Witness Name: BRUCE NORVAL
Statement No.: WITN2235001
Exhibits: **N/A**
Dated: 15th October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BRUCE ROBERTSON NORVAL

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

I, Bruce Robertson Norval, will say as follows: -

Section 1. Introduction

1. My name is Bruce Robertson Norval. My date of birth in GRO-C 1965. My address is known to the Inquiry. My current circumstances are that I am unemployed, chronically sick and heavily dependent on my wife and children for support around the house. Currently, both my adult children live at home. My daughter Catriona is aged 27 and is in between University and a new job. My son Robert is aged 21. He still stays with us and helps with most of the physical jobs around the house. I also live with my wife Christine who is now medically retired. She provides most

of my daily care. I now live on the ground floor of my house as I can no longer deal with the staircases safely.

2. I intend to speak about my infection with Hepatitis C and other infections. In particular, I will speak about the nature of my illness, how the illness has affected me, the treatment I have received and the impacts on my family.

Section 2. How Infected

3. I have haemophilia B, Christmas factor. I am measured at 2.8 per cent factor, which makes me moderate/severe.

4. I have used a number of products over the years and was probably one of the pioneering patients for Factor IX concentrates. Prior to that I suspect that that product that was used on me was Cohn's Fraction. I have received a number of products and have attended a number of hospitals in the UK as detailed further below. I'm currently receiving recombinant DNA products.

5. I mostly received Factor IX which came from the Protein Fractionation Centre, Liberton, Edinburgh but over the years I have also been treated with commercial American concentrate products and products imported from other countries, although I'm not sure exactly where. I was treated with NHS produced Cohn's Fraction early in my life which would have been the only treatment available for severe bleeds at that time in the 1960s and early 1970s. I know that I had Alpha therapeutic product and I know I had Baxter product. I think I had Cutter product but I cannot be absolutely certain at the moment until I have had a proper look at my medical notes.

6. After my Haemophilia diagnosis, I was put under the care of Dr Howard Davies at the Royal Infirmary in Edinburgh from 1968 onwards. I used

to be admitted and put on a drip and injected with blood products via the drip.

7. My medical exposures go across a large number of hospitals. The first place that I was probably treated would be Edinburgh Sick Children's Hospital where they made the diagnosis that I had Haemophilia B. From then on in I tended to be admitted to the Royal Infirmary of Edinburgh onto the adult ward because, in the words of my consultant, I had such a rare condition that he didn't want anyone playing with me. I then moved to Inverness in 1977 where I came under the care of Professor Cook who was in charge of the Raigmore Hospital haemophilia/ haematology department. From 1983, I moved to Dundee and was under the care of Ninewells Hospital between 1983 and 1984 although I can't remember the name of the Consultant.

8. In 1985, I moved to London and came under the care of Christine Lee for a very short period of time before falling out with her after she refused to test me for HIV, which I will discuss later in my statement.

9. I then transferred after a degree of time without any major haematology support to the hospital where I was working at the time which was the Hammersmith Hospital in West London in 1987. I was only there until 1988 when I transferred to St Thomas's Hospital on the advice of the then chair of the Haemophilia Society, David Watters. He arranged for me to have an appointment there. A radical change in my treatment then occurred when I came under the care of Professor Savage at St Thomas's and I started on home treatment and prophylaxis. St Thomas's was also the place where I was eventually tested for Hepatitis C after complaining about chronic symptoms which I now know were connected with hepatitis infection. In 1991, we moved to Lincolnshire. I came under the care of Professor Eric Preston and Mike Makris at Sheffield Hallamshire Hospital where I stayed until 2001. In 2001, I moved back to Inverness and came under the joint care of Edinburgh Royal Infirmary for a while under Dr Christopher Ludlam. I wasn't

comfortable with that so I also maintained contact with the haemophilia centre in Raigmore Hospital in Inverness. I also had major problems with because Dr GRO-D who was in charge of the centre also used to treat me with quite significant contempt. I now currently am still under the care of Raigmore Hospital with a brand new consultant who (for the first time) I feel listens to me.

10. My parents were told that I might get a touch of hepatitis when I was young. They were told that it was mild and that I would clear it as haemophilia boys always recovered from it. It would be Dr GRO-D GRO-D at the Royal Infirmary that told my parents that at that time. My parents were not formally told there was a risk of infection from the products I was receiving. They were told that there was a possibility. It was worded in a very non-risk fashion. It wasn't highlighted and it was very much played down.

11. I have one of the unique distinctions of having been in the trial group for the first Hepatitis C blood test in Britain. I was tested in September 1990. The date sticks in my mind because my wife Christine was five months pregnant and we were due to get married the following month.

12. The doctor actually told me that I had Hepatitis C standing in a clinical room doorway. He didn't even come in to the room. He told me that he was running late for clinics. I walked into the unit at St Thomas's Hospital and said hello to the doctor. It dawned on me about the blood that had been taken before that to test for a new disease and I asked if the result had come back. He said it probably had but he was in a rush as he had a clinic to do. I then went into the treatment room because at that point they were trying to get on top of my bleeding disorder, I had severe problems with my right leg and had difficulty walking. I was connected up to a needle and the doctor came back into the room but didn't enter the room itself. He just stood in the doorway, leaning against the doorjamb. I remember it as clear as day. He was a junior registrar with a double barrelled name. I recall that his name was something GRO-D

He told me I was positive. He told me that it was just a mild infection and not to worry about it. I was actually working in a hepatic unit at the time so I asked what he meant by a mild infection and what the implications were. He said that I might get lymphoma, liver cirrhosis or liver cancer but that I probably wouldn't.

13. No information was given to help me understand and manage my infection. All I was told was that it might develop into lymphoma, liver cirrhosis or liver cancer but that I probably wouldn't.

14. I made the decision to stop drinking alcohol. I was a nurse and was doing my student turn on a liver unit at the time. This was my second attempt to try and get in to nursing as it was what I'd wanted to do. I had found out I was HIV negative so went back and had another go. I knew that I needed to stop drinking but I wasn't a big drinker anyway. It never really agreed with me. Famously, I can go on a bender from time to time but that usually means I'm not mentally very well if I do it. Mostly, I tended not to drink and I changed my diet. I've tried to maintain lower levels of body fat to try and reduce the possibility of developing fat around my bodily organs because of the liver not working properly. Most of what I do health-wise is purely borne from me reading and learning about what other people are doing. The Canadian information from the Krever Inquiry has been hugely influential in decisions that I've made about lifestyle and health.

15. Nobody has ever given me advice on lifestyle or alcohol. The doctors ask me if I drink. I have asked on a few occasions if I can drink and I have been told that I can drink moderately. I have been given no clear guidelines. As a result I've known haemophiliacs that thought moderate drinking was having five pints per week and they're dead.

16. I have learnt how to deal with my infection by sitting down at the computer and reading papers and documents and working things out for myself. I have learned that if I do something and feel unwell, I will not do

it the next day. Removing things from my diet like milk or items with high fat content has helped but only to a certain degree. No matter how much they treat you or give you in terms of anti-virals, you are still dealing with a body that is seriously damaged and a mind that is not working right. You feel like you are in a combat zone when it comes to getting information from some of the doctors. It's almost "them and us" and I doubt that has improved in many of the centres that still have some of the older consultants present.

17. As far as date of infection goes, I was definitely fully symptomatic for hepatitis by 1972 (although I do not which form of hepatitis that I had at that stage). By 1980, I was significantly symptomatic for Hepatitis C with chronic night sweats, poor concentration and difficulties in coping. It's marked in my scholastic career as the point when I dropped from the top end of the class to the bottom end of the class because I could no longer focus or concentrate on classwork.

18. I think that it is probable that I had elevated ALT levels by the early 1980s and possibly quite a bit earlier because the Cohn's fraction that they used to treat me before Factor IX concentrate became available had such a high return rate of hepatitis that I think it's improbable that I got passed my 7th or 8th birthday without having it. Looking back, I remember that I had swollen glands and that the doctors were palping my stomach and that I went through the roof with a particular reflex that's associated with an inflamed liver. I also remember the number of times that they wanted to inspect my hands which I now know was because of a false understanding in medicine that you would have mottled skin on the palm of your hands if you had had liver disease. I can't remember a point when they didn't check my glands.

19. Certainly by 1980, I was actively acting asking my consultant Dr Cook at Raigmore Hospital what was wrong with me as I was waking up covered in sweat, was cold all the time, didn't feel well and couldn't concentrate. My consultant told me there was nothing wrong with me. In fact, the

same consultant wrote a letter for my entry to nursing that said I didn't have hepatitis. I had asked what was wrong with me, why I was struggling and what was going on. I was asking why did I have abdominal pains and why did I feel like this. This was when I was aged 15.

