

## Epilepsy CNS Forum

21<sup>st</sup> of February 2023 13:00 – 14:00 via MS Teams

**Chair:** Flo Kennard (Chair), FK

South Thames Paediatric Network

### Attendees

Amanda Tomalin, AT  
Anne Makunde, AM  
Charlotte Park, CP  
Dee Burt, DB  
George Ward, GW  
Kirsten McHale, KM  
Laura Hutchinson, LH  
Lynn Keen, LK  
Mioara Albery, MA  
Naomi Hodges, NH  
Rachel Fisk, RF  
Rebecca Seamons, RS  
Robyn Greaves, RGr  
Rochelle Gilder, RG  
Sarah Buchan-Tigere, SB  
Sarah Collins, SC  
Sara Mahjabin, SM  
Victoria Urban, VU

Evelina Children's Hospital  
Croydon Health Services  
Surrey & Sussex Healthcare  
University Hospitals Sussex  
East Sussex Healthcare  
Young Epilepsy  
University Hospitals Sussex  
Kings College Hospital  
St George's Hospital  
Epsom & St Helier  
Lewisham & Greenwich  
Dartford & Gravesham  
Kings College Hospital  
Maidstone & Tunbridge Wells  
Dartford & Gravesham  
Kent Community Health  
South Thames Paediatric Network  
Evelina Children's Hospital

### Apologies

Farzana Mirza, FM  
Helen Hordle, HH  
Keita Thomas, KT  
Laura Payne, LP  
Lisa Smith, LS  
Melanie Clark, MC  
Rachel O'Gara-Lu, RO  
Sally Watts, SW  
Sophie Charles, SC  
Stephanie Lawrence, SL

Maidstone & Tunbridge Wells  
Kings College Hospital  
University Hospitals Sussex  
Kingston Hospital  
Ashford & St Peters  
University Hospitals Sussex  
Frimley Health  
South Thames Paediatric Network  
Evelina Children's Hospital  
Royal Surrey County

### Discussion

#### 1. *Welcome and introductions*

FK welcome the group and began introductions

#### 2. *Terms of Reference*

SM shared the draft Terms of Reference. Kirsten McHale was noted as the Deputy. There were no further amendments requested during the meeting.

**ACTION: SM to share the draft to the group. All to provide feedback by the next CNS Forum, after which it will be finalised.**

### 3. Plan for future CNS Forums

FK requested that the group advise what they want the forum to primary focus on. Following this we had discussion as the following potential topics:

- Agenda item regarding tertiary care such as the VNS Referral pathway
- Genome Sequencing requests – a talk through of the process and sharing of experiences. Potentially a teaching session around the consent forms for genetic blood forms for patients as it is complex and time consuming.
- Emergency Care plans – this was previously being worked on through SETPEG members but ran into obstacles. KM advised that Richard Brown Chair of Open UK Regional Epilepsy Network is currently in the process of finalising an emergency care plan and suggested we utilise this.
- A case study around a challenge a team or service had to overcome and learning outcomes from the case.

**ACTION: KM to provide an update on the emergency care plan via Open UK.**

Using slido the group answered a few questions, listed below with summarised answers:

Question	Answer Summary
What are your new and follow up appointment lengths?	Average of 46 mins for a new appt, with 45 min and 60 min new appts being the most common. Average of 26 minutes for a follow up, with 30 min follow up appts being the most common.
What proportion of new Epilepsy patients are seen by the ENS?	Average of 78%, with the answer 100% of patients being seen by the ENS as the most common answer.
Do you hold a nurse prescribing qualification and if no, is it something you would be willing to do as part of your role.	8% advised they have a nurse prescribing qualification and it was split 55/45 in favour of those willing to do nurse prescribing as part of their role.

### 4. Mental Health Screening Tool QI project – Epsom and St Helier

NH presented on the Quality Improvement Programme currently underway at Epsom & St Helier Hospital around the implementation of the HEADS-ED Screening Tool for patients over 5 years old.

Key points include:

- It began in October 2021 with the support of the RCPCH
- When it began there was no psychologist access but that has since changed and there is some limited psychology time with a very strict referral criteria and a long waiting list.
- At Epsom Hospital, it was found that when children come in for the hour long appointments, they can do the HEADS-ED screening tool then though there isn't enough time at follow up appointments. If it were to be used for follow-up appointments, it will likely be used once a year or maybe more depending on the patient.
- At St Helier, they found that the SDQ questionnaire was more helpful as it could be completed before clinic whilst waiting. However, SDQ didn't work for new patients as well as would be needed and is better for follow-ups.

- The HEADS-ED form allows the clinician to open up the conversation and find out more about how the patient is doing at home or school, if they are having any dark thoughts etc. With this it means that children whose parents thought were fine, weren't okay and helped bring up to the surface important issues.
- Around a 50/50 split has been found so far of the patients who have mental health concerns and who does not.
- Referring and sign posting patients to the right place is a challenge since without significant psychology support, it's difficult to have young people engage.
- Most are referred to apps/sites, where they feel the patients' needs more urgent help, they are referred to CAMHS though this doesn't affect waiting list time.
- The next steps would be to look at how beneficial it is to signpost patients to apps or resources.

**ACTION: FK to share the SDQ Questionnaire utilised at Epsom and St Helier.**

5. *BPNA Sodium Valproate update*

KM provided an update on the decision by MHRA to standardise the safety measures around sodium valproate in December 2022 for there to be two clinicians validating the prescription. The decision is currently being challenged by Young Epilepsy. The BPNA also sent out a statement. KM advised she will bring any updates to the group at future forums.

6. *AOB*

The group discussed the current shortage of lamotrigine. MA was advised it is expected to improve within 2 weeks and to use the 100mg dispersible dissolved in water as the next best option.

**Next meeting:** Thursday 11<sup>th</sup> May 2pm – 3pm via MS Teams.