
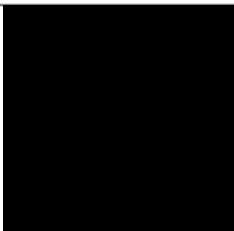


	<p>REGULATION 28 REPORT TO PREVENT FUTURE DEATHS</p> <p>THIS REPORT IS BEING SENT TO: The Royal College of Emergency Medicine ('RCEM'); The Royal College of Physicians; The Faculty of Intensive Care Medicine; The Royal College of Obstetricians and Gynaecologists; The Royal College of Midwives.</p>
1	<p>CORONER</p> <p>I am Emma Brown, Area Coroner for the jurisdiction of Birmingham and Solihull</p>
2	<p>CORONER'S LEGAL POWERS</p> <p>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.</p>
3	<p>INVESTIGATION and INQUEST</p> <p>On 4 August 2025 I commenced an investigation into the death of Chloe Angela ULETT. The investigation concluded at the end of the inquest hearing on the 11th February 2026. The conclusion of the inquest was; Natural causes.</p>
4	<p>CIRCUMSTANCES OF THE DEATH</p> <p>Miss Chloe Ulett died at Birmingham Heartlands Hospital on the 28th September 2024 from a previously undiagnosed urea cycle disorder which had been unmasked by giving birth on the 10th September 2024.</p> <p>Miss Ulett had developed symptoms of excessive drowsiness and confusion by the early afternoon of the 13th September and attended for assessment at the maternity triage unit at Birmingham Women's Hospital that afternoon but she was diagnosed with iron deficiency and discharged. Her altered mental state was not explained by anaemia, and she required admission for investigation.</p> <p>At home Miss Ulett's symptoms increased and a call was made to the maternity unit triage who wrongly advised to continue the treatment for iron deficiency and monitor Miss Ulett overnight instead of advising that she should attend the emergency department. Due to further deterioration an ambulance was called which transferred her to Birmingham Heartlands Hospital where she arrived at 00:32 on the 14th September. By 3.18am she could not speak and had lost the ability to use her arms or legs. Following medical assessment, her differential diagnosis was wide and included suspected encephalitis, meningitis, cerebral venous sinus thrombosis, postpartum infection and postpartum psychosis. The differential was gradually narrowed over the subsequent days and by the evening of the 17th September a Urea Cycle Disorder was suspected based on raised ammonia levels reported during the early hours of the 17th. Miss Ulett was started on appropriate treatment initially with ammonia scavenging medications and then haemofiltration. However, her prognosis at this point was very poor and she subsequently developed persistent seizure activity and cerebral oedema. On the 23rd September it was concluded that there were no further treatment options and her condition was terminal.</p> <p>Occurrence of undiagnosed urea cycle disorders in adults is rare. However, from the outset Miss Ulett's presentation warranted consideration of the Royal College of Emergency Medicine guidance on acute behavioural disturbance which recommended testing of ammonia levels if clinically indicated. Testing was clinically indicated by the 15th September. The decision to discharge Miss Ulett on the 13th September and the delay in ammonia testing were missed opportunities to improve Miss Ulett's chance of survival but did not contribute to her death.</p>

