

Witness Name: Mary GRO-B

Statement No.: WITN2073001

Exhibits:

Dated: 21<sup>st</sup> November 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF MARY GRO-B

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

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

#### Section 1. Introduction

1. My name is Mary GRO-B My date of birth is the GRO-C 1960. My address is known to the Inquiry. I am married to Ian GRO-B we have been married for nearly 40 years. We have one daughter together who is 35 years old and two grandsons aged 2 and 7. GRO-C

GRO-C I have worked in GRO-B for 34 years. I have trouble recalling specific details about the hepatitis C and I have a lot of anxiety about describing matters as I have suffered from a brain tumour in recent years and have had significant surgery in relation to this. Therefore, I am

being supported by my husband Ian, for this statement. I intend to speak about Ian's infection of hepatitis C, in particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and I and our lives together as a family. I would like it noted that I wish to remain anonymous for this statement.

## Section 2. How Affected

2. Ian and I have been married for nearly 40 years, he was diagnosed with haemophilia when he was a child, which runs through his family. Ian was infected with hepatitis C later in life and this affects him to this day significantly.
3. Ian was diagnosed at age 11 with haemophilia type A. He had a tooth extraction and he could not stop bleeding. The severity of his condition was considered to be mild to moderate when he was younger. Now the severity of his condition is considered to be more on the moderate side.
4. Ian has had Cryoprecipitate, ReFacto, Plasma, Factor VIII and DDAVP, he has had these through the years whenever he has had a bleed. It is difficult to be precise about every treatment he received as his records are missing in parts. Most of his records are held under a research archive at the Haemophilia Unit at the Glasgow Royal Infirmary. I know that Ian suffered from terrible nose bleeds throughout the years in the 1980s and 1990s and he required treatment for this. When Ian applied for his records, he did recover a number of records under the research archives at the Haemophilia Unit at Glasgow Royal Infirmary and this indicated that he received batch numbers A6705-87, A6862-87, A7195-874/5/88 for Factor VIII treatment. He also received Factor VIII batch number 019323 in 1985 when he was under the care of Professor GRO-D and Professor Forbes. These batch numbers were significant as this is when Ian was infected with Hepatitis C. When Ian applied for his records at Gartnavel Hospital, Glasgow, where all records from all hospitals in Glasgow are held, he received a small

amount of notes which did not equal his amount of time in hospital or all appointments for his lifetime. When he queried the legal department at Gartnavel they said that was all they could find on the system. Ian then said to them "Well it must be true that files are being shredded". The hospital then phoned back about 30 minutes later saying she had phoned the haemophilia unit in Glasgow Royal Infirmary on his behalf to see if they had any more records there. The hospital reply was yes and that they were not on the main system and that they were held under research. When she asked for them to be sent to her in Gartnavel by taxi, she was told that it couldn't be done as they were not allowed to leave the Haemophilia Unit for the purpose of protecting the patient and the unit. She then asked if she could send someone into the Haemophilia Unit and photocopy everything they had on Ian which they gave permission for.

5. Ian has been treated at Glasgow Royal Infirmary since he was 11 years old. My understanding is that this was a small unit when Ian started to attend. Gartnavel records legal department say that the unit did not treat Ian as a child and he did not attend until he was an adult. This is false. He was transferred there to the haemophilia unit when he had a bleed from Falkirk Royal Infirmary. He remembers being the only boy in a man's ward. It was Ward 3 at the time. Ian's GP was [GRO-C] [GRO-C] in [GRO-C] when he lived there in the 1980s and 1990s. Now he is at [GRO-C] [GRO-C]
6. The date that Ian received the infected blood products was in May 1985 and 1987.
7. I am not aware of any information that Ian or his parents were given about the risk of Ian being exposed to the possibility of infection.
8. Ian was told he had hepatitis C in 1985 and then he was diagnosed a 2<sup>nd</sup> time in 1987. He was in his mid-twenties when he was given the

