Fondation du syndrome
Loeys • Dietz
Syndrome Foundation · Canada

2024 LDSF CANADA Impact Report

Connecting Canada, Aorta, and Data

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1. Message from Leadership

2024 has been a defining year for Loeys-Dietz Syndrome Foundation Canada—marked by growth, impact, and profound reflection. Our journey this year has been shaped by renewed collaborations and a shared commitment to using the power of data to transform lives. But before we highlight the milestones, it is important to ask: *Why does Canada need a foundation dedicated to Loeys-Dietz Syndrome (LDS) and Heritable Thoracic Aortic Disorders (HTAD)?*

Why a Loeys-Dietz Foundation in Canada Is Essential?

Loeys-Dietz Syndrome is a rare and complex genetic condition that requires expert, multidisciplinary care—yet for too long, Canadian families have faced fragmented services, inconsistent diagnoses, and limited research support. Our foundation exists to change that.

1. **Access to Specialized Care:** LDS patients often require urgent, personalized care. We connect families with geneticists and cardiovascular specialists to ensure they receive accurate diagnoses and timely interventions.
2. **Support for Families:** The emotional and logistical burden of living with a rare condition can be overwhelming. We offer resources, peer connections, and navigation services to support families through every step of their journey.
3. **Bridging the Research Gap:** Without a central body to coordinate efforts, research on LDS in Canada would remain siloed. We foster collaboration and ensure that discoveries benefit patients directly.
4. **Advocating for Policy Change:** We work to expand access to genetic testing, accelerate early diagnosis, and support national rare disease strategies.
5. **Ensuring Long-Term Impact:** We innovate in our fundraising model, to be able to sustain our long-term core initiatives, including our national patient registry CAN-ACT.

Our Four Currencies

At Loeys-Dietz Canada, our work is driven by more than just financial support—we operate with four powerful currencies that define our impact.

1. **Funding** – We strategically invest in projects and initiatives that advance research, support patients, and improve care pathways.
2. **Catalyst** – We bring people together. By rallying clinicians, researchers, patients, and partners, we ignite collaboration and drive collective action across Canada.
3. **Relevance** – We ensure the patient voice is never an afterthought. Everything we do is informed by real experiences and urgent needs, making our work deeply meaningful and grounded in reality.
4. **Leadership** – We don't just participate—we lead. From launching national registries to developing support programs, we take initiative and set the standard in the rare disease community.

Milestones in 2024

Among our proudest achievements is the launch of the **CANadian Aortopathy and Connective Tissue Disorders (CAN-ACT) Registry**—Canada's first centralized pediatric database for hereditary aortic diseases. CAN-ACT is transforming how we understand LDS and related HTAD conditions by collecting real-world, clinical, and genetic data from children and youth across 17 sites nationwide. It is a vital tool that empowers clinicians, informs health technology assessments, and lays the foundation for evidence-based care.

In parallel, our **Global Research and Insights Platform (GRIP)** has become a comprehensive database of LDS-related scientific literature. By consolidating and indexing thousands of research articles, GRIP bridges the knowledge gap for clinicians, researchers, and patients alike. It will help accelerating discovery and supporting clinical decision-making.

A Year of Hope, and Heartbreak

This year, we also experienced a profound loss. We honour the memory of **Tyler Cohen-Wallace**, a vibrant and courageous young person in our community who lived with Loeys-Dietz Syndrome. Tyler was not only an inspiration to those who knew him, but also a powerful reminder of why our work matters. His legacy reinforces our commitment to build a future where every child with LDS can live a longer, fuller life surrounded by the support they need and deserve.

Looking Ahead

As we reflect on the progress of 2024, we are reminded that **data is not just a tool, it is a catalyst for change.** Through CAN-ACT and GRIP, we are generating the knowledge required to revolutionize care, reduce uncertainty, and empower families.

To all our researchers, healthcare partners, volunteers, donors, and most importantly our patients and their families: thank you. Your trust and involvement are the foundation of everything we do. Together, we are creating a future where those affected by LDS and HTAD have access to the care, resources, and hope they need.

With gratitude and determination,
Jida El Hajjar
Executive Director, Loeys-Dietz Canada

Joseph Galli
Chair, Loeys-Dietz Canada

2. Research & Innovation

a. GRIP: The LDS Knowledge Engine

The Global Research and Insights Platform (GRIP) is an innovative and living repository of all published scientific literature related to Loeys-Dietz Syndrome (LDS). Launched and curated by Loeys-Dietz Canada, GRIP is the only centralized database in the world dedicated exclusively to compiling, organizing, and analyzing LDS-related studies—spanning genetics, clinical manifestations, diagnostics, surgical outcomes, and emerging therapies.

What Is GRIP?

GRIP is a structured, searchable database that includes to date 1364 scientific articles, case reports, and clinical studies on LDS, sourced from peer-reviewed journals globally. Updated regularly through a combination of manual entries and AI tools, GRIP tracks and categorizes research by various attributes. The platform is accessible to clinicians, researchers, and patients, democratizing access to the most current evidence and enabling cross-disciplinary collaboration.

Why It Matters?

Due to the rarity and complexity of Loeys-Dietz Syndrome, research is fragmented and often difficult to locate or synthesize. GRIP aims to address this challenge by:

- Reducing duplication and research silos by aggregating all known knowledge in one place.
- Helping clinicians stay current on evolving best practices for diagnosis, surveillance, and intervention.
- Supporting researchers in identifying gaps in knowledge and designing impactful studies.
- Enabling evidence-based advocacy for improved care standards, funding, and policy change.
- Providing patients and families with access to understandable summaries of the latest science.

