

Witness Name: Janine Jones

Statement No: WITN1759001

Exhibits: WITN1759002-011

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANINE JONES

I, Janine Jones will say as follows:-

Section 1. Introduction

1. My name is Janine Jones. I was born on the [GRO-C] 1965 and I live at [GRO-C]
[GRO-C].
2. I make this statement on behalf of my late brother, Marc Payton. He was born on the [GRO-C] 1961 and died on the [GRO-C] 2003, aged 41 as a result of Lactic Acidosis, Renal Failure, Liver Failure, HIV and Hepatitis C (Hep C). A copy of his death certificate is exhibited at 'WITN1759002'.
3. My parents are still alive, both in their 80s and not in good health. Emotionally they can't cope with anything to do with the Inquiry. My father has [GRO-C] and my mother has [GRO-C] of the past is not the best.
4. I currently work at Morrisons supermarkets and I live with my husband. I have a son who is 34 years old. He does not live with us.
5. This witness statement has been prepared without the benefit of access to my late brother's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

6. Marc was diagnosed with severe Haemophilia A and I believe it was at approximately 11 months.
7. In 1967, when Marc was 6, he vomited and was very sick. He was rushed to hospital and was given Cryoprecipitate.
8. Marc filled out a questionnaire for the HIV litigation that he was involved in and stated that he was one of the first haemophilic in the UK to receive Cryoprecipitate although there is no medical evidence of that. A copy of the above questionnaire is exhibited at **'WITN1759003'**. I believe he started to receive Factor VIII concentrates (FVIII) to treat his Haemophilia from 1974 onwards. I have exhibited to this statement a large volume of medical records which provides a detailed record of treatment that Marc received at **'WITN1759004'**. I do not know if this is a record of all the treatment that he received.
9. I wish to also add that during Richard Warwick's oral evidence hearing on the 20 June 2019 at Leeds, an exhibit was shown which stated that a Factor VIII batch 'R6511' was an infected batch. I wish to confirm that Marc also received the same infected batch of R6511 on 26 June 1978 following a bleed on his forearm and buttock. This can be seen at exhibit **'WITN1759004'**, page 27.
10. He was initially treated at the Birmingham Children's Hospital (BCH). He then attended Lord Mayor Treloar College (LMTC) in 1972 and was there until 1979 from the ages of 11 to 18. He was then transferred to the Queen Elizabeth Hospital (QEH) when he was 19. Depending on severity of bleed, Marc would receive many doses of FVIII per day or everyday on a regular basis.
11. I believe Marc was infected at LMTC between 1974 and 1979.
12. My parents were not provided with any information or advice beforehand about the risk of Marc being exposed to infection from the contaminated FVIII

concentrate. My father was insistent that no information was provided to them at all. My father has a recollection of being told of a miracle drug coming from America which would revolutionise life.

13. As a result of the contaminated FVIII that Marc received, he was infected with HIV, Hepatitis B (Hep B) and Hep C. There is a medical record dated 8 December 1980 (a copy is exhibited at **'WITN1759005'**), which states in his past history '6.10.70 – 6.11.70 - *during treatment of a haemarthrosis of his left knee, he became jaundiced, L.F.T's indicating hepatocellular damage. He became Australis antigen positive. Jaundice resolved quickly*'. Although his medical records seem to show that it cleared itself, his second ex-wife thinks it came back later in his life and he had the infection when he died.
14. On 22 November 1984, Marc had a blood test for HTLV3 (a copy of the blood test is exhibited at **'WITN1759006'**) and on 8 March 1985, he was told during a routine appointment at the hospital that he had tested positive for HTLV3. He was only 23 when he was told. He had a follow-up appointment with the doctor at the hospital and the nurse and doctor were very blunt with him and told him he had about 5 years to live. The test results were communicated to him in a very matter of fact way, which I believe was cold and harsh.
15. In relation to the Marc's Hep C infection, I note in his medical records that he had a blood test on the 3 June 1991, which came back positive in a report dated 30 September 1991. A copy of the above blood test is exhibited at **'WITN1759007'**.
16. I do not believe that Marc was provided with adequate information to help him understand and manage the infections. He was told to just use condoms when he was told about the HIV infection. Regarding the Hep C infection, he was told not to drink alcohol and not to let anyone come in contact with his blood. I remember when he came and told our parents about this. He never kept anything from us and told us everything which was kept within the family.

17. Marc met his first wife in 1983 and married her in 1987 or 1988. She was

GRO-A

GRO-A

This marriage ended because of the stress of Marc's illness.

18. In the early 1990s Marc married his second wife, who was his first wife's sister. GRO-A

This marriage also ended

because of the stress of Marc's illness.

19. Marc was not provided with much information about the risks of others being infected other than the fact that he should use condoms during sex. He had no children as he was told he was HIV positive at age of 23 and so decided against it. I think he looked into sperm washing but did not make any attempts at it.

Section 3. Other Infections

20. In 1996 and 2001, Marc received a letter stating he was at risk of vCJD as he had been exposed to it. He never bothered to find out or get anymore further information as he didn't want to know to be honest.

