CITATION: *Inquest into the death of Kumanjayi Holmes* [2023] NTLC 7

TITLE OF COURT:	Coroner's Court
JURISDICTION:	Alice Springs
FILE NO(s):	A0056/2021
DELIVERED ON:	31 March 2023
DELIVERED AT:	Alice Springs Local Court
HEARING DATE(s):	30 and 31 March 2023
FINDING OF:	Judge Elisabeth Armitage
CATCHWORDS:	**Child death in care, inherited genetic disorder, removed from family due to disability**

REPRESENTATION:

Counsel Assisting:	Jodi Truman
Counsel for Department of Territory Families:	Michael McCarthy

Judgment category classification:	A
Judgement ID number:	[2023] NTLC 7
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IN THE CORONER'S COURT
AT ALICE SPRINGS IN THE NORTHERN
TERRITORY OF AUSTRALIA

No. A0056/2021

In the matter of an Inquest into the death of

KUMANJAYI HOLMES
ON: 31 OCTOBER 2021
AT: ALICE SPRINGS HOSPITAL

FINDINGS

Judge Elisabeth Armitage

Introduction

1. The deceased was born on 24 May 2006 to Roxanne Morton and Damsien Kelly-Holmes. Her mother asked that she be referred to as Kumanjayi. Kumanjayi was born in the Alice Springs Hospital at full term via normal delivery, she weighed 2,980 grams and there were no antenatal or postnatal complications. She had an elder brother and two younger siblings. She was Aboriginal with family connections to Tennant Creek, Utopia and Murray Downs communities.

2. Kumanjayi passed away on 31 October 2021 at the Palliative Care Ward of the Alice Springs Hospital. She was fifteen years and five months old. She was loved by her family and foster mother and they miss her and grieve her passing. Her death was "reportable" as immediately prior to her death she was a "person held in care" being a "child who is in the CEO's care as defined in the *Care and Protection of Children Act 2007*".[1] This inquest is mandatory.

[1] See section 12 of the *Coroners Act 1993*

Her life before coming into the care of the Department of Territory Families, Housing and Communities

3. In her early years, Kumanjayi and her family predominantly lived at Murray Downs Station, however they also moved between Harts Range, Ampilatwatja, Arlparra and Tennant Creek.

4. On 20 November 2012, when Kumanjayi was just six years of age, a notification was received by the Department of Territory Families, Housing and Communities ("TFHC") from the mobile "Family as First Teachers" ("FAFT") unit. It was reported that Kumanjayi's eyesight was deteriorating and her mother needed assistance to get her to specialist appointments.

5. In 2013 Kumanjayi was diagnosed with severe rod-cone dystrophy and epilepsy. Rod-cone dystrophy (aka cone-rod dystrophy) is an eye disorder that causes progressive vision loss. Kumanjayi was treated with medication.

6. Following a second notification in September 2014, her teacher advised TFHC that Kumanjayi was "blind" and had epilepsy, and the school and her mother were teaching her Braille.

7. On 2 December 2015 a nurse attached to the Royal Flying Doctor Service submitted a third notification reporting that:

    7.1 Her eyesight was deteriorating and her seizure disorder was requiring medication twice per day;

    7.2 She was refusing to go to school or take her medication and her mother was struggling with these challenging behaviours;

    7.3 She required a comprehensive assessment which was difficult to arrange because her family were mobile between communities; and

    7.4 Her mother had indicated that at times she was unable to meet her needs and was contemplating "giving her up" to TFHC.

8. It was also said that Kumanjayi and her siblings were exposed to instances of domestic violence between their parents. This was confirmed in a fourth notification on 15 December 2015 when a hospital social worker reported that Kumanjayi's father had seriously assaulted her mother when the children were present and her mother was in hospital. Sadly, on 24 January 2016, police again reported another serious assault by her father on the mother witnessed by the children, which again resulted in her mother's hospitalisation. Her father was charged and later convicted and sentenced to 4 months imprisonment for that assault.

9. By January 2016 her mother was saying she needed respite as she was struggling to manage Kumanjayi's care. In conversations with a health worker on 2 February 2016 and again with TFHC on 21 March 2016, her mother confirmed her request for respite or assistance.

10. In the seventh notification, on 15 April 2016, it was reported that Kumanjayi had been transported to the Tennant Creek Hospital by ambulance after having an epileptic seizure. TFHC workers attended the hospital and spoke to her mother. They provided her mother with a housing support letter and commenced making other arrangements to support her mother.

