Witness Name: Joan Elizabeth Pugsley
Statement No: WITN4603001
Exhibits: WITN4603002 - WITN4603004
Dated: 24 June 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOAN ELIZABETH PUGSLEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 January 2021.

I, Joan Elizabeth Pugsley, will say as follows: -

Section 1. Introduction

1. My name is Joan Elizabeth Pugsley. (nee Cluitt) My date of birth is GRO-C 1941. I reside at GRO-C. I married my husband Philip Norman Pugsley in 1960. We have three children together, Tina Barton who is aged sixty-one-years-old, Trudy Bailey who is aged fifty-nine-years old, and Philip Anderson who is aged fifty seven-years old. (Phillip changed his name when he was 21 due to the fact that he did not like the surname Pugsley) We also had two grandchildren. Daniel Barton who was eleven-years-old upon his death, and Sorrel Bailey.

2. I am currently retired. Before this, I was employed part time at Osborne Electronics, predominately I was a housewife.

3. I intend to speak about my late husband Philip's infection with HIV, after having receiving contaminated Factor VIII blood product for treatment for his haemophilia. In particular, the nature of how he learnt about his infection, how the illness had affected him and our family thereafter, and the treatment he had received. Philip's date of birth is GRO-C 1941, and his date of death is GRO-C GRO-C 1991.

4. I also intend to speak about my grandson Daniel Barton's infection with HIV, which was contracted in similar circumstances to that of his grandfather Philip. Daniel's date of birth is GRO-C 1981, and his date of death is 19 January 1993.

5. My daughter Tina Barton also provides a witness statement to the Infected Blood Inquiry ("IBI") at **WITN5492001**. She discusses her father's Philip Norman Pugsley and her son's Daniel Barton infection with HIV.

6. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity as I wish for my story to be known in full. As a family we have suffered terribly. I have lost my husband and my grandson to HIV.

7. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

8. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

9. I have constructed this statement without access to both Philip and Daniel's medical records.

Section 2. How Affected

10. In 1958, when I was aged seventeen-years-old, I attended a dance with my friends at the end of the Pier in Ryde, Isle of Wight. It was here that I met Philip. From the point at which we met, we fell in love. Within a couple of years, we got married when we were both eighteen-years-old in 1960.

11. Philip and I wanted to start a family straight away, so by January 1960, I was pregnant with my eldest daughter Tina. On GRO-C 1960 I gave birth to Tina at St Mary's Hospital ("St Mary's"), Parkhurst Road, Newport, PO30 5TG.

12. Thereafter, I gave birth to my second daughter Trudy on GRO-C 1962. Whilst the birth of our second daughter was a happy period for us both, it was also coincided with Philip's twenty-first birthday, so he was not best pleased that he had to miss out on his birthday celebrations.

13. In 1970, I gave birth to my son Philip. Myself and Philip lived with my mother-in-law for the first five years of marriage, to save for a deposit on a house. Thereafter, we moved into our family home where I still live.

14. Throughout Philip's life, he had worked in many different jobs. When we first met in 1958, he worked at a local shop as a labourer. He then took up employment at Woolworths stores due to the enhanced pay. Thereafter, he got a job at the local primary school as a general handyman, and then as a roof tiler. All of these jobs, carried risk, particularly as he was a haemophiliac.

15. When we had married in 1960, Philip's parents had told me that he was a "bleeder." I did not know what this was at the time, so his parents proceeded to tell me that this meant that he was a haemophiliac. I understood his condition to mean that he carried a higher risk of bleeding as his blood did not

clot as readily as normal. I was not told any further information by his parents at this point, other than that it would not affect me or our children. The haemophilia would stop at Philip and that it would not be passed on to our children.

16. I cannot pass comment on the exact point at which Philip had been diagnosed with haemophilia, other than that it was when he was of a younger age. Philip had told me that he had Haemophilia A, and that he was later registered; due to advances in testing, as having fourteen percent clotting factor.

17. I have since come to learn that haemophilia was in Philip's family, and that his mother was a carrier. GRO-C

GRO-C

18. GRO-C, Tina was found to be a carrier. My grandson, Tina's son, Daniel was also born with Haemophilia A.

19. As a young man, Philip did not let his haemophilia get in the way of his ability to achieve what he wanted in life. He carried out employment which he loved; despite the associated risk of injury being enhanced for him; and he had always tried to remain fit and look after himself. Philip was so fit, that he became a body builder. He even tried out for the Mr Universe Championships, which is an annual worldwide bodybuilding event, organised by the National Amateur Body-Builders' Association. Philip enjoyed body building, as he was told that if he looked after himself, in turn, it would help his bleeds.

20. When Philip was growing up, he did not experience many bleeds and it was not on a regular occurrence. On the odd occasion, if he suffered an accident at school; such as being kicked by another child, he would suffer a bleed or

bruising. His injuries would often be treated at home by his mother placing a towel on his bleed.

21. However, as he grew older, depending on the severity of the bleed, he would treat his bleed at home with rest, or, he would be prescribed with painkillers for minor bleeds. Thereafter, for particularly bad bleeds, Philip started on treatment with Factor VIII sometime in the late 1970's at St Mary's. Philip did not receive Cryoprecipitate as treatment before the on-set of the development of Factor VIII.

