Witness Name: GRO-B

Statement No.: WITN10500001

Exhibits: WITN1050002 – WITN1050005

Dated: October 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 My date of birth is GRO-B 1948 and my address is GRO-B I am married and have four children, two daughters and two sons.

2. I have been a registered nurse, midwife and health visitor for 54 years and retired July 2016.

Section 2: How Affected

3. As mentioned above, I have two daughters, who were born in 1975 and 1977. Both are happy and well. There was no known history of bleeding disorders in my family. I then lost a child with severe spina bifida and hydrocephalus. My eldest son was born on GRO-B 1984. GRO-B: S1 has severe haemophilia B, less than

1% clotting Factor IX. S1 later contracted Hepatitis C and was exposed to vCJD from contaminated blood products. GRO-B: S2 was born in 1989 and has severe haemophilia B. He may have been exposed to vCJD, as his Factor IX batch numbers were the same as S1 I am providing this statement to the Inquiry to explain the impact of this on our family for 35 years.

4. S1 was a normal delivery at 40 weeks gestation. Within one to two days he had neonatal jaundice that was treated with light therapy successfully. During light therapy he wore elasticated netting with an eye pad. I believe this netting caused S1 to have a dark bruise on his eyelid. Our GP, Dr GRO-B, thought it was a birthmark. This mark became yellow and disappeared after one month. I now know this was the first sign of S1 haemophilia.

5. At eight weeks S1 had a severe ear infection with excessive pain. This resulted in glue ear and some considerable hearing loss for two to three years. On reflection, I now think that he must have had a bled behind his ear. At 24 weeks of age S1 had bruising below both axilla. We had held him under his arms in a babies' class at the swimming pool and could see the marks of our fingers the next day. Our concerns were taken to a locum GP, who arranged a full blood count. These were normal but S1 clotting factor was not checked at this time. The full blood count ruled out leukemia and liver disease. My husband and I were very anxious about the prospect of liver disease as my husband's brother had died at 12 years old from severe liver disease.

6. Two weeks later, at six months old, S1 sustained a haematoma on his head; he had leaned to the side of his wooden high chair. With a nursing colleague for support we saw GP, Dr GRO-B at 12.30pm on 12 September 1984. She referred us urgently to Dr GRO-B paediatrician at GRO-B Hospital ("GRO-B") at 2.00pm. After the consultation, Dr GRO-B rang me at home at 5.00pm with S1 diagnosis of haemophilia. He said that the type and severity of would be looked at the following week.

7. Following diagnosis, we were referred to GRO-B Haemophilia Centre. Dr GRO-B Haematologist, confirmed S1 diagnosis as being severe haemophilia B less than 1%, on 19 September 1984.

8. Dr GRO-B was very helpful and gave us information about haemophilia. He advised us that clotting Factor IX was available for treating bleeding episodes as they occurred. We were reassured and given information. We were told that we would have 24 hour a day advice from the Haemophilia Centre and were given the contact details for this. We were also given the contact details of The Haemophilia Society ("The Society").

9. This was an emotional time for us to cope with a serious diagnosis but we were relieved it was not leukaemia or liver disease. My husband was still grieving for his mother who had died six weeks before and still had great anxiety and grief about the loss of his brother in childhood. We were both still grieving for the loss of our baby daughter with spina bifida and hydrocephalus, late in pregnancy in 1983.

10. A week after diagnosis, S1 had a large abdominal bruise appear overnight. He had been possibly leaning forward in his baby relax chair the day before, causing pressure on his abdomen. We contacted Dr GRO-B and were seen immediately at GRO-B hospital, 25 miles from home. Dr GRO-B recommended Factor IX treatment intravenously. Dr GRO-B warned us of the risk of contracting mild Hepatitis. He said that symptoms were normally mild and nothing to be worried about. I recall Dr GRO-B saying Hepatitis was a transient virus and it would come and go. Being reassured by this, I did not think there was an issue with S1 being given Factor IX for his treatment for haemophilia. I was not given information about any risk of HIV. Venous access was difficult on a baby but I came away thinking S1 had had the best treatment for his abdominal bleed.

