



HOUSE OF COMMONS

LONDON SW1A 0AA

**Response to Access to Orkambi**

Thank you for contacting me about the availability of Orkambi. I know many families affected by cystic fibrosis have placed a great deal of hope in this drug and believe particular care should be taken to assess its effectiveness.

While the preliminary recommendation is that this treatment is not cost effective, I do think that it is worth exploring if there is a way it can be made available to NHS patients. I was very interested to read a proposal from the Cystic Fibrosis Trust for the creation of an interim arrangement between the drug's manufacturer and the NHS and know that my colleagues in the Department of Health are aware of it.

The independent body which recommends whether particular drugs should be used, the National Institute for Health and Care Excellence (NICE), has taken the initial view that the benefits of Orkambi to lung function, a test of how people with cystic fibrosis are improving overall, are modest. However, NICE does accept that Orkambi helps with the management of the condition and is of particular benefit in reducing sudden hospitalisations. This later point will be particularly important as NICE seeks people's views before publishing further guidance.

While I know the preliminary recommendation must come as a real disappointment, I would encourage you to share your views and experiences with NICE as part of its public consultation on Orkambi which closes on 15th April. Details can be found here:

<https://www.nice.org.uk/guidance/indevelopment/GID-TAG530/consultation/html-content>

I think we all accept that the cost to the NHS must be borne in mind when considering new drugs. It is, however, my hope that we will reach a point where cost effective 'gene specific' drugs will become available to help improve the lives of people with cystic fibrosis.

Thank you again for taking the time to contact me.

Kind regards,

**Edward Timpson MP**

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