22. As an adult, if Philip required treatment of Factor VIII, he would telephone St Mary's and state something along the lines of *"my name is Mr Pugsley. I have a bad bleed and I need to come to the hospital to receive Factor VIII treatment."*

23. Thereafter, Philip would attend St Mary's to receive treatment of Factor VIII. After the blood product was administered, he would be told by the medical staff at St Mary's that he would be discharged home to rest. However, due to his get up and go attitude, and his self-employed status, he would not rest, but go to work. He would always tell us that if he was not working, no money would be coming in and he could not provide for his family.

24. Philip remained well in his health, as through his healthy life style, he was able to manage his bleeds. However, it was not until around 1984, that Philip began to notice that his health had taken a turn for the worst.

25. In 1984, Philip sought medical assistance from his General Practitioner ("GP") Dr Russell at Sandown Medical centre. After initial observations, he was told that he had an unspecified virus. As a result, Dr Russel referred him to the Oxford Haemophilia and Thrombosis Centre, Churchill Hospital ("Churchill"), Old Road, Headington, Oxford, OX3 7LE, for a face to face consultation with Dr Charles Rizza. Dr Rizza was the Director of the Oxford Haemophilia Centre.

26. I attended Philip's face to face consultation with Dr Rizza. After Philip had described his symptoms, he was asked to undergo a number of blood tests thereafter to determine the cause of his ill-health.

27. Two or three weeks later, Philip was asked to attend the Churchill for another face to face consultation with Dr Rizza.

28. Before attending the consultation with Dr Rizza, we had heard about the AIDS virus being prevalent in America in the news. It had also stated that the NHS were buying blood from America, of which, was predominantly being sourced from persons such as drug addicts, prisoners, homosexuals and prostitutes; who were considered to be higher risk with regards to having been infected with the AIDS virus. However, at the time, we did not think much about it. That was until an "unnamed virus" had been mentioned by Dr Russell.

29. Prior to Philip's diagnosis he decided to ask if the "unnamed virus" was in fact, AIDS. In response, Dr Rizza reassured him. He had stated something along the lines of "*you should be fine Philip. You're miles away from where the problem is in the United Kingdom. As you live in the Isle of Wight, it shouldn't be so bad, and you didn't have much Factor VIII in the past so there is nothing to worry about*."

30. After Philip was asked to undertake further blood tests at the face to face consultation, Dr Rizza proceeded to ask me if I would provide a blood test. At that point my mind was racing. I questioned his reasoning behind why he had asked for me to provide a blood test, to which he had stated that it was just a precaution and that I did not need to worry. In those days, you did not question doctors and their methods due to the Seniority, so I had undergone a blood test as requested. Myself and Philip returned home not long after.

31. On the three-hour journey back from the Churchill to our home in the Isle of Wight, I had plenty of time to think about why I had undergone a blood test, and what this could have meant in the grand scheme of things with regards to

both of our health. I had stated to Philip something along the lines of "*I think you must have it. Why else would they have asked me to give them a blood test.*" By "it" I meant HIV. We had heard much in the news about HIV and AIDS, and that it had been discovered to have been transmissible by blood. In response, Philip calmed me down and had told me that I did not need to worry, it was just a precaution they needed to do. This settled my mind.

32. However, two weeks thereafter, we were asked to visit the Churchill again for another face to face consultation with Dr Rizza. This time, at the consultation we were greeted by not only Dr Rizza, but also Dr James Matthews who worked alongside Dr Rizza in the Oxford Haemophilia Centre. As soon as we both entered the room, we knew that there was something wrong.

33. It was at this point, that Dr Rizza proceeded to tell us something along the lines of "*I am very sorry Philip, but your blood tests have returned and it has shown that you have tested positive for HIV. We did not think you would get it on the island. However, if you feel unwell from now on, you can come straight to us any time day or night just phone up.*" Both Dr Rizza and Dr Matthews were very apologetic.

34. Philip and I were so shocked. We did not know what to think, we just sat there and looked at one another. Thereafter, Dr Rizza had told me that I had tested negative for the presence of HIV. No further explanation was given to us.

35. I took this opportunity to ask Dr Rizza how it was possible that I had tested negative for the presence of HIV. Throughout our marriage of over twenty-five years at that point, we had a very good sex life and were not taking any precautions as we did not have any cause for concern to have needed to take safe sex precautions. In response, Dr Rizza had told us that we had just been very lucky, and from that point onwards, we would need to practice safe sex.

36. We were given large thick condoms to prevent any future risks of transmission of Philip's HIV, and, large vaginal suppositories. Such suppositories were Microbicide, which would need to be placed into the vagina at least ten

minutes before sexual intercourse; for the purposes of providing a modest level of protection against HIV acquisition.

37. Aside from the advice we were provided with surrounding safe sex practices from Dr Rizza, we were not told much information about HIV as a virus, which would have allowed us to adequately understand or manage Philip's infection.

38. We were not told what this meant with regards to his future health, or any future treatment he would need. We were simply told that he had tested positive for the presence of HIV, and that if and when he felt unwell, he should contact the Oxford Haemophilia Centre. I do not consider this limited information we were provided with, would be considered adequate enough for us to have been able to manage his HIV.

