

# Cystic Fibrosis a fight we must win

Rt Hon. Boris Johnson MP  
House of Commons  
London  
SW1A 0AA

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Dear Mr Johnson

## Life saving drugs for cystic fibrosis

Cystic fibrosis is one of the most remarkable stories in modern medicine. It is a genetic disease that, less than 50 years ago, took lives in infancy. There are now more than 10,500 people living with cystic fibrosis in the UK and more than half of them are adults.

In only the past tens years, treatment for cystic fibrosis has radically transformed too. In his 2015 State of the Union Address, President Barack Obama, highlighted cystic fibrosis treatments that treat the root cause of the condition as "a new era of medicine" that "in some patients with cystic fibrosis... has reversed a disease once thought unstoppable."

Rapid advances in treatment have continued and have increased the treatable population from 5% to more than 50%, and with a new medicine that is set to fundamentally address the disease in nine in ten people with cystic fibrosis in the UK.

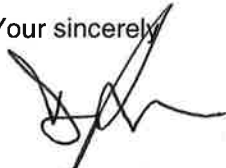
However, the hope, excitement and joy of these breakthroughs has been all-but extinguished by a nearly four-year long battle over money between the company that manufactures these medicines, Vertex Pharmaceuticals and the NHS.

People with cystic fibrosis and their families in the UK have brought their plight to Westminster dozens of times and received reassurance from successive Secretaries of State for Health and Social Care, and the promise of a speedy resolution that Prime Minister Theresa May hoped for in May 2018.

Access is still denied and people need access to these life-saving drugs now.

Can you provide reassurance that an administration that you lead would prioritise a positive resolution to this ongoing crisis for people with cystic fibrosis and their families?

Your sincerely



David Ramsden  
Chief Executive