



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
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
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Jonathan Reynolds MP
Julia Lopez MP
Rt Hon Dr Julian Lewis MP
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Maria Caulfield MP
Marion Fellows MP
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Martin Vickers MP
Rt Hon Sir Michael Fallon MP
Michelle Gildernew MP
Mickey Brady MP
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Mike Wood MP
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William Wragg MP