Annual Report 2022

Connecting the Dots on our Activities and Accomplishments

Fondation du syndrome Loeys • Dietz Syndrome Foundation · Canada

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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.

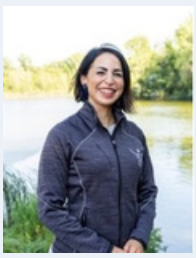
We fostered new strategic alliances with other patient organizations, intensifying our advocacy efforts for rare diseases across Canada. Our active participation in national and international conferences as well as rare disease advocacy meetings raised our leadership status within the realms of Loeys-Dietz 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.

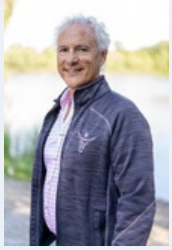
In the year 2022, the gradual relaxation of COVID-19 restrictions served as a reminder that the pandemic had imparted a valuable lesson: the imperative of investing in hybridizing our endeavors. Therefore, we improved our digital footprint; we launched a patient-centered website and initiated Facebook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



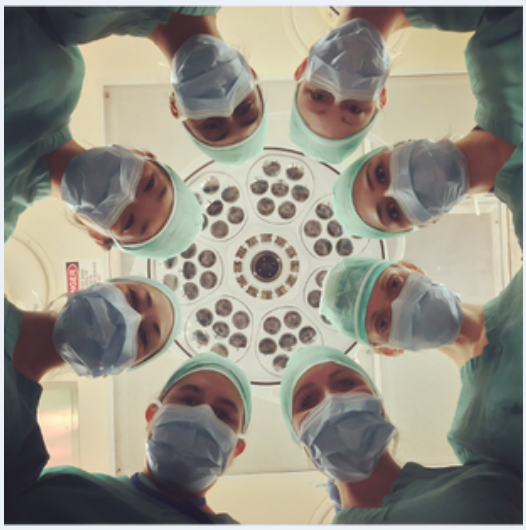
Joseph Galli, Chair

2. Problem Statement

The story of the foundation starts in a way that is all too familiar, with parents looking for answers for their sick children. This story begins in Baltimore at a Loeys-Dietz Syndrome (LDS) conference hosted by John Hopkins University, where two of the three founding parties met. Imagine travelling nearly 12 hours from your hometown, only to find another family going through the same toils as you.

As you would have it, both the Galli and Fratino families met in July 2010 at this LDS conference while looking for answers for their children who had just recently been diagnosed and who had been experiencing severe symptoms. Together, they formed the founding group of the Loeys-Dietz Syndrome Foundation Canada.

The founders agreed that, with no support in the Canadian healthcare system, it was up to them to aid all the Canadian LDS patients (present and future) that would need help in navigating their new diagnosis and disorder. What started as a meeting around a kitchen table in October 2010 launched like a rocket.



By 2011, the Loeys-Dietz Syndrome Foundation Canada (LDSFC) was registered as an official non-profit organization in Canada. Initially collaborating often with its American counterpart, the LDSF Canada has since taken on its own individual path better suited to Canadian ideals.

Loeys-Dietz Syndrome (LDS) is a rare and unconventional disorder that has caused much head-scratching amongst physicians for a long time. Often, it was mistaken for other similar diseases, such as vascular Ehlers Danlos Syndrome (vEDS) or Marfan Syndrome (MFS).

It wasn't until Bart Loeys and Harry "Hal" Dietz pored over strange pediatric cases in 2005 that a new disorder was isolated: Loeys-Dietz Syndrome. It had long caused much confusion because LDS is a connective tissue disorder in the same class as vEDS and MFS and therefore shares many symptoms. However, it is not because the symptoms are similar that they all have the same root cause or lead to the same outcomes. Since the beginning, LDS has demonstrated to be far more severe than vEDS and MFS. LDS also has six different subtypes, as they are caused by mutations in just as many different genes.

2. Problem Statement

The main unifying symptoms of these six subtypes of LDS are significant vascular findings. Most specifically, 2/3 of LDS patients develop an aortic root aneurysm, and nearly all LDS patients have some dilation of their aorta. Therein stems the most serious of the symptoms, as aortic root aneurysms, whether present from birth or have developed over time, have an extremely high likelihood to burst due to the friable nature of the tissues of the arteries. When the aorta, the largest blood vessel in the body, burst or dissects, it causes rapid and extremely deadly internal hemorrhaging in a matter of minutes. When the disorder was coined in 2005, the average lifespan of an LDS patient was only 27 years. With research from a few dedicated LDS champions, longevity and quality of life continue to improve, but further research targeted expressly for LDS patients is challenging to assemble, as many patients remain unknown to us. Therefore, there is an utmost need to establish a registry to collect data from diagnosed patients to inform incidence and prevalence of disease.

