

Witness Name: Myles Hutchison

Statement No.: WITN2168001

Exhibits: WITN2168002-014

Dated: 15th February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF MYLES HUTCHISON

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

#### Section 1: Introduction

1. My name is Myles Hutchison. My date of birth is GRO-C 1972. My address is known to the Inquiry. I am unable to work due to my health. I am married to my wife Gillian and I have a daughter and son. GRO- was born in 2007 and GRO-C was born in 2001. In this statement I intend to speak about my infection with hepatitis C which I contracted as a result of my exposure to contaminated blood products received for the treatment of my haemophilia B. In particular, I intend to speak about my infection, how it has affected my life and that of my family as well as the treatment I have received and how that affected my and their lives.

#### Section 2: How infected

My haemophilia and its treatment

2. I suffer from Haemophilia B, also known as Christmas disease. My medical records consistently describe my condition as moderate in nature. I was diagnosed as doctors had thought I was a battered baby with the bruises that I had from being an undiagnosed haemophiliac. This was how I ended up being tested. There was no family history of haemophilia, so my brother Paul and I were spontaneous mutations. I am currently on medication called Benefix (a factor IX concentrate) twice a week and this is prophylactic in nature. My records suggest that I have been on this since around 1999. Prior to this, I was on the medication Replenine in around 1999 (another factor IX concentrate) and prior to that, I was on the pure Factor IX, DeFix. I was on whole blood until my teenage years, when I was put on replenine. There was never any explanation for this but we trusted doctors to go with the safest option. Prophylactic treatment started when I was 14 and this was home treatment. I had 100s of bleeds, so I would estimate on average that I was treated about 25 times a year. . I believe I may be the last person on Benefix. I believe they are currently talking about trying a new treatment that is longer lasting than Benefix.
3. I have always lived and been treated in Edinburgh. I am currently treated at Edinburgh Royal Infirmary ("RIE"). I was treated initially at Leith Hospital, Edinburgh until I was 4 and after that I was treated at the Western General Hospital, Edinburgh ("WG") until I was 8. It has been said to me that people were typically infected in 1981 to 1982. I was about 9 or 10 at that time and being treated at the RIE.
4. From when I was born to when I was four, I believe I was treated by a Dr Syme at Leith Hospital. Dr Syme said I would be better treated at the WG than at Leith Hospital. At RIE, I was predominantly treated by Professor Ludlam from around 1980. He was in charge of and responsible for my care. I was up there every week when I was a child and they said they were checking my resistance and things like that. I believe that Professor Ludlam was Head of Haematology until fairly recently. I do not like the fact that he may still have access to my file and samples of my blood. I understand that he does and I am concerned that the

information in my records and any historic blood of mine which they hold could still be used for research or anything else without my consent. I do not even know what of my blood they have. I would like to know that and feel I have the right to know what they have and what it is being used for.

5. I never gave my consent for research and I believe that is something that is still ongoing with my blood samples. I understand that Professor Ludlam was hesitant to give evidence at the Penrose Inquiry. I think he should be asked to explain how he has treated people like me and what he has done with our blood or other information relating to us without our knowledge or consent. I recall also being dealt with by another haemophilia consultant at the RIE called Dr Rosemary Dennis. I have known her for around 20 years. A lot of consultants have come and gone. Due to the team being specialised there are only a small number of them and there has been a high rotation of staff coming in and out of the hospital in that team. Everyone who was there initially has left since this Inquiry was announced.
6. I recall that one of the sisters in the old RIE went off sick at one point. Apparently she was warned that if she said too much about what had been going on in the haemophilia unit she would lose her pension. I heard about this through word of mouth with other haemophiliacs in the centre. This was before they stopped taking us in all at once, and I don't know if our conversations together were why they stopped this. I think I would have been 22 or 23 when Billie left. This sister was called Billie Reynolds. She was closely involved with patients and care and would have known all of the patients being treated in the Edinburgh unit and probably known a lot about what was going on in the background which the patients did not.

#### My hepatitis infections

7. I have been infected with hepatitis C, genotype 3. My GP records indicate that my GP knew this on 12 November 1993. I have also been infected with Hepatitis B. I remember that I got a call when I was still in school. I went to St Thomas of

Aquins High School in Edinburgh. I was asked to go across to the RIE in what would have been 1984 when I was around 12. I had been tested for this for a number of years. It appears I tested positive in April 1984. I produce my test results in evidence and refer to them as **WITN2168002**. The hospital was across from my school. I was told that I had severe Hepatitis B. I was very ill as Hepatitis B kills the immune system. I was suffering extreme fatigue and felt really ill. They said to me that it was akin to blood poisoning.

