Witness Name: William Wright

Statement No.: WITN2287001

Exhibits: **NIL**

Dated: 8th October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF WILLIAM WRIGHT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 1st October 2018.

I, William Wright, will say as follows: -

Section 1. Introduction

1. My name is William Wright. My date of birth and address are known to the Inquiry. I am now retired and I have been for some years for medical reasons. I am married, I have a son of 23 and a daughter of 27. I intend to speak about being infected with Hepatitis C as a result

of receiving infected blood products. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.

Section 2. How Infected

2. I have mild haemophilia A. The circumstances in which I became aware of this diagnosis are described below;

3. I received factor VIII concentrate in May 1986, as described below. There is a letter in my medical records from John Hanley, lecturer in haematology to Dr Christopher Ludlam dated 6 December 1996. In that letter it states that the factor VIII concentrate I received was thought by Dr Hanley almost certainly to have been the "NY" product which had been heat treated at 68 degrees for 24 hours. The letter identifies that I received 2,000 units (10 bottles) of factor VIII concentrate from batch number 0430. The letter confirms that that method of heat treatment did not effectively eliminate HCV, that even low levels of HCV were infectious and that from mid-1986 the heat treatment regime used on factor VIII concentrates produced at the Protein Fractionation Centre in Edinburgh changed;

4. I received this product at The Royal Infirmary of Edinburgh, as described below; and

5. The only occasion on which I received factor VIII concentrate was in May 1986, as described below.

6. I had bleeding problems as a child, and after a week of tests in 1974 at Glasgow Royal Infirmary I was told that I was not a haemophiliac and did not need to carry a card. Previously I had carried a haemophilia card until 1974. I was 16 years old and trying to

decide what I wanted to do with my life. Being a haemophiliac, this limited my possibilities of joining the armed forces or police. So, at that point in 1974 I spent a week in the Royal Infirmary having tests. At the end of that week, they decided that I was so mild that I didn't need to be registered as haemophiliac. I did not have any regular bleeding episodes throughout the period since then. I had problems, dental problems mainly, occasional significant bruising but no haematomas. There was one time as a very small child, I remember having a golf ball on my forehead when I bumped into something but I was extremely young and I had problems with nose bleeds which had to be cauterised but I certainly would never have regarded this anything more than mild in terms of my bleeding history. As I grew up as a teenager I indulged in a lot of sports and activities and until the incident in 1986 (described below) I never really thought anything of it and I led a perfectly normal active life. I certainly did not require any treatment by way of blood products for the occasional bleeding incidents as a child which I have described. In my early adulthood, I was aware that these things had happened when I was a child, that I had been tested when I was 16 and that I had been told that I was not to be regarded as a haemophiliac by the staff at the hospital at that time.

7. I have supplemented my memory of the events of May 1986 with entries in my medical records from the time. Some record events at which I was present and some are records of events which related to my case but which took place outwith my presence. At the beginning of May 1986, I slipped on a rocky path and sustained an injury to my left thigh. My thigh was stiff and swollen so I attended my GP in the Medical Centre in Brougham Place, Edinburgh on around 6 May 1986. The GP diagnosed a haematoma and told me to rest. After a few days my knee also became swollen. I returned to the GP on around 9 May 1986. He sent me to the Accident and Emergency Department of Edinburgh Royal Infirmary. He noted in my medical records that I should be referred there because of my

history of bleeding issues and the possibility that I had haemophilia. I saw a doctor at the accident and emergency department of Edinburgh Royal Infirmary who examined me. I was sent home and told to rest for a few days. The doctor advised it was "water on the knee". I wasn't given any further treatment. No follow up was arranged. I was not asked any questions about my history of bleeding. I went home and rested and stayed off my work for a further few days.

