

Date: 02/05/2024

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**epilepsysociety.org.uk**

Dr Mark Chakravarty,

Lead Non-executive Director NICE Appeals – Technology Appraisals and Highly Specialised Technologies, National Institute for Health and Care Excellence,

2nd Floor, 2 Redman Place, London E20 1JQ

Dear Dr Chakravarty,

# Letter of Support for the Appeal from Tuberous Sclerosis Association against the Final Appraisal Determination –

**Fenfluramine for treating seizures associated with Lennox–Gastaut syndrome in people 2 years and over**

We are in full support of the appeal from the Tuberous Sclerosis Association (TSA). The Epilepsy Society is the UK’s

leading provider of epilepsy services.

We feel it is inequitable that people with Lennox-Gastaut syndrome (LGS) will not have access to fenfluramine, while other people with serious epilepsies (i.e. Dravet syndrome) do.

Some people with Dravet syndrome have done very well on the drug, when nothing else has worked, and trial data support its use in Lennox-Gastaut syndrome, too. Denying people with LGS the opportunity to try fenfluramine feels inequitable and difficult to justify. We would like to see further consultation taking place before a final decision is made.

Yours sincerely,

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Head of External Affairs Epilepsy Society

Patron **Her Majesty The Queen** President T**he Countess Howe**

Chief Executive **Clare Pelham**

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**01494 601400**

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