

Witness Name: Lesley Poole

Statement No: WITN2974001

Exhibits: WITN2974002 - 008

Dated: January 2020

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF LESLEY POOLE

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I, Lesley Poole will say as follows:-

#### **Section 1. Introduction**

1. My name is Lesley Poole. I live at GRO-C  
GRO-C My date of birth is the GRO-C 1946. I live with my partner and currently not working.
2. I had two sons, Warren Poole and Simon Poole who had severe Haemophilia A and both were infected with HIV and Hepatitis C (Hep C).
3. Warren Poole was born on the GRO-C 1967 and he passed away in 1996. Warren had learning difficulties.
4. Simon Poole was born on the GRO-C 1969 and he passed away on 29 May 2019.
5. This witness statement has been prepared without the benefit of access to both my sons' 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 Affected**

6. Simon and Warren both had severe Haemophilia A from birth. Haemophilia runs in my family and I am a carrier of Haemophilia.
7. Both boys were treated at Churchill Haemophilia Center and their treating doctors were Dr Rizza and Dr Mathews until we moved 10 years ago. I believe Warren and Simon were given infected blood products whilst we were living in Northampton.
8. Warren and Simon were both treated with Factor VIII Concentrate (FVIII) from a very young age. They were also given blood transfusions. I was not able to drive and therefore had to rely on my ex-husband to take the boys to the hospital to be treated. When we divorced I had to rely on the ambulance service to help me get the boys to the hospital to be treated. In about the late 1970s I learnt that I could treat them at home which made life easier for me. I exhibit at **'WITN2974002'** batch numbers of the FVIII treatment that Warren received and I exhibit at **'WITN2974003'** batch numbers of the FVIII treatment that Simon received.
9. I was never provided with any information or advice beforehand about the risk of being exposed to infection when using FVIII. We didn't think anything of it as we thought the doctors knew what they were doing with the treatment.
10. As stated above, both Warren and Simon were infected with HIV and Hep C. I recall being told that Simon's type of Hep C was a rare one from Egypt. I also believe that, at some stage, Simon was infected with Hepatitis B (Hep B).
11. I found out that there was a link with Hemophiliacs and HIV in or about the mid 1980s. I was working in a sport and social club and I was listening to the radio and there was a news report stating that Haemophiliacs were found to have HIV. My work place just went quiet when this news was broadcast. I was in shock. I sat there trying to get my head around what was being said.

12. We were always attending the hospital and I would have thought that someone would have said something if the boys were at risk of any infection. I then received a letter in relation to Warren, which I exhibit at 'WITN2974004', (date as post mark) which states that blood tests were carried out in Oxford to show whether there had been contact with AIDS-related virus. It continues to state that they have tested about 300 patients, some only once or twice, some as often as five or six times. The letter states that if I wished to know the result of Warren's tests then to let Dr Matthews or Dr Rizza know and they would be happy to discuss them providing they have the results of 3 or more tests. It was confirmed that they had 4 test results for Warren. I believe that Simon received a similar letter. I believe the letters were sent in alphabetical order. Simon went to see the doctors first with my ex-husband and then I took Warren. I was told that Warren had contracted HTML-III (HIV). I recall being told by the doctors that Warren would only have 10 years to live and he died 10 years after being told. I also recall the doctors telling me that we should not tell anyone about the infected status and to keep it between ourselves. I do not know what conversation took place when my ex-husband attended the appointment with Simon. It is possible that he was given similar information.
13. Not much information was given to Warren. I recall one doctor or nurse saying that they didn't have to explain the implications of the infection to Warren because he had learning difficulties. I exhibit at 'WITN2974005' a letter to Dr Robertson from Dr Rizza, dated 21 October 1985. Dr Rizza confirms that he had discussed the whole thing with me, my husband and my two sons in great detail. However, I don't believe much information was given to me or Warren at the time.
14. In or about the late 1980s/early 1990s, Simon received a letter which stated that he had also contracted Hep C from FVIII. They never mentioned any Hep C infection in relation to Warren, they just pushed him to one side. However, having looked through Warren's limited medical records, I note a letter from J.M. Trowell to Dr Robertson, dated 15 October 1985, which states '..... when I examined him he was thin, with no peripheral stigmata of chronic liver disease but he has a palpable liver and spleen and in view of the

