Witness Name: Mrs. GRO-B
Statement No: WITN1777001
Exhibits: WITN1777002/5
Dated: 20th 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 1957 and I live at GRO-B London, GRO-B I live alone. I presently receive disability benefits.

2. I make this statement as the mother of GRO-B: S (DOB: GRO-B GRO-B 1974, DOD: GRO-B 1994) who was infected with HIV, Hepatitis B and C as a result of receiving contaminated blood products.

3. **This 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 with a clotting factor of less than 1%. S was diagnosed with Haemophilia A when he was 18 months after I took him to St Mary's Hospital, Paddington London when his knee had swollen and the swelling would not go down. To the best of my recollection, Dr Simon Bignall

was his consultant at the time. S was treated with Factor VIII from 1976 until he had passed away in 1994.

5. The doctors asked me whether there was any family history of Haemophilia, but I was unfamiliar with the term at that time. My two brothers, GRO-B: B1 GRO-B: B1 and GRO-B: B2 were known as *"bleeders"*. However, they did not receive Factor VIII as they were born in Jamaica where the treatment was not known or used. Instead, they were treated with alternative remedies to ease their pain and suffering. It was not until S s diagnosis of Haemophilia that I became familiar with this medical term.

6. In or around 1967, my mother brought my two brothers to the United Kingdom where they received and died from the contaminated blood products, leaving behind their children. I understand, my two nieces will provide statements of their own in relation to their loss.

7. S was treated at All Saints Hospital Chatham between 1982 and 1985 where he received mainly Cryoprecipitate. The doctors there ignored me when I told them that this treatment was not helping S s bleeds.

8. S also received Factor VIII treatment from St Mary's Hospital Portsmouth until about 1984. He had to go into the hospital on numerous occasions due to his bleeds. There were periods of time in which he had to be hospitalised in order to receive his treatment.

9. When we moved to GRO-B in or around 1984, S was treated at All Saints Hospital under the care of Dr Hayes.

10. S was also treated with Factor VIII at Thanet District Hospital, Margate under the care of his Consultant Dr Winter.

11. I refer to **Exhibit:WITN1777002** which is an short extract of the blood product treatments received by S

12. S also attended the GRO-B GRO-B for a year. He left in approximately 1990.

13. I was never told beforehand there was a risk to S of being exposed to infection from Factor VIII treatments. All the doctor said, was that Factor VIII was the sole thing that would help S with his Haemophilia.

14. S was infected with a combination of HIV, Hepatitis B and Hepatitis C when he passed away on GRO-B 1994. I refer to **Exhibit: WITN 1777003** which is a copy of his Death Certificate which omits any reference to HIV, Hepatitis B, and C as his cause of death.

15. In or about 1986, I found out that S was HIV positive. We had a hospital appointment at Thanet District Hospital with Dr Winter which S and I were both asked to attend. We thought it was for a check up in see how S was getting on with his medication. When we arrived Dr Winter came up to me and said that he had some blood test results which confirmed that S was HIV positive. I asked Dr Winter what HIV was and what it meant. And he said" it was an infection and that S was likely to die within 6 years". S was 12 years old at the time. This news hit me like a tonne of bricks. It was awful news for a mother to hear.

16. I refer to **Exhibit:WITN1777004** which is an extract from the "*U.K. Haemophilia Centre Directors Hepatitis working Party" surveillance records* which states that S was first suspected of having AIDS in on 21st August 1985.

17. I refer to **Exhibit:WITN1777005** which is a record of a blood test dated 1st April 1986 which states S was HIV positive and previously he had been Hepatitis B. positive I was told about this in or about 1986.

18. I was not told beforehand that S would suffer serious side effects when he commenced the AZT treatment for his HIV. I contacted the doctors myself

because I saw S wasting away. At this point they told me about the possibility of side effects such as shingles, enlarged lymph nodes and other nasty side effects. You name it; he had it.

