

Witness Name: Camilla Fay Denny

Statement No:WITN2330001

Dated:16th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAMILLA FAY DENNY

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Camilla Fay Denny, will say as follows:-

1.Introduction

1. My name is Camilla Fay Denny. My date of birth is GRO-C 1954 and my address is known to the Inquiry.
2. I am in the category of an 'affected person' as the only sibling to my older brother Owen Denny, who passed away in 1991 after receiving infected blood products. He had been using blood products for many years to treat his haemophilia, but I believe he was infected with contaminated blood products in around 1980/1981. I am now Owen's only remaining close living relative as both of my parents are also deceased. I have never been married

and I have no children of my own. Owen also never married and did not have any children.

2.How Infected

1. My brother, Owen Denny, was four years older than me and my only sibling. He had to come first in our family all the time, because of how poorly he was and how much treatment he always needed, but we were very close. I remember when we were very little, realising that Owen was different when my Mother was having to push him along in a wheelchair. As a child you just accept things, and this was just our normal life really. Growing up mum was always so positive and strong and so we were too. Our parents paid for Owen to go to a private school because they worried about him being bullied because of how poorly he was and had to wear a calliper on his leg and they wanted him to be looked after. Our Father died of a cardiac Infarction at work where he was a bank manager, at the age of 48 years old in 1971. I was 8 and my brother was 12 at the time and so it was just the three of us left. We were very private and a strong family unit so we were closer as a result of that.
2. When we were in our late teens/early twenties, we both attended the same art college where Owen later went onto become a technician in the photography department and he used to help me with my photography. We used to meet up at lunch times – we got on very well. Owen was the bridge between my Mother and I as he was closer to her than I was. We both lived with my Mother until Owen's death in 1991 and I continued to live with my Mother until she also passed away in 2005.
3. Owen was the only person diagnosed with Haemophilia in our family. The doctors said that it has to start somewhere and so I supposed it had started with Owen. I made the decision when I was very young that I would not have children because I had seen what Owen had gone through with the haemophilia and I did not want to pass that onto any children.

4. Owen was a severe haemophiliac, which was diagnosed when he was two and a half years old when he attended the John Radcliffe hospital in Oxfordshire (where my family lived at the time) with a cut, bleeding lip. He had tripped over the back step. Of course, I wasn't born at the time, so I am relying on my Mother's description of what happened. At that stage, the hospital medical staff were preparing my parents that they were going to lose Owen because of the bleeding and there was nothing they could do, due to the severity of the haemophilia. This would have been in the early 1950's, but my parents couldn't believe what they were hearing and they said, 'you have to do something!'. They wouldn't accept what the doctors were saying, that there was nothing they could do for him. Even then, right from the start my parents had to fight for Owen, and of course he did recover from that injury.
5. It was a time of discovery and of learning for my parents – Owen had severe haemophilia and he would wake up in pain and then realise he'd had a haemorrhage. He didn't need to knock himself or cut himself to have a bleed, he would just wake up in pain. His joints were badly affected, and he had limited movement in both arms because of it and his left knee. He did end up in a wheelchair for a while as a child and he then went on to have a full-length calliper fitted to his left leg so that he could walk properly and my parents had a boot made for him to fit it into. We didn't realise straight away that Owen also never put on very much weight and was ill all the time partly due to the fact that he only ever had one kidney. My parents sent Owen to a private school to make sure that he was looked after as they didn't want him being bullied at school and they were very good there. Eventually, his health did improve vastly for a little while at around the age of 21 years old. He only walked with a slight limp by this time and the calliper was no longer needed.
6. I am not sure that I ever knew exactly which type of haemophilia Owen had – whether type A or B. I know it was definitely not the Christmas type one, but other than that all I can say is that he had a severe form of haemophilia. As a

child, he was treated with plasma for many years. He was treated at the Haemophilia Centre which started initially in the Royal Infirmary in Cardiff in the Children's ward. I think this stopped at 12 years old when then children had to go into the adult ward, which was called William Diamond. There was no comfort there at all; we had to sit for hours and hours on a bench outside when he had his treatment, as I wasn't allowed into the ward as a child. They then moved over to the Heath (University Hospital of Wales) - the A7 block it was called which was the haematology department. I know Owen was always dealt with by Professor Bloom, even as a young child.

