The Coroners Act 2009

IN THE LOCAL COURT OF NEW SOUTH WALES
CORONIAL JURISDICTION

Name of Deceased:	**Kaneesha Simpson**
File Number:	**3718/2009**
Hearing Dates:	**23 – 25 November 2011**
Location of Inquest:	**North Sydney Local Court**
Date of Finding:	**12 December 2011**
Coroner:	**Magistrate Scott Mitchell, Deputy State Coroner**

Appearances:

- Ms D Ward of Counsel instructed by Ms E Sullivan of the Crown Solicitor's office, appeared to assist the Coroner
- Mr. J. Harris, solicitor, of *Legal Aid NSW* appeared for Freda Simpson, Kaneesha's grandmother
- Mr. J. Downing of Counsel appeared for *Sydney Children's Hospital Specialty Network*
- Mr. S. Barnes of Counsel, appeared for Associate Professor Richard Chard

INQUEST INTO THE DEATH OF KANEESHA SIMPSON

FINDINGS

1. This is an inquest into the death of Kaneesha Simpson who was born on 10 May, 2004 and who died at Liverpool Hospital, Liverpool on 29 December, 2009. Kaneesha was the fourth daughter of Tracey Lee Simpson and a granddaughter of Freda Ann Simpson. Kaneesha's father was Roy Barker who played no part in these coronial proceedings and, as I understand it, little part in her life.

2. In this inquest, Ms. D. Ward of Counsel, instructed by Ms. E. Sullivan and Ms. J. Wardle of the *NSW Crown Solicitor's Office*, appeared to assist the Coroner. Mr. J. Harris, solicitor, of *Legal Aid NSW* appeared for Freda Simpson, Kaneesha's grandmother. Mr. J. Downing of Counsel appeared for *Sydney Children's Hospital Specialty Network* and Mr. S. Barnes of Counsel, appeared for Associate Professor Richard Chard.

3. The formal documents including the *P79A* Report were tendered and are **EXHIBIT 1.** The three volume Coronial Brief, to which some slight amendments have been made, is **EXHIBIT 2.** A Statutory Declaration of Ms. Rita Fenech of *Karitane* is **EXHIBIT 3**. No autopsy was undertaken in this case and a note appearing on the file indicates the reason for this as the family's objections due to cultural considerations, Kaneesha and her family being indigenous persons. The opinion of Professor Chard with whom Professor P. Pohlner who reviewed all the papers concurs is that Kaneesha's cause of death was *cardiac and respiratory arrest probably connected with embolic stroke*.

4. Those who appeared at the inquest to give evidence are the following:-
   - The Officer in Charge, Detective Senior Constable Wayne Plumridge;
   - Dr. Megan Sherwood, staff specialist Paediatric Cardiologist at the Westmead Children's Hospitals' *Heart Centre*;
   - Dr. Rosemary Ambler, paediatrician and visiting medical officer at Fairfield Hospital;

- Professor Richard Chard, cardiothoracic surgeon, A/ Professor in the Department of Surgery at the Western School of the University of Sydney and Visiting Medical Officer at Westmead Children's Hospital;
- Kaneesha's mother, Tracey Lee Simpson;
- Kaneesha's grandmother, Freda Simpson;
- Professor G. Sholler, the Head of the *Heart Centre* at Westmead Children's Hospital;
- Professor D.Winlaw, the Head of Cardiothoracic Surgery within the *Heart Centre*; and
- an independent expert witness, Dr.P.Pohlner, Cardiothoracic Surgeon and, until 2008, Head of the Paediatrics at Prince Charles Hospital in Brisbane.

5. The notes of Liverpool Hospital where Kaneesha was born record that, at 18 hours of age, *"baby was noted to be cyanosed on post-natal ward."* She was transferred to *NICU* at *Westmead Children's Hospital* where *"sats 40-50% room air"* was noted. *ECG* and *CXR* examinations revealed that Kaneesha had been born *asplenic*, that is, without a spleen, and suffered from *situs inversus,* a congenital cyanotic heart disease. Professor Chard's diagnosis was *"double outlet right ventricle with pulmonary atresia, atrial situs inversus, complete atrioventricular canal defect with severe hypoplasia of the left ventricle and asplenia."*

6. Dr. Megan Sherwood described Kaneesha's condition as one in which *"the two sides of the heart were not separated so that the blood was completely mixed up within the heart; Instead of two valves in the middle of the heart, there was only one valve; there was only one big blood vessel coming out of the heart (not two, as is normal) and the veins returning from Kaneesha's lungs to her heart returned to the wrong side of the heart."*

7. There is no *cure* for that condition but it can sometimes be palliated and managed, typically, in three stages – firstly by the installation of a *Blaloch Taussig (BT)* shunt, then typically, by the installation of a *Glenn* shunt and, lastly by the installation of a *Fontan* shunt. The *BT* shunt will usually be installed very soon after birth whereas, typically, the *Glenn* shunt might be installed at about 18-24 months and the *Fontan* shunt at about 3-6 years of age. Evidently, at Westmead in 2004 it was thought that, generally, the optimal time for installing a *Glenn* shunt was at about 2-3 years of age and the best time for installing a *Fontan* shunt about 5-8 years of age. Dr. Sherwood told the inquest that

patients like Kaneesha have survived up to 20 years of age or longer with a modified *BT* shunt and, of course, it was envisaged that Kaneesha's life span would have been considerably extended by receiving a *Glenn* shunt and, especially, a *Fontan* shunt in due course.

