

4 November 2020

MILESTONES and JOURNEYS

Most journeys are measured by how close you are to home. Most journeys have a clearly defined end, and that means that milestones are something you can take comfort in. And for the CF community salvation is in sight.

Sometimes it seems the fight against cystic fibrosis (CF) is never ending. A battle waged deep in unknown territory - new drugs, new opportunities and new milestones arrive and we must all sound the trumpets.

This year we came together as a community in an unprecedented way to deal with COVID-19, which uprooted so many plans but inspired huge coordinated action online and has upskilled our community in a way that will help us to be more effective going forward.

In 2021 the battle will be for Trikafta. Just as we did with Orkambi, Symdeko and Kalydeco we have an opportunity here to save CF lives. We hope that the Pharmaceutical Benefits Advisory Committee (PBAC) will sit in March 2021 to decide whether to recommend a listing of Trikafta. In 90% of the CF population this drug is capable of preventing or slowing down irreversible lung damage.

CFA wants the PBAC to be aware of the amazing patient response to this drug therapy. Most of all we want them to know that we will not be taking 'no' for an answer. In that sense it is never too late to begin contacting your local member of parliament and senator or sharing the fight for Trikafta over social media.

Cystic Fibrosis Australia (CFA) also wants Compassionate Access for our community immediately following a positive PBAC ruling as it is cruel to make people wait for lifesaving treatment while commercial agreements are debated and deliberated upon.

2021 will be another year, another big campaign and hopefully another milestone. Either way, the folks here at Cystic Fibrosis Australia have heard the drums and trumpets, we have got our marching orders and we will be going all the way.

If you would like to provide a case study about your experiences with Trikafta or what Trikafta will do for you, complete the Case Study Form [HERE](#) and email it to nickim@cfa.org.au. Trikafta resources are available [HERE](#) and these will help you take the fight to the next level.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke".

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