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Witness Name: **GRO-B**

Statement No.: WITN2707001

Exhibits: 0

Dated: 16 September 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF **GRO-B**

Section 1: Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** My address details are known to the Inquiry.
2. I am married to **GRO-B** We have been married for 19 years, this year. **GRO-B** and I have two children; a 15 year old daughter and a 10 year old son who are both still at home. My daughter starts college next year and my son will be going to big school this year.
3. I am making this statement in memory of my dear mum; **GRO-B: M** who was infected with hepatitis C. Mum told me before she died that she wished she had something about her infection when she was told that she was infected. Mum was too scared to do something about it when she was alive. Now that she is no longer here, I want to do it on her behalf, to let people be aware of what happened.
4. Mum passed away on **GRO-B** when she was only 68 years old.

Section 2: How Affected

5. My mum was a very funny, very witty lady. She was one of eight children and was the one person in the family that everyone went to for advice and support. All of her sisters and brothers went to her; she was the main person in the family, she was like an agony aunt. If I had any problems I would go and see mum and she would sort me out or make me feel better, she just had that way about her. She was always outgoing and had always worked, until she got sick. I was very close to my mum; she used to confide in me and in particular during her last year when she was really depressed. Mum was crying a lot of the time. The way that she was; watching her like this, really upset me. So when my mum died, in one way it was a relief for me because I knew she wouldn't suffer anymore. I knew she didn't want to live anymore and so when she was alive and I knew this, I had to deal with that. I understand why she didn't want to be here anymore; you could tell that she had had enough, she was so sick. Mum was a fighter but she gave up.
6. My mum had three children: GRO-B GRO-B and myself. She was infected by a blood transfusion back in 1988. She had to have a heart valve replacement; a valve that goes through to the heart to help it pump blood around the body. I understood that the valve was damaged and so her blood was not being pumped around her body properly. As a result mum struggled with her breathing to the point that sometimes she would collapse because she couldn't breathe properly.
7. She went to the doctor about it who transferred her to Rotherham Hospital for the problem to be sort out. Mum was dealt with very quickly initially because of the risk of her having a stroke. I remember that she was booked in to have the operation and had a date set but the operation ended up being delayed because the hospital lost her records. During that delay mum suffered a stroke. It is my belief that if mum had the operation when they said initially said they were going to do it, she would not have had the stroke. I remember that she

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had it on my eleventh birthday which was [GRO-B] 1987 and the day that my youngest cousin, [GRO-B] was born. The stroke affected her brain and her speech; she had to learn how to speak again.

8. The heart valve operation was finally rearranged for December 1987. When mum was admitted to the hospital she was suffering from a bad tooth. Mum ended up having to have all of her teeth removed. Mum told me that the hospital told her that as her teeth were connected to her heart, they could not have a bad tooth and so they had to remove all of her top teeth. I could not understand this because mum only had a problem with one tooth. Mum ended up not having the heart valve operation for the second time. I remember that when she came home from hospital at Christmas she was really upset because she had to have false teeth. She told me that she had no choice but to consent to having all her teeth out. Having her teeth removed broke her heart; she was only 41 years of age.
9. The heart valve operation was eventually rescheduled for 13 February 1988. I remember that it was Friday the thirteenth, and I remember that we all joked about it being Friday the thirteenth. My mum was given the blood transfusion during her heart valve operation on Friday the thirteenth February 1988 at Sheffield Northern General Hospital.
10. I understand that mum had to have the blood transfusion because the operation was open heart surgery and very serious, and there was a risk of her bleeding to death if she did not have it. I understand that there was a 50:50 chance of her not making it through the operation. I always remember the day that she had the operation; I realised that mum may not come home. I was an 11 year old child at the time and I found it very upsetting. I also knew she there was no choice; that she had to have it done.
11. When mum was discharged from Sheffield Northern General Hospital and came home, I remember being shocked at the size of her scar; it was massive and travelled all the way from her stomach to just below her neck. You could

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hear the valve ticking all the time; I was more aware of the ticking when she got stressed out. Many people mistook the valve for a pacemaker and I remember mum would correct them and say "*Oh no, it's not a pacemaker, it's a valve*". She explained that it was like a shutter opening and closing, when you heard the tick, it meant blood was going through. The valve was made out of metal. I knew that sometimes the valve operation has to be repeated because it only lasts for a period time. I understand that sometimes it only lasts for 15 years. Luckily my mum's valve lasted beyond the 15 years. She had regular check-ups and was reassured that it was functioning well. I remember a point in time when they wanted to put another one that was made up of a pig's bladder, but she didn't have this in the end. Overall, when mum was initially discharged she seemed fine. Obviously the removal of the teeth further affected her speech, but apart from that she seemed to be well, at least initially.

