



Report to the Minister of Justice and Attorney General Public Fatality Inquiry

WHER	EAS a Public Inqu	iry was n	eld at the the Law Courts i	Building			
in the	City (City, Town or Village)	_of	Edmonton (Name of City, Town, Village)	, in the Province of Alberta,			
on the	17 th to 21 st	_and	27 th day of January,	, $\frac{2011}{\text{year}}$, (and by adjournment			
on the	7 th and 11 th	_day of	February, March 18 th , and	on the 2 nd to 4 th day of November, 2011			
before	Marilena Carmin	ati		, a Provincial Court Judge,			
into the	e death of Saman (Name in Fi		13 (Age)				
of Morinville, Alberta and the following findings were made: (Residence)							
Date a	nd Time of Death	:	approximately 6:2	0 a.m., December 3, 2006			
Place:	se: Stollery Children			Hospital			
("cause of Injuries a	and Causes of Death a ealth Organization – T	edical caus as last revis		ational Statistical Classification of Diseases, e assembled for that purpose and published by the			
("manne	er of Death: or of death" means the minable – The Fatality			micidal, suicidal, accidental, unclassifiable or			
Natural.	•						

Report - Page 2 of 8

Circumstances Under Which Death Occurred:

Introduction

The inquiry into the death of Samantha Martin was held pursuant to the *Fatality Inquiries Act*. Some delay was occasioned as initially the view taken was that this was not a case which fell within the purview of the *Act*, ultimately however, the Board decided that an inquiry was appropriate and a Fatality Inquiry was ordered on July 23, 2008.

The inquiry was held over a number of days, and heard from numerous witnesses. A large number of exhibits were filed, including a large binder of medical records, Children's Services records and other documentation.

Samantha Martin was born to Velvet and John Martin on June 4, 1993. She was diagnosed soon after with Tetrasomy 18p, an extremely rare genetic variation which gives rise to a number of symptoms, including various developmental delays.

Samantha's parents decided to place her in foster care, for a number of reasons, including their grief at learning of the diagnosis, an unfortunately pessimistic prognosis and an unfortunate impression formed by Mrs. Martin that foster care would offer Samantha greater special services than would be affordable for her if she remained with her biological parents. Samantha was placed into foster care when she was 7 weeks old. She was placed with the Himschoot family near Morinville on August 3, 1993. A Permanent Guardianship Agreement was signed on October 24, 2001. Samantha's biological parents were in telephone contact with the Himschoots, and reinitiated contact with their daughter, commencing when she was approximately 3 years old. Their contact with Samantha increased over time, and eventually led to joint guardianship of Samantha on October 24, 2001. In April 2006 Samantha increasingly spent time with the Martins, and eventually Samantha returned to live with her biological parents, not long before her death at the age of 13. Samantha appeared to be thriving after returning to her parents full time on June 27, 2006. Samantha gained weight, going from 49 pounds at the time of her return, which was her approximate weight for the previous 3 years, to 60 pounds by the end of July 2006, and looking much healthier in photos taken after her return to her biological parents. Samantha was nonverbal, but after her return home had started to acquire a few more words. In October 2006, Samantha was seen by Drs. Watt and McIvor at the Glenrose Rehabilitation Hospital Physical Medicine Clinic and it was noted that she had gained 6 kg in weight and 2 cm in height since her examination one year earlier. According to the Information Consolidation prepared by Children's Services, the plan was to rescind the Permanent Guardianship Agreement in December 2006.

The immediate circumstances leading to Samantha's death

Tragically, Samantha became ill on November 29, 2006. She came home from school retching, and began vomiting. She later experienced diarrhea as noted by Mrs. Martin. Samantha settled in the evening and was left with her older brother while the Martins went to the bank, but unfortunately, Samantha's condition worsened. Her brother phoned his parents to say Samantha had stopped talking. The Martins returned home, called an ambulance and Samantha was taken to the Sturgeon General Hospital in St. Albert. She was subsequently transferred to the University of Alberta Stollery Children's Hospital, where a decision was ultimately made to remove life support. She passed away on December 3, 2006. The fact that Samantha was on life support for a period of time contributed to the difficulty in assigning a cause to Samantha's death. It is known that her heart stopped; much less clear is why it stopped.

