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FINDING OF:	Judge Greg Cavanagh
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REPRESENTATION:

Counsel Assisting:	Kelvin Currie
Counsel for Territory Families	Helena Blundell

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IN THE CORONERS COURT
AT DARWIN IN THE NORTHERN
TERRITORY OF AUSTRALIA

No. D228/2017

In the matter of an Inquest into the death of

LEBRON DOUGLAS MARTIN

ON 13 December 2017
AT Katherine District Hospital

FINDINGS

Judge Greg Cavanagh

Introduction

1. The deceased was a four year and two month old Aboriginal child at the date of his death. He was born in the Royal Darwin Hospital on 28 October 2013 to Kara Lee Martin and Dwayne Rogers. He had a rare congenital condition, Niemen Pick Type C (NPC). He was the second child born to his parents with that condition. The first child, born in 2005, survived for a period of only four months.

2. He was born at 28 weeks. His birth weight was 1192 grams. He was placed in the special care nursery for three months. On discharge his weight was 2480 grams.

3. Due to having a second child born with NPC his mother experienced psychological problems prior to his release from hospital. She was diagnosed with post-natal psychosis. It was noted she was “excessively worried about her 12 week old baby”.

4. NPC is a progressive and fatal genetic disorder. It is characterised by the inability of the body to transport cholesterol and other fatty substances inside cells. The fatty substances accumulate in tissues including the brain, spleen and liver and cause damage.

5. In December 2014 at 14 months of age it was noted his liver and spleen were enlarged and he was suffering developmental delay. His weight was 6.075 kilograms. On 29 November 2015 his father took him to Melbourne for his spleen to be removed at the Monash Children's Hospital. He was thereafter prescribed prophylactic antibiotics.

6. His development peaked in early 2016 and from that point he suffered increasingly rapid neurological and functional decline. When he was assessed on 18 May 2017 at the Royal Darwin Hospital by the speech pathologist, the following was said:

> "Lebron appears to fatigue at mealtimes due to the effort to maintain his body position for the duration of a meal (particularly if he is not sitting with support), which increases his risk of aspiration of food and fluid. Lebron's effort at mealtimes will impact upon his ability to meet his daily nutritional requirements."[1]

7. Feeding became more and more difficult. He was put on a pureed diet and then as of 31 July 2017 could only be fed by nasogastric tube. There was consideration that he would need a percutaneous endoscopic gastrostomy (PEG) so that nutrition could be provided directly to his stomach. However he died on 13 December 2017 before that happened.

8. He died because of the progression of the genetic disorder. His death was not unexpected. It would not ordinarily have been a death reportable to the Coroner. However, it became reportable because four months and 15 days prior to his death the Department of Territory Families removed him from his family's care.

9. His removal was not for the usual reasons. I was told at the inquest:

> "Lebron's case was complex and multifaceted. Lebron's matter was not a typical child protection case. While domestic violence, alcohol misuse and physical or emotional abuse are common threads in child protection matters, these issues were not at the core of Lebron's matter. Lebron's case involved a child suffering from chronic and

[1] Report of Celina Lai dated 18 May 2017

terminal illness and parents unable to meet his complex medical needs which resulted in risks over and above those associated with his underlying condition."

10. Removing any child with disabilities from family because of complex medical needs arising from those disabilities is prima facie inappropriate. It is a breach of Article 23 of the *Convention on the Rights of Persons with Disabilities* which reads at sections 3 and 4 (my emphasis):

> **Article 23**
> **Respect for home and the family**
>
> 3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, ***States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.***
>
> 4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. ***In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.***[2]

11. To somewhat similar effect is section 8(3) of the *Care and Protection of Children Act 2007*:

> ***8 Role of family***
>
> *(3) A child may be removed from the child's family only if there is no other reasonable way to safeguard the wellbeing of the child.*

12. My Office indicated at an early stage that the focus of the inquest was to determine if the removal of Lebron was justified. The departmental response received on 20 September 2019 made a number of concessions but continued

[2] Ratified by Australia on 17 July 2008 and entry into force for Australia 16 August 2008

to assert that the removal of Lebron from his family was the appropriate and only available option.

