

ISSUE 08

FABRY AWARE

Education • Empowerment • Innovation • Community • Together



CANADIAN
FABRY
ASSOCIATION

L'ASSOCIATION
CANADIENNE
DE FABRY



WWW.FABRYCANADA.COM

— *Spring e-magazine*

Contents

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

Sections

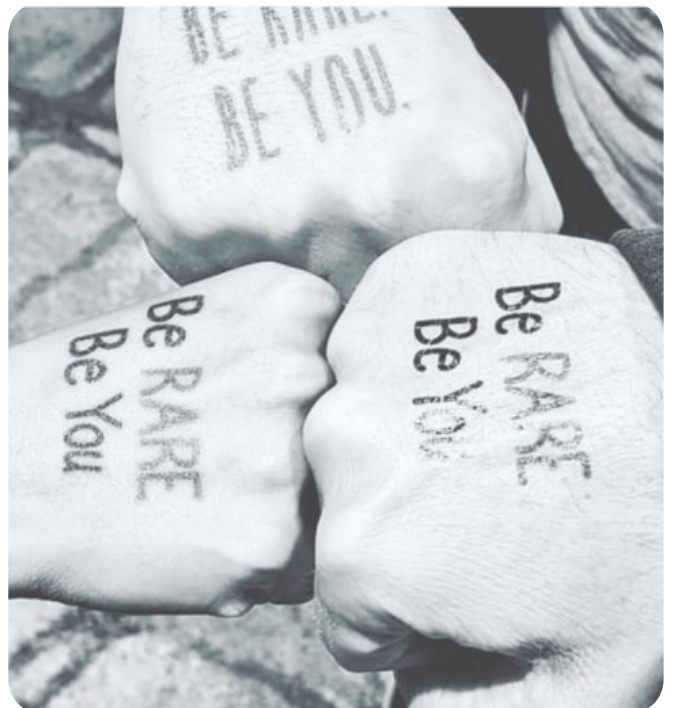
Community Events + News

CFA Updates

Announcements

Sponsor Corner

Closing





Thank you for helping us celebrate **Rare Disease Day**. This is a powerful and deeply moving day. It shines a light on the resilience, the struggles, and the lived truths of those impacted.

WEBINAR

We invite patients, families, friends, and male allies to join us in learning more about how females are impacted by Fabry disease, an area that is often misunderstood and under-recognized.



CANADIAN FABRY
ASSOCIATION

Fabry Disease & Females

A 2-Part Webinar Series

In honour of **Fabry International Women's Day** (the first Saturday in April) and **Fabry Awareness Month**, the Canadian Fabry Association is hosting a special two-part webinar series.

We welcome **patients, families, friends, and male allies** to join us in learning more about how females are impacted by Fabry disease.

 **April 1st**
7:00 PM ET

Speakers:

- Dr. Bichet
- Rebekah Wilzer
- Shiela McNaughton

 **April 15th**
7:00 PM ET

Speakers:

- Dr. West
- Rebekah Wilzer
- Shiela McNaughton



All are welcome. Patients, families, friends, and male allies.

April 1st & April 15th • 7:00 PM ET

Part one link here
(April 1)



 **Link**

Part two link here
(April 15)



 **Link**



CFA
ACF

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DE FABRY

PATIENT EMPOWERMENT MEETING

MAY 23, 2026

MONT SAINTE-ANNE RESORT & CONVENTION CENTER - BEAUPRE, QUEBEC

A DAY OF EDUCATION
CONNECTION AND EMPOWERMENT



Join us for the Canadian Fabry Association "Patient Empowerment Meeting" on May 23rd. This is a supportive gathering created specifically for you to provide education, foster meaningful connections, and strengthen your confidence in managing your health. Through presentations, shared experiences, and open discussion, you will gain practical knowledge about Fabry, treatment options and self-advocacy. The meeting will create a space for individuals to connect with others who share similar experiences, build a sense of community and mutual support all in the backdrop of the beautiful Mont Sainte-Anne Resort in Beaufré, Québec. Mont Sainte-Anne is a year-round resort located 30 minutes outside of Québec City. A short drive from the city, the resort is a haven for outdoor enthusiasts and those who enjoy the beautiful backdrop of the mountains and trails.



**THE CANADIAN FABRY ASSOCIATION IS HOSTING A
1-DAY FABRY PATIENT EMPOWERMENT MEETING**

**REGISTER
NOW**

THIS MEETING IS OPEN ONLY TO PATIENTS RESIDING IN QUEBEC



FOR ENQUIRIES CALL TOLL FREE
866.655.8548



VISIT OUR WEBSITE
fabrycanada.com



THE CANADIAN FABRY ASSOCIATION (CFA) IS COMMITTED TO
IMPROVING THE LIVES OF THOSE WHO LIVE WITH AND ARE
AFFECTED BY FABRY DISEASE IN CANADA.