11. However, on 29 April 2016, before any substantive support was provided, Kumanjayi was again transported to hospital following a seizure at home. When the ambulance attended, all adults at the house were considered to be intoxicated. TFHC case work became focussed on identifying a responsible family member who could care for Kumanjayi and provide respite.

12. By 4 May 2016 Kumanjayi had been hospitalised four times in 2016 for seizures. Medical staff considered she was dishevelled in appearance and identified that she had suffered a fractured right ankle which was placed in a cast. It was apparent that she was not receiving the medication she needed to control her epilepsy. As no suitable family members had been identified as carers, and as her mother recognised that she could no longer manage her

care, with her mother's consent, Kumanjayi was placed into the care of the CEO. She was nine (9) years of age at the time.

Her life in Tennant Creek in the care of TFHC

13. Kumanjayi was initially placed with a Family Day Carer in Alice Springs. After four days her cast cracked and Kumanjayi was taken to hospital. Kumanjayi refused to return to the carer and the carer also indicated she lacked the capacity to provide adequate care to Kumanjayi.

14. She was then placed with Community Staffing Solutions where she remained until 29 July 2016. On that day she was placed into the care of Ms Angela Teasdale ("Ms Teasdale") in Tennant Creek. During her foster carer assessment, Ms Teasdale had advised that she was willing to care for a child with a disability because she was employed as Workforce Development Consultant/Project Co-ordinator with the NDIS and had an in-depth knowledge of disability services and the "extra lines of support for children on a disability plan". Ms Teasdale further reported that due to living and working in remote communities she had an "in-depth knowledge of disabilities" and "FASD, global delays, learning disabilities, cognitive impairments, acquired brain injuries, severe mental health, AOD, suicidal ideation and suicide prevention strategies" were areas of expertise.

15. When Kumanjayi initially commenced living with Ms Teasdale she could still walk, but as the disease progressed she required a walking frame followed by a wheelchair. Kumanjayi was enrolled at the Tennant Creek Primary School, and arrangements were made for afterschool and respite care. There was regular communication between Ms Teasdale and TFHC staff. TFHC reported that Ms Teasdale was proactive in organising extra-curricular activities for Kumanjayi, and the positive relationship she established with Kumanjayi was evident.

16. While TFHC maintained contact with Kumanjayi's parents, it was difficult at times due to their continuing transient lifestyle. There were also issues with alcohol. Despite this, case notes indicate that Kumanjayi's mother proactively sought out information about Kumanjayi's well-being. Although, she was saddened that she could no longer care for Kumanjayi, she acknowledged it was in Kumanjayi's best interests to be cared for by Ms Teasdale.

17. On 29 June 2017, a Protection Order was made in relation to Kumanjayi, with Parental Responsibility to the CEO until 23 May 2024 which would have been Kumanjayi's 18th birthday.

18. On 12 July 2017, a Carer Re-Approval Report was completed for Ms Teasdale. Ms Teasdale's ongoing commitment to Kumanjayi was well established and she advocated strongly for her support. The Report approved Ms Teasdale to be a Specific Foster Carer for Kumanjayi for a period of two years.

19. Due to Kumanjayi's significant needs, extra support was provided to Ms Teasdale including respite for six weeks from September to October 2017 when Kumanjayi was placed with Safe Pathways in Alice Springs.

20. A case note on 17 November 2018 indicated Kumanjayi's neurologist was investigating Batten disease as a possible diagnosis for her degenerative condition. Batten disease is caused by an abnormal variant in the CLN3 gene found on chromosome 16. The National Institute of Neurological Disorders and Stroke explains that this gene directs the production of a protein called battenin. Most children suffering from Batten disease have a missing part in the gene and this protein is not produced. Due to the progression of the disease children experience: rapidly progressive vision loss which begins between ages 4 and 7, learning and behaviour problems, slow cognitive decline (dementia), and seizures commence around age 10. In their teenage years children with Batten disease develop: slow movement, stiffness, and

loss of balance (also referred as Parkinsonism), and lose their capacity for speech and language. Sadly, children with this disease become increasingly dependent on their caregivers and have a shortened life expectancy of between 15 and 30 years.

