

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

Do you have a child or youth with Barth syndrome?

We are a research team at Binghamton University conducting a study on the development of a self-help program to promote participation in everyday activities for children with Barth syndrome across home, school, and community settings.

What will you be asked to do?

You will be asked to complete online questionnaires about your child's self-help abilities, movement and coordination abilities, as well as participate in an interview to share your child's experiences in daily activities.

If you:

- 1) Have a child with Barth syndrome with no severe physical disabilities
- 2) Speak English

Please review the link below, which will provide further details on the research and your rights as a participant.

https://drive.google.com/file/d/17N5Nyu-D2d4PEZi6N87Y6F9-V4Ttibe1/view?usp=drive_link

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

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