Jeane Freeman MSP

Cabinet Secretary for Health and Sport

The Scottish Government

St. Andrew's House

Regent Road

Edinburgh

EH1 3DG

27 August 2019

Dear Ms Freeman

Today the cystic fibrosis (CF) community is gathering to call on Vertex Pharmaceuticals to act immediately and do all they can to make all of their cystic fibrosis medicines routinely available to the UK’s National Health Services.

The Cystic Fibrosis Trust shares the great disappointment you expressed that the Scottish Medicines Consortium (SMC) were unable to recommend the routine use of cystic fibrosis drugs Orkambi and Symkevi on the NHS.

However, we are grateful for the leadership and firm commitment to finding a swift resolution that you and Government colleagues have demonstrated, and particularly the focus and energy in the period since becoming aware of this outcome. I and my colleagues remain committed to supporting these efforts and thank you for creating the opportunity to contribute to finding a rapid, positive outcome, which we hope can be secured with no further delay.

For everyone who cannot access these vital treatments, this situation is a crisis and a resolution is long overdue. The Cystic Fibrosis Trust will continue to hold all parties to account in the interests of our community and look forward to continuing our work together.

Yours sincerely,

David Ramsden

Chief Executive

Cystic Fibrosis Trust