Witness Name: GRO-B

Statement No.: WITN2643001

Exhibits: 0

Dated: 15 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

I, GRO-B will say as follows.

1. My date of birth and address are known to the Inquiry.

2. My father, GRO-B was a severe haemophiliac, with Haemophilia A. He suffered frequent bleeds and required regular medical treatment and operations. Dad had an older brother who had died from severe haemophilia as a child. My mother was disabled as a result of contracting polio in the Oxford polio epidemic of 1956 when she was 11 years old. Mum suffered 14 or 15 miscarriages over the years. My parents had a son before I was born but he died at a day or so old as he also suffered with haemophilia and had a bleed. I was born with left

sided hemiparesis and as a result of this and other issues, I am registered disabled. I have no other siblings.

3. Dad passed away in GRO-B 1988 as a result of developing AIDS through contracting HIV from contaminated blood. Mum took her own life nine and a half years later after almost daily attempts to do so.

4. I am single. I lived in a shared house until December 2018. My landlady opened my post in December and evicted me after reading correspondence from my solicitors about the Infected Blood Public Inquiry about my affected status. I have been homeless since then and am struggling to find somewhere to live.

Section 2. How Affected

5. Dad's severe haemophilia was not particularly stable and he suffered many bleeds. He was frequently treated with Factor VIII for internal and external bleeds. We lived in GRO-B Oxfordshire, for many years and my dad was treated at the John Radcliffe Hospital. We were told that during the time he was treated at the John Radcliffe Hospital he was only treated with Factor VIII from the UK. We moved to GRO-B in December 1984, around two to three years after his treatment was transferred to St Thomas' Hospital where, for the duration of his treatment, his consultant was Mr Savage and the ward sister was Sister Bird. St Thomas' Hospital used imported unheat-treated Factor VIII from the United States. We do not know which batch infected him.

6. When I was just short of five years old I was trained to give my dad Factor VIII. I remember being told it was because my small fingers were more nimble. I was told not to get any lumps in the mixture or air bubbles in the injection, because it could kill my dad. I helped look after both my

parents from a young age, and this included injecting my dad. Mum used a wheelchair due to the polio infection she had contracted as a child. Dad's disabilities were more 'invisible' because he suffered with various issues related to his haemophilia and walked with a calliper on his left leg, as it became weak and wasted due to a bleed when he was a child.

7. Dad gave blood annually, as many haemophiliacs did, to provide samples for experimentation to find a cure for haemophilia. Without dad being informed, one of these samples was tested and found to be positive for HIV, but it was two years before my dad was told.

8. AIDS became very big in the news at that time and dad went to ask for an AIDS test at St Thomas' Hospital. A few weeks later the clinicians told him he had already been tested over two years ago, and that he had tested positive for HIV at that time. As a result of the way this was handled we lost trust in the medical community: the people who were meant to treat him and look after him had known this and kept it from him for two years.

9. I do not know the exact date or dates when dad was given infected blood products, however we found out he was infected with HIV in 1986. The hospital had known for two years so he must have been infected before 1984.

10. Later on, when dad reached out to our local haemophilia society, we found that the same thing had happened to dozens more haemophiliacs. The more we told our story and asked what had happened to others, the more they asked and found out they too had been tested without their knowledge or consent when giving blood.

11. Absolutely no information or advice was provided to our family beforehand about the risk of being exposed to infection or how to protect

ourselves and take precautions. Dad had had Hepatitis B several times when I was a child, as a result of infected Factor VIII. The first time he got hepatitis was when I was about four and I remember he turned bright yellow with jaundice. I remember he told me that there was just an error and they had not properly pasteurised the blood. I think that was what he had been told by the hospital. After that I recall him telling me the blood products were heat treated so there should not be any risk of disease. Dad was not told that the blood products he was given posed any risk of infection.

12. Dad was informed verbally by his consultant, Mr Savage, of his infected status. Mr Savage advised that he should use protection when having sexual relations, to use and wash his sheets separately, to use separate utensils and wash them in boiling water, not to take suits to the dry cleaners, and he was warned of the risk of passing the infection on with blood to blood contact. There was far more information about how not to infect others than about how to keep yourself safe and well. Mum and I were told we should have the test. I was also told to double-glove and inform our G.P. if I suffered a needle stick injury.

