ANONYMOUS

Witness Name: GRO-B
Statement No: WITN5329001
Exhibits: **WITN5329002- WITN5329003**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 September 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1953 and my address is known to the Inquiry. I am a retired electrician and I worked for the GRO-B in Birmingham for 44 years, but I was made redundant during the pandemic. I have 2 grown up daughters, GRO-B: D1 and GRO-B: D2

2. I intend to speak about my late daughter D3 and her infection with hepatitis C (HCV). In particular, the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and our lives together.

3. I am not legally represented and I am happy for the Inquiry Team to support me in providing this statement to the Inquiry. I am aware of the anonymity

provisions and I am happy for my story to be told and possibly act as a warning for others.

4. My ex-wife, GRO-B: EW mother, GRO-B has provided a statement to the Inquiry through her solicitors, Collins. (See GRO-B. Today, she has dialled into our meeting and will assist me with dates and names which I sometimes struggle with due to the traumatic nature of the events that unfolded.

Section 2. How Affected

5. My daughter D3 was born on GRO-B 1984. We were living in D3 GRO-B at the time. She was a healthy baby and she had no issues with her health until when she was around 3 years old and in pre-school. She would get colds quite often and we noticed that her skin would be covered in bruises, without any apparent cause.

6. We took D3 to our GP surgery at the time which was on GRO-B, GRO-B. They sent her to GRO-B for tests and she was placed under the care of Dr EW. He did various tests on GRO-B including a lumbar puncture, and he told us that D3 had aplastic anaemia, which is a form of leukaemia. This meant that her body was not producing enough new blood cells. She was kept in hospital for around 2 months on this initial occasion.

7. EW and I were completely dumbfounded by this news. We had no idea what we should do. You do not expect a child – your child to have such a serious illness. Dr D3 guided us through this period and what we had to do for D3 We were also provided with a social worker for support. EW and I were still very young at the time and found this very difficult to cope with. She had more medical knowledge than me as she was a nursing sister, but this was still very new to her. We were told that our other 2 daughters needed to be tested, but thankfully they tested negative for aplastic anaemia although we had this additional worry awaiting the outcome.

8. We were told that D3 would need a bone marrow transplant from a suitable donor in order to treat her aplastic anaemia. EW and I as well as our children were tested to see if any of us were a match, but unfortunately, we were not. A large number of our extended family were also unsuccessfully tested at this time.

9. Sometime after D3 diagnosis with aplastic anaemia, Dr GRO-D took us into the family room to discuss D3 having Anti-lymphocyte globulin (ALG), which was a trial drug at the time. Unfortunately, this did not work and in fact had a detrimental effect on D3 but everything was trial and error during this period and we would have tried anything to give her a better life. We were told that finding a bone marrow donor for D3 was now the best option for her.

10. While we tried to find D3 a donor, she had a lot of blood and platelet transfusions as her platelets were not producing enough red cells, and this was causing her to bruise. We were told this was the only thing that would help her until a suitable bone marrow donor was found.

11. After her diagnosis and during her initial stay in hospital, D3 had quite a few blood transfusions. After this, she would have at least a monthly transfusion but as her disease progressed it became more like weekly. When D3 eventually came home from the hospital, what she could do was very limited. She was wrapped in a blanket by her mother and I. We had to be careful about how she played to avoid her getting hurt. Her schooling was also interrupted. It was a difficult time as we had to focus so much on D3 care, but we also had 2 other children to take care of.

12. When we learned that a bone marrow transplant was D3 best option, we joined the Anthony Nolan Trust in order to try and find D3 a donor. We were involved in a significant amount of campaigning on D3 behalf, encouraging people to get tested to see if they were a match for D3 All of our family and friends got tested, even family members in America. Sadly, as mentioned none of them were a match.

