Ms Shona Robison
Cabinet Secretary for Health and Sport
The Scottish Parliament
Edinburgh
EH99 1SP

12th October 2017

Dear Ms Robison

**Access to Ivacaftor for R117H mutation**

Today the Welsh government announced that nine people with cystic fibrosis (CF) are set to benefit from breakthrough treatment Ivacaftor (also known as Kalydeco), which has just been approved for extended use for those age 18 and over who have the rare R117H mutation of the cystic fibrosis gene.

The Trust is delighted to hear this news, although not more so than the nine people whose lives will be changed by this treatment. We wish to draw your attention to the 56 people in Scotland who are still awaiting access.

We call upon your government to take urgent action to enable equitable access to Ivacaftor across all UK nations, for the remaining individuals affected by the R117H mutation.

Ivacaftor is one of only two licenced treatments in the UK known to tackle the underlying cause of cystic fibrosis. This groundbreaking treatment, licenced for use in the UK since 2013, has been shown to slow the development of permanent lung damage and improve lung health by up to 64 per cent.

The drug could also significantly extend life expectancy; half of all those who died with cystic fibrosis in 2016 were less than 31 years of age.

It is essential that this transformational treatment is made available to this patient cohort as soon as possible before further irreversible lung damage is done. We ask you to act now to ensure that this vital treatment is promptly extended use for this mutation group without delay.

We look forward to your response.

Yours sincerely,

David Ramsden,
Chief Executive,
Cystic Fibrosis Trust