

Witness Name: **GRO-B**

Statement No.: WITN2245001

Exhibits:

Dated: 10<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 request under Rule 9 of the Inquiry rules 2006 dated the 05 November 2019.

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

### Section 1. Introduction

1. My name is **GRO-B** My date of birth is the **GRO-B** 1974. My address is known to the Inquiry. I am living at home with my wife **GRO-B** I have no children and I work full-time. I am a civil servant in Glasgow. I am married to have **GRO-B** and for 4 years. I intend to speak about my infection of hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life with my family and I. I would like it noted that I wish to be anonymous for this statement.

Infected Blood Inquiry

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## Section 2. How Infected

2. I am considered to be a severe haemophilia sufferer, type A. I was diagnosed with this at birth. I treat myself three times a week whether I need treatment or not, if I didn't I would constantly bleed.
3. I have no idea on the names of all the products I have received. There are 45 years' worth. I received American factor as a child, factor VIII, which was provided by the pharmaceutical company Baxter. All other information would have to come from my medical records, most of which, have been destroyed.
4. I was a patient at Yorkhill Children's Hospital until I was 15 years old and then I was transferred over to the Glasgow Royal Infirmary. The infection occurred when I was under the care of Yorkhill Children's Hospital, Glasgow. I started Factor VIII in 1979 but there are big chunks of my notes that are missing. The early 1980s and the late 1970s records are all gone. I am registered with [GRO-B] GP practice [GRO-B] and I have been registered there all my life. My GP was my next door neighbour. I have also been under the care of Dr Willoughby, he left Yorkhill in 1982 and emigrated to Australia. I am now under the care of Prof. Robert Campbell-Tait who is based at the Glasgow Royal Infirmary, Haemophilia Unit.
5. I started receiving the infected blood in 1979 onwards. There was a 100% infection period for Haemophiliac patients who received this treatment at this time and through the 1980s.
6. When I started the new Factor VIII treatment in 1979, it was emphasised to my parents and I that this treatment was easier to take and would be lifesaving. The old treatment, we had to go Yorkhill Hospital every time I needed treatment and we learned that we could treat any bleeds at home, so it was easier. As a kid running about I was bleeding constantly, 5-6 times a day. We didn't have a car then so the police would have to

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take me to hospital. The hospital taught my mum [GRO-B] to inject me. My Dad is called [GRO-B] he passed away 11 years ago.

7. In 1994, when I was 20 years old, I went on one of my routine haemophilia appointments where Professor Gordon Lowe told me I was infected with hepatitis C. At first I thought he was telling me I had AIDS but then he explained it was a virus that attacks the liver, so I asked him would I need a liver transplant? He said "*It is luck*", and that he was unsure. I could be ok for 3 months, 3 years or 30 years, depending on how fast my liver would deteriorate. Back then, the doctors thought it was only the liver that would be affected, they had no clue what else it could actually do. I had started working the previous year at the civil service and I left that appointment in shock, convinced I was going to die and returned to the office never telling anyone there.
8. Professor Lowe kept emphasising things to me like not to share razors and talked about having protected sex and not sharing toothbrushes. It just finished any idea that I had about having any sort of relationship. It was a nightmare, I was gutted, I was 20 years old and my future was just wiped out.
9. The information that was provided to me was practical in that meeting. It was treated the same as HIV, all the discussions were around the dangers of passing blood on and being about the damage it may do to my liver.
10. I should have been provided with information as soon as they knew, about the risk and about the confirmed infection. My medical notes go back to the mid-1980s and it says in there that I have non-A, non-B hepatitis before it was named hepatitis C. It was named hepatitis C in 1989. I had had raised liver levels in 1984 and I was still never told, they never told my parents either. I believe it was legal reasons that they kept it quiet then as I was still a minor.

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11. When I was told about the infection, I was told on my own. So I hadn't brought my parents with me, I didn't have anyone with me. There was no follow-up, no offer for a councillor, there was nothing. They handed me a leaflet, that was it. I cannot remember the leaflet now. I was just then sent for yearly blood tests from then on and then I started to receive yearly liver scans latterly.

### Section 3. Other Infections

12. I have received 3 or 4 letters over the past 15 years telling me that I might be infected with variant CJD from blood donors who have donated blood and have subsequently died. There is no test that can be conducted to confirm this until after your die. The letter that was sent to me was from the doctors at the Haemophilia Unit at the Royal Infirmary, Glasgow (RIG). I was told in this letter and subsequent letters that I would be unable to donate blood as a result. The letter says that I must advise health care practitioners about this risk and that surgical instruments have to be disposed of after being used on me. This information was just icing on the cake; I was shattered. The problems with hepatitis C are similar to variant CJD so you just don't know if you have this. I don't know what else I have, some people I know through our campaigning, are organising private post-mortems because they don't trust the medical profession at all now. I don't have HIV; I don't have hepatitis B but what other viruses do I have?

