Anonymous
Witness Name: GRO-B
Statement No.: WITN0638001
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Dated: 5 March 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 December 2018.

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

Section 1. Introduction

1. My name and address are known to the Inquiry. My date of birth is GRO-B GRO-B. I am a married man with one surviving child. I intend to speak about my son, GRO-B: S who died aged 18. In particular, I intend to speak about the nature of my son's illnesses, how the illnesses affected him, and the impact it had on him and our lives together as a family. I am providing this statement about the experiences of my wife and myself as we remember them after all this time. For personal and family reasons I wish for mine and my families identity to remain completely anonymous.

Section 2. How Affected

2. My wife, GRO-B and myself married in GRO-B and had our son in GRO-B and our daughter in GRO-B. When our son was born he bruised easily. He would bruise even where the pins held his nappy in place. At first, there was a suggestion by the doctors that we abused him.

3. When our son was still very young he had a fall in our home by the fireplace and he experienced a lot of swelling. We took him to the GP who sent us to King George's Hospital. Our son was in the hospital for 10 days but we still did not know why he bruised so easily. He was eventually discharged and we were extra careful after that but he would still get a lot of injuries, especially his elbows.

4. It was recommended that we go to Bartholomew's Hospital and our son was admitted. They did a lot of tests and asked if anyone in the family had a bleeding disorder. We did not think so but my brother-in-law had a knee problem and could not walk properly. When my wife mentioned this the doctors decided to test the whole family for bleeding disorders. It was discovered that my wife carried the haemophilia gene and that our son had severe haemophilia A in 1978.

5. We were transferred to the London Hospital Haemophilia centre under the care of Dr Colvin and our son began treatment with cryoprecipitate. However, he had a bad reaction to the cryoprecipitate and would get all red and would end up in hospital again. Our life then was only hospital, home, hospital, home and so on. My wife especially found this very difficult with our daughter being a young baby at the time and my wife would get very depressed.

6. Eventually, the doctors suggested Factor VIII treatment. We were so relieved but now we know it was poisoning him. My wife and I were trained to inject him. We were both hesitant at first and I found I could not do it and so my wife injected him. The nurse, who taught my wife, was very patient and kind.

7. It was necessary to inject our son nearly every day because he was such an active boy. We used to have to keep a log of the injections and submit this to the secretary of the Haemophilia Society. We unfortunately threw away this record after our son died because it was too sad having the constant reminders around the house. He loved playing football and would sneak off to play because he knew he wasn't supposed to with his haemophilia. He would scare his mother and myself because he liked to play as the goalkeeper. He was very playful and jolly and had no other problem other than the haemophilia. He supported Leyton Orient even when all his friends supported much bigger teams. He also loved cricket. He was very fun and loving.

8. In 1985, I think, our doctor called and said he needed to tell us something. My wife and I went to the doctor and he told us that our son had HIV and Hepatitis C from infected blood. At that time, everything was very new and the doctors did not know much about the illnesses. We believe we were told in a good way and at the right time, but we were still shocked and devastated.

9. We did not tell our son right away because we did not want to trouble him, but a few months later with our doctor's encouragement we took our son to the doctor. Our son knew that something was not right as he said he was not due another appointment yet and he was confused. It felt like taking a lamb to the slaughter.

10. The doctor told him and he was always a very good doctor; he was very kind and patient. Our son said to my wife "mummy I am going to die". My wife told him he would not and tried to reassure him. We tried to make sure he had as normal a life as possible. I went out and bought him some earphones as he liked technology very much and I thought it might cheer him up.

11. At the time we were only advised not to touch our son's blood with our naked hands; we were told we had to use gloves. We were not told

anything else about the risk of being exposed to infection. We had to ask for further information on precautions to take such as the importance of not using the same toothbrush. A nurse told us that there were treatments and that more were coming so there was hope. We were not offered tests for our daughter or ourselves.

12. Our son was always very good at taking precautions and would grab tissues to mop up the blood whilst my wife put on some gloves. We would destroy anything with bloodstains on and had a special yellow box for such things.

