

# ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN2663001

Exhibits: NIL

Dated: 29th November 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF **GRO-B**

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

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

#### Section 1. Introduction

1. My name is **GRO-B**. My date of birth is the **GRO-B** 1956. My address is known to the Inquiry. I am married to my wife **GRO-B: W** **GRO-B**, whose date of birth is **GRO-B** 1958, and live at home with her. Our kids are now grown up. We have lived in Edinburgh for many years and everything was fine until 2 years ago in July 2016, when we found out that **W** and my daughter **GRO-B: D** were infected with hepatitis C. **D** date of birth is the **GRO-B** 1981. I am self-employed and run a **GRO-B**. I have done this role for 36 years. I intend to speak about **W** and **D** infection of hepatitis C, in particular the nature of their

## ANONYMOUS

illness, how the illness affected them, the treatment received and the impact it had on their lives and our lives together as a family. I would like it noted that I wish to be anonymous for this statement and my daughter [D] wants no part in the Inquiry as she is frightened about the stigma and how it would ruin her life if it came out that she was infected, therefore her name should also not be included.

### Section 2. How Affected

2. [W] and [D] were healthy and had no prior health condition. [W] received a blood transfusion in [GRO-B] 1977 after she collapsed, losing consciousness in the toilet after giving birth to our eldest daughter, [GRO-B] at Simpson's Maternity Ward at the Edinburgh Royal Infirmary. The bleed was quite severe so the doctors gave [W] 2 pints of blood in a transfusion shortly after giving birth. This is the only transfusion that [W] has ever received to my knowledge. After she received the blood transfusion, she became really ill having an unexplained fever. She was lifeless and it took a long time for her to recover from this. I was made aware later on that she had had the blood transfusion but I was not told at the time. Neither of us were ever given information about the risk of being exposed to anything before or after receiving the transfusion.
3. After [W] gave birth to [GRO-B], she fell pregnant again and we lost the child, she had a miscarriage. Then [W] became pregnant with [D]. [D] was born three weeks premature. She had respiratory distress, because her lungs had not developed in full. I remember being fearful that we were going to lose her as well. I remember when [D] was born she was wrapped in a shawl. I was sitting down and the midwife handed her across to me saying: *"You have a baby daughter, congratulations"*. I held her for only a few seconds when the midwife calmly said to me: *"Can you hand her back? Press that buzzer behind you, but don't be alarmed"*. And then a lot of people came running along. I asked what was wrong and the midwife said: *"Nothing, she is fine, she is a bit off colour, we are going to*

## ANONYMOUS

*take along to the nursery overnight, you go home and get a night sleep".* I got up very early the next morning and went straight back to the hospital. They advised that [D] would be in an incubator over that weekend and would be on high oxygen. I went to see her when she was in the incubator and I put my hand in and held hers. It was there I noticed that there was a little drop of blood on her bedsheet. I was told that she had received a 'little drop of blood' to help her. No one had ever spoken to me about it before hand or in detail apart from that comment and I was at the hospital all the time. I never provided consent and no one asked [W] to provide consent either. We never even received information about why she needed the blood transfusion originally. I do not believe that [D] has been infected by [W] while [W] was giving birth to her; I believe that the infection came from a separate transfusion. When I pointed this out to the doctors many years later they said that they thought it would be quite unlucky if two members of the same family, four years apart, had been infected, which left us with the doubt of whether [W] had infected [D] or whether it had been this transfusion. They both had the same type of hepatitis so they were never able to get to the bottom as to the source of [D] infection. The only difference that was identified, was that the levels of the virus in [D] blood were higher than in [W]

4. [D] found out that she been infected with hepatitis C first, so the entire family were then subsequently tested which led to [W] been diagnosed. We never knew where the infection had come from, so we just all got tested just in case. It was a total shock. [D] was pregnant with her second child at the time and she had developed this itching, which can sometimes happen when women are pregnant. The doctors did all these tests, and one of these tests was for hepatitis C and that is how she found out. Everyone else in the family was clear, except [W]. I remember [D] on the phone crying to me as the doctors were insinuating things to her, basically telling her to speak to her husband in relation to how she could have been infected. Her husband, was tested and it came back for him that he was clear as well. Their two children were tested and they also came back clear.

