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Cystic fibrosis wonder drug maker urges NHS to reverse refusal to fund treatment

By **Laura Donnelly**

THE makers of a breakthrough cystic fibrosis drug have attacked the NHS for refusing to fund its use – saying it undermines Theresa May's claims she wants Britain to lead a genomic revolution.

The drug, Orkambi, is at the centre of disputes between ministers, health officials and the pharmaceutical industry. It was approved by the European Medicines Agency in November 2015 but the NHS is so far refusing to fund the treatment, saying it is too expensive. Since then, Vertex, the manufacturer, and NHS chiefs have been at loggerheads. Last month, Matt Hancock, the Health Secretary, urged Vertex to break the "impasse", telling the House of Commons that NHS England had made a "very generous final offer" to the company.

Health officials had said the five-year deal would bring in excess of £1 billion to the company over the next 10 years.

The National Institute for Health and Care Excellence had said the price offered by Vertex was unsustainable.

Jeffrey Leiden, CEO of Vertex, last night said: "Despite universal acceptance of the benefits these medicines bring, people in the UK have been waiting to access these breakthrough medicines for more than 1,000 days, while thousands of people with CF in other countries in Europe and the US have been benefiting from them for years."

He added: "Half of people with this cruel disease will die before they are 31. Science delivered the breakthroughs, but the system is blocking access. This is particularly heartbreaking in the UK, which has the second largest cystic fibrosis patient population in the world."

Earlier this week, a boy of eight with cystic fibrosis urged the firm to lower the price of a drug. Luis Walker, from Horam, East Sussex, told Vertex that Orkambi would make him "feel much better".

The Department of Health has called for a "speedy solution" to be found between NHS England and the firm.

Dr Leiden said the failure to fund the drug was at odds with the Prime Minister's ambition to lead the world in genomics and precision medicine – which meant being prepared to invest in innovations that could radically change treatment in future decades.

He said: "After nearly 20 years of research and development by hundreds of Vertex scientists, we have done what was once thought impossible – discover and bring to nearly half of all cystic fibrosis patients the first medicines to treat the underlying cause of this devastating disease. The Government must act now."

Jeffrey Leiden: Page 21