ISSUE 10

FABRY AWARE

Education • Empowerment • Innovation • Community • Advocacy



CFA ACF
CANADIAN FABRY ASSOCIATION
L'ASSOCIATION CANADIENNE DE FABRY

WWW.FABRYCANADA.COM

Fall e-magazine

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Designed to keep you informed and inspired on your Fabry journey.



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Women's Retreat in PEI:

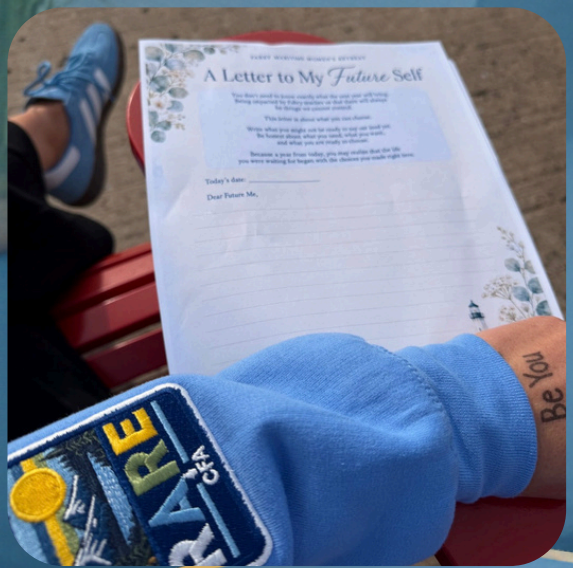
Rare. Connected. Understood

The Women's Summit in PEI offered women living or caring for someone with Fabry disease a meaningful space to connect, share experiences, and find understanding. The gathering was a powerful reminder that community can help people feel rare, connected, and supported.













Community is Medicine

There is something special about bringing a group of women together who just get it.

This September, the Canadian Fabry Association welcomed women from across Canada to beautiful Prince Edward Island for our 2026 Women's Fabry Summit, Rare. Connected. Understood. We came together to learn, to ask questions, to share experiences, and perhaps most importantly, to remind one another that none of us has to navigate Fabry alone.

Our Fabry School brought education to life through smaller, interactive sessions where women and caregivers could learn directly with experts, ask meaningful questions, and gain a deeper understanding of Fabry disease and their health. But some of the most meaningful learning happened outside the classroom. It happened during our community walk, writing letters to our future selves, and it happens while sharing and watching the sunset.

Throughout the weekend, we learned from incredible healthcare professionals, but we also learned from one another. Every woman brought something valuable to the conversation: her experiences, her questions, her wisdom, and her perspective. And somewhere between the Fabry School sessions, the sunset cruise, the pajama party, and all the conversations in between, something wonderful happened. We became a little more connected, a little more informed, and perhaps a little more confident in navigating our own Fabry journeys. We left PEI feeling more informed, more confident in navigating our own Fabry journeys, and with a renewed sense of belonging. And if there is one thing this weekend reminded us, it's that community really is medicine.

To every woman, caregiver, speaker, volunteer, and supporter who made this weekend possible, thank you for being part of something so special.

Until we meet again.
Julia Alton

From Scotland With Heart:

A Reflection on the Fabry Youth at the International Symposium by Dr. Seema Kanwal, ND

Attending the **International Fabry Symposium** in Scotland was one of those experiences that reminds you exactly why this work matters. The conference itself was rich: brilliant minds, emerging research, and the kind of conversations that only happen when the global Fabry community gathers in one room. But what I found myself coming back to, again and again, was the young people.

The Fabry youth who attended were not passive participants. They showed up, fully, bravely, and with questions that stopped the room. Hard questions. The kind that it requires you to understand your own condition, to have sat with it, wrestled with it, and decided that you deserve answers. Questions about their futures, their bodies, their care, and what the science actually means for them.

I was so proud. Not in a distant, observational way, but in the way you feel proud of someone who has chosen against every reason not to, to advocate for themselves. Living with a rare disease as a young person asks an enormous amount. It asks you to navigate a medical system that often doesn't have ready answers. It asks you to explain yourself to peers, to teachers, sometimes to doctors. It asks you to hold uncertainty with grace.

And these young people did all of that, and then they flew to Scotland and asked the hard questions anyway.

To the Fabry youth who were there: you represented this community beautifully. You showed the world that the next generation of Fabry advocates is informed, engaged, and not willing to be sidelined. That matters more than I can say.