## ANONYMOUS

I was going to be tested as well but I had a breakdown 21 years ago and refuse to go near a doctor now.

5. For **W** it was her doctor, **GRO-B** who is recently retired, who gave her the information about the virus. She was tested in July 2016 and the next day she received a phone call from the surgery asking her to come up back up. We knew right away then that **W** was infected. **W** came back and told me that she was given the results and the GP had said to her: *"We are really sorry to tell you, but you do have hepatitis C"*. They told her that she was then going to be referred to the Western General's Infectious Diseases Unit to see a consultant and get treatment. They explained that treatments were much better than what they used to be like. She went to the Western General and she saw the consultant and a very nice nurse called Sarah, who was fantastic. **W** took her medical records with her when she went and the consultant reviewed them and asked her, *"Where did you get this information about the blood transfusion relating to the incident in 1977?"*. **W** explained that she had recovered these records previously and the consultant said, *"Keep a copy of this, this information, it is really hard to come by, it's like gold dust. A lot of people will not get this, so keep it in a safe place"*, which we have.
6. Once **W** found out about the infection, yes, the information was adequate, there was no question. Once they saw that document, they were going to get her straight into treatment as fast as possible. They said to her that the treatment was a six-month course and it was much better than previous treatments.
7. **D** was heavily pregnant when she was diagnosed; it was three weeks before she gave birth when she found out that she had this infection. I remember I asked her *"Why did they check you for this now, but they have never checked you for this before?"* She told me that a hepatitis C test was not checked as standard. She was not able to sleep at night because she was having really bad itching which was incredibly intense, it was only

because the consultant had asked by her chance *"Why do you keep scratching so much?"*, that this all came out. They did not test her straightaway either, they kept an eye on it and it felt like they finally tested her for hepatitis C as an afterthought. When she found out that she been diagnosed with this, the consultant came back and said to her *"You've got hepatitis C"* and threw a cloth down at her and said *"You clear that up"* when she had the blood test. He would not go near her. She felt really violated by this and it was incredibly distressing. This was a consultant at the Royal Infirmary Edinburgh. He told her that they would refer her on for treatment at the Western General but because she had been so close to giving birth she put it all off for a number of months. I believe it was four months before she went for treatment. She was breastfeeding you see and this was her primary concern.

8. [W] had a standard eye test at [GRO-B] a year before her diagnosis and in this test it was revealed that there were changes in her eyes and that she had to go and get her cholesterol checked. This concerned [W] a lot, which she did and her cholesterol levels were fine. There have been a few times in her past medical history when she has had tests done and her liver levels had been elevated. Sarah at the hospital told [W] that this really should have been picked up on then as otherwise she was healthy. It is unclear why her liver levels were elevated but not picked up on in previous tests.
  
9. For [D] there have been a few times that her liver levels were elevated. She was put on medication and we do not even know what the medication was for when she was younger. This medication caused her teeth to turn black and we were told it was due to an iron deficiency. She had just got her teeth and they all fell out straightaway. I remember having to take her to the dentist when she was a baby in my arms. She had to be moved up to the dental hospital in Edinburgh and they ultimately had to remove most of her teeth. She was really young, maybe four or five when this happened. We do not know if this is a direct consequence of hepatitis C, but we have

## ANONYMOUS

three daughters and they were all fed the same way and the other two were fine. When she was crawling about when she was getting a bit older, she would complain that she would have pain in her knees. We took her to the doctor and they said maybe she was just attention seeking but now we wonder. She grew out of this and she became the tallest child out of her class however. She played football for Edinburgh Schools, she ran marathons, she was the fittest member of our family. As a baby, we took her to the hospital with random nosebleeds that would not stop and we have subsequently found out that these were all symptoms of hepatitis C.

