

CITATION: *Inquest into the death of Queenie Michaels* [2003] NTMC 38.

TITLE OF COURT: Coroner's Court

JURISDICTION: Alice Springs

FILE NO(s): A95/2002

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FINDING OF: Mr Greg Cavanagh SM

CATCHWORDS:

CORONERS – INQUEST
Death in Care

REPRESENTATION:

Counsel:

Assisting: Mrs Lyn McDade

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IN THE CORONERS COURT
AT ALICE SPRINGS IN THE NORTHERN
TERRITORY OF AUSTRALIA

No. A95/2002

In the matter of an Inquest into the death of

**QUEENIE MICHAELS
ON 6 NOVEMBER 2002
AT 9 MCDONNELL COURT
ALICE SPRINGS**

FINDINGS

(Delivered 31 July 2003)

Mr GREG CAVANAGH SM:

THE NATURE AND SCOPE OF THE INQUEST

1. Queenie Michaels (“the deceased”) died at about 0758 hours on 6 November 2002 at the home of her foster parents, Mr and Mrs Bevan at 9 McDonnell Court, Alice Springs. The cause of her death was pneumonia complicating cytomegalovirus embryopathy.
2. The death occurred whilst the deceased was under the guardianship of the Minister for Territory Health. Accordingly her death is one which is reportable to the Coroner because she was “in care” vide Section 12 of the *Coroners Act* (“the Act”).
3. Pursuant to Section 15 of the Act a Public Inquest into her death was mandatory.
4. The Inquest took place in Alice Springs on 28 July 2003. Mrs McDade was my counsel assisting.
5. Two witnesses were called, Mrs Jan Bevan, one of the deceased’s foster parents, and Dr Tors Clothier, the deceased’s paediatrician. In addition to

their evidence the Coroners investigation file and 6 volumes of hospital medical records were admitted into evidence.

CORONERS FORMAL FINDINGS

6. Pursuant to Section 34 of the Act, I find as a result of the evidence adduced at the Public Inquest the following:

- (a) The deceased was Queenie Michaels, an Aboriginal female who was born at Kalgoorlie, Western Australia on 8 October 1991.
- (b) The time and place of death was 0758 hours on 6 November 2002 at 9 McConnell Court, Alice Springs.
- (c) The cause of death was natural causes being pneumonia complicating cytomegalovirus embryopathy.
- (d) Particulars required to register the death are:
 - (i) the deceased was a female;
 - (ii) the deceased was Queenie Michaels;
 - (iii) the deceased was an Australian resident of Aboriginal origin;
 - (iv) the death was reported to the Coroner;
 - (v) the cause of death was from natural causes namely pneumonia complicating cytomegalovirus embryopathy. The cause of death was confirmed by post-mortem examination;
 - (vi) the pathologist was Dr Botterill and he viewed the body after death;

- (vii) the deceased's mother was Maxine West;
- (viii) the deceased's father was Kevin Michaels;
- (ix) the deceased lived at 9 McConnell Court, Alice Springs;
- (x) the deceased was a student;
- (xi) the deceased was unmarried;
- (xii) the deceased was 11 years old at the time of her death, having been born on 8 October 1991.

RELEVANT CIRCUMSTANCES SURROUNDING THE DEATH

7. Queenie Michaels was born with CMV embryopathy (cytomegalovirus embryopathy) caused by a viral infection contracted in utero. The virus primarily affects the brain which fails to grow and develop resulting in cognitive disabilities. Queenie consequently suffered from birth, microcephaly (small brain), severe development delay and evolving spastic paraparesis.
8. Dr Clothier in his evidence to me described how the virus affected the deceased and I quote (Transcript P18-19):

“Now she was born with CMV embryopathy, what exactly is that?--- It's a very unpleasant viral infection which the mother acquires during her pregnancy and the virus while infecting the mother crosses the placenta and infects the infant – well the foetus and the – there are specific problems that allow one to recognise children so affected or babies that are born so affected because they usually have a recognisable entity that's called CMV, cytomegalovirus embryopathy. Queenie had, and not unusual, not all of the features but some of the features, enough for us to be pretty confident that's what she had. And it can be confirmed by finding the continued presence of that virus in the urine and by doing serological tests that tell us that the person has developed – the infant has developed antibodies to that virus. It's peculiarly nasty in that it continues to

cause damage after birth so the children can seem relatively good. Obviously that's compounded by the difficulty of trying to assess children who don't do much when they are very little. But the virus continues to be damaging.

