

ANONYMOUS

Witness Name: [GRO-B]

Statement No.: WITN2219001

Exhibits: N/A

Dated: 5th October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF [GRO-B]

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

I, Mr [GRO-B], will say as follows: -

Section 1. Introduction

1. My name is [GRO-B]. My date of birth is the [GRO-B]. My address is known to the Inquiry. I currently live alone. I was previously married and now divorced. [GRO-B]

[GRO-B]

[GRO-B]. I have worked most of my life in commercial type jobs, although more within the voluntary sector, but I have had spells of not working, usually for health reasons. I have worked in the voluntary sector for around 25 years. [GRO-B]

[GRO-B]. I have been involved in campaigning in respect of contaminated blood. I mainly work on the organisational side of campaigning. I intend to speak about being infected with Hepatitis C, in particular the nature of my illness, how the illness affected me, the treatment I have received and the impact it had on my family.

ANONYMOUS

Section 2. How infected

2. I have Haemophilia A. The circumstances in which I became aware of this diagnosis are described below.
3. I have been treated with cryoprecipitate, Factor VIII Porcine, Factor VIII, and NovoSeven. I am not sure if I have had the modern version of Factor VIII. I am unclear which product or batch(es) caused the infection but I may have been multiply infected.
4. I have mainly been under the care of the Glasgow Haemophilia Centre but I have attended some other hospitals.
5. When I was young my family moved to Scotland when I was 5 or 6 years old. Up until this time I would have been in hospitals in Leicester or London. I am not sure what hospitals.
6. I have received products multiple times. I am unable to give a date of each specific occasion. It was possibly the 70s or 80s that I received contaminated product.
7. I have Haemophilia A. I was initially told that I was considered to be a minor Haemophiliac but I later discovered through campaigning that the definition of what is considered to be mild haemophilia has sometimes fluctuated over time. At one point, I remember I was described as being moderately severe but I cannot remember who said this to me. I suspect that I was on the lower end of the spectrum of Haemophilia but perhaps a bit above being a mild haemophilia patient. I think of myself as a mild haemophiliac.
8. I was diagnosed as a haemophiliac at preschool. I think I was living in Leicester, England at that time. We moved around in Scotland and England because of my dad's job. He worked as a shop fitter. I remember I had an accident at 5 years old when I fell in the house which was in [GRO-B] and banged my head. I had a big bleed right in the middle of my forehead. It was at that point that the bleed wasn't stopping. I remember I was taken to the hospital in [GRO-B] and they did some tests. I cannot remember which hospital. It was discovered that I had Haemophilia. I remember my mum telling me that she used to wonder why I seemed to take a bit longer than other people to stop bleeding if I had a small cut as a baby.
9. I believe that when I was first treated I was receiving Cryoprecipitate. I think after that I was given Factor VIII when it was required. I have never received home treatment. I have only ever gone to the hospital to get treatment. I developed at around my late 20s what is known as 'an inhibitor' (or inhibitors) to treatment. In the initial stages I was then given a third type of treatment which was based on pigs' blood. It is known as Porcine Factor VIII. That apparently was to stop me from having a reaction to the human-derived product. Now, I have been told by those treating me that the prescription of choice for me is something called

ANONYMOUS

NovoSeven. Apparently it is more expensive than Factor VIII but because of my inhibitor status it is the way that I am to be treated.

10. I have been treated with Cryoprecipitate, Factor VIII Porcine Factor VIII, and NovoSeven. I am not sure if I have had the modern version of Factor VIII known as 'Recombinant', which means it is not human derived. I am unable to give dates that I have received the treatments. I assume that I made the transition from Cryoprecipitate to Factor VIII when it became available to everybody. I am assuming this was the late 1970's or early 1980s. It may be recorded in my medical records (to which I do not currently have access).
11. I have been primarily under the care of the Glasgow Haemophilia Centre. As I have said, we moved to Scotland when I was 5 or 6 and remained in Glasgow for treatment from then on. Up until we moved I would have possibly been in hospitals in London or Leicester and a couple of occasional treatments when I was on holiday. I remember I was on holiday on a boating trip and I started to have some bleeding problems into my ankle and knee. I was about 23 or 24 at this time. I am sure that I had treatment in Reading and maybe one other place on the route of the River Thames. They were one off treatments due to bleeds while away from my home. I was also working voluntarily in Stoke-on-Trent at one time and had an accident which was quite bad. I had some treatment for bleeding at a hospital in Stoke on Trent. I would have been around 21 years old.
12. My mum mentioned the names that she recalls of the doctors that treated me when I was growing up. As was normal, I began being treated at Yorkhill Sick Children's Hospital, but I don't have any names of clinicians or treatment records for those earlier times. I believe Professor Charles Forbes was the main person who looked after me at the Glasgow Haemophilia Centre initially, also a Dr Willoughby followed by Professor Gordon Lowe. Professor Lowe carried out a fair bit of treatment for me, or supervised it through other more junior doctors. There have been a number of doctors since that time coming and going in terms of my treatment.
13. I recall that it was Professor Charles Forbes then Professor Lowe and now it is Professor Campbell Tait that I see at the Glasgow Haemophilia Unit. Professor Campbell Tait became the senior haematologist when Professor Lowe retired. There have been a number of doctors who have been in for a while and then they move on (possibly Registrars or a similar title). I wouldn't always see Professor Lowe when I went for treatment at the Glasgow Haemophilia Centre. Often at the time of my appointments the nursing staff were well enough aware and they were able to do what was needed for me. I didn't always see a doctor and if I did it

ANONYMOUS

wouldn't always be Professor Lowe. In fact it was less likely to be him. It was usually one of the residents or locums I would see. I cannot remember all their names.

