

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS SUSAN JEAN HALL

I, Susan Jean Hall, will say as follows:-

Section 1. Introduction

1. My name is Susan Jean Hall. I live at GRO-C I was born on GRO-C 1955. I am a widow, disabled and live alone. I have two daughters, Michelle Fuller aged 33 and Leila Hall aged 36 who have also given statements to the Inquiry.
2. This witness statement has been prepared without the benefit of access to Ian's full medical records.

Section 2. How Affected

3. My late husband, Ian Stephen Hall, was infected with HIV and Hepatitis C as a result of receiving contaminated blood products, which he received from the age of 17 until when he passed away aged 38. **Exhibit WITN1264002** is an extract from Ian's medical records evidencing some Factor VIII infusions. **Exhibit WITN1264003** is a copy of Ian's death certificate confirming that he died on GRO-C 1993 and that one of the causes of death was HIV.
4. Ian had Severe Haemophilia A and was under the care of Dr French at The Queen's Medical Centre in Nottingham. He was also treated at Nottingham City Hospital.

5. Ian was provided with no information or advice in relation to the risks of receiving Factor VIII.
6. Ian received a letter from The Queen's Medical Centre, in or around 1985, requesting that he attend the hospital regarding some recent blood test results. Ian told me that he did not remember having any blood tests. Ian attended the hospital alone and Dr French told him that Ian was HIV positive. This bombshell was imparted to Ian in a very direct and matter of fact way. Dr French then briefly mentioned that if we wanted to continue to have sex then we must use protection.
7. Ian was extremely worried because I was already pregnant with our second daughter Michelle at this time. I sought for me and my unborn child to be tested for HIV, which turned out to be negative.
8. I am extremely disappointed with the way in which Dr French imparted this news and the fact that he provided no correct advice or indeed any helpful advice regarding what HIV was and what it meant to Ian.
9. However, Ian's GP, Dr Rapaport, was fantastic and she said of the HIV *"It is something which is new to me but I am prepared to learn about it and help you in every possible way I can"*. She got in touch with the Terrence Higgins Trust who supported Ian.
10. The Hepatitis C news did not come until very much later; I recall that it was in or around 1992. Ian and I had attended The Queen's Medical Centre for his monthly treatment and when he came out of the consulting room, he said to me *"You'll never guess what; I have something else now"*. This something else was Hepatitis C and Ian was provided with no information regarding this virus or how it could be transmitted. Ian was dead within a year of receiving this news.

Section 3. Other Infections

11. I have no recollection of Ian mentioning anything about any other viruses or infections.

Section 4. Consent

12. Ian was regularly tested without his knowledge and therefore without his consent. Ian was not advised that he had been tested for HIV, Hepatitis C or Hepatitis B. **Exhibit WITN1264004** is an extract from Ian's medical records, dated 27th February 1985, confirming that he was antibody positive for HTLV3. This evidences the fact that he was tested without his knowledge or consent.

Section 5. Impact

13. I was pregnant with Michelle when Ian found out that he was HIV positive and his health was fairly good for the next 5 years. However, Ian's physical and mental health deteriorated rapidly when he caught chicken pox in 1990. He became extremely poorly and never regained any form of good health after this. The chicken pox stayed in his system and he was poorly and delirious from this point on. His high temperatures and night sweats were terrible and I had to cool him down with cold flannels.

14. Ian suffered from headaches, migraines, vomiting, photophobia, aphasia, encephalitis, piles, diarrhoea, hot flushes, neck pain, nose bleeds, chest pains, low immune system, dermatitis, gall stones, liver and kidney disease.

15. Ian was on AZT and he was constantly fatigued and used to just lie on the sofa which was so unlike him. Ian must have also been chronically tired due to his Hepatitis C but neither of us knew this at the time. I had to stay very strong for the both of us and I think that the viruses would have defeated Ian if I had not remained so strong; however, this had a real knock on effect on both my mental and physical health.

16. Ian withdrew from sexual activity and as he became increasingly poorly he was unable to assist me with any of the household chores; which was something he used to do prior to his illnesses. This meant that I really struggled both physically and mentally because I was caring for him and also trying to hold everything together whilst also juggling the dwindling finances.

17. Ian became very depressed from about 1990; he sat at home watching the television. He watched Philadelphia and this frightened him because he feared death and feared for his family upon his death. He withdrew from family life although he made a real effort to still

interact with his daughters. I tried to keep things as normal as possible for everyone but it was a real struggle. He lost his appetite and suffered from constant diarrhoea and nausea. I recall Ian telling me that he did not want to continue on the AZT because he was so poorly.

