

Witness Name: Karisa Jones
Statement No.: WITN2019001
Exhibits: WITN2019002
Dated: 11 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KARISA JONES

Section 1. Introduction

I Karisa Jones, will say as follows.

1. My date of birth and address are known to the Inquiry.
2. I met my late husband, John Geraint Jones, when I was thirteen. We were together when I was sixteen and later married. Together we had three girls, Kayleigh, Katrina and Kirstyn. When I was first married I worked as a secretary but I am no longer able to work due to my disabilities.

3. I live near Neath with my partner, Carl, and Kayleigh's two sons, GRO-C

GRO-C

GRO-C

4. My three children, Kayleigh, Katrina and Kirstyn live nearby, as do my mother and father, and we all see each other regularly. Katrina has a daughter, GRO-C age two, who lives with her.

Section 2. How Infected

5. I make this statement first and foremost as an affected person, on behalf of my late husband, Geraint, who died as a result of Hepatitis C. I also make this statement as an infected person, as my husband unknowingly passed Hepatitis C on to me before his death.
6. Geraint used to work in a frozen foods factory. He went to work on 20 June 1990 and a forklift driver drove into him whilst Geraint was unloading a delivery from a lorry. Geraint was pinned by the forklift and suffered severe injuries to both legs. He was admitted to Morriston Hospital, Swansea, where he was operated on to try to save his right leg by using the artery from his left leg but it didn't work and his right leg was amputated above the knee. He received many, many blood transfusions and was in theatre every day. At one stage blood was being transfused and coming straight out of his leg and the staff had to mop it up off the floor. He was in intensive care for four weeks. He gradually recovered and started coming home for weekends in September several months later. Geraint was then back and forward to hospital, having prosthetic limbs fitted and receiving physiotherapy on his remaining leg for a long time. He became diabetic as a result of the accident through shock and became insulin dependent.
7. We adjusted to our new life slowly. We had to move house because the council refused to make adjustments to the house we were in. Our second

daughter, Katrina, was born a month after the accident in the middle of all this. We moved to new council accommodation and a stair lift was installed, as well as a drive. The council only put down half a garden path as they said they couldn't see any need for Geraint to access the end of the garden. We got on with life, and although Geraint suffered with his amputated leg, including dreadful blisters on his stump, he never complained.

8. Six years after the accident Geraint received compensation from his former employer and he bought our family home with it. The house was derelict and we had all of the work done to renovate it. He secured our future.

9. By 2012, we had our first grandchild, [GRO-C] living with us. He was five at the time and on 1 March 2012 [GRO-C]
[GRO-C]
[GRO-C] One
Friday, in April 2012, Geraint and I were due to take [GRO-C]
[GRO-C] Geraint got up in the morning and started vomiting. I thought it was just a bug, and I was in a rush [GRO-C] so Geraint did not come.

10. When we came back [GRO-C] later that morning I could hear Geraint being sick again. I went upstairs and discovered he was vomiting blood. I called an ambulance and he was admitted to hospital. The following Thursday [GRO-C]
Geraint was still an inpatient, and Geraint phoned to say the doctors wanted me to go in for a meeting. I took [GRO-C] with me and we were taken into a side room with Geraint. We were told Geraint had a huge cancerous tumour on his liver and that there was nothing they could do because it had gone too far. We were told Geraint had Hepatitis C which was likely to have caused the cancer and that the Hepatitis C was likely to be a result of his blood transfusions with contaminated blood in 1990.

