



Witness Name: Pauline M Reid

Statement No.: WITN2247001

Exhibits: Nil

Dated: 2<sup>nd</sup> October 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF PAULINE MARGOT REID

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 2<sup>nd</sup> October 2018.

I, Pauline Margot Reid, will say as follows: -

#### Section 1. Introduction

1. My name is Pauline Margot Reid. My date of birth is the GRO-B 1967. My address is known to the Inquiry. I am married to GRO-B with two grown up children, GRO-B and GRO-B. I am not working now due to my ill health. I am now considered by the Department of Work and Pensions as falling into the category of long term sickness. This means that I am in a group of people that are not fit for work and are unlikely to become fit for work in the foreseeable future. I intend to speak about my original condition of Von Willebrands disease and being infected with hepatitis C as a result of receiving contaminated blood products. In particular, the

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nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and I and our lives together. I wish to be anonymous.

**Section 2. How Infected**

2. I have Von Willebrands Disease, type 2M. This is a hereditary condition that has been passed on for at least 5 generations in my family [GRO-C]  
[GRO-C] I was diagnosed when I was 18. When I was 12, I was tested but I was considered to be borderline and did not meet the diagnostic criteria at that point. Throughout my life I have had problems with nose bleeds, mouth bleeds, severe bruising and menstrual problems. The levels of my disease have remained stable throughout my life but the levels can vary from day to day. I maintained very good health and did not require surgery or dental work until the point when I went to hospital to give birth to [GRO-B] in December 1990 at Ayrshire Central Hospital, 81 Kilwinning Road, Irvine.
3. I was given Cryoprecipitate on the [GRO-C] 1990, purely as a precaution in childbirth. I was not having a bleed. It was given to me just in case. This was when I was infected. I did not know the name of the product at the time or the side effects, I was not told any detail until much later on after I knew I was infected. I put my faith in the doctors and did not question them when it came to treatment. I was a 'bleeder', so all that was ever really discussed was confirmation that my treatment was ready for me in the fridge at the hospital. They didn't say names of the products and I didn't ask. When I gave birth to my 2<sup>nd</sup> child, I was given another product known as Haemate P, which is believed to be safer. I was told that this was a safer product by the Haemophilia Unit at Glasgow Royal Infirmary. I cannot

remember the name of the doctor who told me this. By the time I had given birth to my 2<sup>nd</sup> child in 1995, I knew I had been infected from the Cryoprecipitate. Even then, there was never any discussion about the treatment, it was simply a case that Haemate P would be the product that would be used.

4. I was checked more regularly than many other pregnant women due to my bleeding disorder. I was under the care of the Haematology Unit at Crosshouse Hospital, Kilmarnock and the Haemophilia Unit at Glasgow Royal Infirmary. I gave birth both times at Ayrshire Central Hospital. I am uncertain which doctors prescribed the infected blood products to me. I assume that the treatment plan came from the Haemophilia Unit at the Glasgow Royal Infirmary as this is where prior treatment plans had come from for other family members. Crosshouse Hospital Haematology Unit, would have had involvement with the plan as they are my local hospital. I would need to check this in my medical records. At the very least, they would have agreed to the plan. I never viewed the treatment plan so I cannot say for certain who wrote it. It would likely have been agreed and reviewed by more than one Consultant and more than one hospital. My plan would have been given to Ayrshire Central Hospital because that's how the Haematologists would communicate exactly what they wanted the doctors at Ayrshire Central Hospital to do, e.g. what has to be given, when, how much, how many times and for how long afterwards, as usually, treatment is continued for several days after giving birth. I was informed that the product was ready in the fridge well in advance of my due date. Professor Lowe was the head of the haematology department at Glasgow Royal Infirmary in 1990, I believe. My registered GP surgery is GRO-B

5. The infected product could only have been given to me during the birth of GRO-B because I was pregnant with GRO-B when I was told I was infected with hepatitis C, so it would have been GRO-C 1990 I was infected. At the point I gave birth in 1990, I had never

received treatment before. I had never had a blood transfusion before that time I was told I was infected when I was pregnant with GRO-B approximately the end of 1994.

6. I was given Cryoprecipitate and accepted this was to be the correct course of action as I understood that this was normal procedure for anyone with Von Willebrands disease as a precaution. This was done and is still standard practice. The treatment is given to raise your clotting levels so hopefully your blood clots after a procedure/childbirth. When first diagnosed with Von Willebrands, I was tested to see if I could receive DDAVP as this is the man made chemical clotting agent, free from blood and thus free from blood borne viruses. Unfortunately, I did not respond to this so it was deemed this product would not be appropriate. When I required treatment for the first time in 1990, cryoprecipitate was selected by the doctors instead. There was never any discussion about which product was to be used or the possible risks of infection at the time. I only know now, that in December 1990, the risk of infection with hepatitis C was widely known in the medical profession. I was infected needlessly. I could have been given another product or been informed of the risk and been allowed to make the decision myself on whether to take the cryoprecipitate or not. This has always made me angry. Everyone talks about infection in the 1970s and 1980s but what about people like me who were infected in 1990, when the facts were known and the system was about to be changed? I am assuming, I am not the only person infected in 1990. Ignorance and being unaware cannot be claimed at this date. Facts were established about the risk from the product which I received and the way forward by testing for the virus in the collected blood was already or should have been in place, as far as I am aware. Mine was a needless and irresponsible infection. In fact, in my opinion, cases this late are gross negligence. I was given the product after my child was born. It should have been given to me before I gave birth. They just didn't get around to it. It was ready in the fridge and we had asked for it when we telephoned the



