MISS N PERSAUD
HIS MAJESTY'S CORONER
EAST LONDON
Coroner's Court, 124 Queens Road Walthamstow, E17 8QP
[redacted]

REGULATION 28: REPORT TO PREVENT FUTURE DEATHS (1)

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** • [redacted], **National Medical Director, NHS England** [redacted] • [redacted], **President of Royal College of Physicians** [redacted] • [redacted], **Chief Executive Officer, Royal College of GP's** [redacted]
1	**CORONER** I am Nadia Persaud, Area Coroner for the coroner area of East London
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** On 30 January 2023 I commenced an investigation into the death of Andrew Ewin-Ripp (aged 27). The investigation concluded at the end of the inquest on the 25 March 2024. The conclusion was that Andrew died as a result of natural causes (SUDEP). Whilst there was no evidence that the care provided to Andrew contributed to his death, there were concerns that aspects of the care, if left unchanged, could result in further, similar deaths occurring.

4	**CIRCUMSTANCES OF THE DEATH** Andrew Ewin-Ripp suffered from epilepsy. He had been under secondary care neurology services until May 2020, when he was deemed to be well and had been seizure free for 14 months. No clear written advice was provided to Andrew to inform him that he was being discharged, or that he should notify his GP or neurology team if his seizures returned. No information was provided to Andrew on discharge, about how to contact the epilepsy nurses in the event of seizure recurrence. In August 2022 Andrew contacted his GP with a report of having suffered 4 seizures that year, the last having occurred the previous week. On the 9 August 2022 the GP sent an advice and guidance request to a neurology team unknown to Andrew. There was no response to this advice and guidance request by the 4 September 2022. The GP therefore sent an urgent request for an outpatient appointment and for urgent advice relating to medication, to Andrew's secondary care team. This urgent request had not even been triaged by the 1 November 2022. Whilst still awaiting a response from the secondary care team, Andrew suffered a fit in his home address on the 1 November 2022. Andrew was on the phone to his partner at this time. Andrew's partner called the emergency services and through the information that he provided; an emergency Category 1 response was generated. A paramedic arrived at Andrew's home within 5 minutes of the call. The paramedic checked the property and found that it was secure. The London Fire Brigade had to attend to force entry. The emergency team were at Andrew's side 23 minutes after the emergency call. Andrew was found to be in cardiac arrest. Advanced life support commenced rapidly, and a return of spontaneous circulation was gained. Andrew was taken to Queen's Hospital where intensive care was provided. Sadly, despite all efforts by the hospital team, Andrew did not recover. He passed away at Queens Hospital on the 4 November 2022. The unanimous view in relation to his cause of death is sudden unexpected death in epilepsy
5	**CORONER'S CONCERNS** 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: There are believed to be around 500-600 SUDEP deaths in the UK each year. SUDEP deaths are common in young adults. The waiting times for outpatient neurology appointments is in the region of 9 months for the trust concerned. The inquest heard from an independent expert that it is not unusual to have waiting times of more than 6 months for outpatient neurology appointments. In the context of these lengthy waiting times, the following matters were of particular concern: (1) GP practices are not required to carry out annual reviews of epilepsy patients, as they are, for other chronic diseases. The independent consultant neurologist considered that annual reviews by general practitioners would provide an excellent safety net to prevent future SUDEP deaths. The reviews could incorporate checks on compliance with medication; reviews of any seizure activity and reminder of ways to reduce the risk of seizures. (2) There is clear national guidance in relation to how quickly patients should be seen following a first seizure, but no clear guidance around the longer-term monitoring of patients with epilepsy. How soon after the last seizure is it safe to discharge a patient? There is no clear guidance on this.

	(3) After discharge from the secondary care team, there was no clear guidance provided in relation to the importance of maintaining full compliance with medication even if seizure free for a very long period; the importance of notifying the GP and/or the secondary care team about the recurrence of any seizure activity or clear guidance on how best to make contact with the secondary care team in the event of recurrence of seizures. There was no system in place, or guidance, requiring practitioners to ensure that this essential information is passed to patients on discharge. (4) There was no care pathway for incorporating urgent reviews in neurology clinics in response to patients reporting concerns, such as a return of seizures or not tolerating medication.
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 **28 May 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, to the family of Andrew Ewin-Ripp, to the other interested persons to the inquest, to the Care Quality Commission, and the local Director of Public Health 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 other 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.
9	**2 April 2024**