20. It also connects directly to a point when I had pneumonia. I got admitted as an emergency patient into the intensive treatment ward at Raigmore Hospital. The reason it sticks in my mind is because it was shortly after I had been given Factor IX for a PE lesson. I had staved my finger playing basketball and because it was swelling up to the point where it was killing my finger, they had had to treat it. I got pneumonia and was admitted to the hospital. I probably didn't get on to the ward till 1 or 2 in the morning. When I woke up at 6 o'clock in the morning, Dr Christopher Ludlam was at the end of my bed. He had obviously driven all the way from Edinburgh to take blood from me. At that point that would have been a good four or four and a half hour journey in a car. When I asked him what he was doing there, he said that there was a slight risk that I might bleed because of the infection. I now know that this is nonsense. When I asked what bloods he was taking, he actually almost ran out of the ward. It always sticks in my mind. I always wondered what was really going on. I have significant suspicions about the purpose of the blood test. I think they were testing to see if I had a virus caused by the blood product treatment. I think hepatitis B would be the most likely virus that they were looking for at that time. I strongly suspect that the pneumonia was connected to something that was in the product and certainly from that point onwards my health just got much worse, to the point that where by the time I was 18 I was struggling to hold down a job. By the time I was 23, I was really struggling to keep a roof over my head.

21. It is pretty clear to me now that the doctors knew that I had some kind of non A non B hepatitis throughout the 1980s at least. They were monitoring me for some time. I was making significant decisions on where I was going to live, what kind of risks I was going to take, what kind of jobs I was going to take. Those decisions I can say with absolute

certainty would have been completely different decisions had I known that I was chronically sick.

22. If the doctors had bothered to tell me about my infection, I wouldn't have tried to become a rock and roll roadie and travel the world. I wouldn't have worked seven days a week so that I could come back to the Highlands to try and develop a life. I would have slowed down because I would have realised that I was burning what life I had out. No-one bothered to tell me that putting up with a lower standard of living in the attempt to try and build a better future was actually a futile act and that is something that I have remained seriously angry about ever since. I've carried debt because of those failures in information. I borrowed money not long before I got really sick when I was given Interferon that took me years to pay back because I was only receiving a disability benefits cheque so it took me the best part of five years to pay back £2,000 . With compound interest, I probably ended up paying double that. I'm left very angry and left feeling like I wasn't really considered as somebody who had the right to know so that I could make informed decisions about my future and where I might want to go, how I might want to live and what I might want to put up with in order to try and build a better life in the future.

23. I was dealing with doctors who had been testing me for non A non B since the 1970s who had never bothered to give me any advice on it anyway. Once I had realised that, I found it very hard to take any of them seriously thereafter. The relationship between doctor and patient certainly in my case fell apart at that point because of the realisation that they had been withholding the truth from me for so long, a truth that would seriously have changed the way that I had lived my life.

24. I can remember going home on the tube and sitting in the dark after being told about my Hepatitis C infection. I wondered if Christine was even going to stay with me and if I'd hurt or harmed her or my unborn child and everything seemed to spiral from that point. Nobody should be given a diagnosis like that when they are on their own. It is just not

healthy. I know some of the other guys who were infected like me thought about suicide in that period of time between them knowing and then telling someone else. I'm not sure what would have happened to me if Christine had left me. I'm convinced that I probably wouldn't be alive now. I was on my own when I was told. Ideally people should be brought in with a family member, preferably the person that they feel most comfortable with. The information should be clearly given in verbal and written form. Basic advice should then be developed into good healthy living plans. It should be a progression designed around the needs and interests of the patient.

25. It was not a good start to be told you were infected with Hepatitis C from a doorway by someone who was clearly not wanting to be there. This was far from the ideal way to learn about my infection with hepatitis C. The lack of support was not a good start. The interactions thereafter between that department, my wife and I seemed to be more about them trying to downplay things rather than giving me realistic information that allowed me to make plans. I don't really feel that they got any better when I moved to Sheffield or for that matter when I moved back to Inverness.

26. The doctor knew that my wife was pregnant. I then asked him whether my wife and unborn child were infected and I was told that they would test them but that they wouldn't have it. I was told very casually that I probably hadn't infected my wife, despite fact that she was pregnant so there was a risk that I could have infected her. It was all matter of fact and there was no data put in front of me. Occasionally somebody would mention a 12% sexual transfer risk which we now know isn't true. They said that 1 in 10 sexual partners would be infected male to female. The first question that I had was whether this was 10% of partners or 10% of sexual exposure? Does the risk go up depending on how many times that I have sex with my wife or does the risk increase with the number of partners? Nobody ever gave me clear data or advice. That's the point when I started drifting away from taking any of the doctors seriously and

my relationship with medicine broke down into what were necessary contacts to maintain my health only. Beyond that, I avoided healthcare professionals. When I started on home treatment, I had the excuse never to go back and a lot of the time I didn't.

27. Christine had a blood test about two weeks later. It was shortly after we got married. The test was negative so I just tried to push it to the back of my mind after that for a while in the attempt to develop my family and get a proper job.

28. In relation to individuals other than sexual partners, I did most of the risk analysis myself. It was pretty clear that blood to blood contact was not a good idea so I had to keep things like razors and toothbrushes away from the kids and make sure that they understood that they weren't to use or touch them. This was all through my own research. If I was able to access that information myself, why did the doctors not know it or at least not tell me about it? How many other people were unable to access that information and lived in ignorance, potentially endangering their loved ones? I was not given any information by the doctors. I read about the virus and worked out that blood to blood contact was a significant risk because the virus survives so long in dried blood. Toothbrushes that would get blood on them particularly if, like me, you have had gum disease most of your life and razor blades would be risky again for obvious reasons so they had to be treated as high risk. The fact that I had a background in nursing and that I had actually nursed AIDS patients for a short period of time meant that I had a very good understanding of risk and an awareness of risk points. Most of what I know about my disease comes from my own work and my own research and from asking specific questions of experts as a campaigner not as a patient.

29. I was given no information about the risk of infecting others. It was completely downplayed. In common with a number of patients that I have talked to over the years, I made up my own mind about what risks I was willing to expose my family to. For a period of time, I wouldn't even

have sex with Christine without a condom just because I knew that I was really unwell, and I presumed that if I was really unwell that my viral load was probably up and that there was therefore a greater risk to her. I can honestly say that a consultant, doctor or nurse never sat down and gave me formal, proper well informed advice or a leaflet or anything else. Everything relied on me asking the right questions and then if I didn't get the right answer, I would go away and look it up myself.

30. At St Thomas's Hospital, I used my nurse's badge even though I stopped nursing after my diagnosis in 1990 to get me into the medical library there. Ironically, I used to go the haemophilia centre and then pretend I was a member of staff going to the medical library and then start looking up the research to check whether what the doctor had said to me was the truth or the whole truth. Mostly, it was not. There has been a breakdown in all faith with medicine to the point where it is has been about self-empowerment rather than the haemophilia centre telling me anything whatsoever. If anything, I think that particularly when I came to Inverness there was very much a reluctance and reticence in giving me information. I don't think that is an uncommon experience.

Section 3. Other infections

31. I definitely got the Epstein Barr virus from an Alpha therapeutic product that was given to me in 1984. I was obviously still infectious for Epstein Barr when I met my wife in 1988 and this resulted in her getting glandular fever less than two weeks from our first date.

32. Other viruses that were probably present were the herpes virus and HPV (human papillomavirus). The signs that I have had of those throughout my childhood include epididymitis, inflammatory problems to do with the urinary tract and I have some kidney issues which seem to have settled down in later life but they were definitely present when I was younger. I also have concerns about cytomegalovirus which is a liver toxic virus.

33. I know that before I was even in first year of primary school that I had been backwards and forwards to the GP a number of times with a number of painful episodes of epididymitis, which basically meant my testicles were extremely inflamed. Looking back there are probably a number of diseases that could have caused that. I suspect that the herpes virus group was causing most of the problems at that point.

34. There is list of viruses a mile long that I am concerned about that I think are likely to have been in the products that were injected into me on a regular basis. As well as HPV (human papillomavirus), there was definitely parvovirus, P19 and P4, because those were still present in the original recombinant haemophilia treatments because they come from contaminated albumin. Of course, there is also a whole list of heat non sensitive viruses, so viruses that would not have been killed by heat treatment.

