

Vaughan Gething AC/AM
Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau
Cymdeithasol
Cabinet Secretary for Health and Social Services



Llywodraeth Cymru
Welsh Government

Our ref VG/01814/18

David John Rowlands AM
Chair - Petitions committee.
National Assembly for Wales
Cardiff Bay
CF99 1NA

SeneddPetitions@assembly.wales

25 May 2018

Dear David,

Thank you for your invitation to attend the Petitions Committee regarding Petition P-05-797 about access to the cystic fibrosis medicine, Orkambi® (lumacaftor/ivacaftor).

One of the tenets of prudent healthcare is “making the most effective use of all skills and resources”. As such, I am guided by the independent advice that the All-Wales Medicines Strategy Group (AWMSG) and NICE provide about the clinical efficacy and cost-effectiveness of the medicines they appraise. If either organisation recommends a medicine, that medicine will become available in every health board no later than two months after the recommendation is published.

As you know, NICE has already appraised Orkambi® and advised that they do not consider that its cost is in balance with the clinical benefits that a patient would gain from using it. As I noted in previous correspondence, AWMSG has contacted the manufacturer, Vertex Pharmaceuticals, and strongly encouraged them to make a submission for appraisal. The most recent attempt to engage with Vertex was on 27 April when AWMSG invited them to submit any new evidence they may have about how well Orkambi® works. There has still been no response from the company.

If Vertex has new evidence about their medicine’s efficacy, it is their responsibility to submit this evidence to AWMSG or NICE for appraisal. I have recently written to Vertex myself and urged them to do so.

Bae Caerdydd • Cardiff Bay
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Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400

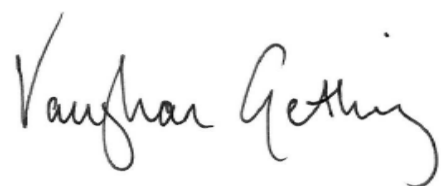
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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

I have made my position clear and I do not think that I could add anything further by attending the Committee.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V' and a long, sweeping tail on the 'g'.

Vaughan Gething AC/AM

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