Poster Tour: Epilepsy

May 6, 11:45 - 12:45

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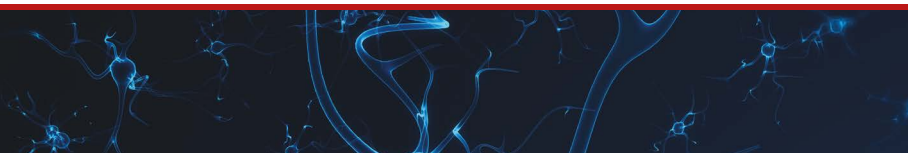

Cryptogenic New Onset Refractory Status Epilepticus in an adult: Clinical pearls and pitfalls of management

Sarah Wrigley[1], Aimal Khan[1], Joe Lu[1], Matthew Walker[1], Corinne Li[1], Marios Kaliakatsos[2], Rachel Brown[1], Jennifer Spillane[1]

[1]National Hospital For Neurology And Neurosurgery, [2]Great Ormond Street Hospital

Introduction: New onset refractory status epilepticus (NORSE) carries a mortality of 22% in adults. Aetiology is determined in only 50% cases; the remainder are considered cryptogenic (cNORSE). Patients with refractory status epilepticus (SE) demonstrate serum/CSF elevations in proinflammatory cytokines. Modulation of innate immunity may therefore be efficacious in refractory SE. International guidelines recommend IL-1 or IL-6 inhibition as second-line immunotherapy for cNORSE, while case series report effective use of intrathecal dexamethasone.

Case report: A 44-year-old woman presented with NORSE ten days following a febrile illness. Initial neuroimaging was normal. CSF was non-inflammatory; however, IL-6 was elevated. Infectious and autoantibody panels were negative. She was classified as cNORSE and required intensive care for over 100 days. Electroencephalographic burst-suppression was achieved using ketamine but prolonged ketamine use caused severe hepatotoxicity. SE persisted following intravenous methylprednisolone, plasma exchange and anakinra treatment, but terminated following administration of tocilizumab and intrathecal dexamethasone. CSF IL-6 remained elevated throughout treatment.

Learning points:

1. Increasing evidence supports the use of tocilizumab and intrathecal dexamethasone in the management of cNORSE

2. IL-6 levels may be raised and remain elevated following effective treatment of cNORSE.

3. Ketamine is effective in refractory SE but use may be limited by hepatotoxicity.

Patients who do not attend their appointment for assessment after a first suspected seizure

Hannah Eaton[1], Tom Atkinson[1,2], Rhys Thomas[1,3], Shan Ellawela[3]

[1]Translational and Clinical Research Institute, Newcastle University, Framlington Place, [2]North Tees and Hartlepool NHS Foundation Trust, University Hospital of North Tees, Hardwick Road, [3]Neurosciences, Royal Victoria Infirmary

Background: NICE guidance recommends that adults with a suspected first seizure are reviewed by a specialist within two weeks. A 2018 audit of our first seizure service demonstrated high did-not-attend (DNA) rates, increased mortality, and reduced attendance among patients from deprived areas. The service was subsequently redesigned and reaudited.

Methods: All adult referrals between 01/01/2025 and 10/02/2025 were included, excluding duplicates and those triaged elsewhere. Distance from the Royal Victoria Infirmary and Index of Multiple Deprivation (IMD) scores were calculated from postcode data. Attendance, appointment modality (telephone vs face-to-face), waiting times, and mortality were extracted from clinical records.

Results: Ninety-six patients were included (41% female, 59% male; mean age 45.1 years). The DNA rate was 27.1%, with no significant association with deprivation, distance, age, or sex. DNA rates did not differ significantly between telephone and face-to-face appointments; telephone reviews showed a non-significant trend towards poorer attendance. Only 4.3% were seen within two weeks; mean waiting time was 51.2 days. Two deaths occurred: one SUDEP and one non-epilepsy-related.

Conclusion: Service redesign has reduced DNA rates and removed socioeconomic and geographic disparities. Appointment modality did not significantly affect attendance. Delays in access to specialist review persist and remain a priority for improvement.