12. Mum consented to having a blood transfusion if she had to have one; she was told that the blood was coming from America. I remember that she made a joke about it; she said at first that she could not understand why she would be receiving American blood and even asked the hospital staff whether they could take some of her own blood and give it back to her. The nurses laughed at her and said '**M** *it doesn't work like that*'. I believe that mum was not given any advice or information before receiving the blood transfusion that there was a risk of infection.
13. Mum was infected with hepatitis C as a result of receiving the blood transfusion.
14. I remember that mum was visiting the GP regularly with various complaints and of course visiting the hospital for check-ups in relation to her heart. I remember that there came a point in time when mum was feeling very unwell in herself; she was constantly feeling sick, her bones were aching, she kept saying she felt itchy all the time; that there was itching under her skin. I also remember that she was tired all of the time and her blood results were haywire. I think that eventually mum's GP realised that something was not right.

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15. Eventually mum was referred to Rotherham Hospital where she went for an x-ray. She then had to go to Sheffield Hallam Hospital to have a biopsy on her liver. Sheffield Hallam Hospital put mum on a ward with drug addicts. It was when mum was having the biopsy she found out she had Hepatitis C; it was from biopsy results, which was a matter of days after biopsy was done. I remember the hospital being unclean. As mum had a low immune system she caught a bug which turned out to be pneumonia. My memory tells me that mum was diagnosed in October 2003; she was told that the only way she could have contracted the virus was through the blood transfusion she had.
16. I do not know what information was provided to mum about the infection, or who provided that information.
17. I think that whatever mum was told that it was not adequate. Mum never knew how bad things could get; how serious the infection was. I think she just thought it was a disease that she would be given pills or medication for and she would be sorted out and she would be fine. I think it was only towards the end of her life when she became really sick, that she realised and knew what it meant.
18. Mum was infected in 1988 and diagnosed 15 years later in 2003. She was carrying the virus/ infection throughout these years. As I understand it, mum was told that it takes 10 to 15 years for the virus to properly get into the system and that is when she started feeling sick. I am not able to say whether or not she should have been provided with information about the virus or infection sooner.
19. I think mum knew that there were risks of others becoming infected because if she cut her finger she would say don't touch me. She knew to keep away from the grandchildren for example if she cut herself. She was told to be careful about cross contamination. She stopped sleeping with my dad; she moved herself into another bedroom. Dad didn't know why at the time but realised later why she did. I was given no information. At first, I remember that when

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was told mum was infected with hepatitis C that I thought that it was HIV. I was relieved because mum was told that hepatitis C was the best one to get. She told me it was the better one out of the two.

Section 3: Other infections

20. I believe mum was infected with hepatitis C only.

Section 4: Consent

21. I do not believe that mum was treated or tested without her knowledge or without her consent. I do believe that she was treated without being given adequate or full information because I believe that the risks of receiving a blood transfusion were not communicated to her. I do not believe she was tested for the purposes of research.

Section 5: Impact

22. The impact of the hepatitis C on my mum was really significant. Ultimately, it cost her, her life.
23. I referred to the physical impact a little earlier in my statement. Mum got to the point where she constantly felt sick and tired and her bones were aching. I also remember that she kept saying that she felt itchy all the time; that there was itching under her skin. I remember that she was tired all of the time. She was in and out of hospital constantly.
24. Her immune system was badly affected; she kept catching any virus that others had. I know that she had to leave her job as a cleaner at the local social club because she could not do it anymore. I remember that she looked so old. Mum used to have lovely hair; she would always put her hair in rollers. Her hair

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started to fall out and became really thin. She was only 68 when she died and today 68 is young.

