Witness Name: GRO-B
Statement No: WITN7262001
Exhibits: nil
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 30 September 2022.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1969 and my full address is known to the Inquiry. I live with my partner; I have four children and five (soon to be six) grandchildren. My partner and I are not in great health, and up until August 2022, I cared for my mum and for many years this has been my full-time role.

2. I intend to speak about my late brother GRO-B: B, who was born on GRO-B 1970 and sadly passed away at the age of 28. He was infected with Hepatitis C ("HCV"), as a result of receiving contaminated blood products to treat haemophilia. In particular, I will describe how he had learnt about his infection, how his illness had affected him, me and our family thereafter.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I wish to be anonymous.

4. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates. I have constructed this statement without access to my brother's medical records.

5. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I am providing this statement on behalf of and in memory of my late mum.

Section 2. How Affected

7. B had severe Haemophilia A, with zero per cent Factor VIII – one of the worst cases in the country. Given the fact that his haemophilia was very severe, I presume he was diagnosed at a very young age, but I was only a child myself and was never told exactly when the diagnosis occurred.

8. B attended GRO-B and then Bristol Royal Infirmary from the age of fourteen.

9. Initially B was treated with cryoprecipitate but this was changed to Factor VIII between the age of seven to eight. I am sure my mother was told that it was cheaper and easier to get hold of and was given no choice over what treatment B received.

10. Due to the severity of his bleeding disorder, B would spontaneously haemorrhage and as a result he required multiple injections of Factor VIII every

day – they were almost constant. He self-administered some of the injections, or myself, or our mum would administer them.

11. I was shown how to administer the blood by the nurse at age nine and I recall it being drummed into me to ensure that there were no air bubbles in the syringe or B would have a heart attack. This was very frightening and put a lot of pressure on me as a young child.

12. We were given a sharps box, which we put at the back of the living room and I was in charge of putting everything in there once it had been used. I had a few needlestick injuries, but I do not think that contracted an infection. Mum did not drive, so we would travel to town by bus and then walk about 45 minutes to take the sharps box back to the GRO-B hospital – which was at the top of one of the steepest hills in Bristol. We would get some funny looks from others on the bus, so we opted to line the used sharps boxes in rows rather than making regular trips on public transport. This was the only reason we would visit the hospital and we would not visit for HCV or haemophilia appointments. B did not have any appointments that I can recall, even though he was living with haemophilia and HCV.

13. Aside from the haemophilia, B was a very happy and bonny child. He could not participate in sports because of the haemophilia, but he loved watching television programmes and the early versions of computer games. Mum was a single parent, so B and I were very close – there is not a photograph from our childhood where our arms are not around each other.

14. Around the age of ten, B started to become unwell and we were called to the hospital at some point where we were told that one of his blood tests had come back positive for HCV. Everything was very matter of fact – we were given the diagnosis and that was it. No information regarding the virus or infection management was provided, all we were told was that in the best-case scenario, B could expect to live until the age of thirty, but he would endure a terrible time at the end. It was very harsh how everything was delivered to us. We

presume B would have been infected shortly after switching to Factor VIII concentrate, given the volume that he was receiving.

15. No specialist referrals were made after the diagnosis and no offer of HCV treatment was made – we were simply told to make the most of the time we had. Blood tests were carried out every now and again to monitor B's Factor VIII levels but as far as we knew, this was all that was being checked.

16. Further to this, no support or follow up appointments were made in relation to the HCV.

Section 3. Other Infections.

17. Other than HCV, I am not aware that my brother had contracted any other infections as a result of receiving contaminated blood as treatment for his haemophilia.

18. I do not know whether B was ever screened for HIV.

Section 4. Consent

19. My mother was not given full and adequate information when B's treatment changed from cryoprecipitate to Factor VIII – there was no option for him to continue on cryoprecipitate and at the time, no one ever questioned the decision of a doctor, especially Mum, who was a very timid and trusting lady.

20. Since everything about the contaminated blood scandal has come out, I do strongly believe that B was tested without consent for the purposes of research.