GRIP is not only innovative; it is the first and only centralized database in the world exclusively focused on Loeys-Dietz Syndrome (LDS). No other initiative aggregates, curates, and tags LDS-specific literature with this level of precision and accessibility. Since GRIP's inception in 2015, LDSF Canada invested 5200 hours and had 17 volunteers that contributed to developing, populating, and maintaining this repository.

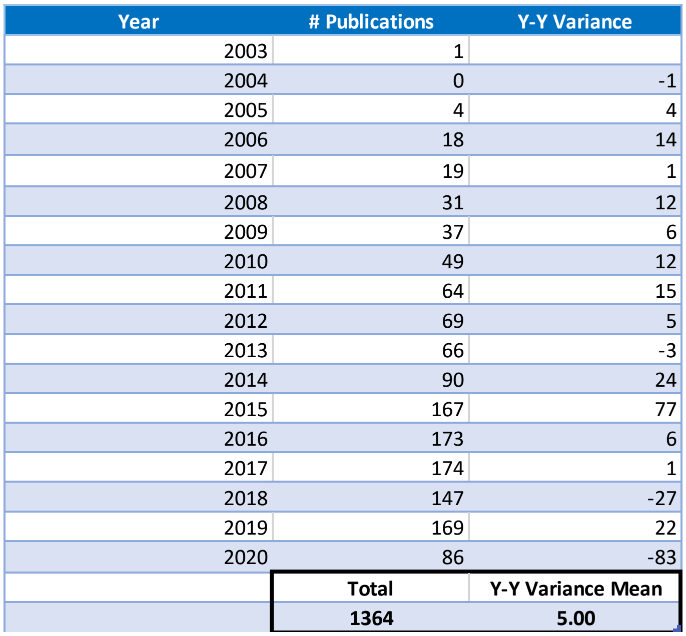
Key Highlights of 2024

- **Human Resources**: In 2024, the project was supported by 0.3 FTE (equivalent of $21,600) and 3 dedicated volunteers.
- **Database Expansion**: GRIP now houses 1,364 peer-reviewed articles. While continuing to cover known LDS-related genes, the database has expanded to include emerging topics such as pain and mental health, reflecting a broader understanding of patient needs.
- **Research Trends**: As expected in academic research, LDS-related publications have steadily increased over time. From 2003 to 2020, the average annual growth was **5 new**

studies per year. A notable dip occurred in 2020, likely reflecting the impact of the COVID-19 pandemic (see Table 1).

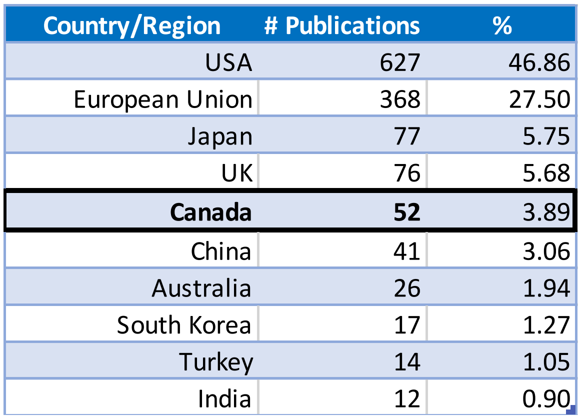
- **Canada's Contribution**: Canadian researchers contributed just **3.89%** of LDS-related publications globally, behind the United States, European Union, United Kingdom, and Japan (see Table 2). For context, Canada's contribution to global cardiovascular disease research is 6%, indicating a stronger presence in other related medical research areas (Nguyen HV et al. 2013*). This disparity highlights a significant underrepresentation in LDS and HTAD research and underscores the critical need for a national foundation dedicated to supporting this field. Tracking this metric over time will be instrumental in assessing the impact of LDSF Canada's efforts to enhance research capacity and influence within the national and international LDS research landscapes.

- **Research Focus Areas**: Preliminary analysis indicates that most studies focus on treatment and disease management. As categorization of the database continues, we aim to gain deeper insights into thematic gaps and future research opportunities (see Table 3).



Year	# Publications	Y-Y Variance
2003	1	
2004	0	-1
2005	4	4
2006	18	14
2007	19	1
2008	31	12
2009	37	6
2010	49	12
2011	64	15
2012	69	5
2013	66	-3
2014	90	24
2015	167	77
2016	173	6
2017	174	1
2018	147	-27
2019	169	22
2020	86	-83
	Total	**Y-Y Variance Mean**
	1364	**5.00**

Table 1: LDS research publications in GRIP per year



Country/Region	# Publications	%
USA	627	46.86
European Union	368	27.50
Japan	77	5.75
UK	76	5.68
Canada	**52**	3.89
China	41	3.06
Australia	26	1.94
South Korea	17	1.27
Turkey	14	1.05
India	12	0.90

Table 2: LDS research publications in GRIP per geography (Top 10)

Research theme	# Publications
Treatment & Care	585
Diagnostics	296
Uncategorized/Other	483

Table 3: LDS research publications in GRIP per theme

** Nguyen HV, de Oliveira C, Wijeysundera HC, Wong WW, Woo G, Grootendorst P, Liu PP, Krahn MD. Canada's contribution to global research in cardiovascular diseases. Can J Cardiol. 2013 Jun;29(6):742-6. doi: 10.1016/j.cjca.2012.09.013. Epub 2012 Dec 6. PMID: 23219608.*

