



Ref: FOIA Reference 2021/22-364

Date: 25th October 2021

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 15th October 2021 requesting information under the Freedom of Information Act (2000) regarding dravet syndrome.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 I am writing to you under the Freedom of Information Act 2000 to request the following information from neurology or psychology departments treating patients with Dravet syndrome, for the purpose of researching the services provided for patients with this condition.

Please detail:

- **What services are provided by your hospital for patients with Dravet syndrome?**
- **Treatment initiation**
- **Titration of dose (consider both starting and maintenance treatment)**
- **Monitoring (incl. echocardiographies, liver function tests, etc.)**
- **Review of clinical presentations (frequency, duration)**
- **On-going prescription of treatments**
- **Completing the Blueteq forms**
- **Other**

If services are not provided at your hospital

- **Where are patients referred to?**
- **What services do they receive at the other location (see above list for examples)?**

We do not require any information that includes identifiable patient information or costs/commercial arrangements.

A1 See below:

1. Children with suspected Dravet Syndrome have access to 2 consultants with special expertise in Epilepsy. They have access to genetic testing as soon as the diagnosis is suspected
2. Treated with the standard regimen - Sodium Valproate+Stiripentol+Clobazam
3. Support from Paediatric Epilepsy Nurse
4. Access to neuro-developmental team for monitoring their development
5. Shared care with Tertiary centre and Outreach Paediatric Neurology Clinics done by visiting Consultant Paediatric Neurologist
6. Access to Ketogenic diet and CBD Oil (Epidiolex) through tertiary centre
7. Regular Monitoring of LFT locally if on CBD Oil or Echocardiogram if starting on a trial of Fenfluramine.
8. Access to participate in national studies on Dravet Syndrome

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.



University Hospitals
of North Midlands
NHS Trust

Yours,

Jean Lehnert
Data, Security & Protection Manager