

CF Europe (CFE) AGM
Vienna
7 June 2023
10.00 - 12.30

Present: Albania, Austria, Azerbaijan, Belgium, Bosnia & Herzegovina, Bulgaria, Czech Republic, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Kosovo, Latvia, Montenegro, the Netherlands, Poland, Republic of Serbia, Slovakia, Sweden, Switzerland, Turkey, Ukraine, United Kingdom

Represented by Proxy: Norway, Spain

Excused: Croatia, Cyprus, Denmark, Georgia, Kazakhstan, Luxembourg, Macedonia, Moldova, Portugal, Romania, Russia, Slovenia

1. Welcome & Agenda (Hilde De Keyser, CEO)
Hilde opened the meeting, welcomed everyone to CFE's AGM in its 20th anniversary.

2. Minutes of last meeting (Hilde De Keyser)
Hilde invited any comments or questions on the minutes of the last meeting or the agenda for today.

3. Activities 2022-2024 (Elise Lammertyn, Head of Research; Lidia Salvatori, Policy and Communications Manager; Claire Francis, Programme Manager, VERA; and Hilde De Keyser)

Elise reported on the Patient Organisations Research Group. The PORG is adding an intermediary online meeting between the 2 face- to-face meetings that now take place and focusing on better communication. Elise described the PORG's work leading the work package (WP) on patient empowerment and revision of other work packages. She also described the PORG's engagement with:

WP 3 (ECFS-CTN) including a summary of the group's input on the topics of stopping trials of inhaled antibiotics and the changing CF population.

WP 4 (European Young Investigators Meeting) which took place 1-3 March 2023 in Paris with support of CFE members in France, Belgium, the Netherlands, UK, Italy and Germany.

WP 5 (ECFS Basic Science Conference Patient Organisation Symposium), which took place 29 March – 1 April 2023 in Dubrovnik.

WP 7 (Facilitating Research collaborations), naming the 3 recipients of the ECFS/ CFE Post-Doctoral Research Fellowships. The fellowship aims to foster basic and translational research in CF. The award is for work done from 2022-2024.

Kors Van der Ent, paediatrician at UMC Utrecht in the Netherlands and HIT-CF principal investigator, was invited to give an update on the HIT-CF project. There have been some delays in the timeline due to changes with biopharma partners. Prof Van der Ent described

the Choices clinical trial expected to launch in Q1 of 2024. The organoid assay for predicting clinical response has received a letter of support from the EMA.

Lidia summarized CFE's work in policy/advocacy, support to members and communications, as follows:

- **Policy/Advocacy:** The PO group on Access (POPI) group, formed in January 2023, is comprised of PO representatives with different backgrounds and expertise (e.g., policy, health research, project management) and works to promote CFE's policy priority, "a fairer and healthier future for all people with CF". Future work will focus on issues related to the social determinants of health and digitalization Lidia described the structure and functions of the group. The POPI group will begin quarterly meetings with policy staff of the CF Foundation in the US to share knowledge and expertise.
- **Access:** CFE, together with the European Lung Foundation and the European Respiratory Society, organised a summit on access to medicines at the European Parliament on 7 December 2022. A statement on the pharmaceutical legislation reform was made in April 2023 and will be followed by statements and briefings including an access advocacy statement, and a policy briefing on inequity in access to CF treatments across Europe.
- **Expansion of the Twinning Project** conducted in partnership with ECFS: CFE obtained a grant from the CF Foundation that will support the strengthening of the Twinning Project for a period of three years. The project will match CF Centres and POs with more resources with those in countries with less resources and will see an increased involvement of POs.
- **Support members:** Support for Ukraine has continued following CFE's fundraising campaign with organized collaborations between European patient organisations and CF doctors. The Ukrainian CF organisation showed a video of conditions for people with CF in Ukraine and said a few words of thanks and encouragement to sustain this support, which is much needed.
- **Communications:** CFE's new website was launched in June 2022. Lidia described the sections still under development and the input requested from CFE members. CFE's first newsletter came out in December 2022, the 2nd one in March 2023. Lidia shared CFE's social media statistics, which shows increased activity, and encouraged all present to subscribe to the newsletter and interact with social media posts.

Claire described the VERA project on enhancing digital healthcare and access to health data for people with CF across Europe. Key activities in the past year have been the launch of a data project in Belgium taking a whole ecosystem approach, acquiring funding for project development from industry and a foundation, building data into other CF work packages such as the Twinning Project, joint influence at the European level, sharing best practices and beginning design of a learning platform.

Hilde informed the group that CFE is entering a new strategic period. A strategic review in the first months of 2023 has shown that to cope with the challenges it faces, CFE needs to

move from a convener to a game changer. The four main strategic proposals are that CFE needs:

- a. to adopt a proper business plan to achieve its data ambition
- b. a strategic partnership with ECFS
- c. to develop clear positioning with all other external stakeholders
- d. to build stronger community by generating and showing value

Hilde walked the group through the process that was followed to complete the strategic review including an overview of workshops and interviews, gathering information from contextual and operational environments, the feedback received, and external challenges identified. Hilde summarized the feedback received, stressing that these reflect interviewees' views only, on suggested actions to take to make a bigger impact on the development of cures and ensuring access to treatments for all, including influencing industry and academic researchers, the EMA and defining its role vis-à-vis over POs.

