



NIAS Ref: 40769-25

RE: Dravet syndrome and Lennox-Gastaut syndrome freedom of information request

Dear

Thank you for your Freedom of Information request. Can we please clarify Northern Ireland Ambulance Service Trust is a first responder and does not treat patients after incidents – we would advise you to redirect your request to health trusts.

Kind regards

Informatics Team

Northern Ireland Ambulance Service

Site 30 | Knockbracken Healthcare Park | Belfast | Northern Ireland| BT8 8SG | |
www.nias.hscni.net

Sent: 28 May 2025 15:42

To: NIAS FOI <foi@nias.hscni.net>

Subject: Dravet syndrome and Lennox-Gastaut syndrome freedom of information request

To Whom It May Concern

I would like to submit an FOI request for the following data for Northern Ireland Ambulance Service HSC Trust:

- The number of patients treated for Dravet syndrome in 2024, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- The number of patients treated for Dravet syndrome in 2025, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- The number of patients treated for Lennox-Gastaut syndrome in 2024, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- The number of patients treated for Lennox-Gastaut syndrome in 2025, ideally separated by month, or quarter



- Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- The above data separated by treatment, focusing on the following treatments:
 - fenfluramine
 - sodium valproate
 - stiripentol
 - clobazam
 - cannabidiol
 - levetiracetam
 - topiramate
 - potassium bromide
 - Other treatments
 - carbamazepine
 - gabapentin
 - lacosamide
 - lamotrigine
 - oxcarbazepine
 - phenobarbital
 - pregabalin
 - tiagabine
 - vigabatrin
 - rufinamide
- Numbers of patients moving from one specific treatment to another e.g. fenfluramide gains from cannabidiol, sodium valproate losses to cannabidiol
- Alternatively, just the numbers of patients on each treatment for each month/quarter will be able to show how the numbers on each treatment are changing

This response has been prepared for disclosure log publication. Only minor editorial or redaction amendments have been made for clarity and compliance with data protection legislation. The substantive content is identical to that provided to the requestor and the original issued version remains the authoritative record.