In addition to severe vascular findings, patients also often suffer from systemic symptoms. These symptoms can range from loose joints to severe orthopedic issues such as scoliosis and kyphosis. Individuals with LDS also suffer from a multitude of dental, ophthalmological issues, as well as digestive problems. Moreover, we are still learning the natural progression of the disease and there are new symptoms being identified, like cancer incidence, and evaluated via increasing patient reports. Due to the different coverage that symptoms can take from person to person, patients often require individualized care involving a plethora of specialists, which poses a challenge for the patient and their family who regularly have to navigate the health care system alone.

LDS is a genetic disorder that can be either inherited by a parent (25% of the cases) or can develop spontaneously in an individual due to a mutation in genes (75% of the cases). Therefore, patients' families and offspring also have a risk of being affected. When a case of LDS is identified, it is important to test immediate relatives and offspring (if necessary). In fact, LDS is inherited in an autosomal dominant manner, meaning that every offspring of a person with LDS has a 50% chance of having the disorder. Not only does this pose a problem for family planning, but it also means that affected parents struggle to be caregivers for their children, especially if the child itself is concerned.

2. Problem Statement

LDS is a disorder that has long puzzled physicians. Before the foundation's inception in 2010, hundreds of individuals had already been diagnosed in the United States since John Hopkins Hospital was the hub of cardiovascular research, but Canada only boasted 30 such individuals. Instead of providing long-awaited answers, receiving an LDS diagnosis seemed to plunge families into a world of unknowns, and things seemed even bleaker. Not only were resources in Canada virtually non-existent for patients with LDS, but many of the existing Canadian patients were resigned to flying to Baltimore every year to hear more about LDS. As a result, it has always been in the foundation's best interest to provide help and support to patients with LDS and their families. Initially, this was on a small scale, where the foundation was only a few steps ahead of the families they were supporting. However, in the ten years since its inception, LDSFC has grown due to committed volunteers and a competent team.

3. 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.

We aim to attain our mission through these 5 strategic pillars:

4. Team

JIDA EL HAJJAR
Executive Director

KENDALL TILTON
Finance Director

LINDSAY PARSONS
Research and Patient Support Coordinator

CHARLOTTE BAYLIS
Education and Communication Coordinator

5. Board of Directors

JOSEPH GALLI
Chair
President, Pentor

DR. NANCY FOURNIER
Director
Senior Project Manager

SALVATORE FRATINO
Secretary
Rosdev

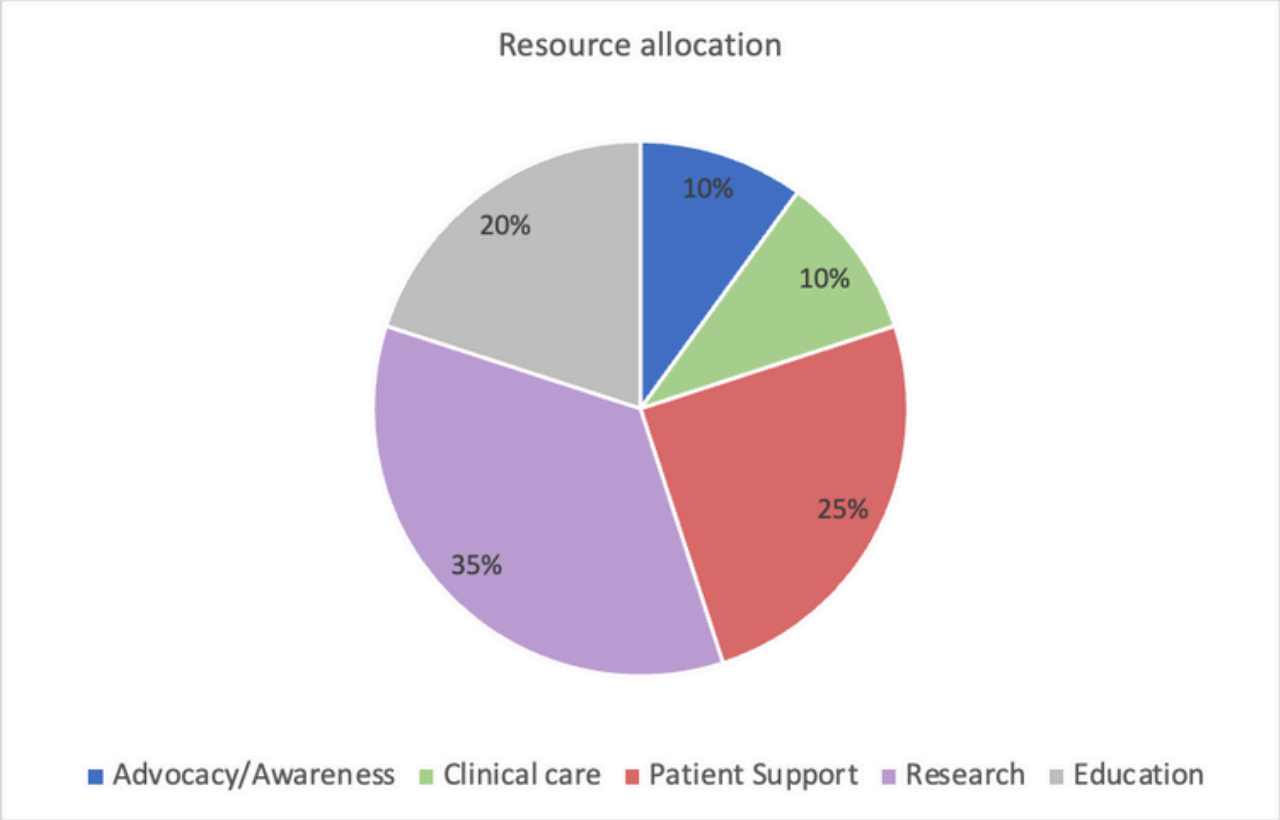
NATALIE COLPRON
Director

YVES GLAUDE
Treasurer
Retired

RICHARD JOLY
Director
Partner, Leaders International

6. Programs and Activities:

We are very excited to present our programs and activities for this year. Our largest focus was tailored towards research and patient support.



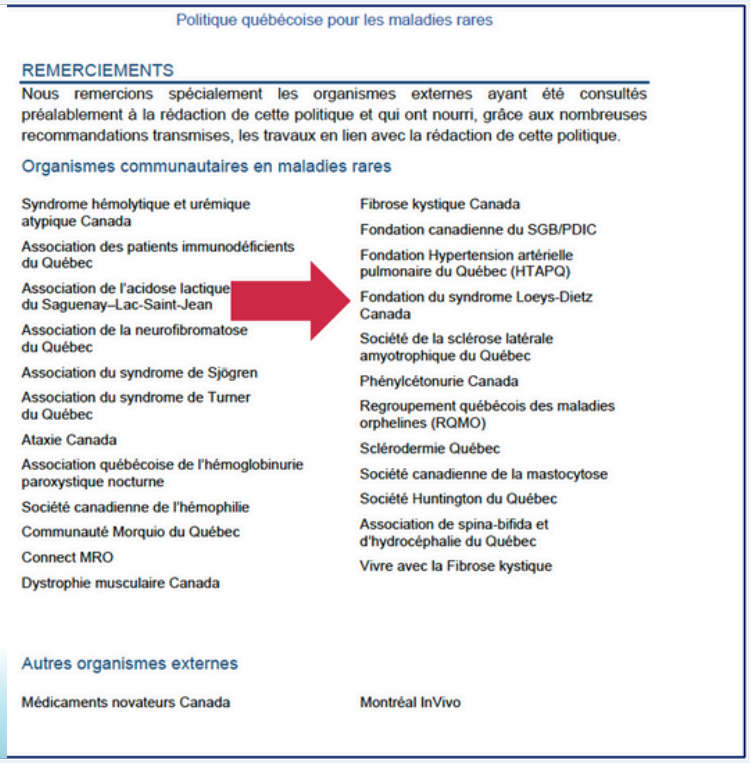
AWARENESS AND ADVOCACY

Awareness & Advocacy

In 2022, the Foundation actively contributed to four 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. Programs and Activities:

Awareness & Advocacy



Politique québécoise pour les maladies rares

REMERCIEMENTS

Nous remercions spécialement les organismes externes ayant été consultés préalablement à la rédaction de cette politique et qui ont nourri, grâce aux nombreuses recommandations transmises, les travaux en lien avec la rédaction de cette politique.

Organismes communautaires en maladies rares

- Syndrome hémolytique et urémique atypique Canada
- Association des patients immunodéficients du Québec
- Association de l'acidose lactique du Saguenay–Lac-Saint-Jean
- Association de la neurofibromatose du Québec
- Association du syndrome de Sjögren
- Association du syndrome de Turner du Québec
- Ataxie Canada
- Association québécoise de l'hémoglobinurie paroxystique nocturne
- Société canadienne de l'hémophilie
- Communauté Morquio du Québec
- Connect MRO
- Dystrophie musculaire Canada
- Fibrose kystique Canada
- Fondation canadienne du SGB/PDIC
- Fondation Hypertension artérielle pulmonaire du Québec (HTAPQ)
- Fondation du syndrome Loeys-Dietz Canada
- Société de la sclérose latérale amyotrophique du Québec
- Phénylcétonurie Canada
- Regroupement québécois des maladies orphelines (RQMO)
- Sclérodermie Québec
- Société canadienne de la mastocytose
- Société Huntington du Québec
- Association de spina-bifida et d'hydrocéphalie du Québec
- Vivre avec la Fibrose kystique

Autres organismes externes

- Médicaments novateurs Canada
- Montréal InVivo

As a parent of a child with Loeys-Dietz syndrome type 2 you never know what the next day is going to bring.
From the time I was five months pregnant I was told that Logan would not survive once he was born because they could not tell me what was wrong with him.

