

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN0125001

Exhibits: WITN0125002

Dated: 31 July 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

1. I, **GRO-B** will say as follows:-

Section 1: Introduction

2. My name is **GRO-B** My date of birth is **GRO-B** 1980. I reside at **GRO-B**

3. I am married **GRO-B**
GRO-B

Section 2: How infected

4. I have two brothers, **GRO-B: B1** **GRO-B** and **GRO-B: B2** We all have severe haemophilia A.

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5. My mum was aware of a history of haemophilia in our family so **B1** was diagnosed within three months of his birth. **B2** and I were diagnosed within two weeks: **GRO-B**

How I was infected

6. I was infected with HIV in 1985 before my fifth birthday but was not told about it until I was 12 years old.
7. I have obtained my records showing when I was tested for HIV from the UK Haemophilia Centre Doctors Organisation's National Haemophilia Database (the "Database") [WITN0125002]. These records show that I was tested on 15 December 1984 and that this was my last negative test result. I was tested again on 30 September 1985; this was the date I first tested positive for HIV. I don't know about my brothers being tested. They probably were, but I cannot confirm this. My parents were not aware of me being tested for HIV. They are aware of another patient at GOSH who was diagnosed with HIV at the same time as me, suggesting there was systematic testing of patients going on at the time.
8. I have also obtained records from the Database which show all the treatment I received for haemophilia from 1981 to 2018. I only had two treatments in 1984. The first treatment that year was cryoprecipitate. It is unlikely that cryoprecipitate would be the source of my infection as it would come from the blood of only one individual. The second treatment in 1984 was Factor VIII which was produced from British blood. I only had one treatment in 1985 and that was Factor VIII produced in Oxford. These treatments can be seen on page 3 of the patient annual treatment record [WITN0125002].
9. As a result of these records and information provided by my mother, I have been able to narrow down the source of my infection to either the second treatment I had in 1984 or the sole treatment I had in 1985. The second treatment I had in 1984 was due to a bad bleed I had in my left elbow in November 1984. For a haemophiliac, the main issue is "target joints" where internal bleeding occurs. My left elbow was my target joint.

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10. My mother has described how I was treated with Factor VIII concentrate from a different batch from my brothers for this bleed. This is, as far as she is aware, the only occasion on which I was treated with a different batch of Factor VIII from my brothers. As neither of them are infected with HIV, we suspect that the batch used to treat my elbow in November 1984 is likely to have been the contaminated batch. This pre-dates the date of my negative HIV test result on 15 December 1984 but it may have been that the infection had not yet incubated by the time I was tested.
11. Home treatment for haemophilia started in 1984. Prior to this, haemophiliacs had to be taken to hospital in response to each bleed. My mum has told me that there were days when she would have to take us to hospital because one of my brothers or I had bleed and then she would have to return later that same day as another one of us had a bleed.
12. The Factor VIII which I believe infected me with HIV was administered by mum from a batch we had in the fridge at home. This is how my mum knows that I was treated through a separate batch from my brothers for my elbow on this occasion.
13. My mum has told me that the Factor VIII treatment I received in 1985 was also given to one of my brothers. Neither of my brothers are HIV positive.
14. To manufacture Factor VIII, all blood taken from donations were pooled. The batch that infected me could have been created from blood from up to 20,000 donors. Anyone who was given that batch could have been infected.
15. At that time the general population did not know about heat treatment, which kills the virus. I have since come to understand that the medical profession was worried about the effectiveness of the blood products for the treatment of haemophilia being reduced as a result of it being heat treated. However, that risk paled in comparison to the risk of people becoming infected with HIV.

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16. The biggest change for me in the treatment for haemophilia was around 1990 when my I went on to prophylaxis. Prophylaxis is a preventative treatment and I currently take it three times a week intravenously. Factor VIII had to be taken on demand when a bleed occurred previously.

Parents Learning of Diagnosis

17. My parents found out that I was HIV positive in early October 1985, shortly before my fifth birthday. This was after the test that I underwent in September 1985.
18. I understand from them that my parents received a phone call from someone at the hospital asking them to come and see them. They said that there was an issue with one of our results. My dad was working away in Liverpool and flew straight back down to London. My mum has said that she knew immediately that this issue would be with my result, as my glands were often swollen as a child. They were informed at the hospital. I was not present.
19. When I was diagnosed my parents were told that I would be lucky to see my tenth birthday. They accordingly always made sure that we had really good summer holidays and tried to give my brothers and me the best of things. We weren't spoiled, far from it as my parents came from working class backgrounds, but we were well loved.
20. In 1986 my dad was diagnosed with depression. My mum has said that at one point, while we were children, they were living separate lives. My dad would go to work in the morning and not come home until late at night. He was struggling with my diagnosis. As children, my brothers and I thought that was normal. My parents argued heavily on occasion; it was a sign that they were not coping.

