**Post template**

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Date

**Urgent need for the National Institute of Health and Care Excellence (NICE) to approve cannabidiol (Epidyolex) for the treatment of Tuberous Sclerosis Complex-associated epilepsy**

Dear Liz Twist,

As Chair of the All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions, I am writing to you to raise concerns about NICE’s initial decision to not fund cannabidiol (brand name Epidyolex) for the treatment of epilepsy related to the rare genetic condition Tuberous Sclerosis Complex (TSC).

This is a very important topic for me because [explain your personal reasons for wanting NICE to approve cannabidiol – try to keep it brief so the letter stays on one page].

NICE has initially rejected cannabidiol for TSC-related epilepsy. However, NICE has not fully considered:

* The significant potential improvement that this treatment could have on quality of life for individuals and families who live with TSC-related epilepsy
* The impact that fewer seizures can have on challenges faced by carers of people with TSC, such as financial, employment and social support
* The health and social inequality currently in the UK for people affected by TSC, with cannabidiol already approved in Scotland and Wales for TSC-related epilepsy

**As Chair of the APPG on Rare, Genetic and Undiagnosed Conditions, I am asking you to:**

* Provide your voice to the campaign by commenting on the NICE consultation. You can do this by going to: https://www.bit.ly/nice-response
* Speaking to your local press to help raise awareness of the inequity, and call on NICE to make this vital treatment available to people with TSC

The deadline for NICE to receive further responses is 29 November 2022. I would therefore appreciate if you can action this as soon as possible.

Please keep me informed of your progress and next steps.

Yours faithfully,

Your name

**Email template**

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