13. Around this time, the GRO-A became involved in the Anthony Nolan Trust and campaigned on their behalf, as his father had been diagnosed with aplastic anaemia and required a bone marrow donation. I can also recall D3, the father of a little girl who also needed to find a bone marrow donor, became quite involved with campaigning at this time too. He owned a car firm in Birmingham. We started the GRO-B GRO-B to get people to sign up as donors. We really went to great lengths to find D3 a donor over the years. You don't know what you are capable of and the rate at which you can drive yourself until the life of your child is at risk.

14. A couple of years after D3 had started to have regular blood transfusions, when she was about 5 or 6 years old, D3 and I noticed that she had a yellowish tint to her eyes. We took her to the hospital and the doctors said her liver was enlarged. D3 stayed in hospital while the doctors ran further tests, and during this time her body seemed to swell up. Eventually, they diagnosed D3 with HCV. We were devastated that she had another serious infection to cope with.

15. At the time we did not know how D3 had come to be infected with HCV. D3 had heard it was an infection that people working in places like sewers became infected with, and we just didn't understand how a little girl like D3 could have become contracted it. We did ask the doctors how she would have got it, but at the time they would not give anything away. We could never get a straight answer to the questions we posed to them.

16. Eventually, we saw that many of the haemophiliacs being treated at GRO-B alongside D3 had also become infected with bloodborne diseases such as HIV and HCV. This was also the case for other children like D3 who were receiving blood regularly, and slowly but surely everyone started to connect the dots.

17. We found out that a lot of the blood being given to the children was unscreened blood from America and it often contained HIV or HCV. We realised that the

government was trying to cover up the fact that this had happened. I don't know why the UK was not producing enough blood products domestically and why they were not screening blood. We should have had the facilities to do this.

18. We were not given any warnings that there was any risk of infection with the platelets and whole blood D3 was receiving. This was categorically never discussed with us. We were told this was the only option available to D3 and although we were consulted about her care, we were lay people and could never have envisaged this could happen to her.

19. D3 said that as Jehovah's Witnesses do not allow blood transfusions as part of their faith, they were given a form of synthetic blood. She said that if she had known the blood was infected she would have tried to get D3 something like that. We should have been made aware of the risks associated with the blood D3 was receiving so we could have made more informed decisions about her care.

20. We were never advised to be tested for HCV nor that D3 sisters should be and we were not told that we would have to inform the Anthony Nolan Trust or any other medical professional we were dealing with, about D3 HCV diagnosis. There was very little information and support provided to us in relation to this diagnosis.

Section 3. Other Infections

21. As far as I am aware D3 was only infected with HCV as a result of the blood products she received. She had her blood tested regularly, but there was no mention of D3 having an HIV test so I am not sure if she was tested for this. If she was, we were never informed of this.

Section 4. Consent

22. Although Dr EW discussed D3 care with EW and I, and we consented to her platelet and blood transfusions, we were not made aware of any risk of infections that could result from these transfusions and we were simply told this was the only option for her. I do not believe we were ever asked to sign any consent forms and it just involved a discussion with Dr D3.

23. When she was diagnosed with HCV it was a massive shock for us as there was never any mention that her blood was being specifically tested for this or any other virus.

24. I felt that some of the drugs being used on D3 were a bit experimental. Some of the drugs were not even approved officially but were still being used. I remember that some of the steroids they tried using on D3 made her very bloated and her face looked like a moon face, all cratered. They said they were trying to get her platelets working again and it was something that was given to haemophiliacs, but it felt like they were just trying things without being sure of the outcome. Having said that, I would have been willing to try anything to give D3 a better chance at life.

Section 5. Impact

25. Finding out that D3 had HCV was devastating. It felt like an anchor was strapped to my ankles and I had been thrown out of a boat. I honestly did not know what to do or how to handle the situation. I felt life draining out of me. EW and I felt terrible - our world completely fell apart. We started to distance ourselves from others. I felt like I was responsible for what had happened as I agreed to her treatment and I had not done enough to protect her. She was only about 6 years old at the time.

