LUPUS
CANADA
Life Without Lupus™

LUPUS CANADA
2025 Impact Report

Providing Hope
Raising **Awareness**
Inspiring **Change**

Working Together to Conquer Lupus

www.lupuscanada.org | 1-800-661-1468
Charitable Registration # 11902 5872 RR0001

Leadership Message

> This year, we continued our work with one guiding belief: **our impact must reflect the real needs of lupus patients and caregivers.**

“Lupus remains misunderstood, underfunded, and often invisible. Canadians living with lupus experience significant and persistent challenges navigating healthcare, accessing treatments, managing daily symptoms, and finding peer support.

Our work this year reflects not only where we have been, but also where we are going, toward achieving equitable access to care, fostering a stronger public understanding of lupus, and a future free from this disease.

We are deeply committed to raising awareness of lupus and ensuring that individuals living with the condition have equitable access to care and treatment.”

Leanne Mielczarek
Chief Executive Officer
Lupus Canada

Mission

Lupus Canada is a national voluntary organization dedicated to improving the lives of people affected by lupus through research, public awareness, advocacy and education.

Vision

Life without lupus.

Critical Barriers Faced by Individuals Living With Lupus

Lupus patients in Canada continue to face systemic challenges that directly impact their quality of life, such as:

Major gaps in lupus-specific research funding lead to delayed innovation and limited understanding of patient-reported outcomes, especially fatigue and quality of life.

Due to inconsistent access to care across provinces, patients face barriers when relocating or seeking specialized care.

Limited access to emerging treatments due to complex regulatory pathways and fragmented provincial coverage decisions.

Low public awareness and persistent stigma, as many Canadians still do not understand lupus, cause isolation, mental health strain and delayed diagnosis.

Due to a lack of coordinated peer support, many patients express a need for structured community support, shared lived experience, and patient-led resources.

Financial strain for students living with lupus while managing a chronic illness and pursuing education increases financial vulnerability.

These gaps shape our priorities and guide the programs that we deliver.

Lupus Canada's Approach To Supporting Canadians Impacted by Lupus

Lupus Canada's work is rooted in three core pillars: **Advocacy, Public Awareness and Research,** which are all supported by education, collaboration, and accountability.

PILLAR ONE: **ADVOCACY**

Driving through leadership and policy change to improve care and access for all Canadians living with lupus

Formed the Lupus Canada Advocacy Task Force

A collaborative group of lupus specialists and patient partners working together to drive meaningful change.

$5 Million for Lupus Research: Putting Urgency on the Federal Agenda

Pre-budget submission for lupus-specific research commitment from the Federal Government, requesting $5M in lupus-specific research funding.

Advocating on Parliament Hill

Engaged with Members of Parliament to advocate for the importance of lupus-specific research funding from the Federal government, as well as, equitable access to care and treatment for those impacted by lupus.

Putting Patients at the Centre of Drug-Access Decisions

Submissions to Canada's Drug Agency (CDA) to represent the patient voice with new therapies coming to market.

National Ethics-Backed Study on Lupus Lived Experience

Conducted by Peripharm (ethics-backed), the Lupus Canada National Survey gathers both qualitative and quantitative data from lupus patients across Canada and will be a critical resource for patient-reported outcomes and informing submissions to CDA as new treatments emerge.

The data collected will provide timely, credible insight into:

Quality of life and fatigue

Productivity loss and daily activity impact

Healthcare utilization and patient-incurred costs

Treatment preferences and access barriers

Differences in burden between urban and rural participants

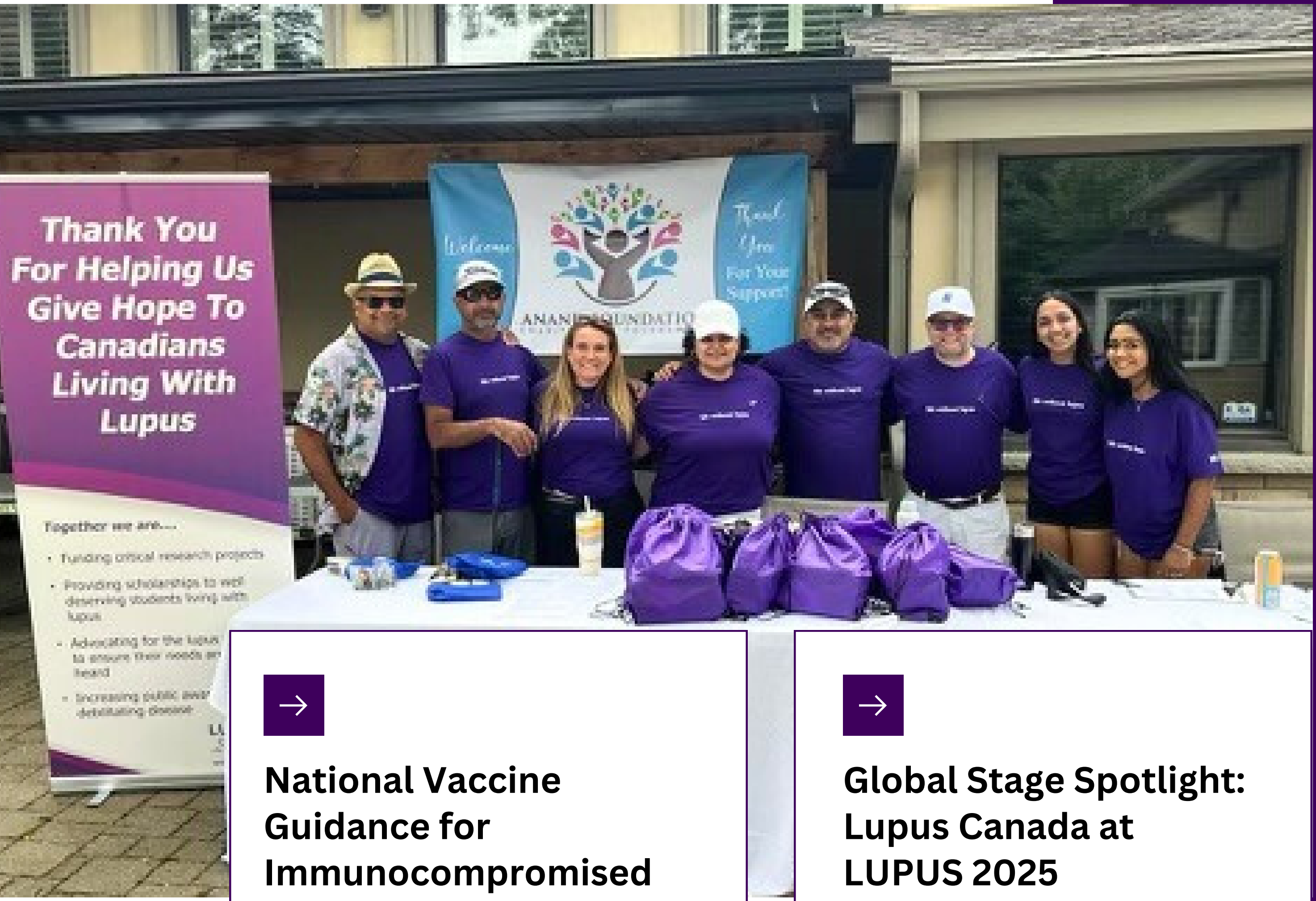
Importantly, this study will serve as the **foundation for a planned economic burden analysis**, including the development of a cost calculator to quantify the real-world impact of lupus in Canada. These insights will directly support **access strategies, policy advocacy, and patient-focused programming** while advancing our mutual goal of integrating innovation that truly meets patient needs.

This work directly targets the most urgent gaps:

- Improving access to treatment
- Influencing emerging therapies
- Generating real-world patient data
- Elevating patient voices in policy conversations

PILLAR TWO:
PUBLIC AWARENESS

Raising national visibility for a disease that remains largely invisible



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National Vaccine Guidance for Immunocompromised Canadians

Released the Vaccine Action Plan to help immunocompromised Canadians navigate vaccine decisions with confidence.

→

Global Stage Spotlight: Lupus Canada at LUPUS 2025

Present in Toronto at LUPUS 2025, a global lupus conference, where we launched the national campaign A Pathway to Progress.