8. The normal *three stage* course of palliation consisting of *BT* shunt*, Glenn* shunt and *Fontan* shunt was complicated in Kaneesha's case, Professor Chard discovered, because of problems, peculiar to the child, to do with pulmonary drainage.

9. From her initial admission in 2004, very shortly after her birth, Kaneesha was under the care of Dr. Sherwood at the *Heart Centre* at the Children's Hospital at Westmead. On 12 May, 2004 she underwent successful surgery for the installation of a *BT* shunt, performed by Professor Chard. Thereafter. according to the practice at Westmead, she would be referred in the future to Dr. Chard for all matters involving heart surgery.

10. After her first operation, both Kaneesha's mother and her maternal grandmother were told that Kaneesha would need two more surgeries. The mother's evidence is that she recalls Dr. Sherwood informing her that the second operation – that is, the installation of a *Glenn* shunt, would occur about the age of three years and that the final operation might take place at about five years of age. Freda Simpson's recollection is that she was told that the operations should take place when Kaneesha turned two and again at age five. Freda Simpson understood *"…that after those surgeries, Kaneesha would be able to live a relatively normal life although restricted. She had to be on medication every day including aspirin to keep her blood thin."*

11. After the *BT* shunt was successfully installed by Professor Chard in *"uneventful surgery,"* Kaneesha was discharged from the Westmead Children's Hospital on 22 May, 2004 for follow up with Dr. Sherwood. Thereafter, Kaneesha saw Dr. Sherwood on 15 September and 30 November, 2004, 22 March and 25 August, 2005 and 5 May, 2006. Usually she was brought to see Dr. Sherwood by her grandmother although Tracey Lee Simpson sometimes accompanied them. Dr. Sherwood told the inquest that, in general terms, Kaneesha was compliant with those check ups and her impression was that Kaneesha was doing well. On 15 September, 2004, Dr. Sherwood noted that Kaneesha demonstrated good shunt flow with trivial atrioventricular valve regurgitation, mild aortic

regurgitation and good biventricular function. In November, 2004, she appeared to Dr. Sherwood to be "*a well looking and interactive infant"* and *"quite stable.*

12. Dr. Sherwood's note on 5 May, 2006 says *"progressing reasonably."* There may have been some concerns as to Tracey Simpson's understanding of Kaneesha's medication regime, particularly regarding aspirin which was important in dealing with *sticky platelets* in the blood and regarding the need for vaccination, especially important for children in Kaneesha's position, but Dr. Sherwood derived considerable comfort from Freda Simpson's apparent understanding of and participation in Kaneesha's care.

13. On 6 December, 2004, Dr. Sherwood wrote to Dr. Mohan, Kaneesha's then *GP*, with a copy to Professor Chard and another to Dr. Mark Westphalen, Paediatrician, that *"…additionally and concerningly, Kaneesha has not yet had any vaccinations, and is planned to have her first vaccination in the next week."* As we now know, that did not happen and Kaneesha remained unprotected for almost another year. On 25 January, 2005, when Kaneesha saw Dr. Khuu of *Mt. Pritchard Supercare Family Medical Centre*, he advised early vaccination. In August, 2005, when Kaneesha saw Dr. Sherwood, the use of Westmead's vaccination clinic was offered but the family indicated that they preferred to make their own arrangements.

14. Finally, on 30 November, 2005, at the age of about eighteen months, and about seventeen months after they were due, Kaneesha received diphtheria, tetanus, pertussis, hepatitis B. and polio Hib, measles, mumps, rubella and meningococcal *C* vaccinations which turned out to be the only vaccinations she ever received. The need of immunisation was particularly marked in Kaneesha's case given her medical condition and vulnerability to infection resulting from the absence of a spleen and it is not clear why there was so long a delay until Kaneesha received her vaccinations.

15. On 5 May, 2006 Dr. Sherwood wrote to Dr. V H Khuu, another *GP,* that *"Kaneesha is progressing reasonably. The next step in her management is to prepare her for further surgery which will be a Glenn shunt. I will arrange for her to have a cardio catheterisation performed . At the same time she will have a complete echocardiogram while she is asleep as she does not cooperate sufficiently while awake for an appropriate study to be performed. Following these investigations, I will arrange for her to see A/Prof. Chard to*

discuss surgery. I have discussed this with Kaneesha's mother. Kaneesha continues to require endocarditis prophylaxis at times of risk."