Future directions:

GRIP is more than a repository, it is a catalyst for accelerating discovery, promoting collaboration, and translating knowledge into better outcomes for individuals living with Loeys-Dietz Syndrome (LDS) worldwide. While our preliminary analysis has yielded important insights, we recognize its limitations. Improving the categorization of research themes remains a priority. Currently, two medical students are supporting this effort by refining thematic classifications and expanding the dataset to include articles published between 2021 and 2025. To enhance the utility of GRIP, we are introducing new search filters and tagging capabilities to sort studies by:

- Author and author institution
- Gene of interest
- Research type (e.g., fundamental, translational, clinical, case reports)
- Research theme (e.g., genetics, surgery, cardiology, musculoskeletal, pain, quality of life, exercise, clinical guidelines, and patient-reported outcomes)

These improvements will support more nuanced analyses, help identify gaps in the literature, and strengthen GRIP's role as a global knowledge hub for LDS research. **Notably, the finding that Canadian researchers contribute only 3.89% of global LDS publications underscores a critical gap and highlights why a national foundation dedicated to LDS is essential to advancing research and driving impact in Canada.** We hope that through our efforts, we will increase the research outputs to 6%, in the next decade.

b. CAN-ACT Registry: A Milestone in LDS and HTAD Research in Canada

The **CAN**adian **A**ortopathy and **C**onnective **T**issue 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 determined based on patient recruitment and the data results of the first phase.

CAN-ACT Registry
CANadian **A**ortopathy and **C**onnective
Tissue Disorders Registry
Registre **CAN**adien des **A**ortopathies et
Maladies **C**ongénitales du **T**issu 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

The CAN-ACT Registry is not just important, it is urgently necessary. To date, there is no Canadian dataset that systematically captures the real-world experience of children and youth living with Heritable Thoracic Aortic Disorders (HTAD). A comprehensive literature review through our GRIP database confirms this absence of national data.

Every research advancement starts with data. Without it, we cannot measure needs, identify patterns, or drive systemic improvements. CAN-ACT is filling this void by building the first pediatric registry for HTAD in Canada, uniting 17 research sites and standardizing data collection across the country. Its design, spanning genetic, clinical, quality-of-life, and longitudinal outcomes, is deliberately built to serve as a national evidence backbone for care, research, and policy.

By investing in CAN-ACT first, LDSF Canada is laying the foundation upon which all future breakthroughs will be built. This registry will finally give Canada the ability to generate our own national data, influence international research collaborations, and ensure Canadian patients are no longer invisible in global research.

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.

<u>Consented Participants:</u> 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.

<u>Waiver of Consent Participants:</u> 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 remains unsuccessful.

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
- 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?

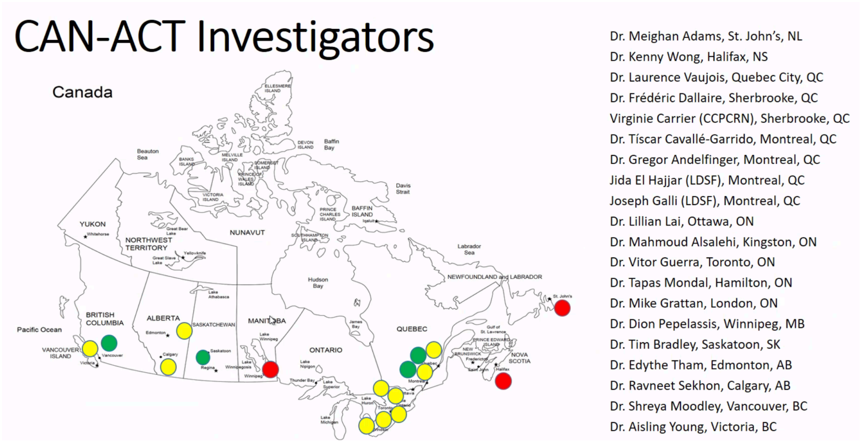
Historically, Canada has lacked a unified resource to track and study rare aortic diseases in children and adults. This has created significant gaps in care, diagnosis, and also research as concluded by our GRIP analysis.

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?

CAN-ACT Investigators and Collaborators

We are honoured to have 17 researchers, 2 patient-partners, and 5 geneticists from coast to coast that are contributing to the registry.



CAN-ACT Investigators

Dr. Meighan Adams, St. John's, NL
Dr. Kenny Wong, Halifax, NS
Dr. Laurence Vaujois, Quebec City, QC
Dr. Frédéric Dallaire, Sherbrooke, QC
Virginie Carrier (CCPCRN), Sherbrooke, QC
Dr. Tíscar Cavallé-Garrido, Montreal, QC
Dr. Gregor Andelfinger, Montreal, QC
Jida El Hajjar (LDSF), Montreal, QC
Joseph Galli (LDSF), Montreal, QC
Dr. Lillian Lai, Ottawa, ON
Dr. Mahmoud Alsalehi, Kingston, ON
Dr. Vitor Guerra, Toronto, ON
Dr. Tapas Mondal, Hamilton, ON
Dr. Mike Grattan, London, ON
Dr. Dion Pepelassis, Winnipeg, MB
Dr. Tim Bradley, Saskatoon, SK
Dr. Edythe Tham, Edmonton, AB
Dr. Ravneet Sekhon, Calgary, AB
Dr. Shreya Moodley, Vancouver, BC
Dr. Aisling Young, Victoria, BC

