FROM RARE TO *Remarkable*

2025 IMPACT REPORT

LCC Foundation

A LETTER FROM OUR *Founder*

My journey into rare disease advocacy began as a mother searching for answers for my son Ben after his diagnosis with LCC/Labrune Syndrome. What started in uncertainty has grown into a global mission grounded in connection, hope, and the belief that every rare diagnosis deserves attention, research, and support. Behind this work are families navigating complex realities, and their resilience continues to drive our purpose forward.

In 2025, we saw meaningful progress across research, community building, and advocacy. We strengthened collaborations with researchers worldwide, welcomed new families into our network, and laid the groundwork for future therapeutic development. Planning for our inaugural Global LCC Family & Research Conference has also become a defining milestone, bringing together science and lived experience in a way that will shape the future of this community.

As we look ahead, our commitment remains clear: accelerate research, deepen global collaboration, and ensure every individual affected by LCC feels supported and seen. The year ahead represents more than continued progress — it marks our collective journey on the Road to St. Louis, where families, researchers, clinicians, and partners from around the world will gather for our inaugural Global LCC Family & Research Conference. This milestone reflects what is possible when a community comes together with shared purpose and hope. Together, we continue moving from rare to remarkable, transforming connection into collaboration and momentum into meaningful change for the future of LCC.

With Gratitude,

Ashley

About THE LCC FOUNDATION

Mission:

The LCC Foundation’s MISSION is to help families across the United States and beyond diagnosed with Leukoencephalopathy with Brain Calcifications and Cysts (LCC) by giving them the resources they need to fight this rare and devastating disease. We advocate funding research efforts that will identify new treatments, therapies, and ultimately a cure for LCC. We seek to raise awareness of LCC thus increasing the probability of earlier diagnosis and treatment.

Vision:

A world where LCC/Labrune Syndrome is no longer defined by uncertainty, but by understanding, connection, and transformative therapeutic progress.

Our Story:

The LCC Foundation was created in April 2022 by Ashley Dike, a year following her son’s diagnosis of Leukoencephalopathy with Brain Calcifications & Cysts (LCC/Labrune Syndrome). With this devastating diagnosis, she became determined to stay positive and do all she could to save Ben’s life. After meeting other affected families in July 2023, she became even more determined to advocate and fund research efforts, to treat and save others.

Our Pillars:

- Patient support
- Research acceleration
- Community connection
- Advocacy & awareness

2025

IMPACT SNAPSHOT

Families Connected:

Throughout 2025, The LCC Foundation expanded its reach by connecting 8 families across multiple countries, ensuring that no family navigates LCC alone.

8

Countries Represented:

Our community continues to grow internationally, strengthening collaboration and shared learning across borders.

12

Educational Materials Produced:

850 informational packets were distributed to hospitals. Education is a cornerstone of impact, empowering families and clinicians with accessible and accurate information about LCC.

1

Funds Raised:

35,200.00 CAD $ **$64,400.00 USD**

Registry Progress:

Patient-centered data priorities established. Data analysis and preparation work were accomplished for publication in 2026.

ADVANCING RESEARCH *for LCC*

Research Collaborations:

- Leukodystrophy & Myelin Disorders Program led by Dr. Jamie Lee Fraser and her team at Children's National Medical Center
- Global Leukodystrophy Initiative-Clinical Trial Network at Children's Hospital Philadelphia *Rised in priority in 2025.
- Andrew Badrock, Postdoctoral Research Fellow at the University of Edinburgh in Scotland (United Kingdom)

Scientific Momentum:

- Natural History Study progress
- MRI scoring development
- Integrated Stress Response (ISR) / RNA research engagement
- International research updates

Research Infrastructure:

- Registry pathways identified and progress made
- Biomarker discussions
- Therapeutic hypothesis work
- Industry engagement

"As both a parent and advocate, I've learned that progress in rare disease doesn't happen by chance — it happens when communities intentionally build the pathways that allow science to move forward. Our work is focused on creating those pathways so meaningful breakthroughs for LCC become possible."

