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# Patients Needed for Research Study on Barth Syndrome

Dr. Bianca Russell and Dr. Yue Huang from the Department of Pediatrics, Division of Genetics at the University of California, Los Angeles (UCLA) are conducting a research study to learn more about the best ways to care for patients with Barth syndrome. The purpose is to gather information about progression, treatments and outcomes for patients with this disorder. We have a special interest in Barth syndrome patients who have a history of seizures or stroke.

## You May Qualify If You

- Are a patient with a clinical or molecular diagnosis of Barth Syndrome
- Have a history of seizures or stroke

## Potential Benefits

You will not directly benefit from participating in this research. The results of this study may benefit this community of rare diseases by helping better understand how to treat patients and what to expect in the future. There is no anticipated financial benefit for participants.

## Participation Involves

- Signing an informed consent and/or assent form.
- Signing a HIPAA authorization form to allow the study team to collect information from your medical record.
- Answering questions regarding your medical history, example of questions:
  - What procedures have you had?
  - What medications do you take?
  - Have you ever had stroke?
  - Have you ever had a brain MRI?  
If so, what was the date and location

**If you are interested in participating in this study**

**Please contact Dr. Bianca Russell and Dr. Yue Huang  
at [yuehuang@mednet.ucla.edu](mailto:yuehuang@mednet.ucla.edu)**