

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN5132001

Exhibits: 0

Dated: x29/04/22 x

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 11 February 2021

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1954 and my address is known to the Inquiry. I am originally from Lancashire but I have lived in GRO-B Gloucestershire ever since attending college in the area. I am single and live on my own.
2. I studied fine art at college but I went on to work as a graphic designer. I worked for an insurance company and then worked as a freelance graphic designer for many years. I still do a bit of design work on the side but graphic design is very much a 'young man's game' now. I am now enjoying part retirement and for the last 7 years I have worked as a cleaner/housekeeper for an American company that requires high level security clearance.

Section 2. How Infected

3. One day in around August 1991, I collapsed in the street. I had been suffering from some gynaecological problems at the time and believed it was linked. I was taken by ambulance to the St Paul's Wing at the Cheltenham General Hospital, which houses their gynaecology unit.
4. My GP, Dr [GRO-B] at [GRO-B] had previously diagnosed me with fibroids. At the time, I had been unhappy with this diagnosis, as it was made without offering me a scan or any form of testing. It turned out that Dr [GRO-B]'s diagnosis was incorrect and I was actually suffering from chronic endometritis. As a result of this problem, I unknowingly developed severe anaemia, which caused me to collapse. My iron level was 4.1 at the time, which is extremely low.
5. As my iron levels were so low, I was told that a blood transfusion was the only way to improve my condition quickly. As I had an uncommon blood group (possibly A negative), I was informed that I would have to wait in hospital until the units of blood were brought to Cheltenham from Bristol. I was not really given any information about the risks associated with blood transfusions, and my treatment plan was decided for me. I was not really given the option to ask any questions about the treatment, or associated risks.
6. At the time I was given the blood transfusion, I had previously heard vague things in the news about problems with blood and that people in America sold blood which was perhaps being used in the UK. It was known that drug users and others desperate for money were regularly donating blood in some American states, which may have caused those receiving the blood to contract various infections, such as HIV.
7. When I received the blood transfusion that caused my infection, it was August 1991 and I was just sure that the NHS had got their act together by then. I

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took it for granted that the blood had been screened and came from UK citizens donating to the Blood Transfusion Service. Maybe I was too naïve and trusting in assuming that blood was now safe. I took it for granted that strict medical screening procedures were in place now, to protect patients.

8. I believe the units of blood arranged for me arrived from Bristol the next day. As I did not have any viable veins in my arms or hands to transfer blood, the transfusion was done through my jugular vein in my neck. It took almost 3 days for me to be given 6 or 7 units of blood. It was an uncomfortable procedure overall.
9. The nurses treating me at Cheltenham Hospital were saying that after the transfusion I would be 'bouncing off the walls', as after being so severely anaemic I would feel so much better with normal iron levels. However, this was not the case for me. After the transfusion, I was discharged even though I felt fevered and unwell. I was very red in the face and I remember joking to friends that I looked like a farmer's wife, and that maybe the Jehovah witnesses had got something right, being against blood transfusions!
10. Although I felt unwell after the transfusion. I just believed the transfusion would now correct my deficient anaemia and I would slowly start to feel better. I thought maybe my body was too damaged to recover as quickly from the anaemia as the nurses said it would. I was just glad to be out of hospital and to be home, and I didn't want to delay getting out of hospital by complaining about still not feeling right, but to be honest nobody asked me how I was feeling.
11. After this incident, my health continued to be poor. I was still having gynaecological issues which were causing me to bleed 3 weeks out of every month. I felt very weak, irritable and generally unwell.
12. As I was continuing to feel this way, sometime in 1994 I asked my GP to refer me for a scan as my condition had worsened. After previously misdiagnosing me with fibroids without a scan, this time he agreed to refer me. During this

scan, it was identified that my ovaries were very enlarged. As a result, I was seen by a consultant quite soon afterwards, and it was suggested that I might have ovarian cancer. An operation was scheduled promptly, and I was admitted into hospital 2-3 weeks later (2 days before Christmas in fact).

13. During an investigative operation, it transpired that I did not have ovarian cancer, but my ovaries were enlarged and damaged due to prolonged endometriosis and the surgeon made the decision to remove them completely and perform a full hysterectomy. I was 37 years old. I began a prescribed course of HRT immediately and stayed in hospital for a week, then returned home to recover.