14. Around 1974 to 1975, when I would have been 12 or 13 years old age, my treatment was split between Glasgow Royal Infirmary and Yorkhill. I felt like a 12 year old in a ward full of men. I am unsure, but I believe that my time at Glasgow Royal Infirmary may have been because there was a treatment or consultant based there that I had to see, as opposed to Yorkhill. I assume I was there for a particular reason, but I do not know what this would have been. I was back and forth to Glasgow Royal Infirmary and Yorkhill around this time.
15. I remember in 1980 I was in my first year at Glasgow University. I was suffering from lots of spontaneous bleeds in my wrists, forearm, hands and gums at different times. I was up at hospital a lot for the bleeding I was suffering at this time. I remember one occasion in 1980 when I came home from a boating holiday which had required treatments away from my regular centre. When I got back I was taken immediately to the hospital and the bleeding had only slightly settled down. I was taken straight to Glasgow Royal Infirmary. I was admitted to the hospital and stayed there for a couple of weeks because my ankle and knee were not settling.
16. I have received different types of treatment throughout my life. I have not done any personal investigations into checking batch numbers. I do not know if this could be done and I would need to find someone who knew how to look at the right things to understand if it meant anything. It is really hard to say the point of infection because I remember there were times that I was just feeling excessively tired and couldn't really understand why. I remember I went to my GP who gave me anti-depressants during my student years. I was stoically against this so I did not fill the prescription. I thought I just need to get on with things. It wouldn't have been until a number of years later more generally that I have seen the connection being made between the beginnings of the effects of Hepatitis C starting to emerge. Those typical and common effects I am referring to are of fatigue, tiredness and joint pain.
17. I remember, looking back, that I was going through some of the typical viral hepatitis symptoms of fatigue, tiredness and joint pain but didn't realise what it could have been that was wrong. The time period is very hard to say as to when I was infected but I think it was from the late 1970's anytime through to the 1980's. Every so often since I left university I have had occasional treatment for bleeds. I had a large amount of treatment about 5 years ago when a simple operation for removing my appendix went wrong. This was approximately in 2010 or 2011 because after the keyhole surgery I wasn't stitched up enough inside so I continued to bleed internally. The hospital where I had my surgery was Glasgow Royal

ANONYMOUS

Infirmery. At that point I can say that I was definitely already infected since I was on the anti-viral treatment and had to stop because of the surgical condition at that point. At home I had a massive gastro internal bleed. After 3 months in intensive care, in 3 different hospitals, I was told that they thought they weren't going to be able to save me because they had to go in again surgically. I was in hospital at Glasgow Royal Infirmery, Gartnavel and [GRO-B] General Hospital. I have had periods where I have not had treatment and some periods where I was having a lot of treatment and that is the norm for me as I do not infuse every day at home the way many people do who have bleeding disorders.

18. I have to presume that I became infected on one or more of the occasions that I was given treatment for the bleeds in my early years. I may even have been infected when I was getting my wisdom teeth out because, as I understand it, you had to get treatment ('cover') before you had one of those procedures done due to the inevitable bleeding. I was about 23 when I got my wisdom teeth out. It could have been any one or more of many times I received treatments for bleeds. This leaves me open to the possibility of being infected multiple times. I know from reading online that there were whole batches of products infected so it could have been on one occasion or on multiple occasions that I have been infected or at least been exposed to hepatitis C or indeed to other viruses. When I was in university for example during my 2nd year I was having spontaneous bleeds to the point I was given permission to repeat my 2nd year. I could have been treated in that year alone 10 or 12 times. As I have become older I am more sedentary than I was as a young student. I don't drink alcohol and never have, never smoked, never used illicit drugs and never injected, so for me there is no other route by I could have been infected other than the treatments I have received for my bleeding disorder. I have only ever had one sexual partner, my former wife, [GRO-B] [GRO-B] and found to be not infected. Thus, I could only have received the virus by infected blood products.

19. My mother was not given information about the risks of infection associated with the products which I received as a child. I have asked her the questions about what she was told. I was the eldest of 3 children. My mum described me as "the experiment one" because she was learning to be a mum while I was learning to be a kid. The fact that I would bleed a bit more than what she thought I should, wasn't enough for her to get involved in the Haemophiliac community because she didn't know at the time what that was or what it was that caused me to bleed like that.

20. It would have been my mum who took me to the hospital when I was a boy. I think that my mum never received any counselling or advice about the risk of infection from the blood products I was being given. For example, when I went to high school I was not to do PE at

ANONYMOUS

all due to "his [my] bleeding", so I would sit and watch the other kids do stuff. Between classes, I was always sent out of class 5 minutes earlier to go down the corridor to the next class, so I wouldn't be jostled in the corridor. That is what it meant to me to have Haemophilia when I was growing up. I had absolutely no concept of it having any link to viruses at all, nor did my mum. She and I were never given any advice about that.

21. I am not entirely clear on the precise details of when I first became aware that I had some kind of a viral infection. I do roughly remember being told, and at the time it didn't feel like a serious or worrying type of discussion. I went in for a normal consultation at Glasgow Royal Infirmary where I went every so often to get my clotting levels (and whatever else) checked. They would often take numerous vials of blood (sometimes up to 12) but I never questioned what these were all for. At some point in the routine check-up someone mentioned "non-A non-B", which I now understand to be non-A non-B hepatitis. It was so casually discussed with me that it didn't make much of a difference to me at that time. It was probably Professor Lowe who provided me with the information that I had this infection and it was more in terms of some practical observations. These practical observations amounted to telling me about the risks of passing on the infection, and telling me to wash my hands regularly. There was discussion about using contraception, and I recall that this would have been around the time that I got married in [GRO-B] so this may have been that year or in [GRO-B] I don't remember and think I did not receive any advice in terms of whether it would have an impact on my life span or other effects of having the virus. It was simply a conversation that I had. There was no literature that I took away from this conversation. Initially, the sense was that I had was that it wasn't really a big deal and that's certainly how I took it, so I never really had anything in my mind to be concerned about at around that time. It was like being told I had bacteria in my stomach and before I could get worried about that I was assured it was ok since everyone has it. I already had experience of the inhibitor situation and to me it was just another complication linked to my bleeding disorder. I had the impression that it would sort itself out.
22. It is worth noting that I have an Autism Spectrum Disorder (Asperger's Syndrome). This was not diagnosed until I was in my mid-40s, but it provides a prism to some aspects of how I have responded or not responded to my growing awareness of having been infected by contaminated blood. Professor Lowe and the team at the Haemophilia Unit were not aware of my diagnosis of Asperger's Syndrome at the likely time of infection.
23. Not long after I got married in [GRO-B] the people at the unit found out and must have considered this to be significant. It was suggested that I come into the unit for a discussion with one of the doctors about the virus. At this stage, it had a name, Hepatitis C rather than

ANONYMOUS

"non-A, non-B". It was only then that I began to recognise that there was a degree of severity about my infection.

