IN THE CORONERS COURT
OF VICTORIA
AT MELBOURNE

COR 2023 004809

FINDING INTO DEATH WITHOUT INQUEST

Form 38 Rule 63(2)

*Section 67 of the **Coroners Act 2008***

Findings of:	Deputy State Coroner Paresa Antoniadis Spanos
Deceased:	HD
Date of birth:	8 March 2012
Date of death:	28 August 2023
Cause of death:	1(a) Pneumonia complicating cerebral palsy 1(b) Perinatal hypoxic brain injury
Place of death:	PXC
Keywords:	In care; Young person; Natural causes

INTRODUCTION

1. On 28 August 2023, HD was 11 years old when she died at home surrounded by loved ones. At the time, HD lived with her family in PXC.

2. HD was born on 8 March 2012 to biological parents SC and VL. She was born with severe epilepsy and cerebral palsy, muscle stiffness, and brain damage. At the time, HD was not expected to survive the first 48 hours of her life. HD did survive and her treating team's prognosis was that she would remain non-verbal and wheelchair bound for life. A nasogastric tube was inserted to assist with feeding and medications.

3. Shortly after her birth, Child Protection became involved in HD's care and assessed that due to her complex and acute medical needs, HD had no effective or appropriate caregiver. As such, a care by secretary order was made conferring parental responsibility for HD on the Secretary to the Department of Human Services[1] (**the Secretary**).

4. When she was three months old, HD was placed into foster care with foster parents EO and LW EA. Mr and Mrs EA received several weeks of training in to how to care for HD's complex health needs and at the time they were advised HD was not expected to live until her first birthday.

5. HD defied the odds and was raised in a loving family home with Mr and Mrs EA where she remained until her death. She was surrounded by family included the biological children of the EAs, HD's biological siblings who were later fostered by the EAs, and other children also fostered by the EAs. She is warmly remembered by her family as a special and uplifting young girl.

6. HD was fostered through OzChild who continue to provide administrative support for HD and her foster parents throughout her life. HD's most recent case manager, Jodie Atkinson, stated the care HD received from the EAs was amazing and could not be faulted.

7. In 2013, a percutaneous endoscopic gastrostomy (**PEG**) tube was inserted through the wall of her abdomen and into her stomach to allow for feeding and medication. This was due to the increasing risk of aspiration. A jejunostomy PEG (**JPEG**) was inserted in 2014 directly into

[1] *Children, Youth and Families Act* 2005 (Vic) s 289; As of 1 February 2021, the Department of Human Services became the Department of Families, Fairness and Housing.

the small bowel to further alleviate the risk of aspiration. From this point onwards, HD received all her feeding through her JPEG.

8. Over the coming years HD continued to suffer regular seizures. She was also diagnosed with cerebral palsy, scoliosis, quadriplegia, central respiratory depression with Type II respiratory failure, recurrent chest infections. She was also diagnosed with KCNQ2, a gene mutation considered to be the cause of her seizures and cerebral palsy.[2]

9. In 2017, HD was placed on a Long-Term Care Order (**LTCO**) with a non-reunification case plan. The effect of the LTCO was that the Secretary retained parental responsibility for HD to the exclusion of all other persons[3] and that the EAs remained her foster parents. The LTCO remained in place until HD's death.

10. Over the course of her life, HD underwent numerous surgeries to address her multiple conditions and improve her quality of life. Her tonsils and adenoids were removed to assist with breathing, a baclofen pump was inserted into her stomach, and she underwent surgeries to release the tendons within her hamstrings and biceps. Rods were inserted into her spine to alleviate HD's scoliosis. She relied on an 'Airvo' machine to assist with her breathing.

11. In the 12 months prior to her death HD experienced a global neurological decline. She was involved with the Victorian Paediatric Palliative Care Program who recognised HD was at risk of an acute deterioration from which she may be unable to recover. Multiple surgeries were planned but ultimately cancelled due to HD's poor condition and a lack of Intensive Care Unit (**ICU**) bed on one occasion.

12. She was admitted to the ICU multiple times in the months leading up to her death. During a visit to the ICU in July 2023, her treating team decided that HD be transitioned to comfort care only and that resuscitation efforts would be withheld in the event of an acute deterioration.

13. Despite her complex health issues, HD had a good life. She loved reptiles, going to petting zoos and holidays. She swam with dolphins in Queensland and played Tinkerbelle in a school play. It is abundantly clear that HD was much loved throughout her short life.

[2] Statement of Professor Nick Freezer, Paediatric Respiratory and Sleep Medicine Physician Monash Health, dated 24 June 2024; Statement of Dr Simon Blair dated 26 February 2024.
[3] *Children, Youth and Families Act* 2005 (Vic) s 290.

THE CORONIAL INVESTIGATION

14. HD's death was reportable by virtue of section 4(2)(c) of the *Coroners Act 2008* (Vic) because, immediately before her death, she was a person placed in care as the Secretary of the Department of Family, Fairness and Housing had parental responsibility for her under *the Children, Youth and Families Act 2005* (Vic).[4] The death of a person in care or custody is a mandatory report to the coroner, even if the death appears to have been from natural causes.

15. The role of a coroner is to independently investigate reportable deaths to establish, if possible, identity, medical cause of death, and surrounding circumstances. Surrounding circumstances are limited to events which are sufficiently proximate and causally related to the death. The purpose of a coronial investigation is to establish the facts, not to cast blame or determine criminal or civil liability.

16. Under the Act, coroners also have the important functions of helping to prevent deaths and promoting public health and safety and the administration of justice through the making of comments or recommendations in appropriate cases about any matter connected to the death under investigation.

