CYSTIC FIBROSIS NZ

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04/19

Welcome To The April Update

Kia ora,

This month our hearts went out to the Christchurch Muslim community as they started to come to terms with the immense tragedy they face.

In our CF community, we felt the loss of our much loved CF ambassador, Kristie Purton. Kristie was someone who wanted to make a difference and who did make a difference; she truly reached out and gave back without question. Kristie was a role model to us all.

May the love and strength of the communities to which we belong offer support at this time.
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This issue contains an update on DHBs taking on the responsibility of funding vital CF medical equipment, a look at increasing clinical trials in NZ, support for a big piece of research, the announcement of the Mark Ashford Scholarship recipient, and much more.

Arohanui.

Jane Bollard
Chief Executive

Help Be The Voice Of People With CF In Aotearoa

As a charity, we're competing with thousands of other not-for-profits in New Zealand to make our voice, our cause and our people heard. But we need your help!

The stories page of our website features 5 people with CF who have shared their story about the affect CF has on their life or of someone they know with CF. These stories are invaluable for our organisation. Stories put a human voice and face to the work CFNZ and the branches do – why everyone works so hard to fundraise, raise awareness and improve the quality of life for people with CF.

We'd love to hear from anyone who's affected by CF and would like to tell their story. Whether you're a parent of a child with CF, you have CF yourself or someone in your family has CF, your story is important. Your voice, your words and your story will support our vision for the future of lives unlimited by cystic fibrosis.

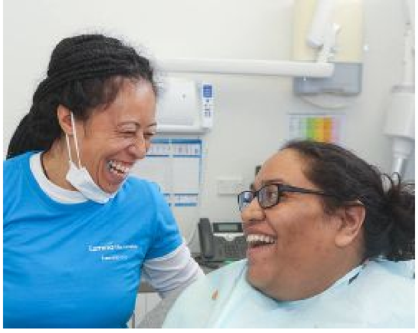
Check out our stories page for some inspiration and email Sarah: sarah@sayline.co.nz if you'd like to share a few words. Thank you.

CF Hits The Big Screen

Five Feet Apart, a film featuring two young people with CF who fall in love, hit NZ last month.

Seeing CF portrayed on screen can be confronting, so we've put together a resource page with information about the film, some of the issues raised, and what support is available. It's important to remember that CF is a complex condition. The story portrayed won't be your story, but it is a story about CF and with that in mind, it's a positive thing to have CF profiled in a major movie that will raise awareness.

If you may be interested in sharing your story with the media, please contact our Marketing & Fundraising Manager at laura@cfnz.org.nz.



Free Dental Treatment For Carers

Caring for a loved one with cystic fibrosis often leaves little time to think about your own health and wellbeing. That's why Lumino The Dentists has partnered with Carers NZ to offer carers free dental treatment on Saturday 11 May as part of Lumino Day 2019. There are limited spaces, so be quick! To register visit: https://bit.ly/2HT3nY5.

Health And Prosperity Through Clinical Trials

CFNZ's CE recently attended a workshop coordinated by New Zealanders for Health Research (NZHR) focused on clinical trials. The workshop, attended by Pharma, DHBs, Ministry of Health, HRC, companies who coordinate clinical trials and a couple of charities, looked at the clinical trial landscape in NZ and what supports, promotes and hinders trials happening in NZ. The participants were overwhelming positive about addressing the obstacles that exist and developed key themes that will inform NZHR advocacy programme. Learn more >

Social & Economic Cost Of CF

In the research field we are pursuing funding for a significant piece of work which would look at the social and economic cost of raising a person with cystic fibrosis across all areas of life. This an expensive, professionally undertaken and vital piece of work which will be invaluable in our advocacy for new drugs, treatments and support services. We have contributions for this work from the CFNZ Wellington Branch and our research fund, and are working on some leads for other funding, so watch this space.

Cross Infection Update

CFNZ's Clinical Advisory Panel (CAP) is providing invaluable guidance and advice to the Board on numerous medical issues. Most recently, CAP finalised a position statement on the infection prevention and control in non-healthcare settings. It is an extremely full document which reflects the global viewpoint, and we feel confident it will provide good direction for our community in many situations. The Board signed off this document and we are currently updating CFNZ policy to reflect these guidelines. These will be made available shortly.

Viv Becomes First Nurse Prescriber

Viv Isles, Clinical Nurse Specialist - Respiratory, has proudly become the first nurse who can write prescriptions for cystic fibrosis. Viv recently completed a post-graduate diploma including pharmacology and prescribing papers, and can now prescribe medications off a set list, within her scope of practice. The impacts of this will be immense - not only does it help the families financially (as faxed scripts can cost up to $5), but the time saved for the families, herself and doctors alike is great, as she can complete scripts in the home. Congrats Viv!

PARI Fundraiser Raises Over $8,000!

Last year saw hundreds of Kiwis go blue in support of CF through our joint fundraising initiative with PARI. For every person taking part in a physical activity whilst wearing a special blue t-shirt, PARI would donate 10 Euro. We're thrilled to report that, thanks to the hard work of our supporters, we raised over $8,000 (5,000 Euros)! This is simply awesome, thank you to PARI and to the CF community for getting stuck into the fundraiser.

Pictured (from left): Phillipa - EBOS, Jane - CFNZ, and Wieland - PARI with the big cheque!

