



To: Medical Directors, all local health boards and WHSSC

February 2020

Dear Colleague,

In November the National Institute for Health and Care Excellence (NICE) issued guidance on the use of *Cannabis-based medicinal products* (NG144) covering prescribing of cannabis-based medicinal products for people with intractable nausea and vomiting, chronic pain, spasticity and severe treatment-resistant epilepsy. Subsequently in December, NICE recommended the use of cannabidiol with clobazam for treating seizures associated with Dravet syndrome (TA614) and with Lennox–Gastaut syndrome (TA615).

In order to support paediatric neurologists who are considering prescribing cannabis-based medicinal products for paediatric patients with severe treatment-resistant epilepsy, Great Ormond Street Hospital (GOSH) is hosting a new UK-wide clinical service. The Refractory Epilepsy Specialist Clinical Advisory Service (RESCAS) provides a forum for the discussion of difficult epilepsy cases that have presented diagnostic and/or management difficulties and have proven refractory to treatment. I attach further details and a referral form for contacting the advisory service.

I would be grateful if you would disseminate this information to your neurology department and other interested colleagues.

Yours sincerely

**DR FRANK ATHERTON**

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## **Refractory Epilepsy Specialist Clinical Advisory Service (RESCAS)**

The new national Refractory Epilepsy Specialist Clinical Advisory Service (RESCAS) is made up of a network of UK paediatric neurology specialists. The service provides a forum for the discussion of difficult epilepsy cases that have presented diagnostic and/or management difficulties and have proven refractory to treatment.

RESCAS is hosted at Great Ormond Street Hospital NHS Foundation Trust (GOSH) but is jointly run with paediatric neurologists from throughout the UK. The service has been commissioned by NHS England and is supported by NHS Scotland, NHS Wales, and Health and Social Care Northern Ireland.

Any regional paediatric neurology centre can refer a case to RESCAS for discussion at a fortnightly virtual multidisciplinary team meeting (MDT). The meeting will have input from Paediatric Neurologists from centres around the UK, including GOSH, with additional input from neurophysiologists, geneticists, radiologists, pharmacy and clinical nurse specialists where appropriate. Written advice will be provided to the referring clinician within five working days of the meeting. In exceptional cases (for example when it would be inappropriate to wait for the fortnightly MDT) interim advice will be provided through an internal MDT including the epilepsy team at GOSH and the referring consultant paediatric neurologist, who will participate through a web link or telephone conference.

RESCAS is an advisory service and complements regional clinical services. The clinical responsibility for the care of patients discussed at RESCAS will remain with the referring paediatric neurology team.

Those wishing to refer must complete the RESCAS referral form and email to

[gos-tr.advisorynetwork.referrals@nhs.net](mailto:gos-tr.advisorynetwork.referrals@nhs.net).

Please note the RESCAS service does not provide out of hours or weekend advice, and will only accept and process referrals from Monday to Friday, 9am – 5pm.

**Refractory Epilepsy Speciality Clinical Advisory Service Referral Template**

<b>Name</b>	
<b>Date of birth</b>	
<b>NHS number</b>	
<b>Address</b>	
<b>GP</b>	
<b>Referring Consultant Paediatric Neurologist (Name + Institution)</b>	
<b>Local Paediatrician (Name + Institution)</b>	
<b>Referral Question(s)</b>	
<b>Previous MDT discussions (indicate as appropriate)</b>	<input type="checkbox"/> Internal MDT (referring paediatric neurology centre)  <input type="checkbox"/> Regional Epilepsy network detail: .....  <input type="checkbox"/> Regional CESS MDT detail: .....  <input type="checkbox"/> National virtual CESS detail: .....
<b>Background information</b>	
<b>Epilepsy syndrome diagnosis ( if known)</b>	

<b>Aetiology of epilepsy (if known)</b>	
<b>Summary of course of epilepsy</b> <ul style="list-style-type: none"> <li>• age of onset</li> <li>• seizure types, evolution</li> </ul>	
<b>Birth history - complication</b>	<b>Yes/No</b>  if yes -details
<b>History of status epilepticus</b>	<b>Yes/No</b>  If yes details:
<b>Relevant Family history</b>	
<b>Current situation:</b> <ul style="list-style-type: none"> <li>• Inpatient or at home</li> <li>• Seizure types</li> <li>• Seizure frequency</li> <li>• Impact of epilepsy (use of emergency seizure medication, hospital admissions/attendances/ education)</li> </ul>	
<b>History of status epilepticus</b>	<b>Yes/No</b>  If yes details:

<b>Clinical examination: Sensory or motor deficits</b>	
<b>Current medication and doses</b>	
<b>Previous medications</b>	
<b>Neurodevelopment</b>	
<b>Developmental milestones:</b>	<input type="checkbox"/> Normal <input type="checkbox"/> Delay / plateaued <input type="checkbox"/> Regression (age onset loss of skills)
<b>If Yes, please specify details</b>	Cognitive impairment: <input type="checkbox"/> Yes <input type="checkbox"/> No Language impairment: <input type="checkbox"/> Yes <input type="checkbox"/> No
<b>Has the child previously had a formal neuropsychology or developmental assessment?</b>	<b>Yes/No</b> Summary:
<b>Psycho social and education</b>	
<b>Safeguarding concerns:</b>	<b>Yes/No</b> If Yes, details:
<b>Investigations</b>	
<b>EEG</b>	Please confirm <input type="checkbox"/> All relevant EEG reports enclosed (mandatory information - we cannot process referral without this) <input type="checkbox"/> EEG data will be presented by referring paediatric neurology team at virtual MDT

<b>MRI Images (other neuroimaging)</b>	Please confirm <ul style="list-style-type: none"> <li><input type="checkbox"/> Reports attached</li> <li><input type="checkbox"/> Images have been send by IEP (mandatory-we cannot process referral without neuroimages)</li> </ul>
<b>Genetic investigation performed</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> No</li> <li><input type="checkbox"/> Yes: all reports attached which tests:</li> <li><input type="checkbox"/> Results pending: which tests:</li> </ul>
<b>Other investigations: Please tick as appropriate</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Metabolic</b></li> <li><input type="checkbox"/> <b>Infection</b></li> <li><input type="checkbox"/> <b>Autoimmune</b></li> </ul>	Please summarise relevant results:

Completed referral forms should be emailed to:

[gos-tr.advisorynetwork.referrals@nhs.net](mailto:gos-tr.advisorynetwork.referrals@nhs.net)