

Research Study Participants Needed

For Focus Groups and Individual Interviews with

Young adults (18-30) with cystinosis*

AND

Mothers and fathers of young adults (18-30) with cystinosis*

The purpose of this research is to understand the experience of growing up with and living with cystinosis as a young adult.

Focus groups will take place July 14-16, 2011 in San Francisco (during the CRN Family Conference**) and will last approximately 90 minutes.

Individual interviews will take place in the following 3-6 months in participant's home or a location convenient to your home. Interviews will last 60-90 minutes.

*Young adults with cystinosis may participate in focus group or interview without their parent participating. Parents may participate in individual interviews only if their young adult child does too. Participants can choose to take part in focus groups, interviews, or both.

**You can participate in study even if you are *not* registered for the CRN Family Conference

Please visit <https://www.surveymonkey.com/s/yacys> for more information and to register to participate. You may also contact researcher by phone or email to discuss this study. Researcher will contact you by phone to discuss your eligibility for the study.

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