

Witness Name: SUSAN ELAINE SPARKES

Statement No: WITN171301

Exhibits: WITN171302-04

Dated: 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN ELAINE SPARKES

I, SUSAN ELAINE SPARKES, will say as follows:-

Section 1. Introduction

1. My name is Susan Elaine Sparkes. I live at [GRO-C], Cardiff, [GRO-C]. I live alone. I have two sons. Alexander was born on [GRO-C] 1980 and Richard was born on [GRO-C] 1984. They are not haemophiliacs

[GRO-C]

2. My husband, Leslie John Sparkes (known as Les), was born on the [GRO-C] [GRO-C] 1932. He died on the 24th March 1990 aged 58.

3. We were married on 4th November 1978.

4. This witness statement has been prepared without the benefit of access to my husband's full medical records.

Section 2. How infected

5. Les had moderate haemophilia B otherwise known as Christmas disease with a clotting factor of 3% - 5%.
6. I met him in 1976 when he was helping out at a friend's charity event for Muscular Dystrophy. I started going out with him at the beginning of 1977. He was a lovely man. After we had been out a couple of times, he told me he was a haemophiliac. He had bowed legs. He would tell anyone at that time who asked him about his legs that he was a haemophiliac. He was diagnosed with Christmas disease in the late 1960's. He told me that he used to spend weeks in bed as a child with bleeds into his joints. I have been able to get some of his medical records but I am visually impaired and I find it difficult to read them. The records do state his diagnosis of Christmas disease.
7. In the earlier days Les used to have cryoprecipitate treatment when he had bleeds. He also had plasma. He had all his teeth removed in the late 60's and had 36 pints of blood given to him at the time. He bled for a good few weeks after.
8. I think it was in the early 1970's that Factor IX became available. I do know that when we got together he had Factor IX. However, Les had a phobia of needles. He had told me that once at the hospital he had had a student doctor to give him blood and they had had difficulties finding a vein. They had so many tries at sticking the needle into him that he ended up scared of needles. He would go out of his way not to go to hospital for treatment. He was absolutely petrified of needles. He would go happily to hospital for check ups but when it came down to having the treatment he was scared. He would not do home treatment because of it. He would not let me do it either. He would rather have bed rest when he had a bleed to avoid the necessity of having a needle stuck in him.
9. Practically from the time we were married I would say to him "come on, you're in absolute agony let's go up to the hospital. I know you do not like the needle but for the sake of 5 or 6 minutes of needle time your pain will then be eased. In the end he would go just to shut me up.

10. Les was under the care of Professor Bloom at the University Hospital Wales, Cardiff. His GP was David Wood of Red House Crescent Health Centre which is now Westway Surgery, Wilson Road, Cardiff CF5 4LJ. Attached as Exhibit WITN171302 is the coagulation defect – treatment record for Les showing his Factor IX treatments. I believe this is incomplete as I believe he had a lot more treatments. He went quite regularly for treatment to the Heath Hospital which is now University Hospital Wales, Cardiff. He would often go to the unit but other times he would go to the ward itself for treatment. Sometimes he would have to go for treatment 3 or 4 days in a row. Sometimes they did not have enough Factor IX and they would have to bring in another batch even though there had been a lot of vials in the fridge the day before. They did not give reasons as to where it had all gone to. I wonder now whether or not some batches had been recalled.

11. As far as I am aware no information was provided to Les about the possibility of being infected by the blood products he was given for his bleeds.

12. In the 1980's we had a letter from Professor Bloom asking us to go and see him. The haemophilia unit was in one room. I remember there was one elderly gentleman who would be up there everyday because he was a severe haemophiliac. He would let anybody stick a needle in him. He was a lovely man who unfortunately had a car accident in the early 80's. Within days of the car accident he passed away. It was reported in the paper as "haemophiliac dies of AIDS". From then on when we went to the unit we would ask questions but we were told "oh that was a one off". We would be sitting there with other people and you could not help but think "I wonder if there is anyone else here who has it".