And that was the case with Queenie?---And that was the case with Queenie. So things evolve. But immediately what happens is that it primarily affects the brain. The brain fails to grow therefore the head fails to grow. Because of the damaged brain there are cognitive disabilities. They are often visual auditory disabilities, which she didn't have. Because of the effect of the damaged brain on the nervous system the children develop spasticity. And the spasticity in turn is compounded by contractures of the joints and dislocation of the hips and those things happen. It is also compounded by distortion of the chest. And as subsequently happened in Queenie's case by what we call a paralytic ileus because of the uneven pull of muscles on the back, the spine becomes distorted. But she had rib distortion well before that. The other effects of the damaged brain were epilepsy. And the epilepsy was hard to control. Jan deals so likely with these things and so well, you know, the difficulties associated with that don't really come out in what you've heard, but she had difficult epilepsy, which we never fully controlled so she was having numerous types of fits and required, in addition to other medications, anti-convulsants of two sorts throughout her life. And she was having, in addition to obvious seizures, she had multiple and frequent absence-type seizures when your consciousness is – (inaudible 11:25:09) of consciousness is just switched off. She had difficulties with her swallowing as a result of the damage to the brain. The complex mechanism of swallowing was obviously adversely affected and she had difficulty feeding and aspirated – that means it got into her lungs, her secretions. She also - - -

(Inaudible 11:25:36) after the feeding tube was inserted?---Yes, after the feeding tube was inserted. And she also had what we call gastrocephogeal reflux, her food coming up out of her tummy prior to and I think after the operation done to try and prevent that. And that and the distortion of her chest resulted in recurrent chest infections. And in an attempt to avoid those we treated her aggressively. We gave her flu immunisations every year. We gave her something called Pneumovax which tries to prevent pneumococcal infections. But despite all of that she had recurrent infections and she also had, early on and what subsequently became more of a problem, an upper airway obstruction problem, which was intermittent and I could never explain that, whereby at times, usually in stress times, she had great difficulty breathing and made an awful noise when she tried to breathe. But as Jan says this litany of woes

really doesn't tell us what Queenie was like. She was an incredible kid.”

9. I should indicate that Dr Clothier had been involved with Queenie providing medical treatment and care to her from the time she was 5 ½ months old until her death, save for a brief period when she was treated by one his colleagues.
10. He also made himself readily available to the deceased's carers and the deceased and was instrumental in ensuring that no extra-ordinary medical measures were taken when the deceased became terminally ill.
11. The deceased was severely mentally and physically handicapped from birth. Her quality of life, and life expectancy was always going to be contingent on the quality of care, emotional and medical, she would receive from others.
12. Her first two years of life were spent with her maternal parents at Fregon in South Australia. In 1993 her mother was jailed and her maternal grandmother brought the deceased to Alice Springs Hospital and asked that she be placed “in care”.
13. Mr and Mrs Bevan received Queenie on 22 July 1993 and remained her carers until her death. Queenie at the time of coming under the care of the Bevans was a baby not only with the congenital conditions already mentioned but was underweight, malnourished, grossly affected by scabies and covered in lice. To use the words carers/foster parents in this context significantly underrates the relationship that started between Queenie and the Bevans in 1993 and continued until her death. Queenie became part of the Bevan family and was loved and cared for by the Bevan family as a bona fide member of it.
14. Throughout her life, Queenie and the Bevans had to deal with many medical setbacks and illnesses. Together they dealt with them and

throughout her life Queenie was able to enjoy a life that was full of love and affection.

15. I had cause to comment to Dr Clothier during the Inquest after hearing Mrs Bevan's evidence as follows (Transcript P19):

“Doctor, in all the experience that I've had with, both as a magistrate and a lawyer and as a coroner, meeting and reading of files where carers are involved, I don't think that I could put any narration of care at a level as high as I've been told about this morning?---No, you know, all I can say it's exemplary care and spiritually uplifting to be around people who do this sort of thing.”