16. Some short time after 5 May, 2006, Dr. Sherwood secured the agreement of Dr. Richard Hawker, a staff specialist at Westmead, to perform the catheterisation procedure. Evidently, a *cardio catheterisation* was an essential step before an operation to install a *Glenn* shunt. The evidence does not go so far as to demonstrate that, at this time, Dr. Sherwood actually referred the patient to Professor Chard and her letter to Dr. Khuu rather suggests that she did not – merely that she intended to do so after the catheterization was completed. She says that she sent Professor Chard a copy of her letter to the *GP* which he says he did not receive.

17. The *cardiac catheterisation* procedure took placed on 22 August, 2006. Dr. Sherwood had intended that, in conjunction with the catheterisation, *"a complete echocardiogram be performed while she is asleep"* but, in the event, this did not happen. Dr. Sherwood's evidence is that her request for an *echocardiogram* was a verbal request and may have been inadvertently overlooked. Evidently, there was no printed form ordering an *echocardiogram* in use at Westmead at the time.

18. The Head of the *Heart Unit*, Professor Sholler was asked about this and told the inquest that, so common and uncomplicated a procedure is an *echocardiogram* that it hardly warrants the creation of a form and should be available on a quite informal request. Nevertheless, since 2009, the hospital's *Clinical Investigation Request* form has been amended so as to include a request for an *echocardiogram*.

19. The *cardiac catheterisation* was uneventful and demonstrated that, as far as her blood pressure was concerned, Kaneesha was suitable for the *Glenn* shunt and, when the results were provided to Dr. Sherwood, sometime in August, 2006, she formed the view that surgery for the installation of a *Glenn* shunt should go ahead and she says that she telephoned Kaneesha's mother and *"asked her to organise to see Dr. Chard to discuss the proposed surgery to perform the Glenn shunt."* She sent no letter confirming this conversation and made no written note of this request and Tracey Lee Simpson does not accept that this request was ever made.

20. Given that the quite inefficient practice of leaving it to families - sometimes quite underprivileged and vulnerable families, themselves to approach the surgeon was evidently the common practice at Westmead at the time and given two entries in the progress notes on 22 August, 2006 – one by Dr. Sherwood herself reading *"home and will contact Mo. With plans for surgery"* and the other by a nurse reading *"…Dr. S. will contact Mo. regarding surgery"* and given that Ms. Simpson has some recollection of a phone conversation with Dr. Sherwood, it is not unlikely that Dr. Sherwood's recollection is correct in this matter but the controversy clearly underlines the inadequacy involved in her failure to keep proper records.

21. In referring Kaneesha to Professor Chard, Dr. Sherwood made no appointments for further cardiological review. Her view seems to have been that, having referred the patient to the surgeon, her own plan for Kaneesha's care and management should defer to his and that, the referral having been made, the child had passed from her responsibility to Professor Chard's. That is most certainly not Professor Chard's view and neither is it the view of Professor Sholler, the head of the *Heart Centre,* who told the inquest that, the date for surgery being uncertain, cardiac reviews by Dr. Sherwood should have continued as before unless countermanded by the surgeon.

22. As it turned out, Dr. Sherwood and Professor Chard were not *ad idem* regarding the need for prompt surgery and his evidence is that, at that time, he thought that Kaneesha was anatomically unsuitable for the installation of a *Glenn shunt* and, he told the inquest, he made a decision to *"grow her up"* and defer surgery for the time being. Professor Chard explained to the inquest that a *BT* shunt and a *Glenn* shunt are both *arterial* shunts whereas a *Fontan* shunt is a *venous* shunt which, in appropriate conditions, will provide better and longer lasting palliation. Indeed, Professor Chard described the *Glenn* as *"a means to an end, the end being a Fontan shunt"* and he was hopeful that, in Kaneesha's case, it might be possible, after the passage of some time and after she had grown a little, to bypass the *Glenn* shunt altogether and proceed straight to a *Fontan.* Thus his decision to *"grow her up."*

23. At that point, Professor Chard's *plan* was to delay surgery in the hope of going straight to a *Fontan* shunt but he did not commit his plan to writing. He told the inquest that he discussed his decision at a regular *joint meeting* of cardiothoracic surgeons and

cardiologists within the *Heart Centre* and he can't recall whether or not Dr. Sherwood was present. Her evidence would suggest that she was not. He did not, he says, speak to her personally about his decision except, perhaps, *in passing,* and neither did he write to her to that effect. It is not entirely clear how Professor Chard proposed to monitor Kaneesha's growth so as to determine when she would have grown sufficiently to justify further surgery but it seems that the surgeon, having decided to delay surgery, assumed that Dr. Sherwood's cardiac reviews would continue while the cardiologist thought that she was no longer expected to involve herself.

