

European Cystic Fibrosis Exacerbation Working Group

Introduction

The CF exacerbation working group was established in June 2018 following an application to the ECFS announced at the close of the 2018 meeting. The objective of this group is to improve the diagnosis, monitoring and treatment of Pulmonary Exacerbation (PEX).

Present Group Members

Robert Gray (lead-coordinator), Damian Downey, Cliff Taggart, Don Urquhart, Michal Shteinberg, Isabelle Durieu, Quitterie Reynaud, Silke van Koningsbruggen-Rietschel, Tania Pressler, Malcolm Brodlie, Barry Plant, Stuart Elborn, Ed McKone, Carlo Castellani.

Group Aims

- Identify the fundamental knowledge gaps in the diagnosis, monitoring and pathophysiology of exacerbation
- Perform a wide-ranging systematic review of PEX literature and formulate research proposals to the EU and similar funding bodies to investigate PEX
- Establish the basis for a precision medicine approach to PEX management by creating a platform for the collection and integration of individual patient data (IPD) and patient self-assessment with ECFS registry data
- Establish a programme of work to investigate the utility of biomarkers in the prediction and assessment of treatment response exacerbation, and translate these findings to clinically useful tests
- Utilise our links with the ECFS CTN to develop projects in the areas of biomarker assessment and pulmonary imaging in relation to PEX
- Interact with members of the North American STOP programme to facilitate further exacerbation research and aim to establish a firm basis for a future international collaborative network

Plan for 2019

Our official launch and first formal meeting will take place at the European CF meeting in Liverpool, June 2019. At this meeting we will:

- Establish terms of reference for the working group
- Identify individual members of the group to lead on each of our stated aims
- Create a roadmap for the working group moving forward
- Make plans to open the group to new members by application

A further meeting (as a 4 hr workshop) will be scheduled for the North American CF meeting in October 2019 with invited attendees from the STOP programme.