IRO

Witness Name: Ian GRO-B
Statement No.: WITN2072001
Exhibits:
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF Ian GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November, 2018.

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

Section 1. Introduction

1. My name is Ian GRO-B. My date of birth is GRO-C GRO-C 1960. My address is known to the Inquiry. I am unable to work due to my disability. I intend to speak about my illness. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family life.

2. I would like it noted that I wish to remain anonymous for this statement.

3. I am married to Mary GRO-B we have been married for nearly 40 years. We have one daughter together who is 35 years old and two grandsons aged two and seven. I have brain fog as a result of contracting hepatitis C. This leaves me with memory loss and confused thinking. There will be things in this statement that I will have forgotten, the events I describe are a long time ago and I may get jumbled up.

Section 2. How infected

4. In 1971 when I was 11 years of age, I had to go to the dentist to have a tooth extracted. My dentist was GRO-C Falkirk. He couldn't stop my gums bleeding after the extraction. I was sent to Falkirk Royal Infirmary and was seen by Dr Birch. I then got transferred to Glasgow Royal Infirmary haemophilia unite for treatment after they could not stop the bleeding. I was diagnosed with having haemophilia type A. Haemophilia runs through my family. The severity of my condition was considered to be mild to moderate at this time. I was given factor VIII blood products to help with the clotting process.

5. Between the years of 1980 and 1990, I suffered with terrible nosebleeds on a regular basis. I would attend Glasgow Royal infirmary at the haemophilia clinic. I was under the care of Professor Forbes. I remember on a number of occasions that I was admitted on to Ward 3 into the care of Professor Forbes. I remember being the only boy in a man's Ward. Some of my records are missing in parts so exact details are only an estimate. I did apply for my medical records and recovered a number of records under the research archives at the haemophilia unit at Glasgow Royal infirmary and that this indicates that I received batch numbers A6705 – 87, A6862 – 87, A7195 – 874/5/88 for treatment for factor VIII. I also received factor VIII batch number 019323 in 1985 when I was under the care of Professor Forbes. I believe on this occasion it was for an arm bleed. This is when I

contracted Hepatitis C by being given contaminated blood.

6. I was not given any information about the risks of being exposed to the possibility of infection. I do not believe my parents were given any information about the risk of me being exposed to the possibility of infection. Not long after I had received the factor VIII blood products in 1985 for my arm bleed, I began to feel extremely unwell. I had stomach cramps, sweats and extreme vomiting. My skin went a yellow colour and I looked jaundiced, the whites of my eyes also became a yellow colour. I was extremely fatigued but was unable to sleep at night. My blood was taken for testing, Professor Forbes told me I had to Hepatitis non A and non B. I did not believe that this was a serious condition at the time as I had Hep B previously. Professor Forbes did not really explain the seriousness of the condition. He did tell me that the infection could be passed on to others through blood to blood contact. He did say that I had to be careful to avoid passing the infection on to others by not sharing tooth brushes or razors. He did mention something about washing cups thoroughly. He said that this was just a safety issue and that I should be aware but it was nothing to worry about. I remember at that time the AIDS virus was very prevalent on the TV. I did not link my infection with the AIDS virus at that time.

7. In 1987, I started getting the symptoms again that I had in 1985. Once again, I had severe stomach cramps, I was vomiting and my skin and the whites of my eyes had turned yellow. I was extremely fatigued and I wasn't sleeping. I knew that the hepatitis was active again. I went back to the haemophilia unit at the Royal infirmary and spoke with Dr Forbes. I told him of my concerns but he said that I couldn't possibly get the infection again. I had been having blackouts and on a number of occasions had fallen down the stairs. Dr Forbes said that he believed I was an epileptic. I remember Mary, my wife, was with me at the time. She was very shocked, how could it be possible that I had hepatitis as well as epilepsy. The epilepsy diagnosis was false but

nevertheless I was put on anti-convulsion medication. GRO-D

GRO-D

GRO-D. It was only when further investigations were conducted that the truth came to light. I had been diagnosed as an epileptic but in fact I was Hep C positive again. The anti convulsants they prescribed me at the time attacked my liver and the Hep C also attacked my liver so I was really unwell, passing out and hurting myself, it caused me to fall downstairs and you may be aware that these falls are extremely dangerous for anyone with a bleeding disorder.

