

4 February 2022

THE TIME IS NOW

Trikafta has been recommended by the PBAC. Now what? Will the Government drag its feet in listing Trikafta for reasons that are only understood behind the veils of power? Will Vertex hold out on technical issues because of a desire to raise the price? Will the upcoming Election play some part in delaying or expediting the whole Trikafta process?

It is evident that there are many uncertainties that lay ahead of us right now. What is certain, however, is that at CFA we have been working non-stop to resolve these important questions and we will not stop advocating for the best outcomes for everyone living with cystic fibrosis. The more allies we engage, the more pressure we can put on these power players and the faster we will get our medicine.



One thing you often hear about in the world of Advocacy is ‘Canberra Time’. Bureaucracy can flow at glacier-pace in our nation’s capital, but the intermittent lightning of ministerial decisions and political expediency can turn stodgy delays into rapid action. Canberra Time is so named because it is unpredictable. At the same time, we are conscious that Vertex has a big part to play in the process too as they work out the details of the agreement with the government. Vertex wrote an open letter to our community this week and you can read it [HERE](#) and my open reply to Vertex can be accessed [HERE](#).

Indeed, the CF Community is not powerless. There is much we can do to ensure that Trikafta remain on the agenda and is prioritised. We have submitted a petition to the APH, which we hope will soon be ratified. If the petition can gain enough signatures, it will be brought

before the Parliament, and we can force our government to acknowledge the urgency of Trikafta.

We are also hosting our Trikafta Summit on Consumer Connect next week (Wednesday 9th February, 6:30pm). Here we will answer your questions about the PBS listing process and announce our game plan for Trikafta advocacy moving forward. I hope you can make it!

This week we have also contacted Greg Hunt, Mark Butler and several other ministers to expediate the listing of Trikafta on the PBS. We have also been in touch with many local and nationally based journalists who are known to be sympathetic to the CF cause to keep Trikafta on the agenda. I have appeared on 2GB with Ray Hadley, and we have connected our CF ambassadors with several news outlets for interviews.

You will see Trikafta in your Facebook feed, you will hear about Trikafta on the radio, your local representatives will receive letters about the importance of Trikafta. We are not content to let this drug languish on *Canberra Time* and every one of you who joins us in this effort can help bring Trikafta a day, an hour or a minute closer. Thank you.

Whether you or your loved ones will personally benefit from Trikafta or not, please be assured that CFA is advocating for EVERYONE in our nation, with CF, to have an abundant and full life.

Warm Regards,
Jo Armstrong, CEO Cystic Fibrosis Australia