JURISDICTION	**:**	CORONER'S COURT OF WESTERN AUSTRALIA
ACT	**:**	CORONERS ACT 1996
CORONER	**:**	Michael Andrew Gliddon Jenkin, Coroner
HEARD	**:**	18 JUNE 2020
DELIVERED	**:**	1 JULY 2020
FILE NO/S	**:**	CORC 1124 of 2018
DECEASED	**:**	Child SJC (Subject to Supression Order)

Catchwords:

Nil

Legislation:

Nil

Counsel Appearing:

Sergeant Assisting: Sgt Lyle Housiaux assisted the Coroner

Counsel: Mr Thomas Ledger (State Solicitor's Office) appeared on behalf of the Department of Communities

Case(s) referred to in decision(s):

Nil

Coroners Act 1996
(Section 26(1))

RECORD OF INVESTIGATION INTO DEATH

I, Michael Andrew Gliddon Jenkin, Coroner, having investigated the death of a female child referred to as ***Child SJC*** *with an inquest held at Perth Coroner's Court, Court 85, CLC Building, 501 Hay Street, Perth, on 18 June 2020 find that the death of* ***Child SJC*** *occurred on 20 November 2017 at Mantra on Hay, 201 Hay Street, Perth, from complications relating to metastatic neuroblastoma in the following circumstances:*

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SUPPRESSION ORDER

Suppression of the deceased's name from publication and any evidence likely to lead to the child's identification. The deceased is to be referred to as "Child SJC".

INTRODUCTION

1. The deceased (Child SJC) died on 20 November 2017, from complications relating to metastatic neuroblastoma, an aggressive form of cancer that predominantly affects young children. She was two years and five months of age. At the time of her death, Child SJC was in the care of the Director General (DG) of the Department of Communities (the Department).[1,2]

2. Accordingly, immediately before her death, Child SJC was a "*person held in care*" within the meaning of the *Coroners Act 1996* (WA) (Coroners Act) and her death was therefore a "*reportable death*".[3]

3. In such circumstances, a coronial inquest is mandatory.[4] Where, as here, the death is of a person held in care, I am required to comment on the quality of the supervision, treatment and care the person received while in that care.[5]

4. The documentary evidence at the inquest consisted of one volume. Professor Nick Gottardo, (Consultant Paediatric Oncologist and Neuro-oncologist, Perth Children's Hospital) and Mr Glen Mace, (the Department's Executive Director, State Wide Services) gave evidence at the hearing. The inquest focused on the involvement of the Department in Child SJC's life and on the management of her medical conditions.

5. On the basis that it would be contrary to the public interest, the State Coroner made a suppression order with respect to Child SJC's name on 7 February 2020, pursuant to section 49(1) of the Coroners Act. The terms of that order are set out on the previous page.

[1] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18)
[2] Exhibit 1, Tab 10, Order - Children's Court of Western Australia (19.08.16)
[3] Section 3, *Coroners Act 1996* (WA)
[4] Section 22(1)(a), *Coroners Act 1996* (WA)
[5] Section 25(3) *Coroners Act 1996* (WA)

MEDICAL ISSUES

Background

6. Child SJC was born prematurely on 26 June 2015, at the Peel Heath Campus (PHC). Because of her prematurity, she was subsequently transferred to King Edward Memorial Hospital (KEMH) where she remained for four weeks.[6,7,8] Child SJC was regularly seen by a child health child nurse between August 2015 and August 2017.[9]

7. During a home visit on 30 November 2015, a departmental caseworker noticed that Child SJC appeared to have a "slight lazy" right eye and was constantly poking out her tongue. These observations were reported to a child health nurse by email, but due to an error in the email address, the information was not received.[10] However, on 10 February 2016, the child health nurse had been made aware of Child SJC's eye and tongue issues and these concerns were discussed with Child SJC's GP.[11]

8. At the inquest, Professor Gottardo said he did not consider these signs were suggestive of a neuroblastoma. He said that neuroblastomas were usually diagnosed when the primary tumour became large enough to be seen or felt and/or caused pain.[12]

9. In any event, on 17 May 2016, Child SJC appeared to have a viral chest infection when she was seen by a locum doctor. She was referred to the PHC and on 18 May 2016, she was seen in the emergency department. She presented with a history of recent falls, wheezing and intermittent vomiting, and was noted to have swelling and bruising around her left eye. She was subsequently transferred to Princess Margaret Hospital (PMH) for further review.[13]

