Dear people with cystinuria,

Please join the Cystinuria Registry.

We hope your participation will be important in the understanding of the disease and in the development of new treatment options for cystinuria.

We are happy to announce the launch of the Cystinuria Registry at New York University School of Medicine. This registry is part of the Rare Kidney Stone Consortium, which in turn is part of the Rare Disease Clinical Research Network. This research is sponsored by the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) and the Office of Rare Disease Research (ORDR). The registry was developed in conjunction with several academic institutions and leaders in kidney stone research worldwide. At NYU, the registry is under the supervision of Dr David Goldfarb and his team.

In this registry, we are planning to enroll patients with cystinuria and collect information about their condition annually. The collected data in this registry will help us to get a better understanding of this condition. The goal of this registry is to collect data about this rare disease, that may help us to develop better treatment protocols in the future.

The privacy and confidentiality of all information collected in this registry is protected and will be used for research purposes only.

We have worked closely with our patient advocacy groups (PAGs), the International Cystinuria Foundation (ICF) and the Cystinuria Support Network (CSN) to support, develop and promote the registry and research on cystinuria.

If you are interested in joining the registry, please follow the link indicated below for further information. Feel free to contact us at cystinuria@nyumc.org or go to our website and start your registration by reading the contract agreement.

Please join the Cystinuria Registry.

http://www.med.nyu.edu/medicine/nephrology/research/current-investigations/accordion/nephrolithiasis-studies/cystinuria-registry/join