Witness Name: GRO-B

Statement No:WITN 1330001

Exhibits:WITN 1330002

Dated: February 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 GRO-B GRO-B GRO-B with my son. I am currently not well enough to work.

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 my husbands' full medical records.

Section 2. How Affected

4) H was diagnosed with Haemophilia A classed as severe ,with less than 0 % clotting factor when he was very young as he bruised often and in the first year of his life he fell out of pram and that was when he was diagnosed.

5) In his early years he lived in Herefordshire so would have been treated around there but I don't know where. His family moved around a lot and he was sent to different schools.

6) Eventually in or about 1969 his family moved to GRO-B and H became a boarder at Lord Mayor Treloar College(" Treloar's") near Alton in Hampshire from 1969 to 1973, under the care of Dr Aronstam and Doctor Wassiff where he was treated with Factor VIII products Kryobulin,Cutter VIII,(Koate) and Travnol/Hyland/Hemofil FVIII. Even after he left Treloar's, his treatments continued at the Haemophilia Centre at Treloar's until his death in GRO-B 1995. I refer to Exhibit 1330002.

7) As far as I am aware no information was given to H or his parents about there being any risk of him being exposed to infection before he was given Factor VIII. All they were told was that it was a miracle drug and that it was the best thing that could have happened.

8) In or about the middle of 1985 we received a letter telling us that H had HIV. We now know, from the records of the National Haemophilia Database (NHD) that he tested positive on 13 September 1984 and they didn't tell us until at least 10 months later. At the time we didn't understand what the HIV diagnosis meant. I remember the letter saying something about unprotected sex and families, I was heavily pregnant at the time and so we were very worried. We immediately contacted the Haemophilia Centre and arranged to see a doctor as we were so concerned. They just played it down saying that there was nothing to worry about; they didn't suggest any tests for me or our child.

9) We found out about the Hepatitis C a long time after he contracted it. According to the NHD records he tested positive for Hepatitis C in March 1974 before he tested positive for HIV, yet we didn't found out about it until approximately 10-12 years later.

10) We were given very little information to understand and manage the infection and the consequences were played down considerably. We didn't know what impact it would have on our lives, so we carried on as usual.

11) We should have been given adequate information as soon as he tested positive for HIV and Hepatitis C.

12) I consider informing us about the HIV infection by letter was a terrible and inappropriate way to tell someone such serious news. I remember it came on a weekend so we couldn't get into contact with anyone to talk about it and had to worry the whole weekend.

13) As mentioned in paragraph 10 above, we were given very little information and certainly none about the risks of others being infected. The doctors were so laid back about it; they only suggested that we had protected sex. We had no idea about how bad it was until we saw the adverts on TV.

Section 3. Other Infections

14)We were not told of any other infections and I don't believe H had any.

Section 4. Consent

15) I believe that my H was tested without his knowledge or consent, and for the purposes of research, as he was tested for both HIV and Hepatitis C without being told, and without being told results. Also the HND records refer to "Dr Craske research work" which H did not know about.

Section 5. Impact of the Infection

16) We had always planned on having two children, so we spoke to the Haemophilia Centre about whether it would be safe to have another child. To

our surprise they were very positive and encouraging and said that they would monitor the T cells, and I was tested throughout the pregnancy. Looking back I'm sure they treated my pregnancy as an experiment and used it for research purposes.

17) I wasn't allowed a home birth and none of the Hospitals would take me due to H HIV. Our GP surgery had a midwife attached, who agreed to assist with a friend of hers. We rented a delivery room in the St Mary's Hospital but when we got there we were put in an abandoned delivery room with no lights or anything. My baby got stuck and all hell broke loose when the other hospital staff realised that we were there. They put the baby and I in an isolation room. When H arrived at the room he was horrified and he said we are going home now and we went home.

