Nederlandse Cystic Fibrosis Stichting (NCFS)

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Institution | Patient organisation/association

Institution identification

Institution ID

1000001051

Institution countries

Netherlands

Type of institution

Patient organisation/association

Institution role

Data holder

Institution website

https://www.ncfs.nl

ENCePP partner

No

Institution description

A longer and better life for everyone with cystic fibrosis (CF) by being an indispensable link between people, care, and science at home and abroad. That is our mission. Every day, we dedicate ourselves to helping everyone with cystic fibrosis and their loved ones. We answer their questions, inform them about developments in medicines and research, and do our best to raise funds to enable new research, among other things. We do this not only within the Netherlands but also in collaboration with foreign CF organizations, such as CF Europe. In this way, we strive to provide a better and longer life for everyone with CF.
To improve care and treatment, we are holder of the Dutch CF Registry. This is a database containing pseudonymized data on virtually all Dutch people with CF. Since 2007, these data are annually collected from all Dutch CF centers, analyzed by us, and published in a public report. With this, we answer important research questions and demonstrate why medication must be available to more people.

Institution details

Experience with collecting data directly from individual patients or respondents:

No

Interest in carrying out research that is funded by pharmaceutical companies:

Yes

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