16. I remain of that view and therefore adopt the unusual cause of relating in its entirety the evidence of Mrs Bevan, so that any one reading these findings can appreciate the level of care and attention, love and affection this little girl received from her foster family (Transcript P9-17):

“Can you briefly tell me the circumstances of how you ended up with Queenie then?---Queenie came to us on respite for 8 weeks. She was very thin, covered in scabies and lice and wasn't a very pretty sight. At the end of the 8 weeks the family came in. She had put on something like 2 and a half kilos. Her general condition had improved dramatically so they then approached Welfare of FACS to keep her in care. And that took another few months, I guess, before it happened. So she came into care of the Government and she stayed with us the whole time.

I want to talk about her family. Which members of her family came to see her?---Her grandmother, Lalla. Too sure that her mother was involved at that stage. No, her mother was in prison, that's right. Her grandmother, Lalla, and her aunty and then her grandfather came into town late one night so they got us to get Queenie out of bed so that he could see how well she looked and how fat and healthy she was. And then the next day they said they wanted her in care and then they shot through for about 9 months. So she was declared – that's how she became a Ward of the State.

So how did she become placed with you on a permanent basis?--- Well at that stage they couldn't find her another place and we already had a little girl with high needs and Queenie was extremely high needs. They just simply could not find another carer who was willing to take her.

So you kept both of them?---Yes.

How much care did Queenie need at that stage?---Well she was very, very difficult to feed, extremely difficult to feed. Probably each feeding took an hour or so. She couldn't drink unthickened fluids at all. She had to have all her fluids thickened. For all that she sounds terrible when you describe her condition she was quite bright. She knew exactly where she was, who had her and she was extremely demanding. And she would actually probably scream half the day. She wanted attention. She wanted to be played with. She wanted to be – yeah, the first 12 months of her life with us were very demanding.

How old was she when you first got her?---She was just under 2, I think she was 21 months when we took her.

And you have children of your own?---I have four.

And at that stage were they – any of those children at home as well?--All four.

So you had four natural children?---Yeah.

And two highly dependent children?---Mmm.

Now after having Queenie for that long you continued to have her, I should say, until her death?---Yeah.

So that's approximately 9 years?---Nine and a half years.

I want you to briefly walk us through what happened in those 9 years and how you associated and related to Queenie, as a family?---Well I guess within the first few months you fall in love with them, warts and all as they say. We never really did intend to keep her. We actually did try and place her probably for – I think it was about 2 years before we finally decided that there was simply no-one else out there that was prepared to take her. And by that stage she had started having seizures and things. But Queenie was, for all the medical evidence you hear, was extremely bright and aware and she sat bolt upright in her chair. She had walkers and standing frames and she never ever came across as somebody that you see in the medical evidence.

THE CORONER: She had a large spark of life in her, did she?---She was huge. Everybody in Alice Springs knew Queenie. She went to holiday programs. She went to normal school. She knew everyone

around her. She knew all her colours. She eye pointed. She used her fists to point. So she never ever was - - -

A little wallflower?---No, certainly wasn't a wallflower. And she was very determined. You know, if she wanted something she wanted it and heaven help that you would change her mind.

MS McDADE: So you developed a way of communicating with Queenie because Queenie could never talk?---No, she never talked. She eye pointed extremely well. She had sounds that she made that I knew what they were. She could yell very loudly.

THE CORONER: She became part of your family?---She was very much a part of our family from virtually day 1.

How did the other kids relate to her?---They loved her to bits, both of them, both the girls. They were just part of the family.

And she loved them?---Oh yes. Yes, she knew them all. And she knew my girlfriends that came to the house. She knew all the kids at school. She knew which room she was in. So she was – yeah, she was part of the family. We didn't lose a foster-child, we lost a daughter, and that's how we felt about her. And, you know, nothing will ever replace her. So she became very much part of the family and part of Tors' group of children with multiple needs.

And she did have multiple needs, didn't she?---She did, but they never ruled her life like other children with multiple needs because she was so bright and out there, they never ruled her life, you know. She had hospitalisations and she had surgeries and she gave us a few scares but she got over them and she went on with life. There was never any long-lasting, you know, they didn't reduce her life as she had these surgeries, they increased her life. And she just kept going, you know.

But she had significant surgery in 1995, when she went to Adelaide for the feeding tube, didn't she?---The feeding tube visit, she was in for five weeks and she tried very hard to die on us then. She had every complication she could've had following that surgery.