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[6] Exhibit 1, Tab 4, Child SJC's Birth Certificate
[7] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), p4
[8] Exhibit 1, Tab 2, Report - FC Const. A Allen, Coronial Investigation Squad, pp1-2
[9] Exhibit 1, Tab 26, Report - Ms T Barrett, Child and Adolescent Health Service (24.09.19)
[10] Email from Ms D Ross (caseworker) to Ms R Malloy (child health nurse), (10.11.16)
[11] Email from Ms D Ross (caseworker) to Ms R Malloy (child health nurse), (10.02.17)
[12] ts 18.06.20 (Gottardo), pp29-30 & pp32-33
[13] PHC - Emergency department medical assessment record, File No. 30800, (18.05.17)

Neuroblastoma diagnosis

10. On admission to PMH on 18 May 2016, Child SJC was noted to have bruising around her left eye (known as "*racoon eye*") and a palpable mass in her abdomen.[14,15]

11. On 23 May 2016, Child SJC was diagnosed with Stage IV high-risk neuroblastoma. The primary tumour site was identified as her right adrenal gland and secondary tumours were identified in her liver and skull, and the bones in her arms and legs.[16,17]

12. Professor Gottardo explained that neuroblastomas are the most common solid tumours that occur outside of the head in children, and although they account for between 5% - 7%, they cause 15% of childhood cancer deaths. High-risk neuroblastomas, like the one Child SJC was diagnosed with, predominantly affect children under 5-years of age.[18]

13. Professor Gottardo noted that the treatment regime for children with high-risk neuroblastoma is "*amongst the most intensive regimens administered to children with cancer*" and includes multi-agent chemotherapy, surgery, radiotherapy, stem cell therapy and immunotherapy. Despite such intensive intervention, the five year survival rate for children with newly diagnosed high-risk neuroblastoma, is only about 50%.[19,20]

14. In Child SJC's case, a further complication was that cells from her neuroblastoma were found to contain the N-myc gene. Neuroblastomas that have this gene have been found to be more aggressive tumours, and the gene is thought to act as a driver for the disease. This gene has been found to be predictive of a poor prognosis.[21,22]

[14] PMH - Inpatient progress notes, File N. H2801817, (18.05.16)
[15] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p1
[16] PMH - Inpatient progress notes, File N. H2801817, (18.05.16)
[17] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p1
[18] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), pp1-2
[19] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p2
[20] ts 18.06.20 (Gottardo), pp16-17
[21] ts 18.06.20 (Gottardo), p12
[22] See also: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC501971/

Overview of treatment

15. Child SJC's treatment, was outlined by Professor Gottardo in the following terms:

a. ***Chemotherapy: 23 May 2016 - 19 September 2016***
In the first phase of treatment, Child SJC underwent five cycles of chemotherapy, which works by killing rapidly dividing cells, such as cancer cells. During this phase, stem cells were also harvested for later stages of her treatment;[23]

b. ***Surgery: 15 August 2016***
In the next phase, Child SJC underwent surgery to remove as much of the primary tumour as possible. The invasive nature of high risk neuroblastomas makes it impossible to remove all tumour cells due to the risk of damaging major blood vessels and other structures. Child SJC's primary tumour was found to be largely necrotic and contained less than 2% viable cancer cells, indicating that the chemotherapy had been successful;

c. ***Mega-therapy: 12 October 2016 - 20 December 2016***
In the third phase of treatment, Child SJC underwent two cycles of mega-therapy, and was given doses of chemotherapy which exceeded the "*maximum tolerated dose*". This level of chemotherapy has been found to be effective against neuroblastomas but destroys bone marrow cells. This side effect is addressed by introducing the stem cells which were harvested earlier;

d. ***Radiotherapy: 23 January 2017 - 9 February 2017***
Following mega-therapy, Child SJC underwent radiotherapy, designed to target any remaining neuroblastoma cells; and

e. ***Biotherapy: 20 March 2017, 90 days post mega-therapy***
Child SJC was then treated with isotretinoin, a derivative of vitamin A that has the effect of slowing the rate at which Neuroblastoma cells divide.[24,25,26]