18) When the Hospital found out H had lesions on the brain, they didn't tell us and we only found out when a letter from DVLA arrived in 1991-1992 in the post revoking his driving licence. I didn't drive at the time so it took away our primary mode of transport. We went to hospital and had a new scan done and they told us that the DVLA did not need to revoke the licence, so it appears the driving licence was revoked unnecessarily.

19) In January 1995 H began to experience rectal bleeding, we went to the GP who referred him to Queen Alexandria Hospital on 23rd January 1995. On 16th March 1996 H was seen by Mr Perry. The examination was rushed and I had to constantly remind him of my husband's degree of disability caused by

the Haemophilia and that his arm was bad at the moment due to a bleed. We were told it was examination only but the doctor did a biopsy with no Factor VIII cover. This lead to excessive bleeding which meant that my husband had to receive 10,000 units of factor VIII at a total cost of £3,300 at 1994 prices. When we asked about why this was done it was indicated that Dr Perry was very worried about it. I believe this episode lead to a marked deterioration in H's mental health.

20) About two weeks later we received a letter by second class post on the 30th March with an appointment to see Miss Senapatti on the same day at 9.30am, as the post comes at 9.30am we had missed it already. We called the hospital and they said to get down he to St Marys Hospital as soon as possible. Two hours after arriving we were seen by Miss Senapatti who hadn't received the histology yet. She examined H and said it was a non malignant polyp and this was later confirmed by the histology. Miss Senapatti's questioning was very insensitive, questions about anal sex, when it is known he contracted HIV from contaminated blood. She said though it was non-malignant it was very large and needed to be removed. She said it would take a few weeks to get the loose ends tied together and to obtain the necessary Haemophilia cover.

21) Some weeks later just before Easter I phoned Miss Senapatti's receptionist to ask why we hadn't been given a date for the operation. I was told on the phone that H had been 'discharged at clinic'. A follow up by our GP revealed he had been transferred to Dr Golding at St Mary's Hospital.

Following this there were numerous attempts by myself, our GP and a Haemophilia Society worker to ascertain who was responsible for my husband's care and when the operation would take place. Various explanations were given including 'awaiting referral letter', 'lost notes', 'No Factor VIII cover', 'A place at the end of the list'.

22) During this period H mental health deteriorated to a point where he was actively considering suicide. On Tuesday 16th May Dr GRO-B had to be called out on a domiciliary visit to assess H as an emergency. We felt a point had come that we could no longer cope as a family and that H needed to be away from home to recover his mental state.

23) Although GRO-B Social Services agreed to fund H for a respite placement however such a placement was difficult to find locally due to H's considerable nursing needs, severe haemophilia, advanced HIV, severe depression and the rectal bleeding.

24) We were very disappointed that the Health Commission would not find a placement for H costing over £130 a day. I understand that Mr GRO-B of the Health Commission told my social worker that the GRO-B Health commission would not fund a placement at GRO-B for H at £130 a day even if Social Services or ourselves topped this up to the£180 a day that it cost.

25) In the end we were extremely grateful to Dr Tobin, H HIV consultant for offering him an acute bed on Ward B2 at St Mary's, this enabled a date for the operation to be finalised. It seemed such a shame that H had to take up an acute bed in a ward when complete care was available to him at GRO-B GRO-B, a HIV nursing home for £180 per day. I'm sure this would have been cheaper that the cost of an acute bed plus the extra psychiatric nurse they needed for him.

26) Eventually H had the operation to remove the polyp on 31st May 1995; he had a convalescence break at GRO-B following the operation which was funded jointly by the Terence Higgins Trust and GRO-B social services.

27) We hoped that this was the end of our problems but three weeks after the operation we had a phone call from the hospital indicating that we should see Miss Senapatti on 29th June 1995. This again raised anxiety. At the appointment we were reassured by Miss Senapatti that although the polyp had been malignant, it was routine to take tissue samples from the area. She told us there would be no question of previous delays being repeated.

28) We attended St Marys for routine pre-op tests on Friday 7th July 1995 which included a chest x-ray. On returning home H began to experience breathing difficulties and a high temperature. The GP felt it was unlikely that H had a serious chest problem as he had just had a chest x ray.

