



COMMUNITY ADVISORY BOARDS : EARLY SUCCESSES

More and more, including patients and the patient perspective is seen as a way to make clinical studies more impactful, possibly faster and certainly more efficient. Community Advisory Boards provide a structure through which to channel this patient voice into affecting meaningful change.

Community Advisory Boards (CABs) are groups who offer their expertise to sponsors of clinical research. They are 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 their given disease areas. Over the past few years we have started to see the difference that the CABs can make in ensuring more impactful clinical studies.

We have highlighted some of the early successes of the CABs below:



EURORDIS has set up **6** active CABs

19 companies have been involved in **14** CAB meetings over a **3** year period



THE DUCHENNE COMMUNITY ADVISORY BOARD

Focuses on making clinical study protocols more efficient and more patient- and family-friendly.

Key successes:

- Discourage the excessive use of biopsies and have reduced the number of biopsies in multiple studies.
- Aim to reduce the burden of clinical studies on patients by having sponsors concentrate on what is important and not what might be «nice to know». Several studies reduced the number of tests and questionnaires involved.
- They discourage the over-extensive use of placebo, in the place of natural history data. At least two studies have reduced the length of placebo use. Studies also improved the randomization ratio of placebo from 1:1 to 2:1, and even to 3:1.
- They have convinced companies to share placebo data after the study, and to consider making individual patient data available to families after the trial ends.

“ We’ve established a relationship of trust and respect and I think that’s the most important aspect, if you have trust and respect between the CAB and the company, from both sides, then you’re going to be able to make changes” *Sally Hofmeister, Duchenne CAB Co-chair, Germany*

THE CYSTINOSIS COMMUNITY ADVISORY BOARD

Worked with a company so their children did not have to stop to not stop their current successful therapy very much prior to the administration of the gene therapy.

Key success:

- The company revised their protocol to now state that previous therapy does not need to be stopped before day 0 of the new trial.

“ While our numbers may be small, our patient advocates – people living with the condition and their parents – are experts in their field. The CAB allows us to have a structured and constructive interaction with those developing research, therapies and trials to ensure their work is of most value to those of us who need it.”

Denise Dunne, Cystinosis CAB Administrator, Ireland

THE CYSTIC FIBROSIS COMMUNITY ADVISORY BOARD

Focuses on building long-term relationships with sponsors to discuss topics effectively.

Key success:

- Created a company ‘Tracker’ to measure progress. It ensures that the relationship is monitored and evaluated, and that goals are reached.

“ It has been helpful to give our input and see that the companies actually listen to us. It is interesting to see how the process of planning a clinical trial happens. Also I have enjoyed getting to know Cystic Fibrosis people from other countries.”

Minna Kivelä, Cystic Fibrosis CAB member, Finland

IS THERE A CAB IN MY DISEASE AREA AND HOW CAN I JOIN?

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. If you already know a CAB for your condition exists, put yourself in direct contact with the group running the CAB. 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 can dedicate at least two hours per week to the CAB, you are interested in science and expanding the role of patients in research, 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 Reference Network of your disease, you can begin the journey!

Even if you do not understand the science, there are various ways of learning: 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. If you need any further information, EURORDIS is here to help.

For more information, please contact Rob Camp: rob.camp@eurordis.org