

Witness Name: Kay Ann Davies

Statement No: WITN3877001

Dated: 21st December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KAY ANN DAVIES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13th December 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Kay Ann Davies will say as follows:-

1. Introduction

1. My name is Kay Ann Davies my date of birth is GRO-C 1959 and my address is known to the Inquiry. I am divorced and have three children and nine grandchildren. I am presently employed as a Carer.

2. How Affected

1. I am the mother of Kirk Ellis who was infected with hepatitis C as a result of his treatment with Factor VIII at the University Hospital of Wales (UHW) Cardiff. Kirk has also submitted a witness statement to the Inquiry.

2. Kirk was admitted to the Royal Gwent Hospital, Newport when he was 14 ½ months old because he suffered bleeding and bruising when he sustained a fall. He was later transferred from the Royal Gwent to the UHW and placed under the care of [GRO-D]. It was at this time that I was told that Kirk had severe haemophilia. I did not understand what [GRO-D] was referring to as I had never heard the word 'haemophilia'. I completely misunderstood because of the lack of understanding of this blood disorder. The only blood disorder that came to my mind was leukaemia. It was only after further discussion with [GRO-D] and a lot of in-depth explanations by him that I had to accept my son actually had haemophilia.

3. To gain some background knowledge of Kirk's haemophilia [GRO-D] [GRO-D] asked me questions about my family tree and asked me if I could prepare one. I informed him that I had one brother and that there were many other male cousins in the family in their teens or early 20's who weren't haemophiliacs. [GRO-D] said in that case I was not to bother preparing a family tree. He explained to me that it was exceptional for Kirk to turn out to be haemophiliac if haemophilia was not already in the family. [GRO-D] seemed to take a special interest in Kirk in light of this and would sometimes come to the ward especially to see Kirk if he had been admitted with a bleed. [GRO-D] [GRO-D] said he could see no point in testing the rest of the family.

4. Kirk was diagnosed as a severe haemophiliac at the outset, but over time I came to realise that in fact he was not severe. I would have conversations with the other parents at the hospital about their experiences and could see the injuries that their children suffered. Many of them were spending huge amounts of time in hospital as a result of bleeds etc. This did not correspond with what was happening with Kirk. I asked for Kirk to be re-tested and met with some resistance from the medical staff to do this but I insisted and eventually they did re-test him. This time the result showed he had moderate haemophilia.

I believe Kirk was given a severe diagnosis originally so they could put him on Factor VIII for research purposes.

5. Kirk received Factor VIII treatment at the Haemophilia Centre at the UHW under the care of [GRO-D]. I believe that it was through this treatment that he became infected with hepatitis C.
6. I was not provided with any information or advice in relation to the Factor VIII treatment or of any risk to Kirk.
7. In approximately 1992 I was told by the medical staff (I cannot recall who specifically) that Kirk had a liver problem but hepatitis C was never mentioned to me. The first time that hepatitis C was ever mentioned to me, was in 1996.
8. In 1996 when Kirk was 15 years old he had a fall and a subsequent bleed which resulted in him being admitted to the UHW. He had admitted to the doctor that he had fallen after drinking alcohol. They called me to the hospital for a meeting with [GRO-D] and this is when he told me that Kirk was infected with hepatitis C. I am almost sure we would have seen [GRO-D] on this occasion although I don't have a definite recollection. I recall it being explained to us that Kirk had hepatitis C but at that time I could not comprehend what I was being told. I just could not take it in. It was the first time that hepatitis had been mentioned to me. It was only when Kirk and I went home and talked it through that the seriousness and full realisation hit me. I was really upset at what I felt I had given to Kirk. I felt so guilty. I had many questions for [GRO-D] at our next appointment. I wanted to know why this had happened to Kirk and I worried what his future was going to be like.
9. When it was explained to us that Kirk had hepatitis C I suspected that the medical staff had known long before they told us. I think they

decided to try and see if they could solve the problem somehow before they needed to tell us.

10. Kirk would attend many of his appointments alone as he got older but he would always discuss the appointment with me afterwards when he came home to keep me updated. He had a good understanding of his treatments and would explain these to me.

3. **Other Infections**

1. Kirk has recently found out that he is also at risk of vCJD. This was revealed from records recently received from the National Haemophilia Database. These records confirm that he was given blood from the relevant infected batches.
2. At the present time, Kirk is suffering with cirrhosis of the liver.

4. **Consent**

1. I believe there is a definite possibility that Kirk was treated and tested without my or his knowledge and consent and without adequate information being provided to us.