13. So, from the early 80's it affected us. When we were sent this letter to ask us to come in we thought we were going to be reassured about what was going on as there was a number of things being mentioned in the press about haemophiliacs.

14. On 15th September 1985 we were taken into a room and Professor Bloom said "don't worry about it but you have the antibodies for HIV but it might not lead to AIDS". In some of the notes it says we were told in July 1985 but that is not true we were told on 15th September 1985.
15. When Professor Bloom told us about the HIV we were given a leaflet or two. The only other person in the room was a social worker. We were told to come to the hospital if Les needed treatment. When we came out of that room Les said to me "I am never coming back for treatment again". He went on to say and I remember his words clearly "I am a murderer; there is something inside me which can kill people". Our whole world crashed around us; Les felt like he had been given a death sentence.
16. The problem is after we were told he was HIV positive he said that if he had stuck to his guns and not had the Factor IX treatment he would not be in this position with HIV. He made me feel like I was the one who made him have the treatment and I will never forgive myself for that; never, ever.

Section 3. Other Infections

17. I know that Les was also infected with non A non B Hepatitis (later called HCV). We were told this in the later stages of his life and whilst he was in the hospital in the last few weeks of his life. Les did not know that he had HCV. Whilst I was not told this specifically I asked Dr Desani after Les had died and he confirmed that he did have HCV.
18. On 25th April 1990 after his death Les' blood was tested positive for HCV. This test came from a blood sample which was taken prior to his death. I did not know that this test was carried out but I attach details of it as Exhibit WITN171303.

Section 4. Consent

19. Whilst I remember the date 15th September 1985 on which we were told Les had HIV, the meeting is a bit of a blur. We were certainly never told that he had been tested for HIV. My husband did not consent at any time to this. He did not know that his blood had been taken for testing for infection. In the back of my mind I do remember a year or so previously that they had indicated they were doing trials for something but I cannot remember what and I would have remembered if they had told us they were testing specifically for HIV.

20. We did not know at any time that they were testing Les' blood and I was not told that his blood was tested on 25th April 1990.

21. I was certainly not aware that a review was being undertaken on 16th June 1992 following a request from the UK Haemophilia Centre Directors Aids Committee and a copy of this is attached as Exhibit WITN171304.

Section 5. Impact of the Infection

22. From the moment Les was told by Professor Bloom that he was HIV positive until the day he died we did not tell a soul. It was just me and him. We were with each other and had always been with each other constantly. No one knew about his diagnosis until after his death. The only other people that knew and with whom we had contact were the doctors and the social worker who would come up every month or two to visit us.

23. He made me promise not to tell a soul. He even made me promise not to tell the paramedics in the event that he was in an accident. It was something that brought us close together but also at the same time tore us apart.

24. At the time we were told about the infection there was a story on Eastenders about a gay guy talking about AIDS and calling it "the gay plague". I would try to distract my husband from all this by turning over the TV channels or hiding the papers if there were articles about HIV in them. From that time on he did not tell anyone that he was a haemophiliac.

25. When we left the hospital after being told of his HIV infection, he felt like a murderer. He would not let the children near him. His body language changed. It took ages for him to touch me again in case he gave me something. I did not know if I was infected until just before he died which I will come back to later in this statement. He desperately wanted to watch his kids grow up and become adults but he did not get the chance to.
26. Prior to his diagnosis in September 1985 Les had been ill. I remember that my son was born GRO-C 1984 and Les had been back and forth for treatment before he was born. Easter that year was in the middle of April; the weather was beautiful for a couple of weeks. Les went down with flu. For him to stay in bed and not eat was very unlike him. He was so ill in April 1984.
27. We were told they could not give us specific information as whether the infection would turn into AIDS next week, next month, or in the next five years. They would not give a time period because so little was known about it. They did not think most people would last 5 or 10 years though. We were left in the dark.
28. After being told this devastating news we decided to get a bank loan and have one nice holiday to make memories for the kids. The following summer we went to Spain for a week. Things were never right again after that. The kids never knew. My eldest son remembers going to and from hospital but he was only very young.
29. I remember that the only advice we were given in respect of reinfection was that we were told to wear condoms. This was what we tended to use anyway for contraception. We had thought we might try for another child, and we had unprotected sex a couple of times before we were told so I am lucky I did not get infected. My sons were never tested but it was always in the back of my mind as Richard was only 18 months old when we were told and we did not know when Les was infected. I had not been tested at that time either. Every time I or the children had a cough or cold it would be in the back of my mind.