persistent abnormalities of his liver function tests, the current AST is still 118, I think it must be presumed that he has a chronic Non-A Non-B hepatitis which is almost certainly from his factor VIII treatment. Our policy is not to pursue investigation with these patients as there is no specific therapy which could be offered but I normally arrange to see them on their routine follow-up visits to the Haemophilia Centre in case any problems or symptoms arise.' This letter clearly confirms that Warren had Hep C, but I was never informed of such infection. I exhibit a copy of this letter at 'WITN2974006'.

15. I do not believe that adequate information was provided to help manage and understand the infections. As stated above, with regards to Warren they just brushed him off.

16. I believe that information should have been provided much earlier. I was giving home treatment so I could have been potentially been infected.

### **Section 3. Other Infections**

17. I believe that Simon was also infected with Hep B. It is possible that he was also at risk of vCJD.

18. I believe Warren was also infected with Hep C but he was not aware of this. I do not know if Warren was infected or exposed to any other infections.

### **Section 4. Consent**

19. I believe that Warren was tested without his knowledge and consent. I believe that when Warren was about 7 years old he was monitored for Hep C (as stated above) and we were never told about this. There were various blood tests that were carried out on Warren which I exhibit at 'WITN2974007', which we were never told about. Also exhibited at 'WITN2974007' is a summary of all the blood tests that were carried out although the first page is missing from his medical records.

20. I also believe Simon was tested without his knowledge and consent. When looking through his medical records I came across various blood tests that

shows he had Hepatitis and was being tested for it and we were never informed of this. I exhibit at 'WITN2974008' blood tests from 1972 through to 1990 and also a summary of blood tests that were carried out.

21. I believe that both boys were treated and tested without being given adequate and full information.

22. I believe that the boys were tested for the purposes of research. Every month the clinic nurse would come and take their blood. On one occasion Simon asked why they needed to have a blood test and she said they take it to 'grow plasma to help them'.

### **Section 5. Impact of the Infection**

23. Warren took everything in his stride. He used to run mini marathons; he would walk everywhere and was always on the go. He was very active. He won medals for handicapped children. Simon was not sporty in that way but was good at golf, darts, snooker and pool. He was good at snooker and pool too. He was the centre of attention when he went to the youth club where I worked. Both the boys had quite active lives.

24. As a result of the infection Warren became lethargic, lost weight, had bad headaches, and generally felt unwell. He kept passing out and had fainting spells. He got pneumonia twice, the first time being 5 years before he passed away. He always had bad chest infections.

25. Warren had skin disorders and sores. He needed special bedding and had to be covered in cream. He also had to wear sheep skin boots on his feet.

26. I believe the infection affected Warren mentally. He started to do strange things. He always came shopping with me on Saturdays and on one particular Saturday he went to the shop opposite which was called 'knicker box' and sold ladies underwear. I ran in and he was looking at underwear and seemed to be in a trance like state.

