



Annual Report 2022

Connecting the Dots on our
Activities and Accomplishments

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1. A Message from our Executive Director and Board Chair

The year 2022 marked an extraordinary chapter for Loeys-Dietz Syndrome Foundation Canada. We accomplished all the objectives we had set for ourselves, driven by the unyielding commitment and encouragement of our dedicated team, patient and research community, as well as our generous donors.

We fostered new strategic alliances with other patient organizations, intensifying our advocacy efforts for rare diseases across Canada. Our active participation in national and international conferences as well as rare disease advocacy meetings raised our leadership status within the realms of Loeys-Dietz Syndrome and rare disease patient organizations. Across the nation, we traveled to heighten awareness about Loeys-Dietz Syndrome, concurrently amplifying our fundraising initiatives. Our inaugural Giving Tuesday campaign “Beating Hearts” achieved unprecedented success.

Our support network for patients expanded significantly with the introduction of a new helpline and the establishment of a comprehensive reference center encompassing over 400 patient resources. More efforts were aimed at creating innovative patient educational materials.

In the year 2022, the gradual relaxation of COVID-19 restrictions served as a reminder that the pandemic had imparted a valuable lesson: the imperative of investing in hybridizing our endeavors. Therefore, we improved our digital footprint; we launched a patient-centered website and initiated Facebook Live series featuring patient stories.

A monumental achievement came in the form of our inaugural LEAP research grant program, resulting in the awarding of four exceptional researchers. Throughout the year, we diligently established our Medical and Scientific Advisory Board alongside our Patient Partnership Committee. Their valuable insights will shape our strategic trajectory, aligning not only with our overarching vision for Loeys-Dietz Syndrome but also our distinctive aspirations within the Canadian context.

This remarkable journey is a collective effort, and we owe it to our extraordinary community. We extend our gratitude for your role in making 2022 an unparalleled year, setting the bar even higher for the promises that 2023 holds.

Jida El Hajjar Joseph Galli

2. Mission and Vision

The Loeys-Dietz Syndrome Foundation Canada (LDSFC) is a national charitable organization committed to advancing research, awareness, education, and support for individuals affected by Loeys-Dietz syndrome (LDS) and related heritable aortic disorders.

Thanks to the remarkable generosity of our donors and the expertise of our esteemed Medical and Scientific Advisory Board and Patient Partnership Committee, the Foundation actively pursues its mission. Our focus revolves around fortifying and empowering the LDS community through the establishment of a robust support network for all those impacted. Additionally, we aim to broaden the horizons of cutting-edge LDS research, pushing the boundaries of knowledge and innovation.

By working altogether, we envision transforming the future of Loeys-Dietz syndrome and related heritable aortic disorders, ultimately saving and enhancing the lives of patients and their families. The collaborative efforts of the Foundation and its valued partners will lead us to a brighter and more promising tomorrow.

3. Team



JIDA EL HAJJAR
Executive Director

KENDALL TILTON
Finance Director

LINDSAY PARSONS
Research and Patient Support
Coordinator

CHARLOTTE BAYLIS
Education and Communication
Coordinator

4. Board of Directors

JOSEPH GALLI

Chair
President, Pentor

DR. NANCY FOURNIER

Director
Senior Project Manager

SALVATORE FRATINO

Secretary
Rosdev

NATALIE COLPRON

Director

YVES GLAUDE

Treasurer
Retired

RICHARD JOLY

Director
Partner, Leaders International

5. Programs and Initiatives

RESEARCH

One of our main pillars to achieve our mission is research. We aim to foster promising research and innovation to hopefully find a cure one day, as well as to promote Canadian LDS research endeavors. Our research investment strategy reverberates with direct impact on the following fronts:

- Increasing overall survival
- Enhancing the quality of life for patients and families
- Understanding the natural history of the disease
- Catalyzing advancements in quality-of-care services

In 2022, our commitment to this pillar was resoundingly evident as we channeled over \$100,000 USD, through the first edition of the LDS Emergence Acceleration Program (LEAP) Impact award. LEAP Impact Award provides investigators with a seed funding grant of \$25,000 USD, leadership development coaching, and access to the Foundation's global network of resources.

