



Cure Cystinosis

International Registry

The new patient Cure Cystinosis International Registry (CCIR) is informing researchers and ultimately accelerating the development of better treatments and a cure for cystinosis. The value of the registry will only be realized with your participation. We strongly encourage patients or caregivers to participate in the registry and help identify the needs of patients with cystinosis and help accelerate research!

IMAGINE WHAT WE CAN DO TOGETHER!

- ★ The CCIR is designed to facilitate the development of new clinical trials and research studies for cystinosis by connecting the patient and research communities. Registered providers receive notification of clinical trials, including recruitment, updates, and result outcomes.
- ★ Medical and research professionals who register on the professional/researcher portal can request de-identified data about numerous clinical characteristics from the patient registry database.
- ★ All of the information provided to CCIR is maintained in a secure database. Information that could identify participants and their family members will not be shared without their expressed written approval.
- ★ By combining the resources of all the members of the cystinosis community, we increase the likelihood of developing advancements in the treatment and care of cystinosis.

Thank you to CCIR Committee Members

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IMPACT CURRENT AND FUTURE CYSTINOSIS RESEARCH

- ★ Communicate with researchers what ailments those with cystinosis are dealing with.
- ★ Individuals of all ages with cystinosis are needed to help develop better treatments. The registry enables you to let researchers interested in cystinosis know that you are open to participating in clinical trials
- ★ Spread the word – we need worldwide participation from all those living with cystinosis! Gathering data about treatments, outcomes, and well-being of these individuals will help researchers get a better 'picture' of what is happening in the body.