8. My parents were called up when I was about 12 in 1984 and told that I had hepatitis B. I refer to a letter from my records dated 24<sup>th</sup> April 1984 which refers to my recent diagnosis with hepatitis B at that time. I produce the letter in evidence and refer to it as **WITN2168003**. It was said to them that I could have got this from my very first injection. I believe the blood was good until they started using American blood and blood from Russian cadavers. I heard about this through speaking with other haemophiliacs at the centre about the time. I also saw a programme about Russian cadaver blood in the press a good 8 or 9 years ago. I think that the Inquiry must investigate if blood came from foreign sources which was used in the manufacture of blood products used here. I do not think that my parents were given any information about what having hepatitis B would mean for me. I was certainly not told that.
9. It was only when I was 13 or 14 that I started to get an inclination that things were not quite right. My mood was not good and dropped around this time. I started suffering from fatigue and getting a strange feeling in my stomach. This was around the time that doctors would feel around my stomach at times when I was in the centre. I also started seeing the biohazard sticker on my medical files. My parents were concerned about treatments and Professor Ludlam was always very vague with them about what the risks were. I do not think that they were ever given any information about the infection risks of the treatment I was given or what the alternatives might be to minimise those risks. I was certainly never given this information while I was a child.

10. I recall that I would be sent to hospital for injections and there were a few times where they used a big hexagonal device that had about 20 needles with files on it. This would have been when I was around 17. I have found out since that this was mainly for people who were stronger than the average haemophiliac. One of the older haemophiliacs at the centre said this to me. Nothing was really said about what the injection was. I assumed it was to do with getting a BCG at some stage, I did ask why and I was told that that would have been for a multi-tester experiment. I asked on the day I got the injection what it was. They did not tell me. I do not know the name of the doctor who I asked. This was done a few times. I felt terrible after those injections. I remember it being slammed into my arm, a bit like a BCG. At no stage did anyone say there was ever any risk from having my factor treatment.
11. I believe my Mum and Dad were told that I had non-A non-B hepatitis and they were not told any symptoms that I might go on to face. I believe that this was very downplayed when it was communicated to my parents. It was suggested that the condition would not be a serious one. I think I was told about this when I was told about having hepatitis B. Professor Ludlam said this to me. They said at this time my infection of both B and C could have come from my first injection. Professor Ludlam said that they did not monitor every batch because the blood came from multiple sources. I believe Professor Ludlam said to my parents and then they told me. My parents would ask questions about it all and then be palmed off. When I asked they said there was nothing for me to worry about. Both my parents and I were devastated with my diagnoses. This was less so with B, because the AIDS scare was more closely associated with hepatitis C.
12. I do not believe that the information given was adequate as it was very, very vague. My Mum has told me since that it was like pulling teeth trying to get information from the doctors, both about the risks of the treatment and about what my diagnosis with hepatitis B or non A non B hepatitis would mean for me and for them. I do believe that I should have been told earlier about my infections and what they would mean for me and that my parents should have been told the risks of my treatment. I feel that my hepatitis was not

acknowledged as anything of any significance until I was around 20 or 21 although I had symptoms well before that (1992/93). My wife reacted badly to my diagnosis. I produce a letter that details this in evidence and I refer to it as **WITN2168004**. My parents were offered a leaflet connected to my diagnosis in October 1993. I produce a letter in evidence and refer to it as **WITN2168005**. I note that parents attended a meeting with Professor Ludlam on around 18<sup>th</sup> November 1994 at which time I was seeing the social worker Geraldine Brown. They were concerned about me and my brother after my hepatitis C diagnosis. The letter says that they had a “fairly full discussion” but my mother thought the information was always vague. It says that they were given some leaflets about the condition. I note that my depression appears to have been addressed separately from my hepatitis C diagnosis as if they were unconnected. I produce this letter in evidence and refer to it as **WITN2168006**.