8. I returned to work on around 13 May 1986. That evening, which was about 10 days after my original injury, I was washing up when my thigh began to swell and became extremely painful. I again attended the Accident and Emergency Department of Edinburgh Royal Infirmary arriving there about midnight. I was seen by Doctor McClure, a senior house officer, who diagnosed a left thigh haematoma. I was lying on a trolley in the Accident and Emergency waiting room. I was in pain. I vaguely recall being asked questions by medical/nursing staff and I informed them of my previous possible diagnosis of haemophilia. I recall when I was on the trolley I was given Entonox (gas and air). I understand from my medical records that Dr McClure subsequently contacted the haematology department. A Dr GRO-D became involved, who was the on call registrar for the haematology department. In turn, a senior house officer in the hospital called Dr GRO-D of the haematology department became involved in my care. My medical records appear to suggest that there was some discussion which took place outwith my knowledge as to what should be done. I understand from the notes that Dr GRO-D asked to be called back but that she fell asleep.

9. No clotting screen took place in order to ascertain my diagnosis. I remember someone saying they were going to be giving me something. It was injected. I was not told what it was. As I was in severe pain, I do not recall being informed of any risks involved in being

given the injection. I do not recall being informed of any risk of infection. I later learned it was Factor VIII concentrate that I was given. The injection was administered by Dr GRO-D I subsequently learned that it was possible to treat bleeds with products which did not carry any or a significantly lesser risk of infection than the factor VIII concentrate which I received. Such products would have included cryoprecipitate or DDAVP. No mention was made of these as possible alternative treatments at the time. In around December 1992, I underwent a liver biopsy in Manchester Royal infirmary. I was given DDAVP at that time to help manage my factor VIII levels.

10. In the early hours of 14 May 1986, I was still in Edinburgh Royal Infirmary. At this time, I was still being treated by Doctor GRO-D who was a Resident in the Haematology Department and Doctor GRO-D who was the on call Registrar under Dr Ludlam, the head of the haematology department. I have since retrieved a letter dated 16th May 1986, from Doctor GRO-D Registrar to Doctor Ludlam and a letter dated 4th July 1986 from Doctor GRO-D to Doctor Ludlam which appear to outline their respective positions regarding their involvement with my treatment in the hospital on the 14th May 1986. There seems to have been some investigation instigated by Dr Ludlam into how I came to be treated as I was. At no point did Dr Ludlam inform me that he had sought those respective versions of events from those two doctors. It took until 1996 when I was serving a legal action for me to discover it. In other words I had to be proactive rather than Dr Ludlam volunteering that there had been a contention or controversy over my treatment that night and he therefore asked doctors for their version of what happened. Subsequently, I have also discovered a letter dated 27 June 1986 written by Dr Boulton, deputy director of the South East Scotland Regional Blood Transfusion Service to the director of the PFC in Edinburgh. In the letter Dr Boulton passes on some comments which he had received verbally from Dr Ludlam. The letter states that Dr Ludlam had a young haemophiliac under his care who was treated with

PFC factor VIII concentrate the month before who was showing signs of NANB hepatitis. I believe that the person referred to was me. In the letter Dr Boulton refers to Dr Ludlam having been "a bit ruthful with his own staff about this because he feels that this patient should have received VIIIY or an equivalent product". I am unsure what the background to this letter is. It appears to me that Dr Ludlam appears to have expressed regret that I was treated as I was and thought that I should not have been so treated. In a letter written by Dr Ludlam to Dr Delamore in Manchester dated 7 December 1987, Dr Ludlam described my infection as "unfortunate".

11. In advance of being infected in the circumstances described above, I was not supplied with any information about the risks of infection associated with the factor VIII product which I was given.

12. Later on 14 May 1986 Dr Ludlam told me that I had a 50% chance of being infected with non A, non B hepatitis from receiving the Factor VIII product but that this was not a serious condition. This was the first and only time I have received Factor VIII. I was not informed at this time of the risk of passing the infection on to others. I was also offered a vaccination for hepatitis B at that time and I feel that this was significant because I recall being informed that it would be costly to vaccinate me against Hepatitis B but there was clearly a concern at that time that there had also been the possibility that I might have been infected with Hepatitis B as well as what was then termed non A, non B hepatitis.