But that was significant surgery?---That was significant surgery, although we'd had other children with it who had just gone down, spent five days in hospital and come out, but she didn't.

And the feeding tube was designed principally at that stage, for fluid intake, not food, is that right?---Yeah, she couldn't drink fluids. She

was still eating reasonably well, struggling to hold her weight a bit. But fluids were the primary problem, yeah. And they'd had to put a nasal-gastric tube down for fluids. But then eventually, probably about 18 months after that, she lost the ability to eat as well. And so she was then totally fed by tube.

I take it, if it's to feed her through, other than using a tube, would've been difficult and time consuming?---Yeah. She was hard to feed. She had problems opening her mouth and she had problems swallowing and everything was pureed and very high calorie, we got it to a fine art. So she continued to gain weight and we got better at making her very high calorie foods that she liked to eat, because she was fussy as well. She knew what she liked and, yeah, so feeding her was long. You know, she had physio and school and feeding and dressing and undressing and bathing, yeah.

So it was 24 – seven?---Yeah, yeah.

And for most of her life, because she was not able to independently do anything was she?---No, no.

Even the basic bodily functions were your responsibility?---Yeah. She was toilet trained, partially toilet trained but still we had to get her to the toilet and back, yeah.

She had a couple of good years in there?---She had – she – I don't really believe she ever had bad years. She had bad patches but I just wish I had have brought her photos of this laughing. She laughed, she screamed, she played. Yeah, she had a very normal life, as much as a child with her disabilities could, yeah.

And you're sure that she could recognise you and your family?---Yes. Everybody, not just me. People that walked in the door, the kids in her class, her group of friends. She had a group of seven normal friends from school used to fight over who was going to push her chair and who was going to choose her colours and who was going to pick up a pencil for her. So she was very popular at normal school, as well.

So what school did she go to?---She went to Bradshaw and she did spend some time in the afternoons up at special school doing physio and stuff like that. But she went to Bradshaw School from the age of five.

And when did she finish going to school?---She stopped school 21 months before she died. She was housebound.

Now she was also receiving occupational therapy and speech therapy and the like all the time?---Yeah, she had every intervention that we could possibly give her.

And it was your responsibility to get her to places where the intervention took place?---No, no. Once they go to school in the Northern Territory, it's one blessing, they do it at school.

They do it at school. That's why the afternoon session?---Yes. But she was also under the Crippled Children's Association in South Australia, because she came from Coober Pedy, which was fantastic. So we had tremendous support from them. They actually came up to Alice Springs at least once or twice a year to see her and make sure her needs were being met. So that was a bonus for us. So we had – we were dipping into two systems, which was really nice.

And the support you got from the Northern Territory system, how would you describe that in relation to your care of Queenie?--- Support from FACS or support - - -

FACS, particularly?---FACS. I don't think I really want to go there. It wasn't fantastic. We had extremely good support for the first couple of years, and then it died off, pretty much, yeah. Towards the end when she was very sick, we had very poor support. We had good support from the time she died to the time she was buried and we've had virtually no support since she died, no. You could count the visits on one hand.

THE CORONER: So they let you bring up, care for – they let you fall in love with the child, but then something, when a child dies like this, that's it, you don't hear from them again?---Not a lot, no. There's very poor – I know they've overworked and they've over stretched but there isn't tremendous amount of support in these circumstances.

MS MCDADE: But you currently have other children in your care?-- -He's the last one. I can – yes, we've - - -

This is Travis?---Yes, he's the last welfare child we'll have. Yes, the others are family placements or packages or whatever, yes.

And how long has Travis been with you?---Travis has been with us nearly six years.

So he was there when Queenie was there too?---Yes.

Now in about 1997 Queenie became totally dependent on the feeding tube, is that right?---Yeah, yeah.

What was her condition like between 1997 and 2000?---Fantastic. She was great. I mean, she had the odd pneumonia's and she had the odd viral infections, but she had (inaudible 11:08:38) intervention much in that stage and she just went to school and came home and she had time out, you know, time in hospital.

She had difficulty with her hip at one stage too, didn't she?---Yes, her hip came out of its socket and we had to – it was felt that it was better to put it back in again. That was major surgery but she flew through that. She was in plaster, full plaster from underarms to her feet for three months.

But Queenie's condition started to become less than good in 2000?---Yeah.