29) On Monday 10th July 1995 at mid day we received a telephone call from Queen Alexandria Hospital enquiring about Factor VIII cover for the operation on Thursday. A couple of hours later the gentleman rang back cancelling the operation due to lack of laboratory back up over the weekend and gave us a new date of 15th August 1995. From this moment on my husband lost his will to live, he had fought for many years against his numerous serious health problems but this set back, was more than he could take, he was even unable to motivate himself to take adequate liquids.

30) On Tuesday 11th July we attended the GU clinic as his temperature was still high and his chest had not improved. He was thought to be dehydrated and was told to drink more fluids and return the next day if he was no better. On GRO-B I begged him to let me take him back to the clinic, reluctantly he agreed, by now he was unable to walk unaided. We attended the GU clinic at 2pm, he was examined and chest x-rays were requested, the results of which were that he was diagnosed as having pneumocystis pneumonia (PCP) and told admission was necessary, however we were told there wasn't a bed at St Marys Hospital and he was to be taken to Queen Alexandria Hospital. As a consequence I had to drive H through the rush hour traffic at about 5.30pm to Queen Alexandria Hospital. His medical condition at this point was extremely serious, he could not walk, he, could barely talk, and was fighting for breath. We were very frightened. We were never offered an ambulance or any hospital transport.

31) We arrived at the Queen Alexandria Hospital and H was given a bed. He was given no treatment, and I had to demand paracetamol for him on a number of occasions as his temperature was rising again. About an hour later we were told that he was being transferred to St Mary's Hospital where a bed had now become available and would be ready at 8pm. In fact an ambulance was not free until 10.30pm. During this time the only medication available to H was oxygen and paracetamol, no one examined him and he was not given any anti-biotics. We were led to believe that the administration of intravenous anti-biotics was crucial and urgent and this is why he was being admitted.

32) Once back at St Marys Hospital his treatment was excellent and the staff on Ward B2 were very helpful and caring as they had always been. Intravenous anti-biotics were started but by this point the chest infection was so advanced that H was unable to pull through and he died on the GRO-B 1995

33) On GRO-B whilst St Marys Hospital was trying to find a bed for H they received a call from the Queen Alexandria Hospital saying the op could go ahead after all.

34) My husband's cause of death is listed on the National Haemophilia Database as AIDS. On the death certificate the cause of death is recorded as Bronchopneumonia. The Doctor advised me that this was the best course of action as if AIDS was on the certificate we wouldn't find anyone to bury him and that a cremation would be our only option (which is not what my husband

wanted). I want to know how the Haemophilia database knew the cause of death when this wasn't on his death certificate

35) Soon after our son was born H started treatment with AZT, for his HIV he knew his health was deteriorating and that's why went he went onto the treatment, which was a very big decision, as he knew the side effects were unpleasant.

36) Once on AZT H health deteriorated substantially. The AZT had awful side effects; he had problems with his teeth, diarrhoea, skin lesions. It also affected his mental state; he became a lot more depressed He suffered with chest problems, a very low T cell count, developed asthma, and started using an inhaler. He changed completely, he became a sick person, he lost his appetite, and would only eat for his daughter if she asked. H also suffered from depression and had a mental breakdown towards the end of his life; he was diagnosed with having Chronic Paranoid Psychosis in the summer of 1994.

37) We had a marvellous GP who I can't say enough good things about. He took us under his wing and told us categorically not to mention it outside family. We lived a very insular life, the children could never have friends back home from school for fear people would find out. A lady up the road who was a friend and a pharmacist guessed in the end when he was deteriorating and all the drugs he was on but she was one of very very few. Before the diagnosis we were social people but then we had this big dirty secret. H had to tell his

boss but it never went further than that. He was a GRO-B at the local council offices, he loved his job, our son learnt to ride a bike at my husband's work.