Learning of diagnosis

21. In the summer of 1993, before I started secondary school, I went to GOSH for a haemophilia check-up. It was not uncommon for us to have our check-ups in the school holidays to avoid us taking time off from school. On this occasion my dad

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also came with us to the hospital. This was unusual as he did not generally attend our appointments.

22. [B2] was with us and he and I were left in the waiting room with my dad while my mum disappeared. I was then taken into a room with my parents and [B2] Di Gibb, one of my doctors, was there with my nurse Kate Khair. That is when they told me I was HIV positive.
23. By the age of 12 when I was told, I knew a bit about HIV as it had been in the news. The people I saw on television were always really ill. Hearing that I was infected with HIV was devastating. I broke down in tears. When I composed myself the first thing I said was "Am I going to die?" For a 12-year-old boy, that was a pretty big thing to face.
24. My older brother, [B1] had been told about my diagnosis the night before. He did not come to the hospital as he was working at that time. When I spoke to him that evening, he said "*You're alright, aren't you? You're going to be alright.*" It was all a bit stiff upper lip and carry on.
25. When I rationalised it, I thought "*I haven't known for seven years and I've been okay, so why can't I continue to be ok?*". I just carried on. I did not know what my life expectancy was.
26. After I was aware that I was HIV positive I saw my hospital notes from GOSH when I was collecting them to take them to an appointment. Inside they stated "*HIV PATIENT UNAWARE*" and this was highlighted and marked so it could not be missed. This was probably a year or two after my being told.

Information provided to me

27. My parents had discussed how to tell me of my diagnosis with the hospital and I felt very supported on the day I was told. Afterwards, I just had to get on with it.

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28. I was never told what I could or couldn't do as a result of being infected by HIV. I don't think a doctor or a nurse ever had a conversation with me about the possibility of sexual transmission of HIV. I learned about it in sex education at school. Having the diagnosis meant that I was interested in the subject and read articles relating to HIV. Having haemophilia meant that I probably matured a little earlier than some due to having to manage my condition. Being diagnosed with HIV added to this.

Section 3: Other Infections

29. I do not recall when I was told that I had Hepatitis C. It felt somewhat insignificant in comparison with my HIV diagnosis. I was also written to in around 2004 and advised I may have vCJD.
30. Both my brothers were also diagnosed with Hepatitis C. Neither of them remember exactly when they were told either. My mother seems to remember being told my older brother **B1** had Hepatitis C when he first moved to St Thomas's Hospital from GOSH. That would have been around the mid-90s.

Section 4: Impact

Initial Impact

31. In the year to 18 months after I had been told I had HIV, I started to look back and make sense of things that had happened prior to me learning of the diagnosis.
32. I unknowingly started treatment for HIV when I was eight years old. The treatment was contained in a syringe and I had to drink it. I vividly remember standing by the sink and telling my mum I didn't want to take it because it tasted bad. My mum said I had to drink it and could have a glass of coke if I did. After that, I had it in my lunch box at school as I had to take it twice a day. Most people had a sandwich and a packet of crisps; I had a sandwich a packet of crisps and a syringe. I later found out that this was my HIV medication, AZT. One day another

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child took the medication from my lunch box and squirted it. My mum had to come to school to give me another syringe with my medication in it.

