

A YEAR SINCE PM'S STATEMENT AND STILL NO RESOLUTION ON ACCESS TO LIFE SAVING CYSTIC FIBROSIS DRUGS

The Prime Minister, Theresa May, a year ago today, said she wanted a “speedy resolution”* in the ongoing negotiations between NHS England, NICE and Vertex so that cystic fibrosis patients could have access to Orkambi** and Symkevi***.

Yet, since then, no resolution has been agreed. And, last month, as Australia becomes the latest country to offer the life-saving drugs, the failure to strike a deal means that England continues to lag behind the rest of the world.

To mark the anniversary of this stalemate, the Cystic Fibrosis Trust and Zoey Jones, mum of 12-month-old Eve (who has Cystic Fibrosis) will hand in 65 yellow roses to Theresa May at number 10 Downing Street, today (Thursday 16 May).

Alongside the 65 roses – a term sometimes used by children to pronounce the name of their disease – the charity will deliver a letter inviting Theresa May to attend a Parliamentary Debate (June 10th) on the issue ***. The letter asks for the Prime Minister to give an update to MPs on what must happen to bring an end to the ongoing negotiations and give cystic fibrosis patients access to these lifesaving precision medicine drugs – Orkambi and Symkevi.

Orkambi is the second precision medicine that targets the root cause of the disease 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 to make it available on the NHS for patients in England, Wales and Northern Ireland is yet to be struck. During that time, a third drug to treat the root cause of the condition, Symkevi, has been approved for use but is also not available on the NHS.

David Ramsden, chief executive of the Cystic Fibrosis Trust, said: “Today marks a year since Theresa May said she was keen to see a ‘speedy resolution’ in the ongoing dialogue between NHS England and Vertex. Yet, the wait goes on. This tragic situation cannot continue. Every day the health of thousands of people in this country is deteriorating – and this is damage to their lungs that can’t be undone. Talks between the three parties – Vertex, NHS England and NICE – must result in action.

“We’re asking for Prime Minister, Theresa May to attend the Westminster Hall debate on Monday 10

June and update the house on what the next steps are. The promise of words and ongoing talks is no longer enough, we need to see the drugs made available now.”

Zoey Jones, mum of 12-month-old Eve who has cystic fibrosis, said: “We’re marking this occasion with 65 yellow roses, a poignant symbol as it’s a term that’s been used by young children with cystic fibrosis to pronounce the name of their disease. The distress caused to the community is incomprehensible, this cannot go on. We are begging the Government to secure a deal.”

- Ends-

Notes to editors

For media enquiries contact the Cystic Fibrosis Trust press office on 0203 795 2193 or pressoffice@cysticfibrosis.org.uk

*Full text from 16 May 2018:

Teresa Pearce MP (Erith and Thamesmead) (Lab)

Q7. This afternoon, 1,000 handwritten letters will arrive at Downing Street asking the Prime Minister to intervene personally in the stalemate between NHS England and the drug company Vertex to get the cystic fibrosis drug Orkambi issued to patients in the UK without delay. One of those letters is from seven-year-old Luis, who says: “Dear Mrs May, Please can you give Orkambi to me so I will feel much better and won’t have to spend so much time in hospital.” What is the Prime Minister’s response? Will she? [905344]

The Prime Minister

The hon. Lady raises an important issue. Cystic fibrosis is obviously a terrible, life-limiting condition, and it is right that patients should have access to cost-effective, innovative medicines and technologies. The issue has been taken up by Members from across the House and, as the hon. Lady mentioned, there is an ongoing dialogue between NHS England and Vertex, but I am keen to see a speedy resolution to the negotiations. I understand that several Members have asked to see me about the issue, and I am happy for that to happen.

**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 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 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](#)