Diagnostic Value and Utilisation of Home Video in Epilepsy Care Within a Tertiary Neurology Department

Vivienne Evans[1], Siddharth Kamath[2], Rhys Thomas[1,3]

[1]Neurosciences, Royal Victoria Hospital, Newcastle Upon Tyne Hospital Trust, UK, [2]School of Medicine, Newcastle University, Newcastle Upon Tyne, UK, [3]Translational and Clinical Research Institute, Newcastle University, Newcastle Upon Tyne, UK

Home video (HV) is a useful adjunct in diagnosis and decision making in epilepsy. But several factors may lead to underutilisation of this resource. These may be technological (inability to open files, lack of centralised storage), clinical (time/clinical pressure; absent context), or technical (poor HV quality). We aimed to highlight the benefit of HV in a tertiary neurology service, and addressable pitfalls that may hinder use.

346 videos submitted by 103 individuals between 1st May 2025 and 31st October 2025were analysed alongside patient letters, diagnoses and outcomes.

On average epileptologists wrote to patients within 16 days (range 1-123 days), with delays most associated with technological difficulty or clinical pressures. 25 individuals received new diagnoses after HV review; including 16 diagnoses of NEEs (alone or alongside established epilepsy) and two cases where HV allowed classification of previously unclassified seizure. In 24 individuals, HV-review triggered medication titration or expediated review, including two direct admissions. In 42 incidences, documentation of HV review was absent.

In conclusion, HV represents a valuable tool for increasing the quality and safety of patient care. However, its use may be curtailed by a range of factors. Future projects aim to address modifiable factors associated with under-utilisation of HV.

Fenfluramine in CDKL5 Deficiency Disorder: Primary Efficacy and Safety Results From a Phase 3 Study

Nicola Specchio[1,2], Eric Marsh[3,4], Orrin Devinsky[5], Ángel Aledo-Serrano[6], Domenica Immacolata Battaglia[7,8], Rajsekar Rajaraman[9,10], Sam Amin[11], Brian Moseley[12], Brian Kilgallen[12], Joseph Sullivan[13]

[1]Bambino Gesù Children's Hospital, IRCCS, Member of European Reference Network (ERN) EpiCARE, [2]University Hospitals KU, 3Children's Hospital of Philadelphia, [4]Perelman School of Medicine at the University of Pennsylvania, [5]NYU Comprehensive Epilepsy Center, NYU Langone Medical Center, [6]Clinical Neurosciences Institute, Blua Sanitas Valdebebas Hospital, [7]Fondazione Policlinico Universitario Agostino Gemelli, IRCCS, [8]Università Cattolica del Sacro Cuore, [9]David Geffen School of Medicine, [10]UCLA Mattel Children's Hospital, [11]University Hospitals Bristol and Weston, [12]UCB, [13]Weill Institute for Neurosciences and Benioff Children's Hospital, University of California San Francisco

Objective: To report primary results from an international, multicenter, randomized placebo-controlled trial (RCT; NCT05064878) of fenfluramine in patients with cyclin-dependent kinase-like 5 (CDKL5) deficiency disorder (CDD). Methods: Eligible patients (1–35y) with confirmed/likely pathogenic CDKL5 mutation, clinical CDD diagnosis, and ≥4 countable motor seizures/week (caregiver-reported) were randomized to fenfluramine 0.7 mg/kg/day (max 26 mg/day) or placebo over 2-week titration (T) and 12-week maintenance (M). Primary efficacy endpoint was countable motor seizure frequency (CMSF) percentage change from baseline over T+M vs placebo; safety was assessed. Results: Safety and modified intent-to-treat populations included 87 (fenfluramine, n=42; placebo, n=45) and 86 (fenfluramine, n=42; placebo, n=44) patients, respectively. Baseline median (range) CMSF was 44 (16–290), fenfluramine and 49 (0–1382), placebo. Median CMSF change from baseline was significantly improved with fenfluramine (−47.6%) vs placebo (−2.8%), P<0.001. Four patients (3, fenfluramine; 1, placebo) discontinued this RCT due to treatment-emergent adverse events (TEAEs). In patients receiving fenfluramine, pyrexia, diarrhea, and somnolence were commonly reported (n=8 each, 19%). No new safety signals were identified, with no valvular heart disease or pulmonary arterial hypertension cases and no deaths in this RCT. Conclusions: Fenfluramine may be a promising therapy for treating CDD-associated seizures.

Attendance rates for epilepsy appointments in relation to deprivation: comparison of face-to-face and virtual appointments.

