

Witness Name: Paul Hutchison

Statement No.: WITN2167001

Exhibits: WITN2167001-005

Dated: 22nd March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF PAUL HUTCHISON

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

I, Paul Hutchison, will say as follows: -

#### Section 1. Introduction

1. My name is Paul Hutchison. My date of birth is [GRO-C] 1974. I am married to my wife Elizabeth Hutchison and we have two children. We have [GRO-C] who is 16 and [GRO-C] who is 12.
2. I am currently unemployed. I worked at Capability Scotland for 15 years as a support worker for disabled adults. I suffer from tiredness and had issues with my back and as I was off so much, I was dismissed on ill-health grounds in December 2013.

#### Section 2. How Infected

3. I suffer from haemophilia B and this is moderate/severe in nature. I was diagnosed as having this shortly after I was born. I believe I was given

my first dose of factor IX at three weeks old at Leith hospital. I have a memory of being told that the factor was sent from Edinburgh Royal Infirmary. I was treated by a Dr Syme who was assisted by a Sister Mackie.

4. I recall when I was younger, my older brother Myles was suspected of being battered because he kept coming up in bruises. They realised this was due to his haemophilia. I remember that the social work and police were involved with Myles at this point.
5. I am not sure of the names of all the treatments I have had for my haemophilia but I do remember the likes of recombinant. I recall that they came in big polystyrene boxes. These were kept cold. My mum was shown how to inject us with the treatment herself as we got older. I would estimate we started with treatment when we were around six or seven years old. I believe they taught my mum to save us having to go into hospital at the time.
6. They wanted to keep us at the Western Hospital at their haematology department but there was some issue where Edinburgh Royal Infirmary would not send treatment to the Western. I knew we would have to go to the Royal Infirmary eventually. I do not believe that they had a ward for children.
7. My brother Myles and I were initially treated at Leith Hospital and I think it was when we were eight or nine years old, we were at Edinburgh Royal Infirmary. We always cried having to go there. The people there were older and we kept seeing them disappearing which can be scary for children.
8. I recall that the first doctor we had at Edinburgh Royal Infirmary was a Dr Tucker and I remember a Sister Phillips. I remember feeling like where we had to go for treatment was underground. It would have been Sister Phillips who initially administered factor VIII to us. I recall at one

stage Dr Tucker left and thereafter we were treated by Professor Christopher Ludlam. Professor Ludlam was head haematologist. I also recall a Sister Billie Reynolds working there. I believe that Sister Billie Reynolds left because of issues with paperwork, although I believe there was more to it than what we were told. I do believe that there is a large volume of medical letters missing from my medical records as there are big gaps in dates. There are rumours that I have heard that she knew about the factor treatment and the contaminated blood and refused to treat people with this. She was brilliant.

9. We were at hospital, I believe, every six weeks but sometimes we would also have to go in-between. Every three months we would get a blood test. My dad did not drive so we would often get the bus to the hospital.
10. At the time of my diagnosis, I was working in Royal Infirmary as a clinical biochemistry assistant. I was given a pseudo name (Alex Austin) as was Myles (Robert Marr) for our blood tests. I believe that Myles was told before me, he was told by Professor Ludlam. They had done a blood test before and I believe I got a letter two days after that. When I spoke to Professor Ludlam he said that they knew that I had non-A non-B for years and I am sure he said that it affected my liver. I felt numb and Professor Ludlam basically told me that I was free to go. I did not hear much about it for weeks. They mentioned that interferon had helped with HIV patients, which suggested that might be what had happened to me. By this, I mean having interferon treatment. Professor Ludlam mentioned doing a biopsy and Myles volunteered to have it so I would not have to. They did not say there was anything that could specifically treat hepatitis C when they told us that we had it.
11. I do feel that I was given inadequate information. I am sure that my mum and dad made an appointment and had not been given any more information than what we had. It seems bizarre to me now they knew that I had non-A non-B, or what is now known as hepatitis C, in my

blood long before they told me. They never said how long they knew but they did say they knew before. I just felt numb at the time they told me.