13. Six weeks later (July 1986) it was confirmed from my raised ALT levels that I had non A, non B hepatitis. I was also feeling nauseous and tired at this time. I was told to avoid alcohol but I was not offered any treatment for the hepatitis at this time. I was led to believe at this stage by Doctor Ludlam that it wasn't that serious and was expected to be short

lived. The impression conveyed to me verbally regarding the lack of seriousness was distinctly at odds with information I later discovered on the internet in a document on the SNBTS website called "The Development of Hepatitis-Safe Factor VIII Concentrates by the Scottish National Blood Transfusion Service". The author of this document is P R Foster BSc, MSc, PhD, CEng, FIChemE and R V McIntosh BSc, PhD of the Scottish National Blood Transfusion Service. In their submission to the Scottish Executive on 9 December 1999, it appears that the SNBTS stated in paragraph 3.2 that "...by the mid-1980's there was growing evidence that NANBH may be a more serious disease". I note this contradicts the information I was given by Doctor Ludlam in 1986. It was not until after I had moved to England in 1987 that I became aware of the possible gravity of the condition when a doctor informed me that I might only have ten years to live.

14. I was given a series of vaccinations for Hepatitis B at Edinburgh Royal Infirmary over the summer and autumn of 1986. At this time in 1986 I was told I had mild haemophilia, with a factor of 41% and told to carry a haemophilia card by Professor Christopher Ludlam on my discharge from hospital. I was married on 9 August 1986 and I moved to the Manchester area in 1987 and registered with a GP in the Medical Centre in Northwich, Cheshire in October 1987. I cannot recall the name of this GP but he referred me to be registered with the Haemophilia Centre at Manchester Royal Infirmary about the end of 1987/beginning of 1988. The Haemophilia Centre referred me to Doctor T Warnes, Consultant Hepatologist. I was then told that I still had hepatitis. Doctor Warnes did say to me in 1988 that I might only have 10 years to live as the hepatitis could go on to cirrhosis of the liver leading to liver cancer. This warning came as a shock as it was at odds with the impression previously conveyed to me in Edinburgh advising on the limited seriousness of the condition. At this time there was no available treatment. Doctor Warnes said that there was a slight risk of secondary infection but this shouldn't stop us going ahead and

having children. Because he said it was a small risk we went ahead and had children. When we weren't trying for children we did use barrier methods of contraception. There was a knowledge within the medical community that the risks of infection were known in 1986 and the likely severity of NANB hepatitis was greater than I had been told. So, looking back at that time, I think that the way I would describe matters would be that it may have been the intention to underplay fears of medics or nursing staff or whoever. My understanding is that in 1986 and 1987 the risks were simply played down while I was in Edinburgh. So, I was fairly shocked when I went I was informed in 1988 that I might only have 10 years to live. That sort of statement was never made to me in Edinburgh that I possibility might only have a 10-year life span because of the possible deterioration of my health. I was 30. I have now just celebrated my 60th birthday. I think we did not get the full story at that time in the mid 80's and I have actually since had contact with the same nursing sister called Mrs Billie Reynolds. She roughly confirmed that the full story was not told. I think it important that nurses like her are spoken to by the Inquiry to try to help get to the full story.

15. Today in 2018, a doctor might say things did not go particularly right for you in your medical treatment and he might suggest to you that you might want to consult a solicitor. The reverse happened in the case of Dr (now Professor) Christopher Ludlam. I was very much kept in the dark about how my infection had come about. In around 1995 I joined the Haemophilia Society. I attended a workshop in Wales on around 22 April 1996. I spoke with a doctor there called Dr David Evans who practised in Sheffield. I was made aware by Dr Evans of the possibility that there may have been alternative treatments which could have been used to treat me in 1986 which would not have infected me. This was the first time I was aware of such a possibility. Dr Evans kindly wrote to me after the workshop telling me that the use of DDAVP in the treatment of mild haemophiliacs had been known

since at least 1977. He referred me to an article from the Lancet from October 1983 which had advised on the use of DDAVP in the treatment of mild haemophiliacs due to the risks of viral transmission from factor concentrates. I also became aware of the fact that there was a factor concentrate ("8Y") available in England at around the time of my infection which would not have infected me. Dr Evans advised me to seek legal advice. When we made Professor Ludlam aware that we were thinking of taking legal action in 1999 based on the information that we had learned, he tried to talk us out of it. I regard that as pretty serious. I think Professor Ludlam, if you are asking me for a judgement, should have informed me of the full story in 1986 /1987. He never informed me or my wife of this at the time and I regard this as a less than full account of what was actually happening behind the scenes and the circumstances within which I had been infected.