[23] See for example: Exhibit 1, Tab 23, PMH Discharge summary, (23.09.17)
[24] Exhibit 1, Tab 16, Report - Prof. N Gottardo (22.10.18), p1
[25] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p1
[26] Exhibit 1, Tab 18, Patient Care Plan - Paediatric Palliative Care

Child SJC's progress and relapse

16. Initially, Child SJC appeared to respond well to treatment and she was discharged home on 10 January 2017. In a letter to her GP of the same date, Dr Bhavna Chawla (paediatric and adolescent oncologist, PMH), advised that Child SJC was "*doing well*" and had achieved a "*complete response*" following induction chemotherapy.[27]

17. Surveillance scans and testing of Child SJC's bone marrow in February 2017, found no evidence of a recurrence of the neuroblastoma and scans on 7 June 2017, showed she was still in remission. However, as Professor Gottardo pointed out, "*remission*" is not the same as "*cancer-free*".[28,29,30]

18. In this context, "*remission*" means that on the basis of diagnostic tests (including scans), there is no evidence of disease. However, because these tests do not descend to the cellular level, there is no way of knowing whether the patient's body is completely free from cancer cells.[31]

19. In Child SJC's case, despite her initially positive response to treatment, her neuroblastoma recurred, and she was said to have "*relapsed*" on 7 August 2017. At that time, a right sided pelvic mass was noted, along with secondary tumours in her right groin, the lymph system at the back of the right knee and her skeletal bones and bone marrow.[32,33]

20. Child SJC's treatment with chemotherapy and immunotherapy, using Dinutuximab Beta (see discussion below), began on 10 August 2017. Despite this treatment, scans on 6 October 2017, showed no response and Child SJC's tumours continued to progress. She underwent palliative radiotherapy, primary to control pain.[34]

[27] Exhibit 1, Tab 14, Letter - Dr BH Chawla (10.01.17), p1
[28] Exhibit 1, Tab 14, Letter - Dr BH Chawla (10.01.17), p1
[29] Exhibit 1, Tab 16, Report - Prof. N Gottardo (22.10.18), p1
[30] ts 18.06.20 (Gottardo), p31
[31] ts 18.06.20 (Gottardo), p17 & p42
[32] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p2
[33] ts 18.06.20 (Gottardo), p29 & p44
[34] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p2

21. In a letter to Child SJC's GP dated 10 October 2017, Dr Shanti Ramachandran (Consultant Paediatric Oncologist, PMH) provided an update on Child SJC's condition in the following terms:

> Thank you for helping us with the management of [Child SJC], who unfortunately has [had] an early relapse of her disease. Sadly, she had a poor response to the salvage chemo-immunotherapy cased on CT evaluation and clinical examination. She is being planned for irradiation therapy and Lutate therapy[35] for symptomatology control.[36]

22. Child SJC was admitted to PMH on 14 October 2017 and diagnosed with a febrile illness. She was discharged to Ronald McDonald House and was scheduled to undergo palliative radiotherapy on 23 October 2017.[37] Lutate therapy (specialised radiotherapy) was to have occurred on 31 October 2017 at Fiona Stanley Hospital, but on 30 October 2017, Child SJC's family declined further treatment, on the basis that it would not prolong her life.[38]

Silver Chain support

23. Child SJC was referred to Silver Chain's hospice service (the Service) on 10 October 2017. The Service provided pain management and other services to Child SJC and she was regularly reviewed by nursing staff and by a palliative care specialist. On 1 November 2017, a palliative medicine consultant and a clinical nurse consultant manager from the Service conducted a home visit. The family agreed with a palliative approach to Child SJC's care and her main medical issues were identified as poor pain control and ongoing fever.[39,40]

24. As a result of the home visit, it was agreed that a Silver Chain nurse would visit three times per week, and the family were provided with a 24-hour contact number to contact a Silver Chain nurse at any time.[41]

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[35] Specialised targeted radiotherapy designed to treat the symptoms of the tumour
[36] Exhibit 1, Tab 15, Letter - Dr S Ramachandran (10.10.17)
[37] Exhibit 1, Tab 22, PMH Discharge Summary (17.10.17)
[38] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p2
[39] Exhibit 1, Tab 5A, Referral - Silver Chain Hospice Service (10.10.17)
[40] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), pp1-3
[41] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p1

