

Witness Name: GRO-B

Statement No.: WITN2026001

Exhibits: WITN2026002-WITN2015

Dated: 21 October 2019

---

WRITTEN STATEMENT OF GRO-B

INFECTED BLOOD INQUIRY

---

**Section 1. Introduction**

1. My date of birth is GRO-B and my address is known to the Inquiry.
2. I am writing this statement about my husband GRO-B:H We have been together for over 40 years and have two daughters aged 30 and 33. I manage a second-hand bookshop in Yorkshire where we live.

**Section 2. How Affected**

3. My husband H was a passenger in a traffic accident in 1978. During the accident he was trapped for some time by his ankle in a van door. He was admitted to St Thomas' Hospital in London and a metal plate was inserted into his ankle. He was in hospital for quite some time – weeks rather than days.

## ANONYMOUS

4. It is our assumption that while he was in hospital he received transfusions of a blood clotting factor. I do not have any further information about the specific product that he received because there are no existing records from St Thomas Hospital from this period.
5. To my knowledge [H] did not receive any information about the risks of receiving blood products before he was given them.
6. As a result of these blood products [H] was infected with Hepatitis C (HCV).
7. [H]'s health started to decline around the mid-1980s. We were living in [GRO-B] until 1986 because I was working there, and [H] was commuting to London for work. When we moved back to London, I remember speaking to a friend about [H]'s skin problems and sending him to an alternative medicine practitioner as we didn't know the cause.
8. We sold our flat in London in 1988 and moved to Yorkshire, where I started my bookshop business. After we moved to Yorkshire in 1988, [H] started being admitted to Royal Halifax Infirmary and St James Hospital for various issues, such as pancreatitis and septicaemia.
9. Around 1989-1990, he was diagnosed with both coeliac disease and cirrhosis of the liver. His notes refer to it as "cryptogenic cirrhosis", which I understand means that it was not known what caused the cirrhosis. **WITN2026002.**
10. In August 1990 [H] complained to his GP that he had been very tired for 7-8 months. Various tests were conducted. I remember his GP joking that [H]'s cirrhosis was caused by alcohol, which angered me.
11. Now having seen [H]'s medical records, I see that the consultant his GP then referred him to noted in a letter to the GP of 1 August 1990, "The low WCC and

low platelet count may be from hypersplenism related to liver disease which I think is related to his previous alcohol abuse." **WITN2026003**. This is not accurate. While [H] did used to drink in a work environment, he was never an alcoholic and by the time of those tests, had stopped drinking entirely. In addition, at no time in his life has he ever "enjoyed" a pint; coeliacs and beer don't mix.

12. In September of 1990, he was referred for a liver biopsy. The referral form, under "clinical details", states "? Alcoholic liver disease". However, the doctor performing the biopsy noted in the histology section that although "the liver is very likely to be cirrhotic", "there is no stainable iron, nor fatty change or Mallory bodies to indicate an alcoholic aetiology". **WITN2026004**. Handwritten notes from the same time as the referral include a list of [H]'s symptoms, which include tiredness and "jaundice – yellow tinge for a few days each week". **WITN2026005**.
13. [H] was never informed that he had HCV at any point during the investigations into his liver disease, despite the fact that his cirrhosis continued to progress, his liver biopsy results were not consistent with alcoholism, and he developed jaundice. I have no idea if the hospitals knew of his status and did not inform him or if it was not discovered until later.
14. [H] did not find out about his HCV infection until 1999. It had been determined that he would need a liver transplant, and we were having a meeting with the liver transplant team at St James's Hospital in Leeds to assess his viability for a transplant. He had developed liver cancer and tests were being done over the period of a week to see if the cancer had spread, which would make him ineligible for a transplant. His consultant said to him casually during this meeting "did you know you have Hepatitis C?" It was then determined that the cancer had not spread, which was our main concern.