16. The advice given about the risk of others being infected as a result of infection varied over the years. Despite the advice of my possible 10 years to live, my wife wanted to have children and thankfully, this is one of the great joys and pleasures that were granted to us. We only had unprotected sex for a month at a time. However, the advice changed over the years and I am aware that others of course did pass on the infection in terms of hepatitis C. The main issue for us was, Rosie, my wife, was never ever tested because financially the consequences might have been catastrophic if she had also been infected, and because we would have then had to have had the children tested. Now that is down to 2 months of exposure but nevertheless, it was a serious consideration. We were advised about the use of things like toothbrushes, razors, etc. If I cut myself, our children were always clearly warned not to go near it, not to touch anything where there might be any sort of blood from me. Our children were warned not to go anywhere near it and my wife was similarly very wary. I was very open, I adopted a policy of being pretty open with friends about it, because if I was outdoors and maybe I cut myself or I could have been a distance

from any help, so people had to know, in terms of having to deal with it if there was any blood involved. So yes, there was information. I passed a considerable number of pamphlets and various publications onto the Penrose Inquiry from the Haemophilia Society, and other sort of publications which were never returned to me following the Penrose inquiry.

Section 3. Other Infections

17. I was informed of the possibility of CJD some years back now, that there was a period where the haemophilia population were at least theoretically exposed to CJD as well. I had letters to that affect about CJD from the haemophilia centre in the early 2000's. I was subsequently informed by Dr Rosie Dennis I was outside the period of potential exposure, because I only had the single dose in 1986. So, do I currently believe I have received any infection other than hepatitis C? I don't know, is the answer to that question. My doubt comes from knowledge that when you take tens of thousands of pints of blood and put them altogether, who knows how many viruses or pathogens are within that particular product. It's not something I personally give a great deal of thought or worry to but I can't help but escape the possibility that there might be something else in there, who knows? But CJD was certainly the main one that we were made aware of at the time.

Section 4. Consent

18. I may have been tested without my knowledge. I don't know for what purposes, I don't know the answer to this. I really don't know how to answer the question about if we have been tested without consent. It is over 30 years since I was infected, but in terms of the early days, I don't know what was tested in that respect. I refer to my answer given above.

19. As is detailed below, after my infection in Edinburgh in 1986, I moved to Manchester. Dr Ludlam was keen to know where I was moving to. Dr Ludlam advised me by letter dated 7 December 1987 that I should register with the Manchester Haemophilia centre. I am now aware from my medical records that by letter dated 8 February 1988, Dr Ludlam acknowledged having received from Dr GRO-D consultant haematologist in Manchester, transaminase test results relating to me. I was not aware that such results were being sent to Dr Ludlam who by that time was no longer involved in my care. In the letter, Dr Ludlam also thanks Dr GRO-D for offering to keep him informed about my future liver function tests. I was not aware that this happened. I am not aware of any reason why Dr Ludlam would need this information at that time.

Section 5. Impact

20. Subsequent to the drama on the 13th and 14th May 1986 I was registered as a mild haemophilia sufferer so when I moved to England I registered with the Manchester Haemophilia Centre who then referred me to the Hepatology unit in Manchester. In 1996 I returned to Edinburgh Royal Infirmary for treatment and I was under the care of Professor Ludlam and Professor Hayes, consultant Hepatologist. I was seen by Doctor Rosemary Dennis who was the senior Registrar under Professor Ludlam. Both of these individuals are now retired. I was also referred to Dr Allison Richardson, Psychologist from the Spittal St Centre in Edinburgh later on.

21. I am asked to describe the mental and physical effects of being infected. In my Penrose Inquiry statement, I indicated that over the next three years after interferon treatment in 2001, while physically my health had recovered (to the extent that I was fit enough to run

a half marathon, complete long walks in the hills and complete rock climbs in the extreme grades), my general mood declined and I became increasingly depressed and alcohol dependent. I had become suicidal. Despite various counselling sessions I am unable to fully identify and explain the causes of this depression but a significant factor was the growing frustration at the lack of progress in securing an effective inquiry into the contamination. I was advised by counsellors 'not to campaign' and to leave it to others. I am now abstinent from alcohol and no longer 'depressed' but I only finally achieved that position during late 2005, into early 2006 with a brief lapse around the period of treatment in 2007.

