Mr Richard Pengelly

Permanent Secretary and Chief Executive

Department of Health and HSC NI

Castle Buildings

Upper Newtownards Road

Belfast

BT4 3SQ

27 August 2019

Dear Mr Pengelly

The Scottish Medicines 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. In our correspondence in April, you wrote that you would reconsider my invitation to meet after the conclusion of the SMC process. Can I ask that we aim to arrange such a meeting at the earliest opportunity?

Yours sincerely,

David Ramsden

Chief Executive

Cystic Fibrosis Trust