

Cystic Fibrosis Switzerland is a patient organization that has been established for 50 years and is recognized throughout Switzerland. It represents the interests of over a thousand people affected by cystic fibrosis and their relatives.

## We are looking for a representative for the

# Patient Organizations Research Group (PORG)

#### Volunteer

The Patient Organizations Research Group (PORG) leads the research-related work at the European level. This working group consists of representatives of the national CF patient organizations that are actively involved in research and research funding.

The goal of the PORG is to enhance partnerships between European member organizations to expand the European CF research network and accelerate access to new medicines for people with CF through research. PORG currently has 11 members, including Belgium, France, Germany, Ireland, Israel, Italy, Luxembourg, the Netherlands, Poland, Switzerland, and the United Kingdom.

More information about the PORG: <a href="https://www.cf-europe.eu/what-we-do/research/">https://www.cf-europe.eu/what-we-do/research/</a>

## Your main tasks as a representative of Cystic Fibrosis Switzerland in the PORG:

• Active participation in PORG meetings (3x per year) inlcuding preparation and follow-up: June: attendance meeting at the site of the European Cystic Fibrosis Society ECFS annual meeting (1 day before the start of the congress).

October: Zoom meeting

January: At the winter meeting of the ECFS usually in Brussels

- Exchange of information with the CFS Board of Directors, CFS Office and Research Commission.
- Occasional editing of articles for the members' magazine Ensemble

### What you bring:

- Interest in topics related to cystic fibrosis research.
- A solid understanding of medical research terminology
- Good oral and written English skills; as well as German or French.
- Time and willingness to travel in Europe to attend meetings

#### What we offer:

- Meaningful, voluntary work with concrete opportunities for participation
- Flat-rate compensation per day of service, travel and accommodation expenses are also covered
- Administrative support of the CFS office

Please email your complete application materials to: info@cystischefibroseschweiz.ch.

For further inquiries, please contact the managing director Christina Eberle: 031 552 33 00.