Scotland was wonderful. **But you were the highlight.**





Fabry Youth Weekend

— By Emma —



The weekend started with an activity where we got to create clay sculptures that we were allowed to bring home with us. We were taught how to make a clay pot first and then we could make whatever we wanted. This gave us a chance to catch up with each other and meet the new people joining us for the first time. We then went to dinner together up by the Edinburgh Castle, such a beautiful spot for a truly enjoyable meal, giving us more opportunity to connect with one another.

The next day we began our meetings. We started by learning about energy and nutrition. For the meetings, we were given lovely workbooks to help us not only absorb the information better but to also bring it home to use in the future when we needed it.

We heard from Dr. Seema Kanwal about energy. She taught us about fight, flight, and fawn. We went over what they meant and how most people have two and how you can come down from these reactions. She also told us we are checking in on our bodies when we wake up to ensure we aren't pushing ourselves too hard. Dr. Kanwal taught us that saying 'should' can be setting yourself up for failure, it is putting too much pressure on yourself, saying 'attempt' is a better way of wording something in a positive way.



Dr. Kanwal then started on nutrition. She informed us that the gut microbiome had a direct correlation on heart disease and how the Mediterranean diet is good for managing GI symptoms. She went over what a good diet looks like for a Fabry patient; plants first, healthy fats, and quality proteins. She then gave examples of each of these groups. We then went over vitamins and which ones are good for Fabry patients to be taking.

For the final topic of our first day of meetings we touched on stress. Dr. Kanwal gave us a recovery toolkit, this gave us resources for stress management, this included activities to do in high stress situations, people you can turn to when you need support, and how to set boundaries with others.

On Sunday morning we did 'ask me anything' with Dr Kanwal, and so we all had the opportunity to ask her questions about anything to do with fabry. She picked three topics that she wanted to discuss, these three topics are often embarrassing or not easy to ask about. After the Q&A we had a chance to discuss everything over the whole weekend and started saying our goodbyes. Everyone in the group wrote notes for each other to bring home year book style for a special memory.

This was a very special trip that I will remember for the rest of my life. I feel like I now have a lifetime bond with the people I have met. The conversations and connections I have made are so special to me. This is such an important trip, I learned so much and met so many amazing people. I have found a family in this group.

Andy's ABC Adventure:

Learning About Fabry

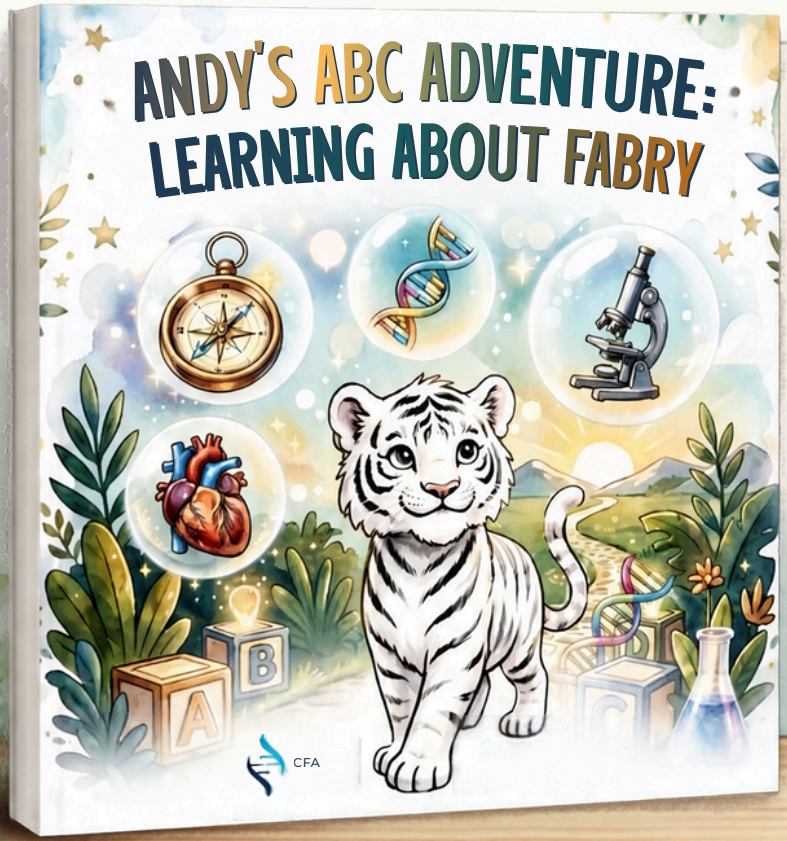
Created by Our Fabry Community

We are excited to share Andy's ABC Adventure: Learning About Fabry, a new children's book created by people whose lives have been touched by Fabry disease.

