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Witness Name: **GRO-B**
Statement No: WITN2351001
Dated: 14th March 2019

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 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is known to the Inquiry.
2. I work as an **GRO-B** and I live with my long-term partner. We do not have any children. I intend to talk about my mum who was infected with Hepatitis C ('HCV'), following a blood transfusion. This lay dormant for a number of years. I will discuss the impact this has had, not only on my mum, but also on myself, father and family members.

2. How Affected

1. It is difficult to know where to start as I was so young when she was infected. As I was just a child, a lot of what I am about to say is what my mum told me

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when I was older. I have some problems remembering in what year events happened but the information I am about to provide is to the best of my knowledge.

2. I remember my mum going into labour with my brother, it was night time because I remember Z Cars being on television. She went to the [GRO-B] [GRO-B] which I think was called [GRO-B] however it is no longer there now. I am [GRO-B] this year and was [GRO-B] when my brother was born in [GRO-B]. My mum gave birth to my brother but there was a complication and she required [GRO-B] surgery. She was subsequently sent home, but she started haemorrhaging and was sent straight back to hospital. As she was haemorrhaging so badly the hospital gave her a transfusion of plasma. As a child of seven, I just remember mum being rushed off in the middle of the night and I went to stay at my aunties.
3. As it was an emergency situation, I doubt that she would have been provided with any information about the risks of being infected prior to the transfusion. Plus, she wouldn't have been in any fit state of mind, having not long given birth and worrying that she was about to bleed to death. She has never said that she was told about the possible risk following the procedure either.
4. Even though the infection lay dormant for a number of years, my mother was infected and living with HCV.
5. When she first became ill years later, she sometimes found it hard to describe how she was feeling, but she used to say that something was wrong, but she didn't know what it was. My parents lived [GRO-B] during this time, so the information I received was via telephone conversations, I didn't actually see them face to face during this period. I can't remember what year this happened, but since then she has never the same.

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6. My mum was diagnosed with HCV in [GRO-B] whilst living in [GRO-]. I know she certainly had hospital appointments [GRO-B] and if they never told her that she had HCV, then they told her that something was seriously wrong. I honestly can't remember fully.
7. From my recollection, when my mum discovered she had infected blood, it was a complete and utter shock as though she had never heard of it before.
8. I'm not sure if my mum was provided with information on how to manage the infection. My parents are very good at researching and are very good with technology. Even if they were given information, I'm sure they would have looked it up themselves anyway.
9. My mum never really drank alcohol. When we were children, there would be a bottle of wine or sherry in the cupboard and it would be brought out when people visited. However, most of the time it would end up being thrown away. Before she knew she had HCV when she was in a social situation and was offered a glass of wine, she would take sips but would invariably then leave it. Before she was infected, her liver would probably have been very healthy.
10. She was very healthy. She liked walking and was physically fit. She always made her own food from scratch and she was a very good cook.
11. If somebody somewhere thought that there was a possibility that my mum could have been infected, then she should have been given the information earlier. If there was no evidence whatsoever of a potential condition or an infection prior to diagnosis I can understand why she wouldn't be told earlier. However, if it is in someone's medical records, that they had plasma in an era where people could potentially have been infected, then someone should have come forward earlier without a doubt. If she had known earlier, she

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could possibly have managed her health even better, and considered cross-infection etc.

12. I can't remember how the test results were relayed to my mum. I do remember though that she was extremely upset and angry; my dad too.

13. I'm not sure what information was given to my mum about the risks of infection, or who gave it to her. However, she did talk to the family about the risk, so she would have got it from somewhere. Inevitably we had to have the conversation about whether we could have been infected. In hindsight, it could have been so easy for myself and my sister to have been infected. As children we had [GRO-B] bandages from our hands up to the shoulder and we had [GRO-B] on our arms and faces. It's scary to think that all it could have taken was for my mum to have had a cut too.

14. I talked to my mum about this and I think the main reason we weren't affected was because my mum didn't like the sight of blood and it made her feel faint. As children she would always say to us, 'if you see me cut myself, just get a chair and push it under my bum and leave me'. This was before she knew she had a contagious disease, but this just made us almost repel against the blood if we ever saw her bleeding.

