QUEENSLAND COURTS

OFFICE OF THE STATE CORONER

FINDINGS OF INQUEST

CITATION:	**Inquest into the death of Samantha Rose Spence**
TITLE OF COURT:	Coroner's Court
JURISDICTION:	Brisbane
FILE NO(s):	2007/20
DELIVERED ON:	29 October 2010
DELIVERED AT:	Brisbane
HEARING DATE(s):	11 December 2009, 22–26 March & 21 April 2010
FINDINGS OF:	Christine Clements, Deputy State Coroner
CATCHWORDS:	CORONERS: Inquest – death of a child, scoliosis correction, Chiari type 1, necessity of brain and spinal scanning

REPRESENTATION:

Counsel Assisting:	Ms Kathryn McMillan SC
Mater Children's Hospital	Mr Boddice SC i/b Minter Ellison

Introduction

Samantha Rose Spence would have turned thirteen on 29 April 2007. She died in the Mater Children's Hospital on 7 April 2007. She was a loved and well cared for child whose significant medical requirements were addressed by her family. Her primary carers were her father and paternal grandparents, particularly her grandmother.

Samantha had a complex medical history with some intellectual deficit although evaluation of her capability varied in different areas of assessment. Dexamphetamine had been prescribed with some success in improving her inattentiveness. She attended Special School.

Overview

Initial investigations

In March or April 2006 her family observed a postural problem which was diagnosed as scoliosis. She was referred to the Mater Children's Hospital Scoliosis Clinic. In June 2006 the curvature of her spine was assessed by an orthopaedic surgeon, Dr Robert Labrom. He evaluated the curvature as severe and it was decided surgery was the appropriate treatment.

Identification of Chiari Malformation and Neurologist Review

In the course of assessment and preparations for surgery, an MRI of the spine revealed a Chiari 1 Malformation. This is a protuberance of the cerebellar tonsils into the largest opening of the base of the skull (the foramen magnum). Samantha was then referred to a paediatric neurologist, Dr Christopher Burke, to assess whether this condition would require treatment prior to the proposed spinal surgery. In September 2006 the decision was reached that the severity of the curvature of the spine exceeded any need for further intervention regarding the Chiari Malformation which was assessed as a-symptomatic. The scoliosis progressed markedly from sixty five degrees in June 2006 to ninety degrees by March 2007.

Operation

Surgery to insert rods to straighten her spine was performed on 5 April 2007 by Dr Geoffrey Askin assisted by Dr Robert Labrom and Dr Otto Von Arx. The anaesthetist was Dr Gregory Moloney. The surgery was successful and there was no indication of problems with either the procedure or the anaesthesia. At completion of the procedure two epidural infusions of morphine for pain relief were started. The anaesthetist Dr Moloney accompanied Samantha to the paediatric intensive care unit (PICU) where he handed over her pain relief management to the acute pain service. Spinal cord monitoring occurred throughout the operative procedure with no indication of a problem.

Paediatric Intensive Care

Samantha was cared for in PICU post surgery from 1.25pm on Thursday 5 April 2007. Her blood pressure was a little low, and she was slightly febrile but these observations did not cause alarm to medical carers.

Transfer to ward

She was discharged to the ward at about 11.30am on 6 April 2007. That was Good Friday of the Easter long weekend.

Samantha's family recall her as being very sleepy and not very responsive. Staff were not overly concerned with her condition although family members voiced concerns. By about 5.00pm nursing staff were also considering whether there was a problem as Samantha appeared still to be very sleepy. Instructions were given to reduce the epidural pain relief, which was done. A ward call was made to have Samantha's condition reviewed by a doctor. Samantha's condition declined rapidly from about 5.15 - 5.30pm.

Respiratory arrest, resuscitation and treatment

The ward call doctor, Dr Skeggs had just arrived to review Samantha's condition when she became unconscious. He could not elicit a response and her condition suddenly declined rapidly. She suffered a respiratory arrest. A code Blue response was called at about 6.00pm. Samantha was resuscitated, intubated and ventilated before being transferred back to PICU. She did not respond to the administration of Narcan, which would have been expected if she was suffering from over sedation. A CT scan and neurological review was undertaken at about 8.15pm. This revealed acute and chronic hydrocephalus and possible tonsillar herniation secondary to cerebrospinal fluid leak. An emergency external ventricular drain was inserted which released cerebrospinal fluid under pressure.

Dr Lister, the head of the PICU, spoke with Samantha's family and explained she had suffered brain damage and was unlikely to survive. Samantha was declared deceased at 2.40pm on Easter Saturday, 7 April 2007.

General medical history

Samantha Rose Spence was born on 29 April 1994. She was delivered by caesarean section after an uneventful pregnancy. As a young child she had ear problems treated by grommets and removal of her adenoids. There were a range of childhood illnesses including febrile convulsions when aged two to three, pneumonia, asthma, and recurrent ear and respiratory infections requiring reinsertion of grommets. At age two she was referred to a paediatrician, Dr Robert McGregor. Developmental delay in reaching milestones in motor skills, speech and crawling was noted. It was suspected she had a hearing difficulty and this was investigated and confirmed. The bilateral middle ear disorders impacted on her speech and language development. Further referrals were arranged to speech pathologists and ear nose and throat specialists. Grommets were inserted again to assist with her ear infections which had diminished her hearing.

By age four and a half Samantha had been diagnosed with global developmental delay, particularly in verbal areas. In 2000 she again needed grommets inserted due to recurrent ear infection. Her hearing and speech development remained adversely affected by these physical problems. She attended the Claremont Special School. Behavioural difficulties, problems with bowel training and head nodding in 2001 prompted her general practitioner, Dr Lawnton to recommend assessment for autism. She experienced gastro intestinal difficulties which also impacted on her

ability to cope in the school environment. Problems with her sight were detected and she was referred for review by the optometrist due to astigmatism.

In 2002, mild to moderate mixed hearing loss was confirmed and hearing aids were fitted. Samantha's hearing capacity was significantly improved but remained the focus of her medical care between 2001 and 2005.

In 2005 her general practitioner referred her to Dr Malcolm Miller, paediatrician and Therese McHugh, a psychologist, regarding her intellectual problems. At this time Samantha was considered to be a socially shy and somewhat withdrawn child, but otherwise happy and enjoying school. Once she developed confidence she enjoyed being with other people, returned affection and was empathetic. It was noted she was very poorly coordinated which led to reluctance to participate in physical activities and concerns with her weight.

It was also recorded Samantha's two siblings had a degree of learning difficulty. Her gait was described as unusual. Her overall presentation was seen to represent a form of intellectual impairment. Dexamphetamine was prescribed. The medication benefited Samantha who appeared to be more interactive, expressive and a little quicker in her thinking.

Throughout Samantha's life she was actively cared for primarily by her father and paternal grandparents. It was noted her mother had significant health difficulties. Her medical care was actively pursued by her family who were committed in their ongoing support for Samantha.

A summary of the family's evidence to the inquest from Samantha's father Shawn Spence and Samantha's grandmother is annexed.[1]

Family issues

(i) Mr Spence and his mother consider their repeated expressions of concern over Samantha's condition were not taken seriously. As her father and grandmother, they were best placed to know Samantha and they were concerned over her condition throughout Friday but felt their concerns were not fully appreciated or properly investigated.

(ii) In hindsight Mr Spence asked why another MRI was not performed after the malformation was detected in August or September 2006. He raised the question whether a pre-emptive shunt placed before the operation was performed on her back, should have been performed.

(iii) Mr Spence considered the nurse from the agency demonstrated a casual attitude and an inability to manage the equipment and monitors which concerned the family then and now. In retrospect Mr Spence also queried whether a major operation should have been scheduled immediately prior to Easter when fewer staff would be expected to be available.

1 Annexure 1

(iv) Mr Spence disagreed with the impression presented by Nurse Murphy that Samantha was chatty and the suggestion she joked about going home. He thought she was "very groggy, very out of it. It was a very laboured, "Oh, can I go?", but yeah, it wasn't Samantha."[2]

I have not referred to all the evidence from the inquest but have summarised some as follows.

Summary of evidence of some of the treating medical team.

Dr Labrom

Dr Labrom is an orthopaedic surgeon with specialist interest in paediatric spinal surgery. He is experienced and has practised in Canada in his area of specialty. He assisted Dr Askin with Samantha's surgery.

He saw Samantha for the first time through a referral to the Scoliosis Clinic at the Mater Children's Hospital. The referral was from another specialist, Dr Licina to whom Samantha had been referred by her treating general practitioner, Dr Lawnton. The clinic operates through the skills and expertise of various visiting specialists and treatment decisions are made drawing on expertise from the team. The clinic runs within the public hospital framework and offers a wide range of surgical, physician, therapist, intensive care and para medical staff expertise.

Access to care for children is generally available within 90 days for assessment by the clinic. Dr Labrom and Dr Askin triage and review the children to ensure children with urgent requirements are seen promptly. He considered the surgical team was well supported by a strong nursing staff led by Sister Reitano.

In Samantha's case, she was first seen by Dr Labrom in June 2006 and then seen prior to her surgery in March 2007 by Dr Fornachs. When first seen by Dr Labrom Samantha had a spinal curvature measured at 65 degrees. By March 2007 the curvature was measured at 90 degrees, a marked increase. Because of the significant increase her surgery was scheduled within the month of March 2007. Assessment indicated Samantha maintained good flexibility suggesting surgical correction could be achieved to a significant effect.

Dr Labrom acknowledged in hindsight she could have been seen towards the end of the year by the orthopaedic team but this did not occur. However, she was seen in September 2006 by a paediatric neurologist, Dr Christopher Burke. This review was arranged after the MRI of the spine was conducted as a standard procedure and revealed a Chiari malformation.

Dr Labrom confirmed the purpose of the referral to Dr Burke was for clearance prior to the proposed orthopaedic surgery. The referral was standard practice where an abnormality is detected in the spinal cord. Dr Labrom stated "we chose Dr Burke because of his vast experience. We figured that a neurophysician comparison to a neurosurgeon, would be a very good place to start and we have a good relationship with our neurophysician services at the Mater Children's Hospital, and we felt that his

2 T2-13, L 1-3

opinion would be valuable, in the way that he could assess the child, in a global sense , as well."[3]

Dr Labrom went on to explain the choice of neurophysician rather then neurosurgeon reflected the view the Chiari malformation was of a mild degree and they really did not suspect there was a requirement for surgical input. Dr Labrom explained to the court the position of the brain at the back of the head which extends to the brain stem and into the spinal cord. The spinal cord passes from the brain into the spinal column via a large hole in the base of the skull called the foramen magnum. There are variations where the cerebellum (the most posterior portion of the brain) can be herniated into the posterior part of the foramen magnum.

Samantha had the mildest type of malformation, graded one and called ectopia, meaning some change in the appearance of, and out of its usual position. In Dr Labrom's experience the Chiari malformation would need to have been much more significant before consideration was given to posterior fossa decompression. If that was required the neurosurgeon would operate to physically remove some of the bone at the base of the skull to allow more room without any risk of traction or compression to part of the brain.

Dr Labrom emphasized the team was very aware of the situation with Samantha and therefore sought the global neurological assessment of her function, particularly with relation to her upper and lower extremity function including the examination he understood was performed by Dr Burke.

Dr Labrom understood the Chiari malformation was a-symptomatic. There was no information in her medical history to suggest neural compression, which in the instance of Chiari malformation, can lead to brisk reflexes or weakness or spasticity. Symptoms can present in a multiple ways but Dr Labrom considered Samantha did not demonstrate any. In particular he said "We had no particularly strong evidence to date she had a hydrocephalus type relationship, as well."[4]

Dr Labrom explained hydrocephalus as increased pressure in the brain, often related to blockage of the normal spinal or brain fluid (CSF) that circulates in the brain.