### Section 4. Consent

13. Well from the notes I have, they were testing me for non-A non-B hepatitis. The results of the tests and liver blood tests which were abnormal, so they were definitely testing me without telling me. It wasn't until 1994, did I receive any information and this was back in 1989.
14. My parents were not asked to provide consent and know I was never

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provided with information about testing, therefore I never provided my consent either.

15. Yes, same reasons, adequate information was not provided about the product itself. All the doctors focused on, was the ease of use with the product, nothing about the danger of using it in the first place.
16. Definitely, I would say so yes, they were testing without telling me so I do believe that I've been used for research.

### Section 5. Impact

17. It was a complete stress being told you had this deadly virus that can kill you. I was devastated and it all continues on to this day. It affects everything, relationships, colleagues, friends and family. I kept it quiet from my work-no one there knew. I told my family and close friends but that was it. I was always tired, more tired than friends of my age. I had a lot of symptoms of stress as well. I have never applied for promotion at work, I couldn't cope with the responsibility of looking after staff. I had enough on my plate with my health. Eventually after 10 years working there, my boss discussed promotion with me and I said no. I told him why and work have been great. I have been 26 years in the same building because the management are great and supportive. I don't take advantage of my health problems, I don't phone in sick all the time etc so they are supportive when things do happen with my health. I started work in 1993, in 1994 and again in 1996, I was off for a long period of time as I had an operation for an ankle bleed. The Civil Service sent out an occupational therapy nurse to check on matters. She had a big copy of my medical notes from work and in the notes was a letter from my GP that I used to live next door to. He had written to my work saying that I had hepatitis C and in his opinion I wouldn't be able to work more than 7 years. This letter was sent to The Civil Service when I applied for the job before 1994. My employer was told, I had the infection before I was. I have asked HR to recover this letter, however they can't recover this

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now, things go missing, it ends up being word-of-mouth. I was absolutely mortified, they knew the whole time, my GP knew the whole time, he was my neighbour and he would come over and ask to borrow needles from me. I thought he didn't realise how bad my health was, but he did. I have also been incredibly stressed from the worry about what might happen. I used to have liver scans once a year and the stress of worrying that a scan would not be ok this incredible. My health is a lot worse now as well. Treatment has made my health worse. I attempted the first generation treatment in 1996 taking Interferon. This was the worst experience I have ever had with the hepatitis, I only lasted 8 weeks on it, the side effects were incredible. I had to inject three times a week in my waist and back then it was 1 or 2 tablets a day. I was a lobster, a full-bodied lobster, I had a full body rash all over my body. All I could do was sleep. I was able to work but I would finish work at 4pm and go home and sleep. They took me off the treatment after 8 weeks and I remember it was so ridiculous the colour I was in that the doctors got me to go to the hospital to have my photo taken. In 2012 the Interferon treatment was tried again. That was comprised of 20 tablets a day, I was taking anti-sickness tablets and 1 injection of Ribavirin. I was off work for six months and I felt like killing myself, it was horrendous. I took the first injection on the Monday night and by Thursday, I thought I was going to faint at work. I thought I was going to collapse, I had to drive home, I don't know how I managed that and then I slept for 6 months. I lost 2 stone and I was sick constantly. I had a horrible taste in my mouth, I couldn't eat but I had no appetite anyway. It was just horrific, management at work were fantastic which helped. I felt terrible, I would say I was depressed and stressed on top of that. I had to attend the Royal once a week for a check-up during this treatment. I was sitting with junkies and alcoholics thinking there is no privacy which made it difficult to endure. I had to make my own way to the RIG, I had a motability badge so I could park in the disabled space but making my way to the hospital was horrendous. Sitting by junkies was awful. I started treatment in July 2012 and after 6 months again, I was taken off and they said I was clear. I spoke to a liver consultant who couldn't guarantee that this would

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remain the case though. The virus could be hidden inside my brain, heart, lungs they don't have tests to declare you fully clear. Just undetectable. No annual liver check up and no scan since treatment. There is no other information, they are just monitoring my liver readings at the Haemophilia Unit.