Can you recall what precipitated that downturn?---She'd already developed late 2000, had developed a slight curvature of the spine and we were looking at seating and things like that. So that sort of, basically, was the last four months of 2000. And then we took her away on a large holiday, she was fine. We came back and then it was – she was obviously curving over more. By that stage we were – everybody was aware of it. And it was beginning of 2001, she just came home from school blue. She couldn't breathe. Terribly, terribly distressed and that was basically the first of the breathing difficulties. And from that day on, she never could sit up again. She sat at 45, and then absolutely flat for the last, probably 12, 15 months of her life. She couldn't sit.

Was it about that time that she stopped going to school?---Yes. She went to school a couple of months after that, but by then she was no longer able to sit up and she was having just so much breathing trouble that she didn't go to school after that, no.

THE CORONER: Where was the funeral?---The funeral was in Fregon.

MS MCDADE: The funeral service was held in Fregon, that was part of the compromised situation concerning non-ventilation incubation in her natural parents, her extended family had the choice of venue of funeral.

THE CORONER: Where was it, Fregon?---Fregon.

Where's that?

MS MCDADE: South Australia, I believe?---South Australia.

THE CORONER: Okay.

(inaudible 11:10:46), around that area?---Yes.

THE CORONER: Did you go to the funeral?---Yes. We had our own funeral here. We were allowed to have our funeral here first. The and the compromise was that if we had a funeral then we had to go theirs, which we did.

You were treated with respect?---Yes, yes.

Good?---We had no problems from her family.

Good.

MS MCDADE: And in fact, Poppa Michaels and Lalla West came to your home throughout these nine years to see - - -?---Yes, yes. They just knocked on the door and came in when they were in town.

And you were quite happy for them to do that?---Yes. We had a very – they had – they knew who could come and who couldn't come. And all our foster children and other children have the same – parents have the same rights. Yeah.

Did her natural mother ever come?---Occasionally. Not for the last – been a long time since we saw her.

But you regularly saw Lalla West, her grandmother?---Yes, regularly saw Lalla and regularly saw Michael – Michael Michaels.

And she knew and recognised them?---God, yes, yes. Yes.

And they had a good relationship?---Yeah, we had photos around and she had her own photo album. And she knew, yeah. She knew who they were when they walked in the door, yeah. And she'd kick and scream and laugh and smile. No, she'd give them the hard look to start with, the you haven't – you've left me. And then she'd smile and play with them and they'd read her stories and talk to her. And they came right up to the last few months before she died.

At some stage before Queenie died, I think about 18 months, she was bedridden, wasn't she?---Yes.

And that required you to give her intensive care for the last 18 months?---Yeah, yeah.

You would have to move her?---We had to do everything for her at that stage. She could not longer sit on the toilet to toilet her. We put a bath in her room that we could put a lifter into. Yeah, she had to be rolled couple of hourly, we had to – and she was still demanding because mentally she was still very with it. So we had to move her all over the house with all the bed all over the house and - - -

THE CORONER: What during the night, you had to get up and move her body over?---I used to roll her and settle her last thing before I went to bed. And unless she woke, I left her to sleep. But towards the end of course we were up all night, all the time.

MS MCDADE: Can you describe for me Queenie's room, and what she had around her as an amenity?---She was just a bit spoilt. She had a hospital bed we bought for a previous person, a proper high-low tilt bed. She had her own VCR, TV, radio, stereo system. We 'd converted a bar in her room into a bath. So she had her own bath in her room. She had glass windows two sides, so she looked straight out into the mountains. She was spoilt rotten. And we loved her. We loved her to bits. But Queenie gave back love, it wasn't a one-sided love. Queenie knew who she loved. She loved her grandparents and she loved kids at school. And she would give Tors the dirtiest look you've ever seen in the world when she walked, in fact, he used to call people in some times and say, look at this kid. And then she'd smile. But when she first saw Tors, it was always, you know, yeah, this particular look she reserved for him. And, yeah, we tried not to tell her she was going to the hospital until we actually got into the carpark. So for all her – you know, she had – she was a very, very lucky little girl. Not just from our point of view, but from schooling, from – you know, the school put up with things that they probably wouldn't have put up with other kids, but she just fitted in so well.

