CFA CANADIAN FABRY ASSOCIATION

volume 14 issue i
Winter 2023

NEWSLETTER

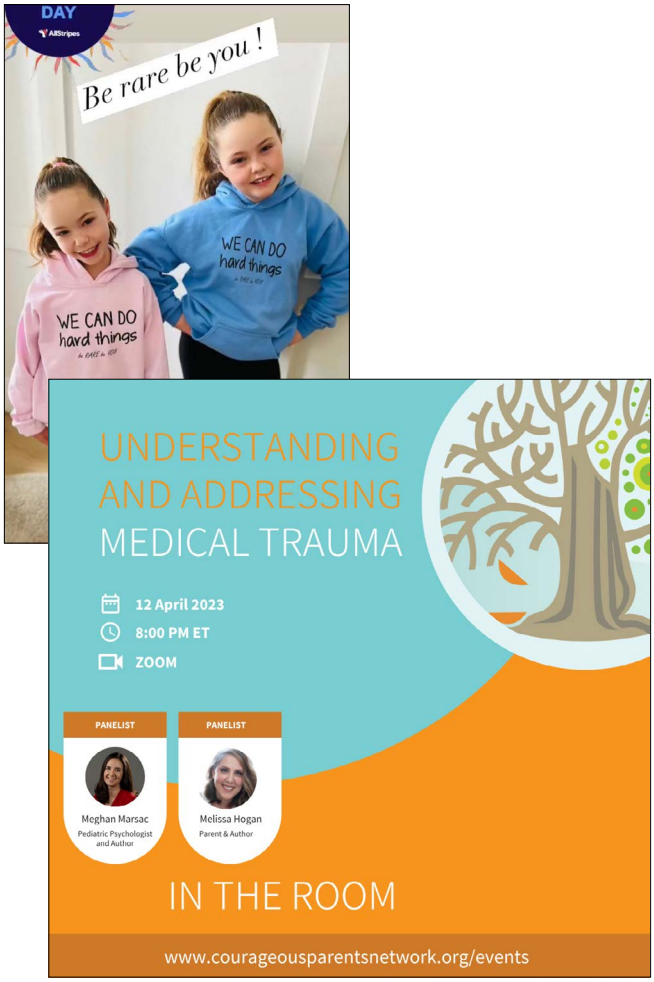
in this issue: | Patient Empowerment Workshop | Courageous Patient Network | Venglustat Clinical Trials | WORLD Symposium | Sangamo Gene Therapy Trial | Chiesi Mental Health | Rare Disease Day

Save the Date! June 3rd, 2023

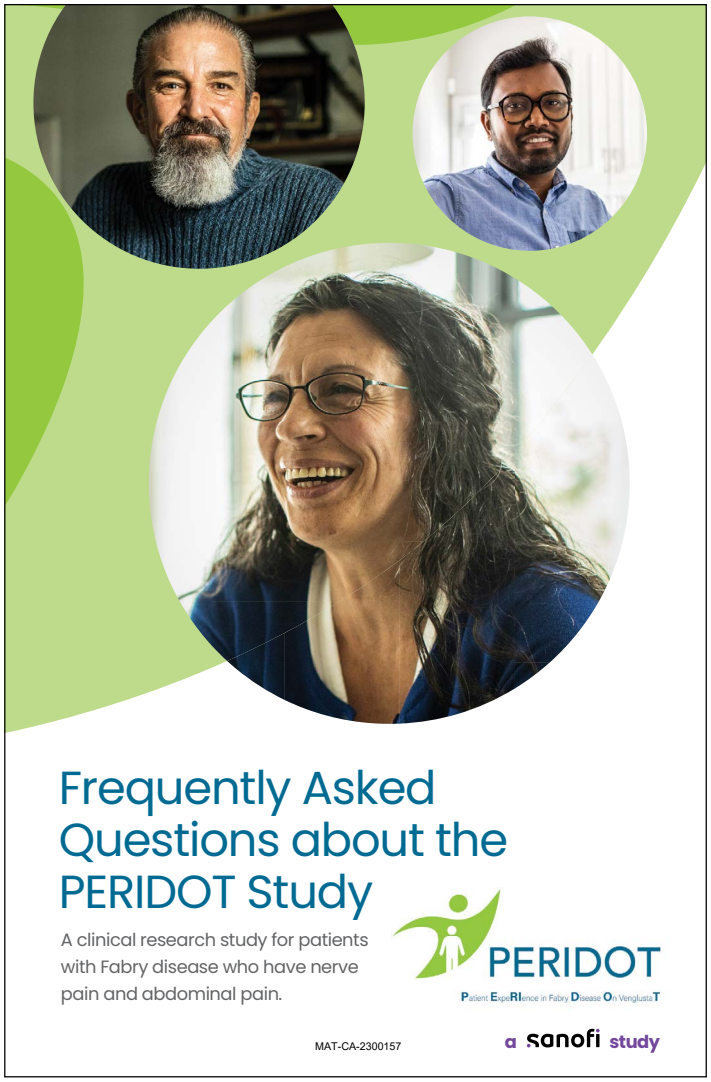
our next Patient Empowerment Meeting for those living in Alberta, Saskatchewan, and Manitoba. Registration will be opening soon.

