Witness Name: GRO-B
Statement No: WITN2899001
Exhibits: 0
Dated: DECEMBER 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. I was born on GRO-B and I live at GRO-B GRO-B. I am married and I have two sons.

2. My (half) brother, GRO-B: B (born on GRO-B 1968) was infected with the Hepatitis C Virus (HCV) from contaminated blood products. He died from liver and kidney failure on GRO-B 2016, aged 47.

3. My sister, GRO-B and my step father (B's father), GRO-B GRO-B have also provided Statements to the Inquiry (Witness Numbers GRO-B and GRO-B).

4. This witness statement has been prepared without the benefit of access to B's full medical records. I have been provided with a limited number of records only. There are parts of B's medical records which would be relevant to the Inquiry but which are missing.

Section 2. How Affected

5. On 12th May 1982 when admitted to the Royal Shrewsbury Hospital (RSH) B's blood was screened and was noted to have a factor VIII clotting level of 11%. It was noted as being thought likely that B had mild Van Willebrand's Disease (VWD) notwithstanding a previous clotting screen in 1977 that revealed 'no abnormalities whatsoever'. Moreover a later clotting screen (done in 2005) also showed normal clotting.

6. B was first treated with Factor VIII (FVIII) concentrate on 12th May 1982 and then on an almost daily basis until discharged from the RSH on 4th June 1982. He was just 13 years old and had injured his right leg whilst playing football (on or around 20th April 1982).

7. On 20th January 1987 B was involved in a road traffic accident and his left femur was internally fixed under FVIII cover the next day at RSH. In the post operative period he was administered 'numerous' units of cryoprecipitate and FVIII concentrate before being discharged on 12th February 1987. He then had more FVIII treatment during his admission to RSH for an operation to drain a haematoma on 13th March 1987 and as an outpatient after he was discharged on 18th April 1987.

8. B was also treated with FVIII concentrate when admitted to RSH for surgery to remove a nail from his left femur between 28th June and 12th July 1990.

9. B may then have also been treated with FVIII concentrate at the Princess Royal Hospital in Telford where he was admitted for two days in 1999.

10. I am now most concerned to understand why my brother was actually given blood products for what was a very mild form of VWD. B's blood clotting factors were reasonable. He may well have never actually required what turned out to be contaminated products in the first place.

11. It wasn't until B collapsed and was hospitalised at the beginning of December 2005 for an unexplained illness that he discovered he had been infected with HCV. A junior doctor was despatched to B's bedside to break the bad news to him on 13th December when it had in fact been noted in his medical record on 9th December 2005 that he was HCV positive with genotype 1A. He was offered no counselling. Just given a couple of leaflets and discharged (on 12th January 2006) to outpatient care.

12. B had been in hospital for nigh on two weeks before he was told by the junior doctor that he had HCV. He was already suffering with ascites and regular bouts of hepatic encephalopathy. When he was first admitted, I remember the hospital staff asking us what drugs he took and how much alcohol he drank. It then transpired that he had liver cirrhosis.

13. B confided in me before telling friends and other family members that he had been given infected blood albeit he was reluctant and too distressed to tell me straight away what he had been infected with. The junior doctor had reminded B that he had had an operation previously and that the 'blood' he was given was infected. He wasn't given any information about how to manage the condition. I, erroneously, assumed that the doctors would cure him. I recall that some six to twelve months after the diagnosis and at my request, I met with B's HCV nurse. I felt that we (his family) should have been provided with information about the risks of others being infected as a result of the HCV infection. That information was not forthcoming to any of us.

14. To the best of my knowledge, no information or advice was provided to B beforehand about the risk of being exposed to infection at any time. Our parents (mother and GRO-B) were never warned about risk. They trusted the doctors to treat B in an appropriate and safe way. I was not given any information nor was I privy to any information from the hospital about the risks. Full and complete information should have been made available from the start to enable my parents and B to make an informed decision, especially when balanced against the mild VWB B apparently had. Some people needed treatment as a matter or life or death. My brother's

condition did not warrant the risks that were taken with his life, risks which resulted in his most untimely and horrible death.

Section 3. Other Infections

15. I am not aware of B being infected with anything other than HCV.

Section 4. Consent

16. I certainly believe that B was treated without his informed consent. B and our parents were not able to provide informed consent as they were not provided with adequate or full information. They were informed that FVIII concentrate would be administered to B as the decided treatment and they would not have questioned the decision, thinking the treatment safe.

17. B may well have been treated for the purposes of research and I very much want to know if he and others were used in that way. B thought so. In later years and very sadly, B referred to himself as a 'lab rat', 'guinea pig' and as a 'PUP' (a previously untreated patient). B was first treated with 20ml FVIII concentrate on 12th May 1982 in dubious circumstances given his mild/borderline VWD diagnosis. They then kept pumping it into him for almost one month (12th May – 4th June 1982). He was given the treatment within months of the circulation of the infamous 'chimp letter' recommending the use of PUPs as being ideal candidates in determining the infectivity levels of new/developing products.