13. Not much information was given at the time. It was only when we asked that we found out blood had been bought from prisoners in America who were taking drugs and such. The doctors reassured us that the blood was all tested and that we should not worry anymore.

14. We were always very strict with our son, maybe too strict, so he never had a tattoo or piercings or a girlfriend so we know he could only have been infected by the Factor VIII, which my wife gave him. We never allowed him to have any beer even though he once asked if he could have a sip and this decision now haunts my wife as she regrets not letting him try it.

Section 3. Other Infections

15. Our son was infected with HIV and Hepatitis C. We do not believe he was infected with any other illnesses. We heard about vCJD but do not believe our son was exposed to it.

Section 4. Consent

16. Mostly, we believe we consented for our son's treatment and testing as his parents. We were very happy with the hospital and our doctor.

However, we did not know that he was being tested for HIV or Hepatitis C and we only knew of the illness when we were told he was infected.

17. Our doctor did offer our son the chance to be a guinea pig for him for new drugs. The doctor said he would be given a fake tablet or a real one and observed. Our son said he did not want to and our doctor respected that.

Section 5. Impact

18. The physical impact of the infections for our son was not too noticeable to us. We were told by our doctor that his liver function would not be as good as it would otherwise have been. However, our son's disposition was very positive and he never complained about any physical impacts of the illnesses.

19. Mentally, our son found it much more difficult. He was very down after being told and he was depressed. He did not have treatment for this. Our daughter, who did not know of his infections, told him he was crying like a little girl. I think he found it hard keeping it from his sister. He lost interest in his studies as he felt there was no point because he would not live long. He was afraid that we would leave him in a home or hospice and never visit and he begged us not to do this. We told him we would never do that to him and that we would always be there for him. He lost interest in his hobbies, in life. He was worried for his future and whether he would get a job or who would marry him. He was no longer the happy go lucky child we knew, but a scared, withdrawn and vulnerable child.

20. His infections complicated his medical care. He would hide issues from his mother and myself. He had a condition with his back passage and had to have an operation for it. He was very scared and the medical professionals were too because of the haemophilia and the infections. He had to receive treatment and be operated on as the last

patient of the day to minimise risk to other patients. He did not understand this and did not like having to wait until last. My wife explained to him that he had to think of others.

21. After the operation many of the staff avoided him and my wife had to change his dressing for him as no one wanted to touch him.

22. Unfortunately, the operation did not work and he had to have another one. Our son took this very hard as he felt he hadn't been treated right in the first place and that was why he needed another operation.

23. However, it was not all negative. Our son had a very good relationship with Dr Colvin and the staff at the haemophilia centre. When the medical students came to study Dr Colvin would tell our son not to help them but he would tell them the answers. He was a very funny boy and the nurses liked him, though they had trouble getting him to stay in his bed for treatment sometimes. Our daughter didn't understand why S got so much attention and felt it was unfair how much time we spent on her brother, but the doctors were patient and kind to her and tried to involve her. The children would do drawings for the doctors.

24. The haemophilia centre put us in touch with another family and child in similar circumstances, which was a comfort. Our son became good friends with the young boy who was also infected. However, the other child died and we could not tell our son as it would only worry and distress him more. We did think after the other boy died that maybe we did not have long with our son.

25. Through my wife's volunteer work with disabled children, we found a swimming class, which our son enjoyed, and it helped him with his limbs.

26. Our son never received any treatment for his infections, to the best of our knowledge. We do not think there was much that could be done at the time. We took him for routine tests every three months as we had done before the diagnosis of HIV and Hepatitis C. We did not experience any difficulties or obstacles in obtaining treatment for our son as far as we are aware.

27. Our son's infections did impact on his medical care, as we had to make people aware so they could protect themselves. However, most were very kind. Our dentist was very good with the children and was very sad when she heard our son had died. However, some were not so kind and one community nurse who visited told us it was a very bad disease in an insensitive way and she refused to touch our son. We asked her not to tell anyone.

