Witness Name: GRO-B
Statement No: WITN3580001
Exhibits: 0
Dated: August 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

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

3. My H has provided a Witness Statement to the Inquiry H.

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

Section 2. How infected

5. H suffers from Haemophilia A classed as severe with a clotting factor of less than 1%.He was diagnosed in or about 1968 when H was about 5 years old.

6. I understand from H that H was initially treated with Cryoprecipitate and that H cannot remember if he received any blood products prior to a hernia operation in or about 1968 which is the first time H recollects receiving a blood product.

7. H has informed me that neither H nor H parents received any advice or information beforehand about any risk of being exposed to infection from blood products.

8. I met H at the Lord Mayor Treloar School (LMT) Alton Hampshire in 1978 when I was about 14 years old.

9. I refer to paragraphs 6 to 7 of my H statement which detail the blood products received, where H was treated, and the names of the consultants under whose care H was.

10. I refer to paragraph 9 of H Statement which sets out that H was infected with Hepatitis B and how and what he was told.

11. H was informed that H was HIV positive on my birthday on(GRO GRO-B) I recollect waiting outside the consultation room at the Manchester Royal Infirmary (MRI) H. When he came out H said that H consultant wanted to speak to both of us. Before I had the chance to take in the news, I was dragged off for a HIV test. I was given no time to think about it and was so traumatised that I never went to receive the results. Only at H next appointment was I told that the was negative.

12. I had a very conservative mother and my parents were not aware that H and I had a sexual relationship. I had to ensure it was nothing that could be passed on.

13. As far as I can remember, no advice or information was provided to us to help manage or understand H HIV infection. My understanding was that if you had HIV, you had AIDS and then you died. That was the general prognosis at the time and no medical professional bothered to negate this view

14. In or about 1986 H tested positive for Hepatitis C. I do not recall exactly how this information was conveyed to me. Again I do not recollect any advice or information being provided, to H or me to help understand or manage the infection, nor did the doctor relay the seriousness of the condition. In fact all of the information we obtained came from Tainted Blood website.

15. I do not believe that adequate information was provided to H or me and that information should have been provided earlier when H first tested positive for HIV and Hepatitis C.

16. I consider that doctor informed H and I in a very callous, cold and indifferent way that H was HIV positive He was very matter of fact and it felt as though he was saying, you have HIV, and now off you go. He did not consider our feelings and there was a total lack of empathy.

Section 3. Other Infections

17. My H received a letter in the 2000s saying that there was a risk that H may have been exposed to vCJD. It was like one blow after another. We did not know much about vCJD and no information was provided to help our understanding. The letter landed on our mat out of the blue. There were no prior consultations or warnings given which seems a very cold way to inform a patient about such a terrible disease.

18. Strangely, when H had a PIP assessment a couple of years ago, a paramedic stated that if H hadn't become ill within 6 months of being exposed to vCJD, he would have nothing to worry about. I am doubtful about this prognosis.

Section 4. Consent

19. I believe the H has been treated and tested without H knowledge and consent and without being given full or adequate information.

20. I strongly believe because of the sheer amount of blood samples taken with very little explanation being given as to why, when H was at LMT that he was tested for the purposes of research. It now seems clear that there must have been an underlying research motive. My suspicions were further raised when I heard the witness testimony at the Public Inquiry.

Section 5. Impact of the Infection

21. When H was first told he was HIV positive H did not expect not to live very long. H was very depressed for a long time, years probably, and H health in the last few years has been extremely poor. H has been suffering from arthritis, gallstones, pancreatitis, all triggered by the Hepatitis C. H lives in constant pain and is always feeling tired and lethargic. This in turn has had a massive impact on every aspect of H life

22. I refer to paragraphs 17 to 25 of H statement and agree with and adopt the same.

23. In 1986, H was treated with Interferon and Ribavirin for his Hepatitis C which he self administered at home for 12 months It involved one weekly injection into the stomach and a daily tablet which cleared the Hepatitis C .

24. I am not a medical professional so I do not consider I am in a position to know whether there are treatments that ought to have been given to H which were not.

25. During the Interferon/Ribavirin treatment, H became very depressed, moody and impatient. H constantly felt as though H was wound up and suffered from severe mood changes coupled with flu like symptoms. The moodiness came almost instantly after the injection and H became very difficult and angry. It was like H was on a short fuse and I would have to walk on eggshells around him. It was not a pleasant time for either of us. On top of that, H had trouble sleeping as H would wake in shivers and suffer night sweats.