25. On 3 November 2017, Child SJC was reviewed by the Silver Chain doctor after her family contacted the Service on 2 November 2017 to report that she was experiencing fevers and irritability. Although Child SJC's fever was thought to be related to her tumour or possibly a virus, she was started on antibiotics.[42]

26. Child SJC's condition appeared to improve over the next two days, but her family reported that she was distressed and a Silver Chain nurse made a home visit at 11.00 pm on 6 November 2017 and administered pain relief.[43]

27. The Silver Chain doctor reviewed Child SJC on 7 November 2017 and noted a new mass in her jaw. Her condition had continued to deteriorate, but she was still interacting with her family and tolerating small amounts of food and water. After speaking with the PMH treating team, the Silver Chain doctor increased Child SJC's pain relief medication.[44]

28. The Silver Chain doctor reviewed Child SJC again on 7 November 2017 after the family reported finding a new mass below her ear. Because of her irritability at night, Child SJC was started on sedating medication and options for respite care in hospital were discussed in case they were required.[45]

29. Routine nursing observations continued for the following five days and when the Silver Chain doctor reviewed Child SJC on 15 November 2017, tumour deposits were identified at her jaw and knee. Her pain medication was reviewed and it was noted that she had received four extra doses of morphine in the previous 24-hours with good effect.[46]

30. On 17 November 2017, a Silver Chain nurse visited the family, and it was felt that Child SJC had deteriorated significantly and her death was imminent.[47]

[42] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p2
[43] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p2
[44] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p2
[45] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p2
[46] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p2
[47] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p2

31. The family spent the weekend at a hotel in Perth with the hope that Child SJC would be well enough to attend a Wiggles concert. As it happened, although Child SJC was able to meet the Wiggles, she was not well enough to stay for the concert itself.[48]

32. On 19 November 2017, a Silver Chain nurse was called to the family's hotel room. Child SJC was distressed, agitated and appeared to be in pain. She was given subcutaneous doses of morphine and midazolam and was started on a continuous infusion at 3.15 pm.[49]

33. The Silver Chain doctor reviewed Child SJC at 11.00 pm at the family's request, and Child SJC was given further doses of morphine and midazolam with good effect.[50] The Silver Chain nurse remained with Child SJC after the doctor left and was present when she died, surrounded by her loving family at 1.27 am on 20 November 2017.[51]

Use and availability of Dinutuximab

34. In his letter to Child SJC's GP dated 10 January 2017, Dr Chawla had noted that ideally, Child SJC's treatment regime should include immunotherapy using an Anti-GD2 antibody (ie: Dinutuximab) as well as isotretinoin, but that:

> [T]here has been a world-wide shortage of Anti-GD2 antibody. Despite our best efforts as a country, we have been unable to procure Anti-GD2 antibody. I should however mention that although Anti-GD2 antibody is considered standard of care for children with high risk neuroblastoma and it has helped short-term survival it has not helped to improve long-term cure rates. Hence immunotherapy will constitute isotretinoin only, unless Anti-GD2 antibody becomes available in the next few weeks.[52]

[48] Exhibit 1, Tab 13, Email - Ms A Lewis, Senior Social Worker, (20.11.17)
[49] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p3
[50] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p3
[51] Exhibit 1, Tab 5, Report - Dr F Findlay, Silver Chain, (27.11.18), p3
[52] Exhibit 1, Tab 14, Letter - Dr BH Chawla (10.01.17), p1

35. Dinutuximab is a chimeric human-murine anti-GD2 monoclonal antibody which is produced by combining human and non-human genetic material. Clinical studies have shown that Dinutuximab may improve the short-term survival of children with high-risk neuroblastoma and it is now considered to be a standard treatment for high risk neuroblastomas.[53,54]

36. This immunotherapy treatment works by introducing an agent into the patient's body which causes an antibody to attach to neuroblastoma cells, making them vulnerable to attack by the body's immune system. At the same time, other agents are given to the patient which have the effect of "boosting" the patient's immune system.[55]