11. In November 1984 and throughout 1985, I started seeing press reports about the risk of contracting HIV from blood and hence the possibility of contracting it from blood products that were made from pooled blood plasma from numerous donors. I was deeply concerned about this and spoke to Dr GRO-B at GRO-B Haemophilia Centre. Dr GRO-B was very open and recommended that I should always refuse imported blood products and instead only give permission for S1 to be treated with British blood products. I put this advice into practice on several occasions particularly when we were being treated at other Haemophilia Centres in the UK, namely Newcastle, Barnstable, Dundee, Truro, and Nottingham, when on holiday or at Haemophilia conferences.

12. The focus in the media of the time was definitely about contracting HIV rather than other viruses such as Hepatitis. Heat treated products were already being given to patients in Scotland and had been for many months. During February 1985 we wrote to our MP GRO-B and Prime Minister Margaret Thatcher. They forwarded the letter to The Department of Health and we had a reply from Lady Trumpington on 17 April 1985 (WITN1050002). We were receiving constant support from The Society who were campaigning for heat treated products to be brought in. It encouraged its members to write to ministers.

13. I am aware that between the age of six months and twenty-three months, S1 had seven treatments of non-heat treated Factor IX given at GRO-B Haemophilia Centre or by Dr GRO-B at GRO-B It had been arranged that we could go to GRO-B for emergency treatment due to the fact that it was closer to home. This would be after calling the Haemophilia Centre to obtain the correct advice.

14. The last dose of non-heat treated factor that S1 received was given in February 1986 at GRO-B S1 venous access was appalling and IVs failed seven times. Dr GRO-B finally gave the injection into a vessel in his groin with five members of the nursing staff holding him down whilst S1 protested

loudly. This was a traumatic experience. Due to this bad experience and my concerns regarding HIV, we tried to only treat the most serious of bleeds; always, seeking advice from the Haemophilia Centre as appropriate. Hence, we avoided further non-heated products for several months.

15. I recall at the end of February 1986 S1 started passing pure white stools for several weeks. This was documented by Dr GRO-B. He was unsettled, tired and not himself. Retrospectively we know this may have been a response to initial infection with Hepatitis C, then known as Non A Non B Hepatitis ("NANB Hepatitis").

16. S1 commenced heated treated Factor 9, Replinine, made by BPL, Elstree, in the summer of 1986. S1 will be able to confirm the exact date of this, based on a review of his medical records.

17. I recall S1 almost being three years old when he was tested for HIV. S1 will be able to confirm the date from his medical records. Thankfully the tests were negative. We received counselling from the Haemophilia Centre before and after the tests. This was a massive relief. We agreed to ongoing testing every six months with routine blood tests.

18. I recall it was 14 October 1987 when S1 was unwell and had a high white blood cell count. Coincidently this was just after his second MMR vaccine. Dr GRO-B felt he was showing signs of NANB Hepatitis. Dr GRO-B reassured us there was nothing to worry about.

19. We received reassurances from Dr GRO-B again on 12 October 1988, following S1 receiving treatment for a bleed on the right side of his abdomen. He said NANB Hepatitis may clear itself.

20. S1 continued to be treated on demand therapy at GRO-B Haemophilia Centre with Replinine. In early 1989 soon after the birth of S1 baby brother, S2 we started to prepare for home treatment. Excellent training was given by Sister GRO-B Haemophilia Nurse. I was already trained in intravenous therapy in previous nursing work; yet, it needed some emotional energy to treat your own five year old child with large intravenous injections that needed to be given slowly. S1 venous access remained poor. Dr GRO-B and Dr GRO-B were supportive.

