

QUALITY OF LIFE IN CYSTINOSIS PATIENTS

Dear Cystinosis Patient/Parent:

During CRN Meeting in San Francisco in July 2011 I will be conducting a survey to gather information regarding the Quality of Life (QOL) for patients with the diagnosis of Cystinosis.

The survey will be performed via personal interview or you will be asked to mark the best answer to the listed questions (1 or 2 pages). Depending on the patient's age, either parents or patients or both will be asked to answer questions. It takes less than 5 minutes to complete it.

If you are interested in participation in the survey, please leave me the message at the CRN meeting registration desk (please leave your contact information, e.g.: room number or cell phone number, so I can contact you).

Information provided in the survey will remain confidential. This questionnaire is completely voluntary and will be used for research purpose only.

Sincerely,

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