Witness Name: GRO-B
Statement No: WITN1550001
Exhibits: WITN1550002-3
Dated: MARCH 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN 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 1948 and I live at GRO-B

2. My husband, GRO-B: H (born on GRO-B 1939), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C (HCV) from contaminated blood products. He died from Acquired Immune Deficiency Syndrome (AIDS) on the GRO-B 1991, aged 51.

3. This witness statement has been prepared without the benefit of access to H s medical records. I have retained some documentation from J Keith Park & Co, representing H as a party to the HIV litigation that ended in 1991, and have exhibited two of the documents to this statement.

Section 2. How Affected

4. H had severe Haemophilia A. He was diagnosed at birth through bleeding from the umbilical chord.

5. H was treated at various Haemophilia Centres to include St Bartholomew's Hospital, the Kings College Hospital and St Thomas's (and Guy's) Hospital. H was under the care of Dr Cathrie and Dr Clark at St Thomas's (and Guy's) Hospital. Latterly he was cared for by Dr Savidge.

6. When H and I met in GRO-B, it was love at first sight. I was GRO-B years old. We married in GRO-B the same year that we met. H was, at that time, treated with plasma and fresh blood at St Bartholomew's Hospital. H's cousin (also with severe haemophilia) received his treatment at the Kings College Hospital. He was treated with cryoprecipitate and H transferred to King's College Hospital on his cousin's recommendation approximately one year after our marriage. He too had cryoprecipitate there.

7. H was only at King's College Hospital for a relatively short period of time before transferring to Guy's Hospital. He was treated with Factor VIII concentrate (FVIII) from the early 1970s. He was also treated with FVIII at the Oxford Nuffield Orthopedic Hospital in 1971 when he had a hip replacement. He had a further hip (revision) operation in the 1980s. Before FVIII treatment, H could be laid up in bed with a bleed for up to a couple of weeks but with FVIII he would be back on his feet again within less than a day. H was a newspaper delivery driver. FVIII enabled H to keep working with little or no disruption.

8. I refer to **Exhibit WITN1550002** being a letter from Dr Clark dated 30th August 1988. H was, apparently, first tested HIV positive in January 1985. I do not believe that he was told that he was HIV positive until October or November of the same year. I remember that we attended an appointment with Dr Cathrie. She said "I do not know how I am going to explain this to you ……." and went on to explain to H and I that H had been identified (from a blood test) as being HIV positive. I recall H commenting "I always thought there was a price to pay" (referring to the FVIII treatment). No warnings were given to us before H was treated with FVIII about the risk of being exposed to infection. It was hailed as a wonderful thing. FVIII made

such a difference to our lives in terms of H s ability to work that H always felt that it was too good to be true.

9. Dr Cathrie told us that HIV was a virus. Being a virus, we both assumed the virus was treatable. When H asked about treatment, Dr Cathrie corrected him and explained that there was no treatment available. H was shocked and eventually said "If I have it, there is nothing I can do." Dr Cathrie went on to say that H may well have given it to me. H was beside himself when he heard that. I had to arrange to have a test and it took around three weeks to be notified thereafter of the result. I was tested negative and all my subsequent tests were negative. I had tests every 6 months or so (even after H s death).

10. The only advice we were offered in relation to managing the infection was to be careful sexually as you could catch HIV from bodily fluids. When my daughter was a year old I was sterilised as I did not want to have any more children. From 1976 I did not need use birth control and I could have easily been infected. I count my blessings every day that I did not contract HIV/AIDS and that I have been able to raise my children.

11. It was later established that H was likely to have been infected with HIV at the University College Hospital where he had had FVIII treatment in January 1984. He had fallen at work and damaged his knee. I refer to **Exhibit WITN1550003** being a letter dated 8th October 1990 asking H to confirm that he received FVIII at that time. H did receive FVIII at that time but I do not know the name of the product.

12. In 1973 H had hepatitis. I do not recall the type of hepatitis that he had but I remember him being very unwell and yellow in colour at that time. We were under the impression that H had recovered. I also remember that H was told that he had non A non B (NANB) Hepatitis at some point but I do not remember when. I am uncertain as to whether that was in 1973 and/or some other time. HIV was what we both worried about. It was only confirmed

to me that H had HCV after he died and I applied through the Skipton Fund.

13. H was under the care of a liver specialist, Dr Trowell, at the Oxford Churchill Hospital, having had liver function tests and scans. Dr Trowell always spoke to H about his 'liver problem'. It was never referred to as NANB or HCV during consultations, just the 'liver problem'.

14. H got friendly with another guy at the hospital who was HIV positive. When H became very unwell and the other guy was still in very good health, I spoke about him to our haemophilia nurse, Chris Harrington. She said "yes but a lot of H's problems are because of his liver". I had not appreciated that to be the case beforehand.

Section 3. Other Infections

15. I do not think that H had any other infections than HIV and HCV.

Section 4. Consent

16. H was tested without his knowledge and consent. He was tested HIV positive at University College Hospital in January 1985. He must have been tested for hepatitis but was not given adequate or full information in relation to it.

Section 5. Impact of the Infection

17. H had AZT treatment but we both knew that HIV was terminal when it developed into AIDS. The psychological impact on us both was huge. H wanted me by his side for much of the time. He was never like that before. Eventually, I had to give up my part time job in a camera shop to look after him. Our son was working but our daughter was still at school. I had to get

our daughter to and from school and try to run the household as best as I could.

