



The European Cystic Fibrosis Society Patient Registry (ECFSPR) wants to appoint an Executive Coordinator

The European Cystic Fibrosis Society Patient Registry is one of the four major projects of the European Cystic Fibrosis Society, a society of European and international experts in all fields of cystic fibrosis (CF) research and care. The ECFSPR collects demographic and clinical data from consenting people with cystic fibrosis in Europe, in accordance with agreed inclusion criteria and definitions. The information is used to measure, survey and compare aspects of CF and its treatment in participating

countries, to deepen our understanding of CF, to improve standards of care, to provide data for epidemiological research and to facilitate public health planning.

The Registry's database includes data from more than 54,000 people with CF, from 40 participating countries, and longitudinal data from 2008 to 2023. It is a unique resource reflecting the reality of CF across Europe.

The Executive Coordinator will be responsible for the day to day functioning of the ECFS Patient Registry and will work in close collaboration with the Registry Director and the ECFSPR team (12 team members from various countries in Europe and backgrounds).

His/her role and required skills will include:

EXPERT COMMUNICATION

The Executive coordinator is the central point of contact for the ECFSPR:

- Provide updates at the bi-annual ECFSPR meetings and presents the ECFSPR at international meetings
- Coordinate periodical newsletters to update on the activities of the ECFSPR
- Ensure accurate and timely dissemination of information through newsletters and other channels

ADMINISTRATION

- Oversee the preparation and publication of the ECFSPR Annual Data Report
- Draft Standard Operating Procedures (SOP) of the different aspects of the ECFSPRs activities and ensure these are up to date
- Organize meetings, teleconferences, and conference calls with various stakeholders
- Coordinate the organisation of the ECFSPR Committees meetings
- Write reports

MANAGEMENT

- Lead a team and oversee data management, ensuring smooth data flow
- Prepare project proposals
- Manage timeframes and budgets
- Develop management plans
- Coordinate and monitor ECFSPR projects
- Ensure agreed timelines are being respected

FINANCE

- Prepare annual budgets
- Prepare costs overviews
- Handle travel expenses requests

TRAVEL

You are expected to travel on site for the organisation of the 2 Steering Committee meetings each year. Besides, you might be required to attend several meetings during the year.



European Cystic Fibrosis Society Patient Registry (ECFSPR) Executive Coordinator

JOB PROFILE FOR THE EXECUTIVE COORDINATOR

- University degree or equivalent training
- At least 3 years' experience in an international environment
- Professional experience in registry work, research or the health care arena
- Positive problem-solving attitude and team worker
- Easy communicator interested in international networking; fluent in English, oral and written; any additional European language is an asset.
- Good computer skills: Word, Excel, PowerPoint, and Management programs
- Strong administrative & organizational skills
- Have the ability to screen, prioritize and effectively manage information flows
- Accurate, with an eye for detail
- Hands-on and calm under pressure
- Ability to work independently and contribute in a team environment

WHAT WE OFFER

- A full-time contract of one year, that could be prolonged
- A challenging job in a stimulating environment
- Opportunity to work from home
- A job that makes a difference
- A job with an international flavour

If you are passionate about making an impact in this area of epidemiology and research and possess the necessary qualifications, we invite you to join our dynamic team.

Please send your CV and cover letter to christine.dubois@ecfs.eu by 12 November 2024.
Only shortlisted candidates will be contacted.

Join us in advancing the mission of the ECFSPR and contributing to improved outcomes for people with CF throughout Europe.
Apply now!

Application deadline: 12 November 2024



Please send curriculum vitae and cover letter to:

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