

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN1037001

Exhibits: None

Dated: 28th October 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows: -

Section 1: Introduction

1. My name is **GRO-B**. I was born on **GRO-B** 1966 and I reside at **GRO-B**. I currently work as the head of a small school, which is part of an academy. I have been a teacher for 30 years.
2. In this witness statement I intend to discuss the infection and subsequent death of my late partner **GRO-B: P** as a result of HIV contracted through contaminated blood products. I make this statement from my recollection of events.

Section 2: How Affected

3. My late partner **P** was born on **GRO-B** 1964. He suffered from severe haemophilia A. Prior to our meeting, he had studied electrical engineering at **GRO-B**. I know that while he was studying in **GRO-B** from 1982 to 1985, he attended Dereford Hospital and received an operation on his lymph nodes. I am told that there were some complications during this operation

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although, unfortunately, I am unaware of the details. I do not know when **P** contracted HIV.

4. **P** and I met in 1985. I had not gone straight to university from school, and instead spent some time working at a local health board. I met him through a friend at work. **P** was then working for **GRO-B**. I was shortly to go away to **GRO-B** to study teaching for four years and so neither of us thought that the relationship would be too serious. However, it was a case of love at first sight.
5. From the very first moment we met, **P** was always open to me about his health conditions. He told me immediately about his haemophilia and he also told me that he had been diagnosed with HIV. I do not know when or how **P** was diagnosed with HIV but he never tried to hide it. I was the only person to know about his HIV and his parents and family did not know until shortly before his death.
6. When I met **P** I was 19 years old. **P** was an incredibly positive person and was very keen on going out and living his life. He always did what the doctors advised him and his attitude was that, if and when his health deteriorated, we would deal with that when it happened. Of course, we knew that his condition had implications for us, and we were always very careful with using barriers and contraception. This became simply part of our life together and neither of us really thought about the consequences. I had met the person that I wanted to be with for life, even though I had been told that that life might not be very long. Shortly after meeting, we had a period of time in a long distance relationship, as I undertook my teacher training course in **GRO-B**. Despite his health conditions we decided to try and make it work.

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7. We had some information on transmission of HIV which is why we took the sensible precaution of using contraception. I am unsure how [P] was given this information or when.
8. As I have mentioned [P] had not informed his family, his parents or his two sisters about his HIV status. This was because of the considerable stigma that existed around HIV at the time. I can recall there being terrifying adverts on the television. As he was the youngest in his entire family, his sisters had always been quite maternal and I do not think that he wanted to be "mummied" by them. His haemophilia had meant that he had always been protected as he had grown up, and I believe that he wanted to step out from his sisters' shadow.
9. By the time I met [P] in 1985, [P] was on home treatment with Factor VIII blood product provided to him by the Royal United Hospital in Bath ("RUH"). He only used the treatment when he had a bleed, and if he felt a bleed come on, he knew what to do. He had been treating himself for so long that at this stage, he had become a professional at it.
10. Throughout most of this period of our life together, [P] health was good and the only issues were caused by haemophilia bleeds into his joints. He had a huge passion for life, and used to enjoy cooking and travelling, as well as consuming food and drink. He had a great love of music and loved to go to gigs, buy records and play the guitar. His positivity and general good health helped us to keep his HIV diagnosis a secret. Fortunately, he always looked fit and healthy.
11. This continued until 1991. I had finished my teacher training in [GRO-B] and the pair of us were thinking about buying a place together. We had been renting a house for a year. Arranging a mortgage was difficult, due to [P] HIV status, and [P] contacted The Haemophilia Society and the Macfarlane Trust to seek their assistance. I understand that he received both money and advice from the Macfarlane Trust, and we managed to obtain a mortgage without having to

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answer many awkward questions. I imagine he had to answer some questions in order to achieve this. He made the phone calls for the mortgage so I am unsure of any further details. I am aware that the endowment policy was in my name in order to avoid questions about **P** haemophilia and potentially about his HIV.