hospital before leaving home. There was a room full of medical professionals and my husband [GRO-B] was saying that the baby was born and I still hadn't received the product. He was getting rather anxious, asking where it was and explaining it should have been given to me before delivery. In the midst of this mayhem, the surgeon and a midwife had a heated discussion. The midwife stated that it had been fifteen minutes since delivery and that if the placenta was not removed within this time it would require surgery to remove it. The surgeon was adamant he was administering this treatment. With hindsight, I wish he hadn't bothered at all.

7. Throughout my life, during the pregnancy in 1990, during the birth, after the birth, absolutely no information or detail was provided to me about the risk of infection. From my point of view, it was just the same product that everyone else in the family had been given for procedures. I had never been in hospital before. I had no reason to question the professionals. Why would I? I trusted them to care for my unborn child and me. No risks were mentioned. If they had been then I would not have taken the treatment and I would have taken my chances. Both my older sisters and my mother who have Von Willebrands had no treatment when they gave birth and they survived with no ill effects. My mother gave birth at Ayrshire Central hospital and my sister also gave birth twice at Ayrshire Central hospital.
8. I attended Glasgow Royal Infirmary for my routine appointment when I was pregnant with [GRO-B]. I cannot recall the dates of this, but it was in 1994. At the end of the appointment as I was leaving, the nurse handed me a leaflet and said something like "*Don't read that now, read it when you're back from your holiday*". I presumed this was a leaflet that all patients got. I read it and went on holiday. The leaflet contained very general information about hepatitis C. The next time I attended the clinic this was for an additional check-up due to my pregnancy. I was on my own and I was asked if I had read the leaflet. I said yes and then there was an awkward strained silence. The

consultant then simply said "You've got it". That was how I was diagnosed. There was no further information provided, there was not even a discussion about what was in this leaflet that I had originally been given before my holiday. They didn't tell me when they had tested for hepatitis, why they had tested for hepatitis; there was no request for permission to test me, they didn't say how long they had known I was infected, and gave me no information about when/how/where I was infected. There was no opportunity to even ask questions. I was then told that a biopsy would be recommended except I was pregnant so this was ruled out. I was then told that Interferon was a drug that was used to treat hepatitis but it was a very nasty treatment. That was the extent of the information I received.

9. Later on that day I got a phone call from my GP, Dr [GRO-D] he is now retired, who was shouting and swearing at me down the phone. He was saying, "Why didn't you tell me?!" and I was summoned to go to the surgery after it was closed at 6 p.m. He was screaming because I hadn't told him. I explained that I had just found out that day and that I would have told him if I had known. So obviously he had found out from the hospital at the same time as I did and he was not pleased. It made me feel like a leper being summoned when the surgery was empty. I really don't know why he was so angry. I had no idea what to do after the conversation with my own doctor. [GRO-B]'s doctor is not in the same GP practice, so we had to contact his doctors, pretty much in confidence, to ask if [GRO-B] [GRO-C] [GRO-C] Of course by this point I had [GRO-B]. I wondered, could she have been infected? [GRO-C] [GRO-C] What about the baby I was carrying, could he be infected? Nothing, no offer of help, no information. A lot of my family have received treatment and three of my family members in London were also infected with hepatitis C as they also have Von Willebrands. I know of things that have happened to them over the years which is how I learned about hepatitis C. My uncle was infected [GRO-C] My point of saying that is that all information

about the infection came from them and not from the medical staff involved with my care here in Scotland.

10. The only other information provided to me about the infection was that people are usually infected with hepatitis C by sleeping around, sharing infected needles or blood products. The very basic information in the leaflet wasn't even discussed. No one mentioned to me any risk to **GRO-B** to **GRO-B** or **GRO-B** I have been with **GRO-B** since I was 16 years old and I have only ever had sex with him. I've never been a drug addict and I had only received a blood product once. When Dr **GRO-D** finished shouting at me, the information that he gave me about hepatitis C was that I had the sword of Damocles hanging over me.
11. After being diagnosed, I had no further conversations with the doctors or anyone about hepatitis C for the next 23 years. I was told at some point I had spontaneously cleared when a PCR test came back negative. I cannot recall when this took place. I was not told that the PCR test was being carried out.
12. I think the leaflet I was handed just before I was diagnosed, would have probably under estimated the effects and scale of this infection. It said something like, it could impact upon your liver. It would have been more accurate, I think, if it had said it probably will. The information was just inadequate, the reality is that the treatment is horrendous and at the time, not particularly successful. Potentially, the infection will kill you. The information in the leaflet was definitely not accurate enough. It didn't really terrify me until soon afterwards when I saw what was happening with other family members down in London. Other than that there was no information given, which is totally inadequate and unacceptable.
13. I think that at the very least from the moment that a virus of a Hepatitis nature was proven to be blood borne, all high risk groups, at the very



