

Witness Name: **GRO-B**

Statement No: WITN0518001

Exhibit: WITN0518002 – WITN518008

Dated: 14 May 2021

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF **GRO-B**

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#### Section 1: Introduction

1. I **GRO-B**  
make this statement to assist the Infected Blood Inquiry in relation to its investigation arising out of the tragic circumstances of the death of my late husband, **GRO-B: H**
2. We married in **GRO-B** in **GRO-B** we would have celebrated our Golden Wedding Anniversary.
3. **H** had severe Haemophilia A, was diagnosed with HIV and HCV and was informed that was as a result of Factor VIII which he had received at St Thomas' Hospital.
4. **H** was the youngest of five boys. Two of his brothers are still alive and the other two have passed away; one of **H** brothers died when he was just 9 months old and it is suspected that he had undiagnosed haemophilia since he passed away following blood loss.
5. **H** passed away **GRO-B** 2003, aged 54yrs old, from heart failure. This heart failure was a consequence of him suffering acute/chronic renal failure in May 1999 due to hypertension and HIV disease. His heart problems exacerbated by the burden of haemodialysis, retroviral infection and anti-

retroviral therapy. Also at his time of passing his liver was in a state of Hepatitis C Liver Fibrosis and Chronic Hepatitis consistent with the known history of hepatitis C infection.

## **Section 2: How Affected**

6. [H]. He was approximately 18 months old when haemophilia was discovered. His family kept chickens at the time and [H] was bitten by one and had to be taken to St Helier Hospital, Carshalton, Surrey. During his younger years, he was treated for various bleeds and trauma at the hospital thereafter with bed rest and treatments that were available at that time.
7. When he was 13 years old, he fell in the swimming pool and suffered a dislocated hip (right side) as a result. He was treated at various hospitals for this, including St Helier and Stanmore hospitals, then finally The John Radcliffe Hospital in Oxford. It was at The John Radcliffe where he underwent arthrodesis of the hip joint. This was a ground-breaking operation for a haemophiliac at that time. [H] was 14 and appeared in a medical journal due to the rarity of the operation.
8. Unfortunately, two years after this operation he was involved in a motorcycle accident where he fractured his tibia and fibula of his right leg. He attended St Helier Hospital Carshalton and [GRO-B].
9. Thereafter from the age of 25 onwards, his treatments began at St Thomas Hospital.
10. After our youngest child was born [H] was admitted into hospital at the age of 26 where he was given huge amounts of blood treatments and blood transfusions (factor VIII).
11. [H] was admitted under the care of Professor Ingram into St Thomas' on the 18th December 1975 after suffering from a massive internal haemorrhage bleed in one lung which then collapsed. The damage to that lung remained to the day of his passing [H] had then developed pneumonia on the other lung

and he had lost so much blood due to the internal haemorrhage that his internal organs began to shut down and he was on the brink of death. I remember clearly how the doctors were very secretive of the treatments they gave [H] during his 6-week stay in St Thomas' and on any other information relating to this particular stay in the hospital. I initially thought they were protecting me because he was so poorly.

12. For the days before that Christmas and several days afterwards he was on the critical list. He was being transfused with massive amounts of blood and blood products, antibiotics, oxygen and other medication.

13. [H] was finally discharged from hospital but it took him until Easter to gain weight following this incident and to regain some semblance of his former self.

#### **HIV and Hepatitis C diagnoses**

14. In or around 1984, when the news came of the fact that [H] had been infected with HIV, we had no choice but to discuss this with the children as they would help him if he needed home treatment, **WITN0518002**. This had an enormous, devastating impact on them. The children could not fathom that their father's medical team could have let this happen, such was the respect they had had for his medical team.

15. The HCV diagnosis was delivered to us in the early 1990's, despite the records showing that there was evidence of chronic non-A, non-B hepatitis with elevated ALT values in 1986, **WITN0518003**. This was another devastating blow.