Dr Labrom conceded there was an association between Arnold Chiari malformation and spinal fluid CSF, spinal fluid flow, but said it was not well understood. He said, "In (our) appreciation of her presentation there was no evidence to suggest this."

Symptoms can be vague including headaches and subtle weakness and chronic fatigue, anorexia, failing to eat, as well as subtle neurological symptoms.

In Samantha's case there were other developmental and intellectual issues that made it more difficult to assess.

3 T2-37 L 4-10.

4 T2-38, L 13-14

Dr Labrom said the family was often the source of the best observations of subtle changes in behaviour but there was no concrete evidence that Samantha was suffering neurologically or from CSF flow dynamics issues in relation to the Chiari malformation or any hydrocephalus.

Dr Labrom excluded the more serious complication of Chiari malformation where a syrinx exists; an opening in the spinal cord was not evident in Samantha. In cases where a syrinx exists there is increased risk of blockage of spinal fluid which is manufactured in the brain and flows downwards.

Dr Labrom also noted a syrinx can exist without a Chiari malformation and can be entirely asymptomatic.

Dr Labrom indicated he would not have changed the manner of surgery had the situation been that it was known Samantha had both a Chiari malformation and a syrinx. However the pre-operative assessment pathway would have been via a neurosurgical review to review the syrinx. An assessment would be made to see whether there was a need for preliminary drainage of the syrinx.

Dr Labrom indicated had there been symptoms suggesting hydrocephalus the response would be the same, namely review by a neurophysician. If hydrocephalus was identified Dr Labrom indicated they would ask advice of the neurosurgeon to see if any further tests, for example assessing the spinal fluid flow via an MRI would be advisable. Advice might include the use of a shunt. However, Dr Labrom indicated even had there been a syrinx, in the vast majority of patients there is no need for a shunt. Likewise patients with Chiari malformations rarely require posterior fossa or foramen magnum decompression. The assessment for Samantha concluded there was no need for surgery regarding the Chiari malformation prior to the spinal surgery.

Dr Labrom estimated he had previously operated on between 10 and 20 patients with Chiari malformation and performed scoliosis correction surgery on these patients.

Dr Labrom confirmed the usual pathway for children after undergoing scoliosis correction surgery is a night in the paediatric intensive care unit to manage the analgesia required for pain relief.

Dr Labrom acknowledged everyone involved in Samantha's care felt desperately sorry after Samantha's unexpected death and especially for the family.

He said the team has responded by even greater diligence in preparation with regard to identifying any abnormality of the spinal cord. A very firm opinion is required from neurological assessments before surgery proceeds. MRI scanning of the entire brain, not just the base of the brain as occurred in Samantha's case, is now performed in the pre operative work up of children. This is done despite there not being a clear scientific justification for doing so, nor strong views in worldwide literature research indicating it is advisable. However, the Mater Hospital has decided to add this screening which they will monitor and review to assess the efficacy and cost efficiency of the practice.

A whole of brain scan could pick up the presence of hydrocephalus if a very experienced radiologist reviewed the ventricles and considered they were showing some expansion with fluid from the normal presentation. The limitation of scanning is it captures an image of a moment in time whereas a condition such as hydrocephalus is a dynamic process. In Dr Labrom's opinion he noted in Samantha's case hydrocephalus had developed very rapidly. The opinion expressed by Dr Labrom was that the best assessment to detect hydrocephalus is by taking a detailed history and by examining the child thoroughly. Scanning can supplement this.

Dr Labrom confirmed the general expectation is that children will at least be able to stand out of bed at an early stage after surgery. World's best practice encourages early mobilisation. It helps respiratory function and it is less likely for pneumonia or thromboembolus to develop. Mobilisation usually occurs whilst the child is still in paediatric intensive care under supervision of the physiotherapist.

Dr Labrom noted it may occur later after transfer to the ward where a particular child may have a functional impairment or some clumsiness or some functional balance issues.

The decision to transfer from the PICU back to the ward was a combined decision of the consultant intensive care physician, Dr Bruce Lister, who was the director of intensive care, and the consultant visiting specialist. Dr Labrom noted it was Good Friday. The arrangement in place between the two surgeons was that Dr Askin visited Samantha on friday and Dr Labrom, on saturday. He visited around lunchtime after completion of urgent surgery at the Princess Alexandra Hospital. Dr Labrom was on call at the Princess Alexandra Hospital over the Easter weekend.

Dr Labrom had reviewed the literature research articles attached to the pathologist's report and noted the phenomena of sudden death associated with patients with Chiari malformation and noted another layer of uncertainty with regards to patients' outcomes regarding the risk of mortality. The condition has been noted in some unexpected, inexplicable and very rapid deaths

Although there was some mention in the material about positional factors of the head in patients with Chiari malformation, Dr Labrom considered there was no critical evidence to suggest Samantha had a positional relationship due to the way Samantha could hold her head, thus it was felt it would be very safe to manage her just like every post operative patient in a rehabilitation setting. He did not see any problem with physiotherapy movements of Samantha's head after surgery.

Dr Labrom said of the surgery-
"There was nothing that I recall in terms of the techniques being a challenge more than usual, and we didn't suffer any significant blood loss issues." [5]

5 T2-50 , L38-39

Dr Labrom could not say why Samantha developed (acute) hydrocephalus which caused her death. He agreed there was an association between Chiari malformation and hydrocephalus.

In hindsight Dr Labrom considered if everyone had better appreciated Samantha's level of intellectual and physical functioning, it may have assisted. The surgeons relied on the assessment of the very experienced neurologist, Dr Burke to assess things like changes in fundus by examining the back of the retina with an ophthalmoscope to look for swelling and signs of chronic hydrocephalus. In hindsight they might have been more inquiring regarding any signs of subtle hydrocephalus. These were not detected prior to surgery. It was not known she was suffering from chronic hydrocephalus.

It was after her collapse and resuscitation that a scan showed changes in the ventricles demonstrating hydrocephalus. A drain was inserted.

Signs of chronic hydrocephalus may be picked up in the neurological observations recorded in the pain management chart.

Dr Labrom was asked to comment on the interval between when Dr Burke assessed Samantha in September 2006 and surgery being performed in March 2007. He was asked whether the Chiari malformation is a static state or should have been reviewed again. In Dr Labrom's experience a low grade Chiari malformation is unlikely to change in any short time frame. Dr Labrom said there are very subtle anatomical variations which remain very static. The Chiari malformation had been identified, there was no syrinx and no signs of hydrocephalus, acute or chronic and so the surgery was scheduled to proceed.

It was noted despite the usual pathway of expectation post surgery, Samantha was not able to sit up and get out of bed on the day following her operation, and she was very drowsy. Dr Labrom considered it was a flag there was some delay in post surgical progress but that the consultant intensive care specialist considered it appropriate she could go back to the ward. However, because of Samantha's overall picture of physical and intellectual circumstances, he considered she was a patient they would watch carefully.

Samantha had a fairly significant level of analgesic to manage pain. She still had two epidurals in place the next day to manage pain relief. The epidural delivery of analgesia also lowers the blood pressure which can impact on the capacity and readiness of the child to sit up and stand. Samantha was recorded as having low blood pressure post operatively.

Dr Labrom did not consider it was a strict pathway to achieve certain steps to enable a decision to be made to discharge to the ward. Every case is different- the pathway is a guide.

To test for raised intracranial pressure requires a skilful assessment of deterioration in the child's neurological and conscious state. An examination of the back of the eye, the fundus, may indicate signs of swelling due to raised venous pressure in the skull. Other signs are loss of consciousness, drowsiness, vomiting, and photophobia.

It is also possible to invasively measure ventricular pressure. This occurred after Samantha's collapse and the scan.

The symptoms however are also experienced frequently in the post operative period with drowsiness, nausea and vomiting being common.

A formal fundal examination has not been included as a required test prior to surgery.

Dr Labrom stated Samantha's surgery was essential given the degree of curvature of her spine which had advanced from 65 degrees to 90 degrees. I accept that evidence.

Dr Christopher Burke

Dr Burke is an experienced consultant paediatric neurologist. By the time of the inquest he no longer had an independent recall of his consultation with Samantha Spence and her family. He could however recall a few matters. His recollection was that Samantha was accompanied by two ladies. His memory differs from the family who explicitly recall Samantha attended in the company of her father and maternal grandmother. He did not take issue with this. He recalled the letter of request from Dr Hay requested review of Samantha to assess whether she needed neurological operation to correct the Chiari malformation prior to the planned scoliosis surgery.

Dr Burke referred to his notes in the medical record which he had used to refresh his memory when preparing his statement. He said he took a history from her (parents). He said he was seeking any history to indicate symptoms of raised intracranial pressure. He was interested to know if there was a history of recurrent headaches, particularly early morning headaches with vomiting.

In broad terms he would have asked whether there were any other symptoms of concern to the family. He would not have detailed specific questions, but rather asked broad questions to elicit information. He indicated he would have proffered examples asking whether Samantha suffered dizziness, or a lot of neck pain. He would not have asked a question about every possible symptom that has been documented with Chiari malformation.

He acknowledged a small percentage of people with Chiari type 1 malformation have hydrocephalus; it is certainly not uncommon.

Dr Burke took a note recorded as – "balance and coordination always poor, maybe a little worse lately, fine coordination hands seems okay, no sensory complaints apart from back pain." Muscle tone was found as normal, balance, fair, and coordination, intact.

There were difficulties in assessing children with severe scoliosis due to the impact of that condition. As well, Samantha had some developmental disabilities, which had to be considered in the overall assessment. Such children can have minor neurological dysfunctions, including problems with balance, coordination, learning, ADHD, which are commonly seen in children with delayed development.

He noted she was seeing a paediatrician, Dr Miller but did not obtain that record or contact Dr Miller. He therefore did not see the reference in Dr Miller's records of an unusual gait recorded in 2006. Dr Burke said he tried to observe Samantha's walk but she was in so much pain from her scoliosis that he could not do that. Her family members indicated Samantha did in fact walk along a line at Dr Burke's request, although he could not recall this.

Nothing in his examination suggested to Dr Burke that Samantha was suffering from hydrocephalus. He was aware she had an MRI of her spine. An MRI had not been performed on her brain. He examined her fundi, by examination of the back of the eye via an ophthalmoscope. The optic nerve is examined to see if there is any swelling. He did not observe any. Dr Burke agreed a person could have chronic normal pressure hydrocephalus, which could be stable at any given time. If there was raised intracranial hypertension, he would have expected to see some change in the optic nerve.

Dr Burke said chronic hydrocephalus was not of concern to surgery, unless there was increased intracranial pressure.

Dr Burke disagreed with the proposition that chronic hydrocephalus could predispose a person to the condition becoming acute. He said it depends entirely on the cause.

It was suggested for the purposes of proposed surgery and the requirement of anaesthetic that the information a child had chronic hydrocephalus would be important. Dr Burke said "It would be of interest, but, you know, I don't necessarily agree that it would affect the – any of the, you know, outcome or the, you know, the procedure itself."[6]

Dr Burke drew the distinction of whether or not the patient had a-symptomatic hydrocephalus, as distinct from a patient with Chiari malformation as well as hydrocephalus. In Dr Burke's opinion he did not consider it was essential for the surgeon to know about the condition of hydrocephalus as scoliosis surgery does not involve a procedure inside the head. It was raised with Dr Burke that the Chiari malformation is at the top of the spinal cord and there is the possibility of an obstruction to the top of the spine. Dr Burke agreed but said it was only if the surgeon was going to open the covering around the spinal cord and cause any changes in the pressure that it would be significant. The surgeon is operating outside the spinal cord. It's not going to have specific effect on the Chiari anomaly.