37. Clinical studies available at the time of Child SJC's treatment, suggested that treatment with Dinutuximab may improve survival rates by up to 10% over a two to three year period. Data on effect of Dinutuximab on survival rates in the longer term was not available at the time of Child SJC's treatment and is still not available, but clinical trials are continuing. Obviously, the hope is that Dinutuximab will offer positive outcomes for some patients over the longer term.[56]

38. PMH had been able to access Dinutuximab at no cost, through its participation in clinical trials being conducted by United Therapeutics (UT), the American biotechnology company that manufactured the product.[57,58]

39. However, as a result of positive clinical trials, demand began to outstrip supply. This phenomenon led UT to announce, in late November 2016, that stocks of Dinutuximab were being reserved for patients living in the United States of America and would no longer be available to patients in Australia.[59,60]

[53] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), pp2-3
[54] ts 18.06.20 (Gottardo), pp38-39
[55] ts 18.06.20 (Gottardo), pp17-20
[56] ts 18.06.20 (Gottardo), p20 & pp38-39
[57] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p2
[58] ts 18.06.20 (Gottardo), p23
[59] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p2
[60] ts 18.06.20 (Gottardo), pp24-25

40. In response to the unavailability of Dinutuximab, PMH worked collaboratively with paediatric hospitals around Australia to identify and source an alternative. Those efforts were successful, and through a European company called EUSAPharma Ltd, PMH was able to obtain a supply of an alternative product known as Dinutuximab Beta. Professor Gottardo explained that although the method of administration of Dinutuximab Beta was slightly different, it was hoped that its potential effects would be similar to Dinutuximab.[61,62]

41. Although Dinutuximab had been provided free of charge, Dinutuximab Beta had to be purchased commercially. Because it was a novel treatment, its use had to be approved by PMH's Drug and Therapeutic Committee (DTC). Further, because Dinutuximab Beta was to be used for several patients in addition to Child SJC and the estimated cost amounted to several million dollars, approval was also required from PMH's executive.[63]

42. The application for approval to use Dinutuximab Beta at PMH was submitted in early April 2017 and final approval was obtained in July 2017.[64] One of the issues for Child SJC's family was the delay in obtaining approval to use Dinutuximab Beta and what effect this may have had on Child SJC's prognosis.

43. At the inquest, Child SJC's carer, who is an interested person under the Coroners Act,[65] was permitted to question Professor Gottardo, and she asked him why the approval process had taken as long as it did. She also asked whether, ultimately, the approval had been prompted by the pressure she had brought to bear (and had threatened to bring to bear) on PMH and its executive.[66]

[61] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p3
[62] ts 18.06.20 (Gottardo), pp25-27
[63] ts 18.06.20 (Gottardo), p26-27
[64] ts 18.06.20 (Gottardo), pp39-40
[65] Section 44, *Coroners Act 1996* (WA) & regulation 17, *Coroners Regulations 1997* (WA)
[66] ts 18.06.20 (Child SJC's carer), pp46-47 & p49

44. Professor Gottardo said he was unaware of any similar applications that involved multiple patients and the expenditure of a significant amount of money. In any event, as the applicant, he was obviously not involved in the approval process, and given it was his application, he was as anxious as anyone for approval to be obtained as quickly as possible.[67]

45. As noted, the use of Dinutuximab Beta was ultimately approved in July 2017 and supplies of this product arrived at PMH one week before Child SJC relapsed and her neuroblastoma recurred. Unfortunately, although Child SJC was treated with Dinutuximab Beta, her tumours continued to grow and the treatment was ultimately unsuccessful.[68]

46. At the inquest, Child SJC's carer outlined the family's position in eloquent and powerful terms. She said that the family considered that had Child SJC been treated with Dinutuximab at an earlier stage, she may have lived longer. As Child SJC's carer put it, every month, week and day with Child SJC was precious, and the family, and indeed Child SJC herself, were fighting courageously for more of that precious time.[69]

47. As respectfully as I can, I want to observe that the family's deep and totally understandable desire to prolong Child SJC's for as long as possible, may have led them to overestimate the potential benefits of immunotherapy, especially in the context of the aggressive neuroblastoma that was ravaging Child SJC's tiny body.

48. In my view, given the clinical factors impacting on Child SJC's condition and the known survivability rates for high risk neuroblastomas like hers, it is impossible to know what effect access to Dinutuximab at an earlier stage may have had on her condition.