Every time Les had a cough I would be worried whether it was going to develop into something more sinister. We lived our life in fear. We were together almost 24 hours a day 7 days a week but once a week whilst my son was in cubs, I would work in the kitchen at the hall washing dishes. I used this time to do my crying as I would be in the kitchen by myself. I could not cry at home because I did not want to show how much I was hurting.

30. In the last 6 to 8 months of his life I could see Les deteriorating. He still refused to go to the hospital. The social worker would come and try to persuade him to go to the hospital but he would not go. Since he had been told of his diagnosis he had refused to go to hospital and only went for X-rays and to the orthopaedic department. He always felt that if he hadn't gone to the haemophilia unit then he would not have HIV. It killed him inside.

31. In September 1989 the four of us went to Butlins. We tried to put a brave face on for the children. The whole time we were there he was not well and he was going down hill. I did not know if this was the beginning of the end and all the time I lived in fear thinking "is this the last week, what's the next step"? His memory was starting to go. We tried to do the best for the kids but he should have been at home.

32. He used to use his wheelchair to go from the bed to our ensuite bathroom. It was in January 1990 when he was doing this to get to get back from the toilet to bed that he fell. He had a bad pain in his arm and a terrible cough. I begged him to go to the hospital but he wouldn't. It had taken us ages to get him up from the floor because he could not put weight on his arm. Everytime he coughed I had to hold his arm in place because of the pain that he was in.

33. In the end we went to Cardiff Royal Infirmary. He just wanted to have an x-ray done. They said to him at the time that he looked very yellow and tired and kept asking him whether he was alright. He would not tell them about the haemophilia but in the end he had to tell them as they were going to take blood. He told them that if they wanted to take blood that they should wear two sets of gloves. The bells then rung and they suddenly realized what he

was saying and they had to get lots of doctors in. HIV was a taboo subject then. He was petrified. They gave him a splint and we went home.

34. From mid January until he went back in to hospital he could not lay down and sleep because of the cough. He would sleep on the sofa downstairs. I slept next to him but he insisted that I went to bed to get some sleep. I didn't though; I would shut the living room door and sleep in the passage on the floor. He did not know this but I was so scared that the children would wake up before me if I was in bed and find him dead in his chair. I hardly slept at that time.
35. The week running up to the 26th February 1990 his condition got worse and worse. I suggested that we ask the doctor to come out. The social worker had been out on the Thursday or Friday so I am sure she had reported back to the hospital. Jenny Jones, a sister at the unit arranged to come out on the Monday or Tuesday to do some blood tests. He was so bad over the weekend that I phoned our surgery. I pretended I was doing something else so that he didn't know I was calling the doctor. I spoke to Dr Wood and told him that I did not know what was happening to Les. I told him that Les was hallucinating and was talking about mice running across the curtains. I told him that I could not cope with it and I did not know if he was going to die. He said to me that he had some minor surgeries but should be finished at 1.30 and then he would come over.
36. He turned up at 11.30 and Dr Wood convinced Les he needed to go to hospital. On the 26th February 1990 he went to The Heath Hospital. As we were going to go to the hospital he turned to me and said "I am never going home again". I said "of course you will come home". I went up with him and that is where he was for the next 4 weeks until he died. He did not come home again.
37. I used to get a taxi at 8.45am, drop one of my boys at school, my other son went in a different taxi as he was at a different school. I would stay at the hospital till I went to collect the boys from school. I would then sort the baby

sitter and the boys tea out and then I would go back to the hospital. I would get a taxi home at around 9pm.

