



The Cystic Fibrosis Registry of Ireland

Cystic Fibrosis Registry of Ireland

Patient Information Booklet



Welcome to the Cystic Fibrosis Registry of Ireland (CFRI).

This booklet will help you to get a better understanding of the CFRI and its main aims and objectives. If you have any questions after reading this please contact us. You will find our contact details on the last page.

Thank you for taking time to read this.

What is the Cystic Fibrosis Registry of Ireland?

The CFRI is a medical research information technology system which records and analyses data about the health and treatment of people with cystic fibrosis (CF) in the Republic of Ireland.

It was established in 2001 to keep medical records of each person with CF in a central database. By doing that we can quickly find out the total number of patients with CF in Ireland, how many are born each year, their symptoms at diagnosis and how the diagnosis is made e.g. sweat test and/or blood test.

The information collected by CFRI staff includes: weight, height, pulmonary function test results, as well as medications and treatments you are prescribed, along with details of any complications you may have. The CFRI also collects information from your annual review.

In order to collect this information the patient/parent will be asked to sign a consent form.

By bringing together and analysing the information on all people with CF in Ireland, we can get a better understanding of e.g. treatments that affect people with CF. Your/your child's information is held on a secure and confidential computer database.

Aims and objectives of the CFRI is to:

- Advance education by collecting and analysing CF information.
- Provide accurate reports in order to monitor and improve treatments.
- Use the information in the best interest of people with CF.
- Provide a CF information service to the Department of Health and Department of Children and Youth Affairs, health boards, hospitals and to health care professionals.
- Provide CF care teams with electronic data and summary reports.

Who is responsible for the CFRI governance?

The CFRI is a legal entity with its own Constitution and independent of other organisations. It is governed by an Executive Council, which is made up of healthcare professionals and patient representatives who oversee the management of the registry.

They ensure that only approved researchers gain access to registry information. Anonymised information is also shared with the European CF registry.

The CFRI is a registered charity that receives core funding through a Service Level Agreement with the HSE and in addition receives charitable donations and research project funding.

Will my information be confidential?

The CFRI is committed to preventing any unauthorised access to patient's information. Making sure your personal information is private and confidential is extremely important to us. Upon registration your/your child records will be assigned a unique identifier (unique code/number). The CF registry database is password protected on two levels. This means that a user must log on to the operating system first and then again onto the database. The most up-to-date encryption software is used to protect the CFRI data.

Only the multidisciplinary team and CFRI staff can identify your information. You/your child will **NEVER** be identified by name on published research and annual reports.

All the information taken from the medical records are protected by data protection regulations in Ireland - Data Protection Acts 1988 and 2003.



How is the information used?

The CFRI information is used to:

- Follow your progress and get an overall picture of everyone with CF in Ireland.
- Produce an Annual Report each year that summarises the information and it is available on the CFRI website (www.cfri.ie).
- Support new health technology assessments.
- Compile reports of new medication for the European Medicines Agency (EMA).
- Support health planning in Ireland and EU.
- Collaborate in international and domestic research.

How do I register?

If you wish to register please contact a member of your multi disciplinary team or the registry direct. Your participation in the CFRI is entirely voluntary. If you do decide to take part you will be asked to sign a consent form. The majority of people with CF in Ireland are registered (>90%). The more people that participate, the better the quality of the information that will come out of the registry.



Can I withdraw from the CFRI?

You can withdraw from the CFRI at any time in the future upon receipt of your written instruction. If you wish to withdraw, you should get in touch with the staff in charge of the registry.

Once you withdraw from the registry your/your child's data will be removed.

Your care will not be affected in any way if you withdraw from the registry.

How will I benefit from registering?

There is no guarantee that having your information on the CF registry will directly benefit you. The CFRI is intended as a service to support all people living with CF.

You will not receive any payment or any other financial benefit as a result of consenting your participation to the registry. No extra visits will be required and you will not incur any expense by participating.



Who should I contact if I have any questions?

If you have any questions about CFRI you can get more information by:

- Asking your CF consultant.
- Visiting the CFRI website at www.cfri.ie.
- Speaking to one of our staff members on telephone number **01-716 31 77** (9am-5pm, Monday to Friday).
- email us at info@cfri.ie.

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