12. While I had been studying in **GRO-B**, **P** had been prescribed Azidothymidine ("AZT") treatment for his HIV from the RUH. I understand that about the time we were planning to move into our house, his T cells had begun to decline, which was an indication of ill health. I can still picture him telling me about this in our new house. Even at this time he was incredibly positive **P** would always come out of the medical appointments and tell me exactly what the doctors had said and how they proposed to proceed.
13. Following this initial decline in T cells, **P** health remained relatively good. He maintained a good appetite, although he did begin to suffer from stomach problems and diarrhoea. Looking back at photographs I can see that he had begun to lose some weight, but I only noticed this in retrospect. He maintained his love of life, food and cooking and his appetite only began to abate in late 1991. I can recall him sitting down to a Christmas dinner and his appetite rapidly abandoning him during this meal.
14. **P** was employed throughout his final illness by the **GRO-B**. Previously, he had worked for three other companies; none of which knew about his HIV status. He had a very strong personality and I think working and remaining positive was his way of coping with the diagnosis. I do not believe that his employers at the **GRO-B** knew about his condition and when he died he was still in service with them. Our new home was very close to his workplace, and so I believe if he ever had to self-administer Factor VIII treatment, he would go home in his lunch break, self-treat and then go straight back to work.

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15. Throughout 1991 **P** did not take a lot of time off work for haemophilia except when he had done something reckless to cause a bleed. A few of his friends knew that he was a haemophiliac but, as I have referred to above, I do not believe that the **GRO-B** did. He was keen on continuing with his life and keeping his condition private.
16. By 1992 **P** was still committed to trying to live. We thought about travelling and **P** obtained a passport, although we only made it as far as Ireland in 1993. We used to regularly take holidays in the UK, travelling to Cornwall, Wales and Scotland. We never let his haemophilia nor his HIV stop us.
17. At this point, I was also teaching and my job took up a lot of my time. In retrospect I am slightly resentful of the amount of hours that I worked and I think that I should have spent more time enjoying **P** company while I could. However, at the time we both wanted to be normal.
18. **P** was a very keen photographer and he used to develop his own photography. This was a long-running interest, which had started before we met. Looking back now at the photographs he took, I can see a distinct change occurring around the time of his diagnosis and the decline of his health. I can see that the photographs became sharper and angrier, and I think this might have been how he expressed his feelings. Despite this however he always took photographs of landscapes and "nice" things, and he remained keen to go out and photograph as much as he could. I believe that I still have his photographs somewhere. They are the type of things that I cannot bring myself to look at, though I cannot throw them away either.
19. By early 1993 **P** health had really started to worsen. He was losing weight and was suffering from stomach problems, as well as hair loss. He had begun

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looking gaunt. He had also begun to feel the cold, as he had no fat left on his body at all and his energy levels were always very low.

20. There were many periods of time during late 1992 and 1993 that [P] had to go into the RUH for long stays, in order to have blood transfusions. I can recall on a number of occasions having to leave work to take him to the hospital. However, I am not sure what these transfusions were intended to treat. I do not think that they were related to his haemophilia but rather to his HIV treatment.
21. By early 1994, [P] was definitely ill and he looked unwell too. I am not sure how much time off work he took, but he certainly began periodically taking sick leave from work. I cannot recall precisely what [P] had told his employers about his declining health although I suspect he told them that he had stomach problems. When his condition had deteriorated sufficiently that he had was no longer able to regularly attend work [P] doctor provided him with a sick note. He remained in employment until his death.
22. [P] continued to take his AZT treatment, and home treatment with Factor VIII. He would only go to hospital if entirely necessary. He also attended for check-ups, which I recall were monthly, although I am not sure about this. It was about this time in 1994 that [P] told me that he had also been diagnosed with Tuberculosis, although I cannot recall him ever suffering from any breathing problems. Whenever he went in to see the doctor he would always come back very positive.
23. It was also about this time that [P] decided to get christened. He was not a religious man but he did it for his mother. I believe that he had begun to think about the end of his life.

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24. I cannot recall precisely when [P] HIV progressed into AIDS. I do know that by 1994 we were fully aware that his infection had progressed to AIDS.
25. By April 1994 he was very weak and had begun to suffer from trouble with his eyesight. I can recall him lying on the bed with the pair of us realising that he was going to have to go back into the RUH. He tried to stay positive but he began spending between two weeks and two month periods at the hospital. I recall that it was about this time that he stopped wanting to read the newspaper.
26. This was a very hard period for the both of us. [P] tried to take care of me and he got all of the paperwork and his will sorted out in advance. The hospital permitted him to come home, which is where he wanted to be. We had considered palliative care, for example, in a hospice, but [P] said that he wanted to be at home. We set up a room for him downstairs and his then brother in law fitted a ramp, so that there was wheelchair access to the house.
27. As well as [P] I also had to take time off work at this point. I told my employers that I needed to do it in order to take care of [P] I was dealing with his care all by myself. [P] was 29 years old and I was 28.
28. At some point in early 1994 [P] father had said in passing, "*he's going to be all right, he does not have that AIDS.*" It was at this point that [P] told his family about his condition. It was very difficult for them to find out, and I recall that his father was blunt and matter of fact whilst his mother and two sisters were absolutely devastated. Around the same time, we bumped into a friend of [P] in town. When they saw [P] they had quickly guessed what was causing his deteriorating health.
29. [P] died at home on [GRO-B] 1994. I can recall that on the weekend before, he had woken up and we had gone for a drive as he had had a strange craving for fried chicken. I recall it was very hard to find fried chicken for him at

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the time but we searched for it. However, the morning afterwards [P] had suffered from a bleed and not noticed, so his arm had become swollen.

