

16 September 2021



There Goes Another Rubber Tree Plant

Just what makes that little old ant think he'll move that rubber tree plant?

In the case of CFA we know we can do it because we've got no choice. If we don't take on Government and big Pharma, then there is no one left to fight for people with CF.

Let's start with what we still don't know about the fate of Trikafta:

1. Will Vertex submit Trikafta to the November PBAC Meeting?
2. Will Vertex compete the Trikafta deal for people with F508del/Minimal function gene mutations?
3. What Minimal function gene mutations are included in the PBAC's recommendation?

Not knowing the 'state of play' impedes our ability to advocate and have our say.

The CF community is renowned for its passion and ability to communicate effectively through the PBAC Portal. We have almost broken the system a number of times in the past with submission numbers nudging 3,000. Not bad for a small grassroots community supporting a rare disease.

Not knowing if Trikafta will even be on the November PBAC Agenda is unacceptable. It is a risk to our whole community, and we must not allow ourselves to be silenced or sidelined.

CFA has been chatting with the Deputy Chair of the PBAC, Jo Watson and she has agreed to two things:

1. All our submissions from 2021 will be used as consumer evidence at the November PBAC Meeting if Trikafta is on the Agenda. This is great news as the portal closes on 22 September 2021.
2. Jo will join me on Consumer Connect to outline the issues currently in play and listen to consumer stories and concerns. This will be a fantastic session to have your say and hear what is holding up the PBAC's recommendation of Trikafta.

The CF Community is so lucky to have a supporter like Jo Watson who is committed to consumer consultation.

'Save the Date' – 12th October, 2021 at 6pm

TO WATCH THE SESSION – LINK [HERE](#)
TO REGISTER AND PARTICIPATE – LINK [HERE](#)

Have your questions ready for Jo so we make the most of the Consumer Connect session. Please send CFA your questions if you wish to remain anonymous to malag@cfa.org.au.

See you online at 6pm on 12th October 2021. Here goes another rubber tree plant.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke".

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