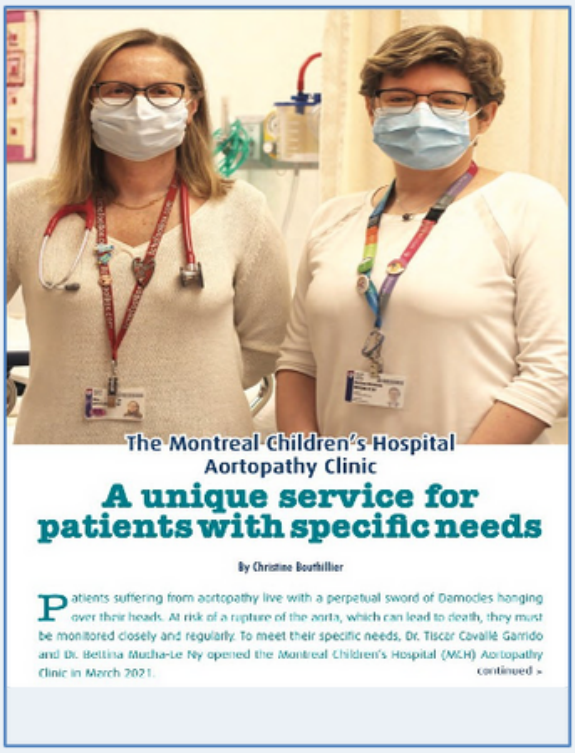
Logan's Loeys-Dietz Syndrome Diagnosis
Finally in October 2018 we were told that Logan had Loeys-Dietz syndrome type 2 and I did not know how to react especially since I had no idea what it was. How was I going to explain this to Logan and his older brother Ryan and younger sister Kaylee as well as everyone else? After the research and meeting with his doctors I realized early on that the syndrome is one that you must stay on top of and make sure that the medications are given and the testing is done and you always follow up with your doctors.

6. Programs and Activities:

Clinical Care

CLINICAL CARE

We collaborated with Dr. Tiscar Cavalle-Garrido at the Montreal Children's Hospital to support the establishment of the Aortopathy Clinic at her hospital. Our contribution was to provide resources via two summer interns that had to do a thorough data analysis, in order to demonstrate the unmet needs of these patients and the case support of establishing this clinic. "Given the rarity of these disorders, the variability of symptoms and the current "silo" model of healthcare provision, patients endure multiple investigations by different specialists over long periods of time before a correct diagnosis is made," says Dr. Cavallé Garrido, a pediatric cardiologist at the MCH.



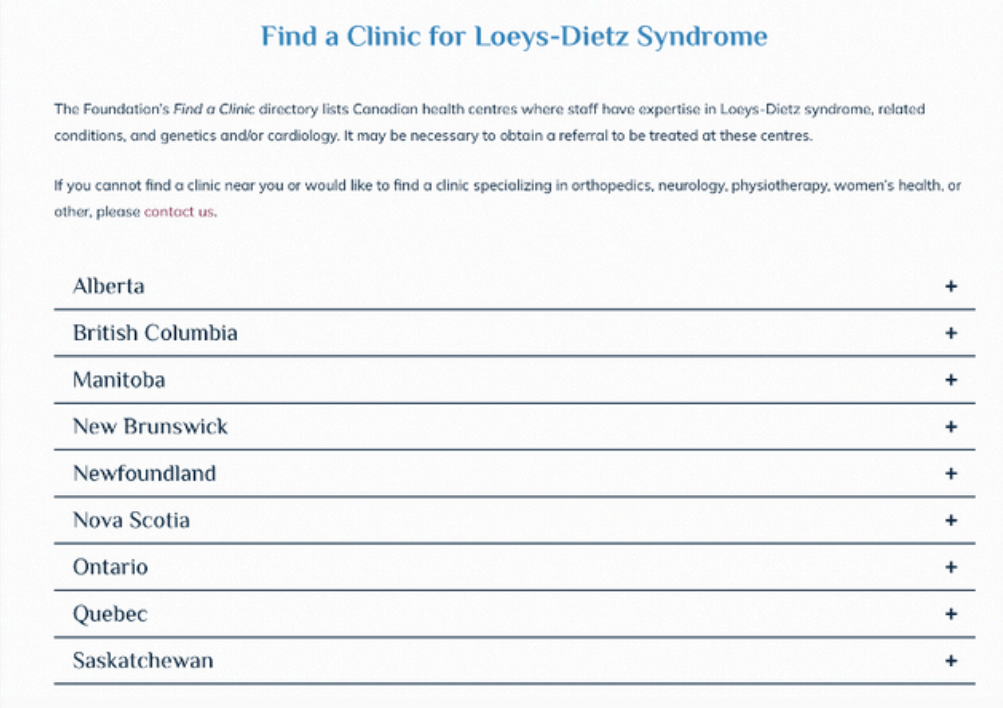
The Montreal Children's Hospital Aortopathy Clinic

A unique service for patients with specific needs

By Christine Bouthillier

Patients suffering from aortopathy live with a perpetual sword of Damocles hanging over their heads. At risk of a rupture of the aorta, which can lead to death, they must be monitored closely and regularly. To meet their specific needs, Dr. Tiscar Cavallé Garrido and Dr. Bettina Mucha-Le Ny opened the Montreal Children's Hospital (MCH) Aortopathy Clinic in March 2021. continued »

This clinic is held four times a year, and about a dozen patients are seen each time.