35. There are certainly signs that I have a greater chronic ill health problem which I think is due to my exposure to and infection with numerous viruses. I was diagnosed by a specialist dentist who dealt with HIV patients as having an immuno-deficiency syndrome because of the condition that my mouth is in. This is the reason why my body finds it very difficult to deal with infections in my gums and I have regular teeth extractions. This is indicative of an immune system that is in collapse and that doesn't work properly. At this very moment, I have two large abscesses on my right leg which have formed in the last 24 hours. These are a regular experience and to me again signs of immune damage that is not being properly catalogued or addressed at the moment. I will be unsurprised if I return at least 12 major viral infections from my own research into the subject.

36. Then of course there is the CJD notification that I received in 2004. I have little doubt at all that I am at risk of Creutzfeldt -Jakob disease. I was in the group of patients who were given the mass notification for

CJD in 2004. I actually received the letter two days before the opening of the Scottish Parliament building. I can remember being very angry about it because I had originally gone to see Stephen Dorrell, the health minister, back in the mid-1990s and asked him about what efforts were being made to reduce CJD risk. I wrote again when recombinant products became available to try and make sure that kids got on to recombinant products as early as possible to remove that risk from them.

37. Receiving the notification was probably the precursor for me GRO-C

GRO-C

GRO-C nobody seemed to be listening. When MSPs came out to speak to us GRO-C very few of them seemed to hold any hope that CJD was going to be recognised as another harm within haemophilia treatment at that point. That is something that has been borne out even by the current SNP administration as they refused to actually acknowledge it GRO-C GRO-C it is why I was so angry. GRO-C GRO-C. There is nothing that terrifies me more than CJD. HIV was a scary disease but the idea of losing yourself, of having your personality and everything you are eaten away by death of your brain cells and to end up being completely dependent and unable to even intellectually interact because of CJD terrifies the hell out of me and always has done. This is a real risk for people like me. People need to sit up and take notice of that.

38. I remember seeing my medical notes when I was a patient in Sheffield Hallamshire hospital. Those notes confirmed that I was HBV antigen positive. I remember a doctor telling me at a clinic in Sheffield in the early 1990s that I had had Hepatitis B. I was not given any further information about this.

39. I now know that I probably infected my father with hepatitis in 1972 which resulted in him nearly going bankrupt as he was self-employed at the time at the time. As a result of the infection, he ended up having to spend a year in bed. It is also connected to his death just over eight years ago where liver failure was the reason that he bled out during heart surgery. It wasn't his heart that killed him, it was his liver damage that killed him. I was certainly one of the patients that was inside the Royal during the Edinburgh Royal Infirmary hepatitis B outbreak that is recorded in 1972 and I certainly was probably responsible for infecting my father with the same virus a short while afterwards after he got covered in my blood when I cracked my head open on a pavement slab. He got so sick he was ill for twelve months.

40. I also believe that it is likely that haemophiliacs will have hybridised viruses and that some of these have not been identified yet.

Section 4. Consent

41. In early childhood, doctors pummelled my stomach looking for a swollen liver. My glands were frequently up and I had swollen glands under my arms to the point of discomfort. I always had an aching body and aching joints. The doctors were recording that and taking bloods from me on a regular basis. I remember seeing in one part of my medical notes a blood test for liver enzymes dating back to when I was 12. The liver enzyme results were well over a thousand which would put me in the same level of liver damage as someone drinking a bottle of whisky a day. Certainly I think I was tested without consent and I certainly think I was monitored without consent and without proper knowledge.

42. I was used for research at Edinburgh Royal infirmary in 1975 or 1976. I cannot remember the exact date. It was a trial for Factor 9 which was a new drug at that time. Looking back on it now it was probably a liver

toxicity test that was being done to see how much factor I could stand before my liver results got worse. I was not told at the time that it was a toxicity test. I was told that I had the rarest form of haemophilia and that I could provide benefits to research. I was injected with factor concentrate every hour for 12 hours and every half hour on the opposite arm I had bloods taken for monitoring. I would be extremely interested actually to see if I could see myself in that piece of research if it was ever published. I would stand out because of my age at the time and Factor IX being so rare. There won't be many people in that age group in that year being trialled.

43. I have recollections of standing in a lecture hall in a vest and pants and being discussed by a large group of doctors. I cannot provide the exact dates for this but it happened at least twice between 1970 and 1975 in Edinburgh Royal Infirmary. I was too young to remember much about what was discussed by the doctors.

44. When my Dad was ill with hepatitis as discussed earlier in my statement, I remember the doctors coming to take blood from him and from talking to my mother I understand that he was never made aware of any connection between my hepatitis and his. It is a common experience in haemophilia that families were asking to give up blood for genetic tests. I remember blood being taken from my whole family. GRO-C GRO-C I have learned from my discussions with my friend Alice Mackie that they also took blood from family members of haemophiliacs who were not blood related to the haemophiliac in the name of "genetic research". This is why we suspect that they were really monitoring family infection transfers. I remember family blood tests sometime after 1972 and before 1974, which I can date because I remember the car that my Dad was driving at that time. I remember further family blood tests being taken in the mid-1970s.

45. Dr GRO-D used to say that I had a rare condition amongst a rare condition and because there were so few young patients receiving factor

IX about, I strongly suspect that I was used a lot more for research than on just those occasions by various consultants, particularly in childhood.

46. I have mentioned earlier in my statement the incident were I woke up to Dr Christopher Ludlam taking blood from me when I was hospitalised for pneumonia earlier in my statement and that I believe that the purpose of the blood being taken was to monitor me for a virus.

47. As mentioned previously in my statement, I did consent to the Hepatitis C test. I am one of the few people in haemophilia who can say that for certain because I was inducted into a clinical trial for the test. To get through that I had to be properly consented and made aware about what I was being tested for. When it came to the Hepatitis C test, I was given the impression that the disease wasn't that big a problem so it would be a lie to say that I fully understood the implications of being tested for Hepatitis C. I certainly didn't at the time. I was desperate for answers as to why I was ill but as for the implications of testing and what the purpose was in relation to me as a patient, that wasn't properly disclosed.

48. I certainly wasn't aware that I had chronic hepatitis until the 1990s when I was in my early 20s. Before that, it was all about having a bleed and being treated for the bleed and in the meantime they went through a series of tests that you'd always had. I can't remember not having my stomach pummelled or not having my glands felt. Looking back on it now, the idea that I had knowledge with what was going on with my body would be completely ridiculous because, if I had, I would have lived my life very differently from the point I left school and maybe my parents would have had a better understanding of why I was struggling at school.

49. I haven't consented for any other tests thereafter. I suspect that in Sheffield there was one particular test done without my consent that I am going to get extremely upset about. I strongly suspect that someone actually took the opportunity while I was having my hip replacement done to take a liver sample. The reason I suspect that is because I had severe

abdominal pain after the operation. My stomach was blown up. The only time I have ever seen that as a nurse is in patients whose stomachs had been pumped full of CO2 to allow a scope to go through their stomach. I suspect that they used my hip as an entry point for a scope and actually went in and had a look. I had a number of scars where they could easily have stuck a scope in and where they could easily have increased the pressure in my stomach so that they could safely introduce the scope.

50. I still think I'm being tested now without my consent. I still think that there are bits and pieces that are being monitored not so much via the haemophilia centre but via the hepatology clinic that have not been fully disclosed. I have two appointments per year for monitoring hepatitis damage and at an appointment this year, I was told that there was no major changes in my liver. I then went to see my haemophilia consultant who called up the same results and showed me that there are significant changes on the surface of my liver. I'm getting told where that there are no problems and then I'm getting another consultant, who I have got a much better relationship with than any doctor that I've had for years, telling me that in fact my liver is getting worse and that it is deteriorating and that the discomfort I'm feeling across that side of my body is related to changes that are measurable. For years, I went for tests and have been told that there was nothing there and then found out that that wasn't entirely true. I was told that my blood tests were alright and then when I had a look, I realised that levels of alpha beta protein, which is a potential cancer indicator, were actually elevated and that there were indications that my body was fighting infections at various points that weren't being properly declared.

51. In about 1992, I consented to being part of the interferon trial, which I discuss below in my statement.

Section 5. Impact

52. I've suffered with depression problems since my mid-teens. I have got no doubt now that that was linked to having hepatitis active in my blood. From that period on, when I went in to the 1980s when HIV was connected with haemophilia, I got threatened with violence on a few occasions and became socially isolated. That further compounded the depression and it also lead to an increase in me being violent which I had never been up until that point, mainly in physical defence of myself after people had done things like broken bottles and threatened to glass me to force me to leave Inverness, my home town. I moved to London to try and get some anonymity at a point when my mental health was probably getting worse. I eventually ending up homeless because I wasn't coping and because I was getting threats of violence from people I was sharing my house with because of HIV, which I don't have, but the connection between haemophilia and HIV had been well established in the press, so nobody believed me.

