Witness Name: GRO-B
Statement No: WITN2917001
Exhibits: 0
Dated: December 2022

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 reside at GRO-B GRO-B My date of birth is GRO-B I am married with children.

2. This witness statement has been prepared without the benefit of access to my husband GRO-B: H full medical records.

Section 2. How Affected

3. My husband H is a very mild haemophiliac with around 30% clotting factor. He was infected through contaminated Factor 8 in the 1980s.

4. H has Haemophilia A, very mild at around 30%. He was treated with Cryoprecipitate and with Factor 8, but we do not have any information regarding

the products. He was treated at the Haemophilia Centre at Manchester Royal Infirmary in the 1980s.

5. As a very mild haemophiliac, H was undiagnosed until he was in his 20s. It was at the age of 22 years old (nearly 23 years old) that he received his first treatment of Factor 8 in the early 1980s for a minor injury which he had suffered similar or worse injuries many times as a child without any treatment, as he was very active including football, rugby and boxing. He did not require the Factor 8 treatment he was given.

6. H was not given any information before or after having the treatment about the Factor 8 blood products and was not given any other options prior to having the treatment. He was not aware that Factor 8 was a blood product and was led to believe it was a medicine.

7. H had not actually been diagnosed as a haemophiliac at the time he was given the Factor 8 for the very first time, the diagnosis came many weeks later after he was given his first treatment of Factor 8. That diagnosis was mild, so he shouldn't have been given the treatment in the first place.

8. No information was given beforehand about the risk of being exposed to infection from the Factor 8.

9. H was infected with HIV, Hepatitis C (HCV), Hepatitis B (HBV) and Hepatitis A, (HAV).

10. We cannot recall H ever being informed of his Hepatitis A infection, this was only discovered when we looked at his medical records a few years ago. In relation to the Hepatitis B infection H was informed of this by telephone that he had had a positive Hepatitis B test, but cannot remember being tested or being informed he was being tested.

11. In relation to the Hepatitis C infection, there is reference in H medical records in 1993 requesting Hepatitis C status and in 1988 the medical notes state "should we start Hepatitis C treatment". H was aware of Non A Non

B Hepatitis and was informed it would not affect him. It was not until much later that he learned that Non A Non B Hepatitis was actually Hepatitis C and he was informed he would be a carrier of the virus for life.

12. In relation to H HIV infection, he was tested for HTLV3 in 1985 which came back antibody positive, but H does not remember the details of this test. He does remember a test in late 1985 for LAV but thought this was Leukaemia. He was informed by letter in late 1985 that he was positive for LAV.

13. No information was given about the infections. Information should have been given and should have been available much earlier.

14. The test results were not communicated adequately by doctors and the results should have been explained in much greater detail.

15. H was no given any information regarding the risks of others being infected as a result of his infections.

Section 3. Other Infections

16. It only became apparent that H had been infected with Hepatitis A when he saw his medical records a few years ago.

Section 4. Consent

17. H was treated and tested without his knowledge, without his consent, and without being given adequate or full information. It is also very possible he was treated and/or tested for the purpose of research given he is a very mild haemophiliac and did not require treatment with Factor 8.

Section 5. Impact of the Infection

18. The infections have severely impacted H mental health for decades, both as a result of the infections and because of the medication taken for them. He has exhausted the NHS mental health services. PTSD counselling did not work for H and seemed to exacerbate his symptoms.

19. As a result of the medication and viruses, some of the medical issues H suffers from are Lipodystrophy, asthma, constant breathlessness, palpitations, chronic fatigue, peripheral neuropathy, polyneuropathy, kidney problems, opportunist infections, regular vision problems, chronic stomach pain, diverticulitis, acid reflux, pruritus, myalgia/arthralgia pain, fibromyalgia and vitamin d deficiency. H health problems get progressively worse year by year.

20. H takes lifelong HAART medication. It is only ever prescribed 6 months at a time and he often worries that he will run out of the medication as the NHS process for prescribing the medication through their supplier is very slow and has on a number of occasions lost the prescription. NHS budget restraints are a problem as when he asked to change his medication he was advised it would be a problem due to budgets.

21. There are difficulties or obstacles in accessing treatments as the newest and best available treatments are not always made available due to NHS budgets.

22. As H had been infected for decades before he was given any treatment, his health has been severely damaged, both physical, his immune system and his mental health especially as he went decades without HAART and this has caused further damage to his immune system unlike newly infected people today who start treatment immediately on diagnosis which avoids damage to their immune system.

23. H has always had great difficulty in finding a dentist to treat him.

24. H has not been able to discuss his infections with anyone other than myself and has been very careful what he had told his children so as to not upset them or interrupt their education or careers. He is now quite introvert and only has a small circle of family that are close.

25. I have had to give up my job to care for H full time. It was impossible to hold down a job and provide care at the same time. My mental health has suffered dramatically and I suffer from extreme anxiety. We very rarely get together with friends and family as social gatherings cause too much anxiety and as such our friends circle is now virtually non-existent. I do not discuss the situation with anyone other than H as I don't want to cause any stress or upset to my children, disrupt their education or careers which leaves me feeling very lonely and isolated.

26. Stigma still surrounds HIV which is the reason we do not discuss this with anyone except between H and myself. Recently close family have become more distant since the start of the public inquiry.

27. H infections have had a massive effect on all the family and no help was available. Our children thought their dad was going to die, yet couldn't discuss it due to the stigma.

28. H had to give up work very early, he had a good career with great career prospects and this meant he lost significant income as well as many years contributions towards his pension. He has not been able to work again since due to the mental and physical health problems caused by the infected blood tragedy. As I had to give up work to care for H I only receive carers allowance so I have lost a good income and future pension.

Section 6. Treatment/care/support

29. H came up against obstacles when he asked to change his HAART as he was informed that NHS budget constraints meant the hospital could not afford to change his medication.

30. I have never been offered counselling or psychological support however H has had numerous counselling sessions and PTSD counselling. None of the sessions H had were successful and only exacerbated his mental health conditions due to having to re-live the horrific treatment of the past.

Section 7. Financial Assistance

31. I have not received any assistance from the Trusts or Funds.

32. EIBSS are quite difficult to deal with at times as they are not very flexible. They ask beneficiaries to jump through hoops to apply for discretionary payments when these beneficiaries are ill and unable to obtain the information EIBSS requires so they end up not applying for the payments they are entitled to. EIBSS do not seem to have a good understanding of their beneficiaries and the ill health they are suffering from. Applying to EIBSS via a begging bowl system is a reminder of the tragic events of the past and adds to the suffering of the beneficiaries they are supposed to be helping. We have not had a respite break due to the application process and the stress and anxiety this process causes to H

Section 8. Other Issues

33. H infections were totally avoidable and unnecessary, he should have never been given the treatment he was given in the first place as he simply didn't need it as a very mild haemophiliac.

34. There should be additional compensation paid to mild haemophiliacs who did not need Factor 8 treatment in the first place without going through a lengthy legal process. H is now GRO-B years old and the legal process would be far

too lengthy and time consuming at his age and would further impact his health and mental wellbeing.

Anonymity

35. I wish to remain anonymous.

36. 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 29/11/22