13. At the inquest the parents of Lebron provided a statement:

> From birth to when Lebron went into care on 28 July 2017, he lived with his immediate and extended family where care was provided by his mother Kara, father Dwayne and grandmother Vivien. When Lebron was little, the family all slept together and Lebron was a happy and cheeky little boy. When he was about 2 years old, he kicked his sister Shauna out of the bed because he always wanted to sleep in the middle between his parents Kara and Dwayne. Lebron's first word was "Kara" and he called his sister Shauna, "baba".
>
> Lebron really loved his sister "baba" and he would pull her nose and slap her to wake her up to play.
>
> Lebron loved eating yoghurt, eggs, spaghetti and one of his favourites was porridge with honey.
>
> Lebron was very happy when he was with his family. Even when he was sick and feeling unwell, he loved Kara and was truly happy when he was with Kara. When Lebron was returning to care we could see the sadness in his eyes and we could tell that he was sad. Kara believes he was wondering why he was not sleeping at his home with his family.
>
> Lebron's face would also come to life when he saw his father, Dwayne. On his visits to Katherine hospital Lebron's favourite toy was a red car which Dwayne would push him around in, Lebron loved this.
>
> We very much wanted Lebron to stay in our care and we worried that Lebron may pass away in someone else's care.
>
> After Lebron passed away in Katherine Hospital at 1.45am on 13 December 2017, his father Dwayne stayed with him till morning as the family did not want Lebron to be alone.
>
> We loved Lebron and we truly miss him.

The Issue

14. The issue is whether the Department of Territory Families could or should have obtained services to support Lebron and his family such that he could

have spent the remaining months of his life with them or whether it was necessary that he be removed.

15. The Department asserted that there was no other option but to take Lebron into care because there were no services in Katherine that could adequately support the family:

> "Had ongoing intensive case management and long term respite care existed in the community this case would have been unlikely to have required intervention of Territory Families. However none of these services existed outside a statutory intervention model … If a similar matter arose in the future, it is likely that the family would have full access to the National Disability Insurance Scheme (NDIS) without need for any statutory intervention."[3]

16. However, in the context of this case, the only support services considered by the Department were the support services contracted and funded by the Office of Disability. That Office indicated that Lebron was too young to be on a "package". The Department considered that the programs funded by that Office were "short to medium term support to build capacity".[4] It was said that they were not what was needed to support Lebron and his family. The Department said that in any event they were aware that those programs were operating at capacity.

17. There was no attempt by the Department to find and fund a support service themselves. The Departmental staff sent a number of emails on 24 July 2017 that may have been an attempt to ask services for assistance.[5] However they did not wait for or receive a response. The following day a foster care placement was obtained for Lebron.

[3] Statement of Karen Broadfoot dated 20 September 2019 paragraphs 103, 107
[4] Ibid paragraph 104
[5] Although I was told by one witness those enquiries were made with a view to support the mother during access.

What happened?

18. The family of Lebron were able to manage his medical needs for the first three years of his life. Those needs were not insignificant and included taking Lebron to hospitals in Katherine, Darwin, Adelaide and Melbourne. However, as his function declined he needed more frequent medical services and his feeding became more and more difficult.

19. On 23 March 2016 Territory Families received a notification about the care of Lebron.[6] The allegations thereafter became repeating themes. They were, in effect, that Lebron was underweight and losing weight, that he only ever put on weight when in hospital, that his parents did not attend appointments unless picked up and they were often not at home when services visited, including the services to pick them up.[7]

20. On 11 April 2016 there was another notification from the hospital that Lebron was failing to thrive. It was thought to be more a poverty issue rather than a medical issue. It was said that Lebron had been "lost to follow up". The notifier thought it would be good for Lebron to go to childcare. [8]

21. That month the family were referred to Good Beginnings, a non-governmental support organisation. Lebron was enrolled in Little Mangoes pre-school. He was noted on 3 May 2016 to be putting on weight.[9]

22. On 4 May 2016 Territory Families organised a case conference with all providers. There were 11 people in total at the case conference. A list was put together with the details of all persons involved, their contact details and the support they were providing.[10] A letter was sent to the Department of

