

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3242001

Exhibits: None

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B and I live at GRO-B with my husband. We have been married for GRO-B years and have two daughters and 4 grandsons. I am a retired GRO-B
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2009. I am aware that my husband GRO-B: H, who is known as H is also providing a witness statement to the Inquiry. He was infected with Hepatitis C (HCV) as a result of being given contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

Section 2. How infected

4. [H] suffers from mild Haemophilia A. He would receive Factor VIII (FVIII) concentrate before he had an operation and then a follow up. His haemophilia means he always has a secondary bleed about 2 days later.

5. [H] was under the care of Lewisham Hospital when he first found out that he had Haemophilia. Then he was under the care of Dr Black and Dr Lesley at Norfolk and Norwich University Hospital when he was infected. His surgical team consultant was Mr George. He is now under the care of York and Leeds.

6. In 1982 following minor surgery for a circumcision [H] was given FVIII which is when I believe that he was infected with Non-A Non-B (NANB) Hepatitis. He became jaundiced and very unwell within about a week. When he was poorly and off work they wanted to take him into hospital but I said no as I would nurse him at home. That was when he was at his low. It takes you a long time to get over any hepatitis and it took [H] about 18 months to fully recover.

7. No explanation was given beforehand to [H] or myself about any risk associated with FVIII. They would have said he was getting FVIII; they would just assume because that is what they have always done. [GRO-B]
[GRO-B] when [H] had the minor surgery in 1982.

8. [H] was infected with HCV as a result of being given contaminated blood products.

9. One week after the surgery [H] became poorly. He suffered from a high temperature, severe abdominal pain, nausea, vomiting, jaundice, and port wine urine. I rung our GP, [GRO-B] and said [H] was not well and explained that he was turning yellow before my eyes. They sent [GRO-B] to our house who confirmed that like me he thought it was hepatitis. [H] just deteriorated from then on. A blood test then diagnosed [H] with NANB Hepatitis.

10. When the doctors knew that NANB Hepatitis was HCV a nurse from Norfolk and Norwich Hospital Haematology called [GRO-B] who was a friend of mine, came round to our house and told me. I don't remember her explaining how serious HCV was.

11. Prior to finding out that [H] had HCV I always insisted that when [H] had a blood test I took a copy of the results home with me. When [H] changed his GP to [GRO-B] I asked for the test results and he asked '*why do you want them, are you going to sue us?*' I asked '*why would I sue?*' [GRO-B] just smiled. He would not let me see the results.

12. We were not given adequate information to help manage the infection. I feel very strongly that more information should have been provided to us about the infection.

13. Information should have been provided to us as soon as the NHS knew.

14. We were not provided with any information about the risks of others being infected as a result of [H] infection. I think they assumed as I was [GRO-B] it was not important. I knew you had to be careful with any hepatitis but I didn't think it was any more serious than anything else I came into contact with [GRO-B]

[GRO-B]

Section 3. Other Infections

15. I do not believe [H] was infected with anything other than HCV.

Section 4. Consent

16. I do not know if [H] was tested without his knowledge or consent.

Section 5. Impact of the Infection

17. As [GRO-B] I was able to monitor [H] ups and downs after his initial infection in 1982. [H] had bouts of feeling feverish and he was not well. I had to take 2 weeks unpaid leave to look after him at his worst and then went part-time doing 2 nights a week, then dropped it to 1 night. My parents were amazing and they used to shop for us. We coped and he recovered after a while.
18. I worried about was the psychological effect on him. It has not always been easy for [H] I had a [GRO-B] friend in Norwich who sat and talked about the effects with him. [H] went through a patch of feeling low. Having the treatment caused [H] to suffer with incredible depression. I have talked long and hard to [H] about his infection and the effects on his liver. At one point he refused to have any more FVIII but that was resolved.
19. [H] currently has severe liver damage and his liver may now fail at any time. He has been checked for cancer because there is a chance the liver could have cancer but now it is okay.
20. [H] was under Dr Fellows from around 1995 who wanted to do a liver biopsy. I asked what good it would do and I said he could tell from the blood test, but he said a biopsy would confirm it. I said no and would not let him. I saw a general surgeon [GRO-B] and asked him if he would stick a needle in a Haemophiliac? And he said he wouldn't. After that Dr Fellows was less hostile. It was as if he was defending himself about the HCV. I am sure they knew.
21. [H] attempted a course of treatment in 2004 at the Norfolk and Norwich Hospital, but he was unable to cope with the side effects. Treatment was aborted instead of adjusting the dose. Having to abort the treatment was very upsetting for [H] as he thought that it was his only hope of clearing HCV.

