



Rt Hon Steve Barclay MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

03/11/2023

Dear Secretary of State,

RE: Access to Modulator Treatments for Cystic Fibrosis Patients

I know you will be aware of the landmark deal in 2020 to secure access to vital cystic fibrosis drugs and I would like to reiterate my thanks to those in your department and in NHS England who helped to make that happen.

I also know that you will be aware of the disappointing news from the National Institute for Health and Care Excellence (NICE), which, while recognising the high effectiveness of the modulator drugs Kaftrio, Orkambi, and Symkevi for people with cystic fibrosis, stated that their current pricing renders them unaffordable for full access via the NHS.

We are conscious that this is an initial decision based on cost considerations and further consultation steps are underway, however, the potential implications of this decision are both profound and deeply concerning for people in our community and their loved ones.

Most people with cystic fibrosis now rely on these life-changing treatments, and we are pleased to have received assurances that their access will not be disrupted. However, the prospect of newly eligible people being unable to access them and a return to a situation where people with CF die far too young, especially when they would know that a treatment exists that could change their lives, is truly an awful prospect.

We cannot overstate the importance of finding a swift and equitable solution to this situation. It is critical that Vertex, NICE, and the NHS join forces immediately to agree a way of ensuring that modulator treatments are accessible to all eligible individuals who can benefit now and in the future.

We strongly urge that a collaborative effort be initiated without delay to bring about a solution that ensures that no one with cystic fibrosis is caused additional anxiety and distress. Time is of the essence, and we are keenly aware of the lives at stake. We implore you to consider the urgency of this matter and the immense difference that your involvement can make in leading that collaborative effort.

We remain available for discussions and collaborative efforts and are eager to work alongside your office to achieve the best possible outcome for people with cystic fibrosis.

At this time of uncertainty, it is important to keep our community updated and we will be sharing this letter with them.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'David Ramsden', with a stylized, cursive script.

David Ramsden
Chief Executive
Cystic Fibrosis Trust