What are the key projects of CNE?

Formalising and establishing CNE as a registered charity.

Development of the Worldwide Cystinosis Community Advisory Board.

Delivery of the biannual International CNE Conference.

Who are CNE?

The members of CNE include representatives from:
- AIRG-España
- AIRG France
- Asociación Cistinosis España
- Associazione Cistinose, Italy
- Cystinose France
- Cystinosis Group Belgium
- Cystinosis Ireland (incl Northern Ireland)
- Cystinosis Foundation South Africa
- Cystinosis Foundation UK
- Cystinosis Research Network, USA
- Cystinose-Selbsthilfe e.V., Germany
- Cystinosis Support Group Australia
- Dutch Cystinosis Group

Since 2016, CNE has expanded to welcome representatives from organisations outside Europe.

Cystinosis Network Europe to date

2016: Eight European organisations come together to form a network to support people with cystinosis and promote research.
2017: Campaign for access to Procysbi.
July 2018: Cystinosis Ireland agreed as secretariat until July 2020.
January 2019: CNE members meet in Dublin and commit to formally registering CNE. Chair elected.
November 2019: First CAB meeting
April 2020: Virtual Cystinosis International Conference

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