30. On the Monday morning [P] began losing the power of speech and I recall him saying that he was being pathetic, because he was in such pain. He became incoherent, and was not making any sense at all. I had to call a nurse in order to administer the Factor VIII for his bleed, as I could not. At the same time, I phoned his family and told them that [P] was seriously ill, as well as calling the GP to come and give [P] something for his pain. Following a period of dozing in his bed [P] very peacefully died, surrounded by myself and his parents.
31. The precise cause of his death remains unclear [P] had been absolutely adamant that AIDS should not be on his death certificate but the GP told us that it had to be somewhere on there. He agreed to list it as the third cause of death but I cannot recall what the others were [P] wishes were respected to an extent.

Section 3: Other Infections

32. Along with his HIV, which later developed into AIDS [P] also contracted Tuberculosis during his illness. I am not entirely sure how I know or where I got this from, but I am fairly sure that he was also suffering from Hepatitis at the end of his life. I can recall him undergoing a test and thinking this was a new diagnosis.

Section 4: Consent

33. As [P] had received his diagnosis with HIV and much of his treatment before I had met him, I do not know if he consented to testing for HIV. As I have referred

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to above, I also believe [P] was tested for Hepatitis. I was later tested for HIV and I know that I consented to this.

34. I do know that whenever [P] came back from meetings with the doctors he always seemed to have been given a great deal of information. He had a good relationship with the doctors at the RUH.

Section 5: Impact

Impact of [P] diagnosis on him

35. Initially [P] diagnosis did not have a massive effect upon him and he tried to prevent it from becoming a big issue. It was only when he knew he was going to die that he seemed to be impacted. [P] seemed to shrink and things did not seem to matter quite so much to him. [P] had previously always loved life and had been full of enthusiasm for food, drink, music, travel and photography.
36. Due to his personality [P] had always tried to keep very positive. However, as I have mentioned earlier, his photography at the time showed a marked change. I believe that he used this as a way to express the emotions that he felt during the deterioration of his health. Nevertheless, he remained positive, upbeat and optimistic right until the very end.

Impact of [P] diagnosis on me

37. I had only ever known [P] with HIV and while I knew that there could be complications and difficulties as a result of his condition, we both tried to make the best of it and get on with things.

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38. One of the ways in which his diagnosis did impact me was the fact that we knew we would never be able to have children. I can recall [P] saying to me that "*it is such a shame that you will not have children with me*". I know that if I was going to have children, I would have wanted to have them with [P]. However, at the time I was so in love that I simply accepted this. My sister is also some years younger than me and I had helped to raise her, so I was in no rush to have children when I met [P] at 19 years old. However, this was still very tough to cope with.

Impact of [P] diagnosis on the family

39. The impact of [P] diagnosis upon his family was devastating. Due to the stigma associated with HIV and his desire to try and live a normal life, [P] family only learned about his diagnosis shortly before his death. [P] father refused to talk about it while his mother, I think, desperately needed to. Both before and after [P] death she and I would have long conversations about him, and not just the nice memories but the bad ones too. I was close to [P] parents and remained so while they lived.

Impact of [P] death

40. The impact of [P] death upon me has been enormous. Although we only spent nine years together it was a huge part of my life. Even though it was 25 years ago it is still having many ongoing effects. I now teach alongside 25 year old teachers and I think it is so strange that my time with [P] is a whole lifetime ago. When they were born, [P] had already gone.
41. [P] death meant that I had no future, and that I had never had a chance to live my life with him. I wish that I had had that opportunity, and I feel that I am still mourning [P] and the life that we never had.

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42. [P] died just before [GRO-B] half term in 1994 and I could not go back to work until September. Even then, when I returned to work, I can recall having to go home at the lunch break in order to cry. Work was very hard for me and I am sure that my students did not get 100% from me at that time. Once people knew that [P] was dying, and after he had died, lots of our friends did come round to help us and made me feel supported.
43. Despite having previously known that we would never have children together, [P] death meant that avenue closed off for ever. You will never know what life may throw at you. Following [P] death, I spent five years alone. Accepting that I, so definitively, would never have children, has been difficult. This might explain why I love to teach. My current partner is very supportive and understanding, but I feel I cannot tell him everything, because it is a whole part of my life that happened before him.