13. Although I believe dad was not provided with adequate information to understand and manage the infection, I do not know specifically how much information the haematologists at St Thomas' knew themselves at that time. I was a young teenager and didn't ask as many questions as I would now. I believed dad was going to die of the plague, because that was all the information that the media was sharing at the time.

14. Dad should have been provided with his results two years earlier, when the hospital tested him for HIV without his consent. He should also have been advised of the risks associated with the blood products he was being given as soon as the risks were known. The risks and precautions

should have been immediately publicised for anyone receiving blood products, whether by transfusion, Factor VIII, Factor X, plasma, etc.

15. Dad's diagnosis was communicated to him without any kind of counselling or preparation. He was just informed that the hospital had already had the test information for a couple of years and this was the result.

Section 3. Other Infections

16. My dad was also infected with Hepatitis B and we suspect several other diseases of varying severity, as a result of being given infected blood products.

Section 4. Consent

17. I know that dad was tested for HIV without his knowledge, consent or being given adequate or full information. I do not know whether this was for the purposes of research. Although he gave his consent for his blood to be used for research purposes to find a cure for haemophilia, as many haemophiliacs did, he did not give his consent for anything else.

Section 5. Impact

18. The mental effect on my father of being diagnosed with HIV was traumatic. At that time the government was starting the tombstone and toe tag television adverts about safe sex. Dad believed he would die immediately from a massive haemorrhage. No one told us anything about the effects of HIV on a patient: we just heard sensationalised news about people bleeding to death from every orifice. I just equated sex with death. My mother had terrible issues around loving my dad, being physically afraid of him and the risk of infection. My dad himself was very

brave and tried to spread awareness of best practice, the latest research and treatment options, until he died.

19. The physical effects were as follows. We began to learn that when someone becomes 'full blown' with AIDS, the first infection they usually get is a very long lasting flu. When dad got this in September 1987 it was the signal to us that he was full blown. We knew more about it by that time because there were more people with AIDS. Dad was six foot six inches and was a strong and fit man. Suddenly his body weight halved and he just shrank. He became skinny and weak and out of breath. It was almost like he had Hepatitis B again, as he was quite yellowish. His flu lasted for four months. The hospital told us that this meant he had AIDS.

20. Although we knew the long lasting flu meant he was full blown, it did not become acute until early morning on Boxing Day 1987. I woke up to mum screaming and screaming and she wouldn't stop. I went into their bedroom and discovered dad was so weak and frail he couldn't get out of bed. As mum was wheelchair bound, she couldn't get across the bed to reach her wheelchair and get up.

21. We called for an ambulance. When mum explained the medical issue, they refused to attend. We phoned St Thomas' directly and asked them to send an ambulance instead. It took four hours for an ambulance to arrive.

22. When we got to the hospital no one wanted to treat dad and he was left on a trolley in A&E for about two days before anyone would touch him. I don't remember whether this was a fear issue, or whether they were full over Christmas. I just remember my dad being hungry and thirsty, struggling for breath and getting bruises from the trolley, because it

wasn't a proper bed. We later found out that this was the first full blown infection, pneumocystis pneumonia.

23. Eventually he received treatment and he started to get better. However, the treatment failed and his condition started to deteriorate very rapidly again. Some sort of treatment was flown over from America for him, we had to sign disclaimers that we wouldn't sue if all of his organs failed or anything else catastrophic happened. Mum was too upset to sign the document and dad was too sick, so I had to sign it. We had a dozen or so days when we left dad seeming well and improving in the hospital, only to find that he was on the critical list and there were messages on the answerphone by the time we got home, about an hour's journey. It was several months before dad was well enough to come home, he had lost even more weight, he was physically unsteady on his feet and he had severe breathing issues, which continued for the rest of his life. It's hard to explain the speed and severity of the worsening of his condition. I became afraid of leaving him to go to school and mum didn't want to leave him to go to work.

24. A few months later he went back to work, but he developed another infection. Although he was back at work he needed lots of blood transfusions, sometimes plasma as well, and sometimes red cells just to keep him alive. The Wellcome Foundation started making super vitamins, which were later found not to work, but the idea was to give thousands of daily vitamins to boost the immune system. Every time dad got an infection and survived it, it was as though I got my dad back, but another part of him didn't work.

