

29 September 2022

## TRIKFATA FOR 6-11 YEAR OLDS

Advocacy is a core component of our role at Cystic Fibrosis Australia. We are your voice but louder, as we liaise with our nation's leaders and key influencers around the country, to get the best outcomes for our community.

This year we have already seen the success of persistent advocacy work paying off with the listing of Trikafta for 12+ year old's with at least one Delta F508 mutation. Still, we have a long way to go and there is much more work to do until everyone has access to the right medication they need.

The Pharmaceutical Benefits Advisory Committee (PBAC) will be meeting in November to discuss the possible listing of Trikafta on the PBS for children aged between 6 – 11. With many worthy medications and vaccines on the agenda to be discussed, we must do all that we can to ensure that Trikafta is made eligible to the 500 Australian children who will benefit from it. There is significant evidence to suggest, that beginning early treatment with modulator therapies could help slow or even prevent the irreversible progression of cystic fibrosis, dramatically altering the course of the disease over time.

This cannot go unnoticed.

Thank you to everyone who provided input towards this meeting through making submissions. By providing input, it helps provide a deeper perspective for the committee to better understand what consumers consider to be the main factors of the proposed medicine or vaccine. As your peak consumer representative body, we also included a submission to the PBAC.

Whilst the PBAC is committed to understanding consumer perspectives and integrating them into its consideration of medicines and vaccines, these opinions may be different than those measured in the clinical trial evidence presented in the submission.

At Cystic Fibrosis Australia, it is important that our communities' voices are heard both locally and internationally. Right now, we are working hard to ensure our CF kids can access Trikafta and we won't stop advocating until they do.

We believe that treatment delayed is treatment denied. Early access to medication is vital and this is what we are striving to achieve with the hope of a positive outcome in the November meeting.

As we continue to ramp up our advocacy work, can you consider making a financial contribution to help support us?

We rely on the support from generous people in the community like you, to help us operate. We do not receive government funding, so donations are very important to help

enable our work.

Please support our work by donating today. Every act of kindness can help change the lives of people living with CF.

We are your voice, amplified.

Please click on the link below to donate, all donations above \$2 are tax deductible.

Thank you for your support.

Jo Armstrong Chief Executive Officer

**Cystic Fibrosis Australia** 

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