12. My brother and I always worried about getting told that we had HIV because of everything that was going on in the press at the time. I do believe that we should have been told earlier than we were. My mum felt very responsible for what happened to us, as she was one administering treatment at home. Mum has not been the same since **GRO-C** She blames herself. **GRO-C** **GRO-C** I do believe this has ruined both of my parents' lives.
13. In terms of cross infection, Professor Ludlam said that there was a possibility of passing on hepatitis C through sex, saliva or blood. They said about not sharing cutlery or glasses. There was no sharing of razors or toothbrushes. Even to this day, this affects me and I worry about my blood getting anywhere even though I have been cleared of the virus. I cut my finger the other day and there was blood on the door handle and I almost lost it with my daughter when she went anywhere near it.
14. I did not start treating myself until I was about 13. I recall that my brother and I went on a haemophiliac's adventure holiday. This was our first time injecting it for ourselves. Myles had already done it himself before but this was the first time I had to get used to it. I had a bit of a fear of the nurse being the one to do it. Sometimes we were better getting a vein than the nurses were.
15. Professor Ludlum came across as if he had our best interests at heart. He called us his boys but I also remember him referring to us as 'pups', which I understand to be an acronym for previously uninfected patients.

16. I remember being called to the ward and there was a big rectangular thing covered in needles, almost like a BCG. He said the test was for the future in terms of our factor treatment. We were kept in all afternoon during this. I remember I had rashes in different parts of my arm. This was never explained to me. I just trusted him as he was a doctor. I had known Professor Ludlam since I was a child.
17. I believe I would have been 19 or 20 when I was told I had hepatitis C. It was Doctor Ludlam who told me I had hepatitis C. My brother Miles had been taken into hospital with another bleed. A few days later a nurse phoned me and made an urgent appointment to see Doctor Ludlam. I went to see him on my own. He just said that he was sorry but I had hepatitis C. I remember he said that it would lead to cancer of the liver. He said there was not a treatment available at that time but there may be one in the future. I remember I went straight to see my brother who was still in hospital. He had been told he had contracted hepatitis C also. I remember we both cried.

### **Section 3. Other Infections**

18. I was infected only with hepatitis C. I have received a letter about VCJD or mad cow disease. After questioning, they did say there was a test for VCJD but it was too expensive.

### **Section 4. Consent**

19. I do believe that I was tested without my parents' consent. I believe this as they knew prior to when they told me that I had hepatitis C. It has been said to me that the blood I had been given over the years was used for research. There are rumours that Professor Ludlam is still using samples. It was never really explained why they were taking blood but they always took a lot of blood. This may be more than is normal.

20. It was only when I was working at the Edinburgh Royal Infirmary that I saw what blood had been used for. They had to use a different name when they were testing the blood as I worked with the hospital. This was instructed by Professor Ludlam. He said this was to protect my privacy when the results came back. They never explicitly said they were taking samples and they never explained why they were taking samples. Professor Ludlam would say, "*There are other tests to be done, we are taking more blood*". I remember them using big 60 millilitre syringes.

### **Section 5. Impact**

21. In terms of my symptoms prior to being diagnosed, I would say that I was always tired when I was younger. I recall having to lie down when I came home from school. I just was not as energetic as other children. I also felt that I used to have colds and flus a lot. I would always just put that down to a bug that was going around. I always had pains but the hospital said that there would be bleeds in my joints just as part of my haemophilia. They said that the pain could be arthritic. I just put this down to the aches and pains a haemophiliac would have normally. I would say that I possibly had brain fog at times. Even now, I still suffer from this where I can go into a shop and often forget what I went in for. I also suffered with rashes and they said it could be psoriasis. I did not notice any effect on my appetite when I was on treatment. I have suffered from depression over the years and I do wonder if this is linked to my hepatitis C. I do not believe that it helped when we were told about our hepatitis C when Professor Ludlam said that we could die from it. I remember both myself and my brother crying.
22. I have never been tested for other conditions like an underactive thyroid.
23. I was treated with interferon and ribavirin when I was 21 or 22. From medical records I had the treatment between June and September,



1995. I produce a letter dated 14/11/1996 in evidence and refer to it as **WITN2167002**. I believe this was as part of a trial. I believe they just had just found out that the results from HIV and AIDS patients were positive from using this treatment. I felt that I was suicidal while I was on this treatment and my parents would not leave me alone for fear of me hurting myself. I had really bad mood swings which continue even now. I used to be very happy-go-lucky but I have had mood swings since my treatment. Initially, it was a six-month treatment and then was to be another following six-month period but they said that I had cleared it after those initial six months.

24. My mum was very spiritual and she knew a healer who had got in touch and came around to the house, she is quite convinced that this is what healed me. I am more the type to question things.

25. They said once I had had my treatment that my levels of hepatitis were low enough that it was at a level where it could do no harm anymore. There is an entry in my medical notes relating to this. I produce this entry in evidence and refer to it as **WITN2167003**. They said if it came back to any level, they would restart treatment. I believe that one result must have come back higher than they expected as I was put on treatment again for four or five weeks. I was getting haematomas in my stomach due to my injecting interferon there. I was taking prophylactic treatment at that point for my haemophilia. I used to dread my treatment because I knew I would feel like crap after. I believe that the injection I had contained both interferon and ribavirin.

