

# Do You or a Loved One Have Barth Syndrome?

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



CCHMC IRB # 2014-7162: V2

## 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. Parents/legal guardians for children or teens under the age of 18 will also be asked to participate in this study.

Participants must have home internet connection to complete online questionnaires.

## What's Involved

Parents/participants will complete 6 questionnaires (6 months apart for 3 years) as well as take part in a focus group (with other parents/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 [BarthSyndromeStudy@cchmc.org](mailto:BarthSyndromeStudy@cchmc.org)

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



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