

Cystic Fibrosis a fight we must win

Dr Sarah Wollaston
Chair
Health and Social Care Committee
House of Commons
London
SW1A 0AA

4 June 2019

Dear Dr Wollaston,

Thank you for your continued work in raising the issue of access to Orkambi, Symkevi, and future cystic fibrosis medicines.

The Health and Social Care Committee Inquiry has played a significant role in holding the parties responsible for the continuing impasse to account and enabling vital transparency for the cystic fibrosis community, during a period in which they have repeatedly felt like the last to know about issues that have a direct impact on their lives and wellbeing.

In the recent correspondence you received from NHS England and Vertex Pharmaceuticals, we were encouraged to learn that the parties have met five times, with further meetings planned. Time is the most precious commodity as thousands see their health decline and fail irreversibly.

On Thursday 30 May, Vertex Pharmaceuticals announced headline results for their fourth cystic fibrosis medicine. Elaxacaftor, combined with ivacaftor and tezacaftor, could radically transform the lives of nine in ten people living with cystic fibrosis in the UK, delivering unprecedented improvements in acute lung health, quality of life and reductions in pulmonary exacerbations – a key driver of decline.

However, for people with cystic fibrosis and their families in the UK, the joy and optimism those results merited was bitterly soured by the fear and anxiety that they may never receive these life-saving drugs or experience their benefits.

We are clear that current talks cannot continue indefinitely. Compromises must be made, and a solution found. I hope you will be able to attend the Westminster Hall debate on the issue on Monday 10 June at 4.30pm to add the voice of those people with cystic fibrosis who submitted to the Inquiry to the debate. The Inquiry continues to provide a vital role in shedding light on these negotiations, and we are on hand to help in any way we can.

If it would be helpful to meet I would very much welcome the opportunity.

Yours sincerely,



David Ramsden
Chief Executive