10. The way the results were communicated was standard for ☐ W ☐ As soon as she walked into her appointment with her GP, she was told straightaway.
11. For ☐ D ☐ it was shameless that the consultant threw a cloth at her, especially when she had just found out that she had this infection. Regardless of how she was infected, she was infected and it was fairly poor to do that to her.
12. The consultant made the recommendation to ☐ D ☐ that everyone should go and get checked which was the advice she was given and led to ☐ W ☐ diagnosis.

### Section 3. Other Infections

13. Neither ☐ W ☐ nor ☐ D ☐ have received any other infections other than the hepatitis C as far as I'm aware.

### Section 4. Consent

14. The hospital did not tell ☐ W ☐ when she received a blood transfusion in 1977 and I was not told this had occurred either. For ☐ D ☐ yes, she was given the blood transfusion without anyone obtaining my consent or ☐ W ☐

## ANONYMOUS

consent. No one ever asked us, no one ever said anything. I remember being quite angry about this.

15. I believe that both [W] and [D] were treated or tested without their consent. I was just about to go home when [D] was born and I was told by the midwife that she was just being kept in the nursery overnight, she was just a wee bit off colour and to go home. That was the Friday night and by the Saturday morning when I was back up early, I discovered she had had a blood transfusion.
16. The first information we got was when we recovered [W] medical records and that is when we found the full extent out of the blood transfusion. The information was definitely not adequate for [D], [D] did not even know that she had had a blood transfusion until [W] told her and we were not told at the time.
17. I do not believe that either [W] or [D] have been tested for the purposes of research.

### Section 5. Impact

18. I have been working in [GRO-B] for 36 years. When the recession hit, it hit us very badly. [W] went out to get a job to help us out. A couple of years later, she then had to stop working and sign off sick because of the treatment. She has attempted to return to work in February 2017 but she has had to go part-time because she is so exhausted. I have been quite stressed as well, I am depressed now. [W] worries that something will happen to her liver now in the future. She will not go out and enjoy herself anymore with a drink or anything. There is a lot of tension between us now as well, we argue a lot more than we ever did before she was diagnosed. [W] has changed a lot, we snap at each other for everything, she has a habit of repeating herself over and over which sets us off arguing. She cannot sleep anymore which is in relation to the treatment. She was warned

## ANONYMOUS

that her sleep would get a lot worse after the treatment because of the effects that it has. As a consequence, she now has to take a lot of sleeping tablets to manage this. She only takes them when she really needs them though, the tablets are called Zopiclone.

19. For [D] she is really stressed. She is terrified people will find out, given the area of work that she works in, which I will not disclose in this statement, she is terrified it will come out. She has gotten herself into a terrible state about this Inquiry, she was worried that her children could be infected by her and she went into quite a rant about it. She said that was going to blow her top if they were. They were not though. She is quite highly strung. She can blow up about things quite easily now. I keep her updated on what is going on with the Inquiry and anything that comes up I will say to her and ask her if she wants to know. Sometimes she does want to know what's going on. She thinks for some crazy reason that if she gets involved in this inquiry her name is going to be put in the papers and have lots of things published against her. I have told her that she can provide a statement and remain anonymous if she wishes, but she has not yet taken me up on this offer.
20. For [W] after she was diagnosed, the consultant asked if [W] had any other conditions. [W] mentioned that she had asthma and the consultant asked her when she was diagnosed with this. [W] said about six years after she received the blood transfusion which caused the consultant to raise his eyebrows and ask for more detail. We asked if this was related and the consultant said "*We do not know, it could be, we just don't know*". She uses an inhaler twice a day now and uses it throughout the day if she feels a bit wheezy, but she finds it is quite manageable. She has never had an asthma attack. There was also another incident where I remember in 1996 when we tried to go on holiday and [W] was bleeding spontaneously quite seriously and we don't know why this was. We thought that maybe she was having another miscarriage but we went to hospital and she was checked and everything was fine, we never received an explanation for this.



