**IN THE WEST YORKSHIRE (EASTERN) CORONER AREA**

**HM AREA CORONER OLIVER LONGSTAFF**

**IN THE MATTER OF LILLY GRACE PROCTOR**

# REPORT TO PREVENT FUTURE DEATHS

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| | **THIS REPORT IS BEING SENT TO:**<br><br>1. [redacted], Chief Executive, National Institute for Health and Care Excellence<br>2. [redacted], Chief Executive Officer, Royal College of Paediatrics and Chid Health |
| 1 | **CORONER**<br><br>I am Oliver Robert Longstaff, Area Coroner for the Coroner area of West Yorkshire (Eastern). |
| 2 | **CORONER'S LEGAL POWERS**<br><br>I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of The Coroners (Investigations) Regulations 2013. |
| 3 | **INVESTIGATION and INQUEST**<br><br>On 7th April 2022 I commenced an investigation into the death of Lilly Grace Proctor, 28/02/2009. The investigation concluded at the end of the Inquest on 25/04/2024. The conclusion of the Inquest was a narrative conclusion reflecting Lilly's admission to and discharge from Pinderfields Hospital over the period 01-02/04/2022, her collapse at home on the early hours of 03/04/2022 and her death later that day in Pinderfields Hospital where she had been brought by ambulance. |
| 4 | **CIRCUMSTANCES OF THE DEATH**<br><br>Lilly Proctor died on 3rd April 2022 in Pinderfields Hospital, having collapsed at home in the early hours of the morning. She was 13.<br><br>A joint paediatric and forensic post mortem examination gave the cause of her death as 1a) Massive Pulmonary Thromboembolism 1b) Deep Vein Thrombosis 1c) Pathogenic PROS 1 Variant (said by the pathologists to have been causative of hereditary Protein S deficiency, a risk factor for venous thromboembolism).<br><br>The findings at post mortem were consistent with Lilly having developed a number of non-fatal pulmonary thromboembolisms prior to her final collapse, and in particular were suggestive of an old thromboembolism having developed around 6th March 2022 when she had sought out of hours advice for a pleuritic chest pain.<br><br>Lilly had a strong family history of thromboembolic disease, her mother having the Leiden Factor V mutation with a history of clots and anticoagulation from the age of 16, and her biological father having had a blood clot some two years before Lilly's death.<br><br>On 1st April 2022 Lilly (with her mother) attended the Emergency Department at Pinderfields Hospital with complaints of shortness of breath and chest pains. Of the five doctors who saw Lilly before her death, only one of them elicited the history of Lilly's |

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| | mother's Leiden Factor V mutation, and none obtained the history of blood clots in both of Lilly's parents. Her presentation was variously thought to be cardiac in origin, symptomatic of hypothyroidism, suggestive of pneumonia, attributable to a viral upper respiratory infection, or related to anxiety.<br><br>An independent expert paediatrician gave evidence to the Inquest that features of an ECG that were thought by treating clinicians to be attributable to Lilly's age were potentially indicative of a number of conditions, including heart strain and pulmonary embolus.<br><br>Lilly was discharged from hospital on 2nd April 2022 with no formal diagnosis and no prescribed treatment. She had been unable to complete an exercise test whereby she had been asked to walk a short distance around the department although her heart rate (which remained above 100 bpm throughout her admission) was recorded as the same at the beginning and the end of the test.<br><br>The combination of Lilly's ECG, a raised inflammatory marker and Lilly's extreme breathlessness would have justified an echocardiogram and 24 hour ECG being performed. Proper consideration of the parental history (if obtained) would have justified consideration of a CTPA investigation to confirm or exclude a pulmonary embolism, although the risks associated with that procedure may have militated against it.<br><br>It cannot be said on the balance of probabilities that any step taken as an alternative to discharging Lilly on 2nd April 2022 would have prevented the tragedy of her terminal collapse the following day. |
| 5 | **CORONER'S CONCERNS**<br><br>During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths will occur unless action is taken. In the circumstances it is my statutory duty to report to you.<br><br>The **MATTERS OF CONCERN** are as follows:-<br><br>(1) Whereas there are screening tools (such as "the Wells criteria") to assist the detection of pulmonary thromboembolism in adults, no child-specific screening tool is available in the UK and no existing screening tool for use in the adult population has been validated for use in children in the UK. The inquest heard evidence of such child-specific screening tools being developed in other countries, of which Italy was an example.<br><br>(2) NICE Guidance NG158 "Venous thromboembolic diseases: diagnosis, management and thrombophilia testing" is specific to adults. There is no corresponding guidance applicable to children. Similarly, the NICE Clinical Knowledge Summary for pulmonary embolism dated September 2023 is specific to adults with no corresponding publication applicable to children.<br><br>(3) The rarity of thromboembolism in children gives rise to a concern that without access to resources similar to those available when dealing with the adult population, clinicians working with children may be disadvantaged in diagnosing and treating the condition, to the obvious potential detriment of their patients. |
| 6 | **ACTION SHOULD BE TAKEN**<br><br>In my opinion action should be taken to prevent future deaths and I believe you or organisation have the power to take such action. |
| 7 | **YOUR RESPONSE**<br><br>You are under a duty to respond to this report within 56 days of the date of this report, |

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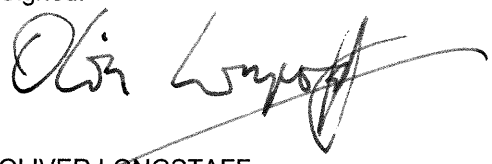
| | namely by 28/06/2024. I, the Coroner, may extend the period.<br><br>Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise you must explain why no action is proposed. |
| 8 | **COPIES and PUBLICATION**<br><br>I have sent a copy of my report to the Chief Coroner and to the following Interested Persons; [redacted] (Lilly's mother), Mid Yorkshire Teaching Trust..<br><br>I am also under a duty to send the Chief Coroner a copy of your response.<br><br>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.<br><br>You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner. |
| 9 | Signed:<br>  <br>OLIVER LONGSTAFF<br>Area Coroner<br>West Yorkshire (E)<br><br>Date: 01 May 2024 |