



New Breathing Machine Donation

The Auckland Branch has been delighted to receive a generous donation from the Hawkesby/Hart family to purchase two new Metaneb machines for adult services at Auckland Hospital.

The Metaneb machine combines three therapies in one - volume expansion, secretion clearance, and nebuliser therapy. The device begins by offering continuous positive expiratory pressure (CPEP) therapy, which helps expand the lungs, and then moves on to the secretion clearance part of the treatment. At the same time, the nebuliser is running throughout the entire therapy session.

The therapy cycle takes approximately 10mins and means that there is only one machine used for all three therapies. The new machines have only just been received by Auckland Hospital and should be up and running shortly. Bruno (right) from the CF community, is pictured top with his good school mate from Kings Prep, Dylan Hawkesby.

Update from the Chief Executive

With CFNZ and PARI Boy Nebulisers turning 50 this year, PARI has decided to mark this anniversary by naming CFNZ one of its Never Out of Breath campaign partners. PARI will donate €10 Euro (around \$16) to CFNZ for anybody who wears one of its t-shirts for a personal or sporting challenge and uploads their photo to the [PARI BOY 50th Facebook Page](#).

We've already had heaps of interest in this, with lots of people ordering t-shirts. The challenge can involve anything from a marathon to school events and dancing for all ages. [Order your t-shirts through the PARI website](#) - limit two per order.

This photo challenge is a great way to support CFNZ and we thank PARI for naming us as one of its charities for the anniversary celebration - the others are the European Cystic Fibrosis Society and the British Lung Foundation.

We'd also love to see the photos of anyone taking on a sports or personal challenge to support CFNZ in this way.

- **CFNZ Chief Executive Jane Bollard**

Newly Diagnosed Guide Almost Ready

We've been working with parents across New Zealand to develop three new guides – *CF at School*, *Friends and Family Guide to CF* and *Newly Diagnosed*. The *CF at School* and *Friends and Family* guides have been reviewed - big thanks to the families who provided feedback. The *Newly Diagnosed* guide is almost at the review stage, and we'd like to invite volunteers to review this guide and provide feedback for us. Please contact Laura at office@cfnz.org.nz if you'd like to be involved.



Fieldworker Funding

Huge thanks to the community trusts which are supporting CFNZ's Southern Fieldworker.

The Trusts Community Foundation,
Community Trust of Mid & South



Nick and Natalia Engaged

Congratulations to Nick Laing and Natalia Holden of Te Awamutu of the CF community who have announced their engagement. Nick popped the question with a sapphire and diamond gold ring after asking for permission from Natalia's dad and after lots of questions from Natalia's five-year-old son about when they were getting engaged. Nick got down on one knee during a candlelit dinner at home to ask Natalia if she will be his wife and she said "yes!". Now they are busy planning their wedding and following honeymoon in the US. Nick is thankful he was able to get travel insurance from the insurance brokers



www.healthinsurance.co.nz. Nick

Canterbury and the W.D Duncan Bickley Trust Fund are contributing to the cost of expenses related to Fieldworker Sue Lovelock's position. Thanks also to some of the lovely feedback from the CF community.

TOBI Podhaler Pharmac Application

CFNZ has submitted an application to Pharmac for the funding of the TOBI Podhaler device which is similar to an asthma inhaler and delivers tobramycin in around 1 minute compared to about 20mins on a conventional nebuliser. This would make a dramatic difference to the lives of people with Pseudomonas infections. We are extremely thankful for the expert help we received filling out this application and the strong letters of support from the CF community. We had hoped that Pharmac's PTAC committee would add it to their minutes for their next meeting in May. This week Pharmac emailed Jane Bollard to say they have reviewed it according to their funding application guidelines and are planning to seek clinical advice from the Respiratory Subcommittee at their next meeting. Pharmac staff also want to discuss the application with us. We will keep you informed about any progress.

New Drug Combo Approved in US

The next generation medicine to treat people with the F508del gene has been approved by the FDA.

The therapy uses a new drug, tezacaftor/ivacaftor in combination with ivacaftor (Kalydeco) to treat patients over 12 who have two copies of the F508del gene or at least one CF gene

says he's been taking more care to stay well now that he's also got Natalia and her son, Heath, to care for. "My lung function has come up. My weight has improved. I haven't had an admission for 18 months!"

Hanmer Holiday Home Closes

Canterbury Branch has informed members that Hanmer House can no longer take bookings from people with cystic fibrosis who were getting accommodation at discount rates.

Cross infection concerns about people with CF staying there and another person with CF using the holiday home not long afterwards have been raised.

The Branch reports: "It is well recognised that transmission (i.e. pass from person-to-person) of bacteria can occur between people with CF and that these bugs can cause problems. With an increasing number of transmissible bacteria, along with new scientific evidence about the length of time these bacteria can survive in environments, the risk is now considered too great for us to be promoting the use of the Hanmer Holiday house by individuals with CF.

"We have had no known cases of cross infection, but we are not willing to put our community at an unacceptable level of risk."

The Branch is now considering other ways to support families needing a break.

CF News is at the Printers

The CF News is being printed in the next few days and hopefully will arrive sometime next week. This issue we honour 50 years of CFNZ. We have some strong and inspiring Adult stories, very interesting articles about trends in care in

that is responsive to treatment. The combo, being called Symdeko, has been shown to be as effective as Orkambi but with fewer side effects.

Australasian CF Social Work Guidelines

The first set of clinical guidelines for CF social workers in NZ and Australia have been completed. The project to develop the clinical practice guidelines began in 2013 and have recently been approved by a number of CF-related groups including CFNZ. The guidelines, [available on the CFNZ website](#), cover a range of issues from diagnosis, childhood, adolescence and transition and transplant.

NZ and also paediatric guidelines being developed. Email Vicky at comms@cfnz.org.nz if you are not on the mailing list or need to change your postal address.

Good Links:

- [Anger over Labour's rare medicine funding](#)
- [Orkambi talks in France breakdown](#)
- [Unexpected germ sources](#)
- [UK survival statistics](#)
- [World Rare Disease Day, Feb 28](#)

Panui - sign up here

Quote of the Month: *"Some advice I would have for everyone, CF or otherwise, would be making sure you have something to look forward to, short term and long term, that's not related to school or CF. This was really helpful for me because it gave me something to focus on that I enjoyed and I didn't feel was tainted by school or CF."*
- Rachael of Otago - from her upcoming feature in the CF News



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