39. We were not told about the risks of others being infected as a result of Philip's HIV; other than safe sexual practices. We were not provided with information such as do not share toothbrushes, razors, or that when Philip suffered a bleed, I was to ensure that I did not come into contact with his blood. As Philip was a haemophiliac, he would suffer accidental knocks here and there. It was inevitable that I had regularly come into contact with his blood when cleaning up.

40. I do not consider that we should have been provided with Philip's HIV diagnosis at an earlier point in time. As far as we are aware, we were told about his positive HIV test result as soon as Dr Rizza and Dr Matthews had become aware of the blood test result themselves.

41. I do not have any views about how the results of Philip's blood test was communicated to us. We were told in a private face to face consultation within Dr Rizza's office, and both Dr Rizza and Dr Matthews had a great amount of sensitivity and empathy for us when they had told us about his diagnosis.

42. After Philip was diagnosed, we had thought about what could have possibly caused Philip's HIV infection. It was at this point, that we considered there to be two possible causes of his infection.

43. Firstly, for various nasty bleeds Philip had suffered in the late 1970's to early 1980's, he would receive Factor VIII blood product as treatment at St Mary's. I have since come to know that the blood product he was given was American sourced, and as a result, carried a much higher risk of infection than that of NHS British blood product. We were told by Mary Fletcher (The health visitor) that they used the American product because it was cheaper

44. Secondly, within a Newspaper Article, dated Thursday 20 December 1990, by Ian Gordon, in the Isle of Wight County Press Newspaper, it was stated that Philip had contracted HIV through a blood transfusion he had been given as treatment in 1982, when he had teeth extracted at St Marys.

45. Whilst I cannot state as fact, what was the cause of Philip's HIV infection, if I had to make an educated guess, it would have been the Factor VIII he had received as treatment in the late 1970's and early 1980's. I believe that this carried a much higher risk of infection than that of the blood he was given during his blood transfusion in 1982.

46. I can only recall a handful of occasions where Philip suffered an injury which required Factor VIII treatment. On one occasion; when he was a roof tiler, he went through a roof and took all the skin off from the sides of his body under both of his arms. Another time, when he worked on the motorways, he dropped a curb block on his toe and it had swollen to such a large size that he required treatment to bring down the swelling. Philip was not exposed to a large volume of blood product throughout his life. Therefore, if this was the source of his infection, he was very unlucky with the blood product he was given. It was the luck of the draw.

47. As far as I am aware, there was no look back exercise that had been carried out to determine the likely cause of Philip's infection.

48. With either the Factor VIII or blood transfusion he was given as treatment, Philip was not provided with information or advice surrounding the associated risks of blood borne infection which came with such treatment.

49. From the point at which Philip was diagnosed with HIV in 1984, he tried to carry on with life as normal as was possible in the circumstances.

50. However, this was particularly difficult, as in September 1985, we were hit with the worst news we could have ever imagined. Our grandson Daniel Barton; who was also a haemophiliac, had been diagnosed with having tested positive for the presence of HIV at the age of four years old. Not only had we as a family had to deal with Philip's diagnosis, but our grandson Daniel too.

51. In February 1990, Philip, Tina, and I were involved in the HIV Haemophilia Litigation, which was brought by those individuals who had been infected with HIV through infected blood products. Myself and Philip were involved on behalf of Philip's infection, and Tina and my son-in-law Mark Barton were involved on behalf of their son Daniel. The Litigation led to every individual infected with HIV receiving an ex-gratia payment of £20,000.

52. With the payment Philip and I received, Philip bought a fishing boat, as fishing was one of his loves in life. Due to his health he couldn't do his diving anymore, he would regularly go out on his boat around the Isle of Wight. However, on one occasion, Tina and I had noticed that he was late coming back home. We got worried, so we called the coast guard for assistance in trying to locate Philip and his boat.

53. Later that night, we had gotten so worried, when we realised that there was a black shadow walking towards us along the road. It was Philip. Immediately we realised that there was something not quite right with regards to Philip's heath and that he had become delirious.

54. Whilst we had managed to understand that the engine on Philip's boat had broken down; which had caused him to be late home, we were unable to understand anything else Philip was saying. We decided to telephone the Churchill for medical assistance. It was at this point, after describing his symptoms, the medical staff asked for an ambulance to bring him to the Churchill for treatment.

55. I decided that the best way to transport Philip to the Churchill would be to transport him myself, so I asked if this would be possible in my car. They agreed, and I transported Philip myself from our home on the Isle of Wight, the journey was a three-hour journey to the Churchill. I put a blanket down in the back of our car with a pillow; Phillip was placed into the back where he stayed for the whole journey.

56. After I had put the telephone down after contacting the Churchill, they must have rang the ferry company which ran from the Isle of Wight crossing to the mainland in Portsmouth, Hampshire. When I got to the ferry, I was told by the staff that I was to get on the ferry first, that I was to be the first off the ferry. Also, that I was able to stay in my car on the car decking so that I could be with Philip. I was delighted when during the crossing; a young man who worked on the ferry came up to me whilst I was in my car to ask if I wanted a cup of tea. This small act of kindness, which made my long journey to the Churchill a little more bearable.

57. However, not long after we left the ferry, the car had broken down. Our car had broken down in the middle of nowhere, so I decided to leave Philip in the car and walk to the top of the hill to the petrol station to ask for assistance. The assistant at the petrol station was able to telephone for a tow truck to provide us with assistance, and take us to the car repairs garage.