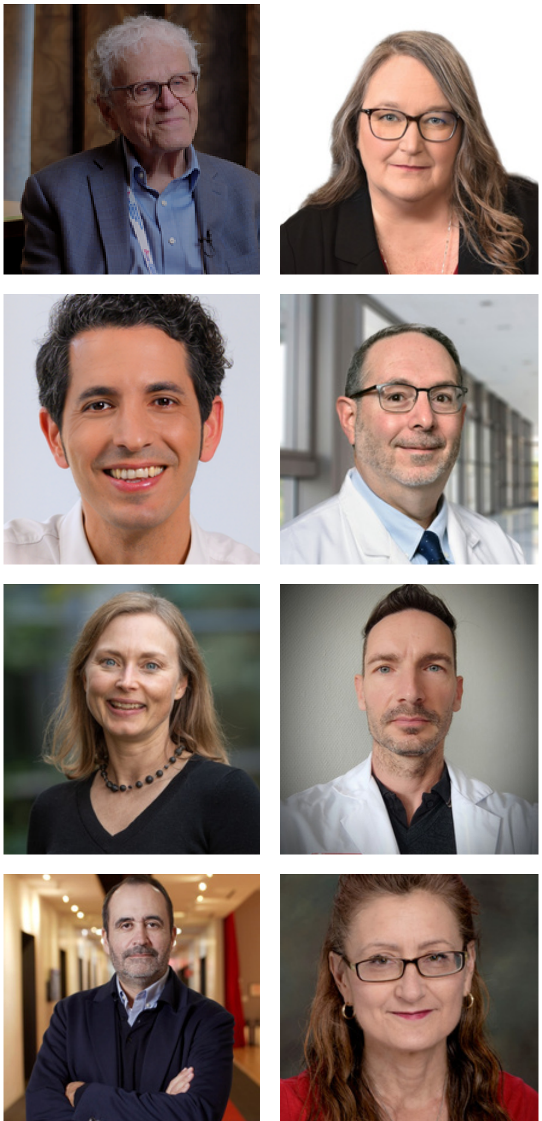
LET'S TALK LUPUS:
A PATHWAY TO PROGRESS

Bringing the **latest insights** from the **LUPUS 2025 Congress directly to Canadians.**

Let's Talk Lupus: A Pathway to Progress brings together leading lupus researchers, experts, and advocates from across the globe **to share breakthroughs in global lupus research, inspire hope, and connect international progress to the realities of living with lupus in Canada.**

Through this campaign, Lupus Canada is amplifying global voices to spotlight the urgent need for:

- Faster diagnosis and equitable access to treatments
- Mental health and patient-centred care
- Research investment and clinical innovation
- Policies that recognize lupus as a critical national health priority



A Nationwide Movement: The Lupus 1000 Challenge

The Lupus 1000 Challenge united organizations, clinics, families, and individual champions across Canada, driving nationwide visibility for lupus and more than doubling our goal by raising over $21,000 to support vital lupus research.

Celebrating Excellence in Lupus Care: Patients' Choice Awards

Launched the first national Patients' Choice Awards, receiving more than 300 submissions recognizing excellence in lupus care.

Youth Engagement: Classrooms for a Cause

Engaged over 300 students across Canada in a hands-on awareness initiative that increased understanding of lupus among young Canadians.

Lighting Canada Purple: 75 Landmarks Illuminated

Coordinated 75 landmark lightings nationwide to elevate lupus visibility and spark public awareness from coast to coast.

Provincial Leadership: World Lupus Day Recognition

Eight provinces and four municipalities issued official proclamations declaring May 10th World Lupus Day, strengthening national visibility and support.

Patients' Choice Awards 2025 Recipient: **Dr. Deborah Levy**

Dr. Levy is a Staff Rheumatologist and Associate Professor of Pediatrics at the University of Toronto, as well as a Team Investigator at the SickKids Research Institute and Clinic Director of the Pediatric Lupus Clinic at SickKids.

Dr. Levy's research focuses on long-term outcomes of childhood-onset lupus and includes national collaborations in systemic lupus erythematosus (SLE), neuropsychiatric SLE (NPSLE), and juvenile idiopathic arthritis (JIA).

