Witness Name: GRO-B
Statement No: WITN0487001
Exhibits: 0
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 and I was born on GRO-B GRO-B, GRO-B I have one son, GRO-B who lives in Liverpool with his two children and his wife.

2. This statement is in relation to my late husband, GRO-B: H, who was born on GRO-B and sadly died on GRO-B, as a result of receiving contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my late husband's full medical records.

Section 2. How infected

4. My late husband, H suffered from severe Haemophilia A. He was a toddler when he was diagnosed with Haemophilia at Alder Hey

Hospital, which is a children's hospital in Liverpool. I believe he was diagnosed because he was suffering from bruises and bleeds.

5. When he suffered a bleed he would stay in hospital for several weeks and would received treatment through drips. He attended a school for special children located off GRO-B, Liverpool.

6. I do not know when H began treatment with Factor VIII. When I met him in or around 1969, he had already begun treatment with Factor VIII because I recall him mentioning that this treatment was a lot easier to administrate than the Cryoprecipitate treatment he received from a very young age.

7. H initially received treatment at Alder Hey Hospital, but when he was older he was treated at Liverpool Royal Training Hospital. Later, his mum was taught how to administer the Factor VIII at home.

8. I do not know if his mother was told that H's treatment was changing to Factor VIII or whether any information about the risks associated with Factor VIII were discussed.

9. I met H at work in or around 1969 when I was 18 and he was 17 years old. H told me about his Haemophilia very early on. We were in a happy relationship for some years and we married in 1975.

10. In 1981, when H was 29 years old, we sold our house and bought a premises for our new business, a restaurant that we intended to fix up and open. Soon after this, H was required to attend a routine appointment; these were usually every three to six months. I attended the appointment with H and when we went in, we sat down and the doctor told us that he had tested some of H's blood that had been frozen from 1979 which was positive for HIV. Prior to this, we did not know anything about the risks of infection.

11. H did not realise that his blood had been taken in 1979 in order to be frozen. He always had routine blood tests, but we were both confused as to

why they would freeze his blood. We were told by the doctor not to worry about anything and that the hospital would look after us. I informed him that we were trying for another baby and he advised us to carry on trying to conceive. Nothing further was discussed. He was so relaxed about it and I thought everything was going to be okay, however, I was worried about H as this was a big shock for him.

12. When I now think back to that day, I believe it was horrendous to tell us that we had nothing to worry about and carry on trying for a baby. In or around 1983, H was seen by another doctor and I remember that this doctor found out we were still trying for a child and said "for God's sake, stop!". This was the first time I was aware of the risks associated with us trying to conceive a child or even the risks of us not practicing safe sex.

13. I was later informed that I needed to be tested, but I was only actually tested in around 1990 when there was an accident with a condom during sexual intercourse.

14. In addition to H s infection with HIV, he was diagnosed with different types of Hepatitis. I do not recall which types of Hepatitis these were, but I know he was not diagnosed with Hepatitis C. As such, I believe it may have Hepatitis A and/or Hepatitis B.

15. After H was diagnosed, they kept talking about different possibilities for Haemophilia treatment. At one point they even started talking about using pig's blood. H was concerned that if he continued using Factor VIII he would be putting himself at risk of further issues and could potentially make himself worse, so he decided to stop taking it for a while to see if things improved. No further treatment was offered to him, so he had to return to Factor VIII products and felt stressed and anxious every time he administered the treatment.

Section 3. Other Infections

16. I am unaware of any other infections that H may have contracted as a result of receiving contaminated blood products. I know that he had many different types of Hepatitis, but not Hepatitis C.

Section 4. Consent

17. H did not give consent for the blood sample to be tested, nor was he aware that there was a risk of infection or a need to test him for these infections. As such, I believe he was tested without his knowledge or consent. I believe he gave consent for the blood to be taken, but not to be used for this purpose.

18. I believe they used a blood sample from something else in 1979, to later test for infections. At the appointment, H was told 'the last blood sample we have of yours that is on file is a frozen sample from 1979'. Around that time he had suffered a very bad hip bleed, so it is likely that the 1979 sample came from this, but he was adamant that he was not informed that his blood would be frozen for later testing.

19. At the time of the sample being taken, we did not suspect that it would be used to test for any infections. H had routine blood tests, so we did not have any reason to worry when they took any samples.