18. I have asthma, bad skin conditions, my legs and arms are itchy, they scab up, it's disgusting. I've been to a dermatology clinic several times. Stress is definitely the main thing though. I went to see a psychologist in July 2018, between everything that has happened last year, I was being reassessed for PIP and transferring onto a new scheme which sent me over the edge. I also had a mental health assessment to help me transfer onto PIP. Other issues that I am continually thinking about in relation to this, refer to the financial side of matters. Professor Goldberg last December, wrote a report on the effects of living with hepatitis C and explained what it was like and how we were treated financially; all these ridiculous charities that have been set up, his report came out published in July and recommended a financial monthly payment and that has been on my mind a lot. The UK Inquiry has been on my mind constantly as well and I have been receiving counselling once a month, for 2 hours right up until Christmas. The counsellor said I had severe stress, I don't have depression anymore though which is good. She was very supportive. My asthma developed in February 2013 I came off Interferon later that year and I had to start wearing glasses. In 2013 I got a lot of chest infections. I have not had a bad asthma attack yet although I use inhalers every day. It's manageable. I have really bad itchy feet, legs and my immune system is compromised. Everything is down to the Interferon, skin rashes, I receive creams for these. I receive a steroid cream and another cream which discolours my skin so I try not to use it too much on my face.
19. I don't know if there have been any other treatments that have not been made available to me. You trust the doctors, they are supposed to be the experts.

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20. I attend the RIG for dental treatment. At one-point the hygienist was on maternity leave and none of the haemophilia patients were being treated. I went to a private dentist and all I had to say was that I was a severe haemophilia patient with a variant CJD risk and I was told they couldn't see me. I had to wait for the nurse to come back at the dental clinic at the hospital. It's embarrassing. There was one time I was in hospital for a foot fuse operation and my bedsheets were in a separate coloured bag to the others, which of course was immediately picked up on by the other patients who questioned why this was. I was mortified.
21. My parents were devastated; they were convinced I had AIDS. I lived through discrimination at primary school as well. Hardly anyone knew and I didn't tell discuss it. My mum felt guilty that they had taught her to inject me. I needed injections 2-5 times a week so I was infected multiple times.
22. When I met the **GRO-B** I didn't tell her about the hepatitis C, she didn't even know I had haemophilia for 18 months, eventually I told her the whole truth. **GRO-C**  
**GRO-C** It was very difficult, but at what point do you tell someone? We worked through it and we are married happily now. I was terrified of losing her, the whole thing has shattered my confidence. Once she came to terms with it, she was fine about it, though her family did look it up on the internet and everything about HIV and AIDS came up and they were panicking. Then they also discovered the hepatitis C online. Ultimately they were ok though.
23. HIV was plastered all over the media, the television, the newspapers, the radio it was worse than Ebola. **GRO-B** going back 30 years ago was a small village and everyone knew everyone. The class I was in at primary school, I sat next to my teacher's nephew. This one night, there was a documentary on about AIDS which featured Yorkhill Hospital. They interviewed my doctor and I went to school the next day where the



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teacher out of the blue, shuffled us all around and I got separated from the nephew and put on opposite sides of the classroom. The head teacher asked my mum for a gown and surgical masks because they were terrified that I would infect them. The same teacher asked Mum does **GRO-B** have AIDS?", my mum said "That's between **GRO-B** and the doctor". That convinced the school that I did have AIDS. There was also a clinic that Mum used to hand in the sharps boxes to, rather than going to Yorkhill. They told her one day that they were going to stop accepting my used needles; she would have to take them to Yorkhill. Another incident, that I found out about later on was that my primary school tried to send me to a special school without telling my parents. Dad went crazy at that one and took me out of the school in primary 7. The priest was raging because I wasn't going to a catholic school anymore. I was sent to a non-denominational school instead and it was made to be a big deal by him. Then I started high school and it was like breathing a breath of fresh air, the teachers were great, my mum went up to the school to talk to them about my health and they were very supportive. There were no problems with the parents when I was in primary school, it was the teachers. There was one instance where I bumped myself and broke the skin. I took a wee bit of wood out of my knee and gave it to my teacher. The teacher phoned my mum and asked her if the wood was safe to hold, I was about 10 or 11 years old.

24. **GRO-B** was made redundant about 11 years ago. I was on half pay as I was off work. As a result of all of it, I had to go back to work sooner than I would have liked, but if I had not done this, we would have lost the house from failing to keep up with mortgage payments. I do imagine if I had not been infected, I would have placed myself as being at a supervisor level now. I have been there for 26 years. I don't want to be doing the same job over and over. Like I say, I couldn't cope with the added stress that promotion brings because my outside stresses with my health. I could have never joined the police, army or navy, I was restricted over my health, so an office job has been the most appropriate.

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Certainly, I would have liked to have done these things but my health would never allow for it.

