



WORK PACKAGE 2: COLLABORATION WITH ECFS PATIENT REGISTRY

(Update July 2018)

Background

Since 2007, a CFE representative is member of the Executive Committee of the ECFS Patient Registry (ECFSPR). All patient organizations are co-funding or completely funding their national registries. Since 2015, a few CF patient organizations are also co-funding ECFSPR.

Significant efforts have already been undertaken to make the ECFSPR more patient-friendly and increase the visibility of the ECFSPR in the CF community. Since 2013, 'At-a-glance annual Registry Reports' are being published alongside the regular annual registry report in order to make the registry data more attractive to patients and their families. Furthermore, a first set of countries was provided with so-called country-specific posters, which are visually appealing posters for a broad public with actual registry data on a European and national level. Also, an interactive map of Europe with country-specific data can be found on the ECFSPR website (<https://www.ecfs.eu/ecfspr>). Finally, the ECFSPR is now active on Twitter.

Aims

Promoting insights in and use of registry data for patients and parents.

Activities

- Active membership of the ECFSPR Executive Committee, representing CFE, and assuring decisions by the ECFSPR are made in the patient's best interest
- Participation in the patient-specific projects, such as the at-a-glance reports, country-specific posters and presence on social media

Deliverables

- Publication of an annual 'At-a-glance Registry Report'
- Provide more countries that contribute data to the ECFSPR with country-specific posters, and update the existing ones
- Expand presence on social media by being active on Facebook
- Execute a survey to evaluate the visibility of the ECFSPR amongst important stakeholders within the CF community (patients, family, healthcare providers, patient advocates)

Countries involved

Belgium, France, Germany, Italy, Luxemburg, Switzerland, The Netherlands, The UK

Work package leader

Elise Lammertyn (Belgium/CFE)



Budget

For the period 2018-2021, Belgium, Luxemburg, Switzerland, Italy and The Netherlands are annually contributing € 30.000 in total to ECFSPR.

N.B.: A lot of registries are contributing in kind (human resources, support of centers, software).