

Cystic

Fibrosis a fight we must win

Rt Hon Boris Johnson MP
Prime Minister
10 Downing Street
London
SW1A 2AA

24 July 2019

Dear Prime Minister,

Life saving drugs for cystic fibrosis

Congratulations on your election as leader of the Conservative Party. I wish you every success as Prime Minister of the United Kingdom.

I wrote to you during your campaign last month to highlight the crisis that people with cystic fibrosis and their families are facing as they continue to be denied access to the most advanced cystic fibrosis medicines.

On Friday 12 July, in the leadership hustings held in Cheltenham, Elizabeth Brennan, mother to 4-year-old Annabelle Brennan, who has cystic fibrosis, asked you to promise to resolve the deadlock that exists between the company, Vertex Pharmaceuticals, and NICE and NHS England.

Thousands of people living with cystic fibrosis have needlessly watched their health decline or have died during more than three years of failed talks. The United Kingdom has led the world in improving the care, treatment and support that people with cystic fibrosis receive, with remarkable improvements in life expectancy and quality but we are now falling behind.

Just last month the results of a new CF medicine, from the same company, which could radically transform the lives of 90% of people living with cystic fibrosis in the UK, has shown unprecedented improvements in health and quality of life.

However, for people with cystic fibrosis and their families in the UK, the optimism of those results has been overshadowed by the fear that they may never receive any of these life-saving treatments.

Current talks cannot continue indefinitely. It would be intolerable for people with cystic fibrosis and their families to endure another summer of impasse.

Will you meet with me, Elizabeth, her family, and a small cross-party delegation of Members of Parliament, to discuss how we can ensure urgent access to these medicines and provide a lasting legacy for those living with cystic fibrosis?

Your sincerely,



David Ramsden
Chief Executive