Find a Clinic for Loeys-Dietz Syndrome

The Foundation's *Find a Clinic* directory lists Canadian health centres where staff have expertise in Loeys-Dietz syndrome, related conditions, and genetics and/or cardiology. It may be necessary to obtain a referral to be treated at these centres.

If you cannot find a clinic near you or would like to find a clinic specializing in orthopedics, neurology, physiotherapy, women's health, or other, please contact us.

- Alberta +
- British Columbia +
- Manitoba +
- New Brunswick +
- Newfoundland +
- Nova Scotia +
- Ontario +
- Quebec +
- Saskatchewan +

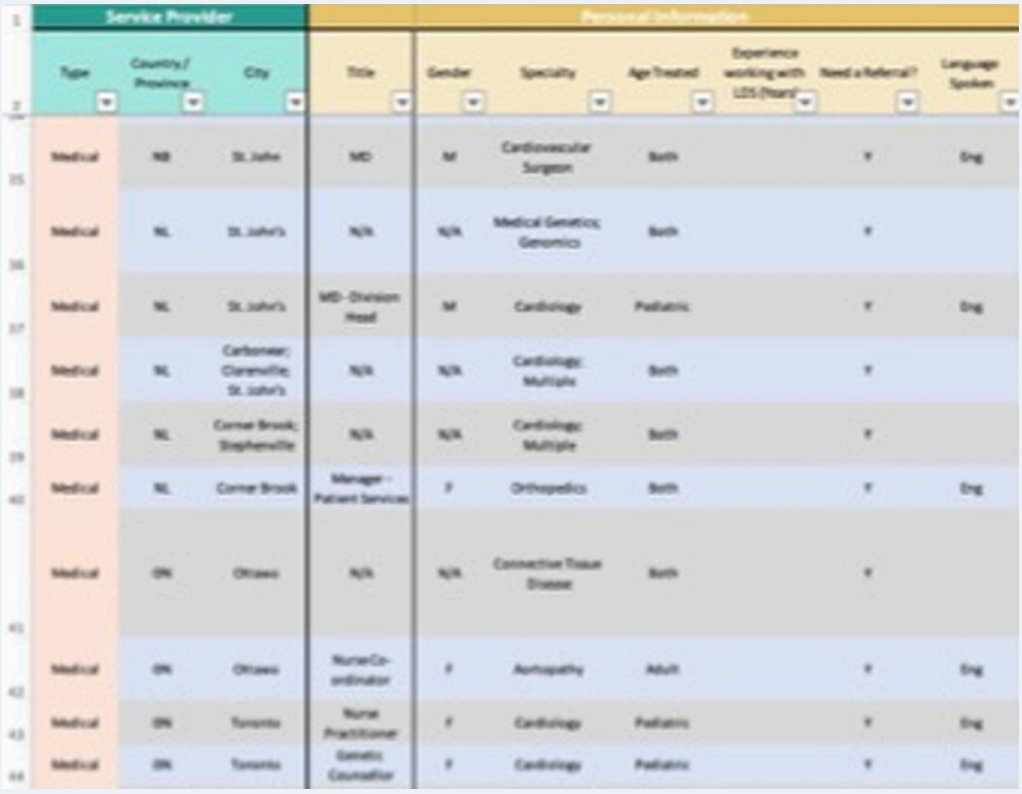
We also developed a consolidated tool on our website that includes all the LDS clinics in Canada to assist patients and families to find the experts in their provinces.

6. Programs and Activities:

Patient Support

PATIENT SUPPORT

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 420 resources for patients and families.



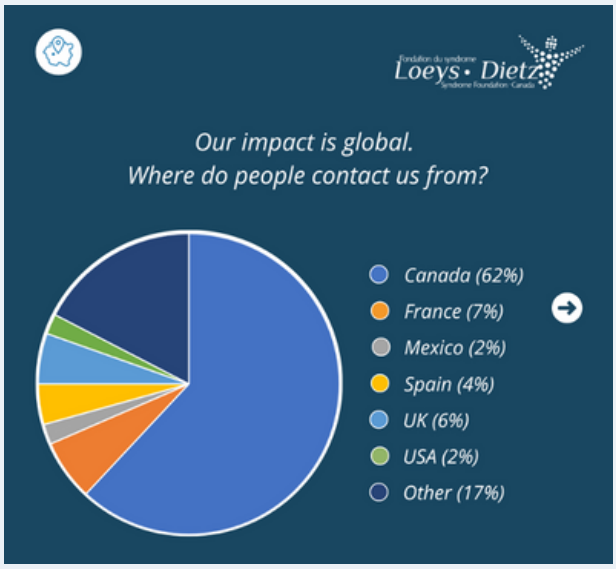
Service Provider			Personal Information					
Type	Country / Province	City	Title	Gender	Specialty	Age Treated	Experience working with LDS (Years)	Need a Referral?	Language Spoken
Medical	NB	St. John	MD	M	Cardiovascular Surgeon	Both		Y	Eng
Medical	NL	St. John's	N/A	N/A	Medical Genetics; Genomics	Both		Y	
Medical	NL	St. John's	MD - Division Head	M	Cardiology	Pediatric		Y	Eng
Medical	NL	Carbonear; Clarenville; St. John's	N/A	N/A	Cardiology; Multiple	Both		Y	
Medical	NL	Corner Brook; Stephenville	N/A	N/A	Cardiology; Multiple	Both		Y	
Medical	NL	Corner Brook	Manager - Patient Services	F	Orthopedics	Both		Y	Eng
Medical	ON	Ottawa	N/A	N/A	Connective Tissue Disease	Both		Y	
Medical	ON	Ottawa	Nurse Co-ordinator	F	Aortopathy	Adult		Y	Eng
Medical	ON	Toronto	Nurse Practitioner	F	Cardiology	Pediatric		Y	Eng
Medical	ON	Toronto	Genetic Counsellor	F	Cardiology	Pediatric		Y	Eng

