

# CF News magazine

Twice a year we publish our magazine **CF News**, which contains news, views and inspiring stories from the CF community.



It's free to everyone and you can sign up on our website or email us to be added to the mailing list.

# CF Panui

Each month we publish an e-newsletter, **CF Panui**, full of news, fundraising activities, and other important information. You can sign up on our website or email us to be added to the mailing list.

# Website



Our website cfnz.org.nz contains a wealth of information about CF and our work. All of our publications are downloadable from our website, and there's lots of information about how you can support CFNZ through fundraising and other activities.

# Other ways we help



#### **CF Research**

We have been investing in cutting-edge research into new therapies and better treatments for over 20 years, and work closely with Cure Kids to fund New Zealand's contribution to global CF research.

#### A Voice for CF

We advocate on behalf of the CF community on issues that matter – access to medicines and equipment, better welfare assistance and equal care for all – and the more people join in, the louder our voice will be.



A special thank you to The Lion Foundation for making this publication possible.

# CTCYSTIC FIBROSIS NZ

# For more information about cystic fibrosis or how we can help you:

info@cfnz.org.nz
Telephone 09 308 9161
Freephone 0800 651 122
PO Box 110 067
Auckland Hospital, Auckland 1148
Suite 2, 79 Grafton Road
Grafton, Auckland 1148

cfnz.org.nz



Support available for people with cystic fibrosis and their families



cfnz.org.nz



# What is cystic fibrosis?

Cystic fibrosis (CF) is New Zealand's most common life-limiting genetic condition. It mainly affects the lungs and pancreas, but over time affects other organs too.

It is caused by a faulty gene passed down from both parents and is usually diagnosed soon after birth.

CF causes mucus in the body to become thick and sticky. In the lungs, this thick mucus is difficult to cough up, trapping certain bacteria and causing inflammation and infections. The sticky mucus also blocks the flow of digestive enzymes from the pancreas to the stomach causing problems with digestion and absorption of food.

#### Who are we?

Established in 1968 as a volunteer support group for parents with a newly diagnosed child, we dedicate ourselves to shaping a brighter future for everyone with CF.

Our team of fieldworkers visit and support families, provide information packs, cover the costs of essential medical equipment, hospital allowances, welfare assistance, and other means of support. We also fund CF research and advocate on behalf of the community for better access to services and care.

# Providing support every step of the way

#### **Fieldworkers**

Our fieldworkers provide dedicated support in the community. They offer a listening ear and can help with a range of issues, such as receiving a CF diagnosis, starting school, leaving home, employment issues, and support with welfare claims. They travel around New Zealand, meeting with clinicians and the CF community.

#### **Branches**

Cystic Fibrosis New Zealand has regional branches run by volunteers. Branches offer peer support from other parents and people with CF, financial support, assistance with equipment (including purchase, service and maintenance) and access to learning opportunities. The branches also coordinate local fundraising initiatives and activities.

## **Financial assistance**

Cystic fibrosis can bring its own financial burden, so we provide a range of grants for people with cystic fibrosis and their families. These include hospital allowances, transplant assistance and physical activity grants.

# **Equipment**

Where equipment is not supplied by a local DHB, branches will supply necessary medical equipment to facilitate treatment. This includes nebulisers, compressors, and consumables.

#### Awards and endowment funds

Our awards and endowment funds help to celebrate and support the amazing achievements of people with CF against the odds. These awards include; the Cystic Fibrosis Achievers Awards, the Chris Howlett Endowment Fund, and the Mark Ashford Scholarship.

### **Online and printed information**

We provide a wide range of up-to-date information about CF in the form of publications and information packs, as well as information on our website.

"CFNZ has been fantastic to us in lots of ways but probably the most important way is just knowing there are people out there who are looking out for and caring for you even though you haven't met. It makes a hard road significantly easier."