Witness Name: GRO-B Statement No.: WITN2149001 Exhibits: WITN2149002-012 Dated: 15<sup>th</sup> October 2020

# 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 1 October 2018.

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

### Section 1. Introduction

1. My name is Mr GRO-B My date of birth is the GRO-B GRO-B 1974. My address is known to the Inquiry. I am a severe haemophiliac who was infected with HIV which later became AIDS and hepatitis C as a result of receiving infected blood products. I intend to speak about my experience of being infected with blood products as a child, the diseases that have emerged as a result of this and how this has affected my life. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and me throughout our lives together. I wish my statement to be anonymous.

### Section 2. How Infected

- 2. I have severe haemophilia A, factor VIII deficiency and I was treated for the first ten years of my life at Yorkhill Hospital in Glasgow. Haemophilia is a painful condition at times, it is debilitating. If you get a bleed you're laid low, sometimes for weeks at a time, trying to get on top of it. I would have to be taken to hospital for an injection every time I had a bleed. If I knocked myself, regardless of the day or time, I would be rushed to hospital. I exhibit a letter as WITN2149002 when I was receiving cryoprecipitate in 1977. My mum was trained to administer home treatment of Factor VIII concentrate in 1979. I exhibit a letter that refers to this as WITN2149003. It was manageable and I was coming to terms with coping and thinking about my life as a young child. Then getting HIV and hepatitis C diagnosis devastated this. After I was diagnosed I was treated by Dr Mathieson was the HIV specialist involved in my care at Raigmore Hospital, Inverness GRO-B GRO-B
- 3. I received American Blood products that were contaminated with HIV and Hepatitis C. I think I also received British products during that time. It is difficult to know how and when exactly I was infected with Hepatitis C, as I think the British blood products had this as well. Certainly though, the HIV came from the American concentrates. I was involved in the American litigation years ago. It was discovered during this litigation that I received an HIV infected American Factor VIII concentrate product in 1981. Reviewing my medical records I note that there are a number of my records that are blacked out around this period. I exhibit one example of this as **WITN2149004**.
- 4. When I was a child, I was a patient at the haematology unit at the Royal Hospital for Sick Children, Glasgow (known as Yorkhill Hospital). This was a children's hospital and I think it was Dr GRO-D who was the haematologist there. I was a young child and as far as I can make out, Dr GRO-D tried his best for me. His heart was in the right place, but

misguided. My family moved to **GRO-B** later on and I would have then been at Raigmore Hospital, Inverness under the care of Dr Taylor and Dr Murray who were in charge of my haemophilia care there. They were the doctors who informed my parents, when I was about 14, that I had HIV.

- 5. The precise dates and times of when I received the various blood products are unknown to me. I am not sure exactly if Yorkhill Hospital is where I received infected products because I left there when I was 10. I think that it was likely I was infected with both HIV and HCV there on the basis of the nature of the products I received and the information I received during the American litigation which suggests that I was infected with HIV in 1981. I have read a document from one of our fellow sufferers that there is a term known as "super infected multiple times" that would apply to me as well. On the basis of that information, I think that I would have been infected with HCV with every injection that I ever had as a child. That is the thing there is not just the hepatitis C, there is HIV, there is all the hepatitis strains and there is a whole heap of pathogens and viruses on top of this. The treatment was not heat treated when I was being treated at Yorkhill and thereafter, it wasn't virally inactive, we were infected with every injection which contained the virus. I would have received 2-3 injections of Factor VIII concentrate a week and if I had a bleed it would have been every day.
- 6. The doctors at Raigmore Hospital, Inverness informed my parents when I was 14 years old in 1988 that I had HIV during an appointment. I was not present. I had been there for four years at this point. I cannot locate notes in my medical records of this discussion with my medical records. What I have located is a reference to AIDS literature being sent to my mother in 1987 which I exhibit as WITN2149005 and a reference to a "detailed discussion" in 1990 with my parents which I exhibit as WITN2149006. My parents asked the doctors how long I had been infected and they informed them that I had been infected for years. If the estimate above is correct, I had been infected when I was

seven. My parents asked the doctors why they had not been informed earlier that when they had been and the doctors said that it was not hospital policy to tell patients. **GRO-D GRO-D** 

**GRO-D** My parents were devastated and came home and told me straight away. My world caved in when they did because as a young lad, I had seen this on the news, all the hysteria, the 'plague'; AIDS was going to wipe people out, it was this horrific death, the suffering. I thought that I was going to die. I believe that I was 7 years old when I probably got infected which is when I received the American blood. My parents were told that I was not expected to live to 18. **GRO-D** 

GRO-D

**GRO-D** I now know that this was not an isolated case; this was right across the board. People were not told of their conditions for years and years. I think it must have been a systematic thing to not tell people and to hush it up and sweep it under the carpet.

