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Witness Name: **GRO-B**

Statement No: WITN6609001

Exhibit: WITN6609002 – 006

Dated: 15 October 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** of **GRO-B** will say as follows:

Section 1: Introduction

1. I am the youngest daughter of the late **GRO-B: F** who was born on the **GRO-B** **GRO-B** 1928 in London and who died on the **GRO-B** 1991.
2. My father was diagnosed at 18 months with severe haemophilia with Factor VIII deficiency of less than 1%.
3. He suffered numerous bleeds during his early life and started home treatments (Cryoprecipitate) for this at Kings Hospital in 1980.
4. I can clearly recall how my father struggled throughout my childhood because of his haemophilia. Therefore, when home treatments became available, my two sisters, **GRO-B** and **GRO-B** and I really felt that these would be of great assistance to him in quickly alleviating any pain, when needed. He also seemed happy to be finally in control of his own health.
5. However, our happiness soon turned to horror when we learned that our father had been infected with HIV and Hepatitis C from blood products supplied by King's College London.

Section 2: How Affected

6. Although we learned of our father's HIV status in 1986, he had actually contracted this in around 1983 [WITN6609002].
7. Furthermore, my father had been exposed to two bouts of jaundice at King's in around 1970 and it was not until many years later that he discovered that he had actually contracted the Hepatis C virus [WITN6609003].
8. I have discovered in my father's medical notes, a copy of his patient summary record, dating from 1970 onwards and which details all of the treatment he received for his haemophilia. I attach this record at [WITN6609004].
9. My sisters and I were very young when we cared for our father and we would help him carry his haemophilia treatment after his hospital appointments. My father's joints, especially his elbows were fused so there we many occasions where I would miss going to school so I could go along with him. He suffered with his hip and his knees, which would lock from time to time. For the most part we were not fully aware of how much pain he was in [WITN6609005].
10. I was very young at the time but we always knew that my father had a bleeding disorder. It was part of our lives.
11. My father was very clever but he didn't have a job per se, he would go to a centre that was set up for people with disabilities where he had his own carpentry workshop and he would create all sorts of crafts. He would also help others, teaching them how to re-upholster items.
12. Gradually, as time passed, he was physically unable to continue going to the workshop. He was no longer able to stand up for long periods of time.
13. I nursed my father as he became more and more ill and I would help him out in any way that I could, bringing him in tea when he asked for it and extra cushions

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- for his limbs. My father often had colds and diarrhoea and he lost a lot of weight along with his appetite.
14. At the time, we put his poor health down to his haemophilia and for obvious reasons did not know the gravity of the situation.
15. During one of my father's routine appointments at Kings College Hospital in 1986, which I attended with him, Dr **GRO-D** asked us both to sit down turned to my father and said **F** *there is something I need to tell you – you are HIV positive*".
16. That was the extent of the diagnosis that was delivered that day. No information, no reason how this had happened nor a discussion regarding any potential treatment. Dr **GRO-D** told my father to look after himself and not to share his toothbrush.
17. My father changed that day. The diagnosis shattered him. We drove home in silence, making our way back to our house to tell my mother and our sisters.
18. He was a very proud man and had always felt in control of his haemophilia. Being able to administer his treatment at home allowed him to live a better life. This news took a devastating toll on him.
19. For the first time my dad was speechless. All throughout the years he felt in control and the need to be on top of things. He kept repeating "*what am I going to do*" over and over. My mum and my sisters were his world and he felt totally hopeless.
20. The TV adverts that were being circulated, spreading the stigma and ill-educated information made it impossible to tell anyone about my father's illness. It was like a ticking time bomb. All we could do was talk to each other and as a result of that, as a family we kept ourselves to ourselves out of fear and being ostracised.
21. My parents moved out of London and finally settled in Kent. I believe part of the reason for the move was due to my father's diagnosis and the constant worry

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- of it being uncovered. The isolation we all felt from the stigma that surrounded HIV at that time was overwhelming.
22. Eventually my father commenced treatment for his HIV at **GRO-B** **GRO-B**. He was trialled on AZT but due to the horrendous side effects, he could only tolerate it for 6 weeks and was withdrawn in June 1989. **[WITN6609006]**.
23. At this time, my parents lived in **GRO-B** and between myself and my husband, we would drive him to his different appointments as he was too ill to drive himself.
24. My father felt unclean after his HIV diagnosis and he was constantly worried that he would pass it on to his family which devastated us. As a result of this fear, he was no longer as affectionate towards his daughters and indeed his grandchildren as he had been before.
25. From the moment the AZT trial began, there was no life left in my father, he was extremely ill, terribly sick all of the time, was unable to hold anything down coupled with diarrhoea. He was a very placid man, would always sit and play with his grandchildren but when he was on that trial he changed. He was short tempered at times, moody, and progressively more depressed as the time went by.
26. On one occasion in the hospital in **GRO-B** shortly before his death, I can remember clearly that blood was pouring out of my father's nose and mouth and the nurses in the ward didn't even try to assist him, instead leaving the family to deal with the situation. We used kidney dish after kidney dish to try and catch as much of the blood as possible; this was very traumatising for me and I still cannot get this image out of my head to this day. We did not have any protective gloves or clothing, to protect my sister and myself from the blood from our father.
27. I can also recall how I gave my father his last ever Factor VIII injection but this did not relieve his pain in any way as his immune system was so low by this

point; he instead started to panic and tried to get off the hospital bed he was on in such a horrendous state. The pain being unbearable. The helplessness I felt at not being able to properly assist my father had a very negative impact on me which left me feeling alone and lost.