21. His second ex-wife was convinced that he had vCJD as he was a completely different man near to the end of his life to what he was before.

Section 4. Consent

22. I believe that Marc was treated and tested without our parents' and his knowledge, consent and without being given adequate or full information. He was close to a few haemophilia nurses and found out most of his information himself and/or from the nurses rather than being told by the doctors.

23. There is a medical record which is undated from the M.R.C Cryoprecipitate Working Party. It looks like a survey or study of incidence of jaundice and it shows that Marc was being given Cryoprecipitate and FVIII was being thrown in. A copy of this medical record is exhibited at 'WITN1759008'. I therefore believe he was being tested on for the purposes of research.

Section 5. Impact of the Infection

24. Marc suffered mentally as a result of the HIV diagnosis. It made him feel like he was hit with a sledgehammer. In 1985, he was 23/24 year old young man, hoping to get married and have a family in the future. Everything that he had planned for himself was destroyed.
25. When he was diagnosed with Hep C about 6 years after being diagnosed with HIV, his whole attitude to life changed. He became completely impulsive and started buying more and more motorbikes, he wanted to buy everything. If you told him not do something, he would go and do the opposite. He felt like he wanted to get everything before he died because he was waiting to die. He would describe himself as invincible. He attempted suicide twice which I only found out in the last 6 months. He went from being very hyperactive to neurotic. He was married twice, but they both ended in divorce.
26. Marc also suffered the physical effects as a result of the infections. He got diabetes and cancer twice, but funnily enough these are not in his records at all. I believe that the above conditions were as a result of the infections.
27. He used to work as a motorbike courier and he was involved in an accident. He was taken to QEH and they gave him FVIII for 6-8 months. He was not getting any better. Approximately 8 months later, he had a scan and he was diagnosed with cancer. He was taken into hospital and was operated on. He was not offered chemotherapy. In 1997, he had pains in his stomach and they found that the cancer had returned on the top of his kidney. He had a major operation for it and he was operated on from his neck to his pelvic area and they completely opened him up. He was given chemotherapy after the operation and at the same was given Interferon to treat the Hep C infection. However, there is nothing about the above events in his medical records. They just all seem to be missing. He believed the cancer was a knock on effect of the infections.
28. From the mid 1990s when he was diagnosed with cancer, he faced a steady decline in health but in the last 5 years of his life, he lost a lot of weight, had

chest infections, thrush, stomach problems and loss of appetite. He had to have fluid drained from his stomach. He never liked to be in the hospital as he spent most of his childhood there. He missed so many appointments, especially after diagnosis as he thought to himself that the damage had already been done to him. Three days before he died, his kidneys failed and we rushed him to hospital but all his organs had failed and he died on GRO-C 2003.

29. Marc received some sort of HIV medication, but I can't remember the name of it or when he started the treatment. I remember when we went on holiday as a family, we had to plan our day according to Marc's medication routine. We had to wait for Marc to be able to have his tablets before we could sit and eat. He had so many tablets that he had to take.
30. As stated above in or about 1997, Marc received a combination treatment consisting of Interferon and Ribavirin for the Hep C. Unfortunately, the treatment did not clear the Hep C. He was once offered a biopsy but he didn't do it as the doctor said it could cause bleed and be risky. I am not sure if he had any further treatment for his Hep C.
31. Marc suffered mental and physical effects as a result of the treatment. He had a total personality change and suffered from fatigue, brain fog and loss of appetite. He also became aggressive and that was not him at all, it was very out of character. He also had diarrhoea constantly and was depressed pretty much all the time. At one point, he tried to commit suicide by crashing his car into tree. He survived and told his second ex-wife that he couldn't cope and that he just wanted to end it all. He was always feeling very down.
32. Marc's private, family and social life was impacted massively as a result of the infections. It was awful. As previously stated, he was married twice, which ended in divorce. His social life was also affected as he withdrew from people. He could not tell people the truth about his health and diagnoses, and so he felt like he was a fraud. Only a few of his friends knew of his Haemophilia but only a few trusted friends knew of his infections.

33. Marc's diagnoses as well as his subsequent death impacted on my private, family and social life. Growing up, I was always told that the reason I was here was to look after Marc and if anything happened to our parents, I was going to be the person to look after him. I took on the role of the big sister even though I was 4 years younger than him. My goal in life was to look after him. When he died, my husband and son helped me pack his possessions away but I felt so strange and it put me in a dark place. I don't think I properly grieved because just before he died, he was involved in the US litigation and after he died, we carried that on for him as he felt so strongly about it. It could have all been avoided, which is the worst part of it all. When he died, I felt like an orphan, I felt like I had no purpose in life. I felt like I had no one to look after anymore. It has had a massive impact on me. Doing this statement has made me realise that Marc's death has had a bigger impact on me than I thought it had.

34. I'm a haemophilia carrier and there was a 97% chance that my children would either become a carrier or a haemophiliac. When I was pregnant with my son, I refused to get a sex of the baby test done due to the high risk of a miscarriage. I told myself that I would take my chances and that if my child turned out to be male and a haemophiliac, I would cope with it as treatment would be better. He was tested at birth and thankfully he wasn't a haemophiliac. My brother made sure all the tests were done from a few hours after birth up until he was 6 years old.