Dr Burke considered the extent of the Chiari malformation was small in comparison to the extent of the scoliosis. He considered Samantha needed the scoliosis surgery. He could not see that the Chiari malformation was responsible for any other deficit relevant to the situation.

He could not recall explaining the Chiari malformation to Samantha's family nor could he recall giving any advice about future management of the condition. He assumed the context was the family had already been advised about the condition

6 T 3 , 67, lines 3-5

and he was focused on assessment for the purpose of proposed necessary scoliosis surgery.

Dr Burke confirmed there would be many people who have either a Chiari malformation and/or a condition of hydrocephalus who are undiagnosed and asymptomatic. Chronic hydrocephalus only becomes a problem when there is raised intracranial pressure.

Dr Burke explained the prolapse of the cerebellar tonsils causes a blockage to the flow of the spinal fluid which then builds up into the cranium and causes an increase in the intracranial pressure.

Dr Burke did not accept the conclusions drawn by Dr Urankar in her autopsy report, which incorporated both the static observations of Dr Tannenberg as well as the information drawn from the medical record including the circumstances of collapse, and subsequent scanning indicating the need for insertion of an extra ventricular drain to release cerebrospinal fluid under pressure.

In Dr Burke's view he considered there was a misreading of the CT scan following Samantha's respiratory arrest. He later reviewed the CT with another radiologist, presumably after Samantha's death.

He referred to page 167 of the medical record which stated-
"*The ventricles are markedly dilated but no transependymal spread of CSF is seen to suggest acute hydrocephalus*."

Dr Burke explained acute hydrocephalus implies there is an obstruction to the flow of CSF, which in the case of a Chiari malformation, is an obstruction to the flow of CSF out of the ventricles, which are the fluid cavities in the brain. It results in "coning" of the brain.

Dr Burke reviewed the CT scan and said there was no evidence of acute hydrocephalus. He considered there is a flaw in considering the clinical evidence.

Dr Burke said, "*I don't think we will ever know for sure exactly what the cause of death was. It was not due, in my opinion, to acute hydrocephalus. It was related to the Chiari anomaly….It is well documented that patients who have Chiari anomalies can die unexpectedly and suddenly. The reason why is often not clear.*"

One possibility is Samantha had a build up of carbon dioxide in her blood, which caused an increase in the volume of fluid in the veins inside her head. The venous drainage from the head all occurs at the back of the brain, and the posterior fossa, which is the part of the brain we are concerned about, particularly with the Chiari anomaly. The fundamental problem in Chiari anomaly is that the posterior fossa is small, (and the picture available to the court) does not show that. The fundamental problem is the posterior fossa is too small for the amount of brain tissue, which is why some of the tissue goes down the foramen magnum. So there is some compression to the back of the brain stem, so if anything caused an increase in the size of the structures in the posterior fossa, it will result in more pressure being put on the brain stem. The brain stem is critical to the breathing and the heart rate. If

venous drainage is altered there can be significant impact. If there is increased pressure inside the venous system draining the blood out of the brain, then there is greater difficulty in draining the blood out of the posterior fossa, increased compression on the brain stem, respiratory centre, and death.

Ii is noted this is similar to the thinking and review performed by Dr Keely when he reviewed Samantha's case except, as far as Dr Burke was concerned, he did not agree with attributing problems with hydrocephalus. Otherwise he agreed with the possible mechanism of death raised by Dr Keely.

Dr Burke considered he had taken more factors into account than Dr Urankar in reaching the conclusion. He referred to the clinical, radiological and pathological to reach his conclusion there was no acute hydrocephalus.

In Dr Burke's view, some unknown trigger precipitated Samantha's death. He agreed something caused raised intracranial pressure but did not accept there had been an acute on chronic hydrocephalus. Dr Burke explained that there was no transependymal spread. There is an increase in pressure within the ventricles and that forces fluid through the lining of the ventricles, forces it out of the brain, and that was not apparent on the scan that Samantha had after her death.

Dr Burke accepted the neuropathology from the autopsy report established underlying chronic hydrocephalus.[7] In Dr Burke's opinion he thought the chronic hydrocephalus had been present for many years. He thought it may well have been a factor in her intellectual impairment, in her attention deficit disorder, but it had been stable over many years, and, in Dr Burke's view, did not cause her death.

To diagnose chronic hydrocephalus requires some form of brain scan. At the time Dr Burke saw Samantha he considered scanning. In response to this question he said- "*It wasn't the question I was asked, and the Chiari anomaly was not causing any increased intracranial pressure. So therefore if there was hydrocephalus, it was not causing any issues that would be relevant to the operation.*"

Dr Burke was asked whether he now accepted it would be beneficial to consider imaging as part of the assessment of children in advance of surgery. He still considered that chronic hydrocephalus was not the cause of Samantha's death (and he disputed she had acute hydrocephalus). He accepted there may be other considerations from an intensive care perspective which recommended brain scans prior to surgery.

His consideration of literature reviews noted that some children with Chiari anomaly die unexpectedly after other forms of surgery, e.g. heart surgery. Therefore he thought there was some support for Dr Keely's hypothesis of increased carbon dioxide levels and the venous pressure. The centre for cardio respiratory responses is critically located in this area and is subject to any change in pressure.

In summary Dr Burke thought the cause of Samantha's death was due to an increase in the pressure on the brain stem, which led to her respiratory arrest.

7 T3-77, L 49-52

The cause of the increase in pressure was unclear in the doctor's opinion, possibly an increase in venous pressure, or the stresses of the operation itself, which might cause vocal cord paralysis.

Dr Burke assumed that Samantha would need an anaesthetic to undergo an MRI of the brain, as the procedure requires lying perfectly still. The anaesthetic itself poses risks. He said he decided it was not justified in the context to take the risk.

I note the evidence of Dr Askin, the principal orthopaedic surgeon in this case, indicated a general anaesthetic was not usually required in the case of most children who undergo an MRI. He said- "*most children, apart from babies and infants are ok in an MRI scan*."[8]

Comment

The changed procedure will now involve both the MRI of the spine and brain at the same time. It is noted there was an assumption being made that Samantha underwent an anaesthetic to undergo the initial MRI of her spine. It is also noted Dr Burke confirmed a CT scan, if performed of the brain, could have shown if there was any hydrocephalus and is a much easier process than an MRI, requiring less sedation. The resolution is less clear. The risk with the CT scan is to balance the risk of additional radiation impacts on the patient. MRI scans are preferred.

Dr Burke thought about a possible connection with her learning difficulties and hydrocephalus. He pointed out he had measured her head, which was at the upper limits of normal. A straightforward Chiari would not cause such an impact; it would have to be another condition such as hydrocephalus to have that effect. He did not reach a conclusion it was hydrocephalus.

Dr Burke remarked the ventricles did not go down to normal after insertion of the drain. He did not accept that (signs of) acute hydrocephalus would disappear after being drained given the time frames involved. He would have expected some further herniation of the brain.

The CT scan that Dr Burke interpreted as not showing the necessary signs to demonstrate acute hydrocephalus was reported by the radiologist as follows-
"Chronic hydrocephalus with cerebral oedema and raised intracranial pressure."

Dr Burked responded- *"well that's an interpretation. I've deliberately focused on the description which is what I would regard as being much more relevant."*[9]

It is noted the radiologist's report went on to note- "*probable early coning"*.

Dr Burked acknowledged people with the Chiari malformation have a small posterior fossa with less room to accommodate any compression in the vital area, putting them at risk when there is epidural pain relief which can cause the hypercarbia and increase the pressure in this area. Dr Burke agreed that although the Chiari malformation had been assessed as not requiring surgical intervention prior to the

8 T8-11, L10-20

9 T 3-84, L14

scoliosis surgery, it should be a condition still to be considered in the management of the child. It should be made apparent to everybody that a child has a Chiari malformation.

Dr Gregory Moloney

Dr Moloney was the anaesthetist for Samantha's procedure. He was unaware that Samantha had a Chiari malformation at the time of the operation. It was not noted in the medical admission records prepared by the admitting doctor on 4 April. That doctor was the resident medical officer in orthopaedic surgery. The information was documented within the medical record

The anaesthetist considered the information was important because it was important to know whether there was any obstruction of the cerebrospinal fluid as a result of compression from the cerebellar tonsils. Had the information been available he would have checked she had been appropriately assessed. He would also have kept her head in a neutral position. Had the underlying chronic condition of hydrocephalus been known, then this would have alerted him to increased risk of raised intracranial pressure. The longer the procedure, the more concern this issue would cause.

Dr Donna Taylor,

Dr Taylor now works as a consultant paediatrician based in Mackay. She worked at the Mater Children's Hospital between 1998 and 2007. She was on duty in PICU during the initial post operative day of Samantha's care. Her recollection was staffing levels were the same irrespective of it being the Easter long weekend. She had no recollection of whether or not she knew Samantha had a Chiari malformation, but did not consider this would have changed the observations that would be made during Samantha's stay in intensive care, which included neurological observations.

When she handed over to Dr Deverill the only concern was mild hypotension. This could be explained as due to fluid loss or epidural medication. Dr Taylor noted her blood pressure did not improve despite administration of fluid bolus, and so the epidural analgesic was reduced. Her blood pressure then responded.

She could not remember being concerned with Samantha's condition. She did not recall laboured breathing but said this would have concerned her if she was aware of it.

She stated it was generally the night registrar's duty to complete the discharge paperwork before discharge to the ward. The decision was then made by the consultant after the morning walk around handover. The consultant was Dr Lister who was accompanied by Dr Ireland. Overnight on the first post operative night Samantha's blood pressure was low and she had poor urine output, but the doctor stated these were within acceptable range. The discharge paperwork is to inform the ward that is receiving the patient, of the patient's condition.

Samantha's low urine output was addressed by giving her a fluid bolus and low blood pressure was addressed by reducing the epidural rate.

Dr Kristopher Skeggs

Dr Skeggs saw Samantha twice on Good Friday. The first time was approximately noon when he was asked to review her due to nausea. Dr Skeggs wrote a detailed case note after seeing her including background of condition, work up and treatment. The information was gleaned from the medical chart and summarised. It included a reference to the Chiari malformation, which had been noted in the outpatient record. He considered this was a condition worth keeping in mind. He recorded instructions to monitor any decrease in urine output or blood pressure. This had been noted by the PICU as an issue. Dr Skeggs said Samantha was lying with her eyes closed but was cooperative with his examination. She was responding to commands and he did not have any concerns about her level of consciousness. He noted decreased air entry to both of her lungs and noted she was to have physiotherapy for suctioning. It was not something out of the ordinary for a post surgical patient.

Dr Skeggs gave contrary evidence re staffing levels which he said was reduced on public holidays. This explained why Dr Skeggs saw Samantha rather than the orthopaedic registrar or resident.

Dr Skeggs said the normal procedure would be to contact the treating team when the patient is discharged from PICU. On a public holiday that would have gone to the registrar on call who may or may not have been in the hospital at the time. Dr Skeggs was not told specifically about Samantha. He only found out she had come onto the ward when the ward nurse asked for her to be reviewed to obtain an order for relief of nausea. There was a printout from PICU that has an entry from both doctor and nurse in PICU listing current issues and noting ongoing instructions for fluids and medications for the ward. Dr Skeggs had access to this information in the discharge summary. The expectation is that the ward call doctor (in this case, Dr Skeggs) would be contacted at some stage to routinely check the patient after discharge from PICU.