Section 5. Impact of the Infection

18. The mental and physical effects of being infected with HCV were devastating beyond words for B. He was also extremely conscious of the shock and hurt that would be caused to us, his family. He was worried about telling our parents and GRO-B, our sister. He would become very distressed and cry and GRO-B knew that something was very wrong with B. Ultimately I had to be the one to tell her because it was unfair for her not to know.

19. B was a clever man and was well aware that people would have a negative opinion about his infection. He bravely decided to go on to break the news of his illness to friends, work colleagues and neighbours. The fear of HCV (and potentially AIDS at that stage) went through his social circle in days. He was almost universally ostracized. Almost without exception he was friendless. He was criticised and despised for potentially putting people at risk. B's social life ended with the diagnosis. He lived alone but returned home to live with our parents.

20. B got very, very sick over a very long period and ultimately died a horrible death. B had several very serious physical health conditions directly attributable to HCV. He had ascites, requiring regular abdominal drains. He had severe leg ulcers. He had severe regular episodes of hepatic encephalopathy. He had endocarditis caused by the necessity for a tooth extraction. He developed liver cirrhosis. He also had a massive hernia.

21. As B became more ill he became less able. He couldn't get to the toilet and was forced to use a commode. He asked for financial support to convert a downstairs bathroom to a wet room but was refused. The severe leg ulcers and very poor mobility resulted in him being confined to a wheelchair.

22. B was seriously ill for the last two or three years. He was huge with water retention because of his liver failure and could not move. The frequency and severity of the bouts of hepatic encephalopathy rendered him unconscious often with no or little warning. He would usually soil and wet himself. We, his family, had to bear the brunt of that, largely his elderly parents. The only answer the local GP had was to suggest calling 999 which we often had to do. Once they knew his condition, he wouldn't be declared an emergency, but we couldn't deal with him. We couldn't lift him or move him. Sometimes we would have to wait hours for an ambulance to take him to A&E. Then the really long wait began. B was a seriously ill man, unconscious, soiled and wet and unable to move because of ascites. I have known him be on a trolley in A&E for 16 hours. We used to sit with him and try to keep him on the bed, sometimes they had to put him on mattresses on

the floor. There was no dignity there at all, not for my brother, not for his parents, not for any of us.

23. One of B's consultants tried to operate a 'revolving door' policy whereby he would be admitted straight to the ward where they knew his condition, but the hospital never allowed it to happen.

24. B suffered with severe depression, suicidal thoughts and wishes. He discussed suicide with me and asked me to help him end his life a number of times.

25. B's last days in the hospital were spent sitting in a chair because they said they didn't have a bed sufficiently big enough to hold him safely. His legs were pouring with fluid and blood from the abscesses, he was unable to move, unable to sleep, unable to use a toilet or change his clothes properly. He knew full well that he was dying, and he knew full well that it was in the most miserable, awful god forsaken state I have ever witnessed any person in. Honestly if someone were to have kept an animal in such a state the RSPCA would have had them in court straight away.

26. B's diagnosis had a profound effect on me emotionally he was my kid brother and I'd always looked out for him. I understood he was probably going to die. This was difficult for me to deal with initially. It got more difficult to deal with as I watched him go downhill, suffering the most miserable effects of the HCV infection.

27. It also had a profound effect on my family, my health, my wife's health, our businesses and our social life. At the time of B's diagnosis my wife, GRO-B, and I lived in GRO-B but had returned to the UK for Christmas. GRO-B is GRO-B and I had lived there for almost 10 years at that point. Our home was there and we had a substantial business there.

28. As an added complication, GRO-B and I had invested heavily in a business here in the UK at B's request in 2003. B had needed a change of life and direction. He ran the business. He was Managing Director but his illness

and treatment meant that he could no longer work. Initially I stayed in the UK to take the reins and GRO-B returned home. We quickly realised that we had to make decisions around B's illness and the business and our investment. We could have sold it, but that would have meant closing the door on B should he recover. It was a very, very difficult decision to make but I decided to try to manage the UK business here and GRO-B tried to manage the GRO-B business there. GRO-B followed me to the UK in 2006 and we then tried to manage both businesses from the UK. This was very full on and extremely stressful. The phones went on a 24/7 basis. The upheaval and stress directly caused by B's diagnosis and illness resulted in GRO-B having major heart failure and open heart surgery in 2008. She still has cognitive issues now. It also resulted in major business problems leading to the collapse of both businesses in 2009. I was diagnosed with a rare eye cancer in 2010 and told that I had just three or four months to live. I was later told that I had been misdiagnosed. In 2016 I was diagnosed with bowel cancer.

