

# ANONYMOUS



Witness Name: **GRO-B**

Statement No.: WITN2223001

Exhibits: WITN2223002-18

Dated: 14<sup>th</sup> January 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF **GRO-B**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 5<sup>th</sup> November 2018.

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

### Section 1. Introduction

1. My name is **GRO-B**. My date of birth is the **GRO-B** 1967. My address is known to the Inquiry. I am currently infected with HIV and underwent treatment which cleared my hepatitis C in around 2014/2015. I intend to speak about my infection, in particular the nature of my illness, how the illnesses have affected me, the treatment I have received and the impact it has had on my family and me and our lives together. I would like it noted that I wish to remain anonymous for this statement.

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## Section 2. How Infected

2. I have severe haemophilia A. I was diagnosed when I was 11 months old (March 1968) as the condition runs in my family. I am aware that my grandmother and mother are both carriers of the haemophilia gene as does my sister. I note that on one occasion when I was small Dr Dawson, my haemophilia consultant, tested the factor VIII levels of my mother and sisters and found my mother and one sister to be carriers. It was recommended that they should have cryoprecipitate cover if they underwent any surgery. I produce a letter from Audrey Dawson dated 15<sup>th</sup> January, 1974 that details her findings in evidence. I refer this letter as **WITN2223002**.
  
3. I have received Factor VIII, Cryoprecipitate and other medication to treat my haemophilia. I started receiving treatment when I was about 5 or 6 years old. When I was small I was given cryoprecipitate when I needed it for bleeds or for treatment cover. For example on one occasion when I was 6 on 28 November 1973 I had a fall and had a bleed into my right knee and thigh. I was treated in hospital with cryoprecipitate. I produce a summary sheet from the Royal Aberdeen Children's Hospital in evidence and refer to it as **WITN2223003**. On 8 December 1977 when I was 10 I spent a few days in Royal Aberdeen Children's Hospital. I was given cryoprecipitate before a dental extraction. I was given some more after the procedure. My blood was tested and my factor VIII levels were found to be low (12%). I was given some factor VIII concentrate to deal with this. I produce a summary sheet from the Royal Aberdeen Children's Hospital and refer to it as **WITN2223004**. On another occasion on 8 April 1981 (when I was 14) I was given cryoprecipitate as cover for some fillings which were inserted into my teeth. During the procedure I complained of some swelling in my elbow and so I was given an extra dose of cryoprecipitate in response to this. I produce in evidence a letter with the details of the procedure and refer to it as **WITN2223005**. I started doing treatment myself when I was a teenager. At that time I

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gave myself treatment at home with factor VIII concentrate. By 22 June 1979 (aged 12) I was described as being seen "fairly frequently" at the ARI with bleeds. I produce in evidence the letter to which this refers as **WITN2223006**. This continued into early adulthood. On one occasion on 3 August 1988 (when I was 21) I was admitted to Aberdeen Royal Infirmary ("ARI") with an abscess in one of my teeth. I was given "quite a lot" of factor VIII concentrate as cover for the extraction procedure. I was sent home with factor VIII concentrate and tranexamic acid to treat myself as required. I produce in evidence the letter to which this refers as **WITN2223007**.

4. As a child I was treated at the Royal Aberdeen Children's Hospital. I have since then been under the care of the ARI. I am registered with Dr **GRO-B** **GRO-B** a GP at **GRO-B** Health Centre. Professor Lewis Ritchie is the only consultant I can recall seeing as a child. The other Consultants who have treated my haemophilia have been Dr Bruce Bennett, Dr Audrey Dawson, Dr Bruce King, Dr Keel and Dr Henry Watson.
5. I do not know the day I was infected with HIV or hepatitis C, given the amount of treatment I have received. The amount of treatment could vary, sometimes I would need treatment every day for a week or it could have been once a month I was being treated. I was severe enough where treatment was needed fairly regularly. I played a lot of football as a child so I would bleed a lot. Up until I got married, I kept a record of every injection. My mother kept a record of every injection I had when I was a child and I just carried on doing the same as an adult. I wasn't asked to do it I just followed my mother's example. I no longer do this though. I believe I have been infected multiple times. When I was 8 years old, in 1976 I was admitted to Aberdeen Royal Infirmary suffering from what, at the time was called non A non B Hepatitis. It is recorded on my notes that I had an episode of "infective hepatitis" at that time. I suppose that it could have been that the doctors knew at that time that I had been infected by the treatment which I had received but I do not think that this was treated as anything other than a transient condition. My treatment

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just continued as it had been at that time. Of course, I later went on to be infected with HIV.