25. Later that year, during a planning meeting at work for the proposed Jubilee extension, he began to feel unwell. He crossed the road to St Thomas' and it turned out he had had a huge bleed into his kidney,

almost a pint. He was tremendously ill and in hospital again. We didn't know if his illness was caused by general haemophilia or whether it was AIDS related, but once he was in hospital it turned out to be due to AIDS.

26. Dad was discharged from hospital for a little bit but it seemed like no time at all before he was back in. He was in a lot of pain and on opiate based pain killers so was no longer really himself. He got sicker and sicker and never came out of hospital again. He died on GRO-B 1988.

27. Dad's further medical complications which resulted from HIV were so many that it is hard to separate it out. He suffered with pneumocystis pneumonia, additional bleeds, a number of internal bleeds he would have had anyway, his gums receded and he had tooth problems, he lost feeling in his hands and feet, his eyesight started going, and his organs started giving up. It all happened so fast that it seemed as if everything was happening at once.

28. Dad received treatment for the different infections, but after that there were so many conditions and so many treatments that I couldn't keep up with it. Very soon everything stopped working and nothing was helping any more.

29. We faced difficulties in accessing treatment on several occasions. For example, the ambulance service refusing to come to our house and when dad was left in A&E for two days. Many of the nurses didn't want to take his blood. They wouldn't wash him, brush his teeth or change his sheets. We had to do all of that ourselves. Certain drugs required suppositories after his veins collapsed and we did that because no one else would. Hospital staff would not always give him food or drink, so our family had to ensure someone was with him all of the time to make sure nothing happened to him.

30. It is hard to know whether there were treatments which should have been made available to him which were not. We didn't know that much about what was available. He was one of the first haemophiliacs to go full blown at St Thomas'. He was also one of the first to have pneumocystis pneumonia which was of a different strain to that which other people had.

31. The mental and physical effects of the treatment dad received were dreadful. He received AZT which was very new and tremendously experimental. It was the most awful, depleting drug and it didn't work. He only received it in the last four or five weeks of his life. AZT was later shown not to work. We were not given enough information about what was happening. Drugs were put in front of us and we were told, 'this is what we have and this is what it is'. There was no choice between drugs. They often didn't know the side effects because the drugs might not have been used on people before.

32. I do not know whether dad's infected status impacted on his treatment, whether medical or dental, other than where I have set this out above. After he was discharged following the pneumocystis pneumonia I don't think he went to the dentist again, but I do not know if he simply had no time and wasn't well enough or whether they refused to see him. He did try to protect us from some of the stigma and poor treatment he received.

33. The impact of HIV and AIDS on our private, family and social life was extreme.

34. During the two years when he was undiagnosed, my parents continued to have sexual relations. When dad then found out he was HIV positive this caused mum a great deal of psychological distress and caused her to have several nervous breakdowns. The hospital advised both mum and me to be tested for HIV. Mum suffered with polio and had always been

quite fragile and quite volatile. The AIDS test was not just one test, but a series of tests over a number of years. It took six months for her first result to come back and then she would have to be tested again. She was tested every six months for two years. She had to live with that fear. Her results were negative.

35. I was 14 at the time I was tested. I did not want to be tested and did not consent. I was held down by five people: one holding my head still, and a person holding down each of my limbs. My results were also negative.

36. As a family, we could not tell anyone about dad's infection because of how AIDS was considered at the time. We tried telling our closest friends who were our neighbours and the very next day they moved out; they rented their house and later sold it and we never saw or heard from them again. At home we stopped having anyone come into the house: we could no longer have a cleaner or a handyman, or the regular carers who used to care for my parents due to their disabilities. No one was allowed to come into our home in case they found out.

37. All social life just stopped. We couldn't eat out and didn't go out anywhere because of the infection risk. We were worried dad might become unwell or cough, or someone might realise what was happening because he looked unwell. I couldn't have friends round to our house. I didn't go to other people's houses because I was so scared if something came out and people realised what was going on. I was told not to tell anyone for fear of being beaten up or attacked.

38. My parents talked to me all the time about not mentioning anything, not even that my father was a haemophiliac. It was very difficult to know what to say when people started talking about AIDS. At school children were wishing AIDS on others as an insult, and I wanted to say something

because I wanted people to understand, but I couldn't say anything. I was a haemophilia carrier and had an accident at school: I bled a lot but could not say anything, or ask for hospital treatment, in case anyone found out. It was like trying to hide and being fearful all the time that someone was going to find out.

