Regulation 28: REPORT TO PREVENT FUTURE DEATHS

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

	REGULATION 28 REPORT TO PREVENT DEATHS **THIS REPORT IS BEING SENT TO:** **1 University Hospital of North Midlands NHS Trust** **2 Brook Medical Centre** **3 Godfrey Care**
1	**CORONER** I am Daniel HOWE, H M Area Coroner for the coroner area of Staffordshire and Stoke-on-Trent
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 25 November 2022 I commenced an investigation into the death of Joshua Ethan BURGESS aged 27. The investigation concluded at the end of the inquest on 31 January 2024. The conclusion of the inquest was that: On 19th November 2022 Joshua Ethan Burgess passed away at his home address after vomiting and aspirating during an epileptic seizure. He was diagnosed with Lennox-Gastaut Syndrome for which he was under the care of a consultant neurologist and medicated with Brivaracetam. Natural causes
4	**CIRCUMSTANCES OF THE DEATH** Joshua Burgess was a 27-year-old male who had severe acquired brain injuries, communication difficulties, impaired executive functioning and severe learning difficulties. He developed epilepsy from the age of 6 years and had a diagnosis of Lennox-Gestaut syndrome for which he was under the care of the Department of Neurology at Royal Stoke University Hospital. In 2019 the Department of Neurology commenced Mr Burgess on 2.5ml twice daily Brivaracetam to control his seizure activity. The dosage was increased to 10ml twice a day in 2020 and responsibility for prescribing the medication was transferred to Mr. Burgess' General Practitioner at the Brook Medical Centre, Bradeley, Stoke-On-Trent. The reason for the change in prescriber was for the sake of convenience as the GP were the prescriber for other medications. Although the Brook Medical Centre were responsible for prescribing Brivaracetam there were no consultations between the surgery and Mr. Burgess or his mother regarding the management of his seizures or a review of medication, these continued to be undertaken by the Department of Neurology at the Royal Stoke University Hospital. In July 2020 the Consultant Neurologist agreed with Mr. Burgess' mother that the dosage of Brivaracetam should be reduced by 2ml every 2 weeks and to be reviewed in 4 months. A letter was sent from the Department of Neurology at Royal Stoke University Hospital to the Brook Medical Centre advising of this planned reduction. No amendment to the prescription was requested and no changes were made following the letter. The

remained as Brivaracetam 10ml twice daily.

In November 2020 a letter was sent from the Department of Neurology at Royal Stoke University Hospital to the Brook Medical Centre advising that the dose of Brivaracetam had been reduced to 3ml twice daily but then back up to 5ml twice daily. No amendment to the prescription was requested and no changes were made following the letter.

In January 2021 a letter was sent from the Department of Neurology to the Brook Medical Centre advising that the dose of Brivaracetam was at 4ml twice daily and the deceased's seizures were "relatively stable". No amendment to the prescription was requested and no changes were made following the letter. The prescription remained as Brivaracetam 10ml twice daily.

On 22 July 2022 Mr. Burgess was moved out of his parent's care by Stoke-on-Trent social services into a supportive living placement in Leicestershire run by Godfey Care. This was undertaken on an emergency basis. When Mr. Burgess arrived at the placement it was reported by staff that the medication bottles were unlabeled and so could not be given to Mr Burgess until confirmation of the prescription was received in writing by the prescriber. The evidence at inquest was that this was a Care Quality Commission requirement.

The deceased did not receive any Brivaracetam between 22 July 2022 and 26 July 2022.

On 25 July 2022 a "Best Interests Meeting" was undertaken involving Mr Burgess' mother, Godfrey care and social services during which the Mr Burgess' mother advised that the correct dosage of Brivaracetam was 4ml twice daily and not 10ml twice daily. The same information was provided by the Department of Neurology to Godfrey Care however the medication was not provided as the information regarding the correct dose had not been provided by the prescriber.