16. Sometime after, everything seemed to take a turn for the worst. [H] felt ill daily and was unable to recover. It just seemed to get worse. It soon became apparent that his sickness was not going to go away and the children started to notice that their father was fading. As [H] needed more and more care, I lived and survived on adrenaline in order to help him cope each day and my sons could not comprehend how I was able to function to the extent that I was.

17. Then in May 1999, [H] was seen at St Thomas' and diagnosed with kidney failure, **WITN0518004**. None of [H] renal doctors would explain why his kidneys were failing and when [H] passed away, he never actually realised the full extent of why his kidneys had failed. The true cause of the impact the viruses [H] had contracted had on him only became clear after [H] death. The first time that the letter that is attached at WITN05108004 came to my attention was when I began drafting my statement. I cannot describe the utter heartache, rage and grief I have recently experienced to read that [H] treating doctors knew since 1999 that he had end stage renal failure (which was conveyed to us), but that the likely cause of it may have been due to his living with retroviral disease. This was never conveyed to us, not one single medical professional sat down and explained the situation to us. [H] died thinking that this was his fault, for the reasons explained regarding pain medications therefore that he had done something wrong. It is so painful to now know that doctors were cognizant of his kidney failure, and clearly the reasons why, yet the patient was completely unaware and was left to die believing this was his doing. This just gets worse and worse with information that we just didn't know. He suffered a great deal because of his kidney failure this is an utter disgrace. Surely he deserved an honest explanation.

18. In July 2018, I received a letter from Dr Dolan at St. Thomas' Hospital informing me that my husband had died of heart and renal problems likely caused or exacerbated by retroviral treatment he had been given for his HIV. This came as a complete shock as we had no knowledge of this treatment and I truly believe that my husband was not consented for retroviral treatment. I am sure that [H] had no knowledge of the risks and that this treatment was not discussed with him. I attached this letter and have labelled it under **WITN0518005**.

19. Furthermore, I also have a letter here from Dr Bevan Centre Director, St Thomas's Hospital 2013 stating the condition of his liver due to HCV at the time of his passing. I attached this letter and have labelled it under **WITN0518006**.

20. Up until this point I did not know why [H] kidneys had failed. [H] had always thought that this had happened because he had taken pain relief for complications for his Haemophilia and he never found out the true reason why this had happened. It was a complete shock to receive this letter after so many years as we both always attended appointments together, so admittedly I was very well-informed. I now note that Chronic Hepatitis C has been linked to Heart Damage. Hardening of the arteries. Left Ventricular Hypertrophy as stated on his Autopsy Report. Was this as a result of HCV and living with Chronic Hepatitis for this horrendous amount of years? So many unanswered questions.

### **Section 3: Other Infections**

21. I have a memory of Hepatitis B. I remember him saying he had immunity. I am not sure if he had this virus at an earlier date and immunity resulted or he was just immune. I think in his ignorance of HCV he thought "*well if I'm immune to Hepatitis B so Hepatitis C won't get me*". Showing the severity of this was never explained to us. I have explained that we were kept in the dark.

### **Section 4: Consent**

22. None whatsoever. As stated above, we always attended appointments together and no treatment, whether that being retroviral treatment or inhibitors, was ever discussed with us. He was taking this treatment unbeknownst to him. Had I had the full set of facts before me and had the doctors told me the truth from the start, I would have done things differently for my husband.

23. I was in and out of hospital with [H] for all of his appointments and was only ever offered screening for HIV. No screening was ever offered for HCV. Therefore I was exposed to the viruses without knowing for a very long time. In 2001, I sought to have my bloods screened for HIV and HCV, **WITN0518007**.

### **Section 5: Impact**

24. [H] was involved in a car accident in late [GRO-B] 2003. He was transferred from East Surrey Hospital to St Thomas' for two reasons; one for his haemophilia and the other was for his need for regular renal dialysis. He was extremely lucky as he steered the car between two articulated trucks and thankfully did not suffer any serious injuries, just broken bones which would mend.

