	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** [redacted] **Secretary of State for Health & Social Care** **Department of Health & Social Care** **C/O** Ministerial Correspondence and Public Enquiries Unit Department of Health and Social Care 39 Victoria Street London SW1H 0EU [redacted]
1	**CORONER** I am Alan Anthony Wilson Senior Coroner for **Blackpool & Fylde**
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** The death of Ryleigh Hillcoat - Bee was reported to me and I opened an investigation, which concluded by way of an inquest commencing 19th June 2024. I determined that the medical cause of Ryleigh's death was: **1a Cardiac arrhythmia** **1b Hyperkalaemia** **1c Rhabdomyolysis secondary to Lipin - 1 deficiency** **II Lower respiratory tract infection** In box 3 of the Record of Inquest I recorded as follows:

	Ryleigh Hillcoat - Bee was three years of age. On 9th August 2021 she was admitted to hospital where it was felt she had developed a respiratory infection. After further investigations, including some concerning blood test results reporting raised liver enzymes and very high levels of creatine kinase, treating clinicians sought some input from a liver specialist at a tertiary centre in Leeds who, by 12th August 2021, had advised that a neuromuscular cause be considered. With Ryleigh's blood tests results improving but still elevated, this advice was not pursued, and at a time when her mobility ought to have been raising concern she was discharged home with a view to further assessment in the community. It was felt that Ryleigh had myositis and hepatitis secondary to infection which had been treated with antibiotic therapy. The reason for her admission to hospital had in fact been an episode of rhabdomyolysis, a potentially serious clinical syndrome which is known to occur in young children, but only rarely. There was a missed opportunity to scrutinise what may have been affecting Ryleigh's mobility before discharge, which could have led to more awareness that her deterioration may have been associated with a neuromuscular problem, although from the available evidence it cannot be established that such enhanced awareness would have prevented her later death. Over the course of the following weeks, her condition was reassuring to the extent that by the time she attended a paediatric clinic on 28th September 2021 she was described as back to her normal self. However, by the early hours of 8th November 2021 she needed to be urgently taken to hospital. She went into cardio-respiratory arrest, and despite life-saving efforts she could not be revived and her death was confirmed at 7.33 am that morning. A subsequent post - mortem examination established that, unknown to medical professionals, Ryleigh had an inherited deficiency. A significant proportion of episodes of rhabdomyolysis prove to be fatal, causing high potassium levels in the blood leaving a child vulnerable to cardiac arrhythmia. Ryleigh had suffered a more significant episode of rhabdomyolysis than had been the case in August 2021, and had been susceptible to such an episode after recently developing a lower respiratory tract infection. In box 4 of the Record of Inquest I determined that: **Ryleigh Hillcoat - Bee died as a result of complications arising from rhabdomyolysis, a potentially fatal clinical syndrome associated with the breakdown of skeletal muscle fibres. It was not appreciated until after her death that Ryleigh had an inherited deficiency known to be a cause of early - onset acute rhabdomyolysis in childhood.**
4	**CIRCUMSTANCES OF THE DEATH** In addition to the contents of section 3 above, the following is of note: As recorded in the conclusion above, rhabdomyolysis in rare in young children, but potentially fatal. Ryleigh was admitted to hospital on two occasions, once in August 2021 and then in November 2021, and on both occasions the possibility she may be experiencing an episode of rhabdomyolysis was not appreciated. The senior, experienced paediatricians based at Blackpool Victoria Hospital had no prior experience of dealing with a rhabdomyolysis case.

	Evidence was given at the inquest by [redacted], a Consultant Paediatrician and Lead Clinician in metabolic medicine. [redacted] had ultimately overseen some genetic testing performed after Ryleigh died which resulted in a LIPIN – 1 deficiency being identified. He expressed the view that there have been cases of rhabdomyolysis in the past which have probably been missed by clinicians. [redacted] is a contributor to a guideline produced by BIMDG (British Inherited Metabolic Disease Group) entitled "Rhabdomyolysis in young children" (copy attached, although the court was informed a revised version is in the process of being finalised.). It is a guideline which highlights how rhabdomyolysis can lead to complications including hyperkalaemia [which can cause cardiac arrhythmias] and acute renal failure. The guideline includes guidance on management of this condition in young children. It was evident at the inquest there was a lack of awareness of the guideline, and of rhabdomyolysis in young children generally, and I was left with the impression that the only way a paediatrician may have any appreciation of this condition would be if that paediatrician has come across a similar case previously. The court also heard from an independent witness, a Consultant Paediatrician, who provided expert opinion. He too works in a general paediatric department at another hospital Trust. He too had no experience of dealing with a case of rhabdomyolysis in a young child before. When preparing his report, he had located just the one NHS guideline from another NHS Trust, a helpful document, which provides advice to clinicians regarding when rhabdomyolysis ought to be considered. What guidance is available to clinicians regarding rhabdomyolysis appears to be scarce. Having considered all of the above, I have determined that I have a duty to write this report.
5	**<u>CORONER'S CONCERNS</u>** 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. I simply raise the following concerns. It is not for the Coroner to be prescriptive about what action is taken. In the circumstances it is my statutory duty to send the report: The **MATTER OF CONCERN** is as follows. – • Ryleigh died from a rare condition, but one known to affect young children. There is a clear lack of awareness of the condition amongst paediatricians in general paediatric departments. • In my view there is a strong likelihood that previous cases of rhabdomyolysis in young children have been missed. • What guidance is available appears to be very limited. • In the event other young children attend a general paediatric department in the future for reasons connected to rhabdomyolysis, there is a concern the condition will go unrecognized and with fatal consequences.
6	**ACTION SHOULD BE TAKEN**

	In my opinion action should be taken to prevent future deaths and I believe 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. Given the approaching holiday period I have extended this period to Friday, 13th September 2**024**. I, the coroner, may extend the period further. 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: • The family of Ryleigh Hillcoat - Bee. • [redacted], Chief Executive, Blackpool Teaching Hospitals NHS Foundation 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 coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner. I also send a copy of this report to the following organisations: BIMDG [British Inherited Metabolic Disease Group] [redacted], Chief Executive Officer, Royal College of Paediatrics & Child Health
9	12/07/2024 Signature____ AAWilson _____ Alan Anthony Wilson Senior Coroner **Blackpool & Fylde**