



## **WORK PACKAGE 3: COLLABORATION WITH ECFS CLINICAL TRIALS NETWORK**

(Update March 2019)

### **Background**

Since the start of the ECFS-CTN in 2008, a close cooperation has been set up with the patient organizations. A patient organization (PO) representative, appointed by CF Europe for a 3 year's period, is member of the CTN's executive committee and participates in their 2-weekly teleconferences. Since 2012, the ECFS-CTN and 8 countries supporting research (PORG countries) have a formal agreement specifying the terms of cooperation and extent of financial support to the CTN infrastructure. The PO representatives supporting CTN are invited to attend the face to face steering committee meetings held twice a year where policies and specific projects are discussed. One of the main activities of the CTN is to coordinate the review of new clinical trial protocols by expert groups of CF doctors, research coordinators, academic researchers and people with CF and their family members. This protocol review system gives patients a voice in setting the research agenda and makes sure that trials take into account the patient experience.

### **Aims**

Representing the patient perspective and priorities, contribute to strengthening the clinical research in the field of CF and accelerate access to new medicines.

### **Activities**

- Contribution to all activities of the Executive Committee
- Input in the CTN business plan
- Review information intended for patients
- Dissemination of information to EU patients
- Active involvement in the Patient Reported Outcome Measures (PROMs) Patient Advisory Group
- Working on patients research priorities
- Participation in the development of the "organoids project" at European level
- Liaising with the patient/family protocol reviewers to discuss their experiences
- Collaborating in creating a patient-friendly informed consent form
- Involvement in conceptualizing a way to bring back trial results to the participating patients and a broader audience in a straightforward manner
- Encouraging the use of a patient thank you letter by the CTN centers
- Inform CF centers on how they can become a CTN center

### **Deliverables**

- 2-weekly teleconference minutes
- Steering committee meeting minutes
- Power point presentations for the steering committee meetings



- Visually attractive ECFS-CTN publications aimed specifically at informing the patient community (annual report, clinical trial results)
- Memorandum of Understanding for the partnership renewal
- Standardized and validated PROMs questionnaire
- Patient-approved informed consent form

### **Countries involved**

Belgium, France, Germany, Italy, Luxemburg, Switzerland, The Netherlands and The UK

### **Work package leader**

Paola De Carli (France) as patient organizations' representative in the CTN Executive Committee for the period 2018-2020

### **Budget**

For the period 2019-2021, Belgium, France, Germany, Italy, Luxemburg, Switzerland, The Netherlands and The UK are annually contributing € 113 750 in total to ECFS-CTN.