

15 March 2023

Trikafta NOW

As part of our commitment to the cystic fibrosis (CF) community, Cystic Fibrosis Australia (CFA), and our federation members, listed below, want to provide you with an update on all that is taking place and affecting our community. While there are many important priorities for the CF community, we have seen disappointing setbacks for those who have been waiting for Trikafta in the eligible 6-11 age group.

Last week the PBAC met and Trikafta was on the agenda. The minutes will be available on 21st April. The next steps in this process are outlined in their timeline [HERE](#).

Our sincere thanks to everyone who has written to their local members. There has been a flurry of letters and meetings with MPs across all political parties.

Further, as a Federation, we have written to Vertex urging them to accelerate the negotiations and in the interim to offer a managed compassionate access program for the children waiting for Trikafta. We are currently awaiting their response.

There has also been much media coverage. We would like to sincerely thank long term CF advocate, Ray Hadley on 2GB for his support. You can hear the discussion he had with Cystic Fibrosis Australia, CEO, Jo Armstrong, here [Miracle drug for sick kids delayed after Department of Health talks break down - 2GB - Sydney's premier news and talk radio station](#)

We continue to urge all stakeholders to accelerate the listing of Trikafta and expedite the process so that the 500 eligible Aussie kids are not caught up in red tape but can quickly receive the medication that was recommended by the PBAC over 4 months ago.

Now more than ever it is crucial our voices are being heard. Please use the hashtag #TrikaftaNOW in your social media to help us spread the word that our CF kids urgently need Trikafta now.

At the end of March, we are holding an event in Parliament House to ensure that the leaders of our nation are keeping the CF community front of mind, through the newly established 'Parliamentary Friends of Cystic Fibrosis' group. The members of the group are key supporters of the CF community which will enable discussions on critical issues impacting the CF community and how members of Parliament can support over 3,600 Australians living with CF, and their families.

We would like to share stories from the CF Community at this event.

Personal stories can have a huge impact as they illustrate the reality of life with CF.

Stories from the community can influence the legislature, shape the media narrative, and support our fellow community members.

We acknowledge the courage it takes to share your story with others and thank those of you who are willing to do so.

Note: We will never share your stories without your permission. Your story can also be shared anonymously.

To share your story, please follow the link [HERE](#). If you would like your story shared at the event in Parliament House, please share your story with us by the **24th of March**.

If you have any issues accessing this link, please send your story and images to bianca@cfa.org.au

Our sincere thanks to chair Dr. Mike Freeland MP, co-chair Dr. Monique Ryan MP, and Mrs. Bridget Archer MP, for making the Friends of Cystic Fibrosis Friendship Group possible.

We will continue to do all we can to ensure the best outcomes for all Australians living with CF.

Jo Armstrong
CEO
Cystic Fibrosis Australia



Lisa Bayakly
CEO
Cystic Fibrosis Western Australia



Shannon Malone-Brierley
President
Cystic Fibrosis Australian Capital Territory



Andre Carvalho
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Christine Umapathysivam
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