Witness Name: GRO-B
Statement No: WITN4016001
Exhibits: 0
Dated: February 2020

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 was born on GRO-B 1982. I live at GRO-B GRO-B.

2. I live here with my husband GRO- and our GRO-B year old son. I also have two step daughters from my husband's previous relationship.

3. GRO-B was infected with Hepatitis C as a result of receiving contaminated blood products.

4. GRO-B has provided a witness statement to the Inquiry under witness number: GRO-B

5. **This witness statement has been prepared with the benefit of access to some of my husband's medical records.**

Section 2. How Affected

6. I first met GRO-B when we worked together for a short time for a GRO-B's GRO-B in GRO-B. In GRO-B we got married and in GRO-B we welcomed our son into the world.

7. In GRO-B when GRO-B was GRO-B years old, he fell over and cut his lip open. His parents were unable to stop the bleeding, so he was taken to the Dorchester Hospital where he was diagnosed with moderate Haemophilia A. He was given an immediate IV infusion and a whole blood transfusion. A statement was duly taken from GRO-B's mother and it was later discovered that she was a carrier because her grandfather was a Haemophiliac.

8. As a child GRO-B was not allowed to play rugby or hockey, but he was allowed to play football. He was a very athletic child and enjoyed sports, so his consultant sent a letter to his school to guide them with which activities he could take part in.

9. GRO-B initially received Cryoprecipitate for any bumps, bruises and dental work. His treatment was later changed to Factor VIII concentrates, but he cannot recall when. As far as he is aware, there was no conversation with his parents regarding the treatment changing to Factor VIII concentrates or the risks associated with it.

10. As a child GRO-B was treated at the Poole Hospital for any tooth extractions. For injuries, he received treatment at the Dorchester Hospital, where he was under the care of Dr Gilliver and Dr Crawford. He also received treatment at a hospital in GRO-B for a one-off accident. He is now under the care of Addenbrookes Hospital in Cambridge.

11. In or around 2008, when GRO-B was working as a yard foreman at a builder's merchants, he had an accident at work which resulted in him losing the top of his thumb. He came home and dressed the wound and went to bed as normal. He woke up at around 4 am and told me that he needed to go to the hospital. There were pools of blood on the bed and on the floor. We went to

GRO-B Hospital and they asked us a few questions. GRO-B mentioned that he was a Haemophiliac and required Factor VIII concentrates, so they promptly administered the treatment. I then asked whether GRO-B had been registered at Addenbrooke's Hospital Haemophilia Centre; he had not so we put this into action. I accompanied him when he registered here and they suggested that he get tested for infections. He was asked to sign a consent form to be tested for Hepatitis A, Hepatitis B, Hepatitis C, HIV and was asked whether he knew if he had ever been exposed to CJD. Until this point, he was unaware that there was a risk of infection from receiving blood products/blood and had no idea that he could have contracted something. We just thought this was part of a routine check-up and that they were being extra cautious. We were not told the exact reasons for the test which was due to the potential risk of infection from infected blood products/infected blood.

12. Following these tests GRO-B was told that he had contracted Hepatitis C. He was advised that he had also been infected with Hepatitis A and Hepatitis B but had cleared them naturally. I believe he received this information face-to-face, from Kingsley Lawrence. Arrangements were then made for him to meet with the Hepatology Department at a later date where he was provided with information as to how to manage and understand the infection.

13. Although he was tested and informed of his infection in 2008, as part of the preparations for providing this statement, we have reviewed some correspondence from the Dorchester Hospital suggesting that he was informed of his infection with Hepatitis C in the 1990s; however, he has absolutely no recollection of this.

14. There are accounts of appointments and so-called discussions with my husband in the medical records in the 1990s which he does not recall ever happening which lead me to think that either the records were falsified or inaccurate information was recorded. I believe that had GRO-B been told of his infection there would be no way he would have ignored his infection, nor refused treatment.

15. Looking back retrospectively, I don't feel that enough importance was placed on providing information to me on the potential of the infection being transferred to me or the potential infection of GRO-B s previous partner and his GRO-B daughters. Surely, it would have been good practice to recommend and action that the immediate family and anyone who could have been infected be tested. There was no such recommendation and little or no information provided; I did my own research and pushed to be tested and communicated for the same to happen with the other family members.