15. My mum and dad [GRO-B] When you sit down and talk about infectious diseases, you can't help but think back and wonder 'what if...?'. Thinking back, thankfully my mum never breast fed my brother.

3. Other infections

1. My mum has [GRO-B] which has come as a result of being infected with HCV. I'm sure my mums' statement will specify the details.

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2. Physically she has [GRO-B] and more recently she has been diagnosed with [GRO-B]. Apparently, that is common with people with an [GRO-B] condition. I was able to go with her to this appointment and she was told it is more than likely to do with her HCV. She has had a few cancelations from the hospital as they couldn't do the procedure straight away, but she has now had it [GRO-B]. I've heard all the gory details on the phone about having to have a [GRO-B]. The worst thing is, they said she may have to have it again. If she didn't have HCV there is a good chance she wouldn't have this [GRO-B]. She also has to go regularly to have [GRO-B].
3. With regards to her [GRO-B] there may have been better medication she could have taken to help if she didn't have HCV. She would have been able to walk and exercise more so it would have helped. Due to the medication that she is on, she can't do these things. There are all sorts of things wrong with her but hopefully she will have discussed this in her statement; these are the issues that I am aware of myself. She just doesn't have the energy that she could have. If she was to have an accident or bleed, she would always have that instant feeling of 'don't touch me' or 'don't come near me'.
4. One of the side effects of HCV is memory loss. Previously she knew all her core recipes off by heart, but in the early days she couldn't remember a thing. She would follow a recipe but even then she would find it difficult. It affected her ability to concentrate and remember. What used to be an automatic task became almost impossible to do. Over the years she has had to rely on dad in the rare times she uses the kitchen.

4. Consent

1. I don't know if my mum was treated without her knowledge or consent. I know she has been in and out of hospital for a number of procedures over the years, but I don't know if blood is or should be checked routinely. I haven't really been in hospital much myself, so I'm not sure what the procedure normally is.

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2. My mum has told me that she has been unable to obtain her medical records and was told they had gone missing. Whether that is all of her records or just part of them I'm not sure. She told me that the hospital couldn't find them.

5. Impact

1. In the early days, she was very ill. I recall the worst time being when we were told to go to her hospital bed to say good bye to her. We all took it in turns to say our good byes. They didn't expect her to last the night and felt there was nothing else they could do for her. The doctors decided not to give her the medication she was taking; I think it was called Interferon. Although it might sound in some ways cruel that they didn't want to waste a tablet, it was the best thing to happen to her as the next day she was feeling a little better.
2. The medication obviously wasn't doing her any good. She was transferred to **GRO-B** as they thought she would have to have a liver transplant, but luckily she didn't need it. It really changed her, she was very different after this. Having to listen to your children saying good bye to you must have been awful. She did say afterwards that it gave her extra strength, she thought – I'm not ready to go yet! Her personality did change after that, I think. The change could have been because of a chemical reaction in the body due to medication, due to HCV itself, or just psychologically because of everything she went through.
3. Mum has become very controlling and she never used to be like that. My dad used to be the controlling one in the relationship, not that my mum was meek or anything as she was a strong character as well. It's as if they have swapped roles now. If I put **GRO-B** on I would say it's because she doesn't have control over her body or her illness, so she needs to be able to control something else in her life instead. It is usually projected on to my dad, as he is always there. He has had to deal with a lot of her internal anger about her situation. I've never heard her rant or shout and she has never broken down in front of me - but that's not to say that she hasn't broken down. However, they

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did spend a lot of time abroad during the initial diagnosis, so I wasn't physically there apart from visits.

