ANONYMOUS

10 DEC 2018

Witness Name: GRO-B
Statement No.: **WITN0598/001**
Exhibits: None
Dated: 7th December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth and my address are known to the Inquiry.

2. I am widow, I live with my partner and have two children and two grandchildren. I have worked in the NHS all my working life. I started as a speech and language therapist before going into research, then I moved to planning services for people with disabilities and finally I went into capital planning.

3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

4. I intend to speak about my late husband, GRO-B: H who was infected with HIV and Hepatitis C virus (HCV). In particular, the nature of his illness, how the illness affected him, the treatment received and the impact the illness had on him and our lives together.

Section 2. How Affected

5. H was born on GRO-B 1945 to a working class family from West Yorkshire. He was the middle of three boys, all of whom were haemophiliacs. His education suffered as a result of his haemophilia but he was intrinsically talented and got a place at Leeds College of Art. I attended Leeds Polytechnic to do a Diploma in

Speech Therapy and met H at the first college dance in September 1967. We married in GRO-B 1972 and had two children together.

6. H had Haemophilia A and he was considered a severe haemophiliac. He attended the Haemophilia Centre at St James' Hospital in Leeds. He was infected with HIV and HCV through Factor VIII. I do not remember the specific name of the products he used to treat his haemophilia, but the bottles of the product had labels with batch numbers on. The staff at the Centre peeled each label off for every treatment and put it onto his records, so this information would be available at St James'.

7. For most of his younger life, H was under the care of a lovely specialist but when she left, another consultant haematologist took over. H died in 2004 and until that time he remained under the care of this second specialist. H was given blood products as a child and continued to take them until the end, save for a reduction in the frequency for a few months after he was diagnosed with HIV. I vividly remember when we were first given the chance to treat his haemophilia at home; it was a wonderful thing. He preferred me to inject him rather than to inject himself. It became part of our lives and the children became quite used to seeing me injecting him.

8. No advice was ever given to us as to any possible risk of infection. We were encouraged to treat haemophilia aggressively, and later prophylactically, to try to limit any long-term joint damage caused by his bleeds.

9. I can confirm that H was tested and shown to be HIV positive at first and then later to be also HCV positive. I remember that some time around 1985 we were asked to attend the clinic at St James' Haemophilia Centre. The consultant told us that there was an issue with the blood products and that some people had been infected, but others were not. As far as I can remember, the consultant did not raise any concerns over H's future health.

10. Soon after that meeting, H was given test results, which showed he was HIV positive (although in that day, it was given another name - "Non A Non B"). The consultant explained that from that moment on H would have to have regular checks to monitor his white blood cell count. I believe information was scant and all I really remember is the shock of the news: at the time HIV was more or less seen as AIDS and therefore a death sentence. I do not exactly recall when H was told he was HCV positive, I just remember it was yet another bombshell for him.

11. I am not sure that providing us with information earlier would have done much good, at least not until a safe Factor VIII alternative became available. He couldn't not have injections: he depended on

them to keep him mobile and working. What we do not know is when a safe alternative became available and whether it was offered to H as soon as it could have been.

12. As to how the results about the HIV were communicated, they did it really badly. Our consultant was a rather shy, awkward person who was not good with people: I remember him blinking a lot when he was speaking to us. He was not giving us any more information other than the necessary ones. I think H's previous consultant would have been completely different. When they told us about the HCV, we did not really understand how important it was; because nobody actually explained it to us. I had to look HCV up.

13. I am not sure that the Haemophilia Centre ever gave us information about the risk for me or for my children being infected. At that time, the press was responsible for dramatising things and the ordinary man in the street believed AIDS could be caught by being in contact or close to an infected person. Given the familiarity around the Haemophilia Centre, as everyone had been going there for years, several of the young men would openly discuss their status and progress. I must say that we got a lot of information about risks through them.

Section 3. Other Infections

14. To my knowledge, H was infected with HIV and HCV only.

Section 4. Consent

15. Hs consultants told us his blood would be tested for a new virus (HIV), but I believe they knew he was infected before then. I say so because Hs blood was taken on a regular basis to monitor his haemophilia so they could have simply used one of these samples to test him for HIV.

Section 5. Impact

16. The impact of HIV and HCV infections on H and the family were just devastating. It blighted all our lives.

17. Once H knew he was infected with HIV and that his brothers also were, he withdrew from social situations. H's brother's deaths brought home the stark reality of what was likely to happen to him; he was extremely depressed.