35. There was a stigma attached to the infections at the time. In the mid-1980s the media showed tombstones and graves of people who had been infected with HIV. This put us all off telling anyone about the infection and keeping it within our family. Marc knew the **GRO-A** family at the time and when it all came out in the press about them, my mother stopped buying the papers (Daily Mail) as there were pictures of graves. We kept it all private due to the stigma that was attached to it at the time. Two times that he was in the hospital, he was kept in a isolation room and there were stickers all over the door, which had a sign indicating 'hazard'. The medical staff also wore contamination suits, which looked like a space suit covered head to toe.

36. Marc did not tell many people about the infections apart from a few friends. He trusted them and it was mainly for their protection as he used to go on motorbike relays, and the fact that his friends could be infected when they tried to help him during an accident was always at the back of his mind.
37. Marc's diagnosis as well as his subsequent death had a massive impact on my parents. My parents have not been the same since everything that happened. They were traumatised. Thankfully my mother has **GRO-C** so she does not talk about it much now but in the past she would not stop talking about what happened to Marc. She blamed herself for Marc being a haemophiliac as she thought it was her fault. My father does not like to speak of it as he was the one who took Marc to the LMTC. My parents blamed themselves in relation to what happened to Marc.
38. My son was also very affected by his uncle's (Marc) death. When he died, my son was 18. My grandson, who is also named Marc was born a few months after Marc died. Marc's death had a mental affect on him. He knew everything about what happened to Marc as we never hid anything from him. My son has known Marc as an infected person all his life. He finds it hard to talk about it now.
39. Our 2 grandmothers were not told about Marc's infections as they were elderly although they knew of his haemophilia. He was the golden child as he was always ill and needed special care. They died without ever knowing what happened to him.
40. Marc left behind 2 very affected stepchildren. His 10 year old stepson developed **GRO-C** and still has it now, aged 30.
41. Marc suffered educational effects as a result of the infections. He went to a special school for his disability and then at the age of 11, went to LMTC. He was so behind with his education because he had lost a lot of time at school. When he was 11, I was 7 and I had better reading skills than he did at that time.

42. He left school with a tailor qualification and became a tailor. He later found a job, but he hated it and left within 6 months. He later became a motorbike courier and that's when he decided to do what he wanted to do. He only gave up this job when his health started to decline in the mid/late 1990s and in the last 5 years he did not work at all. During that time he suffered a lot financially.

43. Other family members such as our aunts, uncles and cousins were all devastated by Marc's death as well.

Section 6. Treatment/care/support

44. Marc faced difficulties in obtaining treatment, care and support. He always felt like the medical staff didn't want to treat him.

45. Marc was not offered any counselling or psychological support as a result of what happened. I believe if it was offered, it may have helped him. I was also never offered counselling. It would have helped if it was offered to me.

Section 7. Financial Assistance

46. In the 1990s, Marc was receiving weekly payments in the sum of £25.00 from the Macfarlane Trust. His second ex-wife said the forms were a nightmare to fill out.

47. From Marc's statement that he prepared dated 4 June 2001, Marc received an initial payment of £20,000 and a further payment in the sum of £32,000. He had to sign a waiver and from the statement it states that he was under pressure to sign the waiver and return it. A copy of Marc's statement is exhibited at 'WITN1759009'.

48. He started the Hep C litigation in 2001 but died in 2003 and as previously stated, we continued the litigation for him. I believe we received £25,000 as a lump sum payment when it concluded.

49. In the last 2 years of his life, Marc moved into a house which he could not buy as he could not get life insurance, but it was part ownership with a company. Once we sold the house, we had to pay that company a 50% share.
50. I do not know what other financial assistance he received.
51. At one time, Marc applied for a grant to have central heating installed in his house and windows. They agreed to give the grant for the central heating but they said they will look into giving a grant for the windows. They needed quotes for everything and the whole process was longwinded, and Marc was not one for filling out forms. I am not sure if he got the grant for the windows.
52. Marc's second ex-wife split with him on friendly terms but she was still concerned as he did not look after himself when living alone, so she contacted the haemophilia nurses who visited him at his house and helped him to fill out forms for financial assistance.

Section 8. Other Issues

53. I find it strange that there are no medical records available from the BCH apart from one transfer letter to QEH.
54. Dr Wilde was very unhelpful and uncooperative. He didn't want to fill out the questionnaires and this could be seen in the medical records.
55. Marc decided to go public and did an article for the BBC news and for the Telegraph. He refused FVIII from QEH and asked if he could have the recombinant which he was rejected. He therefore bought FVIII from the black market because he felt that he did not have a choice. Copies of the above articles are exhibited at **'WITN1759010'**.
56. There is also a preliminary medico legal report on Marc which was prepared in order to assist in determining whether there were grounds for commencing Legal Action in respect of HIV+ infection from which he suffered. A copy of this report is exhibited at **'WITN1759011'**.

57. I do not wish to remain anonymous.

58. I wish to give oral evidence at the inquiry.

Statement of Truth

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

Signed:

GRO-C

Dated

26-6-19