



HOUSE OF COMMONS

LONDON SW1A 0AA

Dr Jeffrey Leiden
Chairman, President and Chief Executive Officer, Vertex Pharmaceuticals
c/o Simon Lem
Vice President, Regional General Manager North Europe
Vertex Pharmaceuticals (Europe) Ltd
2 Kingdom Street
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Our Ref: ZA30776

25 July 2019

Dear Dr Leiden

Four months have now passed since you gave evidence to the House of Commons Health and Social Care Committee and subsequently met with the Secretary of State, the Rt Hon Matt Hancock MP, to discuss the continued lack of access to your cystic fibrosis (CF) medicines for all those who could benefit in England and elsewhere in the UK.

Since that time, we know that NHS England has offered an improved financial proposal, as well as the promise of facilitating – through a managed access arrangement – rapid access to these drugs that thousands of CF sufferers need.

This is an approach supported by CF professionals, represented by the UK Cystic Fibrosis Medical Association, and the patient representative organisation, the Cystic Fibrosis Trust. It is, therefore, deeply disappointing to us all that your company have still not found the compromise to secure this proposal.

We understand that talks between your company and NHS England are continuing, but as weeks have become months, we fear that the wait will not end and it must. We have become so concerned about the lack of progress that we are asking the Government to consider what else it could do to make sure people get these drugs without delay, including procuring them from alternative suppliers by whatever means necessary.

We are alarmed that people with CF and their families are having to seek alternative generic suppliers at great personal cost because they have so little faith that your company will achieve a deal to provide these medicines.

We are aware of your company's engagement with the Scottish Medicines Consortium (SMC), and of the supply of your medicine, Symkevi, through NHS reimbursement to a limited number of people with CF in Scotland. We await the recommendation of the SMC with great interest.

However, we would appreciate a detailed reasoning of your company's decision to engage with the Scottish Health Technology Assessment process but continued refusal, despite the offer of interim access and reimbursement, to participate in the parallel process in England.

We would also like you to explain what more you believe is necessary to end this crisis?



Finally, we ask that you make yourself available for a further meeting with the Secretary of State and we will be asking him to reciprocate.

Yours sincerely

Ian Austin,

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Rt Hon Sir Alan Campbell MP	Heidi Allen MP	Mike Wood MP
Alex Sobel MP	Helen Grant MP	Mohammed Yasin MP
Andrea Jenkyns MP	Helen Hayes MP	Neil Coyle MP
Andrew Griffiths MP	Helen Jones MP	Neil O'Brien MP
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