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

Key Highlights of 2024

- **IN-PERSON National Investigator Meeting:** We held the first IN-PERSON National Investigator Meeting in Montréal on May 31, 2024, bringing together 16 participating investigators and research coordinators in person, 4 virtual participants, and 7 patient-partners for the first dedicated **training session** on the CAN-ACT registry protocol. The agenda was as follows:

Time	Session	Speaker
7:00-8:00 am	**Breakfast & Registration**	
8:00-8:10 am	Welcome and Introductions	CAN-ACT Registry Steering Committee
8:10-8:30 am	CAN-ACT Registry Mission, Goals and Governance	Tiscar Cavallé-Garrido & Tim Bradley
8:30-9:10 am	Scientific Protocol and Patient Questionnaires	Tiscar Cavallé-Garrido & Tim Bradley
9:10-9:40 am	Data Collection and Management	Frédéric Dallaire

9:40-9:50 am	CCPCRN's Role, Budget Management and Resource Allocation	Frédéric Dallaire & Jida El Hajjar
9:50-10:00 am	Role of Loeys-Dietz Syndrome Foundation Canada	Joseph Galli
10:00-10:30 am	General Discussion and Feedback from Investigators	All
10:30-12:30 pm	Consultation and Brainstorming with Patient-Partners	All
12:30-1:30 pm	**Lunch & Networking**	
1:30-1:50 pm	Biobank Planning	Gregor Andelfinger
1:50-2:10 pm	Imaging Bank Planning	Tiscar Cavallé-Garrido & Tim Bradley
2:10-2:30 pm	Automated Syndrome Diagnosis by 3D Facial Imaging	Matthew Adams
2:30-3:00 pm	General Discussion and Feedback from Investigators	All
3:00-3:30 pm	**Coffee Break & Networking**	
3:30-3:50 pm	New Research Proposal #1	All
3:50-4:10 pm	New Research Proposal #2	All
4:10-4:55 pm	General Discussion and Feedback from Investigators	All
4:55-5:00 pm	Closing remarks	
6:00 pm	**Dinner Reception**	

Table 3: Agenda of CAN-ACT investigator meeting

The meeting marked a turning point in cross-site collaboration, including:

- Launch of a co-development process for investigator-led research proposals using CAN-ACT data.
- Dynamic patient engagement session resulting in the formulation of **2 patient-driven research questions** that will be evaluated through CAN-ACT data: 1) identifying clinical red flags at the emergency department and 2) pain management.
- Formation of the **CAN-ACT Consortium**, formalizing a coast-to-coast research network.

LDSF Canada contributed 13,892$ and CIHR contributed a grant of 13,780$ to sponsor the meeting in Montreal.

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

- **Steering Committee Engagement:** We held 12 monthly steering committee meetings to maintain the momentum on CAN-ACT activities.
- **Infrastructure Completion:**
  - Finalized development of the CAN-ACT Registry database platform on REDCap
  - Successfully validated patient symptom questionnaires, exercise assessments, and quality of life instruments

    - E-consent forms were developed, tested, and validated for use across participating institutions

- **Ethics Approvals:** Achieved research ethics board (REB) approvals at 4 of 17 participating sites, with additional submissions in progress.
- **Presence at Vascular 2024 – Vancouver, Canada (October 2024)** Hosted a brief but impactful in-person CAN-ACT check-in during the national Vascular 2024 conference, reinforcing visibility and momentum.
- **LDSF Canada Disbursement:** In 2024, LDSF Canada disbursed 46,000$ to CCPCRN (hosting institution of CAN-ACT at CIUSSS Estrie-CHU de Sherbrooke Hospital-Dr. Frédéric Dallaire account) in direct support of the registry's development and operations.

Future Directions

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

Beyond clinical care, CAN-ACT will also 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

Looking ahead to 2025:

- We will host our next **in-person Investigators Meeting** at **Vascular 2025 in Québec City (October 2025)** to continue strengthening national coordination and patient-partnered research.

- Our new **CAN-ACT website** will be launched to support participant recruitment, data access, and public engagement.

- We anticipate enrolling our **first cohort of 250 patients**, marking a major milestone in national data generation for heritable aortopathies. As of April 2025, data entry has started in 4 sites (Qc and BC).

3. Patient & Family Support

In 2024, Loeys-Dietz Canada continued its commitment to supporting patients and families, offering personalized support through compassion, expertise, and community. Living with LDS can be isolating and overwhelming.

Our support coordinator, trained in peer support, connected individuals with trained volunteers who have lived experience with LDS. These connections were not just informational—they were deeply personal, offering comfort and resilience.

Key Highlights of 2024:

- **Peer Support and mindfulness:** In 2024, we offered 69 patients and families (68 in 2023) emotional support and practical guidance.
  - Reasons for communications:
    - Seeking financial assistance: 1
    - Asking insurance questions: 2
    - Looking for reliable educational materials: 21
    - Looking for a doctor: 29
    - Seeking access to research: 7
    - Seeking medical advice: 8
    - Seeking community support: 7
    - Questioning an emergency situation: 1
    - Looking for volunteer opportunities: 1

- **Resource Directory:** 119 newly added resources in 2024. The biggest growth was in our global organization list with 105 more additions, bringing our total to 641 resources.