> ***"Truly, this represents the hard work and dedication of the entire SickKids Lupus Clinic and not just me — there is no way I could do this on my own!"***

These campaigns shift public understanding of lupus and **increase the visibility of the disease** as they:

- Increase national awareness
- Reduce stigma
- Support earlier diagnosis
- Mobilize communities
- Build momentum for advocacy
- Create space for patient stories

Let’s Talk Lupus: **Conversations with Macenzie**

Created by Lupus Canada in partnership with Toronto-based journalist Macenzie Rebelo, who lives with lupus, Let’s Talk Lupus highlights one individual each month and shares their personal lupus journey.

Danielle P.

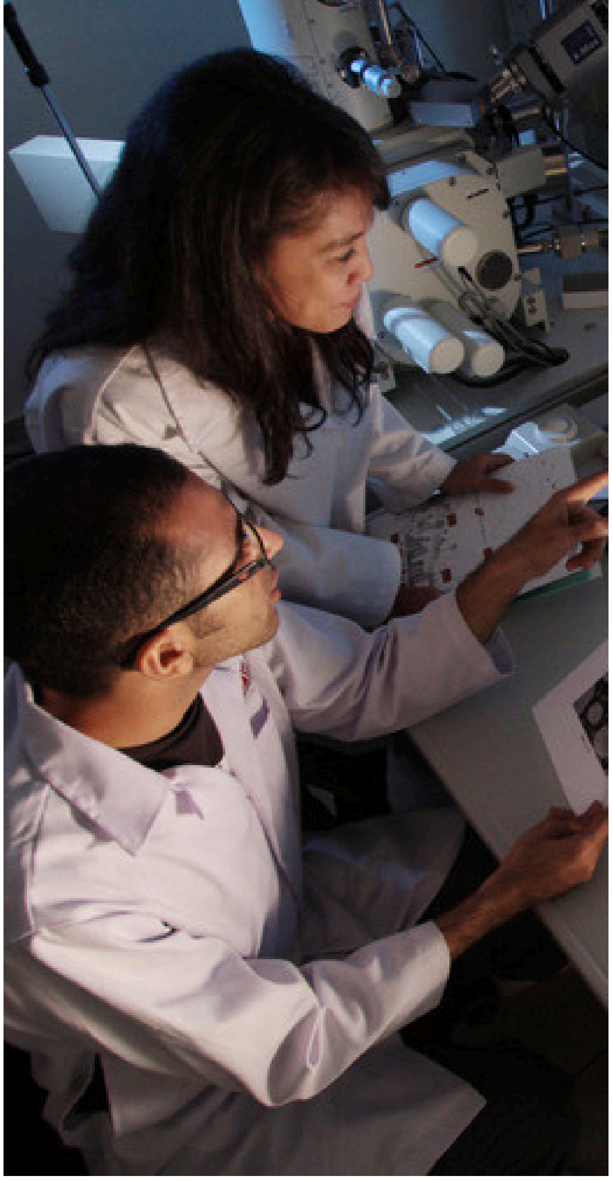
“It’s important that we empower each other and know we’re not alone. Sharing our stories, we can be stronger.”

Jonathan M.

Jonathan is trying to break out of his shell... He has started reaching out to lupus support networks.
“This is why I am doing this interview,”

PILLAR THREE: **RESEARCH**

Investing in the future of lupus care



→ Expansion of the Catalyst Grant: Investing $75,000 in Lupus Research

In 2025, Lupus Canada committed to increasing funding for the Catalyst Grant program from $40,000 to $75,000, underscoring our dedication to advancing lupus-specific research.

Since the program's inception, since 2005 Lupus Canada has

invested over $1.2M

in funding to support research exclusively focused on lupus.

Broadening Research Impact: Catalyst Grant Now Includes Social Sciences

2025 marked the expansion of the Catalyst Grant to include social sciences, reflecting the full spectrum of patient needs and lived experience

Defining the Molecular Drivers of Fatigue in Lupus: A Pilot Study

Awarded the 2025 Catalyst Grant to Dr. Mohamed Osman (University of Alberta) for the project: “Defining the Molecular Drivers of Fatigue in Lupus: A Pilot Study.”

Fatigue is the most commonly reported and least understood lupus symptom. This research responds directly to patient-identified priorities.