Section 3. Other Infections

16. We are aware that GRO-B is at risk of developing CJD as he may have been exposed to this through his treatment with contaminated blood products/blood.

Section 4. Consent

17. Although GRO-B consented to be tested for infections at Addenbrooke's Hospital, I believe he was tested for infections prior to this, without his knowledge and therefore without his consent, at the Dorchester Hospital. He was always asked to give blood which he thought was normal due to his Haemophilia status, but I now believe this was due to the covert testing for infections.

18. I believe he was tested for research purposes, without his knowledge or consent. I consider that he was treated like a guinea pig and I question the moral basis behind this. His medical notes and database information note the term '*Research*' which would point towards this.

Section 5. Impact of the Infection

19. After the initial shock and sheer fear of what the future of GRO-B s health and suffering held, our feelings moved towards anger and almost grief. We were unsure whether we would ever be able to conceive a much wanted child

together. There were so many *'unknowns'* that thinking towards the future seemed impossible and therefore we were only able to take one day at a time.

20. The treatment for Hepatitis C really took its toll on GRO-B both physically and mentally. He was constantly exhausted for the two years of treatment which meant that we were unable to have much quality of life as his energy levels were so low.

21. His treatment consisted of Interferon and Ribavirin, which necessitated taking six tablets three times a day; and in addition he had to inject himself once a week. I believe the treatment was supposed to last for 18 months, but it was extended to two years, which were the longest two years of his life. Fortunately, the treatment was successful and he is now clear of the Hepatitis C.

22. However, throughout GRO-B's Hepatitis C treatment his immune system was heavily compromised so he constantly picked up other illnesses. I would say that this has continued since the treatment.

23. GRO-B suffered for the entirety of the treatment. Not only was he incredibly poorly throughout but he had the added fear of it being unsuccessful, potentially requiring a liver transplant and the consequent possibility of that not working. The amount of anxiety that GRO-B had to endure was unimaginable.

24. It was extremely difficult for GRO-B to accept or acknowledge the existence of his Hepatitis C infection. This virus has negatively affected his state of mind.

25. GRO-B's mental lows and depression made him very difficult to live with at times and he would often shut off from me and those around him. We shied away from seeing friends and didn't feel like we could tell everyone about our situation as we worried that people would want to avoid being in contact with us for fear of '*catching something*'.

26. There is no doubt that GRO-B is a '*shadow*' of his former self. Sadly, the Hepatitis C treatment has led to long lasting and continuing side effects to include tiredness and brain fog. Despite clearing the virus, GRO-B still feels that he cannot be open with people about his condition for fear of judgment, even though he has never done anything wrong. This has resulted in a fairly lonely and stifled existence. We have lost all trust in medical professionals too.

27. Not only did our relationship suffer, but so did his relationship with his GRO-B daughters who live in GRO-B as he was unable to travel to see them so he missed out on parts of their lives as they were growing up and consequently felt he was failing as their Dad.

28. GRO-B also has scarring to his liver which is being monitored. He had the Bird Flu vaccination upon the recommendation of the medical professionals but experienced a number of adverse reactions in response to this and was extremely unwell for a number of weeks.

29. The lasting impact almost presents with symptoms identical to that of Post Traumatic Stress Disorder (PTSD). Furthermore GRO-B's mood and energy levels are very up and down; but in the main both are down. This has also affected the type of activities he has been able to do with our GRO-B year old son.

30. Turning to the effect on me; I personally experienced a multitude of different emotions throughout this whole, now lifelong, ordeal. Our lives will never be the same; GRO-B will never be the same and I am resentful of that. I will never understand how this was ever allowed to happen. Our hopes and dreams were shattered in an instant and the ongoing battles we face with the stigma and tactics deployed, even when requesting medical records, is beyond belief.

31. The emotional and mental strains on me personally have caused physical symptoms. Additionally, I repeatedly asked my GP if I could be tested for Hepatitis C but was told '*You don't need to worry about it*' which was demoralising as I felt no one was listening to what I needed. In the end I demanded to be tested, thankfully it was clear, but I feel I shouldn't have had

to go through a lengthy debate to have a test to safeguard my health and well being. Rather, it should have been a matter of course.