Dr Skeggs expected he would be informed about an altered level of consciousness by the staff if it was considered a concern.

Dr Lister

Dr Lister is a paediatric intensive care specialist and the most senior doctor in that area during Samantha's admission to PICU. He and Dr Askin made the decision to discharge Samantha from PICU to the ward. He agreed the documentation recording the normal care path plan for a scoliosis patient had not been completed as required by nursing staff. However, Dr Lister stated it was not a document that he would usually peruse. The registrars might refer to this document if they had questions about the management of the patient. The document was developed over many years observations, standardising the care to make sure everything that needs to be done is attended to.

Dr Lister confirmed patients are routinely transferred from PICU to the ward on the day following scoliosis surgery.

Dr Lister indicated there would usually be a conversation at handover from PICU to the ward, and completion of documentation. There would usually be a conversation between the Intensive Care Registrar or consultant to the registrar on the ward so

that they are aware of the patient coming to their ward. Handover could occur in intensive care during the ward round. The relevant receiving team attends the PICU. There was a usual practice where the nurse from the ward came to the PICU ward and had a handover from the PICU nurse.

Dr Lister did not expect patients to be sitting up after spinal surgery while still in PICU. The orthopaedic surgeon instructs whether or not the patient can sit up, but in Dr Lister's experience most don't while still in PICU. He would not want children out of bed in the PICU after major spine surgery, and expected they would not be well enough as well as being impeded by attachments.

Dr Lister considered Samantha's condition on reviewing the record after surgery was not of concern. Patients quite often have low blood pressure. The epidural pain relief still had some local anaesthetic after the operation which can have an impact on blood pressure levels. Fluids boluses are given to assist with this as well as for recovery after blood losses during surgery. He considered Samantha's blood pressure had stabilised by midnight after surgery and remained stable for 8 hours.

It was of interest that Dr Lister was unaware that Samantha had a Chiari malformation at the time. He considered it would be information of interest. Had he known this though, he would also have known she would have had been assessed by a neurologist and would have felt reassured by this that there were no problems associated with the anomaly. He was quite clear the existence of the Chiari would not have changed his view on how Samantha should be handled or positioned.

Had it been known she had chronic hydrocephalus this would have prompted the issue of raised intracranial pressure. He would have expected some further investigation had it been known she had chronic hydrocephalus. This might have involved a shunt.

In his experience as an intensivist anaesthetist he sees children with acute rises in intracranial pressure. Usually they would be unconscious from head injuries. Intracranial pressure in such cases would be measured directly via the neurosurgeons probing and measuring brain tissue or in the ventricle.

In Samantha's case however she was not reviewed by the spinal team but was seen subsequently by the ward doctor.

Dr Lister confirmed Samantha returned to PICU after the drain was inserted at about 9.25pm on Friday night. Dr Boon Pang inserted the drain and reported to Dr Lister the cerebrospinal fluid was under pressure. This signified to him that Samantha had raised intracranial pressure and confirmed the CT scan of a hydrocephalus. He said he would have to postulate that the hydrocephalus was acute, because they had no evidence of her having hydrocephalus prior to admission.

In Dr Lister's opinion, after reviewing all the information including autopsy report and literature research, Samantha suffered some alteration in the cerebrospinal fluid outflow. Whether that was actually due to direct pressure or whether it was due to some pathology of the brain stem, or the outflow of the CSF is undetermined. The most likely explanation considered by Dr Lister

was a blockage of CSF drainage, which caused the acute rise in intracranial pressure causing further obstruction to blood flow to her brain, which has resulted in brain death.

Regarding handover, in this case where Dr Lister saw Dr Askin, there was in effect a direct handover from PICU to the surgical team. It was intended Samantha was to go back to the ward. The summary sheet records information needed in the ward. Nurse Rituper physically came down to PICU for Samantha's handover

When Samantha was back on the ward and an issue arose regarding the need for an anti emetic medication, the ward Doctor, Dr Skeggs was called as there was no surgical team in attendance. Dr Skeggs had done his ward round earlier prior to Samantha's transfer to the ward and he was not aware of her arrival around 11am. He would have expected at some point to have been advised of her arrival on the ward. Dr Lister assumed Dr Skeggs would have been responsible for all of the children in the hospitals wards, including medical and surgical.

Dr Lister said the release of CSF under pressure from the drain would not have been from chronic hydrocephalus. He said there may have been dilated ventricles with hydrocephalus, but imaging of flow studies of CSF would be required to know if there was pressure or not. He was not clear on what the mechanism was but something occurred which resulted in raised intracranial pressure. He thought it was quite sudden because the compliance and capability of accommodating increased pressure can continue until a point where there is no more ability for a brain to cope with the increase in volume. Then a sudden rise in pressure can cause unconsciousness, and result in coning.

Mr Boddice put to Dr Lister that the final event of coning appeared to have occurred in Samantha's case, and Dr Lister agreed.[10]

Evidence of nurses

Cherilynn Barlow confirmed staffing arrangements were the same on Good Friday as any other Friday. She was second in charge to the team leader, Melanie Topping, on the Friday shift. She had patients allocated to her. She was not assigned to Samantha's care but became involved when Nurse Fiona Frater asked for advice regarding Samantha. Samantha was on hourly observations and her recording should have been entered hourly. Not all entries had been completed, eg, there was no entry at 4pm for sedation. Fiona Frater approached Nurse Barlow indicating a concern about Samantha's level of "rouseability." Ms Barlow then became aware the family were also concerned over this issue. She did not know Dr Skeggs had seen Samantha about 1pm - 1.30 when he reviewed her regarding low blood pressure and a fall in urine output.

At the time Nurse Barlow considered if a family expressed concern it would be a matter of judgment of the nurse of the degree of that concern whether or not this was recorded in the notes.

10 T4-18, L40-50

Nurse Barlow was unaware at the time Samantha had a Chiari malformation. She considered it an important issue and whether or not the Chiari was symptomatic or asymptomatic, particularly whether there was hydrocephalus. Signs of a chronic hydrocephalus becoming acute could include changes in level of consciousness, alertness and in orientation. They could be vague and subtle. Changes in blood pressure, heart rate and respiratory rate are often very late signs in children. As a hydrocephalus condition advanced it would be expected that heart rate would fall and blood pressure rise. It would be complicated by the effects of epidural pain relief. Trends of changes in condition over time can be an indicator of a problem. Intuitive assessment of a patient also plays a role.

Registered Nurse Jauncey-Cooke worked the night shift on both 5 and 6 April 2007. She was in the Team leader role co-ordinating the unit including patient movement and staff allocation. She also arranges retrieval of critically ill children from regional areas. She confirmed the roster was the same as for any other weekend from a nursing perspective.

She confirmed Nurse Barker was an agency nurse working on night shift. He received orientation from the team leader and clinical support from the nurse who "floats" as required. She agreed he was having difficulty with the electronic recording (as distinct from monitoring) equipment.

This witness indicated had she known Samantha had Chiari malformation she might have considered some symptoms carefully which might be signs of intracranial pressure rather than normal post operative effects. In particular she referred to hypotension, which is also a common occurrence in a post operative patient.

Nurse Jauncey-Cooke did not consider Samantha had a reduced level of consciousness on the first post operative night. She recalled her being awake at some time and speaking with her.

The nurse simply explained had they known of the existence of Chiari malformation they would have been mindful of it and considered the possibility of raised intracranial pressure in interpreting any symptoms.

Observations including rouseability, ability to obey commands and motor response were routinely conducted. As the nurse could recall Samantha responding to her with speech she therefore assessed her at that time as recording a total score of 15/15 on the Glasgow coma scale. She could not recall Samantha having laboured breathing.

At 4.30pm on Friday the observations recorded were still unremarkable, but there was concern expressed by both Nurse Frater and the family which prompted contact with Dr Raveenthiran who directed adjustment of the epidural pain relief.

Nurse Rituper recalled Samantha's grandmother raising the issue of Samantha's sleepiness, but the nurse considered she was rouseable. She could open her eyes on request and wiggle her toes. She thought she was a little more drowsy than an average child post surgery, but not sufficiently to raise concern. Her observations were within acceptable range. She said Samantha was awake when she vomited.

She recalled she did verbally hand over her shift to other nurses about her rouseability but considered she was quite sleepy but rouseable during her afternoon shift.

She handed over to Nurse Frater. Nurse Miles was directly caring for Samantha. Nurse Frater did not recall being told the family had raised concerns but during the course of the shift she became aware of their concerns increasing, and that Samantha was sleepy Nurse Frater said Samantha was still responding to her though, not verbally, but by nodding her head and opening her eyes. This was right up until her sudden arrest at about 6pm on the Friday afternoon.

The observation note records she was awake, but that was not the case when seen by Nurse Frater. Nurse Frater recalled seeing Samantha for the first time after her 3 o'clock start when she was sleeping. By about 4.30pm she approached Nurse Barlow as she was beginning to be concerned. The 4 o'clock sedation score was not completed by Nurse Miles who was not trained to enable her to do so. The pain management team was contacted, but the anaesthetic registrar was in theatre. An order was made to reduce the epidural level. By this time Nurse Frater was expecting Samantha to be more awake than she was. It was expected she would wake up more within approximately half an hour of the epidural being reduced. She still remained very sleepy but her observations were within range. The nurse also checked on her pupils which were normal at that time. Dr Skeggs was called and after his arrival, Samantha arrested and a code blue was called to resuscitate her.

The physiotherapist Lisa Coles

Ms Coles saw Samantha on the ward after her return from PICU. Her role was to monitor her chest, her circulation and then mobilise when able. She said children post scoliosis surgery, do not sit up until the physiotherapist is in attendance. Usually she would not see the child until they were in the ward. The timing of sitting up varies depending on many issues including pain management, blood pressure and vomiting issues. About 60-70% of the children on day 1 post scoliosis operation are able to sit up.

She was aware the family was quite focused on Samantha's sleepiness when she saw her around 11.30 am. She was not concerned at that time, as it was still common for children to have significant effects from pain relief. Samantha did not verbalise while the physiotherapist was present, but she did respond to commands. She repositioned Samantha's head by a couple of degrees to a slightly more upright position. She was aware she had been reviewed by the doctor who had ordered suctioning.

The physiotherapist was unaware of the Chiari malformation. It was an area of interest to her because her own child had a Chiari malformation. Her impression at the time was that Samantha was sleepy due to the two epidurals being administered for pain relief.

INDEPENDENT EXPERT OPINIONS

I have not referred to all of the expert evidence called before the inquest but include the following.

Professor Olaf Drummer

Dr Olaf Drummer reviewed the record of the amount of morphine administered to Samantha for pain relief. He then considered the toxicology results port mortem and statements from the pain relief and anaesthetic treating doctors. From a toxicology perspective Dr Drummer considered the morphine dosage as low. There were many variables to consider in determining an appropriate dose of morphine. The effects of morphine include depression of respiration and the method of administration also varies the impact of the drug. Being morphine "naïve", which Samantha was, also increases the impact. Dr Drummer interpreted the information and concluded that Samantha's ability to eliminate the drug was impaired as her condition deteriorated

Dr Jillann Farmer

Dr Farmer provided evidence in her role as Director of Safety Systems and Clinical Lead Improvement, Patient Safety and Quality Improvement Services for Qld Health. I hasten to point out immediately that she provided an assessment via a clinical tool which was not in use at the time of Samantha's death. The tool referred to is known as CEWT, the Children's Early Warning Tool to detect deterioration in a patient via a structured review of parameters of particular observations. The observations include respiratory rate, respiratory distress, oxygen saturations, temperature, heart rate, blood pressure capillary refill time and level of consciousness. If scores fall out of a prescribed range, a structured response of increasing urgency must be deployed to have the patient reviewed.

