

UNITED KINGDOM CYSTIC FIBROSIS DATABASE

Dear Patient or Parent

To ensure that the care of people with cystic fibrosis (CF) continues to improve, it is essential we have detailed information on the state of health and treatment of as many people with the condition as possible. To provide this information the UK CF Trust started the UK CF Database in 1995 to record accurate details of many aspects of the patients' care and condition in order to improve our understanding of CF and the effects of various treatments.

A short descriptive sheet provides further details about the database and its uses.

Recent regulations state that to include your data we require your written permission. We do hope you will agree to have your medical details being included on this database. Your participation is entirely voluntary and the information will be strictly confidential being identified only as a patient number rather than by your name. Also you can withdraw your permission at any time.

If you agree to participate please would you sign below as indicated.

Thank you for your help.

The person with CF whose data is to be entered into the UK Database:

Name :.....

Name :.....

[If not the patient]

Signature :.....

I am a Patient Parent Guardian Other (give details)

[Please tick as appropriate]

Date :.../.../...

The Data Controller is The Cystic Fibrosis Trust. Our nominated representative to deal with data privacy issues is the Chairman of the Database Steering Committee, should you have any queries about how your information is being used or should you wish your information to be removed from our records. The Chairman of the Database Steering Committee can be contacted at the CF Trust, 11 London Road, Bromley, Kent, BR1 1BY.