18. In 1989 we decided to make our wills: H became more and more moody. There was a strong feeling of anger which I have to admit, sometimes affected our sex life. The HCV diagnosis was a further psychological blow.

19. Physically, once the HCV worsened, he quite rapidly became less mobile and both HIV and HCV made him also lose weight desperately. At my son's college graduation ceremony, H was frail with impaired mobility; my son had to carry him from the car to the seat so H could watch him graduate: it was heartbreaking to see someone who had been so active become so frail.

20. As a result of his HCV infection, H started to retain water and CT scans showed his liver was distended. They wanted to do a liver biopsy but he refused: the procedure was incredibly invasive at that time. In the final 18 months of his life, H's stomach became hugely distended and severely swollen: he was so skinny so he almost looked pregnant. He had difficulty breathing and his heart and liver started to fail. A tap was eventually put in to drain the liquid. Over 2-3 days, 12 litres of liquid was drained. Within 48 hours of the liquid being drained, his heart gave out. I believe it was the weight of the liquid and the pressure that it put on his heart that eventually killed him.

21. I am not sure when H was infected with HIV or HCV but as I mentioned above he found out that he had HIV around 1985.

22. In the early 1990s, once he started a combination treatment, his health improved. As time went on though, he became more prone to bouts of illness. H went through a period of just existing, where life just went on.

23. I remember that when H made it to the 2000s we thought that he might actually survive: at the Haemophilia Centre he was seen as a success story. In the end though, he deteriorated rapidly over 18 months and though he would not consent to a liver biopsy, it appeared that his HCV was causing him major health problems.

24. We were injecting him twice weekly with interferon and this alone caused horrible side effects for 24-48 hours. He went in and out of hospital several times over the last few months of his life and hated it. I fought hard to get him home before he died where at last he could be warm, contented and with his family. My daughter and her partner moved into the house. We cooked a meal, he was in his reclining chair and the TV was on: he was happy.

25. He died in GRO-B 2004. His death certificate states: cardiac arrest, left ventricular aneurysm, left heart failure, liver failure and Hepatitis C.

26. I do not remember the treatment H was on for the HIV. He had no difficulty in accessing treatments. He was a long-term member of the

Haemophilia Centre at St James', so I suspect he was offered the treatment as soon as it became available.

27. For his HCV infection, H was given Interferon, which I injected into him twice weekly. Again, I do not remember there being any issue with his HCV treatment.

28. H experienced a number of side effects as a result of the HIV drugs, including tiredness, diarrhoea, and depression. The Interferon injections caused a real dip for 24-48 hours. He used to have these spells: he experienced really low moods and I remember him feeling so unwell that he did not want to continue with the treatment.

29. I have been very bitter for a long time: I think that towards the end, there was a complete lack of care by most of the people treating him. I feel he was simply given up on. His water retention over the course of the year before his death was obvious and though I pointed it out frequently, very little was done to investigate it. It was only when he was admitted to a different hospital, not St James' but a local hospital close to our house that a tap was put in to drain the liquid. His condition certainly improved but by then, his heart had given up. So no, I do not feel enough was offered or done for him.

30. H's medical and dental care changed completely once it was known that he was infected with HIV. The precautions were just silly. He had always gone to an ordinary dentist but he was told he could no longer see that dentist. Instead he had to have dental treatments in hospital. He had to go into hospital the night before any treatment so that he could be injected prophylactically with Factor VIII. He was quarantined in special side rooms that had warning signs on the door: there was a huge stigma around that. We were looked at differently: everyone was aware that there was a HIV positive person on the ward.

31. Another subtle but impactful effect of H's HIV positive status on his medical care was the treatment (or lack thereof) for his bad knee. Staff at the Haemophilia Centre including the consultant, talked about the possibility of a knee replacement. After he was diagnosed, it seemed as if that went on a back burner and that it was no longer possible.

32. H's life completely changed when he was infected with HIV. H was an introvert but still a social person. As I mentioned above, when he was told he was infected with HIV, he withdrew from social situations. We used to go to a little island off the West Coast of Scotland. Although his mobility was affected by bleeds, we could still do things together as a couple and then as a young family. He would draw or paint from the car whilst the children and I played on the beach or went for walks. We were happy. That all changed. I think

H thought that if he had kept his head down, he could have kept living with HIV: he was already living longer than others at the Centre.