## ANONYMOUS

21. We are not aware of any other complications for [D] other than what happened with her teeth.
22. [W] started treatment in September 2016 to February 2017 and she stayed off work. She went back to work after she completed treatment and then she was starting to get really tired. She had to go to sleep straight away after work as she was just exhausted. She told her employer that she was going to have to work part-time, as she could not cope with it anymore. Previously she had broken one of her toes but she had never had any other problems with them prior to treatment. Now she has arthritis in her big toe, it gets extremely painful. She had only started working in the job for a year and a half before she started but her employer was okay. Skipton or Caxton made up her wages when she went onto half pay, as she needed this assistance, and finally she was declared clear from the virus. Things for us though haven't improved even after she was declared clear. [W] and I used to do a lot together but now we end up bickering over anything. A lot of the times she will say she is too tired, she never had this problem before the treatment. If she lies down, I have to wake her up now, which is quite significant. When she was on the treatment, she would have to take 8 or 9 pills a day. I would often have to check the amounts that she was taking because she was not taking the right doses or the right pills at times due to brain fog that she experienced. I remember one time I was not there so she took the wrong dose. She phoned the hospital and asked what should she do and they thought it would be fine. It became a running joke that [W] would forget everything at one point but this was a consequence of the treatment.
23. [D] was on a short course of treatment once-a-day. The thing I find quite strange is that the treatments were very successful for the condition and it was only a few months that these treatments came in before [W] and [D] were diagnosed. I often wonder if the doctors knew that they were infected and were waiting to tell them once treatment was available. If

## ANONYMOUS

something like this happened, they should have been told. [D] virus is now undetectable. It was just an 8 week course and only 1 tablet a day which is much better than what [W] had. On one hand, I am grateful they have not had to go through the old treatments as they sound worse than the illness itself. On the other hand, they had a right to know if something had been discovered.

24. [W] personality changed. She would do things that she would have never have done before, we used to go out every weekend and now that has completely stopped. She has been told that everything is fine though, but she still has this worry. She was on ribavirin and two other medications but I do not know the names of these medications.
25. At the Western General Edinburgh, for [W] there were no obstacles. With [D] she delayed her own treatment as she was breastfeeding and then she was on an eight week course of treatment and is now declared undetectable.
26. Everything was as it is. It was the best treatment that they had available for both of them.
27. [D] was fine in treatment, I think in her case the levels were taking their time to come down but she was determined, no matter what, to go through with the treatment in full. She would describe it as feeling dirty; she could not believe it had been in her blood for so many years.
28. [D] does not want to tell her friends; she is terrified something is going to come out at her work. She feels dirty, she goes out much less now than she used to. We used to have a laugh because [D] would call the weekend her chill nights, she would have her glass of wine and crisps. Now she does not drink at all. For [W] she used to be really outgoing, we have been together since we were kids so we used to look forward to the point

## ANONYMOUS

where our kids would be grown up and the grandchildren and things would come about. Now [W] does not have the same outlook, she is really snappy and repeats herself over and over. This drives me insane. We have been together for a long time but it was never like this before we found out she was ill. She is also quite paranoid as well now and incredibly forgetful to the point of madness.

29. [W] tells people who are close to her about the infection, but she would hate the thought of it being broadcast. She does not mind telling her close family though; there is no other stigma that has applied to this. [D] however thinks everyone is going to judge her, so it is just her husband and immediate that family know. Her doctor told her "*Just don't tell anyone about the infection*", which I think emotionally has affected her and allowed for a fear inside her to grow.
30. I used to be constantly working. Now, I just send workers out and stay here. I feel like it takes too much out of me, especially with [W] I am getting flashes now, but I hate the thought of having flashes while workers are out with me so I disguise it. That is my own stigma and fear of others judging us.
31. [D] has her own business which I will not disclose for this statement and she also previously worked with [GRO-B] many years ago after she graduated from university. When we originally found out she was infected, she wondered if she had contracted the virus from [GRO-B] [GRO-B] but it was when I said to her "*No, you had the blood transfusion*" that we put two and two together and we got her medical records. She is a clean living girl so I knew it wouldn't be anything other than this for [D] Originally, she wondered if she had been infected at work because she had to clean people up if they cut themselves or anything like that but we know better now.