	<p>Based on information from the Deceased's treating clinicians the medical cause of death was determined to be:</p> <p>1a Hyperammonaemic encephalopathy</p> <p>1b N-acetylglutamate synthase deficiency</p> <p>1c</p> <p>1d</p> <p>II</p>
5	<p><u>CORONER'S CONCERNS</u></p> <p>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.</p> <p>The MATTERS OF CONCERN are as follows. –</p> <ol style="list-style-type: none"> 1. The window of opportunity to consider and make a diagnosis of a metabolic disorder and institute effective treatment is very short, 24 to 48 hours from the commencement of symptoms, and relies on early measurement of ammonia in an adult presenting with behavioural change and confusion. 2. There are no identified NICE or BMJ best practice guidelines which currently recommend testing of ammonia levels for undifferentiated acutely presenting confused patients. 3. Nationally, early measurement of ammonia levels in adults presenting to the emergency department and other units for investigation and management of behavioural change and confusion are not routine practice. 4. The Royal College of Emergency Medicine (RCEM) guideline 'Acute Behavioural Disturbance in Emergency Departments' (Oct 2023) was the most appropriate guideline at the time, it advises doing tests as clinically indicated including appropriate metabolic screen to include blood tests to check ammonia levels. 5. The RCEM guidance was not, however, considered by any of the practitioners in this case (the deceased was treated in the emergency department, by the acute medical team and then in intensive care with several other specialities consulting before ammonia testing was recommended by neurology). 6. The evidence was that this RCEM guidance is not yet embedded in adult medicine in the emergency department. 7. Further, evidence was given that the content and phrasing of the RCEM guidance was not helpful in the context of a case of acute behavioural disorder resulting from a urea cycle disorder because urea cycle disorders or metabolic disorders ('ABD') are not contained in the table of potential factors leading to ABD presentation in section 1, and in section 4 the recommended investigations do not assist in identifying when metabolic screens, and specifically ammonia levels, are clinically indicated. Nor is it clear why ammonia levels are placed in brackets. Additionally, there is no guidance as to the appropriate referral pathway to be followed when ammonia levels are raised. The RCEM guidance was updated in May 2025 but these matters have not changed from the 2023 version. 8. It was acknowledged that the presentation of adults with undiagnosed Urea Cycle Disorders is very rare and ammonia levels will not normally be clinically indicated for patients with ABD. However, it is the rarity of these presentations and the likely inexperience of those outside inherited metabolic diseases teams that gives rise to the need for clear guidance. 9. It was further identified that inherited metabolic disease specialists are aware that a previously undiagnosed urea cycle disorders may be unmasked by giving birth and present for the first time in the post-partum period with symptoms of altered GCS including

	<p>confusion, excessive drowsiness, seizures but this association is not known outside this speciality even in those caring for women in the post-partum period.</p> <p>10. Following Miss Ulett's death the University Hospitals of Birmingham NHS Foundation Trust ('UHB') assessed the speciality teams who could encounter patients presenting with altered consciousness due to unmasked previously undiagnosed urea cycle disorder and identified the relevant specialities were emergency medicine, acute medical, intensive care medicine and maternity services.</p> <p>11. Whilst UHB has done a lot of work internally with the specialities identified to raise awareness of the potential presentation of an unmasked previously undiagnosed urea cycle disorder to an emergency department with acute behavioural disturbance and the need for consideration of ammonia testing at an early stage, there remains a national risk from delay in diagnosis because ammonia testing has not been considered.</p>
6	<p>ACTION SHOULD BE TAKEN</p> <p>In my opinion action should be taken to prevent future deaths and I believe you have the power to take such action.</p>
7	<p>YOUR RESPONSE</p> <p>You are under a duty to respond to this report within 56 days of the date of this report, namely by 9 April 2026. I, the coroner, may extend the period.</p> <p>Given the cross-speciality relevance of the issues in this case it would be acceptable for the response to be made jointly on behalf of some or all the respondents. If this approach is taken please state clearly on the face of the response which organisations it is from.</p> <p>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.</p>
8	<p>COPIES and PUBLICATION</p> <p>I have sent a copy of my report to the Chief Coroner and to the following Interested Persons:</p> <p></p> <p>Birmingham Women's and Children's NHS Foundation Trust</p> <p>University Hospitals of Birmingham NHS Foundation Trust.</p> <p>I have also sent it to NICE and the BMJ who might find it useful or of interest.</p> <p>I am also under a duty to send the Chief Coroner a copy of your response.</p> <p>The Chief Coroner may publish either or both in a complete or redacted or summary form. She may send a copy of this report to any person who she 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.</p>
9	<p>11 February 2026</p>

Signature:



Emma Brown

Area Coroner for Birmingham and Solihull