

Witness Name: Carole Patricia Ann Betts

Statement No: WITN0473001

Exhibits: **WITN0473002-5**

Dated: 29 May 2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAROLE PATRICIA ANN BETTS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 March 2019.

I, Carole Betts, will say as follows: -

Section 1. Introduction

1. My name is Carole Betts. My date of birth is **GRO-C** 1960 and I live in **GRO-C**, my full address is known to the Inquiry. I am married to Derek Betts and we have two children, Simon and Rachel. Simon is 30 and Rachel is 21. They both live with us. The house that we live in used to be my brother John's, before he passed away.
2. My husband is now retired and I work as an administrative assistant at the local hospital. Both of my children also work.
3. I intend to speak about my brother John and his infection with HIV and Hepatitis C. In particular, the nature of his illness, how the illness

affected him, the treatment received and the impact it had on myself and our lives together.

Section 2. How Affected

4. My brother, John Alan Paul Williams, was born on GRO-C 1962. He was diagnosed with severe Haemophilia; I think it was Haemophilia A, when he was 18 months old.
5. I remember him walking into the iron gates at the front of our house and getting two black eyes and a big bump on his head.
6. My parents took him to the doctors and his GP thought that they had been abusing him. Dad didn't like the way the doctor came straight out with that.
7. They took him to see a second doctor for a second opinion. He was then sent to a hospital in London for blood tests. Mum, dad and I also had tests. It was then that they discovered he had severe haemophilia.
8. There was no history of haemophilia in the family, so finding this out was a shock. I have since been to check that I wasn't a carrier. The tests came back negative.
9. I first remember noticing his problems when we lived in GRO-C Dad lived on a farm and I used to go out and play on it. Whenever John came along, Dad would be very careful around him to avoid causing him bleeds.
10. Throughout our childhood, my brother always wanted to come out and play with me, but he couldn't. He was in and out of hospital with cuts, bruises and bleeds in his joints. Whenever he cut himself, he always bled for a long time. He was in and out of hospital like a yo-yo.

11. We lived in [GRO-C] which was quite far from St Mary's hospital, where John was treated. We couldn't afford taxi's so would have to take him on the bus. This was a long journey and he was always in pain.

12. Once we arrived at the hospital, he sometimes had to wait 2 to 3 hours for treatment and often remained in their for weeks.

13. John was originally treated with cryoprecipitate and later moved on to Factor VIII. I remember him going to St Thomas and Guy's hospital to be taught how to mix the Factor VIII.

14. When he first took Factor VIII at home, doctors' came round to check that he was doing it properly. Eventually it was delivered to home and he administered it himself, on a daily basis.

15. When we first moved to Eastbourne, the education authority wanted John to go to a special needs school, however my parents wanted him to go to a normal school and so he did.

16. They informed the teachers that he had haemophilia and they looked out for him. I also looked out for him.

17. He had to avoid sports and stay with someone if he went outside, but otherwise lived a normal school life. He was quite a clever child and ended up getting better exam results than I did.

18. John also had problems with his arms and legs. One arm didn't work, and he was missing a kneecap.

19. As we got older, my dad and brother started to fall out. Dad had witnessed someone getting trapped under a dustcart at work in Eastbourne and [GRO-C] as a result. [GRO-C]

[GRO-C]

20. He would pay the bills etcetera and then whatever was left went on

GRO-C My brother didn't like that and it caused arguments between them. The arguments became physical, however Dad knew that he couldn't fight back as hard as my brother, because of his haemophilia.

21. After I left home, mum often called me and asked me to come over because the two of them were fighting.

22. At the age of 22, my brother then decided to get a council flat and move out, to be away from dad. He got a first floor, one bed flat. Mum would go and stay with him whenever he needed help.

23. As his joints got worse, he decided he needed a ground floor flat and an extra room for people to stay in when they came over to look after him. He got this at about age 29.

24. My dad died from **GRO-C** shortly after. John found him.

25. John normally dealt with any cuts he had himself, however I remember on one occasion he cut his finger on a corned beef tin. He was bleeding so badly that injecting factor VIII wouldn't have been enough to stop the flow. My son, Simon who was 8 at the time went with John to the hospital and took his factor VIII with him, in case the hospital didn't have any. John was seen by a young, I'm assuming junior, nurse who clearly had no idea what to do. Simon had to show her.