13. Information about cross contamination was very vague as they did not tell me or my parents anything beyond the fact that there is a very slim chance of this being transferred sexually. At the hospital, they did not say anything about sharing toothbrushes or razors. I could have put others at risk if I had had a bleed. There was no other information from the government or the NHS about the risks of cross contamination.
14. I recall from about the age of 12 that doctors would press my stomach and ask if it was sore. I feel that in retrospect, it was likely that they knew there was something wrong but they were waiting on symptoms emerging. I think that they were testing for liver damage at that time. I had so many injections, it is hard to pinpoint individual events. I know that when I was on blood plasma, it was the equivalent of 40 pints of blood that they had derived the product from. I would have been on this from birth until my early 20s.
15. I feel like the medical staff treated it as if they thought that the hepatitis problem would go away. I saw boys dropping like flies. I would befriend the other boys on the ward and it would make things easier but I would then see them being taken away on trolleys and would never see them again. I do not know what

happened to them. When it was spoken about my infection was referred to as non A non B hepatitis. It was only when I got my treatment that they started calling it hepatitis C.

16. I recall that Professor Ludlam called up one day and said that a man had died of Variant CJD, also known as Mad Cow Disease, and they said that I received blood from him. Professor Ludlam made clear that I had quite a few treatments from that batch. I believe I was informed of this in November 2002. All they did was say that they had been treating a man who died and the blood traced back to him. There were numerous batches that may have been contaminated; possibly hundreds. They said the chances of me having this were very high because I had so much concentrate over the years. They said that the test for this could cost about £50,000 and as such, I would not be getting it. It was as if they were only telling me in case things started to get bad in terms of my other symptoms. I myself thought that I had dodged a bullet by not having HIV. I was tested for HIV when I was 13. I believe I was tested every 6 months until my mid 20s from then. I assume they were not confident that I did not have it given how much they tested me. They rarely ever specified what the tests they were doing were for. I felt that I was continually dodging bullets. From being a teenager I felt that they were taken more blood than was normal. At times I saw them take the likes of a dozen vials. From the age of 12 there seemed to be a bigger push for taking more blood from me.

17. I always felt that they used my brother as a bargaining chip against me. We were told that we were virtually identical in terms of our DNA, so they would often play up the fact that if I got something done it might save Paul from having it done. When they mentioned the liver biopsy, they implied that if I got it my brother wouldn't have to. I think we have the same strain of hepatitis, although it has affected me more severely. I did drink more at one point because I was having problems with my first marriage and emotional issues I was facing. I recall Professor Ludlam saying that my strain may have been more rampant for whatever reason. My brother is 1 year and 10 months younger than me.

18. My brother and I were on the same treatment up until 2003. Paul could not take replenine. Paul stayed on blood plasma up until about a year ago. I was put on benefix at some point. I did feel pressure to support my brother and often bit the bullet so he wouldn't have to. We were both put on Interferon and Ribavirin when Paul was about 21. I lasted 6 weeks on the first course and couldn't handle the side effects. I think Paul lasted even less time. With my second treatment, I was sent to a liver specialist called Professor Hayes and he put me on treatment due to my liver becoming cirrhotic. I do not recall when Paul's second treatment was.

### **Section 3: Other Infections**

19. I have contracted hepatitis B and C. I have also been warned of the risk of vCJD and they said that the test for this was not cost-effective but they said there was a 90% chance that I have this, as I have explained above. I received a CJD notification letter dated 21<sup>st</sup> September 2004. I produce this letter in evidence and refer to it as **WITN2168007**. I received a further notification letter on the 17<sup>th</sup> February 2009. I also produce this letter in evidence and refer to it as **WITN2168008**.

### **Section 4: Consent**

20. I believe I was experimented on. There were lots of times when I had blood taken when I knew it was not just a standard haemophilia check. They seemed to take more than the couple of vials that would normally be required for the general testing done due to my haemophilia. I believe that these were sent to hepatology. It was only later on when I was about 16 that they mentioned testing for things and they said they were testing for anomalies. I do not know what they mean by anomalies. I believe that my blood may have been tested from around the age of 16 until my mid 20s. Now and again, I am still called up for bloods when I go for a check-up. I would say they take blood maybe a dozen



times a year. It feels as if I am having more and more blood taken. I do not know what it is for.

21. Professor Ludlum would refer to us as 'pups' when we were children which meant previously uninfected patients or previously untreated patients depending on who you asked. I thought that it was a term of affection but it transpires that it may mean that his interest in us was in what our blood test results could tell him about our reactions to the products he was giving us as we were uninfected with viruses when we were young. I believe that our blood was being analysed without our or my parents' knowledge or consent. I heard about the pups term from other people at the time.

