

21 January 2022

WHY WE FIGHT

At CFA we strive to put decision making power in the hands of real stakeholders, the people who are directly affected by CF. No one else should get to decide if you are sick or healthy and what you can and cannot do to improve your life.

Over the past two years, CFA has been waging a constant battle to secure funding for Trikafta in Australia, and the culmination of our efforts could be very close indeed. On Friday of next week, the PBAC will announce their decision about whether or not to list Trikafta as a funding recommendation on the PBS. The current government has pledged to honour PBS recommendations so this would be an effective green light for Trikafta in Australia.

Currently there are only a small group of Australians with Trikafta falling under the old Compassionate Access conditions. This is a woefully inadequate state of affairs, and CFA will not rest until Trikafta is available to all who need it.

But why have we been fighting so hard for Trikafta in particular? Well, Trikafta is a CFTR modulator. People living with CF have impaired CFTR genes and this is the underlying, cellular origin of their entire illness. CFTR modulators help to target this problem at its roots and improve the processing and tracking of CFTR.

Trikafta is not just a CFTR modulator. It is currently **THE** CFTR modulator – the most effective CF drug on the market with the best symptom reduction for the widest cohort of CF patients. The reason for this is that Trikafta is a combination therapy merging three CF wonderdrugs (Elexacaftor, Tezacaftor, Ivacaftor) into one hyper-effective package.

CFA has been trying to get the news out about the benefits (and dire need for) Trikafta in various ways. We have spoken directly to Health Minister, Greg Hunt, as well as various backbench MP's. We have hosted Vertex and PBAC representatives along with ambassadors from the CF community at a summit last year in Canberra. We have provided ACFDR data to Vertex and the PBAC in order to help alleviate disagreements that stalled Trikafta throughout 2021 and we have even hosted the head of the PBAC, Jo Watson, on Consumer Connect. Jo Watson talked about the impact of grassroots advocacy and she ensured our community that its voice was being heard at the highest levels.

Next week we will update you about whether the Trikafta battle is finally over. Regardless of next week's announcement, CFA will never give up pushing to ensure Australians living with CF get the medications they need. Every dose of Trikafta adds precious minutes to CF lives, and that is why we fight.

Best Regards,



Jo Armstrong
CEO, Cystic Fibrosis Australia