Follow Andy the Tiger on an A-to-Z adventure as he learns about life with Fabry Disease. The book introduces important medical concepts while exploring emotions, resilience, and the importance of community.

Inspired by real experiences from patients, families, and caregivers, this book is a wonderful way for children and adults to learn about Fabry together.

100% of proceeds support the Canadian Fabry Association and our work supporting individuals and families affected by Fabry disease.



Get your copy today!

Available on Amazon for $17.99 CAD. Simply search Andy's ABC Adventure: Learning About Fabry.

FABRY PODCAST

A PLACE FOR IMPORTANT CONVERSATIONS



Coming Soon:

Youth & Young Adults: The Questions We Have & The Conversations We Need - Tatevik Yezekyan

Latest Episodes:

Episode 17: - Learning to Live with Grief - Marny Williams

Episode 16: - When Your Body Speaks: Holding Space for Both Fabry and Mental Health - Nadia Ali

SCAN THE QR CODE TO LISTEN



BioMarin Enters Into Licensing Agreement with GC Biopharma & Hanmi Pharm

On October 29, BioMarin announced a licensing agreement with GC Biopharma and Hanmi Pharm related to the development and commercialization of HM15421/GC1134A, an investigative, next-generation enzyme replacement therapy (ERT) for Fabry disease. The therapy is currently in Phase 1/2 clinical development. and is being explored as a long-acting treatment option designed for subcutaneous administration. FSIG will continue to monitor developments in the Fabry treatment landscape and share relevant updates with our community as information becomes available.

To read the entire article, click here

Link

PTC THERAPEUTICS™



UPDATED PRESS RELEASE:

PTC Therapeutics Acquires Sangamo Fabry Gene Therapy Pipeline

PTC Therapeutics has announced the acquisition of Sangamo Therapeutics' Fabry disease gene Therapy program. As a result of this agreement, responsibility for the ongoing development of the investigative program will transition to PTC Therapeutics.

To read the entire article, click here: Link

Idorsia Announces Phase 3 Fabry Study and Collaboration with Nxera

Idorsia has announced the initiation of FAB-KLEAR, a pivotal Phase 3 clinical study in Fabry disease. Building on previous clinical research and long-term patient follow-up, the study will further evaluate an investmental oral therapy as a potential disease-modifying treatment targeting kidney manifestations of Fabry disease. A collaboration with Nxera Pharma has also been announced. Nxera will contribute to the global Phase 3 development program and support potential future commercialization in Japan and select Asia-Pacific markets. FSIG will continue to provide updates on all research and studies as we become aware.

