

# ANONYMOUS

Witness Name: GRO-B ANON

Statement No.: WITN6203001

Exhibits: WITN6203002 - 007

Dated: 19 May 2022

## INFECTED BLOOD INQUIRY

---

### WRITTEN STATEMENT OF GRO-B ANONYMOUS

---

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 May 2022.

I GRO-B will say as follows: -

#### Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1957 and my address is GRO-B
2. I live with my husband GRO-B and we have three grown-up sons, born in 1973, 1977 and 1978.
3. The anonymity process has been explained to me and I have chosen for my statement to be anonymous, simply because few people knew of my infection and I have no wish for it to be known more widely.

4. I intend to speak about my infection with hepatitis C, I understand that it is otherwise known as "HCV", which is how I will refer to the infection throughout this statement. In particular, I will make reference to the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my husband, our family and our lives together.

## **Section 2. How Infected**

5. In [GRO-B] 1977, I gave birth to my middle son at [GRO-B]  
[GRO-B] The birth went smoothly and I had no issues.
6. Within 6 to 8 weeks of giving birth, I decided to have a contraceptive coil fitted. Three days after being fitted with the coil, I woke up one morning bowled over in agony. My husband [GRO-B] immediately phoned for an ambulance and I was rushed to [GRO-B] They later told me that I would have died if my husband had called my GP instead of an ambulance. I needed urgent medical attention.
7. Upon arriving at hospital, I had to have my contraceptive coil removed straight away. This, I understand was done with some difficulty. Somehow the coil had gone too far inside me. Septicaemia had developed in some way around the issue of my coil being fitted.
8. The septicaemia necessitated a large number of blood transfusions over a number of months. Blood was taken out of me and 'clean' blood was put into me because of the infection in the blood. It was essentially to clear out the infection from my blood system. I was in hospital for around 9 months in total and received countless blood transfusions over this period. I also lost six and a half stone over the course of staying in hospital.
9. [GRO-B] recalls that the doctors were fighting over me. Dr Thornbury, the primary doctor in charge of my care, and another doctor had a difference of opinion as to how I should be treated. The other doctor, whose name

## ANONYMOUS

I cannot recall, wanted to operate on an abscess on my stomach, for which I was receiving intravenous antibiotics and heat treatment.

10. Dr Thornbury strongly disagreed with this proposal and said that it would kill me if he operated on me. It seems that they almost came to blows over this, so serious was the disagreement. Dr Thornbury ultimately won the argument and I feel now that it was right not to operate.
11. After being discharged from hospital, it took me a long time to fully recover. Dr Thornbury called me back in after initially being allowed home because he was worried about me having sex with my husband. He said that I wasn't ready and had been discharged prematurely by the other doctor, who wanted to operate on me. He was very concerned about the effect that sexual intercourse would have on my recovery. I was only out for a day before I was taken back in. I remained in hospital for a further 3-4 weeks before being finally discharged. I believe this was to build my weight and strength up also.
12. When I was eventually discharged properly, I was still unwell and nowhere near fit. I struggled to recover to anything like how I had been prior to the coil being fitted and I think it took me around 2 years to feel anything like my old self again. In truth I never fully recovered but it took another 33 years to establish why this was.
13. I used to have extreme night sweats, to the extent that we had to regularly buy new mattresses. At the time this was put down to my hormones. I was put on hormone replacement therapy ("HRT") after the birth of my youngest son in GRO-B 1978, and I remember the doctors subsequently saying that I had been menopausal since my twenties.
14. Throughout the 1980s I had four operations to do with cysts on my ovaries. I had a hysterectomy operation in 1994, after which I stopped taking HRT. I have no idea if I had any further blood transfusions connected with one or any of these procedures.

ANONYMOUS

15. Around this time, I began to feel very tired and generally fatigued. I would complain about this regularly to my GP but it was put down to the number of operations I had, the septicaemia and my arthritis.

16. This fatigue continued throughout the 2000s until GRO-B at GRO-B decided to do blood tests in April/May 2011. This date is confirmed in a letter from GRO-B dated 13 May 2022 (exhibit WITN6203002). GRO-B did not say specifically what he was testing for. I think I had three separate blood samples taken in total.

17. GRO-B called me in for an appointment to discuss my test results. At this appointment, he said that I had hepatitis C. I didn't know what this was at the time, but my husband had some idea and he was in a state of shock. The doctor explained what HCV was and said that it was a very serious disease.

18. GRO-B asked me if I'd had sex with other men and if I had ever taken drugs intravenously, to which I said no. This was all said in front of GRO-B. He did ask me if I had received a blood transfusion, to which I explained I had countless transfusions after developing septicaemia in the 70s.

