IN THE SURREY CORONER'S COURT
IN THE MATTER OF:

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

	THIS REPORT IS BEING SENT TO: • **President, Royal College of Paediatricians** • **JRCALC** • **N.I.C.E** • **Royal College of General Practice** • **Royal College of Emergency Medicine** • **NHS England**
1	CORONER Dr Karen Henderson, HM Assistant Coroner for Surrey
2	CORONER'S LEGAL POWERS I make this report under paragraph 7(1) of Schedule 5 to The Coroners and Justice Act 2009.
3	INVESTIGATION and INQUEST On 8th February 2022 I recommenced an investigation into the death of Louis James Rogers. On 2nd February 2023 I concluded the Investigation. The medical cause of death given was: 1a. Cardio-respiratory arrest 1b. Tonic-clonic seizure 2. Dravet's syndrome I determined: Box 3 & Box 4

	Louis James Rogers was a fit and well baby who had a self-limiting febrile seizure on the 29th September 2020 at 13 months of age. Louis had a further two seizures on the 11th February 2021. He was found in his bed at his home address on 20.47 hours on the 18th June 2021. There were no signs of life. He was transferred to St Peter's hospital, Chertsey but despite further attempts at resuscitation death was certified at 21.53 hours on 18th June 2021 at SPH, Chertsey. Genetic analysis after death confirmed Dravet's syndrome. Louis died by way of natural causes.
1.	CIRCUMSTANCES OF THE DEATH 1. Louis was born fit and well on 1st August 2019. On the 20th September 2020 he had a short self-limiting seizure whilst having a mild cold like illness. He was admitted to St Peters Hospital, Chertsey (SPH) for further assessment and discharged later that day having fully recovered. 2. Louis remained well until the morning of 11th February 2021 when he had a second self-limiting seizure. He was again taken to St Peters Hospital, Chertsey for observation and discharged later that day after being reviewed by a consultant paediatrician. 3. However, shortly after discharge, Louis had a further seizure in the early evening ~ 17.00 hours of 11th February 2021. The emergency services attended and after a period of observation, Louis remained at home. 4. On 1st May 2021 Louis attended the Emergency Department at St Peters Hospital accompanied by his father over concerns of a 1 day history of being lethargic, clingy and wobbly on his feet following a minor head injury 5 days prior. Louis was discharged after observations were normal and no abnormalities, including neurological deficits, were found.

5. On the 13th May 2021, Louis's parents visited and were reassured by the GP following concern over a further seizure whilst Louis was at nursery on a background of concerns over Louis's developmental regression.

6. On 18th June 2021 Louis had been clinically unwell and was laid down to sleep for the night. Louis was found unresponsive a short time later. Emergency services attended and Louis was taken to SPH with ongoing resuscitation but to no avail and Louis was recognised to have died at 21.53 hours on 18th June 2021 at SPH, Chertsey at 22 months of age.

7. Autopsy confirmed Louis had a viral infection at the time of his death and genetic studies confirmed a diagnosis of Dravet's Syndrome, a condition associated with developmental regression and delay, autism and epilepsy which can be triggered by pyrexia and may be resistant to treatment with antiepileptic agents.

CORONER'S CONCERNS

1. Management and investigation of Febrile Seizures

Evidence was heard that a number of children who have 'febrile' seizures subsequently die from 'sudden unexpected death in childhood'. Evidence was provided that there should be greater emphasis on medical education, research and public information for sudden unexpected deaths associated with febrile seizures. Further evidence was heard that referrals for assessment and investigation of febrile seizures should be undertaken earlier to exclude a more severe underlying illness.

2. Information provided to parents/guardians after their child had a Febrile Seizure

Evidence was heard that the NHS website and pamphlet provided to parents/guardians following a child's febrile seizure is insufficiently informative to provide parents with sufficiently detailed information to assist them in picking up potential early indicators of a more severe illness e.g. issues with gait, co-ordination, definition of complex seizures, developmental regression etc.

3. Improvement to and highlighting of the JRCALC guidelines for paramedic management of seizures in children

JRCALC guidelines indicated paramedics should have conveyed Louis to hospital or contacted the GP and/or Out of Hours GP service following Louis's second seizure on 11th February 2020, as the close proximity of two seizures indicated it was a 'complex febrile seizure' rather than a febrile seizure. This led to a lost opportunity to expeditiously trigger further investigation and/or a referral to either the 'first seizure' service or to a specialist paediatrician for further assessment and management. Evidence was heard that improving and highlighting JRCALC guidelines with additional teaching would prevent this happening again.

4. General Practice -

At his mother's request after the possibility of a further seizure, Louis was reviewed by his general practitioner on the 13th May 2021 following which Louis's mother was reassured without a detailed history from Louis's mother or a full neurological examination and in the absence of

	documentation in circumstances whereby it was acknowledged there was sufficient information at that time to refer Louis to secondary services for the management of children with febrile seizures. It would therefore be appropriate to consider providing robust national guidance and education to general practitioners to ensure appropriate history, examination, investigation are undertaken to allow timely referrals to secondary medical services to be undertaken. 5. Febrile Seizure Pathway Evidence was heard that Louis was seen by a number of clinicians without a co-ordinated response to his presentation and that consideration should be given for all hospitals emergency departments and GP's to be provided with a febrile seizure pathway as a checklist to ensure children are not given a diagnosis of a 'febrile seizure when this is not supported by their presentation and for all consultations – including GP appointment and information from the paramedics is available for all clinicians to view to provide a holistic picture and to assist further management.
6	ACTION SHOULD BE TAKEN In my opinion action should be taken to prevent future deaths and I believe that the people listed in paragraph one have the power to take such action.
7	YOUR RESPONSE You are under a duty to respond to this report within 56 days of its date; I may extend that period on request. Your response must contain details of action taken or proposed to be taken, setting out the timetable for such action. Otherwise, you must explain why no action is proposed.
8	COPIES

	I have sent a copy of this report to the following: 1. See names in paragraph 1 above 2. Mr and Mrs Rogers 3. Chief Executive, St Peters Hospital, Chertsey 4. [redacted] 5. [redacted] In addition to this report, I am under a duty to send the Chief Coroner a copy of your response. The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who, he believes, may find it useful or of interest. You may make representations to me at the time of your response, about the release or the publication of your response by the Chief Coroner.
	Signed: Karen Henderson DATED this 28th Day of March 2023