24. Meanwhile, from May, 2006 when Kaneesha underwent the cardiac catheter procedure until August, 2007, there were no further attendances of the child at Westmead Children's Hospital. At the time, this did not alarm Dr. Sherwood because, she says, she had asked Kaneesha's mother to make an appointment to see Professor Chard and had assumed that, from that point, the child would be safe under his care and that he would notify her if he required her to take any particular step. It appears that she did not check to see if the family had made effective contact with Professor Chard. She merely assumed they had done so and that Professor Chard had taken charge. Nor did she formally refer the child to Professor. Chard. Instead she appears to have felt that surgery would soon take place, that Kaneesha had passed into the care of Professor Chard and that her regime of more of less regular cardiology reviews should defer to whatever care regime he might put in place. Professor Chard, on the other hand, did not understand Kaneesha to be in his care at all. In his mind, he had discussed, at a regular staff meeting, the results of the *cardiac catheterisation* which somebody else had undertaken and had expressed the view that surgery should be deferred and that, he thought, was an end to his responsibility at least until there was a formal referral. In his understanding, Dr. Sherwood's care of the child and her regular cardiological reviews would continue.

25. And so, due to this confusion, Kaneesha *disappeared off the radar screen* so far as *Westmead Children's Hospital* was concerned. The evidence is that there was no method in place at Westmead to assist the hospital identify much less make contact with patients who, like Kaneesha during that period, were *lost to follow up.*

26. In fact, when Kaneesha did reappear at Westmead in August, 2007, it was at the *Emergency Department* and in connection with an entirely different matter – a cough and

a fever. Because Dr. Sherwood had failed to make a note of her request that Kaneesha's mother make an appointment to see Dr. Chard to discuss surgery, there was little to warn the staff in *ED* that Kaneesha was awaiting cardiac surgery. More or less by chance, she was seen on this occasion by a cardiology fellow and an appointment was made for her to re-establish her contact with Dr. Sherwood some weeks later.

27. Following on from her presentation at *ED*, Kaneesha was seen by Dr. Sherwood at the *Heart Centre* on 23 October, 2007 and, notwithstanding that at *triage* her oxygen saturation levels were noted as *"significantly below acceptable levels"* and there was clubbing arising from longstanding cyanosis, Dr. Sherwood believed that *"she didn't seem to have deteriorated in her condition."* By that stage, there had been a thirteen month delay in contacting Professor Chard and fifteen months had elapsed since the last cardiology review and, if there had not been a deterioration in Kaneesha's condition, it was more by good luck than good management. But once again, Dr. Sherwood left it to the family to make contact with the surgeon rather than arranging the appointment herself. One might have thought that the history of the past thirteen months suggested that the family could not be relied on to deal with Professor Chard but, according to Dr. Sherwood, she stressed to Kaneesha's family the importance of making contact with the cardiothoracic surgeon without further delay and she handed them a card containing Professor Chard's contact details. She sent a letter to a *GP* (in fact, to the wrong *GP,*) detailing the review and she says she sent a copy of that letter to Professor Chard. He says he never received that copy letter and, again, Kaneesha was caught between two specialists. Dr. Sherwood made no *"back up"* appointment which might have caught the child in the event that the family did not successfully contact Professor Chard. Evidently, such precaution was not the practice at Westmead at that time. And so another year passed before Dr. Sherwood again saw Kaneesha during which there were no cardiac reviews undertaken and no progress was made towards surgery.

28. Dr. Sherwood next saw Kaneesha on 18 November, 2008, this time prompted by a letter dated 10 November, 2008 from *Karitane* to the Director of Clinical Governance at Westmead. It seems a very sad not to say a disgraceful situation where an outside agency feels it necessary to write to the main children's hospital in the state, virtually pleading with the hospital to do something for a little girl who was one of the hospital's own patients. The *Karitane* letter noted that Kaneesha's last appointment with Dr.

Sherwood had taken place in November, 2007, twelve months earlier. In the letter, Nurse Unit Manager Rita Fenech of *Kaitane* noted *"numerous attempts"* by the family to contact Dr. Sherwood and spoke of the family's *"increasing anxiety regarding Kaneesha's health and well being"* and she reminded the hospital - which shouldn't have needed being reminded, that *"in order to maximise Kaneesha's health outcomes, it is essential and urgent that collaboration between the family and Westmead Children's Hospital is undertaken."*

29. On behalf of Karitane, Nurse Fenech told the hospital that "Kaneesha's physical activity is very limited, she becomes tired easily and cannot walk ten metres without becoming breathless. She cannot participate in normal activities with her siblings or peers and is constantly a reluctant bystander." As a result of this appeal, the hospital made an appointment for Kaneesha to see Dr. Sherwood. That meeting took place on 18 November, 2008 when Dr. Sherwood reassured the GP "I will refer her to Dr. Richard Chard for a Glenn Shunt."

