

## OPEN LETTER TO THE CF COMMUNITY

Cystic Fibrosis Australia (CFA) recognizes that Trikafta™ is an urgent medical necessity in this country.

Thanks to you, our message has reached farther than ever - with media appearances spanning from radio to television to local and national news articles and of course new mediums like podcasts and livestreams. It is your stories that are making an impact and your faces that have come to epitomize this struggle.

At the time of writing, we have secured over 37,000 signatures on our Parliamentary Petition and this will ensure that our demands cannot be ignored when this petition goes before the House.

There is more good news. The Chair of the PBAC, Andrew Wilson, has assured us that the price negotiations are proceeding without incident. He is hopeful that the department will finalise an agreement with Vertex soon. From there it will be in the hands of the Minister and Cabinet to expedite the funding and listing of Trikafta™. CFA will keep the pressure up until Trikafta™ is physically in your hands!

We are pleased to hear that the PBAC is confident of a speedy resolution, however we would welcome more transparency from Vertex. In their open letter on February 1<sup>st</sup>, they claimed to empathize with the urgency of our position, but since then they have made no effort to offer peace of mind to our community. The fight for Trikafta™ has become an increasingly public issue, and so we would like to *publicly* offer Vertex this chance to step forward with a commitment to resolving price negotiations before the end of March.

In the case that the listing is not in place by 24<sup>th</sup> March, we implore Vertex to allow the ongoing recruitment to the current Managed Access Program instead of stopping the enrolment of new patients onto the program. CFA has asked them on multiple occasions to make this commitment to the CF community however, to date, we have not been successful. Vertex can make this change with the stroke of a pen; however, they have chosen to hide behind the terms of a contract that they created and only they can change. Vertex have shown NO conscience on this matter. When CFA has approached them, they stonewall and can provide NO reasonable explanations to why they need to cut access for new enrolments. We hope that this approach is not how they are negotiating with the department for health.

Our request is not unreasonable given the circumstances. The PBAC has acknowledged the effectiveness of Trikafta™ and offered a recommendation. The Government has pledged to honour these recommendations. All are aware that CF lives are on the line and that every second counts. We are simply asking the decision makers at Vertex and the Department of Health to hurry up and deliver on what has been promised.

Best Regards



Jo Armstrong  
Chief Executive Officer  
**Cystic Fibrosis Australia**