least, should have been made aware of the potential damage and future risks. Even before there was a clean screening programme, people should have been informed. This would have meant that, 1. You were informed and 2. You could have made an informed decision as a patient whether to use the blood product or not. There was a 6-month period in 1990 where the doctors knowingly continued using cryoprecipitate on people after declaring that this treatment was extremely risky. I only became aware of this after the fact. This was through until the end of 1990. **GRO-B** was born in December 1990. I was never told about this even though it was obviously widely known at this late stage in the Haematology world. There should have been a face to face conversation about the risks of the treatment and the alternatives available to me and about my infection when it was known that I was infected. To this day I still don't know how long it took between testing and telling me that I was positive. I accept that it was early days and that people didn't really know precisely what they were dealing with, however the information sharing and the ignorance was extreme all the way through. Just because they did not know everything about the infection and its risks does not seem to me to be a good reason not to tell me anything about the risks and the fact of infection. I had an incident when I was breastfeeding **GRO-B** in 1995 shortly after I gave birth. I had only had him for a day and a ward doctor said to me "*I don't think you should be breastfeeding.*" They had nine months to say that to me. By this time he had been fed several times so I continued feeding but you worry about whether you have infected him through the milk. The comment about breastfeeding was disgusting and traumatic.

14. It is unclear to me if the way I was told about the infection was intentional. They didn't seem to know too much at the time. However, I should have been asked or told that they were doing a test for hepatitis C. The results should have been communicated immediately, in person, in a direct, unambiguous manner. Handing someone a leaflet to read, not saying specifically it's for you, with no proper follow up, no



proper information about what this infection could mean, no information on how I could have infected my family and no information about how this could impact on childbirth with [GRO-B] was just beyond poor.

15. Someone should have said to me to get [GRO-B] tested, told me whether my unborn child would be infected or not, discussed arrangements for the baby [GRO-B] to be tested and the risk to [GRO-B] and if I had passed the infection onto her as a baby. I would have liked the opportunity to have had that discussion. If someone had said your baby may have it, they should have tested her. There were lots of conversations about the Von Willenbrands disease, however, there was never a discussion about the hepatitis risk issues with anyone.
16. The only reason that [GRO-B] [GRO-C] [GRO-C] For at least four years since infection, I'd been having unprotected sex with [GRO-B] I do know now that this is a real risk because my uncle in London, who was infected and has now died, [GRO-C] There was no discussion about how not to spread the infection. I don't know why this conversation never took place. Maybe, in the early days there was limited knowledge but doctors knew how hepatitis could spread. It would have been a logical conclusion that the infection could be sexually transmitted. Doctors did not seem to want to talk about it or engage at all. I think it is possible they felt responsible and embarrassed. I do not feel like I want to blame the Unit; I was given the product available at that time. However, this is on the assumption that the Unit were unaware of the situation with the contaminated blood at that time and I find it very difficult to believe that they were unaware at that late stage. If they did know, my opinion of them would not be the same. They would then be culpable and complicit. Irrespective of this, not discussing the risk of spreading the infection was reckless.

### Section 3. Other Infections

17. As far as I know, I have only been infected with hepatitis C. However, I've had the 'mad cow notification'. There is a letter that came out to some people, including myself, telling them that I am at risk of having contracted Variant CJD. The letter went on to say if you have surgery, any surgical instruments used in procedures will require to be incinerated rather than sterilised. This letter told me that I had to make sure that anyone treating me, knew about this to avoid spreading a potential infection. There was no support offered in this letter. My recollection is that the notification came from a government body. I was not given the opportunity to discuss this letter with any medical professional I couldn't tell you when I received that notification. It was many years ago, more than five years ago. The NHS should be able to provide the date if required. To the best of my knowledge there is no test, treatment or cure to Variant CJD. It is always fatal and can lie dormant in your system for years. The only way to confirm infection, is a post mortem. [GRO-C] in London has been told by his doctors that once he dies, they are going to do a post mortem on him to see if he has Variant CJD.

18. I haven't even tried to look into this any further. I find the hepatitis C distressing enough without contemplating CJD. To add insult to injury, the notification advises you not to breastfeed. Yet again, it is a bit late as my children are now grown. There is an implication here that I could have infected [GRO-B] and [GRO-B] with CJD. It is things like this that have meant I have suffered from mental health problems for more than 20 years. I presume a copy of that notification has gone to my GP and my GP has never even mentioned it once. The details could be confirmed by looking at my medical records.

#### Section 4. Consent

19. None of my family members with blood disorders were told about this infection. I think they certainly must have been automatically tested for hepatitis C, like me, without their knowledge or consent. People should have been given information about this infection prior to testing them. I have definitely been tested without either my knowledge or consent. I walk into the Haemophilia Unit and present my arm for routine blood to be taken. I am under the impression that the usual tests are being done, e.g. a full blood count and clotting levels are being checked. They never actually tell you what they are checking for. They could be testing for anything and obviously did. I knew nothing about hepatitis C until I was handed the leaflet.
20. I believe it is entirely possible that I have been tested for research purposes. As previously stated, I have been tested without prior knowledge or consent and they don't tell you what they were drawing blood for. They could have been doing anything. I assume all bleeding disorder patients have been tested. It is a possibility that infected donors had their recipients traced by batch number and the authority responsible asked for testing of those recipients. I can only assume that all the Units were instructed to test all their patients for hepatitis C. However, in my case, there was never any consent sought. If someone had said at the time, 'We are testing for this', I would have said yes. The lack of communication was appalling and I wonder if it was deliberate. I don't see the problem in asking, unless it was to keep people in the dark and prevent people from discussing it with one another. Knowledge is power after all.
21. Yes, as I say, I was tested with no information. I was treated with no information; I did not even know the name of the product I received when I gave birth in 1990.
22. I don't know if I was treated or tested for the purposes of research.

