



Department
of Health

From the Lord Prior of Brampton
Parliamentary Under Secretary of State for Health (Lords)

Richmond House
79 Whitehall
London
SW1A 2NS

PO-1045331

020 7210 4850

The Rt Hon Fiona Mactaggart MP
By email to: mactaggartf@parliament.uk

15 AUG 2016

Dear Ms Mactaggart,

Thank you for your email of 4 August to Nicola Blackwood on behalf of a number of your constituents about the availability of the drug Orkambi (lumacaftor in combination with ivacaftor) for the treatment of cystic fibrosis.

I appreciate your constituents' concerns.

I am afraid we have no record of receiving your email of 29 March. Please accept my apologies if that is due to a fault on the part of the Department.

I know that cystic fibrosis can have a devastating effect on the lives of those who suffer from it, and those close to them, and I appreciate how important the availability of effective treatments is to all those affected by this condition.

The National Institute for Health and Care Excellence (NICE) is responsible for making decisions on the clinical and cost effectiveness of treatments. These are very difficult decisions and are made on the basis of very careful consideration of the evidence and public consultation.

As your constituents may be aware, on 27 July, after considering the feedback from its consultation, NICE published its final guidance on Orkambi, which does not recommend its use.


I understand how disappointing this guidance will be to cystic fibrosis sufferers and their families.


The Department of Health is continuing to engage with the drug's manufacturer, Vertex Pharmaceuticals. In cases where a company comes forward with a viable proposal that ministers are able to agree, even after NICE's final guidance has been published, there are mechanisms in place that allow NICE to undertake a 'rapid

review' of its technology appraisal guidance and that can then take the patient access scheme proposal into account.

We have also encouraged the company to engage with NICE and NHS England on this issue.

I hope this reply is helpful.

Yours sincerely


 **.DAVID PRIOR**
Approved by the Minister and signed in his absence