



Department
of Health &
Social Care

*From the Lord O'Shaughnessy
Parliamentary Under Secretary of State for Health (Lords)*

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Your Ref: ZA25939

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24 MAY 2013

Ian Austin MP
House of Commons
Westminster
London SW1A 0AA

Dear Ian,

Thank you for your letters of 19 April to Jeremy Hunt and Greg Clark about the availability of the drug Orkambi (lumacaftor in combination with ivacaftor) for the treatment of cystic fibrosis. As the matters you raise relate to healthcare, your letter to Greg has been passed to the Department of Health and Social Care for reply.

I appreciate the concerns you share with your Parliamentary colleagues.

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.

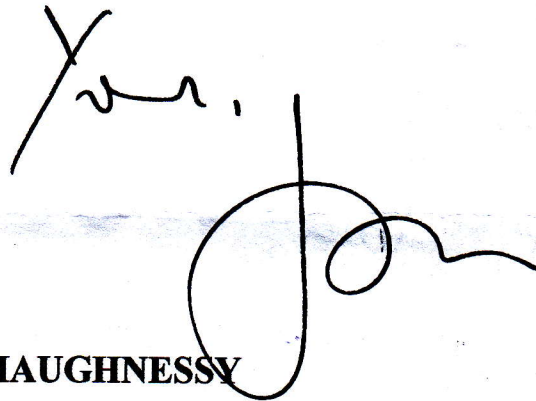
On 27 July 2016, after considering the feedback from its consultation, NICE published its final guidance on Orkambi, which does not recommend its use. I understand how disappointing this guidance will be to cystic fibrosis sufferers and their families.

As you know, on 19 March the availability of Orkambi was debated in the House of Commons and Steve Brine, the Parliamentary Under Secretary of State for Public Health and Primary Care, assured the House that both he and I would continue to take a strong interest in this particular issue.

Following the debate, Steve and I wrote to Vertex in the strongest possible terms urging it to work with NHS England to bring these negotiations to an urgent resolution, and commit to pricing that is responsible and proportionate. Please find a copy of the letter enclosed.

The Government welcomes the ongoing discussions between NHS England and Vertex to agree a deal that would make Orkambi available to NHS patients in a sustainable way that represents value to the taxpayer.

I hope this reply is helpful.

A handwritten signature in black ink, appearing to read 'James O'Shaughnessy', written in a cursive style.

JAMES O'SHAUGHNESSY