30. Following on from her consultation with Kaneesha and the family on 18 November, 2008, Dr. Sherwood wrote a referral letter to Professor Chard on 24 February, 2009, three months later. Perhaps the family had already contacted Dr. Chard's rooms and made a *provisional* appointment and Dr. Sherwood's letter was merely a formality, *post dated, as she explained,* so as to avoid difficulties with medical insurance. The purpose of the appointment with the surgeon was to arrange the surgery which, in Dr. Sherwood's view, had been indicated two years earlier by the *cardiac catheterisation.* But even then, Dr. Sherwood told the inquest, she did not agree that the matter had become urgent and she pointed out that Kaneesha's many presentations to Fairfield Hospital during the time she had been *lost* to Westmead Children's Hospital had related to various viral infections rather than to her heart condition. It seemed to Dr. Sherwood that *"Kaneesha was reasonably well although increasingly cyanosed"* and she thought that the family was not reporting a significant decline in the child's functioning. It may not have occurred to Dr. Sherwood to wonder why *Karitane*, acting on behalf of the family, had appeared so alarmed.

31. In her letter to the surgeon of 24 February, 2009, Dr. Sherwood suggested that he *"meet with the family and organise a surgical date."* Professor Chard saw Kaneesha and her

family on 16 March, 2009 and, on the same day, wrote to Dr. Sherwood, indicating that he had arranged for a *CT angiogram* and expressing a reservation which, evidently, had weighed on him since 2006 namely, that *"there may be a fair distance between the pulmonary veins and the heart and the issue of how to get the upper body drainage into the pulmonary artery without causing major distortions or obstructions pr without using undue quantities of foreign material."* He indicated that he would review Kaneesha when the *angiogram* results were to hand. It is not clear that Dr. Sherwood received this letter (and, if she didn't, that would constitute one of three letters committed to the hospital's internal mail service which have gone missing in this case!) but Dr. Chard's view is that whether she did receive it or not is quite unimportant and that the important thing is that the *CT angiogram* was undertaken.

32. The *CT angiogram* took place on 21 April, 2009 and the report was printed on 10 June, 2009. On the day that Professor Chard booked the *CT angiogram*, he may or may not have completed a form to book a theatre for surgery. The hospital's booking office has no record of such form having been filed. Professor Chard says that, at that stage, he was confident that surgery of one type or another would be necessary whatever might be the *CT* results but he had not settled on any date for surgery. Professor Sholler thinks it would have been pointless in those circumstances to have booked a theatre but I think that it might, at least, have constituted some written note on the hospital's records that the child was awaiting surgery.

33. On reading the results of the *CT angiogram*, Dr, Chard decided that it would be best to operate sooner or later and to evaluate and act on the situation as he found it in theatre and, in particular, to do the best he could to increase the pulmonary blood flow in whatever circumstances he might face. He was sure that one of two strategies would be adopted once Kaneesha was in theatre – either a venous shunt or an arterial shunt with various complicating features regarding the drainage of blood from the right lung. But he thought that there was no urgency in the matter and that surgery could be deferred and he told the inquest that, had there been a deterioration in the child's condition, he would have advanced the case.

34. Perhaps for the same reasons – uncertainty as to the date on which surgery would take place, Professor Chard did not book a theatre. He placed no note of his *plan* in the

hospital's records and neither did he write to Dr. Sherwood to communicate his intentions to her. Instead he told the inquest that *"it was discussed in general terms so that she (Dr. Sherwood) knew that there was the group of options."* It is unclear how detailed this general discussion might have been and Professor Chard's evidence is that, once the *angiogram* results clarified in his own mind what were the surgical options, "*the cardiologist knows we're going to increase the pulmonary blood flow somehow and they know we're probably going to – we'd like to do it with a venous shunt, but if we can't we'll do it with an arterial shunt. That's all they need to know, there's nothing more to discuss."*

35. According to Professor Chard, he had discussed his *plan* with Kaneesha's family back in March, 2009 so he saw little need to repeat that exercise. As he saw it *"they were aware that an operation was required, that the operation would further her – was to improve her clinical state, and that it might progress towards further operations later."* But it appears there was no written plan and thus no plan which was available to be read by the cardiologist, the family or anybody else and, in particular, the date on which surgery might take place remained a matter for Professor Chard to determine in due course.