25. Mum also developed depression. I am not sure if it was as a result of the medication that she had or whether it was as a result of the infection itself. I think it may have been both. I think mum just got fed up because she was in and out of hospital all the time and felt like she was a guinea pig as the medics were constantly sticking needles in her. She felt like she had no life basically she was in and out of hospital all the time. She used to smoke all the time as a way of coping, something that she restarted when she was diagnosed with the hepatitis C. She knew it was bad for her but it was like she had to have something.
26. Mum developed leukaemia and was told that it was as a result of the hepatitis C. What I remember of this time was how bruised she became. If she knocked herself she would get a massive bruise and when she had a needle, her arm developed a massive bruise. I remember she had to have a needle in her marrow to be tested for something and I think that is was something to do with the leukaemia. I am not sure exactly but I know she had to have that done at one point; I recall at the time that it really hurt her. Towards the end of her life the medics noticed cells in her blood; I think that there more white cells than her body could cope with and they were getting worse. Her medical team said it had to do with the medication she was taking; I understand that it was attacking her bones and could cause leukaemia. This really upset mum.
27. Her hair started to go thin; she stopped putting rollers in her hair because she did not see the point of doing it. Mum was totally exhausted all of the time, she turned to skin and bone; her clothes started to hang off her and my mum has always been a little bit chubby, her nickname when she was little was fat. I remember that throughout the last year she looked really down and really old.
28. I went to see her at Rotherham Hospital; she was in the Cancer Ward at the time for some treatment that she needed. I think it was to clean her blood.

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When I arrived to see her I couldn't find her. It turned out that I had previously walked past her. I didn't realise at the time but I had mistaken her for an old lady. Mum knew. When she saw me, she broke down and cried and I too just sat there for an hour or so crying, she looked ill.

29. Mum deteriorated greatly and passed away on GRO-B She died at the District General Hospital in Rotherham. Her death certificate read that the causes of death were: I (a) Cardiogenic Shock; (b) Calcific Aortic Stenosis; and II Chronic Lymphocytic Leukaemia. There is no mention of her having hepatitis C. This has upset the family very much. GRO-B my sister was made to sign the death certificate even though she did not agree with the content because she was told that mum's body would not be released if she did not.
30. Mum was put onto some treatment but I do not know exactly what it was; I remember that she came out in lumps. I am hopeful that this information will be in my mum's medical records and I would like the opportunity to update my statement accordingly if we are able to retrieve them. When mum died I know that the medical teams were still treating her for the hepatitis C. Mum was placed onto a lot of medication. Every time she came back from the hospital she had a new drug. I remember that she kept a track on the taking of her medication by placing a tick in the calendar. If she took medication twice then there would be two ticks on the calendar. One for her blood; for the leukaemia and one for the hepatitis C. I cannot tell you what they were. When she died she had a big carrier bag with all her medication.
31. I do not know whether my mum faced difficulties or obstacles in accessing treatments but I do not think that she did.
32. I do not know if there were treatments that mum ought to have been given.
33. Regarding the mental and physical side effects of the treatments that mum received for her hepatitis C; I know overall that mum had no energy and she was very depressed. I do not know what effects were related to the hepatitis C and what effects were related to the treatment for it. Mum's strength started to

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deteriorate badly. At one point, she had to get a walking stick and she hated it. She associated a walking stick with old people; she felt that she wasn't old and didn't want it so she would avoid taking it anywhere, but, towards the end she had to take with her everywhere as she had no choice. Her bones were weak.

34. I remember that she developed shooting pains in her hands and all the way up her arm and I can remember that she felt like she was getting something in her brain like a fog. She was always going on about her head all the time. I think at one point she went to the hospital to have a brain scan. She used to say that she had something tight in her head and would often put her head in her hands as if she was in a lot of pain. She would crouch over in pain hold her head in her hands, squint her eyes and recoil. She couldn't stand it and she would often ask my dad whether there was something else wrong with her.
35. I remember her saying that she had a fog in her eyes. When she ran water she used to faint; she used to keel over. She would tell me the sound of a water fountain made her faint. If she was talking she could not talk with another person at the same time; each person would have to take their turn. Mum used to get headaches all the time and she simply couldn't cope with noise. I think that the shooting pains in her hands developed into something that made her hands lock and go rigid; she was told that was something to do with her bones. She was told it was arthritis and I think that she was fobbed off with that a lot but I do know that on one set of medication she took caused brittle bones and she would stress about that because she used to think her bones were going to break.
36. As to whether or not mum's infected status impacted upon her treatment, medical and dental care, for other conditions, it is difficult to say. Mum didn't have any top teeth so she never went to the dentist; remember they got rid of her teeth when she had the heart operation. As far as I am aware there were no problems with the bottom teeth. [Regarding her heart, I think that the hepatitis C caused problems with the valve operation. I know they were testing mum on loads of different things. Mum felt like a guinea pig she was told to try

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this and try that. Mum needed to have a valve replaced but the Hepatitis C and leukaemia treatment caused problems. She had to go to Leeds Hospital, but the doctors kept messing her about and changing their minds. In the end it was too late she passed away waiting for them to make a decision on what to do.

