

OCTOBER 2022

- Due to logistical reasons and by mutual agreement with ECFS, it was decided that the preconference meeting preceding the Basic Science Conference will be replaced by a dedicated patient organisation (PO) symposium included in the main conference program in 2023. The PORG members find this a positive evolution as it will increase the visibility of patients and POs for basic scientists. This symposium will be co-organised by the POs of Belgium, France, Italy, Germany, UK and the Netherlands. This is the preliminary program:

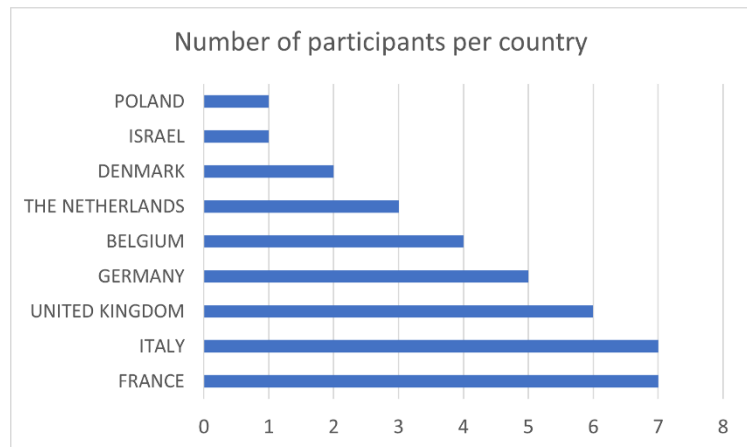
Care for rare: precision medicine to bring innovative therapies to people with rare mutations (a patient organisation symposium)

Moderators: Nicoletta Pedemonte & Elise Lammertyn (CF Europe/Belgian PO) (1h45')

- Patient view (10' video clip)
- Where we are, future perspectives, urgent needs 20' + 10' discussion
Christine Bear (SickKids Toronto, Canada – confirmed)
- Ex-vivo models/translational models 20' + 10' discussion
Isabelle Sermet (Institut Necker-Enfants Malades Paris, France – confirmed)
- Regulatory aspects, hurdles and needs on the way to realize personalized medicine in CF 20' + 10' discussion
Marco Cipolli (Azienda Ospedaliera Universitaria Integrata Verona, Italy – TBC)

Concerning the preconference meeting organised in 2022, the speakers just published an [overview article](#) of what was discussed during the meeting in the Journal of CF.

- Meanwhile, the final selection for the European Young Investigators Meeting (EYIM) 2023 has been made. The organising committee received 100 abstracts from 13 countries. Finally, 36 participants from 9 countries have been selected to participate in EYIM, after peer review of their abstracts.



- In November, a successful National Clinical Trials Network meeting was held in Brussels. The POs from the Netherlands, Germany, France, Belgium, UK and Italy participated. Experiences and best practices were exchanged and existing networks learned a lot from each other, as did countries that did not yet have a national network. Also a guidance document advising on how national networks and the ECFS-CTN should work together, was discussed and will be finalised during a meeting with ECFS-CTN in January.



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