Dear **[insert name and salutation]**,

I am a constituent of yours **who has cystic fibrosis/is a parent/family member/partner of someone affected by cystic fibrosis** (CF). I’m writing to share my experience of cystic fibrosis and the desperate need for urgent access to life-saving drugs. A new CF treatment, a triple combination therapy known as Kaftrio, could treat up to 90% of those living with the condition – including 40% who currently do not have the eligible mutations for the existing drugs, Orkambi and Symkevi. **[Insert your own situation here]**

This drug (also known as Trikafta in the US) has already been licensed by the Food and Drug Administration and shown to make a marked difference to the lives of those with CF. Now that the European Medicines Agency (EMA) has made a positive recommendation and deemed the drug safe and effective, it is expected to be formally licensed in Europe for those aged 12 and over by autumn this year.

The NICE appraisal process had begun alongside this, but disappointingly there has been a delay, and it has been pushed back to January 2021. Appraisal bodies in the devolved nations have yet to announce a date for their appraisal of the drug.

CF is a genetic life-threatening condition that affects over 10,500 people in the UK. The median age at death is just 31 years old.

**[Insert personal story about how CF affects you here]**

The newer triple combination therapy has the potential to be even more effective for those who can’t benefit from existing drugs. While conventional CF treatments treat the symptoms of the condition, these new drugs target the underlying cause. It is not a cure, but it has been shown to significantly reduce decline in lung function – the leading cause of death for someone with CF.

The pandemic has caused disruption to usual CF care, which risks irreparable lung damage. This makes access to this drug even more important at this time.

We have already seen a lengthy campaign for Orkambi and Symkevi and we cannot afford to see this repeated when it comes to the triple therapy. The charity Cystic Fibrosis Trust is urgently calling on all parties to work together to make sure that the triple therapy is made available in the shortest possible time to those who need it, and I ask you to lend your support to this.

For more information please contact [publicaffairsteam@cysticfibrosis.org.uk](mailto:publicaffairsteam@cysticfibrosis.org.uk) for a full briefing.

Yours sincerely,

**[insert name]**

**[Insert address and postcode]**