33. My mum was always petrified of me getting chicken pox. Any time I was ill (which wasn't very often), I would be taken to the doctors. After any such doctor's appointments, B2 and I would stand outside in the corridor and hear our mum cry. I later realised that was because the doctor was the only person she could talk to about my diagnosis.
34. When I went to GOSH I would always see two doctors; a haemophilia doctor and another doctor. She was very nice but I didn't know why I was seeing her. That was Dr Di Gibb. I now know that she was a HIV doctor. She used to come from Mortimer Market to GOSH to run a special clinic for boys with HIV. I later learned Dr Lynne Ball fought tooth and nail for children such as myself to get treatment for HIV at GOSH. Dr Lynne Ball was the haemophilia doctor at the time.
35. I believe I also underwent psychological testing as a child, although I was not aware that was what was happening at the time. I would sit and do puzzles and memory tests. HIV was brand new and they didn't know how it affected those infected mentally or physically; hence I was being tested without even knowing it. My parents knew as my mother would sit in during the tests. I also had brain scans.
36. My mum asked me on a few occasions when I was around 8 or 9 if anyone had ever asked me about being "blood brothers" at school; whereby boys would cut their fingers and share blood as a sign of friendly allegiance. She never told me why or told me not to do it but it made sense why she asked in retrospect. On one occasion I almost said yes, to see what my mother's reaction was.
37. Around age 10, I had headaches for a month. I was admitted to GOSH and had a lumbar puncture. My parents were incredibly upset and it became clear to me after my diagnosis why they had been so worried. I had back problems as a result of the lumbar puncture. I couldn't eat and was put on a drip. I do not think that

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had anything to do with my HIV medication as by that point I had been on it for a couple of years and side effects usually show fairly quickly.

38. Initially the impact of my diagnosis, was just doing all this checking back in my head and making sense of things that had happened. I don't think the diagnosis itself directly had a significant effect; I didn't become depressed or withdrawn and I didn't stop wanting to go to school.
39. On one or two occasions, I do remember crying myself to sleep, thinking I was going to die. I remember thinking back to when Freddie Mercury had died in 1991. With it being so recent, I felt there was still a risk of HIV killing me. I remember my mother asking my brothers and I during car journeys sometimes, if we died, whether we'd want to be cremated or buried. Despite the seriousness of the subject matter, it was always quite light-hearted. On reflection however, it is clear that my parents had considered my funeral at some point.
40. After I was told about my diagnosis, my parents also discussed making an application to the "Make-a-Wish" Foundation. This is a charity for terminally ill children. As I was relatively fit and well, it is something we never get round to doing.
41. As a child I often had swollen glands and thrush in my mouth but these were relatively minor effects of having HIV. This can be seen from a document in my UKHCDO records, namely the survey of patient's HIV infection. Under the question "How would you classify his/her condition? Under "other" it states "well, but has occasional candidal infections".

School and University

42. I grew up in **GRO-B** in **GRO-B** and went to the local state primary school there. I then went to **GRO-B** and then to **GRO-B**

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43. Shortly after my diagnosis my treatment for HIV changed a bit. I had to take a tablet which had to be dissolved in water which was awkward to take. This was called DDI.
44. I didn't miss much school as a result of my infection with HIV. On one occasion, I had a reaction to a new HIV drug, 3TC. I got a rash all over my body and could not go to school.
45. The two main issues in relation to HIV are viral loads and CD4 count. Everyone has a CD4 count; it is an indication of how good your body is at fighting viruses. When I was first diagnosed I had a CD4 count of zero which meant I was incredibly vulnerable to illness. When I was in my late teens, I started to get a CD4 count. When I was a child I had warts on my fingers and toes but as soon as I got a CD4 count they disappeared almost overnight. I was getting better. That fact wasn't lost on me as a teenager. I must have been around 17 at the time.
46. At that time, CD4 count was considered the most significant measure. Now viral load is considered the most important thing. There were times when I changed medications and my viral load shot up to around 30,000. My body would become resistant to the medications but more medications were becoming available to try.
47. My school knew that I had haemophilia, but did not know that I was HIV positive. My mum has told me on one occasion when HIV had been in the news, a parent went to the school and demanded to know my brothers' and my HIV status as she knew we were haemophiliacs. This was when we were all in primary school. The lady who did this was a nurse. The Headmaster refused to tell her. He did not know in any event.
48. Initially no-one therefore knew I was HIV positive. My parents only told our neighbour and my dad's sister. To this day, very few people know.

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49. There was no real support to equip me with how to tell someone that I was HIV positive or of the “do’s and don’ts”. The first person I told was my first girlfriend when I was 16. It was a big thing for me. I had heard stories about how other people with HIV were treated but she was great. We stayed together for a couple of years after I had told her and we went to university together. We split up between first and second year but it was unrelated to the fact that I had HIV. We have stayed in contact. She studied biology and later did work in relation to HIV.
50. I told my best friend around the same time I told my first girlfriend. There was no change in our relationship. I think that’s what teenagers are like; they just roll with things.
51. I stayed on at school to do my A-levels. I was encouraged by the school to go to university. My deputy-head of sixth-form’s previous boyfriend was also a haemophiliac and we had a conversation about HIV but I did not tell her that I was HIV positive.
52. In 1998, I went to The University of East Anglia **GRO-B** In the summer between second year and third year of university I met **GRO-B** my now wife, in Gran Canaria. I told her that I was HIV positive relatively quickly. Other than having to take precautions around sex, she treated me completely normally.
53. On a couple of occasions during the early years of our relationship, the condom we were using split. On both occasions we sought treatment and **GRO-B** was tested for HIV. She took HIV medication for short periods to reduce any risk of infection.

