ANNEX A

REGULATION 28: REPORT TO PREVENT FUTURE DEATHS (1)

*NOTE: This form is to be used **after** an inquest.*

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. Matt Hancock – Department of Health** **2. Prof [redacted] – Chair Royal College of General Practitioners** **3. Chief Executive Officer Medway NHS Foundation Trust**
1	**CORONER** I am Sonia Hayes assistant coroner, for the coroner area of Mid Kent & Medway
2	**CORONER'S LEGAL POWERS** 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. http://www.legislation.gov.uk/ukpga/2009/25/schedule/5/paragraph/7 http://www.legislation.gov.uk/uksi/2013/1629/part/7/made
3	**INVESTIGATION and INQUEST** On 20th December 2019 an investigation was commenced into the death of LUKE OWEN JACKSON, 9. The investigation concluded at the end of the inquest on 7th October 2020. The conclusion of the inquest was a narrative and the cause of death 1a Hypoxic Ischaemic Encephalopathy due to prolonged Cardiac Arrest 1b Hypokalaemia 1c Pneumonia II Becker's Muscular Dystrophy, Epilepsy, Post-Obstructive Hydrocephalus with VP shunt in situ *Luke died on palliative care at the Evelina Children's Hospital on 12th December 2019 of an Hypoxic Ischaemic Encephalopathy due to prolonged Cardiac Arrest caused by Hypokalaemia due to Pneumonia. He was transferred from Medway Maritime Hospital on 6th December 2019 following Cardiac Arrest having been admitted on 4th December with seizures, lower respiratory tract infection and Hypokalaemia. A history of diarrhoea and vomiting was caused by diversion of blood away from the gut as physiological compensation rather than infection. His Becker's Muscular Dystrophy and complex history meant that Luke was unable to correct his potassium as he had lower muscle mass and this resulted in total potassium depletion and raised heart rate. Luke's cardiac arrest was avoidable had his Hypokalaemia been appropriately recognised, managed, and treated in hospital.*

4	**CIRCUMSTANCES OF THE DEATH** Luke had a complex medical history with Becker's Muscular Dystrophy (later confirmed on genetic testing) and was being treated for a chest infection. He was admitted to Medway Hospital with a lower respiratory chest infection and acute gastroenteritis 4 December 2019 He had a fever, tachycardia and hypokalaemia (deficiency of potassium in the bloodstream) with high lactate treated with IV fluids with potassium and antibiotics. Further fluids were prescribed without potassium. On the evening of 05 December, Luke was started on humidified oxygen for mild respiratory distress and his oxygen levels were being monitored. A blood gas was requested, it was not performed. IV fluids were restarted (without potassium). His arm was noted to be very floppy. Luke went into cardiac arrest whilst an inpatient at 06:55 on 06 December 2019 from which he was resuscitated and transferred to the PICU at Evelina Children's Hospital the same day where he was treated and later died on palliative care.
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 could occur unless action is taken. In the circumstances it is my statutory duty to report to you. The Trust has taken action to address the conclusions of its Root Cause Analysis and has learned and disseminated lessons, improving its processes. This Report is made to assist learning in the public interest as evidence was heard from a consultant from a specialist children's hospital that total body potassium depletion is not always recognised in children with myopathies who become unwell. They may present with diarrhoea and vomiting due to shunting of the blood away from the gut to protect vital organs such as the brain and heart. The **MATTERS OF CONCERN** are as follows: – (1) Luke had complex needs and was awaiting results of genetic testing confirmed as Becker's Muscular Dystrophy. He had not been eating and drinking, had loose stools and vomiting that had progressed over a five-day period in a background of a chest infection. His parents had sought and followed medical advice from the hospital by telephone. Luke continued to deteriorate, and he was admitted. The Trust took some steps on admission to address his low potassium. (2) Evidence was heard from a Consultant from the Evelina Children's Hospital that they get almost 2000 referrals a year and many have diarrhoea and vomiting as a first symptom. Issues relating to metabolic derangement in a child with myopathies is not always recognised as total body potassium depletion and that treatment may need to be undertaken in intensive care due to the increased amounts of potassium required to correct the derangement and manage clinical risks: (i) Children with Myopathies - have low muscle mass that compromises their ability to correct their own potassium levels when unwell. (ii) Luke had a chest infection, however his low potassium made him weaker and as it progressed, he was shunting blood away from his gut to compensate (this assists to protect the vital organs such as the heart and brain) which resulted in loose stools and vomiting; this was <u>not</u> a consequence of gastroenteritis. One of the early symptoms of this shunting process is a high heart rate. (iii) A bolus of potassium and fluid resuscitation to treat gastroenteritis was not sufficient to treat total body potassium depletion which requires a central line with significant potassium replacement in intensive care to manage clinical risk.

	(iv) Development of a chest infection requires a child to breath harder and this becomes more difficult in a child with myopathies that is already weakened due to low potassium and will not present with the usual symptoms of respiratory distress. (v) As Luke was treated with oxygen therapy, the monitor alarm set for oxygen saturations did not sound as his oxygen did not deplete and he went into cardiac arrest.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you and your organisation 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 19th April 2021. 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 Chief Coroner and to the following Interested Persons [redacted] (parents of Luke) and [redacted](legal representative for Guy's & St. Thomas' NHS Foundation Trust. I have also sent it to [redacted] (Evelina London Children's Hospital) and [redacted] (Medway Hospital) who may find it useful or of interest. I am under a duty to send a copy of your response to the Chief Coroner and all interested persons who in my opinion should receive it. I may also send a copy of your response to any other person who I believe may find it useful or of interest. 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 coroner, at the time of your response, about the release or the publication of your response.
9	Signature: S. M. Hayes Sonia Hayes Assistant Coroner **Mid Kent and Medway** 21st February 2020