26. Aplastic anaemia had already felt like a death sentence for D3, but we knew that if we found a suitable donor her condition could improve. With HCV it felt

like there was no possible cure. Nothing was ever mentioned about HCV treatment and it was something she was just living with.

27. We were not told that the HCV would affect D3 ability to get a bone marrow transplant, and we continued to look for a donor. I think if we had found a donor for D3 she would have gone ahead with this transplant. D3 still required regular hospital visits for blood and platelet transfusions and EW had to stay with her. At one point, we thought that EW nephew might be a bone marrow match for D3, but in the end, it turned out he was not sufficiently compatible and the components that did not match with D3 could not be corrected by drugs. It is heart-breaking to have that small glimmer of hope which you cling to and then it is cruelly snatched away and you are back to square one. It really told mentally on both EW and I but we had to keep going for D3 sake.

28. EW eventually had to give up work completely to take care of D3 as she had been having to take so much time off. She had been working as a district nurse and she would keep D3 sleeping in the car while she went in to take care of the patient. She would come out to check on her regularly but this was difficult to do and was also not fair or safe for D3 We also become worried about the risk of EW picking up an infection from one of her patients and passing it onto D3 with her immune system now compromised.

29. When EW stopped working, this meant a big drop in our household income. We received no government support and I became the sole breadwinner for our family. We had a mortgage and I had to keep the bills paid, so I ended up doing quite a bit of overtime and worked long hours. This meant I had less time to spend with D3 and the rest of the family. I was also worried about passing on an infection to D3 so I would wash and change my clothes before I saw her.

30. There was a lot of responsibility placed on our eldest daughter D1 around this time, as she was 11 years older than D3 and 10 years older than our daughter D2 Due to this age difference, she often had to take care of D2 and prepare meals for the family if EW was at the hospital with D3 and I

was working. She grew up very quickly as a result of this. It was an awful time and there was a lot of pressure on D1 whilst both D2 and D1 lost out on spending quality time with EW and I. They both really suffered and I felt guilty all the time that I could not give the other children what they needed. I was there to provide financially and I could show my love but I could not provide them with the attention that all children require from a parent. Even now, I think D1 feels like I owe her something as I didn't give her that attention when she was growing up.

31. As D3 was so unwell, she had almost no schooling and was eventually home schooled. Her education was really impacted as well as her ability to spend time with other children of her own age. We were always worried that she would pick up an infection or receive an knock that could cause her health to deteriorate, so home schooling was a better option for D3

32. As D3 HCV progressed, her body changed and her abdomen became very noticeably swollen. They continued to do blood tests on D3 but there was still no mention of any HCV treatment from Dr D3. He continued to oversee D3 care as her consultant, although day to day she would see a number of different doctors.

33. EW and I became desperate to help D3 recover and EW even rushed down to the GRO-B with D3 when she heard there was a faith healer there one day. He had prayed over D3 with other people and EW thought D3 was healed. We were desperate and tried everything that we could at the time. The search for a donor compatible with D3 continued relentlessly and I lost count of the number of appeals we took part in.

34. Sometime in May 1998, D3 condition deteriorated significantly and she was often unresponsive. She was attached to a lot of machines around this time and Dr D3 said that these were helping to keep her alive. We were told that there was nothing more they could do to help her, which was devastating. I remember realising I was going to lose my daughter. D3 was often fed up

with being in hospital and just wanted to go home, but the doctors advised that she should stay in hospital due to her condition.

35. D3 passed away on GRO-B 1998 in EW arms. She was just 13 years old at the time. She had been in quite a lot of pain and she stopped breathing. We later found out that D3 had suffered a brain haemorrhage at this time. Her death certificate listed intracranial haemorrhage and aplastic anaemia as her causes of death. It did not mention the HCV and liver damage she had suffered. **(See Exhibit WITN5329001)**

36. There was no problem with releasing D3 body for the funeral and the undertaker did not create any problems even after we had informed him of the HCV infection. I couldn't believe that over 400 people came to D3 funeral. She had become a bit of a celebrity through all the campaigns we organized to find her a bone marrow donor. Students from her school were all standing outside as we drove past on the way to the funeral. It was all very emotional.