19. GRO-B asked GRO-B outright what the prognosis was. He said that the worst-case scenario was that it would kill me. The GP said that he didn't know if there was any treatment, but he didn't believe there was. He didn't seem to know much about HCV himself. He also said that if we were going to have sex, GRO-B should wear a condom. We were in total shock and this affects us to this day. It showed how transmissible the disease was.

20. GRO-B referred me to Dr Faizallah, Consultant Physician and Gastroenterologist at Arrowe Park Hospital. I saw Dr Faizallah within a couple of months of my HCV diagnosis.

21. In a letter dated 22 December 2011 (EXHIBIT WITN6203003), Dr Faizallah informed GRO-B the head of my GP practice, that I had

## ANONYMOUS

tested positive for HCV and expressed his regret for the delay in arranging the appointment with me.

22. I enclose a copy of my microbiology results dated 15 December 2011 (exhibit **WITN6203004**), showing that I was diagnosed with HCV genotype 2b with a viral count of 740,000 rU/ml.

23. I began a 6 month course of treatment in April 2012 that consisted of interferon injections once a week and ribavirin tablets taken once daily. I attended hospital for tests every fortnight to monitor my progress. These tests showed that my viral load was reducing and I was responding well to the treatment.

24. **GRO-B** had to administer my injections which he hated. He particularly had problems with the pen like injections and we had to insist on syringes being provided.

25. I felt horrendous for two days after receiving each interferon injection. I was freezing cold and completely wiped out, forcing me to stay in bed. It was what I would describe as very severe flu-like symptoms.

26. I completed the 6 month course of treatment and the HCV was undetectable. When I returned a week later for a further test, they found that the HCV had returned. We were devastated by this. They told us that there was nothing else they could do if this treatment failed, and so I was resigned to having a death sentence.

27. However, Dr Faizallah later referred me to Dr Paul Richardson at the Royal Liverpool Hospital. Dr Richardson discussed the possibility of me receiving a trial medication that was being developed. I jumped at the chance and he put me on the list.

28. Around this time, in February 2013, Dr Faizallah arranged for me to have a liver biopsy and ultrasound. This was after **GRO-B** had demanded this should be done as he was concerned about the extent of the damage to my liver over such an extended period. I enclose a letter from Dr

## ANONYMOUS

Faizallah dated 19 February 2013 (**exhibit WITN6203005**) in which he states that he has arranged for a liver biopsy and ultrasound and also confirms that I received a blood transfusion 30 years previously.

29. The ultrasound showed that I had cirrhosis of the liver. Dr Faizallah informed me of this at a face-to-face appointment a few days afterwards. He said that my liver was badly scarred and I had cirrhosis. He told me I should not drink alcohol and should stop smoking. Dr Faizallah discussed the possibility of a liver transplant if I started to appear jaundiced, indicating a deterioration in the condition of my liver.

30. I had a liver biopsy around the same time at Arrowe Park Hospital. It was painful and uncomfortable and I had to remain in the same position on my right side for 8 hours. I did not stay in hospital that night. I was sent home after the biopsy and had to remain still as described.

31. I enclose a letter from Dr McElholm (Gastroenterology, Arrowe Park Hospital) to GRO-B dated 14 June 2013 as exhibit **WITN6203006**. Dr McElholm states that my biopsy showed a necrosis score of 5 and a fibrosis score of 5 'with findings of evolving cirrhosis'.

32. Dr Richardson offered me a course of trial medication around a year after our first appointment. This course consisted of interferon, ribavirin and another tablet (which I cannot remember) that lasted for 3 months. The side-effects were the same as during the first treatment. After completing the course, the HCV was undetectable and it has remained undetectable ever since. I have tests every six months to monitor this.

33. I also have regular fibroscans twice a year to monitor my liver. At the last appointment in December 2021, they said that my liver was holding its own. Since clearing the HCV, my liver condition has not worsened.

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

34. I did not receive any other infections as a result of receiving an infected blood transfusion.

#### **Section 4. Consent**

35. I did not give consent to receive blood transfusions. I was never asked they just did whatever they needed to do to save me.

36. I was not informed that I was being tested for HCV in the first instance, leading to my diagnosis in 2011. So, I did not consent to this explicitly, although I did consent to 'blood tests', believing it to be 'general' whatever that may have meant. It was not itemised i.e. we are going to test you for this, this & this. That never happened.

37. Prior to starting the second course of treatment, I was given a form to consent to all tests, which included HIV. This frightened the life out of me because I was worried that I could have HIV and that this had been missed.

38. I consented to all treatment that I received to clear the HCV.

#### **Section 5. Impact**

39. Whilst being treated in hospital for septicaemia, I was kept away from my GRO-B child. I also had a 5 year old son who needed me to care for him. They were both cared for by my mother-in-law but this was still difficult for me to be away from them. I think on reflection that this has made me closer to my middle GRO-B son. However, at the time this was all very confusing for everyone and I not only missed out on the important 'bonding' weeks with my new born but also a large chunk of my eldest son's life to that point. He was only 5.