38. There were days when he was not very well at all and then he would rally a little. I remember one Wednesday I went in and he was a bit better than he had been. I had to go down to the unit for something before I went home and I went into the unit at about 2.30pm and I spoke to Jenny Jones and a Doctor and we went into the office and I just broke down. I cried my heart out and I told them everything. That was the 28th February. Whilst I was there I had a blood test done. I did not tell Les as it would have killed him if he knew that I was HIV positive as well. I had the tests done as I did not know whether my two sons would be orphans. I made the doctor promise that they would not tell Les. I then composed myself and went to pick up the kids.

39. By the time I got back at 5.00pm the doctor had seen Les, and he had spent an hour with him. Les had opened up to him and it was like a weight had been lifted. Les had swollen up really big so they did a liver biopsy. Over the next couple of days he seemed to get better and better. We talked more and he opened up more. We had been living in our own little world which caused a strain. I would have done anything for him, but the illness caused so many problems. He changed when he had spoken about it to the doctor. He seemed happier.

40. I went in on the Friday and when I went to get some water, the nurses were coming up to the ward. Jenny followed me and she said my results were back and I was negative. I just broke down crying. I was over the moon as well but I felt guilty because I didn't have the infection. I told Les that I had something to tell him and I told him I had been tested and I was negative. He grabbed me and told me that I had just given him ten million pounds. I was so grateful that I had told him because he had been so worried. He said that it would have killed him if I was positive and I remember he was so happy at that time.

41. It was on the GRO-C when I got that news and that was my son's birthday so the boys came in to hospital to see him. He was on good form. He was

happy and had more colour in him. For a few days it was like being on our honeymoon again; he was so happy. We held hands and we cuddled. We had a future together and I felt like things were going to be a lot better.

42. We had a couple of days of what seemed like a "honeymoon period" and then I went in on the Friday, Les was a different person. He was totally out of it. He did not know what was going on. He was really ill. I did not understand what was going on. I do not know if he caught a bug. Over the weekend he slowly came out of it but he was never the same. Towards the end of the week he got sick again. He did not want to get in the bed and he sat on the chair with no clothes on just a blanket. His mother had always told him that people die in bed and he didn't want to get into it. After that weekend he just went down hill.

43. On the Wednesday which was the 23rd March, he was in the chair rocking. A lot of the time what he was saying did not make sense. The blanket would fall off and I would try and keep his dignity by putting the blanket back on him but he was getting worse and worse. I have to say that the week before he wanted to book a holiday. He really wanted to go somewhere for the summer. I did not have the money to book a holiday so I went to the travel agent and I got her to give me something to look like I had booked a holiday. She made me sign something saying it was not real. I showed it to him and he seemed better then. It was almost as though he had something to aim for.

44. On the 23rd the doctors asked me to go into the corridor as they wanted to speak to me. Professor Bloom and a social worker were there and they told me that I had to understand that Les was not well and that he wasn't going to get any better. He told me that he had 6 weeks at the most to live. I was devastated and begged them to let him come home as I had promised Les he would come home. I asked even if he could go home for a day visit as I had promised that he would go home again. They said they would see what they could do but they could not promise. Professor Bloom came to find me later and said that half the ward would shut at the weekend and he would arrange that if things were ok that he would make the beds available for me and the boys so that we could all spend the night together.

45. At 10.00pm that night I put the kids to bed and asked a friend to come over. I told her what they said about the fact that Les would not have more than 6 weeks to live. When I put the children to bed I had told them that Daddy is not well but that we were hoping he might come home for the day or we may stay there for a night but we would have to wait and see. I really wanted him to come home but I did not know how I would really manage with that.

46. When I went back to the hospital he was totally yellow. They kept saying he had non A non B hepatitis. I had talked him into getting into bed. The social worker took me to get something to eat. I could not eat though so I had a cup of tea. When we went back up to the ward Professor Bloom had done his rounds. He took me out into the passage and said that he was sorry but we cannot do the room and told me that Les had gone down so much in the last 24 hours that he did not think he would last another day. I was so shocked; I could not believe what I was hearing.

