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Ref: DM/VJ

Date: 1 June 2020

Mr Mark Bricknell Herefordshire Coroner Town Hall St Owen Street HEREFORD HR1 2PJ

Dear Mr Bicknell

## **Re: Jake Thomas Perry**

Thank you for granting me a 14-day extension to allow me to respond to your regulation 28 report to prevent future deaths with regard to Jake Perry. I am sorry that the current situation with regard to Coronavirus has delayed this important communication.

From the outset, I would like to extend my deepest sympathies to Jake's parents and family.

Jake suffered from a rare gastrointestinal disease, which rendered it necessary for him to receive nutrition through an artificial feeding line. He was under the care of the gastroenterology team at Birmingham Children's Hospital and the children's community nursing team in Hereford. He had direct access to the children's ward in Hereford.

On Saturday 15 July, he attended the children's ward at Wye Valley Trust because he had been unwell with vomiting and constipation. Jake suffered these type of episodes quite often but usually managed to cope with them at home. In addition, he complained of increasing weakness of his legs.

After examination, an initial diagnosis of Guillain Barre Syndrome was made and the paediatric neurologist at Birmingham Children's Hospital contacted. Following the review by second paediatric consultant later in the day Jake's low folate result was noted and the team planned to discuss this with Jake's gastroenterology team at Birmingham Children's Hospital.

The next day Sunday 16 July, Jake continued to deteriorate with increased weakness. The neurologist at Birmingham Children's Hospital was contacted again and both teams were still of the opinion Jake was suffering from Guillain Barre Syndrome.

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Glen Burley, Chief Executive



Jake was reviewed again on 17 July in Hereford when it was felt that some of his signs and symptoms could represent a nephrological problem and the plan was made to discuss with the renal team at Birmingham Children's Hospital. Jake underwent a lumbar puncture on 18 July following which the consultant team at Hereford contacted the neurological team at Birmingham Children's Hospital for a further opinion. Later that day Jake became increasingly unwell. He required intensive resuscitation in our intensive care unit and theatre and because of a concern that he may have suffered damage to bowel underwent a laparotomy that evening. Jake continued to deteriorate following a laparotomy and sadly died at 2030 that evening.

Subsequent investigation has revealed that the parenteral nutrition Jake was receiving had been deficient in B vitamins and had been for several months. Jake's inquest reached the conclusion that this deficiency of B group vitamins led directly to his death.

We conducted our own internal investigation into Jake's death to establish how our care could be improved. The four main findings were:

1. It would have been best practice to have contacted Jake's gastroenterology team at Birmingham Children's Hospital on admission.

2. Although we established that Jake suffered a low folate we did not discuss this with our own dieticians or the parenteral nutrition team at Birmingham Children's Hospital.

3. We did not consider alternative diagnoses as a cause for Jake's presentation. We became focused on the diagnosis of Guillain Barre Syndrome.

4. Our resuscitation and treatment of Jake's metabolic acidosis and impending shock was not timely.

We immediately instigated an action plan to improve our practice. This included the following:

1. To improve the information held on patients with open access to the children's ward.

2. To develop a proforma to include details of all health professionals involved in the care of the patient and the management plan for admission

3. These information proforma's will be updated and reviewed annually by the consultant paediatrician team.

4. An open access standard operating procedure would be developed.

5. The "situational awareness for everyone programme", designed by the Royal College of paediatrics and Child health would be implemented on the ward.

In addition, your regulation 28 report stipulates two actions I need to take:

1. Patients with a medical condition overseen by another hospital should have a named consultant at their local hospital.

2. Where a patient is admitted and has a medical condition overseen by another hospital the specialist Department (generally involved in the patient's care) of the overseen hospital (in addition to any other specialist hospital or Department) should be consulted.

I can confirm that we have developed a standard operating procedure for both the medical division and the surgical division (the paediatric department is contained within the surgical division) which address both of these issues. In addition, I have confirmed with the associate medical directors of the respective divisions, **surgical division** and **surgical division** that the standard operating procedures have been through the relevant governance processes in the respective divisions and are in operation.

I trust the above reassures you and Jake's family that we have reviewed the circumstances around Jakes tragic death, and learned important lessons from it.

Yours sincerely

Jun /

David Mowbray M RCOG Medical Director Wye Valley NHS trust