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CANADIENNE
DE FABRY

Réunion d'autonomisation des patients du Québec de ACF

23 mai 2026

**Delta Hotels par Marriott Mont-Sainte-Anne
centre de villégiature et de congrès**

U n e j o u r n é e d ' é d u c a t i o n , d e c o n n e x i o n e t
d ' a u t o n o m i s a t i o n



Joignez-vous à la réunion canadienne sur l'autonomisation des patients atteints de la maladie de Fabry, qui se tiendra à Beaufort, au Québec, le 23 mai, pour échanger, apprendre et nous soutenir mutuellement!

Grâce à des présentations, ce sera une journée pour se renseigner sur les dernières avancées en matière de traitement, de partager et pour trouver du soutien dans une communauté dédiée à relever les défis de la maladie de Fabry.

Une occasion pour rencontrer d'autres familles et patients, ayant des expériences similaires, de développer un sentiment de communauté et de soutien mutuel.



**L'ASSOCIATION CANADIENNE FABRY ORGANISE UNE JOURNÉE DE
RENCONTRE POUR LES PATIENTS ET LEUR FAMILLES ATTEINTS DE LA
MALADIE DE FABRY, A BEAUFORT, QUÉBEC**

**Inscrivez-vous
dès maintenant.**

CETTE RENCONTRE EST OUVERTE UNIQUEMENT AUX PATIENTS RÉSIDANT AU QUÉBEC.



POUR TOUTE QUESTION, APPELEZ
LE NUMÉRO SANS FRAIS

866.655.8548



VISITEZ NOTRE SITE WEB

fabrycanada.com





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YOUTH & YOUNG ADULT SUMMIT

MAY 23-24, 2026

MONT SAINTE-ANNE RESORT & CONVENTION CENTER - BEAUPRE, QUEBEC

2 DAYS OF CONNECTION
LEARNING & ADVENTURE



THE **CANADIAN FABRY ASSOCIATION** IS HOSTING A YOUTH AND YOUNG ADULT SUMMIT IN BEAUPRE, QC.

THE FABRY YOUTH & YOUNG ADULT SUMMIT WELCOMES DIAGNOSED CANADIAN PATIENTS AGES 16-25 TO AN EDUCATION-FOCUSED EXPERIENCE DESIGNED TO EMPOWER YOU TO LIVE YOUR BEST LIFE WITH FABRY.

THIS SUMMIT OFFERS A SUPPORTIVE SPACE TO DEEPEN YOUR UNDERSTANDING OF FABRY, LEARN HOW TO OPTIMIZE YOUR HEALTH, AND BUILD CONFIDENCE IN SELF-ADVOCACY.

Be **RARE**
Be You



Sainte-Anne Canyon
Beaupre QC



OPEN TO ALL YOUTH & YOUNG ADULTS IN CANADA AGES 16-25
UNDER 18 MUST BE ACCOMPANIED BY A LEGAL GUARDIAN



CONTACT US AT
866.655.8548

CLICK HERE
TO REGISTER
NOW

VISIT US ON THE WEB
fabrycanada.com





Sam Wu

**Registered Psychotherapy
(Qualifying)**



No one should face life's hardest moments alone.

My role is collaborative: to listen deeply, support healing, and empower you to build confidence, clarity, and a fulfilling path forward—integrating mind, body, emotions, and spirit.

As a spiritually informed therapist, I view each person as inherently whole, resilient, and imbued with deep inner strength and meaning-making capacity—even amid life's most painful challenges, such as grief, illness, rare diseases, disappointment, or existential questioning.

My approach honours the spiritual dimension of human experience without imposing beliefs, recognizing that crises often evoke profound questions of purpose, suffering, connection, and transcendence.

I walk alongside you with warmth and humility, helping you uncover your inner wisdom, process loss, and cultivate an authentic life grounded in hope and resilience.

