

Ref: FOI/GS/ID 7009

Please reply to:
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Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Dravet syndrome.

You asked:

- 1. What services are provided by your hospital for patients with Dravet syndrome?*
 - a. Treatment initiation*
 - b. Titration of dose (consider both starting and maintenance treatment)*
 - c. Monitoring (incl. echocardiographies, liver function tests, etc.)*
 - d. Review of clinical presentations (frequency, duration)*
 - e. On-going prescription of treatments*
 - f. Completing the Blueteq forms*
 - g. Other*
- 2. If services are not provided at your hospital*
 - a. Where are patients referred to?*
 - b. What services do they receive at the other location (see above list for examples)?*

Trust response:

1.
 - a. Stipulated by the Tertiary Centre (usually Evelina/Great Ormond Street Hospital or Kings)
 - b. Stipulated by the Tertiary Centre (usually Evelina/Great Ormond Street Hospital or Kings). The Trust would then consider the dose especially if seizure breakthrough/side-effects.
 - c. Bi-annually bloods, echo at the start of treatment, depending on the patient but usually hip x-rays (if in wheelchair), spinal checks. The patients are able to contact the Trust for any issues

- d. Usually 3-6 monthly at the Trust with the consultant and nurse-led clinics alternating (depending on how they are) with additional tertiary clinic input in the complex epilepsy clinic and the Dravet clinic at the Evelina.
 - e. Stiripentol provided by the Trust. Other AEDs such as Sodium Valproate provided by GP/Community Pharmacies.
 - f. The Trust does not use Blueteq for these particular prescriptions as Blue-teq forms are completed at the initiation centre.
 - g. Not applicable
2. I
- a. Not applicable
 - b. Not applicable