11. We had to fight for a referral to Cardiff to see the specialist. We succeeded in getting an appointment and the specialist said Geraint's prognosis was a year to 18 months. The consultant offered chemotherapy straight into the tumour in an attempt to give Geraint more time. Geraint had chemotherapy and it didn't work. They tried a second attempt a few weeks later but again, it didn't work. Geraint was vomiting blood every single day. I wrote to private doctors to ask for second opinions, I even asked for a liver transplant for Geraint, and to offer part of my liver, but we were told nothing would work.
12. Geraint suffered an horrific death. In no time at all he skin was yellow, his eyes were yellow and he went from being a strong man to a skeleton. He had bleeds upon bleeds and he suffered terribly. Sometimes when he suffered a bleed the ambulance crew would put bands around him to try to stop the bleeding. One Saturday he had a bleed and he was so tired they suggested admitting him to hospital. On the Monday they suggested a hospice and he was transferred the same day. He could still speak to me that day. I stayed with him throughout and didn't come home. They put an injection or a drip into him and he was just out of it. I sat by him through the night and he was very agitated. He was trying to climb and was screaming 'get me out of here, take me home'. I made arrangements for him to come home and ordered a special bed, but they told me on the Thursday that he wouldn't make it, so on the Friday all his mates came to see him at the hospice. Later that day Katrina and I were sitting with him. Suddenly I knew he was going and I asked Katrina to leave. He died in my arms.
13. When we first found out Geraint had Hepatitis C the doctors advised that GRO-C GRO-C I got tested. GRO-C I had my test and it came back positive. It turned out I had the same genotype as Geraint: the hospital said he had passed it on to me. Geraint blamed himself, but it was not his fault.

14. I went to see Geraint's doctor at Singleton Hospital, Dr Ch'ng. He was very good and said I needed to start treatment as soon as possible, but because it would make me ill and because of Geraint dying, Dr Ch'ng said that they would hold the treatment off a bit. At that point I couldn't understand why, as I didn't know how ill it would make me.
15. Geraint died on 28 September 2012 and, about three weeks after his funeral, I had to go and see Dr Ch'ng. I had to start treatment and it was the horrendous, the worst thing I have ever experienced. I received Interferon and Ribavirin, injecting once a week and taking 38 tablets a day. My dad was with me the whole time. He took me to every appointment and looked after me at home. I couldn't eat anything as everything tasted like soap and I vomited frequently. I lost five and a half stone in weight. My hair fell out, my skin itched terribly and broke open and bled, and I was too weak to move. I had problems with my bowels, which is one of the side-effects, and I had to have anaesthetic inserted to stop the pain. I have been left with heart problems as a result.
16. The treatment lasted for six months. Two weeks from the end of treatment I felt I simply couldn't take any more. I knew I had to finish the treatment so made myself keep going. And then that was it. Six months later I was told I had cleared the virus.
17. Geraint received no information or advice about the risk of being exposed to infection through contaminated blood.
18. As a result of being given contaminated blood Geraint was infected with Hepatitis C, and I was infected through him. We had the same genotype and the hospital explained that it is likely he would have infected me through sexual relations.

19. Geraint was informed of his infection at Morriston Hospital, Swansea, in April 2012. Although we knew Geraint had Hepatitis C in April 2012 we didn't know whether this is what had killed him. Three years after Geraint's death we had the Inquest and the findings were that Hepatitis C had killed him. His death certificate records contaminated blood as a cause of death. [W2019002] I am in the process of applying for Geraint's medical records, and my own. I recall that at the time there was some difficulty tracing batch numbers for Geraint's transfusions, but then they did manage to find them. I do not have these details at the moment but hope to once I receive our medical records.
20. At the time he was informed that he had Hepatitis C, Geraint was not given adequate information to help him understand and manage the infection. We were not advised not to share certain things, or touch certain things, or anything. The hospital knew we had GRO-C and Kirstyn living with us at the time, but it was down to me to protect the children from it. I Googled information about the virus to find out about the risks. I was very careful around the house. I had to ask for a sharps box to dispose of needles used for Geraint's diabetes – no one offered one to us. I had already been handling all Geraint's blood soaked clothes and towels. Once we knew I was infected it didn't matter. We were just left to get on with it. We had no help.
21. I believe information should have been made available to Geraint much earlier. He should not have had to wait until he was vomiting blood to find out he had Hepatitis C. He should have been told much earlier about the risks of contaminated blood through transfusion. Maybe then he could have been treated, like me.

Section 3. Other Infections

22. I do not believe Geraint or I receiving any infection other than Hepatitis C.

Section 4. Consent

23. I do not believe either of us were treated or tested without our knowledge, consent, or without being given adequate or full information, except where I have explained above, first, when Geraint was not told of the risks of contaminated blood in 1990 when he received the transfusions, or second, when there was a failure to tell him he might have received contaminated blood right up until he was admitted to hospital vomiting blood in 2012.