40. After my diagnosis with HCV, my husband and I sobbed for days GRO-B was convinced that I was going to die. We had to wait two months to be

## ANONYMOUS

seen by the specialist, Dr Faizallah. This was an extremely difficult and worrying period for both of us.

41. When I told my eldest son about my HCV diagnosis, he screamed at me, questioning where I had got it from. By this time he was in his late thirties. None of my children were happy as, in their minds there was this possibility that I had contracted HCV through a lifestyle choice as opposed to an infected blood transfusion. There was a lot of anger.
42. Our marital relationship was severely impacted by my diagnosis. Our sex life became non-existent. After being told to have sex with a condom, this ended our sex life, as this implied that there was a risk of me passing it on to GRO-B. He had to be tested for HCV, as were our 2 youngest sons. Our eldest son chose not to be tested.
43. I felt there was a lot of stigma surrounding HCV. We told our close family but there are still relatives, even now, that don't know about my infection. I told my closest friend and she later told me that her sister had said she shouldn't have anything more to do with me. She ignored this but I believe it shows the extent of the stigma associated with HCV.
44. Even now I don't like discussing HCV. I believe that if our neighbours and friends knew about it, they would have smashed our windows and ran us out of the area.
45. I was also terrified of infecting my grandchildren. I was worried sick that they would contract HCV so I was very cautious around them. I have 8 grandchildren.
46. Our social lives, as a couple, have been affected by my HCV infection. I don't feel able to go out and enjoy myself as much as everyone else. If I do go out, this is normally with friends who know about my HCV. I find this easier.
47. GRO-B was forced to take a lot of time off work to care for me and the kids. As a roofer, if GRO-B didn't work, he didn't receive any income. He



eventually lost his job as a result of the amount of time he was taking off to care for me, although he did find another job.

48. I had always intended to work once the children started going to school but I never felt well enough to do this.

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

49. The doctors identified a problem with my gall bladder through the regular ultrasounds I had. They decided they should leave this until I had cleared the HCV because it wasn't causing me any pain or discomfort. Towards the end it did start to worsen and I eventually had it removed 2 years ago, after my HCV was cleared. I believe they did not want to complicate things by operating on me whilst infected with HCV but this left me vulnerable to other medical issues.

50. I have never been offered counselling or psychological support in consequence of my HCV infection. Both my husband and I were devastated by my infection and I think it would have benefitted both of us. I would have definitely accepted counselling, if it had been offered.

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

51. Until being contacted by the Inquiry investigator in January 2022, no one had ever told me about the availability of financial assistance through trusts, funds or schemes. I have never heard of the Skipton Fund and only began to research the English Infected Blood Support Scheme ("EIBSS") after being informed about its existence by the Inquiry investigator.

52. I have made an application to EIBSS but have encountered problems because my medical records have been destroyed. I have recently requested records from my GP but he was unable to find any pertaining to my treatment for septicaemia in 1977 (**exhibit WITN6203002**).

53. I have also requested a letter from Dr Faizallah but I was informed that he is no longer working at [GRO-B]. The incumbent consultant refused to sign anything because he hasn't met me yet, owing to the pandemic, and I don't know when I will next see him.

54. EIBSS also stated that they could not accept a letter or signature from the hepatology nurse confirming my HCV and the route of transmission. They said that this has to come from the senior consultant of the department or my GP.

55. [GRO-B] my GP, when asked to write the letter dated 13 May 2022 (WITN6203002), asked me whether I had ever taken drugs intravenously or if I had been sexually promiscuous. We understood that he felt that he had to ask these questions, which we accepted but it still made me feel very uncomfortable revisiting them again. That said, I have no complaint about him personally. He is a very good doctor just doing his job.

56. It won't upset us if we are not accepted by EIBSS. It is something we never knew existed so we never even thought about it. However, it would be nice to have some financial support after all we have had to deal with together.

57. My application is ongoing and, as indicated in the letter from EIBSS (enclosed as **exhibit WITN6203007**), they will accept witness statements from the Inquiry. I therefore intend to submit by statement to EIBSS as part of the application.

#### Section 8. Other Issues

58. Had I not been contacted by the Inquiry Investigator, I would never have known about any of this. It has been explained to me by the Inquiry's investigator how infected blood entered the UK blood supply. I had no idea. It is quite unbelievable that this was whole contaminated blood

## ANONYMOUS

issue was allowed to happen. I had no idea before yesterday, the extent of the mistakes that have been made. Our lives, and those of many others, have been so tragically and irreversibly altered as a result.

### Statement of Truth

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

Signed

GRO-B

Dated

19/5-20-22