29. B worked long hard hours to make the business a success. In addition to the financial investment, GRO-B and I provided him with our support in running it. GRO-B was a director. When the business failed B became reliant on benefits. At that time his outgoings were more than his income and his debts accumulated. I know he felt guilty because he was unable to run the UK business. He apologised to me about it, but it was out of his control.

30. GRO-B, B's father, dedicated himself to B and was always with him. He was a saint, rarely leaving B's side right up until he died. When B was still able, he did a lot of research and became actively involved in highlighting the tainted blood scandal to include radio and television interviews. Because he was so open and honest people in our local community stayed away. They did not want to be around B or his family. After he died, they all showed up again and it chokes me when I think about it.

Section 6. Treatment/care/support

31. B first had treatment in an attempt to clear the HCV in 2006. The treatment was planned for 12 months but it was discontinued two months before it was due to finish. There were horrible side effects to the treatment including severe depression. B had suicidal thoughts and he talked about ending his life. However, I believe that B was almost clear of the disease and did not want to stop the treatment. He really wanted to continue with it despite the dire side effects as he had come so far into it. He should have been able to continue with it.

32. No further treatment was offered to B until a new Consultant, Dr Rye, took over B's care which I think was 2014 or 2015. Dr Rye managed to secure the funding for a new treatment drug which had been available under the previous consultant but not offered to B. The treatment was successful but the damage to B's liver had already been done. Moreover, the liver transplant B was then told he needed was blocked because of his various health complications to include the ascites and the huge hernia. In short, B faced severe difficulties in obtaining the treatment he desperately needed.

33. B went through A&E frequently in the last years of his life, often comatose or extremely agitated. Initially he was usually assessed and dealt with as being a drug addict or alcoholic, and/or as being violent or uncooperative. He was of course none of these things, it was just his condition.

34. The medical care that B also received was appalling. Individual care workers and medical staff did their best but the system failed B so badly and I feel so appalled that it is hard to even talk about it.

35. B was not diagnosed with HCV until 20 to 25 years after he had been infected. The NHS knew that there was a problem for many years before that and there must have been files and documents identifying those infected with contaminated blood. B was never contacted to warn him he too may be

infected and/or called in for any type of screening test. Instead he was left at large in the community as a risk to those he lived and worked with. I really think that the NHS had a duty of care to inform B that he was at risk for his own sake. I feel that it was negligent of the NHS to have left any individual that they knew to be infected out in the community.

36. No counselling was ever offered to me personally or made available to the family as far as I know.

Section 7. Financial Assistance

37. B received financial support from the Skipton Fund. He never received support from any other fund. He did apply for a wet room through the local authority because he was unable to access the bath/shower. He was turned down because although the Skipton Fund payments were disregarded for the purposes of personal account, the local authority insisted that it be taken into account for any equipment or modifications to his house.

38. I believe that had B been infected with HIV/AIDS as well as or instead of HCV he would have successfully been able to access appropriate help from, say, the MacFarlane Trust. Is dying of HCV any less traumatic than dying of AIDS? No. This highlights one of the many differences between the confusing array of support providers.

Section 8. Other Issues

39. I would like to recap/highlight the following points of concern:-

    a. It appears unlikely B needed FVIII treatment when it was possible his blood had no clotting abnormality whatsoever and, at worst and in the alternative, he had only mild VWD;
    b. The NHS which new for years that B was probably infected did nothing. This silence prevented an early diagnosis, which could have given him a chance of treatment much sooner;

c. The lack of early diagnosis also meant that B lost opportunities to be put on the transplant list;

d. The silence by the NHS left B s friends, family and colleagues unknowingly at risk of infection;

e. The ongoing regular hospital admissions;

f. The stigma from NHS staff assuming B was a drug addict or alcoholic;

g. Having to go through the same questions, the same terrible route through A&E, even though B s condition was well documented;

h. The hospital promised a 'revolving door' admittance process which meant that B would have gone directly onto the gastro ward. Instead he was forced to spend hours in A&E. Up to 24 hours on occasion;

i. The total lack of support from the NHS;

j. The ongoing and regular hepatic encephalopathy attacks that left B in a comatose state for 24/48 hours, each one having a detrimental effect on his well being, leaving him permanently more unwell and closer to his death;

k. The drug regime that left B confined to the house;

l. The braveness of a young man who knew that due to this complete failure by the NHS that we all trust to make us better, that his life was going to be so cruelly cut short;

m. The family that supported him through every step of the journey, every hospital admission, sitting by his side through the encephalopathy attacks, as there was no support, no one willing to take responsibility for this, nowhere to turn, except the local hospital who frequently treated B like he was a nuisance patient.

Anonymity

40. I wish to remain anonymous.

41. I would like to give oral evidence to the Inquiry on behalf of the family if I can be of further assistance in that way.

Statement of Truth

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

Signed.. GRO-B ....

Dated........ 18th February 2020 ....