The Inquest Touching the Death of Mia Gauci-Lamport
A Regulation 28 Report – Action to Prevent Future Deaths

THIS REPORT IS BEING SENT TO:

- [redacted], **Chief executive, NHS England**
- [redacted], **Health Secretary, Department of Health**
- [redacted], **Chief Executive, Children's Trust, Tadworth**
- [redacted], **Medical Director, Children's Trust, Tadworth**
- **Care Quality Commission**

CORONER
Dr Karen Henderson, HM Assistant Coroner for Surrey

CORONER'S LEGAL POWERS
I make this report under paragraph 7(1) of Schedule 5 to The Coroners and Justice Act 2009.

INVESTIGATION and INQUEST

On 30th July 2024 I recommenced an investigation into the death of Mia Louise Gauci-Lamport. On 6th August 2024 I concluded the Investigation.

The medical cause of death given was:

1a. **STXBP1 related Encephalopathy with Epilepsy**

I concluded in the record of Inquest that Mia had died by way of:

Natural causes

CIRCUMSTANCES OF THE DEATH

Mia had Ohtahara syndrome due to an STXBP1 gene mutation. This causes treatment resistant refractory epilepsy and progressive global developmental delay. She required assistance for all her activities of daily living requiring full-time residential care which had been provided by Tadworth Children's Trust, (TCT), Tadworth from July 2020.

On 10th September Mia was well prior to going to bed and during the early hours of the 11th September 2023. She was last known to be alive at 06.10 hours. A carer entered her room at or around 06.15 but did not undertake any visual checks. Mia was found cyanotic and unresponsive 17 minutes later at or around 06.32 hours. Resuscitation was undertaken but was not successful and she was recorded to have died at the Trust shortly thereafter.

CORONER'S CONCERNS

1. Lack of appropriate monitoring of Mia during the night:

Mia's underlying illness caused seizures which were multifocal, complex and variable from tonic-clonic, myoclonic to cluster and absence seizures. Her care plan stipulated that carers should enter her room every 15 minutes to undertake visual observations throughout the night to ensure Mia was in a safe position, was breathing and not at risk of asphyxiation. However, this did not take place as frequently as specified. Moreover, it was common practice amongst some carers to review images from a video monitor placed over Mia's cot rather than direct visualisation despite it being recognised that the monitor was insufficiently sensitive to reassure the carer that Mia was breathing, seizure free and safe from asphyxiation.

2. Medical Care provided to Mia

Mia's medical records at TCT were neither comprehensive nor easy to understand and did not conform to the expected standard in NHS general or hospital practice to ensure accurate and contemporaneous medical care was being reviewed and documented.

Mia was a 'looked after' child with complex and challenging health needs and could not contribute or make decisions for herself. The independent investigator found regular PEWS (Paediatric Early Warning Scores) assessments were not undertaken to ensure Mia's well-being despite it

being within her care plan. There was no documented evidence that a multidisciplinary clinical review was regularly, if at all, undertaken to ensure Mia's risk was regularly assessed, appropriate monitoring was in place, and care provision was meeting her needs.

Mia was reviewed by a 'privately-funded' consultant employed by but working independently of Great Ormond Street Children's Hospital as and when requested by the medical staff at TCT. The consultant had no terms of reference and did not take responsibility for Mia's ongoing care and was consulted only in relation to adjustments in her medication for seizure control. Due to financial constraints the consultant's service level agreement was temporarily terminated and not available from April to October 2023.

In this context, Mia was not under a specialist NHS paediatric neuro-consultant to ensure her ongoing medical needs conformed to expected practice nationally and for an independent consultant outside of TCT to have regular oversight and co-ordinate investigations and any further multi-disciplinary management she may need given this progressive life-limiting condition.

3. Senior management, Children's Trust, Tadworth

The lack of a robust and adhered to care plan for night observations for Mia mirrors the same concern in the PFD report I issued following the Inquest touching on the death of Connor Wellsted at TCT in 2022.

The Independent investigator commissioned by TCT highlighted ongoing clinical governance limitations including the initial management and investigation of Mia's death, delay in fulfilling the Duty of Candour' obligations, ongoing staff training, ensuring robust procedures were in place alongside regular audits of clinical practice. These are the same issues highlighted in the PFD report I issued touching on the death of Connor Wellsted two years previously.

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.

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.

COPIES
I have sent a copy of this report to the following:

1. [redacted] and [redacted]
2. [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 14th October 2024