first diagnosis. He had suddenly turned quite yellow in 1985 and was experiencing cramps, he was quite unwell, bed bound and was suffering from regular nose bleeds. When the doctors tested him and told him this was hepatitis non A, non B, Ian didn't think this was serious at the time, because he had previously been diagnosed with hepatitis B and thought this was the same thing. No one ever explained the details of the illness. The haemophilia unit had called him to come in, in 1985 to tell him that he had this infection and he was told to be careful about spreading the infection. He was told to tell other doctors and dentists about the infection and be careful about sharing toothbrushes. They didn't fully explain the risk of spreading the infection though. The doctors just said it was a safety issue that Ian should be aware of this but it was nothing to worry about. AIDS was highlighted on TV at the time but originally Ian didn't link the two. The 2<sup>nd</sup> time he was diagnosed was in 1987. I can't recall details of this, Ian tells me it was a casual conversation, at the haemophilia unit. Before the 2<sup>nd</sup> bout of Hepatitis C was confirmed, Ian was positive that he had hepatitis C again as he recognised the same symptoms. The doctors were adamant that it wasn't Hepatitis C and that because he had been collapsing and passing out regularly and randomly they diagnosed him, rather quickly after only a few tests, as epileptic. They proceeded to prescribe anticonvulsants, which attacked the liver making him feel worse as the Hepatitis C, was also attacking the liver. Ian tells me it was Dr [GRO-D], Professor Forbes and Dr [GRO-D] who were involved in the epilepsy diagnosis in 1987. There is a letter in existence which was written on 3<sup>rd</sup> August 1987 that was written to the department of Neurology and Electroencephalography, about the possibility of the troubles he was having being related to epilepsy. They made an incorrect presumption. [GRO-D]

[GRO-D]

only when further investigations were conducted that the truth came to light. It was during this time that we had to put our house up for sale, as we could not afford to keep up with mortgage payments any longer. We had to go on the council waiting list and declare ourselves homeless.

9. In 1985 not a lot of information was provided about the infection. It was just a casual conversation and Ian was led to believe that this was not a big deal, however he did later figure out this was not the case and it was very serious. Our daughter was born in 1983 and by the time of 1985, we were thinking about having more children, however because of this and the diagnosis, we both realised that we didn't want to pass the infection onto any future children. We made the very difficult decision for Ian to have a vasectomy. This was partially driven by a lack of information on the subject, which years later is extremely distressing thinking back, thinking that we could have had more children. We do feel that Ian was encouraged to have a vasectomy very quickly at age 26 and the doctors were a bit too willing to arrange this. Ian had the vasectomy around 1986.
10. Not much information was given at all to understand the infection at either diagnosis point. Ian doesn't remember the name of the consultant who told him about his diagnosis the 1<sup>st</sup> or 2<sup>nd</sup> time. It was really just little bits of information like, don't share toothbrushes, be careful with needles, be careful when having sex. There was nothing else. We ended up doing research ourselves and that is what led to our decision to only have one child. Counselling in hindsight would have been extremely helpful but there was never an offer. They explained very little but with hindsight I do wonder if they did not want us to know anything.
11. Ian found out the information when he became ill, it is difficult to answer if it should have been earlier. I do remember though that Ian was asking questions about the products for a long time before he was officially

diagnosed. He used to see that the products would have American or Australian labels on them, Ian would question this and the doctors told him that was where the bags were made!

12. The information was communicated to Ian quite casually, it was if it was expected and no big deal. This created a false sense of security for Ian and I, they really just left us to draw our own conclusions.
13. Ian was told not to share toothbrushes, to practice safe sex and have separate cutlery. I don't remember Ian being provided with any advice the second time he was diagnosed.