Nurse Corinne Maron, Dr. May Choi, Administrative Assistant Laura Radomsky

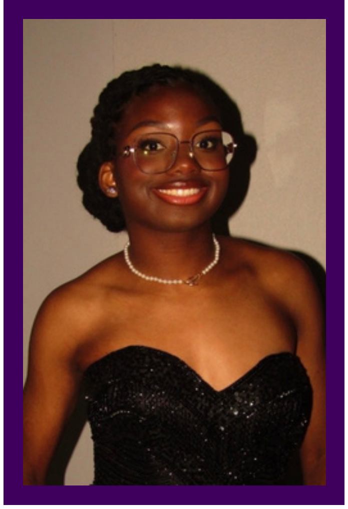
> *“Lupus Canada is a crucial component of my lupus team. They* ***connect my patients with resources and advocate for improved access to tests and treatments.”***
>
> Doctor May Choi
> MD MPH

Dr. Matsos, Dr Konstantinos Tselios and Dr. Legault

At the McMaster Lupus Clinic, our collaboration with Lupus Canada is all about putting patients first. By working together, ***we connect you with trusted education, support, and a stronger community that understands lupus****. This partnership also helps us* ***advocate for new treatments and research****, so that innovative therapies and discoveries can reach patients sooner and improve quality of life.*

Doctor Konstantinos Tselios
MD, PhD

Research funding programs, such as the **Lupus Canada Catalyst Grant**, play a critical role in **advancing the understanding and treatment of lupus in Canada**. These programs facilitate groundbreaking research, enabling scientists and healthcare professionals to explore new concepts, improve diagnostic techniques, and develop more effective treatments for those living with lupus.





Empowering Students with Lupus: $180,000 Awarded Since 2013

The Lupus Canada Scholarship Program has provided $180K in financial support to 83 students living with lupus, reducing financial strain and enabling continued access to education.

Thanks to the continued support of The William Birchall Foundation, ten $2,500 post-secondary scholarships were awarded to students living with lupus.

Voices of the **2025 Lupus Canada William Birchall Foundation Scholarship**

"People sometimes hesitate to make even a small donation because they don't know how much impact it will have. But those small choices accumulate — and they have a huge impact on someone's life. In this case, ***ten people's lives changed*** *for the better because of people's small choices. With lupus being an almost invisible illness, it's extremely hard to get support...* ***so having this is quite literally life-changing.****"*

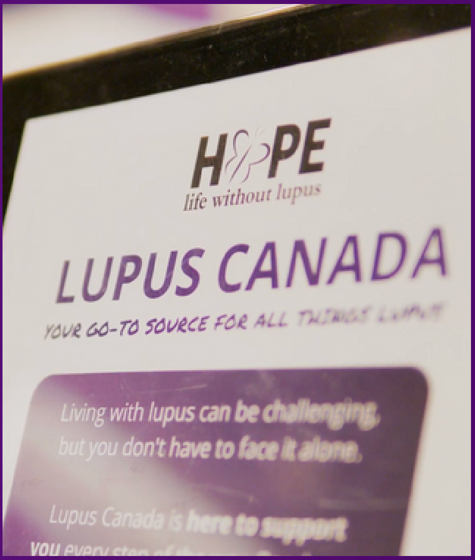
Angelina Kalamenchuk

"Donations don't just support the academic side of our lives – they help with the mental side too. Living with lupus can feel really isolating, so it means a lot to know there are people out there who see you and understand what you're going through. Even if it just helps pay for one specific thing, that support takes away some of the stress and lets you breathe for a moment. ***It shows that you're seen, you're heard, and you deserve this – it's like a little reward that says, we see you, and we're with you.****"*

Jahmeila Moore

“As an organization, we must ensure that we are truly making a difference. If our work is not meaningfully improving the lives of people living with lupus, then we are not doing enough. ***Accountability and transparency are critical so donors can clearly understand how their contributions make an impact for those affected by lupus.”***

Heather Coates
National Fund Development & Engagement Officer



HOPE
life without lupus

LUPUS CANADA

YOUR GO-TO SOURCE FOR ALL THINGS LUPUS

Living with lupus can be challenging, but you don't have to face it alone.

Lupus Canada is here to support you every step

A Year of Progress
Made **Possible by You**

Working Together to Conquer Lupus

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