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02/19

Welcome To The January CF Panui!

The start of a new year is a wonderful time for setting new goals and developing plans to help achieve those goals. At Cystic Fibrosis NZ we will be continuing to explore ways in which we can better support the CF community.

To do this, we are indebted to those who support our organisation. In this newsletter we acknowledge and thank the support of sponsors TeflerYoung, Tasman Insulation, Mylan, PARI and EBOS for their incredible support.

Have a lovely February.

Jane Bollard
Chief Executive

Mark Ashford Scholarship 2019

Applications are open for the 2019 Mark Ashford Scholarship and CFNZ is delighted to announce TeflerYoung as the new sponsor. Thank you to Mark Passey, the CF adult representative on the CFNZ Board who is the owner/director of TelferYoung (Tauranga) Limited. In 1999, Mark won the Mark Ashford Scholarship and he understands the challenges people with CF face.CFNZ would also like to thank and acknowledge Tasman Insulation, manufactures of Pink Batts, who has funded the scholarship for the past 22 years in memory of Mark Ashford.
Read full story >

Cystic Fibrosis Achievers' Awards 2019

Applications are open for this year’s Cystic Fibrosis Achievers’ Awards. Mylan NZ Ltd (brand owner of Creon) is very pleased to announce its continued support of the awards in 2019. "As a company we value our ongoing partnership with CFNZ and welcome the opportunity to play a part in the recognition and celebration of the amazing achievements of people living with CF. We wish all applicants the very best of luck," says Sean Stewart, Country Manager.
Read full story>

Charity Of Choice At Black Clash

Last week Cystic Fibrosis NZ was featured as the official charity partner at the Black Clash event at Hagley Oval in Christchurch. The event offered great exposure, with several volunteers roving the crowds with collection buckets and $2 from every programme sale going towards cystic fibrosis. The total sum raised is still being confirmed.

Pictured below: Two of our fabulous volunteers helping to raise money!

Have Your Say

The CFNZ Board oversees the charity's strategic direction and acts as a voice for the CF community, and we actively encourage people to have their say. The next Board meeting takes place on 24 March and if there are any items for the Board to consider, please email them to admin@cfnz.org.nz by Monday 4 March.

New Board Member

The Board has appointed Melissa Skene, Chair of the Canterbury Branch, to the casual Board vacancy which will be held until the next AGM in October 2019. Melissa has been actively involved with the Canterbury Branch for over 20 years and brings a wealth of experience to the Board. Congratulations Melissa!

Communications Coordinator

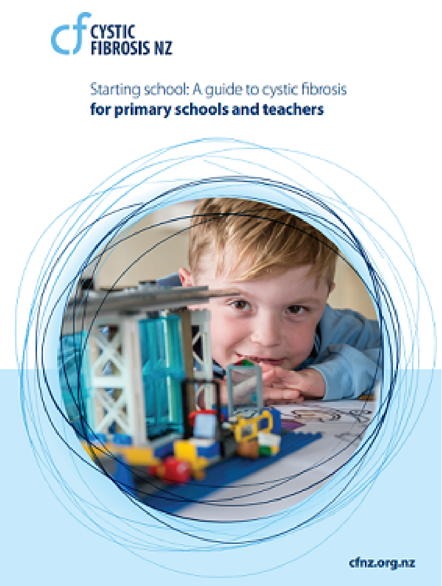
CFNZ has been interviewing potential candidates for the communications role, who will provide the internal and external communications function (CF Panui, CF News magazine etc) for the charity. We've had a fantastic response to the advert and hope to appoint someone shortly.

Expressions Of Interest - Australasian CF Conference

Cystic Fibrosis NZ would like to offer conference grants to assist with the costs of traveling and attending the Australasian CF Conference, 3-6 August 2019, at the Crown Towers Hotel in Perth. We have some limited funding and would like to hear from those who are considering attending so we can gauge interest. Please email admin@cfnz.org.nz.

CF Week 2019

August 12th may seem like aeons away, but here at the Cystic Fibrosis NZ office we're already busy organising our annual appeal week! If you'd like to help out with the street collections 16-17 August, register your interest today and we'll get in touch closer to the date. We are also absolutely thrilled to announce Mylan as a sponsor for this years' CF Week. Thanks, Mylan!


CYSTIC FIBROSIS NZ

Starting school: A guide to cystic fibrosis for primary schools and teachers

cfnz.org.nz

Preparing For School

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. In December we released two new guides to help support you.

- A Guide for Parents of Children with CF
- A Guide for Primary Schools and Teachers

You can download these via the links above, or email admin@cfnz.org.nz for a PDF copy. Printed copies will be available at a later date. The CF Fieldworkers are also available to support you.

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.

CF News, Website & Panui Contributions Wanted

We are keen to hear your stories of things you have done, or things you have achieved, or just about your life journey with CF. Perhaps you would like to impart some of the knowledge you've learned along the way, or simply give the public a glimpse into what life is like as a parent or person with CF. If you would like to either submit a story or be interviewed for one, please contact laura@cfnz.org.nz.

Going Blue For CF

A huge thank you to the team at PARI and EBOS for running the 50 years campaign, which has now come to a close. The campaign saw hundreds of fundraisers across the country getting active in their blue PARI t-shirt, helping to raise money for Cystic Fibrosis NZ. There will be a cheque presentation early this year with the final amount raised.

Advocacy Update

Last year we developed an advocacy strategy, and the focus this year is continuing to implement it and get the changes we know are needed. A major focus for advocacy last year was the campaign to get the treatment Kalydeco publicly funded. In early September PHARMAC called for applications from suppliers of medicines for rare disorders. Vertex, Kalydeco's manufacturer, put in an application for Kalydeco. Right now we're waiting to hear PHARMAC's decision - we expect them to announce their decision soon. If the decision is negative we intend to continue the campaign.

Lisa Woods, the CFNZ Advocate, is also working with branches to identify local advocacy priorities. You can check out progress on advocacy activities on the CFNZ website, including a timeline of activity. Learn more>

Koru Care Experience

Koru Care NZ arranges activities and trips every year for groups of children aged 7-16 and their caregivers.

Northern CF Fieldworker Gretchen Kitching said: "This is a great opportunity to join in on trips with other children who have health conditions and have an experience of a lifetime".

Find out more>

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