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Witness Name **GRO-B**

Statement No: WITN3366001

Exhibits: 0

Dated: June 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 the **GRO-B** and I live at **GRO-B** I am a widow as my husband of **GRO-B** years died suddenly of a heart attack on the **GRO-B**
2. I have one child, a daughter who is **GRO-B** years old who is single with no children.
3. I am the youngest of **GRO-B** children. Although I do not keep in contact with my siblings, I know they are all fit and well.
4. My mother lived until she was **GRO-B** years of age and died of a stroke.
5. I have only ever had one sexual partner who is my late husband.
6. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

7. I was infected with Hepatitis B (Hep B) as a result of a blood transfusion.
8. In **GRO-B** I was taken into **GRO-C** after my 6 monthly ante-natal check-up. I was told that my baby was fine but they were concerned because my weight was poor. They had decided that bed rest in the hospital was appropriate for me. After being admitted in for the first couple of weeks I underwent various tests and procedures which involved having blood products for my iron. I was sent home for the weekend but had to return to the hospital for bed rest again.
9. I was extremely upset and concerned but also confused because I didn't understand what was wrong with me. I did not feel sick nor have back pains and I felt fine generally. My baby was fine, there was lots of kicking and movement with the baby but as I was on my own (my husband was at work) I was told it was for the best and so I went into the hospital for the last three months of my pregnancy.
10. What I do remember is being told one morning by a nurse that the doctor had decided to give me an internal examination to check if everything was okay because I was 2 weeks late by this stage. I said yes not ever realising the real reason for the theatre visit. I was also told that they were going to put me to sleep so it wouldn't be too uncomfortable for me. The next thing I remember was being woken up by the Anaesthetist squeezing my hand and telling me I had a daughter. It was **GRO-B** and when I woke up in the recovery room, I was being given a blood transfusion.
11. At no stage during that time was it ever suggested to me that I would have a Caesarean Section (C-section). At no time did anyone ask me to sign anything authorising an operation. In fact during my post-natal meeting after my operation I mentioned this to the sister at the hospital and she assured me it was for the best and there must be paperwork somewhere authorising the blood transfusion. I told her I definitely had not been told I was going to have a C-section or signed any authorisation for it. She told me I must have been

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mistaken. I told her I was not. She then produced a form and asked me to sign it saying that it was probably just over-looked.

12. It was a huge shock. They hadn't informed me or my husband of their intention to perform a C-section. My husband arrived some hours later when I was groggy in recovery. He was as much in shock as I was as he hadn't been told or given authorisation for the operation and was actually at work when he received a phone call telling him of the birth. I don't know who made that phone call, I imagine a nurse. But worse was to come because I wasn't allowed to see **GRO-B** my daughter, for 3 days. I honestly don't know why, because she **GRO-B** at birth and okay according to staff. I asked my husband if she was okay and he said yes he'd seen her through the glass and she seemed fine and she looked like me. It was only when I was in my own hospital room 3 days after giving birth and resting on the bed with my eyes closed I heard the door open and shut and I sat up and realised there was a cot at the end of the bed and I looked over and for the very first time I saw my beautiful daughter. Nobody told me she was being brought up from intensive care. They just left her there.
13. The whole experience was so emotionally charged for me. I'd been through so much to have a baby and yet I felt hugely robbed and let down. The most important moment of my life - having and meeting my daughter but she was just left there for me to find. The moment I'd been longing for was such an anti-climax. I have never ever felt so alone and so very sad. She was beautiful and still is today but it took a long time for me to bond with her emotionally. There were times when I got very depressed because I didn't feel emotionally connected to her but my mother helped me with my depression and slowly I grew to absolutely adore her.
14. I was released from hospital after 12 days but I wasn't feeling very well at all and was constantly tired.
15. Approximately 6 months later I underwent another operation for the removal of my appendix at the **GRO-C**. At the time it was mentioned to me by the surgeon that he was shocked that the delivering surgeon, during my C-section

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had not noticed and dealt with the very obvious infected 'ready-to-burst' appendix.