5. **Impact**

1. Kirk and I have a very close bond as mother and son and we confide in one another. Kirk is a very loving son.
2. As a child, Kirk had a very happy go lucky kind of personality. He was a happy child. However in the last ten years or so his personality has changed. If things don't go his way he can be short tempered. It doesn't take a lot for him to get a "bee in his bonnet". It seems that he cannot cope with difficult situations. Everything seems to turn into a 'drama', whereas not so very long ago he would have been able to

cope. Kirk is loving towards me and his family but I notice a difference in his attitude. He tends to lack positivity and gets depressed. I think this is because he's in constant pain and finds it hard to cope.

3. Kirk's infection impacted hugely on him and the family. He went off the rails for about two and a half years. It was hell. He went from a gentle, likeable boy to someone who would show off in front of his friends and be very moody and confrontational with me and his siblings.
4. When Kirk was in secondary school he would get depressed and binge eat. This caused him to put on a lot of weight. This behaviour carried on into his early 20's.
5. Kirk was always very close to his grandparents and would spend a large amount of time with them but during these depressive episodes he would even upset them with his moods.
6. Kirk was given four lots of treatment, two of which were Interferon. In 2009 he was given Peginterferon and Ribavirin. The first three treatments did not work but the fourth did and now Kirk is clear of the hepatitis C virus.
7. I am not aware that Kirk experienced any difficulty in accessing treatment(s) or that there were treatments that ought to have been made available to him.
8. As a result of the treatment Kirk received for the hepatitis C his liver has become cirrhotic. This causes him great concern and worry and he is in a lot of pain.
9. Kirk used to go to the UHW for his dental treatment but he would always be left to be the last patient. Sometimes just a check up would take all day just because of the waiting around. I got in touch with a local dentist and explained to him what was happening at the UHW and

he said he was happy to see Kirk and from that day Kirk has attended his surgery without any fuss.

10. I tried to keep family life as normal as possible but it was difficult when Kirk was suffering with depression. He did not want to socialise. He was embarrassed at the increase in his weight through bingeing on food. I think some of his "so called" mates took advantage of him if he had money. He only had one or two "good" mates. Falon and Luke, Kirk's sister and brother, were very close and supportive to Kirk even though through his mood swings, he would lash out at them verbally.
11. The impact of Kirk's illness on me has been very emotional. I blame myself for inflicting this terrible illness on him. I feel enormous guilt about this.
12. When Kirk was diagnosed with haemophilia at such an early age I remember [GRO-D]'s advice to me was not to have any more children as if I had a boy, the chances were that he would also be a haemophiliac. At the time Kirk's haemophilia was well controlled and not causing too many problems so we went ahead and I got pregnant for the second time. I remember attending an appointment at the hospital with Kirk when I told them I was pregnant. The staff suggested that I take a test to find out the sex of the baby and I was advised that if it was a boy then I should consider a termination and they could carry out tests on the foetus. I told them that the baby had been planned and there was no need for any tests to be carried out.
13. When Luke was born, he was tested for haemophilia and [GRO-D] [GRO-D] was extremely surprised when he turned out not to be a "bleeder". Later I had another child Falon. She was tested for haemophilia when she gave birth to her first child and the test showed that she was not a carrier.

14. I still worry a lot about Kirk if he goes into hospital for an operation but I try to keep it to myself. The worry never goes away and is still very raw.

15. In relation to stigma, fortunately we did not suffer in this way. We were always very up front about Kirk's haemophilia and his family and friends understood about this. When he became infected with hepatitis C people did not seem to know much about this virus, the hype seemed to be about HIV.

16. Kirk's education was affected to some extent because he would bunk off school although it didn't seem to stop him from doing the job he wanted to do. He enjoyed woodwork and qualified as a Joiner. He worked for a company called Dudleys for a few years. He then went on to do factory work. He did this for a number of years but had to give it up as he was taking quite a lot of time off through various treatments and operations.

17. Kirk had a good work ethic and carried on working for as long as he possibly could. He never played on his condition. I can remember him being in tears if he could not go into work because he felt so ill. The company tried to help by reducing his hours but in the end it became too much and he had to give the job up.

6. Treatment/Care Support

1. I am not aware of Kirk facing any difficulties in obtaining treatment.
2. Kirk received some counselling at the Haemophilia Centre before he started his second course of treatment. I am unsure as to whether he has received any further counselling.
3. I have never had or been offered any counselling.

7. **Financial Assistance**

1. I am unsure as to what financial assistance Kirk received but I believe this is set out in Kirk's statement to the Inquiry.

8. **Other Issues**

1. I want to ask the Inquiry to find out why this awful thing happened to so many people? Also how was it allowed to happen?
2. I think that the different level in payments depending on where you live in the country is extremely unfair and this needs to be addressed by the Government. There should be a fair distribution of money and there should not be any discrimination.
3. The families of people who are deceased should receive some kind of compensation for their loved ones.

Statement of Truth

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

Signed GRO-C

Dated 21/12/19