

The Hon Greg Hunt MP
Minister for Health
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

26 April 2021

Dear Minister Hunt

Cystic Fibrosis doesn't make the news a lot because our community is small, and our suffering is sometimes invisible. We know that there are other matters pressing for your attention in the sector of Australian Healthcare, especially this year.

But Cystic Fibrosis (CF) deserves your attention today, because we were so close to getting access to the number one CF miracle drug of all time – Trikafta – and now that hope has been snatched away.

The PBAC has failed to recommend Trikafta for Federal funding. Trikafta has a proven trial record and unmatched results for symptom management. We believe that the negotiations fell through on price alone, because the drug itself is a CF miracle.

No one is saying that these are easy decisions, but surely the moral imperative here is undeniable. Trikafta is everything to us. It means survival and quality of life – the ability to leave our beds, to pursue a career and partake and contribute. Trikafta means the lives of young children and sick, long suffering adults. Saved or abandoned.

As Minister for Health your voice is the one we need on our side. Please step up and support our demands for Compassionate Access to Trikafta from Vertex while the negotiations continue. Trikafta will be going up for consideration again and again until it is passed, don't let the ravages of this disease continue needlessly while bureaucracy and greed flourish behind closed doors.

Compassionate Access solves the problem that Vertex created for us when they set the bar for price too high. It gives us back the one thing we need, the one thing we are asking for, time. If time is what you feel you need – time to negotiate, time to find the best deal for Australia – then Compassionate Access solves that problem too.

We don't want to be in the limelight, we don't want to be on the news. But we don't want to be in hospital either, or worse, and our only hope is Trikafta. Please hear us in this desperate hour.

Yours in Hope

Person with CF
Parent of a child with CF
Partner/Carer/ Friend/Sibling of a person with CF