22. I recall one time, I was at RIE/outpatients and I was speaking with the receptionist. The secretary at the reception said that they were shredding my files upstairs for the period when I might have received contaminated blood. I recall going up the following week and that secretary was gone. I remember her saying "they cannot be allowed to get away with something like this". She said that they were trying to hide something from me. I think I was there with my brother because they were changing our treatment at the time. I would have been about 20 or 21. I now realise that my records are missing from about the age of 4 to 15. We were told it was practice to destroy things after a certain amount of time. I never made a complaint.

23. I always try to get on with people like medical staff and other patients and some of them were generally like family friends but I believe that there has been a secret agreement that has been used to silence people. I think this because of the general lack of information and the quietness of medical staff. I remember going into the dental hospital once and the staff who were going to treat me were dressed in hazmat suits. I always felt like we got half truths. The only people who would be open about things were Billie Reynolds and another nurse called Chris, and they were both silenced. I think they knew about hepatitis C long before they ever told us about it.

24. I assumed that when I had injections in hospital with things that I did not know the contents of, they were just school-age vaccinations that were done in hospital because of me being a haemophiliac. I now think these injections were them testing to find out more about the hepatitis C virus. I feel that I was used as a guinea pig.

## Section 5: Impact

### Mental and physical effects of infection

25. In my early teens, I started to notice that I had constant fatigue. I noticed aching in joints and other flu-like symptoms. I put it down to just being a normal everyday thing. This continued to when I was in my early 20s. I was so tired all time. I never really like to take any painkillers or anything like that. My mental health went downhill around this time and I started to suffer from depression and displayed erratic behaviour. I was doing things I normally would not have done. I tried to commit suicide a couple of times. One time I drove my car into another car but I did survive this. The second time, I had been in the hospital and jumped off the pier at Granton Harbour. I ended up just damaging my leg and ended up in hospital. I drove my car into another car in 1997 and I jumped off of Granton Harbor in 1999. I was in a really bad place mentally, with my marriage splitting up. I felt that that there was something wrong with me but no one would tell me what it was. I was scared of what was inside me. There was not much support. Eventually I went to my GP about my depression and he referred me to George Masterton who was a psychologist.

26. I previously worked for the Civil Service in the Inland Revenue and was discharged on ill-health grounds after 13 years working there. I started working there in November of 1989 as an admin assistant. My boss, GRO-D terminated my employment in 2002. I had been off sick a lot. Before I started to become ill I was enjoying work and was in line for a promotion. They stopped paying me long before I stopped because I had ran out of statutory sick pay. I

felt I didn't matter. I understood why they were letting me go, but I felt I was losing a career because of my infection and my symptoms. . I could not concentrate and was suffering from brain fog. I would forget things and had a very bad short-term memory. One of my main issues is that doctors never said that it could be because of my hepatitis C that I was experiencing the symptoms. I was told that everyone gets depressed. I am on antidepressants now. I have been on antidepressants on and off since I was 20. When I went to counselling with George Masterton, he felt that one problem was that I had lost confidence and trust in the haemophilia centre. I think he may even have reported this to them, but nothing happened.

27. I suffer from joint pains. These are aching all the time. I suffer from back pain which may be related to my kidney. Professor Hayes, who is a liver specialist at the RIE, said to stop drinking and smoking. There was mention of a liver transplant if I stopped drinking.

28. I used to be the life and soul of the party but now I am always tired. I find that I am always lying down and unwell. I have often vomited a lot.

29. I was a house Dad because I was not able to work. I do feel that I lost out on time with my children because I could not run about with them like a normal Dad would. It sometimes felt like the life was zapped out of me. My wife is my carer now and has to take me places. My wife had to give up work to care for me. It was very hard to say that I could not cope and could not hold down a job. I found this very depressing. Because of the fact I would have to sleep for so long, my days were getting shorter. I feel that mentally and physically, my symptoms and subsequent treatment played havoc. With being a haemophiliac, I have developed arthritis but I could cope with haemophilia related symptoms before whereas now I cannot. I am too tired and worn down to cope.

30. Being on antidepressants and having haemophilia have an effect on the treatment you can receive for the hepatitis. There was talk of Interferon

treatment in my early 20s (the first half of the 1990s) but they said my blood level and clotting was too low. It is a vicious circle.

