**From:** Rachel Rogers
**To:** Committee, Health (REPS)
**Subject:** Consumer Submission: Parliamentary Inquiry into new drugs and novel technologies
**Date:** Thursday, 3 September 2020 6:12:53 PM

To whom it may concern,

Current issue
a. Speed to market in Australia when drugs are available overseas

I am the parent of an 8-year old child with Cystic Fibrosis. In Australia, there is no way she can access a modulator therapy to address the underlying cause due to her particular genotype.

In the US, children with her genotype have been able to access Kalydeco since 2012, the year she was born. They have reported improved health outcomes. My daughter has nothing and there is nothing on the horizon, at least for the next few years or perhaps at all. I do not know whether she will ever be able to access Kalydeco, I do not know if she will be eligible for Trikafta whenever that is approved. We have nothing to look forward to.

While other children's health is improving because they live in other countries that have access to key modulators, my child's health is deteriorating. It is affecting school attendance, participation in extra-curricular programs, attending playdates, all things that someone her age should be actively involved in. We're at the hospital more often and contacting the clinic teams more frequently. We have had a hospital admission. She is becoming more affected by Cystic Fibrosis and it is affecting the overall health and wellbeing of our family. I don't know what the future holds for my child. She should be able to live her life to the fullest but without therapies such as Kalydeco or Trikafta, her health can only decline. This is unbelievably unfair.

As modulators are made available in other key markets such as the US and Europe, there must be a faster way to make them available for Australians. My daughter, and other children waiting for life changing modulator therapies, deserve this.

Rachel Rogers