21. On 3 January 2019, test results for Kumanjayi confirmed a clinical diagnosis of Batten disease (CLN3). Ms Teasdale was "flattened" by Kumanjayi's diagnosis and she determined to fill Kumanjayi's life with as much experience and fun as possible. Complicating her condition were additional diagnoses of Autism Spectrum Disorder, Intellectual Disability-Severe Impairment Secondaries, Cone Rod Dystrophy, Epilepsy and Incontinence.

22. Following these diagnoses, arrangements were made for her mother to have access with Kumanjayi. Efforts were made to locate her father to inform him of the diagnoses, however he could not be found.

23. Throughout 2019, Kumanjayi had infrequent access with her mother and siblings who had relocated to Katherine. TFHC provided travel funding in January and July 2019 for such visits. Attempts were made to establish regular phone contact however consistent and reliable telephone contact proved challenging.

24. During 2019 TFHC case work focused on addressing Kumanjayi's complex needs. A multi-disciplinary care team was established consisting of a NDIS coordinator, Brain Injury Support, Paediatrician, Neuropsychologist, Paediatric Neurologist, Mobility Instructor, Occupational Therapist, Physiotherapist and Eye Specialist. Kumanjayi was also referred to the Alice Springs Hospital Palliative Care team, and work commenced on end of life decisions with her mother consistent with TFHC's End of Life Planning Procedure for children in care.

25. On 1 September 2019, Ms Teasdale was re-approved by TFHC to be a Specific Foster Carer for Kumanjayi and a respite carer for another child,

for the period 12 May 2019 to 11 May 2021. In August 2019, Ms Teasdale planned to relocate from Tennant Creek to Alice Springs. In October 2019, Ms Teasdale and Kumanjayi moved to Alice Springs so Kumanjayi could have increased access to services. Her TFHC case management was transferred to the Alice Springs office.

26. Due to the aggressive and debilitating nature of Batten disease, Kumanjayi by then required care twenty-four (24) hours per day, seven (7) days per week arranged and overseen by Ms Teasdale. It is clear that Ms Teasdale ensured that Kumanjayi was supported and loved by those who cared for her.

Her engagement with the National Disability Insurance Scheme

27. The National Disability Insurance Scheme ("NDIS") is an initiative of the Commonwealth Government that funds costs associated with disability. It was legislated for in 2013 and entered into full operation in 2020. Administration of the NDIS is handled by the National Disability Insurance Agency ("NDIA"). The operation of the NDIS is overseen by the NDIS Quality and Safeguards Commission ("NDIS Commission").

28. Prior to the introduction of the NDIS, the Northern Territory Government delivered disability services through the Aged and Disability Program administered by the Department of Health. The Northern Territory's trial of the NDIS commenced on 1 July 2014 in the Barkly region with the Northern Territory Government formally transitioning to the full-scheme NDIS on 1 July 2019. Since 2019, the NDIA has been responsible for the delivery of disability services under the NDIS.

29. Although Kumanjayi was referred to the NDIS in July 2014, as at November 2014 she had not been "formally" accepted into the scheme.

30. TFHC attempted to clarify her NDIS status. On 4 and 15 December 2015 they emailed the NDIS enquiring whether she was a client but received no response. A third email was sent on 18 January 2016. On 25 January 2016,

some 18 months after the initial referral, the NDIS manager responded by email that she would "follow up" with the family to "discuss NDIS with them".

31. On 8 February 2016 TFHC sent an email to the NDIA, the child health nurse and school principal, to organise a professionals meeting to discuss Kumanjayi. There is no evidence that meeting took place.

32. On 21 March 2016 TFHC again made contact with NDIS. An NDIS worker committed to updating Kumanjayi's NDIS plan and organising support through Vision Australia and Catholic Care. A copy of Kumanjayi's NDIS case plan was finally provided to TFHC in August 2016 and additional applications for incontinence funding and swimming assistance were made.

33. It appears from the material provided by TFHC that from 17 November 2015, Kumanjayi had a NDIS plan which was initially due to expire on 15 November 2016. Her progressive disease meant that her support needs increased quite rapidly and her NDIS plan required frequent review. However, despite advocacy by both Ms Teasdale and TFHC, the reviews did not occur in a timely manner and her supports did not meet her increasing level of need.

34. On 27 March 2017, TFHC received the reviewed support plan. As Kumanjayi was in the care of the CEO, TFHC was responsible for reviewing her plan to ensure it properly provided for her needs. TFHC and Ms Teasdale considered the proposed support plan to be insufficient for Kumanjayi's needs. Assistance was sought from Brain Injury South Australia, which was the responsible agency for NDIS appeals, and on 13 April 2017 an application for review was lodged.

