

Panui - March: New Developments in CF, Update from the Board, Clinical Advisory Panel Announced, New Breath4CF Deadline, Orkambi Now Unfunded Prescription Medicine [View this email in your browser](#)



New Developments in CF Seminar

Starship Associate Professor Dr Cass Byrnes has given an informative and insightful presentation for CFNZ's Auckland Branch on *New Developments in CF*.

There was an impressive turn out from the CF community for her talk this month which covered the latest research including the emerging new drug tezacaftor and promising new study of triple therapy which includes a new drug compound called VX-440.

Dr Byrnes also revealed comparisons between new precision medicines like Kalydeco and Orkambi, that are not yet funded in New Zealand, to current treatments available in NZ:

Lung Function (FEV1)

Ivacaftor (Kalydeco) up 10.4 percent

Orkambi up 3.5 percent

Tezacaftor / ivacaftor up 4 percent

Inhaled TOBI up 12 percent

Pulmozyme up 5.8 percent

Hypertonic saline up 3.2 percent

Pulmonary Exacerbations

Ivacaftor down 60 percent

Orkambi down 30 - 39 percent

Tezacaftor / ivacaftor down 35 percent

Pulmozyme down 22 percent
Hypertonic saline down 66 percent

Her presentation was followed by a panel discussion with Dr Byrnes and Starship's Dr Mirjana Jaksic, CF Nurse Specialist Jan Tate and Physiotherapist Rebecca Scoones, with a lot of questions raised regarding the lack of funding for new precision medicines in New Zealand.

Dr Byrnes said the high cost of medicine like Kalydeco is the only reason it remains unfunded because she says it ticks all the other boxes for Pharmac.

The Branch has acknowledged the *Wilks Charitable Trust* for providing a grant for the seminar and to *Choice Hotels* for assisting with the venue. The presentation was live streamed on the Auckland Cystic Fibrosis Facebook Page and will also be available on video next month.

Update from the Board

March saw a very full and exciting weekend for the Board. We started on Saturday morning with a facilitated discussion to begin developing a new strategic plan. This plan once completed will drive the work done by the organisation for the next three years.

Certainly advocacy, access to high-quality care, medication and treatment, and strong links to our branches and a strong CF community were some of the priorities identified by the Board.

The plan from here is to gather your ideas and give them full consideration in the process. This process began at the Chairpersons' Conference late last year. We will also get feedback from in-depth empathetic interviews of some families and adults with CF, and from the upcoming CF survey of families and adults.

In late May, a draft strategic plan will be sent out for further consultation. Once it's been finalised a special one-day meeting of CFNZ Chairs will be held to discuss the strategic plan and how we can implement it.

Day two was the March Board Meeting. We would like to thank Waverley Waring who joined us from the Auckland Branch to put forward her passionate thoughts on where CFNZ should be heading and some insightful ideas on how to get there.

The Board is aware of the need to invest in the resources necessary to grow our income and ensure the sustainability of CFNZ. Currently CFNZ is tracking well towards a small end-of-year surplus and the Board has approved the employment of an additional fundraiser, and to contract specialist advice for our Advocacy Plan.

Thanks to Auckland Branch which has generously offered to fund this advocacy expertise. CFNZ is also currently looking to recruit a full-time Administration Manager. Emma Nielsen has cut back her hours to 15 hours a week – Monday, Wednesday and Friday. And sadly 15 May will be her final day with CFNZ.

An area of work that has now been completed is the empathetic interviews with families of newly diagnosed and small children. The information obtained from these interviews has been immensely valuable and is contributing to the educational information in the upcoming new guides. As a result we have decided to commence an equivalent piece of work with Adults with CF. This work is to be jointly funded by Auckland, Wellington and Hawke's Bay branches. Wonderful!

Finally, we have reviewed and approved CFNZ's Health and Safety policy document, with the proviso that there are some areas that need further thought in particular

around the issue of travel for Fieldworkers, and also a comprehensive and definitive cross infection policy.

You will see from this report that we really want to engage and involve our whole community, not just in the strategic process but specific projects. We know there is a wealth of people skills and energy in our CF community. Please don't hesitate as a branch or individual to get in touch if you think you can help.

- **Michele Wilson, CFNZ Board Member**



Great Shot Rylee!

Good to see people taking advantage of PARI's offer to mark its 50th anniversary by donating 10 Euro (NZ\$17) to CFNZ for anyone who completes a personal challenge wearing a PARI shirt and posts a photo on the [PARI BOY 50th Facebook Page](#). Congratulations to Rylee (12) of Hawke's Bay for being the first New Zealander to appear on PARI's Facebook Page wearing a PARI t-shirt with this great action shot of her playing shot put.

[Order your t-shirts through the PARI website](#) - limit two per order.