19. We were given very little information about HIV, other than, we must not use the same towels as S and that S would need sex education in due course. Although S had been self administering the treatment for a little while by then, we were not told that we had to stay away from his syringes. Fortunately he kept all his syringes in a little yellow box safely out of the way of everyone. I could not stomach giving him the injections myself, so the doctors taught him how to do it himself.

20. There were many occasions where S would cut himself and we would touch him and put cream on his cuts with our bare hands. We did not know about the risk of transmission and the disastrous effect it may have had on our family and my other sons.

21. I consider the result of the HIV test should have been given to me as soon as it was known and in a much better manner. I also consider that when I was told S was HIV positive, the doctors should have given me information about the risks of others being infected and to how to protect myself and other sons from infection.

22. I was never provided adequate information on how to manage S s infections. Moreover, I consider that information should have been provided to me from the moment of his diagnosis.

23. When I told my friend GRO-B that S was HIV positive, she advised me that I should wear gloves. GRO-B helped me with S and wore gloves when administering his Factor VIII. This was at a time when I was going through a terrible struggle in my life as a result of domestic violence.

24. No other information was provided to me about the risks of others being infected as a result of S infection. In fact, Dr Winter told me to treat him

like a normal little boy. He never told me that he must not play with other children because there was a risk of transmission.

Section 3. Other Infections.

25. I do not recall receiving a letter that S may have been exposed to vCJD. This may have been due to us having to move so many times or that as he was dead the NHS did not bother to send a letter.

Section 4. Consent.

26. I believe S was tested and treated without his knowledge, consent, or without being given adequate or full information and for the purposes of research as I never gave my consent for him to be tested for HIV, Hepatitis B, or C and he was a minor. The doctors should have told me that they were taking his blood for testing for these infections.

Section 5. Impact

27. On the day that S passed away, he rang me from home and told me he felt very unwell. Fortunately, my employer allowed me to leave work and I came home to find S unable to move and unable to speak in our bathroom. I supported him and managed get him into the car and drive him to Thanet Hospital. When we arrived the doctors placed him in a waiting room for what seemed like an eternity S was then admitted and was lying in a hospital bed with an oxygen mask on his face. I put my hands on his face and he said "*I want to go now*" and he turned over and passed away.

28. All the side effects of the infections on S were horrendous. He was extremely depressed. He became isolated and withdrawn. He did not go out to socialise, he rarely spoke and rarely smiled. He spent a lot of his time in bed as a result of mental fatigue and exhaustion as well as always feeling

cold and shivery. He became depressed as a result of his infections and completely lost any confidence he had in himself.

29. S suffered with shingles, problems with his chest, breathing problems, his liver, terrible mouth ulcers, nose bleeds and boils on his face which would burst unexpectedly. He had a number of problems during his bleeds. He suffered with a loss of appetite; he felt nauseous and he was sick regularly.

30. S received various forms of treatment: AZT, for his HIV, Cotimoxazole, Pentamidine and Fluconozole. We were not made aware of any alternatives, so I cannot say whether something else should have been offered to us at that time. S suffered continuous side effects from the HIV treatment of constant flu-like symptoms, difficulties in breathing, enlarged lymph nodes, shivers, sweats, nausea, runny nose, sore throat, diarrhoea, cramps in his stomach, and herpes which all caused him a lot of pain and discomfort.

31. His infection meant that he had to attend the hospital as an in-patient for dental treatment and other procedures such as biopsies and bronchoscopies. However, I now know that not all haemophiliacs were admitted as in-patients for dental procedures. As a mother at the time, the doctors did not explain anything very well to me, so I just accepted that this is what happened. Nevertheless, I do not recollect S being mistreated by the doctors as a result of his infections.

32. The impact of S diagnosis of HIV was a death sentence on the whole family. We had to endure ignorance, stigma and victimisation from S s school, our neighbours as well as other people within our community causing me to fear for S and his brothers' lives. We were all abandoned because of his infections. S was harassed and hounded which resulted in our family relocating on multiple occasions. The impact of the HIV was constant; we ran but we could not run away from it. The fact that we were living as fugitives to some degree was pushed aside and nobody could relate to our struggle. We became isolated from our friends and from our family.

