Cystic Fibrosis Trust
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Rt Hon Matt Hancock MP
Secretary of state for Health and Social Care
Department of Health
Richmond House
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Tuesday 10th July 2018

Dear Mr Hancock MP

Firstly, may I congratulate you on your new position as Secretary of State for Health and Social care.

I wish you the very best in this most important role at a time of profound challenge and opportunity for the services you now lead.

Could I also draw your attention to a matter of the utmost urgency to the 8,000 people who live with cystic fibrosis (CF) in England?

Cystic fibrosis is a genetic, multi-system condition that requires an extensive regime of daily treatment to manage symptoms including physiotherapy, nebulisers and antibiotics to preserve health and fight disease progression. Complications of the disease lead to increasing levels of healthcare utilisation as the burden of managing CF-related diabetes, liver disease, osteoporosis, and mental ill health take hold over a person's lifetime.

However, in an unprecedented breakthrough, the first medicines to address the root cause of CF have been developed and, over the course of the next five years, we expect that precision medicines for around 90% of people with CF in the UK will be licensed.

At this time of hope and expectation that the tools to beat the disease are within grasp, the UK is falling behind other nations in providing timely access to these therapies.

One of these medicines, Kalydeco (ivacaftor), manufactured by Vertex Pharmaceuticals, is available throughout the UK to treat specific mutation types that account for around 5% of the UK population. Dramatic reductions in risk of death, need for transplantation, and hospitalisation, as well as lower prevalence of complications and infection have shown the radical potential of this innovation in CF care[1].

[1] https://thorax.bmj.com/content/early/2018/05/10/thoraxjnl-2017-210394

Cystic Fibrosis our focus

However, Orkambi (lumacaftor-ivacaftor), also manufactured by Vertex Pharmaceuticals, a treatment that could benefit around 50% of people with CF in the UK, remains unavailable despite receiving marketing authorisation in 2015. The National Institute for Health and Care Excellence (NICE) found the drug to be clinically effective but was unable to recommend the drug for routine NHS use on the basis of the publicly-listed cost.

We have campaigned for two years for the company and the NHS to engage in constructive talks. Representatives of NHS England and Vertex have, to date, held four meetings but no deal has been agreed. Thousands of people with cystic fibrosis are watching on – hoping for progress, angry for time lost – as their health irrevocably deteriorates.

Only last week my colleague Lynsey Beswick, who lives with cystic fibrosis and I met with your predecessor, the Rt Hon Jeremy Hunt MP, to discuss this vital issue, after the Prime Minster had made a public plea for a 'speedy resolution' to the issue.

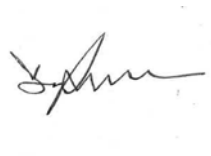
The following day, statements from both the manufacturer, Vertex Pharmaceuticals, and NHS England[2] suggested hope of a speedy resolution is unrealistic but there is simply not the time to wait.

It is now over six months since a UK Parliament petition gathered over 100,000 public signatures in just ten days, triggering a debate where more than 60 MPs spoke at the debate to highlight the urgency of the issue. More recently, correspondence on the issue between the Chair of the Health and Social Care Committee, Dr Sarah Wollaston MP, and the Secretary of State stated that access to medicines "is and always will be a priority for this government"[3].

Could I ask that we meet alongside a small group of cross party supportive MPs, to further discuss what efforts your office and the Government can make to ensure that these negotiations continue and that a deal is reached as soon as possible?

I enclose a briefing on the issue. alongside a personal experience from a patient directly affected by the condition awaiting access to the drug.

Yours sincerely,



David Ramsden
Chief Executive

[2] https://www.cysticfibrosis.org.uk/news/precision-medicine-talks-stall-between-nhs-and-vertex
[3] https://www.parliament.uk/documents/commons-committees/Health/Correspondence/2017-19/Correspondence-with-the-Secretary-of-State-for-Health-and-Social-Care-Orkambi-and-cystic-fibrosis.pdf