



CF-CAB History & State of affairs

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EURORDIS Meeting
Bucharest, May 2019

CF Europe



CF Europe:

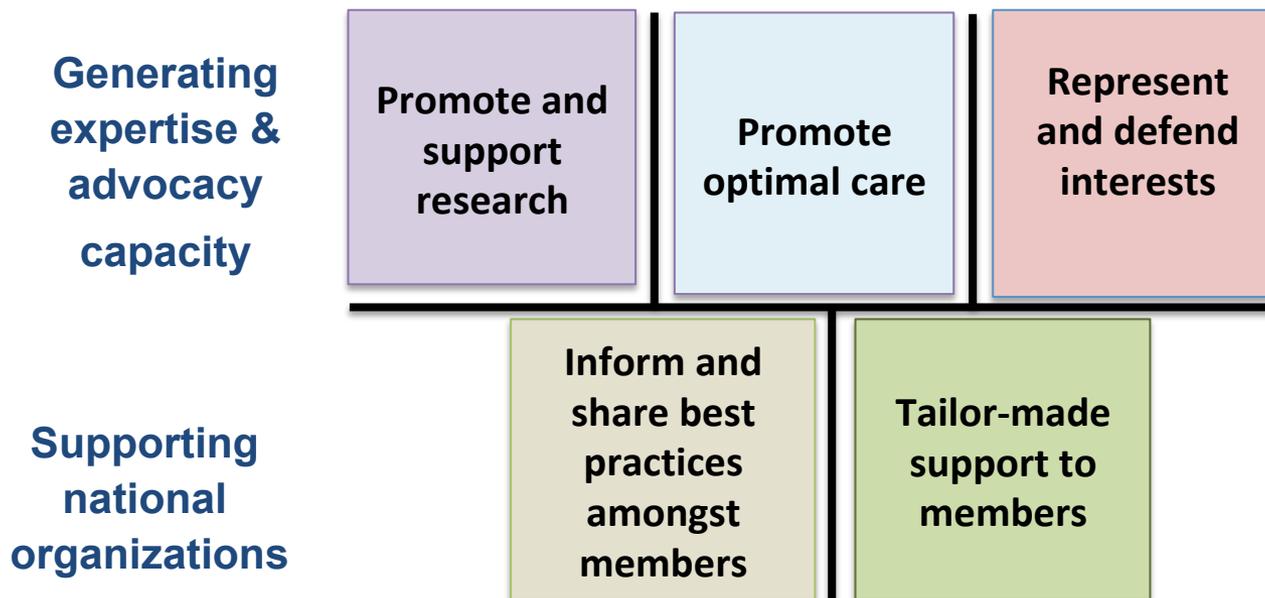
- °2003
- Umbrella association of CF patient organisations
- Members in 34 countries
- Representing +- 40 000 people with CF and their families
- 1,5 FTE

CF Europe

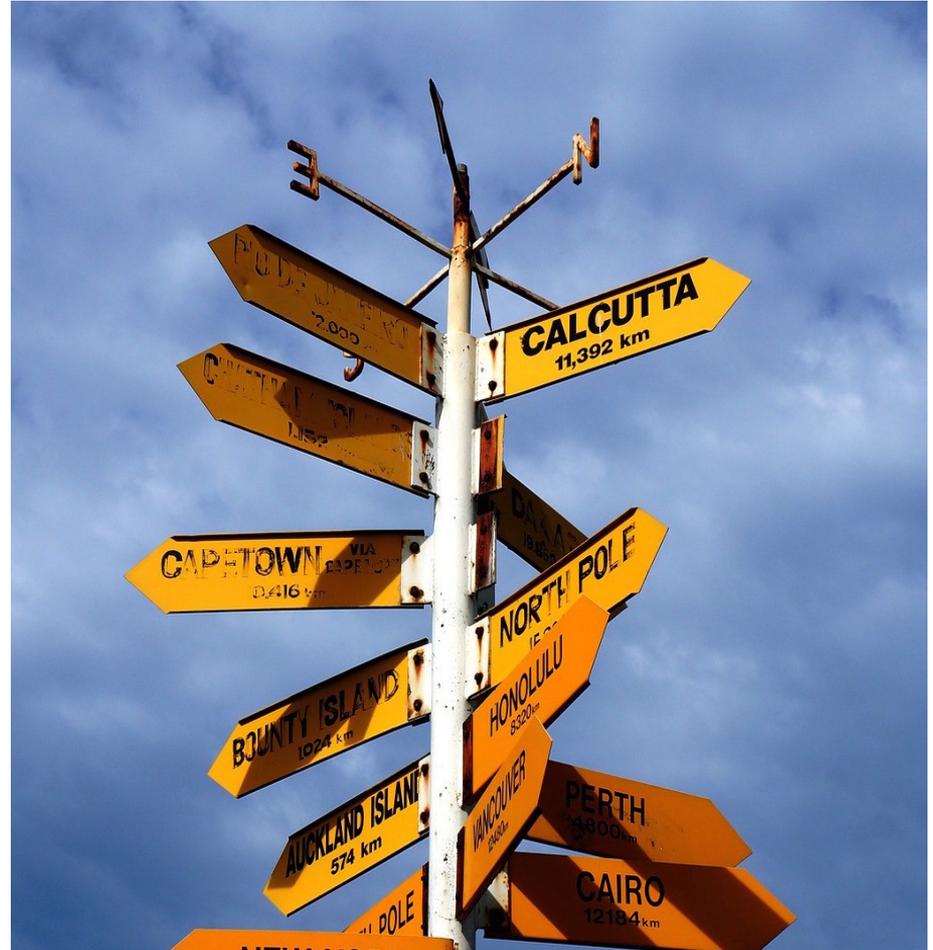
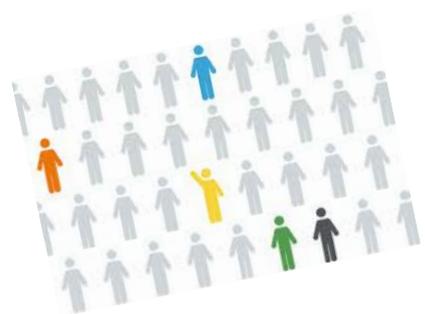