[6] During the course of the inquest I granted leave pursuant to section 27 *Care and Protection of Children Act 2007* as the content of the notifications was of critical importance to the proceedings.
[7] CCIS page 7
[8] CCIS page 11
[9] CCIS page 21
[10] CCIS page 23

Housing to allow them to move to a more appropriate location away from the partying, drugs and alcohol.[11] Respite care was attempted in May 2016, however Lebron's mother became quite agitated about Lebron leaving her.[12]

23. The reports from the service providers indicated that the family were progressing well with the support of Good Beginnings. On 9 June 2016 it was reported by all agencies that engagement had been better. On 9 June 2016 Good Beginnings spoke to the Department about the family. Part of the conversation was in these terms:

> "… the family is trying really hard, and they are getting Lebron dressed and ready for pre-school on time. They always have [his sister] ready and well presented for school … Everyone is able to engage with the family well … it is awesome that all agencies can now do their support and appointments with Lebron when he is at childcare, so there are no issues with not being able to engage or find the family …"[13]

24. On 6 September 2016 and 16 November 2016 Good Beginnings reported that Lebron had continued to attend appointments with allied professionals and was making consistent weight gains. On 15 December 2016 the report was that there were concerns that visiting family members took Kara's food.

25. In recalling the challenges the family had in 2016 a case worker said:

> "I know that one of their biggest issues would be something as small as missing an appointment and that would be alarm bells for everybody that they are now neglecting the child but there are so many other reasons as to why they have missed an appointment; whether or not they have a calendar or diary. There were so many other things, I used to get really frustrated that people hadn't considered, so I know that the Good Beginnings worker was really good with advocating for the clinic to transport as well so they didn't have their own car and then we were finding that the transport

[11] CCIS page 25; Departmental files Pt 1 C85
[12] CCIS page 27
[13] CCIS page 32

provided by Wurli Clinic was quite unreliable so it was just a multitude of issues for the family". [14]

26. By 15 December 2016 Good Beginnings indicated that the family had met their goals and that they would likely be ceasing their involvement in the near future.[15] On 9 February 2017, Good Beginnings sent an email to Territory Families:

> "I'm not sure if you closed Lebron's case but I'm just letting you know that Good Beginnings will be closing our IFFS case with the family due to them satisfying referral concerns. You can see the family's progress on their recent case update. Lebron has an ongoing weekly visit from an OT and therapy support person as well as a visiting speech pathologist. There is a schedule for Lebron's monthly Wurli checks and I have asked … Disability to monitor this to make sure Wurli picks up the family for appointments. Lebron will also be starting at Kintore shortly.
>
> The family are doing well and are linked in to services.
>
> Let me know if you have any thoughts or queries."[16]

27. There was no further contact by the Department with the family, or any other person, relating to Lebron until 22 June 2017.

28. On 1 May 2017 his Consultant Paediatrician, Dr Catherine Boyd, wrote:

> "Lebron has had slow developmental progress, peaking around 2½ to 3 years of age, though the last 6 – 12 months, neurological decline has been noted …Oromotor function has declined over the last 6 months, now slow to feed, and requiring pureed food, and at risk of aspiration."

29. On 22 June 2017 the Department received two notifications. The first notifier, at about 4.30pm, stated that over the last number of months Lebron had been admitted to hospital due to weight loss and was not being weighed regularly at Wurli Wurlinjang Health Clinic. At the beginning of June he

[14] Senior Child Protection Practitioner interview, Part 1, page 4
[15] CCIS page 34
[16] CCIS page 35

weighed only 9.6kgs. It was not known if he was having his daily antibiotics and despite supposedly having two supplement drinks each day he was underweight and it was assumed he was not having them.[17]

30. The second notifier called at about 5.30pm. The Department was told that Lebron had a neuro degenerative disease and a life expectancy of about 12 months. Lebron had difficulty feeding due to his neurological decline and had gone from eating solid food to pureed food. Feeding was labour intensive and although his mother loved Lebron she had limited capacity. Lebron had three hospital admissions that year due to weight loss. The notifier said that extra support was needed for the family, "e.g. transport and parenting support, as the current needs of the family is beyond the capacity of Wurli Wurli to manage."[18]

31. As at 22 June 2017 Lebron had not been taken to Wurli Wurlinjang Health Clinic for 15 days (last on 7 June 2017). It was said that his mother would have run out of antibiotic medication for Lebron. On 26 June 2017 Lebron and his father presented to the Clinic. Lebron was noted to be clean, well dressed and had gained weight.