7. My parents were not given information on the risks associated with receiving the products or on alternative treatment methods which might have been available. They were fairly in the dark about things. That is the other dangerous thing, the doctors only told us when I was 14 years old because I was getting to 'that age' where I was interested in girls. Well, I was interested in girls and it was just plain luck that I didn't infect somebody. My mother was giving me my injections all throughout my childhood, using needles and she could have had a needle stick injury. She could have been infected, or if I had cut myself, there would be blood around the house. The doctors and whoever else was responsible for the policy put my family at risk with that policy. We weren't offered any counselling or anything at all at the time we were told I was infected with HIV. All they said is that it's a blood borne illness and that I would be fine as long as there was no blood to blood contact. There was no other discussion or warning about the risks of being infected with HIV.

- 8. As for the pooled American blood products, I think a lot of these doctors certainly, would have been aware at the start and as time went on about the risk. By the time I received them I think it was blatantly obvious that these were extremely dangerous, that they had a considerable risk of transmitting some sort of virus to me. It is a very difficult position for these doctors to be in. Initially I was raging angry but since then I have calmed down and have a little bit of compassion for the doctors as no one goes into medicine intending on killing people. It is one of these things. They have found themselves in this position, where they have had to give this product, possibly some of them had their hands tied. I mean some of them are outright monsters, but some of them are trying their best and they were caught up in it and could not really speak out and would probably have lost their jobs or taken a lot of heat. Someone made the decision to give me those products. I do not blame the junior doctors and nurses but the people who made that decision.
- 9. I was infected with HIV and hepatitis C. As far as I know, I don't think I was infected with hepatitis B, but this is the thing, so much has been hidden from us I cannot say for certain; I can only say, not as far as I know. A lot of these lesser viruses, they all contribute to ill health, especially when you are infected with HIV.
- 10. After my parents were told about my HIV diagnosis, it took another year before I saw a specialist. I do not know what the delay was. By this point I had developed AIDS. The doctor was a very nice man, Dr Mathieson. He got me on HIV drugs straight away and basically saved my life. But yes I almost died, I have almost died numerous times since then. It is a miracle that I am still here. I was not told about the hepatitis C diagnosis until I was about 20 or 21 years old. I went to a routine appointment at the hospital and it was said to me that I had hepatitis C as well. It was made as a throwaway comment and it was played down. I was told not to worry about the hepatitis C it was the HIV I should worry about. I was told that it wouldn't really affect me. GRO-D

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GRO-D	That was clearly not right.	

- 11. I have located a letter in my medical records dated the 15<sup>th</sup> May 1996 that refers to an appointment I had with Dr Zentler-Munro in 1996. In this strongly worded letter it is very clear that my hepatitis C result is not clearly available to be accessed which I exhibit as WITN2149007.
- 12. I further exhibit a letter from Dr Patrick Zentler-Munro to my GP dated the 23<sup>rd</sup> July 1996 as WITN2149008 which then describes my hepatitis C diagnosis of 1993 and HIV diagnosis. He has clearly located the information he requires but I cannot see a clear route as to how he obtained this information in my records.
- 13. As for the HIV infection news, I wasn't given any information. The doctor never spoke to me. They spoke to my parents and my parents came home and told me. My parents could only tell me the basics; you have been given this virus. They weren't given a lot of information. I didn't know anything else other than what I saw on the news.
- 14. That is the thing. It took a specialist possibly about a year to meet with me after I was diagnosed, so the information was not adequate. I have no idea why it took so long, maybe the referral wasn't posted in the mail, maybe, I can't imagine there would have been a big waiting list though.
- 15. Yes, I should have been warned, about these blood products right from the start. They should never have been used. They were banned by the FDA because they were so dangerous, they were just riddled with viruses. The FDA weren't daft, they knew the blood products were coming from prisons, skid row, sex workers and addicts and that they were loaded with viruses to the point that they were told that they couldn't sell the stuff in their country. Baxter, Armour, they didn't care. These companies said fine, we will sell it abroad. I should have been

told right at the start when they found out. My parents and I should have been told about how dangerous the products were and given the choice about whether to use them or not. The viruses, the tests, the whole thing about tests without consent, there was never any consent or knowledge of consent. They knew for years about my condition and I was kept in the dark about it.

