

Cystic

Fibrosis a fight we must win

Janet Finch-Saunders AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

25 September 2019

Dear Ms Finch-Saunders

The Scottish Government has announced a deal that will see access to Orkambi and Symkevi for everyone with cystic fibrosis (CF) in Scotland who stands to benefit, after reaching an agreement with manufacturer Vertex Pharmaceuticals with support from the UK CF Registry.

The five-year agreement means hundreds who have been waiting, in many cases up to four years, for access to the precision medicines will now have access to these important drugs.

The deal requires Vertex to resubmit the two drugs to the Scottish Medicines Consortium during the agreement period, using new data collected through NHS prescribing. The UK CF Registry, which is maintained by the Trust, will play a vital role in supporting this evidence collection. However, while people with cystic fibrosis in Scotland can celebrate, it a desperate situation that the wait continues for the CF community in Wales.

The Cystic Fibrosis Trust supports the Welsh Government's call for Vertex to submit data for their medicines to the All Wales Medicines Strategy Group. This is the only reasonable next step to take the process forward without further delay and ensure the voices of people with CF and their clinical teams are central to the decision-making process.

We remain hopeful that the Welsh Government and health authorities can help to achieve rapid access by exploring options that allow people with CF to be treated while such a process is undertaken. People with CF and their families must not continue to bear the full burden of the damage caused by this crisis.

Yours sincerely,



David Ramsden
Chief Executive