39. Friends were disappearing from our lives and people were dying. We had a family friend who had six sons who were all haemophiliacs. They used the same batch of Factor VIII at the same time and they all became ill in quick succession. Many people stopped going to haemophilia society meetings, although dad still attended despite the risks of being found out.

40. It is really hard to explain the level of fear we felt. The stigma of HIV and AIDS at the time was very great. It felt like we had done something wrong, the worst thing and that we didn't have a right to exist. My parents already had disabilities and had suffered with discrimination throughout their lives, but everything just amplified.

41. The work-related effects for dad were not initially too severe. Dad was GRO-B at GRO-B He was well liked at work and many people covered for him when he was unwell and could not attend work. He had a lot of unpaid sick leave, particularly when he had four or five months of flu and then the ten month period when he officially had full blown AIDS. He was not paid for a lot of that time. My mother had to take a lot of time off work during this time but she could not explain why and she almost lost her job several times.

42. Financially things were difficult. My parents tried to put money aside because they knew dad was going to die. Their insurance policies were made invalid, when insurance companies changed their rules to exclude

anyone with AIDS, or who was HIV positive. At the time it was not possible to get a mortgage or to get life or health insurance or any kind of loan even if you had only been tested for HIV.

43. My school eventually found out about dad having AIDS, because it was a notifiable disease at the time. I had to drop subjects or change classes because certain teachers wouldn't teach me. I had to take months at a time off school partly to visit dad and partly because the school was deciding whether it was safe to have me attend. Several times I was suspended from school for months at a time.

44. The stigma did not end when dad died. After his death, we attended the Registrar's office to report dad's death. We were kept waiting a long time and other people in the office were staring at us. People spat at us and the tyres on my mum's car were slashed whilst we were waiting.

45. The death certificate gave AIDS as cause of death, we had no option to remove or change this, although it caused us further problems, both social and financial with mortgage companies and insurance, etc. I know that many families of haemophiliacs who died from AIDS bribed and begged doctors and officials to ensure that AIDS was not mentioned on the death certificate. I think this was to lessen the stigma and help with insurance issues. Those families cut ties with others in the haemophilia community, so they wouldn't be outed. I am very worried that those families will not now be able to participate in this Inquiry. There are thousands more people who would come forward if they knew they were able to.

46. We were not allowed to bury my father, but had to cremate him at a certified crematorium by a certain company, as part of the rules surrounding notifiable diseases. We decided not to hold a funeral for him because we were so worried about what might happen if we did.

47. After dad died the impact on mum was very great. She tried to take her own life several times a week and I had to stop her every time. I continued to be her main carer. She was signed off work for a year as she was suffering from depression and we believe that she suffered a nervous breakdown. Nine and a half years after dad's death she succeeded in taking her life whilst she was away at our country house in GRO-B My mother left everything to the G.P., who had failed to treat her depression or hospitalise her after the numerous suicide attempts.

48. My dad's infection with HIV and death from AIDS has cast a long shadow over my life. I was 14 when we found out he was HIV positive, and 17 when he died. I did not have any relationship at all until I was 22 as I equated sex with death and I had been told of all the risks of potentially contracting HIV. I was quite scared of forming relationships and I had a huge part of my life that defined me, which I couldn't tell anyone about. I was also a carer for the rest of my family until I was 30 (when my last blood relative died), as I had no dad, no finances and later, no mum, to help. Some of the relationships I have had subsequently have been difficult, one with an alcoholic, and the most recent with a man who became abusive and nearly killed me, after controlling and isolating me for years, resulting in me living in a refuge for 15 months and losing everything I owned. I am frequently outed as a victim of abuse and a relative of an AIDS victim. I have lost numerous jobs and accommodation because of this.

49. I was supposed to be a high achiever at school and was earmarked for Oxbridge, but my education suffered due to the amount of time I missed. When mum became suicidal after dad died I had to change my plans for further education. I had meant to go to Warwick to read law, but I then changed through clearing to Sussex to study English literature in order to be closer to mum. When that turned out not to be close enough I

changed again to study geology at Greenwich Polytechnic. I never finished my degree because I continued to care for mum and my paternal grandmother and maternal grandparents who became unwell at that time. I helped care for all three grandparents. When my maternal grandmother died 19 or 20 months after my dad, my mum could no longer cope and I needed to spend more time with her, to prevent suicide attempts.