6. I was never informed about the risks of being infected as a result of being given blood products. I do not believe my mother was ever told that there was a risk of me being infected. I am certain of that as I'm sure she would have told me.
7. I was quite young when I was told I had HIV it was 1985 or 1986. I didn't understand what it meant. I remember being taken into a side room and being told by Dr Bennet. There was no real information, all that was said was, you will never have a family. I was advised not to try. At the time HIV was relatively new and very little was known. All I remember are the adverts at the time. They were quite frightening, the very scary television adverts with the words AIDS in the title. I also met with Dr Bennett with my then partner in 1987. I produce in evidence a letter that refers to this meeting as **WITN2223008**. I do not remember the meeting at all. I do not dispute the content of the letter. The letter says that I had only ever been treated with Scottish factor VIII and so I must have been infected by that. I note that my medical records contain a letter dated 27 February 1986 which is to my GP and states that I have tested positive for HTLV III antibody and that I knew at that time, but that my parents did not. I produce this letter in evidence and I refer to it as **WITN2223009**. When I met **GRO-B** my wife, I did tell her I was HIV positive but I didn't know at that point that I had hepatitis C as well. I met **GRO-B** in 1988 or 1989 I would have told her that as well if I had known.
8. I can't recall when I was told about the hepatitis C itself. I was infected with genotype 3. I used to go for a quarterly appointment with the haemophilia doctors and they happened to mention to me that they were concerned about the hepatitis C. I said "*What do you mean?*" and they said "*Well you have hepatitis C as well*", that was how I found out. This was around 1997ish. I was not told that I had been tested for either virus.

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9. When my wife fell pregnant we asked that she was tested for HIV. When looking through my notes one day, I found a piece of paper among my medical records saying that **GRO-B** is clear of HIV and it also states that she is clear of hepatitis, so the doctors knew about the hepatitis C then (1996), but I can't recall anyone telling me that **GRO-B** was clear. I can't recall getting any information about the hepatitis C itself; it was just another disease to deal with but there was no information or advice about what could actually happen. I have had a chance to review my medical records and have found reference to me having Hepatitis C as far back as 1991. There is an entry which states that my GP records contained a reference to me being infected with "unspecified viral hepatitis" from 6 June 1995. I produce this record in evidence and refer to it as **WITN2223010**. There is an entry which states that infection with hepatitis C from blood products dated from 1991. I produce this report in evidence and refer to it as **WITN2223011**. There is a letter dated 8 January 1992 which suggests that I had tested positive for hepatitis C at that time. I produce this letter in evidence and refer to it as **WITN2223012**. I note that my records contain an entry in which Dr Dawson talks about my abnormal liver function tests and stating that I "of course" had hepatitis C and that it was causing abnormal liver function tests rather than my AZT treatment. I produce this entry in evidence and refer to it as **WITN2223013**. I was on their Hep C positive register as at 7 September 1995. I produce a letter referring to this in evidence and I refer to it as **WITN2223014**. My hepatitis C phenotype (3a) was known as at 29 August 1995 and it appears that it was known that it could be treated with Interferon at that time. This was not discussed with me. I produce this letter in evidence and refer to it as **WITN2223015**.
10. I remember being told that there are drugs that stop the infection getting worse for hepatitis C however no-one ever sat me down, no-one said, you took this infected product and this is the infection. No one explained what the long-term outcome of hepatitis C was. The information was not adequate. No one explained the side-effects of the treatments either. No one warned me that if I had this treatment for hepatitis C, I would become a diabetic which is what has happened. I consider this further below.

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11. I would have liked to have known about the hepatitis C earlier, whether it would have stopped anything I don't know, but I had the right to know. When I was finally told about hepatitis C, I believe the doctor told me all he knew that was in my file in around 1997ish.
  
