

ANONYMOUS  
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Witness Name:

GRO-B

Statement No.: WITN0887001

Exhibits: Nil

Dated: 16<sup>th</sup> May 2019

**INFECTED BLOOD INQUIRY**

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**WRITTEN STATEMENT OF** GRO-B **(ANONYMOUS)**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20th March 2019.

I, GRO-B will say as follows: -

**Section 1. Introduction**

1. My name is GRO-B My date of birth is the GRO-B 1955 and my address is known to the Inquiry. I am married with two grown up children and two grandchildren. I intend to speak about how I came to be infected with the hepatitis C virus (HCV). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life.

**Section 2. How Infected**

2. My husband and I lived in South Africa for a few years and when I was there I got Nephritis. Because of this I had a biopsy, which is when I found out that I had polycystic kidney disease. I was diagnosed in 1976.

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They told me that both of my kidneys would fail and that I'd need dialysis in the future. I would have been 21 years old then, I didn't need dialysis until I was 31. I had my two children at the ages of 27 and 29, so thankfully I'd had them before I was given any treatment.

3. I started dialysis in November 1986. Prior to that, due to my anaemia, I had a number of blood transfusions at GRO-B. In April 1986 I was given 3 units of blood. I received 6 units of blood in November 1986, and then 4 units of blood at the time of my kidney transplant, which was on 24<sup>th</sup> April 1987 when I was aged 32. These facts are contained in my medical notes which I was able to see when I applied for my first stage payment in 2018.
4. For my dialysis, I was on Continuous Ambulatory Peritoneal Dialysis (CAPD). Initially, my dialysis was done at GRO-B GRO-B because that was where the unit was but it subsequently changed to The Queen Alexandra Hospital in Portsmouth.
5. In April 1987, within 6 months of starting dialysis, I got the call that a kidney was available for me. I was given a kidney from a deceased donor. It was a good match and things went well from the beginning.
6. 30 years later, when I was diagnosed with having HCV, I asked my consultant if they had tested the transplanted kidney for hepatitis C and I was told that at the time, they only tested for hepatitis B. The infection could have been from either the transplant or from the blood transfusions. I was told however, that it's more likely my infection came from contaminated blood transfusions. When I was seen at Southampton General Hospital, the head of Hepatology signed a form that said as far as he was aware, the blood transfusions were the most likely way of my contracting hepatitis C.
7. No information or advice was provided to me before my transplant or transfusions about the risk of being exposed to hepatitis C.

8. I found out I had been infected with hepatitis C when my kidneys started to fail in 2017. During the run up to this, I'd had bouts of sepsis and they didn't understand why I kept getting these infections. At the time it was attributed to urinary tract infections. They decided that because the kidney was going to fail completely, they would put me on the transplant list. My husband wanted to give me a kidney but he couldn't because he had had testicular cancer 20 years prior and as a result was precluded from doing so.
9. I underwent testing in June 2017 after being unwell for 18 months to 2 years. They called me back 3 weeks later to be retested, due to an issue from one of tests. It subsequently became apparent that the retest was to confirm that I had hepatitis C. It was only then that I found out. Around the middle of July 2017, I received a phone call from Dr. [GRO-C], a renal consultant from The Queen Alexandra Hospital, informing me that I had hepatitis C, as though that was the answer to all my issues. It didn't feel good being informed of my infection over the phone and I was left shocked. There was no explanation as to what it was, how I got it and what the treatment would be. I was alone when I received this call. I think I should have been called in to be spoken to face to face about it, to discuss the infection and its ramifications. I was disappointed that I wasn't brought in. It wasn't a good time.
10. Later that month received a letter informing me that I was not going to be put on the transplant list, due to my HCV diagnosis.
11. I had heard of hepatitis, as [GRO-B] my husband, had worked for the [GRO-B] [GRO-B] so he had been inoculated for hepatitis B.
12. At that time, no information was given to me as to what being infected with hepatitis C meant. All I was told was that it could be treated. That was the sum total of everything I was told at that time. They did say then that I would be referred to the Hepatology Department at Portsmouth for treatment. I was just left shocked.