26. When John was diagnosed with HIV he didn't tell anyone. Not even our parents. The print out data from the National Haemophilia Database, dated 11-08-2011, shows 'Patient HIV data, Date first Positive '20-12-1985' **Exhibit WITNO473002 Refs.**

27. That said the 'Unexpected Futures Section' of the British Library Sound Archive article (The Haemophilia and HIV Life History Project) page 6

says John was diagnosed with HIV in 1984. **Exhibit WITN0473003 Refs.** I will speak more about that project later, John was interviewed by Sian Edwards and we have the transcripts of the recordings made during which John speaks very openly about this life with Haemophilia, HIV and Hepatitis C,

28. John was very private and kept his HIV infection very much to himself. Mum found out eventually, John had left his HIV card on the table and Mum saw it. She didn't say too much about it but John knew she had seen it.

29. After mum passed away, I found out. This was in 1999 or 2000, only a few years before he died. I think John wanted me to know because he had no one to talk to anymore.

30. He couldn't tell me himself, so he took me to an appointment so that somebody else could tell me. He arranged for Stephen Briars, a psychologist at Hove Polytech to tell me. Stephen drafted a letter explaining that he needed to see John and myself in Hove, and John posted it through my door the evening before the appointment as scheduled. The letter didn't state that he had HIV. I called John that evening and asked him what it was all about, he didn't tell me, he just said I would have to wait until the next day, I was really worried, I thought he had cancer or was going to end up in a wheel chair.

31. The next day, he picked me up and we drove to Hove. He kept telling me not to ask questions and we didn't really talk for the whole journey.

32. When we arrived at the appointment, John left the room. The doctor then explained John's medical history to me and that he had contracted HIV through infected blood products.

33. I was upset and annoyed that John hadn't wanted to tell me himself. I kept asking him why and he said that he hadn't been able to. I didn't

really understand what it meant. I asked him how bad it was, and he told me that he didn't know.

34. John didn't tell me because he was afraid of the reactions that I would receive if I ever accidentally told somebody.

35. After he died, relatives found out and it soon spread around the whole family.

36. As I have mentioned earlier, John was infected either in 1984 or 1985. In order to properly explain how John was told about his infection, I am relying on extracts from his contribution to the **'Haemophilia and HIV Life History Project'**. Both John and myself have contributed to this project. I have one copy of the transcripts made which I have retained, albeit it I find the content difficult to read. I also have the interview tapes. There will be copies available, which are held in The British Library Sound Archive.

37. In tape 3, John described the day he was called into the Haemophilia Centre at St Thomas Hospital' to be told about his infection with HIV.

38. John explained that whilst sitting outside the doctor's room waiting to go in he noticed things were slightly different; there was a new doctor dressed in overly casual clothing, the appointment before his seemed to be taking a very long time and Dr Savidge was in the room, which was unusual.

39. John went into the room alone, as he had decided that as he was over 18 years old he was old enough to go in on his own. The new doctor that he hadn't seen before was introduced as Dr Docherty.

40. The two doctors then sat and fiddled around with his papers, waiting for another nurse to come into the room. When she arrived, John was told that she was a specialist nurse.

41. Dr Docherty then explained that he was a doctor to do with HIV. John didn't have a clue what this was but pretended to know what he was talking about.
42. John recalled the doctors examining him and talking in a different tone to usual. He then recalled the doctor's discussing blood products and stated that at that point, he questioned whether his mum should come in.
43. The main advice John remembered being given was to wear two condoms if he was engaging in sex. It seems anything else the doctors' were discussing was very much between themselves, and John just picked up on odd words and phrases.
44. John didn't tell mum what he had been told. He explained that he was mainly concerned with working out how to explain to our parents that he would be attending the hospital more frequently, without telling them why.
45. John began hearing things about HIV on the television and in the news. He decided to go and speak to Dr GRO-D about it; she had always said that he could ring her up if he ever had any problems.
46. John described a change in Dr GRO-D's face that day. He said it was as if she knew what he was coming in to discuss. He also noted that she didn't provide any help or real assistance.
47. Nobody explained what HIV was to John. He was provided with very little information and nobody ever gave him the information he needed.
48. John was also infected with Hepatitis C. He found out in 2000 and was very secretive about this too. He really didn't want anyone to find out. I

accidentally told people at work, without realising the severity of the illness.