37. D3 death was crippling for myself and our family. I felt that the system had failed me and as a result, my daughter was gone. I didn't understand most of the medical jargon the doctors would use about D3 care and I felt like I was never in control of the situation. Although EW tried to explain things to me in layman's terms, I never fully understood what was going on and this was very difficult for me. I felt like I should have done more to protect D3 but at the same time I had no idea what I could do.

38. I know that HCV definitely sped up D3 demise. Once her liver started to deteriorate, that is what killed her in the end. She may have eventually died as a result of the aplastic anaemia, but she still had a chance at life until she became infected with the HCV. Eventually, time ran out for GRO-B and she just became too poorly to have a bone marrow transplant, even if a donor had become available.

39. I fell into depression after D3 died. Once again, I felt like I had been thrown off a boat with an anchor tied to my legs, with one arm up waving for help. The

management where I worked was helpful during this time, but I quickly threw myself back into work and took on a lot of extra work to keep myself busy. I was drinking 3 bottles of scotch and smoking 30 cigars a day to deal with the trauma of D3 death. I didn't seek any medical help and was never prescribed antidepressants, but this was how I self-medicated.

40. I just did not understand how the government could have been so underhanded with other people's lives. They knew the blood was contaminated but gave it to our children anyway. Both children and adults were dying all the time as a result of these blood related infections. I just felt like we had been completely let down and this was difficult to cope with.

41. EW became very depressed after D3 death and she was placed on medication by her doctor including antidepressants and Valium. However, she felt that this medication just masked how she was feeling. There was no psychological support offered to EW or I, and we relied on family support to get through this period. Our extended family were all deeply affected by D3 death, but as she had been ill for so long I think to an extent it had become expected and they could eventually accept what had happened.

42. Our second daughter D2 was very badly affected by D3 death. There was only 9 months between them and she felt D3 loss acutely and still feels it today. She always used to say D3 was her best friend and soulmate and after she died she felt lost. How did you explain the loss of a child to their young sibling? Sure, you can talk about the illness but when they are gone how do you console the sister left behind?

43. Our eldest daughter D1 was also devastated by D3 death, but as she was grown up when D3 died, she has come to accept it more. She understood what was happening a bit better. D3 would always go to D3 if she needed something and they were very close, with more of a mother-daughter relationship than sisters. However, you can either let these things consume you or you can move on, and thankfully D1 was able to move on with her life although she still misses D3

44. I am a catholic and D3 death really shook my faith. I wondered if there is a God up there looking down on us. I wanted to know if I had done something wrong to deserve what had happened to D3 and our family. I would look up various bible quotations to try and make sense of what was happening, when I felt like I was drowning.

45. EW faith was also affected at the time and she did not want to believe anymore. She had been brought up within a Christian church community, but she questioned why God would take away a child. In desperation for answers she went to a clairvoyant in GRO-B who told her that D3 was in heaven with her grandmother and that she still loves animals and takes care of them. She also had a dream of EW telling her that she cannot get her wings because EW wouldn't let her go. She went to Church and was prayed for, and eventually returned to her church community.

46. What happened with EW had a major impact on our marriage. We were constantly under a huge amount of strain, and I recall Dr EW saying to EW and I that these kinds of situations can make or break a relationship. It is difficult to survive as a couple when you have gone through such significant trauma.

47. After D3 died, I prayed that our family would remain close but it was too difficult. I didn't have any psychological support or counselling and could only cope with the situation by keeping myself busy. There was nowhere to turn to for help. I hated to come home to a life without D3 and I preferred to stay at work. I felt like I had failed our family by not being able to save D3 I was consumed by guilt and my self-recriminations now realise that this pushed EW and the family away – although that was never the intention.

