

## **Are You a Barth Syndrome Carrier?**

**What is this research study?** As more boys and men are correctly diagnosed with Barth Syndrome, more women are finding out they are Barth Syndrome carriers. This telephone interview research study explores how Barth Syndrome carriers navigate the family, reproductive, and psychological implications of being a carrier. We hope research study results will help both health care providers and patient organizations provide better care to carriers of X-linked conditions, especially Barth Syndrome!

**Who can participate?** Any woman, age 18 or older, who is a Barth Syndrome carrier

**What will you ask me to do?** Be interviewed by telephone for about 45-60 minutes. The interviewer will be a health care provider who has worked with families affected by Barth Syndrome.

**How do I find out more?** Please call or email us!

Study PI Cindy James at [cjames7@jhmi.edu](mailto:cjames7@jhmi.edu) or 443-287-5985.

Study Genetic counselor Rebecca McClellan at [rmccl4@jhmi.edu](mailto:rmccl4@jhmi.edu) or 410-502-2578

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

### **Contact Us!**

Research study PI Cindy James:  
[cjames7@jhmi.edu](mailto:cjames7@jhmi.edu) or 443-287-5985.

Genetic counselor Rebecca McClellan:  
[rmccl4@jhmi.edu](mailto:rmccl4@jhmi.edu) or 410-502-2578

*Dr. Cynthia James, Principal Investigator  
Study number (IRB 00052976)*