

P-05-797 Ensure access to the cystic fibrosis medicine, Orkambi, as a matter of urgency – Vertex to Chair, 27.09.19

Dear Ms Finch-Saunders,

Following the publication of the correspondence relating to Petition P-05-797, I thought it would be helpful to provide you with an update.

We are in the process of finalising our submissions to AWMSG for Orkambi (lumacaftor/ivacaftor) (ages 2-11) and Symkevi (tezacaftor/ivacaftor). The Orkambi submission will be submitted by 7th October and the Symkevi submission will follow shortly thereafter. The reason for the delay is that we have been updating the dossiers to ensure they provide the same offer as has been agreed in Scotland. Together with the dossiers we will be submitting a Welsh Patient Access Scheme which has been discussed with the Patient Access Schemes Wales Group, in line with the access scheme in Scotland. The agreement in Scotland permits all eligible patients to access these two medicines immediately.

The AWTTTC have previously advised Vertex that we cannot submit a HTA application for Orkambi (ages 12+) as there is current NICE guidance in place not recommending its use. We are continuing discussions with NHS England on a solution to this and would welcome the opportunity to have similar discussions in Wales. It should be noted that Symkevi is licensed for use in the same 12 years and older patient population as Orkambi, but also another population in the 12 years and older patients, allowing greater equity of access for more people with cystic fibrosis (CF) in Wales.

We are committed to working with the authorities in Wales to make our CF medicines available to NHS Wales patients. In parallel, we would be keen to open a discussion with the Minister and/or his senior officials about the agreement we reached in Scotland. We have contacted his Chief Pharmaceutical Officer, offering the same arrangement on an interim basis to allow immediate access to both Orkambi and Symkevi for CF patients in Wales while both medicines are appraised at the earliest opportunity by the AWMSG.

Yours sincerely,

Michael

Michael Oliver
Country Manager, UK

Vertex Pharmaceuticals (Europe) Limited.