## ANONYMOUS

15. The only reference I can find in [H]'s medical notes to [H]'s diagnosis is a handwritten note from 30 August 1999, which I believe was the date of his liver transplant, which states "Hep C cirrhosis." **WITN2026006**. There is no further documentation of his initial HCV test or diagnosis, or any conversation held with him about this.
16. The consultant did not provide any information about what HCV was or how to manage it. We had no idea what the diagnosis signified.
17. If known, I believe we should have been told about the HCV years before. Not knowing of [H]'s infection put myself and our family at risk. I would like to know when our GP was informed, or why none of [H]'s earlier testing or hospital intervention revealed his diagnosis.
18. We were not given any information about how to avoid infecting others. As we left the meeting, one member of the transplant team said to me "we'd better test you", which seemed like an afterthought. I was then tested for HCV, which was negative. Later, I found out more information about HCV from a leaflet given to me at St James' Hospital in Leeds, and from my own internet research. Once I understood the significance of HCV, [GRO-C]  
[GRO-C]

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

19. My husband was infected with HCV only.

### **Section 4. Consent**

20. I do not believe [H] was treated or tested without his consent.

**Section 5. Impact**

21. My husband has suffered from depression to some extent, but he is a remarkably optimistic and positive person.
22. The physical effects of HCV have been too numerous to list, but have resulted in a steady decline in his health. As I mentioned, the HCV had led to liver cancer and cirrhosis and then necessitated a liver transplant by 1999, before we even knew he was infected.
23. The HCV infection did not go away with the transplant, so from 1999 until 2015 his new liver was exposed to the virus, giving him cirrhosis again. He also has kidney problems, which we think are related. And has cellulitis infections that have hospitalised him.
24. If you ask a doctor if any of this is related to his condition, the answer is always 'who knows?' I find that symptoms are all treated individually without any awareness that they could be related to his HCV. For instance, once [ H ] was diagnosed with coeliac disease, his HCV-related symptoms became better because he was able to follow a diet that would give him the nutrients he had been lacking, so his skin cleared and he gained weight. Now, he has growths on his joints that limit his mobility, which are being investigated by the rheumatology department. However, doctors do not regularly consider the interactions between his various conditions and structure his treatment for each condition according to these.
25. Post-transplant, the anti-rejection drugs damage the immune system. Consequently my husband feels the cold very badly, picks up infections, is fatigued, has had to go to his bed during the day, often lacks energy and suffers from brain fog.



# ANONYMOUS

26. [H] was given two treatments for HCV. The first treatment, in 2007-2008, at Calderdale Hospital, was with pegylated interferon and ribavirin, which his system couldn't take. We had a discussion with his treating consultant about the possible side effects of the treatment and this was followed up with a letter to his GP detailing these side effects. I remember the consultant saying that the treatment would be debilitating; that it would be a very tough thing for [H] to go through. **WITN2026007**.
27. In [H]'s notes there is also a document called "Integrated Care Pathway for Nurse-led treatment of Hepatitis C Patients" **WITN2026008**. It is seven pages long and contains the following sections, among others:
- a. Probable cause of transmission: this contains a box titled '*blood transfusion prior to 1991*', which was ticked and next to it written "*leg operation ?? years ago*";
  - b. Symptoms attributable to Hepatitis C: "*some fatigue*" and "*sleeping problems*" are the only recorded symptoms, despite [H]'s nearly 20 year history of liver disease;
  - c. A patient checklist, indicating which information should be communicated to the patient. All sections are ticked as having been completed. Sections include: routes of transmission discussed, diagnosis explained, liver cirrhosis and cancer discussed, information around the tests required given and understood, lifestyle changes discussed, complementary therapy discussed, confidentiality discussed, treatment discussed and understood, genotype discussed and understood, support group information given, consent given to be on the support group mailing list, leaflets given.
28. There are letters from [H]'s treatment team at Calderdale Hospital to his GP from 26 November 2007 and 20 December 2007 in which it is noted that [H]

## ANONYMOUS

"has had absolutely no side effects" and "is very well and has no symptoms". **WITN2026009**. However, this was not the case. The first treatment was appalling physically and mentally. I can honestly say it was the only time I witnessed him in utter despair. He persevered with the treatment as long as he could but ended up in Calderdale General Hospital, too weak to even walk. At that point his doctor agreed it was the right decision for him to stop the treatment. **WITN2026010**.

29. He continued to be monitored for the next several years, and it was decided that we should wait until interferon-free treatment became available and monitor his liver function every 6 months. **WITN2026011**.
30. For his second treatment in January 2016 [redacted] H attended St James's Hospital. This treatment consisted of a 12 week course of sofosbuvir, daclatasvir and ribavirin. **WITN2026012**. This treatment was far less punishing but bad nevertheless, however it was successful and he was declared clear of the HCV in April 2016. **WITN2026013**.
31. He never faced any obstacles in obtaining these treatments, and there are no other treatments I think should have been made available to him.
32. The second treatment was do-able, and he was able to cope with it. However, none of these things are nice to experience.
33. All medical professionals including our dentist have been very understanding of his HCV status. However, any medical procedure is always fraught with danger due to a heightened risk of infection. Over the years small things like a tooth extraction and subsequent infection have been a great source of worry.
34. My husband has never let this illness rule his life. But he has always been surprised by it, always thinking that he could do more physically than he can. He still thinks that way. His situation has been that he was diagnosed with cirrhosis,

