



Cystinosis Network Europe Activity Report 2022

In 2022 CNE undertook activities through its secretariat, Board and working groups – the Community Advisory Board (CAB) and CNE International Conference. The report on the work of CNE is set out here.

Board and Secretariat

In 2022 the Board met on five occasions, online. The meetings addressed areas of governance and setting the organisation's activity plans.

In 2022 the board undertook significant work towards meeting the requirements of the Governance Code as set out by the Charities Regulator including developing policies and procedures and establishing frameworks for our activities.

The annual general meeting of the organisation was held online in November 2022.

The board also supported the co-funding of a special edition of Cells Journal, edited by Prof Elena Levtchenko, dedicated to cystinosis research. The edition was co-funded with Cystinosis Ireland.

Community Advisory Board

The Community Advisory Board (CAB) group met online on four occasions to discuss areas of importance and to plan for interactions and updates with research sponsors. The CAB met in person in Leuven, Belgium, during the international conference. At this meeting the CAB also met with one company. The CAB continued to identify areas of importance to the community and areas for ongoing training for CAB members.

The CAB members also reviewed online patient information materials and gave input on outreach and education programmes proposed by pharmaceutical sponsors. The CAB provided PPI (public patient involvement) support for research applications from academic researchers to ensure the patient voice and perspective is included in the earliest stages of research design.

International Conference

The 3rd International CNE Conference was hosted by the Dutch Flemish Cystinosis Group in Leuven, Belgium, in July 2022. The meeting was a significant success, not least because of the continued impact of covid-19 on the international psyche. For some, travel was still impossible, but the conference had 145 attendees in person which was an excellent turn out in otherwise challenging global conditions.

The recorded sessions, with full translations, are available on the website www.cystinosis.eu as a resource for our international community.

Cystinosis Network Europe, hosted by Cystinosis Ireland 1-2 Cavendish Row, Dublin 1, Ireland
Cystinosis Ireland; Cystinosis Foundation UK; Dutch Cystinosis Group; AIRG France; Cystinose France; AIRG-España; Asociación Cistinosis España; Cystinosis Group Belgium; Associazione Cistinosis; Cystinose-Selbsthilfe e.V., Germany; Cystinosis Research Network; Australian Cystinosis Support Group; Cystinosis Foundation South Africa; Cystinosis Support Mexico; Cystinosis Support Group Turkey; Cystinosis Support Group Russia

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The meeting agenda was:

Thursday 7th July – Research and paramedical conference (professionals only)

Friday 8th July – Patient and family conference

Saturday 9th July – Patient and family conference

Sunday 10th July – Patient and family conference

Member Advocacy

A number of member organisations reported issues with batches of medications towards the end of 2022. Through contacts in the associated company, CNE worked to try to establish the issues causing the problems and made efforts to ensure information was shared to the community as available.

CNE also worked to support national groups who were experiencing issues in accessing therapies either because access is not yet available in their country or where supply lines had broken down for various reasons.