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

26 June 2019

Dear Ms Finch-Saunders,

**Petition P-05-797 Ensure access to cystic fibrosis medicine, Orkambi, as a matter of urgency**

Thank you for your letter of 21 June 2019 requesting an update on access to Vertex medicines for the treatment of cystic fibrosis.

As I informed the Committee earlier in the year, we have been in discussion with the All Wales Therapeutics and Toxicology Centre (AWTTC) which advises the All Wales Medicines Strategy Group (AWMSG), as well as senior officials, regarding health technology appraisals to the AWMSG. We have been seeking clarifications regarding how the appraisal processes would be applied to our medicines, taking into account the specific characteristics and value proposition of our precision medicines.

Following these discussions, we have asked for consideration by AWMSG to allow Vertex to submit evidence for appraisal on Orkambi (lumacaftor/ivacaftor) for all eligible patients, as well as Symkevi (tezacaftor/ivacaftor) to be used in combination with ivacaftor, and await guidance from AWTTC to this effect. We would be willing to propose interim access arrangements for patients in Wales similar to those agreed in Scotland.

We are committed to working with the authorities in Wales to make our cystic fibrosis medicines available to NHS Wales patients. While we continue to seek full access to our medicines in Wales, Vertex has provided lumacaftor/ivacaftor at no cost to 27 patients in Wales and tezacaftor/ivacaftor at no cost to 6 patients in Wales because of critical medical need. Across the UK, we have provided our cystic fibrosis medicines at no cost to over 1,000 patients because of serious medical need.

I will write to you again as soon as the evidence has been formally submitted.

Yours sincerely,



Michael Oliver  
UK Country Manager  
Vertex Pharmaceuticals