



COMMUNITY ADVISORY BOARDS

THE EURORDIS EURO CAB

PROGRAMME

What is a CAB?

Community Advisory Boards (CABs) are groups established, operated and maintained by patient advocates and expert patients to discuss the latest developments, challenges and issues related to medical treatments and procedures under development in your disease area. CABs, with anywhere from seven to sixteen advocates, are involved in scientific as well as policy-related issues (ie, access) medical treatments, medical devices and procedures in development in your disease area, and they provide expert advice to all stakeholders involved in the research, development and service provision of biomedical treatments.

Does there need to be a CAB in my disease area?

For most of history, medical science has evolved with little to no input from the people being studied. CABs change that, and help to design, carry out and communicate on studies that are more rational and inclusive from a patient's point of view, and by doing so, a bond of trust with the researchers can form.

What exactly do CABs give input on?

On a wide variety of topics that they in fact are the experts on: patient outreach, education, feedback on the study and its design, criteria for participation, informed consent forms and processes, compassionate use programmes, retention, and reporting on results...

Who are CAB members?

CAB members are people living with the specific condition, a close family member or carer, and/or a member of a patient organisation that works with the disease.

Why now?

More and more, patients and the patient perspective are seen as a way to make clinical studies more impactful and just, possibly quicker, certainly more efficient.

How can I join a CAB in my disease area?

If a CAB for your condition exists, put yourself in direct contact with the group running the CAB. You can contact the patient organisation in your country or the European/international federation for your disease to see if they are aware of an existing CAB for your disease. Any CAB should have open contacts, a vetting process and adhere to the Code of Practice for the Relations between Patients' Organisations and the Healthcare Industry. If you are able to work in English, you are interested in science and interested in expanding the role of patients in research, you can dedicate at least two hours per week to the CAB, and you have a stable internet connection, you will be very welcome!

What if a CAB does not exist for my disease area?

Working with the European Network of your disease, you can begin the journey! EURORDIS can help in distinct ways to help you get a CAB going.

My patient group is small with limited resources. Can I really do this?

Get in touch with EURORDIS and let's see how to make this work for your Network!

I don't understand the science very well. How can I learn?

There are various ways of learning, at the pace you need. EURORDIS offers training via monthly webinars as well as at the CAB meeting. There are also the EURORDIS Summer School materials online that can be accessed for free. However you need to be educated, EURORDIS can help.

Starting a new CAB: The EURORDIS EUROCAP Programme

The EURORDIS EUROCAP Programme assists patient organisations in setting up and structuring a Community Advisory Board for their disease area. Depending on the administrative capabilities of your Network, EURORDIS can help in distinct ways to get a CAB going.

The EURORDIS EUROCAP Programme includes some common principles and tools for patient groups and sponsors: capacity building of patient advocates, peer-to-peer exchange of experiences across CABs, quality monitoring of the process and outputs of CABs, transparency and prevention of competing interests, promotion of the programme, and evaluation and possible eventual scientific publication.

How can my CAB receive the EUROCAP Seal of Good Practice?

As part of the EURORDIS EUROCAP Programme, CABs can receive the EUROCAP Seal of Good Practice by fulfilling the below criteria.

Mandatory:

- Open Call for volunteers
- Agendas and members are made public
- Work with different developers in the field (when applicable)
- Memorandum of Understanding for each development / research project / study
- Minutes and follow-up of each meeting
- EuroCAP contract signed between CAB and Eurordis
- Elected CAB chair

Important to have:

- Scientific secretariat
- Certification - CAB members followed the eLearning (Open Academy...)
- Horizon scanning activities

CONTACT

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