

Cure Cystinosis International Registry



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The Cure Cystinosis International Registry is a collaborative effort by leaders in the global cystinosis community to establish a comprehensive, international patient registry for cystinosis.

The CCIR is a central hub of information and will be used as a resource for those with an interest in cystinosis. The site will be available to clinicians, researchers, scientists and pharmaceutical companies and will provide them with limited access to a database of information provided by patients and their families. That information could prove vital to advances in the care and treatment for those with cystinosis.

- ★ 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 information provided to CCIR is maintained in a secure database managed by a professional curator. 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.

Your participation is crucial to this goal, and is appreciated. Encourage your patients and colleagues to register today at cystinosisregistry.org.



**CURE CYSTINOSIS
INTERNATIONAL REGISTRY**

www.cystinosisregistry.org

If you have questions about the registry please contact the CCIR Curator at coordinator@cystinosisregistry.org. To request printed brochures, contact the Cystinosis Research Foundation at 949.223.7610 or info@cystinosisresearch.org.