18. H was very sick a lot of the time and his legs itched badly. We had appointments with Dr Trowell at the Churchill Hospital in Oxford and we were there in August 1989 when H was diagnosed with PCP pneumonia. Dr Trowell told us that H should not have come up to Oxford, being as ill as he was and said that H needed to be admitted immediately. He did not want to be admitted to hospital so far from home with me being unable to visit him there. Dr Trowell arranged for H to be admitted back in London at Guy's Hospital. It was there that H was told that, in addition to having liver cirrhosis, his HIV had developed to full blown AIDS. He was told by Dr Cathrie that he had no more than a year or two to live.

19. About two months after H was diagnosed with full blown AIDS, our daughter was rushed to hospital with appendicitis. Dr Savidge told me that she needed FVIII for the operation as she is an asymptomatic haemophilia carrier. I was horrified and said 'no' before I was persuaded that she had to have it. It was such a stressful time with H in a wheelchair at the foot of our daughter's bed whilst the issue was argued out. Dr Savidge said that the FVIII was now 'very pure' but I have had trust issues with the medical profession ever since and there will always be a worry at the back of my mind. Every time my daughter has had FVIII (and recently during a gallbladder removal) I have worried.

20. H developed hepatic encephalopathy albeit undiagnosed at that time (the toxins the liver cannot process affect the brain) and H had bouts of confusion and memory loss that I did not understand to be connected. H's confusion worsened as time went by. We were once driving down a one way street and H stopped the car. He had completely forgotten how to drive a car. I had to get out and take over because we had caused an obstruction in the road and other cars were beeping us. I remember H once called me back into the living room just after I had left it to start washing

up in the kitchen. He said GRO-B can you tell me, what is wrong with me?" Around that time and whilst I was out for a very short time, he got on to the phone and arranged to be transferred to St Thomas's Hospital because he thought that Guy's Hospital had ran out of FVIII. He was thereafter treated in the last 16 months of his life from St Thomas's.

21. H became very emotional and used to cry all the time. He was not emotional before that. He would say "I am not afraid of dying. I am afraid of what I am leaving behind." Our son and daughter were just 21 and 14 years old respectively. He did not want to leave us behind and I believe that he was terrified of dying.

22. When H was told that he had progressed to AIDS, he wanted me with him 24 hours a day, every day. It was not good enough that I was in the house with him; he wanted me sitting right next to him. I would, for example, do the ironing when H was asleep. If he woke up and I wasn't there he would be distraught. This lasted for 16 months and it was emotionally draining. Even when he was in hospital he would not let anyone wash him other than me. He would just say 'my wife will do it'. He was old school, very private and dignified.

23. H did not go back into hospital until GRO-B 1990, and then he was in hospital for a month until he died. On the day he went into hospital he was taken away by an ambulance as he could not breathe. They said he had a collapsed lung due to the PCP pneumonia. The doctors said he had various infections in his body. H had lost so much weight. I stayed there with him as much as I could in the chair next to his bed in his hospital side room. I even slept in that chair at night.

24. H died on a Saturday morning. On Monday we went to get the slip to take to the undertaker. We were warned that we might struggle to find an undertaker because AIDS was the cause of death. The hospital morgue refused to allow us to see H, giving the excuse that they did not have enough staff on duty. It had been explained to us that H could not be

embalmed and we had a small window of time to see him. Dr Savidge and Nurse Chris Harrington intervened so that we could see him one last time in the hospital chapel. Our local (family) undertaker accepted H but his casket could not be open in the chapel of rest. I sat by H s casket just the same. It was a terrible ordeal in addition to our deep grief.

25. We lived amongst friends and neighbours in a close knit community for many years but none of our friends knew. I have always been honest with my friends and I am not a good liar but no-one knew except my two closest friends and close family. We told everyone else that H had cancer. We could not tell anyone about H 's HIV/AIDS diagnosis because of the associated stigma. H and I heard horror stories about people being ostracised and having their houses burned down.

26. My children have been affected by the trauma. They are both really good children with great jobs and families but it could have easily gone the other way for them. They had a really good dad who was always there for them. We were a very close family. We always sat down together for dinner at 7 pm and we would talk about the sort of day we had. H always listened to the children. They have now had to worry about me since I was 43 but if their father was still here they would not have that worry. I consider myself to be lucky they include me in their lives.

Section 6. Treatment/care/support

27. H was never offered any treatment for HCV.

28. After H was told that his HIV had developed to AIDS, he was offered counselling but he did not want it. I do not think H wanted to accept he was dying. Our GP was excellent and would drop in for visits. Nurse Chris Harrington was also very supportive.

Section 7. Financial Assistance

29. H relied on sickness payments when he was too ill to work. I believe he received something by way of income from the MacFarlane Trust but it was not much. We struggled.

30. We received an ex gratia £20,000 payment from the MacFarlane Trust. In June 1991, the litigation payment came through in the sum of £44,250 with a further £16,250 payment being put in trust for my daughter for when she was 18 years old.

31. I received a modest monthly income payment that stopped when my daughter was 17 years old because she started working.

32. I received the Stage 1 and Stage 2 payments through the Skipton Fund. I was at first informed that I was not entitled because there was no evidence that H had HCV. The Skipton Fund was told that the hospital records no longer exist. I told them that St Thomas's Hospital would have some of H's notes which they did but I have not seen them.

Section 8. Other Issues

33. H's death is something I will never get over. I will take the pain of what happened to my grave. H and I should have grown old together. I miss him to this day. Everyone says the pain gets easier but it does not, in fact it gets worse.

Anonymity, disclosure and redaction

34. I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.... GRO-B ....

Dated 15-4-2019.