

# ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN2737001

Exhibits: WITN2737002

Dated: MARCH 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 GRO-B 1949 and I live at GRO-B.
2. My son, GRO-B: S (born on GRO-B 1972), was co-infected with the Hepatitis C Virus (HCV) and the Human Immunodeficiency Virus (HIV) from contaminated blood products. He died from pulmonary hypertension and cor pulmonale (resulting in heart failure) on GRO-B 2000, aged 28.
3. This witness statement has been prepared without the benefit of access to S's full medical records.

### Section 2. How Affected

4. S had severe Haemophilia A. He was diagnosed with haemophilia when he was 2 years old (around the time of the birth of S's younger

## ANONYMOUS

brother [S]. My son, [S] now lives in Australia. He does not have haemophilia.

5. [S] was diagnosed with haemophilia at Great Ormond Street Hospital (GOSH). [S] was treated at GOSH Haemophilia Centre under the care of Professor Hardisty, Dr Hann and Dr Chessels until he was 14 years old. He then transferred to the Royal Free Hospital (RFH) Haemophilia Centre (albeit he was treated at both hospitals for a relatively short period of time). At RFH, [S] was under the care of Dr Goldman and Professor Christine Lee.
6. [S] did not have too many bleeds to start with. As a very small child he was either carried or transported around in his pushchair. As he got older he had more knocks and bumps and was treated for bleeds on a fairly frequent basis. He wanted to do the same sort of things as other children. If they played football, he wanted to play football. He was treated with Factor VIII concentrate (FVIII) from an early age, his main problem area being his ankle joints. We learned how to administer FVIII at home but I continued to take [S] to GOSH for major/persistent bleeds.
7. I do not remember the name or names of the product that [S] was treated with except for a single diary note I found that [S] was, on one occasion, treated with a product manufactured by Alpha (batch number J49601).
8. I do not know when [S] first tested positive for HIV. I was never told. The system at GOSH at that time was that you attended at A&E, you were handed the notes and you were told to take them up to the third floor. If I could, I would quickly flick through the notes because I would, from time to time, come across a nice/personal comment written by a doctor about [S]. One day, when [S] was 11 or 12 years old, I read through the notes whilst [S] had gone to the toilet and came across the note "HTLVIII" (positive). I knew what the note meant and I knew it was bad. I think I had read about it in an HIV/AIDS related article. I did not tell anyone. I

## ANONYMOUS

made myself believe that I was mistaken. I was not ready to accept it. Soon after that the hospital changed the procedure and the notes were handed out for us to take to the third floor in a sealed bag.

9. Before [S] transferred to RFH we were told by GOSH that [S] had developed a serious issue with his (low) platelet count and spleen. He had his spleen removed at the RFH. It was in the first half of 1986, that [S] is father and I were told that [S] was infected with HIV. I do not remember the doctor that told us. It may have been Dr Goldman but I recall Riva Miller (a social worker) also being in attendance. I remember saying "I already know" and "I have read the notes". Riva wanted to tell [S] straight away. I wasn't ready for [S] to know. I put her off until a future appointment.

10. No information or advice was given to us to help us to understand or manage the infection. No advice was given to us in relation to the spread of infection, even though [S] had been isolated in a side ward at the hospital when his spleen was removed and when recovering from an elbow operation shortly after that. In retrospect, I think that the lack of information and advice in relation to the spread of infection was totally unacceptable. Many people were placed at risk. There was a lot of rough and tumble between [S] and [GRO-B] [S] had heavy nose bleeds at school and at the homes of his friends. I had been placed at risk in injecting [S] with the FVIII through needle contact. On one occasion when [S] was having his platelet treatment, the pump syringe to the PICC flew off the car dash board where I had placed it and straight into my foot.

11. When [S] was subsequently told that he had HIV by Riva Miller, he was told that he had to use contraception and nothing more than that.

