



HOUSE OF COMMONS  
LONDON SW1A 0AA

The Rt Hon Matt Hancock MP  
Secretary of State for Health and Social Care  
Department of Health and Social Care  
Ministerial Correspondence and Public Enquiries Unit  
39 Victoria Street  
London  
SW1H 0EU

Our Ref: ZA30776

25 July 2019

Dear Secretary of State

Four months have now passed since you met with representatives of NHS England, NICE, and Vertex Pharmaceuticals CEO, Dr Jeffrey Leiden, to discuss the lack of access to cystic fibrosis (CF) medicines for all those who could benefit in England and elsewhere in the UK.

We are aware that you recently met with Carlie Pleasant, a young woman and mother who has CF, who conveyed to you the personal cost and suffering that thousands of people like her are being forced to endure.

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 the compromise to secure this proposal has still not been found.

We understand that talks between the 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 could be done to ensure that 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 a deal can be struck to provide these medicines.

In August, the Scottish Medicines Consortium (SMC) will make recommendations to NHS Scotland on the routine use of Orkambi and Symkevi, and we await their publication with great interest.

Could you please set out what more can be done to end this crisis?

Finally, we kindly ask that you please make yourself available for a further meeting with Dr Leiden and we

will be asking him to reciprocate.

Many thanks

Yours ever



Ian Austin MP,

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  
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Gillian Keegan MP  
Gordon Henderson MP  
Sir Graham Brady MP  
Rt Hon Greg Clarke MP  
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Rt Hon Harriet Harman MP  
Heidi Allen MP  
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Ivan Lewis MP  
Jack Dromey MP  
James Frith MP  
Jeff Smith MP  
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Julia Lopez MP  
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Kate Green MP  
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Dame Louise Ellman MP  
Maria Caulfield MP  
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Mark Pritchard MP  
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Rt Hon Sir Mike Penning MP  
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Neil Coyle MP  
Neil O'Brien MP  
Nic Dakin MP  
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