



18 February 2022

### **KEEP ON KEEPING ON**

It has almost been three weeks since the announcement has been made that Trikafta has been recommended by the PBAC. Now what? We are waiting and hoping, but yet nothing has been confirmed.

I understand that there are conversations taking place between the Government and Vertex right now. I have been assured this is an active process where the need for urgency is for PBS listing is front of mind but still, we wait.

Amid this uncertainty and seemingly 'quiet' time, CFA is far from quiet, and we are keeping on. In fact, our advocacy work has never been stronger. I have been busy sending letters to ministers, leaders, and having ongoing discussions about accelerating access to Trikafta. I have even suggested that CFA can provide the platform for stakeholder discussions.

My conversations with Vertex have included the repeated request that the Compassionate Access Scheme be extended beyond March for new people during this time. I am hoping for an update from them on this soon.

Each day that goes by I know causes more hardship to people who desperately need this drug now. However, with each day that goes by there is the opportunity for us to continue our action and make our voices heard. We must keep on keeping on! We are not powerless and together we can get the outcomes we need for all people in Australia living with cystic fibrosis (CF).

The petition that I launched to parliament is only a week old and already we are getting thousands of new signatures each day! As I write this, there are almost 10,000 signatures! Thank you! I am sure that by the time you read this, there will be thousands more.

Your voice counts. You count. Whether you have cystic fibrosis or you are reading this because someone you love has cystic fibrosis, please know, that you can make your voice heard to help drive the outcomes we need.

Please continue to share the link and encourage other people to sign the petition. Here is the link [e-petitions – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/e-petitions) This is one very practical way that we can ensure the needs of our community are made known.

Another way to make your voice heard is to follow CFA on social media and share and comment on our posts. We are using the hashtag *#TimeForTrikafta*, this is a great way to bring awareness across social media platforms.

You can write to your local MPs and share your story. Since joining CFA, only 6 weeks ago, I have been so encouraged by the people in our community. You are so inspiring and I have been so moved by the stories that I have heard. Please like Jess, who was on Consumer Connect last week and shared her journey. If you missed the session, you can access it [HERE](#).

On another note, I have been learning this week about new developments in research and technology for people with CF that are on the horizon for us. This includes people with rare mutations. This is very important for CFA because we advocate for everyone and while Trikafta is front of mind currently we know it is one step in the right direction and this is why we keep on, keeping on.

Warm Regards,

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

Jo Armstrong, CEO Cystic Fibrosis Australia