16. When they told my parents about the results, it was far too late. Maybe telling my parents first was the right thing to do, but I should have then been allowed to see a doctor, talk to the doctors, ask questions. I never got to ask any questions and I certainly never got any counselling. I went completely off the rails afterwards. I dropped out of school, I started drinking, taking drugs to escape because I thought I was going to die. My parents were only told about my infection because the doctors deemed that I was at the age where I might spread the infection.

#### Section 3. Other Infections

17. I am not a medically trained person, but according to other campaigners, there were all kinds of infections in the products we received and they all have an impact on your joints, on your ability to clot, on your health, lots of different things. There are people who know a lot more about this than me. It is strange however that a lot of haemophiliacs are controlling their haemophilia and their bleeding episodes and even though they are taking lots of factor drugs and medicine, that there is still a lot of bleeding and problems. Youngsters are having to have their ankles fused and problems as teenagers. If this medicine was working supposedly as it should, this would not happen. I know there is a lot of haemophiliacs that have been exposed and for them that factor VIII barely works at all. For the youngsters, why are they not responding to the drugs like they should? This synthetic factor VIII, there are questions over how well that actually works because on paper it says it works fine and it's touted as this much safer option as it

eliminates the possibility of viruses despite the evidence that indicates that there is some kind of problem with this treatment as well. A lot of youngsters are experiencing their hair falling out or joint operations, they shouldn't be having this. Haemophilia Scotland said that perhaps there was something in the actual blood products that contributed to the coagulation that wasn't in the synthetic products because I think there are various human proteins. But of course, not knowing and being afraid about the products is the result of the problematic relationship we now have with haematologists with the secrets and damage that they have done to us in the past. Would they admit that there was a problem with a synthetic factor VIII as well?

#### Section 4. Consent

- 18. The doctors first started testing me in the 1980s for HTLV III and you can see in the records that they never informed me. It was all there in black and white when I recovered by records for the American litigation I was involved in. I don't have my medical records personally now. We were certainly never told at that time that any testing was going on for a possible viral infection of any kind.
- 19. They did not tell me about the tests they were doing, so that follows that they did not seek my consent.
- 20. Neither my parents nor I were advised of my infections for years, as I said above. Again it is all in my medical records. This whole thing, it's a criminal cover-up on an industrial level, at every level. From the NHS workers, the doctors, the centre of directors, right up to the civil service, the politicians, the pharmaceutical companies. The whole thing is colossal.
- 21. I have been used and tested on for years. I was not informed about the results for years as I have said previously.

#### Section 5. Impact

22. The mental and physical effects of being infected have been devastating. It's been a lifetime of pain and suffering, I don't even know where to start. The illness is really damaging mentally. There's HIV, the toxins in my brain, there's HIV dementia. I've got both of these to an extent, and its only getting worse. I can barely remember anything. If I see a friend, I can't remember the last conversation we had. My friends will say "What's your news?", and for fear of repeating myself, I always say, "Well what did we talk about last time I saw you?" I used to love reading, I am not really able to read a book anymore, not really able to watch a film, to follow it, it's really frustrating.

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a way to adapt and overcome to a certain degree. I rely heavily on technology. I use the laptop for notes, because all my devices can sync up, I can type on a computer and when I'm out, if I suddenly can't remember something, it's on my phone and the information is always there, and vice versa. All that kind of stuff its really difficult for my memory; the cognitive function is the main problem. Some days I look ok, other days I have the brain fog thing where I really struggle to think and speak fluently and to get the words out that I am looking to find. I did ok at school, I think I was above average. The teachers said I was above average; I was intelligent but I dropped out after I was diagnosed with HIV and never went to college or university. I plummeted head first into addiction and have been in recovery for quite a few years. I got clean and sober but then later on I suffered from depression ... I was depressed for years and years and I didn't realise. I never received any proper help until I was diagnosed. I was crying all the time and suicidal and that was the thing, I slipped through the cracks of the system. I really should have been in a rehab or a mental hospital getting proper care and attention but I never got any of that. In its GRO-B

woefully inadequate, the rehabilitation service is terrible. so yeah, terrible anxiety. It's not just the illness,

