

8 April 2022

### **PROGRESS UPON PROGRESS**

As you may know I have been amplifying our voice to our nation's leaders as there is a hive of political activity right now, especially during my time in Canberra. The budget took place last week and with the upcoming election, it is important that whoever is leading our nation, they know about our community and have our needs front of mind. Regardless of the outcome of the election, the interests of people living with cystic fibrosis (CF) must be a priority.

At several of the events I attended speakers including the Prime Minister Scott Morrison and Minister for Health Greg Hunt and others in government verbalised support for people with CF. This week I had a follow up meeting with the PM and he listened intently to me as I spoke about our needs. I tell you this so that you know you have been heard. I realise there is still so much more work that must be done to continue this progress, but this is a good start.

Of course, we will not neglect that it is critical we engage with both sides of the political divide. Indeed, we have also been engaging with the opposition leaders as well. This week CFA attended the Opposition Leader Health Budget. I am hoping to ensure there is a commitment to our community as my communications continue.

While in Canberra I was delighted to spend some time with CFA friend and advocate, Dr Mike Freeland MP and thank him sincerely for his support of us. It was wonderful that Mike chose to present our petition for Trikafta in Parliament even after the PBS listing! Why is that? You might ask. The answer is because he wanted to ensure that your voice is heard in Parliament! Thank you, Mike!

I realise politics is a sensitive subject for many, but for me this is not about being political but ensuring the moral obligation of having the best health outcomes for people in the CF community. In fact, this is part of my job! I must help to ensure we get the best outcomes and that means engaging with our political leaders is important, regardless of who they are personally or which party they are a part of. On top of this, and all the election promises, our leaders must be held to account.

Interestingly, over the last couple of weeks I have been introduced to many people, representing other illnesses and diseases, who have been greatly encouraged by how quickly Trikafta was listed on the PBS. (Although it seemed like an eternity it was only 9 weeks between PBAC approval and PBS listing, when the average time is 31 weeks.) It may not feel fast, and of course there have been setbacks along the way to get to this point, but it has been an encouragement to the wider community. This is a credit to you! You have been an encouragement to many other people who are fighting similar battles to get access to essential medicines quickly.

Of course, we still have a long way to go and there is much more that needs to be done including the availability of Trikafta for those aged 6 -11 and as we spoke about in the Consumer Connect session last week, there is no forgotten 10% of people but a remembered group of people where every week critical work is taking place in precision medicine to ensure no one is left behind. If you didn't see the Consumer Connect you can watch it [HERE](#) where we discuss what else is taking place and CFA's priorities as we continue to press on.

We will progress upon our progress as we keep striving for the best outcomes for everyone in our CF community.

Warmest regards

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

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