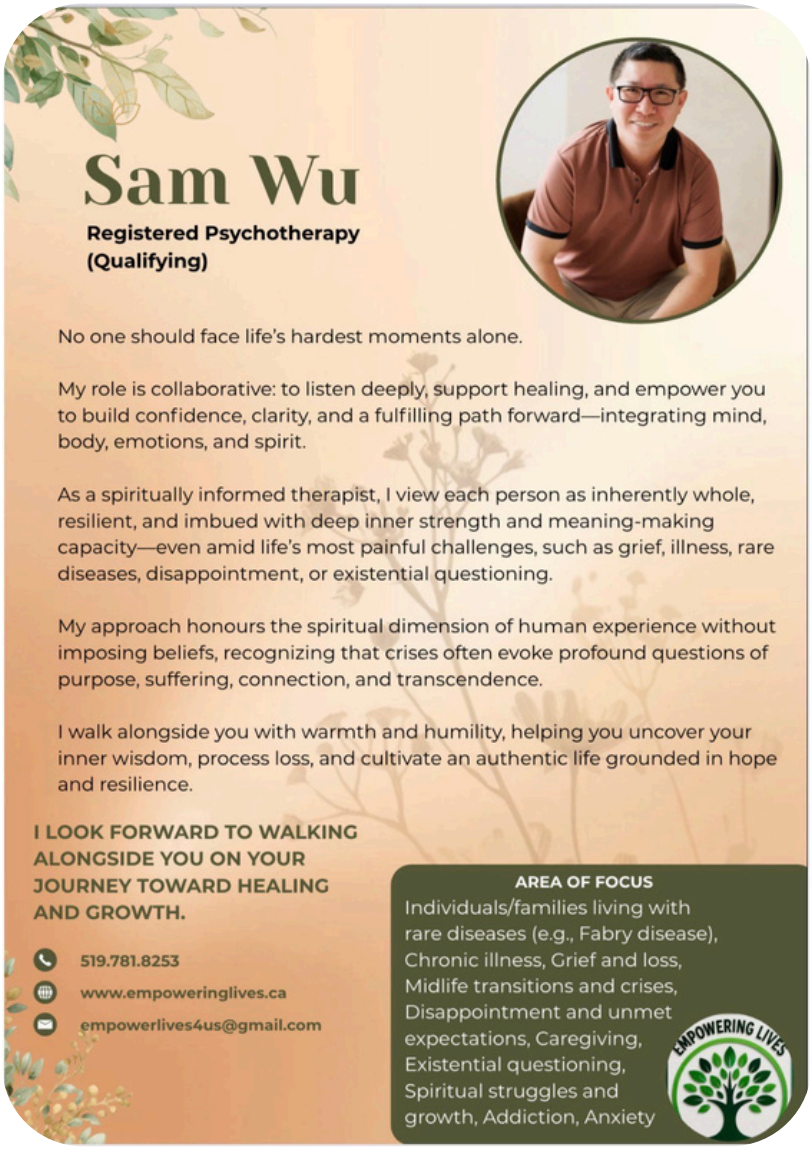
Idorsia

Read the full article here:

Link



CFA Resilience Program



Many of you have already had the opportunity to meet Sam during our Patient Empowerment Meetings across Canada. His willingness to travel, connect in person, and listen deeply has made a meaningful impact. He has become a genuine source of support and light for so many in our community.

Sam brings not only professional expertise, but also a grounded, empathetic presence that resonates with individuals and families navigating the complexities of Fabry disease.

We are offering:

5 sessions covered by CFA

We're proud to be able to share this opportunity for continued support to both patients and caregivers. Offered both in person (Ontario GTA) or over Zoom.

Get in touch with Sam by the contact information provided in the poster. He is honoured to walk alongside you in this journey

CFA Rare Collection

For 20 years, we've stood together, through challenges, resilience and hope.

The **CFA RARE Collection** honours our community, and every purchase directly supports education, connection and care for patients living with Fabry across Canada.







CFA | CANADIAN FABRY ASSOCIATION

Français

GET CONNECTED

Website: www.fabrycanada.com
Facebook: Canadian Fabry Association
Instagram: Canadian Fabry Association
X: CdnFabry
LinkedIn: Canadian Fabry Association

IN PARTNERSHIP WITH

National FABRY DISEASE Foundation

KGA

CFA CANADIAN FABRY ASSOCIATION

The National Fabry Disease Foundation (NFDF) and the Canadian Fabry Association (CFA) are partnering with Kathleen Greer Associates, Inc (KGA) to offer a cost-free NFDF/CFA Family Assistance Program to the U.S. and Canadian Fabry communities. KGA services are available to individuals with Fabry and their immediate family members.

KGA offer a variety of counseling, referrals, webinars, and other resources explained at:
https://www.youtube.com/watch?v=BvU5NKdOGnI&t=192s.

100% confidential service includes **24/7 access** to a network of experts at 800-648-9557 for:
- Mental & emotional health
- Family, home and work support

When using KGA services, enter "fabry" as your company code.



