

The Female Side of Barth – Calling All Adult Women!

What is this research study? As more boys and men are correctly diagnosed with Barth Syndrome, mothers, sisters, daughters, and grandmothers face their own challenges. This questionnaire study builds on interviews we did with Barth Syndrome carriers to measure the emotional, family, reproductive, and psychological implications of having a relative with Barth Syndrome. We are asking ALL ADULT WOMEN to join. We hope study results will help both health care providers and patient organizations provide better care to women in families with X-linked conditions, especially Barth Syndrome!

What will you ask me to do? Complete one questionnaire.

You can fill it out online or we can mail it to you.

Who can participate? Any adult woman who has / had a relative with Barth Syndrome.

Carriers, women who are not carriers, and those not yet tested can all participate.

How do I find out more? Please call or email us to get a questionnaire.

Study PI Cindy James at cjames7@jhmi.edu or 443-287-5985.

Study Genetic counselor Rebecca McClellan at mccllellan@kennedykrieger.org or 410-502-2578

There will be no monetary compensation for participating in this study.

Contact Us!

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Genetic counselor Rebecca McClellan:
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