28. Whilst our son did not die from AIDS, his HIV and Hepatitis C did impact on his care and ability to recover before he passed away. On 1 April 1993, our son went to the leisure centre to take photos for a project for school. He had driven there taking his dad's car after pushing for so long to be allowed to drive. We received a call from the school saying he had fallen and hurt his head and that someone had to collect him and the car.

29. When our son got home he went to bed with a headache and we were told he had a concussion. My wife gave him his last Factor VIII injection as we felt something was wrong and we took him to the Royal London Hospital. His skin turned yellow and he was slurring his words and calling for his dad.

30. I drove to the hospital entrance, we all got out of the car and I left my car in front of the entrance. We took S inside A&E then the haemophilia team came and examined him. They told us that they needed to X-ray him. Then a policeman came and asked me to move my car, before I went S called out "Daddy, Daddy, Daddy."

They took him for the X-ray and while he was there he went into a coma and then he was taken into the theatre for an operation on his head but he never woke up from the coma. The doctor told us that because of his HIV and Hepatitis C he was weakened and he was not responding to medicine.

31. My wife was very distressed as we had been checking in with the hospital and they had said that S was fine and they had even taken him out of intensive care but when my wife visited she found him very ill and taking his last breaths. No one in the ward was even taking any notice or caring for him. She shouted for the nurse and they pressed the crash button. He was in the ward waiting for a second operation but all of a sudden he died, he never came out of the coma. Our son died aged 18 on GRO-B 1993.

32. Our son had a needle in his head to drain fluid from his brain. The undertakers asked if there was anything they needed to know and we told them about his HIV/Hepatitis C. They refused to remove the needle from his head because of the risk of infection. GRO-B GRO-B GRO-B GRO-B

33. After our son's death we had to go through the traumatic experience of going to the coroner's office because there was an inquest into his death. Police came to visit and the CID as foul play was suspected. The police wanted his clothes, but we did not have them as the hospital destroyed them. They also wanted his camera, but they did return this to us. Luckily a friend was there to support us when the police were there, but it was hard as our son had only died the day before. The inquest ruled accidental death. After it was over, our son's chapter closed for them, but it never closed for my family or myself.

34. Our son's school were very supportive and over 200 people attended the funeral. The school did a collection and we asked for it to be

donated to the Haemophilia centre. They also planted a tree opposite his class in his memory with a plaque in his classroom.

35. In the end, we were very relieved that our son did not suffer the terrible end that people with AIDS suffered and that he died with some dignity.

36. Our son's infection had a very significant impact on our daughter. She was not aware of his illness until about a year before S died and she took this very hard. Whilst our son had treatment she was aware of the extra attention he was given when she was younger. Before her brother died and we told her she was shocked and saddened and became withdrawn and depressed. After her brother died, our daughter was very depressed and was very nearly institutionalised at a psychiatric hospital. She would constantly worry that she was ill too and worried that she would die and she would ask us to take her to the hospital as her head hurt or she didn't feel right. Fortunately, a family member came to visit and took her to Europe and she was much better after that. Our daughter also failed some exams and we paid for a private tutor to help her with the retakes.

37. The impact on us as parents was very difficult. We were shocked, devastated and completely numb in receiving the news that our child's life would be cut short. We worried about telling our daughter. My wife especially felt incredibly guilty for being relieved when Factor VIII treatment was possible because that was the thing that was slowly killing him. We are lucky we have our faith as this has helped us. We encouraged our son to live a normal life and have faith, but it was a heart-breaking situation.

38. After our son's death, we would walk a lot, as it was hard to be in the house. I had some counselling for a short time but did not find it very helpful. I was offered medication, but refused. I also suffered from angina since my son passed away and have been admitted to GRO-B GRO-B hospital. My heart condition has continued to deteriorate

from then and I had a bad heart attack in 2012. The medications also cause trouble for my stomach and have damaged the lining. My wife was strong at the time, but struggles far more now. My wife cries a lot and really struggled to help me with this statement.