37. Mum's response to being infected was that she never really discussed it. She would just say "I have got it and will just deal with it. I will just wait and see what happens". That was what my mum was like. I remember she would also say "I will be alright, I will fight it".
38. Looking back on this now, I can see that it obviously affected her relationship with her family; she was always frightened that she could infect any one of us and I expect she retreated from us all a bit as a result. Mum stopped being close to my dad. I noticed that she got very impatient and very irritated with him. I think that this caused a lot of stress for my dad too. I noticed how she would make sure that my dad stayed away from her if he had a cough or a cold as mum didn't want to catch; she so was to sick, she did not want to make things worse. This used to cause a lot of rows between mum and dad. Their relationship got to the point where the slightest thing could cause a row..
39. Dad says that what mum went through profoundly affected her; it did something to her. My dad said that she was not the same woman that he married. Mum got tough and probably a bit too tough; she would have a go at my dad for things, stupid things and they wouldn't talk for days. Sometimes they wouldn't speak for a week and you would always knew if they had a row because if you went to the house it was a nightmare. Dad would be in the kitchen and mum would be in the living room and the atmosphere was horrible. It would affect us all and it got to the stage the family didn't want to go around as often.
40. I think mum was very angry inside; she was angry at what had happened to her, at how her life was taken away and she took it out on my dad. She did not know what else to do. Mum's relationship with her own sisters was affected by the hepatitis C too. Mum was really close to her sisters. My mum was one of

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seven; two boys and five girls. My mum was known as the sick one and that label used to annoy her because mum was bubbly, there was more to her than her sickness.

41. Our whole family was close; all my friends are my cousins, and my mum's sisters and cousins were her friends. Mum was the one that everyone would go to for advice. Everybody would go to my mum's house. Mum would sit and talk about problems and listen, that was what my mum was like and everyone loved her for it. Mum was the heart of the family. She used to take care of people, she remembered people. She used to make buns and trifle and cakes and hampers for everyone at Christmas, She organised a Jubilee street party for the Queen.
42. Even with the stroke mum remained bubbly, but when she got the hepatitis C she, and things, changed. It did something to her, I think she was in shock, I think she thought she had someone's dirty blood in her body. I think she felt dirty. I remember her blood was really dark, like almost black. She would say don't touch it, dirty, I think she thought she was dirty. I think it affected her mentally. During the last five years of her life she couldn't cope with noise; she started having problems with her ears, her bones started ceasing up. She withdrew socially, from everyone.
43. Seeing mum so sick really had a very negative impact on me. I was quite young when she first became sick with her heart. This operation caused me a lot of anguish which continued when her illness and diagnosis with hepatitis C came. When she went into hospital I would worry all of the time and think to myself that she was not going to come home. Losing my mum; my mum dying was my worst fear. Then when during the the last year of her life when she was depressed and so very sick and we had conversations that we had I was relieved that she died. I obviously didn't want her to die but when she did die I was relieved that she was gone because I didn't have to stress about her anymore; I didn't have to worry about her being so sick and depressed and I knew she wasn't suffering any more. She was at peace.