We assisted 25 patients and families with their diagnosis and helped them find multiple resources.

6. Programs and Activities:

Patient Support

# of requests fulfilled: 108
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).



"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."

-A patient with LDS

Another important milestone this year was the creation of the Patient Partnership Committee (PPC).
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.

6. Programs and Activities:

Patient Support

A qualitative study was conducted with the members of the PPC to gain more insights on the lived experience of patients and families with LDS:

Brainstorm
Positive experiences and challenges during:

Diagnosis	Post-Diagnosis	Treatment	Everyday Life

↓

Prioritize Challenges with Polls

↓

Solutions

As a Foundation, what do you believe we could have done to make things better?

Through this study, we determined the challenges faced by the patients and families that were rated as the highest priority:

Lack of knowledge/LDS expertise in Healthcare Professionals
Lack of resources to manage the emotional impact of living with LDS (no support for specific age groups, diagnosis, or loved ones/caregivers)
Lack of information/resources about managing risk as an LDS patient (i.e. continuing or stopping activities & hobbies)
Health is the responsibility of the patient (Healthcare professional errors)

Our next step in the future is to develop tailored solutions and programs for the patients and families in order to respond/assist to mitigate these unmet needs.

6. Programs and Activities:

Research

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.

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.

6. Programs and Activities:

Research

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.

"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

6. Programs and Activities:

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.

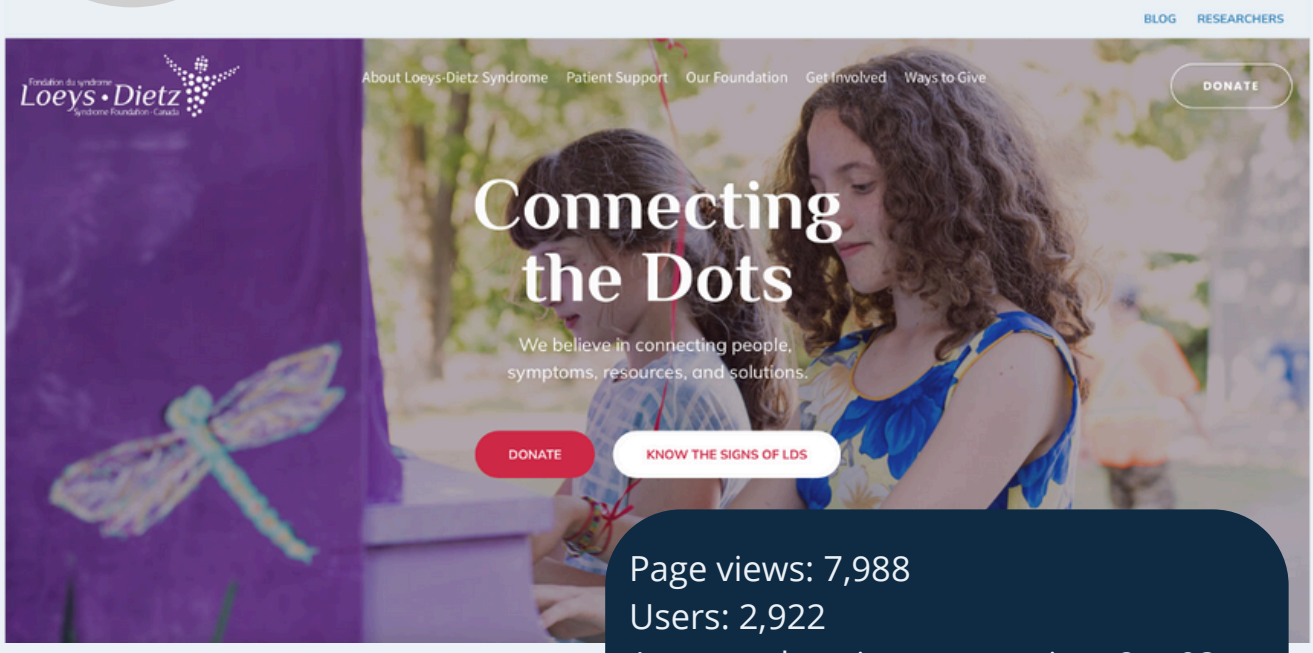
EDUCATION

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

Education

2022 was the banner year where we focused on improving our digital presence.

