**FOI Ref: 6059**

**Category(ies): Clinical – Service Activity**

**Subject: Dravet syndrome**

**Date Received: 15/10/21**

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| **Your request:** | **Our response:** |
| * 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 …. | Children with Dravet Syndrome are primarily under the care of the tertiary service in Sheffield Children’s Hospital  (Ryegate Children’s Centre Neurology)  Supportive care within Rotherham Hospital to include   * Six monthly (Variable) clinic reviews, 30 minute appointments * Titration of maintenance dose * Support with ongoing prescriptions * Referrals for investigations in consultation with Tertiary Centre   Due to the complexity of Dravet Syndrome any initiation of treatment, additional investigations or changes to management plans would be in consultation with the Sheffield Children’s Neurology Team |
| * 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)? | Services provided as stated above  Please contact Sheffield Children’ Hospital Neurology Service for further information. |