12. I do not know when [S] became infected with HCV. [S] was not told that he had HCV until many years later, after he had left home (in his twenties). I do not know how long [S] had had HCV and whether or not he was infected with HCV before or after being infected with HIV. We were

## ANONYMOUS

under the impression that HIV was the predominant concern/threat to [S]'s longevity.

13. We were never warned beforehand about the risk to [S] of being exposed to infection through FVIII blood products.

### Section 3. Other Infections

14. I am unaware of any other infections that [S] had other than HIV and HCV.

### Section 4. Consent

15. [S] was tested without our knowledge and consent and without us being given adequate or full information. We did not know that [S] had been tested for HIV or HCV.

### Section 5. Impact of the Infection

16. [S] was told that he had HIV at a follow-up appointment with Riva Miller. I was present. Before the meeting, Riva asked [S] if he agreed to her video recording the meeting, which she said was for training purposes. He verbally agreed. He was just 15 years or 16 years old. The news of the condition was the biggest shock of his life. He barely spoke. Riva tried to do some counselling with him and open him up to discussion about it. She also made her point about him using contraception. After the appointment, I tried to gee [S] up saying "it is not as bad as all that" and words to that effect.

17. A year or so later [S] had a funny turn and what I believe to have been a nervous breakdown. He was, I believe, in psychological overload trying to process everything in his mind. He came home with his best friends and I was, at first, convinced that he had taken something (a drug). He kept on laughing in an odd, uncharacteristic and disturbing manner and (although he didn't smoke) he kept asking my mother to give him one of her cigarettes. I



demanded that his friends tell me what he had taken and soon established that he hadn't taken anything. They were as concerned as me (they did not know then of his HIV diagnosis). The hospital said I could bring him in for admission and I did. He wasn't right. He was there for a few days in a side ward on his own. He was never the same after that.

18 [S] had a very close friendship with five good friends. He was well thought of by his friends' parents and was always welcomed into their homes. The six of them would go out to Ibiza as a group and his friends would look after [S] because of his haemophilia. [S] subsequently confided in his friends about his HIV when he was 18 or 19 years old and they were very upset that he had not told them sooner.

19 [S]'s girlfriend [GRO-B] was very supportive too. She was born the same year as [S] and they were a couple up until [S] died. [GRO-B] and all of [S]'s friends were very loyal and kept [S]'s HIV status to themselves.

20. Apart from [S] confiding in his close friendship group, we kept [S]'s HIV status to ourselves. Most of our own family members did not know. [S] did not tell [GRO-B] until the year [GRO-B] was due to sit his A levels. [GRO-B] was deeply affected. [GRO-B] had the highest GCSE results in his year at school and was expected to do very well at A level. He ended up having to redo them all again the following year. He went on to University but dropped out. He met his partner whilst working for [GRO-B]. They moved to live in Sidney, Australia together shortly after that.

21 [S] was a very independent person. He passed his driving test and was driving (legally because of mobility) at 16 years old. He was encouraged by the hospital to attend his appointments on his own (and be treated as an adult) from a relatively early age. I was told "you don't need to come in" and stopped going. You can pretty much take who you want to hospital appointments nowadays. [S] had a flat in [GRO-B] and lived there with [GRO-B] from in or around 1993 when I moved out to [GRO-B]. He would have been 21 years old. He phoned me on a regular basis and I saw

## ANONYMOUS

him when he dropped in. He was told that he had HCV some time after he moved out. He was not concerned. He seemed to be under the impression that it was treatable. I was never made aware of how, when and where he was infected. Our worry was HIV but his CD4 count appeared to be under control.

22. [S] developed a number of health issues to include recurring outbreaks of shingles. I remember the first outbreak, applying the cream and hoovering up the shingle scabs. They were like raisins. [S] said that it felt like a belt tightening around his waist.

23. [S] had Interferon treatment for HCV after he moved out in or around 1994. I knew that he was self injecting the treatment into his stomach but I do not now recall how long the treatment lasted. I know that there were a number of very unpleasant side effects of the Interferon treatment to include flu like symptoms and chronic diarrhea. [S]'s weight fluctuated quite a bit. At times he was as skinny as a rake and then shortly thereafter he would have put on a lot of weight.