33. We experienced an extremely difficult situation when S HIV status was leaked to the press. According to Dr Winter, it appeared that somebody at S school leaked this information to the press. However, I have my suspicions that the Maidstone Health Authority informed the Education Authority who in turn informed the school which resulted in this information getting out to the press.

34. At that time, of course, the media was rife with AIDS adverts. There was an awful stigma and an awful injustice surrounding innocent haemophiliacs who contracted these terrible viruses through no fault of their own. People treated us like we were lepers. We were continuously made to feel different and S was always labelled as someone infectious, someone unaccepted.

35. The educational effects on S were significant. I recall receiving a letter from S school informing me that his standard of work was very low which was one of the reasons why S was sent to attend the GRO-B School. However, having been given a few years to live left S with a discouraging attitude and he did not see the point in continuing with education or even trying to revise for exams because he knew he would pass away soon.

36. I know that he tried as best as he could, but he did not see much point in doing so. He left school when he was aged 16. He did not have any qualifications, and any exams that he had passed were passed with *low* grades.

37. I found him a job as a Junior Clerk which he loved. I think this was the only time I saw a smile on S face. At this time, he started to open up a little and he began to gain some confidence in himself. Maybe this was down to the fact that he was working amongst people who did not know about his infection and treated him with respect and did not make him feel uncomfortable. Unfortunately, he only worked for approximately a month until he was riddled with ill-health again. He became extremely weak as a result of the infections as well as the treatments he was receiving.

38. Mentally and physically, I had to be strong for the sake of my children; especially for S because I knew that if I showed weakness, it would affect S deteriorating health even more.

39. My marriage and the family broke down. We were all holding together by a threat and I had to deal with it all on my own. I feel guilty because I had to work. I used to work in London and so I had to leave him at home even when he was very unwell. I suffered from severe depression which lead to severe stress. I was under a continuous and an unrelenting pressure which led to heart problems. I also suffer with osteoarthritis and fibromyalgia. I currently walk with crutches and I am disabled. I am currently waiting for an appointment to have a procedure to assist with my left leg.

40. The impact on S brothers was substantial. His brothers shared the same isolation and were bullied because they stuck up for their brother. They all suffered mentally after S death. One of his brothers left the country. Another brother has gone to prison as a result of getting himself into trouble because he did not know how to deal with S s death. The last brother has attempted suicide and became a heroin addict and is also constantly in trouble with the police. All of his brothers never had a stable home due to us having to move home so often as a result of the stigma relating to S HIV. What happened to our family breaks my heart. None of this would have happened had S not been infected with contaminated blood products.

41. Had S not passed away as a result of receiving the contaminated blood products; he might have possibly been working today, married and with children.

42. We always struggled financially. Whilst S was ill, I continued to work full-time to keep our heads above water and to break even. But when S passed away, my life fell apart and I ended up losing my home. Had he not been infected, he would have been able to work and contribute to the family income; but he was unable to lead a joyful and successful life.

43. I recall that we could not obtain any travel insurance for S when I wanted to take him to see some of our extended family in Jamaica. We took a chance and we travelled without insurance. I remember S had a swelling which was a bleed; however, we had ran out of Factor VIII so I took him to a local hospital in Kingston and they did not know what Factor VIII was. Later that day, my uncle went to a pharmacy and bought a holistic remedy. We rubbed this potion on S swelling and it got better.

44. What happened to S also happened to my two brothers. They arrived in the UK in the late 60's and were given Factor VIII shortly afterwards and throughout the 1970's. Both brothers were receiving treatment and medical care at St Mary's Paddington. One brother B2 continued to receive in-patient treatment at this hospital as well as at home until he died suddenly while on holiday in Jamaica. My older brother B1 not only received care at St Mary's, he also received similar care at Royal Free Hospital Hampstead London and a hospital in GRO-B the area he moved to a few years before his death.

45. When my brothers lived in Jamaica, no-one knew of Factor VIII; they were treated with holistic remedies for their haemophilia. The impact of what happened to them devastated my parents, especially our mother who never came to terms with their HIV status and gradual deterioration in their health. In fact, my older brother, B1 never told the family of his condition; the family did not know until after his death as he kept it a secret from us all.

