

CF Europe CAB

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CF Europe

**Generating
expertise &
advocacy
capacity**

**Promote and
support
research**

**Promote
optimal care**

**Represent and
defend interests**

**Supporting
national
organizations**

**Inform and share
best practices
amongst members**

**Tailor-made
support to
members**

Community Advisory Boards (CABs)

A CAB is a platform consisting of representatives of the patient community who meet with representatives of other organisations, such as companies and research bodies. The main goals of a CAB are to:

Promote dialogue between patient communities and other healthcare stakeholders involved in researching, developing and marketing treatments

Improve patients' understanding of the science behind the disease and how treatments are brought to patients (e.g. regulatory process, pricing mechanisms etc.)

Provide the patient perspective on clinical trials and treatment design so patients' needs are met

Influence how treatments are designed, developed and brought to the market to maximise patient access to new therapies

Rationale for the CF CAB

Following a number of requests for patient inputs coming from other organisations active in the CF area, CF Europe has invested substantial efforts towards more proactive and meaningful patient participation, through the creation of a CF Europe CAB. The CAB is...

A pan-European body, bringing together patient experts from different countries, from different subgroups and with different backgrounds and expertise

A working group of CFE totally independent from any company or other organization

A way for patients to make their expertise available in a structured, transparent way and to have an impact on all stages of medicine development and access to treatments

Patient led and patient driven

A means to ensure my organisation and community's voice are heard on topics of key importance for CF patients such as access to treatments, clinical trials and the future of CF research

A way to improve my understanding and knowledge of CF scientific research, and become a more influential patient advocate

Mission and conditions for success

1. To provide patient inputs to CF scientific research, so the patient perspective is taken into account
2. To improve CF patients' understanding and knowledge of scientific research across Europe to facilitate their ability to partner with physicians and researchers
3. To ensure smoother patient access to innovative therapies by integrating the evidence required for reimbursement into the development process
4. To contribute to research and regulation aspects of legal, policy, and ethics issues
5. To build awareness among researchers, policy-makers and regulators around the needs of CF patients in Europe

Internal conditions for success

- Ensure CAB activities and progress are communicated to the CF Europe membership on a regular basis
- Obtain feedback and discuss ideas with members to make sure all CF patients are equally represented and there is internal consensus on the CAB focus

External conditions for success

- To promote the CF Europe CAB initiative externally
- To develop effective communication between CAB patient representatives and the other stakeholders in the CF community

Activities and achievements to date

External activities

- Meeting November 2016, to discuss feasibility of first CF Europe CAB Meeting
- First CF Europe CAB Meeting March 2017 – a wide array of issues discussed, from patient reported outcomes to the clinical trial configuration
- Second meeting September 2017 – the CF CAB followed up on the first meeting & tabled issues of particular importance
- Another meeting in the pipeline with third CF company
- Ongoing outreach to identify other relevant interlocutors

Internal activities

- March CAB Meeting participant selection
- Worked with members to develop materials needed to set up the meeting
- Pre-meeting strategy session with CAB meeting patient representatives to brainstorm ideas for meeting discussion
- Feedback session with CF Europe CAB participants to evaluate March CAB Meeting and set strategic direction moving forward
- Medium/long-term strategy document and “patient pool” questionnaire (August 2017)

Next steps



“Patient Pool” Questionnaire

To help future meetings’
participant selection

1/3 Year Plan

To define the CF Europe
CAB strategic direction
moving forward

Additional meetings with CF companies

To discuss issues of
relevance for the CF
patient community



Governance



Management

- The CAB is a body of CF Europe and will therefore be led and supported by the CFE board & secretariat
- The CAB members are selected by CFE
- CFE needs to provide a code of conduct and a clear frame

Funding

- Both CFE and the patient experts will be reimbursed for the work done for the CAB meeting
- CFE will work with external experts for some of the aspects of the CAB meeting (legal advice, note taking, ...), that should be covered by the funding for the meeting as well
- Funding will be agreed with individual companies in advance of the meeting

Communication

External communication

- The CFE website will report on the activities of the CAB that are not confidential and the companies involved

Internal communication

- CAB mailing list, containing the contact details of all CAB members and their back ups. These people will receive all communication related to the CAB and the different meetings during their term.
- A DropBox will be created and relevant documents will be shared via