"Through the generous support of the LEAP Impact Award from LDSF Canada, our team is able to use innovative imaging methods to understand the impact of exercise on the cardiovascular system of children with Loeys-Dietz syndrome. In addition to working towards the common goal of improving the lives of these children and families, the coaching opportunities provided by LDSF Canada also contribute significantly to my professional development as a graduate student. I express my sincerest gratitude to LDSF Canada for these impactful opportunities."

**Testimonial from Nairy
Khodabakhshian**

5. Programs and Initiatives

RESEARCH

We are pleased to present our four awardees of the first edition of LEAP:

- **Nairy Khodabakhshian's** project, titled "Vascular and Ventricular Responses to Exercise in Pediatric Loeys-Dietz and Marfan Syndrome", will follow up on previous work completed by her team. Nairy, Ph.D. student at the **University of Toronto**, along with her principal investigator's team have shown that observing the heart and vasculature during exercise can reveal abnormalities that were not visible at rest. Now, they will observe the vascular and ventricular properties of pediatric LDS and Marfan syndrome participants at rest and during exercise. This study will provide new insights into how exercise impacts the cardiovascular system of children with Loeys-Dietz and Marfan syndrome.
- **Dr. Pei-Yu Chen and her co-investigator at the University of Yale** are working on a project entitled "Molecular biology of bone malformation in Loeys-Dietz syndrome." This team is using a mouse model to better define the sequence of events that leads to bone problems in Loeys-Dietz syndrome. They are examining cells that are important for making and repairing skeletal tissues. They are looking to answer the question, "Why do these cells fail to produce good quality bone, cartilage and connective tissue?"
- The project of **Dr. Michelle Keir** is titled "Heritable Thoracic Aortic Disorders: Psychological and Socioeconomic Burden of Living with an Invisible Illness. A Pilot Study." Dr. Keir, clinical assistant professor at the **University of Calgary**, will measure the psychological impact, and quantify the socioeconomic status of living with a Heritable Thoracic Aortic Disorder. The goal of this project is to, first, understand the experience of patients living with Heritable Thoracic Aortic Disorders and, second, provide recommendations to both health care teams and policy-makers to better serve this community.
- **Dr. Gauri Karur's** project is titled "Cardiac Magnetic Resonance Imaging Biomarkers of Myocardial Fibrosis in Loeys-Dietz Syndrome and Association with Mitral Valve Abnormalities: A Pilot Study". Dr. Karur, assistant professor at the **University of Toronto**, and her team will use Cardiac Magnetic Resonance Imaging to evaluate heart muscle health in Loeys-Dietz Syndrome patients. Specifically, they will look for the extent of injury in patients with heart valve abnormalities. This work will lay the groundwork for larger studies to be conducted to help early diagnosis, facilitate optimal treatment and identify patients who are at a high risk for heart rhythm disturbances or other complications

5. Programs and Initiatives

RESEARCH

In 2022, we also achieved another important milestone for this pillar, which was establishing our Medical and Scientific Advisory Board . A debt of gratitude is owed to the exceptional generosity of our experts, as LDSF Canada stands unwaveringly as a cherished and respected catalyst in LDS research in Canada. LDSF Canada has assumed a pivotal role in advancing innovative Canadian initiatives and embraced a resolute dedication to projects that resonate with our community. As we forge ahead, our commitment to kindling hope through research remains steadfast.

EDUCATION AND AWARENESS

Organizing and disseminating indispensable information and resources to educate and empower our community is a keystone of our Foundation's mission.

2022 was the banner year where we focused on improving our digital presence. We launched our new website with patient-centric as well as medically-oriented content. We initiated our monthly newsletters which include educational blog articles. Moreover, we developed new patient-oriented materials, specifically a school packet to support patients and families with school onboarding.

We believe that it is not only imperative to understand the disease, but also, it's just as important to share and learn from human experiences. As such, in 2022, we launched our first Facebook live series "Connecting with LDS" to shed light on patient stories. We happily kicked off our first live with our incredible LDS champion Cynthia Hamilton Urquhart who shared her diagnostic journey and her lifestyle changes after the diagnosis. We also held another live session with various experts in mental health to increase awareness on distress and chronic illnesses like LDS.

We are proud of what we have started, mainly our effort to empower people living with LDS and their caregivers throughout all stages of their journey.

5. Programs and Initiatives

PATIENT SUPPORT AND ADVOCACY

We're pleased to share that we made incredible strides during 2022 in expanding this pillar of our mission, and we keep doing so. We launched our patient support helpline 1-888-LDS-FCAN and we have established a reference center that encompasses over 400 resources for patients and families. We assisted 25 patients and families with their diagnosis and helped them find multiple resources.