49. In the transcript, he explained that "*[hepatitis C] wasn't a worry, wasn't, that wasn't at the front – it was the HIV was more important than the Hepatitis C. But how I look at things at the moment the Hepatitis C seems to be more important. There seems to be things what are going wrong more than the HIV at the moment*".

50. Clearly, both illnesses had a profound impact upon John's life.

51. John fought the infections as best he could, however it was fairly apparent that he did not like taking all his medications. In the last few months of his life, John was very ill. He didn't move off the sofa for weeks and slept downstairs. He was really very poorly. He was shivering and wanting the heating on full in the middle of May.

52. I asked if he had called a doctor. He said "no, I'm not doing that". I said, "yes, you need to go". I called a doctor, he came over and said John needed to go to hospital. He didn't want to go in an ambulance, so I took him.

53. He stayed in Eastbourne General hospital until he died. He wanted to die at home, but he couldn't have, I still feel a little guilty making him go to hospital however it was for the best, there was no one to look after him at home. The hospital staff were very good and cared for him well.

54. Sadly, John's health slowly deteriorated from then on, to the point that he lost his speech. He was very thin and I was shocked as to how much weight he had lost.

55. After he had been in hospital for a little while, I got a phone call at work to tell me John wanted me. I went straight to him. He was still alive, but he couldn't talk. We communicated with thumb gestures.

56. The hospital provided me with a camp bed, so that I could stay over in the ward. I slept there for two weeks and then one morning when I returned to John's room after popping downstairs, I noticed that he wasn't responding.

57. The Chuckle Brother's was on television and I made a comment about how the children, my children, would be watching it at home. John didn't respond. I tried again and he still didn't. I then realised he wasn't breathing and called for a nurse.

58. The nurses came in and confirmed that he had gone. I was proud to have been there at that moment with him.

59. In the end, John just gave up. He stopped taking the amount of medication he needed and died at Eastbourne District General on GRO-C GRO-C 2004. I blame myself that he didn't get to die at home.

Section 3. Other Infections

60. John was infected with HIV and Hepatitis C. I don't believe he was infected with anything else, but I can't be sure.

Section 4. Consent

61. As far as I am aware John consented to all his treatment. He never indicated to me otherwise, however, he was a very private man and I'm pretty sure we did not know everything that he had been through.

Section 5. Impact

62. John's infection had a big impact on his physical and mental state. He struggled to walk, but was too embarrassed to use a wheelchair. He seemed so depressed. I remember one time he decided that he had had enough. He set off walking to Beachy Head. He was going to end his life.

63. We went out looking for him, and I don't know whether he was found or came back on his own accord, but thankfully he did come back.

64. The week before John died, he was very slim. He wasn't eating. I knew something was going to happen. When he went into hospital, I saw the doctors washing him. He looked so thin. His ribs and bones were protruding out of his body.

65. Weeks before John's death, his transcripts record how things were for him health wise: *"I've come off the pills, combination, by my own choice. I feel a lot happier on coming off [...] it's taking them every day [that is difficult for me] – you just got to look at a box of pills and it reminds you – that these can be making you live longer or the damage they could be doing."*

66. After being told he may only have six months to live, he then continued to say: *"[it was] upsetting and – I've got so much to do in six months, being prepared – but I haven't got the strength at the moment to do much. [...] Prepare – things for Rachel, Simon and Carole."*

67. *"In the last couple of weeks I've opened up to quite a few people, which I would never – never have sought any help at all. [...] the time comes when you can only struggle on for so long. And I think this is the point, at the moment, where I do need support and help."*

