

Panui - June: Nigel Latta's CF Adventure, Update from the CE, Pharmac Consumer Voice Review, Awareness Week, B&W Casino Night, Staff News, Speedway Driver's Make-a-Wish Car [View this email in your browser](#)



Canterbury's Nigel Latta Adventure

Award-winning psychologist Nigel Latta will make a rare public appearance when he takes to the stage in August for a speaking engagement to support CF Canterbury and this year's 50th anniversary.

The host of the TV shows' *Beyond the Darklands* and *The Politically Incorrect Parenting Show* has limited his public appearances around NZ so CF Canterbury was fortunate Nigel accepted the invitation to speak at the Isaac Theatre Royal on 21 August in Christchurch.

His presentation, *Adventures in Parentland – The First 10 Years*, will offer ideas

for a more simpler and more enjoyable approach to parenting and dispel some of the myths about raising children.

Tickets are [available here](#) and there's more info on the [Bothy Events Facebook Page](#). Canterbury Branch is looking to sell over 1000 tickets, with proceeds going to support people living with CF in the region.

This is sure to be an entertaining and insightful evening so do come along to support the Branch and to learn how to raise children with the least amount of stress as humanly possible - that's got to be a good thing!

Update from the Chief Executive

I have been fortunate to attend the 41st European Cystic Fibrosis conference on 6-9 June. The highlights for me included attending a nutrition masterclass, the special interest group looking at global consistency of CF registry data (no mean task but progress is being made) and catching up with my colleagues from CF Associations in the Commonwealth (see photo with Nettie Burke, CF Australia and David Ramsden, UK Trust).



Certainly, the key focus of the CE's of Australia, Ireland and UK over the last two years has been campaigning for access to treatment - specifically innovative medicines. This ties in well with what our CF community sees as most important for CFNZ's future direction (as per the CF Insight Survey).

With six rooms operating four or five sessions per day and often four or five speakers per session, it's absolutely heartening to see the level of scientific research being undertaken in Europe (it's also its pretty daunting finding your way around the venue and deciding which sessions to attend even when armed with the programme and the app). Nearly 2000 participants from 56 countries attended and the Belgrade location encouraged attendance by eastern European countries but overall showed a decrease in attendance from last year.

Next month I will begin visiting all branches to talk about our strategic direction with our members. I'll talk about how CFNZ stacks up globally, share the results of our recent CF Insight Survey and our empathetic interviews of families and adults, and invite discussion on the Board's draft strategic direction. If you are interested

in being part of this conversation please contact your branch for details.

- **Chief Executive Jane Bollard**

CF Awareness Week 13-19 August

Cystic Fibrosis Awareness Week is just over six weeks away. This year we are focusing on the importance of advocacy to support all New Zealanders with cystic fibrosis. This is also a great opportunity to highlight CFNZ's 50th anniversary and the amazing support provided over the years.

Local CF branches are always on the look out for more volunteers to help during awareness week. Contact Laura at laura@cfnz.org.nz for fundraising resources and Irene at admin@cfnz.org.nz for chocolate fish, or if you can help volunteer during the week.

A handy guide [50 ways to kick-start your fundraising](#) is available on the website with 50 ideas to run events and activities to support people with cystic fibrosis.

This year it's been great that so many people with CF have been happy to tell their stories but we can always do with more personal stories around Awareness Week because you never know what the media might be interested in. Email comms@cfnz.org.nz if you'd like us to put your name forward to our Awareness Week PR contractor.

Auckland Branch is holding a **Step for CF** Winter Challenge during Awareness Week. Individuals, groups of friends, schools and businesses are being encouraged to step out for CF. Participants download a steps app, gather sponsorship via Givealittle, then head out during Awareness Week to get as many steps as possible and fundraise for CF at the same time. Contact Kath at auckadmin@cfnz.org.nz for more information.

Pharmac Consumer Voice Review

People with CF have been represented at a number of Pharmac Consumer Voice meetings around NZ to look how to improve patient representation for its medicine and device-funding decisions.

Last Friday two CFNZ representatives attended the Pharmac meeting in Wellington for consumer groups where we had a chance to talk to Pharmac Chief Executive Sarah Fitt about Kalydeco.

An earlier meeting in Auckland, CFNZ Chair Jane Drum and also a father of a baby with CF also took the chance to speak to Sarah. There is new long-term data available about the benefits of Kalydeco which CFNZ hopes will lead to new consideration for this medicine for a rare form of CF.

Currently, the Australian medicines funding authority is considering the medication for the F508del gene, Orkambi, for the fourth time and it's hoped Vertex will be willing negotiators.

A wide range of consumer groups attended the meetings including Diabetes New Zealand, Plunket, the Lung Foundation, Grey Power, women's groups, and the NZ Organisation for Rare Disorders.