58. When we reached the car repairs garage, I had noticed that in the rush of trying to take Philip to the Churchill, I had forgotten to pick up my purse. I did not have any money, or a credit card to pay for the repair. I had to telephone a family member so that they could provide their bank card details over the

phone to pay for the car repairs, and thereafter, we were able to continue on our journey to the Churchill.

59. When we eventually reached the Churchill, Philip was immediately admitted to a ward so that the medical profession could observe his health, and so that he could undergo treatment. From memory I think he was admitted for two weeks or so.

60. Thereafter, in 1990, Philip and I endured several trips to the Churchill, as his health had taken a turn for the worst.

61. Philip would also regularly attend the John Radcliffe for consultations surrounding his brain, as to the cause of his frequent delirium. It was at this point that he had undergone a brain scan, which had shown that he had developed toxoplasmosis of the brain. This infection was caused by a single-celled parasite called Toxoplasma gondii. It was usually harmless, but, would sometimes develop as a result of severely weakened immune systems; such as in cases of individuals with HIV & AIDS.

62. It was at this point that I had realised that Philip had now developed full blown AIDS.

63. On 27 December 1990, Philip was admitted to the Churchill for the last time. It was at this point, that one of the doctors who was in charge of his care, had stated something along the lines of "*you do realise Philip is going to die this time?*" to which I replied "*no, he is not. He will not laydown and die.*" The doctor stated in reply "*just look at him, he is very sick.*" This was the first point at which I realised that he may not, this time, return home from hospital as usual. Also, that maybe I would be making the trip back home across the ferry alone.

64. Throughout the period of which he stayed in hospital, I stayed in a single camp bed next to Philip's bed. This allowed me to help with his treatment. He

regularly needed to take tablets to stop him being sick, these were in suppository form.

65. When I was not providing medical treatment, I would regularly walk up and down the corridor outside of his ward room for exercise in the mornings. As all the room doors would be open down the corridor, I would always poke my head into each room and say "*morning*" to every person. I would get small grins in response. It was at this point that I had realised that each room was filled with haemophiliacs who had also developed AIDS. It was hard to comprehend that my Philip was one of them.

66. On the way back to Philip's room, I walked straight past him as all I could see was an old man. That old man was my Philip. To this day, I still struggle to come to terms with this visual of him.

67. Philip remained at the Churchill from 27 December 1990 until GRO-C 1991. I remember his breathing became laboured and I spoke to the nurse who told me he didn't have long.

68. On the afternoon of GRO-C 1991, Philip passed away. Shortly after Philip passed, a doctor asked me if they could take a sample of his brain for research. I declined this, as I did not want Phillip to go through this procedure.

69. The cause of Philip's death is outlined in his Death Certificate, dated GRO-C GRO-C 1991, signed by Registrar of County of Oxfordshire, **(Exhibited as WITN4603002)** cause of death is shown as:

1a. Cerebral Toxoplasmosis
b. Auto Immune Deficiency Syndrome (AIDS)
c. Haemophilia

Certified by G Leadle Bmchb:"

70. After Philip's death, I offered to take Philip's body back in the car to the Isle of Wight, so that he could go to the funeral parlour to be prepared in readiness for his funeral. I had stated to the medical staff at the Churchill something along the lines of "*I took him to the hospital, so I can take him back*;" to which they had stated that this was not possible.

71. Two weeks later Philip was cremated. We did not face any difficulties or issues with regards to the service we were provided with by the funeral directors due to his HIV status. They were family friends so we were treated to the best standard. In my anger, I said to the funeral directors send his bill to the NHS. I refused to pay for his funeral.

Section 3. Other Infections.

72. Alongside HIV, in around the late 1980's, we had suspected that Philip had also been infected with Hepatitis. The identification of the HCV virus had been front page news at the time, so we thought that as Philip had been experiencing issues with his liver, this may have been attributed to hepatitis.

73. Due to our suspicions, Philip and I decided to write to Dr Rizza at Churchill to see whether Philip had been diagnosed with hepatitis. In response, we were told that this was not the case.

74. Due to the above, we do not consider that Philip had developed any other infection or infections other than HIV.

Section 4. Consent

75. I do not consider that Philip had been tested or treated without his knowledge, without full and adequate information having been provided, or without prior consent having been obtained. When he was tested for the presence of HIV in 1984, we were asked by Dr Rizza if Philip could undergo testing, and we went to the Churchill specifically for the purposes of testing.

76. I do, however, consider that when Philip was provided with Factor VIII throughout the late 1970's and 1980's, and his blood transfusion in 1982, whilst he would have given his consent, he would not have been able to provide fully informed consent. At no point, was the possible risks of any blood borne viruses associated with treatment with blood product explained to Philip, which would have allowed him to make an informed decision on whether to proceed despite the associated risks.

77. I do not consider that Philip would have been tested or treated for the purposes of research. Philip was only given Factor VIII as treatment as and when it was needed; albeit it when he had experienced large bleeds.

Section 5. Impact.

Mental/Physical Effect.

78. Up until the point of Philip's HIV diagnosis, he was a very fit man. However, towards the end of his life, his health had taken a turn for the worst due to the effects his HIV was having on his body.