4. I do witness her frustrations and need for control in her life. She has good days and bad days, some days she has to stay in bed all day. She just can't get out of bed because she feels not just tired but also unwell. She's unable to do the things she wants as she feels so unwell at times. Sometimes she will say she just doesn't feel right but can't explain why, other times she will describe her physical symptoms.
5. Mum and dad's relationship is under a lot of pressure and has been since her diagnosis because of frustrations and anger. My dad has a completely different role to play in their relationship now. He is now carer and husband. My dad is also unwell he has to go to hospital next week to check his heart, this is simply extra pressure. My mum does project all of her frustrations on to my dad because he is there for her and he has to find a way of managing those frustrations. He feels guilty if he goes out and leaves her even though she will say that he can if he wants to.
6. Before the diagnosis, they had GRO-B to retire early but reluctantly had to cut it short because of this illness. They just expected to be healthy and to be able to enjoy themselves. They had to moved back GRO-B as they felt it would be easier to get help and much needed family support. Not being able to go abroad is a constant niggle for my dad as he just wants to get them both in a GRO-B abroad but they can't do that now.
7. My mum has to go to GRO-B for her main treatment. It's less often now than it used to be, but every so many months she has to go and have a camera down her throat to check for varicose veins. This is in case they need tying up, because if they were to burst, she could choke on her own blood. This is yet another side effect of the condition.

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8. There was a time when she was in a lot of pain with what she thought was gallstones. I can't remember which hospital it was, I'm guessing [GRO-B] [GRO-B] but they told her she had gallstones. They also said that they couldn't treat it because it's so close to the liver. She spent many days in pain as it came and went. However more recently when she was last in [GRO-B] they told her that it probably isn't gallstones, but they are not sure what it is. I'm hoping they can give her clarity, there just seems to be no let up with her health, it's just constant. Her whole life is hospitals. But she is so strong, she is the strongest woman I know. She has been through so much.
9. This has affected her in all sorts of ways. Just one example, you have a woman in her seventies who has been sent a letter with an appointment to go to [GRO-B] When she gets to the hospital and shows the letter, the receptionist whispers to her, saying she needs to come this way. She had obviously looked at the letter and assumed my mum had something to be embarrassed about. She was brought to a department and was asked to sit and wait. She looked up at the walls and saw posters about STD's and realised she was in the STD clinic. She felt it indicated to her that she was bad and that she had done something wrong. She felt humiliated and disrespected as she is from a generation that would be really offended by that and particularly the way the receptionist treated her. She was really upset when she came back from the hospital.
10. My mum has been getting more frustrated recently as [GRO-B] and she wants to go around and support her. She goes and visits but will then end up in bed herself exhausted afterwards. I know in life things like this happen, it will always involve the illness and death of others, that's normal life. But when you have these situations on top of everything she has, it's much harder. Anyone who is not as ill as she is, when difficult things happen, you know you will get through it and there will be light at the end of the tunnel. However, with my mum she hasn't got that as she has to fight constantly.

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11. My mum is very good at not moaning, but she will tell us if she is going to the hospital. I think her attitude is if she was to talk about it all the time, then it would just make things worse and she wants to switch off from it sometimes. I'm sure there are things she keeps to herself. She does try to have as much of a positive outlook as she can.
12. She can't just decide to do something and then do it, she always has to consider how she is feeling. There are times when there are certain foods she cannot eat which means she can't be far from the bathroom. This obviously limits where she can go or who she can be with. Over the years there are times that she hasn't made it to the toilet on time and she felt it was all part and parcel of what was going on in her body. In the past, there were certain foods she couldn't bear, even though she liked it previously. She would just look at a particular food and it would make her want to vomit.
13. I'm not sure if she faced any difficulty in accessing treatments or whether there were treatments that she should have had but didn't.
14. The events concerning my mum have had a significant impact on me. Having to say goodbye to her in a hospital bed was very hard. It's hard watching the effect the illness has had on my mum but it's equally as hard watching the effect it has had on my dad. I suppose because I [GRO-B] I understand some of the dynamics of what is going on. I can make sense of some of it, not all the time as it's different when you're in the middle of it. Sometimes you stand back and reflect. I understand and can pick up on the emotional stuff, sometimes it is projected onto me and I have to take it away and hold it for them. I have to admit, sometimes I go to my parents and [GRO-B] I have to put my [GRO-B] on as it's like a protective bubble and helps me to manage being with them. Watching their behaviour towards each other can be hard, dad being the carer and mum being the reluctant cared for. Watching their illness is hard too. I do know it is because of their

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frustrations with this condition. I know how they feel as there is not a lot anyone can do, we just feel impotent.