### Section 3. Other Infections

14. Yes, Ian was told there was a risk he had contracted Variant CJD. The doctors weren't able to confirm this because there is no test in existence until after you are dead. One of the products he received has had blood from a donor that died, he was carrying VCJD virus but wasn't told if that is what the donor died from, even though we are not sure if Ian will develop VCJD we still have to tell doctors, nurses, dentists, insurance companies, mortgage lenders etc that he is at risk so it is a constant reminder in our day to day lives. And now he lives with the knowledge that he may also have this. Ian feels like, well ok he might have this, but he doesn't want to deal with it. He received a letter in February 2009 from the Health Protection Agency Scotland, telling him about this. It just left him thinking, what else do I have? What else was in the blood? We have imagined what this might entail and it left our imaginations running wild at what could happen which is very distressing. What we did figure out was that if this did develop, it was not going to be pleasant. Ian is worried that his life insurance will not pay out if they find out that there is a risk he may have Variant CJD. We are scared now that we won't get insurance at all, so we have kept the same premium ongoing no matter the cost. Every year the pay-out decreases but we pay the premium no matter the cost just to make sure

we have life insurance. Ian did ask a doctor, I cannot recall who, was it possible he had CJD. The doctor's response was "*Do you want to know? If you don't know it might not affect your life.*" I find this strange as how could it not affect your life? He has a right to know when he asks, if possible. I think it was a junior doctor or a medical student that may have said this, I just remember that Ian was annoyed.

#### Section 4. Consent

15. Yes, we think he was tested without his knowledge. Every time he goes to the hospital they take blood tests, they don't take small amounts of blood either, they take large amounts. If we ask about what it is for, the answer is usually along the lines of this is nothing to worry about. Before we knew about Hepatitis C, we did accept this as we trusted the doctors.
16. Yes, for the same reasons as above, he accepted they were taking the blood to monitor his clotting levels so he didn't tend to question it, but he didn't provide direct consent for any other testing that may have occurred.
17. Yes, this has been a consistent problem for Ian. I remember a moment when Professor GRO-D said to Ian, "*I am running a lecture, I would like you to come along and speak about your life as a haemophiliac*", Ian agreed as he was happy to discuss this. I can't remember when this took place, what I do know is it was the 2<sup>nd</sup> time he was diagnosed with hepatitis C. So Ian was wheeled into the lecture theatre and he immediately spoke about how he was mis-diagnosed with epilepsy and the hepatitis C experiences; he instantly, without pause, was wheeled straight out the lecture theatre again. It was very much a case of we want you to talk but only if it is about what we want to hear. Professor GRO-D clearly didn't want the mistakes that have been made to be highlighted. These need to be highlighted though, the discussion needs

to occur to allow procedures and things to be acknowledged and to prevent future mistakes.

18. We believe that when Ian was taking the cryoprecipitate treatment he was probably being used for research as well. Ian was constantly worried about what was in this. He fears about what else could be lying dormant in his system. They took bloods then whenever they could. Whenever they spoke to us about matters it always felt like they were being careful to watch what they were saying. Some of Ian's records have surfaced through the research section of Glasgow Royal Infirmary which is the answer in itself.

### Section 5. Impact

19. Ian gets wound up very easily now. He has a different personality, very different from when we first met and got married. He has no trust in the medical profession, frankly he has little trust in anyone. He was infected in 1985 but they continued to give him the non-heated treatment and it is only when he is diagnosed the 2<sup>nd</sup> time in 1987, was he given the heat treatment, to prevent further infection. This utterly filled him with anger. To be diagnosed this terrible infection a 2<sup>nd</sup> time was negligent. What makes it worse is that no one is taking real responsibility for what has been done to him and this is apparently ok. It has taken Ian 30 years to get counselling for what has happened, but no one ever offered in the past. It needed Ian to get to the point of seeking help himself. He realised that he did need professional counselling eventually, but there are several decades of damage done now. Before all of this back in the 1980s Ian was a happy, outgoing person. Now he isolates himself and doesn't see family anymore. I often have to go to family occasions myself, he is too depressed to participate properly. He experiences brain fog now, which is very upsetting for him. He mistakenly feels like he isn't very clever anymore and he is scared in case he makes a fool of himself, or he worries what people will say and think about him.



