



National Assembly for Wales Petitions Committee: Petition P-05-797: Ensure access to cystic fibrosis medicine, Orkambi, as a matter of urgency

20 September 2018

Further to our letter to the Chair of the Petitions Committee dated 12th July indicating that we submitted a portfolio proposal for our cystic fibrosis medicines, we have received responses from the Cabinet Secretary for Health and Social Services, NHS Wales Procurement Services, and the Chair of the All Wales Medicines Strategy Group (AWMSG).

It is clear from these responses that the continuation of discussions on the portfolio, which we had been having with All Wales Medicines Procurement earlier this year, is a route that is no longer open to us.

Whilst this is disappointing and would not have excluded appraisal of our medicines by AWMSG as part of an agreement, we wish to discuss with AWMSG and/or the All Wales Therapeutics and Toxicology Centre (which advises the AWMSG) how we can proceed with appraisals for Orkambi (lumacaftor/ivacaftor) and Vertex's future cystic fibrosis medicines. We hope to meet at the earliest opportunity to take this forward.

We will keep the Committee updated on progress.