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44. Mum's sickness was always in the back of my mind. I can remember in the March before she died we took her to Bakewell for a day out and we nearly rang for an ambulance to her because I thought she was going to pass out. It ended up that she hadn't taken her medication. I miss my mum now because I can't go to her and talk to her about things; she was a little bit like my therapist. She used to make me feel better about things. We were very close and I can't have that with her anymore. She got me through many very difficult things in my life and could always rely on her.
45. I hate Christmas since she has gone, I hate it. Mum made Christmas for us all, whatever we wanted for Christmas my mum would get it. She didn't really like it herself but she made such an effort for everyone so that we could enjoy it. Towards the end of her life Mum had a talk to me and told me how she wished she had done something about her hepatitis C and how she had contracted it because she realised it had made her really ill and depressed and had affected so many people around her.
46. I have carried this with me ever since and this is why I am making this statement to the Inquiry. I feel that mum was poisoned by that blood. The day she had the operation; yes her life was saved but she was also poisoned. I feel very angry about that. It was heart-breaking to watch her deteriorate and to know that she was so sick and in so much pain and that she no longer wanted to be her, it was horrible. Mum died before my 40 birthday. The year I was 40 she would have been 70. I never got to share that with her. She left me a present for my 40 birthday; she knew she wouldn't be here for it. I opened the present she left for me; it was a porcelain box which played music. Mum had placed a little note inside it. My 40 birthday should have been a happy day but it was a very, very sad day for me as I wanted my mum there.
47. I have said that my mum felt dirty with the hepatitis C. I don't think she told anybody else outside of her closest family. I think she kept it to herself mainly. I

don't think anyone in the family would have treated her differently. The stigma is not something that mum ever said anything to me about.

48. When mum was alive, she had a very strong bond with each one of her grandchildren. Really, the grandchildren became her life. She was particularly close to my son and daughter and to my sister [GRO-B]'s children [GRO-B] and [GRO-B]. Since she died, I have notice her grandchildren's memories of her fading. My son for example, can still remember a little bit about mum but as he gets older he is remembering less and less. Mum knew her great-grandchild [GRO-B] who is my niece [GRO-B]'s little girl, but, Mum never got to meet my nephew [GRO-B]'s little boy [GRO-B]. Mum was very close to our [GRO-B] she thought a lot about him. There was a lot of history with [GRO-B] [GRO-B] was very special to mum. I know for a fact that she would be so chuffed that he had a little boy. I get angry because she is not here now to enjoy the people that loved her so dearly. I can see what she and they are missing out on so much. My daughter is going to get married one day, if she gets married mum is never going to be there to share it with all of us.
49. The hepatitis C meant that mum had to pack in work. She had a cleaning job at the time. I cannot remember when this was. As soon as she found out that he had got the hepatitis C everything started to go downhill. Mum managed to get mobility allowance from the government; she had someone who came to the house to assess her and she got mobility for car parking.

Section 6: Treatment/Care/Support

50. Mum didn't receive special treatment; no-one came to see her to talk to her about the hepatitis C. I know my mum confided in a lot of the nurses and I hope that she managed to get care and support way but she was not formally entered into a counselling or treatment programme.

Section 7: Financial Assistance

51. Mum only received the mobility allowance I referred to above. I am not aware of her receiving any financial assistance from anyone as a result of becoming infected with hepatitis C.
52. The family did not know it was possible to obtain financial assistance. I didn't know it existed. No one has ever discussed it with me.

Section 8: Other Issues

53. I would like the Inquiry to find out whether blood was sourced from the prisons and if it was, why. I don't understand how it could have been. I would like to know what was known in relation to this scandal, and when it was known, and why more was not done to prevent it. I want answers; I want to get to the truth of things. If my mum knew that the blood she was going to receive carried a risk of infection and that potentially it was coming from a prison she would not have had it, but, they didn't give her that option. It is too late now for my mum but I would have liked mum to have answers and I want the same for my dad.
54. I would like the Inquiry to know about the fact that my mum wanted to donate her organs; her eyes, her heart, whatever she could to help other people. As she had hepatitis C she was not allowed to be an organ donor. When she was in the hospital she used to let the students use her as part of their training; she wanted to help. She always gave permission for a doctor to learn from her treatment. They were particularly fascinated with her ticker. What she got was classed as antique.
55. The family has not yet seen the medical records; we hope they can be found and that they haven't been messed about with. When mum went she went to Leeds they took her off the warfarin and they shouldn't have done that. I cannot understand why they did that. They knew there were risks that she

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could get blood clots and I cannot understand why they didn't put her back on it. I worry that things like this will mean the records have been messed with.

56. I want to understand why it was that the hepatitis C was not listed on my mum's death certificate. My sister was told that the funeral could not go ahead, if it was not signed as it was. GRO-B my sister, said at the time that where there is hepatitis it has to be recorded, but they did not record the hepatitis C.

Statement of Truth

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

Signed

GRO-B

Dated

16 September 2019