26. I believe that the injection had contained both interferon and ribavirin.

27. I believe there was a year between my diagnosis and treatment. I believe this was because Professor Ludlam said that there was no treatment initially that they could give me. I do recall that they used to tell me quite often how much everything cost. There was a nurse once who dropped a needle as she was about to inject me. There was blood

on the floor and I said I would not take that treatment. She accused me of wasting money. I found quite often, there was a constant guilt trip, a reminder of the cost of these treatments.

28. There are no treatments that I am aware of that I should have given but was not.
29. When I was on treatment, I had symptoms such as a sorehead, aching, shaking with the flulike symptoms and rigours. I found that my coordination was affected while I was on treatment as well. I remember trying to walk to the newspaper shop and I got halfway and had to go back as I found my vision was starting to blur. I did not want to go out when I was on interferon. I believe the interferon put me into a depression. At times I wanted to end things. I had no idea I had partial hearing loss in my left ear. This is a side effect of interferon treatment. I only learned of this after reading my medical records. I produce the record that this relates to and refer to it as **WITN2167004**.
30. In terms of the impact on my social life, I would say that I do not have one, even now. I have a season ticket for Easter Road that I would go to with my son but I feel the cold more so sometimes that deters me from going. Between back problems and tiredness, this has had a huge effect on going out to the likes of football matches. I end up being wrapped up like it is winter all the time because of the cold I feel. I have the heating on constantly.
31. I feel that my depression has never gone away. I feel that talking with a psychologist has made it worse. My brother Myles handled his diagnosis with drinking but I just tried to forget it all and became withdrawn. I was worried about it coming up in conversation. People would ask why I do not work and I was constantly worried about other people's ignorance if I told them the real reason.



32. The stigma of hepatitis C has been prevalent throughout my life. I remember at school, Myles cut his hand once and they made my mum come and clean up the blood from this cut. My haemophilia was even questioned when I was at Capability Scotland.
33. I would say even now, although I am cleared of hepatitis C, I am hyperaware of things around me. I am always taking two steps ahead and it makes me very careful about anything like cutting myself. I am always washing my hands. It does, to some extent, make you paranoid about things.
34. I believe my conditions had a big impact on my family life. With things happening like losing my job at Edinburgh Royal Infirmary and then losing my job capability Scotland being put down to my back injury and my hepatitis C, we had issues like where we did not want to ask my wife's parents for money. At one point, we were living on beans on toast, though we obviously still made sure to feed the children properly. My wife even had to fight for the council house we have now. It was a big weight taken off my shoulders when we got this house. At least now, I have a safety net for my children and wife.
35. I found that I have always been tired so I have not been able to play with the children as much when they were younger as I might have had I not had hepatitis C. I was less involved that I would have liked to have been.
36. When I was first told about how hepatitis can be passed on to sexual partners, I was told that there is a 99.1% chance of the partner of someone with hepatitis C, not being infected. I was also told that the risk of sexual transmission is very low around 3%. I produce a letter from my medical notes that relates to this and identify it as **WITN2167005**. This made me worry for that small amount were someone could. It put me off going out with girls and things. I was

worried anything would happen; it was hellish having to tell people. I worried if it told anyone, they would then tell other people.

37. I was worried about even having children with my wife. I worry to this day about her being infected. GRO-C  
GRO-C

38. I feel at times, I have been a bit of a hermit. My condition has had an impact on my relationship with my wife I feel. I believe that even my tiredness has caused issues sometimes. My wife often wants me to go out with her, but often I just do not have the energy.

39. My kids call me Mr angry. I was talking to GRO-C at a football match recently and he mentioned that I am angry. I think I have been more irritable sometimes because I suffer from soreheads and I am always having to turn the sound down on things like the television.

40. I felt that I was treated differently in hospital. There was an issue with my endoscope. I was going in for an endoscopy and they said that my camera was 15 years old and was not taking pictures. I phoned Myles after this and they mentioned about not operating on things with him. They would not operate on my back and I think it is because of me having had hepatitis C.

41. I recall a dentist making a comment about them throwing away the instruments after treating me. My dentist was on Chambers Street and I remember them coming out dressed like a spaceman to treat me because I think they thought I had HIV or something. This was when I was much younger my dad took my brother and I away from them.

42. I remember that in the hospital they would push on my stomach. Another campaigner called Bruce said that they must have been checking my liver. Once I was diagnosed with hepatitis C, they stopped checking things like that. I believe that all haemophiliacs must feel the

same and must have felt treated like lepers at times in the NHS. I lost all faith in my doctors and I certainly do not believe doctors as easily now as I might have done in the past.

