



Cystinosis Network Europe Cystinosis Network Europe

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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.



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 Procsybi.

2018: International Cystinosis Conference, Berlin, Germany.

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

Who are CNE?

The members of CNE include representatives from:

AIRG-España

AIRG France

Asociación Cistinosis España

Associazione Cistinosi, 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.

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