32. There has been zero support provided to carers and those '*affected*' and little to no support provided to those infected either. Many individuals, partners and families would have desperately benefitted from counselling or similar which would have supported them; but that simply has not been offered.

33. We had to delay trying to conceive a child due to the Hepatitis C and the associated treatment which meant that we were older than we'd hoped when we finally started our family. We then struggled to conceive for a while and I suffered a miscarriage too. I believe this was partly contributed to by the stress I was under in respect of what had happened to GRO-B

34. At some point we will need to tell our son about all of this. I am dreading when that day comes as I simply do not even know where to start in telling him about how such a tragedy occurred which thankfully his Daddy survived, but thousands of poor souls didn't. I'm sure he will then feel all of the emotions of anger, mistrust, deep sadness and pain that we live through on a daily basis. But naturally, at some point he will start to ask questions and we will have answer those questions.

35. In term of employment, following the Hepatitis C treatment GRO-B had to move away from his physically demanding job as he no longer felt he could work outside in such an active role. He therefore had to adapt to learning something new in an office based role. He was then made redundant and he feels like he was penalised because of a combination of his issues/stigma and due to the amount of time needed to attend medical appointments. Furthermore, within the industry in which GRO-B now works it is frowned upon to take time off for medical appointments. He therefore had to book annual leave for such appointments with the consequent effect that he spent less time with us as a family.

36. GRO-B's combination of lack of energy and brain fog led to a lack of confidence and ability. He wanted to study for a professional qualification but he did not feel like he could complete the same. He therefore had limited scope for career progression and a stunted earning potential; all as a result of the Hepatitis C.

37. I therefore had to remain working in a highly stressful job because we needed financial stability and I had to be the "*breadwinner*" to keep a roof over our heads and put food on the table. Otherwise I would have looked to pursue a less stressful career and something more personally fulfilling.

38. I had to return to work following my maternity leave due to the pressure on our finances when I would have preferred to spend longer at home with my son. As a result, I feel like I missed out on a lot of my son's life.

Section 6. Treatment/care/support

39. When GRO-B had to go to the hospital for treatment, he felt as though he was treated like a leper. He was ordinarily shoved in the corner out of the way, which was usually due to the risk of his exposure to CJD. Furthermore, since he was made aware of his exposure to CJD, whenever he ticked a box to say that he had been exposed to CJD, he was always viewed differently which is something that sadly continues to the present day.

40. An example of this centred around his attending for a colonoscopy on 18th January 2019. This was duly carried out and thankfully the results were clear. About a week later he suffered a bleed and was unable to get an appointment for an examination. GRO-B was therefore told that he was going to be given another colonoscopy. However, the medical professionals kept changing their minds and putting it off. We believe that this was because they were struggling to arrange another one at short notice, given that they have to use new equipment due to the risk of CJD exposure.

Section 7. Financial Assistance

41. GRO-B received the initial Stage 1 Payment of £20,000 from the Skipton Fund (SF) in 2009. Addenbrookes Hospital informed him of this assistance when they discussed the Hepatitis C diagnosis with him. In order to receive this payment, he had to contact the SF to obtain a form to fill in. I cannot remember if he had to provide them with medical information or if the hospital provided them with the same. He also received a monthly payment from the SF.

42. He now receives a monthly payment from the EIBSS. In my experience, the EIBSS are not as transparent as the SF.

43. I confirm that I have received nothing from either the SF or the EIBSS.

44. There is a Child Supplement Payment available with the EIBSS, however, in order to qualify your household income must be under £37,900. I feel this qualification amount should be abolished or reviewed. Any household with an income at or below that figure would likely be on the '*breadline*' if they were paying a mortgage, bills and supporting any dependants. Notwithstanding that, a parent may wish to use these contributions to make up for the gap in their future earning potential to provide for their child or their own future.

Section 8. Other Issues

45. There are no other issues.

Anonymity

46. I wish to remain anonymous and 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.

GRO-B

Signed ……

Dated……06 - Feb - 2020