12. I was told not to try for family. I was told that if I cut myself, I should make sure people who are not wearing protection stay away; it was all quite daunting. I note that this does not appear what was said to my GP about the risk of infection with HTLV III when he was told by letter in February 1986 (see above). I was less than 20 years old when I was told about having HIV so it was not in my mind about having a family. I was interested in golf at that time that was the kind of thing I thought about. But there was no advice or information about the possibility of my sperm being cleaned, I was never told anything like that. Later on when I met **GRO-B** we did look into these matters and I now have a daughter, **GRO-B** It was only research that **GRO-B** and I undertook that revealed this option to us We were not provided with any advice about that from the hospital. **GRO-B** ended up having to be tested for the hepatitis C but there was no proper support there either.

### Section 3. Other Infections

13. Around 2005, I was advised by the hospital that there is a risk that I had been exposed to variant CJD otherwise known as mad cow disease. There is no test in existence to confirm this so I was told not to worry about it on that basis. When I get an endoscopy, I have my own endoscopy set stored at the hospital to prevent any potential spread of any potential infection with the surgical instruments. I am taken last thing in the day for any appointments due to my haemophilia/the risk of spreading infections. This is just another thing to deal with and compared with everything else, I have ended up just adding it to the list. I note that there is evidence that I had infection with Epstein-Barr virus. I produce this letter in evidence and refer to it as **WITN2223016**. I also appear to

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have been infected with hepatitis B at some point as I was antibody positive on 24 June 1991. I produce this letter in evidence and refer to it as **WITN2223017**.

### Section 4. Consent

14. They must have treated or tested me without my knowledge because they knew the results of the HIV and hepatitis C tests and didn't tell me that I was being tested. I feel quite angry about this as they must have known for a long time that I had hepatitis C but did not tell me. I didn't know I was even being tested for this and there is no test for the CJD but they knew about the possibility.
15. It follows that if I was treated or tested without my knowledge, this happened without my consent. They didn't tell me about my hepatitis C results for many years.
16. There was no advice about the hepatitis C that was provided about what could happen and what the possibilities were. There was no discussion about the risk of being infected with this or HIV either when I received a blood product.

### Section 5. Impact

17. I am a very positive person, but there is a lot of stigma around HIV. If anyone finds out, I remember there was a time where people would then have presumed I was gay. The HIV is being controlled with the appropriate drugs but the hepatitis C caused me to lose weight, lose strength with my muscles. I got tired. I have a responsible job working in corporate finance, full-time. I was losing concentration and that was what the hepatitis C was doing to me but the doctors still kept this from me for many years.
18. As far as treatment for my hepatitis C is concerned, I started Interferon

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treatment in March 2005. I was taking Ribavirin combined Pegylated Interferon. It was a terrible treatment. I had a lot of aches and pains, pains in muscles that I didn't know existed. The treatment was so bad, that if I were to be offered the treatment again, I don't know if I would take it. I managed to complete 40 out of 48 weeks. After 40 weeks I fell ill with septicaemia. I spent 364 days in hospital over a 22-month period. I had developed encephalopathy. My liver was unable to clean the toxins from my blood. The toxins would go to my brain and I would become unconscious. I was in and out of hospital regularly throughout this period. I had no life. I was in a wheelchair. I couldn't do anything for myself. **GRO-B** had to look after me and take 14 months off work to care for me full-time.

19. I was on the waiting list for about a year from roughly June 2006 and I got a liver transplant with splenectomy in February 2007 as I had cirrhosis. After I got the transplant I felt incredibly weak which was because my heart was starting to fail as well. I was 5 and a 1/2 stone, two surgeons refused to do the heart surgery and a third surgeon thankfully agreed to give it a go. He did warn me that I had a less than 1% chance of survival. I just wanted the operation and I just wanted the transplant, I would have done anything. I used to play football, golf, I was 14 and a 1/2 stone and then I went from that to being wheelchair-bound. I wanted the transplant done and it was touch and go for a while. I would have died had I not received this. One night I got the phone call advising that the liver had become available. I was transported from **GRO-B** to Edinburgh by ambulance in the middle of the night. They ran tests. They weren't sure if I was going to be ok for the transplant but later that day it was approved and I had it done. I was kept in hospital as my heart stopped me making the expected progress with recovery. From February to July 2007 I think I was only home for maybe a week.
20. I did clear the hepatitis C half way through the treatment, but of course I had to stop after 40 weeks and I was not able to complete the full course of treatment, this meant that I was warned that it may come back and in



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2008, it did (as I explain below).