27. There was another occasion when Warren got up at 2 in the morning and took the dog for a walk in his underpants. Luckily his cousin was there to take him home. I rung Mary Brookes, the clinical nurse, who said to bring him straight to the hospital for a brain scan. It was like he had a form of dementia. He couldn't come down the stairs. Someone had to hold him while another moved his feet. He needed Pentamidine once a month. Mary told Warren that the HIV had attacked his brain. She told Warren he was going to die and he had about 6 months left to live. She asked if there was anything he was afraid of and he said he wanted to die at home with his mum. So I kept him at home and learnt how to give him the Pentamidine myself.
28. During the last couples of years of his life Warren got really tired. It was like he had a bad flu all the time. I asked the doctor what Warren felt and they said it was like seasickness all day. He had to snack to keep the sick feeling at bay.
29. When Warren became really poorly they bought out the first anti-retro medication but as soon as he took it he would start projectile vomiting. I used to sit up all night with him and still go to work the next day. My now partner volunteered to sit the night with Warren so I could get some sleep. Warren only tried one lot of medication because he wanted to carry on with his life. Then one day he said 'I am having no more'. Warren wanted his life back. I told him if he didn't take them then he would die and he said he didn't care. He took the medication for about 3 or 4 months before he stopped taking it all together.
30. One day I went into Warren's bedroom and he had a red mark on his forehead. That night I sat with him and held his hand. He never said much. He peacefully passed away that night. I was told that the cause of death was a massive brain haemorrhage which was caused by the HIV.
31. We were all close and looked after each other because we were all in hiding together. I was keeping it all together because the boys depended on me.

32. When Simon came back from his hospital appointment in relation to the HIV result he changed into a completely different person. Prior to finding out that he was HIV positive he was a fun, outgoing, and loving person but when he came back he was in shock. It changed him over night. He was resentful, angry, bitter, and full of hate for everything and everybody.
33. Simon suffered with his mental health. He suffered with agoraphobia after he found out. He shut himself in his bedroom for 3 years and would not come out. He wouldn't even look outside of the window. I was taking driving lessons at the time but I gave up my driving lessons so he could learn to drive instead. He had 3 lessons and then he passed his test first time. The only way he would leave the house was if he was hidden in the car. He would also only go out in the dark so nobody looked at him or would see him. He wore large clothes so he would look big in them. Simon was very paranoid if anyone looked at him. He became very depressed. In the bathroom we had to cover the shower cubical and every mirror. If he heard anyone laughing he would cry.
34. Simon said that the hospital were 'just playing Russian Roulette with my life' and they might as well shoot him. He hated the NHS and hated what they had done to him.
35. Simon physically suffered from liver cancer, cirrhosis, and ascites. Simon lost his teeth and nearly lost his finger and toe nails.
36. Simon must have gone through about 20 combinations of retro virals. After having the treatment Simon suffered dreadfully. He tried every treatment that was available. One of the combinations for HIV that Simon had made him throw up tons of acid in his stomach. Simon physically found it difficult to eat and as a result, lost weight rapidly. In the end he needed to stretch his oesophagus. They wanted to put the camera down his throat first but it would not fit down so they had to do a stretch. They stretched his stomach a tiny bit and put the camera down, which showed that the acid had burnt his oesophagus.

37. Simon was given every medication they could think of. They ran out of options. He was given cocktail after cocktail of medication. He had sickness, his skin fell off, and some medication made him feel lethargic, or gave him bad headaches. The side effects were dreadful. He was anorexic and he struggled to walk. He was tube fed. He would only eat things like soup and custard. Even after the oesophagus stretch he was so paranoid of choking. Everything had to be mashed. He had a dietitian who said he needed plenty of butter and cream. They said he would never be able to eat meat again. I think he had 3 stretches and on the last one they called it day because there was a bit of blood. As a result of all of this Simon stopped having family meals. We had to eat the same as Simon because if he could smell food he could not eat he would get upset. For a while, to get rid of the cravings, he would chew the food and then spit it straight out.
38. Simon went to see Professor Crant who wanted him to start Hep C treatment. The treatment consisted of swallowing big tablet but because of Simon's throat he was unable to take the tablets. When he went there they showed him the big blue tablet and Simon burst into tears because he was so hopeful of the treatment. He had stopped drinking and smoking. He asked if he could crush the tablets but they said no. He was grasping at every straw to live. He came home in floods of tears. He was sent a letter stating that they needed to do a scan for potential treatment but he refused it because he couldn't see the point.
39. After Simon missed two appointments he did eventually attend an appointment to have a scan. Two nurses carried out the scan. One was training and the other was a fully trained nurse. I noticed on the scan that his liver had tiny white spots. I could tell by the nurse's reactions that it was not good news. They both left the room and Simon noticed something was wrong. He got into his wheel chair and I asked 'is that cancer?' She said 'it's not up to us to say, it's up to the Consultant'. Simon then saw Zoe Warwick at Derriford Hospital, she said the white spots were 'age spots' and that he had nothing to worry about.



