

24 March 2022

TRIKAFTA COMPASSIONATE ACCESS UPDATE

This is the update that I didn't want to bring you.

I am devastated to inform you that as of this evening, the Compassionate Managed Access to Trikafta program will no longer be available to new applicants. Vertex has failed to renew or extend the program despite sustained appeals from both CFA and the wider community. To say that I am devastated, is an understatement. I struggle to see the compassion when such life saving medication is being denied and at such a pivotal time.

Thankfully, patients already receiving Trikafta through Compassionate Access will continue to receive the drug, however, there remains a great number of Australians still left at risk. CFA and our affiliated organisations have been fighting for access to Trikafta for a long time. Compassionate Access was always a temporary solution on the journey to getting Trikafta fully funded at the federal level, however it was still extremely important.

Not only did Compassionate Access allow for the most medically vulnerable members of our community to receive access to a critical drug, but it was also a visible sign from Vertex that they were willing to put CF lives first.

Now the stakes are higher than ever because all Australians with CF who have not yet received Trikafta have no other way of getting this vital medication and will have to wait until the drug is fully funded at the federal level – unless of course they pay more than \$21,000 a month to personally fund it!

It would have been so easy for Vertex to reassure Australian families by extending Compassionate Access for the remaining period of negotiation. Instead, our pleas seem to have fallen on deaf ears and I urge Vertex once again to please reconsider the value of Compassionate Access and the desperate need this miracle drug fulfils. Let's hope their resources are indeed expediting the negotiation process for this essential listing so that we are waiting only moments before there is good news for our community.

We cannot wait any longer. We need Trikafta listed on the PBS now.

As it stands, we are closer than ever to achieving this goal. Next week Dr Mike Freelander will personally champion our cause in front of the House of Representatives. All parties are converging in their aims and demands. I am hopeful that victory is in sight for us.

If you stand with CFA in our ongoing battle for Trikafta, please support our intensive Advocacy effort by donating [HERE](#) to the Trikafta Advocacy Fund.

I will continue to keep you updated. It is time for Trikafta.

Thank you for your support.

A handwritten signature in grey ink that reads "Jo Armstrong". The signature is written in a cursive, flowing style.

Jo Armstrong
Chief Executive Officer
Cystic Fibrosis Australia