Samantha's past medical history

Report – Page 3 of 8

Tetrasomy 18p

The Court heard from Dr. Cody and Dr. Hale, a geneticist and pediatrician respectively, who are leading experts from the University of Texas at San Antonio with respect to this rare genetic condition. They have very extensive knowledge and experience with Tetrasomy 18p. They testified that to the best of their knowledge, it does not appear that Tetrasomy 18p is associated with any indications of reduced life expectancy. The condition is so rare that it is hard for them to give accurate estimates, but they felt it was probably one in 100,000. They have attempted through their research to understand the condition better, and have compiled a list of features common to many of the children who have this genetic variation, in an article which became Exhibit 4 in the inquiry. Based on this analysis, it appears that 21 per cent of the children with Tetrasomy 18p have seizures. Many have gastrointestinal difficulties, but other than feeding difficulties especially in the early years of life, the children with Tetrasomy 18p were not noted to be particularly thin or frail. Dr. Maryanne Thomas, a geneticist at the Alberta Children's Hospital, also gave evidence in the inquiry that in her opinion there is no evidence of any link between Samantha's Tetrasomy 18p and her death.

Samantha's previous fractures and bruises

Mrs. Martin raised concerns at the inquiry about various injuries Samantha suffered while in foster care. Children's Services does not appear to have sought an expert opinion on the total number of fractures and the plausibility of the various explanations offered for them, or on the plausibility of explanations offered for various bruises which caused school staff working with Samantha to raise concerns with Children's Services. Samantha herself was nonverbal, and could not be interviewed about these matters. However, although Samantha had a number of bruises on her face and neck and also suffered a number of fractures of her bones while in foster care, including fractures on two separate occasions of her thigh bone, it does not appear from the evidence that there was any causal link between these injuries and her death.

Samantha's weight

Natasha Dancause [Kowalsky] became involved in Samantha's case in January and February of 2006. Ms. Dancause was a specialized investigator with Children's Services who conducted assessments as to level of risk screenings and to decide whether intervention was warranted. Reports were received from several school staff members of scratches and bruises on Samantha's head and neck that were increasing in frequency since Christmas 2005, and concerns about the contents of Samantha's lunch compared to the larger more balanced lunches provided to the biological son of the foster parents. School staff reported to Children's Services that when this was raised with the foster mother, the response was to tell the school to fill Samantha up with water. There was particular concern because Samantha only weighed approximately 51 pounds at 12 years of age and had gained only 2 pounds in 2 years. The screening conducted by Ms. Dancause involved speaking to caseworkers and support workers involved with the child (Valerie Jensen) and the family (Lynn Bell) and to the people from Samantha's school. Ms. Dancause also had received a letter forwarded through Mr. Brian Leonard, February 16, 2006 from Samantha's biological mother, received in November 2005, which outlined a number of concerns about Samantha's care in the foster home. Ms. Dancause did not meet with Samantha and did not make any calls to any doctors responsible for Samantha's care. She relied on case workers and support workers to share information. There were disagreements and issues arising generally between the biological and foster parents. Ms. Dancause decided on February 21, 2006 that the complaints raised about Samantha's care did not require an investigation. The lack of records of medical checkups noted in a Children's Services file review from December 2005 seems not to have been on the radar.

Report – Page 4 of 8

Dr. McGonigle is the pediatrician who saw Samantha from time to time when her foster parents brought her in. He noted it was not a very thick file for someone with Samantha's condition. He usually sees kids like that once every 3 months, and at least once a year for a complete checkup. In contrast, he saw Samantha for the first time in 2000, with a complete checkup in 2002, one when she was 8, and in June 2004. When she became his patient he was not able to obtain the file from the previous doctor who had cared for her. Her sparse visits might mean that she was relatively well. At age 11 Samantha was below the 5th percentile for weight and gained fairly little after that. Dr. McGonigle testified that low weight would be the result of low caloric intake. It does not appear from the evidence that the low weight was the result of Samantha's Tetrasomy 18p, and it appears that Children's Services staff may have erroneously attributed her low weight to her genetic condition. However, Dr. McGonigle felt that Samantha's underweight status which lasted for some years would not have been a contributing factor in her death, because when Samantha was returned to her biological mother and gained a healthy amount of weight, that would have countered any problems that would otherwise have been caused by the previous low weight. The autopsy report indicates that Samantha weighed 42 kg and was 1.42 m tall at the time of her death. Dr. Dowling, the pathologist, also testified that the fact that Samantha weighed far less than she should have for a considerable length of time was not a factor he could connect to her death in light of the other difficulties establishing a cause of death. Accordingly, it does not appear from the evidence that Samantha's underweight years were a contributing factor in her death.