36. In the event, Kaneesha never had the surgery notwithstanding that the need had been demonstrated since at least March, 2009 and, in December, 2009, some 9 months later, she died. Professor Chard told the inquest that *"the child didn't die because she didn't get an operation. She died because she had a heart disease."* Explaining why she didn't get the operation which, at least in his own mind, he had planned for her, he told the inquest *"Logistically it wasn't possible to get her case on in the time frame allowed. I mean, many of our elective cases wait longer than 12 months for an operation and… …this case was and it remains... The case was elective in…the sense that we formulate a plan. I mean, many of our operations we plan, like, a year or two in advance. It's not at all unusual with the…time frame between deciding to do something and actually doing it is highly variable in this area."*

37. "It's a matter of prioritisation in every single operating session. So that if there was a reason to make this child like Kaneesha more palliated, like, if Kaneesha's functional state had decreased, I would have expected the clinic or the parents to have reported it and that I would change the plan. It's like I know something has to happen, it has to happen sometime in the next 12 months, and I'll make it happen when I can. And if something

comes to tell me that it needs to be done sooner, then I'll do it sooner and I'll take someone else and prioritise them differently."

38. It is not clear to me who might have been in a position to come to Professor Chard and tell him that *"it needs to be done sooner."* Despite the efforts which they did make, this burden would almost certainly have been too heavy for Tracey Lee Simpson and even for Mrs. Freda Simpson. Dr. Sherwood couldn't be expected to do it because Professor Chard had not seen fit to disclose his plan to her and, in his view, she knew *"all she needed to know."* And the hospital was unlikely to intervene because Professor Chard probably had not submitted a *Request for Elective Admission,* probably had not notified the hospital of his intention to operate and, consistent with his usual practice, seems to have kept his *plan* to himself, apparently keeping the file in his briefcase *"for weeks and weeks and weeks,"* going through the contents at least once a week and deciding *"when I'm going to do what."*

39. Dr. Chard went on to describe the need to *"ration"* treatment given that *"we can only do X number of operations with the facilities provided. We have Y number of patients of highly variable acuity and we have to try to do the best we can for each patient in a timely fashion and that's what we try to do."*

40. Now, delays in elective surgery are or, at least, have been notorious in New South Wales but I had not understood Professor Chard's explanation for the failure to operate on Kaneesha Simpson to relate to overcrowding in the system and I am not persuaded, if anybody sought to persuade me, that there was an unavoidable delay in Kaneesha's surgery resulting from an overcrowded system. Rather, I had understood Professor Chard to be saying that he was aware of the need for surgery *"sometime in the next 12 month"* or earlier if the parents or the clinic persuaded him of that necessity but that nobody did so and, in the event, the child died, not for want of heart surgery but because she had a heart disease. It was a matter of *prioritisation* and the patient's condition and how drastic might be any clinical change in the patient's condition which would determine the priority.

41. Kaneesha's elevated haemoglobin levels were barely to the point and, as Professor Chard explained, *"are not an indicator"* because, *"haemoglobin levels are inevitably going*

to be elevated." Her oxygen saturation levels, on the other hand, might have been significant as an indicator of deterioration and might prudently have been used to influence her priority for surgery. But, according to Professor Chard, these levels were not to be measured by him - he has no measuring device in his rooms, but were a matter for measurement by the clinic. Sadly, in Kaneesha's case, although Professor Chard decided in April 2009 that surgery was necessary, between April and December, 2009 when she died, nobody was measuring and monitoring her oxygen saturation levels and reporting them to him to enable him to appropriately prioritise her surgery and neither did Professor Chard think to enquire for himself, believing that, as a matter of course, he would be notified of anything significant.

42. Nor, according to Professor Chard, were Kaneesha's growth parameters significant in determining priority or prompting him to operate. Instead, as he explained, because her heart condition was only one of a number of abnormal features of a *"complex syndrome,"* Kaneesha's failure to grow is *"not one of the prominent features of this type of disease that would be immediately referable to heart disease."* Professor Chard was prepared to say that, in Kaneesha's case, a failure to grow is something he would have noted but *"it doesn't really change the priority to do something, and the heart's not going to change the growth pattern in this setting."*

43. In November, 2008, the *Karitane* letter had informed the hospital and, later, Dr. Sherwood that *"the family are becoming increasingly anxious ….I'm particularly focusing on the family's anxiety about her health and observations that physical activity is very limited, tired easily, cannot walk 10 metres without becoming breathless…"* Professor Chard told the inquest that this is the sort of information which, had he possessed it, would have influenced his decision about priority for surgery and would have prompted him to the view that *"it's time – it would be reasonable to go and do something about it."* But his evidence is that these observations, which were contained in a letter from Dr. Sherwood, were never received by him. It is the fact that in March, 2009, about four months later, Professor Chard saw the family in his rooms but, although he enquired after Kaneesha's health in general terms – something along the lines of *"How's Kaneesha?"* – he says that he did not make close inquiries and did not ask about *"her exercise ability and so forth,"* believing that *"this had already been done by cardiology."* The point is, of course, that,

even if cardiology did make such enquiries, Professor Chard remained ignorant of such information as they may have gleaned.

