

ANONYMOUS

Witness Name:

GRO-B

Statement No.: WITN6335001

Exhibits: Nil

Dated: 25. November 2021 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 14 September 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1945. I currently reside in GRO-B London. I am married with two daughters, GRO-B and GRO-B and two grandchildren who are both GRO-B children. I intend to speak about my Hepatitis C (HCV) infection. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact the virus has had on those around me including my family and friends.

Section 2. How Infected

2. I gave birth to my elder daughter, [GRO-B] in [GRO-B] 1975 at St Bartholomew's Hospital (Bart's). I lost a lot of blood when she was born and required a transfusion. I was in a very weak state at the time and I don't remember being advised about the risks of receiving blood. I don't know how much blood I was given. I have been through the paper copy of my records at my doctor's which confirmed that I had received a transfusion.
3. I was in the hospital for a total of 10 days. The baby was not gaining weight and I was suffering from the after-effects of pethidine. I had been unwell before the birth, at risk of pre-eclampsia. In those days 10 days was not an unusual length of time to stay in hospital after a birth. On discharge, I was given the all clear and nothing was said to be wrong with me..
4. I had left my job the previous November, 3 months before [GRO-B] was born.
5. It was possibly in 1997 that I was finally diagnosed with HCV, just over 20 years after my transfusion. I went to see my doctor regarding an issue unrelated to hepatitis. The doctor was either at the [GRO-B] in [GRO-B] or the [GRO-B] in [GRO-B]. He took a blood test and, following on from it, he suggested that my liver wasn't functioning as it should be. He then carried out more tests which indicated that I had liver disease. I am not sure whether I was diagnosed with hepatitis C at the GP surgery or at Lewisham hospital, to which the GP referred me.
6. At the time, I was working for an agency called [GRO-B] as a [GRO-B]. As a condition I had to have a Hepatitis B vaccination and I think that I had already had that when they discovered the HCV.

7. The GP referred me to the local hospital, Lewisham, where the consultant informed me that Hep C was usually life-limiting and there was no treatment available. He asked if I had received a blood transfusion and I was clear that I had. He told me that I could infect my husband and advised me to consider taking precautions with things like toothbrushes, and to use a condom. I should cover any cuts. In terms of protecting the children, he might have said something but I can't remember now.
8. With regard to testing, the children weren't tested but GRO-B my husband, was and he tested negative.
9. I was then referred with my consent to Kings College Hospital ("Kings"), a regional centre for liver research. I was informed that there I would have the best chance of receiving treatment when it became available. At Kings they told me that Hepatitis C was often consequent on blood transfusion, intravenous drug abuse (shared needles) or multiple sexual partners. They asked whether any of those applied to me. I told them that the only one that did was the blood transfusion I had had after GRO-B birth.
10. I do remember that at one point I was told about what would happen if I had a cut, that I should cover it and tell anyone who might come into contact with it that I had Hep C. I can't remember at what point I was told this but it definitely became a part of my practice.

Section 3. Other Infections

11. As far as I am aware, I was not infected with anything other than HCV by way of blood transfusion.

Section 4. Consent

12. I don't remember being asked if I consented to the blood transfusion, but at the time I was in a bad way.

Section 5. Impact

13. My elder daughter, GRO-B has severe disabilities and raising her was a very tiring task. It required my full attention and was very physically demanding. In all likelihood I wasn't aware that I was infected or ill because I was always so tired in any event. Because of this, I don't know to what extent my illness made me more tired.
14. I do feel the cold quite severely, a lot more than other women of my age. I don't remember if I was like that pre-infection but that could definitely be a result of the virus.
15. My liver condition was monitored with liver biopsies and endoscopies. A biopsy in 1997 revealed that I had mild fibrosis. Two years later, a further biopsy showed this had developed into moderate fibrosis.
16. I was first offered treatment at King's in 2000. I was given the opportunity, which I accepted, to take part in a research trial of a new drug regime. It was interferon and ribavirin, a weekly injection and a tablet. It was probably a six-month course that they put me on
17. The support from the clinical team was extremely good whilst I was on the treatment. I was taught how to inject myself at home and I had a mobile phone to ring the nurse if I needed to at any time. I was really made to feel that I was being looked after. They were all extremely supportive and the clinical nurse treated me very well.

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18. I did, however, have a bad reaction to the treatment. It was affecting my white blood count and they were concerned about my tolerating it. I became exhausted. At church I could either sing or stand but I couldn't do both. At home, I had to spend most of my time lying down. I couldn't concentrate or read anything; I suffered from brain fog. I remember that when we were on holiday everyone else went on excursions whilst I had to stay behind at the hotel. We had to hire a cleaner because I was unable to clean around the house.
19. I also became very depressed and I was put on antidepressants when still on the treatment. I should say that I have been depressed a lot of my life on and off. I had had depressive episodes before I got married but the treatment and the tiredness caused a further episode.. As a result of everything, I was unable to work.
20. They took me off the drug trial after 4 or 5 months. I was a non-responder. They told me that they had discovered that my Hep C virus was genotype 1a, and as a result very unlikely to respond to this treatment. At the time there wasn't anything else to offer me.
21. In 2004, I had a liver biopsy in preparation for another drug trial, of pegylated interferon with ribavirin. From this, they discovered that there had been cirrhotic transformation. I had been told that if my liver did deteriorate to the point where it was unable to cope with the amount of cirrhosis I'd have major problems because from then on liver failure would be likely. The liver compensates until that point with few symptoms. It is a bit of a time bomb.
22. The pegylated interferon treatment was a six-month course. The treatment was in development at the time and they were trying to see if it was easier to tolerate. I asked them to prescribe me antidepressants prophylactically and I started on them before the treatment. As a result of this, I didn't suffer from the negative mental health impacts this time. However, I did feel extremely tired once again and I had to take quite a

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long time off work, at the end of which I retired. I also suffered from brain fog once more. Ultimately, this treatment was unsuccessful.