14. After the hysterectomy, my health did improve. However, a few years later, I started having issues with my thyroid. This can often be a complication of having an early hysterectomy, as it can mess up your endocrine system. I always felt a little under par and had aches and pains in my legs, difficulty sleeping, fevers, but I just thought that these were side effects of adjusting the dosage of thyroid medication. The occasional visit to my GP failed to offer any explanation for these symptoms.

15. I did try to avoid the doctors as much as I could even if I felt unwell, but I would have to have regular blood tests to monitor my thyroid. I remember being stopped one day and being told that I looked very ill and yellow (!). I was surprised by this as I thought I was okay. I have always tended to be quite stoic and just get on with things. I would just drag myself out of bed and get on with things. I am quite an independent person, so I don't think I realised how unwell I was.

16. In around 2006, my GP Dr **GRO-B** told me I had HCV at an appointment I attended. I had been having my blood tested yearly or 6 monthly to monitor my thyroid function. He had not told me I was going to be tested for HCV at any time.

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17. Dr **GRO-B** told me that the HCV can cause serious future problems with the liver, and took more of my blood to be tested. This diagnosis came as a real shock to me.
18. As soon as I had been told I had HCV, I immediately thought about the blood transfusion I had been given in August 1991. I remembered how ill I felt following this transfusion, and that something did not seem right at the time and shortly afterwards.
19. Although I have used intravenous drugs in the past, this was always in a very controlled and careful environment. The people I would hang out with were all young professionals with responsible jobs, and it was the kind of scene where drugs were only something that were used at the weekend. I was working for a major insurance company as a graphic designer at the time, and drugs were not something I used daily.
20. Even though I strayed from this group of friends slightly, we didn't see ourselves as desperate drug addicts on the street, (obviously deluded even then!). We worked, were well nourished and presented well. This makes a huge difference and allows you to get away with using drugs without people noticing. I'm not saying we were 'posh addicts', as we did have to meet some dodgy people in order to score drugs, but we were all always careful about how we used equipment and in a sterile environment.
21. Although we did not know about HCV, we were all aware of Hepatitis B as a friend of ours had suffered from it previously when living in London, and had become very ill as a result, though recovered after treatment. We were worried about getting Hepatitis B and always ensured we would not share needles to avoid any cross contamination or infection. I had, in any event, always felt the concept of sharing needles quite 'dirty', so I only ever used my own needles to inject myself.
22. I would visit a chemist in Leicester Square where addicts often picked up prescriptions, and the pharmacist was quite prepared to sell you disposable

needles and syringes and even sold glass and steel syringes. I had one of these, which I would sterilise before use (Milton solution/boiling), but most of the time I would use new disposable syringes.

23. Although chemists in GRO-B were initially against selling needles for addicts to use, it became obvious that there was a need to provide sterile needles and a needle exchange was set up in GRO-B which I would use regularly.

24. However, Intravenous drug use caused my veins to collapse after about 2 years. I think this was probably as a result of chalk in some of the drugs I was injecting at the time. As I could no longer use my veins, I started injecting into my muscles instead.

25. A psychiatrist at Cheltenham Hospital, Jeffrey Marks, created a programme providing medical diamorphine for certain addicts. In order to join the programme, you had to meet a specific criterion. As I was employed and regarded as someone without a chaotic lifestyle, I was able to join this programme as a registered user for 2 and a half years, before it was discontinued, due to it being quite a controversial treatment. I was then moved onto a methadone programme for some time, before weaning myself off methadone gradually, with limited supervision. This was actually very hard to do.

26. I never developed any ulcers or infections of injection sites, despite other addicts suffering from this terribly. None of the friends I took drugs with ever tested positive for HCV, which is one of the reasons I am sure I became infected with HCV as a result of the blood transfusion.

Section 3. Other Infections

27. As far as I am aware, I have not been infected with any other infections as a result of the blood transfusion I was given. I was offered a Hepatitis B injection sometime after completing my treatment for HCV.

