

Worldwide Cystinosis Community Advisory Board

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What is a Community Advisory Board (CAB)?

A group trained of patients and patient representatives who offer their expertise to public or private sponsors of clinical research and early stage researchers.

The same group of patients advises several sponsors in their field.

Agenda and secretariat driven by the patients.

The CAB remains an autonomous and independent board.

What can the CAB offer?

Expertise on:

- patient outreach
- education on research
- clinical studies and their design
- criteria for participation
- informed consent forms and processes
- compassionate use programmes
- better retention of participants
- reporting on results
- autonomy and independence

The CAB includes 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

What are the key principles of the CAB?

1. Neutral setting
2. Confidentiality
3. Transparency
4. Sharing
5. Openness
6. Optimisation of research and development
7. A joint action plan as an outcome of the meeting

Worldwide Cystinosis CAB work to date

July 2018: Briefing from Eurordis at Berlin Cystinosis Conference.

January 2019: First internal meeting and commitment to proceed. Chair elected.

March 2019: Training begins.

April 2019: Initial engagement with sponsors begin.

November 2019: First CAB and Sponsors meeting in Dublin.