### Treatment and effects

31. I had Interferon treatment in 1995. I had visual problems and night sweats. I became depressed on the treatment and could not continue. I was offered the treatment again but could not face the possibility. I produce this letter in evidence and refer to it as **WITN2168009**.
32. In 2003, Professor Hayes (my liver specialist) told me to have Interferon treatment because my liver had viruses and scarring. I had cirrhosis of the liver which I think was diagnosed (as per my GP records) in around November 2001. The treatment I received was Interferon and Ribavirin. This was by injection of Interferon and tablets for the Ribavirin. I am unsure if the Interferon was PEGylated Interferon. I recall that a nurse would take my blood a couple times, and they said they were to lower the levels of treatment I was receiving. My immune system was destroyed around this time through treatment. I was on this treatment for six months and this was successful. I am told that my hepatitis C is now dormant. I continue to have the levels of the virus monitored regularly. The readings are very low and I know that some would refer to this as being clear. I still suffer many effects of being infected that it does not seem like I am clear of anything. Hepatitis B made me very ill. My immune system was not affected by interferon treatment and there was no mention of hepatitis B being a factor in the treatment for my hepatitis C.
33. I had to have a psych test before being sent to have my treatment, I was sent to a Professor Masterton who dealt with psychology. My behaviour was irrational, I thought I was going off my head when I had having the treatment. I was in a dark place when I had the psychological screening. Professor Masterton thought I would be able to cope. In terms of side effects I was told that these would be unpleasant. They said I would feel bad but would get better, but I felt that I got worse. What they said was nowhere near as bad as reality.

The treatment did affect my relationship with my wife as I was not easy to live with during treatment. This lowered my faith even more in the medical profession, and I said I was doing nothing more with them after this treatment.

34. The treatment was hell on earth. I felt bad because of my hepatitis C already, but I felt much worse when I was on treatment. I would go to sleep and not want to wake up. I had a young daughter and she really was the driving force to get me to get up and still continue. I think even if I was a single man and had the same situation, I may not still be here to tell this story. I would not have been able to get through to the end of the treatment.

35. When I was on the treatment, I do believe that my depression did get worse. The psychologist who tested me prior to treatment thought that I could handle the treatment. I produce this letter in evidence and refer to it as **WITN2168010**. I recall at one point we had to have my daughter go live with my wife's sister as we were not able to cope with having her as well. Sometimes I would drink when I was on the treatment just to cope with everything that was going on. The joint pain I had was very bad and my muscles were inflamed. I felt often like I had been run over by a car. As I have said, my young child was my driving force to continue on. I believe that this treatment was around 2003. Since then I have not felt the same. I felt that I still had a spark in myself and my personality prior to the treatment but after the Interferon that was it. I also had really bad skin and this involved discolouration. My legs are brown and I believe that is something to do with my kidneys working overtime. I still get rashes and have itching as a result of the treatment, almost like ants under your skin. It is like being covered in fire ants. There was no support. There was just a nurse who took my blood once a month. She was only there to monitor my results. She was professional but unsupportive. At one point she was going to stop my treatment but I convinced her to continue it.

36. I remember being up at the hospital seeing Professor Ludlam once and he said that because of my liver having non-A non-B hepatitis, that I may require a biopsy. This would have been in February of 1994 when I was 22. There was

no estimation given to how far along the infection was. I think they already knew I was stage 2 at that point. I remember getting my biopsy and I woke up in the middle of this procedure and I recall seeing that the doctor treating me was a different doctor than the one who was there when I went to sleep. I felt my organs moving about. I was then later put to sleep again once they noticed that I had woken up. This biopsy has caused scarring on my liver that cannot be repaired. I am worried that this did heighten the effect of hepatitis of my liver.

37. I do not believe they ever came back to me with results of this biopsy. It is one of the things where they put forms in front of you and because of your position of trust with Doctors, you would just sign things without fully reading them. I do not think that I was told and certainly did not understand that the biopsy might make my liver worse or cause the scarring which it has caused on my liver. I am aware that any damage to my liver causes my ability to clot blood to be even lower than it is already by me being a haemophiliac. I had lots of tests done. I believe that by keeping the information vague, they were avoiding any other questions being asked. This has once again rocked my faith in the medical profession, on top of the research and getting the infections in the first place.