Rajiv Mohanraj, Kabir Josan, Keira Annie Markey, Prajwal Khairnar, Karim Webb, Robyn Hamilton

Salford Royal Hospital

Background: Epilepsy patients face hurdles in accessing care, relating to socio-economic and demographic factors. We analysed Did Not Attend (DNA) rates with respect to Index of Multiple Deprivation (IMD) quintiles for all patients and epilepsy patients; separately for face to face and telephone appointments.

Methodology: We used automated diagnosis pipeline to map diagnosis to demographics for patients attending neurology clinics in Greater Manchester. Outcome of appointment (attended versus DNA) was analysed for each IMD quintile, separately for face-to-face and telephone appointments.

Results: A total of 116,593 patients were included in the analysis, of whom 24880 had a diagnosis of seizure / epilepsy. Patients from more deprived areas had a higher DNA rate. Patients with epilepsy/seizure had a higher DNA rate than that for all neurology across all IMD quintiles. Epilepsy patients from IMD1 (most deprived) had a DNA rate of 13.6% compared to 7.3% in IMD5 ($p < 0.01$). For epilepsy patients, face to face appointments had a DNA rate of 16.5% in IMD1, and 8.4% in IMD5 ($p<0.01$). However, for telephone appointments, there was no significant difference in DNA rate across the IMD quintiles.

Conclusion: Telephone appointments can potentially help overcome barriers to accessing epilepsy care based on deprivation.

Vagus nerve stimulation induced reflex seizures

William Clark[1], Vivienne Evans[2], Joanne Glenton[2], Rhys Thomas[1,2]

[1]Translational and Clinical Research institute, Newcastle University, [2]Neurosciences, Royal Victoria Infirmary

Vagus nerve stimulation (VNS) is indicated for epilepsies of all classifications and it does not have a reputation for seizure aggravation. We report a 23 year old male with a SCN1A-spectrum disorder with many GEFS+ features, with an unusual response to VNS stimulation.

He has a mild intellectual disability, autism spectrum disorder, and holds down two part-time jobs. His epilepsy started with hemiclonic seizures at 6 months. Seizures types include tonic, atonic, absence, focal aware/unaware, focal to bilateral tonic-clonic (FBTCS) and rarely reflex seizures initially triggered by being tapped unexpectedly. In February 2024, VNS was implanted.

Following VNS insertion he had five-weeks of seizure freedom, which was highly unusual for him, but by April he developed frequent reflex seizures with multiple triggers including reading, smart phone use and exercise, severely impacting his quality of life. EEG with reading provocation captured a typical electroclinical event with left hemispheric origin progressing to a FBTCS. He commenced cenobamate and in Oct 2025 the device was switched off. Initial indications are that the reflex seizure frequency has reduced.

The mechanism of increased reflex seizures with VNS is unclear and further research is needed so we can predict VNS response and target implantation appropriately.

Occipital Lobe Status Epilepticus Secondary to Non-Ketotic Hyperglycaemia

Aidan Whitehead[1], Christopher Murphy[1], Samantha Jefferson[1,2], Calvin Soh[2]

[1]Manchester Centre for Clinical Neurosciences, [2]Manchester University NHS Foundation Trust

A 67 year old lady presented with a six week history of intermittent right sided visual flashing, and four weeks of severe left sided headache with nausea, photophobia and scalp tenderness. She had a past medical history of deep vein thrombosis, asthma, hypertension, obesity, and hypothyroidism.

Following initial differential diagnoses of retinal migraine and bilateral posterior vitreous detachment, a right homonymous hemianopia was identified and the patient referred to investigate for stroke. Examination otherwise demonstrated normal cranial nerves including optic discs, eye movements, and pupil responses. Laboratory investigation was predominantly normal aside from HbA1c of 108 mmol/mol.

Initial CT scan was reported as normal, but MRI scan showed marked T2 hypointensity in the subcortical white matter of the left occipital lobe without diffusivity change. The changes were proposed to be due to occipital lobe seizures secondary to non-ketotic hyperglycaemia.

Electroencephalogram captured 2 typical events with corresponding evolution of rhythmic theta activity over both occipital regions, confirming occipital lobe seizures.

Treatment was commenced for new onset type 2 diabetes. Levetiracetam 500mg BD improved the frequency and severity of the visual symptoms by 6 weeks at follow up, and follow up MRI scan is awaited.