16. I also now believe that when some 2 years later after I had my appendix I suddenly developed a huge growth in my throat and it was as a result of the Hep B infection. The growth developed over a matter of hours. I hadn't had any throat problems prior and within hours it made breathing virtually impossible, so much so, I was rushed into GRO-C yet again and underwent an operation to remove the growth and tonsils.
17. I was told the growth was benign but for some strange reason I was kept in an isolation ward. The whole experience was absolutely terrifying and I stayed in isolation for 10 days then returned home to get better. The operation was successful but it left me with even more problems because over a period of months I developed nodules on my vocal chords which were very uncomfortable and felt like I had something lodged in my throat all the time. Consequently I underwent a further operation to have my vocal cords and throat scraped.
18. During this whole period (since my C-section) I had gone from being a very healthy 26 year-old to a very poorly 28 year-old. I lost a lot of weight, looked very poorly and was constantly being told by my husband that I was too thin. Although I was eating as normal, my weight was falling off me. It was suggested by my GP that it was anxiety and I was prescribed 5 milligrams of Valium twice a day (this went on until I was 38).
19. Then I suddenly developed acute colitis and I was transferred again to yet another isolation hospital called GRO-B It was explained to me that as they were unsure of my diagnosis it was the best place for me. There I underwent various tests and a piece of my bowel was taken for testing. I was told that this confirmed that I had ulcerated colitis and after a week, I was discharged with medication. No explanation was put forward as to why I had developed this condition and eventually it was decided, again, that it was probably anxiety.

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20. In fact throughout my thirties with virtually any health concerns I raised it was always put down to anxiety. Consequently when in my early forties I decided to ween myself off of Valium it was extremely difficult for a very long period of time. I suffered very bad withdrawal symptoms that seem to go on for a very long time. At the time, no medical information or reference was made to the withdrawal symptoms experienced but we all now know of the horrendous time and how dangerous these drugs were.
21. For several years I suffered various ailments and my weight was always a problem. I suffered from digestion problems at various stages and would go to my GP in **GRO-B** for medication and advice. It was during this time that I became a vegetarian believing that my condition would be better if I just ate natural foods and nothing processed or complicated.
22. My health and weight seemed to get better and at the age of 52 my husband and I decided a life in the sunshine might improve my health further. We moved to the **GRO-B** and five years following that move I did feel better. But then I suddenly woke up one evening to feel very ill. I thought I had flu and I have never felt that ill ever before. I felt like I was going to die. My whole body felt like it was giving up. I was so scared I went to the local hospital in the middle of the night and asked for their help. I had tests for heart/stroke etc and also blood tests. After waiting for some time, the doctor called me in and told me I should go to the village doctor for the results.
23. I did this the following day and this was the first time I was diagnosed with Hep B. I honestly did not believe him so I sought a doctor in the private health care system and he ran more tests which confirmed the original diagnosis but I didn't believe any of them. It was impossible. I was shocked. I had led a very health conscious lifestyle and was absolutely certain they had made a mistake. I thought they had got me mixed up with someone else. I was confident that if I returned home to England, that it would all be clear and I could relax again. At the time of my diagnosis both my husband and daughter were tested and both tested negative which made me even more convinced they had got me totally wrong. So we sold our property (at a considerable loss) and moved back to the UK.

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24. We moved to the GRO-B area where my daughter lived and worked. I was absolutely confident that I had nothing to worry about because I had led such a normal life. That's why when Consultant GRO-B of GRO-B confirmed the diagnosis, I was totally devastated. He went on to ask me to undergo a liver biopsy and consequently I went into GRO-B in June 2012 and it was confirmed that I did have liver damage.
25. I initially thought I could have been infected with Hep B by a needle used during a vaccination but the doctor spotted a big scar down my belly and realised that I had a C-section. He said he was going to look further into it. He then told me that I was most likely infected with Hep B when I had a blood transfusion because of the large amount of blood that I was given. He said it could not have been a needle like I initially thought as that amount of virus would be completely oblivious to my body and it would clear up itself because I was a very healthy person.
26. Since that day I now have to attend the Hepatology Clinic at GRO-B every 6 months for blood tests and liver scans and it has been explained to me that it is vital to ensure that any changes will be picked up as early as possible.
27. I believe that information should have definitely been provided to me earlier. No body told me anything at the time. At that stage in my life, unlike today, I was not told that I was going to have a C-section or that I was going to be given blood. I had not signed any papers or anything and they decided they were going to put me on anaesthetics. My husband was not even informed of what was going on, he was at work. He wasn't involved in the birth of my daughter at all. I was in a room all alone and no one else was there when I was having a blood transfusion. It was all a bit of a blur.
28. I have never taken drugs of any kind (other than those prescribed by a doctor).