**Section 5. Impact**

23. I am unsure if any of my physical issues are a direct or indirect result of being infected as I have spontaneously cleared however, my ongoing mental health problems are connected to the infection. I have severe anxiety, stress and chronic depression. These have been clinically diagnosed. These have been ongoing since **GRO-B** was born twenty-three years ago but have become much worse over time, ultimately leaving me suicidal at points. It was difficult to pinpoint this as being due to infection originally. There was no real reason for it. I had a good life with no real underlying problems or concerns. Many years after I was diagnosed, I read that depression is commonplace with infected people and nobody knows exactly why. It has affected people who have had different treatments for the hepatitis and those who have had no treatment at all.
24. As far as I am aware, it hasn't yet been determined whether this depression stems from the virus itself or the trauma of the entire situation. However, it is prevalent among infected people. One day, in desperation, I phoned the Hepatitis Trust and asked them if the infection could be the reason for my depression. I was told that it couldn't be the reason. I didn't question this as I am not the expert. I was desperate though. I did ask my psychiatrist once and he did say it was possible due to the trauma of the period. Obviously he couldn't comment on the potential link to the actual virus. The infection did spontaneously clear but the mental damage did not.
25. I have recently, been diagnosed with fibromyalgia which I believe is linked to the hepatitis. Depression is one of the symptoms of fibromyalgia. My depression is all consuming and has affected every part of me and my life. I was not depressed before I discovered I was infected and the trauma of the event has definitely impacted my mental



health. The manner in which I was told, the lack of information and support, my GP nastily verbally abusing me, the maternity hospital treating me like a leper for my 2<sup>nd</sup> child, the breastfeeding fiasco, worrying if you have infected your family, not being able to tell anyone about it because of the fear of being shunned, being treated disdainfully by some medical staff from then on, the stigma and the worry that the active virus could return. It's another deep, dark secret to hide away. These are some of the feelings I experience. I saw a psychiatrist at one point for about four years but I cannot recall the dates now. His name is Dr. Kris and he is based at the Three Towns Resource Centre, Saltcoats. I have been assigned several counsellors and several community psychiatric nurses since my depression diagnosis. I have also been under the care of the community mental health team and have undergone cognitive behavioural therapy several times. I have undergone other types of therapy, including self hypnosis. I have been on many different antidepressants over the years along with diazepam and zopiclone (which is a sleeping tablet). I was on escitalopram for a long time but when my fibromyalgia was diagnosed earlier this year, it was changed to amitriptyline and duloxetine, along with tramadol. My GP is still trying to find the most suitable treatment combination for me. I also suffer from migraine and irritable bowel syndrome, both of which can be exacerbated by stress.

26. Depression has completely changed my life and me as a person. I no longer recognise myself. The depression has also worsened significantly over the years. The past 6 years have been the worst. I had periods of time being off work which were not overly long but the last time I was off, I was suicidal. That was when the community mental health team got involved. I became a recluse and withdrawn. I still am to be honest. I rarely go out. I prefer not to answer the phone or the door. I isolate myself. I am not comfortable around other people - even ones I am close to. I am constantly exhausted and lethargic. I don't sleep well and I can't focus or concentrate. I feel inadequate. I feel like a useless mother, wife, daughter, sister etc. I beat myself up

and this thought pattern becomes a very rapid, downward spiral. I feel like everybody hates me. I feel like people would be better off and happier without me.

27. The depression has severely impacted on all my relationships. My family home has been full of tension and my mood changes. I had some quiet reflection recently and realised that GRO-B had never known the "normal" me. This saddens me.
28. I had headaches before infection but they have worsened and I have suffered from tension and cluster headaches over the years. These resulted in my GP referring me for a brain scan at one point. I have a headache every day to some degree. They can come from nowhere and last for up to a week. It feels like my skull is about to explode. This is accompanied by dizziness and nausea. Irritable bowel syndrome appeared after the infection. This causes me extreme pain and spasms. Stress does trigger bouts of this. Fibromyalgia can cause exhaustion, lethargy and depression. As I already have these, they are now even worse. There are also the physical symptoms. I have chronic pain. I have muscle pain over most of my body; my head, whole back, lower legs, soles of feet, big toe, lower arms, hands, fingers and knees. I am in constant pain. It doesn't matter whether I sit, stand or lie. The leg spasms and back pain disrupt my already poor sleep, making the exhaustion and lethargy worse. I can't walk very far now before my lower back completely gives out, so I rarely go out. I am in pain pushing the vacuum cleaner. Physically, I can't do much at all, this is very debilitating. I have what is called 'fibro fog'. You can't focus or concentrate. There are also memory issues. I used to be an expert at multi-tasking. Now I have difficulty doing one simple task. These days I can take 4 hours to watch a 1 hour recorded television programme because I keep losing concentration, I drift off. I let my e-mails pile up, which is not me. I am fastidious about paperwork and business matters. I will tell myself this simple task of sorting e-mails was the goal for the day, but I still couldn't focus enough to get the job done.