38) Our son's life has been screwed up, he didn't get to grow up with his father or have a male influence, or play football doing the normal things a father and son would do, and this has greatly impacted on him and I believe directly contributed to him suffering from depression , and having drink and drug problems. Both of our children believe their father was murdered by the state.

39) Even now the pain continues our daughter recently found out her father was part of a research project that he didn't know about and that this could have been the source of his Hepatitis C infection and this has greatly upset her.

40) H was a hard worker and loved his work but he had to take a lot of time off work due to his ill health and eventually he had to stop working about 18 months before he died. It was a big decision to give up work. His Employer was good paying a bit extra into H s pension. I still had to find some work as well. When H had to stop working our quality of life went down considerably. We couldn't afford to go on or insure holidays. When it was just the two of us we went to the South of France but as time went on he was not well enough and we couldn't afford it

41) Whilst I had remarried all this dealing with the past had lead to my second husband leaving.

Section 6. Treatment/care/support

42) When H became very poorly we tried to get him into respite care but no one wanted to take him and no one would support him. Eventually The Terrance Higgins trust paid for him to have a very short time at a respite home. He ended up at a couple's HIV home but they wouldn't provide for me to go with him. He felt alienated as he was surrounded by gay couples. He was only there for 2 weeks, but I visited him every day, it was 40 minutes each way. He came out of the respite care on 30th June and then passed away on GRO-B

43) No counseling or psychological support was ever offered to either of us, and we never had any. I was not even offered any bereavement counseling after his death. I have now been diagnosed with PTSD and the psychotherapy I was promised a year ago is no longer available.

Section 7. Financial Assistance

44) We were told about the MacFarlane Trust (MFT) by a social worker and to begin with they were helpful. We received weekly payments of £20 totalling £2905.00 .A winter fuel allowance, as he was always cold of £400.00 and various grants. For building works and a holiday. We were going to have an

upstairs bathroom put in but he died before we could start the process of applying for a grant.

45) After his death all my support stopped, they gave some support to the kids until 16 but only as far as help buying their uniforms (last payment around 2006).

46) We also received the ex-gratia payment of £20,000 from the MFT in or about February 1990 but H didn't want to spend it as we were on our own and couldn't work so he wanted to save it for emergencies.

47) I also received approximately £10-15,000 from the Skipton Trust about 5/6 years ago, I only found out about the Skipton fund by seeing something on Facebook.

48) The process of applying for grants/assistance was disgusting, it was made very difficult, it felt like you had to jump through multiple hoops, we should have been told how to do it. We shouldn't have had to apply it should have been made available to those who were entitled to it and everyone should have been treated the same.

49) I ended up arguing with MFT many times just to receive what we needed, had to justify everything. Once H passed away I just gave up, I couldn't keep going through it and all I received was school uniform allowance which stopped in 2006.

50) All grants from the MFT are means tested which was unhelpful as if you were trying to work you would be worse off. It felt awful having to give financial information just to receive money we were entitled to. All the money from MFT I had to beg for, as [redacted] he passed away early before they started to give better compensation.

51) A major problem with the MFT is that it treats everyone differently. I can't believe some widows receive an allowance and I receive nothing. It's awful to say but the women who became widows later, they had their partners for longer and then received payments once they died.

52) I also asked the MFT for financial help during our son's drug problems (for which his fathers' murder was a large contributing factor) and we were told something along the lines of 'that's not what it's for'. I was told all along I didn't qualify for help once he passed away. I'm going back to EIBS now as I can't work and I am on my own

Section 8. Other Issues

53) I feel there has been a cover up from day one and the more I hear the more I'm convinced of that. The NHS knew what they were doing. I was treated as a guinea pig, putting both mine and my unborn son's life at risk, they were eager and encouraged for me to get pregnant and keep the baby and told me there were no real risks when I asked. The Government are afraid and are hiding it all because they don't want it to come out.

Anonymity, disclosure and redaction

54) I wish to be anonymous and do not wish to give oral evidence

Statement of Truth

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

Signed **GRO-B**

Dated........8/3/2019........................