

Do You or a Loved One Have Barth Syndrome?

Children, Teens and Adults Needed to Volunteer for a Research Study

What

We want to better understand the frequency of depression, anxiety and health related quality of life in people with Barth syndrome (BTHS). We also want to develop a patient/parent-reported, BTHS-specific checklist that will help us identify gaps in clinical care.

Why

We hope this information can be used to learn more about targets for clinical interventions and treatments.

Who

Children, teens and adults, 5 years and older, who have Barth Syndrome may be eligible for participation.

Participants must have home Internet connection to complete online questionnaires.

What's Involved

Parents/participants will complete 3 questionnaires, 6 months apart, as well as take part in a focus group

with other participants and clinical experts to develop and test a BTHS-specific symptom checklist.

Pay

Participants will not be paid for their time, travel or effort during this research study.

Contact

513-803-0366 or hirc@cchmc.org

The study doctor for this research study is John Lynn Jefferies, MD.



Research Foundation

cincinnatichildrens.org/clinical-studies
facebook.com/cincinnatichildrensstudies
pinterest.com/cincykidstudies