



Department
of Health

*From the Rt Hon Jeremy Hunt MP
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The Rt Hon George Howarth MP
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Dear George

Thank you for your letter of 24 March 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 understand how important it is to be able to access the latest effective treatments.

The National Institute for Health and Care Excellence (NICE) is currently consulting on its draft technology appraisal guidance on the use of Orkambi for the treatment of cystic fibrosis in people who are homozygous for the F508del mutation. Although NICE's draft guidance does not recommend the treatment, stakeholders now have an opportunity to comment on this draft guidance and it is important to bear in mind that NICE has not yet published its final guidance. NICE expects to publish this in July. Should the final recommendation also be negative then it would be for NHS England to decide whether or not it will fund the drug.

NICE is the independent body that provides guidance on the prevention and treatment of ill health and the promotion of good health and social care. NICE's guidance is based on a thorough assessment of the available evidence and is developed through wide consultation with stakeholders. NHS commissioners are required to fund drugs and treatments recommended by NICE technology appraisals.

The 2014 Pharmaceutical Price Regulation Scheme includes provision for companies to improve the value of products that are being appraised by NICE through patient access schemes, which are the appropriate mechanism for any arrangement to support managed access. These schemes provide an effective and versatile mechanism for supporting patient access to drugs on a basis that represents value, and Department of

Health officials remain ready to discuss any proposals from the company that could enable NHS patients to access the drug at a cost-effective price.

I hope this reply is helpful.

A handwritten signature in blue ink, appearing to read 'Jeremy Hunt', is positioned above the printed name.

JEREMY HUNT