Witness Name: Paul Henderson
Statement No.: WITN3475001
Exhibits: WITN3475002-004
Dated: 9th July 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAUL HENDERSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27th June 2019.

I, Paul Henderson, will say as follows: -

Section 1. Introduction

1. My name is Paul Henderson. My date of birth is the GRO-C 1964. My address is known to the Inquiry. I am single and I don't have any dependents. I am working right now as a senior service manager in social work. I have been doing this role now for twelve and a half years. I intend to speak about my infection with hepatitis C in particular the nature of my illness, how the illness affected me, the treatment received and the impact it had to me up until the infection was cured in 2010.

2. I do not wish my statement to be anonymous.

Section 2. How Infected

3. I had acute myeloid leukaemia. I was diagnosed in April 1988 and I underwent a course of chemotherapy at Ninewells Hospital in Dundee. This treatment was not working so I was urgently moved to a bone marrow transplant unit at Glasgow Royal Infirmary and had a bone marrow transplant on the 7th July 1988. When I received the transplant, I also received multiple blood transfusions and was infected with hepatitis C. I received countless units of blood.

4. The whole treatment for acute myeloid leukaemia makes you feel incredibly unwell. The treatment was so brutal that I almost died. I was ultimately in hospital for around five months. Gradually I started to feel a bit better. I think I was finally discharged from hospital in September or October 1988. I exhibit an extract from my medical records which mentions my bone marrow transplant as **WITN3475002.**

5. I was under the care of Professor Barnett. He was treating the leukaemia. He was the treating consultant when I was infected but while I was in hospital he moved so I was then transferred onto another consultant but I cannot recall their name. I have never had a transfusion at any other time. As my bone marrow was transplanted, I was considered to be in remission at the end of 1988 but I was told that the leukaemia may come back one day. Thankfully it never has.

6. The doctors told me that I would need constant blood transfusions as I had no bone marrow during the treatment because they had to remove my bone marrow by radiation and chemotherapy. In order to be kept alive, I needed this constant transfusion of blood for several months.

7. There was no conversations about the risks of receiving the blood. I had no awareness of the media at the time or any risks associated with the blood either.

8. Shortly after the bone marrow transplant, I was put in a sterilised room and became deeply unwell. A friend came to visit me and he asked if I had been abroad because I looked incredibly tanned to him. I thought he was joking because I was so unwell. It had been because my skin had changed colour, it had turned yellow. I heard the consultants talking amongst themselves about me being jaundiced. They could not

understand why I had become jaundiced and what had happened. Obviously now I know it was because I was infected with hepatitis C. At the time, they were taking blood tests constantly because of the leukaemia so I have no idea if they were doing blood tests for anything else. I do not think that the doctors knew about hepatitis C then. I am unaware of what the medical understanding was on the subject matter in 1988. After I was discharged, I was still having regular check-ups and blood tests as an outpatient. I still had a Hickman line in my body to enable clinicians to take blood samples easily.

9. I am now registered with Dr Wands, Bruntsfield Health Centre, Forbes Road, Edinburgh and have been since 2007. Prior to this I was registered at Murrayfield Medical Centre, Edinburgh EH12 5SS from 1996 – 2007, Hermitage Medical Practice, Edinburgh, EH10 4RP from 1988 – 1996 and prior to this I was registered from birth up until 1988 at a GP practice in Dundee where I grew up. I cannot recall where this was.

10. Some of what happened around my diagnosis is now clouded in my memory. I remember I was asked to come to the Glasgow Royal Infirmary as they told me that I may have been infected with something. They wanted me to come in to receive a liver biopsy. I went into the Glasgow Royal Infirmary and became an inpatient for a day while they did this. They told me that they needed to check my liver to see if it was damaged. That was in the early 1990s but I cannot recall exactly when. What I do know is the hospital were monitoring me constantly after I was discharged. This was because of the leukaemia and also because I had been jaundiced with no explanation.

11. I cannot recall the information I was given when I was diagnosed. I cannot recall the name of the consultant who diagnosed me. My reaction to finding out that I had hepatitis C was one of disbelief. I felt as though I had just been saved from the leukaemia but now I had contracted this infection. My memory is hazy but I think I was told that there was scarring on my liver and the hospital said that this would be because of the hepatitis infection.