29. I have never been offered treatment for the hepatitis C. It was mentioned once when I was diagnosed and instantly ruled out due to my pregnancy. It was never discussed again after this and I then spontaneously cleared.
30. I had no treatment, I would say the obstacle I faced was that I was never offered treatment apart from the throw away comment.
31. When they eventually managed to spit it out that I had been infected, there should have been some form of discussion and a liver biopsy conducted. A biopsy should have been offered after [GRO-B] was born. I think there probably should have been a discussion about what available treatments there were and if I wasn't to get them, why not? Time is of the essence. I suppose when I look back at this logically, at some point after having [GRO-B] cleared spontaneously so treatment was unnecessary. However, nobody knew I was going to clear spontaneously, so treatment options should have been discussed and offered.
32. There were no mental and physical effects due to treatments as I have not had any treatment.
33. Anybody involved with treating me should be aware of the fact that I've got positive hepatitis C antibodies, therefore, they are at risk and they should be wearing gloves and so on. This should be the first thing they see as it's on the front of my files at the GP and hospital. This is for their protection obviously rather than mine. Infection does have an impact on any further treatment because you get the 'leper' treatment. Many people don't particularly want to touch you or even deal with you from the medical profession. Some will be interested and ask about



your blood condition and subsequent infection. Others, unfortunately, seem to draw their own conclusions and treat you with disdain. As stated, they should all be wearing gloves anyway and I have had cause to say to people that they should be wearing gloves. Other procedures which are done in hospitals involve a Von Willebrands discussion before anything can be done anyway, so infection is another hurdle to discuss. This type of behaviour has gone on right up until the present day. You can hear them whispering and talking about it outside your room. This isn't particularly pleasant.

34. Every time a new doctor sees my file for the first time, they revisit the family tree and the family bleeding history. I remember a time when this occurred with a new doctor at the Haematology Unit. She was pleasant enough, then she brought up the Hepatitis C infection in the discussion. She had no need to but I assumed as we had never met she was curious. I told her I was infected during childbirth. Her attitude changed completely and she was adamant this was not the case and I must have been infected earlier. Comments were made along the lines of, *"No, no that couldn't have been when you were infected. It must have been earlier. You must have had blood products before then. Are you sure you didn't have treatment any other time? Are you sure you didn't have treatment as a child and you just don't remember?"* The conversation continued like that for some time. I then felt like she was treating me like an inferior idiot. As already stated, I had never been in hospital in my life before childbirth, not even as an outpatient. I didn't need to be bullied into recalling previous treatment which I had never had. I will also add that my opinion on when I was infected has never been denied or challenged by any staff in the Unit before or after this. I am led to believe that investigations have been done to link infected people to infected donor blood, i.e. your donor batch is known and recorded and therefore can be traced. I assume that this doctor was unwilling to accept that I was infected at the time when new standards were being introduced, at the very end of the tragic period. However, maybe she was privy to information that I am not. After all, I don't



actually know when I was tested. I assume it was in 1994 when I was pregnant for the second time and they told me I was infected. I cannot recall her name. It wasn't until I was on my way home that I realised just what she had said and it sunk in how distressing the whole conversation was. She was quite defensive, maybe over her profession, but I don't see why. I suppose it could have been worse, she could have said you're some kind of junkie, prostitute. I know this sounds dramatic but it is how her suggestion that I was infected other than as a result of the treatment I received in December 1990 made me feel. I'm the innocent victim of circumstance and it felt like I was being blamed.

35. When I was diagnosed, GRO-C  
GRO-C GRO-B was very worried about my future health and ultimately, if my health deteriorated or I died, the impact on our family unit. He was bewildered at the way I was told, my GP's reaction and treatment in the maternity hospital which I discuss below under stigma. Very few people know about my infection due to the stigma. I feel I am at risk of being shunned or perceived in a bad way. I avoid discussing this if I'm in a social situation. I have heard people close to me having conversations about the Inquiry and they don't know I am infected. GRO-B and the children also would refrain from telling people for the same reasons. I have withdrawn from having any real social life since GRO-B was born. I rarely put myself in social situations. I don't feel particularly comfortable. Much of this is due to depression and having no self-esteem. If you hate yourself and believe others hate you, then you don't want to be in company. When you don't know how you're going to feel 10 minutes from now, you don't make plans. It's easier than breaking them or letting people down. GRO-B would say I don't do anything and this does annoy him. He has missed out on many things due to my depression for example nights out and holidays. I believe GRO-B and my family think I am just weird and ignorant. Maybe they are just fed up with it all now as it has been going on for a long time. I think GRO-B is resentful about some of my issues with depression. In my

opinion, nobody understands depression unless they have experienced it. It is extremely difficult to explain and describe, even if you want to. My family probably feel helpless. They want to help but can't.