32. When asked about his mother's capacity, the Aboriginal Community Worker said "I think mum tries her best but she just needs support and constant reminding what she needs to do".[19]

33. On 30 June 2017 Territory Families spoke with the family at their residence. During that visit Lebron was noted to be clean, neatly dressed and responding positively to family. It was agreed:

- The Department would get a schedule of Lebron's appointments and put them in a pictorial poster that the family could put on the wall;

[17] CCIS pages 35, 36
[18] CCIS pages 37, 38
[19] CCIS page 39

- The Department would contact Good Beginnings or other services in Katherine to assess their needs and provide assistance transporting the family to and from appointments;

- The family would re-enrol Lebron in Child Care on or before Monday 3 July 2017 (he hadn't been enrolled since October 2016);

- The Department would provide updates to the family in the week commencing 3 July 2017.[20]

34. However the Department did not contact the family again for that purpose or arrange support services. The next contact with the family was on 17 July 2017 after the receipt of further notifications.

35. Lebron's mother had taken him to Wurli Wurlinjang Health Clinic for his scheduled appointment. He was noted to have lost significant weight and it was believed he required admission to hospital. His mother said she was "sick of hospitals". She went to look for his grandmother to take him instead.

36. The Clinic asked that she return with Lebron by 2.30pm and they would transport them both to hospital. By 1.40pm she had not returned (and despite not yet being 2.30pm the Clinic clearly had doubts she would return). The Clinic had sent someone to the family residence. However the family were said not to be there, and they could not be located during a drive around the town. The notifier said that if Lebron did not receive medical attention within 24 hours he would be at significant risk. The family had not been found by 3.02pm. [21]

37. Territory Families staff made their way to the family residence. They found the family there. Lebron's mother said that she had visitors and would take

[20] CCIS page 41
[21] CCIS page 43

Lebron to hospital the following day. However when it was suggested that the departmental staff would take Lebron to hospital if she did not, she agreed to take him.[22] Departmental staff said they sighted Lebron. He was sitting in a stroller being pushed around by his mother. In their assessment he was:

> "very lethargic and unresponsive with snotty nose. He didn't smile at the workers when they made attempts to greet him and communicate with him. The mother stated that he had been sleeping a lot". [23]

38. The impression I had during the evidence was that seeing Lebron and forming that opinion had an emotional effect on the staff that may have influenced them in the decisions that followed. It was the first time that one of the staff had seen Lebron and he was thought by the staff to be extremely sick. One of the staff told me:

> "I've been in child protection for ten years and I've never seen a little boy so unwell and so needing to be hospitalised … Well I'm not a doctor. This was a boy that was really, really, really sick and needed urgent medical attention." [24]

39. However, it was clear from the hospital records that the only medical issue from which he was suffering at that time was his loss of weight. He was admitted at 7.14pm. The nursing note at 8.50pm states that he was admitted to the ward at 8.30pm accompanied by his mother. He was noted to be alert and interactive. His observations were stable. He was reviewed at 11.00pm by the doctor. By that stage he had been given 110 millilitres of fluid. His observations were within normal limits and he was sleeping peacefully. There were no concerns.

40. The following day the impression was recorded as "growth faltering 2% to inadequate intake" due to "food security" and "regression of disease". The

[22] CCIS page 48
[23] CCIS page 48
[24] Transcript page 32, 33

plan was for "overnight feeds? bloods tomorrow, notify Territory Families and not to be discharged into mothers care".