Now it became quite apparent in 2001, though, that Queenie was becoming terminally ill, wasn't it?---Towards, the end of 2001, yeah. She'd had quite a few nasty episodes and we knew by then that we couldn't operate. The doctors had decided that she was too compromised to operate and - - -

That's in relation to the spinal fusion?---Yeah. We had – we were ready for spinal rods to straighten her spine and she beat us to it. She just got so compromised we couldn't do it and I guess that was the hardest thing Graham and I ever had to do. Because we had a life

expectancy much, much longer and we lost it. And, yeah, that was a pretty hard day, when they decided they couldn't operate.

And did you start to think about what would happen when Queenie did have a real emergency?---Yeah. Probably about six months after that. By then it was pretty obvious that she wasn't going to last the x number of years they thought she would and Doctor Chang had seen her and we knew that she was pretty – her prognosis was very poor. And so we had family meetings between the family and FACS, Tors, myself and Graham and decided that she was to be treated for pneumonia but not to be ventilated. And that held for about 12 months, I think. And by then it was obvious that she was in big distress and that by treating her pneumonia's we were simply prolonging a very difficult life. And so we made the decision to palliative care her.

And that was made in about July 2002, would that be right?---I think so. No, it was a bit later I think, than that.

August, September?---Yeah, yeah. She – we put her on palliative care and she, by then, was very sick anyway and she lived nine weeks with full palliative care.

And that full palliative care was conducted basically by you, at the end of the day, wasn't it?---Yeah.

You didn't leave your home, did you?---No.

You stayed with her every minute of the day for the nine weeks?---Yeah, pretty much. I had a few, one hour a week, yeah, someone would come and sit with her if she was well enough.

One hour a week respite?---If she was well enough.

And if she wasn't well enough, you'd stay?---Yeah.

And in fact, even in the periods when she was hospitalised, that didn't give you any respite either, did it?---No.

Because you were there?---Yeah, I didn't sleep there, but I stayed there during the day until late at night. And went home, had to go and look after the others. Poor old Graham wore the brunt of a lot of that.

I'm sure Graham gave you great support as well?---He did, yes. And he was there as much as he could be too.

And Doctor Clothier came every day too, didn't he?---Yes, every day for nine weeks.

Whilst the palliative care was - - -?---Yes, twice a day some days.

And you were all there when Queenie expired on the 6th?---Yes, Tors, Graham, myself, palliative care, yes, we were there. I rang them about half past 6, I knew we'd had a terrible night. Tors had gone home about midnight. I'd rung him about 5 to say she was going, and he stayed until about midnight and 5, half past 5 I knew she was going to die. So I rang Tors, palliative care and I rang FACS but they didn't get there in time. And so we were all there. By that stage, she was unconscious.

THE CORONER: Ms McDade, I don't think we need to much more, do we?

MS MCDADE: No, Your Worship.

Thank you very much, Mrs Bevan. You've done a wonderful job?---Thank you."

17. I also adopt the comments made by my Counsel Assisting in her opening (Transcript P7):

"Queenie Michaels, while she was in the care of Mr and Mrs Bevan, experienced a quality of life that was quite exceptional. She was loved and cared for. Everything that could be done for her to enhance her quality of life and ensure her ongoing medical wellbeing was done. More than that. She became part of Mr and Mr Bevan's family and was embraced by them.

And you will hear from Mrs Bevan in relation to that. And you will really, at the end of it, be quite impressed that there are individuals such as Mr and Mrs Bevan that can take on such children and give them so much."

18. I indicated during the Inquest that I would refer the transcript of the Inquest and my findings to the Attorney-General and Chief Minister. I will ensure that is done and I will also strongly urge the Chief Minister to appropriately recognise Mr and Mrs Bevan for what they have done and continue to do for children like Queenie. Without people like the Bevan's what would happen to children like Queenie? Mr and Mrs Bevan are

deserved of public recognition and thanks. Dr Clothier similarly should in my view also be considered for similar recognition.

19. I am satisfied on all the evidence that Queenie Michaels received the best medical and emotional care. The Bevan's lost a daughter and she can't be replaced. I extend my sincere condolences to the Bevans and my most sincere thanks from myself and on behalf of the NT community for what they have done for Queenie, and the other children that are or have been in their care from time to time.

Dated this 31st day of July 2003.

GREG CAVANAGH
TERRITORY CORONER