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Witness Name: **GRO-B**

Statement No: WITN0091001

Exhibits: none

Dated: 30th October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28th January 2019.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** 1962 and my address is known to the Inquiry. I am a retired **GRO-B**. I intend to speak about my infection with hepatitis C that led to liver failure and ultimately caused me to have to have a liver transplant in December 2009. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me and my family.
2. I can confirm that I have appointed Thompsons Solicitors for this matter. I do wish to be anonymous.

Section 2. How infected

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3. On **GRO-B** 1984 I had to have an emergency caesarean after I gave birth to my daughter **GRO-B** I had the caesarean at **GRO-B** **GRO-B** I have anaemia and during the operation, it became necessary for me to have a blood transfusion. I received four units of blood. I was not advised by a doctor after the operation that I had received a transfusion. I was given this information by a nurse who told me that this was the standard procedure.
4. I was never told by Dr McKay or any of the medical team, before or after the operation about the risks of being exposed to any potential infection from receiving a blood transfusion.
5. As a result of being given contaminated blood I was infected with hepatitis C.
6. After my caesarean I stayed in hospital for about a week before I was discharged. I began almost immediately, to feel very unwell. I was feeling very tired and sluggish and quite depressed. I put this down to a number of factors though, my father had died three weeks before my operation, having a caesarean section was a major operation and I also think I had postnatal depression. My husband **GRO-B** was constantly telling me that I needed to go to the doctor.
7. Shortly after I gave birth to **GRO-B** I started to regularly visit my GP, Dr **GRO-B** I would tell her about my continuing low mood and low energy. As part of the investigations into this, she took my bloods to test for diabetes and for thyroid issues which came back clear. I struggled on with these symptoms for the next nine years, continually raising it with my GP. My GP would take blood tests over these years and they would always come back fine. I was constantly tired, irritable and depressed but I did carry on with my life.
8. In 1994/1995, I again went back to my GP with my symptoms of lack of energy and just feeling very unwell. I saw Dr **GRO-B** and she did more

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blood tests. A few days later I received a phone call from her, saying that the tests revealed that I had been infected with hepatitis C. I didn't really know what hepatitis C was other than that it was a blood disorder. I asked her how I had got hepatitis C and all she said to me was that I could have picked it up anywhere. I was very concerned about how I could have got the infection. The only real information about the virus I got was from books that I read myself. I knew the virus had something to do with my liver and that it was a blood disorder but along with the limited information I had, my diagnosis took place during the time that AIDS and HIV was being heavily featured in the news. It left me putting two and two together myself. I also knew that there was an association with drugs and promiscuity, neither of which I had been involved in.

9. She did not give me any information about hepatitis C, therefore I did not realise the seriousness of my condition. I was also not told about the risks of me passing the infection onto my daughter or husband or provided with any advice to prevent this.

Section 3. Other infections

10. I have not been infected with any other infections from the blood transfusion I received, that I am aware of.

Section 4. Consent

11. I knew that Dr GRO-B took my blood for various tests, but I was not told I was being tested for hepatitis C. I do not know if I was ever tested for the purposes of research.

Section 5. Impact

12. From giving birth to GRO-B and being infected with hepatitis C, my life was completely destroyed. Prior to giving birth I was a healthy young woman. I was happily married and GRO-B and I were looking forward to having our baby

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and cementing our family.

13. Almost immediately after I was given the blood transfusion I felt extremely unwell for one year. Physically, I was absolutely exhausted. Mentally I became very depressed. I was irritable and irrational. It was hard for my husband as we had a young baby. I remember my mum saying that I had become a different person because of my mood swings. After this, I became used to how I was feeling, but the symptoms never went away.

14. After my diagnosis in the mid-1990s, my own GP referred me to Dr Rose at Ayr Hospital who sent me for a liver biopsy. This procedure was very painful and uncomfortable. The results came back showing that the hepatitis C had attacked my liver and that it had scarring on it.

15. Dr Rose suggested that I start treatment to clear it. He prescribed me Interferon that I had to inject into my stomach every day. It was horrendous, my stomach was covered in bruises. The side-effects from this treatment were also horrendous. I felt like I had been hit by a steamroller. I had the worst flu like symptoms ever. Physically, I looked terrible, I had big black shadows under my eyes. I would wake up in the middle of the night shivering and feeling cold but **GRO-B** would touch me and say I was red hot. Mentally I was extremely depressed and very irritable. I hated injecting myself, because I knew how ill I would be afterwards. It got so bad I eventually couldn't inject myself any more. I then had to go and see the practice nurse **GRO-B** at my GP surgery to inject me.

