REGULATION 28: REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** Secretary of State for Health and Social Care
1	**CORONER** I am Dr Shirley Radcliffe, Assistant Coroner, for the Coroner Area of Inner West 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.
3	**INVESTIGATION and INQUEST** On 7th February 2020 I commenced an investigation into the death of Alice Beatrice Pettersson, then aged 8 months. The investigation concluded at the end of the inquest on 10th June 2021. **Medical Cause of Death** I (a) Hypoxic Ischaemic Encephalopathy, 1b Cord compression, 1c Achondroplasia **How, when, where Alice Pettersson came by her death:** Alice Beatrice Pettersson died on 25th January 2020 at Great Ormond Street Hospital London **Conclusion of the Coroner as to the death:** Natural Causes
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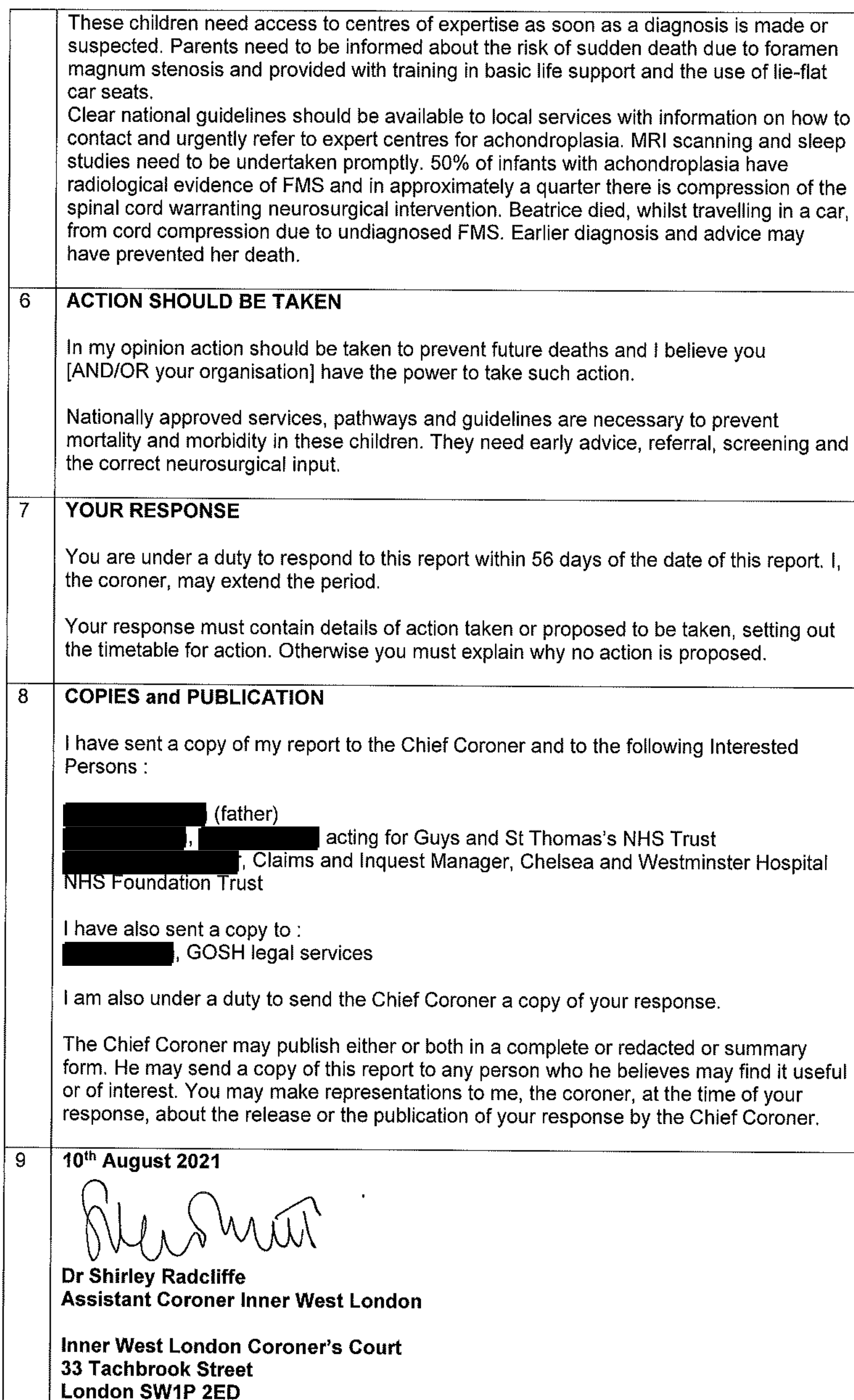
5	**Concerns of the Coroner:** Achondroplasia is the commonest type of skeletal dysplasia with 1 in 20,0000 individuals affected. These infants are at risk of sudden infant death most frequently attributed to foramen magnum stenosis (FMS). There is no designated referral pathway for children with achondroplasia and general paediatric clinical teams are not always aware of the associated risks or clinical scenarios which should prompt immediate referral to centres of excellence. No NICE or other national guidelines are currently available for the early evaluation and management of infants and children with Achondroplasia.



	These children need access to centres of expertise as soon as a diagnosis is made or suspected. Parents need to be informed about the risk of sudden death due to foramen magnum stenosis and provided with training in basic life support and the use of lie-flat car seats. Clear national guidelines should be available to local services with information on how to contact and urgently refer to expert centres for achondroplasia. MRI scanning and sleep studies need to be undertaken promptly. 50% of infants with achondroplasia have radiological evidence of FMS and in approximately a quarter there is compression of the spinal cord warranting neurosurgical intervention. Beatrice died, whilst travelling in a car, from cord compression due to undiagnosed FMS. Earlier diagnosis and advice may have prevented her death.
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. Nationally approved services, pathways and guidelines are necessary to prevent mortality and morbidity in these children. They need early advice, referral, screening and the correct neurosurgical input.
7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report. 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 : ███ (father) ███, ███ acting for Guys and St Thomas's NHS Trust ███, Claims and Inquest Manager, Chelsea and Westminster Hospital NHS Foundation Trust I have also sent a copy to : ███, GOSH legal services 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	**10th August 2021** **Dr Shirley Radcliffe** **Assistant Coroner Inner West London** **Inner West London Coroner's Court** **33 Tachbrook Street** **London SW1P 2ED**