

Cystic

Fibrosis a fight we must win

David J Rowlands
Chair
Petitions Committee
National Assembly for Wales
Cardiff Bay
CARDIFF
CF99 1NA

20 November 2018

Dear Mr Rowlands,

The Cystic Fibrosis Trust is encouraged that the Cabinet Secretary welcomes discussion around using the UK Cystic Fibrosis Registry to support an interim method of access for these vital new medicines for people with cystic fibrosis in Wales. We hope to see some movement in these discussions to ensure that where possible urgent access can be provided.

Monday 19 November marked the third anniversary of the drug Orkambi being licensed by the European Medicines Agency, during which time people who have cystic fibrosis in Wales have suffered an agonising wait.

With an inquiry launched by Dr Sarah Wollaston MP, Chair of the Health and Social Care Select Committee in Westminster, around the availability of Orkambi and other cystic fibrosis drugs, it is vital that Wales are not left out of these investigations into the progress of negotiations.

We are keen to know what steps the Cabinet Secretary will take to ensure Welsh voices are heard while discussions between Vertex Pharmaceuticals and NICE continue to take place.

Will the Committee suggest this issue for debate in the Assembly to enable these concerns to be suitably explored?



David Ramsden
Chief Executive