43. I do believe that my condition may have had an educational effect on my children. They have sometimes had to have a day off because I have not been well and I have been tired. They do worry about me as well. I was worried about the future of whether my children might be looking to go to the likes of university but now with the financial schemes, I believe this will be less of a struggle.
44. I feel that I have been tarred with the same brush as people who have contracted this disease due to a choice of their own and it is as if I do not want to work, whereas I would rather be working.
45. In terms my own education, my concentration was affected, I remember I used to get in trouble for staring out of the window and things. I remember my mum used to try and teach me things and I now question if it was the condition that caused me to not be able to concentrate when I was in school. I do believe this did have an impact on the qualifications I came out of school with.
46. I do believe that my condition has had an impact financially. Prior to getting our council house, we were just making payments on our mortgage but we were struggling. My relationship got to breaking point over the likes of being able to pay the mortgage. It got to stage that the bank were saying about having summer breaks on payments and working it out that way. We even spoke about getting a caravan at some point or moving in with my wife's parents. The council house was the best thing that could happen. It gave me that extra security. I even worry about the likes of my funeral in years to come. I believe my wife, Liz, worries about the fact that I could die early. We have been together for 20 years.

47. I do not have life insurance but I did question this previously. I look at this as out of my price range. I only earned around £690 per month at Capability Scotland.
48. In terms of travel insurance, my wife does sort this if we were to go on holiday. I believe my wife puts me through like anyone would be who is a haemophiliac.

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

49. No support or counselling was ever offered at any point. I had counselling offered to me last year and that is with someone called Gronia O'Brien. She is based at Edinburgh Royal Infirmary and is in the Haematology Department. I get a little bit paranoid about seeing her in case she feeds anything back to the other staff. I stopped seeing her at one point recently just because it was bringing it all back to me.
50. Nothing was ever offered in terms of support to my mum, dad brother or myself really. I think we possibly have benefited from being told at least what was going to happen in terms of my symptoms. I believe it should have been part of treatment plan.
51. I do think that they should have given my mum or dad more information. I think this would have allowed them to process everything that was going on.

### **Section 7. Financial Assistance**

52. In terms of financial assistance, I did receive help for getting a new boiler from the Caxton Fund when I was struggling. I believe I just gave them quotes and they paid for it. They also help with things like school uniforms for the children. I believe I discovered Caxton through my wife looking on the Internet. I did receive a winter fuel allowance of around

£500 per year but we did have to apply every year for this. I also believe the Caxton Fund assisted with the deposit for my Mobility car. At one stage, they did give us a new fridge freezer. People used to complain and I do think some people thought that Caxton was a long drawn-out process. I remember having to chase them on the phone I and felt like I was grovelling.

53. In terms of Skipton Fund, I received £20,000 in 2004. By the time my credit card and many other debts were paid, there was not much left. I received £30,000 in 2016 from the Scottish Government. I have put away £4,000 each for my children for the future.
54. With the new Scottish Infected Blood Support Scheme, I mark myself as severe. I receive £18,000 per year, which amounts to £1575 per month. It is an absolute weight off my shoulders and it really is keeping us afloat now. It is almost like a wage for me and we can put money aside for things if we need to now. I certainly prefer how it is now compared to how it was before.
55. I am currently on benefits and receive PIP payments. I have been awarded this for life. This is difficult for me because my dad has always worked and I wanted to be in the same position as him. I have another three years to wait before I have another medical assessment. I had DLA for life, this has now been changed and I will be assessed again every 3 years for PIP.
56. I do believe there should be more compensation but right now, I am just glad to be getting what I am. I think we should be more like the Irish scheme.

### **Section 8. Other Issues**

57. I was involved with the Penrose Inquiry and I thought it was a total fix and whitewash. I believe that Lord Penrose just made excuses like that



fact that his wife was dying, I think he should have been replaced if he was not able to be as involved as he should have been. He was not even there on the day that the findings were announced. I feel that the Scottish Government were protecting certain people. I believe Professor Ludlam was never going to be held accountable. I feel that the whole inquiry before was a total waste of taxpayer money. I believe that Lord Penrose was either tainted with money or pushed into only going out into certain avenues.

58. When I first started going to Scottish meetings about contaminated blood, things with haemophiliacs and people who received infected blood through transfusions were separate. When they put the two groups together, it sort of took the wind out of my sails. It made it harder to fight in my view.

**Statement of Truth**

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

Signe GRO-C

Dated *13/9/19*