



20 April 2023

[REDACTED]

Dr Karen Henderson  
HM Assistant Coroner for Surrey

Dear Dr Henderson

**LOUIS JAMES ROGERS (DECEASED)**

I am writing in response to the preventing future deaths report we received at the Association of Ambulance Chief Executives (AACE) dated 28<sup>th</sup> March 2023, and I respond as our Managing Director on behalf of AACE, Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and our CEO.

It may be helpful for us to explain that AACE is a private company owned by the English and Welsh Ambulance NHS Trusts. It exists to provide ambulance services with a central organisation that supports, co-ordinates and implements nationally agreed policy. Our primary focus is the ongoing development of the English ambulance services and the improvement of patient care. It is a company owned by NHS organisations and possess the intellectual property rights of the Joint Royal Colleges Ambulance Liaison Committee UK ambulance service clinical practice guidelines (the "JRCALC guidelines"). AACE is not constituted to mandate or instruct ambulance services however it has national influence via the regular meetings of ambulance Chief Executives and Trust Chairs along with a network of national specialist sub-groups.

With regard to your matter of concern relating to ambulance services:

*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.*

I can confirm that I have liaised with the Chair of the JRCALC committee and that a review of the convulsions in children guidance has been undertaken. The JRCALC guidelines are used regularly by ambulance clinicians in everyday practice. Having reviewed our guideline we agree that if our guideline had been followed, Louis should have either been conveyed to hospital on 11<sup>th</sup> February 2021 when he had a second seizure that day or he should have been referred to a GP.

Our guideline for convulsions in children contains a lot of information, detailing points about incidence, severity and outcome, assessment and management. The management section includes information on how to manage an active seizure using medicines and has a section related to when children should be conveyed to hospital. Our guidance is not intended to be a medical textbook and we do not expect paramedics to only use our guidance to support clinical decisions.

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It is important to note that the education and training of paramedics is not within the remit of AACE or JRCALC. Ambulance services have local mechanisms such as seeking senior clinical advice to support decision-making and local pathways are established to determine where it is best to convey a patient and how to refer a patient to community services such as primary care if not conveying a patient to hospital. The guideline has a number of points within it that we wish to highlight:

- Always consider (and actively seek) the underlying cause for the convulsion.
- When managing a febrile convulsion, it is not sufficient to simply manage the convulsion. It is vitally important to seek and identify the underlying infection producing the child's fever, especially if managing in the community (although this should not delay immediate treatment priorities or hospital transport).
- It (*a seizure*) can be related to another underlying condition such as cerebral palsy or a genetic disorder.
- 66% of children only ever have one febrile convulsion; the remainder may have further episodes during subsequent infections.
- 1 in 20 epileptic children have CSE (more common in children with Dravet syndrome and Lennox-Gastaut syndrome).
- Transfer to further care: Any child two years old or less who has had a seizure (even if totally recovered).

The following children may not require transport to hospital:

Children following a febrile convulsion:

- that is not their first and
- who have completely recovered and
- where the carer is happy for the child not to be transported may be left at home, providing that urgent review by the general practitioner (GP) or out-of-hours (OOH) GP is arranged to establish the cause of the fever. If this cannot be arranged by the attending crew, the child must be transported to hospital.

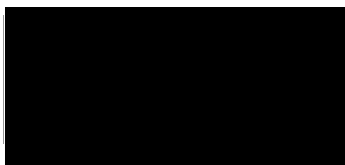
In summary, having reviewed our guidance related to convulsions in children, we do not believe that it needs improving at present. We will review it as part of our ongoing work to ensure that all our clinical guidelines are reviewed on a regular basis and kept as up to date as possible with any new clinical evidence that we become aware of.

We have taken an action to make all the medical directors and lead paramedics of UK ambulance services aware of the circumstances of Louis' death and have asked them to review the JRCALC guidance and any local pathways or guidance in relation to decisions around conveying children after seizures. We have also reminded ambulance trusts of a best practice guidance document that was written, approved and disseminated by NASMeD to ambulance trusts in July 2021: "Conveyance of children by operational ambulance clinicians in face-to-face settings" (attached). This was developed as a result of a Health Services Investigation Branch (HSIB) recommendation issued to us in June 2019 in relation to a case of an undetected button and coin cell battery ingestion in a child.

On behalf of AACE, I would like to extend our sincere condolences to the family of Louis James Rogers.

I hope this response has adequately addressed the concerns that you have raised. If you have any further questions please do not hesitate to get in touch.

Yours sincerely



Managing Director