49. It was clear to me that everyone involved in Child SJC's life, not least Professor Gottardo, would have preferred that she had started immunotherapy using Dinutuximab, as soon as appropriate, once other phases of her treatment regime had been completed.

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[67] ts 18.06.20 (Gottardo), p47
[68] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), pp2-3
[69] ts 18.06.20 (Gottardo and Child SJC's carer &), pp48-51

50. However, the possibility that treatment with Dinutuximab may have had a positive effect on Child SJC's prognosis, must remain a tantalising, but purely speculative prospect.

51. The harsh reality is that because Child SJC's condition showed no improvement when she was treated with Dinutuximab Beta coupled with the fact that when she did relapse, her neuroblastoma returned with such ferocity, this strongly suggests that earlier treatment with Dinutuximab would probably have been similarly ineffective.[70]

52. Professor Gottardo expressed the position in this way:

> [T]he occurrence of a relapse whilst still on therapy (isotretinoin) so soon after completing intensive chemotherapy (approximately 7 months), the extensive nature of the relapse and moreover, the lack of response to immunotherapy combined with chemotherapy at relapse, in our opinion highly suggests that immunotherapy would not have altered the ultimate disease course.[71,72]

53. Nevertheless, I completely understand the family's strong and urgent desire to pursue every possible treatment option. Child SJC's carer can be proud of the fact that her strong and persistent advocacy, has played a role in ensuring that children with high risk neuroblastomas have access to immunotherapy using Dinutuximab.

54. As it happens, Dinutuximab became available to Australian children again in October 2017, a result of an expanded access program by UT. That program continues to this day, but it seems clear that it will not continue indefinitely.[73] As Professor Gottardo explained, at some point, UT will seek to reap a return on their investment, and at that point access to Dinutuximab will be put on a commercial footing.[74]

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[70] ts 18.06.20 (Gottardo), pp40-41 & pp49-50
[71] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p3
[72] ts 18.06.20 (Gottardo), p40-41 and see also ts 18.06.20 (Gottardo), pp49-51 & p52
[73] Exhibit 1, Tab 27, Report - Prof. N Gottardo, Perth Children's Hospital, (04.10.19), p3
[74] ts 18.06.20 (Gottardo), pp23-24

55. I note the Federal Minister for Health was briefed on the situation regarding Dinutuximab in November 2017. Professor Gottardo explained that the therapeutic community is hopeful that Dinutuximab will be placed on the Commonwealth Government's Pharmaceutical Benefits Scheme (PBS), so that at a national level, ongoing supply can be assured.[75]

56. Given the positive effects on short-term survival that have been reported with Dinutuximab and given the current uncertainties about its ongoing supply, it is my sincere hope that the Perth Children's Hospital (PCH), supported by the Western Australian Department of Health, will use every means at its disposal to lobby for Dinutuximab to be placed on the PBS as quickly as possible. I would also urge the Federal Minister for Health, whose support for previous cancer treatments has been commendable, to give favourable consideration to placing Dinutuximab on the PBS.

Comments on Child SJC's medical care

57. Child SJC was diagnosed with a very serious and aggressive form of cancer, known as Stage IV high-risk neuroblastoma, the survival rate for which is, at best, about 50%. The intensive treatment regime used to treat neuroblastoma at PMH (and now PCH), is world-class and includes: surgery, chemotherapy, mega-therapy, radiotherapy, biotherapy and immunotherapy. Having carefully reviewed the evidence in this case, I am satisfied that Child SJC received first-class medical treatment at PMH.

58. Given the clinical uncertainties involved in this case, I am unable to come to any final conclusion about what effect, if any, not having access to Dinutuximab at an earlier stage, may have had on Child SJC's prognosis. However, for the reasons explained by Professor Gottardo, it seems unlikely that the tragic outcome in Child SJC's case would have been different had she received Dinutuximab at an earlier stage.

59. As to involvement of Silver Chain's hospice service, I am satisfied that the care provided to Child SJC by the Service was timely and effective and helped manage her pain and distress during the final phase of her illness. It is also notable that a Silver Chain nurse was present with the family when Child SJC died.

[75] ts 18.06.20 (Gottardo), p35

60. All of the staff involved in Child SJC's care are to be commended for their devotion to duty, and for their skill and expertise. Dealing with patients who are dying from incurable cancer must be a gruelling and emotionally exhausting experience, especially when the patient is a child.