48. After D3 death, I was often working away from home including overseas trips and I had very little communication with EW about how we were both feeling. We blamed ourselves and each other for what had happened and it was a terrible period. Eventually, we drifted apart and EW took the girls and

moved to Kent. This was a catastrophic, on top of what had already happened, as I had lost my happy marriage and family. We had everything we could have wanted until D3 fell ill and I felt like I had lost everything. I was unable to see the girls as much as I would have wanted after this move, and this affected our relationship long term. EW herself now lives in America but we are on speaking terms.

49. D3 and our family did not really suffer from any stigma in relation to her HCV diagnosis. A lot of people still went and got themselves tested to see if they could be a bone marrow donor for D3 through Anthony Nolan. We were able to drum up a lot of support and helped many other people find bone marrow donor matches, even if we never found a donor for D3 and there is a lot of satisfaction - and pride that that was the case.

Section 6. Treatment/Care/Support

50. As discussed above, D3 required various blood transfusions in order to manage her aplastic anaemia, and she continued to have these throughout her life. We knew we had to find a bone marrow donor to have any chance at curing D3 condition, but we were unable to find one before time sadly ran out, in part due to her HCV infection.

51. There was never any treatment suggested for D3 HCV. They did various blood tests on her but we were not given much information about this. I don't know if there was any HCV treatment available at this time.

52. D3 and our family were never offered any counselling or other form of psychological support in order to cope with D3 HCV diagnosis and deteriorating health. After D3 death, we were never offered any support to help cope with this major loss.

Section 7. Financial Assistance

53. I believe EW learned about the Skipton Fund through a social worker at the hospital and she applied for this financial assistance in May 2017. She filled out various forms and informed them that although we were now divorced, I should receive half of the payment as D3 father. In September 2017 we were paid £10,000 each as part of the stage 1 payment from the Skipton Fund. We did not have to sign any conditions or waivers when we received this money.

54. As D3 death was a result of the HCV infection and she had cirrhosis of the liver, we were under the assumption that we would qualify for the stage 2 payment from the Skipton Fund. However, they used some technicality to say we would not qualify for it. I spoke to Nick Fish at the Skipton Fund and pursued this further, but he still said we don't qualify for this. I had even sent medical letters from the hospital over to the Skipton Fund, but this didn't make a difference. I sent the Fund a letter asking for an explanation for this decision, but I never heard anything further.

55. More recently, I received a letter from the English Infected Blood Support Scheme (EIBSS) dated 21 July 2021 saying I was entitled to a further payment in relation to D3 death. (**See Exhibit WITN5329003**) When I contacted them to enquire further about this, I was told that this letter was sent out by mistake and I would not receive any further payment.

56. This seems very unfair and I will be getting in contact with EIBSS to pursue this matter further. EW may have some of D3 medical notes and if necessary, I will apply for the rest of the notes. My main hope is that this will demonstrate the extent of the liver damage D3 suffered as a result of the HCV and how this must have contributed to her subsequent death.

Section 8. Other Issues

57. I feel that the NHS has failed us. As a person who did not understand medical terminology, nothing was ever put to me in layperson terms. I was never told

that the whole blood and plasma D3 was being given was unfiltered. If I had been more aware of the risks, I would have questioned the source of the blood given to D3 and that may have allowed her to live a longer life.

58. D3 death has really damaged my life. I am is not where I want to be or should be. I had a great family and great wife before this happened. I have felt responsible for D3 death all these years even though it is the Government who is truly responsible. The Government is a pack of liars and they caused the death of so many people, including children. Still to this day you cannot donate blood if you had a blood transfusion in the 1980's – to me such a ruling is a damming indictment and just shows the extent to which those in power then and now, must have been aware and to my mind the Government is still hiding something.

GRO-B

GRO-B

Statement of Truth

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

Signed GRO-B

Dated 29/11/2021