53. One of the other things I think that is totally understated is the impact that things like AIDS adverts had in the 1980s and early 1990s had in relation to social exclusion and how people dealt with things. Being told to keep things secret and not to tell anybody was totally and utterly unhealthy. Being told by doctors not to tell an employer that you had haemophilia when it clearly stated on the application form that, if you didn't fully disclose, that you would be liable to summary sacking.

54. My HIV test came about through my rock and roll contacts. I was working for a band called Bronski Beat in 1986 and I happened to mention to one of the guys in Bronski Beat that I was struggling to get an HIV test having been told to "fuck off" by Dr Christine Lee when I went to the Royal Free Hospital and asked for one there. She actually said "fuck off, go back to your own consultant, I don't want anybody else's cast offs". I spoke to Steve Bronski of Bronski Beat and I was introduced to a guy from the Terence Higgins Trust who then introduced me to a doctor in a clinic that was doing tests in private without any names being connected to them. It was very much like the way STD clinics were being run. I had my first

blood test done shortly afterwards which was sometime just at the end of summer or early autumn 1986. The reason I can remember it is that when I got the negative test back, I got really drunk and ended up being beaten up by two police officers who presumed I was on heroin, which I have never taken, because I have scars from injecting needles in my arms and I had short sleeves on. I got badly beaten which resulted in my right testicle erupting which had to be amputated some 20 years later because it had become polycystic and started causing significant infection problems.

55. My second HIV test was through the Terence Higgins trust directly when they started doing the street testing and I walked into their drop in clinic and asked for an HIV test. That would have been in 1987. When I got my second negative HIV test, I then started to believe that I could live my life even though I was clearly not well. I believed the doctors at the time that there was nothing wrong with me, maybe I just needed to try harder. One of the things that has upset me over the years is the idea that I was being told for years that there was nothing wrong with me when the doctors knew full well that there was. They left me thinking that I wasn't doing enough to actually push myself forward and made me feel significantly inadequate. That was a theme picked up by Hamish McDonald when he wrote the play Factor 9 and why I became so secretive and isolated with my parents. I thought most of what was happening was my fault.

56. Self-doubt almost completely sent me over the edge. When doctors were saying "there's nothing wrong with you", "this can't be why you're ill" , "this is all in your head", "you've got survivor guilt because you didn't get HIV", it left me completely doubting myself. There's a point where I think I almost became completely disassociated because I couldn't trust myself and I ended up at that point I think, the second time my marriage just about came to an end, I ended up getting to the point where I was very close to being suicidal. I've had episodes where certainly my temper can flare and there are definite PTSD elements now. I can't stand being

in hospital. My appointments at hospitals have to be arranged so that I am literally in and out in under an hour as I start sweating, shaking and feeling uncomfortable. I can't stand being in hospital buildings.

57. I had an awful lot of viral infections throughout my childhood. My mum describes me as having mumps twice and measles three times, despite having immunisations. I presume this was coming from the blood products that I was being injected with. I had swollen glands throughout my childhood, a swollen abdomen and I had discomfort and problems eating from early childhood.

58. By the time I got to my teens, after my pneumonia at age 15, my education collapsed. I went from being top of the class to the bottom of the class in the space of twelve months. People thought I was skiving. It caused a breakdown in relations between my father, my mother and myself and resulted in a relationship that has never repaired itself to this day.

59. I have struggled to hold down full time jobs. I could work for 2 or 3 days and then get to the point where I literally couldn't pick myself up out of bed in the morning so I would end up losing the job quite quickly. I had large points of instability and got more and more physically damaged as a result of some of the violence I faced as well. I sustained damage to my back and shoulder in particular from being hit by a large wooden bat. The funny thing is, when people think you've got HIV, they want to hit you and they tend to hit you with something rather than their fists as they don't want you bleeding on them.

60. From then on as I moved into my 20s, my health became steadily worse. As I got into my 30s, it became to the point where I was having to rest two or three hours a day during the day after I'd taken the kids to school. I was forced into being a full time house husband even though I wasn't capable because we needed my wife's earnings to pay our mortgage.

61. I am aged 53 now. I've got a collapsed right shoulder from doing a job that I shouldn't have been doing and then getting it hit with a baseball bat. I have peripheral neuropathy which I have certainly had since the Interferon treatment which makes most touch feel painful. I have severe gastric problems. My weight goes up and then it goes way down. It doesn't seem to be very stable. Up until a couple of years ago, I used to vomit every two or three hours a day to the point where food stayed in my stomach for very short periods of time. I used to get so tired being sick I used to fall asleep with my head in the toilet. My daughter actually describes poking me to make sure I was still alive when she was only six. I have got chronic arthritis. I have got severe asthma. I have got issues with my eyes in that sunlight is physically painful to look at. My health is knackered. You get to the point where nothing works right. I've got abscesses on my legs because my immune system is not working right. I've got damaged hair follicles, enough to cause a great big hole in my leg. I've had had several surgeries to remove infections from that particular leg and other parts of my body. I can't cope with work anymore, even around the house.

62. I have become extremely dependent on family members for everything beyond the basics of cooking a meal. I had to give up most of my pets. I used to keep a large number of ducks. I can't keep them anymore because I'm not fit enough to go out and provide the care that is needed from mucking out to keeping the foxes at bay. I'm just not fit enough now. I have trouble dealing with people and crowds. I don't respond well to stress. I feel like I'm in a constant case of collapse. About three months ago after about a month to three months of feeling like I was literally holding myself up through sheer will, my wife got up to find me one night to find me collapsed in the bathroom. I can't actually remember collapsing. I got up and collapsed again at which point my wife said I actually stopped breathing for a good half a minute and only started breathing again when she shoved me and tried to get me to react. I've got to the point now where I can't even rely on my body anymore to do anything. I feel like an old man in a relatively young man's shell.

63. I have already mentioned that I took part in the Interferon trial. I did this mainly out of desperation. It wasn't really what I'd call an informed decision. It was a desperate decision. My liver results were really bad. I was waking up most nights so covered in cold sweat that I was shivering. I don't think I'd have been alive if I hadn't consented to that treatment. In consenting to it, I wasn't fully aware of what the treatment was going to do to me. That was the last time I ever had a full time job. I had a major car crash during that period of time. When I think about it now, I certainly wasn't fit enough to work.

64. Nobody had made me aware about the side effects of treatment. I was told that Interferon would give me mild flu symptoms. If what I experienced is a mild flu, I'd like to know what they think a bad flu is! Mentally and physically, I have never fully recovered from that experience. At that point in time, I was still medically anorexic and needed Ensure and various build up drinks just to maintain any kind of weight. I dropped to nine and a half stone by that point and was just getting sicker and was going through periods of depression. When I had my hip replacement done a couple of years later, I had a massive reaction to the anaesthetic that compounded the depression that I had already felt from the Interferon. I ended up going to bed for six weeks and that almost wrecked my marriage. Christine moved out and we didn't live together for the best part of a year through that period of time. I wasn't coping very well at all.

65. I think the implications of the treatment were completely and totally understated. I'm not entirely convinced that all of the doctors understood what they were doing to us but it struck me that they weren't paying enough attention to actually notice what they were doing to us. Certainly I was complaining about having depression, concentration issues, holding down what at that point I think had been my 23rd attempt at trying to get employment and finally realising that I couldn't cope anymore with a job. At that point, my wife was on a very low income, all of which they

knew at the hospital. They could have at least given me a bit more support in getting towards a point of claiming benefits if nothing else which ended up being a blooming struggle in itself, which I will discuss later in my statement.

66. Since the Interferon treatment, my mental health has certainly got significantly worse. Although it was bad beforehand, it just seems to have been compounded by that treatment. I have major peripheral neuropathy issues and I have almost like an infected arthritis which results in all my joints feeling like they are on fire from my spine right through to my joints in my fingers. Everything burns every day. My asthma has got slowly worse. I've got liver pain over my liver. I'm restricted in what I can eat because if I eat the wrong things then I vomit. Food doesn't stay down. I am getting to the point now where I think that most consultants would be reluctant to actually operate on me as I respond so badly to anaesthetics. The last three anaesthetics I had resulted in significant problems. I remember the last time when I had a sinus repair overhearing the consultant freaking out as they were having trouble getting me to breathe again after they had given me pain control. My body is not processing drugs properly anymore, probably because of the liver thickening. My clotting has got a lot worse as my liver disease has progressed, moving me from having bleeds only on trauma, which was my experience through my early life, to needing prophylactic treatment every 3 to 4 days. My body also seems to now destroy Factor IX at a very fast rate so long acting treatments that are supposed to last for a fortnight actually at the most give me four days before I need to treat again.

