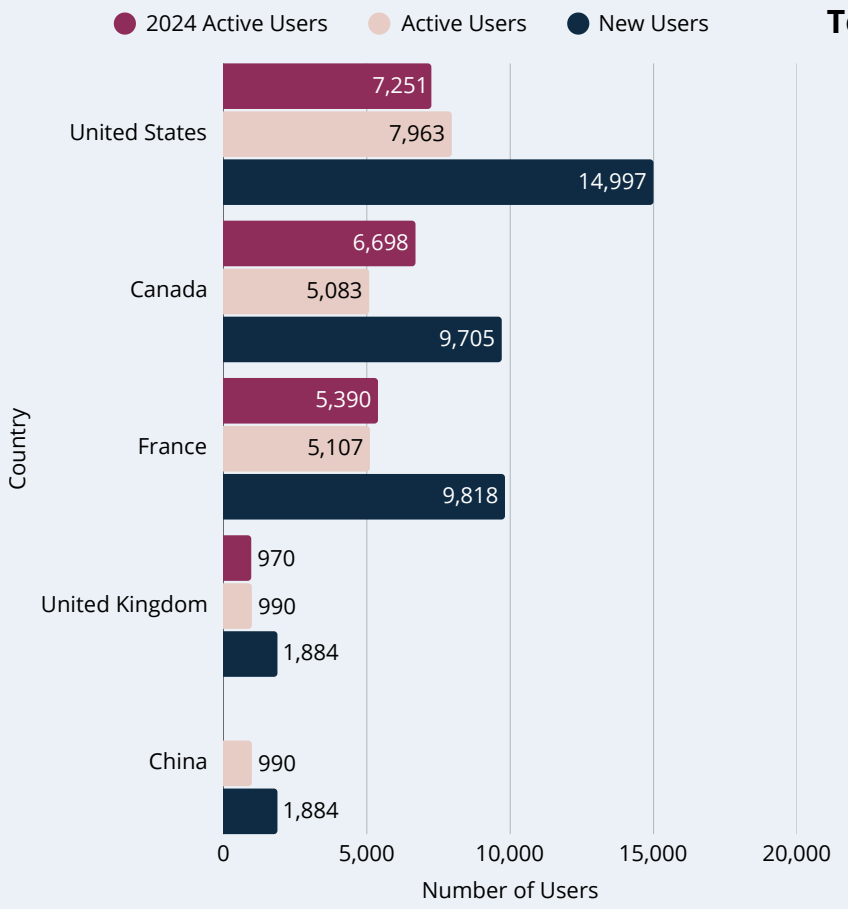
e. Website



- Views: 970, 17% more than 2024
- Watch time (hours): 58.2
- Subscribers 129 (116 in 2024)
- Impressions: 20.5k, up 29% from 2024

6. Social Media and Digital Awareness

e. Website



Top-Visited Pages:

1. What Does Loeys Dietz Syndrome Look Like - An Overview into the Phenotypic Differences across LDS Subtypes
2. About Loeys Dietz Syndrome - Signs and Symptoms
3. FR -Syndrome de Loeys Dietz - Signes et Symptomes
4. FR - Syndrome de Loeys Dietz - Qu'est-ce que le Tissu Conjonctif
5. FR - Syndrome de Loeys Dietz
6. About Loeys Dietz Syndrome Medication

Figure 8: Distribution of website users by country, showing active users, new users, and user counts from 2025
**data for China was not collected in 2024*

6. Social Media and Digital Awareness

f. Newsletter

- Delivery Rate: 98.6% (3,401 successful deliveries)
- Open Rate: 37.6% (1,278 unique opens)
- Click Rate: 10.0% (339 unique clicks)
- Unsubscribe Rate: 0.24% (8 unsubscribes)

Top newsletter:
“October 2024: Participate in Research”

- 341 deliveries, 150 opens
- 44.0% open rate

7. Volunteers

The work of LDSF Canada is made possible through the dedication and expertise of our volunteers. Throughout 2025, volunteers contributed their time and skills to support patient education and research initiatives. Key volunteer contributions included:

- GRIP Project: One high school student volunteer supported the entry and organization of institutional data.
- Workplace Accommodation Booklet: One volunteer contributed to the development of this patient resource.
- Western University Collaboration: Two Master's students conducted a comprehensive review of 20 years of Loeys-Dietz syndrome literature to identify research trends and knowledge gaps.
- Dalhousie University Collaboration: Three medical students initiated two projects focused on (1) mapping the Canadian HTAD landscape, including clinics and research resources, and (2) reviewing the literature on education and social determinants of health in heritable thoracic aortic disease.
- Patient and Community Events: Three volunteers provided support at the London Patient Education Day.
- Educational and Awareness Initiatives: Volunteers also contributed to content development, communications, and awareness activities that expanded the reach of LDSF Canada's programs and resources.

8. Fundraising & Planned Giving Portfolio

This section accompanies our annual financial statements and is intended to provide donors and stakeholders with clear insight into the financial structure and strategy that underpins Loeys-Dietz Syndrome Foundation Canada (LDSF CANADA).

A Pioneering Model in Canadian Philanthropy

At LDSF Canada, we are building more than a foundation, , we are building a future. Our approach to financing is purposefully designed to generate sustained impact over time, rather than depend on unpredictable year-to-year fundraising. In 2018, our co-founder, Joseph Galli, a seasoned entrepreneur and venture strategist, spearheaded an innovative funding strategy that centers around accepting donations of life insurance policies. This makes LDSF Canada the first and only foundation in Canada to build a charitable resource base through a structured portfolio of life insurance assets.

This model ensures that as these policies mature over time, LDSF Canada will be able to fund research, support patient services, and clinician-led initiatives at a scale not otherwise possible through traditional short-term fundraising models.

Model Structure

To manage the complex operations involved in sourcing, triaging, underwriting (medical and financial), maintaining, and tracking our life insurance policy donations, Loeys-Dietz Syndrome Foundation Canada partners with Pentor Charity Services (PCS), an independent service organization founded by our co-founder, Joseph Galli. PCS provides specialized administrative and portfolio management services that are critical to safeguarding the long-term value of these donated assets. In 2025, LDSF Canada accepted 19 new life insurance policies with a combined death benefit value of 20,502,583.00$, bringing our total portfolio to 148 policy donations accounting for 94,784,852.00$.

8. Fundraising & Planned Giving Portfolio

These policies are carefully selected, triaged, and stewarded under a robust process led by PCS. In exchange, LDSF Canada pays PCS fees for these services. These fees ensure that the policies are professionally managed and preserved in accordance with industry standards. To finance the premium payments and PCS servicing costs associated with these policies, Mr. Galli also developed an innovative lending structure through a limited partner fund, which provides LDSF Canada with the capital required to sustain and grow this long-term asset base.

Why You May Not See This Value on Our Financial Statements

Even though LDSF Canada holds policies with more than $94 million in aggregate death benefits, current Canadian accounting standards prohibit us from reporting them as financial assets. This is because insurance policies, while legally owned and controlled by the foundation, lack a fixed duration, which is a requirement for recognition on a balance sheet. As a result, our financial statements do not reflect the true scale of our financial position or the long-term power of our endowment-in-progress.

In addition, life insurance policies are valued at $0 for purposes of calculating the CRA's Disbursement Quota (DQ), which is the minimum amount a charity must spend on its charitable activities each year. This nil valuation is not a flaw, it is a recognition, enshrined in Canadian tax law, that such donations are long-term in nature. Despite this, LDSF Canada has always met its annual DQ requirement.

Key Highlights of 2025:

- We acquired 19 new life insurance donations from donors accounting for 20,502,583.00$ in death benefit value.
- We received proceeds from life insurance policies accounting for 6,844,787$.
- We received cash donations and grants from private foundations accounting for 1,418,641$.