36. I am very close to my mum, who only lives 5 minutes away but I am lucky if I see her once every 3 weeks. I don't go out unless it is to the GP. **GRO-B** has to do the grocery shopping. If I am awake all night and do get to sleep at 8am, then I get up at noon. I usually only have 4 hours sleep. If I wake up at noon, I immediately become down because that's the morning away and I have achieved nothing. I struggle with any appointments for mornings. I haven't been to church for months because I can't make myself wake up and be ready for half past ten. I have been a faithful attender all my life until now. This gets me down too. Severe itching is another symptom that keeps me up at night. I had a sudden and inexplicable aversion to normal smells, e.g. food, air freshener, my dogs. I feel nauseous and gagging constantly. There are things on television that make me nauseous which they didn't before. Normal noises sound loud and irritating like nails on a blackboard. Most food turns my stomach too. After my diagnosis, I discovered these are symptoms called environmental sensitivity. There is also excessive body heat which is unbearable and constant. Depression comes along with fibromyalgia, but I had it back when **GRO-B** was born so that has continued.
37. I am a member of a leisure club. I was having personal training sessions twice a week and was in the gym daily a few years ago. I also swam and went in the sauna and took classes every day. I can't anymore. I have been for a swim only a few times this year. As a result of the debilitating nature of the fibromyalgia, my depression is much worse again but now coupled with this physical illness.
38. Stigma is a valid issue and is important to me. Very few people know. Even within the family, people don't know about my infection. There is a risk of being shunned or treated like a leper or someone distasteful.

Those who do know, wouldn't share the information either, for the same reasons and to protect my privacy. For me there is still a definite stigma. I can say exactly when, where and how I was infected. It wasn't my fault and I am safe to be around. I still wouldn't tell anyone this though. I fear a negative reaction. The way I was told and treated has probably coloured my judgement. If this is the way the medical profession reacted why would I take the risk with the general public? My employer was never informed either. I certainly couldn't face the stigma that disclosure would have created.

39. When I gave birth in 1995, I was put straight into a labour room on admittance. Normally a woman would be assessed and monitored in a birthing room or assessment suite until delivery is imminent. Then you would be moved to the labour room. I was put straight in to the delivery room so that I would only contaminate one room. I was given a public telephone to tell family members I had given birth. A sign was then put on the phone stating "*Out of order*" because the phone had now been contaminated by me and nobody else was to use it. I was put in a separate room attached to the ward. There were two bathrooms for everybody. However, one bathroom had an '*out of order*' sign put on it. This was the toilet I was to use. Everyone in the ward could see the sign, could see that this is not really out of order and could see that I was using it. This leper treatment was not pleasant.
40. The risk of being shunned is too great. The associated stigma is real. Even though GRO-B and GRO- are fine, I was scared that other people wouldn't let their children play with mine through fear. I was also scared people would keep their children away from mine through being suspicious of how you were infected. I have friends who've made comments about AIDS, "*Shoot all these people.*" "*They are all homosexuals anyway.*" I am not homophobic and this is not my opinion. I am merely giving you an example. I asked "what about haemophiliacs and bleeders"? But this friend was adamant. That was a friend's view of the situation. So you decide not to discuss your own circumstances. You've got a big black cloud over you all the time.



41. My family that do know are angry at the way I was told and have been treated without my knowledge or consent. [GRO-B] would have been mortified by the antics in the maternity hospital. It was evident that the bathroom I was using was not out of order. What must people have thought? My family were worried for all of us. We have experienced the grief and devastation of losing my uncle and cousin as a result of this infection. [GRO-C]  
[GRO-C] This causes conflicting emotions in me. I am grateful to be alive, there for the grace of God go I. They were infected just the same as me. I am devastated by their suffering and loss. Maybe it is a little bit of survivors' guilt. I also think the infection is why I never had any more children, which I would have liked. There was a comment made to me by a doctor when I was diagnosed and cleared about changes to the immune system during pregnancy. That might have been when the virus became active and then cleared after pregnancy when the immune system returned to normal. Little seemed to be known at that time or, if it was, it wasn't shared. This is the reason I have no more children. I thought that if their theory was correct, the virus could possibly return during a subsequent pregnancy and do damage, perhaps not even clear. This was too high a risk.
42. [GRO-B] and [GRO-B] have obviously been affected by the resultant depression. To what extent I will never know. I am truly sorry that I have psychologically harmed them in some way. I was suicidal. They must have worried if I ever went out or didn't answer the phone. We don't discuss any of this, but [GRO-B] alluded to it 5 years ago. My sister was staying with us and [GRO-C] I remember [GRO-B] saying, "*She is going to die. I've accepted that. My Gran is old and you are going to commit suicide. Who is going to be here for me?*" That was the moment I realised I had caused them harm, albeit unintentional and out with my control. Luckily, they both seem quite rounded.



43. I think the infection and subsequent events may have coloured **GRO-B** and **GRO-B**'s judgement of medical issues in general. **GRO-B** doesn't go to the Unit for **GRO-C**. He has a telephone consultation. He does not see any point in **GRO-C**. **GRO-C** **GRO-B** is very efficient about medical matters. She will ask questions and will research things. She is aware of patient charters and that as a patient or parent that she has an input to care plans. My mum is very worried. It was her brother and nephew she lost to this infection and it has devastated her to see and experience what has happened to me.
44. There were no educational effects as a result of infection due to when I was infected.
45. My issues evolved from the resultant depression, anxiety and stress. I worked in an administrative role with the same company for thirty years. There were days when I was unable to pretend about the depression and I would phone work and take a holiday. I did mask it for a very long time. The first time I was off sick for this reason was maybe for 3 weeks about 15 years ago. My next absence was for about 3 months, approximately 10 years ago. Six years ago I was absent for 7 months. This was when I first became suicidal. I managed to return for more than 2 years before having to go off again and I had been certified absent by my GP and psychiatrist for a year when I left the company about two years ago. My departure was very traumatic and messy. It left me with no income at all apart from Employee Support Allowance.
46. I dislike my former workplace and dislike many of its employees, even those whom I have no reason to dislike. I am very bitter although I try not to be. It stems from the way I was treated and the manner in which I ultimately left. I feel angry when ex colleagues say that I am retired.

