**CALL FOR APPLICATIONS:**

**ECFSPR-Partnership Project**

**Cystic Fibrosis Patient Registry for Low- and Middle-income Countries Outside of Europe**

Dear Colleagues

The European Cystic Fibrosis Society (ECFS), in cooperation with the ECFS Patient Registry (ECFSPR), is opening a call for applications to join the **ECFSPR-Partnership project.** This project aims to support Cystic Fibrosis (CF) patient registries **for low- and middle-income countries (LMICs) outside of the WHO European Region.**

The ECFSPR has extensive experience in the collection of harmonised and data-quality controlled data from more than 47 countries from the WHO European region. It does this within a standard framework and in accordance with ECFSPR terms of reference.

The ECFSPR Partnership project will help to enhance the epidemiologic knowledge of CF in your country and the other LMIC countries outside the WHO European Region that will join the project. It will achieve this through the sharing of knowledge, experience and the governance structure of the ECFSPR, thereby fulfilling the right of every person with CF (pwCF) to be visible via a registry contribution.

If you would like to participate in this project as a registry partner from an LMIC outside of the WHO European Region, **please complete the application** form and send it to the ECFSPR(for the attention of Lutz Naehrlich: lutz.naehrlich@ecfregistry.eu) **by 30 June 2025 (deadline)**.

The aim of the project is to recruit 10 countries. Applications will be reviewed by the ECFSPR Executive Committee and the results of the call for participants will be announced at the end of July 2025.

If your site is selected the first stage of project should begin immediately, in August 2025, with your application to the relevant local body for ethical approval and/or data protection approval to ensure that all aspects of the cooperation fulfil the legal and ethical requirements in place in your country. You must also obtain informed consent from the pwCF, or their legal guardians.

When legal obligations have been fulfilled the ECFSPR will provide training and access to the online, secure ECFSPR data collection software. Participants will then be expected to provide annual data, for the follow-up year 2024, for the pwCF in your country for whom informed consent has been obtained, with a deadline for data input of 31 December 2025.

After quality control carried out by the ECFSPR statisticians, the first national reports will be produced by the ECFSPR and shared with you and made publicly available in the first half of 2026.

In order to ensure robust data the ECFSPR will also evaluate the diagnostic challenges faced by participants with the aim of closing the gaps in sweat testing facilities and equipment and genotyping capacity. In addition, ECFSPRS staff will visit your centre for an onsite Data Quality Verification Visit.

**The ECFS commitment covers, at no cost to participants, for the entirety of the project duration (2025-2030), the following:** access to the web-based, secure data collection platform; data quality management; production of an annual data report; evaluation and assistance re. diagnostic challenges, at no cost to participants for the entirety of the project duration (2025-2030).

Please see the [Terms of Reference of the ECFSPR](https://www.ecfs.eu/projects/efcs-patient-registry/guidelines) and the ECFS website for further information.

We look forward to working with you on this exciting project and the epidemiology of CF in your country and globally.

Lutz Naehrlich, on behalf of the ECFSPR.

Contact: lutz.naehrlich@ecfregistry.eu