9. Financial Overview

We are committed to financial transparency and accountability. Here is a snapshot of our 2024 financials:

LDSF CANADA Financial Snapshot:

Charitable activities & Contributions to Qualified Donees	$570,095.05
Fundraising	$4,177,271.84
Management and administration	$1,806,285.38
Other expenses (premiums)	$4,400,979.73

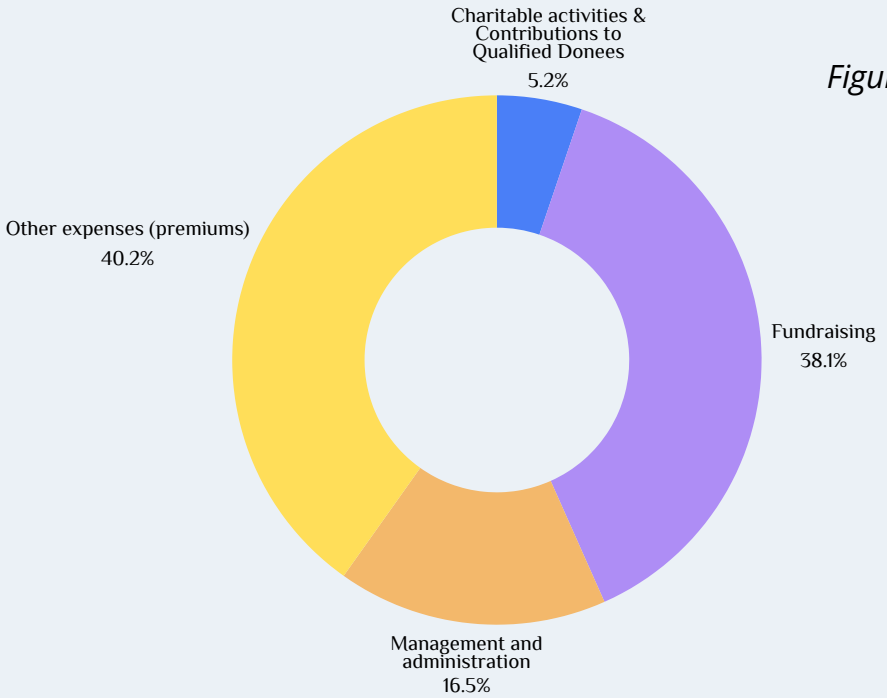


Figure 9: Financial Snapshot

9. Financial Overview

We are committed to financial transparency and accountability. Here is a snapshot of our 2024 financials:

LDSF CANADA Mission Operations:

Patient Support	$97,869.89
Research	$335,420.37
Education and Awareness	$112,853.00
Advocacy	23,951.79

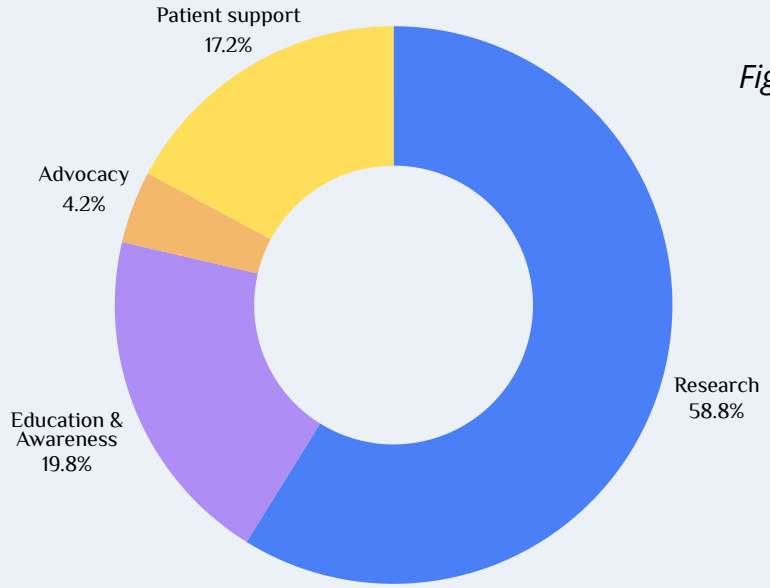


Figure 10: Mission Operations

TOTAL 2025 Financials:
$570,095.05

10. Looking Ahead to 2026

As we look ahead to 2026, we remain guided by a simple principle: patients and families are at the centre of everything we do. Whether advancing research, developing educational resources, advocating for better care, or building new partnerships, our goal is to improve the lives of individuals affected by Loeys-Dietz syndrome and other heritable thoracic aortic diseases (HTADs).