24. My new wife and I attended the Glasgow Haemophilia Unit. I believe it was Professor Lowe that discussed the requirement for me and my wife to be more careful and take precautions in terms of spreading the infection to other people through poor hygiene, blood contact or physical contact. I don't exactly remember ever being given a leaflet to read or offered anybody to go and talk to about it if I felt worried at around that time.

25. We were getting advice in relation to starting a family and how we should use barrier contraception, including doubled-up condoms, beyond that. This did have a negative impact on our intimacy as a couple; including the real possibility of passing on the infection to my wife before being given this new safety information. At the same time we were getting ready to buy a house together. I remember the mortgage company, when they recognised that I had certain health issues, required me to attend a special medical that they arranged privately in Glasgow. The health issue I refer to was simply my having haemophilia. I think it was the Nuffield Hospital, off Great Western Road. It was there that the doctor mentioned about my HIV test being clear. I didn't know that I had been tested for HIV and so I came away from that quite confused. This is all happening during the mid-1990s. When I look back now all I remember was a gradual increasing awareness of my illness. There was no strict time where I felt someone had a discussion with me or took time with me to fully review what was happening with my health. It was more a gradual awareness from speaking to different people, hearing things, then putting two and two together.

26. [REDACTED] GRO-B [REDACTED]
[REDACTED] GRO-B [REDACTED]
[REDACTED] GRO-B [REDACTED] There was clearly a time period of at least 2 years if not more, between the general discussion about having to be aware of my non-A non-B to it being spelt out as something which could be damaging to me and to my family. What I cannot say for certain is how long, before the time I was told about the non-A, non-B infection, had they known that I had non-A non-B? I don't know how long any of the gaps are which is frustrating. The gaps just exist by the way information that trickled down to me. At some point I was told it was non-A non-B and at some point later on I was told I had Hepatitis C. I then found out about the HIV test (which I did not know I had had) during the medical I was sent to for my mortgage. Clearly there had been things going on in the background of which I had not been aware. I am still not sure that I have been given the whole picture.

ANONYMOUS

27. When you are a newly married couple, you didn't think you had to worry about this kind of thing. Especially when both of you had come into that relationship having never had a relationship with anyone else. All of a sudden that purity was tarnished by this infection. It was unpleasant at the time but my wife took it very well. At the same time it did have an impact on us, but I think I was left with more questions over time, but I never really felt sure if I could form a question informed enough to ask someone.
28. I would have thought that at the point someone had tested me for a virus, or had discovered it through a test for something else, that I should have been told at that time. I got the impression that that knowledge was held by them for some time and I didn't know anything at all before I was told about the non-A non-B. Neither my Mum nor I had been told that this was a risk and so I had no reason to think that I might have been infected with anything. I should have been told that I was infected, even if it was discovered on the back of another blood test. We were always getting tested for something and if it was discovered by default then I should have been told. I was usually at the hospital to give 7 or 8 vials of blood on a reasonably regular basis. That was fairly standard. It is quite possible that one or two of them were related to HIV testing or Hepatitis C of which I was not aware. I just thought this was standard and I would have received a phone call if there was a problem.
29. The trigger for having a conversation with me about my diagnosis was not them discovering that I was infected but that I was just married. I believe that information should have been provided to me earlier. It wasn't right that I found out that I had been tested for HIV by a doctor who was assessing to see if I was fit enough to receive a mortgage. I remember thinking about this going back home and thinking "How do I tell my wife this"? I think that the conversation about non-A non-B was quite informal and didn't indicate that this was anything to worry about. When I did have the conversation with the doctors I ended up leaving with more questions than answers. One of those questions was, "Why am I only finding out about this now and not when you found out about it?" I have no answer. I am aware that over time scientific knowledge changes and hopefully people going forward will get more accurate information, but I wonder about the spaces between key events: when was I first infected; when did they know that the treatment might infect me; when did they start testing me because they suspected I might have been infected; when did they find out I was indeed infected; when did they think they had told me sufficient clearly for me to appreciate the gravity of the situation; when if ever were they going to tell me about the extent of the testing and results and risks; when did I actually realise there was a problem; how long had I potentially been at risk of infecting others in ignorance?

ANONYMOUS

30. I was not given information about the risks of others being infected as a result of my infection. At some point I was told about non-A non-B but I don't remember being told anything at all about the risks of me infecting other people. At the time my wife and I met with the doctor the focus was very much on maximising the care we took in our sexual relations to minimise any risk of her being infected. We weren't discouraged from trying to have children. It was suggested we use condoms. I received advice that said we should use two condoms but that just didn't feel nice for a newly married couple who had tried to live virtuous lives and not be exposed to the challenges that people face as a result of promiscuity. We had avoided that in both our single lives as young people and adults. That purity and complete openness was significantly diminished and had a detrimental effect on our relationship and intimacy.

Section 3. Other infections

31. It is practically 100% undeniable that my Hepatitis infection is a result of receiving infected blood products. I can't imagine any other possible infection route. I believe that there are different strains or manifestations of hepatitis, not just A, B, C. I think they are called genotypes. I do not know but I may possibly have been multiply infected with different strains of the hepatitis viruses. I do not know what the implications are for me of the precise nature of my infection.
32. I am also one of the people who received a letter a number of years ago about CJD. The letter said that a person had donated blood in the past and they had died. It went on to detail that at the point of death it had been discovered that they had variant CJD which is the human form of mad cow disease. The letter indicated that I had received blood from a contaminated pool. I understand that the concentrates I got as a haemophiliac were pooled from the blood of many people, sometimes thousands of people, and the blood of this person was part of the pool used to produce a blood concentrate I received. The trouble with CJD is that there is no test for CJD until you die. When you die they investigate the person's brain to see if they have CJD. I can't find out while I am alive if I have this condition. I may or may not have this and unfortunately the symptoms reported for CJD are crossed over with the symptoms that are known to exist for Hepatitis C. There is a lot of uncertainty for me because I just don't know what else has not been discovered before the heat treatment used to make the products safer came into force. Even after heat treatment, it may be that certain viruses could withstand heat treatment to a certain degree that Hepatitis C couldn't stand. The fact that I can't tell you that I have one virus or two or ten, is in itself part of the impact of having this infection.