12. I was then transferred onto GRO-D who was based at Edinburgh Royal Infirmary. At the point I was diagnosed I remember things were appearing in the

press about hepatitis C so I would have read what was going on then. I think there may have been leaflets and I remember being quite worried thinking my life could be limited by this. I was worried about how infectious I might be to others and worried about how quickly this could end up damaging my liver. I remember reading somewhere that there was a chance it could lie dormant for twenty years before things progressed.

13. I cannot remember if the information was adequate to understand and manage the infection. I remember it was done through verbal meetings with a doctor but I may have forgotten the information he gave me through the passage of time. I think the fact that they asked me to come into hospital and do a liver biopsy left me with the impression that this must be serious so I assumed there would be serious implications.

14. Glasgow Royal Infirmary did the biopsy on my liver. At the time I was in fact living in Edinburgh but I didn't question why I had to travel to Glasgow instead of Edinburgh to be tested. It could have been that they asked me where I wanted to go but because Glasgow Royal Infirmary had saved my life, I had a lot of affection for the hospital and the staff working there. I would often go to visit the bone marrow transplant unit anyway to visit the nurses. I have a lot of affection for the whole place and it has deep sentimental ties with me. It could also have been that I was referred there because that is where all my records were at this point.

15. The feeling I had was that the information they gave me at the time, while it was basic, it was because they did not know themselves. The treatments then were basic as well. At the time, they told me there was no cure but there were going to be treatments in the pipeline. There was also a question about the infection being sexually transmitted. They were still looking into this at the time I was diagnosed. They were doing research. I had the impression this was something new that they were gathering information about which is why I believe the information was limited. There was a lot of information in the media around AIDS and HIV at the time I was diagnosed but not too much on hepatitis C. I did know that if I had a cut, I had to be very careful and that there was a risk that the infection could be passed by sexual transmission. The doctors thought it would probably not be spread this way, but they were still doing research on this at the time so there was a theoretical risk.

My own understanding was that the infection would be caused by blood-to-blood contact. I remember feeling quite bad about the whole thing, it left me feeling a bit dirty and infectious.

16. The blood I received saved my life. However if the doctors knew there was a risk with me receiving it, I should have been told about this risk, as it is my right. I do not have any views however about how the results were communicated to me when I was diagnosed.

Section 3. Other Infections

17. I was never diagnosed with any other infections other than hepatitis C.

Section 4. Consent

18. I do not know if I have been treated or tested without my knowledge or consent I would need to review my medical records to form an opinion on this.

19. It is difficult to answer if I have been treated or tested without being given adequate or full information because it is so long ago and again I have not reviewed my medical records to compare. What I would comment on is that I was not made aware that I was going to be tested for hepatitis C.

20. I do not know if I have been used for research.

Section 5. Impact

21. I remember feeling exhausted all the time, and felt that I was going to die younger than I should have, because of the damage to my liver. I was worried that I would infect my girlfriend at the time but I do remember reading that the chance of infecting a partner was less likely or even negligible. However, I was always left with a sense that I could infect someone else through blood. I did have a girlfriend who broke up with me suddenly because she thought I had infected her but I hadn't

and she did test negative. That was quite difficult. I was not depressed though as I am quite a resilient person.

22. I received a treatment to reduce the iron levels in my blood. Through all of the blood transfusions I received, it was discovered around 1994 or 1995 that I had built-up a high level of iron in my liver. I believe I was told that my liver was more at risk because of the hepatitis C so they deemed that it would be best to reduce the levels in my blood although after the passage of time, I am hazy about this. I had a series of venesections where they drew blood from me to reduce the levels of the iron. I had a series of these treatments in the 1990s at the Edinburgh Royal Infirmary. I found these very difficult because I had recovered from leukaemia and I had started work again and was trying to be a healthy person but I had to receive these medical treatments all the time. The treatment itself left me completely exhausted because it was taking blood from me and leaving me wiped out and of course I was also trying to work at the same time. I ended up hating it to the point where I just stopped going. As a result, the levels of iron did not reduce further but it has not had an impact going forward since I have been cured of the hepatitis C itself.