35. On 9 May 2017, the outcome of the review by the NDIS was received. The NDIS made some changes to increase supports to Kumanjayi, however, it was considered they were still not sufficient to provide for her needs. For

example, the new plan did not make provision for a Coordinator of Supports (which had previously been included) seemingly with the expectation that TFHC would coordinate support. However, children not in the care of TFHC were entitled to such assistance. It appeared that the NDIS was assessing Kumanjayi as a "child in care" and not simply as a child with disabilities.

36. On 1 June 2017, Brain Injury South Australia made application for legal funding for Kumanjayi to lodge an appeal which was granted on 1 June 2017.

37. In order to provide evidence of the further supports required, Kumanjayi required a cognitive and autism spectrum disorder assessment. As the NDIS refused to fund the assessment, TFHC provided the funds. On 25 July 2017, Kumanjayi participated in the multidisciplinary assessment with Novita in South Australia. She was assessed as suffering from a range of complex disabilities across all areas of development that fell within a "moderate to severe" range which were likely to be "lifelong". Ultimately the cost of this assessment was recovered on appeal, as the report,

> *"..provided extremely valuable opinions and advice as to the nature and extent of the applicant's disabilities and the supports she requires and...also qualifies as a reasonable and necessary support for the applicant."*[2]

38. On 16 August 2017, a conciliation conference was held between Ms Teasdale, supported by TFHC, and the NDIA. Agreement was reached for additional support, coordination hours and funding for assistive technology. The matter was also listed for a hearing at the Administrative Appeals Tribunal ("AAT") in October 2017.

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[2] LNMT and National Disability Insurance Agency [2018] AATA 431 (6 March 2018) per Deputy President K Bean at [49]

39. Unfortunately, the decision of the AAT was not received until 7 March 2018. The decision varied Kumanjayi's NDIS plan from May 2017 to include the following additional supports:

39.1 Support coordination in the sum of $12,228.32.

39.2 Increased social and community participation in the sum of $2,200.

39.3 Core supports in the amount of $8,779.96.

39.4 Cognitive assessment in the sum of $1,020.

39.5 Assistive technology in the sum of $10,080.

39.6 Improved daily living in the sum of $11,375.70 plus the cost of an orientation assessment.

39.7 Improved relationships in the sum of $5847.45.[3]

40. On the question of which agency was the appropriate provider of respite funding, the Deputy President stated:

> *"... the applicant cannot participate in the usual respite arrangements which apply to children in foster care. Because of her significant disabilities, difficult behaviours and complex needs, when her foster mother is not available to care for her, she must be placed in disability supported accommodation on a temporary basis. I see no room for doubt that this expense is attributable to the applicant's disabilities, is not more appropriately funded as part of a universal service obligation and therefore must be met as a reasonable and necessary support under the NDIS. I note my conclusion in this regard is consistent with the COAG Principles, which expressly acknowledge that additional respite care required as a result of a child's disabilities so as to enable sustainable caring arrangements*

[3] Ibid at [52]

for them will be a reasonable and necessary support under the NDIS."[4]

41. TFHC considered that the revised plan appropriately accommodated Kumanjayi's needs and made provision for her to access a range of supports. Because of the constant deterioration of her health, she was allocated to the NDIS Complex team, she had a dedicated planner and her needs were reviewed every six months. Between 2018 and 2020, the NDIS delivered approximately $360,000 every six months to support Kumanjayi. Ms Teasdale said,

> *"..Batten's you have to plan to be proactive...it was so important to have the funding from the NDIS because the more that you could do with her to keep her physically active, the better it would be for her."*[5]

42. Following a review in May 2021, the NDIS reduced her annual funding to $246,874, a decrease greater than 50% in comparison to her funding for the past two years. From the perspective of TFHC and Ms Teasdale the decision was inexplicable given her care needs were increasing.

43. Her medical records from Congress seem to confirm that her condition was degenerating and her level of need was increasing. Her progress notes for 29 June 2021 include the following:

> *"..wheelchair bound but able to transfer with two helpers and device*
>
> *-essentially blind.*
>
> *-NDIS issues: funding has been reduced, but actually needs increased funding/support, given degenerative neurological condition*

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[4] Ibid at [46]
[5] Statutory declaration of Angela Teasdale dated 24/11/2021 at p5

..

