



Share your experiences with LC-FAOD

Virtual Advisory Board for LC-FAOD Patients and Caregivers

Ultragenyx Pharmaceutical Inc. is planning a virtual meeting for people residing in Canada who are living with or caring for someone living with a Long-Chain Fatty Acid Oxidation Disorder (LC-FAOD). This will help us better understand the needs of the LC-FAOD community and gain a deeper understanding of how best to communicate and work with the community.

We would like to hear:

- Your thoughts and feelings related to your LC-FAOD journey and areas of unmet need within the community
- Your feedback about programs being developed for the LC-FAOD community and what additional resources are needed to support patients and caregivers

If you or someone you care for is living with LC-FAOD and would like to share your experience, please contact our partners at bree@mypatientstory.com or **1-833-598-0564**.





Here are some additional details about the meeting:

- You must be living with or caring for someone living with a LC-FAOD and should be articulate and comfortable with participating in group discussions.
- You must reside in Canada.
- Experience with the following LC-FAOD conditions would be ideal:
 - Carnitine Palmitoyltransferase (**CPT I or CPT II**) Deficiency
 - Very Long-Chain Acyl-CoA Dehydrogenase (**VLCAD**) Deficiency
 - Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase (**LCHAD**) Deficiency
 - Trifunctional Protein (**TFP**) Deficiency
 - Carnitine-Acylcarnitine Translocase (**CACT**) Deficiency
- Given the meeting will be conducted virtually, you must have access to a computer, tablet, or smart phone with a stable internet connection during the December 2020/January 2021 timeframe.
- You will be compensated for your time.
- There will be a few representatives from Ultragenyx participating in the meeting. This Patient and Caregiver Advisory Board is not related to participation in any clinical trial.
- Only minimal information will be shared with Ultragenyx if you express interest in moving forward and agree to allow your information to be shared.
- Participation is limited and not all interested candidates will be eligible.



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