



Cystic Fibrosis Australia  
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3<sup>rd</sup> February 2022

Vertex Pharmaceuticals (Australia) Pty LTD  
Suite 3, Level 3  
601 Pacific Highway  
St Leonards, NSW, 2065

Dear Sabrina Barbic,

**Cystic Fibrosis Australia Open Letter Response to your Open Letter Dated 1 February 2022**

Thank you for your Open Letter to our community. We are grateful to hear that you are taking steps to expedite the PBS listing and we do not think that any of the stakeholders in this process are served by further delays.

Needless to say, Cystic Fibrosis Australia is also committed to resolving the Trikafta question promptly and efficiently. We have the luxury of a single priority: getting effective CF drugs into the hands of patients who need them.

Your letter raised concerns over the willingness of the Government to recognise the value of Trikafta. CFA though continues to support the important principles that the PBAC is tasked to deliver on in Australia, assessing efficacy of treatment and providing access in a resource constrained environment, that will allow universal access to everyone who will benefit. We hope that the PBAC's recommendation is re-assuring in this respect, but we urge you not to hold out for too much extra 'value' in these negotiations. Not unless the health of people with CF can be assured.

To that end, it would be a powerful, positive gesture for Vertex to extend the new enrolments window for Compassionate Access until the listing is achieved. That way the details of the Trikafta deal can be settled with less harm to our community.

We acknowledge the realities of industry; we recognise that your life-saving therapies cannot be developed if the expense is not recovered. However, at CFA we sometimes think that Vertex – amongst other pharmaceutical companies – may even underestimate the value of what they are creating.

You have created a drug that means improved lives to thousands of people across the nation. You have created a panacea for sleepless nights, missed classes, tear-stained faces and shattered hopes in CF families all over the world.

CFA is happy to support the process of negotiation and facilitate discussion between parties, communicating the importance of Trikafta and its place in providing care to people living with CF in Australia. We will continue to provide a voice for all people living with CF and their families.

If Vertex knows the real value of Trikafta then please ensure it gets where it is needed, first by extending Compassionate Access, then by bringing a fair and timely end to the negotiations on which Trikafta continues to hang. Now is the time for bold and generous action.

Best Regards,

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