

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

1 May 2018

Dear Mr Rowlands,

Re: Petition P-05-797 - Ensure access to the cystic fibrosis medicine, Orkambi[®], as a matter of urgency

Thank you for your letter of 23 March 2018 regarding the aforementioned petition, requesting information about the current status of discussions concerning access to Orkambi[®] (lumacaftor/ivacaftor) in Wales.

Since the beginning of this year, Vertex has had several productive discussions with NHS Wales All Wales Medicines Procurement regarding proposals for making our medicines for cystic fibrosis available for eligible NHS Wales patients. This followed meetings last year with key executive agencies of the Government in Wales, including the Welsh Health Specialised Services Committee (WHSSC), and the All Wales Medicines Strategy Group (AWMSG).

We entered the discussions in good faith and, whilst the details of these discussions are commercially confidential, we can report that we have made good progress in advancing our shared ambition to provide access to our medicines as quickly as possible to people with cystic fibrosis in Wales. This included providing a fully costed proposal for all Vertex medicines to NHS Wales at a meeting on 21 February 2018 and following this up with written confirmation of the details on 9 March 2018.

Disappointingly, recent staffing changes in NHS Wales Procurement have meant that a meeting confirmed to take place in early April to discuss those proposals was cancelled by NHS Wales. This staffing issue has, we understand, effectively halted all ongoing procurement discussions, which includes our negotiations. It is unclear as to when and with whom the discussions can re-start.

For people with cystic fibrosis every day counts. Vertex is, therefore, eager to resume discussions as a matter of urgency. I have written to the Cabinet Secretary for Health and Social Services to request his intervention in re-starting the discussions and we hope that the Committee can also support this in your scrutiny of the Government.

We remain committed to continuing to work with all stakeholders to find a solution allowing access to our medicines for people with cystic fibrosis in Wales. We welcome the interest that the Petitions Committee is taking in ensuring that this issue is urgently addressed and remain at your disposal to brief you further if required.

Yours sincerely,



Michael Oliver
UK Country Manager
Vertex Pharmaceuticals