Barts Health NHS
NHS Trust

Barts Health NHS Trust
Paediatric Neurology Department
8th floor Paediatric Offices
The Royal London Hospital
London, E1 1BB
Telephone: 020 73777000 ext. 42476
www.bartshealth.nhs.uk

Ms Mary Elizabeth Hassell
Senior Coroner for Inner North London
St Pancras Coroner's Court
Camley Street
London
N1C 4PP

11/05/2018

Dear Ma'am,

Inquest touching the death of Freddie Dobinson Evans

I write in response to a Regulation 28, Report to Prevent Future Deaths, dated 14 of April 2018, which was made at the conclusion of the inquest into the death of Freddie Dobinson Evans. Barts Health NHS Trust takes Coronial investigations very seriously and I am sorry you have had to make Preventing Future Death recommendations and I am grateful to you for highlighting your concerns.

The concerns you have raised in the Preventing Future Death report are:

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.

Following actions were taken:

1. I have communicated with [redacted] (Clinical Scientist and director of the genetics lab. GOS hospital), who had promptly responded to my email.

2. On 24/04/2018, a meeting was held at the Lab. between [redacted] (GOS hospital Lab manager) and myself [redacted], Consultant paediatric neurologist),

3. [redacted] had listened carefully to the concerns and agreed that there are changes in the results format that was on the way and will be effective from 01/05/2018.

4. These changes were initiated in response to the inquest recommendation for prevention of future deaths.

5. I was shown the new results' template; The new template clearly addresses future directions in case of presence of any abnormality.

6. I will ensure that myself and the paediatric neurology team members keep effective communication with the Clinical scientists shall there remain in clarities.

Many thanks
[redacted]
Consutant paediatric neurologist
Royal London hospital.