21. I was diagnosed with type II diabetes in 2006/2007. It is a complication/side effect of the hepatitis C treatment. Although I had been told that I had cleared the virus as a result of that treatment I have been left with this condition. It wasn't known at the time that this was a side effect of receiving the treatment for hepatitis C but this was later confirmed. I am seen at the diabetes clinic at the ARI. I can't recall the reasoning why I was tested for diabetes, just that I was bedridden when I was tested and it came back saying that I was diabetic. I now give myself insulin to manage it. The diabetes is being controlled now. It could be better, it could be worse. I've never had to change my eating habits other than injecting myself twice a day, it is being controlled quite well.
22. I also had to have an aortic valve replaced because the Interferon gave me septicaemia. It had caused infective endocarditis.
23. Because I was bedridden my right knee locked up and it had to ultimately be replaced. That was on 1<sup>st</sup> April 2009 that I had the procedure. Because of the inactivity during this 2-year period, I had to be on crutches and I have now developed arthritis in my left ankle.
24. As far as clearing the virus was concerned, I was told that it might come back as I had not been able to complete the Interferon treatment. I was tested regularly and that is how I found out it had come back, in 2008. I was offered treatment, but not straight away. It wasn't until 2014 that it started. The drug I was put on this time was Harvoni, not by injections. It was just a tablet once a day. The side effects were harsh. I had no energy. I couldn't walk to the bottom of our drive without being shattered. That was the worst thing for me. There were no mental effects from being on the treatment. How I managed to work through that 12 months I'll never know. I was working full time throughout.
25. For the HIV, I receive a treatment known as Kaletra which is a liquid to

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keep the virus at bay. There are no drastic physical or mental side effects from taking this. I have been on this since 2005/2006. I did take AZT treatments at one point in time. I did not have any side effects with the AZT. I am reminded by my records that this started in August 1992. I produce this letter in evidence and refer to it as **WITN2223018**.

26. I believe had been offered what treatments were available though I may have been able to have been treated for my hepatitis C earlier than I was.
27. I do not think that my infections have stopped me accessing any other medical treatments. I have a dentist who is aware of everything. I haven't required a lot of medical treatment other than what I have described above.
28. I couldn't get life insurance for a long time. If I go to the United States the travel insurance is a fortune. It's about £1100 for a 2-week holiday.
29. There was one stage when I was given two or three days to live. I had to sit my 8-year-old daughter, **GRO-B** down and tell her I might be not here for too much longer. That is not something I would ever like to do to her again. **GRO-B** and I are like two peas from the same pod, we are very close. She was so young; she didn't fully understand what it meant. I don't discuss it with her now. It's very upsetting and we don't want to cast it up again. **GRO-B** remained positive for me, throughout this whole period, she had to rent a flat in Edinburgh during the transplant and the heart operation. **GRO-B** had to stay at home with her grandparents. I am sure they all have their thoughts, but it is something we don't talk about now.
30. I think in total **GRO-B** had to rent the flat in Edinburgh for about 6 or 7 months, which meant that **GRO-B** lived with her grandparents. Even when I was in Aberdeen Hospital, **GRO-B** used to sit with me all day from mid-morning to the end of the day, so really **GRO-B** was looked after for

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the full 22 months by her grandparents and my sisters. I think I have missed out on a large chunk of her childhood. From the age 7-10, those are the years a child develops their own personality and I missed out on a lot of this. **GRO-B** is getting married on the **GRO-B** and every time I practice my speech, I cry. My daughter means everything to me **GRO-B** was never held back. She got frustrated at times when she couldn't see **GRO-B** and I but she has ultimately been ok. From her perspective, what would happen is that she would go to bed and I would be there. However I would get unwell during the night from the encephalopathy and she would wake up the next day and I wouldn't be there.