79. Tina and I had started to notice that Philip's appearance was slowly changing, as he was losing a lot of weight. In the end, all his weight had virtually dropped off of him. He went from being a 16 stone stocky guy, to weighing around five stone something.

80. Philip had also become light sensitive, and he would easily get excruciating headaches. He also experienced fatigue and was always tired to the point that he had to give up employment. His coordination was also affected, he had dizziness and his strength had gone.

81. Thereafter, Philip would spent large amounts of time in bed resting, and a "good day" would be where he got his legs out of bed and walk across the room. Simple conversation also became much of an effort for Philip too, as he

found it difficult to talk. During one of the conversations Philip and I did have, he had told me that he was frustrated that he could not finish the things he had once wanted to do, as it was very difficult for him to be able to do them physically.

82. Alongside Philip's physical health, his HIV infection had an impact on his mental health. In the last two years of his life, he had developed delirium and was easily confused; as previously stated between **Paragraph 53 to 61, Section 2** of my witness statement. This was difficult for us as a family to watch his sudden declining of his mental state.

Treatment

83. Philip did receive AZT for about a year before he died. He suffered with his eyes, whether this was connected to the drug I cannot say. I cannot pass comment on whether he had faced any difficulties or obstacles in accessing treatment. As far as I am aware, he was not offered any other treatment. If there were difficulties experienced by the medical staff in being able to gain access to treatment for Philip, then I was not made aware of this. I do however remember the chemist in Boots, commenting on how much the AZT cost when I went to collect it. I was annoyed at this as it was not his fault he had contracted the virus. The state had given it to him, they should pay.

Impact

84. Philip must have realised that his health was taking a turn for the worst, and that towards the end of his life that he was getting very ill. Of an evening, we would often sit and watch television together. On one occasion, it was reported on the news that iconic celebrities, such as the actor Rock Hudson was dying from AIDS. It was also reported that Freddy Mercury didn't look well. Before the news presenter got a chance to say anything, Philip stated something along the lines of "*they all have AIDS*!" This was not a pleasant thing for Philip to have seen as it was something which was quite personal to

us. Due to this comment, he must have understood what his infection had meant to him and his future. This would have been very frightening for him.

85. It was not only Philip who suffered with regards to his HIV diagnosis, but, also myself. When he was diagnosed, he had said to me "*if you want to go, you can go. I know it is not going to be a pretty life for you.*" I was shocked at what he had said, but I knew that I could never imagine walking away from him, particularly at this point of our lives. In response, I had told him "*I had said for better or for worse, and I am not going to leave you. That will be the end of it.*"

86. Philip was and has always been my rock. He took me out of poverty as I was growing up, and we had fallen in love from such a young age. We were childhood sweethearts, and I was not going to leave him. Whilst I understand that he would not have made this comment light heartedly, he must have been trying to protect me from the life that was to come which would be painful for us both. Even towards the end of his life, he was always trying to protect me. He was such a kind-hearted man, and this was one of the reasons I had fallen in love with him.

87. Whilst I had decided that I was not going to leave my husband due to his HIV infection, our relationship was affected. We had always had quite an active sex life from the point of our marriage. Our friends used to joke that if it was raining, Phillip would not be on a roof and he would be home and we were not to be disturbed.

88. **GRO-C**

89. As a family unit, we have gone through so much within such a short period of time. Around 1984 after Philip's HIV diagnosis, and 1985 after Daniel's diagnosis, we were dealing with a lot. My daughter Tina Barton has provided

a separate witness statement (**WITN5492001**), which outlines her story with regards to the loss of her father and her son.

90. When Philip had found out about Daniel's HIV diagnosis, Philip took it particularly hard. On one occasion he had stated something along the lines of "*I wish I had more bleeds as that would have meant that I could have had Daniel's ones, and that way, he may not have had HIV then.*" By that Phillip meant the contaminated Factor VIII.

91. In hindsight, I feel awful, as I would ring up Tina to ask how she was, and how Daniel was. I now feel dreadful that I would ask them all how they were except for Mark.

92. However, it was not possible for both of their HIV diagnosis' to be forgotten about, as around that time, we would turn on the television to be greeted by advertisements on AIDS. I can recall watching the "*AIDS: Don't Die of Ignorance Campaign*" which was launched in 1986 by the Department of Health and Social Security ("DHSS").

93. I understand that this campaign was being used as an education tool to inform persons on HIV, but, it was too close to home for us. It was real life for us as a family. I believe that the advert had only highlighted that AIDS was a death sentence and that you were not to go anywhere near anyone with AIDS. I can recall the large tombstone on the advert clearly, as I used to wonder whether that would be my Philip or my Daniel.

94. After Daniel had been told about his HIV diagnosis around 1990, at the age of eight years old, we would tell him that if he wanted to speak to anyone about it, then he could talk to his grandad. However, not long after, in 1991, his granddad had passed and he was no longer there for him.

95. I often wonder what Daniel must have thought when his grandad passed. Did he connect the dots to have known they had both had the same infection, or,

whether this may have been his future path with regards to his health? I will never know.

96. Within such a short period of time, I suffered so much pain, suffering, and grief. Within two years of Philip's death on GRO-C 1991, Daniel had died on 19 January 1993 at the age of eleven years old. Then, within two years of Daniel's death, I was diagnosed with breast cancer. Life can be so cruel.

