

Cystic Fibrosis a fight we must win

Cystic Fibrosis Trust response to Vertex and Minister Letters regarding the Petition P-05-797 Access to Cystic Fibrosis medicine Orkambi

The Cystic Fibrosis Trust is campaigning to ensure the precision medicine Orkambi, manufactured by Vertex Pharmaceuticals, is made available to patients with cystic fibrosis (CF) living in Wales as soon as possible.

We are therefore encouraged to hear that the Welsh Health Minister Vaughn Gething and NHS Wales acknowledge the importance and urgency of appraising new cystic fibrosis medicines for use on the NHS in Wales.

However, the Trust is concerned that description by the Minister and the manufacturer of the current state of progress, outlined in separate correspondence to the Petitions Committee, is inconsistent.

Although both the Minister and Vertex both acknowledge that there have been meetings to discuss access to Orkambi in Wales, the Trust is disappointed to learn that there are no further meetings planned and must conclude that progress has stalled, which can only result in further delay for people with cystic fibrosis in Wales to access proven, effective and first-in-class medicines.

The Cystic Fibrosis Trust notes that Vertex claims to have provided “a fully costed proposal for all Vertex medicines to NHS Wales at a meeting on 21 February 2018”, which is not recognised in the Minister’s correspondence but would be of significant public interest and importance.

Welsh citizens deserve to be provided with the latest and most accurate information the Welsh Government holds.

The Trust is calling for an intervention from the Petitions Committee to enable an opportunity for the Welsh Assembly to clarify with the Minister the current circumstances in relation to access to Orkambi and gain an understanding of the forward process. We believe there is a strong public interest in providing transparency and accountability across the issue, which is demonstrably of significant importance and urgency to thousands of Welsh citizens.

Every day, week or month that passes has severe implications for those living with CF both in the short and longer term. This includes impact on quality of life, irreversible lung damage and ultimately life expectancy. People with cystic fibrosis simply do not have time to wait for negotiations to conclude, let alone begin or fail to progress.