16. It was a really bad time in my life. I wasn't happy with Dr Rose at all. I didn't feel he was looking after me properly. I was supposed to see him every twelve months, but sometimes it was eighteen months before I saw him between appointments. When I went on treatment for hepatitis C, I only managed it for eight or nine weeks before it was stopped. Dr Rose told me that he didn't think that one single treatment would sort things for me and he felt that eventually I would need a cocktail of drugs, which in the end was correct. Dr Rose was not a Hepatologist, he was a Gastroenterologist with

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an interest in blood products. He liaised with a doctor in Glasgow Royal Infirmary, who I never saw. His information was second hand. I don't feel that Dr Rose should have treated me for hepatitis C. There were points I felt like he was using me as a guinea pig. I was constantly back and forward to hospital having paracentesis. I remember I went down four dress sizes, almost overnight. On one occasion I had twenty four litres of fluid drained from my stomach.

17. I remember my partner came to Ayr hospital with me during one appointment, and he said to Dr Rose that it was clear I was getting worse and his response to my partner was, "Well I don't have a crystal ball, I can't tell you what is going to happen", but he still never referred me to Edinburgh Royal Infirmary. I ended up having to refer myself there with Dr **GRO-B** and my sister's help. After I did, he came and spoke to me about it and his tone felt as if I had done something wrong by doing so. It was not acceptable. In my opinion I would have died if I had not referred myself to Edinburgh Royal Infirmary.

18. My stomach being swollen with fluid was the start of my liver failing. I was put on Furosemide and spironolactone and ended up being admitted as many as ten times into Ayr hospital to have the fluid drained from my stomach.

19. In 2004 I was offered another treatment for hepatitis C. I saw Cathy Scott the nurse practitioner at Edinburgh Royal Infirmary. I was put on a course of treatment over three months of pegylated Interferon and Ribavirin tablets. The side-effects were the same as the first course of treatment. Physically I looked horrendous and lost a lot of weight while also having ascites. I was skin and bone but with a swollen stomach where I was retaining fluid. I had all the same flu like symptoms I had experienced the first time. Mentally, I was very depressed, almost suicidal. In **GRO-B** 2002 my mum died and then in **GRO-B** 2003 my husband **GRO-B** died **GRO-B** **GRO-B** I then went onto the treatment in 2004 and I suffered suicidal thoughts whilst on the treatment. I felt due to my bereavements and

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hepatitis C there was nothing much to live for.

20. I was only on the treatment for eight weeks. I was attending my local GP to have my bloods taken regularly. After eight weeks I was told that Cathy Scott had instructed that I come off the treatment as there was a problem with my bloods, again the treatment was not working.

21. I staggered on for a few years, very ill and very depressed. My sister GRO-B was constantly phoning Dr Bathgate's secretary at Edinburgh Royal Infirmary to try and get me an appointment. In September 2009 I had an assessment week at Edinburgh Royal Infirmary where all manner of tests were carried out. At the end of the week, Professor Hayes came to my bedside and told me that I was a candidate for a liver transplant. I remember the following month I was very unwell physically. I was constantly in and out of Crosshouse Hospital to get my stomach drained as I was filling up with fluid. Mentally I was very depressed and anxious about whether a donor would be found. In October 2009, I was advised that I was in the final stages of liver failure. It was a very stressful time.

22. On 2 December, 2009. I received a phone call at home from the Edinburgh Royal infirmary to say that they were sending an ambulance, as they had a liver for me. I was absolutely terrified and delighted at the same time. I remember being quite emotional. Everything happened quite quickly after that. I had the transplant that day. The liver transplant was a success and I had a good recovery. I was very lucky. I was discharged on 16th December, 2009, but of course, I still had hepatitis C.