8. I went to my own doctor, Dr Aitcheson, at the GRO-C as I believed my hepatitis had returned. He did do a blood test and I recall two days later the doctor came to my home address and said yes you have got hepatitis again.

9. In 1985 and 1987 not a lot of information was provided to me about the infection. It was just a casual conversation between myself and Professor Forbes that led me to believe that the condition was no big deal. However, I did do my own research and found out that was not the case and it was very serious. Around the time I received my diagnosis, my wife and I were thinking about extending our family. We had a daughter who was born in 1983 and we would have liked her to have siblings. I did not want to pass the infection on to any future

children. I didn't know at that time very much about the infection but I was certain I did not want to pass it on to anyone else. I therefore made the decision to have a vasectomy. This was a very distressing time as both my wife and I had planned to have more children in the future. When I discussed my thought processes regarding future children onto the medical staff, I was almost encouraged to have a vasectomy fairly quickly. I had the vasectomy effectively around 1986 aged only 26.

10. I did not get very much information at all to understand or manage the infection in either 1985 or 1987. It was a very light-hearted and casual conversation where Dr Forbes just talked to me about not sharing toothbrushes and to be careful with needles. He did also tell me to use protection when having sexual intercourse. I ended up doing research myself regarding hepatitis C, it was during this research that I realised that the condition was very serious.

11. I do believe that I should have been given information at the earliest opportunity when it was discovered I had hepatitis C. I do believe that I should have been given more information about the blood products that I had received, before I was officially diagnosed. Very often when I was receiving factor VIII blood products at the Royal infirmary, I would notice that the bag had American and Australian labels on them indicating that that was where the blood had come from. I do remember I questioned this but I was always told by the doctors that the blood was from the United Kingdom but the bags that the blood was in were manufactured in America and Australia.

12. The information that I had contracted hepatitis C was said to me very casually, it was as if it was no big deal. I was very much left on my own to draw my own conclusions as to what the prognosis would be.

13. I was told not to share toothbrushes or razors and to practice safe sex. Dr Forbes did mention having separate cutlery and cups. In February

2009, I received a letter from the health protection agency, Scotland, telling me that there was a risk that I had also contracted variant CJD. The doctors weren't able to confirm this because there is no test in existence until after you are dead and they do a post-mortem. I was informed at the haemophilia clinic that one of the products I had received had been from a donor who had died. This donor was carrying the VCJD virus but I do not know if that is what he had died from. Even though it cannot be established if I do have variant CJD, I have to live with this every day. I have to tell doctors and nurses, dentists, insurance companies, mortgage lenders etc. that I am at risk. I find this very stressful and embarrassing and it is constant reminder on the back of my mind every day of my life. Not only do I have to live with the hepatitis virus, I also have to live with the knowledge that the variant CJD virus could also be in my blood and I could get symptoms of this infection at any time. I often wonder what else do I have. I worry constantly regarding my future health. I have imagined what this infection would entail, I have researched this infection and realise the symptoms are quite similar to hepatitis C, I am often stressed and anxious and worry about my wife's financial security should I have variant CJD and the prognosis for it. I worry that my life insurance will not pay out if they find out that there is a risk I have variant CJD. I am worried that we won't get insurance or cover at all so I keep paying premium ongoing no matter what the cost. Every year the pay-out decreases but we pay the premium no matter the cost, just to make sure I have life insurance. I remember I did ask a doctor, I cannot recall who, was it possible I had CJD. The doctor's response was in "Do you want to know?", "If you don't know it might not affect your life". I can remember being really annoyed at this comment, I live every day with the knowledge I may have this infection and it affects every aspect of mine and my wife's financial security.

Section 4. Consent

14. I do believe that I was tested without my knowledge. Every time I

attended hospital, I had my blood taken. I would often ask why they were taking my blood to be told it's just routine, I trusted the doctors and nurses to be doing their job, it just became standard procedure.

15. I assumed they were taking my bloods to monitor my clotting levels so I didn't really question it. I did not consent for any other testing that may have occurred.