67. I was in the clinical trial for Interferon high dose, 3,000 units every 3 days. I think that this was in 1992 although I would need to double check my medical notes. I was on it for just over 6 months when my health became so bad that they had to take me off it. It resulted in my wife moving out of the house with the kids for a while. My behaviour got worse. I went through a period of being suicidal. I don't think mentally or physically I

have ever recovered from that point in time. If anything, ironically I felt better with an active virus than I do now supposedly with no active virus measurable in my system.

68. Interferon is the only treatment I have had for my Hepatitis C. I don't think my life has ever been right since. I don't think my mental health or physical health has ever recovered since taking Interferon. I have had gastric problems since. Since the Interferon, my body temperature is really low. Instead of having a standard body temperature of 37.8 degrees, my body temperature comes out at 36 degrees, just half a degree about the level for hypothermia. As a result, it has given me some significant problems in identifying when I need to take treatments for bacterial and viral infections and has given me difficulty in managing symptoms from flu through to bronchial infections that I've had in the past. It hasn't been the same since I had that treatment. The most profound effect has been the mental effects since the Interferon. I was struggling before then and it was like someone had kicked the legs from under me and I still feel like that now.

69. I've been offered other anti-virals since and I've actually refused them. The reason I've refused them is because I still think that there is too much ignorance about potential long term effects and that the death rate will probably go up in people with multiple viruses (like me) who have been given anti-virals. Certainly the evidence from other research projects around the world suggests that it's not a good idea for haemophiliacs to take these new anti-virals and I'm not going to be one of the people that it gets trialled on them. So when it comes to treatment it might be worthwhile remembering that I don't trust treatment at all and that my Interferon experience has left me to the point now where I would let everybody go first, wait for three years and see if any of them are still alive before I'd even consider taking treatment.

70. Technically, I have had a negative PCR since Interferon treatment in 1992 but there has been a continuous slow, marked decline in my liver

function which is now accelerating which is why they offered me the other anti-viral option.

71. Before the Interferon treatment, I didn't have any difficulties in accessing treatment. I was in the hospital in Sheffield that was trialling Interferon at the time so I was automatically offered it on the basis of my liver enzyme results being over 1,200 which was extremely high and needed to be managed. I was clearly not eating and struggling to maintain any kind of life so it was offered to me as an act of mercy to be fair to the doctors. I certainly didn't have any difficulty in accepting it and if anything currently the problem is trying to remind doctors that I don't want any new anti-viral treatments. I find that at just about every appointment they make an attempt to try and put me onto these drugs which I don't want and would only take if I had felt that I had no choice but to take them or not stay alive. Some of these drugs I am so scared of I would rather die than take.

72. As already stated, I can't claim to have had any difficulty in accessing treatment for my Hepatitis C in the past. The issues that I have are around what I was told about the risks that I was taking with the treatment but actually obtaining treatment wasn't an issue.

73. I've mentioned the HBV virus that I had in the 1970s. I have no idea what they gave me in terms of treatment for that.

74. I've got little doubt that particular parts of my diagnosis have had an impact on care access. One of the ones I have just now is that I have been diagnosed with an oesophageal ulcer which should be monitored every year, in fact twice a year, but it would involve using an endoscope. Since the CJD notification came through, nobody wants to use an endoscope on me. A couple of doctors have said "oh I'll get someone to use an endoscope on you" and then it's never happened. I know full well that no consultant worth his salt is going to want to use £12,000 worth of equipment whet they can never use again just to see if I've got the 1 in 5 chance of my oesophageal ulcer turning to cancer. I just manage it

now with drugs. I definitely think that monitoring wise the CJD notification has had a huge impact.

75. Dental care has been at best chaotic. They used to call it conservative dentistry. This basically meant not doing anything other than pulling your teeth out as and when they went rotten. As a result I've got no molars left in my mouth whatsoever as they have all been pulled out.

76. During the CJD period, I was fortunate enough discover a consultant dentist at Raigmore hospital who was willing to take me and other haemophilia patients on that had these risks and manage them appropriately. She has been very honest with me that there are treatments that she would have offered other patients that I won't get because of my underlying conditions. This is because of what she described as my immune-deficient mouth which meant that things like implants would not work and she has even got concerns about false teeth actually causing problems in relation to gum disease. This means that I am now desperately holding on to a mouthful of very broken, very damaged teeth where the enamel has worn off from being sick regularly. They are cracked and damaged from being beaten and they are painful continuously to the point of giving me regular sore throats, regular headaches, discomfort and significant social problems in relation to showing my teeth. You will never see me smiling in pictures. It used to inhibit me talking to people and it still bothers me now when I'm talking to people that they might notice that my teeth are absolutely horrible. They have become almost translucent and as a result they just look black and horrible. As someone who used to take good care of my teeth, I now look forward to the day when the last one is pulled out because I absolutely hate them. They do nothing for me apart from give me pain and discomfort and allow me to bite into a steak.

77. I have become very restricted in what I ask doctors for. It's important to understand that I actually limit my contact with medicine. I don't think I'm unique and I actually think that is quite common. If something is wrong,

they're going to take me in to hospital and they're going to sit me down for three days and I'll get bored senseless and then they'll just send me home. If I've got enough treatment in the fridge, I'll just do it myself. So I've stopped going in, asking questions and making things clear. I have spent years going into tests where I've had things shoved up me and down me. I've had a campylobacter test which basically involves having a tampon put down your throat and then pulling it back up. I got to the point where it all seemed pointless. I was asking myself what it was actually achieving. I felt that it wasn't changing anything. For the sake of my mental health, I've stopped engaging. I rely very heavily on the blood tests and the monitoring that goes on in my case up to six times a year to identify any potential cancer risks or to identify anything that needs immediate attention, which probably isn't very safe. Beyond that, I put up with and ignore things and try to avoid spending time in hospital. I don't see any future benefit in the medical model in as far as making me well goes, so a lot of the time I don't see the point in actually getting involved with doctors in the first place.

78. My wife reminded me recently that, when we first met, as soon as she found out I had haemophilia, the first thing she asked me straightaway was "do you have HIV?" This was the common experience which is why most of us kept secret about our haemophilia but I certainly wasn't going to have a physical relationship with somebody without telling them that I was a haemophiliac.

79. When I started campaigning, my daughter was uninvited from a party aged 4 and I noticed thereafter stopped going to quite so many birthday parties. She became more and more socially isolated, which had an impact on her mental health significantly by the time she got to her teens.

80. My son has had to put up with an awful lot as well but he's a big toughie so he tended to stand up to the bullies but it did result in me going in and out of the school frequently having to deal with questions about why he

had punched other kids. Frequently, it was to do with abuse connected with me.

81. My relationship with my parents right up until my father's death unfortunately was terminally broken. It's never going to fix itself. My relationship with my sister is seriously damaged and is never going to be repaired. I don't get on with that whole side of my family. They thought I was wrong to stand up to the doctors and that I was wrong to disagree with them. They thought that I was just a numpty that left school at 17 with a handful of O grades and what did I know. Other parts of my family have been very supportive. My wife's family would probably have preferred that she didn't stay with me for a long time so were very supportive to her when she wanted to leave me and seemed to disappear when she came back at times when we could have really done with a babysitter.

82. I certainly wouldn't speak for Christine or my kids. All I can do is say second hand what I am aware of in terms of impact on them. My wife has suffered significantly mental health wise, socially and career wise. She was forced to do jobs to earn incomes for family need rather than because she wanted to go down that particular line. I certainly think I left her with very few choices when it came to what she did with her life. Now she has had cancer and has been forced into medical retirement, I've made sure she can have her horses and she can spend her time and albeit it's her money that she's spending, it's something that she's never had before. She has never had the luxury of actually spending on herself. It's always been about maintaining the family.

83. My daughter suffered from self-harming from her mid-teens. In her second year in university, we got contacted to tell us that she was in the psychiatric unit at Edinburgh Royal with severe psychosis. It turned out to be a reaction to anti-depressants which she had been on, despite my disapproval of those particular drugs. It had been kept secret from me, which I now feel terrible about. My daughter was so scared about how I

would react towards the doctors because everybody thought I was anti doctor that she didn't feel able to tell me about what had been going on. She spent over two years recovering from that and she was unable to complete her biochemistry degree. She went back and obtained an Arts degree in drama and writing at honours level but is still struggling to move on.

