

Volunteers needed to take part in interviews

In the context of the study "Development of a patient-reported outcome to measure the health-related quality of life of children and adolescents with cystinosis: QUALIFY-US" of the Department of Medical Psychology at the University Medical Center Hamburg-Eppendorf (UKE) in Germany, we are conducting interviews with children, adolescents and young adults with cystinosis as well as their parents. The aim of the study is to develop and validate a disease-specific questionnaire to measure the health-related quality of life (HrQoL). Therefore, we aim to identify all important aspects of HrQoL, and learn more about the challenges and management of the disease and the needs of patients living with cystinosis. Based on these findings, a disease-specific questionnaire is being developed to help take into account all aspects of the disease that are important from the point of view of the patients as well as their families in the treatment of cystinosis, thus ensuring optimal therapy for the patient.

We are looking for:

- ❖ **children, adolescents and young adults** with a confirmed diagnosis of cystinosis aged **8-26 years** as well as at least one of **their parents**
- ❖ **parents of 0-7 years old children** with a confirmed diagnosis of cystinosis

As compensation for your time, each participating family will receive a \$17.25 voucher

The interviews and/or group interviews will take place online as a video conference (using Cisco Webex Meetings) and will take approximately **90-120 minutes** of your time.

If you would like to participate or have any questions about the study, please contact **Isabell Suck** or **Stefanie Witt** (e-mail: quality-of-life@uke.de).

Thank you for your support!

Principal Investigator:

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