Section 5. Impact.

21. B became very very depressed after his HCV diagnosis, as it was made extremely clear it would be a rarity for him to reach the age of thirty – this was crushing and he felt as though his life was over.

22. Mum also went into a downward spiral after the diagnosis and had a nervous breakdown. We were a single parent family and so in order to support the family, at around nine years old, I ended up taking on a job at the local garage, cleaning cars before and after school, so that I could help pay the household bills. I ended up taking over all of the financial matters as Mum struggled to cope.

23. My mother was instructed by the hospital that she had to inform the school about B s HCV positive status. Unsurprisingly, this information did not remain private and other pupils came to know about his infection. As a result, B became a social prier – all of his friends bar one became afraid that they would contract the virus and he found schooling very difficult post diagnosis. When his only friend got a girlfriend, he felt guilty and ended up dropping off as well. He loved school – particularly Science, History, Maths and English, but he ended up hating it. He felt so lonely and isolated.

24. The stigma received as a result of his HCV infection was purely within the educational environment, and as a result of what happened at school, Mum did not want anyone else finding out.

25. I took it upon myself to look out for B at school and if he ever felt unwell, I had permission to leave early so that I could take him home.

26. Due to the family situation, I was given permission to sit four of my O-Level examinations two years early at the age of 14, so that I could leave school and provide financial support to the family. B and I were both in the top stream at school and there was an expectation that I would later attend university, but after B s diagnosis with HCV this was no longer possible. I should have

gone back to school to sit another six O-Level exams, but my boss refused to give me the time off work.

27. B s schooling was massively affected by his ill health – he had been expected to take 11 O-Level examinations, but ended up only sitting two and he ended up in an office role after leaving school.

28. B could not receive dental treatment because of his HCV positive status and could only be treated at GRO-B. Due to his severe haemophilia, he had to be on a drip for two weeks after he had an extraction.

29. B had a girlfriend, GRO- during his teenage years and I can only describe her as the love of his life – they completely adored each other. It had always been a desire of my brother to have children – he adored kids and before his schooling was impacted, wanted to become a paediatrician. GRO- came from a big family and that was something they both wanted for themselves. They ended up splitting up when B was 19 because she desperately wanted children and he could not risk infecting her. To B his life was over, but he could not end GRO-s as well.

30. B s depression deepened after the breakdown of his relationship with GRO-B and he stopped eating at the age of 20. We thought it was a phase, but later found out that he had asked someone to end his life for him.

31. Doctors were not that concerned to start with – they shoved it off and remarked that eating disorders only affect teenage girls. B was 6'4, big built and used to lift weights, so in time the weight loss became very noticeable. Only then was he prescribed protein drinks and encouraged to take them. He was not referred for any counselling or psychological support.

32. Around this time I had my first child, who B absolutely adored, but unfortunately this was not enough to rally him. Mum and I tried to convince him to get better for the little ones, so that he could see them grow up, but we could not get through to him and he became weaker and weaker. It was just drummed

into us to get the protein drinks into him, but we were not provided with any support. We used to beg and plead with him, but he was so down. This went on for several years and he ended up passing away in 1999 at the age of 28.

33. B was at home when he passed away and it was a horrible death.

34. I recently found B s death certificate which wrongly detailed that he had Von Willebrand's disease and B had Haemophilia A. Further to this, B s cause of death is stated as being anorexia, cardiac arrest and secondly HCV. Which is incorrect as B died of HCV and the other issues followed.

35. B felt there was nothing at all to live for – he lost GRO- could not have children of his own, was lonely and had a death sentence hanging over him – that he would not live past the age of 30. It was stressed that he would be lucky if he made it to that age and that he would be hospitalised during the horrific end. The way he was told that it would be a slow, painful death felt like they took his life.

36. He never got to see my children grow up or have any children of his own – he loved children so much and would have made the most amazing father as he was so caring and all in all a fantastic person.