40. Due to his throat issues he couldn't eat or drink. He was fed through a tube. Then he got bloated and was admitted to hospital again about 2 years ago and a doctor came in and said 'have you come in here to be cured or come in here to die'. Simon looked at him and the doctor said 'you do know you have a tumour on your liver?' Simon did not know this as he thought they were age spots. This was the first time we heard that he had cancer.
41. They did a liver biopsy and gave him chemotherapy but it didn't work. Simon said he was never having chemotherapy again due to the pain.
42. Simon went to see another top doctor, who was a cancer expert. On his last scan it showed the cancer had entered his portal vein. They said they could cut three quarter of his liver away but because the cancer was in his veins there was nothing more they could do.
43. Simon passed away from liver cancer on the 29 May 2019. His liver was in a bad condition and they put it down to drink. He had Hep C since he was a child and as a result he had liver cancer.
44. Simon got one of his girlfriend's pregnant before he knew he had HIV. I told her mum because she was so young. I said she should not have a child that young but she kept it. The baby girl was born on Christmas Eve. They weren't together for long. Simon went round on Christmas Eve to give her a card and money but she had already met someone else, he was politely told to go away. I never got to see her after that.
45. When Simon got involved in a second relationship he was very open about his infection. I believe things were going well between them. One day Simon came home and told me to sit down. He proceeded to tell me that his girlfriend had given birth. I didn't even know she was pregnant. I thought 'you bloody idiot'. Mary, the clinic nurse, came over to test his girlfriend and his son. It took four hours to test them but they were all clear.
46. His then girlfriend worked night shifts so I would help him get his son ready so all Simon had to do was put him to bed. His then girlfriend started seeing

someone else from work. She was nasty to Simon because of his HIV status. She was at her sister's house and told Simon not to come in the house. She was trying to take the council house off Simon which he got through medical needs. She took everything and left him in a puddle of water. I never saw his son again.

47. After that relationship was over, Simon found someone else and got married. I believe his wife had bipolar. The marriage was dreadful. I told Simon not to have any more children. I believe that Simon's then wife was jealous of the mother of his son and therefore got herself pregnant. They both came into my kitchen and said 'before you start she is pregnant but she has been tested and tested negative for HIV'. That marriage didn't work and they split up.

48. His then wife was drinking and did not know how to look after their child. When they broke up she threw Simon out of the house which they bought together. I think Simon had a £10,000 loan from the MacFarlane Trust and he had to pay it back when the house was sold. I bought him jewellery and his then wife took it and sold it. It got to the point where I had to pay for his TV license and bills as he couldn't afford anything. She went through a stage of wanting to go nightclubbing every night. It all went pear shaped and he was left with his laptop. Her parent's looked after their daughter. They moved away and I don't see her.

49. Simon knew that he was going to get worse. Warren was the 6<sup>th</sup> member of the family to die and Simon was the last man standing. It gave him mental health issues. When Warren died at home it affected Simon a lot and I didn't know that it had a huge impact on him. I felt guilty about this.

50. I didn't have a social life, mainly because of Warren. When I had Warren's funeral that was the first time I saw my outer family for 10 years. Then when Simon passed away I realised I had not seen them for 20+ years.

51. After Warren died Simon didn't want to stay in Northampton so we had to move and moved to Cornwall. No body knew of Simon's infected status. My next door neighbour was new and she was a bit nosey and asked what was

wrong because 'he didn't look well'. I said he had haemophilia and she looked at me as if she didn't know what it was. Next year will be the 10th year I have lived in Cornwall and I don't know a soul. Apart from my sister I am isolated, but she lives 5 miles from me and I can't drive. She also has a hectic social life and I don't expect her to give that up. All my sisters have been great but they are back at home and now I'm here, I'm stuck again. I also still have a mortgage to pay.