Dr Farmer applied technique to review Samantha's observations after surgery leading up to the time of her collapse. The review did not result in a situation requiring a greater response than what had occurred. In other words, this tool would not have assisted in identifying and predicting the serious decline to enable earlier intervention.

I note however the Mater Heath Service has indicated it is liaising with Queensland Health to implement this additional tool.

Dr Cameron Hastie

The specialist anaesthetist Dr Hastie considered it was noteworthy for an anaesthetist to keep in mind the patient had a Chiari malformation irrespective of whether or nor it was symptomatic. It may change the approach to the anaesthetic, particularly in the post operative phase where intensive care management would be considered more appropriate. He doubted it would prompt him to manage the patient's head position differently in the operation. He would have positioned a patient's head slightly up in both a scoliosis procedure and if he was aware a patient had a Chiari malformation. . It would certainly prompt inquiry to ensure the Chiari had been appropriately reviewed prior to surgery. Some questions of parents of a child might be asked to ensure there was nothing to indicate the Chiari was symptomatic.

Had it been known the chid had chronic hydrocephalus it would of course be information of importance to the anaesthetist who would manage anaesthetic manoeuvres of the patient to avoid possible increases in intracranial pressure.

Dr Hastie considered the anaesthetic drugs used for Samantha were appropriate in type and dosage to manage anaesthesia and pain relief. He considered the management of Samantha after her return to the ward and the subsequent review of analgesia was appropriate.

Dr Hastie considered the autopsy report of Dr Urankar and the associated literature and agreed with the discussed probable causes of death.

Dr Raymond Chaseling

Dr Raymond Chaseling assisted the inquest with independent expert medical review of the information available regarding Samantha's condition and management. He was expertly qualified as a specialist paediatric neurosurgeon working at the Westmead Hospital in Sydney.

He agreed the CT Scan showing 8 millimetre projection of the tonsils was within the definition of Chari type 1 malformation. He distinguished the more severe form of the abnormality which usually required shunts due to known hydrocephalus and more complex presentations.

He stated it is only if there is some concern that elective decompression is undertaken.

He agreed that Chiari malformation type 1 is not a contraindication for scoliosis surgery. This was in the context of the child not having any known hydrocephalus. He advocated a multi disciplinary approach, which is what is offered at the Mater Hospital. However, he suggested neurosurgical input in the pre-surgery review. He acknowledged the benefit of hindsight in offering his opinions to the inquest.

He considered had he been in the role to advise regarding the Chiari malformation and the prospect of scoliosis surgery, he would have included discussing and explaining the condition with the family. He accepted however that the condition had been referred to Dr Burke after it had been identified and Dr Burke assumed it had already been discussed with the family. He noted Dr Burke perceived his role was to assess suitability for scoliosis surgery.

It is noted Dr Chaseling advocated dissemination of information about Samantha's tragic death in the interests of broadening knowledge in the field and in the hope other deaths can be avoided.

Even if asymptomatic, when seeing a child with Chiari malformation he indicated he tended to review them with scanning to make sure a syrinx is not developing, which occurs in about 50% of cases.

Dr Chaseling indicated an MRI of the brain would be used to see whether there is any pre-existing hydrocephalus. He said this reluctantly in a sense because he was conscious of hindsight bias, particularly as he also works in the role of clinical risk manager for the Westmead Hospital. He could not see any reason not to do either a CT scan of the head or an MRI of the brain. He said as clinicians it is known that hydrocephalus is often associated with Chiari

malformations, particularly when the child also had a history of developmental delay or difficulty at school and macrocephaly (enlarged head).

In Dr Chaseling's experience and practice a child with a Chiari type 1 malformation would have an image of the whole neural active brain and full spinal cord. Likewise if a child came to him with an MRI scan of the brain showing Chiari type 1 he would also order an MRI of the spine. He considered this is current best practice.

It was suggested to him that Dr Burke considered an MRI but that in his opinion this would require an additional anaesthetic so that Samantha was sufficiently still during the procedure. He did not consider the additional risk was warranted. Dr Chaseling responded, if this was the thinking then a CT scan of the brain should be performed fairly quickly without an anaesthetic. Dr Chaseling concurred there is now an attempt to reduce exposure to CT scans due to radiation.

Dr Chaseling noted since Samantha's tragic death the Mater Hospital now routinely performs MRI of both the spine and brain prior to scoliosis surgery. Dr Chaseling agreed this was best practice.

It was noted Dr Burke conducted a fundoscopy but this did not reveal signs of raised intracranial pressure. However in Dr Chaseling's opinion he said raised pressure, seen as swelling of the optic disc is often not present even though pressure might be raised.

From his perspective as a neurosurgeon he considered a paediatric neurosurgical review of a child with Chiari type 1 malformation would be of assistance. It was pointed out the treating surgeon requested an opinion of a specialist neurologist because of their global view.

In Dr Chaseling's experience at Westmead he was used to a practice which included neurosurgical review of children with Chiari malformation. Often there were referrals from neurologists to the neurosurgeon for review also, at least for review of the radiology. He acknowledged there are different views on this. He raised some opinions which suggest that the Chiari malformation is a causative factor in the scoliosis.

As a neurosurgeon he considered he was better equipped to appreciate the practical implications of Chiari malformation and its complications of hydrocephalus.

He noted scoliosis had been documented in literature reports as the presenting identifier of a Chiari malformation, even in the absence of syrinx .The implication is that the Chiari malformation is causing the scoliosis. A consideration is then to be given whether to treat the Chiari malformation by decompression as a first management of the scoliosis condition. It is noted at this point that the orthopaedic surgeon Dr Askin, held a contrary view. He said there was no evidence to demonstrate that if a Chiari malformation is corrected it prevents development of scoliosis. [11]

11 T8-12, L30-53

However it was noted that in Samantha's case her scoliosis was quite severe and needed surgical treatment.

With respect to Samantha's cause of death, Dr Chaseling reviewed two CT scans of Samantha's brain. The first was prior to the introduction of the ventricular catheter to drain and the other taken after the procedure.

It was noted Dr Burke did not accept there was evidence of acute hydrocephalus on 6 April 2007. He referred to the report of the CT scan which said- "*The ventricles are markedly dilated but no transcendental spread of CSF is seen to suggest acute hydrocephalus*."

Dr Burke did not consider there was acute hydrocephalus in the absence of signs of coning on the post collapse CT.

One conclusion that had been drawn was Samantha died after chronic hydrocephalus with cerebral oedema, and raised intracranial pressure and probable early coning.

Dr Chaseling considered all of the information available. He concluded it was a situation of acute on chronic hydrocephalus. He based this on absence of transpendymal leakage of CSF into the periventricular region. He did not think this negated an acute dilation of the ventricular system. He noted that after the introduction of the ventricular catheter the post operative CT scan shows that the ventricles have markedly come down in size. In other words they wanted to be smaller after release of the pressure. He explained in chronic hydrocephalus, if it was just due to chronic hydrocephalus, the walls of the ventricles normally become very stiff and they basically don't collapse. Dr Chaseling considered this was evidence that there was an acute component which was reversible as demonstrated after the insertion of the drain in which the subsequent scan showed a dramatically decreased size of the ventricles.

As Dr Chaseling expressed it- "*We deal with hydrocephalus all the time. Just because you haven't got pre ventricular changes of transependymal seepage of CSF, doesn't mean that you haven't got acute hydrocephalus. We see kids coming in with blocked shunts and we see ventricles that are markedly dilated compared to what they're normally like, and not - in fact, not that many of them actually have transependymal changes. I kind of don't take much notice of that*."[12]

He also noted that by definition Samantha had really had chronic foramenal herniation because the cerebellar tonsils are herniated through the foramen magnum.

Also, on reviewing the scan (after her collapse), Dr Chaseling said it was extremely worrying as there was complete obliteration of all the cerebrospinal fluid spaces underneath the brain surfaces and over the surface of the brain.

[12] Ts-12 30-50

This indicates there is no space within the skull, and presumably this is the basis of ventricular enlargement and maybe brain swelling too. The foramen magnum would be crowded because of the known Chiari malformation with less room to move

He considered if the scan was seen in a person who was drowsy they would be rushed to theatre, because of the risk of sudden death.

Dr Chaseling also noted the pathologist's conclusion that there was acute hydrocephalus after considering the clinical information about the release under pressure of the CSF from the drain.

Dr Chaseling also reviewed the neurosurgical report from Dr Tannenberg which he considered showed evidence of long term hydrocephalus. This was evidenced by cerebral swelling. Also the ventricles were not as big as when scanned prior to the insertion of the drain. The degree of hydrocephalus evident on the scan prior to the drain insertion was clear to a marked degree, "very dramatic" in Dr Chaseling's words.

He also agreed with the observation of the Neuropathologist Dr Tannenberg who noted ***"bats wing ventricular development that this was a sign of chronic hydrocephalus."***

At post mortem there was no haemorrhage or infarction of the cerebellar tonsil, so that there was no real evidence that there had been herniating of the brain through the foramen magnum. (Dr Burke likewise remarked on this.)

However Dr Chaseling noted post mortem inspection often does not show damage to the cerebellar tonsils, and does not necessarily reveal evidence of herniation in deaths from sudden acute hydrocephalus.[13]

At post mortem examination the cerebral aqueduct was open. Dr Chaseling wondered whether this was illogically blocked, and after insertion of the drain, no longer deformed by a grossly dilated third ventricle and was then patent. In other words, there can be functional obstruction of the cerebral aqueduct. He wondered whether this was a possible trigger to precipitate the hydrocephalus.

On the issue of cause of death, Dr Chaseling noted the pathologist concluded raised intracranial pressure due to acute on chronic hydrocephalus (having regard to the comments of the second pathologist). The underlying contributing causes were noted to be surgically treated scoliosis. Other contributing factors were noted as Chiari malformation

In broad terms Dr Chaseling agreed. He noted there are reports of sudden death in patients with Chiari malformation without trauma. Children can die from acute hydrocephalus, and from acute on chronic hydrocephalus. There is also evidence of children with Chiari 1 malformation having unusual respiratory patterns, not only in sleep but after surgery.

13 T5-14, L 35-40

He agreed with most commentators it was impossible to say exactly what the precise cause of death was. He offered an opinion that there had been an acute obstruction on the basis of chronic hydrocephalus.

In hindsight, had an MRI of the brain been performed pre surgery and the condition of chronic hydrocephalus been identified, there may then have been further consideration of Samantha's overall picture, which included some learning difficulty and a head of large size. This may have led to consideration of whether further intervention or measurement of degree of hydrocephalus was indicated. The involvement of an ophthalmologist and neurosurgical review would be relevant had hydrocephalus been diagnosed. However Dr Burke's clinical opinion after assessment did not lead him to a conclusion of hydrocephalus although he had noted the possible association of Chiari malformation, hydrocephalus, a large head size and some learning difficulties.

From the point of view of his anaesthetic colleagues, Dr Chaseling noted there was consensus they would like to know if a patient has Chiari type 1 malformation. They would want to know it had been neurologically or neurosurgically assessed but otherwise would probably not alter their techniques.

Autopsy

Autopsy examination was undertaken by the pathologist Dr Kathryn Urankar and informed by the specialist neuropathologist's report of Dr Tannenberg. It was noted that Chiari malformation is usually present from birth and that hydrocephalus can develop over time.