Total number of resources	**641 (522 in 2023)**
Medical	170 (169 in 2023)
Paramedical	56 (56 in 2023)
Legal	12 (12 in 2023)
Financial	48 (38 in 2023)
Psychological	121 (120 in 2023)
Genetic Testing	17 (16 in 2023)
Educational & Informational	57 (56 in 2023)
Clinical Trials	4 (4 in 2023)
Global Organizations	156 (51 in 2023)

4. Advocacy & Awareness

Loeys-Dietz Syndrome is rare, but it should not be invisible. In 2024, our advocacy efforts gained ground in the hearts of Canadians.

As Vice-Chair of the Canadian Organization of Rare Disorders, LDSF CANADA's Executive director worked closely with CORD to ensure LDS and related rare disorders were included in national and provincial rare disease strategies. We advocated for establishing networks of clinical and research expertise for rare diseases in Canada.

Key Highlights of 2024:

- **Rare Disease Day (February 29, 2024):** Our Executive Director represented LDSF CANADA at the national Rare Disease Action Day in Ottawa, which marked the launch of the *Canadian Rare Disease Network (CRDN)*—a significant milestone for the rare disease community**.** The work of the CRDN focuses on three interconnected pillars:
    - Diagnostics & Registries Pillar: Accurate, timely diagnostics and robust patient registries to facilitate research and improve understanding of disease mechanisms and natural history.
    - Innovative Therapies Pillar: Pharmacological and non-pharmacological innovations, including holistic approaches – medical devices, therapeutic techniques, and lifestyle interventions for overall well-being.
    - Care, Support & Empowerment Pillar: Children and adults with rare diseases and their families have multi-dimensional needs requiring comprehensive support: medical, mental health, disability, psychological wellbeing, school/education, finances, social and home care needs.

https://canadianrdn.ca/rare-disease-day-marks-the-formal-launch-of-the-canadian-rare-disease-network/**.**

- **Living with LDS Storytelling Campaign:** We shared the powerful journey of Amiel, an LDS community advocate, through a three-part blog and social media series: 1) An Unhealthy Fixation on Cardiovascular Causation; 2) Bags, Tags, and (Mis)Identifying the Green Flags; 3) Trauma Response to A Life-Changing Diagnosis. The stories were shared on our website and social media and gathered 655 views on social media and 217 blog views.

Trauma Response to A Life-Changing Diagnosis

You Have it". After months of waiting for an official diagnosis, my results were given to me through these three life-changing words.

"You Have it". "As expected, based on the results of your genetic testing and CHEO blood sample, you are in fact positive for the SMAD-3 variant of LDS". – Genetic Counsellor

"For some patients, they say "waiting is the hardest part" of receiving a medical diagnosis. But I disagree. Given my personal experience, it's that exact moment of knowing your life will never be the same. That grief you feel for your own body who has to endure countless changes. The initial loss of freedom you encounter as you alter your daily activity. The overall transition of "finding a new normal" in changing your diet, occupation, and lifestyle. It is difficult to put into words just as much as it is difficult to experience."

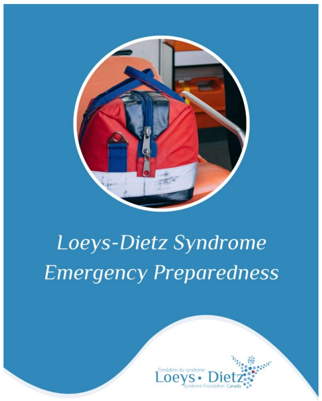
- **Bringing Value-Based Healthcare to LDS Advocacy:** This year, our Executive Director completed the Green Belt Certification in Value-Based Healthcare from The Decision Institute, an internationally recognized leader in VBHC education. This certification equips us with the tools to align healthcare outcomes with what truly matters to patients—improving quality of life while ensuring efficient use of resources. For LDSF Canada, this training strengthens our ability to advocate for care models that are not only evidence-based, but also patient-centered, equitable, and sustainable. Whether informing clinical pathways or shaping research priorities, VBHC principles guide us to deliver better outcomes for every dollar invested.

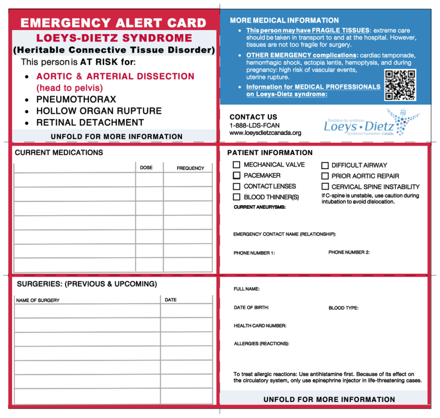
5. Educational Initiatives

At LDSF Canada, we believe that informed patients and families are empowered patients and families. In 2024, we developed timely, relevant, and bilingual resources to help individuals with Loeys-Dietz syndrome (LDS) navigate medical care, understand their condition, and make informed choices about advocacy and treatment.

Key Highlights of 2024:

- **Emergency Preparedness Toolkit**
  An emergency can strike at any moment for individuals with LDS. In December 2024, we released a new, patient-centered educational resource: the *Emergency Preparedness Toolkit*. This included an ER Alert Card and detailed guidance in both English and French. Designed to support quick and effective communication in emergency settings, the booklet was accessed 60 times by year-end and is now a permanent resource in our education library.