24. [S] then developed a worrying issue with his breathing. His voice became horse. He was also in a lot of pain with his joints. It became a huge struggle to [S] to do ordinary every day things. His ability to breathe and to walk was awful. He could not even get out of his car at the Haemophilia Centre to lower the car park barrier. He would drive over it instead. [S] and I were out in Australia for three weeks in February 1999 visiting [GRO-B]. [S] had to stop and rest having just crossed one road on the way back from the beach, a very short distance to where [GRO-B] lived.

25. Over the course of that year and the following year, I travelled backwards and forwards to Australia. I worked in a school enabling me to travel during the school holidays. In the summer of 2000, [S] told me that he had an appointment at the Royal Free about his breathing in October. It was arranged that I would go with him. [S] wanted me there because he said I had "a big mouth", meaning I would ask questions. [S] was a

character. He was always very comical. By way of example, when he had his spleen operation, he announced that he wasn't going to be "split open by Spitz" (Professor Spitz being the name of the Consultant) and after the operation he showed people his scar and told them he had been bitten by a shark. Back then, he announced that he wanted to be a croupier when he grew up (because a Chinese Nurse he had at that time showed him card tricks).

26. I went out to Australia [GRO-B] 2000. [GRO-B] called me in Australia the evening before [S] died. [S] was in hospital in intensive care and was not expected to make it through the night. This news came as a terrible shock to me as I had no idea that [S] was so very unwell. I was with [GRO-B] and his partner and we were scrambling around trying to get an immediate flight home. Professor Christine Lee also spoke to me. She gave me her home phone number and said I could ring her at any time (through the night). In retrospect, I cannot help but feel suspicious about that. At 3.00 am (Australian time) the hospital called and told me [S] had passed away.

27. I refer to **Exhibit WITN2737002** being the Royal Free Hospital Postmortem Report and [S]'s Death Certificate. The documents are inconsistent in terms of cause of death. It is however apparent that both HIV and HCV were significant contributory causes. It was retrospectively explained to me by Professor Lee that [S]'s heart had become enlarged. [S]'s enlarged heart, pressing on his lungs had caused the breathing issues. The issue should have been investigated and addressed.

28. I have also discovered that the medical profession were aware that one of the possible side effects/complications of Interferon was that it was found to lead to pulmonary hypertension and enlargement of the heart.

#### **Section 6. Treatment/care/support**

29. As stated at paragraphs 27 and 28 above, [S]'s pulmonary hypertension issue should have been properly diagnosed and treated sooner. I do not



## ANONYMOUS

understand why they would not have been able to identify an enlarged heart from xrays.

30. When [S] attended dental appointments, the dental staff were covered from head to foot in protective clothing, like space suit outfits. It was an uncomfortable experience for [S]

31. [S] did not have any counselling apart from the meetings he had with Riva Miller at the hospital.

### **Section 7. Financial Assistance**

32. [S] received a lump sum through the MacFarlane Trust in 1991. I do not remember exactly how much he received. Some of the money (and subsequent payments by way of grants) was used towards the deposit needed for his mobility cars. He was not a drinker or smoker but he used to go to a club in [S] where he would treat some of his friends to champagne. He then became affectionately known as [GRO-B] He always tried to live life to the full and enjoy life.

33. [S] also received a modest monthly income.

34. I received the Stage 1 and Stage 2 payments from the Skipton Fund after [S]'s death. Nutmeg liver is listed in the Anatomical Diagnosis of [S]'s Postmortem Report.

### **Section 8. Other Issues**

35. I do not have [S]'s medical notes and records. I understand that they are only kept for a period of no more than 10 years.

### **Anonymity**



## ANONYMOUS

36. I wish to apply for anonymity and I understand that this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence.

### Statement of Truth

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

Signed..

GRO-B

Dated

29th March 2017.