



3 February 2023

Advocacy Update

It is disappointing that I must start this communique with no further update as to when Trikafta will be made available to our CF kids. It has been since November 2022 when the PBAC recommended this treatment to children aged between 6 – 11yrs with at least one F508Del mutation, and yet we still have had no clear timeline as to when we can expect to see these benefits accessed through the PBS listing.

Our community knows that the sooner people can access Trikafta, the sooner the benefits can be realised, including a reduction in infection, and reduced hospitalisation. It will also ensure less intervention is needed over time, such as a reduction in lung and liver transplants, and a reduction in the need for breathing machines and intensive care stays.

We know how important it is that our kids can access Trikafta as soon as possible. We are urging all parties to accelerate discussions and list Trikafta on the PBS without delay.

We need Trikafta NOW.

Whilst there is no certainty on when our kids can access Trikafta, 2023 has already started with a bang! We have been increasingly ramping up our advocacy work and have received some great media coverage on Channel 10 and ABC which can be seen via this link [Cystic Fibrosis - Trikafta Advocacy Plan](#). This link will be constantly updated as we continue to generate more traction.

I would like to say a huge thank you to the Lotz and Sewell families who have shared their respective stories with the national news. This is a very brave and bold thing to do and really helps the general public understand the impact of life with cystic fibrosis.

I would also like to say thank you to Lyndall Grace, whom you may have seen is currently on this season of Channel 9's Married at First Sight. Lyndall has done a wonderful job highlighting the impact of cystic fibrosis, and the importance of accessing Trikafta. We wish Lyndall all the best on her quest to find love.

Whilst our current messaging is on our CF kids accessing Trikafta, please know we are still advocating for ALL Australians living with CF and doing all we can for the many people who are not eligible or who are unable to access the right treatments. We know there is a wide range of issues that our community face each day that need to be addressed.

You are not forgotten.

As your national advocacy organisation, we will not stop campaigning until everyone with cystic fibrosis has the support they need.



As we focus on this critical work, we know we have a big year ahead and rely on your support to ensure we can do this. All donations, big and small, are appreciated.

[DONATE HERE](#)

All donations over \$2 are tax deductible.

Thank you for your support and for trusting Cystic Fibrosis Australia to be your Voice, Amplified.

Warm Regards,

Jo Armstrong

Chief Executive Officer

Cystic Fibrosis Australia