

## JUNE 2022

- This PORG meeting was the first one with Sylvia Hafkemeyer from Mukoviszidose e.V. (Germany) as new chair. Sylvia succeeds Vincent Gulmans from NCFs (the Netherlands) who has retired. Good luck Sylvia!
- In April, several PORG members met with the European Clinical Trials Network (ECFS-CTN) Investigator Trial Committee (ITC) (more about the ITC in the CTN [2020 annual report](#) p.16-17) to discuss common interests. The PORG members explained that there are currently several projects ongoing looking into what people with CF and their carers consider as research priorities (CFE's own patient research priority survey and the [JLA Research Priority Refresh](#)). As the PORG financially contributes to the CTN, it is important that the CF community's priorities are taking into account and any future investigator-initiated trial (IITs) should be aligned with the identified research priorities. The possibility of allocating additional funds to IITs was discussed with the PORG. Next joint PORG-ITC meeting will be scheduled in fall when results of all patient research priority exercises are available.
- In November, a dedicated National Clinical Trials Network meeting will be organized, open for all countries that already have an own clinical trials network, and for interested parties with the intention to build a national trials network in the future.
- Pursuing a career in research is challenging for young researchers. To incentivise an academic career, CF Europe, together with ECFS, [funds young postdoctoral researchers](#) with a 2-year grant. The first round of funding was granted in autumn 2020 and a second funding round was evaluated recently (external review + ECFS and CFE representative): [three new researchers will be starting their projects in fall 2022](#). The PORG members, in consultation with ECFS, discussed whether the grant should offer 3 instead of 2-year funding (with less awardees) to facilitate publication and application for a subsequent academic position and funding. Furthermore, a survey will be developed and sent out to the participants of the past 3 editions of the European CF Young Investigators Meeting (EYIM). The idea here is to ask young investigators what they perceive as hurdles to stay in CF research. This will give us a better idea of what is needed to motivate young researchers to stay in the field.
- The PORG members brainstormed about the topic for the preconference meeting to the ECFS Basic Science Conference taking place in March 2023. It was suggested to focus on 'challenges for people with rare mutations', with special attention to the mechanism of action of modulators, as this may open the door to using them in people with rare mutations and understanding why they do or do not respond (ex vivo testing). The topic will be suggested to the ECFS board and if agreed, planning the preconference meeting will start soon.
- HIT-CF and organoid biobanking: the PORG discussed the possibilities to support the HIT-CF biobanking approach. Vaincre la Mucoviscidose reported on a biobanking initiative as pilot project in France. You'll find more information on HIT-CF and organoid biobanking in the [HIT-CF newsletters](#).



If you have any questions, please contact Elise Lammertyn ([elise.lammertyn@cf-europe.eu](mailto:elise.lammertyn@cf-europe.eu)) or Sylvia Hafkemeyer ([shafkemeyer@muko.info](mailto:shafkemeyer@muko.info))