

In this issue: Auckland Uni Sportsman of the Year, Update from the Chief Executive + Pharmac Update, Kiwibank Hero, Citramel Study Results, CFNZ Raffle + Charity Cricket [View this email in your browser](#)



Vaughan Somerville - Auckland University Sportsman of the Year!

Vaughan Somerville has been awarded the Auckland University Sportsman of the Year Award for helping to lead his Futsal team to victory at the NZ Universities Futsal Championship earlier this year.

Vaughan, who lives with CF, won Goal Keeper of the Tournament - the Auckland Uni team were the underdogs so victory was particularly sweet.

Vaughan, who is currently studying for a law degree and for his PhD in health sciences, has also been honoured with speaking at the Starship Foundation black tie ball tomorrow night about his extensive experience at Starship Hospital over the years.

Update from the Chief Executive

CF needs considered in new Wellington Children's Hospital

As part of the consultation phase of the new children's hospital in Wellington, CFNZ is being asked to provide input to ensure the needs of children with CF are met in the region. The majority of the initial input, provided by CFNZ staff, clinical staff and the CFNZ Wellington Branch, is being incorporated in the preliminary hospital design. The new hospital build is happening at speed, with a room prototype available in November, focus groups, individual interviews, a survey (Nov to early Dec); and ongoing consultation on health care services design until hospital opening at the end of 2019.

Keeping the pressure on for innovative medicines in NZ

I would like to acknowledge and thank the members of the Kalydeco for Kiwis group and others who actively lobbied their MP and the Minister of Health for increased

funding for the medicines budget for rare diseases and in support of innovative medicines. CFNZ will be preparing a submission to the new Minister of Health and I encourage everyone to do so. In July we were advised that Pharmac could not negotiate on Kalydeco while Vertex was not engaged with them. We have now received news that Eilis Quinn, Country Manager at Vertex, has sent updated information on Kalydeco to Pharmac and has offered to meet. The information has not been released to CFNZ.

Most comprehensive report on CF in NZ due at year end

Input to PORT CF, the NZ CF data registry, for 2016 is now closed and the stats are being extracted. The report, which will show valuable insight on the current CF picture in NZ, will be the most comprehensive yet. Huge thanks to DHB and CFNZ staff for the input of data and to the CF community for agreeing to participate.

New respiratory clinical trial network

A new Respiratory Medicine Clinical Trial Network is being set up by the Thoracic Society of Australian & New Zealand (TSANZ). The Network will address all areas of respiratory health across both Australia and New Zealand (with the exception of lung cancer which already has its own strong group). CFNZ and CF Australia will be asked to provide a representative to the CF programme of work.

Lobbying for nation-wide funding of CF medical equipment

In July we met with Pharmac with the aim of the agency taking over the funding of compressors and nebulisers currently provided by CFNZ. Following further discussions, Pharmac has given its support for CFNZ to approach DHBs currently not funding CF devices to form arrangements with them, and to take over the ordering, distribution and servicing of these in the near future. The long term, and potentially lengthy approach suggested, is a funding application from CFNZ or another interested party for Pharmac to fund compressor and nebuliser devices.

Tobi Podhaler patient submission underway

Vicky Tyler, Information Coordinator is also progressing with a patient submission regarding Tobi Podhaler, which significantly reduces nebulisation time, and we hope the Clinical Advisory Panel will have a role in supporting the CFNZ patient submission.

- Jane Bollard, CFNZ Chief Executive



Mark Passey Appointed Adult Rep

Tauranga businessman Mark Passey has been appointed Adult Representative on the CFNZ Board. Mark is owner/director of Telferyoung in Tauranga.

As a former recipient of the Mark Ashford Scholarship in 1999, Mark has also announced plans for a new scholarship for the CF community, launching next year as part of CFNZ's 50th anniversary.



Get your tickets for the CFNZ Raffle!

This year we have some great prizes up for grabs including the 1st prize limited edition signed All Blacks rugby jersey from the New Zealand Lion Series 2017 worth \$2500, 2nd prize is a 43" LG Full HD LED TV valued at \$1010 and 3rd prize enjoy a 3-day getaway at any one of Choice NZ properties worth \$700.

Other prizes include two tickets to the WOMAD Festival and a My Food Bag voucher. CFNZ is running the raffle a little differently this year – previous sellers will not receive raffle ticket books automatically in the post. They need to be ordered online or from an order form that's been mailed out to our amazing ticket sellers. Last year we ran out of raffle tickets so get in early this year – raffle closes 6 December.

[See all prizes on the CFNZ website.](#) [And order online here.](#)



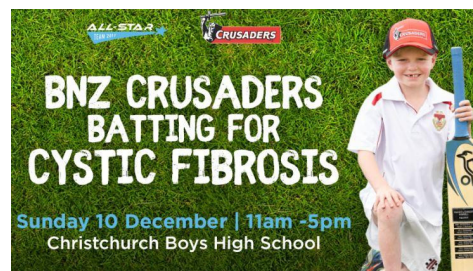
Hanging out to support CF

October's Pole-tober-fest for Canterbury Branch produced a record result, with \$4500 raised.