26. I do not think I have been the person that I was since before H diagnoses with HIV and Hepatitis C. After the diagnoses I fell into depression and had to receive a lot of counselling for that. I still do not sleep easily today and what happened to H had been a burden on our relationship since the day we were informed about H infections. I have never really gotten over it and each time H falls ill, or is diagnosed with another condition, I think to myself, is this when it starts? Will he be able to survive this too?

27. Before we knew about H infections, we would go on holidays together, often travelling to the USA. After we were told about the infections we felt that option was no longer open to us as on the visa application we had to disclose H HIV status. At that time the US authorities were extremely strict and probably would not have permitted H entry. Now the rules may have been relaxed however it was a deterrent for us.

28. I was absolutely devastated to hear about H infections. We were childhood sweethearts who met at LMT and both of us wondered how long our relationship would continue. Due to both our disabilities, we decided for then that we would not have children; however once we were informed about the infections, should we have wanted to change our minds, the opportunity was no longer available to us. That choice was taken from us. Meanwhile, our friends were having children and sometimes we felt as though we had missed out on having a family. A couple of years after our marriage, we tried to see a doctor for H to have a H, but H was turned down for being too young.

29. For as long as I can remember, we have told very few people about H Infections We kept it to close family members and friends as we were worried about the stigma. This meant that we couldn't openly discuss the matter and only a few close friends knew which added to our stress. We were constantly worried that news would leak out.

30. My parents knew about H infection. Unfortunately, I didn't have much of a relationship with my parents and my mother told me that when H died, she would not help me bury H

31. In terms of H job, H was a nurse and absolutely loved it. H was not obliged to disclose his infection as H role did not entail any invasive surgery. Unfortunately H had to take early retirement on medical grounds due to chronic fatigue and arthritis. I recollect that he would come home from work and tell me that H had nursed patients who were fitter than he was.

Section 6. Treatment/care/support

32. If H needed dental care, H had to go to the dental clinic at the MRI. Since our move to Lincolnshire; H has been registered with a local community dentist.

33. The only trouble H had accessing treatment was when H had a hernia operation in late 2018 at Lincoln County Hospital. It was just after Christmas and they were aware that H had HIV and was infected with Hepatitis C, but that did not concern them. They panicked more at the fact that H had received a letter regarding vCJD. I found it strange as surely the issue should have been what he had already been diagnosed with.

34. No counselling or psychological support was ever made available to me in consequence of what happened at the time of diagnosis. Eventually, at the latter end of the 1980s, I was referred to a counselor through the MRI. I only saw her three times and we were never offered counselling again. For the most part, we were left to our own devices.

Section 7. Financial Assistance

35. I refer to paragraphs 34 to 37 of my H statement which set out the amounts financial assistance received.

36. I find the applications for financial assistance horrendous. It should have nothing to do with means testing and people should not have to jump through hoops to be eligible. It is meant to be medical compensation.

37. Furthermore, the amount [redacted] receives is wholly insufficient. If a patient, due to medical negligence, contracted a condition such as MRSA and you sued a hospital privately, that patient could walk away with millions. Unfortunately, we could no afford to sue privately. In addition to this, to get what we did, [redacted] had to sign a waiver agreeing not to pursue any further claims. The odds were stacked up against people for years. Even today I don't feel as though our chances are great as the Government has had over 40 years to cover their tracks.

Section 8. Other Issues

38. Someone should be held accountable and justice must take its course. If it was a private firm or individual caused a tragedy on such a huge scale with so many deaths they would be prosecuted for corporate manslaughter, instead people were knighted and made baronesses. How is that fair or right?

39. I have received the Chair's determination, refusing to designate me as a Core Participant to the Inquiry. I am upset and very angry at this decision as is my [redacted] who will not be able to discuss or disclose information or documents with me unless they are made public at a later stage. This decision will prevent me being able to support my [redacted] at what will be a very difficult time for him when old memories and emotions will be stirred and he will need more than ever my support. This decision has made me less optimistic that the Inquiry has the will or ability to carry out its duties in a fair and reasonable way.

40. I feel that in making this decision to deny me Core Participant status, they are implying that since my [redacted] is alive, what have I got to bleat about? It also seems, and I do not know if this is true, that the emphasis has shifted to people who were perfectly healthy before they received a transfusion of infected blood. It is almost as though they are saying that the Haemophiliacs were

broken already so it doesn't matter if they break a little bit more. I really hope that I am wrong, but it is hard to think with any optimism after all these year.

Anonymity, disclosure and redaction

41. I wish to be anonymous and I am willing to give oral evidence at the Public Inquiry.

Statement of Truth

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

Signed.. GRO-B ....

Dated............20/8/19...........................