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## Informed Consent form

Dear Patient, dear Parent(s) / Legal Guardian(s),

Your centre (*name*) in (*city, country*) and the European Cystic Fibrosis Society (ECFS) Patient Registry (“European Registry”) collect data from people with CF in Europe to measure, survey and compare aspects of CF and its treatment, to deepen the knowledge of the disease, provide data for epidemiological research, encourage new standards of care, and facilitate public health-planning.

Your centre in (*city, country*) and the European Registry invite you to participate in this important research project and ask your **explicit consent** to collect and process your personal data for the above-mentioned purposes. Your centre in (*city, country*) and the ECFS will each act as independent data controllers of your personal data. This means that we need your consent for both registries.

The data in the European Registry is pseudonymised, which means that identification is not possible without additional information. The European Registry is not able to identify you, only your clinician, or other authorised medical staff in your centre can do this.

The European Registry may visit centres to verify that the informed consent of the patient or his/her legal guardian(s) has been obtained in accordance with local and European legislation, and that the collected data matches the information in the patient medical record to ensure the quality of the data. Only authorised people from the European Registry, who have signed a confidentiality agreement with the centre, will be given access to the information.

In the future, your data may be included in a global registry and used for additional research projects. For scientific purposes personal data may be processed outside Europe. The necessary precautions will be taken to safely process your personal data. If you believe that your rights have been infringed, you have the right to lodge a complaint with the supervisory authority. For the European Registry we advise you to contact the Coordinator, [www.ecfs.eu/projects/ecfs-patient-registry/contact](http://www.ecfs.eu/projects/ecfs-patient-registry/contact).

Data will be processed as long as it is necessary to improve the research on CF.

Information about the processing of your personal data in your country and by the European Registry is available on the websites (*website address of your registry*) & [www.ecfs.eu/ecfspr](http://www.ecfs.eu/ecfspr). If you have any questions about the use of your data please contact the Registry of (*centre name*) at (*contact details*) and/or the European Registry at [www.ecfs.eu/projects/ecfs-patient-registry/contact](http://www.ecfs.eu/projects/ecfs-patient-registry/contact).

**Please read this document carefully. If you agree, please complete the information below as indicated.**

We thank you for your support.



I agree that my data is used in the European Cystic Fibrosis Society Patient Registry (ECFS) and can be verified by authorised personnel.

Name of the patient (parent / legal guardian): .....

Signature of the patient (parent / legal guardian): .....

Date: .....

Name of the patient (parent / legal guardian): .....

Signature of the patient (parent / legal guardian): .....

Date: .....

Signature of CF clinician: .....

Date: .....