



Welcome To The September Panui!

Kia Ora <<First Name>>,

We ended August with the very sad news of the passing of CFNZ patron, Sir Bob Elliott.

A wonderful, much loved man who has made such a difference to so many lives, especially in the CF community. Read more about the legacy Sir Bob has leaves behind, and a tribute from Denis Currie, CFNZ President.

This month marks the beginning of our new fundraising campaign, SWEATEMBER.

We are delighted to see people getting involved in all sorts of different sweaty activities - from rowing to trampolining, cheerleading, and running. In this issue of the Panui, we introduce you to some of our Sweaty Champions and teams who are doing their bit to Sweat4CF.

There's still time to sign up to the FREE CFNZ x Beam online exercise programme, find out how to register, below.

Read the latest news from the Board, an advocacy update, and some sweet community stories.

We hope you have a safe and happy September (hopefully sweating!)

The CFNZ Team



Thank You, Sir Bob Elliott

Cystic Fibrosis NZ, and the CF community, mourns the loss of their patron Sir Bob Elliott.

Sir Bob made an extraordinary, lifelong contribution to cystic fibrosis, notably for his work on the new-born screening test, which he believed added 30 years of life for people with cystic fibrosis. His passion for research into childhood illnesses, along with co-founding the medical charity Cure Kids were other highlights.

CFNZ President Denis Currie said, “Sir Bob has left an extraordinary legacy, with people throughout New Zealand and the world who have lived lives that would simply not have been possible without his efforts.”

“There are many Kiwis with cystic fibrosis out there who grew up with Sir Bob, and who will remember not just a brilliant researcher and doctor but a true friend who cared. We will miss him dearly,” said Mr Currie.

“His most recent focus around the new cystic fibrosis drug Trikafta was a further example of his deep humanity and care for cystic fibrosis people right until the end.”

“The impact he has made on the CF community worldwide, is a legacy that will live on for many years to come.”

[Read more about Sir Bob >](#)



Over 300 Superstars Sweating For CF This SWEATEMBER!

1 September marked the start of our new virtual fundraiser – SWEATEMBER. The campaign challenges Kiwis to commit to any sweaty activity to get fit and raise money to support people with CF and their families. There's already over 300 people sweating for CF, and we're over a third of the way to our \$150,000 goal.

Here's a few sweaty people that you may recognise:

- **The Salty Chicks** – team of 8 adults with CF from across the country
- **Rowing New Zealand** – rowing to the Vertex HQ to get Trikafta!
- **Rip.Kiwi** – our very own Julian from CF Otago riding 30km vertical
- **Otago Peninsula Trust** – 12 sweaty superstars from the OPT
- **Christchurch Hospital Adult CF Team** – sweating clinicians!
- **Shelley Gruchy** – the wonderful Shelley from Taranaki Branch
- **One of us sweats more than the others** - NZ's 164th lung transplant recipient, Lizzie, clocking up 164km with her parents
- **The Mermaids** – even our CE Jane is sweating 30k in the pool

Plus hundreds of other amazing, sweaty, kind and generous superstars all committed to making a difference to people with CF. Thank you all so much!

 **Stand Out With A Sweat4CF Sweatband** 

Purchase sweatbands and headbands [here >](#)

To sign up, visit www.sweat4cf.org.nz. By getting SWEATY you'll help bring life-saving medicines such as Trikafta to New Zealand, provide support and information through our CF Social Workers, and fund research for a life unlimited.

Mylan NZ Is An Enthusiastic Supporter Of Cystic Fibrosis NZ And We're Delighted To Share That The Company Is Our Key Sponsor For This Years' Sweatember Fundraiser.

Many people with CF will know of CREON® - the capsules containing special enzymes to help the body break down the food you eat. Mylan, CREON® brand owner, has supported Kiwis with CF for a number of years through its sponsorship of the CF Achievers' Award, CF Week, various projects, and most recently, as sponsors of Sweatember.

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



Sweating In The Media

We are extremely grateful to the many individuals and families in our community, who have shared their stories and inspiration to SWEAT4CF; online, in the paper and on the radio.

Check out their interviews, and Sweatember's media coverage 

- Local Matters - [Raising a sweat – and funds – for CF support](#)
 - Otago Daily Times - [Fibrosis fundraiser has skin in the game](#) and [Sutty's Sweaters running the hard yards for CF](#) (in the photo above!)
 - StopPress - [Sweatember: Cystic Fibrosis NZ launches new virtual campaign](#)
 - Bay of Plenty Times - [Tauranga Cystic Sister Nikki Reynolds takes on new challenge](#)
 - Coast FM – [interview with Nikki](#)
 - The Hits Dunedin - [interview with Hannah and Chelsey](#)
 - The Hits BoP – [Interview with Nikki](#)
 - The Breeze Waikato – [interview with Christopher](#)
 - Scoop - [Kiwis Challenged To Sweat For CF This September](#)
 - Timaru Herald - [Challenge to raise awareness and funds for cystic fibrosis](#)
-

