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HM Coroner's Court
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National Medical Director
NHS England
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20 June 2023

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Louis James Rogers who died on 18 June 2021

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 28 March 2023 concerning the death of Louis James Rogers on 18 June 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Louis' family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Louis' care have been listened to and reflected upon.

I am grateful for the further time granted to respond to your Report, and I apologise for any anguish this delay may have caused Louis's family or friends. I realise that responses to Coroner Reports can form part of the important process of family and friends coming to terms with what has happened to their loved ones and appreciate this will have been an incredibly difficult time for them.

Management of febrile seizures and guidance for clinicians

In your Report you express concerns for the management and investigation of Febrile seizures and the link to Sudden Unexpected Death in Childhood (SUDC), febrile seizure pathways and national guidance for General Practice.

The National Institute for Health and Care Excellence (NICE) are responsible for producing clinical guidance for health and care practitioners on the issue of febrile seizures. Their guidance on [Epilepsies in children, young people, and adults \(NG127\)](#) covers the diagnosis, treatment and management, referral recommendations and information and support for the management of epilepsy and seizures in children:

Regarding General Practice guidance, there is also a [Clinical Knowledge Summary \(CKS\)](#) on febrile seizure, which provides best practice advice for Primary Care practitioners. This includes clear guidance on assessment of a child, following a febrile seizure and on where referrals should be made to secondary care and paediatricians. This includes the following:

- Immediate hospital assessment by a paediatrician should be arranged:
 - For a first febrile seizure (or if a child has not been previously assessed by a paediatrician).
 - If the child is less than 18 months of age, there is diagnostic uncertainty about the cause of the seizure, or for recurrent complex febrile seizure.
 - If there is any focal neurological deficit, recent antibiotic use, or there is parental/carer anxiety or difficulty coping.
- Urgent hospital assessment should be considered if:
 - There is unexplained fever and no apparent focus of infection.
- Referral to a paediatrician or paediatric neurologist should be arranged if:
 - The child has neurodevelopmental delay and/or signs of a neurocutaneous syndrome or metabolic disorder.

NHS England has been sighted on the response to your Report from NICE, who have advised that there is sufficient national guidance regarding the management of febrile seizures.

The [British Paediatric Neurology Association](#) (BPNA) provides a series of one/two-day courses on Paediatric Epilepsy Training, which are recognised as exemplar training by the [International League Against Epilepsy](#) (ILAE) and are endorsed by numerous international colleagues:

- PET 1 is a 1-day course for all doctors and nurses involved in the care of children with seizures. This is generally for Paediatricians / Paediatric Nurses but is also open to GPs.
- PET 2 is a 2-day course for paediatricians and nurses in district hospitals with an interest in epilepsy focussing on epilepsies in younger children.

Patterns of presentation, guidance for referral, red flags for further investigation as well as Sudden Unexpected Death in Epilepsy (SUDEP) / communication with children and families are at the core of this national training programme. National education with reference to childhood epilepsy for paediatricians at a local and regional level has improved markedly with the roll-out of this programme over the last 18 years.

The gene (SCN1A) mutations that cause the majority of Dravet Syndrome cases cause a wide spectrum of seizures and epilepsies, with Dravet Syndrome being at the extreme end, but febrile seizures on the other. The possibility of Dravet Syndrome would be a concern in children presenting with prolonged, unilateral, and frequent febrile seizures in the first year of life, which would need to be genetically investigated. The ILAE recommends genetic testing in 'children aged 2-15 months presenting with a recurrent seizure of aetiology with recurrent prolonged focal or generalised convulsive seizures with or without a fever'. We have consulted with Paediatric Neurology specialists who have advised that Dravet Syndrome is being recognised at an increasingly younger age and knowledge about appropriate management is improving widely.

Regarding the pathway for febrile seizures, any assessment for a febrile seizure should include an assessment of the child's and their family's history, as the NICE guidance makes clear. We would also recommend that, wherever possible, there is a single named paediatrician for any child to ensure continuity of care. The [NHS England](#)

[Shared Care Records programme](#) will also help join up information held on patients who have had contacts between different health care providers and services. National interoperability between all public sector services is a priority workstream for the 2023/25 programme.

Information for parents and carers

You also raised a concern regarding the information provided to parents/carers after their child has had a febrile seizure. The guidance referenced above outlines the information and support that should be provided to parents and carers, following a seizure.

The Association of Child Death Review Professionals (ACDRP) have also requested to update the [NHS website page on febrile seizures](#) to include updated information on complications of febrile seizures, risks of epilepsy and further guidance on SUDC. This is expected to be updated shortly.

The increased risk of children who have experienced febrile seizures of developing epilepsy, having neurodevelopmental delays, or suffering SUDC is very low. Febrile seizures are very common in childhood and there is a balance to be met to avoid disproportionately concerning parents and carers. We have heard from Paediatric Neurology specialists that the advice within the leaflet on febrile seizures should be tailored to safety-netting during seizure, management of infection and who to contact if further seizures occur.

Where there is concern about a child who is suffering from seizures, particularly where there may be suspicion of Dravet Syndrome, parents and carers would be expected to be counselled on the increased risk of epilepsy related death, forms of monitoring and sleep safety. Unfortunately, no monitoring methods or device are 100% effective to avoid SUDEP.

Other actions

As a result of your Report, we will also be asking colleagues from each of the seven NHS regions to share the learnings from this matter and the guidance available with their Integrated Care Boards for cascading to relevant healthcare professionals.

I would also like to highlight the National Child Mortality Database [Thematic Report](#) (published December 2022) which includes a recommendation for action by the Department of Health and Social Care (DHSC), NHS England and National Child Mortality Database (NCMD) to 'Ensure there is robust and consistent national training available on the child death review statutory process, Sudden Infant Death Syndrome (SIDS), Sudden Unexplained Death in Childhood (SUDC) and available resources'. Work is underway to review this and other related actions, to include providing high-quality support for families on these issues as well as to improve the evidence base for research on SIDS and safer sleep, and on SUDC and association with febrile seizures. We will also look to engage with the Royal College of Paediatrics and Child Health (RCPCH) on this matter.

Regarding any updates to be made to JRCALC guidelines for paramedic management of seizures in children, I have been sighted on the response to your Report from the

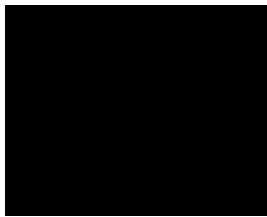
Association of Ambulance Chief Executives (AACE) who are the appropriate organisation to respond to this concern. I note that they have reviewed the JRCALC guidelines related to convulsions and that they are satisfied they provide the appropriate guidance.

NHS England is also sighted on Surrey Heartlands Integrated Care System's Child Death Review into the death of Louis and will consider if any further actions are required to be taken by us, following its completion.

I would also like to provide further assurances on national NHSE work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around preventable deaths are shared across the NHS at both a national and regional level and helps us pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,



National Medical Director