52. When Warren passed away I knew I was going to lose my other son so I took out a £5,000 loan and bought two burial plots side by side in Northampton so they could be together when they passed. However, because we moved out of the jurisdiction of Northampton Simon couldn't be buried there. So I had to have him cremated and then get permission from the Northampton council to bury his ashes. I had to have two services and another headstone made. It was all a bit complicated. We have been through absolute hell. I wanted to move back to Northampton to be near them but it's difficult for me.

53. When I first found out about the HIV I was devastated. We were all so close. Once I got divorced we looked after each other. The boys thought the world of me. I used to feel so bad because I gave them haemophilia. It ruined my life. How can I have a relationship and tell them I have two boys and both have HIV? I was lucky with my partner at present because I believe he understood me. He was so angry because they were two beautiful boys and they did not deserve it.

54. In the mid 1980s when it came on the radio while I was working the stigma started immediately. I worked behind the bar and one day I went to give someone their change and they grabbed my arms and said 'is it true your kids have AIDS?' I got really upset and thought I could not work there anymore. They put two and two together. The stigma got worse and worse and then people would go after the boys.

55. Someone wrote that Simon Poole has AIDS at the side of a block of flats across the road from where we lived. I had to call the council to get it removed. Someone also drove straight into Simon's car and wrote his car off.
56. Warren was also affected by the stigma. There was an incident where Warren took the dog for a walk and a gang of young youths surrounded him. Warren was only told that he had bad blood and that he should be careful around people. He only knew the limited information about the infection. The gang surrounded him and said he had AIDS, which frightened him because he had seen the TV adverts about it. He hit one of them because he was scared. The police came to the house and arrested Warren. They wouldn't let me see him even though I told them he had learning difficulties. Warren told them the truth about what happened so they didn't press charges. They said they were sorry he had to go through that.
57. On another occasion we were woken up at 2.45am by someone continuously knocking on the door. When I answered the door a man was stood with a gun in his hand and said we had to get off the estate as soon as possible. I just shut the door and sat on the stairs. We were all scared then. I only owed £6,000 on the mortgage, but I had to put the house on the market straight away and we had to move. I had to get another £30,000 mortgage because Simon wanted to move to the other side of town where no one knew us and he needed a garage for his car because of what happened before. Simon moved a week before me because he was that scared and he just camped on the floor.
58. When we moved people found out about the boys infected status and broke into the garage and stole Simon's radio and speakers. They even helped themselves to the freezer. We were getting scared again but Warren was poorly so we found it difficult to move again.
59. When Warren passed away Simon was not coping, mentally. We then moved again and he picked the furthest place he could to run away, this was when we moved to Cornwall. I had to take a £50,000 mortgage to come here.

60. The boys went to a special school in a place called Walbridge, called Fairfields School. Warren got a job at Work Bridge but when he started his employment he was getting very tired. I told him he had to slow down because he was getting poorly. He said he had to go to work because they needed him. He was on a machine which wrapped birthday cards in cellophane and he loved his job.
61. Warren was really ill but he was still going. Going to work was his world. We had to drive him to work in the end. We agreed he would go part-time because he used to fall asleep on the bus ride home. He went part-time for a little while but he knew his health was deteriorating. Everything was being taken away from him slowly. He became bedbound when he had the brain scan.
62. Simon was at college doing electrical electronics but he left. He was afraid that people would find out about his infected status. Simon did quality control for work but they found out he was a haemophiliac and said he could not work there anymore. They offered him a brush to sweep the floors. He also tried roofing but unfortunately he had an accident and fell through. He tried to work but he started getting a lot of trouble with his ankles because of his bleeds and he was worried about his infected status. He bought these straps so he could walk but without them he couldn't walk. He then got a job repairing televisions but he got a bleed in his elbow so he called in sick. I took him to work with me and his boss phoned our home phone, Warren answers and he said 'he is at the snooker hall' so they sacked him, because they thought he was skiving but actually I worked at the snooker hall and I was treating him there.
63. When they said Warren had 6 months left to live I told my boss I needed the time off because my son was near the end of his life. I had worked there for 30 years and my boss couldn't give me a few months off. The owner found out and told my boss to come to my house and apologise. I finished work on the Friday and Warren died on the Sunday. I think he gave me two weeks off and then I had to go back to work.

