

ECFS Minutes of the Standards of Care Meeting 6 June 2019, ECFS Liverpool

Present; Carlo Castellani, Alistair Duff, Jacqui Lowdon, Nichola MacDuff, Jacqueliën Noordhoek, Pavel Drevinek, Nataliya Kashirskaya, Isabelle Fajac, Edwin Brokaar, Marlies Kerstan, Silvia Gartner, Martin Stern, Chris Dubois.

Apologies received; Kevin Southern, Stefano Aliberti.

1.0 Updates

- 1.1 Quality Standards for Adult Cystic Fibrosis Care initiative is being led by Stefano Aliberti (Milan). This is at the stage of collating a list of all EU CF centres with contact details. GDPR statements might not be too easy to collect but will be necessary.
- 1.2 ECFS Pharma book; (Carlo is leading on this, with Daniel Peckham) to be published in 2020. Invitations to chapter-leads and authors have been made. Most have accepted. Deadline for first drafts - Nov 19
 - 1.2.1 Guidelines Framework for clinical topics; aims to establish a consistent framework for writing ECFS guidelines when the Society endorse/commission a clinical topic. Up until present, guidelines have been produced differently. Work on this paper will continue in 2019. Further update at the winter meeting 2020.

2.0 ECFS SoC Twinning Project

- 2.1 The basic premise of this project is to improve standards of care in some CF centres by it 'twinning' with a well-established one to build expertise and resources. At the ECFS Board Meeting (June 2019), the group received a preliminary approval, pending exploration of feasibility. Scope of the project is to optimize the use of resources and the centre according to the framework/best practice documents
- 2.2 Aim of today's meeting is to discuss feasibility and if so, what the roadmap is, subject to final Board approval
- 2.3 Samya Nasr, Professor of Pediatrics, University of Michigan, gave an excellent presentation on her and the UM team's experience of a partnership with a large CF centre in Marmara, Turkey. Samya took the opportunity to build on her experience with the CFF accreditation programme to explore challenges. Samya kindly agreed to have her presentation placed on the ECFS SoC website, (see ECFS SoC 'Projects/Twinning' tab)
- 2.4 Pavel Drevnek and Jacqueliën Noordhoek have agreed to facilitate a SoC 'Twinning' feasibility project facilitators. They stated that the first step is to map Western and Eastern EU CF centres who want to participate and scope a pilot study without a formal call for centres. This will be based on willingness to participate, and

existing European Reference Network (ERN) Lung group of centres

- 2.5 Discussion took place on; (i) what the role of ECFS and CF Europe should be. It must be more than match-making to provide an ECFS framework, within which the mentor/mentee centres work, (ii) the need to include the views of those centres who will be mentored to co-produce the framework, (iii) examples of such initiatives failing because of cultural misunderstandings and, (iv) the need to learn from two existing 'twinning' projects involving Southampton and Athens and possibly Cambridge and Macedonia

3.0 Date and time of next meeting - 23/24 January 2020, Brussels (TBC).