Witness Name: GRO-B

Statement No: WITN 1494001

Exhibits: WITN 1494002/3

Dated: 2 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B GRO-B with my second husband. I am retired.

2. I make this statement as the widow of GRO-B: H who was infected with HIV, Hepatitis B and C as a result of receiving contaminated blood products.

3. **This statement has been prepared without the benefit of access to H full medical records.**

Section 2. How Affected

4. H was diagnosed with Haemophilia A classed as severe, with less than 0.01 % clotting factor after he was born as he had a bleed in his stomach at birth.

5. From about 1969 until about 1976 H was treated at Manchester Royal Infirmary (MRI) with Cryoprecipitate or FFP, he was initially under the care of a Doctor Stevens, then a Doctor GRO-D and finally a Doctor Hay . From about 1976 onwards they started treating him with Factor VIII (BPL), Cutter FVIII, (Koate) Factorate , and Travenol/Hyland /Hemofil FVIII, until 2008 when he died,further details of his treatment are set out in the records of the National Haemophilia Database (HND). I refer to Exhibit WITN1494002

6. We were not given any information or advice that there was any risk of being GRO-B from being given blood products.

7. In or about June 1985, we were called into the MRI to talk about the latest blood results; we met with Dr GRO-D and Dr GRO-D We sat down and were told H had tested positive for HIV. They were calling a lot of people in, it looked very busy. We asked some questions for example; what does it mean? They told us that there was nothing to worry about, that it was just an antibody; they said that if anything happens, there will just be flu like symptoms. We also asked about having children and were told that we definitely could not have children. I asked why we couldn't have children if it's not something to worry about? They said "it's in its early stages" and they didn't know what was going to happen. They also told us that we had to have protected sex. I remember we started thinking they weren't actually telling us anything here. So we came home and tried to research what the illness was ourselves.

8. I have now seen the HND records and these show H first tested positive for HIV on the 1st February 1985 and was jaundiced in August 1976 but we were not told about the jaundice until a lot later. I'm sure that he had a form of Hepatitis in1976 as he was really ill and jaundiced but I don't recall being told about it.

9. There was little to no information provided to us on how to live with and manage the HIV or Hepatitis B and C.

10. We should have been told as soon as H tested positive for all of the infections that he contracted through contaminated blood.

11. They should have told us earlier and they didn't give us anywhere near enough information. They completely played the whole thing down; telling us there was nothing to worry about. You relied on the doctors to treat you and know what is best, they did save H life a few times but they also killed him.

12. There was very little information given to us apart from not to have kids and have protected sex. They seemed to take it for granted that we would know about it being blood-borne but we only found out because we researched it once we got home. There must be loads of kids who didn't get told and so didn't know.

Section 3. Other Infections

13. H was told he had had hepatitis A, D and F as well as vCJD although his medical records don't actually reflect all of these. We received a letter in or about 2004 that told us that it was possible that he had vCJD.

Section 4. Consent

14. I believe H was treated or tested without his knowledge, or consent, and without being given adequate or full information, and for the purposes of research as he was never told he was being tested for HIV, Hepatitis A,B,D and F.

Section 5. Impact of the Infection

15. H was desperate to keep it quiet, he was a very private man and was very aware of the stigma out there, surrounding his conditions, from other people and the TV adverts. He definitely suffered mental anguish; as we were living in fear of his infection being discovered. He was a very laid back man but had moments of anger and sadness, he wondered why this was happening to him, and I couldn't do anything to help him, which was awful.

16. We lost a lot of friends as we started to withdraw from our social lives due to the fear of people finding out and then later, H lethargy and bad joints stopped us from going out very much at all. Also as the doctors told us we couldn't have any children we were heartbroken, but there wasn't anything we could do. We had both planned on having a family, and wanted kids and it was very hard to face the fact that we couldn't.

17. As the infections progressed H was getting more tired, and slowing down, he was lethargic, moody, depressed, and very insular. He started to withdraw into himself which was very difficult for me to see as well.

18. In or about 2007 H developed liver cancer which then spread to his lymph nodes and stomach. He also had cirrhosis of liver.