Being retired early implies access to your pension. I was denied ill health retirement because I was not terminally ill. Also, this is based on physical illness with no thought or parity being given to mental illness. So I am not happily enjoying my retirement, I am ill and unable to work with nineteen years to go before my state pension and many before I can access my occupational pension. Before I was signed off sick, I would sit at work and keep checking the time. It wouldn't be a case of getting through the day with the depression. It would be a case of could I get through the next five minutes. I was barely existing and not really living.

47. Now, as I am still unfit to work, I receive Employment Support Allowance in the support group from the DWP. This is National Insurance contribution based. If I did not have adequate contributions, I would receive nothing as income based ESA is means tested and I would be ineligible as **GRO-B** works. I had just had my 30 years' service award and I was on the same salary for all those years (except for annual pay rises). I never anticipated being unable to work from the age of 48. I'll not be able to receive state pension until I'm 67. My company have twice denied me ill health retirement so I can't access my occupational pension. **GRO-B**'s basic salary is the same as mine was, so our household income has halved. I expected to remain with my employer on that salary for another seventeen years. Luckily our mortgage was paid off and we had no significant debt. We had very little savings either as we had a shortfall in the endowment policy covering the mortgage, which we used our savings to pay. So we were just starting to save again. Fortunately, **GRO-B** works or we would have been in a terrible situation. We were accustomed to never having to worry about paying bills, buying clothes and food or having a roof over our head. We were not huge earners and didn't live extravagantly but had the good fortune of being able to cover basic costs of living with ease. We were and still are helping our children and assisting them through University. With our household income halved and little savings, I have started to worry about finances in the future. In

addition to my own health issues, GRO-C. I worry if something was to happen to him. How would I cope?

48. I also need to add in a comment about insurance. I have always had insurance for everything, life, house, travel etc. I would never lie to an insurance company and if they ask about hepatitis testing, which they do, I answer honestly. I tell them I have been tested but I am clear. However, I am still heavily penalised financially. The underwriters weight this information heavily. I've never had insurance denied by anyone but you pay astronomical premiums. Anything financial to do with your household, whether it's a mortgage or a loan, it turns into a hassle. They say things like, "*We'll give you an answer straight away.*" and then they want medical statements. I have life insurance. I have always managed to get insurance but the premium is really high. Yet all you're saying is I've had it, I don't have it now and I didn't get any treatment. I shouldn't be treated any differently than anyone else but that's not the way it works. If you add depression to your quotations, which I have had to do, your premiums are through the roof, even though I have never received treatment as either an inpatient or outpatient for mental health issues.

### Section 6. Treatment/Care/Support

49. There was no psychological support offered to me for hepatitis C. There wasn't even medical support which, considering I was pregnant and breastfeeding GRO-B and all that was to unfold, there should have been some support in place. The counselling and support which I have now received has been as a result of mental health issues. That was instigated by my GP as a completely separate issue. This is completely inadequate, I should have been properly supported when I was diagnosed and I believe that GRO-B would have benefitted from support as well.

50. A liver biopsy would have been good as that would have shown whether there was/is a problem with my liver. At least a discussion about starting treatment, before the all clear, would have been helpful. I would have liked to have seen the hepatologist as the expert to discuss what they knew about hepatitis C, what can it do etc, rather than me trying to find out by myself. Counselling would have been invaluable. I am sure I wouldn't be in the state I am now, with regards to mental health, if timely psychological support had been given.

### Section 7. Financial Assistance

51. My family in London made me aware of the Skipton fund. This would have been at the time the Skipton fund was made available. I have never had any information from the Haemophilia unit or anyone else about financial support that is available. I applied to the Skipton fund. I have recently started receiving support from the S.I.B.S.S.

52. I was rejected by the Skipton fund. I applied at the beginning, so maybe 23 years ago. The reason I was rejected was because I apparently, did not meet the criteria. I had spontaneously cleared in too short a timescale. I think the time quoted was that I had cleared within six months of infection. This turned out to be erroneous. The time period used should reflect the period between infection and clearing. The Skipton fund assessed the period between diagnosis and clearing. These are two very different things. I had been infected for at least five years before clearing. The Skipton fund made an error but I didn't know that. I was unaware of any other financial assistance and just carried on. I went to a Haemophilia Scotland conference about two years ago and there was a seminar about payments. Afterwards I asked the question about my circumstances and they said, "*You must have received a payment.*" I said I hadn't but they never got back in touch with me to offer assistance. To be fair, this was at the time when the S.I.B.S.S. was being created and maybe, once it was established, they



forgot about my query. I always felt guilty about the financial side of things. I was clear so I should be grateful, which I am. On the other hand, I am being penalised financially with insurance and I have been significantly impacted mentally. I am stuck in the middle. If I got some financial help, then I could afford to pay these premiums. Then one day I contacted the Scottish Infected Blood Forum but they did not respond either. However last October I phoned the Scottish Infected Blood Support Scheme and asked a generic question. The immediate answer was, "Oh you must be receiving a payment." I said no and that I had been rejected by the Skipton fund. They said they found this strange and sent out the forms to me. Last month I got a payment from the Scottish Infected Blood Support Scheme. I received an award letter confirming I am chronically infected stage 1.