44. There is a policy document entitled *"Waiting Time and Elective Patient Management Policy,"* published by *NSWHealth* which advocates priority for surgery in accordance with need and deals with various categories of patients. In particular, it provides for a category in which *"admission within 30 days is desirable for a condition that has the potential to deteriorate quickly to the point that it may become an emergency."* Professor Chard told the inquest that he had never read that document and, instead, adopts his own, *"less formalised"* practice in allocating priority which still aims to give top priority to those at risk of sudden death as opposed to Kaneesha whom he saw as somebody whose symptoms needed to be alleviated and whose functioning needed to be improved but who was not, as he understood it, at risk of death.

45. The difficulty with that position, it seems to me, is that it is not clear how Professor Chard was to inform himself or be informed as to the category to which Kaneesha properly belonged and the degree of priority which should have been accorded to her. Her *haemoglobin* levels and growth parameters, even had they been reported to him, would evidently have countered for little. The family's concerns expressed to his secretary had gone unnoticed. Dr. Sherwood was largely *out of the loop* as far as Professor Chard's *plan* was concerned. The relevant policy document of *NSWHealth* remained unread and Kaneesha's physical deterioration, in other circumstances a potentially influential factor, went unreported to and unnoticed by him. He did not notice, he told the inquest, that, after the *angiogram* was conducted and he had decided on surgery, the quarterly cardiology reviews had ceased and he told the inquest that *"I don't usually note the non-appearance of letters at three monthly intervals."*

46. We know that the reason cardiology reviews ceased was that Professor Chard decided to operate but kept the likely date of Kaneesha's surgery to himself while Dr. Sherwood assumed, firstly, that surgery would take place reasonably promptly and, secondly, that Professor Chard's treatment plan would supplant her own. One might have thought these to have been reasonable assumptions but Professor Chard does not. Instead, his evidence is that *"a referral for surgical assessment is that, it's not a takeover (of) care. At*

no stage have I ever provided a cardiology service because I am not a cardiologist." In that view, he is supported by Professor Gary Sholler and Professor David Winlaw.

47. In summary, it seems that, once Professor Chard categorised Kaneesha as deserving of surgery in the fullness of time, there was nobody in a position to raise her case with him and suggest that surgery should no longer be delayed. Tragically, he told the court that *"I actually remember in December thinking that she would be a case that was sufficiently urgent for me… …a case which I regarded as sufficiently urgent to say that I can justify this as a semi urgent case that I could be doing during the closedown (6 weeks end of year/New Year) period."*

48. What prompted Professor Chard to think of her then is not clear but, at any event, Kaneesha died on 29 December, 2009. What difference early surgery would have made will never be known.

49. Kaneesha spent the last day of her life with her grandmother, happily playing in a local park. She ate lunch and went home to her mother at about 7pm complaining of a stomach ache. She fell asleep in her chair and was put to bed. Shortly before midnight, she awoke, went to the toilet and asked for a drink. She was given fruit juice but it is not clear that she drank it. She laid back in bed and started to fit and then went limp. Her mother tried to wake her without success and called for help. *CPR* was administered without success. An ambulance was summoned and Kaneesha was transferred to Liverpool Hospital where she arrived at 12.44am. She was pronounced dead at Liverpool Hospital at 1.03am on 29 January, 2009.

50. Professor Peter Pohlner offered three recommendations for the management of patients with complex congenital heard disease and cyanosis. Firstly, he believes there should be *"regular follow up by the treating cardiologist at three to six monthly intervals as outpatients, with an echo, oxygen saturation evaluation and haemoglobin level where the oxygen saturations are <75% measured on oximetry."* In that regard, he would have little opposition at Westmead where Professor Sholler said that the haemoglobin might require more frequent measurement. Secondly, Dr. Pohlner recommended that *"a patient nurse manager, familiar with cyanotic complex congenital heard disease be assigned to this group of patients and their carers to ensure compliance with medications and attendance*

at outpatient appointments when made and to immediately notify the related medical specialists of emergent issues raised by the carers." Essentially, this has already been bettered at Westmead as has his third recommendation, namely that *"prioritisation for surgical intervention at WCH be formalised for all patients with cyanotic congenital heart disease on an urgent (< 1 month), semi-urgent (1-3 months) and elective basis consistent with agreed criteria between paediatric cardiologists and cardiac surgeons and the involved support teams."*

51. Professors Sholler and Winlaw were very forthcoming and candid in the evidence they gave to this inquest. They acknowledged systemic shortcomings in the processes of Westmead Children's Hospital some of which have already been corrected. For instance, the *Heart Centre* now includes a Clinical Nurse Consultant who has the function of case managing cases involving neonates, cases *"involving major problems putting the patient outside the normal pathway to cure"* and hyperplastic left heart patients. Once a patient comes under the purview of the *CNC*, as Kaneesha would have on at least two of those bases, he or she is likely to be case managed until achieving adulthood.

