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## **MISSION ACCOMPLISHED: TRIKAFTA ON THE PBS 1<sup>st</sup> April 2022**

I am absolutely delighted to tell you that Trikafta has been officially funded on the PBS and will be available from Friday April 1<sup>st</sup>, 2022. Cystic Fibrosis Australia (CFA) greets this news with unequivocal relief and joy. Trikafta has been recommended and funded for individuals 12 years and over who carry at least one f508del mutation. Trikafta will improve and lengthen the lives of so many people living with cystic fibrosis (CF). We can expect fewer hospitalizations, fewer transplants, greater health outcomes and more participation in the workplace not to mention many other physical, social, and emotional improvements for people.

CFA, the members of the CF federation, many other affiliated groups and people across our community have supported our advocacy work in getting this great outcome. Thank you.

We have campaigned online, in the media and through our political and advocacy channels. We have worked tirelessly to amplify all voices from the CF Community and pushed hard to limit all delays in accessing Trikafta. We have been asking for Trikafta to be made available immediately and from the 1<sup>st</sup> April 2022, that will be the case for many people. This is no April fool's day joke!

It has been quite an emotional roller-coaster, as it was only a few days ago that I updated you with great sadness that the Compassionate Managed Access Program was not extended for new people. Now we can celebrate this outcome that will such great benefits!

As you can imagine, CFA is extremely pleased that the drug will be made available so soon. We asked for lightning speed between Vertex and the government, and this is what we got! Thank you!

I would like to personally thank Minister Greg Hunt for his stalwart support of CFA, Andrew Wilson, the Chair of the PBAC, Jo Watson, the Deputy Chair of the PBAC and Dr Mike Freeland MP, all of whom have been a great friend to our cause. Thank you sincerely.

I would also like to thank the team at Vertex for their part in expediting the discussions to ensure a quick

listing of Trikafta. Thank you.

Although it may not feel like it, this listing has actually happened very quickly indeed, especially when considering the time, it has previously taken with other medications. Thank you to all parties who have listened to us to ensure that Trikafta was made available on the PBS as soon as possible.

This is a true victory for individuals living with CF and for their friends and families. As a community we have been fighting for Trikafta since prior to registration knowing how it could offer direct and tangible improvement in the lives of people with CF. Now, so many of our friends and family who are living with CF can now look forward to longer, more active, and more fulfilled lives with access to this game-changing medication.

I am proud of all parties in this negotiation for coming together and delivering a fast result. We are especially proud of the brave and resilient effort displayed by our CF ambassadors, in particular Jess Ragusa, and the thousands of donors, signatories and campaigners who have made Trikafta a truly national cause.

The fight for Trikafta in Australia has been a historic effort and a true underdog story. It is yet more proof that substantial changes are possible, even on behalf of those living with Rare Disease. Cystic Fibrosis Australia will continue to work for better outcomes through driving awareness, research, advocacy, and the powerful optimism of the CF Community.

This announcement is a true celebration. I do realise that there is still much work to be done for people living with CF and especially I acknowledge the 10% of Australian's who will not benefit from Trikafta. I want to assure you that we are still advocating and working hard for you and your needs. In fact, the work of Cystic Fibrosis Australia is to relentlessly ensure the best outcomes for all Australians with CF. Today we can see part of this come to fruition, but we will not stop working as we strive for abundant life for everyone in our community.

We know what works, we know how to achieve our dream of Lives Unaffected By CF, let's keep working together as a community and keep pushing for more wins like this.

Warmest regards,

A handwritten signature in cursive script, appearing to read 'Jo Armstrong', written in a dark ink or grey color.

Jo Armstrong, Chief Executive Officer

**Cystic Fibrosis Australia**