



The European Cystic Fibrosis Society Patient Registry (ECFSPR) wants to appoint an Operations Manager

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 (countries defined as Europe by the World Health Organisation) and 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 enhance 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 42 participating countries (and growing), and longitudinal data from 2008 to 2023. It is a unique resource reflecting the reality of CF across Europe.

The Operations Manager will join and be an integral part of a strong team of 12 people from various countries with diverse backgrounds and expertise.

His/her tasks will include:

STRATEGY AND FINANCE

- Together with the ECFSPR Executive Committee, the ECFS Board and Registry team members, contribute to the development of short and long-term strategy for the Registry;
- Write the business plan;
- Produce the annual budget and monitor expenditure;
- Prepare cost overviews, together with appropriate team members;
- Explore external funding opportunities.

ADMINISTRATION

- General Data Protection Regulation (GDPR): Organise and manage all GDPR-related processes and administration, with the ECFSPR GDPR consultant;
- Standard Operating Procedures (SOPs): coordinate and manage completion and dissemination of SOPs together with the Registry Data Quality manager, and organise and deliver training for team members and Registry collaborators;
- Human resources: contracts, evaluation, training;
- Organise and moderate meetings with the ECFSPR Executive Committee;
- Organise, participate in and moderate meetings with other internal and external stakeholders, as required.
- Write minutes from meetings as required.

COORDINATION

- Project planning: together with the team, establish timelines, deliverables and milestones for ongoing and upcoming ECFSPR projects;
- Work with the team to ensure timelines are adhered to and deliverables and milestones are achieved;
- Oversee planning and organisation of Team meetings and Registry participation in the annual ECFS conference (see below under "Communications")
- Prepare status reports as required.

MANAGEMENT

With the team and the ECFSPR Executive Committee, oversee project management practices and the day-to-day activities of the ECFSPR. Major decisions will be taken together with the team and the Executive Committee of the Registry and sanctioned by the Board of the ECFS.

COMMUNICATIONS

Participate in and present at international meetings and conferences:

- ECFSPR Steering Group and team meetings in January (3-4 days);
- ECFSPR team meetings in Spring and Autumn (2-3 days);
- ECFS conference in June, including Steering Group meeting (4-5 days);
- Other as required.

Contribute to

- Regular ECFSPR newsletter;
- Press releases;
- Other external communications.



European Cystic Fibrosis Society Patient Registry (ECFSPR) Operations Manager

THE IDEAL CANDIDATE – MUST HAVES:

- University degree or equivalent training
- Excellent administrative and organisational skills;
- Experience in the preparation and management of budgets;
- Expertise in Word, Excel and PowerPoint and comfortable using other project management tools;
- The ability to screen, prioritize and manage his/her own workflow;
- Team worker, sensitive to the needs and motivation of other team members;
- Excellent interpersonal and communication skills (oral and written);
- Fluent in English, both oral and written;
- Accurate, with an eye for detail without losing sight of the bigger picture;
- Positive problem-solving attitude;
- Flexibility and the ability to adapt to changing circumstances;
- Calm under pressure.

Preferred but not essential

- Knowledge of any other European language, apart from English;
- Experience of working in an international environment;
- Professional experience in registry work, research or the health care arena;
- A working knowledge of Cystic Fibrosis;
- Experience in human resources;
- Experience of networking;
- Knowledge of European GDPR

WHAT WE OFFER

- A full-time contract of one year, that could be prolonged;
- The chance to become part of a valued, dedicated and efficient team;
- A challenging job in a stimulating and evolving environment;
- The opportunity to work from home;
- A job with an international flavour;
- The chance to make a difference .

If you are passionate about making an impact in this area of epidemiology and research and possess the necessary qualifications, we invite you to send your CV and cover letter to christine.dubois@ecfs.eu by 2 March 2025.

Only shortlisted candidates will be contacted.

In-person interviews will be held in Frankfurt on 10 and 11 April 2025.

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

Application deadline: 2 March 2025



Please send curriculum vitae and cover letter to:

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