Vaughan Gething AM

Minister for Health and Social Services

Welsh Government

5th Floor

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Dear Mr Gething

Thank you again for the time you took to meet with the Cystic Fibrosis Trust last month, where we spoke about the importance of the appraisal by the Scottish Medicines Consortium (SMC) of cystic fibrosis (CF) drugs Orkambi and Symkevi.

As you know, the SMC process has concluded 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.

Your statement to the Assembly two weeks ago made clear that you hope that the manufacturer will proceed urgently with submission to the All Wales Medicines Strategy Group (AWMSG), after careful consideration of their responsibility to price their medicines affordably.

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 Welsh Government and NHS Wales to offer the support that we hope will facilitate urgent progress in Scotland.

Yours sincerely,

David Ramsden

Chief Executive

Cystic Fibrosis Trust