

## Cystic Fibrosis Association of New Zealand

The Cystic Fibrosis Association of New Zealand aims to ensure increased life expectancy and improved quality of life for people with CF and their families; through research to achieve better control and ultimately a cure for the condition.

The Association's activities include providing: information about CF, support: social and financial, education, communication, advocacy, promoting public awareness, encouraging and funding research, and raising funds to ensure these services to the CF community continue into the future.

For more information about Cystic Fibrosis and the work of the Association, and to find out how you can access help or offer your help please contact our National Office or visit our website.

[www.cfnz.org.nz](http://www.cfnz.org.nz)



## Shares in Life Foundation

The CF Association established a research fund in 1993. Research funds are managed by the Shares in Life Foundation.

The Foundation was set up by a number of passionate individuals connected to the CF cause, who wanted to see NZ take part in the push for better control of CF and ultimately a cure for the condition.

The belief that CF can be cured, is not unrealistic. The only thing that stops us is finding enough money for research. This research needs to be completed by the best minds with the best possible resources.

Enquiries about supporting the Shares in Life Foundation can be made to the address below.



### Cystic Fibrosis Association of New Zealand

Level 1, Broadway  
62 Riccarton Road  
PO Box 8241  
CHRISTCHURCH 8440

Phone: 0800 651 122 or 03 341 8024

Fax: 03 341 8025

Email: [info@cfnz.org.nz](mailto:info@cfnz.org.nz)



# Port CFNZ Cystic Fibrosis Data Registry



### Introduction

In early 2011, the Cystic Fibrosis Association of New Zealand launched a new data registry for people with Cystic Fibrosis in New Zealand.

This data registry, Port CFNZ, has been developed by the Cystic Fibrosis Foundation in the USA and is currently also in use in the United Kingdom.

The registry is a benchmarking and data collection tool that will assist clinicians to compare their CF Clinic patient outcomes against those of other clinics around NZ and across the world. It is our intention that the registry will be a source not only of important data information, but will also be used as a quality improvement tool.

All people with CF in New Zealand have the option of being part of this data set, and only data from those who give permission will be entered into the registry.

Once up and running, each year an annual data 'snapshot' will be taken, from which a Data Registry Report will be compiled. This snapshot will allow comparison of clinics within NZ and across the world, identify points that need specific attention, and help define quality improvement strategies.

All data reports from Port CFNZ will have any personal identification details removed to ensure the participant's privacy. The only personnel privy to your details are your own CF health

professionals and the Registry Administrator.

Information from Port CFNZ will be available to CF researchers as a source of anonymous data which can assist them with planning their research.

Data is collated from tests currently undertaken during your clinic visits and hospitalisations. No extra testing is required as part of Port CFNZ. This data is then entered into the registry by your own CF health professionals to maintain your privacy.

Not only will Port CFNZ give useful data to clinicians, but on a personal level, will provide people with CF (and their carers) direction on day-to-day management of the condition to create a healthier lifestyle, to prolong and improve quality of life.



### Am I eligible to participate?

Anyone with Cystic Fibrosis who attends a medical clinic in New Zealand is eligible to take part in Port CFNZ.

Whether you want to take part or not is your choice. If you choose not to take part, this will not have any effect on your future healthcare.

If you do agree to participate, you can change your mind at any time and we can remove your information from the Port CFNZ Registry.

Parents will be asked to provide permission for their affected children under the age of 16 years.

### What do I have to do?

You will be approached through your CF clinic, but if this has not happened and you are interested in finding out more about Port CFNZ, we can put you in touch with the relevant CF clinicians in your area, who will explain the Registry to you. Contact the CFANZ Office, details on the back of this brochure.

If you do decide to participate you will need to sign the Patient Consent Form which will then be forwarded to the Registry Administrator at the Cystic Fibrosis Association of New Zealand.

From that point on, there is nothing for you to do, other than attend your clinic follow-ups as usual.