EMERGENCY ALERT CARD
LOEYS-DIETZ SYNDROME
(Heritable Connective Tissue Disorder)
This person is **AT RISK for:**
- **AORTIC & ARTERIAL DISSECTION (head to pelvis)**
- PNEUMOTHORAX
- HOLLOW ORGAN RUPTURE
- RETINAL DETACHMENT

UNFOLD FOR MORE INFORMATION

MORE MEDICAL INFORMATION
- **This person may have FRAGILE TISSUES**: extreme care should be taken in transport to and at the hospital. However, tissues are not too fragile for surgery.
- **OTHER EMERGENCY complications:** cardiac tamponade, hemorrhagic shock, ectopia lentis, hemoptysis, and during pregnancy: high risk of vascular events, uterine rupture.
- **Information for MEDICAL PROFESSIONALS on Loeys-Dietz syndrome:**

CONTACT US
1-888-LDS-FCAN
www.loeysdietzcanada.org

CURRENT MEDICATIONS

	DOSE	FREQUENCY

PATIENT INFORMATION
☐ MECHANICAL VALVE
☐ PACEMAKER
☐ CONTACT LENSES
☐ BLOOD THINNER(S)
☐ DIFFICULT AIRWAY
☐ PRIOR AORTIC REPAIR
☐ CERVICAL SPINE INSTABILITY
If C-spine is unstable, use caution during intubation to avoid dislocation.
CURRENT ANEURYSMS:
EMERGENCY CONTACT NAME (RELATIONSHIP):
PHONE NUMBER 1:
PHONE NUMBER 2:

SURGERIES: (PREVIOUS & UPCOMING)

NAME OF SURGERY	DATE

FULL NAME:
DATE OF BIRTH:
BLOOD TYPE:
HEALTH CARD NUMBER:
ALLERGIES (REACTIONS):

To treat allergic reactions: Use antihistamine first. Because of its effect on the circulatory system, only use epinephrine injector in life-threatening cases.

UNFOLD FOR MORE INFORMATION

- **Top-Performing Social Media Post:**
  Our most engaged post of the year celebrated a major shift in public awareness and policy: *"The Aorta is Recognized as an Organ in Its Own Right."*

In the news:

Aorta is recognized as "an **organ** in its own right."

"EACTS/STS Guidelines for Diagnosing and Treating Acute and Chronic Syndromes of the Aortic Organ"

Published by:
The European Association for Cardio-Thoracic Surgery (EACTS) & The Society of Thoracic Surgeons (STS)

Link in bio.

Instagram – Reach: 193 | Likes: 20 | Interactions: 21
Facebook – Reach: 814 | Likes: 17 | Interactions: 11
X (formerly Twitter) – Impressions: 177 | Likes: 3 | Engagements: 8

- **Growing Our Digital Community**
  Instagram: 352 followers (310 in 2023)
  LinkedIn: 277 followers (231 in 2023)
  Facebook: 970 page likes (974 in 2023)
  X: 112 followers (108 in 2023)
  YouTube: 116 subscribers (106 in 2023)

- **Website Impact**

Our website continues to be a trusted hub for evidence-based resources and real-life stories. In 2024:

  - Page Views: 123,647 (75,485 in 2023)
  - Active Users: 26,917 (15,981 in 2023)
  - Avg. Time per Session: 2 min 37 sec (2 min 15 sec in 2023)
  - Avg. Pages per Session: 4.59 (4.72 in 2023)
  - Top Countries:

United states rose from ranking 3rd in 2023, to ranking first in 2024. This is possibly due to our SEO-driven web content and our educational materials.

Country	Active users	New users	2023 (Users by country)
United States	7251	13440	3035
Canada	6698	12667	3848
France	5390	10215	3288
United Kingdom	970	1830	470
Belgium	786	1493	-

  - Top-Visited Pages:

1. Homepage
2. French-language overview of LDS signs and symptoms
3. Phenotypic differences across LDS subtypes
4. English overview of LDS signs and symptoms
5. Connective tissue education in French
6. Living well with LDS
7. Genetics and LDS (English and French sections)

  - Blog Highlights: We expanded our blog to cover emerging issues in genetics, surgery, and mental health, including:

Exploring Frontiers in Genetic Medicine
Unveiling the Mindful Solution: Managing Chronic Pain in Loeys-Dietz Syndrome
An Unhealthy Fixation on Cardiovascular Causation
Bags, Tags, and (Mis)Identifying the Green Flags
Loeys-Dietz Syndrome: Cardiovascular Complications & Preparing for Surgery

- **Newsletter 2024**

Our bilingual newsletters served as a critical tool to share new resources and opportunities. Top-performing themes by click-through rate:

  - Emergency Preparedness & Resources for the LDS Community – 22.6% CTR
  - Treatment Recommendations, Guidelines & School Support – 16.8% CTR
  - Participate in Research! – 14.4% CTR
  - Giving Tuesday Campaign – 9.0% CTR

Theme	Opens (5)	Clicks (%)
Empowering Families: A Comprehensive Guide to Family Planning with LDS (Renforcer les familles: Un guide complet de la planification familiale avec SLD)	60.6%	4.4%
2024 Aortopathy Fellowship Accepting Applications (2024 Bourse clinique et de recherche sur l'aortopathie : les candidatures sont acceptées)	72.4%	2.5%
New Program: a Beacon of Hope for Pain Relief! (Un nouveau programme, une lueur d'espoir pour le soulagement de la douleur !)	60.4%	3.7%
Treatment Recommendations, Guidelines and School Support! (Recommandations de traitement, lignes directrices et soutien scolaire !)	70.4%	16.8%
Participate in Research! (Participez à la recherche !)	62.5%	14.4%

This Giving Tuesday, Join us in Building a Better Tomorrow (En ce Mardi je donne, rejoignez-nous pour construire un avenir meilleur !)	56.8%	9.0%
Emergency Preparedness & Resources for the LDS Community (Préparation aux situations d'urgence et ressources pour la communauté SLD)	73.2%	22.6%

These initiatives reflect our unwavering commitment to turning knowledge into power—so that every person affected by Loeys-Dietz syndrome is better equipped to face today’s challenges and tomorrow’s possibilities.