41. At 11.10am on the morning of 18 July 2017 the local departmental manager sent an email to the Placement Unit. It read:

> "We're planning to remove a medically sensitive little boy named Lebron Martin. He's 3.8 years old and will need a dedicated carer in context of medical sensitivity. He's currently in Katherine Hospital … We'll be in court Thursday or Monday."[25]

42. At 11.31am that morning (18 July 2017), Territory Families wrote to the Hospital indicating that among other things the Department was applying for a Protection Order for the CEO to have parental responsibility for Lebron.[26]

43. At 12.20pm Departmental staff met with a doctor and the social worker at Katherine District Hospital. They were told of his dramatic regression over the last 12 months and particularly the last 6 months. That Lebron was not getting the nutrition he required to thrive and live a quality life. They were told that was partly because he was very difficult to feed and primarily due to the difficulties he had swallowing. They were told that the hospital had been informed that Lebron is not being fed because there was no food in the house. They said that was because family were eating the food and leaving none for Lebron's mother to feed him.[27]

44. They were told that Lebron had not been getting his Fortini supplement. It was believed that to be the case because it was reported that:

- his mother was drinking it herself;
- his mother didn't attend Wurli Wurlinjang every week to pick it up; and

[25] CCIS page 74
[26] CCIS pages 58, 62
[27] CCIS page 50

- when Wurli Wurlinjang staff went to the home to get the family, the family were not there.[28]

45. They were told that this was the third admission since April 2017 and that he had been admitted due to malnutrition or weight loss concerns. The last time he was extremely sick and had to be flown to Darwin. They were told that on discharge he had weighed 10.52kg. However on admission the day before he had lost 1.5kg (weighing 9.02kg). They were told that was because he had not been appropriately fed.

46. It was the medical team's assessment that without a regular service that would attend the family home every day to "literally feed him at least one meal", he was at risk of serious health complications or death. They said that he would be in hospital for at least a week until he regained the weight of 10.52 kilograms.

47. The next day (19 July 2017) Departmental staff returned to the hospital to speak further with the doctor and social worker. This time they also included the Aboriginal Liaison Officer (ALO). The social worker and the ALO proposed, what the Department described as a "very less intrusive intervention". They suggested that Lebron remain in his mother's care and proposed that a service provider attend the home at least once a day to feed Lebron.

48. The Departmental staff then stated to the hospital staff:

> "the family previously engaged with Good Beginnings, Wurli Wurlinjang's Wellbeing Program who were literally doing everything for the family including transporting Lebron to and from child care, doing groceries for the family and taking Lebron to his appointments, but when these services ceased, the current concerns started to surface."[29]

[28] CCIS page 50
[29] CCIS page 51

49. Rather than being an indication that like services should be reinstated to support the family, it seems that the Department believed it to be a reason that Lebron needed to be taken into care. It is difficult to see how that can be interpreted in a positive light for the Department.

50. It was clear that there were potentially a number of contributing factors to Lebron's loss of weight. However there was no attempt to understand what Lebron's feeding regime was at that time. No person asked Lebron's mother how much she fed him, when she fed him, what Fortini feeds he had or whether she was having difficulties with food security or was drinking the Fortini herself.

51. Rather, the departmental staff assumed the weight loss to be due to neglect. They asked the medical team if the one meal a day "would be sufficient to sustain his life and provide him with the quality of life he deserves". The doctor responded, that like any child he required more than one meal and in his case he needed in 3 main meals and 2 supplementary Fortini feeds each day. That was the basis for the Department thereafter insisting that there was a need for a support service to provide three meals a day. They said there was no service available to provide that level of support.

52. The Paediatrician in Darwin prepared a report addressed to Territory Families. It gave an explanation of his disease and went on to state:

> The biggest concern for Lebron has been the diseases' effects on his neurological function. This has resulted in Lebron being very weak, and he has lost a lot of muscle strength and function over the last 9 months. For example, he used to pull himself to stand, but he is no longer doing this. He is losing his ability to move his eye muscles (has difficulty looking up). He has worsening fine motor and gross motor function. He has declined in his ability to seek and swallow food. He requires that food be pureed, and he requires a long time to feed. Hence he has been commenced on supplement nutrition over the last 6 months, guided by the hospital dietician.
>
> Lebron's weight management has consequently been challenging. He has had 3 admissions to hospital for weight loss over the last 6 months. With the appropriate type of food (ie pureed), and the