Section 3. Other Infections

29. I have not received any other infections as a result of the blood transfusion.

Section 4. Consent

30. I believe I was treated and tested without my knowledge and consent as I did not provide my consent and did not have any knowledge that I was going to have a C-section or a blood transfusion.

31. Soon after I was tested positive for Hep B at my GP, **GRO-B** in **GRO-B** I was sent to **GRO-B** and tested for HIV which came back negative. I did not know that I was being tested for HIV until I saw the results.

32. In relation to the C-section, I believe I was treated and tested without being given adequate or full information, as they just went ahead and did everything without asking me.

33. I do not know whether I was treated and tested for the purposes of research. I believe it was a massive mistake somewhere.

Section 5. Impact of the Infection

34. I have suffered mental effects as a result of the Hep B. It has led me to have a completely different life and consequently be a completely different person. I am now extremely anxious about all aspects of life. Life is miserable with a constant worry. From the moment of confirmation of my condition my life has changed dramatically. Although my husband was supportive, it became very obvious that the best way for him to deal with it was not to mention it at all and therefore I was not expected to mention it either. I became exceedingly depressed and started suffering from extreme dizziness and anxiety but when I talked to my GP he sent me for Cognitive Behavioural Therapy (CBT). I did not find this helpful at all and it never touched the root of the problem and we never discussed the Hep B diagnosis. In fact I have been told by one medical professional that 'it was just bad luck' that I got the infection. I cannot believe anyone would be so casual and give an almost flippant response to a completely devastating diagnosis.

35. It makes the whole thing worse (if that's possible). No-one appears to understand or even care. I now have to disclose my deepest personal health

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details to all medical staff that I see and some are very obviously not as 'enlightened' as others.

36. I have also suffered physical effects as a result of the infection. I am still suffering various ailments that last longer than normal because my immune system is constantly fighting the Hep B and even the smallest of ailments has the propensity to develop into a huge problem or infection purely because of the virus I was given 44 years ago. Because of the lack of poorly digested nutrition being processed by my liver, I now suffer from osteoporosis and attend GRO-B for injections to help manage my very weak bones. I have suffered 3 spinal breaks and have recently had various scans for my neck vertebrae which are very weak. I was also told that my liver was a bit fatty. It was all a bit vague and I was not provided any further information. They make it sound like it's nothing to worry about which is mentally shattering and I just can't accept it.

37. I have suffered further medical complications as a result of the Hep B. I have all sorts of odd things going wrong with me now. I have a nasty foot infection and the NHS is running vascular tests on my foot to find out what it is. Nothing is straight forward anymore; everything blows into a problem health wise. As previously stated my immune system can't cope with everything so any infection could get out of control and even a flu can kill me. It's extremely depressing and upsetting. I have been looking after myself since I was a young girl by going to the gym and taking vitamins. It's not fair that this has happened to me.

38. I did not receive any treatment for the Hep B. I didn't particularly want it either after the advice I received in Spain. A young doctor told me that if I was given treatment, it would take away the normal functions of my liver and I will be on the treatment forever. I was therefore left with the dilemma of whether to wait and see if I got better or worse without treatment. It was then decided that I did not need any treatment. At GRO-B I was told not to drink any alcohol and be healthy. The rules were upsetting.

39. The Hep B has impacted on my private, family and social life. I cannot

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emphasise enough the total devastation that this has had on my life. My marriage was miserable for the final years and yet we had been so happy when we started our journey together. In the end, the condition built a brick wall between us and we couldn't talk to one another anymore because I knew my husband just didn't want to acknowledge what I had. My husband and I didn't have sexual relations since after I had my daughter as I was ill and poorly all the time. It became the accepted norm. In the end, we ended up having separate rooms. We started out great, healthy and happy but sadly it didn't last. Even when we stayed in Spain, we had separate bedrooms. In a way that kind of saved him from being infected by me. It had a huge ripping effect.