37. Mum and I could not afford to pay for the funeral, so had to take out loans to cover the costs.

38. Mum barely coped after B passed away – she gave up completely and her health declined rapidly. She could barely function and was not eating or drinking. I ended up washing, dressing and spoon feeding her every day.

39. I was in the middle of completing an accountancy course when B passed, but I had to stop this once Mum's health declined in order to care for her. My life could have been very different had B not been infected with HCV as both the prospect of attending university and completing a vocational course later in life became impossible.

40. In 2001 Mum was diagnosed with breast cancer, which I am completely convinced was stress related and, in the beginning of 2002, she had a mastectomy, after which she had to keep going back to the hospital for regular checks. By this point she was housebound and very much struggling to cope, so I went round every day to care for her – there was not a single day that I did not see her. I ended up sorting all her household finances because she could not take on any extra stress.

41. Around 8 years later, a lump was found in the other breast and Mum underwent a second mastectomy. Unfortunately the cancer remained in the lymph nodes and spread. In 2014 she was diagnosed with lung cancer – the doctors assumed it had spread from the lymph nodes because it was very close. She was given a prognosis of 3 months, but kept on because she wanted to see justice for B She was trying to hold on because she wanted someone to admit that the contaminated blood scandal should have never happened.

42. In 2016/17 the doctors said they must have diagnosed her in error, but she soon declined in health and eventually succumbed to the cancer in August 2022.

43. I have not been able to function since Mum died – for many years I cared for her every day and she is still not cremated because I cannot afford the fees associated with a funeral. I feel that it is so unfair that I am unable to do this.

44. Mum and I have spent our entire lives feeling guilty that it did not happen to us. To this day, both of us felt that it should not have been B who contracted HCV and died so young. It was not fair that we both survive and he did not – I have always felt that it should have been me.

45. Mum was adamant that she wanted B s story to be known, hence why I have submitted a written statement to the Inquiry.

46. I strongly believe that my mum contracted HCV from B as when she passed away, she was bright yellow and her only complaint was pain in her side, which

I believe was her liver. At the time, I had assumed part of the blood testing would have included a HCV test, however, I have recently found that a HCV test would not have been included in standard blood testing.

47. I have never been HCV tested even though I had needle stick injuries when administering blood products to B I have recently requested a HCV test from my GP but they have refused. I am currently speaking with the Hepatitis C Trust and they are helping me to obtain a test.

Section 6. Treatment/Care/Support

48. B was never referred to hepatology as a result of his HCV infection and no follow up appointments were ever made. We just went to the hospital to pick up treatment from the Haemophilia Centre and to return sharps. We were completely left alone and not offered any form of counselling or psychological support.

49. Our lives would have been completely different if HCV treatment as well as psychological support had been offered. B and Mum may still be here today. He just did not want to experience the horror story they said he would have to endure towards the end of his life – perhaps if he had counselling this may have been different. After being told to enjoy what he had left and that he would not be able to have a family of his own, he felt completely written off by the medical profession.

Section 7. Financial Assistance

50. No medical professional ever informed us that we would qualify for financial assistance as a result of B s infection with HCV. This is why I left school and went into full time employment at the age of 14 because my mum was struggling with finances. Even when I had my own family, I had to help her out.

51. The Inquiry Investigator has made me aware of the English Infected Blood Support Scheme (EIBSS) during my statement interview and this was the first time that I became aware of financial support.

52. I have since tried to apply for EIBSS financial assistance. My mother has passed away and so I am the closest person to my brother. As mentioned, I regularly administered blood products to my brother, I also began working at nine years old to support the family and then left school two years early to work full time to support our single parent family. I also experienced needle stick injuries. However, I am told that I am not eligible to receive financial assistance.

Section 8. Other Issues

53. The contaminated blood scandal has taken away so many people's lives, even those who were not infected – Mum pretty much stopped living the day B was diagnosed with HCV.

54. Someone needs to take full responsibility for what is happened and those affected should be properly compensated.

Statement of Truth

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

Signed GRO-B

Dated 07/12/22