THE DEPARTMENT'S INVOLVEMENT WITH CHILD SJC

Contact with the Department: 2011 - 2014

61. The Department's involvement with Child SJC's family began in 2011 with respect to Child SJC's siblings. In 2012, Child SJC's mother was pregnant with Child SJC's older brother and as a consequence of her transient lifestyle and polysubstance use issues, this child was taken into the care of the DG. Child SJC's other brother, who was born in 2013, was taken into the care of the DG in 2014, due to parental drug use, transience and lack of engagement with the Department. However, he was successfully reunited with his father in October 2015.[76,77,78]

Child SJC is born and taken into care

62. After Child SJC was born, the Department conducted an assessment and concluded that she was likely to be emotionally harmed by her mother. However, the assessment determined that Child SJC's mother was making progress with respect to addressing her substance use and mental health issues. As a result, Child SJC was released into the care of her mother and placed on a 12-month supervision order (the Order).[79]

63. The Order was subject to several conditions including that Child SJC's mother agreed to abstain from alcohol and drugs, submit to random urinalysis tests, and permit unannounced home visits. Although she missed some appointments with a departmental support service, in general terms, Child SJC's mother appeared to be coping adequately, and the Department received positive reports on her parenting and Child SJC's well-being.[80]

[76] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), pp2-4
[77] Exhibit 1, Tab 2, Report - FC Const. A Allen, Coronial Investigation Squad, p2
[78] Exhibit 1, Tab 7, Child Death Notification (14.09.18), p2
[79] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), p4
[80] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), pp4-5

64. Following Child SJC's diagnosis with Stage IV high-risk neuroblastoma, concerns were raised with the Department by staff at PMH about her mother's ability to cope with Child SJC's complex medical condition, given her substance use and mental health issues.[81,82]

65. In June 2016, PMH were unable to contact Child SJC's mother to obtain consent for surgical procedures related to Child SJC's cancer, and there were real concerns that the opportunity to treat her neuroblastoma would be lost.[83,84]

66. A safety and well-being assessment (SWA) commenced on 2 June 2016 determined that Child SJC would require intensive treatment over the next 18-months that would compromise her immune system. During that period, her needs would need to be consistently attended to and she needed to be looked after in a stable and hygienic environment.[85,86]

67. The Department determined that Child SJC's mother was not coping with Child SJC's diagnosis and would be unable to provide her with the level of care that her complex medical needs required. As a result, on 15 June 2016, Child SJC was taken into the care of the DG for a period of two years.[87] After assessment, Child SJC was placed into the care of her maternal great-grandmother.[88,89,90]

68. A care plan was prepared and included a provision for Child SJC's mother to maintain contact with her child in a safe and supervised manner. She was also consulted in relation to decisions about Child SJC's medical treatment and medical care.[91,92,93,94,95]

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[81] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), p5
[82] Exhibit 1, Tab 7, Child Death Notification (14.09.18), p2
[83] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), p5
[84] Exhibit 1, Tab 7, Child Death Notification (14.09.18), p2
[85] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), pp5-6
[86] Exhibit 1, Tab 7, Child Death Notification (14.09.18), p2
[87] See: Exhibit 1, Tab 10, Order of the Children's Court of Western Australia (19.08.16)
[88] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), p6
[89] Exhibit 1, Tab 7, Child Death Notification (14.09.18), p2
[90] See also: Exhibit 1, Tab 25, Family Genogram
[91] Exhibit 1, Tab 6, Report - Ms J Tang, Department of Communities (21.11.18), p6
[92] Exhibit 1, Tab 7, Child Death Notification (14.09.18), p2
[93] Exhibit 1, Tab 8, Provisional Care Plan (23.06.16), p4
[94] Exhibit 1, Tab 9, Culture & identity plan (23.06.16), p1 & Tab 12, Culture & identity plan (23.01.17), p2
[95] See also: Exhibit 1, Tab 11, Care plan meeting (19.01.17)

69. A safety plan dated 11 August 2017, provided for Child SJC's mother to have up to four hours unsupervised access per day. The plan contained provisions to deal with any substance use by Child SJC's mother and a requirement that Child SJC's caregivers take her to all required medical appointments.[96]

Comments on the Department's involvement with Child SJC

70. The Department's decision to make Child SJC the subject of a 12-month supervision order seems to have been appropriate in all of the circumstances. The decision to take Child SJC into the care of the DG in June 2016, following her diagnosis, was motivated by concern that her mother would be unable to deal with Child SJC's complex medical needs. Again, this seems to have been prudent.

