

9 April 2021



ALLEY-OOP AND WE SCORE

Everything I know about sport can be summed up in a few sentences. Most of it was absorbed over the years as tidbits gleaned by osmosis from my sons and husband. But the skill of great sporting achievements is not lost on me and there is no denying the athletic perfection of an alley-oop.

In basketball, an alley-oop is where one player on the attacking team pops the ball up for a teammate within range of the hoop. The teammate then flies in for a dunk and the result is a spectacle of skill and cooperation that never fails to draw a reaction from the crowd. I am given to understand that it is an extremely difficult feat of precision and athletics and that my chances at the manoeuvre would not be good as a first timer.

These unfortunate limitations on my basketball career do not trouble me, however, because I believe that the cystic fibrosis (CF) community is in the process of performing our very own alley-oop on the public stage. Last month we held our breath as the Pharmaceutical Benefits Advisory Committee (PBAC) entered into closed-door discussions on the viability of Trikafta for public listing. If the PBAC recommends Trikafta and the Government accepts that recommendation, then CF lives all across the country will be lengthened and enriched for decades to come.

Trikafta is not an alternative or a possible strategy for CF treatment, it is a genuine all-in-one CF miracle drug. We have spoken at length about the huge impact of this intervention on lung capacity, lung degradation, weight gain, mental health, exacerbations and hospitalisation rates for CF Trial groups.

Cystic Fibrosis Australia (CFA) is not prepared to sit back and accept a world where Australians with CF are denied the right to lifesaving medicine because a room full of executives couldn't agree on the price.

But, like any well-executed alley-oop, this is a manoeuvre that unfolds in stages. Not only did we need to apply pressure to the PBAC itself, which we have already done through a sustained campaign of write-ins from our vibrant community, but we also need to make sure that the politicians know that, once the PBAC recommendation comes through, immediate access is the only option.

Let's get this done. Write to Minister Hunt and ask him to negotiate for immediate Compassionate Access for all those eligible ([HERE](#)). Write to Vertex and ask them to have a heart and offer immediate Compassionate Access as part of their price and contract negotiations ([HERE](#)).

To stretch my sports analogy to its absolute breaking point, the PBAC have popped up the ball and this chance show the Ministers that Trikafta is a must-have for the Australian health sector is our opportunity to slam dunk it. Keep an eye out for the PBAC announcement on 23 April 2021.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke". The signature is written in a cursive, flowing style.

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