19. In 1985 after the HIV diagnoses, H joints gradually got worse and worse until he couldn't get around; this was not helped by his depression which meant he also didn't want to go out. In or about 2007 I had to give up work to look after him because he couldn't cope at home alone. My office was closing and I was offered redundancy and I had to take it as I couldn't travel to the new branch and leave him or move house.

20. We went on holiday in May 2007, and H was very tired and he didn't want to sit in the sun (which was very unlike him), he was also wheel chair bound at that point. When we went to see Dr Hay at the MRI and he

GRO-D. Soon after we arrived home, H was sick and continued being sick, so I called an ambulance which took us back to the MRI. We saw Dr Hay the following day and he GRO-D. H had lots of tests done, and I remember being told by a sister in haematology that his GRO-D

21. However it turned out he had terminal liver cancer, which came as a massive surprise to us considering he had been having scans every 3 months on his liver. They briefly talked of a transplant but we were told he would not survive the operation.

22. I have a letter from H M Coroners Office that states a post mortem was carried out but there was definitely not one. I refer to Exhibit WITN1494003.

23. When H passed away I was told by the Coroner's office there had to be an inquest. I was concerned about H HIV status coming out as it was a secret. So I asked for a private inquest and was told it had to be Public, but to help they would 'not advertise' the inquest. As a result only H sister, the police liaison and I knew. The Coroner also said" if there's ever any compensation to be paid you should get it because of the details on the death certificate". I was also told by the Coroner he had a 'memo/instruction' that anything Haemophiliac/ tainted blood that came across his desk had to have an inquest and that it was a nationwide instruction.

24. H should have been able to have the new knees he needed but when we went in to the MRI we were told the only option was to cut his legs off (this was from an orthopaedic Doctor). Also if the cancer was diagnosed earlier he may have been able to have a liver transplant.

25. When H was being treated with AZT it affected his teeth and so he often saw the dentist at MRI. He also suffered from diarrhoea which impacted on the effects of his anti epilepsy medicines. H had a complicated medical history; he had suffered a sub cranial haemorrhage, and when he recovered he was left with post operative epilepsy, which was completely controlled with Tegretol. When the MRI found out about his HIV and his T4 cells started to drop, he was put on AZT. He didn't want to start this treatment and wasn't very happy about it,but it was the only treatment at the time. Dr Bolton told him you can't stay on Tegretol (anti-epilepsy medication) with the AZT and he was moved to Epilim which never controlled his epilepsy. One day he was eating his tea, and went into a Grand Mal seizure, he chocked on his food and turned blue. He was taken to the MRI and the next day Dr Hay said to GRO-D GRO-D GRO-D We said "no you have to change the drugs back";, arguments ensued. We eventually got to talk to the head of neurology who agreed H should go back on to the Tegretol at a higher dose and from then on until the time of his death his epilepsy was controlled.

26. The Hepatitis C was treated with Interferon and Ribavirin,unfortunately H was so sick while on these medications that the only thing he could tolerate was ice-cream. He came off the treatment early as he just couldn't take the side effects. Interferon just made everything he was going through worse. He also suffered from terrible migraines from it.

27. On many occasions various Doctors refused to operate on H for the new knees, elbow and the liver transplant he needed because of his HIV and Hepatitis C. He also had to go to the dental hospital as no normal dentist would touch him. They also put on gowns, masks and gloves and

made it very obvious to other people that he was viewed as infectious; he was also always made to go last in the day.

28. The HIV and Hepatitis infections absolutely destroyed H life, before they eventually took it in GRO-B 2008. Our social life no longer existed where as previously we were very sociable, our social life was whittled down to just the two of us. My family didn't know anything, but his family did. We were living with constant fear of people finding out and it didn't bear thinking about what their reactions would have been if they had found out, or the stigma we would have faced. We heard stories of people not letting HIV positive people in the house or near their children.

29. We could not have children and that was particularly devastating for us, we asked about sperm washing and other methods but were told it wouldn't be possible for us. There was no assistance made available and they asked "why would you want to". We were told by a haemophilia nurse that any child would definitely have haemophilia which just wasn't true, a daughter would have been a carrier and a son could have been fine.