Supply Of Vital CF Medical Equipment

Last year, after discussions with Pharmac, we advised DHBs that CFNZ was moving out of the provision of medical devices which are vital to the treatment of a person with CF. We have had good uptake by DHBs and are following up on a few still to engage with Ebos, NZ's suppliers of PARI nebulisers and compressors. CFNZ's Clinical Advisory Panel is developing guidelines for DHBs, and Ebos and PARI are available to give support, product advice and training to DHB personnel.

NZORD- A Collective Voice For Rare Disorders

As you are aware we are awaiting the decision of Pharmac's PTAC regarding the funding of Kalydeco. The NZ Organization of Rare Disorders (NZORD) Chief Executive and staff meet regularly with Pharmac who at their recent meeting confirmed their commitment to rare disorders and its community. They detailed that the Rare Disorders Subcommittee had received all submissions sent to Pharmac (that's over 170 for Kalydeco alone!) and that there would be progress on some of the recommendations made by this committee. Pharmac is currently looking at equity issues and is working on a policy framework to the Minister of Health. They are also supporting the Government's new Living Standards Framework which connects with the wider wellbeing strategy and have worked with Treasury on the measures of wellbeing.

CFNZ welcomes Gill Greer, NZORD's acting Chief Executive. Gill is addressing NZORD's own funding issues and CFNZ will be advocating to the Ministry of Health of the value of funding NZORD as a collective voice for rare disorders.

Have Your Say Too

We are currently finalising our CFNZ Advocacy Strategy adding a focus on local and regional issues. If you feel there is something CFNZ should be advocating for in your area please contact your local branch or CFNZ directly on ceo@cfnz.org.nz. Big thanks to everyone who is actively involved in advocating for a better future for those with CF. If you haven't already, check out what's happening on our advocacy page.

Caleb Awarded 2019 Scholarship

Generously funded by TelferYoung, the Mark Ashford Scholarship is awarded each year for excellence in tertiary education. This year the scholarship has been awarded to architecture student Caleb Skene.

"It is an absolute honour to receive the scholarship in recognition of my achievements in the study of architecture! I feel proud knowing the meaning behind the award and grateful for the possibilities it will give me in developing my knowledge, such as travelling and experiencing my favourite buildings first hand", Caleb explained.

Congratulations Caleb, very well deserved. A big thank you to sponsor TelferYoung too!

Pictured: Caleb and his Mum, Canterbury Chair & CFNZ Board member, Melissa Skene.

Social Event For Wellington Parents

CFNZ Wellington Branch is hosting a catch up for parents on **Wednesday 1 May** at 7pm at **The Thistle Inn**, Mulgrave Street, Thorndon. This is a great opportunity to meet and chat to other parents of children with CF. Please RSVP to wellington@cfnz.org.nz

Meet The Sponsor - Mylan

Each month we'll be meeting some of our wonderful corporate supporters who enable us to continue supporting the CF community. This month we're getting to know Mylan.

Many people with CF will know of CREON® - the capsules containing special enzymes to help the body break down the food you eat. But what about the company behind the capsules?

Meet Mylan NZ Ltd, CREON® brand owner and long standing, active and very valued supporter of CFNZ. Mylan sponsor the CF Achiever’s Award and our annual CF Week, and recently helped fund the 2018 Adult Insights project. This exciting project provided CFNZ with valuable information on the experiences of adults living with CF and how we can better support them in the future. Globally, Mylan is focused on making high quality medicines and is committed to setting new standards in healthcare, working together around the world to provide 7 billion people with access to high quality medicines. Within NZ, Mylan is one of the largest suppliers of medicines used by Kiwis every day.

A big thank you to Mylan for its commitment to CFNZ and the CF community!

Fundraising Boost For Canterbury

This year got off to a great start for the CF Canterbury branch, who received a cheque for $7,500 from the 15th Argent Lifetime Charitable Golf Day. The tournament, held on 22 February, helped raise money for Cystic Fibrosis Canterbury and Ronald McDonald House South Island. A huge thank you to Lifetime and everyone involved for the generous donation which will help support people with CF in Canterbury.

Pictured: Nicky Churton accepting the donation on behalf of the Canterbury branch

CF Raffle Is Running A Little Late!

We'll publish prizes and how to purchase your tickets shortly. Thanks for your patience.

Showing 'Grant-Itude' To Our Funders

This month we received funding towards the purchase of equipment and resources from The Lion Foundation, Youthtown Inc, Trust House and Trillian Trust. We also received funding towards operating costs from The North & South Trust Ltd, Four Winds Foundation Ltd, CERT and the W.Duncan Bickley Trust Fund. A huge thank you to these funders for their support.

CF Conference 2019

Registrations are open for this year's Australasian CF Conference, held in Perth from 3–6 August. The conference provides a collaborative and educational forum for the CF community and CF professionals to help advance CF research and care. To find out more about the conference, visit the CF Australia website.

Conquer The Bridge!

Thinking of running the Auckland Marathon? CFNZ Auckland Branch is inviting people to join the CF Team and raise money together. A great opportunity to be a part of something big, make new friends, and stay motivated! For more info contact Auckland Branch Coordinator Kath at auckadmin@cfnz.org.nz.

Need More Information?

Visit the CFNZ website for latest news, resources, information, apply for grants, find contact details and more. Go to www.cfnz.org.nz >