

CCIR and You – Help Us Find a Cure!

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The new Cure Cystinosis International Registry (CCIR) was launched in the Spring of 2021. Considering the ultra-rare nature of the disease, with only an estimated 600 patients in the United States, individual input from patients is extremely important and useful. Furthermore, individuals with cystinosis often experience widely different symptoms and complications often requiring unique and individualized treatment and care. This further illustrates the significance of participation in the registry. The registry is a key link between patients and researchers, which ultimately both enables and guides research on improved treatment for cystinosis. Your participation in the patient registry can help accelerate research towards improved treatment and a cure. This presentation will provide a brief introduction to the registry and provide preliminary insight on current participation and the valuable data it is providing. This presentation is a call to action for families to participate and be part of progress towards better treatment a cure.