21. On 12 May 1993 S1 aged nine, was diagnosed with Hepatitis Cat a routine clinic appointment. I cannot recall being advised that any specific testing was being done for Hepatitis C but was aware S1 had six monthly blood tests for liver function, HIV and factor levels. I always asked for results in each clinic. Even when S1 was diagnosed with Hepatitis C, there did not appear to be any great concern that S1 had contracted this through contaminated blood products. It was presented in a very casual way, as if to just let you know it is now called Hepatitis C instead of NANB Hepatitis.

22. On 7 April, 1995 a liver scan was discussed by Dr GRO-B in clinic. It appeared normal. Further Hepatitis tests were done with my consent. Genotyping of Hepatitis C was done on 12 May 1995. No results were given and the significance of this was not disclosed to us. Only in adulthood, at the age of 21, did S1 find out that he was Genotype 1, which is the most difficult to clear.

Section 3: Other Infections

23. S1 has remained negative for HIV.

24. S1 has received two notifications of having received blood products in January 2001 and September 2004. The Society had sent information letters to its members in advance of the notifications being issued by the hospital

(WITN1050003). I was a GRO-B of The Society at that time and will provide a separate statement to the Inquiry in relation to my role.

25. In 2001, I was expecting a call from GRO-B Haemophilia Centre regarding vCJD notifications, due to the information which had been provided by The Society. At 5.30pm in the evening of the day on which I was expecting the call, Dr GRO-B rang and told me about haemophiliacs receiving blood from a donor who had later died of VCJD. He asked if we and S1 wanted to know if S1 had been treated with Factor which contained blood from this donor or not. I declined as I knew there was nothing you could do about it once you had vCJD. I was told there were five other families affected in the GRO-B area. I was invited into the hospital to discuss any concerns; I did not take up this invitation.

26. This was a horrendous time because S1 was suffering from a severe hip bleed and I was also managing with my younger son S2 treatment for haemophilia. I recall there being a lot in the press about vCJD and everyone within the haemophilia community was worried and expected to receive a vCJD notification.

27. In 2004 S1 received a second vCJD notification.

28. It was a personal decision of mine, not to know definitely about vCJD. I understand that S1 might have obtained the information about a year after the second vCJD notification. This knowledge has affected how he receives care in hospital. His notes are labelled "high infection risk" and his procedures are undertaken after all other patients have been treated.

29. S2 was left to make his own decision about vCJD notification after the age of consent at 16, if he wished. We would always be supportive if he wished to find out.

Section 4: Consent

30. As mentioned above, S1 was diagnosed with Hepatitis C in May 1993 at a routine clinic appointment. Whilst I was not aware of any specific testing for Hepatitis C being conducted on S1 I knew the test was to be introduced due to information provided by The Haemophilia Society. I knew LFTs and factor levels were routinely tested at each clinic, which took place six monthly or as required. I always asked for results to be explained. I did give specific consent for HIV testing.

31. As a nurse I knew the NHS used to store some blood and sometimes organs as a matter of routine.

Section 5: Impact

Impact of fear and stigma in relation to HIV

32. I was very fearful about HIV from blood products. HIV testing did not become available for many months after the press reports began circulating in November 1984. However, haemophiliacs were now dying in the UK, as well as America, from HIV. We had to live for a long time not knowing whether S1 had contracted HIV. There was media frenzy regarding HIV at the time. I understand that The Society has made contemporaneous press reports available to the Inquiry.

33. I had a huge fear I was going to lose another child; this affected my emotional health. Dr GRO-B was incredibly supportive. All I could plan was another child, just in case. There was a 75% chance it would not have haemophilia and even if it did the treatment was now more safe from viruses. We had waited 14 years in our marriage for a son. However, I had two further miscarriages.

34. I was still working and coping as a parent but I was distraught by the thought of losing S1 I developed a full body, red rash, as did S1 I was scared that this was linked to HIV but the dermatologist that I saw believed this was triggered by anxiety. My husband required treatment for GRO-B and GRO-B relating to his concerns about S1 being infected with HIV, the shock of his mother's early death and loss of his brother in childhood.