#### Barriers to treatment and information

38. In terms of any barriers to treatment, I feel that they knew I was having a hard time mentally. I am still on anti-depressants to this day and I feel like doctors use my haemophilia as an excuse for how I feel rather than actually mentioning hepatitis C as a cause of the symptoms I faced. I am wanting to get my weight down and my diabetic doctor had said about weight loss surgery but I believe that nothing will happen as I don't get anything offered to me because of my hepatitis C. I currently have six gallstones and seven kidney stones and excuses are always given as to why they will not treat me for these. I now feel a tightness of my back because of my kidneys.

39. One thing I found disgusting over the years was that doctors would go on about the cost of the factor treatment. I remember when I was in Leith Hospital, I had a bleed and my uncle was incredibly angry because the doctor had questioned why I should get the treatment because of the cost of it. Another similar thing that happened was when I was given my Interferon injections. I recall there was a nurse called Susan at the RIE and she said to me that the Interferon treatment cost £50,000. It seems like we are meant to be made sure how much the treatments cost and be grateful for the treatments we are getting. I even recall one time when I was in accident and emergency, a doctor said that I did not look to be in pain when I was. I think this is harsh because people deal with pain differently and quite often I will joke to try and get through these hard times. I have now developed a terrible phobia of hospitals. I think this is, in no small part, due to the fact that they made me feel guilty about the cost of treatment.
40. My phobia of hospitals has led to my GP often treating me in relation to my haemophilia. I have not been to hospital for over a year. Because I have not been to hospital, it has sometimes been difficult to even receive my factor treatment. I feel sorry for those who are in hospital now because they have no trust in the doctors. Those that were responsible for the contaminated blood have now all left but the mistrust they caused remains.
41. I felt there was more treatment available for those who had contracted HIV. I feel like medical professionals use HIV and the scandal around it to cover-up hepatitis C. I feel like people with HIV were more privy to information than I ever was.
42. As I have said, I have kidney stones and gallstones and doctors have been refusing to treat or operate on this. I went to get an endoscopy and they had to use one of their oldest endoscopes and refused to do it. Apparently, everyone has their own endoscope and mine is one of the oldest. I note that on an endoscopy request form 1 April 2008 my records contain a starred note that I am a vCJD risk and there is a need to use one of the "dedicated" scopes. I

produce these records in evidence and I refer to them as **WITN2168011**. This risk is all over my medical records in relation to almost every surgical procedure being contemplated for me. In places I am classed as being at “high risk” of vCJD. I produce an entry from my medical notes and I refer to it as **WITN2168012**. My records contain a completed vCJD exposure assessment form from 19 July 2006. This suggests that I was exposed to an implicated batch of HT DEFIX between September and November 1987. I produce the assessment form in evidence and refer to it as **WITN2168013**. It also states that I was treated with factor 9 from a patient who died from CJD. I produce this entry in evidence and refer to it as **WITN2168014**.

43. I feel that I get the brush off from doctors as a result and there have been so many times that surgeries have been mentioned but they end up not happening. I feel they do not want my blood on the table because of the cost of having to replace that table.

44. I do feel that I am more socially withdrawn than I was before. I used to be the guy that in work and in my social life who would organise parties. I loved life and I think that other people really use that to their advantage. I love being part of things. It felt like overnight this part of me was gone. I do feel that part of the reason why I have become more socially withdrawn is because I am avoiding talking about my condition. At the time of my diagnosis there were a lot of ads about haemophiliacs and drug addicts having HIV, so this made me concerned about people knowing about my haemophilia then, in case they made any assumptions. When I started to see the symptoms the spark went out of me. I was worried about my own longevity. I think it would help if there was some clarity about this whole scandal. I think that this would help with people's understanding more widely as well.

45. I remember in high school there was the whole HIV scare; people seemed to associate that with haemophilia. I ended up in fights and would end up in hospital. I found that if I was aggressive that would stop them fighting with me. I did not receive any counselling for this aggression.



46. Now, I would rather be at home than out about. I feel like since people know about my condition and my infection, that they judge me for it. The BBC interviewed me after the Penrose Inquiry and that does make me worry about other people's ignorance when they see me on TV in relation to contaminated blood.