18. Shortly after this, Ian did come off the AZT and his health plummeted. Ian was frightened to go to the toilet and when he did he had both severe bleeding and diarrhoea. On one occasion it was really bad and I recall that he shouted for me when he was on the toilet upstairs. I went to him and the bathroom was covered in blood. He could not move off the toilet and I telephoned my brother, David, who was a paramedic and he came to our rescue and managed to get Ian to hospital. Ian required considerable Factor VIII and blood transfusions as a result of this incident and he remained in hospital for about a week.

19. Ian always kept a thermometer by his bedside and constantly tested himself for infections because he knew that if he got an infection he struggled to get rid of it and he knew that the end would be nearer.

20. Ian and I went to a hospice to see what it was like because Ian did not want his daughters to see him so poorly. He was scared to put any of us through such tough times. He also spent a lot of time upstairs towards the end of his life as he was so terrified of dying that he could not even face his daughters.

21. Ian did not tell anyone that he was infected. Dr French told him not to tell anyone about his HIV because it was clouded in stigma. HIV was all over the newspapers and Haemophiliacs were getting so much mental and physical abuse because everyone thought that they had HIV. Ian and I therefore decided not to tell anyone, apart from my family, about his infections. At the time we had just moved to a housing estate and we decided that we would bring the girls up without telling anyone. The stigma was so bad that Ian did not even tell his own parents. Ian felt that he was able to confide in my parents and they were phenomenal and ensured that Ian was included in absolutely everything. They were our only support network.

22. I do not believe Leila got tested for any of the infections but Michelle and I were tested for HIV but I had to fight for the test.

23. Ian and I met at college and it was definitely love at first sight. He was a marvellous man. Following college, he embarked upon a number of jobs; one of which was building and

repairing fruit machines, which he loved. Everyone always came to Ian if they had an electrical problem. He was extremely clever and took pride in being able to sort out people's electrical problems.

24. Ian was so passionate about electronics and later in life he undertook a course in this field. However, as his health worsened and his depression deepened he used to say to me that there was no point in him continuing with the course. I always encouraged him to follow his passions and he managed to complete the course in 1992. He was hoping to get a job at one of the hospitals fixing monitors but he died a year after completing the course.

25. Looking back, it was unbelievable what we accomplished as a family in 1993. Two weeks before our family holiday to Spain, Ian was rushed back into hospital with severe bleeding and hospitalised for a week. The day before we were due to fly Ian was still in a wheelchair; unable to walk. Ian asked his haematology consultant, Dr Dolan, whether he was going to die if he flew to Spain. Dr Dolan replied "*Look Ian, just go and enjoy yourself*".

26. I must have unpacked and packed our suitcases about 8 times the evening before we were due to fly. Ian and I were squabbling about it. Ian wanted me to go alone with the girls but I did not want to go without Ian. However, our neighbour reassured me that she would get Ian on a later flight so that he could join us. I sobbed all the way to the airport.

27. Ian duly arrived in Spain and we were thrilled. We all enjoyed ourselves and I am so glad that we were able to enjoy our last holiday together. However, looking back at the photographs I now realise how ill Ian really was.

28. Approximately a week after our Spanish holiday, Ian organised Leila's birthday. He loved celebrations and particularly birthdays, Halloween and Christmas. He also handed me an envelope which contained 4 Christmas pantomime tickets and he said "*I won't be one of them.*" He knew that he would not survive as long as that Christmas and it broke my heart. He said "*It has beaten me. I am knackered and cannot take anymore. If I die to save other people it will be a blessing.*" And we left it at that. It turned out that Ian was right as he died before the Christmas of 1993.

29. Ian and I also got married in 1993 because Ian wanted everything to be in order before he died. This was a bittersweet day.

30. Ian suffered with severe migraines and on one occasion, close to his death, he was unable to lift his head from the pillow. I telephoned the Haematologist and the GP and was

brushed off by both. In utter distress, I spoke to my sister who was training to be a nurse and she asked me whether Ian could put his head down to his knees and if not that he could have meningitis. Ian was unable to do this. I managed to get Ian's friend to transport him to hospital. I had to stay with the girls but as soon as I had arranged childcare I rushed to the hospital to be with Ian.

31. When I got to the hospital, the receptionist did not know where Ian was. I finally found him and he was in a terrible mess because he had been sick all over himself. A nurse told me that she was unable to clear him up because she did not have gloves on. I saw red; my poor defenceless Ian was lying there covered in sick. It was so out of character for me but I swore at the nurse and I cleaned Ian up myself.

