

Date

Dear MP or Senators

I am writing to you as a member of the Australian Cystic Fibrosis Community.

Cystic Fibrosis (CF) is an awful disease to live with, its symptoms are often very difficult to manage. I have learnt not to expect miracles, but I certainly do still expect fairness.

Now it is clear that, at least in this round of PBAC applications, we will receive neither. The miracle is right there just out of reach because Vertex and the Government were unable to come to an agreement on price.

My family will suffer, other families will suffer, some may even lose the ones they love.

Individuals cannot afford Trikafta on their own, we need help. But it is a cutting edge medicine with proven effectiveness. Trikafta improves lung function, decreases exacerbations and improves weight gain for an overwhelming majority of CF patients.

There is no substitute, there is nothing that can offer the same hope, the same lease on life.

Please use your power to help make the powers that be reconsider Trikafta. There is always something that can be done, always a proposition to be made or an angle explored. Please step up the pressure and hopefully your efforts will bring both parties to the negotiation table.

In the meantime, CF Australians need Compassion Access to Trikafta so that lives and life years can be saved while the negotiations are dragging.

I am one person, but there are many more like me and we are all standing up to be counted. Please stand with us and don't let your Government give up on us by giving up on Trikafta.

Yours in Hope

Person with CF

Parent of a child with CF

Partner/Carer/ Friend/Sibling of a person with CF