Whether Samantha suffered from seizures

Lorna Huff testified at the Inquiry. She was the assigned caseworker for Samantha Martin from September 1998 to August 2005. She does not have a degree in social work, which is not required in the province of Alberta, but did have an education degree and was a registered social worker. Her responsibilities included seeing the child, having contact with the foster home, to be aware of everything that was going on in terms of the care Samantha was receiving, to talk to the doctors, to the foster mother, and to see the child in face to face visits, as well as having contact with the biological mother, to ensure the child's best interests were met. A case conference was held at Samantha's school November 21, 2002, where concerns were raised by the school that there was a possibility Samantha might be suffering from seizures, and suggesting that the doctor be consulted with respect to an encephalogram to rule out a seizure disorder. A report was prepared setting out in detail the substance of the meeting and the recommendations (Exhibit 6). Mrs. Huff's notes from the case conference indicate "E.E.G. to rule out seizure disorder" and the note had a star beside it to indicate to Mrs. Huff that it was important to follow up on. Although Mrs. Himschoot and Mrs. Martin were not at the case conference, Mrs. Huff felt the foster mother was aware of the seizure issue, and testified that "Joanie was very attentive to the child's medical needs," "very often" took Samantha to the doctor, and "would have followed up with Dr. McGonigle." Dr. McGonigle was not advised of seizure activity by Mrs. Himschoot, and never received a copy of the consultation report which referred to the need to assess for possible seizures. Dr. McGonigle testified that if he had seen the report he would have assessed Samantha for seizures. He testified however that not all children with seizures are placed on medication. Dr. DeCaen, another pediatric expert, also testified it is possible seizures might not be treated. Dr. DeCaen indicated that would be a decision that should be made by a physician.

Five days after the November 21 case conference, there was a further meeting (this time an Individual Program Plan meeting to discuss Samantha's educational goals) at Samantha's school where many of the same individuals were present, as well as the foster mother and the caseworker. Although the records do not indicate that the issue of possible seizures was addressed at this meeting, it does appear that the foster mother indicated that she planned to take Samantha to Dr. McGonigle for a medication review. On December 3, 2002, the foster mother advised Mrs. Huff that Dr. McGonigle had increased Samantha's medication and asked that the school document their concerns. It is not clear whether the issue of possible seizures was ever discussed during this phone call, but the contact notes

Report – Page 5 of 8

from the Children's Services file together with Dr. McGonigle's records and evidence appear to suggest the issue discussed was Resperidal which was being prescribed for behavioral issues and which had nothing to do with seizures.