CFE is striving for a longer and better life for people with [cystic fibrosis](#).
CFE envisages a future where a final cure is found and access is given to all persons with Cystic Fibrosis.

By supporting national patient organisations and building expertise and advocacy capacity for European policy, research and care, we will drive up standards for everyone living with CF in Europe.



CF CAB



CF CAB

selection

CFE Brussels Secretariat calls for Members in countries to submit list of potential national candidates to attend meetings for the following 2 years

Members prepare and send CFE Brussels Secretariat national candidates

CFE Brussels Secretariat conducts initial candidate assessment, prepares draft list of final CAB Members and submit it to CFE Board*

CFE Board votes on draft CAB Members

Yes

The list is approved



community



training

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

What being a CAB member entails

2-year engagement

You are the voice of
your national patient
community

You attend 2 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

What a CAB member can expect from CFE



Clear volunteer
statute and
agreement

Clear selection
procedure

Support where
needed

Timely
communication on
questions and
meetings

Training and
preparation of the
meetings

Further development
of the CAB
concerning partners/
issues/ ...

Governance



Management

- The CAB is a body of CF Europe and will therefore be led and supported by the CFE board & secretariat

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 is created

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

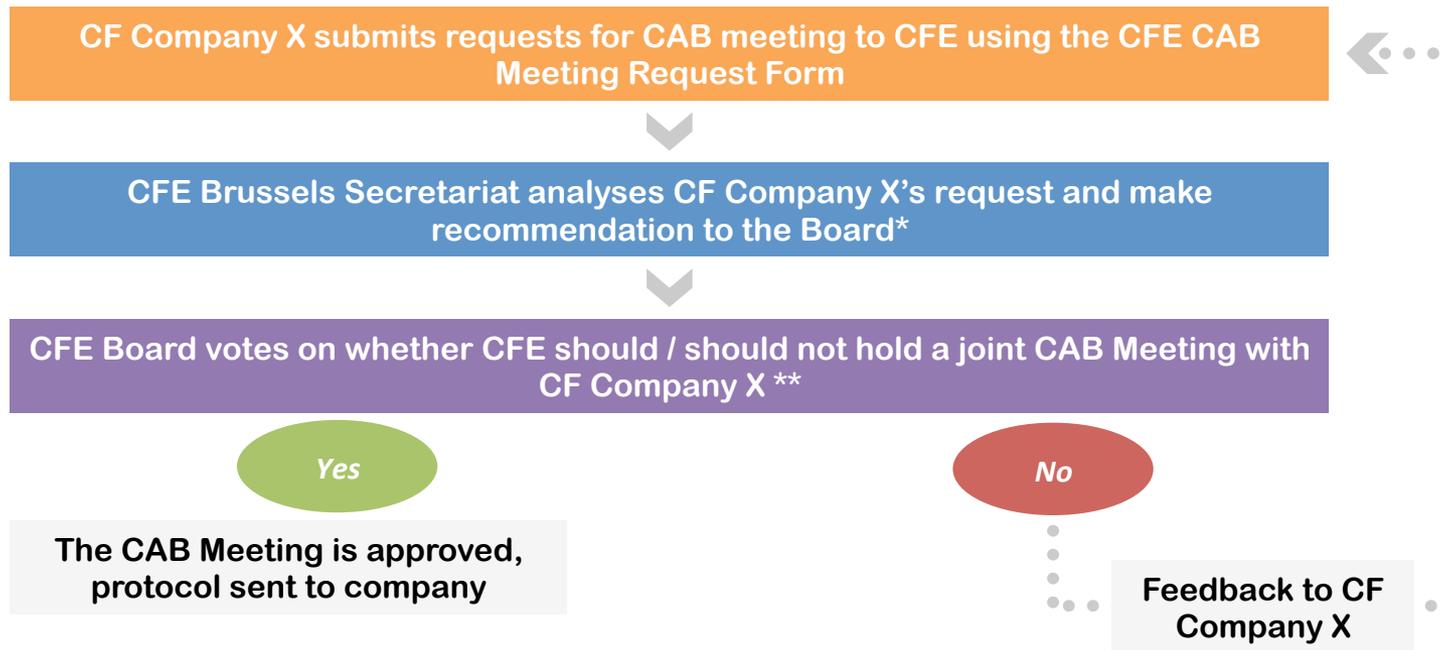
CAB Members' Selection Process (internal)



* 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)

CAB Meeting Request Process (internal + external)



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

** Simple majority required (50%+1)

Where are we now?