— Ashley Dike, Founder & Executive Director, The LCC Foundation

SUPPORTING FAMILIES *around the World*

In 2025, The LCC Foundation continued to serve as a vital point of connection for families navigating LCC/Labrune Syndrome. Newly diagnosed families were welcomed into a growing global network where shared experiences, trusted information, and peer support helped reduce isolation and build confidence during the diagnostic journey.

Peer connection remained central to our impact. Through facilitated introductions and ongoing communication, families exchanged practical guidance, emotional encouragement, and lived experience, strengthening resilience across the community. Educational outreach also expanded through informational packets distributed to hospitals and digital resources shared with families and clinicians, helping improve awareness and understanding of LCC.

Most importantly, global family relationships continued to deepen, uniting individuals across countries with a shared voice and renewed hope for research progress and future treatments.

STORY SPOTLIGHT ✨

When Matthijs and Naomi from the Netherlands discovered The LCC Foundation through our website, it marked the beginning of a meaningful connection across continents. After meeting with the family via Zoom, we facilitated introductions between their local medical team and LCC experts in our network. These conversations created an opportunity to share knowledge, discuss care considerations, and provide guidance that might not have been otherwise accessible.

This moment reflects the power of global connection — where a single outreach can lead to collaboration, shared expertise, and increased confidence for families navigating complex medical decisions.

COMMUNITY IN *Action*

Fundraisers:

- 50/50 Superbowl Raffle – February 2025
- March Madness Basketball Squares – March 2025
- Roll n' Stroll in-person event – April 2025
- Stronger September – September 2025
- From Rare to Remarkable End of Year Campaign – November 2025

What we learned:

As The LCC Foundation continued to grow, 2025 offered important insights that are shaping our strategy and strengthening our path forward.

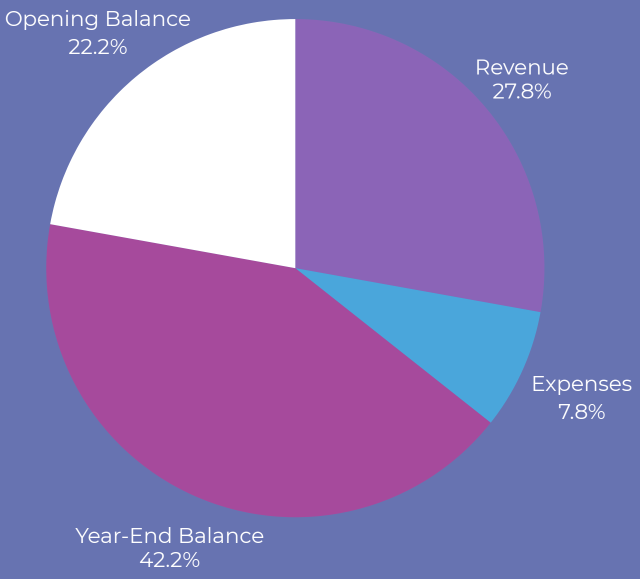
- Community connection drives momentum.
- Peer-to-peer initiatives and awareness campaigns demonstrated that families and supporters are eager to participate when given meaningful ways to engage, share stories, and contribute to progress.
- Education remains a critical need.
- Outreach efforts confirmed that many families and clinicians still have limited awareness of LCC, reinforcing the importance of accessible educational resources and continued advocacy.
- Global collaboration is essential in ultra-rare diseases.
- Cross-border connections between families, researchers, and clinicians highlighted the value of shared expertise and the impact of building an international support and research network.
- Infrastructure building is foundational to research progress.
- Registry planning, data conversations, and research partnerships underscored that establishing the right infrastructure is a necessary step before therapeutic development can accelerate.
- Momentum builds trust and partnership.
- Consistent communication, transparency, and visible progress strengthened relationships with families, donors, and research partners, creating a stronger foundation for future initiatives.