Mrs. Huff believed that Mrs. Himschoot had a lot of experience with medically fragile children, as a large number of such children were placed in her care, and Mrs. Huff appears to have been under the impression that Samantha had monthly visits with doctors. However, this does not appear to be an accurate understanding, as an EEG was never sought by the foster mother for Samantha, and although the foster mother did take Samantha to the doctor from time to time for various needs, she did not bring her for regular physical checkups with the pediatrician. The health records disclose a period of 3 years where Samantha was not seen by a pediatrician or family doctor (Exhibit 21shows a gap from 1997 to 2000, viewed in light of Mrs. Himschoot's evidence that Dr. Berhmann was the pediatrician before Dr. McGonigle, and then briefly Dr. Janika). This was unusual for a child with her complex medical needs, according to Dr. McGonigle and Dr. DeCaen. Mrs. Huff, although she was the caseworker for Samantha, appears to have been ill informed as to the frequency or nature of Samantha's medical visits, and relied heavily on what the foster mother told her was going on. Mrs. Huff did not notify Dr. McGonigle, the pediatrician, about the suggestion that an encephalogram be done to rule out a possible seizure disorder. She assumed the foster mother, who was not at the case conference, had done it. Mrs. Huff never attempted to confirm with Dr. McGonigle or Mrs. Himschoot that the seizure issue had been assessed by the doctor. Mrs. Himschoot testified she did not convey a concern about seizures to Dr. McGonigle, as she felt she would want to know more before going to a doctor, and testified that she feels the same way now. Mrs. Huff testified that she spent time with Samantha and never saw any seizure activity. Exhibit 6, a Consulting Services report which discussed the school's concerns about possible seizures, was shown to Mrs. Huff, who indicated she had received it but did not forward the document to Dr. McGonigle; she did not know if the report was sent to the foster mother or biological mother. The consultation report recommended that the report be forwarded to Dr. McGonigle as well as data collected about Samantha's performance and behaviour at school so that Dr. McGonigle could assess the information prior to seeing Samantha. The school felt that it required written permission from the foster mother prior to forwarding the report to Dr. McGonigle. Mrs. Huff felt "it did not seem to be a big issue".

Mrs. Huff was required to have in person visits with Samantha at least once every 3 months, but longer periods went by; 14 months went by with no face to face visits according to Children's Services' internal review, during the period from July 12, 2001 to September 19, 2002, but Mrs. Huff testified she did not document two in-person visits, as paperwork was not her strength. There were also gaps of 7 or 8 months at times, although Mrs. Huff sometimes visited Samantha more than once every 3 months. Mrs. Huff testified that her case load made it difficult to keep up with her paperwork. (A previous worker for Samantha also had had only 3 face to face visits with Samantha during the 26 month period from February 1996 to April 1998 (according to the Children's' Services file review), whereas policy would have required at least 8 or 9 visits in that kind of time frame. Mrs. Huff took over in September 1998.

Lorna Huff testified that Samantha's condition came with difficult behavioral issues and Mrs. Huff felt she would never have been able to find a placement for Samantha that would have been equal to let alone better than the quality of care she was receiving in the foster home.

Valerie Jensen took over from Lorna Huff in 2005 as the Children's Services case worker for Samantha. On September 15, 2005, a Children's Services review of the file found no record of annual medical or dental checkups. A further December 2, 2005 review of the file was completed by Diane Martin who noted that there had been no face to face meetings with Samantha since February, and also again noted that there was no indication of annual medical/dental checkups in the file.

It appears there were no face to face visits documented with Samantha after February 2005 until

Report – Page 6 of 8

November 23, 2005, and then again until March 21, 2006 (then June 13, 2006) notwithstanding the December 2, 2005 review.

The comprehensive file review by Children's Services prepared after Samantha's death (dated June 4, 2007) notes that the last medical report on Samantha's file as of June 2006 was from Dr. McGonigle on June 15, 2000. (Alberta Health Services billing records indicate a visit with Dr. McGonigle on June 14, 2000 which is categorized as diagnostic evaluation, limited, not requiring the taking of a complete history/evaluation.) The foster mother provided details to Valerie Jensen about Samantha's recent medical visits, which the foster mother indicated was with Dr. McGonigle December 29 of 2005. (It appears from AHS billing records that there was also a visit April 19 of 2006.)

Upon her return to the biological parents, the Martins, Samantha was taken to the pediatrician Dr. Roseman, who on November 15, 2006 arranged for an EEG to investigate the issue of seizures, after the biological mother and a teacher of Samantha's had witnessed what they felt might be seizures; this EEG was to have taken place on November 30, 2006. An earlier EEG that Mrs. Martin had scheduled October 16, 2006 with Dr. Starreveld was inconclusive. Mrs. Martin testified that Dr. Roseman witnessed a seizure in the office on November 14, and her communication log with the school aid Carla for November 14, 2006 certainly appears to bear this out, but the doctor did not recall the incident, although he felt he had been confident they were dealing with seizures. (Mrs. Martin also told Children's Services in September 2006 that she had told the foster mother in 2002 about her concern about seizures in children with Testrasomy 18P but nothing was done; this was documented by way of a letter that Mrs. Martin had sent to Mrs. Himschoot. Mrs. Martin had sent a letter to the foster mother dated October 4, 2002 suggesting Samantha be checked for seizures as a result of her research on Tetrasomy 18p disclosing it to be quite common in children with Tetrasomy 18p.)

