Belfast Health and Social Care Trust
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FOI/36975

12 June 2026

Dravet Syndrome

The Business Service Organisation of the Health and Social Care Board (HSCNI), through the BSO Family Practitioner Services Department, told me that you, as the Neurology Unit, may be able to assist or advise me regarding where I should address my FOI request.

Please provide the aggregated data per:

- ***Tertiary Neurology Centre***
- ***Tertiary Paediatric Neurology Centre***
- ***Secondary Neurology Centre***
- ***Regional Adult Neurology Centre***
- ***Secondary Adult Neurology Centre***

Two periods should be considered:

- ***Prescriptions issued on or before 31/12/2024 (Period 1)***
- ***Prescriptions issued between 01/01/2025 and 31/12/2025 (Period 2)***

This process should be applied independently for each of these two periods.

Please note that patient-level data should not be reported. Instead, patient-level values should be aggregated to generate median values (and, where applicable, associated measures of dispersion) for the population of interest.

Find below the information we are seeking:

1. **Total number of patients with Dravet syndrome per centre at period 1 and period 2.**

2. **Age at initiation (median – interquartile range) of each of the following medications in Dravet syndrome patients per centre at period 1 and period 2, namely:**

   - **Stiripentol (DIACOMIT)**
   - **Fenfluramine (FINTEPLA)**
   - **Cannabidiol (EPIDYOLEX)**

3. **Total number of patients with Dravet syndrome per centre currently treated with only one Dravet-specific anti-seizure medication at period 1 and period 2, namely:**

   - **Stiripentol (DIACOMIT)**
   - **Fenfluramine (FINTEPLA)**
   - **Cannabidiol (EPIDYOLEX)**

→ **Please include the median (interquartile range) current dosage per patient (mg/kg/day).**

→ **Please include the median (interquartile range) patient's current age.**

***Important:* In this analysis, patients may receive concomitant prescriptions of other "general" anti-seizure medications (e.g. valproate or clobazam), but should only be treated with only one of the treatments listed above.**

4. ***Total number of patients with Dravet syndrome per centre currently treated with a concomitant combination of Dravet-specific anti-seizure medications, namely:***
   - ***Stiripentol + fenfluramine***
   - ***Stiripentol + cannabidiol***
   - ***Stiripentol + fenfluramine + cannabidiol***
   - ***Fenfluramine + cannabidiol***

   → ***Please include the median (interquartile range) current dosage per patient for each treatment (mg/kg/day).***

   → ***Please include the median (interquartile range) patient's current age.***

   - ***Important:* In this analysis, patients may receive concomitant prescriptions of other "general" anti-seizure medications (e.g. valproate or clobazam) in addition to the following combination listed above.**

To respond to this request would require a manual review of a very large number of individual patient records, potentially ranging from many hundreds to several thousands, including both electronic records and paper records that predate the introduction of the Epic system.

The information required to respond to this is not held in a readily extractable format and would require detailed examination of each record, with subsequent collation. It is therefore not possible to provide the information without undertaking a significant manual exercise, which would require more than 18 hours work to complete.

Belfast Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the Freedom of Information Act under Section 12. Section 12 of the Freedom of Information Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as Belfast Trust. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.