23. For one or possibly both of the treatments mentioned above, my viral load was dropping but it wasn't cleared. I wasn't particularly worried about the viral load, I just wanted to clear it.
24. They offered me another treatment in 2009. I believe that it was a variation of previous treatments and it still used interferon. I told them that I didn't want it. Since I was well and I didn't know how long I would be well for, I wanted to help my daughter with my new-born grandson.
25. In 2015, Kings offered me a new drug trial. It was a new treatment which operated totally differently, using a different drug developed by Gilead Industries. It was a single tablet. This treatment was successful in clearing me of the virus.
26. Following on from the successful Gilead trial I had fibroscans regularly, as part of a new five-year trial to see whether and how the liver recovers after this treatment has eliminated the virus. I had regular monitoring, more frequent and more detailed than I would have had anyway because I had opted to take part in this new trial. We had been notified at the early stages that with HCV there was an increased risk of liver cancer. I was told, after the virus was cleared, that there was an even greater risk of liver cancer after successful treatment because the liver, in trying to regenerate, can produce cancerous cells. More recently when checking by endoscopy for varices they have also found spots, though not actual varices, in my upper digestive tract.
27. In 2019 at Kings, they picked up something questionable during one of my regular ultrasound scans. I was referred for a CT scan and the initial concern was found to not be a problem but something else was picked up in my liver. They initially said that they'd do another scan in a few months' time but an experienced consultant saw the scan and said that I needed an MRI.

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28. The MRI showed a very small cancer in my liver. This was in February and I received treatment for the cancer in March. They dealt with it extremely quickly and there was no pain. I was in overnight and then it was gone. Follow-up checks proved this to be the case.
29. I will soon be having CT scans on the whole of my trunk as well as blood tests to check my condition. I am certain that the cancer was caused by the HCV.
30. It has been on my mind that there is an increased likelihood of an earlier death. In 2005 I went online to look at HCV prognosis and it said five years life from cirrhotic transformation. That was playing on my mind. I have outlived that prognosis as a result of successful treatments but I do think about earlier death a fair amount since the cancer was found.
31. All of this causes me some anxiety and my husband GRO-B even more. Even before the diagnosis we often talked about death, what we would like for our funerals etc. The effect of all the illness makes death a nearer prospect. We have considered that I might go before GRO-B even though he is older than me.
32. I stopped work because there was no suitable treatment available and I believed I had a very limited life outlook. I wanted to use my remaining healthy years differently.
33. I think that GRO-B has been very concerned about my health for a long time. It is a constant concern for her. GRO-B is totally unaware and she has lived away from home since the 1990s. She is currently in a care home and has been there since 2001.

34. GRO-B was always concerned because we didn't know how long I had left. All this time I didn't think that I was going to last many years more. It has been more of a concern since the cancer was identified.

35. I was always determined to tell people of my diagnosis because I don't think that people should be made to carry stigma for having it. The culture in my family has always been to be open about things.

36. I had no problems with the church. They accepted my word when I told them that I got it from a transfusion.

37. There has never been any experience of stigma because I have always been so open about the HCV.

38. I have been strongly advised not to drink any alcohol because of the state of my liver, although, to begin with, I did allow myself a small sherry before dinner when on holiday. The difficulty is that social events are often accompanied with wine. We host wine tastings and I can taste it but I have to spit it out. As a result of not being able to drink alcohol when others do, I do often find myself getting tired when others are being stimulated.

Section 6. Treatment/Care/Support

39. Generally, there have been no obstacles in obtaining care and support; I have never had any difficulties getting treatment from dentists etc.

40. Before receiving the second treatment for hepatitis, I had interviews with psychiatrists in relation to the depression. This was arranged through Kings. They also offered me a support group to join. However, I very quickly found myself being the one facilitating it due to my experience as a social worker. Because of this I decided to stop

attending. I was also asked by Kings if I needed assistance with domestic chores.

Section 7. Financial Assistance

41. In relation to the financial assistance available, I don't know where I heard about it first. Kings probably did recommend it at some point.

42. I had no problem at all with the application, I explained how I thought I had contracted the virus. I had already delved into my medical records at my GP surgery and the relevant medical professionals were able to get involved.

43. I have received two single payments and now I receive monthly payments. Since my cirrhosis grew worse, the payments have increased.

44. There were no pre-conditions to the payments, they just asked how I would like to receive the money. I don't remember signing anything to say that I wouldn't take action against the government or the NHS.

Section 8. Other Issues

45. I am very lucky to have found Kings. When having the trials, I have always had good support and been able to talk easily to the nurses and liver specialists. They have always been very responsive, informative and supportive.

Statement of Truth

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

Signed _____

GRO-B

Dated

25.11.21 15.11.21

GRO-B

GRO-B