

7 March 2023

DEVASTATING NEWS, THE SYSTEM HAS LET US DOWN.

Cystic Fibrosis Australia (CFA) and our state and territory members have had an emergency meeting today and together we bring you this update. We have received the devastating news that the discussions with the Department of Health and Vertex regarding Trikafta for 6–11-year-olds, have come to a standstill and been referred back to the Pharmaceutical Benefits Advisory Committee (PBAC).

This is unbelievably frustrating as the PBAC have already recommended Trikafta for the 6-11 age group! Now the system has let us down as negotiations have stalled, disadvantaging those it is meant to serve.

The time taken and ongoing delays we are experiencing is unconscionable.

There are 500 Aussie kids waiting for Trikafta. The cystic fibrosis (CF) community were jubilant when a positive recommendation was made late last year, yet here we are going backwards! The crux of the dispute appears to be regarding metrics about uptake and compliance rates, which is the number of children who are likely to start treatment and those who will continue to use it. This is surprising given that there is significant data on this.

We call on the Health Minister, Mark Butler MP, to do all that he can to accelerate the listing of Trikafta on the PBS, without the delay and expedite this process. The Department of Health and Vertex must do the right thing by the CF community. Children living with CF cannot wait any longer.

All stakeholders need to accelerate this process.

It is unacceptable to cause this worry to families and young people living with CF. We need an immediate resolution.

This news has come at a time when our neighbours in New Zealand are celebrating that Trikafta will be available for those eligible with CF aged 6 and older from April 1st, 2023. This is great news for New Zealand. However, it is unbelievable to think that two countries so close have such significant inequity of access to this critical medication.

What does this mean?

- The PBAC will meet this week
- The outcome and minutes from the March meeting will be available on the 21st April
- Listing of Trikafta is now likely to be delayed further.

What can we do?

Now, more than ever, our voices need to be heard. Here are just a few members of Parliament we suggest you write to, share your story, and urge to expedite Trikafta onto the PBS as soon as possible.

- Your local member
- Mark Butler MP, Minister for Health
- Anne Ruston MP, Shadow Minister for Health.

We are sad to deliver this devastating update, but please be assured that as the peak body for CF, and your national voice, CFA along with its state and territory members will not stop advocating for Trikafta to be made available for the 6–11-year-old age group. Last month, alone, CFA contributed to 125 media pieces advocating for Trikafta and we will not stop. You can see many of the media pieces here [Cystic Fibrosis - Trikafta Advocacy Plan](#)

Further, we are in discussions with the Department of Health, Vertex, and the PBAC. On top of this, we are holding an important event in Canberra before the end of this month to advocate for the CF community.

CFA is meeting with all stakeholders to progress this with absolute urgency.

Our advocacy work will continue to push harder than ever before. We will continue to advocate for access to Trikafta for 6–11-year-olds and a range of other important matters for the CF community, including support and therapies for people who are not eligible for Trikafta. No one is forgotten.

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