> appropriate time to offer Lebron food, he is able to eat safely and he can demonstrate weight gain … Over the last 6 months, we have endeavoured to have Lebron reviewed regularly through his GP clinic to monitor his weight, but the family often fail to attend these weekly appointments. It seems that Kara has limited family support to help her with caring for Lebron. At the most recent admission, Lebron had lost over 1 kg of weight, which is very concerning.
>
> It is clear that Lebron's nutritional needs are not being met by his mother or family in the community with the current measures being put in place. There are also concerns that the family have not been adherent with the daily dose of amoxicillin, resulting in Lebron being at risk of serious bacterial infection and sepsis. This has resulted in adverse effects on his health and nutrition. This places him at risk of infections, and developmental decline, and death, over and above his already increased risk of this due to his underlying condition.
>
> Kara always presents as very caring for Lebron and clearly loves her son, though with the current level of support she is receiving in the community (from her family) she has not been able to meet Lebron's basic nutritional needs."

53. Until 25 July 2017 Lebron put on weight while in Hospital. By 25 July 2017 he was 10.3 kilograms. His weight did not increase from that point.

54. On Thursday 27 July 2017 the Department picked up the family members and took them to the hospital where they were told that Lebron was being taken into care. Among many other things, Territory Families staff stated to the family:

> "… that due to ongoing concerns regarding Lebron not being appropriately fed, and missing out on his daily medications and crucial medical appointments, and the department failing to identify or source a support service that would be able to attend the family home to feed Lebron at least three meals every day, a decision has been made for him to come into the CEO's care.
>
> … The Department have secured a placement for Lebron in Katherine, and would be facilitating him to have daily access with his mother and family (between 10am and 4pm) at Ms Martin's residence.

> … they will be working collaboratively with the family and will support Ms Martin, Mr Rogers and the other identified key family members to attend Lebron's appointments.
>
> The workers assured Ms Martin and the family that the placement secured for Lebron was in Katherine, and "daily access will be facilitated."[30]

55. The following day, Friday 28 July 2017, the Department filed an application for a Protection Order in the Local Court at Katherine. The proceedings were adjourned to 18 August 2017 and the daily care and control of Lebron was given to the Chief Executive Officer of the Department during the adjournment.

56. The plan had been to keep Lebron in hospital until he reached 10.5kgs. However, over the weekend while still in hospital his weight dropped dramatically. He lost 400grams. On the Monday (31 July 2017), after two weeks in hospital, he was only 500grams above his admission weight.

57. It was suspected that he was aspirating food into his lungs. A speech pathologist assessment was organised. She was of the opinion that it was not safe for oral feeding to continue and he was fitted for a nasogastric tube that afternoon.

58. Lebron's mother stayed on at the hospital and fed him using the nasogastric tube. It was noted in the nursing notes on 4 August 2017:

> "Observed Kara to do the NGT feeds this morning. She did well, knows what to do."[31]

59. At 12.30pm that day Lebron was discharged from hospital to departmental staff along with the tubes, feeding pump and Nutrini Multifibre. It was another four days before he saw any of his family again. He had access to

[30] CCIS pages 82, 83
[31] Third Volume, Katherine District Hospital Medical Records

his family on 8 August 2017 and then on most weekdays thereafter for three hours in the morning.

60. That wasn't in accordance with the representations made by the Department on 27 July 2017. The time for access was cut back ostensibly because it was thought the mother should not feed the child at all. On reflection however the Department conceded that the mother should have fed Lebron while on access:

> "I acknowledge that allowing Ms Martin to feed Lebron, or attempting to let her do so should have been supported by the Department. This would have afforded Ms Martin privileged time to nurture her child and feel empowered to meet one aspect of his daily care when she was unable to provide full time care to her child".[32]

61. On 9 August 2017 the carer advised Territory Families that she would be needing respite from 16 – 23 November 2017.[33] There appeared to have been no arrangements made for that respite until shortly before that date. On 15 November 2017 the family were informed that Lebron was being taken to Darwin for a week.

62. The following day Lebron was driven to Darwin by the carer and left with a respite carer whom he had not previously seen. Over the week that followed he was taken to the Emergency Department of the Royal Darwin Hospital on three occasions. The carer drove him back to Katherine on 23 November 2017. He appeared sick and was admitted to Katherine District Hospital where he stayed for 5 days.