Increasing dementia

Increasing alzheimers shake

Needing greater support 2/1

More loss of continence

Requires assistance with feeding"[6]

44. On 26 May 2021 TFHC lodged a Freedom of Information ("FOI") request to the NDIS to ascertain its justification for reducing supports. On 21 July 2021 the NDIS FOI team sent an email outlining that it had "not actioned the FOI request" as it "may have been misplaced" by the FOI team.

45. Time and resource intensive review and appeal processes were recommenced. Following an unsuccessful review, the appeal was scheduled to be heard in November 2021. Her NDIS funds were depleted in about August and she passed away before the listed appeal date.

46. Ms Teasdale described the experience with NDIS this way,

> *"...it was sad because I had to be able to give her my love and support and care for her, but at the same time deal with challenging a monster of a system that was disgracefully and inhumanely negating any level of impact of disability that she had, and I should never have been put in that position [and] ...because the funding had been diminished completely the staff weren't being paid for over 5 weeks.."*[7]

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[6] Central Australian Aboriginal Congress Patient Summary for Damilia Holmes printed 06/12/2021 12.45.34, entry 29/06/2021

[7] Statutory declaration Angela Teasdale dated 24/11/2021 at p9

47. It was distressing for her carers and TFHC staff that there was so much complexity in securing NDIS funding for services to meet Kumanjayi's significant and growing care needs arising from her disabilities. There is currently a Royal Commission inquiring into the operation of the NDIS and I do not wish to pre-empt its findings but note that Kumanjayi was an extremely vulnerable recipient of the NDIS for whom the scheme should have operated better.

Her care in Alice Springs until her passing

48. On 6 February 2020 her parents expressed a wish that Kumanjayi remain in TFHC care but did not support a Permanent Care Order being granted to Ms Teasdale as they wanted Kumanjayi to remain connected to family.

49. Although the care provided by Ms Teasdale was considered by TFHC to be excellent, from time to time there were grievances that arose between Ms Teasdale and Kumanjayi's support workers and school. At one stage these grievances resulted in the withdrawal of some support services. However TFHC considered that in cases as complex and difficult as this case, it was not uncommon for there to be tensions between carers and service providers.

50. TFHC considered that Ms Teasdale was an exceptional advocate for Kumanjayi and she constantly sought improved and higher standards (including from TFHC themselves) on her behalf. For example, early on Ms Teasdale identified a tricycle that would support Kumanjayi's movement and independence. Following intense and persistent advocacy, funding for this was provided by the NDIS and TFHC staff witnessed Kumanjayi's joy when she independently achieved mobility on the tricycle. Later, when her mobility was extremely limited, Ms Teasdale requested specialist transport for Kumanjayi to allow her to continue to attend school, appointments and extracurricular activities. Although the NDIS did not fund the purchase or lease of a vehicle, on 13 October 2020, the CEO approved for TFHC to lease

a vehicle with specialised wheelchair access for Kumanjayi at a cost of $36,146.67.

51. By August 2021 Kumanjayi's TFHC care plan documented that she required 2-3 staff to support any mobility activities at school and was spending most of her days in a wheelchair. She required support to move around in her wheelchair and used a harness to ensure she was safe. Her toileting required the support of 2-3 people and took from 30 to 90 minutes and it was not uncommon for Kumanjayi to become very distressed. She needed full assistance to eat and drink.

52. Despite these challenging circumstances, Ms Teasdale continued to ensure that she participated in recreational, leisure and social activities. Kumanjayi continued to enjoy swimming, visits to the Desert Park and Reptile Centre, movies, cultural and music events.

53. On 26 August 2021, there was only two weeks of funding left in Kumanjayi's TFHC care plan and her NDIS funding was depleted. TFHC determined to provide $147,700.14 additional funding for Kumanjayi's care from September 2021 to her death in order for her to remain in the care of Ms Teasdale with the appropriate supports. The crisis situation which was allowed to develop placed unnecessary stress on Ms Teasdale and Kumanjayi's immediate care team. While the process of calculating and securing additional funding was complex, TFHC acknowledged it would have been prudent to address her funding situation earlier, so as to avoid the crisis. This was an appropriate concession.

54. On 2 October 2021, Kumanjayi was admitted to the Alice Springs Hospital Emergency Department (ED) due to increased abnormal movements, aspiration pneumonia and constipation. The hospital records reveal a decline in her health over the previous three months. Kumanjayi was transferred from ED to the Paediatrics ward and discharged back into the care of Ms Teasdale on 10 October 2021.