13. After finding out I was infected with hepatitis C, I didn't receive an appointment to see anyone until November 2017, four months later. I had had absolutely no contact with anyone about my HCV since the call informing me in June.
14. I knew that hepatitis C was a liver virus, I didn't have much information about it, I didn't know the effect it would have on my liver and how damaged my liver may be.
15. My appointment in November at Southampton was really good, very straightforward. They were shocked that I had not been tested for hepatitis C during the last 30 years. They explained a lot to me regarding the hepatitis C infection and they did a number of blood tests. They told me there was not a lot of funding and treatment costs £46,000 for a 12-week course. I was told I'd have to wait six months for treatment due to the cost of it and because they could only see 10 people a month.
16. I had a polycystic kidney and my liver was similarly affected which apparently meant that they couldn't do a fibro scan, as they couldn't 'see' it properly. I had ultra sound instead. My liver is very big but I think I was quite fortunate as there were no signs of scarring or cirrhosis. I was told by my doctors that I was quite lucky, given that I had unwittingly been walking around for 30 years with HCV. That was at least some good news.
17. The consultant at Southampton discussed my medical history. I was asked if I'd used drugs or shared needles and about my lifestyle, present and historically. I was then told that I was most likely infected with hepatitis C through one of my blood transfusions. He also asked me if I had considered seeking compensation, which I hadn't realised I could get.

18. It was about a week later when a consultant then told me there that was a waiting list for a kidney transplant but in view of my failing kidney, they would discuss my case at their next MDT (Multi Disciplinary Meeting). I believe it was mentioned that I would need treatment for my hepatitis C before I received my transplant. The following month, December 2017, I was offered treatment, a drug called Mavyret, which I was given to understand was a fairly new combination drug that they said would be suitable for transplant patients.
19. I believe I was prioritised for this treatment because I was waiting for a 'new' kidney. The drug was quite new, I think it's the best drug there is now for treating HCV. I completed a 12-week course of Mavyret, one tablet a day at 2pm each day. It's important to take it at the same time each day. It was imperative that I did not miss a dose and it had to be within 2 hours either side of 2pm. I was pleased as there were no side-effects of the drug. I was feeling quite ill due to my failing kidney anyway but the drugs did not make it any worse. My assumption is that there were no side effects for me through taking Mavyret.
20. Every 2 weeks, at Hepatology, throughout the 12-week course I had blood tests. They could see the drug was acting quickly as it was reducing the viral loading. By February 2018, 2 months after starting the treatment, the virus was undetectable, it was very effective.
21. Initially I had been told that I would have to wait until completing the 12-week course of treatment, before commencing dialysis but it was then decided that could start dialysis in January 2018, just a month after beginning the treatment. I think this was because the drug was working and had reduced my viral loading sufficiently.
22. My liver was last scanned on the 29<sup>th</sup> March this year and that was after my 48-week test following treatment. They said they couldn't see any cirrhosis and I was discharged from Hepatology in Southampton.

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23. I believe I should have been advised of the risk of hepatitis C as early as 1992, when information became available that viruses had been transmitted to patients through blood products. I should have been told that I may have been infected due to receiving blood transfusions in 1986/1987 and having a kidney transplant in 1987.

24. Very little information was given to me about the risks of others being infected. Someone from the Hepatology Department at Southampton advised me of the very low risk of transmitting hepatitis C to my husband through sexual contact.

### **Section 3. Other Infections**

25. As far as I'm aware, I don't believe I have received any other infections through blood given to me, other than hepatitis C. However, I do now have hypothyroidism as a result of my infection and I'm on a daily drug for that as well, Levothyroxin. I have been told that the condition is associated with hepatitis C.

### **Section 4. Consent**

26. I'm not aware of being treated without my consent. I consented to the treatment for my kidney transplant, along with blood transfusions but I would never have consented to being given contaminated blood.

### **Section 5. Impact**

27. Being diagnosed with hepatitis C affected the life span of my transplanted kidney, and I also suffered from sepsis in July 2012, August 2015, and March 2016.

28. Prior to being cleared of HCV, when having dialysis, I had to have my own machine which couldn't be used on anyone else. It did make me feel different and self-conscious, because my dedicated dialysis

machine had to be taken away immediately after each session. In normal circumstances after use in the morning for instance, they would run a cleansing cycle through the dialysis machine and prepare it for the next patient in the afternoon. In my case they took the machine away and it was just used for me only. I also had to be kept segregated in another room when I dialysed. In that respect, it did make me feel like everyone else was wondering, "Why is that person going into that room, they must be contagious".

29. With regard to the dentist; they simply made a note of my hepatitis C infection and were fine about it.

30. I haven't had any adverse reactions from people really, but then it was for such a short period that I knowingly lived with HCV. I do remember initially, when I had a fistula in my arm for an operation, one of the nurses said 'Oh you won't be able to have a transplant then', which was hurtful and an unkind thing to say, when you're thinking that's your only hope. No others though, if anything people have been quite good. I don't know why, but when I was in Portsmouth the doctors just seemed to know. Even when I've had tests on my stomach, one doctor said "I hear you've been infected with hepatitis C - and 'we' did it to you". It felt like an informal, off the cuff acknowledgement that there had been a massive institutional error.