Section 5. Impact of the Infection

20. It was difficult for H to accept his HIV diagnosis and he struggled immensely with the news. It became even more difficult for H to cope with his infection as he later suffered from terrible psoriasis, which spread from his elbows up to his face. H's potassium levels became dangerously low in the last few years of his life. He also had kidney failure, from the other infections that he caught, due to his suppressed immune system.

21. H suffered from thrush in his throat, which meant that he struggled trying to eat and had to have tiny meals which I would pre-prepare for him the night

before. Towards the end of his life, H lost a lot of weight, it was as though he was only skin and bone. I recall attending an comedy event with him and a comedian saw him walking across the room, he said to the crowd "now that's an advert for AIDS isn't it". This deeply upset both of us, but it shows how thin H became.

22. As H's HIV progressed to full-blown AIDS, his potassium levels were low and as I mentioned above, his kidneys started failing.

23. H's personality completely changed, and he went from being a very easy-going guy to suddenly becoming very serious. I put this down to him not having time to do the things that he wanted to do in his life; he did not have time for the petty things anymore.

24. H also lost strength in his personality, as he had always been very independent but now had to ask for help. Later on in his illness, his energy completely went. H was always a very independent, loving and caring individual. He never complained and just carried on. So it was very difficult for him to ask for help, for example for me to put cream on his body for his psoriasis.

25. H and I were working on opening a restaurant, so he focused his time and energy on this. He became obsessed with completing the building of the restaurant and his social life fell to the wayside. If he started anything to do with the family, he felt determined to finish it.

26. H s two main friends were also Haemophiliacs, so they used to sit together and talk about everything. Some people, including one of his friends, had mental problems as a result of his infection, and his mind deteriorated. H became fearful that this would happen to him, so he wanted to keep himself stimulated. He wanted to get all of the classic books so he could read them. I also used to get broken clocks and vacuum cleaners and H would mend them, so that the virus would not attack his mind.

27. As treatment for his HIV, H went on AZT medication. However, his treatment was constantly changing and it seemed as though the doctors did not know what they were doing. H did not suffer from a lot of side effects from his treatment, other than psoriasis, loss of appetite and general fatigue.

28. When H was diagnosed with HIV, I was very worried about him. As he already had Haemophilia, I was always aware of his health issues but I did not wrap him up in cotton wool. However, HIV was a completely different illness and more worrying. It was a very difficult time for us, as we had a young child and had sold our house and bought a restaurant. The restaurant was very run down and required a lot of work before we could set it up. It was turmoil for both of us, but we learnt to stay calm.

29. H worked until he died, but he had to let me take over and cover for him at the restaurant. He was a very proud man, but he had to admit he could no longer do all of the shifts or do any outside catering anymore. We suffered financially due to his illness, and H also suffered mentally as he felt a sense of failure and depression. I tried to stop this feeling, but I was unable to. He would not own up to anyone financially and ask for help.

30. H's infection has also affected me in many ways, including the stress and concern that comes with worrying about him. I started to attend more check ups and I wanted to know more about his condition; I soon realised that this was more serious than the doctor first made out to be.

31. It was the biggest blow in my life to not have anymore children. In around 1983/4, I contacted the doctor to see if we could test H's sperm to see if it had been infected. They got in touch with a lab in Scotland that said I was years ahead of myself and they were still looking into this. It took me years to accept that I could not have anymore children. I could not share this with H because he would think he had let me down, even though he had not.

32. When H's health deteriorated I was very busy with the restaurant. I had to work on my own and although H helped with the management, he could not work because it was very physically demanding. H was in hospital for

a while, so I taught myself how to massage so that I could massage his feet to calm him down. I would then go and work a full shift, whilst someone sat with our son GRO-B After this, I would return back to the hospital to see H My main worry was that I would run out of energy, which I could not afford to do as I needed the energy to cope and financially support my family.

33. Hemophilia was always a part of H s life, but HIV was a demon that was inside him. It tested him in many ways and whenever he though he could control it, it attacked another part of his body. It shows on the outside as well and there is a stigma that comes with this. It broke all of his friendliness; he did not want to meet people and became secretive.

34. Our private life was affected as well, as he would not ask me to make love to him very often, then it stopped completely. It is a very lonely thing to experience as I wanted to be close to him but he did not let me. I realised that I was going to lose him and I wanted to be as close as possible to him before that time came.