39. The infections had a wider impact as we, to this day as per our son's wishes, keep his infections secret from the wider family. We would live in fear of his death and of people finding out about his HIV and Hepatitis C. We found it difficult seeing his friends growing up and wondering what the future held for him. We still find it very hard seeing his friends now much older and grown up because he never had the chance.

40. The stigma was well known from horrible TV adverts. My wife would turn the TV off to save my son and us some of the distress of seeing these programmes.

41. Additionally, the school our son attended sent a representative to our house to try and find out if he was infected with HIV. They sent someone three times and my wife and son would hide from them. We had two visits from the school as they left their card and one visit from a social worker from the local Council. It was a very frightening time, a nightmare. We were afraid the rubbish men would not want to collect our rubbish if they knew. We were afraid people would not want to visit if they knew. A social worker from the council came to visit and we tore up the calling card and put it down the sink. We never complained about how we were subjected to these visits because we were made to feel that we were somehow in the wrong. Living, keeping it a secret was, and still is, very hard. My wife told my son never to tell anyone because he would be treated like dirt.

42. We eventually took our son out of that school and sent him to another school. His education was disrupted by his illness as he lost confidence and motivation and interest in his studies. The school only

knew about his haemophilia not his HIV or Hepatitis C. When our son took his GCSEs he failed them.

43. Our son was always concerned he would not get a job. At one point he had wanted to be an accountant like me, but after his diagnosis he lost interest and motivation as he thought he was dying and there was, therefore, no point. He made many applications that were not successful. However, a friend of my wife's, who she meet when she helped with the disabled children taking the swimming, managed to get him a job at GRO-B, which he enjoyed. He only had this job for three months before he died but while he was there he was encouraged and had hopes of becoming a manager. He wanted to be the goalkeeper for the staff football team.

44. The financial implications of our son's illness were far reaching. We are not wealthy people but fortunately we have always had a roof over our head and food on the table so we have been okay. However, my wife had to give up work to look after our son and be there in case the school sent him home, which did happen often.

Section 6. Treatment/Care/Support

45. Our son was not offered any treatment for his infections other than the trial, which he refused. He was not offered psychological support or counselling.

Section 7. Financial Assistance

46. When we were told our son had been given infected blood we considered suing and were recommended a firm of solicitors. Unfortunately we threw away all the paperwork, but it was a firm in GRO-B in GRO-B. I did not qualify for legal aid so they asked our son to apply. He succeeded. We gave a statement. There was a lot of publicity at that time about the infected blood and litigation. All of

a sudden the government agreed to compensate everyone and we got 2 lump sums of money. We received the first immediately and the second was put in trust. We don't remember signing any undertaking in order to receive the money.

47. The Haemophilia Society encouraged us to apply to the Macfarlane Trust and received a monthly allowance of around £30 I think. They paid for our son's last holiday to see his family abroad, for a computer for him and for a humidifier for his room. We were very happy with them. When we told them he died we did not get anything anymore.

48. We received a letter from the Terrence Higgins trust asking if we wanted to claim from them and we did so for our son's Hepatitis C infection. This was only four or five years ago now. We did not have any medical evidence anymore so they wrote to our doctor and it was sorted and they gave us a lump sum. They said there was another payment for another liver condition, but we did not know what it was and did not apply, as we did not want to bother the doctor again.

49. We only received what we were offered and never sought anything more. My wife received carer's allowance whilst our son was alive and he received disability allowance. I did not have to pay car tax whilst he was alive either.

Section 8. Other Issues

50. We joined the Haemophilia Society when our son was first diagnosed and always found them very supportive. Every year we were invited to attend gatherings but we did not go.

51. We have fought for all these years and even now it is so difficult to tell the story. Even after 25 years it still hurts and nothing will make that pain go away. My wife still gets very upset and cries whenever our son is mentioned.

Statement of Truth

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

Signed GRO-B

Dated 12.3.19.