We were seated in groups with a Pharmac representative on each table and asked to name three priorities for improvements. There were common themes throughout the groups:

- Patient representation at the level of drug-funding decisions such as what happens in Scotland and Australia
- For high-users of the health system to be represented on the Consumer Advisory Committee
- For Pharmac to consult closer with patient groups when introducing changes to medicines

At an earlier Pharmac Community Conversations meeting in Auckland attended by 30 people, CFNZ raised the following points:

- There appeared to be a barrier between pharma companies being able to engage with Pharmac

- There also seems to be a disconnect between the Pharmacology and Therapeutic Advisory Committee (PTAC) Respiratory Committee and CF specialists
- The need for two consumer representatives on PTAC – it was considered a bit intimidating for one person
- Concern that Pharmac takes the cheapest option but not necessarily the best – this was in regards to nebuliser compressors
- The idea of a group of patients trialling new medicines or devices if Pharmac decides to change suppliers (there've been concerns with the generic Ventolin product)

Anyone can provide feedback for the review and there is a [three-question survey available](#) to fill out at the Pharmac website. There is also the chance to email further feedback and CFNZ will be making a submission. The deadline for this is 5 July.



Betting on a Good Night

It's Black and White for Hawke's Bay's Casino Night. The Branch is celebrating the first night of Spring on 1 September with its annual casino night fundraiser.



Free Delivery or Gift for Entertainment Books

Buy an Entertainment Book by this Saturday (midnight 30 June) and get free delivery (normally \$8) or a \$10 Countdown gift card. For free postage select Track & Trace delivery and enter the promo code FREEPOSTNZ at checkout, or to get the free \$10 Countdown gift enter promo code CDGIFT at checkout.

Gamble the night away on roulette and black jack tables - all for a good cause - supporting the amazing CF community.

Tickets available on [Event Finder](#) and include canapés, five drinks and gambling chips - come along wearing black and white, and bid on some of the fabulous auction items available.

For more information email Claire at cfcasinohb@gmail.com.

[Auckland](#)

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Mt Albert Grammar Fundraising Superstars

Huge thanks to Mt Albert Grammar School students in Auckland for offering to collect donations for CFNZ.

The students raised hundreds of dollars by taking CFNZ buckets into each classroom. They also spoke to all the classes about the condition and what it involves.

The girls had heard about CF in a health science class and wanted to know more about it and that's what led to their offer to help raise donations. Their support is very much appreciated.



CF Speedway Driver's Wish Comes True

There's a good reason why Oliver Klotz is racing a midget car dedicated to the Make-A-Wish Foundation. Ten years ago the Foundation and NZ motor cross champ Josh Coppins surprised Oliver with a mountain bike - his biggest wish at the time. Now 24, it's not surprising

that Oliver has developed a taste for motor sport and has decided to enter the TQ (three quarter) midget car races at Speedway in Westport. Oliver, who lives and works in Nelson, is keen to give back to Make-A-Wish for helping him to follow his dream and is planning to fundraise for them as well.

New Zealanders with CF aged between 3-17 years are eligible for Make-A-Wish grants. Phone Make-A-Wish for an application form on 0800 807080. There have been some amazing wishes come true over the years including one young man who won a trip to see Manchester United play. International travel is now limited to Australia because of travel insurance restrictions.

Winter Energy Payment

Work and Family's Winter Energy Payment will be available from 1 July to help with the cost of heating homes during the winter.

People who qualify for this are those who receive either:

- New Zealand Superannuation
- Veteran's Pension
- Emergency Maintenance Allowance

Vicky Signs Off

Sadly, this will be my last CF Panui because I'm leaving my part-time job as Information Coordinator at CFNZ to take up a new role at the Blind Foundation, which is a full-time role. It seems like a good time to leave after finishing the CF News winter edition which should be posted in mid-July. It's been an absolute honour getting to know the CF community and telling some of your amazing stories. I will remain a staunch supporter of your cause and will continue to wish for a cure for CF. Thanks to everyone for their help during my 3.5 years working here.

- Vicky Tyler

Charity Cricket - Save the Date

This year's Cystic Fibrosis Cricket fundraiser match will be held **Sunday 16 December** in Christchurch. There's a push to make the 2018 event extra special to commemorate our 50th birthday. We will keep you up-to-date with developments. Many thanks for the Crusaders' ongoing support!

- Jobseeker Support
- Jobseeker Support Student Hardship
- Sole Parent Support
- Supported Living Payment
- Youth Payment
- Young Parent Payment
- Emergency Benefit

Those who qualify don't have to do anything. They will automatically receive \$20.46 a week if single with no dependent children or \$31.82 a week for those with a partner or dependent children. This will be paid from 1 July to 29 September 2018. From 2019, it will be paid from 1 May to 1 October.

Livewire website for over 12s

[Livewire is a website](#) for Aussie and NZ teens who are living with a chronic illness. The website welcomes over 12-year-olds to share stories, have a rant, and to make friends. Plus there's a pop quiz first Tuesday of every month. The website already has a number of people with CF who are excited to chat to others with CF. There is also a private group dedicated for members with CF.

Good Links

- [Tattoo warning for lung transplant recipients](#)
- [Tobacco smoke speeds lung function decline](#)
- [CF antioxidant study](#)
- [HIT CF study for Europeans with rare genes](#)
- [Three CF researchers win awards](#)
- [Yoga for cystic fibrosis - YouTube video](#)

[Panui - sign up here](#)

Quote of the Month: *"Life doesn't throw you second chances, catch the first – take it from a goalkeeper."* - Vaughan Somerville, CF Achiever and Auckland University Sportsman of the Year



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Our mailing address is:

Cystic Fibrosis New Zealand
PO Box 110067
Suite 2 79 Grafton Road
Auckland, 1010
New Zealand

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