Professional Life

54. When I finished university I returned home to live with my parents. **GRO-B**

GRO-B

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55. I didn't discuss my medical condition with prospective employers. I had some experience of discrimination based on having haemophilia when I was younger. **B2** and I were applying for summer jobs and we disclosed the fact that we had haemophilia on the first five or six of our applications. We didn't get any calls back. When we submitted our next application we decided not to disclose it and got calls about the jobs we applied for the same afternoon. I assume the treatment would have been far worse if I had disclosed I had HIV in addition to being a haemophiliac. This made me wary of telling prospective employees about my medical conditions.
56. When I obtained **GRO-B** I told my **GRO-B** that I had haemophilia but not that I was HIV positive. People are often surprised to hear that there is so much stigma surrounding HIV. In response I ask whether they have seen the film Philadelphia, as that film accurately portrayed how I felt **GRO-B** **GRO-B**
57. **GRO-B** my experience of people with HIV and/or hepatitis C did nothing to disabuse me of the notion that attitudes towards the virus had or where changing. **GRO-B** **GRO-B** **GRO-B** I was told by the staff that the person had HIV and hepatitis C. I was warned by the staff to be careful. They were discussing the persons diagnosis quite freely, albeit out of his ear-short. It was clear to me that they thought the person was "dirty" and both viruses were highly contagious.
58. Growing up I would have liked to join the Army but I could not because of my medical conditions, specifically my haemophilia. Around 2014 I made enquiries to become an officer in the RAF but was told that I was ineligible as if I was deployed in conflict they could not guarantee that they could get my medication to me.

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Personal Life

59. In the late-2000s my wife and I considered having children. I had read articles about people with HIV having children through sperm-washing. This was something my wife was aware of and we discussed it with my HIV doctor.
60. We had a round of sperm washing. This is a process by which sperm is “washed” and as much of the HIV virus as possible is removed. We had one round which was unsuccessful. Shortly after the NICE guidance changed for couples trying to have a baby where one partner has HIV. Remarkably, the new guidance said that the easiest way to have children was to have unprotected sex, as long as the person had had an undetectable viral-load for a prolonged period of time.
61. As a result of this change to the NICE guidance, the likelihood of funding for sperm washing was reduced and, if we had wanted to have a second round of sperm washing we would have had to pay for it. We had never been sure about having children; it was not going to make or break our relationship, therefore we decided not to have any further rounds. A side effect of my treatment for HIV is that it reduces sperm count, so further rounds may not have been successful. We may, however, have had further rounds if we had not had to pay for it. I understand the guidance between areas varies as to how many rounds will be funded. It felt cruel that we were not able to conceive children naturally due to NHS treatment, but would then have to fund anything more than one round of treatment if we wanted to keep trying.
62. The process for the sperm-washing was not a particularly easy one. We both had to go through various tests and then go to hospital at certain times, me to provide a sample and **GRO-B** to be artificially inseminated. **GRO-B**
- GRO-B**
- GRO-B** The Chelsea & Westminster was the only hospital in the country that offered sperm-washing. I was very fortunate to be living geographically close to it at the time we were going through all this.

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63. The NICE guidance was confusing as it said to have unprotected sex to try and conceive but go back to having protected sex thereafter. I did not feel comfortable following this guidance, although my wife was a bit more relaxed about it. This change in the NICE guidance occurred before the current U=U guidance that having an undetectable viral load means that a person cannot transmit HIV was issued. At the time, something called "The Swiss Statement" had been issued. This was in 2008. It was issued due to people who were HIV+ with an undetectable viral load, having sex with an HIV- partner, despite them knowing of the condition. In some countries people were being prosecuted for this. Whilst the guidance was effectively the same as today, it was very new and it was greeted with cautious optimism.