53. I received support from the Scottish Infected Blood Support Scheme. I received a lump sum last month as I am a stage 1.
54. Most of this has been answered above. To give them credit, the lady at the S.I.B.S.S. was extremely helpful, pleasant and efficient. When I received the award letter, I cried. I woke GRO up to show him. Within a week of receiving the application form the award was made. The tears were not for the money. It was the relief, the recognition for all the trauma, all the worry and the loss. Up until that point, you wonder is this just me? I do wonder how many more people are out there, like me, not getting support.
55. In my experience, there was no one out there giving advice. I received no advice from the Unit, the Haemophilia Society or my GP. Haemophilia Scotland, the Scottish Infected Blood Forum and the S.I.B.S.S. did not exist then. To be fair to my GP, I was probably the practice's only infected patient and he was not an expert.
56. I am asked if I have any further comments about the various trusts and funds available. Yes. Who is responsible for providing this information

to infected people? In my situation, as previously stated, my family in London made me aware of the Skipton fund and I am unaware of / have never heard of any others. Without my family disseminating this information to me I would have known nothing. After being rejected erroneously all those years ago by the Skipton fund, why was I not given the correct criteria and told to resubmit an application? Why was I not informed of these other sources of funding to try? The issue of being rejected by the Skipton fund has been raised many times over the years. Why didn't any of the experienced people I spoke to give me this funding information? Is it the responsibility of the infected person to find out relevant information? It shouldn't be. Is there an inner circle where only certain infected people are given the information? I cannot comment on any other sources of funding other than the Skipton fund as I have never heard of any. I could and should have received this payment when I applied approximately 23 years ago. I was also informed when the S.I.B.S.S. was formed (when the UK payment scheme divided into national payment schemes) that it would be handling ongoing financial payments for those infected in Scotland who were already in receipt of payments and were registered through the Skipton fund, i.e. not those rejected. So I would still be in the dark if it hadn't been for me making a chance phone call last October. There is a definite lack of communication and inconsistencies in the information provided. Perhaps this lack of information is only related to stage 1 people. No amount of financial assistance is going to bring people back, stop people dying, give people their health back or right the injustices that have been committed. I just want the truth and facts of the situation in the public domain for people to get closure. I also want to ensure that another medical disaster is avoided if possible. There are lessons to be learned. There were, no doubt, pitfalls and errors. Root cause analysis is used in other industries This should be no different. I also have comments about parity between physical and mental health with regards to financial assistance. This has not happened yet. Mental health disparity is a widespread issue in the UK and is not restricted to this Inquiry. It is a recognised and highly

publicised topic currently. Mental health is the second class citizen behind physical health. It shouldn't be. Specific to the Inquiry, the mental health damage to those infected and affected has now been acknowledged – but not financially. It should be from now on. I also believe the financial disparity which affects stage 1 people and stage 1 widows/widowers should be addressed immediately. I don't think any payments should be means tested.

**Section 8. Other Issues**

57. My solicitors are going to review my medical records which may help in answering some of the remaining questions I have about my infection.
58. I requested my records from the UKHCDO and received these at the end of 2018. There is no mention within these records of me receiving cryoprecipitate in 1990. There was also no mention of me receiving Haemate P. The records say that I received DDAVP at a time when I did not. They also incorrectly say that I did not receive a "mad cow" notification. The records incorrectly say that I am not infected with any blood borne viruses. I phoned the UKHCDO and told them about these inaccuracies. I assume that they are inputting the information that they are receiving from Haemophilia Centres. It concerns me that I have had so few treatments and my records are inaccurate. My initial reaction was that it was a cover up.
59. 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) Who made the decision that I was to be given cryoprecipitate in 1990?
  - (b) Why was that decision taken?



- (c) Did I need to be given the cryoprecipitate at all? Could I have been given a safer product?
- (d) What was or should have been known by the doctor who were responsible for my care about the risks of me being infected in December 1990?
- (e) How much cryoprecipitate did I receive in December 1990? Where did it come from?
- (f) Why was I not told about the risks of cryoprecipitate or the alternatives available for me at that time?
- (g) Could measures like testing of blood for the hepatitis C virus or surrogate testing for that virus have been introduced earlier in Scotland? Would that have made the product I received safer?
- (h) When was my blood tested for the virus?
- (i) When did it show up as positive?
- (j) Who knew I was infected?
- (k) Why was I not told until years later that I was infected?
- (l) What treatment options could and should have been offered to me for my infection?
- (m) Why did I and my family receive no support around the time I was told of my infection?
- (n) To what extent are my ongoing symptoms caused by my infection with hepatitis C?
- (o) 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

19th April 2019