32. Ian had lost his sight at this point; he had also fallen out of bed and was very ill. He was rolling around in agony and did not recognise anyone at this point.

33. Ian was diagnosed with cryptococcal meningitis.

34. The night before Ian died was the worst night of my life. I sat beside his bed; he was not the same person. There was nothing I could do. He was really suffering. This strong man would have hated me to see him the way he had become.

35. The next day Ian's eyes had gone white and he said "*I cannot breathe*". The doctor said they thought that it was best to let him go because he was unable to breathe unaided.

36. I remember being called to Ian's bed and as I came out of the lift it was like everything was going in slow motion. I do not know how I got to his bed; but as soon as I did, he stopped breathing.

37. After Ian passed away things were terrible. Both our girls suffered from domestic violence

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 I really hit rock bottom. I felt as though I had let our girls down but I could not do anything as Michelle's partner was also abusing me.

38. I felt as though my whole world had collapsed around me. I strongly believe that if Ian was around he would have protected us from this abuse.

39. In a way, I did not grieve for Ian very much. I kept it all bottled up. When I went through the menopause I suffered a mental breakdown and I blamed myself for not being able to keep our girls safe. They have reassured me time and time again that none of this was my fault.

40. It is now 26 years since Ian was taken from us and it has left a huge void in my life. My heart goes out to our girls and their children because they are missing a father and a grandfather. Every day hurts me but I am doing my best as a mother and grandmother but not a day goes by when I don't miss my Ian.

Section 6. Treatment/Care/Support

41. The way Ian was treated in The Queens Medical Centre and in Nottingham City Hospital was degrading and unacceptable. He was frequently left alone and hospital staff refused to help him because he had HIV. He suffered in a very cruel way as a result of the stigma.

42. Ian's dentist used to be entirely gowned and basically covered from head to toe which was also degrading.

43. Ian never had the chance to undergo any treatments for his Hepatitis C because he was dead within a year of finding out that he had this virus.

44. Ian had a very good counsellor called Arleta. She was fantastic and we remain friends today. I was not offered any counselling either during the times when Ian was told that he was suffering from HIV and Hepatitis C or when he passed away. I feel that the system overlooked me. As far as I am aware, neither of my daughters were offered any type of psychological support.

Section 7. Financial Assistance

45. I believe that Ian found out, via his Haematologist, that he was entitled to financial assistance in or around the late 1980's.

46. Ian received about £20,000 from the Macfarlane Trust in or around 1991. He also received a further £80,000 before he passed away.

47. Ian also received a monthly allowance from the Macfarlane Trust but he was not aware that he could apply for grants.

48. Ian never had any dealings with or received any funds from the Skipton Fund.
49. When Ian passed away I received the widowed mother's allowance from The Macfarlane Trust which was about £200 per month.
50. The Macfarlane Trust also funded part of Ian's funeral.
51. Ian and I never had any difficulty with the Macfarlane Trust because we had a really good social worker who assisted us with the application procedures.
52. However, the Macfarlane Trust reduced my widowed mother's allowance when Leila left home aged 16 so I did struggle at this time as a result of the reduced support. Once Michelle reached 18 the Trust stopped supporting me financially.
53. However, I contacted them again about 7 years ago and managed to secure intermittent support over the last 7 years.
54. I did not try and seek financial assistance from the Skipton Fund after Ian had died but a few years later I received payment from them regarding Ian's Hepatitis Infections.
55. It was my daughter, Leila who was contacted by the Haemophiliac nurse under Mr Dolan regarding the Skipton Fund in or around 2013 as I believe that they had traced her because her son is a Haemophiliac.
56. I therefore made contact with the Skipton Fund and managed to secure the Stage 1 payment of £20,000 which was in or around 2013.
57. A few years later, I received the Stage 2 payment of £50,000. Ian must have had cirrhosis but neither of us knew this.

Section 8. Other Issues

58. Ian and I were part of the American Litigation and we received about £23,000 in or around 1991.
59. Ian was a member of The Birchgrove Group but after Ian passed away I was not really supported by them.

60. I got in touch with The Tainted Blood Campaign Group because it was a support group for bereaved people whose partners were contracted with HIV. This was so I could receive regular updates from them.

Conclusion

61. I want justice for Ian and closure for myself.

Anonymity, disclosure and redaction

62. I do not want to apply for anonymity and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C

Dated... 13/01/2019