47. In terms of the stigma of hepatitis C, I saw a difference with people I work with when they found out. As soon as you have a bleed they sort of treat you differently. This has also caused problems with intimacy for me. I feel that I get nervous around physical contact. I love my wife Gillian and I loved my first wife at the time and I just don't want to hurt anyone. I was always told I'd dodged a bullet by not having HIV. My wife Gillian has never been tested as far as I'm aware but she may have been tested during her pregnancy. GRO-C

GRO-C If you love someone you don't want them to feel as I have often felt. It is something I have been paranoid about. I feel that I second-guess myself. I have sometimes felt that people were looking at me after I had been on TV and sort of assuming that maybe they had seen me and knew of my condition. I feel that HIV and hepatitis are treated as if they are in the same bracket.

#### Effect on education and employment

48. In terms of educational effect, I would say that I missed a lot of school. Some of this was just due to having bleeds and I would be treated as an inpatient sometimes. There are some issues that I now believe may have been symptoms of hepatitis C, those were the symptoms of tiredness and fatigue. Teachers would notice that I was very tired and I had a lot of sick leave because of hepatitis, I believe in retrospect. By this, I mean symptoms that I now think were hepatitis. It is hard to pinpoint what was just a symptom of haemophilia and what was a symptom of hepatitis C. I do feel that my symptoms did definitely affect my grades. I recall that teachers thought I was bright but I just

could not take information in. I have since done an IQ test and I believe that this came back quite high. Even my daughter notices now that I sometimes trail off in conversations. I got bullied in primary school because I had been flagged up as a haemophiliac and I was put in front of everyone and they were told that they couldn't hit me which made them just want to hit me more.

49. I really thought that my job in the Civil Service would be a career. My phone skills were amazing and I was training other people. Due to the sick leave I had to have, it meant that a promotion was completely out of the question. There were others that started at the same time as me who got promoted while I did not progress. I found that I would lose files that were simply sitting at my desk and I could not organise myself. I do feel that I lost my career because of my health. As I previously said, I was dismissed from my job on health grounds. I was given a payment of £2,500 when I was dismissed.

#### Financial effects

50. I am currently on benefits and have been on disability benefits because of my joint problems. For years we have struggled as a family. I paid rent for years when I should not have had to and this should have been covered by benefits. Some weeks we had £20 to feed the family. I started going for medical assessments when the employment support allowance started but I only went once and I have never been made to go back.

51. I do not have any life insurance. I remember when I got my first mortgage, I could only get a certain type of cover and that would only cover a non-hepatitis related death.

52. Travel insurance has also been quite expensive due to my condition. When I got my Skipton money, I took the children to Disneyland Paris. The insurance was too high and I just took the risk of going without insurance. The insurance would have cost us £480 just for that trip alone. I could not have afforded that.

Effect on family life

53. My first marriage was destroyed because of my mental state. Everything went south when I was then experiencing symptoms of hepatitis C. I was always going to my doctor at that time. When my wife and I broke up, we sold the house and I moved into my parents' house and that was very demoralising.

54. When I tried to take my own life, I just could not cope any more. I feel that if the medical staff had listened to my symptoms and linked them to hepatitis C, I could have dealt with it better. Instead, they were just these unexplained symptoms. I did not know when they came from because lack of information given to me.

55. In terms of the effect on my children, I would say that my daughter **GRO-C** **GRO-C** cried a lot in the past. I brought her up because my wife was out working. My daughter worries about me all the time and she has seen things on TV **GRO-C** **GRO-C** She was even worried about me when she was four or five years old. She also saw me when I was on my Interferon and was suffering the symptoms of this. There was no support offered for my daughter but she is very insular. I do feel now if help was needed we would not have gone to the NHS because my trust in them is so low now. I believe it was easier for my son because he was much younger. He missed out on having to see some of the treatments and symptoms.

56. I have always used humour as a coping mechanism to deal with what was going on around me. My hepatitis C robbed me of my personality and I lost my zest for life. I have no friends other than my wife. I do not socialise outside of my family. People sort of get a vibe that there is something wrong even though I am not the sort of person to complain. I feel that I value my friends more than they valued me.

57. My wife was a care assistant for disabled people; this was a job she enjoyed until April 6<sup>th</sup> 2012 when she had to give it up to care for me. My wife did not want to give up work. I feel that I have lost the confidence I used to have and now when I go out I like to have someone with me. I feel that I have lost my self-respect. I had three jobs at one point and now I am completely unable to work. I feel that people do not understand. My wife only claims for a carer's allowance as she needed to stop working in order to care for me. I do not think it has been fair on either of us. We struggled for a long time and would often forgo meals so that our children could eat. My wife has always been a cheery person, [GRO-C] I think this was also because of everything we've had to deal with together. There has never been any support. My wife and I do talk to each other about our whole situation and we are very open with one another.