71. Once Child SJC was in the care of the DG, the Department worked closely with her caregiver to ensure her safety. Through this process, Child SJC's mother was able to maintain a close relationship with her child and was consulted with respect to decisions relating to Child SJC's care.

72. On the basis of the evidence contained in the Brief and after hearing oral evidence from Mr Mace, I am satisfied that the care, supervision and treatment provided to Child SJC by the Department was of an acceptable standard.

[96] Exhibit 1, Tab 20, Safety Plan (11.08.17)

CAUSE AND MANNER OF DEATH

Report of Child SJC's death

73. Child SJC's death was not reported to the State Coroner by the Department as it should have been.[97] Instead, on 24 November 2017, a Silver Chain doctor issued a medical certificate certifying cause of death (the Certificate).[98]

74. In his evidence, Mr Mace confirmed that since Child SJC's death, the Department had amended its procedures. This change has ensured that the death of children under the care of the DG who were receiving palliative care are routinely reported to the State Coroner.[99] This is obviously a pleasing development.

75. In this case, the State Coroner was eventually made aware of Child SJC's death on 14 September 2018, at which time the Certificate was rescinded and an investigation into the circumstances of Child SJC's death was undertaken.[100]

76. In Child SJC's case, a post mortem examination of her body was not performed because the report of Child SJC's death was not received by the State Coroner until after Child SJC's funeral.

Cause of death

77. The Certificate described the cause of Child SJC's death as "*metastatic neuroblastoma, liver, skeletal and nodal disease"*. On the basis of the available evidence, I am satisfied that Child SJC died from complications of metastatic neuroblastoma.

78. I find that Child SJC's death occurred by way of natural causes.

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[97] ts 18.06.20 (Mace), p58
[98] Exhibit 1, Tab 3, Medical certificate cause of death (24.11.17)
[99] ts 18.06.20 (Mace), pp58-59
[100] Exhibit 1, Tab 2, Report - FC Const. A Allen, Coronial Investigation Squad, pp5-6

RECOMMENDATION

79. In light of the observations I have made, I make the following recommendation:

> ***Recommendation No.1***
>
> I recommend that as a matter of urgency, the Perth Children's Hospital, supported by the Western Australian Department of Health, use every means at its disposal to lobby for Dinutuximab to be placed on the Pharmaceutical Benefits Scheme (PBS). I would also recommend that the Federal Minister for Health give favourable consideration to placing Dinutuximab on the PBS.

CONCLUSION

80. Child SJC was a much loved little girl, who developed an aggressive form of cancer known as a Stage IV high-risk neuroblastoma. As the name suggests, the prognosis for children with this form of cancer is guarded, with clinical studies suggesting a survival rate of only 50%.

81. Despite a range of treatments, including surgery, chemotherapy, mega-therapy, radiotherapy, biotherapy and immunotherapy, Child SJC succumbed to her condition, and died in the presence of her family, in the early hours of 20 November 2017.

82. During the inquest, it was abundantly clear that Child SJC was dearly loved by her mother. However, as a result of the limitations imposed on her by her own issues, she was unable to consistently provide Child SJC with the level of care that her complex medical needs demanded. Child SJC's great-grandmother stepped forward and became her foster carer.

83. This commendable act clearly inflicted a huge personal toll, and at the inquest, she spoke in moving terms about her beloved great-grand daughter, whose antics and personality had so endeared her to the staff at PMH and elsewhere.

84. Child SJC's great-grandmother's strong advocacy, which has helped ensure that other children being treated for neuroblastomas have access to Dinutuximab, is also to be warmly applauded.

85. Having carefully reviewed all of the available evidence in this matter, I am satisfied that the standard of care, supervision and treatment that Child SJC received from the Department, from PMH and from the hospice service of Silver Chain was appropriate. I can only hope that the efforts of those advocating for Dinutuximab to be placed on the PBS will be rewarded.

MAG Jenkin
Coroner
1 July 2020