**I LOOK FORWARD TO WALKING
ALONGSIDE YOU ON YOUR
JOURNEY TOWARD HEALING
AND GROWTH.**



519.781.8253



www.empowerlives.ca



empowerlives4us@gmail.com

AREA OF FOCUS

Individuals/families living with rare diseases (e.g., Fabry disease), Chronic illness, Grief and loss, Midlife transitions and crises, Disappointment and unmet expectations, Caregiving, Existential questioning, Spiritual struggles and growth, Addiction, Anxiety



FABRY PODCAST

A PLACE FOR IMPORTANT CONVERSATIONS

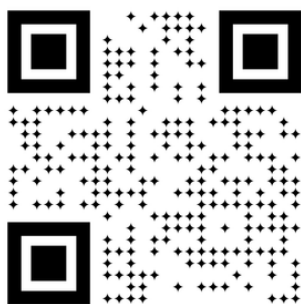


Episode 14: A Life Shaped by Fabry – Jerry Walter

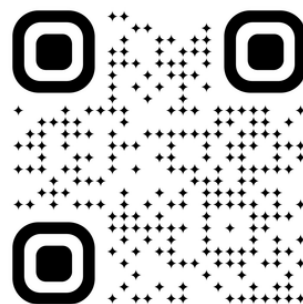
Episode 13: Fabry & the Kidneys with Dr. Michael West

Episode 12: A Modern Era in Cardiac Care: Fabry Disease AI, & the Power of Partnership with Dr. John Jefferies

Episode 11: EMDR Therapy & Fabry with Linda Quaranta



SCAN THE QR CODE
TO LISTEN



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.



GET IN TOUCH!



GET CONNECTED

Website: www.fabrycanada.com

Facebook: Canadian Fabry Association

Instagram: Canadian Fabry Association

X: CdnFabry

LinkedIn: Canadian Fabry Association



GRATITUDE STORIES



If you would like to recognize
someone, please reach out to:

Julia Alton at:

julia.alton@fabrycanada.com

As part of our **20th anniversary** celebrations, the Canadian Fabry Association is collecting gratitude stories recognizing healthcare professionals who have made a meaningful impact in the Fabry community. If there is a healthcare professional - physician, nurse, or care team member who has made a meaningful difference in your Fabry journey, we would love to hear their story.

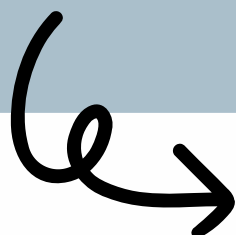
These gratitude stories will help us highlight the **compassion, dedication, and excellence** that exist within Fabry care across Canada.



The Canadian Fabry Association is encouraged to see continued innovation in the field of Fabry disease. The FDA granting Orphan Drug Designation to Glafabra's investigational cell therapy represents an important milestone in the development pathway for potential new treatments. While this designation does not mean the therapy is approved or available yet, it reflects ongoing progress in the scientific community's efforts to explore new approaches for treating Fabry disease.

We remain hopeful as research continues and look forward to learning more as development advances.

Click here to read more:

A dark blue rounded rectangular button containing a white circular icon with a diagonal arrow and the word "Link" in a pink sans-serif font.

[Link](#)

Live-cel™ Therapy - One Treatment for Years of Relief

Contact:
Chris Hopkins
Dm +1 801 631 9114
chris@glafabra.com

Glafabra
Therapeutics

A clinical-stage
biotherapeutics
development company



Company Overview

- Lead asset for Fabry in clinic - Safe, Effective and Durable.
- Seasoned operators from the cell and gene therapy industry.
- Live-cel(TM) technology - a cell-based gene therapy approach.
- Targeting Fabry and other enzyme deficiency disorders.
- Ex vivo autologous - patient's own immune cells engineered to provide missing enzyme.

Financial Info

Raising
\$0.5 M

Valuation
\$5 M

Problem

Current standard of care in Fabry treatment is enzyme replacement therapy (ERT) and requires high frequency protein infusions - patients need to get the jab-for-the-bag every other week. They need to build their lives around tedious clinical visits. Our Live-cel infusions use patient cells and last 130x longer. With Live-cel, patients only need to repeat an infusion procedure every 3-5 years. Patients get all that time back with their family and can now go away easily, for extended-stay trips.

Location

Park City, UT, USA

Business Stage

pre-seed

Business Type

Healthcare, Biotech,
Biopharma development

Highlights

- Glafabra has recruited Uncommon Cures to help guide us on clinical trials design and regulatory submissions.
- Glafabra has signed LOI with University of Utah to be our main clinical trials and cell manufacturing site.
- Glafabra has signed Exclusive Options Agreement with the Medical College of Wisconsin for patent covering our cell engineering technology.

Go-To-Market Strategy

Glafabra's go-to-market strategy is a repeat demonstration of the Fabry therapy under a phase 2 clinical trial in the US. Also, we plan to demonstrate the same core technology platform can be applied to Gaucher and Pompe diseases. Demonstration that our approach is effective in more than one disease will indicate our approach is broadly applicable to 100s of other genetic diseases. Multi-indication demonstration will drive a \$1-\$4 billion exit when we achieved multi-indication phase 2 efficacy data before 2030.

What Makes Us Special

- Clinical stage startup - Our lead asset clinically demonstrated in Canadian clinical trial.
- Filing an IND in early 2026, in collaborating with Uncommon Cures.
- Therapy can be re-dosed as needed every 3-5 years
- Team is comprised of seasoned experts in biopharma development.