The neuropathologist Dr Tannenberg examined the brain post mortem at a particular time, contrasted with information subsequently available to the pathologist and reviewing pathologist who were able to incorporate clinical information of observations of the patient during life and in the course of treatment. **Thus Dr Tannenberg did not see some signs of raised intracranial pressure, as this condition had been treated with the insertion of an external ventricular drain. However, Dr Urankar noted Dr Tannenberg's recording of the ventricles being moderately dilated with a bat's wing appearance which Dr Urankar explained is evidence of typical chronic hydrocephalus. She pointed out Dr Tannenberg's observations recorded "*the dilatation extends into the third ventricle*",[14] meaning another space in the brain where the fluid had built up and flowed back into. The third ventricle is dilated and the lining of the floor here is attenuated (stretched, thinned.) These changes take time to occur but the pathologist could not say how long. Only imaging performed at different times would record the changes.**

Dr Urankar's report incorporated more information including the clinical observations of the patient during life as well as the findings at autopsy. This resulted in the conclusion of raised intracranial pressure. Dr Urankar acknowledged consideration of the clinician's information of the insertion of

[14] T3-5,L 26-31

the external ventricular drain which released a large amount of fluid under pressure.

Dr Urankar also presented research from the literature which noted when there is an acute hydrocephalus developing; the typical signs of raised intracranial pressure are not seen. This was consistent with the findings of Dr Tannenberg who noted he did not observe uncal herniation transtentorial grooving. It was opined this may be due to the slightly different mechanism of raised intracranial pressure.

Dr Urankar also explained and discussed the opinion of the independent anaesthetist, Dr Keely who thought the mechanism of death was due to diffuse ischaemic brain injuries.

Dr Urankar stated the raised intracranial blood pressure decreases blood flow to the brain leading to hypoxic brain injury, and ultimately, death. In Dr Urankar's opinion something triggered the development of acute hydrocephalus from the chronic condition.

She discussed the low blood pressure and elevated carbon dioxide may have triggered cerebro vasodilatation leading to increased cerebral blood volume, blood flow and ultimately changes in intracranial pressure. This in turn led to brain damage due to lack of oxygen and brain swelling.

Dr Urankar considered head positioning would not have any relevance to blocking of drainage of cerebro spinal fluid unless it was over a prolonged time. There is no evidence to indicate the physiotherapist positioning of Samantha's head during suctioning could have caused any adverse effect.

Her review of the literature showed a group of deaths associated with the condition of a Chiari malformation with hydrocephalus. When some other factor is then added, this triggers the balance and sudden death can occur.

Dr Urankar confirmed there are other literature reports documenting sudden unexpected deaths of people with Chiari malformation where there is no other known precipitating event. The cause of death in such cases remains unknown. There is a hypothesis of some impairment of respiratory function which is controlled by the area of the brain stem affected by Chiari malformation. Dr Urankar said –

"*They can't prove anything, but the hypothesis is that because of the malformation, there's some associated either compression of the respiratory centres, some reflex pressure induced abnormalities on all the cardio-respiratory centres in that area. It's a very vital area of the brain stem, and the hypothesis is there's some abnormality associated with the deformation of those tonsils*."

Dr Urankar agreed it seemed very difficult or perhaps impossible to predict these deaths.[15]

Dr Urankar concluded the Chiari malformation and scoliosis with recent corrective surgery were underlying contributory factors leading to Samantha's death. The surgery must be considered as a factor contributing to the development of acute hydrocephalus and death. Dr Urankar considered the possibility of postural changes might also be relevant.

I accept Dr Urankar's opinion that the Chiari malformation and the surgical correction of the scoliosis should be recorded as being part of the underlying cause of sequence of events leading to Samantha's death.

The autopsy confirmed there was no sign of surgical complication. The autopsy also confirmed it was a Chiari malformation type I, not involving the more serious complication of a syrinx.

I accept Dr Urankar's interpretations and conclusions which incorporate the findings from Dr Tannenberg, the findings at autopsy, the clinician's observations and records and the literature review of other sudden unexpected deaths where Chiari malformation was identified. I accept the interpretation of Dr Tannenberg's findings and all the other information referred to by Dr Urankar in concluding Samantha had underlying chronic hydrocephalus, superimposed with acute hydrocephalus.

In particular I accept there was no surgical error which caused Samantha's death but that surgery was part of the sequence of events necessarily leading to the circumstances in which chronic underlying hydrocephalus was triggered into an acute raised intracranial pressure developing.

In the course of the pathologist's evidence it was noted that it is possible to have a chronic condition of hydrocephalus throughout one's life. It is only if some trigger precipitates the sudden onset of an acute elevation in intracranial pressure does it become a life threatening condition. It is also possible to have Chiari I type malformation without having hydrocephalus at all.

Dr Keely advanced a hypothesis. Possible trigger events can include the effects of epidural administration of narcotics. Respiration will necessarily be decreased as respiration slows and the level of carbon dioxide can rise. This can lead to cerebrohypoxia. This is one sequence of events which can destabilise the balance and trigger the increase of a chronic situation of hydrocephalus into an acute condition.

The reviewing pathologist, Dr Robertson from the Victorian Institute of Forensic Medicine, noted deteriorating respiratory and neurological status approximately 30 hours after surgery over a 4-5 hour period. This occurred in an essentially "well" patient before the procedure.

[15] T3-9, L 47-54.

Dr Robertson also concurred there was anatomical evidence of chronic hydrocephalus recorded in Dr Tannenberg's report where he noted ventricle being moderately dilated with bat's wing appearance.

She could not say for what length of time the condition had existed but said it obviously had not happened in the last 24 hours.

Underlying chronic hydrocephalus pre-disposes to the development of acute hydrocephalus. Dr Robertson noted some literature reports suggested an acute positional change can be a factor in the development of acute hydrocephalus, particularly in the presence of Chiari malformation.

However, she considered the totality of all the circumstances including the procedure itself, the length of the operation while the patient was in an unusual position and then the post-operative course, were significant factors. An acute positional change could not be ruled out as a relevant factor.

Her conclusion regarding information about the pain relief was more emphatic. She stated the concentration of narcotics was not a major factor leading to Samantha's death. The surgery was not causative of acute hydrocephalus, but it was related in time and considered to be a factor, especially in the presence of the Chiari malformation which predisposes a person to acute hydrocephalus.

Conclusions regarding cause of death

Summarising the conclusions of the autopsy report of Dr Urankar, which incorporated the neuropathology results of Dr Tannenberg , and having regard to the independent review by the pathologist Dr Robertson, it is clear that Samantha died due to raised intracranial pressure. This was due to acute hydrocephalus which had developed as an exacerbation of chronic hydrocephalus, often seen in association with the Chiari type I malformation which Samantha had. The development of the acute hydrocephalus occurred after the essential, but long surgical procedure to correct Samantha's severe scoliosis. The surgery could not be said to directly cause the rise in intracranial pressure, but it was a factor in the sequence of events which concluded with a well child with a chronic neurological condition developing life threatening acute hydrocephalus and raised intracranial pressure.

In accepting these conclusions I have had regard to the dissenting opinion of Dr Burke who did not accept there was acute hydrocephalus and did not consider this was the underlying cause of raised intracranial pressure causing death. The weight of medical opinion including the three pathologists as well as independent reviewing experts is in favour of the condition of acute hydrocephalus being present. There remains uncertainty as to the trigger event or sequence of factors which precipitated the chronic condition of hydrocephalus changing to an acute condition with raised intracranial pressure. However the consensus focuses on the physical limitation of space in a critical area of the brain due to the Chiari malformation, which restricts the brain's capacity to compensate for increase in pressure and or volume and the drainage of CSF.

Hospital review of circumstances of Samantha's death and responses

Samantha's death was unexpected and was reported as required as a sentinel event on 7 April 2007. Dr Geoffrey Hirst, who is the Director of the Surgical Services at Mater Health Services, holds the role of Senior Risk Management Consultant, clinical Safety and Quality Unit (CSQU) Mater Health Services. He submitted a document summarising the hospital's review and response to Samantha's death.[16] (footnote Exhibit B38)

Importantly I note there was a family meeting with the Spence family on the 15 May 2007. I consider these meetings are of enormous benefit to the family in gaining an understanding of what occurred and providing an opportunity to speak with significant members of the treating team. It can facilitate the process of grieving once a family feels they have been heard and they can ask questions and have them answered.

As a result of the clinical review that was undertaken, a number of recommendations were made and have been implemented.

1. As discussed in Dr Labrom's evidence, a decision was reached that every child undergoing scoliosis surgery will have an MRI of both the spine and the brain. I note the hospital considers that although this may not be clinically required for every child, it has been decided to elevate the pre surgery scanning to a higher level. I also note the hospital will review this protocol over time. This step has been added to the scoliosis care path and has been implemented from 6 November 2009.

2. Where there is an identified need for spinal cord monitoring with proposed scoliosis correction, all children should be reviewed by a neurologist shortly before surgery. This was also implemented from 6 November 2009. All cases are medically assessed to consider the need for neurological review prior to admission for surgery.

3. The handover procedure for both medical and nursing staff regarding pain management status as the child is moved from PICU to the ward has been reviewed. A detailed checklist for handover from PICU to ward staff has been devised and included in the spinal care paths. Importantly, pre-agreed milestones are stipulated and if there is variance, or clinical concern, there is a pre-agreed identified person to contact for advice/review. The regime of a contact person for issues relating to concern over pain management has been extended through days 1 and 2 post return to the ward. These changes have been implemented and are being monitored and audited by the hospital. In particular, PICU staff have received training emphasizing that a patient cannot be transferred to the ward unless the handover process is fully completed, including all documentation of PICU to ward handover checklist. The improved handover checklist forms part of the roll out of broader review of handover procedures within Mater Health Services.

[16] Exhibit B38

4. A full time Monday to Saturday paediatric pain management nurse has commenced work conducting a daily ward with the anaesthetic registrar (excepting Wednesday and Sunday.) The nurse assists in providing in-service education to staff regarding epidurals and pain management.

5. A review of the expected observations in post scoliosis surgery patients has been undertaken to ensure they are appropriate to alert staff to any significant deterioration in consciousness. In particular there is a prompt in the care-path to document concerns expressed by parents or carer and to document the response to those concerns, including documentation in the handover checklist. This applies for handovers from- PICU to ward, emergency to ward, and recovery (PICU) to ward. These improvements have been incorporated into the broader roll out throughout Mater Health Services of the clinical communication tool for clinical handover, (SHARED).[17] Specific nurse education has been focused on escalation steps to be taken when they have concern or carers/parents express strong concern regarding their child's condition.

6. As part of the training, nurse and junior doctors are encouraged to call for help and the "Speak up for Safety" workshop program promotes this. The workshops are conducted by Dr Stephen Walker, Director of Clinical Training. It was noted the CEO wrote to all staff in late 2009 encouraging and supporting this initiative.

7. The Spence family felt some concern about the apparent lack of familiarity shown by an agency nurse with monitoring equipment and computer skills. Although the hospital did not consider this was established by the clinical review process, new Agency Nurse Unit Orientation Checklist forms have been introduced.

8. The consent form for scoliosis surgery has been reviewed to ensure comprehensive information to enable a documented procedure for fully informed consent.

CORONIAL FINDINGS section 45 Coroner's Act 2003.

In accordance with Section 45 (2) I find;

(a) the identity of the deceased person was Samantha Rose Spence, who was born on the 29 April 1994.