64. I haven't worked for 10 years. Simon couldn't cope down in Cornwall and he was hitting the bottle like mad. So, I had to give up a good job and beautiful home to move down.

65. My grocery bill was around £170 a week because Simon wanted to eat different things. My electric bill was £600 plus because Simon wanted the heating on all day and also have the electric blanket on. He also had to have the TV on as he couldn't sleep in silence.

#### **Section 6. Treatment/care/support**

66. Warren received no support whatsoever.

67. I received some support from the clinic nurse.

68. They offered Simon mental health counselling but Simon would just say 'are they going to cure me because if they weren't then they were wasting his time'.

#### **Section 7. Financial Assistance**

69. Simon was in control of his own money so I do not know exactly what he received. I believe he received the Stage 1 payment from the Skipton Fund and one payment of £25,000 from the Macfarlane Trust. I believe he also received monthly payments.

70. As stated above, I believe Simon had a £10,000 loan from the Macfarlane Trust, which he had to pay back when the house was sold.

71. When Simon got a second hand car Warren wanted to know where he got the money from because Warren had not received anything from any of the Trusts or Funds that were set up. Simon felt a bit guilty because he had read a letter which said they weren't going to give Warren anything. Simon fought for his brother to receive some money. The Macfarlane Trust came down from London and met Simon and myself. Simon asked why Warren couldn't have his pay out. Simon said that the money belonged to us, so if his brother

wanted to put it on a bet then so what, they said 'save it for the future' but Simon said 'what future'. Their future had been taken away.

72. Warren did eventually received £25,000 back in the 1990's thanks to Simon who fought for it. They told me this was an interim payment while they were investigating.

73. Warren did not receive a monthly payment like Simon.

74. Warren never received anything from the Skipton Fund because he did not know he had Hep C. I then claimed on his estate 10 years ago because in 2009 the Skipton Fund got in touch with me and asked if I wanted to claim. I did not know that Warren had Hep C so I phoned Dr Giangrande and I asked him and he confirmed that they were correct Warren was also infected with Hep C.

75. I applied to the Macfarlane Trust once for a new mattress but they said no.

76. I also asked for a new boiler from the Macfarlane Trust. I said they could apply straight to the gas board. They wrote back and asked for 3 quotes. I had one quote but we needed it fixed as soon as possible. The Trust took so long in getting back to us that Simon and I went halves and paid for it ourselves. We didn't try to get it back because they never gave us anything so I didn't ask for anything.

77. I received £1,000 when Warren passed away.

## **Section 8. Other Issues**

78. Simon was the 7<sup>th</sup> family member to die because of this tragedy. I had already lost Warren. My sister lost 2 sons, my cousin lost 2 sons, and we lost an uncle. We still have 2 haemophiliacs in the family who have Hep C. My GRO-A. It tore my family apart. When everything about the HIV came out meetings and conversations about it went quiet and underground. You just go into hiding once you have had a taste of the stigma.

79. My father was a Haemophiliac and had the same 0% clotting factor as my two boys. FVIII was not around when my father had bleeds. I was told that they stopped the bleeds with snake venom, or a blood transfusion. He went through years and years and lived until he was nearly 90. I therefore do not believe that it was necessary for my two sons to always be treated with FVIII.

80. I tried to apply for all the medical records for Simon and Warren and was only provided with limited records.

**Anonymity, disclosure and redaction**

81. I am not seeking anonymity.

82. I would be 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 .....

Dated 27-1-2020