We launched our new bilingual website with 24 new pages of patient-centric as well as medically-oriented content.



Page views: 7,988
Users: 2,922
Average duration per session: 2m 03s
Average pages per session: 2.17

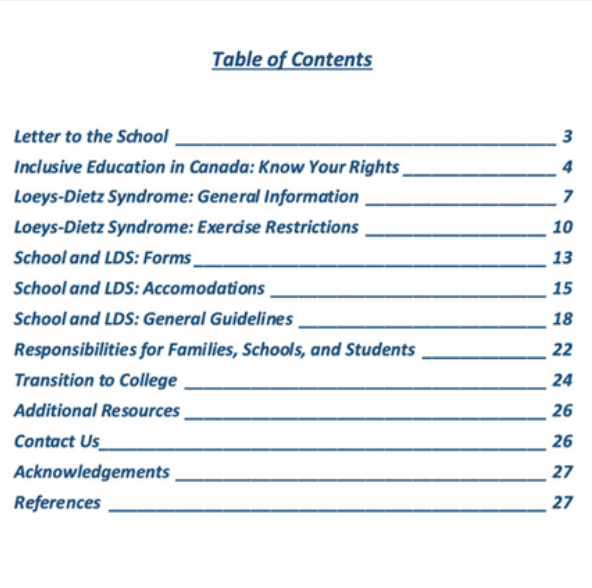
6. Programs and Activities:

Education

The pages that have the highest number of visits are mainly related to our educational blogs, medical information related to LDS and the impact of LDSF Canada:

	Page	Pageviews	% Pageviews
1.	/	1,669	20.89%
2.	/fr/informations-médicales/loeys-dietz-syndrome	285	3.57%
3.	/our-foundation/our-impact/	219	2.74%
4.	/about-loeys-dietz-syndrome/signs-and-symptoms/	209	2.62%
5.	/content/did-you-know	207	2.59%
6.	/blog/	167	2.09%
7.	/fr/notre-fondation/notre-impact/	165	2.07%
8.	/medical-information/differential-diagnosis	160	2.00%
9.	/giving-tuesday/	153	1.92%
10.	/fr/mardi-je-donne/	139	1.74%

We also initiated our monthly newsletters which include educational blog articles sent to 3,784 subscribers. Moreover, we developed new patient-oriented materials, specifically a school packet to support patients and families with school onboarding.



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The announcement of this booklet as well as the announcement of the LEAP awardees were the most read newsletters in 2022.

6. Programs and Activities:

Education

2022 Newsletter Themes	Opens (%)	Clicks (%)
LEAP Impact Award	28.9	3.1
Chronic Pain	27	1.4
Connective Tissue in the News	25.8	1.6
Caregivers	24	0.8
LDS Helpline	25.6	0.9
LDS Awareness Month	24.9	1.2
Travelling with LDS	30.3	1.5
School and LDS	36.5	8.5
Pediatric to Adult Care	31.7	1.3
LEAP Impact Award Recipients	39.6	11.6
IBD	28.1	0.9
2022 Highlights	28.7	0.9

6. Programs and Activities:

Education

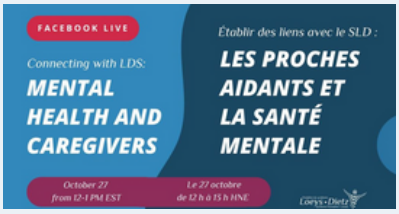
We believe that it is not only imperative to understand the disease, but also, it's just as important to share and learn from human experiences. As such, in 2022, we launched our first Facebook live series "Connecting with LDS" to shed light on patient stories. We happily kicked off our first live with 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.

Cynthia's Story (May)

Minutes Viewed: 111
Engagements: 24
Views: 58
Likes/Reactions: 9

Mental Health and Caregivers (October)

Minutes Viewed: 629
Engagements: 39
Views: 116
Likes/Reactions: 9



LDS and Family: Cynthia and Steve's Story (November)

Minutes Viewed: 297
Engagements: 16
Views: 116
Likes/Reactions: 6

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.

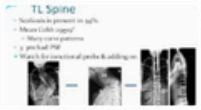
191 followers
931 page likes
150 followers
92 subscribers
76 followers

Our digital community is growing!

6. Programs and Activities:

Education

Most viewed videos on YouTube!

