



ECFS European Twinning project Terms of Reference

Establishment

The European Cystic Fibrosis Society (ECFS) with its mission to improve survival and quality of life for people with CF strongly supports professional and educational activities that help improving the CF care in every European country. The ECFS patient registry output data show considerable discrepancy in clinical outcomes across Europe and to address this issue, the ECFS proposes the project of a long-term **centre-to-centre partnership** where one CF centre guides, advises and helps another CF site to optimise the care for CF patients.

Terms of Reference

DEFINITIONS

Mentor site: A well-established CF centre with state-of-the-art expertise in CF care. In the initial phase of the project, mentor sites will be selected amongst the ECFS-CTN sites as they have already been assessed by ECFS.

Mentee site: Any CF care-providing establishment which expresses an interest in participating in the Twinning project and is open to the guidance offered by the Mentor site.

Pair: Paired mentor and mentee sites. The pairing will be proposed by the Twinning Executive Board based on the information provided in the application forms.

AIM AND DESCRIPTION OF THE PROJECT

The aim of the project is to address the challenge of clinical outcome discrepancy across Europe through the twinning of two sites. The ambition is to build up a long-term collaborative partnership between Mentor and Mentee sites and address specific needs of the mentee site to optimise patients' clinical outcomes.

It is expected of the twinning pair to organize at least one visit to the mentee site within the first 6 months. The visit will include a CF physician and possibly a CF nurse and/or other CF team members. The aim of the visit will be to establish a partnership, to get an overview of the mentee site, to discuss unmet needs and opportunities. A summary report from this visit with a clear action plan is to be drafted by the pair and will serve as basis for the continuation of the funding.

GRANT DURATION

The pair will initially be funded for six months. Upon the review of the summary report, the grant and financial support can be extended by one year. The pair has the option to submit summary reports every year and thus, to ask for yearly funding repeatedly. If approved by the ECFS Board, this will entitle the participants to get longer-term funding.

FUNDING SUPPORT

Up to Euro 2,000 in the first six months of the project, then up to 4,000 per year, that is available for the costs of travel and accommodation for the purpose of site visits (both of Mentee and Mentor sites). The expenses will be refunded via expense claim forms where original receipts/invoices need to be attached and submitted to the ECFS central office. Other eligible



costs beside travel and accommodation include onsite translator services if needed.

LANGUAGE

The application must be in English.

APPLICATION PROCEDURE

The mentor and mentee application forms (see separate documents) are to be filled out and sent back to this address: christine.dubois@ecfs.eu by the deadline advertised.

The deadline to send the applications is: 30 September 2020 (23:59 CET)

EVALUATION OF APPLICATIONS

A Twinning Executive Board (TEB) will be appointed by the ECFS-Standards of Care Group. The TEB will review the application forms and match pairs according to expertise needed and offered. The twinning pair proposals will be presented to the ECFS Board for final approval.

TIMELINE FOR THE FIRST CALL

- Call: 1 September 2020 to 30 September 2020
- Evaluation and selection: October 2020
- Results: 2 November 2020
- Launch of a six-month project initialization: As from November 2020
- Summary report: by 30 April 2021
- Results: June 2021
- 1st project extension: June 2021 to April 2022