ANONYMOUS

Section 4. Consent

33. I believe that I have been tested on more than one occasion without my knowledge or consent. It automatically follows for me that where there is no informed consent, then I wasn't given full or even adequate information about the testing, why it was being done or what that would involve. This comes on top of the fact that I am no longer confident in the processes that I freely allowed myself to be part of in being treated in the first place. I feel that my mum and I were not properly informed about the known or suspected risks. I trusted those involved who were responsible for my care. Against that background, I am increasingly of the view that some of the testing which has been done on my blood without my knowledge or consent did end up being used in research. This arises from the secrecy I have experienced and heard about from others. No doubt the hospitals and doctors will say that the testing without my knowledge or others' knowledge was for the common good. I am aware that others have had the same or similar experiences as a result of speaking with people in the same position as me. In recent times, for around the last 2-3 years, I have been part of an investigation group into older adults with bleeding disorders. I am part of this through Glasgow Royal Infirmary. I believe I am part of this group due to my age bracket. When I go for my regular reviews and they do the blood tests, they use that information and anything I report to help the research. I believe the research is to assist with understanding those infected who are now living to a greater age of later life. (When I was born the life expectancy for a person with a bleeding disorder was about 40 years.) I presume that research processes within this group are approved and reviewed by a research and ethics committee beforehand. However, I am not at all confident that such consensual rigour has taken place in the past.

Section 5. Impact

34. Coinciding with the period of my infection there has been an increase in the number and range of negative health impacts that I have suffered. In particular, I am tired all the time and would say that that was even more of a problem than when I was younger. There were times in the recent past when I could easily sleep for 16 or 18 hours a day and even when getting up, I did not feel like I was fully rested. I always look forward to going back to sleep again – not because I want to but because my body demands it. I still feel tired a lot. I have even had two different employers say to me *"You're looking really tired. Are you ok?"* They would encourage me to go to the car and have a sleep for an hour during the working day because they recognised they would get less out of me tired. I would feel terrible if I didn't have that

ANONYMOUS

sleep. For several years now I have self-medicated with caffeine tablets for when I need to get things done. I can sleep very easily on trains, buses, theatres and friends' houses. Tiredness is one significant impact which is detrimental because I have ultimately had to rejig my whole life to allow me to work around it. That is one main reason why I became a [GRO-B] [GRO-B]. I work when I know I can and if I need to have a day of rest I can do that and manage that time. For example, when I came back from the Preliminary Hearings in London for the Inquiry, I slept for most of the Thursday and Friday. I got nothing done. Even though I had loads to do, I just physically couldn't keep my eyes open.

35. Apart from the fatigue I also sometimes get confused. People talk about those infected by hepatitis C as having 'brain fog' and this is right for me. I get overwhelmed and feel the pressure of having to do things making me struggle. I lose the capacity to think logically and how to get through a task. This has increased lately and anyone who knows me can confirm that this is not like me in the past.
36. I also I have a constantly annoying sense of always feeling sore somewhere in my body. Today for example, my knees and my legs feel stiff and sore, often times it's my neck and shoulders and upper back, sometimes it's my lower back and I can't explain why I am sore. It is aches and pains all the time for me now and probably for the rest of my life. It was made worse at the point of receiving the failed anti-viral treatments (two attempts) which appeared to magnify all the negative impacts of having hepatitis.
37. I have been on anti-depressant medication for around 7 years now which is far longer than is recommended as far as I understand. I currently take sertraline, 150mg a day. I still see a psychologist, [GRO-B]. The pressure of needing to secure regular employment and having to deal with the effects hepatitis C is a lot. I still occasionally take panic attacks though as long as I stick to the regime I appear to be doing better and feel more stable in that regard. Those with Asperger's are more prone to mental health issues. Remaining on the medication appears to be keeping matters stable at present but I am still being reviewed regularly.
38. I have developed an under-active thyroid which was diagnosed about four years ago. I am not clear how long I had the under-active thyroid before diagnosis. I am now on medication for that on a daily basis. I have gained a great deal of weight during this time. I was previously known for being thin and I haven't recognised a change in my diet or lessening of my physical activity. I have had to change my wardrobe 3 times over the past few years because of the weight gain. This turns out to be quite expensive by nobody seems to take account of that.

ANONYMOUS

39. I have developed skin problems. I now have a treatment for my back which is erupting every so often. I use a specialist shampoo which is actually used topically for such skin conditions and is prescribed. It helps the condition. I also get Canesten cream for other eruptions wherever they erupt. It is now just my GP that deals with this but I did see a specialist at GRO-B he expected I would need to return for a specialist review.
40. I have osteoarthritis in various joints, manifest as lumps and bumps all over the place which has come up at the same time as these other problems. I developed problems with these at the same time as I was receiving Interferon and Ribavirin treatment, which could be another contributing, complicating and co-morbidity factor.
41. I have headaches that I am getting treatment for but I am using painkillers to manage the aches and pains, due to my haemophilia. I have the beginnings of serious arthritis problems I believe. The normal treatment is steroids for my type of arthritis but that is contra-indicated for haemophilia. So for me it is all about pain management. Often I take painkillers that are meant to treat the pains in my hands, head and knees at the same time. It also sometimes helps with the back and shoulder pains. I am fortunate compared to some people who have a whole raft of medications that they need to take on a daily basis. Maybe, it is also good that I have chosen to live a life without alcohol and tobacco because I have tried to keep my liver as healthy as possible whilst recognising it needs all the help it can get because of the hepatitis.
42. I also have hydrocele problems, which is the gathering of liquid water mainly in the scrotal area. I am advised against treatment at present because the risk of the surgery is significantly more dangerous for haemophiliac patients. The risks through surgery would outweigh any benefit. Although this can be uncomfortable it is mostly manageable. It does lead to further worries about missing the early signs of cancer due to the difficulties with regular self-examination because of the complicating factors.
43. I have a varicocele too. I have this in my scrotal area. It is to do with veins in the blood carrying areas of the scrotum, specifically when they get blocked. As before, no treatment can be identified that is sufficiently safe. It is annoyingly uncomfortable.
44. I have vitiligo, which manifests as white pigments on my skin in parts of my body. I have also developed tinnitus, again as with the other health issues listed, I understand these can be a side effect from the virus and/or the treatment.
45. Taking all my health problems together, you would expect that a man going through his 30's 40's and into his 50's would maybe experience one or two of them but to have all of them

