

3 April 2023



## CONTINUING TO ADVOCATE

It has been a very busy time of advocacy in response to the frustrating news that the listing of Trikafta for children with at least one F508del mutation has been referred back to the PBAC. The minutes of the meeting are not due to be publicly available until the 21st of April.

We cannot continue waiting so our CEO, Jo Armstrong, has spent some important time in Canberra with our nation's leaders. In fact, it wasn't only regarding the urgent need for the Trikafta listing to be expanded but for the broader interests and needs of the cystic fibrosis (CF) community as well, including accessible and affordable therapies for all people with CF, including those with rare mutations and those who do not respond to current therapies, mental health, fertility, and aging.

We recently attended the Thoracic Society of ANZ Conference and had the opportunity to engage with leading CF clinicians and researchers. We were very encouraged by the reports of the improving landscape for people with CF and the clinical research being carried out. Indeed, there was considerable work taking place, to ensure effective therapies for people with rare mutations and people who do not respond to modulator therapies. We are pleased to report that throughout the CF sessions, there was a strong theme of support and effective therapies for every person with CF, including frequent statements from clinicians that "no one should be left behind". This includes the importance of the type of future support people with CF will require as life expectancy increases.

Our CEO, Jo Armstrong, had the incredible privilege of speaking at the recent launch event for the newly established Parliamentary Friends of Cystic Fibrosis in Canberra. The room was packed to capacity with representatives from across the CF community including Federation Members, Board Members, clinicians, families, and friends of people with CF. We heard firsthand the experience of life with CF from CFA President Mitch Messer, Bradley Dryburgh, Jess Ragusa, and Shannon Malone-Brierley, thank you for sharing your experiences. It was very moving indeed. Please see the photos from the event below.

Many of you also shared your stories with us to take to our nation's leaders and we were able to do this at the event as well. Thank you.

Our sincere thanks to the Chairs Dr. Mike Freeland MP, Dr. Monique Ryan MP, and

Mrs. Bridget Archer MP who established the group, and all the MPs who have become members and have been advocating for the CF community.

It was deeply encouraging by the number of MPs who attended the launch event and showed considerable concern for the people in their electorates living with CF. There were various conversations about the need for therapies for all people in the CF community and those who do not respond to modulator therapies or who are not yet eligible for them as well as support for the current Trikafta listing to be expanded to include 6-11-year-olds.

Thank you to everyone who has written to their local MPs, there have been so very constructive conversations as a result of your letters. Many MPs have reached out to Cystic Fibrosis Australia (CFA) for information and our conversations are continuing until we get the progress we need.

As your representative peak body, CFA will continue to advocate relentlessly for all Australians living with CF.

Together we can ensure that the CF community is front of mind for our nation's leaders and especially at a crucial time like this.

Speaking of which, we are delighted to learn that in the upcoming July PBAC agenda, Orkambi is listed for 1 and 2-year-olds. Hopefully, there is a positive recommendation in due course. We know that early intervention and access to medicines can help save lives.

Thank you to everyone in our community for your support whether it has been sharing your story, attending important events and meetings, or financially supporting the advocacy work of Cystic Fibrosis Australia.

Together we can progress the outcomes for the CF community.

Ps. If you would like to financially contribute to the work of CFA please donate via this button.

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Photos from the Parliamentary Friends of CF event below:



Thank  
you





Thank you



Thank you

