

27 January 2021



NO TIME LIKE THE PRESENT



Some of you may be wondering why Cystic Fibrosis Australia (CFA) is still posting images of wrapped gifts along with our slogan 'No Time Like The Present, No Present Like Time' even though it is a month after Christmas. If that's the case then I'm afraid, with all possible respect, that you haven't been listening.

The gift of time is very precious, and it is not every day that you get a chance to really add years to the lives of others. However, the fight for Trikafta in Australia is going on right now in the leadup to the Pharmaceutical Benefits Advisory Committee (PBAC) hearing on 10th March 2021 and decades of life are on the line for thousands of Australians with cystic fibrosis (CF).

There is 'No Time Like The Present' because this is what we have been leading up to, waiting for and campaigning for. We are on the verge of access to a true CF miracle drug, effective for 90% of people with CF and capable of reducing hospitalisation, antibiotic use and exacerbations by half. We are on the verge of saving lives that last year were faced with little hope.

There is No Time Like The Present because if we must act now and set out our demands. This time around Cystic Fibrosis Australia (CFA) is taking a new approach to our advocacy. In the Trikafta debate we do not need to prove Trikafta's efficacy – clinical trials around the world have done that already.

Instead, CFA is feeling positive about TGA approving Trikafta and the PBAC recommending it for reimbursement. With that in mind we are asking that Vertex provide immediate Compassionate Access to all eligible people following the PBAC decision.

It is estimated that Vertex Trikafta revenue will be \$6.6 billion by 2025 and while this is great for shareholders, why should people with CF have to wait as commercial negotiations drag on, especially as we cannot impact this part of the process.

To achieve immediate Compassionate Access would be the greatest milestone of all and could change the HTA process and negotiations for all health conditions in the future.

The rest of the world had gifts in December, we have our time right here, right now. Let the PBAC know how important Trikafta is to the Australian CF community by leaving your comments on their Consumer Portal [HERE](#). The PBAC portal closes on 10 February 2021 ... just two weeks to go.

Now is also the time to write to your local member or senator and share your story. To contact a Member of Parliament or Senator [CLICK HERE](#) for their contact details. Letters are available [HERE](#).

There is No Time like the Time you can give to CF Lives by following the links and spreading the word for Trikafta. All the arguments are [HERE](#) on the CFA website.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke". The signature is written in a cursive, flowing style.

Nettie Burke, CEO
Cystic Fibrosis Australia
0404 034 294
nettieb@cfa.org.au