63. The Court proceedings were finalised on 24 November 2017. Territory Families sought an order for parental responsibility to the CEO for two years. It was noted that the mother consented to the two year order hoping

[32] Statement of Karen Broadfoot dated 20 September 2019 paragraph 120
[33] CCIS page 113

that she would be reunified with Lebron thereafter. There was no representative for the child.[34]

64. Lebron went back to the carer's residence for a number of days and then was readmitted to the hospital on 4 December 2017. He did not leave hospital again. His mother sat with him each day. He died in the early hours of 13 December 2017.

65. As to the respite care arrangements the Department said:

> "It is conceded that the failure to specifically plan for respite care at a point where Lebron's medical treatment was at a palliative stage, ought to have been managed better and proposed changes to both protocols and the selection of respite carer are aimed at ensuring future case management of terminally ill children in care is improved." [35]

Formal Findings

66. Pursuant to section 34 of the *Coroner's Act*, I find as follows:

(i) The identity of the deceased was Lebron Douglas Martin born 28 October 2013 in Darwin, in the Northern Territory.

(ii) The time of death was 1.45am on 13 December 2017. The place of death was Katherine District Hospital in the Northern Territory.

(iii) The cause of death was respiratory failure secondary to pneumonia on a background of Niemen Pick Type C disease.

(iv) The particulars required to register the death:

1. The deceased was Lebron Douglas Martin.
2. The deceased was of Aboriginal descent.
3. The deceased was a child.
4. The death was reported to the Coroner by Katherine District Hospital.

[34] Which would appear inconsistent with section 94 *Care and Protection of Children Act 2007*
[35] Statement of Karen Broadfoot dated 20 September 2019 paragraph 121

5. The cause of death was confirmed by Dr Luke De La Rue.

6. The deceased's mother was Kara Lee Martin and his father was Dwayne Rogers.

Comment

67. Lebron Martin was born with a degenerative disease. There is no cure. By three years of age he was losing function. His medical and nutritional needs became challenging for his family. Initially they were given support but when support was withdrawn they struggled.

68. Until the age of three years and nine months all he knew was his family (and for a short period in 2016, childcare). His parents were observed to love him. It was in his best interests to remain with them.

69. It was incumbent upon the Department of Territory Families to support the family so they could cope with the challenges that came with multiple medical providers and the difficulties in feeding him.

70. However, it is clear that the Department did not understand that to be its role. When it was indicated by the Office of Disability that they could not fund or provide sufficient support, the Department of Territory Families considered the only option to be the removal of Lebron from his family.

71. In my view they were not justified in so doing. The Department should have ensured that there was continuing support for the family after the success of that support in 2016. If there were further concerns about the feeding and medical care, that should have been properly investigated and appropriate support put in place. That may have included assistance with one meal or three meals a day and transport to and from medical appointments.

72. To do so would have been a reasonable way to safeguard the wellbeing of Lebron and therefore would have been in compliance with, and would not have breached section 8(3) *Care and Protection of Children Act 2007*. To do so was required by the *Convention on the Rights of Persons with Disabilities* which states the government is to provide early and comprehensive

information, services and support to disabled children and their families. To do so would have avoided breaching the *Convention on the Rights of Persons with Disabilities* as a disabled child would not have been removed from his family because of his disability. To do so would have meant that a child would not have been separated from those he loved and who loved him in the last four months of his life.

73. At a relatively early date the Department of Territory Families were notified of my concerns in relation to this case. On the first morning of the inquest they were provided a copy of the *Convention on the Rights of Persons with Disabilities*. It was therefore disappointing that it took until the end of the evidence before the concession was made that the Department should have done more to support the family.

74. When the concession was eventually made, I commented:

> "That's all we wanted, instead of people getting stubborn and perhaps defensive, good people, good people getting a bit stubborn and defensive. We just want to try and learn from this and you don't learn when people are, 'I was right, 100 percent', well, no one is right 100 percent." [36]

Recommendation

75. I **recommend** that the CEO Territory Families ensure that staff have the training and resources to appropriately support children with disabilities and their families.

Dated this 22 day of November 2019.

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GREG CAVANAGH
TERRITORY CORONER

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