40. The stigma of having Hep B is totally misunderstood and has led me to have a 'leper' type feel to the whole condition. Even disclosing it to various health professionals leads me to quickly follow up with an explanation of the contaminated blood I received during my C-Section. I am totally and utterly embarrassed and thoroughly depressed that I now have the stigma of a virus that is very much frowned upon.
41. I would ask the Chair and the panel to look favourably upon my case. I'm certain there are all sorts of incidents and attitudes I have missed out in my statement, but a recent example might sum up my life now: My cottage is very small and when my husband died suddenly in GRO-B my next-door neighbours (who had always been wonderful good friends) offered to let me use their house and drive for the funeral. I was so grateful for these lovely people. Some weeks after I became ill and was taken into GRO-B by the paramedics for a nasty kidney infection. As described earlier, I pulled out my letters from GRO-B confirming my Hep B diagnosis for the paramedics to read. I left these letters on my kitchen table and while I was away in hospital my neighbour entered my house with a set of keys she had and saw the letters in question. Since my return from hospital (some two years ago now) she has never once invited me in for coffee as was the norm before or been friendly like before. We talk only over the fence. For a long time I was absolutely distraught because I couldn't think that decent kind people would be so hurtful

but sadly that just isn't the case. I wanted her to be comfortable again with me as before so as a way of making it right again. I apologised to her.

42. I don't mention anything about what happened to anyone anymore which is difficult as I can't be myself. That is what it's like living with the 'leper' syndrome. Words cannot adequately describe how miserable and sad life is now. I do not have any friends and I honestly believe this it's the only way for me now, but it is so lonely and isolating.

43. I suffered work-related effects as a result of the Hep B. I used to work in **GRO-B** for a group of auditors and I have also worked as a personal assistant to a managing director at **GRO-B**. I had to give work up when I was just 52 as I became so tired and couldn't concentrate and that was one of the reasons why I moved to Spain. My husband was not keen on me giving up work as we had a mortgage to pay off. My husband worked for an **GRO-B** company at **GRO-B** and asked his manager if he could retire early so that we could move to Spain as I knew that there must be a different way to life.

44. My diagnosis of Hep B had an impact on my daughter. She had to be tested to see if she was infected because of me. Both my husband and daughter had a separate bathroom from me. I had an en suite and both of them shared the family bathroom. It was a huge shock for her and my husband when they were tested and their results came back negative. I remember them looking at me feeling guilty as they felt like they let me down in some way.

Section 6. Treatment/care/support

45. I have not faced any difficulties in obtaining care and support. **GRO-B** has been very supportive after I was diagnosed. They send me to a specialist nurse every 6 months and at this appointment I have a liver scan.

46. I was offered psychological support and as previously stated I was referred to CBT. I was taught how to control my mind but the whole thing about Hep B which I believe was causing my depression in the first place was not addressed. The CBT therefore did not help at all.

Section 7. Financial Assistance

47. I have no savings or independent financial source other than my state pension and a small work pension.

48. I have received absolutely no financial help from anyone. I now live in rural GRO-B 100 miles away from GRO-B and when I have to attend the hospital I am genuinely finding it very difficult to cover the cost of the trip there and back (roughly 200 miles) and yet when I asked a junior doctor once whether it would be possible for a once a year trip, she responded with haughty disgust and said "we are doing this for you" (almost a favour it appeared). I did want to point out to her that the infection was given to me by the NHS but I didn't have the courage and I'm genuinely really depressed and tired of the whole debacle. I therefore attend every 6 months and speak to my regular specialist nurse as I know it is very important for my future. It would be helpful if I could be given some sort of financial support.

Section 8. Other Issues

49. The details above are given to ensure that the Chair of the Inquiry and those on the panel understand it is not possible for me to have contracted the Hep B virus in any way other than a blood transfusion given to me when I was at GRO-C after the C-section on GRO-B. The infection has had an utter devastating ripple effect on my entire life.

50. It feels so unjust that I have never been advised or supported financially in any way about my situation and that the responsible body or groups who made decisions which effected so many lives should now be seen to be accountable.

51. Someone somewhere had made horrific decisions. Did they not care? Do they not know how this has affected people? I would like answers for what has happen.

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Anonymity, disclosure and redaction

52. I wish to remain anonymous.

53. 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 June 2019.