33. After he was diagnosed, H stopped wanting the Factor VIII injections because he knew they were contaminated. He would use strong analgesics to numb the pain from the bleeds. It was ridiculous because the damage was done – but in the end we did not talk much about it. Eventually he allowed me to start injecting him prophylactically with Factor VIII again.

34. H's family were almost completely wiped out because of infected blood. As I said earlier, his elder brother GRO-B who was such a character, suddenly died of AIDS in the late 1980s. Two years later, H's younger brother who he was very close to, GRO- became ill and went into hospital. I remember visiting him vividly: the horror of realising that they had put him down the end of a ward in complete isolation and people being unwilling to visit for fear of catching the infection, was dreadful. GRO-B's health declined quite quickly and he eventually died: it must have been so hard on H We sort of drifted apart from GRO-B's wife after he died. I guess we could not see her or talk to her about it because it was just a reminder of what was coming.

35. H's illnesses were incredibly hard on me. Before he was infected, I would happily tell friends and family all about H's haemophilia: it was interesting and a fairly rare condition and I was almost proud to be with him because of it. All of a sudden, the fact that I was not able to talk about his infection to anyone was a huge thing for me. We felt we had to keep the knowledge of his condition strictly to ourselves: the stigma was such. I think we withdrew. Life changed completely and from that moment on we were blighted.

36. Seeing him go through all of the treatments was wearing, demoralising and depressing. It was heart-breaking when he would hide his bleeds and drug himself up. I remember that at that time I assumed I was infected too. H had a period of cold-like illnesses so I tried to figure out if I had some similar symptoms too.

37. I believe that H's HIV was the downfall of our marriage. The sexual side of our relationship really suffered; that had been a hugely successful part of our relationship before. He was not keen to use precautions and I did not want him to use precautions. Every now and then there was also some anger in the way he did it.

38. It was all understandable but I met someone and gradually moved out of our home in 1993. I just needed some normality. My partner, who I am still with now, offered me a normal, loving relationship. He was a lot of things that H was not: he was well, healthy and strong. It was amazing to have a relationship with someone who was ordinary. H

was obviously devastated, and now I have to live with that. The children more or less moved out too around college age so life became pretty miserable for him.

39. I loved him to death, literally and metaphorically, even after I left. I continued to go back to the house every day after work to look after any of my children's needs and to prophylactically inject H

40. I continued to pay the mortgage on our family house and I gave H half my salary. We remained married up to his death in 2004. We were bonded from the start, and right until the end. After he died, and for some time, I continued to go back to the house every day to feed the cats: that was the only time that I felt happy.

41. The stigma he suffered was huge: from the awkwardness about the infection by all the hospital staff in the beginning, to having to declare his status on all forms such as insurance, and to be declined for insurance later on. I did not tell my GP because I did not want to him to know. We could not talk about his status at all with anyone outside the family. I remember always being petrified that his status would become common knowledge and I would have been stigmatised too. I was worried that if I told the children they would let it slip. So we did not tell them until they were older. Two good friends stuck by him, but all the others drifted away.

42. Things have changed now but at that time we lived in a period in which if you had AIDS you would die; there was no treatment and it was a death sentence. I do believe that he did not get the care he should and would have received had he not being infected. In his final weeks, there was no warm communication: the consultant was non-existent. He would not come and talk to us, he did not give us any time.

43. We (myself and children) were offered to be tested but we declined. I was tested for HIV later, when I began to live with my partner. He was also tested and we both resulted to be negative. This was a hugely stressful thing we had to do. When I tried to get a mortgage with my partner, we had a great deal of difficulty. We were upfront about the tests we had had, but we were declined an offer simply because we had been tested for HIV. In the end we had to arrange special insurance at a higher cost.

44. I think the overriding feeling for the children was just sorrow. I think they felt sorrow for the fact that he bore it all. They just thought he was stoic. I don't think they realised how ill and frail he was becoming in the last few months because both were away at college. My daughter was totally shocked when she saw him after his last stay in hospital.

