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**Press Release**

[Add date here]

[For Immediate release]

**???? from ?????? takes part in Belfast protest to campaign for new precision cystic fibrosis medicines to be available on the NHS**

????? (name and where the person or family is from) joined protestors in Belfast (on Friday 22 June 2018) demanding new precision medicines are made available for those with cystic fibrosis.

Protestors took part in the community-led day of action demanding that drug manufacturer Vertex and HSC agree a deal so the cystic fibrosis drug Orkambi becomes available on prescription in the UK.

???? said they are backing the campaign because ??? (details to go here).

??? added: “quotes to go here”

The protest took place outside Belfast City Hall between Noon and 2pm on the day.

Orkambi is a precision medicine that around 50 per cent of people in the UK with the devastating, life-shortening condition cystic fibrosis could benefit from, including young children. It could help 111 people in Northern Ireland.

Conventional cystic fibrosis treatments currently available in the UK only target the symptoms, but precision medicines are the first to tackle the underlying cause of cystic fibrosis.

Orkambi is not a cure, but it has been found to slow decline in lung function – the most common cause of death for people with cystic fibrosis – by up to 42 per cent.

It received its European license in November 2015 and in June the following year NICE recognised it as an important and effective treatment. But, despite this, they did not recommend the drug be available on the NHS.

This means it is unavailable to most people with cystic fibrosis across the UK, despite being licensed for use for people aged six years and upwards.

Lynsey Beswick, Public Affairs Manager for the Cystic Fibrosis Trust, said: “We’re incredibly impressed by the cystic fibrosis community for arranging this protest.

“We fully back their demand to make Orkambi and other precision medicines available on prescription for those in Northern Ireland with cystic fibrosis.

“The passion, determination and tenacity of all those that are campaigning and are going/have gone on the protest is incredible.”

Cystic fibrosis is a life-shortening, inherited condition leading to severely reduced quality of life and life expectancy. Half of all people who died with CF last year were under the age of 31.

People living with this condition experience a build-up of thick, sticky mucus that causes chronic lung infections and progressive lung damage.

Daily life itself can be a struggle and people with the condition face a huge burden of daily treatments.

For more information about cystic fibrosis and the campaign go online at www.cysticfibrosis.org.uk

**Notes to Editors**

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
* Cystic Fibrosis is a life shortening genetic condition – the median age of death is 31 years old
* 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

**Contact**

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