35. It was a shame that this infection affected us, because we were so close before his diagnosis. He was my best friend, my business partner, my life partner. I did not ever think I would lose him so quickly and in such a horrible way. I was broken after he passed away as I felt that a massive part of me was missing. I eventually bought a little cottage and I have managed to pick myself up and carry on. I did not think I would ever be able to do this, but I had to remain strong and look forward.

36. H kept his infection a secret from his family until 1990. To be so secretive towards your loved ones is terrible. This was particularly true for H s mum, who he was very close with. They were all so upset and angry when they found out, but they understood and respected H s decision not to tell them earlier.

37. I also had to keep H s infection a secret and I had no one to talk to; the only people I talked to were his two Haemophiliac friends who were not very talkative at all. Sometimes I wanted to talk to another woman as I thought

another lady would understand my pain, however, H made me promise that I would not talk to anyone about this and that I would keep it private. With regards to telling people what happened to H I just tell them that he died of cancer of the blood.

38. H suffered from issues obtaining other medical treatment, in particular dental care. He had the same dentist for many years, who one day shook his hand and told him in a very nice way that he was unable to treat him anymore. He then had to receive dental treatment at the Liverpool Dental Hospital, where everyone would be fully gowned up and wearing masks, this made H feel very uncomfortable.

39. My son was only 15 when H died and I was so worried about him missing out on having him around. We informed GRO-B of H s infection in around 1992. Prior to informing him, I went into his school and informed the head teacher that H was very ill and GRO-B does not know about this; we agreed that the conversation would not go any further than the room. Soon after, we went on a family holiday and took GRO-B fishing, where we then told him about H s infection.

40. When he went back to school, he gave up on everything. The news really affected his education and when his dad passed away, he went off the rails. GRO-B began taking tablets and I had to frighten him into stopping, by giving him an ultimatum that he either stopped or left the family home. GRO-B has now turned his life around and is nearly 40 years old, with two children and a lovely wife. However, he will never forget what happened to his father and the days leading to his death.

41. Due to H s illness his family were very close. His mum would help care for him and his dad would take him to hospital appointments and run around after him. H missed out on getting to look after his mum and dad when they got older. He was also close with his sisters who were distraught when they lost their brother.

Section 6. Treatment/care/support

42. In 1984, we went to see two male counsellors. They asked questions about how we were feeling and then just said "I think you need a holiday, that's what you need". This was a stupid suggestion. The first one we just laughed off, because we knew that was not going to fix anything. However, when we attended again and a holiday was suggested, I was very unhappy and snapped at the counsellor.

43. In around 1987, I suggested to the doctor that some of the wives of people who had been infected with HIV or Hepatitis C meet up. The doctor recommended we do it at the hospital so that he could send a counsellor to sit with us. Although we had all had counselling, we said that this was the best thing that we had done. All sitting together and talking was very therapeutic as we could understand each other's pain.

Section 7. Financial Assistance

44. Towards the end of H s life, he told me that we needed to get a shower installed because it was difficult for him to get in and out of the bath tub. We received a grant from the Macfarlane Trust for this. In order to receive this grant we got the shower installed and we were reimbursed, which they did without any issues.

45. H received a payment of £60,000 in an out of court settlement. The Government said this was not compensation, but it was a living allowance for Haemophiliacs. In order to receive this payment, he had to agree to the precondition that he would not sue them or bring it up again. He felt as though he was forced to sign this waiver because we needed the support. I recall H feeling very bitter and hurt about this. He said "I'm being murdered".

46. He also received a working allowance, which was paid monthly. He only received this for the last seven months of his life, but it helped a lot.

47. I did not receive any assistance from the trusts or funds after H's death, until about four years ago. I worked and believed that if I could pay for things myself then I should not ask for help. However, four years ago my friend said she was getting her roof done and received money for things for her house from the Macfarlane Trust. She informed me that she received payments every month. I called the Macfarlane Trust and asked for money towards a new roof and they sent me forms to fill in. I now receive £600 a month from them.

48. At first the Macfarlane Trust was fantastic. However, when the NHS took over and it became EIBSS it took me four months to sort everything out. It was quite stressful, but I knew it had to be done.

Anonymity, disclosure and redaction

49. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

50. I do not wish to provide oral evidence to the Inquiry.

Statement of Truth

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

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

Dated......25 | 5 | 2019................