Board And Advocacy News

Trikafta Campaign

The campaign to encourage Vertex to apply for access to New Zealand for Trikafta and for Pharmac to fund it, has gained some great coverage recently, thanks largely to the media stories around Sir Bob Elliot and Bella. This is a highly complex issue and unfortunately it's unlikely to deliver us Trikafta overnight. However, Jane and her team, working in collaboration with "Trikafta for Kiwis", have made good use of the media coverage and are working constructively with Pharmac and Vertex to help lever open the door. They are also developing a wider advocacy strategy that will give us the best chance of ultimate success. It is certainly a tantalising prospect and it will remain one of the Board's top priorities for the next while.

Vertex is currently in discussions with key stakeholders in New Zealand, and has confirmed it will be applying for Pharmac funding using the available pathways.

More Board Updates

The Board met on the 1st of September over Zoom, with the key items on the agenda being:

- Reflecting on Sir Bob's enormous contribution
- The structure review project, of which the consultation process is being extended
- Sweat4CF
- Advocacy

Read the full update [here](#) >



Come Out Of COVID In A Place Of Wellness

CFNZ X Beam Programme

There is still time to register for three months of FREE Beam Team online exercising, catered to people living with CF.

CFNZ has been very fortunate to receive a grant from Te Hiringa Hauora – the Health Promotion Agency in NZ, to enable all people aged 16 years or over with CF in New Zealand and new mums of babies with CF to engage with the Beam online exercise platform for a 3 month pilot programme, with the aim to make it easier for you to be more active, achieve your goals and make some positive connections.

If you are younger than 16 but would still like to participate, talk to your Fieldworker – we will allow some flexibility on this.

Beam helps people with cystic fibrosis to get more active in a way that makes them feel good, with on-demand and

live classes, group support and handy resources. They also have a programme targeted at post-natal mums, and we encourage mums with young children with CF to engage with this part of the platform – it's important to look after yourself too!

Learn more, and find out how to join, [here >](#)

COVID-19 Update

As you'll know, Auckland moved to Alert Level 2.5 on Monday, while the rest of NZ remains at Alert Level 2.

For Aucklanders, there is additional restrictions on social gatherings, encouragement to wear a mask / face covering whenever they leave their home, and is mandatory on public transport.

Auckland CFNZ staff and contractors returned to working from home since moving back to Alert Level 3. As we move to Alert Level 2.5 our Auckland staff will continue to work from home and our Northern fieldworker Gretchen will continue to connect with people with CF and their families virtually.

Read the full update [here >](#)

Adults Wellbeing Guide

We Are Still On The Lookout For Input!

This guide is aimed at people with cystic fibrosis aged 15 and over and will include topics such as nutrition (including alcohol), travelling, mental and emotional wellbeing, exercise, sexual health and fertility/pregnancy/family planning.

Find Out More About How You Can Help, [Here >](#)

This has been made possible thanks to a grant from the Health Promotion Agency / Te Hiringa Hauora.






Helmet And Scooter For Aspen

Aspen used his Breath4CF grant on a scooter and helmet - getting his exercise in, and looking pretty cute too!

"Aspen absolutely loves riding his scooter. After continually trying to use his older brothers two wheeled scooter he was so excited to get his own. You should see him go!"

Chocky Fish Sales Going Swimmingly

Thank You To Everyone Who Has Sold Chocky Fish This Year.

A special mention to these girls, Milly and her friend selling Chocky Fish in Wellington in honour of their cousin, our bright spark, Juliet Hubbard 



📖 The Winter Issue Of The CF News Is Coming Out Soon! 📖

In a bid to reduce our printing costs and carbon footprint, we'd love to know if you'd be happy to receive the twice yearly magazine, digitally. All the same content straight to your inbox, ready to read anywhere, any time.

We'll still be doing a print run for those signed up to receive the printed magazine, but hope to move towards a more digital format. If you're happy to be taken off of the printed mailing list, be sure to update your preferences [here >](#)

Showing Gratitude

A big thank you to the following sponsors who have provided funding over the last couple of months. We are so very grateful.

- Te Hiringa Haiora – Health Promotion Agency – funding the Beam initiative for all people with CF to help improve overall wellbeing
- Community Trust of Mid and South Canterbury and The Southern Trust for Fieldworker support
- Mainland Foundation, Four Regions Trust and Louisa & Patrick Emmett Murphy Foundation for equipment
- NZ Community Trust for operating costs

If any Branches would like assistance with funding for specific things, you are welcome to get in touch.



Get involved

Donate

To unsubscribe from this email please click [here](#)

www.cfnz.org.nz

PO BOX 110 067, Auckland 1148



This email was sent to <<Email>>

why did I get this? [unsubscribe from this list](#) [update subscription preferences](#)

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