## ANONYMOUS

was ill for years, then had a cancer diagnosis, and then a transplant gave him a second chance. Consequently he is grateful to be alive and it has meant he has been home with our children the whole of their childhood. These have been the happiest times in his life which he would have missed had he been working! I have tried to shield him from any impact his illness has had on myself and our daughters and on our finances, in the belief that if he had truly understood our situation he would have lost what health he had.

35. Physically, mentally and emotionally I am now feeling utterly drained and exhausted. At 67 I have had nearly 30 years of looking after my husband and our daughters. I have had to try to maintain a decent life style with very little income, which I feel I have done well; both of my daughters are successful. However, I am not in the place I should be by this age, and that my friends are in. There have been times we have been in a lot of debt and this has been terribly stressful; in fact we still are in debt for our house so the stress continues.
36. Very sick people don't remember being ill, they are too busy dealing with pain and discomfort. Sometimes I say to my husband 'do you remember when..' and he doesn't remember a thing. Nothing in the years pre-transplant, the actual transplant, any hospital admissions, nothing. I remember them all. The memories are awful. Liver disease is an ugly illness, calling ambulances in the middle of the night because he is choking because he's vomiting blood, trying to get it out of his mouth, coming back home in the early hours and my young daughters wanting to know where he is and why there are sheets strewn on the landing covered in blood. Him crying on a stretcher saying he's so cold. I have many memories like this, but one should suffice to indicate how mentally and emotionally draining life has been and all the time keeping upbeat for the children. Until recently, post HCV, we have been too tired to have a social life so I do now see that we missed out on that.



## ANONYMOUS

37. We have never told anyone outside of the family about the HCV. Not because it was a 'dirty secret' just because it was private. I don't think our daughters were very keen as they got older having to shout at their father not to bleed over kitchen surfaces if he'd cut himself. Children are good, for them it's just the way things are.
38. My husband was unable to work at all after his diagnosis of cirrhosis in 1989. The diagnosis explained everything, his exhaustion, brain fog, shakes (he was a graphic designer). He stopped working a year after his cirrhosis diagnosis in 1989. This was a financial blow but I don't think he would be alive now if he hadn't been able to rest whenever he needed to. After resting he always rallied and as we had two small children (one and four at the time) we both felt they were our priority in terms of what energy he had.
39. I had opened a bookshop when we moved to Yorkshire in 1988 as I planned to be self-employed because we had two small children. My husband was the main breadwinner. He was well paid and commuted to London two days a week as a freelancer. We had a substantial amount of money from the sale of our London property and planned to buy two properties in Yorkshire to rent. The shop, the freelance and the rent would have given us an adequate income. In effect we had to use the money we had to subsidise ourselves. Bookshops are not lucrative but mine kept us going, along with remortgaging twice and finally equity releasing (to my regret) our home when we couldn't settle the interest only mortgage. That's my husband's fault, as in all my financial planning I always assumed he'd be dead and we would have downsized! The financial effects have been massive.
40. One of my daughters was one when my husband was diagnosed with cirrhosis, the other four. Basically he was sick all their childhood, having a transplant when one was 10 and the other 13. These were tough times for them and they still say he's been ill all their lives. We have become a very, very close family. They are

## ANONYMOUS

loving girls, always concerned about him, and in retrospect I can see they are too concerned and I wish they had never had these worries. I think the closeness that family trauma brings has made it harder for them to live independent lives.

41. The educational effects on our youngest daughter were significant. When she was 7 she refused to go to school and dropped out for 6 months. When she was 12, so just post-transplant, she refused to go again. This time it was impossible to make her. She was quite clear she didn't want to go in case Daddy wasn't there when she got back. Due to her experience of this it seemed a fair worry to have. I decided to home school her, which actually lasted right up to GCSE level. Again, this took massive amounts of work for me, although my husband went to French classes with her which was nice. She joined the local sixth form for A levels and got a place at Royal Holloway. However, due to her separation issues she was only there a week and dropped out. Following this she underwent cognitive behaviour therapy and the following year she went to York University, closer to home, but she still had terrible fears. I had to accompany her, getting a 6.40am train with her to get her in for 9am lectures. She had the brains but not the confidence. In year 2 of university I persuaded her sister to move to York and share a flat with her. Bit by bit she got braver. She now lives in London and is just finishing her PhD. Again, the effort was worth it but it shouldn't have been like this.
42. Our older daughter, who was 14 at the time of [H]'s transplant, seemed to be less affected by his illness. However, in recent months I have asked her if she was interested in preparing a statement for the Inquiry and she refused, saying she couldn't go there. To me, this shows that [H]'s illness has affected everyone in our family in different ways, and that just because someone's struggle is not obvious to others does not mean it doesn't exist.