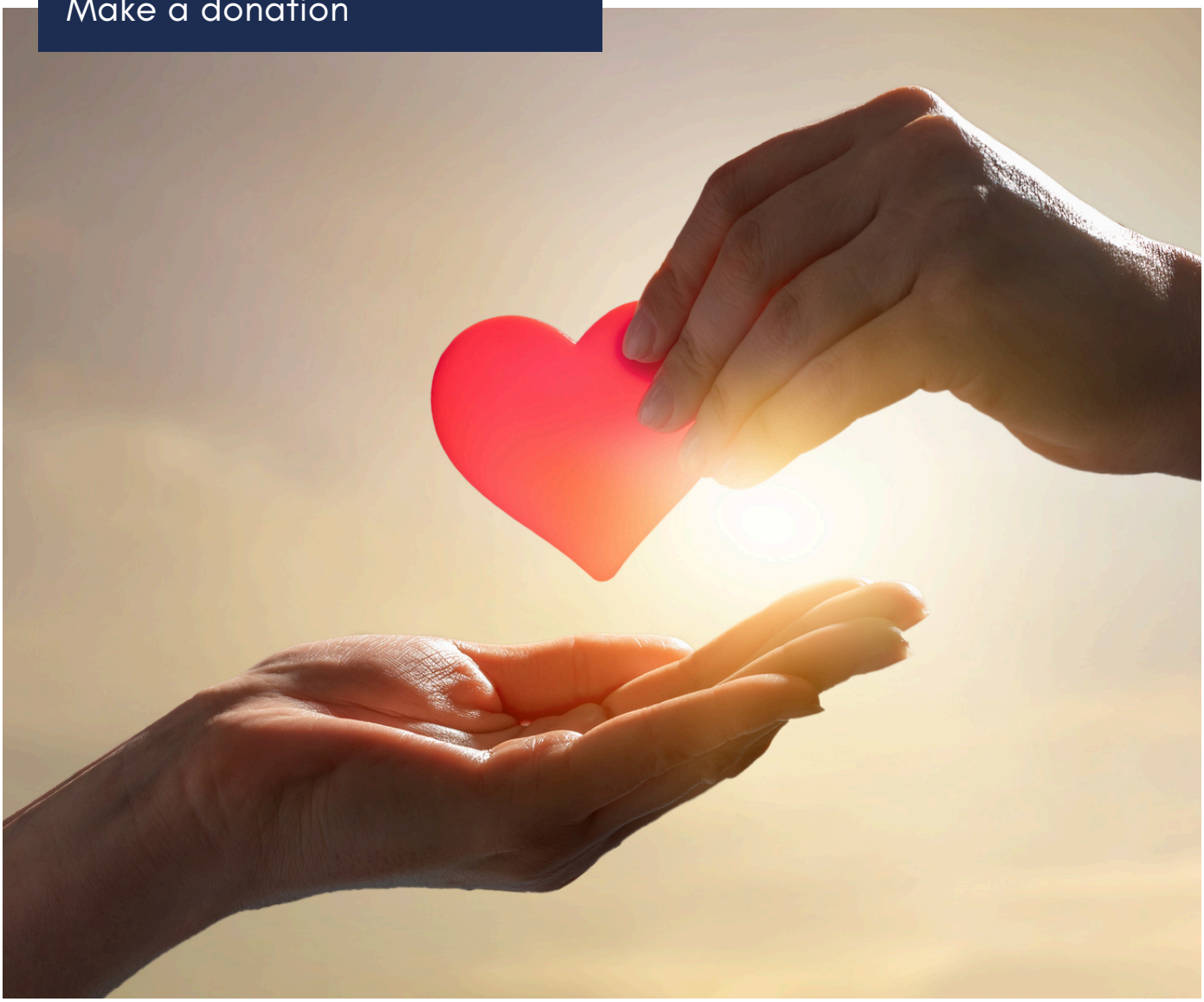
KGA offers mental health, family, work, and home support, referrals, webinars, and other resources explained at:

https://www.youtube.com/watch?https://www.youtube.com/watch?v=BvU5NKdOGnI&t=192s

Please note that the video was recorded before our CFA partnership so the CFA is not mentioned in the video, but the entire program applies to the Canadian Fabry community also.

****Please use the webinar link above rather than the inactive link in the image below.**

The NFDF and CFA teams



Make a Donation

Thank you for making an impact, it makes a difference.

Your generosity directly contributes to the events and initiatives that bring patients and families education, support, and a sense of community. It enables the CFA to continue to advocate, bring awareness, and support research.
To make a donation to the Canadian Fabry Association visit www.fabrycanada.com.

Or send a cheque to the address below:

The Fabry Charity Association
1964 Hawkridge Dr.
Thunder Bay, ON.
P7J 1H2

Sponsor Corner

Thank You
for your support

We would like to thank all of our supporters that helped make this newsletter possible.

We would like to thank all of the **physicians**, **specialists**, and **medical professionals** that have helped in so many ways. From providing guidance on medical terms and details to caring for members of our community every day.

We would also like to thank all of the **patients and family members** that have volunteered their time and energy to assist in all the many ways that are necessary in the creation of such a large effort. It is through their efforts that we hope to inform and build a community of Fabry patients for the benefit of patients, their families, and caregivers.

Thank you to our **industry leaders** for your support and collaboration. We receive financial support from Pharmaceutical companies who are currently committed to advancing medical research, developing groundbreaking treatments, ensuring access to essential medications, and continuing to create hope for Fabry patients.

All your support **empowers** us to achieve our mission and **create positive change** in the world.

sanofi

Takeda

Amicus Therapeutics

Chiesi
global rare diseases