22. **GRO-C**

23. My health recovered sufficiently that between 20 April 2007 and 3 May 2007 I had my fourth and final attempt at Interferon treatment. This was Roche pegylated Interferon in combination with Ribavarin. I tried again because even though I was told the chance of success was 30-40%, I had responded to the treatment positively in 2001 and if it was successful this time, it would prevent any further deterioration of my liver towards cirrhosis. I understood that if I delayed the treatment and my liver developed cirrhosis in the meantime, then even if subsequent treatment was successful, I would still be left with the cirrhosis. However, I was floored by the treatment even though I had gone part-time at work, in anticipation of being unwell. I was extremely tired, nauseous with flu like symptoms including aches and pains and found the treatment very difficult. There were

inevitably still some work pressures and starting treatment also coincided with a BBC Newsnight Report on the contamination controversy. I lapsed from alcohol abstinence and as alcohol can compromise the treatment's efficacy it was stopped.

24. I did not go back to work after 2007. I was medically retired at the age of 49 and can provide documentation to this effect. I found interferon treatment very challenging. I commonly refer to it as akin to mind altering chemotherapy. In my experience it is highly toxic and affects one's outlook on life. A common side effect is depression, and I was very wary of it in 2007, because I did not want to go back to the position previously where I was depressed, suicidal and angry. However, I was pretty ready to give it up after 6 weeks so it never succeeded. In terms of the interferon, I think one of the problems which hit me in the previous attempt was that while I was on the drug I started becoming depressed. Then, when I got bad news in 2001 that my treatment had not succeeded, I began to drink too much. While the interferon may have cleared my body physically, a year later in 2002, my bad mood and bad outlook hadn't been cleared. In 2007, I was reluctant to proceed with the treatment, with only 40% chance of it succeeding against the damage that I might do to myself and my family if I reverted to that very dangerous self-harming behaviour. I never recovered in 2007 from the fatigued state I had sustained during my final attempt at interferon treatment. In 2015, I went through an alternative therapy involving orally taken treatment with 'Sofosbuvir'. Whereas in 2015 you swallowed pills and the side effects were very much diminished; the depression and moods and loss of appetite when injecting interferon strongly resembles having a hangover every day, every morning, constant headache and nausea and feeling exhausted. When advised to attempt the new oral 'direct acting antivirals' I went through a course pretty well with minimal side effects. I had been advised by a haematologist and hepatologist I needed to do something because my white cell count and levels were going through the floor and my platelets levels were also

decreasing which was a strong indicator of potential deterioration towards liver cancer or non-Hodgkin's lymphoma. I had no option but to seek treatment at that time. Prior to 2015 I had already been diagnosed with liver cirrhosis . I am now no longer regarded as having hepatitis C. I had a 'successful' sustained viral response to the direct acting antivirals but the scarring in my liver has left me with cirrhosis. I have now been 12 years abstinent from alcohol. My current situation is that I have 'compensated cirrhosis'.

25. I have been monitored via a host of ultrasound, MRA and CT scans and I see a specialist nurse twice a year to give blood samples. I have also endured numerous endoscopies.

26. Following the last attempt at Interferon/Ribavarin treatment in May 2007 I developed a chronic fatigue condition. Since stopping the treatment I never regained my previous health and had to give up work in December 2007. The weekend before I started my last treatment (April 2007) I had a weekend away with my wife and had a very full day's climbing and hill walking. Although I believe hepatitis had affected my stamina in the hills over the years, I was still fit and active until this time. As I understand it, medical science can provide no explanation or treatment for my fatigue condition which arose following my last attempt at Interferon/Ribavarin treatment, though I think that the clinical review chaired by Prof David Goldberg (May 2018) concludes that it is now recognised that fatigue is a notable side effect of that treatment.