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22. When we moved to Yorkshire in 2009 when [H] retired he started to deteriorate. He started feeling unwell, was slightly jaundiced and had flu like symptoms. As soon as we got to York they said they could not deal with him and he would have to go to Leeds.
23. [H] had treatment again in January 2013 and this time it was successful. The treatment involved tablets everyday and injections once a week. While he was on the treatment his haemoglobin dropped to 9 and then 7. His white cells were dreadful. [H] was covered in a rash. Whenever I gave him another injection he deteriorated even more. [H] was not allowed to go out or mix with anyone because he was so ill. They wanted to give him another drug because his white blood was so high but I was worried about any side effect this extra drug may have caused.
24. It is difficult for [H] to receive any treatment now as various GP's worry about the effects the treatment may have on [H] Liver.
25. Our family are very caring but our social life can be very difficult at times as we are keeping [H] HCV infection a secret. We did not tell [H] parents as they wouldn't understand. They knew [H] had Hepatitis but we left it at that.
26. If someone asked why [H] does not drink, I would say he has FVIII and that affects his liver. Most people just accepted this.
27. We have always kept [H] infected status quiet. When he was first jaundiced in 1982 the neighbour's children were not allowed to play with our daughters.
- GRO-B**
- GRO-B** He did test me though but I was negative. It never crossed my mind to get tested prior to this. I waited until I got the results and then I told **GRO-B** that I was negative.

28. I have always been strong and positive but at times I feel very sad for [H] I am lucky that he is still with me. When the girls were younger, I worked at night so I could be there when they got home from school. When [H] was diagnosed with NANB Hepatitis in 1982 I had to take unpaid leave to nurse him at home, as I did not want him in hospital, as at the time there were strikes of ancillary staff on the ward at the Norfolk and Norwich Hospital.
29. When [H] was able to start eating again he had to have a very low fat diet, which was expensive. We had two young daughters at the time causing finances to be stretched.
30. The numerous trips to the hospital for blood tests etc were expensive too. Our house to Leeds is [GRO-B] miles each way. We asked if we could claim for fuel but they said no. The company [H] worked for were very understanding regarding sickness and his slow recovery.
31. All types of insurance are a problem. Our daughter has a villa in [GRO-B] so we like to go on holiday there but [H] holiday insurance costs just as much as the trip. I could not live with myself if went away without insurance. Some travel insurers refused to cover [H] but eventually we found one holiday insurance company called Allclear Travel Insurance in Romford, who were brilliant, so we now get holiday insurance with them.

Section 6. Treatment/care/support

32. No counselling or support was provided to [H] or me but luckily I had close friends who helped [H] We were lucky that I had [GRO-B] and we had good friends like [GRO-B] who come to speak with [H] when he is worried and puts things in perspective.

Section 7. Financial Assistance

33. [H] found out about the Skipton Fund through Dr Turner who was a Haematologist at the Norfolk and Norwich Hospital.

34. In 2004 [H] received a £20,000 lump sum payment, however, in order to receive the lump sum payment [H] had to sign a waiver stating that he would take no further claims against the NHS.

Section 8. Other Issues

35. I feel like [H] has been so lucky. Our size in the scandal is tiny compared to the horrendous times others have been through. We thought it was horrendous at the time when we did not know it was something that the NHS had done. I have spoken to a lot of people about it and what people have suffered is dreadful.

Anonymity, disclosure and redaction

36. I am seeking anonymity and would like my statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

37. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed...

GRO-B

Dated... 08. 07. 2019