Section 4. Consent

28. I was not asked to consent to the blood transfusion I was given. As stated above, I was given no explanation as to the risks involved with a transfusion and did not think that blood would *not* have been screened for infection in August 1991. I trusted the NHS to be doing the correct things.

29. I did not consent to being tested for HCV. My GP, Dr [GRO-B] ordered these tests without my knowledge, when I was having my blood tested for thyroid related issues.

30. I did consent to the HCV treatment I was given at Cheltenham General Hospital. However, I was not warned about how severe and long lasting the side effects could be.

Section 5. Impact

31. Finding out that I was infected with HCV was a real shock. Although I had suffered from generally feeling quite unwell, I had always attributed this to other things including problems with my thyroid. Looking back, a lot of the symptoms I was having are probably attributable to HCV as opposed to thyroid issues including the insomnia and muscle aches and pains.

32. At the time of my diagnosis, I was working from home as a freelance graphic designer. This was a very stressful period as there were constant deadlines for printing and proofs. This was very exhausting and probably made much worse by the HCV, but I pushed myself to keep going. I would try to rest

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whenever I needed to, which thankfully I was more able to do as I was working from home.

33. After my diagnosis with HCV, I immediately thought about someone who I was very close to, who I helped nurse when they were dying of terminal cancer in 2000. I felt extremely guilty about possibly having infected them with HCV without my knowledge, which could have made his condition considerably more complicated.

34. Around 6 weeks or so after being diagnosed with HCV, in around early 2007, I started treatment at the Benhall Clinic, located in Cheltenham General Hospital. There was no question that I would be offered treatment following my diagnosis, and there seemed to be a kind of drive to treat HCV in the area. I also had a liver scan which showed I had a fatty liver.

35. Throughout my treatment at the clinic, the doctors were courteous and civil, but it felt like it didn't matter how you presented yourself, it was always a forgone conclusion that you were a junkie and that you'd brought this on yourself. However, I was lucky to have an absolutely brilliant specialist HCV nurse, Mike Bunting, who was extremely supportive throughout my treatment.

36. At my first appointment at the clinic, Mike said that I should definitely have the treatment as my liver damage was not advanced and I had a moderate inflammation of the liver. This meant that I would likely respond better to the treatment than someone with more advanced liver damage.

37. Possibly a reason why my liver damage was not advanced is because I have mostly abstained from alcohol and have never been a "drinker", even in my youth. This may have helped slow down the impact of the HCV on my liver. I believe I was also told what genotype of HCV I had at this initial appointment.

38. Despite being told I was a good candidate for treatment, I was warned that the treatment did not work for everyone and that some people had multiple rounds of treatment without success. Mike was hopeful this would not happen

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to me, but said there was a possibility of trying again if it did not work the first time. The cost of this treatment was never discussed and I was not aware that it was expensive.

39. I agreed to start the HCV treatment which consisted of weekly Interferon injections and daily Ribavirin tablets. My course of treatment was to be 6 months long. I was shown how to inject myself with the Interferon (in the stomach area) by Mike, and I would do this at home every Sunday. I also required weekly blood tests to monitor how I was responding to the treatment. This was made difficult as the blood had to be taken by a femoral stab to a vein in my groin, which was very uncomfortable.
40. The treatment was a gruelling process and the side effects were horrendous. I had been warned that it would feel like I had a heavy dose of flu during the 'first flush' of the treatment and to take Panadol if I felt unwell. However, it was much worse than just initial flu-like symptoms and I felt extremely unwell throughout the whole 6-month treatment.
41. After starting the HCV treatment, I suffered from headaches, severe aches and pains and nausea. I also suffered from mental effects, feeling quite low and depressed, which I had been never warned about as a possibility. I think I should have been told about just how bad the side effects could be, so I could have been better prepared.
42. Within the first month of treatment, I begged Mike to come off it. He said that my blood test results were already looking positive and he said that he thought the treatment would work for me. He encouraged me to try and stay on it for a bit longer, which ended up being the full 6 months.
43. I can't think of what I hated more, the Interferon or the Ribavirin. The Ribavirin made me feel sick but the effects of the Interferon were equally as bad, if not worse.