27. In effect I never recovered to my state of health in the weeks since stopping that final interferon treatment. I understand that other people are known to have been similarly affected.

28. I have now regained some energy but do not expect to fully regain the energy I had prior to 2007. As a volunteer, I chair a relevant charity, Haemophilia Scotland. As a trustee and chair there are substantial responsibilities as a volunteer. We have a turnover of approaching £200,000 and three members of staff including a chief exec who reports to me. While I am no longer employed in terms of paid work I feel it necessary to be active for the charity in support of all those affected by bleeding disorders in Scotland, infected or otherwise. I have been able to recover some physical strength but will never recover to previous levels. I believe it's not just age. I often have to have a sleep in the afternoon, I can go 2 or 3 days at a time being fairly active in terms of volunteer work or going for a walk in the hills or rounds of golf, but after that, I wouldn't say I crash because that is what was happening back in 2007 but I still really need time to recover. I'll never regain what I would probably say would have been my physical position if I had never been infected at 60 years old. My peers who I indulged in outdoor activities with, are all fitter than me now. I still spend time with them but I just don't have the energy that they have. I think fatigue can have a lot of effects on memory. I have certainly managed to regain a degree of self-confidence that I probably didn't have back when I gave the statement in 2009 for Penrose which was two years after the last attempt at treatment. I say here I often have to pace myself in the day and sleep in the afternoon.

29. I had 4 attempts at interferon treatment and I was unable to complete all of these because of the impact it was having. In 2015, I was treated with the direct-acting anti-virals which finally led to my sustained viral response. For greater purposes, I was cleared of the virus after many years.

30. I have never been refused treatment or faced obstacles in this regard that I am aware of. Since being infected, I don't believe there are treatments that should have been made available to me that were not, other than the possibilities of when I was originally infected, having been offered DDVDP or cryoprecipitate or 8Y as an alternative to the factor 8 at that time. However, it appears from what records show, there was no consideration given to the use of DDAVP at the time I was treated, as a previously untreated patient in 1986.

31. My dental care has been impacted upon. Living in Dunkeld, Perthshire, there is a dentist in the village who is quite familiar with Hepatitis C. There was clearly an instruction for some years that I always had to be the last patient of the day. I became aware that after fiddling around in my mouth he then had to take his instruments and had to be particularly careful with respect to sterilisation processes; as someone who carried the virus, and also for a period of time regarded as potentially exposed to CJD.

32. Instead of my career, being infected has been the defining factor in my life. To a certain extent my wife and family and now two sociable, bright children that both graduated from university and are doing very well in life and I am deeply grateful for that. However for 30 years there is never a day that goes by when I do not reflect upon what might have been, what I might have succeeded in in terms of my work, life or my career. And also, what might I have achieved, had I been able to avoid the dark years from 2001 to 2005. Now this continues to very directly define my current life. I have contact with hundreds of people who have been infected. I have spent a lot of time in people's homes, hearing their stories most of which are worse than mine. Their stories are often distressing and heart-breaking. While I am no longer depressed or negative or suffering from low mood, I feel a sense of duty toward their plight. Many have died. I feel I need to allow their stories to be heard as well.

33. I adopt a policy of being open about the infection and have no further comments about stigma for my experience.

34. The two full attempts at interferon treatment have meant a loss of earnings. I was self-employed at the time, I had to work part-time and could not take on more work. I also remained self-employed longer than I might have because I was always concerned that the possibility of further treatment meant I may have to have time off work. As my line of work has been mostly for charities, sick leave can have significant financial implications for the organisation. When I had to give up work in 2007, I was earning £25k. My wife now has to work full time. I no longer receive incapacity benefit. The Scottish Blood Infected Support Scheme has a different scheme to the rest of the UK which was introduced in 2016. I thus benefit from what's called stage 2 support where I receive £27,000 per annum under the Scottish scheme because I am regarded as stage 2 as I have liver cirrhosis. I have sustained a substantial loss of earnings over my career. The amount of this loss is certainly much more than that I originally received from the Skipton Fund.