FINANCIAL Transparency

$46K GROWTH

The LCC Foundation increased its financial position by approximately $46,000 in 2025, reflecting strong donor engagement and strategic fundraising success.

$97K YEAR-END BALANCE



LEADERSHIP GIVING

Multiple five-figure contributions and donor-advised fund gifts accelerated mission progress and strengthened long-term sustainability.

DIVERSE FUNDING

Support was generated through individual donations, peer-to-peer campaigns, matching gifts, merchandise, and grants — enhancing financial resilience.

MATCHING GIFTS

Corporate matching programs amplified individual generosity, increasing the overall impact of community-driven support.

Financial growth in 2025 strengthened organizational readiness, supported infrastructure development, and created momentum toward expanded research collaboration and the Global LCC Family & Research Conference.

THE ROAD TO St. Louis

The inaugural Global LCC Family & Research Conference represents a defining milestone for the LCC community. For the first time, families, researchers, clinicians, and industry partners from around the world will gather in a shared space designed to accelerate collaboration, strengthen support systems, and advance research readiness. This conference is not only an event — it is a strategic step toward building the infrastructure necessary for therapeutic progress.

Road to St. Louis Progress
- Venue secured and planning underway
- Key speakers confirmed
- Scientific agenda framework established
- Sponsor outreach initiated and expanding
- Scholarship strategy development in progress
- Industry engagement conversations launched
- Growing international family and researcher participation

TO HELP FUND:

REGISTER TO ATTEND:

WITH DEEP Gratitude

The progress shared throughout this report reflects the collective strength of a remarkable community. We are deeply grateful to the families, donors, volunteers, researchers, clinicians, and partners whose compassion, dedication, and belief in this mission continue to move the LCC community forward.

💙 Donors & Supporters

Your generosity fuels research readiness, community connection, and advocacy efforts, creating meaningful opportunities for progress and hope.

🤝 Volunteers & Partners

Through outreach, event support, and collaboration, volunteers and organizational partners help expand our reach and strengthen the foundation of our work.

🧬 Researchers & Clinicians

Your commitment to discovery and patient care drives scientific understanding and brings the possibility of future treatments closer to reality.

👦👦👧👶 Families

Families remain at the heart of our mission. Your resilience, openness, and willingness to share your journeys continue to inspire connection, advocacy, and progress.

⭐ Legacy of Love

Within our community are families whose journeys include profound loss. We honor these children, adults, and the families who carry their memories forward with extraordinary courage and love. Their stories continue to shape our mission, inform our advocacy, and inspire our pursuit of greater understanding and therapeutic progress.

Every adult and child's life leaves a lasting imprint on this community. Their legacy lives on through connection, remembrance, and the shared commitment to building a future where hope, support, and answers are more accessible for every family impacted by LCC.

JOIN THE Journey

The progress achieved in 2025 reflects what is possible when a community comes together with shared purpose and hope. As we continue the journey from rare to remarkable, there are many ways to help shape the future for individuals and families affected by LCC.

💙 **Donate**
Your generosity fuels research readiness, family support initiatives, and advocacy efforts that bring hope and progress closer to reality.

🎤 **Sponsor the Conference**
Support the inaugural Global LCC Family & Research Conference and help create a space where science, lived experience, and collaboration accelerate discovery.

🧬 **Partner in Research**
Researchers, clinicians, and industry partners are invited to collaborate in advancing understanding and therapeutic exploration for LCC.

📊 **Join the Registry**
Participation in patient-centered data initiatives strengthens research infrastructure and helps drive meaningful scientific progress.

🤝 **Volunteer**
Share your time and talents to support events, outreach, and community programs that expand connection and awareness.

📖 **Share Your Story**
Your experience has the power to inspire others, strengthen advocacy, and contribute to a deeper understanding of life with LCC.

🌍 **Follow & Stay Connected**
Engage with the LCC community through social channels to stay informed, share updates, and help amplify awareness worldwide.

Together, we are transforming connection into collaboration, and hope into progress — building a future where every family affected by LCC feels supported, seen, and closer to meaningful answers.

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