An Audit of Women's Health Counselling in the Epilepsy Clinic

Rudramun Gopal[1], Rose Erritsos Dulson[1], Emily Pegg[1,2]

[1]Manchester Centre for Clinical Neurosciences, [2]University of Manchester

Background: NICE recommends proactive, personalised preconception counselling and menopause information for women with epilepsy. MBRRACE identifies preconception counselling, including contraception advice as essential to improving care and reducing maternal mortality.

Methods: Electronic records of 126 women attending the epilepsy clinic at Manchester Centre for Clinical Neurosciences were reviewed and categorised by age. Notes for patients under 55 were reviewed for contraception documentation and counselling, those aged 45 and under for preconception counselling, and those over 45 for menopause information. Women with severe learning disability were excluded from the contraception and pre-conception analyses.

After the initial audit, a prompt to record contraception use was added to the electronic clinic template. A prompt was also introduced to include automated menopause information in the clinic letter, when applicable.

Results: In the initial audit cycle, preconception was discussed with 15% of patients and contraception discussed in 53% of those not documented to be using contraception (56%). Menopause was discussed in 36%. Information provision varied by staff role and physician sex. There was no significant improvement after prompts were added to the clinic template.

Conclusions: Improved integration of women's health considerations into routine epilepsy care is vital to improve health outcomes.

The Public Health and Economic impact of SUDEP: A Hamiltonian Markov Chain Monte Carlo Model

Alexander Grundmann[1,2], Rhys Thomas[1,2]

[1]Royal Victoria Infirmary, [2]Translational and Clinical Research institute, Newcastle University

SUDEP is the leading epilepsy-related cause of death, yet UK public health and societal burden estimates are lacking. This limits the ability of research and clinical communities to understand SUDEP risks and justify investment in preventative strategies.

We therefore developed a Hamiltonian Markov Chain Monte Carlo model integrating pooled SUDEP incidence and age/sex distributions from registry studies, UK epilepsy prevalence, and ONS life tables. Economic burden was estimated using a societal cost-of-illness framework with human capital approach for productivity losses and QALY-based intangible costs (£70,000/life-year), following established methodology.

We estimated 1,060 annual UK SUDEP deaths (90% CrI:705–1,596), 61% of which were male. Mean age at death was 40.6 years, with 41.7 years of potential life lost per death. Male incidence (1.84/1,000 PWE-years) exceeded female (1.17/1,000). Lifetime SUDEP risk for those diagnosed aged 5, 25 and 45 was 11.04%, 8.23% and 5.40% respectively. Total annual societal economic burden was £1.50 billion (90% CrI:£1.00–2.27B).

SUDEP causes over 1,000 UK deaths annually with substantial productivity impact due to young age at death. This £1.5 billion annual burden and high lifetime risk for young-onset epilepsy underscore the need for ongoing research into risk modelling, preventative strategies and improved mechanistic understanding.

Newcastle's First Experience With EASEE® Epicranial Neuromodulation For Drug-Refractory Focal Epilepsy: A Two-Patient Case Series.

Lavindren Luke Panneerchelvam, Mohammed Akbar Hussain, Ming Lai, Rhys Thomas

Newcastle Upon Tyne Hospitals NHS Foundation Trust

Background: Many patients with focal epilepsy remain drug-resistant and are unsuitable for resective surgery because of non-lesional imaging, widespread epileptogenic networks, or overlap with important brain regions. The Precisis EASEE® system is an epicranial neuromodulation device delivering cortical stimulation for seizure suppression.

Methods: We report the first two patients in Newcastle implanted with the EASEE® device. Both had drug-resistant focal epilepsy and were not candidates for resection. Patient 1 had MRI-negative sleep-related hypermotor epilepsy with a right parietal–frontal network. Patient 2 had left fronto-parietal focal cortical dysplasia. Epicranial electrodes were placed over the epileptogenic zone and connected to a chest-wall pulse generator.

Results: Implantation was uncomplicated, taking place on 01/04/25 and 03/09/25, respectively. Both patients experienced mild local discomfort that resolved. Patient 1 had early improvement with variable seizures. Patient 2 showed a reduction in nocturnal seizures from 3–4 per week to 1–2 per week and aborted an aura using patient-activated stimulation. EASEE® programming was adjusted over time to balance seizure control and tolerability.

Conclusion: Epicranial focal neuromodulation with the EASEE® device appears feasible and acceptable in selected patients with non-resectable focal epilepsy and may offer a practical alternative when resection is unsafe. Further follow-up is required to assess durability.