



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
London
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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 ,

Adrian Bailey MP
Rt Hon Sir Alan Campbell MP
Alex Sobel MP
Andrea Jenkyns MP
Andrew Griffiths MP
Angela Smith MP
Ann Coffey MP
Antoinette Sandbach MP
Bambos Charalambous MP
Rt Hon Ben Bradshaw MP
Ben Lake MP
Bill Grant MP
Bim Afolami MP
Bob Neill MP
Bob Stewart MP
Caroline Lucas MP
Catherine McKinnell MP
Chris Hazzard MP
Chris Matheson MP
Crispin Blunt MP
Darren Jones MP
Sir David Amess MP
David Linden MP
David Warburton MP
Derek Twigg MP
Rt Hon Sir Desmond Swayne MP
Diana Johnson MP
Elisha McCallion MP
Fiona Bruce MP
Francie Molloy MP
Gavin Shuker MP
Sir George Howarth MP
Gerald Jones MP
Gillian Keegan MP
Gordon Henderson MP
Sir Graham Brady MP
Rt Hon Greg Clarke MP
Gregory Campbell MP
Guto Bebb MP

Rt Hon Harriet Harman MP
Heidi Allen MP
Helen Grant MP
Helen Hayes MP
Helen Jones MP
Rt Hon Sir Hugo Swire MP
Ian Paisley MP
Ivan Lewis MP
Jack Dromey MP
James Frith MP
Jeff Smith MP
Jeremy Lefroy MP
Jim Shannon MP
Jo Swinson MP
John Howell MP
Rt Hon John Spellar MP
Jonathan Lord MP
Jonathan Reynolds MP
Julia Lopez MP
Rt Hon Dr Julian Lewis MP
Julian Sturdy MP
Karl Turner MP
Kate Green MP
Rt Hon Keith Vaz MP
Kerry McCarthy
Rt Hon Kevan Jones MP
Layla Moran MP
Lilian Greenwood MP
Lloyd Russell-Moyle MP
Dame Louise Ellman MP
Luke Hall MP
Maria Caulfield MP
Marion Fellows MP
Mark Pritchard MP
Rt Hon Mark Tami MP
Martin Vickers MP
Rt Hon Sir Michael Fallon MP
Michelle Gildernew MP
Mickey Brady MP

Rt Hon Sir Mike Penning MP
Mike Wood MP
Mohammed Yasin MP
Neil Coyle MP
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Nic Dakin MP
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Nick Bowles MP
Nigel Adams MP
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Paul Farrelly MP
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Robert Courts MP
Roger Godsiff MP
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William Wragg MP