(b) Samantha Rose Spence died in hospital two days after orthopaedic surgery performed on 5th April 2007. The surgery was essential to correct severe scoliosis of her spine. There was no surgical complication. Samantha had a pre-existing Chiari type 1 malformation which had been identified and neurologically assessed as asymptomatic and not requiring intervention prior to the scoliosis surgery. Samantha's condition remained within expected parameters post surgery until the afternoon of 6th April when she

[17] "SHARED" Situation, History, Assessment, Risks, Escalation/ Expectation, and Documentation Exhibit B38, Appendix 1

became increasingly drowsy and harder to rouse. She suddenly went into respiratory collapse at about 6.00pm that evening. A CT scan of her brain revealed grossly dilated ventricles consistent with hydrocephalus. An extraventricular drain was inserted and cerebrospinal fluid was released under pressure. Samantha remained unresponsive and a repeat CT scan at around 8.00am on 7th April 2007 confirmed cerebral oedema.

(c) Samantha died on 7th April 2007

(d) The place of death was Mater Children's' Hospital, Brisbane, Queensland

(e) Samantha Spence died due to raised intracranial pressure due to acute on chronic hydrocephalus in the context of surgically treated scoliosis. A Chiari malformation was a significant contributing condition.

CORONIAL COMMENTS, section 46.

Coronial comments pursuant to Section 46 of the Coroner's Act can be made where an inquest relates to public health or safety, the administration of justice or ways to prevent deaths happening in similar circumstances in the future.

I have recorded the responses of the Mater Health Services who have carefully reviewed the circumstances of Samantha's death and implemented improvements. These improvements are to be commended, and I endorse and adopt these recommendations, which it is hoped will enhance the safety of patients. Most notably there has been a decision to include both spinal and brain MRI scanning of children who are to undergo scoliosis surgery. While there was some indication this may not be warranted and is considered an added precaution, I note there was also persuasive expert evidence that suggests this is a wise course and now considered best practice. I note clinical examination including inquiring into the history of a patient may not reveal the presence of chronic hydrocephalus. Indeed even an examination of the fundus by ophthalmoscope may not show signs of raised intracranial pressure. It was noted that signs of swelling of the optic disc may not be present even though intracranial pressure may be raised. [18]

The evidence is clear that a small number of sudden unexpected deaths occur in the context of Chiari malformation. What is much less clear is the underlying cause. Some of these deaths occur without any known cause or event. Others have occurred where a range of trigger events have later been identified. These trigger events may include- surgery, trauma, raised intracranial pressure, blockage of cerebro spinal fluid outflow, suspected interference with respiratory function possibly associated with hypercarbia and pain relief, positional changes and compression on the brain stem.

I therefore commend the MRI scan of both the brain and the spinal column noting that expert radiological review may be able to add additional critical information to identify underlying hydrocephalus associated with Chiari malformation. This may then require further assessment prior to surgery, including consideration of neurosurgical opinion.

[18] See Dr Chaseling's evidence

The Mater Health Services has completed a detailed review and response. I recommend that the changes and improvements they have implemented are circulated to both the private and public health sectors within Queensland. It is hoped this will assist in improving patient safety.

I also note that in this case there was a referral from the general practitioner to the orthopaedic surgeon Dr Licina, who reviewed Samantha's x-rays and immediately referred her on to the specialist scoliosis clinic at the Mater Children's Hospital. In due course Samantha was incidentally diagnosed with a Chiari type 1 malformation. However, there was no formal report from the scoliosis clinic back to the treating general practitioner advising him of the diagnosis of Chiari malformation.

I note the orthopaedic surgeon Dr Askin said, "*the general practitioner should have a letter sent back to them after the patient is reviewed in the clinic. That would be at least what we would expect to happen*."

It is of course important to inform the general practitioner of any diagnosis and proposed treatment. Further relevant information may arise which the treating general practitioner may then be prompted to submit to the specialist treating team.

I recommend a review of processes to ensure the primary treating general practitioner is kept informed of the ongoing treatment of the patient.

I noted Dr Chaseling's recommendation that a formal paper be written to disseminate the learning and reflections arising from Samantha Spence's death. I will contact the relevant specialist colleges to invite their consideration of this. The court can facilitate access to the various expert reports which have greatly assisted the understanding in this inquest.

In closing this inquest I acknowledge the assistance provided by all counsel and instructing solicitors, and the contribution from the treating team as well as independent expert witnesses. Samantha's death was an unexpected tragedy which shocked and saddened her family and health carers. Her loss is mourned and it is hoped this inquest has assisted in clarifying the circumstances of her death. In particular it is to be hoped the review and changes implemented may reduce the risk of other deaths occurring in similar circumstances.

Chris Clements
Brisbane
29 October 2010

Appendix 1

Summary of Evidence from Samantha's family

Samantha's father, Shawn Robert Spence gave evidence. He and his wife Karen had three children. He confirmed Samantha was born on 29 April 1994. She attended the Claremont Special School at Silkstone and was in the intermediate class.

Mr Spence recalled Samantha was detected with developmental delay at any early stage in areas of motor skills, speech and crawling. She was seen by a paediatrician, Dr McGregor when she was two and a half years old. Samantha was assessed and it was concluded she had mild to moderate global retardation. She commenced formal schooling at the Special Education Unit at Ipswich Central Primary School. From the age of six she attended Claremont Special School.

Mr Spence acknowledged his mother; Sandra Spence was very close to Samantha and had a special supportive role throughout her life. Samantha spent most weekends with her grandmother and grandfather.

In 2005 Mr Spence remembers they took Samantha for a medical reassessment with paediatrician Dr Miller at Ipswich. He referred her to a clinical psychologist Dr Therese McHugh who reviewed Samantha in June 2006. Although it was considered Samantha was functioning in the intellectually impaired range the psychologist assessed her as demonstrating well developed literacy skills and verbal reasoning. Her greatest deficit was in visually presented information. It was considered her placement within the special school was appropriate.

At the end of the assessment it was considered that Samantha was not suffering from global retardation. She was diagnosed with a form of Attention Deficit Hyperactive Disorder. However Samantha was not hyperactive but rather withdrawn and inattentive. She had a short attention span and she was generally slow to learn.

Dr Miller prescribed dexamphetamine which was considered to have achieved a positive stimulus for Samantha. Her father thought she was more active with other children and more expressive. He thought she was a little quicker in her thinking.

It was in March or April 2006 when the family became concerned about Samantha's posture. She was leaning to the left and her left shoulder was dropped lower then the right. She complained of back pain.

Her general practitioner, Dr Simon Lawnton arranged x-rays which established the diagnosis of scoliosis. The first orthopaedic surgeon who saw Samantha's x-rays was Dr Paul Licina. He immediately referred Samantha to the Mater Children's Scoliosis Clinic after reviewing the imaging without requiring seeing Samantha. Dr Licina considered Samantha was best treated by the specialist holistic clinic.

In May 2006 her condition was described in radiology reports as severe scoliosis deformity, convex to the right in the thoracic region and convex to the left in the lumbar region. Orthopaedic review was recommended.

Neither Dr Licina nor Dr Lawnton received reports back from the treating team at the Mater Children's Clinic. The difficulty appears to be the referral on from one doctor to the next which broke the normal chain of communication back to the initial referring doctor.

Mr Spence recalled Samantha was seen by Dr Labrom. The family was advised Samantha definitely required surgery to correct the spinal curvature. Mr Spence said; "*It was explained to us that two rods would be placed either side of her spine, and that that would straighten her spine up, and there would be possibly some fusion of certain vertebrae*."[19]

He could recall asking how soon Samantha would be up and walking, and he was told the next day. He could not identify which doctor but recalled it was one of the first two doctors they visited.

He recalled in August or September 2006 Samantha had an MRI scan of her spine in preparation for the operation. A malformation was detected which Mr Spence recalled was in her upper spine. He understood it to be a narrowing of her spinal chord at the top of her spine. Because the abnormality was detected Samantha then saw a neurologist at the Mater Children's Scoliosis Unit in about October or November 2006. Mr Spence recalled the neurologist, Dr Burke, who reviewed the MRI findings, indicated the malformation would not cause a problem and the surgery could proceed.

Mr Spence's recollection of Dr Burke's explanation of the malformation was as follows-
"*The specialist who reviewed the results of the image…explained it off as being a thinning of the spinal chord, up the top*."[20] Mr Spence did not recall the word malformation being used, or the use of the words Arnold - Chiari.

Mr Spence said;
"*The concern being at the time was that they had to do the MRI to make sure that the chord was not too thin. That during the surgery that obviously they wouldn't hurt it or damage it and that in his opinion, that it wasn't too bad. That they would monitor Samantha's chord during the surgery anyway, just to make sure that nothing was going the wrong way. That he did some checks on her motor skills and so forth, and seemed to be quite happy. He did a background check on her, trying to find out some history on Samantha's health and intellectual problems.*"[21]

Mr Spence recalled Dr Burke using the word "herniating" when describing the concern about the thinning of the spine (in Mr Spence's words.) Mr Spence did not understand the term herniating other than – "*just a tear, and that there would be damage to the spinal cord, and it was a thinning of the spinal cord*." [22]

19 T2-6, L 41-44
20 T2-7, L 7-10
21 T2-7 L17-26
22 T2-18, L 52-53

Mr Spence recalled that Dr Burke observed her walking, and he recalled Dr Burke testing her reflexes with the hammer test on her knees, ankles and muscles. He got her to do some standing up, balancing and walking.

Mr Spence also indicated they told Dr Burke about a number of hospital admissions and that she had grommets and had hearing aids at one stage. He recalled they were with Dr Burke for a good hour. He could not recall whether or not they mentioned concerns they had raised with the paediatrician Dr Miller about Samantha's gait and that she would sometimes have problems with balance.

Mr Spence said there was no mention by Dr Burke of the name Arnold Chiari malformation in the consultation. The first time that name was used to the family was after Samantha had arrested and they were told Samantha was likely to die. This was on the day she died, the 7th April 2007.

When prompted at the inquest, Mr Spence did recall seeing Dr Hay with Samantha, prior to the referral to Dr Burke. It was Dr Hay who explained the need for an MRI. Mr Spence recalled the explanation as "*There's thinning of the spine there, and I need you to see the specialist in regards to that little issue there*." This was to see whether the scoliosis surgery could go ahead. Mr Spence recalled Dr Hay showing him the scan picture from the MRI. He could not recall a drawn diagram.

Mr Spence recalled Dr Burke did not seem concerned about Samantha undergoing the surgery, and that the surgery could proceed. He explained her spine would be monitored during the surgery to make sure there was no damage.

Samantha was seen in the scoliosis clinic in March 2007, about 1 month prior to the surgery. He recalled a number of appointments at the end of 2006 were cancelled by the clinic and the surgery was put back.

Samantha's condition prior to hospital admission

Mr Spence recalled Samantha had a headache on a swimming day in the lead up period before the operation. It may have been a swimming carnival, when she had been swimming all day and out in the sun. She also had a bit of a sinus problem that day. Mr Spence's mother took Samantha to the doctor that afternoon. They were advised by the general practitioner Dr Lawnton it was probably dehydration. Samantha had a tendency not to drink water. She was prescribed some antibiotics for her sinus, rest and plenty of water. There was a bit of a reaction to the antibiotics and the medication was stopped on the advice of the doctor. She recovered.

Mr Spence thinks she had two headaches in the 2-3 weeks prior to admission, but he considered them relatively minor, lasting a couple of hours, maybe a day at the most. His mother also considered the headaches prior to admission were not concerning. At the pre screening before the operation on the 4 April there were no recent health issues raised.

Paediatric Intensive Care Unit

Mr Spence recalled Samantha starting to "shudder "in her sleep, which they reported to Nurse Dent on at least three occasions. The nurse placed blankets on Samantha as she was shivering a lot as though she was extremely cold. Her hands were cool.