- 23. Further physical problems are that I had non-Hodgkin's disease, cancer, twice. I had to undergo chemotherapy, and radiotherapy. The 1<sup>st</sup> time was when I was 30, when it was just in my arm. The 2<sup>nd</sup> time I was riddled with it, my bones, my legs, loads of internal organs. It was a miracle I survived that. The 2<sup>nd</sup> time the cancer was discovered, I had a heart attack. I had such a high fever. I was walking about in a blackout for about 2 weeks. I have no recollection of where I had been or what I had done and I went to the hospital for an appointment to see why I was in such pain, fell over and took a heart attack. But they brought me back to life and discovered I had cancer and treated me for it.
- 24. From the age 14 when my parents told me, I was traumatised, severely traumatised. I couldn't concentrate in school, I would just be very withdrawn, isolated. GRO-B GRO-B

**GRO-B** Shortly after finding out I was infected with HIV, I was in school; someone had an aerosol can and said "You can get high from that". I thought ok, I really wanted to escape from the pain I was in. I started breathing in aerosols. Then, when I was 16, I started drinking and smoking cannabis and then I was in full scale active addiction for years. I realised further on that this was going to kill me, perhaps more so than my infections, so I had to look into recovering and that was a story and a journey in itself. I am now clean and sober.

25. HIV has weakened my heart so I have to take medication for that, but it is quite complicated. They can't give me all the medication that they want to as they feel it would lower my blood pressure further and my blood pressure was already getting dangerously low. I have just recently embarked on a fitness regime. I would have done that anyway but I had a lot of problems with bleeding, getting my haemophilia under control. My haematologist suggested we double my prophylactic dose

over a course of a week. Because of that I have now gone from 6,000 units to 12,000 units and because of that I am actually able to work out and I am much more robust. I am able to exercise and my blood pressure has begun to rise again. I am getting fitter and stronger.

- 26. I have been treated for non-Hodgkin's lymphoma. This left me with general ill health, run down, looking and feeling terrible. I was mentally unable to cope, feeling isolated. Then there was the social impact, not being able to have a career, the financial things, fighting tooth and nail to get every penny out of the government as well as the physical things that I have covered above.
- 27. There is also the medication I have had to take since a teenager. They really used to be really harsh, the AZT and all these first drugs that came out. Now there appear to be debates, if in hindsight, these drugs did more harm than good. They were so toxic, it was a low level chemotherapy, it really damaged your central nervous system. I had terrible anxiety, paranoia. I really struggled to function, had social anxiety. I had a horrible time forming friendships or romantic relationships or relationships with work colleagues. It was a disaster and I never slept properly for years and you know that's one of the worst possible things for anyone anywhere. I was always exhausted, waking up in the morning feeling like a car was parked on top of me. But I would get up and try and get on with things. Yes, terrible, the HIV drugs were terrible.
- 28. Then there was the early generation of hepatitis C drugs. The Ribavirin and Interferon treatment was horrendous. Some people kind of tolerated it, but other ones.... Some people actually committed suicide or needed long term psychiatric care. I took it twice, once in my 20's, I managed it for 6 or 7 months but I was drinking at the same time. The 2<sup>nd</sup> time I tried it in my 30's I actually ended up in a psychiatric hospital. I had to come off it at once because it really affected me. I could actually feel the top of my brain fizzing, like a bottle of lemonade that had been

shaken up, it was sparkling and fizzing. The doctors at the hospital saw the state of me, highly distressed and full of anxiety so they gave me diazepam, to calm me down. It was not long after that, that I was put in the psychiatric hospital, I was in a state of acute confusion. I was about 30 when that happened. There has been a whole catalogue of that and physically all kinds of suffering, the side-effect sheet that you get with these pills, I've had most of them, muscle cramps, diarrhoea, flatulence, stomach problems, pains, fever, rashes, just on and on and on. I was admitted to **GRO-B**, psychiatric ward in **GRO-B**. I exhibit a letter which refers to this distress as a result of the hepatitis C treatment as **WITN2149009**.

- 29. I don't know all about the obstacles, but I do know that because of the strains of the NHS, they don't always give you the best, most expensive treatment first. They try out cheaper models of pills and if that doesn't work they bump you up to more expensive stuff. There have been times where I have asked, am I on the best treatment and it has been tweaked. I am on a blood based factor VIII product, I had a bit of trouble getting on that treatment as it was a Spanish based product called Fandi which is more expensive. It took wrangling to get that.
- When I had cancer the 1<sup>st</sup> time, the Haematologist in Inverness,
  Dr Forsyth said he was going to be in charge of my care. What he proposed was that he was going to take me off my HIV drugs and give me chemotherapy. I exhibit a letter from Dr Forsyth to Dr GRO-B as WITN2149010 with this proposal in October 2003.

