Regulation 28: Prevention of Future Deaths report

Freddie Oliver DOBINSON-EVANS (died 10.04.17)

	THIS REPORT IS BEING SENT TO: **1. Dr Lucy Jenkins** **Director** **North East Thames Regional Genetics Laboratory** **Great Ormond Street Hospital for Children** **Levels 5 & 6 Barclay House** **37 Queen Square** **London WC1N** **2. [redacted]** **Consultant in paediatric neurology** **Royal London Hospital** **Whitechapel High Road** **London E1 1BB**
1	**CORONER** I am: Coroner ME Hassell Senior Coroner Inner North London St Pancras Coroner's Court Camley Street London N1C 4PP
2	**CORONER'S LEGAL POWERS** I make this report under the Coroners and Justice Act 2009, paragraph 7, Schedule 5, and The Coroners (Investigations) Regulations 2013, regulations 28 and 29.
3	**INVESTIGATION and INQUEST** On 21 April 2017, one of my assistant coroners, Edwin Buckett, commenced an investigation into the death of Freddie Dobinson-Evans, aged one year. The investigation concluded at the end of the inquest on 1 March 2018. I made a determination at inquest of death by natural causes. I recorded a medical cause of death of:

	1a post cardiac arrest syndrome 1b Dravet syndrome
4	**CIRCUMSTANCES OF THE DEATH** Freddie's Dravet syndrome was not diagnosed in life. At the time of his death he was being investigated, and a diagnosis of complex febrile convulsions had been made by his treating clinicians.
5	**CORONER'S CONCERNS** 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. The **MATTERS OF CONCERN** are as follows. Following a testing request made for Freddie on 20 February 2017, a report was issued from the laboratory at Great Ormond Street Hospital on 7 June 2017. It was headlined: *No clearly pathogenic variant detected. Diagnosis not confirmed.* [redacted] spoke to Freddie's father the following day and told him that Freddie's genetic test results were "absolutely normal". In fact, Freddie did have a pathogenic gene mutation in the SCN1A gene and died as a result of Dravet Syndrome. By the time the report was issued, Freddie had already sadly died and so of course the misdiagnosis had no consequences for him, but such a situation could have significant consequences for another child.
6	**ACTION SHOULD BE TAKEN** In my opinion, action should be taken to prevent future deaths and I believe that you have the power to take such action.
7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report, namely by 14 May 2018. I, the coroner, may extend the period.

	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** I have sent a copy of my report to the following. • HHJ Mark Lucraft QC, the Chief Coroner of England & Wales • Care Quality Commission for England • [redacted], Freddie's parents • Homerton University Hospital NHS Trust • Barts and The London NHS Trust I am also 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, the Senior Coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner.
9	**DATE** **SIGNED BY SENIOR CORONER** 14.03.18