A key priority for 2026 will be to increase patient enrollment in the CANadian Aortopathy and Connective Tissue Disorders (CAN-ACT) Registry, strengthening the national data infrastructure needed to better understand disease progression, clinical outcomes, and variations in care across Canada. Expanding participation in the registry will help ensure that future research reflects the diverse experiences of individuals and families living with HTAD.

We will also continue to support the growing portfolio of consortium-led research projects highlighted throughout this report. These studies address questions that matter most to patients and families, including earlier diagnosis, risk prediction, family screening, quality of life, care pathways, and access to specialized services. By fostering collaboration among patients, clinicians, researchers, trainees, and healthcare organizations, CAN-ACT is creating a sustainable research ecosystem that will generate new knowledge and translate discoveries into meaningful improvements in care.

In 2026, we will expand our patient education efforts through the launch of the AORTA App, a digital platform designed for both clinicians and patients living with heritable thoracic aortic diseases. The app translates evidence-based guidelines into practical tools that support patient education, informed clinical decision-making, and more consistent, patient-centred care. We will also broaden our website and educational resources to better serve the entire HTAD community by including comprehensive information on Marfan syndrome, vascular Ehlers-Danlos syndrome (vEDS), and other related heritable thoracic aortic diseases, ensuring that more individuals and families have access to trusted, evidence-based information.

10. Looking Ahead to 2026

Building community connections will remain a priority. We look forward to hosting the 4th Heritable Aortic Disorders Symposium (HAD4) in Vancouver, featuring both a Scientific Day for clinicians, researchers, and allied health professionals to share the latest advances in HTAD research and clinical care, and a Patient Day dedicated to educating, empowering, and connecting individuals and families living with heritable thoracic aortic diseases. We also look forward to hosting our second Patient Education Day in Montréal, Québec, providing another opportunity for patients and families to learn from experts, connect with peers, and engage directly with healthcare professionals.

To further improve access to supportive care, we will launch a national Supportive Care Clinic Directory to help individuals and families locate physiotherapists, occupational therapists, psychologists, osteopaths, and other allied health professionals with expertise in connective tissue disorders, hypermobility, and HTADs.
Beyond our programs, we will continue to strengthen our leadership within Canada's rare disease community by actively contributing to national working groups, advisory committees, and policy initiatives that advance the diagnosis, care, and treatment of rare diseases. Through the leadership of our Executive Director, Dr. Jida El Hajjar, LDSF Canada will continue to represent the HTAD community on provincial, national, and international committees, helping to shape research priorities, care standards, and health policy.

As our work expands, so does our commitment to ensuring that patient voices remain embedded in every stage of the process—from setting research priorities to designing educational resources and informing policy discussions. Through collaboration, innovation, and a shared commitment to improving care, we are building a stronger future for the Canadian HTAD community.

10. Looking Ahead to 2026

Strategic Priorities for 2026

- ✓ Expand CAN-ACT Registry enrollment across Canada
- ✓ Advance consortium-led research projects
- ✓ Launch the AORTA App for patients & professionals
- ✓ Expand website to include Marfan, vEDS & other HTADs
- ✓ Host HAD4 Symposium in Vancouver
- ✓ Host Patient Education Day in Montreal
- ✓ Launch national Supportive Care Clinic Directory
- ✓ Strengthen patient partnership & engagement
- ✓ Represent HTAD community on advisory committees
- ✓ Translate research into tools & policy recommendations