15. I've not had therapy about my mum, but I have had therapy **GRO-B** of my **GRO-B** as it is **GRO-B** to do so. The hardest thing was watching my parents suffer. I had to intervene when my mum was first in hospital. My dad was living **GRO-B**. My uncle and aunty didn't quite understand the situation. I think they just didn't want to accept it. They were putting pressure on my dad and unbeknown to my dad I had to intervene to keep the extended family in order, which was something I never had to do before. He was under so much pressure as he thought his wife was about to die, so I felt it wasn't something he needed to know about.

16. I was tested and was told it was OK but I'm not sure if my siblings were tested or not. I had done a placement in **GRO-B** as part of my **GRO-B**. Not long after I graduated, they contacted me to see if I could go on their records just in case they ever needed to call me in. I explained about my mum and asked if they would test me; they did, and it came back clear. I'm not sure if this would show on my medical records because it was done as part of the employment system.

17. In the early days because my parents **GRO-B** I didn't see a great deal of what they went through. If they lived here, I would have witnessed a lot more. As they were away a lot, it has protected me from it, in the early days anyway.

18. In the early days of diagnosis, I wasn't very open about my mum's condition. However, if someone asked me directly if my mum had a serious health condition then I would tell them. I am far more open about it now, obviously with my mum's permission or I wouldn't talk about it otherwise. Most of my life I have worked with **GRO-B**. My outlook is, I'm not going to treat my mum any differently unless she needs to be to.

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19. My dad had to live away from his home for a long time in the early days. He had to [GRO-B] He needed to be near the hospital, so it wasn't that easy for him to stay anywhere else. He needed to be on call really. It was very lonely for him and his [GRO-B] [GRO-B] Any friends that he used to have locally he had to reacquaint himself with them. It was a difficult time for him.

20. Other than my father, I'm not quite sure what impact it has had on other family members. It's interesting that I don't know as that just shows we don't really discuss it. However, it has been quite a long time now, mum is just mum, and dad is just dad and they just get on with it really. We certainly talked about it in the early days, but it is out of our hands, there is nothing we can do about it.

21. There has been a financial effect on my parents. They used to [GRO-B] and had to [GRO-B] It was a [GRO-B] and they lost money on the house when they had to sell it. It meant they could only afford a one-bedroom bungalow here which needed a lot of work doing to it. They had such a lovely big house abroad. They couldn't buy a house as my mum couldn't manage stairs, so it had to be something on the flat. Driving too and from [GRO-B] also cost a lot of money. There may have been other financial effects, but my parents are quite private people and they are from a generation that doesn't really talk about finances and I don't ask.

22. It didn't have an effect on me financially when my mum was diagnosed, because by then I was living and working independently.

6. Treatment/Care Support

1. I'm not sure if my mum faced any difficulties in obtaining treatment or support. The [GRO-B] so she had to

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travel there. I don't think the local hospital [GRO-B] had the relevant expertise to treat her here.

2. My mum did get involved with a couple of charities, but I can't remember what they were called. I think one of them did offer a counselling service to my mum and family members if they wanted it. I think my mum may have gone to one of the sessions. This wasn't at the beginning though, it was much later on, so we had been through the worst of it.

7. Financial Assistance

1. My parents have received some compensation, but I don't exactly know what. My dad is an [GRO-B] and has worked [GRO-B] so he is used to getting information and preparing reports. He was good at finding things out. There are others my dad knows of that are not like him and were not able to find things out. Luckily because my dad discovered a lot of information, he was able to put his request forward in a way that made sure he would be listened to. He knew how to ask for support. It was my dad that was doing all this as my mum didn't have the mental capacity to do it because of her illness. Previously she used to have the capacity as she also worked as a [GRO-B]
2. I've not received any compensation, but I've also not sought it. I've just presumed there isn't any available to me.

8. Other Issues

1. I have no further issues that I would like to discuss.

Statement of Truth

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

Signed... GRO-B

Dated... 14th MARCH 2019