Other Impacts

64. When attending GOSH I got to know the other boys with haemophilia and HIV, who attended the same clinics as I did, and my parents got to know their families. After I had learned about my diagnosis, one of the boys I knew from attending the clinics at GOSH died as a result of his infection with HIV. He was not someone that I knew well. He was an Orthodox Jew and he and his family did not interact as much with the other families, however, losing a fellow patient had an impact on my parents and me.
65. I became good friends with one of the boys who attended GOSH who also had HIV. He was a couple of years older than me but we were close. We did drug trials together at GOSH. I remember spending two days with him on a Factor VIII trial. His first name was **GRO-B: F** the same as **B2** He had been told when he was a child that he had HIV.
66. When he got older he went off the rails a bit and stopped taking his HIV medication. He sadly passed away in 2006 when he was in his late twenties. I still see his mum occasionally, as do my parents. I last saw her **GRO-B** **GRO-B** in October 2018. She said that she wonders if she had not told him at he had HIV until he was older, as my parents did with me, whether

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the outcome would have been the same. Many witnesses have already spoken about "survivors-guilt". I very much feel this when I see [F]'s parents. It's clear to me that this eats [F]'s parents up inside. It feels unbearably cruel.

67. I went to [F]'s funeral in 2006. I travelled there on my own and my parents and [B2] travelled together. I remember they were about 10 minutes late arriving and the service had already started. I didn't know anyone else there other than [F]'s family. It was probably the most difficult day of my life. At the end, we all stood crying and holding each other. We didn't need to say anything. I knew how lucky I was to still be alive, but again, this was a stark reminder that people were still dying from HIV and I could be next. Living with my infections is like having a constant cloud hanging over you.

Travel to America

68. The time I have always felt stigma due to being HIV positive is when I travel to America. Until Barack Obama became President, anyone with HIV had to get a visa to travel there. I was always taken into a room to be questioned when entering the country. It was degrading and made you feel like a criminal.
69. [GRO-B] in 2003, I went to visit my best friend who was in Los Angeles. I went to get my visa at the US embassy and was interrogated like I was attending a police interview. I was asked the same questions again and again as if they were trying to see if I changed my story. Before going in, I was in a room with others of a similar age to myself. Many of them were travelling to the US for summer/sports camps and were also attending visa interviews. Many of them were chatting about what they were going to do. I was petrified someone would ask me what I was going to do, so I kept my head down and ignored everyone.
70. Even now, whilst there is no requirement for me to have a visa, there is a marker on my passport when I travel to America. My wife and I were getting the boat from Victoria, Canada to Seattle; travellers have to clear US customs before they get on the boat. We were first to arrive at the terminal and last to board the boat

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due to me being interrogated in respect of my HIV. I was taken into a separate room with my wife where I was once again questioned. Next to me was an Australian man and his wife who had also been taken aside. The man had tested positive for radiation hence why he was there. He was on an around the world tour having been diagnosed with terminal cancer. He tested positive for radiation due to his treatment. There was no privacy and whilst the officers were trying to be pleasant about the whole situation, it left us with bad memories of what had otherwise been an excellent holiday.

Section 5: Treatment / Care / Support

71. All the treatment which I received was provided on the NHS. My dad was a **GRO-B** and my mum became a house wife as she had three sons with haemophilia. We did not have access to private health care. The NHS infected me, but otherwise the treatment it has provided to me has been incredibly good. I wish others had been as fortunate as me.
72. If it were not for the GOSH doctors fighting for Di Gibb to come and hold HIV clinics at the hospital, I don't know where I would be. I was treated at the best children's hospital in the world.
73. During school holidays, I took part in drug trials at GOSH. We would stay there for a day or two and they would take urine samples from us every hour. We often did these with **F** who I have mentioned in paragraph 65. We would have water fights with syringes and go to McDonalds for lunch. It was all paid for by the drug companies. It was my version of normal. These trials related to my haemophilia.
74. When I went to university in 1998 I did not transfer to another hospital. I stayed at GOSH for treatment for as long as possible because the treatment was great. Around 2000, I started being seen at University College Hospital as Dr Ri Liesner, who had treated me at GOSH in relation to haemophilia, worked there and I wanted to keep continuity. Around 2004, Dr Liesner advised me I needed to go

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to a comprehensive care centre which is when I moved to the Royal Free Hospital, where I remain a patient for my haemophilia.

75. In terms of my HIV care, I attend the Mortimer Market Clinic at University College Hospital. I transferred there as Dr Di Gibb was moving away from London. She passed me onto one of her colleague's Dr Ian Williams. In over 30 years I have only ever seen two HIV doctors. The continuity of my care has been excellent.