Section 3: Other Infections

N/A

Section 4: Consent

28. As far as I am aware, my parents were not properly informed of any risk associated with any treatments that he received.

Section 5: Impact

29. I would often attend appointments with my father and help him carry his bags of treatment and I was with him on the day that he was told that he had contracted HIV and Hepatitis C. I can still vividly recall my father's mouth freezing in horror.

30. I was 28 years old when I lost my father. I started to experience the worst vivid nightmares which would result in me grinding my teeth. I also suffered alopecia on two occasions.

31. After my father passed away in 1991, my husband and I tried to assist my mother as much as possible; she was not coping well with her late husband's death and she, too, became quite ill with cancer.

32. As a result of my father's illness, death and the subsequent death of my mother, I became quite neurotic and edgy and I started to drink alcohol due to the stress I felt. I also found it difficult to cope with day to day tasks. I was diagnosed with depression which I still have to this day and also had regular suicidal thoughts.

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33. Furthermore, I have two sons who suffered with haemophilia and I had to look after his bleeds and to ensure that they were being adequately treated. As a result of this stress, my alcohol consumption became worse as I continued to drink excessively in order to block out my feelings. My marriage suffered hugely as a result of this, my husband and I had a lot of stressful arguments, resulting in the suffering of our children.
34. My father would have been able to help me with my boys, he would have known how to tend to their bleeds. They were only 2 and 4 years old when he died. It is and was a huge loss not having him around.
35. Being the youngest, my husband and I carried most of the burden as we were close by. My mother was very lonely after he died and so we took her on as many holidays as possible, a way to distract her I guess. I was able to care for my mother who was diagnosed with cancer soon after my father's death.
36. We were very fortunate that we were able to help my parents but it was not without its pressures. My marriage suffered as a consequence but we pulled through.
37. My mother died in 1996, 6 years after her diagnosis and I did what I could to take care of her as much as I could until this happened. I however, have lost all confidence in myself and have very little self-worth after everything that has happened in my private life.
38. I began to drink again after my mother's diagnosis and subsequent death. I felt there was always a huge amount of pressure. Eventually I sought help and was prescribed antidepressants in 1996. I still had dark days, but they took the edge off and helped me get back out into the world.
39. My depression held me back from so many opportunities. I still cannot work, I feel that I do not respond well to pressure or responsibility.
40. Both of my sons are in their 30's now and I have an 11 year old grandson who I have taken care of since he was a baby. Professor Savidge was in charge of

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their treatment and I will be forever grateful to him for getting them the correct treatment.

41. Sometimes I suffer from panic attacks to this day and I continue to feel lost inside. I would like to see justice being served for my late father and for all of those who were infected with contaminated blood products so that I can finally move on with my life once and for all.

Section 6: Treatment/Care/Support

42. We, as a family, received no counselling and I recall clearly how my father was given only very basic advice, he was told that he should 'keep well' and not share his toothbrush with anyone. No counselling was offering to my father when he was alive or to our family when he passed away.

Section 7: Financial Assistance

43. In 2017 I was advised to apply for the first stage of the Skipton Fund regarding my later fathers' Hepatitis C infection. My two sisters and I received this between us.
44. After this, I then applied for the second stage as our father had chronic liver disease (which was stated on his death certificate). We were not awarded this as they stated we had a lack of medical information and an assumption that he had died of cancer over his liver disease.
45. In June 2019, I reapplied finally after tracking down who and where I needed to contact. I received the forms, filled them out and sent them on to Dr Dolan at St Thomas'. I asked him to give his overall opinion. My father was treated at St Thomas' under Prof Savidge as he had his hip replacement carried out there in 1988.
46. After some time, I contacted EIBSS where they confirmed that they had no knowledge of my father even though we had received the first stage payment

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and receiving the stage 2 forms directly from them. This was quickly resolved however the application was declined.

Section 8: Other Issues

47. On the day that my father died, my son had an ankle bleed and we had to travel to the hospital, which was where my father was admitted. It transpired that my son did not require the injections and so I took my son up to visit my father in the ward. My husband arrived and took my son outside to play while I sat with my father.
48. It was only by chance that I was there in the hospital that day. My sisters were out dealing with a house move, my mother was in the hospital rest room when my father died.
49. I was very affected by my fathers' illness, I watched him physically and mentally deteriorate, I gave him his last factor 8 on the ward of GRO-B the day before the horrendous blood vomiting caused by end stage liver disease.
50. I held his hand the morning he died on my own, so it was left to me to tell my mother that he had passed away.
51. My life was badly impacted by all this. I suffered deep depression and anxiety. I lost my hair twice due to the stress. Understandably, due to everything going on, I was unable to hold down any job.
52. I was also helping my mother constantly with sorting everything out for her, as well as being at her side to deal with every challenge she faced. It took a great toll on me, with my own Haemophiliac boys and husband who felt my burden.
53. I feel so angry that my father was infected with all of these terrible viruses and the fact that it is taking so long to get any truths hurts more and more with each passage of time. He could have been warned about the risks and made an informed decision at that time. He was not given a choice and he didn't know

that he had one. If he had known was ahead for him, he would not have accepted it.

54. Whilst I am grateful for the Inquiry for carrying out investigations, I must admit that it has brought back many bad memories.

Statement of Truth

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

Signed

GRO-B

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Dated

15/10/21