20. Physically he suffered from problems with his gall bladder back in 2010 and we now understand that this could be related to the hepatitis C as well. He had to have this removed. His way of thinking has changed and it means in aspects of his life, he struggles to be competent to do some tasks which is extremely difficult for him. I do most of the driving, he rarely drives and even if he is driving he does not do this on his own. He forgets where he is going and forgets directions, ending up in the wrong place. He has discussed this with his GP, he isn't a danger though. It just takes him longer to process information. Names are a problem for Ian which is embarrassing for him.
21. Ian has never had any treatment for hepatitis C. The first time he was diagnosed, the infection spontaneously cleared, there was never any discussion about treatment. When it came to the point of the 2<sup>nd</sup> diagnosis, Ian had started having cramps unexplained pains. He felt it had come back, it felt familiar, it was the same symptoms, but when he raised it with the doctor they kept dismissing him at first until the point further investigations were done. It was only him pushing matters again which is fitting with history. About 4 or 5 years ago, Ian also had problems with his gall bladder and had to have this removed. When he came out of theatre the surgeon said to him "*You are an expensive patient. We had to archive everything in the theatre because you have a variant CJD risk*". Ian has told me he felt incredibly dirty when the surgeon said this to him. The surgeon was referring to the instruments they had used on him. He was then told that the instruments would be kept for Ian specifically in case he required another operation. Now, Ian finds that it will be 6pm and he will be really tired and has to go to bed. He has bad joints and other serious daily bleeding problems which he has self-infused treatment at home for.
22. Ian has had counselling treatment. He looks ok on the surface but underneath he is not happy. Now, he goes to see a counsellor at Glasgow Royal Infirmary once every 6 weeks. He also attended Rachael Vicars at Falkirk for support previously. I attended all his

appointments with him, as living with him was very difficult as we did not understand what was happening to him in relation to his brain fog. He has really been trying to deal with things emotionally now for the past 4 years. It was quite difficult for a while because there was a time it felt like Ian wasn't listening to me, he couldn't remember what we were discussing and we fell out a lot because I couldn't understand. Now I go to all of his counselling appointments with him to discuss how I am feeling as well. This has been a big help because I had to carry on for years and hold everything together. He can't say how he is feeling and sometimes he gets frustrated and upset with the grandchildren. He can't stand the noise in the room when everyone visits so he has to take himself out of the situation. Rachael has given Ian a CD to listen to when he becomes too confused or stressed. It has been really hard though. I don't know what he is thinking or what he means half the time. I work as well, so I feel stretched all ways. He wants to make time for the grandchildren but I know when he gets frustrated he just has to remove himself. It's not that he doesn't want the kids there, he does, it just he struggles with how lively and all the noise of everything going on at once. Ian feels his relationship with his family especially his grandsons, has been greatly affected. This has put even more pressure on him and he feels guilty about removing himself from family occasions. Ian always looked forward to teaching and passing on his skills to his grandsons but feels unable to do so without having any confidence in his abilities.

23. Yes, psychological support. He was sent to an old person's group in Falkirk which was for people with old age and dementia. It was just not appropriate. After a long time searching and enquiring eventually we saw Rachael Vickers in Falkirk Royal Infirmary memory clinic. She taught him some coping skills and he received talking therapy. She had previous experience with HIV patients. He really got a lot out of it. In the 1980s, it was a nightmare just to get someone to listen to him at all, when he realised the hepatitis C had come back.