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GRO-B	with Dr Forsyth and talked to me after.	She said,
"That sounds like	madness because, no matter what treatm	nents you
give someone with HIV, you always maintain the HIV drugs to keep		
the immune syste	m working". Every other medical profession	nal I have
spoken to since th	en has said that if I had done this, it would	have
killed me. I was ac	lvised to go to the Royal Hospital, Chelsea	in London

for treatment. I did, but they didn't have the adequate haemophilia resources to deal with me, so  $1_2$ 

was then sent to the Royal Free Hospital in a taxi. I was advised to just show up at the accident and emergency department to try and get admitted. That is where I went to get the chemotherapy. I had to fight to get treatment down there and I had to contact the Minister for Health in Scotland, Malcolm Chisholm at the time for his assistance getting treatment. The MacFarlane Trust that was set up to help AIDS patients. They did their best, they managed to rent a flat for me next to the Royal Free Hospital where I went through a horrendous winter going through chemotherapy. I was so ill, I could barely walk and I had to walk up this hill to the Royal Free Hospital daily. Yes, I had to essentially blast people down the phone to get help. I exhibit a letter that refers to where I was and what was happening by December 2003 as **WITN2149011**.

31. I believe that there were treatment plans that I could have had at the time when I was a child. I should have not been given American products in the first place. Lord David Owen said Scotland should have been self-sufficient and he set aside money from the budget for that, but then he got shifted to another job and his plans were shelved and they never went forward with the plans for self-sufficiency. The Government just bought these infected American blood products and infected thousands of people. I should have recieved HIV treatment far earlier, the HIV doctors generally did their best for me as did the Hepatitis C doctors; however, I say that and there is the Haematologist saying that, we can actually double your medicine dose from 6,000-12,000 units. I was in hospital at the Edinburgh Royal Infirmary because I was having massive problems controlling my bleeds. I was having a terrible time with my shoulder which I thought was due to a bleed, I could not even lift a cup when I was admitted. The doctor said if you are having trouble controlling your bleeds we can double your dosage. He said there's a range of acceptable ranges with people on Factor VIII so we went for this. Since doing so, I have been great, I have been to the gym, swimming 3-4 times a week, I am getting fit and strong. When I got home from the hospital, I cried, I wept, because I am 43, why has it taken until I am 43 for someone to say you could be on double the

dose of haemophilia medicine and it will help you. I thought of all the times... if you have a bleed you can't do anything. You have to lie flat on your back and if you are living on your own, some days you've got to get up, make your dinners, get washed, life goes on. I've spent, even just this year, I've spent weeks at a time, just stuck in the house on my own. Where I live, I am outside the city. A lot of friends can't drop in and don't have cars, so I have become quite isolated. Haematologists get a lot of heat from the civil service about the cost of the haemophilia medicine, because it is an expensive medicine. It costs the NHS a fortune. It's not our fault though, we are just born with the condition. Apparently they have introduced these 'treatment sheets' now where you have to fill out how much medicine you have had, when you've taken it, why you've taken it, how many times and they say it is to manage your condition, but what people are discussing is that apparently it is to protect the Civil Service and costs.

- 32. Getting hepatitis C and HIV has devastated my life. Having cancer, having heart attacks, all the suffering, all the rashes and fevers feeling unwell and physical and mentally exhausted. At points, I was starting to get visual distortions. I think it is just something that happens when your suffering sleep deprivation, I was at the traffic lights one day driving my car when I put my foot on the brake because I felt I was rolling backwards. The car wasn't moving; it was the fear, I felt like it was moving away from me, I was getting visual distortions. Horrendous. Terrible.
- 33. It's a lot more complicated to treat someone with all these conditions isn't it. They have to take all these other precautions. This CJD thing too there's a lot of uncertainty about that. They don't know how this is going to pan out, it might come to nothing or it might be another epidemic in a few years if illness develops. I have not been advised I may have been infected with CJD as far as I know. I did get called in by Professor Ludlam in Edinburgh. I think he said, I hadn't been exposed to CJD through my treatment but I am not really sure. This is

the thing, given the track record of how much they have concealed from us. I am not worried about it because I have bigger fish to fry with everything that has happened to me. Most medical people are alright, but I've had junior doctors come to take blood from me and they have a big bloody space mask on, they are covered in aprons like their working for the FBI and all they are doing is taking a bit of blood from me.