On 26 July 2022 the deceased was given Brivaracetam 10ml twice daily. The evidence at inquest was that this was likely due to a manager from Godfrey Care being given the prescription details during a call to the 111 service.

On 27 July 2022 a letter was sent from the Department of Neurology to the Brook Medical Centre explaining that Mr Burgess had been moved to a care organisation on an urgent basis and there was confusion over what medication he should be taking. A request was made to forward a list of his medication but also included information from his last review within the Department of Neurology that Brivaracetam at 4ml twice daily was the appropriate dose.

On 28 July 2022 the Brook Medical Centre sent a list of prescribed medication to Godfrey Care. As there had been no changes to prescription since July 2020 the recorded prescribed dose of Brivaracetam was 10ml twice daily although the dose that he has been given during the preceding 2 years was 4ml twice daily.

Mr Burgess continued to receive Brivaracetam at dose of 10ml twice daily until 5 September 2022 when he was seen in a clinic at Department of Neurology at Leicester Glenfield Hospital and established that there had been a sudden increase in the Brivaracetam dose from 4ml twice daily to 10ml twice daily. The plan was for the medication to be reduced to 9ml twice daily and then to continue to reduce by 1ml twice daily at weekly intervals until he was back to the "well tolerated" dose of 4ml twice daily.

Prior to 22 July 2022 whilst being given Brivaracetam at 4ml twice daily Mr Burgess experienced 5-6 seizures per week. Following the cessation of medication between 22-26 July 2022 and the increase in Brivaracetam to 10ml twice daily he was experiencing about 5 seizures per day and of longer duration.

The medication was reduced as per the instruction from Department of Neurology at

	Leicester Glenfield Hospital. On 23 September 2022 Mr Burgess was taken back into care of his mother. Although there had been a hospital attendance on the on 15 November 2022 the seizures had stablised to a similar frequency as before the sudden interruption and increase in medication. On 19 November 2022 Mr. Burgess was sadly found unresponsive at his home address with death being verified by attending paramedic. He had passed away after vomiting and aspirating during an epileptic seizure.
5	**CORONER'S CONCERNS** Although not causative in Mr. Burgess death during the course of the investigation my inquiries 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: (brief summary of matters of concern) 1. The Neurology department of the Royal Stoke University Hospital operated a system whereby it did not instruct the prescribing GP to amend the prescription of Brivaracetam when changes to dosage had been agreed with Mr Burgess' mother. The evidence from the Consultant Neurologist was that an assumption was made that when changes to medication had been discussed and agreed that Mr Burgess' mother would attend the GP surgery to discuss the changes in medication. The same witness gave evidence that it was assumed a pharmacist within the GP surgery would read the correspondence from the neurology department and make the necessary changes to prescriptions without express instructions to do so. 2. The "workflow" within the Brook Medical Centre was such that letters sent from the Neurology department discussing changes in medication (albeit not containing a request to amend the prescription) were processed by support staff and not referred to a clinician to consider and so no changes were made to the prescription. 3. The letter of 27 July 2022 from the Neurology department to Brook Medical Centre seeking clarification as to the correct dosage of Brivaracetam was processed by support staff and a summary medications sent without referral to a clinician. 4. Godfrey Care were informed by Mr Burgess' mother and the Neurology department of Royal Stoke University that the appropriate dose of Brivaracetam was 4ml twice daily. Medication was withheld between 22-26 July 2022 due to the information not being in writing from the prescriber, however the evidence at inquest was that 10ml twice daily was commenced on 26 July 2022 following a call to the 111 service.
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 April 09, 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 have also sent it to • **NHS England** • **Care Quality Commission** • **Stoke-on-Trent, Adult Social Care** who may find it useful or of interest. I am also 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 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 by the Chief Coroner.
9	**Dated: 13/02/2024**  **Daniel HOWE** **H M Area Coroner for** **Staffordshire and Stoke-on-Trent**