7. Initially, for many years Owen was treated with plasma and then this moved onto the cryoprecipitate, although I'm not sure when this started. He had to go into hospital for this to be administered. By the time he was in his late teens onwards I would say, he used to have to inject himself at home, with the Factor VIII which he used to get from the Haemophilia Centre at the Heath Hospital in Cardiff. He would keep it in the fridge and then just take it out as and when he needed it and inject himself in his arm – his arm was always covered in bruises from this. Each time he did this, the needle would have to be put straight into a little box we had been given by the hospital and he had special medical wipes to clean things up and clean the blood away. He had to fill out a form each time he used the Factor VIII, where he recorded which joint was affected and things like that. The forms then had to go back to the hospital as well as the needles which had to be emptied into a big closed container – like a bio-hazard bin.
8. It was around 1980/1981 when he would have been infected with hepatitis C (HCV) as a result of injecting the Factor VIII. He used to have blood tests in the out-patients appointments and so this is how it was discovered. There came a point when Owen knew that the blood they were using had been causing other people to be infected with HIV and hepatitis. It was just well-known at that time in the ward where he used to go for treatment and for his out-patients appointments, although no-one officially spoke to him or told him of the risks involved at all. It wasn't that anyone medical sat him down and

explained things or talked to him about it, but it was just freely known amongst the haemophiliacs on the ward that people were being infected and they were dying. Everyone kept it very quiet. There was a stigma attached to being infected, by people who were ignorant. It is the ignorant people in this world who are the bullies.

9. Owen used to talk about people who he used to see regularly at the outpatients' appointments, just no longer being there and how sad it was as they must have died. It just seemed to him to be a risk he had to take because he knew that the blood products were saving his life – the Factor VIII was something he had to have. At some stage we came to realise that it was all happening because the Government were refusing to pay to have the blood heat-treated. We knew that Professor Bloom knew this and we felt that he had the power to do something as the Head of Haematology – to get together with the other heads in other hospitals and do something about it. But he did nothing, even though he knew what was being done and the risks to the patients and the lives being lost. It seemed to me that he just took his professorship and kept quiet.
10. Owen was first diagnosed with hepatitis C (HCV) when he was in his late 20's I think. He was told at an out-patients appointment which of course, there is no record of for some reason. He had been very poorly leading up to this and had been in bed with a high temperature. He had taken time off from his job at the college to go to the appointment. He did not tell them in work that he had haemophilia or that he was going for these appointments, because of the stigma and so he had to just take it as a day's annual leave as he always did. No information was provided when he was given the diagnosis other than the fact that he had contracted hepatitis C (HCV). He just accepted automatically that it had come from the blood – it was not information freely given but he just knew that this is what was happening to haemophiliacs who had to have the Factor VIII.

11. At what Owen thought was a routine out-patients appointment a few years later, in the mid 1980's, he was just told very cold and matter of fact that he had HIV. There was no feeling or empathy. They said he had HIV and that it would develop into AIDS and there was a life-limit on this – that he would not live very long – it was a death sentence. We thought he could have been told in a kinder way. He went for a routine appointment and he was just told it would end in his death. There was no support given to Owen in any form whatsoever. We were never given any support either.
12. I found out about the HIV because mum and Owen were talking in the kitchen after his appointment and I came in and Mum said I think we should tell your sister. He had needed to get home to us on his own after being told he had HIV – Owen was a big softie really and I did wonder how he felt trying to get home to us from that appointment to tell us. This would have been difficult for him. He explained it all to me and that it meant he would die. I was in my late twenties I think when we found out that Owen was going to die as a result.
13. Owen died about four or five years after he found out on the 31st of March 1991 at the age of 40 years old. His death certificate said natural causes, which we were not happy with and could not understand how they could claim this as he had been infected with HIV and hepatitis C (HCV) by the Factor VIII that hadn't been treated and had been given to him by the doctors who knew this and knew the risks.