16. I believe I was treated and tested without being given adequate or full information. I remember on one occasion when I was at the hospital, Professor GRO-D approached me and said that he was running a lecture to medical students. He asked me if I would speak to the audience about my life as a haemophiliac. I agreed to this. I was in a wheelchair at the time as I had had a toenail removed. I remember he pushed me in the wheelchair into an auditorium where all the students were. I began to speak about my experiences of contracting hepatitis C and how it had affected my life. I also spoke about my misdiagnosis of epilepsy. In the middle of speaking about these experiences Professor GRO-D suddenly grabbed the wheelchair and wheeled me out of the auditorium before I had finished speaking. It was obvious to me that Professor GRO-D did not want me to speak about those experiences. It would seem to me that he did not want the mistakes that had been made broadcasted. I felt annoyed at the time as I believe students can only learn by listening to the mistakes and experiences of other individuals.

17. I do believe that my bloods were tested for the purposes of research. The fact that some of my medical records have surfaced through the research section of the haemophilia unit at Glasgow Royal speaks for itself. The mental and physical effects of being infected with hepatitis C has been profound on my life. Physically, I'm constantly fatigued, I am often in bed at 6PM. Mentally I am not the man I used to be. I used to be an outgoing person and love to socialise, I was happy with my life and my glass was always half full. Since I was infected with

hepatitis C my personality has changed beyond all recognition. I became and still am very depressed. I isolated myself from my friends and family. I have lost all confidence in myself and due to the brain fog, I do not want to make a fool of myself and feel that I'm better off being isolated. I remember on one occasion when I was in a public house socialising with some friends. We were playing darts, as I was playing I couldn't subtract my score. I felt such a fool, humiliated and embarrassed and I just left. It is these sorts of incidents that caused me to become withdrawn.

18. In 2010, I had to have my gallbladder removed. My gallbladder had been damaged by me contracting hepatitis C. Due to my brain fog, which is also linked to the hepatitis C, I struggle to do tasks that would have come easily to me in the past. Tasks that came so easily to me before are now a major issue. I rarely drive any more but if I do I always want somebody in the car with me. I often forget where I'm going and forget directions, ending up in the wrong place. I have two young grandson's and I worry that I could be a danger to them. I find myself doing ridiculous things like putting bleach in the fridge. These sort of incidents cause me great anxiety when my grandchildren are around.

19. I have never had any treatment for hepatitis C. In 1985, when I was first diagnosed the infection spontaneously cleared. In 1987 I was being treated wrongly for epilepsy as opposed to hepatitis C and therefore no treatment was mentioned at that time. Through my plight to get justice for myself and others, who were given contaminated blood and blood products, I am aware that there was a treatment available called interferon. I am aware that this is a gruelling treatment with severe side-effects. I am not sure if this treatment would have helped me

20. I do not know if there were any other treatments available to me at that time. If there were, they were not offered to me. Sometimes I wonder if

the treatment for Hep C was deliberately withheld from me, maybe it was all part of some research. I feel that to have been infected twice with different batches was beyond negligence I should never have been given untreated product after contracting Hep C, the first time which led to a second infection and a misdiagnoses of epilepsy.

21. About five years ago, due to my infection with hepatitis C, it was discovered my gallbladder was damaged and I had to have an operation to remove it. When I came out of the theatre I remember the surgeon saying to me "You are an expensive patient. We had to archive everything in the theatre because you have a variant CJD risk". The surgeon was referring to the instruments they had used on me. He told me that the instruments would be kept for me specifically, in case I required further operations. I remember I felt deeply embarrassed and dirty at that time. I was forever conscious of informing medical professionals of my condition for fear of infecting them. I remember on one occasion I was due a blood test. I was at my local doctor's surgery. I noticed there was a notice on the wall saying that they were changing from a paper system to a computer. I went in to see a nurse to have my bloods taken. I do not recall her name. As she was about to take my bloods I asked her to put her rubber gloves on she replied with a laugh and said "why? Are you a druggie", this made me so angry. I informed her of my infected status and also that I was at risk for VCJD. My infected status was not on the computer. It wasn't transferred over by the third party company acting on behalf of the NHS to transfer from paper files to Doctors Surgery computers, this isn't good enough. Just another stigma problem to make me feel dirty and ashamed. I remember she became annoyed that the system hadn't flagged up my infected status. She started rummaging through cupboards in two rooms trying to find rubber gloves only to go and knock on a doctor's door to ask them if they had a pair of rubber gloves. I found this extremely embarrassing and again I must stress again very uncomfortable and dirty.