Meeting preparation and follow up

- An agenda will be circulated prior to each meeting
- A preparative meeting will be organized prior to each meeting
- There will be a report available of each meeting

CAB Members' Selection Process (internal)



* Selection made to insure equal representation across geographical regions and CF patient subpopulations. Selection criteria include: patients represented, knowledge of science behind CF, ability to communicate in oral / written English, level of commitment

** Simple majority required (50%+1)

What being a CAB member entails

2-year engagement

You are the voice of
your national patient
community

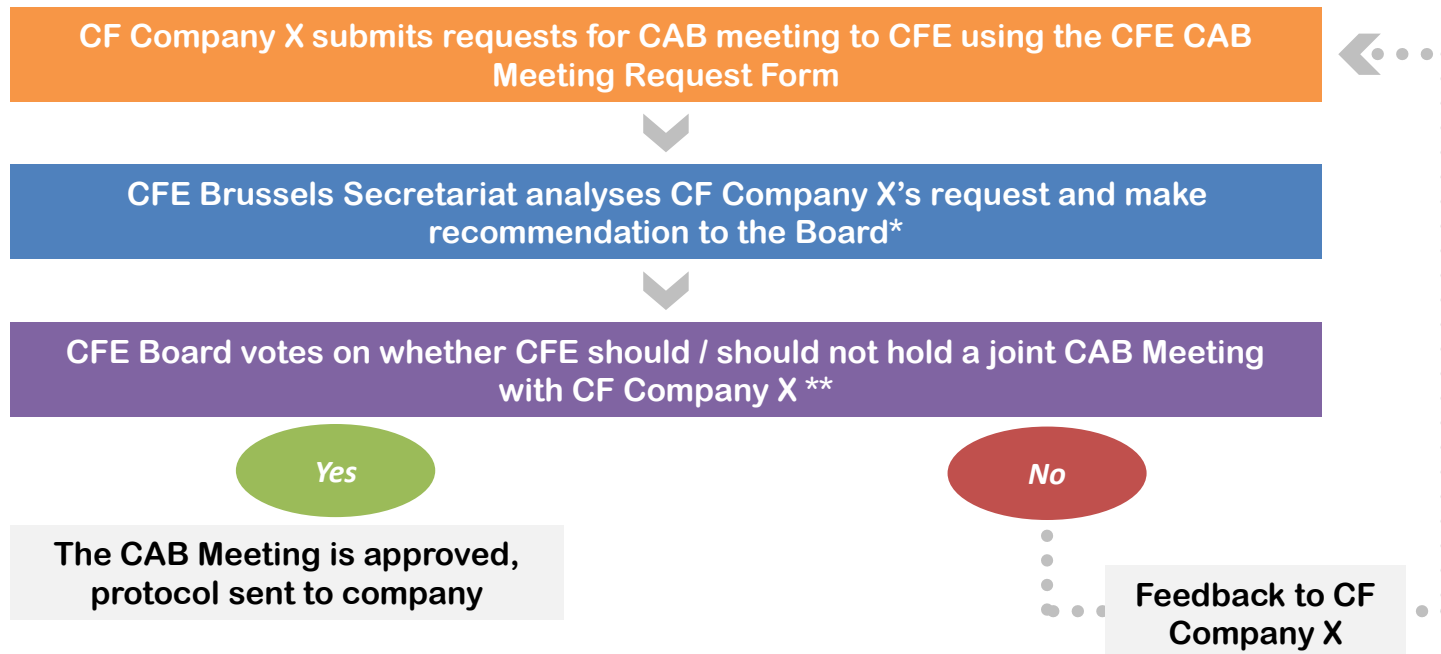
You commit to attend
[number TBD] CAB
meetings / year

You follow up on
meeting actions as
agreed / needed

You have identified
your 'back-up' and
you brief him / her
regularly on CAB
activities and
meetings

If not familiar with
the position of your
patient community on
a topic for
discussion, you
consult your
members before the
meeting

CAB Meeting Request Process (internal + external)



* E.g. based on relevance of the topic, company reputation, calendar availabilities

** Simple majority required (50%+1)

Carpark – other issues for discussion

- **Develop draft protocol for meeting organisation**
- **Develop draft document to send to companies prior to the meeting explaining our expectations**
- **Discuss collaboration with ECFS**
- **Absent friend principle (those who cannot make a meeting are informed about meeting discussions / outcomes)**
- **Cross Infection**