24. The mindfulness treatment has helped and allowed him to take time out when he is feeling agitated and upset. He goes away and lies down in a dark space; he then thinks about decisions and feelings he has at the time. He finds this quite helpful.
25. Ian has to tell every medical professional he sees about his infected status. Then there was the story I describe above about the surgeon's insensitive comments about archiving the instruments in the theatre. He also found that when he was coming round from anaesthetic from the operation that it took longer for him to recover, his reactions, they were longer and slower because of the brain fog. Ian hates having to inform people continually about the infection, its embarrassing. There was one experience where he kept having to tell the Practice Manager at his GP surgery because they were changing their computer system and it wasn't done properly. So he went to see a medical professional and it didn't flag up that he had hepatitis C and at risk for VCJD. He told her and she asked him if he was a druggie. He said no and explained, and she was annoyed about this, that the system hadn't flagged this up. She started rummaging through the cupboards trying to find some gloves. This made him feel dirty.
26. Ian doesn't go out now; he has no social life to speak of. He is not confident anymore, especially with new people. He is a bit wary about mixing with others and would rather stay at home. He doesn't drink, he doesn't want to go out, which means he gets lonely. He doesn't see our daughter or the grandchildren as much, and he has no hobbies to speak of. He used to like photography, but he can't focus on it now, he found he was doing things like not taking the lens cap off, or forgetting to put in an SD card into the camera over and over again. He became frustrated and ultimately sold it. He doesn't see his sister much either. No one in the family really wants to discuss, which increases his isolation. Its only in the last few years that he has properly

acknowledged that this is not his fault. Before he felt he couldn't talk about it.

27. We didn't tell our daughter until about 4 or 5 years ago, about the hepatitis C. We kept it from her. She had known about the haemophilia though. She once told us that she was sad that she was a lonely child and wanted a sibling, which very much upset us because of our earlier decisions to have a vasectomy based on limited information. Over the years, I have suffered from periods of anxiety. I have just gone back on anti-depressants because I feel like my heart is pounding and I can't cope. I constantly worry that Ian is going to get worse. I worry, will I cope as he gets worse, will he cope? The emergence of the Inquiry is making things worse at the moment. I see him sitting in tears at points and when I ask him what is wrong, he can't get the words out to express himself.
28. Our daughter told us that she always felt isolated at school being an only child. This was because she was at hospital a lot so she would write about dad being in hospital. She did it so much, that a teacher contacted us because they thought she was making it up. About 4 years ago when he was forgetting a lot of things and not able to find things around the house, this was ultimately what prompted the conversation about the hepatitis C. Her reaction has been quite strong. She understands illness, our family have been quite ill in recent years. She has lost, her Grandmother, then Ian's Dad, her Uncle passed on and then I had the brain tumour in 2000, so she has the maturity and experience to understand. I was on anti-consultants myself during the brain tumour period, because I was having repeated seizures. The doctors wanted me to come off the medication, but I wouldn't for a long time because Ian needed me to manage things for the both of us. It wasn't good for me; it was necessary though.
29. I am constantly worried about Ian. Especially now, I worry how he will be in the future. I have had a tumour and it is not a guarantee that it will

never come back. I worry, if I go before him, how will he cope? I worry all the time, which puts me under a lot of pressure. I am working part time and taking Ian to a lot of medical appointments in Glasgow. I need to juggle shifts with travel time. I notice now that Ian is prone to saying things with "no filter" anymore. This means that he can hurt people's feelings without meaning it. My daughter has said to me that he has hurt her feelings by doing this, but he really can't help it. She knows he is ill, but it is hurtful. Every day it is a different day; we can never tell how he will be anymore.

30. The doctors told Ian when he was diagnosed not to tell anyone. Don't mention it. They warned him that people will wonder how he contracted hepatitis C. We worried that people would think we were dirty and no one would want to know us. It always scared us in case someone found out. That was a constant fear in the back of our minds so we learned to just keep quiet. Many years ago, Ian thought it would be fine to tell our best friends. I suppose their reaction was natural, fear. Ian would kiss a friend on the cheek to say hello, and there were two friends that asked about how easy it was to spread the infection by doing this. Ian was up front and reassured them, it was not something that could be caught this way, but they still went behind his back and spoke to a doctor. Later on they admitted doing this, which hurt Ian's feelings. We are still good friends but have lost many other friends after revealing his condition. We had all been friends for a long time before hand. I feel like my family have drifted away from us because they do things that we can't afford to do anymore or Ian doesn't want to join in. I think he thinks they don't care because he's too ill. I think we have said no a lot historically, so now they don't ask because they presume we won't go. I think people at my work presumed that Ian had AIDS because he had haemophilia which a lot of people did know. He is really lucky that he hasn't caught AIDS as well. We do feel like there was a period of time where we were constantly defending ourselves, reminding people that Ian was not a junkie and this was not his fault.