3. Other infections

1. I do not know of any specific other infections that Owen had contracted, but he did develop these awful boils all over his body which we felt was linked to the Factor VIII treatment. He would tell the nurses at the Haemophilia Centre about them, but he always would come back and say to mum that they hadn't taken any notice and wouldn't offer any sort of advice or opinion on them or tell him what he could do about them or to see any other expert or department. They were obviously sore and uncomfortable – it's bad enough

when you have one boil, it bothers you, but they were all over his back. He never felt that the nurses were very bothered about these things; the only nurse I can remember the name of was Sister GRO-D who is still alive now. In those days, you weren't 'mamby-pambied' and so I think he never thought to make a complaint or say anything about that – it's just how things were at the time.

2. At one stage though he did shed all his skin and they were considering sending him to the tropical diseases centre in London. They sent him up to research places in London which I think may have been the London School of Tropical Medicine and he was told it was all to do with the treatment he was having and he just had to accept it as part of it all really.

4.Consent

1. Owen was never told about the risks of contracting any diseases. He never had a medical professional sit down and explain anything about that. There was never any information available and we were never told anything by the hospital – no advice going forward or what we should do to manage the virus or anything like that. Professor Bloom never said anything at all about risks or explained anything properly – he didn't answer questions properly- he was always quite sneaky. Owen always said that Professor Bloom had known that the blood had come from prisoners and prostitutes in America who had been paid for it, but he didn't seem to care about this – he didn't really have much time for the haemophiliacs we felt.
2. I don't think he was ever treated or tested without consent or for research in any other way. They often took blood tests and just said if you don't hear anything back from us then assume everything is fine.

5.Impact

1. We tried to be a strong and positive family because mum was so positive. Owen never wanted to dwell on things and he didn't want to be defined by the

diagnoses he had. He just always wanted to get on with his life. But there was a stigma that we had to live with even around the haemophilia and having to have treatments and the risks of haemophilia. We were a very private family as a result and kept to ourselves. This could be quite isolating – it was like living a double life really for all of us. We did not want to be targets.

2. Mum was the head of a special school and I was a teacher in a comprehensive school when we found out that Owen had HIV. I could not have ever revealed to anyone that Owen had HIV. People at mum's school and my school and at the college where Owen worked would not have understood and would have made life very difficult. People were very ignorant at the time about it and they did not understand that there were very limited ways to contract HIV. People thought it was easily passed on and people were also very nasty about it.
3. Our neighbour GRO-D was awful to us and very threatening as she suspected that Owen had HIV and she used to stand in the street shouting that people should keep away from the gates of our house because Owen had AIDS and they should keep their children away. Mum tried to talk to her and explain that even if Owen did have that, he wouldn't pass it on that way, that there were only a very limited number of ways to get it. She tried to reason with her but she kept screaming when she saw us. So mum would say let's go out in the car to diffuse things and that's the only way to calm her down and so that is what we always did in the end. Some people in the community would be ok to us about what she was saying and we'd say 'you know what GRO-D is like', so we didn't tell them about Owen or anything, we would just say that really. We never went to the police about any of this because we didn't want to inflame things further and those were different times. There wasn't really such a thing as hate crime then.
4. Professor Bloom was requested by the parents of a child, around that time, to attend the school of their little boy who had contracted HIV, to explain to the school community in Laleston (Bridgend) that he had HIV, but that it couldn't

just be easily passed on etc. To explain the facts to them so they wouldn't be ignorant about it. It was meant to be to try and get the school to understand and allay fears but they were all awful about it to the child and their parents. So we knew we could never say anything about Owen, because people just didn't understand. We kept it all very low key.