22. I do not have a social life any more, I rarely go out. I have no confidence any more to mix with others. Because of my brain fog, I often forget people's names, this is of huge embarrassment to me. For these reasons I would rather stay in. As my wife is out working I often get lonely. One of my biggest regrets is my relationship with my grandchildren. They are normal, boisterous boys but very often very noisy. If they are at my house I often take myself upstairs to avoid being in their company as the noise becomes too much for me. This is a source of great sadness for me as I long to have a close relationship with them. My parents split up when I was a young boy and I was brought up with my grandfather. My grandfather had extremely high standards that he passed on to me. I want to pass on these standards to my grandchildren for example, cleaning their shoes. I am often accused of being snappy with the boys. I used to be a carpet fitter and I have many skills that I wish to pass on to my grandson's but with the brain fog I've lost my confidence, I do not see my daughter or my grandchildren as much as I used to. I do enjoy gardening but in the winter months it's difficult to get out into the garden. I used to like photography but I can no longer focus on it. I found I was doing silly things like not taking the lens cap off, or forgetting to put in an SD card into the camera. I found I was doing this repeatedly and I became extremely frustrated with myself and ultimately sold my photography equipment. I do not see much of my extended family as nobody wants to discuss my condition. This obviously increases my isolation. I do carry a lot of guilt around, particularly in relation to how my infected status has affected my wife. I'm clearly a different person to the man she married. My wife suffered from a brain tumour some years ago, after extensive surgery, she herself was on anticonvulsants to prevent seizures. The doctors wanted her to come off the medication but she refused for a long time because she felt she had to look after me. We have been married nearly 40 years but my illness and the effects it had on me has put a strain on our marriage at times. I can be very moody and snappy and get extremely depressed. I also feel guilty for how my infected status has impacted on my daughter as a child. My

decision to have a vasectomy meant my daughter grew up with no siblings. She once told my wife and I that she was a lonely child and always wanted sibling. She has told us that she always felt isolated at school, being an only child. We did not tell her that my Hep C status stopped us from giving her a sibling. She did not know until we told her around the age of thirty.

23. I am well aware of the stigma that surrounds hepatitis C. I remember the doctors telling me when I was diagnosed not to tell anyone. Hepatitis C is associated with people that use drugs. The doctors warn me that people will wonder how I contracted hepatitis C. I worried that people would think I was dirty and would not want to know me. It always scared my wife and I in case someone found out. I lived in constant fear that someone would find out about my infected status. For this reason my wife and I didn't tell anyone about my condition for many years. We didn't even tell our own daughter until about four or five years ago.

24. Many years ago, I decided I would tell my wife and I's best friends that I had hepatitis C. They were obviously concerned as to whether the infection was contagious. I would often kiss my wife's friend on the cheek as we were leaving. I remember she asked me if she could catch hepatitis C from me kissing her. Despite my reassurance that the infection could not be passed on to others this way I now know that they went to a doctor to speak about my condition and how the infection could be passed on. This really hurt me at the time. The stigma and the misunderstanding of how hepatitis C can be passed on to others affected my relationship with my father. My parents had split up when I was young and I lost contact with him. Many years ago my older sister told me that she had found out where my father was, I was desperate to meet him. She refused to give me his address. She told me the reason was that she didn't want me meeting him in case I infected him with hepatitis C. I did eventually meet my father but her decision to not tell me where he was robbed me of a longer

relationship with him as he died quite young through an industrial accident. My wife and I have lost many friends after revealing my condition.

25. There were no educational effects of being infected with hepatitis C.

26. I have always been a hard-working man and took pride in providing for my family. In the 1980s, I was working with GRO-D, driving a van doing dispatches. I had been employed with GRO-D for over eight years before my diagnosis. When I was having seizures and blackouts and was being wrongly tested for epilepsy, the doctor took my driving licence away from me. Ultimately I was no longer able to work. I subsequently lost my job and could no longer afford to pay the mortgage. I ultimately lost my home and as a family we had to move into council accommodation. Financially, things were very bad at that time I remember sometimes only having £5 to last us as a family all week. This put a great deal of strain on my wife and I.