84. My son has had behavioural problems most of his life. He had chronic infections in his ear. I don't know how much my antigenic inheritance might have impacted on either of the kids' health but I suspect there has been some damage done. Robbie's big problem now is that he thinks that he needs to look after his dad so he won't leave home because he feels like he needs to keep an eye on me. I feel that both my kids are now stalled in moving forward. I actually made a point to my wife recently of making sure that she knew that I wouldn't have a problem if she left me and that I wouldn't take the house from her. I don't want them to feel like they're tied to me. I've got to convince my son that he doesn't need to look after his dad and my daughter that I'm not going to drop down dead if she doesn't come home every night.

85. My infection has had an absolutely and completely devastating effect on my family. It has completely changed the way that their lives have gone from their earliest point. My daughter has told me that when she was aged six, she used to come up and poke me when I had vomited all night on the toilet to check that I was still breathing and that she used to be nervous about opening doors when she came home from school in case I was lying dead on the floor. My son has told me about his fear as well. This made me suddenly realise the huge impact that I've had on their lives. This has left me with a massive sense of guilt that I'm never going to get rid of because there's nothing to minimise that. Realistically, it is guilt that belongs because, although it might not be my fault, it's still guilt that belongs.

86. In relation to my diagnosis for Hepatitis C, I think one of the things that gets missed a lot and is possibly more common in the haemophilia than non-haemophilia groups is that I wasn't actually that concerned about myself when I was diagnosed with Hepatitis C. What I was concerned about was the harm that I might have done to my wife and unborn child. I spent years not knowing one way or another if I had HIV therefore I didn't actually have any sexual partners for two years. I became obsessed with the idea that I did really want a family probably more so than any other young man of my generation. For Christine to have been pregnant at the time of my diagnosis with Hepatitis C was a real kick. I felt terrible and I felt that I had maybe destroyed them. I certainly knew probably at that point that my health was going to take us off on a very different life than the one that we had been hoping for with both of us working and supporting each other to a situation where only one of us was able to work most of the time.

87. I don't really have a social life. I have a few close friends that I've known for years that I don't have to explain myself to and I enjoy their company. These include the people that wrote the play Factor 9 and there is an old friend of mine called John and a couple of female friends I have known since school. Outside of that, my friends are fellow infected individuals who you just don't have to explain yourself to or make apologies to for not being able to do something or for suddenly having to run off to be sick. After Factor 9 the play came out, people well-meaningly tried to be nice but I found that difficult as well. I feel that it is a case of if you weren't there, you don't know. When people are trying to be nice, sometimes all that results from that is that you make yourself come across as more ignorant than you did before.

88. I remember going to parties with my wife's workmates. The first question that the other husbands would ask me was whether I worked. They then wanted to get into a discussion about why I didn't work and why I was a house husband. They want to know why I was staying at home when my

wife was working. Those were discussions that I didn't want to get into so I stopped going to these parties.

89. I was so ill when the kids were younger that frequently I didn't go on family days out or if I did I would be sitting in the car watching them. It affected my social life and my family life completely and completely changed what it would have been and how it would have been. From when my children were toddlers and certainly from Catriona being aged 6 and from Robbie's birth, nothing was normal and I don't think it ever can be. This has led to large amounts of stress and to my relationship still being hard work at times.

90. Stigma has got me beaten, has had me kicked in and it has lost me jobs. Stigma started with HIV. Nobody knew about the risks before that. When the headline appeared in the papers, "All Haemophiliacs have HIV", I lost my job. I was described by the head of the School of Nursing as an "unacceptable infection risk". I was ordered off the ward and asked to leave the nursing home immediately. I was then dumped in the railway station with all of my belongings, not knowing what the hell had happened. I came back to my home town where people started saying I had HIV and threatening to glass me and on one occasion ended up in a major punch up and ended up being badly beaten.

91. I then moved from Inverness to London with very little money just to get away and to try and find some anonymity. Unfortunately one of the people I shared a house with found a letter from the Royal Free and made the connection between my haemophilia and HIV again. I ended up homeless after he coshed me across the back of the head as I was walking up the stairs and threatened to stab me. I went into the room, packed everything I had and left that night. That then resulted in nearly 18 months of homelessness, couch hopping and sleeping in studios. I used to work for a few bands and used to get to kip in the studio. Eventually I ended up unwell and sleeping rough most of the time and I

got assaulted by a group of guys when I was in west London and ended up in hospital.

92. At that point, I was introduced to a social worker and I was put into homeless families where I stayed for again about 18 months. During this period of time I went between complete desperation and some attempts at hope. I got my flat in Kilburn in late 1987. I tried to get a job again and went back to nursing. I knew I didn't have HIV and didn't think there was any reason why I shouldn't go back to nursing. My consultant Dr Cook filled out a letter saying I didn't have hepatitis. I enjoyed being back on the ward again and I enjoyed working. I had a council flat but because it was in London, I needed to do extra hours just to keep going so I was also working as a stage hand and doing agency nursing. I was working up to 30 days per month and only having one day off each month.

93. I then met my wife which now in retrospect I realise probably saved my life. We moved to Scunthorpe. Again our housing choices were determined by my inability to earn a reasonable income, which left us on a council estate next to a junkie who used to break into our house all the time. We couldn't go on holiday without coming back to find that the house had been broken into. We eventually moved to a village called Redburn which is a village in North Lincolnshire, just outside Scunthorpe.

94. During this period of time, my doctors were saying that I was overplaying my symptoms, including the doctors from Sheffield. My wife stopped believing me and thinking that I was mentally rather than physically unwell which resulted in more problems. We ended up separated for a good few months where we lived separately. She lived in a house across the road from me. There were several times where our marriage almost came to an end. I was trying to hold it together. I became more and more isolated from everybody else and it seemed to be me against the world. We had no support from my family and almost the opposite of support from my wife's parents which I can understand up to a point but it

certainly wasn't helpful in relation to me being a good father to their grandchildren.

95. We moved to Inverness in 2001 after my wife got a chance to work in a community team as a physiotherapist, which was her original career. We moved into a small ex council house in Fortrose. We got fortunate within the property market and were able to buy a country house a few years later which is the house that I now live in. This is about the most stable my life has ever been. Outside of campaign work I have a quiet existence which I think is an antidote or certainly a reaction to my early life which was nothing but chaos. I remember starving at night because I had no money, going to sleep because there was nothing to eat, facing violence, having people put knives in my face, being smacked over the back of the head with a baseball bat and doing jobs which I shouldn't have done just because I wasn't physically capable. This did even more damage to my body. I wanted to be able to earn and not be dependent on others. All I wanted was to actually stand on my own two feet and I've certainly never been able to do that.

96. In terms of educational effects, I was regarded as a swot in my class. I was bright and intelligent. I have severe dyslexia which gives me problems in written work but the Professor who actually diagnosed my dyslexia said that I'd come up with a unique coping mechanism that he'd never seen before. I was able to cope in most levels of education beyond written work. I needed just a little support in written work which I felt that I didn't get. Most of the time I could cope pretty well with my schooling. By the time I had my pneumonia aged 15, my schooling just collapsed. I went from being top of the class to the bottom of the class. I couldn't cope anymore with classes as I wasn't able to focus or concentrate. We'd get homework back and it was like trying to wade through treacle. It was just hopeless.

97. After school, I went to try nurse training which was ended after 12 months because I was regarded as an unacceptable infection risk after

the HIV connection was made with haemophilia. I went to London and I did attempt to do a course on computer programming. Again, my health got in the way. I couldn't do the extra study work or do the full 40 hours per week in what was basically an apprentice type role so I was forced to give that up very shortly afterwards. I had one last shot at the age of 30 at doing social work at a college part time but found that I was getting so ill that I was struggling to cope. I was getting so tired and that ended up in me being involved in a severe car accident on the A15. I was nearly killed. It think it was the combination of Interferon, being too tired and taking on study that I just no longer was capable of. Since then, I haven't had any real contact with education beyond what I've taught myself. I've got the kind of mind that likes to learn so I do try and read things that extend my brain on a regular basis.

98. I've never had a stable job. I don't think I've held down a job for more than 12 months in my life. I think I was capable of earning a decent wage educationally. I just never got there because of my health. I have tried all sorts of jobs. I worked as a roadie where at least people didn't ask me if I had HIV as they didn't care. I tried working in an office and felt brain dead sitting there shifting paper from one place to another but again my physical health just wasn't going to let me hold down a job. The last job I got was actually a 12 month temporary contract which was given to me on the basis of my health which was ended by my employer after they decided that the six weeks I had to take off as a result of my car accident meant that they were not contractually obliged to keep me on. Since then, from the age of 30, I have not worked so it is now nearly 24 years since I last had a job.

