



## **Development of a Self-Help Program for Children with Barth Syndrome**

We are a research team at Binghamton University conducting survey research to develop a self-help program to promote participation in everyday activities for children with Barth syndrome at home, at school, and in community settings. We are inviting up to **25 parents of children with Barth syndrome** to participate in this study. Parents will receive a \$50 gift card as compensation for completing the study surveys.

Who can participate?

**Parents of children with Barth syndrome:**

- 1) Their child's age is between 7 and 17
- 2) Speak English

What will you be asked to do?

**Parents** will complete three online questionnaires about their child's ability to take care of themselves and their child's level of fatigue in daily life. **Their child's participation is optional.** If their child chooses to participate, they will complete two questionnaires with the researcher via Zoom, asking about their daily activities and what matters most to them. An additional \$30 gift card will be provided for the child's participation.

**Should you choose to participate in this study, please contact:**

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*Please review the link below for more details about the research and your rights as a participant.  
This study has been reviewed and approved by Binghamton University's IRB.*

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