35. There was a huge stigma regarding HIV and this prevented any discussion regarding S1 well-being with anyone, other than immediate family and those closest to us. People who were infected were having graffiti put on their houses and we did not know if S1 had HIV or not. I was however able to speak to my best friend who was also a nurse and was very supportive.

36. I took all the precautions in the home in relation to infection control. My amazing childminder was aware too. She attended an informal support group for childminders and was supervised by a social worker. The social worker tried to discuss S1 potential HIV status at a group meeting. I complained about this social worker to Children's Services on the grounds of breach of confidence and raising of hysteria in our small local rural community.

37. On another occasion, the play group leader who led the local playgroup in GRO-B refused to admit S1 at the age of three due to the HIV risk associated with S1 having a bleeding disorder. I fully discussed infection control with her but she said it was not acceptable to other parents. After S1 test result was negative for HIV, he was accepted into the playgroup in GRO-B The Haemophilia Centre advised them about the normal infection control procedures for all children.

38. I was a GRO-B nurse, health visitor, and very aware of professional concerns about HIV and other viruses. I became involved in teaching the public and school children about the HIV campaign and safe sex.

Impact of Hepatitis C and the subsequent treatment

39. On 10 October 1995, following his diagnosis with Hepatitis C and initial scan, S1 had elevated LFTs and as a result Dr GRO-B recommended further liver scans. S1 had a liver scan on 4 December 1995 at GRO-B Hospital under the care of Dr GRO-B His LFT results appeared normal by this time and there were no issues with his blood. We were however advised S1 may need Interferon therapy over six months to try and clear the Hepatitis C. This was to be discussed with Sheffield regional Haemophilia Centre. We were given the general risk warnings about potential side effects of Interferon I have exhibited the information sheet that we received from the hospital with this statement (WITN1050004).

40. I recall being told that Interferon was the only drug for the treatment of Hepatitis C at the time. It would be given subcutaneously into his abdomen in the evening three times a week. Whilst Dr GRO-B was honest and said he was not too optimistic. With limited success rate of the treatment, it was the only one available. S1 was also struggling with severe pain in his ankle as bleeds had caused avascular necrosis and his ankle joint had died. As a result he was put in a calliper for a year. So there was lots of emotional impact for him in his first year in a new grammar school.

41. At this time, I attended a study day organised by The Society where consultants started to suggest that Hepatitis C may progress to become liver disease over 30 years or more. A research report was prepared by Mandy Cheetham in relation to Haemophilia and Hepatitis C (WITN1050005). Mandy Cheetham and John

Morris, the viral support workers employed by The Society, were incredibly supportive to families.

42. On 27 October 1995 S1 commenced Interferon therapy of three million units subcutaneously. He had a significant reaction of shivering, severe headaches and felt very unwell. After contacting the hospital, the dosage was reduced. Paracetamol made little difference to the side effects that S1 was experiencing, which were more severe than expected.

43. It was a very tough time for an eleven year old as he continued his treatment without missing a dose. The main side effects of Interferon were ongoing headaches, chest pain, skin infections and lethargy. He was visibly tired all the time and this affected his mood. S1 became grumpy and this had significant implications for his progress in a grammar school. He had entered with a very high admission score and it was sad to see him not achieving his potential.

44. In 1996 after Interferon therapy, we were told S1 viral load was down but the Hepatitis C had not been cleared. There was no other treatment available and we were told we would have to wait for a new treatment to be developed. This was difficult to accept, particularly as S1 was now to be prone to all infections as a result of Interferon (and later Ribavirin) therapy.

45. On 19 March 1999 S1 started receiving recombinant blood products, Benefix Factor 9. This occurred because during March 1999 he started on a trial of new heat treated Factor. He was given his first dose at GRO-B Haemophilia Centre. I looked at the box which showed it was American factor 9 blood product. I immediately complained as we had never given consent for American products to be used. S1 was withdrawn from the trial of the new blood product and Dr GRO-B commenced him on Recombinant Factor 9 for the home treatment of bleeding disorders.