On Samantha's November 15, 2006 examination by the pediatrician, Dr. Roseman, Samantha appeared to be doing well and weighed 61 pounds, but Samantha passed away before Dr. Roseman had a chance to complete the investigation into whether she required treatment for seizures.

The issue of possible absence seizures had been raised long before, by the Physical Medicine Clinic at the Glenrose Rehabilitation Hospital, on June 4, 1996, when Samantha was 3 years old. In a composite report prepared by S. Acheson, R.N., the Coordinator for the Physical Medicine team, it was noted that the foster mother was advised to discuss the issue of the possible absence seizures with Dr. Berhmann, who was at that time Samantha's pediatrician, as the nurse felt she had seen what could be absence seizures during the clinic that day. Dr. Berhmann's file was not available to the inquiry, as it was picked up by Mr. Himschoot in 1997 and apparently misplaced or lost. The report does indicate a copy was being sent to Dr. Berhmann. It appears however from Mrs. Himschoot's evidence that the seizure concern likely was not followed up on. It appears from the Alberta Health Services records that Samantha was last seen by Dr. Berhmann on August 6, 1996 (the only visit with this doctor after the Physical Medicine Clinic referred to above). However the records indicate the August 6th appointment was for "diagnostic interview and evaluation, described as limited (visit not requiring complete history and evaluation)".

What conclusions if any can be reached about the cause of death

Numerous doctors testified at the inquiry. Dr. Idikio conducted the autopsy on Samantha at the University of Alberta Hospital. He could not determine a cause of death. He indicated that some damage to the lining of the colon leading to sepsis was a possibility, but he had insufficient evidence to determine whether that had in fact occurred.

Dr. Adrian Jones testified. He is a pediatric gastroenterologist. He did not see Samantha as a patient, but reviewed extensive medical records and provided the Court with his opinion. He was of the view

Report – Page 7 of 8

that a possible cause of death was perhaps a laryngospasm due to a minor reflux of acidic fluid from the stomach which was possibly aspirated onto Samantha's larynx. Dr. Adrian Jones felt sepsis was not a likely cause of death as there were no indications of abnormalities in Samantha's liver; however he could not rule it out as a possible cause of death. Dr. Jones could not say definitively that laryngospasm was the cause of death. No food debris was observed by medical staff when Samantha was intubated, but Dr. Jones felt that this could be because Samantha had not eaten for several hours, or that the laryngospasm may have been triggered by acid rather than food particles. He testified that laryngospasm would be very high on the list of possible causes of death; and in cross-examination felt it was the probable cause of death.

This may well be the case, but the absence of evidence on this point means that we cannot know this to be the cause of death. Although Dr. Jones (and Dr. DeCaen, who accepted Dr. Jones' opinion as a possibility but who is also not a pathologist) clearly has some relevant experience in this area, he is not a trained and qualified forensic pathologist. Dr. Dowling's training and extensive expertise is specifically with respect to the issue of cause of death. Where Dr. Adrian Jones' opinion conflicts with Dr. Dowling's evidence, I prefer the evidence of Dr. Dowling. Dr. Dowling testified as an expert in forensic pathology. For 18 years he was the Chief Medical Examiner for the province of Alberta. He has a wealth of experience in identifying cause of death.

I find that the cause of death cannot be determined with any certainty, as indicated by Dr. Dowling. However, Dr. Dowling did testify that some of the more plausible causes that may have led to Samantha's death are a seizure, or septic shock. He testified that if seizures are untreated, that would increase the risk of death.

