	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. Chief Executive Officer of Mid and South Essex NHS Trust,** [redacted] **2. NHS England**
1	**CORONER** I am Rebecca Mundy, assistant coroner, for the coroner area of Essex.
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.
3	**INVESTIGATION and INQUEST** On 21 October 2021 I commenced an investigation into the death of Chloe Anne Tapp, 20. The investigation concluded at the end of the inquest on 9 February 2024. The conclusion of the inquest was natural causes.
4	**CIRCUMSTANCES OF THE DEATH** Chloe was a 20 year-old girl with a medical history including microcephaly, an underdeveloped heart and epilepsy. She first began experiencing seizures at only a few months old. She was formally diagnosed with epilepsy when she was two years old and began taking sodium valproate to treat it, eventually moving to dual treatment with lamotrigine. She had been under the care of a paediatric consultant neurologist, but on turning 18, needed to be transferred to an adult consultant neurologist. There was a significant delay in this transition, and she did not see an adult consultant neurologist until September 2021. Chloe received an appointment for 3 September 2021, this took place over the phone despite Chloe being non-verbal. The consultation, therefore, was with her mother and there was no ability for the consultant to visually assess Chloe or her tremors. The consultant felt Chloe's tremors were likely related to her prolonged use of sodium valproate and as a result agreed a plan to taper Chloe's medication so that she was only taking lamotrigine. The plan needed to be gradual due to the risks associated with use of these two drugs at higher doses. There is a difference of opinion as to how this change would be affected and who was to implement it; the evidence led me to prefer Chloe's mother's account of the consultation. On request, a handwritten tapering regime was sent out to Chloe following the consultation explaining the changes that her mother was to implement. She was advised to call the neurology department if she had any queries or concerns. The tapering regime was complicated, and Chloe's mother wanted to ensure that she had understood it correctly. Several attempts to call the neurology department were unsuccessful. The regime was also, in fact, incorrect; it had been based upon an assumed dose of the

	medication that Chloe was taking; Chloe's medication was in millilitres as she had a liquid diet through a feeding tube, however, the consultant was unfamiliar with millilitres and usually worked with milligrams. She looked up the "usual" dose on the BNF and based the tapering regime on that. The consultant's account was that she had in fact adjusted the regime later in the consultation upon realising that Chloe was on higher doses than assumed, but neither a copy of the original nor the amended regime were entered onto Chloe's records. On 22 September 2021 Chloe had an unwitnessed fall and from her body language appeared to have hurt her right leg. On 6 October 2021 Chloe was still suffering with her leg and had a productive cough. Her mother took her to the Emergency Department; her chest x ray was clear but infection markers in her blood were slightly elevated. She was given antibiotics as a precautionary measure for her chest, analgesia and paracetamol and discharged. On 7 October 2021 around 1am Chloe suffered a tonic clonic seizure, an ambulance was called and in the meantime her mother administered emergency medication, shortly after Chloe suffered a further seizure and then stopped breathing. Her father followed advice from the emergency services and administered CPR. An ambulance arrived at 1.26am. Chloe was unresponsive and in respiratory arrest. It was noted that multiple suctioning was required due to vomit and saliva and she had a temperature of 40. She then suffered a cardiac arrest. One of the doctor's treating Chloe was of the opinion was her high temperature had developed as a result of the dramatic seizures she experienced, rather than due to separate infection; her chest scan the day before was clear and infection makers only slightly raised and in addition, her temperature was 36.5 by the time she was admitted to the emergency department. Chloe was admitted to hospital in the early hours of 7 October2021; her chest x ray showed bilateral pleural effusions. Ultimately the efforts of all those caring for her were unsuccessful and she passed away on 8 October 2021. An independent consultant gave evidence that whist Chloe could have had a subtle chest infection on 6 October, this would not have been enough to overwhelm her in the manner that occurred on 7 October. However, being unwell may have been a trigger for the seizure, particularly as there appeared to have been an extended period of her requiring antibiotics for infections. They did not consider that the medication change more than minimally contributed to her seizure or her death; the seizure could have occurred without any of the changes or triggering factors. The cause of death was established on the evidence as '1a Epilepsy and pneumonia'. Chloe's death was therefore from natural causes.
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. In the circumstances it is my statutory duty to report to you. The **MATTERS OF CONCERN** are as follows:

- Neurology departments are so overwhelmed and/or understaffed that a vulnerable young girl (particularly so during the Covid-19 pandemic), was not referred in a timely manner to adult neurology services and in fact, it transpired a referral had not been made at all. This appears to have been done for the first time in August 2021.
- An initial consultation with a complex non-verbal patient was arranged over the telephone, notwithstanding the concerns about a tremor which would have required visual assessment.
- An overworked consultant under considerable pressure, did not have time before or during the consultation to establish the dose that Chloe was taking and/or apply the appropriate conversion factor, for medications that can interact negatively at higher doses.
- No note was made of the tapering regime for the medication change in Chloe's notes.
- A handwritten note of a tapering regime based on incorrect doses was sent to Chloe.
- The same regime was repeated in a letter to the Epilepsy Nurses, but this letter was not received until October 2021 (in paper form) as the initial email was sent to an address that no longer existed.
- Phone calls and messages left with the neurology department went unanswered, at a time when clarity over the tapering regime was needed.
- The consultant in question gave evidence of a very bleak picture of ongoing practice in the neurology department; a letter from all four consultants in that department had been sent to the Trust in July 2023, where patient care was described as 'sub-optimal', and numerous concerns were set out including:
    - Chronic staff shortages in respect of doctors, nurses and administrative staff within the neurology department
    - Substantial and unsafe backlogs for first and follow up appointments
    - Inability to answer, in a timely manner, the volume of phone calls, phone messages and emails from patients/carers raising queries.
    - The delays / ways in which investigations are carried out and reported, and the way in which clinical staff can access results.
- A further letter was sent by Chloe's consultant in January 2024 in lieu of her attending a meeting where progress was to be discussed. That letter highlighted that, not only did the concerns remain live, she believed that the department had now reached levels of 'unsafe practice'.
- The state of the department, compared to when Chloe died was described as 'worse'.
- Notwithstanding Chloe's death in 2021, the letter in July 2023 and follow-up in January 2024, many of the more significant actions identified remained as part of an Action Plan. Business cases were being drawn up for a number of areas (but not additional consultants) and these had not yet been approved, nor was it guaranteed that they would be.
- The independent consultant neurologist in giving evidence expressed that this

	was not an unfamiliar picture across a number of different Trusts and that there was a recognised shortage of neurologists and increase in demand for that speciality nationally.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you and/or 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 25 April 2024. 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: i. Chloe's parents [redacted]; ii. [redacted] 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.
9	**28 February 2024**