### **Section 6: Treatment/Care/Support**

58. With counselling, I have only been offered this for my mental health problems in isolation. It has been offered for the depressive symptoms that I had but never for hepatitis C itself directly. I remember when I was a teenager, I did feel it would have been helpful for me to have treatment then. I would go to see my GP and he would say that he did not know why I was feeling the way I was. I feel that they should have offered some sort of counselling and information. They never offered anything. They only gave me counselling when I tried to hurt myself. They never said anything about physical health or the link with my hepatitis C during this counselling. It was as if that was being ignored though it was the cause of everything. I hated myself for years. I do feel I would have benefited hugely from treatment and counselling rather than being cast adrift.

### **Section 7: Financial Assistance**

59. In terms of the Caxton fund, I would claim for things like when I needed a new fridge, school uniforms for the children, high-priced furniture and things like the

garden fence. We had to send the Caxton fund quotes for these things and we always needed two quotes and they would always take the lower quote and that would be what they would give us. I did not receive any heating allowance. I did not have much do with different grants. In terms of the form, you just had to explain why you needed it and this could be sent by e-mail and this was quite an easy process.

60. In terms of Skipton fund, I received £20,000 in 2004. In 2011, I had reached stage two so I received £25,000. Prior to the Scottish Infected Blood Support Scheme I received £15,000 a year which was split over 12 months. After the £25,000 payment, I believe I got around £1150 per month. This continued until the Scottish Infected Blood Support Scheme. I found Skipton to a very easy process. I know that a lot of others complain about it.

61. With the new Scottish Infected Blood Support Scheme, the payment is now up to £27,000 per year. This payment is split out over the year and amounts to roughly around £2250 a month. As I was Stage 2 on Skipton, I was marked as "severe" automatically for this. There was an automatic changeover to this new fund. I do feel the financial system is a lot better now that it had been before. It feels almost like a salary now. I do not like the disparity between the other funds. An Irish person in my situation would have been getting £700,000 in the 80s. The disparity makes me feel very angry.

62. I feel that they do not take family into account and they give from one hand and take away with another. By this I mean that although there is this new fund, there is no trust to go to when there are big expenses like there was with Caxton. You could go to Caxton for the likes of appliances, boiler problems and school uniforms but that is gone now. There is no emergency fall back like there was with Caxton. Rather than being able to claim for things we need, it is more a matter of having to manage your own money. I feel that we would own a house by now if I was not in the situation I am in.

63. At one stage my wife and I were homeless as we had been renting privately and my sick pay had run out. We applied for help and had to move out. The system said that we had made ourselves homeless. We ended up in temporary housing with a baby. This would have been when [GRO-C] was three weeks old. This would have been in [GRO-C] 2001. My wife was a carer so she was not the best paid. They did not take account of people having debts. I first went to East Lothian Council since we lived there, but they were no use. I then went to Edinburgh City Council because I worked in their jurisdiction and they dealt with everything. I asked for help from the hospital social worker but they only gave us a carpet for our living room. They said it was the best they could do.

64. I live in constant fear of the thought of my family being in pain and what they would go through if I passed away. I find it very hard to deal with that. I feel that the doctors are putting up barriers to me getting treatment I need in hospital. I feel like I am past my best. I feel like the hospital do not want their mistakes on show and I feel like one of their mistakes. I have to put on a brave face but I am hyperaware of my own mortality. I am also worried that the biopsy I had could take years off of my life. I feel like they have claimed that people did not know about the potential harm they were doing to us and that they have used that to their advantage.

### **Section 8: Other Issues**

65. I did not participate in the Penrose Inquiry but I did follow it. I went to the final hearing. The whole thing was an absolute waste of time. This was an opportunity for us to get answers but it gave way too much protection to those who are responsible for what happened. I felt that it dragged out for far too long and cost too much money. There is a sense of betrayal that haemophiliacs all feel from that Inquiry. I feel there was no thought to and no compassion for what really happened to everyone. I felt we were left on the scrapheap. I felt betrayed and let down. I have felt those things about the medical profession for a long time. The Penrose Inquiry made these feelings much worse.

66. I do not wish for my statement to be made anonymous.

## Statement of Truth

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

Signed

**GRO-C**

Dated

13th September 2019