



Welcome To The December CF Panui!

Kia ora koutou katoa,

Reflecting on the year behind us, the opportunity to listen to three people talk openly about their journey with CF during the course of a week really stands out in my mind. Firstly, Nichola at Government House, then Ollie in the gym with Joseph Parker, and finally Shane at the Christmas Tree Festival. Their willingness to speak so frankly about their lives is an inspiration to us all.

The CFNZ team and I feel honoured to be part of an organisation that has achieved so much and has such a will to move forward (no pressure!). This year we've made great effort to find out what is important to you, our community, and what you want the future to look like. We invite you to read about some of our **recent progress and learnings** that underpin our future direction.

We will take a short break and be back next year ready to move forward with the challenges of 2019. Until then we wish you a wonderful festive season and a relaxing holiday.

Meri Kirihimete,
Jane and the CFNZ team



Spreading Christmas Cheer At Wellington Airport

The CF Christmas Tree Festival arrived on 1st December and funds raised help support children and adults living with CF. Over 40 organisations such as NZ Rugby Union, Coca Cola and David Jones have come on board to sponsor and dress trees displayed at the airport.

At the opening gala the winners for the best trees were announced, with **Streetwise Coffee** taking 1st place, **Scape Goats** in 2nd, and **Stacks Furniture** in 3rd. Congratulations and a huge thank you to all the sponsors. If you're passing through the airport this festive season, make sure you plan enough time to have a look at all the gorgeous trees.

Mark Ashford Scholarship 2018

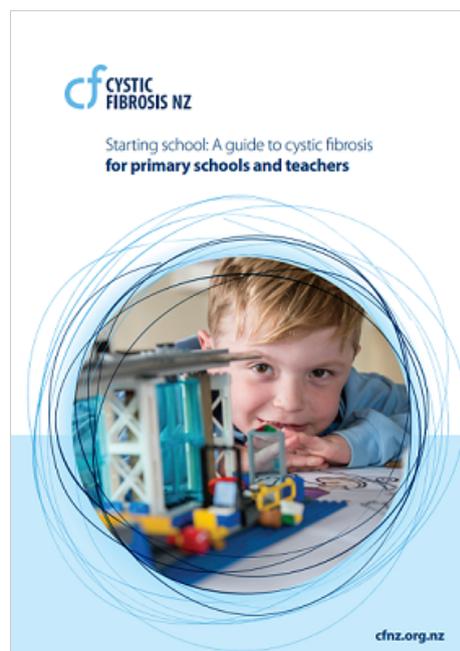
This year's Mark Ashford Scholarship was awarded to Damien Bell from Te Awamutu. Damien is half way through his three year degree, studying towards a Bachelor of Applied Information Technology at WINTEC in Hamilton. "It's a real honour to be recognised for the hard work and commitment I've been putting in over the last year and a half with my studies. I plan to use the money towards covering some of my fees. This will help ease the burden of my student loan allowing me to pursue some of my other life ambitions. A huge thanks to Tasman Insulation and CFNZ for providing this opportunity," Damien says. [Read full article >](#)

CF At School Guides Now Available

Starting school is a big milestone in every child's life, and as a parent of a child with CF, it usually comes with a few extra challenges and worries. We've developed two new guides to help support you.

- [A Guide for Parents of Children with CF](#)
- [A Guide for Primary Schools and Teachers](#)

Printed copies will be available in the New Year. Thank you to The Lion Foundation and SKIP for funding this project, and to the families who shared their experiences.



Employers Guide To CF - Reviewers Needed!

We're looking for individuals with CF from any trade or field who will soon be entering the world of work, are recently employed, or have been working for a longer period of time to provide feedback. If you happen to have a great boss or know an employer of someone with CF - we'd love to hear from them too. Get in contact with [Sarah](#) for more details.

New CF Resources - Have They Been Helpful?

Earlier in the year, we published two new guides to support during the new diagnosis stage of cystic fibrosis. We'd love to share how either of the following guides have helped a family:

- [A Guide to CF for Parents and Caregivers](#)
- [A Guide to CF for Family, Whanau, and Friends](#)

If you have any feedback, please get in touch with [Sarah](#).