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44. I was working throughout the treatment, but as I was working from home, I could take a rest when I needed to. However, it was still very hard to keep up with everything and the pressure of deadlines. Working while on this treatment was very rough, but what was the alternative? I just had to get on with it as I was struggling financially, this was my livelihood and I could not afford to stop working.
45. Receiving my HCV diagnosis and my time on the treatment was made more difficult as I felt unable to share this information with my family or the people that I worked with, due to the stigma attached to an HCV diagnosis; it was very similar to how you might be treated if you told someone you had HIV.
46. My family was based in Lancashire and had no idea about my drug use, and this was not something I wanted to share with them. If I told them about the HCV, they would presume it was as a result of drug use and I don't think many people would really believe you if you told them you became infected as a result of a blood transfusion, as it seemed such an unlikely possibility. I only told 2 people about my diagnosis, and only because they had also been former drug users and would be less judgemental.
47. As I was having weekly blood tests and I would not really be able to hide the symptoms I was suffering as a result of the HCV treatment, I avoided visiting my family in Lancashire for a long time. My sister had her first child around the time of my treatment and did not understand why I had not gone to visit her. I told her that I was unwell and had a problem with my liver, without going into details. I have still not shared the details of my diagnosis with my family and to this day they do not know what I have been through.
48. Not being able to share a really big thing in my life like this was difficult, and I've always felt like I am carrying around a secret. For my current job as a cleaner where I work around 30 hours a week, I needed to undergo a very high-level security clearance. This takes around a year to complete and costs the company approximately £25,000, where you pretty much bare your soul to them, because they have access to Home Office/medical/police records. I just

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could not disclose to them that I had HCV and received treatment for it, but they could have found out this information when performing my security clearance.

49. An old friend I told about the HCV became quite paranoid that he may have become infected, as he thought he had some of the typical symptoms. Mike, my HCV nurse, had previously told me that if any of my close contacts wanted to be tested for HCV he would go to their houses and do this for them. My friend wanted to get tested and Mike kept his word and went over and did a test for him, which was thankfully negative.
50. I was really grateful that Mike truly went out of his way to be supportive, especially at a time where I could not rely on my family for this kind of support. The fact that none of my friends who did drugs with me tested positive for HCV also helped to confirm in my mind that I had become infected as a result of infected blood.
51. After I had completed the 6-month course of HCV treatment, I was told I was clear of HCV. My ALT levels, which are an indication of liver function, continued, until recently, to be tested every 6 months, alongside my thyroid. I believe my ALT levels are now okay and they have been around 20 IU/L for the last few years. When I started treatment, I think my ALT levels were around 150 IU/L or higher, so it is a dramatic decrease. I don't know much about how the liver functions, but I was not told about any liver scarring and I'm not aware of any ongoing problems. I have not had any further referrals to the clinic.
52. Learning that I had HCV was just another added problem in my life. It was hard to keep optimistic after this diagnosis, as everyone knows that when your liver goes, that's it. I felt even more damaged and believed this was just another thing my body was going to have to bear.
53. Once I had cleared the HCV, I tried my best to move on from it. You cannot get bogged down with things and I tried hard to not let this affect my work and

life. However, it made me feel like I needed to be very healthy, and I am very conscious to avoid drinking alcohol.

54. One of the hardest things about having something like HCV is the stigma attached to the diagnosis. As soon as I was told about the HCV by my GP, Dr **GRO-B** I felt the stigma associated with having such a diagnosis and his attitude towards me seemed to change. As I described above, the doctors treating me for HCV were also quite cold, and seem to look down on you as just being a junkie. As a result of this stigma, I refrained from seeking dental treatment during the time I knew I had HCV. I was too embarrassed to have to disclose my HCV to my dentist and go through the whole thing again. I just did not want to deal with more embarrassing details about my past.

55. I don't think much has really changed with regards to the perception surrounding HCV patients. Most recently, a friend of mine who suffered from Guillain-Barre Syndrome was in hospital for a year, and I later found out she had also been diagnosed with HCV through blood testing, although at first, she was quite reluctant to share this information with me. She has never indulged in recreational drugs and never had any idea that I had HCV 20 years earlier.