6. 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.

A Pioneering Model in Canadian Philanthropy

At LDSF Canada, we are building more than a foundation—we are building a sustainable future. Our approach to financing is purposefully designed to generate long-term impact, 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 planned giving model that centers on accepting **donations of life insurance policies**. Importantly, these policies are not from LDS patients, but rather from philanthropic individuals who wish to make a long-lasting charitable impact.

LDSF Canada is the first and only foundation in the country to build a structured, diversified portfolio of life insurance assets to support research, patient services, and clinician-led initiatives at a scale not otherwise possible in rare disease philanthropy.

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 2024, LDSF Canada accepted 33 new life insurance policies with a combined death benefit value of $16,615,000, bringing our total portfolio to 131 policy donations accounting for $77,022,269.00.

Policies with Cash Surrender Value (CSV)

LDSF Canada also began accepting and owning life insurance policies with Cash Surrender Value (CSV). These policies offer tangible, reportable financial value that is now reflected in our audited financial statements. Unlike traditional life insurance gifts that hold long-term unrealized value, policies with CSV can provide short- to medium-term liquidity, which increases our financial flexibility and planning capacity.

Why You May Not See This Value on Our Financial Statements

Despite holding $77 million in future value, current Canadian accounting standards do not allow charities from reporting death benefits as financial assets on the balance sheet. 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.

Navigating our Model with Transparency and Oversight

We are aware that traditional charity rating systems are not equipped to evaluate our model. Their focus on short-term liquidity and spending ratios overlooks long-term strategic approaches like ours. That's why we have taken steps to independently verify our governance model, financial practices, and the fairness of our vendor relationships. Our board is active in overseeing risks and operations, and LDSF Canada retains full control over all strategic decisions, including which policies to accept and how funds will eventually be deployed.

Key Highlights of 2024:

- **33 new life insurance donations** from 31 donors ($16,615,000 in death benefit)
- **Total policy portfolio**: 131 active policies ($77,022,269 in death benefit)

- **CSV of life insurance policies** reflected in financial statements for the first time amounting for $1,380,167 in assets, including $790,558 in cash revenue.

Looking Ahead: Investing in the LDS Community's Future: We are investing in tomorrow knowing full well that today's model may not yet be widely understood. But the logic is sound, the oversight is in place, and the vision is powerful. As our policies mature, LDSF Canada will be positioned to fund ground-breaking research, support early-career scientists, sustain building the CAN-ACT registry and biobank, and create lifelong resources for families affected by Loeys-Dietz syndrome and related aortic conditions. We thank our donors, partners, and community for believing in this long game. We are not only funding today's operations—we are shaping the future of care, science, and support for the LDS community across Canada and beyond.

7.Fundraising-Grants and Donations

While our planned giving model is designed to secure long-term financial sustainability, grants and cash donations remain a vital source of support for our immediate programs and annual operations. These funds enable us to act with agility—to respond to urgent patient needs, invest in new initiatives, and deliver meaningful impact today.

Direct Donations

In 2024, we received 79 individual cash donations, totaling $191,798. These contributions came from patients, families, healthcare providers, board members, and community supporters who believe in our mission and want to see it advance. These unrestricted funds help cover critical needs such as:

- Patient education materials and toolkits
- Research meeting logistics and stakeholder engagement
- Core operational costs that keep the foundation running day-to-day

Every single donation, regardless of amount, played a part in expanding our reach and reinforcing our commitment to serving the LDS community across Canada.

Grant Funding

In addition to individual donations, LDSF Canada secured five grants in 2024, amounting to $23,780.00. These grants supported a range of targeted projects, including:

- The CAN-ACT Registry
- Production and distribution of emergency preparedness materials

We remain deeply grateful to our grant-making partners for their belief in our mission and for enabling us to drive forward data, care, and community-building initiatives.

8. Volunteers

We are proud to benefit from the energy, dedication, and expertise of volunteer medical students and professionals from across Canada. Their contributions have been instrumental in advancing our educational resources and research initiatives.

Key Highlights of 2024:

- Eight university projects were developed in 2024, led by dedicated volunteers from three institutions:

University	# of students	Projects
Dalhousie University (Medical School)	2 (2024-2025 term)	- Craniofacial Manifestations in LDS Booklet - vEDS Emergency Preparedness Booklet

DALHOUSIE UNIVERSITY NOVA SCOTIA CANADA		
University of Ottawa uOttawa	5	- Manifestations of LDS by Body System - Head-To-Toe Review & Update - Cardiovascular Complications & Surgery Blog - Patient Registries Blog Article - Factsheets: MFS, vEDS, Arterial Tortuosity Syndrome, Shprintzen-Goldberg syndrome, Cutis Laxa, ACTA2-associated aortic or arterial disease, FLNA-associated aortic or arterial disease, LOX-associated aortic or arterial disease
University of Toronto UNIVERSITY OF TORONTO	1	Supervised and supported patient recruitment for a research project at SickKids Hospital: “From lived experiences to systemic change: Patient perspectives on the diagnostic journey of Loeys-Dietz syndrome”