23. I was going back and forth over the next few years to be monitored at the hospital. I remember sometime in 2014 I saw Dr Bathgate. He told me that there was a treatment in America. When this became available in the UK, he immediately referred me to Dr Rose's department in Ayr. Due to my previous experience with Dr Rose, I asked not to attend there so he referred me to Dr Sam Allen in November 2015 at the Blood Borne Virus Clinic in Crosshouse Hospital. I was advised that the new treatment for hepatitis C

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was expensive, so Dr Allen applied for funding for it.

24. In February 2016 I had my bloods taken at a routine appointment and it was discovered that my viral load for hepatitis C was very high. I was then given this new treatment. I had to take seven tablets a day for twelve weeks. I cannot remember the name of the tablets. There were hardly any side effects with this treatment. Perhaps the occasional headache. The treatment was a success and I felt like a new woman.

25. I never experienced any problems for dental care. I found that when I had to attend hospital due to my ascites, no matter the time of my appointment, I would be kept waiting until I was the last patient of the day. This was because of the hospital's anxieties of cross contamination. It is very upsetting to think about this, even now.

26. Being infected with hepatitis C totally destroyed my life. My husband was very stressed and anxious when it was discovered I had hepatitis C. I genuinely believe that the stress of my illness contributed **GRO-B** and death. **GRO-B** he was the love of my life. I had known him since I was fifteen. I have never remarried.

27. **GRO-B**

28. Being constantly tired and mentally low because of hepatitis C and then the liver failure made me turn to alcohol as a way of escapism. This was exacerbated by the death of Mum and **GRO-B**. Binge drinking caused many problems in my life. Since my liver transplant, I do not drink at all.

29. I knew there was a stigma attached to hepatitis C. It is associated with

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promiscuity and intravenous drug use. Throughout my illness I didn't tell anyone about my infected status. I did tell my immediate family but that was all. I remember Dr Rose tested [GRO-B] for the infection after my diagnosis, fortunately they came back negative. Nevertheless, I felt soiled, dirty and contaminated. I didn't tell anyone else I had the infection. I eventually told my sister, but I could tell she embarrassed about it. I only told [GRO-B] at the point of my liver transplant. [GRO-B]

[GRO-B]
[GRO-B]

30. [GRO-B] I had to give my job up in 2006 mainly because I was too exhausted to work anymore. I found when I finished work that I had too much time on my hands which is when I started to drink.

31. I eventually found part-time work [GRO-B]. Having hepatitis C stopped me from having full-time employment and thus also a work pension.

32. I inherited half my mother's estate when she died and I also received money for death-in-service when my husband [GRO-B] died. If it wasn't for this money I really don't know how I would have survived financially. After I received my transplant, I also received disability living allowance.

Section 6. Treatment care support

33. I have never been offered any counselling or psychological support relating to the hepatitis C. I do believe counselling and support should have been given. It may have stopped me turning to alcohol as a crutch if there had been someone to talk to about my illness.

Section 7. Financial assistance

34. Dr Rose advised me that I was entitled to get financial assistance from the Skipton Fund for being infected in 2003/2004. Professor Hayes wrote to me

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advising that I was in fact entitled to a stage 2 payment as I had developed cirrhosis. He sent me a form to fill in and Professor Hayes then endorsed it and sent it off to the Skipton Fund. This would have been in 2003/2004.

35. In 2004 I received a lump sum from the Skipton Fund of £20,000. A few years later, I received a phone call from the Skipton Fund to tell me I was entitled to a further lump sum and quarterly payments. I received £25,000 and I chose to receive quarterly payments of £3687.25. I believe this amount could have been spread out monthly. I do remember I also received a fuel payment of £500 from the Caxton fund. In 2008 I was awarded £2225 a month from the Scottish Infected Blood Support Scheme, which I continue to receive now.

36. The process of applying for financial assistance was straightforward and I did not encounter any preconditions to my application.

37. I am very grateful for the money I have received. It enables me not to have to worry about paying the bills. It does not however compensate me for not being capable of working full-time and earning a full-time wage in my lifetime. It doesn't compensate me for the years I have lost, for the confusion, the suffering and not managing. It completely changed me as a person.

Section 8. Other issues.

38. I asked Dr Rose where I had got the blood transfusion from and if they had the batch numbers in my records. He advised that he could not locate any batch numbers in my records, which leads me to believe that pages must have been removed at some point.

Statement of Truth

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

Signed

GRO-B

Dated Nov 4, 2020