**CYSTIC FIBROSIS TRUST CALLS FOR IMMEDIATE ACCESS TO LIFE-SAVING DRUGS**

The Cystic Fibrosis Trust is urging NICE, NHS England and the pharmaceutical company Vertex to reach a deal on the cost of life transforming cystic fibrosis drugs and make them available on the NHS without delay.

The House of Commons Health and Social Care Committee Inquiry is hearing evidence from Vertex Pharmaceuticals, NICE and NHS England regarding the ongoing and protracted negotiations for the drugs Orkambi and Symkevi\* to help move discussions forward and break the stalemate between the three parties, today (Thursday 7 March).

Orkambi is the second precision medicine that targets the route cause of the condition and would benefit around half of people with cystic fibrosis (CF) in the UK.

It has been licensed for use for over three years, but a deal is yet to be struck that makes it available for patients in England on the NHS. During that time, a third drug to treat the root cause of the condition, Symkevi, has been approved for use but is not available on the NHS.

David Ramsden, chief executive of the Cystic Fibrosis Trust, said: “All three parties – NICE, NHS England and Vertex - must reach a compromise and end the agonising three year wait for this these life-saving medicines. Each day that passes without a deal means the risk of more damage to the lives and prospects of thousands of children and adults with cystic fibrosis across the UK. This tragic situation must end. We hope the Committee can support efforts to find a deal. We know from countries around the world that it is possible to reach an agreement and we remain committed to supporting all parties to find a compromise that works. We don’t want to see people with cystic fibrosis once again subjected to the anguish of the divisive public spat. No more excuses, we need action now.”

Emma Boniface, 30 from London who has cystic fibrosis, said: “Knowing Orkambi is available and I am denied access to it is devastating. I've struggled to maintain my health and stayed hopeful that one day CF won't be as debilitating as it is. Knowing the outcome of my health is in the hands of strangers and, based upon a monetary value is scary, dehumanising and extremely distressing.”

Macauley Tinston, 22 from Northamptonshire, who has cystic fibrosis, said: “I take drugs everyday just to tick along but taking Orkambi would double my days. It’s disheartening to know that Orkambi is there, but not available to me. It’s as if the battery on my clock is running out and a replacement is just a fingertip away, but I can’t have it. It’s upsetting that there has been such hard work and research into providing ground-breaking treatment, just for it to not be accepted due to a financial agreement.”

Jenny Agutter, Call the Midwife actor whose niece has cystic fibrosis, said: “Today is a landmark in the fight for access to life-changing cystic fibrosis medicines. I hope that The Health and Social Care Committee urge all parties involved to find common ground and end this unacceptable wait.”

-Ends-

**Notes to editors**

For media enquiries contact the Cystic Fibrosis Trust press office on 0203 795 2193 or [**pressoffice@cysticfibrosis.org.uk**](mailto:pressoffice@cysticfibrosis.org.uk)

\*Orkambi is a combination medicine, made up of ivacaftor and lumacaftor. Lumacaftor helps get more proteins to the surface of cells in the body’s organs, and ivacaftor helps the chloride channels in the cells to operate more effectively. The combination of these two things helps to keep a healthy balance of salt and water in the organs. Orkambi is manufactured by Vertex Pharmaceuticals.

\*\*Symkevi is a new, dual combination therapy ​which uses two drugs together in one treatment. Symkevi combines ivacaftor with new drug compound tezacaftor, supporting chloride transfer in the body’s cells. Symkevi is manufactured by Vertex Pharmaceuticals.

**About cystic fibrosis**

Cystic fibrosis is an inherited disease caused by a faulty gene. This gene controls the movement of salt and water in and out of your cells, so the lungs and digestive system become clogged with mucus, making it hard to breathe and digest food.

* Half of all people who died with cystic fibrosis last year were under the age of 31
* There are over 10,400 people with cystic fibrosis living in the UK and the population is growing every year
* Two million people in the UK are carrying the faulty CF gene without realising it. If two carriers have children, there’s a one in four chance their child will have the condition, which slowly destroys the lungs and digestive system
* People with cystic fibrosis often look perfectly healthy. But it’s a lifelong challenge involving a vast daily intake of drugs, time-consuming physiotherapy and isolation from others with the condition. It places a huge burden on those around them and the condition can critically escalate at any moment
* Half of people with cystic fibrosis alive today are expected to live into their forties, thanks to earlier diagnosis and ongoing developments in care and treatments

**About the Cystic Fibrosis Trust**

* The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited for everyone affected by cystic fibrosis
* For confidential advice, support and information on any aspect of cystic fibrosis, including help with financial support contact the Cystic Fibrosis Trust helpline on (+44) 0300 373 1000 or 020 3795 2184
* The work we do is only made possible by the generous donations from our supporters. Visit [www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk/) to find out more about cystic fibrosis, the work of the Trust and how you can help our fight for a life unlimited.
* To support our fight for a life unlimited by cystic fibrosis text BEATCF to 70500 to give £5 to the Cystic Fibrosis Trust. [Terms](https://www.cysticfibrosis.org.uk/privacy-policy/terms-and-conditions)