34. Having HIV has had a massive impact. Trying to have girlfriends has been difficult and I am not able to have children now. I think I might have been able to at one point when I was younger. I did go to a sperm donation centre where they freeze my sperm to a certain date. I don't think they kept it or its past its shelf life now or I wasn't ready to be having children at that point. That was possibly before the chemotherapy; now, having had cancer twice and all these other infections, I am infertile, I won't be able to have children. Trying to have a partner, there's a lot of people who wouldn't entertain the possibility of being with someone who had hepatitis C and has HIV. Yes, it's been really difficult. I have felt really isolated in GRO-B , where there's barely anyone else there. I felt terrified and I didn't know what to say. I felt really isolated and alone and this probably contributed to me drinking and taking drugs. Trying to build friendships was difficult, I didn't know what to say to people. I felt for years, I had this terrible dark secret that I couldn't tell people and then I got the realisation that there's nothing to be ashamed of, it's just an illness that I got through no fault of my own. It's just been a total mess. I suppose it's tied in with my addiction as well, the isolation and the pain I've caused myself and others, yeah, the whole thing with sex and having HIV and hepatitis C, being a young man, and also an alcoholic and an addict it was a disaster waiting to happen. That's one of the things that drove me to enter recovery, this fear that I would wake up one night so out of my head that I would end up infecting someone. There was a lot of fear around this as well. Even with a stable loving relationship, what would happen if I did infect my partner. I've never been able to have

unprotected sex for that reason. In fact, I took a vow of celibacy when I was a teenager when they told me because I was terrified of infecting someone. I decided I would just not have sex. I was being daft, I never lost my virginity until I was 17 because of that though and I have never been able to have a normal sex life.

- 35. It is a terrible thing having the stigma attached to your diagnosis. People didn't understand what it was but, yes, on the whole, the community I was brought up in, were mainly pretty decent about it. There were pockets of the community that lived in fear and ignorance though. I had GRO-B who told me not to sneeze in the house and things like that. That really hurt my feelings.
- 36. Being diagnosed as a 14 year old, with no support and no hope, resulted in me having to drop out of school with only a few O grades. I was smart enough that I could have gone onto university. The diagnosis came at a crucial turning point in my life. I rejected everything GRO-B GRO-B

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GRO-B	, it's very difficult, because I was so physically		
and mentally unwell.	GRO-B		GRO-B
	GRO-B		
GRO-B I was di	rinking a lot and rea	lly angr	y. That has left me

with a lot of regrets from missed opportunities.

- 38. I've not been able to work, I've got by on benefits. There's more financial support now for the infected, more than there used to be. I do remember I was just sort of getting by daily and struggling a long time ago. I've probably done better financially than a lot of the other infected people, because of course I have HIV and Hepatitis C, so I get payments for both. I also got the stage 2 support because I have had cancer twice, but there is a lot of them who have been suffering terribly, but according to the system, not suffering enough to be getting any ongoing support.
- 39. I've never been able to get any sort of life insurance. I've never bothered with travel insurance. I had troubles getting a mortgage as well, barely anybody could get a mortgage at one point. I did get a financial adviser through the MacFarlane trust who managed to arrange a mortgage for me with one company who would do it, but it was a fight all the way.
- 40. There was a huge impact on my parents when I was infected. They were devastated. My mum had some sort of **GRO-C** . My dad gave up a well-paid job **GRO-B** to come home and look after us all. He started **GRO-C** . He couldn't cope, so yeah it devastated them and their physical and mental health as well. When you care about someone so much and you see them go through so much, it affects you and it affected them. My brother, he thought I was a goner, he's thought that loads of times when he's seen me in hospital beds, wired up to machines, tubes coming out of me, at death's door. There have been lots of times he thought he was going to lose his brother.