New Clinical Advisory Panel Announced

CFNZ is pleased to announce the new Clinical Advisory Panel set up to provide expert advice to CFNZ. The Panel includes Associate Professor Cass Byrnes (Chair), Adult Physician Dr Mark O'Carroll, CF Nurse Specialists Jan Tate and Cath Lamont, Physiotherapists Rebecca Scoones and Trish Goulter, Dietitian Tory Crowder, CFNZ Chair Jane Drumm and CFNZ Chief Executive Jane Bollard. It's hoped the new Panel will meet soon. We will keep you informed with any updates.



Tommo's Trek for Maddy

Mark Thomson is walking the Camino to join his father-in-law Terry Wilson as he walks the Camino for a second time followed by a film crew that's profiling Kiwis who have embarked on the spiritual journey to walk 800 kilometres across Spain to the cathedral of Santiago de Compostela. Mark is also walking in memory of his step-daughter Maddy Stuart who passed away with CF in 2016. He has kindly set up a



CFNZ Bowled Over

Huge thanks to the Birkenhead Bowling Club and Rotary Birkenhead which raised an incredible \$8000 for CFNZ following their bowling day for CF and to help support one of their member's - Curtis Ennor of the CF community. Jane is pictured here with Curtis (left) and representatives from the Bowling Club and Rotary at the cheque presentation this month. This was the highest total raised for any charity by the Club, which is keen to support us again.

Last Chance for CF Achievers' Awards

Entries for the CF Achievers' Awards close on 1 April. The Awards cover four categories - Sport, Education, the Arts and Leadership and are used to celebrate the impressive achievements of people with CF. Late applications can be emailed to Awards Committee Chair Denis Currie in PDF format deniscurry@xtra.co.nz and must be received by this Sunday. [Application form available on the website.](#)

Entertainment Books Back

Entertainment Books are available for Auckland, Waikato and Bay of Plenty, Wellington, Canterbury and Nelson, and Otago regions this year. There are loads

[Givealittle fundraising page](#) with funds going to CFNZ and Cure Kids.

CF at School Guide

The CF at School Guide for Parents is the next new publication almost ready to roll. We are still looking for advice from parents about how they manage CF at school for their children. We'd love to hear any tips and insights that could be helpful for other parents with school age children. Contact Laura at office@cfnz.org.nz.

Meanwhile, there's been a delay on the release of the New Diagnosis Guide because we are seeking feedback from the Paediatric Society's Clinical Network for Cystic Fibrosis. We do welcome parents to review it once it's ready.

Orkambi Now Unfunded Prescription Medicine in NZ

The medication lumacaftor has now been listed as a prescription medicine in New Zealand with the drug licensing authority, Medsafe. This means that people who would like to pay for the drug Orkambi (a combination of the drug compounds lumacaftor and ivacaftor) themselves can import it from an overseas supplier provided they have a doctor's prescription. Meanwhile, at this stage Vertex says it has no plans to submit Orkambi for government funding.

New Deadline for Breath4CF

Applications for Breath4CF grants now need to be in by 15 June each year to allow processing before 30 June, which is the end of the

of discounts in the Books along with the chance to support CF. Entertainment Books cost between \$65-\$70. Most are available early April apart from Canterbury which is available early May. You can pre-order the Books:

[Auckland](#)

[Waikato & BOP](#)

[Wellington & Manawatu](#)

[Canterbury & Nelson](#)

[Otago](#)

Flu shot reminder

This year's flu vaccine has been updated to include a new strain to combat the "Aussie flu" which has hit hard in the UK and Europe. Pharmac is funding a new "quadrivalent" seasonal flu vaccine, to be available by April, that's designed to protect against four strains of influenza, including two "A" and two "B" strains including the life-threatening H3N2 strain which overloaded the hospital system in the UK and USA, where hospitalisation rates were worse than during the swine flu epidemic. Flu shots are free for New Zealanders with CF.

Te Whero Family on Maori TV

Big thanks to the Te Whero whānau who ran in Auckland's Round the Bays to support CF and were [featured on Maori Television](#) this month.

Quote of the Month: *"CFNZ is doing such great things for all the kids and I'm one of the lucky ones. I haven't had nearly as many hospital admissions as some people with CF, but they still keep fighting."*

- Curtis Ennor - speaking at the Bowling Presentation in Birkenhead, Ak

financial year. The Breath4CF activity grant is available for all people with CF (\$300 for adults and \$150 for under 6s each financial year). The aim of the grant is to remove cost barriers for physical exercise which improves lung health for people with CF. [Application form available here](#). **Note:** this form will be available to fill out electronically on the new website which is expected to go live next month.

Good Links:

- [Australia to increase access to genetic testing](#)
- [7 tips to prevent reflux aspiration](#)
- [Mental health matters for lung transplant - personal story US](#)
- [Australia's new Bachelor star has a brother & sister with CF](#)
- [The difference between Symdeko and Kalydeco](#)
- [Ireland Dancing with the Stars judge is interviewed about having CF](#)

Panui - sign up here



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