47. I broke down then and the social worker took me to a room for 20 minutes and I just cried. I did not know what to do. I sat the kids down and I had to tell them that daddy would not be coming home for the day, and that they did not think daddy would live for much longer. My oldest boy went into his bedroom sobbing saying 'you promised me' over and over again. I said there were plans but he had gone down hill so very quickly and was really ill. I was trying to settle both of them, and eventually I got them to sleep.

48. Alex did not want to go to school the following day, but Richard at 6 was so young, he just did not understand. GRO-C

GRO-C Alex was 9 when his dad died. Whilst Richard did not understand; he wanted to go to school. In the end he did not go. At 7.00am I was getting ready to go up to the hospital. Francis was coming at 8.30am to look after the boys but at 7.00am I got a phone call from the sister on the ward just saying Les had had a good night and he was not too bad and not to worry. However, in the back of my mind I was think she was telling me something different and I needed to get

up there straightaway. While I was waiting for Francis I phoned a taxi so as soon as she turned up I went straight to the hospital.

49. When I went to the hospital he was on a morphine drip. Every time he moved, it was so painful for him. I walked in the room; Les was moaning. The bed was soaking; he was soaking. Every time he was moved this yellow pus was just coming out of his body everywhere. In the end I asked the nurses to put a catheter in because he was incontinent. I would not wish that on anyone. His whole body was swollen and leaking yellow pus.

50. He had had no treatment for the HIV because he would not go to the hospital for treatment. It was only when he went into hospital he had one or two doses of AZT. He did seem to pick up but I do not know what happened. All I know was that night I phone home to see if the boys wanted to come in. Francis said she would have a word with them and they said no at first but then decided they wanted to come in. I said that I needed 5 minutes because I needed to speak to the nurse first. The nurse checked his pulse and said they did not think he was going to go yet. The boys came in for half an hour and they said goodbye to Daddy. I sat with him all night, and held his hand; I told him things that I had only kept to myself. I sat there and in the morning, at about 10 to 12 the nurse brought a dinner in and told me to eat it. I sat at the table and it broke my heart crying. I said to the nurse that if he had not had the Factor IX treatment he would not be dying now. I felt so guilty because it was my fault he was in there and he was dying. As I said it he coughed and he was sick a little bit. The nurse checked on him and told me that he had gone. I am sure he had heard me talking with the nurse. I had never seen a dead body, and he had changed a lot in the way he looked. I was under the impression that dead bodies changed a lot so I only sat with him for 10 minutes because I did not want to see him change. I told him that I loved him. I wish I had stayed longer with him.

51. He died on 24 March 1990. The death certificate states a) bronchopneumonia b) HIV infection c) Fracture IXI treatment for haemophilia B. There is no mention about HCV.

52. I will never get over his death. I remember everything so vividly and I am distraught. We had never told anyone about his HIV. We had heard of the Birchgrove group and we did receive newsletters from them. The social worker would try and persuade us to go to a meeting. We had gone to the place 3 or 4 times but we would just sit outside. Les could not go in; he was too scared to see everyone. The media had reported that people with AIDS looked like skin and bones and he was scared that he was going to walk in and see everybody like that.
53. Shortly after Les had died there was a Birchgrove Group meeting and the social worker said that she would pick me up and take me to the meeting. I agreed to do that. I am so glad that I did go because there was so much support in that room. I had been on 1 or 2 trips with the children so I had met a couple of people but I did not know anybody well and I never told anyone about Les and the fact he had HIV.
54. I went to the hospital on the Monday to get his death certificate and I had to go with the social worker because there was no one else I could take with me. No one knew that Les was infected with HIV. I remember that Les wanted to go to one funeral home not the other in the town. He wanted to go to Summers funeral parlour but we could not use them. I had to go to Morgan's, as he had done a couple of funerals before in The Valleys with people who had died of AIDS so he understood what was needed. We were not allowed to see Les in the funeral parlour. I believe that once they had been put in the bag that is where the body stayed. They could not open the bag in case of infection. Les was not embalmed.
55. On Monday I spoke to the sister, who I was friendly with and arranged for the social worker to take me to town. We had to go to the Coroner's office as we had to get something from there. I do not know how I would have survived without the social worker.
56. I will always say that if I had had a car at the time that the 3 of us would be in the car with a hose pipe because I did not want to be there; I did not want to

exist. I did not want to register his death because I did not want people to see that he had HIV. I got a letter from Professor Bloom saying that he died in the hospital with the date and so in certain places I did not show his death certificate but some people I did have to show and because it had HIV on it, it was so hard. As far as the kids were concerned I told them and everyone at the time that Les had died of blood cancer.