52. Nowadays at Westmead Children's Hospital, *"disadvantaged"* families of which Kaneesha's may have been one will be *flagged* by cardiologists or the Clinical Nurse Consultant *(CNC)* as *"at risk*" which may trigger the involvement of the hospital's *Child Protection Unit*. Further, it is a most important function of the *CNC* to maintain contact with the families of patients, particularly where those families may be *disadvantaged*. It is unlikely that, nowadays, Kaneesha's family would be required *to fend for themselves* as, I think, to a large degree they were.

53. Further, the regular staff meetings at the *Heart Centre* have become more formalised. The membership has been expended to include not only cardiothoracic surgeons and cardiologists but also, where relevant, radiologists, *IC* staff, the *CNC* and perhaps speech, physio and occupational therapists and others. Nowadays, the agenda is prepared by the *CNC* as opposed to the secretarial staff who, Professor Sholler informed the inquest, were in charge back in 2006. Nowadays certain types of cases, of which Kaneesha's would be one, are routinely listed for discussion. The agenda is not restricted to cases where there has been surgery or where surgery is planned and includes cases involving *parasurgical* procedures such as *catheterisation* and *angiogram.* The proceedings and the decisions

are recorded on the shared drive. Interested medical staff can call up the conference case sheet and see the *plan* for each child dealt with. Clinicians involved in the care of particular patients whose cases have come up for discussion and who may have been absent from the meeting receive a written memorandum of the decision reached by the meeting. So, in Kaneesha's case, the decision to *"grow the child"* would have been documented. Further, a note of each decision is placed in the medical records of the relevant child.

54. Another reform of procedures and systems at Westmead Children's Hospital which has been introduced since Kaneesha's time involves a *fail safe* appointment being made wherever and at the time a child is referred to a surgeon. Had this occurred in Kaneesha's case, she would not have been *lost to follow up* because, at the same time the family were asked to contact Professor Chard, an appointment for review by Dr. Sherwood would have been fixed.

55. Professor Winlaw described the present system of *keeping tabs* on the progress of patients and ensuring that everybody who needs to know is up to date with the *plans* for each child and that no child is allowed *slip through the cracks*, as *"robust and going a long way to preventing a repetition of Kaneesha's case"* but he conceded that more needs to be done. I think both propositions are true but it does seem that the reforms and changes put in place by Professor Sholler and Professor Winlaw and their colleagues at the *Heart Centre* at Westmead Children's Hospital since Kaneesha's death, though, I was repeatedly assured, not directly in response to that death, are very worthwhile. But I think the evidence in this inquest demonstrates that more needs to be done and **I would recommend that *the Sydney Children's Hospital Specialty Network* introduce and implement the following additional policies and procedures at the *Heart Centre* at Westmead Children's Hospital :-**

- **A policy to ensure that all decisions concerning surgical and *parasurgical* procedures made during joint surgical review meetings are properly documented, included in the medical records of each patient the subject of discussion at such meetings and promptly communicated in writing to any relevant clinician missing from the meeting;**

- **A policy to ensure that should a treating clinician decide in a particular case to depart from a decision of the meeting, such change or changes be promptly communicated in writing to the Head of the *Heart Centre* or the Head of Cardiothoracic Surgery within the *Heart Centre* and a copy inserted in the patient's medical records;**
- **A policy to ensure that a referral by a cardiologist to a surgeon be accompanied, at the time the referral is made, by a letter of referral sent to the relevant surgeon with a copy to be placed in the medical records of the patient;**
- **A policy to ensure that a *back up* appointment for review by the treating cardiologist is made and documented whenever a cardiologist refers a patient to a surgeon or other clinician for surgical or *parasurgical* treatment;**
- **A policy to ensure that a referral by a cardiologist to a surgeon or other clinician for surgical or *parasurgical* treatment be accompanied by advice that the patient re-present to the cardiologist within a prescribed period, but not more than 6 months, in the event that such treatment does not occur within that time;**
- **A policy to ensure that the Head of Cardiothoracic Surgery within the *Heart Centre* compile and maintain a surgical waiting list or lists detailing all patients for whom surgery is planned or contemplated within 12 months.**

Finding

My findings are that Kaneesha Simpson who was born on 10 May, 2004 died at Liverpool Hospital, Liverpool on 29 January, 2009 of Cardiac and Respiratory Arrest probably connected with Embolic Stroke.

Magistrate Scott Mitchell,
NSW Deputy State Coroner.
Glebe
12 December 2011