97. After Philip had to give up employment due to his ill-health, we struggled financially as we did not have a household income. We applied for sick benefit from the Government, and we managed to get very basic payments. We had hardly any money so we struggled to feed the family. Luckily, we had family members who were farmers and were able to give us potatoes and eggs from their farm so that we could make our meals.

98. After Philip's diagnosis, straight away, Philip and I attended an appointment at the Bank regarding our mortgage in an attempt to set in place measures should something occur in the future. Around that time, AIDS was on the news more prevalently, so it was more commonly known. I had heard a number of stories that couples with whom one or both of them had contracted HIV, that they had been refused advice surrounding their mortgage. We did not hold much hope.

99. Upon entering the office of the mortgage advisor, he had stated something along the lines of "*I understand that you want to amend your mortgage?*" Philip replied in an annoyed state "*I am sorry if you are about to ask me if I have AIDS, then you can forget it. I am sick to death of people asking if I have AIDS*!" Thereafter, the mortgage advisor did not ask about the state of our health. Therefore, we did not lie about Philip's health, as they did not ask.

100. However, after Philip's death, my son was in a financial position whereby he could live in the family home and pay for our mortgage and the bills where it was necessary. When we were given the money from the Litigation settlement we had been given in February 1990, and a number of

other claims thereafter, I was able to pay off our mortgage so that we had security in our family home.

101. I was also able to pay for a builder to come to our house to finish the extension that Philip had started before he had become too ill.

102. When Philip's health had taken a turn for the worst after his HIV diagnosis, I did not tell people about the real reason as to why he remained in the family home for long periods of time. Before this point, everyone knew Philip as a busy roof-tiler who was always in demand, so he was always out of the house.

103. I had kept his HIV diagnosis within the family, and had only told close friends. We told everyone else that he had a stroke. This was mainly due to the stigma attached to HIV at the time, and the fear of how people would react or treat us thereafter, as AIDS was considered the plague.

104. I made the mistake of telling one of my close friends about Philip's HIV; with whom I had previously thought I could trust. She took the attitude that he was the scum of the earth and that he should be locked away. I did not speak to her after this point.

105. Shortly before his death Phillip decided to speak openly about what had happened to him.

106. On 13 December 1990, a Newspaper Article was published by Maurice Leppard, in the Southern Evening Echo, which published Philip's HIV status, and the effects it had on his life. The Article consists of three columns, totally a quarter of a page in length. It outlines as follows:

Entitled: "***The virus can destroy a way of life***

BATTLING against the odds was a way of life for Philip Pugsley, but he never let being a haemophiliac cramp his lifestyle.

He provided that every day in probably the toughest job you will find on any building site a self-employed roof tiler.

Well muscled and 13 stone, he took the demanding work and the debilitating blood condition he had suffered from since birth in his stride.

Today Philip, 49, lies in the front room, turned bedroom, of his home in GRO-C *wracked by Aids-related virus HIV that has struck him and 1,200 haemophiliacs nationwide after they were infected with contaminated blood.*

But, as headlines trumpeted "£42 Million More for Blood Victim," he wanted only one thing - not money but "to get back to normal."

His bed is downstairs because he now weighs only eight stone, and having a "good day" means being able to get his legs out of bed and walk across the room.

It was five years ago that Philip was diagnosed HIV-positive at the Haemophilia Centre in Oxford, apparently the result of the transfusion he had three years before when having teeth extracted at St Mary's Hospital, Newport.

Doctors tried to reassure him and his wife Joan, 49, that because of his age and fitness there was a good chance it wouldn't develop into full-blown AIDS related virus.

Although he was determined to not to let it worry him, his wife recalled: "We tried to get on with life but it is there constantly in the back of the mind – like a prickle in a finger it is always there."

> *Then two and a half to three years ago Philip became seriously ill. "it obviously took off He had to give up work because his coordination was affected, he had dizziness and his strength was gone," said Mrs Pugsley.*
>
> *Recently her husband has returned home from a month's treatment in the Oxford Centre first secondary virus that caused swelling in the brain and affected his coordination more seriously.*
>
> *A £20,000 payment from the Government in February helped to ease the couples financial worries – at one stage they were receiving only £53 a week in benefits – and they are not sure yet how much they would get from the latest money offered by the Government."*

107. Thereafter, I felt ostracized from the community. As his HIV diagnosis had been published in the press and I had originally told the community that Philip had a stroke, everyone knew that I was lying. I would regularly attend my local pub with a group of close friends, when I began to notice that everyone would be staring at me, or look me up and down. I can only assume that this was due to Philip's HIV, and due to the stigma attached to the virus. Everyone was fearful of contracting the virus, so they did all they could to keep me at arms-length. People can be so cruel.

108. On one occasion, after Philip's death I can recall walking out of my home to see my neighbour who was talking to another neighbour. One of my neighbours had turned around to me and stated something along the lines of "*Here, Joan, how is your Daniel?*" to which I replied stating "*what do you mean*?" My neighbour then proceeded to say "*How is he after Philip dying*?" to which I replied stating "*he is fine*," and hurried off up the road.