23. I remember GRO-D offering me a course of interferon, but it did not have a high percentage success rate at the time he offered it. I presume he told me the percentage of people cured through it. This was in the late 1990s when he approached me with this offer. My leukaemia was over by this point and I was trying to get on with my career. I was told that the treatment would last a year or so and I thought, how on earth can I take a whole year off work and have no money coming into the house? Therefore, I said this to him and that I did not at that point feel unhealthy. I queried if it was necessary for me to have treatment at this point. I did not feel depressed or have symptoms that you feel when you have hepatitis C, except perhaps feeling tired. He agreed with me and said that I could always think about the treatment at a later point. My clear memory was that GRO-D agreed and that he thought I was being sensible and rational in my own assessments of the situation. Later on, but I cannot recall when, I was seeing another doctor for a check-up at the Edinburgh Royal Infirmary and he said in the course of this appointment, when reading my medical file, “I see you have refused treatment” for hepatitis C, to which I said no, I didn't refuse treatment at all. I thought

this was a bit strange. I was actually shocked, which is why I remember it so clearly. I explained the conversation to the doctor that I had actually had with GRO-D GRO-D. I do not understand how this turned into me refusing treatment. I have no idea why GRO-D would write this. If he did, I do not know what would have been in it for the hospital for them not to treat me then. I always thought that GRO-D seemed a friendly, approachable and professional man.

24. I am in a secure job and after a period, I thought that I should address the hepatitis C. At this point, I asked about treatment again and this commenced in 2006. I was only on this treatment for a couple of months as I became very unwell and had to stop. It was interferon and I think ribavirin that I was taking. At the same time this was going on, I was promoted at work to a role with a lot of responsibility in senior management. I ended up having to take sick leave in my first week because of the treatment. That was also part of the reason I ultimately stopped treatment as I needed to perform in my job. I exhibit an entry in my medical records that refers to this under **WITN3475003**. I had breathing problems and mental health issues, which I had never experienced before then, when I started the treatment. I developed depression then, proper depression, I just had to stop. I wanted to be away from people at lunchtime and be all by myself, walk in the woods by myself. It was not like me at all. I can only describe it as a bleakness. I remember one lunchtime I went for a walk and I could not breathe or move to the point my girlfriend had to help me. I think I was probably offered counselling the first time I tried treatment but I didn't take this offer up. I felt better when the treatment stopped and I did recover normally.

25. The second time I tried treatment was in 2009. I took the same course of treatment of interferon and Ribavirin. At this point, I had been doing my job for a couple of years and thought if I did not do the treatment then, I would never do it. I asked for permission from work because I explained to them that there would probably be an impact, which there was. My employer agreed, so I completed the full course of treatment this time. I did the course for one year in total. The side effects this time were pretty awful but I did not get the depression that time. I had some breathing issues, shortness of breath etc, but mainly, it was anaemia that was the biggest issue for me. I lost a lot of weight and went down to eight and a half stone. I had

constant flu symptoms shivering, aches and pains. The treatment centre I attended was fantastic; I had a fantastic hepatitis C nurse, Kim Macbeth. She was so good I wrote a letter to the chief executive of NHS Lothian praising the care she showed me. By 2009, I was under a different consultant but I cannot recall their name.

26. In March 2010, I was given the all clear. I cannot remember if there were follow-ups from the treatment afterwards. I do not think I have been left with lasting consequences from the treatment. At points during the treatment, I was able to do some work at home but I have no idea how I managed this, because my haemoglobin levels were terribly low. They did a follow-up test to confirm I was still clear, which I was. I do remember that at this follow up appointment, they said to me that my liver was not damaged at all, it was a healthy liver; but I remember being told back in the 1990s that my liver was being scarred but perhaps my memory is mistaken. They said there was no sign of scarring and the hepatitis C nurse, Kim Macbeth said she could not understand where that comment had come from originally. Perhaps I picked up the information wrong, I am not sure now. I cannot remember when the final follow-up was. I am glad that this chapter has been closed in my life. I do not wish follow-ups now. I would be interested to review my medical records over the comments around my liver.