Another important milestone this year was the creation of the Patient Partnership Committee. The committee's primary goal is to advise the Foundation's team and the board of directors on important matters for patients, caregivers, and families. The Patient Partnership Committee enables LDSF Canada to provide patient-centred activities that acknowledge patient experiences, stories, and knowledge.

Furthermore, in 2022, the Foundation actively contributed to various consultations with provincial and national government roundtables regarding the development of the provincial (Qc) and national Rare Disease Strategy. We are proud to have voiced the concerns of patients living with hereditary aortopathies to policymakers and we are eagerly waiting to perceive the impact of these strategies on the lives of patients, once implemented.

6. Impact Stories

"No way you could do better. Thanks Lindsay!"

"The help I received was fabulous. I didn't feel I needed more."

"I was very impressed with your organization, from the time that I emailed my questions, and after my zoom call with Lindsay, she educated about the different aspects of LDS, felt very comfortable with her, and how quickly she followed up. Extremely positive experience."

From Paul B: "I contacted the Foundation on multiple occasions: for myself and for my family. They have always been supportive, understanding and willing to make the time to listen to my concerns and helped me tackle some of the problems that come with having LDS and supporting a loved one with LDS."

6. Impact Stories

of requests fulfilled: 108

Countries of patients who reached out: Belgium (2), Canada (72), Chile (3), Czech Republic (2), France (10), Iraq (1), Morocco (2), United States (13), Unknown (3)

Reasons for communications: Financial Assistance (5), Looking for education (23), Looking for Professional or Doctor (28), looking for access to research (21), seeking medical advice (18), seeking community connection (9), Questioning if a situation is an emergency (2), Looking for volunteer opportunities (2).

CAMPAGNE
DE DONS

Coeurs battants



DONATION
CAMPAIGN

Beating Hearts

THANK YOU so much for making our 2022 "Beating Hearts" donation campaign a huge success!

*Together, we raised \$12,196 dollars (over 12 times our goal!) for Loeys Dietz syndrome (LDS) support, research, education, and awareness!
Together, we are building a better future for people affected by LDS.*

Every heartbeat counts. Every dollar counts. Thank you.

7. Collaborations and Partnerships

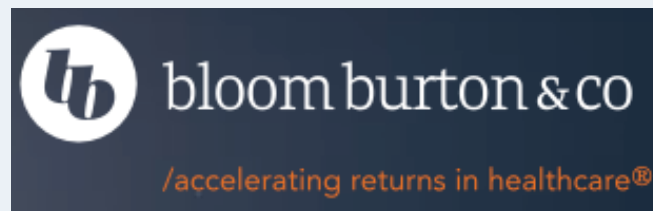
In 2022, we expanded our network of vital partners. LDS Canada proudly collaborates with national and international organizations to advance the cause of rare diseases and genetic aortopathies. Together, we push the boundaries to stimulate a more positive patient-focused ecosystem.

In 2022, our growing network included:

Provincial (QC)



Canadian



International



V A S C E R N



THE **MARFAN**
FOUNDATION



CLARITY
COLLABORATIVE FOR LONGITUDINAL
AORTIC RESEARCH IN THE YOUNG

8. Volunteer and Community Engagement

Our remarkable mobilized community never fails to motivate us. We'd like to thank all of our volunteers for their commitment and passion as well as for choosing to spend their time and talents helping the LDS community. Our resource directory, programs, blog articles, research inventory, website, and fundraising efforts are better off because of you.

A big thank you as well to the medical students at the University of Ottawa who assisted us with the creation of our educational materials.



We are forever grateful for their determination laying the basis for our shared success.

9. Transparency and Accountability

Our board of directors always aim for the highest standards of governance and compliance by ensuring transparency in the operations and financial management of LDSF Canada. We acknowledge the diligent and meticulous work of our external auditors to support us with best practices in accounting and financial reporting.

10. Acknowledgments and Gratitude

On behalf of the Canadian Loeys-Dietz Syndrome community, we are forever overwhelmed by your continued support in making our rare disease matter. For more information on LDS, to sign up for our newsletter, or make a donation: please visit: <https://loeysdietzcanada.org> or contact us at: info@loeysdietzcanada.org
Toll-free: 1-888-LDS-FCAN