



11 March 2022

Fifty-Eight Thousand Two Hundred and Seventy Four Reasons

Cystic fibrosis (CF) can sometimes be overlooked as a rare disease and this is a great shame. Over time we have cultivated a wider and wider network to make sure that the concerns of people with CF are at the forefront of those in power. We have joined cause alliances such as Accessible Design and the Rare Disease Alliance. We have established relationships with ministers and politicians at the State and Federal level. But when push comes to shove, we have always relied on our community to stand with us and fight.

As a result, we have been able to secure multiple high level media engagements, including a segment this week on Channel Ten's 'The Project'. We have had amazing ambassadors writing letters, contacting local news and extolling the need for Trikafta. Special mention must go to Jessica Ragusa, who has campaigned tirelessly on socials, livestreaming and even TV. Thanks also to Nick Cummins aka The Honey Badger. His messages to Australia on behalf of people living with CF have been extremely heartfelt and characteristically charming.

The campaign for Trikafta has set a new benchmark CF awareness in this country because today there are 58,274 Australians out there who can say they stood up for the cause. That is incredible! There are fewer than 4,000 Australians living with cystic fibrosis today and we succeeded in amassing over 58,000 signatures, more than ANY other petition currently registered with the Federal Government.

I am liaising with Dr Mike Freeland, a member of Parliament who understands the medical gravity of cystic fibrosis and the importance of Trikafta. We have asked him to speak on behalf of our petition to the House of Representatives. This will further increase the impact of our already weighty argument, to "Get Trikafta listed in Australia NOW!"

Vertex is also showing signs of a practical and concrete commitment to ending the interminable delays. This week I received the following statement from them to share with you-

"Vertex appreciates the impact of the current uncertainty around PBS-access to Trikafta for the CF community. Vertex shares the Community's urgency for access because we understand the impact our treatments can have on the lives of people

living with CF. The current discussions with the PBAC and Government are going well, and we are progressing quickly through the process. Vertex wants to assure you that we remain committed to finalising the last stages of the process prior to the upcoming budget and hope that a PBS listing will follow soon after.”

We are encouraged by their willingness to set timeframe for resolution. We are even more encouraged to know that, along with Cystic Fibrosis Australia (CFA), there are 58,274 watchful eyes who will hold them to their promise.

It is important to acknowledge that some individuals with CF will not benefit directly from Trikafta and must rely on other therapies. They too are a part of this upcoming victory because the fight for Trikafta has helped Australia realise that CF is a serious issue and that funding CF medicine is an important priority.

While the petition may have closed, our efforts at CFA continue both in front of the cameras and behind the scenes with letters and meetings with key decision makes and leaders across our nation. It is critical to me that we get the outcomes our community needs and deserves.

While the team and I have been busy with this vital advocacy work, I am acutely aware that CFA itself is funded by donations. This means that we rely on the support of the community for donations for us to sustain our work. If you have been pleased with the work that we have been doing, then may I boldly ask you to consider donating to help us to continue carrying out this essential role?

Our donations page is linked [HERE](#) and all donations above \$2 are tax deductible.

Let's keep working together to get the best outcomes for all people in Australia living with cystic fibrosis.

Best Regards

A handwritten signature in cursive script that reads "Jo Armstrong".

Jo Armstrong
Chief Executive Officer
Cystic Fibrosis Australia