

2nd December

Your Voice, Amplified

In exactly two weeks we will know the outcome from the November PBAC meeting. I think we are all hoping that there will be some good news to celebrate ahead of the festive season.

As we learnt from CFA President Mitch Messer at our most recent Consumer Connect Session ([watch here](#)), the decision has been made, and the PBAC are currently doing their due diligence prior to making the announcement.

Whilst I know we are all on the edge of our seats, awaiting this decision, I want you to know that I am doing all I can to ensure your voices are being heard by our national decision makers, especially the Department of Health. Indeed, I am in regular contact with a range of key stakeholders on a regular basis to ensure the best outcomes are secured for our community.

It is coming up to my one-year anniversary since I commenced as CEO at Cystic Fibrosis Australia. In that time, I have met many incredible people from our community who have not only shared their stories but also helped me to understand the realities of the daily challenges of living with CF. Thank you for sharing your journey with me.

Whilst I cannot say first-hand what living with CF is like, I truly appreciate everyone in our community who has contributed to my growing knowledge. It is with this information that I have been better able to communicate the needs of our community with our nation's decision makers through our advocacy work, especially regarding access to medications like Trikafta.

As I commenced my life at CFA in January 2022, we shortly received the recommendation from the PBAC to list Trikafta on the PBS for the 12+ age group. How wonderful would it be if we can end 2022 with another positive recommendation?

By April 2022 Trikafta was available on the PBS to be accessed by many in our community – while it felt like the weeks and months dragged on between the PBAC decision and the PBS listing, in comparison to other medications, it was a quick process. My hope is that we see an even quicker listing process in the future. No one should have to wait to access the medicines they need.

As we wait for the upcoming announcement it is at the top of my mind that this decision can go one of three ways and we must be prepared for all. Of course, the only answer we want is for Trikafta be recommended for the 6-11 age group. But with this, we know there will be caveats that we must prepare for. So, whilst we prepare for this outcome to be made public, just know that I am already thinking about our next possible steps and our response, and I will keep you updated once the PBAC decision has been made.

I want to acknowledge that there are people in our community who have rare mutations, or who do not respond to modulator therapies that feel forgotten, but this is not the case. You are very much remembered. I regularly meet with various leading medical professionals and researchers to better understand how we can ensure advancements for everyone in our community, including the very much 'remembered 10%'.

Amid some of the great successes of 2022 there is so much more to do! As we look towards the end of the year, we are not slowing down but pulling out all the stops to get the outcomes we need and I

will continue to advocate and collaborate with those in our sector to ensure I can be Your Voice, Amplified.

To help support our work, please donate today.

All donation over \$2 are tax-deductible.

Jo Armstrong

Chief Executive Officer
Cystic Fibrosis Australia