46. My mother felt guilty for believing that bringing her children to the UK, would be a good idea as she wanted them to be with the rest of the family in the UK as well as have access to better health care under the NHS. Instead of being treated with appropriate healthcare, they were given contaminated factor VIII, causing stigma, isolation, fear and death through no fault of their own. My mother later died, not knowing the reason why her sons had been chosen to be used as guinea pigs without hers or, when they became adults, either of my brothers' consent.

Section 6. Treatment/Care/Support

47. S missed many hospital appointments due to his ill-health but I do not think the medical practitioners took this on board. I recall S receiving a letter from Dr Winter which stated that it was "*unforgivable*" to have sent a transport driver away who had travelled 100 miles to pick S up for his appointment at Thanet Hospital. At this point, S began to be paranoid and believed that Dr Winter was acting against him.

48. We experienced obstacles in receiving treatment. We were never told whether there was alternative treatment available; and if there was, it was not offered to us. Travelling to and from hospital was an obstacle in itself, as we had to travel long distances to get to the hospital; a transport driver was available very infrequently.

49. When S died we were not allowed to have the lid of his coffin open as is our tradition, so the lid remained closed before and throughout his funeral and S brothers, family, friends and I were not able to say our last goodbyes properly.

50. No counselling or psychological support has ever been offered or received by any members of our family. On one occasion when we told Dr Winter we were struggling, he still did not direct me or my sons to an organisation which would have been able to help us. I had to deal with everything on my own.

Section 7. Financial Assistance

51. In 1991 S received £23,500.00 in compensation which was held in trust until he was 18 and then was paid out to him. At the time of the settlement we were told we had to sign a waiver otherwise we would not receive any money.

52. I received an ex-gratia Stage 1 payment of £20,000.00 in approximately 2011 from The Skipton Fund. I then applied for Stage 2 payment but they turned me down on the basis that they wanted evidence to confirm that B1 suffered with cirrhosis. S did not fit into any of the categories and I argued that the contaminated Factor VIII blood product caused his infections and this should have been enough. Eventually, I received a Stage 2 payment of £50,000.00 in about 2013.

53. I found out about The Skipton Fund through the Haemophilia Society webpage on the internet.

54. The process of applying for financial assistance, in particular the Stage 1 payment was reasonable. However, the process for the Stage 2 payment was extremely difficult. I could not afford the solicitor fees and did not understand medical terminology but I persevered and wanted to win in light of the injustice caused to my son.

55. I received a grant from The MacFarlane Trust ("MFT") of £849.49 to pay my Council Tax debt. The process of applying for this particular grant was also extremely difficult. After I received the grant, I received a phone call which resembled an interrogation which completely put me off applying to The MFT ever again.

56. The amount of financial assistance, or in other words "*hush-money*", does not reflect the impact which these infections had on families. I was not treated with any empathy; their attitude was extremely hostile and negative. I was given the impression that I was wasting their time.

Section 8. Other Issues

56 I am mad at the Government and the NHS service. I am mad with the Government for knowing that contaminated blood was imported into the country. They were told by numerous countries not to allow it in. When I found this out quite recently, I was completely shocked. They destroyed ordinary people's lives. They are ordinary people themselves but made awful and

unjust decisions. I have now had 33 years of anger walking around inside of me.

57 Even now, walking into the hospital about my own medical issues, I doubt all of the medical practitioners and I do not trust what they say. How can I trust anybody now?

58 They have used my son and other haemophiliacs as guinea pigs to benefit themselves. What happened was brutal and traumatic for everybody.

59 I wish that the Government would admit to their wrongdoing and apologise for what they did to hurt the many families affected.

60 It is not about money, because nothing will bring my son back, but I need someone to be accountable.

Anonymity, disclosure and redaction

61 I wish to apply for anonymity. Due to my health problems I will be unable to give oral evidence to the Inquiry.

Statement of Truth

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

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

Dated..20|3|2019..........................