### Section 6. Treatment/Care/Support

There has never really been any kind of support for me for a lot of this.
 Psychologically, I wasn't given a counsellor when I was diagnosed, I was just told to get on with it. I exhibit a letter from GRO-B to my

GP in 2000 pointing out my distress and that counselling was not enforced after my diagnoses as WITN2149012. It really traumatised me. I had to drop out of school and all the rest. The Inquiry is offering a counselling service which is really good but, its 30 years too late. Yes one of my doctors a few years ago said, "You've most likely got PTSD because you've been through numerous life threatening events, you've almost died numerous times". I have symptoms of heightened alertness and wariness, anxiety, trouble sleeping, outbursts of anger and surprising emotions. I explode and shoot my mouth off and do things that I don't mean. The doctor who said I probably had PTSD, it was the HIV doctor in Inverness. He was a kind man; he really did his best for me. I'm possibly a bit better now, just there was a point when I was on edge, nerves, just a nervous wreck, somebody would close a door and I would jump out of my skin, or someone would lift their hand and I would recoil and flinch.

#### Section 7. Financial Assistance

- 42. Yes, so I am not sure when I found out about the financial support that was available. I think it took maybe a year or two to get it sorted.
- 43. I believe I received a lump sum from the MacFarlane Trust and certainly from the Skipton Fund, I think I received £20,000 and then a further £30,000. If you are stage 2, then there are regular payments from both and certainly it's now been amalgamated with the infected blood scheme, I get payments every month and this is good because this is one less thing to worry about. With money coming in, I have been able to put this to good use and I've done lots of good things which has allowed me a certain quality of life. There's a lot more to life than money but it's a huge worry for people. It would have been awful if I had, had to bust a gut in a dead end job, because I don't have an education. I am not even able to get an education now, because I can't remember anything. I would have loved to have gone to university or college. I can't even read a book now.

- 44. It was not a question of how I got the viruses so there was never any debate about that when applying. Dr McKenna who said I had PTSD, he was also the doctor who assisted me with receiving me the stage 2 payments from the Skipton fund. He wrote a strongly worded letter. saying I have got hepatitis C related cancer and I was definitely eligible. I have received money from MacFarlane and Skipton fund and I have got all the maximum payments having had both viruses and having had my cancer and Hepatitis C related cancer puts me in stage 2, but as I say we have had to fight the Government and reports and petitions to get to this point. With Professor Goldberg writing this big report laying out the psychological impact and trying to get it through to them. Just because you don't have sclerosis or cancer, doesn't mean you're not suffering. It's important for financial support because there's so many people who are too ill to work but don't get any sort of financial support. Too ill to work, but not ill enough to get financial resources. It is terrible that this has happened in the first place but further to that, people are living in poverty because of it, is horrendous.
- 42. The Trusts have been alright for me. I have heard that they used to do discretion things as well, so my mum applied once or twice for some help with a washing machine or maybe like a respite break. I think they did help with that, but you know this is the common thing that people say, it is a bit demeaning to have to go "cap in hand", can we get some money to get a washing machine or to go on holiday for a week? That this is the whole thing, you've got to prove that you are skint, you had to prove that you needed what you were applying for. People have to get supportive letters and then go and get two or three quotes from different companies. The Trusts would pick the lowest quote and then you would need to get a receipt to prove that you had bought it. It was a hassle, a bit of a demeaning process because you were thrust into this situation, through no fault of your own.

- 43. You had to prove your case and get quotes from different companies, the whole process and then you had to discuss your case with them, to see if you were deserving or not.
- 44. It is demeaning and its humiliating, I have had to apply for things and I have had to fight Governments since this has happened. All the letter writing and petitions and articles. **GRO-B**

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**GRO-B** It is extremely difficult. If this was a regular case of an organisation giving someone HIV on their own and we had the proper legal representation, we would receive what we are entitled to. We are entitled to millions just for the HIV and then probably millions for hepatitis C and then add in all the human rights abuses and the tests and the research without the consent. All the other lies, abuse and then the whole cover up and everything that happened and how we were silenced in some ways. All the murky dark things that happened, I would say we are due millions and millions pounds each really.

#### Section 8. Other Issues

- 45. All documents that I did have, I have passed to Haemophilia Scotland but as I suspect there are other campaigners who have loads more information than I have at present.
- 46. I do not believe that my solicitors have been provided with a full copy of my medical records. A full copy of the batch numbers of the products that I received that were contaminated were not located. The test sample that confirmed my HIV diagnosis in the 1980s was not located, notes about the discussion that my parents had with the hospital when I was diagnosed were not located and there were a number of records that were blacked out and illegible.

# Statement of Truth

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

	GRO-B	
Signed		

Dated Oct 15, 2020