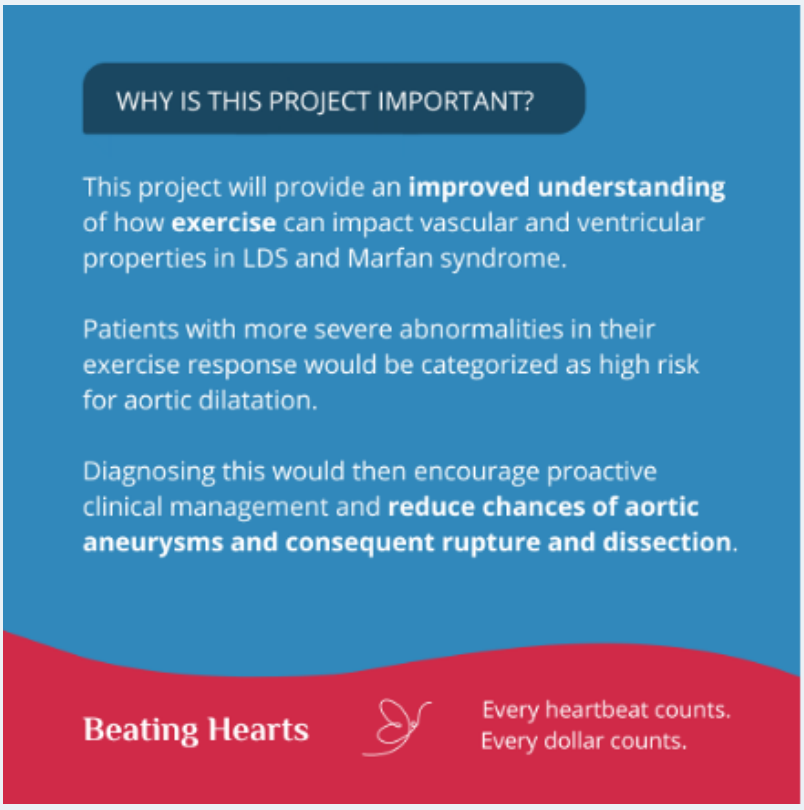
	Content		Average view duration	Views
1		2022 Recipients of the First LEAP Impact Award Oct 13, 2022	1:38 (36.5%)	59
2		Loeys Dietz Syndrome & Shriners Apr 9, 2015	5:33 (6.3%)	31
3		Gastroenterology and Nutrition issues in Loeys-Dietz syndrom... Feb 25, 2015	6:10 (26.3%)	19
4		Connecting with LDS | Mental Health and Caregivers Oct 31, 2022	4:50 (8.2%)	16
5		Craniofacial features, issues, and surgery in LDS, Dr. Christoph... Feb 25, 2015	5:06 (47.4%)	16

7. Campaigns:

This year, we launched our first even Tuesday Giving campaign entitled “Beating Hearts”. Through this campaign, we were able to raise 9,000$ CAD from recurrent and new donors.

7. Campaigns:


LEAP IMPACT AWARD RECIPIENT
Nairy Khodabakhshian
Responses to Exercise in Children with Loeys-Dietz and Marfan Syndrome
Beating Hearts
Every heartbeat counts.
Every dollar counts.


WHY IS THIS PROJECT IMPORTANT?
This project will provide an improved understanding of how exercise can impact vascular and ventricular properties in LDS and Marfan syndrome.
Patients with more severe abnormalities in their exercise response would be categorized as high risk for aortic dilatation.
Diagnosing this would then encourage proactive clinical management and reduce chances of aortic aneurysms and consequent rupture and dissection.
Beating Hearts
Every heartbeat counts.
Every dollar counts.

8. 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)

MONTRÉAL INVIVO 15 ANS

RQMO
REGROUPEMENT QUÉBÉCOIS DES MALADIES ORPHELINES

Canadian

Canadian Digestive Health Foundation

bloom burton & co
/accelerating returns in healthcare®

CORD Canadian Organization for Rare Disorders

Caregivers Alberta | CARING FOR CAREGIVERS

International

European Reference Network
VASCERN

THE MARFAN FOUNDATION

CLARITY
COLLABORATIVE FOR LONGITUDINAL AORTIC RESEARCH IN THE YOUNG

9. 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.

10. 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.

11. Future Directions:

In reflecting on the remarkable journey of 2022, we are immensely proud of the numerous firsts and unique achievements we accomplished together. These success stories are a testament to the collective dedication and passion of our extraordinary community. We extend our heartfelt gratitude for your invaluable contributions, which made 2022 an unparalleled year and set the bar even higher for the promises that lie ahead in 2023.

As we chart our course for the future, we are committed to embarking on new initiatives and research endeavors that address the unmet needs voiced by patients, families, and experts alike. One such endeavor involves delving into the landscape (incidence, prevalence and more) of LDS in Canada and comprehending its profound impact on families. We are thrilled to announce the upcoming launch of the CAN-ACT registry in 2023, which will serve as a pivotal tool in advancing our understanding and response to LDS.

Additionally, recognizing the critical importance of support for patients navigating their healthcare journeys, we are excited to introduce a peer-to-peer support program designed to provide invaluable assistance to individuals living with LDS. This initiative underscores our unwavering commitment to holistic care and underscores our dedication to enhancing the well-being of those we serve.

As we eagerly anticipate the opportunities and challenges that 2023 will bring, we remain steadfast in our mission to foster innovation, compassion, and excellence in all that we do. Together, we will continue to push the boundaries of possibility and make a meaningful difference in the lives of individuals and families affected by illness.

12. 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