35. Up until 2015 our finances were significantly affected by the diagnosis of Hepatitis C in various ways. I took out insurance in 1987 on a term basis to cover my original mortgage. This insurance was higher due to my haemophilia. At this time, I did not know about the implications of Hepatitis C. My wife is covered by life insurance and critical illness. Up until 2015 I had not tried getting life insurance so I do not know exactly what the position would have been. We just had to live with the insecurity. Up until 2015 with regards to travel insurance I usually had to pay more but was always able to get cover. Since 2015, the insurance issue does remain, but I have found that with travel insurance, it has diminished, since I now have a steady viral response and my Factor VIII level is now over 80%. If you

are over 50%-100%, that is regarded as normal. Mine has gone up to 80% in the years since I have been infected. So while I still carry a haemophilia card, I don't normally suffer from bleeding problems. If insurance is loaded it might be the same as it is for haemophilia as it might well be for liver cirrhosis. Even if insurance is loaded, compared to previously, £27,000 per annum goes a long way to helping with this issue. I wouldn't say insurance is a primary concern in that regard, but it was a concern previously for many years.

36. The impact on my wife of my being infected has been enormous and she's been incredibly supportive, loyal and loving but she's had to work full time throughout this. She works for the Care Inspectorate. She is an inspector of elderly care services. She became the main income earner, and when I went off the rails between 2001 and 2005, she supported the family home and me at a very difficult time. Other marriages haven't survived that sort of pressure. I owe her a huge amount. She has suffered enormously because of this in all sorts of ways, emotionally, financially and she has remained strong throughout. Our children, also witnessed the sort of destructive moods that I displayed in 2001 to 2005. My daughter was a teenager at the time, my son was just a young boy. He graduated last year from Glasgow University with a 2:1 and is now studying as a post graduate. My own mother and father and my wife's mother and father were also affected by my problems with depression and alcohol. I was never able to tell them about the possibility of the 10 years prognosis in 1988. I think that would have been pretty hard for them to handle, the idea that their son might die before them. That came out when my behaviour deteriorated. They are elderly now, but they've now come to accept it and life has moved on, but for a considerable amount of time, it was tough for not only family but friends as well. It affected relationships when I was depressed.

Section 6. Treatment/Care/Support

37. Yes, there have been obstacles in relation to accessing care and support. There was a situation in 2007 when after the 4th attempt at interferon treatment, there was an issue, about whether I might revert to the damaging behaviour I had exhibited between 2001-2005. There was a case conference, at which Dr Allison Richardson, psychologist, Peter Hayes Consultant Hepatologist and a consultant psychiatrist were present. I was very tense at that conference as having had 4 attempts at interferon treatment to get rid of the virus in 2007 the only path before me was then liver cirrhosis and death. I remember a very tense moment when the psychiatrist, because of the tension in the room at that time threatened to call the meeting off. I had wanted to see what the options were and when the psychiatrist threatened this, I challenged him and asserted I would report him. He backed down. The same doctor told me he gave evidence at the Penrose Inquiry that he had been concerned for Professor Ludlam's state of mind. He never seemed to display much empathy or sympathy to the patients in that situation. He admitted that he had dined with Professor Ludlam. The meeting was a very difficult moment when we were reaching the end of the road in terms of treatment for hepatitis C. He wanted to cancel the meeting because I had requested that the meeting be recorded. He seemed to find this as a threat. Peter Hayes the consultant Hepatologist, didn't mind. But the psychiatrist clearly felt uncomfortable about the fact that I was being fairly assertive about my own position. I think it was something he was not used to, patients being so assertive with him.

Section 7. Financial Assistance

38. I knew about the financial assistance that was available because I was involved in the lobbying of this to get this implemented back in 2004 and 2005.

39. The payments I have received from the Skipton Fund and the NSS are as follows:

- 1st April 2004 - £20,000 at start of Skipton fund
- 12 July 2011 - £25,000
- 4 August 2011 - £25,000
- 4 August 2011 - £1503 paid as a first monthly sum
- April 2012 – adjusted to £1157 per month
- 1st April 2013 - increase to £14,191
- 1 April 2014 - increase to £14,574
- 1 April 2015 - increase to £14,749
- 1 April 2016 remained at £14,749
- On the 22nd December 2016 I received a lump sum of £12,251 via the Skipton fund on the instructions of the Scottish Government. It is "the difference between your current and increased annual payments paid as a lump sum. Your regular payment at £1229 per month will remain until end of March 2017."
- 3 April 2017 - new scheme £27,000 per year due to advanced Hepatitis C infection but backdated to September 2016, paid in monthly instalments of £2,250.