Meet the Team

Chris Hopkins
CEO



Elizabeth Wagner
COO

Krista Casazza
Reg. Sci.



Dwayne Barber
Clin. Ops

IN PARTNERSHIP WITH



National
FABRY DISEASE
Foundation



CFA

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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=BvU5NKdOGnl&t=192s>.

100% confidential service includes **24/7 access** to a network of experts at [800-648-9557](tel: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:

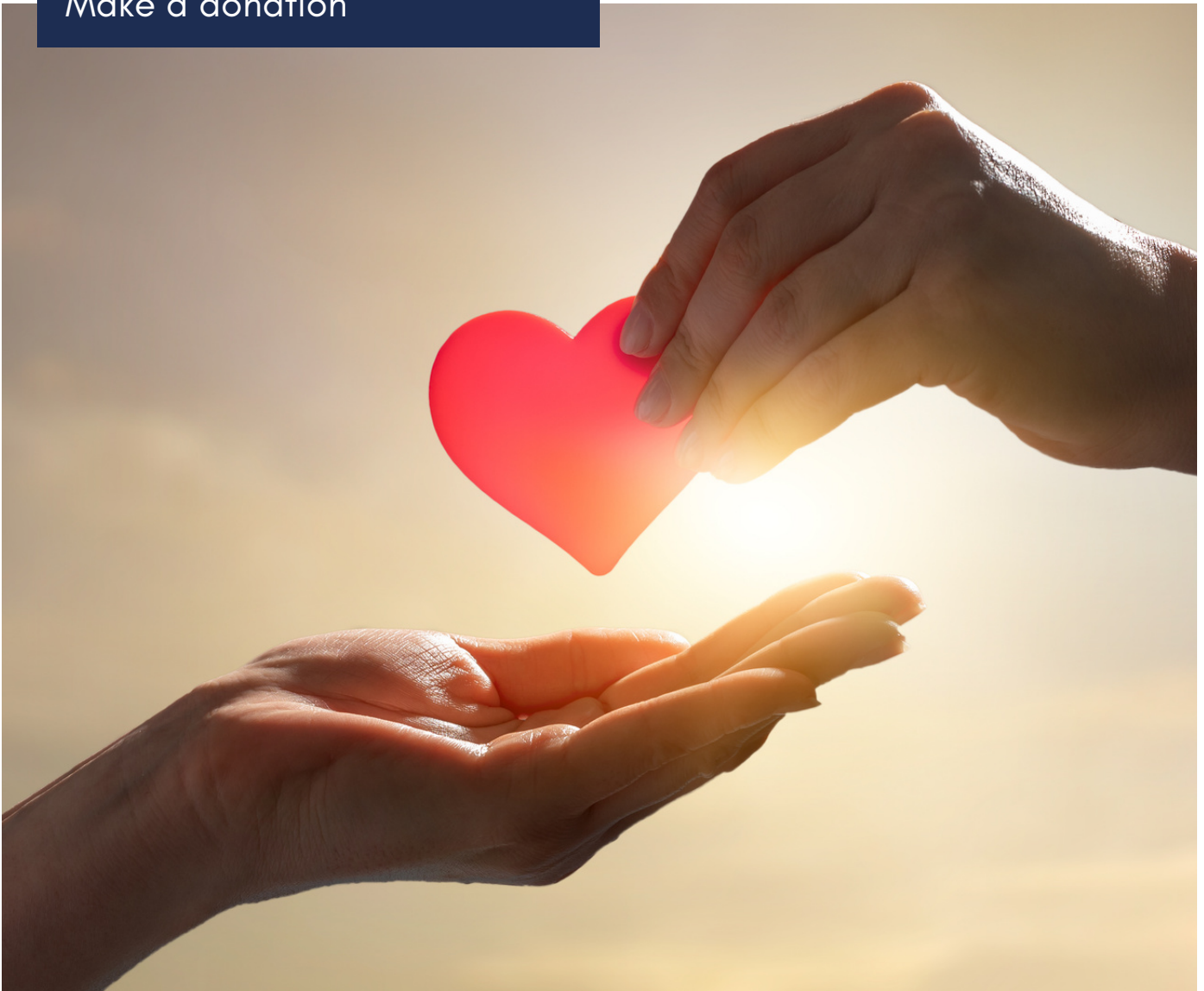
<https://www.youtube.com/watch?v=BvU5NKdOGnl&t=192s>

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



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.

The Sanofi logo, featuring the word "sanofi" in a lowercase, sans-serif font. The letters "s" and "i" have a small purple dot above them.