109. I could have given them both a thump for what they had just asked me, but, I did not as Daniel was still at school. For Daniel's sake we did not draw attention to ourselves. I was unsure whether a number of my neighbours had connected the dots between Philip's death and Daniel. They knew that Daniel

was a haemophiliac like his granddad, and, it had been reported on the news that a number of haemophiliacs had contracted AIDS as it had been found to be transmissible by blood. I was worried. If they had realised the truth, pupils and staff may have treated Daniel differently at school. We did not want this for him, so we did all we could to keep his infection hidden.

Section 6. Treatment/Care/Support

110. I do not consider that Philip faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HIV. I feel that both the Churchill, the John Radcliffe, and St Mary's have all been very honest with Philip and I with regards to the treatment we have received surrounding his HIV infection.

111. There is only one issue that I do consider that honestly may not have played a heavy part in the treatment Philip had received. As previously mentioned, this was surrounding the associated risks of blood borne infection not having been explained before he was provided with Factor VIII and a blood transfusion in 1982.

112. I do not consider that Philip's infected status impacted upon the dental care he had received. Philip was not previously refused dental treatment. If Philip was in need of a tooth extraction, he would undergo surgery at the Churchill or at St Mary's due to the risks associated with his haemophilia. Other than that, for general dentistry, he would attend our family dentist in GRO-C and then at St Mary's Hospital dental unit.

113. Whilst I had noticed that Philip was always the last in the queue for his dental appointments, and that the dentist would always be gowned up with a mask, I knew the reasoning behind this. This being, the risk of transmission of HIV through contact with his blood. I did not have any problems with his experiences in the dentistry setting.

114. Counselling or psychological support has not ever been made available to either Philip, I, or our children as a consequence of his HIV diagnosis. The children and I were also not offered any counselling or psychological support as a result of Philip's death.

Section 7. Financial Assistance

115. As previously discussed at **Paragraph 51, Section 2** of my witness statement, in February 1990, Philip, Tina, and I were involved in the HIV Haemophilia Litigation which was brought by those individuals who had been infected with HIV through infected blood products, or affected. Philip was provided with an ex-gratia lump sum payment of £20,000.

116. Within a Newspaper Article, dated Thursday 20 December 1990, by Ian Gordon, in the Isle of Wight County Press Newspaper, the efforts to gain compensation for Philip's HIV diagnosis had started to gain traction on the Isle of Wight. A small summary of the facts were outlined within the Article. The Article consists of four columns, which fills half of a page. I have produced the article in its entirely, as follows:

> Entitled "***Cash or court fight poser for victims of Aids Virus.***
>
> *THE additional money offered by the Government as compensation for people who contracted an Aids-related virus through contaminated blood transfusions poses a problem for victims like 49-year-old Philip-Pugsley,* GRO-C.
>
> *They can either accept the relatively small share offered to them or face a long court battle that they may not live to see resolved.*
>
> *Philip is one of 1,200 haemophiliacs throughout the country who were infected with contaminated blood before the danger was realised.*

Five years ago he weighed 13 stone and was in great demand throughout the Island as a skilled self-employed roof tiler, despite the haemophilia he had suffered since birth.

Today, he weighs 8st and spends most of his days lying in a downstairs bedroom in his house in GRO-C*, being looked after full-time by his wife Joan.*

It was five years ago that he was diagnosed HIV positive at the Haemophilia Centre, Oxford, having been infected through a blood transfusion three years before when having teeth extracted at St Marys Hospital, Newport.

"We never thought anything like this would reach the Island. We thought it was something that happened elsewhere" Joan told the County Press.

Both Islanders by birth, the couple have been married for 30 years and have lived in their present home for the past 26 years.

For a time after Philip was forced to give up his work because of his deteriorating health, they received only £53 a week in benefit to live on.

Later they became eligible for invalidity benefit and in February this year, they received a payment of £20,000 from the Government.

"It has been a help," says Joan, "but little compared with what Philip would have expected to earn in that time had he been able to continue working."

"On the face of it the £42 million now offered by the Government sounds fantastic but when it is shared out amongst everyone who is eligible it amounts to nothing like what we had hoped for."

Although Joan says she has been advised by her solicitor not to divulge to the media the precise amount now being offered to her husband, she said it was little more than the payment of £20,000 they had already received.

"The money is being allocated so that people with dependent children will receive a larger share, and since our three children are grown up we will get only half what some people are getting," she said.

The Government is hoping that those eligible will settle for the amounts offered without claiming more through the courts.

The Pugsleys have been advised by their solicitor to accept the offer even though it is smaller than they might have expected, since to fight for a larger payment could involve a protracted court battle lasting as long as five years, with no guarantee of a satisfactory outcome at the end of it.

By that time, in any case, many of the sufferers will be dead.

"We had a phone call from our solicitor last week suggesting that we attend a meeting of haemophiliacs in London the very next day to discuss whether to accept the Government's offer," said Joan.

"But Philip has not been able to drive for over a year now, so I have to do any driving and there is no way I could face the trip to London."

Philip recently returned home from a month's treatment at the Haemophilia Centre in Oxford for a secondary virus causing a swelling in the brain and more seriously affected his coordination.