99. I have never earned and have struggled to borrow. When I did borrow, I ended up borrowing at a point that my health collapsed so it then took me years longer to pay it off. I had to borrow more money to pay back money that I had borrowed. This got me into a chain where, if I hadn't maintained it, I would have been bankrupt by now. The only reason we've got a house at all is my wife's income.

100. I would say that every year I spend around £6,000 on campaigning through phone calls and travelling. In addition to this, I believe that I am down about £20,000 to £30,000 per year in comparison to my benefits income, which is around £12,000 per year. I come from a background where everybody else is in business and is self-made. My father was a self-made man, my brother-in-law is a self-made man. They'd all paid off their mortgages by the time they were younger than me. They all had businesses. My brother in law drives a £100,000 Jaguar car. Up until recently, I struggled to get anything that wasn't zero deposit on the mobility list.

101. I have experienced complete financial devastation. I am economically nowhere near where I would have been. I come from a family of well off, capable, middle class businessmen who worked their way out of a working class background in the 1960s. My whole family is like that. The women are all extremely bright and the men are all extremely hard working and apply themselves.

102. I receive £2,500 per month from the Scottish Infected Blood Support Scheme. I've got a benefits income of about £1,100 per month. I still think I'm probably down even with that amount of money. I would say that I receive £1,500 to £2,000 less per month that I would have earned if I'd been left to work and get on in my life.

Section 6. Treatment/Care/Support

103. I have had significant difficulties in receiving psychological treatment, which has been a great need for me over the last 30 years. I have frequently been inappropriately referred to counsellors that were totally unprepared to deal with the kind of problems that I'd faced. On one occasion I was asked to go and see a cognitive counsellor. The young woman in her 30s said that she had never dealt with anyone like me so I just turned around and walked straight back out and never went

back. I'm not interested in being somebody's practice piece. Psychological support has been non-existent. I probably got more help through marriage counselling than I've ever had through medical services and ended up paying for it myself at a point when we really couldn't afford it. However, we couldn't afford to split up so we were caught between a rock and a hard place.

104. Psychological treatment has been inadequate. Psychologists and counsellors whom I have seen have attempted to get me to drop the campaign which I was never going to do. They have attempted to minimise what I was going through to make it more "handleable", which was the phrase used at one point. This was ridiculous. At that point, I was throwing up on a daily basis and could barely walk some days and mentally I was struggling to function. To have somebody then try and minimise that experience in an attempt to help me cope with it was just so completely absurd that I couldn't take any of them seriously.

105. Counselling was completely and totally inadequate mainly because the counsellors just weren't up to the task. This wasn't the fault of the counsellors. I personally have been calling for a specialist counselling service to be provided to all haemophiliacs across the country. I think there needs to be some kind of specialist service akin to what the army uses for Post-Traumatic Stress Disorder so that we actually have people that are qualified, capable and are writing reports that results in changes rather than having us recorded ad hoc across the country with various counselling techniques. We're not getting clear data and therefore we're not getting the input that we need politically to influence the kind of support and help that we get.

106. I would like to thank the Inquiry for providing psychological support which allowed me to be able the opening day of the Inquiry when I felt like curling up in a ball. Being able to sit in a room quietly with a counsellor and just say what I needed to for 40 minutes probably kept me going for the rest of that week. Since then I've phoned the

counselling service once more at a point when I wasn't coping and I've got no doubt that I will probably have to do it again.

107. I have had to fight for support for my eating problems. I was fortunate enough to find a decent GP who helped me to deal with that. I now have to try and keep my weight down rather than trying to keep my weight up which is quite a unique experience for me and has only been a problem for me in the last eight years.

108. I said earlier in my statement that I don't really see medicine as offering me solutions anymore. I tend to feel like it offers me more problems than solutions so I no longer seek that kind of support on a regular basis. I tend not to want medical intervention at all now. I think my view is quite simply put as "just leave me the hell alone, you've done enough damage". The more I let medicine and various people in to my life, the less control I seem to have over it. Control is all I've really got now and I'm quite determined to hold on to that little bit of my sense of self.

109. I abandoned an awful lot of medical arguments a long time ago because I just found that it was making me more unwell. I found that the idea of going to a doctor or a hospital expecting change or that something would get better which didn't then happen was actually making me mentally unwell. I stopped asking for help and I stopped questioning things. Every so often, I'll shock my haemophilia consultant by listing all the things that I have been ignoring for a while and then that usually results in some intensive medical input which gets us nowhere because I hate being in hospital. I hate being around medicine and I don't openly seek help any more so silence tends to be my protective point.

Section 7. Financial assistance

110. For a large chunk of my life, I have been completely dependent on the benefits system.

111. I didn't receive any financial assistance at all until the early 2000s when they brought in the Skipton Fund. I received the first payment, which I believe was £20,000 at that point. I wasn't diagnosed as being at stage 2 until another 3 years later after kicking up a fuss with my former haematologist Professor Christopher Ludlam and getting him to refer me up to the specialist liver unit at the Edinburgh Royal Infirmary. I had to have some intrusive tests which resulted in me having to make long journeys to Edinburgh from my home north of Inverness. That was a nearly 400 mile round trip on four separate occasions to develop the evidence to the point where it became impossible for Skipton to refuse me payments. Until that point, I was economically so unstable that even the slightest bill could have finished our family off. After doing a scan and having a long discussion with the consultant, the decision was made to point out that I did have cirrhotic damage to my liver that fulfilled the criteria so I was moved to stage 2. That was four years after the Skipton Fund was started. I always resent the idea that Skipton should have been but was not paying me for four years.

112. The Skipton Fund attempted to refuse me payment even after my diagnosis of cirrhosis so I had to get my consultant to actually go to bat for me with the Fund which resulted in a further three month delay in payment. This would have be close to £3,500 worth of payments which weren't made. I had to fight to get Skipton Fund payments.

113. As previously mentioned in my statement, I receive monthly payments from the Scottish scheme. Being at stage 2 has left me economically relatively stable for the first time in my entire life so at the age of what was then 52 years, I finally reached a point where I wasn't living in complete terror of brown bills and didn't have an urgent need for

money. I actually have savings for the first time in my adult life and we are able to afford to go on a few holidays, although a chunk of that was actually funded from my wife's pension and from an insurance payment paid out for her because of her cancer.

114. I have never applied for extra help from any of the trusts by applying for grants. My wife Christine's income was such that it was clear that it was always a waste of time trying to do that, despite the fact that we were struggling each month just to try and pay the bills. The forms were overly complicated, completely intrusive and I was unwilling at that point anyway to explain myself for the sake of what would end up being only a couple of hundred quid at the most. I didn't see the sense in putting myself through it for the sake of such a piffling amount of money. It didn't seem to have the value that the effort required.

115. I am in the unique position of having campaigned for most of these schemes to exist and being in the frontline as they came into existence. I can't say that any of the financial assistance forms that I have seen are really accessible. They look worse than most of the benefits forms that I've ever had to fill in and are significantly more intrusive in relation to what they are trying to find out about partner and children's incomes. I've often resented that idea that my wife's income should be taken into account in this because I don't think that she should be paying for something that was done to me long before she ever met me.

116. I don't see that victims were ever at the forefront of the schemes and trusts. Their purpose was to save money and to reduce impact on the public purse. This has certainly been the experience I have had in interactions with these schemes, both for myself or on behalf of others. I have assisted others on a number of occasions to apply to the schemes. I felt like the schemes were not being upfront in making sure that people knew exactly what they could apply for or how they could apply for it.

117. I am one of the people that helped negotiate the new Scottish scheme after the Penrose Inquiry report in 2015. The Skipton Fund trustees came up to meet with us. They quite frankly shocked us to the core with their attitude towards victims and how their mode of operation seemed to be centred particularly on government savings and maintaining budget levels. The victims seemed to be totally irrelevant to the process.

118. I also had to fight to keep two of my benefits. I had to fight to get my mobility benefit. I had to fight to get my care component. It took seven years to get the Disability Living Allowance component sorted out properly, which included a medical. I've been accused of benefit fraud on several occasions and had benefit fraud investigations because people have thought that I was either driving too nice a car, which was a mobility car, or because I didn't look sick to them.

119. I had the last medical for my benefits about six years ago where the doctor came in and was clearly ignorant about a large chunk of my medical condition. They were assessing my fitness to work. Fortunately my wife's medical training enabled her to stop me from getting angry at the doctor and chucking him out of my house. My wife started to correct his misconceptions early on and make him understand that the idea of me working in a booth was completely absurd because I did not have the physical tolerance to stay and concentrate for that length of time, let alone in a job that would have done my head in simply because it would have challenged me in no way shape or form whatsoever. Certainly being intelligent with a disability in general seems to be something that you are not supposed to express in employment choices.

