

CCIR: Be Part of the Cure

Clay Emerson, PhD, PE

CRF Trustee

The new Cure Cystinosis International Registry (CCIR) was launched in the Spring of 2021. The new registry is a complete overhaul of the original (pre-2020) registry with new questions providing insight into ever-changing modern treatments and management of cystinosis. 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 to researchers. Further illustrating the importance of the registry is the fact that individuals with cystinosis often experience widely different symptoms and complications requiring unique and individualized treatment and care. The patient registry is a key link between patients and researchers and ultimately both enables and guides research towards 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 and an ultimate cure.