40. With the Skipton fund the process of applying for financial assistance I went straight to the Skipton Fund to apply for this. I can't remember if I needed evidence from my medical nurse, however I know when I went up to stage 2 I needed a supporting letter from Peter Hayes, Consultant Hepatologist.

41. Generally speaking, apart from completion of the necessary documentation, I do not recall difficulties applying for assistance.

42. I cannot at this point recall any preconditions to applying for financial assistance.

43. One particular recollection was that in the early days of the Skipton fund when I enquired about how many staff were being employed to deal with enquiries I was effectively told to mind my own business.

Section 8. Other Issues

44. I would like to give a supplementary statement to the Inquiry. I am likely to have details to add to the narrative about my own case given above. I have been unable in the time available to consult with my medical records as fully as I would like. There may be details which I would wish to add.

45. I will also offer further documentation to the Inquiry that I have gathered over the course of over 20 years. This documentation will be relevant of a number of the Inquiry's terms of reference, including term of reference 1 concerning how people became infected in Scotland. I have been trying to get answers to questions relating to all of the Inquiry's terms of reference for 20 years as a campaigner for a public inquiry and in my current role with Haemophilia Scotland. A lot of the people who have also been asking similar questions and whom I knew well have now died. I know a good deal about many of their cases, views and experiences. I lived through the Penrose Inquiry during which I was a core participant. This was at times a very frustrating process. I spent a lot of time working with legal

colleagues at Thompsons Solicitors. I consider it necessary for me to be allowed more time to assist the Inquiry in a further statement in order to set out the evidence which I have collected over the last 20 years.

46. I would like the Inquiry to try to find out the answers to the following questions which are important to me and which arise from the circumstances of my infection:

Treatment for my bleed in May 1986

(a) Why was I sent home from the hospital on 9 May 1986 with no investigation of my bleeding history?
(b) Could an alternative course at that time have avoided me ending up having a factor VIII concentrate?
(c) What was or should have been known by the doctors who were responsible for my care about the risks of me being infected with viruses from the treatment I was given on 14 May 1986?
(d) What was known at that time about the possible consequences of HCV infection?
(e) Why was I not told about the risks of the treatment I received or the alternatives available for me at that time?
(f) What system was in place at the time to make sure that treatment decisions were taken in accordance with all known information about infection risks?
(g) Who was responsible for that system, if any?
(h) What efforts, if any, had been made by government/ the SNBTS to protect patients like me from becoming in infected in 1986?
(i) Should I have been treated with no products at all?
(j) What alternative products could/ should have been made available to treat me?
(k) Why was I given a factor concentrate without having a clotting screen?
(l) What investigations were undertaken into the circumstances of my infection after it happened? Why were they undertaken? What did they conclude?

Testing

(m)What hospital or government policies existed in the 1986 in relation to infected people being told about the nature and possible consequences of infection?

(n) Why was I not given more information about the possible consequences and risks of my infection when I was told of my diagnosis?

(o) Why was information about me requested and/ or sent to Dr Ludlam in Edinburgh after I moved to Manchester?

Other viruses

(p) Am I infected with any other viruses, like CJD?

(q) How did that happen?

(r) What does that mean for me?

The consequences

(s) To what extent are my various medical problems caused by infections due to my exposure to blood products/ the treatment I have received for my HCV infection or has my ability to cope with them been adversely influenced by that exposure/ treatment?

Treatments for the infection

(t) Why was I not told about the known side effects of the treatments I have received for my hepatitis C infection, in particular Ribavirin and Interferon treatment?

(u) Why was I expected to tolerate these treatments? What alternatives could have been offered?

Support

(v) Why is so little weight placed on the mental health consequences of infection with hepatitis C in decision making around the provision of treatment and financial support?

Statement of Truth

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

Signed GRO-C

Dated 11/04/19