



Department  
of Health

From Steve Brine MP  
Parliamentary Under Secretary of State for Public Health and Primary Care  
The Lord O'Shaughnessy  
Parliamentary Under Secretary of State for Health (Lords)

39 Victoria Street  
London  
SW1H 0EU

Simon Bedson  
Senior Vice President & General Manager Commercial International  
Vertex Pharmaceuticals (Europe) Ltd  
Level 8, 5 Merchant Square  
London W2 1AS

19 APR 2018

*Dear Mr Bedson,*

We are writing to you about the availability of Orkambi for people with cystic fibrosis, following the debate introduced by Paul Scully MP, Member for Sutton and Cheam.

Not only has the petition that led to the debate now received over 116,000 signatures, but we were struck by the number of MPs who spoke so passionately on behalf of their constituents. Rarely has Westminster Hall been so full with MPs from all parties uniting on such an important issue.

As the Minister who responded on the day and as the Minister responsible for medicines pricing and regulation, we are writing to you to ask you to bring these negotiations to an urgent resolution.

We recognise and appreciate the significant contribution Vertex is making in its aim to progress towards a cure for cystic fibrosis. We also know that you understand the difficult task NHS England faces in ensuring access to Orkambi, while also securing value for the NHS and NHS patients and the role that NICE plays in this. NHS England and NICE are independent and operate freely from political intervention. However, the Government will rightly stand by any proposal that will provide the best value and outcomes for patients and the NHS.

We appreciate that these are difficult issues, but the counter-offer from NHS England to your last proposal was an important demonstration of its significant commitment to taking a collaborative and flexible approach in any discussions with you if you can commit to pricing that is responsible and proportionate to the benefits patients receive.



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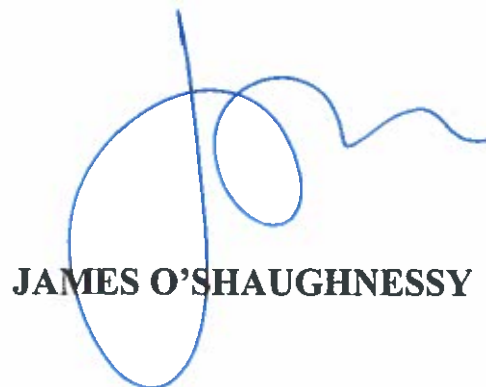
To reiterate the heartfelt and vitally important points made in the debate, and in the many letters we have received from patients suffering from this disease and their friends and families, time really is of the essence. Therefore we ask you as a matter of the utmost urgency to proceed with negotiations in a way that is constructive and supports our joint aim of securing access to your medicines currently licenced in the UK at a price that is cost-effective and fair. We urge that you provide all available data supporting the cost-effectiveness of your proposal promptly to ensure progress towards an agreement.

A final deal is not for Ministers to approve but we truly believe this can be a mutually satisfactory arrangement for both parties.

We are copying this letter to Paul Scully MP, Ian Austin MP and other Members who have expressed an interest in this important matter.



**STEVE BRINE**



**JAMES O'SHAUGHNESSY**