



20 January 2020

## **20/20 VISION**

The 2020 Calendar here at Cystic Fibrosis Australia (CFA) is crisscrossed with highlighter, underlines and exclamation marks. CFA is ready to hit the ground running with what we hope will be a record year.

Last year we were fighting to push lifesaving drugs over the line at the PBAC. This year we want to expand Australia's role in the clinical trials process for cystic fibrosis (CF) drugs and get all Australians with CF access to the very latest in medical technology and treatments.

That starts with our community. We need to organise our participation the way that so many other aspects of our cause - fundraising, advocacy, education - are already streamlined. We believe that a formal clinical trials network for Australians with CF will put us first in line for next generation CF drugs and treatments.

Major CF communities like the US and the UK already operate under a national research and funding consensus. With this in mind CFA will be holding a research priority setting program for consumers, researchers and clinicians in the second half of 2020. This will involve national consultation, international collaboration, online surveys and local Think Tanks.

The CF research community in Australia is highly regarded and it is growing. We make major research contributions worldwide and we are diverse and organised. The clearer we are about our goals for the next decade, the more progress we will see.

As always, it is our passionate community members, our outstanding researchers and our dedicated medical specialists who will steer this process.

If you would like to be involved, please email Nicki Mileham at [nickim@cfa.org.au](mailto:nickim@cfa.org.au) .

We are continuing to develop 'Peer Review Mark 2' to ensure the best and most innovative clinical practice and care. Peer Review Mark 2 will bring together consumers and clinical staff to gain a better understanding of CF Centre dynamics and provide the opportunity to reflect on practice and resources and standardise care.

We will also be looking at long term infrastructure, we need data to improve health outcomes, we want improved communication, environment and equipment. Most of all we want benchmarking and longitudinal tracking in the ACFDR.

CFA likes to cover the spectrum with our fundraising ideas. In 2020 we have Everyday Heroes like Hannah Newman ready to run for cystic fibrosis and we have amazing artists like Taneil Willing supporting us through their work.

Alan and Jenny Tunks and Conquer CF have been long time supporters of CFA and our research through the ACFRT. Investec continues to provide our offices free of charge and L J Hooker is our oldest corporate partner, having supported CFA for decades.

We are also setting up for some more ambitious fundraisers. Once again, we have partnered with Nathan Charles, CF's homegrown rugby trail blazer. This year Nathan is set to out-do himself. He has planned a CFA-sponsored trip to Papua New Guinea to complete the legendary Kokoda Trek. Details of how you can support or join Nathan are in the link below.

<https://www.cysticfibrosis.org.au/get-involved/events/events-listing/cfa/trek-for-cf-research>

A new year unfolds for CFA with new plans and aspirations, but the goal is the same - Lives Unaffected by CF. And plans mean nothing if they don't fulfil our dreams.

Kind regards

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