Section 5. Impact

24. The mental impact on Geraint of finding out he was infected with Hepatitis C made him very, very quiet. Neither of us could talk about it. I couldn't begin to understand what he was feeling. He was a broken man after that. When we found out he had infected me he was devastated.
25. For me, when I found out I was also infected, I was devastated. Nothing could describe how I felt. I could not believe it had happened to us. It broke both our hearts. We had been together since I was 16, we were best friends, we never went anywhere without each other. We had a fantastic, happy marriage. It destroyed us.
26. The physical effects of the virus on Geraint, before diagnosis, were that he had a very itchy leg on his calf. He went to the doctor about it and was given different creams but nothing helped. He also suffered a lot of pain in his stomach and felt as if his ribs were bruised all the time. He went to the GP a few years before diagnosis and was told it was muscular.
27. As for me, I went to the doctors about four years before my diagnosis because my liver readings were high and for several weeks I had to have liver reading tests, but they put it down to some of the tablets I was taking. They never

tested me for Hepatitis C. I was also very tired all the time and suffered with flu type symptoms now and again. A few weeks before Geraint was diagnosed I was in bed for two weeks and I didn't know what the matter was. I felt so ill, I was very cold and shivering and I couldn't shake it off, I had never experienced anything like it. I went to the doctor and he said it was a virus, and it would pass.

28. After Geraint was diagnosed his physical symptoms worsened. His stomach became huge and swollen, he couldn't wear his artificial leg because there was so much fluid in his stump. The doctors tried to take the fluid out of his stomach and his legs. He couldn't walk. He was very tired all the time. He couldn't eat anything at all; they gave him these special shakes but he couldn't keep them down, we tried homemade soup, we tried everything. He just wanted to be sick all of the time. I remember him telling me once that he was frightened to go to sleep, he was petrified of what might happen to him. I would stay up all night watching over him to check he was still breathing.
29. For me, the physical effects after diagnosis were overshadowed by the grief I felt for Geraint. I had no support except from my parents. I have described elsewhere what the effects of treatment were, and, once treatment started, I was too weak to move from one chair to the next.
30. The further medical complications and conditions which arose for Geraint as a result of Hepatitis C were his liver cancer, and terrible build-up of fluid causing his stump to swell, and his yellow skin and eyes.
31. For me, the medical conditions have included the flu like symptoms which I continued to suffer on a weekly basis, and I have itchy skin all of the time. My skin is scarred as a result, as I am itching from morning until night. I also suffer with tiredness, and I continue to have severe problems with my bowels.

32. As for the treatment we received for Hepatitis C, for Geraint it was too late. Although he tried two courses of injection chemotherapy, it did not work, and he was not offered a liver transplant as he was too unwell.
33. For me, I was treated with Interferon and Ribavirin for six months. I have described the side effects that I suffered as a result of this treatment above. I do not receive any follow-up. I was simply told that I had cleared the virus and it was not active, for now. I am very worried it will come back. No one has mentioned whether it is possible for it to come back. All I have been told in terms of follow-up is to go to my GP when I get concerned. It is as if you are put to one side once you have had the treatment. It doesn't matter if your skin is itching so much it bleeds, or if you are suffering mentally, constantly asking yourself whether it is going to come back. I am living in fear, how would I ever get through the treatment again?
34. I have not experienced any difficulties or obstacles in accessing treatment. Geraint did, and we had to fight for an appointment with the specialist in Cardiff, as I have explained above. I do not think there are any treatments which ought to have been offered to either of us which were not.
35. For Geraint, the mental and physical effects of his chemotherapy were appalling. He felt awful, he lost his hair, he turned into a skeleton. I sat there watching him slowly waste away and die and there was nothing in my power I could do to stop it.
36. I have set out above the mental and physical effects the treatment with Ribavirin and Interferon had on me. It was absolutely horrendous: something you will never forget and never get over. It is something you learn to live with. It almost drove me crazy, and I had to pay for counselling for myself.
37. I do not think our infected status has impacted on our treatment, either medical or dental.