ANONYMOUS

appear at the period when the hepatitis started and the treatment followed, means that the conditions I have detailed are having more of an effect on me. There is evidence to tell us that you can have these side effects with the treatments. I would suggest that collectively, this is a strong indicator, that I have been negatively impacted, both by hepatitis C and by the failed attempts to treat me through anti-viral therapy.

46. I have views and suspicions related to the new anti-viral treatments but not particularly about the availability of treatment for my infection. It is more about the blanket claims of these being a 'cure', about them being safe, and having no side-effects. My experience makes me doubt. If I am right to doubt then that is an issue of ongoing public health concern. If I am wrong then that is an issue for the Inquiry since it demonstrates a chronic trust issue based on past behaviours of the State.

47. The first anti-viral treatment I received (in the early 2000s) was Interferon. I was told that there was less than a 50% chance that it would cure the hepatitis but the chance of it working was worth it. I had to self-inject 3 times a week and it was to go on for a year possibly around 2002 to 2003. The first time I took it I was pleased at my ability to have given myself the injection. I had a social event to attend that night. As the evening wore on I started to feel really unwell, like a very very bad flu. It got so I could hardly move. I had to leave early. I was forced to crawl into the house because I could not walk. My wife said she thought she was going to lose me. I was shivering uncontrollably and very ill. The next day we phoned the hospital. They said that some people have a bad reaction to the treatment. They suggested that on the days I was going to be taking the Interferon that I take two paracetamols and go to bed. At the time I had two young children, a busy responsible job and a position in the community. This was significantly detrimental to my ability to function. That happened 3 evenings a week where I lost time due to having to take the Interferon injection. There would also be a residual impact for the day or two after taking the injection where I was feeling pretty rubbish. That went on for three months and then I was tested to see how I was responding. I was told that it wasn't having an effect and I was to stop the treatment. I was frustrated that I had gone through all the difficulty for three months and it hadn't worked. I have to say I was also glad at the same time because the last thing I wanted was to go through that treatment for another nine months.

48. Then, in 2012 (I think), I was offered 'combination therapy' which was one injection of Interferon a week and tablet (Ribavirin). I started that and the same horrible things happened again as when I had had the Interferon alone. I was trying to live my life and I had an idea of what I could expect this time. I prepared myself for taking the medication. The rates of cure were higher than previously with this medication regimen and so I took the treatment. Then;

ANONYMOUS

three months into the treatment, I had terrible pains. I attended my GP and I was told I had a grumbling appendix. I was told I would have to stop the treatment because I had to get this appendix out. I wasn't able to have treatment while I was having an operation as the treatment caused my white blood cell level to drop. I then had the near fatal appendix operation that then became an internal bleed that almost ended my life. I think this was definitely as a result of the treatment prior to the surgery and the low white blood cell level caused by the treatment.

49. My sense was that by this time all the doctors and nurses generally acted in good faith and wanted to rid me of this virus. The gastroenterology department at Glasgow Royal Infirmary worked closely with the haemophilia department there. These departments had a good relationship as far as I could tell and they were very supportive of me.
50. I do believe that the Doctors underplayed the potential side effects to me about treatment paths. This was obviously not helpful. I was one of those people that would read the slip of paper inside the packet of the medication to make sure I understood what I could expect. I was amazed at the number impacts these medications could cause. I couldn't say that anybody treating me was not careful. They cared about my treatment at the time but I would say the underplaying of the side effects was the main issue for me. As I was not told by the medical staff that I might suffer these effects, I did not think they would affect me. As a result, I was completely unprepared for how bad it would be to take any treatment.
51. The background to all of this, stemming from the late 70s and early 80s, was that Factor VIII was going to change our lives and it was this great thing. I think it has been completely detrimental to the community that this was all that we were told. On top of this, I certainly feel that the possible side effects of the treatment for hepatitis C were not explained to me. Half the haemophilic population have died from the virus and the treatment side effects. On occasions it has nearly been responsible for my demise. In terms of anti-viral treatment, I still feel as though I am being pushed towards treatment because it doesn't involve injections and is taken for a far shorter time period. I am being strongly encouraged to take these pills but my experience of these medications is extremely negative and my sense is that they haven't been around long enough for long term impact studies to be done. My experiences in the past make me think I am again being kept in the dark. As I try to overcome the effects of what has been done to me already and try to manage my life in terms of being self-employed, I am currently reluctant to expose myself again to treatments. I am already hearing from people I know that there might be more side effects or more impacts than we are really being told about. The trust is just not there to allow me to make the 'right' decision for me.

ANONYMOUS

52. In the broader context of engaging with healthcare providers, every time I go for a blood test or any kind of medical procedure then I need to make sure that they understand that I have hepatitis C. As a matter of public health I also need to notify them of the potential CJD status which means people take extra precautions to make sure there is no cross contamination. In the surgical procedures that I have had and because of my potential CJD status the medical equipment had to be quarantined. I understand it is policy to sterilise equipment for someone not infected and quarantine where someone is infected. In my own life I know that the infected community is often not offered certain surgical procedures because it's too expensive due to the amount of treatment equipment which has to be quarantined. I think that hospitals managers and doctors make economic decisions not to treat infected people in certain ways due to cost. I know one man, GRO-B, required an intervention due to arthritis and he was basically told he would never be treated because of age and infection. If they treat you, that equipment basically has to be quarantined which is too expensive.