Section 8. Other issues

120. I started campaigning almost as soon as I was diagnosed with Hepatitis C in 1990 because I knew that what I was being told wasn't true or couldn't be completely true. I knew that it was only half of the truth. I've been campaigning now since 1990. Throughout the 1990s it was about collecting information and about trying to find documents. I then came into contact with my friends Robert Mackie, who I hadn't seen for a large number of years, and his wife Alice who became basically our researcher and who backed up every piece of work that I ever did. I could ask her a stupid question and she would go and find me an answer for it. Over the noughties, our relationship developed as a small campaign group with me asking the questions, Alice finding the paperwork and the answers and Robert searching his memory because he was ten years older than me and was able to remember things that were going on in the unit at the RIE when I was a kid that I wasn't aware of. This included examples he could recall when I was actually the patient that he was talking about.

121. As a campaigner, one of the things that I think that the Inquiry needs to wrap its head around is that those of us that have campaigned, living and dead, made a very particular choice that resulted in us becoming very isolated from our medical practitioners and led to an "us and them situation." We almost had to accept that because we were foing to be seen as kicking up a fuss by searching for answers we were going to get lesser care than our fellow haemophiliacs. I certainly think that that's borne out by my life experience and particularly the hostile manner shown to me by my previous consultant at Raigmore Hospital, Dr GRO-D who quite frankly I had no working relationship with whatsoever.

122. I have mentioned in my statement that I don't go to medicine and look for solutions. The problem with campaigning is that I've not allowed myself the denial that most people have in relation to daily life. This

campaign has been my daily life. I get up every day and do something to do with the campaign for at least two hours every day and have done so for over twenty years now. I read at least two medical research documents per day. That is just par for the course. Instead of reading a morning paper, I'll sit and read a paper about cytomegalovirus in haemophilia or parvovirus in haemophilia or new information on hepatitis. I try and make sure that I am as up to date as I possibly can be. I ask questions that are relevant and challenging but in that process I've ended up very much on the opposite side of medicine. Those of us who have campaigned and who have searched for answers have ended up very much outside of the units that were supposed to care for us. We have ended up with major issues in trust and that has undoubtedly compounded further our poor mental and physical health throughout our lives. I now have a wonderful consultant who has the time for me and who has listened and understands why I am the way I am.

123. I want to give a fuller statement to the Inquiry in relation to my campaign work about how things have developed, why they developed and why it is that we are looking at the current terms of reference which I undoubtedly have spent a large chunk of my life shaping and coming up with the reasoning for. I regard myself now as an expert patient and think that it is reasonable to regard myself in this way. I can narrate the history of this disaster not because I wrote it but because I lived it and I have worked to understand it. I was there at the beginning of this campaign and I'm one of the few fortunate ones to still be alive at the end of it. There are few of us that fulfil that criteria. I think it is important that the voices and questions of campaigners are heard within this Inquiry, that the reasonable questions that we have all asked for decades are finally addressed and that this Inquiry is willing to hear from people like me who will challenge it, who will ask questions of it and who will push it. Also, my campaigning has meant that I have been in contact with many people, many friends who are no longer with us. I feel that I can tell their stories as well as mine and that their stories also need to be heard. I certainly hope that at some point during this process that, as a

campaigner, I will be given respect from this Inquiry and asked searching questions about what I have lived and what I have leared about its terms of reference which I am more than happy to answer under oath.

124. The only contact that I have ever had with my medical records was when I was given them at an appointment within the hospital. I used to get in to the habit of nipping in to the toilet and having a quick read through and seeing where they were going. As a result, I became very aware, particularly in Sheffield, that what was being said to my face and what was being said behind my back were two different things.

125. I have never recovered my medical notes, initially because I predate the entitlement to recover medical notes and then because when they did become available, I couldn't afford it. Most recently and certainly since the Penrose Inquiry, it has become clear to me that actually not having recovered them might be a good thing. There has been no attempt to get my records from any hospital by me. I have now kept that position deliberately. I would like to see how complete a set of notes we can get and how much it actually matches up with my experience. I strongly suspect that there are bits of my notes that are less than complimentary towards me. I think not having recovered my notes, having been such a vocal member of the campaigning group and having been so closely involved over these years that those notes will be extremely revealing. I think that recovering them in an official way, particularly in light of no editing rules which the Inquiry can impose, would give us a chance to actually forensically analyse these documents beyond their content, to actually look at whether or not things have been removed, have been taken out or if there is a disconnect between the information on one piece of paper to the information on another.

126. It would be my hope to recover my notes but to do so with some kind of legal backup, simply because I do think that these notes could end up being important to the Inquiry's investigations. I was probably one of the first patients in the world to be given Factor IX so my early notes

will chart out the beginnings of concentrate therapy within haemophilia. I was probably one of the first people to be given liver toxicity testing in relation to factor concentrate exposure, which was in about 1976 and I certainly was one of the first patients to be treated or tested for my hepatitis C openly in the 1990s. Beyond that, I have also had the misfortune in the 2000s of coming across Professor Christopher Ludlum again and I do think that he has been quite influential in the background in my interactions with other consultants. I would be intrigued to know what he has written on various referral letters, particularly because of the way that the referrals were dealt with.

127. I think we should get my notes now but I think it needs to be done in a very formal way because if they are untouched, it gives us a unique opportunity to actually look at this as a proper case study. Once the records are recovered and considered, I certainly think it would be appropriate to give a further statement based on their contents and any comment that might come from the content or lack thereof in relation to particular key dates, such as my pneumonia in 1980 when Professor Ludlam drove all the way up from Edinburgh overnight to take blood from me and ran away when I asked him what it was for. I think that it offers us an opportunity to look at the attitudes of doctors to a campaigner like me. I would like to see exactly what they have said and written about me which, I think, might also be crucial I understanding the massive disconnect that has so shattered me mentally and physically, has isolated from me from the medical profession and has resulted me in living in a house a quarter of a mile away from anybody else because I can't deal with people anymore. I think it will all be reflected in those notes. I can't say that I'm completely settled with the idea of looking at them. There is a degree of trepidation as to what I might find out or what they thought of me but I think that because they will untouched we should go after them. I would like to do a proper job in analysing them with my experience in campaigning, with my understanding of medicine, with my ability to read through them and to put cross reference them with key dates such 1976, 1980, 1990 and 1992 and certainly the stuff that was

going on in the 1980s when the doctors were writing that I didn't have hepatitis on medical forms. I think that exercise would give us a chance to see how honest the relationship was, how honest the disclosure was between consultant and patient. I know that it was not.

128. I am nervous about it and there is a degree of protectionism in dealing with it in the round rather than on an individual basis but I think it is something that I will need to go through and I do need to tackle. I think the Inquiry would gain significantly from looking at individual cases, not just mine, but also cases similar to mine where we could actually see the impact not only of viruses but also of campaigning on attitudes towards patient care, quality of care, what was being written and what was being passed on to other medical professionals.

129. I would wish to give a further statement to the Inquiry once my records have been recovered and once I have had the opportunity to review these with my legal representatives.

130. I would also like to mention more about recombinant products. I moved to recombinant DNA products for the first time in 2016. I had previously not been on recombinants because I was allergic to the original Factor IX recombinant drug that was on offer. My move in 2016 was actually prompted by seeing a report that BPL had failed a Medicines Inspectorate report on the computer system that deferred unsuitable donations from going into the pool to make plasma products. I still have issues in taking the recombinants, I have to take antihistamines to not react to them. Technically the drug I'm taking now is still at research level so I suppose that's the fourth one. On one occasion, less than 3 months ago, my wife found me unconscious lying flat on the floor of the bathroom as a result of an allergic reaction to the new drug that I am on now. I am so scared of the potential harm that I might do to others through using the BPL blood based product that I felt that I had no choice but to move over to this drug regime despite the fact that it's clearly challenging my health and my physical condition.

131. I believe I have reliable evidence and can provide reasoning to explain my belief that haemophiliacs like me were used as research subjects.

132. I wish to inform the Inquiry's investigations and direct them towards relevant areas of investigation based on my knowledge and experience. Through my research, I have located journal articles which I believe are relevant and explain the genesis of blood products and the epidemiology of hepatitis. I would be very happy to share what I have discovered and learned to assit the Inquiry in fulfilling its terms of reference.

Statement of Truth

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

Signed **GRO-C**

Dated 28/02/2019