

# LC-FAOD Odyssey

## Contribute to critical medical research (from your home!)

Visit <https://picnichealth.com/lcfaod> to learn more and sign up

Want help signing up? Call (415) 801-0572



## LC- FAOD Odyssey Overview

The goal of this study is to better understand how long-chain fatty acid oxidation disorders (LC-FAOD) appear in the real world, in real people like you. PicnicHealth gives you access to your complete medical history by collecting, digitizing, and encrypting all of your medical records, from all of your doctors and other healthcare professionals (e.g., dietitian, nutritionist). This unique IRB-approved study is a collaboration between Ultragenyx Pharmaceuticals and PicnicHealth. De-identified information from your medical history will be shared with Ultragenyx to help advance research. Signing up for this study will take no more than 10 minutes, you can be compensated up to \$150 in the first year for enrollment and completion of short surveys (~10 minutes each) and enrollment will not affect your ability to participate in clinical trials.

## How does this study work?



Sign up, share the names of all your doctors in less than 10 minutes, and complete an initial survey



PicnicHealth compiles and de-identifies your medical records and you complete additional short surveys



Researchers use this de-identified data to improve their understanding of LC-FAOD to improve future quality of care

## Study Details

### How do I qualify for this study?

Anyone who has an LC-FAOD diagnosis (such as CPT I, CACT, CPT II, VLCAD, TFP, or LCHAD) in the United States is eligible for this study.

### Will I receive any investigational medications in this study?

No, there are no investigational medications in this study. If you are receiving an investigational medication in another study, you may still participate.

### Why are there surveys?

Surveys can collect information that does not exist in medical records. You may be asked to complete an initial survey once and a subsequent survey up to four times a year. Each will take approximately 10 minutes.

### Who is sponsoring this study?

This study is a collaboration between Ultragenyx Pharmaceuticals and PicnicHealth.

### Will I be compensated for this study?

Yes, you can be compensated up to \$150.00 in the first year. This can include \$50.00 for completing an initial survey and \$25.00 for completing subsequent surveys up to four times a year.

### Will I still be able to participate in clinical trials if I join this study?

Absolutely. Signing up for this study will not impact your ability to sign up for clinical trials.

### How are patient rights protected for this study?

In order to protect patient rights, this study has been approved by an Institutional Review Board (IRB). IRBs make sure that people in research are protected and that federal laws are followed. Additionally, PicnicHealth will always protect your rights and privacy by de-identifying your data before sharing it with researchers.

To learn more and sign up at visit [picnichealth.com/lcfaod](https://picnichealth.com/lcfaod)  
You can also email us at [faodstudy@picnichealth.com](mailto:faodstudy@picnichealth.com)