- 2 meetings a year for 2,5 years
- 3 companies so far, 3 new companies showing interest for the next CAB meeting in October
- Members from 12 countries & open call for new members

The tracker

1 for each company

Responsibility of 1 of
the CAB members
per company

Updated after each
meeting

Communication tool

Getting everyone
aligned

,Keeping track of
activities

,Fucus on big picture

How to use this document



This company tracker is an overarching reference document, used to set goals, capture outcomes and measure progress / success for each company CAB. It can be used to onboard new CAB members.

Contents

1. Company Overview

Key information about the company, to support drafting of specific goals / onboard new CAB members

2. CFE CAB Overarching Goals

The overarching goals of the CAB, to keep in mind when drafting specific goals for individual CAB meetings

3. Company CAB Goals

A place to note down and keep track of specific goals and questions for individual CAB meetings

4. Success Tracker

A place to keep track of company feedback, updates and progress with our requests and goals

How to use:

Before each CAB, this company tracker should be referred to. It can be used to develop new goals / questions based on past meetings.

Before each CAB, this document should capture:

- Our goals for each meeting, including specific questions to ask the company representatives

After each CAB, this document should capture:

- Updates / progress / successes with the company, related to each goal

The document should support an enhanced feedback loop between the CAB and companies. It will provide an at-a-glance overview of ongoing topics to be followed up on.

Overview: [Company name]



Company logo

[Company name]

Working with CF CAB since:

Number of CAB meetings:

Key contacts:

Key Facts

Include here any key facts relevant to CF CAB work, e.g. products on market, pipeline products, countries with / without access, ongoing or upcoming clinical trials, etc.

Key Dates

Include here any key dates / internal timelines that have been communicated to the CAB. E.g. timeline for launching pipeline products, opening of clinical trials, release of new patient materials, next CAB meeting, etc. E.g.:

28 October 2019: Next CAB meeting

November 2019: Expected launch in Germany

CFE CAB Overarching Goals

If overarching goals are refined during discussions with CAB members, this slide will require an update accordingly! N.b. we have included only goals relevant for company meetings, not 'horizontal' goals (e.g. increase # of companies interested)

The below goals apply to all of our CAB meetings. They should be reviewed as a first point of call before all upcoming CABs, prior to setting specific goals for that meeting.

As far as possible, make sure that our specific goals for individual CAB meetings are in-line with these overarching goals.

CF CAB Priorities

Clinical Trials	Closer interaction with companies, facilitating early contact with CT design, to make trials more patient-oriented
Inequalities	Diminish the inequalities (in diagnostics, treatment, CTs, patient information, etc) around Europe
Access	Improve patient access to new drugs and clinical trials in Europe
Research	Get more companies interested in the CF field, to accelerate research; Increase research in organs affected by CF other than the lungs
Knowledge	Empower patient representatives through increased knowledge and knowledge-sharing

CF CAB Goals

Clinical Trials	Give input about PROM and review informed consents in X% of CAB meetings by 2020.
Inequalities	Increase the number of new drugs / clinical trials in Eastern Europe by X% by [date].
Access	Improve access to CFTR modulators in Europe by X% by [date].
Research	Address other organs in research in X% of CAB meetings by 2020.
Knowledge	Organize X training sessions to CAB members before 2020.

Our goals for the [Company] [date] CAB (1/2)



Before each CAB, we should capture our **specific goals for the meeting** on these slides.

Our goals should be supported by direct questions to ask the company representatives. This increases accountability and supports our ability to follow-up. CAB outcomes and follow-ups can be captured in the next section.

Clinical Trials

Overarching goal: E.g. input into clinical trial design of upcoming...
Key Questions: E.g. which quality of life measures will be considered in your upcoming trial? Will there be an opportunity to review them and provide inputs?

Inequalities

Overarching goal:
Key Questions:

Our goals for the [Company] [date] CAB (2/2)



Access

Overarching goal:
Key Questions:

Research

Overarching goal:
Key Questions:

Knowledge

Overarching goal:
Key Questions:

Our success tracker (1/2)



For each of our goals, we should track our progress / successes in the below boxes.

Things to track include: where companies said they'd follow up, have they? Where companies said feedback would be taken on board, was it?

Priority area	Goal	Our request	Company action / updates
Clinical Trials			
Inequalities			

Our success tracker (2/2)



Priority area	Goal	Our request	Company action / updates
Access			
Research			
Knowledge			



Company Tracker

[Insert Company name here]

Last updated: [date]