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

13 November 2019

Dear Ms Finch-Saunders,

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

Further to my last communication to you of 27th September regarding Petition P-05-797, I'm pleased to provide you with the latest update.

On 24th October, Vertex and NHS England reached an agreement on access to our currently licensed cystic fibrosis (CF) medicines and any future indications of these medicines. This included provisions for an agreement on the same terms to be offered to the NHS in Wales and Northern Ireland, aligned to the specific patient numbers of Wales and Northern Ireland. We have therefore been in intensive discussions with Welsh Government officials on extending access.

We are pleased that the Minister for Health and Social Services has today announced that NHS Wales has accepted an offer to make Orkambi (lumacaftor/ivacaftor) and Symkevi (tezacaftor/ivacaftor) available to eligible patients in Wales, as well as to expand access to Kalydeco (ivacaftor) to all eligible patients (see Cabinet Statement: Written Statement: Access agreement for the cystic fibrosis medicines Orkambi® and Symkevi®, 13 November 2019).

Previously, your Committee asked for confirmation as to when appraisal applications would be made to the All Wales Medicines Strategy Group (AWMSG) in respect of lumacaftor/ivacaftor and tezacaftor/ivacaftor. I can confirm that these were submitted to the AWMSG in October, however, it is expected that these appraisals will be suspended in view of the above developments and provision for appraisals of these medicines by the National Institute for Health and Care Excellence (NICE) in due course.

We are pleased that the agreement will give access to our licensed medicines to all eligible CF patients (approximately 270 patients) in Wales.

Yours sincerely,



Michael Oliver  
UK Country Manager  
Vertex Pharmaceuticals