56. Although my friend's HCV treatment was much easier than mine was, she said that the doctor treating her had given her a statistic of how many HCV patients are drug users. He was in effect pointing to the route of her HCV transmission. She was very upset at the implication and told only her husband. This was very recently, and it shows that not much has changed in relation to the stigma suffered by HCV patients.

57. I still suffer from the stigma surrounding HCV and drug use in many ways, especially from the medical community.

Section 6. Treatment/Care/Support

58. After I was diagnosed with HCV, I received treatment quickly. However, I feel that if Dr McMinn had treated me appropriately, I would not have ended up in a situation where I required such a major blood transfusion, and would not have become infected with HCV. I feel let down by the treatment I received from him, and I do not think he should have diagnosed me with fibroids without offering me a scan.

59. I was not offered any counselling or psychological support following my diagnosis with HCV and subsequent treatment. The treatment made me depressed, and as I mentioned above, I had not been warned about this being a possibility. As this is actually a common side effect, I believe psychological support should have been offered to patients on this treatment.

Section 7. Financial Assistance

60. I found out about the Skipton Fund through Mike, my HCV specialist nurse. When he told me about a fund which was available for those who had become infected with HCV through blood transfer, I was initially sceptical about applying as I thought that they would immediately refuse me, due to my previous intravenous drug use. However, Mike encouraged me to apply and was very encouraging, which is why I did.

61. I made an application to the Skipton Fund disclosing my intravenous drug use, but I did not hear anything back from them for some time, so I when I decided to call them with regards to the outcome of the application, I was told over the phone that my application had been rejected due to my intravenous drug use in the past being more of a risk factor than the large amount of blood I had been transfused with.

62. I asked the man I spoke to on the phone if they knew where the blood I was given came from, and he said they had only been able to trace 3 of the donors of the blood I had been given, with the assistance of the Blood Transfusion Service. He said that if the other donors came forward after testing positive for

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HCV to say they had donated blood, it could be traced back to me and their decision might be reconsidered.

63. During this conversation, it felt like I was being asked to sit tight until the people who had donated the blood I received possibly came forward to say they had HCV, and it all sounded very far-fetched. I felt like I was just being fobbed off and a short period of safe intravenous drug was used against me.

64. If I had been dishonest and not disclosed my previous drug use, maybe I would have been successful in my application to the Skipton Fund. It felt like a foregone conclusion that if you had any intravenous drug use at all, your application would be unsuccessful and I do not think this is fair, as it really depends on the individual circumstances.

65. On the phone call to the Skipton Fund, I asked if I could appeal their decision and I was told I could. I decided to go ahead and make this appeal, sending the Skipton Fund a detailed letter laying out my background and explaining how safe my drug use had always been. However, my appeal was rejected. After this appeal was rejected, I decided that I was done with the entire thing and did not want to humiliate myself further.

66. I feel I was treated like I was just a junkie by the Skipton Fund, and I think they thought I was trying to use this opportunity to get some money which I wasn't entitled to. If there was only enough money in the pot for haemophiliacs and those in difficult positions where they had gone on to infect family members for example, I would have understood. But if there were funds for everyone infected and affected, I do not understand why I was rejected just on the basis that I had used drugs for a short period. I feel that they should have taken the context of my drug use into account.

67. I think that the Skipton Fund should have more actively investigated my situation, as well as the situations of others who were rejected. I'm sure people who were worse off than me didn't get any financial support either. The money from Skipton would have really helped me at the time as I had to

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continue working through my treatment, which was extremely difficult to do and I could have avoided this if I had some financial support.

68. The way I was treated by the Skipton Fund made me feel like they didn't really care what happened to me because I used drugs. Although I am considering making an application to the EIBSS for financial support, the money wouldn't help as much today as when I was in that 'dark place' previously.

Section 8. Other Issues

69. I was lucky to clear the HCV infection and I know many people suffered much greater consequences from having HCV than I have. I want the Inquiry to help provide more support for these individuals who have suffered a great deal.

70. I also want the Inquiry to hold the Skipton Fund to account in relation to their decision making about who deserved financial assistance.

Statement of Truth

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

Signed

GRO-B

Dated

29/04/22

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