Courageous Parents Network

(CPN) is hosting a webinar on Understanding & Addressing Medical Trauma: April 12, 2023.



PATIENT EMPOWERMENT QUESTION: Q. How many rare diseases have been identified in the world?



Venglustat Clinical Trials

Link: https://www.fabrycanada.com/venglustat-trials-approved-sanofi/

Venglustat Trials Approved! (Sanofi) We have exciting news, Sanofi has two new trials that were approved!

CARAT:
Excerpt from the document:
This clinical research study is seeking adults with Fabry disease to investigate the effect of a new investigational oral drug on the heart.

Clinical Trials (.gov) link. This is the official information posted on the government site.
http://clinicaltrials.gov/ct2/show/study/NCT05280548

PERIDOT:
Excerpt from the document:
This clinical research study is seeking adults with Fabry disease to investigate the effect of a new investigational oral drug on nerve pain and abdominal pain.

Clinical Trials (.gov) link. This is the official information posted on the government site.
http://clinicaltrials.gov/ct2/show/study/NCT05206773

Stay tuned for the WORLD Symposium highlights with Dawn Laney - Date TBA

Rare Disease Day

Thank you to the Fabry community for participating in Rare Disease Day. A day that aims to bring awareness to the 7000+ rare diseases. We stand together as we bring awareness, understanding, and recognize everyone who makes up the rare disease community and their determination to better the lives of all those affected.

Chiesi Mental Health + Fabry Disease Survey

To help improve the understanding of how Fabry Disease can affect the mental health of individuals and their families, we launched a special anonymous survey with Chiesi intended for members of the Fabry community. We invite you to share your perspectives.
Link: https://lnkd.in/gQ6hTEt4

Donations to the CFA are greatly appreciated

Sangamo Gene Therapy Trial

Link: https://www.fabrycanada.com/content/uploads/Sangamo_Fabry_CAN_website_PDF.pdf

Link: https://www.fabrycanada.com/content/uploads/Sangamo_Fabry_Infographic_Design__V1.0_US_CANADA_040222.pdf

PATIENT EMPOWERMENT ANSWER:

A. 7000+ rare diseases have been identified around the globe.

OUR INTERNET PRESENCE

Our Website: ***www.fabrycanada.com***

Facebook: Canadian Fabry Association

Instagram: Canadian Fabry Association

Twitter: ***@CdnFabry***

THANKS TO OUR SUPPORTERS

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

We receive financial support from these Pharmaceutical companies who are currently providing hope for Fabry patients through their research and the products they provide.

Amicus Therapeutics
Sangamo Therapeutics
Chiesi
idorsia
SANOFI GENZYME Empowering Life
Takeda

We would also 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.

And of course we would 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.

MAKE A DONATION

Would you or a family member like to make a donation so that we can continue to educate and advocate for the best treatment as well as communicating with and for Fabry patients in Canada?

The Canadian Fabry Association (CFA) is a registered not-for-profit organization.
If you are interested in making a charitable donation and would like a tax receipt, please make your cheque payable to The Fabry's Charity Association.

100% of donations to the CFA are used to promote education, patient support and access to treatment for Canadian Fabry patients. You can make donation cheques payable to The Fabry's Charity Association and mail the cheque to us.

Send the cheque to:
The Fabry's Charity Association
1964 Hawkridge Dr.
Thunder Bay, ON
P7J 1H2
or register online by visiting our website:
www.fabrycanada.com

Thanks for your donation to the CFA! It goes to help Canada Fabry patients, their families and caregivers.