31. There were no educational effects of being infected with hepatitis C.
32. In the 1980's Ian was working with GRO-C driving a van doing dispatches; because he was having seizures and the doctors originally didn't know why he was having seizures, he lost his job. He had been doing this for over 8 years before this happened. This meant he was then off work for a while because he was really quite ill, having quite a lot of nose bleeds. Over the years he has tried to do a few odd jobs here and there and even tried taxi driving at one point, but this wasn't going to work ultimately. He worked for a company called GRO-C at one point. This was a company that bought and sold things on credit and he would deliver the goods, but then he hurt his back while doing this and he was not able to do this anymore either. Now he doesn't work at all, the brain fog means he is not able to work at all.
33. My work as a sales assistant has been ok through this whole experience. My immediate boss lets me go to counselling with Ian and adapts my shift patterns around this. I have dropped a day because I could not cope with the full 5 days a week and they have worked with me on this. I now feel at this point that I have to reduce my working hours again to look after Ian but also to relieve stress myself.

### **Section 6. Treatment/Care/Support**

34. Ian has not really been supported throughout this whole experience by the medical profession. It has always felt like a 'us and them' mentality. I think they are protecting themselves not just Ian. Yes, Ian has psychological support but he had to go and find one through the Haemophilia Society. The support is Glasgow based. No one offered a counsellor spontaneously. The GP referred him to group therapy to an inappropriate place as I describe above. He also started seeing a counsellor who had experience working with people with AIDs and HIV. A previous psychologist put Ian on anti-depressants which he was very reluctant to take at first as he has enough toxins in his body already.

He did try them but he didn't like them as he had a very bad reaction which put him in a very dark place. The side effects of said anti-depressant were not suitable for haemophiliacs as it had an effect on people with bleeding and liver disorders. Ian felt terrible and his tongue was really swollen so he stopped them immediately. She also was telling him how he was feeling, which he didn't like, it was only when he saw Rachael did his attitude begin to change. He felt she had a real understanding of how he was feeling and was keen to keep seeing her.

### **Section 7. Financial Assistance**

35. We found out about the trusts and funds through our own research, GRO-A and GRO-A through Haemophilia Scotland. The doctors did not give us the information.
36. Ian has received £30,000 from Skipton and the £20,000 from Skipton, ex gratia of course. No compensation. It feels like bribery. We got a letter from SIBSS recently advising that we would be getting a monthly payment starting on the 15<sup>th</sup> December 2018, but on the date I am providing this statement I do not know how much this is for. We have received assistance with heating allowance and we attempted to apply for a fridge freezer at one point.
37. We used one of their forms to apply for a fridge freezer, it was incredibly complicated and this wasn't something that could wait, we needed it for his treatment. We also had to jump through a lot of hoops for the awards it felt, filling in a very lengthy application. However now with the money we have received, it has allowed us to pay off the mortgage and things are a bit easier.
38. The form itself looked like you wouldn't get anything because it was so difficult that it was not worth it, it was deliberately difficult, I feel.

39. I don't think there were preconditions applied no.
40. More or less we have had to wait all this time for a little bit of assistance. For a lot of other people it is too late now. There are widows who have received nothing and have never been able to apply for life insurance. He got infected, everyone got infected the same way, nothing else matters. There are people who are considered stage 1 who have died before stage 2s. We don't know what to trust from the Government or the medical profession. We feel like doctors have benefitted from Ian's suffering. The trust is gone.

### Section 8. Other Issues

41. Ian has provided an audio recording to Dan Farthing to provide to the Inquiry of Professor Christine Lee. She is based down in England, it is an interview in 2015 where she says she knew 100% that people who received the blood would be infected with hepatitis C.

### **Statement of Truth**

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

Signed

GRO-B

Dated

22/2/19