30. Until you've been in this position you just can't or won't be able to understand that feeling in the pit of the stomach and your heart beating so fast, the mental anguish has often been worse than the physical for me.

31. The impact on H family was substantial as H mother lost a husband and two sons within 6 years.

32. H went to Primary school but lost a lot of time due to bleeds. He went to Secondary School but left early and then was home schooled and didn't achieve any exam qualifications; this was due to the haemophilia though.

33. H was on benefits as he was never able to work due to the damage to his joints. He did apply for a job at GRO-B Police department and was offered the job but then the insurance company would not cover him to work in the building as he had HIV and the job offer was withdrawn.

34. I worked for the Post Office and had a good job but I had to take a lot of time off to look after H In 2007 I took redundancy at 48, and paid off our mortgage, but we were left with no income or money and H was terminally ill at this point, and I needed to look after him We did receive some money from the government; namely carer's allowance and benefits.

Section 6. Treatment/care/support

35. On many occasions various Doctors refused to operate on him for the new knees, elbow and the liver transplant because of his HIV and Hepatitis C. He also had to go to the dental hospital as no dentist would touch him. They also put on gowns, masks and gloves and made it very obvious to other people that he was viewed as infectious; he was also always made to go last in the day.

36. I had some bereavement counseling through my GP and I was diagnosed with extreme anxiety and PTSD. There was some counseling offered to us at MRI for HIV, but when we went he only seemed to be interested in our sex life, so we stopped going as it was making us feel very uncomfortable.

Section 7. Financial Assistance

37. I can't quite recollect exactly but I believe we were told about the possibility of financial assistance by someone from MRI or the Haemophilia society.

38. We received £400 per month from the Macfarlane Trust(MTF) until a year after H died. Two or maybe three years later MFT sent a letter stating that I was entitled to monthly payments, so I filled out the forms and started receiving monthly payments again which continue to date, and are approximately £750 a month (it was again means tested taking into account my small pension and my new husbands pension). We spoke to a nice woman called Keisha at MFT who apparently left because she didn't like the way MFT was going.

39. We also received the winter fuel allowance while H was alive however, again this payment stopped after his death. Recently out of the blue I was told I could now have the winter allowance again this year. I haven't had a grant since H died. Before he died we received grants for a new washing machine and boiler.

40. We also received £23500 from the MTF from the 1991 HIV litigation; they told us that if we didn't sign the waiver that no one would get any money.

41. I have also received from the Skipton Fund £20000 in 2004 and £25000 in 2007.

42. There was always uncertainty about whether you would be successful in any application for assistance and you were made to jump through many hoops and complete a lot of paperwork. We had to ask for everything and this made us feel like we were begging. We were entitled to that money; it should have just been given to us.

43. The Trust's were supposed to be there to help us, but they just don't anymore. I sent a letter to the Terrance Higgins Trust who are now

holding the money previously held by the MFT for the benefit of Haemophiliacs with HIV and their families and they said that they hadn't received the details of the former registrants of the MFT so they could not help. They have the money and they are holding it, we have widows in our group who have lost or are losing houses because the money they are entitled to is not being given to those who need it. This is wrong.

Section 8. Other Issues

44. There are so many things I would like to say, but I will just say the way the Haemophilic community and their families have been treated by successive Governments and especially the civil service is disgusting. I think John Major and Maggie Thatcher are up to their necks in it. I feel they were just waiting for all the Haemophiliacs to die, if it hadn't been for Jason Evans and a few others it definitely would have been like that.

45. The one thing that hurts the Government is having to pay out money, it doesn't seem to care about the people, just the cost. A lot of doctors are good clinicians but they just see the disease and not the person and the fact that these people have lives. The main issue is that together the government and the doctors have murdered people.

46. I remember GRO-D and someone else going on a conference that was paid for by a pharmaceutical company, and I think the relationship between Doctors and Pharmaceutical companies should be investigated to see if there is any conflict.

Anonymity

47. I wish to be anonymous and would like 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 2/4/19