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

43. [H] did not face any difficulties getting treatment.
44. [H] was never offered any counselling relating to his HCV. Around the time of his first course of treatment, he was offered access to a support group for people with liver conditions. However, this did not interest him. From his experiences at the liver unit in Leeds, it seemed that the main audience for that support group would be alcoholics and drug users, and his experiences as someone infected by contaminated blood would not be addressed there.

**Section 7. Financial Assistance**

45. We received assistance from the Skipton Fund from 2007.
46. In 2005, I read an article in the Guardian about the Skipton Fund. We submitted an application for Stage 1 and 2 payments together, as [H] qualified for a Stage 2 payment due to his liver transplant. Skipton refused our application because there was no documentation of the cause of [H]'s HCV.
47. [H]'s treating doctor who had filled in the Skipton form for us had anticipated this, writing in his cover letter *"I should imagine unfortunately that this will not be an automatic pass by the Skipton Fund Organisation as they will probably require more information. I am happy to help out as much as possible, although I imagine they would want from you some further dates surrounding your road traffic accident in 1978 as this is presumed to be in the index for your infection. I am very sorry if that causes more problems, however, as I explained to you, I can only fill in on the form the information I actually have in front of me in your medical notes."* **WITN2026014.**

## ANONYMOUS

48. An appeal was submitted, and this was refused as well due to confusion about whether [H] was still PCR positive for HCV. Finally, we got Dr Southern, the Head of St James Hospital's Hepatology department to write a letter to the Skipton Fund on 5 August 2005 **WITN2026015**. He explained [H]'s history and noted *"I do, however, hope the point that this gentleman required liver transplantation because of chronic hepatitis C means that the necessity to prove he is still PCR positive is negated."*
49. This seemed to swing the decision in my husband's favour. By 2007, our application was granted and we received both the Stage 1 and Stage 2 payments.
50. I do not feel the financial assistance is enough. If you have a house repair or a big fuel bill you have to ask for assistance as you have no savings, nothing put aside. Recently we read we could claim for a new mattress. The 'rules' say we are allowed one, but only after sending a doctor's proof of my husband's health needs. Even after all this time. How come a body affiliated to the Health Service doesn't understand the post-transplant needs of a man of 72? We didn't pursue it, did we really want our GP to know how broke we are? No, it's all humiliation and we're not going there.
51. Had all of this never happened we would have been like our friends, mortgage paid, debt free, travelling, whereas I still today have the trauma of the fuel bills to contend with. Our £500 allowance comes nowhere near covering heating a house on the Pennines for a sick man. The most recent change to the EIBSS scheme, which has put us on par with those in Scotland, has been extremely helpful and a big step in the right direction.



**Section 8. Other Issues**

52. I have just finished this witness statement and on reading it through I see I have omitted to say how angry I am and also how sad. I am sad for what we've missed and for how hard it's been. I am so angry that I've witnessed someone I love suffer so much and be so shabbily treated by uncaring complacent buck passing governments.
53. I don't care about getting apologies from the government. I just want decent compensation so that we can relax and finally put our feet up. Governments have waited until so many are dead, will we finally just get money to fund our places in care homes? Because I am English I am embarrassed to talk about money for fear of being thought greedy, and I fear that governments and media have played on this attitude to ignore our experiences. But we are in a much worse place financially than we would have been if [H] had not been ill, through no fault of our own, and we deserve to be compensated for that.
54. My solicitors have obtained records from Calderdale and Huddersfield, Leeds Teaching Hospitals and St James Hospital. I am concerned that there are still no records available from St Thomas' Hospital pertaining to [H]'s accident in 1978. Without this, there is no documentation of him having received blood products. There are also no records pertaining to [H]'s diagnosis of HCV, aside from the brief handwritten note in his records that I referenced earlier.

**Statement of Truth**

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

Signed

GRO-B

Dated .....21 October 2019.....