53. I have depression and I had been under the care of a CPN. I am now monitored by my GP. I have had sessions with a psychiatrist and two different psychologists because of issues around confidence, stigmatisation, the stress, the unknowingness of it all and sometimes the panic attacks. Sometimes I would be shopping and I would just feel like I could not cope with that setting. I could not cope with being away from the safety of the couch or bed. I have been known just to leave my shopping or trolley and walk out of the store. There was one time when I was helping someone with something at their work and I was the last to leave. As I started to leave I started to have a panic attack and after about 45 minutes of not getting over this I thought I just needed to get home. I got as far as the motorway and I thought I was a danger to the other road users. I pulled off the motorway and I phoned someone and I told them how I was feeling. They sent an ambulance for me and the ambulance took me to hospital. It was a severe panic attack. I was having problems breathing and hearing what was being said to me. I am normally able to overcome pretty much anything. I am pretty resilient that way. I attribute this to my Asperger's Syndrome because I don't have to attach any kind of significance to things. I was having panic attacks a lot over the last few years.

54. Having hepatitis C has got to be up there as one of the most negative things you can tell someone about yourself. It was a contributory factor to the breakup of my marriage. It is a factor in my restricted social life. I worry about what people think when they discover that I have a virus which is in their minds associated with very negative social behaviours such as illegal drug use and/or unsafe sexual practices. Whether that is true or not, it is the perception of the public.

ANONYMOUS

55. When I go to the part of the hospital where they are monitoring hepatitis, I am often left sitting in a waiting room. All the posters are about "*how to dispose of needles properly*" and "*how to minimise passing an infection onto someone else*" and sometimes some of the people you share that waiting room with are clearly there for very different reasons. They are there because they have dependencies to alcohol and drugs which is the reason why their liver is so badly affected. The common thought among people like me if I am sitting in that waiting room is what if my neighbour walks by and sees me there and puts 2 and 2 together and gets 10. It is really embarrassing. I end up not telling people and having a life where I have to keep making judgements about what point I tell people things or not tell people things about my health. I also worry about what would happen if they found out and whether I would feel I should have told them earlier. The worry is there that if I tell a person and I didn't really need to, that they would then treat me differently. If you are a young person who starts to get into a relationship with someone, at what point do you tell the other person? If you make the decision to do it too early you may put them off and you could have had a great relationship but it is lost. If you leave it and do it later, there is a chance that they will say that you should have told them earlier. That's a terrible burden to have and living your life with a stigma which you can't fully explain yourself is a real challenge. I think it's one of the most under recognised areas of detriment that people like myself have suffered.
56. It is entirely possible that by the time I went to university (1979) I was already infected. I certainly remember going through a phase where I was hardly able to stay awake in lectures. I went to the library to study many times and I would end up with my head on my desk. There was a terrible effect on my quality of work. I was on one end of the spectrum, struggling to get through, always looking for excuses to submit things late, not really able to take in what was said in a lecture or tutorial and yet at other points I was producing work that achieved the top mark in the whole year. I would suggest that if I was able to produce a quality of work that is the top of the whole year then the impact on me was arguably that I didn't realise anywhere near my full potential. I never got to finish university and never got a degree. Most people when they find that out I don't have a degree can't believe it. They just presume I have a degree because of what I do and where I am. I just couldn't finish the degree as I struggled with staying awake too often. And I was not a student who went out drinking and going to parties as most people assume all students do.
57. It is one of the great sadnesses in my life that I never got that degree. I went to a school in a fairly poor area of Glasgow, so much so that it had been so long since someone from that secondary school had been to university they didn't even have the application forms. I was the great white hope that at last someone would finally go to university. I did but I couldn't

ANONYMOUS

finish. Who knows what I could have achieved in a professional capacity if I hadn't been labouring on with the burden with the infection which was then multiplied by failed attempts to treat it. That infection was not in any way because of a poor lifestyle choice on my part at all. I went to Glasgow University for a year and that was where I began to struggle. Then I took a couple of years out to get well. I went to Strathclyde University where I successfully negotiated 1st year but started having problems in my 2nd year. I had to repeat 2nd year and ultimately had to drop out at the end of the second 2nd year. At Glasgow I was doing physics, chemistry and maths which are not easy subjects. When I went to Strathclyde I was pursuing a joint degree in psychology and philosophy, also doing sociology, statistics and politics. I couldn't finish either degree course.

58. When I had to finish university prematurely, there were a number of years where I was 'floating' because I couldn't do anything. I didn't know what was going on with me generally. I then found a niche in the voluntary sector which had a degree of flexibility in employment arrangements. I focussed on policy development, income generation, training and campaigning. They allowed me to be part of what they did and they recognised the skills that I brought to them which would have otherwise been backed up by a university degree. I have worked in those voluntary settings for a while, did well in each location, and moved from job to job a couple of times. I never had to apply for those jobs as I was head-hunted from one to the other. I ended up in a senior role in a national organisation being paid over £40,000 per year and then things just got on top of me. Health issues mainly related to the viral infection was a big part of that. The bosses at work were visiting me at hospital, giving me reassurance, things like that. I ultimately had to just stop working. I stopped working for 4 or 5 years and then spoke to a couple of friends of mine and through various circumstances with those friends we decided to make a go of this venture where we are self-employed but working in a loose association to maximise our respective skill sets. During that fallow period I earned nowhere near the previous £40,000-plus per year. I'm not even halfway there yet, but at least I am doing something. That is because of my determination not to lie down and submit to this illness. I have been fortunate enough to have opportunities to allow me to move into a field where if I have to take a couple of days off, I probably can do that reasonably easily. I can work as long as I want, wherever I want. But I have had to make significant changes to my previous career progression. I could have expected by now to be in line for a position as a chief executive of a national voluntary organisation probably.

59. There was a significant impact on my relationship with my wife after the conversation about hepatitis C. It became clear quickly I had come with baggage. When we looked at getting a mortgage we could only look at a certain type of package as I couldn't get the life insurance

ANONYMOUS

cover we needed. We could only go for a repayment mortgage and that was a higher cost than the other types of mortgage. That is not a good start when you're trying to make your way in the world. [GRO-B]

[GRO-B]

[GRO-B]

[GRO-B]

We were traditional. We didn't live together until after our honeymoon and suddenly the thing that was going to join us together was greatly reduced. Then there was the whole thing about being careful. It certainly was not a positive thing for our relationship.