46. Whilst S1 got relatively mediocre results from school, I feel like he would have got much better results had his education not been impacted by Hepatitis C and the subsequent Interferon treatment.

47. S1 was not accepted for sixth form in his school, GRO-B He went in for two days in school in September 2000, already on crutches, again with a bleed, and at an interview they told him he was not a grammar school potential now, in spite of having enough GCSE to be accepted. After the interview he sat on a wall outside as he was only able to walk a few yards. He waited for me to collect him and find another school during that day.

48. S1 commenced studying at the University of GRO-B in September 2002. He moved into Halls of Residence and lived independently; it was 130 miles from home. Fortunately, he had a Motability car to access treatment and care in an emergency locally but he remained in the care of GRO-B Haemophilia Centre. During 2004 and 2005 he was advised to commence further treatment of Hepatitis C with Interferon and Ribavirin orally.

49. Again there were many side effects of the treatment. Again the side effects were skin infections, including MRSA, tiredness and exhaustion and significant depression. S1 failed parts of the early years of his degree and transferred from Aerospace to Sport, leaving with a HND in Sport after five years. His family offered him practical help and continuing emotional support. His partner (who is now his wife), GRO-B became extremely supportive too. He had no loans or grants. He was fully funded by his family and so had no debt.

50. Unfortunately, Interferon and Ribavirin did not successfully clear the Hepatitis C virus. S1 continued to have his struggles with Hepatitis C.

51. S1 immune system was compromised and this continues to be to this day. I recall that in August 2004, we were due to go on holiday and shortly before we

were due to leave S1 had a sore throat and then glandular fever. He saw a GP, who accidently caught his throat with a spatula. Twenty minutes later at home it bled profusely. After treatment he was examined at GRO-B Haemophilia Centre and further blood tests were done. He was given antibiotics and a treatment plan of factor was decided. Over the next 48 hours S1 was very unwell. My husband and younger son left for Scotland with us planning to join when we could by train. Over the next night S1 throat became obstructed by swelling and his breathing was compromised. He was blue lighted by ambulance to GRO-B County Hospital on 4 August 2004, shortly before midnight. He was admitted, given further factor IX and more antibiotics. Four days later, S1 was deteriorating and almost motionless in bed, but the haematologist, Dr Adelman, said he was going on holiday and that S1 had had enough treatment. I was very concerned and stayed with S1 until 11.00pm.

52. After a 50 mile round trip and little sleep I arrived back at 7.00am to see the ENT consultant at 7.45am on 9 August 2004. He said he was very concerned about S1 and he needed a specialist infection unit. He asked me where such a unit could be found together with a comprehensive Haemophilia Centre. I knew Dr Makris, Consultant Haematologist, at Sheffield and had every confidence in his care. Thankfully, it was immediately arranged to transfer S1 as an emergency to Sheffield Hallamshire Hospital. However, the ambulance failed to arrive until 5.54pm in spite of me constantly asking about it. The reason for the delay was S1 had a Hepatitis C infection and the journey had to be made after all other use of the ambulance that day. Dr Makris was furious and stayed most of the night treating S1 with Factor IX, IV antibiotics and cortisone. S1 was in hospital for a further two weeks. His care has since remained with Dr Makris at Sheffield. S1 and his wife, GRO-B will discuss the care provided by Dr Makris in greater detail in their statements.

53. S1 eventually cleared the Hepatitis C virus after 33 years, on 13 July 2017, following a third episode of treatment. I am unsure what this treatment consisted of but it will be discussed by S1 in his statementto the Inquiry.

54. Contaminated blood has been a very traumatic experience for our family. Dealing with haemophilia alone has been difficult enough. The worst time was not knowing for two to three years if S1 had contracted HIV through contaminated blood. This seriously impacted on mine and my husband's mental health. During this time we felt we were about to lose S1 and this influenced our decision to have another child, even after a very difficult obstetric history.

