



21 April 2021

WHY NOT!

As final discussions take place between the PBAC and Vertex regarding the fate of Trikafta for 2200 Australians with cystic fibrosis, the CF Community is ready to ask **WHY NOT**.

*Consumers are not part of the drug reimbursement and assessment negotiations. **WHY NOT***

*Consumers are not able to view Pharma submissions to the PBAC. **WHY NOT***

*Compassionate Access is not provided to all eligible recipients immediately following a positive PBAC recommendation. **WHY NOT***

And if Trikafta is not recommend for reimbursement by the PBAC we are going to ask **WHY NOT** and request two things.

1. A Stakeholder Meeting involving Minister Hunt's office, Vertex, the PBAC, Dept of Health, Cystic Fibrosis consumers and Cystic Fibrosis Australia.
2. Access to the Vertex's PBAC submission and the PBAC response documents.

In what realm is it considered appropriate for consumers to be kept in the dark while their health and life expectancy are being decided by backroom bean counters and bureaucrats?

After the overwhelming stresses of the COVID-19 Pandemic on us all and in particular people with CF it is time to innovate and make great change. Opportunities for real change are fleeting and fragile. Timing and solidarity are everything.

Too many good people hide their light under a bushel these days. Their insight and courage and charisma runs deep within them, but it is locked away behind glass like a fire alarm. Pull the alarm. Break the glass.

Proactive members of the wider CF community are already sharing their stories of desperation, frustration, hope and real life experience. Join your voices to theirs.

CFA will continue to petition the HTA Inquiry to ensure that consumers become the masters of their own health destiny. Contact the Chair Trent Zimmerman MP trent.zimmerman.mp@aph.gov.au and Deputy Chair Dr Mike Freeland Mike.Freeland.MP@aph.gov.au and have your say about the issues with the current Health Technology Assessment process.

Share with them the ways consumers could be used to add value and expertise. For inspiration CFA's submission to the Health Technology Assessment Parliamentary Inquire can be found [HERE](#).

We all have our fingers and toes crossed that a positive PBAC recommendation is announced on Friday but we all must be ready to ask **WHY NOT**.

Kind regards

A handwritten signature in black ink, appearing to read "Nettie Burke". The signature is fluid and cursive, with the first name "Nettie" being more prominent than the last name "Burke".

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