

# Worldwide Cystinosis Community Advisory Board

## What are the key principles of the CAB?

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

## Who are the Worldwide Cystinosis Community Advisory Board?

The CAB includes representatives from:

AIRG-España  
 Asociación Cistinosis España  
 Asociación Mexicana de Cistinosis AC  
 Cystinosis Ireland (incl Northern Ireland)  
 Cystinosis Foundation UK  
 Cystinosis Research Network, USA  
 Cystinose-Selbsthilfe e.V., Germany  
 Dutch-Flemish Cystinosis Group  
 Vaincre les Maladies Lysosomale (VML) France

This group is nominated to represent our full membership –  
[www.cystinosis-europe.eu](http://www.cystinosis-europe.eu)

## What is a Community Advisory Board?

- A group of patient representatives who offer their expertise to public or private sponsors of clinical and other research
- The same group of representatives advises several sponsors in their field
- *Agenda and secretariat driven by the patients*
- *The Cystinosis CAB Members are adults with cystinosis or parents or carers of people with cystinosis. All are experts in the condition and educated in research and research processes.*
- *Sponsors of research include pharmaceutical/healthcare companies; and researchers in hospitals, universities, and other settings*

*The Worldwide Cystinosis CAB was established under the processes of the EuroCAB programme of EURORDIS but now operates autonomously.*

## What can the CAB offer?

Patient representatives offer their expertise on:

- Patient outreach
- Education on research
- Clinical studies and their design
- Criteria for participation
- Informed consent forms and processes
- Compassionate use programmes
- Retention of participants
- Reporting on results
- Input and feedback on the development of tools for community use
- Patient input at the earliest stage of project development

## Worldwide Cystinosis CAB 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:** discussions with Sponsors begin

**November 2019:** first CAB and Sponsors meeting held in Dublin

**April & May 2021:** virtual CAB and Sponsor meetings

**March 2023:** in person CAB and Sponsor meetings

**Ongoing:** training and discussion of issues of relevance and importance to the community and research priorities.



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