The fundraiser initiated by Juliet Hubbard (left) and her Liberate Pole and Exercise class began as a small show, raising \$400. Now four years later the show which features burlesque, acrobatics and pole dancing has grown in popularity to the point that Juliet's story about how her Liberate classes help her lung function was featured in both the Christchurch Mail and [The Press](#) last week.

Kiwibank Hero - Melissa Skene

Congratulations to Canterbury Branch Chair Melissa Skene who has been awarded a Kiwibank Local Hero Award, which rewards everyday people doing extraordinary things in their community. Melissa gave up a full-time career to help run Canterbury Branch 18 years ago. She is incredibly supportive to new parents who value talking to someone who has been through what they are facing. She helps organise fundraising and is pictured (left) with fellow branch member Sandy Champion for Z Energy's Good in the Hood. Melissa will receive a medal at a Kiwibank award ceremony in December.



35th Crusaders Charity Cricket Match

The Crusaders Charity Cricket Match will be held on Sunday

Off the hook: 19-year-old Dylan Booth has hooked some big fish in his time but that's nothing compared to the impressive sponsors he's hooked for his [YouTube FishingForeverFilms Channel](#). He's won sponsorship from Black Magic Tackle and Daiwa, and also attracted the interest of two of the biggest fishing YouTubers who have 2 million followers combined and who are coming to NZ to fish with Dylan this summer! Not surprisingly, Dylan aced his interview for a job at Hunting & Fishing in Dunedin.

All Black Supports Auction for CF

On top of raising thousands during CF Awareness Week Streetwise Coffee came up with a very cool idea for raising funds – auctioning kids' bikes with helmets signed by famous New Zealanders including Olympic gold medallist Dame Valerie Adams, Silver Fern Maria Tutaia, motorcross champ Levi Sherwood and All Black Dan Coles (helmet pictured here).

The bikes and helmets fetched over \$2000 on Trade Me which brought the amount Streetwise has donated to over \$7000 - a very impressive result which we are very thankful for.



Waikato's Warehouse Joy

Waikato Branch really raked in the tokens from The Warehouse Bags for Good voting programme, receiving a big cheque for \$8037 from a total of nine stores. And there's more good news Warehouse stores at Te Awamutu, Morrinsville and Matamata still have CF voting boxes so be sure to ask for a token if you buy a shopping bag at the counter.

December 10. Cantabrians can come along to enjoy the Crusaders battle it out with an All Star team of players. It's a great family day out enjoying the game, a sausage sizzle, autograph signings, charity auction (including art), bouncy castle and a children's cricket academy. [See the CFNZ website for more info.](#) [And see the CFNZ Facebook Event Page for updates.](#)

Citramel Update

The NZ Breathe Easy Board has announced that the results of the early phase clinical trial of Citramel in patients with cystic fibrosis has shown that the treatment was safe and well tolerated but did not show effective results at the dose tested. The Board is disappointed that to date, this potential therapy for those living with cystic fibrosis has not had the impact everyone hoped for. The Breathe Easy team is presently planning additional studies and with higher doses in mind. The next step is to further analyse sputum samples to study why some dissolved very well in Citramel and others did not. The second area of research is to conduct a clinical trial with increased doses of Citramel after the sputum research provides further information.

[See full Breathe Easy Release](#)

Marathon Effort in Auckland

Good luck to all the Auckland Branch marathon runners this Sunday 29 October.

Insurance brokers, Willis Towers Watson, has a team of over 20 at the starting line and is fundraising through [Givealittle](#).

And there's still time for any other keen runners to sign up for the event. All athletes will receive a massage and bacon butties at the finish line.

30 years of Golf

Canterbury Branch's Golf Tournament turns 30 at a special tournament at Templeton Golf Course next Friday 3 November. The Ambrose tournament costs \$140 per team of four and includes a free BBQ and food served during the tournament, plus prizes for every player. Contact Nicky for tickets. Email: doug.nick@orcon.net.nz or phone 021 515 767.

CF Smart for School

Cystic Fibrosis Australia has developed a set of guides about kids with CF at day care, primary and secondary school. The guides are available on the [CFSmart website](#). There are also [modules for teachers](#) interested in gaining a certificate for their knowledge of CF in the classroom.

CFNZ is currently working on a project to update its website and key publications, including information for schools. If you'd like to participate in this project, either by sharing your experience, tips, advice or any other input, please contact Laura at office@cfnz.org.nz

And Marathon Effort in the South

Courtney is also running the Queenstown Half Marathon to support her boyfriend who has CF (both pictured here).

Courtney has witnessed the toll that CF can take so has decided to raise funds for CFNZ by setting up her own [Everydayhero Page](#) for donations, with the aim of raising \$3000. Best of luck for the race Courtney!



Good Links:

- [Don't touch toys at the doctors office](#)
- [Potential new method for treating fungal infections](#)
- [Music festivals with CF - UK factsheet](#)
- [Healthy ways to gain weight](#)
- [How CF is depicted in popular media](#)
- [Vaping is as bad as smoking - study](#)

Panui - sign up here

Quote of the Month: *Thank you to Dan Coles, Dame Valerie Adams, Levi Sherwood and Maria Tutaia. Thank you to the entire Streetwise family. Thank you all for helping Cystic Fibrosis NZ in their quest to make a difference for Kiwis with Cystic Fibrosis. Thank you from the bottom of our lungs.*

- Streetwise Facebook Post





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