32. [W] had to give up work for six months while she underwent the treatment. She is a [GRO-B] [GRO-B] She has now returned to this on a part-time basis. She had originally taken this job to help us through a financial crisis when the recession happened in 2007, so this led to a financial burden for us, but we did get assistance from either the Skipton or the Caxton fund.
33. I have said to [D] that the doctors should be more ashamed than her but I understand that she doesn't want to advertise her infection. She does not want her name mentioned anywhere, she does not want to lose her livelihood.
34. I had a breakdown after my brother died of a heart attack in the mid 1990s. When I was trying to bring myself out of everything, part of my coping mechanism was to carry a small flask of whiskey around with me. I would never drink it, but I would just keep it with me in case I ever needed to calm down. I never used it and I found that in 2013, I was able to stop taking the flask around with me. After [W] was diagnosed, I started to get the anxiety again. I went from 2013 until early 2017 with very few anxiety episodes. Now I find I am getting really anxious again and returning back to this little flask of whiskey. I am working on controlling this and letting it wash over me when it happens.

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

35. I have never been offered support. The same for [D] and for her immediate family. [W] has never been offered psychological support either. They have never made it available, but I do know that now there are a lot of people who are infected and affected asking about this. I have never been tested for hepatitis C because I hate doctors, but I do believe that the emotions around this have pushed me back from my own recovery for my

own mental health issues that I dealt with in 2013. We have lived decent lives and we did feel at one point, why us? We realise it could have happened to anyone though. With [D] and [W], their relationship has been damaged. The two of them at one point, were at loggerheads for a long time. Before they were very close but I remember one incident after it all came out, that I had to step in on the two of them as they were screaming and shouting at each other. I do not know if there is underlying distress and hurt, that [D] secretly believes that [W] has infected her or vice versa. I think though, If I am honest the bond has been damaged because of it and they have drifted apart because of this.

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

36. When [W] was originally diagnosed, she was told by the consultant that she would receive a payment from the government. The doctor would have been the one that made her aware.
37. [W] received an ex gratia payment of £20,000 whilst she was going through treatment and then before treatment finished, she received £30,000. She was told that once treatment was over, if she wanted to go on holiday, the fund would pay. They gave us money to do this; they also bought her a three-piece suite. She received the heating allowance and a one-off payment of £500 and this was then increased to £1000 per annum from the Scottish Infected Blood Support Scheme. A few months ago, in October, they started to give [W] £461 a month. She then got a letter on the impact of hepatitis and said that there was going to be a review of this. [W] is considered stage one. There was a dispute between stage one and stage two because stage two received £27,000 per year but stage one didn't. The review came back and found that stage one patients were worse than stage two in some cases, so the NSS asked [W] to sign a document and send it to them. Recently they wrote back to us and said that they had taken note of what she had discussed with them and she was going to be receiving a payment in the near future but we do not know how much it was

## ANONYMOUS

going to be for. This will go into our bank account on the 15th December 2018 and will be backdated to September. At the point of providing this statement, I do not know what the payment will be.

38. [D] received £50,000 and got a heating allowance but she would not apply for anything else as her husband's income and her income are too high.
39. When [W] went part-time, she was not going to get anything from the funds because I was self-employed. I had to hand in my books to them and I remember asking them why they were considering my income, as it was [W] that was infected. They said that it was because we are man and wife, that I had to support her no matter what, so they had to take my income into account.
40. I am not money orientated but I feel the Government/NHS were giving no support previously. For example, now [W] gets £461 a month from the Scottish Infected Blood Support Scheme. What about the money she would have received if she had been told 40 years ago? They are 40 years too late.

### Section 8. Other Issues

41. I understand that people need the transfusions and things. What makes me angry though, is that there is a possibility that people knew that the blood was infected before giving it to everyone. The people had their choice taken away. [D] and [W] had their choices taken away.

ANONYMOUS

**Statement of Truth**

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

Signed

GRO-B

Dated

15/8/09