55. My husband worked as an engineer and I was employed part time as a health visitor. We have constantly financially supported S1 and his family until last year.

56. S1 was too unwell to succeed at university and has not been able to work full time due to Hepatitis C and the subsequent treatment. This has had serious financial implications for him and his wife. Until recently he was unable to apply for a mortgage or any life insurance.

Section 6: Treatment/Care/Support

57. As noted above, dealing with Hepatitis C has been really difficult and traumatic. My GPs Dr GRO-B and Dr GRO-B were amazingly supportive. I received counselling in 2000 relation to Hepatitis C, with a psychologist, at Leicester General Hospital. This was arranged through my GPs. This helped me deal with some of the guilt about giving S1 haemophilia and exposing him to contaminated blood.

58. There were no social workers or psychological support available at the hospitals which we were attending for S1 treatment.

59. I feel Dr GRO-B Haematologist, at GRO-B Haemophilia Centre, was not supportive at all times. He advised me at 34 weeks of pregnancy with S2 that I should not have another child. He was antagonistic, asking us to reconsider, as S1 care was complex and expensive. He said it was another one to be looked after. I replied I was capable of caring well for my own children at home and I hoped he would be able to give good medical care if required. There was a 75% chance of the baby not having haemophilia.

60. S2 was born in January 1989 at GRO-B hospital and was diagnosed with severe haemophilia. It was Dr GRO-B who caringly gave me this diagnosis. I left hospital shortly afterwards and cried. My daughters of 12 and 14 years comfortingly said, *"if we can care for one, we can manage two"*. We have been very strong as a family and still continue to be closely supportive to all members.

61. On another occasion Dr GRO-B informed me in the middle of a Paediatric ward that *"my boys are the most accident prone in* GRO-B *and worth more than their weight in gold"*.

62. I received no support in connection with the vCJD notification, but this is likely to be because we declined this information.

63. Dr GRO-B Sister GRO-B and Sister GRO-B from GRO-B Haemophilia Centre care gave amazing professional care. We also received exceptional care from Professor Makris and team at Sheffield Comprehensive Care Centre.

64. The Society has provided constant support to my family for 35 years. Information has always been available. It has been timely and appropriate.

Section 7: Financial Assistance

65. S1 received £20,000 as a Stage One payment for having acquired Hepatitis C from contaminated blood products. I and other families felt under pressure to sign a waiver, before this fund could be received by anyone. S1 received no further financial support, except from his family, whilst at home and university.

66. We applied for Disability Living Allowance for S1 from the date of his diagnosis in November 1984. It was granted but it was hard work completing the application forms; The Society helped me with these.

67. S1 will set out in detail the financial assistance that he might have applied for and received since he left university in the statement which he will provide to the Inquiry.

Section 8: Conclusion

68. I believe that S1 was one of the youngest babies to be infected between his first treatment on 25 September 1984 and the date of his last non-heat treated product in early February 1986. If the government had made available heat treated factor at the same time that it was made available in Scotland, it is likely that S1 would not have been infected. This would have changed his life.

69. I have heard, as a member of my local haemophilia group, that only two patients with haemophilia were infected with HIV by contaminated blood products in Lincoln compared with 60 in Newcastle.

70. I find it really sad that there has been so many deaths and broken families as a result of the contaminated blood scandal. We have all had dreadful experiences and I would like The Inquiry to get to the bottom of how this was allowed to happen. Our close friend's son died last year from contaminated blood. I feel we are always one step from that heartache with our family.

71. I wantthere to be some kind of acknowledgement for what affected families have gone through. Dealing with haemophilia alone is difficult enough, without the roller coaster ride caused by the contaminated blood scandal.

Statement of Truth

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

Signed .....GRO-B.....

Dated.....16 October 2020.....