68. Finally, at the end of the transcript, John explained that he made these tapes because *"me and Carole are not the type of people what can talk together, so really the tapes are important, because, who knows she can just put them in the recorder and play them back – hear my voice – even though she might not want to hear my voice at least they're on tape."*
69. He wasn't happy with the treatment he received at Eastbourne District General in the earlier years. He had to wait in long queues, was in and out like a yo-yo and rarely got answers to his questions.
70. However, as time went on he was treated quite well. He was well looked after and enjoyed going to St Thomas'.
71. I don't know what medication he took for the HIV, but in the transcripts he listed what he was taking for the Hepatitis C: *"I'm on DDH, is it Saquinavir and Requinavir?, Septrin, Fluconazole, what's the other one? A couple more I can't remember the names of them"*.
72. *"In the morning I'm taking one, two, two, three, eight tablets in the morning. And six in the evening and then one two hours after nine o'clock, so about eleven o'clock, twelve o'clockish."*
73. He then continued to say *"Wish I wasn't taking them really but knowing that they're doing some good, maybe encouraging me to take them. If they wasn't showing good results then perhaps, I may be having second thoughts but at the moment they seem to be correcting things."*
74. He explained the side effects of these tablets: *"feel like I want to be sick after taking one of the tablets, well three of the tablets of one kind. Back pain a little bit but I don't know whether that's to do with the drugs or not. I think we're most probably using the drugs, which is doing maybe some damage to the liver I don't know. Yeah that's it really, a*

few headaches, which I never suffered with headaches before that's about it."

75. His infection impacted upon his private life. He had a few girlfriends but nothing serious. He ended an existing relationship when he found out about the HIV. He felt it was unfair on the girl. From this point, he started to draw himself away from everyone.

76. He knew the risks of HIV and I assume this was why he no longer wanted a partner or any children. This is a shame because I know he did before. He used to look forward to that part of life.

77. The infection didn't massively impact upon his work life. He maintained a job as a dental clerical officer at the Dental Practice Board, in Eastbourne. However, he did want to become a social worker in a children's home and his infection and medical condition prevented him from doing this.

78. John's infection and death have also had a big impact on myself. After he died, I felt like I had no one to run to anymore; no one who would listen to me.

79. I tried counselling, but I couldn't do it. I couldn't talk to someone sat there like a brick wall.

80. I still think he's out there somewhere, watching over me.

81. I really miss John. There are a lot of things in the house that belong to him and I can't touch them; I can't change them.

82. I go over to the cemetery occasionally, but not very often. I find it too upsetting.

83. We didn't really suffer from any stigma surrounding HIV, because people didn't know that John had it until after he died.

Section 6. Treatment/Care/Support

84. John was never offered any counselling or psychological support. He asked for this, but nothing came of it.

85. In 2011, I requested information from the National Haemophilia's Database. They provided me details of John's treatment for his Haemophilia. On page 2 of this document it shows that in 1977 John received Cryoprecipitate in Eastbourne. In 1980, Kryobulin, again in Eastbourne. The first time Factor VIII (BPL) is prescribed was in 1981 at St Thomas Hospital. Page 1 of this printout also shows that John received Factor VIII from France in 1992-3. **Exhibit WITN0473005 Refs.**

Section 7. Financial Assistance

86. John received a stage 1 payment from the Skipton Fund, however there was no indication that his illness qualified for the stage 2 payment, so he didn't get anything more.

87. He also received regular payments from the Macfarlane Trust. They contributed to his funeral.

88. Finally, he received mobility benefits, which consisted of a car and Disability Living Allowance.

89. John bought a house in 1995 and paid off the mortgage the February before he died.

Section 8. Other Issues

90. John died of HIV, however his death certificate lists Bronchopneumonia, Haemophilia and type II diabetes as his cause of death. **WITN0473004 Refs**

91. I was told that I couldn't collect the certificate straight after his death because they hadn't decided what to put on it. Eventually, GRO-C Coroner's Office called to say that they had put this instead of HIV, apparently to avoid the stigma associated with HIV.

92. From John's interview transcript, I know that he wrote to MP, Ian Gow. He found him supportive. He also got involved with a group called the Birchgrove Group which sought to get the government to listen and do something about what had happened.

93. He did not find GRO-D supportive at all.

94. I would like to know why infected blood was used in this country. Why, after the government apparently knew the blood was dangerous, they continued to allow contaminated blood to be used in blood products such as Factor VIII.

Statement of Truth

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

Signed

GRO-C

Dated

29. 05 19