Special Celebration To Mark 50 Years

Volunteers, health professionals, staff and friends from all over New Zealand celebrated 50 years of CFNZ supporting people with CF and their families. Governor General, the Rt Hon Dame Patsy Reddy, and Sir Peter Gascoigne welcomed over 100 guests to Government House in Auckland on 5 December. After a warm welcome from Dame Patsy, CFNZ President Denis Currie reflected on the past 50 years and how far the organisation has come.

[Read the full story & watch the timeline video >](#)

L-R CFNZ CE Jane Bollard, CFNZ President Denis Currie, the Rt Hon Dame Patsy Reddy, Sir Peter Gascoigne, CF adult representative Nichola Wilson, CFNZ Chairperson Jane Drumm and CFNZ Patron Professor Bob Elliot.

Advocacy Update

This year there's been a particular focus on building our capacity for advocacy. We've developed an advocacy strategy that covers many different areas, all with the goal of improving life for people with cystic fibrosis. We're currently talking with Branches to get their feedback and hear how we can support local advocacy efforts. Once the strategy is a finalised we'll put out a summary so everyone can easily see our advocacy priorities and how we will achieve them. [Read more >](#)



Campaign Response From The Minister Of Health

Following our approach to all parliamentary MPs highlighting the need for Kalydeco and other precision medicines in New Zealand, we received a response from Hon Dr David Clark the Minister of Health on 18 December. [Read letter >](#)



Joseph Parker Meets Ollie

Earlier in December 25 year old Ollie from Nelson had the experience of a lifetime with boxing legend Joseph Parker and his coach Kevin Barry, which The Project NZ kindly covered.

This formed part of our position as Official Charity Partner at the recent Parker V Flores match in Christchurch. Thanks Joseph and Duco for the support!

[Watch the video](#) to find out what these two fighters got up to!

A Big Thank You For The Support

Cystic Fibrosis NZ relies on the generosity of donors, funders and corporate partners to support and advocate for the CF community. Our supporters meant that in 2018 we were able to:

- Launch the Kalydeco for Kiwis campaign, advocating for access to innovative medicines

- Provide 151 welfare grants (worth \$39k) including winter heating help, grocery vouchers and assistance with transport to hospital
- Launch the new CFNZ website, bringing up to date information to the CF community
- Provide 295 Breath4CF grants (worth \$63k) to ensure cost is no barrier to staying healthy
- Establish a new strategic research initiative with Cure Kids
- Continue providing support from our three regional fieldworkers
- Provide 37 transplant grants (worth \$8k) to assist with expenses associated.

Thank you for making this possible.

We would also like to acknowledge the recent support we have received from the following funders: The Lion Foundation, Pelorus Trust, Blue Waters Community Trust and the John Ilott Charitable Foundation. Their valuable support of both the National office and branches helps us to achieve our strategic goals. Thank you!

We're Hiring!

Cystic Fibrosis NZ will be advertising for a Communication Coordinator in the new year. We are looking for someone, preferably Auckland based, who is digital-savvy and can help with both external and internal communications. This a part-time role working with a great team. Anyone interested can [email the Chief Executive](#) after 7 January 2019 for more information.



Going Blue For Cystic Fibrosis

This year marked the 50th anniversary of both CFNZ and PARI BOY - and as part of this we've been running a joint-campaign, where PARI will donate 10 euros for every shirt worn at a personal challenge.

We recently ran a 'Blue Shirt Week' to encourage people to get active, and were thrilled to see so many people getting involved! For any challenges between 24 December and 1 January PARI will **DOUBLE** the donation to 20 euros - a whopping \$32 (or so!) per participant! Now that's an awesome incentive to work off the Christmas dinner. [Read more >](#)

Christmas Close Down

The CFNZ office is closed from 4pm on Friday 21 December and reopens at 8am on Monday 7 January 2019. If you need help during this time, please see your GP or for more urgent matters A&E. CFNZ Central Fieldworker Jude can be contacted on 021 192 6234 for emergencies during the close down period. Merry Christmas from all of the team at Cystic Fibrosis NZ!



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