The conclusions taken from the strategic review include:

- a. to develop and adopt a proper business plan to achieve its data ambition
- b. For ECFS and CFE to maintain separate legal identities, but to work together as equal partners to achieve common goals. A partnership agreement will be developed.
- c. Regarding external stakeholders, considering the feedback received, CFE will define who to approach, why to approach these organisations/persons, and what kind of relationship we want.
- d. CFE will work toward a structure that allows more members greater involvement and will put more effort into showing its value.

With these conclusions top of mind, CFE will finalize the strategic plan 2024-2028 in the months ahead.

Hilde invited questions and comments, which included:

Regarding real world data, if all members create their own apps and they are not shared or aligned, this could cause real difficulties very quickly. Claire responded that this is why CFE wants to work at the European level. It's a live and current topic. We don't have all the answers yet and this is why we want to discuss this with you. Hilde added that CFE needs Members to tell CFE where they need CFE to work with them, not only on RWD but also on other projects.

Regarding the strategy, could you elaborate on how the 4 proposals are linked to the main objectives? Hilde responded that data is needed for effective advocacy essential to increase access. It is clear that CFE cannot move ahead without ECFS. In regards to the focus on external stakeholders, we need policies to reflect what we need. Our sister organisations that focus on that are essential there. For example, with the next legislation on orphan medicine products, we absolutely needed EPF and EURORDIS to reflect our voice in their advocacy work.

A member asked if CFE is in contact with Vertex save Us an organisation that goes after pharma re pricing. Hilde responded that CFE also takes on companies but not in the papers. CFE is in contact with this organisation from time to time. They know us and we know them. We both work for access but use different tactics.

Another member representative said the actions and ambitions are commendable but need a funding plan to support it. Members applauded the addition of foundation funding from CFF.

4. Finances 2022 – 2024 (Stefan Joris, CFE Executive Board)

Stefan presented the financial reports from 2021 and 2022. He apologized that 2021 wasn't ready last year. That's why both 2021 and 2022 are being presented this year. Revenues were very close to predicted for 2021. Expenses were lower, however, because of delays in the HIT CF project. CFE's role in the project is dissemination and as the project was delayed, there wasn't much to disseminate. CFE therefore ran a surplus of just over 76 700 EUR.

2022 revenues were up slightly in 2022, and differed a bit from what was anticipated. Revenue from the CAB was lower, as CAB meetings are now being managed by EUPATI-Spain. However, expenses for the CAB were also reduced. Emergency support for Ukraine generated 80 000 EUR. This also covered CFE's costs associated with coordinating this support, which came to 20 000 EUR. Another area of increased spending was events, as we have returned to holding our membership meeting face-to-face.

The budgets for 2023 and 2024 were also presented. CFE's global expenses for 2023 are expected to be 596 550 EUR and 2024 are expected to be 611 550 EUR. A new source of revenue will be the grant funding from the CF Foundation. A deficit of -6662 EUR is expected in 2023 and – 3440 in 2024. Increased costs are due to staff increases. CFE has the reserves to cover this.

A member representative asked whether CFE had considered increasing membership fees to generate more income or simply asking those members who can afford it to give more. A suggestion was made for big associations to create a round table of sorts to discuss giving more.

The Member representative responded that CFE should not be afraid to talk to members about increasing fees based on capacity going forward.

5. Elections 2023-2024 (Hilde De Keyser)

Hilde showed a slide of the items requiring a vote and showed videos of the people running for election to the CFE Board.

Once all voters' ballots were collected, staff counted the votes in an adjacent room.

6. Other business (Hilde De Keyser)

Hilde thanked Jacqueliën Noordhoek for her exceptional service as Board President over the years and presented her with a gift on behalf of CFE and members.

7. Voting results (Hilde De Keyser)

Voting results are:

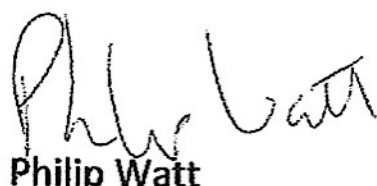
- Marco Magri and Audrey Chansard were re-elected. Renate Kos, Milan Sedlacek and Andreas Hager were elected.
- Precise votes are:
 - Financial report 2021 – approved by all
 - Financial report 2022 – approved by all
 - Annual report 2022 – approved by all
 - Discharge of members of the board – approved by all
 - Budget 2023-2024 – approved by all but 2 abstentions
 - Membership Organisation form Gaza – approved by all but 3 abstentions
 - Marco Magri: 28 votes
 - Renate Kos: 23 votes
 - Milan Sedlacek: 27 votes
 - Audrey Chansard: 26 votes
 - Andreas Hager 25 votes

The 2022-2023 CFE Board members therefore are:


Philip Watt, Marco Magri, Stefan Joris and Renate Kos for Western Europe; Przemysław Marszałek and Milan Sedlacek for Eastern Europe; Nick Medhurst, Audrey Chansard and Andreas Hager as independent board members.

Former Board members include: Birgit Dembski, Dragan Djurovic, Ilknur Gorgun, Dimitris Kontopidis, Jacqueliën Noordhoek, Betim Zllanoga, Michaela Reagan.

The meeting ended at 12.30.



Philip Watt
President, CF Europe



Stefan Joris
Secretary, CF Europe