Section 6. Treatment care support

27. I do not feel I have been supported throughout this whole experience by the medical profession. It has always felt like an 'us and them' mentality. From the way I have been treated, I have no trust whatsoever in medical professionals. It has taken me over 30 years to get counselling for what has happened, I had to seek it out myself, no one ever offered. My doctor did refer me to a group in Falkirk for counselling. This was a group for people with dementia. This did not support me in any way. I remember the doctor at this group prescribed me with antidepressants. As soon as I began to take these antidepressants I felt extremely ill, I clearly had a bad reaction to them. My tongue swelled up and I was shaking. I remember looking on the leaflet with information about the drugs and it clearly stated they should not be given to anyone with a blood disorder. I immediately

stopped taking the pills and went back to see the doctor. Rather than support me, I felt she did quite the opposite, she did not seem to listen to me, she was almost telling me how I was feeling rather than me telling her. They then sent me to a psychologist, her name was Rachel Vickers, I saw her for about a year. I found her to be very helpful. She talked to me about mindfulness and gave me a CD to listen to, to help me relax. About two years ago, the Scottish government accepted that the people who had been infected through contaminated blood or blood products should be offered counselling to come to terms with their experience. I have been going to Glasgow Royal infirmary at the haemophilia clinic once a month now to see a psychologist, her name is Grainne. I do find this support very helpful. I just wish I had been offered counselling over 30 years ago. My wife attends these appointments with me in order to understand my mood swings.

Section 7. Financial assistance

28. I found out about the trusts and funds providing financial assistance through my own research. I found out through Haemophilia Scotland, in particular by GRO-A and GRO-A The doctors did not give us the information.

29. In 2003, I received a lump sum of £20,000 from the Skipton fund in either 2015 or 2016, I received a lump sum of £30,000 from the Scottish government. I recently got a letter from the SIBSS advising that I would be getting a monthly payment starting on 15th December 2018. I have since received my first monthly of £1500. This is to be for three years and then I will be re-assessed. I have received assistance with a heating allowance, I cannot remember how much that was for.

30. The form for Caxton was complicated and too long. I remember I tried to apply for a new fridge freezer at one point. The forms I had to fill in were very complicated and it was a very lengthy application. The form itself looked like I wouldn't receive anything because it was so difficult

it was not worth it. It felt to me that it was deliberately difficult. We didn't proceed.

31. I don't think there were preconditions applied.

32. I had to wait for many years for financial assistance. And even now the people that have been infected are classed into categories Stage 1 and Stage 2. These categories affect how much people received. I do not understand this, I feel it is almost as if they had tried to conquer and divide. I was infected, everyone got infected the same way. Nothing else should matter. No amount of compensation can equate to my suffering and mental torture. Being infected cost me everything my job, my home and my private and social life. For some, it cost them their lives, leaving many widows. The money I received paid of my mortgage. I needed to do that for financial security. I had already lost a home through my inability to work. I did not want to risk that happening again so as soon as I received the £30,000 I paid my mortgage off.

Section 8. Other issues.

33. I am also very deeply concerned about the matter of the Glasgow Royal haemophilia unit being moved to another location in the hospital. At the present location all haemophilia patients' files and records are held within the unit. When the move happens the new location does not have the space to store the patient's files within the new unit therefore they will be kept in a separate location away from the unit under a touch security keypad, and I don't know where and we all know how safe keypad systems are, one person gets the code then the next thing everyone knows the code. I am extremely concerned that moving these important files could result in documents being tampered with or going missing while the Inquiry is in progress. If anything did go missing they could easily blame it on the move if found out. It would be easier for this to happen if the files and records are not stored within the actual unit. I believe the person who is in charge of the mover is Melanie

McColgan, General Manager, Specialist Oncology and Clinical Haematology, NHS Greater Glasgow and Clyde, GRO-C.

34. I have provided an audio recording to Dan Farthing, head of the enquiry, of Professor Christine Lee. She is based down in England. It is an interview she did in 2015 where she says she knew 100% that people who received the blood would be infected with hepatitis C.

35. I wish to remain anonymous in this inquiry.

Statement of Truth

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

Signed GRO-B

Dated 17/3/2019