60. In terms of children I would say we tried to protect the children from getting concerned, but sometimes they would wonder why dad was still in bed. [GRO-B]

[GRO-B]

[GRO-B]

There were things that normal dads did with their kids which I could not. [GRO-B]

[GRO-B]

[GRO-B]

[GRO-B]

61. In terms of family, my mum was always worried as she knew something was wrong. If I was talking to her then halfway through a conversation I would be falling asleep. That is not normal when you are 40. She would worry an awful lot. [GRO-B]

[GRO-B]

[GRO-B]

[GRO-B]

I am 56 now. I think that bleeding disorder people living longer is an area where the medical profession is still coming to terms with managing. The contaminated blood scandal is a major complication to getting to grips with this phenomenon.

62. My infected status has had the effect that I am not allowed to be a first aider or do things like I would like to do. I have to tell people about my status at work. I need to tell the first aider and HR people. You never know what reaction you are going to get to that.

Section 6 Treatment/Care/Support

63. I have faced difficulties and obstacles in relation to treatment. I have also had issues surrounding accessing counselling or psychological support that has been offered. I didn't feel at the time that I gave enough weight to the impact of what I had been told about being infected. I put that down to the way I was told I was infected and the little weight that the medical profession put on telling me of my infection. Due to my infection being treated as if

ANONYMOUS

it was not serious the psychological impact wasn't trauma like a single instance of something like being told you have cancer. I had a gradually growing awareness that I had a virus that was life threatening and certainly life limiting. It became something I had to take account of in almost everything I chose to do including where I lived, how I lived, what I did in terms of work, what aspirations I should curtail because of what might happen. I remember when I was at university having my unusual health struggles, they sent me to a psychologist because they thought there was something wrong with me in that regard. I think they thought that I was making it up and they couldn't see anything wrong with me. The psychologist said within 2 minutes that there wasn't anything that I was mentally doing to make myself ill and they couldn't help me. Of course, at the time I didn't know about my Hepatitis C status.

64. If I was to go for laser eye surgery this would be a 'no' as well because of the potential of the equipment being infected. This is just one simple example which illustrates how I feel excluded from society as I cannot access things like this. It is hard enough to be socially integrated when you have a Spectrum Disorder, but having a 'dirty' virus is possibly worse.

65. I know that there is a scheme in Scotland based in Edinburgh which is only one person for the whole of Scotland for psychological support. The person doing this is a Psychologist called Graine O'Brien for a period of 3 years. I think it came about through the Financial Review Group. I could probably avail myself of that but I haven't to date. I have used my GP as a mechanism for getting access to a clinical psychologist and I have sessions every 2 weeks when I go over a number of issues. It often touches on the issues surrounding my infection and anxiety. The accessing of this professional support is something I pursued on my own because I am able to advocate for these things. I do a lot of work with my charities for making the case for something happening or for getting funding. I worry for those who don't have that capacity.

66. There are a number of people who have difficulty accessing benefits who are infected by blood products:

	GRO-B
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	GRO-B
	GRO-B
	GRO-B

GRO-B The whole area of benefit provision for people whose health and capacity are reduced due to viral infections is problematic. Hopefully the Inquiry will highlight this as an area where the State can improve its support and approach to people who cannot operate without welfare help from the very state that is making it difficult for them to access that

ANONYMOUS

support, even though it cause the problem in the first place. That is a real 'double-whammy' and rankly unfair.

67. In terms of general condition management and support to maximise my capacities, I find that I can more readily get treatment for pain rather than an intervention to tackle the actual problem to being addressed. I feel that the way the State and its agents are set up, it means there is no holistic and effective way of dealing with a person who is infected. The NHS might acknowledge the damage of the infection they caused, but the DWP are not set up to respond to this; quite the reverse, despite the inherent cause and effect.

Section 7. Financial effects

68. By the time the first payment schemes for Hepatitis came about I was already actively involved in campaigning work to seek support to overcome the consequences of infected blood products and blood transfusions. I was involved in the lobbying of Malcolm Chisholm, the then minister for health and community care in Scotland, for financial support for infected and affected individuals (which they were very careful not to call compensation). This resulted in the announcement from Westminster, almost simultaneously to Mr Chisholm's announcement, that the Skipton Fund was being set up. The Skipton Fund started to make an initial one off payment of £20,000 to people who could demonstrate they had received contaminated blood and had been infected by Hepatitis C. I received this around 12 years ago.

69. I received money from the Caxton foundation that allowed a top up to my income. I received three or four of these payments to help with a car, cover for a break in and some household goods which stopped working. I received those payments between 2010 to 2014 which broadly coincided with the time I was not able to work myself.

70. My wife made sure that the big things were dealt with after we got divorced GRO-B
GRO-B The money I got from the early schemes, from benefits and from when I was working in decent paid jobs, paid for the house we lived in and the flat I moved into when we separated. These homes are fully paid off. thankfully. I only wish all of my fellow contaminated blood victims could have some of the same security. Most do not. I have in the last six out of seven years lived on less than 20% of what I used to live on. I received a £30,000 payment from the Skipton fund which was authorised by the Scottish Government in 2016. This was in response to the Financial Review Group's work. The Scottish Government had not set up the Scottish fund at this time so the Skipton Fund used its established systems to effect

ANONYMOUS

payments. At the end of the ex-gratia devolution process for payments that £30K was all but gone. That is part of the reason I had to get back into the world of work as the money was running out. I had to cash in my ISA and downsize a few things. I don't do holidays. I have not been on holiday for over a decade. I don't do things that people do with their free time when they have it. I work a lot to try and build up my business but I don't have very many savings. I don't have the security of insurances or pensions at all. I don't have a pension. I don't really have anything apart from my flat to hand over to my sons if anything was to happen to me. My oldest son has classic autism and will always need help and support. I always thought that my main aim as his father would be when I retired or died that I would leave enough of a legacy for him to be taken care of properly. That has not been possible. There have been times earlier in my life when I was struggling but I did not know why I was struggling. I had to rely on charitable help because of my inability to do things that I thought I should be able to do but couldn't, mainly due to contaminated blood.