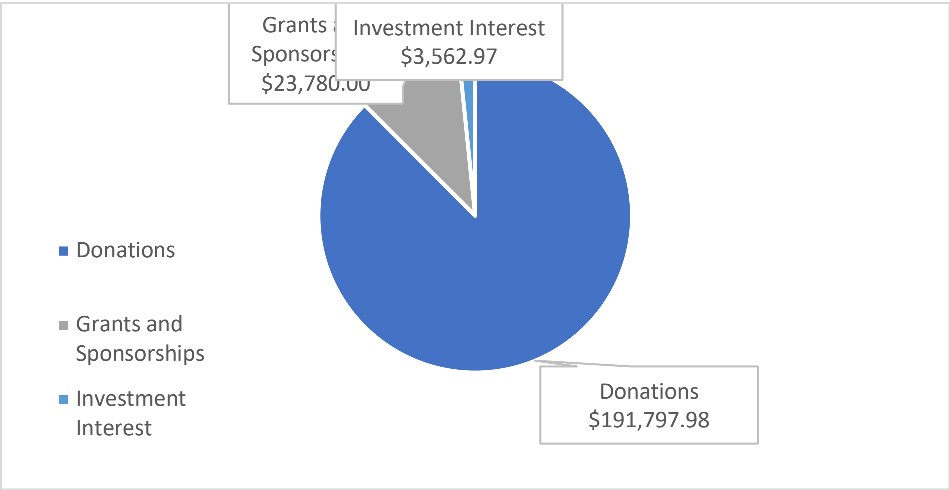
- **Additional Volunteer Contributions:**
  - A **Medication Information** webpage was developed by a volunteer pharmacy assistant, with expert review provided by their supervising pharmacist.
  - **GRIP Support**: One volunteer categorized LDS-related articles, while two others sourced contact information for researchers to expand GRIP’s network.

These volunteer-led efforts not only expand our reach and capacity but also foster the next generation of clinicians, researchers, and advocates committed to transforming care for those affected by Loeys-Dietz syndrome and related conditions.

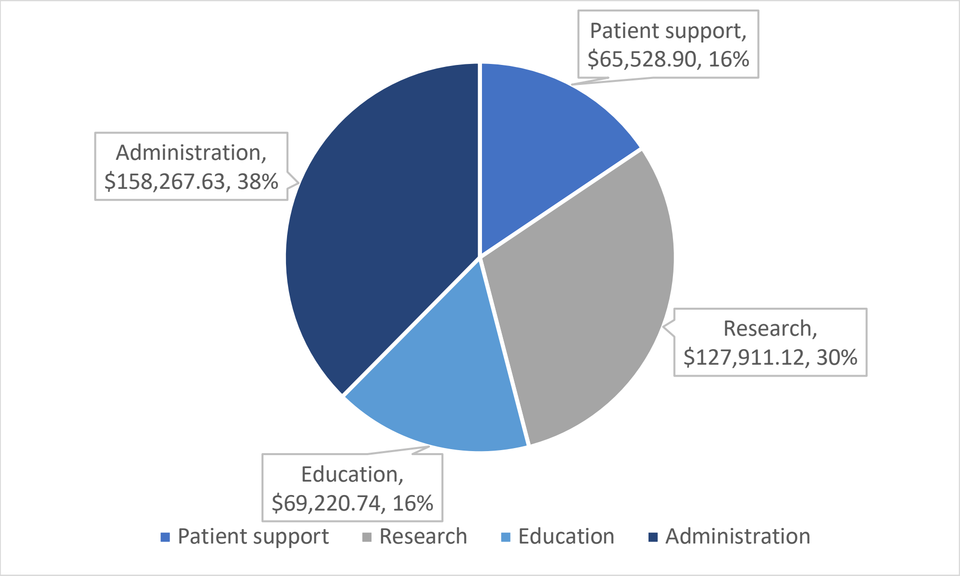
9. Financial Overview

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

LDSF CANADA Mission Operations-Revenues:



LDSF CANADA Mission Operations-Expenses and Program Investments:



10. Looking Ahead to 2025

As we enter 2025, our vision is clearer than ever: to ensure that every person affected by Loeys-Dietz Syndrome in Canada has access to world-class care, cutting-edge research, and a strong, supportive community.

We will expand the CAN-ACT Registry to accelerate discoveries. We will scale GRIP's capabilities to include real-time literature updates and machine learning tools for research synthesis.

We will advocate for systemic changes in how LDS is diagnosed and managed—working with partners to ensure every patient has timely access to testing and treatment. And we will continue to build the case for sustained investment in rare disease care.

We are grateful to each and every one of you who has made this progress possible. The road ahead is long, but we are not walking it alone.

Despite operating with limited financial resources, we are incredibly proud of what we've achieved, proof that bold ideas, strategic thinking, and a united community can drive meaningful change. Our long-term investments in initiatives like the CAN-ACT Registry, and our innovative approach to planned giving, reflect a courageous and forward-thinking commitment to securing a better future for all those affected by LDS and HTAD.

Strategic Priorities:

- Expand CAN-ACT Registry enrollment and data linkages with global partners.

- Deepen GRIP integration with AI-powered analytics.

- Amplify patient awareness to inform national policy and practice.

- Ensure funding sustainability through multi-year grants.

Together, we are rewriting what's possible for people living with Loeys-Dietz Syndrome in Canada and around the world. Thank you for being part of this mission.