13.04.2023

Dr Karen Henderson
HM Assistant Coroner for Surrey

Re: The Inquest Touching the Death of Louis James Rogers A Regulation 28 Report – Action to Prevent Future Deaths

Dear Dr Henderson,

Further to your Regulation 28 Report the Royal College of Emergency Medicine (RCEM) were sorry to learn about the death of Louis James Rogers and we extend our condolences to his family.

We understand from your report that Louis had an undiagnosed rare genetic condition Dravet's syndrome [1] which led to a seizure whilst asleep and then unfortunately death (Sudden unexpected death in epilepsy [SUDEP]). We are aware that increased body temperature can be a trigger for seizures in Dravet's syndrome and that these seizures may be of a complex nature (lasting longer than 15 minutes or occurring again within 24hr [2]; last longer than 10 minutes or febrile seizures associated with other features, such as weakness, on one side of the body [3]). Your report suggests that there may have been a missed opportunity to recognise a complex febrile seizure on the same day Louis had been discharged from hospital (after seeing a paediatrician) following an attendance with a seizure.

As I am sure you are aware, febrile seizures are common (2-5% of all children) between the ages of 3-5 years [4] and this accounts for a significant number of emergency department (ED) attendances. The National Institute for Healthcare Excellence has issued guidance on the treatment of febrile seizure as well as the indications for referral to a paediatrician; which includes the first presentation of a febrile seizure, complex febrile seizure and any child under the age of 18 months [5]. The majority of children who have febrile seizures do not require hospital admission or multiple investigations. It is important that children are not unnecessarily admitted to hospital or subjected to invasive investigations with low yields but which cause anxiety and/or distress.

RCEM would be happy to work with NHS England / National Institute for Healthcare Excellence, Royal Colleges and other interested parties to help develop further evidence based or consensus guidance in this complex area of clinical practice. We are mindful that this would be a significant undertaking and that it would therefore not be appropriate for RCEM to take the lead on such a project.

Yours,

[redacted]

[redacted]
Chair of Quality in Emergency Care Committee

[1] Dravet Syndrome is a rare, life-limiting & devastating genetic neurological condition, occurring in 1/15,000 live births in the UK. The condition causes treatment-resistant epilepsy & intellectual disability alongside a spectrum of associated conditions including autism, ADHD, challenging behaviour, difficulties with speech, mobility, feeding & sleep. https://www.nhs.uk/services/service-directory/dravet-syndrome-uk/N10497324
[2] Febrile seizures - NHS (www.nhs.uk)
[3] Epilepsies in children, young people and adults (nice.org.uk)
[4] Febrile Seizures | Epilepsy Foundation
[5] Scenario: Management after a febrile seizure | Management | Febrile seizure | CKS | NICE