71. I am now registered with the new Scottish Infected Blood Support Scheme. I have had £1,000 a year for the first few years. The first payment would have been around April 2016.
72. When the Skipton fund was set up we were led to believe that it would try to make their processes and interactions user friendly. When the Governments introduced the Skipton Fund they made it a bureaucratic process. It was a means tested process and I remember having a public argument with the Chief Executive of the Skipton Fund about what they were doing and the poor execution of the Fund when it came to supporting victims. I found that when I spoke to the staff, they were mostly ok, but you really had to jump through hoops, voluminous paperwork and provide significant information about yourself to prove that you were in relative poverty as a result of the contaminated blood infection. The same state that is asking you to grovel for money is the one that infected you. That didn't feel good and their reactions were awful. There are times I could have made claims for financial assistance but I couldn't face the begging bowl process.
73. The new scheme in Scotland which is meant to be easier is not. In my opinion it shouldn't be a scheme based in the same department of the same organisation that caused the initial infections to begin with. It is a conflict of interest when a government agency is handling the scheme and making judgements about it. The Scottish Government were supposed to design a user friendly form and the first thing the SIBSS did was to take the design of the previous scheme from the Skipton Fund as the model for the new forms. They adopted the worst of the old schemes instead of the best. They were meant to have a review of how they delivered the services and that was somehow forgotten about. I don't feel any questions have ever been answered properly about the schemes and the design of the schemes that I raised

ANONYMOUS

when we first met the senior staff with oversight of SIBSS, or the relevant Scottish Government officials. The old Skipton scheme was not fit for purpose in my opinion. The new scheme in Scotland is might appear like a gold standard compared to the previous Skipton scheme. However, it is also not good enough in working with infected people in my opinion. It should be overseen by a separate organisation independent from the Government. Whatever the results from the Inquiry I think they need to make sure the Governments learn the lessons of the few things we got right in Scotland with the financial scheme as well as what Scotland got wrong both financially and through the Penrose Inquiry.

74. The schemes should not be means tested and health tested. I believe that the level of the scheme a person is on being determined by how much your liver has been impacted, and how ill you are, reinforces the negative impacts of being infected. There should only be one question, namely "*were you infected as a result of NHS treatment.*" I would be prepared to get a smaller amount of money for me if everyone got treated fairly to reflect that their lives were so severely impacted. None of the current schemes are fit for purpose and the Governments should not be the gatekeepers. This is what I think of the schemes in place at present.
75. When the trusts were set up, it was sold to those infected as the best way of ensuring infected people were helped. What we need is an independent body that can assess without fear or favour how to provide support to people in a way which is fair, how to do it in a way that is more secure and maintains a level of dignity for those involved so the infected person is not going "cap in hand" for support.
76. I did a calculation based on my own experiences in terms of what I lost from potential earnings from the point when I was infected and began to experience detriment by infection. Up until the point where I can retire I calculate that if I were to be compensated for lost income as a result of being infected, not even including compensation for all the less tangible things like the mental health impact, loss of work opportunities, loss of family friends, increased costs in terms of insurance and heating bills, then the total would amount to over £600,000. That's a conservative estimate based on actual loss of income earnings. The schemes don't even recognise that loss, particularly in the context of historic loss, including loss of opportunity. If people think that the scheme should just make sure they aren't in poverty this is a slap in the face. Many of the infected are people who are very competent, very able, influential, having had lots going for them, their own businesses, the beginnings of great careers or good educational starts in life and that was taken away from them and they were left to be dependents.

ANONYMOUS

77. We need to find a way of identifying the average salary of a British person and making that the starting point of the annual payment that goes to an infected person or to the affected people such as widows and those who have been secondarily infected. The payment should be tied to inflation. There should be a scheme that includes the government underwriting insurance for infected people so they can secure financial products, holidays and other things that people can normally enjoy had they not been infected. There should be access to priority treatment opportunities through the NHS and other resources that allow people the dignity to lead a life. That is the scheme I am looking towards. That would be what is fair, in my view.

Section 8. Other Issues

78. In terms of supplementary evidence I don't personally hold very much documentation. I have lots of minutes of meetings of the Scottish Infected Blood Forum (SIBF), Haemophilia Scotland, West of Scotland Haemophilia Group and Haemophilia Group forum. I don't have minutes of meetings other than open meetings and meetings related to our activities with campaigning. There are some campaigners like Bruce Norval and Alice Mackie that have research information and know more of meetings with doctors and others regarding things like heat treatment. I am in the process of going through what material I do have at home. If I discover anything I will pass it to Thompsons who can collate and check if it will be relevant. I will be happy to provide a further or supplementary statement if this becomes necessary.

79. I wish for Thompsons Solicitors to recover my medical records on my behalf and that Thompsons Solicitors and I be given the opportunity to review these in full. It may be that I will wish to give a further statement to the Inquiry once my full records have been made available to me.

80. I wish for Thompsons Solicitors to recover my medical records on my behalf and that Thompsons Solicitors and I be given the opportunity to review these in full. It may be that I will wish to give a further statement to the Inquiry once my full records have been made available to me.

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

- a. What was or should have been known by the doctors who were responsible for my care about the risks of me being infected from the treatment I was given as a child?
- b. Why were my Mum and I not told about the risks of that treatment or the alternatives available for me at that time?

ANONYMOUS

- c. When was my blood tested for hepatitis C, HIV or any other virus?
- d. Who knew I was infected before I did?
- e. Why was I not told until years later that I was infected?
- f. Could I have been given more information about the likely consequences of my infection earlier than I was?
- g. What genotypes of the virus am I infected with?
- h. If I am multiply infected, how did that happen?
- i. What impact does this have on the future for me?
- j. Why did I receive correspondence about possible infection with CJD?
- k. How likely is it that I am infected with that condition? What does that mean for me?
- l. To what extent are my various medical problems caused by infection due to my exposure to blood products or has my ability to cope with them been adversely influenced by that exposure?
- m. Why was I not told about the known side effects of the treatments I have received for my hepatitis C infection?
- n. Why is so little weight placed on the mental health consequences of infection with hepatitis C in decision making around the provision of treatment and financial support?

Statement of Truth

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

Signed

GRO-B

Dated

19 April 2019