5. I never married and I chose not to have children because of the difficult life that Owen had. Owen had two relationships really. One was with an air hostess whose family was very concerned about the haemophilia. Another relationship ended when the Father of the girl rang my Mother to say that he didn't want his daughter involved with Owen because of the haemophilia. After the diagnosis of hepatitis C (HCV) and then HIV, he did not have any other relationships again as he did not see the point and he knew that he could infect people.
6. In terms of Owen having access to other treatments, I just know that he never saw GP's about anything. Whenever there was anything at all he just had to go to the ward in Cardiff. My Mother would phone them if he was ill and they would say bring him up. Once he had the diagnosis of HIV all that used to happen in addition really was that they monitored him for weight loss. He didn't have any medication for it – I don't think there was anything they would give at the time. Things are different now, but there was nothing then, you just knew they would get AIDS and die. Owen was always determined to try and live a normal life and he always soldiered on and worked as much as he could at the college, but he could never tell them about his illness. The stigma was too much.
7. When Owen died, the impact on us was devastating, especially for my Mother. I tried to help her get through the grief but I don't think she ever got over it – she really suffered and so did I. I feel that I have never had any proper closure about any of it.

6.Treatment/Care Support

1. Owen never had any counselling or support before or after his diagnosis and neither did we. Nor did mum or I get any support, information, counselling or anything at all after his death. I feel so strongly that he should have been treated better and had support and we should have been able to bury him the way we wanted because Owen always just soldiered on and he deserved that.

7.Financial Assistance

1. Owen never had anything and neither did we. He never pursued anything to do with money or compensation.

8.Other Issues

1. There are numerous medical records missing. There is absolutely nothing in the medical records that shows the numerous out-patients appointments he attended at the Heath hospital, which were at least 80 in number, if not more. These appointments were so important, yet I cannot find anything recorded about them. When I asked about where these were, I was told they could not find anything else in the records and that they had sent everything. I think these have been destroyed.
2. The other thing that really concerned and upset both myself and my Mother, is to do with Owen's death. My Mother and I discovered him dead on the bathroom floor at three thirty a.m. on a Sunday morning. He hadn't been very well and had been very confused in the week leading up to his death. What he had been saying wasn't making sense and my Mother had said she was feeling worried about him. Even Owen knew at times, that what he had said didn't make sense. Mum had decided that if he didn't improve over the weekend she would ring the Haemophilia ward and he could go in, as he had open access like that. Owen had also lost weight and had dropped from around 11 stone to about 10 stone I think. He was always very slim, but he

was now looking very gaunt in the face. After we found him, we could tell straight away that he had died - his eyes were very deep. When we rang 999, they took him away to hospital and we were never allowed to see him again. Professor Bloom's secretary then contacted us to say that the body had to be cremated within 48 hours because of the HIV and that we had to use a specific Undertaker's in Cardiff – Pidgeon and Sons.

3. My Mother was not happy at all about this and she was annoyed that the message just came from Professor Bloom's secretary and not anything from him personally. She was adamant that we wanted to use our Undertaker in GRO-C and that she wanted him buried in a bricked grave and not cremated. They had been very determined that we only had 48 hours to get the body cremated but on day three, Professor Bloom seemed to relent and say that we could have the body to be buried as we wished but that it had to be a closed casket and we could not see or open it all. Mum and I eventually said to each other that we hoped that Owen was actually buried in GRO-C and that he had not been taken and cremated in that 48 hours, because we had no way of knowing for sure. But it seemed strange that a day after the time limit had already passed, he then said we could have the body back. So we don't know if we actually did bury Owen in GRO-C or not and I feel very bitter about this. My Mother never really ever got over it, right up until her death.
4. I have never been involved in any other litigation and neither has Owen or any of my family.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed..

GRO-C

Dated...

16th February 2019.