Volunteers Needed for a Research Study of Bone Health and Muscle Strength

Children and adults with cystinosis are at risk for musculoskeletal disease. This research study, performed by Drs. Mary Leonard and Paul Grimm, will be the first comprehensive evaluation of bone structure and muscle strength in children and adults with cystinosis. The results of this research study may be used to develop clinical trials to improve bone health, muscle strength and quality of life in children and adults with cystinosis.

What Is the Purpose:

To examine bone structure and muscle strength in children and adults with cystinosis, compared to those without cystinosis.

Who is Eligible to participate:

Children and adults ages 5 to 60 years with cystinosis.

What is required:

- Participants will be asked to complete a single study visit, lasting about 3 hours.
- Participants will be asked to complete questionnaires, physical assessments, and bone scans.
- Participants will be asked to provide a small amount of blood, about 2 tablespoons, for laboratory studies.

Participants will be given a picture of their bone scan, an analyzed DXA report, and $150 gift card.

For more information please contact:

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For further information regarding questions, concerns, complaints about this research or your rights, please call 1-866-680-2906.