31. No one knows I have HIV other than close family and friends. I haven't lost any friends because of it. It's not nice having to tell them though, when I have. We kept the diagnosis of hepatitis C to ourselves, which wasn't a problem until I became unwell. Everyone knows I have hepatitis C now. Everyone was great though. I didn't lose any friends. I had a fear about telling people because I thought I might lose them but the friends I have are close and I hold them dear. I don't discuss the HIV because there is no cure for HIV. I'm a very positive guy and I don't want anyone thinking 'oh poor guy, he has got HIV'. It is not a death sentence like it used to be but it's just easier to only tell people when they need to know.
32. I couldn't go out and I had no energy to go out for long periods when I was receiving the treatment. I was focused on my work but I lost out on a number of promotion opportunities. I lost a fortune in bonuses but my main aim was to get better.
33. Last year I stopped work in August 2018. It was too much. I was shattered all the time. I was able to do the job but I was just not as quick anymore after I returned after my illness. It took me longer to do things and it left me shattered at the end of each day. I asked to retire at a time where the bank were looking for a reduction in numbers. They didn't want me to go but because of my illness they accepted I couldn't carry on. I asked to be medically retired for my pension as well because I basically

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can't work. I can't do any manual work. I wanted to stop while I could enjoy life.

34. I actually calculated that my illness, purely from **GRO-B** having to pay bits and pieces like the £12 a day to park the car at the hospital etc. has cost us in the area of around £50,000 to do what we did. There has been a loss of bonuses, promotions and ultimately this has had a knock on effect on my pension. I probably receive about £15,000 per year less from my pension as a result. I was approached by other financial institutions at much higher salary opportunities but I knew I could never work with them for 2 reasons. 1. I would fail the medical and 2. The only life cover I could get was my death in service benefit and I knew I wouldn't get that if I moved. I was restricted in what I could do. I can't do the work anymore; I would fall too ill. So I'm restricted in what I can do from here on.
35. If it wasn't for **GRO-B** I probably wouldn't have managed. It has had a huge effect on her life but you would have to discuss this with her. She was a receptionist at a hospital when I was going through treatment. She was unable to go back to work. Through the whole period when she cared for me, her employer was brilliant. She works for the NHS so she was properly supported.
36. One other thing I will add is that though we were always told to apply for support from the Government, we have never received a penny from any Government body. **GRO-B** applied for the carers allowance during the 22-month period she looked after me and she was told no, she would not get this because she left her job of her own free will. She had no choice, she had to look after me. Luckily we were in the position where we would be ok without this, but there was no support in the form of allowances or benefits from the Government at any stage.

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## Section 6. Treatment/Care/Support

37. I have had all the treatment that was available. Most of the support has come from my family. I'm a very positive person, I had my wife and my wife had me that was enough, we got through it. Psychological support was made available but it is not something that I require. We are a very strong family on both sides. My sisters might have appreciated support and I know my mum and Dad would have appreciated psychological support. They kept their thoughts to themselves. They were very strong. Losing a child is one of the worst things a parent can go through and that is how it looked to them for a long time.

## Section 7. Financial Assistance

38. I was made aware of MacFarlane Trust and the Skipton Fund. I believe it was my consultant haematologist Dr Henry Watson who made me aware of this.
39. The MacFarlane trust gave me £25,000 in 1987 or 1989 and the Skipton Fund gave me £50,000. I can't remember the exact amounts and dates now. I now receive £3,084 per month from the NSS fund which started shortly after the Penrose Inquiry. That is the only reason I was able to retire, otherwise I would have had to have carried on working; those payments started two years ago.
40. It was quite easy to access the support which I have received from the MacFarlane, Skipton and NSS. I filled in an application form and then I was supported by the doctors who witnessed and signed the form.
41. I remember when I received the first payment for the MacFarlane Trust I had to agree to take no further action at the time. At the time, I didn't really know what that meant. I just agreed not realising what it entailed.

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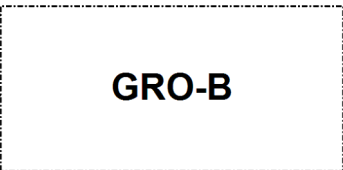
42. I don't know how they reached the figure that they reached with my financial assistance, I think it should be a wee bit more, but then I am always going to think that. I think it should be a lump sum, not just a monthly amount.

### Section 8. Other Issues

43. I don't know why **GRO-B**'s blood test results are in my medical records and also it showed that she was clear of hepatitis C, which is proof she was tested for hepatitis C without her knowledge or consent.
44. My medical records have been recovered by Thompsons solicitors. I would welcome the opportunity to review these in full.

**Statement of Truth**

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

Signed  GRO-B

Dated 18/6/19