Dr. Dowling testified that the manner of Samantha Martin's death was natural; in other words, it is clear that she died of natural causes. However, with respect to the cause of death, he explained the difficulties in drawing a precise conclusion. Although he did not perform the autopsy on Samantha, he reviewed the autopsy report prepared by the pathologist at the University of Alberta Hospital, along with other documentation, and primarily focused on the medical information available. He defined cause of death as a disease or injury that initiates the downhill sequence of events ending in death. He testified that there are really only a couple of things that come to mind as possibilities. From Samantha's history of absence seizures, he noted that people with seizure disorders can die suddenly and unexpectedly from having a seizure even though it is no different than other seizures they have had previously. It is not known why this happens, but it does occur. He testified it is difficult to say whether Samantha had a seizure, but that it is certainly possible, in which case the cause of death would be seizure disorder due to her underlying Tetrasomy 18p. He testified that this is possible even in the case of absence seizures. Another possibility, although rare, is that the impacted fecal material in Samantha's large bowel may have rubbed away just the inner lining of the bowel, allowing bacteria to seep into the bloodstream, even though there was no perforation, leading to sepsis and death. Dr. Dowling indicated there is insufficient information available to determine whether that in fact occurred. That Samantha was in hospital for a few days after her collapse makes it more difficult to assess as well. These two possibilities were the ones that Dr. Dowling would attach the greatest weight to; he is not aware of any other possibilities that resulted in Samantha's death, even though he is aware that others have attempted to suggest some other causes. Although Dr. Dowling was quite cautious in drawing conclusions, he was fairly firm in rejecting the hypothesis of Dr. Jones that aspirated stomach contents on the larynx could have caused the death; in Dr. Dowling's opinion, that is not a cause of sudden death. Aspiration of stomach contents is actually caused by death, rather than the other way around. Dr. Dowling acknowledged he cannot rule out the possibility completely, but testified it makes no sense in his experience. The absence of evidence of aspiration means it cannot be inferred that this is probably what occurred.

Dr. Dowling testified that he simply did not have enough information to say precisely what happened to

Report – Page 8 of 8

Samantha, and therefore in his opinion the cause of death is undetermined.

Dr. Dowling testified that untreated seizures can certainly put a person at greater risk of dying because of their seizure disorder. However, a seizure disorder can result in death even where the individual is being treated and taking appropriate medication. He agreed it was fair to say there would be an increased risk without medication, but stated that it would not be absolute. Dr. Dowling's evidence about the possibility of seizure disorder playing a role in the cause of death was persuasive in light of his experience and expertise.

Recommendations for the Prevention of Similar deaths:

I find that the manner of death was natural, and that the cause of death may well have been a seizure, but due to the absence of evidence, it is not possible to say that this was the probable cause of death. However, given the evidence that seizures were likely an issue for Samantha, and in light of the extensive evidence I have heard, I am of the view that it would be appropriate in this case, to make certain recommendations to aid in the prevention of other deaths bearing in mind the purpose of the legislative provisions for the *Fatality Inquiries Act* clearly includes the attempt to avoid preventable deaths in the future. The evidence in this case leads me to make the following recommendations:

That Children's Services should ensure that those caseworkers who work with a foster child have accurate and up to date information from a reliable medical source about the child's disability and in particular, the impact, if any, of the disability on the health, weight, and fragility of the child. This needs to be well understood in order for the worker to make informed assessments about how the child is doing in care, especially in the case of a nonverbal child who cannot communicate concerns with the child's worker.

That Children's Services should look at enhancing current policies to ensure that children are actually receiving their annual medical checkups as required, including a diary system so that the issue is flagged and not inadvertently overlooked.

That where a recommendation comes from a reliable source (such as a school assessment) that a doctor examine the child for a possible medical issue that the child may be experiencing, that processes are in place to ensure the issue is flagged for follow up by Children's Services in an effective and meaningful way, including required entry by the Children's Services child care worker or other support staff at Children's Services into a diary system.

Ensure that caseworkers for the child have a reasonable case load so that they have the time they need to be able to adequately document and follow-up on medical needs of the child.

DATED _	October 2, 2012 ,		
at	Edmonton	, Alberta.	Original signed
		,	Marilena Carminati
			A Judge of the Provincial Court of Alberta