Psychological Support

76. In terms of psychological support, there was a counsellor at the hospital called Candy Duggan. I did not undergo any formal counselling but at the end of my appointments she would just sit down and have a chat. My appointments were every three months.
77. I feel psychological care was missing; I have never formally been offered any other psychological support. I don't think this would have made a difference to me but it might have to others. At the time everyone was learning. I was offered some around when I took Interferon for my Hepatitis C but I feel something formal should have been offered. I was completely unprepared for the side-effects of the Interferon treatment. As a patient I had spent many years being told medications "might" have certain side-effects. When many of them didn't you become a little dismissive when told again and again.
78. There was no real support offered to my parents. They would meet other parents at the hospital and they would support each other. People also congregated around the litigation in 1990 in relation to HIV and have done so again with the Inquiry. There should have been better support for my father when he suffered from depression following my diagnosis. He went to see a psychiatrist and was prescribed anti-depressants. However, he couldn't continue taking them due to the side-effects.
79. Following my diagnosis, my relationship with my GP was relatively good. In the absence of psychological support, it was helpful for my mum that we could

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always see the same person all the time. There was another doctor at the surgery, Dr **GRO-B** to whom my mum felt able to talk about the fact I had HIV. My parents couldn't talk to anyone else about it due to the stigma surrounding HIV at the time. This is why **B2** and I would end up standing in the corridor while our mum cried to the doctor following my appointments.

Treatment for HIV

80. My treatment for HIV is provided at Mortimer Market in London and has been since 2017.
81. My viral load became negligible around my early 20s and is now undetectable. It has only been in the last three to four years that the advice that an undetectable viral load means that the virus is untransmittable has been issued. This is known as "U = U".

Treatment for Hepatitis C

82. I had treatment for Hepatitis C in or around 2006. It was absolutely horrendous. The first time I had the treatment I had it at Mortimer Market on a Friday morning. I was out in central London with friends that evening and by 8pm I felt awful and had to get a taxi home. It felt like the worst flu I had ever had multiplied by ten. I felt suicidal, which is not a feeling I have experienced many times in my life. Initially I had an excruciating headache, and felt incredibly hot, having constant sweats. I would lie in bed, incapacitated and not be able to do anything. Within a few hours I started to feel better, but then felt incredibly cold and started shivering. It was a warm evening, despite which I was curled up under a duvet. I realised I wasn't getting better at all, I was simply transitioning from one sensation to another. I felt terrible all day Saturday and Sunday. On the Monday I got up and went to **GRO-B**
83. Thereafter, I injected the treatment at home once per week and started taking it on the Friday evening. This meant I was sleeping when the symptoms started. I would be ill all day Saturday and would be just about functioning by Sunday and

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would go to work on Monday. I never took any time off work. On reflection, I am surprised I managed. This lasted for around six months. My wife and I had very little social life around this time. We spent the week working and the weekend would be spent inside, with my wife effectively nursing me.

84. With HIV medication, I am always given a list of side effects. If there are 12 side effects on the list, I might experience two of them. With the Hepatitis C treatment, I experienced all of the possible side effects. It gradually got better week by week. The suicidal feelings were the most acute the first time I had the treatment. From attending the Inquiry hearings, I realise now that I also suffer with brain fog and memory issues. I used to have a very sharp memory for details, but now not so much. I struggle to remember names and places.
85. **B2** and I both cleared Hepatitis C after our first round of treatment. My older brother had a horrendous time. He only cleared it last year after three or four rounds. He also has cirrhosis of the liver. It scares me what might happen to him in the long-term. He has **GRO-B** children.

Self-Support

86. I have always considered it important to stay fit and active to contribute to my overall health. haemophiliacs have traditionally not been encouraged to do exercise but I believe it helps my general health. One of the side effects for my medication for HIV is that it can reduce bone density, so I take part in weight bearing exercise to counteract this **GRO-B** **GRO-B** I have scans every few years to check my bone-density. The last one was in 2018. My bone density is currently in the normal range.

Section 6: Financial Assistance

87. In 1990 or 1991, when I still had not been told I was HIV positive, my parents took part in the group legal action relating to the transmission of HIV by blood products. I was going to be one of the test cases in the litigation as I had apparently been infected with British blood. My parents will be able to provide

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more information in relation to this in their witness statements, but I have seen this in the legal papers they still have from the case.

