

Cystic Fibrosis our focus

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Cabinet Secretary for Health and Sport,
The Scottish Government,
St Andrews House,
Regent Road,
Edinburgh,
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Wednesday 4th July 2018

Dear Ms Freeman MSP,

May I congratulate you on your new position of Cabinet Secretary for Health and Sport.

I would like to provide you with some background and an update on our campaign for access to medicines for people with cystic fibrosis.

Cystic Fibrosis is a genetic condition affecting the lungs and digestive system, it affects 10,400 people across the UK - around 900 people in Scotland. Half of those with Cystic Fibrosis will die before they are 31 years old.

Orkambi is a new precision medicine that targets the root cause of cystic fibrosis and is currently unavailable in the UK. Current treatments for the condition can only provide symptomatic relief, but Orkambi could slow decline by up to 42%.

You may have seen a recent debate in the chamber at Holyrood on the subject of access to Orkambi which highlighted that despite the drug being licensed in 2016, the treatment is still no closer to being available to around 40% of eligible Cystic Fibrosis patients living in Scotland.

The Cystic Fibrosis Trust would welcome the opportunity to meet with you to discuss this issue further as a matter of urgency.

In the meantime please find a full briefing enclosed.

Yours sincerely,



Lynsey Beswick
Public Affairs Manager
Cystic Fibrosis Trust