57. My sons were 18 when they were told that their father had actually died from HIV. It killed me working up to the day to tell them. I could not cope. I had told no one about it but I felt like I had to tell someone who was not connected to the hospital about it. So I told a friend and her husband. They seemed alright with it. I had contact with them for 3 years or so but then our friendship fizzled out. They were a couple and I was single.

58. I was in touch with another couple and I arranged to go out for a meal with them and on the way home I asked them to pull up as I wanted to talk to them. She was a social worker, with a medical background and was familiar with AIDS. She had done all the training so she knew all about it. It took me ages to get the courage to tell them. I told her then that Les had not died of blood cancer but that he was a haemophiliac who died of HIV. She asked me why I had not told her before. It broke my heart and I was crying saying that Les did not want anyone to know. She said that I should have told them before. I told them that I wanted to but that I just couldn't. The following day I phoned them and they made some excuse saying they were going out and that was the last time I heard from them.

59. And that was why I never told people. It has only been over the last year that I have told people and I have gone public now; my husband did not do anything wrong and died when he should not have done. I am in touch with people and have support from Tainted Blood.

Section 6. Treatment/care/support

60. On the whole I found that the hospital staff did not treat him differently to other patients. They would wear gloves but really up until the last two days of his life I did everything myself for him while I was at the hospital.

61. He did have false teeth at the time that he was told he had HIV so he did not need a lot of dental treatment. He only went when he needed a new set of teeth but he had no problems.

62. I know when he went to A&E in the latter stage of his life and when he said he had HIV the doctor's attitude did change. They called the haematologist down to see him.

Section 7. Financial Assistance

63. Les worked but he had not worked for a long time. It was in 1978 when he last worked because he had had an accident at work. A stepladder fell on him, but he never claimed. He did not get sick pay so we just got benefits after that.

64. We had money from the Skipton fund in 2009/2010. I had to prove he had HCV. I never had paper work to prove he had HCV. It was Dr Desani who confirmed it. I was in a lot of debt. I thought I would lose my house. I cannot remember how much it was. I think it was about £30,000 or £40,000. I remember I had Stage 1 and 2 payments. I also received money from the Macfarlane Trust but they took some of the money and put it into a trust fund for the boys.

65. I continued to get benefits. I cannot remember clearly but when the children were 19 the money paid to me was reduced and it completely stopped when a new system came out. I was paid a lump sum from the Welsh government. It was about £60,000-£70,000.

66. At first in December 1989 when we heard about the HIV litigation we were not a party to it as he was worried about the publicity and the fact his name

would come out. He was emphatic he did not want anyone to know. We did eventually join it. In January 1990 we had a payment of £20,000. After Les died, I was going to be a good mum and cope. For the first couple of months I did not want to use the money because I thought it was blood money.

67. However, I did not cope. I was drinking bottles of vodka and taking tablets.

68. After 2 years I had to ask for help. If I had a car we would have been gassed. I did not want to be alive anymore.

69. In the end I had to let the children go into shared care. GRO-C

GRO-C

GRO-C I had them 4 nights a week and they went to someone else for 3 nights a week; the social worker from the hospital helped me. I do not know where I would be if I hadn't had the help then. I am visually impaired myself.

70. As a result of this my relationship with my children has never been the same. The illness and my husband's death has ruined our lives.

I do not wish to remain anonymous when my statement is published.

I am willing 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

SUSAN ELAINE SPARKES

Dated

20/2/19