55. On 14 October 2021, Kumanjayi's condition deteriorated and she was re-admitted to hospital. Her disease had progressed to such an extent that on 27 October 2021 she was transferred to the Palliative Care Ward for end-of-life care. During her last days, TFHC arranged for her family to attend and remain in Alice Springs and she was surrounded by her family and Ms Teasdale when she passed away on 31 October 2021 at 6.25pm.

56. Following her passing, TFHC supported her family with all funeral arrangements and, in accordance with the family's wishes, her funeral was at Murray Downs where she spent her early childhood.

Cause of Death

57. Following her death, and having reviewed the medical records, Dr Marianne Tiemensma, Forensic Pathologist, recommended there was:

> *"... no reason to believe that the decedent died from any other than her known, underlying natural conditions, and this is not considered to be an unexpected or unexplained death, and there is no suggestion of neglect or lack of care".*

58. Dr Tiemensma suggested that the cause of death be certified as "Complications of Batten disease (CLN3)" and that in her opinion there was "(n)o need for a medico-legal autopsy". Her mother and Ms Teasdale accepted that recommendation and no autopsy was conducted.

59. The coronial investigation found no suspicious circumstances surrounding her death.

Conclusions

60. During the time that Kumanjayi was in the CEO's and Ms Teasdale's care she was loved and cared for, and her needs were provided for as best they could be in the circumstances of her disease. I commend Ms Teasdale on the care she provided to Kumanjayi.

61. TFHC conducted a Practice Review ("the Review") following her passing, and the Review formed part of the evidence in this inquest. It was unfortunate that there were significant challenges in funding Kumanjayi's care needs at sufficient levels and in a timely manner. At times there seemed to be a stalemate between the NDIS and TFHC as to which agency had responsibility to fund her care services. But Ms Martina O'Brien, Executive Director of Families Central Australian Region, explained that;

> *"given the relative age of the scheme there remained uncertainty with respect to the division of responsibilities between the Department and the NDIS (which) was only resolved through proceedings at the AAT. Child Protection Practitioners are not experts in disability support and it is clear that, at times, these processes caused them some difficulty."*[8]

62. In spite of these difficulties, the involvement of TFHC and its Disability and Development Team ("DDT") established in 2020 contributed positively to the provision of services to Kumanjayi. I understand that the purpose of the DDT is to support children in care, like Kumanjayi, to ensure they receive appropriate supports and NDIS funding in accordance with their needs.

63. On behalf of the TFHC, Ms O'Brien explained that there is work occurring nationally to streamline communications between the NDIA and the various child protection agencies in each Australian jurisdiction. The DDT is currently working with the NDIA on a data sharing agreement which should

[8] Affidavit, Martina O'Brien, dated 11/10/2022 at [137-138]

allow the Department to have greater access to the details of the NDIS plans of children in out-of-home care.

64. In addition, I am told that the DDT now has a monthly 'operational meeting' with the NDIA where they are able to discuss issues relating to NDIS plans for children in out-of-home care. Ms O'Brien is hopeful that improved communication and a more collaborative working relationship between TFHC and the NDIA will reduce the need for appeals and the risk of NDIS plans running out of funding. These monthly meetings were commenced in response to the difficulties identified in the management of Kumanjayi's care.

65. I make no recommendations in relation to this death.

Formal Findings

66. Pursuant to s34 of the Act, I make the following formal findings:

    i. The identity of the deceased person was Damilia Kelly Holmes born 24 May 2006 at the Alice Springs Hospital, in Alice Springs in the Northern Territory of Australia.

    ii. The time and place of death was approximately 6.25pm on 31 October 2021 at the Alice Springs Hospital Palliative Care Ward, in Alice Springs in the Northern Territory of Australia.

    iii. The cause of death was complications of Batten disease (CLN3).

    iv. Particulars required to register the death:

        a. The deceased was a female.

        b. The deceased's name was Damilia Kelly Holmes.

        c. The deceased was a child.

        d. The deceased was of Aboriginal descent.

e. The death was reported to the Coroner.

f. A post-mortem examination was not carried out with the consent of the Coroner's office.

g. The cause of death was confirmed by Dr Marianne Tiemensma.

h. The deceased's mother was Roxanne Morton, and her father was Damsien Kelly-Holmes.

Dated this 31 day of March 2023.

ELISABETH ARMITAGE
TERRITORY CORONER