17. Victoria Police assigned Senior Constable Jeremy Plug to be the Coroner's Investigator for the investigation of HD's death. The Coroner's Investigator conducted inquiries on my behalf, including taking statements from witnesses – such as family, the forensic pathologist, treating clinicians and investigating officers – and submitted a coronial brief of evidence.

18. This finding draws on the totality of the coronial investigation into the death of HD including evidence contained in the coronial brief. Whilst I have reviewed all the material, I will only refer to that which is directly relevant to my findings or necessary for narrative clarity. In the coronial jurisdiction, facts must be established on the balance of probabilities.[5]

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[4] *Coroners Act 2008* (Vic) s 3.

[5] Subject to the principles enunciated in *Briginshaw v Briginshaw* (1938) 60 CLR 336. The effect of this and similar authorities is that coroners should not make adverse findings against, or comments about, individuals unless the evidence provides a comfortable level of satisfaction as to those matters taking into account the consequences of such findings or comments.

MATTERS IN RELATION TO WHICH A FINDING MUST, IF POSSIBLE, BE MADE

Identity of the deceased

19. On 29 August 2023, HD, born 8 March 2012, was visually identified by her cousin, FU, who signed a formal Statement of Identification to this effect.

20. Identity is not in dispute and requires no further investigation.

Medical cause of death

21. Forensic Pathologist Associate Professor Linda Iles, from the Victorian Institute of Forensic Medicine (**VIFM**), conducted an examination on 31 August 2023 and provided a written report of her findings dated 4 September 2023.

22. The post-mortem examination was consistent with the known history.

23. In her report dated 4 September 2023, A/Prof Iles provided an opinion that the medical cause of death was *1(a) pneumonia complicating cerebral palsy* secondary to *1(b) perinatal hypoxic brain injury* and considered HD's death was due to natural causes.

24. Throughout the course of the investigation, statements were obtained from Paediatrician Dr Simon Blair[6] and Paediatric Respiratory and Sleep Medicine Physician Professor Nick Freezer[7] which suggested the cause of HD's epilepsy and cerebral palsy was a KCNQ2 gene mutation, not a perinatal injury.

25. As such, I sought a further opinion from A/Prof Iles in light of the information contained within Dr Balir and Professor Freezer's statements. Based on the new information, A/Prof Iles advised that[8] the medical cause of HD's death could be reasonably attributed to *1(a) pneumonia complicating cerebral palsy* secondary to *1(b) KCNQ2 developmental and epileptic encephalopathy*.

26. I accept A/Prof Iles' opinion.

[6] Dated 26 February 2024.
[7] Dated 24 June 2024.
[8] A/Prof Iles provided the opinion in an email to the Court dated 25 February 2025 retained on the Court file.

Circumstances in which the death occurred

27. Throughout August 2023 HD continued to deteriorate at home. On 21 August 2023, her Paediatric Palliative Care Physician, Dr Bronwyn Sacks, approved Mr and Mrs EA's election for HD to have end of life care at home. The decision was supported by the Child Protection on behalf of the Secretary as they continued to hold parental responsibility for HD.

28. On 28 August 2023, HD was at home surrounded by family and loved ones. She had been peacefully asleep for the last few days. Her oxygen levels and respiratory rate gradually decreased. Mrs EA switched her heart rate and oxygen monitor off to avoid the alarm sounding.

29. At 1.15 pm it was evident to Ms EA that HD had passed away. She briefly turned on the heart and oxygen monitor on which confirmed HD had peacefully passed away.

FINDINGS AND CONCLUSION

30. Pursuant to section 67(1) of the *Coroners Act 2008* I make the following findings:

    a) the identity of the deceased was HD, born 8 March 2012;

    b) the death occurred on 28 August 2023 at PXC;

    c) the cause of HD's death was from *1(a) pneumonia complicating cerebral palsy* secondary to *1(b) KCNQ2 developmental and epileptic encephalopathy*; and

    d) the death occurred in the circumstances described above.

31. The available evidence does not support a finding that there was any want of clinical management or care on the part of any of HD's treating professionals that caused or contributed to her death.

32. I convey my sincere condolences to HD's family and her treating team for their loss. I wish to acknowledge the love and care provided to HD by her foster parents who selflessly gave her the best quality of life possible, and the many clinicians involved in her clinical management and care.

33. I direct the Principal Registrar to provide a copy of this finding to the Registrar of Births, Deaths and Marriages so that the cause of death can be re-registered in accordance with my findings above.

PUBLICATION OF FINDING

Pursuant to section 73(1B) of the Act, I order that this finding be published on the Coroners Court of Victoria website in accordance with the rules, with redactions as to the identity of HD, her parents and sibling as required by section 534 of the *Children, Youth and Families Act 2005.*

DISTRIBUTION OF FINDING

I direct that a copy of this finding be provided to the following:

Amy Norder, Child Protection, senior next of kin

EO and LW EA

Monash Health c/- HWL Ebsworth

Commission for Children & Young People

Registrar of Births, Deaths and Marriages

Senior Constable Jeremy Plug, Coroner's Investigator

Signature:

Deputy State Coroner Paresa Antoniadis Spanos

Date: 12 March 2025

NOTE: Under section 83 of the ***Coroners Act 2008*** ('the Act'), a person with sufficient interest in an investigation may appeal to the Trial Division of the Supreme Court against the findings of a coroner in respect of a death after an investigation. An appeal must be made within 6 months after the day on which the determination is made, unless the Supreme Court grants leave to appeal out of time under section 86 of the Act.