45. H was incredibly intelligent: he has passed that onto our children. His education suffered terrifically as a result of the haemophilia. Art was his salvation. He used to draw: we wrote a book together, which he illustrated and that was then published. As a pair we did silk screen printing. His HIV became a barrier for his success in his career though, not his haemophilia. The HIV and treatment were his downfall: literally and mentally. He worked in computing in the early days and then got a job at a silk screen printers. From there, he moved to an advertising agency. He had to take longer and longer periods off work as he became more and more ill. Eventually, he had to stop working altogether in the 1990s. This obviously had huge financial implications for him. The disability allowance and a car under the Motability scheme were lifelines for which we will always be grateful.

46. I did not suffer any educational effects as a result of H 's HIV or HCV. In terms of work-related effects, I was based at the GRO-B GRO-B GRO-B so I could always be with H at appointments and I could easily see him when he was an in patient. I am not sure how I did it in the end but I managed to balance work with looking after H It became financially very tough for me. As I said earlier, as soon as H stopped working I gave him half my salary. My partner was fantastic during that time as it was hard on both of us. When H died, I had not realised he had run up debts: it was a bit of a desperate time for me and my partner but we somehow got through it all.

Section 6. Treatment/Care/Support

47. As already mentioned above, H faced a number of difficulties accessing both dental care and a knee replacement that would have improved his mobility greatly.

48. I do not think that counselling or psychological support was ever offered to H Having said that, if he was offered anything I am not sure he would have accepted. I know that the Macfarlane Trust ("MFT") community was a source of comfort for H If support had been offered to me during that time though, I would have taken it. There was a kind of on the side business with the nurses at St James': they were warm hearted and asked how I was doing. The nurses at the Haemophilia Centre were "salt of the earth people". The MFT offered me counselling after H died but I did not take it.

Section 7. Financial Assistance

49. I do not know exactly how H found out about the Trusts and Funds. I think it must have been through the MFT newsletter that he received. I don't think it was through the hospitals.

50. In 2003 H started to receive monthly payments from the MFT and in August 2004, just two months before he died he also received a lump sum payment of £20,000 from Skipton Fund. After his death, I received a stage 2 payment of £25,000 payment from Skipton Fund, and in 2010 a £22,500 payment from the haemophilia litigation proceedings.

51. I remember that after H submitted the application, it took a long time for the MFT to send him the money. I am not sure about the application process itself though because H sorted it out by himself.

52. For the stage 2 Skipton Fund payment, the Macfarlane Trust and Skipton Fund administrators were wonderfully supportive. They helped me to pluck up the courage to deal with H's consultant again in order to get evidence for a stage 2 payment. I almost felt like I was begging for the consultant's support.

53. He wrote back to me: I felt as he rubbed it in that H had never had a liver biopsy because in his letter the doctor despite all the evidence we had, he still stated that he could not conclusively say whether his liver was damaged. I wanted to put his letter in the bin, but instead I sent it to the Skipton Fund and the application was successful. That was the only obstacle I faced.

54. I am not aware of any preconditions being imposed on making an application for financial assistance.

55. The people at the MFT were absolutely brilliant and incredibly supportive. In January 2005 I was left in tears after I read the letter they sent me after H's death. I remember, in that early time after his death, that the warmth of their words was simply incredible. Financially, the Trusts and Funds were a lifeline. H had run up a lot of debts (on the assumption that he would get the Skipton Fund £20K payment he had already got builders in to refurbish the bathroom and the rewire of the house), so thanks to that money I have been able to pay off all of his credit cards and the funeral costs.

Section 8. Other Issues

56. H campaigned from his seat at home, but I did not. The litigation proceedings in 2010 was very difficult and for me, the outcome was not satisfactory at all. I was torn between continuing to fight a cause H had fought whilst he was still alive and just wanting to move on with my life. I attended a meeting with lots of affected people and ended up settling for what seemed a pretty paltry sum or at least that's what I thought considering what had happened to H and the repercussions on us all as a family.

57. I am in wonder and amazement that this Inquiry has ever happened. H is long gone now but I know that he wanted people to be held to account. So I want that for him. I also want the Inquiry to find out what actually happened, to find out who knew what and if it ever could have been avoided.

58. Since the Inquiry has started, I feel like I am back to being behind H helping him in his fight for answers. He never moaned, he never complained. He had a cross to bear, and then he was given another cross, then another one. He just bore it all.

59. To me, the real tragedy has been that for all this time I had to see the years passing by without being able to talk about his story; I finally have my chance to do it. One person died but the ripple effect was on every person around him.

Statement of Truth

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

Signed GRO-B

Dated 7th December 2018