**Statement from David Ramsden, Chief Executive of the Cystic Fibrosis Trust, following a meeting with Dr Jeffery Leiden, Chief Executive of Vertex Pharmaceuticals on Wednesday 4 September 2019**

Last week, families joined the Cystic Fibrosis Trust outside Vertex international headquarters in London, to highlight the lives lost during the nearly four years of negotiating failure and the urgency of reaching a deal with the NHS across the whole UK.

Today, Carlie Pleasant and I spoke directly with Vertex boss Dr Leiden, outlining the devastating impact not having access to the precision drugs Orkambi and Symkevi is continuing to have on people’s lives.

It was deeply moving to hear Carlie tell the story of what the wait has meant, directly to one of the people who can make a deal happen.

These drugs are the first of their kind, treating the root cause of the disease. They are paving the way for more drugs coming down the pipeline – known as the triples - that will benefit up to 90 per cent of people with cystic fibrosis.

Cystic fibrosis is a progressive disease, so those who will benefit from Orkambi and Symkevi need them now to give them the best chance possible that they will benefit from the next generation of medicines.

Each day we wait people’s health deteriorates, and this damage cannot be reversed. The roller coaster ride of hope, excitement, disappointment and anxiety as talks are reported is taking its toll on our community.  Indeed, for some, the fact these drugs exist but are beyond the reach of the thousands who need them is such a cruel injustice that they have told us that that they would rather they didn’t exist at all.

During our call, Dr Leiden reiterated his commitment to ensuring the drugs are made available to all of those people with cystic fibrosis in the UK who would benefit.  He talked of the “multiple proposals” that have been made, however, he was not able to give us any concrete evidence of progress.

We know that aspects of commercial deals need to remain confidential, but we really do not want to hear any more reports of “talks”, we just want the drugs to be available.

At times it is hard to remain optimistic, but we hope that the Secretary of State for Health, Matt Hancock and Dr Leiden will have their promised meeting soon. We also understand that the Scottish Government and Vertex Pharmaceuticals are moving forward with the discussions that were reported in August.  If there is a significant breakthrough in Scotland we hope it will lead to rapid progress across the whole UK so that people are not left lagging yet further behind.

There are over 10,500 people with cystic fibrosis in the UK and the Cystic Fibrosis Trust will keep up the fight until everyone who should have these lifesaving drugs so.