

Research Being Conducted: Fatigue in Barth Syndrome



As part of a mixed-methods study, Virginia Commonwealth University is conducting research on perceived fatigue and energy expenditure associated with having Barth syndrome. Our aim is to develop a model for predicting fatigue levels and inform future Barth syndrome clinical research studies. Participants will be asked to wear an activity tracker for 2 weeks and report their energy levels throughout the day. We are recruiting participants that:

- Are ages 5 and up
- Have a confirmed diagnosis of Barth syndrome
- Understand English

Interested affected individuals and parents/caregivers are asked to complete the eligibility survey:

https://redcap.vcu.edu/surveys/?s=4ECX43AMY4

OR...