25. Financially, the bank would not grant me a mortgage. 11 years ago, it was the Bank of Scotland. We went to a different bank and I explained my situation with the hepatitis C, the haemophilia and the financial monthly payments and they are happy with that so we were able to get a mortgage in the end. Travel insurance I can get, but it's over £100 for a 2-week holiday. I don't have life insurance and I probably couldn't get any if I tried. If I drop dead, the Civil Service will pay out and **GRO-B** will get an in service, death benefit.
26. **GRO-B** is a strong person, she can handle things. She has moved here from **GRO-B**. She has her head screwed on. We have no children, she was pregnant 12 years ago and the doctor told us there was a chance that the virus could spread to the baby but it would be luck. We made the difficult decision at that point to terminate and not have children. I was absolutely gutted and she was absolutely gutted. I blame myself. I listen to people talking about their kids every day, I hate it, I absolutely hate it when people mention their children. We had to be realistic though, hepatitis C and god knows what else is in my blood.

### Section 6. Treatment/Care/Support

27. I was told about the infection in 1994 but I wasn't offered any support. The first time I received psychological support was in July 2018. Psychological support should have been offered 20 years ago, when we were told. Now it feels like it was too late. The support is not for everyone, it is a personal choice, I dearly needed it in the summer of 2018 but I would have benefited from it many years ago.

Section 7. Financial Assistance

28. I am heavily involved in the West of Scotland Haemophilia unit and the campaigning, I knew about the Caxton Foundation and the Skipton fund through this.

29. I was awarded DLA for life in 1991. I was 17 years old. Then the Conservative Party brought in PIP and I knew I would have to transfer. Eventually it happened in 2018, I had to go around everyone as a result. I had to get supportive letters from the haemophilia doctors, psychologists, a letter from Dan Farthing and Tom Leggett, SIBS letters and then I asked if I could pay privately to see my GP and the GP said we don't do PIP applications as we are overwhelmed with the application forms. I paid £100 to see an orthopaedic surgeon. No GP support at all. In August, I had to go for my 1 to 1 interview. The day before the assessment, I punched myself in the arm to make myself bleed, I bleed easily and I was advised 30 years ago that they could turn you down at any opportunity therefore I punched myself. I was advised not to wear jewellery or a watch or a shirt with buttons on it. If you can wear a shirt with buttons on it, it shows you are capable of working. So I turned up wearing a shirt with swollen arms, no buttons and I was in agony. I walked as far as I could to get my ankles to swell up beforehand. I turned up at the centre in Glasgow at 9am for my appointment which then went on for an hour and a half. The assessor introduced herself as a nurse and began reading from a computer, yes or no answers, she wouldn't let me divert from what we were discussing and from all of that, I was downgraded from high rate, to middle rate which meant I was going to lose the car. My nerves were shattered and if I lost the car I would have to take redundancy and leave work. I can't walk to work from the bus stop, I panicked and spoke to Tommy Leggett and he got **GRO-B** **GRO-B** involved. He was very involved and I was awarded high rate for 11

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years so it worked out in the end but it was a horrific experience. I have also received £20,000 from the Skipton Fund ex gratia.

30. In 2011, it was announced that there was going to be an annual payment set up for everyone who develops cirrhosis, so you had to be on your death bed to receive it. When [GRO-B] lost her job, I phoned up Skipton and my GP agreed to fill out a form to apply for the stage 2 payment. I was declined, my health had not yet reached the crisis point. That letter was ripped up. I was gutted by this, I was in bed, on this treatment, convinced I was going to get the support, but then it was just another knock back. Skipton also advertised that you could apply for household items etc. I had an operation, an ankle fusion, and during my recovery, I had a bleed and there was blood all over my sheets and my mattress, it totally saturated the mattress. I contacted Skipton and they sent me out argos vouchers to get new sheets. I had to justify this to them. Mum said to [GRO-B] and I that we could move in with her, when we were unsure if we were going to be able to make our mortgage payments. I contacted Caxton and they agreed to give me an extra £750 a month, but only while I was on treatment. They didn't take into account the side effects of treatment or consider the fact that you are ill forever from the treatment. We received 3 months of payments, not backdated and to get this I had to jump through a number of hoops, trying to track down a liver doctor to fill in the relevant form. Eventually when the form was completed, I had to drive all the way down to the RIG to pick it up. It was a nightmare, Caxton made it really difficult and out of all that, we only received 3 months of support.
31. Back in the day it was an insult, we had to do all the work for the Skipton fund we had to complete big long forms and they were stealing the money from us. This was blatantly a cost saving exercise, there are no stages. Stages are a front. You don't have stage 1 or 2 HIV purely because of what it is, there is no stage 1 or 2 hepatitis C either, it's purely because so many of us caught it that they have decided to do this, to try

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and keep costs down, it's a cost saving exercise. The hope is that we die, sooner rather than later.

**Section 8. Other Issues**

- 32. Tainted Blood have a lot of documents that they will be disclosing to the Inquiry.
- 33. Thompsons Solicitors are recovering my medical records and I will be given an opportunity to review what is released to them.

**Statement of Truth**

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

Signed **GRO-B** \_\_\_\_\_  
Dated 25.2.19