The nurse also checked her chest and side with a stethoscope. Mr Spence said he was quite scared when he heard Samantha breathing very deeply-"a very laboured breath, - (he) never ever heard anyone breathe like that before."[23]

The nurse explained her blood pressure was a little low and an extra saline drip was given at about 4.30pm. A second check with the stethoscope was performed by the nurse at this time. He indicated he thought her chest had cleared.

After a change in shift, the family recalled two new sisters commenced work. They recalled them as Jan and Jackie and a casual male agency nurse called Tim. They observed the male nurse (Barker) appeared to have little experience in reading the computerised monitors.

Mr Spence raised his concerns with one of the orthopaedic surgeons, Dr Askin. His fears were allayed with an explanation about the effects of anaesthetic and that Samantha would have less compression on her lungs and it would take her lungs a little while to re-learn how to breathe properly again.

On his return the next day, his mother told him Samantha had woken up briefly, and said she had a sore throat. She was given panadol and fell back to sleep. Nurse Barker swabbed her mouth. She vomited twice overnight during her sleep while her grandmother was present. This occurred at about 9.30 and 10.30 on Thursday evening.

The nursing sister Jacqui (Jauncey-Cooke) reassured her this was common after an anaesthetic. Medication was added to her drip to reduce the vomiting.

Her temperature was gradually rising and about 9.30pm after vomiting for the third time Samantha woke up and said she felt hot. She also said she had a numb left leg. Nurse Tim checked her and was reassured he could feel Samantha obeying his direction to press against his hands with her feet. She was quite groggy and her breathing was still laboured.

Nursing staff expected to transfer Samantha to the normal ward later that Good Friday morning. Mr Spence was still concerned about her low blood pressure, and laboured breathing. Her temperature had returned to normal.

At about 8.00am Mr Spence was told by Nurse Helen (Murphy) to expect Samantha to be transferred about 11am from the PICU to the ward. She reassured him about his concerns over her breathing and low blood pressure.

It was around this time that Dr Askin visited and checked all of Samantha's monitors. He spoke with Mr Spence and told him the operation had gone extremely well and had successfully straightened her back. Mr Spence expressed his concerns about Samantha's breathing. Dr Askin explained Samantha's back was straighter so there was less pressure on her lungs. Her lungs would take a while to adjust to there being less pressure.

23 T2-11, L53-55

Mr Spence recalled Samantha had undergone a lung capacity test on 4 April. They were told her lung capacity was reduced and it could take 12 months to normalise after the operation. Mr Spence accepted the explanation from Dr Askin.

Dr Labrom also visited early on saturday morning while Mr. Spence was present and gave a similar report of the operation and assurances.

Samantha woke up briefly while Mr Spence was with her. He recalled there was a very short conversation during which Samantha asked if the operation was over and whether she could go home. Mr Spence reassured her it was over but she would have to get better before she could go home. He asked her if she was in any pain, to which she said, "No." Mr Spence talked with her about getting her a book before she went back to sleep. Mr Spence said she was very groggy during this conversation and there were long pauses during the conversation.

About 10.00am on Good Friday Samantha's paternal grandfather visited. Samantha remained very groggy and slow.

Transfer to ward

From 10.00am the process of moving Samantha to the ward started. Her grandparents went ahead to the ward and her father accompanied Samantha. She asked her father about the whereabouts of her grandparents, but immediately dozed off again.

She was settled into the new ward. Her uncle and aunt visited and also remarked about her grogginess and noticeable breathing. Mr Spence again raised this with staff, this time with Nurse Belinda, who reassured him it was a normal reaction after the procedure.

Mr Spence and his mother remained with Samantha during that day. They thought she seemed to be falling into a deeper sleep as the day progressed [24]and her breathing was laboured. She was checked hourly by the nurses and Mr Spence pointed out on three occasions that the blood pressure monitor indicated her blood pressure was fluctuating between normal and low. Mr Spence recalled a visit by a doctor named Kris (Skeggs) who also reassured the family all was well.

At about 3.30pm in the afternoon of Good Friday, Samantha vomited what appeared to Mr Spence to be blood. She remained asleep throughout this. Mr Spence called Nurse Belinda (Rituper) who advised it was not blood, but old vomit.

At 4.00pm the physiotherapist, Lisa (Cole) arrived and Mr Spence and his mother expressed their concern about Samantha's breathing. The physiotherapist said the noisy breathing may be due to some vomitus in her airways. She suctioned Samantha and she reacted to this procedure making it difficult. Her jaw was clenched tight. Some mucus was cleared. The physiotherapist then re-positioned her head on the pillow making her a little more inclined upwards to assist her breathing.

24 TT2-14, L 1-20

About this time Mr Spence and his mother were becoming quite anxious and again raised their concerns with nursing staff. Nurse Belinda called in a member of the pain management team.

Mr Spence expressed his concern in the inquest as follows-

"*By that stage [at about 4.00pm on Good Friday] we were in a panic, blind panic. We knew there was something definitely wrong by this stage. Recollecting back onto what Dr Labrom had told us, that she would be up and walking the next day, well, the next day had gone almost past, and she still wasn't walking, still wasn't conscious. We were getting very anxious because we just didn't seem, -the concern just wasn't there, and we were being sort of brushed off, to a certain extent, as if, "What do you know?"* [25]

It was explained that the vomiting was not a problem. Mr Spence raised his concern over Samantha's sleepiness and laboured breathing. This was met with an explanation stating this was normal and due to two drips, one with morphine and one with local anaesthetic which would continue until morning.

At 4.45pm another nurse (Fiona Frater) checked Samantha. Mr Spence again raised the issue of drowsiness and her breathing. This nurse checked her vital signs and then sought assistance from a more senior nurse, Cherilynn Barlow. An attempt was made to contact the pain management doctor, but that doctor was in surgery. The doctor rang back and directed the morphine drip to be turned down. Mr Spence recalled the nurse removed heart monitor stickers from Samantha's chest. Samantha did not react to this. This prompted the nurse to check her again and to call for a medical review.

Dr Kris Skeggs instructed the nurse to turn the morphine pump off and to check Samantha for any response. However the doctor still reassured Mr Spence and his mother there was nothing wrong.

Dr Skeggs returned about half an hour later around 6.00pm to review Samantha. Mr Spence overheard him say "I think we've narced her"- which Mr Spence understood to be excessive narcotics. The nurse left and returned with a trolley.

It was at this time that the doctor himself appeared concerned and somewhat flustered. He called for assistance from another nurse. Mr Spence saw the oxygen percentage drop from 96% to 30% in a matter of seconds. The heart rate monitor dropped from 120 beats to 50 beats per minute. Mr Spence was calling the numbers out to the doctor as he observed them and the doctor was responding, saying-"what is it now?"

There was then the sudden arrival of many staff to assist Samantha and Mr Spence and his mother were ushered out. A code Blue response had been initiated.

25 T2-16, L 12-21

Mr Spence and his mother were supported by two nurses during efforts to resuscitate Samantha. They were told she had been given a drug to counteract the morphine and she was taken back to PICU.

Return to Paediatric Intensive Care Unit

By about 7.00pm Samantha was back into PICU and the family waited for news. They were told Samantha was going to have a CT scan as she had not responded to the anti- morphine drug, suggesting this was not the problem.

After the scan, the head of PICU, Dr Lister spoke with the family. He explained the scan revealed some brain damage and some fluid on the brain. Samantha had severe hydrocephalus. Mr Spence indicated there were no known previous problems. Mr Spence recalled Dr Lister expressing the view some of the brain damage was pre-existing. Samantha needed urgent operative intervention to drill a small hole to remove excess fluid. Because of her youth medical staff expected she would make a good recovery.

The surgery was performed at about 8.30pm. The neurosurgical registrar Dr Pang explained to the family the procedure had been successful in draining fluid and he hoped she would recover over the next 24 hours.

On Saturday morning Mr Spence returned to the hospital about 6.30am. Dr Lister spoke with Mr Spence and informed him Samantha's prospects were very poor. He informed Mr Spence Samantha had suffered irreparable brain damage and she was unlikely to survive the day. Testing was performed which confirmed there was no brain activity and life support was terminated. Samantha died that day, on 7 April 2007.

Grandmother's evidence

Sandra Spence also gave evidence at the inquest. She is Samantha's paternal grandmother. She and her husband were very close to Samantha throughout her life and gave enormous time, support and love to her. Samantha spent weekends with her grandparents as well as school holidays. She provided a detailed statement and gave evidence at the inquest. Her evidence was consistent with Mr Spence and included additional detail in her statement.

Mrs Spence attended medical appointments with Samantha and her father leading up to the surgery. She was very much aware of the increasing curvature of Samantha's spine between June 2006 and March 2007. She knew Samantha was experiencing pain and was increasingly restricted in her ability to stand and walk.

Mrs Spence's recollection of the explanation of the MRI findings was of a narrowing of the spinal cord. She thought it was Dr Otto who explained this and that the neurologist had cleared Samantha to go ahead with the surgery. She attended the appointment with Dr Burke and understood he was assessing Samantha to see if the operation would go ahead or not after the discovery on the MRI of the spinal cord "narrowing."

She recalled Dr Burke asking for Samantha's medical history and anything that was related to her family. Her learning difficulties were mentioned, as well as the head

nodding behaviour. She recalled Dr Burke asked Samantha to walk along a straight line with her arms held out.

She thought the appointment was 30-35 minutes long. She could not recall the use of the term "Arnold-Chiari malformation". She did remember Dr Burke informing them of the risk associated with the procedure which included infection, paralysis, nerve damage, and rod failure. The highest risk the family were alerted to was of rod failure.

Mrs Spence recalled the pre-operative questionnaire with a nurse which was focused on Samantha's general wellness at the time, and that she did not have any chest complaints.

Mrs Spence recalled the anaesthetist visited at around 5.30pm the night before the operation and spoke at length regarding Samantha's medication and medical history. He ordered medication to calm Samantha who was very anxious.

After the operation Mrs Spence confirmed Samantha was shuddering and that this was not alleviated by the application of a couple of blankets. Her grandmother observed and heard Samantha's laboured breathing after the operation. She said it was different to her recollection of Samantha's asthmatic breathing as a child. She described the breathing as – a big inhalation of breath, and then she'd hold on for quite some time before she would be able to get it out again. It was as if she was struggling to get extra oxygen into her lungs.[26] Mrs Spence said she raised the issue about Samantha's breathing with the nurse Michael, and then with the two senior female nurses during the night shift.

Mrs Spence expected Samantha would be fairly sedated the day after the operation; however she also recalled the nurse who admitted Samantha had explained Samantha would get out of bed in a very limited way the day after the operation. Although Mrs Spence could recall being told Samantha would be on morphine for three days before the use of a self administering device, she considered Samantha's level of sedation was greater than she had anticipated.

She confirmed she and her son raised concerns with the proposed move from PICU back to the ward. They expressed concern over low blood pressure to Nurse Helen Murphy, who reassured them. Mrs Spence confirmed Samantha was not joking, as suggested in one of the nurse's statements. Samantha had very limited communication with pauses between words.

After transfer to the ward Mrs Spence confirmed she became less responsive with just slight nods as acknowledgment. Samantha appeared to be going into deeper sleep. She recalled the physiotherapist did show Samantha some exercises but Sam found them very difficult and she was very slow in responding to the physiotherapist.

Mrs Spence recalled it was Dr Lister who first used the term "Chiari malformation" and explained what it meant with a diagram. This was on the day Samantha died.

[26] T1-25