38. The impact of being infected with Hepatitis C has affected our private, family and social life in the following ways.
39. Our private life was greatly affected. Geraint blamed himself for infecting me and became impotent and had to see a specialist for treatment. He felt he had let me down, but that was the last thing I cared about. As a couple, romantically, we just didn't exist anymore, we could cuddle but that was it.
40. The virus affected our family. Everyone was devastated and it put a strain on all of us because we didn't know what would happen next. Every time Geraint coughed we were worried it would be another bleed.
41. Our social life ended. Geraint would not let anyone see him the way he was. I would not leave Geraint alone and only left the house when the Macmillan nurses came in and I would go out to do some shopping. Katrina graduated in the summer of 2012 and Geraint was determined to be there. He vomited blood in the morning and he struggled to get himself ready but he just put a brave face on that day. We went for a meal afterwards but he couldn't eat anything.
42. I feel stigmatised by the infection. I have to tell people about it and couldn't have my nails done for my daughter's wedding because they refused to do them one I told them. You feel like a leper because you have to tell people so that they are aware of it and do not put themselves at risk. When my nephew was born I wouldn't pick him up unless I had gloves on in case I had a cut or something and put him at risk. I was very, very cautious around the children. If I fell or hurt myself and bled I wouldn't let anyone near me to see to me. Some people treat me as if I am a leper and they refuse to touch me, or to touch things I have touched. I only tell close family and friends. It is not something I want to talk about. I just live with it. When Geraint died people around our neighbourhood thought he had died of AIDS. People thought I had AIDS.

43. Financially, the infection has greatly affected our lives. When Geraint died, [GRO-C] and I were living off £53 per week. We would have been homeless if we didn't own this house. [GRO-C] and I went without. My family had to look after us.
44. The impact of the infection on my family has been very sad. My brother died shortly after I finished treatment, less than a year after Geraint. My parents have suffered terribly as a result. They lost their son, and they are worried terribly about me, even to this day. My dad took me to every single appointment and was with me every single day, he was devastated. My daughters live in fear of it coming back. They are frightened in case the same thing happens to me that happened to Geraint. I hold this family together and without me I do not know what would happen.
45. As I have explained at the start of this statement, until very recently, four of my five grandchildren lived with me. I feel that my infected status has impacted on the local authority's consideration of me as a carer. In the past, the local authority have asked me about my health, asking whether or not I am ill and whether this affects how well I can care for the children. I have tried to explain that no one knows much about the side effects of what I am going through. I feel they have used my ongoing symptoms against me. I have lodged a complaint that I am being discriminated against on grounds of disability.

Section 6. Treatment/Care/Support

46. The only difficulties or obstacles we have faced in terms of obtaining treatment, care and support in consequence of being infected with Hepatitis C was when we had to fight to see the specialist in Cardiff.
47. Neither Geraint nor myself were ever offered any counselling or psychological support in consequence of being infected. I was not offered any bereavement

counselling when Geraint died. As I have explained above, I had to pay privately for counselling. This was after I had finished treatment. One day, after dropping GRO-C at school, I had a breakdown. I found myself at a roundabout and didn't know where I was. I paid £40 for three sessions counselling with a therapist my aunt had recommended. The counsellor was wonderful and helped very much.

Section 7. Financial Assistance

48. I found out about the financial assistance available when I received a letter in the post from the Skipton Fund. When Geraint and I were first diagnosed he received £50,000 and I received £25,000. We also received £200 per month from the Caxton Fund from when Geraint was diagnosed. I currently receive £690 per month from WIBSS.
49. The process of applying for financial assistance was straightforward the WIBSS are very helpful. I have asked WIBSS for help with putting in a disabled shower downstairs and am waiting to hear whether they will help me. They ring me to keep me updated. There were no preconditions to receiving financial support.
50. In terms the amount of financial assistance we have received, how can you put a price on someone's life? We are struggling. I cannot work due to my ill-health, and when I am unwell with the flu like symptoms I suffer I need constant support from my partner.

Section 8. Other Issues

51. I would like the Inquiry to find out why and how this scandal happened. I would like the Inquiry to understand how it has totally destroyed lives. I want answers to why I had to sit and watch the person I loved die.

Statement of Truth

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

Signed .

GRO-C

Dated 11/2/2019:.....