

Dear Ministers (DHSC & BEIS),

We are writing to ask that you meet with us to explore what further efforts the Government can make to expedite access to ground-breaking drugs for people with cystic fibrosis in England.

You will be aware that in 2016, NICE was not able to recommend the use of cystic fibrosis treatment, Orkambi, on the NHS due to uncertainty around its long-term value, impact and cost-effectiveness.

You will also be aware that the drug's manufacturer, Vertex Pharmaceuticals, submitted a fresh proposal to NICE and NHS England last month.

It has been over two years since Orkambi was granted its license by the EMA and 18 months since NICE's recommendation called Orkambi an important and effective medicine for the management of cystic fibrosis.

During this period, the treatment has been available to patient communities in the USA and several European nations and its license has been expanded to include treatment of younger children with this life-limiting, progressive genetic disorder.

The Government's response to Sir Hugh Taylor's important Accelerated Access Review opens by stating:

"The Government's ambition is that NHS patients should be among the first in the world to get life-changing treatments. Achieving this goal is only possible by working in close partnership with our world-leading life sciences sector."

In the context of the current situation relating to Orkambi, and with a new cystic fibrosis medicine developed by Vertex Pharmaceuticals, Symdeko, due to have its marketing authorisation confirmed by the European Medicines Agency (EMA) in the coming weeks, will you agree to meet with us, the company and the Cystic Fibrosis Trust to discuss this matter that is of the utmost urgency to the thousands of people and families that await progress?

Regards,

Ian Austin MP for Dudley North