25. A few days later he suffered a cardiac consequence and passed away. An Inquest followed [H] death and I have attached a copy of the Autopsy Report which is marked as **WITN0518008**.

26. The impact of Inquest caused further trauma to our family, we were consumed with grief as it was then we had to endure a hearing which investigated and detailed how [H] died, which was so chilling to hear. Furthermore, it appeared in the papers which added further unwanted stress and attention at an already fragile time.

#### **Impact on our children**

27. We had [GRO-B]. [H] was always determined not to show his sons the pain he was in, as a family, we did all of the normal things that families do. The children were aware that their dad had haemophilia. However, being the brave man that he was, [H] did not let his pain affect their lives. As they got older, I remember the children realising that their dad was just that, a brave man and they had the most tremendous amount of admiration, love and respect for him.

28. As [H] had multiple joint repair operations, the children, from a very young age were used to spending time in St Thomas' hospital with him whilst recovering. That was the way of life for our family, so much so that like their parents, the boys became friendly with the doctors. Over the years, whilst [H] was recovering from various operations, he always tried to speed up his recovery so he could come back home as soon as possible.

29. Then the news came of HIV virus which left the children reeling. As this devastating news dawned on them, and the level of respect that they held for

Prof Savage, my son said “No, Prof Savage wouldn’t let this happen to dad. He wouldn’t let it happen”.

30. From then on, his health deteriorated. He became sick daily. The children could see their father fading before their eyes. [ H ] fought this and tried to work and function but it quickly became apparent that this was not going to go away.

31. When he was diagnosed with kidney failure, the children were terrified – scared that” this was it” was this beginning of AIDS.

32. We had a dialysis machine fitted at home and I was trained so that to give him some semblance of normality. It was never explained to us why his kidneys failed, all of our questions were avoided. As stated above, the true cause of this only became clear after his passing. The devastating effects that kidney failure had on his other organs and on his heart especially is very obvious to us all now. The dialysis was a very debilitating treatment and just zapped his strength. Whilst taking its toll on his heart.

33. The impact of losing their father left a huge hole in their lives. After us telling them of his HIV and HCV status. Which we felt we had no choice but to do as they would help him with anything in moments of need. We just couldn’t put them at risk from blood contamination.

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34. Furthermore, while one of my sons obtained qualifications, the other was unable to concentrate on his schooling and accordingly, he did not manage to obtain qualifications. He did, however, become accomplished in the career he ultimately chose but he would have chosen a different path had this terrible situation not occurred. To this day, both of my sons still struggle to speak about their father.

35. The ramifications of these viruses and in the end losing the man they worshipped remain. It cannot be denied that their lives and mine would have been extremely different had their father and my husband not received contaminated blood products.

### **Impact on me**

36. I lived and survived on adrenaline to be able to cope with everyday life. There were days that I remember being able to almost taste the stress, the acid of anxiety.

37. For so long, I remained strong on the outside but struggled hugely internally; I had fully taken over the role in caring for [H] but living in such anxious conditions eventually took its toll on me and [H] death and the aftermath of his death has been devastating for me. I was not only his life partner; I was his kidney dialysis nurse. Everything I did daily revolved around him. To this day, I sometimes feel as though the shutters have come down, there are so many blanks. I felt unable to discuss this tragedy with my GP; I had intended on speaking with my GP about this period in my life but I did not feel able to do so nor did I want anything recorded on my notes which indicates that the long instilled stigma relating to these viruses is still alive in me.

38. Part of my coping mechanism is to have a type of brain fog; I guess I do not want to remember. A type of self-preservation.