50. I have a phobia of needles (dating from the time I was tested for HIV without my consent), blood tests and a mistrust of medical professionals in general, which has negatively affected my own health and I've nearly died twice, because doctors thought I was suffering from the trauma of my dad's death rather than firstly, atypical pneumonia, and secondly, erythema multiforme following a miscarriage.

51. I have sometimes not been believed when I tell people how my parents died. When I am believed, my physical ailments are thought to be psychosomatic or caused by trauma, which has led to delay in diagnoses of physical issues, including asthma, anaemia, thyroid problems and cancer.

52. I currently walk with crutches and a splint on my leg. I also have arthritis in my thoracic and lumbar spine, and severe arthritis and disintegration in my cervical spine. I believe this is from being a young carer and pushing my mother's wheelchair and transferring her to the bath and car from an early age. I have spinal tumours, asthma, kidney disease, endometrial tumours and polyps, inflammatory bowel disease and I have been unable to eat solid food or sleep lying down for over a year, due to breathing issues. I had an urgent gynaecological operation cancelled last November at less than one day's notice, apparently because of my haemophilia carrier status, although the surgeon later phoned me to discuss my AIDS status.

53. I am in the process of applying for dad's medical records. I anticipate there will be many gaps because I know that at the time a lot of things were not recorded. One explanation for this is that there may have been an attempt to reduce the stigma associated with the disease. I know that after my mother died when I asked for a referral for counselling there was no record in my medical records of my father's illness or what he died of, or the fact I had had a HIV test myself. At the Inquest into my mother's death I had to relay much of the information about my father's illness and death to the Coroner's Officer as there was very little in my mother's medical records about it.

Section 6. Treatment/Care/Support

54. As I have described above, dad frequently faced difficulties in obtaining treatment, care and support. The worst occasions that stand out are when we were unable to get an ambulance to come out to collect him and when he lay untreated in A&E for two days. Staff routinely refused to care for dad, whether it was taking blood, washing, giving injections or medication, or providing drinks and food.

55. No counselling or psychological support was ever offered to my parents or me in consequence of what happened.

Section 7. Financial Assistance

56. We have not received any financial assistance from any of the Trusts and Funds set up to distribute payments.

57. We were one of the first families to take legal action against the government. Our case became a class action together with other haemophiliacs to secure compensation. Our family received

compensation GRO-C Most of the compensation went to pay my mother's legal bills GRO-C I received a payment GRO-C Although we were awarded costs, they didn't cover everything and my mum actually received far less compensation, once these costs were paid. The total compensation was less than one year of earnings for my dad, between his GRO-B GRO-B role at GRO-B and other outside work undertaken.

Section 8. Other Issues

58. From the moment when dad discovered he had been HIV positive for two years without being told, our family became concerned that medical professionals had withheld information and not provided us with the truth. This feeling continued throughout dad's treatment as we had no knowledge of what treatments were available and were reliant on those who had withheld the diagnosis from us to treat and care for him. We had no choice but to trust in them.

59. I hope the Inquiry addresses two things first and foremost. First, I hope the testimony and findings are open and conveyed swiftly and clearly, without ambiguity or sensationalism. Second, I hope issues surrounding knowledge, consent and dignity are carefully considered. I think there was, and still is to a certain extent, a view among the medical profession that haemophiliacs are only alive because of advances in medical science, that they are lucky to be alive and are living on borrowed time, and anything that happens to them therefore doesn't matter. When I was eight I attended an appointment with my father where the consultant told him to be grateful he was still alive because if it wasn't for Factor VIII he would have been dead twenty years earlier. The expectation was that haemophiliacs should be grateful for whatever life they had. This attitude has created enormous difficulties for human dignity, treatment and the

giving of information. So many of the problems haemophiliacs have experienced stem from this one attitude and this is what needs to change.

60. I hope the Inquiry will achieve lasting change in how the medical and allied professions cope with unknown disease. AIDS was so frightening for many people because of the lack of knowledge. I hope protocols can be developed around the safety and dignity of patients and also for society as a whole.

Statement of Truth

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

Signed

GRO-B

Dated 15 February 2019