Rt Hon Matt Hancock MP

Secretary of State for Health and Social Care

Department of Health and Social Care

Ministerial Correspondence and Public Enquiries Unit

39 Victoria St

Westminster

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27 August 2019

Dear Mr Hancock

The Scottish Medicine Consortium (SMC) has concluded appraisals of cystic fibrosis (CF) medicines, Orkambi and Symkevi, and was unable to recommend either drug, citing the submitting company’s justification of their proposed cost as not sufficient.

While this news is gravely disappointing to us all, we are encouraged that the Scottish Government and the medicines’ manufacturer, Vertex Pharmaceuticals, remain engaged in talks to make possible the widest availability of these medicines, wherever clinically appropriate, as a matter of urgency.

The Cystic Fibrosis Trust is pleased to have supported the progress of these talks by contributing expertise in the collection and analysis of real-world evidence through medicines monitoring. However, for many, this sense of urgency and positivity is already too late. This is a crisis and access must be agreed now.

Today, the cystic fibrosis community is gathering at Vertex Pharmaceuticals’ international headquarters in London to call on them to do all they can to make all of their cystic fibrosis medicines routinely available on the National Health Service.

However, it is apparent that any agreement must involve the participation of all stakeholders and we would welcome the opportunity to continue work with your colleagues in the Department, NHS England and NICE to offer the support that we hope will facilitate urgent progress in Scotland.

Yours sincerely,

David Ramsden

Chief Executive

Cystic Fibrosis Trust