### **Cremation**

39. I recall a discussion that was had at St Thomas' Hospital after Prof Savage delivered [H] diagnosis. It was made apparent that a burial would not be an option for us. At the time of his passing, I didn't question this I just followed what I thought was protocol. [H] did know in life that he would not be buried on [GRO-B] [GRO-B] near his mum, dad and brother. So whilst he didn't like the thought of it, I took comfort in the fact that he knew. So I decided to do my best for him and have his ashes interred on an island in the centre of a lake in the garden of remembrance 10 minutes from my house. That means I can visit him and he has a special place. Telling him at the time that he was at his final resting place, on an island, just like Princess Diana and just as special. This was the nicest resolution I felt to the situation that I found myself in. This did not go down



well with his brothers and it was hard to explain why and the only way I could resolve this was to explain that that was what he wanted. His diagnosis was never shared with any of the family as that was what he wanted. This remains so to this day. Only I and his sons know to this day. He felt shame and the very real effects of the stigma attached. I must honour his wishes at this enquiry. So I retain anonymity for him myself and my sons.

#### **Section 6: Treatment/Care/Support**

40. I do not remember any counselling being offered to either of us. We certainly did not have any.

#### **Section 7: Financial Assistance**

41. [H] was a successful corporate chauffeur and had his own business. Due to his health problems whilst alive, [H] could not work at times and this led to financial hardship. With a small amount each month from The Macfarlane Trust we struggled on and managed to stay in the home we had bought together. However, [H] was uninsurable due to his infected status.

42. When [H] died, I worked long hours and continued to function as I had been for many years but approximately one year after his death, I was resigned to selling [H] business as trying to run it became too difficult without him.

43. I worked very hard for accountancy agencies and as a management consultant. For all intents and purposes I was functioning and earning, trying to keep the house we lived in together. However, in September 2007, with great sadness I was forced to sell the family home as I was no longer able to afford to live there despite the fact that I was working as much as ever.

44. I had been paying the mortgage alone and although I had struggled on for 4 years, this soon became impossible and I lost not only my beloved husband but eventually our home which had so many precious memories. It was heart-

breaking to sell the home I lived in with [ H ] and I have been renting ever since. I feel a tremendous amount of guilt that I couldn't keep the home that he worked so hard for. I can only rent now as I could not afford to buy anywhere else. I now rely on state benefits and a little help from EIBSS. Everything that we achieved together in life has gone.

### **Section 8: Other Issues**

45. In June 2009, I was involved in a car accident. I was stationary at the time and hit in the rear then pushed out into oncoming traffic. I was driving a Smart Car so there was not too much in the form of protection at the rear of the car. It was recognised that I felt the impact more than if I had been in a normal saloon car.

46. The result of the accident left my back damaged and my spine twisted, so I was literally knocked off my feet.

47. Following the accident I was unable to move and had to remain at home during a long period of time. This inevitably resulted in me having a breakdown. The loss of [ H ] and the terrible circumstances surrounding it all came flooding in. I could no longer disguise this by distracting myself with work or being occupied with being outside.

48. This presented itself in so many ways, mainly severe and unrealistic thoughts.

49. I began seeing a Counsellor and was prescribed antidepressants. Initially it did provide me with the coping skills and I thought that I was doing relatively ok on a day to day basis – until the Inquiry commenced. Since then, I have been struggling again with anxiety and flashbacks. It has been horrific to relive these memories but even though he was very private about his blood status. I feel I have no choice but to be his voice at the inquiry. It is the right thing to do. I trust this deeply painful private information and details to you knowing you will treat it all with anonymity and respect his wishes.

50. My wish is that this Inquiry finally finds the people responsible for this tragedy, and that this can never be allowed to happen again. It has destroyed so many lives. I have only touched the surface of how he and we were affected. I hope from this statement you are able to understand the devastation and carnage that has been wreaked on us and all these poor innocent victims and their families. We have all lived a very different life than we should have. My husband and so many more paying the ultimate sacrifice. This is just one family and there are so many of us. Calling this a tragedy seems an understatement.

**Statement of Truth**

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

Signed           GRO-B          

          GRO-B          

Dated 14. 5. 2021.