Although any financial help is better than nothing, only the discovery of a cure will prevent the tragedies suffered by Philip Pugsley and others

> *like him, but, says Joan, "I think it is going to come too late for my husband."*
>
> *A spokesman for the IW Health Authority said it was aware of claims being made against the authority by patients who had had blood transfusions at St Mary's Hospital."*

117. Sometime in the late 1980's Philip, myself, my daughter Tina, my son in law Mark, and a couple named GRO-A were approached by Mark Mildred who was already involved with the Haemophilic cases. We were asked whether we would consider being involved in a court case against the Government. The aim of the case was to gain compensation for Philip, Daniel, and GRO-A s son; who was only a few years older than Daniel, with whom they had all been infected with HIV due to contaminated blood product they had received as treatment for their haemophilia. Myself and Philip would bring about a claim on behalf of Philip, Tina and Mark on behalf of Daniel, and GRO-A on behalf of their son.

118. We met with Mark Mildred a solicitor at Pannone Napier Solicitors in London who started the claim on our behalf. We were told that we had a good case as it was obvious that Philip and Daniel would have contracted HIV from blood treatment and no other source. It was a very cut and dry case.

119. However, before we were due to go to court, the Government offered us an out of court settlement. Philip would receive £35,000, Daniel would receive £21.500, and GRO-A s son would receive £21.500. In return for accepting the amount offered within the settlement, we would have to sign a disclaimer.

120. This disclaimer consisted of two conditions. The first condition being that, upon accepting the payment, we were no long able to bring about further legal action against the Government with regards to their HIV infections. The second condition, was that all of Philip's, Daniel's and GRO-A s son's medical records had to all be returned to the Heath Authority.

121. Later on I received £85.000 in payment from the Heath Authority. This is detailed within a letter dated 09 April 1991, from Mark Mildred, Pannone Napier Solicitors, **(Exhibited as WITN4603003),** the offer of £85,000 in settlement amounts is outlined.

122. the conditions of the disclaimer are outlined.

123. As I was struggling financially as a family around this point, I decided that I would sign the disclaimer so that I could again access the compensation amounts.

124. In 1991, Mary Fetcher, a health worker at the Churchill had told us that the Macfarlane Trust were offering financial assistance for persons who had contracted HIV from contaminated blood and/or blood product.

125. Thereafter, Philip and I made an application to the Macfarlane Trust for financial assistance. I cannot recall too much detail surrounding the process of applying for financial assistance as this was quite a long time ago. However, as far as I can recall we did not face any difficulties or obstacles when applying for and/or obtaining financial assistance. It was a relatively straight forward process.

126. To gain the financial assistance offered to Philip and I, we had to sign a disclaimer. I was not permitted to bring about any future legal action to sue the Government for Philip's HIV infection thereafter. With a heavy heart, I decided to sign the disclaimer.

127. Within a letter, dated 29 June 1991, from Mark Mildred, Pannone Napier Solicitors, the amount upon which we were awarded by the Macfarlane Trust was outlined. **(Exhibited as WITN4603004)** it states as follows:

> *"I have received the sum of £32,000 from the Trust and enclose a cheque for that sum. They have written to you independently about disregard of this sum for welfare benefit purposes.*
>
> *£4,250 belongs to you as your husband's widow, and £27,750 goes into the Estate to be dealt with under the terms of the Will or intestacy."*

128. To date, I have received numerous payments from the Macfarlane Trust. I was granted a lump sum amount for my conservatory to be built, and another for my windows to be updated.

129. I now receive a monthly payment of £1500 from the England Infected Blood Support Scheme ("EIBSS"); which was originally named the Macfarlane Trust. I also receive the winter fuel support scheme payment of approximately £500 per annum.

Section 8. Other Issues

130. My Philip would want the IBI to establish the truth surrounding the Contaminated Blood Scandal. He always blamed the Scandal on GRO-D GRO-D. He used to state something along the lines of "*I am sure* GRO-D *knew the Government was buying blood from America which was not safe.*"

131. Philip would want the IBI to find out as close to the truth as is possible with what happened, the reasons why it was allowed to happen, and who knew?

132. I am providing a witness statement to the IBI as I wish to give Philip and Daniel a voice. The Contaminated Blood Scandal has not only taken my husband, but also my grandson. There needs to be answers and I believe that the IBI will try to achieve this for us.

133. When Philip passed away in 1991, I was still very young. I did not know how to cope and it was a particularly difficult period for me. To this day, Philip is always on my mind. He will never be forgotten as he was such a large part of my life. He had given me three beautiful children and thirty years of happiness together. When the IBI investigator had made contact with me to facilitate the taking of my witness statement, it set my mind racing. I could not turn off that night, and I could not sleep. It almost felt that Philip was with me again.

134. Philip was strong; full of life and his life was cut short due to his Factor VIII treatment, which was meant to save his life. He was my husband, and I wished we could have spent a longer life together. He was such a kind and gentle man and he simply trusted the NHS with the treatment they were providing him with. He was my husband, my lover and my best friend.

135. I have been asked if I ever contacted the Archer Inquiry. I have a very vague memory of this. I can say they never contacted me after my initial contact with them.

Statement of Truth

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

Signed GRO-C

Dated 24/6/21.

Table of Exhibits:

Date	**Notes/ Description**	**Exhibit number**
04 February 1991	Death Certificate of Philip Normal Pugsley, signed by Registrar of County of Oxfordshire	**WITN4603002**
09 April 1991	Letter, from Mark Mildred, Pannone Napier Solicitors	**WITN4603003**
29 June 1991	Letter from Mark Mildred, Pannone Napier Solicitors	**WITN4603004**