Director-General Health & Social Care and Chief Executive NHSScotland Paul Grav

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Mr David Ramsden Chief Executive Cystic Fibrosis Trust 2nd Floor One Aldgate London EC3N 1RE

4 July 2017

Dear Mr Ramsden

Thank you for your letter of 26 June, about access to Orkambi for the treatment of cystic fibrosis.

I can appreciate how devastating a cystic fibrosis diagnosis is and how distressing it can be for patients and their families.

The Scottish Medicines Consortium (SMC) did not accept Orkambi for routine use in Scotland because the submitting company did not justify the treatment's cost in relation to its health benefits, or provide robust clinical and economic analyses. Vertex did not take any steps to work with the NHS to reduce the price of the product to a level where costs would be justified in relation to potential health benefit.

The Cabinet Secretary for Health and Sport, Shona Robison MSP, wrote to Vertex earlier this year to encourage them to take forward discussions with National Procurement colleagues in NHS National Services Scotland. Those talks are now underway.

Meantime, clinicians can request access to medicines on a case by case basis where they feel there would be significant clinical benefit to the patient. Decisions on whether to prescribe any medicine are for the clinical judgement of the clinicians involved based on individual patient need and informed by advice and guidance about the drug.

We welcome continued engagement with the Cystic Fibrosis Trust and thank you for taking the time to write to me.

Yours sincerely

Paul Gray





