29th July 2024

Announcement: Trikafta PBS Expansion to 2+ year old's.

Dear Community,

Cystic Fibrosis Australia, as your Peak National Body, are thrilled to announce that Trikafta will now be available on the Pharmaceutical Benefits Scheme (PBS) for children aged 2+ with at least one F508del mutation starting Thursday 1st August 2024. This significant expansion will benefit approximately 290 children, including 100 children who will gain access to a modulator for the first time.

Your voice has been heard.

Thank you to everyone who wrote a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) and shared their story, including people like Ashley and Lucas. You may remember that only a few weeks ago we were seeking your support for our advocacy for little children waiting for Trikafta, children like Heath.

At just 4 years old, Heath lives with the challenges of cystic fibrosis, a genetic condition that affects the lungs and digestive system. However, in those four years, Heath and his family have benefited from an incredible care team, learned how to manage his CF with treatments and therapies, and will now have access to a modulator once listed on the PBS. Ashley and Lucas have been awaiting the PBS listing of Trikafta before he commences school. Like any parents, they wanted to ensure he was equipped for all that is ahead of now. Thanks to ongoing advocacy efforts, Heath's story is significantly different than many CF patients born in previous decades.

Advocating together is transforming lives.

It is evident that working together gets results. Thank you to everyone who has been a part of this great outcome, including our dedicated Federation Members who tirelessly work with Cystic Fibrosis Australia around the country. We extend our heartfelt thanks to the Health Department, Vertex Pharmaceuticals, and everyone involved in making this expansion possible. Our collective efforts have driven real change, especially for our youngest CF Warriors, and we should all take pride in this achievement today.

Together, we can drive the change that our community needs.

With over 40 years of experience, CFA has forged strong long standing collaborations, networks, and partnerships that drive continuous and transformative changes for our community. The expansion of Trikafta is a testament to the effectiveness of our persistent efforts and your faithful partnership with us. Thank you.

Today's announcement underscores the importance of persistent and collaborative work within this space. We celebrate this milestone alongside the hundreds of children and their families who will now benefit from earlier access to this life-changing treatment. Early intervention has the potential to limit lung damage and improve daily life, thus enhancing both quality of life and life expectancy for children with cystic fibrosis.

Together, we will continue to fight for our community, ensuring that all aspects affecting those with CF are continually addressed and advocated for. Today, we celebrate progress and look forward to more advancements in the future. I recognise that today will be difficult for people who do not benefit from this announcement, and it is clear that we still have so much more work ahead of us. Today does mark progress in furthering our cause.

We won't stop advocating for all people with cystic fibrosis as we continue to strive to ensure that everyone has the support they need.

Thank you for your unwavering support.

Cystic Fibrosis Australia will be broadcasting live via our Facebook Page, from Parliament House from approximately 9am, featuring remarks from Health Minister Mark Butler.

Warm Regards,

Jo Armstrong
CEO
Cystic Fibrosis Australia