88. The Macfarlane Trust (the "MFT") was established as a direct result of the litigation. The Government said that it would make ex gratia payments without admission of fault. I think the Government thought that they would make the payments in 1990 or 1991 and the relevant people would be dead in 10 years.
89. My parents went to meetings regarding the settlement and found it incredibly difficult. All of the claimants had to agree to the settlement or no one got a penny. There were people there that were dying and they wanted to make sure they left something for their children. Others felt that they should hold out longer for more money. The haemophilia community that had been infected or affected ("the Community") I feel was blackmailed by the Government into accepting the settlement. My mum had strong views at the time. She still feels that if the Community had held out for longer at that time, then some of the issues we are still dealing with today would have been resolved back then.
90. My parents were awarded £20,000 for me which was to be held in trust. I think my parents also received a payment of £20,000, some of which they used to take my brothers and me on holiday.
91. In order to be paid the money, my parents, and all other claimants, had to sign a waiver stating that they would not take any further action in relation to HIV. At the last minute Government also included Hepatitis C in the waiver. This was before anybody really knew the full extent of the potential infections with Hepatitis C.
92. At this time Hepatitis C was so new it was still called Non-A Non-B Hepatitis. My parents did not know that I had Hepatitis C. It can remain latent for many years and not show any symptoms.
93. In around 2001, I got in contact with the solicitor who represented my parents in 1990 to discuss challenging the waiver. The advice I received was negative.

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94. When I was told that I was HIV positive I was also told about the money held in trust for me. When I was 14 or 15, I wanted a guitar and was able to access £1,000 from it.
95. I now get regular payments from the English Infected Blood Scheme which is run by the Department of Health. I get £18,000 per year as I have HIV and Stage 1 Hepatitis. How much an infected person is entitled to depends on their income.
96. Requests for discretionary financial assistance could be made to the MFT for additional funds, for example, if you were moving house. The only time I ever asked the MFT for a discretionary payment was when I asked for money to buy a laptop [GRO-B]. The MFT gave me the money but said, “*We are aware how much [GRO-B] make*”. This was written in a letter to me. I seem to remember one of the trustees at the time was a [GRO-B]. It made me feel like I should not be asking for the money. I did not need the Trust’s help again, but if I had, I do not think I would have asked for it after that disgraceful response from the MFT. Despite all that I had been through and what I had achieved, I was made to feel guilty for asking for anything.
97. In addition to the MFT payments, I also received money from the Skipton Fund. Some of this was used to pay for my [GRO-B] in 2002, which cost just over £10,000 and the remainder was used to fund my travel to and from London and other expenses for living. I worked part-time [GRO-B] to help fund my way through.

Section 7: Other Issues

My reflections

98. Initially the campaign for an inquiry to take place in relation to infected blood (the “Campaign”) was not something that I followed as I had always been fit and well despite having HIV and Hepatitis C. However, [GRO-B] [GRO-B] I attended a debate in Parliament and learned more about the Campaign. I have since discovered that people are dying at a rate of one every four days as

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a result of the use of infected blood. It has made me question why the Community has had to go and beg the Government for an inquiry. I feel that, in our darkest hour, Government abandoned us. It played on the fact that there was a stigma surrounding infection with HIV and Hepatitis C and the that people were sick and dying.

- 99. I think if these events happened today, the treatment of the Community would not be the same. When John Major was Prime Minister, he said we should apply to the National Lottery for funding. I find that shocking, as it was the NHS that infected people.
- 100. In relation to the settlement of the litigation, I think that adding Hepatitis C to the waiver, when the Community did not know the potential impact of this, was a disgraceful sleight of hand by Government.
- 101. The launch of the Inquiry itself has had a significant impact on my life. My parents have always told me that the papers in relation to the litigation in 1991 were available for me to read if I wished. As I had always been fit and well I'd always wanted to live my life by looking forward. The Inquiry has caused me to stop and look back. In 2017, I finally read the papers. Whilst there is not a great deal in there, my parents' statements are contained in there which I have never read before. I never knew my father had suffered with depression until recently. I've always imagined the trauma my parents have been through, but seeing it in black and white was incredibly difficult. My father told me about when they celebrated GRO-B at a restaurant, he had to take himself off to the toilet to cry as he didn't know how many more birthdays I would see.

Statement of Truth

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

Signed GRO-B

Dated..... 31/vii/19