27. I have never experienced difficulties in accessing the treatment. The only question in my mind is the conversation with GRO-D The conversation I had with him left me with the impression that the treatment was not urgent, I was not going to die at that point. I am assuming I got the full information though, as he was the expert. I hate associating myself with hospitals and sickness, it is not how I define myself. Maybe I was being naive about this and I could have had treatment earlier, I do not know. I am not aware of other treatments that I could have had at the time.

28. The infection never affected treatment for things like dental care or other medical conditions.

29. When I was living with my former partner, we bought a house together. Just over a year later I started treatment and around three to four months later she left me. When I started the treatment I was off sick from work as it made me feel very ill. I do not know if the treatment contributed to the relationship failing, as there were

various factors at play, but I was in a weak spot at the time. I was not out working, I was home, sick and taking care of the house and I think that may have contributed to a negative perception of me.

30. I have not experienced much stigma with hepatitis C. I have not kept it a secret. The rest of my family were worried and upset around the diagnosis as expected. My sister Rowena still worries now. If I become ill even with a cold, she worries it is more serious because of what has happened. There was an issue around what I would tell girlfriends and I did have a girlfriend who broke up with me when she found out. It is not really the thing you want to tell girls that you meet.

31. There was an impact on my working life as I was off for a long time so they brought someone else in to cover for me and it undermined my role at work. It made me seem less competent. I think it affected how I was perceived at work, certainly for a period, it had a negative effect on their confidence in me. It took a long time to recover from this but that is certainly not an issue now, it was worth it in the end. My employer overall has been very supportive. This negative perception of me I would say continued for a couple of years after I came back from being off sick.

32. I remember trying to get a mortgage and I told the broker I applied to that I had hepatitis C. His response was, "*we are not a charity you know*". I was ultimately able to get a mortgage in the end. I also tried to get life insurance but I could not get it because of the hepatitis C so I ended up not pursing this as an option. I still have to declare now that I have had hepatitis C in the past when applying for things which I do not feel is fair.

Section 6. Treatment/Care/Support

33. I do not feel I have had any trouble with accessing anything I need in terms of support or counselling. Counselling is not something that I feel would have helped me.

Section 7. Financial Assistance

34. I raised the question in 2003 about if I was eligible for compensation given what had happened to me. I exhibit a letter referring to this as **WITN3475004**. I found out about the Skipton fund when they wrote to me and told me that I was eligible. I received £20,000 in the early 2000s. In 2016 my other sister Josephine told me she saw something in the news about there being additional funding available so I looked it up online and phoned again and asked them. In that conversation I was that I was entitled to an extra £30,000! They contacted me again last year and said I could get additional monies as well, which I applied for. I now receive a monthly amount.

35. The process of applying for me was quite straightforward. I phoned SIBSS, they confirmed to me that yes I was due money and then I applied.

36. I filled out a form, sent it back and they said yes and they put the money straight into my bank account. They also contacted me again and told me there was more money available. It was very straightforward and well organised. I cannot remember if my doctor filled out the form. It was a quick process. There were no obstacles in applying but I would not have known about it at all if Josephine had not told me. There were no preconditions imposed on applying.

37. I received £20,000 from the Skipton Fund while I was still infected with hepatitis C in the early 2000s. I thought the amount was low considering the impact on my life and the scandal around the whole subject matter. I have this incredible gratitude towards them because I do always consider that my life was saved by the NHS, with the bone marrow transplant and all the professionals involved. I used to think that maybe hepatitis C will have shortened my life but at least the doctors saved my life because had I not received the treatment for my leukaemia, I would be dead, without a doubt, thirty odd years ago. At the time, it felt like it was a small price to pay and that has been my view about it, to an extent. The NHS saved my life and they saved it again in 2009 through the hepatitis C treatment. In terms of the amounts of money received, the amounts could always be higher considering

the impact the infection has had and what everyone has been put through.

Section 8. Other Issues

38. I have no other issues to raise.

Statement of Truth

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

Signed **GRO-C** ____

Dated Jul 10, 2020

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