Impact of [P] death on the family

44. The impact of [P] death on his family is very hard to put into words. They were devastated and they were very angry, as they just thought that he should not have died.
45. I can recall that my younger sister, who had grown quite close to [P] had to do her GCSEs one morning and then attend [P] funeral in the afternoon. She was seven years old when [P] and I met and 16 years old when he died. She was close to him and was extremely upset.
46. My brother was lovely and supportive, and my father tried to be around if and when he was needed. [P] also did not tell any friends about his condition. When he eventually died, it came as a great surprise to many of his friends who were completely unaware that he was even ill.

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47. We told so few people about [P] because of the secrecy and the stigma, and at the end only close friends and family knew what had happened. When I told other people that my partner was ill people assumed cancer, and we never hurried to correct them. Some people never asked how he died.
48. [P] father simply refused to talk about it which was very difficult for his mother who I believed needed to. It is very sad how much they went through and also sad for them that I remained their only link to their son. They were lovely people, and I have tried to stay in contact with [P] sisters via cards, Christmas and birthday messages.
49. I can recall a recent conversation with one of [P] best friend's wife. During our conversation it became apparent that she had no idea that [P] had died of AIDS because his best friend, her husband, had not told her. I believe this was due to the stigma. I had no problems with her knowing, as they were close friends, but that illustrates the stigma of the illness.

Impact on work and finances

50. For the majority of his illness both [P] and I remained in work. In a way we were lucky as we were both still working and we had no children and so I believe we were okay financially.
51. However, both before and following his death, I was on unpaid leave. When [P] died, I could not work as I was grieving. I worked at a very small school and so there was no support. I also had to go for an entire term without my pension which increasingly became a worry.

Section 6: Treatment, Care and Support

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52. I do not have any complaints about the treatment and support that [P] received. The doctors at the RUH were very good, and they had a very good relationship with [P]. I would sometimes go in with him to his appointments and the doctors were so lovely but I cannot recall their names. I have to assume they were always upfront with [P] and he always seemed to know what was going on and he remained positive.
53. I do not believe that [P] ever had any difficulties in obtaining treatment. Even when we had to visit a different GP from [P] named GP, he was very sympathetic. I recall that we attended around Christmas time and the doctor seemed relieved saying, "*at least you have a genuine reason for being here*".
54. [P] used to receive dentistry work at the RUH and occasionally had to stay in for treatment, although we never had any issues with this. I recall that he had a lovely old-fashioned dentist who was a very nice man and I assumed that he knew all about his HIV status. He was happy to treat him [P] was very lucky in this way.
55. In 1993 I do recall that [P] was given a motability car in order to assist him with getting around. I believe he was entitled to this due to his haemophilia rather than his HIV.
56. The RUH also provided counselling to me, both before and after [P] death. We were provided with bereavement counselling, which at the time I thought was a bit unhelpful, although in retrospect I believe that it might well have helped.
57. I think [P] was also offered this counselling although I cannot be sure. I think as I was offered it, he would have been too. He was certainly the type to talk about things so he probably would have gone. He was very well known at the RUH and I believe that they would have offered him this support.

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Section 7: Financial Assistance

58. I recall that at some point [P] went through a Bristol solicitor in order to join the litigation class action and received some Government money, although I cannot recall how much. I do recall that the money we received from the litigation was sufficient for us to be able to give some to his parents and friends; it must have been a good amount.
59. I cannot recall the nature of the payment that we received from the Macfarlane Trust although I do believe that there was a payment. [P] sorted all of the applications for financial assistance, and he never spoke to me about the process, so I cannot comment on whether or not it was easy or difficult.

Section 8: Other Issues

60. I believe that this Inquiry should make sure that somebody is held accountable and is made to take responsibility for what happened. I believe that we deserve an apology and that the families who have been devastated by this condition should be compensated.
61. I do not have a family and so I feel I do not need it, but there are many people who lost husbands, fathers and sons who deserved to be compensated. I am appalled by the entire situation and it should never have happened. [P] sisters are very pleased that I am engaging in the Inquiry and are hugely supportive of me. Most of all I want to give [P] a voice.

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Statement of Truth

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

Signed:...

GRO-B

Dated:.....

28.10.19