

## **Cystinosis Network Europe Worldwide Cystinosis Community Advisory Board**

Cystinosis Network Europe (CNE) is an umbrella grouping of patient support, advocacy, and research organisations in Europe and beyond. The group originally came together informally to provide peer support to national organisations and to facilitate hosting a family and research conference every two years in Europe. CNE co-ordinates the Cystinosis Community Advisory Board (CAB) which is a group of patient representatives who offer their expertise to public or private sponsors of clinical and other research. The CAB members are experts in cystinosis by experience – adults living with the condition and parents and grandparents of both children and adults with cystinosis – as well as being highly trained in research processes up to and including engagement with regulatory and reimbursement authorities. The CAB offers a way for sponsors of research to engage with the cystinosis community in a structured and meaningful way to improve research outcomes.