31. My career had been with the NHS GRO-B In my last role, I worked 3 days a week as an GRO-B at GRO-B I had gone from full time to part time in 2011, due to my health. I reduced my hours because of the tiredness and the fatigue, which I put down to my kidney but now realise that the HCV would have contributed to how I subsequently had the bouts of Sepsis in 2012, 2015 and 2016. I also had a lot of pain in my liver and I was losing weight inexplicably. I felt constantly sick really. Prior to my retirement in July 2017, I had been on sick leave for seven months.

32. When I retired, I was 4 years short of my full occupational pension. I've taken a substantially reduced final pension, missing out on those final years. It has made a difference of a couple of hundred pounds a month.
33. When I took early retirement, my husband also retired a year earlier than he would otherwise have done, so that he could look after me. We had to move out of our house, our family home, and move from GRO-B to where we live now in GRO-B where houses are cheaper. We needed to reduce our mortgage because of our severely reduced income.
34. When I started on the HCV treatment, my main concern was that my transplant would be delayed by my falling down the list. I had been put on the waiting list in June 2017 but when they found out I had hepatitis C they took me off. They should have kept me on the transplant list and just suspended or 'paused' my place until the infection was cleared. So, having initially thought that I would have to start again at the bottom, I was told on the 1<sup>st</sup> April this year, that there was a new rule that would enable me to be backdated to when I started the dialysis.
35. Prior to being put back on the transplant list, the surgeons required a letter from my Hepatologist Mark Wright, to say that there would be no reoccurrence of the HCV. That was done and I later learned that I had only slipped back to January 2018 (the start of my dialysis) and not June 2017. So, I've lost 6 or 7 months but it could have been worse. At the time of being taken off it, I would have been on the transplant list for two years, and a normal average wait is two to three years, so I am still on track.
36. Due to my HCV status, before it was cleared I was prevented from being transferred to and attending a satellite kidney dialysis unit in GRO-B, which is considerably nearer to my home. So, instead I had to complete a 50 mile return journey three times a week to Portsmouth, until three months after completing the HCV treatment. On these

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occasions my husband had to take me and wait the 5 hours it took to dialyse.

37. You never know when you could be called up for a transplant and you don't know where you are on the list either. A lot of people get one sooner than three years, others have to wait longer. It depends on the match and you never know when you're going to get that phone call. I was very lucky with my initial transplant in 1987 because I went in and everything was fine.

38. Because of the short time span of my knowing that I had HCV and because my kids were grown up, I believe the impact of being infected with hepatitis C on my family was fairly minimal. After the initial shock I was left angry at the thought that it was due to contaminated blood and how long this whole conspiracy of silence around has lasted. I had it for 30 years but I'm just thankful I'd already had children and I couldn't pass it on. Ultimately, after discovery I was treated quickly and they were positive about the new treatment so I didn't have a lot of concerns there.

39. My family and friends were very understanding when I informed them of my infection.

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

40. I haven't experienced many difficulties or obstacles in obtaining treatment, other than the initial delay of being made to wait four months for an initial appointment to be seen by Hepatology. Once you find out you've been infected, you worry about when you're going to be seen and when treatment is going to start.

41. No counselling or psychological support has been made available to me as a result of being infected.

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

42. Once I was diagnosed I was directed by one of the medical team to look into EIBSS (England Infected Blood Support Scheme). From April 2018 I received stage 1 payment of £20,000 plus £4,000 per year, which equates to £333 per month (I am paid monthly) .
43. They also informed me about income top up. I didn't think this would apply to me, but it did so I also receive £245 per month, which also started from April 2018.
44. It was easier to get than I thought it would be. I applied and they said that they needed information on the blood transfusions. This took a couple of months, while waiting for my medical notes. This delay in obtaining my medical records, although within the guidelines, did result in a delay to my application. I submitted the paperwork in January 2018 and they wrote back and said it was accepted and I received the payment in the April.
45. I can't understand how the payments from EIBSS can be so different, as it seems to be a lot higher in Scotland than here. I think if you have to give up work because of ill health, you lose a substantial amount of income. I had to give up work because of a combination of hepatitis C and my kidney, but my kidney may not have failed if I hadn't been infected with hepatitis C.

#### **Section 8. Other Issues**

46. The way that the UK had been importing blood from dubious sources such as prison inmates and people with unhealthy lifestyles without thought, is a scandal and it has been made even worse by the way that it was allowed to continue long after it was known about. I hope that this Inquiry finds the answers to how this was allowed to happen and ensures that nothing like it will be allowed to happen ever again.

**Statement of Truth**

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

Signed \_\_\_\_\_ GRO-B

Dated 16<sup>th</sup> May 2012